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Critical Illness Survivors' Perceptions of Their Recovery: An Interpretive Phenomenological Inquiry

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CRITICAL ILLNESS SURVIVORS' PERCEPTIONS OF THEIR RECOVERY:
AN INTERPRETIVE PHENOMENOLOGICAL INQUIRY

by

Kelly Calkins

A Dissertation Submitted in
Partial Fulfillment of the
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ABSTRACT

CRITICAL ILLNESS SURVIVORS' PERCEPTIONS OF THEIR RECOVERY: AN INTERPRETIVE PHENOMENOLOGICAL INQUIRY

by

Kelly Calkins

The University of Wisconsin Milwaukee, 2018
Under the Supervision of Professor Peninnah Kako, PhD, RN, FNP-BC

Surviving critical illness with its physical, cognitive, and psychosocial morbidities is a growing clinical and research challenge and an important public health concern. Currently, there are few interventions for survivors of critical illness after hospital discharge. Potential interventions include rehabilitation services, Intensive Care Unit (ICU) diaries and ICU follow-up clinics, however, most survivors do not have access to these post-hospital interventions.

The purpose of this study is to gain a better understanding of how critical illness survivors experience their recovery, interventions they use, and what they perceive as facilitators and barriers to their recovery. A better understanding of these factors, as reported by critical illness survivors, may lead to identification and development of interventions that can be more broadly implemented in the community setting.

This multi-site study was guided by interpretive phenomenology, using semi-structured interviews. Purposive sampling was used to identify study participants from six different ICUs. Eighteen participants were recruited for the study. Interpretive phenomenological analysis (IPA) was used to analyze interview transcripts. Six major themes emerged from the interviews; *Experiences of Recovery*, *Self-Managing Recovery*, *Following Recommendations*, *Support*, *Barriers to Recovery*, and *Unmet Needs*.

Major findings of this study included participants' reports of unmet needs of mental health and psychological recovery that were not addressed by healthcare providers. In addition,

participants also lacked appropriate knowledge of what to expect during their recovery, which contributed to frustration and anxiety.

Findings from this study have implications for nursing practice, education, and research. Nurses are in a unique position to help patients cope with their emotions prior to discharge and provide them with anticipatory guidance once they are discharged. Carefully planned discharge should include a discussion of barriers that critical illness survivors may encounter once they are discharged and also include guidance on how to problem solve those challenges.

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CHAPTER 1: INTRODUCTION

Chapter One includes the background and significance of the study, statement of the problem, purpose and specific aims, assumptions, definition of terms, and chapter summary.

Background and Significance

The Society of Critical Care Medicine (SCCM) estimates that each year more than 5.7 million patients in the United States will be admitted to an Intensive Care Unit (ICU) (Society of Critical Care Medicine Statistics, Retrieved October 24, 2018). Improvements in the treatment of critically ill patients have advanced so that an increasing number of patients are surviving to discharge. Historically, the management of patients in the ICU focused on survival. However, due to the reduction in mortality rates it is imperative that the care of critically ill patients also focus on the goals of long-term health, wellness, and optimal functioning (Elliott et al., 2014; Needham, Davidson & Cohen, 2012).

Patients in the ICU are at increased risk of complications and can experience multiple acute, often overwhelming recurrent stressors. These stressors and adverse events can affect patients long after they are discharged. The ICU environment can involve experiences and treatments including painful procedures, difficulty breathing, mechanical ventilation, limited ability to communicate, vasopressors, sedation, delusions, and hallucinations (Davidson, Harvey, Bemis-Dougherty, Smith, & Hopkins, 2013; Kiekkas, Theodorakopoulou, Spyrtos, & Baltopoulos, 2010; Jones et al., 2010) that may contribute to complications. Distressing components of an ICU stay also include social isolation, tense atmosphere, lack of privacy and control, and sleep deprivation (Gruber, 2008).

It is increasingly recognized that ICU survivors suffer important long-term complications that are commonly underestimated by ICU practitioners (Oeyen, Vandijck, Benoit, Annemans &

Decruyenaere, 2010). Approximately 75% of ICU survivors experience problems in multiple aspects of life, including physical functioning, mental health, work issues, and limitations of activities of daily living, such as eating, bathing, grooming, toileting and transferring (Griffiths, Barber, Cuthbertson, & Young, 2006). The persistence of physical and mental health symptoms contributes to decreased quality of life and long-term survival (Needham et al., 2012).

Many ICU survivors report limitations in physical function, which is slow to improve (Scruth, 2014). Critically ill patients are often subject to prolonged immobilization. This can lead to neuromuscular weakness and subsequent impairment of physical function lasting for months to years after discharge from the ICU (Desai, Laim, & Needham, 2011; Dowdy, Eid, Dennison, 2006; Needham et al., 2012).

One third of ICU survivors develop persistent and ongoing cognitive dysfunction (Scruth, 2014). Long-term cognitive impairment following critical illness has dramatic effects on patients' ability to function autonomously (Brummel et al., 2012). Cognitive impairments may adversely impact the quality of life, ability to return to work at previously established levels, and ability to function effectively in emotional and interpersonal domains (Hopkins & Jackson, 2009). Former ICU patients have reported slow mental processing, difficulty remembering appointments, impaired visual and spatial ability, impulsivity, learning problems, difficulty concentrating, shortened attention span, and decreased reaction time (Gruber, 2008).

Negative emotions associated with an ICU stay can last for months to years after an ICU discharge. After leaving an ICU, patients may experience psychological or emotional effects, including depression, anxiety or tension, loss of control and self-esteem, loneliness, isolation, amnesia, persistent and vivid dreams, hallucinations, or delusions (Gruber, 2008). The stress and

negative emotions have both immediate and long-term effects on ICU survivors' psychological and emotional well-being.

Survivors of critical illness experience multidimensional compromise during their recovery (Needham et al., 2012), making recovery challenging. The unique assortment of complex problems that can occur during recovery often require specialized and individualized support to enable recovery (Ewens, Chapman, Tulloch & Hendricks, 2013). Post-ICU impairments are a major burden for survivors, families, and for the health care system. Burdens include increased rates of institutionalization in nursing homes and rehabilitation units, frequent repeat hospitalizations, and other increased healthcare utilization (Cheung et al., 2006; Unroe et al., 2010). Early intervention and treatment is critical to the long-term adjustment and subsequent recovery of patients post-critical illness.

Situating the Researcher

In phenomenological research, developing an understanding of how one's personal experiences impact the research is crucial. The researcher for this study has worked in critical care for many years. Over those years, she has seen an increase in patients surviving critical illness. During this time, she has developed an interest in the long-term outcomes of these survivors. The researcher has paid particular attention to the support that has been given to the patient's physical function while in the hospital and the lack of cognitive and psychosocial support provided to patients. This has increased her interest in survivor's recovery from their critical illness, including physical, cognitive and psychosocial outcomes. She is also interested in the interventions and support available to them after discharge from the hospital.

During her doctoral coursework and research pilot study, the researcher has had the opportunity to interview critical illness survivors about their perceptions of their life following

their critical illness. The pilot study also looked at the support they have received and the coping skills they utilized during and after their critical illness. These experiences have increased her interest in survivors' recovery and fueled a desire to gain a greater understanding of the phenomenon of critical illness survivor experiences of recovery after discharge from the hospital.

Problem Statement

Surviving critical illness, along with its physical, cognitive, and psychological morbidities is a growing clinical and research challenge (Iwashyna, 2010), as well as a public health concern (Davidson et al., 2013). Increased numbers of critical illness survivors create new challenges for understanding and addressing survivorship among the critically ill. Currently, there are limited interventions and support available for survivors of critical illness after discharge from the hospital.

It is well documented in the literature that more patients are surviving critical illness and a large percentage of survivors go on to suffer negative complications. However, it remains unclear what survivors are doing to facilitate their recovery once they are discharged home from the hospital. Evidence of interventions such as rehabilitation, Intensive Care Unit (ICU) diaries, and Intensive Care Unit (ICU) follow-up clinics exists in the literature. Unfortunately, these interventions are not available to a majority of survivors.

The current level of discharge planning and communication with survivors, families, and clinicians is inadequate given the magnitude of post-ICU impairments. It is not known what these survivors experience as barriers to recovery. A better understanding of these factors, as reported by survivors, may lead to the identification and development of interventions that can be more broadly implemented in the community setting. This knowledge will enable nurses to provide better support to critical illness survivors.

Purpose and Specific Aims

The purpose of this study was to gain a better understanding of how critical illness survivors experience their recovery, the interventions they use and what they perceive as facilitators and barriers to their recovery. Having a better understanding of patients' experiences during their recovery, interventions utilized and how survivors perceived these interventions worked, will help health care providers gain greater insight into potential interventions. Discovering what survivors perceive to be barriers to their recovery will help health care providers develop interventions to better support them and improve long-term outcomes.

Research Questions

The following research questions guided this study:

- 1) How do critical illness survivors describe their experiences with recovery after discharge from the hospital?
- 2) What interventions have critical illness survivors utilized to assist in their recovery after discharge from the hospital?
- 3) What do critical illness survivors perceive as barriers to recovery from their critical illness once discharged home from the hospital?
- 4) What are critical illness survivors doing to overcome these barriers?

Assumptions

Assumptions for this study were made in several ways such as personal assumptions, assumptions in the method, patient selection, individual, and transcribed interviews.

Personal

It is assumed that some survivors that do not have access to post-hospital interventions must be initiating their own interventions to assist in their recovery. It is also assumed that survivors encounter barriers and challenges to their recovery.

Method

Little is known about what critical illness survivors do to facilitate their recovery. Therefore, it is assumed that a qualitative study would be the best method to study this phenomenon.

Patient Selection

Patients who were in the ICU for three days or more and required mechanical ventilation were selected for this study. According to the literature, these patients are at greater risk for developing negative complications during their recovery. Therefore, it is assumed that these survivors may perceive their recovery differently than critical illness survivors that were in the ICU for less than three days and did not require mechanical ventilation.

Individual Interviews

It is assumed that survivors interviewed for this study responded honestly and accurately to interview questions about their experiences during recovery, the interventions they utilized during their recovery, and barriers they experienced during recovery.

Transcribed Interviews

It is assumed that the transcribed interview will be an accurate account of each survivor's statements and maintain the survivors' intended meanings.

Definition of Terms

Intensive Care Unit

A hospital unit in which patients requiring close monitoring and intensive care are treated. An ICU contains highly technical and sophisticated monitoring devices and equipment and is staffed by personnel trained to deliver critical care. A large tertiary care facility usually has separate units specifically designed for the intensive care of adults, infants, children, or newborns.

Critical Illness

A life-threatening condition, which can be caused by a disease, medical condition, or trauma, in which death is possible or imminent.

Critical Illness Survivor

A critical illness survivor is an individual who has survived a critical illness and a stay in the ICU. For this study, I included critical illness survivors who were hospitalized in the ICU for three or more days and required mechanical ventilation.

Post Intensive Care Syndrome (PICS)

The term “post-intensive care syndrome” is preferred by the Society of Critical Care Medicine to describe the new or worsening impairment of physical, cognitive, or mental health status arising after a critical illness and persisting beyond acute care hospitalization (Needham et al., 2012). These impairments can last for weeks, months, or even years (Elliott et al., 2014). PICS is a concept used to define the phenomenon of unpleasant physical, cognitive and psychosocial symptoms that occur as a result of critical illness and ICU care.

Interventions

For the purpose of this study, interventions are any action a survivor takes to facilitate their recovery or to cope with survival from their critical illness and stay in the ICU. This can be an action the survivor develops independently or in collaboration with a provider.

Sedation

Sedation is a medication that is given to induce a state of being relaxed, sleepy, or to decrease agitation in order for patients to tolerate medical procedures. For the purpose of this study, sedation is a medication that is given by continuous IV infusion.

APACHE II Score

The APACHE II score is a severity of disease classification system. It uses a point score (0-71) based upon initial values of 12 routine physiological measurements, age, and previous health status to provide a general measure of severity of disease. This is calculated with values from the first 24 hours of an ICU stay (Knows, Draper & Wagner, 1985).

Summary

In this introductory chapter, the researcher has established that more patients are surviving critical illness. Of these survivors, many suffer negative outcomes including functional, cognitive, and/or psychosocial deficits. Although it is known more people are surviving critical illness and many of them suffer negative consequences, further research is needed on what survivors are doing to assist in their recovery. There are some interventions discussed in the literature to assist critical illness survivors with their recovery, such as physical rehabilitation, ICU diaries, and post ICU clinics; however, these interventions are not available to most survivors. It is important to discover what critical illness survivors do to facilitate their recovery when they do not have access to these interventions. Having a better understanding of what these survivors do to assist in their recovery - and whether it is helpful - will help healthcare providers develop interventions to improve the long-term outcomes of critical illness survivors.

In Chapter Two, the literature on survivors' perceptions of recovery from their critical illness is reviewed. Further elaboration on the negative outcomes suffered by critical illness survivors - specifically PICS - and current interventions utilized by critical illness survivors are also discussed.

CHAPTER II: REVIEW OF LITERATURE

A review of the literature on the recovery of critical illness survivors is presented in this chapter. The chapter begins with a discussion on the challenges of caring for survivors of critical illness. Next, critical illness survivors' experiences and outcomes are discussed. A discussion on current interventions for critical illness survivors follows. Finally, significant gaps in the literature are summarized.

For this review, articles were selected from the National Library of Medicine's database including PubMed, the Cumulative Index of Nursing and Allied Health Literature (CINAHL), and MEDLINE. Articles were included to inform this review if they were written in English, peer-reviewed, and included adults over the age of 18. Retrieved articles were further screened to include those that pertained to critical illness survivors, survivor experiences, survivor outcomes or interventions to support survivor's recovery. Articles were also hand-searched from the references of key articles. Selected articles included qualitative and quantitative studies, meta-analysis and critical reviews. A total of 49 articles were included in the literature review.

Challenges of Caring for Survivors of Critical Illness

Improvements in the treatment of critically ill patients have advanced so that an increasing number of patients are surviving to discharge. Historically, the management of patients in the ICU focused on survival (Bemis-Dougherty & Smith, 2013). However, due to a reduction in mortality rates, it is imperative that the care of critically ill patients also focus on the goal of long-term health, wellness, and optimal functioning (Elliott et al., 2014; Needham et al., 2012). Surviving an episode of critical illness is just the beginning; survivors have a wide-range of needs for post-hospital support (Kress & Herridge, 2012).

It is increasingly recognized that ICU survivors suffer important long-term complications, which are usually underestimated by ICU practitioners (Oeyen et al., 2010). Approximately 75% of ICU survivors experience problems in multiple aspects of life, including physical functioning, mental health, work issues, and limitations of everyday life (Griffiths, Barber, Cuthbertson, & Young, 2006). Early intervention and treatment is critical to the long-term adjustment and subsequent recovery of patients post critical illness. Recovery from critical illness is often complicated and difficult to navigate. Barriers to recovery include lack of access to care and services, lack of information about services offered, and lack of care coordination and treatment (Leonard, 2012). Due to the high costs and long-term effects of an ICU stay, this critical health care problem requires an urgent response from legislators and health policy experts.

Survivorship is a major issue for critical care providers (Needham, Feldman, & Kho, 2011). Increased numbers of critical illness survivors create new challenges for understanding and addressing survivorship among the critically ill. Discharge from the ICU no longer marks recovery from critical illness. Survivors of a critical illness display a unique assortment of atypical and complex problems which often require specialized and individualized support to enable recovery (Ewens et al., 2013). In addition to the ongoing impact on survivors, post-ICU impairments are a major burden for families and for the health care system, with increased rates of institutionalization, frequent repeat hospitalizations, and other increased healthcare utilization (Cheung et al., 2006; Unroe et al., 2010).

Once the patient is discharged from the hospital, the enormous financial burden and impact of critical care continue. Up to 50% of ICU survivors require long-term care or inpatient rehabilitation that may not be covered by insurance (Harvey, 2012). The Study to Understand

Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) found that 29% became financially impaired because they were unable to return back to work, and 20% reported that their family members had to leave their jobs in order to care for them (Hopkins & Girard, 2012). Therefore, recovery from a critical illness places a huge financial burden on the patient, family, healthcare system, and society.

Clinicians are continually challenged to meet the emotional, psychological, and physical needs of survivors as they progress along the care continuum from the ICU to recovery. Follow-up of survivors of critical illness after hospital discharge differs within and across healthcare systems. The primary care physician is often the primary point of contact. With the breadth of a primary care provider's clinical practice and the small percentage of their patients being critical illness survivors, most primary care providers are not familiar with the challenges that critical illness survivors may experience (Aitken & Marshall, 2015).

The National Institute for Health and Care Excellence (NICE) published clinical guidelines in 2009 for the rehabilitation of patients after critical illness. These guidelines recommend clinical assessment of the critical care patient at the earliest opportunity to determine the risk of developing physical and psychological morbidity. At-risk patients should have individualized short and medium-term goals set. These goals are from a multidisciplinary team consisting of physiotherapy, occupational therapy, speech and language therapy, psychology, and nutritional support. These goals should be reviewed regularly not only in the hospital but after discharge as well. Patients should be seen again in 2-3 months at a specific critical care follow-up clinic, where any new physical or psychological problems can be addressed, and referrals made to specialists (National Institute for Health and Care Excellence, 2009).

In the United Kingdom, 30% of National Health Service locations have a post-ICU clinic designed to address patient outcomes after critical illness (Iwashyna & Netzer, 2012). However, in the United States, both post-ICU and post-hospital discharge care rests primarily with clinicians other than the intensivist who provided the critical care (Myers, Smith, Allen, & Kaplan, 2016). Although critical care follow-up services are being run in some hospitals, this is not universal. Many patients are followed-up by surgical or medical teams that may not recognize the complexity of the issues. A high degree of vigilance is necessary to avoid overlooking these issues and to ensure that patients are referred to the appropriate specialists (Cantlay, 20015).

This dissertation study focused on critical illness survivors' recovery after discharge from the hospital; however, in order to fully understand the complications that many critical illness survivors suffer after discharge, it is imperative that one understands the risk factors that critical illness survivors are exposed to while they are in the ICU.

Risk Factors for Developing Complications

For critically ill patients, the ICU environment can involve stressful experiences including social isolation, tense atmosphere, lack of privacy and control, sleep deprivation (Gruber, 2008), painful procedures, physical or traumatic injury (Kelly & McKinley, 2009), physical deconditioning and inadequate nutrition (Krumholz, 2013), immobility (Agard et al., 2014), difficulty breathing, mechanical ventilation, limited ability to communicate, sedation, delusions, hallucinations, and delirium (Agard, Lonmorg, Tonnesen & Egerond, 2014; Jones et al., 2010). There are numerous risk factors which cannot be modified, such as the unexpected nature of the hospitalization and feelings of mortality that can have an impact on patients and their recovery (Kelly & McKinley, 2009). The patient's personality, external situations, life

experiences, personal challenges, and preexisting anxiety may also influence their ability to handle stress (Myers et al., 2016). Baseline cognitive impairments, depression, anxiety, PTSD and female sex have also been shown to increase the incidence of complications after survival of a critical illness (Agard et al., 2014).

Critical Illness Survivors' Outcomes

Survivors of critical illness experience multidimensional compromise during recovery (Needham, Davidson, & Cohen, 2012), making recovery challenging. Many ICU patients struggle to recover following critical illness and may be left with physical, cognitive and psychological problems, which have a negative impact on their quality of life (Jones, 2014). The term Post-Intensive Care Syndrome (PICS) is preferred by the Society of Critical Care Medicine to describe the new or worsening impairments in physical, cognitive, or mental health status arising after critical illness and persisting beyond acute care hospitalization (Needham, Davidson, & Cohen, 2012). This syndrome is a constellation of complications that may follow a stay in an ICU. The persistence of symptoms including reduced ability to perform activities of daily living, reduced capacity for ambulation, depression, posttraumatic stress syndrome, and anxiety contributes to an adverse effect on the individual's quality of life and long-term survival (Bemis-Dougherty & Smith, 2013).

Of the 5.7 million patients who receive critical care in the United States each year, it is estimated that 50% to 70% will acquire PICS (Myers, Smith, Allen, & Kaplan, 2016). PICS frequently persists for months or even years. It restricts activities of daily living, reduces quality of life, and decreases the ability to return to former employment (Hopkins & Girard, 2012; Kress & Herridge, 2012). For this review of literature, the researcher will discuss in greater detail complications that comprise PICS in three domains: physical, cognitive, and psychosocial.

Physical

Post-ICU physical function impairments are a major health burden for survivors, their families, and the health care system because of the associated high rates of institutionalization, frequent repeat hospitalizations and other increased health care use (Needham et al., 2011).

Patients hospitalized for an acute illness or injuries are at risk for loss of function, not only in the short term but also extending well past the original acute care hospitalization (Herridge, 2011).

Following a critical illness, physical functioning may be impaired for up to five years (Calvo-Ayala, Khan, Farber, Ely, & Boustani, 2013).

Recovery from muscle mass loss, weakness, and critical illness polyneuropathies can take several months after discharge and can further complicate physical recovery (Jones, 2014).

Patients who require prolonged mechanical ventilation in the ICU were found to have persisting limitations performing daily activities due to loss of muscle strength and general physical fitness (Davidson et al, 2016; Van Der Schaaf et al, 2009). These persistent physical problems prevent many ICU survivors from returning to work (Fonsmark & Rsendahl-Nielsen, 2015; Van Der Schaaf et al., 2009).

