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# Stress Appraisal, Coping Behaviors, and Level of Distress in an Ethnically Diverse Sample of Mothers with a Child in the Pediatric Intensive Care Unit

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UNIVERSITY OF MIAMI

STRESS APPRAISAL, COPING BEHAVIORS, AND LEVEL OF DISTRESS IN AN  
ETHNICALLY DIVERSE SAMPLE OF MOTHERS WITH A CHILD IN THE  
PEDIATRIC INTENSIVE CARE UNIT

By

Mary E. Ernst

A DISSERTATION

Submitted to the Faculty  
of the University of Miami  
in partial fulfillment of the requirements for  
the degree of Doctor of Philosophy

Coral Gables, Florida

August 2017

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Stress Appraisal, Coping Behaviors, and Level of Distress  
in an Ethnically Diverse Sample of Mothers with a Child  
in the Pediatric Intensive Care Unit

(August 2017)

Abstract of a dissertation at the University of Miami.

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Having a child in the Pediatric Intensive Care Unit (PICU) places parents at risk for Acute Stress Disorder (ASD) symptoms. ASD symptoms, or primary negative responses to a traumatic event, may increase parents' risk for developing long-term Posttraumatic Stress Disorder (PTSD) one or more months later. The purpose of this study is to examine the stress appraisal, coping behaviors, and level of distress due to ASD in an ethnically diverse sample of mothers with a child in the PICU, while controlling for socioeconomic factors. A quantitative cross-sectional design, which surveyed mothers with a child age one day to 17 years in the intensive care unit, was used for this study. The instruments included in the survey were a Parent Demographic Sheet, the Pediatric Stressor Scale: Pediatric Intensive Care Unit, the Brief COPE, and the Acute Stress Disorder Scale. Results of this study add to the literature on parental stress and coping behaviors of minority mothers with a child in the PICU and can be used to guide culturally tailored nursing interventions to improve coping and decrease ASD symptoms in this population of mothers.

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## Chapter 1 - Introduction

More than 200,000 children are admitted to a pediatric intensive care unit (PICU) annually (Turner, Simpson, Li, Scanlon, & Quasney, 2011; Ularntinon, Bernard, Wren, St. John, Horwitz, & Shaw, 2010). While differences in mortality rates do not appear to be associated with race/ethnicity after admission to the PICU (Epstein, Wong, Khemani, Moromisato, Waters, Kipke, & Markovitz, 2011; Flores, 2010; Turner, Simpson, Li, Scanlon, & Quasney, 2011), racial/ethnic minority children demonstrate an increased risk for admission to a PICU compared to white non-Hispanic (WNH) children (Flores, 2010; Mitchell, Bilderback, Sande, & Okelo, 2016; Turner et al., 2011). This may be due in part to the “extensive, pervasive and persistent” racial disparities seen for minority children in areas such as asthma and unintentional and intentional injury (Flores, 2010, p. e979). Minority children experience higher rates of poverty, drowning, firearm and household injuries, respiratory illnesses, and are at higher risk for being victims of violence, all of which can result in a PICU admission (Epstein et al., 2011; Flores, 2010; Mitchell, Bilderback, & Okelo, 2016).

The pediatric population in the United States (US) has surged in recent years, most notably among Hispanics. These demographic changes will be reflected in PICU across the country. Trends suggest that minority children will comprise half of the pediatric population by 2040. Hispanic children nationwide currently comprise the largest minority group, followed by African American (AA) children. In large cities with ethnically diverse populations, such as Miami, Florida, children are often the “minority majority” (Flores, 2010, p. e981).

Minority majority means that while Hispanic children are considered a minority nationally, in Miami-Dade County they are the majority. For example, 2014 data shows that Hispanics of any race comprise the majority of the population in Miami-Dade County at 66%, while AAs and WNHs constitute 17% and 15% of the population, respectively (RER Planning Research & Economic Analysis, 2015). For urban PICUs like those in Miami, understanding the stress and coping experiences of ethnically diverse families with a child in the PICU is critical to providing quality, family-centered care.

### **Parental Stressors and Coping with a Child in the PICU**

Since the emergence of the PICU over 40 years ago, many developments have occurred in the care provided to patients and families. Medical technology, medications, treatment plans, and the philosophy of care have advanced significantly. These changes contribute to the decreasing mortality rates for children admitted to the PICU (Shudy, de Almeida, Ly, Landon, Groft, Jenkins, & Nicholson, 2006). The one consistent phenomenon is the distress that a parent will experience when their child is admitted to the PICU.

PICU admissions often occur suddenly in previously healthy children with little exposure to the hospital environment. The novelty of the PICU environment and the uncertainty and ambiguity of the child's health outcome are factors in the degree of distress experienced by parents (Lazarus & Folkman, 1984). It is no surprise then that parents of children with unplanned admissions to the PICU experience higher levels of distress compared to parents of a child with a planned admission (Board & Ryan-Wenger, 2003; Eberly, Miles, Carter, Hennessey, & Riddle, 1985).

Researchers have conducted a substantial number of qualitative and quantitative studies over the past 30 years to gain insight into parental experiences in the PICU (Ames, Rennick, & Baillargeon, 2011; Board & Ryan-Wenger, 2003; Foster, Whitehead, Maybee, & Cullens, 2013; Johnson, Nelson, & Brunnquell, 1988; Kassam-Adams, Fleisher, & Winston, 2009; Melnyk, 1994; Miles, Carter, Riddle, Hennessey, & Eberly, 1989; Miles & Carter, 1982; Seideman, Watson, Corff, Odle, Haase, & Bowerman, 1997). Based on these findings, the most salient stressor for parents is that the outcome for the child is often unknown. In addition, changes in the parental role and the child's behavior and emotional responses have been the commonly reported stressors, with mothers experiencing greater distress than fathers in both of these areas (Carter, Miles, Buford, & Hassanein, 1985; Jee, Shepherd, Boyles, Marsh, Thomas, & Ross, 2012; Lisanti, Ryan Allen, Kelly, & Medoff-Cooper, 2017). Other stressors include the child's appearance, the sights and sounds of the PICU environment, procedures done to the child, and the PICU staff's communication and behaviors (Melnyk, Feinstein, & Fairbanks, 2006; Miles & Carter, 1982; Seideman et al., 1997; Shudy et al., 2006). Research has shown that providing parents with parental role and child behavioral information can result in decreased parental distress (Melnyk, 1994; Melnyk, Feinstein, & Fairbanks, 2006), yet routine assessment of parental distress and the implementation of formal interventions for parents are not routinely utilized in the PICU setting (Marsac, Hildenbrand, Kohser, Winston, Li, & Kassam-Adams, 2013; Winston, Kassam-Adams, Garcia-Espana, Ittenbach, & Cnaan, 2003).

Having a child diagnosed with a life-threatening illness or injury is recognized as a potentially traumatic event by the American Psychiatric Association and is often

viewed within a posttraumatic stress framework (Woolf, Muscara, Anderson, & McCarthy, 2016). The experience of having a child admitted to the PICU was found to put parents at risk for experiencing Acute Stress Disorder (ASD) symptoms in the initial phase of the trauma (Ularntinon et al., 2010). The trauma for parents in this situation is the potential threat to their child's life, health or future (Woolf et al., 2016). In addition, the environmental stressors associated with the PICU can add to the parent's level of distress. ASD symptoms include dissociation, re-experiencing, avoidance and arousal, and coincide with the intense fear or helplessness experienced in response to a trauma. These symptoms occur in the acute phase of the trauma, which is considered to be between 3 days and 4 weeks after the trauma (Sadock, Sadock, & Ruiz, 2015). These primary negative responses, i.e., ASD symptoms, may indicate parents have a higher risk for developing long-term Posttraumatic Stress Disorder (PTSD) (Balluffi, Kassam-Adams, Kazak, Tucker, Dominguez, & Helfaer, 2004; De Young, Hendrikz, Kenardy, Cobham, & Kimble, 2014; Kassam-Adams, Fleisher, & Winston, 2009; Ularntinon et al., 2010), although the predictive relationship between initial ASD and the development of PTSD remains debatable (Bryant, Friedman, Spiegel, Ursano, & Strain, 2011).

The diagnosis of PTSD is made when symptoms persist for at least one month after the trauma. Symptoms of PTSD include intrusive nightmares or flashbacks, a sense of helplessness or lack of control, and hypervigilance or overprotectiveness toward the child. These negative psychological outcomes can occur even when the child achieves a full physical recovery from their injury or illness (Sadock, Sadock, & Ruiz, 2015; Ularntinon et al., 2010).

The rate of parental ASD varies from 15 - 48%, while rates for those who go on to display PTSD symptoms are estimated to be 15 - 25% (Nelson & Gold, 2012; Ularntinon et al., 2010; Woolf et al., 2016). Prior trauma exposure of the parent and factors such as medical trauma to the child, perceived life threat and pain associated with PICU care are predictors of parent ASD in the initial phase of the trauma. Parent ASD and poorer child health outcomes are predictors of parent PTSD after discharge from the PICU. These PTSD symptoms may impair a parent's ability to manage the care of their well, recovering, or disabled child (Kassam-Adams et al., 2009). Although it is clear that parents of PICU patients experience significant distress, there is little evidence to show what healthcare providers are doing to assist them (Rzucidlo & Campbell, 2009; Ward-Begnoche, 2007; Winston et al., 2003).

Understanding the relationships between stressors, coping and a parent's level of distress can be the foundation for interventions to better assist parents in managing a PICU experience. Coping is a complex, ever changing phenomenon. How a parent is able to cope with the situation is multifactorial. Research on parental coping in the PICU has provided data to support that being with the child, getting information, and feeling that the child is getting the best possible care are some of the most important needs of parents (Jee, Shepherd, Boyles, Marsh, Thomas, & Ross, 2012; Melnyk, 1994; Miles & Carter, 1985; Seideman et al., 1997). Most recently it has been suggested that subjective appraisals by the parent about the child's illness or injury, regardless of the medical severity of the illness, can have a great impact on parental psychological outcomes (Woolf et al., 2016).

Early studies on parental distress in the PICU include, almost exclusively, samples consisting of WNH mothers. Research focusing on the specific needs and coping behaviors of parents from other ethnic groups in the PICU are limited (Noyes, 1998; Shudy et al., 2006; Woolf et al., 2016). While international research on parental distress and coping in the PICU has been published from nine different countries over the past 10 years, research with ethnically diverse samples in the US has been relatively sparse, which limits the generalizability of outcomes to ethnic minority populations (Foster, Whitehead, Maybee, & Cullens, 2013). Given the demographic changes predicted in the US in the coming years, this lack of research in ethnically diverse populations on the issue of parental distress in the PICU is especially concerning (Flores, 2010).

### **Theoretical Framework**

The primary theory that underpins the current study is Lazarus and Folkman's Transactional Model of the Stress and Coping Process (Lazarus & Folkman, 1984). By utilizing this framework, the relationship between the variables will be tested in the context of parental stress and coping in the PICU/CICU. The Multicultural Model of Stress, which is an expanded version of Lazarus & Folkman's Model, is incorporated as a backdrop to the stress and coping framework to allow for the inclusion of ethnic diversity into the model in an explicit way (Slavin, Rainer, McCreary, & Gowda, 1991). The dissertation framework and specific aims addressed are depicted in Figure 1.1.

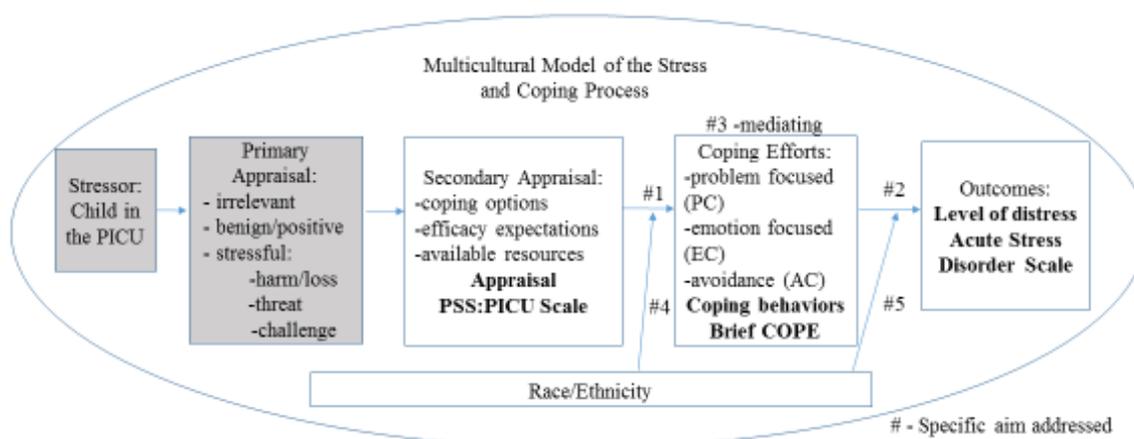


Figure 1.1. Theoretical framework and specific aims addressed.

The proposed study will add to the literature on parental stress in the PICU/CICU by testing the relationships between the variables in the Stress and Coping Model in the context of having a child in the PICU/CICU. Part of the analysis will examine the potential mediating effect of the type of coping behaviors on the level of distress of the mothers. By including an ethnically diverse sample, the moderating effect of race and ethnicity, if any, on the relationship between environmental stressors and coping behaviors and the relationship between coping behaviors and level of distress will be assessed.

In multicultural cities like Miami, it is important to include ethnically diverse samples when doing research so that a variety of populations are represented in the data. Capturing the similarities and differences of the individuals in a diverse sample can act as a baseline for future studies. It can also provide guidance to nurses caring for diverse families in the PICU/CICU setting. Results of this study can be used to develop culturally tailored nursing interventions for ethnically diverse mothers experiencing the stress of having a child in the PICU/CICU in the effort to minimize the incidence of ASD and PTSD in mothers.

