COPING STRATEGIES AND POST-TRAUMATIC STRESS SYMPTOMS IN
POST-ICU FAMILY MEMBERS

by

AMY B. PETRINEC

Submitted in partial fulfillment of the requirements
for the degree of Doctor of Philosophy

Dissertation Advisor: Barbara J. Daly, PhD, RN, FAAN

Frances Payne Bolton School of Nursing
CASE WESTERN RESERVE UNIVERSITY
May, 2014
CASE WESTERN RESERVE UNIVERSITY
SCHOOL OF GRADUATE STUDIES

We hereby approve the thesis/dissertation of

Amy B. Petrinec

Candidate for the Doctor of Philosophy degree*

Committee Chair
Barbara J. Daly, PhD, RN, FAAN

Committee Member
Christopher Burant, PhD

Committee Member
Polly Mazanec, PhD, RN

Committee Member
Alan Hoffer, MD

Date of Defense
February 25, 2014

*We also certify that written approval has been obtained
for any proprietary material contained therein.
Dedication

This dissertation is dedicated to my husband, Drazen Petrinec, and my children,

Benjamin and Emily.
# Table of Contents

Title Page ........................................................................................................ i
Committee Signatures Page .......................................................................... ii
Dedication ........................................................................................................ iii
Table of Contents ........................................................................................ iv
List of Tables ................................................................................................ vii
List of Figures ................................................................................................ viii
Acknowledgements ....................................................................................... ix
Abstract ........................................................................................................... x

## Chapter I: Introduction ............................................................................. 1
  Background .................................................................................................... 1
    Critical Care Environment ........................................................................ 2
    Chronically Critically Ill Patients ............................................................... 3
    Family Decision-Makers .......................................................................... 4
    Coping ........................................................................................................ 5
  Theoretical Framework .............................................................................. 6
    Transactional Model of Stress and Coping ............................................... 6
    Conceptual Framework ........................................................................... 8
    Conceptual Model .................................................................................... 12
    Assumptions ............................................................................................. 13
  Significance .................................................................................................. 13
  Purpose ......................................................................................................... 14
  Research Questions ..................................................................................... 14
  Long Term Objective .................................................................................. 15

## Chapter II: Literature Review ................................................................. 16
  Families Experiences of ICU Patients ....................................................... 16
    Qualitative Studies .................................................................................... 16
    Quantitative Studies ................................................................................ 19
    Interventions .............................................................................................. 22
    Summary of ICU Family Member Experiences ...................................... 24
Family Decision-Makers ................................................................. 25
History and Ethics ........................................................................ 25
FDM Experiences in the ICU ....................................................... 29
ICU FDM Stressors ....................................................................... 31
Summary of FDM Experiences .................................................... 34
Experiences of Family Members after ICU Hospitalization ............ 34
  Post-traumatic Stress Symptoms ............................................. 35
  Concurrent Psychological Symptoms ....................................... 41
  Interventions .......................................................................... 44
Coping ......................................................................................... 45
  Coping and PTSD ................................................................. 47
  ICU Family Coping ................................................................ 49
  Summary of Coping ................................................................ 53

Chapter III: Methods ..................................................................... 55
  Design ..................................................................................... 56
  Setting .................................................................................... 56
  Sample .................................................................................... 57
    Sample Criteria ..................................................................... 57
    Sample Size ......................................................................... 57
    Procedure ............................................................................. 58
  Measurement ............................................................................ 60
    Demographic Form ............................................................ 60
    Brief COPE Instrument ..................................................... 61
    Impact of Event Scale-Revised ........................................... 65
  Data Collection ........................................................................ 68
  Data Analysis .......................................................................... 69
  Threats to Validity .................................................................... 73
  Human Subjects ....................................................................... 73

Chapter IV: Post-traumatic Stress Symptoms in Post-ICU Family Members: Review and
Methodological Challenges .......................................................... 75
  Abstract ................................................................................... 76
  Introduction .............................................................................. 77
  Methodological Issues ............................................................ 79
    Sample .................................................................................. 79
    Setting ................................................................................. 81
    Inclusion and Exclusion Criteria ......................................... 82
    Measurement ........................................................................ 87
    Interventions ....................................................................... 94
  Discussion .............................................................................. 95
Chapter V: Coping Strategies and Post-traumatic Stress Symptoms in Post-ICU Family Decision-Makers

Abstract..........................................................................................................................101
Introduction ..................................................................................................................103
Methods .......................................................................................................................105
Sample and Setting.......................................................................................................105
Design............................................................................................................................106
Measurement ...............................................................................................................107
Data Analysis...............................................................................................................109
Results .........................................................................................................................110
Characteristics of Patients and FDMs .................................................................110
Post-traumatic Stress Symptoms ..............................................................................110
FDM Coping Strategies and Post-traumatic Stress Symptoms ..........................111
Predictors of PTSD Symptom Severity .................................................................112
Discussion ..................................................................................................................113

Appendix .......................................................................................................................127

A: DSM-IV Diagnostic Criteria for PTSD..............................................................127
B: Informed Consent Document ..............................................................................129
C: Patient Demographic Form ...............................................................................132
D: FDM Demographic Form ..................................................................................133
E: Brief COPE Form ................................................................................................135
F: IES-R Form ............................................................................................................137

Bibliography .................................................................................................................139
### List of Tables

<table>
<thead>
<tr>
<th>Table</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Studies Measuring PTSD in Family Members after ICU Hospitalization</td>
<td>39</td>
</tr>
<tr>
<td>2</td>
<td>Brief COPE Strategy and Subscale Reliability</td>
<td>63</td>
</tr>
<tr>
<td>3</td>
<td>Variables, Measures, and Instruments</td>
<td>68</td>
</tr>
<tr>
<td>4</td>
<td>Summary of Post-ICU Family PTSD Symptom Studies</td>
<td>98</td>
</tr>
<tr>
<td>5</td>
<td>Summary of Changes to PTSD Diagnostic Criteria DSM-IV to DSM-V</td>
<td>99</td>
</tr>
<tr>
<td>6</td>
<td>Patient and FDM Characteristics</td>
<td>121</td>
</tr>
<tr>
<td>7</td>
<td>Coping Strategies of FDMs and Comparison Over Time</td>
<td>122</td>
</tr>
<tr>
<td>8</td>
<td>Correlations (Pearson’s r) Between Coping Strategies and IES-R Score</td>
<td>123</td>
</tr>
<tr>
<td>9</td>
<td>T1 Coping Strategy Prediction of Post-traumatic Stress Symptom Severity</td>
<td>124</td>
</tr>
<tr>
<td>10</td>
<td>T2 Coping Strategy Prediction of Post-traumatic Stress Symptom Severity</td>
<td>125</td>
</tr>
</tbody>
</table>
# List of Figures

<table>
<thead>
<tr>
<th>Figure</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Figure 1.</td>
<td>Theoretical Model of Stress and Coping</td>
<td>7</td>
</tr>
<tr>
<td>Figure 2.</td>
<td>Conceptual Model of ICU FDM Stress and Coping</td>
<td>12</td>
</tr>
<tr>
<td>Figure 3.</td>
<td>Mediation of T2 Avoidant Coping Between Patient Death and PTSD Symptoms</td>
<td>126</td>
</tr>
</tbody>
</table>
Acknowledgements

This study was made possible through the support of many individuals. I thank the members of my committee, Dr. Christopher Burant, Dr. Alan Hoffer, and Dr. Polly Mazanec, for their expertise and support. I am particularly grateful for the wisdom, guidance, and support of Dr. Barbara Daly, my advisor and dissertation committee chair. Lastly, I am indebted to the staff nurses on the intensive care units as well as colleagues from the Frances Payne Bolton School of Nursing: Amy Lipson, PhD, Research Associate, Mary Leuchtag, LISW, Research Assistant, and Barbie Boveington-Molter, Department Assistant. I sincerely appreciate their dedication and enthusiastic support of this research endeavor.
Coping Strategies and Post-Traumatic Stress Symptoms in post-ICU Family Decision-Makers

Abstract

by

AMY B. PETRINEC

Family decision makers (FDMs) experience high levels of stress during the ICU hospitalization and are at risk for post-traumatic stress disorder (PTSD) symptoms after the death or discharge of the patient. There is empirical evidence demonstrating a relationship between coping strategy and PTSD symptoms. The purpose of this research study was to describe the coping strategies utilized by FDMs of ICU patients, examine how these coping strategies changed over time, and examine the relationship between ICU FDM coping strategy and later PTSD symptoms.

Seventy-seven adult ICU FDMs were the subject of this study. The mean IES-R score for the sample was 23.14 ($SD = 15.90$). FDM problem-focused coping scores were highest while avoidant coping scores were lowest at both measurement time points (Time 1: problem-focused $M = 3.10$, $SD = .74$; emotion-focused $M = 2.82$, $SD = .46$; avoidant $M = 1.55$, $SD = .34$; Time 2: problem-focused $M = 2.88$, $SD = .72$; emotion-focused $M = 2.66$, $SD = .53$; avoidant $M = 1.61$, $SD = .46$). The use of problem-focused ($t = 2.53$, $p = .01$) and emotion-focused ($t = 2.98$, $p < .01$) coping decreased over time while avoidant coping ($t = 1.29$, $p = .20$) use remained stable. Regression analysis using Time 1 coping strategies and patient/FDM characteristics significantly predicted later IES-R score ($R^2 = .30$; $F (7,69) = 4.14$, $p = .001$) with death of the patient the only independent predictor of PTSD symptom severity ($B = 12.47$, $p < .01$). Regression analysis using Time 2 coping strategies and patient/FDM characteristics was a better predictor of IES-R score ($R^2 = .42$).
.50; \( F (7,69) = 9.90, p < .001 \) with avoidant coping (B = 16.98, p < .01) and problem-focused coping (B = 6.26, p .01) being independent predictors of later IES-R score. Time 2 avoidant coping mediated the relationship between patient death and later PTSD symptom severity.

ICU FDM coping strategies appear to have a significant influence on later PTSD symptoms. An understanding of these coping strategies use may provide opportunities for focused nursing interventions to diminish later PTSD symptoms.
CHAPTER 1: INTRODUCTION

Critically ill patients have benefitted from technological advances in life sustaining treatments, but critical illness can significantly impact patients and their families. The chapter will discuss the need for family members to assume the role of family decision-maker (FDM) for critically ill patients. The decision-making role is a stressful experience, especially for families of chronically critically ill (CCI) patients who suffer a prolonged and unpredictable ICU course. This chapter will discuss the degree to which FDMs struggle after the decision-making process with a significant incidence of post-traumatic stress disorder (PTSD) symptoms. The magnitude of the problem will be presented by discussing the critical care environment, the prevalence and characteristics of CCI patients, the experience of family decision-making, and the relationship of coping strategy to PTSD symptoms. The theoretical and conceptual framework with appropriate conceptual linkages, meta-paradigm assumptions, and significance to nursing is presented. The transactional model of stress and coping provides the theoretical framework for the study and informs the proposed conceptual linkages. The purpose of this study is to evaluate coping strategies utilized by FDMs of ICU patients and the relationship between coping strategy and subsequent PTSD symptoms. Finally, the research questions and long term objectives are discussed.

Background

Family decision-makers (FDMs) of critically ill patients experience tremendous psychological distress during and after the intensive care unit (ICU) experience. Approximately thirty six percent of family members of ICU patients are taking anxiolytic or antidepressant drugs and over eight percent are taking psychotropic drugs on discharge
or death of their ICU family member (Lemiale et al., 2010). In the months following the ICU experience, family members, especially FDMs, are at risk for significant psychological distress including symptoms of generalized anxiety disorder, depression, panic disorder, PTSD, and complicated grief (Anderson, Arnold, Angus, Bryce, 2008; Anderson et al., 2009; Azoulay et al., 2005; Gries et al., 2010; Jones et al., 2004; Kross et al., 2011; Siegel, Hayes, Vanderwerker, Loseth, & Prigerson, 2008). Several authors have identified family member characteristics (age, gender, relationship to patient, previous decision-making) and patient ICU hospitalization factors (patient age, length of ICU stay, patient outcome) that influence post-ICU psychological distress (Azoulay et al., 2005; Gries et al., 2010; Kross et al., 2011). A task force of the Society of Critical Care Medicine proposed the term post intensive care syndrome-family (PICS-F) to describe new or worsening psychological symptoms in ICU family members after hospitalization (Needham et al., 2012). The recognition of the impact that illnesses can have on families echoes earlier recommendations by the Institute of Medicine (2001) for a health care system that supports family members.

**Critical Care Environment**

More than 6.5 million patients are admitted to the ICU each year in the United States, of whom 540,000 will die (Bion & Hall, 2007). Critical care evolved from the idea that patients with life threatening illness are better treated if grouped in specific areas of the hospital (Society of Critical Care Medicine, 2012). During the mid-nineteenth century, Florence Nightingale recognized the advantages of a separate area for recovery of post-surgery patients (Frost & Thompson, 1994). The first such unit in the United States opened at Johns Hopkins hospital in 1923 for postoperative neurosurgical patients.
The widespread need for intensive care units did not arise until the polio epidemics of the mid-twentieth century (Goldhill, 2005). During this period of time, the number of patients requiring “iron lungs” for ventilator support outstripped the available resources. Subsequently, some patients had tracheal tubes placed with medical students squeezing bags to ventilate patients. The mortality rate in the group of patients treated with positive pressure ventilation was clearly superior to those treated with the “iron lungs”. According to Goldhill (2005), the experience with polio patients led the development of equipment and facilities for looking after critically ill patients. By the late 1960’s, most US hospitals had at least one ICU (Society of Critical Care Medicine, 2012). The ability to care for critically ill patients has improved with steady advances in medical knowledge and technology. The demand for critical care has increased alongside the technological improvements, with older and sicker patients requiring increasingly complex life sustaining treatments. By 2007, the number of US adult critical care beds totaled 67,357 (Carr, Addyson & Kahn, 2010). The expense of running an ICU is approximately 20% of hospital costs despite representing only 10% of all hospital beds (Rivera, Dasta, & Varon, 2009). Furthermore, the doubling of persons over age 65 by the year 2030 is expected to substantially increase the need for critical care services (Angus et al., 2004).

**Chronically Critically Ill Patients**

The majority of patients admitted to an ICU survive the acute illness and leave the ICU after a brief stay (LeGall et al., 1995). In contrast, chronically critically ill (CCI) patients do not recover quickly and experience a prolonged and unpredictable ICU course (Carson & Bach, 2002). Depending on the CCI definition used, 5-10% of critically ill
patients are CCI patients. The hallmark of CCI patients is the need for mechanical
ventilation (Wiencek & Winkelman, 2010). Additionally, CCI patients manifest multi-
system organ dysfunction, increased length of ICU stay, impaired cognition, recurrent
episodes of instability, and high mortality. In the SUPPORT trial (1995), 38% of patients
who died spent at least 10 days in an ICU. The average ICU length of stay is 6.1 days for
all ICU patients compared to 15-25 days for CCI patients (Daly, Douglas, Kelley,
O’Toole, & Montenegro, 2005; Douglas, Daly, Gordon, & Brennan, 2002; Nierman,
2002; Rosenberg, Zimmerman, Alzola, Draoer, & Knaus, 2000; Society of Critical Care
Medicine, 2012). Furthermore, mortality rates are two to three times higher in CCI
patients than all ICU patients (Daly et al., 2005; Douglas et al., 2002; Society of Critical
Care Medicine, 2012; Teno et al., 2000). According to Hickman, Daly, and Douglas
(2010), “The acuity of CCI patients, their impaired cognitive status, and their poor
survival outcomes despite aggressive use of health care resources increase the complexity
of the decision-making process” (p. 411).

**Family Decision-Makers**

Patients in the ICU are often intubated, sedated, or neurologically compromised,
which precludes them from actively participating in the decision-making process (Ely et
al., 2001; McNicoll et al., 2003). Approximately 95% of ICU patients rely on a substitute
decision-maker, usually a FDM, to participate in communication and decision-making
with the health care providers at some point during their ICU illness (Prendergast,
Claessens, & Luce, 1998; Smedira et al., 1990). Burden and stress are universal and
pervasive experiences of these FDMs (Braun, Beyth, Ford, & McCullough, 2008;
Engstrom & Soderberg, 2004; Vig et al., 2007). CCI patients experience complex and
prolonged ICU courses, which magnify the uncertainty and difficulty of decision-making processes. Expected outcomes for CCI patients are poorly understood by FDMs and ICU physicians alike (Cox et al., 2009; Nelson et al., 2007). The risk of loss of a loved one and the difficulty of making end-of-life decisions add to the anxiety and stress of FDMs. Furthermore, family members of ICU patients experience a high prevalence of PTSD symptoms following the ICU experience (Anderson et al., 2008; Azoulay et al., 2005; Gries et al., 2010; Jones et al., 2004; Lautrette et al., 2007; Pillai et al., 2006; Pillai et al., 2010). Thus, interventions to support FDMs and reduce stress-related adverse effects of the role are needed.

**Coping**

The relationship of coping to psychological and physical health outcomes has been studied extensively in the behavioral literature (Penley, Tomaka, & Wiebe, 2002). Incorporating the ideas of Lazarus and Folkman (1984), researchers describe three categories of coping behavior: problem-focused, active emotion-focused, and avoidant emotion-focused (Ben-Zur, 2005; Carver, Scheier, & Weintraub, 1989; Roth & Cohen, 1986). In general, problem-focused and active emotion-focused coping are considered adaptive and positively correlated with improved mental health outcomes while avoidant coping is considered maladaptive and related to negative mental health outcomes (Coyne & Racioppo, 2000; Olff et al., 2005; Penley et al., 2002). Avoidant coping is a predictor of decreased psychological adjustment in individuals suffering from acute and chronic health problems and is associated with PTSD symptoms following a traumatic event (Glass et al., 2009; Krause, Kaltman, Goodman, & Dutton, 2008; Nielsen, 2003; Smith, Tarakeshwar, Hansen, Kochman, & Sikkema, 2009; Stanton, Danoff-Burg, & Huggins,
To date, no quantitative studies investigating the relationship between coping strategies utilized by ICU FDMs and subsequent PTSD symptoms have been undertaken.

**Theoretical Framework**

**Transactional Model of Stress and Coping**

Transactional stress and coping theory described by Lazarus and Folkman (1984) provides the theoretical structure for the current study. The theory assumes a continuous mutual interaction between an individual and the environment. Primary appraisal is the individual’s initial evaluation of what the environment or situation portends for the individual. If the environment is appraised as personally significant and threatening, secondary appraisal occurs weighing the environmental demands with available personal resources to deal with the demands of the threat. Personal factors (individual) and situation factors (environment) influence the appraisal process. Person factors that influence the appraisal process include personal commitments and beliefs. Situation factors that influence appraisal include novelty, predictability, uncertainty, ambiguity, and duration. Primary and secondary appraisal often occur simultaneously and are difficult to separate from each other. Stress arises from the cognitive appraisal that the demands of the environment are taxing and outweigh the personal resources of the individual. Stress is associated with emotions that arise after cognitive appraisal but are inseparable from the stress experience. Reappraisals are determined simultaneously by perceiving environmental demands and personal resources. They can change over time due to coping effectiveness, altered requirements, or improvements in personal abilities.
The experience of stress mobilizes coping efforts. Coping is defined as the cognitive and behavioral efforts to manage specific external or internal demands that are appraised to exceed the resources of the person. Lazarus and Folkman further divide coping into problem-focused coping (efforts to change or master the environment causing stress) and emotion-focused coping (efforts to change the individual’s emotional response to the stressor). Most people use problem-focused and emotion-focused coping simultaneously and to varying degrees depending on the stressor, the individual, and the situation. Successful coping manifests as psychological adaptation defined as the management of stress resulting in acceptable continued social functioning, morale, or somatic health. Inadequate coping would manifest as maladaptation. Figure 1 demonstrates the theoretical linkages of transactional stress and coping theory.

*Figure 1. Theoretical model of stress and coping (Lazarus & Folkman, 1984)*
**Conceptual Framework**

**Family decision-making.** The majority of critically ill patients require a surrogate, or substitute, decision-maker to make treatment decisions on their behalf due to mental incapacity from illness, medications, or delirium (Ely et al., 2001; Luce, 2003; McNicoll et al., 2003). The role of surrogate decision maker is most often assumed by a family member. There are several justifications for the use of family members as surrogate decision makers (Arnold & Kellum, 2003; Brock, 1996). First, the patient’s family should know the patient best and can put the illness event in the context of their shared life experience. The family is most likely to be able to identify the wishes and desires of the patient. Additionally, the family would be most likely to desire the “best treatment” for the patient. Finally, the family is a moral unit responsible for its members. A vast majority of individuals prefer close family members to make treatment decisions on their behalf (Kelly, Rid, & Wendler, 2012). A FDM may be: a) a family member previously designated by the patient as the legal durable power of attorney, b) a family member who was verbally chosen by the patient, but legal documentation does not exist, c) a relative, or friend, who is available and assumes the role of decision maker, or d) a legal guardian. Treatment decisions are made according to a bioethical hierarchy of standards widely accepted by legal and medical organizations: patients’ known wishes, substituted judgments, and best interests (Berger, DeRenzo, & Schwartz, 2008). The most desirable basis upon which to make treatment decisions is implementing the patient’s explicit and known wishes. In the absence of explicit wishes, FDMs are urged to use substituted judgment (determine what the patient would probably have wanted). Finally,
if it is unclear what the patient would have likely chosen, FDMs are asked to make decisions based on what is in the best interests of the patient.

**Stress.** Stress is the relationship between an individual and the environment in which environmental demands are appraised to exceed personal resources (Lazarus & Folkman, 1984). The interaction is mutual with continuous appraisal and reappraisal. In the current study, the appraisal of stress arises from the interaction between the FDM and the ICU environment. The role of ICU FDM has been repeatedly shown to be associated with high levels of stress in qualitative and quantitative studies (Auerbach et al., 2005; Braun, Beyth, Ford, & McCullough, 2008; Engstrom & Soderberg, 2004; Paparrigopoulos et al., 2006; Vig et al., 2007). Furthermore, there are person factors (variables unique to the individual) and situation factors (variables unique to the environment) that influence stress appraisal and coping.

**Coping Strategy.** Coping is the cognitive and behavioral efforts used to manage demands appraised as stressful (Lazarus & Folkman, 1984). As explained previously, coping strategies are different domains of coping and are broadly divided into problem-focused coping and emotion-focused coping. All coping strategies are used simultaneously and to varying degrees.

**Problem-focused coping.** Problem-focused coping strategies are efforts utilized by the individual experiencing stress to change or master the environment causing stress. The individual takes an active role in lessening the demands of the environment or increasing their personal resources to meet the needs of the environment. Examples of problem-focused coping include information seeking, improving personal skills, problem-solving, and planning.
**Active emotion-focused coping.** Active emotion-focused coping are efforts directed at changing the individual’s emotional response to environmental demands. This type of coping represents an active effort on the part of the individual to change the emotional significance of stressful events. Examples include positive reframing, humor, acceptance, and use of emotional support.

**Avoidant emotion-focused coping.** Avoidant emotion-focused coping are efforts directed at suppressing or disengaging from the emotional significance of stressful events. The individual is attempting to distance him or herself from the emotional response to stress rather than change the emotional response. Examples of avoidant coping include self-blame, substance use, behavioral disengagement, self-distraction, and denial.

**Post-traumatic stress disorder (PTSD).** Post-traumatic stress disorder (PTSD) can be characterized as a prolonged stress response syndrome (Wilson, 2004). According to the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV), PTSD occurs after exposure to a stressor in which the person experiences or witnesses events that threaten death or serious harm to the individual or others (American Psychiatric Association, 2000). The individual experiences feelings of fear, helplessness, or horror during exposure to the stressor. The exposure to the stressor results in three symptom clusters that must be present for at least a month after exposure to the stressor: intrusive recollections, avoidant/numbing symptoms, and hyper-arousal symptoms. The symptoms cause significant distress or impairment in personal, social, or occupational functioning. Appendix A outlines the essential diagnostic criteria and symptom clusters of PTSD.
The prevalence of PTSD in the U. S. population is estimated to be 6.8% with women demonstrating higher rates than men (Kessler, Chiu, Demler, & Walters, 2005). First described in soldiers, PTSD has been described following exposure to many different traumatic events such as personal assault, sexual assault, confinement, and natural disasters (Javidi & Yadollahie, 2010). More recently, PTSD is recognized as a consequence of many different acute and chronic illness experiences in patients and their family members (Alonzo, 2000; Berna, Vaiva, Ducrocq, Duhem, & Nandrino, 2012; Elklit & Blum, 2011; Kross, Gries, & Curtis, 2008; Nielsen, 2003). Alonzo (2000) cites sudden unexpected illness onsets, invasive medical therapies, and cumulative adversity as stressors that potentiate the onset of post-traumatic stress symptoms. PTSD is associated with substantial morbidity and diminished quality of life (Pace & Heim, 2011; Seedat, Lochner, Vythilingum, & Stein, 2006). PTSD patients lose an estimated $3 billion dollars annually due to disability (Kessler, 2000).

Acute stress disorder (ASD) must be differentiated from PTSD. ASD and PTSD are the only two psychiatric diagnoses in which a traumatic exposure is integral to the diagnostic criteria. ASD can be a precursor of PTSD but differs in two fundamental ways: a) the diagnosis of ASD can be made only within the first month following the traumatic event and b) requires three symptoms of dissociation. PTSD does not include a dissociative cluster. The relationship between ASD and PTSD is unclear. Bryant, Creamer, O’Donnell, Silove, and McFarlane (2008) conducted a multisite study to determine the relationship between ASD and PTSD and reported that the majority of people who develop PTSD do not initially meet the ASD diagnostic criteria. In a review of 22 studies to determine ASD’s ability to predict PTSD, Bryant (2011) reported that
most of the studies indicated that at least half of adults diagnosed with ASD subsequently developed PTSD demonstrating reasonable positive predictive power. However, the sensitivity of ASD was poor, showing that the majority of individuals who eventually developed a diagnosis of PTSD initially did not meet the criteria for ASD.