Cognitive

Altered cognitive function is an important negative outcome of critical illness. Evidence suggests that neurotransmitter abnormalities and occult diffuse brain injury are important pathophysiologic mechanisms that underlie cognitive dysfunction associated with critical illness (Granja, Anaro, Dias & Costa-Pereira, 2012). Acute Respiratory Distress Syndrome (ARDS) survivors found activities that require executive function, memory, attention or quick mental processing speed to be very difficult or impossible (Hopkins et al, 1999, 2005) and impaired cognitive function can affect anywhere from 30% to 80% of patients discharged from the ICU during the first year (Davidson et al, 2016; Granja et al, 2012). Risk factors for developing

cognitive dysfunction include age, sepsis, delirium, delusions or hallucinations in the ICU (Fonsmark & Rosendahl-Nielsen, 2015; Granja et al, 2012 and Jones, 2014). While improvements in cognitive function occur during the first year, impairments can persist. Seventy percent of ARDS survivors had neurocognitive compromise at hospital discharge, 45% at one year and 47% at two years (Hopkins et al, 1999, 2005).

Psychological

Reported incidence and severity of anxiety and depression in ICU survivors vary across studies most likely due to methodological differences (Granja et al., 2012). Prevalence of these problems are difficult to establish due to a number of methodological reasons that include use of self-report questionnaires, number of different questionnaires used and variation in administration and timing (Rattray, 2013). However, it is estimated that about 30% of critical illness survivors will suffer from anxiety, and 10-50% will suffer from PTSD (Davidson et al., 2014, Harvey, 2012), and 28% will suffer from depression (Wade et al., 2012) post-ICU discharge.

Psychological problems such as anxiety, depression and post-traumatic stress disorder are common and have a negative impact on survivors' ability to engage in rehabilitation after ICU discharge (Jones, 2014). Survivors who present with moderate levels of anxiety during critical illness may be at a higher risk for developing symptoms of anxiety, depression, and PTSD during recovery than those with low or no anxiety (Castillo, 2013). Many survivors struggle with psychological problems such as severe anxiety, depression, and false memories (Abdalahim & Zeilani, 2014; Alpers, Helseth & Begbom, 2012). Survivors also report on-going sleep disturbances, nightmares and flashbacks (Fonsmark & Rosendahl-Nielsen, 2015). Others discuss their symptoms of PTSD such as withdrawal, panic, nightmares, flashbacks, and fear when "flashing back" to their ICU stay (Afarid et al., 2012; Alpers et al., 2012; Deacon, 2012; Prescott

& Iwahyna 2014). All of these negative emotional responses can hinder the survivors' recovery process.

Critical Illness Survivor Evaluations

ICU survivors identify a need to interact with other ICU survivors and validate that their experience is common for someone who had been through a critical illness (Deacon, 2012).

Survivors feel unsure of what to expect during their recovery, causing fear and worry (Czerwonka et al., 2014). These studies support the fact that survivors need detailed information and reassurance about the progress of their illness. Many survivors struggled for independence and focused on overcoming everyday physical and functional challenges (Argard et al., 2012) so they could participate in normal activities of daily life (Agard et al., 2012; Deacon, 2012; Locsin & Kongsuwan, 2013).

According to a study by Czerwonka and colleagues (2014) the informational needs of survivors changed over time. The information that they needed while hospitalized differed from what they needed once they were at home. Survivors' questions about their experiences and medical conditions persisted after returning home and they were uncertain where to turn for answers. Many survivors commented that there was little continuity in the healthcare professionals who provided care to them across the various care environments (ICU, general ward and home) (Czerwonka et al., 2014). Survivors felt that the level of attention from healthcare providers was highest in the ICU and lowest in the community, where many participants discussed receiving no follow-up from a healthcare professional. Survivors who did not receive any follow-up services mentioned that physical and sometimes psychological symptoms emerged only after they returned home (Czerwonka et al., 2014). At one to two years post-ICU discharge, many survivors desired more contact with the health care team. They

wanted the opportunity to ask questions and get feedback on how recovery was going (Czerwonka et al., 2014).

This section has reviewed the literature on critical illness survivors, the risk factors associated with the development of complications, survivors of critical illness outcomes and experiences. Next, what is currently known about interventions for survivors of critical illness after discharge from the hospital will be discussed.

Post-ICU Interventions

Although post-hospital discharge interventions are limited, there is research on rehabilitation, ICU diaries, and ICU follow-up clinics. Each of these interventions will be discussed in detail.

Rehabilitation

One intervention for survivors of critical illness is rehabilitation. The studies evaluating post-hospital discharge rehabilitation following a critical illness have shown varying results. The varying results could be related to the fact that there is not a standard for providing rehabilitation after hospital discharge. It is unclear what components should be included in post-hospital discharge rehabilitation. There is great variation in programs, the timing of the programs, and the assessment of the program.

A systematic review found that the only effective interventions in improving long-term physical function were exercise and physical therapy (Calvo-Ayala et al., 2013). Findings of the systematic review also indicated that the earlier the interventions are started, the better the outcomes may be. Many of the effective interventions discussed in the review began in ICU or the hospital and continued post-ICU. Some studies showed significant improvement in physical functioning as well as improvement in mental well-being (Batterman et al., 2014; McWilliams et al., 2012). Although there were improvements in physical functioning, it was not always

sustained (Batterman et al., 2014). In contrast, other studies showed there were no improved outcomes, such as improvements in physical function and health-related quality of life, in the intervention group (group with physical rehabilitation) compared to the standard care group (Cuthbertson et al., 2009; Elliot et al., 2011).

Intensive Care Unit Diaries

Another strategy which has attracted significant interest has been the implementation of patient diaries in ICU. Intensive care unit diaries, also known as intensive care diaries, photo diaries, or prospective diaries, are initiated by intensive care nurses and kept by nurses or co-authored by other healthcare providers and relatives (Jones, Capuzzo, & Flaatten, 2006; Roulin et al., 2007). Diaries complement the hospital chart by offering a description of the illness trajectory in everyday language with a compassionate tone, rather than the emotionally neutral and high technology vernacular (Egerod & Christensen, 2009; Egerod & Christensen, 2010). Patient diaries have been described as a low-cost intervention to reduce post-discharge symptoms of post-traumatic stress disorder (PTSD), anxiety and depression (Jones et al., 2009; Knowles & Tarrier, 2009; Rubson, 2008).

Patient diaries help ICU survivors who have difficulty in constructing a narrative of their experience because of sedation and severity of illness, which may have detrimental effects on their recovery (Jones, Griffiths, Humphris, & Skirrow, 2001; Jones et al., 2007). Patient diaries in ICU have been used in Denmark, Sweden, and Norway starting in 1984 and have since been seen in other European countries (Egerod, Schwartz-Nielsen, Hansen, & Laerkner, 2007). In Sweden and the United Kingdom (UK), diaries have been used as a debriefing instrument to help patients deal with symptoms of post-traumatic stress disorder (Backman & Walther, 2001; Jones et al., 2007). In Norway, patient diaries are viewed as an expression of caring rather than therapy (Storli, 2001). In Denmark, diaries have been handed over without systematic follow-

up, while in the UK, diaries have been an integral part of an aftercare program (Jones, Humphris, & Griffiths, 1998). Norwegian hospitals provide follow-up and require that each diary is approved before they are given to the patient (Storli & Lind, 2009; Storli, 2001).

Diaries may contribute to the reduction in survivors' memory gaps and enable them to comprehend the severity of their illness and set realistic goals to achieve meaningful recovery (Egerod & Christensen, 2009; Knowles & Tarrier, 2009; Roulin, Hurst, & Spring, 2007). Survivors have reported diaries helped them to recover the time they had lost, provided a sense of being loved when reading their family's diary entries, legitimized their experience, and enabled them to come to terms with the severity of their illness (Combe, 2005; Egerod & Bagger, 2010; Ewens et al., 2013). Diaries can be effective in aiding psychological recovery and reducing new-onset PTSD (Jones et al., 2010). Survivors' feedback about their diary was very positive with the majority reading it a number of times over the two-month follow-up period.

Researchers have concluded that reading the diaries may yield an effect similar to Cognitive Behavioral Therapy (CBT). Like CBT, the diaries help survivors change the way they think about their illness and enable the reaction of autobiographical memory (Ewens et al., 2013). In one study, participants agreed that the diary alone provided incomplete information and did not necessarily bring back memories, but did help complete their story. The diaries might help post-ICU patients to gradually construct or reconstruct their own illness narrative, which is pieced together by their fragmented memory, the diary, pictures, the hospital chart and accounts from family and friends (Egerod & Bagger, 2010).

The ICU diary is an innovative, low-cost intervention. ICU diaries are prevalent in Scandinavia and parts of Europe, but not elsewhere (Ewens, Hendricks & Sundin, 2014).

Implementation and ongoing use of diaries and international guidelines to clarify the intervention

have been proposed, but not yet mentioned in the National Institute for Health and Care Excellence (NICE) guidelines (National Institute for Health and Care Excellence, 2009). Further investigation is warranted to explore the potential benefits of diaries for survivors and improve the evidence base, which is currently insufficient to inform practice (Ewens et al., 2014).

ICU Follow-Up Clinics

Another intervention to improve the quality of life of ICU survivors is the implementation of ICU follow-up clinics. These clinics were pioneered in a UK center in the 1990s as a treatment and support modality for ICU survivors (Griffiths & Jones, 2011). These clinics are usually nurse-led with or without multi-professional input, with the broad aims of screening survivors for complications and providing or referring them to specialist services as necessary (Egerod et al., 2013; Griffiths et al., 2006; Modrykamien, 2012). Although post-ICU clinics are one potential method to address these patient needs, there is currently mixed evidence on their effectiveness on patient outcomes, and funding and resourcing this type of service in the United States needs further exploration and evaluation (Elliott et al., 2014).

ICU follow-up services are available in some healthcare systems, but the extent to which these are available worldwide is variable. The follow-up clinics for ICU survivors are mainly offered in European countries: ten were located in the United Kingdom, three in Sweden, two in Norway, two in the United States, one in Scotland, and one in Portugal (Lasiter, Oles, Mundell, London, & Khan, 2016). Studies on ICU follow-up services frequently describe patient-reported experiences of critical illness but are silent on other important outcomes such as cognitive function, hospital readmission and cost-effectiveness (Aitken & Marshall, 2015).

ICU follow-up clinics are appreciated by the survivors. They experienced the follow-up as valuable in the processing of their feelings and emotions. It provided some survivors with the

tools to move on from their experiences of being a patient in the ICU by providing support and an opportunity to discuss and understand their experiences (Harladsson et al., 2015; Jensen et al., 2016).

There is no one accepted model for the delivery of ICU follow-up clinics. They may be led by a nurse, doctor or a combination of both. A primary nurse-led approach is the most common (Griffiths et al., 2006). There currently are many limitations in the delivery of post-ICU care. First, there is a lack of supporting evidence showing its effectiveness. Next, financial constraints may limit the number of services provided. Lack of source funding may represent a key limiting aspect, as ICU clinics are not always in the general ICU budget. These issues may preclude further opportunities for the creation and development of these types of clinics (Modrekamien, 2012).

Gaps in the Literature

The current level of discharge planning and communication with survivors, families, and clinicians is inadequate given our current knowledge of the magnitude of post-ICU impairments. Critical illness survivors' primary care providers, who are usually providing care after ICU discharge, are often not prepared to provide and coordinate care for critical illness survivors (Needham et al., 2012). Uncertainty exists regarding the best approaches and timing for providing post-ICU care. Knowledge about health issues during early phases of recovery after hospital discharge is emerging, yet, is still very limited. Follow-up times in many studies vary from several months to years and may not offer information about problems encountered during the early stages of the recovery process (Kelly & McKinley, 2010).

Currently, after-care for critical illness survivors is very limited. Although we know there are some interventions for critical illness survivors such as rehabilitation, ICU diaries, and

ICU follow-up clinics, most critical care survivors do not have access to these interventions post-hospital discharge. We currently don't know what critical illness survivors who are discharged from the hospital and do not have access to formal interventions are doing to facilitate their recovery. Also, we do not know what these survivors experience as barriers to their recovery. An understanding of what critical illness survivors are doing once they are discharged home from the hospital to facilitate their recovery will help guide improvement of existing interventions and support development of novel interventions.

Summary

The burden of critical illness on ICU survivors is a substantial, under-recognized public health problem with major implications for patients, families and the healthcare system. Critical illness survivors present excess mortality and prolonged physical and neuropsychological morbidity with different stages of severity for years after discharge from intensive care (Granja, Amaro, Dias, & Costa-Pereira, 2012). Follow-up of survivors of critical illness after hospital discharge differs within and across health systems. This study filled the gap by finding out from critical illness survivors, what they are doing once they are discharged home from the hospital to facilitate their recovery as well as what challenges and barriers they encountered. Chapter three will describe the research methodology used to explore critical illness survivors' perceptions of their recovery after discharge from the hospital.

CHAPTER III: METHODOLOGY

The study's research methodology is described in this chapter. First, the philosophy which informs the study and provides a rationale for the research approach will be discussed. Next, setting and sample selection are described. This followed by an overview of the research design, human subject protections, recruitment, setting and sample, data collection methods, data management, and analysis. Finally, scientific rigor of the research is presented.

Philosophical Underpinnings

This cross-sectional, qualitative dissertation study used phenomenology as the underlying framework. The researcher will discuss briefly how this philosophy relates to this study. To adequately study critical illness survivors' experiences during recovery, it is imperative to use a lens that allows the researcher to understand survivors' perspectives.

Phenomenology

Phenomenology is a strong philosophical tradition developed by Husserl and Heidegger. It is an approach to thinking about the life and the lived experiences of individuals. Phenomenology refers to an individual's perception of the meaning of an event, as opposed to the event as it exists externally to that person (Rodgers, 2005). According to Rodgers (2005), the philosophy of phenomenology emphasizes the interplay between objects and perceptions, aspects of reality are contributed by and thus shaped by the human experience and that human experience is in turn shaped by the events and objects. People shape their realities, and these realities shape the people in return (Rodgers, 2005).

Phenomenology is focused on "the things themselves" describing the totality of the "lived experience" of an individual regarding some situation or occurrence (Rodgers, 2005, p. 78). To a phenomenologist, there would be little, if any, benefit to studying critical illness recovery as an

object of experience, but rather critical illness recovery can be understood by examining it as it is lived, complete with the elements contributed by the individual's situation or history.

Phenomenology allows for the exploration of the contextual and unique aspects of all situations. It explores recovery as people live through it or with it. Since phenomenology refers to a person's perceptions of the meaning of an event as opposed to the event as it exists externally to that person, phenomenology is an appropriate lens for creating knowledge on a survivor's recovery from a critical illness.

The two main types of phenomenological approaches evident in the nursing literature include descriptive (eidetic) phenomenology and interpretive (hermeneutic) phenomenology (Cohen & Omery, 1994). The primary difference between the descriptive and interpretive approaches is in how the findings are generated and used to develop knowledge (Lopez & Willis, 2004).

Descriptive Phenomenology

Husserl's (1970) philosophical ideas about how science should be conducted gave rise to the descriptive phenomenological approach to inquiry (Cohen, 1987). Husserl believed that subjective information should be important to a scientist seeking to understand human motivation because human actions are influenced by what people perceive to be real. He also believed that a scientific approach was needed to bring out the essential components of the lived experiences specific to a group of people (Lopez & Willis, 2004).

An important component of Husserlian phenomenology is a belief that it is essential for researchers to shed all prior personal knowledge in order to be able to grasp the essential lived experiences of those being studied (Lopez & Willis, 2004). The goal of the researcher is to obtain transcendental subjectivity. According to Lopez and Willis (2004), transcendental subjectivity is when the impact of the researcher on the inquiry is constantly assessed, and biases

or preconceptions are neutralized so that they do not influence the study. Descriptive phenomenologists have proposed specific techniques to accomplish minimizing bias, such as bracketing. Bracketing involves the researcher setting aside ideas, preconceptions, and personal knowledge when listening to and reflecting upon the lived experiences of participants (Drew, 1999).

An assumption underlying Husserl's approach is that there are features to any lived experience that are common to all persons who have the experience. These are referred to as universal essences, or eidetic structures (Natanson, 1973). For the description of the lived experiences to be considered a science, commonalities in the experiences of the participants must be identified, so that a generalized description is possible (Lopez & Willis, 2004).

Interpretive Phenomenology

Heidegger modified and built on the work of Husserl, challenging some of his assumptions about how phenomenology could guide meaningful inquiry. Heidegger's philosophical ideas gave rise to interpretive (hermeneutic) phenomenology. A central tenet of interpretive phenomenology is that the relation of the individual to his lifeworld should be the focus of phenomenological inquiry (Cohen, 1987). The term lifeworld expresses the idea that individuals' realities are invariably influenced by the world in which they live. He believed that humans could not abstract themselves from the world. Therefore, it is not the pure content of human subjectivity that is the focus of a hermeneutic inquiry, but rather, what the individual's narrative implies about what he or she experiences every day (Lopez & Willis, 2004).

Another philosophical assumption underlying the interpretive phenomenological approach is that presuppositions or expert knowledge on the part of the researcher are valuable guides to inquiry and, in fact, make the inquiry a meaningful undertaking. Heidegger (1962) emphasized that it is impossible to rid the mind of the background of understandings that has led

the researcher to consider a topic worthy of research in the first place (Koch, 1995). It is a researcher's knowledge of the phenomenon that leads him or her to the realization that research is needed in an area that is understudied and leads to specific ideas about how the inquiry needs to proceed (Lopez & Willis, 2004).

Interpretive hermeneutic phenomenology goes beyond mere description of core concepts to look for meanings embedded in common life practices. These meanings are not always apparent to participants but can be discovered from the narratives produced by them (Lopez & Willis, 2004). Interpretive phenomenology was the theoretical approach that the researcher used to guide the study on survivors of critical illness experiences of recovery after discharge from the hospital.

Design and Rationale of Study

This cross-sectional, qualitative study utilized a phenomenological approach to examine critical illness survivors' experiences of recovery from a critical illness, barriers encountered during recovery, and interventions survivors utilized to assist in their recovery after discharge home from the hospital.

Qualitative approaches are considered appropriate when investigating phenomena with limited prior research (Joubish, Khurram, Ahmed, Fatima, & Haider, 2011). Although research has been conducted on survivors' experiences, survivor outcomes, and interventions, such as rehabilitation, ICU diaries, and ICU follow-up clinics, little research has been conducted regarding what survivors, who do not have access to the above interventions, have done to assist in their recovery. This researcher anticipated that the challenges survivors encountered are related to their experiences, thus researching survivors' lived experiences of recovery through interpretive phenomenology was important to identify ways that health care providers can

support survivors during recovery. To achieve an understanding of the problem, the following research questions were designed to guide this study:

- 1) How do critical illness survivors describe their experiences of recovery from a critical illness?
- 2) What interventions have critical illness survivors utilized to assist in recovery after discharge from the hospital?
- 3) What do critical illness survivors perceive as barriers to recovery from a critical illness once discharged home from the hospital?
- 4) What have critical illness survivors tried to help them overcome these barriers?

Qualitative methods permit inquiry into selected issues in great depth with attention to detail. The study had a narrow focus as the aim was on individual critical illness survivors' experiences. Data was gathered from in-depth interviews with critical illness survivors. Interviews were conducted at least four weeks after the survivor was discharged from the hospital.

Procedures

Human Subjects Protection

A reliance agreement was obtained between the four participating hospitals as well as the University of Wisconsin Milwaukee to rely on the Medical College of Wisconsin (MCW) to be the institution of record for the research study. The study was approved by the Institutional Review Board at MCW (Appendix B). Leaders from each of the units provided their approval to post flyers and for the researcher to identify potential participants from their units (Appendix).

Setting

Participants were recruited from six different ICUs at four different hospitals.

Participants were recruited from the following sites: a 12-bed general ICU at a community

hospital, a 20-bed general ICU at a regional hospital, a 24-bed general ICU at an urban hospital, and a 26-bed medical ICU at a large level one trauma and academic hospital. After approximately five months of recruitment, only six interviews were completed. Sites were therefore expanded to include a 24-bed surgical ICU and 20-bed cardiovascular ICU at the level one trauma and academic hospital.

Prior to the start of the study, an email was sent out to staff explaining the study and the study inclusion and exclusion criteria used to identify potential participants. A study flyer (Appendix D) was posted in the nursing breakroom as a reminder of the study and recruitment flyers (Appendix D) were posted in the family waiting rooms.

Sample

Purposive sampling was used based on the following inclusion and exclusion criteria to identify study participants from each of the six ICUs. Participants were eligible if they were over the age of 18, spoke and understood English, in the ICU for three or more days, and required mechanical ventilation for at least 24 hours. These criteria were selected as the investigators only speak and understand English and participants who are hospitalized in the ICU for three or more days and require mechanical ventilation are at increased risk for developing negative consequences from their critical illness and ICU stay. Survivors were excluded if they had a cognitive impairment that made them unable to consent and subsequently participate in an interview. Any potential participants that were discharged to a post-acute institution (e.g. rehab or nursing home) or had altered mental status at the time of the scheduled interview were not included in the study.

Screening occurred two to three times per week in each ICU. Staffing boards were reviewed, and the researcher spoke to staff to identify potential participants and verify participant eligibility. Once potential participants were identified, potential participants or their family

members were approached to discuss the study. Potential participants or their family members were given a permission to contact form (Appendix E). Any questions were answered and understanding of the form was verified. If the potential participant (or their family member), were interested in being contacted after discharge regarding the study they signed a permission to contact form and provided contact information. Potential participants with completed permission to contact forms were contacted via their preferred contact method approximately two weeks after discharge to discuss the study and schedule an interview for at least four weeks after hospital discharge.

Early in the study, there was difficulty reaching potential participants who signed permission to contact forms, so an amendment was approved to allow a study reminder email to those potential participants who provided email addresses as a method to contact. After the first few phone calls to potential participants, several participants preferred to be interviewed over the phone. An IRB amendment was submitted and approved that allowed telephone interviews in addition to in-person interviews. Early in the study, it became apparent that many of the survivors who agreed to participate in the study did not remember the appointment for their interview. The researcher then started to make a reminder phone call and/or email to ensure the participants remembered and were still available for the interview.

