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A Comparison of the Effects of a Web-Based Education Program about the ICU Environment and a Standard Education Program on Anxiety, Depression, and Acute Stress Experienced Among Family Members of ICU Patients

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Environment and a Standard Education Program on Anxiety, Depression, and Acute

Stress Experienced Among Family Members of ICU Patients

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Louis in partial fulfillment of the requirements for degree
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Dedication

This dissertation is dedicated to my great-aunt, Phyllis Shirley, who was my first introduction to nursing and nursing education. My heart is heavy that she was unable to see me complete this dissertation as she passed away 11 months before the defense.

This dissertation is also dedicated to my parents, Timothy and Michele Sullivan, and to my in laws, Ron and Doris Lewis. Your support over the years while I pursued my degree despite all of my challenges was appreciated more than I think it was ever acknowledged.

Finally, this dissertation is dedicated to my husband, Dr. Drew Lewis, and my daughter, Carolyn Lewis. Having both members of the household in graduate school at the same time was more than difficult. Drew, I especially appreciate your attentive care to our young daughter and making sure we were all fed over the past several months while I finished my dissertation. Drew, I also thank you for the Ph.D. student sympathy you were able to give when things were challenging with my dissertation.

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Abstract

Family members of ICU patients may experience anxiety, depression, and acute stress disorder symptoms. A need identified by the multi-society task for critical care research was to study the usefulness of interventions to quantify and treat anxiety, depression, and stress symptoms experienced by family members of ICU patients (Deutschman et al., 2012). This task force encouraged investigating using technology to address this need. (Deutschman et al.). The purpose of this prospective, quasi-experimental nonequivalent control group (pretest/posttest) design study was to compare the effect of standard ICU education and a web-based education program about the ICU environment on the level of anxiety, depression, and acute stress disorder symptoms among family members of ICU patients. Participants (n = 127) included 63 enrolled in standard ICU education and 64 in web-based education.

This study found family members of ICU patients experienced anxiety, depression, and acute stress disorder symptoms, reinforcing findings of previous studies. This study was unable to conclude if a web-based education program could reduce anxiety $F(1, 49) = .60$, $p = .444$, partial $\eta^2 = .01$, observed power = .12.; depression $F(1, 49) = 1.39$, $p = .244$, partial $\eta^2 = .03$, observed power = .21; or acute stress disorder symptoms ASDS $F(1, 48) = .65$, $p = .425$, partial $\eta^2 = .01$, observed power = .12 IES-R $F(1, 48) = .00$, $p = .988$, partial $\eta^2 = .00$, observed power = .05 experienced by family members of ICU patients. This study reinforced that family members with lower education levels reported statistically significantly increased levels of stress compared to family members of ICU patients with higher education

levels Λ = .84, F (12, 317.78) = 1.86, p = .039, partial η^2 = .06, observed power = .84.

Family members of ICU patients who had a prior experience within the past two

years were found more likely to report anxiety, depression, and acute stress

symptoms than family members who had not had an ICU experience within the past

two years Λ = .92, F [4,122] = 2.70, p = .034, partial η^2 = .08, observed power = .74.

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Chapter I

Introduction

In this chapter the background, problem, and purpose regarding usage of a web-based education program about the ICU environment by family members of intensive care unit patients are discussed. The research questions, significance of the problem, and theoretical definitions are presented.

Background

Having a family member admitted to an intensive care unit (ICU) is a traumatic experience. Most ICU admissions are unplanned and the family member is typically extremely ill. The focus of the health care team of nurses, doctors, and respiratory therapists at admission is stabilizing the patient. During this initial admission phase, worried families are left sitting alone in a waiting room; often they know little about what is happening or how to prepare themselves for the initial visit to see their family member in the ICU.

There is often a need for ICU patients to have life supporting measures. When life-supporting measures are used, the patient may undergo a dramatic alteration in their physical appearance. Family members of ICU patients are faced with life supporting equipment they know little about and changes in their family member's appearance that can be frightening. Multiple intravenous (IV) catheters, IV bags, IV pumps, ventilator, endotracheal tube, central venous lines (CVLs), dialysis treatment, bed side monitor, EKG pads, blood pressure device, pulse oximeter, pressure bags, blood warmer, liquid tube feeding, feeding tube, nasogastric (NG) tube, restraints, suction canister, urinary (Foley) catheter, and

chest tube can be upsetting and overwhelming for family members when they are able to visit their loved one (Taylor & Ahrens, 1999).

Thus, for families of ICU patients, this unexpected admission to an ICU may lead to stress, anxiety, uncertainty, and depression occuring in a very short time frame. Research has reported that 42% to 73% of family members of ICU patients experience anxiety and 16% to 56% experience depression during a family member's admission to an ICU (Anderson, Arnold, Angus, & Bryce, 2008; Bailey, Sabbagh, Losielle, Boileau, & McVey, 2010; Chartier & Coutu-Wakulczyk, 1989; Fumis & Deheinzelin, 2009; Gries et al., 2010; Jones et al., 2004; Lautrette et al., 2007; Maruiti, Galdeano, & Farah, 2008; Pochard et al., 2001; Pochard et al., 2005). This is in sharp contrast to the lower incidence of anxiety in the general population (18.1%) and mood disorders, including depression (9.5%) (Kessler, Chiu, Demler, Merikangas, & Walters, 2005).

Research has suggested that family members of ICU patients may experience not only anxiety and depression, but also acute stress disorder, with some studies suggesting that family members may develop posttraumatic stress disorder (Anderson et al., 2008; Auerbach et al., 2005; Azoulay et al., 2002; Gries et al., 2010; Jones et al., 2004; Lautrette et al., 2007; Paparrigopoulos et al., 2006, Sundararajan, Martin, Rajagopala, Chapman, 2014). Several of the major research studies establishing psychological distress in family members of ICU patients were done in countries outside of the United States (Bailey et al., 2010 ; Chartier & Coutu-Wakulczyk, 1989 ; Fumis & Deheinzelin, 2009; Jones et al., 2004; Lautrette et al., 2007; Maruiti et al., 2008; Paparrigopoulos et al., 2006;Pochard et al., 2001; Pochard

et al., 2005; Sundararajan et al., 2014). This study will contribute to the body of knowledge about family members of ICU patients in the United States.

Problem

When the needs of family members were investigated, family members of ICU patients have also consistently reported a lack of information and knowledge about the ICU environment and ICU equipment (Al-Mutair, Plummer, Clerehan, & O'Brien, 2013; Bijttebier, Vanoost, Delva, Ferdinande, & Frans, 2001; Chartier & Coutu-Wakulczyk, 1989; Kinrade, Jackson, & Tomany, 2009; Lee & Lau, 2003; Rukholm, Bailey, Coutu-Wakulczyk, & Bailey, 1991). Thus, family members of ICU patients are experiencing symptoms of anxiety, depression, and acute stress disorder and are not provided with adequate information about the ICU environment that may reduce this stress.

Advances in neurobiology have scientifically shown that humans under stress have a reduced recall capacity and recognition performance (Schwabe & Wolf, 2010). Thus, humans experiencing a stressful situation are not as capable of remembering information presented to them one time.

Education in ICUs typically consists of verbal explanations and pamphlets. Some hospitals are also using a web-based education program with information about the ICU. However, there has been a paucity of research conducted on the effects of a web-based education program with information about the ICU environment for family members of ICU patients particularly in relation to their experience of anxiety, depression, and acute stress disorder. There have been several studies showing computer based education programs have been successful

for patient and family education in other medical fields including burn care, surgery care, and asthma care (Beamond, Beischer, Brodsky, & Leslie; 2009; Keulers, Welters, Spauwen, & Houpt, 2007; Krishana, Balas, Francisco, & Konig, 2006; Lo et al., 2011; Lo, Hayter, Hsu, Lin, & Lin, 2010).

Kleinpell, Silva, Tully & Hancock (2005) conducted the only study on the use of a web-based education program on ICU family member's satisfaction with care. Surveys given to ICU family members and ICU nurses prior to implementation of the web-based education program found nurses were spending a large proportion of time re-educating family members about ICU equipment (KIeinpell et al.). ICU family members had high satisfaction scores with information and communication on the post implementation surveys; however, no actual numbers of satisfaction were reported with this study (Kleinpell et al.).

Problem Statement

Clearly research has established that family members of ICU patients experience anxiety, depression, and acute stress disorder. The multisociety task force for critical care research identified the need to investigate the usefulness of interventions to quantify and treat common disturbing family symptoms such as depression, anxiety, and stress disorders (Deutschman, Ahrens, Cairns, Sessler, & Parsons, 2012). This task force also encouraged the investigation of using technology to address these issues (Deutschman et al.). The problem is that ICU nurses have little time to educate family members immersed in a frightening environment where their loved one is connected to a variety of life supporting measures. Therefore, this study was needed to determine if an easy to use web-

based education program with information about the ICU environment (pictures of an ICU room with an ICU patient and the associated life support equipment that family members can click on that explains the equipment) can reduce anxiety, depression, and acute stress disorder symptoms among family members of ICU patients.

Significance

Little is known about the effectiveness of computer education programs for family members of patients in the ICU. Family members of ICU patients experience decreased mental and physical function because of anxiety associated with having a family member admitted to the ICU (Van Horn & Tesh, 2000). This study will contribute to the body of knowledge about the effectiveness of an easy to use web-based education program with information about the ICU environment to educate family members of ICU patients about the ICU environment to decrease family member's anxiety, depression, and acute stress symptoms. This study will also address a key research priority established by the multisociety task force for critical care research (Deutschman et al., 2012).

Purpose

The purpose of this study was to examine the effect of a web-based education program about the ICU environment on anxiety, depression, and acute stress disorder symptoms among family members of ICU patients in a hospital in the Southeastern United States. A comparison was made between family members using the web-based education program about the ICU environment and family members using the standard education program provided by physicians and nurses.

Selected demographic variables, previous experiences in the ICU, and computer usage were used to characterize the sample. These variables include the family member's age, gender, relation to the patient, highest level of education, average computer usage, previous ICU and hospital experiences, highest level of education, if the admission was planned, and perception of the education provided by nurses and physicians

Research Questions

This study was designed to answer the following questions:

1. What are the levels of anxiety, depression, and acute stress disorder symptoms among family members of ICU patients in the Southeastern United States?

2. Is there a significant difference in the levels of anxiety, depression, and acute stress disorder symptoms among family members of ICU patients who use standard ICU education with a web-based education program about the ICU environment versus family members of ICU patients who receive only the standard ICU education by physicians and nurses?

3. Is there a significant difference between age, gender, educational level, relationship to patient, previous ICU experience, or planned versus unplanned ICU admission and anxiety, depression, and acute stress disorder symptoms among family members of ICU patients?

Associated Assumptions

The associated assumptions for this investigation were:

1. Explanation of the ICU environment to family members of ICU patients should be standard of care.

2. Individuals in this study will have varying levels of hospital experience and education.

3. Individuals in this study will have varying levels of computer usage experience.

Definition of Terms

The following terms for this study are defined:

Acute stress disorder. A psychiatric disorder that occurs 48 hours to 30 days after a traumatic event (Bryant & Harvey, 2000). The person experiences psychological numbness and detachment, reduced environmental awareness, and disassociation from reality or self (Bryant & Harvey).

Posttraumatic stress disorder. A psychiatric disorder that occurs 30 days after a traumatic event (Bryant & Harvey, 2000). The person re-experiences the traumatic event, avoidance of stimuli that are associated with the traumatic event, persistent increased arousal, and must have social or occupational impairment (Bryant & Harvey).

Anxiety. An emotional state of uneasiness that is in response to a perceived or real threat (Morton & Fontaine, 2013).

Depression. Persistent sad mood with a loss of interest or pleasure in almost all activities, and feelings of worthlessness or guilt (National Institute of Mental Health, 2011).

Family member. A self-identified relative of a patient admitted to an intensive care unit. Anticipated relations include, but are not limited to: spouse, life partner, parent, step-parent, sibling, child, step-child, grandchild, grandparent, step-grandchild, or step-grandparent.

Intensive care unit. A specialized care area in a hospital with equipment, nursing, and medical personnel, necessary to deliver close monitoring and frequent interventions to an intensive care patient.

Web-based ICU education program. An educational program on the internet **ICU-USA.com** (Taylor & Ahrens, 1999); the user interacts with the website in order to receive ICU education.

Chapter II

Review of Literature

This chapter presents a review of related literature and the conceptual model based on the review of the literature. The review of the literature is discussed and summarized as it relates potential sources of stress, ICU family member stress response, traditional ICU education, and web-based education program about the ICU environment for family members of ICU. Adult learning theory will also be presented.

Conceptual Model

The conceptual model, Stress Response of Family Members of ICU Patients (SRFMICUP), was derived from the Potential Sources of Stress of Parents in the Pediatric Intensive Care Unit model developed by Miles, Carter, Hennessey, Eberly, and Riddle (1989) and was broadened as a result of the review of the literature (see figure 1). Miles et al. determined that parental stress response for parents of children in the pediatric ICU arose from three potential sources: a) personal/ family factors, b) situational factors, and c) environmental stimuli.   Miles et al. suggested that personal/ family factors that could influence the parental stress response included variables such as age, education level, parental role, and personality factors such as the parent's tendency of anxiety; situational factors variables include amount of parental preparation for the ICU experience, whether the admission was planned or unplanned, and the perceived severity of the child's ailment; and

environmental factors were defined vaguely as psychosocial and physical facets of the ICU environment.