**Conceptual model**

In this study, the FDM interacts with the ICU environment. The resultant appraisal of stress mobilizes coping in response to stress. Coping is the independent variable of the study and is conceptualized as the different coping strategies employed by the FDM. The FDM simultaneously utilizes all three coping strategies to greater or lesser degrees. The coping strategies result in psychological adaptation to stress with varying degrees of success. Maladaptive coping manifests as psychological distress, conceptualized as symptoms of PTSD (dependent variable).

![Diagram](Figure 2. Conceptual model of ICU FDM stress and coping.)
Assumptions

There are three meta-paradigm assumptions in the study: transaction, process, and context. First, the individual environment interaction is transactional in nature. The individual and the environment influence each other through a continuous interactive process. This transaction is subject to a process of appraisal and reappraisal with emotions following but inseparably linked to cognitions. The meaning of the transaction is determined by the underlying context, which drives the experienced cognitions and emotions.

Significance

The experience of FDMs of ICU patients is incompletely understood. The literature identifies the role with significant psychological distress, which places the FDM at risk for PTSD symptoms. Stress symptoms can have a debilitating effect on an individual’s ability to function socially or make important decisions. Family members of patients discharged from the ICU are often assisting with the care of these patients at home while concurrently vulnerable to adverse psychological outcomes.

Nurses are on the front lines of caring for patients and their families. ICU nurses are often the most frequent point of contact between family and the health care team. The close contact and rapport place nurses in a unique position to assess the needs of patients and their families. The relationship between family member and nurse often sets the tone for the ICU experience more than any other staff (Linnarsson, Bubini, & Perseius, 2010). Nurses are seen as the members of the health care team providing continuous and holistic care and are identified as the key resource for ICU family members (Jamerson et al., 1996). Insight into coping strategies utilized by FDMs and the relationship between
coping strategies and subsequent PTSD symptoms may provide nurses an opportunity to identify FDMs at risk for PTSD. Furthermore, early identification of PTSD risk may allow for tailored interventions in ICU FDMs during the ICU illness in order to reduce acute stress as well as post-traumatic stress. Training individuals in the use of effective coping skills is a component of treatment for PTSD (Foa, Davidson, & Francis, 1999). Finally, identification and early intervention during the ICU illness for FDMs at risk for PTSD may improve communication between FDMs and the healthcare providers, which in turn, may improve the quality and timeliness of decision-making.

**Purpose**

The purposes of the proposed study are to determine: (a) the coping strategies utilized by FDMs of ICU patients early in the ICU admission and 30 days following hospital discharge or death of the patient for whom the FDM made decisions and (b) the relationship between coping strategies utilized by FDMs during and after the decision-making experience and PTSD symptoms experienced by FDMs 60 days after hospital discharge or death of the patient for whom the FDM made decisions.

**Research Questions**

The purposes of the study will be met by answering the following research questions:

**RQ1:** What are the coping strategies utilized by FDMs of ICU patients on study enrollment (3 to 5 days after ICU admission) and 30 days following hospital discharge or death of the patient for whom the FDM made treatment decisions?
**RQ2:** Do coping strategies utilized by FDMs of ICU patients change from study enrollment (3 to 5 days after ICU admission) to 30 days following hospital discharge or death of the patient for whom the FDM made treatment decisions?

**RQ3:** What are the levels of PTSD symptoms experienced by FDMs of ICU patients at 60 days following hospital discharge or death of the patient for whom the FDM made treatment decisions?

**RQ4:** What is the relationship between coping strategies utilized by ICU FDMs and the experience of post-ICU (60 days following hospital discharge or death of the patient for whom the FDM made treatment decisions) PTSD symptoms?

**RQ5:** To what extent do FDM coping strategies predict post-ICU FDM PTSD symptoms?

**RQ6:** To what extent do FDM coping strategies predict post-ICU FDM PTSD symptoms controlling for FDM and ICU patient factors?

**Long Term Objective**

The long term objective of this study is to provide a better understanding of the factors that predispose ICU FDMs to the development of PTSD symptoms in order to: (a) identify opportunities for early identification of FDMs at risk for PTSD and (b) provide opportunities for PTSD prevention and early treatment intervention.
CHAPTER II: LITERATURE REVIEW

Since Hampe (1975) first described the needs of grieving spouses in a hospital setting, a growing body of literature has arisen describing the needs and experiences of family members of critically ill patients. The chapter will review and summarize the body of literature investigating the experiences of ICU family members. The role of FDM is discussed including the history and ethics of family decision-making, the experiences of ICU FDMs, and the stressors associated with the FDM role. The stress experienced by ICU families can result in symptoms of post-traumatic stress after the ICU hospitalization. The prevalence of post-ICU PTSD symptoms, the associated risk factors for developing post-ICU PTSD symptoms, and concurrent post-ICU psychological symptoms are summarized. Furthermore, coping strategy is associated with PTSD symptoms following a variety of different stressors. The relationship between coping strategy and PTSD symptoms is discussed. Finally, a summary of literature investigating coping in family members of ICU patients is presented.

Families Experiences of ICU Patients

Qualitative Studies

Qualitative research describes admission to the ICU as a time of tremendous uncertainty, chaos, turmoil, and stress for family members of the ICU patient (Agard & Harder, 2007; Engstrom & Soderberg, 2004; Jamerson et al., 1996; Johansson, Fridlund, & Hildingh, 2005; Soderstrom, Saveman, Hagberg, & Benzein, 2009). The uncertainty of the initial ICU experience results in feelings of helplessness and disorientation (Johansson et al., 2005; Lee & Lau, 2003). Several studies echoed the theme of diminished comprehension and understanding (Eggenberger & Nelms, 2007; Soderstrom et al.,
The family views the critical illness as a “crisis situation” because of “uncertain prognosis, fear of death or permanent disability, role changes, financial concerns and unfamiliarity of the intensive care environment” (Bijttebier, Vanoost, Delva, Ferdinande, & Frans, 2001, p. 160). A reflection by Crunden (2010), an ICU nurse in Great Britain, following ICU hospitalization of his wife, recalls feeling “dazed and confused” and “could hardly comprehend what was happening” during the initial days of his wife’s ICU course despite being quite familiar with the ICU environment.

Following the initial shock of ICU admission of a family member to an ICU, qualitative studies relate tremendous emotional lability, described by Linnarsson, Bubini, and Persius (2010) as an “emotional rollercoaster” (p. 3104). Family members describe feelings of hope and despair occurring simultaneously or alternating between the two emotions during the same ICU visit (Engstrom & Soderberg, 2004; Kleiber et al., 1994; Soderstrom et al., 2009). However, the majority of described emotions had a negative connotation: anxiety, fear, discouragement, anger, numbness, sorrow, and guilt (Agard & Harder, 2007; Eggenberger & Nelms, 2007; Engstrom & Soderberg, 2004; Jamerson et al., 1996; Johansson, Fridlund, & Hildingh, 2005; Soderstrom, Saveman, Hagberg, & Benzein, 2009). The persistence of the stress, uncertainty, and emotional turmoil can ultimately result in feelings of physical exhaustion and psychological desperation (Delva, Vanoost, Bijttebier, Lauwers, & Wilmer, 2002; Eggenberger & Nelms, 2007).

Jamerson and colleagues (1996) identified several themes or stages in response to a family member in the ICU. The first stage, hovering, is the initial state of confusion, stress, and uncertainty. The idea of being present with the patient and maintaining a vigil early in the ICU hospitalization is a common emotional theme (Agard & Harder, 2007;
Eggenberger & Nelms, 2007; Engstrom & Soderberg, 2004). Jamerson et al. (1996) further describe *information seeking* as the response stage used to move out of the hovering state and to identify the patient’s progress. *Tracking* is the process of observing and analyzing patient care along with evaluating family satisfaction with the environment and caregivers. Finally, garnering of resources is the act of acquiring resources for themselves and their family member in order to meet perceived needs. The stages identified by Jamerson et al. (1996) broadly describe the initial stress experience (hovering) followed by appraisal/reappraisal (tracking) and types of coping (information seeking and garnering of resources) with the stress of the ICU experience.

The sample sizes of the studies reviewed ranged from one to 41 patients. The qualitative methods included unstructured interviews, semi-structured interviews, narrative interviews, thematic analysis, grounded theory, and hermeneutic phenomenology. Although summarizing qualitative findings can risk the loss of the rich contextual experiences described by family members, several generalities can be gleaned from qualitative descriptions of ICU family member experiences. First, the initial admission to the ICU is highly stressful due to the uncertainty, unfamiliarity of the environment, and risk of personal loss. The initial stages of experience are associated with confusion and diminished comprehension of events. Emotional responses vacillate greatly but dysphoric feelings tend to predominate given the unpredictable nature of critical illness and the persistent fear of losing a loved one. General descriptions of coping and adapting to the situation follow the initial reaction.
Quantitative Studies

Two studies quantify emotional reactions and general psychologic symptoms in family members of ICU patients (Perez-San Gregorio et al., 1992; Plaszewska-Zywko & Gazda, 2012). Perez-San Gregorio and colleagues (1992) evaluated 72 family members of trauma patients admitted to an ICU 48 hours after admission with a scheduled interview and the Clinical Analysis Questionnaire (CAQ), an instrument used to measure psychopathologic aspects of personality. A psychologist, unbeknownst to family members, performed the interview and the CAQ. The authors demonstrated a high prevalence of psychological symptoms when compared to a control group including hypochondria (83%), paranoia (76.7%), suicidal depression (75.3%), apathy-withdrawal (72.6%), low energy depression (64.4%), anxious depression (56.2%), and schizophrenia (50.7%). Women (n=40) obtained statistically significant higher scores ($p < .05$) in hypochondria, anxious depression, and low energy depression when compared to men (n=33). Plaszewska-Zywko and Gazda (2012) measured emotional response to ICU admission in 60 family members using the Courtauld Emotional Control Scale. The prevalent emotions were anxiety, uncertainty, fear, depression, and nervousness. Women experienced stronger negative emotions than men.

Two studies by nurse researchers examined the behavioral responses of family members to critical care hospitalization (Halm et al., 1993; Van Horn & Tesh, 2000). The descriptive studies had small sample sizes. Halm et al. (1993) had family members complete the Iowa ICU Family Scale, a self-report tool measuring sleep, eating, activity, family role, and support behaviors, daily during the first week of ICU admission and then weekly until discharge from the ICU. Stress was highest at the time of admission,
reached a plateau at day 6 and then dropped steadily until discharge. Furthermore, family members reported less sleep, poorer quality of sleep, decreased nutritional intake, and an increased use of cigarettes, alcohol, and over-the-counter and prescription medications. Van Horn and Tesh (2000) found similar changes in sleeping and eating patterns as well as identifying family members enduring multiple concurrent stressors.

High levels of stress among family members of ICU patients is commonplace (Auerbach et al., 2005; Chui & Chan, 2007; McAdam, Dracup, White, Fontaine, & Puntillo, 2010; Paparrigopoulos et al., 2006; Pielmaier, Wlader, Rebetez, & Maercker, 2011; Pillai, Aigalikar, Vishwasrao, & Husainy, 2010; Pillai et al., 2006). Samples were composed of family members recruited from trauma, surgical, and general medical ICUs. Levels of stress were measured between 24 hours of admission and up to 23 days after admission with the majority within a week of ICU admission. Measurement tools used to measure stress during the ICU admission included the Impact of Event Scale (IES) in two studies, the Impact of Event Scale-Revised (IES-R) in four studies, and the Acute Stress Disorder Scale (ASD) in one study. The studies unanimously described high levels of stress among family members during the ICU admission. Auerbach et al. (2005) demonstrated high levels of acute stress among 40 family members of patients admitted to a surgical trauma ICU. Using the Acute Stress Disorder Scale, stress levels in family members on admission of a loved one to the ICU were as high as stress levels of individuals admitted to an inpatient psychiatric unit for treatment of PTSD. Two studies (n = 40 and 32 respectively) measured stress levels early in the ICU course and at the time of discharge (Auerbach et al., 2005; Paparrigopoulos, et al., 2006). Although stress levels were highest early in the ICU course, family members continued to have
significant levels of stress at the time of their family member’s discharge from the ICU. Female gender was the most commonly associated factor with higher levels of stress (Chui & Chan, 2007; McAdam et al., 2010; Paparrigopoulos et al., 2006; Pielmaier et al., 2011). Chui and Chan (2007) identified lower educational attainment, unexpected ICU illness, and length of ICU stay as independent factors for higher levels of stress in a sample of 133 Chinese family members. Paparrigopoulos et al. (2006) recognized trait anxiety as a significant predictor of the severity of stress symptoms. Pillai et al. (2010) described ability to pay for hospitalization and the Hospital Anxiety and Depression Scale (HADS) score as independent predictors of stress levels experienced by a sample of 166 ICU family members.

Family members of critically ill patients also demonstrate a high prevalence of anxiety and depression during the ICU illness (Bailey, Sabbagh, Loiselle, Boileau, & McVey, 2010; McAdam et al., 2010; Paparrigopoulos et al., 2006; Pillai et al., 2010; Pochard et al., 2005). Anxiety and depression were measured concurrently using the HADS instrument in three studies (McAdam et al., 2010; Pillai et al., 2010; Pochard et al., 2005). Paparrigopoulos et al. (2006) measured anxiety (n = 32) using the Spielberger’s State-Trait Anxiety Inventory (STAI) and depression using the Center for Epidemiological Studies Depression Scale (CES-D). Bailey et al. (2010) measured anxiety (n = 29) using the STAI instrument without measuring depression. Two of the studies using the HADS instrument measured anxiety and depression (n = 74 and 166 respectively) within a week of ICU admission (McAdam et al., 2010; Pillai et al., 2010). The prevalence of family members with clinically significant anxiety symptoms (HADS anxiety score > 10) was 42-48% and clinically significant depression symptoms (HADS
depression score > 10) was 16-32%. Pochard et al. (2005) measured anxiety and depression symptoms using the HADS instrument in 544 ICU family members at death or discharge of the patient. Anxiety or depression was present in 75.5% of all family members and 82.7% of spouses. Patient age, patient severity of illness measured by the Simplified Acute Physiology Score II (SAPS II), and being a spouse were independently predictive of anxiety. Patient age, SAPS score, and patient death were predictive of depression. Studies measuring anxiety using the STAI demonstrated high levels of anxiety in family members early in the ICU course (Bailey et al., 2010; Paparrigopoulos et al., 2006). Furthermore, Paparrigopoulos et al. (2006) described depression symptoms using the CES-D in 97% of family members after ICU admission. Before discharge from the ICU, 87% of family members had depressive symptoms with trait anxiety being the most significant predictor of severity of depressive symptoms.

**Interventions**

The results of interventions to reduce family member anxiety during an ICU illness have been mixed. Halm (1990) used a quasi-experimental design to evaluate the effect of support groups on family member anxiety during critical illness. The study showed no difference in anxiety levels between the experimental and control groups. Daly, Kleinpell, Lawinger, and Casey (1994) found no effect of an information pamphlet and a family group session on ICU family anxiety levels or scores on the Critical Care Family Needs Inventory. Kloos and Daly (2008) examined the effect of a family-maintained journal on anxiety of family members of patients undergoing coronary artery bypass surgery. State and trait anxiety was measured in family members pre-operatively using the State-Trait Anxiety Inventory. The State Anxiety Inventory was completed on
postoperative day three. Although anxiety levels were decreased at the postoperative time point, there was no difference in anxiety levels between the journal and control groups.

Chien, Chiu, Lam, and Ip (2006) used a quasi-experimental design to evaluate the effect of a needs-based education program on Chinese ICU family anxiety levels and need satisfaction. Family members were administered the Chinese version of the Critical Care Family Needs Inventory (C-CCFNI) at the time of ICU admission of their family member. The experimental group received an individual education program based on the results of the CCFNI while the control group received the usual ICU orientation by ICU nurses. Anxiety levels and need satisfaction were measured before and after the ICU orientation using the Chinese versions of the STAI and CCFNI respectively. Family members in the experimental group had significant reductions in levels of anxiety, $F(1, 62) = 5.63$ ($p = .006$), and a significant increase in level of satisfaction of family needs, $F(1, 62) = 5.61$ ($p = .006$). The sample sizes of the studies reviewed ranged from 55 to 91 family members.

Transfer of a patient from the ICU can produce significant psychological symptoms for family members referred to as “transfer anxiety” (Schwartz & Brenner, 1979). Anxiety results from feelings of abandonment and perceptions of a lower level of care and attention (Chaboyer, Kendall, Kendall, & Foster, 2005; Cutler & Garner, 1995). Brooke, Hasan, Slark, and Sharma (2012) published a meta-analysis regarding the efficacy of information interventions in reducing transfer anxiety of ICU family members. They included randomized controlled trials comparing intervention to reduce transfer anxiety measured by STAI with standard care. Their analysis identified five studies enrolling 629 patients. Using pooled odds ratios (ORs), family members’ transfer
anxiety was significantly reduced in the intervention arm of information provision (OR, 1.70; \( p = .01 \)) compared with the control arm (OR, 0.42; \( p < .001 \)).

**Summary of ICU Family Member Experiences**

ICU hospitalization can have profound psychological effects on the patient’s family members. Qualitative and quantitative studies identify significant uncertainty, fear, stress, and anxiety shortly after admission. These early emotions often temporarily result in diminished cognitive capacity of the family members while they try to adjust to the ICU environment. Ongoing stressors, appraisal and reappraisal of the ICU experience and mobilization of coping resources follow the initial shock of the ICU admission. Although emotional responses are labile, the predominant types of emotions are negative. High levels of stress are unanimously described along with a significant prevalence of anxiety and depression symptoms. Family member factors associated with symptoms of stress, anxiety, and depression include female gender, trait anxiety, and lower levels of education. Patient factors associated with higher levels of stress anxiety, and depression symptoms include: age of the patient, severity of patient’s illness, length of ICU stay, and death.

Intervention studies to diminish stress, anxiety, or depression symptoms in ICU family members during the ICU admission have been few and focused largely on diminishing anxiety. One of four intervention studies demonstrated a decrease in anxiety levels in the experimental group. However, several studies have shown information interventions to significantly decrease ICU transfer anxiety in ICU family members. No intervention studies were identified that evaluated depression or stress during the ICU hospitalization.
Sessler (2005) best summarizes the ICU family experience. The hospital is not a familiar place and the sights, sounds and smells of the ICU remind one that within this intimidating place, lives hang in balance. Although the doctors and nurses are kindhearted and competent, news of progress is infrequent, often fragmented and at times conflicting. The waiting room is wanting, with little privacy for conversation or to collect one's thoughts. There is a murmur of hushed conversation, punctured by occasional sounds of grieving or forced levity. Soon the battle is apparently turning: the threat of the immediately life-threatening illness has lessened. However, the protracted campaign of chronic critical illness, with new enemies, such as, nosocomial infections emerge, taxing one's endurance and willpower. Sleep is scarce and fragmented and diet consists of coffee and fast food. Mail piles up and calls go unreturned. Simple joys are not nearly as neither simple nor as joyful. Gut wrenching decisions about critical issues must be made and often provoke emotional conflict and second-guessing, both internally and among the collective family. Usually, there eventually is sufficient recovery for graduation from the ICU to new challenges, but often the devastating loss of this beloved one occurs despite the efforts and anguish of many. (p. 1101)

Family Decision-Makers

History and Ethics

The beginnings of ethical and legal debates about decision-making for incapacitated patients can be traced to the use of mechanical ventilation as a life
sustaining treatment in the late 1950’s (Truog, 2008). Prior to the use of ventilators, respiratory failure lead to cardiac arrest and death while severe neurological injury led to apnea and death. Mechanical ventilation allowed physicians to keep these patients alive. According to Brock (1994), the first ethical standard of medical practice is to protect the autonomy of the competent patient. The individual has a right to determine what is and is not done to his or her body. However, significant challenges to autonomy occur when critically ill individuals are unable to participate in decision-making about their care, especially the continuation or removal of life sustaining therapies when their wishes are not known.

Surrogate, or substitute, decision-making was first legally recognized in the *In re Quinlan* case of 1976 when the New Jersey Supreme Court ruled that surrogate decision-making was an extension of patient autonomy. The ruling stated that a person’s right to make decisions for themselves becomes meaningless if surrogates cannot exercise that right for them when the person is incapacitated. Partially in response to Quinlan and several other controversial end-of-life court decisions in the 1970’s and 1980’s, Congress passed the Patient Self-Determination Act (PSDA) in 1990 (Allen-Burge and Haley, 1997). The PSDA requires institutions that receive federal money for health care to inform patients of their rights to autonomy and to refuse medical treatment. The intent of the legislation was to increase awareness of end-of-life treatment issues and use of advance directives (Emanuel, Weinberg, Gonin, Hummel, & Emauel, 1993; Kapp, 1994). Federal and state law has gradually codified the authority of family members to make medical decisions for incapacitated patients when advance directives are not present.
Brock (1996) describes several moral and ethical grounds for family members serving as surrogate decision-makers. First, authority for decision-making has been legally given to family members by a democratic political process. As a democratic society, we have recognized families as appropriate decision-makers for incapacitated individuals. Secondly, the patient can exercise his or her self-determination by establishing a Durable Power of Attorney for Health Care (DPAHC). The DPAHC promotes individual autonomy by designating who is to be the surrogate and what preferences are to guide the surrogate’s decision-making. Third, a family member will usually know the patient best and consequently will make the best decisions on behalf of the patient. Fourth, except for the incompetent person, the family member will be most affected by the treatment decisions to be made and have a significant stake in the decision-making process. Fifth, distributive justice requires consideration of the effects of treatment decisions on the family. Restated, the family will bear the burden and consequences of certain treatment decisions and, therefore, should have decision-making authority. Finally, the family is an independent moral unit with decision-making responsibility for its members. The family is a recognized societal entity with a mandate to champion the welfare of its members. Kelly, Rid, and Wendler (2012) presented a systematic review of individuals’ goals for surrogate decision-making. The review included qualitative and quantitative studies providing data on 22,828 individuals. The purpose of the review was to evaluate how adults want treatment decisions to be made for them during periods of incapacity. Most of the respondents were elderly and seriously ill.
The authors presented three conclusions: (a) a majority of individuals wants a close family member to act as their surrogate decision-maker with the belief that the family member would know which treatments the individual would want, (b) individuals want to reduce the burden on their families, and (c) there is significant variation in the amount of leeway individuals want the surrogate to have in the decision-making process.

In the United States, the vast majority of surrogate decision-makers are family decision-makers (FDMs). FDMs make up to 75% of medical decisions for patients hospitalized with life-threatening illness and 44-69% of decisions for nursing home patients (Hiltunen, Medich, Chase, Peterson, & Forrow, 1999; Kim, Karlawish, & Caine, 2002). Approximately 95% of ICU patients cannot make treatment decisions for themselves (Prendergast, Claessens, & Luce, 1998; Smedira et al., 1990). Decision-making is composed of a bioethical hierarchy of three standards endorsed by medical and legal governing organizations (Berger et al., 2008). Decision-makers should first institute the explicit wishes of the patient. These wishes are commonly referred to as advance directives and often enumerated in a living will completed by the patient before his/her current state of mental incapacity. Wishes also can be informally communicated to family members. Despite increasing public awareness and legislative attempts to increase the use of advance directives, the vast majority of Americans do not compose a living will or advance directives (Fagerlin & Schneider, 2004). In a study by Pollack, Morhaim, and Williams (2010), a representative sample of 1195 Maryland adults were interviewed over the telephone. Approximately 34% reported having advance directives with individuals over the age of 65 more likely to have them compared to younger adults. In the absence of explicit wishes of the patient, FDMs are called upon to make decisions using
substituted judgment (Berger et al., 2008). FDMs make decisions based on their best estimate of what decision the patient would have made. Finally, if the FDM is unsure of what the decision the patient would have made, the bioethical standard of best interests is used for decision-making. The FDM makes decisions that are in the best interests of the patient.

In summary, surrogate decision-makers are called upon to make decisions on behalf of incapacitated patients and from a legal viewpoint, represent an extension of patient autonomy. The majority of surrogate decision-makers are FDMs. There are ethical and moral grounds to support family members as appropriate substitute decision-makers. Furthermore, individuals overwhelmingly endorse close family members as desired surrogates. The vast majority of ICU patients require surrogate decision making by an FDM. The standards by which FDMs are called upon to make decisions follow an accepted bioethical hierarchy.

FDM Experiences in the ICU

A significant body of qualitative research describes the unique experiences of ICU FDMs (Abbott, Sago, Breen, Abernethy, & Tulsky, 2001; Apatira et al., 2008; Braun et al., 2008; Chambers-Evans & Carnevale, 2005; Hayes, 2003; Jeffers, 1998; Kirchhoff et al., 2002; Limerick, 2007; Radwany et al., 2009; Schenker et al., 2012; Tilden, Tolle, Nelson, Thompson, & Eggman, 1999; Vig et al., 2007; Weigand, 2008). The sample sizes of the studies were generally small (n = 8 to 56) except for Apatira et al. (2008) which included 179 decision makers. The majority of the studies used individual structured or semi-structured interviews. Braun et al. (2008) and Kirchhoff et al. (2002) utilized a focus group setting. Schenker et al. (2012), Apatira et al. (2008), and Weigand (2008)
interviewed FDMs during the ICU experience. The remaining authors administered the interviews and focus groups at varying times after the ICU experience (within 4 weeks to 15 years). Although the studies examined aspects of various treatment decisions, they all examined the impact of end-of-life (EOL) decisions.