Data Collection

Data were collected using individual semi-structured interviews. Most of the interviews took place in the survivor's home (11 interviews), five interviews were over the phone, one interview took place in a private room at the hospital after a follow-up doctor appointment, and one interview took place in an office at a church where the survivor worked. Each location was chosen by the survivor to ensure they would be comfortable in the environment.

Field notes were taken during and after each interview, and the researcher kept a reflective journal throughout the data collection and data analysis phases of the study. The reflective journal was used to keep a record of the researcher's experiences, opinions, thoughts, and feelings during the study. The interview began with an overview of the study and discussion of informed consent (Appendix F) which included consent for the interviews to be digitally recorded. Dates of hospitalization were collected from the participants' medical record. The survivors were assured that the information collected would be kept confidential and that they could refuse to answer any questions. Consent was obtained after the participants could verbalize the purpose of the study and what they would be asked to do if they chose to participate. One survivor decided that she did not want to participate after reviewing the consent.

At in-person interviews, the survivors signed and were given a copy of the consent form, which contained a phone number for the crisis hotline in case they were having difficulty after the interview. Phone interviews required verbal consent. If possible, the consent was sent via email prior to the interview for their review. If that was not possible, the consent was read to them over the phone, and verbal consent was obtained. For all phone interviews, the consent was sent to participants in the mail after the interview.

Survivors completed a demographic form (Appendix H) prior to the interview. The form included age, race/ethnicity, marital status, if they lived alone, the highest level of education, employment status, and religious preference. The interview was semi-structured (Appendix G). The researcher used probes and follow-questions to expand on their responses and direct the interview to ensure the aims of the study were met.

After approximately 14 interviews, data saturation began to occur. Five additional participants were interviewed to ensure that data saturation was achieved. Data saturation occurs

when little new information can be added with additional participants (Polit & Beck, 2012). The interview recordings were transcribed by the researcher and a transcriptionist. The researcher corrected errors in the transcripts by reading along with the recording.

After completion of all interviews a retrospective chart review (Appendix G) was completed on all participants. Data retrieved from the chart included days in the ICU, days on the ventilator, whether participants received vasopressors and sedations. For this study sedation use meant the participant received a continuous drip of IV sedation medication. The APACHE II score was calculated on each participant. The APACHE II score is a severity of disease classification system. It uses a point score (range 0-7) based on values of 12 routine physiologic measurements, age and previous health status to provide a general measure of severity of disease (Knows, Draper & Wagner. 1985).

Data Analysis

Interpretive phenomenological analysis (IPA) was used to analyze interview transcripts. IPA analyzes in detail how participants perceive and make sense of things which are happening to them. It draws upon the fundamental principles of phenomenology, hermeneutics, and idiography. The approach involves a detailed examination of the participant's lifeworld; it attempts to explore personal experience and is concerned with an individual's personal perception or account of an object or event, as opposed to an attempt to produce an objective statement of the object or event itself (Smith & Osborn, 2012).

IPA is a dynamic process with an active role of the researcher. The researcher influences the extent to which they get access to the participant's experience and how, through interpretive activity, they will make sense of the participant's personal world (Pietkiewicz & Smith, 2012). Access to the participant's experience depends upon and is complicated by the researcher's own

conceptions. These are needed in order to make sense of that other personal world through a process of interpretative activity. Thus, a two-stage interpretation process, or double hermeneutic, is involved. The participants are trying to make sense of their world, and the researcher is trying to make sense of the participants trying to make sense of their world (Smith & Osborn, 2012).

IPA also relies upon idiography. Idiography refers to an in-depth analysis of single cases and examining individual perspectives of study participants, in their unique contexts. The fundamental principle of the idiographic approach is to explore every single case before producing general statements.

While it is possible to obtain data suitable for IPA analysis in a number of ways, probably the best way to collect data for an IPA study is through the semi-structured interviews (Smith & Osborn, 2012). This form of interviewing allows the researcher and participant to engage in a dialogue whereby initial questions are modified in the light of the participants' responses and the investigator is able to probe interesting and important areas which arise (Smith & Osborn, 2012).

Data collection and analysis occurred simultaneously. Analysis began immediately after each interview. This allows for more details to be captured as well as adaption of future interviews based on what was learned from the previous ones. The analysis in IPA requires sustained engagement with the text and a process of interpretation. IPA is not a prescriptive methodology; there is no single, definitive way to perform IPA. It is meant to be adapted to one's own way of working as well as to the topic being investigated (Smith & Osborn, 2012). Outlined below are the IPA steps that guided the analysis.

All interviews were transcribed and checked for accuracy. The data were analyzed on paper and use of an electronic qualitative database (NVivo). The transcripts were read numerous

times to gain a better understanding of survivors' responses. Open coding began with highlighting salient statements and adding researcher comments/notes in the margins. Each section of salient statements was then assigned a code. The codes were grouped into subthemes and subthemes were placed into themes. The researcher then listed the themes and looked for connections between the themes. During this process, the researcher was able to see that many of the themes were similar and that salient statements could be placed in more than one theme. These salient statements were temporarily placed in both themes until it was determined which theme was the most appropriate.

A table of themes was developed. At this time, some of the themes were dropped because they did not fit or they were not rich in evidence. This process was repeated with each interview. Once all transcripts were analyzed final table of themes was generated. Each transcription was reviewed numerous times to ensure the salient responses of the survivors were captured.

Scientific Rigor

According to Lincoln and Guba (1985) trustworthiness of a research study is important in evaluating its worth. Trustworthiness involves establishing credibility, transferability, dependability, and confirmability.

Credibility

Credibility involves confidence in the 'truth' of the finding. The accurate and truthful depiction of participants' lived experience was achieved through prolonged engagement. To increase credibility, the researcher engaged in prolonged engagement and invested a significant amount of time to develop a true understanding of what it is like to recover from a critical illness. Another way to ensure credibility is to conduct peer debriefing. Some authors advocate using an external colleague or 'expert' to support the credibility of the findings (Appleton 1995, Burnard 2002, Casey 2007). More than half of the transcripts were given to the researcher's major

professor and content expert to review, pull salient excerpts and code. The researcher then met with both committee members to review the data and ensure they were finding the same salient excerpts and codes. Developed themes were shared with the researcher's major professor and content expert for validation and accuracy.

Transferability

Transferability refers to showing that the findings have application in other contexts. A rich and vigorous presentation of the findings, with appropriate quotations enhances transferability (Hraneheim & Lundman 2004). The responsibility of the researcher lies in providing detailed descriptions for the reader to make informed decisions about the transferability of the findings to their specific contexts (Bogdan & Biklen, 2003; Firestone 1993; Lincoln & Guba, 1985; McKee 2004; Stake 1995). In order to assist with transferability, the researcher included detailed descriptions from the participants to support the study findings and themes.

Dependability

Rigor can be achieved by outlining the decisions made throughout the research process to provide a rationale for the methodological and interpretive judgements by the researcher (Houghton & Murphy, 2012). Dependability refers to showing that the findings are consistent and could be repeated. To address this issue, the researcher completed an inquiry audit where the researcher's major professor and content expert audited and examined the process and the products of the study. To assess the trustworthiness of a study, it is necessary to examine the process by which the end-product has been achieved and present faithful descriptions recognizable to the readers (Horsburgh 2003; Rubin and Rubin 1995).

Confirmability

Confirmability is the degree of neutrality or the extent to which the findings of a study are shaped by the respondents and not researcher bias, motivation or interest. The researcher developed a reflexive journal to assist with confirmability. The reflexivity journal highlights how the researcher's history and personal interests brought them to the research and demonstrates how the theoretical perspective affected data collection and research (Toffoli & Rudge 2006; Van Maanen 1991). The researcher used a reflexive journal to document the research process, methodological decisions and rationale, logistics of the study, and reflections on the study including values and feelings during the study.

Ethical Considerations

The primary ethical considerations for this study were confidentiality and the sensitive nature of some of the questions. Participants were assured that they could stop the interview at any time and that they could skip any questions that they did not want to answer. They were also provided with the crisis hotline number. Participants were assured their data would be kept secure and confidential.

Summary

This chapter discussed the study's methodology, design, recruitment and data collection methods, analysis, scientific rigor, and ethical considerations. Chapter four will present the demographics data, and chapter five will present the results of interview analysis.

CHAPTER IV: DESCRIPTION OF PARTICIPANTS

In this chapter, participants' demographic data and contextual information will be presented. These data shaped the stories of recovery from their critical illnesses. Demographic descriptions include age, race, marital status, housing, education, and employment (Appendix C). ICU-specific participant descriptions include APACHE II score, days in the ICU, days on the ventilator, vasopressor and/or sedation (Appendix D). The APACHE II is a severity of disease classification system. It uses a point score (range 0 to 71) based upon initial values of 12 routine physiologic measurements, age, and previous health status to provide a general measure of severity of disease (Knows, Draper & Wagner, 1985). The narrative summary will describe a brief history of the participants' recovery experience which includes their support, challenges, and interventions.

A total of 43 permission to contact forms were completed; of those, 19 participants consented, 11 potential participants did not answer the follow-up phone call or email, seven changed their minds and no longer wanted to participate, three died, two were still hospitalized at the time of recruitment completion, and one was discharged to a rehabilitation facility. Of the 19 participants who consented and completed the interview, 18 were included in the study.

Seven participants changed their minds about participation after completing permission to contact forms. One participant was re-hospitalized at the time of scheduled interview. Another stated she was too busy with follow-up procedures and appointments and two participants declined after learning more about the study. Two participants scheduled interviews or reached out to set up an interview but did not communicate further. One participant's mother signed the permission to contact form, but the survivor did not wish to participate.

One participant was withdrawn from the study by the researcher after consent and interview completion. Consent from the participant was obtained after he verbalized the purpose and procedure of the study. However, by the end of the interview the researcher questioned the participant's competence. A few of his answers were off and he seemed to be confused. Since the researcher was not absolutely confident that the participant was competent, this interview was removed from subsequent analysis. The participant was not aware the interview was not included in the study.

Demographic Statistics

Eighteen participants were included in this study. Participants had a median age of 62 years (range 19 to 76). Most participants identified as Black/African American (56%) or White/Caucasian (44%), had completed high school (44%) or some college (22%) and were employed part-time (17%), unemployed (22%), disabled (44%) or retired (17%). Participants were married (50%), single (44%) or divorced (6%). Most participants lived with family, spouse or friend (78%), while others lived alone (22%) (Appendix I).

Participants' stay in ICU ranged from three days to 48 days with a median of 5.5 days. The ventilator days ranged from one day to 16 days with a median of four days. All participants received sedation while 74% received vasopressors. Participant APACHE II Scores ranged from seven to 32 with a median of 22 and a median predicted mortality rate of 40% (Appendix J).

Narrative Summary

This narrative summary describes a brief history of each individual participant's ICU stay and recovery experience, including their support, challenges, and interventions utilized during recovery. The contexts of the participants' ICU stays and background during recovery provided

valuable information that impacted the findings discussed in the next chapter. Participants were assigned pseudonyms to protect their privacy and ensure confidentiality. Following is a brief summary of the 18 study participants' ICU stays and recovery experiences.

Barbara

Barbara was a 62-year-old African American woman who was in the ICU for four days. She was grateful to be alive and planned to live life to the fullest. Barbara had completed some college and was disabled. She lived alone but had support from physical therapists, occupational therapists, and health aids that came into her home several days a week to provide therapies. She described her support as “excellent”. Her son and grandson also come over to her house and do things for her.

When discussing her recovery, she described numerous challenges such as transportation to church, the store, and appointments. Barbara had required numerous appointments and surgery on her leg since she was discharged from the hospital. She also described having difficulty with her memory and remembering “daily things”. Barbara reported feeling depressed during her recovery; describing that her mood had been happy and sad.

Barbara was taking an active role in her recovery by participating in therapy, exercising, getting her nails and hair done, and going out shopping when she could. To help with her memory she was using memory books. Barbara relied on her faith, prayer, medications, and talking to someone to help with her mood during her recovery. She also had a nurse that was working on obtaining transportation for her to get to church and to go out shopping.

Chuck

Chuck, a 62-year-old African American male, lived at home with his wife. He had been in the ICU for six days. Chuck had completed high school and was retired. He described his

recovery as painful, frightening, and slow. He still had a T-tube drain in place during the interview, which was causing him pain, and a Peripherally Inserted Central Catheter (PICC) line for antibiotics. His interview was completed as quickly as possible since he had been at the hospital for hours already due to a doctor appointment and he was tired and in pain. Challenges to his recovery included frequent doctor appointments, sometimes two to three times a week, 40lb weight loss, and feeling weak and tired.

Chuck had support from his wife, family and visiting nurses who assisted with his care during the day while his wife was at work. The visiting nurses cared for his wound, PICC line, T-tube drain, and gave him his IV antibiotics. He tried to be as active as he could with the pain and weakness, but he needed frequent naps.

Matt

Matt was a 48-year-old white male who was in the ICU for nine days. He lived with his wife and children. Matt had his Master's degree and was on disability. He described his recovery as being "up and down." Matt discussed his weakness, fatigue, and shortness of breath, which often caused him the need to sit down. He described feelings of uncertainty with his shortness of breath. He was being worked up for the shortness of breath, but the doctors had not found a cause yet. Matt felt that he was a little bit moodier than usual during his recovery.

He reported having support from his wife, family, and friends, which he described as "outstanding." Friends had helped with his young children and made meals for his family. During his recovery, Matt described wanting to "return to normal." For him returning to normal included getting out of the house and going to his children's basketball games. To help assist with his recovery, Matt participated in therapy, exercising, and going to a counselor to address

his mood. One of the issues that Matt described as being the most difficult part of his recovery was managing his expectations of recovery, i.e., not knowing what to expect.

Bill

Bill, a 61-year-old Caucasian male, had been in the ICU for ten days. He was single and lived alone. Bill had a Master's degree, worked part time at his church, and was able to go back to work two weeks after discharge. He stated that although he "lives alone, he is not alone." He had support from his family and his church family. Bill described his recovery as "perfect"; he was gaining stamina and strength every single day.

One of the biggest challenges that Bill talked about was not having insurance. Since he did not have insurance, he was unable to get the recommended follow-up care. Although he was unable to have the recommended follow-up care, Bill described being blessed that he was receiving help from the financial office at the hospital to assist with his hospital bills and medications. Bill also discussed his unmet needs of finding a spiritual advisor. He described being depressed and feeling sad. Bill was struggling with why he survived and wanted to talk to a spiritual advisor about his experience. To assist in his recovery, Bill talked about following the doctor's orders, eating better, taking naps, and lots of prayers.

Sue

Sue was a 57-year-old African American female. She was in the ICU for three days. Sue had completed high school and was disabled. She currently lived with her daughter and her daughter's family. Before this hospitalization, she lived with her niece who frequently did not pay their rent and consequently had been evicted from their home several times over the last few months. Sue reported that she was getting evicted the day she was admitted to the hospital. When asked about her recovery, Sue stated "I'm doing ok, better than it has been."

Sue reported support from her family, especially her daughter. She described feeling like she was a burden for her daughter, who was young and needed to go and have fun.

Challenges to her recovery included the need for money for gas to get to her frequent appointments. To overcome her transportation challenges, she started taking cabs to get to her appointments. To help with her recovery, Sue was trying to reduce her stress, take naps, and pray.

Marg

Marg, a 65-year-old Caucasian female, was in the ICU for six days. Marg completed some college, was disabled, and lived with her significant other. She said she was scared to come home from the hospital. When asked about her recovery, she described it as “great, I have visiting nurses as many times a week as they feel I needed them.” Marg was sent home with a wound vac and PICC line. The visiting nurses helped care for the wound vac and gave her IV antibiotics. She also had support from her family and friends. Her daughter helped coordinate her care and set up her medications.

When Marg discussed her recovery, she discussed difficulty with her memory, frequent appointments, care-coordination between doctors, medication changes, and feeling sad, especially about her wound vac. To assist with her recovery, Marg took notes and kept a calendar of appointments. She relied on her family to help take her to appointments and set up her medications. Marg took naps, went shopping with her family, and to the casino with friends to cope during her recovery.

Doug

Doug was a 56-year-old Caucasian male. He was in the ICU for 48 days. Doug completed high school, was employed as a valet part-time, and was back to work at the time of

the interview. Doug described his recovery as “good.” He was single and lived with his father, who helped support him during his recovery. Doug was discharged home with a feeding tube and needed help caring for the tube. His dad helped flush the tube, put the feedings in the bag, and change the bags.

Besides the challenge with his feeding tube, Doug also had difficulty keeping track of all of his appointments and struggled with weakness and his breathing. To help keep track of his appointments Doug kept a calendar and relied on help from his dad. Doug felt like he recovered faster once he was at home because he could get up and walk whenever he wanted. In the hospital, he wasn’t allowed to walk by himself and would have to wait for staff to take him for a walk. Doug was prescribed an inhaler to help with his breathing.

Tosha

Tosha, a 50-year-old African American woman, was in the ICU for ten days. She was single, lived with her two children, completed some college and was disabled. While talking about her recovery, Tosha talked a lot about her mood and how thankful she was to be alive. She also discussed how her life had changed since her illness and that she didn’t do drugs anymore. Her support primarily came from her children, “they helped with everything.”

Challenges to her recovery included re-hospitalization for her hyperglycemia, pain, weakness, and memory. Tosha had difficulty remembering all of her appointments, so she would tell her daughter to help her remember. She also would read, meditate and talk to others to help assist with her recovery.

William

William was a 50-year-old African American male and was in the ICU for three days. William was married. He was visiting with his aunt out of town when he became hospitalized.

William completed high school and was unemployed. When talking about his recovery, he said it was “rough and complicated” due to the pain and numerous hospitalizations. William had recently had a heart attack and open-heart surgery before he had come to visit his aunt. While he was visiting his aunt, he developed a reaction to a medication requiring another hospitalization.

William was very thankful to be alive and discussed a strong relationship with God. Some of his biggest challenges included pain, weakness, transportation to his appointments, and affording his care. He was prescribed rehabilitation but was unable to afford it, so he quit going. Instead, he walked on the treadmill at home and took walks around the house. William was working with a nurse from the hospital to set up transportation to and from his appointments. William said he was following the doctor’s recommendations, took walks, napped, and relied on God to keep him on the “right track.”

Jim

Jim, a 63-year-old African American male, was in the ICU for three days. He lived with his wife, completed some high school and was disabled. When asked about his recovery, Jim said “it’s been good. I’ve got some other medical things to deal with, but it’s been good”.

Jim’s wife was with him during his interview. They reported problems with Jim’s memory since his hospitalization. During the time of the interview, they had set up his grandson to be with him during the day while his wife was at work to make sure he took his medications and followed his fluid and diet restrictions. Their grandson was going to be moving out, so Jim’s wife talked about quitting her job to care for him. Some of Jim’s challenges to his recovery included hospital readmission, poor memory, weakness, shortness of breath, and feeling afraid to do things for fear of becoming short of breath. To help overcome these barriers, Jim relied on

support and help from his family. He would also take notes to help him remember his medications, and he would take naps.

Patricia

Patricia was a 76-year-old African American woman. She was in the ICU for four days. Patricia recently moved into a new apartment by herself, before that she lived with her sister. She completed high school and was retired. Patricia described her recovery as “pretty good” and she was “rapidly getting better.”

When she described her recovery, she discussed her need for assistance. Her daughter has seven children so she was busy and couldn't help her much. She had some close friends but did not like to ask them for help. Specifically, she stated needing help with transportation, grocery shopping, and laundry. Patricia no longer drove, so she needed someone to drive her to her appointments and to the store. In addition to needing a ride to the store, she did not have the energy to walk around the store.

Jennifer

Jennifer, a 19-year-old African American woman, was in the ICU for six days. She had completed some college and was back to work part-time at the time of the interview. She discussed difficulty going back to work after her hospital stay because of weakness. Jennifer lived at home with her mother. When asked about her recovery, she said it was difficult because of pain, weakness, difficulty with her vision, and her mood.

Jennifer reported support from her family and friends, but when she was in pain she got “agitated” and “didn't want to be bothered.” She described being withdrawn, “I just stay to myself. I go to my room, don't talk to nobody and listen to music.” To help with her recovery, Jennifer described taking a hot shower or bath, relaxing, or laying down. Approximately a week

after the interview, Jennifer texted the researcher and asked for help with her mood and physical recovery. The researcher encouraged her to contact her primary care provider or the crisis hotline, per the study protocol.

Steve

Steve was a 71-year-old Caucasian male. He was in the ICU for five days. Steve was married, lived with his wife, had his Doctorate, and was unemployed. His wife was present for the interview. When asked about his recovery, Steve described being “happy” to be alive. He reported his recovery was slower than he cared for it to be, but it was faster than the doctors told him it would be. Steve struggled with weakness, weight loss, and muscle loss. He took lots of naps and was able to pay for a rehab program and personal trainer to assist with his recovery.

Another issue that Steve struggled with was his memory. He had difficulty remembering things, such as his medications. To assist with his memory, he would write things down. Steve and his wife also described a “disconnect” with information about what services would be provided at home and what services they actually received. In the hospital, Steve signed up for visiting nurses, however, once he was home a representative called him, discovered he wasn’t home-bound, and told him he didn’t qualify for the program. Steve and his wife were looking forward to having a nurse check on him once he was home and were disappointed when they found out a nurse would not be coming.

