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Symptom Experiences of Family Members of Intensive Care Unit Patients at High
Risk of Dying

by

Jennifer L. McAdam

DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF PHILOSOPHY

in

Nursing

in the

GRADUATE DIVISION

of the

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

Dedication and Acknowledgements

To my mom, Patty Berg (1945-2003), wherever you are, I hope there are flowers, friends, Grandma C, and that the Vikings always win the Super Bowl. I also hope that you are proud of me and that I never stop amazing you.

This dissertation is the culmination of hard work over the course of three years. I am thankful for the generosity of the numerous people who have helped me along the way. First, I want to thank the Betty Irene Moore Foundation for their generous fellowship that gave me this opportunity to fulfill my dream of obtaining a PhD. I also want to thank all of my classmates and professors who challenged my thinking and consistently offered encouragement. I am also grateful for Dr. Steve Paul. He has given me many valuable experiences and opportunities as well as helped me analyze and understand my study findings. I want to thank all the staff at UCSF Moffitt-Long Hospital for their help and support with this work. I especially want to thank the family members who participated in the study, especially at such a challenging time in their life.

I cannot adequately thank my committee members for their patience in reading draft after draft and all of their generous support. Dr. Kathy Dracup who has been a role

model and mentor. She has instilled in me the importance of research and publication. Dr. Dorrie Fontaine who has been a positive voice throughout the whole process. Dr. Doug White who has provided a unique interdisciplinary perspective on my dissertation study. How he has so much energy with three small children at home still remains a mystery. And my advisor, Dr. Kathleen Puntillo, who is a gifted professor and has given me so many opportunities to grow in this area of research. I only hope I can be half the nurse, professor and researcher that she is.

I want to thank my “Sex and the City” girlfriends for getting me out of the house and reminding me there is more to life than school and research. I also want to thank other friends who have kept me sane along the way. Finally, I want to thank my family. My sister-in-law, Erin, for always being there. Luna, for keeping me entertained while I worked at home. And my love, what can I say, I could have never done this without you. Thank you so much.

Of note, several chapters in the dissertation are either in press and/or are published. Chapter 2, “Family members of patients in the ICU: What symptoms do they experience?” is currently in press and will appear in the *American Journal of Critical Care*. Chapter 3, “An integrated model for assessing symptom experiences of families of ICU patients at high risk of dying,” is in review for the journal *Advances in Nursing*

Science.” Chapter 5, “Unrecognized contributions of families in the intensive care unit,” is a reprint of the material as it appears in *Intensive Care Medicine*. The co-authors listed in all the publications directed and supervised the research that forms the basis for the dissertation.

Symptom Experiences of Family Members of Intensive Care Unit Patients at High Risk of Dying

ABSTRACT

Objective: To describe the symptom experiences of family members of patients at high risk of dying in the intensive care unit and to assess risk factors associated with an increase in symptoms.

Design: Prospective, cross-sectional, descriptive study.

Setting: Three intensive care units at a tertiary medical center in the Western United States.

Participants: A convenience sample of 74 family members of 74 ICU patients at high risk of dying participated in the study.

Interventions: None.

Measurements and Results: We assessed the results from several reliable and valid instruments of 74 family members 3-5 days after the patient's admission to the ICU.

Overall the prevalence of symptoms was high, with over 56.8% of our sample having symptoms of traumatic stress, 79.7% having symptoms of anxiety and 70.3% having symptoms of depression. We also found that family members suffered from other symptoms such as tired, sadness, and poor appetite at moderate to severe levels of distress. Independent factors associated with an increase in severity of family members'

symptoms included younger patient age, younger family member age, female gender of the family, and family member's race other than White. In addition, we found that the majority of the family members were coping and functioning at high levels during the ICU experience.

Conclusions: Family members are important to patient care in the ICU. They are often required to participate in end of life decision making for the patient at high risk of dying. Family members in our study had high levels of psychological and physical symptoms, often at distressing levels. More support and understanding of family members' symptom experiences is needed in order to understand the long term effects of symptoms and to improve family centered care in the ICU.

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CHAPTER 1

Dissertation Introduction: Symptom Experiences of Family Members of Intensive Care Unit Patients at High Risk of Dying

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Dissertation Introduction: Symptom Experiences of Family Members of High Risk of Dying Intensive Care Unit Patients

The intensive care unit (ICU) is often a place where family members suffer the most,¹ especially family members of patients at high risk of dying. These patients are usually sedated, mechanically ventilated, and non-communicative, leaving the burden of decision making on the family. End-of-life decisions may be stressful and unprecedented for most family members.² In addition, the family members may have to prepare for the potential loss of a loved one. This situation can be overwhelming and impact the family member's own physical and mental health.^{1, 3-6} Despite these facts, research has been limited on family members of high risk ICU patients, specifically their symptom experiences, risk factors associated with an increase in symptoms, and the impact these symptoms have on their well being.

In chapter 2, we discuss research articles on family member's symptom experiences. Most of the research focused on psychological symptoms such as traumatic stress, anxiety and depression. The large majority of studies were completed in countries other than the United States and focused mainly on family members of patients who were discharged from the ICU, not at the end of life. The results of this literature review have been submitted to the *American Journal of Critical Care Nursing* (currently in press).

Chapter 3 of this dissertation discusses the development of the Family Care Symptom Model, which is a combination of the Symptom Management Theory,⁷ Stress, Appraisal and Coping Theory⁸ and the Circumplex Model of Families.⁹ The previous three models have been combined into one because of the inability of one theory or model to fully explain the symptom experiences of family members of high risk of dying ICU patients. The development and discussion of the conceptual framework has been submitted to the *Advances in Nursing Science* (currently in review).

Certain methodological challenges arise when studying family members' symptom experiences. Consideration for both psychometric and contextual issues in selecting the most appropriate instruments is needed. Discussion of measurement issues and instruments used in family symptom research can be found in Chapter 4.

Involving family members in the care of patients at the end of life in the ICU has been strongly supported by national and international critical care organizations.^{10, 11} Yet little is known regarding the contributions to care and actual work that family members do while visiting their loved ones at high risk of dying in the ICU. A secondary analysis of family interviews from the Soros Project on Death in America was undertaken to answer the following question: What are the contributions to care of family members in terms of the roles they encompass while their loved ones are at high risk of dying in the

ICU? Although this paper does not directly address family members' symptom experiences, it does discuss an additional burden placed on family members that could impact their symptom experience. The results of this study can be found in Chapter 5 and have been published in *Intensive Care Medicine* (McAdam, Arai, & Puntillo, 2008).

Chapter 6 presents the results of my dissertation study, "Symptom experiences of family members of ICU patients at high risk of dying." The overall purpose was to understand the psychological and physical symptom experiences of family members of ICU patients at high risk of dying and to investigate other risk factors that may be associated with an increase in symptoms. The specific aims of this study were to:

- Identify and describe the levels of traumatic stress, anxiety, depression, and other symptoms in families of high risk ICU patients.
- Identify and describe coping techniques and methods of family functioning.
- Investigate the relationship between a family member's level of coping, level of functioning, socio-demographic variables (e.g. gender, age, education) and patient variables (e.g. severity of illness, age, diagnosis) on family members' levels of traumatic stress, anxiety and depression.

This manuscript will be submitted to *Critical Care Medicine* at its completion (projected: summer 2008).

Chapter 7 concludes the dissertation work with a summary of the key findings along with implications for practice and future research recommendations.

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CHAPTER 2

Dissertation Review of Literature: Family members of patients in the ICU: What symptoms do they experience?

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[Submitted to the *American Journal of Critical Care*, in press, used with kind permission
from American Association of Critical-Care Nurses (AACN)]

“Family members of patients in the ICU: What symptoms do they experience?”

ABSTRACT--Concern for the family members of intensive care unit patients at high risk of dying is both a necessary and integral part of providing holistic nursing care. When patients are at high risk of dying, families experience burdens such as decision making and treatment choices that can cause them psychological and physical symptoms. The most common are stress, anxiety and depression. These symptoms in turn can impact their general well being. During the last two decades a number of quantitative and qualitative studies have assessed symptoms in family members. In this review of the literature, the current state of the science on family symptom experiences in the ICU is reviewed and critiqued. The review is accompanied by a discussion of risk factors associated with an increase in symptom experiences. Overall, surveys using self report measures were the most common study design. Limitations of the studies include convenience sampling, small sample sizes, and a lack of patient characteristics making comparison and utilization of findings difficult. Recommendations to address gaps in the literature are highlighted, and future research goals are discussed.

KEY WORDS: Family, Symptoms, end-of-life, Intensive Care

“Family members of patients in the ICU: What symptoms do they experience?”

Every year in the United States, approximately 20% of Americans die in an ICU,¹ with over half of those dying after the withdrawal or withholding of life sustaining measures.² Many of these patients are sedated, mechanically ventilated, confused, or comatose, leaving the patient unable to communicate their wishes.^{3,4} The non-communicative state of the patient places much of the burden regarding decision making and treatment choices on family members.⁵⁻⁷ This type of experience may impact family members negatively by increasing their stress levels and increasing their risk of psychological and physical symptoms.

Concern for the family of ICU patients at high risk of dying is both a necessity and an integral aspect to providing holistic care in this setting. In the last five years, clinical practice guidelines⁸ and a consensus document⁹ were published supporting and encouraging family centered care in the ICU. Recent recommendations for incorporating family centered care include assessing psychological symptoms such as stress and anxiety levels of the family members. Potential benefits to this care philosophy include improved satisfaction with care and reduced symptom burden for family members.⁸ Yet, before this recommendation can be incorporated into practice, more research is needed on

what types of symptoms family members experience, the impact of these symptoms, and what type of interventions are more effective in reducing these symptoms and improving outcomes for both patients and their families.

Currently, most researchers studying family members in the ICU have focused mainly on family members' needs¹⁰⁻¹⁶ and satisfaction with care.^{13, 15-20} There has been considerably less published on family members' symptom experiences and even less on symptom experiences of family members of ICU patients at high risk of dying. In order for ICU clinicians to provide appropriate care to both family members and patients in the ICU, knowledge of family members' symptoms is the first step. Therefore, the purpose of this paper is to critically review the current literature on what is known regarding family members' symptom experiences in the ICU along with factors that may influence their symptom experiences. Gaps in the literature will be highlighted, implications for practice will be provided and suggestions for future research will be presented.

Integrated Literature Review

The current relevant literature was searched using the electronic databases PubMed, PsycInfo, and CINAHL. Key words and combination of key words searched included: "family" or "signs & symptoms" or "stress" or "anxiety" or "depression" or "critical care" or "intensive care" or "end-of-life" or "terminal care" or "palliative care"

or “coping” or “experiences”. The dates of the search were not limited due to the relatively new emphasis on this topic in the literature. Abstracts were reviewed for relevancy and content. The limitations applied to the search were “English only” and “adult ICU patients.” Review articles, abstracts, conference proceedings, editorials, case studies, anecdotal commentaries, and studies that focused primarily on pediatric and neonatal ICU populations were excluded. Adult studies that also included children and infants were retained for analysis. The final search strategy used was to review the obtained articles’ reference lists for any further pertinent articles. The results yielded a total of 18 studies that met the criteria and are summarized in the Appendix.

Historical Symptom Research

Research on family members’ symptoms in critical care had its origins in the middle of the 1970’s. Most of the research was qualitative and descriptive in design and had small to moderate sample sizes ranging from 20 to 166 family members. The majority of these studies were completed in single centers and included mostly patient populations from coronary care units. Most of the family members consisted of female spouses of patients recovering from either a myocardial infarction or coronary artery bypass surgery. The time frame to assess symptoms ranged from hospitalization to up to 6 months after the patient’s discharge.

Overall the findings from these studies suggested that female spouses of ICU patients reported multiple emotional feelings such as anxiety, depression, and fear.²¹⁻²⁵ The findings also revealed that female spouses suffered from multiple stressors such as potential loss of their partner and family disruption during their experience in critical care.²⁶⁻²⁹ Although these studies provided a foundation upon which to study family symptoms, they lack generalizability because of the relatively small sample sizes, predominantly female samples, and the exploratory nature of the research.

It was not until the early 1990's that investigators appreciated that family members in the ICU could potentially suffer from clinically diagnosable psychological conditions.³⁰ Perez and colleagues studied 76 family members of gravely ill ICU patients with traumatic head injuries.³⁰ They found that over 50% of family members reported symptoms of depression, hypochondria, suicidal depression, low energy depression, and anxious depression. Although these investigators focused on family members from a specific patient population, they published one of the first studies to suggest that families may suffer from psychological symptoms that could be detrimental to their physical and mental health.

Several investigators have built upon previous work by examining family members' symptoms and associated risk factors. Most confirmed that family members

suffer from psychological symptoms such as anxiety, depression, stress, acute stress disorder (ASD), post traumatic stress disorder (PTSD)-related symptoms, and post traumatic stress reactions (PTSR). The following section will summarize this research.

Survey Research on Stress, Depression, and Anxiety

Stress

Most of the research measuring stress in family members has been at the descriptive level. One cross-sectional study³¹ and six longitudinal and descriptive studies^{16, 32-36} were reviewed in which the sample sizes ranged from 32 to 284 family members. They included mostly patient populations from medical, surgical, cardiac, and trauma ICUs. Only one of the studies included family members of pediatric and neonatal ICU patients.³⁵ The majority of these studies were completed in single centers. A variety of instruments were used to measure stress (see table 1), and the time frame for stress measurement varied from 24 hours after admission to 90 days after the patient's death or discharge from the ICU. All of the studies focused on the family member's own self report of symptoms.

Overall stress response scores,^{32, 35} traumatic stress scores,^{31, 33, 34, 36} and ASD scores¹⁶ were high in family members in the ICU. In one study of 40 family members of patients in a trauma ICU the authors reported the family members to have ADS scores

very close to those of patients admitted for PTSD at a psychiatric unit.¹⁶ In another descriptive study of 133 Chinese family members, the researchers reported high levels of PTSD-related symptoms, with 70.7% of the family members in their sample having high levels of traumatic stress.³¹ French investigators studying 284 family members found that the overall prevalence of PTSR was moderate and affected 33%.³⁶ In addition, they reported that family members with high PTSR also had more severe anxiety and depression symptoms.

Factors associated with higher stress response scores, ASD, PTSD-related symptoms, and PTSR in family members have been reported. Azoulay and colleagues using a multivariate linear model found that, on average, PTSR scores were significantly higher in females, children, and those who felt the information regarding the patient's condition was incomplete.³⁶ Chiu & Chan also found that females had significantly higher traumatic stress scores than males ($t = -4.60, p < .001$). They also reported that family members had significantly higher traumatic stress scores if they had lower education levels ($F = 3.0, p = .05$) and the ICU admission was unplanned ($t = -2.2, p = .03$).³¹ Several investigators reported that stress response scores and ASD scores were higher for family members on admission to the ICU but tended to decrease by the time of discharge of the patient.^{16, 32, 34, 35} However, other investigators³¹ found that the patient's

longer length of stay was significantly associated with higher traumatic stress levels in family members ($r = 0.5, p < .01$). Because length of stay was not clearly reported in two of the studies^{16,36} and because length of stay varied from a mean of three days³⁵ to 26 days³⁴ in the other studies, it remains in question as to what degree length of stay influences stress levels in family members.

Only two of the seven descriptive studies compared the impact of patient mortality on family members' traumatic stress and PTSD scores.^{33,36} Tilden and colleagues studied traumatic stress levels in 74 family members two months after they had to make end-of-life decisions in the ICU. They found that traumatic stress scores were significantly higher in family members of patients who did not have any form of advance directives compared to family members of patients who had either verbal or written advance directives.³³ Azoulay and others assessed PTSD scores in 234 family members of patients discharged from the ICU and compared them to PTSD scores in 50 family members of patients that died in the ICU. They found that the prevalence of PTSD increased in family members of patients who died in the ICU, particularly if the family member was involved with end-of-life decision making (81.3%).³⁶

Depression

One longitudinal study³⁴ and four descriptive studies on depression in family members³⁶⁻³⁹ were reviewed. Study sample sizes ranged from 32 to 836 family members. Most of the studies included family members of patients in medical, surgical, and cardiac ICUs, with only one study including pediatric ICU patients.³⁹ The majority of the studies were prospective and descriptive in design and were completed in multiple hospitals. Most of the investigators used the same instrument to assess depression, the Hospital Anxiety and Depression Scale (HADS),⁴⁰ with one group using the CES-D⁴¹ (see table 2). The time frames for measuring depression varied, from 3-5 days after admission, 3 months after discharge, or at the time of the patient's death or discharge from the ICU.

In general, the findings indicated that depression affected around 15%³⁷ to 35%^{38, 39} of family members. When investigators assessed factors associated with depression, they found that being a spouse of the patient (OR = 2.1, $p = .0001$) and being female (OR = 2.0, $p = .0001$) significantly increased the risk of depression symptoms.³⁹ In addition, inconsistent information given to family members regarding the patient's condition was associated with significantly higher risk of depression symptoms (OR = 1.67, $p = .04$).³⁹

One investigator team^{38, 39} compared the impact of patient's severity of illness and mortality on family members' depression symptoms. In a study completed in 2001,

Pochard and colleagues³⁹ found no significant correlation between the patient's severity of illness or mortality and family members' depression scores. However, Pochard and colleagues in another study completed in 2005,³⁸ reported that family members of patients who died in the ICU had two times the odds of having depression symptoms than family members of a patient that survived (OR = 2.09, p = .011). They also found that the patient's severity of illness score impacted upon depression in family members, but the impact was negligible. The discrepancy between these two studies of the same authors could be explained by the differences in patient characteristics. Although there was no information provided about patient diagnoses, the severity of illness scores were lower (median Simplified Acute Physiology Score II = 38 versus 42) and the length of stay was shorter (median = 9 days versus 14 days) in Pochard and colleagues' first study in 2001³⁹ compared to their follow up study in 2005.³⁸

Anxiety

Several investigators examined anxiety in family members of ICU patients.^{34, 36-39,}
^{42, 43} Most of these studies were descriptive, and the sample sizes varied from 32 family members to 836 family members. The majority of the studies were conducted at a single center and focused mainly on patients from medical, surgical, and cardiac ICUs. One study also included pediatric patients.³⁹ Timeframes used to measure anxiety varied and

generally ranged from 48-72 hours after patient admission, 3 months after discharge, or at the patient's death or discharge from the ICU. The main instruments used in these studies were the Spielberger State Trait Anxiety Inventory (STAI),⁴⁴ the HADS,⁴⁰ and the Brief Symptom Inventory (BSI).⁴⁵ (See table 2).

The prevalence rate of anxiety in family members in several of the studies ranged from 35%³⁷ to 73%.^{38,39} Other investigators reported that intensity levels of anxiety in family members ranged from moderate⁴² to high.^{34,43} Risk factors associated with an increase in symptoms of anxiety in family members included being a spouse of a patient,^{34,38,39} being a female family member,^{34,38} having an unplanned ICU admission and having a lower educational status.⁴³ Other researchers reported that family members of patients with neurological illness and traumatic injuries had significantly more anxiety than other family members.⁴² Having no regular meetings with a physician or nurse was also significantly associated with an increased risk of anxiety in family members (OR = 1.36, $p = 0.02$), as was the patient having an absence of chronic disease (OR = 1.52, $p = 0.02$).³⁹ Reider also reported that coping strategies may have an impact on anxiety levels in family members,⁴² whereas others have cited that family needs may impact anxiety in family members.⁴³

Only one of the seven descriptive studies compared the prevalence of anxiety on family members of ICU non-survivors (n =91) to the prevalence of anxiety on family members of ICU survivors (n = 435). Even though both groups had high prevalence rates of anxiety, the researchers did not find a significant difference in anxiety prevalence between the two groups.³⁸

Qualitative Research on Family Symptoms

Qualitative methods were used in two of the studies on family members' experiences and symptoms in the ICU.^{46, 47} Kleiber and colleagues used an exploratory, descriptive, and longitudinal design to assess changes in family members' emotions over time in five ICU settings. They had 52 family members complete daily ICU logs with open-ended probe questions while they were visiting in the ICU. They found that family members, especially during the first few days of the ICU stay, had many strong emotions such as fear, anxiousness, exhaustion, helplessness, and sadness. They also found that family members of patients in the medical ICU had more negative feelings than those in other types of ICUs.⁴⁷

Titler and colleagues used a phenomenological approach to assess the effect of critical care hospitalization on family members from multiple perspectives. They interviewed and audiotaped 23 family members, nine patients, and 12 ICU nurses. They

reported that both patients and family members had feelings of guilt, fear, and uncertainty. They also reported potential stressors in family members that could cause symptoms such as significant changes in family relationships, multiple conflicts within the roles of the family, and lack of communication within the family. Of note was that nurses' perceptions of the impact of critical care on the family member were not as severe as the families.⁴⁶

Experimental Research on Family Symptoms

Two studies on family members of ICU patients provided interventions to reduce PTSD-related symptoms, anxiety, and depression levels in family members. Two other studies focused on reducing just anxiety levels in family members.

Lautrette and colleagues used a randomized controlled trial design in 22 ICUs in France to test the effectiveness of a proactive communication intervention on reducing PTSD-related symptoms and symptoms of anxiety and depression in family members of ICU patients at the end-of-life. The intervention involved an end-of-life conference based on the mnemonic VALUE.^{48,49} This includes specified guidelines where clinicians *V*alue what the family wishes to discuss, *A*cknowledge the family members' emotions, *L*isten, ask questions in order to *U*nderstand who the patient was as a person, and *E*licit questions from the family members. They found that the prevalence of PTSD-related symptoms

was lower in the intervention group (45% versus 69%, $p = .01$). They also reported that the prevalence rates of anxiety and depression were lower in the intervention group compared to those in the control group (anxiety, 45% versus 67%; $p = .02$; depression 29% versus 56%; $p = .03$).³

In another study, Chien and others used a quasi-experimental pre-post test design to test the effectiveness of a needs based education program on reducing anxiety levels of Chinese family members of patients in a medical ICU in Hong Kong. The intervention involved an hour-long educational session focusing on specific family members' needs on both days 2 and 3 of the ICU stay. Investigators reported that the educational sessions significantly reduced anxiety levels in the treatment group when compared to the group receiving standard care ($t = 2.37$, $p = .006$).¹³

Jones and colleagues tested the effectiveness of a self-help educational module on reducing family members' PTSD-related symptoms, depression, and anxiety. They found that the intervention did not significantly reduce PTSD-related symptoms, anxiety, or depression in the treatment group.⁵⁰ Halm and colleagues used a quasi-experimental design to measure the effects of a support group intervention on anxiety in family members of patients in a surgical ICU. They also reported no statistically significant

difference in reducing anxiety levels between the treatment group (n= 25) and the control group (n = 30).⁵¹

Two of the four intervention studies significantly lowered psychological symptoms in family members, whereas the other two showed no significant results. These findings may best be explained by the specificity of the interventions. It is possible that general interventions (e.g. informational booklets and support groups) are not as effective in reducing family members' symptom experiences as more individualized interventions (e.g. targeting family members' specific needs and using a specific proactive communication technique).

Summary Critique of the Literature

In this review of the literature, 18 studies have been presented. Eight-nine percent were quantitative and 11% were qualitative. Of the quantitative studies, 78% were descriptive and 22% were experimental. Most often only one symptom was assessed, but in several studies, multiple symptoms such as PTSR, PTSD-related symptoms, anxiety and depression were measured together. The main findings from all of the quantitative studies suggest that family members of ICU patients have high levels of stress, including PTSR, PTSD-related symptoms, and ASD. These findings also suggest that family members have high anxiety levels and moderate depression levels. The studies also

reveal that certain variables are associated with higher levels of psychological symptoms in family members (See table 3.) The main findings from the qualitative studies suggest that family members suffer from negative emotions and multiple stressors that could impact family relationships, roles, and communication.

Overall the use of self report measures and surveys was the predominant methodology. Of the four experimental studies, only two showed any statistically significant results. Therefore, despite promising data from these studies, family symptom assessment and interventions are still at the early phase of development. Although these studies help build a knowledge base of family members' symptom experiences, there are several limitations. Convenience samples, small sample size, and a lack of description of patient sample characteristics make it difficult to compare and generalize findings across settings and patient populations. Some of the researchers did not describe the content of the survey items or reliability of the tools,^{32, 35} although several others provided more detail regarding the instruments used, along with their established reliability and validity.^{16, 33, 34, 36, 38, 39, 43} There were no consistent timeframes for measuring the symptoms (range was 48 hours after ICU admission to 3-6 months after ICU), so it is difficult to know the best time to capture the symptom experience. However symptoms appeared to have occurred at all timeframes, indicating that family members may suffer

from symptoms throughout the ICU experience and long afterwards. Another limitation in family members' symptom research was that most of the studies were completed in countries other than the United States where the healthcare system and ICU cultures are vastly different. Finally, the majority of studies did not focus on family members of ICU patients at high risk of dying, but rather on family members of patients who were discharged from the ICU. Thus it remains unclear if the symptom experience may differ for the family members of high risk patients.