## **The Impact of Race/Ethnicity on Appraisal, Coping Behaviors and Level of Distress**

Race and ethnicity are constructs that are not easily distinguished or defined, and the utility of applying these factors in isolation to contrast outcomes between individuals is arguable (Baer et al., 2013). In the current study, race and ethnicity are included as two variables of many that will be used to categorize, compare and understand potential differences in individual outcomes related to the stress process of mothers with a child in the PICU/CICU. There is research that suggests that there are ethnic and racial differences in the appraisal, coping behaviors and distress levels of parents whose child experiences an illness or injury, and those studies will be discussed below.

Stressors for Hispanic parents may be different than those for WNH parents. In a pilot study, researchers tested the Spanish Parental Stressor Scale: Pediatric Intensive Care Unit (SPSS:PICU) on a small sample ( $N = 18$ ) of Hispanic parents with a child in the PICU. These responses were compared to the results of the original studies on the PSS:PICU, which included a majority of WNH mothers. Researchers found differences in what parents reported to be most stressful about being in the PICU. Specifically, Hispanic parents demonstrated increased distress related to sights and sounds in the PICU and procedures done to the child. In comparison, WNH mothers were most distressed by the change in parental roles and the child's behavior and emotions. Results suggest that there may be differences in what aspects of the PICU are stressful to parents based on ethnicity (Rei & Fong, 1996).

In a study by Yeates et al. (2002) which focused on coping behaviors of parents whose child suffered a traumatic brain injury, researchers found that AA parents relied more on religion, mental disengagement and denial in coping with their child's injuries.

This was in contrast to WNH parents who relied more on acceptance. Ratings of parent distress and family burden were lower for AA parents during the acute phase of the trauma, but higher than WNH parents at 6 and 12 months post injury. Comparisons at each time point were made while controlling for socioeconomic status (SES).

Researchers found that race was a consistent moderator of family outcomes, independent of SES, and suggest that the utilization of different coping behaviors between racial groups may contribute to the contrast in outcomes (Yeates, Taylor, Woodrome, Wade, Stancin, & Drotar, 2002).

African American parents may experience higher rates of ASD and PTSD than WNH parents. While diverse samples have not often been found in the literature on this topic, one study was found that specifically compared racial differences in mental health outcomes for parents of children admitted to the PICU. In a prospective, longitudinal study looking at ASD symptoms and long-term PTSD occurrence, researchers found that AA parents had a higher symptom severity of ASD in the acute phase of the trauma compared to WNH parents. AA parents were also found to be more likely to develop PTSD symptoms months after discharge (Balluffi et al., 2004).

Beyond the three studies aforementioned, there remains a paucity of literature specific to parental distress in the PICU/CICU that focuses on ethnically diverse populations. The small percentage of minority parents represented in most samples make generalizability of results to other populations unreliable. In addition, many studies address stressors, coping behaviors, or mental health outcomes individually, instead of viewing how these variables may relate to one another in the framework of the stress and coping process.

Therefore, more data is needed to describe the stress and coping process for ethnically diverse mothers with a child in the PICU/CICU. Nurses are the frontline healthcare professionals interacting with parents consistently throughout their hospitalization. It is vital for nurses to understand the impact that PICU/CICU stressors will have on parents and some of the different ways that parents may cope with the situation. It is important that nurses are knowledgeable about the potential negative outcomes that the PICU/CICU experience may have on parents. Lastly, nurses must be made aware of ways in which they can positively intervene to improve mental health outcomes for ethnically diverse mothers in the PICU and CICU (Balluffi et al., 2004; Lisanti, Ryan Allen, Kelly, & Medoff-Cooper, 2017; Yeates et al., 2002). Outcomes from this study can provide baseline information for nurses to develop and implement ethnically tailored interventions for minority parents navigating their family's experience in the PICU or CICU.

### **Purpose, Specific Aims and Hypotheses**

The purpose of this study is to examine the appraisal, coping behaviors, and level of distress in an ethnically diverse population of mothers with a child in the PICU/CICU. Analyses will be performed while controlling for socioeconomic factors. The specific aims and hypotheses (H) of this study are presented below and depicted above in Figure 1.1.

Specific aim 1: To examine the relationship between appraisal and coping behaviors of ethnically diverse mothers with a child in the PICU/CICU when controlling for socioeconomic factors.

H1: There will be a significant relationship between appraisal and coping behaviors.

Specific aim 2: To examine the relationship between coping behaviors and level of distress of ethnically diverse mothers with a child in the PICU/CICU when controlling for socioeconomic factors.

H2a: The use of problem focused coping will be inversely associated with level of distress.

H2b: The use of emotion focused coping will be inversely associated with level of distress.

H2c: The use of avoidance coping will be positively associated with higher levels of distress.

Specific aim 3: To examine if coping behaviors mediate the relationship between appraisal and level of distress in ethnically diverse mothers with a child in the PICU/CICU when controlling for socioeconomic factors.

H3: Coping behaviors will mediate the relationship between appraisal and level of distress.

Specific aim 4: To examine if race or ethnicity moderates the relationship between appraisal and type of coping behaviors utilized by ethnically diverse mothers with a child in the PICU/CICU when controlling for socioeconomic factors.

H4: Race/ethnicity will moderate the relationship between appraisal and type of coping behaviors.

Specific aim 5: To examine if race or ethnicity moderates the relationship between type of coping behaviors and level of distress experienced by ethnically diverse mothers with a child in the PICU/CICU when controlling for socioeconomic factors.

H5: Race/ethnicity will moderate the relationship between the type of coping behaviors and level of distress.

## Chapter 2 – Literature Review

### Theoretical Foundation

The classic Lazarus and Folkman’s Transactional Model of the Stress and Coping Process (1984) guided this dissertation on mothers with a child in the PICU and provided the conceptual framework upon which the study was built. This framework was utilized frequently in previous studies on parental stress in the PICU (e.g., Shudy et al., 2006) and will be discussed and explained in detail in the following sections. The model is depicted in Figure 2.1 below.

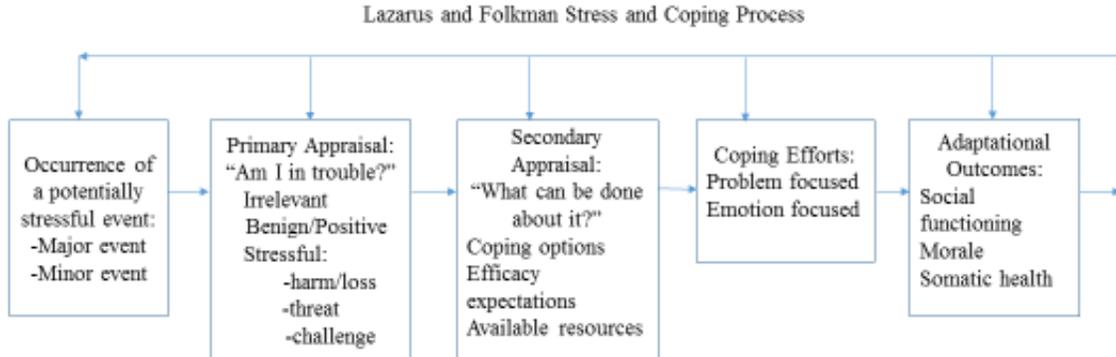


Figure 2.1. Lazarus and Folkman (1984) Stress and Coping Process.

Lazarus and Folkman’s view of stress incorporates the interaction between the person and their environment and the fact that an individual’s perception of stress will change over time (Folkman, 2010). Acknowledging the changing perceptions of stress over time, this study focused specifically on the initial, acute stress experienced by mothers whose child was admitted to the PICU/CICU for the first time. As shown in Figure 2, this framework divides the stress and coping process into five areas: the occurrence of a potentially stressful event, primary appraisal, secondary appraisal, coping efforts, and the adaptational outcome.

The occurrence of a stressful event is the initial step in the stress and coping process. This incident is determined by the individual to be a major or minor event. How a person experiences this event is a very individualized, complex and interactive process. The definition of stress for the purposes of this study is “a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being” (Lazarus & Folkman, 1984, p. 19).

Once the stressful event has occurred, a cognitive, or primary, appraisal ensues. This appraisal is an evaluative process that is encompassed by the question “Am I in trouble?” There are many factors that impact an individual’s primary appraisal of an event. Some of these are the timing, predictability, novelty, uncertainty, ambiguity, and temporal factors related to the event. Two other important factors that influence this appraisal are commitment and beliefs. Commitment refers to the meaning or importance that the event has to a person (Lazarus & Folkman, 1984). In the context of having a child in the PICU/CICU, a mother’s level of commitment is at its absolute highest when it comes to the life and health of her child, thus making any mother extremely vulnerable to stress in this situation. The second factor is a mother’s beliefs. Beliefs refer to an individual’s understanding of how things are in the environment, such that an event is appraised based on a person’s ability to control the outcome of that event (Lazarus & Folkman, 1984). Mothers are thrust into the stressful environment of the PICU/CICU and generally have very little control over the outcome for their child.

The primary appraisal allows the individual to determine if the event is irrelevant, benign-positive, or stressful. The personal quality of the primary appraisal generates

emotions and explains why an event can have very different meanings for people (Folkman, 2010). The primary appraisal is the mediating factor that puts the stress and coping process into motion. If the event is irrelevant, or deemed not to be a true stressor, then the process is stopped. In the case of a benign-positive, or major or minor stressful event, a secondary appraisal occurs (Lazarus & Folkman, 1984). For the purposes of this study, having a child unexpectedly admitted to the PICU/CICU for the first time is assumed to be a major stressful event for mothers. The uncertainty and lack of control over the outcome of the event contributes to the overwhelming stress of the mothers.

The secondary appraisal is encompassed by the question “What can be done about it?” This appraisal is an intellectual process in which the individual assesses what can be done about the stressful event. This includes thinking about: a) coping options and behaviors, b) the individual’s own efficacy expectations, and c) available resources to produce a desired outcome. Primary and secondary appraisals interact with each other to determine the emotional reactions of the individual. A person engages in continual, ongoing reappraisals of the event as more and more information from the environment is assessed (Lazarus & Folkman, 1984).

In an effort to alleviate stress, the individual implements coping behaviors. Coping is defined as “constantly changing cognition and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (Lazarus & Folkman, 1984, p. 141). Coping in the context of mothers with a child in the PICU is considered a process which takes effort; it is not viewed as a static trait of the individual.

There are a variety of coping behaviors that can be demonstrated, many of which can be evaluated as positive or negative depending on the context of the situation. As frequent reappraisals of the event occur, new coping behaviors can be initiated. This is a cyclical, interwoven process involving cognition and emotion interacting in a bidirectional manner (Folkman, 2010; Lazarus & Folkman, 1984). In the original stress and coping theory diagrammed previously, the two kinds of coping behaviors posited were emotion focused and problem focused coping behaviors. Problem focused coping behaviors are directed at managing the cause of the stress and emotion focused coping behaviors are directed at regulating the emotional response to the stress (Lazarus & Folkman, 1984). Carver (1997) operationalized coping behaviors into problem focused, emotion focused and dysfunctional strategies, breaking out behaviors he found unhelpful into the category of dysfunctional coping. These categories of coping behaviors will be used in the current study, but with the dysfunctional coping category being renamed the avoidance coping category (Cooper, Katona, & Livingston, 2008).

The product of the stress and coping process is an adaptational outcome. The individual is changed as a result of experiencing the stressful event. The consequences of this process can occur in the areas of social functioning, morale, or somatic illness. The outcomes can be considered positive or negative depending on the individual's ability to cope with that specific event (Folkman, 2010; Lazarus & Folkman, 1984). The relationship between social functioning, morale and somatic health outcomes is a complex and individualized one. Depending upon the interaction of the stressor and the individual, a positive outcome in one area does not necessarily mean a positive outcome

in the other areas. Each outcome area should be assessed individually for each person (Lazarus & Folkman, 1984).

The Transactional Model of the Stress and Coping Process will be applied to the specific context of a parent managing the experience of having a child suddenly admitted to a PICU/CICU due to illness or injury. In the following sections the evolution of knowledge and practice in the area of parental stress and coping with a child in the PICU/CICU will be presented. A synthesis of the literature will be provided as a backdrop to the current study so that it can be put in the theoretical context in which it is intended.

### **Parental Distress with a Child in the PICU**

An unexpected illness or injury to a child is a stressful event for the parent. Seeing the child for the first time with cardiac monitors, lines and tubes attached to them can be traumatic and overwhelming. The alarms from equipment, medical terminology spoken by healthcare workers, and the inability to touch, hold and protect the child are just a few of the stressors that parents will experience while in the PICU (Miles et al., 1989b). It is estimated that on average, 25% of parents will suffer from PTSD as a result of the PICU experience, regardless of the outcome of their child (Ularntinon et al., 2010). A timeline of research on parental stress and coping in the context of the PICU setting is presented in the following paragraphs.

#### **PICU environment.**

In the late 1970's and early 1980's, parents were given minimal access to their critically ill children. Technology created an unwelcoming physical environment and the healthcare team considered parents to be in the way and "visitors" to their children and

the PICU. Early studies found that parents with a child in the PICU experienced more stress than parents with a child on the general floors (Jay, 1977; Miles, 1979). What was not yet known was the source of parental stress and how to measure it.

### **Instrument development.**

The pioneering research associated with parental stress in the PICU was done by Miles and Carter (1982), nurse researchers who had clinical experience in the PICU setting. Miles and Carter (1982) used an inductive approach to determine what aspects of the PICU environment were perceived by parents to be stressful. Their initial work was based on Selye's (1936) theory of stress and Roy's (1976) model of the nursing process. Clinician observations and formal and informal interviews were categorized and coded into dimensions of stressors perceived by parents in the PICU environment. This research was utilized to develop a scale to measure parental perceptions of stressors in the PICU named the Parental Stressor Scale: Pediatric Intensive Care Unit (PSS:PICU) (Miles & Carter, 1982).