FDMs unanimously identified stress as an unavoidable component of ICU decision making (Abbott et al., 2001; Braun et al., 2008; Chambers-Evans & Carnevale, 2005; Hayes, 2003; Jeffers, 1998; Kirchhoff et al., 2002; Limerick, 2007; Radwany et al., 2009; Schenker et al., 2012; Tilden et al., 1999; Vig et al., 2007; Weigand, 2008). Anxiety was also identified with the FDM role (Abbott et al., 2001; Braun et al., 2008; Chambers-Evans & Carnevale, 2005; Kirchhoff et al., 2002). The most commonly identified factor contributing to FDM stress and anxiety is the feeling of being responsible for the life or death of a loved one (Braun et al., 2008; Hayes, 2003; Jeffers, 1998; Kirchhoff et al., 2002; Limerick, 2007; Radwany et al., 2009; Schenker et al., 2012; Tilden et al., 1999; Weigand, 2008). FDMs describe sentiments such as “I’ve always dreaded being in a situation like this, where you do have to take responsibility for decisions you make about somebody else” and “I don’t want to have to choose his life or death” (Schenker et al., 2012, p. 1660). Tilden et al. (1999) used the term “shouldering the surrogate role” with respondents commonly using the terms “difficult”, “intense”, “painful”, and “overwhelming” (p. 435). Radwany et al. (2009) reported that 39% of FDMs experienced guilt related to decision making. Several authors described retrospective feelings of guilt among FDMs and concerns about having done the “right thing” or prolonging suffering for their loved one (Chambers-Evans & Carnevale, 2005; Hayes, 2003; Jeffers, 1998; Kirchhoff et al., 2002; Limerick, 2007; Tilden et al., 1999).
Furthermore, FDMs often have a sense of loneliness, that no other person carries the burden of making the “right” decision except the FDM (Jeffers, 1998; Tilden et al., 1999; Weigand, 2008).

Anderson, Arnold, Angus, and Bryce. (2008) described anxiety and depression levels in ICU FDMs using the HADS instrument. A small sample of 50 FDMs was assessed for anxiety and depression upon enrollment, which occurred within the first week after the patient was admitted to the ICU. The prevalence of anxiety was 42% and the prevalence of depression was 16%. In a secondary analysis of their data, Anderson et al. (2009) compared the prevalence of anxiety and depression to the decision-making preferences of the FDMs. Decision-making preference was determined by administration of the Control Preferences Scale at the time of study enrollment. Over half (58%) of the FDMs preferred shared decision-making, 25% preferred an active decision-making role, and 17% preferred a passive role. In the groups that preferred an active, shared, or passive role, respectively, the anxiety rates were 42%, 25%, and 88% ($p = .007$) and depression rates were 8%, 11%, and 50% ($p = .026$). Despite a small sample size, the authors concluded that FDMs with a preference for a passive decision-making role were most likely to be anxious and depressed.

**ICU FDM Stressors**

Many different stressors influence the experience of ICU FDMs. Vig et al. (2007) identified four areas that affected the family decision-making experience: (a) surrogate characteristics and life circumstances (competing family responsibilities, poor decision maker health, increased physical distance between the FDM and the patient, and financial barriers), (b) surrogates’ social networks (family conflict), (c) surrogate-patient
relationship (not being able to follow the patient’s preferences, not knowing the patient’s preferences, emotional attachment to the patient, and weighing patient’s preferences against patient’s quality of life), and (d) surrogate-clinician communication and relationship (inadequate or conflicting information, too many involved clinicians).

Several authors describe family discord or lack of agreement about decision making as a stressor to FDMs (Limerick, 2007; Schenker et al., 2012; Weigand, 2008). Majesko, Hong, Weissfeld, and White (2012) prospectively interviewed 230 ICU FDMs about their perceived ability to act as a FDM. Independent predictors of lower confidence in the FDM role were lack of prior decision maker experience, no prior discussions with the patient about treatment preferences, and poor quality of communication with the ICU physician.

Uncertainty about patient preferences is one of the most commonly identified stressors among ICU FDMs (Braun et al., 2008; Chambers-Evans and Carnevale, 2005; Hayes, 2003; Tilden et al., 1999; Vig et al., 2007). When decision makers know the treatment preferences of the patient, their role can be reconceptualized from a decision maker to a reporter or enforcer (Braun, Naik, & McCullough, 2009). Some FDMs feel a sense of accomplishment and pride in ensuring that the preferences of the patient were fulfilled (Braun et al., 2008; Vig et al., 2007). Abbott et al. (2001) found that 63% of FDMs had previously spoken about treatment preferences with patients, which lessened the burden of treatment decisions. Davis and colleagues (2005) examined the relationship between stress and the presence of advance directives in 105 FDMs of terminally ill patients. FDMs of patients with advance directives reported lower stress as measured by the IES compared to FDMs of patients without advance directives ($t = -3.44, p = .001$).
However, knowing the patient’s preferences does not always ease the emotional burden of decision making. “Your decision is cut and dry, but it’s a hard decision to make” (Vig et al., 2007, p. 1277). Jeffers (1998) described no change in perceived burden of decision making in FDMs guided by advance directives or previous discussions with patients about treatment preferences.

Uncertainty about prognosis and the patient’s illness outcome is another stressor that family members of ICU patients experience. Most FDMs are not familiar with the ICU and rely on clinicians to orient them and provide information to navigate the decision-making process. A majority of FDMs prefer some form of shared decision making in their role of FDM (Anderson et al., 2009; Heyland et al., 2003; Lind, Lorem, Nortvedt, & Hevroy, 2011; Silberfeld, Grundstein-Amado, Stephens, & Deber, 1996). Family members are often willing to assume the role of FDM but rely on clinicians to provide information that is sufficiently specific and timely on which to base decisions. Conversely, poor communication or conflicting information from clinicians can potentiate FDM stress and emotional turmoil (Abbott et al., 2001; Limerick, 2007; Radwany et al., 2009). Apatira and colleagues (2008) interviewed 179 FDMs of incapacitated patients at high risk for death. Several themes emerged from the study: (a) timely discussion of prognosis is essential, (b) withholding information to allow for “false hope” was morally unacceptable, and (c) physicians are looked to primarily for truth while hope is sought elsewhere. Verhaeghe, van Zuuren, Defloor, Duijnste, and Grypdonck (2007) described similar findings and concluded that “falsely positive” prognostic information led to increased distress among FDMs and loss of trust in the clinicians.
Summary of FDM Experiences

Superimposed on the stress, uncertainty, and anxiety of a loved one experiencing critical illness is the tremendous emotional burden that accompanies decision-making on the patient’s behalf. The responsibility of making decisions where life and death hangs in the balance is a difficult and sometimes overwhelming burden to bear. There is a sense of loneliness in the decision making process with a concern about making the “right or wrong” decision. Even after the decision-making experience is over, FDMs harbor residual feelings of regret or doubt about the process and decisions. Anxiety and depression is common and more likely in FDMs who prefer a passive decision-making role.

Several stressors contribute to the difficulty of the decision-making role. Factors identified as increasing the FDM burden include lack of decision-making experience, prognostic uncertainty, patient preference uncertainty, family discord, poor FDM-clinician communication, and FDM-clinician conflict. Advance directives can lessen the burden of family decision-making but do not completely alleviate the stress of the FDM role. Furthermore, FDMs insist on frequent, timely, and accurate communication with clinicians to facilitate a shared decision-making process.

Experiences of Family Members after ICU Hospitalization

Family members of ICU patients experience tremendous stress, anxiety, and depression during the ICU illness (McAdam et al., 2010). Those experiences seem to be magnified when family members are called upon to serve as FDMs during the ICU hospitalization (Azoulay et al., 2005; Davis et al., 2005; Tilden et al., 2001). The psychological symptoms during the ICU experience may put family members at risk for
more long-term adverse psychological outcomes. According to Schmidt and Azoulay (2012),

Family members may witness invasive treatment as well as unfamiliar medical procedures and devices. Then, the acute admission to ICU, their long length of stay, the death threatening and the uncertain trajectory of this chronic critical illness exposes family members to damaging psychological consequences that can last several years after the ICU. (p. 540)

A task force of the Society of Critical Care Medicine proposed the term post intensive care syndrome family (PICS-F) in recognition of the persistent psychological burden experienced by ICU family members after hospitalization (Needham et al., 2012). The purpose of the task force was to increase awareness and education of PICS-F, to understand and address barriers to practice, and to identify research gaps and resources. Symptom clusters recognized as part of PICS-F include stress and post-traumatic stress, anxiety, depression, and complicated grief (Schmidt & Azoulay, 2012).

**Post-traumatic Stress Symptoms**

Symptoms of stress following an emotionally difficult experience can be normal and expected. When those symptoms cause severe distress or interfere with personal, social, or occupational functioning, they are considered pathologic (American Psychiatric Association, 2000). According to the DSM-IV, pathologic symptoms of stress within a month of the stressor suggest symptoms of acute stress disorder (ASD) while symptoms that persist past a month indicate post-traumatic stress disorder (PTSD). Originally described in soldiers, PTSD has been associated with many different stressors including
natural disasters, assault, confinement, physical trauma, and medical illness (Javidi & Yadollahie, 2012).

Early studies of post-ICU family member experiences describe symptoms of anxiety, insomnia, and fatigue (Hentinen, 1983; Jones, Macmillan, & Griffiths, 1994). Subsequently, authors have described PTSD symptoms in ICU family members following ICU discharge in French (Azoulay et al., 2005; Garrouste-Orgeas et al., 2012; Lautrette et al., 2007), Indian (Pilla et al., 2006; Pillai et al., 2010), United States (US) (Anderson et al., 2008; Gries et al., 2010), and United Kingdom (UK) cohorts (Jones et al., 2004; Jones et al., 2012). More than half the studies examined PTSD symptoms in family members without identifying those that served in the FDM role (Garrouste-Orgeas et al., 2012; Jones et al., 2004; Jones et al., 2012; Pillai et al., 2006; Pillai et al., 2010). Azoulay et al. (2005) and Gries et al. (2010) evaluated PTSD symptoms in family members but identified family members that participated in decision making. Anderson et al. (2008) and Lautrette et al. (2007) examined PTSD symptoms in FDMs only.

**Measurement instruments.** Measurement of PTSD symptoms varied across studies. The Impact of Event Scale (IES) was used to measure PTSD symptoms in four studies (Anderson et al., 2008; Azoulay et al., 2005; Jones et al., 2004; Lautrette et al., 2007). The IES instrument is a scale used to assess the severity of stress symptoms following an event with higher scores indicating higher degrees of stress symptomatology (Sundin & Horowitz, 2003). Three groups of investigators used scores greater than 30 to identify individuals with significant PTSD symptoms and high risk for PTSD (Anderson et al., 2008; Azoulay et al., 2005; Lautrette et al., 2007). Jones et al. (2004) used IES scores greater than 19 to identify individuals whose symptoms were concerning for
PTSD. Three studies (Garrouste-Orgeas et al., 2012; Pillai et al., 2006; Pillai et al., 2010) assessed PTSD symptoms using the IES-R instrument, which is a revised version of the original IES instrument incorporating diagnostic criteria of DSM-IV (Weiss & Marmar, 1997). Higher scores indicate higher severity of PTSD symptoms. Garrouste-Orgeas et al. (2012) used IES-R scores above 22 while Pillai et al. (2006, 2010) used IES-R scores above 26 to identify individuals with significant symptoms of PTSD. Gries et al. (2010) assessed PTSD symptoms using the Posttraumatic Stress Disorder Checklist Civilian Version (PCL) while Jones et al. (2012) utilized the Post-traumatic Stress Syndrome-14 (PTSS-14) screening tool. The scales do not confirm a diagnosis of PTSD but rather are used to determine individuals at risk for PTSD based on symptomatology.

**Prevalence of PTSD symptoms.** The time after ICU admission at which PTSD symptoms were measured varied widely amongst the studies. Measurements of PTSD symptoms occurred from 2 months to several years after ICU discharge. Studies measuring PTSD symptoms within six months of the ICU illness reported a prevalence of PTSD symptoms from 33% to 69% (Anderson et al., 2008; Azoulay et al., 2005; Jones et al., 2004; Lautrette et al., 2007; Pillai et al., 2010). Prevalence of PTSD symptoms measured greater than six months after ICU death or discharge varied widely. Garrouste-Orgeas et al. (2012) described a prevalence of PTSD symptoms measured at 12 months after ICU discharge to be 68-80%. Gries et al. (2010) reported a prevalence of PTSD symptoms of 14% measured at least six months and up to four years after ICU death. Pillai et al. (2006) measured PTSD symptoms two years after ICU discharge reporting a moderate severity symptom prevalence of 12-14% and severe symptom prevalence of 4-5%. Comparison of prevalence rates is difficult due to differences in timing of
measurement and instrument used. In general, French cohort studies report higher prevalence of PTSD symptoms than US, UK, or Indian cohorts. Gries et al. (2010) attributes the differences to different measurement time points, different levels of family participation in decision-making, low response rate in their study, and cultural factors. The prevalence of ICU family PTSD symptoms within the first six months after ICU discharge or death appears to be relatively consistent across the studies. Furthermore, Jones et al. (2004) found no difference in PTSD symptoms when measured at 8 weeks and later at six months after ICU hospitalization. There appears to be a low but significant prevalence of PTSD symptoms (12-14%) greater than six months after ICU death or discharge (Gries et al., 2010; Pillai et al., 2006). Gries et al. (2010) found no significant association between PTSD symptoms and length of time from patient death to PTSD symptom measurement (6 months to 4 years). See Table 1 for a summary of study sample sizes, instruments used to measure PTSD symptoms, timing of PTSD symptom measurement, and prevalence of PTSD symptoms.
Table 1. Studies measuring PTSD in family members after ICU hospitalization

<table>
<thead>
<tr>
<th>Author/Country</th>
<th>Country</th>
<th>Sample</th>
<th>Tool/ score</th>
<th>Timing of PTSD symptom measurement</th>
<th>Prevalence of symptoms of PTSD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jones et al., 2004</td>
<td>UK</td>
<td>104 ICU family members</td>
<td>IES &gt; 19</td>
<td>8 weeks &amp; 6 months after discharge from ICU</td>
<td>49% at 8 weeks and 6 months; no difference in groups</td>
</tr>
<tr>
<td>Azoulay et al., 2005</td>
<td>France</td>
<td>284 ICU family members</td>
<td>IES &gt; 30</td>
<td>3 months after death or discharge from ICU</td>
<td>33.1% in entire group; 50% in relatives of patients who died</td>
</tr>
<tr>
<td>Pillai et al., 2006</td>
<td>India</td>
<td>177 ICU family members of trauma patients</td>
<td>IES-R ≥ 26</td>
<td>2 years after ICU death or discharge</td>
<td>14% at 2 years</td>
</tr>
<tr>
<td>Lautrette et al., 2007</td>
<td>France</td>
<td>126 FDMs of dying ICU patients</td>
<td>IES &gt; 30</td>
<td>3 months after death</td>
<td>Intervention group with lower scores on IES at 3 months (45% vs. 69%) (p = 0.01)</td>
</tr>
<tr>
<td>Anderson et al., 2008</td>
<td>US</td>
<td>50 FDMs of ICU patients</td>
<td>IES &gt; 30</td>
<td>6 months after ICU death or discharge</td>
<td>35%</td>
</tr>
<tr>
<td>Gries et al., 2010</td>
<td>US</td>
<td>226 family members of dying ICU patients</td>
<td>PCL</td>
<td>6-48 months after ICU death</td>
<td>14%</td>
</tr>
<tr>
<td>Pillai et al., 2010</td>
<td>India</td>
<td>166 ICU family members</td>
<td>IES-R &gt; 26</td>
<td>2 months after ICU death or discharge</td>
<td>35%</td>
</tr>
<tr>
<td>Garrouste-Orgeas et al., 2012</td>
<td>France</td>
<td>Family members of ICU patients</td>
<td>IES-R ≥ 22</td>
<td>12 months after ICU discharge</td>
<td>80% pre-diary, 31.7% diary; 67.6% post-diary (p &lt; .0001)</td>
</tr>
<tr>
<td>Jones et al., 2012</td>
<td>UK</td>
<td>36 relatives of patients recovering from ICU admission</td>
<td>PTSS-14</td>
<td>1, 3 month(s) after ICU discharge</td>
<td>Intervention group with lower levels of scores on PTSS-14 (p = .03) at 3 months</td>
</tr>
</tbody>
</table>

RCT = randomized control trial, IES = Impact of Event Scale, IES-R = Impact of Event Scale-Revised, PTSS-14 = Post-Traumatic Stress Syndrome-14, UK = United Kingdom, US = United States of America, FDMs = family decision makers, PCL = Post Traumatic Stress Disorder Checklist Civilian Version, PTSD = Post-traumatic stress disorder
Associated risk factors. Azoulay et al. (2005) identified decision-making as a factor that increased the prevalence of PTSD symptoms in ICU family members. Higher rates of PTSD symptoms were noted among those who shared in decision-making (47.8%) with the highest prevalence of PTSD symptoms found in family members who shared in end-of-life decisions (81.8%). Although Gries et al. (2010) measured PTSD in family members, the majority (84%) participated in decision-making. The authors found that discordance between decision-making preferences and actual decision-making role was associated with increased PTSD symptoms. In a secondary analysis of the study population in Gries et al. (2010), Kross et al. (2011) described higher levels of PTSD symptoms in family members who participated with early family conferences, which may indicate discordance between actual and desired decision-making role or lack of time to mentally prepare and accept the impending death of a loved one. In French populations, the role of FDM increases the prevalence of PTSD symptoms. It is less clear whether this association is present in other ICU family populations. Satisfaction with decision-making role preference may be an important factor in the association between FDM role and PTSD symptoms.

Several authors have described associations between the nature of the relationship between FDM and patient and PTSD symptoms (Azoulay et al., 2005; Gries et al., 2010; Kross et al., 2011). Azoulay et al. (2005) reported adult children of ICU patients having higher rates of PTSD symptoms than other relatives. Gries et al. (2010) found that having a relationship with the patient other than spouse or adult child and knowing the patient for a shorter length of time was associated had higher PTSD symptoms. Kross et al. (2011) reported family members of older patients with lower levels of PTSD symptoms and
suggested that critical illness and death of younger patients may place family members at higher risk of psychological burden. Echoing this idea, Pillai et al, (2010) found a higher prevalence of PTSD symptoms in parents of ICU patients. Given the largely disparate findings in these studies, a firm association between the FDM-patient relationship and PTSD symptoms is elusive.

Death of the patient is identified as a risk factor for PTSD symptoms (Azoulay et al., 2005; Pillai et al., 2010). Azoulay et al. (2010) reported PTSD symptom prevalence of 50% in family members whose relative died in the ICU. Kross et al. (2011) described an association between PTSD symptoms and being present at the time of the patient’s death. Conversely, Anderson et al. (2008) found no difference in PTSD symptom prevalence between bereaved and non-bereaved family members.

Some authors associate female gender with a higher risk of family member PTSD symptoms following critical illness (Azoulay et al., 2005; Gries et al., 2010). Other authors have not demonstrated this relationship (Anderson et al., 2008; Garrouste-Orgeas et al., 2012; Pillai et al., 2010). However, female gender has been shown to be an independent risk factor for the development of PTSD in other patient populations (Javidi & Yadollahie, 2012). Other risks for PTSD symptoms identified in single reports include family member level of education (Pillai et al., 2010), family member history of psychological treatment (Gries et al., 2010), patient severity of illness (Azoulay et al., 2005), and patient psychological burden (Jones et al., 2004).

**Concurrent Psychological Symptoms**

**Anxiety.** Anxiety is a common symptom found among family members after ICU illness (Anderson et el., 2008; Azoulay et al., 2005; Garrouste-Orgeas et al., 2012; Jones
et al., 2004; Lautrette et al., 2007; Pillai et al., 2010; Siegel et al., 2008). The majority of studies assessed anxiety using the Hospital Anxiety and Depression Scale (HADS) (Anderson et al., 2008; Azoulay et al., 2005; Garrouste-Orgeas et al., 2012; Jones et al., 2004; Lautrette et al., 2007; Pillai et al., 2010). In these studies, the cutoff score on HADS (scores above which indicate significant anxiety symptoms) varied from 8 to 15 with the most common cutoff being 11.

The prevalence of anxiety symptoms measured within six months of ICU death or discharge ranged from 15-69% (Anderson et al., 2008; Azoulay et al., 2005; Garrouste-Orgeas et al., 2012; Jones et al., 2004; Lautrette et al., 2007; Pillai et al., 2010). Anxiety prevalence tended to be higher in French samples. Siegel et al. (2008) measured anxiety anywhere from 3-12 months after ICU death and reported generalized anxiety disorder in 10% of family members. Jones et al. (2004) found no change in anxiety scores when measured at eight weeks and then again at six months after the ICU hospitalization. Anderson et al. (2008) found a decrease in anxiety levels from one month to six months after ICU hospitalization. Azoulay et al. (2005), Anderson et al. (2008), and Pillai et al. (2010) reported an association between PTSD symptoms and anxiety symptoms. Azoulay et al. (2005) related an anxiety prevalence of 72.3% in high PTSD symptom patients compared to 37.9% in low PTSD symptom patients ($p < 0.0001$). Jones et al. (2004), however, found no association between anxiety symptoms and PTSD symptoms measured at six months.

**Depression.** Depression is identified frequently in post-ICU family members (Anderson et al., 2008; Azoulay et al., 2005; Garrouste-Orgeas et al., 2012; Gries et al., 2010; Jones et al., 2004; Lautrette et al., 2007; Siegel et al., 2008). Study samples were
similar in size and country of origin to the samples used to measure anxiety levels. The HADS instrument was commonly used to measure depression (Anderson et al., 2008; Azoulay et al., 2005; Garrouste-Orgeas et al., 2012; Jones et al., 2004; Lautrette et al., 2007). Gries et al. (2010) measured depression using the Patient Health Questionnaire while Siegel et al. (2008) utilized the Structured Clinical Interviews for DSM-IV. The period for measuring depression was identical for anxiety except the investigation by Gries et al. (2010) which measured depression symptoms from six months to four years after patient death. In the studies utilizing the HADS instrument, the cutoff score (scores above which indicate significant depression symptoms) varied from 8 to 15 with the most common cutoff being 11.

The prevalence of depression symptoms ranged from 6-56% (Anderson et al., 2008; Azoulay et al., 2005; Garrouste-Orgeas et al., 2012; Jones et al., 2004; Lautrette et al., 2007). The variability in the prevalence of depression can be at least partially explained by the use of different instruments, different instrument cutoff points, timing of measurement, and different populations. Depression prevalence tended to be higher in French samples. Jones et al. (2004) and Anderson et al. (2008) found no change in depression scores when measured at eight weeks and then again at six months after the ICU hospitalization. Azoulay et al. (2005) reported a depression prevalence of 40.4% in high PTSD symptom patients compared to 10% in low PTSD symptom patients ($p < 0.0001$). Gries et al. (2010) stated that 10.6% of family members met criteria for both PTSD and depression but did not comment on a statistical relationship. Jones et al. (2004), however, found no association between depression symptoms and PTSD symptoms measured at six months.
Complicated Grief. Anderson et al. (2008) reported no association between patient death and the prevalence of ICU family PTSD symptoms. However, 46% of bereaved family members had complicated grief measured by the Inventory of Complicated Grief, and all bereaved family members with PTSD symptoms had complicated grief ($p = .001$). There was no association between anxiety or depression and complicated grief. Siegel et al. (2008) described a 5% prevalence of complicated grief measured by the Structured Clinical Interviews for DSM-IV.

Interventions

Intervention studies evaluating PTSD symptoms in post-ICU family members have shown some promise in diminishing the burden of PTSD symptoms (Garrouste-Orgeas et al., 2012; Jones et al., 2012; Lautrette et al., 2007). Lautrette et al. (2007) investigated the impact of an end-of-life conference communication strategy and bereavement brochure on psychological symptoms of family members of dying ICU patients. The authors identified lower prevalences of anxiety (45% vs. 67%, $p = .02$), depression (29% vs. 56%, $p = .003$), and PTSD symptoms (45% vs. 69%, $p = .01$) in the intervention group compared to controls measured three months after death of the patient. Two studies demonstrated a decreased prevalence of family member PTSD symptoms following the use of ICU diaries (Garrouste-Orgeas et al., 2012; Jones et al., 2012). Jones et al. (2004) provided ICU family members with an ICU rehabilitation program one week after ICU discharge, which consisted of a six week self-help manual containing information about recovery from the ICU, psychological advice, and practical advice. The authors reported no difference in anxiety, depression, or PTSD symptom scores between
intervention and control groups measured at eight weeks and six months after ICU discharge.

**Coping**

Lazarus and Folkman (1984) define coping as “constantly changing cognitive and behavioral efforts to manage external and/or internal demands that are appraised as taxing or exceeding the resources of the person.” In their conceptualization, coping is process-oriented rather than trait-oriented and concerned with the context of the stressful encounter and the specific thoughts, emotions, and actions a person experiences over the course of the stressful encounter. Coping is concerned with two functions: (a) problem-focused coping (managing the problem with the environment causing stress) and (b) emotion-focused coping (regulating the emotional response to the problem). Emotion-focused coping can be further classified into active processes (coping strategies to change a negative emotional response) and avoidant processes (efforts to minimize the impact of negative emotional responses) (Ben-Zur, 2005; Holahan & Moos, 1987). Within each broad category of coping type there are many different specific coping mechanisms. For instance, problem-focused coping would include efforts to become better educated about a stressor or active planning to deal with a stressor. Examples of emotion-focused coping would include active mechanisms (religion, positive reframing, or acceptance) and avoidant activities (denial, self-distraction, substance use). According to the conceptual model, there is no “right” or “wrong” way to cope. Both aspects of coping are used in tandem, with different strategies predominating at different times based on the stressor, the individual, and the situation.
Given the diversity of specific coping responses to stress, authors have used the
general categorizations, or ways of coping, to make meaningful assessments of coping
strategies (Roth & Cohen, 1986; Suls & Fletcher, 1985). Many authors use the categories
of coping offered by Lazarus and Folkman to assess the effectiveness of the coping
An alternative categorization of coping offered by Moos (1990) describes approach-based
coping (directly resolving the stressor) and avoidance-based coping (avoiding thinking
about the stressor or controlling the associated emotions). “Although considerable overlap
between these two classification schemes exists (i.e., most problem-focused coping is
approach-based, and most emotion-focused coping is avoidance-based), they are not
entirely parallel” (Sharkansky et al., 2000). Problem-focused coping and active emotion-
focused coping are grouped together by some authors as active coping strategies and are
generally considered adaptive coping responses while avoidant coping is considered
maladaptive (Coyne & Racioppo, 2000; Holahan & Moos, 1987; Olff et al., 2005;
Schnider, Elhai, & Gray, 2007).

