University of Alberta

Incidence of Post-Traumatic Stress Disorder Symptoms in Family Members of Adult Intensive Care Patients

by

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A thesis submitted to the Faculty of Graduate Studies and Research
in partial fulfillment of the requirements for the degree of

Master of Nursing

Faculty of Nursing

Edmonton, Alberta
Fall 2006

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Ottawa ON K1A 0N4
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Your file Votre référence
ISBN: 978-0-494-22209-6
Our file Notre référence
ISBN: 978-0-494-22209-6

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Abstract

Post-traumatic stress disorder (PTSD) is known to occur in some intensive care unit (ICU) patients, yet the effect of a patient's ICU stay on the psychological well-being of their family member has received little attention. This prospective observational study investigated the incidence of PTSD symptoms in family members of patients admitted to the ICU and examined the relationship between family member involvement in treatment decisions with the incidence of PTSD symptoms. Nearly one quarter of family members were found to be at high-risk for developing PTSD. Family members involved in decision-making demonstrated no greater risk for developing high-risk PTSD symptoms than those not involved in decision-making. While increased participation in decision-making improved satisfaction, congruency regarding the family member's preferred role in decision-making was identified as an important factor in satisfaction. Further research is required to identify factors influencing family members' risk for PTSD and to develop preventative and early-detection strategies.

Acknowledgements

I would like to thank the Royal Alexandra Hospital Foundation for their support and interest in this project, who graciously bestowed a research grant to assist with the completion of this research.

To my thesis supervisor, Dr. Carolyn Ross, thank you for your hard work and dedication to detail and timelines. Your advice and guidance was greatly appreciated.

Thank you to committee member Dr. Priscilla Koop, whose research with families has inspired me from the moment I met her, for her interest in the ICU family member and for showing me that research really can produce results that are so true to life. Your thoughtful suggestions will stay with me for years to come.

I would like to extend a special thank you to committee member Dr. Allan Shustack for encouraging me to pursue this line of research and for always challenging me to think beyond the obvious

One of the most important principles of successful research is supportive teamwork. I would like to extend heartfelt appreciation to Gwynne MacDonald, Pat Thompson and Norine Whalen for their never-ending assistance and support throughout this research endeavor.

This research study would not be possible without the assistance and support of the nursing and medical staff of the RAH Adult ICU. Thank you for your participation and encouragement throughout this process.

Most importantly, I would like to thank the family members who so graciously participated in this research study during a difficult and trying time in their lives. I thank you for your strength and courage.

Thank you to all of my friends and family for their support and encouragement throughout this entire process. Their support has never wavered and I will be forever grateful.

Finally, I would like to thank my best friend and husband, Dan. You have always envisioned my true abilities, long before I could ever see them. You have encouraged me to step forward toward greatness, while providing me strength when I was weak or faltered. You have been my silent strength, ever loyal and present. You are my partner, my colleague, my companion and friend, and my life is forever changed by your love and inspiration. I am forever grateful for all that you give.

Dedication

In memory of my Mother,

Sandra Joan DeGeer

August 24, 1944 – April 19, 2000

All that I am or ever hope to be, I owe to the unconditional love of my Mother.

Those who are remembered never truly die.

I shall not forget.

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CHAPTER ONE

Introduction

Although the emphasis in the Intensive Care Unit (ICU) has predominantly been placed on regaining the patient's physical health and function, the psychological impact of the ICU experience on the patient and their family member has increasingly been acknowledged as a fundamental component that impacts their long-term recovery (Perrins, King, and Collins, 1998). The incidence of depression and anxiety among family members of adult ICU patients is high (Griffiths & Jones, 2001; Scragg, Jones, and Fauvel, 2001; Tedstone, 2004); however to date, the prevalence of other psychological illnesses such as post-traumatic stress disorder (PTSD) are only just beginning to be investigated (Tedstone, 2004).

PTSD is a complex anxiety disorder with six criteria that must be fulfilled to receive the diagnosis (American Psychiatric Association, 2000). Criterion A requires an exposure to a traumatic event or series of events that is directly experienced or subjectively observed and results in a response of intense fear, helplessness, or horror. This response must be followed by three distinct clusters of symptoms. Cluster B symptoms include re-experiencing the traumatic event in at least one of the following ways: recurrent and intrusive distressing recollections or dreams of the event, acting or feeling as if the traumatic event were recurring, and intense psychological distress or physiologic reactivity at exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event. Cluster C symptoms include persistent avoidance of stimuli associated with the trauma and numbing of general responsiveness as indicated by at least three of the following: efforts to avoid thoughts, feelings or conversations associated with the trauma, efforts to avoid activities, places or people that arouse recollections of the trauma, inability to recall an important aspect of the trauma, markedly diminished interest or participation in significant activities, feelings of detachment or estrangement from others, restricted range of affect, or sense of foreshortened future. Cluster D symptoms include persistent symptoms of increasing arousal indicated by at least two of the following: difficulty falling or staying asleep, irritability or outbursts of anger, difficulty concentrating, hyper-vigilance, or exaggerated startle response. Criterion E states that the duration of the symptoms must be more than one month and Criterion F states that the disturbance must cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.

Although most people relate PTSD to a catastrophic event such as combat, being taken hostage, torture, or rape, new research suggests that many different stress-inducing situations may cause PTSD. Specifically, PTSD has been found to occur in family members of heart transplantation recipients with the same prevalence rate and characteristic features of the patients themselves (Dew et al., 2004; Stukas et al., 1999). Two other studies have found that 33 to 49% of family members of patients in European ICUs experience PTSD symptoms two to six months after their ICU experience (Azoulay et al., 2005; Jones et al., 2004). Although there are no clear reasons why these family members experience PTSD symptoms, there is a logical connection between their ICU experience and PTSD. Family members of ICU patients are exposed to considerable psychological and physical stress during their often prolonged ICU experience. Stress reactions such as anxiety and depression have been found in both ICU patients and their family members after their stay in ICU (Tedstone, 2004). As well, living in a state of perpetual stress can overwhelm a person's coping resources and lead them to psychological disorders like PTSD. Azoulay et al. (2005) suggest that participation in decision-making increases the risk of PTSD symptoms of ICU patient family members in France, yet Heyland et al (2003) suggest that the majority of family members involved in end-of-life decision making in Canada want to share the decision making responsibility with the physician. To date, there have been no studies that investigate the incidence of PTSD or its relationship with involvement in decision making in the Canadian ICU family population.

Purpose of the Study

The purpose of this study was to add to our knowledge about the psychological impact of an ICU experience on family members in Canada. The specific objectives of this study were to determine the incidence of PTSD symptoms in the family members of adults who have received care in the ICU at the Royal Alexandra Hospital (RAH) and to describe the relationship between family member involvement in treatment decisions and the incidence of PTSD symptoms. The specific research questions addressed were:

1. What proportion of family members of patients admitted to the RAH Adult ICU experience symptoms of PTSD?
2. What is the relationship between the degree of family member involvement in treatment decisions and the incidence of PTSD symptoms?
3. What is the relationship between family member participation and satisfaction in the decision-making process and the incidence of PTSD symptoms?

CHAPTER TWO

Literature Review

Post-traumatic stress disorder (PTSD) is a complex disorder involving an individual's subjective experience to a traumatic event and the ongoing sequelae of their stress reaction. In this Chapter, literature relevant to the purpose of the study is presented. The definition and history of PTSD is explained, followed by a review of the stressors that family members of ICU patients experience. Reactions to these stressors in the form of anxiety and PTSD are explored, and finally, a discussion of the evolving trends in substitute decision-making in the Intensive Care Unit (ICU) completes this literature review.

Using OVID, the CINAHL, MEDLINE, HealthSTAR, EMBASE, ERIC, AMED, PsycINFO, Global Health, EBM Reviews, and Health and Psychosocial Instruments databases were searched from 1966 through August 2006. Search terms were used to collect articles relevant to this topic including "psychological distress", "stress reaction", "post-traumatic stress disorder", "anxiety", "family members", "care givers", "intensive care", and "critical care". Multiple combinations of these search terms were used and the relevant articles are discussed in this research proposal. Finally, bibliographies of articles identified through this process were searched for additional relevant articles.

Post-Traumatic Stress Disorder

The diagnosis of PTSD requires an exposure to a traumatic event or series of events, directly experienced or subjectively observed, in which the person responds with intense fear, helplessness, or horror, and is followed by three distinct clusters of symptoms of re-experiencing the event, avoidance of stimuli related to the event, and hyperarousal (American Psychiatric Association, 2000). Although descriptions of the effects of severe traumatic events on individuals have existed for a long time, PTSD was not recognized as a distinct diagnosis until its initial inclusion into the Diagnostic and Statistical Manual, 3rd Edition (American Psychiatric Association, 1980). Throughout the century prior to the official recognition of PTSD, researchers and clinicians noted somatic, physiologic, and behavioural effects of trauma. For example, in 1871, Da Costa described autonomic cardiac symptoms of soldiers who fought in the American Civil War (Trimble, 1981), in the early 1900s, psychoanalysts described "traumatic neurosis" resulting from traumatic events, and physicians used the term "shell shock" to describe brain trauma caused by the terror induced by exploding shells in World War I (Moreau and Zisook, 2002).

The modern understanding of PTSD has evolved since it's first description in DSM-I as a "gross stress reaction" (American Psychiatric Association, 1952). This diagnosis suggested that every individual had a breaking point and that a severe reaction would be a relatively natural response given a severe enough traumatic event (Moreau and Zisook, 2002). In the DSM-II version (American Psychiatric Association, 1968), emphasis was placed on the temporary nature of the psychological response to an overwhelming trauma by renaming the category "transient emotional reaction". It was not until longitudinal studies of Vietnam veterans were conducted that researchers realized these "reactions" were anything but transient for many of the affected veterans (Moreau and Zisook, 2002). The DSM-III version (American Psychiatric Association, 1980) defined the disorder of PTSD for the first time when it included the long-term effects of these stress reactions in the diagnosis of PTSD, thus separating PTSD from other stressful experiences and stress reactions. In this version of the DSM, a diagnosis of PTSD required relevant symptoms to be present for at least 6 months, but in the revised version, DSM-III-R, the duration of symptoms was shortened to 1 month (American Psychiatric Association, 1987).

Perhaps the two most significant changes in the diagnosis of PTSD occurred with DSM-IV, when the stressor criterion expanded to acknowledge the subjective component of a traumatic event (American Psychiatric Association, 1994). With the first change, it was no longer necessary for the afflicted person to be the direct victim of the traumatic event. The unexpected death of a relative or close friend or witnessing a traumatic event could result in PTSD. For example, PTSD developed in 7.5 % of bystanders of traumatic accidents (Kessler et al., 1995) and 2% of those who learned of traumatic events (Breslau et al., 1999). One study reported that PTSD developed in approximately 14% of those who experienced the sudden, unexpected death of a loved one (Breslau et al., 1999), making this event the single most frequent traumatic event to occur in both men and women, accounting for 39% of cases of PTSD in men and 27 % of cases in women (Breslau et al., 1998).

Secondly, in DSM-IV, the event criteria changed to include any traumatic event that resulted in intense fear, helplessness, or horror. In earlier versions of the DSM, a catastrophic event such as combat, being taken hostage, torture, and rape was required for the resulting stress reaction to be considered PTSD. But as the terms of reference for PTSD changed in DSM-IV to include the victim's subjective appraisal of an event, it allowed for the inclusion of many different stress-inducing situations and conditions. For example, Perry et al. (1992) showed that the severity of PTSD symptoms in burn victims was not proportional to the extent of their injury, but rather to the person's perception of the injury. Other studies have demonstrated a relationship between "low-magnitude" trauma such as marital disruption, death of a loved one, failed adoption plans, miscarriage, and poisoning with the onset of PTSD (Burstein, 1985; Helzer, Robins, and McEvoy, 1987).

It has been suggested that no other diagnostic category has gone through as many alterations and permutations as has PTSD (Moreau and Zisook, 2002). Perhaps it is because of lack of awareness of these most recent changes that most health care professionals still only associate PTSD exclusively with the concept that a single, life-threatening traumatic disaster is required to qualify a person for the diagnosis of PTSD. Research and education must emphasize the new criteria for the diagnosis for PTSD, as many patients may be diagnosed with other anxiety disorders if not considered a candidate for, and therefore not assessed for PTSD.

The psychological and biological response to a traumatic event is determined by the characteristics of both the event and the person involved (Yehuda, 1999). The initial response to stress is inherently hormonal, however the ongoing biological stress response is often influenced by the person's subjective interpretation of the event (Foa et al., 1999). Factors that contribute to the intensity of a person's response to a psychologically traumatic experience include the degree of controllability, predictability, perceived threat, relative success of attempts to minimize injury to oneself or others, and actual loss (Foa, Zinbarg, and Rothbaum, 1992; Lane and Hobfoll, 1992). Experiencing or learning about a traumatic event challenges a person's sense of safety, leading to feelings of vulnerability and powerlessness (Foa et al., 1999; Resick and Schnicke, 1993). Recovery from the event involves confronting human vulnerability in a way that promotes the development of resilience. However, the body's biological responses in the aftermath of a traumatic event may perpetuate a state of fear that interferes with the restoration of feelings of safety (Foa and Kozak, 1986). Living in a state of perpetual stress can overwhelm an individual's coping resources and lead them to avoid thoughts and feelings associated with the traumatic event.

A significant number of comorbid conditions have been found to exist with PTSD. The earliest described comorbid findings were somatic physical symptoms such as fatigue, sleep disturbances, myalgia, joint pain, loss of memory and/or concentration, and headaches (McFarlane et al., 1994). Epidemiological studies have consistently correlated PTSD with other psychological conditions, particularly anxiety and depression disorders (Brady et al., 2000; Creamer, Burgess and McFarlane, 2001; Kessler et al., 1995; Perkonigg et al, 2000; Zayfert et al, 2002). Numerous studies have demonstrated substantial biopsychosocial impairment in those with PTSD, including occupational distress (Blanchard et al., 1996), somatic distress and concomitant medical illness (McFarlane et al., 1994), poor quality of life (Cordova et al., 1995), suicidality (Davidson et al., 1991; Ferrada-Noli et al., 1998), impaired intimacy (Riggs et al., 1998), increased burden to spouse or partner (Beckham, Lytle and Feldman, 1996), and generalized social dysfunction (Blanchard et al., 1998). Since the inception of DSM-IV, the validity of PTSD has become well-established and PTSD is currently considered one of the most prevalent and disabling psychiatric disorders in both the civilian and military population (Yehuda, 1999).

