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Patients' Perceptions of Quality of Life and Resource Availability After Critical Illness

Michelle McMoon
Walden University

Walden University

College of Social and Behavioral Sciences

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Michelle McMoon

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Review Committee
Dr. Hilda Shepeard, Committee Chairperson,
Public Policy and Administration Faculty

Dr. Lee Bewley, Committee Member,
Public Policy and Administration Faculty

Dr. Kathleen Schulin, University Reviewer,
Public Policy and Administration Faculty

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Abstract

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Michelle McMoon

MS, Marquette University, 2005

BS, Virginia Commonwealth University, 1998

Dissertation Submitted in Fulfillment
of the Requirements for the Degree of
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Abstract

Physical, psychological, and social debilities are common among survivors of critical illness. Survivors of critical illness require rehabilitative services during recovery in order to return to functional independence, but the structure and access of such services remains unclear. The purpose of this qualitative study was to explore the vital issues affecting quality of life from the perspective of critical illness survivors and to understand these patients' experiences with rehabilitative services in the United States. The theoretical framework guiding this study was Weber's rational choice theory, and a phenomenological study design was employed. The research questions focused on the survivors' experiences with rehabilitative services following critical illness and post-intensive care unit quality of life. Participants were recruited using purposeful sampling. A researcher developed instrument was used to conduct 12 semistructured interviews in central North Carolina. Data from the interviews were coded for thematic analysis. The findings identified that aftercare lacked unity, was limited by disparate information, and overuses informal caregivers. In addition, survivors' recovery depended on being prepared for post-intensive care unit life, access to recovery specific support structures, and the survivors' ability to adapt to a new normalcy. Survivors experienced gratitude for being saved, which empowered them to embrace new life priorities. The implications for social change include improved understanding of urgently needed health care policies to provide essential therapies and services required to support intensive care unit survivors on their journey to recovery.

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Dedication

This dissertation is dedicated to the brave critical illness survivors who shared their journeys with me. Thank you for giving me the opportunity to share your experience.

Acknowledgments

This dissertation would not have been possible without the love and support of my husband. At many times throughout these years, I relied on his strength and grace, and for that, I am forever grateful.

It is with deep admiration that I express appreciation for my chair, Dr. Hilda Shepeard. Her words of wisdom, encouragement, and knowledge were always there when I needed them, even when I didn't know what I needed. In addition, none of this would have been possible without my entire committee: Dr. Lee Bewley you are an inspiration and motivator. Thank you for being a part of this from its early inception and helping me lay the groundwork for this study early on.

Thank you, Dr. Rita Bakhru and Mary LaRose, RN, who worked alongside me throughout participant recruitment and helped me learn about critical illness survivor clinics. Your work continues to be an inspiration to me and I hope to collaborate for years to come.

My family and friends have all remained remarkably patient with me throughout the last four years, and I express sincere gratitude to them for loving me through this.

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Chapter 1: Introduction to the Study

Due to advances in medical technology over the last three decades, an increasing number of patients are surviving critical illness. Patients, families, and clinicians have seen an overall decrease in mortality from catastrophic illness, yet the fight for survival does not end with a discharge from the intensive care unit (ICU). Patients are left with cognitive, physical, and social impairments and devastating recovery limitations that may also decrease quality of life. Health care services and medical researchers have used quantitative methodologies to develop therapeutic interventions to improve medical care during acute illness. However, qualitative research has become increasingly used as researchers have discovered that recovery from critical illness is expressed by far more than survival data. The importance of patient perception as it relates to the overall experience of critical illness recovery is essential (Hashem et al., 2016). By using qualitative methodology with a rational choice theory (RCT) framework, I designed this study to understand the patient's perception of quality of life after surviving critical illness and the recovery resources that support their journeys to recovery.

By using qualitative inquiry, I aimed to assist in generating recommendations for improvements in health care policies related to targeting recovery resource allocation. The term *quality of life* (QOL) is subjectively defined. Unlike other disease processes, researchers have found QOL assessment difficult due to the complexities of critical illness and its effect on multiple organ systems. Although a similar protracted course has occurred in diseases such as cancer, critical illness differs because it is often acute in its onset and accompanied by rapid deterioration. People with critical illness face a prolonged cascade of inflammatory processes that limit recovery. By giving the survivors an opportunity to define QOL and connect their QOL goals to the current process of recovery, gaps in current resources may become more apparent. The long-term care (LTC) support and rehabilitative services available to survivors should become an important component of future policy changes. Survivor input on aftercare, including discharge planning, transitioning of care between facilities and home, navigating recovery resources, and understanding barriers to accessing these services, will help develop a more comprehensive program for this growing population of survivors.

Social change begins with identifying a problem that affects society and finding a way to address it. I provided the first step in understanding ways to help critical illness survivors return to their lives and to develop health care policies to support their changing needs. Hospital leaders can improve care transitions for society by improving access to recovery resources. The burden of critical illness survivorship does not lie within the confines of one patient experience nor one family. The economic impact of surviving critical illness affects patients, families, health care resource use practices, and communities as a whole.

One recent study found that survivors of critical illness, with concomitant respiratory failure and an average age of 55, had a high likelihood to discharge to a skilled nursing facility and could incur costs of approximately $3.5 million per functioning survivor (Herridge et al., 2016). Further, more than 18% of Medicare patients who survived critical illness required LTC, and more than 10% of patients privately insured prior to ICU admission transitioned to Medicare or Medicaid insurance in the first year after ICU discharge (Hill et al., 2016; Kamdar et al., 2017). In the United States, Medicaid is the largest supporter of LTC (Dingell, 2015). Unfortunately, neither Medicare nor Medicaid were intended to support these services. Due to this misappropriation of resources, leaders face a fragmented system that is difficult for patients and families to navigate (Broyles et al., 2016). Thus, policy changes that incorporate the patient experience will support the creation of services that mirror the recovery trajectory.

This chapter presents a background of critical illness survival, the problem statement, and the purpose of the proposed study. Additionally in this chapter, I discuss the research questions, theoretical framework, nature of the study, definitions, assumptions, scope and delimitations, limitations, and social significance. I conclude the chapter with a summary and transition to Chapter 2.

Background

Researchers have used the term *critically ill* in medical literature since the early 1950s. Later, Safar and Grenvik (1977) defined critical illness as encompassing a variety of ailments that are thought to have the highest rates of mortality. By 1970, the Society for Critical Care Medicine was developed to create a forum for critical illness research and knowledge exchange. The technological advances that occurred from the 1950s to the 1970s shaped what the medical community now refers to as *critical care medicine*.

The early years of critical care medicine centered around improving major life-saving technologies, including the initiation of respiratory resuscitation techniques, into the medical system. This development was closely followed by cardiopulmonary resuscitation, including implementation of long-term life-support (i.e., ventilators) being used in practice as early as the 1960s (Safar & Grenvik, 1977). During this period of rapid innovation, it became apparent that enough lives were being saved using advanced prehospital and intrahospital emergency services to warrant a dedicated unit, known as the ICU, into most community hospitals nationwide (Safar & Grenvik, 1977). Although the primary efforts were focused on improvement in early resuscitation techniques and provider specialization, Safar and Grenvik (1977) observed early on the high economic burden for some survivors of these critical illnesses, commenting, "At least 500,000 of the 50 million accidentally injured suffer lasting disability and thereby become a multi-billion-dollar burden on the economy" (p. 88). In the following decades, researchers and practitioners focused on life-saving techniques and specialty physician training to care for these patients.

Diminished mortality and advances in medical research continued throughout the following decades, leading to an unprecedented rate of critical illness survivors (Fan et al., 2014) despite an overall rise in illness severity (Zimmerman, Kramer, & Knaus, 2013). However, survivorship entails more than just leaving the hospital. Success in reducing ICU mortality created a population of survivors whose lives are forever changed from critical illness. In 2014, conclusive research demonstrated that QOL be prioritized as an outcome measure for future critical care trials (Kaukonen, Bailey, Suzuki, Pilcher, & Bellomo, 2014). One of the only ways to fully understand QOL is to obtain the lived experiences from survivors.

Literature reviewed for this study found that most experts have examined QOL by looking at generic QOL instruments that have not been validated in critical illness (Lim, Black, Lamping, Rowan, & Mays, 2016). Researchers have studied specific disease states (Needham et al., 2014) or focused on one aspect of the recovery process (Parry, Huang, & Needham, 2017). Critical care researchers have neglected studying the lived experience of the patient as an evaluative method for understanding QOL and currently offered recovery options. Additionally, health care utilization is a large component of policy decision-making. Lack of care transition programs for recovery creates a cycle for survivors that includes over 30% being readmitted to the hospital within the first 6 months, thereby indicating needed improvement in postdischarge services (Dingell, 2015; Hill et al., 2016; Lone et al., 2016). The recovery struggles patients are facing could be ameliorated with better LTC and recovery policies.

Due to the complex nature of critical illness survival, researchers should gather an in-depth understanding of the patient experience after discharge. The patient perception of the recovery trajectory has become an essential component to gain clarity around discharge practices and transition to home life (Hashem et al., 2016). A multidimensional perspective that holds the patient experience at its core is critical to understanding how the different dimensions of recovery affect survivor QOL and how to develop support structures for this growing patient group (Kean et al., 2017). I filled a gap in this understanding by focusing specifically on the critical illness survivors’ perceptions of QOL and their experiences with recovery. I was the first to examine both QOL after critical illness from the perception of the survivor and the experience of recovery after discharge in the United States. In addition, clinicians can use the results of this study as an adjunct to current clinical strategies, while focusing on improving patients' recovery and not only prolonging their lives.

Problem Statement

Due to advances in medical technologies over several decades, patients have survived critical illness at unprecedented rates, leading to a population of survivors with significant impairments that require prolonged rehabilitative services (Needham et al., 2014). Despite this rapidly evolving knowledge, no researchers have fully investigated the patient perception of barriers to recovery nor ways to develop funding of health policies related to QOL preservation after an ICU stay in the United States (Kamdar et al., 2017). Appropriate care transitions from the ICU to settings such as LTC facilities and home health care for survivors of critical illness are likely of equal importance to medical management during hospitalization. Improved recovery is associated with a reduction in health-care utilization, readmission rates, and most importantly, increased survivor QOL (Hill et al., 2016). In the United States, Medicaid is the largest supporter of LTC, but neither Medicare nor Medicaid were intended to provide LTC services (Dingell, 2015). More than 18% of Medicare patients who survived critical illness required LTC, and more than 10% of patients who were privately insured prior to ICU admission transitioned to Medicare or Medicaid insurance in the first year after ICU discharge (Hill et al., 2016; Kamdar, 2017).

Health care utilization is a large component of policy decision-making. Due to a lack of care transition programs for recovery, 30% of survivors are readmitted to the hospital within the first 6 months, indicating needed improvement in postdischarge services (Hill et al., 2016; Dingell, 2015; Lone et al., 2016). The recovery struggles patients are facing could be ameliorated with better LTC policies that might not be obvious to the external observer.

In the literature I reviewed for this study, I found that most experts have examined QOL by looking at generic QOL instruments that have not been validated in critical illness (Lim et al., 2016). The lived experiences of patients as an evaluative method for currently offered recovery options has been neglected in critical care research. I contributed to the literature by providing policy makers with data to consider when developing health policies related to the recovery resources targeted at improving QOL for critical illness survivors.

Purpose Statement

The purpose of this qualitative phenomenological study was to understand the patient perception of QOL after surviving critical illness and how survivors can illuminate gaps in current health policies to provide better recovery resources for this growing population. I sought to understand the experience of survivors, how their QOL was affected, and how they experienced recovery. I disseminated the results of this study to improve health care providers' understanding of how patients experience critical illness recovery. In addition, these results added to the growing body of qualitative literature that has supported new hypotheses in recovery research. The methods included semistructured interviews of adult critical illness survivors to understand better QOL and recovery in this specific patient population. Survivors with high QOL have reduced rehospitalizations and less overall health care costs (Ruhl et al., 2017).

Research Questions

RQ1: What are the issues important to preserve quality of life from the perspective of critical illness survivors?

RQ2: How do survivors of critical illness describe rehabilitative services after discharge?

Theoretical Framework

The theoretical framework that guided this qualitative research study is RCT. I chose this theory due to its use in economics, sociology, and psychology foundations. Researchers can use this theory to support the internal morality of people and that, when afforded the opportunity and all the correct information, people will make rational choices (Buetow, 2007). Specifically defined, RCT is the process of determining available choices and choosing the most preferred based on subjective preset criterion (Levin & Milgrom, 2004). The choices people favor align with subjective, well-defined assumptions; therefore, different people may feel connected to different choices (Levin & Milgrom, 2004).

Survivors of critical illness have faced being on the verge of death; thus, they may think about value and quality in new ways (Kean et al., 2017). One opportunity that surviving catastrophic illness may give the survivor is the opportunity to choose the life they lead as opposed to the one that has accumulated over years (Kean et al., 2017). Individuals are seen as motivated by needs or goals that represent their preferences. RCT is used in health care due to the underlying assumption that patients will draw on personal preference to make decisions, but patients usually do not receive the necessary information to make rational choices in the current health care system (Epstein, 2017). When people face life-prolonging decisions, their engrained preferences may be unavailable (Epstein, 2017). Thus, consumers of health care may not make the best decisions because they do not receive, nor understand, all options available. Providers bear the responsibility of giving correct information to patients and families so they can make rational choices. With the improvement of medical therapeutics and technological advances, informed decision-making must include not only the acute illness narrative, but also the legacies of these interventions and the influence these have on QOL following survival. People cannot make rational choices without this important understanding. I used this framework to provide a more formal understanding of the empowerment of choice related to illness and QOL preservation as an adjunct to clinical decision-making.

Nature of Study

In this qualitative study, I used a phenomenological research design for several reasons. Researchers of critical illness survival and recovery have focused on mortality outcomes and quantitative data collection. Although the medical community has reduced overall mortality in previously high-mortality diagnoses, only recently has it become apparent that the physiological consequences of catastrophic illness can last for months and even years after discharge. Researchers can look to the survivors to understand the residual effects of current therapeutic interventions, the myriad of symptoms influencing recovery after illness, and the effects on survivor QOL (Hashem et al., 2016). Currently used QOL instruments were not validated in the critical care population, leaving qualitative inquiry as the most reliable research design to address the concept. In this research, I sought to describe the lived experiences of the survivors, their QOL, and their recovery journeys.

Several strategies of inquiry are available in qualitative methods. Phenomenology is a method of inquiry concerned with describing the phenomena of interest from the perspectives of the people involved. I intended to gain an understanding of the perceptions of QOL from survivors of critical illness and to fully understand their experiences with recovery.

The structure of this design included a semistructured interview process with adult critical illness survivors within 18 months of acute illness. I used purposeful sampling strategy for participant recruitment, and I aimed to enroll between 15 to 30 participants. I recruited via advertisements in a post-ICU clinic located in central North Carolina. Those interested in participation responded to the advertisement, and I used a screening tool to ensure they met requirements for inclusion and then I obtained informed consent. I audiotaped interviews and took researcher notes. Participants could choose to have the interview by phone or in-person. I completed transcription of the interview. I kept password-protected files and used pseudonym reporting, and I will keep a locked-safe of private data for 5 years following the study. In addition to manual analysis, I analyzed data using qualitative research analysis software. I used a research team to verify thematic development and to assist in minimizing researcher bias.

Definitions

Critical illness: Life-threatening illness that affects one or several organ systems, and death is possible or imminent (Boonen & Van den Berghe, 2014).

Patient-centered outcomes: Care coordinated around patients and health care treatment outcomes so patients can make informed health care choices based on personal values and health care options (Patient-Centered Outcomes Research Institute, 2013).

Post-intensive care syndrome (PICS): A syndrome characterized by new or worsening impairments in physical, cognitive, or mental health status arising after critical illness and persisting beyond acute care hospitalization (Aitken et al., 2016).

Quality of life (QOL): The World Health Organization (2018) defines QOL as individuals' perceptions of their position in life in the context of the culture and value systems they live in and in relation to their goals, expectations, standards, and concerns.

Sequelae: An aftereffect of a disease, condition, or injury ("Sequelae," n.d.).

Assumptions

This study was based on several assumptions. The first was that participants who self-selected to participate in the study would answer questions truthfully. In addition, I assumed patients admitted to a critical care unit were critically ill and recovery resource availability was similar for all people leaving the ICU. These assumptions were necessary because many ICUs have different admission criteria, and different areas have access to inconsistent levels of recovery resources. I intended to bring awareness to health care providers, policy makers, patients, and families regarding QOL of critical illness survivors and their access recovery resource.

Scope and Delimitations

I explored the perceptions of QOL from the perspectives of critical illness survivors and described the recovery process, access to resources, and other aftercare experiences that might have influenced their QOL. I chose to study patient perceptions of QOL and recovery resource availability because researchers had identified the symptoms facing survivors of critical illness, but research of structured recovery programs have inconclusive results (Jensen, Overgaard, Bestle, Christensen, & Egerod, 2017). The path to recovery and its complexities is best understood by exploring the lived experiences of the survivors (Hashem et al., 2017).

The sample for this study was comprised of English-speaking critical illness survivors who were within 18 months of ICU discharge, over 18 years of age, and had been on mechanical ventilation for at least 48 hours. I recruited all participants from a county in central North Carolina. Participants came from various backgrounds, genders, ethnicities, ages, and education levels.

Grounded theory is a theoretical framework that could have been closely related to this study and used to develop a theory for future studies. However, I did not use this framework because I aimed to understand the perceptions of QOL and the phenomenon of critical illness recovery. I did not intend to create a framework of the perception of survivors. I intended to create a structured interview guide, process, and depth of description from the participants at various levels of recovery; therefore, I aimed to improve the likelihood of transferability to other critical illness survivor populations. Methods included triangulation, coding, and code book preparation. I used all three of these procedures to improve the credibility and transferability of the findings of this study. I confirmed transferability when I compared findings from this study to other similar studies available in the literature.

Limitations

Qualitative inquiry was a limitation because data would not be generalizable to the population. Other limitations included the narrow focus of participant experiences with QOL and recovery after survival. Participants self-selected participation by answering a recruitment ad, which might overrepresent participants experiencing challenges and seeking support.

In addition, qualitative researchers have relied on personal communication between researcher and participant. Inherent to this study design was interviewer and participant bias. The best way to reduce the effect of researcher bias is to identify and understand it exists. During the interview process, researcher bias could have led to limitations by influencing the participant answers through body language or tone. In addition, participants could have altered their answers in an effort to "please" me or assist me in getting the answers that the participant perceived I might have wanted. McCambridge, Witton, and Elbourne (2014) termed this phenomenon the *Hawthorn effect*. I addressed these limitations in several ways. The interviews were recorded and transcribed. After transcription, I asked the participants to verify the accuracy of the transcription. In addition, I used researcher notes during the interview to add thick descriptions of the process. Lastly, I used a research assistant to confirm theme development.

Significance

There is limited evidence-based research on critical illness survivor QOL and the relationship that rehabilitation resources have on survivor QOL. At the time of this study, few researchers had focused on understanding the constellation of symptoms that survivors face and how leaders could create support structures for survivors. Short-term success such as mortality is easier to study, whereas the subjective nature of long-term follow-up and morbidities following critical illness is more difficult to standardize. In addition to prolonged morbidity and mortality, survivors have experienced readmissions at a higher rate compared to other age-matched cohorts without critical illness histories (Lone et al., 2016), yet no collaborative care models for recovery have existed in the United States (Khan, Lasiter, & Boustani, 2015).

I contributed to the current knowledge in two distinct ways. First, I explored the patient perception of QOL, the meaning of QOL, and the effects the illness had on QOL. Previous researchers have focused on quantitative tools to assess QOL, but these tools have not been validated in critical illness (Lim et al., 2016). In using this method, researchers have limited patients to answering preselected questions as opposed to discussing their experiences openly and adding insights into personalized recovery.

Second, this research was the first to incorporate recovery resource and aftercare questions into the lived experiences of these patients. By using a validated set of categories for LTC services and supports, I examined the participants' experiences with recovery and currently offered therapeutics. Research into recovery programs has become increasingly popular in the last decade, yet the results of these studies have shown inconclusive results (Hodgson & Cuthbertson, 2016). By including the lived experiences of the patients, I added to other research to facilitate policy changes for this group of survivors.

I explored resources being used to aid in the recovery of critical illness survivors. In addition, I might have created awareness among policy makers to this growing population. Families, patients, communities, and health care providers celebrate together when patients' lives are saved, yet the legacy of illness remains. Those living with muscular dysfunction have faced difficulties with activities of daily living, social withdrawal, and post-traumatic stress disorder; moreover, these morbidities persist for months and years after discharge, even in the youngest populations of survivors (Kamdar et al., 2017). Changing the culture of medical management includes seeing beyond the acute illness and even beyond the first few days of admission. Critically examining patient care must go beyond the boundaries of the ICU and into the QOL of these survivors. Instituting therapeutic techniques in tandem with life-saving methodologies could improve access to aftercare resources so patients can return to living the lives that health care providers saved. Thus, I aimed to change the continuum of care from survived to surviving.

Summary

Future policy developers should understand the QOL impairments that critical illness survivors face. I provided information about this subject by studying the lived experiences of survivors who have used currently available recovery resources. Survivors suffer from the sequelae of critical illness for months and years after discharge.

Researchers studying resources needed to assist in recovery for this growing group of patients have yet to provide conclusive evidence regarding what policy makers must include, who would benefit the most, and the long-term services available to aid in the recovery journey. Despite knowledge that diminished QOL has been documented in survivors, researchers thus far have focused on disease-specific states, generic QOL instruments, or physical rehabilitation alone. By completing this study, I have provided the patient perspective of QOL and the lived experience of their journey toward recovery. Policy makers could use the information from this study to understand the rehabilitative needs of this population of ICU survivors.

The purpose of this study was to understand, through both QOL and recovery resource availability, the experience of surviving a critical illness. I used RCT to understand information in this study and to continue supporting self-determination with medical decision-making. I added information regarding the survival journey for participants to assist health care providers, patients, and families in making more informed decisions.

In Chapter 2, I provide an in-depth review of current literature about the global issues that critical illness survivors have faced, recovery resource rationale, and economic influences of survival. Combining patients' perceptions of QOL and their experience with recovery could improve the morbidities currently plaguing this particular population.

Chapter 2: Literature Review

Introduction

Due to advances in medical technologies over several decades, patients have survived critical illness at unprecedented rates, leading to a population of survivors with significant QOL impairments requiring prolonged rehabilitative services (Needham et al., 2014). Researchers have shifted their focus from mortality to QOL and care transitions after critical illness, to LTC facilities and home health care, in order to assist patients to return to their preillness QOL. Improved recovery leads to reduction of health care utilization, reduced readmission rates, and increased survivor QOL (Hill et al., 2016; Ruhl et al., 2017). Historically, critical illness researchers have used generic QOL instrument tools, but these tools do not incorporate the survivor perception of QOL to understand the aspects of their recoveries that are most important (Lim et al., 2016). The purpose of this qualitative phenomenological study was to understand the patient perception of QOL after surviving critical illness and how survivors can help illuminate gaps in current health policies to provide better recovery resources for this growing population.

The remainder of this chapter includes the literature search strategy, the theoretical framework for this study, and key concepts related to the problem. I end this chapter with a summary and conclusion of key themes, knowledge in the discipline, and how this study fills the gap; then I transition to the methods in Chapter 3.

Literature Search Strategy

I used a systematic search strategy to deliver high-quality academic relevance to the study. The literature I obtained was from the Walden University Library databases, online publications in the Centers for Disease Control and Prevention online publications, and Centers for Medicare and Medicaid Services databases. To add to the current body of literature, I prioritized patient perception throughout the search. I scoured databases, such as PubMed, Science Direct, MEDLINE with full text, EBSCO Host complete, PsychINFO, Political Science Complete, Google Scholar, and MEDLINE, to retrieve information relevant to *survivors of severe illness, critical illness survivorship, quality of life in critical illness survivors, recovery resource availability,* and *the economics of critical illness*. Terms used included Boolean terms AND, OR, and quotations to refine searches and combine certain terms. In addition, I used keywords from relevant papers and used the reference lists of seminal papers to gain a full scope of the literature in this area. The articles reviewed for this paper spanned publication dates from 1977 to 2017.

Key terms included *critical care, critical illness, quality of life, patient perception, survivor perception, intensive care, recovery resources, patient readmission, long-term care,* and *coping behaviors*. After accessing articles with various combinations of these word phrases, I refined the search further to include only critical illness survivors and the studies that focused on common physical, social, and psychological issues these survivors face. From the preliminary literature review I determined three main search themes that required individual search strategies: (a) LTC policy, (b) quality of life, and (c) critical illness survival. For example, search words of *long-term care* + *United States*

+ *policy* in the Political Science Complete database revealed eight published articles relevant to the topic of this study. I then further identified and used the references from these articles or publications. Then, *critical care* + *quality of life* in PsychINFO revealed several relevant articles, and within those articles, survival was the primary topic. Therefore, I added the keyword *survival* to the above search (*critical care* + *quality of life* + *survival*). Critical illness QOL research has been discussed over several decades. Due to the longitudinal nature of these studies, the literature review also included conference task force data, Centers for Disease Control and Prevention articles, Long-Term Care Scorecard updates, and dissertations in the same subject area.

Theories Foundation

Qualitative researchers have used theories to shape the types of questions asked and data collection methods used (Taylor, Bogden, & De Vault, 2016). Researchers have used the theoretical framework to create a connection between the meaning, nature, and barriers associated with a phenomenon of research (Swanson, 2013). For the foundation of this research, I used Weber's RCT as the theoretical framework. Weber's analysis on rational choice dated back to his posthumous publication *Economy and Society* in 1922 (Thomas, 2015). In later decades, researchers expanded RCT into economic theory of crime and applied it to the utility model of choice in criminal behavior. In the 1960s, Agnew broadened the self-centered scope of RCT to include others' preferences when making decisions (Paternoster, Jaynes, & Wilson, 2017).