Implications for Practice

Even though symptom research on family members of ICU patients at high risk of dying is in its infancy, the findings from current studies can shed some light on how to reduce family members' symptom burden. Investigators have documented risk factors associated with an increase in symptom experiences in family members (see table 3). These risk factors can be identified during a family assessment. Once identified, ICU clinicians can offer spiritual and emotional support to the family and intervene as appropriate with referrals to chaplain services or another service according to hospital policy. ICU clinicians can also be proactive in their approach with family care conferences. Incorporating a structured care conference that improves communication, such as the one discussed earlier by Lautrette and colleagues has been shown to

significantly reduce symptoms of PTSD, anxiety and depression in family members making end-of-life decisions.³ In addition, ICU clinicians can have regular meetings with family members and provide them with honest and consistent information about the patient. This may reduce anxiety and depression in family members.^{38, 39} Finally, ICU clinicians can develop supportive relationships with family members by assessing their needs and by showing compassion and respect for the family and their decisions. This supportive relationship has been linked to an increase in family satisfaction and could possibly reduce family members symptom burden.^{52, 53}

Directions for Future Research

In this review of the literature on family members' symptoms, a number of gaps can be identified. The most noticeable is the lack of information on the symptom experiences of family members of ICU patients at high risk of dying. Only two of the 18 articles focused specifically on this population. Although the findings from other studies could cautiously be generalized to all families in the ICU, more research is needed on the risk factors for family members of high risk patients.

Another area that requires further investigation is the lack of information regarding patient factors such as length of stay, severity of illness, and patient mortality rates found in previous studies.^{16, 32, 35, 36, 42} Because of the conflicting results, more

descriptive research on these factors is required to see if they are associated with an increase in family members' psychological symptoms. Knowledge of these factors will help clinicians identify those family members at an increase risk and intervene as appropriate.

Prior research included samples consisting mostly of Caucasian, female, and educated family members.^{16, 32, 35, 42, 46, 47} Therefore, our knowledge of the symptom experience in males and people of diverse cultural and educational backgrounds is limited. More descriptive research is needed on diverse samples of family members to assess if variables such as a family member's cultural and educational background affect symptoms in family members. Future research should also focus on the role of spiritual care to assess the impact this may have on reducing family members' symptom experiences. Research is also needed on other factors such as family coping skills, needs, and family functioning. These factors have been found to be associated with an increase in psychological symptoms in family members in other studies^{13, 31, 42, 43, 46} and in other critical care populations such as in neonates in ICUs.⁵⁴

Most researchers have focused mainly on psychological symptoms of family members such as stress, anxiety, and depression. There remains a gap in knowledge regarding other types of symptoms that family members may suffer from such as sleep

and fatigue problems, appetite problems, or pain. Physical symptoms need to be assessed because these symptoms could affect overall well being.

Most of the research on family symptoms has been cross-sectional and descriptive in design. Additional research should focus on mixed methods research designs along with longitudinal and interventional studies. Mixed methods designs are more comprehensive and may be useful in identifying variables unique to this population using both qualitative and quantitative strategies. Longitudinal studies would allow researchers to assess long term consequences of symptoms in family members such as complicated grief or PTSD reactions. Interventional studies would allow researchers to test strategies to reduce symptom burden in family members that may prevent long term consequences of these symptoms.

Organizationally, studies are needed that assess hospital or ICU factors that may affect symptoms in family members. Studies are needed that assess ICU clinicians' perceptions of the severity of family members' symptoms and ascertain if those are similar or different from the families' reports. If there are discrepancies, this could impact the amount of support and interventions offered to the family members. Studies are also needed that compare hospitals that have end-of-life protocols or palliative care programs with hospitals that lack such policies and programs. From these studies, researchers can

determine if hospital policies on end-of-life care, such as end-of-life care conferences, affect the level of support for families and help reduce symptoms in family members.

Although research on end-of-life care in the ICU has raised potential ethical issues for investigators, these concerns are not unique to this field of study. Yet, researchers in this field need to demonstrate appropriate research questions, appropriate methods and valid findings that are generalizable. They should ensure that the consent process remains thoughtful and that the study design ensures maximum benefits while minimizing risks to subjects.⁵⁵

Conclusion

Family members play an integral role in the care of the dying patient in the ICU. They are expected to make unprecedented decisions and deal with many difficult situations. In turn, they may suffer from psychological symptoms such as stress, PTSD-related symptoms, anxiety, and depression, which can impact their general well being. Researchers have developed a knowledge base on variables associated with an increase in family members' symptom experiences. However, additional research is critical in expanding our knowledge on family members' symptom experiences in the ICU especially at the patient's end-of-life. Further research will help clinicians develop supportive measures that will assist family members during this difficult time.

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Table 1. Instruments to measure stress

| Instrument | Measures | Score Range | Psychometric Properties |
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| Acute Stress Disorder Scale (ASDS) ⁵⁶ | 19-item survey uses a 5-point Likert scale to measure acute stress and predict PTSD | Range 19-95 Higher scores indicate more ASD Suggested cutoff point = 56 for the total ASD score, although this is arbitrary | Cronbach's alpha = 0.96 Test-retest = 0.94 after one week interval Content, construct, and criterion validity have been documented. |
| Impact of Event Scale (IES) ⁵⁷ | 15-item survey uses a 4-point Likert scale (0, 1, 3, and 5) to measure traumatic stress; has been used in post traumatic stress research | Range 0 to 75 Higher scores indicate more traumatic stress. Two common cut off points used in research, (not as diagnosis) are scores greater than 19 indicates concern for developing PTSD and scores higher than 30 indicates high probability of developing PTSD | Cronbach's alpha = 0.86 Content, construct, and criterion validity have been documented. |
| Iowa ICU Family Scale (IIFS) ³⁵ | 61-item survey uses a Likert response to measure stress indirectly based on answers to behavioral questions on sleep, activity, eating, family roles, and support systems | Score on the stress subscale varies depending on the answers to the behavior questions but could range from 0-61 Higher scores indicate more stress | Cronbach's alpha = 0.86 for the stress subscale Content validity has been documented. |

Table 2. Instruments to measure anxiety and depression

| Instrument | Measures | Score Range | Psychometric Properties |
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| Hospital Anxiety and Depression Scale ⁴⁰ | 14-item survey uses Likert scale to measure anxiety and depression | Two subscales Anxiety (7-items) Depression (7-items) Each subscale score can range from 0-21 Total score range 0-42 Higher scores indicate more anxiety and depression Suggested cutoff point for each subscale is greater than 10 | Cronbach's alpha = 0.93 for anxiety and 0.90 for depression subscales Content, construct, and criterion validity have been documented. |
| Spielberger State-Trait Anxiety Scale (STAI) ⁴⁴ | 20-items uses a 4-point Likert scale to measure state and trait anxiety levels | Score range 0 to 80 Higher scores indicate more anxiety | Stability ranges from .16 to .62 for the state And .65 to .86 for the trait scales Validity has been documented |
| Brief Symptom Inventory (BSI) ⁴⁵ | 6-item subscale uses a 5-point Likert scale (0-4) to measure current point in time psychological anxiety | Range 0-24 Higher scores indicate more anxiety | Cronbach's alpha for the anxiety dimension 0.81. Test-retest reliability 0.79. Content, construct, and criterion validity have been documented. |
| Center for Epidemiologic Studies Depression Scale (CES-D) ⁴¹ | 20-item scale uses a 4-point Likert scale (0-3) to measure current symptoms of depression | Range 0-60 Higher scores indicating more depression symptoms | Cronbach's alpha range from 0.83-0.88. ⁵⁸ Content, construct, and criterion validity have been documented. |

Table 3. Symptoms in family members and associated risk factors

| Symptom | Associated Risk Factors |
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| Stress (Overall/Traumatic/PTSR/PTSD-related) | Female ^{31,34,36} Children and younger family members ^{35,36} Patient death ³⁶ End-of-Life decision making ³⁶ Incomplete information ³⁶ Lack of advance directive ³³ |
| Depression | Female ^{34,39} Spouse ³⁹ Inconsistent information ³⁹ Patient Death ³⁸ ICU Type ³⁷ |
| Anxiety | Female ^{34,38,39,43} Spouse ^{34,38,39} ICU Type ³⁷ Patient Diagnosis ^{39,42} Lower family education ⁴³ No regular family meetings with clinicians ³⁹ Family member's lack of coping skills ⁴² Family needs not met ⁴³ |

Appendix. Studies on family symptom experiences

| Study (Date) | Method | Sample/ Characteristics | Results | Critique | Conclusion |
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| Azoulay, et. al., 2005 ³⁶ | Descriptive, longitudinal study to assess possible stress related morbidity among family members in the ICU Instruments • IES • HADS | Family N = 284 Median age 51 (41-61) 67.6% female 48.2% spouses Patients 55.6% male Median age 59 (45-73) 90% poor chronic health status French sample | 33.1 % of family members had scores indicating post-traumatic stress reaction symptoms; Increased to 50% when the patient died; 60% if patient died after end-of-life decision making; 81.8% if family members involved with end-of-life decision making; 49.3 % of family members had anxiety; 20.1 % of family members had symptoms of depression | Strengths Large sample size Multiple ICUs; multiple hospitals Used well validated and reliable instruments Limitations Study done in French ICU's which may be very different from the culture in U.S. ICUs Sample mostly females and spouses | PTSR symptoms are common in family members of ICU patients 3 months after the ICU experience. Family members of patients who died in the ICU are at higher risk. |

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| Tilden et al., 2001 ³³ | Descriptive, longitudinal study to assess levels of family stress associated with decisions to withdraw life-sustaining treatments and to assess factors that affected stress Instrument • IES | Family N = 74 at Time 1 N = 65 at Time 2 Mean age = 48.7 69% female; 81% White; 32% spouses 41% adult children Patients N = 51 49% female 84% White Mean age = 60 | Stress levels high at both time 1 and Time 2 but significantly higher at Time 1; Family stress highest in family members of patient that had no advance directives (31.5) versus verbal (28.7) versus written (21.3) (F = 5.28, p = 0.02); Ethnicity, absence of advance directives, and commuting distance explained 14% of the total variance in family member stress | Strengths Used reliable and valid instruments Assessed stress levels in family members of patients that died in the ICU or hospital Limitations More than one family member per patient, limits external generalizability of findings No patient characteristics given | These findings add to the literature the importance of advance directives in reducing stress related to family decision making. |
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| Auerbach et al., 2005 ¹⁶ | Descriptive study with repeated measures (admission and discharge) to assess family members emotional stress and level of psychopathological dysfunction Instrument • ASDS | Family N = 40; 65% female 45% white; mean age 45 No patient characteristics reported | Family members had high levels of ASD; mean score; very close to scores of pts admitted to a PSTD unit at a psych unit; significant difference in ASD scores between admission and discharge t = 3.17, p < .005 | Strengths Reliable and validated instrument Limitations No patient variables mentioned; Small sample size; mostly female, educated, single institution | Family members had high levels of ASD on admission but these decreased by discharge. Family members in the ICU are not at risk for developing PTSD. |
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| Halm, et al., 1993³⁵ | Exploratory, descriptive design to assess the behavioral responses of adult family members to a critical illness event over time Instrument • IIFS | Family N = 52 94.2% white 40% college educated 46% parents 29% spouses Patients LOS < 3 days | 80% of ICU admissions were perceived by family members to be emergent; stress scores high on admission and decreased after; no difference in stress response scores based on types of units, or acuity of pts; stress response scores significantly higher if pts had no improvement $F(2,50) = 4.04, p < .05$; Younger family members had higher stress response scores ($r = -.31, p < 0.05$) | Strengths Based on theoretical frameworks: Lazarus and Folkman: Coping Theory and Crisis Theory Multiple ICU units and patient diagnoses Limitations Small sample size, single institution Sample mostly white and educated No psychometric properties given for the instrument used to measure stress | Family members have high overall SRS. Nursing should design interventions that reduce stress in family members. |
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| Van Horn & Tesh, 2000³² | Descriptive study to assess the behavioral responses of adult family members to the critical care hospitalization over time Instrument • IIFS | Family N = 50; Mean age 46.3 (13.2); 70% female 44% children 18% spouses 64% white 52% high school or higher Patient LOS < 10 days | Family members had 1) Poor sleep 2) Diminished appetite 3) Less active 4) Overall high stress response scores but women had higher scores; Multiple stressors for family members | Strengths Based on theory: Beralantffy's General Systems Theory and McCubbin and Patterson Double ABCX Model of Adjustment and Adaptation Assessed other behaviors like sleep. and appetite Limitations Small sample from one institution Mostly female, white, and educated No patient variables reported Multiple family members for the same patient to draw conclusions; limit external validity | Family members of ICU patients endure multiple concurrent stressors that can threaten family integrity. |
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| Pochard, et. al., 2001³⁹ | Prospective multi-center descriptive study to determine the prevalence and factors associated with symptoms of anxiety and depression in family members of ICU patients Instrument • HADS | Family N = 836; Median age 45 66.4% male 23.5% spouses 22.8% parents 24.7% children Patients Median age 59 65.6% male SAPS II score 38 (0-130); LOS 9 days (3-99) Mortality 18.5% French sample | 69.1 % of family members had symptoms of anxiety; 35.4% of family members had symptoms of depression | Strengths Large number of subjects, from a variety of community and university ICU's. They measured symptoms using a well-validated tool Limitations Study done in French ICU's which may be very different in practice and culture from U.S. ICU's Potential for Type II error because of such a large sample size Including more than one family member limits external generalizability | Anxiety and depression are common in family members of ICU patients. Females and spouses are more at higher risk for both. |
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| <p>Pochard, et. al., 2005³⁸</p> | <p>Prospective, descriptive, design to assess risk factors of anxiety and depression in family members in the ICU</p> <p>Instrument</p> <ul style="list-style-type: none"> HADS | <p>Family N = 544 Median age 47 (35-60) 65% male 81% catholic 35% spouses 28% adult children</p> <p>Patients Median age 61 (42-74) 61.9% male SAPS II 42 (29-55) LOS 14 (7-26) Mortality 17.1% French sample</p> | <p>73.4% had symptoms of anxiety; 35.3% had symptoms of depression; 80.3% of spouses versus other family members had anxiety (p = 0.01); Symptoms of depression more common in family members of non-survivors than survivors (48.3 % versus 32.7%, respectively, p = 0.008)</p> | <p>Strengths Prospective study done on a large number of subjects, from a variety of community and university ICU's. They controlled for effect size from each institution by taking 5 patients and their family members from each site.</p> <p>Limitations Study done in French ICU's which may be very different practices and culture from U.S. ICU's; Including more than one family member limits external generalizability</p> | <p>Anxiety and depression are common in family members of ICU patients at discharge or death of the patient. Family members of patients who died in the ICU and spouses are at higher risk.</p> |
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| <p>Young, et. al., 2005³⁷</p> | <p>Single measurement matched comparison group study to describe the prevalence of anxiety and depression for ICU and cardiac patients and their relatives.</p> <p>Instrument</p> <ul style="list-style-type: none"> HADS | <p>ICU Group Family (n= 20) Age 53.30 (13.94) 75% female Patient (n = 20) Age 54.15 (16.85) APACHE II 14.65 (8-24) LOS 19.05 (2-57)</p> <p>Cardiac Group Family (n= 15) Age 60 (12.51) 80% female Patient (n = 15) Age 60 (11.60) LOS 7.13 (3-12) English sample</p> | <p>Family members in the ICU group had significantly more anxiety than patients in the ICU group (t = - 2.65, p < 0.01); Family members in the ICU group had significantly more symptoms of depression than family members in the cardiac surgery group (t = 2.12, p < 0.05); 35% of family members had clinical diagnosis level of anxiety</p> | <p>Strengths They used a comparison group to see if any differences occurred between different types of ICU patients and relatives Used well validated tool to measure anxiety and depression</p> <p>Limitations Had a small sample which may have underestimated the results (low statistical power); no power analysis Completed in one ICU cite Completed in England which may have a different healthcare system and ICU culture</p> | <p>Psychological needs of relatives are equal to or greater than that of the patients. Family members may need more follow up services.</p> |
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| <p>Delva, et al., 2002⁴³</p> | <p>Descriptive, correlational study to explore the needs and anxiety levels of relatives faced with stress of a family member's critical care hospitalization in relation to the relatives' age, gender, educational level and type of kinship to the patient</p> <p>Instrument</p> <ul style="list-style-type: none"> STAI-S | <p>Family N = 200 65% female Age 48 (14.39) 30% spouses 28.5% adult children 25% high school educated</p> <p>Patients N= 120 78% male Age 55.05 (22.47) 66.7% intubated 54.2% first ICU admission Mean LOS < 48 hours Belgium sample</p> | <p>Positive significant correlation between perception of threat and anxiety in family members $r = 0.30, p = 0.0001$; Mean anxiety score = 54.35 (13.55) very high (range is 25-79); Significant negative correlation between age and anxiety, $r = -.15, p = 0.0311$; Female family members more anxious than males $F(1, 198) = 15.30, p < 0.001$; Family members with lower education more anxious $F(2,194) = 3.37, p < 0.01$; Anxiety higher if admission was not planned $F(1, 198) = 7.68, p < 0.01$</p> | <p>Strengths Used reliable and valid tools Large sample</p> <p>Limitations Completed in Belgium, different ICU practice and culture Including more than one family member limits external generalizability</p> | <p>Relatives anxiety levels are found to be significantly related to certain demographic variables</p> |
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| <p>Reider, 1994⁴²</p> | <p>Descriptive study to examine anxiety in family members of critically ill patients</p> <p>Instrument</p> <ul style="list-style-type: none"> BSI | <p>Family N = 75 79% female Age 49 (19-83) 38% spouses 26% children</p> <p>Patients 55% male Age 55 (18-87) 41% heart disease 15% trauma APACHE II 15 (0-37)</p> | <p>Mean family members anxiety scores = 8; range (0 – 20); Better coping associated with lower anxiety ($r = -.21, p < 0.05$); Younger patient age correlated to higher family member anxiety ($r = .41, P < .001$) and younger age of the family member correlated to higher anxiety levels ($r = .32, p < .01$); Coping strategies, family members age, Type of illness explained 25% of the total variance in anxiety in family members</p> | <p>Strengths Theory based (Double ABCX Model of Family Adjustment and Adaptation) Addressed other factors related to symptoms: coping and family structure</p> <p>Limitations Mostly female, white sample</p> | <p>Factors associated with anxiety in family members include mainly age, coping skills and patient diagnoses.</p> |
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| <p>Halm, 1990⁵¹</p> | <p>Quasi-experimental design to compare the effectiveness of conventional beside support and structured support groups in decreasing anxiety in relatives confronted with critical illness in the family</p> <p>Instrument</p> <ul style="list-style-type: none"> STAI | <p>Family Control Group N = 30</p> <p>Treatment Group N = 25 Age 51.15 (18-80) 36 females 19 males 40% spouses in control group and 28% in the treatment group</p> <p>Patient Control group 40% cardiac surgery 56.7% LOS 1-3 days</p> <p>Treatment Group 40% neuro surgery 48% LOS 1-3 days</p> | <p>High State Anxiety levels in both Treatment and control groups; No significant difference in anxiety between the two groups after intervention</p> | <p>Strengths Used tool with established reliability and validity Theory based: Crisis theory</p> <p>Limitations Large refusal rate 50% Evaluated more than one family member, limits external generalizability No randomization; so people more likely to want the support group would volunteer; other confounders like group variations in critical illness situations i.e. type of surgery, LOS No power analysis stated</p> | <p>There were no differences in post anxiety reduction between the control and treatment group. However, there was a decrease in the treatments group anxiety level.</p> |
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| <p>Chien, et al., 2006¹³</p> | <p>Quasi-experiment; pre-post test design to examine the effects of a needs based education program for Hong Kong Chinese family members of relatives in critical care</p> <p>Instrument</p> <ul style="list-style-type: none"> STAI | <p>Treatment N = 34 Age 37.8 (7.75) 52.9% Male 32.4% Parents 26.5% spouses 23.6% sibling/other</p> <p>Control N = 32 Age 35.9 (6.98) 53.1% Male 31.2% Parents 28.1% spouses Chinese sample</p> | <p>Both groups had high anxiety scores on admission; Treatment group had significant reduction in anxiety than the control ($F(1,62) = 5.63, p = 0.006, \eta^2 = 0.18$).</p> | <p>Strengths Treatment given by a same nurse trained in the intervention; improves consistency and limits bias</p> <p>Limitations Single site ICU; limits generalizability Completed in China where the healthcare system and ICU practice and culture may be different than in the U.S. Lack of randomization may lead to staff bias; treatment diffusion</p> | <p>The formulation of a family education program should be based on the results of a family needs assessment in order to meet the families' needs and reduce their anxiety.</p> |
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| <p>Jones, et al., 2004⁵⁰</p> | <p>Randomization trial to test the effectiveness of a self-help rehabilitation package post ICU in improving symptoms of anxiety, depression, and PTSD in family members</p> <p>Instruments</p> <ul style="list-style-type: none"> HADS IES STAI | <p>Family Experimental N = 47 Age 62 (17) Control N = 37 Age 60 (15.4)</p> <p>Patients Experimental Age 53 (17-77) LOS 14 (2-114) APACHE II 17 (4-28) Control Age 61 (17-84) LOS 12 (2-110) APACHE II 16 (6-34) English sample</p> | <p>There were no significant differences in anxiety, depression or PTSD symptoms in the two groups of family members at any time frame</p> | <p>Strengths Used well validated and reliable instruments Measured state trait of anxiety Randomization and blinding decreases potential confounders and bias</p> <p>Limitations Completed in England, different medical and ICU culture Small sample, potential for a Type I error; not enough power to detect differences between groups Question the usefulness of a general informational packet; it may go unused or may not be specific enough for family</p> | <p>Family members had high level of psychological distress and written information concerning ICU recovery for the patient did not reduce this distress.</p> |
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| <p>Lautrette, et al., 2007³</p> | <p>Randomized control trial to evaluate the effect of a proactive communication strategy that consists of an end-of-life family conference according to specific guidelines and that concluded with a brochure on bereavement (VALUE Criteria)</p> <p>Instruments</p> <ul style="list-style-type: none"> • HADS • IES | <p>Family Experimental N = 63 Age 54 (47-58) Spouses 36% Adult Child 54% Control N = 63 Age 54 (46-64) Spouses 42% Adult child 42%</p> <p>Patients Experimental Age 74 (56-80) 52% male 43% acute resp failure Control Age 68 (56-76) 59% male 43 % acute resp failure French sample</p> | <p>Intervention group had longer care conferences: 30 minutes vs. 20 minutes and spent more time talking: 14 minutes vs. 5 minutes; Intervention group had lower PTSD scores and lower prevalence of PTSD type symptoms; Intervention group had lower anxiety and depression scores and lower prevalence of anxiety and depression symptoms</p> | <p>Strengths Used well validated and reliable instruments Randomization and blinding decreases potential confounders and bias</p> <p>Limitations Completed in France, different medical and ICU culture No mention of effect of the brochure on outcome</p> | <p>Providing family members of patient who are dying in the ICU a bereavement brochure and using a proactive communication strategy may lessen their burden of bereavement.</p> |
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| <p>Titler, et al., 1991⁴⁶</p> | <p>Phenomenological qualitative design to describe the effects of admission to critical care on the family members as perceived by the family members, patients and nurses</p> | <p>Family All spouses (n= 12) Age 41.4 (36-50) 10 females Children (n = 11) All boys Age 13,6 (7-18) Patients (N = 9) Age 37.8 (36-53) 7 males; 2 died during the ICU stay Nurses 9 females; 3 males Age 28.6 (25-39) At least one year of critical care experience</p> | <p>Family members reported on lack of communication about feelings and reported a perceived overriding threat: vulnerable, uncertain, fear, guilt; Reported intense emotions like fear, anger, guilt, and despair; Multiple disruption of home routines; Changes in relationships: “tearing the family apart”; Role conflict within the family: frustration; Nurses perception different than the families; not as severe as the families report</p> | <p>Strengths Explored multiple perceptions on the impact of critical care on the family</p> <p>Limitations Small sample, mostly female</p> | <p>Critical care hospitalization can be threatening to the family and may result in a variety of emotions. Incongruencies exist among patients, family members and nurses’ perceptions.</p> |
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| <p>Kleiber, et al., 1994⁴⁷</p> | <p>Mixed exploratory, descriptive, longitudinal qualitative design to describe the emotional responses of family members over time in the critical care setting and to describe supportive behaviors of others</p> | <p>Family Age 38.5 (18-71) 79% female 29% spouses 46% Parents 94.2% White Patients Average LOS < 3 days</p> | <p>Day 1 feelings: fearfulness, terrified, worried; relief; In general: fear, worry, anxious, exhausted, happy, helpless, sad, anger; Friends, nurses and Drs identified for giving “great” support; Family members of patients in the NICU and MICU had more feelings of guilt</p> | <p>Strengths Exploratory look at emotions of family members Limitations Single site ICU; limits generalizability Sample mostly female, married; educated and white</p> | <p>Family members of critically ill patients experience emotional turmoil throughout the ICU stay.</p> |
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| <p>Chui, & Chan, 2007³¹</p> | <p>Cross-sectional descriptive study to examine the stress and coping strategies of family members who had a relative admitted to a critical care setting in Hong Kong. Instrument • IES</p> | <p>Family N = 133 60.9% female 37% adult children 33.1% spouses Age 44.9 (14) Patients 60.9% male Age 58.5 (19) LOS 3.5 days (1.7) Range (1-7 days) 36.1% septicemia 24.1% cardio-respiratory problems 15% traumatic injuries Chinese sample</p> | <p>70.7% had high levels of stress; mean coping scores were high; moderate positive correlation between stress and coping ($r = 0.5, p < 0.001$); Moderate negative correlation level of stress and use of passive appraisal strategies (denial) ($r = -0.6, p < 0.001$); Females had higher levels of stress than males ($t = -4.6, p = 0.01$); Parents had higher stress levels ($F = 2.5, p < 0.001$) and used passive appraisal strategies more than other family members ($F = 3.5, p = 0.001$); Lower education family members had higher stress ($F = 3.0, p = 0.05$); Emergent admission indicated higher stress levels; Patients LOS associated with higher stress ($r = 0.5, p < 0.001$)</p> | <p>Strengths One researcher for data collection: increases consistency Used reliable and valid instruments Limitations Single site ICU; limits generalizability Sample mostly female, educated, younger age Completed in China, different medical and ICU culture</p> | <p>Family members of critically ill patients experience high levels of stress and use multiple coping strategies</p> |
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| <p>Paparrigopoulos, et al, 2006³⁴</p> | <p>Longitudinal descriptive pilot study to investigate the short-term psychological sequelae of ICU treatment on patients' family members by assessing their traumatic stress, anxiety, and depression symptoms in Greece.</p> <p>Instrument</p> <ul style="list-style-type: none"> • CES-D • IES • STAI | <p>Family N = 32 50% female Age = 40.2 (13.8)</p> <p>Patients Age 44.6 (18.6) LOS 25.5 days (16.4) Range (8-88 days) APACHE II 11.8 (4.8) Deceased 0% Greek sample</p> | <p>Time Point 1/Admission: 97% had symptoms of state anxiety; 97% had symptoms of depression; 81% had symptoms of traumatic stress. Time point 2/Discharge: All symptoms decreased significantly. Risk factors included: higher state anxiety in spouses than other family members ($p = 0.026$); Trait anxiety was a significant predictor of PTSD symptoms; Female family members had higher levels of traumatic stress than male family members ($p < 0.009$).</p> | <p>Strengths Used reliable and valid instruments Limitations Single site ICU; limits generalizability Small sample mostly educated, younger age Completed in Greece, different medical and ICU culture</p> | <p>Family members of ICU patients exhibit high levels of psychological distress. Women and spouses tend to be more at risk.</p> |
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CHAPTER 3

Dissertation Conceptual Model: An integrated model for assessing symptom experiences of families of ICU patients at high risk of dying

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**“An integrated model for assessing symptom experiences of families of ICU patients
at high risk of dying”**

ABSTRACT --- The experience of end of life is common for many family members of patients in the Intensive Care Unit (ICU). Yet, this experience can be difficult and may result in increased symptoms in these family members. In turn, these symptoms can have a negative impact on their overall well-being and increase their sense of burden. In this article, pertinent literature is reviewed and variables that increase family members symptom experiences are identified. A conceptual model based on the Symptom Management Theory, Stress, Appraisal, and Coping Theory, and the Circumplex Model is proposed to explain the symptom experience in family members. Finally, clinical recommendations are discussed.

