

**EXPLORING PRIMARY PALLIATIVE CARE NEEDS  
IN SURVIVORS OF CRITICAL ILLNESS**

by

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## EXPLORING PRIMARY PALLIATIVE CARE NEEDS IN SURVIVORS OF CRITICAL ILLNESS

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University of Pittsburgh, 2021

**Background:** Survivors of critical illness often experience profound changes in their lives after the intensive care unit (ICU). Although there is promise seen in the increased survival of ICU patients, there are numerous, troubling long-term consequences for these survivors. Given the substantial impairment seen, critical illness survivors possess care needs that are clearly within the scope of palliative care, however the role of palliative care has yet to be clearly defined in critical illness survivors.

**Purpose:** The purpose of this project was: (1) to explore palliative care needs of critical illness survivors in the post-ICU clinic setting through the lens of both survivors and post-ICU clinic interprofessional clinicians, and (2) provide further insight into the overall symptom burden in this population and its effects on health-related quality of life.

**Methods:** Aims 1 and 2 utilized semi-structured interviews and framework analysis to explore the broader experience of surviving critical illness and the impact of these factors on other health care planning. Aim 1 interviewed a diverse group of 17 critical illness survivors and Aim 2 interviewed 29 international post-intensive care unit (ICU) clinic interprofessional clinicians. Aim 3 utilized a retrospective, patient-level cross-sectional observational design of 170 critical illness survivors (aged  $\geq 18$  years) seen during an initial post-intensive care unit (ICU) outpatient clinic visit between June 2018 and March 2020. De-identified patient demographics, clinical characteristics, and functional status were abstracted, along with self-reported symptom burden

using PEACE Tool. These data were evaluated for symptom prevalence and severity and its effect on overall health score reporting. Exploratory factor analysis (EFA) was used to identify symptom clusters measured approximately 1 month after hospital discharge, and hierarchical regression analysis was used to examine relationships between the identified symptom clusters and overall health score reporting (EQ-VAS) controlling for age, current in-clinic Lawton IADL score and current Clinical Frailty Scale (CFS).

**Results:** Important themes in the critical illness survivor interviews highlighted persistent symptom burden, patient-centered goals for care, spiritual change and significance, understanding and interpreting illness, and a list of multifaceted social needs. Interviews with interprofessional clinicians identified palliative needs for ICU survivors and their families, however, some confusion persists among clinicians regarding the complete definition of palliative care and how it can be incorporated into their current post-ICU clinic practice. Key elements of palliative care for ICU survivors identified included: revisiting goals of care, symptom management, patient and family support, communication (e.g., medical interpretation, expectation management), spiritual support, and provision of goal-concordant care. For Aim 3, the most prevalent symptoms included weakness/low energy (79.4%), diminished level of function (70.0%), pain (76.5%), and sleep disturbance (67.1%). Symptoms with highest level of severity included pain ( $6.15 \pm 2.88$ ), incontinence ( $5.72 \pm 3.12$ ), and sleep disturbance ( $5.71 \pm 2.65$ ). Additionally, unmet social needs, such as not feeling prepared/fear of future (51.2%), ineffective coping/not in control of care (48.8%), and perceived lack of support (35.9%) were reported. Spiritual distress was reported in 13.5% of patients. The EFA model identified 3 symptom clusters: the stress response cluster, the fatigue/sleep disturbance cluster, and the anxiety/depression cluster. Factor 3 (fatigue/sleep

disturbance symptom cluster) and factor 4 (anxiety/depression cluster) were strong predictors of overall health score reporting, along with age and current CFS score.

**Conclusions:** Survivors of critical illness suffer an extensive symptom burden beyond the typically reported manifestations of post-intensive care syndrome (PICS). In addition to symptoms in physical, cognitive, and psychological domains, symptoms associated with social needs are widespread. These findings support standardization of symptom assessment and management in patient surviving critical illness. Additionally, these findings suggest that both critical illness survivors and post-ICU clinicians recognize ongoing holistic care needs which may be well managed by applying a primary palliative care approach to address these unresolved and wide-ranging concerns.

## TABLE OF CONTENTS

<b>PREFACE.....</b>	<b>XV</b>
<b>1.0 DISSERTATION PROPOSAL.....</b>	<b>1</b>
<b>1.1 INTRODUCTION .....</b>	<b>1</b>
<b>1.2 SPECIFIC AIMS .....</b>	<b>3</b>
<b>1.3 BACKGROUND .....</b>	<b>4</b>
<b>1.3.1 Critical illness survivorship .....</b>	<b>4</b>
<b>1.3.2 Symptom reporting after critical illness .....</b>	<b>7</b>
<b>1.3.3 Exploring symptom clusters.....</b>	<b>9</b>
<b>1.3.4 Review of specialty post-ICU follow-up care.....</b>	<b>11</b>
<b>1.3.5 Overview of palliative care and its suggested role in post-ICU care.....</b>	<b>13</b>
<b>1.3.6 Limitations of primary palliative care in post-ICU follow-up care .....</b>	<b>14</b>
<b>1.4 SIGNIFICANCE.....</b>	<b>15</b>
<b>1.5 INNOVATION.....</b>	<b>16</b>
<b>1.6 PRELIMINARY WORK .....</b>	<b>17</b>
<b>1.6.1 PUBLISHED MANUSCRIPT: Caring for the Critical Illness Survivor: Current Practices and the Role of the Nurse in ICU Aftercare.....</b>	<b>17</b>
<b>1.6.2 PUBLISHED ABSTRACT: Exploring Goals of Care in Patients Surviving Critical Illness .....</b>	<b>18</b>
<b>1.6.3 PUBLISHED ABSTRACT: Implementation of a primary palliative care intervention in patients surviving critical illness: A process evaluation.....</b>	<b>19</b>
<b>1.7 RESEARCH DESIGN AND METHODOLOGY.....</b>	<b>20</b>

<b>1.7.1</b>	<b>Theoretical approaches and philosophical assumptions .....</b>	<b>20</b>
1.7.1.1	Theoretical principle for Aims 1 and 2 .....	21
1.7.1.2	Theoretical principle for Aim 3 .....	22
<b>1.7.2</b>	<b>Overview of the Critical Illness Recovery Center (CIRC).....</b>	<b>23</b>
<b>1.7.3</b>	<b>Approach for Aim 1 .....</b>	<b>27</b>
1.7.3.1	Study design.....	27
1.7.3.2	Sample, recruitment, and rationale.....	27
1.7.3.3	Data collection .....	28
<b>1.7.4</b>	<b>Approach for Aim 2 .....</b>	<b>29</b>
1.7.4.1	Study design.....	29
1.7.4.2	Sample, recruitment, and rationale.....	29
1.7.4.3	Data collection .....	30
1.7.4.4	Data analysis for Aims 1 and 2 .....	31
<b>1.7.5</b>	<b>Approach for Aim 3 .....</b>	<b>33</b>
1.7.5.1	Study design.....	33
1.7.5.2	Population and Sample.....	34
1.7.5.3	Data sources and collection .....	34
1.7.5.4	Variables and measures.....	35
1.7.5.5	Data analysis plan for Aim 3.....	43
<b>1.7.6</b>	<b>Anticipated study limitations .....</b>	<b>48</b>
1.7.6.1	Aim 1 limitations .....	48
1.7.6.2	Aim 2 limitations .....	49
1.7.6.3	Aim 3 limitations .....	49



1.7.7	Potential benefits of proposed research .....	49
1.7.8	Importance of knowledge to be gained .....	50
1.7.9	Protection of human subjects and reduction of risks .....	51
2.0	<b>ADDITIONS AND CHANGES TO THE PROPOSED STUDY.....</b>	<b>53</b>
2.1	CHANGES TO AIM 1.....	53
2.2	CHANGES TO AIM 2.....	54
2.3	CHANGES TO AIM 3.....	54
3.0	<b>SUMMARY OF COMPLETED DISSERTATION STUDY .....</b>	<b>57</b>
3.1	<b>AIM 1 RESULTS.....</b>	<b>57</b>
3.1.1	<b>UNPUBLISHED MANUSCRIPT: Exploring the Intersection between Palliative Care and Critical Illness Survivorship: A Qualitative Study of Patient Experiences .....</b>	<b>57</b>
3.1.1.1	Abstract.....	57
3.1.1.2	Introduction.....	58
3.1.1.3	Materials and Methods.....	60
3.1.1.4	Setting and ethical approval.....	60
3.1.1.5	Study design, participants, sampling, and recruitment.....	60
3.1.1.6	Data collection and generation.....	61
3.1.1.7	Data analysis, researcher reflexivity, relationship with participants, and rigor .....	62
3.1.1.8	Results .....	63
3.1.1.9	Theme 1: Persistent symptom burden .....	65
3.1.1.10	Theme 2: Patient-centered goals for care .....	67

3.1.1.11	Theme 3: Spiritual change and significance.....	69
3.1.1.12	Theme 4: Understanding and interpreting illness .....	70
3.1.1.13	Theme 5: Ongoing social and practical support needs.....	72
3.1.1.14	Discussion.....	77
3.1.1.15	Conclusions .....	80
3.1.2	Additional Considerations for Completed Aim 1 Study .....	81
3.1.2.1	Discussion of data collection procedures .....	81
3.1.2.2	Discussion of data analysis procedures.....	81
3.2	AIM 2 RESULTS.....	87
3.2.1	UNPUBLISHED MANUSCRIPT: Extending the Culture of Palliative Care to Critical Illness Survivors: A Qualitative Inquiry of Post-ICU Clinic Interprofessional Clinicians .....	87
3.2.1.1	Abstract.....	87
3.2.1.2	Introduction.....	88
3.2.1.3	Materials and Methods.....	89
3.2.1.4	Setting and ethical approval.....	90
3.2.1.5	Study design, participants, sampling, and recruitment.....	90
3.2.1.6	Data collection and generation.....	91
3.2.1.7	Data analysis, researcher reflexivity, relationship with participants, and rigor .....	93
3.2.1.8	Results .....	94
3.2.1.9	Defining Palliative Care.....	95
3.2.1.10	Key elements of palliative care that may benefit ICU survivors	100

3.2.1.11	Barriers and facilitators in delivering palliative care to ICU survivors .....	103
3.2.1.12	Discussion.....	109
3.2.1.13	Conclusions.....	111
3.2.2	Additional Considerations for Completed Aim 2 Study.....	112
3.2.2.1	Discussion of data collection procedures .....	112
3.2.2.2	Discussion of data analysis procedures .....	112
3.2.2.3	Additional findings.....	114
3.3	AIM 3 RESULTS.....	116
3.3.1	Reporting of Aim 3.....	116
3.3.2	UNPUBLISHED MANUSCRIPT: Exploring the Landscape of Symptom Burden in Critical Illness Survivors.....	116
3.3.2.1	Abstract.....	116
3.3.2.2	Introduction.....	118
3.3.2.3	Methods.....	119
3.3.2.4	Measures .....	120
3.3.2.5	Results .....	126
3.3.2.6	Discussion.....	130
3.3.2.7	Conclusion.....	132
3.3.3	Results of Aim 3b and 3c.....	132
3.3.3.1	Aim 3b results.....	132
3.3.3.2	Aim 3c results .....	136
3.3.3.3	Aim 3b and 3c discussion.....	138

<b>3.4</b>	<b>CONCLUSION .....</b>	<b>139</b>
<b>3.5</b>	<b>IMPLICATIONS AND DIRECTIONS FOR FUTURE WORK .....</b>	<b>139</b>
<b>APPENDIX A.....</b>	<b>.....</b>	<b>140</b>
<b>APPENDIX B.....</b>	<b>.....</b>	<b>147</b>
<b>APPENDIX C.....</b>	<b>.....</b>	<b>148</b>
<b>APPENDIX D.....</b>	<b>.....</b>	<b>149</b>
<b>APPENDIX E .....</b>	<b>.....</b>	<b>151</b>
<b>APPENDIX F.....</b>	<b>.....</b>	<b>153</b>
<b>APPENDIX G.....</b>	<b>.....</b>	<b>157</b>
<b>APPENDIX H.....</b>	<b>.....</b>	<b>158</b>
<b>Bibliography.....</b>	<b>.....</b>	<b>160</b>



## List of Figures

<b>Figure 1: Post-intensive care syndrome (PICS) conceptual diagram. ....</b>	<b>6</b>
<b>Figure 2: Integration of primary palliative care in the treatment of critical illness survivors: a conceptual framework. ....</b>	<b>24</b>
<b>Figure 3: Aim 1 conceptual framework for studying palliative care needs in critical illness survivors.....</b>	<b>25</b>
<b>Figure 4: Aim 2 conceptual model for studying interprofessional clinicians’ perceptions of primary palliative care delivery in the post-ICU clinic setting.....</b>	<b>25</b>
<b>Figure 5: Theory of symptom experience in critical illness survivors, adapted from the Theory of Unpleasant Symptoms (TOUS), adapted from (Lenz et al., 1997). ....</b>	<b>26</b>
<b>Figure 6: Techniques to ensure qualitative rigor and trustworthiness.....</b>	<b>33</b>
<b>Figure 7: Domains of Palliative Care Assessment Measured. ....</b>	<b>38</b>
<b>Figure 8: Symptoms to be examined in EFA.....</b>	<b>47</b>
<b>Figure 9: Aim 3 - Exploratory Factor Analysis (EFA) sequence model. ....</b>	<b>48</b>
<b>Figure 10: Revised variable list for EFA. ....</b>	<b>56</b>
<b>Figure 11: Symptoms considered for EFA model.....</b>	<b>134</b>
<b>Figure 12: EFA factor loading.....</b>	<b>135</b>
<b>Figure 13: Scree plot.....</b>	<b>136</b>
<b>Figure 14: Relationship between symptom clusters and overall health score.....</b>	<b>137</b>

## PREFACE

“The best way out is always through” – Robert Frost

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## **1.0 DISSERTATION PROPOSAL**

Section 1.0 of this document summarizes the approved dissertation proposal finalized at the comprehensive examination and overview.

### **1.1 INTRODUCTION**

Although the initial successes of critical care medicine have historically been gauged by short-term mortality outcomes, focus has now shifted to improving long-term outcomes for the increasing number of critical illness survivors. Survivors of critical illness often experience profound changes in their lives after the intensive care unit (ICU). Although there is promise seen in the increased survival of ICU patients (approximately 80%), there are numerous, troubling long-term consequences for these survivors (Zimmerman et al., 2013). Half of these survivors will experience at least one component of post-intensive care syndrome (PICS), a constellation of new or worsening physical, psychological, and cognitive disabilities, which can have intense long-term negative effects on quality of life, capacity to regain independence, or ability to be employed (Needham et al., 2012). As a consequence of both an aging population and the dramatic improvement in survival rates in those suffering from critical illness, PICS is rapidly becoming a major public health concern. In addition, 30% of ICU survivors experience subsequent unplanned hospital readmissions within the first 6 months following their ICU stay, with over one-quarter of

all unplanned readmissions involving a subsequent ICU admission (Hua et al., 2015). ICU survivors without preexisting chronic conditions are five-fold more likely to develop a new chronic condition compared to non-ICU control patients without preexisting chronic conditions (van Beusekom et al., 2019). Importantly, approximately one in five ICU survivors die within the year following their ICU stay, with most events occurring within 90 days of ICU discharge (Szakmany et al., 2019). Critical illness survivors also report significant physical, cognitive and psychological symptom burden, such as pain, fatigue, anxiety, depression, and post-traumatic stress, which have dramatic impacts on their quality of life, capacity to regain independence, or ability to be employed, and often persist for months or years after hospital discharge (Brown et al., 2019; Choi, Hoffman, et al., 2014; Davydow et al., 2009; Dowdy et al., 2005; Kamdar et al., 2020; J. McPeake et al., 2019; Nikayin et al., 2016; Pandharipande et al., 2013; Parker et al., 2015). These functional dependencies are also reflected in discharge trends after ICU stay, with only 35% able to return home, and 31% discharged to long-term acute care and 34% to some level of rehabilitation after a critical illness (Herridge et al., 2016).

Given the substantial impairment seen, critical illness survivors possess care needs that are clearly within the scope of palliative care, however the role of palliative care has yet to be clearly defined in critical illness survivors. Palliative care provides an overall approach to care that improves quality of life and alleviates suffering for those patients and families living with serious and chronic debilitating illness, regardless of prognosis (Kavalieratos et al., 2016; Morrison & Meier, 2004). With shortages of specialty palliative care clinicians increasing (Kamal et al., 2019) and a high threshold of symptom burden for consultation, the provision of a structured primary palliative care intervention, defined as the delivery of a goals of care discussion, basic symptom assessment and management, care coordination, and support by a clinician not board-certified in

palliative care (Quill & Abernethy, 2013), may prove to be beneficial in this population. With the use of this approach, primary palliative care can be tailored to assist survivors of critical illness and their families gain a realistic understanding of the trajectory of intensive care unit (ICU) survivorship and the nature of PICS and facilitate future healthcare choices—in *the context of the patient's goals and values*—from available treatment options, as well as provide a holistic lens for assessment and management of survivor symptom burden.

Research is needed to establish the scope of the problem that primary palliative care may address by more clearly describing current unmet palliative care needs, which range from goals of care discussions to comprehensive symptom assessment and management in ICU survivors. The purpose of this project is: (1) to explore palliative care needs of critical illness survivors in the post-ICU clinic setting through the lens of both survivors and post-ICU clinic interprofessional clinicians, and (2) provide further insight into the overall symptom burden in this population and its effects on health-related quality of life.

## 1.2 SPECIFIC AIMS

**Specific Aim 1:** *To explore palliative care needs, including perceptions and preferences, in critical illness survivors in the post-ICU clinic setting.* Through semi-structured interviews with ICU survivors, areas to be explored include: (1) broader experience of surviving critical illness, (2) future goals of care, (3) symptom burden, (4) family support, and (5) the impact of these factors on other health care planning.

**Specific Aim 2:** *To examine the beliefs, attitudes, and behaviors of post-ICU clinic clinicians in providing primary palliative care interventions, including potential barriers and*

*facilitators, to critical illness survivors and their families.* Perceptions of palliative care needs for critical illness survivors and their families and current primary palliative care delivery in this setting, with focus on practices associated with goals of care conversations, care coordination and support, and management of symptom burden in the post-ICU clinic setting across sites will be explored through semi-structured interviews.

**Specific Aim 3:** *To investigate unresolved symptoms and symptoms clusters among survivors of critical illness upon initial presentation to a post-ICU clinic.*

*Aim 3a: Identify unresolved symptoms and potential symptom clusters in survivors of critical illness upon initial presentation to a post-ICU clinic. Descriptive statistics will be used to provide a comprehensive picture of symptom burden.* Exploratory factor analysis will be utilized to identify potential symptom clusters in ICU survivors presenting to an initial visit to a post-ICU clinic.

*Aim 3b: Examine the potential relationships between symptom clusters and reported health-related quality of life.* Multivariate regression analyses will be performed to examine the relationship between symptom clusters and health-related quality of life in ICU survivors.

## **1.3 BACKGROUND**

### **1.3.1 Critical illness survivorship**

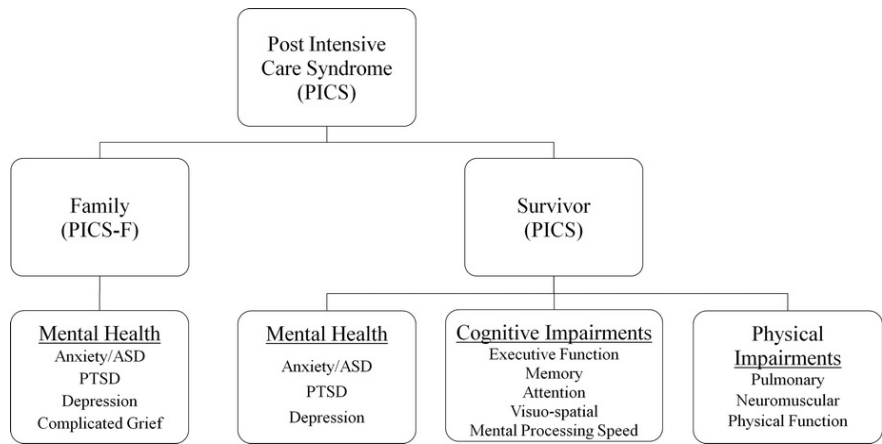
Over the last three decades, a rapidly expanding volume of critical care literature has emerged to address issues faced by critical illness survivors including: survival, quality of life, morbidity, functional status, joblessness, and costs of care (Angus & Carlet, 2003). However,

surviving critical illness goes beyond recovery and longer-term outcomes; it embodies an enduring, dynamic process of transitioning from critical illness to survivorship which involves physical, psychological, and social transitions and adaptations (Kean et al., 2017). Survivors of critical illness emerge from a highly technical acute hospitalization, filled with unfathomable interventions and therapies, and multifaceted disease processes (Iwashyna, 2010). They are discharged alive but face profound existential uncertainties and both complex and fragmented post-discharge care.

Survivorship after critical illness is a multidomain process, where the domains are interrelated, and the focus is on optimizing all dimensions of a person's life. The longer-term sequelae of critical illness involves constant change and transition along a continuum and is targeted during survivorship after critical illness. The associated health responses affect all aspects of the whole person, including physical, cognitive, psychological, social, and spiritual components. Common features of survivorship after critical illness involve strength, persistence, and energy in the face of hardship, seen not only in the survivor, but also in others close to the survivor (family, friends, caregivers) (Needham et al., 2011). Other portrayals of survivorship include the physical, neuropsychological, economic, and caregiver related consequences associated with critical illness (Kress & Herridge, 2012), which more generally aligns with the concept of post-intensive care syndrome (PICS).

As a consequence of both an aging population and the dramatic improvement in survival rates of those suffering from critical illness, PICS is rapidly becoming a major public health concern. In 2012, a stakeholders' conference convened by the Society of Critical Care Medicine (SCCM) defined and operationalized the long-term consequences of critical illness for survivors and their families. As a result, the term "post-intensive care syndrome" (PICS) was developed as

the recommended term to describe new or worsening impairments in physical, cognitive, or mental health status arising after critical illness and persisting beyond acute care hospitalization. The term is applied to both ICU survivors (PICS) and their family member/support people (PICS-F) (Needham et al., 2012). Figure 1 depicts the original conceptual diagram created at this conference.



ASD, acute stress disorder; PTSD, posttraumatic stress disorder. (Needham et al., 2012)

**Figure 1: Post-intensive care syndrome (PICS) conceptual diagram.**

Unplanned hospital readmissions within the first 6 months following an ICU stay are a reality for over 35% of ICU survivors, with over one-quarter of these unplanned readmissions involving another ICU admission (Hua et al., 2015). Recent research suggests that ICU survivors without preexisting chronic conditions were five times more likely to develop a new chronic condition compared with surviving non-ICU control patients without preexisting chronic conditions (van Beusekom et al., 2019). Importantly, approximately one in five ICU survivors die within the year following their ICU stay, with most events occurring within 90 days of ICU discharge (Szakmany et al., 2019).

Researchers continue to modify and expand this concept of critical illness survivorship to include effects on quality of life, social recovery, and financial toxicity (Hauschildt et al., 2020; J. McPeake et al., 2019; Meyer-Frießem et al., 2020). Critical illness survivors and their families must also navigate and adjust as they move through these transitions along the survivor continuum. Challenges encountered include healthcare communication gaps and fragmentation of care (Admon et al., 2019; Govindan et al., 2014). Concurrently, support needs and priorities often change across the trajectory of survivorship, but these changes are not being adequately addressed due to the lack of evidence-based patient-centered guidelines to meet the multidimensional needs of ICU survivors and their families (Czerwonka et al., 2015; Scheunemann et al., 2020). The goal of critical illness survivorship care is to effectively implement interventions to provide the best holistic care to improve quality of life, to better address the needs of patients and their families, and to improve the ability to alleviate the post-ICU burden for surviving patients and their loved ones.

### **1.3.2 Symptom reporting after critical illness**

Symptom experiences currently describing the critical illness survivorship journey consist of major themes surrounding physical, cognitive, emotional, and social well-being. As a result, comprehensive assessments of symptoms important to survivors of critical illness include measures of physical, cognitive, psychological, and social health (Eakin et al., 2017).

Critical illness survivors often report substantial physical, cognitive, and psychological symptom burden, such as pain, fatigue, anxiety, depression, memory and concentration issues, and post-traumatic stress, which can have dramatic impacts on their quality of life, capacity to regain independence, or ability to be employed. These may persist for months or years after hospital

discharge (Brown et al., 2019; Choi, Hoffman, et al., 2014; Davydow et al., 2009; Dowdy et al., 2005; Kamdar et al., 2020; J. McPeake et al., 2019; Nikayin et al., 2016; Parker et al., 2015). Physical symptoms reported by critical illness survivors, such as sleep disturbance, fatigue, weakness, and pain, (Choi, Hoffman, et al., 2014; Langerud et al., 2018; Wang et al., 2019) highlight the need to further strengthen the strategies in post-ICU care to assess and manage symptoms in survivors, as they are associated with poorer long-term clinical outcomes.

Moreover, psychological symptoms are similarly prominent with approximately 20% of critical illness survivors suffering from clinically significant post-traumatic stress disorder (PTSD) symptoms; roughly 35% experience anxiety, and over 25% suffer from significant depression, and these symptoms persist for months to years following critical illness with little change to prevalence (Davydow et al., 2009; Davydow et al., 2008; Nikayin et al., 2016). Cognitive impairment in critical illness survivors has been compared to deficits seen in moderate brain injury patients and mild Alzheimer's disease, and approximately 25% of these patients continue to experience cognitive impairment twelve months after hospitalization (Pandharipande et al., 2013). There is limited data regarding symptoms related to spiritual distress in the post-ICU setting, with research primarily focused on the reflection of the ICU experience and revisiting the meaning of their lives (Magarey & McCutcheon, 2005; McKinney & Deeny, 2002). Survivors of critical illness also face the potential for a significant socio-economic burden, affected by the continued lack of independence and autonomy as evidenced by job loss, occupational change, or worse employment status due to existing comorbidities and post-ICU impairments, with only about half of survivors returning to work by one year (Griffiths et al., 2013; J. M. McPeake, P. Henderson, et al., 2019). Following return to work, 20%-36% of survivors experienced job loss, 17%-66%



occupation change and 5%-84% worsening employment status (fewer work hours) (Kamdar et al., 2020).

Additionally, the physical, psychological, and financial stress associated with the role of caring for a survivor of critical illness can negatively affect the health of a family caregiver (Foster & Chaboyer, 2003; van Beusekom et al., 2016). Fatigue, a common symptom seen in family caregivers, is associated with greater symptom distress and long-term patient institutionalization (Choi, Tate, et al., 2014). Caregiver employment concerns are also well documented, with reports of almost 50% of caregivers who were employed prior to the critical illness of their loved one critical illness, either reduced their work hours, quit their job, or were fired in order to provide informal care, resulting in significant financial burden (Douglas et al., 2010; Swoboda & Lipsett, 2002). Of those caregivers affected, 38% reported that it was somewhat difficult to pay for basic needs such as food, housing, medical care and heating, and others reported moving to a less expensive home, delaying educational plans or medical care for themselves or another family member, or filed for bankruptcy due to the financial burdens (Swoboda & Lipsett, 2002). Due to the substantial variety of symptom burden in family caregivers, including anxiety, depression, and PTSD, there is a need for development of a formal screening for family caregiver symptoms (van Beusekom et al., 2016).

### **1.3.3 Exploring symptom clusters**

To better identify symptom management strategies, the concept of symptom clusters has been studied in other illness populations as a way to discover more effective approaches to reducing the severities of these reported symptoms. A symptom cluster a) consists of 2 or more symptoms that are related to each other and that occur together, b) is composed of stable groups

of symptoms, c) is relatively independent of other clusters, d) may reveal specific underlying dimensions of symptoms, and e) may or may not share the same etiology (Kim et al., 2005). Typically, relationships among symptoms within a cluster should be stronger than relationships among symptoms across different clusters. Symptom clusters have demonstrated clinical relevance to some cancer populations, showing effects on functional status, in predicting death, and secondary effects on other symptoms with adequate control of cluster (Dodd et al., 2001; Gift et al., 2003; Given et al., 2002). Research on symptom clusters in noncancer conditions, such as HIV disease, chronic kidney failure, COPD, and heart failure is in an earlier stage (Breland et al., 2015; Jurgens et al., 2009; Lee & Jeon, 2015; Moens et al., 2015). Similar to cancer populations, the occurrence of symptom clusters in these other populations is associated with decreased functional status and quality of life, along with increased mortality and health care utilization (Miaskowski et al., 2017).

Despite the reported high number of concurrent symptoms that critical illness survivors experience, there is little research examining symptom clusters in this population. Limited patterns of co-occurrence between the components of PICS have been explored, finding although many ICU patients report at least one component of PICS, there is low concurrent reporting of disability, depression, and cognitive impairment in ICU survivors (Marra et al., 2018). Other findings focused on mental health and functional outcomes have suggested that physical disability after critical illness contributes to depression in this population, driven by somatic rather than cognitive symptoms (Jackson et al., 2014). Additionally, ICU survivors with reported psychiatric symptoms (PTSD, depression) have been reported to be more likely to have reports sleep disturbances (Wang et al., 2019). A comprehensive review of physical symptoms after surviving critical illness discovered a moderately positive correlation between weakness, pain, fatigue, and sleep

disturbance, suggesting some clustering among physical symptoms, however the sample size was small and adequate power was not achieved (Choi, Hoffman, et al., 2014). Work is needed to further define co-occurring patterns of symptoms, and to understand better the clinical, biological, and social factors related to the ability to withstand and recover successfully from critical illness.

#### **1.3.4 Review of specialty post-ICU follow-up care**

Although there is now heightened awareness regarding in the care and management of ICU survivors, this has been slow to translate into action. There is a need for structured follow-up for the majority of survivors of critical illness as these patients can experience a number of well-recognized long-term sequelae (Bakhru et al., 2019; Mikkelsen et al., 2020; Sevin et al., 2018). Despite insufficient evidence of effectiveness of specialty post-ICU follow-up care in relation to health-related quality of life (HRQoL), mortality, depression and anxiety, PTSD, physical function, cognitive function, ability to return to work, (Schofield-Robinson et al., 2018), patients and families continue to attend and engage with post-ICU follow up recovery programs, suggesting that both clinicians and patients perceive them as beneficial. There is a growing need to evaluate interventions focused on improving recovery, function, and quality of life in critical illness survivors. Researchers and clinicians alike are working to validate this “proof of concept” of post-ICU follow up clinics (Bloom et al., 2019; Eaton et al., 2019; Haines, McPeake, et al., 2019; Haines, Sevin, et al., 2019; Khan et al., 2015; McPeake et al., 2017; Modrykamien, 2012; Snell et al., 2020). The emergence of post-ICU COVID complications in recent days has also caused a bigger push to create a specialized space for the care of these patients (Mayer et al., 2020; O'Brien et al., 2020).

Specialty post-ICU outpatient programs focus on reducing psychological distress among survivors and their families, improving care coordination, augmenting support, and facilitating physical recovery through optimized management (Lasiter et al., 2016). In 2006, a national survey of intensive care follow-up clinics was conducted, which found of 298 reporting ICUs in the United Kingdom (UK), there were 80 intensive care follow-up clinics in existence at that time (Griffiths et al., 2006). No similar comprehensive national surveys are available for other countries. Moreover, there is limited evidence of health outcomes for patients who attend such clinics (Williams & Leslie, 2008).

It is difficult to predict which patients will receive the most benefit from ICU follow-up clinics, as this is no evidence to guide this and each patient's experience during critical illness and treatment differs widely. In a recent study, patients reported that ICU recovery programs improved care by treating ongoing physiologic problems; improving symptom status; normalizing their experience and helping them manage their expectations; internally and externally validating their progress in recovery; and reducing feelings of guilt (McPeake et al., 2020). Currently, there is agreement that 1) prediction of post-ICU problems and providing anticipatory guidance to survivors of critical illness are tasks ICU researchers and clinicians should address, 2) the broad framework of PICS remain useful for organizing an approach to caring for these patients, with an increasing emphasis on the social aspects of their recovery, 3) individualized clinical judgment in the context of team-based care remains the foundation of post-ICU care, and 4) there remains an urgent need to test the comparative effectiveness of varying strategies of care for survivors of critical illness (Mikkelsen et al., 2020). While these research and practice innovations to improve outcomes of survivors of critical illness are established and refined, the current recommendation for post-ICU care includes: early initial assessment for PICS using validated screening tools, with

reassessment along the path of survivorship, and prioritization of high-risk patients; however gaps remains regarding standardized treatment recommendations (Mikkelsen et al., 2020).

### **1.3.5 Overview of palliative care and its suggested role in post-ICU care**

With high rates of potential complications and substantial life-long implications for critical illness survivors there are large gaps in our understanding of the burden of recovery or approaches to decrease this burden for individual patients. Palliative care is one approach to better identify individual challenges to ICU survivorship and individualize care to facilitate overcoming these challenges. However, the term palliative care is often confused with end of life or hospice services limiting its application to persons with chronic illnesses who might benefit (Beasley et al., 2019). Palliative care benefits patients with serious and life-limiting illness by providing services focused in symptom management, goal setting, support, and care coordination while they simultaneously pursue curative treatments (Kavalieratos et al., 2016).

Primary palliative care refers to the basic skills and competencies required of all physicians and other health care professionals, including the delivery of a goals of care discussion, symptom assessment and management, care coordination, and support – congruent with the patient’s goals (von Gunten, 2002). There has been extensive research into the benefit of primary palliative care in other serious or life-limiting disease states, including cancer, heart failure, dementia/Alzheimer’s disease, acquired immunodeficiency syndrome, and others (Aiken et al., 2006; Bekelman et al., 2015; Chapman & Toseland, 2007; Clark et al., 2013; Dudley et al., 2018; Engelhardt et al., 2006; Farquhar et al., 2016; Given et al., 2002; Lowther et al., 2015). In beginning to provide a roadmap for the delivery of palliative care in survivors of critical illness, addressing symptom management and coping are hallmarks of early palliative care across the

illness trajectory, but palliative care interventions may need to prioritize topics differentially based on patient's individual needs and preferences (Bannon et al., 2019; Hoerger et al., 2018).