Stressors in the ICU

The family members of ICU patients are exposed to considerable stress. To begin with, admission to an ICU usually occurs because of an acute and critical condition. The admission is usually unexpected, and the patient's condition is often unstable (Freichels, 1991). Research has demonstrated that family members of ICU patients perceive the admission of their loved one to an ICU as a very stressful event, which enhances feelings of fear and threat (Daley, 1984; Engli and Kirsivali-Farmer, 1993; Kleiber et al., 1994; Koller, 1991).

These feelings of fear and anxiety are likely compounded by the sights and sounds experienced in the ICU environment. The medical and technical equipment, such as the constant monitoring of the patient and related alarm signals, has been found to increase anxiety in family members (Delva et al., 2002). Disruptions of the patients' physical integrity are very disturbing to family members, including the results of traumatic injuries, surgery, and having tubes in their relative's nose and mouth (Fontes Pinto Novaes et al., 1999). Even during recovery, family members struggle as they witness their relatives endure symptoms related to their illness, such as anxiety, confusion, pain, and insomnia (Fontes Pinto Novaes et al. 1999). Furthermore, family members frequently perceive that they have little understanding of their loved one's illness or condition. This perception, which is completely dependent on the communication efforts of the doctors and nurses in the ICU, augments their feelings of anxiety and helplessness (Delva et al., 2002; Lam and Beaulieu, 2004; Leske, 1991; Lopez-Fagin, 1995; Molter, 1979).

The organizational structure and physical environment of the ICU is often another source of stress for family members of ICU patients. Restricted visiting hours, alternating nursing staff, inadequate waiting room space, and lack of conference rooms for private discussions increases feelings of stress, frustration, and helplessness for family members (Lam and Beaulieu, 2004; Leske, 1991; Lopez-Fagin, 1995; Molter, 1979).

Finally, not all patients survive their admission to ICU. Some patients die rapidly after their admission to the ICU, while others linger in critical conditions for several days to weeks. Of all the stressors faced by family members in the ICU, there is none greater than preparing for the unexpected and imminent death of a loved one following a critical illness.

Stress Reactions in Family Members in the ICU

While many studies have investigated the prevalence of psychological disorders among patients who survive their stay in the ICU, few have investigated the psychological effects of the ICU stay on their family members. Family members witness their loved one in a critically ill state for days or weeks, constantly fearing deterioration or death, with often an unclear understanding of the patient's illness or its trajectory (Skirrow et al., 2001). There is even some evidence that the psychological impact of the ICU experience may be greater for the family members than for the patient (Gilliss, 1984; Lynn-McHale et al., 1997). Although it would be surprising if having a relative as a patient in the ICU did not have a short-term impact on mental health, it is not known whether this short-term distress is translated into a persistent disorder. Promoting good mental health in family members of patients in the ICU is important, as it may be even more of a burden for family members to participate in decision-making regarding treatment decisions and end-of-life decisions when suffering symptoms of stress reactions themselves (Pochard et al., 2001). In addition, family members are often required to be the caregivers of ICU patients after discharge. Although there is little information about the mental health of caregivers of ICU patients, there is a large body of literature suggesting that caregivers in general are at additional risk of mental health problems (Johnson et al., 2001) and physical health problems (Swoboda and Lipsett, 2002).

Family Member Anxiety In The ICU

A review of the literature identified seven studies that have investigated the level of anxiety in family members of ICU patients. Three of these studies (Chartier and Coutu-Wakulczyk, 1989; Delva et al., 2002; Rukholm et al., 1991) measured levels of anxiety using the Spielberger's State Trait Anxiety Inventory (STAI) which measures both trait anxiety, a stable characteristic that predisposes an individual to interpret situations as threatening or benign, and state anxiety, a fluctuating emotional state dependent on the situation in which the individual finds themselves (Spielberger, Goruch and Lushene, 1970). Another three studies (Davies, 2000; Jones and Griffiths, 1995; Pochard et al., 2001) used the Hospital Anxiety and Depression Scale (HADS), which is a measure of anxiety and depression and is a more clinically useful tool as it provides cut-off scores for probable clinical "caseness" of anxiety or depression (Zigmond and Snaith, 1983). The remaining study (Reider, 1994) measured anxiety using the Brief Symptom Inventory (BSI). The BSI is a self-reporting symptom inventory that is scored in terms of nine primary symptom dimensions, including six items that reflect anxiety. The BSI can be used to diagnose clinical cases of anxiety when the inventory is completed in its entirety (Derogatis, 1993).

All of the studies were cross-sectional and all but one were limited as they only provided information about family members' anxiety levels while their relative was in the ICU. Of the five studies where the timing of measurement was reported, the mean varied between 31 to 210 hours (five days) after admission, a time duration when one would expect the majority of family members to have high anxiety levels. Only one study investigated anxiety levels after discharge (Davies, 2000) using the HADS scale sent by mail at either one week or six weeks post-discharge. Ideally, a prospective design with repeated measures on the same individual could track anxiety levels and identify family members who have persistent mental health difficulties continuing for months after discharge.

In those studies that used the STAI, state anxiety levels were much higher than Spielberger's predicted norms (Chartier and Coutu-Wakulczyk, 1989; Delva et al., 2002; Rukholm et al., 1991). This is not surprising, as high anxiety levels while a loved one is in the ICU may be deemed to be an appropriate reaction to a stressful situation. However, some caution needs to be used when interpreting these results, as the only study that also measured trait anxiety (Rukholm et al., 1991) found that trait scores for the ICU relatives were also significantly higher than the norms reported by Spielberger. This suggests that the subjects in this sample were generally more anxious at baseline than those in the Spielberger's norms.

Two of the studies using the HADS found clinically significant anxiety symptoms in 69-75% of family members of patients while in the ICU (Jones and Griffiths, 1995; Pochard et al., 2001). However, in the third study (Davies, 2000), when anxiety was measured at one week compared to those measured at six weeks after discharge, scores were significantly lower at six weeks, suggesting that anxiety decreases over time. It should be noted however, that the response rate at six weeks (58%) was considerably lower than at one week (80.5%) and therefore may not have been a representative sample potentially biasing the results.

In Reider's study (1994), anxiety was measured using just the six-item anxiety symptom dimension of the BSI. Although the family members had a mean score of 8 compared to a mean of 2 in the norms for non-patient samples, the significance of this finding is not reported, and the usefulness of measuring just one of the nine symptom profiles is questionable. BSI scores can be used to diagnose clinical cases of anxiety when the measure is used in its entirety, but the significance of the findings is unclear when the entire tool is not used (Derogatis, 1993).

These seven studies indicate that symptoms of anxiety can occur in family members of patients in the ICU. This is not surprising given that the serious illness of a loved one would likely cause concern and worry. Whether this short-term distress is translated into a persistent disorder and whether it interferes with the caring-giving or decision-making roles of the family member is largely unknown due to the lack of any longitudinal anxiety research.

Post-Traumatic Stress Disorder in Family Members in the ICU

Although they are not directly linked in the literature, there is a logical connection between family member anxiety and PTSD. Although family members may witness a violent injury or the unexpected death of a loved one, they are more frequently exposed to the traumatic event of seeing their loved one critically ill and on life support in an ICU. Under the new DSM-IV criteria, if the family member perceives a threat to the life or physical integrity of their loved one and the family member responds to this event with fear, helplessness or horror, they have met the first criterion for the diagnosis of PTSD. Should this reaction be followed by symptoms of re-experiencing the event (flashbacks and nightmares), avoidance of reminders of the event (avoids talking about the event), and hyperarousal (difficulty sleeping, poor concentration, irritability, and anger), the family member is considered to be experiencing symptoms of PTSD. In the previously described anxiety literature, family members experiencing symptoms of PTSD could easily have been diagnosed with anxiety because the symptoms of PTSD and anxiety are difficult to differentiate when using generalized tools such as the STAI, HADS, and BSI. Although the use of reliable and validated screening instruments specific for discerning PTSD symptoms are only just beginning to be used in the ICU family member population, it reflects the new understanding of the trauma, anxiety and stress these families experience.

A review of the literature identified only four studies that have investigated the presence of PTSD in family members of adult ICU patients. Stukas et al. (1999) investigated the prevalence of PTSD in heart transplant recipients and their caregivers at the University of Pittsburgh Medical Center one year after transplantation and found that family caregivers experienced PTSD at rates equivalent to those of the transplant recipients. While conducting individual structured interviews with 142 caregivers and 158 heart transplant recipients, they measured PTSD using the actual Composite International Diagnostic Instrument (CIDI) used by psychologists to yield a diagnosis of PTSD based on the DSM-III-R criteria. The respondents were classified as definite PTSD cases, according to the DSM-III-R, if they reported the following symptoms for a period of at least one month: 1) persistently re-experiencing the traumatic event in at least one of four possible ways (e.g. recurrent nightmares about the transplant), 2) persistent avoidance of stimuli associated with the trauma, or the numbing of general responsiveness as indicated by the presence of three of seven possible symptoms (e.g. efforts to avoid thinking about the transplant), and 3) persistent increased arousal, as indicated by the presence of two of five possible symptoms (e.g. difficulty concentrating). "Probable" cases of PTSD were assigned when they either 1) met the duration criteria but were one symptom short in one of the three categories or 2) met the symptom criteria but reported a duration of less than 4 weeks but more than two weeks.

Stukas et al. (1999) found that 7.7% of the caregivers were suffering from PTSD and another 11% of caregivers were "probable" cases of PTSD, while 10.5% of the heart transplant recipients were suffering from PTSD and an additional 5% of recipients were "probable" cases of PTSD. In addition, they identified several risk factors for PTSD in both the recipient and caregiver, including female gender, having a history of psychiatric illness, and having a decreased amount of social support. Stukas et al. (1999) found that not only was the prevalence of PTSD similar for both the heart transplant recipients and their caregivers, the characteristic features of the disorder were largely the same for both groups. They concluded that the events and circumstances associated with chronic illness can be perceived as traumatic for family members and can lead to PTSD. Although the study does suggest for the first time that family members are at risk for PTSD, it is difficult to assess whether the PTSD in the family caregiver was related to the critical illness of their family member, a result of the burden and responsibility of the care-giving role, or some other factor.

In 2004, a second group of researchers from the University of Pittsburgh Medical Center continued the above research and examined the onset, timing and risk for many psychological disorders in 190 family caregivers of heart transplant recipients over a 36 month duration (Dew et al., 2004). They found that 22.5% of these family caregivers were suffering from PTSD as measured by the CIDI with the DSM-III-R criteria previously described. PTSD occurred almost exclusively early post-transplant, with most cases occurring in the earliest months after the transplant, and thus were categorized as acute PTSD (occurring within the first six months after the event). Because other psychological disorders such as generalized anxiety disorder and major depressive disorder increased over time, Dew et al. (2004) concluded that the PTSD was likely a result of the caregivers' response to the acute stressors of the transplant experience, rather than the burden of the care-giving role.

The remaining two studies investigated the presence of PTSD in family members of generalized adult ICU patients. Jones et al. (2004) evaluated the effectiveness of a 6-week self-help rehabilitation program following critical illness in reducing the psychological distress in patients and family members following ICU admission in the United Kingdom. Although this blinded, randomized controlled trial failed to show that written information concerning recovery from the ICU reduced psychological distress in both patients and their family members, the data did show that 49% of family members from both family member groups had significant symptoms of PTSD at six months after discharge from the ICU.

In their study, Jones et al. (2004) measured PTSD symptoms using the Impact of Events Scale (IES). The IES is a 15-item questionnaire that has been widely used for many years and found to be reliable across a broad range of traumatic events (Sundin and Horowitz, 2003). Although the IES is not diagnostic of PTSD, it is a quick and reliable tool that detects symptoms indicating a risk of PTSD. Each of the 15 items is scored on a 6-point scale rated from 0 to 5, resulting in a range from 0 to 75 total points with higher scores indicate more severe PTSD symptoms (Horowitz, Wilner and Alvarez, 1979). Although a score greater than 19 was originally suggested as a level of symptoms that were a cause for concern (Horowitz, Wilner and Alvarez, 1979), others have suggested that scores higher than 30 indicate a post-traumatic stress reaction that has a significant risk of developing into PTSD (Aardal-Eriksson et al., 1999; Mayou, Ehlers, and Hobbs, 2000; Sundin and Horowitz, 2002). Jones et al. (2004) used the more conservative score of 19 for their study and found that 49% of family members had significant symptoms of PTSD at six months after discharge from the ICU. This result might have been considerably lower had the more recently suggested higher cut-off score of 30 been used, but it is impossible to tell as only score ranges were reported, not the frequencies of scores.

The most comprehensive study investigating PTSD symptoms in family members of ICU patients was conducted by the FAMIREA Study Group (Azoulay et al., 2005). This longitudinal study was performed in 21 medical-surgical adult ICUs in France between March 2003 and November 2003. Azoulay et al. (2005) conducted telephone interviews with the family member of an ICU patient who was the highest in the hierarchy for substitute decision-making ninety days after the patient had died or was discharged from the ICU. During the interview, the family member completed the IES, HADS and the 36-item Short-Form General Health Survey. Of the 459 eligible patients, 284 (62%) interviews were conducted on family members (87 family members refused to participate in the study and 88 family members could not be reached). PTSD symptoms consistent with a moderate risk of developing PTSD (IES greater than 30) were found in 94 (33.1%) family members. Higher rates of PTSD symptoms were found in family members who felt that communication was incomplete in the ICU (48.4%), who shared in decision-making (47.8%), and whose relative died in the ICU (50%).

End-of-life decision-making had a significant impact on PTSD symptoms in family members. Higher rates of PTSD symptoms were found in family members whose relative died after end-of-life decisions were made by a physician (60%) and most notably, in family members who shared in end-of-life decision-making (81.8%). This association between sharing in end-of-life decisions and a high risk of PTSD raises questions as to whether bereavement symptoms may have been misclassified as PTSD symptoms or that these symptoms may have been caused by bereavement (Zisook, Chentsova-Dutton and Shuchter, 1998). However, Azoulay et al. (2005) found that although 50% of family members of patients who died had significant PTSD symptoms, so did 28.9% of the family members of patients who survived. As well, previous research using the IES has found that it is effective in discriminating between PTSD symptoms and bereavement-related symptoms (Horowitz, Wilner and Alvarez, 1979). Since only one fifth of the study patients died, Azoulay et al. (2005) suggested that other factors were likely contributors to PTSD symptoms in family members, including having witnessed a critical event or experiencing prolonged periods of stress during their ICU experience.