There are limited studies in critical care research that use a theoretical framework, but qualitative research has become popular as researchers have shown links among patient perception, mortality (Schnittker & Bacak, 2014), and survivor self-management to rehabilitation programs (Nekhlyudov, O'Malley D, & Hudson, 2017). Thus, more studies with theoretical framework structures may contribute to these qualitative endpoints in the future. I found few researchers who used a theoretical framework to describe the survival phenomenon in critical illness; therefore, I expanded the search to include theoretical frameworks within other survivor groups.

The mortality decline seen in critical illness is also paralleled in many previously life-threatening diseases. Cancer patients have seen a remarkable decline in mortality; much like critical illness survivors, cancer has shifted from an acute illness to a chronic disease (Iadeluca, Mardekian, Chander, Hopps, & Makinson, 2017). Cancer survivorship rose as one of the largest bodies of literature representing long-term survivors. Priority was given to transactional models of stress, coping strategy theories, social cognitive theory, and liminality, as these are theoretical frameworks consistently used in cancer survivor research.

Choice is a large part of modern health care. In the setting of critical illness, advanced technologies have led to the unique ability to extend life even if this extension prolongs suffering. Thus, most of the world has begun limiting life-sustaining treatments or the withdrawal of treatments when futility is likely (Mark, Rayner, Lee, & Curtis, 2015). The health care provider, family, and patient make this choice. In addition, patients are consumers in the health care marketplace, consciously evaluating services, professionals, and quality (Collyer, Willis, Franklin, Harley, & Short, 2015). RCT refers to a behavioral theory with three basic assumptions: (a) patients act with intention, (b) individuals make stable consistent choices, and (c) individuals prefer more, rather than less, choice (Collyer et al., 2015). When given the correct information, RCT theorists have contended that people will make a rational choice, even when facing risk and uncertainty (Levin & Milgrom, 2004). Researchers have used RCT in health care to better understand patient consumption of health care resources. Wu, Lowry, and Dongsong (2015) used RCT in the context of patient compliance. They found that RCT was a key theoretical foundation for understanding patient compliance with medical recommendations. Although RCT has not specifically been applied to critical illness survivors, research may benefit from this evidence-based theoretical foundation for patients, which may influence their decisions when transitioning from patient to survivor.

Researchers have used other theories in studies that pertain to long-term survivors. Byers and Smyth (1997) applied the transactional theory of stress and coping to critically ill patients. They used this model to help bedside nurses understand mechanisms to decrease stress during acute illness. Stress has a negative influence on acute illness by increasing cardiovascular work (Byers & Smyth, 1997). The authors concluded that during acute illness, this theoretical model can change bedside nursing practices to assist patients to cope better with their acute illnesses and use resources available during primary illness.

In 2016, Dutch researchers examined two specific coping styles: avoidant and task oriented. The authors hypothesized that critical illness survivors with a task-oriented coping style would have a better QOL during recovery (Dettling-Ihnenfeldt, de Graaff, Beelen, Nollet, & van der Schaaf, 2016). Coping during acute illness is important. They concluded that, although task-oriented coping strategies were useful in reducing the emotional recovery of critical illness survivors, there was not a statistically significant difference in the physical component of recovery regarding coping style.

In 2017, Kean et al. published the first critical illness survival study using a theoretical framework for survivorship. Kean et al. (2017) used Charmaz's constructivist grounded theory approach to understand the issues facing critical illness survivors as they transitioned from acute to chronic illness. Constructivists have maintained that realities are constructed by individuals within the changing confines of their circumstance. The physical, psychological, and economic effects of critical illness produce the life survivors face upon discharge. Reengagement with their preillness roles is a key component of social recovery that will allow survivors to adapt to their new normality. Kean et al. (2017) found that the stages of recovery sequentially moved from physical recovery to emotional and social survivorship.

Kean et al. (2017) described the long-standing implications of critical illness survivorship as physical, psychological, social, and economic, but they sought to critically examine the dimensions of change facing survivors and how services could be developed to support this population. *Recovery* implies that a survivor will return to their preillness state; *survivorship* refers to an active process that allows survivors to engage with their postillness self (Kean et al., 2017). Kean et al. defined that an important component of recovery transitions is the realization that their previous life has ended but the passage into their postillness life has yet to begin (Kean et al., 2017).

Bruce et al. (2014) defined *liminality* as the qualities of transitions between experiences that create uncertainty. Bruce et al. studied liminality as a theoretical framework for cancer survivors. Using patient narratives, Bruce et al. described the experience of living in the in-between state of prolonged life and life-threatening disease. They found that participants stayed in the in-between state and did not transition to living. As a lens for bedside nursing care, liminality can be used to better assist narrative stories among caretakers, patients, and families. By understanding the liminal transitions patients with life-threatening disease face, nurses can provide more meaningful holistic support resources that assist in QOL improvements (Bruce et al., 2014).

Researchers also explored personality theories to determine if personality traits could better describe successful recovery. Researchers have used social cognitive theory of personality to state that people are not reactive organisms but are influential beings who govern their own actions to produce self-serving results (Bandura, 1986). Strong coping efficacy could be associated with higher QOL. Hoffman, Lent, and Raque-Bogdan (2013) used this theory as a framework for understanding how people would cope with early-stage cancer. Hoffman et al. highlighted the importance of environmental supports, self-management, and belief systems for patients with newly diagnosed cancer. The results compared emotional recovery and the goals of returning to baseline versus coping with the current functioning postdisease (Hoffman et al., 2013). Social cognitive theory could be a viable framework, but Hoffman et al. concluded that this framework would concern emotional recovery, which limited the lens of research.

I chose RCT as the framework to support this study because it addresses the internal morality of all people and the process by which they make decisions. By using this theoretical frame work, I intended to understand the patients' perceptions of recovery resources and to understand their needs during recovery. I used RCT to examine the research questions fully. Ultimately, patients may be left with legacies of their critical illness, but they have chosen to move on. Survivorship is a process where survivors choose their lives moving forward. I used RCT to support survivorship and for researchers to better understand how to empower patients to make choices as they transition into the next phase of life. Unlike early-stage cancer patients, critical illness patients often do not know the complexity of their illness nor the trajectory of recovery for weeks into their management. Little is known in the public about the significant detrimental effects of critical illness. Generalized knowledge of the effects of critical illness and the lasting effects on QOL are less commonly known.

Literature Review Related to Key Concepts

Qualitative researchers collect an in-depth understanding of a phenomena and this method has contributed to randomized control trials (Hashem et al., 2016). Providing a context with which researchers can begin to understand the lived experiences of patients' survival trajectories is one way the field of survivorship can develop successful frameworks for recovery (Eakin et al., 2017). The existential components of recovery are difficult to capture with quantitative data alone; thus, researchers of new trials in critical care and survivor recovery have used qualitative methodologies. I focused on studies that contributed to the constructs of interests related to this study.

Understanding the resource availability for survivors was one research area recommended by health care policies but neglected in early survivor literature (Prinjha, Field, & Rowan, 2009). Prinjha, Field, and Rowan (2009) and Deacon (2012) published several of the first qualitative studies; they evaluated the lived experiences of patients in the context of recovery services offered. Prinjha et al. (2009) described the recovery trajectory of survivors of critical illness as prolonged and suboptimal and concluded that, unfortunately, without understanding the experience of the patient, readmission is the only way to determine survivor recovery success. They also found that survivors suffered a constellation of symptoms, including physical, emotional, and psychological issues; services directed at these categories would be an important component of their recovery. In contrast, Deacon's (2012) patients felt that the most significant physically debilitating issues included weakness and extreme fatigue. In addition, Deacon found that approximately one-third of survivors experienced cognitive dysfunction, thus concluding that patients deserved a comprehensive approach to recovery design. In both Prinjha et al.'s and Deacon's research, participants valued having an ICU clinician provide follow-up services as opposed to general practitioners, which were novel findings. The future of research should include prediction of patients who might need prolonged or specialized recovery resources (Deacon, 2012). The researchers concluded that qualitative data methods were appropriate to use when perception and experience of the user needed to be further understood (Deacon, 2012; Prinjha et al., 2009).

Survivors need support, but both the nature and timing of these needs have been less understood. Czerwonka et al. (2015) conducted a study in Canada, RECOVER, to explore the timing of survivor and caregiver recovery access. Adding to the previous grounded theory research approaches by Prinjha et al. (2009) and Deacon (2012), Czerwonka et al. used the timing it right framework to best determine when patients would need recovery resource implementation. The authors found that recovery services could be targeted toward various phases of recovery over time. To add to this finding, Pattison, O'Gara, and Rattray (2015) discovered that recovery trajectory depended on chronic medical conditions, follow-up, and disease recurrence; additionally, anxiety and depression among survivors negatively influenced survivor recovery. These results corroborated those previously reported by Deacon (2012). However, Pattison et al. (2015) found that survivors' anxiety and depression were more likely to be timed with disease state or recurrence, as opposed to Deacon (2012), who found that survivors described early timing of psychological symptoms independent of other disease states.

Prinjha et al. (2009) concluded that survivors desired aftercare services and believed that the current system could not provide appropriate care. Deacon's (2012) study survivors believed that the three main components of a holistic rehabilitation program included (a) patient information and education, (b) personal support, and (c) full physical assessment and therapy. Czerwonka et al. (2015) reached similar conclusions and found that when survivors lack continuity of care, their needs change across the recovery trajectory. In addition, not knowing what to expect contributes to anxiety and fears for survivors during the recovery process. Patients and family members did not know where to obtain information or receive follow-up care, nor did they know where to obtain answers to questions if they had a problem that persisted after hospitalization.

None of these studies was done in the United States, nor was the patient perception of QOL discussed. Understanding recovery needs within the context of the U.S. patient experiences, QOL, and rehabilitative resource availability had not been addressed in the current literature.

Despite hospitals noting an overall rise in illness severity, health statistics reveal a continuous decrease in mortality (Zimmerman et al., 2013). Despite this realization, longitudinal follow up and the effect critical illness has on QOL remains controversial. In seminal work from 2003 and 2011, Herridge et al. studied the QOL of critical illness survivors at 1 and 5 years, respectively. In both studies, the authors concluded that even 5 years after ICU discharge, these patients continued to suffer from physical, psychological, and social sequelae of critical illness. Hofhuis, van Stel, Schrijvers, Rommes and Spronk (2015) contradicted these studies in a 5 year follow-up study that, after correction for natural decline, showed patients regained their age-specific QOL at 5 years post ICU stay. The Herridge et al. (2003) study followed the 109 patients enrolled for 5 years and in 2011, Herridge et al. (2011) published 5 year data with similar prolonged dysfunctions. However, Hofhuis et al. concluded that reduced QOL in ICU survivors at 5 years was minimal and could be irrelevant for future research. They used the SF-36 QOL instrument, and neither used qualitative research design to discuss the questionnaires' accuracy in estimating QOL (Herridge et al., 2011; Hofhuis et al., 2015). These controversial conclusions are likely due to methodological differences, variance in measurement instruments, and lack of baseline knowledge of QOL (Jeitziner et al., 2015).

Most critical illness researchers have focused on quantitative methodologies to explore common rehabilitative needs of critical illness survivors. Researchers could evaluate validated instruments to further understand the effect that debilitations have on patient QOL. As early as 1998, Heyland et al. (1998) published a retrospective study examining how researchers had evaluated QOL in critical illness survivors and how many trials used the generic QOL tools that were available. They found that despite literature supporting the assessment of QOL after critical illness, few researchers included QOL outcome measures in their trials (Heyland, Konopad, Noseworthy, Johnston, & Gafni, 1998). Lim et al. (2016) elaborated on these findings suggesting development of a standardized way to evaluate QOL in survivors of critical illness. They found that current generic instruments do not adequately capture this survivor groups' perceptions. Since patients suffer prolonged morbidity after discharge, successful ICU treatment can no longer be evaluated with generic instruments or based on mortality alone.

Due to economic influences, researchers have continued to study survival. From 2000 to 2014, the cost of critical care has doubled, the number of critical care beds has increased by over 17%, and the survival of the population has increased (Halpern, Goldman, Tan, & Pastores, 2016). Further researchers should explore the failures of rehabilitative programs and the impacts these programs could have on critical illness survivors QOL. Policy makers could also use this information to reduce the economic burden on the health care system.

Physical Rehabilitation

Survivors face physical disabilities that are associated with higher health care costs. In addition, physical disability decreases the likelihood the person will return home and can be used as a predictive influence on prolonging length of stay (Parry et al., 2017). The constellation of symptoms and pathophysiology associated with immobility have created a new diagnosis in critical illness survivors called ICU acquired weakness (ICU-AW) (Kress & Hall, 2014). During acute illness, immobility leads to a cascade of physiologic changes where patients feel weak, fatigued, and breathless. Patients lose approximately 30% of lean muscle mass within the first 10 days of admission, and 25% to 40% of ICU patients suffer from ICU-AW (Parry et al., 2017). Thus, early mobility became the focus of inquiry for improving this component of survivors' QOL.

Despite this evolving knowledge of physical debilitation, only a fraction of critical illness survivors receives rehabilitative services at discharge (National Institute for Health and Care Excellence, 2017). To improve physical function for discharge home, researchers have focused on early mobilization during acute illness. The seminal early mobilization trials were Schweickert et al. (2009) and Burtin et al. (2009). After these successful trials, the researchers developed the first early mobility protocols for ICU patients to help reduce the effects of ICU-AW. Burtin et al. and Schweickert et al. concluded that early mobilization for critically ill patients enhanced functional recovery and improved QOL after discharge. Through these early mobility trials, Burtin et al. and Schweickert et al. defined the utilization of physical therapy in the early days of critical illness as safe and tolerated. Furthermore, it reduced the time of ventilator support (Burtin et al., 2009; Schweickert et al., 2009).

To corroborate these early findings, Schaller et al. (2016) studied early mobilization specifically amongst surgical patients following ICU admission. Through this multicenter, international, randomized control trial, Schaller et al. evaluated early mobilization versus standard of care in 200 patients over the course of 4 years. The authors hypothesized that utilization of a surgical intensive care early mobilization protocol would decrease length of stay and improve functional recovery at hospital discharge (Schaller et al., 2016). The secondary outcome was improved QOL which was measured 3 months after discharge. Although functional status at hospital discharge and ICU length of stay were both reduced in the early mobilization patients, there was no significant difference between the two groups' QOL 3 months postdischarge (Schaller et al., 2016).

In a summary of early mobilization trials, Iwashyna and Hodgson (2016) concluded that although early mobilization could be used to decrease ICU length of stay and lead to higher functional abilities at discharge but further research is needed before absolute determination of these claims can be made. The conflicting results between functional outcome improvement and improvement in QOL after discharge has continued to plague researchers in this field (Iwashyna & Hodgson, 2016). In addition, these conflicting results have shown a gap between the subjective assessment of QOL and the effect of mobilization on this perception.

Other researchers have studied physical dysfunction within specific, high mortality diagnoses often seen in the ICU. Researchers have focused on acute lung injury survivors due to their substantial physical dysfunction and reduced QOL following critical illness. Fan et al. (2014) found that acute lung injury survivors from the ICU were discharged with physical impairments that reduced their QOL for up to 2 years postdischarge. In contrast, Shelly, Prabhu, Jirange, Kamath, and Vaishali (2017) studied individualized home-based exercise programs in critical illness survivors with acute lung injury to determine the programs' effect on QOL after discharge. Fan et al.'s (2014) strengths were finding that bed rest during hospitalization was an independent risk factor for weakness at discharge but they relied on patient recall for baseline functional status, and did not report posthospital rehabilitation utilization (Fan et al., 2014).

Taking a different approach, Shelly et al. (2017) studied participants randomized into two groups: control versus treatment. The treatment group received individualized treatment programs, weekly reminder calls, and a 4 week follow up with the SF-36 QOL screening. Shelly et al. concluded that individualized physical rehabilitation programs improved QOL in patients discharged from the hospital after a minimum of 48 hours in the ICU compared with standard treatment discharge plans (Shelly et al., 2017).

Compared with previous studies, I elaborated the point that when given the correct information, patients could make appropriate informed choices to participate in rehabilitation programs. The main weaknesses in Shelly et al.'s (2017) study was that patients received standard physical therapy in both groups during hospitalization, but the authors did not comment on early mobilization as a standard of care. Prior studies evaluating postdischarge physical rehabilitation in critical illness survivors did not show statistically significant differences in QOL (Walker et al., 2015). The variance of these findings could have been because early mobilization became standard of care after the Schweickert trial in 2009, and many conflicting studies were published before the early mobilization strategies were popularized.

Focused Rehabilitation

Other researchers have chosen to study rehabilitative programs that focus on the primary dysfunctions facing ICU survivors (physical, psychological, and social) or a combination of two of these legacies of critical illness. Following critical illness survival, psychological symptoms, specifically depression, are prevalent in up to 40% of survivors and is associated with an increase in hospital readmissions and decreased QOL (Choi, Tate, Rogers, Donahoe, & Hoffman, 2016). In addition, other studies have found that survivors were more willing to accept high-burden medical treatment and death than long-term cognitive impairment (Girard, Dittus, & Ely, 2016). These findings have shown psychological inclusion as a priority for recovery program enhancement.

Two research groups that focused on psychological rehabilitation were Fumis, Ranzani, Martins, and Schettino (2015) and Choi, Tate, Rogers, Donahoe, and Hoffman (2016). Fumis et al. studied depression and anxiety amongst survivors (and their family members) who were discharged from the ICU. Choi et al. focused on the contribution of depression and anxiety on discharge disposition for these survivors. Fumis et al. made two large contributions surrounding rehabilitation. First, survivors who suffer from anxiety and depression while in the ICU are at highest risk for these consequences upon discharge. Second, patient anxiety reduces in the first 90 days of discharge. Choi et al. concluded that LTC for survivors of critical illness was a risk factor for depression; however, both of these authors did not correlate depressive symptoms as a cause for diminished QOL. Future researchers should focus on validated instruments to evaluate QOL and depression in the critically ill.

More recently, researchers addressed the unique geographical issues that survivors face and turn to technology to create a virtual connection with survivors. For example, researchers have used e-mail or phone interventions to assist with the psychological legacies of critical illness. Mindfulness meditation is an awareness practice used in various settings to assist with quieting the mind, alleviating stress, and improving resilience (Savel & Munro, 2017). To address the psychological needs of survivors, Cox et al. (2014) developed a telephone mindfulness meditation training intervention to assist patients struggling with the debilitating psychological sequelae of critical illness. In this pilot trial, Cox et al. concluded that improving access and connecting with their ICU experience, exploring flexible study designs, and considering personalized choice are the future of rehabilitative trials (Cox et al., 2014).

The physically debilitating effects of critical illness are more obvious to the external observer than the psychological and cognitive dysfunctions plaguing survivors. Psychological recovery is a critical component to QOL improvements and limited qualitative data has been collected. Jensen et al. (2016) developed a nurse led critical illness recovery program that focused on the psychological issue’s survivors faced. The authors used an illness narrative to facilitate both physical and psychological recovery.

This Danish recovery program was comprised of three consultations by nurses. The first consultation was in person and the remaining consultations were by phone at 1 and 3 months postdischarge. Unfortunately, Jensen et al. (2016) failed to improve QOL, reduce symptoms, or improve social cohesiveness in survivors when compared with the general public (Jensen et al., 2016). Two weaknesses stand out in this trial. First, a participant was included in the results, even if only one of the three interventions were received. Second, Danish citizens have paid rehabilitation services and are well informed regarding their options. Comprehensive postrecovery rehabilitation that is paid by the government makes comparison to United States studies difficult.

Dziadzko, Dziadzko, Johnson, Gajic, and Karnatovskaia (2017) used qualitative methodologies to understand further the cause of psychological sequelae from the perspective of the survivor. Dziadzko et al. used a qualitative design to create themes based on patients' and family perception of contributors to psychological symptoms during recovery (Dziadzko, Dziadzko, Johnson, Gajic, & Karnatovskaia, 2017). The strength of this study was the large sample size compared to other qualitative studies and the thematic discovery of several factors that reduced psychological symptoms while in the ICU. Results found connection with psychological symptom reduction at discharge. The themes that emerged could contribute to the developing research dedicated to understanding psychological trauma following critical illness (Dziadzko et al., 2017). To date, research remains conflicted about the effect of psychological impairments plaguing survivors, if these symptoms caused QOL reduction, or if a combination of factors caused depression.

Age-Related Recovery

Researchers have hypothesized age as an independent risk factor associated with reduced QOL. As the population continues to outlive the previous generation, exposure to critical illness and survival from critical illness will become more common. Understanding age-related QOL predictors can assist with treatment decisions during acute illness. In 2015, two age-related QOL studies were published.

Research correlations amongst survivors of critical illness and age have also shown inconclusive findings (Heyland et al., 2015). Understanding the effects of critical illness treatments on the elderly is important for prognostication and assisting patients, families, and caregivers with treatment decision-making during hospitalization. Heyland et al. (2015) studied physical recovery of patients aged 80 or older for 1 year after ICU admission. In addition, Heyland et al. (2015) sought to understand qualities that made survivors more likely to return to baseline. At one year, 50% of patients had died and only 26% had recovered to or near baseline (Heyland et al., 2015). Jeitziner, Zwakhalen, Bürgin, Hantikainen, and Hamers (2015) also published a QOL study but they compared QOL amongst people over the age of 65 for 1 year following critical illness. Where Jeitziner et al. (2015) used a convenience sample and compared it with community-based age-matched controls. The critical illness survivors had lower physical and mental health scores compared with the comparison group and QOL was significantly lower compared with the controls. The differences amongst the groups were present at baseline, indicating that patients who are admitted to the ICU already had lower QOL than people who were not admitted. Jeitziner et al. pointed out the lack of pre-QOL information as a weakness for most studies, and that variation of instrument use in QOL function might cause variations in results. A strength of the Heyland et al.'s (2015) study was inclusion of the Frailty Index at admission to the ICU, which was a significant independent predictor of poor long-term outcomes. Inclusion of the Frailty Index could inform clinicians during discussions around life-preserving therapies and the effects on QOL and mortality if survival should occur (Heyland et al., 2015).

It is difficult to compare the Heyland et al.'s (2015) methods with Jeitziner et al.'s (2015) due to age differences, sampling baseline characteristics, and Heyland et al.'s (2015) inclusion of various other quantitative indices such as the Frailty Index. Moreover, these studies were done in different countries. Much like other studies mentioned above, variation amongst public health programs in each country creates a larger scope of including variation among insurance structures and access to rehabilitative services.

Combined Programs

Focus on the constellation of symptoms facing survivors became the theme of the 21st century as most ICU patients now survive to discharge (Dziadzko et al., 2017). Researchers have combined patient-centered outcomes to determine if a coordinated rehabilitation effort may improve QOL in survivors (Aitken & Marshall, 2015). In 2015, RECOVER investigators found that intensive nutrition and physical rehabilitation therapies during and after hospital had no effect on survivor QOL. In 2016, McWilliams, Benington, and Atkinson (2016) studied out-patient physical rehabilitation programs and the effect these programs had on survivor QOL. The authors concluded that despite a subjective improvement in QOL, there was no quantifiable change in participant functional capacity (McWilliams, Benington, & Atkinson, 2016).

Although only a methods proposition, Heyland et al. (2016) published an article advocating for a new trial that combined early nutrition therapy with the known benefits of early mobilization to assist in recovery. Heyland et al. hypothesized that nutrition and exercise could be used to attenuate the effects of ICU-AW, thus improving functional recovery. This methodological paper had an ongoing trial association and the results has yet to be published. One weakness was that the authors planned to focus only on functional recovery, as opposed to, a patient centered QOL measure.

The subjective nature of survival and the nascent understanding of recovery likely contributes to these controversial results. Capuzzo and Bianconi (2015) examined 20 years of critical illness survivor data. The authors cross-referenced the data with QOL end points. Capuzzo and Bianconi concluded that the controversial research thus far was likely due to the persistent rise in illness severity and the aging population which limited comparison to previous QOL and recovery outcomes data.

Central Concepts in Development

Despite controversies amongst research results and QOL outcomes, several commonalities among patients recovering from critical illness have appeared throughout the years. These common themes are now the focus of recovery research: physical (Parry et al., 2015) psychological (Needham et al., 2012), social (Eakin et al., 2017) and financial (e.g., joblessness, re-admission, economic impacts) (Kamdar et al., 2017). Recovery is on an individual timeframe and no policies currently exist to improve survivorship transition (Kean et al., 2017). Short-term outcomes such as mortality and length of stay are easier to obtain but the larger impact of critical illness, both economically and personally, comes after the primary transition. Most researchers attempting to understand the long-term influence of critical illness have completed small, focused studies, which often used different methodologies, which impairs comparison (Garland, Olafson, Ramsey, Yogendran, & Fransoo, 2015). From the last several years, the main concepts have led to researchers focusing on patient-centered outcomes, understanding of the financial influences of survival, and studying individualized recovery plans.

Economic Concepts of Survival

Labor market outcomes are one way that researchers can evaluate economic influences to assist patient-centered outcome research. Survivors' abilities to work and earn (labor market outcome) influence well-being and QOL (Garland, 2017). After a significant health event, one can experience a cascade of events related to loss of health including lost earnings and productivity, as well as an increased need for informal care (Garland, 2017). Kamdar et al. (2017) published a landmark study evaluating the joblessness and lost earnings of survivors of critical illness. This study showed that 1 year postsurvival nearly half of previously employed patients were jobless (Kamdar et al., 2017). In addition, Kamdar et al. (2017) revealed that people who did not return to work suffered a consistently lower QOL compared to their employed counterparts. In addition, significant gender and socioeconomic disparities existed amongst critical illness survivors. The greatest delays noted for return to work include older, non-white survivors

(Kamdar et al., 2017). Whereas, women experienced higher rates of in hospital mortality (Garland et al., 2015). Future researchers should focus on these notable inequalities.