In situations that do not require instantaneous action to sustain life, the patients' values, goals, and treatment preferences can and should be confirmed (Curtis & Mirarchi, 2020). This is important for a number of reasons, including that goals and preferences change over time and circumstances. A change in circumstances, including health and wellness state, may modify views about life-sustaining treatments but also current treatment approaches. Ideally, goals of care conversations should be revisited throughout the critical illness survivorship course, when thoughtful discussions, based in previous healthcare experiences can assist in 1) informing the patient's understanding of their new and/or ongoing disabilities, 2) setting reasonable expectations for the future, and 3) choosing, within the context of their goals and values, future healthcare treatment options. These discussions between the patient and the post-ICU clinic interprofessional clinician generate information regarding quality of life, decision-making preferences, and surrogate decision-making for future illness stages.

### **1.3.6 Limitations of primary palliative care in post-ICU follow-up care**

Involvement of primary palliative care services in patient care has been associated with better understanding of diagnosis and prognosis, increased patient satisfaction, improved symptom control, and decreased healthcare utilization in acute care settings (Modrykamien, 2012; Rabow et al., 2003). Despite the identified need for palliative care in critical illness survivors, there is currently only one documented post-ICU clinic currently providing an integrated primary palliative care intervention, defined as the delivery of a goals of care discussion, holistic symptom assessment and management, and family caregiver support by a clinician not board-certified in

palliative care (Eaton, 2020). Unfortunately, with the initiation of post-ICU recovery programs, some have chosen to exclude patients receiving or requiring specialty consultative palliative care services, as these patients are referenced as “palliative care/hospice” in the reporting (Bakhru et al., 2019; Lasiter et al., 2016; Paratz et al., 2014). Another program included palliative care as a feature of their initial clinic design, however, it was reported that the patients and families were almost uniformly “focused on recovery to baseline” (Sevin et al., 2018). These decisions are likely due to confusion regarding the definition and role of palliative care in this population, as seen in other serious and life-limiting patient disease processes (Bernacki & Block, 2014; Dudley et al., 2018; Shin & Temel, 2013). Other post-ICU programs reviewed included a comprehensive symptom assessment component to their practice (Cuthbertson et al., 2009; Griffiths et al., 2006; Schandl et al., 2011), but without other documented primary palliative care components reported.

The addition of a structured primary palliative care intervention in post-ICU follow-up clinics may increase opportunities to address a variety of patient needs, such as psychological concerns, spiritual needs, physician-patient-family communication, and goals of care (Teixeira & Rosa, 2018). With a focus on early primary palliative care engagement, potential trajectories and help with long-term planning can assist critical illness survivors in making decisions consistent with the goals over time.

#### **1.4 SIGNIFICANCE**

With the identified high prevalence of unmet palliative care needs in this population, the knowledge gained in this investigation can assist in the development of a structured delivery of primary palliative care in the post-ICU care setting. These interventions can be tailored to assist

survivors of critical illness and their families to gain a realistic understanding of the trajectory of intensive care unit (ICU) survivorship and the nature of PICS and to facilitate future healthcare choices—in the context of the patient’s goals and values—from available treatment options, and to provide a holistic lens for assessment and management of survivor symptom burden.

This research will clearly describe current unmet palliative care needs, ranging from goals of care to comprehensive symptom assessment and management in critical illness survivors through the lens of both survivors and post-ICU clinic interprofessional clinicians, and provide new insight into the overall symptom burden in this population and its relationship to patient reported health-related quality of life. By promoting the integration of a structured primary palliative care in the post-ICU clinic setting, the aims of this study may directly improve the patient and family experience of critical illness survivorship, and has been identified by experts in the field as needed in furthering the field of critical illness survivorship (Azoulay et al., 2017; Modrykamien, 2012; Teixeira & Rosa, 2018).

## **1.5 INNOVATION**

This study will be the first to provide a multi-faceted description of the primary palliative care needs in survivors of critical illness and their families. Additionally, despite a high symptom burden in patients surviving critical illness, to the best of my knowledge there is no research examining symptom clusters in survivors of critical illness. Testing for symptom clusters may lead to the discovery of interrelated symptoms, and thereby help clinicians to understand the spectrum and interconnectedness of the symptoms associated with surviving a critical illness, as well as begin to consider which symptom clusters are independently associated with over functioning and



health status. This will assist in the future development of interventions to mitigate symptom burden, thereby improving overall function and quality of life. These findings will contribute to our growing understanding of the primary palliative care needs of critical illness survivors.

## **1.6 PRELIMINARY WORK**

### **1.6.1 PUBLISHED MANUSCRIPT: Caring for the Critical Illness Survivor: Current Practices and the Role of the Nurse in ICU Aftercare.**

This published manuscript provides additional background regarding the current practices in caring for survivors of critical illness and their families. This review examined emerging practices in relation to ICU aftercare for both patients and caregivers, with specific emphasis on the critical role of the nurse. As highlighted in this article, PICS morbidities contribute to ongoing challenges for survivors of critical illness and their family members, and post-ICU clinics, peer support, and ICU diary aftercare programs offer approaches to reinforce family-centered care in the ICU as well as enhance patient and family member experiences with recovery from critical illness. Reprint permission approval letter from the American Association of Critical Care Nurses can be found in Appendix A, along with the full manuscript reprint.

## **1.6.2 PUBLISHED ABSTRACT: Exploring Goals of Care in Patients Surviving Critical Illness**

This published abstract reviews the records of all initial patient visits in the Critical Illness Recovery Center (CIRC) at UPMC Mercy from June 2018 to March 2020. The aims of this study were to determine the frequency with which goals of care conversations occur, how often goals of care change among critical illness survivors evaluated in a post-ICU clinic, and factors that may influence these changes in future healthcare wishes. Data reviewed included the frequency of documented goals of care conversations in the CIRC, any changes documented in goals of care as a result of the conversation, and/or completion of written documentation outlining their healthcare wishes.

To our knowledge, this is the first study to explore the utility of exploring goals of care after critical illness. Goals of care conversations are a key opportunity to improve advance care planning, and are intended to align treatments, decisions and care plans with a patient's values, preferences and understandings given their current clinical circumstances (Bernacki & Block, 2014; Block, 2001). With the understanding that surviving a critical illness may create a state of ongoing life-limiting illness for survivors, these study results provide several new insights into the identification of patients that may benefit from goals of care conversations as well as identifying which patients may be more likely to change their goals of care following critical illness. When reflecting on experiences with prior medical management, nearly one-quarter of the patients who participated in a goals of care discussion in a post-ICU clinic determined that previously utilized aggressive treatments are no longer consistent with their current goals and values. Full and suitable acknowledgement to the original source along with a hyperlink to the abstract can be found in Appendix B.

### **1.6.3 PUBLISHED ABSTRACT: Implementation of a primary palliative care intervention in patients surviving critical illness: A process evaluation**

The Critical Illness Recovery Center (CIRC) clinic was created to deliver outpatient interdisciplinary care to survivors of critical illness and their families at risk for post-intensive care syndrome (PICS), a constellation of physical, cognitive, psychiatric, and social disabilities resulting from their critical illness. We discovered that a vital aspect of this care model includes the provision of a primary palliative care intervention, defined as the delivery of a goals of care conversation, holistic symptom assessment and management, and delivery of family caregiver support by a clinician not board-certified in palliative care.

The aim of this study was to evaluate the implementation of this intervention in the CIRC clinic. We reviewed the electronic health records (EHRs) of all patients seen in the CIRC clinic at UPMC Mercy from June 2018 to June 2019. We also examined weekly staff spreadsheets logs and explored clinician beliefs and perceptions regarding the utilization of primary palliative care in the treatment of critical illness survivors. The following process evaluation components were examined: recruitment, context, implementation, barriers, and fidelity. We evaluated whether this primary palliative care intervention in the CIRC clinic was implemented as planned and identified implementation facilitators, barriers, and areas for improvement. Facilitators included prima facie acceptability of the intervention, as measured by robust participation, and the presence of a clinician with formal palliative care training to guide the intervention. Barriers included time constraints for engaging in meaningful discussions regarding future goals and healthcare preferences and workflow issues with other members of the interprofessional team. Intervention successes included patient participation in goals of care discussions (n=95, 81.2%), documentation of code status and patient identified surrogate decision maker (100% and 97.4% respectively), and

family supportive counseling (100%). Identified areas for improvement included standardizing documentation in changes in healthcare wishes, more clearly defining a symptom management plan, and creating a workflow that allows for completed advance directive documentation to be uploaded into the inpatient and outpatient EHR in real time. Importantly, one barrier identified included no clearly documented operational approach for determining which clinic patients participate in a goals of care discussion and no clear indication of which patients should be billed for an advance care planning visit. The findings of this process evaluation have implications for clinical practice and further research regarding the ongoing development and delivery of primary palliative care to patients and their families surviving critical illness. Full and suitable acknowledgement to the original source along with a hyperlink to the abstract can be found in Appendix C.

## **1.7 RESEARCH DESIGN AND METHODOLOGY**

### **1.7.1 Theoretical approaches and philosophical assumptions**

The proposed adapted conceptual framework which this project is based upon conceives its underpinnings from both current foundations and practices of critical illness survivorship and palliative care (Figure 2). This model depicts a three-step approach which includes 1) the known consequences of patients and their families/caregivers surviving a critical illness, 2) the delivery of primary palliative care interventions, and 3) the expected outcomes. Consequences of surviving a critical illness are adapted from the conceptual model of post-intensive care syndrome (PICS) (Figure 1), developed in 2012 by an interprofessional conference of stakeholders, and continues to

be utilized currently (Needham et al., 2012). As our knowledge continues to develop, there is also an exponential growth in the literature surrounding critical illness survivorship. We now consider post-ICU mortality, new and/or worsening chronic conditions, and unplanned readmissions to be equally important adverse outcomes (Hua et al., 2015; Szakmany et al., 2019; van Beusekom et al., 2019). As our knowledge evolves, we now have a heightened awareness of impaired social health, including employment concerns, compromised social roles, and the financial toxicity that results from the long-term consequences of surviving a critical illness (Hauschildt et al., 2020; J. McPeake et al., 2019; J. M. McPeake, P. Henderson, et al., 2019). The delivery of a primary palliative care intervention, as outlined in the conceptual model is adapted from a palliative care consensus report which provides the current overview for components of primary palliative care and its delivery expectations (Weissman & Meier, 2011). The identified outcomes of the model highlight the current gaps in outcomes research and clinical care in critical illness survivorship (Azoulay et al., 2017). With this adapted conceptual model in mind, proposed conceptual frameworks for each aim can be found in Figures 3, 4, and 5, respectively.

#### **1.7.1.1 Theoretical principle for Aims 1 and 2**

Aims 1 and 2 are informed and guided by the principles of ethics of care. As research is relational and requires care, ethics of care advocates that ethical decision making has emotional as well as cognitive components and begins with the awareness of the fragility and vulnerability of the human condition, and recognizes human beings are interdependent, and for this reason, need respect, protection, and care (Edwards, 2009; Hewitt, 2007). Research ethics based in caring should value the relationship and personhood of the participant, focused on rigor, and balanced by moral concerns (Branch, 2015; Hewitt, 2007). Ethics of care highlights the disparity of position and power between the clinician-researcher and the participant, and posits that through reflexivity,

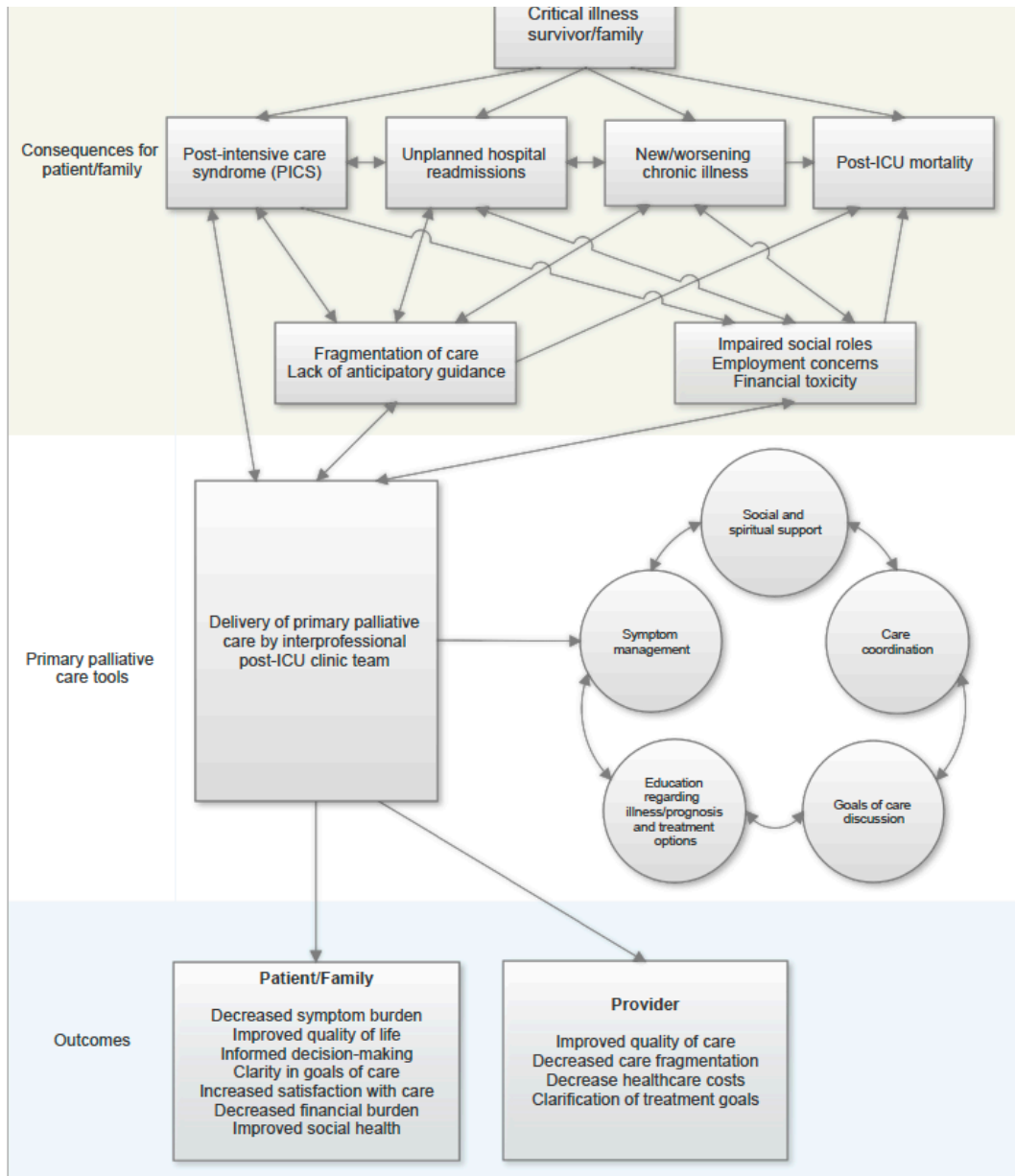
the clinician-researcher can create a research relationship grounded in rapport, honesty, and emotional closeness, while recognizing the potential abuses of power, which have the potential to increase with deeper levels of rapport. (Campbell & Wasco, 2000). Ethics of care takes into consideration aspects that classical ethics have overshadowed: trust and responsibility, protection of individuality, the context in which the relationship takes place, and the quality of the relationship (De Panfilis et al., 2019).

### **1.7.1.2 Theoretical principle for Aim 3**

Aim 3 derives its underpinnings from an adaptation of the Theory of Unpleasant Symptoms (TOUS). This middle range theory was created as a means for integrating existing information about a variety of symptoms and posits three structural elements: the symptoms that the patient is experiencing, the factors that influence them, and the consequences of that experience (Lenz et al., 1997). Importantly, the theory asserts not only can symptoms occur alone, but more than often, multiple symptoms can occur simultaneously. Figure 5 depicts the adapted TOUS to visually demonstrate potential relationships between the symptoms that critical illness survivors experience, the factors that may influence these symptoms, and the potential consequences of the symptom experience. The interrelationships of these proposed symptoms as well as their individual and/or symptom cluster relationships between influencing factors and potential consequences are currently unknown, therefore are not represented in the proposed framework. The purpose of this aim is to explore and describe these relationships, thereby refining and evolving the framework.

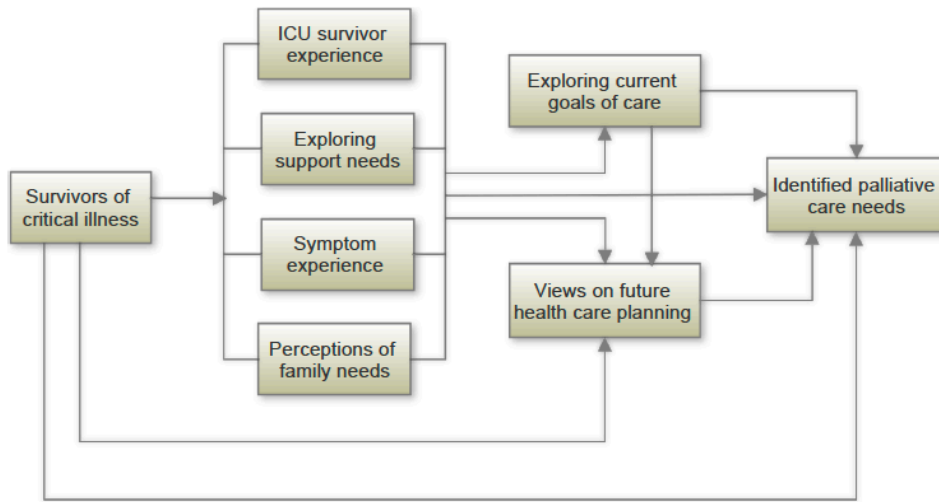
### **1.7.2 Overview of the Critical Illness Recovery Center (CIRC)**

The Critical Illness Recovery Center (CIRC) at UPMC Mercy is the only documented post-ICU clinic currently providing an integrated primary palliative care intervention, defined as the delivery of a goals of care discussion, holistic symptom assessment and management, and family caregiver support by a clinician not board-certified in palliative care (Eaton, 2020). This project will recruit patients and use clinical data from the CIRC (Aims 1 and 3). General inclusion criteria for invitation to the CIRC clinic include:  $\geq 18$  years old with an ICU length of day  $\geq 4$  days with identified PICS risk factors (sepsis, respiratory failure requiring mechanical ventilation, delirium), or by physician referral. Patients discharged from the hospital to a long-term acute care hospital or inpatient rehabilitation hospital are seen in clinic after they are discharged from these extended acute care facilities to home or a skilled nursing facility, or equivalent (assisted living facility, personal care home). Primary clinical exclusion criteria for the CIRC clinic include a) limited rehabilitation potential (defined as new or continued long term residence in nursing home facility), b) limited life expectancy (defined as  $< 6$  months life expectancy or actively enrolled in hospice services), c) incarceration, d) severe psychiatric disease, e) history of nonadherence with medical treatment, defined as leaving the hospital against medical advice (AMA) or previous history of nonadherence to prescribed post-hospital therapies or outpatient visits, or f) non-English speaking patients. These exclusion criteria are applied to the eligible clinic patients prior to hospital discharge by the CIRC clinic clinical team. Patients are screened for eligibility for CIRC clinic referral during the hospitalization, are educated and followed after discharge from the ICU, and are contacted via telephone by the CIRC social worker for regular clinical follow-up and appointment scheduling.



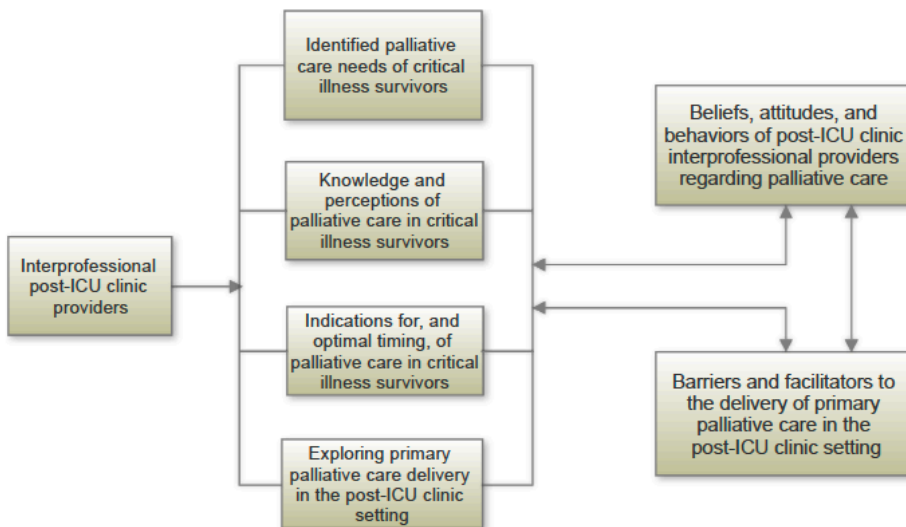
**Figure 2: Integration of primary palliative care in the treatment of critical illness survivors: a conceptual framework.**





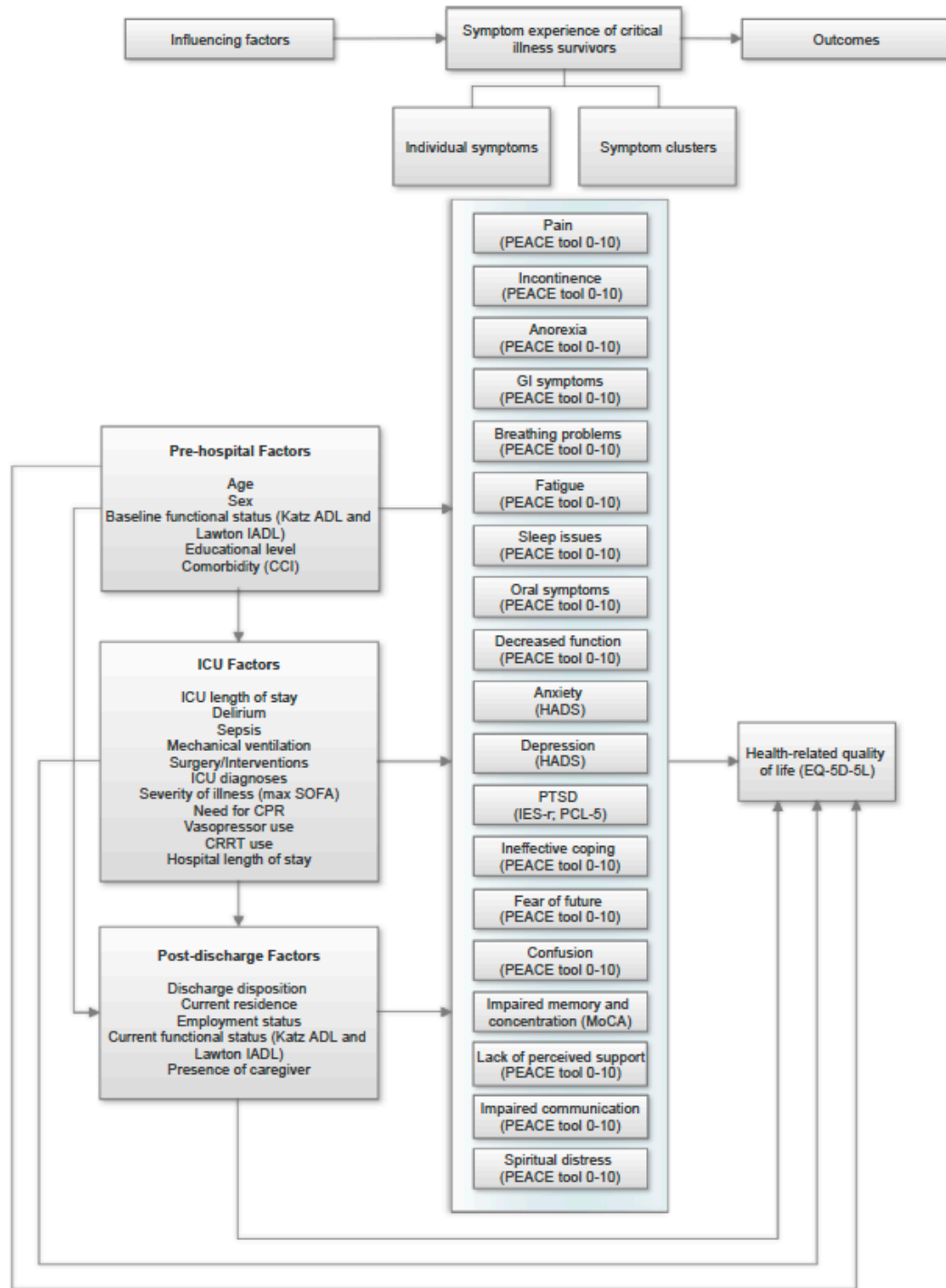
Conceptual framework for studying palliative care needs in critical illness survivors

**Figure 3: Aim 1 conceptual framework for studying palliative care needs in critical illness survivors.**



Conceptual framework for studying interprofessional clinicians' perceptions of primary palliative care delivery in the post-ICU clinic setting.

**Figure 4: Aim 2 conceptual model for studying interprofessional clinicians' perceptions of primary palliative care delivery in the post-ICU clinic setting.**



**Figure 5: Theory of symptom experience in critical illness survivors, adapted from the Theory of Unpleasant Symptoms (TOUS), adapted from (Lenz et al., 1997).**

### **1.7.3 Approach for Aim 1**

#### **1.7.3.1 Study design**

Aim 1 will use semi-structured qualitative interviews to explore the palliative care needs, including perceptions and preferences, in critical illness survivors in the post-ICU clinic setting. Through this approach, the goal is to identify commonalities and differences, and subsequently focus on relationships between different parts of the data, thereby seeking to draw descriptive conclusions clustered around themes (Gale et al., 2013). A pre-determined interview script will be used to elicit responses and discussion. Areas to be explored include: (1) broader experiences of surviving critical illness, (2) future goals of care, (3) symptom burden, (4) family support, and (5) the impact of the above factors on other health care planning.

#### **1.7.3.2 Sample, recruitment, and rationale**

We will use purposive sampling maximum variation to select participants, to ensure the representativeness of the diversity of the CIRC clinic population (Palinkas et al., 2015). The intent of maximum variation sampling in this aim is to 1) yield high-quality detailed descriptions of each case, documenting uniqueness, and 2) examine important shared patterns that cut across cases and derive their significance from having emerged out of heterogeneity (Suri, 2011). Variations in sampling will include age, sex, Charlson Comorbidity Index (CCI), and ICU length of stay. Given that sample size in qualitative research is often adaptive and emergent, the principle of saturation will be applied to sampling in the aim, defined as the point when no new information or themes are observed in the data (Sim et al., 2018). Following recommendations for various purposeful

sampling strategies, the initial sample size for Aim 1 is estimated to be up to 30 participants (Sandelowski, 1995).

Inclusion criteria:

- At least one in-person visit to the CIRC clinic
- Access to telephone and/or computer with internet for audio interview
- Community dwelling
- English-speaking

Exclusion criteria:

- Currently residing in nursing facility
- Anticipated limited life expectancy, defined as 6 months or less, or active enrollment in hospice services, determined after first CIRC clinic visit
- Involved in current specialty outpatient palliative care services
- Decisionally impaired adults, assessed by the administration of the University of California, San Diego Brief Assessment of Capacity to Consent (UBACC)

### **1.7.3.3 Data collection**

Data collection will take place by semi-structured telephone interview, with the participant after their initial visit to the CIRC. After verbal informed consent has been obtained via telephone, the PI will perform all interviews. All interviews will be digitally recorded, transcribed verbatim, and completely de-identified by the PI. Interviews are anticipated to last 30-40 minutes, but participants can stop the interview at any time.

The interview guide is based on reviews of the existing qualitative literature regarding critical care survivorship and palliative care research (Bernacki & Block, 2014; Czerwonka et al., 2015; Dinglas et al., 2018; Dudley et al., 2018; Engström et al., 2008; Kavalieratos et al., 2014; McPeake et al., 2020; J. M. McPeake, M. O. Harhay, et al., 2019; Starr et al., 2020). Some questions are based on existing models used for goals of care conversations in the seriously ill (Bernacki & Block, 2014). The patient interview script can be found in Appendix D.

#### **1.7.4 Approach for Aim 2**

##### **1.7.4.1 Study design**

Aim 2 will use semi-structured qualitative interviews with current post-ICU clinic interprofessional clinicians involved with the Critical and Acute Illness Recovery Organization (CAIRO). Beliefs, attitudes, and behaviors, including barriers and facilitators, regarding palliative care needs for critical illness survivors and their families will be explored. The utilization of and primary palliative care components in the post-ICU setting, with focus on practices associated with goals of care conversations, care coordination and support, and managing symptom burden in the post-ICU clinic setting across sites will also be explored.

##### **1.7.4.2 Sample, recruitment, and rationale**

CAIRO is a global collaborative of multidisciplinary groups dedicated to improving outcomes for ICU survivors and their families whose mission is to promote and support global collaboratives to advance innovations in critical and acute illness recovery through 1) outreach and education, 2) policy and advocacy, and 3) research and evaluation. Interviewees will represent current interprofessional clinicians in the post-ICU clinic setting (physicians, nurses, pharmacists,

rehabilitation specialists, social workers, and psychologists) from the US. Approval to contact post-ICU clinic collaborative members of CAIRO has been obtained from the executive committee of CAIRO. Additionally, this investigator serves as the newly appointed co-chairperson of the post-ICU clinic collaborative and has a professional relationship with clinicians at all sites currently involved in CAIRO's post-ICU clinic collaborative.

A stratified purposeful sampling will be utilized to recruit post-ICU clinic interprofessional clinicians from diverse practice backgrounds (i.e., medicine, nursing, rehabilitation services, social work, psychology, and pharmacy). Diversity in age, sex, and years of experience will also be considered during participant sampling. Snowball sampling will be utilized to allow participants to suggest colleagues from other disciplines at their respective sites who might provide valuable insights based on clinical experience and expertise. Given that sample size in qualitative research is often adaptive and emergent, the principle of saturation will be applied to sampling in the aim (Sim et al., 2018). Following recommendations for various purposeful sampling strategies, the estimated sample size for Aim 2 is up to 30 participants (Sandelowski, 1995).

(i) Inclusion criteria:

1. Maintain current clinical practice in post-ICU outpatient program
2. Access to telephone and/or computer with internet for audio interview
3. English-speaking

#### **1.7.4.3 Data collection**

Data collection will take place by semi-structured telephone or video interview with the participant. All the interviews will be performed by this principal investigator after informed consent has been obtained. The interview will be digitally recorded, transcribed verbatim, and completely de-identified. Interviews are anticipated to last 30 minutes. The semi-structured

interview guide was adapted from other projects examining the role of palliative care in other disease states (Bostwick et al., 2017; Kavalieratos et al., 2014; Waite, 2019), and will contain the following domains: 1) needs of ICU survivors and their families/support people, 2) knowledge and perceptions of primary palliative care, 3) indications for primary palliative care, 4) barriers to providing primary palliative care in ICU survivors. A clinical vignette that describes a standardized ICU survivor case, will be sent to the participant prior to the interview for review, and will be utilized during the interview, as such methods may be helpful when exploring values and perceptions (Hughes & Huby, 2002). Interview themes and clinical vignette can be found in Appendix E.

#### **1.7.4.4 Data analysis for Aims 1 and 2**

A framework analysis will be utilized in this aim. This technique is: 1) generative and is driven by the original accounts of the participants, 2) dynamic that allows change, addition, or amendment throughout the analytical process, 3) systematic, allowing a methodical treatment of the data, and 4) comprehensive (Srivastava & Thomson, 2009). The framework approach offers a systematic structure to manage, analyze and identify themes, enabling the development and maintenance of a transparent audit trail (Ritchie & Spencer, 1994). Data analysis will be performed using NVivo12 (version 12, QSR International) to code and query transcripts. Framework analysis has seven stages: (1) transcription; (2) familiarization with the interview; (3) coding; (4) developing a working analytical framework; (5) applying the analytical framework; (6) charting data into the framework matrix; (7) interpreting the data (Ritchie & Spencer, 1994). Please refer to Figure 6 for techniques used to ensure qualitative rigor and trustworthiness of data. To help ensure data trustworthiness and enhance the credibility of the framework, three interprofessional researchers (nursing, medicine, social work) will perform data analysis coding and codebook

development. By incorporating more than two coders on the coding team, a level of intersubjectivity within the team may be achieved, thereby providing an additional level of scrutiny and rigor to the coding process through added perspectives of different researchers that may produce a more thorough analysis than with a smaller coding team (MacQueen et al., 1998; Olson et al., 2016). To develop the codebook, the coding team will independently open code a subset of the transcripts (two each of patient interviews and clinician interviews). Codes will be identified through an emergent process. The coding team will then meet to discuss and compare the preliminary open coding and initial codebooks for each aim will be developed from the discussion. Intercoder reliability (ICR) will be performed on 25% of a randomly selected subsample of the data set and will be implemented across repeated rounds (after every 10 transcripts) until satisfactory reliability (target  $\geq 0.70$ ) is achieved (Campbell et al., 2013). As there are multiple coders, Fleiss' kappa will be used to evaluate intercoder reliability (Fleiss, 1971). All coders will meet regularly to compare coded transcripts and negotiate any discrepancies until consensus of code meanings is formed, and the codebook will be revised accordingly (Creswell & Miller, 2000; Gale et al., 2013; Miles & Huberman, 1994). The PI will function as the lead coder, coding every transcript and manually enter each coder's work into a master NVivo file. Each transcript will require 2-3 coders. After initial coding of all transcripts is complete, all three coders will meet to begin identifying themes. Through an iterative process, related codes will be combined into themes. After all transcripts are examined together, themes will be conceptually ordered to describe the data and explain relationships among themes. Development of a codebook and use of memos to track how categories and themes are formed will allow for auditability of the analysis. With the guiding ethical principle of ethics of care utilized throughout the qualitative research process, the risk for exploitation, through role confusion, therapeutic misconception, and



misrepresentation, along with concerns for social desirability, will be continually considered and limited through development of an ethical research relationship and researcher reflexivity. Techniques to be used to limit social desirability bias include refining the wording and prefacing of questions, clearly defining the role of the participant, and assessing and addressing motivations for socially desirable responses (Latkin et al., 2017).