Mike

Mike, a 65-year-old Caucasian male, was in the ICU for five days. He was married, lived with his wife, had his Bachelor’s degree, and was unemployed. When asked about his recovery, Mike described it as difficult and long. He discussed his difficulty with mobility and impaired judgement. He required assistance and felt like his wife went back to work too soon. Mike

struggled with physical mobility and described how he adapted his daily activities to accommodate his limitations. For example, he couldn't go upstairs for a while because of weakness and instability, so he washed his hair and body in the sink downstairs.

One of the biggest things that Mike talked in depth about was his psychological struggles, stating “the other stuff, more psychological, mental type stuff hangs on.” He described the many interventions he had to assist with his recovery, such as physical therapy, occupational therapy, and dietician, but more important, he discussed what he was missing during his recovery, which was someone to talk to about his mental condition.

To assist with his recovery Mike, researched and read articles about critical illness recovery, wrote notes to help with his poor memory, read the newspaper, and did cross word puzzles to stimulate himself mentally. Also, he talked to friends and family about his recovery, and went to the gym to exercise. Although he took an active part in his recovery, he still struggled physically and mentally. He reported having support from his wife, family, and friends, yet still felt unsupported with his mental recovery.

Daryl

Daryl was a 64-year-old African American male. He was in the ICU for five days. Daryl was married, lived with his wife, completed high school, and was disabled. When asked about his recovery, Daryl stated his recovery has been slow. He struggled with both the physical and emotional recovery. Daryl described having “a lot of family problems, and deaths.” The stress related to his family had affected his physical health, “when I get upset and stressed” that triggers an asthma attack. Daryl states he knows he needs to let his family take care of their own problems and focus on his health, but he is struggling with how to change something he had done

his whole life. This hospitalization was a wake-up call for him; he came to the realization that he could die and that he needs to take care of himself.

Other challenges that Daryl has encountered included numerous hospitalizations, his memory, feeling stressed and guilty about his family, and feeling depressed because of his physical limitations. To assist with these challenges, Daryl reported support from his wife, he wrote notes to help with his memory, joined a gym, followed the doctor's recommendations, went to his appointments, and lost weight.

Bob

Bob, a 46-year-old African American male, was in ICU for five days. He was single, he stayed with his mother or girlfriend, completed the fourth grade and was unemployed. Bob was staying with his girlfriend at the time of the interview. When asked about his recovery he stated he was "doin' good", he was exercising, up walking around and "doin' stuff." He was able to bathe and get dressed independently. However, Bob did indicate that he was having difficulty sleeping because of pain. He stated his girlfriend had helped him a lot and that he counts on her.

Deb

Deb was a 64-year-old Caucasian woman. She was in the ICU for eight days. Deb was married, lived with her husband, completed high school, and was retired. She described her ICU stay as a "very bad experience" and she had a lot of frustration regarding her hospital stay and recovery. This frustration was related to poor communication with the doctors regarding what actually happened to her and all of her follow up appointments after discharge. She stated that no one could "diagnose her."

Another source of frustration was the cost of services and medications. The doctors made her have a sleep study and get a CPAP machine that she didn't qualify for and could not

afford. Deb voiced frustration with the cost of the medications she was prescribed. She could not afford them all, so she talked to her pharmacist to decide which medications to fill.

Deb reported support from her daughter, grand-daughter, church, and neighbors. They helped with the vacuuming, made meals, and checked in on them. To assist with her recovery, she looked up information on the computer about her condition, tried to eat healthy, watched TV, sat outside and watched the birds, and talked to her husband and neighbor.

Dale

The last participant, Dale, was a 56-year-old Caucasian male. He was in ICU for 14 days. Dale was married, lived with his wife, completed his GED, and was disabled. He discussed how the experience changed his perspective on life, “it scared the heck out of me. I don’t take things for granted anymore.” Dale has seven children but did not have contact with many of them for quite some time before his ICU hospitalization. Since his hospitalization Dale states, he keeps in contact with his children, he communicates better with his family and they are all closer.

Dale’s hospitalization and recovery were complicated. He had several cardiac arrests while in the ICU which required defibrillation. Dale was sent home with a life-vest until he could have a pacemaker/defibrillator placed. He was also sent home with a feeding tube which became infected and needed to be removed.

Challenges that Dale reported were weakness, feeling dizzy, weight loss, memory issues, and, feeling edgy and grumpy. Dale participated in cardiac rehabilitation for a few weeks but then stopped. He stated he was riding bikes, walking, and being active. To assist with his recovery, he stated “I’ve done what they told me to do”, he was taking his medications and wearing his life-vest. An unmet need that he discussed was getting help with cessation of

smoking. He stated that he did really well for two weeks, but then he went back to smoking even though he knows he should not be. Dale described being scared and cautious to do things for fear of having another heart attack. That was unusual for him, he normally would jump right in, and now he stops to think as to whether or not he should do it.

Summary

In this chapter, the researcher described the demographic data, ICU data and contextual data that shaped the recovery for each of the study participants. Chapter Five will discuss the common themes of the study using participant interviews.

CHAPTER V: RESULTS

This chapter presents common themes from the participants' individual interviews. The overall aim was to elicit participants' experiences of recovery after critical illness and barriers they encountered during recovery. The interviews were semi-structured to allow the participants to direct the conversations and describe their experiences in detail. To ensure the aims of the study were met, probing questions were asked. The participants described their experiences of recovery from their critical illness, discussed what they did to facilitate their recovery and any challenges or barriers.

To address the aims of the study four open-ended questions were used: 1) How do critical illness survivors describe their experiences with recovery after discharge home from the hospital?, 2) What interventions have critical illness survivors utilized to assist in their recovery after discharge from the hospital?, 3) What do critical illness survivors perceive as barriers to recovery from their critical illness once discharged from the hospital?, and 4) What are critical illness survivors doing to overcome these barriers? Overall, six major themes emerged, *Experiences of Recovery, Self-Managing Recovery, Following Recommendations, Support, Barriers to Recovery, and Unmet Needs*. Themes in relation to the study questions are presented next. The six major themes identified as answers to the research questions were developed by analyzing, separating, and combining codes as displayed in Tables 1-3.

Research Question 1: Experiences of Recovery

The first research question was "How do critical illness survivors describe their experiences with recovery after discharge home from the hospital?" Themes were included as answers to this question if they were related to their experience of recovery. *Experiences of Recovery* was the major theme. It included how participants described their recovery from their

critical illness after discharge from the hospital. Within this major theme were the subthemes; *Physical Experiences, Emotional Experiences, Evaluation of Recovery, Uncertainty and Gaining New Perspective.*

| Experiences of Recovery | | | | |
|---|--|--|--|--|
| <p><u>Physical</u></p> <ul style="list-style-type: none"> • Weakness • Fatigue • Pain • Tired • Blurry vision | <p><u>Emotional</u></p> <ul style="list-style-type: none"> • Gratitude • Scared • Afraid • Frustration • Helpless • Loved | <p><u>Evaluation of Recovery</u></p> <ul style="list-style-type: none"> • Slow • Hard • Painful • Rough • Ups & Downs • Tough • Struggle | <p><u>Uncertainty</u></p> <ul style="list-style-type: none"> • What to expect during recovery • What to expect for rest of life | <p><u>Gaining New Perspective</u></p> <ul style="list-style-type: none"> • New outlook • Live life to the fullest • New appreciation • Aware of mortality • Happy to be alive • Second chance |

Table 1. Subthemes and examples related to experiences of recovery.

Participants described their physical and emotional experiences of recovery and the uncertainty they felt with their recovery. Many of the participants discussed the physical changes that occurred during their recovery. A majority of participants described feeling weak, tired, and unable to physically do what they were able to before they became sick. For many, it took a long time for their physical abilities to return. Participants also used feelings and emotions when describing their recovery. Many participants reported feeling scared, frustrated, helpless, paranoid, loved, and grateful. Uncertainty was also discussed by many participants. They felt uncertainty with what to expect during their recovery and the rest of their life. The following section describes the subthemes in greater detail.

Physical Experiences

When participants described their physical experiences, they discussed weakness, trouble with mobility, and how they needed assistance. Many of these participants did not expect to be

so weak or need as much help as they did which was difficult for them. The following selections described those experiences.

Weakness. Weakness was described by a majority of participants. Matt talked about how weakness was one of the hardest parts of recovery. “The hardest part is just being so weak all the time, and I was just not used to that” (Matt, 48-year-old, 9 days in ICU). Similarly, Mike talked about how the doctors prepared him to expect to be weak after a stay in the ICU but he did not expect to be as weak as he was. “They said I’d lose about 40% of the strength that I had, and I think it was at least that much because I felt frail when I got out of there compared to when I went in” (Mike, 65-year-old, 5 days in ICU).

Mobility Issues. Weakness led to difficulty with mobility for many participants. Tosha described how she experienced a fall related to her weakness. She thought she could just get up and move, but her legs were weak, and she fell. “Oh, these legs wouldn’t do nothin’, they were so weak. I’m thinkin’ I could just get up and move, and I couldn’t. I landed on the floor” (Tosha, 50-year-old, 10 days in ICU). The weakness that a majority of participants experienced affected their ability to be independent and many required assistance in order to ambulate.

Needing assistance. Mike talked about how he needed assistance during his recovery which was not something he was expecting.

Yeah, it was difficult; at first, I had trouble with mobility which I was not anticipating. But being in bed for like 10 days or whatever, um.... So I had trouble with that. I had trouble getting out of the van and getting into the house, and I needed assistance (Mike, 65-years-old, 5 days in ICU).

Emotional Experiences

Participants described a multitude of emotions during their recovery including feeling scared, afraid, helpless, depressed, and down. They were scared to go home, afraid to resume activities for fear of the return of symptoms and felt helpless since they could not do many activities they could before their illness. They felt depressed and down related to their experience.

Afraid and scared. Participants lived in fear of something going wrong with their health while at home after being discharged. For example, Marg still remembered how afraid she was to go home, “I was scared to go home, I do remember that.” (65-year-old, 6 days in ICU). Jim described being afraid to do things for fear that something bad would happen; that he would have difficulty breathing and could ruin things for others.

Well, I am afraid to do a whole lot you know... what if it's something else? What if I get short of breath? It was my brother's surprise birthday, and I don't want to screw that up, so I stayed home.” (Jim 63-year-old, 3 days in ICU)

This fear often caused avoidance and caution. For instance, Dale talked about how his wife noticed that he was being cautious at home after being discharged. He explained that he was afraid of having another heart attack.

I guess I get scared of doing things, like my wife's telling me the other day “I've never seen you so cautious.” I'm not usually cautious about anything. Normally I jump right into anything, and now I stop and try to think about it and think if I should do it or not do it (laughs) Yeah, I don't want to do anything that's gonna cause me to have another heart attack (Dale, 56-year-old, 16 days in ICU).

Helpless and frustrated. Other participants described feeling helpless and frustrated since they were not able to complete tasks and chores at home. Mike described feeling helpless and frustrated once discharged back home because he was not able to take care of chores at home like he normally did.

When I first got out, I got frustrated with things and I felt kind of helpless, especially with the stuff that I normally do. You know with the gardening and taking care of the yard and all of this, so that all got let go. That was frustrating for me and just my limitation on what I was able to do. I mean even though I wanted to do things, I just couldn't (Mike, 65-year-old, 5 days in ICU).

Depressed. Others described feeling depressed during their recovery. Barbara described having “ups and downs” during her recovery.

Well, I have been a little depressed. My mood has been happy, and then it has been sad. So, I have been on and off just like a faucet, you can turn me on, and the water runs, and you can turn me off and it just goes off (Barbara, 62-years-old, 4 days in ICU).

Evaluating Their Recovery

Many participants weighed in on how they felt their recovery was going. Some participants indicated that they were given some expectations for their recovery before being discharged from the hospital while others did not have any idea of what to expect. Participants gave diverse descriptions of their recovery as slow, long, ups and downs, and quick and fast.

Slow and long. Steve indicated that the doctors had told him to expect a long recovery. Although he was prepared for a long recovery, he still felt like his recovery was slower than he wanted it to be.

Probably slower than I would care for it to have been, or be, but also faster than, the docs warned me it would be. So I guess I'm in the middle there, which is probably not too bad (Steve, 71-years-old, 5 days in ICU).

Ups and downs. Matt described how his recovery had been up and down. He felt at first he was recovering very quickly but then had slowed down since then.

Um, kind of ups and downs; I guess I was kind of amazed how quickly after my illness I started re-bounding, but then it slowed down quite a bit. Which is the hard part because I guess the expectation is you get better and better you know, I should be expecting continuous improvement, and that hasn't been the case (Matt, 48-year-old, 9 days in ICU).

Quick and fast. In contrast, Bill described how fast his recovery was and that he has a hard time believing that his body went through that trauma.

Well, even the nurses told me in the hospital they were amazed at how fast I was recovering. For some reason, my body just recuperates really quickly. But it's kind of weird; I don't feel any ill effects. I feel as though nothing bad happened. The only reminder that I have of it [my illness] is like, the eight pill bottles on my dresser." (Bill, 61-year-old, 10 days in ICU).

Uncertainty

Many participants described uncertainty when discussing their recovery. They were unsure of what to expect during or after their recovery. For example, Mike discussed the fact that although he was out of the hospital didn't mean he was OK. He didn't know what the outcome of his recovery was going to be. "As far as I am concerned, I'm not, you know, I'm not

sure that I am out of the woods even though I am out of the hospital” (Mike, 65-year-old, 5 days in ICU).

Participants described managing their expectations during their recovery. Most of them didn't know what to expect and had come up with expectations of their own. Matt discussed having difficulty when his expectations didn't match up to what was happening with his recovery.

I think the biggest thing is managing expectations. I don't know what to expect. It's the first time I've obviously been through this, so I don't know what to expect. I just have my perceptions of what to expect, and they don't necessarily match (Matt, 48-year-old, 9 days in ICU).

Bill had resolved to living in uncertainty as he expected that his recovery would be for the rest of his life.

I certainly don't know what to expect in these remaining years that I have left, you know; the time after my recovery, which I believe will be the rest of my life. So as far as I am concerned, I am doing O.K. (Bill, 61-year-old, 10 days in ICU).

Gaining a New Perspective

Many of the participants discussed feelings of gratitude, an awareness of their mortality, a new outlook, and appreciation of being alive.

Gratitude. Barbara described her gratitude with survival and was thankful she was able to continue doing the things that she needed to. She wanted to make sure that she lived life to the fullest every day.

I thank God that I am alive, and I am able to survive and do the things that I need to do. I am just thankful that I am here to try to do that. I try to get by every day, to do the best I can with my life and to live, to live it to the fullest (Barbara, 62-year-old, 4 days in ICU).

Awareness of mortality. Participants also discussed how they were now aware of their own mortality. They had taken life for granted in the past but were now aware that they had been given a second chance at life and they were going to take advantage of that.

Before I was saved, I just lived my life, but now I'm livin' life, but I'm knowin' about life because I was almost gone. I was almost dead and to have a second chance; I'm gonna take advantage of it now (Tosha, 50-year-old, 10 days in ICU).

Other participants describe how their illness was a wake-up call for them. They had seen themselves as immortal, and now they realize they could die. "I've come to the realization that I'm, that I'm not superman and that I have my frailties just like everybody else and I could die if I don't take care of myself and so that was a wakeup call" (Daryl, 64-year-old, 5 days in ICU). Similarly, Dale talked about how his near-death experience made him realize that he could die. "I always thought I was like bullet proof and uh, you know, I found out I'm not." (Dale, 56-year-old, 16 days in ICU).

New outlook and appreciation. Participants reported that these near-death experiences have changed the outlook on life for them and caused them to not take time or people for granted anymore. They were making a point to make time for family and keep in better contact with loved ones they hadn't had contact with for a long time.

I know it scared the heck out of me. I do a lot of things now that I didn't use to. I don't take anything for granted anymore. I try to stay in contact with my kids, I got one son I didn't talk to for two years, my daughter, I don't think I talked to her for five years, I

communicate with them now, and calling them, and take time out to do that. And I think I communicate with my wife a little bit better and stuff like that. I don't get upset easy, I try to stay calm (Dale, 56-year-old, 16 days in ICU).

Deb felt the experience made her stronger by making her no longer afraid to die. After having a near death experience, she decided that when she dies, she will get to be with her family and God and that would be OK with her.

I almost feel like it made me a stronger person, in a sense that I don't know how to explain it. I'm not scared; I'm not scared about dying I guess is what I wanna say. I'm not afraid to die now. And I'll be by family and be with God, and I'm just fine with that. And I think that makes me a stronger person to accept the things I cannot change, you know (Deb, 64-year-old, 8 days in ICU).

Research Questions 2 & 4: Interventions During Recovery

Research questions two and four focused on interventions that participants used during their recovery therefore many of these themes overlapped. Since both of these questions asked what participants did to assist in their recovery, it was decided to combine these two questions for presentation of results. The second research question was "What interventions have critical illness survivors utilized to assist in their recovery after discharge from the hospital?" The fourth research question was "What are critical illness survivors doing to overcome these barriers?" Themes were determined to be answers to these questions if they were related to what participants did to help with their recovery. The three major themes are *Self-Managing Recovery*, *Following Recommendations* and *Support*. Within the major theme *Self-Managing Recovery*, are the subthemes *Medical Management*, *Adaptations to Lifestyle*, and *Seeking Normalcy*. The major theme *Support* includes the subthemes *Social Support*, *Medical Support*,

Spiritual Support, and *Self-Support*. Answers to research questions two and four included three themes: *Self-Managing Recovery*, *Following Recommendations* and *Support*. These were developed from subthemes displayed in Table 2.

| Self-Managing Recovery | Following Recommendations | Support |
|--|---|--|
| <u>Medical Management</u> <ul style="list-style-type: none"> • Frequent appointments • Medical procedures • Feeding tube • Wound Vac • PICC line • Re-hospitalization | <ul style="list-style-type: none"> • Take medications • Go to Dr. Appointments • Follow recommended diet | <u>Social Support</u> <ul style="list-style-type: none"> • Family • Friends • Church family |
| <u>Lifestyle Adaptation</u> <ul style="list-style-type: none"> • Unable to drive • Unable to climb stairs • Unable to return to work | | <u>Medical Support</u> <ul style="list-style-type: none"> • Physical Therapy • Occupational Therapy • Visiting nurses |
| <u>Seeking Normalcy</u> <ul style="list-style-type: none"> • Getting back to normal | | <u>Spiritual Support</u> <ul style="list-style-type: none"> • God • Prayer • Church |
| | | <u>Self-Support</u> <ul style="list-style-type: none"> • Writing notes • Keeping a calendar • Seeking information • Talking to family or friends • Watching TV |

Table 2. Subthemes and examples related to interventions to assist in recovery

As each participant described their recovery many of their descriptions included ways that they were managing the challenges and barriers that they encountered during their recovery. Their descriptions included their *Self-Management of Recovery*, *Following Recommendations* and the important role *Support* plays in their recovery.

Self-management of Recovery incorporated how the participants were managing their recovery at home. Self-management included using medical devices, scheduling medical

appointments, managing medical conditions, adapting daily life to physical and emotional limitations, and seeking ways to get back to their normal routine.

Managing Medical Needs

Several participants were sent home with medical devices such as feeding tubes, wound Vacuum Assisted Closure, PICC lines, and life-vest. These devices needed to be cared for at home. The participants discussed how these devices affected them and often that they needed help caring for them at home. Doug was sent home with a feeding tube. He discussed what he needed to do with his feeding tube at home and the fact that he wouldn't have been able to care for it by himself.

He [my dad] helped me out a lot with the feeding machine, and that 'cause I couldn't have done that alone 'cause you had to change the bag and then the solution I could put in, yes, but then I realized I had to flush the tube that was in me- twice a day, once in the morning and once at night, and the bags had to be changed every day. I couldn't, I wouldn't have been able to do that alone (Doug, 56-year-old, 48 days in ICU).

Dale was also sent home with a feeding tube. He spoke of his challenges managing his feeding tube that ended up being infected.

Yeah, I got my feeding tube out last Monday. It had an infection in it. I went to the emergency room because of the infection. I was getting stuff out of it. They gave me two medications for that and cleared it up (Dale, 56-year-old, 16 days in ICU).

Frequent doctor appointments and procedures. Several participants discussed having frequent doctor appointments and procedures after they were discharged home from the hospital. Some discussed having appointments up to two to three times a week. Matt described finally getting to the point where he had a week with no appointments.

It slowed down quite a bit, this week I have no appointments, so this might actually be like my first week with no appointments. Right now, I am seeing my oncologist every other week (Matt, 48-year-old, 9 days in ICU).

In addition to having frequent doctor appointments several participants discussed being re-hospitalized, sometimes more than once.

Re-hospitalization. William discussed how he had been hospitalized in the ICU three or four times in the last six months. He had suffered from a heart attack and open heart surgery.

Then I got back home here and maybe a week or two, and I was back in ICU again for some other sickness, and I was having chest pains again. I have been in the ICU three or four times (William, 50-year-old, 3 days in the ICU).

Lifestyle Adaptations

Another way that participants described managing their recovery was the many different lifestyle adaptations they made due to symptoms they were experiencing during their recovery. Many participants described different ways that they had made changes to their everyday routine such as washing their hair in the sink, sitting down when necessary, and using a motorized cart while grocery shopping. Mike found it difficult to go upstairs and get in the bathtub, so he would wash up in the sink:

So, I didn't go upstairs for a while. I washed my hair and kind of washed up in the sink for a while because I didn't want to get in the tub. The daily tasks, you know as far as making the food and things, I just wasn't, capable of doing that right away. (Mike, 65-year-old, 5 days in ICU).

William described how he would have to sit down as soon as he got tired or he would end up on the floor:

Once I get tired, I sit down because I know if I don't sit down, I'll be on the floor. My legs will give out, I had that done before, and that ain't a good feeling. I just make sure I know when to sit down (William, 50-year-old, 3 days in ICU).