Readmission rates are an important component of economic evaluation of health care policy programing. Leaders of U.S. health care policy should prioritize improving care transitions and reducing readmission rates. Readmission has become so commonplace that readmission costs are becoming equivalent to costs of original admission (Jones et al., 2015).

Bagley and Levy (2014) reported on the essential health services provisions incorporated into the Affordable Care Act. Rehabilitative and habilitative services and devices are considered essential; therefore, staff of all state insurances must comply with incorporating rehabilitation into their coverage (Bagley & Levy, 2014). Researchers have viewed rehabilitation as essential to the critical care continuum (Rattray, 2014).

Despite limited understanding of the ultimate cause for readmissions within the ICU survivor population, lack of rehabilitative resources is a likely contributor. In 2017, van Sluisveld et al. (2017) studied ICU readmissions and compared these with in hospital mortality. The authors found no association between discharge practices and ICU readmissions; however, they found readmitted patients are found to experienced higher adverse events, causing an increase in resource utilization for both patients and the health care system (van Sluisveld et al., 2017). Elliott, Worrall-Carter, and Page (2014) found that readmitted ICU patients had mortality rates six times higher compared to nonreadmitted patients. Risk factors for readmission are underdeveloped but can be explained by lack of long-term follow-up (Khan, Lasiter, & Boustani, 2015) and lack of full understanding of what patients need in a comprehensive program (Prinjha et al., 2009).

Over half of the 5 million U.S. ICU admissions each year are comprised of patients over the age of 65 (Balas et al., 2015). Survival has created a group of older adults who face the chronicity of illness, along with other age-related comorbidities. Wunsch et al. (2010) studied critical illness survivors over the age of 65 and found that Medicare patients were more likely to be rehospitalized within 1 year. In addition, Medicare patients had higher mortality rates at 3 years and were more susceptible to changes in functional abilities compared to their age-matched cohorts (Wunsch et al., 2010). Similarly, chronically ill cancer patients have seen the same phenomenon. For example, Iadeluca et al. (2017) identified the most frequently diagnosed cancers and compared functional limitations of survivors with current health care utilization. They found that the economic burden of cancer is dependent upon the increase noted in survival. To understand the economics further, Zheng et al. (2016) studied the economic burden of the most prevalent cancers. Zheng et al. discovered that cancer survivors experienced higher economic burden compared with their noncancer, age-matched counterparts. In addition, joblessness and loss of productivity were the highest cause of economic burden facing cancer survivors (Zheng et al., 2016). Kamdar et al. (2017) found similar results in young, previously employed survivors of critical illness. In addition, regardless of age, critical illness survivors have a higher utilization of public insurance programs, such as Medicaid.

Individualized Recovery

Survivors of critical illness have substantial morbidity after hospital discharge. Collectively, survivors face disabilities now referred to as PICS, which are associated with a significant reduction in QOL (Hashem et al., 2016). Understanding the patient experience is an essential component to facilitate future research focused on patient-centered outcomes. Although the burden of recovery has been well-established from previous research (Hill et al., 2016), utilization of health services and individualized recovery needs are less understood (Garland, 2017). In addition, the timing of such needs and when to intervene are concepts in need of development (Hodgson & Cuthbertson, 2016).

Predicting patients who may face a reduction in QOL after surviving critical illness can be a research focus for the future. One common weakness in most studies to date is a lack of input from the patients. Quantitative studies include instruments that assess QOL but patients are limited to the questions within these instruments which may not elicit the most pertinent aspects of recovery (Lim et al., 2016). Continued utilization of various generic instruments hinders not only full understanding of the patient experience but also limits study comparability. By understanding the patient perception of available services and the recovery trajectory, I intended to better understand patient needs during recovery to assist future research in policy development for recovery resource implementation.

Chronic Illness Recovery

The chronicity of survival is not unique to critical illness. Over these same decades, advances in medical technology improved survival in many previously life-threatening diseases such as cancer (Li, Matthews, Dossaji, & Fullam, 2017), stroke (Chuluunbaatar et al., 2016), and heart disease (Bluvstein et al, 2013). These improved survival rates changed terminally ill patients to chronically ill patients. Survivors have faced similarities that can assist in transition care, recovery resource allocation, and policy planning as our population ages in parallel with the population of survivors. Literature has indicated several commonalities amongst this new population of chronically ill patients. Physical debilitation, social limitations, and psychological/emotional impairments have impacted survivors in all disease categories (Feemster et al., 2015; Richardson et al., 2011).

According to Richardson et al. (2011), survival amongst previously life-threatening cancers has risen and the population of cancer survivors will increase approximately 3% per year. Similar to the advancements shown in critical care treatments, researchers have attributed the growth of cancer survivors to early detection and improved treatments (M. T. Halpern & Argenbright, 2017). The legacies of these improved treatments remain a large part of survivor recovery research. Thus, researchers have focused on the importance of coordinated, comprehensive cancer survivor care plans. This change from short-term outcomes such as mortality to comprehensive rehabilitative strategies has created an evolutionary change in the mindset of cancer researchers as they began to include QOL as a primary endpoint.

Nekhlyudov et al. (2017) published a series of papers on ways to create a survivorship program that included appropriate medical follow up, patient self-management, and policy changes about medical care reimbursement. In contrast, Halpern and Argenbright (2017) focused on ways to evaluate recovery programs where leaders had emphasized the relevant health effects for survivors. Despite researchers focusing on a recovery pathway, reduction in QOL amongst cancer survivors was still not well understood (Leung, Smith, & McLaughlin, 2016). Much like critical illness, diversity among the primary disease state makes comparison across studies difficult. Research dedicated to specific cancer types such as breast (Ganz et al., 2013); head and neck (Richardson, Morton, & Broadbent, 2016); prostate (Skolarus, Wittmann, & Hawley, 2017); colorectal (Kobayashi et al., 2017); urologic (Gore, 2017); and lung (Singer et al., 2015); all showed support for the same categorical morbidities. These morbidities include physical, psychological, and social dysfunctions as causes for complications of surviving cancer that would lead to reductions in QOL, similar to the pattern shown in critical illness survivor literature.

In acute cardiac survivors, QOL outcomes are important predictors of recurrent hospitalization and death (J. R. Wu, Lennie, Frazier, & Moser, 2016). Maru et al. (2015) followed elderly heart failure patients utilizing physical rehabilitation concepts. The authors concluded that physical rehabilitation benefitted heart failure patients for improved rehabilitation and more importantly, home-based rehabilitation improved quality life years, decreased mortality, and reduced hospital costs (Maru et al., 2015). However, the patient perspective of the treatment programs was not a study endpoint.

Much like cardiac disease and critical illness, strokes are another acute illness that suddenly leave survivors with debilitating legacies of disease and treatment. The World Health Organization estimated that approximately 15 million people experienced a stroke annually. Disability adjusted life years continues to influence developing countries at higher rates than first-world countries; moreover the effect of stroke on people under age of 65 is on the rise, and environmental factors such as air pollution have emerged as significant contributors to the global stroke burden (Feigin et al., 2016). Survival from stroke may lead to physically debilitating functional statuses where patients experience less independence, decreased ability to return to work, and heightened depression (Chuluunbaatar et al., 2016). Stroke survivors face similar disabilities with those in previously described chronically ill patients. To my knowledge, there have been no studies comparing these chronically ill survivor needs in order to collaborate resources and improve policies while addressing recovery across multiple medical disciplines.

Key Areas for the Future

As therapeutic medical interventions continue to improve mortality outcomes for previously terminal illnesses, the chronically ill survivor population continues to rises (Fan et al., 2014; Feemster et al., 2015; Iadeluca et al., 2017; Richardson et al., 2016). Therefore, better understanding of survivor needs to support recovery is imperative for policy planning in the future (Garland et al., 2015). Survivors of critical illness require comprehensive recovery programs that address both the deleterious effects of disease and its treatments. Unfortunately, the current long-term resources are inconsistent and fragmented. Garland et al., (2015) described LTC resources as expensive and inefficient while Mechanic (2014) added that LTC lacked high-quality management required for funding and policy creation. This fragmented and inefficient system coupled with complex survivor sequelae makes creation of a comprehensive program in chronically ill survivors difficult to structure (Jackson, Mitchell, & Hopkins, 2015). Policy creation is warranted not only for the improved QOL it brings to patients, but also for reduced resource utilization and hospital readmission rates (Hill et al., 2016). Understanding the intention of current long-term policies and their provisions would provide a framework from which policy leaders could make changes.

Other ways health care policy is addressing postacute care and rehabilitative services are by limiting reimbursement for readmitted patients, supporting collaborative care between hospitals, creating improved quality metrics for postacute care facilities (e.g. skilled nursing facilities), and bundling payments for services across the spectrum of illness (Mechanic, 2014). These improvements in policy may create controversy regarding the postacute care quality metrics that are tracked by Medicare and their relationship to hospital readmissions (Neuman, Wirtalla, & Werner, 2014). Despite these studies, the cause of readmissions and what risk factors can be identified to target patients at risk has yet to be determined. Critical illness survivor readmissions are not specifically tracked by Medicare databases (Hua, Gong, Miltiades, & Wunsch, 2017) but several researchers have attempted to find ways to improve recovery and rehabilitative services to assist in reducing revolving readmissions.

Neuman, Wirtalla, and Werner (2014) compared the quality of care provided by a skilled nursing facility and associated readmission to the hospital. They specifically studied skilled nursing facility performance measures provided by Medicare and examined readmissions amongst patients to determine if poor performance within these measures could predict readmissions. Neuman et al. (2014) did not find a correlation between quality measure performance and hospital readmission rates amongst Medicare beneficiaries. They did find that one in four patients discharged to a skilled nursing facility are readmitted to the hospital and two-thirds of these readmissions were preventable (Neuman et al., 2014). A key area in need of expansion for the future.

Causes of Readmission: A Reflection of Aftercare Resources

In the United States, sepsis accounts for the most expensive inpatient diagnosis (Liu et al., 2014) with the highest rates of postacute care readmission (Pfuntner, Wier, & Steiner, 2013). Several researchers have used data from sepsis patients to better understand readmission because sepsis has a high incidence, has decreased mortality in recent years, and disabilities after sepsis are common (Liu et al., 2014). In addition, comparison is often extrapolated using sepsis in critical illness survivors because sepsis coupled by an ICU admission is an independent risk factor for readmission (Liu et al., 2014). Readmission is one of the only currently available ways to determine the efficacy of aftercare / recovery resources, researchers have approached recovery program examination by studying causes of readmission.

Liu et al. (2014) retrospectively studied sepsis survivors to determine if risk factors could be identified, and ultimately modified, to reduce readmission rates. The authors found that advanced age, comorbid disease burden, admission to an ICU during the course of hospitalization, and presepsis health care utilization rates were amongst the highest risk factors for patients to return to the hospital within the first 30 days of discharge. The following year, Jones et al. (2015) found conflicting results, noting that young, previously healthy patients were at higher risk for readmission compared to older patients, and furthermore, readmission was independent of illness severity. Liu et al. (2014) found noninfectious causes of readmission were the highest, whereas Jones et al. (2015) concluded that independent risk-factors included age, current malignancy, nonelective admission, one or more procedures during hospitalization, low hemoglobin levels and high red cell distribution at discharge. Improving care transitions and postdischarge rehabilitation after sepsis could improve long-term mortality (Jones et al., 2015). However, neither set of researchers included measures of functional outcomes, cognitive status, or co-morbidities amongst readmitted patients.

Due to the limited investigation into the postdischarge needs of sepsis survivors, Ortego et al. (2015) investigated *why* patients return to the emergency department and how many are readmitted. The authors hypothesized that readmissions could be related to a consequence of sepsis that other studies did not identify. By utilizing a novel risk-stratification tool, Ortego et al. (2015) found that 23% of stratified at risk survivors were readmitted within the first 30 days, and 30% of these patients required ICU level care (Ortego et al., 2015). In addition, Ortego et al. (2015) found that increased length of stay, higher previous health care utilization, and an oncologic diagnosis were the three risk factors associated with readmission. The authors note that a significant limitation of this study was failure to capture the burden experienced by sepsis survivors and recommended complimentary studies to elaborate the patient experience and the utilization of recovery resources (Ortego et al., 2015).

By comparison, comorbid disease burden was found to be a prevailing risk factor for sepsis survivors being readmitted. More specifically, Ortego et al. (2015) and Jones et al. (2015) both concluded that cancer was a risk factor for readmission. Liu et al. (2014) stratified by using a comorbid index but did not extrapolate individual comorbidities. The only common thread among all these studies was a recommendation for innovative strategies to accelerate recovery and development of a stratification process for high risk patients. These two factors should be included in future research (Jones et al., 2015; Liu et al., 2014; Ortego et al., 2015). One way to use risk stratification could be to preidentify people at highest risk for postdischarge morbidity and analyze recovery resources that would benefit these survivors.

Standardized Strategies

As critical illness continues to improve life-saving strategies, survivors continue to suffer from life-long disabilities. Comprehensive program development for survivors coupled with unique strategies to identify patients with the highest needs are necessary for the future of policy support. Lack of standardization amongst earlier survivor trials has made comparison difficult (Eakin et al., 2017). Leaders of the National Institutes of Health created a chronic disease survivorship network using physical, psychological, and social recovery measurement strategies to help evaluate new treatments (Cella et al., 2010). This survivorship network is now referred to as the patient-reported outcomes measurement information system and is used to standardize future research for chronic disease survivors. In 2017, Eakin et al. applied these measurement strategies to critical illness survivors. Utilizing a qualitative study design, Eakin et al. (2017) evaluated patient perception of recovery with the patient-reported outcomes measurement information system framework to see if this framework could be translated to trials for critical illness survivors. Although survivors of critical illness might have similar disabilities in their recovery trajectories, they differed from people with other chronic diseases. Other disease processes are typically not acute and critical illness survivors are often unaware of the post-ICU impairments they may face (Eakin et al., 2017). Eakin et al. (2017) confirmed that comprehensive research dedicated to understanding the issues important to survivors of critical illness should include physical, mental, and social measurements. Furthermore, focuses on the perception of the survivor with qualitative study design is key to uncovering this understanding (Eakin et al., 2017).

Self-Reported Health: Patient Perspective

Self-reported perception of health (SRH) is a well-known predictor of mortality and thus, a strong indicator of overall health (Schnittker & Bacak, 2014). Cancer researchers have used patient perception to evaluate the patients' understanding of illness trajectories (Richardson et al., 2016). Due to the acute nature of critical illness, there is limited data in critical care utilizing patient perception of health to preidentify patients' recovery needs. Despite qualitative data examination in the field of critical illness, to my knowledge no researchers have asked a self-rated health scale for purposes of establishing the relationship between critical illness survivors' SRH and long-term recovery. By understanding the issues important to preserving QOL in critical illness survivors, researchers can begin to outline the necessary inclusions of recovery options and align these needs with policies and funding.

SRH has been validated in various ways. Researchers have studied SRH regarding (a) cognitive dysfunction (McHugh & Lawlor, 2016), (b) compared it to clinical assessment (Schnittker & Bacak, 2014), (c) examined against disease diagnosis (Falconer & Quesnel-Vallee, 2017), and (d) analyzed with morbidity and disability (Wu et al., 2013). In addition, Wu et al. (2013) found an association between SRH and objective health statuses by comparing disease prevalence and laboratory abnormalities. Thus, they concluded that SRH might be the only individual indicator that is comprehensive enough to evaluate an individual's health status. Incorporating self-ratings of health into the recovery trajectory may assist survivors of critical illness to establish rehabilitation planning, individual programming, and targeted follow up strategies for high-risk patients.

Researchers have used SRH has also been used to examine readmission rates and found that there is an age-related divide amongst causes of readmission. Poor lifestyle is the leading cause of readmission for people aged 40–64 (Gabay, 2016). Younger people facing admission related to lifestyle are of significant concern to health care economics, as younger people have longer life trajectories. Readmissions are a known correlate with critical illness survivors and studies have shown that 16% to 27% of survivors are readmitted within the first 30 days (Hua et al., 2017). To elaborate on the relationship between SRH and disability, Gabay (2016) studied SRH and its relationship to readmission rates. The authors focused on patient empowerment as it relates to hospital readmissions and found that higher SRH was strongly associated with lower readmissions. By utilizing patient empowerment theory, Gabay (2016) found that during illness, patients relied on internal and external resources to assist in improving health outcomes. Education, internal health control, and efficacy of treatment were all modifiable through appropriate education. Incorporating comprehensive strategies had a large impact on improving health outcomes (Gabay, 2016). The patient perception of QOL after surviving critical illness could assist in closing the gap of understanding between patient SRH and recovery care following discharge.

Rehabilitative Services and Insurance Coverage

Medicare beneficiaries account for 15.6% of the U.S. population, while Medicaid has become the largest provider of health care in the United States, covering 22% of the population (Halpern et al., 2016). In addition, Medicaid is the largest supporter of LTC. More than 18% of Medicare patients who survived critical illness require LTC, and more than 10% of patients who were privately insured prior to ICU admission transition to Medicare or Medicaid insurance in the first year after ICU discharge (Kamdar et al., 2017). The complexities of the health care marketplace pay structure also negatively influence other chronic survivor groups. For example, approximately 40% of cancer patient expenditures are out-of-pocket (Zheng et al., 2016). Researchers have suggested that elderly Medicare beneficiaries have less economic impact compared to those facing cancer at younger ages due to the tendency towards more aggressive treatment (Miller et al., 2016). This finding mirrored the recent discoveries of Kamdar et al. (2017), who found younger survivors of critical illness had the largest economic impact due to joblessness after ICU stay.

Centers for Medicare and Medicaid Services defined long-term acute care hospitals as facilities where the length of stay was 25 days or greater, and these would provide patients with high acuity, complex medical care including advanced mechanical ventilation management (Centers for Medicare & Medicaid Services, 2013). The goal of LTC services is to help beneficiaries with activities of daily living and to provide them with services that improve QOL (Dingell, 2015). However, conflicting opinions exist as to whether Medicare or Medicaid were developed to fulfill the LTC void. Dingell (2015) described LTC as an afterthought in modern medical coverage using examples of the complex network of fragmented programs to provide care to low-income and disabled people. Regardless of the intent, Medicaid provides the most LTC benefits to date. In addition, privately insured and Medicare patients often falsely assume that they already have LTC coverage (Dingell, 2015). This misconception could lead to confusion after discharge regarding resource availability and out-of-pocket costs.

The number of older adults needing LTC in the next 20 years is estimated to double (Broyles et al., 2016), while LTC admissions after critical illness has already tripled in the last 2 decades (Ehlenbach, 2014). In addition, mortality for patients receiving LTC rose, reaching approximately 77% mortality in 1 year (Ehlenbach, 2014). Improved care transition to LTC facilities, appropriate understanding of what role these centers will play, and the chronic complexities facing these patients should be used to inform policy planning. As this rapidly growing population ages, chronic critically ill patients will continue to need services far beyond their acute illness. The number of Americans over 65 is projected to increase by approximately 7% by 2050, while Americans over 85 are projected to increase from 1.8% to 4.3% by 2050 (Galston, 2012). Without appropriate follow up and recovery structures, survivors will continue to return to emergency departments likely resulting in readmission. Lack of a coordinated follow up plan leads to high costs and possibly higher readmission rates, thereby placing a strain on both the patient and the health care system (Khan et al., 2015).

Although physical function is a key component to recovery, survivor care encompasses a range of symptoms that must be integrated into LTC (Iwashyna, Cooke, Wunsch, & Kahn, 2012). Legacies of chronic illness span beyond the broad categories of physical, psychological, and social phenomenon revealed in previous literature. If these were the only sequelae requiring aftercare for survivors, then recovery program research would not be so inconclusive. Additional aspects of the recovery trajectory that researchers have found warrant further exploration include pain (Choi et al., 2014), sadness (Mosher, Winger, Given, Helft, & O'Neil, 2016), fatigue (Choi et al., 2014; Spadaro et al., 2016), and insomnia (Aitken & Marshall, 2015; Ganz et al., 2013; Mosher et al., 2016). Inconclusive recovery research has indicated existential components of recovery can only be revealed through the lived experience of survivors. Critical care researchers have not studied the lived experience of the patient as an evaluative method for understanding QOL and currently offered recovery options.

Summary and Conclusion

Advancements in medical technology and therapeutics continue to improve mortality outcomes in many life-threatening disease states. This continued improvement in short-term outcomes has left groups of survivors with unintended legacies of their illnesses and related treatments. Successful treatment of critically ill patients can no longer be measured by mortality alone. The physical, psychological, and cognitive debilitations facing patients for years after discharge must be supported by a structured, QOL-focused program that follows individual patient trajectories. Although researchers have recommended QOL research for decades, understanding of the patient experience after ICU discharge is years behind the gains in medical therapeutics.

The literature reviewed for this paper spanned from 1977 to 2017. Possibly, the first QOL study in critical care was published as early as 1988. Even at that early phase of advanced treatment technologies, Patrick, Danis, Southerland, and Hong (1988) stated that QOL after survival might influence decisions about life-sustaining therapies during acute illness. Patrick et al. concluded that full understanding of the QOL experienced by patients would not only assist in decision-making but would also provide additional outcome measures for clinicians and policymakers. As the trajectory of survival continued to out pace QOL literature, themes within the recovery of critically ill patients have arisen. Physical, psychological, and cognitive dysfunction are the known legacies of survivors to date. To bridge the gap of understanding among these themes and survivor resources, I intended to understand the experience of recovery from the user of the recovery services to help recovery resource policy supports for this growing population.

I used RCT to guide the theoretical framework in several ways. Survival, cost, and employment might not be the only outcome measures important to patients. Patient and family choice throughout their treatment trajectory into recovery was a recommended area of study for critical illness survivors (Eakin et al., 2017). I added to the small qualitative body of literature, attempting to understand how to support the prolonged morbidities patients face during their recovery period.

Survivorship transitions are currently under development (Kean et al., 2017) and barriers to ICU recovery such as access to LTC and rehabilitation could benefit from policy changes. Despite a large body of literature articulating the legacies of critical illness, many unanswered questions remain regarding the experience of the ICU survivor. In addition, previous trials have not improved patient-centered outcomes after surviving critical illness (Hodgson & Cuthbertson, 2016). I focused on utilizing qualitative inquiry to explore the lived experience from the perception of the critical illness survivor. Previous studies showed strong correlations with critical illness therapeutics and post ICU debilitation; however, their weaknesses were that most research continued to focus on quantifiable data and left a void in understanding of the lived experience.

In Chapter 3, I focus on illustrating the study purpose and explained the relevance of the study to survivors, families of survivors, communities, and health care systems nationwide. The third chapter outlines the research design and rationale, threats to validity, instrumentation use, trustworthiness, and ethical considerations.

Chapter 3: Methods

Introduction

The purpose of this qualitative study was to understand the patient perception of QOL after surviving critical illness and how survivors can help illuminate gaps in current health policies to provide better recovery resources for this growing population. The following sections include research design and rationale, the role of the researcher, methodology, issues of trustworthiness, and a chapter summary.

Research Design and Rationale

The central research questions were:

RQ1: What are the issues important to preserve quality of life from the perspective of critical illness survivors?

RQ2: How do survivors of critical illness describe rehabilitative services after discharge?

Central Research Concepts

Due to the high mortality of most ICU diagnoses, discharge from the ICU has always been considered the standard measurement of success, but most patients survive the acute phase of critical illness and are left with long-lasting sequelae (Marchioni, Fantini, Antenora, Clini, & Fabbri, 2015), shifting the opinion of successful treatment from simply discharge to long-term outcomes such as recovery and QOL. In recent years, researchers have used the term PICS to describe these symptoms survivors face after discharge (Kean et al., 2017). Although PICS in critical illness survivors changes their long-term QOL, there is a paucity of research dedicated to an in-depth understanding of the patient experience of surviving and the true essence of these changes. PICS research has become popular as the population ages in parallel with the number of ICU survivors (Eakin et al., 2017). This shift in focus has led to an evolving field of research dedicated to long-term QOL directed outcomes as opposed to studying discharges from the ICU. Researchers have advocated for qualitative research as an essential component for this developing field of research (Hashem et al., 2016).

To create effective therapeutic interventions that may reduce the long-lasting effects of critical illness, development of a patient-centered outcome set ("core outcome set") is necessary (Hashem et al., 2016). By aligning measurements, researchers can synthesize findings and have a more direct comparison of trial conclusions. Unlike previous literature, alignment of measurements will allow a more relevant synthesis of the interventions' effectiveness. Understanding the recovery trajectory from the perspective of the patient is imperative for developing patient-centered outcomes, both individualized and thematic (O'Cathain et al., 2014). By using qualitative inquiry, the phenomenon of QOL can be further explored, allowing researchers to target therapeutic intervention strategies better during this crucial recovery period. In addition, the burden of survivorship does not affect survivors alone. Families, communities, and health care systems lack comprehensive care planning; thus, readmission has become one of the ways policy planners can measure the success of critical illness treatment.

Health care utilization is a large component of policy decision-making. Appropriate care transitions from the ICU to settings such as LTC facilities and home health care for survivors of critical illness are likely of equal importance to medical management while patients are hospitalized. Lack of transition programs for recovery creates a cycle for survivors that includes over 30% being readmitted to the hospital within the first 6 months of discharge, indicating needed improvement in postdischarge services (Hill et al., 2016; Lone et al., 2016). Patients have faced recovery struggles that could be ameliorated with better LTC policies that are not obvious to the external observer. I sought to understand the lived experiences of survivors to monitor and evaluate the services provided. Currently, the clinical benefit and cost-effectiveness of follow-up services remains unclear.

Qualitative Inquiry

Qualitative research is a study methodology designed to describe life experiences and give them meaning. Due to the subjective nature of qualitative data synthesis, rigorous and appropriate methodologies are used to ensure the data are generalizable (Bearman & Dawson, 2013). I chose qualitative methodology because it was the best method to understand the complexities of the phenomenon of critical illness survival. Examining the use of resources, QOL preferences, and recovery resources from the perspectives of the patients who used these would allow future research to find a way to incorporate patient preferences into recovery. The diversity and magnitude of survivorship requires a multidisciplinary approach dedicated to the study of ICU survivors after hospital discharge (Turnbull et al., 2016). Only recently has qualitative research been advocated as a necessary part of this understanding.