- |  |
|--|
| <ul style="list-style-type: none"><li>A. Credibility<ul style="list-style-type: none"><li>a. Iterative questioning of participants</li><li>b. Expert review of protocol and interview guide</li><li>c. Frequent debriefing of analytic team</li></ul></li><li>B. Transferability<ul style="list-style-type: none"><li>a. Contextual review</li></ul></li><li>C. Dependability<ul style="list-style-type: none"><li>a. Audit trail tracking and detailing decision rules and justifications</li></ul></li><li>D. Confirmability<ul style="list-style-type: none"><li>a. Bracketing</li><li>b. Disciplinary triangulation (nursing, social work, medicine)</li><li>c. Member-checking – will invite participants to review manuscript before submission for publication</li></ul></li></ul> <p>Adapted from: (Ahern, 1999; Kavalieratos et al., 2014; Patton, 2014; Shenton, 2004)</p> |
|--|

**Figure 6: Techniques to ensure qualitative rigor and trustworthiness.**

### **1.7.5 Approach for Aim 3**

#### **1.7.5.1 Study design**

For Aim 3, a retrospective, patient-level cross-sectional observational design will be utilized to 1) provide a comprehensive description of patient-reported symptoms, 2) identify the presence of symptom clusters, and 3) examine the potential relationships between symptom clusters and reported health-related quality of life in a cohort of critical illness survivors who were seen during an initial post-ICU clinic visit in the Critical Illness Recovery Center (CIRC) from

June 2018 to March 2020. The purpose of this aim is to summarize the symptom data so that relationships and patterns can be explored and better understood. The University of Pittsburgh Institutional Research Board (IRB) reviewed the research proposal and provided a waiver of HIPAA authorization to access protected health information and IRB approval as an exempt application. (IRB protocol: STUDY20030027).

### **1.7.5.2 Population and Sample**

One hundred ninety-seven patients were seen in the CIRC for initial clinic visits from June 14, 2018, through March 12, 2020. During this time, the CIRC clinic saw patients from three separate ICUs within UPMC Mercy Hospital, Pittsburgh, PA, including a medical/surgical ICU, a neurologic/neurosurgical ICU, and a trauma and burn ICU. The decision was made to truncate the sample size at 197 due to the widespread outbreak of the novel coronavirus disease (COVID-19), as patients after March 12, 2020, may have experienced a difference in inpatient and outpatient healthcare delivery due to COVID-19, whether they were receiving care due to a COVID-19 infection or not, which may lead to a confounding bias.

### **1.7.5.3 Data sources and collection**

Data to be analyzed will be abstracted from the electronic health record (EHR) from the initial post-ICU clinic visit as well as the initial hospitalization and ICU stay that supported a visit to the CIRC. Clinical medical record review of patients seen in the CIRC will be performed by this principal investigator, who is a clinical team member in the CIRC and Department of Critical Care Medicine at UPMC Mercy. Structured progress notes and clinical data will be abstracted from both Powernote (Cerner) and EPICcare EHRs. Clinical data will be entered into REDCap, with a random check of 5% of the entered cases to evaluate reliability. All study data will be

assigned an ID number within REDCap. Identifiable data will be stored in REDCap, with the identifier codes, separately from data to be used for analysis. Separation of identifiers linked to study ID codes will enable anonymity in analyses.

#### **1.7.5.4 Variables and measures**

A complete list of variables for Aim 3 can be found in Appendix F.

##### ***Demographic and clinical characteristics***

Demographic data to be extracted from the EHR include age, sex, race, education level, current residence (as determined during initial clinic visit), and employment status (pre-hospitalization and during initial clinic visit). Clinical characteristics include pre-hospitalization, in-hospital, and in-clinic characteristics. Clinical characteristics to be collected from the EHR and reported include ICU diagnosis on admission, SOFA score, ICU length of stay, hospital length of stay, and presence of delirium (as measured by the Intensive Care Delirium Screening Checklist (ICDSC)), mechanical ventilation, need for cardiopulmonary resuscitation (CPR), need for surgery or procedures in interventional radiology (IR), use of continuous renal replacement therapy (RRT), sepsis, and vasopressor use in the ICU. All these characteristics provide a detailed picture of illness severity during the ICU stay and are commonly reported in ICU survivor literature. All other tools and measures are described in detail below.

The Charlson comorbidity index (CCI) assigns a summative risk mortality score (range 0-24) based on a range of comorbidities to predict the one-year mortality of patients (Charlson et al., 1987). The use of the CCI in health services research is widespread and robust, its reliability has been widely investigated, its predictive and concurrent validity has been very well studied, and its

test-retest and interrater reliability is moderate to good (Austin et al., 2015; Charlson et al., 1987; de Groot et al., 2003; Quan et al., 2011). As baseline comorbidity reporting and adjustment is an important component of clinical prognosis, the CCI will be the comorbidity summary measure utilized, and it will be calculated based on initial hospitalization data from the EHR.

The Katz Index of Independence in Activities of Daily Living (ADL) tool and Lawton Instrumental Activities of Daily Living Scale (IADL) data will be abstracted to obtain objective reports on patients' pre-hospital and in-clinic function (Katz et al., 1970; Lawton & Brody, 1969). The Katz ADL measures the adequacy of performance in six functions of activities of daily living (bathing, dressing, toileting, transferring, continence, and feeding). A score of 6 indicates full function, 4 indicates moderate impairment, and 2 or less indicates severe functional impairment (Katz, 1983; Katz et al., 1970). The Lawton IADL measures more complex functioning as compared to the Katz ADL, and includes 8 domains (food preparation, housekeeping, laundering, telephone use, shopping, transportation use, medication management, and handling finances) (Lawton et al., 2003; Lawton & Brody, 1969). Persons are scored according to their current highest level of functioning in that category. A summary score ranges from 0 (low function, dependent) to 8 (high function, independent). Both tools were completed during the initial clinic visit by the clinic occupational therapist (OT) through patient and family interview. Both tools are widely accepted in both clinical practice and research of ICU survivors (Jackson et al., 2014; Needham et al., 2011; Pollack et al., 2017; Sareen et al., 2020; Sevin et al., 2018). However little evidence exists for formal reliability and validity testing on either measure. There have been recommendations for use of the Katz ADL and the Lawton IADL in the clinical setting as a result of their good sensitivity, specificity, and predictive values, all of which have great significance in the clinical situation (Hoyer et al., 2018; Törnquist et al., 1990). Limitations of both instruments

includes the self-report or surrogate report method of administration rather than a demonstration of the functional task, and this may lead either to over-estimation or under-estimation of ability. In addition, because these tools are intended to measure functional ability at one point rather than over time, these instruments may not be sensitive to small, incremental changes in function.

The sequential organ failure assessment (SOFA) scoring system is a widely validated tool to assess the extent of a patient's organ function or failure in the ICU (Lambden et al., 2019; Vincent et al., 1996). With reliability testing, the intraclass correlation coefficient was .889 for the total SOFA score, and the weighted kappa values were moderate (0.552) for the central nervous system, good (0.634) for the respiratory system, and almost perfect ( $>0.8$ ) for the other organ systems (Arts et al., 2005). This score is based on six different subsections including respiratory, cardiovascular, hepatic, renal, coagulation, and neurological systems. The maximum SOFA score, which describes the highest daily SOFA score during the ICU stay, will be calculated, and reported to demonstrate severity of ICU illness in this patient population. The highest daily SOFA score has been identified as a useful predictor of outcome, can represent the cumulative organ dysfunction experienced by the patient (Ferreira et al., 2001).

### ***Symptoms/Health-related Quality of Life***

A comprehensive battery of measures was used to assess the symptoms that critical illness survivors reported during their initial visit to the CIRC. Of the symptoms reported between June 2018 and March 2020, the Montreal Cognitive Assessment (MoCA) (Nasreddine et al., 2005) was used to assess for cognitive symptoms; the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983) was used to report symptoms of anxiety and depression, the Impact of Events – revised (IES-r) (Weiss, 2007) and the PTSD checklist for DSM-5 (PCL-5) (Weathers et

al., 2013) were used to assess symptoms of PTSD; and the Physical, Emotive, Autonomy, Communication, Economic, and Transcendent (PEACE Tool) (Okon & Christensen, 2018; Okon et al., 2004) was used to assess for a range of holistic symptoms. The EQ-5D (Michael Herdman et al., 2011) is a self-report tool that was collected as a measure of health-related quality of life. Patients exhibiting difficulty with completing the self-report assessments were assisted by the outpatient clinic nurse to minimize fatigue and issues with literacy or cognitive impairment. From these tools, a total of 19 symptoms will be evaluated for potential symptoms clusters in this population. Figure 7 provides the comprehensive list of symptoms.

<b>Domains of Palliative Care Assessment</b>	
<b><i>Physical Symptoms</i></b>	
	Pain
	Anorexia
	Incontinence (bowel and bladder)
	GI symptoms (nausea, vomiting, constipation)
	Breathing problems/cough
	Fatigue
	Sleep issues
	Oral discomfort (ulcers, dryness)
	Diminished level of functioning
<b><i>Psychological</i></b>	
	Anxiety
	Depression
	PTSD
	Adjustment and coping
	Fear of future
<b><i>Cognitive</i></b>	
	Confusion/restlessness
	Cognitive dysfunction
<b><i>Social and economic needs</i></b>	
	Outside support
<b><i>Communication and care coordination</i></b>	
	Impaired communication of needs
<b><i>Transcendent</i></b>	
	Spiritual distress

**Figure 7: Domains of Palliative Care Assessment Measured**

Cognitive impairment is assessed through administration of the MoCA. The MoCA is a 30-point test, which includes the following components: a short-term memory recall task (5 points) involving two learning trials of five nouns and delayed recall after approximately 5 minutes; a visuospatial abilities assessment using a clock-drawing task (3 points) and a three-dimensional cube copy (1 point); a multiple assessment of executive function using an alternation task adapted from the Trail Making B task (1 point), a phonemic fluency task (1 point), and a two-item verbal abstraction task (2 points); an attention, concentration, and working memory assessment using a sustained attention task (target detection using tapping; 1 point), a serial subtraction task (3 points), and digits forward and backward (1 point each); a language assessment using a three-item confrontation naming task with low-familiarity animals (lion, camel, rhinoceros; 3 points), a repetition of two syntactically complex sentences (2 points), and the aforementioned fluency task, and finally, orientation to time and place is evaluated (6 points) (Nasreddine et al., 2005). The following ranges are used to grade severity: 26-30 = normal, 18-25 = mild cognitive impairment, 10-17 = moderate cognitive impairment and less than 10 = severe cognitive impairment. Content validity was assessed by the original authors by comparing scores from MoCA and the Mini-Mental State Exam (MMSE) and correlation was found to be high ( $r = 0.87$ ), sensitivity was found to be high at 90%, and the specificity of the MoCA (defined as the ability to identify non-cognitively impaired subjects) was 87% (Nasreddine et al., 2005). Test-retest reliability was high, with an intraclass correlation coefficient of 0.92, and the internal consistency was also found to be high with a Cronbach's  $\alpha$  of 0.83 (Nasreddine et al., 2005). The MoCA is strongly recommended as a screening tool to detect dysfunction long-term cognition in critical illness survivors and was administered by the speech therapist in the CIRC during the initial visit (Mikkelsen et al., 2020).

Two subscales of the HADS (anxiety subscale and depression subscale) are used to measure symptoms of anxiety and depression. The HADS is a patient self-report measure of 14 items, seven items for the anxiety subscale and seven for the depression subscale. Each item is scored on a response-scale with four choices ranging between 0 and 3, and each subscale is summed to obtain scores. Recommended cut-off scores are 8-10 for borderline cases, and 11 or greater for definite case in each subscale (Zigmond & Snaith, 1983). The HADS has been validated in many languages, countries, and settings and is one of the National Institute for Health and Care Excellence (NICE) recommended tools for diagnosis of depression and anxiety (Bjelland et al., 2002; Health, 2011). The HADS is strongly recommended for use in assessing symptoms of anxiety and depression in critical illness survivors, with studies reflecting internal consistency of Cronbach's  $\alpha$  greater than 0.80 for both anxiety and depression, and strong correlation with the Depression and Anxiety Stress Scale (DASS) in both anxiety ( $r = 0.88$ ;  $p < 0.0001$ ) and depression ( $r = 0.93$ ;  $p < 0.0001$ ) in this population (Chesley et al., 2020; Davydow et al., 2009; Mikkelsen et al., 2020; Nikayin et al., 2016; Sukantarat et al., 2007).

Over the time period of June 2018 through March 2020, the CIRC utilized two different PTSD screening tools, the IES-r, and the PCL-5. The IES-r was used from June 2018 to February 2019, and the PCL-5 was used from February 2019 to March 2020. The decision to switch these clinical measures was due in part to the IES-r being retired by the developer secondary to revisions in PTSD criteria in the DSM-V (limiting the use of the IES-r to investigators with ongoing research or prior permission) (Umberger, 2019). Although some researchers continue to support the use of the IES-r in the ICU survivor population due to psychometric evidence in acute respiratory failure survivors, citing its use can be continued due to developer permission and the tool being out of copyright, the CIRC leadership team opted to change the measure to the PCL-5 (Hosey et al., 2019;



Umberger, 2019). The PCL-5 was chosen as a replacement because it aligns fully to DSM-V criteria and includes questions to assess for negative alterations in cognition and mood. Fortunately, there are studies examining convergent validity between the two measures, showing the correlation between the PCL-5 and the IES-R yields a significant, positive correlation ( $r = 0.55-0.82$ ,  $p < .001$ ) suggesting strong convergent validity. Regarding the corresponding PCL-5 and IES-R subscales, a positive, statistically significant correlation has been observed in each case (intrusion:  $r = 0.53-0.76$ ; avoidance:  $r = 0.52-0.68$ ; arousal:  $r = 0.52-0.81$ , all  $p < .001$ ) (Ashbaugh et al., 2016; Sveen et al., 2016). These two PTSD measures will be recoded to a nominal dummy variable for analysis indicating either presence/absence of PTSD symptoms based upon individual tool total scores, as the established cut-off scores represent clinical concern for PTSD symptoms and are not being utilized to make a PTSD diagnosis.

The IES-R is a 22-item self-report measure (for DSM-IV) that assesses subjective distress caused by traumatic events (Weiss, 2007). Clinic patients were asked to indicate how much they were distressed or bothered by their recent ICU stay by each question listed. Items are rated on a 5-point scale ranging from 0 ("not at all") to 4 ("extremely"). The IES-R yields a total score (ranging from 0 to 88), and subscale scores can also be calculated for the Intrusion, Avoidance, and Hyperarousal subscales. For clinical use, the CIRC utilized total score as an indicator for PTSD symptoms, with a score of 24 or more causing concern for PTSD. The IES-r has been widely used to assess for PTSD symptoms in critical illness survivors and has shown high internal consistency ( $\alpha = 0.96$ ) and high correlation with the Clinician-Administered PTSD Scale (CAPS), the current state-of-the-art PTSD diagnostic measure at that time (Pearson  $r = 0.80$ , Spearman  $\rho = 0.69$ ) (Bienvenu et al., 2013; Parker et al., 2015). The PCL-5 is a 20-item patient self-report measure that assesses the 20 DSM-5 symptoms of PTSD. A total symptom severity score (ranging from 0

to 80) can be obtained by summing the scores for each of the 20 items. The PCL-5 can also be broken down into subscale scores, based upon DSM-5 symptom clusters, however, the CIRC utilized total score as a clinical indicator for the presence of PTSD symptoms. Initial research suggests that a PCL-5 cutoff score between 31-33 is indicative of probable PTSD across samples (Weathers et al., 2013). Although the PCL-5 has been adopted by the National Center for PTSD and it has been shown to be a psychometrically sound instrument in initial studies with veterans with good internal consistency ( $\alpha = .96$ ), test-retest reliability ( $r = .84$ ), and convergent and discriminant validity, it has not yet been validated in ICU populations (Bovin et al., 2016).

The PEACE Tool allows for a comprehensive clinical palliative symptom assessment, and includes physical, psychological, cognitive, illness understanding, social and economic needs, spiritual concerns, and care coordination concerns (Okon & Christensen, 2018). This assessment allows for capture of potential refractory physical symptoms in critical illness survivors, including pain, confusion, fatigue, breathlessness, insomnia, nausea, constipation, and anorexia. The PEACE tool is a 16-item self-report measure, rated on a 11-point range from 0 (none) to 10 (worst imaginable), with higher scores indicating more severe symptoms. There are nine physical symptom questions (pain, anorexia, incontinence, gastrointestinal symptoms, respiratory symptoms, oral symptoms, decreased physical functioning, fatigue, sleepiness), three psychological/cognitive symptom questions (anxiety, depression, restlessness/confusion), one question regarding concerns with patient autonomy, one question regarding communication of needs, and one socio-economic concerns question, and one question regarding spiritual concerns. There is currently no data on reliability and validity in research for this tool, however it has been developed for clinical utility to capture a holistic picture of symptom reporting, capturing both face validity and content validity. An argument may be made that theoretical validity or an overall

meaning to the PEACE tool is not necessary, because the goal may simply be practical: to identify a few active symptoms using a consistent listing and scoring system across patients. More research is needed to determine whether a factor structure exists and in which specific clinical contexts it might apply. Anxiety and depressive symptoms are being measured by HADS tool, which is a widely utilized measure, with good reliability and validity. Because of this, the anxiety and depression questions measured by the PEACE Tool will not be utilized in this analysis.

The EQ-5D, a five-item questionnaire (with dimensions of mobility, self-care, daily activities, pain, and emotional well-being), developed by the EuroQOL Group ("EuroQol--a new facility for the measurement of health-related quality of life," 1990; Group, 1990; M. Herdman et al., 2011; Shaw et al., 2005), which includes a global health state measurement ranging from 0-100, will be used to report quality of life. Reliability and validity have been examined in ICU survivor populations with a Cronbach's  $\alpha$  statistic higher than 0.7, and significant correlations have been noted between this tool and the SF-36 ( $p < 0.001$ ) (Khoudri et al., 2012; Shah et al., 2016). The EQ-5D is recommended as an objective measure of health-related quality of life in critical illness survivors (Mikkelsen et al., 2020). This questionnaire is patient self-report and was completed by patients during their initial clinic visit. A health state index score will be calculated from individual health profiles using the United States specific value set, which then will be used in analysis (Shaw et al., 2005).

### **1.7.5.5 Data analysis plan for Aim 3**

#### ***Descriptive statistics***

All analyses will be conducted in SPSS Version 27 (IBM Corp. Released 2020. IBM SPSS Statistics for Macintosh, Version 27.0. Armonk, NY: IBM Corp.). Given a variable's level of

measurement and data distribution, appropriate descriptive analyses will be used to summarize the demographic and clinical characteristics and the prevalence of each symptom.

To describe central tendency for ratio variables (Appendix F), mean and standard deviation (SD) will be used for normally distributed variables. If the normality assumptions are not satisfied, median and interquartile range (IQR) will be used. For describing nominal variables (Appendix F), frequency, percentage, and the mode will summarize central tendency and the range will summarize the variability. Ordinal variables will be described using median and IQR.

### ***Data screening procedures***

Prior to the primary analysis to address Aim 3, all data will be screened for accuracy, potential outliers and influential values, amount and pattern of missing data, and potential violations of assumptions for the planned statistical analyses. For continuous variables, means, standard deviations, minimum values, maximum values, and ranges will be examined for plausibility. For discrete variables, data will be assessed for out-of-range category values and inaccurately entered data. Both univariate and multivariate outliers for discrete and continuous variables will be screened. Outliers will be identified using frequency distributions to check for any uneven category splits on categorical variables. For continuous variables, histograms, boxplots, normal probability plots, and de-trended normal probability plots will be used to identify points that are far removed from the bulk of the data for continuous type variables. In addition, Z-scores will be calculated for each continuous variable, and any continuous variable with  $|Z\text{-score}| > 3.29$  will be flagged as potential outlier (Tabachnick et al., 2007). Mahalanobis distance and scatterplots will be used to identify multivariate outliers.

For the treatment of missing data, first, data will be explored and checked for the amount of missing data by looking at the percentage of cases having any missing data, distribution of

univariate, multivariate, and bounded missing data. Then, the pattern of missing data will be examined by exploring the occurrence of missing data by variable and by participant and their combination. From these results, univariate missing or multivariate missing, missing completely at random (MCAR), missing at random (MAR) or missing not at random will be identified. If an observation was missing not at random, and if that patient was missing more than 50% of items within one symptom scale, that patient will be excluded. For cases of MAR and MCAR, multiple imputation will be used to handle missing data.

### ***Aim 3 specific data analysis strategy***

An exploratory factor analysis (EFA) to search for potential clustering of symptoms into factors will be performed. (EFA) will be conducted using principal axis factoring (PAF) as the extraction method with the promax rotation method (based on the assumption that the factors are correlated) to identify symptom clusters from the 19 symptoms measured during the initial CIRC clinic (Tabachnick et al., 2007). EFA is primarily used in research for theory development, psychometric instrument development, and data reduction (Costello & Osborne, 2005; Samuels, 2017). Given its heuristic nature, EFA is suitable for the exploratory nature of this aim. Refer to Figure 8 for a complete outline of the symptoms to be examined in this EFA. EFA will assist in revealing any latent variables that may cause the manifest variables to covary (Costello & Osborne, 2005; Yong & Pearce, 2013). Additionally, exploratory factor analysis is based on correlation matrix and correlation is free of change of origin and scale (Samuels, 2017; Yong & Pearce, 2013). Thus, the difference in the possible range of scores as well as difference in the scale or scaling unit does not influence the correlation. Hence, EFA, which is based on correlation will not be influenced by differences in the scale of items.

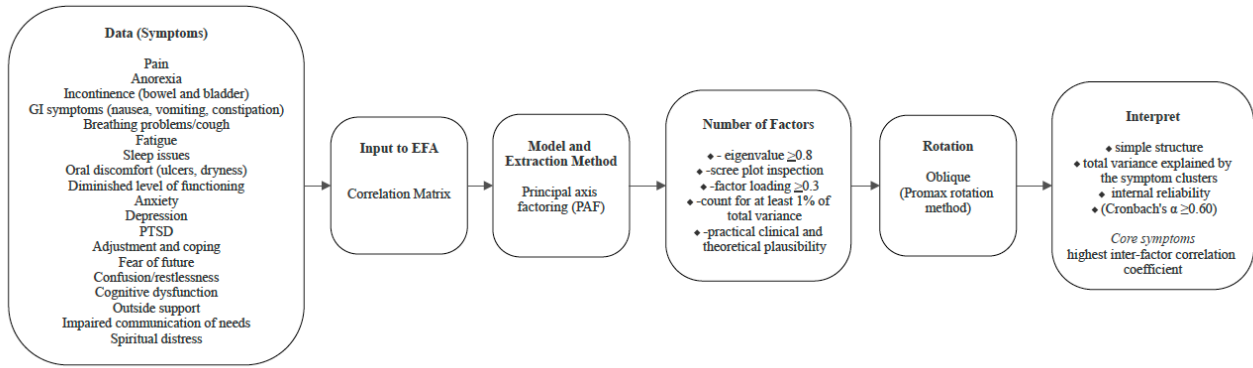
Normality among symptom variables will be assessed by skewness and kurtosis, and linearity among pairs of variables will be assessed through inspection of scatterplots. Transformation may be considered for substantial skewness and kurtosis or non-linearity. Cases will be assessed for both univariate and multivariate outliers. With regard to missing data, predictive mean matching (PMM) may allow for the extraction of the proper number of factors and yield the lowest bias for factor loading by a large margin (McNeish, 2017; Rubin, 1986). Given the exploratory nature of this study, the number of factors is based on (1) eigenvalue  $\geq 0.8$  and scree plot inspection, (2) factor loadings  $\geq 0.3$ , (3) each should account for at least 1% of the total variance, and (4) practical clinical and theoretical plausibility of symptoms likely to co-occur and to represent distinct symptom clusters. These criteria were selected in order to include the largest number of symptoms in the analysis. A symptom cluster will be identified if symptom total correlation with Cronbach's  $\alpha$  is  $\geq 0.60$ . A Cronbach's  $\alpha$  coefficient  $< 0.60$  will be interpreted with caution. The best fit of symptom grouping will be determined according to the following criteria: simple structure, total variance explained by the symptom clusters, and internal reliability of the symptom clusters measured by Cronbach's  $\alpha$ . Core symptoms will be defined as those with the highest inter-factor correlation coefficient (Item-total  $r$ ). Figure 9 outlines the EFA sequence model.

Multiple linear regression analysis will be used to identify symptom clusters that are significantly associated with HRQOL, adjusting for age, sex, educational level, comorbidities, and functional status, based on significant univariate analysis ( $p$ -value  $< 0.10$ ). Hierarchical regression analysis will be used with control variables entered first, and symptom clusters entered in step 2. Multiple linear regression was chosen as it is a means to identify the strength of the effect that the symptom clusters have on health-related quality of life, while allowing the inclusion for further

relevant independent variables, such as age, sex, educational level, comorbidities (CCI score), and functional status (Katz ADL and Lawton IADL scores). Assumptions of linearity, homoscedasticity, and absence of multicollinearity will be assessed. Linearity assumes a straight line relationship between the predictor variables and the dependent variable, and homoscedasticity assumes that scores are normally distributed about the regression line (Solutions, 2013). Linearity and homoscedasticity will be assessed by examination of a scatter plot. The absence of multicollinearity assumes that predictor variables are not too related and will be assessed using Variance Inflation Factors (VIF). VIF values over 10 will suggest the presence of multicollinearity (Tabachnick et al., 2007). Dummy coding will be used to enter the nominal independent variables (sex, educational level).

<b>Symptom Assessment Tools</b>	<b>Symptom(s) Measured for EFA</b>	<b>Scoring</b>
Hospital Anxiety and Depression Scale (HADS)	Anxiety	Anxiety sub-score 0-21)
	Depression	Depression sub-score (0-21)
Montreal Cognitive Assessment (MoCA)	Cognitive dysfunction	Summative (0-30)
Impact of Events - Revised (IES-r)	PTSD	Summative (0-88)
PTSD checklist for DSM-5 (PCL-5)	PTSD	Summative (0-80)
Physical, Emotional, Autonomy, Communication, Economic, Transcendent (PEACE Tool)	Pain	Scale (0-10)
	Anorexia	Scale (0-10)
	Incontinence (bowel and bladder)	Scale (0-10)
	GI symptoms (nausea, vomiting, constipation)	Scale (0-10)
	Breathing problems/cough	Scale (0-10)
	Fatigue	Scale (0-10)
	Sleep issues	Scale (0-10)
	Oral discomfort (ulcers, dryness)	Scale (0-10)
	Diminished level of functioning	Scale (0-10)
	Adjustment and coping	Scale (0-10)
	Fear of future	Scale (0-10)
	confusion/restlessness	Scale (0-10)
	Outside support	Scale (0-10)
	Impaired communication of needs	Scale (0-10)
	Spiritual distress	Scale (0-10)

**Figure 8: Symptoms to be examined in EFA.**



**Figure 9: Aim 3 - Exploratory Factor Analysis (EFA) sequence model.**

## 1.7.6 Anticipated study limitations

### 1.7.6.1 Aim 1 limitations

Patient interview data will only be collected from a single site, limiting its generalizability to the entire ICU survivor population. The findings will serve as pilot data to inform a larger, multi-site study to generate generalizable findings. Family and caregiver voices will not be included in this study, and their role in the survivorship continuum is vital. To mitigate this potential limitation for the project, a future qualitative study which includes family and caregivers to further refine approaches to implementing primary palliative care in the post-ICU setting will be conducted. There is risk for social desirability bias, as the interviewer may have provided outpatient clinic care to a portion of the participants. This limitation will be minimized by ensuring rigor in interview questioning techniques, including indirect questioning, question prefacing, and providing assurances. Additionally, through the creation and maintenance of an ethical research relationship by the PI with the participant, this limitation will be minimized through acknowledge of bias, reflexivity, professional boundaries, and clear definition of research aims.



### **1.7.6.2 Aim 2 limitations**

Clinician interview data will only be collected from sites currently participating in CAIRO's post-ICU clinic collaborative, limiting generalizability to the entire post-ICU clinic clinician population. The findings will serve as pilot data to inform larger, more diverse studies to study to generate generalizable findings. Additionally, there is a risk of selection bias, as no clinicians outside of the CAIRO network will be recruited. To minimize this, we will sample a mix of clinicians based upon length of CAIRO membership, thereby attempting to elicit responses from new members who have not fully participated in this group.

### **1.7.6.3 Aim 3 limitations**

Due to the cross-sectional design of Aim 3, data used in the analyses will be abstracted from the medical record and therefore may lack consistently documented clinical and demographic information that would typically be collected in a prospective research study. Additionally, only clinical data from the initial clinic visit will be used to create the symptom clusters, so the stability of these clusters over time is not known. This first study exploring symptom clusters in ICU survivors will lay the groundwork for future study of symptom clusters in larger populations of ICU survivors and stability over time.

## **1.7.7 Potential benefits of proposed research**

Participation in this study involves minimal risk only. According to 45 CFR 46.303(d), minimal risk is defined as the probability and magnitude of physical or psychological harm that is normally encountered in the daily lives, or in the routine medical, dental, or psychological examination of healthy persons.

For Aims 1 and 2, there is no direct benefit to either group for this project. The interviews will provide an opportunity for survivors of critical illness to share their perceptions and experiences in areas of surviving critical illness, views on future goals of care, symptom burden, family support, and health care planning. Interviews with post-ICU interprofessional clinicians will provide an opportunity to discuss both their perceptions and experiences with utilizing primary palliative care skills. For Aim 3, there is no direct benefit expected as a result of this analysis since there will be no direct contact with research participants. The proposed study may be beneficial for developing future insight into the overall symptom burden in this population, ultimately leading to improved processes for care that positively impact ICU recovery and survivorship. The risks of this study may include infrequent frustration or fatigue with the interview process, or an unfavorable emotional response to discussion of the hospital stay for patient participants.

### **1.7.8 Importance of knowledge to be gained**

The knowledge derived from this project: (1) may provide data that supports further exploration into the benefits provided by a primary palliative care approach for critical illness survivors and their families, and (2) may promote the integration of a structured primary palliative care in the post-ICU clinic setting. This will provide evidence of efficacy of primary palliative care and critical illness survivor clinics, supporting more widespread use of these services across the country.

### **1.7.9 Protection of human subjects and reduction of risks**

For Aims 1 and 2, verbal consent for participation in this study will occur prior to initiation of any study activities. Potential participants for Aim 1 will be approached directly by the PI, who is also responsible for their care at the clinic appointment or by telephone after their first clinic appointment. For Aim 2, potential participants will be recruited through email. If the potential participant indicates interest, the PI will describe the study including the overall study aims, the level of participation required of study participants including the audio recording of interviews, risks, benefits (or lack thereof), confidential nature of the study and efforts to maintain confidentiality, voluntary nature and right to stop the interview or withdraw from the study. All questions will be answered to verbalized satisfaction. If the potential participant requests time to consider study participation, the PI will ask the potential participant for an acceptable follow-up time frame. Potential participants will be asked to explain the study, risks and benefits of participation, and the activities involved in study participation. As survivors of critical illness are at risk for post-intensive care syndrome (PICS), they are at risk for cognitive impairment (a component of PICS) as a result of their critical illness. With this in mind, after reviewing the telephone verbal consent script with the potential participant, the research team will also administer a brief assessment of decisional capacity for clinical research with the University of California, San Diego Brief Assessment of Capacity to Consent (UBACC). Question #3 of this survey will be mandatory. If a participant demonstrates understanding and is interested in providing informed consent, the research team member will proceed with verbal informed consent via telephone. A waiver of written consent has been requested as this project presents no more than minimal risk of harm to participants and the research activity involves no procedures for which written consent is normally required outside of the research context. Study participants will

be permitted to take breaks during the assessments, if needed, to minimize fatigue and frustration. Study participants will also be explicitly told that they can decide not to participate and can stop the interview, or refuse individual questions, at any time. This will be explained to participants at the time of informed consent and prior to the assessment session. All interviews will be audio recorded by the investigator. Sensitive information such as participant and family names, participant demographic information, IRB consents, digital audio files, audio recorder, and field notes will be kept in a secure location. Data will be recorded and identified by participant code numbers only. These materials will be kept under lock and key, accessed only by the PI and the data analysis team. Identities of participants will not be revealed in publications or presentations derived from this project. Identifiable data will not be released to any person or entity except as required by law.

For Aim 3, there is no direct contact with participants, so there is no direct risk. Breach of confidentiality is a potential risk in any research study; however, data are extracted by an investigator with clinical access to the data and identified in databases using only a study ID that does not reveal the identity of the participant. Information linking the participant's identity with their study ID is maintained in a password-protected computer file. De-identified data for this analysis will be maintained indefinitely by this investigator on a password-protected computer.

## **2.0 ADDITIONS AND CHANGES TO THE PROPOSED STUDY**

Several changes were made to this dissertation proposal after the comprehensive examination and dissertation overview and have been approved by all committee members. The detailed information about the aforementioned changes is listed below.

### **2.1 CHANGES TO AIM 1**

Three trained coders will initially independently code a random subset of 5 transcripts line by line, resolving any differences by discussion. All transcripts will be coded once, with intermittent dual-coding (20% of transcripts) to avoid developing idiosyncratic coding habits (Campbell et al., 2013). In the coding phase, inter-coder reliability (ICR) will be applied to the coding frame, allowing for reflexivity and dialogue within the research coding team. Inter-coder reliability (ICR) will be measured with Cohen's kappa in NVivo12 (version 12, QSR International), based on the main identified codes, between each set of coders (eg. coder 1 and coder 2, coder 2 and coder 3, and coder 3 and coder 1). ICR results will be reported individually, and not in aggregate, as pooling all coders' reliability figures could potentially "hide" or cancel out codes that do not perform very well (O'Connor & Joffe, 2020). After completing coding, the research team then will review all statements, discuss any differences, and resolve any remaining discrepancies by consensus.