KEYWORDS: Family, Symptoms, Anxiety, Depression, Post traumatic stress, End-of-life, Intensive Care

**“An integrated model for assessing symptom experiences of families of ICU patients
at high risk of dying”**

The majority of Americans want to die at home,¹ but a significant minority die instead in an intensive care unit (ICU), where there is an emphasis on technology and life-saving procedures. Of the approximately 2.4 million deaths that occur annually in the United States, 20% of those occur in an ICU.² Depending on diagnosis, age, and case mix, mortality rates in this setting can range anywhere from 5% to 69%.³ The experiences associated with having a loved one die in an ICU may have a tremendous impact on the family members of the patient. This experience may cause psychological and physical symptoms and lead to negative outcomes, thus impacting the overall well-being of family members.

Researchers studying families of patients in the ICU have focused primarily on their needs,⁴⁻⁶ satisfaction with care,^{7,8} communication,^{9,10} decision making,^{11,12} and on improving the quality of the death and dying experience.^{13,14} Although this prior research has provided a foundation for understanding the family’s experience in the ICU, family members’ physical and psychological symptom experience is not well understood. Few investigators have examined this topic, and of these, most were completed in countries outside the United States and focused on family members of patients whom were already

discharged, rather than on those family members of patients receiving care at the end of life.

Since family members play an integral role in patient care and are often advocates and decision makers for patients at the end of life,¹⁵ it is important that clinicians understand the family members' symptom experiences and the impact these symptoms have on their overall functioning and well-being. Therefore, the purpose of this review paper is to provide a comprehensive conceptual model that will enable clinicians to assess family members who are at increased risk for suffering from symptoms by examining the key variables involved in symptom development. Finally, suggestions will be offered to reduce the symptom burden of family members and minimize negative outcomes during this challenging time.

Why Family Members Have Symptoms: A Conceptual Framework

The following conceptual model, the Family Care Symptom Model, (see Figure 1) combines concepts from three different theoretical approaches: the Symptom Management Theory,¹⁶⁻¹⁸ Stress, Appraisal and Coping Theory,^{19, 20} and the Circumplex Model of Families.²¹ Each will be reviewed briefly, followed by a description of the Family Care Symptom Model, which integrates concepts from these three approaches and

allows a more comprehensive approach to identifying variables associated with an increase in symptoms in family members.

Symptom Management Theory

The Symptom Management Theory was developed to guide research in the area of symptom management across varying age groups, diagnoses and settings. The main goals of the theory are to assist in formulating appropriate research questions, to develop reliable and valid instruments to measure common variables, and to guide appropriate intervention strategies to reduce symptoms. It is a commonly used framework in nursing research for the study and treatment of symptoms.¹⁶⁻¹⁸

The theory contains three major contextual domains;

- 1) Symptom experience.
- 2) Symptom management strategies, and
- 3) Outcomes

The theory also incorporates the dimensions of nursing science including;

- 1) Individual variables (e.g. age and gender),
- 2) Environment variables (e.g. ICU environment), and
- 3) Health and illness variables (e.g. risk factors and prior and current health status).^{16, 17, 18}

Stress, Appraisal and Coping

Stress, appraisal, and coping theory was developed by Lazarus and Folkman to conceptualize and describe the unique stress response in individuals. The authors discuss four underlying assumptions that are integral in understanding their theory. First, stress is ubiquitous and occurs throughout life events and life changes. Second, stress and the subsequent response are individual in nature. Third, stress has physiological, psychological, and sociological components that are interrelated. Finally, the response to stress is based on a dynamic and reciprocal relationship between the individual and the environment. According to stress, appraisal, and coping theory, four factors affect the interpretation and response to stress: 1) the event itself; 2) cognitive appraisal; 3) coping; and 4) outcome.^{19, 20}

The Circumplex Model

The Circumplex Model was developed in 1979 by family therapists Olson, Russell and Sprenkle and was revised in 2006. The model integrated a plethora of theoretical concepts previously used to describe family systems into three broad dimensions. The main goal of Olson and colleagues was to bridge the gaps that often occur among theory, research and practice by providing strong operational definitions of theoretical concepts, stating testable hypotheses for research, and providing a schema for

clinicians to assess balanced and unbalanced families in practice. The underlying assumptions of the model are based in systems theory. According to this model there are three broad dimensions that describe family dynamics: cohesion, flexibility, and communication. The researcher or clinician can assess family functioning and describe families as being balanced or unbalanced.²¹

Family Care Symptom Model

Although these three theoretical approaches offer a wealth of knowledge regarding family symptoms, used alone they are insufficient to explain the phenomena of family symptom experiences in the ICU. The Symptom Management Theory was developed in the context of physical illness (e.g. cancer and acquired immune deficiency syndrome) in patients and was not specifically developed for explaining family symptoms. The theory also relies mostly on socio-demographic variables to explain symptoms. Although these variables are important to consider, they do not constitute the full spectrum of predictors. Stress, appraisal and coping theory add other dimensions to our understanding of family symptoms by addressing the underlying concepts of stress, resources, and adequacy of coping mechanisms. Yet, again, the model does not capture the whole experience because it fails to consider the influence of family functioning on the symptom experience. Finally, the Circumplex Model provides a conceptualization of

the family system that takes into account different types of family functioning; yet if used alone, it would be insufficient to explain the family symptom experience in the ICU.

Therefore, a model that incorporates views from all three frameworks is proposed to provide a comprehensive guide for clinicians to improve the care of family members in the ICU, but especially those of patients at the end-of-life.

In this integrated model key concepts and variables include: *the event, stressors, appraisal, individual family variables, patient variables, environmental variables, coping variables, family functioning variables, and symptom experiences*. (See table 1 for examples and descriptions). The variables of individual family, patient, environment, appraisal, coping, and family functioning may be mediators that affect the way that family members assess and respond to the ICU experience which ultimately may lead to family symptoms. At any step in the model, clinicians may assess and intervene to minimize the symptom experience. Each of the steps and variables will be reviewed as they contribute to the Family Care Symptom Model.

Stressors in the ICU

Multiple factors contribute to the symptom burden that family members experience in the ICU. The first factor is the ICU setting itself. Clinicians in the ICU are expected to provide aggressive therapy using advanced technology with the ultimate goal

of saving patients' lives. This expectation is commonly referred to as the technological imperative,²² and may lead family members to experience hope even in the face of impending death. When this ideal goal fails and the patient dies, the conflict surrounding the end-of-life experience may lead to increased symptom burden for family members.²²

A second factor is the high acuity level of patients requiring ICU care, which may require mechanical ventilation and sedation. Patients are unable to communicate their own wishes, and their non-communicative state is often interpreted by family members to be life threatening.²³ A final factor is the expectation by clinicians that family members will be advocates and participate in decision-making for the patient at the end of life.²⁴ The types of end-of-life decisions required of family members are often complex and unprecedented. Many times family members are unable to understand the diagnosis or the multiple complicated treatment options available for the patient, which further leads them to experience high levels of symptom burden.^{25, 26}

Individual Family Variables

Gender. The effect of gender on the symptom experience in family members has been one of the most studied variables in this type of research. The evidence regarding gender on the family symptom experience has been fairly consistent, with most studies suggesting that female family members tend to experience more symptoms than male

family members,^{23, 25-29} with the exception of one study that found gender had no significant effect on symptoms.³⁰ Most studies were completed in countries other than the United States. One of the largest studies on family symptoms involved 836 family members from 43 French ICUs. The investigators found female gender to be an independent predictor of both anxiety and depression.²⁸ This finding was replicated in a Belgian ICU.²³ Other researchers from Spain also reported that female family members suffered more from hypochondria, anxiety, depression and guilt than did their male counterparts.³¹

Other researchers have found a link between female gender and PTSD symptoms. In a large study of 284 family members completed in France, investigators found that females scored higher on a traumatic stress instrument than males, controlling for other variables, such as patient and family characteristics, in a multivariate linear regression model.²⁶ The only study that did not find female gender to be a predictor of anxiety, depression and stress was completed in Norway,³⁰ but a small sample size may have resulted in inadequate power to detect differences.

Kinship. Investigators have examined the relationship between family members and the patient as a contributing factor to the symptom experience.^{25, 26, 28, 29, 32} Pochard and colleagues reported the variable of spouse to be an independent predictor of anxiety

and depression,²⁸ with the former confirmed in a second study.²⁵ Although depression was not statistically significant in the second study, it was clinically significant, with over 38% of spouses in their sample reporting high depression scores.²⁵ Other researchers in France found the relationship of a child to the ICU patient was a significant predictor of PTSD-reactions. They reported that, on average, adult children scored higher on a traumatic stress instrument than other family members.²⁶

Age. The evidence regarding the effect of family member age on family member symptoms is conflicting, but suggests that younger age is associated with an increase in symptom experience. Although some researchers report that age does not affect symptoms in family members,^{25, 26, 28} others have found a direct relationship between younger age and an increase in symptom experience.^{23, 32} Halm and colleagues reported that the younger the age of the family member, the higher the reported stress level.³² Another researcher also supported this finding: as the age of the family member increased, the level of anxiety decreased.²³ Yet, both of these findings revealed weak to moderate correlations.

Education. Only two groups of investigators examined the impact of education level on the family symptom experience.^{23, 29} Delva and colleagues found that family members with lower education had more anxiety than those with higher education.²³

Others reported that family members with lower education exhibited significantly higher stress levels than those with higher education.²⁹

Patient Variables

Severity of Illness/Death of Patient. Severity of illness and patient death may impact family members' symptom experiences. Pochard and colleagues found that the higher the patient's severity of illness score, the greater the anxiety and depression among family members.²⁵ In another study, patient death was associated with higher PTSD-reactions.²⁶ Other investigators found significantly more depression in family members of patients who died in the ICU.²⁵ Yet, several researchers found that severity of illness or death of a patient had no impact on family member symptoms,^{28, 30, 32, 33} so the role of severity of illness and patient death remains unclear.

Nature of the Patient's Condition/Nature of Diagnosis. A few researchers have investigated the impact of patient diagnosis and whether the nature of the patients' conditions (e.g., acute or chronic) affects family member symptoms.^{26, 28} French researchers found that when a patient had a diagnosis of cancer the family member's experienced higher levels of traumatic stress.²⁶ These authors also reported that the presence of a chronic disease (e.g. heart failure) in patients led to family members scoring lower on a traumatic stress questionnaire.²⁶ Pochard and others found that the absence of

chronic disease in patients was an independent predictor of anxiety for family members.²⁸

Given the paucity of data, more research is needed regarding the effect of the nature of the diagnosis on family symptoms.

Patient Age. Several investigators assessed the variable of patient age on family member symptoms.^{23, 25, 26, 28, 33-35} Even though the data are conflicted, several investigators have documented younger patient age as increasing family member symptoms. For example, younger patient age (less than 20 years) was an independent predictor of depression in family members in a French study.²⁸ Younger patient age was confirmed in two other studies and was associated with an increase in symptoms of anxiety and depression in family members.^{23, 25} A few researchers found minimal association between patient age and family symptoms,^{26, 33-35} so this variable remains questionable.

Environmental (ICU) Variables

Relationship with clinicians. The relationship with clinicians as perceived by family members may be another factor that influences their symptom experience. One group of researchers found that, when clinicians successfully met family members' needs, anxiety was significantly reduced.³⁶ Another study reported that family members had poorer emotional adjustment if they felt their relationship with the physician was low

in affiliation, meaning less friendly and more hostile in nature.³⁷ One researcher, using qualitative methods, reported higher levels of stress in family members when they reported poor communication with clinicians.³⁸ Even though research in this area is scant, the family's relationship with the clinician appears important to symptom manifestation.

End-of-life Decision Making. End-of-life decision making can affect the families' symptom experiences. One group of investigators³⁹ studied PTSD levels in 74 family members two months after they had to make end-of-life decisions in the ICU. They found that traumatic stress scores were significantly higher in family members of patients who did not have any form of advance directives compared to those who had either verbal or written advance directives. Azoulay and others²⁶ assessed PTSD scores in 50 family members of patients that died in the ICU and compared them to PTSD scores of 234 family members of patients discharged from the ICU. They found a significant increase in the prevalence of PTSD in family members of patients who died in the ICU, particularly if the family member was involved with end-of-life decision making.

Appraisal Variable

Appraisal. The meaning ascribed to the ICU admission can influence symptom burden in family members. Kirchhoff and colleagues found that family members' appraisals of events were key. They specifically cited uncertainty, lack of control, and

novelty of the situation to be the most stressful aspects that affected family member appraisal of the situation.³⁸ Titler and others suggested that a common theme among family members was a perceived over-riding threat of the situation that left them feeling vulnerable and uncertain.⁴⁰ Other researchers discovered that, when an admission was not planned, anxiety of family members increased significantly. In fact, there was a moderate positive correlation between relatives' perceptions of the degree of threat and their level of anxiety.²³ The variable of appraisal, although methodologically challenging to measure, does indeed have an impact on the symptom response of family members and needs to be considered further in research.

Coping Variables

Coping. A few investigators have examined the process of coping and resources used by family members in the ICU. Most studies have been qualitative in nature and describe coping as phases or stages.^{38,41,42} Jamerson and colleagues describe four phases family members go through to cope with the complex situation of a loved one in the ICU. The first phase is *hovering*, which is conceptualized as the initial admission as the family experiences confusion, stress and uncertainty and is in a general state of crisis and shock. The second phase is *information seeking* where the families become active and more focused. The third is *tracking*, where they observe, analyze and evaluate the patient's care

on an ongoing basis. Finally, the fourth is *garnering resources* where the family starts to think of their needs and seeks out support.⁴² Another qualitative report stated families live in a vortex, and use story telling and faith as coping mechanisms.³⁸ Johansson and colleagues found in their study of 18 family members of ICU patients that coping strategies were dependent on internal and external resources of the individual family member. The most common coping techniques were repetitive vocalization of feelings, mastering feelings by knowing their own capacity and needs, and suppressing their feelings.⁴¹

A few quantitative studies also assessed coping in family members.^{34, 35, 43, 44} Leske and colleagues found that coping techniques were influenced by patient diagnoses. They found that family members of gunshot wound patients had significantly worse coping skills than family members of patients in motor vehicle crashes or following cardiac bypass surgery.³⁵ Other researchers reported several coping techniques, labeled confronting (information seeking) and optimistic (positive thinking), to be the most useful and effective for ICU family members.^{43, 44} Other researchers found that age may impact coping and that older family members have more resources and coping skills than their younger counterparts.³⁴ In this study, prior experience also impacted coping and the

investigators found that family members with more prior stresses and strains had less resources and fewer coping skills.

Family Member Variables

Cohesion/Flexibility/Communication. Although these variables have not been studied extensively in the ICU, there is beginning evidence that they may impact family member symptoms. In one qualitative study, major themes that emerged when examining the family roles included: significant changes in the family relationships, multiple conflicts within the roles of the family, and lack of communication among family members.⁴⁰ Another qualitative study found that family members reported themes of family fragmentation and multiple role changes based on the increased responsibility they experienced with an admission to the ICU. These families also reported multiple symptoms such as anxiety, depression, anger, guilt and fear.⁴⁵ Leske reported that 40% of the overall variance in family members' well being could be explained by past stressors, strains, and transitions.³⁴

Symptom Experiences/Outcomes

There may be potential negative consequences for family members as a result of the ICU experience. There may be an increase in stress and symptom burden on family members.^{25, 26} Family members experiencing psychological symptoms may then have

difficulty comprehending information,⁹ may make poor decisions,⁴⁶ and may over or under-estimate risks in treatments for the patient.⁴⁷ Researchers have documented that symptoms in family members may lead to a decrease in their quality of life and mental health²⁶ and may lead to physical illness.³² Some researchers have found that, following the ICU experience, family members may suffer the symptoms of post traumatic stress disorder (PTSD)²⁶ and may suffer complicated grief.⁴⁸

Conclusions about variables affecting family member symptoms

Although more research is still needed, it is possible to draw some conclusions from the research conducted to date about the effects of selected variables on family member symptoms. In general, symptoms appear worse in female family members, in family members who are spouses and children of patients, and in younger family members. Symptoms are also more prevalent in families of patients with worse severity of illness scores and/or an acute onset of the illness. Those families with patients at high risk for dying are also likely to be symptomatic. Another risk variable is a poor relationship of the clinicians to the family, as well as the family being involved in end of life decision making in the absence of an advanced directive. Other variables such as appraisal of the situation and coping mechanisms play an important role in family members' symptoms. Finally, family functioning itself with its degree of cohesion and

adaptability may impact the symptom experience. See Table 2 for a description of risk variables and recommendations for nurses on intervening by lessening the symptom burden and potential negative outcomes of families in the ICU.

Conclusion

Family members are an integral component of care in ICUs. They are important to the patient as well as to ICU clinicians. Yet, family members are at an increased risk of suffering from symptoms that can impact their overall well-being. Using a comprehensive conceptual model will allow ICU clinicians to assess family members who are at an increase risk of symptoms, provide appropriate interventions, and conduct further research in order to improve holistic care for all family members, but especially for those of patients at the end of life.

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Legend

Figure 1. Family Care Symptom Model

Table 1. Examples of Conceptual Model Variables

Table 2. Clinical Recommendations

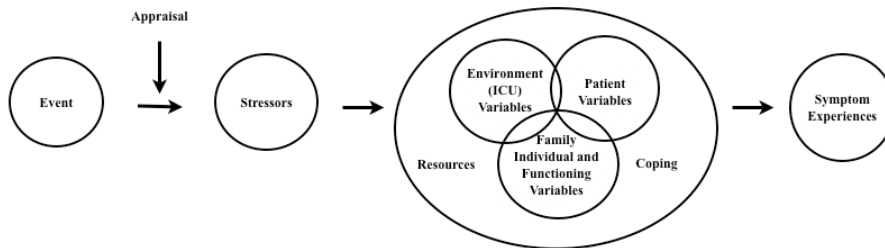


Figure 1. Family Care Symptom Model

Table 1. Examples of Conceptual Model Variables

| Variables | Examples |
|--------------------------------------|--|
| <i>Event</i> | ICU admission |
| <i>Appraisal</i> | Assessing the event as life-threatening |
| <i>Stressors</i> | ICU setting, technology imperative |
| <i>Individual Family Variables</i> | Age, gender, relationship to patient |
| <i>Patient Variables</i> | Severity of illness, acuity, age |
| <i>Environmental (ICU) Variables</i> | Relationship with clinicians, decision making |
| <i>Coping</i> | Passive coping skills, positive thinking, information seeking |
| <i>Family Functioning Variables</i> | Cohesion, flexibility, communication, other role strains, other responsibilities |
| <i>Outcomes</i> | Symptoms (anxiety, depression, PTSD), complicated grief |

Table 2. Clinical Recommendations

| |
|--|
| <p><i>Clinical Recommendation:</i> Identify family members who are at high risk for symptoms by assessing their individual family member socio-demographic variables</p> |
| <p>Based on prior research, those at risk tend to be:</p> <ul style="list-style-type: none"> • Female^{23, 26-29, 31} • Spouse^{25, 28, 29} • Younger in age^{23, 32} • Lower educational level^{23, 29} |
| <p>Beside nurses and advanced practice nurses can identify these risk factors as part of a family assessment. Once identified, they can intervene and make appropriate referrals to chaplain services or another service depending on the hospital's policy. They can also offer spiritual and emotional support.</p> |
| <p><i>Clinical Recommendation:</i> Identify family members who are at high risk for symptoms by assessing patient variables</p> |
| <p>Although more research is needed, evidence has shown that those family members at risk include:</p> <ul style="list-style-type: none"> • Patients who are acutely ill²⁵ • Patients with a high likelihood of dying^{25, 26} • Patients who are younger in age^{23, 25, 28} |
| <p>Beside nurses and advanced practice nurses can recognize families who are at high risk for symptoms and be proactive in initiating family care conferences to discuss the situation with the family. In a recent study by Lautrette and colleagues, a proactive communication strategy and a structured type of care conference led to a significant reduction in anxiety, depression, and PTSD in family members.⁴⁹</p> |
| <p><i>Clinical Recommendation:</i> Identify family members who are at high risk for symptoms by assessing environmental variables</p> |
| <p>Based on prior research, those at risk include:</p> <ul style="list-style-type: none"> • Perceive poor relationships with ICU clinicians^{37, 38} • Involved with EOL decision making, particularly if no advanced directive^{26, 39} |
| <p>Bedside nurses and advanced practice nurses can intervene by developing supportive relationships with the family. When family members feel unsupported, perceive clinicians to be unsympathetic, or experience poor communication, they report greater symptoms. ICU clinicians can reduce symptoms in family members by being present, being honest, keeping family members updated with the patient's condition, offering support, and by providing accurate, thorough, and timely information.</p> |

Clinical Recommendation: Identify family members who are at high risk for symptoms by assessing appraisal and coping variables

Those at risk include:

- Appraise the situation to be threatening^{38, 40}
- Experience an unplanned or emergent admission²³
- Use ineffective coping strategies (e.g., passive appraisal)^{34, 35}
- Have multiple role strains³⁴

Bedside nurses and advanced practice nurses can determine family members' appraisal of the ICU admission along with the level of threat or uncertainty they are experiencing during this time. As discussed in this review, family members often state feelings of being out of control and feeling threatened by this experience. Clinicians can intervene at the time of admission and throughout the ICU stay by giving family members additional support and understanding their sources of stress. ICU clinicians can also encourage family members to discuss their feelings and seek out additional resources such as family friends and spiritual care.

Clinical Recommendation: Identify family types who are at an increased risk of symptoms by assessing family functioning variables

Those at risk include families with:

- Strain or conflict from multiple roles⁴⁰
- Low family cohesion⁴⁵
- A history of poor communication⁴⁰

Bedside nurses and advanced practice nurses can assess family members' levels of cohesion along with their communication skills. Families with a balanced level of cohesion along with positive communication skills will function more adequately during this time than those classified as extreme family types. However, it is important for ICU clinicians to recognize that an admission to the ICU can often create a crisis situation in all family types and provide interventions as appropriate. This is also an appropriate time to assess other stressors occurring in the family along with other roles and responsibilities they are facing (e.g., from career or other family members). Advanced practice nurses can assist the family in finding resources and make appropriate referrals to help them manage their increase in responsibilities during this challenging time.

CHAPTER 4

Dissertation Measures Paper: Discussion of instruments to measure family symptoms, coping and functioning

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Introduction

End-of-life in the intensive care unit (ICU) can be challenging for family members of patients at high risk of dying. Family members are often burdened to make decisions and treatment choices on behalf of their loved ones. These decisions are often difficult and unprecedented. This whole experience may burden family members and leave them suffering from psychological and physical symptoms. In order to measure these symptom experiences, reliable and valid instruments need to be evaluated. Therefore, the purpose of this paper will be to review the basic psychometric properties of instruments and to discuss common instruments used in measuring symptoms in family member research. Other instruments used in this dissertation study to measure concepts such as family coping, family functioning, and patient severity of illness are also discussed.