Decision Making in the ICU

Clinical decision-making in the ICU is often complex, involving frequent interactions among patients, families, and health care providers regarding the appropriate level of technological interventions. Despite a high regard for the principles of patient autonomy, the reality is that most ICU patients are too ill or too sedated to participate meaningfully in the decision-making process (Ferrand et al., 2001). In the absence of useful health care directives, health care providers attempt to determine if the appropriate family member is willing and able to reflect the patient's own preferences and values and is willing to participate in clinical decision-making on the patient's behalf. As such, the vast majority of treatment decisions in the ICU, including end-of-life decision-making involve substitute decision-makers (Prendergast, Clasessens, and Luce, 1998).

Research suggests that there may be problems with the communication and decision-making process in the ICU from the family member's perspective. Abott et al. (2001) interviewed 48 families of patients previously admitted to the ICU in the United States who had been considered for withdrawal or withholding of life-sustaining treatments. Almost half of the family members experienced conflict with a health care professional during their ICU experience and the majority of conflicts were about inadequate communication or perceived unprofessional behaviour. Malacrida et al. (1998) surveyed the family members of patients who died in the ICU in Switzerland and found that while 83% of the family members were satisfied with the care their relatives received, criticisms focused on the information received and the way it was communicated. Heyland et al. (2003) surveyed 789 Canadian ICU patient substitute decision-makers and found that with respect to their preferred role in end-of-life decision-making, 14.8% of substitute decision-makers preferred to leave all decisions to the physician, 23.8% preferred that the physician make the final decision after considering their opinion, 39.1% preferred that the physician shared responsibility with them in making the final decision, 21.8% preferred to make the final decision after considering the physician's opinion, and 0.5% preferred to make the treatment decision alone. The substitute decision-makers in this study who preferred to leave all decisions to the physician rated overall satisfaction higher compared to those who preferred more active roles, while satisfaction with overall decision-making was significantly higher for those whose actual role was congruent with their preferred role compared to those whose preferred and actual role were different. While it is clear that the majority of these Canadian substitute decision-makers desired participation in end-of-life decision-making for their relatives (Heyland et al., 2003), the FAMIREA Study Group in France found that only 47% of family members desired to share in decision-making for their relatives and only 15% of these family members progressed to actually sharing in the decision-making process (Azoulay et al., 2004).

Summary

Family members of ICU patients are exposed to considerable stress from both the emotional response of having a loved one who is critically ill and the physical experience of the ICU environment. Although family member anxiety is common during the first week of their loved one's ICU stay (Chartier & Coutu-Wakulczyk, 1989; Delva et al., 2002; Jones & Griffiths, 1995; Pochard et al., 2001; Reider, 1994; Rukholm et al., 1991), the effects of prolonged anxiety are just beginning to be investigated. Symptoms of PTSD have been reported to occur in 7.7% to 49% of family members of ICU patients

(Azoulay et al., 2005; Dew et al., 2004; Jones et al., 2004; Stukas et al.,1999). Current research demonstrates considerable variability in the desire to participate in decision-making among family members of patients in the ICU. The FAMIREA Study Group's research in France (Azoulay et al, 2005) has been the only study to connect the participation in decision-making with negative psychological outcomes in which 81.8% of family members who shared in end-of-life decision-making showed significant symptoms of PTSD. It is unclear whether these family members desired the decision-making role, but the evidence seems compelling that further studies should be conducted to investigate the association between the substitute decision-making role and the occurrence of PTSD symptoms.

The purpose of this study was to investigate the incidence of PTSD symptoms in family members of patients admitted to an Adult ICU in Edmonton, Alberta and to examine the relationship between the degree of family member involvement in treatment decisions and the incidence of PTSD symptoms. The results of this research will provide considerable insight into the development of PTSD and evaluate the consequences of ICU family members as substitute decision-makers in the Canadian population. Information obtained from this study will assist in the identification of family members who are at risk for PTSD symptoms and identify the need for implementing interventions for family members early on in their ICU experience. The available research strongly suggests that family members have the potential to develop symptoms of PTSD, which if left untreated, could be detrimental to both the family member and patient's short and long-term quality of life.

CHAPTER THREE

Methods

The purpose of this study was to investigate the incidence of PTSD symptoms in family members of patients admitted to the RAH Adult ICU in Edmonton, Alberta and to examine the relationship between the degree of family member involvement in treatment decisions and the incidence of PTSD symptoms. In this Chapter, the research design including the setting and sample, research instruments, and data collection are outlined followed by a description of the data analysis. The chapter concludes with a discussion regarding ethical considerations.

Research Design

The data for this study was drawn from a larger project entitled "Incidence of Post Traumatic Stress Disorder Symptoms in Family Members and Survivors of the Intensive Care Unit: A Pilot Project". This longitudinal prospective descriptive study commenced March 20, 2006.

Setting and Sample

The subjects were recruited from the 24-bed Adult ICU at the RAH in Edmonton, Alberta. The RAH serves a diverse community within the Capital Health Authority and is a referral site for British Columbia and northern Canada, treating over 450,000 patients annually. The Adult ICU at the RAH provides life support to critically ill adult patients with overwhelming medical and surgical multi-system illnesses from a variety of causes including septic shock, pneumonia, neurotrauma, multiple trauma, catastrophic surgical illness, severe metabolic derangement, and renal and liver failure.

The target population for this study consisted of family members of adult patients in ICUs. The accessible population was family members of patients in the ICU at the RAH in Edmonton, Alberta. The sample was one family member per patient who met the following inclusion/exclusion criteria and voluntarily consented to be in the study. Inclusion criteria were:

1. 18 years of age or older
2. able to speak and understand English
3. visited the patient during their ICU stay of > 48 hours with mechanical ventilation
4. considered to be the highest in the hierarchy for substitute decision-making

Exclusion criteria were:

1. less than 18 years of age
2. cognitive impairment
3. language barrier
4. unable or unwilling to be available for a 2 month follow-up period
5. history of severe pre-existing psychotic illness or PTSD

A consecutive sample of family members of patients admitted to the Adult ICU over 10 weeks between March 20, 2006 and May 29, 2006 were included in this study.

Research Instruments

Demographic Variables: The family member's date of birth, gender, race, relationship to the patient, and contact information was collected at the time of enrollment from the family member. The patient's date of birth, gender, race, admitting diagnosis, Acute Physiology And Chronic Health Evaluation II Score (APACHE II), length of stay, and status at discharge was collected from the patient's chart and recorded on the family member's Case Report Form (Appendix A) created by the Principal Investigator. APACHE II is a severity of disease classification system for adult patients admitted to the ICU (Knaus et al., 1985). It uses a point score based upon the initial values of 12 routine physiologic measurements, age, and previous health status and is calculated on all ICU patients 24 hours after admission. An increasing score (range 0 to 71) is closely correlated to an increased mortality risk. It is routinely calculated on all patients in the ICU and is used to determine the patient's eligibility for certain types of treatment and to describe a patient's morbidity and to predict mortality.

Symptoms of Post Traumatic Stress Disorder: Symptoms of PTSD were measured using the United Kingdom Post-Traumatic Symptom Scale (UK-PTSS-14) (Appendix B). Part A of the UK-PTSS-14 consists of four yes/no questions regarding ICU memories. Part B of the UK-PTSS-14 consists of 14 Likert-type questions with responses ranging from "never" (scored as 1) to always (scored as 7). The total scoring range of Part B is 14-98. A higher score indicates the greater probability that the participant fulfills the diagnostic criteria for PTSD.

The Post-Traumatic Stress Scale ten item tool (PTSS-10) was originally developed by the Division of Disaster Psychiatry at the Armed Forces Joint Medical Service in Oslo, Norway (Holen, Sund, and Weisaeth, 1983). The PTSS-10 was scored in a yes/no fashion and was originally designed as a clinical screening instrument to identify those at risk of developing post-traumatic stress reactions. The direct wording of the items was closely related to the PTSD diagnostic criteria at the time (DSM-III-R), providing good initial validity (Eid, Thayer, and Johnsen, 1999).

A revised ten-item version of the PTSS-10 using a Likert scale from 1-7 was created in 1989 (Weisaeth, 1989) and has been translated into English (Raphael, Lundin, and Weisaeth, 1989), German (Schade, 1997), and Bosnian (Dahl, Mutapcic, and Schei, 1998). The modified PTSS-10 was originally used to study stress reactions after torture, terror attacks and mental disorders among refugees (Lavik et al., 1996; Weisaeth, 1989; Weisaeth and Muhlum, 1990), army units in combat (Mehlum, 1995), long term effects of combat experience (Eide, 1995) and military training accidents (Herlovsen, 1994; Johnsen et al., 1997).

In 1999, Stoll et al. modified the PTSS-10 to measure symptoms of PTSD in patients recovering from critical illness. Stoll et al. (1999) measured the validity and reliability of the modified scale in a cohort of 52 long-term acute respiratory distress syndrome (ARDS) survivors that received ICU treatment. This ICU-modified PTSS-10 showed a high internal consistency (Crohnbach's $\alpha = 0.93$) and a high test-retest reliability (intraclass correlation coefficient $\alpha = 0.89$). There was evidence of construct validity demonstrated by the linear relationship between scores and the number of traumatic memories from the ICU the patients described (Spearman's $r_s = 0.48$, $p < 0.01$). Criterion validity was demonstrated by receiver operating characteristic (ROC) curve analyses resulting in a sensitivity of 77.0% and a specificity of 97.5% for the diagnosis of PTSD.

Although the ICU-modified PTSS-10 was revised to address ICU patients specifically, it did not completely meet the DSM-IV criteria for the diagnosis of PTSD. The ICU modified PTSS-10 failed to have any items assessing generalized numbness of feelings or persistent re-experiencing of the event (i.e. flashbacks) and had only one item directly linked with avoidance of reminders of the event. The UK-PTSS-14 was created to address these omissions and to balance the number of items in the three DSM-IV symptom categories (Twiggs et al., 2003). Four new items (11-14) were derived from the symptom descriptions in the DSM-IV, with the first addressing re-experiencing the event and the last three assessing avoidance. Twiggs et al. (2003) measured the validity and reliability of the UK-PTSS-14 in a cohort of 44 ICU survivors at 5-14 days, two months, and three months following discharge from the ICU in two UK district general hospitals. The UK-PTSS-14 was internally reliable at all three time-points (Cronbach's $\alpha = 0.89$, 0.96 and 0.84 respectively). Test-retest reliability was highest between 2 and 3 months (ICC = 0.9). Concurrent validity at 3 months was also high against the Post-traumatic Stress Diagnostic Scale (PDS) ($r = 0.86$) and the Impact of Event Scale (IES) ($r = 0.78$). Predictive validity was highest at 2 months ($r = 0.85$ with the PDS and $r = 0.71$ with the IES). ROC curve analysis suggested the highest levels of sensitivity (86%) and specificity (97%) for the diagnosis of PTSD was at 2 months with an optimum decision threshold of 45-46 points.

While the current study is the first to utilize the UK-PTSS-14 tool with family members of patients in the ICU, the UK-PTSS-14 was administered once at 2 months and was found to have similar internal reliability as that with ICU patients (Cronbach's $\alpha = 0.87$). Continued testing of the UK-PTSS-14 is ongoing in the UK with both family members and survivors in an adult ICU setting (personal communication, C. Jones, 2006).

Construct validity of the scale has been analyzed by testing the relationship between traumatic memories and PTSS scores (Schelling, Stoll and Meier, 1998; Twiggs et al. 2003). The presence of traumatic memories in patients who survived their ICU stay has been associated with a high prevalence of PTSD (Schelling et al., 1998). Patients with more traumatic memories from the ICU should have more pronounced PTSD and this should be adequately reflected in the scores of the questionnaire. In this study, the

UK-PTSS-14 scores increased as the number of traumatic memories increased (Spearman's $r_s = 0.394$, $p = 0.01$).

Degree of Family Member Involvement in Treatment Decisions: The family member's involvement in decision-making was recorded by the physician after every family conference during the patient's ICU stay on a previously described (Azoulay et al., 2005) standardized form (Appendix C). The degree of family member involvement in discussions regarding treatment procedures, appropriate level of care, and end-of-life decisions was described using a scale from 0 to 4, where 0 indicates no participation in the discussion; 1, that the family member discussed the patient's wishes but left the decision to the physician; 2, that the family member stated his or her opinion but left the decision to the physician; 3, that the family member made the decision based on the patient's wishes; and 4, that the family member made the decision after listening to the opinion of the physician. There were seven physicians who participated in family conferences and recorded family member involvement in decision-making during the data collection period. All of these physicians attended a one hour instructional session in which the use of the tool was discussed and examples were provided. The physicians also had access to assistance from the Principal Investigator to answer any questions regarding completion of the form on a daily basis.

Family Member Participation and Satisfaction in Decision Making: Each family member was asked to rate their involvement in decision-making and their satisfaction with their level of involvement in decision-making using two questions with five-item Likert scales (Appendix B). These questions were posed near the end of the telephone interview and after the family member had completed the UK-PTSS-14. A final open-ended question was posed asking if there was anything else that could have been done to assist the family member during their experience while visiting their loved one in the ICU (Appendix B). All three questions were developed by the thesis committee and were loosely based on the questions posed to family members by Heyland et al. (2003) during a satisfaction survey of substitute decision makers in the ICU.

Data Collection

The study was conducted in the Adult ICU of the RAH. Data collection commenced once ethical and agency approval was obtained. During the study period, the family member responsible for substitute decision-making was considered for enrollment. The family member considered to be the highest in the hierarchy for substitute decision-making was the person appointed by the patient while they were still capable, as listed in an advance directive or by court order. Other substitute decision-makers, in order of ranking, included the patient's spouse or partner, child, parent, sibling, or other relative. The Research Nurse of the larger study or the Principal Investigator of this study approached the appropriate family member and gave them an information sheet about the study during the first week of the patient's ICU stay (Appendix D). The Research Nurse or Principal Investigator explained the study and obtained consent from those individuals agreeing to participate (Appendix E).