## **2.2 CHANGES TO AIM 2**

Three trained coders with expertise in critical care medicine and palliative care medicine (nurse, physician, social worker) will initially code a subset of 5 transcripts line by line, resolving any differences by discussion. We will then use a bank of coded statements, based on the main identified codes, to test ICR to assess for coder drift. Coders will judge whether or not each item met the code definition. All transcripts will be coded once, with intermittent double coding (20% of transcripts) to avoid developing idiosyncratic coding habits. After completing coding, the research team then will review all statements, discuss any differences, and resolve any remaining discrepancies by consensus.

## **2.3 CHANGES TO AIM 3**

With regard to missing data, 26 cases were excluded from this analysis (n = 5 had no symptom survey data reported, n = 7 had > 50% symptom survey data missingness, and n = 14 had < 50% symptom survey data missingness), leaving 170 cases. A manual chart review of these 26 cases revealed clinic visit time constraints as the primary reason these cases were missing data. Predictive mean matching (PMM) was considered to impute item missingness, which would allow for the extraction of the proper number of factors and yielded the lowest bias for factor loading by a large margin as compared to other imputation techniques, and mean imputation is acceptable when <10% of the data are missing (McNeish, 2017; Rubin, 1986). However, with the true factor structure unknown, theoretically recommendable multiple imputation methods, such as PMM, cannot simply be applied. Additionally, Chi Square tests examining potential relationship with sex,

age, education level, and severity of illness (worst 24hr SOFA score, CCI, hospital length of stay, and ICU length of stay) against all items with missingness exceeding 5% was performed and the data demonstrated that the missingness was missing completely at random (MCAR) (Li, 2013). After running multiple analyses, each employing a different missing data strategy (PMM, listwise deletion), and comparing results, the decision was made to run the exploratory factor analysis model with complete cases only (n=170), and listwise deletion was utilized (Li, 2013), as the sample size was sufficient for the number of factors to be examined. (Mundfrom et al., 2005).

As several critical illness survivor qualitative studies have drawn attention to reports of irritability and subjective cognitive complaints in critical illness survivors (Brück et al., 2019; Hashem et al., 2016; Pattison et al., 2015; Walker et al., 2015), separate measures for irritability and concentration were included in this analysis. This decision was also based upon the qualitative interviews performed in Aim 1, where both subjective cognitive complaints and irritability emerged from the interview. Both irritability and poor concentration have also been reported as frequent non-specific symptoms, related to both cognitive impairment and PTSD, in other ICU survivor populations (Bienvenu et al., 2013; Gordon et al., 2004). These individual items were extracted from the PTSD screening tools utilized in the CIRC clinic and are measured on a 0-4 scale. Both PTSD screening tools use comparable questions for these items (Figure 1). Due to the objective nature of the MoCA, it was removed from this analysis. Subjective patient-reported cognitive symptom complaints were captured in the PEACE tool (confusion), and the PTSD screening tools (concentration and irritability).

After the initial EFA model development and execution, a revision to the symptom variables included in the EFA was performed, as some of the original variables included did not meet the traditional definition of a symptom as typically presented in symptom science literature

(Miaskowski et al., 2017). For that reason, the following variables were removed from the EFA model: perceived lack of control and perceived lack of support. However, these variables were retained in the prevalence and severity reporting. Also, the variable “diminished level of function” was also removed from the EFA, as this measure has already been collected objectively with the Lawton IADL assessment. The current Lawton IADL score will be used as a control variable in the regression analysis when examining potential relationships between overall health rating (ES-VAS) and identified factors from the EFA. Additionally, to retain the concentration and irritability variables originally extracted from the PTSD assessments tools while also continuing to include each domain related to PTSD in the EFA (Blevins et al., 2015), individual items across both PTSD tools pertaining to avoidance, intrusion, and arousal and reactivity were extracted from the PTSD tools and entered in the EFA. The revised variable list can be found in Figure 10.

Symptom Assessment Tools	Symptom(s) Measured for EFA	Scoring
Hospital Anxiety and Depression Scale (HADS)	Anxiety	Anxiety subscale score (0-21)
	Depression	Depression subscale score (0-21)
Impact of Events - Revised (IES-r)*	Irritability	Scale (0-4)
	Concentration	Scale (0-4)
	Avoidance	Scale (0-4)
	Intrusion	Scale (0-4)
	Arousal and reactivity	Scale (0-4)
PTSD checklist for DSM-5 (PCL-5)*	Irritability	Scale (0-4)
	Concentration	Scale (0-4)
	Avoidance	Scale (0-4)
	Intrusion	Scale (0-4)
Physical, Emotional, Autonomy, Communication, Economic, Transcendent (PEACE Tool)	Arousal and reactivity	Scale (0-4)
	Pain	Scale (0-10)
	Anorexia	Scale (0-10)
	Incontinence (bowel and bladder)	Scale (0-10)
	GI symptoms (nausea, vomiting, constipation)	Scale (0-10)
	Breathing problems/cough	Scale (0-10)
	Fatigue	Scale (0-10)
	Sleep issues	Scale (0-10)
	Oral discomfort (ulcers, dryness)	Scale (0-10)
	Fear of future	Scale (0-10)
Confusion/restlessness	Scale (0-10)	
Spiritual distress	Scale (0-10)	

\* PTSD assessment tool items will be collapsed into a single variable for each symptom measured in the EFA (eg. New irritability variable recoded from 2 irritability questions, one from each assessment tool)

**Figure 10: Revised variable list for EFA.**



### 3.0 SUMMARY OF COMPLETED DISSERTATION STUDY

#### 3.1 AIM 1 RESULTS

##### 3.1.1 UNPUBLISHED MANUSCRIPT: Exploring the Intersection between Palliative Care and Critical Illness Survivorship: A Qualitative Study of Patient Experiences

###### 3.1.1.1 Abstract

**Objective:** To explore the broader experience of surviving critical illness through the lens of palliative care including: 1) future goals for care, 2) symptom burden, 3) need for support, and 4) the impact of these factors on other health care planning.

**Design:** Qualitative inquiry using semi-structured interviews and Framework analysis.

**Participants:** Single-site study with a diverse group of 17 critical illness survivors previously attending the Critical Illness Recovery Center (CIRC) at UPMC Mercy.

**Measurements and Main Results:** We explored ongoing and unresolved critical illness survivor concerns using a framework designed to emphasize primary palliative care assessment components. Important themes in these interviews highlighted persistent symptom burden, patient-centered goals for care, spiritual change and significance, understanding and interpreting illness, and a list of multifaceted social needs.

**Conclusion:** In this single-site study, critical illness survivors 13 to 33 months from their intensive care unit (ICU) experience described ongoing holistic care needs, which may be well managed by

applying a primary palliative care approach to address these unresolved and wide-ranging concerns.

**Keywords:** palliative care, critical illness survivor, ICU recovery, post-intensive care syndrome, qualitative

### **3.1.1.2 Introduction**

Over the last three decades, a rapidly expanding volume of critical care literature has emerged to address issues faced by critical illness survivors including: survival, quality of life, morbidity, functional status, joblessness, and costs of care (Angus & Carlet, 2003). However, surviving critical illness goes beyond recovery and longer-term outcomes; it embodies an enduring, dynamic process of transitioning from critical illness to survivorship which involves physical, psychological, and social transitions and adaptations (Kean et al., 2017).

Survivors of critical illness emerge from a highly technical acute hospitalization, filled with unfathomable interventions and therapies, and multifaceted disease processes (Iwashyna, 2010), only to face overwhelming uncertainties involving their future well-being. Approximately 30% of ICU survivors experience subsequent unplanned hospital readmissions within the first 6 months following their ICU stay, with over one-quarter of all unplanned readmissions involving a subsequent ICU admission (Hua et al., 2015). ICU survivors without preexisting chronic conditions are five-fold more likely to develop a new chronic condition compared to non-ICU patients without preexisting chronic conditions (van Beusekom et al., 2019). Notably, one in five ICU survivors die within the year following their ICU stay, with most events occurring within 90 days of ICU discharge (Szakmany et al., 2019). Critical illness survivors also report significant physical, cognitive and psychological symptom burden, such as pain, fatigue, anxiety, depression,

and post-traumatic stress, which have dramatic impacts on their quality of life, capacity to regain independence, or ability to be employed, and often persist for months or years after hospital discharge (Brown et al., 2019; Choi, Hoffman, et al., 2014; Davydow et al., 2009; Dowdy et al., 2005; Kamdar et al., 2020; J. McPeake et al., 2019; Nikayin et al., 2016; Pandharipande et al., 2013; Parker et al., 2015). These functional dependencies are also reflected in discharge trends after ICU stay, with only 35% able to return home, 31% discharged to long-term acute care, and 34% to some level of rehabilitation after a critical illness (Herridge et al., 2016).

Given the substantial impairment seen, critical illness survivors possess care needs that are clearly within the scope of a palliative care framework, however despite recognizing the high burden of palliative need in older ICU survivors (Baldwin, et al., 2013), the role of palliative care has yet to be clearly defined in critical illness survivors. Palliative care provides an overall approach to care that improves quality of life and alleviates suffering for those patients and families living with serious, life-limiting, and chronic debilitating illness, regardless of prognosis, and across the disease trajectory (Kavalieratos et al., 2016; Morrison & Meier, 2004). With shortages of specialty palliative care clinicians increasing (Kamal et al., 2019) and a high threshold of symptom burden for consultation, the provision of a structured primary palliative care intervention, defined as the delivery of a goals of care discussion, basic symptom assessment and management, care coordination, and support by a clinician not board-certified in palliative care (Quill & Abernethy, 2013), may prove to be beneficial in this population.

Through semi-structured interviews with critical illness survivors, we explored the broader experience of surviving critical illness through a lens of palliative care which included: 1) future goals for care, 2) symptom burden, 3) need for support, and 4) the impact of these factors on other

health care planning. We used framework analysis to describe the intersection of critical illness survivorship and palliative care through patient discourse with regard to lived experiences.

### **3.1.1.3 Materials and Methods**

This study was reported using the Consolidated Reporting of Qualitative Research (COREQ) checklist (Tong et al., 2007).

### **3.1.1.4 Setting and ethical approval**

This descriptive qualitative study was conducted with critical illness survivors who attended a specialty post-ICU clinic program in Pittsburgh, PA between 2018-2020. The study design and protocol were approved by the University of Pittsburgh Institutional Review Board (IRB) (protocol STUDY19090073). Data were collected through semi-structured telephone interviews with each participant.

### **3.1.1.5 Study design, participants, sampling, and recruitment**

A qualitative research approach was used to explore how critical illness survivors exist in the context of their individual survivor journey and to describe complex experiences that do not fit a quantitative model of hypothesis testing (Al-Busaidi, 2008). Patients previously attending at least one post-ICU clinic visit at the Critical Illness Recovery Center (CIRC) at UPMC Mercy were asked to participate in the study by CIRC clinicians. Inclusion criteria were as follows: community dwelling patients 18 years or older, with access to telephone and/or computer with internet for audio interview, and ability to participate in English. Exclusion criteria were as follows: current residence in a nursing facility; anticipated life expectancy of 6 months or less, or active enrollment in hospice services, determined after first CIRC clinic visit; involved in current

specialty outpatient palliative care services; and decisional impairment, assessed by the administration of the University of California, San Diego Brief Assessment of Capacity to Consent (UBACC). Verbal informed consent was obtained before each interview. We used purposive sampling with maximum variation to select participants, to ensure the representativeness of the diversity of the CIRC clinic population (Palinkas et al., 2015). The intent of maximum variation sampling in this aim is to 1) yield high-quality detailed descriptions of each case, documenting uniqueness, and 2) examine important shared patterns that cut across cases and derive their significance from having emerged out of heterogeneity (Suri, 2011). With these aims in mind, variations in sampling included age, race, sex, Charlson Comorbidity Index (CCI), and ICU length of stay. All participants who were approached as described above agreed to participate.

#### **3.1.1.6 Data collection and generation**

A semi-structured interview guide was developed based on reviews of the existing qualitative literature regarding critical care survivorship and palliative care research (Bernacki & Block, 2014; Czerwonka et al., 2015; Dinglas et al., 2018; Dudley et al., 2018; Engström et al., 2008; Kavalieratos et al., 2014; McPeake et al., 2020; J. M. McPeake, M. O. Harhay, et al., 2019; Starr et al., 2020). Some questions were based on existing models used for goals of care conversations in the seriously ill (Bernacki & Block, 2014). Questions were refined through review and discussion with members of the research group (TE, AL, LS, JS). All interviews were undertaken by one researcher (TE), who is a female palliative care nurse practitioner and has experience in qualitative methodology and undertaking interviews of this type. The interviewer was known to some of the participants through their role in direct clinical care. Because of this, the guiding principle of ethics of care was applied, highlighting the disparity of position and power between the clinician-researcher and the participant, and positing that through reflexivity, the

clinician-researcher can create a research relationship grounded in rapport, honesty, and emotional closeness, while recognizing the potential abuses of power, which have the potential to increase with deeper levels of rapport. (Campbell & Wasco, 2000). Data collection took place by telephone with the participant after an initial visit to the CIRC. All interviews were audio-recorded, transcribed verbatim, and completely de-identified. No repeat interviews were undertaken. Participants were recruited until data saturation was achieved as determined by the analysis team (TE, AL, BD).

### **3.1.1.7 Data analysis, researcher reflexivity, relationship with participants, and rigor**

We applied a Framework analysis technique to analyze data across primary palliative care assessment domains (Gale et al., 2013). This included: 1) transcription; 2) familiarization with the interview; 3) coding; 4) developing a working analytical framework; 5) applying the analytical framework; 6) charting data into the framework matrix; and 7) interpreting the data (Srivastava & Thomson, 2009). Three researchers (TE, AL, BD) with different research backgrounds independently undertook preliminary sweeps of the data to familiarize themselves with the interview. Three trained coders (TE, AL, BD) together initially coded a subset of 5 transcripts line by line, resolving any differences by discussion. By incorporating more than two coders on the coding team, a level of inter-subjectivity within the team was achieved, thereby providing an additional level of scrutiny and rigor to the coding process through added perspectives of different researchers that produced a more thorough analysis than with a smaller coding team (MacQueen et al., 1998; Olson et al., 2016). All transcripts were coded once, with intermittent dual coding (20% of transcripts) to avoid developing idiosyncratic coding habits. After completing coding, the research team reviewed all statements, discuss any differences, and resolve any remaining discrepancies by consensus. Codes were not mutually exclusive, and more than one code could be

applied to a single piece of text. Coding was grouped under key themes in a working analytical framework grounded in primary palliative care assessment components (Weissman & Meier, 2011) and iteratively checked across the interview transcripts. Data analysis was performed using NVivo12 (version 12, QSR International) to code and query transcripts, as well as to develop the framework matrix. The researchers met regularly to discuss and address any issues as they arose throughout the study. During the final analysis, TE, supported by discussions with the rest of the team, developed final themes. Key quotes to support the findings were then independently extracted by TE and BD. With the guiding ethical principle of ethics of care utilized throughout the qualitative research process, the risk for exploitation, through role confusion, therapeutic misconception, and misrepresentation, along with concerns for social desirability, was continually considered and limited through development of an ethical research relationship and researcher reflexivity (Hewitt, 2007). Member checking occurred during the review of the manuscript and was undertaken with 10% of the participants to ensure the trustworthiness of the data.

### **3.1.1.8 Results**

Interviews occurred over a six-week period in February-March 2021. Seventeen critical illness survivors participated in the interviews. Detailed participant demographics are presented in Table 1, and overall demographics are presented in Table 2. Participants' ages ranged from 34 to 80 years (median age, 66). Interviews occurred approximately 1 year to 3 years after ICU stay (median 20 months). Interviews lasted between 15 minutes and 50 minutes (mean 28 minutes).

Using an adapted framework designed to emphasize primary palliative care assessment components (Weissman & Meier, 2011), the following themes and subthemes were identified. In the text, subthemes are presented in bold and italicized, and quotes italicized.

**Table 1. Overview of participants**

Age	Sex	Race	ICU admission diagnosis	ICU length of stay (days)	Time since ICU stay (months)	Charlson Comorbidity Index (CCI)
67	F	White	Guillain-Barré syndrome	33	18	2
60	F	White	Community acquired pneumonia; ARDS	29	33	2
63	M	White	Bacterial meningitis	10	26	5
56	F	White	Necrotizing fasciitis	17	32	3
49	F	Black	Ischemic stroke	19	13	1
53	M	White	Septic shock	42	30	1
72	F	White	Subarachnoid hemorrhage	8	31	6
62	M	Black	Ischemic stroke	17	17	2
80	F	White	Hemorrhagic shock 2/2 GIB	8	15	6
77	F	White	Ischemic stroke, STEMI	8	13	4
73	F	Black	Acute on chronic respiratory failure	10	33	4
72	M	White	Burn injury	29	33	5
38	M	Black	Polytrauma/motorcycle crash	5	20	0
66	F	White	Acute respiratory failure secondary to diaphragmatic rupture	9	19	2
34	F	Black	Polytrauma/motor vehicle crash	12	30	0
76	M	White	Septic shock	15	18	5
73	F	Black	Polytrauma/motor vehicle vs. pedestrian	6	17	3

ICU, intensive care unit; F, female; M, male; ARDS, acute respiratory distress syndrome; GIB, gastrointestinal bleeding; STEMI, ST elevation myocardial infarction.

**Table 2. Overview of interviews**

Total participants	N=17
Age, median (IQR)	66 (56, 73)
Sex, no. (%)	
Female	11 (64.7%)
Male	6 (35.3%)
Race, no. (%)	
White	11 (64.7%)
Black	6 (35.3%)
ICU length of stay (days), median, (IQR)	12 (8, 19)
Time from ICU stay to interview (months), median, (IQR)	20 (17, 31)
Charlson Comorbidity Index (CCI), (total score), median (IQR)	3 (2, 5)
ICU diagnosis, no. (%)	
Sepsis or septic shock	5 (29.4%)
Neurological disorders	5 (29.4%)
Trauma	3 (17.6%)
Acute respiratory disorders	2 (11.8%)
Burn	1 (5.9%)
GI disorders	1 (5.9%)

ICU, intensive care unit; GI, gastrointestinal.



### 3.1.1.9 Theme 1: Persistent symptom burden

All but one participant (*PA9, female, 80 years old, 15 months from ICU stay*) reported persistent symptoms which are commonly observed in the post-intensive care syndrome (PICS) framework, including ongoing physical, psychological, and cognitive dysfunction (Needham et al., 2012).

#### ***Unresolved physical symptoms***

Persistent pain was a common complaint across the diverse group of participants:

*'No, it's still the same. It's just chronic every day. Like I said, it's just a matter of how much pain.'* (*PA4, female, 56 years old, 32 months since ICU stay*)

Fatigue and sleep disturbances were also commonly reported:

*'Oh yeah. I'm not near strong, and I'm not near as, you know, I tire out easy... and I'm slower at doing things, and I get tired easy. My stamina's down... and sometimes I get busy, and I have to sit down, things like that.'* (*PA12, male, 72 years old, 33 months since ICU stay*)

*'One thing, see I don't have a, a steady sleep schedule. I... fall asleep, I may not, I might go to bed at eleven o'clock and, you know, not fall asleep until almost daylight.'* (*PA11, female, 73 years old, 33 months since ICU stay*)

#### ***Unresolved psychological symptoms***

Participants spoke about the psychological impacts of their critical illness; three patients became tearful during the interviews during their survivor journey. Depression was commonly discussed:

*'Depression is huge. It's, depression is, like, a process, it's not even like a battle, it's, like, a constant conflict that I need to keep myself in check and move forward, you know.'* (PA2, female, 60 years old, 33 months since ICU stay)

Ongoing issues with anxiety were reported, with two participants describing severe anxiety states and panic attacks since their critical illness:

*'The smallest thing that happens in my house becomes a crisis whereas before it would have been something that I would have just handled or called a repairman or whatever. But it causes all this anxiety and I become frantic about, 'Oh my God, I have to call one of my boys, they've got to come over here and do this.' It's just, like, this hyper reaction to everything and I don't know why that is.'* (PA7, female, 71 years old, 31 months since ICU stay)

Reports of events triggering past ICU memories were commented on by several participants:

*'As I mentioned before, sometimes certain sounds particularly will trigger memories. Um, in this just occurred last week: I'm sitting in the ICU [visiting] with another patient and there's an alarm ventilators make when something is wrong, it's like a honking horn. And this went off and, um, yeah, I was just sitting at the nurse's station, I hear that go off and yeah it triggered that memory, that was me when I extubated myself at two in the morning. I don't remember doing it, but I remember, I don't have a direct recollection of it, but the sound made me anxious.'* (PA3, male, 63 years old, 26 months since ICU stay)

### ***Unresolved cognitive symptoms***

Participants shared stories of ongoing cognitive complaints, highlighting concentration and memory concerns:

*‘But I would, I would say, like, the cognitive because I don't know what it is about this, this whole critical illness experience, but I think, and the fact that, this cognitive stuff came later... I'm still short of loose ends at times. I have a lot of difficulty, like, focusing and concentrating on things for any length of time.’ (PA7, female, 71 years old, 31 months since ICU stay)*

#### **3.1.1.10 Theme 2: Patient-centered goals for care**

Throughout the interviews, there were many instances that highlighted what participants felt was a good quality of life and how this informs what they want for their future healthcare, as well as some identified needs for guidance in making future healthcare decisions. Subthemes identified include life-altering experience, quality of life, influence of critical illness on changing healthcare wishes, and advance care planning need.

#### ***Life-altering experience***

Many participants described their critical illness experience as “life-changing”:

*‘Yeah, the VA gave me a living will, I have one, I have one that I filled out a long time ago, but things changed. I'm neglecting to fill it out, you know, just sitting down doing it, uh, I can't just make myself do it, but I'm gonna [sic] have to.’ (PA12, male, 72 years old, 33 months since ICU stay)*

*And after this happened to me, about a year and a half later, you know, I went to an elder law attorney, you know, and because I thought this was a life altering experience for me and, you know, I had a will made up, I had powers of*

*attorney for finance and health drawn up.’ (PA7, female, 71 years old, 31 months since ICU stay)*

*‘Completely. It’s turned 180 degrees. Um, because of the remnants of the disease, I wasn’t able to clear it completely.’ (PA1, female, 67 years old, 18 months since ICU stay)*

### **Quality of life**

Discussions surrounding what constitutes a good quality of life were very individualized from participant to participant:

*‘Acceptable would be coming back home and, and doing what I’m doing now. Um, what would not be acceptable would be being vegetative. Um... That would just not be acceptable.’ (PA1, female, 67 years old, 18 months since ICU stay)*

*‘Oh, if I had to be in a wheelchair and couldn’t fend for myself, my bowels and stuff, I wouldn’t want that. No, I don’t wanna [sic] be an invalid, you know, and have to go in the home, that kind of stuff, I don’t really want that.’ (PA6, male, 53 years old, 30 months since ICU stay)*

### **Influence of critical illness on changing healthcare wishes**

As a result of their critical illness, some participants discussed changing healthcare wishes based on this personal illness experience:

*‘Yeah, I hate, I was on the feeding tube for a while, both in the ICU and out. Uh, I’ve been on one before because of the esophagostomy, but I do not want to be on a feeding tube again. Like, it was just terrible. Yeah, we’re working on that because my husband doesn’t all agree with what I want. ... ’cause I told him, ‘No,*

*no feeding tube and no long term, do I wanna [sic] be on the vents'. So, yeah, he knows but he, he says I'm selfish, like... I said, 'If I'm not well enough to be there, then why keep me on a machine?' (PA14, female, 66 years old, 19 months since ICU stay)*

### ***Lack of awareness about advance directives and advance care planning***

Some participants revealed that they do not discuss their healthcare wishes with their families, or have no guidance or support in making these decisions:

*'No, I haven't thought about it. I want to be taken care of; I know that... I don't want to, you know, how they say, do you have a living will, is that what's it called? Yeah, well, I don't, I don't wanna [sic] be just left to die. I wish that, um, I would want them to do what they could for me.'* (PA11, female, 73 years old, 33 months since ICU stay)

*'I just take for granted that they'd know what to do and get the best out of it. Like I said, that, both of my daughters are nurses.'* (PA16, male, 76 years old, 18 months since ICU stay)

#### **3.1.1.11 Theme 3: Spiritual change and significance**

The role of spirituality and religion was widely discussed by participants as a profound piece of their survivorship journey. Subthemes identified include ongoing and/or unmet spiritual needs, search for spiritual meaning/finding spiritual purpose in critical illness experience and identifying/applying spirituality to critical illness experience.

### ***Ongoing and/or unmet spiritual needs***

Some participants highlighted how their critical illness affected the way they expressed their spirituality:

*'It's, um, is as strong as ever, but it's not as faithful as ever, you know, but it's strong. You know, when I came out of the hospital, I didn't get right back in churches and the volunteering that I did at the church, you know, I wasn't able to do that anymore.'* (PA11, female, 73 years old, 33 months since ICU stay)

### ***Search for spiritual meaning/finding spiritual purpose in critical illness experience***

Many others described a need to make spiritual meaning out of their critical illness:

*'I just feel even more connected to the Lord than I was before because I feel that, you know, he got me through this, he has me here for a reason, I don't think he's revealed it to me yet.'* (PA7, female, 71 years old, 31 months since ICU stay)

### ***Identifying/applying spirituality to critical illness experience***

Reaffirming faith or a deeper belief was conveyed in many participant interviews:

*'...it was the incident that really increased my faith, spiritually. To know that I had been through all that and came out alive. So, it gave me a stronger spiritual faith, I was strong spiritually already, but this is really, that's why I call it 'The Incident' ... that gave me the courage and strength to just see this as that, something that strengthens my faith.'* (PA17, female, 73 years old, 17 months since ICU stay)

## **3.1.1.12 Theme 4: Understanding and interpreting illness**

Many participants recognized and discussed a need for communication regarding their critical illness survivor trajectory. Participants spoke of appreciating and depending on

clarification, interpretations of their conditions, and reassurance from their providers. Subthemes include validation of critical illness experience, provision of hope, expectation management, and acknowledgement of ongoing illness and dysfunction.

### ***Validation of critical illness experience***

Participants shared the importance of affirming that their feelings and opinions regarding their critical illness are valid and worthwhile:

*'I found it very helpful to be told that these things I was experiencing were not out of the ordinary for something like this... you know, all those folks [post-ICU clinic staff] kind of really made me feel that, 'Yes, these are things that happen', and it just gave me some consolation that I was not imagining this, or I wasn't losing my mind, or on the trail to something even darker happening to me.'* (PA7, female, 71 years old, 31 months since ICU stay)

*'Yes, but I think, I think, you know, I want to be heard. When people are new out of the ICU and, you know, I think it you have to believe them.'* (PA2, female, 60 years old, 33 months since ICU stay)

### ***Provision of hope***

Feelings of hope were discussed as a necessity as the participants navigate their survivor experience:

[in reference to hope] *'Well, you can't take that thought away from me. Yeah, we just can't take that thought away.'* (PA4, female, 56 years old, 32 months since ICU stay)

*'You know, but I have hope, even with things that come my way that I didn't expect. People, people need hope.'* (PA2, female, 60 years old, 33 months since ICU stay)

### ***Expectation management***

Some participants were able to verbalize realistic expectations for their survivorship journey, while others displayed a need for assistance in setting and managing expectations:

*'I hope it gets better, but, reality speaking, I'm gonna [sic] always need some help.'* (PA13, male, 38 years old, 20 months since ICU stay)

*'I have no idea, I really have no idea how long I'm going to need help 'cause [sic] my goal in getting help is to overcome what's come my way, and to be at my best. But new things arrive all the time, new things have, new struggles have arrived, new factors...'* (PA2, female, 60 years old, 33 months since ICU stay)

### ***Acknowledgment of ongoing illness and dysfunction***

Despite the length of time from ICU stay, many participants verbalized permanent and/or persistent illness and dysfunction:

*'I still am unable to do an awful lot. Which really, really bothers me. And then not being able to work physically, which I have really been trying hard to push myself, and I cannot.'* (PA4, female, 56 years old, 32 months since ICU stay)

*'Because, like I told the doctor, I don't feel like myself, and I'm on, it's two years later.'* (PA17, female, 73 years old, 17 months since ICU stay)

### **3.1.1.13 Theme 5: Ongoing social and practical support needs**

The biggest multifaceted theme to emerge was the need for persistent social and practical support. Forms of support discussed by participants spanned across functional, emotional,



financial domains, and types of support providers included family, friends, and healthcare providers.

### ***Lack of empathy for the critical illness survivor experience***

Some participants discussed the lack of emotional support from family, healthcare providers, or their community in both acknowledging and understanding the thoughts and feelings of the survivor:

*'And the thing that I've noticed though from everybody is they don't know how to handle; they don't know what to say if I complain about something. Like, if I complain about my hands, or I complain about my crappy balance, or I complain about something, anything. I get crickets. So, I've just stopped talking about it.'* (PA1, female, 67 years old, 18 months since ICU stay)

*'It's just, just like, it's so different now, and when you try to tell a regular person, a healthy person, 'I can't get anything done.' They go, 'Oh, neither can I.' No, you don't, just don't understand.'* (PA2, female, 60 years old, 33 months since ICU stay)

### ***Becoming a burden***

The concept of “being a burden” to others was a common thread across interviews. Participants reported ongoing worry about making someone, whether that be family, friends, or community, accept or be tasked with assisting with the difficulties of their persistent dysfunction:

*'I mean, it's a hassle for my daughter because she has two children. So, either I'm taking up space in her living room... She had to change her house around because of me.'* (PA5, female, 49 years old, 13 months since ICU stay)

*'I think it affected all of them because my daughter had to take care of me and my husband... and she was taking care of me and him, but mainly so much was for me. I told her she had to go and check up on herself and she would be like, 'I'm okay', but it was more than that for her, you know, she has cancer...' (PA17, female, 73 years old, 17 months since ICU stay)*

### ***Needs for ongoing support***

Participants report an ongoing need for longer term support after critical illness. Many participants struggled to meet their daily physical, emotional, and financial demands.

*'Uh, we talked about that, about how everybody's [family] stressed out. Uh, a lot because I depend on them a lot more, for food shopping, cleaning, uh, cooking.'* (PA13, male, 38 years old, 20 months since ICU stay)

### ***Stressed relationships***

Stress associated with the critical illness survivor experience has carried over into personal relationships for some of the participants:

*'You know, so, they, like, baby me, and I can't, I have a terrible time trying to handle it. So, you know, everybody worries about me too much and I don't like it. (PA4, female, 56 years old, 32 months since ICU stay)*

*'Like, people get mad at me [for being insensitive to their problems], that's the one thing about this whole illness... Uh, a couple of them are angry with me now because they talk about their problems and, frankly, after all the stuff I've been through, and seen in the hospital, and then doing this group therapy, and stuff... and that makes people a little bit angry.'* (PA6, male, 53 years old, 30 months since ICU stay)

### ***Changing roles***

Changes in family, social, or professional roles were described widely, with some participants sharing their concerns regarding new identities as a result of critical illness:

*'My children never thought I would need help with anything. And then, coming home from the nursing home, they have to adjust the fact that, 'Oh, you can't do this?' Like, my, my one daughter kicks in right away, she sees me some days and she goes, 'Here, mom, let me cut your meat.' Because on some days, I can't cut my meat. That's nuts.'* (PA2, female, 60 years old, 33 months since ICU stay)

### ***Employment concerns***

Many participants described an inability to work, along with discussed extended lengths of time out of the work environment. There were worries shared regarding re-entry into the workforce after a critical illness:

*'So, I didn't work, and now, trying to get back into that is my toughest thing, and that's where I think... [post-ICU clinic] ... they might try to reach out and have people, like, maybe headhunters, whatever, for jobs. To get people acclimated back into the work environment because that's your main concern.'* (PA6, male, 53 years old, 30 months since ICU stay)

*'I need help getting a job, that's it. Vocational help, because I've been out, I've been out for a while, so it's tough to get back in, that's, even re-training to another field. Like, I'm not opposed to get, I mean, I'm older don't get me wrong, but hey, I've always like school, I would go back to school or whatever.'* (PA4, female, 56 years old, 32 months since ICU stay)

### ***Healthcare costs***

Participants reported not only the initial burden of healthcare expenses during and after their critical illness, but also shared ongoing difficulties in affording maintenance care:

*'You know, I always try to stay insured but, you know, there's always some type of prescriptions and, you know, when that first happened, that was definitely my big concern. You know, I knew that whatever I had in my savings, it wasn't going to cover it in all the time I was down for.'* (PA15, female, 34 years old, 30 months since ICU stay)

*'Of course, financially, 'cause [sic] I'm not allowed to work... medication which I haven't been able to have because [health insurance company] didn't want to pay for the medicine.'* (PA5, female, 49 years old, 13 months since ICU stay)

### ***General financial concerns***

Ongoing overall financial issues, which were characterized as a result of their critical illness by the participants, were disclosed, including disability payments too low to support monthly expenses and issues surrounding permanent loss of income.