This scale was designed to: 1) assess the stressors for parents in seven domains related specifically to the intensive care environment, 2) determine which behaviors by the healthcare team were helpful to parents, and 3) determine which coping behaviors the parents utilized. With a sample of 510 parents, Miles et al. (1989) performed an item analysis and exploratory factor analysis to assess the seven domains of the PSS:PICU. Initial psychometric properties and reliability and validity of the PSS:PICU were then published (Miles, Carter, Hennessey, Eberly, & Riddle, 1989).

Miles and Carter (1985) also developed the Parental Coping Scale:PICU (PCS:PICU). This scale was divided into two sections. The first section assessed the

frequency of specific staff interventions and parental perceptions about the helpfulness of each intervention. The second section assessed the coping behaviors utilized by parents and their perception of the helpfulness of those behaviors. In this initial study, researchers broke down coping behaviors into appraisal focused (e.g., having hope, believing child is getting the best care), problem focused (e.g., seeking information, asking questions) and emotion focused (e.g., sharing concerns, crying, seeking comfort) categories (Miles & Carter, 1985). While the PCS:PICU scale has not been used in recent studies, the PSS:PICU remains the most frequently utilized scale in quantitative research focusing on the stressors of PICU parents (Shudy et al., 2006). There are a number of modified versions for the tool, including the PSS:Neonatal Intensive Care Unit (PSS:NICU), PSS:Infant Hospitalization (PSS:IH), and the PSS:Child Hospitalization (CH). Recent studies have used the PSS:IH and PSS:CH when assessing parents with infants and children in the CICU (Franck et al., 2010; Lisanti et al., 2017; Shaw, DeBlois, Ikuta, Ginzburg, Fleisher, & Kloopman, 2006).

### **Parental Stressors in the PICU**

The alteration in parental role and the child's behaviors and emotions were found to be the two most consistent stressors for parents in the PICU (Eberly et al., 1985; Johnson et al., 1988; LaMontagne, Johnson, & Hepworth, 1995; Lisanti et al., 2017; Miles & Carter, 1982; Seideman, et al., 1997). Alteration in parental role is encompassed by parents feeling that they are helpless in performing normal parenting duties, such as nurturing and caring for their child. Items such as being separated from the child, the inability to protect, console or hold the child, and not knowing how to help their child

through this experience are reported to be the most stressful for parents (LaMontagne et al., 1995; Lisanti et al., 2017; Miles et al., 1989; Seideman et al., 1997).

The stressor of the child's emotions and behaviors includes responses of the child to PICU care. This encompasses things such as child unresponsiveness, rebellion, withdrawal, or showing signs of pain, along with the child's expressions of anger, fear or sadness (Lisanti et al., 2017; Miles & Carter, 1982; Seideman et al., 1997). Research studies supporting these stressors will be discussed in more detail.

In a study funded by the National Institutes of Health and conducted by Miles, Carter, Riddle, Hennessey, and Eberly (1989), nurse researchers used a sample of 510 parents from five different PICUs to evaluate their conceptual model on parental stress and to test the PSS:PICU scale. The sample included 324 mothers and 186 fathers, with 85% of the sample consisting of WNH parents. The most stressful items for parents were the alteration in parenting role and the child's behaviors and emotions. The four most stressful items in the alteration in parental role dimension were the inability to protect, help and hold the child, along with being separated from the child. The four most stressful items in the child's behaviors and emotions dimensions were seeing the child in pain, inability of the child to communicate, and seeing the child frightened and sad. Results supported findings from an earlier pilot study by the authors and was the foundation for parental stress research (Carter et al., 1985; Miles et al., 1989).

In 1996, a pilot study by Rei and Fong was conducted in which their newly developed Spanish Parental Stress Scale: Pediatric Intensive Care Unit (SPSS:PICU) was utilized with Hispanic, Spanish-speaking parents. The sample consisted of 20 parents, 15 mothers and 5 fathers, who self-identified as Hispanic. The highest stressors for Hispanic

parents were sights and sounds of the PICU, procedures and the child's behaviors and emotions. These results were compared to previous studies on WNH samples completed by Miles and Carter and researchers found differences in Hispanic parents' stressors when compared to those of WNH parents (Rei & Fong, 1996).

Additional research using both the PSS:PICU and a variety of qualitative measures found similar themes surrounding parental stress. For example, Johnson, Nelson, and Brunnquell (1988) utilized the PSS:PICU in studying parent and nurse perceptions of parent stressors in the PICU. Their sample was 93% WNH parents and included 29 mothers and 12 fathers of 32 children in the PICU. In this sample the child's behavior and emotions, procedures and the child's appearance were the top stressors, while alteration in parental role ranked just fifth. In a study by LaMontagne and Pawlak (1990), a qualitative interview was completed to assess stress themes among parents with a child in the PICU. The sample included 30 parents, 24 mothers and 6 fathers, with 77% of participants identifying as WNH. The top stressors identified were an alteration in parenting role, need for information and uncertainty over outcome. In a replication study by LaMontagne and colleagues (1992) researchers again found that the alteration in parental role and uncertainty of outcomes were primary stressors for parents (LaMontagne, Hepworth, Pawlak, & Chiafery, 1992).

With the alteration in parenting role and the child's behaviors and emotions being consistently ranked as high stressors for parents, researchers made consistent recommendations for ways to assist parents in coping with the stress of a PICU experience. Recommendations included the development of interventions to help parents reestablish their parenting role, to educate and assist parents in understanding the child's

emotional needs and typical behavioral reactions, as well as to teach parents techniques to intervene and comfort their child in a positive way (Johnson et al., 1988; LaMontagne & Pawlak, 1990; Miles et al., 1989). Importantly, one group of researchers advocated for open visitation policies for parents, which was not common practice at that time. The recommendation was based on the consistent finding that the alteration in parental role and specifically being away from their child caused the most stress for parents (Johnson et al., 1988). Today, open visitation policies for parents are consistently implemented in PICUs around the country.

### **Differences of stressors in the PICU and NICU.**

As pediatric critical care became increasingly specialized, Neonatal Intensive Care Units (NICUs) separated from PICUs to focus on the management of problems associated with prematurity and the long-term care required. With the creation of a new specialty, researchers began to explore the unique stressors for each group of parents. Seideman and colleagues (1997) compared parental stress and coping in the PICU versus the NICU and found that parents in both units experienced high distress related to parental role alterations and the child's behaviors and emotions. However, PICU parents experienced greater distress in these areas, had different coping behaviors, and needed more assistance in the parenting role than did NICU parents (Seideman et al., 1997). Although the sample size was small, this study highlighted the different parental needs and experiences in the two units, guiding future researchers to consider NICU and PICU parents as separate populations to be studied. As the management of children with congenital heart disease became more specialized, Cardiac Intensive Care Units (CICUs) have also separated from PICUs in some organizations. While recent studies have begun

to focus on parental stress in the CICU specifically (Franck et al., 2010; Lisanti et al., 2017), differences in parental distress and coping behaviors in the PICU and CICU have not been the focus of research.

#### **Differences between mothers and fathers.**

A majority of early and current studies on parental distress in the PICU primarily focused on the perspective of the mother in the role of 'parent' (Shudy et al., 2006). Mothers were more consistently at the bedside of the child and therefore were most often the de facto participants in research studies. Researchers found that mothers experienced higher rates of distress and were more likely than fathers to experience ASD and PTSD (Baluffi et al., 2004; Bronner et al., 2009; Colville et al., 2009). For example, in a study of 17 mother-father dyads with a child in the PICU, Colville and colleagues (2009) found differences in rates of distress and types of coping behaviors between mothers and fathers. When a mother-father team is managing the stress of having a child in the PICU, fathers tended to focus more on traditionally male, problem focused coping behaviors. This includes asking questions and seeking information. Mothers in the dyad experienced more distress about being away from the child and therefore were more often at the bedside and more involved with the day to day care of the child. The dynamic of mothers assuming the more nurturing role and remaining with the child may leave them more exposed to the medical trauma associated with care in the PICU (Colville et al., 2009).

#### **Outcomes of PICU stressors on parents.**

It was not until the late 1990's that researchers began to associate parental stressors in the PICU with the risk of parents having ASD symptoms in the acute phase of the hospitalization and PTSD symptoms after discharge (Melnyk, Alpert-Gillis, Hensel,

Cable-Beiling, & Rubenstein, 1997; Noyes, 1998; Seideman et al., 1997). Board and Ryan-Wenger (2002) conducted a prospective, longitudinal study to examine the effects of the PICU experience on maternal levels of distress and perceptions of family functioning. In this sample ( $n = 31$ ), PICU mothers experienced higher levels of self-reported ASD symptoms during hospitalization compared to mothers on the general care unit. The highest reported stressors in the PICU mothers were the alteration in parental role and the child's behaviors and emotions. Although the longitudinal sample sizes were small ( $n = 11, 13, 18$ ), mothers reported stress related symptoms and difficulties with family functioning as long as 6 months after a child's PICU experience. (Board & Ryan-Wenger, 2002; Board & Ryan-Wenger, 2003).

Balluffi and colleagues (2004) performed a longitudinal study to examine the prevalence and relationship between ASD symptoms and PTSD symptoms in parents with a child in the PICU. Thirty-two percent of parents ( $n = 272$ ) met symptoms for ASD in the acute phase and 21% of parents met criteria symptoms for PTSD at follow-up after discharge. Balluffi and colleagues (2004) also compared racial differences in ASD and PTSD between AA and WNH parents. While AA parents had slightly higher symptom severity scores, there was no significant difference in the prevalence of ASD in AA parents ( $n = 57$ ) and WNH parents ( $n = 195$ ). However, both mothers and AA parents were more likely to develop PTSD over time. In addition, while the association between ASD and PTSD was similar for all parents, the association was greater for AA parents. AA parents who experienced ASD in the acute phase went on to develop PTSD at a rate of 70%, compared with 31% of WNH parents. While the differences were significant,

researchers advise that results should be interpreted with caution due to the discrepant numbers in each sample size (Balluffi et al., 2004).

Lastly, Bronner and colleagues (2009) completed a study in the Netherlands on parents with children who had an unplanned admission to the PICU. This sample ( $n = 115$ ) consisted of 69 mothers and 46 fathers. 12% of parents met criteria for PTSD 3 months after discharge from the PICU, with mothers reporting significantly more PTSD than fathers (Bronner et al., 2009). Results from these studies suggest that mothers and AA parents with a child in the PICU may be at higher risk for both ASD and PTSD symptoms (Balluffi et al., 2004; Board & Ryan-Wenger, 2002; Board & Ryan-Wenger, 2003; Bronner et al., 2009). Identifying at-risk parents in the PICU/CICU and providing interventions to minimize parental distress experienced in the acute phase of a PICU/CICU hospitalization may impact mental health outcomes for parents after discharge (Ularntinon et al., 2010).

### **Coping Behaviors of Parents with a Child in the PICU**

Compared to research focusing on parental stressors and the psychological outcomes of distress on parents in the PICU, there has been significantly less research focused on the coping aspect of this process. As with parental stressors, Miles and Carter (1985) were the first to examine coping patterns of parents with a child in the PICU. Parent perceptions about the helpfulness of the coping behaviors utilized was obtained retrospectively by parent self-report using the Parental Coping Scale:PICU (PCS:PICU). The sample ( $n = 36$ ) consisted of 21 mothers and 15 fathers of 27 hospitalized children, with 86% of parents identifying as WNH and 75% married. Sixty-five percent of the admissions in this sample were expected or planned (Miles & Carter, 1985).

Researchers found six coping behaviors that all parents in this study utilized. Those were being near their child, both making sure and believing that the child was getting good care, praying, and both seeking information and asking questions about the child. One of the most used and most helpful coping behaviors according to parents was “being near my child as much as possible”, with 92% of parents stating that this item was moderately or extremely helpful (Miles & Carter, 1985, p. 19). In this initial study, coping behaviors were categorized as problem focused, appraisal focused, and emotion focused (Miles & Carter, 1985). Problem focused behaviors were used most frequently and included activities such as asking questions, seeking information and being vigilant about the child’s care. These behaviors were reported to be very helpful for a majority of parents. The appraisal focused strategies of believing the child was getting the best possible care and having hope were also used frequently and were viewed by parents as being very helpful. The two most commonly used emotion focused behaviors were praying and seeking comfort from others. Seventy-eight percent of parents found praying very helpful, while only about half found seeking comfort from others as very helpful (Miles & Carter, 1985).

LaMontagne and Pawlak (1990) examined coping behaviors of parents in the PICU using the relative scores method for Lazarus and Folkman’s Ways of Coping Questionnaire. In contrast to Miles and Carter (1985), the Ways of Coping Questionnaire was divided into two scales, problem and emotion focused coping, which were not consistent with Miles and Carter’s scales, making comparisons difficult. The sample ( $n = 30$ ) consisted of 24 mothers and 6 fathers, with 77% identifying as WNH. In this sample parents used more emotion focused (56%) versus problem focused (44%) coping

behaviors overall. The two strategies used most were seeking social support in the problem focused category and positive reappraisal in the emotion focused category.

LaMontagne and Pawlak (1990) attempted to test the relationship between the primary stressor identified by parents with the type of coping behaviors utilized. It was found that parents who identified uncertainty as their primary stressor used more emotion focused coping strategies. Parents who identified the alteration in parental role as their primary stressor used problem and emotion focused coping behaviors equally. The three stressor themes identified were loss of parenting role, information need, and uncertainty over outcomes (LaMontagne & Pawlak, 1990).

