Published in final edited form as:

West J Nurs Res. 2016 January ; 38(1): 57–78. doi:10.1177/0193945914544176.

Post-traumatic Stress Symptoms in Post-ICU Family Members: Review and Methodological Challenges

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Abstract

Family members of intensive care unit (ICU) patients are at risk for symptoms of post-traumatic stress disorder (PTSD) following ICU discharge. The aim of this systematic review is to examine the current literature regarding post-ICU family PTSD symptoms with an emphasis on methodological issues in conducting research on this challenging phenomenon. An extensive review of the literature was performed confining the search to English language studies reporting PTSD symptoms in adult family members of adult ICU patients. Ten studies were identified for review published from 2004–2012. Findings demonstrate a significant prevalence of family PTSD symptoms in the months following ICU hospitalization. However, there are several methodological challenges to the interpretation of existing studies and to the conduct of future research including differences in sampling, identification of risk factors and covariates of PTSD, and lack of consensus regarding the most appropriate PTSD symptom measurement tools and timing.

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 may add to the anxiety and stress of family members (Hickman, Daly, Douglas, & Clochesy, 2010). 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, 2009; 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, Walder, Rebetez, & Maercker, 2011). Factors 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). Most recently, a significant prevalence of post-traumatic stress disorder (PTSD) symptoms have been recognized in post-ICU family members (Schmidt & Azoulay, 2012).

In the *Diagnostic and Statistical Manual of Mental Disorders*, PTSD is defined as a stress disorder occurring at least one month after exposure to a traumatic event (5th ed.; *DSM-5*; American Psychological Association [APA], 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 complex and difficult area.

Methods

The salient literature was searched using PubMed, Medline, 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", "critical care", and "family burden". Initially, 221 articles were identified in PubMed, 80 in in Medline, 38 in Cinahl, and 36 in PsycInfo. After duplicates were removed, abstracts were reviewed to identify articles concerned with post-ICU PTSD symptoms in adult family members of adult ICU patients. Finally, the reference lists of the articles identified in the initial search were reviewed for further pertinent literature. From this search strategy, ten

studies were identified that reported on prevalence of post-ICU PTSD symptoms in families of adult ICU patients. The following sections will review the findings of the studies and the methodological challenges influencing analysis of the current literature and planning of future research studies.

Results

To date, ten studies have described PTSD symptoms in ICU family members of adult patients following ICU discharge (Anderson, Arnold, Angus, & Bryce, 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; McAdam, Fontaine, White, Dracup, & Puntillo, 2012; Pillai et al., 2006; Pillai, Aigalikal, Vishwasrao, & Husainy, 2010; see Table 1).

Sample

Identification of a representative sample of ICU family members is critical to reliable and generalizable findings in PTSD symptom studies. 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), Lautrette et al. (2007), and McAdam et al. (2012) 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. The samples tended to be homogeneous and predominantly Caucasian (63–88%) although some French authors differentiated samples by whether family members were French or other nationality (Anderson et al., 2008; Garrouste-Orgeas et al., 2012; Gries et al., 2010; Lautrette et al., 2007).

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; McAdam et al., 2012; 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 PTSD 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 prevalence of 14–46% (Anderson et al., 2008; Gries et al., 2010; Jones et al., 2004, 2012; McAdam et al., 2012; Pillai et al., 2006, 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, 2012; McAdam 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. 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) and McAdam et al. (2012) 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; McAdam et al., 2012). Several characteristics have been identified as risk factors in ICU family members.

Family decision-maker role: Family members are often called upon to make medical treatment decisions on behalf of their incapacitated critically ill loved one. Family surrogate decision makers experience many conflicting emotions and tension in the role (Schenker et al., 2012, 2013). Predictors of lower confidence in family decision-making role include lack of prior decision-making experience, lack of prior discussions with the patient about treatment preferences, and poor quality of communication with the ICU physician (Majesko, Hong, Weissfeld, & White, 2012). 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), Anderson et al., (2008), and McAdam et al. (2012) also reported a high prevalence of PTSD symptoms among FDMs (69%, 35%, and 42% respectively). Several studies do not identify family members who participated in decision-making making comparisons among studies difficult (Jones et al., 2004; Garrouste-Orgeas et al., 2012; Pillai et al., 2006, 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; Garrouste-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 family member 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 et al., 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; McAdam et al., 2012; 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 Disorders (DSM-III)* of the APA (3rd ed.; 1980). The diagnostic criteria for PTSD were further refined in the *DSM-IV-TR* (4th ed.; text rev.; APA, 2000) and recently published *DSM-5* (5th ed.; APA, 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-TR*. The following section will briefly discuss the diagnostic criteria of PTSD as described in the *DSM-IV-TR*, the tools used to measure PTSD symptoms, and the changes in PTSD diagnosis recently proposed in the *DSM-5*.