*'Oh it's 'awesome' being on disability... is just unbelievable. I'm hardly meeting my bills; I'm taking money from this one month and putting it on another. It's just nowhere near enough money. When you go on disability, they actually need to give you money to live off of instead of stressing out about that on top of everything else.'* (PA4, female, 56 years old, 32 months since ICU stay)

*'Oh, you know, we've always depended on two incomes, and I'm concerned about my wife, you know, she's gone back to one income, that kind of stuff.'* (PA12, male, 72 years old, 33 months since ICU stay)

**Table 3. Interview themes and subthemes**

<b>Persistent symptom burden</b>	<ul style="list-style-type: none"> <li>- Unresolved physical symptoms (pain, fatigue, sleep)</li> <li>- Unresolved psychological symptoms (anxiety, depression, post-traumatic stress disorder)</li> <li>- Unresolved cognitive symptoms (memory, concentration)</li> </ul>
<b>Patient-centered goals of care</b>	<ul style="list-style-type: none"> <li>- Life-altering experience</li> <li>- Acceptable quality of life</li> <li>- Influence of critical illness on changing health-care wishes</li> <li>- Advance care planning need</li> </ul>
<b>Spiritual change and significance</b>	<ul style="list-style-type: none"> <li>- Identifying/applying spiritually to critical illness experience</li> <li>- Search for spiritual meaning/finding spiritual purpose in critical illness experience</li> <li>- Ongoing and/or unmet spiritual needs</li> </ul>
<b>Understanding and interpretation of illness</b>	<ul style="list-style-type: none"> <li>- Acknowledgment of ongoing illness uncertainties</li> <li>- Expectation management</li> <li>- Provision of hope</li> <li>- Validation of critical illness experience</li> </ul>
<b>Ongoing social needs</b>	<ul style="list-style-type: none"> <li>- Lack of empathy for the critical illness survivor experience</li> <li>- Employment concerns</li> <li>- Healthcare costs</li> <li>- General financial concerns</li> <li>- Becoming a burden</li> <li>- Need for ongoing support</li> <li>- Stressed relationships</li> <li>- Changing roles</li> </ul>

### **3.1.1.14 Discussion**

For over 10 years, critical illness survivorship literature has reported a need for holistic care in this population. Many other qualitative critical illness survivor studies have represented this same survivor voice (Cox et al., 2009; Czerwonka et al., 2015; Dinglas et al., 2018; Eakin et al., 2017; Hauschildt et al., 2020; Kang & Jeong, 2018; König et al., 2019; Lee et al., 2009; Maley et al., 2016). As we see in these interviews of participants 13 to 33 months after critical illness,

associated responses affect all aspects of the whole person, including physical, cognitive, psychological, social, and spiritual components. With the arrival of the post-ICU clinic, we have begun to shift focus to optimizing all dimensions of a survivor's life. However, the longer-term sequelae of critical illness involve constant change and transition along a continuum of survivorship. The weight of critical illness survivorship far exceeds the resources provided with current post-ICU care.

Much of the reported symptom burden in this study is consistent with what is currently reported in the post-intensive care syndrome (PICS) symptom literature (Brown et al., 2019; Mikkelsen et al., 2020). These findings only further validate the need to manage symptoms in the long-term, as some of these participants were almost 3 years from their critical illness and continue to endorse ongoing significant symptom burden. Spirituality and faith are a central part to many patients; however, spiritual issues are often overlooked. Themes and subthemes revolving around ongoing or unmet spiritual needs as well as the search for spiritual meaning or purpose in the critical illness experience quickly and clearly emerged from these interviews highlighting a gap in our current post-ICU care. Importantly, many of the concerns seen in these interviews are consistent with other survivors living in chronic, life-limiting, debilitating disease states (Kavalieratos et al., 2017; Mechler & Liantonio, 2019; Murali et al., 2020; Petrillo et al., 2021). Throughout these interviews, participants shared how surviving a critical illness was *life-altering* for them, and how this experience has changed their perspectives... on relationships, on health, on needs, and on future healthcare decision making. Participants were largely comfortable in talking about their future healthcare wishes, what an acceptable quality of life looks like, and how their critical illness experience is now informing future decision making. More broadly, these interviews show critical illness survivors are looking for us to provide guidance along their trajectory of

ongoing illness uncertainties, and more notably, a balance of hope and expectation management, and a recognition that what they have experienced and felt is valid and worthwhile. All participants shared stories of ongoing social needs, with lack of empathy for the critical illness survivor experience as one of the biggest gaps in support. The perception, real or perceived, of feeling misunderstood by friends, family, community, and even healthcare providers is a big challenge for survivors. Three of the participants actively participate in a patient and family ICU survivor peer support group and reported that their involvement in peer support has lessened this burden for them. Not surprisingly, many participants described ongoing financial concerns related to employment concerns, healthcare costs, and cost of living expenses. These findings are consistent with recent literature regarding return-to-work concerns and financial toxicity following critical illness (Hauschildt et al., 2020; McPeake et al., 2017; J. M. McPeake, P. Henderson, et al., 2019). These overwhelming social needs make a compelling argument for including social work as a core discipline of post-ICU care (Lewis et al., 2021).

The goal of critical illness survivor care is to provide personalized care that focuses on the unique needs of survivor (Eaton et al., 2019). As observed in these interviews, there are substantial unmet needs, and incorporating interprofessional primary palliative care into current post-ICU practice may prove a potential solution to meeting the needs of these survivors. Symptom management (including that of cognitive symptoms), psychosocial and spiritual support, care coordination, and communication regarding healthcare wishes, with the overall goal of improving quality of life should naturally be a part of critical illness survivor care, however, some of these domains remain overlooked or are not the primary focus of care in this population. Research is needed to examine the implementation of interventions in these palliative care domains and

evaluate both the efficacy and effectiveness of these interventions on critical illness survivor outcomes.

There are limitations to these data. Patient interview data was collected from a single site, limiting its generalizability to the entire critical illness survivor population. The findings may serve as pilot data to inform a larger, multi-site study to generate generalizable findings. Family and caregiver voices were not included in this study, and their role in the survivorship continuum is vital; future research should include these perspectives. There is risk for social desirability bias, as the interviewer provided outpatient clinic care to a portion of the participants. This limitation was minimized by ensuring rigor in interview questioning techniques, including indirect questioning, question prefacing, and providing assurances. Additionally, through the creation and maintenance of an ethical research relationship by the PI with the participant, this limitation was minimized through acknowledge of bias, reflexivity, professional boundaries, and clear definition of research aims.

### **3.1.1.15 Conclusions**

In this study, multiple domains of ongoing need were identified in critical illness survivors 13-33 months from initial ICU stay. These needs intersect with, and may be met with the holistic approach to treatment that a palliative care framework offers, as these interventions can be tailored to assist survivors of critical illness and their families gain a realistic understanding of the trajectory of intensive care unit (ICU) survivorship and facilitate future healthcare choices—*in the context of the patient's goals and values*—from available treatment options, provide a holistic lens for assessment and management of survivor symptom burden, and assist in ongoing support needs across the illness trajectory.



### **3.1.2 Additional Considerations for Completed Aim 1 Study**

#### **3.1.2.1 Discussion of data collection procedures**

Qualitative data were collected for participants meeting inclusion criteria and verbally consenting to participation; this resulted in 17 participants for Aim 1. Data was obtained through audio recorded telephone interviews with each participant individually. Interviews were transcribed verbatim by a paid transcription service, and then reviewed by the PI to ensure data were captured how answers were spoken by the participant. Transcripts were also de-identified at this stage by the PI. Memo taking was utilized during each interview, and a reflexive diary was kept and utilized before and after each interview for improving reliability and removing bias (Ahern, 1999). Major items recorded in the reflexive diary included evolving perceptions and personal introspections. The reflexive diary was also useful in refining the understanding of the role of the clinician-researcher. A log of methodological decision points was also maintained during each research team transcript review and coding meeting. This assisted in determining when data saturation was met, and enrollment was ended.

#### **3.1.2.2 Discussion of data analysis procedures**

A Framework analysis was used for the analysis of this study. Major themes regarding primary palliative care assessment domains (Gale et al., 2013) were applied to the framework. Data were analyzed with the following stepwise approach. First each interview was transcribed as discussed in the above section. Second, prior to initiating coding, the full breadth of qualitative data was read, including transcripts and reflective notes, by the PI to initiate overall thoughts and impressions, and create familiarization with the interviews. Additionally, three researchers (TE, AL, BD) with different research backgrounds independently undertook preliminary sweeps of the

data to familiarize themselves with the interviews. Third, three trained coders (TE, AL, BD) together initially coded a subset of 5 transcripts line by line, resolving any differences by discussion. There was a mix of inductive and deductive coding throughout the process, as some codes were predetermined based on what is known about critical illness survivors and primary palliative care in current peer-reviewed literature, and some opening (inductive) coding occurred with emerging themes regarding life transitions acknowledgement of critical illness identity, and patient identified needs. Then, all transcripts were coded once, with intermittent dual coding (20% of transcripts) to avoid developing idiosyncratic coding habits. Early stages of coding were performed with pen and paper. Fourth, a working analytical framework was developed after the first five transcripts were coded. Coding was grouped under key themes in a working analytical framework grounded in primary palliative care assessment components (Weissman & Meier, 2011) and iteratively checked across the interview transcripts. Fifth, the analytical framework was applied by indexing subsequent transcripts using the existing categories and codes. Importantly, although the analytical framework was applied using existing categories and codes, due to the nature of qualitative data collection, there were additional codes identified through open coding throughout this stage along with refined codes. After completing coding, the research team reviewed all statements, discuss any differences, and resolve any remaining discrepancies by consensus. Sixth, data was entered into the framework matrix using NVivo12 (version 12, QSR International) to code and query transcripts. The matrix comprised of one row per participant and one column per code. Last, themes and subthemes were generated from the data set. This was influenced by pre-determined research objectives along with new concepts emerging inductively from the data. The research team met regularly to discuss and address any issues as they arose throughout the study. During the final analysis, TE, supported by discussions with the rest of the

team that saturation was reached, developed final themes and subthemes. Key quotes to support the findings were then independently extracted by TE and BD. Member checking occurred during the participants’ review of the manuscript and was undertaken with 10% of the participants. Inter-coder reliability (ICR) was measured with Cohen’s kappa in NVivo12 (version 12, QSR International), based on the main identified codes, between each set of coders (eg. coder 1 and coder 2, coder 2 and coder 3, and coder 3 and coder 1). ICR results are reported individually, and not in aggregate, as pooling all coders’ reliability figures could potentially “hide” or cancel out codes that do not perform very well (O’Connor & Joffe, 2020). Please refer to Table 1 for ICR results. Key themes and subthemes with quotations can be found in Table 2.

**Table 1. ICR results for main codes**

<b>Major codes</b>	<b>Coder 1 and Coder 2 Kappa*</b>	<b>Coder 2 and Coder 3 Kappa*</b>	<b>Coder 1 and Coder 3 Kappa*</b>
New possibilities in life	1	1	0.93
Coping/ Growing pains after illness	0.90	0.98	0.94
Advanced care planning			0.91
Illness-related guilt			0.90
Expectation management	1	1	
Financial concerns	0.88	0.86	0.82
Appreciation of life			0.88
Inadequate healthcare resources			0.86
Lingering effects of critical illness	0.91		0.87
Validation	1	1	0.77
Changing roles		0.91	
Ongoing supportive care needs		1	0.78
Symptoms	0.80	1	0.87
Spiritual needs and concerns	1	1	1
Support	0.93	0.80	

\* Cohen's kappa statistic measuring intercoder reliability

**Table 2. Key themes and subthemes with quotations**

Theme	Quotation
<b>Persistent symptom burden</b>	
Unresolved physical symptoms	<p>PA4: "No, it's still the same. It's just chronic every day. Like I said, it's just a matter of how much pain."</p> <p>PA12: "Well, I don't do it as much, and I'm slower at doing things, and I get tired easy."</p> <p>PA11: "One thing, see I don't have a, a steady sleep schedule. I... fall asleep, I may not, I might go to bed at eleven o'clock and, you know, not fall asleep until almost daylight."</p>
Unresolved psychological symptoms	<p>PA2: "Depression is huge. It's, depression is, like, a process, it's not even like a battle, it's, like, a constant conflict that I need to keep myself in check and move forward, you know."</p> <p>PA3: "As I mentioned before, sometimes certain sounds particularly will trigger memories. Um, in this just occurred last week: I'm sitting in the ICU with another patient and there's an alarm ventilators make when something is wrong, it's like a honking horn. And this went off and, um, yeah I was just sitting at the nurses station, I hear that go off and yeah it triggered that memory, that was me when I extubated myself at two in the morning. I don't remember doing it, but I remember, I don't have a direct recollection of it, but the sound made me anxious."</p> <p>PA7: "The smallest thing that happens in my house becomes a crisis whereas before it would have been something that I would have just handled or called a repairman or whatever. But it causes all this anxiety and I become frantic about, "Oh my God, I have to call one of my boys, they've got to come over here and do this." It's just, like, this hyper reaction to everything and I don't know why that is."</p>
Unresolved cognitive symptoms	<p>PA2: "Like, like things go in my head, like, "I would really like to learn this, it's important that I learn new things for cognitive help. Oh, but you're not going to remember anything. You can't remember it, you can't even remember conversations that you have."</p> <p>PA7: "But I would, I would say, like, the cognitive because I don't know what it is about this, this whole critical illness experience, but I think, and the fact that, this cognitive stuff came later... I'm still short of loose ends at times. I have a lot of difficulty, like, focusing and concentrating on things for any length of time."</p>

Theme	Quotation
<b>Patient-centered goals for care</b>	
Advance care planning need	<p>PA11: "No, I haven't thought about it. I want to be taken care of, I know that. I don't, I don't want to, you know, how they say, do you have a living will, is that what's it called? Yeah, well, I don't, I don't wanna [sic] be just left to die. I wish that, um, I would want them to do what they could for me."</p> <p>PA16: "I just take for granted that they'd know what to do and get the best out of it. Like I said, that, both of my daughters are nurses."</p>
Life-altering experience	<p>PA12: "Yeah, the VA gave me a living will, I have one, I have one that I filled out a long time ago, but things changed. I'm neglecting to fill it out, you know, just sitting down doing it, uh, I can't just make myself do it, but I'm gonna [sic] have to."</p> <p>PA7: "And after this happened to me, about a year and a half later, you know, I went to an elder law attorney, you know, and because I thought this was a life altering experience for me and, you know, I had a will made up, I had powers of attorney for finance and health drawn up."</p>
Quality of life	<p>PA1: "Acceptable would be coming back home and, and doing what I'm doing now. Um, what would not be acceptable would be being vegetative. Um... That would just not be acceptable."</p> <p>PA12: "Oh, if I had to be in a wheelchair and couldn't fend for myself, my bowels and stuff, I wouldn't want that. No, I don't wanna [sic] be an invalid, you know, and have to go in the home, that kind of stuff, I don't really want that."</p>
Influence of critical illness on changing health-care wishes	<p>PA14: "Yeah, I hate, I was on the feeding tube for a while, both in the ICU and out. Uh, I've been on one before because of the esophagostomy, but I do not want to be on a feeding tube again. Like, it was just terrible. Yeah, we're working on that because my husband doesn't all agree with what I want. ...cause I told him, 'No, no feeding tube and no long term, do I wanna [sic] be on the vents'. So, yeah, he knows but he, he says I'm selfish, like... I said, 'If I'm not well enough to be there, then why keep me on a machine?'"</p>

Theme	Quotation
<b>Ongoing social needs</b>	
Lack of empathy for the critical illness survivor experience	<p>PA1: "And the thing that I've noticed though from everybody is they don't know how to handle, they don't know what to say if I complain about something. Like, if I complain about my hands, or I complain about my crappy balance, or I complain about something, anything. I get crickets. So, I've just stopped talking about it."</p> <p>PA2: "It's just, just like, it's so different now, and when you try to tell a regular person, a healthy person, 'I can't get anything done.' They go, 'Oh, neither can I.' No, you don't, just don't understand."</p>
Employment concerns	<p>PA3: "So, I didn't work, and now, trying to get back into that is my toughest thing, and that's where I think... [post-ICU clinic]... they might try to reach out and have people, like, maybe headhunters, whatever, for jobs. To get people acclimated back into the work environment because that's your main concern."</p> <p>PA6: "I need help getting a job, that's it. Vocational help, because I've been out, I've been out for a while, so it's tough to get back in, that's, even re-training to another field. Like, I'm not opposed to get, I mean, I'm older don't get me wrong, but hey, I've always like school, I would go back to school or whatever."</p>
Healthcare costs	<p>PA15: "You know, I always try to stay insured but, you know, there's always some type of prescriptions and, you know, when that first happened, that was definitely my big concern. You know, I knew that whatever I had in my savings, it wasn't going to cover it in all the time I was down for."</p> <p>PA5: "Of course financially, 'cause [sic] I'm not allowed to work... medication which I haven't been able to have because [health insurance company] didn't want to pay for the medicine."</p>
General financial concerns	<p>PA4: "Oh it's 'awesome' being on... disability... is just unbelievable. I'm hardly meeting my bills, I'm taking money from this one month and putting it on another. It's just nowhere near enough money. When you go on disability, they actually need to give you money to live off of instead of stressing out about that on top of everything else."</p> <p>PA12: "Oh, you know, we've always depended on two incomes, and I'm concerned about my wife, you know, she's gone back to one income, that kind of stuff."</p>
Becoming a burden	<p>PA5: "I mean, it's a hassle for my daughter because she has two children. So, either I'm taking up space in her living room... She had to change her house around because of me."</p> <p>PA17: "I think it affected all of them because my daughter had to take care of me and my husband... and she was taking care of me and him, but mainly so much was for me. I told her she had to go and check up on herself and she would be like, 'I'm okay', but it was more than that for her, you know, she has cancer..."</p>
Needs for ongoing support	<p>PA13: "Uh, we talked about that, about how everybody's [family] stressed out. Uh, a lot because I depend on them a lot more, for food shopping, cleaning, uh, cooking."</p> <p>PA15: "Uh, I think the only help I normally always need is, uh, like, some physical work, like, around the house, hanging pictures that, you know, climbing ladders or taking trash out because, you know, I stay kinda [sic] on a hill. So, it was definitely my biggest concern, so thank God for my family for getting it together."</p>
Stressed relationships	<p>PA4: "You know, so, they, like, baby me, and I can't, I have a terrible time trying to handle it. So, you know, everybody worries about me too much and I don't like it."</p> <p>PA6: "Like, people get mad at me, that's the one thing about this whole illness, I'm a good listener, I have a lot of friends and... Uh, a couple of them are angry with me now because they talk about their problems and, frankly, after all the stuff I've been through, and seen in the hospital, and then doing this group therapy, and stuff... and that makes people a little bit angry."</p>
Changing roles	<p>PA11: "Well, they became more of the parent, they, you know, started to take care of me, and we were concerned about my health rather than, instead of maybe being concerned about them and what they're doing it, and it, it was reversed, you know."</p> <p>PA2: "My children never thought I would need help with anything. And then, coming home from the nursing home, they have to adjust the fact that, "Oh, you can't do this?" Like, my, my one daughter kicks in right away, she sees me some days and she goes, "Here, mom, let me cut your meat." Because on some days, I can't cut my meat. That's nuts."</p>

Theme	Quotation
<b>Understanding and interpretation of illness</b>	
Acknowledgement of ongoing illness and dysfunction	<p>PA4: "I still am unable to do an awful lot. Which really, really bothers me. And then not being able to work physically, which I have really been trying hard to push myself, and I cannot."</p> <p>PA11: "It changed 360, you know, whatever, what I used to do without even thinking, I can't do anymore. I could cook, my energy, and it took me a long time to build up my strength, and still it's not built, built up."</p> <p>PA17: "Because, like I told the doctor, I don't feel like myself, and I'm on, it's two years later. But he said, "You've been through a lot."</p>
Expectation management	<p>PA13: "I hope it gets better, but, reality speaking, I'm gonna [sic] always need some help."</p> <p>PA2: "I have no idea, I really have no idea how long I'm going to need help 'cause [sic] my goal in getting help is to overcome what's come my way, and to be at my best. But new things arrive all the time, new things have, new struggles have arrived, new factors..."</p>
Provision of hope	<p>PA4: [in reference to hope] "Well, you can't take that thought away from me. Yeah, we just can't take that thought away."</p> <p>PA2: "You know, but I have hope, even with things that come my way that I didn't expect. People, people need hope."</p>
Validation of critical illness experience	<p>PA2: "Yes, but I think, I think, you know, I want to be heard. When people are new out of the ICU and, you know, I think it you have to believe them."</p> <p>PA7: "I found it very helpful to be told that these things I was experiencing were not out of the ordinary for something like this... you know, all those folks [post-ICU clinic] kind of really made me feel that, 'Yes, these are things that happen', and it just gave me some consolation that I was not imagining this, or I wasn't losing my mind, or on the trail to something even darker happening to me."</p>

Theme	Quotation
<b>Spiritual change and significance</b>	
Identifying/applying spirituality to critical illness experience	<p>PA12: "Yeah, I believe stronger than I did, that's for sure. I always knew there were was a God, but now I know there is one. Let's put it that way."</p> <p>PA17: "... it was the incident that really increased my faith, spiritually. To know that I had been through all that and came out alive. So, it gave me a stronger spiritual faith, I was strong spiritually already, but this is really, that's why I call it 'The Incident' ... that gave me the courage and strength to just see this as that, something that strengthens my faith."</p>
Search for spiritual meaning/finding spiritual purpose in critical illness experience	<p>PA2: "My greatest fear is, is not being a good steward, which is what God is giving me."</p> <p>PA7: "I just feel even more connected to the Lord than I was before because I feel that, you know, he got me through this, he has me here for a reason, I don't think he's revealed it to me yet."</p>
Ongoing and/or unmet spiritual needs	<p>PA11: "It's, um, is as strong as ever, but it's not as faithful as ever, you know, but it's strong. You know, when I came out of the hospital, I didn't get right back in churches and the volunteering that I did at the church, you know, I wasn't able to do that anymore."</p>

## 3.2 AIM 2 RESULTS

### 3.2.1 UNPUBLISHED MANUSCRIPT: Extending the Culture of Palliative Care to Critical Illness Survivors: A Qualitative Inquiry of Post-ICU Clinic Interprofessional Clinicians

#### 3.2.1.1 Abstract

**Objective:** To examine the beliefs, attitudes, and behaviors of post-intensive care unit (ICU) clinic interprofessional clinicians regarding palliative care, and to explore potential barriers and facilitators to delivering palliative care to ICU survivors and their families.

**Methods:** Qualitative inquiry using semi-structured interviews with members of the Critical and Acute Illness Recovery Organization (CAIRO) collaborative sites (follow-up clinics). Framework analysis was used to synthesize and interpret the data.

**Results:** Twenty-nine international post-ICU clinic interprofessional clinicians were interviewed. Some confusion persists among clinicians regarding the complete definition of palliative care and how it can be incorporated into their current post-ICU clinic practice. Largely, clinicians interviewed identified palliative needs for ICU survivors and their families. Key elements of palliative care for ICU survivors identified included: revisiting goals of care, symptom management, patient and family support, communication (e.g., medical interpretation, expectation management), spiritual support, and provision of goal-concordant care. Different attitudes regarding timing and appropriateness of palliative care interventions for ICU survivors were found. Barriers to palliative care delivery in the post-ICU clinic setting were primarily a result of individual internal factors surrounding palliative care knowledge, the lack of self-efficacy, and a

need to shelter and protect the ICU survivor and their family from interventions that may adversely affect their recovery (eg. goals of care discussion). Facilitators which may promote the use of primary palliative care techniques include clinician first-hand experience, perceived value, and a positive attitude regarding palliative care.

**Conclusion** The integration of basic palliative care techniques with current post-ICU clinic care may provide ICU survivors an extra layer of support with symptom management, revisiting goals of care and long-term planning, ongoing patient and family assistance, and care coordination. More work is needed in basic palliative care training and education to eliminate individual internal barriers to palliative care delivery in the post-ICU clinic setting.

**Keywords:** palliative care, ICU recovery, post-intensive care syndrome, qualitative, post-ICU clinics, ICU follow-up

### 3.2.1.2 Introduction

*‘And I think we have to get away from, at least have a paradigm shift about what we mean by palliative care, especially when they’ve just been through this life changing event.’* (post-ICU clinic physician in reference to an ICU survivor)

With high rates of potential complications and substantial life-long implications for critical illness survivors, there are large gaps in our understanding of the burden of recovery and approaches to decrease this burden for individual patients and their families. Post-ICU care frameworks incorporating a palliative care philosophy may aid in better identifying individual challenges to ICU survivorship and individualize care to facilitate overcoming these challenges. However, the role of palliative care has yet to be clearly defined in ICU survivors. The term palliative care is often confused with end of life or hospice services limiting its application to persons with serious or chronic debilitating illnesses who might benefit (Beasley et al., 2019).



Palliative care benefits patients with serious, chronic and life-limiting illness by providing services focused in symptom management, goal setting, support, and care coordination while they simultaneously pursue curative treatments (Kavalieratos et al., 2016). There has been extensive research into the benefit of palliative care in other serious or life-limiting disease states, including cancer, heart failure, dementia/Alzheimer's disease, acquired immunodeficiency syndrome, and others (Aiken et al., 2006; Bekelman et al., 2015; Chapman & Toseland, 2007; Clark et al., 2013; Dudley et al., 2018; Engelhardt et al., 2006; Farquhar et al., 2016; Given et al., 2002; Lowther et al., 2015). In beginning to provide a roadmap for the delivery of palliative care interventions for survivors of critical illness, addressing symptom management and coping are hallmarks of early palliative care across the illness trajectory, however palliative care interventions for ICU survivors may need to prioritize topics differentially based on patient's individual needs and preferences (Bannon et al., 2019; Hoerger et al., 2018). Palliative care in the setting of post-ICU survivorship may emerge to include both primary palliative care strategies and specialty palliative care.

In an effort to better understand the beliefs, attitudes, and behaviors of post-ICU interprofessional clinicians regarding palliative care, we performed a qualitative inquiry which identified how post-ICU clinicians define palliative care and what key elements of palliative care may benefit ICU survivors and their families. We also explored potential barriers and facilitators in delivering palliative care interventions to ICU survivors and their families.

### **3.2.1.3 Materials and Methods**

This study was reported using the Consolidated Reporting of Qualitative Research (COREQ) checklist (Tong et al., 2007).

#### **3.2.1.4 Setting and ethical approval**

This descriptive qualitative study was conducted with international post-ICU follow-up clinic interprofessional clinicians involved with the Critical and Acute Illness Recovery Organization (CAIRO). The study design and protocol were approved by the University of Pittsburgh Institutional Review Board (IRB) (protocol STUDY19090073). Data were collected through individual semi-structured interviews with each clinician.

#### **3.2.1.5 Study design, participants, sampling, and recruitment**

A qualitative approach was used to increase our understanding of the complexity of the role of palliative care in post-ICU follow-up care delivery, as research is scarce in this area and relevant variables and associated outcomes are not apparent. CAIRO is a global collaborative of multidisciplinary groups dedicated to improving outcomes for ICU survivors and their families whose mission is to promote and support global collaboratives to advance innovations in critical and acute illness recovery. Interviewees represented international clinicians providing care in the post-ICU clinic setting. Inclusion criteria were as follows: actively working in clinical practice in post-ICU outpatient program, access to telephone and/or computer with internet for audio interview, and English-speaking.

Verbal informed consent was obtained before each interview. A stratified sampling strategy was utilized to recruit post-ICU clinic interprofessional clinicians from diverse practice backgrounds (e.g., medicine, nursing, rehabilitation services, social work, psychology, and pharmacy) (Robinson, 2014). Diversity in age, sex, and years of experience was also considered during clinician sampling. Chain referral was utilized to allow participants to suggest colleagues from other disciplines at their respective sites who might provide valuable insights based on clinical experience and expertise (Ghaljaie, Naderifar, & Goli, 2017).

### **3.2.1.6 Data collection and generation**

A semi-structured interview guide (Table 1) was adapted from other projects examining the role of palliative care in other disease states (Bostwick et al., 2017; Kavalieratos et al., 2014; Waite, 2019), and contained the following domains: 1) needs of ICU survivors and their families/support people, 2) knowledge and perceptions of palliative care, 3) indications for palliative care, 4) barriers to providing palliative care to ICU survivors. Questions were refined through review and discussion with members of the research group (TE, AL, TL, LS, JS). Prior to the interview, a clinical vignette that described a standardized ICU survivor case was reviewed by the participants (Table 2), as such methods may be helpful when exploring values and perceptions (Hughes & Huby, 2002).

One researcher (TE), who is a female palliative care nurse practitioner and has experience in qualitative methodology and undertaking interviews of this type, conducted all the interviews by audio or video call, between February and March 2021, after verbal informed consent was obtained. The interviewer was known to some of the participants through their collaborative role within CAIRO. The interview was audio-recorded, transcribed verbatim, and completely de-identified. No repeat interviews were undertaken. Participants were recruited until data saturation was achieved as determined by the analysis team (TE, AL, TL).

**Table 1. Semi-structured Interview Guide: Domains of Interest and Sample Questions**

<b>Domain of Interest</b>	<b>Sample Question</b>
Needs of critical illness survivors and family members/caregivers	<p>Broadly speaking - what needs do your ICU survivor patients possess?</p> <p>In regards to ICU survivor families and caregivers, what needs do they possess?</p> <p>How effective do you believe that you are in your clinical practice in managing your ICU survivor patients' needs?</p> <p>How effective do you believe your post-ICU clinic team is in managing ICU survivor and family needs?</p> <p>If you could change anything about your post-ICU clinic practice (either personally or your team), what would it be?</p>
Knowledge and perceptions of palliative care	<p>Could you describe your professional experience with palliative care ? (Probe: in any practice setting?)</p> <p>In your opinion, in what ways could palliative care interventions be helpful in the management of ICU survivor patients?</p>
Indications for, and optimal timing of, palliative care in critical illness survivorship	<p>In your opinion what makes an ICU survivor appropriate for palliative care?</p> <p>Is there a role for palliative care in your post-ICU clinic? (If yes, what role? If no, can you tell me more?)</p> <p>Conversely, are there patients or situations where palliative care would not be helpful for ICU survivors?</p>
Barriers to palliative care in critical illness survivorship	<p>What are some of the barriers that you believe might be impeding the uptake the use of palliative care techniques in ICU survivor care?</p>
Adapted from (Kavalieratos et al., 2014)	

**Table 2. Clinical Vignette of ICU Survivor Used in Interviews**

· CB is a 65-year-old female, previously employed and functionally independent, with a PMH of COPD. She spent 22 days in the ICU for treatment of acute respiratory failure, severe ARDS, and septic shock secondary to community acquired pneumonia. ICU interventions included mechanical ventilation, chemical paralysis and prone ventilation, and high dose vasopressors. The remainder of her hospital stay (9 days) was unremarkable, and she was discharged to a skilled nursing facility and eventually home after hospital discharge.

· She presents to your post-ICU clinic from home (40 days after her ICU discharge) with the following complaints: significant hair loss, crippling whole body pain which is affecting her sleep, and issues with memory, concentration, word-finding, and tremors. She reports that she is “fatigued and gets short of breath very easily”. She lost 6% of her body weight during her hospitalization. She is currently not driving or working. Her daughter is present for the visit and is reporting caregiver burden and some symptoms of anxiety, as she is worried “what is next for her mother”.

### **3.2.1.7 Data analysis, researcher reflexivity, relationship with participants, and rigor**

We applied a Framework analysis technique integrating a priori assumptions grounded in palliative care principles and hypotheses to both inductively and deductively analyze data across interprofessional clinician beliefs regarding how they define palliative care and ICU survivor and family palliative care needs, as well as perceived barriers and facilitators to delivery of palliative in this population. This included: 1) transcription; 2) familiarization with the interview; 3) coding; 4) developing a working analytical framework; 5) applying the analytical framework; 6) charting data into the framework matrix; and 7) interpreting the data (Srivastava & Thomson, 2009). Three trained coders with expertise in critical care medicine and palliative care medicine (nurse, physician, social worker) independently undertook preliminary sweeps of the data to familiarize themselves with the interview. The coding team then initially independently coded a subset of 5 transcripts line by line, resolving any differences by discussion. We then used a bank of coded statements, based on the main identified codes, to test intercoder reliability (ICR) and to assess for coder drift. Coders judged whether each item met the code definition. By incorporating more than two coders on the coding team, a level of inter-subjectivity within the team was

achieved, thereby providing an additional level of scrutiny and rigor to the coding process through added perspectives of different researchers that produced a more thorough analysis than with a smaller coding team (MacQueen et al., 1998; Olson et al., 2016). All transcripts were coded once, with intermittent double coding (20% of transcripts) to avoid developing idiosyncratic coding habits. After coding was completed, the analysis team (TE, AL, TL) reviewed all statements, discuss any differences, and resolve any remaining discrepancies by consensus.

Coding was grouped under key themes in a working analytical framework and iteratively checked across the interview transcripts. Data analysis was performed using NVivo12 (version 12, QSR International) to code and query transcripts, as well as to develop the framework matrix. The researchers met regularly to discuss and address any issues as they arose throughout the study. During the final analysis, TE, supported by discussions with the rest of the team, developed final themes. Key quotes to support the findings were then independently extracted by TE and AL.

### **3.2.1.8 Results**

Interviews occurred over a six-week period in February-March 2021. Twenty-nine interviewees from 15 different international sites (Canada, the United States, the United Kingdom) participated in the study. These interviewees represented professions including medicine, nursing, social work, psychology, rehabilitation services, and pharmacy. Detailed participant demographics are presented in Table 3. The sample was largely female clinicians (21 participants, 72.4%) working in an academic setting (20 participants, 69.0%). Median length of time in clinician role was 16 years (IQR 7, 21), and median length of time working in a post-ICU clinic was 3 years (IQR 1, 4). Interviews lasted between 25 minutes and 55 minutes (median 43 minutes).