Basic psychometric properties

Surveys were the predominant data collection method used in measuring symptoms in family members in the ICU. Surveys allow inferences to be made about unobservable, abstract concepts based on observed answers to questions (Burns & Grove, 2001). The benefits of using surveys include the amount of information that can be gathered about a concept in a short amount of time and the flexibility of how data are

collected because surveys can be given in many formats such as by telephone, in person, or by mail (Polit & Hungler, 2004).

There are multiple limitations to consider when using surveys. First, most instruments rely on structured questions. This could potentially limit the content validity of a concept by missing key aspects of a concept. Second, most instruments rely on multiple questions to get at the concept, which can increase subject burden. Finding a balance between too few or too many questions is challenging. Another major issue with most surveys is the lack of testing and reporting on the psychometric properties, which threatens internal validity (Shadish, Cook, & Campbell, 2002). Culture, education, and language issues are always a concern with surveys as most surveys are developed on homogenous, White, and educated samples (Switzer et al., 1999). A final consideration of using surveys is the administrative costs if a survey is under copyright or needs to be translated into another language (Switzer et al., 1999).

Basic Instrument Properties

Reliability is a psychometric property required of all instruments (Nunnally & Bernstein, 1994) because it indicates that the results are repeatable, stable, and consistent (Ferketich, 1990). Reliability is an estimate of an instrument's precision and ability to

detect the true score rather than measurement error (Nunnally & Bernstein, 1994).

Because the true score is elusive, reliability is more of an estimate rather than a fact.

One measure of reliability is internal consistency, which is often reported as Cronbach's alpha. This is the best estimate of how the items on an instrument cohere. Cronbach's alpha is sensitive to item numbers so it generally improves as more items are added to an instrument. The value ranges between 0.00 and 1.00, with higher values indicating stronger reliability. Kuder-Richardson-20, another measure of internal consistency, is similar to Cronbach's alpha but is used when the scales are dichotomous (Nunnally & Bernstein, 1994).

Another estimate of reliability is test-retest correlation. Test-retest is a measure of consistency across multiple measurements where correlations are generated between two administrations of the same instrument. Higher coefficients indicate more consistency and stability of an instrument. This main limitation of test-retest is the time interval between administrations of the survey. If the timing is too short, subjects may remember the answers from the first administration and have carry over effects. If the interval is too long, threats of maturation or history may become an issue (Nunnally & Bernstein, 1994).

Validity is defined as an instrument's ability to measure what it claims to measure (Nunnally & Bernstein, 1994). Validity is an ongoing process that is never completed;

rather, it is established for a particular sample in a given situation. There are three main types of validity: content, criterion, and construct. Content validity (face validity) is the extent to which items in a measure accurately reflect the extensiveness of the concept. This type of validity assures that the items look like they measure the concept. It is usually established by a group of experts experienced in the concept. Criterion validity is the extent with which an instrument is correlated to a “gold standard” already used to measure the concept. It is usually reported as a validity coefficient. Construct validity is the degree in which an instrument measures the theoretical construct it was designed to measure. It is a relatively new way to establish validity and is usually done through factor analysis (Polit & Hungler, 1995).

Surveys Used in Family Member Symptom Research

There were three main instruments used in family member symptom research in the ICU to measure stress reactions: the Acute Stress Disorder Scale (ASDS) and the Impact of Event Scale (IES) and the Impact of Event Scale-Revised (IES-R). The ASDS measures levels of acute stress reactions, whereas the IES and IES-R measure perceived stress following a traumatic life event. Following will be a brief review and critique of the instruments.

Acute Stress Disorder Scale

The ASDS was created by psychologists Bryant, Moulds, and Guthrie in 1999 with three main purposes; 1) to provide identification of acute stress disorder (ASD), 2) to provide a self-report measure of ASD, and 3) to predict persons at risk of developing subsequent PTSD. The need for this self-report measure was also three-fold. First, a quick self-report measurement was needed after the addition of ASD into the DSM-IV manual. Second, since a clinical interview on ASD is time consuming, a self-report survey was needed in place of the clinical interview. Third, the only other self-report measure to assess ASD, Stanford Acute Stress Reaction Questionnaire (SASRQ), does not have sufficient data supporting its ability to detect ASD or subsequent PTSD (Bryant, Moulds, & Guthrie, 2000).

The ASDS is composed of a total of 19 items with four sub domains. The sub domains include 5 items on dissociation (feelings such as numbing, detachment, and absence of emotional responses), 4 items on re-experiencing (includes recurrent images, thoughts, dreams, or flashbacks), 4 items on avoidance (avoiding thoughts, feelings, conversations and people who remind one of the traumatic experience), and 6 items on arousal (feelings of restless, insomnia, difficulty concentrating and irritable) (Bryant & Harvey, 1997). The items are comprised of questions such as, “During or after the trauma, did you ever feel numb or distant from your emotions?” or “Have you had

dreams or nightmares about the trauma?” Items are then scored on a Likert scale from 1 = “Not at all”, 2= “Mildly”, 3= “Medium”, 4 = “Quite a bit”, and 5= “Very much”. The total score ranges between 19 and 95. The authors suggest an arbitrary cut-off point of 56 for the total ASDS score; cutoff points of greater than 9 for the dissociative subscale; and greater than 28 for the cumulative scores on re-experiencing, avoidance, and arousal subscales. The timeframe for answering the questionnaire is posed as how one has felt since the traumatic event.

Psychometric Properties

Psychometric properties of the ASDS were assessed in five studies on a variety of patient samples by the instrument’s authors. The patient samples in these studies included those who suffered from motor vehicle accidents, nonsexual assault, industrial accidents, and bushfire survivors. The samples included equal numbers of women and men who were mostly Caucasian, although a small minority of the sample were of Asian and Mediterranean decent.

Content validity of the ASDS has been established. This is evidenced by the development of the ASDS items based on the DSM-IV diagnostic criteria on the diagnosis of ASD. Content validity was further strengthened by including input from six clinical psychologists experienced in diagnosing ASD (Bryant, Moulds, & Guthrie,

2000). After the items were completed, the authors had them reviewed and verified by five content experts. These experts rated each item (mean, SD) on a scale of 1 (not at all) to 5 (extremely) on their relevance 4.86 (0.93), specificity 4.44 (0.43) and clarity 4.51 (0.27). All items had uniformly high ratings.

Criterion validity of the ASDS was reported using convergent and predictive validity. Convergent validity was established on a sample of 99 patients who suffered from one of the following: motor vehicle accidents, nonsexual assault, or industrial accidents (Bryant, Moulds, & Guthrie, 2000). These participants were given the ASDS to complete along with the ASDI interview tool for acute stress, Dissociative Experience Scale-Taxon (DES-T) (Waller, Putnam, & Carlson, 1996), Impact of Event Scale (IES) (Horowitz, Wilner, & Alvarez, 1979), and the Beck Anxiety Inventory (BSI) (Beck & Steer, 1990). The authors reported moderate to strong correlations with all the instruments except the DES-T. (See table 1 for validity coefficients). The authors suggest that the low correlation of the ASDS to the DES-T may be due to the DSM-IV's ambiguous definition of dissociation. This definition lacks specific timeframes for dissociative symptoms to occur and lacks parameters between normal and pathological dissociative reactions (Bryant & Harvey, 1997). The authors also suggest the low

correlation could be due to the documented limitations of the DES-T survey to index pathological dissociation (Nash et al., 1993).

Predictive validity was established on a sample of 82 patients that survived a bushfire trauma. The patients were evaluated with the Clinician Administered PTSD Scale, Form 2 (CAPS -2) (Blake et al, 1995) assessment which is considered the gold standard and the ASDS tool as a comparison. The authors report that a cutoff score of 56 on the ASDS total score had the best predictive validity of PTSD, with 91% sensitivity and 93% specificity (Bryant, Moulds, & Guthrie, 2000).

Construct validity was established by conducting the factor structure of the ASDS on two separate samples of patients. The first sample consisted of 99 PTSD unit inpatients who suffered from accidents or non-sexual assaults (Bryant, Moulds, & Guthrie, 2000). The second sample included 107 community based patients who survived a bushfire (Bryant, Moulds, & Guthrie, 2000). The first study, using principal components analysis with varimax rotation resulted in a three factor model explaining 74% of the total variance. The Kaiser Guttman rule was used in retaining items on a factor with eigenvalue greater than one (Nunnally & Bernstein, 1994). In the second study, a four factor solution was found to explain 66% of the variance using the Kaiser-Guttman rule. This structure is most consistent with the DSM-IV criteria, however the

authors conclude that more research is needed on different populations to determine the best factor structure.

Reliability of the ASDS has been documented. In the study mentioned earlier on 107 patients whom suffered from bushfires (Bryant, Moulds, & Guthrie, 2000), internal consistency measured using Cronbach's alpha for the total instrument was 0.96; for the dissociation cluster it was 0.84; for re-experiencing it was 0.87; for avoidance it was 0.92; and for arousal it was 0.93. Test-retest reliability after a one-week interval between administrations was 0.94. The authors concluded that the ASDS shows promise for screening individuals at risk for acute traumatic stress due to high levels of internal consistency and stability (Bryant, Moulds, & Guthrie, 2000).

Psychometric Issues of the ASDS: Summary

This measure has demonstrated strong evidence of validity. It was highly correlated to other instruments along with the gold standard ASDI to further establish validity. Although it did not correlate strongly with the DES-T, the authors provided rationale for this finding. The only critique of the ASDS is the factor structure of the instrument. A future consideration would be to perform a confirmatory factor analysis based on the four theoretical sub-domains to test the factor structure (Nunnally &

Bernstein, 1994). Reliability of the survey is also sound with strong stability and internal consistency.

Contextual Issues

A criticism of the contextual issues of the ASDS concerns the sample populations used in developing the instruments (Switzer, et al., 1999). The cultural, educational, and socio-economic backgrounds of the test samples were not clearly stated. Also, this survey has not been used extensively in other countries and languages so it may not be appropriate in cultures that are less willing to admit emotional problems.

Impact of Event Scale

The IES was developed by Horowitz and colleagues in 1979 as a self-report measure to assess perceived stress in bereaved individuals (Horowitz et al., 1979). It soon became a standard instrument used to measure perceived stress in a variety of major life events (Sundin & Horowitz, 2002). Although the IES was constructed before the diagnosis of PTSD was added to the DSM-III, this instrument became one of the most widely used measurement tool to assess the risk of developing PTSD (Joseph, 2000; Sundin & Horowitz, 2002). It is short and simple to complete and can be used to determine persons at risk of PTSD who may need treatment (Sundin & Horowitz, 2003).

There are a total of 15 items on the IES that are in two subscales labeled avoidance and intrusion. Intrusion refers to unwanted thoughts and images, troubled dreams, and repetitive behavior. The intrusion subscale contains 7 items consisting of statements such as, “I thought about it when I didn’t mean to,” and “Any reminder brought back feelings about it.” Avoidance refers to denial, dulled sensations, and emotional numbness (Horowitz et al, 1979). The avoidance subscale is comprised of 8 items ranging from, “My feelings about it were kind of numb,” and “ I tried not to think about it.” The format for answering the questions consists of Likert scale responses on how the person has felt within the last seven days. These responses include; 0 = “not at all”, 1 =”rarely”, 3 = “sometimes”, and 5 = “often.” The total possible score of the total instrument ranges from 0-75, with higher scores indicating greater frequency of avoidance and intrusive thoughts. The possible score range on the avoidance and intrusive subscales are 0-40 and 0-35, respectively. The suggested threshold scores for the total IES instrument as recommended by the instrument’s authors is as follows: less than 8.5 is cause for low clinical concern, 8.6 to 19.0 is cause for medium clinical concern, and greater than 19 is cause for high clinical concern. However, these cutoff points do not indicate any specific clinical diagnosis and are subjective (Horowitz, 1979).

Psychometric Properties

Validity of the IES has been explored. Content validity was established by developing items based on processing theories about how people overcome traumatic life events and on the author's own extensive experience in the field of psychiatry (Horowitz, 1979). Further evidence of content validity was provided by pilot testing the IES on 66 adults (16 men, 50 women) who sought psychotherapy after a recent life event such as bereavement, accidents, violence, illness, or surgery. The authors incorporated the subject's comments from the pilot test and revised and clarified items as needed (Horowitz et al., 1979).

Criterion validity of the IES has been reported by using both convergent and predictive validity measures. Convergent validity was established by comparing the IES to several other instruments that measured PTSD, including the PTSD Inventory (Solomon & Mikulincer, 1988) and the Structured Clinical Interview (CAPS-1) (Neal et al., 1994). The correlations between the IES and these other measures were strong and indicate the instrument's ability to measure similar concepts found in existing PTSD measures (see table 2). The IES was also compared to other global measures of distress such as the General Health Questionnaire (GHO) (Spurrell & McFarlane, 1995) and the Stanford Acute Stress Reaction Questionnaire (SASRQ) (Classen et al., 1998). These correlations indicate moderate validity coefficients indicating that the IES measures

aspects of global distress but also has discriminative abilities to measure information beyond general global distress (See table 2).

Although IES items were not specifically developed to measure PTSD, some researchers have assessed the predictive validity of the IES in its ability to differentiate persons who develop or do not develop PTSD. Bryant and Harvey (1996), in a study of 81 subjects seeking psychiatric treatment after a motor vehicle accident, reported that the IES differentiated those who received a diagnosis of PTSD and those who did not in their sample. They concluded that the IES was sensitive to PTSD (Bryant & Harvey, 1996).

Another group of investigators suggested that a cutoff point of 35 or greater on the IES would produce the highest positive predictive value (0.88) and the lowest misclassification error (11.4%) in their sample of 77 civilian and military personal from the United Kingdom (Neal et al., 1994). However, McFarlane and colleagues (1988) suggested that a cut off of greater than 30 on the IES would indicate a high risk of developing PTSD in their sample of 429 firefighters. Other investigators suggested a cutoff of greater than 24 on the IES as indicative of high risk of developing PTSD in their sample of 106 patients following a motor vehicle accident (Mayou et al., 2000).

Therefore suggested cutoff points remain in question and may depend on sample characteristics.

Construct validity was established in a sample of 72 outpatients who sought treatment after the death of a parent (Zilberg et al., 1982). Using principal components analysis with Varimax rotation, the authors reported a forced two-factor structure solution to be the most ideal. They retained factors with eigenvalues greater than 1.00 as their criteria (Nunnally & Bernstein, 1994). The two factors were avoidance with 8 items loading .40 to .86 and intrusive with 7 items loading .58 to .75. This structure explained 56% of the total variance. Although this is the most frequently cited study on the factor structure of the IES, the sample size was potentially too small for the structural analysis (as a minimum of 200 subjects is recommended) (Nunnally & Bernstein, 1994). Perhaps a principal axis factor analysis would have been more appropriate since the intrusive and avoidance factors are correlated to each other at 0.41 (Horowitz et al., 1979). This technique would account for the intercorrelation and may yield more accurate and more realistic results than the principal components analysis (Nunnally & Bernstein, 1994).

Reliability of the IES has been reported. Horowitz and colleagues (1979) tested the internal consistency and test-retest on a sample of 66 adults who sought treatment after suffering from a traumatic life event. Internal consistency for the IES was Cronbach's alpha = 0.86 for the whole instrument, with 0.78 for the intrusion subscale and 0.82 for the avoidance subscale (Horowitz et al., 1979). Test-retest measures for the

IES on this sample when measurements were taken one week apart were 0.87 for intrusion subscale and 0.79 for avoidance subscale. However, Weiss and Marmar (1997) reported test-retest results on two different samples. One measured at six weeks apart found 0.94 for intrusion subscale and 0.89 for avoidance subscale. However, at a one year time interval, they found 0.57 for the intrusion subscale and 0.51 for the avoidance subscale (Weiss & Marmar, 1997). Therefore, it was suggested that test-retest intervals should occur within 6 weeks to provide the most stability (Sundin & Horowitz, 2002).

Psychometric Issues

The IES has evidence of validity; however issues remain. Although the majority of items on the IES have face validity, there have been some concerns raised regarding a few of the items. Some researchers have commented that some items appear to be more neutral and may not be accurate indicators of distress. For example, the item, “I had dreams about it” may not be descriptive enough to clearly delineate distress (Joseph, 2000). Another researcher argues that some items on the IES do not specify the nature of intrusive thoughts, such as in bereavement. One could score high in intrusive thoughts but those thoughts may be highly associated with fond or nostalgic memories, not necessarily traumatic memories. The researcher argues that this could lead to erroneous

findings (Raphael, 1997). Also, the IES does not contain items on hyperarousal and arousal symptoms, which are in the DSM-IV's definition of PTSD (Joseph, 2000).

Construct validity as evidenced by the factor structure also appears to be dependent on the sample population. There have been three factor solutions reported in samples of disaster survivors (Joseph et al., 1994), assault victims (Foa et al., 1995), and non-clinical samples (McDonald, 1997). There has been a one factor solution reported for Vietnam Veterans (Hendrix et al., 1994). Although internal consistency is strong, stability is found to be more accurate if the interval between measurement times is less than six months (Sundin & Horowitz, 2002).

Contextual Issues

The authors report that persons of various educational, economic, and cultural backgrounds are able to use the instrument and have no trouble understanding its purpose or in completing the questionnaire (Horowitz et al., 1979). The IES has also been a widely used measure of traumatic stress and has been used extensively in family symptom research in the ICU (Azoulay et al., 2005; Laurette et al., 2007).

Impact of Event Scale-Revised

The IES-R, developed by Weiss and Marmar in 1997, was an extension of the original IES instrument. The improvement of this tool over the original is that it parallels

the DSM-IV criteria for PTSD by adding items that measure the hyperarousal domain of PTSD in addition to the intrusion and avoidance domains. It remains relatively short and simple to complete and can be used to determine persons at risk of PTSD who may need treatment (Weiss and Marmar, 1997).

There are a total of 22 items on the IES-R that are in three subscales labeled avoidance, intrusion, and hyperarousal. Intrusion refers to unwanted thoughts and images, troubled dreams, and repetitive behavior. The intrusion subscale contains 7 items consisting of statements such as, “I thought about it when I didn’t mean to,” and “Any reminder brought back feelings about it.” Avoidance refers to denial, dulled sensations, and emotional numbness (Horowitz et al, 1979). The avoidance subscale is comprised of 8 items ranging from, “My feelings about it were kind of numb,” and “ I tried not to think about it.” Hyperarousal refers to anger, irritability, jumpiness and trouble concentrating (Weiss, 2004). This subscale consists of 7 items such as “I had trouble concentrating.”

The format for answering the questions has changed slightly from the original and consists of responses focusing not on the frequency of symptoms, but rather, on how distressing the symptoms were to the person within the last seven days. These responses range from 0 to 4 and include; 0 = “not at all”, 1 = “a little bit”, 2 = “moderately”, 3 = “quite a bit”, and 4 = “extremely.” Even though a total sum score can be calculated

(ranging from 0-88, higher scores indicating more symptomology), the authors recommend using the mean of the items. The suggested threshold score for the total IES-R instrument and subscales is a cutoff of 1.5 or greater to indicate a risk of PTSD symptoms. However, this cutoff point should be used with caution as it does not indicate any specific clinical diagnosis and is subjective in nature (Weiss, 2004).

Psychometric Properties

Validity of the IES-R has been explored. Content validity was established by developing items based on processing theories about how people overcome traumatic life events and on the author's own extensive experience in the field of psychiatry (Weiss, 2004). Further evidence of content validity was provided through pilot testing the IES-R on emergency personnel that responded to traumatic events at the Loma Prieta earthquake (Weiss, 2004).

Criterion validity of the IES-R has been reported by using both convergent and predictive validity measures. Convergent validity was established by comparing the IES-R to the Mississippi Scale for Combat-Related PTSD, Civilian Version (MCSCV; Keane et al., 1988) and the SCL-90-R (Derogatis, 1994). The correlations between the IES-R and these other measures were strong and indicate the instrument's ability to measure similar concepts found in existing PTSD measures. The correlations of the IES-R with

the Michigan Alcohol Screening Test (MAST; Selzer, 1971) were low indicating strong divergent validity as the IES-R should not correlate with a measure on alcohol abuse.

Although the IES-R items were not specifically developed to measure PTSD, some researchers have assessed the predictive validity of the IES in its ability to differentiate persons who develop or do not develop PTSD. It has been suggested that a cutoff point of 1.5 or greater on the IES-R would produce the highest positive predictive value of 0.90, a negative predictive power of 0.84, sensitivity of 0.91 and specificity of 0.82. (Creamer, Bell & Failla, 2003).

Construct validity was established on a sample of 120 male Vietnam veterans seeking treatment for PTSD and 154 male Vietnam veterans living in the community. Using principal components analysis with varimax rotation, the authors reported that either a one or two factor solution was most ideal. The two factor structure explained 62% of the total variance. A three factor solution did not add any significant information (Creamer, Bell & Failla, 2003).

Reliability of the IES-R has been reported. Creamer and colleagues (2003) tested the internal consistency and test-retest on the same sample as mentioned above. Internal consistency for the IES-R was Cronbach's alpha = 0.96 for the whole instrument, with 0.94 for the intrusion subscale, 0.87 for the avoidance subscale, and 0.91 for the

hyperarousal subscale (Creamer, Bell, & Failla, 2003). Test-retest measure for the IES-R were 0.73 for intrusion subscale, 0.77 for avoidance subscale, and 0.71 for the hyperarousal subscale (Weiss, 2004).

Contextual Issues

The authors report that persons of various educational, economic, and cultural backgrounds are able to use the instrument and have no trouble understanding its purpose or in completing the questionnaire (Weiss, 2004). However there remain several contextual concerns in using the IES-R. The first is defining what is considered to be a traumatic event. The second is in defining the time frame for measuring the symptoms of traumatic stress. And finally, there is a lack of normative data on the best cutoff points for the instrument (Weiss, 2004).

Anxiety and Depression

The most frequently used instrument to measure anxiety and depression in family member symptom research in the ICU is the Hospital Anxiety and Depression Scale (HADS). The HADS, published by psychiatrists Zigmond and Snaith in 1983, is a self-assessment mood scale designed specifically for use in non-psychiatric hospital inpatients and outpatients. The authors developed the tool to enable a general practitioner to quickly and accurately measure two common forms of neurosis in a hospital setting: anxiety and

depression. These symptoms occur most often and have the potential to negatively impact patient outcomes (Moorey, et al., 1991). The authors wanted this tool to be brief, highly discriminate between anxiety and depression, and not be dependent on physical conditions or illness.

The anxiety subscale is composed of 7 items containing statements such as “I feel tense or wound up” and “ I can sit at ease and feel relaxed.” The depression subscale is composed of 7 items including “I still enjoy the things I used to enjoy” and “I feel cheerful,” with the total instrument containing 14 items. The authors alternated the order of responses along with alternating anxiety and depression items to minimize response bias. Questions were scored with a Likert scale of four responses 0-1-2-3 with scores ranging between 0 and 42. Also a “GHQ scoring” method can be used (0-0-1-1) to assess true cases, borderline cases, and non-cases. They used the four-response scale to prevent patients from opting for a middle of the road response. The two subscales scores on the “GHQ scoring” are 7 or less representing non-cases, 8-10 borderline cases, 11 or more indicates cases. It takes about 3-5 minutes to complete. Although, the scores were initially developed to reflect the present state of mood, a compromise by the instruments authors was reached to have it reflect how the patient felt during the past week (Zigmond & Snaith, 1983).

Psychometric Properties

Validity of the HADS has been explored. Content validity was established by reviewing pertinent literature on anxiety and depression along with the authors' experience in their field of psychiatry. Domain sampling of anxiety items was guided by the Hamilton Anxiety Scale (Snaith et al., 1982). Domain sampling of depression items was based on the anhedonic depression state (inability to gain pleasure, flat affect and mood) since it is the central psychopathological feature of depression that responds well to antidepressant therapy and provides more useful information to the clinicians (Zigmond & Snaith, 1983). Testing the instrument and receiving feedback from a sample of patients further established content validity. The authors stated that most patients found the scale to be very acceptable and reported no trouble understanding its purpose or in completing the questionnaire.

Criterion validity was established by comparing the two authors' psychiatric interview assessments of anxiety and depression on a sample of 100 general in-patients to their scores on the HADS questionnaire. The two authors used a structured interview tool where they rated the patients on a five-point scale (0-4). They conducted all interviews jointly until they were confident that they had a standardized interview technique. However, they do not report any measure of Cohen's kappa or intraclass correlation

coefficients (ICC) for agreement and association (Nunnally & Bernstein, 1994). To test the ability of the tool to indicate severity of anxiety and depression the authors compared the psychiatrists' scores to the subscale scores. The Spearman correlations for anxiety and depression were moderately high ($r = 0.74, p < 0.001$; $r = 0.70, p < 0.001$, respectively). The authors concluded that the subscale scores could be used to screen for anxiety and depression and to measure levels of severity of the concepts.

Further evidence of criterion validity was established by using a receiver operating curve (ROC). Wilkinson and Barczak (1988) found that all the data points were well above the diagonal line with the area under the curve being 0.958. Using the cutoff scores of 7 or less for non-cases, 8-10 for borderline cases, and 11 or greater for cases, they reported sensitivity to be 90%, specificity 86%, and the lowest overall misclassification rate 12% (Wilkinson & Barczak, 1988).