Figure 1. Stress Response of Family Members of ICU Patients
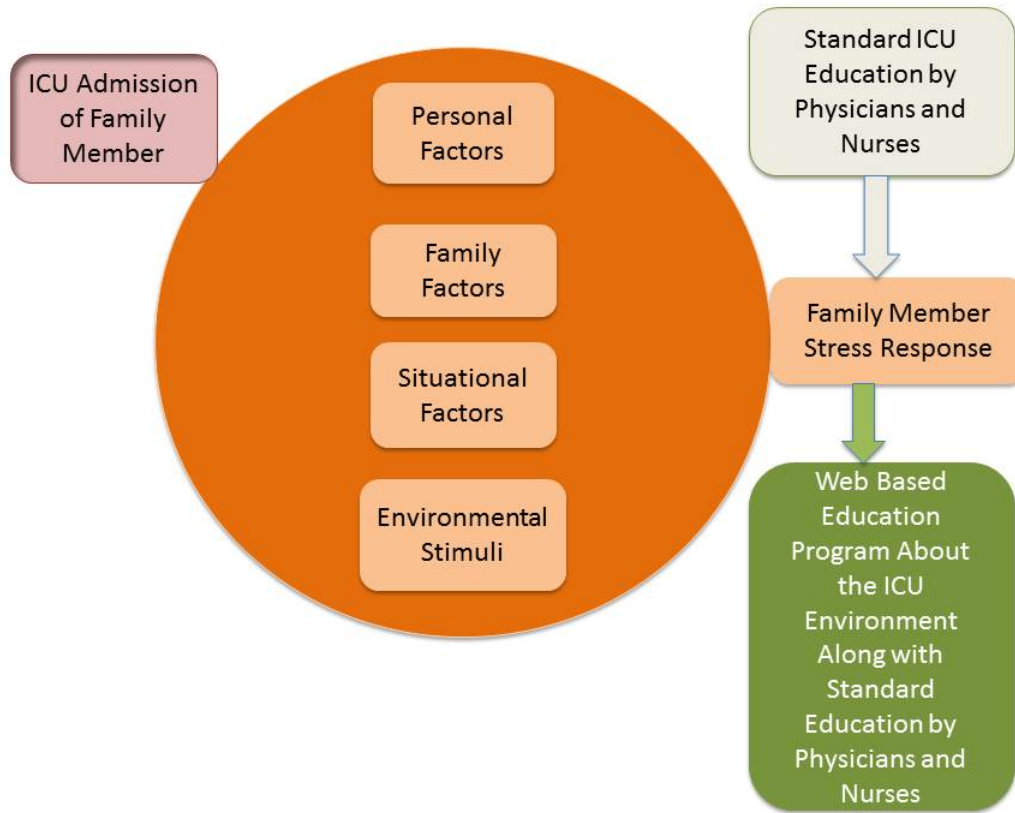
The SRFMICUP model includes the following concepts: ICU admission of a family member, personal factors, family factors, situational factors, environmental stimuli, family member stress response, standard ICU education programs by ICU physicians and nurses, and web-based education program about the ICU environment. A discussion of each of these in the concepts and how they relate to each other in the SRFMICUP follow.

ICU Admission of Family Member

The SRFMICUP begins with the admission of a family member to the ICU. This admission may be planned or unplanned. The ICU admission of a family member brings life to a momentary halt for the relatives of the ICU patient. Thus, this concept is in a red box. According to the Society of Critical Care Medicine (2012), ICU patients are a heterogeneous group of patients who share a need for a higher level of acute care than most hospitalized patients and are among an estimated five million patients admitted to ICUs in the U.S. This ICU admission of a family member initiates a complex stress reaction. Multiple studies have documented a significant amount of stress experienced by family members when a relative is admitted to an ICU (Azoulay et al., 2005; Chui & Chan, 2007; Pochard et al., 2001; Pochard, et al., 2005; Sundararajan et al., 2014). For this study, ICU admission of a family member refers to a person having a relative require care provided exclusively in an ICU. Relative is a "relation, member of the family, kinsman, kinswoman, connection" (The Oxford American Thesaurus of Current English, 1999).

The SRFMICUP developed for this study differs from the Miles et al. (1989) in that the SRFMICUP separates personal/family factors into their own categories. This was done to be able to differentiate the more intricate family interactions that could influence an adult family member's stress response. Thus, the factors that impact the family member of the ICU patient include personal factors, family factors, situational factors, and environmental stimuli. The ICU admission of a family member initiates a reaction among these personal factors, family factors, situational factors, and environmental stimuli. Thus, these concepts are within a yellow-orange circle representing the yielding process the relative goes through. Schwabe and Wolf

(2010) investigated learning under stress exposing participants to a stressful or

non-stressful environment and found participants in the stressful environment

experienced a reduction in memory recall and recognition. These findings were

suggestive of impaired learning abilities of humans while under stress (Schwabe &

Wolf). Thus, the yielding process in the SRFMICUP refers to a complex interaction of

numerous variables the family member experiences that need to resolve in order for

the family member to comprehend education.

Personal Factors

Personal factors can increase or decrease the stress reaction. Two studies

found that personal factors such as gender and education level significantly

increased the stress experienced by the family members, (Chui et al., 2007; Pochard

et al., 2005). Miles et al. (1989) listed personal variables as parental role, parental

age, education level, trait anxiety (an individual's propensity for anxiety), other life

stresses, and other concerns.

Family Factors

The SRFMICUP expands the family factors from the parental role described

by Miles et al. (1989) to an adult family member with more complex roles (spouse,

life partner, parent, step-parent, sibling, child, step-child, grandchild, grandparent,

step-grandchild, or step-grandparent), yet retains Miles and Carter (1983) family

factors of concurrent life events and family coping mechanism. King and Gregor

(1985) described several family factors that contribute to an individual's stress

response to the ICU admission of a family member. These factors include loss of a

healthy member, fear of permanent disability or death of the ill family member,

concern that the injury or illness will result in chronic pain for the patient, family member obligation to continue usual roles such as working while the family member is critically ill, being away from home, and needing to stay in unfamiliar places in order to be with loved one in the ICU (King & Gregor, 1985).

Situational Factors

Situational factors can increase or decrease the stress reaction. Situational factors for an adult ICU patient are similar yet different from the situational factors for the pediatric ICU patient. Miles et al. (1989) found that situational factors such as child's age, health prior to admission, severity of illness, ICU visits, planned or unplanned admission, and preparation for the admission were significant influences on parental stress. All of these situational factors in the pediatric ICU also apply to the adult ICU. The adult ICU patient has additional situational factors not present with a pediatric ICU patient, unique to the adult ICU patient that includes patients' employment, role changes within the family, and financial concerns (King & Gregor, 1985).

Environmental factors

Miles et al. (1989) described environmental factors vaguely as psychosocial and physical facets of the ICU environment. Environmental stimuli are the same for both the pediatric and adult ICU experiences. ICU environmental stimuli can increase or decrease the stress reaction. Sinuff, Giacomini, Shaw, Swinton, and Cook (2009) conducted a qualitative study in which a theme emerged that family members were frightened by alteration in physical appearance of the patient. Anxiety in ICU family members was associated with mechanical ventilation use for

the ICU patient (Fumis & Deheinzelin, 2009). Environmental factors can also include ICU rules and regulations, procedures, smells, sounds, equipment, and unfamiliar caregivers (King & Gregor, 1985). King and Gregor also noted that family members experienced increased stress when the ICU patient was unconscious and/or on the ventilator.

Family Member Stress Response

The model developed by Miles et al. (1989) limits the stress response only to parents of pediatric ICU patients. The SRFMICUP was broadened from parental stress response to family member stress response. Based on the review of the literature, the ICU family member stress response includes anxiety, depression and acute stress disorder symptoms. The family member stress response is in a yellow – orange box to represent that the stress response; the individual may be cautious as if they were approaching a yellow light in which the family member will either yield and proceed forward or come to a complete stop depending upon the magnitude of the stress response.

Anxiety. After reviewing definitions and uses of anxiety, analysis of the concept of anxiety resulted in a synthesis of the defining attributes of anxiety. Reviews of anxiety entries yielded three common themes throughout (Barlow, 2000; Bay & Algase, 1999; Whitley, 1992; Whitley, 1994). The first theme is a presence of a subjective experience usually consisting of an overwhelming, vague, anticipatory apprehension (Barlow; Bay & Algase; Whitley, 1992; Whitley, 1994). The experience of physiological symptoms is also present (Barlow; Bay & Algase;

Whitley, 1992; Whitley, 1994).   Finally, the source of anxiety may or may not be identifiable (Barlow; Bay & Algase; Whitley, 1992; Whitley, 1994).

Research has shown that among family members of ICU patients about 35% to 73% of relatives experience anxiety during a family member's admission to an ICU (Anderson et al., 2008; Azoulay et al., 2005; Bailey, et al., 2010; Fumis & Deheinzelin, 2009; Gries et al., 2010; Jones et al., 2004; Lautrette et al., 2007; Maruiti, et al., 2008; Pochard et al., 2001; Pochard et al., 2005). The lifetime prevalence of anxiety in the general population is 28.8% (Kessler, Chiu, Demler, & Walters, 2005). Most of the research investigating the anxiety levels in family members of ICU patients has been descriptive or qualitative in nature (Anderson et al., 2008; Auerbach et al., 2005; Azoulay et al., 2005; Bailey et al., 2010; Chartier & Coutu-Wakulczyk, 1989; Delva, Vanoost, Bijttebier, Lauwers, & Wilmer, 2002; Fumis & Deheinzelin, 2009; Maruiti et al., 2008; Paparrigopoulos et al., 2006; Pochard et al., 2001; Pochard et al., 2005; Siegl, Hayes, Vanderwerker, Loseth, & Prigerson, 2008; Young et al., 2005).

Only a few studies about anxiety in family members of ICU patients have been interventional in nature (Halm, 1990; Johnson & Frank, 1995; Jones et al., 2004; Lautrette et al., 2007). Three of these interventional studies with a more active in nature intervention demonstrated statistically significant reductions in anxiety for the intervention group when compared to the control group (Halm, 1990; Johnson & Frank, 1995; Lautrette et al., 2007). These interventions consisted of support groups, twice daily phone calls using a checklist to update family members on patient's status, and a bereavement brochure with a proactive

bereavement conference with the ICU physicians respectively (Halm, 1990; Johnson & Frank, 1995; Lautrette et al.2007). However, it should be noted that use of the bereavement brochure was not measured (Lautrette et al., 2007). Thus, it is difficult to conclude that the bereavement brochure contributed to the statistically significant reduction in anxiety for the intervention group (Lautrette et al., 2007). The other intervention study consisted of a six week self-help manual and there was no statistically significant difference between the control and intervention groups (Jones et al., 2004).

An interesting finding in one study comparing ICU patients and relatives to elective cardiac surgery patients and relatives found that ICU patient relatives reported a statistically significant higher level of anxiety than the actual ICU patient (Young et al., 2005). Women and spouses were more likely to experience anxiety (Chartier & Coutu-Wakulczyk, 1989; Fumis & Deheinzelin, 2009; Paparrigopoulos et al., 2006; Pochard et al., 2001). Anxiety in ICU family members was associated with mechanical ventilation use for the ICU patient (Fumis & Deheinzelin, 2009). In a descriptive study, no significant correlation was found between the perception of informational support or satisfaction with care and anxiety levels (Bailey et al., 2010).

Depression. Research has also established that about 16% to 56% of family members of ICU patients experience depression during a relative's admission to an ICU (Anderson et al., 2008; Azoulay et al., 2005; Fumis & Deheinzelin, 2009; Gries et al., 2010; Jones et al., 2004; Lautrette et al., 2007; Maruiti et al., 2008; Paparrigopoulos et al., 2006; Pochard et al., 2001; Pochard et al., 2005; Siegl et al.,

2008; Young et al., 2005). The lifetime prevalence of mood disorders in the U.S. population, which include depression, is 20.8% (Kessler et al., 2005). Considering several studies investigate the prevalence of anxiety and depression in family members of ICU patients at the same time, it is not surprising to find that the majority of studies examing depression in family members of ICU patients are descriptive in nature (Anderson et al. 2008; Auerbach et al., 2005; Azoulay et al. 2005; Delva et al., 2002; Fumis & Deheinzelin, 2009; Gries et al., 2010; Maruiti et al. 2008; Paparrigopoulos et al., 2006; Pochard et al., 2001; Pochard et al., 2005; Siegl et al. 2008; Young et al., 2005).

Few studies investigating depression in family members of ICU patients have been intervention studies (Jones et al., 2004; Lautrette et al., 2007). Jones et al. (2004) used a six-week self-help manual and was not able to find any statistically significant difference between the group who received a self-help manual and the group who did not receive the self-help manual. Lautrette et al. (2007) used a bereavement brochure and proactive bereavement family meetings and found a statistically significant difference in depression symptom rates in the group receiving the bereavement brochure and proactive bereavement family meetings of 29% compared to the group who did not receive the bereavement brochure and proactive bereavement family meetings at 56% (Lautrette et al., 2007). However, the study did not ask the participants how many used the bereavement brochure. Thus, it cannot be concluded that it is responsible for the decrease in depressive symptoms among the group who received both the bereavement brochure and the family meeting.

A greater number of depression symptoms in family members of ICU patients has also been correlated with female than male gender (Fumis & Deheinzelin, 2009; Gries et al., 2010; Pochard et al., 2001). Anxiety symptoms in family members of ICU patients were also found to be predictive of depressive symptoms (Paparrigopoulos et al., 2006). Lower education levels and lower socioeconomic status also were predictive of depressive symptoms (Gries et al., 2010; Paparrigopoulos et al., 2006).

Acute stress disorder symptoms. Acute stress disorder symptoms in family members of ICU patients specifically refers to the time period that is 48 hours to 30 days after a traumatic experience (American Psychiatric Association [APA], 2000; Bryant & Harvey, 2000). The period between the occurrence of the trauma and 48 hours afterwards is called the acute stress reaction and is a transient response (Bryant & Harvey, 2000).   Acute stress disorder is believed to be an antecedent to the development of post-traumatic stress disorder (PTSD) (APA, 2000; Bryant & Harvey, 2000).

This study focuses on acute stress disorder symptoms. However, if acute stress disorder symptoms continue beyond a time period of 30 days after trauma, it is referred to as PTSD (American Psychiatric Association [APA], 2000; Bryant & Harvey, 2000). Research investigating posttraumatic stress symptoms in family members has shown symptom rates of 14% to 69% (Anderson et al., 2008; Azoulay et al., 2005; Gries et al., 2010; Jones et al., 2004; Lautrette et al., 2007; Pillai et al., 2006; Sundararajan, et al., 2014). Other research investigating stress, but not reporting a percentage of the participants experiencing stress, found high levels of

stress in family members of ICU patients when compared to the general population (Auerbach et al., 2005; Chui & Chan, 2007; Paparrigopoulos et al., 2006).