Penley et al. (2002) reported a meta-analysis comparing the association of coping
to physical and health outcomes. The authors reviewed literature assessing coping
strategies using the Revised Ways of Coping Questionnaire (WOC-R) originally
developed by Folkman and Lazarus (1980) or the Ways of Coping Checklist (WCCL),
which is a revision of the WOC-R instrument by Vitaliano, Russo, Carr, Maiuro, and
Becker (1985). Problem-focused coping was associated with psychological health
outcomes ($r = .10$). The association was a positive correlation with health outcomes from
chronic stressors ($r = .31$) and a negative correlation with health outcomes for acute
stressors ($r = -.11$). Avoidant coping demonstrated a negative correlation with psychological health outcomes ($r = -.36$). Type of stressor did not moderate the association between avoidance and psychological outcomes.

**Coping and PTSD**

A growing body of research points to the relationship between coping strategy and PTSD symptomatology. Arias and Pape (1999) found that greater use of emotion-focused coping, absolutely and relative to problem-focused coping, had a direct effect on PTSD symptomatology. Avoidant coping, a passive emotion-focused strategy, may be protective in the early period after a traumatic stress, but may be maladaptive in the long term (Bryant & Harvey, 1995; Suls & Fletcher, 1985). Cross-sectional studies have demonstrated a consistent relationship between avoidant coping and post-traumatic stress symptoms following a variety of different stressors including war, natural disasters, motor vehicle accidents, and assault (Bryant & Harvey, 1995; Glass et al., 2009; Krause, Kaltman, Goodman, & Dutton, 2008; Oflaz, Hatipoglu, & Aydin, 2008; Pacella et al., 2011; Sutker, Davis, Uddo, & Ditta, 1995; Ullman et al., 2007).

Specific to illness as a stressor, a relationship between avoidant coping and PTSD symptoms associated with different physical health problems has been demonstrated in cancer, spinal cord injury, and HIV-positive patients (Elklit & Blum, 2011; Nielsen, M. S. (2003; Smith et al., 2009). Schnider et al. (2007) reported that avoidant emotional coping style predicted post-traumatic stress symptom severity among college students reporting a loss. The investigators enrolled 126 college students who had experienced an unexpected loss. Coping strategy was measured using the Brief Cope instrument and symptoms of PTSD were measured using the PTSD Checklist (PCL). They found a significant
correlation between all three coping strategies and severity of PTSD symptoms: problem-focused coping \( (r = .48, p < .001) \), active emotion-focused coping \( (r = .43, p < .001) \), and avoidant emotion-focused coping \( (r = .81, p < .001) \). Subsequent path analysis, taking into account the covariates of trauma frequency and years since traumatic loss, demonstrated avoidant coping as the only coping strategy significantly associated with PTSD symptom severity \( (\beta = .78, p < .001) \). Oflaz et al. (2008) examined the relationship between coping strategy and PTSD symptoms in 51 earthquake survivors. The investigators measured coping using the Coping Strategies Scale (CSS) instrument. Avoidant coping strategy demonstrated a significant effect on PTSD symptom severity \( (\beta = .404, p = .003) \).

Longitudinal studies have demonstrated that coping strategies are associated with psychological symptoms of PTSD at a later time point (Benotsch et al., 2000; Krause et al., 2008; Mellman, David, Bustamante, Fins, & Esposito, 2001; Sharkansky et al., 2000). The samples investigated in the studies included Gulf War veterans, domestic violence victims, and traumatic injury victims. Time between measurement of coping strategy and PTSD symptoms ranged from two to 24 months with significant variability in the instruments used to measure coping strategy. Benotsch et al. (2000) measured coping using the WCCL instrument; Sharkansky et al. (2000) utilized the CRI instrument. Krause et al. (2008) used avoidant coping items from both scales, and Mellman et al. (2001) measured coping using the COPE instrument. Sharkansky et al. (2000) demonstrated that approach-based (active) coping in a war zone was related to lower levels of psychological symptoms. Benotsch et al. (2000), Krause et al. (2008), and
Mellman et al. (2001) reported a significant association between avoidant coping efforts at the earlier time point and severity of PTSD symptoms at the later time point.

**ICU Family Coping**

Qualitative studies describing the experiences of ICU families also help identify problem-focused and emotion-focused coping mechanisms used by family members to manage the stress of the experience. Jamerson et al. (1996) described four general categories of ICU family member experience that broadly describe the process of stress, appraisal, and coping: (a) hovering (stress), (b) tracking (appraisal/reappraisal), and (c) information seeking and garnering of resources (problem-focused coping). The need for information was a common problem-focused coping strategy among ICU family members (Agard & Harder, 2007; Braun et al., 2008; Engstrom & Soderberg, 2004; Soderstrom et al., 2006; Vig et al., 2007). Frequent and accurate information was essential to enduring uncertainty and forming personal cues in the ICU environment (Agard & Harder, 2007). Maintaining hope, particularly through religion and faith, is a commonly identified emotion-focused coping strategy (Boyd et al., 2010; Braun et al., 2008; Jeffers, 1998; Plakas, Boudioni, Fouka, & Taket, 2011; Schenker et al., 2012; Vig et al., 2007). Positive reframing, humor, acceptance, and pursuing emotional support from others (friends, family, nurses, and physicians) are other active emotion-focused coping strategies reported by ICU family members (Braun et al., 2008; Eggenberger & Nelms, 2007; Schenker et al., 2012; Vig et al., 2007). Avoidant emotion-focused coping strategies tend to be described infrequently but include denial, self-distraction, and substance use (Halm et al., 1993; Johansson, Hildingh, & Fridlund, 2002; Nyamathi, 1987).
Johansson et al. (2002) generated a theoretical model of coping in ICU family members emphasizing the mechanisms individuals utilize to manage their feelings (emotion-focused coping): mastering feelings, excluding feelings, alleviating feelings, and recycling feelings. The mechanisms are influenced by the family members’ perceived internal resources (emotional and intellectual) and external resources (social support).

Reider (1994) reported one of the earliest studies measuring coping in ICU family members. The author measured coping using the Family Crisis Oriented Personal Evaluation Scales (F-COPES) and anxiety using the Brief Symptom Inventory (BSI) instrument in 75 family members of critically ill patients within the first 48-96 hours after ICU admission. The F-COPES measures problem-solving behaviors families develop to respond to problems (McCubbin, Olson, & Larsen, 1987). It includes five subscales of family coping behaviors (acquiring social support, reframing the situation in a new perspective, seeking spiritual support, mobilizing the family to acquire and accept help, and passive appraisal of the situation) with higher scores in each subscale indicating more use of the particular method and higher total score indicating more use of coping in general. The study found that total family coping score was inversely related to anxiety ($r = -.21, p < .05$). The coping subscale of passive appraisal was also inversely related to anxiety level ($r = -.26, p < .05$) while the remaining subscales were unrelated to anxiety level. A more recent study measured coping using the F-COPES instrument and stress using the IES-R instrument in family members in a Hong Kong ICU (Chui & Chan, 2007). Stress and coping were measured 24 hours after admission to the ICU in 133 family members. Reframing was the most frequently used coping method while passive appraisal was the least used coping method. There was no difference in use of coping
methods based on gender although parents of ICU patients utilized passive appraisal more than other groups of relatives. Use of passive appraisal demonstrated a significant inverse relationship with stress level \( r = -.6, p < .05 \) while the remaining four coping subscales demonstrated statistically significant positive correlations with stress level.

Hickman, Daly, Douglas, and Clochesy (2010) investigated the relationship between informational coping style, stress, and depression symptoms in 210 ICU FDMs within several days of ICU admission. The investigators employed the approach and avoidance classification scheme to contrast FDMs according to their disposition for processing information. Utilizing the Cognitive-Social Information Processing model, the authors categorized individuals based on their information coping preference as either monitors (approach-oriented) or bluters (avoidance-oriented). Although role stress was the most significant predictor of depression, monitors had a significantly higher level of depression than bluters. Passive coping methods appear to provide a psychological benefit in ICU family members experiencing acute psychological distress. These findings corroborate other coping literature with the caveat that passive coping strategies may have untoward chronic psychological consequences (Bryant & Harvey, 1995; Suls & Fletcher, 1985).

Twibell (1988) investigated coping in 59 ICU family members using the Jalowiec Coping Scale (JCS) within seven days of admission to a critical care unit. The JCS measures the degree of use and effectiveness of 60 coping methods grouped into eight styles (Jalowiec, 1988). The use of confrontive and optimistic coping styles was significantly correlated with age. Additionally, effective use in five of the eight coping styles was also significantly correlated with age. Spouses and children coped less
effectively with critical illness than other family members. The author concludes that older individuals use more coping strategies than younger family members and are more effective in the use of coping strategies which may at least partially explain why children of ICU patients were less effective with coping. Furthermore, a close relationship with the patient (spouse or child) may influence coping effectiveness because of the magnitude of the perceived risk of loss. Casarini, Gorayeb, and Filho (2009) reported a relationship between age and the use of coping strategies based on the stressor using the Ways of Coping Checklist to measure coping strategy use. No other demographic variables were associated with coping strategy use. Age appears to have an influence on coping strategy use although identifying specific trends is difficult given the sparse data and differences in coping scales used.

A study of 120 Turkish ICU family members measured coping styles using the Ways of Coping Inventory (WCI) and anxiety using the STAI 24 hours after patient admission (Acaroglu, Kaya, Sendir, Tosun, & Turan, 2008). Submissive and helpless coping styles were positively correlated with anxiety levels. Furthermore, female gender was associated with higher use of social support while lower education level was associated with higher use of submissive and helpless coping styles. Sullivan et al. (2012) reported a high prevalence (51.7%) of learned helplessness among family members and FDMs of ICU patients. In their study, lower education levels increased the risk of learned helplessness. Therefore, lower levels of education may be associated with passive coping methods.

Wartella, Auerbach, and Ward (2009) reported a longitudinal study investigating coping strategy and emotional distress in 51 family members of neuroscience ICU
patients. The authors measured coping using the COPE instrument and emotional distress using the Brief Symptom Inventory, which measures symptoms of depression, anxiety, somatization, and hostility. The COPE and BSI instruments were administered within 72 hours of admission, at the time of ICU discharge, and 30 days after ICU discharge. The use of problem-focused and emotion-focused coping increased across the three time points. Problem-focused coping was not associated with level of emotional distress at any time point. Emotion-focused coping was significantly related to emotional distress at the initial time point and at discharge from the ICU ($r = .30, p < .05$ and $r = .29, p < .05$ respectively). This association was largely accounted for by the Denial subscale ($r = .60, p < .001$ and $r = .71, p < .001$). Emotion-focused coping was not significantly associated with emotional distress at 30 days after ICU discharge but the Denial subscale continued to have a significant effect ($r = .44, p < .001$). Shaw, Bernard, Storfer-Isser, Rhine, and Horwitz (2012) measured coping strategy using the Brief COPE and PTSD symptoms using the Davidson Trauma Scale (DTS) in 56 mothers of premature infants in the neonatal ICU. Mothers were assessed using the Brief COPE at seven to ten days after ICU admission and using the DTS one month after ICU discharge. Higher levels of education was associated with increased use of all three coping strategies (problem-focused, emotion-focused, and avoidant coping). Avoidant coping use was associated with an increased risk of PTSD symptoms (RR = 1.09, 95% CI 1.02-1.15; $p = .008$).

**Summary of coping**

Coping is a commonly investigated concept. Lazarus and Folkman’s (1984) transactional model of stress and coping has significantly influenced the conceptualization of coping and its relationship to psychological outcomes. Coping
strategy is broadly categorized into problem-focused and emotion-focused strategies. Emotion-focused can further be divided into active and avoidant coping efforts. Empirical evidence suggests that avoidant coping strategies may be associated with negative psychological outcomes. Avoidant coping strategy has been implicated as a risk factor for PTSD in several different patient populations.

Qualitative studies examining the coping experiences of ICU family members describe strategies that generally coincide with the categories proposed by Lazarus and Folkman (1984). Some cross-sectional quantitative studies describe diminished acute emotional distress in ICU family members utilizing passive or avoidant coping methods. Research in other patient populations has demonstrated an acute benefit to use of avoidant coping strategies with a risk of maladjustment at a later time. However, some studies have described increased acute emotional distress in family members utilizing avoidant coping strategies. Furthermore, avoidant coping strategies are associated with higher levels of emotional distress at a later time point (after ICU hospitalization) including PTSD symptoms. Age and level of education appear to influence the use of different coping strategies. To date, no study has described the coping strategies conceptualized by Lazarus and Folkman in adult ICU FMDs and their relationship to PTSD symptoms.
CHAPTER III: METHODS

The chapter discusses the research methodology including design, setting, sample, procedure, measurement, data collection, and data analysis for this study. The purposes of the proposed study were to determine the coping strategies utilized by FDMs of ICU patients early in the ICU admission and 30 days following hospital discharge or death of the patient for whom the FDM made decisions and explain the relationship between coping strategies utilized by FDMs and PTSD symptoms. The purposes of the study were met by answering the following research questions:

**RQ1:** What are the coping strategies utilized by FDMs of ICU patients on study enrollment (3 to 5 days after ICU admission) and 30 days following hospital discharge or death of the patient for whom the FDM made treatment decisions?

**RQ2:** Do coping strategies utilized by FDMs of ICU patients change from study enrollment (3 to 5 days after ICU admission) to 30 days following hospital discharge or death of the patient for whom the FDM made treatment decisions?

**RQ3:** What are the levels of PTSD symptoms experienced by FDMs of ICU patients at 60 days following hospital discharge or death of the patient for whom the FDM made treatment decisions?

**RQ4:** What is the relationship between coping strategies utilized by ICU FDMs and the experience of post-ICU (60 days following hospital discharge or death of the patient for whom the FDM made treatment decisions) PTSD symptoms?

**RQ5:** To what extent do FDM coping strategies predict post-ICU FDM PTSD symptoms?
RQ6: To what extent do FDM coping strategies predict post-ICU FDM PTSD symptoms controlling for FDM and ICU patient factors?

Design

The study design was a single group descriptive longitudinal correlational study to describe coping strategies and symptoms of PTSD in FDMs of ICU patients and the extent of the relationship between FDM coping strategies and post-ICU symptoms of PTSD. The single group was a convenience sample of FDMs of incapacitated ICU patients. The study design was chosen to describe the coping strategies of the FDM as measured by the Brief Cope instrument at two time points: enrollment to the study and 30 days after patient discharge from the hospital or death. Symptoms of PTSD were measured by the IES-R at 60 days after patient discharge from the hospital or death and were correlated with coping strategies at both time points (enrollment and 30 days after discharge from the hospital or death). This was one of the first studies to measure coping strategies of adult ICU FDMs using the Brief COPE instrument and the relationship between coping strategies and post-ICU FDM symptoms of PTSD.

Setting

The research setting was three ICUs (Neurosurgical, 14 beds; Medical, 20 beds; and Surgical, 20 beds) at University Hospital Case Medical Center in Cleveland, Ohio. This setting was chosen because it is a busy metropolitan hospital with strong ties to the Frances Payne Bolton School of Nursing and could provide a representative sample of ICU FDMs in a metropolitan setting. Data was collected by the research assistant (RA) in a private conference room near one of the ICUs, a waiting area located outside of each of the three ICU’s, the patient’s room, or by phone depending on the FDMs preference.
Sample

The sample for the study was obtained from all FDMs of ICU patients at risk for CCI hospitalized at University Hospital Case Medical System. A convenience sampling method was used to ease the time it took to obtain subjects to participate in the study and to minimize selection bias by consecutively choosing every accessible FDM who met the study criteria. The major disadvantages to a convenience sample are risk of bias due to self-selection, which may influence the representativeness of the sample.

Sample Criteria

Study inclusion criteria for ICU patients at risk for CCI are: a) mechanical ventilation or ICU stay of greater than five days, b) lack of cognitive decisional capacity as indicated by the assigned nurse, c) age over 18 years, d) has an identified family decision maker, and e) is not expected to be transferred out of the ICU within 48 hours. Patients who require greater than 72 hours of mechanical ventilation are at increased for death or prolonged hospitalization. This criterion has been used to identify patients at risk for CCI (Daly et al., 2005). Exclusion criteria for ICU patients at risk for CCI include: a) able to make their own care decisions and b) family meeting is planned to discuss withdrawal care of the patient or withdrawal of care has been decided. Study inclusion criteria for FDMs of ICU patients at risk for CCI are: a) over 18 years of age, b) identification as the primary person responsible for ICU patient decision-making, and c) able to speak English.

Sample Size

The sample size was determined on G-Power (3.13) a priori. Based on an alpha of .05 and power of .80, 76 FDM’s were needed for the study assuming a medium effect.
size (0.15) in regression of three independent variables (three coping strategies) on the dependent variable (PTSD symptoms). A medium effect size was chosen based on previous studies examining the relationship between coping strategies and PTSD symptoms, and the relationship between coping strategy and PTSD symptoms has not been evaluated in adult ICU FDMs. To accommodate the expected attrition of 20%, 91 participants were initially planned for the study. The time line for enrolling patients was to be 9-12 months, with an additional 6 months to allow all FDM’s to complete the remaining time points and allow for statistical analysis and interpretations of results.

**Procedure**

The research assistant (RA) rounded in the ICU’s on a daily basis to identify patients and FDMs eligible for the study. The RA reviewed a daily roster containing the patient names, diagnoses, and neurological status. Once a patient was identified as being at risk for CCI, the bedside nurse was approached to verify the patient’s current neurological status and cognitive capacity. If eligibility criteria were met, the RA approached the FDM at the bedside while visiting the patient. The study was verbally explained to the FDM and if the FDM expressed an interest, an informed consent was presented and reviewed. The participant was provided time to read the informed consent document in its entirety and ask questions prior to enrolling in the study. The FDM was asked to sign the consent after reading and agreeing to the terms of the study. A copy was provided to the participant prior to conducting the interview. The FDM was given the choice to sit by the patient’s bedside or visit a nearby private room designated for families to complete the 15-minute interview. The RA read the questions and documented the FDM’s responses. When a patient met the eligibility criteria for the study but the
FDM was not present at the patient’s bedside, the RA asked the bedside nurse to call the family member and ask if he/she would be willing to speak to the RA regarding a potential research study. The RA explained the study to the potential participant by phone and either arranged a time to meet the participant face to face for enrollment or conduct the interview by phone. The phone interview was conducted in a private room with a closed door. If the RA did not hear from the family member within 24 hours, additional attempts were made to contact the family member for a total of three attempts.

The study design had three data collection points: Time 1 (T1) = day 3 to 5 after ICU admission, Time 2 (T2) = 30 days after discharge from the ICU or death of the patient, and Time 3 (T3) = 60 days after discharge or death of the patient. The demographic form was administered at T1. The Brief COPE instrument was administered at two time points: T1 and T2. The IES-R was administered at T3 only. At 30 days after discharge from the hospital, the FDM was contacted by phone call, e-mail, or standard mail. Preference for follow-up was identified on enrollment to the study. After three attempts to reach the study participant by the preferred method, another method was attempted once. The same process was followed at 60 days after discharge from the hospital or death of the patient.

Attrition is a threat to a longitudinal study. The sample size was computed to account for a predicted 20% attrition rate based on previous longitudinal studies of ICU family members in the U. S. (Anderson et al., 2008; Gries et al., 2010). Steps to minimize attrition included: (a) recording the best time to follow-up with FDMs and adhering to this time frame, (b) using multiple methods to contact FDMs based on their preferences, and (c) sensitivity to the FDMs’ time when conducting the follow-up calls. Additionally,
a $10.00 gift card was presented to the FDM on enrollment to the study and again at T3 provided the FDM completed all three time points of the study.

Measurement

Demographic Form

Patient and FDM characteristics were obtained from the FDM and the patient’s medical records. The patient variables obtained with the demographic form were chosen for the purpose of assessing the representativeness of the sample and for measuring variables identified as possible confounding variables for coping strategy or PTSD symptoms. Patient characteristics measured included age, gender, ethnicity, length of ICU stay, length of hospital stay, and final disposition of the patient (death or discharge from ICU). Age, gender, and ethnicity of the patient were obtained obtained to distinguish the representativeness of the sample. Furthermore, age of the patient has been identified as a covariate of PTSD. FDMs of older patients are reported to have lower PTSD symptom severity than FDMs of younger patients (Kross et al., 2011, McAdam et al., 2010). The length of ICU stay has been associated with higher levels of stress (Chui & Chan, 2007). Disposition of the ICU patient has also been identified as a covariate of PTSD symptom severity in post-ICU FDMs (Azoulay et al., 2005; Pillai et al., 2010). Death of an ICU patient is associated with higher levels of PTSD symptoms in ICU FDMs when compared to FDMs of patients who survived the ICU admission. However, Anderson et al. (2008) found no difference in PTSD symptom prevalence in bereaved versus non-bereaved family members of ICU patients.

FDM characteristics assessed on the demographic form included age, gender, ethnicity, relationship to the patient, previous decision-making experience, documented
power of attorney, and documentation of a living will. Age, gender, and ethnicity was assessed to determine the representativeness of the FDM sample. Age of the FDM has been associated with PTSD symptom severity. Younger FDM age is associated with higher symptoms of PTSD (McAdams, 2010). A higher prevalence and severity of PTSD symptoms have been reported in women when compared to men (Azoulay et al., 2005; Chui & Chan, 2007; Gries et al., 2010; Paparrigopoulos et al., 2011, McAdam et al., 2010). The relationship of the FDM is identified as a covariate to post-ICU PTSD symptom severity (Azoulay et al., 2005; Gries et al., 2010; Kross et al., 2011). The relationships of spouse, parent, or child are associated with higher levels of PTSD symptoms ICU family members. Documentation of a living will and durable power of attorney was assessed because FDMs describe diminished stress when the wishes of the ICU patient are known or have been discussed prior to the ICU illness (Braun et al., 2009; Vig et al., 2007).

**Brief Cope Instrument**

Coping strategy was measured by the Brief COPE instrument. The Brief COPE instrument is a 28-item measure of coping strategies (Carver, 1997). The Brief COPE is based on the model of coping of Lazarus and Folkman (1984) and the model of behavior regulation by Carver and Scheier (1981, 1990). The Brief COPE is derived from a longer 60-item instrument called the COPE Inventory (Carver, Scheier & Weintraub, 1989). The Brief COPE was developed to decrease participant burden and to reduce redundancy within the scale. The Brief COPE instrument consists of 14 subscales of two items each. The items are scored using a 4-point Likert scale with responses ranging from 1 (I haven’t been doing this a lot) to 4 (I have been doing this a lot). Each of the 14 subscales
can be reported as a total score (2-8) or a mean score (1-4) with higher scores indicating more use of the particular type of coping effort. Based on conceptual and theoretical literature, Schnider, Elhai, and Gray (2007) grouped the 14 subscales into three coping categories: a) problem-focused coping (active coping, planning, using instrumental support, and religion), b) active emotion-focused coping (positive reframing, humor, venting, acceptance, and use of emotional support), and c) avoidant emotion-focused coping (self-blame, substance use, behavioral disengagement, self-distraction, and denial). Each category score is reported as a mean score ranging from 1 to 4. Higher scores represent higher use of the coping strategy (problem-focused, active emotion-focused, and avoidant emotion-focused). Cooper, Katona, and Livingston (2008) examined the psychometric properties of the Brief COPE and grouped the subscales slightly differently from Schnider et al. (2007) based on previous groupings reported by Coolidge et al. (2000) using the original COPE instrument. Table 2 summarizes the groupings reported by Cooper et al. (2008) along with the Cronbach’s α for each grouping and the reliability of each subscale originally reported by Carver (1997). This study used the groupings reported by Cooper et al. (2008).
Table 2.

*Brief Cope Strategy and Subscale Reliability*

<table>
<thead>
<tr>
<th>Brief Cope Strategies</th>
<th>Cronbach’s α&lt;sub&gt;a&lt;/sub&gt;</th>
<th>Subscale</th>
<th>Cronbach’s α&lt;sub&gt;b&lt;/sub&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Problem-focused coping</td>
<td>.84</td>
<td>Active coping</td>
<td>.68</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Planning</td>
<td>.73</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Instrumental support</td>
<td>.64</td>
</tr>
<tr>
<td>Active emotion-focused coping</td>
<td>.72</td>
<td>Positive reframing</td>
<td>.64</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Humor</td>
<td>.73</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Religion</td>
<td>.82</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Acceptance,</td>
<td>.57</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Emotional support</td>
<td>.71</td>
</tr>
<tr>
<td>Avoidant coping</td>
<td>.75</td>
<td>Self-blame</td>
<td>.69</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Behavioral disengagement</td>
<td>.65</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Substance use</td>
<td>.90</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Self-distraction</td>
<td>.71</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Denial</td>
<td>.54</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Venting</td>
<td>.50</td>
</tr>
</tbody>
</table>

Note: a = Cooper et al. (2008); b = Carver (1997).