**Table 3. Characteristics of Study Participants**

Total participants	N=29
Age, median (IQR)	42 (39, 52)
Sex, no. (%)	
Female	21 (72.4%)
Male	8 (27.6%)
Professional role, no. (%)	
Physician	10 (34.5%)
Nurse	5 (17.2%)
Pharmacist	4 (13.8%)
Physical Therapist	3 (10.3%)
Social Work	2 (6.9%)
Psychologist	2 (6.9%)
Respiratory Therapist	1 (3.4%)
Speech Therapist	1 (3.4%)
Occupational Therapist	1 (3.4%)
Practice Setting, no. (%)	
Academic	20 (69.0%)
Non Academic	4 (13.8%)
Both	5 (17.2%)
Years in Professional Role, median (IQR)	16 ( 7, 21)
Years Working in Post-ICU clinic, median (IQR)	3 (1, 4)

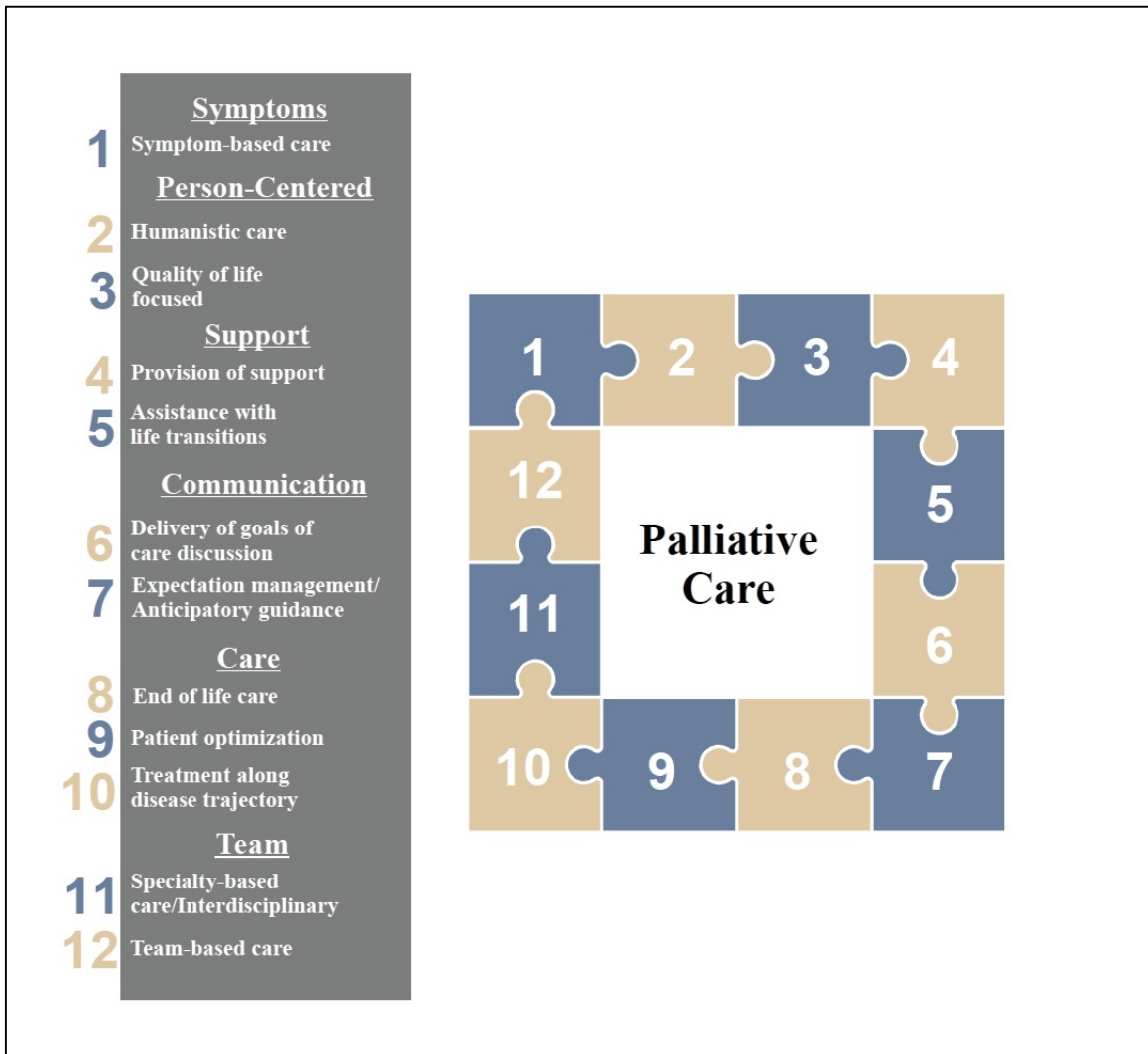
We initially applied a framework of palliative care principles (Ferrell et al., 2018) to help in determining themes and subthemes, but also allowed for inductive coding, which offered the opportunity for additional themes to emerge from the data. The following themes and subthemes were identified regarding how post-ICU clinicians defined palliative care (Figure 1) and key elements that may provide benefit to ICU survivors (Figure 2).

### 3.2.1.9 Defining Palliative Care

We found a variation in how post-ICU clinicians defined the concept of palliative care, demonstrating a lack of clarity regarding the expansive scope of palliative care. Even though many participants were able to accurately communicate multiple dimensions of palliative care, it was rare that a participant conveyed a comprehensive definition which embodied all palliative care principles. All but one participant recognized palliative care to be more than end-of-life care. Major

themes included symptoms, person-centered, support, team, care, and communication domains (Figure 1).

**Figure 1. Defining Palliative Care: Post-ICU Clinic Clinician Responses**



***Symptoms***

Across disciplines, participants commonly defined palliative care as symptom-based care.

This was primarily in reference to managing distressing symptoms.

*‘Palliative care, I understand as symptom-focused care, so, so treatment that is focused on managing and reducing distressing symptoms to patients’ (Physician).*



*'I'm very familiar with palliative care and I would define it as care that addresses symptoms that patients are having difficulty with, it's causing distress for them'* (Nurse).

### ***Person-Centered***

Identifying the patient as the center of care in palliative care delivery was frequently referenced with statements regarding holistic care, providing care across all facets of life, and whole person care with a relational focus. Many participants focused their definitions of quality-of-life statements.

#### *Humanistic Care*

*'How I would define it is, essentially, to start being humanistic about care... taking into account people's best interests'* (Pharmacist).

*'I would describe palliative as a supportive role, a holistic and human role in a medical, kind of, de-humanized system'* (Physical therapist).

#### *Quality-of-Life Focused*

*'They don't even have to be terminal, but for patients to be able to live and have a better quality of life with their, with what their dealt with... their chronic disease'* (Respiratory therapist).

*'I don't like the term "quality of life" because I think it's overused, but "What makes for a good day for you?"'* (Social Worker).

### ***Support***

There were numerous examples provided by participants emphasizing the importance of support as part of palliative care. Some spoke of emotional or practical support, reassurance, along with the combination of education and emotion. Others discussed helping and supporting a patient and their family through life changes, whether those changes are based in loss or change in function, ability, or relationships.

### Provision of support

*‘...but it’s a way to make people feel comfortable with their illness and help them cope with it in a positive way’ (Speech therapist).*

*‘It means supporting the patient and their family member along the continuum of what they’re going through’ (Physician)*

### Assistance with life transitions

*‘Like, adjustment to what’s going on with them from a health standpoint, how that’s impacting them. I think loss of independence is something that we just don’t spend enough time talking to people about, and how that affects them’ (Social Worker).*

### **Communication**

Providing goals of care discussion, anticipatory guidance, and management of expectations are all ways participants described how palliative care utilizes communication techniques.

Participants stressed the importance of communication in palliative care, as it elicits the patient’s values and priorities, established within the existing clinical context.

### Delivery of goals of care discussion

*‘...just assessing where the individual is, and their understanding of what their condition is and how it’s impacting them, and re-framing and asking them their goals’ (Physical therapy)*

*‘And also, just in general, discussing the goals and the wishes of the patient in their treatment’ (Physician).*

### Expectation management/Anticipatory guidance

*‘Some patients have unrealistic expectations, and so palliative is very good at, maybe, helping patients and their families identify what is realistic’ (Pharmacist).*

### **Care**

*‘And I think that all you have to do is care, it’s the care part of the term, you know’ (Physician).*

When discussing care in the context of palliative care, much of the interviews described a deeper level of care that meets individual patient and family needs, whether that care is

provided at the end-of-life, to optimize patients given their limitations, or across all stages of a patient's illness. Care was described as co-occurring with clinician emotion at times.

#### End-of-life care

*'But literally... whatever the patient and family wants at the end because we are doing that out of love, I truly believe we're doing it out of love'* (Nurse).

#### Patient optimization

*'And utilizing all resources towards, you know, common patient goals. And they should really be those patient-centric goals that have to do with everyday life'* (Occupational therapist).

#### Treatment across disease trajectory

*'...what I think personally, when we are diagnosed with something which is chronic or cancer related, we should involve palliative from the get-go. And I, I love, there is a research diagram from palliation that it kind of puts palliation and treatment [together]. And at the beginning of the disease, you have more treatment and less palliation, and the more the disease progresses, you do more palliation and less treatment or curative treatment.'* (Nurse)

### **Team**

Participants generally referenced palliative care as specialty-led program or service. Palliative care was often referred to as an interdisciplinary joining of expertise, or a "team approach" to care.

#### Team-based care

*'But I think patients and family members often benefit having a team like that involved because, mainly because they can, they're able, oftentimes, to frame things differently or take more time to answer questions that we are not able to answer'* (Physician).

#### Specialty-based/Interdisciplinary

*'Often, multidisciplinary in that nursing is involved, social services can be involved, pastoral care can be involved'* (Pharmacist).

### 3.2.1.10 Key elements of palliative care that may benefit ICU survivors

Some participants reported that they deliver palliative care interventions in their post-ICU clinic:

*'I think a lot of what the post-ICU, a lot of post-ICU care is palliative care under that broader definition, right? We're treating symptoms, we are providing patient and family support' (Physician).*

Other participants reported delivering interventions harmonious with palliative care interventions without consciously labeling as them as such:

[in response to post-ICU clinic priorities] *'Yeah, so, frankly, I would, I try to start by asking patients where they want to start. Like, what, what's most limiting for them. And, so, you know, her daughter is, you know, her daughter... So, I think there's, her daughter has concerns, I think I would start by asking the patient what her overall goals are' (Physician).*

However, when discussing specifically how palliative care may benefit ICU survivors, participants tended to back-step and describe only the “sickest” ICU survivors as patients that may benefit from palliative care:

*'I think, well, first off, I would think of, of someone who's generally older rather than younger, and somebody who's post ICU care, or progress, isn't going well. They're not, they are not getting back to baseline. In fact, they are quite far from, from baseline. Um, they may want to change the direction of their therapies. So, those would be, I think, more suited for palliative care' (Physician).*

In exploring potential palliative care elements that may benefit ICU survivors and their families, themes surrounding symptom management, goal-directed therapy, support, communication, and spiritual support emerged from the interviews as palliative care interventions that may benefit this population.

#### ***Symptom management***

Many participants labeled symptom management as a key element of palliative care for ICU survivors across all stages of their illness trajectory.

*'Um, I think I would say palliative care, in the sense of symptom management, I think could potentially be appropriate at all stages of ICU recovery. (Physician)*

### ***Focus on goal-directed care***

Participants recognized critical illness as a life-changing event for ICU survivors and their families. Because of this, some shared that revisiting healthcare goals and formal advance care planning would be beneficial in this population. There was an overall sense that palliative care may assist in developing goal-concordant care.

#### *Discussion of patient goals*

*'I think oftentimes people who have been through the ICU have new perspectives on their goals and what they would be willing to go through... you know, when palliative care comes in and globally says like, "What's most important to you?" That's a different perspective and a different approach that probably is good for patients and family members. So, I think [palliative care] would be really helpful for, for those kinds of things.'* (Physician)

#### *Goal-concordant care*

*'And then in clinic, we do, do some with patients and talk to them about their experiences and what they're going through, what their goals are, and how they want to get from point A to point B, and what point B looks like. And, uh, what are their most important things in the next year of their life, and how can we help them achieve those goals, etc.'* (Physician)

#### *Advance care planning*

*'And, so, I will give them the general written information we have just about, you know, their right to have power of attorney for healthcare document, to execute one of those, to execute a living will, to name somebody, to be their spokesperson.'* (Physician)

### ***Support***

Patient and family support was referenced as a foundational block of how palliative care may benefit ICU survivors and their families.

### Patient and family support

*'And then I think the part of palliative care that also is really important in the post-ICU clinics is the inclusion of the family.'* (Social Worker)

[in reference in palliative care in post-ICU clinic setting] *'...giving support to patients and families, provide them support.'* (Physician)

### **Communication**

Participants described a need for ongoing communication so that all involved have a clear understanding of what to expect and when to expect it. Many participants referenced the provision of anticipatory guidance as part of this need. Additionally, participants described a “reframing” or medical interpretation role for palliative care. This provision of medical information and meaning would allow the patient and family to “make sense” of their survival journey.

### Expectation management

*'So, in this patient population, I think that would be extremely helpful and fit so well because most of the time there is that, you know, difference in baseline to after ICU or in ICU. And, so, being able to have more in-depth conversations that aren't, that are happening in the same places as care with the rest of their therapy, but really focused to make sure that everyone has a realistic idea of where we are.'* (Pharmacist)

### Medical interpretation

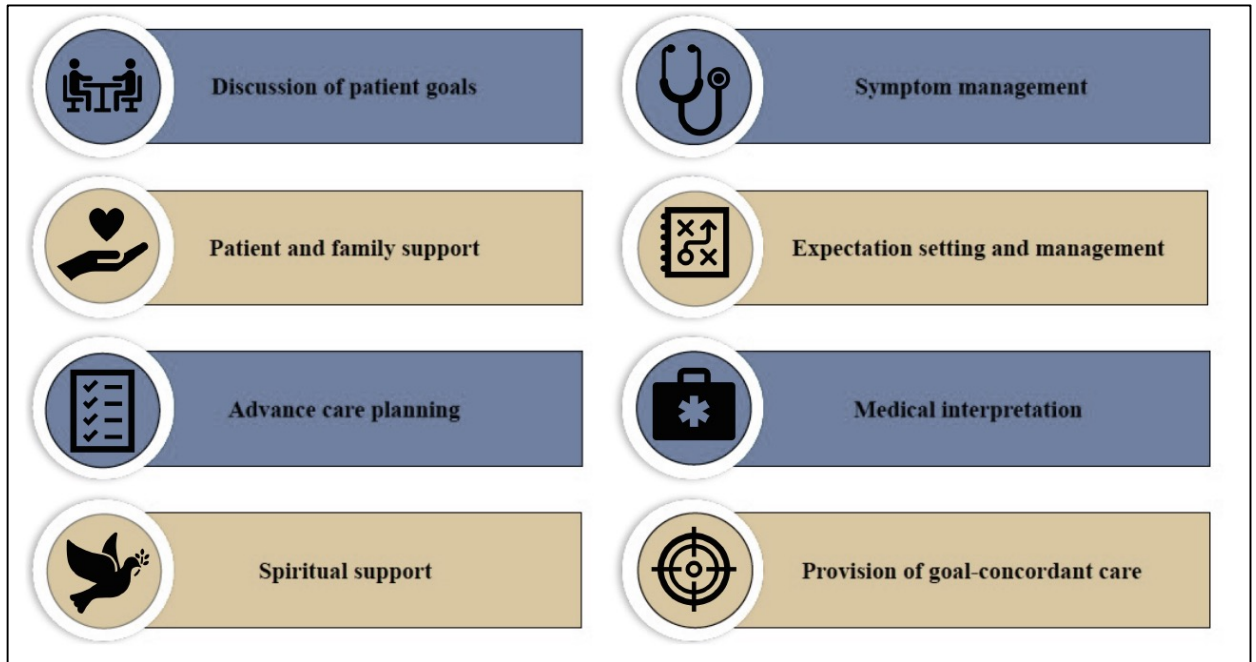
*'Okay, I think they could go in and, after we made all our recommendations, maybe they would have to hear what we all had to say as a team, and say what we still think is a missing link that's not helping this person... they may be able to see where they could find that gap of care that's missing that we're not seeing.'* (Occupational therapist)

### **Spiritual support**

Providing support, counseling, and resources to address spiritual and/or religious needs and concerns was identified as a key element of palliative care in ICU survivors.

*‘Many, many of our patients have a spiritual faith that is part of their recovery. So, we want to support that. If there is some enhancement that can be offered, you know, we want to have, we want to have the spiritual aspect. (Nurse)*

**Figure 2. Clinician Identified Palliative Care Key Elements for ICU Survivors**



### 3.2.1.11 Barriers and facilitators in delivering palliative care to ICU survivors

During analysis, by allowing themes surrounding barriers and facilitators to naturally emerge, we discovered a latent pattern involving internal and external factors that in turn affect the knowledge, attitudes, and behaviors of post-ICU clinicians regarding palliative care delivery to ICU survivors. Identified barriers (Figure 3) and facilitators (Figure 4) highlight these internal and external factors.

#### ***Internal factors - Barriers***

The majority of barriers to palliative care delivery in the post-ICU clinic setting identified by clinicians were related to individual internal factors. Emerging subthemes involved interrelated notions rooted in the knowledge, attitudes, and behavior of each clinician.

### Misconception of palliative care

Statements supporting misconceptions regarding palliative care delivery to ICU survivors pertained to misunderstanding of some palliative care principles or which patients may benefit from palliative care.

*'And those are the ones who, you know, have maybe end-stage lung disease or pain that's just not getting better and they're really uncomfortable and they want pain control, and those are the ones who, I think, could benefit from out-patient palliative care [specialty palliative care].'* (Physician)

*'I guess because I can't escape the notion of palliative being something for, you know, the incurable, inexorably, sort of, heading towards end-of-life.'* (Physician)

### Lack of self-efficacy

In the instances where clinicians felt various palliative care may be beneficial, some clinicians voiced uncertainty or ineffectiveness in delivering palliative care in the post-ICU clinic setting.

*'And I don't think that I have, I think I probably have the soft skills to do that, but I think the actual skills to do that is probably something that far goes beyond my ability...'* (Physical therapist)

*'I have had not a lot of success with sort of, goals of care conversations in ICU survivors.'* (Physician)

### Perception of taking away hope

In some conversations, there was a perception that giving more information regarding prognosis or attempting to discuss healthcare wishes would take away hope, thereby affecting meaningful recovery.

*'So, and to talk about hope.... you know, we never want to take away hope.'* (Social Worker)

*'I think everyone feels very strongly that you want to do everything that you can. So, any, any kind of deviation from a full court press feels like a big, can make patients feel like we're giving up... everything else feels like a huge step backwards and, like, you're giving up.'* (Physician)



### Protector/gatekeeper

Some clinicians share viewpoints that patients and families should be shielded from the perceived distress that discussing goals of care may cause during their initial time after discharge.

*'And, you know, you don't wanna [sic] scare them and give them anxiety about going into an ICU again, you know what I mean?'* (Physical therapist)

### Clinician resistance

Opposing or delaying the implementation of palliative care services were related to issues surrounding prognostic uncertainty and comments questioning palliative care as a core component of ICU survivor care.

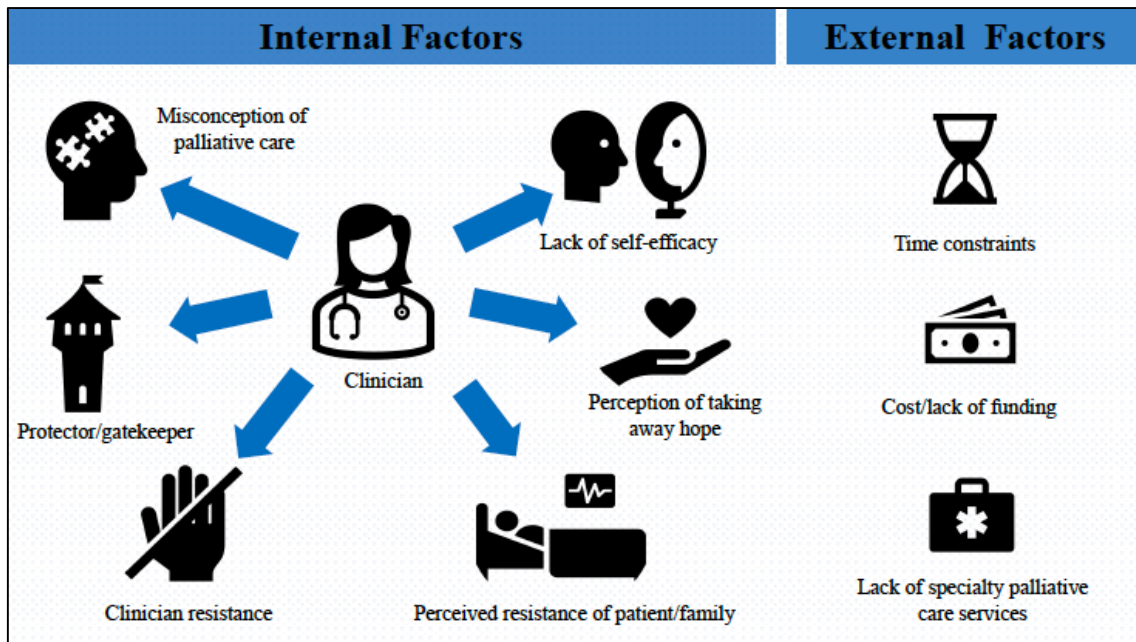
*'I think we need to give people some time to pause and reflect. I don't really know what the optimal timing would be. Sometime maybe, like, three to six months after their ICU stay.'* (Physician)

### Perceived resistance of patient/family

Some clinicians describe assumed behaviors that ICU patients and their families may exhibit as a response to palliative care delivery in the post-ICU clinic setting.

*'So, I think some of the barriers from patients are the sense that they're all better now, so why are you bringing up tough topics? So, I think some patients would not be receptive to talking about goals of care 'cause [sic] they feel like, "Oh my god! I'm all better!'"* (Nurse)

**Figure 3. Clinician Reported Barriers to Palliative Care Delivery in the Post-ICU Clinic Setting**



***External factors - Barriers***

Clinicians described the biggest external factors affecting palliative care delivery in the post-ICU clinic setting to be related to cost, time, and lack of specialty palliative care resources.

*Time constraints*

Concerns regarding lack of time during the post-ICU clinic visit for the provision of palliative care were widely discussed.

*‘And if I had more time, I’d love to engage more in conversations with goals of care. But we, honestly, run out of time.’ (Physician)*

*‘Sure. I think, um, as with a lot of other things in healthcare and trying to implement, to use new techniques, I think that time is a barrier.’ (Physical therapist)*

*Cost/Lack of funding*

Lack of financial support was reported as a potential barrier to implementing palliative care interventions in the post-ICU clinic setting.

*'Resource is one thing. I mean, palliative care is not well-funded in the United, in the UK.'* (Physician)

*'Because right now, our clinic is struggling to find a home. And, so, like just the financial piece right now and expanding is just, like, not in the picture. So, it's hard to even like think about, "Oh, in a perfect world, what would our clinic, would our clinic have XY & Z?" I just can't even imagine because we can't get other providers right now.'* (Social Worker)

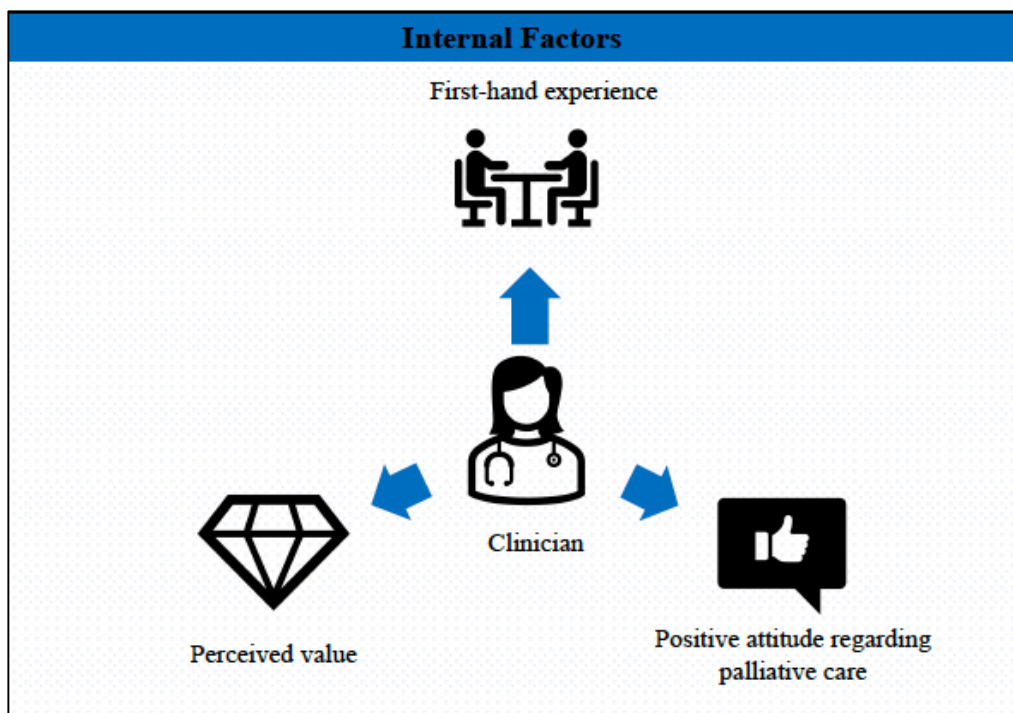
Lack of specialty palliative care services

As the vast majority of clinicians emphasized the delivery of post-ICU clinic palliative care as a specialty-based service, the most common barrier described was lack of specialty palliative care services.

*'It might be that, another barrier might be that we can't have somebody just, this palliative care person in our clinic one day a week, the cost of that when they have to be in the hospital.'* (Occupational therapist)

**Figure 4. Clinician Reported Facilitators to Palliative Care Delivery in the Post-ICU**

**Clinic Setting**



### ***Internal factors – Facilitators***

Unlike the emerging subthemes related to barriers to palliative care delivery in the post-ICU clinic setting, all facilitators were based upon individual internal factors. Subthemes associated with facilitators to palliative care delivery in the post-ICU clinic setting included perceived value, first-hand experience, and positive attitude regarding palliative care.

#### *Perceived value*

Clinicians described a broad range of ways they perceive value in palliative care in terms of the potential benefits to ICU survivors.

*‘Well, if we go back to what I said in the very beginning as, potentially, some of the biggest needs of ICU survivors, I mean, I know we’re kinda [sic] on a different topic, but, um, palliative care probably addresses each and every one of those.’* (Physician)

*‘In our, speaking about our clinic, I think every single one of them could benefit from palliative care in some fashion’* (Physician)

*‘So, you know, it’s hard to say who wouldn’t benefit, ‘cause probably everyone could benefit right?’* (Social Worker)

#### *First-hand experience*

Some interviews highlighted professional experience with palliative care interventions as a key facilitator.

*‘You know, I’m more than comfortable having goals of care conversations and doing a lot of this stuff on our own.’* (Physician)

#### *Positive attitude regarding palliative care*

Many clinicians shared positive experiences regarding specialty palliative care in their current practice.

*‘And there are just certain [palliative care] people that I just love working with who I think are just, like, you sit it in family meetings with them and you listen then*

*you say, like, “I’m totally stealing the way you said that because it was so good and clear.” (Physician)*

### **3.2.1.12 Discussion**

To the best of our knowledge, this is the first study to explore how post-ICU clinicians define palliative care and what key elements of palliative care they feel may benefit ICU survivors and their families. Additionally, this is the first study to explore potential barriers and facilitators in delivering primary palliative care interventions to ICU survivors and their families in the post-ICU clinic setting. All clinicians identified one or more components of palliative care, and all but one clinician recognized palliative care to be more than end-of-care or hospice care. However, despite many clinicians having experience practicing alongside specialty palliative care or providing primary palliative care interventions in the inpatient ICU setting, it was rare for a clinician to provide a fully comprehensive definition that included all palliative care principles. Clinicians generally spoke of palliative care as a specialty service as opposed to a set of care principles. Interestingly, throughout the interviews every single clinician described essential components of their post-ICU clinic practice that were synonymous with the definition of palliative care, but some failed to recognize this post-ICU clinic care as primary palliative care. All clinicians discussed a function of their role as managing symptom burden and providing ongoing patient and family support. Additionally, there was a cry for help across clinician interviews for more assistance in care coordination after critical illness, as the interplay between ICU survivors and social determinants of health continue to affect recovery from critical illness (McPeake, 2021).

Many clinicians described the need to revisit goals of care after critical illness, however, stipulations were often placed on these statements. The lack of time and clinician comfort and expertise were all highlighted as reasons this does not typically occur in the post-ICU clinic setting. Some clinicians felt that revisiting goals of care should be delayed initially to determine if it is

ultimately necessary. In situations that do not require instantaneous action to sustain life, the patients' values, goals, and treatment preferences can and should be confirmed (Curtis & Mirarchi, 2020). This is important for a number of reasons, including that goals and preferences change over time and circumstances. A change in circumstances, including health and wellness state, may modify views about life-sustaining treatments but also current treatment approaches. Ideally, goals of care conversations should be revisited throughout the critical illness survivorship course, when thoughtful discussions, based in previous healthcare experiences can assist in 1) informing the patient's understanding of their new and/or ongoing disabilities, 2) setting reasonable expectations for the future, and 3) choosing, within the context of their goals and values, future healthcare treatment options. Goal setting may also help to prioritize the intervention that are going to provide the most benefit, while de-emphasizing those that add less value.

Despite the identified need for palliative care in critical illness survivors, to the best of our knowledge, there is currently only one documented post-ICU clinic currently providing an integrated primary palliative care intervention, defined as the delivery of a goals of care discussion, comprehensive symptom assessment and management, and family caregiver support by a clinician not board-certified in palliative care (Eaton, 2020). Fortunately, many key elements of palliative care that may benefit ICU survivors were identified in this study, which may allow for further examination into potential integrated palliative care delivery models in the post-ICU clinic setting to meet these needs. More research is also needed to establish the full scope of the problems that palliative care may address by more clearly describing current unmet palliative care needs, which range from goals of care discussions to comprehensive symptom assessment and management in ICU survivors.

Potential barriers to palliative care delivery in the post-ICU setting are primarily related to the knowledge, behavior, and attitude of post-ICU clinicians. More palliative care education and training is needed to assist with integrating these principles into current post-ICU clinic practice. There are limitations to these data. Clinician interview data was only collected from sites currently participating in CAIRO's post-ICU clinic collaborative, limiting generalizability to the entire post-ICU clinic clinician population. The findings will serve as pilot data to inform larger, more diverse studies to study to generate generalizable findings. Additionally, there is a risk of selection bias, as no clinicians outside of the CAIRO network participated. To minimize the cultural impact of CAIRO membership, we sampled a mix of clinicians based upon length of CAIRO membership, thereby attempting to elicit responses from new members who have not participated in this group from its inception.

### **3.2.1.13 Conclusions**

The integration of basic palliative care techniques with current post-ICU clinic care may provide ICU survivors an extra layer of support with symptom management, revisiting goal of care and long-term planning, ongoing patient and family assistance, and care coordination. More work is needed in basic palliative care training and education to eliminate individual internal barriers to palliative care delivery in the post-ICU clinic setting. Policy changes could address external barriers and facilitate practice change.

## **3.2.2 Additional Considerations for Completed Aim 2 Study**

### **3.2.2.1 Discussion of data collection procedures**

Approval to contact post-ICU clinic collaborative members via email of was obtained from the executive committee of CAIRO, of which the PI also serves in an executive committee role. The PI has a professional relationship with at least one clinician at all sites currently involved in CAIRO's post-ICU clinic collaborative. This email recruitment method was submitted and approved as part of the University of Pittsburgh Institutional Review Board (IRB) study approval.

Qualitative data were collected for participants meeting inclusion criteria and verbally consenting to participation; this resulted in 29 participants for Aim 2. Data was obtained through audio or video interviews with each participant individually, which were audio recorded. Interviews were transcribed verbatim, and then reviewed by the PI to ensure data were captured how answers were spoken by the participant. Transcripts were also de-identified at this stage by the PI. Memo taking was utilized during each interview, and a reflexive diary was kept and utilized before and after each interview for improving reliability and removing bias (Ahern, 1999). Major items recorded in the reflexive diary included evolving perceptions and personal introspections. The reflexive diary was also useful in refining the understanding of the role of the researcher. A log of methodological decision points was also maintained during each research team transcript review and coding meeting. This assisted in determining when data saturation was met, and enrollment was ended.

### **3.2.2.2 Discussion of data analysis procedures**

We applied a Framework analysis technique to analyze data across interprofessional clinician beliefs regarding ICU survivor and family needs, barriers and facilitators to delivery of



palliative care in this population and identified key elements of palliative care for ICU survivors. Data were analyzed with the following stepwise approach. First each interview was transcribed as discussed in the above section. Second, prior to initiating coding, the full breadth of qualitative data was read, including transcripts and reflective notes, by the PI to initiate overall thoughts and impressions, and create familiarization with the interviews. Additionally, three trained coders (TE, TL, AL) with expertise in critical care medicine and palliative care medicine (nurse, physician, social worker) independently undertook preliminary sweeps of the data to familiarize themselves with the interview. Third, three trained coders (TE, AL, BD) together initially coded a subset of 5 transcripts line by line, resolving any differences by discussion. There was a mix of inductive and deductive coding throughout the process, as some codes were predetermined based on what is known about the use of palliative care in other disease states, and some opening (inductive) coding occurred with emerging themes regarding the utilization of palliative care techniques in the post-ICU setting. Then, all transcripts were coded once by TE and AL, with intermittent double coding (20% of transcripts) to avoid developing idiosyncratic coding habits. Early stages of coding were performed with pen and paper. To assess intercoder reliability (ICR), we used a bank of coded statements, based on the main identified codes, to test (ICR) to assess for coder drift. Coders judged whether or not each item met the code definition. This test was developed by a qualitative researcher trained in developing and administering this test (LS). Fourth, a working analytical framework was developed after the first five transcripts were coded. Coding was grouped under key themes in a working analytical framework grounded in interprofessional clinicians' beliefs, attitudes, and behaviors regarding the use palliative care in an ICU survivor population, and iteratively checked across the interview transcripts. Fifth, the analytical framework was applied by indexing subsequent transcripts using the existing categories and codes. Importantly, although the

analytical framework was applied using existing categories and codes, due to the nature of qualitative data collection, there were additional codes identified through open coding throughout this stage along with refined codes. After completing coding, the research team reviewed all statements, discuss any differences, and resolve any remaining discrepancies by consensus. Sixth, data was entered into the framework matrix using NVivo12 (version 12, QSR International) to code and query transcripts. The matrix comprised of one row per participant and one column per code. Last, themes and subthemes were generated from the data set. This was influenced by pre-determined research objectives along with new concepts emerging inductively from the data. The research team met regularly to discuss and address any issues as they arose throughout the study. During the final analysis, TE, supported by discussions with the rest of the team, developed final themes and subthemes. Key quotes to support the findings were then independently extracted by TE and AL. Member checking will occur with 10% of the participants and prior to submission of manuscript for publication.