Construct validity was assessed by studying a subset of 17 in-patients (from the sample of 100 that were discussed earlier) who had distinct differences between the interviewers' assessment scores and patients' HADS scores to test the ability of the two subscales to measure different aspects of the mood disorders. Interviewers' ratings of anxiety correlated moderately with the anxiety scores ($r = 0.54, p < 0.05$). Interviewers' ratings of depression correlated more strongly with depression scores ($r = 0.79, p < 0.01$).

Wilkinson and Barczak (1988) also tested whether the instrument was influenced by physical illness by comparing scores of those who were physically ill ($n = 100$; 60 deemed non cases, 40 deemed cases) to normal healthy sample scores, depression ($t = 0.17$, n.s.) and anxiety ($t = 0.59$, n.s.) They concluded that there was support for the subscales assessing different aspects of the mood disorder and that the tool was not influenced by physical illness. However, these results should be interpreted with caution due to the small sample size.

Further evidence of construct validity was established in a sample of 568 in-hospital cancer patients. Using an oblique factor rotation based on the assumption that the factors of anxiety and depression were correlated (Nunnally & Bernstein, 1994), the authors found that a two-factor solution was the most ideal, explaining 53% of the variance. The authors only kept factors that met the Kaiser-Guttman rule (Nunnally & Bernstein, 1994). Almost all factors loaded on the appropriate subscales with a 0.45 cutoff point except one question, "I can sit at ease and feel relaxed" loaded higher on depression instead of the intended anxiety factor. The authors concluded that these factors are correlated, so the finding is not surprising. This two-factor structure was stable across cancer diagnoses and gender (Moorey, et al., 1991).

Reliability of the HADS has been established by testing 100 adult general medical outpatients between the ages of 16 and 65 who suffered from a wide variety of illnesses. Internal consistency of the tool was measured using the Spearman's correlation. The anxiety items correlations ranged from 0.41 to 0.76, with all the items being statistically significant ($p < 0.01$). The depression items had correlations ranging between 0.30 and 0.60 with all being significant ($p < 0.02$). One depression item was removed for two reasons: (1) it kept the scale balanced (there were originally 8 depression items), (2) the question had a weak correlation of 0.11 (p n.s.). The reported Cronbach's alpha was 0.93 for the anxiety scale and 0.90 for the depression scale (Zigmond & Snaith, 1983).

Psychometric Issues

The HADS measure had strong evidence of validity that was explained thoroughly. It was able to be compared to the gold standard of a clinical interview to further establish criterion validity. The only critique of the content validity is that there may be some subjective, abstract elements of the two constructs (anxiety and depression) which make them somewhat difficult to measure with a questionnaire. Yet, overall, the HADS appears to validly assess the two emotional symptoms. There were no issues of reliability with the HADS; it has been used extensively and has been found to be reliable and valid in general inpatients and outpatients (Zigmond & Snaith, 1983) as well as in

ICU patients and ICU family members (Azoulay et al., 2005; Eddleston, White, & Guthrie, 2000; Pochard, et al., 2001).

Contextual Issues

A criticism of the contextual issues of the HADS concerns the sample populations used in developing the instrument (Switzer, et al., 1999). The cultural, educational, and socio-economic backgrounds of the test samples were not stated, but it can be assumed that the subjects were Caucasian, middle class adults that spoke English. Although this instrument has been used extensively in other countries and languages (McDowell & Newell, 1996), it may not be appropriate in cultures that are less willing to admit emotional problems. Another issue for the HADS is that it only measures the state aspect of anxiety and depression. It is not appropriate for determining trait or chronic emotional problems (Wilkinson & Barczak, 1988).

Severity of Illness

Patient's severity of illness has been found to be associated with an increase in symptoms in family members of ICU patients in prior research (Azoulay et al., 2005; Pochard et al., 2001; Pochard et al., 2005). There are several instruments that measure a patient's severity of illness. The instruments used most often in the ICU include the Acute Physiology and Chronic Health Evaluation (APACHE II and III) (Knaus et al.,

1985 & Knaus et al., 1991, respectively), the Simplified Acute Physiology Score II (SAPS II) (La Gall et al., 1993), and the Mortality Probability Model (MPM) (Lemeshow et al., 1985; Lemeshow et al., 1988; Lemeshow et al., 1993). The psychometric properties of the APACHE II will be reviewed in this paper. The rationale for only reviewing the APACHE II is that it is one of the most frequently used instruments in other ICU studies and this will allow comparisons to be made of study findings. For more in-depth information on the other measures, please see citations listed above.

APACHE II

The APACHE II was developed by Knaus and colleagues in 1985 as a severity of disease classification system. The instrument uses physiologic variables to predict the probability of death for patients admitted to an ICU. The score is based on several patient variables including physiologic derangement, admitting diagnosis, chronic illness, and age. The goal of this classification system is to quantify the degree of abnormality by using the values from multiple physiologic variables (Knaus et al., 1985). The APACHE II provides useful information and is beneficial in providing precise estimates of the benefit and indications of ICU care (Knaus et al., 1985).

The APACHE II consists of 12 acute physiological variables (APS), an age variable, and a chronic health variable. Each of these variables is scored based on

assigned weights. A summary of the variables along with the scoring methods are included in table 3 (see table 3). In general, a score of zero indicates a normal value for that variable and a higher score indicates more severe disease. All of the variables are mandatory to complete. If a variable is missing, the variable is scored as zero. Only the worst value of each variable is recorded. The timeframe for recoding information on the APACHE II is the first twenty-four hours of a patient's admission to the ICU. The total APACHE II score is calculated by adding the APS (includes the GCS) + age points + chronic health points. The total score on the APACHE II ranges from 0 to 71, however, there has been no documentation that any patient has exceeded a score of 55 (Knaus et al., 1985).

Psychometric Properties

Content validity of the APACHE II has been established. Knaus and colleagues (1985) used the variables from the original APACHE instrument. The original APACHE consisted of 34 items and had documented reliability and validity. This instrument was a useful measure in classifying ICU patients according to severity of disease. However, because of the original APACHE instrument's complexity, the authors developed the APACHE II in an attempt to simplify the tool. Using a multivariate comparison technique, Knaus and others (1985) were able to reduce the items from 34 down to 12

without losing any significant information. The authors reported that these 12 variables were easier to complete, provided the highest statistically significant R^2 (explained variance), and the highest correct classification rate (Knaus et al., 1985).

Criterion validity of the APACHE II was also reported. Knaus and colleagues (1985) compared APACHE II scores from ICU patients to see if these scores could predict actual hospital mortality rates. The researchers collected these data from 13 hospitals throughout the United States, representing 5,815 ICU admissions. The patients in the study were mostly from medical surgical ICUs (see Knaus et al., 1985, Table 1. p. 821; and Table 2, p. 822 for further information on the demographic information of the hospitals and patients). They reported a significant relationship between APACHE II score and hospital mortality rates. They found that for every five-point increase in the APACHE II score there was a statistically significant increase in mortality rate. For example, an APACHE II score of 30 to 34 with a 73% death rate for patients was significantly lower than an APACHE II score of 35 or higher with an 84% death rate for patients (chi-square = 7.5, $p = 0.01$). The same holds true for both the low and intermediate scores on the APACHE II (Knaus et al., 1985).

Further predictive validity was established using a classification matrix and an ROC curve. Individual estimated death rates were computed by using the following

equation: $\text{Ln}(R/1-R) = -3.517 + (\text{APACHE II score} \times 0.146) + 0.603$ (only if post emergency surgery + (Diagnostic category)). A predicted risk of 0.50 was established as the best cutoff point that predicted death. Using this criterion, the overall correct classification rate was 86%, the sensitivity was 47%, specificity was 94.9%, positive predicative value was 69.9%, and the negative predictive value was 87.9%. The authors report that the misclassification rate decreases as the predicted risk of death increases, however, sensitivity also decreases substantially (Knaus et al., 1985).

Another group of researchers tested the criterion validity of the APACHE II in terms of the tool's ability to discriminate based on case mix variations (Glance et al., 2000). They used data from 6,806 patients treated in a single ICU. Using a computer simulated program based on the data set, they created a variety of different case mixes ranging in mortality rates between 5% and 18%. They found that, with increases in simulated mortality rates, the Hosmer-Lemeshow C statistic increased significantly suggesting poor calibration and poor discrimination of the APACHE II based on case mix. Therefore, they suggest that future researchers should use caution when comparing widely different case mixes with the APACHE II (Glance et al., 2000).

Reliability of the APACHE II has been documented using two measures of agreement: the ICC and weighted kappa (Damiano et al., 1992). Damiano and colleagues

(1992) collected data from 11 hospitals and recorded the APACHE II information on 400 consecutive ICU admissions. To measure agreement, 196 patient records (from the 400) were re-abstracted with a separate group of researchers recording the APACHE II score. The researchers examined each of the physiological variables separately and computed an ICC using a repeated measures ANOVA. ICC is an appropriate measure because this achieves a higher standard of reliability between raters than do correlations (Nunnally & Bernstein, 1994). The ICC score can range from -1 to +1, where 0 is no inter-rater reliability and +1 implies perfect reliability. One note of caution, however, is that the ICC is really a measure of agreement, not a true correlation coefficient. Damiano and others reported ICC ranging from 0.45 to 0.97 for each separate APS variable, with an overall APS ICC of 0.903. The GCS was assessed separately using a weighted kappa. This is appropriate measure versus using a Cohen's kappa because the GCS is scored on an ordinal scale and has different weights assigned to each category (Nunnally & Bernstein, 1994). The authors reported the weighted kappa of the GCS to range from 0.69 to 0.92. These indicate fair to excellent agreement in its appropriateness to assess severity of disease (Landis & Koch, 1977; Damiano et al., 1992).

Psychometric and Contextual Issues

This measure has demonstrated evidence of validity. The only concern regarding validity is using the APACHE II when comparing ICUs with a wide variety of patient case mixes and mortality rates. Reliability has also been established with fair to excellent agreement noted. There are no major contextual issues with the APACHE II. It is widely available, at no cost to the user, and takes relatively little time to complete (Knaus et al., 1985).

Family Functioning Instrument

The measurement of family functioning has not been commonly used in family research in the ICU. However, this concept may influence family members' symptom experiences. For example, a critical care experience such as end-of-life, may interfere with family functioning and challenge current family patterns and behaviors. If the event or crisis is not managed properly, the result could affect the physical and psychosocial health of the family (Landsman et al., 1990). It is important to consider family functioning when assessing family symptoms in the ICU, therefore, the Family Adaptability and Cohesion Evaluation Scale (FACES) is one measure of family functioning that will be reviewed in this paper for potential use in family symptom research in the ICU.

Family Adaptability and Cohesion Evaluation Scale

FACES IV was developed by family therapists, Gorall, Tiesal, and Olson in 2006 and is a revised form of the previous FACES II (Olson, Bell, & Portner, 1982) and FACES III instruments (Olson, Portner, and Lavee, 1985). FACES IV is a self-report instrument investigating family functioning by assessing family members' cohesion and flexibility (Gorall, Tiesal, & Olson, 2006). Cohesion is defined as, "the emotional bonding that family members have toward one another" (Olson & Gorall, 2006, p. 3) and flexibility is defined as, "the quality and expression of leadership and organization, role relationships, and relationships rules and negotiations" (Olson & Gorall, 2006, p. 3). The main goals of the instrument's authors include:

1. Developing a self-report measure that taps into the full dimensions of cohesion and flexibility,
2. Developing a measure that adequately assesses the revised Circumplex Model,
3. Developing an instrument that is reliable and valid, and;
4. Developing a family assessment tool that is useful to both researchers and clinicians who work with families (Gorall, Tiesal, & Olson, 2006).

The FACES IV instrument has been used in a variety of fields including psychology, family medicine, and psychiatry, and in many disciplines, such as social work, education, and gerontology (Kouneski, 2000).

FACES IV consists of a total of 42 items measuring two subscales of cohesion and flexibility, balanced and unbalanced. Balanced levels indicate healthy family functioning, whereas, unbalanced levels indicate problematic family functioning. The balanced subscale contains 14-items and the unbalanced subscale contains 28 items. Examples of item statements include, “Family members are involved in each others lives”, “there is no leadership in this family”, and “it is important to follow the rules in our family”. Respondents answer using a five point Likert scale, ranging from, 1 = “strongly disagree”, 2 = “generally disagree”, 3 = “undecided”, 4 = “generally agree”, and 5 = “strongly agree”. Scoring can be done by hand or by computer software, and a ratio for balanced/unbalanced subscales or a total score can be obtained.

Psychometric Properties

Content validity of the FACES IV has been established in multiple ways. First, the items were derived from previously validated instruments, FACES II and III. Second, the items were reviewed by experts in family therapy. Third, the items are based on a strong theoretical foundation, the Circumplex Model for Families (Olson et al., 1979). Fourth, the authors of the FACES IV have extensive experience in family therapy and family functioning. Finally, the concepts of cohesion and flexibility have thorough operational definitions (Olson & Gorall, 2006).

Criterion validity was established in a study by Gorall and colleagues (2006) by comparing the FACES IV instrument to the Self-Report Family Inventory (SFI) (Hampson, Hulgus, & Beavers, 1991), Family Assessment Device (FAD) (Epstein, Baldwin, & Bishop, 1983), and the Family Satisfaction Scale (Olson & Stewart, 1989). A sample of 469 college students completed all of the surveys for comparison. It was a diverse group consisting of White, Asian, and Hispanic students. The author's reported that FACES IV had strong significant validity coefficients when compared to the other tools (See table 4).

Construct validity of the FACES IV has been established using the student sample mentioned above. Gorall and colleagues (2006) used maximum likelihood factor analysis with oblique rotation to assess the factor structure. Oblique rotation was chosen because prior research has shown that cohesion and flexibility are correlated (Kouneski, 2000) and this technique controls for that correlation (Nunnally & Bernstein, 1994). In assessing the unbalanced items, a four factor solution was chosen based on retaining items loading at 0.35 or higher. The percentage of variance that each factor explained in the unbalanced scale is as follows: Factor 1 (Disengaged) – 26%; Factor 2 (Rigid)– 13%; Factor 3 (Enmeshed) – 8%; and Factor 4 (Chaos)– 5%. In assessing the balanced items, a two factor solution was indicated based on the leveling off of the scree plot and retaining

items that loaded at 0.35 or higher. The percentage of variance explained in each factor includes Factor 1 (Cohesion) – 44% and Factor 2 (Flexibility) – 11% (Gorall et al., 2006).

Reliability of FACES IV was also assessed. Gorall and colleagues, using the student data, reported that the Cronbach's alpha ranged from 0.77 for the four unbalanced scales to 0.89 for the two balanced scales. Cronbach's alpha for cohesion = 0.87, for flexibility = 0.78. Test-retest reliability coefficients were not tested with FACES IV (Gorall et al., 2006).

Psychometric issues

Reliability and validity of the FACES IV have been established. The instrument reveals two dimensions with six subscales of family functioning that are documented as important in the literature (Gorall et al., 2006). FACES IV has a clear, concise response format and adequate response range. The authors have not reported on test-retest reliability, so this remains an area that needs further research. Another critique is that this concept of family functioning is so complex that a simple questionnaire such as the FACES IV may not get at all of the dimensions of family functioning.

Contextual Issues

A criticism of the contextual issues of the FACES IV concerns the sample population used in instrument development. In this case, college students may not be

representative of the greater family population. Although the authors state that the sample was diverse, it included a very small percentage of minority college students, so cultural, educational, and economic issues will require further clarification. Also, scores may be subject to response bias because all the items are scored in a positive direction. Finally, The FACES IV is copyrighted and requires a fee for use.

Family Coping Instrument

Coping strategies have been assessed in several studies on family members in the ICU (Leske et al., 1998; Leske et al., 2003; Twibell et al., 1998; Reider, 1994; Koller, 1991). However, only two groups of researchers associated coping strategies with family members' symptom experiences (Reider, 1994; Chiu & Chan, 2007). Assessing how family members cope with the ICU experience, especially at the end-of-life, can give insight into their mental and physical health and their overall well being. Although there are several instruments to measure family coping strategies, the Family Crisis Oriented Personal Scales (F-COPES) has been used most frequently on family members in the ICU (Leske et al., 1998; Leske et al., 2003; Chui & Chan, 2007; Twibell et al., 1998; Reider, 1994; Koller, 1991). The psychometric properties of this instrument will be reviewed in the following section.

Family Crisis Oriented Personal Scales

The F-COPES was created by professors McCubbin, Olson, and Larsen in 1981 as a measurement of problem solving strategies utilized by families during a crisis. The authors developed the instrument to define, measure, and assess the unique dimensions of coping that families use in managing their stress (McCubbin et al., 1983). They wanted to integrate coping strategies that incorporated both intra-family processes and community processes in the management of family stress (Grotevant & Carlson, 1989). The authors hypothesized that families with more coping strategies would adapt to stressful situations more successfully than families with less coping strategies (McCubbin et al., 1981).

The F-COPES includes 29 statements regarding how family members respond to family problems or difficulties. The following lists the five subscales and items associated with each:

1. The acquisition of social support, or the family's ability to actively engage in acquiring support from friends, neighbors and family; measured with 9 items;
2. Re-framing, or the family's ability to redefine stressful events in order to make them more manageable; measured with 8 items;
3. The family's ability to seek spiritual support; measured with 4 items;
4. The family's ability to mobilize, acquire and accept help from others (i.e. community resources); measured with 4 items; and

5. Passive appraisal, or how families cognitively minimize or deny problems; measured with 4 items (Grotevant & Carlson, 1989).

The opening stem of each item includes, “When we face problems or difficulties in our family we respond by...” The family member answers the statement based on the level of agreement or disagreement with that particular item. The answers are on a five-point Likert scale ranging from 1 = “Strongly agree,” 2 = “Moderately agree,” 3 = “Neither Agree or Disagree,” 4 = “Moderately Disagree,” and 5 = “Strongly disagree”. All items are written in a positive manner. Higher scores indicate that family members use more coping strategies and have more successful adaptation. The authors suggest certain cutoff points to define levels of coping: less than 50 is considered low in coping strategies; 51-99 is considered moderate in coping strategies; and greater than 100 is considered high in coping strategies. Scores can be obtained for the total scale or for each of the five subscales by summing the appropriate items (McCubbin et al., 1981).

Psychometric properties

Content validity of the F-COPES has been established. The authors thoroughly reviewed the literature on coping theory and research. They also reviewed other inventories on family coping to generate 49 items for the instrument that included key items highlighted in past research on the topic of coping (McCubbin, 1981). They tested

the 49 items on a sample of 119 undergraduate and graduate students to assess for clarity and variance. After the data were analyzed, the number of items was reduced to 30.

Further evidence of content validity includes the authors' extensive experience in the content area of coping behavior and family stress (McCubbin et al., 1981).

Construct validity was established by conducting a factor structure on the F-COPES. McCubbin and colleagues (1981) used principal components factor analysis with Varimax rotation to test the factor structure of the F-COPES on the same sample of 119 students. They retained items with eigenvalues greater than 1.00 and factor loadings greater than 0.38. They reported a five factor solution to be the most ideal, consisting of acquiring social support, reframing, seeking spiritual support, mobilizing family to acquire and accept help, and passive appraisal. They confirmed the five-factor structure on another sample of 2,740 family members (McCubbin, 1981). The final F-COPES instrument consists of a total of 29 items with five factors, however, the authors do not mention of the amount of total variance each factor explained.

Reliability of the F-COPES has been documented. Using the sample of 2,740 family members (only 2,582 family members were included in the analysis), Cronbach's alpha for each of the five subscales was computed separately. The values ranged from the lowest of 0.63 (passive appraisal subscale) to the highest of 0.83 (acquiring social

support subscale). The Cronbach's alpha for the total F-COPES scale was 0.86. Test-retest reliability coefficients of the F-COPES were measured on a sample of 116 undergraduate, graduate, and high school students. After a 4 to 5 week interval between testing, the reliability coefficients ranged from a low of 0.61 (reframing subscale) to a high of 0.95 (seeking spiritual support subscale). Test-retest reliability of the total F-COPES scale was 0.81 (McCubbin et al., 1981).

Psychometric Issues

The F-COPES has evidence of reliability and validity. However, there are several concerns with the psychometric properties of this instrument. First, there was no documentation of criterion validity for the F-COPES to indicate the instrument's ability to concur with other coping tools. Second, using a principal components factor analysis assumes that the factors are not correlated to each other. This may not be realistic and an oblique factor analysis (assumes correlation between factors) may have given a more accurate factor structure (Nunnally & Bernstein, 1994). Third, all of the items from, "watching TV" to "seeking assistance from community agencies and programs," have equal weights, which could make the overall F-COPES score unclear or less meaningful. Finally, reliability of certain factors such as passive appraisal may need further

clarification due to its low internal consistency value (0.62) (Grotevant & Carlson, 1989), as a value of 0.70 or higher is generally deemed adequate (Nunnally & Bernstein, 1994).

Contextual Issues

Critiquing the contextual issues of an instrument requires knowledge of the sample population (Switzer et al., 1999). Since there were no sample demographics given in the discussion of the F-COPES, critiquing the F-COPES use in different cultural, socio-economic, and educational groups remains in question. Another concern using the F-COPES includes a potential response bias because all of the items are keyed in a positive direction. Also, family members may view and interpret item statements differently, so comparison and interpretation across family members is varied. Finally, the F-COPES is under copyright and requires a fee for usage. Yet, overall the instrument is straightforward, easy to administer, and takes relatively little time to complete. The F-COPES is appropriate for persons 12 years or older (Birenbaum, 1991), has been used in family member research in the ICU (Chiu & Chan, 2007; Leske et al., 1998; Leske et al., 2003), and has been translated into multiple languages including Spanish, French, Hebrew, and Chinese (Neabel et al., 2000; Chui & Chan, 2007).

Other Symptoms in Family Members

The Edmonton Symptom Assessment Scale

Family members of patients that are at high risk of dying in the ICU may suffer from other symptoms besides stress, anxiety, and depression. Symptoms such as pain and fatigue, among others also need to be addressed. The Edmonton Symptom Assessment Scale (ESAS), although designed to measure these types of symptoms in patients, has potential to be used in family member symptom research to gain additional information in this area.

The ESAS was developed by Bruera and colleagues (1991) to assess common psychological and physical symptoms in palliative care patients with cancer (Bruera, et al., 1991). Their goal was to create an instrument that was shorter than other symptom instruments and easier to complete. This tool can be used in clinical practice, in research in multiple patient populations, and can be used for quality improvement efforts (Paice, 2004).

The ESAS consists of nine symptoms that respondents rate on a numeric rating scale from 0 to 10. Zero means the symptom is absent whereas 10 indicates that the symptom is at the worst possible severity. The symptoms include pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, shortness of breath, and sensation of well-being. A respondent can add one additional symptom if needed. The timeframe for the symptoms is at the time of the assessment. The total symptom distress score is the sum of

all symptoms. There is no subscale score for this tool. This instrument is designed to be administered as self-report or as a questionnaire given by an interviewer.

Psychometric Properties

Content validity of the ESAS has not been thoroughly discussed by the authors. However, the author's choice of the nine symptoms on the ESAS was developed from their review of other symptom instruments for common symptoms experienced in cancer patients. Further evidence of content validity is the authors' experience in palliative care and their knowledge of symptoms in these types of patients (Bruera, 1991).

Criterion validity of the ESAS is demonstrated in a study that assessed 233 cancer inpatients. The authors compared the ESAS items to both the Memorial Symptom Assessment Scale (MSAS) and the Functional Assessment Cancer Therapy (FACT). The correlations between the ESAS and the other instruments were strong and statistically significant indicating the ability of the ESAS to measure similar concepts found in the existing symptoms checklists (Chang, Hwang, & Feuerman, 2000). Additional concurrent validity was established by another group of investigators. They assessed 40 inpatients diagnosed with cancer and compared their ESAS scores to the scores on both the Rotterdam Symptom Checklist (RSCL) and the Brief Pain Inventory (BPI). They

reported weighted kappa values ranging from satisfactory (0.45) to good (0.61) between the scales (Philip, Smith, Craft, & Lickiss, 1998).

Reliability of the ESAS has been reported. In a study of 233 inpatients diagnosed with cancer that completed the ESAS the overall Cronbach's alpha was 0.79. In this same sample, test-retest correlations were 0.86 ($p < 0.0001$) at 2 days and 0.45 ($p < 0.05$) at one week between test administrations respectively (Chang, Hwang, & Feuerman, 2000).

Psychometric and Contextual Issues

The ESAS has evidence of validity; however several issues remain. There is no thorough discussion of content validity by the authors on tool development. Also there is no mention of construct validity. However, the ESAS appears to be valid and reliable in both inpatients diagnosed with cancer (Chang, Hwang, & Feuerman, 2004; Jenkins et al., 2000; Rees et al., 1998) and ICU patients that are mechanically ventilated (Nelson et al., 2001). Contextual issues are also of concern with the ESAS. In several of the studies, patients required more explanation on how to use the ESAS than other instruments (Chang, Hwang, & Feuerman, 2000; Paice, 2004). Also, questions remain whether it is appropriate in other populations besides cancer patients. Yet, overall, the use of the ESAS has potential to be applicable to family symptom research compared with other longer

symptoms checklists because the symptoms on the ESAS are more realistic in pertaining to family members, the tool is shorter in length, and the authors are open to revisions and modifications.