Higher levels of stress and posttraumatic stress symptoms were associated with female gender, lower education levels, unexpected ICU admission, and sharing in decision-making (Azoulay et al., 2005; Chui & Chan, 2007; Gries et al., 2010). Paparrigopoulos et al. (2006) found state anxiety one week after the relative's admission to the ICU was a predictor of developing posttraumatic stress symptoms three days prior to the anticipated discharge of the patient. Sundararajan et al. (2014) also found high anxiety scores as predictive of PTSD symptoms. However, Anderson et al. (2008) did not find any association between anxiety and depression symptoms experienced by family members of ICU patients during the patient's ICU stay and the later development of PTSD. Auerbach et al. (2005) found that upon a relative's admission to an ICU, family members had on average an ASD score of 44.65; an ASD score of 44.93 was criteria for being admitted to the PTSD unit of a psychiatric hospital.

Important to the SRFMICUP model are standard ICU education programs by ICU physicians and nurses and web-based education program about the ICU environment. These two educational programs are presented:

ICU Education Programs by ICU Physicians and Nurses

The SRFMICUP model incudes a grey box and arrow representing the standard ICU education provided by physicians and nurses. Although the importance of patient education is well known, there have been few studies to

determine if these education programs can reduce the stress response in family members of ICU patients.

The standard ICU education received by family members in the ICU consists of verbal explanations by ICU physicians, specialty physicians (such as pulmonologists, cardiologists, nephrologists), ICU staff nurses, and palliative care nurses. Family members are also occasionally given pre-printed handouts prepared by the hospital primarily on infectious diseases, isolation precautions, and resuscitation status. Handouts are also given to family members if the patient is restrained that explain the need for restraints.

In a typical ICU setting, family members are provided with a variety of educational pamphlets and materials. Additionally, verbal explanations about the patient and the ICU environment are provided by physicians, nurses, and other health care providers interact with the families about the patient and the ICU environment. The education materials in this investigation are presented in Chapter 3. This traditional form of education for family members of ICU patients follows a pedagogical model. In a pedagogical framework of education, the teacher of the material has full responsibility of deciding what needs to be learned, how and when it were learned, and evaluation if it has been learned (Knowles, Holton, & Swanson, 1998).

There have been a few interventional studies done on various ICU education programs. Chavez & Faber (1987) studied the effects of an educational orientation program on self-repots of stress and the physiologic responses of blood pressure and heart rate in family members of ICU patients. The group receiving an

educational orientation program had a statistically lower heart rate after the visit than the group who did not receive the educational orientation program (Chavez & Faber). Chein, Chiu, Lam, & Ip (2006) studied the effects of an individualized needs-based education program on anxiety and satisfaction of family members of ICU patients. The group receiving an individualized needs based education program had a significant reduction of anxiety and increase in satisfaction when compared to the group that did not receive an individualized education program (Chein et al.). Lautrette et al. (2007) investigated the educational effects of a proactive end of life conference and a bereavement brochure on anxiety, depression, and posttraumatic stress symptoms. The group who received a proactive end of life conference and a bereavement brochure on anxiety, depression, and posttraumatic stress symptoms had significantly lower anxiety, depression, and posttraumatic stress symptoms compared to the group who did not receive any of these interventions (Lautrette et al.).

Web-based Education Program about the ICU Environment

The green box and arrow represents the web-based education program about the ICU environment used in this study. The review of literature found one research article conducted on the effects of a web-based education program about the ICU environment for family members of ICU patients. Rolls, Smith, Zhang, Wise & McGloin (2012) stated family members of ICU patients should use a computer kiosk in the waiting room to access information. Rolls et al. failed to provide information about what information was contained on the computer kiosk. Rolls et al. reported that family members who used the kiosk found the information helpful.

In a related web-based education program, Roy et al. (2012) found military family members who used a web-based PTSD education program were able to increase their understanding of PTSD and facilitated behavioral changes in military family members.

Computer education programs are closely related to web-based education programs. There have been several studies showing computer based education programs have been successful for patient and family education in other medical fields including asthma care (Krishana et al., 2006), burn care (Lo et al., 2010), PTSD (Roy et al., 2012), stoma care (Lo et al., 2011), and surgery care (Beamond et al., 2009; Keulers et al., 2007). Krishana et al. (2006) found that children who used a computer education program about asthma had a statistically significant reduction in emergency department visits, school days missed, days of asthma symptoms, and days of activity limitation. Lo et al. (2011) found a statistically significant improvement in attitudes, behaviors, and self-care knowledge with stoma patients who used a computer based education program compared to stoma patients who did not use the computer based education program. Keulers et al. (2007) found that knowledge was significantly higher in the group of carpal tunnel surgery patients that received their education about carpal tunnel surgery from the computer based education program compared to the group that received their carpal tunnel education from a physician; satisfaction was the same for both groups.

Adsit (1996) defined multimedia education: using computers with audio, graphic animation, still or motion pictures, and text as part of the patient education process. Thus, multimedia education is essentially the same as computer education

programs previously discussed. Lo et al. (2010) found the participants who used a multimedia education program on a computer had a statistically significant improvement in burn knowledge, increased pressure garment compliance, and reduced anxiety compared to participants who did not use the multimedia education program on a computer. Beamond et al. (2009) found first metatarsophalangeal joint arthrodesis surgical patients were able to increase their knowledge by 25% after using a multimedia education program about the surgery. Also, 90% of the patients from the study conducted by Beamond et al. reported that their questions were answered as well or better with using the computer education program than the verbal explanation provided by the surgeons.

Important to this investigation are findings from two studies that reported lack of computer skills did not impair use or retention of knowledge from the computer based education programs (Beamond et al., 2009; Krishana et al., 2006). Also important to this investigation is the recommendation by the multisociety task force for critical care research (Deutschman et al., 2012) that the use of technology should be investigated to reduce stress, anxiety and depression in family members of ICU patients.

Adult Learning Theory

Adult learning theory is import in this investigation because the intervention uses of education programs for adult family members of adult ICU patients. Thus, adult learning theory merits consideration in construction of the educational interventions.

The andragogical model developed by Knowles is a standard used in adult learning. The andragogical model of adult learning is based on six assumptions (Knowles et al., 1998): first, the adult learner has a need to know; second, the adult learner has a developed self-concept; third, the adult learner has experiences that were drawn on as part of the learning process; fourth, the adult learner experiences a readiness to learn; fifth, the adult learner has a life centered approach to learning; and sixth, the adult learner has motivation to learn, with internal motivation being the most powerful motivator.

Despite the extensive consensus in the literature that family members need ICU information and therefore, education, there is a paucity of research using interventions with an explicit foundation grounded in adult education theories. Mitchell and Courtney (2005) used an educational intervention based on Knowles' Theory of Adult Learning, a brochure for family members of ICU patients preparing to be transferred out of the ICU to a regular floor setting. Mitchell and Courtney found that although the brochure was based upon the six principles of adult learning stated by Knowles, not all six principles were necessarily present for family members of ICU patients when the family members required education.

In this investigation, Knowles' adult learning theory is important for understanding the usefulness of the two proposed education programs and why a web-based education program about the ICU environment may be more suited to adult learners than the traditional verbal and pamphlet education program provided by nurses and physicians. Knowles et al. (1998) first assumption posits that the adult learner has a need to know. In this investigation, family members of a

patient admitted to the ICU have a need to know information about the ICU. This is

illustrated by numerous studies investigating the needs of family members of ICU

patients. Many of the studies reviewed reported that one of the greatest needs of

family members of ICU patients was the need for information (Auerbach et al., 2005;

Bijttebier et al., 2001; Browning & Warren, 2006; Chartier & Coutu-Wakulczyk,

1989; Chein et al., 2006; Davidson et al., 2010; Delva et al., 2002; Jamerson et al.,

1996; Kinrade et al., 2009; Lee & Lau, 2003;; Rukholm et al., 1991; Verhaeghe et al.,

2007). Some of the initial studies done on ICU family member needs found the

greatest concerns of family members of ICU patients were about the physical

suffering of the patient, the patient's level of consciousness, and the sight of the

apparatus surrounding the patient (Chartier & Coutu-Wakulczyk, 1989; Rukholm et

al., 1991).

Johansson, Fridlund, & Hildingh (2005) found ICU family members were

empowered by trusting their own ability when faced with confronting a situation

with their family member in the ICU. The second principle of adult learning that the

learner has a developed self-concept (Knowles et al., 1998) is not as visibly present

in the literature as other adult learning principles. The lack of a more developed

application of the self-concept principle for family members of ICU patients is

reflective of the findings by Mitchell and Courtney (2005) that not all six principles

of adult learning were present for education needs of family members of ICU

patients.

Family members' prior experiences with ICUs relate to the third principle of

adult learning theory, the role of the learner's experiences (Knowles et al., 1998). In

this investigation, family members of an ICU patient were asked about their previous experiences with ICUs. Jamerson et al. (1996) recommended that nurses assess the family members' prior experiences with ICUs as part of the education process for the family members. Sinuff et al. (2009) found that over the course of an ICU stay, family member's experiences with the ICU changed. Interestingly, Sinuff et al. found that despite two-thirds of the family members in their study having previous experiences with mechanical ventilators, the ventilator was not perceived to be associated with life support. Thus, additional education was specifically needed to correct this misconception that previous experience had influenced the understanding for these family members.

Jamerson et al. (1996) reported results that embodied four of the six principles of adult learning. Jamerson et al. found that family members of ICU patients have: a need for information and education about the patient's condition and environment, the first principle of adult learning; previous ICU experiences that can be drawn upon for learning, the third principle of adult learning; and a motivation to learn about what is occurring with the patient when they are ready to learn more information and details about what is occurring with their loved one, embodying the fourth and sixth principles of adult learning.

Using a web-based education program about the ICU environment is consistent with adult learning principles established by Knowles et al. (1998) because web-based materials allow the family member of an ICU patient to choose what they wish to learn about the ICU environment, when learning takes place, how much information is received, and in what context the family member draws on

previous knowledge for the learning experience. It is important to note that family

members of ICU patients may not adhere to all six adult learning principles (Mitchell

& Courtney, 2005).

Chapter III

Methodology

In this chapter the research design and questions are presented. The power analysis, sample and setting, operational definitions, instrumentation, human subject's protection, data collection, and analysis are described.

The purpose of this study was to compare the effect of the standard ICU education and an easy to use web-based education program about the ICU environment with only the standard ICU education provided by physicians and nurses on the levels of anxiety, depression, and acute stress disorder symptoms among family members of ICU patients.

Research Design

This study was a prospective, quasi-experimental nonequivalent control group design with pretest and posttest. This study compared the effects of the standard ICU education and web-based education program with information about the ICU environment with only the standard ICU education provided by physicians and nurses and the level of anxiety, depression, and acute stress disorder symptoms among family members of ICU patients. Selected demographic variables (age, gender, educational level, relationship to patient), previous experiences in the ICU, planned versus unplanned admission, and computer usage were used to characterize the sample.

Research Questions

This study was designed to answer the following research questions:

1. What are the levels of anxiety, depression, and acute stress disorder symptoms among family members of ICU patients in the Southeastern United States?

2. Is there a significant difference in the levels of anxiety, depression, and acute stress disorder symptoms among family members of ICU patients who use standard ICU education with a web-based education program about the ICU environment versus family members of ICU patients who receive only the standard ICU education by physicians and nurses?

3. Is there a significant difference between age, gender, educational level, relationship to patient, previous ICU experience, or planned versus unplanned ICU admission and anxiety, depression, and acute stress disorder symptoms among family members of ICU patients?

Power Analysis

The independent variable for this study was an ICU web-based education program. The dependent variables are anxiety, depression, and acute stress disorder symptoms. Anxiety and depression symptoms were measured by the Hospital Anxiety and Depression Scale. Acute stress disorder symptoms were measured by the Acute Stress Disorder Scale and the Impact of Events Scale - Revised.

The standard alpha level is .05 and standard power level for nursing research is .80 (Polit & Beck, 2008). With a power level of .80, there is a 20% chance of accepting a false null hypothesis (Polit & Beck). An estimated effect size of .50 for a medium effect is used for this study because of a planned use of the t-test.

According to Polit & Beck, it is uncommon for nursing research studies to expect

effect sizes greater than .50. (Polit & Beck). Polit and Beck provided tables with an

approximate sample size necessary to achieve the selected level of power. To have

an estimated effect size of .50 and a power of .80, 63 family members of ICU patients

who use standard ICU education along with a web-based education program about

the ICU environment and 63 family members of ICU patients who receive only the

standard ICU education by physicians and nurses for a total of 126 participants

were needed.

Sample and Setting

Family members of ICU patients were recruited from waiting areas in four

ICUs in a medium sized community medical center in a mid-sized Southeastern

United States urban area. The medical, surgical, and cardiac ICUS were three

separate ICUs consisting of 12 beds per unit for a total of 36 medical, surgical, and

cardiac ICU patients located on three separate floors stacked upon each other. The

fourth ICU was the Neurological ICU with 9 beds located in a separate area of the

hospital. Thus, there were a total of 45 ICU beds. The surgical and neurological ICUs

were on the same floor of the hospital, but in different areas. Patients in the ICUs

were ethnically diverse and from the surrounding metropolitan and rural areas. The

investigator coordinated the recruitment of the family members to participate in the

research with the nurse managers, the assistant nurse managers, charge nurses,

staff nurses, the palliative care team, and physicians. In addition, flyers advertising

the study were posted in the waiting room and in the ICU rooms for potential

participants to contact the researcher (see Appendix A).

Inclusion criteria were having a family member admitted to the ICU as an ICU status patient within the past 48 hours, were able to read and write English, be 19 years of age or older, and have physically visited the patient since the patient's admission to the ICU. Cognitively impaired family members were excluded from the study. Nursing judgment was used to assess for cognitive impairment exclusions. More than one family member per patient was eligible to participate as long as they met the inclusion criteria. There was a limit of four family member participants per patient to prevent sampling bias.