Another reason for using qualitative methodology is that its inclusion in patient-centered outcome research allows the patient perspective to influence useful and relevant hypotheses in future randomized control trials for survivors of critical illness (Keeley et al., 2016). Successful treatments of acute illness are not measured by short-term outcomes alone; rather, successful care extends beyond the acute episode and hospitalization into assisting patients with reclaiming their lives postdischarge (Kean et al., 2017). My research adds to the field by creating an avenue for survivors to describe their experiences, so that policy change may support the needs of these survivors.

Although most research in the field of critical illness has been quantitative, I believed qualitative research was the most appropriate for this study because it was the best method to understand lived experiences. Quantitative researchers have elaborated core domains in need of focus for the future, but the lack of consistency in years past and use of various instruments have made data difficult to compare (Turnbull et al., 2017). Additionally, the effectiveness of LTC and patient-centered outcomes related to these recovery options is understudied (Ehlenbach, 2014). Qualitative research has been underused despite the large discrepancy of recovery priorities between providers and patients (Turnbull et al., 2017). Allowing patients to participate in the qualitative data collection with thematic examination and the views from the end-user could assist in conceptualization of recovery in this specific survivor population.

Survival was the phenomenon of interest. The complexities associated with psychological, physical, and social issues might not be revealed through generic data collection instruments. Interviews could also reveal the existential components of survival. I used a phenomenological strategy to explain the experiences of patients in a natural environment through semistructured interviews that allowed description of the essence of the experience.

Prior to beginning this study, I examined and rejected other strategies within the qualitative method. Narrative strategists explore the story of an individual throughout a period. One qualitative study in critical illness was conducted to describe the patient recovery trajectory using an illness narrative (Jensen et al., 2017). Jensen et al. (2017) found that recovery from critical illness requires patients to move toward a new orientation in life. Health care professionals can use this new orientation to explain the recovery trajectory so patients and families are more prepared for the recovery. This strategy is helpful if surviving is generalized, but past research has shown a void in individualized recovery programs and resource allocation to these resources (Shelly et al., 2017). Although researchers can use case studies to describe the case, the theme, and lessons from the case ("Qualitative Approaches," n.d.), I aimed to understand the phenomenon of survival, QOL, and recovery. I did not choose case studies within each group of critical illness survivors because research to date has found the similar recovery needs in all groups of survivors. The patient reported outcomes measurement information system framework was developed after studying years of critical illness survivor data that indicated patients would experience physical, psychological, social, and economic recovery issues after discharge (Turnbull et al., 2017). These case examples have already been shown in the current literature.

Grounded theory is a qualitative strategy that researchers use to develop a theory grounded from observations. This strategy was not an option because I did not aim to develop a theory based on the views of survivors. Researchers have used several grounded theory approaches in critical illness studies. Kean et al. (2017) used a grounded theory approach to better understand the patient transition experience after critical illness. Researchers can use this theory to create a shared reality between the researcher and the researched, which is relevant as full understanding of the phenomenon of survival was not well-described in this population (Kean et al., 2017). Pattison, O’Gara, and Rattray (2015) used e-mail interviews to understand the patient experience and if memories post-ICU could be ameliorated with discussion. Using grounded theory, the authors sought to propose a survival theory from past survivors. Deacon (2012) also used grounded theory to understand the recovery process for survivors. The author found that a holistic approach to ICU rehabilitation was needed, but further study into these holistic methods and the efficacy must be established (Deacon, 2012). All these researchers supported the need for better understanding of the phenomenon of recovery and the needs survivors face after discharge; thus, I chose phenomenology as the research strategy for this qualitative study.

Role of the Researcher

I was the primary instrument for this qualitative research study, and I was the instrument for data collection and interpretation. I conducted the semistructured interviews with participants. I self-identified with the patient population for several reasons. I am a critical care provider and have dedicated my professional career to critical illness. In addition, my husband and mother have both survived critical illness on several occasions; thus, I have seen survival from the perspective of caregiving and family. I conducted my research by advertising to local primary care/internal medicine clinics and a post-ICU clinic not associated with my place of employment. My role as a provider in the ICU did not influence participant enrollment. Patients often have voids in memories during their hospitalization, so I might need to disclose my participation in their care. If a patient chose to enroll in this study, and I discovered that I was their ICU provider, I addressed the issue by disclosing this information and giving the patient the opportunity not to participate. I had no personal relationships with the locations for enrollment.

I managed my bias through transparency. I was open about my opinion about the lack of recovery resources and lack of policy support for these survivors. However, I could not tell from the data whether patients had resources, if they chose not use resources, or if there were ongoing illnesses preventing them from engaging in resources. During my tenure in ICU medicine, I witnessed the amazing success of new treatment methodologies that have increased survival in previously high-mortality diseases. Yet, I have not seen an improvement in survivor recovery resources. As a provider, it is difficult for me to communicate with families and patients about recovery because the recovery trajectory is not well understood. Due to these research inconsistencies, providers choose not to tell patients about the physical, psychological, and social struggles they may face during recovery. Providers now know the legacies of critical illness and must improve communication with patients and families without diminishing the success of surviving.

Another bias I revealed in my role as the researcher was as a former family caregiver of two critical illness survivors. I have seen firsthand the legacies of critical illness in a young, healthy 45-year-old man, as well as these effects on a healthy, vibrant

70-year-old woman. Despite my knowledge of illness and the trajectory of recovery, I was surprised when my mother had difficulty returning to her high-functioning baseline. As months went on, my mother shared her fear surrounding her postillness limitations with me because she was never told that critical illness recovery could take months or even years. This prolonged recovery made her believe she was alone and that perhaps her slow recovery might be due to lack of trying or failure to improve her health. After several years she began expressing these feelings only to discover her recovery was normal and even better than most. My husband is a physician, and discovering his recovery problems was also difficult. He was a former marathon runner and body builder, yet it took him over 2 years before he could reclaim his preillness health.

Understanding my role as the researcher and revealing my personal bias allowed me to be open to unexpected outcomes throughout the study. I worked with a research assistant during the coding and analysis process and recorded every interview to assist in reducing the known biases. I used informed consent to educate participants prior to participation in the study, and they had the right to refuse or withdraw at any time. Some of the topics related to intensive care recovery were sensitive and might have produced some anxiety or difficult emotional responses. Establishing trust between the researcher and participant was paramount in developing a way for these emotions to be appropriately processed. In addition, participants were deidentified after consent, thus protecting their identities. I applied for Institutional Review Board (IRB) approval through Walden University and the Recruitment site.

Methodology

The target population consisted of critical illness survivors in central North Carolina. This qualitative sample strategy was created using a four-point approach that included (a) defining a target population, (b) deciding on a sample size, (c) devising a sample strategy, and (d) sourcing the sample (Robinson, 2014). The sampling strategy used was purposeful sampling. Purposeful sampling is a technique used in qualitative research to recruit individuals with particular experiences with the phenomenon of interest (Palinkas et al., 2015). Although several types of purposeful sampling exist, criterion sampling is the most widely known (Palinkas et al., 2015) and the subtype I chose for this study. In this research, purposeful sampling was the premier strategy because it is the most beneficial when the study warrants the willingness of participants. Because purposeful sampling relies on a selection process to target participants of a particular interest, it was not as generalizable as other sampling strategies. However, I intended to understand a phenomenon of interest; thus, purposeful sampling strategy aligned best.

The sampling strategy was derived from the 13 previous qualitative studies relevant to these research questions. Of the 13 studies, nine researchers used purposeful sampling, two used convenience, and two used a self-selected sampling strategy. Some researchers used random sampling in a concurrent quantitative research study. Although this technique did yield a higher number of participants, purposeful sampling would improve the depth of understanding with a smaller sample size. Convenience sampling was rejected because it had the lowest yield for generalizability and reliability (Robinson, 2014). Another sampling strategy that was rejected for this study was the use of a cohort from a previous quantitative study with an auto-enrolling qualitative component. Survivors in this study were at various stages of recovery in order to identify recovery and resource utilization benefits and limitations along the total recovery trajectory.

Participant Selection Criteria

Several qualitative studies throughout the years have had limited or no inclusion criteria (Deacon, 2012; Prinjha et al., 2009). In these studies, participants were self-selected by responding to a generic ad (Appendix A) requesting survivors to participate in research. Inclusion and exclusion criteria for this study were based on a compilation of previous studies and communication with experts in the field, to ensure the tool aligns with the research questions. This study only included adult participants. Other common inclusions used for this study included an ICU stay longer than 48 hours and 48 hours of mechanical ventilation (Dziadzko et al., 2017; Eakin et al., 2017; Jensen et al., 2016; Kean et al., 2017; Pattison, et al., 2015). Mechanical ventilation is a known contributor to the legacies found in so many critical illness survivors and is common among critically ill patients (P. Wischmeyer, personal communication, January, 18, 2018). In addition, researchers have used the primary language of the researcher for smooth communication; thus, English was an inclusion criterion. Lastly, consistent with other studies, I excluded participants who could not participate due to physical or psychological dysfunction (Czerwonka et al., 2015; Jensen et al., 2017; Kean et al., 2017). Therefore, the full inclusion criteria for this study were the following: (a) critical illness survivors, (b) within 18 months of discharge, (c) with a 48-hour ICU stay, (d) minimum of 48-hours of mechanical ventilation, (e) over the age of 18, and (f) ability to speak and read English. Participants were excluded if they had functional, emotional, or psychological limitations causing them to be unable to sustain a 60 minute interview. Collection of demographic information from participants was also gathered such as sex, age at the time of the admission, readmission since ICU stay, education level, marital status, living arrangements, employment, and race.

I screened participants who contacted me to determine eligibility for the study by using a screening guide (Appendix B). The screening guide was also used to gather the demographic information for participants. I assigned the participants with participant identification codes that I used for the rest of the study.

Sample Size

Sample size is an influential factor for generalizability of the qualitative study method; however, there is little standardization of sample size across qualitative strategies (Robinson, 2014). As conceptual saturation is reached, a researcher may choose to increase or decrease the sample size (Robinson, 2014). In the literature review, sample size ranged from five to over 300 among qualitative studies. Many researchers used cohorts within an ongoing quantitative study, recruiting participants automatically in the qualitative arm if they met inclusion criteria in the quantitative arm; these studies had the highest number of participants (Jensen et al., 2017; Kean et al., 2017; Walker et al., 2015). In addition to using the qualitative literature, I explored sample size through personal communication with two post-ICU clinics in the United States. The clinic in North Carolina only saw approximately 30 to 40 critical illness survivors in their first full year (D. Files, personal communication, October 17, 2017). Alase (2017) stated that phenomenological, qualitative research sample sizes should aim for between two and 25 participants. The researcher can use this strategy to obtain the essence of the true individual experience, thus shifting focus to quality not quantity of participants (Alase, 2017). Given the previous literature, personal communication, and qualitative research recommendations, I aimed to enroll between 15 and 30 participants. However, to remain consistent with qualitative methodology, conceptual saturation was used to guide completed enrollment.

During my initial efforts to identify participants, I advertised to internal medicine, primary care, and an ICU follow-up clinic in central North Carolina. Initial recruitment targeted specifically counties in North Carolina. Identification of internal medicine clinic recruitment was derived from expert recommendation in the area. One post-ICU clinic was recommended by an expert in the field of ICU recovery (C. Sevin, personal communication, September 28, 2017). I sent a letter requesting permission to post my advertisement for a minimum of 60 days to clinic directors. The letter included instructions that the staff was not recruiting, screening, or encouraging participation in the research. I directed any questions to my number on the advertisement. After appropriate permission from clinic directors, staff received fliers to advertise the study and were asked to distribute to every follow up patient, as well as post at the check-in and on any bulletin boards patients could see in the clinic. Walden IRB gave conditional approval to complete this portion of the research and coordinate with clinics on IRB specific needs they would require.

Once a potential participant attended clinic, I used the screener to determine eligibility. When eligibility was established, I discussed participation in the study either by phone or in person. Instructions regarding the interview timeline were discussed with participant at the time of the initial screening. The consent form was verbally discussed at the time of the screening and reviewed and signed at the time of the interview. If the participant chose a phone interview, then I sent a consent form to them and obtained verbal consent, per IRB guidelines, and the verbal consent was placed with patient information. As needed, I established a follow up within 7 days of the screening to answer any questions. At the conclusion of the screening, the interview type (phone or in-person), date, and time was established. The participants were given my contact information for any questions.

Conceptual saturation is reached when the data analysis fails to reveal any new data or themes. Setting goals for sampling within qualitative studies is often difficult and requires an iterative process of sampling and resampling before saturation occurs (Palinkas et al., 2015). If, after the 60-day recruitment process, the participant pool had not been adequate to achieve conceptual saturation, I would have expanded recruitment efforts to include a larger radius of counties in central North Carolina, increased the number of internal medicine clinics, and reconnected with clinics that had low participant flier distribution.

Instrumentation

As the primary instrument for this qualitative study, I used the interview tool, took field notes, and audiotaped the interview. After the interview, participants had time to review the field notes and verify its accuracy. Within 7 days of the interviews, I e-mailed or mailed participants a copy of their transcribed audiotaped interviews.

The data collection instrument (Appendix C) was produced through an examination of research in the field and to align with the research questions being used for the semistructured interviews. I developed the questionnaire using previous studies, with author permission. I developed one question that, to my knowledge, has been the only qualitative research to ask participants to define the term QOL. The next developmental method for the instrument used was a review of previous literature about the same or a similar topic. This study was unique because I not only explored the QOL components from the lived experiences of the participants, but I also linked the aftercare and rehabilitation policies; thus, I created questions from three previous qualitative trials on QOL (Deacon, 2012; Eakin et al., 2017; Walker et al., 2015) and the Long-Term Care Services and Supports (LTSS) state scorecard ("Methodology," 2017). Although I used none of the tools in entirety, I contacted all authors and received permission to use those questions.

Researcher Developed Instrument

Deacon (2012) addressed the issues that critical illness survivors face after discharge and created five neutrally framed, semistructured, open-ended questions for data collection. Eakin et al. (2017) also self-developed an 18-question interview instrument. The instrument was developed and validated by five experts in critical illness recovery, hospital administration, and public health along with a pilot study with two critical illness survivors (M. Eakin, Personal Communication, March 7, 2018). Lastly, Walker et al. (2015) used focus groups and self-created several open-ended questions that evolved the conversation. Walker et al. suggested that semistructured interviews be encouraged in future research to allow participants to describe their recovery process in a private setting. The senior author, S. Bonner, described creation of the questions through a literature review of previous trials coupled by recovery policies in the United Kingdom (S. Bonner, Personal Communication, March 12, 2018).

The LTSS scorecard was developed by the National Advisory Panel (“Methodology,” 2017). Beginning with the first report in 2011, the National Advisory Panel evaluated the data indicators within each of the five dimensions of the scorecard and has continually evaluated the indicators to ensure they stay relevant. Key stakeholders in the LTSS development process include the Public Policy Institute of the American Association of Retired Persons, the Commonwealth Fund, and the SCAN Foundation (Reinhard et al., 2014). QOL is amongst the top three categories on the scorecard. The National Advisory Panel reflects on this score in order to measure policy effectiveness. Aftercare services received by critical illness survivors were evaluated using the predetermined categories already established in the current literature.

The instrument questions were used in previous, qualitative studies and were approved for use by those authors. Expert panels and advisory committees validated the LTSS subquestions. All questions, concepts, and categories used in the current instrument were used in the past, but this study was the first to use these concepts together. Therefore, I conducted mini-testing to validate the questionnaire further. Like all previous trials related to these concepts, I used expert consensus to test the questions. The consensus included experts in the field of critical illness recovery, rehabilitation, and post-ICU care. Then, the questionnaire was used to interview two survivors recruited with the same methods I intended to use. The goal of the mini-test was to ensure the questionnaire being used was structured appropriately and would result in participants answering questions based on what I intended to discover.

To improve the validity of qualitative methodologies, Alase (2016) recommended that trustworthiness, member-checking, triangulation, and auditing be used to ensure consistency in data collection and interpretation. One of the most important parts of data collection for the qualitative researcher is to attain credible and transferable results from the study (Alase, 2017). I consistently assessed the research process and evaluated the quality of the data throughout the data collection period.

Procedures for Recruitment, Participation, and Data Collection

After IRB approval (approval number 09-06-18-0576535), I contacted managers of three internal medicine clinics in central North Carolina. I contacted them by e-mail and/or mail with the letter describing the study. I selected all clinics after recommendations from experts in the counties of interest. I called non-responders after 7 days to follow up and discuss questions. After the site leaders understood the study and flier distribution process, I intended to bring fliers to the clinic and have an instruction sheet for all staff to ensure staff did not participate in recruitment or discussion about the study. Staff was educated on deferring any questions to the name and number on the flier. I followed up in person at each clinic 7 days after distributing the fliers to ensure understanding. The fliers were distributed for 6 months. When participants contacted me to inquire about the study, I used the screening guide to determine inclusion in the study. After I gained participant eligibility, I obtained informed consent either by phone or in person. Participants who chose not to be audiorecorded will need to have a written informed consent signed prior to beginning the interview process. The interview date was scheduled during the screening. At the time of the interview, I discussed the risks and benefits of the study with participants and I reviewed informed consents. Participation remained voluntary, and all participation, including interviews and screening, remained confidential.

I used the interview guide and questionnaire were used to conduct semistructured interviews with participants in the study. Clinic staff agreeing to hand out fliers are not acting as community partners. According to the Walden University IRB, advertising within a community organization did not require a community partner agreement. However, individual site leaders might choose to have an additional IRB through their organizations before participant recruitment would begin. My request to post participant recruitment fliers was sent to clinic directors. The request included information about the study and length of recruitment. Potential participants would voluntarily participate in this study outside of their follow-up appointments. If patients choose to disclose their own personal health information during the course of the interview process, it is not considered protected health information (Walden IRB Chat room, personal communication, March 6, 2018). Informed consent was discussed and included in the final research results. The participants received an interview protocol prior to beginning the interview. The data were collected from participants in a location of their choosing or by phone. Two qualitative studies have used phone interviews to improve patient participation (Deacon, 2012; Eakin et al., 2017). Findings have shown that such interviews eliminate the travel needs and potentially improve patient comfortability and honesty in answering questions (Deacon, 2012). Researchers have examined this method of using technology as a way to capture patients who have been discharged and due to their ongoing disabilities, cannot meet in person (Balas et al., 2015).

The researcher was the sole collector of the data. One interview per participant was conducted, and the interview length was determined by the length of the mini-test. I audiorecorded the session and took field notes. Participants were given the opportunity to see the transcribed notes of their audiorecordings to verify the answers to the questions. Participants who choose not to be audiorecorded could still participate in the study. I included field notes during data analysis. Participant had the opportunity to review the field notes to verify accuracy at the time of the in person interview.

I obtained informed consent from all participants. The participants received a copy of the consent electronically by e-mail, or if they preferred, I gave them a paper copy. I tracked participants in the qualitative software program and used a spreadsheet appropriately to indicate where participants were in the process (consent obtained: yes/no, interview scheduled, interview completed, etc.).

Data Collection

The format of the interviews consisted of semistructured, open ended questions using familiar language. The questions were structured to be neutral in bias (i.e. “Please provide some comments about the aftercare you received or would like to have received?”). As the interviewer, I had to establish trust and comfortability with the participants early on in the interview. By developing a rapport with my participants, I could elicit honest, deliberate answers to the research questions being asked. As the researcher, I had to accept and understand when to appropriately interject, and when to allow silence to enable participants to recall their experiences fully.

To build a relationship of trust with the participants, the start of the interview began with a reflection on the purpose of this study. In addition, I reminded participants of my role as the researcher and my role as a provider in an ICU setting. Despite these roles being mutually exclusive, disclosure of both roles provided background to the study purpose. Participants had the choice whether to be audiorecorded and nobody declined. Field notes were taken during each interview.

For the interview exit strategy my gratitude was given for participation in the study. I addressed other questions regarding the study at that time. At the conclusion of the interview, the participants could validate their statements and review the field notes to ensure the essence of their statements was captured. No follow up was required. The recording of the interview was labeled with the participant de-identifier and transported with the researcher. The recordings were transcribed and data files stored in qualitative data collection software.

Previous research has shown that the use of post-ICU diaries can relieve some stress associated with the legacies noted in critical illness survivors (Jensen et al., 2016). So, as a thank you for participation, I offered participants an ICU diary.

Data Analysis

This qualitative phenomenological study's purpose was to examine the perceptions of QOL after surviving critical illness and understanding the recovery process from the perspective of the survivor. By utilizing a semistructured personal interview process for data collection, I have provided insight of the lived experience of the critical illness survivor. Conventional content analysis is an analytic process for qualitative researchers utilizing phenomenology (Hsieh & Shannon, 2005). Braun and Clarke's (2006) six-step guide included the following: familiarizing oneself with data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and generating a report interpreting the themes related to the phenomenon. Data analysis followed this structured stepwise iterative process throughout the data collection process. A detailed description of the participant experience was transcribed from audiotaped interviews and field notes. The iterative process of coding with theme development persisted throughout the study which required reorganization of the data as the study continued and themes were developed. The analysis was organized using qualitative software. Discrepant cases were examined and analyzed as to the underlying reason the case was outside the theme development. These discrepant cases are reported in the results.

Issues of Trustworthiness

To establish trustworthiness, I followed Lincoln and Guba's (1985) four techniques for the qualitative researcher. Credibility, transferability, dependability, and confirmability provided the structure for this study to establish trustworthiness.

Credibility

Through credibility, a qualitative researcher can establish their findings as truthful. In this research study, I established credibility through triangulation. I used triangulation to establish credibility by comparing the field notes collected during interviews with the audiotaped recordings. I used two collection methods to compare the findings of the two processes. In addition, I asked participants to review the field notes at the end of the interview process.

Transferability

The concept of transferability (external validity) is founded in the understanding that the findings of one study can be generalized to another (Lincoln & Guba, 1985). One-way qualitative researchers can establish external validity is by providing detailed, thorough descriptions of the data collected (i.e. thick description). I used thick description through field notes and audiotaped interviews. I provided a detailed description of the lived experience of the participant and their perceptions of their experiences. I used a clear protocol to allow replication, should another researcher decide to replicate this study. The participants included a range of survivors, from various cultural backgrounds, genders, and incomes; therefore, improving the likelihood of transferability.

Dependability and Confirmability

Dependability is the qualitative counterpart of reliability, and confirmability is the quantitative counterpart of objectivity. A research partner performed an external audit after the data were anonymously coded with pseudonyms. In addition, this research used an audit trail that included a step-by-step process of the semistructured interview, the field notes, interview recordings, and documentation maintenance. Researchers must understand their positions within the study and the angle that they should use to investigate a phenomenon (Hsieh & Shannon, 2005). Failing to mention preconceptions could be misconceived as bias within qualitative inquiry; therefore, I used a reflexivity journal to ensure my preconceptions remained transparent throughout each phase of the study.

Ethical Procedures

The ethical rights of participants were protected by adhering to the policies and procedures of site of recruitment (IRB00053070) and Walden University's Institutional Review Board (IRB) prior to any participant contact. Recruitment materials and process was conducted with the highest level of integrity. Participants voluntarily participated in the research study. At the time of participation, a detailed description of the process and informed consent was obtained. The participant could ask any questions. Their voluntary participation was to understand the phenomenon of survival and how recovery resources could assist in the process. When unanticipated discussions occurred about specific details regarding the participants' health statuses or disease-related disclosures, or if the participant had questions related to their current state of health, I interrupted the interview process and discussed follow up with their provider. Voluntary disclosure of health information from participants was not considered PHI and thus, did not require PHI to be added to the IRB application according to the Walden University IRB. In addition, participants were aware that policy questions, financial disclosures, or assistance with bills was outside of the purview of this study. However, resources were available through their follow up clinic, and participants were redirected to seek assistance in their facilities.

Several aspects of recovery might invoke emotional responses from the participants. I remained aware of the psychological sequelae of critical illness and although unintended, some questions might provoke uncomfortable memories or feelings for some participants. If that situation arose, the participant could stop the interview process. Building trust with the interviewee and providing a safe space for discussion was an important aspect of this qualitative interview process. The post-ICU clinic had psychological resources and participants received information on ways to obtain an appointments, as appropriate.

Participants were informed both verbally and in writing about the study, and a complete informed consent was signed and copied for each participant. The purpose of an informed consent is so participants can be prepared by the researcher for the study contents (Dudovsky, 2017). Voluntary participation was discussed in detail, including withdrawal from the study if at any point that the participant would choose and for whatever reason. In addition, participant confidentiality and anonymity were of paramount importance to the researcher. I discussed the details of pseudonym usage and storage of information with participants in detail. Electronic data was deidentified. Making it impossible to link participant names with the data collected.

Data was stored by password-protected qualitative analysis software. Audio files will remain on a password-protected computer equipment owned and accessible only by the researcher. Once transcription was complete, the audio files would kept in a safe for privacy protection. After 5 years, the audio files will be destroyed.

Although I did not collect data within my workplace, nor with participants that are employees or former employees, I acknowledged as the researcher that my role as an ICU clinician might create an unwarranted power differential. Several researchers acknowledged that critical illness survivors preferred to have follow-up and discussions surrounding their ICU stays with a clinicians familiar with critical illness (Czerwonka et al., 2015; Kean et al., 2017). Some survivors have lapses of memory or active dreams after their ICU stay. Past researchers have suggested that patients find it helpful to describe these memories to a knowledgeable provider and gain further understanding of the nature of these memories' relationships to their ICU stays (Jensen et al., 2017). As the researcher, I must ensure the integrity of this research is upheld. I disclosed my role as an ICU clinician during informed consent allowed me to give examples of things that I could not discuss during the interview process.