LaMontagne et al. (1992) replicated the above study with 47 parents. Researchers found that older and less anxious parents utilized more problem focused coping behaviors and were more involved in the care of their child. Overall, researchers found that parents of younger children were more stressed by role alteration, while parents of older children had more worries about outcomes (LaMontagne et al., 1992). It should be noted that LaMontagne, Johnson, and Hepworth (1995) found that only three published studies had focused on parental coping with a child in the PICU. Two of the three studies were completed by the researchers themselves. In an effort to assist clinicians in managing parental distress in the PICU, the researchers developed a framework for critical care practice. This framework emphasized that parent appraisal of stressors and the use of specific coping behaviors are influenced by person and situation factors. Person factors include the ethnicity, age and anxiety level, while situation factors include prior trauma experience, support and socioeconomic status. Researchers suggested interventions related to the parent's primary stressor, as mentioned previously. For example, parents

experiencing stress in parental role alteration could be involved in activities such as bathing and holding the child for exams. Parents with stress about child outcomes may focus more on monitoring their child's daily progress. One universal finding was that all parents wanted to be involved in the care of their child in whatever way possible (LaMontagne et al., 1995).

### **Coping Behaviors Associated with ASD and PTSD**

Bronner and colleagues (2009) used the Utrecht Coping List and the Peritraumatic Dissociative Experience Questionnaire to study coping and outcomes in parents after a PICU admission. Researchers found that avoidance coping and peritraumatic dissociation were significantly associated with symptoms of PTSD in parents 3 months after discharge. Researchers recommended that clinicians assess parents for these behaviors and symptoms in order to identify parents who are in need of further assessment and psychosocial support after discharge (Bronner et al., 2009). Colville and colleagues (2009) found that when parents used a shared coping model, it was mothers who spent the most time at the child's bedside. This exposed mothers to more medical trauma associated with the care of their child compared to fathers. Researchers suggested that this dynamic between parent dyads might provide insight into why mothers experienced higher rates of ASD and PTSD than did fathers in this sample (Colville et al., 2009). In 2 randomized, longitudinal interventional studies by Melnyk (1994; 1995), parents were provided with information on the child's expected behaviors and emotions and the parental role in the PICU. The intervention resulted in reduced parental stressors and enhanced emotion and problem focused coping behaviors in parents receiving the

information. The intervention group also had lower self-reported PTSD symptoms compared to control parents at 6 and 12-month follow-up assessments.

### **Possible Predictors of ASD and PTSD in Parents**

With data mounting on the prevalence of poor mental health outcomes for parents after a PICU experience, researchers focused on examining possible predictors of ASD and PTSD. The parent's prior trauma exposure, perceived life threat to the child, acute child pain, number of invasive procedures on the child, and child ASD are potential predictors of parental ASD. Kassam-Adams, Fleisher, and Winston (2009) conducted a longitudinal study and exploratory analysis to determine the rates of and relationship between ASD and PTSD in parents of children with traffic-related injuries who had a PICU experience. In this sample, predictors of parental ASD included the parent's prior trauma exposure, perceived life threat to the child, acute child pain, and child ASD. Predictors of PTSD included parent ASD, prior trauma exposure and poorer post-trauma child physical health (Kassam-Adams, Fleisher, & Winston, 2009). In Balluffi and colleagues (2004), parents' degree of worry that their child might die was the only predictor of PTSD severity. Perceived life threat to the child has been identified as both a predictor of ASD and PTSD according to these studies, and should be considered a salient factor when assessing parental risk for both.

In a longitudinal study of parents of children 1 to 6 years of age who experienced burn injuries, De Young and colleagues (2014) evaluated the relationship between parent and child development of self-reported posttraumatic stress symptoms (PTSS) 6 months after a burn injury. Almost one quarter of parents had a "probable PTSD diagnosis" based on the severity of symptoms and impairment in functioning cutoffs on the Posttraumatic

Diagnostic Scale (PDS) at 1month post injury (De Young, Hendrikz, Kenardy, Cobham, & Kimble, 2014, p. 13). Parent ASD and child ASD were the best predictors of parent PTSS at 1month post injury. Independent predictors of parent PTSS at 6 months were number of invasive procedures on the child, parent ASD, parent 1month PTSS and concurrent child PTSS (De Young et al., 2014). Similarly, Landolt and colleagues (2012) found that parent PTSD symptoms at 1 month were longitudinally related to child PTSD at 1 year. Findings of both studies suggest a bidirectional link between parent and child experiences of ASD and PTSD over time. Therefore, parental response to a traumatic event such as a PICU experience, may impact the psychological outcomes for their child in the PICU and vice versa (De Young et al., 2014; Landolt, Ystrom, Sennhauser, Gnehm, & Vollrath, 2012).

In summary, prior trauma exposure of the parent, perceived life threat to the child, child pain/invasive procedures and parent ASD symptoms are the suggested predictors of parental PTSD after a PICU experience. Parental display of the symptoms of ASD can often be observed and assessed by clinicians during the PICU/CICU stay. Researchers suggest that minimizing medical trauma, providing interventions to assist parents with coping and routine screening for ASD may improve psychological outcomes for parents and children after a PICU experience (De Young et al., 2014). Interventions aimed at identifying and decreasing or moderating these predictors can potentially improve outcomes for parents and children after a PICU admission (Kassam-Adams et al., 2009).

### **Synthesis of the Literature and Areas for Future Research**

Since the identification and study of parental distress began in the 1980's, four literature reviews have been published in an effort to summarize what is known and guide

future research on the topic. In the first, Noyes (1998) suggested increasing the number of qualitative research studies, a greater focus on parental coping behaviors, and expanding research based on a family framework. Noyes also identified a need for research focused on the stress and coping experiences of different ethnic and cultural groups (Noyes, 1998). Board and Ryan-Wenger (2000) used McCubbin and McCubbin's resiliency model of family stress as the framework for critically reviewing the literature on parental stress in the PICU. The authors identified the primary stressors as parental role alteration, uncertainty, need to be with their child, and the need for information. In regard to coping behaviors, parents used both emotion focused and problem focused coping strategies depending upon what was identified as the primary stressor. Thirty-eight research studies were critiqued. The authors found that seventeen different theories guided the studies and coping was measured by three different instruments. Sixteen of those studies operationalized parental stress using the PSS:PICU. Lastly, researchers identified a bias toward WNH subjects and recommended more diverse samples in future studies (Board & Ryan-Wenger, 2000).

Shudy and colleagues (2006) synthesized research studies on the impact of critical illness and injury on families. Their literature review was extensive, comprehensive and included articles published between 1966 and 2005. Consistent with previous reviews of the literature, the primary stressors for parents were the alteration in parental role and child emotions and behaviors. Studies showed differences in the rate and types of stressors experienced by mothers and fathers. Finally, Shudy and colleagues (2006) pointed out that the majority of samples were limited to English-speaking families and white, married mothers, stressing the urgent need for research of stress and coping

patterns in fathers, various ethnic and racial groups, and among those with less traditional family structures (Shudy et al., 2006).

Ularntinon and colleagues (2010) provided an overview of research on parental stress reactions and intervention studies in the PICU and NICU from 1966 through 2009. The authors state that there are two targets for intervention: parental role alteration and reducing parental distress to maximize functioning. The authors list two formal interventions for parents in the PICU, which will be discussed in more detail in the intervention section. They also presented six core components that should be included in those interventions based on the literature. Suggestions for future research include the testing and evaluation of preventative and interventional programs for parents in the PICU, in addition to evaluating the impact of program outcomes (Ularntinon et al., 2010).

Most recently, Woolf et al. (2016) performed a systematic review of studies published from 1998 through 2013 which looked at parental stress responses following a serious childhood illness or injury (SCII). This umbrella diagnosis incorporated a variety of potential parental stress experiences that had mostly been studied independently. SCII included parental stress associated with traffic accidents, new cancer and diabetes diagnoses, as well as the trauma of being in a NICU or PICU. Based on their review, researchers advocate for hospital-wide approaches for identifying and minimizing ASD in parents and for a more standardized approach in definitions and measures used to assess parents. The researchers also expressed concern about the underrepresentation of fathers and minorities in the studies reviewed (Woolf et al., 2016).

In summary, parental role alteration, the child's emotions and behaviors, and perceived life threat are consistent stressors for parents with a child in the PICU. All

researchers agreed that future studies should focus on minority parents' stress and coping experiences, and that consistency in terminology and measures for ASD and PTSD are needed. Finally, assessment and intervention studies with a focus on reducing the incidence of ASD and PTSD in parents after a PICU experience are needed in order to improve outcomes.

### **How PICU/CICU Nurses Assist Parents to Cope**

The primary role of the PICU/CICU nurse is to manage the care of the critically ill child in collaboration with the medical team. However, the responsibility for supporting parents, reducing parental distress, and facilitating parental coping consistently falls upon the same PICU/CICU nurse. The combination of managing a critical patient and providing the level of support needed by parents during this stressful time is a daunting task for even the most experienced PICU/CICU nurse.

In spite of all the challenges, the PICU/CICU nurse is in a unique position to reduce distress in parents. Some things that have proven helpful is to educate parents on the child's monitors, medications, equipment, procedures, and plan of care. The nurse can encourage parental presence at the bedside, provide emotional support and encourage parental involvement in the care of the child. Additionally, the nurse can consistently provide information about the child's condition and answer questions on an ongoing basis (Foster et al., 2013; Jee et al., 2012; LaMontagne et al., 1995; Melnyk, Feinstein, & Fairbanks, 2006; Rei & Fong, 1996). All of this occurs on a very individualized basis. The amount of time, knowledge, experience and resources that one particular PICU/CICU nurse has can vary greatly from nurse to nurse and setting to setting. How

can individual nurses best be assisted to meet the needs of parents experiencing a PICU/CICU admission?

Parents and their ill or injured children admitted to a PICU/CICU are known to be at risk for ASD and PTSD. However, no evidence supports that assessments of parents or structured interventions are being used with any consistency in PICU/CICUs around the country (Winston et al., 2003). Online resources with screening tools and protocols are currently available for nurses and parents. However, lack of knowledge about the tools and lack of a systematic implementation of any tools into practice, have left parents and families to manage the “normal” stress response after a PICU/CICU admission on their own (Rzucidlo & Campbell, 2009). It is imperative that nurses are able to assess and intervene during this critical time for parents so that psychological outcomes for families after a PICU/CICU experience can be improved.

In order to adequately address the issue of parental distress, PICU/CICU nurses need tools to assist them in providing evidence based coping support for parents. Two formal interventions, both developed by nurses, were found in the literature. Their purpose was to assist with reducing parental distress and supporting positive parental coping strategies in the PICU/CICU. Both will be discussed in more detail.

The first intervention was developed by Martha Curley (1988) and is called the Nursing Mutual Participation Model of Care (NMPMC). This model is a supportive intervention that elicits information on parental expectations, beliefs and attitudes about their child's illness or injury and their perceptions of stressors through open-ended questions. The goal of this intervention is to establish rapport and to provide a framework for nurses to foster active parental involvement with their child while in the PICU. A

sample of 33 parents, mostly female, WNH and married, were enlisted as part of a control and experimental group. The control group received the usual care from the PICU staff while the experimental group were enrolled in the NMPMC, which provided parents knowledge about their child's care and how they could participate in that care. The perceived magnitude of stressors was significantly different between the two groups as measured by the PSS:PICU (Curley, 1988). A replication study was done in 1992 with similarly positive outcomes (Curley & Wallace, 1992).

The second intervention was developed by Bernadette Melnyk (1994) and is called the Creating Opportunities for Parent Empowerment (COPE) Program. This is a parent focused intervention based on self-regulation theory, which postulates that parents respond to distress through both emotion focused and problem focused strategies. To support parents' problem focused coping skills, Melnyk developed an audiotaped educational intervention. The tapes provide parents with: 1) knowledge and understanding of the typical responses of children hospitalized in intensive care units, and 2) a range of activities designed to both increase parent participation in the care of their child and to assist parents to promote adaptive coping behaviors in their child. The goal of the intervention is to decrease parental distress and increase parental empowerment, which would enable parents to intervene and support their child in a positive manner (Melnyk, 1994). Grant funded interventional research was performed to test the COPE program using an experimental design (Melnyk, 1994). The sample consisted of 108 mothers, with 72% identifying as WNH. Mothers were randomly assigned to one of four study groups: 1) control group, 2) parental role education, 3) child behavioral information, and 4) combined education (COPE program/intervention group). Outcomes

showed a significant difference in maternal knowledge about child behavior and parental role information and greater participation in the care of their child in the intervention group when compared to the control group. The educational information was also found to decrease maternal and child anxiety in the intervention group (Melnyk, 1994).

Using the same data, Melnyk (1995) tested the mediating effects of parental beliefs on maternal anxiety and participation in care in the framework of self-regulation and control theory. Results support the hypothesis that maternal anxiety is mediated through parental knowledge (parental beliefs) in regard to their hospitalized child's behaviors and emotions and their role in assisting the child. Parental role information had both direct and indirect effects on mothers' participation in the care of their child (Melnyk, 1995). Melnyk's COPE intervention has been the subject of a number of randomized controlled trials in which positive outcomes have continued to be demonstrated (Melnyk et al., 2006).

Nursing researchers suggested that by removing barriers to parent participation in care, mothers became more effective at understanding, predicting and intervening on behalf of their child. Maternal support was found to be a critical factor in children's post-hospital adjustments, especially in regard to painful procedures that the child must undergo and the maternal support provided during those encounters. These studies provide a sound framework for understanding the mechanism behind the importance of educational interventions for parents with a child in the PICU/CICU. It demonstrated positive outcomes in parent participation in care and in the effects of those interventions on both maternal and child distress after discharge (Melnyk, 1994; Melnyk, 1995; Melnyk et al., 2006).

Research on both interventions suggests improved mental health outcomes, increased knowledge and an increased ability of parents to support their child in dealing with the stress of the PICU. These interventions could provide a standardized, evidence based intervention to potentially assist parents and families through this stressful experience. However, lack of knowledge of the resources and, in one case, the cost and lack of access to the intervention are limitations that keep them from being both utilized and further researched.