Patricia described her difficulty with going grocery shopping. She didn't have the energy to walk around the store and would only go to a grocery store if there was a motorized cart for her to ride in:

I really don't have the energy to walk around in the grocery store. 'Cause I won't go to the store, not unless they have one of those carts that you can ride around in and pick out what you want (Patricia, 76-year-old, 4 days in ICU).

Seeking Normalcy

Many participants expressed their desire to return to normal. Getting back to normal included activities such as going to their children's basketball games, going to church, getting back to work, and resuming their hobbies.

I think the biggest thing is just trying to get back in, back into the normal life. Because I think initially when I came home, I was kind of like in isolation at home, you know, wasn't really doing anything. A lot of that was because I was weak, you know, just to get in and out of the house was kind of a chore, but I think the biggest thing was just, you know, going to the son's basketball games, going to my daughter's basketball games. You know, just trying to do things like a normal person would. Trying to incorporate more lifestyle type things is the biggest thing (Matt, 48-year-old, 9 days in ICU).

For Bill, getting back to normal routine meant going to church, "...but I have been to church every single Sunday, even started playing the organ again." (Bill, 61-year-old, 10 days in ICU).

Mike described his normal routine as being able to get back to his hobby of stock research analysis:

I'd go back on the computer once I could get upstairs and I would do my stock research analysis. You know because that's what I really like doing and I missed that, so I would get back into just the normal routine (Mike, 65-year-old, 5 days in ICU).

Following Recommendations

Participants often stated they were following recommendations to assist recovery. For some participants following recommendations included taking medications, following their diet or going to their appointments. For some, this was a change from previous behavior. Daryl described that he was following the doctor's recommendations; "So I am taking care of my health and going to the doctors and all my appointments. Whatever's wrong with me, getting it done." (Daryl, 64-year-old, 5 days in ICU).

Dale described that he was doing the best he could to follow the doctor's recommendations but sometimes he messed up.

I've done what they told me to do, I mean, I'm taking my medications and wearing the vest, and I'm just pretty much doing what they told me to do as much as I can. I've goofed up a few times. I've missed a couple times taking my pills. I am just staying active, trying to do things (Dale, 56-year-old, 16 days in ICU).

However, some participants were not doing anything to assist with their recovery. When asked what they were doing, some stated that "no one" told them what to do. Tosha was having difficulty with her physical recovery but wasn't doing anything to help with her recovery

because she said no one told her what to do yet. When asked if she was doing anything to help with her difficult physical recovery, Tosha answered: “No, they didn’t tell me what to do yet.” (Tosha, 50-year-old, 10 days in ICU). Dale had a similar response when talking to him about his difficulties with his memory since his illness; the researcher asked if he was doing anything to help with his memory and he said: “Nobody’s told me what to, you know, what to do for it.” (Dale, 56-year-old, 16 days in ICU).

Support

A majority of participants discussed the different types of support they had received. The types of support identified by participants included *social support*, *medical support*, *spiritual support* and *self-support*.

Social Support. Social support was the support that was provided by family, friends, neighbors, or church family. Social support was a very important part of many participants’ recovery.

Bill talked about his church family during his recovery and the amount of support they had given him. He described it as having a “whole bunch of mothers” he didn’t know he had. Although they could be a little overwhelming at times, he described being humbled by the amount of support he received.

I live alone, but I am not alone. That’s my church family, it’s like I have 17,000 mothers. I’ve gotten a lotta support, and like I said, a whole bunch of mothers that I didn’t know I had saying “are you taking your meds?” So yes, it’s very humbling, to have so many people be concerned about your wellbeing (Bill, 64-year-old, 10 days in ICU).

Similarly, Dale described having a good support system. He stated he received support from his family.

I have a good support system as far as my family. My family, my wife, I sit and I talk to her. So, I got a good support system (Dale, 56-year-old, 16 days in ICU).

Another participant, Deb, felt that she had a lot of support from her family, church, and neighbors. She felt everyone stepped up to the plate to help out.

Wonderful, I mean everybody's stepped up to the plate. My daughter and my oldest granddaughter, they'll come in, mom, do you need anything done? Maybe they'll vacuum, give my husband a break, you know, because we just went through cancer with him and he's weak too. The church people, when I got home, they were bringing us meals and like I said, it's been wonderful with the neighbors. The neighbor man he walks over and says, oh I got a cucumber for you (Deb, 64-year-old, 8 days in ICU).

However, some participants struggled trying to care for themselves after their loved ones needed to return to work. For example, Mike, indicated when his wife went back to work her support was greatly missed, he felt like he was left alone too early, and really needed help and support yet.

Once I got out of the hospital, they [my family] were here; my wife was here when she wasn't working. My personal opinion, she could have taken a little more time off of work. You know, because I think I was like, kind of pushed out of the boat before I was ready to swim. But it is what it is. But they were able to help me when I needed help because somebody was always around (Mike, 65-year-old, 5 days in ICU).

Medical Support. Some participants had access to medical services such as visiting nurses, physical therapy, occupational therapy, and wound nurses. These participants describe how support from these services impacted their recovery. Marg was sent home with a wound Vac and Peripheral Inserted Central Catheter (PICC) line for IV antibiotics. She described her

experience with the visiting nurses, “It was great. I mean, I had visiting nurses as many times a week as they felt I needed them. It was like three times a week. I had that wound vac so they'd change that” (Marg, 65 years old, 6 days in ICU). Steve discussed how he ended up taking advantage of the cardiac rehab program at the hospital. They thought he had a heart attack, so they set him up with this program as an outpatient after discharge. It was then determined that because he did not have a heart attack he did not qualify for the program. However, they told him about a different program he could participate in for \$4 a session. He decided if he was going to restart an exercise program, having it done under supervision was probably a better idea. “What I did do is, take advantage of the rehab program at the hospital and I'm still involved with that” (Steve, 71-year-old, 5 days in ICU). Dale discussed the support that he had from his doctor; he felt that his doctors really took an interest in his recovery.

I have a good support system as far as my doctors. The doctors constantly take interest, they don't just, you know, “well you need to see somebody” they'll sit and talk to me about things (Dale, 56-year-old, 16 days in ICU).

Spiritual Support. Spiritual support was also another theme that emerged from many participants' interviews. The spiritual support described included prayer and their relationship with God. Barbara described how prayer and reading her bible was helping her with her depression:

I was going to talk to my primary doctor and then from my primary doctor place they may have a psychiatrist that I can talk to, but right now prayer is helping me a lot and reading my Bible. Yup that's what I doing right now (Barbara, 62-year-old, 4 days in ICU).

William discussed his relationship with God and how he was relying on him to keep himself going and on the right track with his recovery.

To me, I've been praying to God and talking to God and that's the way I will keep myself going. You know, I don't have no other way else but to try to keep myself on the right track with God. God is what we all need in life (William, 50-year-old, 3 days in ICU).

Self-Support. Self-support was discussed by almost every participant. Self-support incorporates different skills that the participants employ to help assist in their own recovery, such as writing notes, keeping a calendar, and seeking information about their illness. Self-support also includes different coping strategies the participants used such as taking naps, talking to family and friends, watching TV, and reading. Barbara had numerous self-support strategies that she incorporated in her recovery:

Besides doing my exercises and doing my therapy, I go to my doctor when I am supposed to, I take my medications, I get out and I don't stay in the house, I get out. I get my nails done. The beautician comes in and does my hair, I use these bands to help exercise my arms to exercise my legs and then I get my walker and walk down and back (Barbara, 62-year-old, 4 days in ICU).

Tosha would write, talk, read and meditate to assist with her recovery: "I'll write; I talk it out. I got a book that I read with meditations." (Tosha, 50-year-old, 10 days in ICU).

Many participants discussed difficulty with their memory during their recovery. Some of them had ways of how they dealt with their memory issues such as writing things down and memory books. Daryl said "So I am training myself in detail, I try to remember things; if I can't remember then I write it down." (Daryl, 64-year-old, 5 days in ICU). Barbara used books to trigger her brain and memory: "...there are tricks in there like pictures to find what is missing,

just something to trigger your thoughts, your brain, your mind. I have a book in there that does that.” (Barbara, 62-year-old, 4 days in ICU).

Mike read articles about critical illness and stay in the ICU and how it can affect mental health to help him understand and cope with what he went through.

I did some reading after the fact about ICU psychosis and- how it affects about 40% of the people that are put in there and I thought, “Well, I’m definitely in that category,” because I saw stuff that I know wasn’t there. But at the time I wasn’t sure (Mike, 65-years-old, 5 days in ICU).

Several participants discussed different coping skills or strategies that they used to help support them during their recovery. Some of these strategies included watching the birds, talking, and exercise. Deb enjoyed sitting out on her deck watching the birds:

Actually, sitting on my deck; my long oxygen tube goes out on the deck, and I can sit there every morning. I sit there and I watch my oriels come to the bird feeder, I watch the cardinals, you know, I just love to watch the birds (Deb, 64-year-old, 8 days in ICU).

Participants liked to talk to others about what they had been through. Mike described that sharing his critical illness experience with others was not so much so they knew what happened but more about him wanting to talk about what happened, “Just to verbalize some of that [his critical care experience]so that other people, you know ... uh, I mean, that was more not them wanting to know, it was more me wanting to talk about it” (Mike, 65-year-old, 5 days in ICU).

Another participant, Daryl, talked about assisting with his recovery by joining a gym and having private lessons: “Well, we joined a gym and we paid for private lessons for me to go in and stuff like that.” (Daryl, 64-year-old, 5 days in ICU).

In contrast, a few participants discussed how they relied on themselves during their recovery and that it wasn't anyone's responsibility but their own to get through their recovery. Barbara said her recovery was for her to deal with: "It is for me to deal with, the best way I can and that is what I am doing." (Barbara 6- year-old, 4 days in ICU). Similarly, Sue stated that her recovery was all her and that she had to do it herself: "No it's all me. It's all about me. I've got to get myself back. Ain't nobody else gonna do it." (Sue, 57-year- old, 3 days in ICU).

Research Question 3: Barriers to Recovery

The third research question was "What did critical illness survivors perceive as barriers to recovery from their critical illness once discharged from the hospital?" Themes were determined to be answers to this question if they were related to the challenges and barriers encountered since discharged home from the hospital. The major themes that answered the question were *Barriers to Recovery* and *Unmet Needs*. The subthemes to the major theme *Barriers to Recovery* include *Physical, Cognitive, Psychosocial, Financial, and Transportation*. Themes were developed from codes displayed in Table 3.

| Barriers to Recovery | Unmet Needs |
|--|---|
| <p style="text-align: center;"><u>Physical</u></p> <ul style="list-style-type: none"> • Weakness • Difficulty sleeping • Pain • Short of Breath | <p style="text-align: center;"><u>Mental health</u></p> <ul style="list-style-type: none"> • Need to talk to someone regarding mental health |
| <p style="text-align: center;"><u>Cognitive</u></p> <ul style="list-style-type: none"> • Poor memory • Forgetful | <p style="text-align: center;"><u>Coordination of care</u></p> <ul style="list-style-type: none"> • Lack of communication about appointments • Lack of communication about illness |
| <p style="text-align: center;"><u>Psychosocial</u></p> <ul style="list-style-type: none"> • Depressed • Sad • Agitated • Isolation • Withdrawn • Moodier • Unpredictable • Stressed out | <p style="text-align: center;"><u>Spiritual counseling</u></p> <ul style="list-style-type: none"> • Need counsel on why participant survived |
| <p style="text-align: center;"><u>Financial</u></p> <ul style="list-style-type: none"> • No insurance • Problems with housing • Unable to get recommended cares • Unable to fill medications | |
| <p style="text-align: center;"><u>Transportation</u></p> <ul style="list-style-type: none"> • No transportation to appointments • No transportation to store | |

Table 3. Subthemes and examples related to challenges and barriers to recovery

Barriers to Recovery

Participants encountered numerous barriers to their recovery once they were discharged home. These barriers include *physical barriers, cognitive barriers, psychosocial barriers, financial barriers, and transportation barriers*. The subthemes will be described in further detail below.

Physical barriers. Participants described physical barriers, such as weakness and pain, which impaired their recovery. Many of the participants talked about weakness.

Weakness. Jennifer discussed how she was unable to return to work for a few weeks due to weakness, “After I got out of the hospital, I was so weak. Oh, I couldn’t do anything. I couldn’t go back to work till like April because I was so weak” (Jennifer, 19-year-old, 6 days in ICU).

Dale talked about his muscle and weight loss which contributed to his weakness:

But yeah, I feel a lot different; I don’t have the strength that I did. I weighed 193# when I went in the hospital and I dropped all the way to 148#, and now I’m back up to like 173#, so I lost a lot of muscle (Dale, 56-year-old, 16 days in ICU).

Pain. A few participants described how pain was a barrier to their recovery. William talked about how the pain he was experiencing was “rough” and hindering his sleep because he was discharged without pain medications and was still waiting to see a doctor who could prescribe him pain medications.

It’s just the soreness that I still have and they’re not giving me pain medicine for it. I haven’t had pain medicine just about since I left the hospital. I don’t know what they can prescribe me for this pain that I’m still having but it is rough; I haven’t been sleeping (William, 50-year-old, 3 days in ICU).

Another participant, Jennifer, talked about how the pain would cause her to become agitated:

When you are in pain, like when I get pain, then I get agitated and that’s when the attitude comes because I don’t want to be bothered, like, I can’t talk (Jennifer, 19-year-old, 6 days in ICU).

Cognitive Barriers. Several participants discussed issues they experienced with their memory since their critical illness. Their issues included loss of short-term memory, struggling with managing daily things such as remembering phone numbers or how to work the phone.

One participant, Barbara, discussed the problems she was having with her memory during her recovery. She struggled with daily things and found it scary when she could not remember daily activities

Memory..... is not all that good. No, some things I remember and somethings I don't, and that's kind of scary. Yeah that's kind of scary. Just remembering daily things, remembering life, remembering my telephone number, remembering what I need to do that day or get the phone or how to work the phone, just little bitty things (Barbara, 62-year-old, 4 days in ICU).

Dale, who was also struggling with his short-term memory, also discussed issues that he had with his memory after his illness.

Um, my short-term memory is kinda gone, um I tend to forget a lotta things that I just found out about or I just, you know, things I was supposed to do, I forget all about them. That's one reason we haven't met in person (laughs) but um, yeah, my short-term memory is not the best (Dale, 56-year-old, 16 days in ICU).

Psychosocial barriers. Participants discussed many aspects of emotional health such as depression, agitation, sadness, and being withdrawn. Many participants reported that these feelings hindered their recovery. Jennifer, who was 19 years old, resorted to staying in her room and listening to music as she explained: "I just stay to myself. I just go to my room, like, not talk to nobody, listen to music." (Jennifer, 19-year-old, 6 days in ICU).

Participants' mental wellbeing was interrelated with their physical illness. For instance, Daryl discussed how his emotional and mental health could trigger his physical health. He described how he would have an asthma attack when he would get upset. His stress levels and psychosocial health were inhibiting his physical recovery.

I have no idea but I just get upset, you know when I get upset it triggers an attack. You know, so it escalates andI'm getting upset, and pacing, and saying "I don't know what I am gonna do, but I can't take this", and that triggers the emotional end which triggers the asthmatic end (Daryl, 64-year-old, 5 days in ICU).

Financial barriers. Several participants discussed being frustrated because of the inability to have recommended care because they could not afford it. This was a common theme with several participants. One of the participants, Bill, described how he was not able to have his recommended test for a "spot" they found on his pancreas because he did not have insurance and he could not afford it.

The frustrating thing is not having insurance to do as much of the follow ups. I mean, as I said, my sister is more concerned about the pancreas than I am. See our father died of pancreatic cancer and she's concerned that because of that, whatever this spot or thing they found on the tip of my pancreas could be the start of that (Bill, 61-year-old, 10 days in ICU).

William discussed how they wanted him to participate in physical therapy, but he couldn't afford it, so he didn't go.

They wanted me to go to therapy, and I told them I couldn't afford it, so I didn't go to it anymore. I told them I could get on the treadmill here at home and I can take walks around the house so many times, and you know, just keep myself active because I don't have the money right now to do nothing' (William, 50-year-old, 3 days in ICU).

Another participant, Deb, talked about all of the new medications that they prescribed for her. She was on a limited income and couldn't afford all of the medications, so she went over the medications with the pharmacist and decided which medications to continue.

I mean there were medications that I got put on that cost a small fortune. They add in all these extra medications and this and that and the other thing, and I can't pay for it, you know. I mean I only get \$1,200 a month (Deb, 64-year-old, 8 days in ICU).

Transportation Barriers. Having difficulty with transportation to the store and appointments was another barrier that was discussed by some participants. For example, Barbara used a scooter, but it would not fit on the transportation van. This prevented her from being able to get out and go shopping.

Challenges and barriers were being able to get on that van and go to the store. I can't take my chair because they don't have a van big enough or the lift on there for this, so they were not equipped for a person like me to do that. You have to use a wheelchair, but they don't have a wheelchair up there for someone my size, they have a baby chair (Barbara, 62-year-old, 4 days in ICU).

Several participants faced challenges with finding transportation to needed frequent appointments after being discharged. For instance, William, who was staying with his aunt, was not familiar with the area so he does not know the bus routes. He reports struggling with getting to his appointments for lack of reliable transportation.

So she's [the nurse] trying to help me get a ride back and forth to the doctor. I don't have any other way to get there because she [my aunt] works a lot. I don't know the area, I know nothin' about the buses, I don't know nothin' about how to get nowhere but stay right here where I am at (William, 50-year-old, 3 days in ICU).

Unmet Needs

Some participants discussed their unmet needs related to their recovery. Their unmet needs included mental health issues, coordination of care, and spiritual counseling. Participants

described unmet needs as resources or information about their recovery that they needed to receive either in the hospital or during their recovery but failed to receive it.

Mental health. Some participants described needing to talk to someone regarding what they were experiencing mentally with their illness and recovery. Participants felt that the healthcare providers failed to address what was most needed by them. For example, Mike talked about occupational therapy and the dietician that worked with him while he was in the hospital. He felt there was little value in seeing them. He felt he would have benefited more from being able to talk to someone regarding his mental health.

I would have traded both of those for maybe an hour with somebody that talked to me about my mental condition. I maybe would have appreciated talking to somebody about the other stuff that was going on in my head more than anything else (Mike, 65-year-old, 5 days in ICU).

Coordination of care. Some participants discussed needing better communication with health care providers about what happened to them with their illness and appointments that were being made for them.

It was frustrating that they had all these appointments made for me that I knew nothing about. So maybe they need to discuss stuff like that when they send you home. They give you a print out, say now you have some appointments coming up, but that's it. I had one appointment that I cancelled because when I called I didn't know who it was with, what it was about, and they said, "well you're scheduled for surgery because you have gallstones", I said, I don't remember him telling me I had gallstones, so I called and cancelled (Deb, 64-year-old, 8 days in ICU).

Spiritual counseling. Participants prioritized the need for spiritual counseling after the trauma of surviving a critical illness. For instance, Bill talked about his struggle with why he survived and did not understand why he was still here and wanted to find a spiritual director to help him understand why he survived.

That's part of the reason why I'm kind of sad, 'cause..... I don't know why and I need to like find a spiritual director. I talked to my former pastor, and she gave me some answers, not that she can, but I want to know why I am still here. I've asked God that every day, it's like "why am I still here" 'cause I don't know. So that's why I am sad (Bill, 61-year-old, 10 days in ICU).

Summary

Through these interviews with 18 critical illness survivors it was discovered that there is no one "cookie cutter process of recovery" (Matt, 48-year-old, 9 days in ICU). However, many survivors had very similar experiences and barriers to their recovery.

The aims of the study were addressed by the responses of the participants. This included how they described the recovery from their critical illness since discharge from the hospital. Participants described their physical and emotional experiences as well as their evaluation of recovery, the uncertainty they experienced, and gaining new perspectives. Participants also described the physical, cognitive, and psychosocial barriers as well as the challenges affording recommended care, transportation, and the various unmet needs experienced. The participants discussed the many ways that they assisted with their recovery and helped to manage the barriers they encountered. Participants were able to self-manage the medical aspects of their recovery which for some included feeding tubes, drains, wound vac, numerous appointments, procedures, and some re-hospitalizations. Several participants discussed ways that they adapted their

lifestyle due to the physical and cognitive limitations they were experiencing due to their illness and hospitalization. They discussed how they followed recommendations. Support was discussed by every participant whether it was social support, medical support, spiritual support, or self-support. Each of these themes were expanded on using participant quotes.

Chapter Six will discuss the findings of this study and relate them to existing literature in addition to important considerations, implications for practice, policy, theory, and recommendations for future research.

CHAPTER VI: DISCUSSION

The purpose of this study was to elicit the experiences of survivors of critical illness after they were discharged home. Eighteen critical illness survivors shared their experiences on how they managed their recovery since being discharged. Currently, there is no protocol or standard of practice for recovery from a critical illness. This study found that critical illness survivors are resilient and resourceful in the development of strategies to manage their recovery at home. Many of the physical, cognitive, and psychosocial barriers experienced by participants after discharge were related to ICU care. Obstacles to healing included poorly organized care coordination and spiritual distress related to surviving a critical illness. Lack of mental health resources and healthcare providers' inadequate attention to post-ICU psychological recovery were also described as major barriers by participants.

This exploratory study addressed questions about the recovery experiences of critical illness survivors. This qualitative study, guided by interpretative phenomenology, sought to understand the approaches survivors take to facilitate their recovery. Interpretive phenomenological (IPA) method allows the unique stories of survivors to be heard. IPA relies on idiography, which refers to in-depth analysis of single cases and the examination of individual perspectives within their unique contexts. The fundamental principle of the approach is to explore each case before producing general statements. New insight into the recovery process emerged from examining post-ICU recovery through the lens of survivorship using IPA method. This resulted in a greater understanding of the challenges survivors face and allowed for increased perspective of survivors' management of barriers to their recovery. Survivors described the fear and uncertainty that was pervasive during the post-ICU period. However, survivors also reported being grateful to be alive and thankful to be given another chance at life.