Summary

Through this qualitative, phenomenological study, I sought to understand survivor QOL and resource availability during recovery from critical illness through qualitative inquiry. In this chapter, I detailed the appropriateness of the design method, the sample size, inclusion and exclusion criteria for the study, instrument utilization, foundation for use, and ways that I ensured trustworthiness throughout the study. I framed the methodology to the research questions, and I detailed discussions about other possible qualitative methodologies that I rejected prior to carrying out the plan described here. I recruited critical illness survivors from a post-ICU clinic in central North Carolina. I obtained informed consent and I conducted the research either in person or by phone. Sample questions and the study purpose was discussed in detail with the participants prior to consent for participation.

The ethical plan for the study included planning for participant safety, including follow-up services if aspects of this study provoke unintended feelings that would have disrupted the participant. Chapter 4 will detail the findings of the research.

Chapter 4: Results

Introduction

The purpose of this qualitative phenomenological study was to understand the patient perception of quality of life after surviving critical illness and how survivors can help illuminate gaps in current health policies to provide better recovery resources for this growing population. I wanted to understand the experience of survivors and how their QOL is affected by recovery. The results of this study are disseminated to improve health care providers' understandings of how patients experienced critical illness recovery. In addition, these results can be added to the growing body of qualitative literature that supports new hypotheses in recovery research. The methods included semistructured interviews of adult critical illness survivors to better understand QOL and recovery in this specific patient population. Survivors with high QOL have reduced rehospitalizations and less overall health care costs (Ruhl et al., 2017). I created the research questions to focus on issues related to QOL preservation and a descriptive account of the aftercare process, including rehabilitative needs, ongoing debilitations, and access to care. This chapter is organized by the following sections: (a) setting, (b) demographics, (c) data collection, (d) data analysis, (e) trustworthiness, (f) results, and (g) summary.

Setting

The study was conducted in a post-ICU clinic in central North Carolina in one of the only post-ICU recovery clinics in the United States. Participants were all treated at the study site during their ICU stay and were scheduled for appointments in the ICU recovery clinic at discharge. The clinic has approximately a 50% no-show rate for follow-up (personal communication, R. Bakhru, January, 2019). There were no personal or organizational conditions that influenced participants or their experience at the time of this study that could influence the interpretation of study results.

Demographics

I evaluated the perceptions of adult critical illness survivors on QOL and aftercare resource availability when discharged. Table 1 shows a full demographic breakdown of study participants. Adults included in this study were one African American woman (P5), eight Caucasian men (P1, P3, P4, P6, P9, P10, P11, and P12), and three Caucasian women (P2, P7, and P8). Of the 12 people interviewed, only one had been readmitted to the hospital since their original ICU stay (P6). Nine participants were married (P1, P4, P5, P6, P8 P9, P10, P11, and P12), two were not (P2 and P3), and one was a widow (P7). All participants were in a private home prior to ICU admission. Three participants, P2, P9, P12, were discharged to an acute care rehab facility prior to returning home. One participant, D11, was still living in a LTC facility for rehabilitation at the time of the interview and was scheduled to be discharged home the following week. Education level among participants varied greatly with two participants having some high school (P7, P10), five high school graduates (P5, P6, P9, P11, and P12), two with some college (P2, P8), and three participants completing a college degree or more than one college degree (P1, P3, and P4). None of the five participants who were working full-time (P1, P2, P6, P9, and P10) prior to their ICU stay went back to working full-time.

Table 1

Demographic Characteristics of Participants

	Readmission	Race	Education	Married	Residence before	Residence after	Employed full-time before	Employed full-time after
P1	No	Caucasian	2 AS	Yes	Private	Private	Yes	No
P2	No	Caucasian	Some college	No	Private	Acute care	Yes	No
P3	No	Caucasian	AS	No	Private	Private	No	No
P4	No	Caucasian	BS	Yes	Private	Private	Retired	Retired
P5	No	African American	HS	Yes	Private	Private	No	No
P6	Yes	Caucasian	HS	Yes	Private	Private	Yes	No
P7	No	Caucasian	Some HS	Widow	Private	Private	No	No
P8	No	Caucasian	Some College	Yes	Private	Private	No	No
P9	No	Caucasian	HS	Yes	Private	Acute care	Yes	No
P10	No	Caucasian	Some HS	Yes	Private	Private	Yes	No
P11	No	Caucasian	HS	Yes	Private	LTC	Retired	Retired
P12	No	Caucasian	HS	Yes	Private	Acute care	No	No

Purposeful sampling was the data collection method, specifically targeting adult survivors of critical illness from all backgrounds, education levels, and ages. The opportunity to participate was given to every patient who came to follow up in the post-ICU recovery clinic and met criteria for this study.

Data Collection

During the course of 6 months, 21 people were approached about this study with a study flier. Of those 21 people, 12 consented and completed the interview. Two potential participants expressed interest vocally but later chose not to participate due to family obligations. Participants were recruited from a post-ICU clinic in central North Carolina. Recruitment began after IRB approval in December 2018 and was completed in June 2019. I used only one instrument for this study. I conducted interviews either by phone or in person at the post-ICU clinic. With permission from each participant, I recorded all interviews. The original methods outlined in Chapter 3 included a broader target population from other counties in North Carolina, but after conditional Walden IRB approval was obtained, in September 2018, I followed the methods outlined in Chapter 3 and experienced several recruitment difficulties.

I began recruitment by sending a letter and study flier to local clinic mangers at three internal medicine clinics and a post-ICU clinic in various counties in North Carolina. When I received no response, I followed up both by mail and in person to the clinics within 2 weeks and then 4 weeks of the original mailing. After this follow-up, the managers revealed limitations to recruitment. First, one clinic manager at a Durham clinic could not participate because they require all research to include both Spanish and English-speaking participants. Staff at another clinic in Wake County stated they did not have a population that would meet criteria for the study, and staff of another clinic stated they were a part of a larger academic medical center that would require their own IRB process prior to posting the flier. The post-ICU recovery clinic responded to the request, and the leaders also required a facility-specific IRB; however, all their patients identified as survivors of critical illness. This characteristic improved the chances for recruitment; therefore, I completed the IRB application, which was accepted on October 26, 2019. My student status to perform research was added to the IRB on December 5, 2018, and I submitted the IRB approval from the study site to the Walden IRB on December 5, 2018. On December 7, 2018, the Walden IRB authorized the research to begin. I completed the first two interviews after the December 7, 2018, full approval.

The study site post-ICU recovery clinic had clinic hours on most Tuesday afternoons. During these clinic hours, participant recruitment occurred. The study site research nurse received copies of the study flier, consent, and screening tool. When participants were coming to the clinic, she checked the patient's history for required inclusion criteria, and if they met eligibility, she would contact me in one of two ways. Either I would come to the clinic, give the flier to the potential participant, and discuss the research study after the patient appointment; or she would give the participant the study flier, which included the contact information for participation at a later date. I obtained informed consent for each participant prior to the start of the interview. I obtained consent either in person and a copy was given to the participant or verbal consent was obtained and documented by phone, in accordance with the requirements of the study site's IRB.

In both phone and in person interviews, all audio recordings began after I obtained consent and these did not include any protected information. After the recording completed, I reviewed field notes with the participant. The recordings were transcribed and transferred into a qualitative research software program to assist with accuracy. I sent the transcript to participants by either e-mail or mail. If any discrepancies arose after receipt of the transcript, they were instructed to send me the information by e-mail or by phone to discuss.

Data Analysis

Data analysis followed Braun and Clarke's (2006) six-step guide to qualitative analysis. Initial analysis began with familiarization of the data. I began this step by transcribing the audio recordings using automated transcribing software. I then audited the transcription for errors, organized the transcript by interview question, and added researcher notes from the interviews. I continuously read interview transcripts to become familiar with the data. These transcripts were read, and initial codes were derived. Conventional content analysis with inductive coding continued throughout the course of participant recruitment. Generation of initial codes by reading several interviews and coding featured using a systematic fashion across the data set. When new codes were noted, I reread the previous interviews to determine appropriateness of new code. This inductive coding process continued throughout the course of the data collection period.

The third step began after initial codes were created. I grouped codes into themes and created thematic matrices to align the developing themes to the research questions and the phenomenon of recovering from critical illness. The thematic development continued to evolve, and I reviewed, edited, and refined, as the I received the data. The finalized themes were then defined with quoted examples from participants in the qualitative codebook. The research team later used this codebook to confirm the thematic development I had done. All data were continuously updated in the qualitative analysis software. Codes, themes, and revisions were all done by me throughout the data collection phase.

Preliminary Analysis

Preliminary coding was performed by using one-word or short phrases from the interviews and followed the recurrence of these codes within several transcripts. Then, I analyzed these codes and placed them in groups as themes. Figure 1 shows an example for RQ1; recurring codes included (a) activities of daily living, (b) breathe better, (c) preserve strength, and (d) live healthier; these became the theme *adapting to a new normal*. Similar iterative coding and thematic development occurred with RQ2. For example, codes included the following (a) family provided assistance, (b) limited community resources, and (c) aftercare not covered; these became the theme *dominated by informal caregiving*.

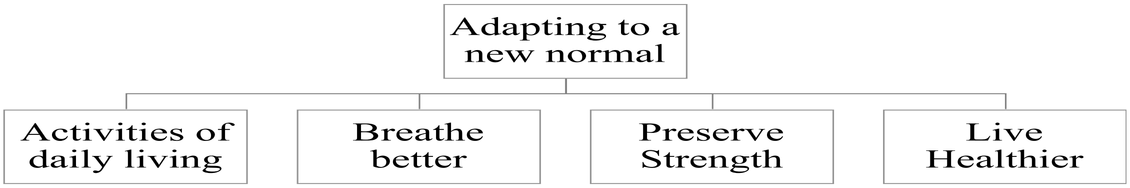

Figure 1. Adapting to new normal.

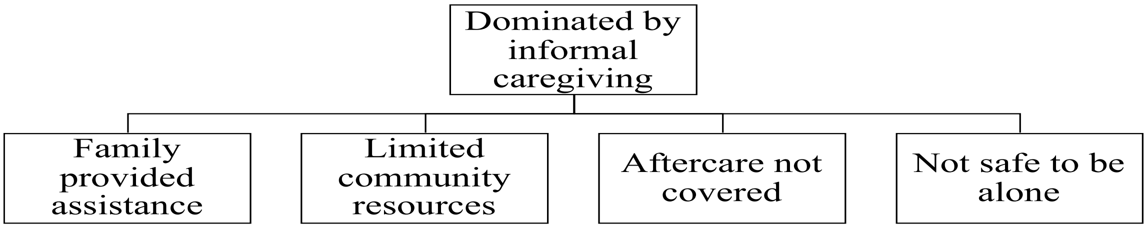

Figure 2. Dominated by informal caregiving.

Thematic Identification

The specific themes generated the following information from the data. Themes for RQ1 became the following: (a) gratitude for life saved, (b) engaging in new life priorities, (c) feeling supported and informed, (d) feeling prepared, (e) independence, and (f) adapting to the new normal. For RQ2, themes emerged as (a) lacks unity, (b) limited by disparate information, (c) unknown financial burden, (d) unclear recovery trajectory, and (e) dominated by informal caregiving.

Gratitude

All participants were grateful about the treatment they received in the ICU and their abilities to pursue life once again. Some equated QOL with the gratitude of being saved. P1 stated,

> Well, naturally if the ICU had not been a success, I wouldn't even have a life right now, so, from that I gather that whatever life I have right now was totally contributed to the care I received in ICU.

Other codes emerged into themes concerning the influence that the ICU had on participants' desire to reprioritize their lives, structuring their time with their families, and finding ways to live a healthier lifestyle in an effort to avoid further ICU admissions. P12 said,

> I wasn't ready. I have too much of my life left to live. I ain't done much. My wife and I have only been married 9 years, that's just too small of a time. They can't be without me yet. They can't support their selves.

The nontangible connection with life enabled participants to restructure their way of life. P9 explained it like this:

> Your priorities might change a little bit. You don't look at things the same... They're still responsibilities. You've got to take care of things. …all the things that they do with the monthly bills and I don't know, things that it's helped me to see. I mean, I do look at things differently.

Others took the opportunity to use the recovery process as a way to create healthier habits to avoid the ICU experience again. According to P8:

> [I am] living healthier. I'm trying to lose weight, I quit smoking. It was scary to be in the ICU and remembering everything. So, I don't want to be in that position again. So, I'm trying to do everything to prevent that to happen.

These life changes were made by participants who developed a new appreciation for life, reprioritizing their lives and goals, which was followed by the next common theme of *adapting to a new normal*.

Adapting to a New Normal

Participants described ways that their lives differed and that they had adapted to new limitations not present prior to their illnesses. This new theme, adapting to a new normal, was elicited in various ways throughout the interview. Participants described the adaptations they needed to make to preserve their QOL. By using adaptive techniques, participants described the ability to be at home with new "normal" daily routines, which allowed them to become, slowly, more functionally independent. For example, P6 said,

> I wanted to keep working. I didn't want to have to sit around but my job… I was in construction and everything you do is lifting and carrying. It's hard work and the dust and paint and chemicals, it's just too much. I couldn't do it.

Others described this adaptation regarding the lives they left behind. P12 said, "Well, I was sick for so long, I forgot what social was." These adaptations resulted in a desire to set goals for each day and find ways to do more each day to improve. P3 said,

> Every day is trying to accomplish more goals, more steps today, doing more things. I will create chores for me to do just so I can do something and, exercise more. I just want to do more than what I did the day before.

These adaptations could only occur when participants began to understand their limitations. Given the acute nature of critical illness and the memory lapse that most participants described during their hospitalization, it was difficult for many people to understand the limitations they would have; therefore, preparation for discharge and informed support structures would be necessary to improve this understanding.

Preparation, Information, and Support

The following themes for preservation of survivors' QOL also entailed feeling (a) prepared, (b) supported, and (c) informed. Most survivors in this study had familial supports that were helpful but many had limited information regarding their recovery trajectories or what to expect once discharged. Feeling unprepared or lacking information created a reduced QOL for some participants and a constant state of confusion as to what was next, and what would constitute *normal* recovery paths. For example, P8 commented about how important understanding what to expect when it comes to flashbacks and memory problems:

> I think someone with a high risk of like depression or anxiety, some, you know, possibly, hey, you know, there's a chance that you can have flashbacks or different emotional feelings or something, and the nightmares. And you know, just possibly some insight on what possibly could happen with people with higher risk of anxiety or depression.

Others felt unprepared for their physical recoveries and were unsure of how to actively participate in their care because they did not know what a normal recovery process would be like, nor did they have anyone to ask. P2 recalls,

> I mean maybe that's standard; I have no idea. I've never done outpatient physical therapy before. I never done inpatient physical therapist before. So, you know, I have no idea if that's normal. Not Normal. I don't know.

Furthermore, support included discharging patients with the available tools to continue healing. For some participants, this support included purchasing supplies on their own in order to keep from returning to the hospital, only to find that the supplies were not covered by insurance. P3 stated,

> The dressing that is working for me, it's like a foam pad and they cut it up. That's all it is, with some silver in it. I tried to buy it on Amazon and Amazon sells a pad but not with the silver in it. To get the silver you have to have a medical license or a business license and I have neither of those. And I don't know why you need it because it's just a foam pad with silver.

Survivors of critical illness who participated in this study felt grateful for having their lives saved. This empowered them to embrace new life priorities and making adaptations to their new normal. This new path needs to be laid in a foundation that begins with preparation, support, and information as to what to expect during recovery in order to preserve their QOL and give them the tools needed to move past their debilitations.

Lacks Unity

The lack of preparation, information, and support for critical illness survivors lead to a recovery program theme of *lacks unity*. Subthemes for lacks unity included (a) variations in insurance, (b) unknown recovery trajectory, (c) limited by disparate information, and (d) unknown financial burden. Participants not only did not know about some of the recovery problems they would face, they also were uninformed of the financial implications that this type of hospitalization and aftercare might require. During the coding and thematic process, I noted that participants with and without prior insurance, did not know the financial costs of their hospitalization. Several privately insured participants (P6 and P9) described large, costly, bills that were nonnegotiable. P9 stated, "They're [hospital employees] not allowed to tell if they don't cover a certain insurance company or not." P6 shared a similar experience stating, "And then the hospital, helped pay some, but I still had to pay $7,000 out-of-pocket. I'm still paying on it." Most participants were unaware of how much was being paid or if bills had been received. P1 stated, "I do know we have received bills, already in the mail, but I do not know the status. I know I have insurance and they're paying, but I don't know how much and how much we owe or whatever." The final analysis developed themes from participants on important issues to preserve QOL for survivors as well as themes related to the description these survivors have for the aftercare they received. Understanding these themes and creating sustainable programs for survivors after discharge could reduce hospital readmissions and overall healthcare costs.

Discrepant Case Analysis

Several discrepant cases were reviewed and included in the study results. Despite some varying information, all discrepant cases contributed to overarching themes of other survivors. For example, P5, defined QOL as *thanking God*, which was not a concept mentioned by other participants. Only two others mentioned spirituality at all, P9 and P12, and it was not in the context of contribution to QOL. In addition, P5 had a difficult time following the questions, answering almost all questions with a comment about leaving things up to God. This finding was incongruent with any of the other interviews. P5 did contribute to the consistency of feeling grateful for being saved by stating, "[I]f it wasn't for people like y'all, I wouldn't be here right now."

Additionally, P4 answered most questions with brevity, although I interpreted his body language during the interview as fearful of sharing the experience openly. One of the limitations of any qualitative study is the honesty and openness of the participant. Despite this demeanor, P4 contributed to the unanimous theme of *gratitude* and *engaging in new life priorities*. He said, "I've got some different goals, scale my life back some and see my grandchildren more."

One participant, P1, believed that the recovery program was "right on the money" and that the program "didn't leave anything out." He described in detail how attentive the providers were, how coordinate the care was, and how much follow up specialty care he received; including psychological counseling. Through personal voluntary disclosure I later learned that this participant had an underlying diagnosis of cancer and much of the aftercare he was receiving was due to the fully coordinated and structured cancer care, not a part of an ICU recovery program.

The results section includes a rich description of the themes related to each research question. A full description of the issues important to preserve QOL and the recovery experience of this group of survivors is examined there. The data analysis continued throughout the data collection and continued on for several months after completion.

Evidence of Trustworthiness

I prioritized establishing trustworthiness throughout the course of this study using Lincoln and Guba's (1985) four techniques for the qualitative researcher. By utilizing a systematic process of credibility, I established transferability, dependability, and confirmability, trustworthiness.

Triangulation was used throughout the study to established credibility. I reviewed researcher field notes and the interviewees and I read the transcribed audiorecordings (with one exception, P12, who passed away just days after being interviewed). In addition, I sent to the participant a copy of the transcribed interview (by e-mail or U.S. postal service depending on participant preference). Only editorial comments were made from some participants after receiving the transcript.

Thick description was used to establish external validity. By providing thorough descriptions of the data collected through field notes and audiotaped interviews, I outlined a clear protocol for replication of this study. The participants from this study were from various backgrounds, education levels, and ages, which improved transferability in qualitative research.

The research team completed an external audit as they were familiar with qualitative coding and code book utilization. The research team evaluated the transcripts, notes, and analyzed the raw data to verify coding. In addition, an audit trail, which included a process for the semistructured interviews, field note documentation, and reflexivity journal maintenance was maintained throughout the course of the study.

Results

The term Quality of life (QOL) is defined by the dictionary as “the standard of health, comfort, and happiness experienced by an individual or group” (“Quality of Life,” n.d.). It is with this definition in mind researchers have studied QOL within groups of survivors, including those surviving critical illness. However, no study to date has determined personal definitions of QOL and if that coincides with the medical construct associated with QOL. Thus, the first study question for this research sought to understand the survivor definition of the term *quality of life* and the participant answers are outlined in Table 2.

Table 2

Participant Definition of Quality of Life

Document name	Segment
P8	To be happy. To be happy. Happy and healthy.
P7	The quality of life means spending time with my great grandson.
P4	Get up every morning and be mobile and eat good food. And see my grand babies.
P1	I would say the level at which you're able to talk function with your daily routine. I guess.
P3	Just being able to be ambulatory and get around.
P5	I think it's good. I was lucky. As I thank God, God is.
P2	being able to hold a job without restrictions being able to do what I want to when I want without restrictions.
P10	I don't know. It's important. I guess that's it. Importance
P9	Being, having good health; family there, that's very, very important

When coding specifically within this question, the general theme of QOL from the perspectives of critical illness survivors was to participate in their lives, function in their daily routines, spend time with families, and have good health. However, the variation of these definitions, when compared to the general definition, should be considered when future research is dedicated to understanding QOL in this survivor population. In addition, the themes that emerged from the data reveal that participants QOL is improved when they engage in new life priorities and adapt to their *new* normal, which is somewhat contradictory to how they defined QOL in the beginning.

I used the following research questions to explore the lived experience of critical illness survivors on the paths to recovery:

RQ1: What are the issues important to preserve quality of life from the perspective of critical illness survivors?

RQ2: How do survivors of critical illness describe rehabilitative services after discharge?

Answering these research questions will provide useful information for future studies in this large group of survivors. I coded and developed themes related to the research questions. Then I created a thematic matrix to reveal areas that are congruent throughout.

Research Question 1: Quality of Life preservation

To preserve QOL for critical illness survivors, they need to feel prepared, supported and informed, adapt to the new normal, and engage in new life priorities. Adapting to a new normal had the highest response rates of participants describing their recovery and what their lives were like at the time of this study. Figure 3 shows a graphic depiction of the main themes. P12 said, “I don’t remember stuff. Maybe I got a little something wrong up there, I don’t know. I tried to buy a drink, for $5 just dumb stuff like that. So, I try not to mess with money right now.” As participants describe their recovery process, lack of preparation arose as the second most common barrier to QOL. The theme *feel prepared* is a priority as these participants struggled with a true understanding of what effect critical illness had on their bodies. P9 recalled,

> I didn’t even realize how, what this would do to my body, it’s…it’s so amazing. It’s so amazing how it, how much strength I lost. It just, it just totally muscle strength and endurance. How much it takes away from you.

Others, described the need for preparation by detailing how they envisioned recovery to go, only to find out how much longer it would actually take. P2 expressed,

> What my thinking was that I would come home from the hospital, be home for a week, and I'd go back to work full time and life would go back to normal. I never realized that it would be so difficult and that my body would still be healing and that when you're in bed for 55 days, it takes a toll on your body and it takes a long time for your body to recover. Nobody ever explained that to me that it was going to be harder.

The third most common emerged theme for RQ1 surrounding support and information. This theme was defined differently than preparation as support was noted to be from staff, caregivers, and insurance. Preparation involved knowledge of what was to come, while support was how people used external aid during recovery. P9 said, "But I did a real good walk down the hall. And that was, uh, that was the first time I'd really accomplished something without a walker. Them walking the side of me without any assistance." Having supportive staff, made participants believe they had somewhere to go for assistance and that the people involved in their care really wanted them to get better. P1 stated, "That really gives you a good feeling that you're not just somebody, a number or just a paycheck for some people, you know."

Lastly, engaging in new life priorities emerged from the data as participants continuously described feeling changes due to this experience. They changed in ways they did not expect, thereby forcing them to look at life in a new way. This finding was evident in several of the participant answers to various questions. Being able to engage in new life priorities helped improve their QOL as they focused their priorities on the future. P1 stated, "I am just trying to enjoy the time I have. And again, take it day by day." P3 reflected, “It’s just put a lot of things in perspective. Like I know I’m trying to focus on getting the weight off.” Others used their experiences as motivation for getting better and going home. P2 said, “I was so sick and tired of being in the hospital. I was ready to make the improvements that I could come home and resume my life, so I gave them 200 percent when I was in there.” Figure 3 shows participants’ overall themes for preserving QOL.

Figure 3. QOL preservation.

RQ2 Describe Aftercare

All participants could describe their experiences with aftercare resource availability regarding their recovery trajectories. Most described an overarching theme that aftercare resources were not well coordinated and thus the theme of *lacks unity* emerged. Figure 4 depicts the themes related to the RQ2. Most responses concerned limited coordination, unknown aspects of recovery, particularly physical, limited, or no, psychological resource availability, lack of structured comprehensive programing, disjointed communication with staff, hospital, burden on families, and unknown financial / out-of-pocket costs. Four subthemes of lacks unity included (a) limited by disparate information, (b) unclear recovery trajectory, (c) unknown financial burden, and (d) variations in insurance. The second theme that emerged regarding aftercare was the dominance of informal caregiving.

Participants were asked whether or not anyone discussed the aftercare that they might require after ICU discharge. P8 stated, “I don’t remember too much of them discussing the services; except just to be in contact with your provider and come to this appointment on this day type of thing.” P6 recalled, “If they did, I don’t remember having it.” One participant struggled with SOB at home, had difficulty doing her activities of daily living, and wanted to participate in a recovery rehabilitation program, however, she received disparate information from her primary doctor regarding rehabilitation. P7 stated, “I participated in a regular exercise schedule but doctor Dr. XYZ told me to not do it (exercise) right now since my lungs were bad, and I should wait about a month before I start back exercising.”

Additional comments about the lack of coordination were made regarding staff in the hospital providing information but that the out-patient resources were unavailable, or required a long waiting period before an appointment could be made. This disconnection led to an unclear recovery trajectory for these participants. P2 stated,

> A case worker came in and talked to me the day I was discharged from the hospital, but you know, they’re always in a hurry and they said, you have this appointment, this appointment, this appointment, this appointment, scheduled.

> And I needed to see a neurologist, but couldn't get an appointment until January 8th, and it was only November. What am I supposed to do between now and January 8, I'm trying to go back to work.

This disjointed communication and lack of unity created a sense of fear from participants who were unsure what to expect next and where to get accurate information regarding recovery.