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Instrumentation

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Instruments used to measure the variables in this study were the Hospital Anxiety and Depression Scale, Acute Stress Disorder Scale, Impact of Events Scale - Revised, demographic questionnaire, and a education satisfaction survey. Following is a description of the instruments:

Hospital Anxiety and Depression Scale

The Hospital Anxiety and Depression Scale (HADS) was developed by Zigmond and Snaith (1983) to assess anxiety and depression in general hospital setting but not used to make a diagnosis of a psychiatric disorder (See Appendix B). The HADS has a Cronbach alpha ranging 0.68 to 0.93 with a mean of 0.83 for anxiety and 0.67 to 0.90 with a mean of 0.82 for depression subscales content; construct & criterion validity have been documented from a review of literature including over 700 studies in adult general populations and medical illness populations (Bjelland, Dahl, Haug, & Neckelmann, 2002). The HADS has been successfully used in several studies examining anxiety and depression in family members of ICU patients

(Anderson et al., 2008; Fumis et al., 2009; Jones et al., 2004; Lautrette et al., 2007; Maruiti et al., 2008; Pochard et al., 2001; Pochard et al., 2005).

The HADS, developed for screening purposes only, consists of a total of 14 items with two subscales for anxiety and depression (Zigmond & Snaith, 1983). The depression and anxiety subscales each have seven items (Zigmond & Snaith, 1983). The HADS is a self-report measure using a four point Likert scale in which participants rate the statements as zero (*not at all*) to three (*very often*) (Zigmond & Snaith, 1983). The higher the score, the greater probability of the participant having anxiety or depression (Zigmond & Snaith, 1983).   A score of eight is considered a mild case for either depression or anxiety and subscales of 16 or higher are considered severe (Snaith, 2003). The HADS is easy to complete and takes two to five minutes (Snaith, 2003). If used as a pretest and posttest, there should be one week between administrations of the pretest because it asks the respondent to rate the items over the past week (Snaith, 2003).

Acute Stress Disorder Scale

The Acute Stress Disorder Scale (ASDS) was developed by Bryant, Moulds, and Guthrie (2000) as a screening instrument to measure acute stress reaction to identify acutely traumatized individuals at risk to develop subsequent PTSD. Bryant et al. reported that the internal consistency for the ASDS was established by calculating alpha coefficients in adult survivors of a traumatic event. The total ASDS score had an overall alpha of 0.96 (Bryant et al.). The ASDS dissociation subscore had an alpha of 0.84 (Bryant et al.). The ASDS re-experiencing subscore had an

alpha of 0.87 (Bryant et al.).   The avoidance subscore had an alpha of 0.92 (Bryant et al.). The arousal subscore had an alpha of 0.93 (Bryant et al.).

The Acute Stress Disorder Scale has been used successfully in a study examining acute stress in family members of ICU patients (Auerbach et al., 2005). The ASDS was developed to provide a self-report measure to identify acute stress disorder, be a self-reporting version of the Acute Stress Disorder Interview and predict subsequent PTSD (Bryant et al., 2000).

The Acute Stress Disorder Scale is a self-report measure consisting of 19 questions in which participants rate how they feel since a traumatic event (Bryant et al., 2000). The 19-items are on a five point Likert scale in which the participants rate the statements as 1 (*not at all*) to 5 (*very much*) (Bryant et al., 2000) (See Appendix C).   Two additional questions ask the participant to briefly describe the recent traumatic experience and to answer yes or no if the experience frightened them (Bryant et al., 2000). The ASDS has four sub scores: re-experiencing (4 items), avoidance (4 items), dissociative (5 items), and arousal (6 items) (Bryant et al., 2000).   These sub scores reflect the diagnostic criteria for acute stress disorder (Bryant et al., 2000).   A total score of 56 on the ASDS was found to be predictive of 91% of those who would eventually develop PTSD and 93% of those who did not develop PTSD (Bryant et al., 2000). The ASDS takes approximately two to five minutes to complete.

The Impact of Events Scale – Revised

The Impact of Events Scale – Revised (IES-R) was revised by Weiss and Marmar (1997) to add an additional assessment of hyperarousal symptoms with the

assessment of intrusion and avoidance symptoms that were assessed in the original

version of the impact of events scale to be reflective of the DSM-IV criteria for PTSD

(see Appendix D). The intrusion subscale has a Cronbach alpha of 0.87 - 0.92; the

avoidance subscale has a Cronbach alpha of 0.84 - 0.86; and the hyper arousal

subscale has a Cronbach alpha of 0.79 - 0.90 (Weiss & Marmar). Weiss and Marmar

reported the internal consistency of the IES-R was established from two different

cohorts of adults who witnessed traumatic events.

The IES-R is comprised of 22 items with three subscales: hyper arousal,

avoidance, and intrusion (Weiss & Marmar, 1997). The original impact of events

scale consisted of 15 items and did not have the hyper arousal subscale (Weiss &

Marmar, 1997). The IES-R added the seven items for the hyper arousal subscale as

well as one new item to the intrusion subscale for a total of eight items on the

intrusion subscale (Weiss & Marmar, 1997). The IES-R did not add or change any

items to the existing eight item avoidance subscale (Weiss & Marmar, 1997). The

IES-R takes approximately five to seven minutes to complete.

The IES has been successfully used in several studies investigating both acute

stress and posttraumatic stress disorder symptoms in family members of ICU

patients (Anderson et al., 2008; Azoulay et al., 2005; Chui & Chan, 2007; Lautrette et

al., 2007; Paparrigopoulos et al., 2006). The IES-R has been used in studying acute

stress and posttraumatic stress disorder symptoms in family members of ICU

patients (Pillai et al., 2006; Sundarajan et al., 2014).

Demographic Questionnaire

The eight question demographic questionnaire was developed by the investigator to characterize the sample using selected demographic variables of age, gender, level of education, and relationship to the patient, if this was planned or unplanned ICU admission, average computer usage, and if the family member has had any experience with an ICU in the past 2 years (see Appendix E).

Education Survey

The education satisfaction survey was developed by the investigator to be administered during the posttest period (see Appendices F and G). The survey has two versions, one for the group who receives both the web-based education program along with the standard ICU education by ICU physicians and nurses and one for the group who only receives the standard education by ICU physicians and nurses.

The survey for the group who received both the web-based education program along with the standard ICU education by ICU physicians and nurses has five questions. Three questions ask the participant to rate on a four point Likert scale the education provided by ICU nurses about the ICU, education provided by ICU doctors and to rate the web-based program ICU-USA.com. Each of these questions also asks the participant to explain their selection.   In addition, this version asks the participants to explain any additional information they would have liked to have received from the nurses and doctors as well as any additional information that could have been included on ICU-USA.com that would have helped them.

The survey for the group who received only the standard ICU education by ICU doctors and nurses has three questions. These three questions are the exact same questions as the first three questions from the survey for the group who received both the web-based education program along with the standard ICU education. Two questions ask the participant to rate on a four point Likert scale the education provided by ICU nurses about the ICU and education provided by ICU doctors. Each of these questions also asks the participant to explain their selection. In addition, this version asks the participants to explain any additional information they would have liked to have received from the nurses and doctors.

ICU Education Programs

Web-Based ICU Education Program

The web-based education program about the ICU environment called ICU - USA.com. ICU-USA.com was developed by Taylor & Ahrens (1999).   Taylor is a physician with extensive experience in critical care education. Ahrens is a doctorally prepared critical care clinical nurse specialist. The ICU-USA.com website was developed in response to the problem that ICU nurses and physicians do not spend adequate time in communication with ICU patients and family members. ICU-USA.com allows family members to tour an ICU room. This ICU-USA.com room has a patient restrained, lying in a hospital bed with members of the ICU team at the bedside. The ICU-USA.com patient is intubated on a ventilator, has a bedside monitor, feeding tube, feeding pump, a dialysis catheter placed in the internal jugular vein, central venous catheter, intravenous pumps and bags, vital sign monitor, epidural cassettes, and pressure bags. This ICU-USA.com program allows

for users to click on the different equipment, ICU patient, and members of the ICU

team to link to a detailed picture and explanation.   The cursor will change from an

arrow to a hand when it hovers over a piece of equipment, patient, or ICU team

member that is linked with additional information. When a family member clicks on

a piece of equipment, a closer picture of the equipment is shown. The more detailed

picture links to an ICU-USA.com written description with selected frequently asked

questions about the equipment. The ICU-USA.com website also has informational

pages on predicting outcomes in the ICU, questions to ask, ICU medical information

which includes information on diagnoses, equipment, procedures, laboratory tests,

supplies, and a medical glossary. The investigator was available to assist family

members with initial use of the program and answer questions if needed.

Standard ICU Education

The standard ICU education received by family members in the ICU consisted

of verbal explanations by ICU physicians, specialty physicians (such as

pulmonologists, cardiologists, nephrologists), ICU staff nurses, and palliative care

nurses. Handouts were also provided to family members if the patient is restrained

that explained the need for restraints.

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Informed Consent

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Approval to conduct the study was obtained from the Human Rights Review

Board at Baptist Princeton Medical Center and the Institutional Review Board at the

University of Missouri – St. Louis and the University of Alabama. An approved

consent form was given to each participant (see Appendix H). The informed consent

described the purpose of this study, the participant's rights, the costs and benefits to

participating, and how to contact the investigator for questions. The family members' names and contact information were kept in a locked file cabinet separate from the instruments by the investigator. Family members were asked to fill out a separate participant contact form (see Appendix I). When data collection was completed, the names and contact information of the family members were destroyed to protect their identity.

Data Collection

Participants were recruited from the four ICUs. Family members in the waiting rooms and family members of patients admitted within the past 48 hours to the ICU were invited to participate in the study. In addition to active recruitment, snowball sampling was encouraged. Any family member in the ICU could approach the investigator and ask to participate, or additional family members up to four of the same patient could ask to participate. After initial poor recruitment efforts, a grant was written and funded to provide each participant with a $10 cash incentive given at the end of the enrollment which facilitated recruitment of participants.

Family members who consented were randomly assigned to either the web-based education program about the ICU environment or the standard education by physicians and nurses. Randomization of family members participating occurred by alternating the units that received the web-based education program about the ICU environment. For example, the first week of the study, the intervention group was recruited from the medical and cardiac ICUs. Comparison group participants were recruited from the surgical and neurological ICUs. The second week, the intervention group was recruited from the surgical and neurological ICUs and the

comparison group was recruited from the medical and cardiac ICUs. The use of separate units is needed so that family members randomly assigned to the standard education program will not request the computer to access the web-based intervention. The use of separate units also allow for a diversity of patient problems.

Family members who agreed to participate were offered to be taken to a smaller, isolated waiting area and complete the participant contact form, demographic questionnaire, HADS, ASDS, and IES-R. However, many family members declined to relocate to the smaller, isolated waiting areas and chose to participate while staying in the large waiting room. Each family member was asked to provide contact information so they could be reached to take the HADS, ASDS, and IES-R a second time as well as complete a brief survey. Family members in the web-based education program about the ICU environment group accessed the program using a laptop computer provided by the investigator. Family members in the web-based education group received website navigation instructions (see Appendix J). Family members in the standard education received the standard information about the ICU provided by physicians and nurses.

Snaith (2003) advised waiting one week to administer the Hospital Anxiety and Depression Scale (HADS) because the respondent is asked how they felt in the past week. Thus, one week after completion of the pretest, the family member was contacted to complete posttest. If the family member was in the ICU waiting room, they again were offered to be taken to a smaller, isolated waiting area and complete the HADS, ASDS, IES-R, and ICU education satisfaction survey. However, not all family members chose to relocate to conclude participation in the study. If

participants could not meet in the ICU setting one week after the pretest,

participants were called by the investigator and asked to complete the HADS, the

ASDS, the IES-R, and a brief survey via telephone in the same order as those

participants completing in person.

If a family member became distraught while participating in the study, they

were permitted to stop. The participants were given the option of taking a break

from filling out the forms and continue at a later time or to withdraw from the study.

If participants were distraught and needed assistance, the prepared plan to use

standard practice for handling distressed family members in this particular

intensive care unit was followed. The standard practice is to assess the family

member's need and involve the appropriate ancillary service such as palliative care,

social work, or pastoral care to address the family member's need.   However, only

one family member became distressed during participation. That participant

decided on taking a break and then resumed filling out the forms after a short

period of time passed. The offer was made and declined by the distressed

participant to contact ancillary services.

Data Management and Analysis

Data were de-identified and stored in a secured, locked cabinet by the

investigator. Consent forms and contact forms were separated from the instrument

forms. The primary investigator collected all the data. Data was analyzed by the

investigator using the SPSS 22.0 statistical package. A statistician was consulted to

verify correct statistical test usage and results.

The data were analyzed using descriptive statistics, independent samples t-test, mixed ANOVAs, and MANOVA with univariate ANOVAs for significant MANOVA results. The variables of interest were anxiety, depression, acute stress disorder symptoms, and treatment intervention (web-based education program versus standard education). The independent variables were gender, age, relationship to patient, education level, planned admission, computer experience, and ICU experience within the past two years.   Missing data were handled by assigning the mean of the group to the person for the missing data. The mode of the group was assigned to the missing data if it was a categorical variable.

Chapter IV

Results

This chapter presents the sample profile of participants. Results for the research questions are presented.