Several authors have investigated the reliability of the Brief COPE scale. The 14 subscales have internal reliabilities ranging from a Cronbach’s α of .50 to .90 with nine items ≥ .65 (Carver, 1997). Schnider and colleagues (2007) described a Cronbach’s α of .80 for the problem-focused portion of the scale, a Cronbach’s α of .81 for the active emotion-focused coping portion, and a Cronbach’s α of .88 for the avoidant emotion-focused coping items. Cooper et al. (2008) reported the reliability of the Brief COPE in a population of family caregivers for people with Alzheimer’s disease. The authors related good internal consistency for problem-focused, active emotion-focused, and avoidant
emotion-focused scales ($\alpha = .84, .72, .75$ respectively). Test-retest reliability over a one-year span was demonstrated among caregivers in whom burden scores did not significantly change: active emotion-focused coping ($r = .58, p < .001$), problem-focused coping ($r = .72, p < .001$), avoidant coping ($r = .68, p < .001$). Change in burden score over two years correlated with change in problem-focused coping ($r = .33, p < .01$) and avoidant coping ($r = .32, p < .01$) but not in active emotion-focused coping. Change in active emotion-focused correlated with change in problem-focused and avoidant coping ($r = .40, r = .26; p < .05$). The authors concluded that the Brief COPE instrument demonstrates good reliability but that more information is needed in regard to the sensitivity of active emotion-focused coping to change.

Several authors have reported validity of the Brief COPE instrument. Carver et al. (1989) reported the initial content, convergent, and divergent validity for the subscales of the original COPE scale. Cooper et al. (2008) examined convergent and divergent validity of the Brief COPE in caregivers of dementia patients. Avoidant coping was significantly correlated with avoidant attachment ($r = .40, p < .01$). Emotion-focused coping was correlated with the number of confidants ($r = .29, p < .01$). Regression analysis indicated the following convergent and divergent validity: active emotion-focused coping was predicted by secure attachment ($\beta = .23, p < .05$); avoidant coping was predicted by burden ($\beta = .36, p < .05$) and less secure attachment ($\beta = -.25, p < .05$); problem-focused coping was predicted by avoidant attachment ($\beta = .22, p < .014$) and less secure attachment ($\beta = -.25, p = .011$). The Brief COPE instrument has not been used to date in a sample of adult ICU patient FDMs but has been used to assess coping strategies in victims of trauma, natural disasters, and cancer (Glass et al, 2009; Pacella et
Snell et al. (2011) reported a 3-factor solution for the Brief COPE instrument in a sample of 147 adult patients with a mild traumatic brain injury. The three scales reflected approach coping (problem-focused), avoidance coping, and help-seeking coping styles. Although a 3-factor solution was found, the items loading on the approach and help-seeking scales differed somewhat from the problem- and emotion-focused loadings reported by Cooper et al. (2008). The dysfunctional or avoidant scale items were identical. Cronbach’s α for the solution reported by Snell et al. (2011) were .80 for problem focused coping, .77 for avoidant coping, and .84 for the help-seeking scale.

Impact of Event Scale-Revised (IES-R)

Symptoms of post-traumatic stress were measured by the Impact of Events Scale-Revised (IES-R). The IES-R is an instrument for detecting symptoms of post-traumatic stress. Horowitz, Wilner, & Alvarez (1979) proposed the original IES. The scale provides information on both the presence of stress related symptoms and their severity. The 15-item instrument has two subscales: intrusion and avoidance. The revised fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) identifies three symptom clusters of PTSD: intrusion, avoidance, and hyperarousal (American Psychiatric Association, 2000). released a revised version of the IES with three subscales corresponding to the three symptom clusters described in the DSM-IV. The IES-R is a 22-item instrument scored using a 5-point scale ranging from 0 (not at all) to 4 (extremely) for each item. Total scores may range from 0-88 with higher scores indicating higher levels of post-traumatic stress symptoms. Three mean sub-scores may also be computed: the intrusion subscore (seven items), the avoidance subscore (eight
items), and the hyperarousal subscore (seven items). The intrusion score reflects how persistently thoughts and impressions associated with the event reappear. The avoidance score assesses behaviors designed at avoiding people, places, or activities that act as reminders of the stressful event. The hyperarousal score reflects physiologic symptoms such as insomnia, irritability, and hypervigilance.

Several authors have reported reliability for the IES-R. Creamer, Bell, and Falilla (2003) reported a Cronbach’s α of .96 in a sample of Vietnam veterans with and without confirmed PTSD. High levels of internal consistency for the subscales have been reported: intrusion (Cronbach’s α = .87 - .94); avoidance (Cronbach’s α = .84 - .87); hyperarousal (Cronbach’s α = .79 - .91) (Creamer et al., 2003; Weiss & Marmar, 1997). Test-retest reliability across a six month interval ranged from .89 to .94 (Weiss & Marmar, 1997). Beck et al. (2008) examined the psychometric properties of the IES-R in a sample of motor vehicle accident survivors. The authors reported Cronbach’s α for the total scale (.95) as well as the three subscales: intrusion (.90), avoidance (.86), and hyperarousal (.85).

Validity of the IES-R is reported in several patient populations. Creamer et al. (2003) reported concurrent validity with a correlation of .84 between the IES-R and the PTSD Checklist. However, confirmatory factor analysis did not support a 3-factor solution consistent with the three subscales. An exploratory analysis suggested either a one or a two-factor solution. The correlations between the subscales of the two instruments were higher in the sample without a diagnosis of PTSD than with a confirmed diagnosis of PTSD, suggesting that the IES-R may be sensitive to a broad construct of traumatic stress in those with lower symptomatology. These findings were
reproduced in a sample of motor vehicle accident survivors (Beck et al., 2008). In the study by Beck et al. (2008), the mean sub-scores of the IES-R demonstrated significant correlations with the sub-scores of three other measures of post-traumatic symptoms (Clinician Administered PTSD Scale, PTSD Symptom Scale-Self Report, and the original IES). A confirmatory factor analysis reported a three-factor solution with all factor loadings for each of the three sub-scales greater than .45. Creamer et al. (2003) also reported discriminative validity of the IES-R for PTSD with scores above 24 suggesting clinically significant posttraumatic stress symptoms. Scores above 33 were highly predictive of the diagnosis of PTSD with a sensitivity of .91 and a specificity of .82. Beck et al. (2008) reported lower sensitivity and specificity for correctly predicting PTSD at 77.6 and 61.9 respectively. Table 3 summarizes the independent variables, dependent variables, and instrument used to measure the variables.
Table 3.

Variables, Measures, & Instruments

<table>
<thead>
<tr>
<th>Type of Variable</th>
<th>Variable</th>
<th>Instrument</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient/FDM Variables:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ICU Patient Factors</td>
<td>Age on admission</td>
<td>Medical Record</td>
</tr>
<tr>
<td></td>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Ethnicity</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Length of ICU admission</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Length of Hospital admission</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Disposition</td>
<td></td>
</tr>
<tr>
<td>FDM Factors</td>
<td>Age on enrollment</td>
<td>Demographic Form</td>
</tr>
<tr>
<td></td>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Ethnicity</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Relationship to patient</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Previous ICU decision-making</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Power of Attorney</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Documentation of living will</td>
<td></td>
</tr>
<tr>
<td>Independent Variables:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Coping Strategies</td>
<td>Problem-focused coping</td>
<td>Brief COPE</td>
</tr>
<tr>
<td></td>
<td>Emotion-focused coping</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Avoidant coping</td>
<td></td>
</tr>
<tr>
<td>Dependent Variable:</td>
<td>Outcome variable</td>
<td>Symptoms of PTSD</td>
</tr>
<tr>
<td></td>
<td></td>
<td>IES-R</td>
</tr>
</tbody>
</table>

Note: ICU = Intensive Care Unit; Disposition = discharge from hospital of death; FDM = Family Decision Maker; PTSD = Post-Traumatic Stress Disorder; IES-R = Impact of Invent Scale- Revised

Data Collection

The RA either in person or over the phone collected the data. Each participant entered into the study was assigned a code. The master list to link the individually identifiable data was kept on a secure computer at CWRU and on an Iron Key secure USB drive. The Iron key and coded documents were kept in a locked file cabinet in a
secure office at the Frances Payne Bolton School of Nursing. The data and codes will be kept until data are published. The responsible investigator and the research assistants had access to data and codes. The data was analyzed using the Statistics Package for the Social Sciences (SPSS, Version 21) software. The information obtained was entered into the network database using a network connected mobile device or entered from an initial paper instrument. Data coding included dichotomous data, categorical data, ordinal data, and continuous data. Data was entered into the SPSS file by one RA and then re-checked by having an additional person read the scores from the hard copies while the RA checked the accuracy of the previously entered data. No more than 20 subjects were entered or checked at one time point in order to minimize errors that may occur from fatigue.

**Data Analysis**

Descriptive statistics were used to assess frequencies and variability of the data. This included evaluation of mean, range, and standard deviation. Variability of each item was appraised by having a range of responses without having any one category account for greater than 90 percent of all category responses. Descriptive statistics was also used to determine coding inaccuracies, outliers, and missing data. Testing for normality was done using skewness and kurtosis. Influential cases or outliers and linearity were evaluated through examination of frequencies and partial plots.

The acceptable alpha level was set at 0.05. Demographic variables for the patient and FDM that were nominal or ordinal were described using absolute N and proportion. Demographic variables for the patient and FDM that were interval/ratio were described using measures of central tendency (mean, median, and mode), measures of dispersion.
(SD), and proportion (%). The tests for normal distribution included mean, median, mode, skewness, and kurtosis.

**RQ1:** *What are the coping strategies utilized by FDMs of ICU patients on study enrollment (3 to 5 days after ICU admission) and 30 days following hospital discharge or death of the patient for whom the FDM made treatment decisions?*

The key variable is coping strategies employed by ICU FDMs and this variable yields interval/ratio level data. This descriptive question was answered by reporting measures of central tendency (mean, median, and mode), measures of dispersion (SD), and proportion (%) for the three subscales of the Brief Cope instrument. The data was examined for normality and variability. The measures included coping strategies at T1 and T2.

**RQ2:** *Do coping strategies utilized by FDMs of ICU patients change from study enrollment (3 to 5 days after ICU admission) to 30 days following hospital discharge or death of the patient for whom the FDM made treatment decisions?*

The key variable in RQ2 is coping strategies and this variable yields interval/ratio level data. The means of the three subscales (emotion-focused coping, problem-focused coping, avoidant coping) of the Brief Cope were compared at T1 and T2. The test of difference between coping strategies at T1 and T2 is a dependent samples t-test. Since all assumptions were met, the data was treated parametrically.

**RQ3:** *What are the levels of PTSD symptoms experienced by FDMs of ICU patients at 60 days following hospital discharge or death of the patient for whom the FDM made treatment decisions?*
The key variable is PTSD symptoms experienced by ICU FDMs and measured by the IES-R scale. This variable yields interval/ratio level data. This descriptive question was answered by reporting measures of central tendency (mean, median, and mode), measures of dispersion (SD), and proportion (%) for the IES-R instrument. The data was examined for normality and variability.

**RQ4: What is the relationship between coping strategies utilized by ICU FDMs and the experience of post-ICU (60 days following hospital discharge or death of the patient for whom the FDM made treatment decisions) PTSD symptoms?**

The fourth research question examines the relationship between coping strategy and post-traumatic stress symptoms. Coping strategies yields interval/ratio level data and symptoms of PTSD yield interval/ratio level data. The means of the three subscales (emotion-focused coping, problem-focused coping, avoidant coping) of the Brief Cope at T1 and T2 were compared to the total score of the IES-R. A correlational analysis was performed between the three scores on the Brief COPE instrument at both time points and the IES-R instrument using Pearson’s correlation coefficient. The variables were examined for linearity, normality, and constant error variance. Since all assumptions were met, the data was treated parametrically.

**RQ5: To what extent do FDM coping strategies predict post-ICU FDM PTSD symptoms?**

The fifth research question examined the extent to which coping strategy predicted the severity of PTSD symptoms. The independent variables are the three coping strategies (problem-focused, emotion-focused, and avoidant) measured by the Brief COPE. The dependent variable is PTSD symptoms measured by the IES-R. This question was answered utilizing regression analysis. Two separate regression analyses were
performed. The first regression model examined the extent to which the three coping strategies measured at T1 predicted severity of PTSD symptoms. The second regression model examined the extent to which the three coping strategies measured at T2 predicted severity of PTSD symptoms.

The data was assessed to insure that the assumptions for multiple regression were met. The assumptions that were tested included adequate variance, absence of influential cases, linearity, constant error variance, and normality of error. Normality and variance was assessed using measures of skewness and kurtosis. Influential cases were examined using Cook’s D and partial plots. Linearity was tested using partial plots with added fit line.

**RQ6:** To what extent do FDM coping strategies predict post-ICU FDM PTSD symptoms controlling for FDM and ICU patient factors?

The sixth research question examined the extent to which coping strategy predicted the severity of PTSD symptoms controlling for FDM and ICU patient factors. The independent variables are the three coping strategies (problem-focused, emotion-focused, and avoidant) measured by the Brief COPE, the relationship of the FDM to the patient (spouse, parent, child, other), and the disposition of the patient at 30 days (death or discharge from the hospital). The dependent variable is PTSD symptoms measured by the IES-R. This question was answered utilizing regression analysis. Two separate regression analyses were performed. The first regression model examined the extent to which the three coping strategies measured at T1, relationship of the FDM to the patient, and patient disposition predicted severity of PTSD symptoms. The second regression model examined the extent to which the three coping strategies measured at T2,
relationship of the FDM to the patient, and patient disposition predicted severity of PTSD symptoms.

The data was assessed to insure that the assumptions for multiple regression were met. The assumptions that were tested included adequate variance, absence of influential cases, linearity, constant error variance, and normality of error. Normality and variance was assessed using measures of skewness and kurtosis. Influential cases were examined using Cook’s D and partial plots. Linearity was tested using partial plots with added fit line.

**Threats to Validity**

Threats to internal validity of a longitudinal design include loss of subjects between data collection points (mortality) and administration of the same instrument at two times over the course of the study (testing). Selection bias is also a threat of internal validity as those experiencing the most stressful symptoms may refuse to enroll in the study. If FDMs prefered to complete the Brief Cope or IES-R at T2 and T3 by mail versus phone interview, instrumentation may be a threat due to a change in the format in which the survey was administered. A threat to external validity is a skewed sample of the population of ICU FDMs. FDMs who use avoidant coping strategies may have preferentially avoided participating in the study skewing the description of coping strategies toward FDMs that utilize active coping strategies. This is referred to as selection effects.

**Human Subjects**

The researcher obtained approval from the Institution Review Board University Hospital Case Medical Center. No members of vulnerable groups were included in the
study. Foreseeable risks to participants enrolled in this study were an inconvenience to their time, a breach of confidentiality, and revelation of a subject’s identity. Additionally, participants may have experienced discomfort in answering particular questions and burden from requirements to fulfill. Alternatively, family members may also have found the interview comforting and a time to express their feelings. Procedures to minimize the risks from being realized included: (a) the study was presented as a volunteer opportunity that may be discontinued at any time, (b) all information was stored in a locked office on a secure computer, (c) participant was offered a private location for obtaining their responses, and (d) participants were reminded that they may skip a question if it is not something they wish to answer. During enrollment, the FDM was made aware that the patient’s care would not be influenced by their choice as to whether or not to participate in the study. A $10.00 gift card was presented to the FDM on enrollment to the study and again at the conclusion of the data collection provided the FDM completed all three time points of the study.
CHAPTER IV: Post-traumatic Stress Symptoms in Post-ICU Family Members:
Review and Methodological Challenges

Preface

This chapter presents the first manuscript for publication, which was submitted to the Western Journal of Nursing Research on March 10, 2014. This chapter provides a brief review of the literature concerning post-ICU family member PTSD symptoms. The chapter also addresses methodological issues that pertain to interpreting the results of the literature and conducting future research in post-ICU family symptomatology.
Abstract

Family members of critically ill patients experience high levels of stress during the intensive care unit (ICU) hospitalization and are at risk for symptoms of post-traumatic stress disorder (PTSD) following discharge. There is a growing body of literature recognizing the impact of critical illness on family members and identifying factors that may increase the risk for post-ICU PTSD symptoms. However, analysis of the current literature demonstrates methodological challenges to the interpretation of existing studies and to the conduct of future research. This article summarizes the current literature regarding post-ICU family PTSD symptoms and identifies methodological issues in conducting research on this challenging phenomenon. An understanding of these issues may explain some of the variability in study findings as well as facilitate future development of research studies through modification and enhancement of sampling techniques, establishment of standardized PTSD symptom instruments and measures, and development of efficacious ICU family interventions.

Keywords: ICU family, stress, PTSD, critical care, methods
More than 6.5 million patients are admitted to the ICU each year in the United States, of whom 540,000 will die (Bion & Hall, 2007). Patients in the ICU are often intubated, sedated, or neurologically compromised, which precludes them from actively participating in the decision-making process (Ely et al., 2001; McNicoll et al., 2003). Approximately 95% of ICU patients rely on a substitute decision-maker, usually a family decision maker (FDM), to participate in communication and decision-making with the health care providers at some point during their ICU illness (Prendergast, Claessens, & Luce, 1998; Smedira et al., 1990). Burden and stress are universal and pervasive experiences of these FDMs (Braun, Beyth, Ford, & McCullough, 2008; Engstrom & Soderberg, 2004; Vig, Starks, Taylor, Hopley, & Fryer-Edwards, 2007). A complex and prolonged ICU course, the risk of loss of a loved one, and the difficulty of making end-of-life decisions add to the anxiety and stress of family members. In one survey, thirty six percent of family members of ICU patients were taking anxiolytic or antidepressant drugs and over eight percent were taking psychotropic drugs on discharge or death of their ICU family member (Lemiale et al., 2010). In the months following the ICU experience, family members are at risk for significant psychological distress including symptoms of generalized anxiety disorder, depression, panic disorder, and complicated grief (Anderson, Arnold, Angus, Bryce, 2008; Anderson, Arnold, Angus, & Bryce, 2009; Azoulay et al., 2005; Gries et al., 2010; Jones et al., 2004; Kross et al., 2011; Siegel, Hayes, Vanderwerker, Loseth, & Prigerson, 2008).

High levels of stress among family members of ICU patients is commonplace (Auerbach et al., 2005; Chui & Chan, 2007; McAdam, Dracup, White, Fontaine, & Puntillo, 2010; Paparrigopoulos et al., 2006; Pielmaier, Wlader, Rebetez, & Maercker,
Factors that have been shown to be associated with higher levels of stress include female gender, length of ICU stay, lower educational levels, family member trait anxiety, and family member symptoms of anxiety and depression (Chui & Chan, 2007; McAdam et al., 2010; Paparrigopoulos et al., 2006; Pielmaier et al., 2011; Pillai et al., 2010). Most recently, a number of studies (see Table 1) have identified a significant prevalence of post-traumatic stress disorder (PTSD) symptoms in post-ICU family members (Anderson et al., 2008; Azoulay et al., 2005; Gries et al., 2010; Jones et al., 2004; Lautrette et al., 2007; Pillai et al., 2006; Pillai et al., 2010).

PTSD is a stress disorder occurring at least one month after exposure to a traumatic event (American Psychological Association, 2013). The prevalence of PTSD in the U. S. population is estimated to be 6.8% with women demonstrating higher rates than men (Kessler, Chiu, Demler, & Walters, 2005). First described in soldiers, PTSD follows exposure to many different traumatic events such as personal assault, sexual assault, confinement, and natural disasters (Javidi & Yadollahie, 2010). More recently, PTSD has been recognized as a consequence of many different acute and chronic illness experiences in patients and their family members (Alonzo, 2000; Berna, Vaiva, Ducrocq, Duhem, & Nandrino, 2012; Elklit & Blum, 2011; Kross, Gries, & Curtis, 2008; Nielsen, 2003). Alonzo (2000) cites sudden unexpected illness onsets, invasive medical therapies, and cumulative adversity as stressors that potentiate the onset of post-traumatic stress symptoms. PTSD is associated with substantial morbidity, diminished quality of life, high levels of medical utilization, and high economic costs (Kessler, 2000; Pace & Heim, 2011; Seedat, Lochner, Vythilingum, & Stein, 2006).
Early identification of PTSD risk may allow for tailored interventions in ICU family members during the illness in order to reduce acute stress as well as post-traumatic stress. However, there are a number of methodological issues pertaining to the study of post-traumatic stress in family members of ICU patients that can influence the validity, relevance, and generalizability of research in this challenging population. The purpose of this paper is to review the relevant literature pertaining to post-traumatic stress symptoms in ICU family members and the methodological challenges that must be addressed in conducting research in this challenging area.

**Methodological Issues**

The salient literature was searched using PubMed, CINAHL, and PsycInfo electronic databases. The search was limited to English language studies with no year limits. Keywords used in the search included: “ICU family”, “ICU decision-maker”, “stress”, “post-traumatic stress”, “post-traumatic stress disorder”, “PTSD”, “intensive care unit”, and “critical care”. The search was limited to “adult ICU patients”. Abstracts were reviewed for appropriate content and relevance to the topic. Finally, the reference lists of the articles identified in the initial search were reviewed for further pertinent literature. From this search strategy, nine studies were identified that reported on prevalence of post-ICU PTSD symptoms in families of ICU patients. Aspects of study design that are important in evaluating validity and generalizability of findings include sample and measurement decisions.

**Sample**

Identification of a representative sample of ICU family members is critical to reliable and generalizable findings in PTSD symptom studies. To date, nine studies have
described PTSD symptoms in ICU family members following ICU discharge (Anderson et al., 2008; Azoulay et al., 2005; Garrouste-Orgeas et al., 2012; Gries et al., 2010; Jones et al., 2004; Jones, Backman, & Griffiths, 2012; Lautrette et al., 2007; Pillai et al., 2006; Pillai et al., 2010) (Table 4). More than half the studies examined PTSD symptoms in family members without identifying whether they served in the FDM role (Garrouste-Orgeas et al., 2012; Jones et al., 2004; Jones et al., 2012; Pillai et al., 2006; Pillai et al., 2010). Azoulay et al. (2005) and Gries et al. (2010) evaluated PTSD symptoms in all available family members but identified and separately analyzed those family members that participated in decision-making. Anderson et al. (2008) and Lautrette et al. (2007) examined PTSD symptoms in only FDMs. In most studies, samples have been generated using consecutive convenience sampling techniques, which may limit generalizability of study findings.

Enrollment of ICU family members into clinical studies early in the ICU hospitalization can be difficult. Initial consent refusal rates are not always published in studies but have been reported to range from five to thirty eight percent (Anderson et al., 2008; Azoulay et al., 2005; Lautrette et al., 2007; Pillai et al., 2010). Reasons for refusal to participate can include high levels of acute stress, sensitive questions about PTSD symptoms, inability to understand the study, and disinterest in participating in research. In the author’s experience, the most common reason given by family members for refusal to participate is the feeling of being overwhelmed by the ICU experience. Participation in a study represents an added burden and responsibility at a time when personal resources are already seemingly stretched to their limit.
Setting

The type of ICU or ICU population (surgical, medical, trauma, etc.) may influence stress and prevalence of PTS symptoms. Different types of ICU settings, which reflect different population characteristics, may be associated with varied sets of expectations based on the age of the patients, the suddenness of the illness, and the anticipated outcomes. Chui and Chan (2007) found that family stress levels were higher in families of ICU patients who experienced an unplanned ICU admission compared to families of individuals who experienced a planned ICU admission (IESM = 26.2 vs IESM = 22.9, \( p = .03 \)). Diagnosis at the time of admission did not influence stress levels. However, Azoulay et al. (2005) reported higher levels of PTSD symptoms in family members of ICU patients admitted for malignancy and hematologic disorders and lower levels in families of ICU patients admitted with chronic heart failure (\( p < .05 \)). Pillai et al. (2010) demonstrated no difference in family PTSD symptom prevalence when comparing trauma and medical ICU families two months after the ICU illness.

The country from which the sample is taken can also influence the prevalence of PTSD symptoms. In general, French cohort studies have reported higher prevalence of PTSD symptoms than US, UK, or Indian cohorts, with a symptom prevalence of 33-82% (Azoulay et al., 2005; Garrouste-Orgeas et al., 2012; Lautrette et al., 2007). The remaining cohorts report a symptom of prevalence of 14-46% (Anderson et al., 2008; Gries et al., 2010; Jones et al., 2004; Jones et al., 2012; Pillai et al., 2006; Pillai et al., 2010). Gries et al. (2010) suggested that cultural factors may explain some of the differences in PTSD symptom prevalence between French cohorts and US cohorts. The authors reported that discordance between decision-making preferences and actual
decision-making role was associated with increased PTSD symptoms. The French medical system tends to be a more paternalistic system in which the physician has the final say in regard to decision making with variable amounts of input from family members (Pochard, Azoulay, Chevret, Vinsonneau, & Herve, 2001). This may impact the discordance between decision-making preference and actual decision-making role.

**Inclusion and Exclusion Criteria**

**Patient.** Characteristics of the patient and the patient’s ICU course can influence the risk of PTSD in family members. The majority of patients admitted to an ICU stabilize quickly and are discharged after a short ICU stay (Society of Critical Care Medicine, 2012; Wiencek & Winkelman, 2010). Most studies examining PTSD symptoms in ICU family members have excluded patients who stabilize quickly by only including patients with an ICU stay of at least 48 hours (Anderson et al., 2008; Azoulay et al., 2005; Garrouste-Orgeas et al., 2012; Jones et al., 2004; Jones et al., 2012; Pillai et al., 2010). Intuitively, a short uncomplicated ICU stay would seem to be less likely to increase the risk of PTSD symptoms in family members when compared to families who experience a long and complicated ICU course. However, several studies have demonstrated no relationship between patient ICU length of stay and family member prevalence of PTSD symptoms (Garrouste-Orgeas et al., 2012; Jones et al., 2004; Lautrette et al., 2007).