### **Lack of Ethnically Diverse Samples in Research**

In each of the literature reviews presented above, a gap has been identified in regard to studies on the specific needs and coping behaviors of ethnic and racial minority parents with a child in the PICU (Board & Ryan-Wenger, 2000; Noyes, 1998; Shudy et al., 2006; Ularntinon et al., 2010; Woolf et al., 2016). Most studies had a majority of WNH mothers in their samples. Only one published study with a non-White sample focused specifically on parental stress and coping in the PICU (Rei & Fong, 1996) and another study compared outcomes of ASD and PTSD in a sample of AA and WNH parents with a child in the PICU (Balluffi et al., 2004). Others which included more diverse samples did not include comparisons between groups (Noyes, 1998).

As the previous studies suggest, there continues to be a paucity of research on parental stress and coping of ethnically diverse parents with a child in the PICU in the United States (US). In a meta-synthesis of qualitative research on parents', children's and health care providers' experiences of care in the PICU, of the 29 studies published between 1998 and 2011 which were included in the analysis, just 9 of those studies were conducted in the US. Four focused on deaths in the PICU, one on physician

communication, two on nurse-family relations, and one focused on the child's stress in the PICU (Foster et al., 2013). The last study was looking at family boundary ambiguity in the PICU and parents' perceptions of what would help alleviate this distress. The sample in this last study was composed of 100% WNH parents (Tomlinson, Swiggum, & Harbaugh, 1999).

The lack of progress in ethnically diverse research on parental stress and coping in the PICU is especially concerning given the cultural changes predicted in the US in the coming years (Flores, 2010). A renewed focus on ethnically diverse parents and their stress experiences and coping strategies in the PICU would benefit healthcare providers in tertiary care settings. Critical care nurses, who will be caring for increasing numbers of ethnically diverse children, are the frontline in mitigating the negative outcomes of the PICU/CICU experience on families and must be provided with culturally sensitive tools.

### **Racial and Ethnic Differences in Coping Outside of the PICU**

In a number of studies, researchers suggest that parental coping behaviors may correlate with race in response to a variety of stressors. In a study by Allen and Marshall (2010) it was found that religious coping was more common among AA parents compared to WNH parents with chronically ill children. There was a strong positive correlation between AA parents' coping and spirituality, and AA parents in this study reported that spirituality and spiritual beliefs were important coping resources (Allen & Marshall, 2010).

Yeates and colleagues (2002) compared family outcomes over time for AA and WNH parents of children who suffered a traumatic brain injury (TBI) in one group and orthopedic injuries only (OI) in another group. Comparisons were made while controlling

for socioeconomic status in all analyses. The TBI sample consisted of 72 WNH and 18 AA children and families and the OI group consisted of 32 WNH and 23 AA children and families. The biological mother was the primary caregiver in 90% of the cases and was the person who responded to the surveys. The situational version of the COPE measure was used to assess coping behaviors in this study. Findings indicate that race was a significant moderator of parent and family outcomes, independent of socioeconomic status, and that race accounted for significant differences in four coping areas. Religious coping, mental disengagement and denial were used more by AA parents, while more WNH parents used acceptance. Findings also show that AAs had lower distress levels in the OI group at 6 and 12 months after injury, but higher levels of distress at 6 and 12 months after injury in the TBI group. Family burden was less for AA compared to WNH parents at all time points, except for baseline in the OI group. Yeates and colleagues stated that the differences in coping behaviors used by parents may be the more salient factor, as opposed to race per se, that moderates outcomes for families over time. In this study, socioeconomic status related to the use of active coping strategies, while cultural differences, such as race, related to the use of avoidant or emotion focused coping when a child is injured (Yeates et al., 2002).

### **Racial and Ethnic Differences in Level of Distress Outside of the PICU**

Whether and what role race/ethnicity might play in mental health outcomes remains unclear. Kassam-Adams, Fleisher, and Winston (2009) did not find race to be a predictor of outcomes when looking at ASD and PTSD in parents of injured children. Their sample ( $n = 334$ ) was diverse and included 55% AA, 40% WNH, and 5% other race/ethnicity parents. In a study examining risk and protective factors for PTSD in AA

versus WNH student volunteers after Hurricanes Katrina and Rita, results showed that there were significantly higher rates of PTSD in AA versus WNH volunteers. These higher rates of PTSD were related to the higher level and more severe types of stressors being experienced by AA student volunteers after Hurricanes Katrina and Rita. While faith factors had no direct effect in this study as a protective factor for PTSD as researchers had hypothesized, hope among AA student volunteers was found to be related to lower levels of PTSD symptoms (Ai et al., 2011). Additionally, it was found that while AA student volunteers had higher experiences of previous trauma, such as witnessing violence or homelessness, those did not predict PTSD in the current trauma. In contrast, for WNH students with previously experienced trauma, those previous trauma experiences predicted PTSD in the current trauma. This discrepant finding between AA and WNH students suggests that AAs may be more “resilient with respect to higher levels of peritraumatic positive emotions, which in turn appeared to protect their mental health” suggesting that “racial factors should be considered in research in psychological and community social services” (Ai et al., 2011, p. 415-416).

In examining PTSD prevalence among an ethnically diverse sample of pregnant women ( $n = 647$ ), a review of secondary data by Seng and colleagues (2012) found that AA women experienced a significant amount of discrimination based on both their race and gender and experienced the greatest number of types of trauma exposures (Seng, Lopez, Sperlich, Hamama, & Reed Meldrum, 2012). The prevalence of PTSD symptoms was four times higher for AA pregnant women compared to other racial groups (Seng, Kohn-Wood, McPherson, & Sperlich, 2011). Additionally, discrimination and trauma exposures contributed significantly to explaining variance in PTSD symptom levels in the

women in this sample (Seng et al., 2012). While measurement of previous trauma exposures is outside of the scope of the current study, evaluation of ASD symptoms as a proxy for level of distress should include an understanding of the contextual impact that these factors may have, especially in light of the fact that previous trauma exposures may be a predictor of both ASD and PTSD in parents with a child in the PICU (Kassam-Adams, Fleisher, & Winston, 2009). Previous trauma exposure may have a potential confounding effect on rates of ASD, particularly in AA mothers.

### **Socioeconomic Factors in Studies Involving Race or Ethnicity**

When looking at racial differences in a variety of topics, a confounding variable in analyzing results tends to be the socioeconomic status (SES) of participants. However, two studies were found that controlled for SES while comparing racial differences in coping behaviors. Yeates and colleagues (2002) described previously was one of those studies, and the other will be discussed in more detail (Brantley, O’Hea, Jones, & Mehan, 2002; Yeates et al., 2002).

Brantley and colleagues (2002) sought to examine the ethnic differences in coping behaviors in a sample ( $n = 480$ ) of low income primary care patients. The sample was primarily AA and female, with outcomes compared to WNH low income patients. Even with using low income patients as a built-in control for SES, significant differences were found between AAs and WNHs in regard to income, education, age and marital status, with a significant main effect found for ethnicity. Results suggest that low income patients use a significantly greater number of coping strategies compared to higher income patients. One explanation posited is that low income patients experience a greater number of chronic, daily stressors, calling for the use of a wider range of coping

behaviors. In this sample, AA patients also used two emotion focused coping behaviors significantly more than WNH patients. One coping behavior often used in AA patients was distancing, which is defined as detaching oneself or minimizing the importance of the situation. The other most significantly different coping behavior used by AAs was positive reappraisal, which is focusing on personal growth or the religious meaning behind the stressful situation. Thus, when SES was held constant, this sample of AA and WNH patients differ in a couple, but not all coping behaviors (Brantley et al., 2002). Due to the multifactorial nature of the stress and coping process, SES in the current study will attempt to be controlled for when comparing data, in an effort to minimize confounding effects.

### **Conclusion**

With over 30 years of research on parental stress in the PICU, some common themes have emerged in regard to parental stressors, coping behaviors, and mental health outcomes for parents with a child in the PICU. Uncertainty about the child's outcome, the alteration in parental role, and the child's emotions and behaviors are major stressors for parents. Unplanned admissions cause parents more distress than planned admissions. Mothers and fathers experience distress differently in the PICU, with mothers experiencing more negative mental health outcomes than fathers (Balluffi et al., 2004; Colville et al., 2009; Shudy et al., 2006; Ularntinon et al., 2010). The use of certain emotion focused coping behaviors, such as denial and distancing, led to poorer mental health outcomes (Yeates et al., 2002). Parents experiencing ASD symptoms while in the PICU may be more likely to experience PTSD symptoms long after discharge, regardless of the child's health outcome (Shudy et al., 2006; Ularntinon et al., 2010).

Theory-based educational interventions and screening tools to assist parents have been developed and tested (Curley, 1988; Kassam-Adams et al., 2009; Knapp, Sole, & Byers, 2013; Melnyk et al., 2006). However, due to minimal utilization of available tools and resources and the lack of implementation research, outcomes for parents remain unchanged (Rzucidlo & Campbell, 2009; Ularntinon et al., 2010). In addition, the majority of research on parental stress and coping is only generalizable to WNH parents, due to the relative homogeneity of samples in the literature. One consistent gap remains the lack of ethnic diversity in research on parental stress and coping in the PICU (Board & Ryan-Wenger, 2000; Shudy et al., 2006). No studies were found that focused on an ethnically diverse sample of parents and their stressors, coping behaviors, and level of distress with a child in the PICU.

As mentioned in Chapter 1, Hispanic children are the largest minority, followed by AA children as the second largest minority in the US. Ethnically diverse children are at higher risk than WNH children for injuries and illnesses that will ultimately result in a PICU admission for the child and family (Epstein et al., 2011; Flores, 2010). Despite these facts, the literature review presented above demonstrates a lack of research focus on ethnically diverse parents and their unique experiences of stress and coping with a child in the PICU/CICU. The lack of data on minority populations supports the need for research in this area. Exploring the stressors, coping behaviors and level of distress in an ethnically diverse sample of parents with a child in the PICU/CICU is the first step in identifying and understanding any culturally specific experiences of parents during this process. Results can guide future interventions designed to assist parents during this

challenging experience, with the ultimate goal of decreasing the incidence of ASD and PTSD in ethnically diverse parents who have experienced a PICU/CICU admission.

## Chapter 3 - Methods

### Design

A quantitative cross-sectional design was used for this study. Mothers were approached between 24 hours and 4 days after their child was admitted to the PICU or CICU and asked to participate in the study. If they consented, the mothers completed an electronic survey. The survey contained four instruments, including a Parent Demographic Sheet, the Pediatric Stressor Scale: Pediatric Intensive Care Unit (PSS:PICU), the Brief COPE, and the Acute Stress Disorder (ASD) Scale.

### Setting

The setting was the PICU and the Cardiac Intensive Care Unit (CICU) of Nicklaus Children's Hospital (NCH) in Miami, FL. NCH is a 289 bed free-standing pediatric specialty and teaching hospital. It is a designated Magnet® facility with a philosophy of family-centered care. The hospital has three intensive care units: a PICU, a CICU and a Neonatal Intensive Care Unit (NICU). Due to the unique environment, lengthy stays and chronic issues associated with the care of premature infants in the NICU, only parents with children in the PICU or CICU were recruited for this study. The PICU manages a variety of areas of pediatric illness, including hematology/oncology, pulmonology, neurology, surgical and trauma patients. The CICU manages any congenital or acquired heart disease in children.

The PICU and CICU consist of identical floor plans. All patient rooms are private and have an area specifically designated for parents. The parent area includes a couch, which opens into a bed so that parents can sleep in the room with their child, a chair, a

television, wireless capability, access to a bathroom, and a curtain for privacy. Each unit also has a parent lounge and kitchen area with a table where families can eat outside of the room, if desired. Parents and siblings have 24-hour access to the child and all families have access to social work, chaplain, and childlife services upon admission to the PICU and CICU.

### **Sample**

Mothers with a child in the PICU or CICU constitute the convenience sample in this study. The term mother is defined as the female caretaker with primary decision making responsibility for the child. This may include a grandmother, step-mother, or foster mother, depending on the family situation of the child in the PICU or CICU. Inclusion criteria were initially: 1) mothers with a child less than 18 years of age in the PICU or CICU for a minimum of 48 hours, 2) a first-time unplanned admission to the PICU or CICU, 3) the ability to read and write in English or Spanish, and 4) willingness to participate in the study. During data collection, it was noted that potential participants were transferred out of the PICU in less than 48 hours and were lost to follow-up. As the timeframe had become a hindrance to recruitment, the minimum 48 hour inclusion criteria was eliminated. Exclusion criteria were: 1) mothers of chronically or terminally ill children, 2) mothers of children admitted with suspected abuse, and 3) mothers less than 18 years of age.

The sample was limited to mothers/female caretakers based on research showing differences in stressors, coping behaviors and mental health outcomes between mothers and fathers in previous research on parental stress (Balluffi et al., 2004; Board & Ryan-Wenger, 2002; Board & Ryan-Wenger, 2003; Colville et al., 2009; Shudy et al., 2006).

The sample was also limited to first-time unplanned admissions based on research showing differences in stress levels for parents of children with unplanned versus planned admissions to the PICU. Parents of children with unplanned admissions generally experience greater stress levels (Board & Ryan-Wenger, 2003; Eberly et al., 1985). In addition, as Lazarus and Folkman's (1984) view of the stress and coping process acknowledges that perceptions of stressors and level of distress change over time, this study focused specifically on the initial, acute distress experienced by mothers with a child in the PICU or CICU for the first time. Mothers of newly admitted children to the PICU and CICU who met the inclusion criteria were approached by the Student Investigator (SI) generally between the first 24 hours to the first four days after admission. Limiting the sample in these ways was an attempt to control for other factors that may impact an individual's stress and coping process, such as gender and the timing, predictability, and novelty of the event.

G power© version 3.0 (Faul, Erdfelder, Lang, & Buchner, 2007) was used to estimate sample size. Power analyses were conducted to estimate the appropriate sample size to adequately power the main statistical analysis for this study (i.e., specific aim 3). The minimal participant goal was 97 mothers. This estimate was based on a medium effect size ( $f^2 = .15$ ) determined by previous study means and standard deviations using Cohen's  $d$ ,  $\beta = .80$ , and  $\alpha = .05$ . The number of predictor and control variables was set at eight and the number of tested predictors was set at four.