Sample Profile

A total of 127 participants were enrolled in the study, with 63 (49.60%) in the standard education group and 64 (50.40%) in the standard education with a web-based education program about the ICU environment group. The sample was characterized utilizing descriptive statistics (see Table 1). The majority of participants were female (82.68%), with 50 (79.50%) in the standard education group and 55 (85.90%) in the standard education with a web-based education program about the ICU environment group. Additionally in both groups, this was an unplanned admission for the majority of participant's patients with 48 (72.60%) in the standard education group and 45 (70.30%) in the standard education with a web-based education program about the ICU environment group.   In the standard education group, 60 (95.24%) participants completed the entire demographic questionnaire. In the standard education with a web-based education program about the ICU environment group, 62 (96.88%) participants completed the entire demographic questionnaire. In the standard education only group, three participants did not answer at least one of the following questions: (a) their relationship to patient, (b) patient's health status, or (c) reason for admission. In the standard and web-based education group, two participants did not answer

reason for admission, with one of those participants also not answering their relationship to the patient. A total of 51 (40.16%) of the 127 enrolled participants followed up with 26 (50.98%) in the standard education group and 25 (49.02%) in the standard education with a web-based education program about the ICU environment group. Only 50 (39.37%) completed all follow up instruments consisting of the HADS, ASDS, IES-R, and the follow up questionnaire.

Table 1

Categorical Demographics of Participants Receiving Standard Education and Standard Education with Web-based Education Program

Characteristic	Standard ed. (n = 63)		Standard and web ed. (n = 64)	
Gender				
Male	13	(20.6)	9	(14.1)
Female	50	(79.4)	55	(85.9)
Age				
19 - 20	4	(6.3)	3	(4.8)
21 - 30	9	(14.1)	9	(14.3)
31 – 40	9	(14.1)	10	(15.9)
41 – 50	13	(20.3)	8	(12.7)
51 – 60	17	(26.6)	19	(30.2)
61 – 70	9	(14.1)	11	(17.5)
71 -80	3	(4.7)	2	(3.2)
>80	0	(0.0)	1	(1.6)
Education Level				
eighth grade	1	(1.6)	1	(1.6)
Some high school	5	(7.9)	5	(7.8)
High school graduate	18	(28.6)	17	(26.6)
GED	3	(4.8)	4	(6.3)
Some college	26	(41.3)	24	(37.5)
four year college graduate	7	(11.1)	5	(7.8)
Graduate school	3	(4.8)	8	(12.5)
Relationship to Pt				
Spouse	5	(8.1)	10	(15.9)
Son	6	(9.7)	6	(9.5)
Daughter	12	(19.4)	21	(33.3)
Granddaughter	9	(14.5)	2	(3.2)
Niece	2	(3.2)	3	(4.8)
Sister	11	(17.7)	10	(15.9)
Brother	3	(4.8)	1	(1.6)
Other	15	(23.8)	11	(17.2)
Computer Use				
Daily				
<1 hr	4	(6.3)	13	(20.3)
1 -3 hrs	13	(20.3)	4	(6.3)
>3 hrs	20	(31.7)	21	(32.8)
Weekly				
Once/week	4	(6.3)	4	(6.3)
2 -3 times/ week	15	(23.8)	16	(25.0)
Never	7	(11.1)	6	(9.4)
Admission Type				
Planned	15	(23.8)	19	(29.7)
Unplanned	48	(76.2)	45	(70.3)
Prior ICU Experience w/in 2 yrs				
Yes	33	(52.4)	23	(35.9)
No	30	(47.6)	41	(64.1)
ICU Unit				
MICU	16	(25.4)	17	(26.6)
CICU	12	(19.0)	21	(32.8)
Neuro ICU	16	(25.4)	17	(26.6)
SICU	19	(30.2)	9	(14.1)

Results

Research question 1. What are the levels of anxiety, depression, and acute stress disorder symptoms among family members of ICU patients in the Southeastern United States? Independent samples t tests were used to establish the levels of anxiety, depression, and acute stress symptoms among family members and to compare means between the standard education only group and the standard education and web-based education group to look for any significant differences upon enrollment. Level of anxiety was measured using the Hospital Anxiety and Depression Scale (HADS). The HADS instrument categorized scores into three categories: 0 to 7 no anxiety, 8 to 10 possible anxiety, 11 to 21 probable anxiety (Zigmond & Snaith, 1983). There were 63 participants in the standard education group and 64 participants in the standard education and web-based education group. There was no statistically significant difference found between anxiety symptom level scores upon enrollment, (within 72 hours of a family member's ICU admission) for the standard education group (*M* = 10.00, *SD* = 4.57) and the standard and web-based education group (*M* = 10.31, *SD* = 4.76), 95% CI [-1.33, 1.95], *t*(125) = .37, *p* = .709. No difference between groups was found; however, both groups' mean raw scores indicated possible anxiety.

The raw anxiety scores from the HADS were used for data analysis. The literature generally presents the anxiety and depression subscale results from the HADS according to three categories described with the HADS (Zigmond & Snaith, 1983). The HADS categorical scores for the two different study groups upon enrollment are presented in Table 2.

Table 2

HADS Categorization of Anxiety and Depression Occurrence upon Enrollment

Variable	Standard ed. (n = 63)		Standard and web ed. (n = 64)	
No Anxiety	18	(28.6)	19	(29.7)
Possible Anxiety	18	(28.6)	13	(20.3)
Probable Anxiety	27	(42.9)	32	(50)
Total with Possible or Probable Anxiety	45	(71.5)	45	(70.3)
No Depression	39	(47)	44	(50)
Possible Depression	14	(22.2)	10	(15.6)
Probable Depression	10	(15.9)	10	(15.6)
Total with Possible or Probable Depression	24	(38.1)	20	(31.2)

Depression was measured using the Hospital Anxiety and Depression Scale (HADS). The HADS instrument categorized scores into three categories: 0 to 7 no depression, 8 to 10 possible depression, 11 to 21 probable depression (Zigmond & Snaith, 1983). There were 63 participants in the standard education group and 64 participants in the standard education and web-based education group. There was no statistically significant difference found between depression symptom level scores upon enrollment, (within 72 hours of a family member's ICU admission) for the standard education group (*M* = 6.43, *SD* = 4.32) and the standard and web-based education group (*M* = 6.35, *SD* = 3.89), 95% CI [-1.53, 1.36], *t*(125) = -.11, *p* = .911. Both groups' mean raw scores indicated no depression.

Acute stress disorder symptoms were measured using the Acute Stress Disorder Scale (ASDS) and Impact of Events Scale – Revised (IES-R). ASDS possible scores range from 19 to 95. There is no scoring categorization for the ASDS; however,

Auerbach et al. (2005) reported an ASDS score of 44.93 was criteria for being admitted to the PTSD unit of a psychiatric hospital. IES-R possible scores range from 0 – 88. There is also no scoring categorization for the IES-R as the intention of the instrument is to capture the experience of subjective symptoms. There were 63 participants in the standard education group and 64 participants in the standard education and web-based education group. There was no statistically significant difference found between stress symptom scores measured by the ASDS upon enrollment, for the standard education group (M =47.46, SD =17.86) and the standard and web-based education group (M = 44.28, SD = 18.72), 95% CI [-9.61, 3.24], t(125) = -.98, p = .329. There also was no statistically significant difference found between stress symptom scores measured by the IES-R upon enrollment, for the standard education group (M =40.59, SD =19.97) and the standard and web-based education group (M = 38.08, SD = 19.97), 95% CI [-9.52, 4.50], t(125) = -.71, p = .480.

Research question 2. Is there a significant difference in the levels of anxiety, depression, and acute stress disorder symptoms among family members of ICU patients who use standard ICU education with a web-based education program about the ICU environment versus family members of ICU patients who receive only the standard ICU education by physicians and nurses?   Of the 127 participants recruited, 51 (40.2%) participated in follow up. Follow up consisted of completing the HADS, ASDS, and IES-R for a second time, as well as the follow up questionnaire with only 50 (39.3%) completing all follow up instruments. One participant only completed the HADS instrument. A mixed ANOVA was run for each measure.

Anxiety symptoms levels scores upon follow up for participants in the standard education group were an average of 8.31 (n = 26). Anxiety symptoms levels scores upon follow up for participants in the standard education and web-based education group were an average of 10.12 (n = 25).   Both groups had a significant reduction in anxiety symptoms from enrollment to follow up, $F(1, 49) =$ 11.85, $p < .001$, partial $\eta^2 = .20$, observed power = .92. There was no statistically significant difference in anxiety symptom scores between the standard education group and the standard and web-based education group at follow up $F(1, 49) = .60$, $p = .444$, partial $\eta^2 = .01$, observed power = .12. Both groups' mean raw scores indicate possible or probable anxiety at follow up.

Depression symptom level scores upon follow up for participants in the standard education group were an average of 5.92 (n = 26). Depression symptoms levels upon follow up for participants in the standard education and web-based education group were an average of 7.84 (n = 25).   There was no significant difference found for both groups in depression symptoms from enrollment to follow up $F(1, 49) = .15$, $p = .705$, partial $\eta^2 = .00$ observed power = .07. There was no statistically significant difference in depression symptom scores between the standard education group and the standard and web-based education group at follow up $F(1, 49) = 1.39$, p = .244, partial $\eta^2 = .03$, observed power = .21. The standard education group's mean raw score did not indicate depression; however, the standard education and web-based education groups' raw mean scores did indicate possible depression at follow up.

Acute stress disorder symptom scores upon follow up for participants in the standard education only group were an average score of 44.36 (n = 25) on the ASDS and 26.76(n = 25) on the IES-R. Acute stress disorder symptom scores upon enrollment for participants in the standard education and web-based education group were an average score of 45.84 (n = 25) on the ASDS and 29.48 (n = 25) on the IES-R. For both the ASDS and the IES-R, the higher the score, the more severe the stress symptoms. There was no significant difference for either group between enrollment and follow up on the ASDS $F(1, 48) = .19$ $p = .662$, partial $\eta^2 = .00$, observed power = .07. There was no statistically significant difference in stress symptom scores on the ASDS between the standard education group and the standard and web-based education group at follow up $F(1, 48) = .65$, $p = .425$, partial $\eta^2 = .01$, observed power = .12. There was a significant difference for both groups' experience of acute stress symptoms between enrollment and follow up on the IES-R $F(1, 48) = 23.48$, $p < .001$, partial $\eta^2 = .33$, observed power = .997. There was no statistically significant difference in anxiety symptom scores on the IES-R between the standard education group and the standard and web-based education group at follow up $F(1, 48) = .00$, $p = .988$, partial $\eta^2 = .00$, observed power = .05.

Research question 3. Is there a significant difference between age, gender, educational level, relationship to patient, previous ICU experience, or planned versus unplanned ICU admission and anxiety, depression, and acute stress disorder symptoms among family members of ICU patients? Six separate multivariate analysis of variance (MANOVA) tests were run for each individual demographic variable. Each MANOVA included four dependent variables measuring three

constructs: (a) anxiety symptoms measured by the HADS, (b) depression symptoms measured by the HADS, and (c) acute stress disorder symptoms measured by the ASDS and the IES-R. For five of the six MANOVAs-- gender, education level, relationship to patient, previous ICU experience, and planned versus unplanned admission--Box's M was not statistically significant. Thus, there is assumed equal covariance of the dependent variables across five of the demographic variables. This suggests that Wilks' Lamada should be used to interpret the MANOVA F for gender, education level, relationship to patient, previous ICU experience, and planned versus unplanned admission (Meyers, Gamst, & Guarino, 2006). Box's M was statistically significant for age, indicating there was an unequal covariance of the dependent variables. Thus, for age, Pillai's Trace should be used to interpret the MANOVA F (Meyers et al., 2006).   Also, Bartlett's Test of Sphericity was statistically significant for all six MANOVAs. See Appendix K for means and standard deviations for the demographic variables on the dependent variables.

No significant multivariate main effect was found for age, Pillai's trace = .10, $F(20, 484)$ = .61, p = .91, partial η^2 = .02, observed power = .48.   No significant multivariate main effect was found for gender, Λ = .90, $F(20, 392.31)$ = .60, p = .91, partial η^2 = .03, observed power = .38. No significant main effect was found for original categories for relationship to patient, Λ = .55, $F(84, 397.44)$ = .78, p = .91, partial η^2 = .14, observed power = .97. Because there were 22 relationship categories reported (see Table 1) with some categories only having one or two participants, the relationship to patient variable was collapsed in SPSS into 10 related relationship categories to patient. A MANOVA was re-run with the

transformed relationship to patient variable. Still, no significant main effect was found for collapsed categories for relationship to patient, Λ = .88, F(36, 421.45) = .76, p = .668, partial η^2 = .07, observed power = .83. No significant main effect was found for planned ICU admission versus unplanned ICU admission Λ = .94, F(4, 122) = 2.03, p = .10, partial η^2 = .06, observed power = .59.

A statistically significant main effect was found for previous ICU experience, Λ = .92, F [4,122] = 2.70, p = .034, partial η^2 = .08, observed power = .74. To identify the source of the main effect, univariate ANOVAS were conducted on each of the dependent variables. All four dependent variables were found to have significant ANOVA F statistics. Previous ICU experience affected anxiety symptoms as measured on the HADS Anxiety subscale, F(1, 125) = 11.03, p <.001, partial η^2 = .08, observed power = .91. Participants who had previously experienced an ICU admission themselves or with a family member within the past two years had higher anxiety symptom scores than participants who had not experienced an ICU admission themselves or with a family member within the past two years. Previous ICU experience affected depression symptoms as measured on the HADS Depression subscale, F(1, 125) = 4.16, p = .044, partial η^2 = .03, observed power = .53. Family members of ICU patients who had previously experienced an ICU admission themselves or with a family member within the past two years had higher depression symptom scores than participants who had not experienced an ICU admission themselves or with a family member within the past two years. Previous ICU experience affected stress symptoms as measured on the ASDS, F(1, 125) = 5.39, p = .022, partial η^2 = .04, observed power = .63. Family members of ICU patients

who had previously experienced an ICU admission themselves or with a family member within the past two years had higher stress symptom scores as measured by the ASDS than participants who had not experienced an ICU admission themselves or with a family member within the past two years. Finally, previous ICU experience affected stress symptoms as measured on the IES-R, $F(1, 125) = 4.99$, $p = .027$, partial $\eta^2 = .04$, observed power = .60. Family members of ICU patients who had previously experienced an ICU admission themselves or with a family member within the past two years had higher stress symptom scores as measured by the IES-R than participants who had not experienced an ICU admission themselves or with a family member within the past two years.