The relationship between severity of ICU illness and family PTSD symptoms is also unclear. Azoulay et al. (2005) demonstrated a significant relationship between severity of illness and PTSD symptoms while other authors have found no association (Garrouste-Orgeas et al., 2012; Jones et al., 2004). Garrouste-Orgeas et al. (2012)
reported a relationship between the patient need for mechanical ventilation and subsequent PTSD symptoms among family members. Jones et al. (2012) required at least 24 hours of mechanical ventilation for inclusion in their study. Furthermore, ICU hospitalization outcome (death or discharge of the patient) may also influence PTSD symptoms. Azoulay et al. (2005) and Pillai et al. (2010) identified patient death as a risk factor for ICU family PTSD symptoms while Anderson et al. (2008) found no difference between bereaved and non-bereaved family members.

**Family.** In identifying the target sample for study of post-ICU family member PTSD symptoms, inclusion and exclusion criteria are clearly important. Investigating all family members available during a patient’s ICU stay would be one option for investigating PTSD symptoms (Azoulay et al., 2005, Jones et al., 2004). Other options would be to identify a “primary” family member using next of kin rules or identifying family members who are thought to be at higher risk of PTSD symptoms after ICU hospitalization (Anderson et al., 2008; Lautrette et al., 2007). Several characteristics have been identified as risk factors in ICU family members.

**Family decision-maker role.** Azoulay et al. (2005) identified decision-making as a factor that increased the prevalence of PTSD symptoms in ICU family members. Higher rates of PTSD symptoms were noted among those who shared in decision-making (47.8%) with the highest prevalence of PTSD symptoms found in family members whose decisions involved end-of-life issues (81.8%). Lautrette et al. (2007) and Anderson et al., (2008) also reported a high prevalence of PTSD symptoms among FDMs (69% and 35% respectively). Several studies do not identify family members who participated in decision-making making comparisons among studies difficult (Jones et al., 2004;
Garroutse-Orgeas et al., 2012; Pillai et al., 2006; Pillai et al., 2010). Gries and colleagues (2010) reported a low overall prevalence of PTSD symptoms in ICU families (14%) but identified discordance between decision-making preferences and actual decision-making role as a risk factor for PTSD symptoms ($p = .005$). In a secondary analysis of the study population in Gries et al. (2010), Kross et al. (2011) described higher levels of PTSD symptoms in family members who participated in early family conferences, which may indicate discordance between actual and desired decision-making role or lack of time to mentally prepare and accept the impending death of a loved one.

Concordance between decision-making preference and actual decision-making role may be an important factor in the association between decision-making and PTSD symptoms. Variability in the clear identification of family decision-makers in the family ICU PTSD literature hampers comparisons between studies. Furthermore, some families prefer and utilize a shared decision-making approach, obtaining consensus among members of the family, while conflict between family members and lack of consensus during decision-making can increase the stress of the decision-making role (Vig et al., 2007). Thus, the FDM role has variations in expectation and experience that may influence the risk of PTSD symptoms. Future studies on post-ICU family PTSD symptoms should clearly identify the FDM and investigate other FDM variables such as role preference, decision-making style, and family concordance.

**Family member gender.** Some authors associate female gender with a higher risk of family member PTSD symptoms following critical illness (Azoulay et al., 2005; Gries et al., 2010). Other authors have not demonstrated this relationship (Anderson et al., 2008; Garroutse-Orgeas et al., 2012; Pillai et al., 2010). However, female gender has
been identified as an independent risk factor for the development of PTSD in other patient populations such as combat, victims of crime, natural disasters, and motor vehicle accidents (Brewin, Andrews & Valentine, 2000; Javidi & Yadollahie, 2012).

**Family member-patient relationship.** Several authors have described associations between the nature of the relationship between FDM and patient and PTSD symptoms (Azoulay et al., 2005; Gries et al., 2010; Kross et al., 2011). Azoulay et al. (2005) reported adult children of ICU patients having higher rates of PTSD symptoms compared to other familial relationships such as parent or sibling ($p < .05$). Gries et al. (2010) found that having a relationship with the patient other than spouse or adult child and knowing the patient for a shorter length of time was associated with higher prevalence of PTSD symptoms ($p = .003$). Kross et al. (2011) reported that family members of older patients had lower levels of PTSD symptoms and suggested that critical illness and death of younger patients may place family members at higher risk of psychological burden. Echoing this idea, Pillai et al. (2010) found a higher prevalence of PTSD symptoms in parents of ICU patients. Given the largely disparate findings in these studies as with other variables, a firm association between the FDM-patient relationship and PTSD symptoms is elusive.

**Family member level of education.** Pillai et al. (2010) described a higher prevalence of PTSD symptoms among family members who never completed high school. The authors suggest that this relationship may be due to lower social support and inadequate coping resources. The relationship between level of education and risk of PTSD symptoms has not been described in other ICU family populations but has been
reported in other PTSD populations with lower levels of education being associated with a higher prevalence of PTSD symptoms (Brewin, Andrews & Valentine, 2000).

**Family member psychological treatment history.** Gries et al. (2010) noted medical care for psychological symptoms (medication use or outpatient counseling) in the year prior to ICU admission of a family member was associated with increased PTSD symptoms. Obtaining sensitive information on the psychiatric history of ICU family members can be difficult and may cause some to shy away from participating in a study of PTSD or refusal to answer particular questions about their psychological history. The influence of pre-admission psychological issues is important because persons with a significant burden of PTSD symptoms also have an increased risk for concomitant depression, anxiety, and complicated grief (Anderson et al., 2008; Azoulay et al., 2005; Garrouste-Orgeas et al., 2012; Gries et al., 2010; Jones et al., 2004; Lautrette et al., 2007; Siegel et al., 2008).

**Attrition.** Although ICU family members are usually identified for participation in PTSD symptom studies during the ICU hospitalization, the measurement of PTSD symptoms is typically performed at a time point after the ICU experience. Attrition of participants can decrease the power and generalizability of the findings. In post-ICU PTSD symptom studies, attrition rates have been reported of 14 percent to 57 percent (Anderson et al., 2008; Azoulay et al., 2005; Garrouste-Orgeas et al., 2012; Gries et al., 2010; Jones et al., 2004; Jones et al., 2012; Lautrette et al., 2007; Pillai et al., 2006; Pillai et al., 2010). Although it is difficult to know, family members suffering the most from PTSD symptoms may also be the most likely to decline continued participation in a study following the ICU illness. Cross sectional study designs may decrease attrition rates when
compared to longitudinal designs but limit the ability to determine causal and sequential relationships or changes in variables over time. One possible strategy to limit attrition is provision of an incentive for family members to complete the study, but there is no evidence that this is effective.

Measurement

Measurement of the phenomenon is central to the validity of any study. In the case of PTSD symptoms, there have been a variety of instruments and interpretations of scales. The instruments reflect the diagnostic criteria of PTSD and are intended to measure the prevalence and severity of PTSD symptoms. Therefore, an understanding of PTSD diagnostic criteria is essential in selecting an instrument that effectively measures PTSD symptoms.

PTSD Diagnostic Criteria. PTSD was first recognized as a psychiatric disorder with the publication of the third edition of the Diagnostic and Statistical Manual of Mental Health Disorders (DSM-III) of the American Psychiatric Association (1980). The diagnostic criteria for PTSD were further refined in the DSM-IV (2000) and recently published DSM-V (2013). The tools used to measure post-traumatic stress symptoms in post-ICU family members were developed to reflect the diagnostic criteria enumerated in the DSM-III and DSM-IV. The following section will briefly discuss the diagnostic criteria of PTSD as described in the DSM-IV, the tools used to measure PTSD symptoms, and the changes in PTSD diagnosis recently proposed in the DSM-V.

Post-traumatic stress disorder (PTSD) can be characterized as a prolonged stress response syndrome (Wilson, 2004). According to the DSM-IV, PTSD occurs after exposure to a stressor in which the person experiences or witnesses events that threaten
death or serious harm to the individual or others (American Psychiatric Association, 2000). The individual experiences feelings of fear, helplessness, or horror during exposure to the stressor. The exposure to the stressor results in three symptom clusters that must be present for at least a month after exposure to the stressor: intrusive recollections, avoidant/numbing symptoms, and hyper-arousal symptoms. The symptoms cause significant distress or impairment in personal, social, or occupational functioning.

Several important changes to the diagnostic criteria of PTSD can be found in the DSM-V (American Psychiatric Association, 2013). First, PTSD is no longer classified as an anxiety disorder but is described in a new section identified as trauma and stress related disorders. In the most recent guidelines, the traumatic event is delineated as exposure to actual or threatened death of self or a loved one, serious injury, or sexual assault. Recurring exposure to stressful situations such as experienced by police officers or first responders is specifically included. The DSM-V expands the three symptom clusters from DSM-IV to four symptom clusters: re-experiencing, avoidance, negative cognitions and mood, and arousal. Similar to the DSM-IV, the symptoms need to be present for more than a month after removal of the traumatic stressor. However, the designation of chronic PTSD for symptoms that persist greater than six months has been removed. For individuals with prominent dissociative symptoms, a dissociative subtype of PTSD has been added. See Table 5 for a summary of differences between DSM-IV and DSM-V.

**Measurement Tools.**

Several tools have been used in studies examining post-ICU PTSD symptoms. Decisions about which measurement tool is best suited for studying PTSD symptoms in
ICU family members are important when discussing reliability and generalizability of study findings.

**Impact of Event Scale (IES).** The Impact of Event Scale (IES) is an instrument for detecting symptoms of post-traumatic stress. Horowitz, Wilner, & Alvarez (1979) proposed the original IES. The scale provides information on both the presence of stress related symptoms and their severity. The 15-item instrument has two subscales: intrusion and avoidance. The items are scored on a four point scale (0 = not at all, 1 = rarely, 3 = sometimes, 5 = often). The total score ranges from 0 to 75 with higher scores indicating higher levels of post-traumatic stress symptoms. The scale has been used in many different populations to measure PTSD symptoms and following many different stressors (Sundin & Horowitz, 2002). The IES has demonstrated adequate reliability and validity across a range of traumatic events and outcome studies. The scale is simple, versatile, and can be administered over the phone.

Impact of Event Scale (IES) was used to measure PTSD symptoms in four studies (Anderson et al., 2008; Azoulay et al., 2005; Jones et al., 2004; Lautrette et al., 2007). Three groups of investigators used scores greater than 30 to identify individuals with significant PTSD symptoms and high risk for PTSD (Anderson et al., 2008; Azoulay et al., 2005; Lautrette et al., 2007). Jones et al. (2004) used IES scores greater than 19 to identify individuals whose symptoms were concerning for PTSD. The cutoff scores are not used to identify individuals with PTSD but to estimate the risk of having PTSD.

**Impact of Event Scale-Revised (IES-R).** Weiss and Marmar (1997) released a revised version of the IES with three subscales corresponding to the three symptom clusters described in the DSM-IV. The IES-R is a 22-item instrument scored using a 5-
point scale ranging from 0 (not at all) to 4 (extremely) for each item. Total scores may range from 0-88 with higher scores indicating higher levels of post-traumatic stress symptoms. Three mean sub-scores may also be computed: the intrusion subscore (seven items), the avoidance subscore (eight items), and the hyperarousal subscore (seven items). The intrusion score reflects how persistently thoughts and impressions associated with the event reappear. The avoidance score assesses behaviors designed at avoiding people, places, or activities that act as reminders of the stressful event. The hyperarousal score reflects physiologic symptoms such as insomnia, irritability, and hypervigilance.

Several authors have reported reliability for the IES-R. Creamer, Bell, and Falilla (2003) reported a Cronbach’s α of .96 in a sample of Vietnam veterans with and without confirmed PTSD. High levels of internal consistency for the subscales have been reported: intrusion (Cronbach’s α = .87 - .94); avoidance (Cronbach’s α = .84 - .87); hyperarousal (Cronbach’s α = .79 - .91) (Creamer et al., 2003; Weiss & Marmar, 1997). Test-retest reliability across a six month interval ranged from .89 to .94 (Weiss & Marmar, 1997). Beck et al. (2008) examined the psychometric properties of the IES-R in a sample of motor vehicle accident survivors. The authors reported Cronbach’s α for the total scale (.95) as well as the three subscales: intrusion (.90), avoidance (.86), and hyperarousal (.85). Creamer et al. (2003) reported concurrent validity with a correlation of .84 between the IES-R and the PTSD Checklist. Creamer et al. (2003) also reported good discriminative validity of the IES-R for the diagnosis of PTSD. Scores above 33 were highly predictive of the diagnosis of PTSD with a sensitivity of .91 and a specificity of .82. Beck et al. (2008) reported lower sensitivity and specificity for correctly predicting PTSD at 77.6 and 61.9 respectively. Garrouste-Orgeas et al. (2012) used IES-
R scores above 22 while Pillai et al. (2006, 2010) used IES-R scores above 26 to identify individuals with significant symptoms of PTSD. Variability in the cutoff scores used to identify individuals with “high” levels of PTSD symptoms using the IES and IES-R makes comparisons between studies difficult and may explain inconsistent findings.

Posttraumatic Stress Disorder Checklist Civilian Version (PCL-C). The PCL-C is a 17-item self-report rating scale to assess symptoms of PTSD (Weathers, Litz, Herman, Huska, & Keane, 1994). The items are scored on a five point scale (1 = not at all, 2 = a little bit, 3 = moderately, 4 = quite a bit, 5 = extremely). The 17 items are divided into three subscales that correspond with the three symptom clusters of PTSD described in the DSM-IV (American Psychiatric Association, 2000). The PCL-C can be scored two different ways. The total score can range from 17 to 85 with higher scores indicating higher PTSD symptom severity. Weathers et al. (1994) suggested a cutoff score of 50 and above as a predictor of PTSD risk in male military veterans. Blanchard, Jones-Alexander, Buckley, and Forneris (1996) found a cutoff score of 44 and above to have better diagnostic efficacy in a sample of motor vehicle and sexual assault victims with a sensitivity of .94 and a specificity of .86. Each individual item can also be scored dichotomously with scores of three or greater considered a symptom while scores of one or two are not. Significant risk for PTSD requires one intrusive symptom, three avoidant symptoms, and two arousal symptoms. Cronbach’s alpha coefficient was .94 with test-retest correlation coefficients of .92 at immediate retest, .88 at one week retest, and .68 at two weeks retest in a sample of university students (Ruggiero, Del Ben, Scotti & Rabalais, 2003). The authors reported good convergent validity with other PTSD symptom scales and discriminant validity with a diagnosis of PTSD. Similar
psychometric properties have been demonstrated by other authors (Dobie et al., 2002; Walker, Newman, Dobie, Ciechanowski, & Katon, 2002). However, Gries et al. (2010) is the only study that used PCL-C in examining post-ICU family PTSD symptoms.

**Post-Traumatic Stress Syndrome 14-Question Inventory (PTSS-14).** Jones et al. (2012) utilized the PTSS-14 in a United Kingdom (UK) family member PTSD pilot study. The PTSS-14 was developed in the UK as a simple and easy to administer screen for PTSD symptoms incorporating diagnostic criteria of the DSM-IV (Twigg, Humphries, Jones, Bramwell & Griffiths, 2008). The structure of the instrument is based on the PTSS-10 which was reflective of the diagnostic criteria of DSM-III (Holen, Sund & Weisaeth, 1980). The PTSS-14 is composed of two parts. Part A consists of four yes/no questions about memories that relatives may have from the time of the critical care illness (e.g., nightmares, breathlessness, anxiety). Part B consists of 14 questions about PTSD symptoms scored on a one to seven scale (1 = never, 7 = always). Total score can range from 14 to 98 with higher scores indicating more severe PTSD symptoms. Although psychometric testing in ICU patients has been sparse, one study by Twigg et al. (2008) demonstrated good internal consistency, test-retest reliability, concurrent validity, and predictive validity.

**Summary of PTSD measurement tools.** A complete discussion of the measurement tools available for assessing PTSD symptoms in all populations is beyond the scope of the current discussion. Only the tools used to date in studies examining PTSD symptoms in post-ICU family members have been discussed. The tools used to measure PTSD symptoms reflect the symptom clusters delineated in the DSM manual. It should be noted that none of the scales are intended to make the diagnosis of PTSD but to
indicate the degree to which PTSD symptoms are being experienced or as a screening tool for individuals who may benefit from more formal testing for PTSD. The lack of standardization in measurement tools for assessing PTSD symptoms in post-ICU family members not only makes comparison of studies difficult and explain some of the variation in the prevalence of PTSD symptoms, but also raises questions of validity. To date, there is no strong consensus about which instrument or cut-off values correlate best with the diagnostic gold standard, a full psychiatric assessment by a mental health professional.

**Timing of Measurement.** The time after ICU admission at which PTSD symptoms were measured is another source of variation among the studies. Measurements of PTSD symptoms occurred from 2 months to several years after ICU discharge. Studies measuring PTSD symptoms within six months of the ICU illness reported a prevalence of PTSD symptoms from 33% to 69% (Anderson et al., 2008; Azoulay et al., 2005; Jones et al., 2004; Lautrette et al., 2007; Pillai et al., 2010).

Prevalence of PTSD symptoms measured greater than six months after ICU death or discharge varied widely. Garrouste-Orgeas et al. (2012) described a prevalence of PTSD symptoms measured at 12 months after ICU discharge to be 68-80%. Gries et al. (2010) reported a prevalence of PTSD symptoms of 14% measured at least six months and up to four years after ICU death. Pillai et al. (2006) measured PTSD symptoms two years after ICU discharge reporting a moderate severity symptom prevalence of 12-14% and severe symptom prevalence of 4-5%.

Measurement of PTSD symptoms at a certain time point after ICU discharge is somewhat arbitrary, especially when the patient survives the ICU illness. Death of the
patient is a clear event to determine an appropriate later time point (at least one month after death for PTSD symptoms) to measure PTSD symptoms. However, the magnitude of the PTSD symptoms arising from the loss of a loved one are difficult to separate from the symptoms resulting from the ICU experience. When the patient survives, discharge from the ICU or from the hospital does not necessarily remove ongoing stressors. Some patients may be discharged to a long term care facility with persistent chronic medical issues. Other patients may experience a long hospital course following transfer out of the ICU prior to hospital discharge. Patients who are discharged home may require significant care giving from their family members. Family members may feel ill-prepared to care for a chronically ill family member (Schmidt & Azoulay, 2012). The phenomenon of caregiver burden is well described in other populations and may contribute to ongoing stress in family members following hospital discharge (Chenier, 1997; Etters, Goodall & Harrison, 2008; Grunfeld et al., 2004). In a study of caregivers of long term ventilator patients, Douglas and Daly (2003) demonstrated a drop in physical health scores and elevated caregiver overload scores as significant contributors to symptoms of depression in family member caregivers.

**Interventions**

Intervention studies evaluating PTSD symptoms in post-ICU family members have shown promise in diminishing the burden of PTSD symptoms. Lautrette et al. (2007) investigated the impact of an end-of-life conference communication strategy and bereavement brochure on psychological symptoms of family members of dying ICU patients. The authors reported a lower prevalence of anxiety (45% vs. 67%, \( p = .02 \)), depression (29% vs. 56%, \( p = .003 \)), and PTSD symptoms (45% vs. 69%, \( p = .01 \)). Two
studies demonstrated a decreased prevalence of family member PTSD symptoms following the use of ICU diaries (Garrouste-Orgeas et al., 2012; Jones et al., 2012). However, an earlier study by Jones et al. (2004) evaluating the effect of a self-help manual for family members following ICU discharge demonstrated no difference in anxiety, depression, or PTSD symptom scores between intervention and control groups at eight weeks and six months after ICU discharge. Although there is some evidence to suggest that the degree to which family members experience PTSD symptoms following ICU discharge is amenable to intervention, further studies are needed to elucidate the most efficacious method, valid instrument, and timing of intervention.

**Discussion**

The demand and use of ICU services has increased steadily since the middle of the 20th century and the growth is expected to continue with the aging population. The psychological impact of critical care illness can continue to affect the patient and family long after the ICU illness is over. Family members provide support and decision-making during and after the ICU illness. Often, they are also providing direct care after discharge from the hospital. Symptoms of PTSD in this vulnerable group can be significant and can impact their ability to function in society. A better understanding of the experience of ICU family members, the risk factors for developing PTSD symptoms, and opportunities for intervening in the stress response may provide opportunities to provide family centered care in the ICU environment.

As has been noted earlier, there are several methodological challenges in studying PTSD in post-ICU families. Obtaining an adequate sample can be challenging and is influenced by enrollment procedures and attrition rates. Variables to consider in obtaining
a representative sample include type of ICU, patient diagnosis, and cultural factors. Although the data establishing risk is not strong, focus on family members who are likely to be at higher risk for PTSD symptoms, decision-makers and families of patients at risk for a prolonged ICU course, may be the most efficient approach to identify modifiable factors that influence the severity and prevalence of PTSD symptoms. Furthermore, obtaining an accurate psychological history of ICU family members also appears to be important in assessing PTSD symptom risk.

Measurement challenges include choice of measurement tool and timing of PTSD symptom measurement. The IES-R and PCL-C instruments have been used previously in ICU family members and demonstrate adequate psychometric properties. Standardization of the measurement instrument used in PTSD research for ICU families would help limit variability in prevalence and severity of symptoms reported in the literature. The IES-R has been most widely used, and at this point, enables the greatest amount of comparison among studies. However, recent changes in the diagnostic criteria of PTSD in DSM-V will almost certainly prompt further revisions in the measurement tools for PTSD symptoms, given the history of changes that occurred after publication of previous editions of the DSM manual. With the recognition of post intensive care syndrome-family (PICS-F) by the Society of Critical Care Medicine and increasing research in studying the experience of post-ICU family members, some recommendations about the best tool for assessing PTSD symptoms may be forthcoming to help guide future investigations (Needham et al., 2012). Additionally, reporting PTSD symptom prevalence is clearly influenced by measurement time frame. Patients experiencing early symptoms of PTSD
(three to six months after ICU discharge) should be reported separately from individuals experiencing symptoms one or several years after the ICU illness.

A better understanding of the post-ICU factors that promote PTSD symptoms is essential to understanding the phenomenon. Longitudinal studies examining the trajectory of family PTSD symptoms following ICU hospitalization are needed. Examination of coping strategies used by ICU family members may help elucidate the dynamic relationship between the stress of the ICU experience and the adaptation or maladaptation experienced afterward. Additionally, the influence of caregiver burden and ongoing post-ICU stressors have received little attention to date. While some intervention studies have demonstrated a reduced prevalence and severity of PTSD symptoms, better understanding of the mechanism of these interventions is needed to guide further refinement in identification and support of at risk family members. It is clear that ICU families struggle during and after the ICU experience. Further studies are necessary to understand their experience and to tailor interventions that may have a beneficial effect in reducing stress and PTSD symptoms.
Table 4.
**Summary of Post-ICU Family PTSD Symptom Studies**

<table>
<thead>
<tr>
<th>Author</th>
<th>Country</th>
<th>Sample</th>
<th>Tool/ Cutoff score</th>
<th>Timing of PTSD measurement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jones et al., 2004</td>
<td>UK</td>
<td>104 family members of ICU patients</td>
<td>IES &gt; 19</td>
<td>8 weeks &amp; 6 months after discharge from ICU</td>
</tr>
<tr>
<td>Azoulay et al., 2005</td>
<td>France</td>
<td>284 family members of ICU patients</td>
<td>IES &gt; 30</td>
<td>3 months after discharge from ICU or death</td>
</tr>
<tr>
<td>Pillai et al., 2006</td>
<td>India</td>
<td>177 relatives of ICU trauma patients</td>
<td>IES-R ≥ 26</td>
<td>7 days after admission to ICU and 2 years later</td>
</tr>
<tr>
<td>Lautrette et al., 2007</td>
<td>France</td>
<td>126 FDMs of relatives of dying ICU patients</td>
<td>IES &gt; 30</td>
<td>3 months after death</td>
</tr>
<tr>
<td>Anderson et al., 2008</td>
<td>USA</td>
<td>50 FDMs of ICU patients</td>
<td>IES &gt; 30</td>
<td>6 months after enrollment into study</td>
</tr>
<tr>
<td>Gries et al., 2010</td>
<td>USA</td>
<td>226 family members of dying ICU patients</td>
<td>PCL-C</td>
<td>6-36 months after death</td>
</tr>
<tr>
<td>Pillai et al., 2010</td>
<td>India</td>
<td>166 relatives of ICU patients</td>
<td>IES-R &gt; 26</td>
<td>5th day of ICU admission, 2 months after discharge or death from ICU</td>
</tr>
<tr>
<td>Garrouste-Orgeas et al., 2012</td>
<td>France</td>
<td>143 family members of ICU patients</td>
<td>IES-R ≥ 22</td>
<td>12 months after ICU discharge</td>
</tr>
<tr>
<td>Jones et al., 2012</td>
<td>UK</td>
<td>36 relatives of patients recovering from ICU admission</td>
<td>PTSS-14</td>
<td>1, 3 month(s) after ICU discharge</td>
</tr>
</tbody>
</table>

FDM = Family Decision Maker; IES = Impact of Event Scale; IES-R = Impact Of Event Scale-Revised; PTSD PCL-C = Post Traumatic Stress Disorder Checklist Civilian Version; PTSS-14 = Post-Traumatic Stress Syndrome-14; UK = United Kingdom; USA = United States of America
Table 5.
Summary of Changes to PTSD Diagnostic Criteria from DSM-IV to DSM-V

<table>
<thead>
<tr>
<th>Criterion</th>
<th>DSM-IV</th>
<th>DSM-V</th>
</tr>
</thead>
</table>
| Stressor                   | The person has been exposed to a traumatic event in which both of the following have been present:  
- The person has experienced, witnessed, or been confronted with an event or events that involve actual or threatened death or serious injury, or a threat to the physical integrity of oneself or others.  
- The person’s response involved intense fear, helplessness, or horror. | Similar language to DSM-IV in regard to event or stressor with specific language specifying repeated prolonged exposure to stressful situations (e.g. police officers or first responders).  
The response of intense fear, helplessness, or horror has been removed since it did not have utility in predicting PTSD |
| Symptom Clusters           | 3 Clusters:  
- Intrusive recollections  
- Avoidance  
- Hyperarousal            | 4 Clusters:  
- Re-experiencing  
- Avoidance  
- Negative cognitions and mood  
- Arousal |
| Duration                   | Duration of symptoms is more than 1 month                              | Duration of symptoms is more than 1 month                              |
| Subtypes                   | Chronic- symptom duration of greater than 3 months  
Delayed onset-symptom onset greater than 6 months after stressor | Chronic and delayed subtypes removed  
Preschool subtype-children younger than 6 years  
Dissociative subtype-prominent dissociative symptoms |

PTSD = Post-traumatic stress disorder; DSM-IV = Diagnostic and Statistical Manual of Mental Health Disorders-IV; DSM-V = Diagnostic and Statistical Manual of Mental Health Disorders-V
CHAPTER V: Coping Strategies and Post-Traumatic Stress Symptoms in post-ICU

Family Decision-Makers

Preface

This chapter presents the second manuscript for publication, which will be submitted to Critical Care Medicine. This chapter provides the background of post-ICU family PTSD symptoms, the methods and results of the dissertation study, and a discussion of the significance and limitations of the study.
Abstract

Family decision makers (FDMs) experience high levels of stress during the ICU hospitalization and are at risk for post-traumatic stress disorder (PTSD) symptoms after the death or discharge of the patient. There is empirical evidence demonstrating a relationship between coping strategy and PTSD symptoms. The purpose of this research study was to describe the coping strategies utilized by FDMs of ICU patients, examine how these coping strategies changed over time, and examine the relationship between ICU FDM coping strategy and later PTSD symptoms.