This chapter will present the current study findings in relation to the literature and research questions. Following the discussion of the findings, study implications for research, practice, policy, and limitations will be discussed.

Survivors identified unmet needs of mental health and psychological recovery, care coordination, and inadequate knowledge about the recovery trajectory as major barriers. Other qualitative studies have examined patient, family, and nurse experiences of an ICU stay and recovery (Agard, et al., 2012; Cypress 2010), but did not focus on survivors' barriers at home. Phenomenological methods offers an increased understanding of survivors' perceptions and experiences. Implications for providing survivor support during the early recovery period, as discussed later in this chapter, were informed by survivors' perceptions. Descriptions of survivors' perceptions add to the current body of literature, which centers on measuring anxiety, depression, post-traumatic stress disorder, and quality of life (Castillo et al., 2013; Cox et al., 2012; Cuthbertson et al., 2009; Jones et al., 2010) rather than the patient experience of recovery.

The findings presented in this study focused on the common themes across all participants even though the eighteen participants shared individual stories. Six major themes emerged from the interviews: *Experiences of Recovery*, *Self-Managing Recovery*, *Following Recommendations*, *Support*, *Barriers to Recovery*, and *Unmet Needs*. These findings will be discussed in the following section.

Experiences of Recovery

Experiences of recovery have been explored in the literature in different ways. Previous studies focused on survivor memories of the ICU stay (Ewens, Hendricks, & Sundin, 2018; Wade et al., 2012; Warlan & Howland, 2015). Unsettling false memories were interwoven with real events from their hospitalization, and survivors experience intrusive memories,

“flashbacks”, or nightmares. In a study by Ewens et al. (2018), participants reported having no recollection of being in ICU, and if they did remember it, the memories were diverse and frequently distressing. The current study did not have similar findings, as it focused on recovery at home and there were no direct questions about the ICU stay. In this study, *experiences of recovery* included the subthemes *physical and emotional experiences, uncertainty, gaining new perspectives, and evaluation of their recovery*.

Many participants reported feelings of fatigue, weakness, and loss of muscle strength. These physical complications are consistent with other studies. Jones (2014) and Rattray (2013) have reported similar findings, especially for patients who have been in ICU for more than one week. Participants found tiredness difficult because they did not expect the fatigue and weakness to be so severe or to last so long.

Participants described feeling scared to go home, afraid to resume activities, and feeling helpless because they were unable to do many activities. Prior to their illness, participants had been able to perform tasks such as cooking, cleaning, going upstairs, driving, gardening and snow blowing. Other studies found survivors similarly struggled for independence, recovering physical strength, regaining functional capacity, resuming domestic roles (Agard, Egerod, Tonnesen et al., 2012) and resuming their role in the family (Abdallah & Zeilani, 2014).

Uncertainty

The subtheme *uncertainty* has been noted in the literature. Survivors struggle with fear of relapse (Christensen & Egerod, 2016), experience symptoms of anxiety and depression following discharge (Knowles & Tarrier, 2009) and feel anxious and lonely as they face an uncertain recovery trajectory (Ewens, Hendricks & Sundin, 2018). In this study, participants discussed the *uncertainty* they felt with recovery since they did not know what to expect or how long recovery

would last. Also, survivors reported uncertainty about whether their symptoms or illness would come back.

Gaining a New Perspective

Although negative aspects of recovery were reported in this study, multiple participants were optimistic, expressed gratitude, described a new appreciation for life and *gaining a new perspective*. Participants were more aware of their own mortality and were happy to be alive. Participants often described their recovery as “going great”. *Gaining a new perspective* has been mirrored in the literature. Jensen et al. (2016) found that participants moved forward towards a new orientation in life. In addition, survivors perceived their general health to be good despite experiencing significant physical limitations and disturbed sleep during recovery (Kelly & McKinley, 2010).

Evaluation of Their Recovery

Evaluation of their recovery has also been discussed in the literature. In this study, participants described their recovery alternatively as slow, rough, hard, having “ups and downs”, quick and fast. Some participants indicated that they felt they were given expectations for their recovery that did not match up to their experiences. Others had no idea of what to expect. Similarly, Gruber (2008) found survivors may be happy to be alive but may have unrealistic expectations of a quick recovery, leading to frustration.

Self-Management of Recovery

There is limited literature on the major theme *Self-Management of Recovery*. *Managing Medical Needs*, applying *Lifestyle Adaptations* and *Seeking Normalcy* are strategies the participants reported.

Managing Medical Needs

Several participants were sent home with medical devices, including feeding tubes, T-tube drains, PICC lines, and wound vacs. Participants discussed how the devices affected them and how they relied on assistance from family or visiting nurses.

Lifestyle Adaptations

Lifestyle Adaptations incorporated how participants adapted daily activities and routines. Routines were disrupted due to the symptoms such as weakness, feeling tired, or not trusting their physical and mental abilities. For example, participants changed activity locations to avoid stairs. Some avoided activities all together, such as driving, because of mental limitations. Weakness and fatigue symptoms are discussed extensively in the literature as related to critical illness survivors (Desai et al., 2011; Needham et al, 2012; Scruth, 2014).

Seeking Normalcy

Seeking Normalcy, or wanting to “get back to normal”, is another subtheme of *Self-Management of Recovery* that participants addressed. Participants struggled to get back into their daily activities and indicated the importance of this accomplishment during recovery. Getting back to normal life included going to their children’s basketball games, attending church, getting back to work, and resuming hobbies. *Seeking Normalcy* is consistent with other studies, which have reported impairment in activities of daily living in all ICU survivors assessed in the first week after discharge from the ICU (Schaaf, Dettling, Beclan et al, 2008). Harvey (2012) found that 50-70% of patients have difficulty with activities of daily living one year later.

Following Recommendations

Participants reported *following recommendations* such as going to appointments, eating healthy, and being active in order to assist in recovery. However, some participants did not implement any strategies to alleviate problems when experiencing physical, emotional, or

cognitive challenges. Survivors may need additional explanation and assistance to navigate recovery. They may not seek help on their own even if they are struggling. *Following recommendations* highlights the potential importance of screening tools that could be given to patients prior to discharge and at scheduled follow-up appointments. These tools would help identify patients who are experiencing challenges or are at risk for developing difficulty, allowing health care providers to initiate interventions and provide appropriate support. *Following recommendations* needs further exploration of descriptive data on this theme.

Support

Participants described *support* during recovery, including the subthemes *social support*, *medical support*, *spiritual support* and *self-support*.

Social Support

Participants described the *Social support* they received as ‘great’. Family, friends, neighbors and fellow church members provided most of the social support. Social support included making meals, helping with childcare, cleaning, and wellbeing checks. The effects of social support have been discussed in the literature. Social support can enhance the diminished physical dimension of quality of life in ICU survivors (Tilburgs, Nijkamp, Kakker & Van der Hoeven, 2015) and may improve mental health and related long-term outcomes such as employment status (Deja et al., 2006). The use of peer support as a mechanism for informal support also appears to have a significant impact on the recovery trajectory of ICU survivors (McPeake et al., 2017).

Medical Support

Medical support includes support from physicians, physical therapy, visiting nurses, wound care nurses, and personal trainers. Participants prefer assistance and support from health care professionals who understand what they experienced and the associated difficulties (Ewens,

Hendricks & Sundin, 2018). Ewens, Hendricks & Sundin (2018) found that specialized support services should be established for survivors in the early stages of recovery to prevent exacerbation of psychological complications. Similarly, Maley, et al. (2016) found clinicians have a profound therapeutic impact on survivors during recovery in terms of their ability to reassure, educate, rehabilitate, prepare, and support survivors after critical illness.

Spiritual Support

Spiritual support was another subtheme of *Support*. *Spiritual support* included going to church, ‘church family’, and/or a relationship with God. Participants relied on prayer and their relationship with God to support recovery. This is consistent with other studies, where participants reported recovery facilitation through spiritual and family support (Maley, et al., 2016).

Self-Support

Self-support included incorporating coping strategies and interventions utilized by participants without much assistance. Participants described various coping strategies they used to help “support” recovery such as writing notes, talking to family and friends, seeking information about their condition, watching TV, and reading. Self-support needs further exploration to identify what survivors utilized to assist with recovery and determine whether it is beneficial.

Barriers to Recovery

Barriers to recovery was a major theme of this study. Participants encountered numerous barriers once discharged. These barriers included *physical barriers*, *cognitive barriers*, *psychosocial barriers*, *financial barriers* and *transportation barriers*. *Physical*, *cognitive*, and *psychosocial barriers* that the participants described such as difficulty with mobility, problems with memory, and struggles with depression are consistent with the literature on PICS (Jones,

2014; Myers, et al., 2016; Needham, Davidson, Cohen, et al., 2012). Increasing numbers of survivors are at risk for physical, cognitive, and/or mental impairments that may persist for months or years after hospital discharge (Elliott, Davidson, Harvey, Bemis-Dougherty, et al., 2014). Participants in this study described difficulty with weakness and physical mobility after their ICU stay, such as trouble getting out of a car or getting into the house.

Cognitive Barriers

Participants reported *cognitive* impairment, including difficulty remembering appointments, medications, telephone numbers, and other daily things. Participants relied on family or writing notes to assist with poor memory. Long-term cognitive impairment is common following critical illness and has dramatic effects on patients' abilities to function autonomously (Brummel, Jackson, Girard, et al., 2012).

Psychosocial Barriers

Psychosocial barriers included feelings of depression, anxiety, fear, having sad moments, getting upset, and being withdrawn. Psychological barriers are reported in the literature. Anxiety, depression and post-traumatic stress disorder are common after ICU discharge and have a negative impact on the patients' ability to engage in rehabilitation (Jones, 2014).

Financial and Transportation Barriers

Personal finances influenced participants' ability to obtain recommended treatment, as there were limited resources to cover medical costs. Healthcare providers should be aware of patients' overall financial constraints. Options for cost-effective treatments need to be explored. If recommended treatments are not affordable, providers should recognize that patients are not simply noncompliant. In this study, participants explained how they were unable to have recommend scans, medications, rehabilitation services and procedures due to cost. Barriers to medical compliance may include paying rent, bills, or buying food rather than getting the

recommended treatment. One participant discussed how she was being evicted for not paying rent the day she was admitted to the hospital. Unstable housing affects patients' ability to obtain appropriate healthcare services.

Participants described *transportation* as another barrier to recovery. *Transportation barriers* are related to financial barriers, as one participant stated she had difficulty getting gas to go to her follow-up appointments. Healthcare providers could advocate by providing transportation resources for their patients. The findings add to the literature on the financial impact that critical illness imparts on patients and families by describing the financial barriers associated with recovery.

Unmet Needs

Unmet Needs was a major theme in this study. Participants identified unmet needs at discharge or during their recovery. Lack of communication with healthcare providers was identified as problematic. Participants reported that their critical illness and recovery were not discussed clearly with them. A few participants were frustrated with poor communication regarding follow-up appointments and care. They stated that they did not feel included in the planning of their recovery. Many were just given a list of appointments with no explanation as to with whom appointments were scheduled or the purpose of the appointments. In Prinjha, Field and Rowan (2009), survivors described follow-up as a valuable part of their recovery. Survivors reported follow-up appointments and communication made an important contribution to their physical, emotional and psychological recovery. Survivors without follow-up felt abandoned or disappointed, as they lacked the opportunity to be monitored or obtain more information (Prinja, Field & Rowan, 2009). Unmet needs and lack of support was echoed in a study by Ewens et al.

(2018) which found that participants felt unsupported by the healthcare system that helped to save their life.

One participant reported spiritual distress and the need to find a spiritual counselor as another *unmet need*. The participant discussed struggling with the need to know why he survived a critical illness. He reported asking God every day why he survived and wanted to find a spiritual director to help him understand. This description of spiritual distress is similar to that of another study, in which patients strived to understand experiences of their illness and recovery (Storli, Lindseth & Asplund, 2008). Participants in the study by Storli, Lindseth and Asplund (2008) reported valuing their spiritual and religious rituals more after the illness. Spiritual distress related to survival requires further exploration.

Survivors described the need to talk to someone about what they were experiencing mentally. Participants reported talking to family and friends as a way to support recovery. According to participants, talking about their experiences benefitted them more than the person they were talking to; it felt therapeutic to discuss the illness and recovery. However, participants still felt the need to talk to a healthcare provider about the mental effect of the critical illness and recovery. One participant stated that he would have traded his appointments with the occupational therapist and dietician for time to talk to a mental health professional. Unmet needs are an important finding of this study, one that requires further research. These findings give healthcare providers knowledge about the survivors' unmet needs. This knowledge can provide the health care team with ideas on ways to provide support and improve outcomes for critical illness survivors.

Implications for Nursing Practice

The findings of this study have several implications for nursing practice. A major finding was that critical illness survivors have psychological challenges during recovery that were not addressed by healthcare providers. The prevalence of psychological and physical morbidity with associated reductions in quality of life in this population have been well-reported in the literature (Aitken & Marshall, 2015; Bemis-Daugherty & Smith, 2013; Catlay, 2015; Jones, 2014, Myers et al., 2016; Needham et al., 2012 & Scruth, 2014). However, a strong evidence-based framework to support and promote psychological recovery was not found in the literature (Ewens et al., 2018).

Multidisciplinary follow up after ICU can be of value in identifying untreated physical and psychological problems in ICU survivors (Schandl et al., 2011). Schandl et al. (2011) found that patients screened and treated for physical and mental health problems in the first six months post-discharge appear to have little need for further psychological follow-up. Improving long-term physical, cognitive and psychological outcomes includes the need for early screening and treatment in survivors. Participants in this study suffered physical, cognitive, psychological problems and spiritual distress. Addressing these diverse problems requires a comprehensive, multidisciplinary approach.

Critical care providers would benefit from adopting the multidisciplinary approach taken by cancer care providers. The American Cancer Society provides a cancer navigator website that provides information and support related to diagnosis, tips for staying healthy and active during and after treatment, and sources on finding and paying for treatment. The cancer navigator website also provides access to local support services and programs for patient, caregivers and

families (American Cancer Society, December 3, 2018). This holistic approach to providing care would be beneficial for critical care survivors.

Clinicians can have a profound impact on survivors by providing support and reassurance which can help mitigate psychological compromise. Nurses are in a unique position to help survivors cope with their emotions prior to discharge and provide anticipatory guidance for once they are home (Warlen et al., 2015). Nurses can provide patients with a detailed summary of their ICU stay prior to hospital discharge. Each patient in ICU would be assigned a primary nurse. This nurse would be responsible for providing a majority of the patient's care and would have detailed knowledge about the patient, their illness and ICU stay. The primary nurse would provide the patient and family with a debriefing prior to hospital discharge. At the debriefing the patient would have an opportunity to discuss any problems or concerns and ask questions regarding their illness and hospital stay. Providing patients with a frame of reference could help them come to terms with their experiences, reinforce real memories and eliminate gaps in their memory (Warlan & Howland, 2015). This debriefing would provide the nurse an opportunity to evaluate patients and advocate for mental health consultation for patients who are struggling and at risk of developing further complications.

Nurses are in a unique position to help survivors cope with their emotions prior to discharge and provide anticipatory guidance once they are home (Warlen et al., 2015). Nurses should be involved in critical care discharge planning, care coordination and follow-up care. As a component of discharge planning, survivors should be screened for complications. Regular appointments should be scheduled after ICU discharge to identify and address unmet needs. Support services should be established for survivors in the early stages of recovery to prevent exacerbation of complications (Ewens et al., 2018). Effective evaluation of recovery requires

integration of outcomes assessment into routine clinical practice by an interdisciplinary team (Aitken et al., 2015).

Participants in this study reported not knowing what to expect during recovery. The information patients received about recovery was inaccurate at times, causing frustration and anxiety. Accurate discharge information has been well-received by survivors (Bench et al., 2015). However, discharge information is not standardized or regularly provided. Evidence-based information about recovery should be provided to survivors and their families upon discharge (Ewens et al., 2018). Written discharge information should include what to expect during recovery and how to seek additional support if necessary (Ewens et al., 2018). Nurses should provide information about recovery to survivors and their families prior to discharge and at scheduled intervals during recovery. Recovery information should describe potential barriers that survivors may encounter such as physical, cognitive and psychological challenges. Survivors should also be provided with ideas about problem solving during recovery.

Implications for Policy

Once survivors are discharged from the ICU, the enormous financial burden and impact of critical care continues. Critical illness survivors suffer readmission, future surgeries and procedures, costly rehab services, and continued doctor visits. In addition, many suffer lost productivity to society as many have prolonged time off or work due to the critical illness (Nelson, Cox, Hope, & Carson, 2010; Kahn, Benson, Appleby, Carson, & Iwashyna, 2010). The cost of hospital readmission was \$528 million dollars in 2016, the most recent year for which statistics are available (Kaiser Health News, 2016). Recovery from a critical illness is often complicated by limited access to care and limited availability of information about services offered, care coordination, and treatment (Leonard, 2012).

Participants in this study suffered from hospital readmissions, surgeries, procedures, rehabilitation services, and frequent doctor visits. They reported difficulty obtaining care due to financial constraints and problems with care coordination. Policy makers and advocates could use the study findings to inform practical strategies for promoting support and improved outcomes for critical illness survivors. Nurses can assist in policy development by advocating for survivors at the local, state, and national levels. Increasing awareness that these costly problems exist is the first step to addressing this critical issue.

Findings from this study may help policy makers understand the importance of quality resources for critical illness survivors after ICU discharge. This study could inform the development of policy for the implementation of structured community resources and follow-up care for survivors of critical illness. The case management model is one option to explore. This model assigns a case manager to discharged patients who provides personal guidance during recovery and as they move through the complex health care system. Case managers assist survivors and their families with insurance problems, finding community resources, explaining treatment and care options, communicating with their healthcare team, assisting caregivers, and managing medical paperwork (Simon, 2013). The case manager could help critical illness survivors navigate the physical, cognitive, psychological, financial, and transportation barriers described in this study.

Implications for Research

Important implications for future research emerged from this study. A large-scale longitudinal study assessing barriers and facilitators to recovery as well as unmet needs is needed to assess the long-term recovery of critical illness survivors. Complications can persist for

survivors, but the survivor's perceptions of their recovery and barriers associated at each stage is not known.

This large-scale longitudinal study will be a mixed methods approach. It will need to be designed to fully explore the multiple dimensions which can affect a survivors' recovery. This would include personal characteristics, relationships, community and spiritual characteristics, and examine modifying factors such as socio-demographics, cultural differences and social support. This would also include factors such as access to care, insurance, and transportation.

Participants in the current study described physical, cognitive, psychosocial, and financial barriers which impacted their recovery. These barriers would need to be further explored in this study. This study would include the following instruments: Functional Independence Measure (FIM), Impact of Events Scale-Revised (IES-R), Repeatable Battery for the Assessment of Neuropsychological Status (RBANS), Medical Outcomes Study Short Form (SF-36v2), and Multidimensional Scale of Perceived Social Support (MSPSS). Functional Independence Measure (FIM) is used to assess physical and cognitive disability (Hall et al., 1993). The IES-R is used to assess levels of post-traumatic distress (Weiss, 2004). RBANS measures the neuropsychological status of adults cognitive functioning and profile impairment across five domains: immediate memory, visuospatial/constructional, language, attention, and delayed memory (Randolph, 1998). SF-36v2 measures quality of life across eight domains: physical functioning, role functioning, bodily pain, general health, vitality, social functioning, role emotion, and mental health (Ware et al., 2000). MSPSS measures perceived support from family, friends, significant others or a global perceived support (Zimet et al., 1988).

The study would also include a qualitative interview asking participants to describe their recovery from critical illness. The interview would specifically address barriers and facilitators

to their recovery as well as any unmet needs encountered. The assessments would be completed at discharge, one month, three months, six months, nine months and one year. The knowledge gained in this proposed study would help determine how health care providers can best assess survivors' recovery and support them at each stage of recovery.

Currently, there is not a recognized recovery assessment tool. Research is needed to develop a recovery assessment tool that can be administered by health care providers prior to ICU discharge and at scheduled intervals to identify complications early. It is important to measure the recovery outcomes at regular time points throughout the recovery pathway to identify problems and guide selection of interventions to prevent, minimize or overcome the complications. A recovery assessment tool would screen participants for complications or risks of complications related to their physical, cognitive and psychological status. It would also screen for any unmet needs. The proposed longitudinal mixed methods study could provide knowledge to assist in the development of a recovery assessment tool. Once this tool is developed, research on implementation and effectiveness will be needed.

Findings in this study highlight the fact that survivors do not feel supported by healthcare providers during recovery. Participants had unmet mental, psychological and care coordination needs. Survivors reported not knowing what to expect during recovery. To address unmet needs, a standard of care practice for ICU survivors needs to be developed. This standard of practice would include resources to give critical illness survivors at discharge, incorporate the recovery assessment tool, and provide suggested intervals for follow-up. Resources would include what to expect during recovery, common barriers such as physical, cognitive, psychosocial, financial, and transportation barriers and directions for accessing help.

The National Institute for Health and Care Excellence (NICE) published clinical guidelines in 2009 for the rehabilitation of patients after critical illness. The NICE guidelines focus on assessing patients in the ICU, at ward transfer, on the ward, and prior to discharge home. If patients have rehabilitation needs at discharge the guidelines recommend assessment again at two-three months after discharge. Research has indicated that some survivors develop complications after hospital discharge (Czerwonka et al., 2014); therefore, patients need to be assessed after hospital discharge even if they do not have needs at discharge. This proposed standard of practice would expand on the guidelines recommended by NICE to provide structured support and screening at regular intervals after discharge.