In an effort to increase power due to limited numbers of participants in some categories, education levels were collapsed from seven categories into four related categories: eighth grade and some high school (n = 12), high school graduate and GED (n = 42), some college (n = 50), four year college graduate and graduate school (n = 23). A significant multivariate main effect was found for revised education levels, $\Lambda = .84$, $F (12, 317.78) = 1.86$, $p = .039$, partial $\eta^2 = .06$, observed power = .84. To identify the source of the main effect, univariate ANOVAS were conducted on each of the dependent variables. Only stress symptoms as measured by IES-R had a significant ANOVA F statistic, $F(3, 123) = 2.89$, $p = .04$, partial $\eta^2 = .07$, observed power = .68. Tukey post-hoc comparisons showed a statistically significant difference in stress symptoms as measured by the IES-R between participants who had an eighth grade or some high school education and those who had a four year college degree or graduate school. Those who had an eighth grade or some high

school education had significantly higher stress symptom scores on the IES-R compared with those who had a four year college degree or graduate school.

Evaluation of ICU-USA.com program

Of the 64 participants who were assigned to use the ICU-USA program, 25 completed a follow up evaluation of the ICU-USA program. Of the 25 participants who followed up, only 16 reported that they used the program. The ICU-USA program was rated excellently by 11 (68.75%) participants, good by 4 (25%) participants, and fair by 1 (6.25%) participant. Participant comments about the program were extremely positive and included comments such as, "I think it was a good tool. I wish they would set that up in the CICU waiting room or any ICU waiting room.", "Whoever put it together, they took the time to explain it in terms the layperson can understand. It was very informative.", "It told me a lot about the things that were on her.", "Very informative and thorough", and "A lot of great information."

Chapter V

Conclusion and Recommendation

This chapter presents a summary of the problem, a summary of the design and purpose, as well as a discussion of the results to the research questions. This chapter also discusses limitations of the study, implications for nursing practice, and recommendations for future nursing science and research.

Summary of the Problem

Family members of ICU patients may experience anxiety, depression, and/or acute stress disorder symptoms. In order to address the problem, a multi-society task force for critical care research identified the need to investigate the usefulness of interventions to quantify and treat anxiety, depression, and stress symptoms experienced by family members of ICU patients (Deutschman et al., 2012). This task force also encouraged investigation of using technology to address this need. (Deutschman et al.).

Summary of the Design and Purpose

The purpose of the study was based specifically on the recommendation of the multi-society task force (Deutschman et al., 2012), to investigate using technology to meet the needs of family members of ICU patients. This study used a prospective, quasi-experimental nonequivalent control group design with pretest and posttest that compared the effects of the standard ICU education and web-based education program with information about the ICU environment with only the

standard ICU education provided by physicians and nurses and the level of anxiety, depression, and acute stress disorder symptoms among family members of ICU patients. Thus, the purpose of this study was to determine the effects of using a web-based education program, ICU-USA.com on anxiety, depression, and acute stress disorder symptoms experienced by family members of ICU patients.

Discussion of Results

Research question 1. This investigation sought to determine the levels of anxiety, depression, and acute stress disorder symptoms among family members of ICU patients in the Southeastern United States. This study found 45 (71.5%) of those in the standard education only group and 45 (70.3%) of those in the standard education with web-based education program with possible or probable anxiety. These findings are consistent with the reported incidence of anxiety in this population of 35% to 73% in the literature (Anderson et al., 2008; Azoulay et al., 2005; Bailey, et al., 2010; Fumis & Deheinzelin, 2009; Gries et al., 2010; Jones et al., 2004; Lautrette et al., 2007; Maruiti, et al., 2008; Pochard et al., 2001; Pochard et al., 2005).

This study also found 24 (38.1%) of those in the standard education only group and 20 (31.2%) of those in the standard education with web-based education group had possible or probable depression. These findings are consistent with the literature reported incidence of depression in this population of 16 to 56% (Anderson et al., 2008; Azoulay et al., 2005; Fumis & Deheinzelin, 2009; Gries et al., 2010; Jones et al., 2004; Lautrette et al., 2007; Maruiti et al., 2008; Paparrigopoulos

et al., 2006; Pochard et al., 2001; Pochard et al., 2005; Siegl et al., 2008; Young et al., 2005).

In addition, this study found a mean acute stress disorder scale (ASDS) score of 47.46 (SD = 17.86) for those in the standard education only group and a mean ASDS score of 44.28 (SD = 18.72) for those in the standard with web-based education group. This is similar to the findings Auerbach et al. (2005) reported with a mean ASDS score of 44.65 and SD = 14.70. There is no scoring or categorization for the ASDS; however, Auerbach et al. reported an ASDS of 44.93 was a criteria for being admitted to the PTSD unit of a psychiatric hospital.

This study found mean Impact of Events Scale (IES-R) score of 40.59 (SD = 19.97) for those in the standard education only group and a mean IES-R score of 38.08 (SD = 19.97). It is difficult to compare the IES-R scores found in this study to the literature because previous studies identifying acute stress disorder symptoms and possible PTSD either used the IES-R, but scored according to the Impact of Events Scale (IES) scoring or used the IES (Anderson et al., 2008; Azoulay et al., 2005; Chui & Chan, 2007; Jones et al., 2004; Paparrigopoulos et al., 2006; Pillai et al., 2006; Sundararajan et al., 2014). The investigator of this study did not realize at the time of study design that previous studies utilized the IES or used the IES-R but scored according to the scale included with use of the IES. Thus, it was difficult to compare exact findings from this study with incidence reported in the literature. All of the questions from the IES are included on the IES-R. However, the IES-R has additional questions for hypervigilance screening. It should be noted that the use of

the IES was not ideal for acute stress disorder or PTSD screening since the hypervigilance category was not addressed.

Research question 2. This investigation sought to determine if there was a significant difference in the levels of anxiety, depression, and acute stress disorder symptoms among family members of ICU patients who use standard ICU education with a web-based education program about the ICU environment versus family members of ICU patients who receive only the standard ICU education by physicians and nurses. Both groups had significant reduction in anxiety from enrollment to follow up. No statistically significant difference in anxiety symptoms scores between groups was found at follow up. Neither group had statistically significant differences in depression scores from enrollment to follow up. No statistically significant difference in depression symptom scores were found at follow up between groups. Neither group had statistically significant differences found on stress symptoms as measured by the ASDS from enrollment to follow up. No statistically significant difference in stress symptoms as measured by the ASDS was found upon follow up between groups. Both groups did experience a significant reduction in stress symptoms scores as measured by the IES-R between enrollment and follow up. However, there was not statistically significant difference found between groups in stress symptom scores as measured by the IES-R between groups at follow up.

While there were no statistically significant differences found between groups, this does not mean the web-based education program would not have made a difference on anxiety, depression, or acute stress disorder symptoms under

different circumstances. This study planned a repeated measures MANOVA to

answer research question 2. However, when performing a repeated measures

MANOVA on this study's follow up data for question 2, because of the low follow up

rate of participants, there was only an observed power of .05. This means there was

only a 5% chance of detecting a significant difference if one existed. This study was

designed to enroll 126 participants, with a total of 127 participants actually enrolled

in the study. However, a fatal flaw with this design was not understanding that 126

participants were needed for follow up and only 50 (40%) participants completed

the follow up process. In an effort to work with the existing data, consultation with

a statistician led to the decision to utilize a mixed ANOVA in lieu of the repeated

measures MANOVA. This meant a separate ANOVA was run for each variable of

interest. There was an observed power of .12 for the anxiety variable, .07 for the

depression variable, .07 for stress variable measured on the ASDS, and .12 for stress

variable measured on the IES-R.   This means there was only a 7% to 12% chance of

detecting any significant differences if they existed.

Also of note, of the 25 who followed up and were assigned to the standard

education with web-based education program group, only 16 (64%) reported

actually using the ICU-USA.com program between enrollment and follow up. Thus,

there was an even smaller likelihood of detecting a significant difference between

groups since there were very few who actually utilized the web-based education

program.

No previous studies have investigated the effect of a web-based education

program on family members experiences of anxiety, depression, and acute stress

disorder symptoms. The number of interventional studies on anxiety, depression, and acute stress disorder symptoms in family members of ICU patients is limited. A few have reported a significant decrease in anxiety, depression and acute stress disorder symptoms in family members of ICU patients (Chavez & Faber, 1987; Chen et al., 2006; Lautrette et al., 2007). While no significant difference was found in the current study, this may be attributed to the lack of power associated with this study.

Research question 3. This investigation sought to determine if there was a significant difference between age, gender, educational level, relationship to patient, previous ICU experience, or planned versus unplanned ICU admission and anxiety, depression, and acute stress disorder symptoms among family members of ICU patients.

Age. This investigation did not find any significant differences for the variables of age and anxiety, depression, and acute stress disorder symptoms among family members of ICU patients.

Gender. In this investigation no statistically significant differences were found between gender and anxiety, depression, and acute stress disorder symptoms. This finding differs from reports in the literature where females were more likely to experience anxiety, depression, and acute stress disorder symptoms than males (Azoulay et al., 2005; Chartier & Coutu-Wakulczyk, 1989; Chui & Chan, 2007; Fumis & Deheinzelin, 2009; Gries et al., 2010; Paparrigopoulos et al., 2006; Pochard et al., 2001). It should be noted that failure to detect a difference in this investigation between genders may have been because of the over representation of female

participants, 105 (82.68%) and the observed power was .38. This means there was only a 38% chance of detecting a significant difference for gender if one existed.

   Education level. Lower education levels were found to be predictive of depressive symptoms and higher levels of acute stress disorder symptoms in family members of ICU patients (Azoulay et al., 2005; Chui & Chan, 2007; Gries et al., 2010; Paparrigopoulos et al., 2006). This investigation also found a statistically significant difference between education level and acute stress disorder symptoms as measured by the IES-R. Education levels for this study were examined by collapsing seven categories listed on the demographic information sheet into four related categories: eighth grade and some high school (n = 12), high school graduate and GED (n = 42), some college (n = 50), four year college graduate and graduate school (n = 23). The difference was isolated to the categories between participants who had an eighth grade or some high school education and those who had a four year college degree or graduate school. Those who had an eighth grade or some high school education had significantly higher stress symptom scores on the IES-R compared with those who had a four year college degree or graduate school indicating higher distress.

   Relationship to patient. This investigation did not find any statistically significant difference between relationship to patient and anxiety, depression, and acute stress disorder symptoms. This differs from literature reports that spouses were more likely to experience anxiety symptoms (Chartier & Coutu-Wakulczyk, 1989; Fumis & Deheinzelin, 2009; Paparrigopoulos et al., 2006; Pochard et al., 2001).

Previous ICU experience. In this investigation, there was a significant difference found for previous ICU experience. Further exploration for the source of the main effect found there were statistically significant differences for anxiety, depression, and acute stress disorder symptoms measured by both the ASDS and IES-R. Those participants who had previously experienced an ICU admission themselves or with a family member within the past two years had higher anxiety, depression, and acute stress disorder symptom scores than those who had not previously had an ICU admission within the past two years. This was a surprising finding because the investigator thought that previous experience may serve as a mitigating factor for anxiety, depression, and acute stress symptoms experienced by family members of ICU patients. Finding that previous ICU experiences (self or family member) is associated with higher distress symptoms may lend support to the findings in the literature that family members of ICU patients may experience PTSD (Anderson et al., 2008; Azoulay et al., 2005; Gries et al., 2010; Jones et al., 2004; Lautrette et al., 2007; Pillai et al., 2006).

Planned versus unplanned admission. Unexpected or unplanned ICU admissions have been associated with higher levels of acute stress disorder symptoms (Azoulay et al., 2005; Chui & Chan, 2007; Gries et al., 2010). This investigation found no statistically significant differences between a planned or unplanned ICU admission and anxiety, depression and acute stress disorder symptoms in family members of ICU patients.

Demographic question responses. Demographic information provided by participants on the demographic questionnaire developed by the investigator was

assessed (see Appendix E). Demographic variables were compared to demographic variables reported in the literature.

Gender. This study had predominately female participants, 105 (82.68%). The number of females in this study was in the higher end range of demographic information reported in the literature where 60.9% to 75% were female participants (Anderson et al., 2008; Auerbach et al., 2005; Bailey et al., 2009; Chartier & Coutu Wakulczyk, 1989; Chui & Chan, 2007; Gries et al., 2010; Maruiti et al., 2007; Siegel et al., 2008).

Age. This study also had a wide range of age of participants from 19 to 81 years, with the largest concentration of participants aged 41to 60 years. This is also similar to demographic information reported in the literature where ages ranged from 13 to 90 years (Anderson et al., 2008; Auerbach et al., 2005; Bailey et al., 2009; Charier & Coutu-Wakulczyk, 1989; Chui & Chan, 2007; Paparrigopoulos et al., 2006; Pochard et al., 2001). This study's participants had a wide range of educational preparation.

Education level. There were not as many four year college graduates anticipated by the investigator. The largest concentration of participants selected some college as their highest level of education. Unfortunately, the option of an associate's degree or technical certification was not presented as an option for participants. Several studies also reported a lower level of university graduates as participants (Charier & Coutu-Wakulczyk, 1989; Chui & Chan, 2007; Gries et al., 2010; Paparrigopoulos et al., 2006; Siegel et al., 2008).

Relationship to patient. This study purposely left the definition of family member open to the participants. Participants ended up identifying 22 different familial relations to the patient. However, no participant identified as a father or father-in-law to the patient. Since this study was investigating the use of a web-based education program, average computer usage was assessed for participants which had not been previously reported in this population. While a little more than 50% of total participants use a computer daily, about 10% of participants never use a computer with an additional 6% of participants reporting computer usage only once a week. The family member's ICU admission was unplanned for the majority of the participants. More participants in the standard education only group had previous ICU experience within the past two years. Only one study had reported on previous ICU experience with 41.4% of the participants having a previous ICU experience (Bailey et al., 2009).