Once consent was obtained, the demographic information was collected from the family member and patient's chart and recorded in the family member's Case Report Form. The Case Report Form was kept in a binder in the Research office. The Research Nurse or Principal Investigator informed the family member that they would be contacted by telephone to complete the telephone interview 2 months (± 2 weeks) post ICU discharge or death of the patient.

Following every family conference while the patient was in the ICU, the attending physician completed the Family Conference Data Sheet describing the degree of family member involvement in discussions regarding treatment procedures, appropriate level of care, and end-of-life decision-making. The physician placed the completed Family Conference Data Sheet in a designated binder at the ICU desk. The completed Family Conference Data Sheets were picked up daily by the Research Nurse and placed with the Case Report Form in the binder in the Research office.

Two months (± 2 weeks) post ICU discharge or death of the patient, the Research Nurse conducted a telephone interview with the family member (Appendix F). The Research Nurse administered a telephone questionnaire that included the UK-PTSS-14 to determine the presence of PTSD symptoms and the three questions developed by the thesis committee to determine the family member participation and satisfaction in decision-making (Appendix B). Each interview lasted between five to 15 minutes. The completed telephone questionnaire was placed in the binder in the Research office with the Case Report Form and Family Conference Data Sheets.

The UK-PTSS-14 score was calculated at the completion of the telephone interview. When the score exceeded 45, the Research Nurse informed the family member about their risk for PTSD and asked the family member for permission to forward their name and telephone number to the study psychologist. When the family member agreed, the Research Nurse forwarded their information to the study psychologist. If the family member did not agree, the Research Nurse recommended that they make an appointment with their family physician to further discuss their symptoms.

Data Analysis

Data were entered into the SPSS v.14.0 for Windows program for statistical analysis. The data were double-checked by the Research Nurse and Principal Investigator upon entry into the computer database with the original Case Report Form, Family Conference Data Sheet and interview questionnaire including the UK-PTSS-14. If any datum fell out of range, it was re-checked against the original Case Report Form, Family Conference Data Sheet or UK-PTSS-14. If discrepancies were suspected, the original ICU record was checked against the Case Report Form for accuracy. Data entry took place in pairs to ensure accuracy during the creation of the computer database.

Descriptive statistics were used to summarize the demographic and clinical characteristics of the family members and patients including age, gender, race, relationship to patient, patient's admitting diagnosis, APACHE II score, length of stay in the ICU and hospital and disposition at discharge. Descriptive statistics were also used to address the incidence of family member PTSD symptoms. The frequency and percentage of family members who scored greater than 45 on the UK-PTSS-14 were categorized as high-risk for PTSD. Pearson's Chi Square test was performed to evaluate the difference in proportions between the categorical variables such as gender, relationship, patient diagnosis, participation in decision-making, and satisfaction in decision-making and the family members categorized by PTSD score. Pearson's correlation was used to evaluate the presence of a correlation between the interval and ratio variables such as family member and patient age, length of ICU stay, length of hospital stay, and APACHE II score with the family member interval UK-PTSS-14 score. Analysis of variance was performed to evaluate the differences among groups such as race and the discharge disposition of patients and the family member interval UK-PTSS-14 score. Finally, univariate linear regression was performed to evaluate the relationship between the number of family member ICU memories, level of decision-making, level of participation in decision-making, and satisfaction with level of participation in decision-making and the family member interval UK-PTSS-14 score. Data were analyzed using SPSS v. 14.0 and an $\alpha = 0.05$ was designated a priori for level of significance.

The final open-ended interview question was analyzed using qualitative research methods. Content analysis was performed to identify, code, and categorize patterns in the data. Themes derived from the content analysis were then described and discussed.

Ethical Considerations

Prior to the initiation of the study, the University of Alberta Health Ethics Board and Capital Health Authority approved the proposed study. Upon arrival to the ICU and after determining eligibility, the family members were informed of the purpose of the study, procedures involved, risks, benefits, voluntary participation, and confidentiality. It was stressed that the family member was under not obligation to participate and could withdraw from the study at any time. The family member understood that both choosing not to participate in the study or early withdrawal from the study would not influence the care provided to the family member or patient.

An information sheet was provided outlining the purpose, procedures, risks, benefits, voluntary participation and withdraw of this study. A consent to participate form was signed by the family member prior to the initiation of the study and was obtained and witnessed by the Research Nurse or Principal Investigator. No direct benefits or risks to participating in the study were identified. While no research study can guarantee that no harm would come to the enrolled subjects, no apparent harm was noted among the family members during the course of data collection.

A psychologist was on standby during the data collection portion of this study to assist any family member who requested counseling. A score of greater than 45 on the UK-PTSS-14 is associated with a high probability that the patient fulfills the diagnostic criteria for PTSD. All family members who scored greater than 45 on the UK-PTSS-14 were referred by the Research Nurse to the psychologist working with the larger project entitled "Incidence of Post Traumatic Stress Disorder Symptoms in Family Members and Survivors of the Intensive Care Unit: A Pilot Project" if permission was granted.

All data will be kept confidential. The names of the patient and family member will not appear on any data. The data were coded with a study number and will be stored and locked in a secure location for seven years. Material that is published regarding the findings of the study will not include any patient or family identifying information.

CHAPTER FOUR

Results

The purpose of this study was to investigate the incidence of PTSD symptoms in family members of patients admitted to the RAH Adult ICU in Edmonton, Alberta and to examine the relationship between the degree of family member involvement in treatment decisions and the incidence of PTSD symptoms. In this Chapter, descriptive statistics are used to define the family member sample and to provide an overview of the study variables. The key research questions are then discussed, followed by qualitative analysis of the final interview question. A discussion of other factors affecting PTSD symptoms will complete this chapter.

Description of the Sample

There were 214 patients admitted to the RAH Adult ICU during the 10 week data collection period between March 20, 2006 to May 29, 2006. Of these 214 patients, 135 (63.1%) patients did not meet the following inclusion criteria: 43 (20.1%) patients did not receive mechanical ventilation during their ICU visit, 63 (29.4) patients were ventilated less than 48 hours during their ICU visit, 19 (8.9%) patients died within 48 hours of their admission to ICU, and 10 (4.7%) patients had family members who did not visit during their ICU stay or were not the substitute decision-maker. In addition, 5 (2.3%) family members met the exclusion criteria: 3 (1.4%) family members did not speak or understand English well enough to consent to the study and 2 (0.9%) family members were unable to participate in the 2 month follow up interview. Of the 74 (34.6%) family members eligible for enrollment, 4 (5.4%) family members refused to participate in the study, 2 (2.7%) withdrew consent at the time of the telephone interview, 3 (4.1%) were unable to be contacted to complete the interview, and 1 (1.4%) was hospitalized and subsequently withdrawn from the study. A total of 64 (86.5%) interviews were completed.

The characteristics of the family members enrolled in the study are presented in Table 1. The mean age and standard deviation of the family members was 51.99 ± 13.87 years with a range of 27 to 83 years. There were 40 (58.8%) female and 28 (41.2%) male family members enrolled in the study and the majority were Caucasian (n = 59, 86.8%). The most common relationship to the patient was wife (n = 22, 32.4%), son (n = 12, 17.6%), husband (n = 9, 13.2%), or daughter (n = 8, 11.8%). Only 5 (7.4%) family members had a history of minor psychological problems, specifically anxiety or depression.

The demographic characteristics of the patients of the family members enrolled in the study are presented in Table 2. The mean patient age was 59.41 ± 18.75 years with a range of 17 to 85 years. There were 22 (32.4%) female and 46 (67.6%) male patients, the majority of whom were Caucasian (n = 58, 85.3%).

The clinical characteristics of the patients of the family members enrolled in the study are presented in Table 3. The most common admitting primary diagnosis was respiratory failure (n = 17, 25%) and the most frequent secondary diagnosis of the patient was pneumonia (n = 12, 17.6%). The mean patient Apache II Score was 21.17 ± 7.01 with a range of 8 to 42. The mean patient length of stay in the ICU was 14.07 ± 13.79 days with a range of 3 to 92 days. Of those patients who survived their ICU visit, the mean length of hospital stay was 28.89 ± 20.76 days with 7 (11.5%) patients remaining in the RAH and 17 (27.9%) patients remaining in rehabilitation or auxiliary

Table 1: Family Member Characteristics

Family Member Characteristics (n=68)	
Age Mean ± SD[a] (Range)	51.99 ± 13.84 (27-83)
Gender f[b] (%)[c]	
Male	28 (41.2)
Female	40 (58.8)
Race f (%)	
Caucasian	59 (86.8)
Asian	1 (1.5)
North American Indian	5 (7.4)
Other	3 (4.3)
Relationship f (%)	
Wife	22 (32.4)
Husband	9 (13.2)
Mother	5 (7.4)
Father	5 (7.4)
Daughter	8 (11.8)
Son	12 (17.6)
Sister	3 (4.4)
Brother	1 (1.5)
Other	3 (4.4)
History of Psychological Problems f (%)	
Yes	5 (7.4)
No	63 (92.6)

[a]SD = standard deviation, [b]f = frequency, [c]% = percentage.

care facilities at the two month interview. There were 7 (10.3%) patients who died in the ICU and 61 (89.7%) patients discharged alive from the ICU. Of those patients discharged alive from the ICU, another 7 (10.3%) patients died on the ward prior to hospital discharge. There were no patients who died after hospital discharge during the data collection period.

Table 2: Patient Demographic Characteristics

Patient Demographic Characteristics (n=68)	
Age Mean ± SD[a](Range)	59.41 ± 18.75 (17-85)
Gender f[b] (%)[c]	
Male	46 (67.6)
Female	22 (32.4)
Race f (%)	
Caucasian	58 (85.3)
Asian	1 (1.5)
North American Indian	5 (7.3)
Other	4 (5.9)

[a]SD = standard deviation, [b] f = frequency, [c]% = percentage.

Family Member Involvement in Treatment Decisions

The family member's involvement in decision-making was recorded after every family conference during the patient's ICU stay. The degree of family member involvement in discussions regarding treatment procedures, appropriate level of care, and end-of-life decisions was recorded by the physician using a scale from 0 to 5. There were a total of 126 family conferences of which 41 (32.55%) were decision-making conferences and 85 (67.5%) were information sharing conferences. Twenty six (37.1%) family members did not have a family conference during their relative's ICU stay. There were 41 decision-making conferences spread amongst 18 family members with a mean of 2.98 ± 2.34 (range1-9; mode = 1). The pattern of level of decision-making by family members is presented in Table 4.

Table 3: Patient Clinical Characteristics

Patient Clinical Characteristics (n=68)	
APACHE[a] II Mean ± SD[b] (Range)	21.68 ± 7.25 (8-42)
Classification f[c] (%)[d]	
Medical	34 (50)
Surgical	34 (50)
Primary Diagnosis f (%)	
Respiratory Failure	17 (25)
Septic Shock	13 (19.1)
Multiple Trauma	13 (19.1)
Multiple Trauma with Head Injury	9 (13.3)
Other Medical	12 (17.6)
Other Surgical	4 (5.9)
Secondary Diagnosis f (%)	
Pneumonia	12 (17.6)
GastroIntestinal Surgery	11 (16.2)
Spinal Cord Injury	4 (5.9)
Sepsis	4 (5.9)
Other Medical	10 (14.7)
Other Surgical	3 (4.4)
LOS[e] Mean ± SD (Range)	
ICU[f]	14.07 ± 13.79 (3-92)
Hospital	28.89 ± 20.76 (4-85)
Disposition f (%)	
Died in ICU	7 (10.3)
Died in hospital	7 (10.3)
Alive at discharge	54 (79.4)

[a] APACHE=acute physiology and chronic health evaluation, [b]SD = standard deviation, [c]f = frequency, [d]% = percentage, [e]LOS = length of stay, [f]ICU=intensive care unit.

Table 4: Level of Decision-Making by Family Members

Family Member Level of Decision-Making (n=18 family members)	**Focus of 41 Conferences[a] N (%)**		
	Procedures (n=19)	**Level of Care (n=23)**	**End of Life (n=23)**
Family member did not participate in decision-making	12 (63.2)	7 (30.4)	5 (21.7)
Family member discussed patient's wishes but left the decision to the physician	1 (5.3)	3 (13)	4 (17.4)
Family member stated his/her opinion but left the decision to the physician	1 (5.3)	1 (4.3)	1 (4.3)
Family member made the decision based on the patient's wishes	2 (10.5)	8 (34.8)	8 (34.3)
Family member made the decision after listening to the physician's opinion	3 (15.8)	4 (17.4)	5 (21.7)

Note. [a] Decisions may have been made in several of the categories (procedures, appropriate level of care and end-of-life decisions) during each family conference.

A total of 54 decisions were recorded during the 41 decision making family conferences, of which 34 (63%) were made by the physician and 20 (37%) were made by the family members as shown in Table 5. Of the 18 family members involved in the decision-making family conferences, 8 (44.4%) did not participate in any decision-making, 5 (27.8%) made all of the decisions, and 5 (27.8%) made decisions in partnership with the physician. Family members were least involved in decision-making related to procedures and more involved in decision-making related to appropriate level of care and end-of-life decisions. Overall, family members were involved in active decision-making 55.6% of the time.

Table 5: Responsibility For Decision-Making

ID Number	Number of Decisions Made By Physician[a]	Number of Decisions Made By Family Member[b]	Overall Responsibility For Decision-Making
01	1	0	Physician
03	4	0	Physician
05	1	0	Physician
06	1	0	Physician
10	0	1	Family Member
11	0	3	Family Member
14	2	1	Joint
15	5	2	Joint
27	1	0	Physician
28	0	1	Family Member
30	0	3	Family Member
36	1	0	Physician
37	2	0	Physician
40	1	0	Physician
45	3	2	Joint
49	0	1	Family Member
53	4	3	Joint
61	8	3	Joint

Note. [a]The decision was categorized as made by the physician if the family member did not participate in decision-making, discussed the patient wishes but left the decision to the physician, or stated his/her opinion but left the decision to the physician. [b]The decision was categorized as made by the family member if the family member made the decision based on the patient's wishes or made the decision after listening to the physician's opinion.