Limitations

This was a cross-sectional, descriptive, qualitative study that employed purposive sampling. It may apply to patients in similar situations, but it has limited generalizability. The cross-sectional, in-depth interviews completed at 1-3 months after discharge focused on early recovery and therefore lacked participants' perceptions of long-term recovery. Although data saturation was reached and common themes emerged among the participants, more participants may have provided additional findings.

The interviews were conducted and analyzed by a single researcher using IPA methods. Although the study was done by a single researcher, guidance was provided by senior researchers. Review and confirmation of emerging themes, subthemes, and analysis was done in collaboration with a content expert committee member and the major professor.

IPA is a dynamic process which requires the researcher to have an active role. The researcher influences the extent to which she gets access to the participant's experience and how she will make sense of the participant's personal world (Pietkiewicz & Smith, 2012). Access to

the participant's experience depends upon - and is complicated by - the researcher's own beliefs and values. As the primary researcher, self-biases must be recognized, accepted and factored into the analysis as the researcher's point of view. The researcher has been practicing as a critical care nurse for over 15 years and has been influenced by previous experiences. To control for these self-biases, the research kept a reflexive journal and sought guidance from her committee.

Conclusion

The current body of ICU recovery literature fails to address the ways in which critical illness survivors assist with their own recovery and face the many barriers they encounter. Although it has been recognized that critical illness survivors experience a multitude of complications that last well beyond their stay in the ICU, more work needs to be done to identify ways to manage these complications in the home and community.

This study found that survivors do not feel supported by healthcare providers during recovery. Participants had unmet mental, psychological and care coordination needs. Not knowing what to expect during recovery was also reported by survivors, which led to anxiety and frustration. To address these important findings, the next step will be to develop and implement an assessment recovery tool and standard of care protocol for ICU survivors. Findings from this study support the view that recovery from a critical illness should begin in the ICU and continue well after discharge. This exploratory study lays the groundwork for further studies that will lead to improvements in long-term outcomes for critical illness survivors.

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APPENDIX A: Evidence Tables

I. Survivor Outcomes

| Authors/Date | Objective | Design | Sample | Analytic Strategy | Findings |
|--|---|----------------------|--------------|--|---|
| Aitken & Marshall 2015 | Determine the best evidence on monitoring and optimizing outcomes of survivors of critical illness. | State of the Science | N/A | N/A | Ongoing measurement of outcomes is essential to optimize the delivery of interventions to those who most need support. |
| Bemis-Dougherty & Smith, 2013 | Discuss PT's management of patient's with PICS | Review | N/A | N/A | Discussed the importance of F/U after ICU discharge to improve the long term outcomes of survivors. |
| Calvo-Ayala, Khan, Faber, Ely & Boustani 2013 | Identify effective interventions that improve long term PF in ICU survivors | Review | 14 studies | Two reviewers independently evaluated the studies and critically appraised and extracted data. | The only effective intervention to improve long-term PF in critically ill patients is exercise/PT. |
| Castillo, Aitken & Cooke 2013 | The Intensive Care Anxiety and Emotional Recovery (ICARE) study protocol proposes the development of a statistical model to determine the relationship between state anxiety during ICU stay and symptoms of anxiety, depression and PTSD on three occasions. | Prospective Study | 104 Patients | Standardized questionnaires. Multilevel regression analysis | There is enough evidence to propose an existing relationship between state anxiety during the stay in ICU and adverse emotional outcomes during recovery. |

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|---|---|--|------------------|---|---|
| Catlay 2015 | Discuss long term consequences of critical illness | Review | N/A | N/A | Specialized critical care follow-up clinics may have a role in detecting and managing specific post-critical care morbidity |
| Ewens, Hendricks & Sudin 2018 | To investigate stories of recovery through the lens of ICU survivors | Qualitative Interpretive biographical approach | 6 participants | Face to Face interviews Memos Field notes Patient diaries were analyzed | Participants considered their lived had irreparably changed yet felt unsupported by a health care system that "saved" them. |
| Fonsmark & Rosendahl-Nielsen 2015 | Describe and evaluate the knowledge gained from outpatient follow-up at a tertiary intensive care unit. | Quantitative | 101 participants | HADS scale 90 minute interview to determine existing physical, neuropsychological or psychological problems. | Data confirmed that a large proportion of ICU survivors suffer considerable long-term physical and neuropsychological sequelae. Intensive care follow-up may address these specific problems and initiate the needed interventions. |
| Granja, Amaro, Dias & Costa-Pereira 2012 | Provide a review of adult ICU outcome studies and discuss how they have improved the delivery of ICU care | Comprehensive Review | N/A | N/A | The burden of critical illness in ICU survivors is a substantial public health concern with major implications for patients, families and the health care system |
| Jones 2014 | Discuss the current state of recovery Post ICU. Review research into patients' recovery and what can be done to improve this. | State of the Science | N/A | N/A | Many ICU patients struggle to recovery following a critical illness and may be left with physical, cognitive, and psychological problems, which have a negative impact on the quality |

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| | | | | | of life. |
| Kelly & McKinley 2010 | To determine the quality of life, particularly physical function, of intensive care survivors during the early recovery process. | Descriptive Study | 39 Participants | SF 36 | Survivors of critical illness perceive their general health to be good despite experiencing significant physical limitations and disturbed sleep during recovery. |
| Kress & Herridge 2012 | Discuss the medical and economic implications of physical disability and survivorship | Review article | N/A | N/A | Approaches to reduce physical debilitation offers promise to impact economic burden. |
| Myers, Smith, Allen, & Kaplan 2016 | Discuss post-ICU syndrome | Review article | N/A | N/A | Specific and focused education about the key features of PICS and potential interventions may increase recognition and reduce its effects on survivors. |
| Needham, Davidson, Cohen, et al. 2012 | To report on a 2 day SCCM conference aimed at improving the long term outcomes of critical illness survivors | Stakeholders meeting | N/A | N/A | Improving care for ICU survivors and their families requires collaboration between practitioners and researchers in both inpatient and outpatient settings. |

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|----------------|--|--------|-----|-----|--|
| Scruth 2014 | Discuss complications of an ICU stay and discuss ways to prevent the complications | Review | N/A | N/A | The goals of critical care must include a multidisciplinary approach to prevent long-term consequences of critical care. |
|----------------|--|--------|-----|-----|--|

II. Survivor Experiences

| Author/Date | Objective | Design | Sample | Analytic Strategy | Findings |
|---|--|---|----------------------------------|--|---|
| Abdalahim & Zeilani 2014 | To describe the experiences of Jordanian survivors of critical illness 3 months after discharge from ICU. | Qualitative Descriptive | 18 Jordanian survivors | Open ended interviews Interview transcripts were analyzed using content analysis. | Survivors describe the discharge from the hospital as a means of rescue from death. They began to value their spiritual and religious rituals. Negative traumatic experiences hinder their recovery process, patients struggled to resume their power and role in the family. |
| Agard, Egerod, Tonnesen & Lomborg 2012 | To explore and explain the challenges, concerns, and coping modalities in ICU survivors living with a partner or spouse during the first 12 months post ICU discharge. | Qualitative Longitudinal grounded theory study | 18 patients 18 partners | Semi-structured interviews. Interviews done at 3 and 12 months | ICU survivors struggled for independence and focused on 'recovering physical strength', 'regaining functional capacity', and 'resuming domestic roles'. |
| Alpers, Helseth & Bergbom 2011 | To gain knowledge on what factors contribute to inner strength in critically ill former ventilator treated patients. | Exploratory descriptive design. | 6 survivors 3 men and 3 women | A hermeneutic approach was used to interpret the data. | There are certain factors that promote the inner strength of patients undergoing ventilator treatment. These factors are: 'support of next of kin', wish to go on living', to be seen', and 'signs of progress' the presence of one's |

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| | | | | | next of kin has prime significance in promoting inner strength. |
| Cypress 2010 | Understand the experiences of patients, their family members as well as the nurses who care for them in the ICU. | Qualitative phenomenological study | 15 participants 5 patients 5 family members 5 nurses | Interviews analyzed using Van Manen's holistic, selective, and detailed line by line approach. | Adaptation in the ICU, as experienced by the participants form 3 categories, integrates family as a unit, physical care/comfort, physiological care and psychosocial support resulting in transformation. |
| Czerwonka, Herridge, Chan, Chu, Matte & Cameron 2014 | Explore participants' experiences and needs for information, emotional support, and training at 3, 6, 12 and 24 months after ICU discharge. | Qualitative pilot study | 5 survivors 7 family members | Qualitative interviews analyzed using framework methodology | Interventions designed to improve family outcomes after critical illness should address both the survivors' and caregivers' support needs as they change across the illness and recovery trajectory. |
| Deacon 2011 | To explore former ICU patients' views on what the key components of a post ICU rehabilitation program should be. | Qualitative study | 35 participants 30 females 5 males | Findings were analyzed using thematic analysis | Survivors experience a broad array of physical and psychological challenges. Healthcare providers need to ensure a holistic approach to coordinate and facilitate rehabilitation. |
| Storli, Lindseth & Asplund | Explore the meaning of living with memories from | Hermeneutic-phenomenological approach | 10 former ICU patients | In-depth interviews. | Some participants strive to understand |

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| 2008 | the ICU. | | | | experiences and reactions, living with these memories is interpreted as a journey, having someone and something to live for implied strength. |
|------|----------|--|--|--|---|

III. Rehabilitation

| Author/Date | Objective | Design | Sample | Analytic Strategy | Findings |
|---|---|--|---|--|---|
| Batterman, Bonner, Wright, Howell, Hugill & Danjoux 2014 | Explore the effect of an 8 week hospital based exercise training program on physical fitness and QOL | Minimized control trial | 30 participants- Control 29 participants- Intervention | Multiple regression | The intervention appeared to accelerate the natural recovery process and seems feasible. |
| Brummel, Jackson, Girard, et al. 2012 | The purpose of the protocol trial will be to determine the feasibility of early and sustained cognitive rehab paired with physical rehab. | RCT trial | N/A | Delis-Kaplan Executive function system tower test (D-KEFS) Timed up&go test (TUG) Mini-Mental State Examination (MMSE) | If the protocol is found feasible, the findings will lay the groundwork for a larger multi-center trial. |
| Calvo-Ayala, Babar, Khan, Farber, Ely & Boustani 2013 | Identify effective interventions that improve long-term PF in ICU survivors | Systematic Review | 14 studies | Review | The only effective intervention to improve long-term PF in critically ill patients is exercise/PT, its benefits may be greater if started earlier |
| Cuthbertson, Rattray, Campbell, Gager, Roughton, Smith, Hull, Breeman, Norrie, Jenkinson, Hernandez, Johnston, Wison & Waldmann 2009 | To test the hypothesis that nurse led follow up programs are effective and cost effective in improving quality of life after discharge from the ICU | Pragmatic, non-blinded, multicenter, randomized controlled trial | 286 participants | SF 36 | A nurse led intensive care program showed no evidence of being effective or cost effective in improving patients' QOL in the year after discharge from the ICU. |
| Elliott, McKinley, Alison, Aitken, | Test the effect of an individualized 8 | RCT | 195 participants | SF 36 physical function, 6 | This individualized 8 week home |

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|---|--|-------------------|-----------------|--|---|
| King, Leslie, Kenny, Taylor, Foley & Burmeister 2011 | week home-based physical rehabilitation program on recovery. | | | minute walk test | based rehab program did not increase the underlying rate of recovery in this sample. |
| McWilliams, Atkinson, Carter, Foex, Benington & Conway 2008 | Assess the impact of an outpatient physiotherapy-lead rehabilitation program on exercise capacity and anxiety and depression scores. | Prospective Study | 38 patients | 6 minute walk test and incremental shuttle walk test HADS | Outpatient physiotherapy lead rehab appears to improve both exercise capacity and anxiety and depression scores. |
| Melhorn, Freytag, Schmidt, Brunkhorst, Grag, Troitzsch, Schlattmann, Wensing & Gesichen 2014 | Determine which interventions are effective to support survivors of critical illness | Systematic Review | 18 studies | Two reviewers extracted data and assessed risk of bias independently | Interventions which have substantial effects in post-ICU patients is rare. Positive effects were seen for ICU diary interventions for PTSD. |
| O'Neill, McDowell, Bradley, et al. 2014 | To investigate the effectiveness and cost effectiveness of a 6 week exercise program on physical function. | RCT | 68 participants | SF 36 HADS | If it is effective it will improve outcomes that are meaningful to inform the design of a future multi-center study. |

IV. ICU Diaries

| Authors/Date | Objective | Design | Sample | Analytic Strategy | Findings |
|---|--|---|---|--|---|
| Akerman, Ersson, Fridlund & Samuelson 2013 | Identify the preferred content and usefulness of an ICU-diary as described by ICU patients | Descriptive, exploratory cohort design with a mixed methods approach | 115 answered questionnaire 15 participated in an interview | Questionnaire was analyzed by descriptive statistics and categorized by content, interviews were categorized by content analysis | It is essential that the ICU diary be complete and amplified by photos, all appearing in chronological order. |
| Egerod & Bagger 2010 | Explore patients' experiences and perceptions of receiving ICU diaries. | Triangulation design combining Focus groups and ICU diaries for 4 former ICU patients. | 4 former ICU patients | Patient narratives, inductive coding technique | Diaries might help ICU patients to gradually construct or reconstruct their own illness narrative, which is pieced together by their fragmented memory, the diary, the pictures, the hospital chart and the accounts from family and friends. |
| Egerod & Christensen 2009 | Describe the structure and content of patient diaries written for critically ill patients. | Qualitative, descriptive and explorative design | 25 patient diaries | Narrative approach analysis | Patient diaries acknowledge the patient experience and provide new insights into nursing performance. |
| Egerod, Christensen, Schwartz-Nielsen & Agard 2011 | Explore how patients and relatives use diaries in the context of the illness trajectory. | Qualitative multi-centered design | 19 patients | In-depth semi-structured interview technique | ICU diaries are useful to patients as well as their relative. |
| Ewens, Chapman, Tulloch & Hendricks 2013 | To explore survivors' and family members' perceptions and utilization of diaries following | Qualitative descriptive design | 18 participants | Surveys | The use of patient diaries are received positively by participants. They are simple, |

| | | | | | |
|---|---|----------------------|--------------|---|---|
| | hospital discharge. | | | | cost effective initiative which enabled survivors to piece together the time they had lost. |
| Ewens, Hendricks & Sundin 2014 | To critically appraise the available literature related to the use, prevalence, purpose, and potential therapeutic benefits of ICU diaries following discharge from the hospital. | Review of literature | 22 articles | 12 step approach described by Kable | Diaries are prevalent in Scandinavia and parts of Europe but not elsewhere. Further investigation is needed. |
| Jones, Backman, Capuzzo, Egerod, Flaatten, Granja, Rylander & Griffiths 2010 | Evaluate whether a prospectively collected diary of a patients' ICU stay when used during convalescence following a critical illness will reduce PTSD. | RCT | 352 patients | ICUMT, PTSS screening tool, PTSD scale, PDS | The provision of an ICU diary is effective in aiding psychological recovery and reduce g the new incidence to new PTSD. |

V. ICU Follow-up Clinics

| Author/Date | Objective | Design | Sample | Analytic Strategy | Findings |
|--|--|--|--|---|---|
| Cox, Porter, Hough, White, Kahn, Carson, Tulsy & Keefe 2012 | Develop and pilot test a telephone-based coping skills training intervention for survivors and their caregivers. | Cross sectional quantitative | 58 participants 21 patients 23 caregivers | HADS Scale PTSS Scale | A novel telephone based coping skills training intervention was acceptable, feasible, and may have been associated with a reduction in psychological distress among survivors. |
| Egerod, Risom, Thomsen, Storli, Eskerud, Holme & Samuelson 2012 | Describe and compare models of intensive care follow up in Denmark, Norway, and Sweden to help inform clinicians regarding the establishment and continuation of ICU aftercare programs. | Multicenter, comparative Qualitative Design | Denmark: 8 out of 48 ICU's provided follow-up 8 informants Norway: 18 out of 70 ICU's provided follow-up 18 informants Sweden: 30 out of 86 ICU's provided follow-up 5 informants | Combined data from semi-structured telephone interviews with unreported data from a precursory investigation. | ICU follow up programs in the Scandinavian countries have evolved as bottom up initiatives conducted on semi-voluntary basis. We suggest reframing follow-up as an integral part of patient therapy. |
| Fonsmark & Rosendahl-Nielsen 2015 | Describe and evaluate the knowledge gained from outpatient follow-up at a tertiary ICU. | | 101 ICU patients | HADS questionnaire | Data confirmed that a large proportion of ICU survivors suffer considerable long-term physical and neuropsychological compromise. ICU follow up may contribute to address these specific problems and to initiate needed interventions. |

| | | | | | |
|---|--|--|------------------|---|--|
| Haraldsson, Christensson, Conlon & Henricson 2015 | Describe how ICU patients experience a follow up session. | Qualitative design | 7 men 5 women | Semi-structured interviews. Qualitative content analysis was utilized. | This study highlighted the need for increasing collaboration between ICU staff and staff in other units to provide support to this patient group in order to reduce their suffering. |
| Jensen, Overgaard, Bestle, Christensen & Egerod 2016 | To describe the patient experience of ICU recovery from a longitudinal perspective by analyzing follow up consultations at three time points. | Descriptive multicenter longitudinal qualitative design. | 12 patients | Thematic analysis and narrative theory were used to explore mechanisms of recovery using audio-recordings of consultations, patient photographs and reflection sheets as the sources of data. | The study provides an understanding of the process of ICU recovery. Recovery evolves through narratives of moral danger, risk of relapse and moving forward towards a new orientation in life. |
| Jonasdottir, Klinke & Jonsdottir 2015 | TO analyze and synthesize the structure, content, types of outcome variables and advantages of nurse led follow up of adult patients after discharge from the ICU. | Integrative review | 17 papers | Integrative review method merged with the recommendation of the PRISMA statement. | Nurse led follow-up might promote patients' health and enable use of adequate resources. |
| Lasiter, Oles, Mundell, Landon & Khan 2016 | Identify evidence describing benefits of interventions provided in ICU survivor follow up clinics. | Scoping Review | 20 reports | Scoping review following the stepwise Arksey and O'Malley process. | Although ICU follow up clinics exist, evidence for interventions and effectiveness of treatments in these clinics remains underexplored. |
| Modrykamien 2012 | Focus on the most common long term outcomes post ICU admission, and will emphasize the importance of | Review | NA | | ICU follow up clinics seem intuitively to be important for both patients and relatives. Despite the lack of supporting evidence |

| | | | | | |
|--------------------------------------|--|---|------------------------|---|---|
| | developing ICU clinics to provide comprehensive care to ICU survivors. | | | | and financial constraints still remain, there is now a growing understanding of long term outcomes. |
| Prinjha, Field & Rowan 2009 | Explored patients' perceptions and experiences of ICU follow-up services | Qualitative | 34 former ICU patients | Qualitative interviews analyzed using thematic analysis | Former patients said they valued ICU follow-up, which made an important contribution to their physical, emotional and psychological recovery. Those without follow up care often felt abandoned or disappointed because they had not opportunity to be monitored or get more information. |
| Samuelson & Corrigan 2009 | To establish an intensive care after-care program and to conduct a preliminary evaluation of the follow up service from the patients' and relatives' perspectives. | Descriptive and evaluative design was used. | 170 survivors | Evaluation questionnaire | The development and preliminary evaluation of this nurse-led intensive care program resulted in a feasible program requiring modest resources, with a high level of patient and relative satisfaction. |
| Storli & Lind 2008 | The aim of the study was to explore the meaning of patients' lived experience of being followed-up in a program consisting of patient diaries, post ICU care conversations and visits back to the ICU. | Qualitative hermeneutic-phenomenological design | 10 patients | Data was analyzed by using a hermeneutic-phenomenological approach. | Patients' seek to understand experiences they have undergone. They search for meaning in experiences and memories. |
| Schandl, Brattstrom, Swensson-Raskh, | To describe a multidisciplinary ICU follow up and the methods | Quantitative design | 61 patients | Impact and Event Scale Hospital Anxiety | Multidisciplinary follow up after ICU can be of value in identifying |

| | | | | | |
|--------------------------------------|---|-------------------|------------|--|---|
| Hellgren, Falkenhav & Sackey 2011 | used for identifying and managing physical and psychological problems in ICU survivors. | | | and Depression Scale | untreated physical and psychological problems of ICU survivors. Patients screened and treated in the first 6 months appear to have little need for further follow up after ICU. |
| Williams, Sci & Leslie 2011 | To examine the frequency and reasons patients admitted to ICU's who survive critical illness are excluded from study participation or lost to follow-up and consider the possible implications and solutions. | Literature review | 10 studies | Literature search of online databased MEDLINE, EMBASE and CINAHL from 2006-2010. | Reasons for loss to follow-up included no response, inability to contact the patient, too ill or admitted to another facility. The most appropriate method of care follow-up has yet to be established yet but is likely to involve an eclectic model that tailors service provision to support individual patient's needs. |

APPENDIX B: IRB Approval Letters

*Medical College of Wisconsin /
Froedtert Hospital
Institutional Review Board*

To: Jill Guttormson, PhD, RN
Kelly Calkins, MSN, RN

Date: 12/1/2017

Re: Project Title: Critical Illness Survivor's Perceptions of their Recovery

PRO ID: [PRO00030586](#)

IRB Approval Date: 12/1/2017

IRB Expiration Date: 11/30/2018

The MCW/FH Institutional Review Board #5 has granted approval for the above-referenced submission in accordance with 45 CFR 46.111 by expedited review, Categories 5, 6, and 7.