Seventy-seven adult ICU FDMs were the subject of this study. The mean IES-R score for the sample was 23.14 (SD = 15.90). FDM problem-focused coping scores were highest while avoidant coping scores were lowest at both measurement time points (Time 1: problem-focused $M = 3.10$, $SD = .74$; emotion-focused $M = 2.82$, $SD = .46$; avoidant $M = 1.55$, $SD = .34$; Time 2: problem-focused $M = 2.88$, $SD = .72$; emotion-focused $M = 2.66$, $SD = .53$; avoidant $M = 1.61$, $SD = .46$). The use of problem-focused ($t = 2.53, p = .01$) and emotion-focused ($t = 2.98, p < .01$) coping decreased over time while avoidant coping ($t = 1.29, p = .20$) use remained stable. Regression analysis using Time 1 coping strategies and patient/FDM characteristics significantly predicted later IES-R score ($R^2 = .30; F (7,69) = 4.14, p = .001$) with death of the patient the only independent predictor of PTSD symptom severity ($B = 12.47, p < .01$). Regression analysis using Time 2 coping strategies and patient/FDM characteristics was a better predictor of IES-R score ($R^2 = .50; F (7,69) = 9.90, p < .001$) with avoidant coping ($B = 16.98, p < .01$) and problem-focused coping ($B = 6.26, p .01$) being independent predictors of later IES-R score. Time
avoidant coping mediated the relationship between patient death and later PTSD symptom severity.

ICU FDM coping strategies appear to have a significant influence on later PTSD symptoms. An understanding of these coping strategies use may provide opportunities for focused nursing interventions to diminish later PTSD symptoms.
Family members of critically ill patients experience tremendous psychological distress during the intensive care unit (ICU) experience (Auerbach et al., 2005; Chui & Chan, 2007; McAdam, Dracup, White, Fontaine, & Puntillo, 2010; Paparrigopoulos et al., 2006; Pielmaier, Wlader, Rebetez, & Maercker, 2011; Pillai, Aigalikar, Vishwasrao, & Husainy, 2010; Pillai et al., 2006). In some instances, the magnitude of the psychological distress can be clinically significant and personally traumatic. Lemiale and colleagues (2010) reported that thirty six percent of family members of ICU patients are taking anxiolytic or antidepressant drugs and over eight percent are taking psychotropic drugs on discharge or death of their ICU family member. In the months following the ICU experience, family members are at risk for ongoing psychological distress including symptoms of generalized anxiety disorder, depression, panic disorder, post-traumatic stress disorder (PTSD), and complicated grief (Anderson, Arnold, Angus, Bryce, 2008; Anderson et al., 2009; Azoulay et al., 2005; Gries et al., 2010; Jones et al., 2004; Kross et al., 2011; Siegel, Hayes, Vanderwerker, Loseth, & Prigerson, 2008). More recently, the prevalence and severity of PTSD symptoms in post-ICU family members have been increasingly recognized in the literature (Anderson et al., 2008; Azoulay et al., 2005; Garrouste-Orgeas et al., 2012; Gries et al., 2010; Jones et al., 2004; Jones, Backman, & Griffiths, 2012; Lautrette et al., 2007; Pillai et al., 2006; Pillai et al., 2010).

Critically ill patients are often intubated, sedated, or neurologically compromised, which precludes them from actively participating in the decision-making process (Ely et al., 2001; McNicoll et al., 2003). A majority of ICU patients rely on a substitute decision-maker, usually a family decision maker (FDM), to participate in communication and decision-making with the health care providers at some point during their ICU illness.
Burden and stress are universal and pervasive experiences of FDMs (Braun, Beyth, Ford, & McCullough, 2008; Engstrom & Soderberg, 2004; Vig et al., 2007). Although the majority of patients admitted to an ICU survive the acute illness and leave the ICU after a brief stay, a significant minority experience complex and prolonged ICU courses, which may magnify the uncertainty and perplexity of the decision-making processes (Carson & Bach, 2002; Wiencek & Winkelman, 2010). The risk of loss of a loved one and the difficulty of making potentially life or death decisions may add to the anxiety and stress of FDMs. The high prevalence of PTSD symptoms following the ICU experience in FDMs of ICU patients compared to other family members may reflect these extreme threats (Anderson et al., 2008; Azoulay et al., 2005; Lautrette et al., 2007).

The relationship of coping to psychological and physical health outcomes has been studied extensively in the behavioral literature (Penley, Tomaka, & Wiebe, 2002). Incorporating the concepts of Lazarus and Folkman (1984), researchers describe three categories of coping behavior: problem-focused, emotion-focused, and avoidant (Ben-Zur, 2005; Carver, Scheier, & Weintraub, 1989; Roth & Cohen, 1986). In general, problem-focused and emotion-focused coping are considered adaptive and are positively correlated with improved mental health outcomes while avoidant coping is considered maladaptive and related to negative mental health outcomes (Coyne & Racioppo, 2000; Olff et al., 2005; Penley et al., 2002). Avoidant coping has been shown to be a predictor of decreased psychological adjustment in individuals suffering from acute and chronic health problems and associated with PTSD symptoms following a traumatic event (Glass et al., 2009; Krause, Kaltman, Goodman, & Dutton, 2008; Nielsen, 2003; Smith,
Tarakeshwar, Hansen, Kochman, & Sikkema, 2009; Stanton, Danoff-Burg, & Huggins, 2002; Ullman, Townsend, Filipas, & Starzynski, 2007). The use of avoidant coping strategies also have been associated with increased emotional distress among neuroscience ICU family members and with higher risk of PTSD symptoms in mothers of premature neonatal ICU infants (Shaw, Bernard, Storfer-Isser, Rhine & Horwitz, 2012; Wartella, Auerbach & Ward, 2009). However, there has been little data examining coping strategies utilized by FDMs of adult ICU patients and the relationship between coping strategies and PTSD symptoms.

The purposes of the current study were to determine: (a) the coping strategies utilized by FDMs of ICU patients early in the ICU admission and 30 days following hospital discharge or death of the patient for whom the FDM made decisions and (b) the relationship between coping strategies utilized by FDMs during and after the decision-making experience and PTSD symptoms experienced by FDMs 60 days after hospital discharge or death of the patient for whom the FDM made decisions.

**Methods**

**Sample and Setting**

The institutional review board of the study site approved this study. The current study was part of a larger NIH-funded study examining decision-making of FDMs of ICU patients (1RO1NR013322-01). The research setting included three adult ICU’s at a large tertiary care center. The study inclusion criteria for ICU patients were: a) mechanical ventilation or predicted ICU stay of greater than five days, b) lack of cognitive decisional capacity, c) age over 18 years, and d) has an identified family decision maker. Exclusion criteria for ICU patients included: a) able to make their own care decisions and b) family
meeting planned to discuss withdrawal of life-sustaining interventions for the patient or withdrawal in process. Study inclusion criteria for FDMs of ICU patients were: a) over 18 years of age, b) identified as the primary person responsible for ICU patient decision-making, and c) able to speak English.

**Design**

The study design was a descriptive longitudinal correlational study to identify coping strategies and symptoms of PTSD in FDMs of ICU patients and the extent of the relationship between FDM coping strategies and post-ICU symptoms of PTSD. A research assistant (RA) rounded in the ICU’s on a daily basis to identify patients and FDMs eligible for the study. Once a patient was identified as being eligible for the study, the bedside nurse was approached to verify the patient’s current neurological status and cognitive capacity. If eligibility criteria were met, an RA approached the FDM at the patient bedside. Enrollment and initial interviews were obtained at the bedside or a nearby private room according to the preference of the FDM. When a patient met the eligibility criteria for the study but the FDM was not present at the patient’s bedside, the RA explained the study to the potential participant by phone and either arranged a time to meet the participant face to face for enrollment or conducted the interview by phone.

The study design had three data collection points: Time 1 (T1) = day 3 to 5 after ICU admission, Time 2 (T2) = 30 days after discharge from the hospital or death of the patient, and Time 3 (T3) = 60 days after discharge or death of the patient. The demographic form was administered at T1. The Brief COPE instrument was administered at two time points: T1 and T2. The Impact of Event Scale-revised (IES-R) was administered at T3 only. At 30 days after discharge from the hospital, the FDM was
contacted by phone call, e-mail, or standard mail. Preference for follow-up was identified on enrollment to the study. After three attempts to reach the study participant by the preferred method, another method was attempted once. The same process was followed at 60 days after discharge from the hospital or death of the patient. A $10.00 gift card was presented to the FDM on enrollment to the study and again at T3 provided the FDM completed all time points of the study.

**Measurement**

**Demographic Form.** Patient and FDM characteristics were obtained from the FDM and the patient’s medical records. Patient characteristics included age, gender, ethnicity, length of ICU stay, length of hospital stay, and final disposition of the patient at 30 days (death or discharge from ICU). FDM characteristics included age, gender, ethnicity, relationship to the patient, previous decision-making experience, documentation of a living will, and designation of durable power of attorney.

**Brief Cope Instrument.** Coping strategy was measured at T1 and T2 by the Brief COPE instrument which is a 28-item measure of coping strategies (Carver, 1997). The Brief COPE is based on the model of coping of Lazarus and Folkman (1984) and the model of behavior regulation by Carver and Scheier (1981, 1990). The tool is derived from a longer 60-item instrument called the COPE Inventory (Carver, Scheier & Weintraub, 1989). The Brief COPE consists of 14 subscales of two items each. The items are scored using a 4-point Likert scale with responses ranging from 1 (I haven’t been doing this a lot) to 4 (I have been doing this a lot). Each of the 14 subscales can be reported as a total score (2-8) or a mean score (1-4) with higher scores indicating more use of the particular type of coping effort. Based on conceptual and theoretical literature,
several authors group the 14 subscales into three coping categories or strategies: a) problem-focused coping, b) emotion-focused coping, and c) avoidant coping (Coolidge et al., 2000; Cooper, Katona, and Livingston, 2008; Schnider, Elhai, & Gray, 2007). Each category score is reported as a mean score ranging from 1 to 4. Several authors have reported on the reliability, content validity, convergent validity, and divergent validity for the three coping strategy subscales (Cooper et al., 2008; Schnider et al., 2007; Snell, Siegert, Hay-Smith, & Surgenor, 2011). The Brief COPE instrument has not been used to date in a sample of adult ICU FDMs but has been used to assess coping strategies in mothers of neonatal ICU patients as well as victims of trauma, natural disasters, and cancer (Glass et al, 2009; Pacella et al., 2011; Shaw, Bernard, Storfer-Isser, Rhine, & Horwitz, 2012; Wong, et al., 2006).

**Impact of Event Scale-Revised (IES-R).** Symptoms of post-traumatic stress were measured by the Impact of Events Scale-Revised (IES-R) at T3. The IES-R is an instrument for detecting symptoms of post-traumatic stress. Horowitz, Wilner, & Alvarez (1979) proposed the original IES. The scale provides information on both the presence of stress related symptoms and their severity. The 15-item instrument had two subscales: intrusion and avoidance. Weiss and Marmar (1997) released a revised version of the IES with three subscales corresponding to the three symptom clusters of PTSD described in the Diagnostic and Statistical Manual of Mental Disorders-IV: intrusion, avoidance, and hyperarousal (American Psychiatric Association, 2000). The IES-R is a 22-item instrument scored using a 5-point scale ranging from 0 (not at all) to 4 (extremely) for each item. Total scores may range from 0-88 with higher scores indicating higher levels of post-traumatic stress symptoms. Several authors have reported validity and reliability.
of the scale in varied patient populations (Beck et al., 2008; Creamer, Bell, & Falilla, 2003; Weiss & Marmar, 1997).

**Data Analysis**

Descriptive statistics were used to assess frequencies and variability of the data. Nominal or ordinal variables were described using absolute N and proportions. Interval/ratio variables were described using means and standard deviations. Bivariate associations were examined using Pearson correlations and Chi-square analysis. Differences between groups were examined using dependent samples *t*-tests, two sample *t*-tests, and one-way ANOVA. Associations between demographic variables, coping strategies, and PTSD symptoms were evaluated using multiple regression models, after confirming that the data met test assumptions. Two-sided *p*-values < .05 were considered statistically significant. Data were analyzed using the Statistics Package for the Social Sciences (SPSS, IBM Corp., Armonk, NY) version 21 software. The sample size was determined on G-Power (3.13) a priori. Based on an alpha of .05 and power of .80, 76 FDM’s were planned for the study assuming a medium effect size (0.15) for regression of the dependent variable (PTSD symptoms) on the three independent variables (coping strategies). A medium effect size was chosen based on previous studies examining the relationship between coping strategies and PTSD symptoms, and the relationship between coping strategy and PTSD symptoms has not been evaluated in adult ICU FDMs. Assuming an attrition rate of 20%, a total of 96 FDMs were required to obtain the calculated sample size of 76.
Results

Characteristics of Patients and FDMs

Over the study period from August, 2012 to September, 2013, a total of 176 FDMs and patients met the eligibility criteria and were approached to participate in the study. Sixty-four FDMs (36%) declined participation in the study. One hundred twelve FDMs were enrolled and completed the demographic form and Brief COPE instrument. Five individuals asked to be removed from the study after initial enrollment. Another 30 FDMs could not be reached after discharge from the hospital yielding an attrition rate of 31%. The remaining 77 FDMs provided data for all three study time points. Individuals completing the study tended to be older than individuals lost to attrition ($M = 57.01$, $SD = 13.82$; $M = 49.53$, $SD = 13.16$; $t (105) = -2.55$, $p = .01$). The presence of a living will [$X^2 (1) = 4.08$, $p = .04$] or durable power of attorney [$X^2 (1) = 4.08$, $p = .04$] was higher in the sample completing the study. There were no other differences between the sample and the individuals lost to attrition.

The demographic characteristics of the hospitalized ICU patients and their FDMs are summarized in Table 6. The patients were predominantly white (74%) and equally divided between male and female. The ICU mortality rate was 30%, which increased to 43% by 30 days after hospital discharge. FDMs were predominantly female (79.2%) and white (71.4%) and the majority of FDMs were spouses (46.8%) or children (28.6%) of the hospitalized patient.

Post-traumatic Stress Symptoms

The mean IES-R score for the sample was 23.14 ($SD = 15.90$). Eighteen (23%) FDMs had IES-R scores above 33 and 32 (42%) had scores above 24. Bivariate
correlations between patient/FDM variables and IES-R score were not significant except for patient disposition (deceased/alive) at 30 days ($r = .36$, $p = .001$). The IES-R score differed among FDMs based on the disposition of the patient at 30 days (deceased: $M = 29.70$, $SD = 15.83$; alive: $M = 18.23$, $SD = 14.23$; $t (75) = -3.34$, $p = .001$). The IES-R score also varied according to the relationship of the FDM to the patient, with children of ICU patients having the highest IES-R scores ($M = 29.18$, $SD = 16.04$) and other FDMs (siblings, power of attorney, etc.) having the lowest IES-R scores ($M = 11.44$, $SD = 7.38$). The difference in the mean scores was statistically significant ($p < .05$). The IES-R scores of spouses ($M = 22.11$, $SD = 15.06$) and parents ($M = 24.10$, $SD = 19.31$) were not statistically different from each other or the other relationship categories. No other differences were noted in IES-R score among the patient and FDM characteristics.

**FDM Coping Strategies and Post-traumatic Stress Symptoms**

Problem-focused coping scores were highest among the three coping strategies at enrollment and 30 days after hospital discharge as shown in Table 7. Problem-focused coping scores decreased over time. Emotion-focused coping scores also demonstrated a decrease over time. Avoidant coping scores did not change from enrollment to 30 days after hospital discharge. Female FDMs used higher amounts of avoidant coping at enrollment (T1) than men (Female: $M = 1.60$, $SD = .33$; Male: $M = 1.37$, $SD = .37$; $p = .02$), but the difference was no longer detected at 30 days following hospital discharge (Female: $M = 1.63$, $SD = .44$; Male: $M = 1.56$, $SD = .51$; $p = ns$). No other differences in the use of coping strategies were found among FDM characteristics.

Tables 8 summarizes the relationships among the coping strategies at the two time points (T1, T2) and with severity of post-traumatic stress symptoms experienced by
FDMs at 60 days post-hospital discharge (T3). At enrollment (T1), all of the coping strategies demonstrated moderate correlations with each other but avoidant coping was the only strategy to have a significant relationship with IES-R score ($r = .27$, $p < .01$). Coping strategies 30 days following hospital discharge (T2) continued to exhibit significant correlations with each other. All three coping strategies demonstrated significant relationships with IES-R score.

**Predictors of PTSD Symptom Severity**

A linear regression model of coping strategies measured at T1 did not demonstrate significant explanation of the variance in IES-R score with an $R^2$ of .09, $F (3, 73) = 2.35; p = .08$. Using patient and FDM variables that demonstrated a significant correlation with IES-R score, a second model was examined adding the predictors of FDM relationship to patient and patient outcome (deceased/alive). As shown in Table 9, the second regression model provided a statistically significant explanation of IES score variance [$F (7,69) = 4.14, p = .001$] with patient death being the only independent predictor of post-traumatic stress symptom severity. Post hoc analysis based on the sample size of 77, significance level of .05, seven predictor variables, and an $R^2$ of .30 reflected a power of .99 for the model.

In contrast, a linear regression model of coping strategies measured at T2 did explain a statistically significant amount of the variance in IES-R score, $F (3, 73) = 19.41, p < .001, R^2 = .44$. When the patient outcome and FDM relationship to patient were added to the model, the variance in IES-R score explained by the model increased slightly ($R^2 = .50$). As shown in Table 10, avoidant coping and problem-focused coping at T2 were independent predictors of IES-R score whereas death of the patient was no
longer a significant independent predictor of IES-R score. Post hoc analysis based on the sample size of 77, significance level of .05, seven predictor variables, and an $R^2$ of .50 reflected a power of .99 for the model.

Having identified that avoidant and problem-focused coping were significant predictors of PTSD symptom severity, we then tested whether these coping strategies mediated the relationship between patient death and later PTSD symptoms. Using the method described by Baron and Kenny (1986), we tested path A (Figure 3) demonstrating a significant relationship between death of the patient and IES-R score. In path B, we performed regression analysis between patient death with T2 avoidant coping and T2 problem-focused coping. Patient death was a significant predictor of T2 avoidant coping but not of T2 problem-focused coping ($\beta = .03, p = .77$). To complete the test for mediation, IES-R score was regressed on avoidant coping and patient death shown in path C, demonstrating a mediating effect of avoidant coping between patient death and PTSD symptoms.

**Discussion**

The findings of the current study corroborate those of other investigators concerning the prevalence of PTSD symptoms. Using the data and recommendations published by Creamer et al. (2003), 23% of FDMs had IES-R scores highly predictive of PTSD (IES-R > 33) and 42% had scores that demonstrate clinically significant symptoms of PTSD (IES-R > 24). Several investigators have documented post-traumatic stress symptoms in post-ICU family members with prevalence rates within the first six months after ICU hospitalization ranging from 33% to 69% (Anderson et al., 2008; Azoulay et al., 2005; Garrouste-Orgeas et al., 2012; Gries et al., 2010; Jones et al., 2004; Jones et al.,
2012; Lautrette et al., 2007; Pillai et al., 2006; Pillai et al., 2010). However, comparison between studies is difficult due to differences in sample populations, instruments used to measure PTSD symptoms, timing of symptom measurement, and analysis of instrument score (Anderson et al., 2008; Azoulay et al., 2005; Jones et al., 2004; Lautrette et al., 2007; Pillai et al., 2010).

Our study examined PTSD symptoms exclusively in FDMs. Similarly, the FDM role has been associated with a higher prevalence of PTSD symptoms in French populations (Azoulay et al., 2005; Lautrette et al., 2007). However, this relationship is less clear in other ICU family populations. Some studies investigating post-ICU family PTSD symptoms do not differentiate between family members who did or did not participate in the decision-making process (Jones et al., 2004; Jones et al., 2012; Pillai et al., 2006; Pillai et al., 2010). Gries and colleagues (2010) reported that discordance between decision-making preferences and actual decision-making role was associated with increased PTSD symptoms, and thus the impact of the role of FDM may be a significant risk factor.

Several authors have identified family member characteristics (age, gender, relationship to patient, previous decision-making experience) and patient ICU hospitalization factors (patient age, length of ICU stay, patient outcome) that influence post-ICU psychological distress (Azoulay et al., 2005; Gries et al., 2010; Kross et al., 2011). We found patient outcome and relationship of the FDM to the patient as the only patient or FDM variables with a statistically significant association with severity of PTSD symptoms. Azoulay and colleagues (2005) also reported an association between patient death and PTSD symptoms with end-of-life decision-making by family members for
patients who died resulting in a PTSD symptom prevalence of 81.8%. Our study also found that FDMs who were children of the patient had higher IES-R scores than other FDMs. Azoulay et al. (2005) reported a higher prevalence of PTSD symptoms among adult children of ICU patients. However, Gries et al. (2010) described a higher frequency of PTSD symptoms in family members having a relationship with the patient other than spouse or adult child while Pillai (2010) noted a higher prevalence of PTSD symptoms in parents of ICU patients. Given the largely disparate findings in these studies, a firm association between the FDM-patient relationship and PTSD symptoms is elusive. Furthermore, FDM gender was not significantly associated with PTSD symptom prevalence or severity in the present study as has been demonstrated by other authors and in other PTSD patient populations (Azoulay et al., 2005; Brewin, Andrews & Valentine, 2000; Gries et al., 2010). However, the majority of FDMs in this study were female which may have limited the ability to demonstrate a relationship between gender and PTSD symptoms.

The study also presents new data on the coping strategies utilized by ICU FDMs during and after the ICU experience. FDMs used all three coping strategies to varying degrees during the study period. The use of problem-focused coping was highest at both time points followed by emotion-focused with avoidant coping being the least utilized. These findings support previous qualitative and quantitative studies of coping in ICU family members identifying higher use of problem- and emotion-focused coping strategies and lower reported reliance on avoidant coping (Agard & Harder, 2007; Braun et al., 2008; Chui & Chan, 2007; Johansson, Hildingh, & Fridlund, 2002; Vig et al., 2007). Information seeking by family members of ICU patients is a frequently used
problem-focused coping strategy early in the ICU course and may represent an attempt to contextualize the ICU illness, form personal cues, and achieve a semblance of mastery of the stressful environment (Agard & Harder, 2007; Braun et al., 2008; Jamerson et al., 1996; Soderstrom et al., 2006; Vig et al., 2007). Concurrently, the high stress of the ICU illness mobilizes active emotion-focused coping such as the use of religiosity, humor, acceptance, and pursuit of emotional support (Braun et al., 2008; Eggenberger & Nelms, 2007; Schenker et al., 2012; Vig et al., 2007). During the ICU course, FDMs may become more comfortable with the ICU environment and rely less on problem and emotion-focused coping strategies over time, possibly influenced by improvement in their family member’s condition. Alternatively, problem and emotion-focused coping may be insufficient or ineffective to meet the stress demands of the ICU illness resulting in persistent use of avoidant coping over time, which may explain the decrease in the use of problem, and emotion-focused strategies over time while use of avoidant coping remained stable.

The three coping strategies demonstrated moderate positive associations with each other, which reflect mobilization of diverse coping strategies during times of significant stress (Cooper et al., 2008; Lazarus & Folkman, 1984; Schnider et al., 2007). At T1, avoidant coping demonstrated a moderate association with subsequent IES-R score while problem- and emotion-focused failed to show a similar association. At time 2, however, all three coping strategies demonstrated positive associations with severity of PTSD symptoms with avoidant coping demonstrating the highest positive association. These findings suggest that although the overall use of the coping strategies by FDMs decreased or remained stable over time, a subset of FDMs continued to use sustained or higher
levels of coping strategies. Additionally, the FDMs who used the higher levels of coping strategies over time also tended to be the FDMs experiencing higher amounts of PTSD symptoms.