In addition to the confusion surrounding the recovery process and resource utilization, most participants had financial burdens after illness that were confusing and delayed. Participants were either privately insured, used federally sponsored insurance (Medicare and/or Medicaid), or were uninsured. Although the type of insurance was not specifically asked during this interview, participants were asked to describe interactions with insurance, payment planning, and who paid for the services that were needed during recovery. During the course of their description, it was often clear what type of insurance they had and those who were uninsured discussed being uninsured. This question indicated variations in insurance coverage that contributed to the lack of unity for recovery support.

For example, five study participants had private insurance (P1, P2, P4, P6, and P9). Among these five participants, three had specific issues with insurance that required multiple phone calls, advocacy letter, or resulted in out-of-network coverages and large bills. One participant, P1, had no idea what bills came or who paid those bills. P9 believed that the insurance company was covering much of his hospitalization; however, he was responsible for paying an out-of-network cost for his emergency room visit. He recalled, “They [hospitals] aren’t allowed to tell if they don’t cover a certain insurance company or not.” He believed this response was excessive given he was in an emergency situation and would not have been able to choose an in-network provider. P6 had a similar experience, over a year after his hospitalization he was still paying off medical bills. He said, “And then one hospital helped me pay some, but I still had to pay $7,000 out-of-pocket. I’m still paying on it.” P2 had difficulties with obtaining coverage for several aspects of recovery; the most notable was her acute care facility that was recommended by the doctor. P2 described her experience with insurance, “everything with Private Insurance A, was a fight.” Specifically, the denials were for acute care facility, recommended by her doctor, versus discharge to a nursing home, recommended by her insurance. The doctor recommended two weeks at an acute care facility but it took multiple denials of coverage, phone calls, and finally a physician letter to the insurance company before authorization occurred. This delayed P2’s discharge, which resulted in multiple communication issues. Social work told P2 to go to a nursing home, and the doctor told P2 that she needed acute care rehabilitation. These unknown, or known, financial burdens create an under-current of anxiety for survivors. In addition, they knew their informal caregivers / families were dealings with these additional burdens.

Three participants self-identified as uninsured during the interview. All three, P8, P10, and P12, described applications for Medicaid being submitted while they were in the ICU. P10 was uninsured during the hospitalization and didn’t qualify for physical therapy. P10 described, “I was not walking at my baseline at all, not what I was used to at all.” In addition to being sent home without resources, P10 was concerned about the financial impacts of his hospitalization. He said, “We’re still waiting on Medicaid. Waiting on a decision. Oh, we’re getting the bills anyway; it’s stressful, especially when I ain’t working.” P8 had a similar experience, “I don’t know what’s going on now, my husband turned everything in…but that’s about it. I haven’t gotten any bills yet, it’s coming, but I haven’t gotten a bill yet.” It is unclear how long the application process takes, but it limited these survivor’s ability to access rehabilitative services.

The last group of participants were already enrolled in government funded insurance programs. Most of these participants spoke highly of their interactions with insurance, P11 stated, “All they do is write the checks.” Additionally, P5 had a similar experience: “Our insurance paid for everything, when I go to the doctor I don’t pay for nothing.” P3 expressed a slightly different experience as he had ongoing needs that turned out to be uncovered when he went home. His ongoing wound care required a specific type of wound care supply. The same supply had been used while he was in the hospital and was the only one that worked for him. However, it was not until he was discharged and attempted to purchase these supplies to continue the care at home, was he informed that Medicaid doesn’t pay for that type of wound care. They would pay for him to be discharged to a nursing home until his wounds healed, but would not pay for the same supply for him to use at home.

Informal Caregivers

An important theme throughout the aftercare resource discussion involved informal caregiving. I observed during this study that informal caregivers were the solution to the nonunified recovery process. All participants in this study attended clinic with a family member. They all described family assistance throughout the course of their recovery. For example, P7 described a need for a shower chairs and other assistive devices after she went home. P7's son went and bought her these supplies, and paid out-of-pocket. P12, a 41 year-old survivor, moved in with his parents because he could not get ready, dress, shower, and ambulate safely, despite spending 2 weeks in acute rehab prior to returning home. P1, P3, and P4 all described family that helped them recover. P1's sister met with the home health nurse and took over care due to the cost of the home health nurse. P3's dad drove him to appointments until he could take himself, and P4's wife provided his assistance when he transitioned to home. P2 described her roommate/best friend as her advocate. She described instances where her roommate had to defend her, advocate for her recovery program, and, at times, had conflicts with staff who were requesting she be discharged to nursing homes as opposed to acute rehab as suggested by her doctor. In addition, despite going to acute rehab for 2 weeks after her discharge, when she returned home she still could not be left alone at home. She required help with her activities of daily living, walking, and getting to her appointments.

In addition, during the course of these interviews, I noted that informal caregivers became the memory for participants. The participants relied on their close families or friends to provide historical information about their illness, transitions of care, and recovery process. During his hospitalization, P9's wife would have friends and family call him, and she held the recording up to his ear so he could hear people encouraging him to get better. Additionally, she kept a photo journal for him, and when he went home and was asking questions about his illness, she showed him how sick he was by using pictures. The lack of recollection of the ICU stay created a void for these participants and thus, contributed to their inability to fully understand why they were having trouble with recovery. The need for preparation, support, and information, to preserve QOL, for these participants, was made possible by their informal caregivers. In addition, the support services after hospitalization would not have been possible without the contribution of family and friends, even those who went to a formalized recovery program.

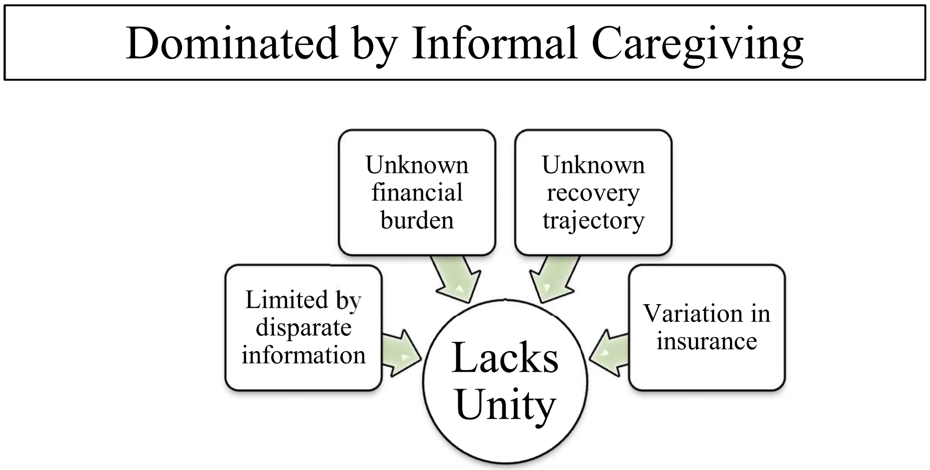

Figure 4. Description of aftercare resource availability.

Links between RQ1 and RQ2

The overarching themes among RQ1 and RQ2 connected in several ways. Participants believed preparation was an important way to preserve their QOL but they described aftercare resource availability as lacking unity, leading to an unknown recovery trajectory. Providing participants with more preparation at discharge would not only improve their QOL, but could also reduce caregiver burden and improve return of functional independence.

The same link was found between QOL requiring support and information, but aftercare was described as limited, and providing disparate information. Participants wanted to feel informed and to participate in their recoveries. Their underlying feeling of gratitude became a way for them to newly align with their lives by engaging in new life priorities and making adaptations to continue on the road to independence. By informing the participants of the recovery options and community supports, participants could become more involved in their care and the burden being placed on unqualified informal caregivers could be alleviated.

Gratitude

All participants expressed gratitude for their lives being saved. This theme was the only unanimous theme throughout the course of this study. Participants believed they would not even have the opportunity to have a QOL, if it had not been for the heroic efforts of their ICU care. This sentiment was expressed regardless of the physical, emotional, or psychological sequelae that they experienced after discharge. Thus, gratitude became the foundation for survivors QOL and it allowed them to move forward, engage in their new life priorities, and adapt to their new normal. P12 stated “It flipped my whole life upside down. Yeah. But I don’t care, I am glad I got my life back.” P6 expressed gratitude when he said “They saved my life.” Several participants (P4, P11, and P12) responded to the first interview question with a reverence of gratitude. Statements about having a life now and were given the chance to live it, that alone gave them a feeling of quality. Additionally, some respondents described an existential component to their gratitude of being saved, such as P2 who felt “Blessed because I wasn’t even supposed to be here. But I still lost a lot.” And P5 said “Believe in God. Don’t wait till you’re sick to call on God. God is good all the time.” This gratitude was a primary influencer in participant recovery.

Discharge Destination

Three participants went to an acute care rehab facility (P2, P9, and P12) and one went to a skilled nursing facility with rehabilitative services (P11). These participant interviews were initially coded with the entire interview set of participants, and then analyzed separately to determine if any differences occurred in QOL perceptions or the recovery experiences amongst those with formal rehabilitative services prior to returning home. Two participants, P2 and P9, had to request, to go to acute rehab prior to returning home. Both of these participants describe being told about an acute care facility, but needing advocates to assist in navigating them to their preferred discharge destination. During the discharge experience, P2 recalled “Everything with private insurance A was a fight, especially getting transferred to the rehab center. It took a month and they denied me being transferred to the rehab center.” P9 and his wife were unaware of rehabilitative services or facilities and when they were learning about discharge to a nursing home, a staff member recommended that they should ask about a specialized acute care rehabilitative center near the hospital. P9 said,

> We didn’t know what you had to do. It’s like we thought maybe there were certain people could only use it [acute care rehab center]. We were just like asking can we go there cause we, heard, we heard a lot of good things about it.

P11 was the only participant who went to a skilled nursing facility after his ICU stay. He described the aftercare discussion as brief, and transitions between care very limited. The facility he chose to go to was the only one near his home town, thus he had little input on where he could go after his ICU stay. He described his physical state prior to going to the skilled nursing facility when he reflected back and said, “I couldn’t walk. I barely could stand and even then it wasn’t for more than 10 seconds.” After 5 weeks in the facility, he was seen in the post-ICU clinic and participated in this interview. Although he had come along way, he still needed help with walking, bathing, and pacing himself due to shortness of breath. He was being discharged 2 days after the interview completed and was scheduled for out-patient therapy to continue his recovery process.

Summary

The purpose of this study was to understand the critical illness survivor experience with recovery and what aspects are most important to preserve their QOL after discharge. This phenomenological qualitative study was conducted to allow for the patient experience to highlight gaps in current recovery resources for this growing group of survivors. I specifically focused on the lived experiences of the critical illness survivors over the age of 18, within 18 months of discharge, and on mechanical ventilation for a minimum of 48 hours.

The data for this study were gathered by using semistructured questions for two research questions. The first portion of the interview focused on RQ1 and the second portion of the interview was designed to focus on RQ2. At the conclusion of the study, 12 participants were interviewed during the course of 6 months, and the iterative process of coding and analysis was done throughout the course of recruitment. These data resulted in thematic matrices, coded by me, to answer the research questions. Critical illness survivors felt grateful for being saved, and to preserve the QOL after survival, these participants needed to feel prepared, supported, and educated. Having their lives saved made them engage in new life priorities to allow their QOL to take on new levels of appreciation. The recovery process lacked unity, was dominated by informal caregiving, had unclear financial burdens, and was limited by disparate information.

This chapter included the research setting, demographics, data collection methods, data analysis, and data results. In addition, the research process was described in detail, including ways of establishing trustworthiness and credibility. In Chapter 5, I will reiterate the purpose and nature of this study. In addition, the interpretation of these key findings will be compared to the current literature. I will also compare these results with other studies. In addition, I examine the results within the theoretical framework and how these findings can influence future study.

Chapter 5: Discussion, Recommendations, and Conclusions

Introduction

The purpose of this qualitative phenomenological study was to understand the patient perception of QOL after surviving critical illness and how survivors can help illuminate gaps in current health policies to provide better recovery resources for this growing population. I wanted to understand the experience of survivors and how their QOL was affected by recovery. The results of this study can improve health care providers' understandings of how patients experience critical illness recovery as well as provide information for policy makers to influence recovery programs for these survivors. In addition, these results have added to the growing body of data that supports new hypotheses in recovery research. The methods included semistructured interviews of adult critical illness survivors to better understand QOL and recovery in this specific patient population. Survivors with high QOL have reduced rehospitalizations and less overall health care costs (Ruhl et al., 2017).

Key Findings

Results from these interviews showed that critical illness survivors were grateful for their lives, which brought an appreciation for QOL. In addition, participants' QOL was interdependent on the key themes: support, informed, and prepared. These findings were supported by key research in the field, such as Jensen et al. (2017) and Deacon (2012) who studied key components of post-ICU rehabilitation that contribute to QOL. The current results indicated that preservation of QOL for survivors starts with surviving.

This process brought participants to the next phase of recovery, engaging in new life priorities by adapting to new normal levels of function.

In addition, participants in this study found that the aftercare journey lacked unity, was limited by disparate information, and had an unknown recovery trajectory. Even participants who went to an acute care recovery program prior to returning home had major functional limitations that required home caregiving. Several participants described the first few days at home after being discharged when they began to realize how much care they needed in doing typical everyday activities. In addition, these survivors began to realize ways they would need to restructure their lives to align it with new life goals surrounded by family and reprioritization of time. None of these participants could return to their preillness work lives, which was described in several ways. A few participants wanted to reassess how much time they were spending at work and if that was a useful way to spend time given their recent near-death experience. Others believed that returning to work was part of their QOL and, thus, continued to feel inhibited by their new normal.

Overall I found that participants' QOL and aftercare resource availability were intertwined. Feeling prepared for the recovery journey, being educated and informed about their illness and process, being able to adapt to their new normal, and having gratitude transformed their decisions to engage in new life priorities. Aftercare influenced QOL for these survivors because it lacked unity and had unknown financial burdens, had limited and disjointed communication, and created confusion as participants moved through their recovery journeys.

Interpretation of the Findings

The foundation of this study involved recognizing a gap in the current literature surrounding critical illness survivors' QOL and their experiences during recovery. A rising body of literature has been published around the world that defines a prolonged, high-mortality state for ICU survivors, yet the lived experiences of these survivors had gone unexplored. This study process began with examining critical illness survivors' definition of QOL, issues affecting their QOL, and their experience with the recovery process in terms of access, transitions, insurance, and rehabilitative programming. This study has added to the public policy literature by documenting the lived experiences of critical illness survivors during recovery and their interpretation of how the supports following this catastrophic disease state could be improved for future survivors. In addition, this is the only study that used qualitative inquiry to examine the recovery process in the United States.

The first research question asked about the issues important to preserve the QOL from the perspective of critical illness survivors. In this qualitative, phenomenological approach, I gathered information of the phenomenon of recovery in this specific survivor population. The only way to fully understand the problems that ICU survivors face during recovery is to get the patient perspective of the recovery process (Hashem et al., 2016). This shift in research comes after multiple, large, multicenter quantitative trials have failed to improve the recovery journey for this population of survivors.

Research examining the recovery process for critical illness survivors has been increasing in the last decade. Seminal publications have revealed that the improvement in mortality outcomes has also led to an increase in the population of people being discharged to acute care rehab (Kaukonen et al., 2014). Other researchers have defined the psychological, physical, and social sequalae plaguing survivors as PICS (Needham et al., 2012) and a full understanding of the lived experience through qualitative inquiry has been recommended (Hashem et al., 2016). Qualitative inquiry has been used in several studies to understand different aspects of recovery and the effect recovery has on QOL. Through improved policy supports, survivors may be able to experience more cohesive recovery programs that are not financially burdensome and that provide cohesive continuity of care.

Key themes from this study are supported in qualitative studies throughout the field of critical illness. For example, Walker et al. (2015) found that participants wanted to feel cared about and supported emotionally; Deacon’s (2012) participants also described information and education as key components to QOL preservation. Conversely, Jensen (2016) found that due to tax-paid rehabilitation services, their patient population felt well-informed about rehabilitation. These health care policy differences are one barrier to cross-comparing study results being conducted throughout the world. Future studies in the United States should include a closer assessment of barriers to access for recovery resources and funding allocation for the necessary rehabilitative needs of this survivor population. Another study—published in Denmark, where public health insurance is also provided—showed that recovery after rehabilitation from critical illness required months of rehabilitation, extensive sick leave for informal caregivers, and a large economic impact on the health care system (Agard, Lomborg, Tonnesen, & Egerod, 2014).

In 2012, these same Danish researchers found that QOL was dependent on functional capacity, notably physical, and the participants' goal was to return to their premorbid physical function and domestic participation (Agard, Egerod, Tonnesen, & Lomborg, 2012). Similarly, in my study, participants were adapting to their new normal by slowly integrating their previous activities as tolerated by their new limitations. In addition, Agard, Egerod, Tonnesen, and Lomborg (2012) found that participants were focused primarily on short-term goals during recovery and did not appear as focused on the psychological debilitations they were experiencing. This could be due to the fact that physical function is such an obvious form of debilitation that survivors are not even aware of the memory loss and traumatic aspects of recovery until later. Another possibility is that caregivers have become so ingrained in the recovery process and supplement memories so thoroughly that participants do not realize where their memories end and the caregivers' memories begin. These participants all used their caregiver for supplemental memory and historical reference, much like Jensen et al.'s (2017) findings that patients recovering from critical illness relied on relatives as a primary source of historical information. In addition, my study participants acknowledged having problems with thinking and memory, yet they lacked insight in the ICU as the causative agent. Instead, they placed emphasis on old age or previous health conditions that were prior to their ICU stay. It was interesting to note that problems with thinking and memory did not interfere with their daily life until after the ICU stay, but none of these participants associated the ICU as the cause for these deficits.

Physical dysfunction has been the primary focus for recovery in survivors of critical illness due to significant muscle loss during hospitalization. To address this physical morbidity, a seminal paper published a comprehensive whole-body rehabilitative strategy that improved predischarge functional status of survivors at discharge (Schweickert et al., 2009). Physical dysfunction is a significant contributor to increasing length of stay, health care utilization, and QOL (Parry, Huang, & Needham, 2017); therefore, improving functional recovery, by using physical therapy, is a way to decrease the number of critical illness survivors facing disabilities after discharge. Several studies have shown ways to improve predischarge functional status (Parry et al, 2015; Schaller et al., 2016; Schweickert et al., 2009), yet much like this study, participants in other studies have continued to describe reduced physical function and desire to improve access to functional rehabilitation. Deacon (2012) examined survivors' QOL following discharge and revealed that they needed improved assessment and therapy to assist in their recovery process. Similarly, Walker et al. (2015) found early improvement in physical fitness for participants who used a structured exercise intervention. These findings indicated that although known deficits were discovered that prolonged the morbidity of critical illness survivors, using interviews to understand the lived experience revealed that the disability was not necessarily the cause of reduced QOL. Being prepared for the recovery journey and given appropriate support mechanisms could assist these survivors and their families.

Quality of Life and Recovery

I examined the correlation with QOL and the recovery process. Physical, psychological, and social morbidities have been presumed causes of reduced QOL and studies for recovery program changes have failed to correlate with QOL improvement. For example, recent focus on the ICU causative effects and post-traumatic stress disorder during discharge have produced several studies specifically addressing psychological issues facing survivors and if their recovery journey could be improved with structured programming. Most recently, Wade et al. (2019) found no difference in survivors who underwent a structured psychological intervention program versus standard treatment. They hypothesize that these results were negative for several reasons, the timing of the support, the people delivering the psychological care, or that their illness early on was too severe causing them to be preoccupied with their fatigue. This preoccupation inhibited them from fully participating in the psychological support. This aligns with data from this study as participants discussed psychological issues, however, the focus was more on improving activities of daily living, reducing SOB, and physical function.

The findings from this study have emphasized the importance of examining all aspects of recovery, not only negative symptoms of PICS. Feelings of gratitude noted unanimously amongst the survivors of this study, have also been reported in other studies. Jensen et al.'s (2017) participants describe gratitude for being alive, regardless of the difficulties experienced during the recovery process. Agard et al. (2012) also found participants showing gratitude and renewed connectedness with loved ones. This connectedness seemed to positively influence recovery and it was encouraging to learn that survivors report a positive aspect to recovery. This sentiment is important for critical care providers and researchers as some studies hypothesize that surviving with these prolonged debilitations is worse than death. My study participants used their gratefulness to engage in new life priorities, thereby enabling them to become resourceful and adaptive with their limitations. Researchers to date have focused primarily on the negative outcomes of recovery and less on these existential components that are prominent among survivor's. Perhaps these positive attributes are not as obvious to an external observer. This study added to the growing qualitative research that will assist in exploring these components of recovery in the future.

Influences of Long-Term Care Services and Supports

In the United States, limited published data exists on the lived experience of critical illness survivors during rehabilitation. However, I found that participants are faced with a health care system that lacks unity, is disjointed, and negatively influenced their QOL. This subsequently impacts the survivor's ability to physically care for themselves, participate in activities of daily living, and when applicable, return to work. In addition, their debilitation increases the need for familial supports and these informal caregivers are also less likely to return to work. Critical illness is an acute illness with chronic consequences that requires survivor rehabilitative services that are supported by LTC public policies.

LTC does not only include a nursing home or formal care. In the United States, over 1.5 million people are receiving LTC in the community, and one in five households has an informal caregiver providing these services (How Many Caregivers, 2015). To qualify as a LTC recipient, one must need assistance with at least one basic self-care task; therefore, critical illness survivors should be able to use the structured services that already exist. Furthermore, the American Disabilities Act defines disability as a person with a physical or mental impairment that substantially limits one or more major life activities (ADA network, n.d.). However, the fragmented nature of the LTC system and the lack of optimized structured recovery data makes it difficult to deliver appropriate services.

In this study, participants all struggled with one or more self-care task when they returned home, even if they attended a formal acute care program. In addition, they all report having informal caregivers as their primary caregiver. Iwashyna (2012) discovered that understanding the full impact of postcritical illness disability was difficult to ascertain due to the limited formal understanding of survivor needs after discharge. In addition, the health care system is so strained, that adding another defined disability to the current system will require a large body of formal research that is still in its infancy. This study is one of the first studies to ask survivors their experience with recovery and understand the aftercare for the U.S. survivors. PICS has been studied throughout the world, but most of the economic and post-ICU studies being done internationally are difficult to compare given the lack of universal health care coverage in the United States. The Affordable Care Act, Medicare, and Medicaid act as the most comparable government-funded insurance programs, however, the ability for these programs to coordinate LTC has proven to be controversial over the last several decades.

Medicaid disability participants account for only 15% of enrollees, however, almost 50% of expenditures (Iwashyna 2012). Adding this large population of critical care survivors could have significant impact on public health care costs at both national and state levels. The Affordable Care Act attempted to address the void in structured rehabilitation by creating a group of defined essential health benefits. According to the Affordable Care Act, rehabilitative services are an essential health benefit but the way to pay and implement these services is left up to the state (Bagley, 2018). This creates another difficult barrier to standardizing survivor services across the country.

Research into recovery supports is important for survivors as the number of critically ill surviving to discharge rises, increasing numbers of patients are discharged to acute or LTC, and the population continues live longer. There continues to be discord among policy makers in the United States in addressing the LTC service needs, how it should be financed, and how to create an adequate infrastructure (Miller & Nadash, 2014). A formal recovery process must begin with the foundation of policy support.

The aftercare experience for survivors in this study also had several subthemes such as limited by disparate information, unknown financial burdens, and variation in insurance. This finding aligned with Pattison et al. (2015) and Czerwonka et al. (2015) whom both found similar discontinuity of care in survivor experiences and the desire for survivors to shift from dependence to independence. Deacon (2012) also found that participants needed personal support as well as therapy to provide tools for recovery. This finding aligned well with my study participants who described an unknown recovery trajectory and being nowhere near their baseline functional status when discharged to home. This cascade of events leads to a large group of family and friends, informal caregivers, to continue providing the necessary rehabilitation support that was once being provided by highly qualified and trained health care professionals. Informal caregivers are not only not qualified to provide this type of supportive care, researchers have found that posttraumatic stress disorder symptoms also impact the caregivers of the critically ill and therefore, may lead to gaps or delays in recovery (Kang & Jeong, 2018). Czerwonka et al. (2015) reported that families do not feel there is continuity of care for critical illness survivors which contributes to feelings of fear of the unknown navigation for recovery. This feeling was also true among participants who commented on feelings of fear of the unknown which makes returning to their baseline QOL, difficult.

A focus for the future could be forms of electronic follow up including e-mail, web-based video conferencing, and telemedicine, to reduce the burden on informal caregivers. To better address the void of resources for survivors, Pattison et al. (2015) suggested e-mail follow-up as an affordable way to improve access to care, and provides long-term access to knowledgeable ICU staff who are aware of the specific sequelae these patients and families may encounter.

In conclusion, findings of this study indicate that critical illness survivor QOL is dependent on preparedness, information, and support. They currently feel that the aftercare process lacks unity due to disparate information, variations in insurance, and unknown financial implications of their hospitalization or recovery. In addition, the recovery foundation relies heavily on informal caregivers. The current body of research identifying PICS syndrome and a core-outcome set to unify study results. Qualitative inquiry can align with quantitative trials to capture the essence of the patient experience. The participants in this study value their life being saved and were able to adapt to their new normalcy. This ability to adapt brought on a new sense of engagement with their life priorities. Regardless of the debilitating effects critical care left them with, QOL is dependent on feeling grateful for having this life to continue experiencing. Aftercare resource focus needs to begin with a structured, informed, support system that gives these survivors a better understanding of what to expect after they leave the confines of the hospital. It is only through policy support that these rehabilitative services can be implemented.

Rational Choice Theory

Informed decision-making is an important part of today's health care. As therapeutic interventions continue to lengthen life years, patients and families are constantly faced with decision-making. It is with this in mind that RCT was chosen as the theoretical framework for this study. If patients are given the appropriate information, RCT, posits that they will make a rational decision. For critical care survivors, rational choices could include utilizing in-patient rehabilitation centers, formalized nursing home care, or out-patient services. Without the appropriate information, the decisions that are made could appear irrational. For example, all patients want to go home. Being out of the hospital is one of the only goals that every patient in a hospital may have. However, this may not be a rational choice when debilitations in ADL's could be improved with short-term stays in LTC facilities.