### **Recruitment and Procedures**

The PICU and CICU Nursing Directors and medical and nursing staff were informed about the nature and timing of the study as explanation for the Student

Investigator's (SI) presence on the unit and interaction with parents. Flyers with information about the study were posted as a reminder in the PICU and CICU nurses' lounge. Upon arrival to the unit, the SI met with the Nursing Director or her designee (ND), which was typically the charge nurse for that shift. The SI was provided with the room numbers of potentially eligible families based on the inclusion/exclusion criteria. The ND or bedside nurse was asked for input about the appropriateness of the timing to approach potential participants. If the family had received bad news, if testing or surgery was pending, or if the parents were sleeping or visiting with family members, the SI would delay the approach and return at a more optimal time.

The SI approached potential participants once determining the appropriate time. Upon introduction, the SI informed the participant about the study and gauged interest. If the participant was interested, the SI provided her with a computer tablet containing the electronic survey. Four versions of the survey were available based on the unit where their child was admitted (i.e., PICU, CICU) and their stated language preference (i.e., English, Spanish). The first page of the survey contained an information sheet providing more information about the study and their rights as participants. If the participant was still interested after reviewing the information sheet, she continued to the survey questions. The surveys were primarily completed at the bedside. Upon completion of the surveys, the participant was asked to initial a receipt and received a thank you card with a monetary incentive (\$10) as compensation for their time.

### **Human Subjects Protection**

IRB approval was obtained from both the University of Miami and NCH in November 2016 and February 2017, respectively. Additional approval was obtained in

February 2017 to modify the inclusion criteria as previously described. The SI met with the PICU and CICU leadership teams to explain the study design and procedures and to respond to any questions or concerns prior to proceeding with data collection. As potential participants were identified, the SI was responsible for approaching the mothers, providing information about the study, and answering any questions that the mothers may have had.

### **Consent process.**

A waiver of written consent was obtained from the University of Miami and NCH IRBs. The first page of the electronic survey provided information to participants about the voluntary nature of the study, the ability to discontinue participation at any time without impacted their child's care and about the anonymous and de-identified nature of the survey (see Appendix A). Participants were informed of what they would be asked, the anticipated length of time it would take to complete the survey and what support they could expect if they experienced any emotional upset as a result of their participation. Contact information for the SI, immediate supervisor and both the University of Miami and NCH research offices was also provided. Participants were informed that their consent was implied by completing the survey. The SI remained available to the mothers to respond to questions or concerns as they completed the surveys.

### **Risks.**

As this was an emotionally stressful time for the mothers, there was the risk that mothers may experience increased emotional upset related to completing the surveys. If increased emotional upset was experienced by mothers and they chose not to continue

participation, the survey was to be discontinued immediately. The mother would be referred to the unit social worker and/or psychologist to assist them during this time.

### **Benefits.**

There were no direct benefits to participants in the study. Participants were informed that the data collected may assist other parents experiencing the stress of a PICU or CICU stay and that they might potentially benefit from sharing their personal experiences about having a child in the PICU or CICU as a means of coping with the stress.

### **Measures/Instruments**

Four different surveys options were available: a) PICU English survey, b) PICU Spanish survey, c) CICU English survey and d) CICU Spanish survey. The instruments used in this study included a Parent Demographic Sheet, the Pediatric Stressor Scale: Pediatric Intensive Care Unit (PSS:PICU), the Brief COPE, and the Acute Stress Disorder Scale (ASDS). Participants all completed the Parent Demographic Sheet first, but the PSS:PICU, Brief COPE and ASDS scales were completed in random order in an attempt to mitigate missing data.

The Parent Demographic Sheet was an 18 question survey developed for this study. It included variables such as parent and child age, marital status, income, type of household, religion, and education. In assessing race, mothers were first asked, “Which one or more of the following would you say is your race?” For mothers selecting more than one race a follow up question, “which group would you say best represents your race?” was asked. In regard to ethnicity, all mothers were asked, “Are you of Hispanic, Latina, or Spanish origin?” If the answer was yes, a follow up question, “Which of the

following best describes you?” was asked, with a list of options such as Cuban, Puerto Rican, Nicaraguan, etc., in addition to the option of “other”, for which a description could be typed. Questions on place of birth, country of origin and years in the US were asked to appropriately characterize our immigrant population. This form took approximately five minutes to complete.

The next instrument was the PSS:PICU, which is a 37 item scale designed by Miles and Carter (1982) to measure the source of stressors that parents may experience specifically related to the PICU environment. The PSS:PICU results in an overall score for the scale and scores for each of the seven subscales. The subscales include questions about: the child’s appearance, sights and sounds of the PICU, procedures done to the child, behaviors of professional staff, parental roles, communication with professional staff, and behaviors and emotional responses of the child. Questions are based on a Likert scale from 0 – 5, with 0 being “not experienced”, 1 being “not stressful” to 5 being “extremely stressful”. Higher scores indicate increased levels of stress experienced by parents. Internal consistency of the scales in the initial testing of the instrument ranged from a Cronbach’s alpha of .72 to .99 on the subscales and .95 for the total scale (Miles & Carter, 1982). The PSS:PICU has been used frequently in research on parental stress in the PICU with reliability data reported to be  $\alpha = .95 - .96$  for the total scale and subscale reliabilities ranging from .62 - .95 (Rei & Fong, 1996; Seideman et al., 1997). The PSS:PICU has been used with minority parents, and has been translated into Spanish, Chinese and Arabic. In the current study, Cronbach’s alpha for the total scale was .94, with subscales ranging from .75 to .89.

The Brief COPE scale (Carver, 1997) consists of 28 items designed to assess the different ways in which people respond to stress. The Brief COPE is a shortened version of the original COPE scale which has 60 items. The shorter version of the scale was chosen in an effort to minimize respondent burden on mothers during this stressful time and took about 5 minutes to complete. The original and Brief COPE scales are flexibly designed to measure situational coping behaviors or trait coping behaviors, based on the item wording and instructional context provided to participants. For this study, the scale instructions and stress language in each item focused specifically on the current coping behaviors being utilized by mothers in the context of having a child in the PICU or CICU (Carver, 1997).

Mothers were asked to report how often they used a variety of coping behaviors while in the PICU/CICU. The Brief COPE was divided into the following three subscales of coping behaviors: 1) problem focused, 2) emotion focused, and 3) avoidance behaviors. Problem focused coping included six items assessing active coping, seeking instructional support and planning behaviors. Emotion focused coping included 10 items assessing the use of emotional support, positive reframing, acceptance, religion, and humor. Avoidance coping included 12 items focusing on self-distraction, denial, behavioral disengagement, venting, self-blame and substance use (Carver, 1997). The item breakdown for each category is consistent with Cooper, Katona and Livingston's (2008) study using the Brief COPE.

Items on the Brief COPE are based on a Likert scale from 1 – 4, with 1 being “I haven't been doing this at all” to 4 being “I've been doing this a lot”. While there is no total coping score calculated for the Brief COPE, results from the initial study were

presented for each of the 14 subscales, with each subscale consisting of two items. The Cronbach's alphas ranged from .50 to .90 (Carver, 1997). The Brief COPE has been used in prior research with ethnically diverse populations (Burns et al., 2008; Yeates et al., 2002). In published studies using the subscales of problem focused coping, emotion focused coping and avoidance coping behaviors, the Cronbach's alphas ranged from .72 to .84 (Cooper et al., 2008; Burns, Feaster, Mitrani, Ow & Szapocznik, 2008). Initial Cronbach's alphas for the current study ranged from .58 to .82.

The Avoidance Coping (AC) subscale was problematic with an initial Cronbach's alpha of .58. In reviewing the items and data in the AC scale, it was found that only one mother had answered "used a little bit" on the question of alcohol use to cope, with the remaining mothers answering "haven't been doing this at all". As most mothers were at the bedside of the child continuously, alcohol use did not seem like a reasonable coping option for this sample and the lack of positive responses to that item may have contributed to the lower reliability score on that scale. This item pair was removed and the Cronbach's alpha increased to .65. The item-total statistics analysis was reviewed and based on those results another item pair related to diversional activity was removed, leaving a total of eight items in the AC scale, with the alpha = .74. The scale was dichotomized due to non-normality.

The fourth scale was the Acute Stress Disorder Scale (ASDS). This scale was used to assess the outcome measure/dependent variable, which is the self-reported level of parent distress. This scale measures the frequency of symptoms related to ASD in the area of dissociation, re-experiencing, avoidance and arousal, but is not intended to diagnose ASD in study participants. It should be noted that the reliability of the diagnosis

of ASD in the early stages of trauma being a predictor for PTSD at a later time remains an area for debate (Bryant, Friedman, Spiegel, Ursano, & Strain, 2011). The ASDS includes 19 items designed to assess how the individual has felt since the occurrence of a traumatic event. In this case the traumatic event was having a child in the PICU/CICU. The items ask about feeling distant, upset, irritable, and having memories or nightmares about the trauma. Items on the ASDS are based on a Likert scale from 1 – 5, with 1 being “Not at all” to 5 being “Very much” (Bryant et al., 2000). The self-report ASDS was chosen as the measurement tool for level of distress in this study due to its reliability and frequent use in other studies on parental distress. The published Cronbach’s alphas for the total scale were .90 or greater in studies of parents with children diagnosed with cancer (Woolf et al., 2016). The Cronbach’s alpha for the current study was .95 and met normality standards. The ASDS scale took approximately 5 minutes to complete. The final reliability for all scales is listed in Table 3.1.

Table 3.1. Reliability of scales.

Scale	Cronbach’s Alpha
PSS:PICU (Total scale)	.94
Child’s Appearance	.80
Sights and Sounds	.87
Procedures	.75
Staff Behaviors	.76
Parental Role	.85
Staff Communication	.86
Child Behavior and Emotions	.89
Brief COPE (Total scale)	.86
Problem Coping (PC)	.82
Emotion Coping (EC)	.78
Avoidance Coping (AC)	.74
Acute Stress Disorder Scale	.95

### **Data Security/Confidentiality**

No personally identifiable information was collected as part of this study. Mothers were informed that data from the tools would be identified only by number to maintain anonymity. Survey data were collected via computer tablet through Qualtrics. The survey data were downloaded from Qualtrics onto the SI's computer at the University of Miami. The data spreadsheets were stored on a password protected computer in the SI's locked office. In addition, this anonymous data were only shared with the SI's research team as needed for assistance with data analysis. The data were analyzed and reported in aggregate, with no reference to individual participants.

### **Data Analysis**

Data were downloaded from Qualtrics into SPSS version 24.0 (IBM, Armonk, NY) which was used for data analysis. The data from the four surveys were merged and then coded and checked for missing data and errors. One survey taken by a father and another missing a significant amount of data were removed. This left a final total of 103 surveys completed. Descriptive statistics were calculated (e.g., means, frequencies, standard deviations) for each variable examining the distributional assumptions and visual representation of the data. Reliability of the survey scales was calculated using the Cronbach's alpha coefficient, with a goal of .7 for each scale (Pallant, 2013).

#### **Data cleaning and assumptions check.**

A number of variables were recoded, such as child's age groups being transformed from continuous to categorical data and setting and language variables given numeric values. For the Brief COPE subscales, items were combined to create variables that included problem coping only, emotion focused only, and avoidance coping only

scales that would be used to perform the regression analyses. The racial and ethnicity variables were reviewed and transformed into a single race/ethnicity variable, which included Hispanics (1), AAs (2) and WNHs (3). Finally, the PSS:PICU scale was computed into a new variable which took into account the number of “not experienced” or 0 scores when determining the scores for the total scale and subscales. This new variable was then used when performing regression analyses.

Descriptive statistics performed for all three scales showed a non-normal distribution of scores. Square root and log10 transformation were performed on the PSS:PICU scale and results remained non-normal. It was decided that since the PSS:PICU was only to be used as a predictor variable that it would be used without transformation. The Brief COPE subscales had Kolmogorov-Smirnov results as follows: problem focused coping = .020, emotion focused coping = .010, and avoidance coping = .000. Testing with square root and log10 transformation were also negative. The subscales were then dichotomized into low use and high use scores and dummy coded. Scores of 1 and 2 were valued at 0, or low use, and scores of 3 and 4 were valued at 1, or high use. The ASDS also violated normality assumptions (Kolmogorov-Smirnov = .001). Square root was run with a non-normal results, but the log10 transformation resulted in a Kolmogorov-Smirnov = .200, thus meeting normality standards for the ASDS as a continuous variable.

### **Statistical Analyses**

A series of regression analyses were conducted to address the five major aims of this study. Preliminary analyses were completed and assumptions for multicollinearity, normality, linearity and homoscedasticity were met (Pallant, 2013; Vik, 2014).

*Aim 1: To examine the relationship between appraisal and coping behaviors of ethnically diverse mothers with a child in the PICU when controlling for socioeconomic factors.* A binary logistic regression was performed to analyze specific Aim 1 since the dependent variables of PC and EC were not continuous. The model contained five independent variables: the total PSS:PICU (stressors) score and the mothers' age, educational level, income and marital status (socioeconomic factor/control). The analysis for each dependent variable was performed separately.

*Aim 2: To examine the relationship between coping behaviors and level of distress of ethnically diverse mothers with a child in the PICU when controlling for socioeconomic factors.* Multiple regression was performed to analyze specific Aim 2 since the dependent variable was continuous and the independent variables were dichotomous. Tests for multicollinearity were negative and tests for normality, linearity and homoscedasticity were met.

*Aim 3: To examine if coping behaviors mediate the relationship between appraisal and level of distress in ethnically diverse mothers with a child in the PICU when controlling for socioeconomic factors.* For specific Aim 3, Mplus ® version 7.31 was used to test for mediation. First a regression analysis was conducted to test the relationships of all variables in the model. Then a mediation analysis was performed using the 1000 bootstrapping method.