Positive associations between coping strategies and PTSD symptoms have been described in other PTSD populations with avoidant coping having the strongest positive association with PTSD symptoms (Glass et al., 2009; Krause, Kaltman, Goodman, & Dutton, 2008; Oflaz, Hatipoglu, & Aydin, 2008; Pacella et al., 2011; Schnider et al., 2007). Some authors have presumed the presence of PTSD symptoms causes the use of avoidant coping (Coyne & Racioppo, 2000; Schnider et al., 2007). However, other authors have reported avoidant coping as a predictor of later PTSD symptoms in several different PTSD populations including Gulf War victims, domestic violence victims, and traumatic injury victims (Benotsch et al., 2000; Krause et al., 2008; Mellman, David, Bustamante, Fins, & Esposito, 2001; Sharkansky et al., 2000). A recent study measured coping strategy using the Brief COPE and PTSD symptoms using the Davidson Trauma Scale (DTS) in 56 mothers of premature infants in the neonatal ICU (Shaw, Bernard, Storfer-Isser, Rhine, & Horowitz, 2012). Mothers were assessed with the Brief COPE at seven to ten days after ICU admission and the DTS one month after ICU discharge. Avoidant coping use was associated with an increased risk of PTSD symptoms (RR = 1.09, 95% CI 1.02-1.15; p = .008).

Our study did not demonstrate an association between coping strategies early in the ICU course and later PTSD symptoms. The only independent predictor of PTSD symptoms excluding T2 coping strategies was patient death. However, T2 coping strategies (avoidant coping and problem-focused coping) were significantly predictive of
PTSD symptom severity with avoidant coping mediating the relationship between patient death and later PTSD symptoms. These findings suggest that the relationship between coping strategies and PTSD symptoms in our sample arises during and after the ICU hospitalization rather than as an early antecedent predictor of PTSD symptoms. The presumably high stress of the ICU experience, influenced in part by the outcome of the patient, mobilizes coping strategies. The transactional model of stress and coping by Lazarus and Folkman (1984) predicts interaction between coping strategies and the experience of stress. The use of avoidant coping in response to ongoing ICU and post-ICU stressors may play a role in sustaining and accelerating PTSD symptom severity as has been shown in other traumatic stress populations (Benotsch et al., 2000; Krause et al., 2008; Mellman et al., 2001; Sharhansky et al., 2000). Problem-focused coping has been associated with negative psychological health outcomes from acute stressors but positive health outcomes with chronic stressors, suggesting psychological difficulty in the short term but improved psychological adjustment in the long term (Glass et al., 2009; Penley et al., 2002; Schnider et al., 2007).

Patient death did not have a significant association with T2 problem-focused coping in our study. Use of problem-focused coping may have been related to other factors in the ICU and post-ICU course. Discharge of the patient from the ICU or hospital may represent a new stress environment where problem-focused coping is often used at higher levels than other coping strategies. Although FDMs may have found the use of problem-focused coping successful in other stress situations, the strategy may be inadequate in the ICU setting. The uncontrolatability and unpredictability of the ICU and
post-ICU course may overwhelm FDMs who preferentially use problem-focused coping strategies, resulting in early PTSD symptomatology.

Our study had several limitations. First, the study sample was small and relatively homogeneous. Second, the sample may be biased in that refusal rates and attrition were high. It is possible that FDMs who used higher rates of early avoidant coping declined participation of the study. Furthermore, FDMs experiencing the highest degree of PTSD symptoms may have been lost due to attrition. Third, data were collected from FDMs in several different types of ICU, which introduces the possibility of specific ICU factors influencing the results. Fourth, the study relied on self-report measures to assess PTSD and coping strategies. The IES-R instrument does not make the diagnosis of PTSD but identifies the severity of PTSD symptoms being experienced. Future studies with ICU family members may benefit from a formal clinician administered exam for PTSD.

The relationship between coping strategy and PTSD symptoms is important for several reasons. It may provide a mechanism that helps to explain the effect of FDM and ICU variables on subsequent development of PTSD symptoms. Second, it may provide an opportunity for focused interventions that target maladaptive coping strategies to diminish later PTSD symptoms. Coping strategies are amenable to treatment interventions and interventions to diminish avoidant coping use have been associated with reductions in PTSD symptoms (Butler, Chapman, Forman, & Beck, 2006; Sikkema et al., 2013; Zayfert & Becker, 2007). Intervention studies using ICU diaries or tailored communication strategies have shown some promise in diminishing the burden of PTSD symptoms although the mechanism accounting for the reduction is unknown (Garrouste-Orgeas et al., 2012; Jones et al., 2012; Lautrette et al., 2007). Replication of the study
findings in a larger more heterogeneous population would be helpful to examine the extent to which coping strategies may influence weaker relationships that our study did not identify between risk factors and PTSD symptom development. A larger study would also allow further psychometric testing of the Brief COPE in the ICU family population. Finally, longitudinal studies with later post-ICU time points are needed to determine whether the relationships between coping strategies and PTSD symptoms persist.
Table 6.

*Patient and FDM Characteristics*

<table>
<thead>
<tr>
<th>Patient characteristics</th>
<th>61.7 (23–86)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age, years mean (range)</strong></td>
<td>61.7 (23–86)</td>
</tr>
<tr>
<td><strong>Gender, N (%)</strong></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>37 (48.1%)</td>
</tr>
<tr>
<td>Male</td>
<td>40 (51.9%)</td>
</tr>
<tr>
<td><strong>Ethnicity, N (%)</strong></td>
<td></td>
</tr>
<tr>
<td>African-American</td>
<td>20 (26%)</td>
</tr>
<tr>
<td>White</td>
<td>57 (74%)</td>
</tr>
<tr>
<td><strong>Length of ICU stay, days mean (range)</strong></td>
<td>13.4 (3-63)</td>
</tr>
<tr>
<td><strong>Length of hospital stay, days mean (range)</strong></td>
<td>19.4 (3-78)</td>
</tr>
<tr>
<td><strong>Disposition at 30 days post-hospital discharge, N (%)</strong></td>
<td></td>
</tr>
<tr>
<td>Deceased</td>
<td>33 (43.9%)</td>
</tr>
<tr>
<td>Facility</td>
<td>32 (41.6%)</td>
</tr>
<tr>
<td>Home</td>
<td>12 (15.6%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>FDM characteristics</th>
<th>57.0 (21-86)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age, years mean (range)</strong></td>
<td>57.0 (21-86)</td>
</tr>
<tr>
<td><strong>Gender, N (%)</strong></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>61 (79.2%)</td>
</tr>
<tr>
<td>Male</td>
<td>16 (20.8%)</td>
</tr>
<tr>
<td><strong>Ethnicity, N (%)</strong></td>
<td></td>
</tr>
<tr>
<td>African-American</td>
<td>21 (27.4%)</td>
</tr>
<tr>
<td>Latino</td>
<td>1 (1.3%)</td>
</tr>
<tr>
<td>White</td>
<td>55 (71.4%)</td>
</tr>
<tr>
<td><strong>Relationship to patient, N (%)</strong></td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>36 (46.8%)</td>
</tr>
<tr>
<td>Child</td>
<td>22 (28.6%)</td>
</tr>
<tr>
<td>Parent</td>
<td>9 (11.7%)</td>
</tr>
<tr>
<td>Other</td>
<td>10 (13%)</td>
</tr>
<tr>
<td><strong>Previous decision-making experience, yes, N (%)</strong></td>
<td>49 (63.6%)</td>
</tr>
<tr>
<td>Living Will, yes, N (%)</td>
<td>27 (35.1%)</td>
</tr>
<tr>
<td>Durable power of attorney, yes, N (%)</td>
<td>28 (36.4%)</td>
</tr>
</tbody>
</table>

FDM = Family Decision Maker; ICU = Intensive Care Unit; LTAC = Long Term Acute Care
Table 7.

*Coping strategies of FDMs and comparison over time*

<table>
<thead>
<tr>
<th>Coping Strategy</th>
<th>T1 Mean (SD)</th>
<th>T2 Mean (SD)</th>
<th>Test t (76)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Avoidant</td>
<td>1.55 (.34)</td>
<td>1.61 (.46)</td>
<td>1.29</td>
<td>0.20</td>
</tr>
<tr>
<td>Emotion-focused</td>
<td>2.82 (.45)</td>
<td>2.66 (.53)</td>
<td>2.98</td>
<td>0.00</td>
</tr>
<tr>
<td>Problem-focused</td>
<td>3.10 (.74)</td>
<td>2.88 (.72)</td>
<td>2.53</td>
<td>0.01</td>
</tr>
</tbody>
</table>

FDM = Family Decision Maker; SD = Standard Deviation; T1 = Enrollment; T2 = 30 days after hospital discharge or death
Table 8.

*Correlations (Pearson’s r) between Coping Strategies and IES-R score*

<table>
<thead>
<tr>
<th></th>
<th>Avoidant</th>
<th>Emotion-focused</th>
<th>Problem-focused</th>
<th>IES-R Score</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Time 1 Coping Strategies</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Avoidant</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Emotion-focused</td>
<td>.30&lt;sub&gt;b&lt;/sub&gt;</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Problem-focused</td>
<td>.37&lt;sub&gt;a&lt;/sub&gt;</td>
<td>.42&lt;sub&gt;a&lt;/sub&gt;</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>IES-R Score</td>
<td>.27&lt;sub&gt;b&lt;/sub&gt;</td>
<td>.12</td>
<td>.01</td>
<td>-</td>
</tr>
<tr>
<td><strong>Time 2 Coping Strategies</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Avoidant</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Emotion-focused</td>
<td>.32&lt;sub&gt;b&lt;/sub&gt;</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Problem-focused</td>
<td>.19&lt;sub&gt;c&lt;/sub&gt;</td>
<td>.48&lt;sub&gt;a&lt;/sub&gt;</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>IES-R Score</td>
<td>.60&lt;sub&gt;a&lt;/sub&gt;</td>
<td>.23&lt;sub&gt;c&lt;/sub&gt;</td>
<td>.38&lt;sub&gt;a&lt;/sub&gt;</td>
<td>-</td>
</tr>
</tbody>
</table>

Note: a = (p < .001); b = (p < .01); c = (p < .05)
IES-R = Impact of Event Scale – Revised
Table 9.

*T1 Coping Strategy Prediction of Post-traumatic Stress Symptom Severity*

<table>
<thead>
<tr>
<th>Model</th>
<th>B</th>
<th>S.E.</th>
<th>β</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>2.58</td>
<td>11.61</td>
<td>-</td>
<td>.22</td>
<td>.83</td>
</tr>
<tr>
<td>Avoidant coping T1</td>
<td>9.78</td>
<td>5.26</td>
<td>.21</td>
<td>1.86</td>
<td>.07</td>
</tr>
<tr>
<td>Emotion-focused coping T1</td>
<td>3.62</td>
<td>4.07</td>
<td>.10</td>
<td>.90</td>
<td>.37</td>
</tr>
<tr>
<td>Problem-focused coping T1</td>
<td>-4.00</td>
<td>2.60</td>
<td>-.19</td>
<td>-1.54</td>
<td>.13</td>
</tr>
<tr>
<td>Relationship spouse vs child</td>
<td>7.15</td>
<td>4.01</td>
<td>.20</td>
<td>1.78</td>
<td>.08</td>
</tr>
<tr>
<td>Relationship spouse vs other</td>
<td>-6.28</td>
<td>5.38</td>
<td>-.13</td>
<td>-1.17</td>
<td>.25</td>
</tr>
<tr>
<td>Relationship spouse vs parent</td>
<td>7.32</td>
<td>5.23</td>
<td>.16</td>
<td>1.40</td>
<td>.17</td>
</tr>
<tr>
<td>Patient death at 30 days*</td>
<td>12.47</td>
<td>3.40</td>
<td>.39</td>
<td>3.66</td>
<td>.00</td>
</tr>
</tbody>
</table>

Note: Dependent variable = IES-R score; Model summary: $R^2 = .30; F (7,69) = 4.14, p = .001$

IES-R = Impact of Event Scale – Revised; FDM = Family Decision Maker; S.E. = Standard Error; T1 = Time 1

* p < .05
Table 10.

*T2 Coping Strategy Prediction of Post-traumatic Stress Symptom Severity*

<table>
<thead>
<tr>
<th>Model</th>
<th>B</th>
<th>S.E.</th>
<th>β</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>-20.83</td>
<td>8.18</td>
<td>-</td>
<td>-2.55</td>
<td>.01</td>
</tr>
<tr>
<td>Avoidant coping T2*</td>
<td>16.98</td>
<td>3.61</td>
<td>.49</td>
<td>4.70</td>
<td>.00</td>
</tr>
<tr>
<td>Emotion-focused coping T2</td>
<td>-2.25</td>
<td>3.05</td>
<td>-.08</td>
<td>-.74</td>
<td>.46</td>
</tr>
<tr>
<td>Problem-focused coping T2*</td>
<td>6.26</td>
<td>2.21</td>
<td>.28</td>
<td>2.84</td>
<td>.01</td>
</tr>
<tr>
<td>Relationship spouse vs child</td>
<td>5.03</td>
<td>3.25</td>
<td>.14</td>
<td>1.55</td>
<td>.13</td>
</tr>
<tr>
<td>Relationship spouse vs other</td>
<td>-2.74</td>
<td>4.57</td>
<td>-.06</td>
<td>-.60</td>
<td>.55</td>
</tr>
<tr>
<td>Relationship spouse vs parent</td>
<td>8.07</td>
<td>4.40</td>
<td>.17</td>
<td>1.83</td>
<td>.07</td>
</tr>
<tr>
<td>Patient death at 30 days</td>
<td>5.55</td>
<td>3.13</td>
<td>.17</td>
<td>1.77</td>
<td>.08</td>
</tr>
</tbody>
</table>

Note: Dependent variable = IES-R score; Model summary: \( R^2 = .50; \) F(7,69) = 9.90, \( p < .001 \)
IES-R = Impact of Event Scale – Revised; FDM = Family Decision Maker; S.E. = Standard Error; T2 = Time 2
* p < .05
Avoidant Coping

Death of Patient

Post-traumatic Stress Symptoms

\( \beta = .44, p = .000 \)

\( \beta = .55, p = .000 \)

\( \beta = .36, p = .001 \)

\( \beta = .12, p = .26 \)

*Figure 3.* Mediation by T2 avoidant coping between patient death and PTSD symptoms.
Appendix A

DSM-IV Diagnostic criteria for PTSD

**Criterion A: Stressor**
The person has been exposed to a traumatic event in which both of the following have been present:
1. The person has experienced, witnessed, or been confronted with an event or events that involve actual or threatened death or serious injury, or a threat to the physical integrity of oneself or others.
2. The person’s response involved intense fear, helplessness, or horror. In children, it may be expressed instead by disorganized or agitated behavior.

**Criterion B: Intrusive recollection**
The traumatic event is persistently re-experienced in at least one of the following ways:
1. Recurrent and intrusive distressing recollections of the event, including images, thoughts, or perceptions. In young children, repetitive play may occur in which themes or aspects of the trauma are expressed.
2. Recurrent distressing dreams of the event. In children, there may be frightening dreams without recognizable content.
3. Acting or feeling as if the traumatic event were recurring (includes a sense of reliving the experience, illusions, hallucinations, and dissociative flashback episodes, including those that occur upon awakening or when intoxicated). In children, trauma-specific reenactment may occur.
4. Intense psychological distress at exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event.
5. Physiologic reactivity upon exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event.

**Criterion C: Avoidant/numbing**
Persistent avoidance of stimuli associated with the trauma and numbing of general responsiveness (not present before the trauma), as indicated by at least three of the following:
1. Efforts to avoid thoughts, feelings, or conversations associated with the trauma
2. Efforts to avoid activities, places, or people that arouse recollections of the trauma
3. Inability to recall an important aspect of the trauma
4. Markedly diminished interest or participation in significant activities
5. Feeling of detachment or estrangement from others
6. Restricted range of affect (e.g., unable to have loving feelings)
7. Sense of foreshortened future (e.g., does not expect to have a career, marriage, children, or a normal life span)

**Criterion D: Hyperarousal**
Persistent symptoms of increasing arousal (not present before the trauma), indicated by at least two of the following:
1. Difficulty falling or staying asleep
2. Irritability or outbursts of anger
3. Difficulty concentrating
4. Hypervigilance
5. Exaggerated startle response

**Criterion E: Duration**
Duration of the disturbance (symptoms in B–D) is more than 1 month.

**Criterion F: Functional significance**
The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.

Specify if:
Acute: if duration of symptoms is less than 3 months
Chronic: if duration of symptoms is 3 months or more

Specify if:
With or without delay onset: onset of symptoms at least 6 months after the stressor

Appendix B

INFORMED CONSENT DOCUMENT

Project Title: ICU Family Decision Maker Coping and Stress Study

Introduction and Purpose
You are being asked to participate in a research study about coping strategies and symptoms of stress in families of persons cared for in the intensive care unit (ICU). Making decisions for patients in the ICU can be a difficult and stressful experience. The purpose of the study is to learn more about how family members of patients in the intensive care unit cope with the difficulties of making decisions for their family member and how these coping strategies are related to stress after the intensive care unit admission is concluded. You were selected as a possible participant because you are a family member or significant other of a patient who has required more than 3 days in the ICU and are helping to make medical decisions on behalf of your family member. Participation will involve being interviewed several times by research nurses. We are also asking you to give permission for us to get some information from your family member’s medical record because he/she is not able to give consent him/herself. Please read this form and ask any questions that you may have before agreeing to be in the research. Researchers at Case Western Reserve University are conducting this study.

Procedures
If you agree to be a participant in this research, we will ask you a few questions about yourself such as age, ethnicity, emotional health, length of time knowing patient and the coping strategies you use to deal with stressful situations. The initial interview will take about 15 minutes. You will be asked about coping strategies again 1 month after your family member is discharged from hospital through a brief phone call, e-mail, or mail. We would like to check with you a second time, 2 months after hospital discharge to see how you and your family member are doing. At that time, we would ask you about the about feelings of stress you may still be experiencing related to the ICU experience. We would also like to get some information from your family member’s medical record about his/her age, condition, length of stay in the hospital, and discharge plans. Each of the interviews will take about 15 minutes. We will try to schedule the interviews at a time that is convenient to you or over the telephone if you would prefer.

This informed consent document will be presented to you by a research nurse involved in the study. The consent procedure will take place in the ICU. The time for entry into the study is the third day of the ICU illness and you may take 24 hours to think about your decision to participate in the study. You have no obligation to participate in the study. The interviews and all interactions with the research study will be in English.

Risks and Benefits to Being in the Study
This study does not involve medical treatment of you or your family member. The only study procedures are the interviews. The risk of the study is that you may find talking about how you are coping or experiencing stress upsetting to you. You may stop the
interview at any time if you find the questions distressing. You may choose not to answer certain questions. If you find the interview upsetting, we can stop the interview and refer you to someone who can provide support and counseling. You may choose to stop participating in the study at any time. Your participation (or non-participation) will have no effect on the care that your family member receives. A research nurse employed by the Case Western Reserve University will obtain all research data and none of the data will be communicated to any healthcare personnel at the hospital.

**Benefits**
There are no benefits expected from participating in this study, although some people find talking about their feelings helpful.

**Compensation**
A ten dollar gift card will be given to each family member who enrolls in the study. Another ten dollar gift card will be presented at the conclusion of the study provided participation by the family member has occurred at each designated time point (enrollment, 30 & 60 days).

**Confidentiality**
The records of this research will be kept private. In any sort of report we might publish, we will not include any information that will make it possible to identify a participant. Research records will be kept in a locked file, and access will be limited to the researchers, the University review board responsible for protecting human participants, and regulatory agencies.

**Voluntary Nature of the Study**
Your participation is voluntary. If you choose not to participate, it will not affect your current or future relations with the University Hospitals Case Medical System. There is no penalty or loss of benefits for not participating or for discontinuing your participation.

**Contacts and Questions**
The researcher conducting this study is Amy Petrinec, RN. You may ask any questions you have now. If you have any additional questions, concerns or complaints about the study, you may contact her at 330-715-2987.

If the researchers cannot be reached, or if you would like to talk to someone other than the researcher(s) about; (1) questions, concerns or complaints regarding this study, (2) research participant rights, (3) research-related injuries, or (4) other human subjects issues, please contact Case Western Reserve University's Institutional Review Board at (216) 368-6925 or write: Case Western Reserve University; Institutional Review Board; 10900 Euclid Ave.; Cleveland, OH 44106-7230.

You will be given a copy of this form for your records.

**Statement of Consent**
I have read the above information. I have received answers to the questions I have asked. I consent to participate in this research. I am at least 18 years of age.
Print Name of Participant: ________________________________

Signature of Participant: ________________________________ Date: ______

Signature of Person Obtaining Consent_______________________ Date: ______
## Appendix C

### ICU Family Decision Maker Coping and Stress Study

**Patient Demographic Data Form**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Description</th>
<th>Code(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>Age on admission</td>
<td>PTAGE</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td>PTSEX</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>1 = Caucasian</td>
<td>PTRACE</td>
</tr>
<tr>
<td></td>
<td>2 = African American</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3 = Asian</td>
<td></td>
</tr>
<tr>
<td></td>
<td>4 = Hispanic</td>
<td></td>
</tr>
<tr>
<td></td>
<td>5 = Other</td>
<td></td>
</tr>
<tr>
<td>Length of ICU admission</td>
<td>Number of days</td>
<td>PTLOS</td>
</tr>
<tr>
<td>Disposition</td>
<td>1 = Death</td>
<td>PTDIS</td>
</tr>
<tr>
<td></td>
<td>2 = Discharge</td>
<td></td>
</tr>
</tbody>
</table>
Appendix D

ICU Family Decision Maker Coping and Stress Study
Family Decision Maker Demographic Data Form

Address/phone/email______________________________________________________________

______________________________________________________________________________

______________________________________________________________________________

Best time and number to call for follow-up
__________________________________________

Age Age on enrollment ________ FDMAGE

Gender 1 = Female
0 = Male ________ FDMSEX

Ethnicity 1 = Caucasian
2 = African American
3 = Asian
4 = Hispanic
5 = Other ________ FDMRACE

Relationship to patient 1 = Spouse
2 = Child
3 = Sibling
4 = Parent
5 = Legal guardian
6 = Power of attorney
7 = Other, specify: ______

FDMRELA
<table>
<thead>
<tr>
<th>Variable</th>
<th>Coding</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Previous ICU decision making experience</td>
<td>1 = No, 2 = Yes</td>
<td>FDMEXP</td>
</tr>
<tr>
<td>Annual Household Income</td>
<td>1 = $20,000 or less, 2 = $21,000 to $49,000, 3 = $50,000 or greater</td>
<td>FDMSES</td>
</tr>
<tr>
<td>Documentation of living will</td>
<td>1 = Yes, 2 = No</td>
<td>LWILL</td>
</tr>
</tbody>
</table>
Appendix E

Brief COPE Instrument

<table>
<thead>
<tr>
<th></th>
<th>I haven't been doing this at all</th>
<th>I've been doing this a little bit</th>
<th>I've been doing this a medium amount</th>
<th>I've been doing this a lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I've been turning to work or other activities to take my mind off things.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. I've been concentrating my efforts on doing something about the situation I'm in.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. I've been saying to myself &quot;this isn't real&quot;.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. I've been using alcohol or other drugs to make myself feel better.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. I've been getting emotional support from others.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. I've been giving up trying to deal with it.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. I've been taking action to try to make the situation better.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. I've been refusing to believe that it has happened.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. I've been saying things to let my unpleasant feelings escape.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. I've been getting help and advice from other people.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. I've been using alcohol or other drugs to help me get through it.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. I've been trying to see it in a different light, to make it seem more positive.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. I've been criticizing myself.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. I've been trying to come up with a strategy about what to do.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
15. I've been getting comfort and understanding from someone.

16. I've been giving up the attempt to cope.

17. I've been looking for something good in what is happening.

18. I've been making jokes about it.

19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.

20. I've been accepting the reality of the fact that it has happened.

21. I've been expressing my negative feelings.

22. I've been trying to find comfort in my religion or spiritual beliefs.

23. I've been trying to get advice or help from other people about what to do.

24. I've been learning to live with it.

25. I've been thinking hard about what steps to take

26. I've been blaming myself for things that happened.

27. I've been praying or meditating.

28. I've been making fun of the situation.
### Appendix F

IES-R Instrument

| 1. Any reminder brought back feelings about it | I haven’t been doing this at all | I’ve been doing this a little bit | I’ve been doing this a medium amount | I’ve been doing this quite a lot | I’ve been doing this an extreme amount |
| 2. I had trouble staying asleep |
| 3. Other things kept making me think about it |
| 4. I felt irritable and angry |
| 5. I avoided letting myself get upset when I thought about it or was reminded of it |
| 6. I thought about it when I didn’t mean to |
| 7. I felt as if it hadn’t happened or wasn’t real |
| 8. I stayed away from reminders about |
| 9. Pictures about it popped into my mind |
| 10. I was jumpy and easily startled |
| 11. I tried not to think about it |
| 12. I was aware that I still had a lot of feelings about it, but I didn’t deal with them |
| 13. My feelings about it were kind of numb |
| 14. I found myself acting or feeling as though I was back at that time |
| 15. I had trouble falling asleep |
| 16. I had waves of strong feelings about it |
| 17. I tried to remove it from my memory |
18. I had trouble concentrating

19. Reminders of it caused me to have physical reactions, such as sweating, trouble breathing, nausea, or a pounding heart

20. I had dreams about it

21. I felt watchful or on-guard

22. I tried not to talk about it
Bibliography


142


Crunden, E. (2010). A reflection from the other side of the bed—an account of what it is like to be a patient and a relative in an intensive care unit. *Intensive and Critical Care Nursing, 26*, 18-23.