The participants in this study supported the idea that if given the information necessary to understand the recovery trajectory, being prepared, informed, and supported, their QOL and recovery experience might have been improved. Adapting to a new normal is difficult when it is unexpected. Understanding physical, emotional, and psychological limitations that may occur with recovery, participants in this study may have been able to request detailed services that could meet their individual needs.

In a 2017 article outlining rational decision-making in medicine, Djulbegovic, Elqayam, Dale and Coppola categorize overuse and underuse of services as causes or barriers to rational choices. Underuse, was defined as the following:

> Failure to deliver a service that is highly likely to improve the quality or quantity of life, that represents good value for the money, and that patients who were fully informed of its potential benefits and harms would have wanted. (Djulbegovic, Elqayam, Dale & Coppola, 2018, p. 20)

As was found in this study, participants could not fully participate in informed decision-making and underused services that could assist in their quality or quantity of life. For example, participants were asked about the opportunity to choose discharge setting. Of the 12 participants, choices regarding discharge varied case-by-case and most participants did not associate these choices with informed decision-making. For example, P6 recalls the desire to go home was so strong he did not appropriately consider rehabilitative services. In retrospect, he recalls, he should have. Some participants had no choice due to insurance status (P10) or were required to choose rehab due to their profound physical disabilities (P11 and P12). Others were given no choice, other than home, P1, P3, P6, P7, and P8. Lastly, P5 refused formal rehabilitation and went home with her husband and an assist device. This discord between discharge planning and participant understanding of recovery disables rational choices from being made. In addition, lack of unified discharge exemplified the findings from this study because participants were prepared or informed about recovery and thus, either make decisions that could negatively influence their QOL, or they did not use rehabilitative services that could assist them in adapting to their new limitations.

Limitations of the Study

There were several limitations of this study. Qualitative research was a limitation due to its lack of generalizability to the whole population. In addition, qualitative researchers rely on the participant and interviewer which can possibly create a subconscious bias in the results. These participants were selected at a post-ICU clinic at a single-center in central North Carolina. Recruitment at a clinic dedicated to ICU survivors might have influenced recruitment to only those seeking help after discharge; thus possibly overrepresenting only people experiencing issues. This clinic has a 50% no-show rate which could result in not capturing people who were readmitted or those who are too ill to be brought to an out-patient clinic. No prior health information was collected, thus limiting the study to understand how previous health status impacted QOL following an ICU admission. Lastly, recruitment was limited to those who attended the post-ICU clinic and resulted in a racially monogamous population. This lack of diversity could underrepresent issues that may be specific to certain populations.

The number of participants originally presented in the proposal was not achieved. Originally this research sought to recruit and interview 15 to 30 participants. This sample size was an estimate based on other studies and the volume of the clinics that were originally proposed. However, after 10 interviews, the conceptual saturation was being reached, thus two more interviews were completed, verifying that no new information was being presented and recruitment ended after 12 interviews.

Recommendations

Based on the stated limitations of this study, I would recommend that a future study of inquiry be expanded to other settings. Critical care survivors are often discharged to LTC facilities and may not have access to specialist follow up clinics such as the one used to recruit for this trial. Based on my experience with these survivors, being at home had a positive impact on their reflection of QOL and recovery. Perhaps this would be different for people who were unable to return home.

Survivors from this study placed high importance on preparedness, support, and information about the recovery trajectory to preserve QOL. By entering a nonunified recovery process, survivors were left to create their own recovery path. I recommend health policy in the United States create survivor guidelines that mirrors other chronic disease states such as cancer, and/or other nationally implemented programs such as those found in the United Kingdom.

In 2009 the leaders of the United Kingdom's National Health Service created a clinical guideline for rehabilitation following critical illness. These guidelines, the NICE guidelines, support a structured, goal-oriented recovery program that includes physical and nonphysical assessments surrounded by continuity of care throughout all aspects of critical care recovery. This type of comprehensive program could help survivors prepare and use available resources.

Knowledge could also be gained from utilizing examples from centralized cancer care. Cancer patients are also known to suffer from similar long-lasting debilitations following prolonged treatment (Nolte et al., 2016). Knowledge of these ongoing debilitations led to a recommendation from the Institute of Medicine to provide a coordinated care path for cancer survivors (Nekhlyudov et al., 2017). In addition, specific types of cancers have created cancer-specific QOL measurement tools to examine the experiences of these survivors to improve their prolonged morbidity (Osborne et al., 2014). I would recommend that the future of critical illness survivors could be improved with a tool for QOL specifically intended for critical illness survivors. It is clear from this study and others in the field that being brought to the verge of death and having a chance at life again gives survivors a different perspective on what quality means and how their life is impacted by prolonged limitations. It was my experience during the course of this study that survivors understood recovery would be difficult only after attempting to reintegrate back into their usual life. Laying an informed foundation of preparedness should be a feature of future research.

Furthermore, I recommend focus on awareness efforts that inform the health care community about the physical, social, and psychological sequelae facing survivors of critical illness. Underutilization of rehabilitative specialties could be due to this lack of understanding of these ongoing debilitations. In addition, having informed discharge practices from qualified ICU personnel, could improve communication for patients and families empowering them to be a more active participant in this complex process as opposed to the passive navigator that they have become thus far.

Implications

This study influences social change in many ways. First, critical illness survivors have long-standing debilitations that impact their everyday life. By understanding their perspectives of the term *quality of life* and the implications this disease process had on their quality, leaders can create future policy to assist in expansion of recovery support and opportunities. In addition, this study influences social change by extending the research dynamic of this survivor population to include a supportive infrastructure to prepare them for the recovery journey. As patients continue to be saved, their engagement in life priorities change and it is difficult for an external observer to fully understand how to structure this preparation without first hearing from the survivors themselves.

Currently, critical care survivors are discharged to a fragmented system that fails to fully meet their needs. Their informal caregivers are placed in positions that fundamentally require more advanced training and skill. These caregivers are also facing their own ongoing anxiety and fear after having witnessed the catastrophic illness from which their loved one suffered. By understanding the recovery journey these patients faced, further research can be done to prepare, inform, and support survivors who are forced to embrace this new level of normalcy, both physically and emotionally. Social change begins with one idea that can help impact society at every level. Critical illness spares no one, and all people are susceptible to the sequelae of this catastrophic disease state. Therefore, recovery process improvement and could transcend all people in society regardless of age, race, ethnicity, or socioeconomic status.

Based on the participants' perspectives in this study, I conclude that QOL can be improved if patients are prepared, informed, and supported during recovery. Their gratitude for living enables them to embark in new life prioritization and adapt to their new life normal. Some of their prolonged morbidity can be ameliorated with improved coordination of care, unified information, and formalized recovery support in lieu of informal caregiving.

Conclusion

My qualitative research into 12 critical illness survivors aligned with current literature and emphasized the need for further policy support for this group. Successful recovery is an individual process that requires preparedness, unity, supports, and informed choices. Although important to the recovery process, informal caregivers can no longer be the mainstay therapeutic navigators for this complex group of patients and the sequalae of their catastrophic illness. Informed decisions begin in the hospital and throughout the illness trajectory. Without properly implemented health policy, these survivors will continue to suffer from reduced QOL, increased hospital readmissions, and high mortality rates for years after discharge, regardless of their age or preillness health status. Current discharge planning may fail to prepare survivors and families because of the inconclusive trial data thus far. However, this void in data does not mean rehabilitative services lack effectiveness, but it does create a system of underuse and overuse as seen with the participants in this trial. Standardization of therapeutic interventions is the only way to ensure that all people have access to resources that allow them to engage in their new life normal and to enjoy their newfound gratitude for being saved.

References

ADA National Network. (n.d.) What is the definition of a disability under ADA. Retrieved from https://adata.org/faq/what-definition-disability-under-ada

Agard, A., Egerod, I., Tonnesen, E. & Lomborg, K. (2012). Struggling for independence: A grounded theory study on convalescence of ICU survivors 12 months post ICU discharge. *Intensive and Critical Care Nursing*, 28, 105–113. doi:10.1016/j.iccn.2012.01.008

Agard, A., Lomborg, K., Tonnesen, E. & Egerod, I. (2014). Rehabilitative activities, out-patient visits and employment in patients and partners the first year after ICU: A descriptive study. *Intensive and Critical Care Nursing,* 30, 101–110. doi:10.1016/j.iccn.2013.11.001

Aitken, L. M., Castillo, M. I., Ullman, A., Engstrom, A., Cunningham, K., & Rattray, J. (2016). What is the relationship between elements of ICU treatment and memories after discharge in adult ICU survivors? *Australian Critical Care, 29*(1), 5–14. doi:10.1016/j.aucc.2015.11.004

Aitken, L. M., & Marshall, A. P. (2015). Monitoring and optimising outcomes of survivors of critical illness. *Intensive Critical Care Nurse, 31*(1), 1–9. doi:10.1016/j.iccn.2014.10.006

Alase, A. (2017). The interpretative phenomenological analysis (IPA): A guide to a good qualitative research approach. *International Journal of Education & Literacy Studies, 5*(2), 9–11. doi:10.7575/aiac.ijels.v.5n.2p.9

Bagley, N., & Levy, H. (2014). Essential health benefits and the Affordable Care Act: Law and process. *Journal of Health Politics, Policy, and Law, 39*(2), 441–465. doi:10.1215/03616878-2416325

Balas, M. C., Bonasera, S. J., Cohen, M. Z., Hertzog, M., Sisson, J. H., Potter, J. F., . . . Burke, W. J. (2015). Measuring functional recovery in older patients discharged from intensive care units: Is advanced technology an option? *Journal of Applied Gerontology, 34*(3), NP22–40. doi:10.1177/0733464813480267

Bandura, A. (1986). *Social foundations of thought and action*. Englewood Cliffs: Prentice-Hall.

Bearman, M., & Dawson, P. (2013). Qualitative synthesis and systematic review in health professions education. *Medical Education, 47*(3), 252–260. doi:10.1111/medu.12092

Bluvstein, I., Moravchick, L., Sheps, D., Schreiber, S., & Bloch, M. (2013). Posttraumatic growth, posttraumatic stress symptoms and mental health among coronary heart disease survivors. *Journal of Clinical Psychology in Medical Settings, 20*(2), 164–172. doi:10.1007/s10880-012-9318-z

Bodzek, S., Franek, G., & Kapusta, Z. (2016). Selected aspects of quality of life of patients after ischemic stroke. *Journal of Neurological & Neurosurgical Nursing, 5*(2), 69–75. doi:10.15225/PNN.2016.5.2.5

Boonen, E., & Van den Berghe, G. (2014). Endocrine responses to critical illness: Novel insights and therapeutic implications. *Journal of Clinical Endocrinology and Metabolism, 99*(5), 1569–1582. doi:10.1210/jc.2013-4115

Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77–101. doi:10.1191/1478088706qp063oa

Broyles, I. H., Sperber, N. R., Voils, C. I., Konetzka, R. T., Coe, N. B., & Van Houtven, C. H. (2016). Understanding the context for long-term care planning. *Medical Care Research and Review, 73*(3), 349–368. doi:10.1177/1077558715614480

Bruce, A., Sheilds, L., Molzahn, A., Beuthin, R., Schick-Makaroff, K., & Shermak, S. (2014). Stories of liminality: Living with life-threatening illness. *Journal of Holistic Nursing, 32*(1), 35–43. doi:10.1177/0898010113498823

Buetow, S. (2007). Non-attendance for health care: When rational beliefs collide. *The Sociological Review, 53*(3), 592–610. doi:10.1111/j.1467-954X.2007.00723.x

Burtin, C., Clerckx, B., Robbeets, C., Ferdinande, P., Langer, D., Troosters, T., . . . Gosselink, R. (2009). Early exercise in critically ill patients enhances short-term functional recovery. *Critical Care Medicine, 37*(9), 2499–2505. doi:10.1097/CCM.0b013e3181a38937

Byers, J. F., & Smyth, K. A. (1997). Application of a transactional model of stress and coping with critically ill patients. *Dimensions of Critical Care Nursing, 16*(6), 292–300. doi:10.1097.00003465-199711000-00002

Capuzzo, M., & Bianconi, M. (2015). Our paper 20 years later: 1-year survival and 6-month quality of life after intensive care. *Intensive Care Medicine, 41*(4), 605–614. doi:10.1007/s00134-015-3654-z

Cella, D., Riley, W., Stone, A., Rothrock, N., Reeve, B., Yount, S., . . . Group, P. C. (2010). The Patient-Reported Outcomes Measurement Information System

(PROMIS) developed and tested its first wave of adult self-reported health outcome item banks: 2005–2008. *Journal of Clinical Epidemiology, 63*(11), 1179–1194. doi:10.1016/j.jclinepi.2010.04.011

Centers for Medicare and Medicaid Services. (2013). What is long term care? Retrieved from https://www.cms.gov/Regulations-and-Guidance/Legislation/CFCsAndCoPs/LTC.html

Choi, J., Hoffman, L. A., Schulz, R., Tate, J. A., Donahoe, M. P., Ren, D., . . . Sherwood, P. R. (2014). Self-reported physical symptoms in intensive care unit (ICU) survivors: Pilot exploration over four months post-ICU discharge. *Journal of Pain Symptom Management, 47*(2), 257–270. doi:10.1016/j.jpainsymman.2013.03.019

Choi, J., Tate, J. A., Rogers, M. A., Donahoe, M. P., & Hoffman, L. A. (2016). Depressive symptoms and anxiety in intensive care unit (ICU) survivors after ICU discharge. *Heart Lung, 45*(2), 140–146. doi:10.1016/j.hrtlng.2015.12.002

Chuluunbaatar, E., Chou, Y. J., & Pu, C. (2016). Quality of life of stroke survivors and their informal caregivers: A prospective study. *Disability and Health Journal, 9*(2), 306–312. doi:10.1016/j.dhjo.2015.10.007

Collyer, F., Willis, K., Franklin, M., Harley, K., & Short, S. (2015). Healthcare choice: Bourdieu’s capital, habitus and field. *Current Sociology Monograph, 63*(5), 685–699. doi:10.1177/0011392115590082

Cox, C. E., Porter, L. S., Buck, P. J., Hoffa, M., Jones, D., Walton, B., . . . Greeson, J. M. (2014). Development and preliminary evaluation of a telephone-based mindfulness training intervention for survivors of critical illness. *Annals of*

American Thoracic Society, 11(2), 173–181. doi:10.1513/AnnalsATS.201308-283OC

Czerwonka, A. I., Herridge, M. S., Chan, L., Chu, L. M., Matte, A., & Cameron, J. I. (2015). Changing support needs of survivors of complex critical illness and their family caregivers across the care continuum: A qualitative pilot study of Towards RECOVER. *Journal of Critical Care, 30*(2), 242–249. doi:10.1016/j.jcrc.2014.10.017

Deacon, K. S. (2012). Re-building life after ICU: A qualitative study of the patients' perspective. *Intensive Critical Care Nurse, 28*(2), 114–122. doi:10.1016/j.iccn.2011.11.008

Dettling-Ihnenfeldt, D. S., de Graaff, A. E., Beelen, A., Nollet, F., & van der Schaaf, M. (2016). Coping style and quality of life in Dutch intensive care unit survivors. *Rehabilitation Psychology, 61*(2), 165–172. doi:10.1037/rep0000084

Dingell, D. (2015). The wide range of challenges facing seniors. *Harvard Journal on Legislation, 52*(2), 309–325. Retrieved from https://harvardjol.com

Djulbegovic, B., Elqayam, E., Dale, W., & Coppola, A. (2017). Rational decision making in medicine: Implication for overuse and underuse. *Journal of Evaluation in Clinical Practice*, 24, 655–665. doi:10.1111/jep.12851

Dudovsky, J. (2017). Ethical considerations. Retrieved from https://research-methodology.net/research-methodology/ethical-considerations/

Dziadzko, V., Dziadzko, M. A., Johnson, M. M., Gajic, O., & Karnatovskaia, L. V. (2017). Acute psychological trauma in the critically ill: Patient and family perspectives. *General Hospital Psychiatry, 47*, 68–74. doi:10.1016/j.genhosppsych.2017.04.009

Eakin, M. N., Patel, Y., Mendez-Tellez, P., Dinglas, V. D., Needham, D. M., & Turnbull, A. E. (2017). Patients' outcomes after acute respiratory failure: A qualitative study with the PROMIS framework. *American Journal of Critical Care, 26*(6), 456–465. doi:10.4037/ajcc2017834

Ehlenbach, W. J. (2014). The sobering reality of outcomes when older adults require prolonged mechanical ventilation. *Journal of American Geriatric Society, 62*(1), 183–185. doi:10.1111/jgs.12599

Elliott, M., Worrall-Carter, L., & Page, K. (2014). Intensive care readmission: A contemporary review of the literature. *Intensive Critical Care Nurse*, 30(3), 121–137. doi:10.1016/j.iccn.2013.10.005

Epstein, W. N. (2017). Nudging patient decision-making. *Washington Law Review, 92*(3), 1255–1315. Retrieved from https://www.law.uw.edu/wlr

Falconer, J., & Quesnel-Vallee, A. (2017). Pathway from poor self-rated health to mortality: Explanatory power of disease diagnosis. *Social Science Medicine, 190*, 227–236. doi:10.1016/j.socscimed.2017.08.008

Fan, E., Dowdy, D. W., Colantuoni, E., Mendez-Tellez, P. A., Sevransky, J. E., Shanholtz, C., . . . Needham, D. M. (2014). Physical complications in acute lung injury survivors: A two-year longitudinal prospective study. *Critical Care Medicine, 42*(4), 849–859. doi:10.1097/CCM.0000000000000040

Feemster, L. C., Cooke, C. R., Rubenfeld, G. D., Hough, C. L., Ehlenbach, W. J., Au, D. H., & Fan, V. S. (2015). The influence of hospitalization or intensive care unit admission on declines in health-related quality of life. *Annals of American Thoracic Society, 12*(1), 35–45. doi:10.1513/AnnalsATS.201404-172OC

Feigin, V. L., Roth, G. A., Naghavi, M., Parmar, P., Krishnamurthi, R., Chugh, S., . . . Stroke Experts Writing, G. (2016). Global burden of stroke and risk factors in 188 countries, during 1990-2013: A systematic analysis for the global burden of disease study 2013. *Lancet Neurology, 15*(9), 913–924. doi:10.1016/S1474-4422(16)30073-4

Fumis, R., Ranzani, O., Martins, P., & Schettino, G. (2015). Emotional disorders in pairs and their family members during and after ICU stay. *PLOS one*, *10*(1), 1–12. doi:10.1371/journal.pone.0115332

Gabay, G. (2016). Exploring perceived control and self-rated health in re-admissions among younger adults: A retrospective study. *Patient Education Counseling, 99*(5), 800–806. doi:10.1016/j.pec.2015.11.011

Galston, W. (2012). The long-term is now. *Democracy: A Journal of Ideas, 26*, 60–71. Retrieved from https://democracyjournal.org/

Ganz, P. A., Yip, C. H., Gralow, J. R., Distelhorst, S. R., Albain, K. S., Andersen, B. L., . . . Anderson, B. O. (2013). Supportive care after curative treatment for breast cancer (survivorship care): Resource allocations in low- and middle-income countries. A Breast Health Global Initiative 2013 consensus statement. *Breast, 22*(5), 606–615. doi:10.1016/j.breast.2013.07.049

Garland, A. (2017). Labor market outcomes: Expanding the list of patient-centered outcomes in critical care. *American Journal of Respiratory Critical Care Medicine, 196*(8), 946–947. doi:10.1164/rccm.201705-0880ED

Garland, A., Olafson, K., Ramsey, C. D., Yogendran, M., & Fransoo, R. (2015). A population-based observational study of intensive care unit-related outcomes. With emphasis on post-hospital outcomes. *Annals of American Thoracic Society, 12*(2), 202–208. doi:10.1513/AnnalsATS.201405-201CME

Girard, T. D., Dittus, R. S., & Ely, E. W. (2016). Critical Illness Brain Injury. *Annual Review of Medicine, 67*, 497–513. doi:10.1146/annurev-med-050913-015722

Gore, J. L. (2017). Incorporating the patient into urologic cancer research. *Urology Oncology, 35*(9), 546–547. doi:10.1016/j.urolonc.2017.08.003

Halpern, M. T., & Argenbright, K. E. (2017). Evaluation of effectiveness of survivorship programmes: How to measure success? *Lancet Oncology, 18*(1), e51–e59. doi:10.1016/S1470-2045(16)30563-0

Halpern, N. A., Goldman, D. A., Tan, K. S., & Pastores, S. M. (2016). Trends in critical care beds and use among population groups and Medicare and Medicaid beneficiaries in the United States: 2000-2010. *Critical Care Medicine, 44*(8), 1490–1499. doi:10.1097/CCM.0000000000001722

Hashem, M. D., Nallagangula, A., Nalamalapu, S., Nunna, K., Nausran, U., Robinson, K. A., . . . Eakin, M. N. (2016). Patient outcomes after critical illness: A systematic review of qualitative studies following hospital discharge. *Critical Care, 20*(1), 345. doi:10.1186/s13054-016-1516-x

Herridge, M. S., Cheung, A., Tansey, C., Matte-Martyn, A., Diaz-Granados, N., Al-Saidi, F., Cooper, A., Guest, C., Mazer, C.D., Mehta, S., Stewart, T., Barr, A., Cook, D., & Slutsky, A. (2003). One-year outcomes in survivors of the acute respiratory distress syndrome (ARDS). *The New England Journal of Medicine*, 348(8), 683–693. oi:10.1056/nejmoa022450

Herridge, M. S., Moss, M.R., Hough, C.L., Hopkins, R.O., Rice, T.W., Bienvenu, O.J., & Azoulay, E. (2016). Recovery and outcomes after the acute respiratory distress syndrome (ARDS) in patients and their family caregivers. *Intensive Care Medicine*, 42, 725–738. doi:10.1007/s00134-016-4321-8

Herridge, M. S., Tansey, C. M., Matte, A., Tomlinson, G., Diaz-Granados, N., Cooper, A., . . . Canadian Critical Care Trials, G. (2011). Functional disability 5 years after acute respiratory distress syndrome. *New England Journal of Medicine, 364*(14), 1293–1304. doi:10.1056/NEJMoa1011802

Heyland, D. K., Garland, A., Bagshaw, S. M., Cook, D., Rockwood, K., Stelfox, H. T., . . . Day, A. G. (2015). Recovery after critical illness in patients aged 80 years or older: A multi-center prospective observational cohort study. *Intensive Care Medicine, 41*(11), 1911–1920. doi:10.1007/s00134-015-4028-2

Heyland, D. K., Konopad, E., Noseworthy, T. W., Johnston, R., & Gafni, A. (1998). Is it ‘worthwhile’ to continue treating patients with a prolonged stay (>14 days) in the ICU? An economic evaluation. *Chest, 114*(1), 192–198.