Family Member Participation and Satisfaction

Family members were asked to rate their level of participation in decision-making and their satisfaction with their level of involvement in decision-making using a 5-point Likert scale. Eleven (17.2%) family members stated they participated in decision-making a very great deal, 22 (34.4%) stated they participated a great deal, 13 (20.3%) stated they had some participation, 12 (18.8%) stated they participated very little, and 6 (9.4%) family members stated they did not participate at all in decision-making. While only 18 family members were involved in formal decision-making family conferences, it is clear that many other family members felt they contributed in the care of their loved one during their ICU stay, perhaps in less formal ways. The family member self evaluation of involvement in decision-making corresponds well with the physician's evaluation of family member involvement in decision-making. Of the 18 family members involved in formal decision-making family conferences, 12 (66.7%) rated their decision-making level the same as the physician rating, 4 (22.2%) rated their decision-making level higher than the physician rating and 2 (11.1%) rate their decision-making lower than the physician rating.

The majority of family members were completely satisfied with their level of participation in decision-making (n = 48, 75%), while 13 (20.3%) family members would have preferred a little more involvement and 3 (4.7%) would have preferred much more participation. None of the family members indicated a desire to participate less or not at all in the decision-making process.

Symptoms of Post Traumatic Stress Disorder

Symptoms of PTSD were measured using the United Kingdom Post-Traumatic Symptom Scale (UK-PTSS-14) (Appendix B). Part A of the UK-PTSS-14 consisted of four yes/no questions regarding the recollection of specific ICU memories. Thirty-six (56.3%) family members from the sample did not recall any traumatic memories of their ICU experience, 14 (21.9%) had one traumatic memory, 8 (12.5%) had two traumatic memories, 4 (6.3%) had three traumatic memories, and 2 (3.1%) reported that they had all four traumatic memories of their ICU experience. Of those family members who reported traumatic memories, the most common memory was of severe anxiety or panic (n = 23, 82.1%). Memories of nightmares, severe pain, and troubles breathing or feelings of suffocation were each reported by 9 (32.1%) family members.

Part B of the UK-PTSS-14 consisted of 14 Likert-type questions with a scoring range of 14-98. Family members who score greater than 45 have a high-risk of fulfilling the diagnostic criteria for PTSD. The mean UK-PTSS-14 score for all family members was 32.56 ± 15.20. As shown in Table 6, the symptoms with the greatest severity were sleep problems (2.97 ± 2.17), irritability (2.77 ± 1.64), and a bad conscience, blame myself, or feelings of guilt (2.77 ± 1.90). Table 6 also compares the PTSD symptoms of those who scored equal to or less than 45 with those who scored greater than 45 on Part B of the UK-PTSS-14. The symptoms with the greatest severity in the high-risk family member group were symptoms closely linked to PTSD (a bad conscience/blame myself/ feelings of guilt, depression, and feeling as if my plans for the future will not come true) while the symptoms of the lower risk family members were more generalized symptoms (sleep problems, irritability, and the need to withdraw).

The relationship between the number of recalled traumatic memories and the family member's UK-PTSS-14 score is demonstrated in Figure 1. Univariate linear regression was performed to evaluate the relationship between the number of memories and UK-PTSS-14 score ($r = 0.305$, $p = 0.014$). The resulting prediction model, UK-PTSS-14 score = 4.255 (number of memories) + 29.238, indicates that family members with 3.7 traumatic memories correlates to a UK-PTSS-14 score of 45 or greater. Although the correlation is somewhat low ($r = 0.305$), it is important to note that only two family members recalled all four traumatic memories and that there is a large standard error. Perhaps a larger sample might demonstrate a higher correlation.

Table 6: Symptoms of Family Members Grouped by UK-PTSS-14 Score

Symptom	**ALL (n=64)**	**PTSS[a] ≤ 45 (n=49)**	**PTSS > 45 (n=15)**
	Mean ± SD[b]	**Mean ± SD**	**Mean ± SD**
Sleep Problems	2.97 ± 2.17	2.47 ± 1.98	4.60 ± 1.99
Nightmares	1.34 ± 1.10	1.14 ± 0.54	2.00 ± 1.96
Depression (feeling dejected/downtrodden)	2.61 ± 1.85	1.98 ± 1.30	4.67 ± 1.92
Jumpiness (easily frightened by sudden sounds/moves)	2.16 ± 1.75	1.80 ± 1.41	3.33 ± 2.23
The need to withdraw from others	2.63 ± 1.91	2.20 ± 1.72	4.00 ± 1.89
Irritability (easily agitated/annoyed & angry)	2.77 ± 1.64	2.31 ± 1.34	4.27 ± 1.67
Frequent mood swings	2.38 ± 1.77	1.71 ± 1.04	4.53 ± 1.96
A bad conscience, blame myself, have guilt feelings	2.77 ± 1.90	2.14 ± 1.49	4.80 ± 1.70
Fear of place/situations which remind me of the ICU[c]	2.06 ± 1.86	1.57 ± 1.49	3.67 ± 2.09
Muscular tension	2.52 ± 1.81	2.14 ± 1.66	3.73 ± 1.79
Upsetting, unwanted thoughts/images of my time in ICU	2.28 ± 1.86	1.67 ± 1.31	4.27 ± 2.02
Feeling numb (can't cry, unable to have loving feelings)	1.81 ± 1.48	1.29 ± 0.68	3.53 ± 2.03
Avoid places/people/situations that remind me of the ICU	1.77 ± 1.54	1.27 ± 0.76	3.40 ± 2.23
Feelings as if my plans/dreams for future will not come true	2.59 ± 2.02	1.98 ± 1.52	4.60 ± 2.20
Total PTSS	32.56±15.20	25.67 ± 8.80	55.07 ± 8.07

[a] PTSS = United Kingdom post traumatic syndrome scale, [b]SD = standard deviation, [c]ICU = intensive care unit.

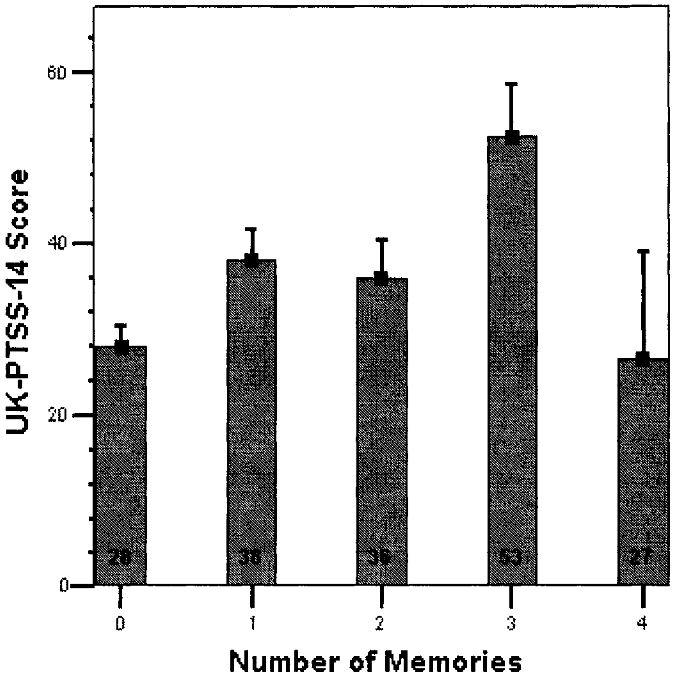

Figure 1. Relationship between the number of memories the family member has and their UK-PTSS-14 score. Univariate linear regression demonstrated a significant relationship between the number of memories and UK-PTSS-14 score (r = 0.305, p = 0.014). The resulting model predicts that family members with 3.7 traumatic memories correlates to a UK-PTSS-14 score of 45 or greater.

Incidence of PTSD Symptoms

There were 15 (23.4%) family members who scored greater than 45 on Part B of the UK-PTSS-14 and were subsequently categorized as high-risk for PTSD. As shown in Table 7, 11 (73.3%) were female and 4 (26.7%) were male, ranging in age from 30 to 78 years (53.87 ± 13.79). There were 11 (73.3%) Caucasians, 1 (6.7%) North American Indian, and 3 (20%) other and were most frequently the patients' wife (n = 8, 53.3%), son (n = 2, 13.3%) or daughter (n = 2, 13.3%). Only 2 (13.3%) of these high-risk family

Table 7: Family Member Characteristics Grouped by UK-PTSS-14 Score

Family Member Characteristics	**UK-PTSS-14[a] ≤ 45 (n=49)**	**UK-PTSS-14 > 45 (n=15)**
Age Mean ± SD[b] (Range)	52.39 ± 14.09 (27-83)	53.87 ± 13.79 (30-78)
Gender f[c] (%)[d]		
Male	24 (49)	4 (26.7)
Female	25 (51)	11 (73.3)
Race f (%)		
Caucasian	46 (93.9)	11 (73.3)
Asian	1 (2)	0 (0)
North American Indian	2 (4.1)	1 (6.7)
Other	0 (0)	3 (20)
Relationship f (%)		
Wife	11 (22.4)	8 (53.3)
Husband	8 (16.3)	1 (6.7)
Mother	5 (10.2)	0 (0)
Father	4 (8.2)	1 (6.7)
Daughter	5 (10.2)	2 (13.3)
Son	10 (20.4)	2 (13.3)
Sister	2 (4.1)	1 (6.7)
Brother	1 (2)	0 (0)
Other	3 (6.1)	0 (0)
History of Psychological Problems f (%)		
Yes	3 (6.1)	2 (13.3)
No	46 (93.9)	13 (86.7)

[a]UK-PTSS-14 = United Kingdom post traumatic syndrome scale, [b]SD = standard deviation, [c]f = frequency, [d]% = percentage.

members had a history of anxiety or depression. The patient demographic characteristics in relationship to UK-PTSS-14 score are displayed in Table 8 while the patient clinical characteristics in relationship to UK-PTSS-14 score are displayed in Table 9. The most frequent admitting primary diagnoses of the patient were respiratory failure (n = 4, 26.7%) and multiple trauma (n = 4, 26.7%) and the most frequent secondary diagnoses of the patient were pneumonia (n = 2, 13.3%) and gastrointestinal surgery (n = 2, 13.3%).

The mean patient Apache II Score was 19.93 ± 2.94 with a range of 14 to 24. The mean patient length of stay in the ICU was 14.33 ± 8.77 days with a range of 6 to 33 days. All of the patients whose family members scored greater than 45 on Part B of the UK-PTSS-14 survived their ICU visit (n = 15, 100%). The mean length of hospital stay was 33.00 ± 21.01 days with 1 (6.7%) patient remaining in the RAH and 3 (20%) patients remaining in rehabilitation or auxiliary care facilities at the 2 month interview. There were 4 (26.7%) patients who died on the ward prior to hospital discharge. There were no patients that died after hospital discharge. The demographics of family members who scored equal to or less than 45 with those who scored greater than 45 on Part B of the UK-PTSS-14 are compared on Table 7.

Table 8: Patient Demographic Characteristics Grouped by UK-PTSS-14 Score

Patient Demographic Characteristics	**UK-PTSS-14[a] ≤ 45 (n=49)**	**UK-PTSS-14 > 45 (n=15)**
Age Mean ± SD[b] (Range)	58.18 ± 18.42 (18-84)	61.80 ± 19.00 (17-85)
Gender f[c] (%)[d]		
Male	32 (65.3)	11 (73.3)
Female	17 (34.7)	4 (26.7)
Race f (%)		
Caucasian	46 (93.9)	11 (73.3)
Asian	1 (2)	0 (0)
North American Indian	2 (4.1)	1 (6.7)
Other	0 (0)	3 (20)

[a]UK-PTSS-14 = United Kingdom post traumatic syndrome scale, [b]SD = standard deviation, [c]f = frequency, [d]% = percentage.

Table 9: Patient Clinical Characteristics Grouped by UK-PTSS-14 Score

Patient Clinical Characteristics	**UK-PTSS-14[a] ≤ 45 (n=49)**	**UK-PTSS-14 > 45 (n=15)**
APACHE[b] II Mean ± SD[c] (Range)	21.53 ± 7.95 (8-42)	19.93 ± 2.94 (14-24)
Classification f[d] (%)[e]		
Medical	23 (46.9)	7 (46.7)
Surgical	26 (53.1)	8 (53.3)
Primary Diagnosis f (%)		
Respiratory Failure	12 (24.5)	4 (26.7)
Septic Shock	11 (20.4)	2 (13.3)
Multiple Trauma	8 (16.3)	4 (26.7)
Multiple Trauma with Head Injury	6 (12.2)	3 (20)
Other Medical	8 (16.3)	2 (13.3)
Other Surgical	4 (8.2)	0 (0)
Secondary Diagnosis f (%)		
Pneumonia	9 (18.4)	2 (13.3)
GastroIntestinal Surgery	8 (16.3)	2 (13.3)
Spinal Cord Injury	3 (6.1)	1 (6.7)
Sepsis	1 (2)	1 (6.7)
Other Medical	7 (14.3)	1 (6.7)
Other Surgical	2 (4.1)	1 (6.7)
LOS[f] Mean ± SD (Range)		
ICU[g]	15.04 ± 15.51 (3-92)	14.33 ± 8.77 (6-33)
Hospital	30.16 ± 20.88 (4-85)	33.00 ± 21.01 (7-71)
Disposition f (%)		
Died in ICU	6 (12.2)	0 (0)
Died in hospital	3 (6.1)	4 (26.7)
Alive at discharge	40 (81.7)	11 (73.3)

[a]UK-PTSS-14 = United Kingdom post traumatic syndrome scale, [b]APACHE=acute physiology and chronic health evaluation, [c]SD=standard deviation, [d]f=frequency, [e]%=percentage,[f] LOS=length of stay, [g]ICU=intensive care unit.

Descriptive Variables and UK-PTSS-14 Score

There were no significant differences in UK-PTSS-14 scores found between the genders of either family members or patients, although the family member gender (female) trended towards a difference (F = 3.38, df = 1,62, p = 0.071). There were no significant correlations found between the family member and patient age, length of ICU and hospital stay, and APACHE II score with UK-PTSS-14 score. There were also no significant differences found between the observed and expected frequencies among the patient's primary diagnosis and UK-PTSS-14 score nor secondary diagnoses and UK-PTSS-14 score. Although there was no significant difference among the family member race categories and UK-PTSS-14 score using analysis of variance (F = 1.98, df = 3,60, p = 0.127), there was a significant difference found between the observed and expected frequencies among the family member race category and the family member grouped by UK-PTSS-14 score ($\chi^2 = 10.81$, df = 3, p = 0.013). Specifically, all family members in the other category had a UK-PTSS-14 score greater than 45 as shown in Figure 2.