Summary

Surveys are the predominant measure of family symptoms in most studies. All of the instruments to measure family symptoms of stress, anxiety, and depression, such as the ASDS, IES, IES-R, HADS, F-COPES, ESAS, and FACES-IV, discussed in this paper had fairly strong psychometric properties. The main area of concern with these instruments is the contextual validity. All of them were developed and tested on Caucasian samples leaving questions regarding the appropriateness of these instruments for family members of different cultures, education, and socioeconomic backgrounds. Another concern with the instruments is missing data. None of the instruments mentioned the percentage of missing items allowed to still have a valid score or how to impute missing values if needed. A researcher using these instruments would have to decide the best approach to dealing with this problem. This could lead to bias and erroneous results. The APACHE II does not have the same issues as the other instruments. It has established reliability and validity and missing data are not allowed as all areas get a score.

It is challenging to select the best instruments to measure symptoms in family members of patients at high risk of dying in the ICU. In regard to the best measure for traumatic stress in family members, the use of the IES-R would be more preferable over the original IES and the ASDS. The IES-R has been designed for traumatic stress around bereavement issues and incorporates the domains of PTSD. This would be more appropriate in measuring stress in family members of patients at high risk of dying in the ICU. The best measure for anxiety and depression is the HADS. This instrument is short, easy to complete, has established reliability and validity, and has been used in family member research in the ICU (Pochard et al., 2001; Pochard et al., 2005; Lautrette et al., 2007). The measure of family coping using the F-COPES is suitable because it is shorter and easier to complete than other family coping scales (McCubbin et al., 1983) and has been used in prior family symptom research in the ICU (Reider, 1994). However there remain some issues regarding the tool's criterion validity and the internal consistency of the passive appraisal subscale. Measurement of family functioning with the FACES-IV instrument is appropriate because this tool is reliable and valid. Although FACES-IV has not been used in family research in the ICU, it has been used extensively in other family research and has promise in this population (Olson & Gorall, 2006). Finally, the use of the ESAS to measure other family symptom experiences in an exploratory format has

potential to be used in family symptom research. Although this tool does not have extensive psychometric properties, it does have some evidence of reliability and validity. Also, the tool is brief and easy to complete, can be modified to be more applicable to family members, and the symptoms may be more realistic to family members.

Conclusion

Family members are an integral component of care in the ICU, yet because of this may suffer from symptoms such as stress, anxiety, and depression. There are many areas in research that need further exploration in order to enhance better understanding of the ICU family members' symptom experiences. With continued research, using a variety of reliable and valid instruments to measure family members' symptom experiences, care for the family members of patients at high risk of dying in the ICU will continue to improve.

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Table 1. Validity Coefficients of the ASDS

| Scales | ASDS ^c Items |
|---|-------------------------|
| | Validity coefficients |
| ASDI ^a Total score (clinical interview) (Bryant & Harvey, 1996) | .86* |
| DES-T ^b Dissociative symptoms (Waller, Putnam, & Carlson, 1996) | .18 |
| IES ^c -Intrusion Re-experiencing (Horowitz et al., 1979) | .81* |
| IES ^c -avoidance (Horowitz et al., 1979) | .87* |
| BAI ^d Arousal (Beck & Steer, 1990) | .78* |

- $p < 0.001$
- ^a = Acute Stress Disorder Interview
- ^b = Dissociative Experience Scale-Taxon
- ^c = Impact of Event Scale
- ^d = Beck Anxiety Inventory
- ^e = Acute Stress Disorder Scale

Table 2 Validity Coefficients of the IES to Other Measures

| Variable and Measure | Intrusion Subscale of the IES ^e | Avoidance Subscale of the IES ^e |
|--|--|--|
| CAPS-1 ^a (Neal et al., 1994) | 0.75*** | 0.79*** |
| PTSD Inventory ^b (Solomon & Mikulincer, 1988) | 0.79** | 0.60** |
| GHQ ^c Anxiety Depression (Spurrell & McFarlane, 1995) | 0.53** | 0.37* |
| | 0.44** | 0.52** |
| SASRQ ^d Dissociation Avoidance Hyperarousal Re-experiencing (Classen et al., 1998) | 0.58** | 0.61** |
| | 0.52** | 0.49** |
| | 0.53** | n.s. |
| | 0.73*** | 0.49** |

- p<0.05; **p<0.01; ***p<0.001
- ^a = Structured Clinical Interview
- ^b = Post traumatic Stress Disorder Inventory
- ^c = General Health Questionnaire
- ^d = Stanford Acute Stress Reaction Questionnaire
- ^e = Impact of Event Scale

Table 3. APACHE II Variables

| Variables | Scoring (Weights) |
|---|---|
| (APS)*: Temperature, mean arterial pressure, heart rate, respiratory rate, oxygenation (A-aDO ₂ or PaO ₂), arterial pH, serum sodium, serum potassium, serum creatinine, hematocrit, white blood count | Scores range from (0 to +4) on high abnormal values AND (0 to +4) on low abnormal values Zero indicates normal value Four indicates severely abnormal value |
| Glasgow coma scale (GCS) | Score of 15 minus the GCS Range from 3 to 15 |
| Age | 0 if < 44 2 if 45-54 3 if 55-64 5 if 65-74 6 if 75+ |
| Severe chronic health problems | 5 points for non-operative or emergency postoperative patients 2 points for elective postoperative patients as two other variables. |

* = Acute Physiology Score

Table 4 Validity Coefficients for FACES IV

| Scale | FACES IV ^c |
|--|-----------------------|
| | Validity coefficient |
| SFI ^a (Hampson et al, 1991) | 0.93 |
| FAD ^b (Epstein et al., 1983) | 0.91 |
| Family Satisfaction (Olson & Stewart, 1989) | 0.93 |

- ^a = Self-Report Family Inventory
- ^b = Family Assessment Device
- ^c = Family Adaptability and Cohesion Evaluation Scale IV

CHAPTER 5

Unrecognized Contributions of Families in the Intensive Care Unit

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ABSTRACT

Objective: To describe the work and contributions to care that family members perform while their loved one is at high risk of dying in the Intensive Care Unit.

Design: Exploratory, descriptive analysis.

Setting: Two intensive care units at a tertiary medical center in the Western United States.

Participants: Through purposive sampling, 25 family members of 24 ICU patients at high risk of dying participated in the study.

Interventions: None.

Measurements and Results: Three independent raters coded transcripts of audiotaped interviews with family members about their experiences in the ICU. Recurring themes were categorized into roles that family members take on while their loved one is in the ICU. These work roles consisted of active presence, patient protector, facilitator, historian, coach, and voluntary caregiver.

Conclusions: Family members are important to patient care in the ICU. They perform multiple roles that are often not valued or go unrecognized by ICU Health Care Providers. More support and appreciation of family members' contributions to care may provide families opportunities for intimacy and promote a sense of belonging in the highly technical environment of an ICU.

Descriptor: nursing care

Key Words: intensive care units; family; critical care; family experiences; family roles;
end-of-life care

INTRODUCTION

There is no denying the importance of family members to patients in the Intensive Care Unit (ICU). Integrating a family centered approach to care, especially at the patient's end-of-life in the ICU, is strongly supported and encouraged by national and international critical care organizations as a means of improving end-of-life care.¹⁻⁴ The benefits of family centered care are numerous and include improvements in satisfaction and quality of patient care,⁵⁻¹⁰ improvements in the delivery of holistic care,¹¹ and improvements in providing supportive care to one another during difficult situations.^{12,13}

Most investigators studying family members in the ICU have focused on family needs and satisfaction with care.^{8,11,14-19} The actual work that family members do and the important contributions that they make to patient care are often missing from the literature. Therefore, the purpose of this report is to highlight the work of family members in terms of the roles they encompass while their loved ones are at high risk of dying while in the ICU.

MATERIALS AND METHODS

We conducted a descriptive study to investigate symptoms of ICU patients at high risk of dying from the perspectives of families, nurses, and physicians. Here we focus on

a secondary analysis of interviews of family members regarding their contributions to the work of caring for their loved ones.

Subjects

Subjects in this report were 25 family members of 24 high-risk ICU patients.

Criteria for patients being “at risk” were defined as the presence of at least one of the following: (1) an ICU stay of three days or longer, identified in research as a high risk factor for prolonged ICU stay and mortality;²⁰ (2) more than one organ system involved; and, (3) an attending physician’s report that the patient had a high likelihood of death.

Research nurses identified patients who met inclusion criteria through consultation with the ICU nurse in charge; the patient’s nurse; the ICU attending physician; and through a chart review of the patient’s status. The patient’s family member was identified as someone who, according to the nursing staff, spent the most time in the ICU with the patient. A patient’s family member was defined here to include a non-biological “significant other” if that person was the closest person to the patient. Data collection took place in two intensive care units at a tertiary medical center in the Western United States. The patient’s family member was asked to participate in the study, and informed consent was obtained. Human subjects’ approval was obtained from the Institutional Review Board of the University where this research was conducted.

Measurements

During audiotaped interviews we asked family member to describe any symptoms they had observed in the patient during their visit to the bedside. They were also asked what they thought was being done by health care professionals or themselves to manage the symptoms. All interviews were conducted privately in or near the ICU. In the course of the interviews, we found that all family members went well beyond the discussion of symptoms and provided extensive descriptions of their experiences as a family member of a seriously ill ICU patient. These discussions provided the data for the analysis reported here.

Analysis

Taped interviews of the family members were transcribed verbatim, and data were analyzed by the first author, a PhD student (JM), a PhD-prepared research nurse (SA), and the study's Principal Investigator (KP). The qualitative descriptive technique²¹ was used for analysis. This process entailed the selection of variables to be studied (in our case, experiences and actions of family members) and presentation of results that we deemed to be "information-rich."^{21, pg 338} Our process of data analysis was similar to that described by Murphy and colleagues.²² After independently listening to the taped interviews and reading all of the transcripts of these interviews in their entirety, the three

members of the team met several times over a three month period to analyze the findings. Each offered what they considered to be meaningful discussions by family members of actions that they took with the patient or health care provider in the course of the patient's ICU stay. The actions were sorted into themes that were agreed upon to represent specific work roles of the family members. Findings from this process are reported as descriptive information.

RESULTS

The majority of the family sample was female (60%) and Caucasian (84%), with a mean (SD) age of 52.6 (14.9). The relationship to the patient was as follows: spouse (48%), parent (12%), daughter, (16%), and son (12%). Patient ages ranged from 23 to 90, with a mean (SD) age of 59 (18.2). The mean (SD) APACHE II score for these patients was 27.2 (9.78), and nine of the 25 patients (39.1%) died during their hospitalization.

Table 1 presents the six major themes regarding families' contributions to care and work roles that were derived from the data: (1) Active Presence; (2) Protector (3) Facilitator; (4) Historian; (5) Coach; and (6) Voluntary Caregiver. Examples of each theme are also included in Table 1.

Work Roles

Active Presence

This role is characterized by the family member's physical presence at the bedside of the patient and the desire to maintain a vigil while the patient is in the ICU. Most of the families in this sample were present for multiple hours a day. This role is evidenced by the following example from a wife of a patient admitted with Congestive Heart Failure (CHF):

Interviewer: "I know you're there at his bedside. Is there anything in particular that you do in response to how he's feeling?"

Wife... "Well, I just try to make him know, I want him to know I'm here, and I want him to be aware that we care...But, I want him to know we're here. Be aware, even when I'm sitting, quiet, not saying anything. I'll say to him 'I'm going to sit right here, if you need me, just say something and I'll be there.' Just so he's aware of that."

This role is often active versus passive because the family is directly involved with the day-to-day decisions and care of the patient. The father of a young adult ICU patient with sepsis and hepatic failure noted:

Father... "Now some parents and some spouses will sit there...you know, they'll sit there, they'll [the family] read a book... or something like that. The doctors and nurses come and go, and they [the family] don't care. They don't ask any questions... But you know, here, we're interested in, 'where are you going, what's the latest thinking on this blood pressure?'"

The role of active presence was an important one for many families in this study because they reported that patient's "felt safer" and "more comfortable" when they were present. The following quotes from the daughter and a son of two patients with respiratory failure help to demonstrate this point:

Daughter: ... "I think she feels safer when I'm there, all the time, you know, she'll, she'll just open her eyes and look and go back to sleep, just to see if I'm there. And then maybe feel a little safer."

Son... "When he comes out from sedation, I'm going to stay here. Because he's very tuned to my sound. When I talk to him, he is responding to me more than anybody else. The nurses are ... you know, in English he doesn't say English anything. If it is Russian, good, but he responds to my voice better than anybody else's. So I stick around so I will make him feel comfortable. If I'm here, maybe he'll be more comfortable..."

Protector

The role of patient protector encompasses the family members' apparent need to take on the role of advocate, defender, and watchdog over their loved one's care while they are in the ICU. When family members were asked questions about the patient's care, their answers incorporated all of these functions. The following quote from a mother of a patient with sepsis and hepatic failure illustrates the desire to protect the patient:

Mother... "we feel as though we have made a difference, my husband and I, by being here, just to be a support to him, to make sure that the right people are seeing him, to help to monitor maybe the dosages of medications... So, they're very much aware of dosages for him, that he just has to almost have a pediatric dosage... So, by us being here, I think that we've been able to see some things happening, uh, we know him, maybe put some flags up, you know... My husband does a lot of checking with people at other

institutions, or gets on the internet, checks information that he might be able to find, on a procedure, a medication, you know, any thing that we can do.”

Another participant, a daughter of a patient with Acute Respiratory Distress Syndrome (ARDS), also exemplifies the role of patient protector:

Daughter ... “We’ve come in, and her arm would be all smashed up against the side[rail], and nobody else would notice that. And the first night of surgery, they put her into bed and I came in and the rail was up in her arm, and her hand was completely jarred back, like this. And so, I pried it out, and I put it down normally, and I know that they had moved her into bed, and they were trying to get everything else going, but, little things like that, discomfort. Like when she rolled over and her arms were smashed against the rail, so we’ve had to ask if we could move her over, just to get her, so she’s not smashed. Just a few things like that. Once in a while the bed would rotate, and nobody, like we felt that if we weren’t there, she would have been, you know, compromised for a while, without anybody, attention wise...”

Facilitator

Many family members reported taking on the role of a facilitator. This encompasses the family members translating, explaining, and interpreting information for both the patient and the healthcare providers. The following quotes from a wife of a patient with CHF and the daughter of a patient with ARDS are examples of this role:

Wife... “I tell them when I think he needs some attention, or think that they haven’t been there at all, or when he’s hurting. Sometimes I realize that it might be too soon for another shot, but I think they need to know. I feel that’s why I’m here.”

Daughter ... “And I’ve also had a little bit of frustration with uh, with my mom’s confusion, and some of the staff. [says] ‘Oh, no she appears fine’. And then my sister said, ‘no, she’s really confused’. And then they’ll do, ‘oh, yeah, you’re right’... I just told my sister when she’s here not to get frustrated because they don’t know her as well as you do... but, you just tell them, ‘you know, in my opinion, my mom looks a little bit

confused, and you need to take a little more time with her, you know. She might be nodding her head, but I don't know if she really knows what you're saying'."

Historian

Family members often functioned in the role of patient historian. This role describes their intimate knowledge of the patient along with their knowledge of the patient's prior medical status, history, and wishes. The following quotes from a mother of a patient with pancreatic cancer and the son of a patient with sepsis emphasize this role:

Mother... "And then sometimes I can, you know, speak on her behalf telling the doctors and the nurses how she feels and definitely some of my observations and some of my ah, knowledge, of you know, what happened before, and what is her medical history and things like that."

Son... "Well I know because she has told me what kind of treatments she wanted and didn't want. Not what she wanted but what she didn't want. This is the first time she has had a ventilator. I didn't really understand what ... you know, what's involved, how painful it could be, and how upsetting it could be. But this is definitely the kind of treatment that she doesn't want."

Coach

In this study a coach is seen as someone who motivates, comforts, and maintains hope in the patient during challenging situations. Family members functioned as coaches for patients by offering support, encouragement, and understanding. This was evidenced by the following comments:

Interviewer: "Is there anything in particular that you're doing in response to how he feels?"

Wife... “Hold his hand, or his head, you know, I talk to him. Tell him ‘we’re going to get through this, we’re going to make it, we can do this... Got to be positive.’ He’ll be OK.”

Interviewer: “What did you do today when you spent time with your father? Anything that you think helped make him more comfortable today?”

Son... “I hold his hand all the time when I come over here. I try to comfort him and tell him that he is getting better. ‘Just hang on a little bit more and your chest is getting better, you’re healing, and we are here, and everybody is waiting for you, and I’ll be waiting for you to get well’. I try to comfort him. I mostly hold his hand. Gives me comfort and maybe him, too.”

Voluntary Caregiver

This last theme identifies actual care that the families provided to patients. We termed this role as a “voluntary caregiver” with the work including massaging, repositioning, distracting, and performing activities of daily living. The daughter of a chronically critically ill patient noted:

Daughter... “They taught me how to suction her, so I sometimes just kind of do it myself if I know the nurse is busy or something. I position her pillows, always trying to move her, you know, pull her upper body sideways, or fix her feet with the pillows, and then, when she does get anxious, if I can’t find the nurse, I try to remind her that her oxygen is fine and she can breath slowly. She says like she feels like she can’t, she says, ‘I can’t’, and I try to kind of work with her, you know, but, she’s just so anxious sometimes, she just doesn’t realize that she can calm down... So, I try to just, you know, to ‘watch me, breath like me’...”

Another patient’s daughter reported:

Daughter... “Well, there for a while my sister and I were here together... We take turns, try to do; like one gets the washrag, one gets the sponge. What we try to do is moisten her mouth, her mouth is very dry. She’s frustrated that she doesn’t get to drink, or

anything like that. So we try to make sure that she gets a swab, and we moisten her lips because they get really dry. We noticed that they were blistering so we keep that [the moisturizer]on. Uh, we just are attentive to little things like that.”

DISCUSSION

While much has been written about family members in the ICU, this is the first study to delineate and describe the extensive work that is done by families of high-risk ICU patients. The premise that family members do substantial work while their loved one is in the ICU may not seem apparent. However, the families in this study described multiple roles that they performed.

We found how important it was for family members to be physically and actively present at the patient’s bedside. Family proximity to the patient or seeing the patient regularly has been identified in survey research to be a significant need for families;^{17, 23-}²⁷ however, the family members in this study provided detail and context to this need. They believed that the patients felt safer, more comfortable, and responded more positively to their voices. They also believed that their presence was active because they could respond for the patients during the HCPs’ visits.

The families in this study also discussed the importance of protecting the patient. This role of protector has been found in parents of children and infants in the ICU.^{28,29} However, only one study on family members of adult ICU patients corroborated this role.

Kirchhoff and colleagues found that family members of patients who died in the ICU reported a strong desire to protect the patient and reported feelings of guilt if they did not achieve this role.³⁰ Other investigators ascertained the patient's view on families in the ICU and found a common feeling of vulnerability among ICU patients and that these patients appreciated when family members watched over and protected them.⁶

Families are aware of the different practices and opinions among HCPs which can cause a decrease in satisfaction and an increase in frustration in family members.^{8,18} This awareness of family members may explain why they take on the role of patient protector in order to assure coordinated, safe, and appropriate patient care.

In our study, we had family members who discussed being both facilitators and historians for the patient. They assisted in communicating with HCPs about the patient and vice versa. Family members may assume these roles because ICU patients often have cognitive changes and difficulty communicating, leaving family members to be their voice. HCPs rely on family members to assist in decision making since the family usually knows the patient's past medical history and their medical wishes.³¹⁻³⁴ If family members are provided opportunities and encouraged to be the patient's voice, they may look back on their ICU experience as less distressful as previously reported.^{35,36}

Consistent with other researchers,^{28,37} we also found that it was important for family members to be directly involved with patient care by providing massages, oral care, bathing, and assisting with turning. Engstrom and Soderberg³⁷ reported that family members felt helpful and positive when they were performing patient care. When family members are assisted to provide this care safely, it can offer intimacy between loved ones, which is often missing in highly technical ICUs. In addition to these caregiving roles, family members also described how they provided comfort, support, and hope to the patient. Moreover, patients have noted that families involved in care and communication make them feel more secure, reassured, comfortable, and more linked to reality.⁶

Our study has several limitations. Our sample size was small and derived from ICUs in one institution. Thus, generalizability of the findings is limited. Furthermore, more targeted questions specific to the family members' roles and experiences may have elicited other responses and identified other family roles. Yet, clearly we served as a "sounding board" for families who provided rich details of their own experiences of being a family member of a seriously ill ICU patient.

This study offers important insights into how HCPs can recognize the work and contributions to patient care that family members offer. Our findings can provide the

basis for development of interventions to better support families during this time. HCPs can encourage open visiting hours on their units and provide comfortable waiting room areas for families so they can be present with the patient. It is important for HCPs to allow family members to be active in patient care by providing physical interventions according to their interests and ability and as tolerated by the patient. HCPs can provide family members with accurate, current information by keeping them updated on the patient's condition. HCPs can invite family members to participate in patient rounds of their loved one to make them feel more part of the care.

CONCLUSIONS

Family members are an integral part of patient care in the ICU. They need to be recognized for the contributions they make and invited “into the world and work” of ICUs. Providers can encourage this invitation and support practices of family members that promote intimacy and feelings of belonging during times of family stress. Future research may confirm the importance of family work to the well-being of family members as well as to their loved ones who are patients in the ICU.

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Table 1. Potential Advantages and Disadvantages of Family Contributions to Care

| Advantages | Disadvantages |
|--|--|
| Proximity to their loved ones provides emotional support, comfort, assurance, and information in terms patient understands | Family fatigue and stress from long hours at bedside |
| Increase in patient safety if they are “spokespersons” by providing patient history data, seeking rationale for treatments | Family guilt if patients don’t do well in spite of their efforts |
| Offers intimacy between patient and family member during direct care routines such as washing, touching, massaging | Additional work for patient’s HCPs due to frequent interactions with the family |
| Family members may feel more of a sense of control in an environment that often seems out of control | Loss of HCP’s concentration on patient if distracted by family |
| May help increase family members’ satisfaction with care | Potential for family- staff conflict if family is dysfunctional |
| Provides memories of helping their loved ones, especially for families of patients who do not survive the ICU | Tension between patient’s family and HCPs about treatment decisions and procedures |

Unrecognized contributions of families in the intensive care unit

Abstract *Objective:* To describe the contributions to care that family members perform while their loved one is at high risk of dying in the intensive care unit. *Design:* Exploratory, descriptive analysis. *Setting:* Two intensive care units at a tertiary medical center in the western United States. *Participants:* Through purposive sampling, 25 family members of 24 ICU patients at high risk of dying participated in the study. *Interventions:* None. *Measurements and results:* A qualitative, descriptive technique was used for data analysis. Three independent raters coded transcripts of audiotaped interviews with family members about their experiences in the ICU. Recurring themes were categorized into roles that family members take on while their loved one is in the ICU. These work roles consisted of active presence, patient protector, facilitator, historian, coach, and voluntary caregiver. *Conclusions:* Family members are important to patient care in the ICU. They perform multiple roles that are often not valued or go unrecognized by ICU health care providers. More support and appreciation of family members' contributions to care may provide families opportunities for intimacy and promote a sense of belonging in the highly technical environment of an ICU. **Keywords** Intensive care units · Family · Critical care · Family experiences · Family roles · End-of life care

Introduction

Integrating a family-centered approach to care, especially at the patient's end of life in the intensive care unit (ICU), is strongly supported and encouraged by national and international critical care organizations [1, 2]. The benefits of family-centered care include improvements in satisfaction and quality of patient care [3, 4], in delivery of holistic care [5], and in providing supportive care to one another during difficult situations [6]. Most investigators studying family members in the ICU have focused on family needs and satisfaction with care [4, 7, 8, 9]. The actual work that family members do and the important contributions that they make to patient care are often missing from the literature; therefore, the purpose of this paper is to highlight the contributions and roles of family members while their loved ones are at high risk of dying in the ICU.

Materials and methods

We conducted interviews of families to investigate symptoms of ICU patients at high risk of dying. Findings about patients' symptoms have been reported previously [10]. Due to the richness of family interviews, we performed a secondary, qualitative analysis of interview content that focused on family members' discussions of their overall experiences to answer the research question: Do ICU family members make a contribution to the care of their loved ones? Here we focus on those findings. This

question is best approached qualitatively because of the dearth of literature on families' actual roles during their loved ones' ICU stays.

Subjects

The subjects were 25 family members of 24 high-risk ICU patients. (Two family members of one patient were interviewed on two separate occasions.) Criteria for patients being "at risk" were defined as the presence of at least one of the following: (a) an ICU stay of 3 days or longer, identified in research as a high risk factor for prolonged ICU stay and mortality [11]; (b) more than one organ system involved; and, (c) an attending physician's report that the patient had a high likelihood of death. Over a 16-month period, we accrued a convenience sample of patients whom research nurses identified as meeting inclusion criteria. The patient's family member, which could include a non-biological "significant other," was asked to participate in the study, and informed consent was obtained. Data collection took place in two ICUs at a tertiary medical center in the western United States. These ICUs (one 24-bed and one 16-bed) have liberal visiting policies that include visits by children and pets. Human subjects' approval was obtained from the Institutional Review Board of the University where this research was conducted.

Measurements

We conducted audiotaped interviews of the family member privately in or near

the ICU, and the interviews provided the data for the analysis reported here. Interviews were conducted by trained members of our research team, including the principal investigator (K.P.).