Heyland, D. K., Stapleton, R. D., Mourtzakis, M., Hough, C. L., Morris, P., Deutz, N. E., . . . Needham, D. M. (2016). Combining nutrition and exercise to optimize survival and recovery from critical illness: Conceptual and methodological issues. *Clinical Nutrition, 35*(5), 1196–1206. doi:10.1016/j.clnu.2015.07.003

Hill, A. D., Fowler, R. A., Pinto, R., Herridge, M. S., Cuthbertson, B. H., & Scales, D. C. (2016). Long-term outcomes and healthcare utilization following critical illness: A population-based study. *Critical Care, 20*(76), 1–10. doi:10.1186/s13054-016-1248-y

Hodgson, C., & Cuthbertson, B. H. (2016). Improving outcomes after critical illness: Harder than we thought! *Intensive Care Medicine, 42*(11), 1772–1774. doi:10.1007/s00134-016-4526-x

Hoffman, A. J. (2013). Enhancing self-efficacy for optimized patient outcomes through the theory of symptom self-management. *Cancer Nursing, 36*(1), E16–26. doi:10.1097/NCC.0b013e31824a730a

Hoffman, A., Lent, R., & Raque-Bogdan, T. (2013). A social cognitive perspective on coping with cancer: Theory, research and intervention. *The Counseling Psychologist, 41*(2), 240–267. doi:10.1177/00111000001246

Hofhuis, J. G., van Stel, H. F., Schrijvers, A. J., Rommes, J. H., & Spronk, P. E. (2015). ICU survivors show no decline in health-related quality of life after 5 years. *Intensive Care Medicine, 41*(3), 495–504. doi:10.1007/s00134-015-3669-5

How many caregivers. (2015). Retrieved from https://www.caregiver.org/selected-long-term-care-statistics

Hsieh, H. F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research, 15*(9), 1277–1288. doi:10.1177/1049732305276687

Hua, M., Gong, M. N., Miltiades, A., & Wunsch, H. (2017). Outcomes after rehospitalization at the same hospital or a different hospital following critical illness. *American Journal of Respiratory Critical Care Medicine, 195*(11), 1486–1493. doi:10.1164/rccm.201605-0912OC

Iadeluca, L., Mardekian, J., Chander, P., Hopps, M., & Makinson, G. T. (2017). The burden of selected cancers in the US: Health behaviors and health care resource utilization. *Cancer Management and Research, 9*, 721–730. doi:10.2147/CMAR.S143148

Iwashyna, T. J., Cooke, C. R., Wunsch, H., & Kahn, J. M. (2012). Population burden of long-term survivorship after severe sepsis in older Americans. *Journal of American Geriatric Society, 60*(6), 1070–1077. doi:10.1111/j.1532-5415.2012.03989.x

Iwashyna, T. J., & Hodgson, C. L. (2016). Early mobilisation in ICU is far more than just exercise. *Lancet, 388*(10052), 1351–1352. doi:10.1016/S0140-6736(16)31745-7

Jackson, J. C., Mitchell, N., & Hopkins, R. O. (2015). Cognitive functioning, mental health, and quality of life in ICU survivors: An overview. *Psychiatric Clinics of North America, 38*(1), 91–104. doi:10.1016/j.psc.2014.11.002

Jeitziner, M. M., Zwakhalen, S. M., Burgin, R., Hantikainen, V., & Hamers, J. P. (2015). Changes in health-related quality of life in older patients one year after an intensive care unit stay. *Journal of Clinical Nursing, 24*(21-22), 3107–3117. doi:10.1111/jocn.12904

Jensen, J. F., Egerod, I., Bestle, M. H., Christensen, D. F., Elklit, A., Hansen, R. L., . . . Overgaard, D. (2016). A recovery program to improve quality of life, sense of coherence and psychological health in ICU survivors: A multicenter randomized controlled trial, the RAPIT study. *Intensive Care Medicine, 42*(11), 1733–1743. doi:10.1007/s00134-016-4522-1

Jensen, J. F., Overgaard, D., Bestle, M. H., Christensen, D. F., & Egerod, I. (2017). Towards a new orientation: A qualitative longitudinal study of an intensive care recovery programme. *Journal of Clinical Nursing, 26*(1-2), 77–90. doi:10.1111/jocn.13372

Jones, T. K., Fuchs, B. D., Small, D. S., Halpern, S. D., Hanish, A., Umscheid, C. A., . . . Mikkelsen, M. E. (2015). Post-acute care use and hospital readmission after sepsis. *Annals of American Thoracic Society, 12*(6), 904–913. doi:10.1513/AnnalsATS.201411-504OC

Kamdar, B. B., Huang, M., Dinglas, V. D., Colantuoni, E., von Wachter, T. M., Hopkins, R. O., . . . Blood Institute Acute Respiratory Distress Syndrome, N. (2017). Joblessness and lost earnings after acute respiratory distress syndrome in a 1-Year national multicenter study. *American Journal of Respiratory Critical Care Medicine, 196*(8), 1012–1020. doi:10.1164/rccm.201611-2327OC

Kang, J. & Jeong, Y. (2018). Embracing the new vulnerable self: A grounded theory approach on critical care survivors' post-intensive care syndrome. *Intensive & Critical Care Nursing*, 49, 44–50. doi:10.1016/j.iccn.2018.08.004

Kaukonen, K. M., Bailey, M., Suzuki, S., Pilcher, D., & Bellomo, R. (2014). Mortality related to severe sepsis and septic shock among critically ill patients in Australia and New Zealand, 2000-2012. *JAMA, 311*(13), 1308–1316. doi:10.1001/jama.2014.2637

Kean, S., Salisbury, L. G., Rattray, J., Walsh, T. S., Huby, G., & Ramsay, P. (2017). ‘Intensive care unit survivorship’ - A constructivist grounded theory of surviving critical illness. *Journal of Clinical Nursing, 26*(19-20), 3111–3124. doi:10.1111/jocn.13659

Keeley, T., Williamson, P., Callery, P., Jones, L. L., Mathers, J., Jones, J., . . . Calvert, M. (2016). The use of qualitative methods to inform Delphi surveys in core outcome set development. *Trials, 17*(1), 230–235. doi:10.1186/s13063-016-1356-7

Khan, B. A., Lasiter, S., & Boustani, M. A. (2015). CE: Critical care recovery center: An innovative collaborative care model for ICU survivors. *American Journal of Nursing, 115*(3), 24–31. doi:10.1097/01.NAJ.0000461807.42226.3e

Kobayashi, S. T., Diz, M., Campolina, A. G., De Soarez, P. C., Ribeiro, U., Jr., Nahas, S. C., . . . Hoff, P. M. (2017). Integrated care pathway for rectal cancer treatment: health care resource utilization, costs, and outcomes. *International Journal of Evidence Based Healthcare, 15*(2), 53–62. doi:10.1097/XEB.0000000000000099

Kress, J. P., & Hall, J. B. (2014). ICU-acquired weakness and recovery from critical illness. *New England Journal of Medicine, 371*(3), 287–288. doi:10.1056/NEJMc1406274

Leung, J., Smith, M. D., & McLaughlin, D. (2016). Inequalities in long term health-related quality of life between partnered and not partnered breast cancer survivors through the mediation effect of social support. *Psychooncology, 25*(10), 1222–1228. doi:10.1002/pon.4131

Levin, J., & Milgrom, P. (2004). Introduction to Rational Choice. Retrieved from http://web.stanford.edu/-jdlevin/Econ%20202/Choice%20Theory.pdf

Li, C. C., Matthews, A. K., Dossaji, M., & Fullam, F. (2017). The Relationship of patient-provider communication on quality of life among african-american and white cancer survivors. *Journal of Health Communication, 22*(7), 584–592. doi:10.1080/10810730.2017.1324540

Lim, W. C., Black, N., Lamping, D., Rowan, K., & Mays, N. (2016). Conceptualizing and measuring health-related quality of life in critical care. *Journal of Critical Care, 31*(1), 183–193. doi:10.1016/j.jcrc.2015.10.020

Lincoln, Y., & Guba, E. (1985). *Naturalistic Inquiry*. Newbury Park, CA: Sage.

Liu, V., Lei, X., Prescott, H. C., Kipnis, P., Iwashyna, T. J., & Escobar, G. J. (2014). Hospital readmission and healthcare utilization following sepsis in community settings. *Journal of Hospital Medicine, 9*(8), 502–507. doi:10.1002/jhm.2197

Lone, N. I., Gillies, M. A., Haddow, C., Dobbie, R., Rowan, K. M., Wild, S. H., . . . Walsh, T. S. (2016). Five-year mortality and hospital costs associated with surviving intensive care. *American Journal of Respiratory Critical Care Medicine, 194*(2), 198–208. doi:10.1164/rccm.201511-2234OC

Marchioni, A., Fantini, R., Antenora, F., Clini, E., & Fabbri, L. (2015). Chronic critical illness: The price of survival. *European Journal of Clinical Investigation, 45*(12), 1341–1349. doi:10.1111/eci.12547

Mark, N. M., Rayner, S. G., Lee, N. J., & Curtis, J. R. (2015). Global variability in withholding and withdrawal of life-sustaining treatment in the intensive care unit: A systematic review. *Intensive Care Medicine, 41*(9), 1572–1585. doi:10.1007/s00134-015-3810-5

Maru, S., Byrnes, J., Carrington, M. J., Chan, Y. K., Thompson, D. R., Stewart, S., . . . Investigators, W. T. (2015). Cost-effectiveness of home versus clinic-based management of chronic heart failure: Extended follow-up of a pragmatic, multicentre randomized trial cohort - The WHICH? study (Which Heart Failure Intervention Is Most Cost-Effective & Consumer Friendly in Reducing Hospital Care). *International Journal of Cardiology, 201*, 368–375. doi:10.1016/j.ijcard.2015.08.066

McCambridge, J., Witton, J. & Elbourne, D. (2014). Systematic review of the Hawthorne effect: New concepts are needed to study research participation effects. *Journal of Clinical Epidemiology, 67*(3), 267–277. doi:10.1016./j.jclinepi.2013.08.015

McHugh, J. E., & Lawlor, B. A. (2016). Executive functioning independently predicts self-rated health and improvement in self-rated health over time among community-dwelling older adults. *Aging Mental Health, 20*(4), 415–422. doi:10.1080/13607863.2015.1018866

McWilliams, D. J., Benington, S., & Atkinson, D. (2016). Outpatient-based physical rehabilitation for survivors of prolonged critical illness: A randomized controlled trial. *Physiotherapy Theory and Practice, 32*(3), 179–190. doi:10.3109/09593985.2015.1137663

Mechanic, R. (2014). Post-acute care--the next frontier for controlling Medicare spending. *New England Journal of Medicine, 370*(8), 692–694. doi:10.1056/NEJMp1315607

Methodology. (2017). Retrieved from http://www.longtermscorecard.org/methodology

Miller, E. & Nadash, P. (2014). The affordable care act and long-term care: Marginal advancement on the status quo. *Home Health Care Services Quarterly*, *33*(4), 194–210. doi:10.1080/061621424.2014.956959

Miller, K. D., Siegel, R. L., Lin, C. C., Mariotto, A. B., Kramer, J. L., Rowland, J. H., . . . Jemal, A. (2016). Cancer treatment and survivorship statistics, 2016. *CA: A Cancer Journal for Clinicians, 66*(4), 271–289. doi:10.3322/caac.21349

Mosher, C. E., Winger, J. G., Given, B. A., Helft, P. R., & O'Neil, B. H. (2016). Mental health outcomes during colorectal cancer survivorship: A review of the literature. *Psychooncology, 25*(11), 1261–1270. doi:10.1002/pon.3954

National Institute for Health and Care Excellence. (2017). Rehabilitation after critical illness. *National Institute for Health and Clinical Excellence Guideline*. Retrieved from https://pathways.nice.org.uk/pathways/rehabilitation-after-critical-illness

Needham, D. M., Davidson, J., Cohen, H., Hopkins, R. O., Weinert, C., Wunsch, H., . . . Harvey, M. A. (2012). Improving long-term outcomes after discharge from intensive care unit: Report from a stakeholders' conference. *Critical Care Medicine, 40*(2), 502–509. doi:10.1097/CCM.0b013e318232da75

Needham, D. M., Wozniak, A. W., Hough, C. L., Morris, P. E., Dinglas, V. D., Jackson, J. C., . . . National Institutes of Health, N. A. N. (2014). Risk factors for physical impairment after acute lung injury in a national, multicenter study. *American Journal of Respiratory and Critical Care Medicine, 189*(10), 1214–1224. doi:10.1164/rccm.201401-0158OC

Nekhlyudov, L., O'Malley D, M., & Hudson, S. V. (2017). Integrating primary care providers in the care of cancer survivors: Gaps in evidence and future opportunities. *Lancet Oncology, 18*(1), e30–e38. doi:10.1016/S1470-2045(16)30570-8

Neuman, M. D., Wirtalla, C., & Werner, R. M. (2014). Association between skilled nursing facility quality indicators and hospital readmissions. *JAMA, 312*(15), 1542–1551. doi:10.1001/jama.2014.13513

Nolte, L., Kinnane, N., Lai-Kwon, J., Gates, P., Shilkin, P., & Jefford, M. (2016). The impact of survivorship care planning on patients, general practitioners, and hospital based staff. *Cancer Nursing 39*(6), E27–E35. doi:10.1097/NCC.0000000000000329

O'Cathain, A., Goode, J., Drabble, S. J., Thomas, K. J., Rudolph, A., & Hewison, J. (2014). Getting added value from using qualitative research with randomized controlled trials: A qualitative interview study. *Trials, 15*, 215–220. doi:10.1186/1745-6215-15-215

Ortego, A., Gaieski, D. F., Fuchs, B. D., Jones, T., Halpern, S. D., Small, D. S., . . . Mikkelsen, M. E. (2015). Hospital-based acute care use in survivors of septic shock. *Critical Care Medicine, 43*(4), 729–737. doi:10.1097/CCM.0000000000000693

Osborn, T., Ramsenthaler, C. de Wolf-Linder, Schey, S., Siegert, R., Edmonds, P., & Higginson, I. (2014). Understanding what matters most to people with multiple myeloma: A qualitative study of views on quality of life. *BioMed Central, 14*(496), 1–14. doi:10.1186/1471-2407-14-496

Palinkas, L. A., Horwitz, S. M., Green, C. A., Wisdom, J. P., Duan, N., & Hoagwood, K. (2015). Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Administration and Policy in Mental Health*, 42(5), 533–544. doi:10.1007/s10488-013-0528-y

Parry, S. M., Denehy, L., Beach, L. J., Berney, S., Williamson, H. C., & Granger, C. L. (2015). Functional outcomes in ICU - What should we be using? An observational study. *Critical Care, 19*, 127. doi:10.1186/s13054-015-0829-5

Parry, S. M., Huang, M., & Needham, D. M. (2017). Evaluating physical functioning in critical care: Considerations for clinical practice and research. *Critical Care, 21*(1), 249. doi:10.1186/s13054-017-1827-6

Paternoster, R., Jaynes, C., & Wilson, T. (2017). Rational choice theory and interest in the "fortune of others". *Journal of Research in Crime and Delinquency, 54*(6), 847–868. doi:10.1177/0022427817707240

Patient-Centered Outcomes Research Institute. (2013). Patient centered outcomes research. Retrieved from https://www.pcori.org/research-results/patient-centered-outcomes-research

Patrick, D. L., Danis, M., Southerland, L. I., & Hong, G. (1988). Quality of life following intensive care. *Journal of General Internal Medicine, 3*(3), 218–223. doi:10.1007/bf02596335

Pattison, N., O'Gara, G., & Rattray, J. (2015). After critical care: Patient support after critical care. A mixed method longitudinal study using email interviews and questionnaires. *Intensive and Critical Care Nursing, 31*(4), 213–222. doi:10.1016/j.iccn.2014.12.002

Pfuntner, A., Wier, L., & Steiner, C. (2013). *HCUP Statistical Brief #16*. Retrieved from http://www.hcup-us.ahrq.gov/reports/statbriefs/sb146.pdf

Prinjha, S., Field, K., & Rowan, K. (2009). What patients think about ICU follow-up services: A qualitative study. *Critical Care, 13*(2), 1–10. doi:10.1186/cc7769

Qualitative Approaches. (n.d.). Retrieved from http://www.cirt.gcu.edu

Quality of Life. (n.d.). Retrieved from http://www.dictionary.com

Rattray, J. (2014). Life after critical illness: An overview. *Journal of Clinical Nursing, 23*(5-6), 623–633. doi:10.1111/jocn.12379

Reinhard, S., Kassner, E., Houser, A., Ujvari, K., Mollica, R., & Hendrickson, L. (2014). Retrieved from http://www.longtermscorecard.org/publications

Richardson, A., Addington-Hall, J., Amir, Z., Foster, C., Stark, D., Armes, J., . . . Sharpe, M. (2011). Knowledge, ignorance and priorities for research in key areas of cancer survivorship: Findings from a scoping review. *British Journal of Cancer, 105 Suppl 1*, S82–94. doi:10.1038/bjc.2011.425

Richardson, A. E., Morton, R. P., & Broadbent, E. A. (2016). Changes over time in head and neck cancer patients' and caregivers' illness perceptions and relationships with quality of life. *Psychology & Health, 31*(10), 1203–1219. doi:10.1080/08870446.2016.1203686

Robinson, O. (2014). Sampling in interview-based qualitative research: A theoretical and practical guide. *Qualitative Research in Psychology, 11*, 25–41. doi:10.1080/14780887.2013.801543

Ruhl, A. P., Huang, M., Colantuoni, E., Lord, R. K., Dinglas, V. D., Chong, A., . . . Needham, D. M. (2017). Healthcare resource use and costs in long-term survivors of acute respiratory distress syndrome: A 5-year longitudinal cohort study. *Critical Care Medicine, 45*(2), 196–204. doi:10.1097/CCM.0000000000002088

Safar, P., & Grenvik, A. (1977). Organization and physician education in critical care medicine. *Anesthesiology, 47*(2), 82–95. doi:10.1097/00000542-197708000-00002

Savel, R. H., & Munro, C. L. (2017). Quiet the mind: Mindfulness, meditation, and the search for inner peace. *American Journal of Critical Care, 26*(6), 433–436. doi:10.4037/ajcc2017914

Schaller, S. J., Anstey, M., Blobner, M., Edrich, T., Grabitz, S. D., Gradwohl-Matis, I., . . . International Early, S.-g. M. R. I. (2016). Early, goal-directed mobilisation in the surgical intensive care unit: A randomised controlled trial. *Lancet, 388*(10052), 1377–1388. doi:10.1016/S0140-6736(16)31637-3

Schnittker, J., & Bacak, V. (2014). The increasing predictive validity of self-rated health. *PLoS One, 9*(1), e84933. doi:10.1371/journal.pone.0084933

Schweickert, W. D., Pohlman, M. C., Pohlman, A. S., Nigos, C., Pawlik, A. J., Esbrook, C. L., . . . Kress, J. P. (2009). Early physical and occupational therapy in mechanically ventilated, critically ill patients: A randomised controlled trial. *Lancet, 373*(9678), 1874–1882. doi:10.1016/S0140-6736(09)60658-9

Sequelae. (n.d.). In *dictionary.com* online database. Retrieved from http://www.dictionary.com/browse/sequelae?s=t

Shelly, A. G., Prabhu, N. S., Jirange, P., Kamath, A., & Vaishali, K. (2017). Quality of life improves with individualized home-based exercises in critical care survivors. *Indian Journal of Critical Care Medicine, 21*(2), 89–93. doi:10.4103/ijccm.IJCCM_433_16

Singer, J. P., Chen, J., Katz, P. P., Blanc, P. D., Kagawa-Singer, M., & Stewart, A. L. (2015). Defining novel health-related quality of life domains in lung transplantation: A qualitative analysis. *Quality of Life Research, 24*(6), 1521–1533. doi:10.1007/s11136-014-0875-5

Skolarus, T. A., Wittmann, D., & Hawley, S. T. (2017). Enhancing prostate cancer survivorship care through self-management. *Urologic Oncology, 35*(9), 564–568. doi:10.1016/j.urolonc.2017.05.008

Spadaro, S., Capuzzo, M., Valpiani, G., Bertacchini, S., Ragazzi, R., Dalla Corte, F., . . . Volta, C. A. (2016). Fatigue in intensive care survivors one year after discharge. *Health and Quality of Life Outcomes, 14*(1), 148. doi:10.1186/s12955-016-0554-z

Swanson, R. (2013). *Theory building in applied disciplines*. San Francisco, CA: Berrett-Koehler.

Taylor, S., Bogden, R., & De Vault, M. (2016). *Qualitative Research Methods* (4th ed.). Hoboken, NJ: Wiley & Sons, Inc.

Thomas, W. (2015). *Max Weber on rationality in social action, sociological analysis, and in modern life*. Retrieved from http://www.rational-action.com/hello-world/

Turnbull, A. E., Rabiee, A., Davis, W. E., Nasser, M. F., Venna, V. R., Lolitha, R., . . . Needham, D. M. (2016). Outcome Measurement in ICU Survivorship Research From 1970 to 2013: A Scoping Review of 425 Publications. *Critical Care Medicine, 44*(7), 1267–1277. doi:10.1097/CCM.0000000000001651

Turnbull, A. E., Sepulveda, K. A., Dinglas, V. D., Chessare, C. M., Bingham, C. O.,… & Needham, D. M. (2017). Core Domains for Clinical Research in Acute Respiratory Failure Survivors: An international modified Delphi consensus study. *Critical Care Medicine, 45*(6), 1001–1010. doi:10.1097/CCM.0000000000002435

van Sluisveld, N., Bakhshi-Raiez, F., de Keizer, N., Holman, R., Wester, G., Wollersheim, H., . . . Zegers, M. (2017). Variation in rates of ICU readmissions and post-ICU in-hospital mortality and their association with ICU discharge practices. *British Medical Center Health Services Research, 17*(1), 281–290. doi:10.1186/s12913-017-2234-z

Wade, D., Mouncey, P., Richards-Bell, A., Wulff, J., Harrison, D, Sadique, Z., Grieve, R., . . .Rowan, K. (2019). Effect of a nurse-led preventive psychological intervention on symptoms of posttraumatic stress disorder among critically ill patients. *Journal of American Medical Association*, 321(7), 665–675. doi:10.1001/jama.2019.0073

Walker, W., Wright, J., Danjoux, G., Howell, S. J., Martin, D., & Bonner, S. (2015). Project Post Intensive Care eXercise (PIX): A qualitative exploration of intensive care unit survivors' perceptions of quality of life post-discharge and experience of exercise rehabilitation. *Journal of Intensive Care Society, 16*(1), 37–44. doi:10.1177/1751143714554896

World Health Organization. (2018). WHOQOL: Measuring Quality of Life. Retrieved from http://www.who.int/healthinfo/survey/whoqol-qualityoflife/en/

Wu, J. R., Lennie, T. A., Frazier, S. K., & Moser, D. K. (2016). Health-Related Quality of Life, Functional Status, and Cardiac Event-Free Survival in Patients With Heart Failure. *Journal of Cardiovascular Nursing, 31*(3), 236–244. doi:10.1097/JCN.0000000000000248

Wu, D., Lowery, P., & Dongsong, Z. (2015). Patient compliance behavior in a mobile healthcare system: An integration of theories of rational choice and planned behavior. As presented in the International Conference on System Sciences, Hawaii.

Wu, S., Wang, R., Zhao, Y., Ma, X., Wu, M., Yan, X., & He, J. (2013). The relationship between self-rated health and objective health status: A population-based study. *BioMedCentral Public Health, 13*, 320-325. doi:10.1186/1471-2458-13–320

Wunsch, H., Guerra, C., Barnato, A. E., Angus, D. C., Li, G., & Linde-Zwirble, W. T. (2010). Three-year outcomes for Medicare beneficiaries who survive intensive care. *JAMA, 303*(9), 849–856. doi:10.1001/jama.2010.216

Zheng, Z., Yabroff, K. R., Guy, G. P., Jr., Han, X., Li, C., Banegas, M. P., . . . Jemal, A. (2016). Annual medical expenditure and productivity loss among colorectal, female breast, and prostate cancer survivors in the United States. *Journal of the National Cancer Institute, 108*(5). doi:10.1093/jnci/djv382

Zimmerman, J. E., Kramer, A. A., & Knaus, W. A. (2013). Changes in hospital mortality for United States intensive care unit admissions from 1988 to 2012. *Critical Care, 17*(2), R81, 1–9. doi:10.1186/cc1269

Appendix A: Recruitment Flier

Have you recently been a patient in the Intensive Care Unit (ICU)?

Would you like to participate in a research study dedicated to understanding Quality of Life and the recovery process after your hospitalization?

Participants will be*:

- **Over age 18**
- **Within 18 months of ICU discharge**
- **Mechanical Ventilation for 48 hours**
- **Speak and read English**

*Participation is Voluntary

Please contact XYZ

This study is being conducted for PhD dissertation completion
through Walden University
Please take this flier home

Appendix B: Screening Tool

Hello. My name is Michelle McMoon, and I am a Doctoral candidate at Walden University. My dissertation research is on the perceptions of critical illness survivor quality of life and the resources available for recovery. This will be a phenomenological study, meaning, the phenomenon of survival will be explored through the experience of the survivor. Thank you for being willing to talk to me about your experience as a survivor, your quality of life, and your experience with recovery and resources for recovery, since your hospitalization. Please understand, I do not have, nor plan to have, access to your personal health information from your hospitalization. Before the study questions begin, I will ask a few basic questions to gain better understanding of similarities amongst people in the study.

The interview will take approximately 60 minutes. There are no wrong answers to the questions. The questions are structured as open-ended so that you can be as candid as you prefer. If at any time a question makes you feel uncomfortable you may choose not to answer. It is my intention to gain insight into your experience so that the health care community and policy makers can better understand how to provide resources for critical illness survivors.

The comments you provide are confidential, and I won't use your name in any description or summary I write. I will record our conversation to help ensure my notes are accurate. My research assistant and I are the only people with access to these recordings. According to my University's policy, these recordings will be kept in a locked location and then destroyed by fire after five years. Do I have your permission to record? Do you have any questions before we begin?

Demographic data collection

1. Have you been re-admitted to any hospital since your ICU stay?
2. What race do you associate yourself most closely with?
3. What is your education level?
    a. High school or less
    b. High school graduate
    c. Some college
    d. College graduate
    e. Advanced level education above undergraduate college
4. Are you married?
5. Where did you live prior to your ICU admission?
    a. where do you live now?
6. Did you work full-time prior to your ICU admission?
    a. Are you still full-time employed at same job?

Appendix C: Interview Guide

RQ1: What are the issues important to preserve quality of life from the perspective of critical illness survivors?

1. How would you define the phrase “Quality of life,” what would you include?
2. How has your stay in ICU affected your QOL following discharge?
3. Please describe components you feel are important to preserve your QOL
    a. How do you feel physically now, and since your ICU stay?
    b. How, if at all, has your physical health changed since your ICU stay (physical health examples: walking, moving, eating, standing, stairs, etc.)
    c. How would you describe your social interactions now, (i.e. family interactions, what do you do for fun)?
    d. Have you noticed any changes in your thinking or memory? If yes, tell me more about that
    e. Have you had trouble focusing, planning things, or with your attention? If yes, tell me more about that
4. How, if at all, have your goals or life plans changed since being in the hospital?

RQ2: How do survivors of critical illness describe rehabilitative services after discharge?

1. Were you prepared by the staff for the aftercare needs you would require after discharge from the ICU?
    a. If yes, what information was given and by whom

   b. If no, what would you have wanted to know

2. How have you been doing since you came home from the hospital?
   a. Can you walk me through the timeline of your recovery after the hospital?
      i. If needed: What was it like when you were first discharged from the hospital?
      ii. If needed: what is it like now?
3. Please provide some comments about the aftercare you received or would have liked to receive?
   a. Transitions- Were the transitions between facilities / home coordinated (i.e. did you feel that the staff in the hospital spoke directly with the staff at the facility you went to or used)
   b. Ease of access- Can you describe what services you used and how easy it was to coordinate these services when you left the hospital? (i.e. Long term care, nursing home, skilled care, or home care; informal caregiver like your family)
   c. Choice- Were you (or your family) involved in the choice of discharge setting
   d. Insurance/payment- Please describe the interaction you or your family had with your insurance company or payment planning for the services you needed. Who paid for the services you needed (i.e. long-term care, home health care, family care).

        i. Describe how involved your insurance plan was in these service coverages?

4. Can you describe the timing of your rehabilitative services?
    a. Were the supports you received at the time you needed them?
5. Were these supports appropriate (at the right level for you at the time you received them)
    a. If so, can you describe how you received therapies – physical, psychological? Did you use any community supports?
    b. If not, how could timing have been improved?
6. If you were designing a rehabilitation program for patients who have been in the ICU, what would you include?