*Aim 4: To examine if race or ethnicity moderates the relationship between appraisal and type of coping behaviors utilized by ethnically diverse mothers with a child in the PICU when controlling for socioeconomic factors.* Logistic regression was

performed to test specific Aim 4 since the dependent variables of PC and EC are dichotomous.

*Aim 5: To examine if race or ethnicity moderates the relationship between type of coping behaviors and level of distress experienced by ethnically diverse mothers with a child in the PICU when controlling for socioeconomic factors.* Multiple regression was performed with the use of an interaction term to test for moderation in specific Aim 5 since the DV was continuous.

#### **Follow-up tests.**

Descriptive statistics were performed by racial/ethnic group for each scale. In addition, the Generalized Linear Model was used to compare racial/ethnic differences between groups for each of the scales and effect sizes were computed.

## Chapter 4 – Results

### Sample Characteristics

Participants were 102 biological mothers and 1 foster mother with a child in the PICU/CICU. The mean age was 33 years. Over half (58%) of mothers were married and 18% were unmarried but living with a partner. The majority (79%) reported living in a two parent household. Only 14% lived in a single parent household while the remaining 7% reported living with extended family. The majority (88%) of households had 5 or less people living in the home, including the child in the PICU/CICU (see Table 4.1).

Table 4.1. Demographics (n=103)

		Frequency	Percent
Marital status	Married	60	58
	Single	18	18
	Divorced	7	7
	Living with partner, not	18	18
Household	Single parent	14	14
	Two parent	81	79
	Other	7	7
	Missing	1	1
Educational Level	Some high school	6	6
	HS or GED	26	25
	College 1-3 yrs	31	30
	College graduate	23	22
	Advanced degree	17	17
Born in the US	Yes	52	51
	No	50	49
	Missing	1	1
Religious preference	Christian	78	76
	Jewish	2	2
	Islam	1	1
	No preference	22	21

The majority (76%) of mothers describe themselves as Christian. Included in this group are Catholics (30%), Baptists (5%), Non-Denominational (4%) and 7 other religious groups. Over one-fifth (21%) of mothers report having no religious

preference. Of those with a preference, 76% report that religion is extremely or very important, 14% moderately important, while 10% say that their religion is slightly or not at all important. When asked about country of origin, 51% of mothers reported that they were born in the US, while 49% were born outside of the US. A higher proportion of Hispanics were born outside of the US compared to that of AA and WNH mothers, 63% versus 24%. The average number of years that non-natives have lived in the US is 14.2 years for Hispanics and 11.8 years for AAs/WNHs.

Less than 6% of mothers did not complete high school. One quarter completed high school and 30% had some college. Another 39% had a college degree or higher. Interestingly, mothers had a higher mean educational level than that of their partners, 4.17 compared to 4.00. Although well educated, the annual household incomes reported were somewhat skewed to the lower end of the spectrum (See Table 4.2). Nearly half of the sample reported having an income of less than \$34,999 annually, with a sample mean of 5 people per household. Fifty-four percent earn less than \$49,999. Twenty-four percent report annual household incomes \$50,000- \$99,999 and another 20% report making \$100,000 or greater of annual income per household.

Table 4.2. Annual household income from all sources before taxes.

Income (n=101)	Frequency	Percent
Less than \$14,999	20	19
\$15,000 to \$24,999	16	16
\$25,000 to \$34,999	12	12
\$35,000 to \$49,999	7	7
\$50,000 to \$74,999	16	16
\$75,000 to \$99,999	9	9
\$100,000 to \$149,999	11	11
Greater than \$150,000	10	10

In regard to the age of the children in the total sample, 62% were less than 1 year of age. Toddlers made up 8%, preschoolers 6%, school aged 12% and teenagers 13%. However, variances were noted in the age of the children when the sample was divided by unit, as can be seen below in Table 4.3.

Table 4.3. Age categories in PICU versus CICU (n=103).

	PICU		CICU	
	Frequency	Percent	Frequency	Percent
Neonates 0-29 days)	5	8	17	42
Infants (1 mo-1yr)	27	44	15	37
Toddlers (1-3yrs)	7	11	1	2
Preschoolers (3-6yrs)	3	5	3	7
School aged (6-12 yrs)	10	16	2	5
Adolescents (>12 yrs)	10	16	3	7
Total	62	100	41	100

### Race and Ethnicity

When collapsing the race and ethnicity groups there were four individuals who identified as biracial and one as biracial and Hispanic. These mothers were grouped into the category selected as best representing them when collapsing the race and ethnicity data. Based on those responses, a combined Race/Ethnicity variable for all mothers was made. The categories include Hispanics, African Americans/Blacks and white non-Hispanics (see Table 4.4). Data for Hispanic mothers' country of origin is shown in Table 4.5 to highlight the diversity within the Hispanic group.

Table 4.4. Combined race/ethnicity.

	Frequency	Percent
Hispanic	60	58
African American/Black	16	16
White non-Hispanic	27	26
Total	103	100

Table 4.5. Hispanic mothers' country of origin.

	Frequency	Percent
Cuban	29	45
Colombian	6	9
Venezuelan	6	9
Dominican	5	8
Honduran	3	5
Mexican	3	5
Puerto Rican	3	5
Argentinian	2	3
Nicaraguan	2	3
Other: Brazilian, Chilean, Costa Rican, Ecuadorian & El Salvadoran (1 each)	5	8
Total	64 (4 mixed race/ethnicity)	100

### Relationship between Stressors and Coping Behaviors

The hypothesis for specific Aim 1 states that there will be a significant relationship between appraisal (stressors) and coping behaviors. Logistic regression was performed to analyze this relationship for both problem focused and emotion focused coping. The full model containing stressors and the four control variables was statistically significant,  $\chi^2(17, N = 96) = 28.51, p < .05$ . However, the only independent variable that made a unique, statistically significant contribution to the model was the total PSS:PICU score. Since none of the variables making up the socioeconomic factor (parent age, marital status, income and education) were statistically significant as predictors, the decision was made to leave the controls out of further analyses involving appraisal and coping.

The relationship between stressors and emotion focused coping was not statistically significant,  $B = .396, SE = .279, p = .156, 95\% CI = [.86, 2.57]$ . The

relationship between stressors and problem focused coping was statistically significant,  $B = 1.024$ ,  $SE = .317$ ,  $p = .001$ , 95%  $CI = [1.50, 5.19]$ ,  $OR = 2.78$ . Avoidance coping was left out of this analysis due to lack of use among sample participants.

### **Relationship between Coping Behaviors and Level of Distress**

The hypotheses for specific Aim 2 states that the use of both problem and emotion focused coping would be inversely associated with level of distress. Avoidance coping was left out of this analysis due to lack of use among sample participants. Multiple regression was performed. None of the independent variables (control variables) correlated with level of distress and were left out of further analyses. The relationship between emotion focused coping and level of distress was not statistically significant,  $\beta = .068$ ,  $SE = .041$ ,  $p = .097$ , 95%  $CI = [-.01, .15]$ . The relationship between problem focused coping and level of distress was statistically significant,  $\beta = 1.451$ ,  $SE = .109$ ,  $p = .000$ , 95%  $CI = [1.24, 1.67]$ ,  $R^2 = .142$ .

### **Coping Behaviors Mediating Stressors and Level of Distress**

The hypothesis for specific Aim 3, based on Lazarus and Folkman's Transactional Model of the Stress and Coping Process, states that coping behaviors will mediate the relationship between appraisal (stressors) and level of distress. Since it was determined that there was no significant relationship between emotion focused coping and level of distress, only problem focused coping was tested as a mediator. First multiple regression was used to test each relationship of the proposed model, as shown in Table 4.6.

Table 4.6. Relationships of variables in the mediation model.

	$\beta$	$SE$	$p$ -value	95% $CI$
Distress on Stressors	0.134	0.016	0.000	.10, .17
Problem Coping on Stressors	-0.538	-5.393	0.000	-.73, -.34
Distress on Problem Coping	0.091	2.442	0.015	.02, .16

A mediation analysis was then performed using the 1000 bootstrapping method in path analysis with Mplus 7. Results of the mediation analysis confirmed a full mediating effect of problem focused coping in the relationship between stressors and level of distress, shown in Table 4.7. This is demonstrated by the direct effect of distress on stressors becoming non-significant with the introduction of the problem focused coping variable into the model.

Table 4.7. Mediation of coping behaviors on level of distress.

	$\beta$	$SE$	$p$ -value	95% $CI$
Distress on Stressors	-0.01	-0.204	0.838	-.10, .08
Indirect Effects	-0.049	-2.16	0.031	-.10, -.01

### **Race/Ethnicity Moderating Stressors and Coping Behaviors**

The hypothesis for specific Aim 4 states that race/ethnicity will moderate the relationship between stressors and coping behaviors. Interaction products were computed for AA and stressors and Hispanics and stressors. Logistic regression using the interaction products was performed.

In the analysis for problem coping, while the full model with all predictors was statistically significant,  $\chi^2(5, N = 98) = 18.80, p < .05$ , race/ethnicity did not significantly moderate the relationship. The interaction variables for both Hispanics ( $\beta = .451, SE =$

.286,  $p = .115$ , 95%  $CI = [.90, 2.75]$ ) and AAs ( $\beta = .184$ ,  $SE = .268$ ,  $p = .493$ , 95%  $CI = [.71, 2.03]$ ) were not significant.

For emotion focused coping, the full model with all predictors was statistically significant,  $\chi^2(5, N = 98) = 14.13$ ,  $p < .05$ . In addition, race/ethnicity did significantly moderate the relationship between stressors and emotion focused coping for both AAs ( $\beta = .591$ ,  $SE = .265$ ,  $p = .026$ , 95%  $CI = [1.08, 3.04]$ ) and Hispanics ( $\beta = .745$ ,  $SE = .309$ ,  $p < .016$ , 95%  $CI = [1.15, 3.86]$ ) as seen in Table 4.8.

Table 4.8. Moderation of race/ethnicity on stressors and coping behaviors.

		<i>B</i>	<i>SE</i>	<i>p</i> -value	95% <i>CI</i>
Problem focused	PSS:PICU (Stressors)	0.702	0.249	0.005	1.24, 3.29
	Hispanics	-0.015	0.244	0.951	.61, 1.59
	AAs	0.583	0.291	0.045	1.01, 3.17
	Hispanics x Stressors	0.451	0.286	0.115	.90, 2.75
	AAs x Stressors	0.184	0.268	0.493	.71, 2.03
Emotion focused	PSS:PICU (Stressors)	0.149	0.240	0.534	.73, 1.86
	Hispanics	0.007	0.255	0.979	.61, 1.66
	AAs	0.454	0.263	0.084	.94, 2.64
	Hispanics x Stressors	0.745	0.309	0.016	1.15, 3.86
	AAs x Stressors	0.591	0.265	0.026	1.08, 3.04

### **Race/Ethnicity Moderating Coping Behaviors and Level of Distress**

The hypothesis for specific Aim 5 states that race/ethnicity will moderate the relationship between coping behaviors and level of distress. Preliminary analyses were completed and assumptions for multicollinearity, normality, linearity and homoscedasticity were met. Interaction products were computed for AA and problem and emotion focused coping and Hispanics and problem and emotion focused coping. Multiple regression using the interaction products was performed.

There was no statistically significant moderation of race on the relationship between problem focused coping and level of distress. The interaction variable for both

AAs ( $\beta = .067$ ,  $SE = .048$ ,  $p = .167$ , 95%  $CI = [-.03, .16]$ ) and Hispanics ( $\beta = .053$ ,  $SE = .041$ ,  $p = .200$ , 95%  $CI = [-.03, .13]$ ) were not significant. However, a statistically significant result for Hispanics alone was found,  $\beta = -.083$ ,  $SE = .028$ ,  $p = .004$ , 95%  $CI = [-.14, -.03]$ . There was a statistically significant moderation of race/ethnicity on the relationship between emotion focused coping and level of distress in both Hispanics ( $\beta = .119$ ,  $SE = .043$ ,  $p = .007$ , 95%  $CI = [.03, .20]$ ) and AAs ( $\beta = .114$ ,  $SE = .044$ ,  $p = .010$ , 95%  $CI = [.03, .20]$ ). See results in Table 4.9.

Table 4.9. Moderation of race/ethnicity on coping behaviors and level of distress.

		<i>B</i>	<i>SE</i>	<i>p</i> -value	95% <i>CI</i>
Level of Distress	Problem Focused Coping (PC)	0.114	0.037	0.003	.04, .19
	Hispanics	-0.083	0.028	0.004	-.14, -.03
	AAs	-0.044	0.041	0.290	-.13, .04
	Hispanics x PC	0.053	0.041	0.200	-.03, .14
	AAs x PC	0.067	0.048	0.167	-.03, .16
Level of Distress	Emotion Focused Coping (EC)	0.035	0.037	0.349	-.04, .11
	Hispanics	-0.105	0.026	0.000	-.16, -.05
	AAs	-0.047	0.033	0.156	-.11, .02
	Hispanics x EC	0.119	0.043	0.007	.03, .20
	AAs x EC	0.114	0.044	0.01	.03, .20

### Follow-up Comparisons of Racial/Ethnic Groups

Comparisons between racial/ethnic groups were examined for each of the scales using descriptive statistics and the Generalized Linear Model was used to compare differences between groups. Racial/ethnic groups had no significant differences in stressors,  $\chi^2 (2, N = 100) = 2.11$ ,  $p = .348$ . There were few people in the AA and WNH groups, which may have limited statistical power. The PSS:PICU scale comparisons are presented in Table 4.10 and top four stressors for all groups are presented in Table 4.11.

Table 4.10. Comparison of means for PSS:PICU scale by race/ethnicity.