**Table 1. Intercoder reliability (ICR) test between coders**

<b>Specific Codes Tested</b>	<b>TE - AL</b>
End-of-Life Care	0.79
Resistance to palliative care utilization	0.78
Inadequate healthcare resources	0.83
Discussion of patient goals	
Positive attitude regarding palliative care	0.69

### **3.2.2.3 Additional findings**

As a clinical vignette was used in this study to examine judgments and decision-making processes of the clinician-participant, the relationship between the clinical vignette to internal, external, and construct validity was examined. These three components of validity are conceptually distinct but functionally related (Evans et al., 2015). In regard to internal validity, a

concrete, detailed, hypothetical vignette provides a better means to acquiring interview data as compared to asking abstract questions regarding attitudes and perceptions, which may introduce investigative bias (Schoenberg & Ravdal, 2000). To examine construct validity, each participant was asked if the clinical vignette was a “typical or atypical” case seen in their clinic. All participants reported that the clinical vignette was a typical ICU survivor case seen in their post-ICU clinic program. Additionally, the use of a realistic clinical vignette may produce results that generalize to real-world situations, therefor reflecting external validity (Evans et al., 2015) and may serve as a strong predictor for real-world clinical behavior (Wallander, 2012).

### 3.3 AIM 3 RESULTS

#### 3.3.1 Reporting of Aim 3

Aim 3 is organized as seen below. Aim 3a results can be found in the following section (3.3.2). Aim 3b and 3c are reported separately in section 3.3.3.

**Aim 3: To investigate unresolved symptoms and symptoms clusters among survivors of critical illness upon initial presentation to a post-ICU clinic**

*3a: Describe unresolved symptom burden and ongoing social concerns of survivors of critical illness*

*3b. Identify potential symptom clusters in survivors of critical illness*

*3c: Examine the potential relationship between symptom clusters and reported overall health score*

#### 3.3.2 UNPUBLISHED MANUSCRIPT: Exploring the Landscape of Symptom Burden in Critical Illness Survivors

##### 3.3.2.1 Abstract

**Background/Aim:** An unintended consequence of surviving critical illness is one of persistent symptom burden. Critical illness survivors often experience multiple symptoms concurrently and these symptoms can affect their quality of life. The aim of this study was to investigate unresolved symptom burden among survivors of critical illness and examine the association between symptom severity and overall health score reporting.

**Design:** A retrospective, patient-level cross-sectional observational design.

**Methods:** Critical illness survivors (aged  $\geq 18$  years) seen during an initial post-intensive care unit (ICU) outpatient clinic visit between June 2018 and March 2020. A convenience sample of 170 patients was used, with sample size truncation due to the widespread outbreak of the novel coronavirus disease (COVID19). De-identified patient demographics, clinical characteristics, and functional status were abstracted, along with self-reported symptom burden using PEACE Tool. These data were evaluated for symptom prevalence and severity and its effect on overall health score reporting.

**Results:** The majority of patients were male (92/170, 54.1%), and median age was 61 years. Median length of time between hospital discharge and initial post-ICU clinic visit was 34 days. The majority of patients were residing at home (110/170, 64.7%). Most prevalent symptoms included weakness/low energy (79.4%), diminished level of function (70.0%), pain (76.5%), and sleep disturbance (67.1%). Symptoms with highest level of severity included pain (6.15 +/- 2.88), incontinence (5.72 +/- 3.12), and sleep disturbance (5.71 +/- 2.65). Additionally, unmet social needs, such as not feeling prepared/fear of future (51.2%), ineffective coping/not in control of care (48.8%), and perceived lack of support (35.9%) were reported. Spiritual distress was reported in 13.5% of patients. Only 5.3% of patients had returned to work and 12.1% had returned to driving at the time of the initial post-ICU clinic visit. Symptoms affecting overall health score reporting (EQ-VAS) the most included depression, confusion/restlessness, weakness/low energy, anxiety, and sleep disturbance.

**Conclusions:** Survivors of critical illness suffer an extensive symptom burden beyond the typically reported manifestations of post-intensive care syndrome (PICS). In addition to symptoms in physical, cognitive, and psychological domains, symptoms associated with social needs are

widespread. These findings support standardization of symptom assessment and management in patient surviving critical illness.

**Keywords:** symptoms, critical illness survivor, ICU recovery, post-intensive care syndrome, quality of life

### **3.3.2.2 Introduction**

Critical illness survivors often report substantial physical, cognitive, and psychological symptom burden, such as pain, fatigue, anxiety, depression, memory and concentration issues, and post-traumatic stress, which can have dramatic impacts on their quality of life, capacity to regain independence, or ability to be employed; and these may persist for months or years after hospital discharge (Brown et al., 2019; Choi, Hoffman, et al., 2014; Davydow et al., 2009; Dowdy et al., 2005; Kamdar et al., 2020; J. McPeake et al., 2019; Nikayin et al., 2016; Parker et al., 2015).

#### ***Conceptual framework***

This study derives its underpinnings from an adaptation of the Theory of Unpleasant Symptoms (TOUS). This middle range theory was created as a means for integrating existing information about a variety of symptoms and posits three structural elements: the symptoms that the patient is experiencing, the factors that influence them, and the consequences of that experience (Lenz et al., 1997).

#### ***Aim***

The purpose of this study was to investigate unresolved symptom burden among survivors of critical illness and examine the relationship between symptom severity and overall health score reporting.

### **3.3.2.3 Methods**

#### ***Design***

A retrospective, single-center, cross-sectional observational design was utilized in a cohort of critical illness survivors seen during an initial post-ICU clinic visit in the Critical Illness Recovery Center (CIRC) at UPMC Mercy, University of Pittsburgh Medical Center from June 2018 to March 2020. The decision was made to truncate the sample size due to the widespread outbreak of the novel coronavirus disease (COVID-19), as patients seen after March 12, 2020, received a different inpatient and outpatient healthcare delivery due to COVID-19, whether they were receiving care due to a COVID-19 infection or not, which may have led to a confounding bias.

#### ***Population and sample***

A convenience sample of 170 critical illness survivors seen in the CIRC for initial clinic visits from June 2018 through March 2020 was used for this study. Participants in the CIRC clinic were adults 18 years or older with an ICU stay greater than 4 days, having a diagnosis of sepsis, acute respiratory failure and/or delirium. Patients are typically seen in the CIRC clinic within 30 days of hospital discharge.

#### ***Data collection***

Data was abstracted from the electronic health record (EHR) from the initial post-ICU clinic visit as well as the initial hospitalization and ICU stay that supported a visit to the CIRC. The University of Pittsburgh Institutional Research Board (IRB) reviewed the research proposal and provided a waiver of HIPAA authorization to access protected health information and IRB approval as an exempt application. (IRB protocol: STUDY20030027).

### 3.3.2.4 Measures

#### *Demographic and disease characteristics*

Demographic data abstracted from the EHR included age, sex, race, education level, current residence (as determined during initial CIRC clinic visit), and employment status (pre-hospitalization and during initial CIRC clinic visit). Clinical characteristics include pre-hospitalization, in-hospital, and in-clinic data. Prehospital characteristics include: Charlson Comorbidity Index (CCI), determined by prehospital comorbidities, and measures of activities of daily living (e.g., Katz ADL and Lawton IADL), obtained by self-report during the CIRC clinic visit. Clinical characteristics collected from the inpatient stay include: ICU diagnosis, worst 24-hour SOFA score, ICU length of stay, hospital length of stay, and presence of delirium (as measured by the Intensive Care Delirium Screening Checklist (ICDSC) collected every shift during the ICU stay), presence of sepsis/septic shock, presence of mechanical ventilation, delivery of cardiopulmonary resuscitation (CPR), delivery of surgery or procedures in interventional radiology (IR), use of continuous renal replacement therapy (RRT), and use of vasopressors in the ICU. All these characteristics provide a detailed picture of illness severity during the ICU stay. In-clinic characteristics include: the Montreal Cognitive Assessment (MoCA), the Clinical Frailty Scale (CFS), and self-reported measures of activities of daily living (e.g., Katz ADL and Lawton IADL).

#### *Critical illness survivor symptoms and patient reported quality of life*

A comprehensive battery of measures was used to assess the symptoms that critical illness survivors reported during their initial visit to the CIRC (Figure 1). The Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983) was used to report symptoms of anxiety and



depression, the Impact of Events – Revised (IES-r) (Weiss, 2007) and the post-traumatic stress disorder (PTSD) checklist for DSM-5 (PCL-5) (Weathers et al., 2013) were used to assess symptoms of PTSD; and the Physical, Emotive, Autonomy, Communication, Economic, and Transcendent (PEACE Tool) (Okon & Christensen, 2018; Okon et al., 2004) was used to assess for a range of symptoms. The EQ-VAS (Michael Herdman et al., 2011) was collected as a measure of overall health reporting.

### **Figure 1. Symptom and Social Concerns Measures**

<p><b><i>Hospital Anxiety and Depression Scale (HADS)</i></b> Anxiety Depression</p> <p><b><i>Impact of Events - Revised (IES-r)</i></b></p> <p><b><i>Post-traumatic Stress Disorder Checklist for DSM-5 (PCL-5)</i></b> PTSD Confusion/restlessness Irritability</p> <p><b><i>Physical, Emotional, Autonomy, Communication, Economic And Transcendent (PEACE Tool)</i></b> Pain Anorexia Incontinence (bowel and bladder) GI symptoms (nausea, vomiting, constipation) Breathing problems/cough Fatigue Sleep issues Oral discomfort (ulcers, dryness) Diminished level of functioning Adjustment and coping Fear of future Outside support Impaired communication of needs Spiritual distress</p>
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Two subscales of the HADS (anxiety subscale and depression subscale) were used to measure symptoms of anxiety and depression. The HADS is a patient self-report measure of 14 items, seven items for the anxiety subscale and seven for the depression subscale. Each item is scored on a response-scale with four choices ranging between 0 and 3, and items in each subscale

are summed to obtain subscale scores (Zigmond & Snaith, 1983). The HADS has been validated in many languages, countries, and settings and is one of the National Institute for Health and Care Excellence (NICE) recommended tools for diagnosis of depression and anxiety (Bjelland et al., 2002; Health, 2011). The HADS is strongly recommended for use in assessing symptoms of anxiety and depression in critical illness survivors, with studies reflecting internal consistency of Cronbach's  $\alpha$  greater than 0.80 for both anxiety and depression, and strong correlation with the Depression and Anxiety Stress Scale (DASS) in both anxiety ( $r = 0.88$ ;  $p < 0.0001$ ) and depression ( $r = 0.93$ ;  $p < 0.0001$ ) in this population (Chesley et al., 2020; Davydow et al., 2009; Mikkelsen et al., 2020; Nikayin et al., 2016; Sukantarat et al., 2007).

Over the period of June 2018 through March 2020, the CIRC utilized two different PTSD screening tools, the IES-r, and the PCL-5. The IES-r was used from June 2018 to February 2019, and the PCL-5 was used from February 2019 to March 2020. The IES-R is a 22-item patient self-report measure (for DSM-IV) that assesses subjective distress caused by traumatic events (Weiss, 2007). Clinic patients were asked to indicate how much they were distressed or bothered by their recent ICU stay by each question listed. Items are rated on a 5-point scale ranging from 0 ("not at all") to 4 ("extremely"). The IES-R yields a total score (ranging from 0 to 88), and subscale scores can also be calculated for the Intrusion, Avoidance, and Hyperarousal subscales. The IES-r has been widely used to assess for PTSD symptoms in critical illness survivors and has shown high internal consistency ( $\alpha = 0.96$ ) and high correlation with the Clinician-Administered PTSD Scale (CAPS), the current state-of-the-art PTSD diagnostic measure at that time (Pearson  $r = 0.80$ , Spearman  $\rho = 0.69$ ) (Bienvenu et al., 2013; Parker et al., 2015). The PCL-5 is a 20-item patient self-report measure that assesses the 20 DSM-5 symptoms of PTSD. A total symptom severity score (ranging from 0 to 80) can be obtained by summing the scores for each of the 20 items.

Although the PCL-5 has been adopted by the National Center for PTSD and it has been shown to be a psychometrically sound instrument in initial studies with veterans with good internal consistency ( $\alpha = .96$ ), test–retest reliability ( $r = .84$ ), and convergent and discriminant validity, it has not yet been validated in ICU populations (Bovin et al., 2016). The decision to switch these clinical measures was due in part to the IES-r being retired by the developer secondary to revisions in PTSD criteria in the DSM-V (limiting the use of the IES-r to investigators with ongoing research or prior permission) (Umberger, 2019). Although some researchers continue to support the use of the IES-r in the ICU survivor population due to psychometric evidence in acute respiratory failure survivors, the CIRC leadership team opted to change the measure to the PCL-5 (Hosey et al., 2019; Umberger, 2019). The PCL-5 was chosen as a replacement because it aligns fully to DSM-V criteria and includes questions to assess for negative alterations in cognition and mood. Fortunately, there are studies examining convergent validity between the two measures, showing the correlation between the PCL-5 and the IES-R yields a significant, positive correlation ( $r = 0.55-0.82$ ,  $p < .001$ ) suggesting strong convergent validity. Regarding the corresponding PCL-5 and IES-R subscales, a positive, statistically significant correlation has been observed in each case (intrusion:  $r = 0.53-0.76$ ; avoidance:  $r = 0.52-0.68$ ; arousal:  $r = 0.52-0.81$ , all  $p < .001$ ) (Ashbaugh et al., 2016; Sveen et al., 2016). For the purpose of this study, the total scores of the IES-r and PCL-5 were transformed to convert the scales into a common measurement scale for analysis.

The PEACE Tool allows for a comprehensive clinical palliative symptom assessment, and includes physical, psychological, cognitive, illness understanding, social and economic needs, spiritual concerns, and care coordination concerns (Okon & Christensen, 2018). This assessment allows for capture of potential refractory physical symptoms in critical illness survivors, including pain, confusion, fatigue, breathlessness, insomnia, nausea, constipation, and anorexia. The PEACE

tool is a 16-item self-report measure, rated on a 11-point range from 0 (none) to 10 (worst imaginable), with higher scores indicating more severe symptoms. There are nine physical symptom questions (pain, anorexia, incontinence, gastrointestinal symptoms, respiratory symptoms, oral symptoms, decreased physical functioning, fatigue, sleepiness), three psychological/cognitive symptom questions (anxiety, depression, confusion), one question regarding concerns with patient autonomy, one question regarding communication of needs, one socio-economic concerns question, and one question regarding spiritual concerns. There is currently no data on reliability and validity in research for this tool, however it has been developed for clinical utility to capture a holistic picture of symptom reporting, capturing both face validity and content validity. More research is needed to determine whether a factor structure exists and in which specific clinical contexts it might apply. Anxiety and depressive symptoms were measured by HADS tool, which is a widely utilized measure, with good reliability and validity. Because of this, the anxiety and depression questions measured by the PEACE Tool were not be utilized in this analysis.

As several qualitative studies have drawn attention to reports of irritability and subjective cognitive complaints in critical illness survivors, and both have been reported as frequent non-specific symptoms in ICU survivor populations, relating both to cognitive impairment and PTSD (Brück et al., 2019; Hashem et al., 2016; Pattison et al., 2015; Walker et al., 2015), items assessing for irritability and concentration were included in this analysis.. These individual items were extracted from the PTSD screening tools utilized in the CIRC clinic and are measured on a 0-4 scale. Both PTSD screening tools use comparable questions for these items (Figure 2).

## Figure 2. Irritability and Concentration Items

<p><u>Irritability</u></p> <p>IES-r q4: “I felt irritable and angry”</p> <p>PCL-5 q15: “Irritable behavior, angry outbursts, or acting aggressively”</p> <p><u>Concentration</u></p> <p>IES-r q18: “I had trouble concentrating”</p> <p>PCL-5 q19: “Having difficulty concentrating”</p>
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The EQ visual analogue scale (EQ-VAS) is part of the EQ-5D-5L instrument introduced by the EuroQOL Group and records the patient’s self-rated health on a vertical visual analogue scale, where the endpoints are labelled ‘The best health you can imagine’ and ‘The worst health you can imagine’ (EuroQOL Group, 1990; M. Herdman et al., 2011; Shaw et al., 2005). The EQ-VAS can be used as a quantitative measure of health outcome that reflect the patient’s own judgment. The EQ-5D is recommended as an objective measure of health-related quality of life in critical illness survivors (Mikkelsen et al., 2020), and reliability and validity has been examined in ICU survivor populations with a Cronbach’s  $\alpha$  statistic higher than 0.7, and significant correlations have been noted between this tool and the 36-Item Short Form Survey (SF-36) ( $p < 0.001$ ) (Khoudri et al., 2012; Shah et al., 2016).

### ***Statistical analysis***

Analyses were conducted using IPMC SPSS version 27 (IBM Corp. Released 2020. IBM SPSS Statistics for Macintosh, Version 27.0. Armonk, NY: IBM Corp.) and statistical significance was defined as  $p < 0.05$ . Values are presented as the means with standard deviations and medians with interquartile ranges, where appropriate to summarize the demographic and clinical characteristics and the prevalence of each symptom. Spearman rank correlations coefficients were

used to determine the strength of the association between each symptom reported and the patient's reported overall health score. Absolute values of rho ( $r_s$ , in either direction from 0) of 0-0.19 were regarded as very weak, 0.2-0.39 as weak, 0.40-0.59 as moderate, 0.6-0.79 as strong and 0.8-1 as very strong correlation (Cohen, 2013).

### 3.3.2.5 Results

#### *Demographic and clinical characteristics*

The demographic and clinical characteristics of the sample are summarized in Table 1. The median (IQR) patient age of this sample ( $n=170$ ) was 61 years (IQR 51, 68.25). Approximately 54% ( $n=92$ ) were male. About one-quarter (25.9%) of patients were admitted for sepsis ( $n=44$ ), followed by neurological disorders ( $n=39$ , 22.9%), trauma/burn ( $n=35$ , 20.6%), and acute respiratory failure ( $n=13$ , 12.4%). Over 78% ( $n=134$ ) of the sample experienced acute respiratory failure, 74.7% ( $n=127$ ) experienced delirium, 66.5% ( $n=113$ ) experienced acute kidney injury (AKI), and 55.9% ( $n=95$ ) experienced any sepsis/septic shock while in the ICU. The median (IQR) worst 24-hour SOFA score was 7 (4, 10), and the median (IQR) ICU length of stay was 10 days (8, 17). Total median (IQR) mechanical ventilation days were 6 (3, 11) and total median (IQR) vasopressor days were 4 (2, 6). Median (IQR) length of time between hospital discharge and initial CIRC clinic visit was 34 days (22, 51.25).

With regard to changes seen in functional status (Table 2), of the 57 patients who were working prior to their critical illness, only 5.3% ( $n=3$ ) had returned to work by the time of the initial CIRC visit, and of the 113 patients who were driving prior to their critical illness, only 12.1% ( $n=15$ ) had returned to driving by the initial CIRC visit date. Pre-hospital baseline medians (IQR) for Katz and Lawton ADLs were 6 (6, 6) and 8 (6, 8), respectively; ceiling effects were

observed for both measures. Lower ADL scores were observed at the initial CIRC visit; medians (IQR) for Katz and Lawton ADLs were 5 (2, 6) and 2 (1, 4), respectively. The median (IQR) CFS scores demonstrated a change from a “no frailty” score of 3 (2, 4) pre-hospital status to a “mild to moderate frailty” score of 5 (5, 6) at the initial CIRC visit.

**Table 1. Patient demographics and clinical characteristics**

Total patients seen in CIRC	N=170
<i>Pre-hospital characteristics</i>	
Age, median (IQR)	61 (51, 68.25)
Sex, no. (%)	
Male	92 (54.1%)
Female	78 (45.9%)
Race, no. (%)	
White	137 (80.6%)
African American	30 (17.6%)
Asian/Middle Eastern	3 (1.8%)
Level of Education, no. (%)	
Did not graduate high school	15 (8.8%)
High school graduate/equivalent	98 (57.6%)
Some college/Associate's degree	27 (15.9%)
Bachelor's degree	25 (14.7%)
Graduate/professional degree	5 (3.0%)
Charlson Comorbidity Index (CCI) (total score), median (IQR)	3 (1.75, 5)
<i>In-clinic characteristics</i>	
Current residence, no.(%)	
Home	110 (64.7%)
Skilled nursing facility (SNF)	55 (32.4%)
Other	3 (1.8%)
Length of time between hospital discharge and initial CIRC visit (days), median (IQR)	34 (22, 51.25)

**Table 2. Change in functional status**

	<i>Pre-hospital</i>	<i>Initial clinic visit</i>
Employment status, no. (%)		
Working/student	57 (33.5%)	3 (5.3%)
Sick leave	NA	54 (94.7%)
Retired	53 (31.2%)	NA
Disabled	36 (21.2%)	NA
Unemployed	24 (14.1%)	NA
Driving, no. (%)		
Yes	113 (66.5%)	15 (12.1%)
No	11 (6.5%)	109 (87.9%)
Not applicable	46 (27.1%)	NA
Katz Index of Independence in Activities of Daily Living (ADL), median (IQR)	6 (6, 6)	5 (2, 6)
Lawton Instrumental Activities of Daily Living Scale (IADL), median (IQR)	8 (6, 8)	2 (1, 4)
Clinical Frailty Scale (CFS), median (IQR)	3 (2, 4)	5 (5, 6)

### ***Symptom prevalence***

The prevalence (%) and mean (SD) symptom severity scores of each measured symptom are summarized in Table 3. Patients reported a significant number of symptoms during their initial CIRC visit, including symptoms rarely reported in previous critical illness survivor literature. The most prevalent symptoms included physical complaints of weakness/low energy (79.4%), self-reports of diminished level of function (70%), pain (76.5%) and sleep disturbance (67.1%). Other reported symptoms included cognitive complaints of confusion/restless (57.6%), irritability (55.3%), and concentration (43.6%). Interestingly, patient-reported complaints surrounding social needs such as fear of future/not being prepared (51.2%), ineffective coping/loss of control (48.8%), and perceived lack of support (35.9%). Anxiety (40%), depression (37.6%), and PTSD (14.2%) symptoms reported in this sample are comparable to previously published ICU survivor literature. Other symptoms identified included: breathing issues (42.9%), appetite loss (38.2%), incontinence of bowel and/or bladder (37.6%), GI symptoms (including nausea, vomiting, diarrhea) (30%), and oral discomfort (dryness, ulcers) (23.5%). When considering severity of symptom on a 0-10 scale (1-3 mild, 4-7 moderate, 8-10 severe), all symptoms measured along this scale fell within a



moderate severity range (4-7), with pain as the most prominent symptom severity score with a mean of 6.15 and SD +/- 2.88. According to the HADS scoring scale, both anxiety and depression prevalence and mean scores were considered within the definitive cases range and are consistent with current ICU survivor literature (Davydow et al., 2009; Nikayin et al., 2016). PTSD prevalence and mean score (47.63) suggest the need for post-traumatic stress response treatment, and are also consistent with current ICU survivor literature (Parker et al., 2015).

**Table 4. Symptom prevalence and severity among initial CIRC visit patients**

<i>Patient-reported symptoms (n=170)</i>	<i>Prevalence (%)</i>	<i>Severity mean (SD)</i>
Weakness, low energy <sup>a</sup>	79.4%	5.52 ± 2.79
Diminished level of function <sup>a</sup>	70.0%	5.60 ± 2.99
Pain <sup>a</sup>	76.5%	6.15 ± 2.88
Sleep disturbance <sup>a</sup>	67.1%	5.71 ± 2.65
Confusion/restlessness <sup>a</sup>	57.6%	4.32 ± 2.69
Irritability (scale 0-4) <sup>d</sup>	55.3%	1.96 ± 0.99
Not prepared, fear of future <sup>a</sup>	51.2%	4.95 ± 2.75
Ineffective coping/not in control of care <sup>a</sup>	48.8%	4.78 ± 2.93
Concentration (scale 0-4) <sup>d</sup>	43.6%	1.73 ± 0.97
Breathing problems/cough <sup>a</sup>	42.9%	4.33 ± 2.31
Anxiety <sup>b</sup>	40.0%	11.15 ± 2.92
Anorexia/appetite loss <sup>a</sup>	38.2%	4.54 ± 2.39
Incontinence (bowel and bladder) <sup>a</sup>	37.6%	5.72 ± 3.12
Depression <sup>b</sup>	37.6%	10.94 ± 2.91
Perceived lack of support <sup>a</sup>	35.9%	4.87 ± 2.73
GI symptoms (nausea, vomiting, constipation) <sup>a</sup>	30.0%	4.39 ± 2.56
Oral discomfort (ulcers, dryness) <sup>a</sup>	23.5%	4.35 ± 2.61
PTSD <sup>c</sup>	14.2%	47.63 ± 11.64
Spiritual distress <sup>a</sup>	13.5%	4.57 ± 2.64

<sup>a</sup>Based on a 0-10 scale  
<sup>b</sup>Based on a 0-21 scale: standard cut-off thresholds of  $\geq 8$  for positive screen  
<sup>c</sup>Based on 0-80 or 88 scale: standard cut-off threshold of  $\geq 33$  for both scales for positive screen  
<sup>d</sup>Based on 0-4 scale

***Association between symptoms and overall health score***

Spearman correlations between symptoms and overall health score are shown in Table 5. revealed statistically significant relationships between anxiety, depression, fatigue, sleep disturbance, and confusion with overall health score reporting (EQ-VAS) at the  $p < .001$  level.

Additionally, pain, fear of future, lack of control, decreased function, PTSD symptoms, lack of support, appetite loss, and decreased concentration were statistically significant at the  $p < .05$  level. The correlation coefficients varied with a moderate negative relationship seen with depression (-0.42,  $p < .001$ ); moderate to weak negative relationships seen with confusion (-0.38,  $p < .001$ ), and fatigue (-0.37,  $p < .001$ ); and weak negative relationships (-0.20-0.29,  $p < .05$ ) seen with fatigue, confusion, anxiety, pain, fear of future, fatigue, perceived lack of control, sleep disturbances, decreased function, and PTSD symptoms (Dancey & Reidy, 2007).

**Table 5. Correlation using Spearman’s correlation coefficient ( $r$ ) between individual symptoms and overall health score (EQ-VAS).**

( $N=167$ )	$r_s$	$p$
Depression	-0.42	<.001
Confusion/restlessness	-0.38	<.001
Weakness, low energy	-0.37	<.001
Anxiety	-0.28	<.001
Sleep disturbance	-0.28	<.001
Pain	-0.26	.001
Not prepared, fear of future	-0.23	.003
Ineffective coping/not in control of care	-0.22	.004
Diminished level of function	-0.21	.006
PTSD	-0.20	.010
Perceived lack of support	-0.19	.015
Anorexia/appetite loss	-0.17	.026
Concentration	-0.17	.026
GI symptoms (nausea, vomiting, constipation)	-0.13	.095
Irritability	-0.13	.104
Spiritual distress	-0.11	.130
Oral discomfort (ulcers, dryness)	-0.11	.160
Breathing problems/cough	-0.07	.351
Incontinence (bowel and bladder)	0.01	.903

### 3.3.2.6 Discussion

The purpose of this study was to examine more comprehensive symptom experiences by critical illness survivors and to investigate their impact on overall health score reporting. We found

that in addition to the commonly reported PICS symptoms seen in critical illness survivors, there were various new domains with considerable prevalence and severity identified in this study. Pain remains highly prevalent, along with physical symptoms of appetite loss, incontinence of bowel and/or bladder, GI-related symptoms, and oral discomfort (ulcers, dryness). We examined the social and support domains of autonomy, communication, and economic need and found that critical illness survivors report these needs at a higher prevalence and severity than a few of the mainstays of PICS (anxiety, depression, and PTSD). The social concerns found in this study strengthens the emerging interest in examining social needs and recovery from critical illness and the importance of increasing our attention to issues of one's social health after critical illness (J. M. McPeake, P. Henderson, et al., 2019). We also found that spiritual distress occurred at similar rates and severity as PTSD symptoms. These results suggest that survivorship after critical illness is a bigger multidomain process than originally suggested in the PICS model, where the domains are interrelated, and the focus should be on optimizing all dimensions of a person's life. The associated health responses affect all aspects of the whole person, including physical, cognitive, psychological, social, support, and spiritual components. Additionally, more work is needed in exploring the spiritual needs of critical illness survivors.

Our findings offer important implications. The substantial symptom burden experienced by critical illness survivors in this sample highlights that appropriate symptom assessment with standardized collection and management need to occur after acute care discharge. The findings of this study need to be considered in light of limitations. First, the study was cross-sectional in nature and included a heterogenous populations of critical illness survivors. Thus, our analyses can describe associations, but cannot attribute causation. Second, the generalizability may be limited, as the study population was restricted to a single site. Last, although the PEACE tool captures both

face and content validity, there is currently no data on reliability and validity in research for this tool. This limitation speaks to the ongoing need for valid and reliable symptom measurement tools for the critical illness survivor population.

### **3.3.2.7 Conclusion**

Patients surviving critical illness suffer an extensive symptom burden beyond the identified manifestations of PICS (eg. decreased physical function, cognitive complaints, anxiety, depression, and PTSD symptoms). Heightened awareness, formal assessment, and empiric treatment of symptoms may markedly improve quality of life for survivors of critical illness. This study adds to the growing knowledge on symptom science in critical illness survivors not only through the provision of a more comprehensive picture of symptom burden in critical illness survivors, but also through the investigation of their effects on overall health score reporting. To eliminate this significant symptom burden, interprofessional research and clinical efforts will be required to increase our understanding of the etiology of symptom burden, evaluate current treatment and management, and disseminate effective therapies to critical illness survivors.

### **3.3.3 Results of Aim 3b and 3c**

#### **3.3.3.1 Aim 3b results**

##### ***Discussion of data analysis procedures***

With regard to missing data, 26 cases were excluded from this analysis (n=5 had no symptom survey data reported, n=7 had > 50% symptom survey data missingness, and n=14 had < 50% symptom survey data missingness), leaving 170 cases. A manual chart review of these 26

cases revealed clinic visit time constraints as the primary reason these cases were missing data. Additionally, Chi Square tests examining potential relationship with sex, age, education level, and severity of illness (worst 24hr SOFA score, CCI, hospital length of stay, and ICU length of stay) against all items with missingness exceeding 5% was performed and the data demonstrated that the missingness was missing completely at random (MCAR). Predictive mean matching (PMM) was considered to impute item missingness, however, with the true factor structure unknown, theoretically recommendable multiple imputation methods, such as PMM, cannot simply be applied (Morris et al., 2014). After running multiple analyses, each employing a different missing data strategy (PMM, listwise deletion), and comparing results, the decision was made to run the exploratory factor analysis model with complete cases only (n=170), and listwise deletion was utilized as the sample size was sufficient for the number of factors to be examined.

An exploratory factor analysis with principal axis factoring (PAF) and promax-rotated factor loadings was performed to identify related symptoms reported by critical illness survivors. A correlation matrix between symptoms was generated and examined to ensure sufficient correlations and lack of extreme multicollinearity and singularity between items for the factor analysis (Field, 2013). Given the exploratory nature of this study, the number of factors was based on (1) eigenvalue  $\geq 0.8$  and scree plot inspection, (2) factor loadings  $\geq 0.50$  due to smaller sample size, (3) each should account for at least 1% of the total variance, and (4) practical clinical and theoretical plausibility of symptoms likely to co-occur and to represent distinct symptom clusters (Costello & Osborne, 2005; Guadagnoli & Velicer, 1988; Osborne et al., 2014). These criteria were selected in order to include the largest number of symptoms in the analysis, while still considering statistical significance with a smaller sample size. Symptom clusters were identified if symptom total correlation with Cronbach's  $\alpha$  was  $\geq 0.60$ . The best fit of symptom grouping was

determined according to the following criteria: simple structure, total variance explained by the symptom clusters, and internal reliability of the symptom clusters measured by Cronbach's  $\alpha$ . Core symptoms were defined as those with the highest inter-factor correlation coefficient. Symptoms considered for EFA model can be found in Figure 11. These symptoms were selected as they met traditional definition of symptom typically presented in symptom science literature (Miaskowski et al., 2017). Oral discomfort and spiritual distress were excluded from the factor analysis as they had < 25% occurrence across cases. After the first EFA model was run, pain was removed due to low communality (.182); variables with low communalities (less than .20) are eliminated from the analysis (Child, 2006). Coefficients were suppressed <.45 due to sample size to obtain simple structure (Pearson, 2008).