Relationship Between Level of Decision-Making and UK-PTSS-14 Score

The results of univariate linear regression procedures did not demonstrate a significant relationship between the level of decision-making and UK-PTSS-14 score. Similarly, analysis of variance did not demonstrate a significant difference between the levels of decision-making and UK-PTSS-14 score. Table 10 compares the type of conference and family member participation in decision-making with their UK-PTSS-14 score.

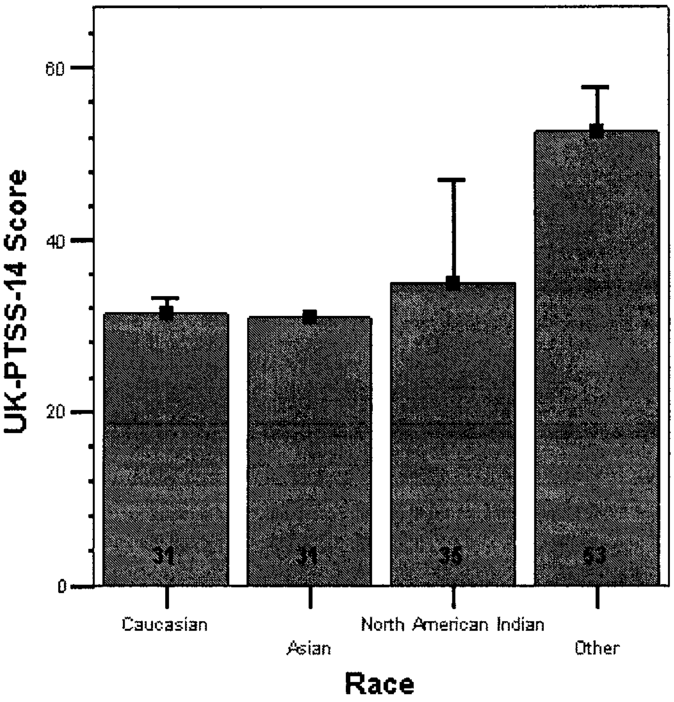

Figure 2. Family member race in relationship to their UK-PTSS-14 score. Pearson Chi square demonstrated a significant difference between the observed and expected frequencies among the family member race category and the grouped UK-PTSS-14 score ($\chi^2 = 10.81$, df = 3, $p = 0.013$). The Other category included two Filipino family members and one Hindu family member.

Table 10: Family Member Conference Type and Participation

Conference Type and Participation	**UK-PTSS-14[a] ≤ 45 (n=49)**	**UK-PTSS-14 > 45 (n=15)**
	f[b] (%)[c]	**f (%)**
No family conferences	17 (34.7)	7 (46.7)
Information only conferences	20 (40.8)	2 (13.3)
Decision-making conferences where physician made all of the decisions	6 (12.2)	2 (13.3)
Decision-making conference where physician and family member made decisions together	3 (6.1)	2 (13.3)
Decision-making conference where family made all of the decisions	3 (6.1)	2 (13.3)

[a] UK-PTSS-14 = United Kingdom post traumatic stress syndrome, [b]f = frequency, [c]% = percentage.

Participation and Satisfaction in Level of Decision-Making and UK-PTSS-14 Score

While there was a significant difference between the observed and expected frequencies between family member participation and satisfaction in level of decision-making ($\chi^2 = 18.87$, df = 8, p = 0.016), univariate linear regression did not demonstrate a significant relationship between either the level of participation or the satisfaction in level of decision-making with the UK-PTSS-14 score. Of the family members who reported that they were involved in decision-making either a great deal or a very great deal (n = 33), 31 (93.9%) were completely satisfied with their level of decision-making. Yet, when family members reported some participation, very little participation, or no participation in decision-making (n = 31), only 17 (54.8%) were completely satisfied with their level of decision-making. As shown in Table 11, there were no obvious differences between the participation patterns and satisfaction of the family members grouped by UK-PTSS-14 score. Both groups had family members who participated at all levels of decision-making and the majority of both groups were completely satisfied with their participation in decision-making.

Qualitative Comments

The final question of the interview asked the family member if there was anything else that would have helped them during their relative's stay in the ICU. Content analysis was used to identify, code, and categorize patterns in the data. Themes derived from the content analysis are described using the following headings: communication, proximity, ICU environment, patient care, financial and spiritual.

Table 11: Family Member Participation And Satisfaction in Decision-Making

Family Member Participation	**UK-PTSS-14[a] ≤ 45 (n=49) f[b](%)[c]**	**UK-PTSS-14 > 45 (n=15) f (%)**
No participation	4 (8.2)	2 (13.3)
Very little participation	8 (16.3)	4 (26.7)
Some participation	11 (22.4)	2 (13.3)
A great deal of participation	18 (36.7)	4 (26.7)
A very great deal of participation	8 (16.3)	3 (20)

Family Member Satisfaction with Participation		
Would like to have participated much more	2 (4.1)	1 (6.7)
Would like to have had a little more participation	9 (18.4)	4 (26.7)
Completely satisfied with my participation	38 (77.6)	10 (66.7)
Would like to have been involved a little less	0 (0)	0 (0)
Would like not to have participated at all	0 (0)	0 (0)

[a] UK-PTSS-14 = United Kingdom post traumatic stress syndrome, [b]f=frequency, [c]% = percentage.

Communication

Of the 40 comments provided by the family members, 23 (57.5%) were related to communication. These comments were further divided into the categories of general communication (n = 7, 17.5%), consistency of communication (n = 3, 7.5%), communication with the physician (n = 6, 15%), and communication with the registered nurse (n = 7, 17.5%).

General Communication: The general comments regarding communication were requests for more information regarding their relative's condition, "I would like to have been more informed of what was going on with my husband" (F004), and more frequent communication early on during their relative's ICU stay, "At the beginning I wanted more information given to us. We had no idea what was going on at the beginning. The unknown is the worst and the first few days we had no answers. In the end, we had more conferences" (F015).

Consistency of Communication: The family members described inconsistent communication, "One person would tell us one thing and another would tell us something else" (F005), and differences in the delivery of communication, "Some of the doctors were very gentle and good at explaining but others were not" (F014). There were also comments regarding the rotation of both the physicians and nurses, "It also bothered me that the doctors were changing every week" (F014), and, "We had a different nurse everyday and I feel this decreased the quality of care and consistency of information" (F067).

Communication with the Physician: The family members requested more time to discuss detailed information with the physicians, "A lot better communication about the medication she was getting and what was going on with her" (F042), "More time with the doctors so that I would have had a bit more information to what lead up to his condition" (F075), and "The doctors should have called me to explain why he was being transferred out" (F026).

Communication with the Registered Nurse: The comments provided from the family members regarding their communication with the registered nurses were both detailed and specific. They had traumatic memories of detailed experiences, " The nurse told me that she thought the breathing tube came out one day too early and that really scared me" (F033), and "We all felt very bad that we may have been over-stimulating our Mom when she was in a coma. A nurse told us we were and we just wish someone would have explained to us how to talk to someone that was in a coma" (F011). Family members also equated the registered nurse's depth of caring with their verbal communication, "Some nurses don't feel for others. I would like to have (preferred) if some of the nurses were more caring. I actually had a fight with one of the nurses and I wish that wouldn't have happened" (F047), "We had one nurse who really upset us. (She) told us that she did not like my husband and that he was very aggressive and that he pinched her. She asked us if he was normally an aggressive person. This really upset me and my daughter" (F066), and "This nurse didn't like my son – it was quite obvious. She was very mean. The others were very nice" (F047).

Proximity

Three of the four comments from the family members regarding proximity requested the ability to sleep in their relative's room overnight, "The only thing that would have helped me is if I could have kept staying overnight. Everyone wanted me to go home yet I wanted to be with my wife" (F073), and "I was very satisfied but I was not allowed to stay and it bothered me that I couldn't stay overnight" (F014). Others found traveling to the hospital difficult, "If I would have had a place to sleep in the room – I had to walk about 1.5 hours back to the hotel late at night" (F012), and "I wish I would have been closer. I live in Beaumont so the travel was hard" (F027).

ICU Environment

The ICU environment comments focused on the visiting rules and waiting room. Some family members struggled with the number of visitors allowed in the patient's room at a time, "Coming from a very big family it was difficult to get in and see her. One time our minister came and he waited 2 hours and could not get in" (F030). Others found the waiting room "...small, noisy and crowded. There was very little privacy" (F016). Yet, the majority of comments described the waiting room as a barrier to communication, "Having to wait in the visiting room was upsetting because we never knew why we had to wait. We were just told that they were busy with him. I found that quite unsettling because we never knew if there was something wrong or bad happening" (F043), "I waited in the waiting room on her second and third day in ICU and buzzed in about 4 times and wanted to see her. Nobody came to tell me what was going on and I was extremely worried. The nurses kept saying they were busy" (F042), and "I didn't like to wait in the waiting room and push the buzzer. I felt like I was forgotten. A few times I was but I didn't want to bother the nurses" (F031).

Patient Care

There were 3 comments from family members regarding patient care. One family member wished to be more involved in the physical care provided to their family member, "One thing we noticed was (some) nurses didn't want us to help with care. My sister was an ICU nurse, and maybe they didn't know this, but they didn't like us or want us to help with the care of my dad and we wanted to help, especially because we know the nurses are busy" (F071). One wife stated, "I wish they had taken the breathing tube out sooner. I really wanted him to be able to talk to me" (F028). Finally, another family member wished to be more involved in end-of-life decisions, "I left numerous numbers to call us and no one called us. He was resuscitated unnecessarily – he did not want to suffer" (F037).

Financial

Financially, family members struggled with the expense of accommodations, “This was and is a great burden on us. Even with the hotel room being at a discounted rate, it was still $100/night” (F008) and they found returning to work difficult, “It would have helped if...would have given me more time off. I work as a lab tech...and it was very hard to go back to work” (F071), and “The only thing that would have helped was if I could have had more time off work” (F032).

Spiritual

Finally, there was one family member who commented on their spiritual needs, “I just needed more time to pray. I would like to have had a visit from the pastor” (F039).

Other Factors Affecting PTSD Symptoms

Disposition

There were 51 (79.7%) family members whose ICU relative was alive at the time of the follow-up interview and 13 (20.3%) family members whose relative had died. Of the 13 patients who had died, 6 (46.2%) of them died in the ICU and 7 (53.8) died after discharge from the ICU while on the hospital ward. Table 12 displays the family member and patient characteristics of these two groups. The mean UK-PTSS-14 score for the family members whose relative died in the ICU was 24.33 ± 9.37 while the mean UK-PTSS-14 score for the family members whose relative died on the ward doubled that of those who died in ICU (46.57 ± 18.07). Analysis of variance demonstrated a significant difference among patient disposition categories for family member UK-PTSS-14 score as shown in Figure 3 (F = 4.38, df = 2.61, p = 0.017). Family members who relatives died in the ICU had the lowest UK-PTSS-14 scores, even lower than family members of relatives who survived their hospitalization. And, although the family members whose loved ones died on the ward had more time to prepare, their UK-PTSS-14 scores were significantly higher.

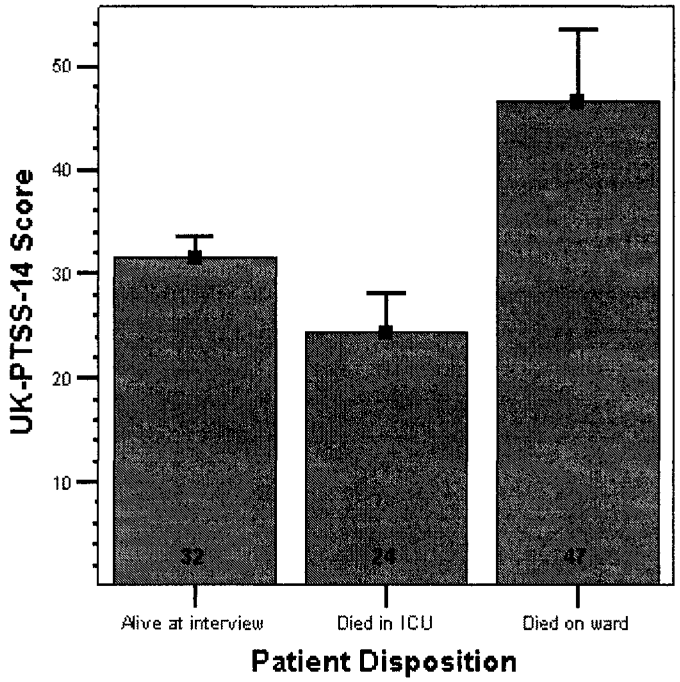

Figure 3. Family member UK-PTSS-14 score in relationship with their relative's disposition and location of death. Analysis of variance demonstrated a significant difference among patient disposition categories for family member UK-PTSS-14 score (F = 4.38, df = 2.61, p = 0.017).

Table 12: Characteristics of Family Members and Patients Grouped by to Location of Death

Family Member Characteristics	**Patients Who Died in the ICU[a] (n=6)**	**Patients Who Died on the Ward (n=7)**
Age Mean ± SD[b] (Range)	57.00 ± 10.10 (42-69)	60.57 ± 20.23 (30-83)
Gender f[c] (%)[d]		
Male	2 (33.3)	1 (14.3)
Female	4 (66.7)	6 (85.7)
Race f (%)		
Caucasian	6 (100)	6 (85.7)
Other	0 (0)	1 (14.3)
Relationship f (%)		
Wife	1 (16.7)	4 (53.3)
Husband	1 (16.7)	0 (0)
Daughter	1 (16.7)	1 (14.3)
Son	1 (16.7)	1 (14.3)
Sister	1 (16.7)	0(0)
Other	1 (16.7)	1 (14.3)
History of Psychological Problems f (%)		
Yes	0 (0)	1 (14.3)
No	6 (100)	6 (85.7)
Patient Characteristics		
Age Mean ± SD (Range)	73.67 ± 14.77 (45-84)	77.00 ± 6.27 (67-83)
LOS[e] ICU	12.00 ± 6.60 (4-20)	27.29 ± 16.50 (10-54)
Gender f (%)		
Male	4 (66.7)	5 (71.4)
Female	2 (33.3)	2 (28.6)
Race f (%)		
Caucasian	6 (100)	6 (85.4)
Other	0 (0)	1 (14.3)
Patient Classification		
Medical	6 (100)	1 (14.3)
Surgical	0 (0)	6 (85.7)

[a]ICU = intensive care unit, [b]SD = standard deviation, [c]f = frequency, [d]% = percentage, [e]LOS = length of stay.