Post-traumatic stress disorder (PTSD) can be characterized as a prolonged stress response syndrome (Wilson, 2004). According to the *DSM-IV-TR*, 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 (APA, 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-5* (APA, 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-5* expands the three symptom clusters from *DSM-IV-TR* to four symptom clusters: re-experiencing, avoidance, negative cognitions and mood, and arousal. Similar to the *DSM-IV-TR*, 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 2 for a summary of differences between *DSM-IV-TR* and *DSM-5*.

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, and 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. Horowitz (1982) initially described scores above 19 as representative of high symptom levels. The difference between using 19 or 30 as a cutoff score significantly impacts the ability to make comparisons between studies.

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-TR*. 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. McAdam et al. (2012) used the total IES-R score of 33 (reported as a mean score of 1.5) recommended by Creamer et al. (2003) to represent high risk 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. 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-TR* (APA, 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 screening tool for PTSD symptoms incorporating diagnostic criteria of the *DSM-IV-TR* (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, 1983). 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; McAdam et al., 2012; 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) 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. A continuum of ongoing stressors arise or persist after the ICU hospitalization that can significantly impact the levels of PTSD symptoms experienced by family members. Furthermore, controlling for these various stressors in a research setting can be difficult.

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, focusing 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. Symptoms of complicated grief, anxiety, and depression are commonly reported along with PTSD symptoms (Anderson et al., 2008; Azoulay et al., 2005; Garrouste-Orgeas et al., 2012; Gries et al., 2010; Lautrette et al., 2007; McAdam et al., 2012; Pillai et al., 2010)

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-5* 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. Family members 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 (Garrouste-Orgeas et al., 2012; Jones et al., 2012; Lautrette et al., 2007). 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.

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Table 1

Summary of Post-ICU Family PTSD Symptom Studies

Author	Country	Sample	Tool/ Cutoff score	Timing of PTSD measurement
Jones et al., 2004	UK	104 family members of ICU patients	IES > 19	8 weeks & 6 months after discharge from ICU
Azoulay et al., 2005	France	284 family members of ICU patients	IES > 30	3 months after discharge from ICU or death
Pillai et al., 2006	India	177 relatives of ICU trauma patients	IES-R 26	7 days after admission to ICU and 2 years later
Lautrette et al., 2007	France	126 FDMs of relatives of dying ICU patients	IES > 30	3 months after death
Anderson et al., 2008	USA	50 FDMs of ICU patients	IES > 30	6 months after enrollment into study
Gries et al., 2010	USA	226 family members of dying ICU patients	PCL-C	6–36 months after death
Pillai et al., 2010	India	166 relatives of ICU patients	IES-R > 26	5 th day of ICU admission, 2 months after discharge or death from ICU
Garrouste-Orgeas et al., 2012	France	143 family members of ICU patients.	IES-R 22	12 months after ICU discharge
Jones et al., 2012	UK	36 relatives of patients recovering from ICU admission	PTSS-14	1, 3 month(s) after ICU discharge
McAdam et al., 2012	USA	41 family members of ICU patients at risk for dying	IES-R>33	3 months after ICU death or discharge

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 2

Summary of Changes to PTSD Diagnostic Criteria from DSM-IV-TR to DSM-5

Criterion	DSM-IV-TR	DSM-5
Stressor	<p>The person has been exposed to a traumatic event in which both of the following have been present:</p> <ul style="list-style-type: none"> • 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. 	<p>Similar language to <i>DSM-IV-TR</i> in regard to event or stressor with specific language specifying repeated prolonged exposure to stressful situations (e.g. police officers or first responders)</p> <p>The response of intense fear, helplessness, or horror has been removed since it did not have utility in predicting PTSD</p>
Symptom Clusters	<p>3 Clusters:</p> <ul style="list-style-type: none"> • Intrusive recollections • Avoidance • Hyperarousal 	<p>4 Clusters:</p> <ul style="list-style-type: none"> • 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	<p>Chronic- symptom duration of greater than 3 months</p> <p>Delayed onset-symptom onset greater than 6 months after stressor</p>	<p>Chronic and delayed subtypes removed</p> <p>Preschool subtype-children younger than 6 years</p> <p>Dissociative subtype-prominent dissociative symptoms</p>

PTSD = Post-traumatic stress disorder; DSM-IV = Diagnostic and Statistical Manual of Mental Disorders-IV-TR; DSM-5 = Diagnostic and Statistical Manual of Mental Disorders-5