Evaluation of ICU-USA.com program. A limited number of participants assigned to use the web-based education program reported using the program, 16 (64%). Of those who reported using the ICU-USA.com program, 15 (93.75%) rated it as good or excellent. Participant comments about the program were extremely positive and included comments such as, "I think it was a good tool. I wish they would set that up in the CICU waiting room or any ICU waiting room," "Whoever put it together, they took the time to explain it in terms the layperson can understand. It was very informative," "It told me a lot about the things that were on her," "Very informative and thorough," and "A lot of great information."   The positive comments and ratings are reflective of the high satisfaction scores with information

and communication that were reported in the one study that previously used this

program (Kleinpell et al., 2005).

Implication for Nursing Science and Practice

Based on the findings of this investigation, the following implications for

nursing science and practice are presented:

- It is important for ICU nurses to assess levels of anxiety, depression, and

  acute stress symptoms in family members of ICU patients. The HADS, ASDS,

  and IES-R were easy to administer to waiting family members. It is

  important to note that ICU nurses should only use either the ASDS or the IES-

  R because questions on both are similar.

- It is important for ICU nurses to understand family members of ICU patients

  may have difficulty comprehending information presented to family

  members of ICU patients.

- ICU nurses should be cognizant that family members of ICU patients that

  experience anxiety, depression, and acute stress disorder symptoms are not

  limited to a first-degree relative such as a spouse, parent, or child.

- For study participants who used the ICU-USA.com program, the program was

  well received and useful. Because the ICU-USA.com program is readily

  available and easy to use, nurses in ICUs may consider recommending the

  program to family members of ICU patients and/or having a computer

  available in ICU waiting areas for family members to access the ICU-USA.com

  program to gain information about the ICU environment. This is supported

by Rolls et al. (2012) who reported family members of ICU patients should use a computer kiosk in the waiting room to access information.

- Nurses in ICUs should be aware that previous ICU experiences may increase the levels of anxiety, depression, and acute stress disorder symptoms in family members of ICU patients. Thus it is important to assess family members' previous ICU experiences.

- Nurses in ICUs should be aware that family members of ICU patients with lower education levels may experience increased level of acute stress disorder symptoms.

Implications for Conceptual Model

This study used the Stress Response of Family Members of ICU Patients (SRFMICUP) conceptual model to guide the development and design of the study. This model was derived by the investigator based off the Potential Sources of Stress of Parents in the Pediatric Intensive Care Unit model by Miles et al. (1989) and broadened based on the review of literature (see Figure 1). The conceptual model was useful for this investigation because the model addressed common factors that should be considered when studying sources of stress in the ICU environment for family members of ICU patients. For example, this investigation did confirm that a proposed personal factor variable of education level influenced the family member's stress response. Further refinement of this model is needed to determine which factor the variable previous ICU experience belongs. Because previous ICU experience was found to influence the family member's stress response. Previous ICU experience could fit within the personal factor because the individual's previous

ICU experience, or within the situational factor or an environmental factor because the family member encountered the ICU environmental stimuli again. Although this study was unable to determine the effectiveness of using a web-based education program compared to standard education by physicians and nurses for family members in an ICU, the conceptual model was still found to be effective in guiding the design of the study.

Recommendations for Future Research

Based on the findings of this investigation, the following recommendations for nursing research are presented:

The surprising finding from this study was that participants who had an ICU admission experience within the past two years reported statistically significantly higher levels of anxiety, depression, and acute stress disorder symptom scores than those who did not have an ICU admission experience within the past two years. Future research should explore previous ICU experiences, perhaps asking type of ICU, or relation to the patient previously admitted, or if the current patient was previously admitted to the ICU.

In this study, lower education levels were found to be associated with higher acute stress disorder scores. Future research is needed to determine if the web-based education program is more or less beneficial for participants with lower education levels.

While this study was in progress, new diagnostic criteria for ASD and PTSD were published, which exclude witnessing an illness or natural death from the definition of a traumatic event (APA, 2013). In contrast, results from this study

indicate a high intervention illness or natural death in an ICU environment may have a similar PTSD effect on family members of ICU patients.

The follow-up response rate was 40% for the participants in this investigation. Future research needs to develop strategies to improve the follow-up response rate. Strategies offered based on this study include: (a) offer options for preferred follow up contact such as phone call, text message or email, as well as best time of day to be reached; (b) offer instruments on the internet via a survey management program such as Survey Monkey or Qualtrics; (c) increase research team members to manage three to five follow up contacts of family members; and (d) establish a follow up time frame of seven to ten days based on the ASDS and IES-R recommended minimum of seven days.

This investigation found that in this setting, an incentive of $10 cash was needed to increase participation in the study. Initially, only 17 participants from approximately 400 family members approached were enrolled in the study. After the incentive was introduced, there were 286 people approached with 110 agreeing to participate for a recruitment rate 38.46%.

Future research should consider use of an ICU that offers open visiting hours versus closed visiting hours. The ICUs used for this study offered closed visiting hours, where family members could visit their family member only four times a day for thirty minutes.   Positive effects of open visiting hours ICUs where ICUs let visitors come and go as the visitors desire with the exception of shift change and other extenuating circumstances have been documented (Cappellini, Bambi, Lucchini, & Milanesio, 2014).

Upon enrollment, consideration should be given to obtaining an APACHE II score to measure the severity of patient's condition and to confirm the patient's diagnosis via the electronic health record (EHR). In this investigation, the researcher asked the family members the diagnosis and no information was verified from the EHR. Accurately tracking diagnosis and patient's outcome at follow up may be helpful to determine if a correlation exists between patient severity of diagnosis and outcome on anxiety, depression, and acute stress disorder symptoms.

Although this investigation did not determine the effectiveness of the ICU-USA.com program, this well designed and easy to use web-based education program directed at family members of ICU patients merits further research to determine its usefulness in reducing stress for family members of ICU patients.

Researchers should consider including questions to determine if family members actively sought out information on the internet about the patient's diagnosis or information about ICU equipment or procedures. This information may help researcher determine if icu-usa.com is useful when compared to other internet health information resources such as WebMD, an organization that provides health information, or MedlinePlus, a National Library of Medicine health information resource for patients' families.

Conclusion

This study has reinforced previous findings that family members of ICU patients experience anxiety, depression and acute stress disorder symptoms within the first 72 hours of admission of a family member to the ICU. This study found that family members of ICU patients who had a prior experience within the past two

years were more likely to experience anxiety, depression, and acute stress disorder symptoms than family members who had not had an ICU experience within the past two years. This study reinforced that family members of ICU patients with lower education levels experienced statistically significantly increased levels of stress compared to family members of ICU patients with higher education levels. This study was not able to conclude if the ICU-USA.com web-based education program could reduce anxiety, depression, and acute stress disorder symptoms experienced by family members of ICU patients because of a low follow up rate. However, this well designed and easy to use web-based education program directed at family members of ICU patients merits further research to determine its usefulness in reducing stress for family members of ICU patients.

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Appendix A

Family Members of ICU Patients Wanted for a Research Study

What:
- A study looking at a way to help family members learn about the ICU which may help lower anxiety, depression, and stress in family

Who:
- Family members of ICU patients admitted within the past 48 hours
- Must be age 19 or older

When:
- Mondays – 9:30 am – 10:30 am, 12pm – 1 pm, 1:30 -2:30 pm, 4 pm – 5 pm
- Tuesdays – 12 pm – 1 p, 1:30 – 2:30 pm, 4 pm – 5 pm, 5:30 pm – 6:30 pm
- Wednesdays – 1:30 pm – 2:30 pm, 4 pm – 5 pm, 5:30 pm – 6:00 pm, 7:00 pm – 8:00 pm
- Thursdays - 12 pm – 1 pm, 1:30 – 2:30 pm, 4 pm– 5 pm
- Fridays – 9:30 am – 10:30 am, 12 pm – 1 pm, 1:30 pm – 2:30 pm
- Saturday – 9:30 am – 10:30 am, 12 pm – 1 pm, 1:30 pm – 2:30 pm
  OR
- Appointments can be made at your convenience if above times do not work for you. **Please call or text Chrystal Lewis at (314) 703-7208** to schedule an appointment.

What is involved:
- Completing several questionnaires that will take about 15 minutes
- You may be asked to view a program on a computer that explains the ICU setting and commonly used equipment - this will take approximately 15-20 minutes
- Completing the same questionnaires one week later - either in the hospital or by telephone

Where:
- Waiting rooms of the ICU

By:
- Chrystal Lewis, MSN, RN
- A doctoral student at University of Missouri-St Louis (UMSL)
- Instructor at the University of Alabama Capstone College of Nursing

Appendix B

Hospital Anxiety and Depression Scale (HADS)

Code Name:_____

Date: _____

Instructions: Read each item. Check the empty box next to the statement that is the closest to how you have been feeling in the past week. Don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought out response.

A	**I feel tense or "wound up":**	
	Most of the time	3
	A lot of the time	2
	From time to time, occasionally	1
	Not at all	0

D	**I still enjoy the things I used to enjoy:**	
	Definitely as much	0
	Not quite so much	1
	Only a little	2
	Hardly at all	3

A	**I get a sort of frightened feeling as if something awful is about to happen:**	
	Very definitely and quite badly	3
	Yes, but not too badly	2
	A little, but it doesn't worry me	1
	Not at all	0

D	**I can laugh and see the funny side of things:**	
	As much as I always could	0
	Not quite so much now	1
	Definitely not so much now	2

	Not at all	3

A	**Worrying thoughts go through my mind:**	
	A great deal of the time	3
	A lot of the time	2
	From time to time, but not too often	1
	Only occasionally	0

D	**I feel cheerful:**	
	Not at all	3
	Not often	2
	Sometimes	1
	Most of the time	0

A	**I can sit at ease and feel relaxed**:	
	Definitely	0
	Usually	1
	Not often	2
	Not at all	3

D	**I feel as if I am slowed down:**	
	Nearly all the time	3
	Very often	2
	Sometimes	1
	Not at all	0

A	**I get a sort of frightened feeling like "butterflies" in the stomach:**	
	Not at all	0
	Occasionally	1
	Quite often	2
	Very often	3

D	I have lost interest in my appearance:	
	Definitely	3
	I don't take as much care as I should	2
	I may not take quite as much care	1
	I take just as much care as ever	0

A	I feel restless as I have to be on the move:	
	Very much indeed	3
	Quite a lot	2
	Not very much	1
	Not at all	0

D	I look forward with enjoyment to things:	
	As much as I ever did	0
	Rather less than I used to	1
	Definitely less than I used to	2
	Hardly at all	3

A	I get sudden feelings of panic:	
	Very often indeed	3
	Quite often	2
	Not very often	1
	Not at all	0

D	I can enjoy a good book or radio or TV program:	
	Often	0
	Sometimes	1
	Not often	2
	Very seldom	3

Appendix C

Acute Stress Disorder Scale (ASDS)
Bryant, R., Moulds, M., & Guthrie, R. (2000). Acute Stress Disorder Scale: A self-report measure of Acute Stress Disorder. *Psychological Assessment, 12*(1), 61 - 68.
Contact: Richard Bryant, PhD rbryant@psy.unsw.edu.au

Briefly describe your recent traumatic experience:

Did the experience frighten you?   Yes   No

Please answer each of these questions about how you have felt since the event.
Circle one number next to each question to indicate how you have felt.
> **1 =** *Not at all*
> **2 =** *Mildly*
> **3 =** *Medium*
> **4 =** *Quite a bit*
> **5 =** *Very much*

1. During or after the trauma, did you ever feel numb or distant from your emotions?	1	2	3	4	5
2. During or after the trauma, did you ever feel in a daze?	1	2	3	4	5
3. During or after the trauma, did things around you ever feel unreal or dreamlike?	1	2	3	4	5
4. During or after the trauma, did you ever feel distant from your normal self or like you were watching it happen from outside?	1	2	3	4	5
5. Have you been unable to recall important aspects of the trauma?	1	2	3	4	5
6. Have memories of the trauma kept entering your mind?	1	2	3	4	5
7. Have you had bad dreams or nightmares about the trauma?	1	2	3	4	5
8. Have you felt as if the trauma was about to happen again?	1	2	3	4	5
9. Do you feel very upset when you are reminded of the trauma?	1	2	3	4	5
10. Have you tried not to think about the trauma?	1	2	3	4	5
11. Have you tried not to talk about the trauma?	1	2	3	4	5
12. Have you tried to avoid situations or people that remind you of the trauma?	1	2	3	4	5
13. Have you tried not to feel upset or distressed about the trauma?	1	2	3	4	5

14. Have you had trouble sleeping since the trauma?	1	2	3	4	5
15. Have you felt more irritable since the trauma?	1	2	3	4	5
16. Have you had difficulty concentrating since the trauma?	1	2	3	4	5
17. Have you become more alert to danger since the trauma?	1	2	3	4	5
18. Have you become jumpy since the trauma?	1	2	3	4	5
19. When you are reminded of the trauma, so you sweat or tremble or does your heart beat fast?	1	2	3	4	5

Appendix D

Impact of Event Scale – Revised

INSTRUCTIONS: Below is a list of difficulties people sometimes have after stressful life events. Please read each item, and then indicate

how distressing each difficulty has been for you DURING THE PAST SEVEN DAYS with respect to _____,

which occurred on _____. How much were you distressed or bothered by these difficulties?

Item Response Anchors are 0 = Not at all; 1 = A little bit; 2 = Moderately; 3 = Quite a bit; 4 = Extremely.

The Intrusion subscale is the MEAN item response of items 1, 2, 3, 6, 9, 14, 16, 20. Thus, scores can range from 0 through 4.

The Avoidance subscale is the MEAN item response of items 5, 7, 8, 11, 12, 13, 17, 22. Thus, scores can range from 0 through 4.

The Hyperarousal subscale is the MEAN item response of items 4, 10, 15, 18, 19, 21. Thus, scores can range from 0 through 4.