CHAPTER FIVE

Discussion

The purpose of this study was to investigate the incidence of PTSD symptoms in family members of patients admitted to the RAH Adult ICU in Edmonton, Alberta and to examine the relationship between the degree of family member involvement in treatment decisions and the incidence of PTSD symptoms. In this Chapter, the research questions will be discussed in relation to the study findings and current literature. A discussion of other factors affecting PTSD symptoms will then occur, followed by an examination of the limitations of the study. The chapter will end with a conclusion discussing the significance of the study and future research directions.

Incidence of PTSD Symptoms

Nearly one quarter of family members in this study had scores on the UK-PTSS-14 suggesting a diagnosis of PTSD. Although this is the first study to utilize the UK-PTSS-14 tool with family members of patients in the ICU, the incidence in this study is similar to that of the other four studies in this area. Stukas et al. (1999) and Dew et al. (2004) used the CIDI and found that 18.7% and 22.5% of family members of heart transplant recipients respectively had PTSD related to their ICU experience. Both Jones et al. (2004) and Azoulay et al. (2005) used the IES but Jones et al. (2004) found an incidence of 49% using a risk score greater than 19, while Azoulay et al. (2005) used a more recently suggested higher cut-off score of 30 to predict PTSD and found an incidence of 33.1%.

The high incidence of PTSD symptoms in ICU family members in this study is both an interesting and alarming finding. To my knowledge, this is the first study performed in Canada to investigate the incidence of PTSD symptoms in family members of patients in an Adult ICU. To date, ICU family members have gone undiagnosed and untreated for symptoms of PTSD. This first glimpse at our high rate of PTSD symptoms in family members of ICU patients suggests a need for seeking preventative and early-detection strategies along with treatment options. Although there has been an increased focus on the physical and emotional outcomes of ICU survivors in order to improve their long-term quality of life (Dowdy et al., 2005; Herridge et al, 2003), there is very little research and even fewer programs that focus on these outcomes for ICU patient family members. Furthermore, 60% of these high-risk family members had relatives that survived to hospital discharge, suggesting these same family members would most likely be involved in care-giving roles to some extent. The extra burden of PTSD symptoms on top of their care-giving role can only have devastating effects on their care-giving abilities.

Level of Decision-Making and PTSD Symptoms

Decision-making was not associated with the development of high-risk PTSD symptoms. Family members who participated in decision-making did not demonstrate any greater risk of PTSD symptoms than those who attended family conferences but did not participate in decision-making. In fact, all of the family members whose relatives died in the ICU participated in family conferences and none of them had UK-PTSS-14 scores in the high-risk category. This finding differs from the study conducted in France by Azoulay et al. (2005), which reported that 50% of family members whose relatives died in the ICU and 81.8% of family members who shared in end-of-life decisions had a high risk of PTSD. Although the sample size in the current study was smaller than the

Azoulay et al. (2005) trial, family member participation in decision-making was very similar; 28% of family members in this study were involved in decision-making while 24.3 % of family members were reported to be involved in decision-making in the France study (Azoulay et al., 2005).

It is possible that the contrasting results in these two studies may be explained due to cultural differences. Previous investigations have noted considerable cultural variations in attitudes towards end-of-life decisions and the involvement of family members in those decisions (Vincent, 2001). While participation of family members in medical decisions is customary in North America (Heyland et al., 2003; Jacob, 1998; Sjokvist et al., 1999), it is less common in many European countries (Abizanda, et al, 1994, and Ferrand et al, 2001). Low rates of family information and participation in decision-making have been reported in France (Pochard et al, 2001) and have been attributed to the fact that ICU staff members in France might still be in the early stages of a shift from paternalism to autonomy (Azoulay et al., 2004). This new expectation of family member involvement in decision-making may explain the 31.8% increase in PTSD symptoms of family members who were involved in end-of-life decision-making. While this role may be new for the family member of an ICU patient in France, family members of ICU patients in Canada, where advanced directives and family member involvement in decision-making is more common, may not feel this extra burden of involvement in decision-making.

Alternatively, the failure to show a relationship between involvement in decision-making and risk for PTSD may have been due to the small sample size. Replication of this study using a larger sample size is required to clarify the relationship between decision-making participation and the risk of PTSD.

Participation, Satisfaction and PTSD Symptoms

No significant relationship was found between either the level of participation in decision-making, or the level of satisfaction in decision-making, and the UK-PTSS-14 score. There were no obvious differences between the participation patterns and satisfaction of the family members grouped by UK-PTSS-14 score. Both the lower-risk and high-risk groups had family members who participated at all levels of decision-making and the majority of both groups were completely satisfied with their level of participation in decision-making. These findings parallel those of a recent study investigating the perspectives of substitute decision-makers for patients in six Canadian ICUs. Heyland et al. (2003) found that most substitute decision-makers wanted to share decision-making responsibility with physicians and that the majority of substitute decision-makers were satisfied with their decision-making experience.

While increasing levels of decision-making produced higher levels of satisfaction in this study, over half (54.8%) of family members who reported some participation, very little participation or no participation at all were completely satisfied with their level of participation in decision-making. These findings are supported by Heyland et al. (2003), who reported that 14.8% of Canadian substitute decision-makers preferred to leave all decisions to the physician and by Azoulay et al. (2004), who found that 53% of family members of ICU patients in France did not wish to share in decision-making. This would seem to suggest that while increased participation in decision-making improved satisfaction for the family members who wanted to participate in decision-making in this study, there still remains an important group of family members who are content not to participate in decision-making. Both Heyland et al. (2003) and Azoulay et al. (2004) have suggested the need to evaluate individual family member role preferences in decision-making. The inclusion of this question in a family assessment tool may assist both ICU nurses and physicians to communicate more sensitively and effectively to meet the unique informational and decisional needs of individual ICU family members.

Other Factors Affecting PTSD Symptoms

Communication

While the relationship between family member satisfaction with communication and the UK-PTSS-14 score was beyond the scope of this research project, it is clear that communication affects overall family member satisfaction. The majority of qualitative comments from the family members requested more information about the patient's condition, earlier communication during the ICU admission, more consistent communication among the health care team and described the waiting room as a barrier to communication. It is clear that all family members want to be fully informed of their loved ones condition irrespective of their desire to participate in decision-making. This finding corresponds to a Canadian multi-center satisfaction study (Heyland et al., 2002), which found that family members were least satisfied with the waiting room atmosphere and frequency of physician communication. Family members who rated the completeness of information provided by the ICU staff as excellent or very good were much more likely to give an overall rating of their ICU experience as completely satisfactory. Azoulay et al. (2001) also conducted a multi-center satisfaction survey of family members of ICU patients in France and found that satisfaction was highest when personalized information was delivered by a well-structured health care team and when the information provided was honest, loyal, timely and noncontradictory.

Although there seems to be a relationship between communication and satisfaction, the relationship between family member communication and symptoms of PTSD requires further investigation. Azoulay et al. (2005) found that perceived incompleteness of information was independently associated with increased family member PTSD symptoms, but this has not been evaluated in a Canadian setting. It has been acknowledged that involving family members in decision-making is time consuming (Azoulay et al., 2004). Often, family conferences only arise when facilitation of the transition from curative to palliative care becomes necessary (Azoulay and Sprung, 2004). The quality and frequency of communication with family members may be influenced by the perceived outcome of the patient. Additional research is required to evaluate the relationship between the frequency and quality of communication with long-term psychological outcomes in family members of ICU patients.

Communication with the Registered Nurse

Family members described detailed and personal memories of their communication with registered nurses in the ICU. Some family members had traumatic memories of specific incidents with particular registered nurses. It is not known if traumatic memories regarding specific events in the ICU have any relationship with the development of PTSD symptoms, although half of the family members with specific traumatic memories had high-risk UK-PTSS-14 scores. Further research is required in this area.

Some family members equated the registered nurse's depth of caring with their verbal communication. The Canadian multi-center satisfaction study (Heyland et al., 2002) reported that family members who rated courtesy, compassion, and respect to both the patient and the family member by ICU staff as "excellent" were much more likely to give an overall rating of their ICU experience as completely satisfactory. This study found that the main determinants to overall satisfaction have more to do with how the ICU staff treat and communicate with patients and their family members rather than environmental issues such as the waiting room atmosphere. The effects of family member perception of caring are important and have not been evaluated in their relationship to PTSD symptoms. It is also important that registered nurses understand the connection between both their verbal and nonverbal communication with family members and the family member perceptions of caring. Further research to investigate unique communication strategies that would optimize the communication with family members in the critical care environment could provide insight and suggest changes in our practice that will improve the psychological outcome of ICU family members.

Proximity

Family members described the need to be close to their relatives in ICU, wanted to visit more frequently, and requested the ability to sleep in their relative's room overnight. While ICU staff may feel that visiting restrictions provide respite to the family member (Gottlieb, 2003), ICU family members may disagree. Strang, Koop and Peden (2002) studied family caregivers of relatives with advanced cancer and found that caregivers who were physically separated from their loved ones for respite purposes reported the physical separation did not provide them with relaxation and in fact often increased their stress levels. These caregivers recognized that their loved one was close to death and wanted to spend all remaining time with their dying relative. They reported feeling that the pursuit of interests unrelated to their care-giving role was frivolous and not in keeping with the gravity of the situation. It is not unreasonable to suggest that there are many parallels between the family caregiver of a relative with advanced cancer and a family member of a patient in the ICU. Both endure the threat of death of their loved one and the stress of anticipatory grief. Further research is required to evaluate the effect of family member proximity to their loved one while in ICU and to explore how this need for proximity could be met while not interfering with patient care.

Disposition

Unlike the France study (Azoulay et al., 2005), every family member of a patient who died in the ICU had a lower-risk PTSD score, were very involved in decision-making and were completely satisfied with their level of participation in decision-making. It would seem from these findings that end of life care at the RAH ICU is excelling at meeting the needs of these family members. However, the mean UK-PTSS-14 score doubled in family members whose relative died on the hospital ward. The reason for the increased symptoms of PTSD in this group of family members is unclear. Heyland et al. (2006) studied seriously ill patients and their family members' perceptions about what mattered most in end-of-life care. Family members identified "trust and confidence in the doctors looking after the patient" and "that information about your family member's disease be communicated to you by the doctor in an honest manner" as two of the items rated most frequently as "extremely important". Clearly there is an urgent need to determine the factors that affect the family member's negative psychological outcome when their relative dies on the ward. A suggested first step is to evaluate the process of discharging a palliative patient from the ICU to the ward. Further investigations comparing the communication styles of ICU and ward physicians and the family member expectations when discharged to the ward should also be conducted.

Limitations of the Study

This study has several limitations. The inclusion criteria requiring the patient to be mechanically ventilated for a minimum of 48 hours limited our ability to study both the family members of the critically ill patients who died before the 48 hour time period and those whose family member required mechanical ventilation for less than 48 hours. While this allows for comparison between this study and previous family member PTSD research, it is both interesting and important to establish the incidence of PTSD symptoms in these previously unstudied groups of family members.

Telephone interviews two months after ICU discharge required a reliable method of contacting family members. Our patient population included those with a low socio-economic status and many of our family members either did not have a telephone or permanent address at which they could contacted, thus limiting the generalizability of the results.

Although data were collected on the race of the family member, this is not always reflective of their ethnicity, making it difficult to interpret the findings that all of the family members in the "other" category of race scored high on the UK-PTSS-14 scale.

There was also minimal data collected on the patients regarding their chronic illness status. This information may have shed some light on additional factors affecting the PTSD scores. Perhaps the family member of a patient with chronic illness and multiple hospital admissions would have a different ICU experience than a family member of a patient with a sudden and unexpected illness.

Interrater reliability was not established among the physicians who completed the family conference evaluation forms. The busy clinical environment of an active critical care ICU does not lend itself easily to the doubling up of physicians at family conferences for purely research purposes. While it was deemed impractical for two physicians or the Principal Investigator to attend every family conference during the study period, it is possible that the physicians may have scored family members differently resulting in observer error that may affect the reliability of the tool.

The small sample size in this study may have limited the ability to determine statistically significant relationships between key variables and symptoms of PTSD. However, it is important to note that the findings did demonstrate a similar incidence of high-risk PTSD symptoms in family members of ICU patients compared to previous reports using other populations.

Finally, the UK-PTSS-14 scale has good reliability, validity and predictability in identifying those at high-risk for developing PTSD, but does not identify family members who experience symptoms severe enough to impact their daily lives yet still may not meet the full diagnostic criteria of PTSD. Further testing of this scale to create multiple risk categories would be helpful to identify these family members.

Significance of the Study

This longitudinal, prospective, observational study demonstrated that nearly one quarter of family members are at high-risk for developing PTSD. Family members involved in decision-making experienced no greater risk for developing high-risk PTSD symptoms than family members not involved in decision-making. While increased participation in decision-making improved satisfaction for family members, the concept of congruency regarding the family member's individualized preferred role in decision-making was identified as an important factor in satisfaction. These findings suggest that family members should be viewed as much more than simple visitors to the ICU. The family is an important and legitimate focus for ICU staff. The identification of family members at risk for PTSD is an appropriate role for ICU nurses and physicians and family member referrals to mental health professionals must become an important component of critical care.

By following family members of patients in this Canadian ICU, a greater understanding of PTSD in our population has been achieved, while interventions aimed at reducing the incidence of PTSD must still be sought. Currently, there are few follow-up programs for our ICU families in Canada and to date, ICU family members have gone undiagnosed and untreated for PTSD. More research is required to address the factors influencing the family member's experience of PTSD symptoms as the need to provide follow-up care for this population becomes increasingly evident. Preventative and early-detection strategies must be sought while the search continues to provide optimal care for family members of ICU patients both during and after their ICU experience.