Symptom Assessment Tools	Symptom(s) Measured for EFA	Scoring
Hospital Anxiety and Depression Scale (HADS)	Anxiety	Anxiety subscale score (0-21)
	Depression	Depression subscale score (0-21)
Impact of Events - Revised (IES-r)*	Irritability	Scale (0-4)
	Concentration	Scale (0-4)
	Avoidance	Scale (0-4)
	Intrusion	Scale (0-4)
	Arousal and reactivity	Scale (0-4)
PTSD checklist for DSM-5 (PCL-5)*	Irritability	Scale (0-4)
	Concentration	Scale (0-4)
	Avoidance	Scale (0-4)
	Intrusion	Scale (0-4)
	Arousal and reactivity	Scale (0-4)
Physical, Emotional, Autonomy, Communication, Economic, Transcendent (PEACE Tool)	Pain	Scale (0-10)
	Anorexia	Scale (0-10)
	Incontinence (bowel and bladder)	Scale (0-10)
	GI symptoms (nausea, vomiting, constipation)	Scale (0-10)
	Breathing problems/cough	Scale (0-10)
	Fatigue	Scale (0-10)
	Sleep issues	Scale (0-10)
	Oral discomfort (ulcers, dryness)	Scale (0-10)
	Fear of future	Scale (0-10)
	Confusion/restlessness	Scale (0-10)
	Spiritual distress	Scale (0-10)

\* PTSD assessment tool items will be collapsed into a single variable for each symptom measured in the EFA (eg. New irritability variable recoded from 2 irritability questions, one from each assessment tool)

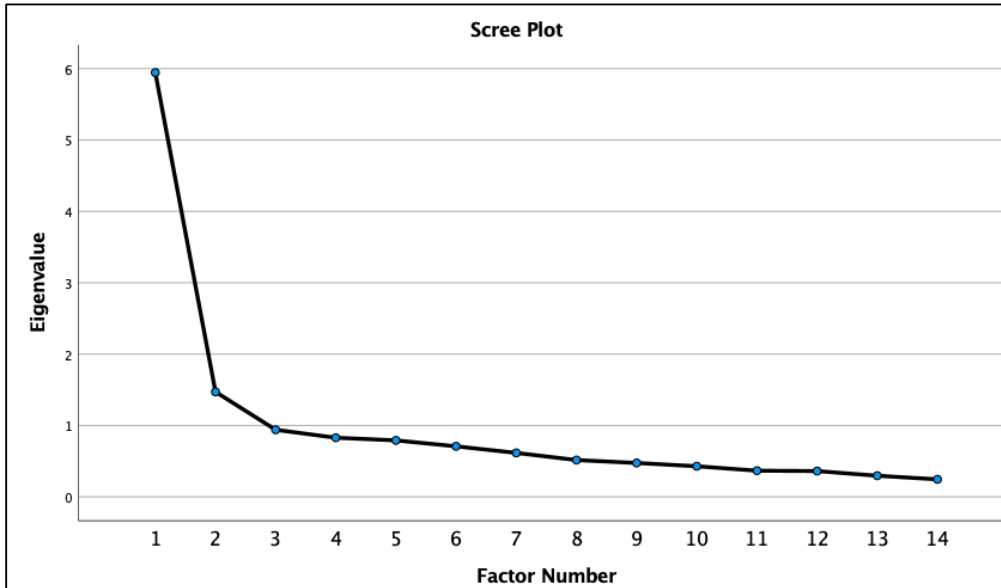
**Figure 11: Symptoms considered for EFA model**

### ***Factor loading and symptom clusters***

Figure 12 shows the factor loading from the exploratory factor analysis without suppressed coefficients. Core symptoms in each cluster were determined based on stability across dimensions and clinical plausibility. A high cutoff of 0.50 for factor loading was used for all analyses. Figure 13 shows the scree plot, considering an eigenvalue  $\geq 0.8$ . Three symptom clusters were identified: the stress response cluster, the fatigue/sleep disturbance cluster, and the anxiety/depression cluster. Cronbach's  $\alpha$  for the stress response cluster was 0.798, for the fatigue/sleep disturbance cluster 0.733 and for the anxiety/depression cluster 0.759.

Symptom (N=170)	Factor loading			
	Factor 1	Factor 2	Factor 3	Factor 4
Anxiety	0.399			<b>0.451</b>
Depression				<b>1.018</b>
Appetite Loss				
Incontinence of bladder/bowel		<b>0.502</b>		
GI symptoms		<b>0.904</b>		
Weakness, low energy			<b>0.931</b>	
Sleep disturbance			<b>0.575</b>	
Confusion				
Irritability	<b>0.493</b>			
Concentration	<b>0.540</b>			
Avoidance	<b>0.654</b>			
Intrusion	<b>0.964</b>			
Hyperreactivity	<b>0.816</b>			
Fear of future	0.348	0.440		
Cronbach's alpha	<b>0.798</b>	0.54	<b>0.733</b>	<b>0.759</b>
Factor 1 - Stress response cluster				
Factor 3 - Fatigue/sleep disturbance cluster; Factor 4 - Anxiety/Depression cluster				

**Figure 12: EFA factor loading**



**Figure 13: Scree plot**

### 3.3.3.2 Aim 3c results

#### *Discussion of data analysis procedures*

For multiple linear regression analyses, aside from the three identified symptom clusters, we considered the following variables for inclusion in the model: demographic characteristics (age, sex), morbidity and functional characteristics (CCI, CFS, current Katz ADL, current Lawton IADL), and of illness (ICU length of stay, worst 24hrs SOFA score). These variables were chosen on the basis of being major clinical or demographic variables and their prior associations with known dysfunction in critical illness survivors. Due to non-normality of data, individual Spearman correlations were run to investigate the relationship between each of the variables and symptoms, and EQ-VAS score. The final regression model included only age, current Clinical Frailty Score (CFS), and current Lawton IADL score, as these were significantly correlated with EQ-VAS score at  $< .10$ . Assumption of singularity was met as the independent variables were not a combination



of other independent variables. There were no independent variables that were highly correlated, no extreme univariate outliers and no multivariate outliers. Residual and scatter plots examined as well (normality, linearity, homoscedasticity) and all regression assumptions were met.

***Relationship between symptom clusters and overall health score***

A three-stage hierarchical multiple regression analysis (Figure 14) revealed that at stage one, age contributed significantly to the model, ( $F(1,165) = 4.638, p = .033$ ), with an  $R^2$  of .027 and accounted for 3% of the variation in overall health score. Introducing the current CFS score and Lawton IADL variables also demonstrated a significant regression equation ( $F(3,163) = 5.569, p = .001$ ), with an  $R^2$  of .092, and explained an additional 7% of variation in overall health score. Finally, the addition of all three symptom clusters was also significant, ( $F(6,160) = 8.286, p < .001$ ), with an  $R^2$  of .236. When all variables were included, model demonstrated that factor 3 (fatigue/sleep disturbance symptom cluster) and factor 4 (anxiety/depression cluster) were strong predictors of overall health score reporting. Additionally, both age and current CFS score were predictors of over health score reporting. Together the five independent variables accounted for 24% of the variance in overall health score.

Variable	B	t	sr <sup>2</sup>	p	R	R <sup>2</sup>	Δ R <sup>2</sup>
Step 1					.17	.03	.03
Age	.226	2.154	.03	<b>.033</b>			
Step 2					.30	.09	.07
Age	.301	2.785	.04	<b>.006</b>			
current CFS	-3.533	-3.190	.06	<b>.002</b>			
current Lawton IADL score	.266	.307	.00	.759			
Step 3					.49	.24	.14
Age	.211	2.004	.02	<b>.047</b>			
current CFS	-2.416	-2.306	.03	<b>.022</b>			
current Lawton IADL score	-.085	-.104	.00	.917			
Factor 1 (Stress symptom cluster)	2.525	1.112	.01	.268			
Factor 3 (Fatigue/sleep disturbance cluster)	-1.717	-2.911	.04	<b>.004</b>			
Factor 4 (anxiety/depression cluster)	-1.407	-2.761	.04	<b>.006</b>			

Note: N = 168

**Figure 14: Relationship between symptom clusters and overall health score**

### **3.3.3.3 Aim 3b and 3c discussion**

To the best of our knowledge, symptom clusters have not been widely examined in the critical illness survivor population; however single symptoms, the co-existence of symptoms, and symptom domains (i.e. PICS domains) have been broadly studied (Choi, Hoffman, et al., 2014; Choi et al., 2016; Jackson et al., 2014; Langerud et al., 2018; Nikayin et al., 2016; Parker et al., 2015; Wang et al., 2019). These findings illustrate the need for additional focus by clinicians in the post-acute setting symptom management, as the level of this symptom burden seen may hinder interventions targeted at critical illness survivor optimization in the post-ICU setting. Also highlighted is the importance of continued and expanded examinations of symptom clusters and co-occurrence as a correlate of health-related quality of life and other consequences in critical illness survivors. This may drive future efforts directed toward developing interprofessional approaches to symptom management interventions that target either multiple, concurrent symptoms or a single symptom and its associated effects on other symptoms in a cluster as a method of improving QOL and other consequences in critical illness survivors. A consideration to these data is that only clinical data from the initial clinic visit was used to create the symptom clusters, so the stability of these clusters over time is not known. This first study exploring symptom clusters in ICU survivors will lay the groundwork for future study of symptom clusters in larger populations of ICU survivors and stability over time.

### **3.4 CONCLUSION**

Survivors of critical illness suffer an extensive symptom burden beyond the typically reported manifestations of post-intensive care syndrome (PICS). In addition to symptoms in physical, cognitive, and psychological domains, symptoms associated with spiritual and social needs are widespread. These findings support standardization of symptom assessment and management in patient surviving critical illness. Additionally, these findings suggest that both critical illness survivors and post-ICU clinicians recognize ongoing holistic care needs which may be well managed by applying a primary palliative care approach to address these unresolved and wide-ranging concerns.

### **3.5 IMPLICATIONS AND DIRECTIONS FOR FUTURE WORK**

This work may assist in providing a foundation of knowledge that can assist in intervention development for the delivery of palliative care in the post-ICU clinic setting. These findings also provide new insight into the bigger landscape of symptom burden in critical illness survivors. Taken together, these results may directly improve the patient and family experience of critical illness survivorship.

Further investigation is needed to understand and describe the family and caregiver experience after critical illness, including the examination of perceptions and preferences regarding the delivery of palliative care in the post-ICU clinic setting more fully. Ideally, additional efforts undertaken in future research would be directed toward developing interprofessional approaches to symptom management interventions in this population.

## APPENDIX A

American Association of Critical Care Nurses (AACN) reprint approval letter and full manuscript reprint for: Eaton TL, McPeake J, Rogan J, et al. Caring for survivors of critical illness: current practices and the role of the nurse in intensive care unit aftercare. *Am J Crit Care*. 2019;28(6):481-485. doi: <https://doi.org/10.4037/ajcc2019885>. All rights reserved. Reprinted with permission.

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NURSES

January 22, 2021

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# CARING FOR SURVIVORS OF CRITICAL ILLNESS: CURRENT PRACTICES AND THE ROLE OF THE NURSE IN INTENSIVE CARE UNIT AFTERCARE

By Tammy L. Eaton, MSN, RN, FNP-BC, ACHPN, Joanne McPeake, PhD, MSc, BN (Hons), RGN, Julie Rogan, MSN, CNS, ACCNS-AG, Annie Johnson, APRN, ACNP-BC, and Leanne M. Boehm, PhD, RN, ACNS-BC

**T**he success of critical care medicine has historically been gauged by short-term mortality outcome. With technological advances, many patients now survive what were previously fatal critical illnesses, generating an expanding population of critical care survivors. Many survivors suffer with new or worsening impairments in physical, cognitive, or mental health status arising after a critical illness and persisting beyond acute care hospitalization, which has been termed *post-intensive care syndrome* (PICS).<sup>1</sup> This term can be applied to a survivor or to a family member who often experiences significant social and psychiatric burdens caring for a survivor of critical illness.<sup>1,2</sup> It is estimated that PICS develops in more than 2.4 million Americans who survive critical illness each year, including approximately two-thirds of Medicare beneficiaries who survive critical illness.<sup>3</sup> As a consequence of both an aging population and the dramatic improvement in mortality rates in those with critical illness, PICS is rapidly becoming a major public health concern. For these survivors, new impairments after critical illness can have dramatic impacts on their quality of life or ability to be employed and may persist for months or years after hospital discharge.

In this review, we examine emerging practices in relation to intensive care unit (ICU) aftercare for both patients and caregivers, with specific emphasis on the critical role of the nurse.

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## Approaches to ICU Aftercare

The role of the ICU aftercare program is to specifically address the physical, mental health, and cognitive impairments associated with PICS in order to improve the survivorship experience for patients and caregivers. The goal of ICU aftercare programs is to provide personalized care that focuses on the unique needs of ICU survivors; however, no one standard model of care is currently in place. Peer support, post-ICU clinics, and ICU diary aftercare programs are currently being implemented and investigated internationally with modest results.<sup>4-6</sup> A description of each program and modes of delivery is provided in the next sections. These ICU aftercare programs can be implemented in isolation or in combination, depending on resources, to provide a more comprehensive recovery program.

## Post-ICU Clinics and Recovery Programs

Post-ICU clinics and recovery programs have been established in many hospital systems internationally.<sup>4,7-9</sup> These clinics have taken a variety of forms in terms of professional input and process. Wide variation exists in the staffing of post-ICU clinic recovery programs more generally, for example.<sup>10</sup> Some clinics are led by a single discipline (ie, nurse or physician led); others include members of the entire multidisciplinary team.<sup>11</sup> More recently, single-center data have described a model that uses staff from both health and social services, with the aim of supporting some of the socioeconomic problems that patients, and indeed their caregivers, face during the ICU recovery period.<sup>12</sup> On a small scale, this approach appears to

be well received by patients; however, more work is required to understand the contextual differences across health care systems and how such support can be optimally implemented.<sup>12,13</sup>

There has been debate in the literature regarding the type of expertise the team delivering post-ICU care should have.<sup>14</sup> Some commentators have stated that this care is best delivered by specialists in rehabilitation, whereas others believe that ICU providers should lead this care either in isolation or in partnership with rehabilitation specialists.<sup>15,16</sup> Recent data suggest that by having staff from the ICU involved in post-ICU care, outcomes and care delivery across the entire ICU pathway may be improved by understanding patients' and caregivers' experience more fully.<sup>17</sup> Single-center evidence also suggests that having the ICU staff involved in care over the entire recovery trajectory of the patient may help reduce staff burnout and increase joy in work.<sup>18</sup>

The interventions delivered within clinics internationally also vary in their format and process. Some clinics have patients attend as a stand-alone appointment, and some provide follow-up at pre-defined intervals (eg, 3 months and 12 months). Other models have an approach similar to that of pulmonary rehabilitation in that they offered

staggered, regular interventions to promote goal setting and patients' changing needs. This overall lack of a standardized approach and professional input is not necessarily reflective of need, but rather what is feasible with the limited funding and limited evidence of effectiveness.<sup>17</sup>

## Peer Support Programs

Although not a clinician-centered model, peer support for ICU survivors and their families can serve a crucial role in the recovery process by providing a foundation of both taking and giving support as a healing approach if done with mutual respect.<sup>19</sup> Through this approach to ICU aftercare, survivors and their families are provided an opportunity to facilitate their own recovery and improve their quality of life by relating to others with shared experiences.<sup>20</sup> Current models of peer support for ICU survivors and their families include group sessions that coincide with post-ICU outpatient clinic visits, information sessions led by a content expert, group sessions that are cofacilitated by ICU staff, peer-to-peer mentoring, and group sessions that are held for the loved ones of patients while the patient remains critically ill.<sup>6,10</sup> Peer support can also occur online through discussion boards that can be joined and referenced by ICU survivors and their families from around the world, and through teleconference options, which allow for real-time participation for those who live a long distance or are too debilitated to travel and attend the in-person peer support session. Recruitment of ICU survivor and family participants commonly occurs through the distribution of advertisements and brochures around the hospital and medical center, during follow-up phone calls or visits, and/or through direct mailings or emails.

## ICU Diary Programs

ICU survivors can have lingering stress, anxiety, depression, and posttraumatic stress disorder (PTSD) symptoms, and many have long posited that gaps in memory occurring during critical illness are an important contributor.<sup>21-23</sup> In recent publications, use of ICU diaries was associated with reduced symptoms of anxiety and depression and improved health-related quality of life in ICU patients,<sup>24</sup> and ICU diaries are recommended in guidelines for family-centered care in the ICU.<sup>25</sup> However, new evidence suggests no difference in PTSD symptoms at 3 months after discharge in ICU patients receiving mechanical ventilation who had used an ICU diary compared with patients who had not used an ICU diary.<sup>26</sup> Written by the patient's loved ones and members of the

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## “Nurses are uniquely trained and positioned within the health care system to become leaders within ICU aftercare programs.”

hospital's care team, the ICU diary may help ICU survivors begin to make sense of time they have forgotten and may provide a unique approach for reflection on their critical illness experience. Along with providing the patient with information about what is happening, which equipment is making noise, and who is spending time with them, the entries provide messages of support, encouragement, and hope for recovery. ICU diary programs are unique to each health care system and may include photographs of the patient throughout their critical illness, so that progress can be visualized. The loved ones of a patient may feel empowered with a sense of purpose as they write daily entries in the ICU diary.<sup>25</sup> Loved ones help the staff understand who the patient is by filling out the pages that highlight the patient's preferences. Patients are encouraged to write in their own ICU diary if and when they feel able.

The ICU diaries are not always immediately read by patients once they leave the ICU. Rather, after several weeks or months, the patient may feel ready to debrief the ICU stay. Debriefing occurs by reviewing the diary with a member of the hospital's care team during a post-ICU clinic visit, discussing entries of importance during a peer support session, or by going through the diary with loved ones independently from the hospital's care team. Further research is needed to explore whether formal debriefing plays a role in decreasing psychological symptoms and improving health-related quality of life. Patients who do not remember any of their stay in the ICU use their diary to put names to faces during peer support sessions or during a planned visit to the unit when they feel ready for it.

### Role of Nurse Leaders in ICU Aftercare

Nurses are uniquely trained and positioned within the health care system to become leaders within ICU aftercare programs. Throughout the world, nurses are currently advancing clinical care and science for ICU survivors and their families as clinicians, advocates, and researchers.

#### Clinician

As ICU survivor research continues to evolve, more evidence will be available to guide the

development of ICU aftercare programs. Nurses will undoubtedly continue to play a significant role in translating these discoveries into action for our patients and family members who have experienced critical illness. Nurses, with the foundational training in holistic patient-centered care and nursing metaparadigm, are uniquely qualified to lead initiatives in both the development and implementation of these programs. Currently, advanced practice registered nurses (APRNs) as well as registered nurses have roles in the creation, facilitation and education, leadership, and staffing of post-ICU clinics, peer support groups, and ICU diary programs. Existing peer support programs for ICU survivors are often using nurses as the key facilitators.<sup>6</sup> In many instances in the United States, the APRN leads the interprofessional team that designs and establishes a peer support program that works within the confines of the individual institution. Identification and recruitment of survivors for ICU aftercare programs can be performed by the APRN through follow-up phone calls and rounding on ICU survivors after their transition from the critical care unit. Many post-ICU clinics also use the APRN as one of the outpatient providers. Throughout the world, research and innovation on and implementation of diary programs have often been initiated by nurses.<sup>27-29</sup> Along with education and supporting family members to write entries, nurses are also the most likely care team member outside of the patient's loved ones to use the ICU diary. Debriefing the ICU stay with the patient using the ICU diary is also often performed by a nurse at the post-ICU clinic or at a peer support session. Evaluation of and education about ICU aftercare programs are commonly managed by nurses, who solicit feedback from participants and work with the team to adjust the programs as needed. The nurse also shares pertinent information with the staff nurses to improve care delivery at the bedside.

#### Advocate

Raising awareness of PICS is essential to ensure that patients and families recovering from critical illness receive needed support during recovery. Nurses in all roles participate in advocacy as a caring competency, whether it be one-on-one patient encounters or on a global scale.<sup>30</sup> Nurses can advocate for



“Future research and innovation must attempt to address the recovery arc of caregivers and how to best intervene to improve outcomes for this vulnerable group.”

ICU survivors and their families through educational initiatives that target colleagues as well as patients and their family members. Additionally, assisting patients and their families in identifying ICU aftercare resources will support their recovery trajectory and overall well-being. Nurses can also advocate for the ICU survivor by fostering the multidisciplinary collaboration seen in ICU aftercare.<sup>31</sup> A team approach to ICU survivor care provides an avenue to an interdisciplinary plan of care. Finally, empowering ICU survivors to play an active role in the creation of patient-centered goals allows patients to take control of their health care decision and actions affecting their recovery trajectory.<sup>17</sup> Nearly endless opportunities are available for nurses to bridge the gap between illness and recovery for ICU survivors through hospital, national organization, and public policy initiatives. One example is the Critical and Acute Illness Recovery Organization (CAIRO), an international consortium of health care professionals, survivors of critical and acute illness (including their loved ones), and scientists. Cofounded by nurse leaders, the mission of CAIRO is to advance the practice and science of critical illness recovery through the development and evaluation of new ways to help patients and families heal from critical and acute illness.

#### Researcher

Research focused on ICU aftercare is necessary to evaluate effectiveness and outcomes and to establish evidence-based recommendations that organizations can use to create new programs. Nurse scientist training involves both qualitative and quantitative methods enabling effective contribution to advancing ICU aftercare program research. Nurse scientists are in an ideal position to promote the development of innovative methods in caring for ICU survivors and their family members. Nurse-led qualitative methods to explore ICU survivors' and families' experiences and goals of recovery<sup>32,33</sup> as well as quantitative approaches to decreasing symptom burden and increasing quality of life<sup>20,34</sup> are shaping the science of recovery from critical illness for ICU patients and their families.

#### Future Directions for ICU Aftercare

As the numbers of available ICU aftercare and recovery programs continue to expand, the demand for such programs is also likely to increase. Currently, many of the available programs are in large urban centers and are associated with large academic medical centers. Innovative aftercare delivery models are being explored to address these barriers, for example, the use of mobile ICU recovery programs<sup>35</sup> or the use of telemedicine services for ICU survivors. An underdeveloped area in our understanding of post-ICU care delivery is the support needed by caregivers. Caregivers and close family members experience social and emotional problems similar to those experienced by patients in the year following critical illness.<sup>36</sup> However, it is not clear whether caregivers and family members have the same recovery trajectories. Spikes in emotional and mental health problems, for example, may appear at different stages. Future research and innovation must attempt to address the recovery arc of caregivers and how to best intervene to improve outcomes for this vulnerable group.

#### Conclusion

As ongoing challenges for survivors of critical illness and their family members persist, post-ICU clinics, peer support, and ICU diary aftercare programs are working to mitigate the effects of PICS. These services offer approaches to reinforce family-centered care in the ICU and to enhance patients' and family members' experiences with recovery from critical illness. As demand for ICU aftercare programs increases, nurses will play an important role in the development, implementation, and sustainability of the programs as key members of the multidisciplinary ICU recovery team.

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#### FINANCIAL DISCLOSURES

None reported.

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## **APPENDIX B**

Published abstract: Exploring Goals of Care in Patients Surviving Critical Illness

Eaton, T., Castiglia, R., Qureshi, A., Lewis, A., & Butcher, B. (2020). 60: REEXPLORING GOALS OF CARE IN PATIENTS SURVIVING CRITICAL ILLNESS. *Critical Care Medicine*, 48(1), 30.

## APPENDIX C

Published abstract: Implementation of a Primary Palliative Care Intervention in Patients Surviving Critical Illness: A Process Evaluation

Eaton, T. L., & Butcher, B. W. (2020). Implementation of a Primary Palliative Care Intervention in Patients Surviving Critical Illness: A Process Evaluation. In C26. ENHANCING PRACTICE ENVIRONMENTS FOR PATIENT AND FAMILY CARE, IMPROVING OUTCOMES, AND ADHERENCE (pp. A4628-A4628). American Thoracic Society.

## APPENDIX D

### Patient Interview Guide

I am interested in learning more about the needs of patients that have survived an extended or complicated stay in the intensive care unit. I would like to hear about your experiences following your ICU stay. All of your responses will be kept completely confidential; no one will be able to associate you with your responses. You will be identified by an ID number and not by your name. Thank you so much for taking the time to talk with me today.

Begin recording and make sure to state the date, time, location of interview, participant ID number.

Let's first talk a little about your ICU stay.

- Can you tell me in your own words why you were in the ICU this admission?
- How long were you in the ICU?
- What are some of the things you remember about being in the ICU?
  - (Probe: what things did you see, hear, feel?)
  - (Probe: what people do you remember seeing?)
- Tell me about any conversations you have had with your family about your ICU stay since you left the ICU.

Now let's talk a little about how you think things are going for you so far.

- How do you think your life is going to change as a result of this illness?
- What is your greatest fear after this critical illness?
- What impact do you think your illness has on your family members/caregivers?
- What kind of help do you current need?
- How long do you think you will need help?
- What are your biggest concerns about your health moving forward?
  - (probe: physically, mentally, socially, economically, spiritually)

Next, I'd like to talk a little bit about any ongoing symptoms you may have right now.

- What are the biggest/most troublesome symptoms you are currently experiencing?

- How many of these are new since your ICU stay?
- Are these symptoms improving or worsening (or unchanged) as time goes on?
- How do you think these symptoms affect your day-to-day activities?

Lastly, I want to ask you about your feelings regarding making future plans for your healthcare.

- What are your hopes or personal goals in the next year?
- (In what ways) Do you find that after your ICU stay that you look at what you want for your healthcare is now different in any way?
- Suppose your health would get worse, what concerns would you have?
- If your health would get worse, what medical treatments would you want or not want?
  - (probe: do you think you would pursue the same treatments?)
  - (probe: would you want to go back to the ICU, would you want invasive or aggressive care/therapies)
- Have you talked to your family about what would happen if your health got worse?
  - (probe: what did you talk about?)
  - (probe: what kinds of things do you think it would be important to talk about)
- What is most important to you as you think about the future?

Is there anything else that you think is important for me to know?

## APPENDIX E

### Post-ICU Interprofessional Clinicians Interview Guide

Adapted from (Kavalieratos et al., 2014)

<b>Domain of Interest</b>	<b>Question</b>
Needs of critical illness survivors and family members/caregivers	On the whole, what needs do your ICU survivor patients possess? (Probe: What do you think are the biggest unmet needs in ICU survivors currently?)
	What needs do the families and caregivers of ICU survivors possess?
	How effective do you believe that you are in managing your ICU survivor patients' needs?
	If you could change anything about your post-ICU clinic practice, what would it be? (Probe: Are there care aspects you would add/delete?)
Knowledge and perceptions of palliative care	What is your familiarity with palliative care? How do you define it? (Probe: What comes to mind when you hear the phrase palliative care/primary palliative care/specialty palliative care?)
	(Probe: Throughout our conversation, I've been using the term "palliative care," and I've been hearing you use the term "hospice." Are those interchangeable for you, or do you see a distinction between them?)
	Can you describe your professional experience with goals of care discussions, symptom management, care coordination, and patient and family/caregiver support? (Probe: in any practice setting)
	Can palliative care be helpful in the management of ICU survivor patients? If so, how? If not, why not?

**Domain of Interest****Question**

Indications for, and optimal timing of, palliative care in critical illness survivorship

In your opinion, what makes an ICU survivor eligible for palliative care?

In your opinion what makes an ICU survivor appropriate for palliative care?

Barriers to palliative care in critical illness survivorship

What are some of the barriers that you believe might be impeding the uptake the use of primary palliative care techniques in ICU survivor care?

Is there anything else that you think is important for me to know?

**Clinical Vignette (to be discussed after review of first domain of questions with post-ICU clinician)**

- C.B. is a 65-year-old female, previously employed and functionally independent, with a PMH of COPD. She spent 22 days in the ICU for treatment of acute respiratory failure, severe ARDS, and septic shock secondary to community acquired pneumonia. ICU interventions included mechanical ventilation, chemical paralysis and prone ventilation, and high dose vasopressors. The remainder of her hospital stay (9 days) was unremarkable, and she was discharged to a skilled nursing facility for 30 days and eventually home after hospital discharge.
- She presents to your post-ICU clinic from home with the following complaints: significant hair loss, crippling “whole-body” pain which is affecting her sleep, and issues with memory, concentration, word-finding, and tremors. She reports that she is “fatigued and gets short of breath very easily”. She lost 6% of her body weight during her hospitalization. She is currently not driving or working. Her daughter is present for the visit and is reporting caregiver burden and some symptoms of anxiety, as she is worried “what is next for her mother”.

**Vignette Questions:**

What aspects of this case stand out the most for you and why?

What treatment priorities stand out for you and why?

What aspects of this care would your team manage within your post-ICU program?

Are there specific outside referrals that come to mind when you hear/read this case?



## APPENDIX F

### List of aim 3 variables

Variables	Level of Measurement	Descriptive Statistics
<i>Pre-hospital characteristics</i>		
<b>Age</b>	Ratio	Mean, SD (Median, IQR if nonnormal)
<b>Sex</b> Female Male	Nominal	Frequency, %, Mode
<b>Race</b> Caucasian African American Other	Nominal	Frequency, %, Mode
<b>Education level</b> Did not graduate high school High school graduate Some college College graduate Master's degree Doctorate/professional degree	Ordinal	Median, IQR

<b>Charlson Comorbidity Index (CCI) score (0-24)</b>	Ratio	Mean, SD Median, IQR if nonnormal
<b>Katz Index of Independence in Activities of Daily Living (ADL)</b>	Ratio	Mean, SD Median, IQR if nonnormal
<b>Lawton Instrumental Activities of Daily Living Scale (IADL)</b>	Ratio	Mean, SD Median, IQR if nonnormal
<i>In-hospital characteristics</i>		
<b>ICU diagnosis on admission</b> Sepsis, ARDS due to infection or septic shock Acute Respiratory Failure <sup>a</sup> Cardiogenic shock, CHF, myocardial infarction, or arrhythmia Upper airway obstruction <sup>b</sup> Neurologic disease or seizure Trauma Burn Other surgical procedure <sup>c</sup> Other diagnoses <sup>d</sup>	Nominal	Frequency, %, Mode
<b>SOFA score<sup>c</sup> (worst)</b> Respiratory (0-4) Nervous system (0-4) Cardiovascular system (0-4) Liver (0-4) Coagulation (0-4) Kidneys (0-4) Composite score (0-24)	Ratio	Median, IQR
<b>Length of ICU stay (days)</b>	Ratio	Mean, SD (Median, IQR if nonnormal)
<b>Length of hospital stay (days)</b>	Ratio	Mean, SD (Median, IQR if nonnormal)

<b>Presence of delirium in ICU</b>	Nominal	Frequency, %, Mode
<b>Presence of mechanical ventilation in ICU</b>	Nominal	Frequency, %, Mode
<b>Presence of sepsis in ICU</b>	Nominal	Frequency, %, Mode
<b>Need for CPR</b>	Nominal	Frequency, %, Mode
<b>Need for surgery/interventional radiology procedure</b>	Nominal	Frequency, %, Mode
<b>Vasopressor use in ICU</b>	Nominal	Frequency, %, Mode
<b>Continuous renal replacement therapy (CRRT) use in ICU</b>	Nominal	Frequency, %, Mode
<i><b>In-clinic characteristics</b></i>		
<b>Current residence</b> Home Apartment Assisted Living Skilled nursing facility (SNF) Other	Nominal	Frequency, %, Mode
<b>Employment status</b> Working Retired Student Sick leave Disabled Unemployed	Nominal	Frequency, %, Mode
<b>Katz Index of Independence in Activities of Daily Living (ADL)</b>	Ratio	Mean, SD Median, IQR if nonnormal
<b>Lawton Instrumental Activities of Daily Living Scale (IADL)</b>	Ratio	Mean, SD Median, IQR if nonnormal
<b>Montreal Cognitive Assessment (MoCA)</b>	Ratio	Mean, SD Median, IQR if nonnormal

<b>EQ-5D-5L</b>	Ratio	Mean, SD Median, IQR if nonnormal
<b>Overall health rating (0-100)</b>	Ratio	Mean, SD Median, IQR if nonnormal
<b>Hospital Anxiety and Depression Scale (HADS)</b>	Ratio	Mean, SD Median, IQR if nonnormal
<b>Impact of Events – Revised (IES-r)</b>	Ratio	Mean, SD
<b>The PTSD Checklist for DSM-5 (PCL-5)</b>	Ratio	Mean, SD
<b>PEACE Tool (0-10 Likert scale)</b> <b>Physical (9 items)</b> <b>Emotional (3 items)</b> <b>Autonomy (1 item)</b> <b>Communication (1 item)</b> <b>Economic (1 item)</b> <b>Transcendent (1 item)</b>	Ratio	Mean, SD Median, IQR if nonnormal

## APPENDIX G



### APPROVAL OF SUBMISSION (Expedited)

Date:	February 10, 2021
IRB:	MOD19090073-002
PI:	Tammy Eaton
Title:	Exploring Primary Palliative Care Needs in Survivors of Critical Illness
Funding:	None

The Institutional Review Board reviewed and approved the above referenced study. The study may continue as outlined in the University of Pittsburgh approved application and documents.

#### Approval Documentation

Review type:	Modification / Update
Approval Date:	2/10/2021
Approved Documents:	<ul style="list-style-type: none"><li>• Aim 1 telephone script - patient participant, Category: Data Collection;</li><li>• Aim 2 Interview script - Post-ICU clinic providers, Category: Data Collection;</li></ul>

As the Principal Investigator, you are responsible for the conduct of the research and to ensure accurate documentation, protocol compliance, reporting of possibly study-related adverse events and unanticipated problems involving risk to participants or others. The HRP Reportable Events policy, Chapter 17, is available at <http://www.hrpo.pitt.edu/>.

Continuing review (CR) can be submitted by clicking "Create Modification/CR" from the active study at least 5 weeks prior to the expiration date.

Clinical research being conducted in an UPMC facility cannot begin until fiscal approval is received from the UPMC Office of Sponsored Programs and Research Support (OSPARS).

If you have any questions, please contact the University of Pittsburgh IRB Coordinator, [Juliet Mancino](#).

*Please take a moment to complete our [Satisfaction Survey](#) as we appreciate your feedback.*

## APPENDIX H

### University of Pittsburgh Institutional Review Board

Human Research Protection Office  
3500 Fifth Avenue, Suite 106  
Pittsburgh, PA 15213  
Tel (412) 383-1480  
[www.hrpo.pitt.edu](http://www.hrpo.pitt.edu)

### APPROVAL OF SUBMISSION (Exempt)

Date:	March 25, 2020
IRB:	STUDY20030027
PI:	Tammy Eaton, MD
Title:	Review and analysis of characteristics, treatments, and outcomes of critical illness survivors and their families seen in a post-ICU clinic setting
Funding:	None

The Institutional Review Board reviewed and approved the above referenced study. The study may begin as outlined in the University of Pittsburgh approved application and documents.

#### Approval Documentation

Review type:	Initial Study
Approval Date:	3/25/2020
Exempt Category:	(4) Secondary research on data or specimens (no consent required)
Determinations:	<ul style="list-style-type: none"><li>• Waiver of HIPAA authorization</li></ul> The IRB has approved a waiver of HIPAA authorization to access protected health information.
Approved Documents:	<ul style="list-style-type: none"><li>• Exempt application form, Category: IRB Protocol;</li></ul>

As the Principal Investigator, you are responsible for the conduct of the research and to ensure accurate documentation, protocol compliance, reporting of possibly study-related adverse events and unanticipated problems involving risk to participants or others. The HRPO Reportable Events policy, Chapter 17, is available at <http://www.hrpo.pitt.edu/>.

Clinical research being conducted in an UPMC facility cannot begin until fiscal approval is received from the UPMC Office of Sponsored Programs and Research Support (OSPARS).

If you have any questions, please contact the University of Pittsburgh IRB Coordinator, [Amy Fuhrman](#).

Please take a moment to complete our [Satisfaction Survey](#) as we appreciate your feedback.

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