Analysis

Taped interviews were transcribed verbatim, and data were analyzed by the first author, a PhD student (J.M.), a PhD-prepared research nurse (S.A.), and the study's principal investigator (K.P.). The qualitative descriptive technique [12] was used for analysis. A qualitative methodology is used to explore peoples' experiences under various conditions and social contexts in order to discover or explain a phenomenon when little prior work has been accomplished [13]. This process entails the selection of variables to be studied (in our case, experiences and actions of family members) and presentation of results that we deemed to be "information rich [12]." Our process of data analysis was similar to that described by Murphy and colleagues [14]. Each team member independently listened to the taped interviews and read all of the transcripts. They then met and offered what they considered to be meaningful descriptions of actions taken by family members with the patient or health care provider (HCP). The actions were then sorted into themes. Differences of opinion about the themes and examples of those relevant sections of the transcripts were re-reviewed by the members during several

analysis meetings. Final themes and examples of specific work roles of the family members were agreed upon by all members of the analysis team. Findings from this process are reported as descriptive information.

Results

Families were interviewed separately a median of 8.5 days after the patient's ICU admission. The majority of the family sample was female (60%) and Caucasian (84%), with a mean age of 52.6 years (SD 14.9 years). Families included spouses (48%), parents (12%), daughters, (16%), and sons (12%). Patient ages ranged from 23 to 90 years, with a mean age of 59 years (SD 18.2 years). We purposively chose patients with various medical or surgical diagnoses such as sepsis, multiple organ dysfunction syndrome, adult respiratory distress syndrome, or complications from surgeries in order to get a larger representation of "at-risk" ICU patients. The mean (SD) APACHE II score for these patients was 27.2 (9.78), and nine of the 25 patients (39.1%) died during their hospitalization. We derived six major themes of families' contributions to care and their roles from the data. The themes included: (a) active presence; (b) protector (c); facilitator; (d) historian; (e) coach and (f) voluntary caregiver. These themes represented physical, emotional, and advocacy care. (Please see ESM for direct quotations from family members that represent each of these themes.)

Family roles

Active presence

Active presence is characterized by the family member's physical presence at the patient's bedside and the desire to maintain a vigil while the patient is in the ICU. This role was an important one to many families because they reported that the patient "felt safer" and "more comfortable" when they were present.

Protector

The role of patient protector encompasses the family members' apparent need to take on the role of advocate, defender, and watchdog over their loved one's care while they are in the ICU.

Facilitator

Being a facilitator encompassed the family members translating, explaining, and interpreting information for both the patient and the health care providers.

Historian

As historians, family members used their intimate knowledge of the patient's prior medical status, history, and wishes to inform HCPs.

Coach

A coach was seen as someone who motivates, comforts, and maintains hope in the

patient during challenging situations. Family members functioned as coaches by offering support, encouragement, and understanding.

Voluntary caregiver

Voluntary caregiver identifies actual care that the families provided to patients. We termed this role as a “voluntary caregiver,” with the work including massaging, repositioning, distracting, and performing activities of daily living.

Discussion

While much has been written about family members in the ICU, this is the first study to delineate and describe the extensive contributions to the patient’s care by families of high-risk ICU patients. The premise that family members do substantial work in the ICU may not seem apparent, however, the families in this study described multiple roles that they performed. It was extremely important for family members to be physically and actively present at the patient’s bedside. Family proximity to the patient has been identified to be a significant need for families [15, 16]; however, the family members in this study provided detail and context to this need. They believed that the patients felt safer, more comfortable, and responded more positively to their voices. They also believed that their presence was active because they could advocate for the patients during health care providers’ (HCP) visits and could coach them to maintain hope and

stay positive.

The families in this study also discussed the importance of protecting the patient. Kirchhoff and colleagues found that family members of patients who died in the ICU reported a strong desire to protect the patient and reported feelings of guilt if they did not achieve this role [17]. Other investigators found a common feeling of vulnerability among ICU patients and that these patients appreciated when family members watched over and protected them [3] in order to assure coordinated, safe, and appropriate patient care.

In our study, we had family members who discussed being both facilitators and historians for the patient, communicating with HCPs about the patient, and vice versa. Family members may assume these roles because ICU patients often have cognitive changes and difficulty communicating, leaving family members to be their voice. The HCPs rely on family members to assist in decision making since the family usually knows the patient's past medical history and their medical wishes [18]. If family members are provided opportunities and encouraged to be the patient's voice, they may look back on their ICU experience as less distressful than previously reported [19].

We, like others [20], found that family members wanted to be directly involved with patient care by providing massages, oral care, bathing, and assisting with turning.

When family members are assisted to provide this care safely, it can offer intimacy between loved ones, which is often missing in highly technical ICUs. Patients have noted that families involved in care and communication make them feel more secure, reassured, comfortable, and more linked to reality [3].

For the above reasons, we believe that this type and extent of family involvement should not only be allowed, it should be a mandatory part of the patient's care in the ICU. This stance comes from our combined years of ICU nursing practice as well as our research when we have observed on numerous occasions what family members contribute to their loved ones' care. At the same time, we recognize that there are advantages as well as disadvantages to this type of family involvement and have outlined some of them in Table 1.

Our study has several limitations. Our sample size was small and derived from ICUs in one institution. We were unable to determine the influence of various factors on interviewees' responses such as type of family member interviewed, their gender or ethnicity, or the impact of the particular organization in which this study was conducted; thus, generalizability of the findings is limited. Furthermore, more targeted questions specific to the family members' roles and experiences may have elicited other responses and identified other family roles. Yet, clearly we served as a "sounding board" for

families who provided rich details of their own experiences of being a family member of a seriously ill ICU patient.

This study offers important insights into how HCPs can recognize the work and contributions to patient care that family members offer. Our findings can provide the basis for development of interventions to better support families during this time. The HCPs can encourage open visiting hours so that families can be present with the patient. It is important to allow family members to be active in patient care by providing physical interventions according to their interests and ability and as tolerated by the patient. The HCPs can provide frequent updates on the patient's condition and can even invite family members to participate in patient rounds of their loved one to make them feel more part of the care.

Conclusion

Family members are an integral part of patient care in the ICU. They need to be recognized for the contributions they make and invited "into the world and work" of ICUs. Providers can encourage this invitation and support of family members that promote intimacy and feelings of belonging during times of family stress. Future research may confirm the importance of family work to the well-being of family members as well as to their loved ones who are patients in the ICU.

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Table 1. Potential Advantages and Disadvantages of Family Contributions to Care

| Advantages | Disadvantages |
|--|--|
| Proximity to their loved ones provides emotional support, comfort, assurance, and information in terms patient understands | Family fatigue and stress from long hours at bedside |
| Increase in patient safety if they are “spokespersons” by providing patient history data, seeking rationale for treatments | Family guilt if patients don’t do well in spite of their efforts |
| Offers intimacy between patient and family member during direct care routines such as washing, touching, massaging | Additional work for patient’s HCPs due to frequent interactions with the family |
| Family members may feel more of a sense of control in an environment that often seems out of control | Loss of HCP’s concentration on patient if distracted by family |
| May help increase family members’ satisfaction with care | Potential for family- staff conflict if family is dysfunctional |
| Provides memories of helping their loved ones, especially for families of patients who do not survive the ICU | Tension between patient’s family and HCPs about treatment decisions and procedures |

Electronic Supplement Material

ACTIVE PRESENCE

This role is evidenced by the following example from a wife of a patient admitted with Congestive Heart Failure (CHF):

Interviewer: “I know you’re there at his bedside. Is there anything in particular that you do in response to how he’s feeling?”

Wife... “Well, I just try to make him know, I want him to know I’m here, and I want him to be aware that we care...But, I want him to know we’re here. Be aware, even when I’m sitting, quiet, not saying anything. I’ll say to him ‘I’m going to sit right here, if you need me, just say something and I’ll be there.’ Just so he’s aware of that.”

This role is often active versus passive because the family is directly involved with the day-to-day decisions and care of the patient. The father of a young adult ICU patient with sepsis and renal failure noted:

Father... “Now some parents and some spouses will sit there...you know, they’ll sit there, they’ll [the family] read a book... or something like that. The doctors and nurses come and go, and they [the family] don’t care. They don’t ask any questions... But you know, here, we’re interested in, ‘where are you going, what’s the latest thinking on this blood pressure?’”

The following quotes from the daughter and a son of two patients with respiratory failure help to demonstrate this point:

Daughter: ...”I think she feels safer when I’m there, all the time, you know, she’ll, she’ll just open her eyes and look and go back to sleep, just to see if I’m there. And then maybe feel a little safer.”

Son... “When he comes out from sedation, I’m going to stay here. Because he’s very tuned to my sound. When I talk to him, he is responding to me more than anybody else. The nurses are ... you know, in English he doesn’t say English anything. If it is Russian,

good, but he responds to my voice better than anybody else's. So I stick around so I will make him feel comfortable. If I'm here, maybe he'll be more comfortable..."

PROTECTOR

The following quote from a mother of a patient with sepsis and hepatic failure illustrates

the desire to protect the patient:

Mother... "we feel as though we have made a difference, my husband and I, by being here, just to be a support to him, to make sure that the right people are seeing him, to help to monitor maybe the dosages of medications... So, they're very much aware of dosages for him, that he just has to almost have a pediatric dosage... So, by us being here, I think that we've been able to see some things happening, uh, we know him, maybe put some flags up, you know... My husband does a lot of checking with people at other institutions, or gets on the internet, checks information that he might be able to find, on a procedure, a medication, you know, any thing that we can do."

Another participant, a daughter of a patient with Acute Respiratory Distress Syndrome (ARDS), also exemplifies the role of patient protector:

Daughter ... "We've come in, and her arm would be all smashed up against the side[rail], and nobody else would notice that. And the first night of surgery, they put her into bed and I came in and the rail was up in her arm, and her hand was completely jarred back, like this. And so, I pried it out, and I put it down normally, and I know that they had moved her into bed, and they were trying to get everything else going, but, little things like that, discomfort. Like when she rolled over and her arms were smashed against the rail, so we've had to ask if we could move her over, just to get her, so she's not smashed. Just a few things like that. Once in a while the bed would rotate, and nobody, like we felt that if we weren't there, she would have been, you know, compromised for a while, without anybody, attention wise..."

FACILITATOR

The following quotes from a wife of a patient with CHF and the daughter of a patient with ARDS are examples of this role of facilitator:

Wife... “I tell them when I think he needs some attention, or think that they haven’t been there at all, or when he’s hurting. Sometimes I realize that it might be too soon for another shot, but I think they need to know. I feel that’s why I’m here.”

Daughter ... “And I’ve also had a little bit of frustration with uh, with my mom’s confusion, and some of the staff. [says] ‘Oh, no she appears fine’. And then my sister said, ‘no, she’s really confused’. And then they’ll do, ‘oh, yeah, you’re right’... I just told my sister when she’s here not to get frustrated because they don’t know her as well as you do... but, you just tell them, ‘you know, in my opinion, my mom looks a little bit confused, and you need to take a little more time with her, you know. She might be nodding her head, but I don’t know if she really knows what you’re saying’.”

HISTORIAN

The following quotes from a mother of a patient with pancreatic cancer and the son of a patient with sepsis emphasize this role of historian:

Mother... “And then sometimes I can, you know, speak on her behalf telling the doctors and the nurses how she feels and definitely some of my observations and some of my ah, knowledge, of you know, what happened before, and what is her medical history and things like that.”

Son... “Well I know because she has told me what kind of treatments she wanted and didn’t want. Not what she wanted but what she didn’t want. This is the first time she has had a ventilator. I didn’t really understand what ... you know, what’s involved, how painful it could be, and how upsetting it could be. But this is definitely the kind of treatment that she doesn’t want.”

COACH

Coaching was evidenced by the following comments:

Interviewer: “Is there anything in particular that you’re doing in response to how he feels?”

Wife... “Hold his hand, or his head, you know, I talk to him. Tell him ‘we’re going to get through this, we’re going to make it, we can do this... Got to be positive.’ He’ll be OK.”

Interviewer: “What did you do today when you spent time with your father? Anything that you think helped make him more comfortable today?”

Son... “I hold his hand all the time when I come over here. I try to comfort him and tell him that he is getting better. ‘Just hang on a little bit more and your chest is getting better, you’re healing, and we are here, and everybody is waiting for you, and I’ll be waiting for you to get well’. I try to comfort him. I mostly hold his hand. Gives me comfort and maybe him, too.”

VOLUNTEER CAREGIVER

The daughter of a chronically critically ill patient noted:

Daughter... “They taught me how to suction her, so I sometimes just kind of do it myself if I know the nurse is busy or something. I position her pillows, always trying to move her, you know, pull her upper body sideways, or fix her feet with the pillows, and then, when she does get anxious, if I can’t find the nurse, I try to remind her that her oxygen is fine and she can breath slowly. She says like she feels like she can’t, she says, ‘I can’t’, and I try to kind of work with her, you know, but, she’s just so anxious sometimes, she just doesn’t realize that she can calm down... So, I try to just, you know, to ‘watch me, breath like me’...”

Another patient’s daughter reported:

Daughter... “Well, there for a while my sister and I were here together... We take turns, try to do; like one gets the washrag, one gets the sponge. What we try to do is moisten

her mouth, her mouth is very dry. She's frustrated that she doesn't get to drink, or anything like that. So we try to make sure that she gets a swab, and we moisten her lips because they get really dry. We noticed that they were blistering so we keep that [the moisturizer] on. Uh, we just are attentive to little things like that."

CHAPTER 6

Dissertation Study: Symptom experiences of family members of intensive care unit patients at high risk of dying

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ABSTRACT

Objective: To describe the symptom experiences of family members of patients at high risk of dying in the intensive care unit and to assess risk factors associated with an increase in symptoms.

Design: Prospective, cross-sectional, descriptive study.

Setting: Three intensive care units at a tertiary medical center in the Western United States.

Participants: A convenience sample of 74 family members of 74 ICU patients at high risk of dying participated in the study.

Interventions: None.

Measurements and Results: We assessed the results from several reliable and valid instruments of 74 family members 3-5 days after the patient's admission to the ICU.

Overall the prevalence of symptoms was high, with over 56.8% of our sample having symptoms of traumatic stress, 79.7% having symptoms of anxiety and 70.3% having

symptoms of depression. We also found that family members suffered from other symptoms such as tired, sadness, and poor appetite at moderate to severe levels of

distress. Independent factors associated with an increase in severity of family members' symptoms included younger patient age, younger family member age, female gender of

the family, and family member's race other than White. In addition, we found that the majority of the family members were coping and functioning at high levels during the ICU experience.

Conclusions: Family members are important to patient care in the ICU. They are often required to participate in end of life decision making for the patient at high risk of dying. Family members in our study had high levels of psychological and physical symptoms, often at distressing levels. More support and understanding of family members' symptom experiences is needed in order to understand the long term effects of symptoms and to improve family centered care in the ICU.

Key Words: traumatic stress; anxiety; depression; symptoms; intensive care units; family; critical care; family experiences; end-of-life care

Symptom Experiences of Family Members of Intensive Care Unit Patients at High Risk of Dying

Introduction

Having a family member as a patient in an intensive care unit (ICU) is difficult especially if the patient is at high risk of dying in the ICU. ICU clinicians often rely on family members to make decisions for critically ill non-communicative patients regarding their care and treatment.¹ These families may also have to prepare for the potential loss of a loved one. This ICU experience may be unanticipated, unprecedented, and may impact family members negatively by increasing their risk of psychological and physical symptoms.²

Symptoms, especially psychological symptoms, in family members of ICU patients have been the focus of recent research. In a study of 284 French family members, Azoulay and colleagues reported that post traumatic stress disorder (PTSD) symptoms occurred in 33% of their sample. Higher levels of these symptoms were associated with the family losing a loved one in the ICU (50%) or if they were involved in end-of-life decision making (81%).³ In addition, other investigators have reported high levels of anxiety (ranging from 35% to 73%) along with moderate levels of depression (ranging from 15% to 35%) in family members of ICU patients.^{2,4}

Most family symptom studies have been conducted in Europe, and not all were focused on family members of patients at high risk of dying in the ICU. Also, little research exists on how these family members cope with their ICU experience and function as a family unit during the patient's time in the ICU. Finally, knowledge regarding a broader range of family symptoms such as pain, fatigue, and appetite problems is limited. Understanding the broader symptom experiences of family members of high risk ICU patients is integral to determining the most appropriate interventions that can be targeted to the family.

The purpose of this study was to understand the psychological and physical symptom experiences of family members of ICU patients at high risk of dying and to investigate other risk factors that may be associated with an increase in symptoms. The specific aims of this study were to:

- Identify and describe the levels of traumatic stress, anxiety, depression, and other symptoms in families of high risk ICU patients.
- Identify and describe coping techniques and methods of family functioning.
- Investigate the relationship between a family member's level of coping, level of functioning, socio-demographic variables (e.g. gender, age, education) and patient

variables (e.g. severity of illness, age, diagnosis) on family members' levels of traumatic stress, anxiety and depression.

Methods

Study Design and Setting

This prospective cross sectional study was conducted in a large west coast university hospital in three adult ICUs between October 2007 and February 2008. The types of ICUs were medical/surgical, cardiovascular and neurovascular. They are all open units where patients are cared for by an ICU team and specialty services. All of the ICUs have very liberal visiting practices that allow family members to spend considerable amount of time at the bedside.

Sample

Family members were considered for inclusion if they 1) were an adult family member of an adult ICU patient (over the age of 18); 2) visited the patient at least once while the patient was in the ICU; 3) identified themselves as closest to the patient or most likely to be involved with the patient's care; 4) read and spoke English; 5) were a family member of a patient "at risk." Patients "at risk" were defined as having an Acute Physiologic and Chronic Health Evaluation (APACHE II) score of 20 or greater (measure of severity of illness with established reliability and validity),^{5,6} an ICU length of stay of

at least 72 hours, and were mechanically ventilated. “Family” was defined as the person who was closest to the patient and would be most involved in their treatment and care decisions. A family member did not have to be a blood relative. Only one family member per patient was enrolled.

Measures

The Impact of Event Scale-Revised (IES-R) is a 22-item questionnaire that measures traumatic stress in individuals. Each item is scored with a five-point (0-4) response format to indicate how distressing each item has been during the past week. Subscales of the IES-R include: intrusion (8 items), avoidance (8 items), and hyperarousal (6 items). The authors recommend using the mean total IES-R score and mean subscale scores as opposed to total sum scores.^{7,8} When reporting prevalence, a cutoff score for the total IES-R and subscales can be used. A score of 1.5 or greater (equivalent to a score of 33) has been reported to indicate a moderate level of distress with the highest sensitivity (0.91), specificity (0.82), positive predictive power (0.90), and negative predictive power (0.84).⁹ However, the authors suggest using caution when interpreting results using a set cutoff point since there is still debate over the time elapsed since traumatic event, severity of traumatic event, and a lack of normative data. This questionnaire has established validity and reliability with a Cronbach’s alpha = 0.92 for

intrusion, 0.85 for avoidance, and 0.90 for hyperarousal.^{7, 8} The Cronbach's alpha for the total instrument in this study was 0.93.

The Hospital Anxiety and Depression Scale (HADS) is a 14-item screening questionnaire that measures clinically significant anxiety (7 items) and depression (7 items) in individuals. Each item is rated on a four point (0-3) scale for a total sum distress score ranging between 0 to 21 for both anxiety and depression. When reporting prevalence of anxiety and depression, cutoff scores between 8 and 10 have been classified as indicating possible clinical disorder.¹⁰ More recently a cutoff score of 11 or greater has been recommended for use in research to indicate a probable clinical disorder.¹¹ The HADS is simple to use and has established reliability and validity, with a Cronbach's alpha = 0.93 for anxiety and 0.90 for depression.¹⁰ In this study the Cronbach's alpha was 0.87 for anxiety and 0.73 for depression.

The Family Crisis Oriented Personal Scales (F-COPES) is a 29-item measure that assesses family members' problem solving and behavioral strategies used during crisis situations. The questions are rated on 5 point scale (1 = strongly disagree to 5 = strongly agree) with higher scores indicating better coping. The five subscales consist of: reframing, spiritual support, mobilizing family, social support, and passive appraisal. A total score from 0 to 145 can be obtained by summing the items. The following cutoff

points are suggested: low (less than 50), moderate (51-99), and high (greater than 100).

This measure has documented reliability and validity in this population.¹² The

Cronbach's alpha in this study was 0.80.

The Family Adaptability and Cohesion Evaluation Scale (FACES IV) is a 42-item questionnaire used to measure the level of family functioning. It is scored on a 5 point response format (1 = strongly disagree to 5 = strongly agree). It measures the ratio between balanced functioning (flexibility and cohesion) and unbalanced functioning (disengaged, enmeshed, rigid, and chaotic) to achieve a total ratio score. The total ratio score can measure the amount of balance versus unbalance in the family system. The hypothesis is that unbalanced families will have poorer family functioning and have more problems dealing with crises situations.¹³ A ratio score above 1 indicates a balanced family system. A ratio score of less than 1 indicates an unbalanced family system. This measure has documented reliability and validity.¹⁴ The Cronbach's alpha in this study was 0.78.

Edmonton Symptom Assessment Scale Revised (ESAS-R) is a 9-item scale that assesses other symptoms such as pain, tired, scared and sad that family members may experience. The family members rate the symptoms on a numerical rating scale of 0 (best) to 10 (worst). A mean score for each symptom can be obtained along with

symptom severity at the mild (1-3), moderate (4-6), and severe (7-10) level. This tool has established reliability and validity.¹⁵ The Cronbach's alpha in this study was 0.82.

Procedures

An initial chart review of each patient was completed to determine a patient's eligibility for the study. Family members who met inclusion criteria were approached in the patient's room by the principle investigator (JM) approximately 3-5 days after the patient's ICU admission. They were told of the study purpose and, if they agreed, they were enrolled. Informed consent was obtained at that time. The family member was taken to a private location where the study questionnaires were completed. In addition, they completed socio-demographic information along with two questions rating their understanding of information and consistency of information (both questions rated 1 = poor to 5 = excellent) presented to them in the ICU by healthcare providers. The following characteristics of family members and patients were collected: (1) *family variables*: age, relationship, gender, ethnicity, education, coping, family functioning and ICU experience; and (2) *patient variables*: gender, age, presence of an advance directive, diagnosis, severity of illness, code status, and ICU final disposition. To ensure optimal quality of the data, recruitment and enrollment were completed by one researcher (JM) who is a nurse with extensive experience in working with ICU patients and family

members. The PI (JM) was present throughout the survey process to answer questions and to ensure completeness of the data. The study was approved by the International Review Board where the study was conducted.

Statistical Analysis

SPSS version 13 was used to analyze the data (SPSS, Inc., Chicago, IL). All continuous variables were described with means and standard deviations. Categorical variables were reported as proportions and frequencies. Three separate multiple linear regression models were used to test the effects of the independent variables on the continuous dependent variables of stress, anxiety and depression. Only independent predictors that reached a significance of $p < 0.15$ at the univariate level were included in each regression model. Potential interactions among the independent variables in the models were evaluated. Information on the performance of the three multiple regression models was assessed by the percentage of variance in the dependent variables that was explained by the models independent variables (R^2). Unique contributions of independent variables to the models were measured by the percentage of variance explained by that variable (R^2 -change). In addition, broader symptom experiences of family members (e.g. pain, tired and sad) were presented, with means and standard deviations for each symptom as well as the prevalence of each symptom at the moderate and severe level.

Results

Family Member Characteristics. Over the study period, a total of 181 consecutive patients were screened, and 95 met the study criteria. The family members of these patients were approached to be enrolled in the study with 21 refusing, leaving a total of 74 family members (see Figure 1 for reasons of refusal and non-inclusion criteria).

Characteristics of the family members and patients are presented in Table 1. Most of the study participants were female (58.1%) with a mean (SD) age of 51.3 (13.1).

Racial/ethnic composition of the family group was diverse, but the majority of family members were Caucasian (59.5%). Most family members had prior ICU experience (63.5%), were educated at a college level or higher (71.6%), and rated the information received and consistency of information given by ICU personnel at a very good to excellent level. The mean (SD) of the rating for information received was 4.6 (0.69) and for consistency of information was 4.6 (0.65).

Patient Characteristics. A total of 74 patients of the enrolled family members were included in the data collection and analysis. The mean age (SD) of the patients was 58.9 (14.9). The patient's mean (SD) APACHE II score was 31.5 (6.7). There was a diverse range of diagnoses, but the majority of the patients had ARDS/sepsis (33.8%) followed by multi-system organ failure (25.7%). Most of the patients were in the medical/surgical

ICU (60.8%), followed by neurovascular ICU (28.4%) and cardiovascular ICU (10.8%).

Most of the patients were female (60.8%), Caucasian (60.8%), had a full code status (83.8%), and had no documentation of an advance directive in their medical chart (87.8%). The median length of stay was 12 days (range 3-139), and the ICU mortality rate of the patients was (27%).

Levels of traumatic stress, anxiety, depression and other symptoms

Overall, the mean (SD) scores for family members' levels of traumatic stress were moderate to high (IES-R = 1.7 (0.88), range 0 to 4). As indicated in Table 2, 56.8% of family members had an IES-R score of 1.5 or greater indicating a significant risk of PTSD symptoms. The subscale scores also indicated moderate to high traumatic stress levels in family members. A significant majority of family members scored high on the intrusion and hyperarousal subscales, whereas slightly less than half of family members scored 1.5 or greater on the avoidance subscale.

The overall levels of family members' anxiety and depression were moderate to high (11.8 (4.7) and 9.6 (4.2), respectively). Table 3 presents the number and percentage of family members that scored above the borderline cutoff (a score of 8 or greater on each subscale) and clinical cutoff (a score of 11 or greater on each subscale) scores for symptoms of anxiety and depression. In addition, there were strong correlations between

traumatic stress and anxiety ($r = 0.81, p < 0.0001$), traumatic stress and depression ($r = 0.61, p < 0.0001$), and anxiety and depression ($r = 0.75, p < 0.0001$).