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Subject Initials: ___ **Subject number:** F___ ***Keyed: init_____***

Appendix A

Incidence of Post Traumatic Stress Disorder Symptoms in Family Members and Survivors of the Intensive Care Unit: A Pilot Project

FAMILY CASE REPORT FORM

PTSD (Family): Qualification

A family member will be eligible for inclusion into this study if all Inclusion Criteria are answered 'yes' and all Exclusion Criteria are answered 'no'

INCLUSION CRITERIA

		Yes	No
1.	Is the Family member 18 years of age or older?	☐1	☐2
2.	Is the Family member able to speak and understand English	☐1	☐2
3.	Has the Family member visited the ICU patient during their ICU stay of ≥ 48 hours with mechanical ventilation?	☐1	☐2
4.	Is the Family member the highest in the hierarchy for substitute decision making for the ICU patient?	☐1	☐2
5.	Did the Family member provide written and dated informed consent to participate in the study?	☐1	☐2

All must be answered yes to qualify

EXCLUSION CRITERIA

		Yes	**No**
1.	Is the Family member cognitively impaired?	☐1	☐2
2.	Does the family member have a language barrier?	☐1	☐2
3.	Do you anticipate difficulty in locating the family member in the two month follow up period	☐1	☐2
4.	Is the family member unable or unwilling to participate in the 2 month follow up interview?	☐1	☐2
5.	Does the family member have or has had any severe pre-existing psychotic illness?	☐1	☐2

All must be answered 'no' to qualify

Subject Initials: ___ ___ ___   **Subject number:** **F**___ ___ ___   ***Keyed: init*______**

Incidence of Post Traumatic Stress Disorder Symptoms in Family Members and Survivors of the Intensive Care Unit: A Pilot Project

A. PTSD (Family): Demographics

1. Date of Birth: ___ ___ - ___ ___ ___ - ___ ___ ___ ___
dd mmm yyyy

2. Gender: ☐1 Male ☐2 Female

3. Race:
Caucasian ☐1
Black ☐2
Asian ☐3
Hispanic ☐4
North American Indian ☐5
Other (specify) ☐6 ____________________

4. Relationship to the ICU patient:
The family member is the ICU patients' (mark only one)

Wife	☐1	Daughter	☐5
Husband	☐2	Son	☐6
Mother	☐3	Sister	☐7
Father	☐4	Brother	☐8
Other (specify)	☐9 ______________		

5. Does the subject suffer from any pre-existing psychotic illness?
☐1 Yes ☐2 No

B. PTSD (ICU Patient): Demographics

1. Date of Birth: ___ ___ - ___ ___ ___ - ___ ___ ___ ___
dd mmm yyyy

2. Gender: ☐1 Male ☐2 Female

3. Race:
Caucasian ☐1
Black ☐2
Asian ☐3
Hispanic ☐4
North American Indian ☐5
Other (specify) ☐6 ______________________

Incidence of Post Traumatic Stress Disorder Symptoms in Family Members and Survivors of the Intensive Care Unit: A Pilot Project

4. Hospital Admission: __ __ - __ __ __ - __ __ __ __ (day month year) Time: __ __ : __ __

5. Hospital Discharge: __ __ - __ __ __ - __ __ __ __ (day month year) Time: __ __ : __ __

6. ICU admission: __ __ - __ __ __ - __ __ __ __ (day month year) Time: __ __ : __ __

7. ICU discharge: __ __ - __ __ __ - __ __ __ __ (day month year) Time: __ __ : __ __

8. ICU primary admitting diagnosis: ____________________

9. ICU secondary admitting diagnosis: (NA if not applicable or none) ____________________

10. APACHE II Score: ________
(score over 24 hour period, starting from time of ICU admission)

11. Status at ICU discharge: ☐1 Alive ☐2 Deceased

12. Status as Hospital discharge ☐1 Alive ☐2 Deceased

13. Status at time of telephone interview ☐1 Alive ☐2 Deceased

14. If deceased, record date of death __ __ - __ __ __ - __ __ __ __ (day month year)

15. Did this subject's family member take part in the ICU Survivor portion of this study? ☐1 Yes ☐2 No
If yes, Patient CRF # S___ ___ ___

C. PTSD: Family Conference Data Sheet

Was there a family conference data sheet completed for the ICU patient?

☐1 Yes ☐2 No

If yes complete the following table using codes 00 - 4

Date	A. Discussion to perform procedures *(e.g. tracheostomy)*	B. Discussion about appropriate level of care *(e.g. inotropes, code status, etc)*	C. Discussion about end of life decisions *(e.g. withdrawing care)*
__ __ - __ __ __ - __ __ __ __ day month year			
__ __ - __ __ __ - __ __ __ __ day month year			
__ __ - __ __ __ - __ __ __ __ day month year			
__ __ - __ __ __ - __ __ __ __ day month year			
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__ __ - __ __ __ - __ __ __ __ day month year			
__ __ - __ __ __ - __ __ __ __ day month year			
__ __ - __ __ __ - __ __ __ __ day month year			

0 – no participation in discussion
1 – family member discussed patient's wishes, left decision to MD
2 – family member stated his/her opinion, left decision to MD
3 – family member made decision based on patient's wishes
4 – family member made decision after listening to MD's opinion
5 – not discussed

Subject Initials: __ __ __ **Subject number:** F__ __ __ ***Keyed: init*_____**

Incidence of Post Traumatic Stress Disorder Symptoms in Family Members and Survivors of the Intensive Care Unit: A Pilot Project

PTSD (Family): Telephone Interview

1. Telephone interview completed? ☐1 Yes ☐2 No

2. If yes, date completed:

   __ __ - __ __ __ - __ __ __ __
   day month year

3. In no, reason telephone interview not completed:

   ☐1 Subject refused; consent withdrawn
   ☐2 Lost to follow-up
   ☐3 Other: ____________________________

Subject Initials: ___ **Subject number:** F___ *Keyed: init*_____

Incidence of Post Traumatic Stress Disorder Symptoms in Family Members and Survivors of the Intensive Care Unit: A Pilot Project

PTSD (Family): COMMENTS

☐ **No Comments**

- If the patient was readmitted to ICU please add readmit and discharge dates on this comment page; as well a comment on whether the subject was mechanically ventilated for ≥48hrs

Appendix B
2 Month
Family Member Phone Interview (UK-PTSS-14)
(*2 months ± 2 weeks post ICU discharge*)

Family Member Name ____________________ Phone #______________________

ICU pt discharge date: ___________ Date due: ________________

Date done: _________

A. When I think back to the time of my family member's severe illness and the time I spent visiting him/her in the ICU, I remember:

Nightmares	☐ Yes	☐ No
Severe Anxiety or Panic	☐ Yes	☐ No
Severe Pain	☐ Yes	☐ No
Troubles to breath, feelings of suffocation	☐ Yes	☐ No

B. Presently (this means in the past few days) I suffer from:

Answer on a ***scale of 1-7*** *with* ***1 being never****, and* ***7 being always***

1. Sleep problems ___
2. Nightmares ___
3. Depression *(I feel dejected/downtrodden)* ____
4. Jumpiness *(I am easily frightened by sudden sounds or sudden moves)* _____
5. The need to withdraw from others _____
6. Irritability (that is, I am easily agitated/annoyed and angry) ____
7. Frequent mood swings ____
8. A bad conscience, blame myself, have guilt feelings _____
9. Fear of places/situations, which remind me of the ICU ____
10. Muscular tension ____
11. Upsetting, unwanted thoughts/images of my time in ICU ____
12. Feeling numb *(ie can't cry, unable to have loving feelings)* _____
13. Avoid places, people or situations that remind me of the ICU ____
14. Feelings as if my plans/dreams for the future will not come true ___

Office use only Total score = sum of scores on part B: 14-98 points

2 Month
Family Member Phone Interview

1. To what extent did you participate in decision making about your family member's care during his/her stay in intensive care?

   ☐ Not at all
   ☐ very little
   ☐ some
   ☐ a great deal
   ☐ a very great deal

2) How satisfied were you with the level of involvement you had in decision making about your family member's care during his/her stay in intensive care?

   ☐ I would like to have participated much more
   ☐ I would like to have had a little more involvement
   ☐ I am completely satisfied with my participation
   ☐ I would like to have been involved a little less
   ☐ I would like not to have participated in decision-making at all

3) Is there anything else that would have helped you during (patient's name) stay in Intensive Care at the RAH?

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Signature of person conducting interview ______________________

Printed name ________________________________

Family Conference Data Sheet

Date: __ __/ __ __ __/ __ __ __ __ **Time:** __ __ __ __ h
dd mmm yyyy

Name of substitute decision maker: __________________________
(family member who is highest in hierarchy for the decision making)

The substitute decision maker is the ICU patients'

☐Wife	☐Husband	☐Mother	☐Father
☐Daughter	☐Son	☐Sister	☐Brother
☐Other (specify)____________________			

A. Discussion to perform procedures *(e.g. tracheostomy)*
- ☐ 0 – no participation in discussion
- ☐ 1 – family member discussed patient's wishes, left decision to MD
- ☐ 2 – family member stated his/her opinion, left decision to MD
- ☐ 3 – family member made decision based on patient's wishes
- ☐ 4 – family member made decision after listening to MD's opinion
- ☐ 5 – not discussed

B. Discussion about appropriate level of care *(e.g. inotropes, code status, etc)*
- ☐ 0 – no participation in discussion
- ☐ 1 – family member discussed patient's wishes, left decision to MD
- ☐ 2 – family member stated his/her opinion, left decision to MD
- ☐ 3 – family member made decision based on patient's wishes
- ☐ 4 – family member made decision after listening to MD's opinion
- ☐ 5 – not discussed

C. Discussion about end of life decisions *(e.g. withdrawing care)*
- ☐ 0 – no participation in discussion
- ☐ 1 – family member discussed patient's wishes, left decision to MD
- ☐ 2 – family member stated his/her opinion, left decision to MD
- ☐ 3 – family member made decision based on patient's wishes
- ☐ 4 – family member made decision after listening to MD's opinion
- ☐ 5 – not discussed

☐ Other Information given

Physician Signature ______________________

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Appendix D

INFORMATION SHEET (Family Member)

Incidence of Stress Symptoms in Family Members and Survivors of the Intensive Care Unit: A Pilot Project

Principal Investigator:	Dr. A. Shustack	Phone 735-4096
	Dr. R. Seutter	Phone 735-4724
	Kara Livy	Phone 735-5696
	Gwynne MacDonald	Phone 735-5696

Introduction

Studies have shown that some people feel stressed when they visit a family member in an ICU. Sometimes this stress can continue, even after your loved one has left the ICU. We are trying to learn more about this stress that continues in family members after their loved one has left the ICU.

Purpose of the Study

The purpose of this study is to determine the number of people who are having symptoms of stress after their family member has left the ICU.

Study Procedures

If you agree to take part in this study, you will be asked to answer one set of questions. A Research Nurse will call you two months after your family member has been discharged from the ICU to ask you these questions. The phone call will take about 20 minutes of your time.

If you have a stress reaction from your loved one's stay in the ICU, we will refer you to a psychologist who is working with the study to help you.

Risks

There are no expected risks associated with taking part in this study. There is a possibility you may become upset when thinking about your family member's stay in ICU. If needed, we will refer you to the study psychologist.

Benefits

There is no way to be sure that you will benefit from taking part in this study although the results of this study may benefit other family members of ICU patients in the future.

Voluntary Participation

Agreeing to take part in this study is up to you. If you do not want to be in the study, your family member's care will not change. If you change your mind after you have agreed to take part in the study, you can stop the study at any time without affecting your family member's care.

Confidentiality and Anonymity

Your name and any other personal information will not be recorded on the interview form. Each interview form will be coded for the purposes of data records. The data from the study will be kept in a secure area for at least seven years after the study has been completed and will be available only by the investigators and research nurses. The data will be destroyed after 7 years.

The information from this study may be published or presented at conferences. One of the investigators, Kara Livy, will be using this data for personal academic reasons. Your name or any material that identifies you will not be used on any of the information used.

By signing this consent form you give permission to the study staff to access your family member's personally identifiable health information, which is under the custody of other health care professionals, as deemed necessary for the conduct of the research.

Questions and Concerns

If you have any questions about the study at any time please do not hesitate to call the Critical Care Research Office at 735-4096 and ask to speak to one of the investigators or their research nurses.

If you have any concerns about any aspect of this study, you may contact the Capital Health Authority Patient Relations Office, at (780) 407-1040. This office has no connection with the study or research staff.

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Appendix E

CONSENT FORM (Family Member)

Incidence of Stress Symptoms in Family Members and Survivors of the Intensive Care Unit: A Pilot Project

Investigators: Dr. A. Shustack, Dr. Ray Seutter, Gwynne McDonald, Kara Livy

	Yes	No
Do you understand that you have been asked to take part in a research study?	☐	☐
Have you read and received a copy of the attached Information Sheet?	☐	☐
Do you understand the risks and benefits involved in your taking part in this research study?	☐	☐
Have you had a chance to ask questions and discuss this study?	☐	☐
Do you understand that you are free to withdraw from the study at any time without having to give a reason and without affecting your care?	☐	☐
Has the issue of confidentiality been explained to you, and do you understand who will have access to your family members medical records, including personally identifiable health information?	☐	☐

Who explained the study to you? ______________________________

I____________________agree to take part in this study by voluntarily signing this form:
Printed name of Subject

Yes ☐ No ☐

______________________ ______________________________
Signature of Subject Date Time

______________________ ______________________
Signature of Witness Date

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

____
Signature of Person Conducting Informed Consent Discussion Date

____
Signature of Investigator/Designee Date

*Subjects Initials*________

Appendix F

Telephone Follow-up Guidelines (Family Member)

'Hi [*potential participant's name*], my name is [*researcher's name]* and I am calling from the Royal Alexandra Hospital. I am the research nurse you met before you left the hospital who asked you to take part in the research study regarding your feelings related to your family member's ICU stay. You were given a copy of the information sheet before you left the hospital.

Before we start with the questionnaires, I first want to see if you have any questions, and make sure you are still in agreement to taking part in this study because even though you agreed to take part, you can withdraw at anytime, without giving a reason if you don't want to.

Also I would also like to remind you that if you have any concerns about any aspect of this study, you may contact the Capital Health Authority Patient Relations Office, at (780) 407-1040. Are you still in agreement to take part in this study?

[IF NO] 'Thank you, good-bye.'

[IF YES] Continue

'Is this a good time for you? I need about 15 or 20 minutes of your time'

[IF NO]

'OK, when would be a better time? (Schedule a mutually agreeable time)

[IF YES] Continue

'Great. Thank you. Let's begin' (Start questions following the questionnaires)