Approval has been granted for the following institutions:

Froedtert & the Medical College of Wisconsin Hospitals and Health Partners
Froedtert Hospital Campus (including all specialty clinics, the Cancer Center and the Eye Institute)
Marquette University
UW-Milwaukee
Ascension Hospitals Mercy Medical Center

The items listed below were submitted and reviewed when the IRB approved this submission. Research must be conducted according to the IRB approved document listed below:

Proposal (1)
Alteration of Consent final
Calkins - St. Elizabeth ICU Letter - 10-11-2017
Kelly study approval letter.Mercy
Kelly Jean Calkins rsearch support letter.St.Joe
Froedtert.MICU support letter ICU survivors

Advertisement.FamilyWaitingRoom
CalkinsCV2017
Calkins.Study.Flyer.Nurses
Demographic form
Permission to Contact Form final.9.12
IRB.Interview Guide.KC

The IRB has granted approval of an alteration of the informed consent requirements at 45 CFR 46.116 for this project. However, you must use the IRB-approved consent language.

The IRB has granted approval of a waiver of HIPAA authorization requirements at 45 CFR 164 for this project.

Decedent data may be accessed in accordance with 45 CFR 164.512.

Any and all proposed changes to this submission must be reviewed and approved by the IRB prior to implementation. When it is necessary to eliminate hazards to subjects, changes may be made first. This should be followed promptly by a Reportable Event for a protocol deviation and Amendment.

In accordance with federal regulations, continuing approval for this submission is required prior to 11/30/2018. The Continuing Progress Report (CPR) must be received by the IRB with enough time to allow for review and approval prior to the expiration date. Failure to submit the CPR in a timely manner may result in the expiration of IRB approval.

A Final Report must be submitted to the IRB within 30 days of when all project activities and data analysis have been completed.

All Unanticipated Problems Involving Risks to Subjects or Others (UPIRSO) must be reported promptly to the MCW/FH IRB according to IRB Standard Operating Procedures (SOPs).

If your project involves the use of any Froedtert Health resource such as, space, staff services, supplies/equipment or any ancillary services - lab, pharmacy, radiology, protected health/billing information or specimen requests, OCRICC approval is required before beginning any research activity at those sites.

If you have any questions, please contact the IRB Coordinator II for this IRB Committee, Dana Hirn Mueller, at 414-955-8601 or dhirn@mcw.edu.

Sincerely,

Kathryn Gaudreau
David Clark, PhD
IRB Chair

APPENDIX C: Support Letters

Courtney Shears, MBA, RN, BSN, CCRN
Patient Care Manager
Mercy Medical Center
500 S. Oakwood Road
Oshkosh, WI 54904

October 5, 2017

To Whom It May Concern,

As Nurse Manager of the ICU at Mercy Medical Center, I am pleased to offer support for the study: Critical Illness Survivor's Perceptions of their Recovery (PI: Jill Guttormson, PHD, RN and Kelly Calkins, PhD Candidate, RN). This research study will provide knowledge and insight of the critical care experience and the patient's perceptions which will help the advancement of critical care nursing. The information gained from this study will also help our ICU at Mercy Medical Center gain valuable information to improve our quality of care and to offer better support to the patients we serve.

Kelly Calkins discussed this study with the ICU leadership team and we support her.

Sincerely,

Courtney Shears, MBA, RN, BSN, CCRN
Patient Care Manager
Mercy Medical Center
920-223-1009



Ascension

October 9, 2017

To Whom It May Concern:

This is a letter of support for academic research progression for Kelly Jean Calkins project, **Critical Illness Survivor's Perceptions of their Recovery**". Her intent is to interact with our staff leadership for subject selection for her research: intubated and ventilated patients who are discharged to home. This is exciting research and the CCU at St Joseph Hospital, Part of Ascension Wisconsin is pleased to assist her. We have received the IRB review of Protocol #1148 dated 8-30-2017 and consider our screening participation to direct the student for subject selection as not "engaged" in research.

Please contact me for the opportunity to introduce you and your project to the staff nurses at our next CCU staff meeting, October 24, 2017 at 0800 in M102.

Sincerely

Leslie Daugherty, BSN, RN, CCRN
Patient Care Supervisor
St Joseph Hospital: Part of Ascension
5000 W. Chambers Street
Milwaukee, WI 53210
Leslie.daugherty@ascension.org

414-447-2709

St. Joseph Campus, 5000 W. Chambers Street, Milwaukee, WI 53210 | www.ascension.org



Froedtert Hospital
9200 West Wisconsin Avenue
Milwaukee, WI 53226
froedtert.com

September 28, 2017

To Whom It May Concern,

As Nurse Manager of the MICU at Froedtert Hospital, I am pleased to offer support for the study: Critical Illness Survivor's Perceptions of their Recovery (PI: Jill Guttormson, PHD, RN and Kelly Calkins, PhD Candidate, RN). This research study will provide knowledge about the experiences of patients who have been in the ICU. This is valuable information that can inform future nursing practices in the MICU.

Kelly Calkins discussed this study with the MICU leadership team. Natalie McAndrew, the Clinical Nurse Specialist who oversees research projects that influence nursing workflow, also has reviewed this project and provides endorsement of this work.

Sincerely,

Jennifer Neubauer

Jennifer Neubauer, BSN, RN
Nurse Manager, Medical Intensive Care Unit and RRT
Froedtert Hospital
Ph.(414) 805 8803
Pg.(414) 314 2632

Natalie S. McAndrew

Natalie S. McAndrew, MSN, RN, ACNS-BC, CCRN
Clinical Nurse Specialist, Medical Intensive Care Unit
Phone: 414-805-1062
Pager: 414-314-2351
Email: natalie.mcandrew@froedtert.com



St. Elizabeth Hospital

Fremont Tower
1506 S. Oneida St.
Appleton, WI 54915
October 11, 2017

To Whom It May Concern,

As the Director of Nursing over the ICU at Ascension St. Elizabeth Hospital, I am pleased to offer support for the study: Critical Illness Survivor's Perceptions of their Recovery (PI: Jill Guttormson, PHD, RN and Kelly Calkins, PhD Candidate, RN). This research study will provide knowledge about the experiences of patients who have been in the ICU. This is valuable information that can inform future nursing practices in the ICU at Ascension St. Elizabeth Hospital.

Kelly Calkins discussed this study with the leadership team in the ICU and we have no concerns with issuing her access to our patient population.

Sincerely,

Jamin Homan

**Jamin Homan DNP RN
Director of Patient Care Services
St. Elizabeth Hospital**

(920) 831-1537

Jamin.homan@ascension.org

APPENDIX D: Recruitment Flyer

Nursing Research Study: Critical Illness Survivor's Perceptions of their Recovery

➤ **Purpose:** To gain a better understanding of how critical illness survivors experience their recovery, the interventions used during their recovery, as well as what they experience as facilitators and barriers to their recovery.


➤ Research staff will screen for eligible patients by checking with the charge nurse and staff nurses.

➤ Permission to contact and all data collection will be completed by research staff.

Eligibility Criteria

- ❖ 18 years or older
- ❖ Speaks and Understands English
- ❖ In the ICU for 3 or more days
- ❖ Mechanical Ventilation for > 24 hours

Researcher Contact Information:
Kelly Calkins, MSN, RN
University of Wisconsin
Milwaukee
College of Nursing
920-410-5738
calkinsk@uwm.edu



APPENDIX E: Permission to Contact

Permission to be Contacted for Research

Critical Illness Survivors' Perceptions of their Recovery

You are receiving this information because you or your family member has been a patient in the critical care unit and was on the ventilator (breathing machine).

What is the purpose of this permission form? Jill Guttormson from Marquette University and Kelly Calkins from the University of Wisconsin Milwaukee, are conducting a study to better understand the experience of recovering from critical illness. This form is to determine if you might be interested in hearing more about this study after you are discharged from the hospital.

What happens if I complete and sign this form? If you sign this form, you are giving permission for the researcher to contact you about two weeks after you are discharged from the hospital. You can decide at that time if you wish to participate in the study or not. You do not have to participate. You may withdraw permission to be contacted at any time by contacting Kelly Calkin at calkinsk@uwm.edu or (920) 410-5738.

What happens if I don't sign this form? You do not have to sign this form or provide contact information. You are free to say yes or no. Whether or not you sign this form, your usual medical services will not change.

Are there any risks to my signing this form? Providing your contact information may involve some loss of privacy. However, access to your contact information will be limited to only the individuals directly involved in this research study. No information will be used for any other research study. Your contact information will not be shared with anyone else.

Are there any financial considerations? There will be no cost or payment to you if you sign this form.

What do I do if I have questions, now or later? You can talk with the study team about any questions, concerns or complaints you have about this study. Contact Kelly Calkins at (920) 410-5738 or calkinsk@uwm.edu with questions.

If you have questions about your rights as a potential study participant, want to report any problems or complaints, obtain information about the study, or offer input you can call the Medical College of Wisconsin/Froedtert Hospital Research Subject Advocate at 414-955-8844.

What happens now? If you are interested in hearing more about this study, please complete the form and sign below. If you change your mind after you provide your information, simply tell the researcher when they contact you that you are no longer interested and no further contact will be made.

Contact Information

Name of Patient: _____

Email: _____

Home Phone: _____

Cell Phone: _____

Do we have your permission to leave a voicemail about the study?

Yes

No

By signing my name below, I give permission to the research team to contact myself or my family member about participating in the research study.

Name (please print)

Signature

Date

Relationship to Patient (if applicable)

APPENDIX F: Informed Consent

Dear Critical Illness Survivor

You are invited to participate in a research study examining the recovery from a critical illness after discharge from the hospital. We will look specifically at what you have done to help with your recovery as well as what barriers you have had during your recovery.

Although you will not get personal benefit from taking part in this research study, your responses may help us understand more about the recovery of critical illness survivors. Participation in this study is completely voluntary, and you may choose to withdraw from the study at any time. We hope to interview 30 people

If you choose to participate, you will be asked to fill out a demographic survey and participate in an interview. The demographic survey asks details such as your age, gender, ethnicity, marital status, employment status and living arrangements. This information will only be used to provide general details about survivors who participated in this study. The interview will take about an hour to complete and will be digitally recorded.

The study team needs your permission to access, collect and use some of your health information in order to provide general information about the survivors who were included in this study. This information will be retrieved from the electronic medical record. We will only collect and use information needed for the study. The protected health information (PHI) originates from the services you have received at Froedtert Memorial Lutheran Hospital, St. Joseph's Hospital, St. Elizabeth's Hospital or Mercy Medical Center. **The health information we will collect and use for this study is:** admission diagnosis, days in the ICU, days on the ventilator, medical interventions, treatments, test results and medical history. The only people allowed to handle your health information are those on the study team, those on the Institutional Review Board (IRB) and those who check on the research activities to make sure the hospital's rules are followed. If you agree that we can collect this information from your medical record, we ask that you sign this form.

Your response to the survey will be kept confidential to the extent allowed by law. When we write about the study you will not be identified and your name will not be used in presentations or publications.

Although we have tried to minimize this, some questions may make you upset or feel uncomfortable. You are free to skip any questions or stop the interview at any time. If you experience distress after completion of this interview you may contact the crisis hotline at 1-800-273-8255. The crisis line provides safe, confidential, free support and/or assistance 24 hours a day.

If you have questions about the study, please feel free to ask a member of the research team; contact information is given below. If you have questions about your rights as a research participant or want to report any problems or complaints, you can call the Medical College of Wisconsin/Froedtert Hospital Research Subject Advocate at (414) 456-8844.

Thank you in advance for your assistance with this important project.

Sincerely,

Jill Guttormson, MS, PhD, RN
Marquette University
Milwaukee
College of Nursing
414-288-3819
jill.guttormson@marquette.edu

Kelly Calkins, MSN, RN, CCRN
University of Wisconsin
College of Nursing
920-410-5738
calkinsk@uwm.edu

If you agree to participate in this study, we ask that you provide your signature indicating you understand your rights as a participant in this study.

I agree to participate in this study.

Date: _____

Signature _____

Date: _____

Researcher signature _____

I give permission for the research team to access my electronic medical record as described in this form.

Date: _____

Signature _____

Date: _____

Researcher signature _____

APPENDIX G: Interview Guide

Interview Guide

1. Tell me about your critical illness experience.
2. How would you describe your recovery from your critical illness and ICU stay?
3. How has it been living your life since being discharged from the hospital?
4. Tell me what have you done to facilitate your recovery since discharge from the hospital?
 - a. How do you perceive that it has helped you in your recovery?
 - b. What do you perceive that health care providers could do to better assist you in your recovery?
5. Tell me about challenges that you have encountered since you were discharged from the hospital.
 - a. How have you managed these challenges?
6. Tell me about your physical recovery from your critical illness.
 - a. Are you back to your baseline physical function?
 - b. What have you done to assist in your physical recovery?
7. Tell me about your memory (cognitive function) since your recovery from your critical illness.
 - a. Have you noticed any changes to your memory?
 - b. If so, what have you done about these changes?
8. Tell me about your mood (psychosocial function) since recovery from your critical illness.

- a. Have you experienced any anxiety or depression with your recovery from your critical illness?
 - b. If so, what have you done about this?
9. Is there anything else you would like to share with me?

APPENDIX G: Chart Review Data

Chart Review Data

1. Diagnosis
2. Days in ICU
3. Days on mechanical Ventilation
4. Vasopressors
5. Sedation

Data to calculate APACHE II score

1. Age
2. Temperature
3. Mean Arterial Pressure
4. Heart Rate
5. Respirations
6. Potassium
7. Sodium
8. Creatinine
9. White Blood Cells
10. Hematocrit
11. Glasgow Coma Scale
12. ABG's: PH/PaO2/PCO2/%FIO2
13. Calculated APACHE II Score:

APPENDIX H: Demographic Form

Demographic Form

Thank you for agreeing to participate in this research. As part of the study we are collecting demographic data to describe our sample. Please fill out this survey. Feel free to skip any questions you do not want to answer.

1. What is your gender? Female Male Transgender
2. How old are you? 18-25 years 26-49 years 50-64 years 65 and older
3. What is your race/ethnicity?
 - Asian or Pacific Islander
 - Black/African American
 - Hispanic/Latino
 - American Indian/Native American
 - White/Caucasian
 - Other _____
4. What is your marital status?
 - Married
 - Single
 - Separated
 - Divorced
5. Do you live alone?
 - Yes
 - No
6. What is the highest level of school you completed?
 - Some high school
 - High school
 - Some college
 - Associate degree
 - Bachelor's degree
 - Master's degree
 - Doctorate
7. Are you currently employed?
 - Full time
 - Part time
 - Unemployed
 - Disabled
8. If you are currently working, are you back to work?
 - Yes
 - No

9. What is your religious preference?
- Catholic
 - Lutheran
 - Protestant
 - Jewish
 - Mormon
 - Muslim
 - Other _____
10. Do you currently practice your religion?
- Yes
 - No

APPENDIX I: Demographic Data

| Descriptor | Percentage % | Number |
|---|---------------------|---------------|
| <i>Race</i> | | |
| Black/African American | 56% | 10 |
| White/Caucasian | 44% | 8 |
| <i>Marital Status</i> | | |
| Married | 50% | 9 |
| Single | 44% | 8 |
| Divorced | 6% | 1 |
| <i>Housing</i> | | |
| Alone | 22% | 4 |
| Lives with Family/Spouse/Friend | 78% | 14 |
| <i>Education</i> | | |
| Grade School | 6% | 1 |
| Some High school | 6% | 1 |
| High school | 44% | 8 |
| Some College | 22% | 4 |
| Bachelor | 6% | 1 |
| Masters | 11% | 2 |
| Doctorate | 6% | 1 |
| <i>Employment</i> | | |
| Part-time | 17% | 3 |
| Unemployed | 22% | 4 |
| Disabled | 44% | 8 |
| Retired | 17% | 3 |
| <i>Currently Working</i> | | |
| Yes | 17% | 3 |
| No | 83% | 15 |
| <i>Religion</i> | | |
| Catholic | 22% | 4 |
| Lutheran | 17% | 3 |
| Apostolic | 6% | 1 |
| Baptist | 22% | 4 |
| None | 22% | 4 |
| No answer | 11% | 2 |
| <i>Currently Practicing Religion</i> | | |
| Yes | 50% | 9 |
| No | 44% | 8 |
| No answer | 6% | 1 |

APPENDIX J: ICU Data

| Survivor | Age Years | APACHE II Score % Mortality | # Days in ICU | # Days on Ventilator | Vasopressors Yes/No | Sedation Yes/No | Miscellaneous |
|----------|-----------|-----------------------------|---------------|-----------------------------|---------------------|-----------------|--|
| Barbara | 62 | 32.0 71% | 4 | 3 | Yes | Yes | |
| Chuck | 62 | 22.0 40% | 6 | 4 | Yes | Yes | |
| Matt | 48 | 22.0 40% | 9 | 8 | Yes | Yes | |
| Bill | 61 | 21.0 40% | 10 | 7 | Yes | Yes | |
| Sue | 57 | 12.0 12% | 3 | 2 | No | Yes | |
| Marg | 65 | 24.0 40% | 6 | 1 | Yes | Yes | |
| Doug | 56 | 14.0 12% | 48 | 4 12 16 total days | Yes | Yes | Participant was intubated twice during his ICU stay |
| Tosha | 50 | 31.0 71% | 10 | 7 | No | Yes | |
| William | 50 | Unable to calculate | 3 | 2 | Yes | Yes | Unable to calculate APACHE II score due to an arterial ABG was not drawn |
| Jim | 63 | 30.0 71% | 3 | 1 | Yes | Yes | |
| Patricia | 76 | 24.0 40% | 4 | 4 | Yes | Yes | |
| Jennifer | 19 | 10.0 12% | 6 | 5 | Yes | yes | |
| Steve | 71 | 13.0 12% | 5 | 1 | Yes | Yes | |
| Mike | 65 | 7.0 6% | 5 | 3 | No | Yes | |
| Daryl | 64 | 22.0 40% | 5 | 2 | Yes | Yes | |
| Bob | 46 | 22.0 40% | 5 | 4 | Yes | Yes | |

| | | | | | | | |
|------|----|-------------|----|----|-----|-----|--|
| Deb | 64 | 22.0 40% | 8 | 5 | Yes | Yes | |
| Dale | 56 | 20 40% | 16 | 14 | No | Yes | |

Curriculum Vitae

Kelly Calkins

EDUCATION

PhD

University of Wisconsin-Milwaukee, College of Nursing December 2018
Advisor: Dr. Peninnah Kako
Dissertation Title: Critical Illness Survivors' Perceptions of Their Recovery

MSN

University of Wisconsin-Oshkosh, College of Nursing May 2014

BSN

University of Wisconsin-Oshkosh, College of Nursing May 2001

TEACHING EXPERIENCE

2018-present Instructional Academic Staff, University of Wisconsin-Oshkosh
College of Nursing
Accelerated Nursing Program Boot camp
Junior II Lab

2012-2014 Instructional Academic Staff, University of Wisconsin-Oshkosh
College of Nursing
Junior I Clinical
Junior II Clinical

PROFESSIONAL EXPERIENCE

2012-present Post Anesthesia Care Unit, Mercy Ascension Hospital, Oshkosh, WI.
Staff Nurse

2004-present Intensive Care Unit, Mercy Ascension Hospital, Oshkosh, WI.
Staff Nurse

2001 to 2004 Cardiac, pulmonary, Renal floor, Mercy Ascension Hospital, Oshkosh, WI.
Staff Nurse

CERTIFICATIONS

2016 Collaborative Institutional Training Initiative (CITI) for Social and Behavioral
Researchers
2018-2020 Advanced Cardiac Life Support
2018-2020 Basic Life Support
2017-2020 Certified Critical Care Nurse
2017-2019 Pediatric Advanced Life Support

RESEARCH SUPPORT

Funding

2018-2018 Building Bridges Dissertation Grant (\$2500.00)

Ongoing Research

2017-present Dissertation: Critical Illness Survivors Perceptions' of their Recovery: An Phenomenological Inquiry

PRESENTATIONS

2015 Distinguished presenter Nursing Student Association (NSA) meeting

2016 Student poster presentation at MNRS March 2016

Calkins, K.J. & Leske, J. (2016) Family member demographics: Strengths and outcomes after resuscitation after trauma. Poster presentation at Midwest Nursing Research Society Annual Conference, Milwaukee, WI., May, 2016.

2016 Student poster presentation at Eta Nu Poster Symposium November 2016: 2nd place PhD Students.

Calkins, K.J. & Leske, J. (2016) Family member demographics: Strengths and outcomes after resuscitation after trauma. Poster presentation at Eta Nu Poster Symposium, Milwaukee, WI., November, 2016

2017 Student poster discussion presentation at MNRS April 2017

Calkins, K.J. & Kako, P (2017) Post traumatic growth: A review of literature. Poster discussion at Midwest Nursing Research Society annual conference, Minneapolis, MN, April, 2017.

2017 Student poster presentation at Building Bridges May 2017: 1st place poster award

Calkins, K.J. & Kako, P. (2017) Post intensive care syndrome: A pilot study of patients' perceptions. Poster presentation at Building Bridges building bridges to research-based nursing education conference, Milwaukee, WI. May, 2017.

SERVICE

2016-present Omro Youth Wrestling Board-Secretary

2017-present Omro Youth Baseball Board-Secretary

HONORS & AWARDS

2016/2018 Jonas Nurse Leader Scholar Award

2014/2016 Nurses for Wisconsin Grant

2013/2014 Willard and Margaret Blanke Scholarship

2009 Delores Wassman Nurse Mentor Award

PROFESSIONAL MEMBERSHIPS

American Thoracic Society

American Association of Critical Care Nurses

UW-Milwaukee Doctoral Student Nurses Association-Treasurer 2016-201

Midwest Nursing Research Society

Sigma Theta Tau International