The prevalence of a broader range of family symptoms is depicted in Figure 2.

The prevalence of family members who experienced each symptom at either the moderate or severe level is presented in Figure 3. The most intense symptoms for family members based on mean (SD) scores are listed in Table 4.

Family Coping and Functioning

Overall, the majority of family members had high total coping scores [(104.7 (13.3))] and could be classified as having either moderate (36.5%) coping scores, ranging from 51 to 99, or high (63.5%) coping scores of 100 or greater. The most common type of coping strategy used by family members was reframing (mean 3.91, SD 0.56), and the least used coping strategy was seeking spiritual support (mean 3.30, SD 1.3).

All family members in the sample were considered to have healthy (balanced) family functioning (defined as a ratio score of greater than 1). The family member's cohesion ratio score was high [(2.16 (0.82))], meaning that the family unit was close to one another during the ICU experience. Their flexibility ratio score was also high [(1.74 (0.58))], indicating that the family unit was adaptable to the ICU situation. Their total mean ratio score which measured overall family functioning was also high [(1.95 (0.65))].

Relationship between correlates and family members' traumatic stress, anxiety and depression

Traumatic Stress

Factors independently associated with higher traumatic stress scores in family members ($p < 0.15$) were family member education, patient's age, family member's age, and female gender of the family member. These predictors were added to the regression simultaneously resulting in a significant overall model (R Square = 0.229, $F = 5.122$, $p = 0.001$) and explaining approximately 23% of the total variance in family member's level of traumatic stress. See Table 5. In the multiple linear regression model, coefficients that were significantly associated with higher traumatic stress levels were patient's age in 5 year increments ($t = -2.220$, $p = 0.03$), family member's age in 5 year increments ($t = -2.379$, $p = 0.02$), and female gender of the family member ($t = 2.659$, $p = 0.01$). This indicates that, for every 5 year increase in patient age, the family members' mean traumatic stress scores decreased by at least 0.01 points or by as much as 0.14 points. Likewise, for every 5 year increase in family members' age, family members' mean traumatic stress scores decreased by at least 0.01 points or by as much as 0.16 points. Finally, female family members' mean traumatic stress scores were higher than male family members' mean traumatic stress scores by at least 0.13 points or as much as 0.88

points. Patient's age uniquely explained 6% (R^2 -change), family member's age uniquely explained 6%, and female gender uniquely explained 8% of the total variance in traumatic stress.

Anxiety

Factors independently associated with higher anxiety scores in family members ($p < 0.15$) were the family member's education, family member's race/ethnicity, patient's age, family member's age, and female gender of the family member. When these predictors were added simultaneously to the overall model in Block 1, they were significant (R Square = 0.236, $F = 4.194$, $p = 0.002$) and explained approximately 24% of the total variance in family members' anxiety levels. See Table 6. Coefficients significantly associated with higher anxiety levels were patient's age ($t = -2.466$, $p = 0.02$) and female gender of the family member ($t = 2.329$, $p = 0.02$). However, when an interaction term for patient age and family member gender was added to the overall model in Block 2, the increase in R^2 was significant (R^2 -change = 0.075, $p = 0.009$). This indicates that there was an interaction between patient's age and gender of the family member on family members' anxiety levels. Therefore, the relationship between the patient's age and the family member's anxiety levels depends on family member's gender. For both females and males, the patient's age had an inverse relationship to

anxiety suggesting that as the patient's age increased anxiety levels of the family member decreased. However, the slope for males was markedly steeper than that for females. For males, for every 5 year increase in patient's age, anxiety levels decreased 1.0 point, whereas for female family members, for every 5 year increase in patient's age, anxiety levels decreased by only 0.06 points. The value of the difference between the two slopes was 0.922, significant with a $t = 2.705$, $p = 0.009$.

Depression

Factors independently associated with higher depression scores in family members ($p < 0.15$) were the family member's education level, the family member's race/ethnicity, the family member's total coping score, the patient's age, and female gender of the family member. When these predictors were added simultaneously to the overall model in Block 1, it was significant ($R\text{ Square} = 0.221$, $F = 3.859$, $p = 0.004$) and explained approximately 22% of the total variance in family members' depression. See Table 7. The only coefficient that was significantly associated with higher depression levels was female gender ($t = 2.297$, $p = 0.025$). However, when interaction terms were added to the model in Block 2, there were two significant interactions. The first one was between family race/ethnicity and family gender, and the second one was between patient age and family gender. Therefore, the relationship between family member's

race/ethnicity and family member's depression levels depends on family member's gender. Female family members of a race other than Caucasian had significantly higher depression levels than male family members of a race other than Caucasian. There were no differences in depression levels between female and male Caucasians. The value of the interaction (-4.894) was significant with a $t = -2.697$, $p = 0.009$. Likewise, a patient's age and a family member's depression level also depends on family member's gender. For males (slope = -0.635), patient's age had an inverse relationship to depression indicating that as the patient's age increased, depression levels of the family member decreased. For females, as the patient's age increased, depression levels actually remained relatively constant (slope = 0.03). The value of the difference between the two slopes was 0.667 with a $t = 2.279$, $p = 0.026$.

Discussion

The present study provides data on the broader symptom experiences of family members of patients at high risk of dying in the ICU. To our knowledge, we are the first to measure these symptoms in family members of ICU patients at high risk of dying in the United States. Although the IES-R and the HADS do not determine clinical diagnoses of PTSD, anxiety and depression, they do reveal the prevalence and distress of these symptoms. In family members of patients at high risk of dying in the ICU, we found that

over half (56.8%) had PTSD symptoms, 79.7% had symptoms of anxiety, and 70.3% had symptoms of depression 3-5 days after the patient's admission to the ICU. This has tremendous implications for ICU clinicians to incorporate a family centered approach to care. In the United States, a shared decision making philosophy is recommended,^{16, 17} and families are often involved in end-of-life care conferences and decision making for the patient. However, high levels of traumatic stress, anxiety and depression that we and others^{2-4, 18-20} have found in family members provide a potential ethical risk. Families with these symptoms may overestimate and/or underestimate treatment decisions for the patient²¹ or may not comprehend information presented to them.²² They may also try to alleviate their symptoms by making rash decisions in order to reduce the amount of burden and uncertainty they feel. Although family members in our study rated both information and consistency of information at a high level, ICU clinicians may need to be prudent in how they run care conferences and present information to families by allowing family members more time to comprehend information. This type of structured end of life care conference was shown to reduce symptoms of PTSD, anxiety and depression 90 days after the ICU experience in family members in a study by French investigators.²³

We also found that a large majority of family members suffered from intrusive and hyperarousal symptoms during their ICU experience. These also could have practical

implications when involving family members in decision making about the patient's care. Family members who suffer from hyperarousal symptoms have trouble concentrating and may not understand the information presented to them. Those that have intrusive thoughts or disturbing images about the ICU experience could be at risk for sleep disturbances and a decrease in their overall mental health.⁸ These are potentially amenable to intervention by ICU clinicians by better preparing family members with what they may see, hear or experience while visiting in the ICU; allowing family members more time to understand information presented to them; and by keeping them informed of the patient's status on a regular basis.

Our findings of high levels of traumatic stress were consistent with others who measured this in family members early in the patient's ICU stay.^{19,20} Yet, our findings were higher than previously reported by French investigators, where 33% of family members were at high risk of PTSD symptoms.³ This discrepancy is probably due to differences in time measurement. Azoulay and colleagues measured family members at 90 days post ICU, whereas we measured them at 3-5 days after ICU admission. It has been documented that the risk of traumatic stress symptoms may be high initially in family members but may decrease over time.⁸ More research is needed on the effects of traumatic stress in family members over time.

We found high levels of anxiety symptoms in family members, a finding consistent with others.^{2, 4, 24, 25} This can indicate to ICU clinicians that, regardless of multiple risk variables (e.g. patient's status, time measurement), most family members have symptoms of anxiety that need to be acknowledged in order to better care for the family. We also found high percentage of depression symptoms in most family members 3-5 days after the patient's admission to the ICU. This was higher than previously reported by other investigators,^{2, 4, 24} where depression symptom prevalence ranged between 25-35%. This could indicate that the families in our study were trying to cope and prepare for a poor outcome for the patient. This would be consistent with Pochard and colleagues' findings where the odds of a family having depressive symptoms increased significantly if the patient died in the ICU.⁴

Independent predictors of traumatic stress, anxiety and depression such as younger patient age, younger family member's age, family member race/ethnicity, and female gender of the family member have also been reported by others to impact family symptoms.^{2-4, 19, 25, 26} We also found significant interactions between patient's age and family member gender on both anxiety and depression levels as well as between family member race/ethnicity and family member gender on depression levels. Although these

are not amenable to intervention, they do provide ICU clinicians with knowledge regarding which family members are at increased risk for suffering from symptoms.

Unlike others^{3, 4, 24} we did not find a statistically significant relationship between patient diagnosis or severity of illness on levels of traumatic stress, anxiety or depression. In our study, all the patients were at risk of dying and had high APACHE II scores, leaving little to no variation to find any differences. Also, the patient's diagnosis may not have been as important to family members' symptoms as their perceived level of threat to the patient. Other variables reported in the literature as impacting traumatic stress, anxiety and depression such as family relationship to the patient, the family member's rating of information, consistency of information, lack of an advance directive, and code status did not have significant results in our study. It is possible that we did not have enough power in the groups to find significant differences or that we did not have enough variability of these factors to find differences (i.e. 84% versus 16% were full code, 88% versus 12% had no advance directive).

Family coping and family functioning were hypothesized to impact stress, anxiety and depression in family members as they had in other studies.^{19, 27, 28} Even though the families in this study had high levels of symptoms, they appeared to be coping and

functioning as a family unit. Since no families scored low on coping or family functioning, we could not adequately assess their impact on family symptoms.

There are several possible reasons for our findings of high coping and family functioning. First we had an educated sample (72% at college level or higher) that may have been aware of more resources available to them; or they may have had more coping techniques already in place. Second, most family members (64%) had a prior experience in the ICU and may have already developed coping skills. In regard to family functioning, only one family member per patient completed the questionnaire (for data analysis purposes) so it may not have reflected the full scope of family functioning. If multiple family members completed the survey, a different level of family functioning may have been found. It is also possible that during times of crisis, the family pulls together and becomes closer and more flexible. Future research should focus on multiple family members and how they cope and function during this experience.

To our knowledge we are the first to quantify the prevalence and severity of a broader range of symptoms experienced by ICU family members (e.g., tired, sad, and scared). We found that family members suffered from a variety of these symptoms, often at moderate to severe levels of distress. Prior qualitative research disclosed that family members reported fear, worry, exhaustion, helplessness, sadness and anger.²⁹ Others have

assessed behavioral responses of family members during critical illness and noted that families reported sleep difficulties, changes in their appetite, and were less active.^{30, 31}

We also found a myriad of symptoms to be distressing for family members. This is important for ICU clinicians to be aware of because of the potential of these symptoms to impact the physical and mental health of the family members. ICU clinicians can consider establishing policies to refer family members for counseling to discuss their feelings of sadness, anger, or guilt. They can also provide family members with information on adequate sleeping arrangements and encourage family members to eat properly. Future research on the long term effects of these symptoms on family members is warranted.

Our study has several limitations. First, it was conducted at one center on a small sample of family members, limiting the generalizability of our findings. Second, we had little variation in several of the independent variables such as the patient's severity of illness and code status. Finally, we did not measure baseline symptoms in families to know if an increase in the symptoms were associated with the ICU experience or if they were already present in the family member.

Conclusion

Family members are an important part of care in the ICU, especially when a patient is at risk for dying. ICU clinicians rely on family members for making decisions about treatment and care for the patient. We found that family members do suffer from high levels of traumatic stress, anxiety and depression as well as several other symptoms. However, we found that families cope and function well during the ICU experience of their loved one. ICU clinicians who are aware of these symptoms can attempt to reduce the symptom burden in order to prevent long term negative consequences for family members.

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Table 1. Family Member and Patient Characteristics

| Family Members N = 74 | |
|--|--------------------------|
| Mean age (SD) years (range) | 51.31 (13.10) (20-76) |
| Gender, % female | 58.1% |
| Relationship to patient (%) | |
| Spouse/Partner | 43.2% |
| Adult Child | 33.8% |
| Parent | 10.8% |
| Sibling | 10.8% |
| Other | 1.4% |
| Race/Ethnicity (%) | |
| White | 59.5% |
| Asian/Pacific Islander | 20.3% |
| Hispanic | 13.5% |
| African American | 6.8% |
| Prior ICU Experience, % yes | 63.5% |
| Family live with patient, % yes | 56.8% |
| Level of Education, % college or greater | 71.6% |
| Patients N = 74 | |
| Mean age (SD) years (range) | 58.92 (14.86) (26-91) |
| Gender, % female | 60.8% |
| Race (%) | |
| White | 60.8% |
| Asian/Pacific Islander | 20.3% |
| Hispanic | 12.2% |
| African American | 6.8% |
| APACHE II mean (SD) (range) | 31.5 (6.7) (20-45) |
| Diagnoses (%) | |
| ARDS/Sepsis | 33.8% |
| Multi-organ system failure | 25.7% |
| Neurovascular disease | 21.6% |
| Other (Cardiovascular, Cancer) | 18.9% |
| Code Status, % Full Code | 83.8% |
| Advance Directive, % No | 87.8% |
| Length of Stay median days (range) | 12 (3-139) |
| Mortality rate | |
| Died in the ICU | 27.0% |
| Died during Hospitalization | 12.2% |

Table 2. Impact of Event Scale-Revised Measure of traumatic stress.⁸ A cutoff of 1.5 has been established as indicating high risk of PTSD symptoms.⁹ N = 74.

| | Mean | SD |
|--|-----------|---------|
| IES-R Mean Total (range 0-4) | 1.74 | 0.88 |
| | Frequency | Percent |
| IES-R, cutoff score of 1.5 or greater | 42 | 56.8% |
| IES-R Intrusion Scale | 35 | 67.6% |
| IES-R Hyperarousal Scale | 50 | 52.7% |
| IES-R Avoidance Scale | 39 | 47.3% |

Table 3. Hospital Anxiety and Depression Scale

Measure of anxiety and depression. Subscale total scores range from 0-21. Subscale cutoff scores of 8 or greater indicates borderline risk for symptoms of anxiety and depression, subscale cutoff scores of 11 or greater indicates risk for clinical symptoms of anxiety and depression.¹⁰

| | Mean (SD) | Prevalence (%) of Family Members at a <u>Border Line</u> Cutoff (score of 8 or greater) | Prevalence (%) of Family Members at a <u>Clinical</u> Cutoff (score of 11 or greater) |
|---------------------|-------------|---|---|
| Anxiety Subscale | 11.80 (4.7) | n = 59 (79.7%) | n = 44 (59.5%) |
| Depression Subscale | 9.62 (4.2) | n = 52 (70.3%) | n = 32 (43.2%) |

Table 4. Edmonton Symptom Assessment Scale Revised Symptom intensity on a NRS (shown in descending order). The scores can range from 0-10, where 1-3 is mild, 4-6 is moderate, and 7-10 is severe.³²

| Symptom | Mean (SD) |
|------------------|-----------|
| Sadness | 6.7 (2.9) |
| Scared | 6.5 (3.1) |
| Tired | 5.7 (2.7) |
| Worst well being | 5.4 (2.8) |
| Anxiety | 5.2 (3.0) |
| Worst Appetite | 4.4 (2.6) |
| Depression | 3.8 (3.2) |
| Pain | 2.4 (2.9) |
| Nausea | 1.0 (2.1) |

Table 5. Regression on Traumatic Stress Mean Scores

| Model 1 | B | Std Error | t | Sig | 95% CI Lower Bound | 95% CI Upper Bound |
|----------------------------------|----------|------------------|----------|------------|---------------------------|---------------------------|
| Constant | 3.584 | 0.595 | 6.024 | 0.0001 | 2.397 | 4.771 |
| Family Education* | -0.238 | 0.212 | -1.123 | 0.265 | -0.662 | 0.185 |
| Patient age in 5 year increments | -0.073 | 0.033 | -2.220 | 0.030 | -0.138 | -0.007 |
| Family age in 5 year increments | -0.085 | 0.036 | -2.379 | 0.020 | -0.156 | -0.014 |
| Female gender | 0.505 | 0.190 | 2.659 | 0.010 | 0.126 | 0.884 |

* Family education was measured in two groups College or higher = 1, High school or less = 0

Example: For every 5 year increase in patient's age, family member's traumatic stress mean scores decreased by at least 0.01 or by as much as 0.14.

For every 5 year increase in family member's age, family member's traumatic stress mean scores decreased by at least 0.01 or by as much as 0.16.

Female family members mean traumatic stress scores are higher than male family member's mean traumatic stress scores by at least 0.13 or as much as 0.88.

Table 6. Regression on Anxiety Total Sum Score with Interaction

| Model 2 | B | Std Error | t | Sig | 95% CI Lower Bound | 95% CI Upper Bound |
|----------------------------------|----------|------------------|----------|------------|---------------------------|---------------------------|
| Constant | 26.941 | 3.894 | 6.918 | 0.0001 | 19.168 | 34.714 |
| Family Education* | -1.717 | 1.081 | -1.588 | 0.117 | -3.875 | 0.442 |
| Family Race** | -0.954 | 1.029 | -0.927 | 0.357 | -3.008 | 1.100 |
| Patient age in 5 year increments | -0.985 | 0.265 | -3.724 | 0.0001 | -1.513 | -0.457 |
| Family age in 5 year increments | -0.327 | 0.198 | -1.649 | 0.104 | -0.722 | 0.069 |
| Family gender | -8.385 | 4.093 | -2.049 | 0.044 | -16.554 | -.215 |
| Patient age * Family Gender | 0.922 | 0.341 | 2.705 | 0.009 | 0.242 | 1.602 |

* Family education was measured in two groups College or higher = 1, High school or less = 0

** Family race was measured in two groups Caucasian = 1, Other (Asian, Black, Hispanic) = 0

Table 7. Regression on Depression Sum Total Scores with Interaction

| Model 2 | B | Std Error | t | Sig | 95% CI Lower Bound | 95% CI Upper Bound |
|----------------------------------|----------|------------------|----------|------------|---------------------------|---------------------------|
| Constant | 19.823 | 4.324 | 4.584 | 0.0001 | 11.190 | 28.456 |
| Family Education* | -1.681 | 0.960 | -1.751 | 0.085 | -3.598 | 0.236 |
| Family Race** | 1.485 | 1.402 | 1.060 | 0.293 | -1.313 | 4.284 |
| Patient age in 5 year increments | -0.635 | 0.230 | -2.760 | 0.007 | -1.094 | -0.176 |
| Family Coping | -0.039 | 0.032 | -1.196 | 0.236 | -0.103 | 0.026 |
| Family gender | -2.612 | 3.583 | -0.729 | 0.469 | -9.765 | 4.542 |
| Patient age 5 * Family Gender | 0.667 | 0.293 | -2.279 | 0.026 | 0.083 | 1.252 |
| Family race * Family Gender | -4.894 | 1.814 | -2.697 | 0.009 | -8.517 | -1.272 |

* Family education was measured in two groups College or higher = 1, High school or less = 0

** Family race was measured in two groups Caucasian = 1, Other (Asian, Black, Hispanic) = 0

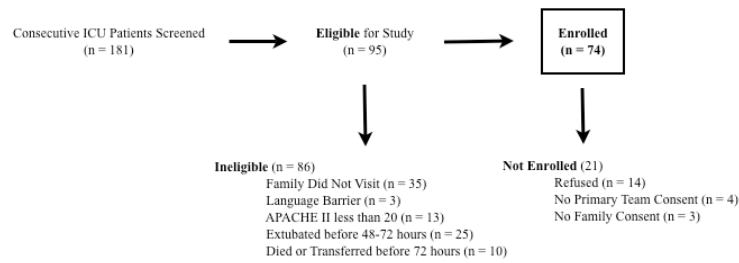


Figure 1. Recruitment of study subjects. We screened patients at 24–48 hours who were mechanically intubated. We recruited family members of patients that were in the ICU for at least 72 hours, were intubated, and had an APACHE II score of 20 or greater.

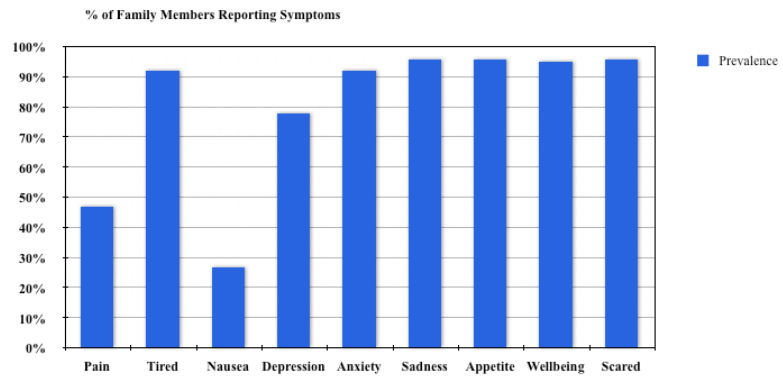


Figure 2. Prevalence of physical and psychological symptoms among family members of high risk of dying ICU patients (n = 74).
 For appetite and well being: it is the worst appetite and worst well being

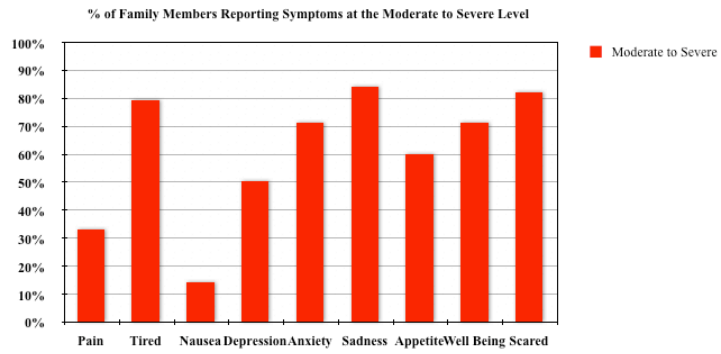


Figure 3. Percent of family members reporting at least one symptom episode rated as moderate to severe (n = 74).
 For appetite and well being: it is the worst appetite and worst well being

CHAPTER 7

Dissertation Summary: Symptom Experiences of Family Members of Intensive Care Unit Patients at High Risk of Dying

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Dissertation Summary: Symptom Experiences of Family Members of High Risk of Dying Intensive Care Unit Patients

The review of the research literature identified gaps in the knowledge of family members' symptom experiences. Some of these included a lack of knowledge on risk factors, such as coping skills and family functioning and their impact on family symptoms, as well as limited information on the broader symptom experiences that go beyond stress, anxiety and depression. It also revealed limited findings on the symptom experiences of family members of patients who were at high risk of dying while in the ICU. Therefore, the data collected prospectively on 74 family members of patients at high risk of dying in the ICU were used to learn more about these families' symptom experiences.

This data set was determined to be a good fit for the proposed research because it contained an appropriate sample, measured many research based predictors of family symptoms, and had a small amount of missing data. A power analysis determined that the sample size was sufficiently large enough to test the overall models. Approval for this study was obtained from the University of California, San Francisco's Committee on Human Research (CHR #: H2280-31295-01).

The results showed that family members of patients at high risk of dying in the ICU were mostly female, spouses of the patient, Caucasian, educated, and had prior experience in the ICU. Overall we found that over half (56.8%) had PTSD symptoms, 79.7% had symptoms of anxiety, and 70.3% had symptoms of depression 3-5 days after the patient's admission to the ICU. Linear regression models demonstrated independent correlates associated with an increase in traumatic stress (younger patient age, younger age of the family member, and female gender of the family member), anxiety (younger patient age and female gender of the family member) and depression (younger patient age, family member race other than Caucasian, and female gender of the family member) in family members.

We also found that family members suffered from a variety of other symptoms such as being tired, scared, and sad. These were often at moderate to severe levels of distress in many of the families surveyed. Surprisingly, we did not find any significant association between coping and family functioning on family symptoms. Most of the families in this study had high levels coping and family functioning. So, even though they had complaints of symptoms, they appeared to be coping and staying together as a family unit. More research is needed on assessing multiple family members at different coping levels to see if these variables have an impact on family symptoms.

This research demonstrated that family members of high risk of dying ICU patients do indeed suffer from a broad range of psychological and physical symptoms. These results have ethical implications when involving family members in end-of-life care conferences. Families with these symptoms may not comprehend information presented to them; or they may try to lessen their symptom experience by making rash decisions in order to reduce the amount of uncertainty they feel.¹⁻³ ICU clinicians will need to be more prudent in how they present information to families by allowing family members more time to comprehend information, especially in end-of-life decision making.

Family members are important to patient care in the ICU especially when clinicians rely on them to be the voice of the patient. However, more needs to be known about what impact this has on family members' symptom status and overall well being. Future research will need to focus on appropriate interventions that can lessen the symptom burden in family members. Investigators should also assess the longitudinal effects of symptoms on family members. Finally, more research will be needed on the risk factors associated with poor long term outcomes in family members such as PTSD and complicated grief.

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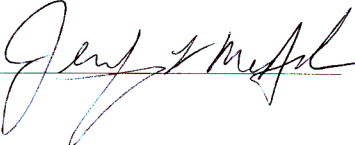
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