1. Any reminder brought back feelings about it.

2. I had trouble staying asleep.

3. Other things kept making me think about it.

4. I felt irritable and angry.

5. I avoided letting myself get upset when I thought about it or was reminded of it.

6. I thought about it when I didn't mean to.

7. I felt as if it hadn't happened or wasn't real..

8. I stayed away from reminders of it.

9. Pictures about it popped into my mind.

10. I was jumpy and easily startled.

11. I tried not to think about it.

12. I was aware that I still had a lot of feelings about it, but I didn't deal with them.

13. My feelings about it were kind of numb.

14. I found myself acting or feeling like I was back at that time.

15. I had trouble falling asleep.

16. I had waves of strong feelings about it.

17. I tried to remove it from my memory.

18. I had trouble concentrating.

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

20. I had dreams about it.

21. I felt watchful and on-guard.

22. I tried not to talk about it.

Total IES-R score:_____

Appendix E

Demographic Questionnaire

Code name:_____

Instructions: Please answer the following questions.

1. What is your age in years? _____

2. What is your gender?

    ____ Female ____ Male

3. What is your highest level of education?

    ____ 8th grade   ____ GED   ____ Graduate school
    ____ Some high school   ____ Some college
    ____ High school graduate   ____ 4 year College graduate
4. What is your relationship to patient? _____

5. Was this a planned admission?

    ____ Yes   ____ No

6. What was the patient's health status before admission to the ICU?

    Poor _____ : _____: _____: _____ : _____ Excellent

7. Why was the patient admitted to the ICU?

    _____

8. How often do you use a computer? Mark only one.
    Daily   **Weekly**   ___ Never
    __ < 1 hr   ___ Once/ week
    ___1 – 3 hrs   ___ 2 -3 times/ week
    ___ > 3 hrs

9. Have you or a family member had an ICU experience within the past 2 years?

    ___ Yes   ____ NO

Appendix F

Code Name:_____

ICU Satisfaction Survey for Web-Based Education and Standard Education

1. Please rate the education provided by the nurses about the ICU.
       ____Excellent   ____Good   ____Fair   _____Poor
       Please explain:

2. Please rate the education provided by the physicians.
       ____Excellent   ____Good   ____Fair   _____Poor
       Please explain:

3. Can you tell me anything else the nurses and doctors that might be included that would help you?
       Please explain:

4. Please rate the web-based education program ICU-USA if you used it.
       ____Excellent   ____Good   ____Fair   _____Poor   ____ Did not use
       Please explain:

5. Can you tell me anything the web-based education program ICU-USA if might be included that would help you?
       Please explain:

Appendix G

Code Name:_____

ICU Education Satisfaction Survey for Standard Education

1. Please rate the education provided by the nurses about the ICU.
    ____Excellent   ____Good   ____Fair   ____Poor
       Please explain:

2. Please rate the education provided by the physicians.
    ____Excellent   ____Good   ____Fair   ____Poor
       Please explain:

3. Can you tell me anything else the nurses and doctors that might be included
    that would help you?
       Please explain:

Appendix H

INFORMED CONSENT FORM

TO TAKE PART IN A RESEARCH STUDY

TITLE: A Comparison of the Effects of a Web-Based Education Program about the ICU Environment and a Standard Education Program on Anxiety, Depression, and Acute Stress Experienced Among Family Members of ICU Patients

PROTOCOL NO:

PRINCIPAL INVESTIGATOR: **Jody Oliver, BSN, RN**
Princeton Baptist Medical Center
701 Princeton Avenue SW
Birmingham, AL 35211-1399
(205) 783-7674

CO-PRINCIPAL INVESTIGATOR: **Chrystal Lewis, MSN, RN**
University of Alabama
Box 870358
Tuscaloosa, AL 35487-0358
(314) 703-7208

A. INFORMATION ON THE RESEARCH STUDY

Please read this form carefully before you sign it. This consent form will help you decide whether or not to take part in this study. As you read it, you may find words that you do not understand. If you do, be sure to ask your doctor or one of his staff to explain them to you. After you finish reading and the study doctor or a staff member has fully explained the study to you, you should ask the study doctor any questions that you might have about the study. After he answers all your questions and you agree to be part of the study, you will be asked to sign this form. You need to completely understand the risks and benefits of the study before you decide to take part. You will be given a copy to take home.

1. <u>**Why is this study being done?**</u>

You are being asked to participate in the above research study conducted by Chrystal Lewis, a doctoral student at the University of Missouri St. Louis and faculty advisor, Dr. Jean Bachman, which is being sponsored by University of Missouri – St. Louis.   The purpose of this study is to explore the effects of a computer based education program about the intensive care (ICU) environment on the experience of anxiety, depression, and stress among family members of ICU patients. There will be a total of approximately 126 participants in this study.

2. **What is involved in participating in this study?**

    If you agree to participate in this study, the following will take place:
    You will be asked to complete the following forms:
    1. A participant contact information form asking for your name, the initials of the family member in the intensive care unit, and your telephone number. This will take 1-2 minutes to complete.
    2. A form asking for general information about yourself: age, gender, education, your relationship to the hospitalized patient, the reason for the hospital admission, your frequency in using a computer, and whether or not you have had a family member hospitalized in the ICU in the past two years. This will take 2-5 minutes to complete.
    3. The Hospital Anxiety and Depression Scale: a 14-item questionnaire asking you to rate your frequency of experiencing various emotional states in the past week. This will take 2 -5 minutes to complete.
    4. The Acute Stress Disorder Scale: a 19-item questionnaire asking you to indicate the degree to which you have experienced various common responses to difficult situations. This will take 2-5 minutes to complete.
    5. The Impact of Events Scale-Revised: a 22-item questionnaire asking you to indicate how many certain items have been upsetting to you in the past week. This will take 5-7 minutes to complete.
    Total time for visit 1: 15- 30 minutes.

    Everyone will receive ICU information by the staff as routinely given.

    Some participants will be asked to view a computer program explaining the ICU environment and commonly used equipment. Participants will be randomly chosen to view the computer program. If you are asked to view the computer program, the researcher will show you how to use the program and will also be available to help you with any technical difficulties in using the program. The program allows you to click on a piece of equipment and learn more about how and why it is used to provide patient care and find answers to questions about the ICU. Viewing the program takes an additional **10 -30 minutes** and will be available for you to use at a time of your convenience in a private room in the ICU.   If you view the computer program, you will also be given information on how to view it on your own at home or on any computer or tablet. Other information about the ICU environment will be provided by ICU staff which is given to all patients and family members in the ICU.

    One week after you complete the forms, you will be asked to complete the following forms a second time: 1. The Hospital Anxiety and Depression Scale
    2. The Acute Stress Disorder Scale
    3. The Impact of Events Scale- Revised

    You will also complete a short survey of your satisfaction with the teaching you received from the ICU staff or the computer program. This will take about 3 minutes to complete.

The researcher will contact you by telephone to determine your preference in completing these follow-up forms. You may complete them in person at the hospital or you may answer the questions over the telephone by having the researcher ask you the questions on the phone.

Total time for follow up: 15- 30 minutes

This will complete your participation in the study: no further contact by the researcher will be made for this study.

3. <u>**What are the risks and discomforts from taking part in this study?**</u>

    The following risks or discomforts may occur from participation in this research study.

    The risks or discomforts from participating in this study are minimal. Some of the survey and questionnaire items may be uncomfortable to answer, but you are free to skip any items for which you have no answer or would prefer not to answer. There is always a risk of loss of confidentiality; however we will take care to prevent that from happening. All forms and surveys will be coded with a unique code number and will not contain information that identifies individuals. The contact form does ask for your name and telephone number, but this is needed in order to assign code numbers and to contact you to complete the follow-up questionnaires. Only the principal investigator will be able to connect names to code numbers and this information will be destroyed after being put into a password protected computer file to which only the principal investigator will have access.

4. <u>**What are the benefits of taking part in this study?**</u>

    The following benefits may occur from participation in this research study.
    Benefits to participating in this study include a potential for improved education about the ICU environment.   Also, your participation will help society by increasing awareness of what family member needs of ICU patients are. In addition, you will receive $10 upon completion of the first visit.

5. <u>**What are the alternatives to participating in this study?**</u>

PARTICIPATION IN THIS RESEARCH STUDY IS ENTIRELY VOLUNTARY

   a. If you decide not to take part in the study, you will not be giving up any of your rights, and you will not be denied any benefits or medical care. You will still receive the same amount of education that is provided to all ICU patients and family members. .

   b. After you begin the study, you are free to stop taking part in the study at any time. You will not be giving up any of your rights. You will not be denied any benefits or medical care.

6. What are the costs of participating in this study?

There are no costs to you to participate in this study.

7. What about confidentiality?

While absolute confidentiality cannot be guaranteed, every effort will be made to keep your personal information confidential. To help insure this confidentiality, information obtained from this study will be maintained in the following manner: Consent forms and contact forms will be separated from the instrument forms. The consent forms will be stored in a separate, locked cabinet. Data will be entered into a password protected database. The data will be de-identified.
In addition, your personal information may be disclosed, if required by law. If you have any questions or concerns regarding this study, or if any problems arise, you may call the Investigator, Chrystal Lewis at 314-703-7208 or the Faculty Advisor, Dr. Jean Bachman 314 516-6075. You may also ask questions or state concerns regarding your rights as a research participant to the University of Missouri- St. Louis Office of Research Administration, at 314- 516-5897.

AUTHORIZATION TO USE AND SHARE PERSONAL HEALTH INFORMATION

a. **What information about you may be used and shared?**
    We are asking you to take part in the research described in this consent form. To do this research, personal health information that identifies you will be collected, copied, and used for research related purposes. We may collect the results of tests, questionnaires and interviews. We may also collect information from your medical record. We will only collect information that is needed for the research that is described in this consent form. Examples of the information that may be collected include your name, address, telephone number, date of birth, Social Security number and results of all the tests and procedures done before and during the study. For you to be in this research, we need your permission to collect and share this information.

b. **Who will use and share my information?**
    You are allowing the study investigator and her staff to use, copy and share your personal health information with the Baptist Health System and its representatives, the Baptist Health System Human Research Review Board, Jody Oliver, and Chrystal Lewis

c. **Who will receive my information?**
    We will share your health information with people at the hospital who help with the research. We may share your information with other study doctors outside of the hospital. We may also share your information with people outside of the hospital who are in charge of the research, pay for or work with us on the research. Some of these people make sure we do the research properly. They are the study sponsor or representatives of the sponsor, the Food and Drug Administration, the Department

of Health and Human Services agencies, the Baptist Health System Human Research Review Board and maybe even government agencies in other countries.

d. Why will my information be shared?
Your information will be used and shared to conduct the study and to evaluate and analyze the results of the research.

e. How long will my information be used or shared?
If you sign this form, we will collect and use your health information until the end of the research. We may collect some information from your medical records even after your direct participation in the research project ends.

f. What if you do not give permission?
If you sign this form, you are giving us permission to collect, use, copy and share your health information including your medical records. You do not need to sign this form. If you decide not to sign this form, you cannot be in the research study. You need to sign this form if you want to be in the research study. We cannot do the research if we cannot collect, use and share your health information.

g. What if you want to cancel your permission?
If you change your mind later and do not want us to collect or share your health information, you need to send a letter to see section 8. The letter needs to say that you have changed your mind and do not want the study doctor to collect and share your health information. You may also need to leave the research study if we cannot collect any more health information. We may still use the information we have already collected. We need to know what happens to everyone who starts a research study, not just those people who stay in it. **Please note that canceling this permission is not the same as deciding not to take part in the study (see Section 9).**

h. Is your information protected once it is given to others?
Some of the people that will use your personal health information may share it with someone else. If they do, the same laws that the hospital must obey may not protect your health information. It may be used or shared without your permission.

8. HOW TO LEARN MORE ABOUT THE STUDY OR RAISE CONCERNS

Jody Oliver or Chrystal Lewis will answer any questions you have about this study. These individuals are available to answer your questions before, during, and after the study. They can be contacted at (205)783-7674 or (314)703-7208.

If you have any questions about your rights as a research subject, contact the Baptist Health System Human Research Review Board, Suite 1000 Ridge Park Place, 1130 22nd Street South Birmingham, Alabama 35205 at (205) 715-5308.

9. Can I withdraw or be withdrawn from the study?

The Principal Investigator will share with you any new information that becomes available that could affect your willingness to continue in this study. Your participation in this study is voluntary, and you may withdraw from this study at any time by notifying the principal investigator in writing of your decision to do so. It is important that you notify the investigator of your decision to withdraw so that he/she can discuss any safety issues which may involve your withdrawal. Your decision to withdraw will not result in any penalty or loss of benefits to which you are otherwise entitled.

After you begin the study, you are free to stop taking part in the study at any time. You will not be giving up any of your rights. You will not be denied any benefits or medical care. If your study doctor feels that you are in any danger or the study treatment is not working, your study treatment could be stopped without your consent. If this happens or you decide not to be in the study any longer, you will be encouraged to come back one more time for a final checkup

Please note that your decision to quit the study or your being withdrawn from the study

does not cancel the permission you gave to use and disclose your health information in

the study. To cancel the permission you gave to use and disclose your health information, you need to send a letter to Chrystal Lewis (see Section 7.g.).

If you withdraw from the study, please notify the investigator at: lewischr@umsl.edu or in writing:

Chrystal Lewis
The University of Alabama
Box 870358
Tuscaloosa, AL 35487-0358

I have read this consent form and have been given the opportunity to ask questions. I will also be given a signed copy of this consent form for my records. I hereby consent to my participation in the research described above.

_____   _____

Participant's Signature   **Date**

_____   _____

Signature of Principal Investigator or   **Date**
Co-investigator

_____   _____

Signature of Individual Obtaining Consent   **Date**
(If other than investigator)

Appendix I

Participant Contact Form

Your Name: _____

Code Name: _____

Patient's Initials: _____

Today's Date: _____

Best Phone Number to Reach You at: _____
(This were used to contact you for follow up.)

Please provide your email address if you would like to receive a copy of the study's findings: _____

Appendix J

ICU – USA Instruction Card for Home Use

How to access from home or other computer:

1.) Go to http://www.icu-usa.com/

2.) Login in using your user ID: _____

3.) Click on the "Table of Contents" button on the left side of the screen.

4.) Click on the topic you want to learn more about.

5.) You can click on "Tour an ICU room" to click on equipment to get

explanations of the equipment you will encounter.