	Hispanics ( <i>N</i> = 57)		AAs ( <i>N</i> = 16)		WNH ( <i>N</i> = 27)		<i>p</i> -value
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	
PSS:PICU Total	2.70	0.902	3.02	1.244	2.94	0.793	.363
Child's Appearance	2.74	0.165	3.54	1.405	3.01	1.198	.117
Sights and Sounds	2.45	1.217	2.66	1.533	2.74	1.134	.586
Procedures	2.98	1.143	3.18	1.347	3.13	0.991	.744
Staff Behaviors	1.94	1.079	2.17	1.481	1.59	0.887	.260
Parenting Role	2.68	1.43	3.34	1.581	3.16	1.115	.147
Staff Communication	2.67	1.231	2.84	1.735	2.41	0.851	.669
Child Behavior & Emotions	2.97	1.121	3.29	1.531	3.02	1.206	.160

Table 4.11. Top four stressors by race/ethnicity.

Rank	Hispanics	AAs	WNHs
1	Procedures	Child's Appearance	Altered Parental Role
2	Behaviors and Emotions	Altered Parental Role	Procedures
3	Child's Appearance	Behaviors and Emotions	Behaviors and Emotions
4	Altered Parental Role	Procedures	Child's Appearance

Racial/ethnic groups had no significant differences in problem focused coping behaviors,  $\chi^2(2, N = 101) = 5.90, p = .052$ . There was a significant difference between AAs when compared to WNHs,  $\beta = -1.540, SE = .747, p = .039, 95\% CI = [-3.01, -0.08]$ . In post hoc tests using pairwise comparisons, AAs were significantly different in the use of problem focused coping compared to both Hispanics ( $p = .002$ ) and WNHs ( $p = .016$ ). The magnitude of differences between groups was examined using Cohen's *d*. There was a small effect size (Cohen's  $d = 0.2$ ) between AAs ( $M = 18.56, SD = 3.48$ ) and WNH ( $M = 17.63, SD = 4.63$ ) and a medium effect size (Cohen's  $d = 0.5$ ) between AAs and Hispanics ( $M = 16.29, SD = 5.03$ ).

Racial/ethnic groups had no significant differences in emotion focused coping behaviors,  $\chi^2(2, N = 101) = 5.29, p = .071$ . There was a significant difference between

AAs when compared to WNHs,  $\beta = -1.319$ ,  $SE = .671$ ,  $p = .049$ ,  $95\% CI = [-2.63, -.01]$ . In post hoc tests, AAs were significantly different in the use of emotion focused coping compared to both Hispanics ( $p = .014$ ) and WNHs ( $p = .033$ ). There was a small effect size (Cohen's  $d = 0.4$ ) between AAs ( $M = 29.56$ ,  $SD = 4.29$ ) and WNHs ( $M = 27.70$ ,  $SD = 4.84$ ) and a medium effect size (Cohen's  $d = 0.6$ ) between AAs and Hispanics ( $M = 26.36$ ,  $SD = 6.22$ ). The problem focused and emotion focused scale comparisons are presented in Table 4.12 and 4.13.

Table 4.12. Means for problem focused coping items by race/ethnicity.

	Items	Hispanics	African Americans	White Non-Hispanics
Problem Coping	I concentrate my efforts on doing something about the situation I am in	2.66	2.69	2.82
	I get help and advice from other people	2.74	3.46	2.90
	I try to come up with a strategy	2.69	3.15	2.75
	I take action to make the situation better	3.00	3.15	3.03
	I try to get advice or help from others about what to do	2.43	3.23	2.54
	I think hard about what steps to take	2.78	3.23	2.88
	Group Totals:			
	Mean	16.29	18.56	17.63
	Standard Deviation	5.03	3.48	4.63
	Confidence Intervals	14.97,17.61	16.71,20.42	15.80,19.46

Table 4.13. Means for emotion focused coping items by race/ethnicity.

	Items	Hispanics	African Americans	White Non-Hispanics
Emotion Coping	I get emotional support from others	3.00	3.46	3.09
	I try to see it in a different light, to make it seem more positive	3.05	3.54	2.99
	I accept the reality of the fact that this has happened	3.07	3.00	3.28
	I try to find comfort in my religion or spiritual beliefs	2.93	3.77	2.91
	I make jokes about things	1.41	1.92	1.65
	I get comfort and understanding from someone	2.97	3.15	3.10
	I look for something good in what's happening	3.09	3.15	2.88
	I try to learn to live with it	2.67	2.77	2.76
	I pray or meditate	3.03	3.62	3.10
	I make fun of the situation	1.14	1.31	1.16
	Group Totals			
	Mean	26.36	29.56	27.70
	Standard Deviation	6.22	4.29	4.84
	Confidence Intervals	24.27,28.0	27.28,31.85	25.79,29.62

Ethnic groups had significant differences in level of distress,  $\chi^2(2, N = 103) = 15.40, p = .000$ . There was a significant difference between Hispanics compared to WNHs,  $\beta = -.127, SE = .042, p = .003, 95\% CI = [-.21, -.04]$ . In post hoc tests, Hispanics were significantly different in level of distress compared to both AAs ( $p = .001$ ) and WNHs ( $p = .003$ ). There was a medium effect size (Cohen's  $d = 0.7$ ) between Hispanics ( $M = 1.52, SD = .187$ ) and WNHs ( $M = 1.65, SD = .169$ ) and a large effect size (Cohen's  $d = 0.8$ ) between Hispanics and AAs ( $M = 1.68, SD = .198$ ).

## **Problems and Alternate Strategies**

Response burden and missing data were considered potential problems. Efforts to minimize both were considered in survey development, scale selection, and data collection design. The demographic data sheet was kept short. The Brief COPE scale was selected instead of the COPE scale, which is the original and longer version. The decision to use a computer tablet that could be easily picked up and put down as parents attended to their child's needs was an effort to minimize burden. Alerts for missed responses were built into the survey and provided to participants at the end of each page in an effort to minimize missing data from inadvertently skipped questions. This gave the participant the opportunity to go back and answer the missed question or, if the participant intentionally skipped a question, they were free to click through the alert without posting a response.

An initial problem experienced during the study was a shortened timeline due to delays in the IRB process at the recruitment site. This 2 month delay during a time of high census in the PICU, resulted in the decision to recruit participants from both the PICU and the CICU at the onset of data collection instead of recruiting from the PICU only. Based on PICU data from 2014 and 2015, there was an average of 145 admissions per month. A 25% participation rate was estimated in planning recruitment, which resulted in an estimated monthly recruitment of 36 participants, or nine per week.

Data collection was begun on December 15<sup>th</sup>, 2016, which is typically a time of low census, particularly in the schedule driven CICU. To manage a potential recruitment problem, participant numbers were monitored on a weekly basis, with special attention paid to reasons why the nine participants per week goal was or was not being met. It was

apparent in the first few weeks that a significant number of parents were excluded due to language issues, specifically an inability to read and respond in English. With the high proportion of Hispanic parents in Miami, this was not unexpected, but a lack of funding had initially limited the possibility of translation. With an additional grant obtained at the end of 2016, it was decided that the survey would be translated into Spanish and made available to participants. Professional translation was completed, IRB changes were approved and data collection in English and Spanish began on January 15<sup>th</sup>, 2017.

## Chapter 5 – Discussion

The influence of race/ethnicity on the stress and coping process for parents with a child in the PICU/CICU has not been extensively studied. What is known is that having a child in the PICU increases parents risk for Acute Stress Disorder (ASD) (Ularntinon et al., 2010). Similar results have been found in studies of parents with a child in the CICU (Franck et al., 2010; Lisanti, Ryan Allen, Kelly & Medoff-Cooper, 2017). This initial parental stress can potentially lead to negative mental health outcomes for parents after a PICU experience, even if the child's health outcome is positive (Balluffi et al., 2004, De Young et al., 2014; Kassam-Adams, Fleisher, & Winston, 2009; Ularntinon et al., 2010). A frequently cited gap in the literature on parental stress is the lack of research on minority populations (Board & Ryan-Wenger, 2000; Shudy et al., 2006; Woolf et al., 2016). With the changing demographics in the US and the PICU/CICU population, understanding the impact of race/ethnicity on parental stress is important for improving mental health outcomes for parents. The primary goal of this study was to present data on the stress and coping process in an ethnically diverse sample of mothers with a child experiencing an acute admission to the PICU/CICU. Results from this study expand the literature on parental stress and coping with a child in the PICU/CICU. It provides data on the acute stress and coping experiences of ethnically diverse mothers in this setting. It provides comparisons between racial/ethnic groups on stressors, coping behaviors and level of distress as a baseline for comparison for future research. This study also provides data on the relationships between stressors, coping behaviors and level of distress in mothers in the PICU/CICU.

### **Sample Diversity**

A critical aspect of this research was to obtain a diverse sample, since the majority of studies reflect primarily the experiences of WNH mothers. Miami, Florida has a uniquely diverse population. Hispanics in Miami come from a variety of Caribbean and Central and South American countries. Cubans are the majority of the Hispanic population (45%) and Hispanics are the majority population in Miami-Dade County. The racial/ethnic groups represented in the current study reflect the diversity of the community. One quarter of the sample was WNH and fifteen percent were AA. Hispanics (63%) made up the largest racial/ethnic group in this sample, with most having lived in the US an average of 10 years. Most Hispanic mothers were bilingual, with only one third requesting to complete the survey in Spanish. Almost half of all mothers in this sample were born outside of the US (49%).

Socioeconomic status (SES) is often considered to be a confounding or proxy variable in research on race or ethnicity (Slavin, Rainer, McCreary, & Gowda, 1991). In a recent systematic review by Woolf and colleagues (2016) looking at early stress responses in parents after a serious illness or injury to their child, three studies found SES associated with acute stress, 5 studies found SES not associated with acute stress. To examine the independent effects of race/ethnicity in this study, socioeconomic status (i.e., income, education, age and marital status) was controlled for in the analyses. However, analysis showed that SES was not associated with stressors, coping behaviors or level of distress. In other words, for these mothers experiencing the acute phase of the stress and coping process related to their child's illness or injury, income, education, age and marital status was not associated with their level of distress. One rationale is that SES

may only impact distress outcomes in the long term. For example, SES was not associated with acute distress in this study, when the outcomes for the child were still uncertain. Once parents are further removed from the acute phase of the trauma and the uncertainty is removed, SES may become a more salient variable impacting parental level of distress.

Another finding related to SES variables involved the educational and income level of the mothers. The educational level of the sample was above average, with 68% of mothers having at least some college education or higher. In contrast, the income level of the sample was lower than average, with almost half reporting incomes of less than \$34,999 per year. The finding of higher education levels and lower incomes mirror trends in Miami-Dade County (RER Planning Research & Economic Analysis, 2015). This lack of confluence between education and household incomes could potentially be related to a number of factors for mothers in this sample. For example, educational degrees and professional attainment from other countries is not always recognized in the US. This causes many well educated and professional non-natives or Spanish speakers to seek lower paying jobs, which specifically impacts Miami with its large number of immigrants. Also, perhaps the higher educated mothers were at home with children or temporarily out of work due to having a child. Lastly, gender disparity of salaries in the workplace could be another factor.

As mentioned in the literature review, parental distress in the CICU and PICU have been studied independently. This sample is unique in that it includes mothers from both the PICU and CICU. This decision was made based on the similarity of the unit designs and environment, the similar outcomes for PICU and CICU parents when studied

separately, and the fact that many “PICUs” often include cardiac patients when there is not a separate CICU. While the child’s age was not a focus of this study and did not impact the results, combining the units decreased the average age of the patients and skewed them toward one year or younger. Since many complex congenital heart defects are diagnosed either prenatally or in the neonatal period, many cardiac patients undergo surgery during the early weeks of life (Lisanti et al., 2017). This might be a consideration for researchers studying either combined or separate units, if the age of the child is a variable of interest.

### **Race/Ethnicity, Stressors and Coping Behaviors**

One important outcome of this study is that there were no statistically significant differences between AA, WNH and Hispanic mothers in regard to PICU/CICU stressors in the context of acute stress. In other words, mothers experienced similar stressors in the acute phase of their PICU/CICU admission and race/ethnicity was not a differentiating factor. Results suggest that currently available interventions such as the COPE Program (Melnik, 1994) and the Nursing Mutual Participation Model of Care (Curley, 1988), which have demonstrated effectiveness in reducing parental distress, may be effectively implemented with diverse samples of mothers.

Race/ethnicity was also used to compare the type of stressors that mothers experienced in the PICU/CICU environment. WNH mothers found the altered parental role to be the highest stressor, followed by procedures done to the child, and the child’s behaviors and emotions. These results are consistent with the literature, as altered parental role and the child’s behaviors and emotions were identified among the highest stressors for WNH parents in multiple studies over the past 30 years (Shudy et al., 2006).

Altered parental role items include “not taking care of my child”, “not being able to hold my child”, “not being able to be with my crying child” and “not being able to visit/see my child when I wanted”. The child’s behaviors and emotions items include “crying or whining”, “inability to talk or cry”, “acting or looking as if in pain”, or showing “confusion”, “fright”, “anger”, “sadness”, or “uncooperative behaviors”. The subscales not included among the top stressors are sights and sounds, and the staff behaviors and communication.

AA mothers found the child’s appearance to be the highest stressor, followed by altered parental role and the child’s behaviors and emotions. There are no direct comparisons for AA mothers’ stressors in the literature, as AAs generally make up a small percentage of many samples and those with larger samples did not compare stressors between racial/ethnic groups. Future studies should include larger samples of AA mothers so that there can be more generalizability of the results.

Hispanic mothers found procedures done to the child to be the highest stressor, followed by the child’s behaviors and emotions and the child’s appearance. These results are similar to Rei & Fong’s (1996), in which procedures and the child’s behaviors and emotions were among the highest stressors for Hispanic parents. In both of these studies, altered parental role was ranked fourth among the stressors, which differs from WNH and AA mothers in this sample and from the literature in general.

Trends were observed in the mean scores for each category of stressor. AA mothers’ mean scores were consistently the highest in each category among the racial/ethnic groups, while the Hispanic mothers’ mean scores were consistently the lowest among the groups. In spite of these variances, however, the mothers in this sample

were more alike than different in their experiences of acute stressors in the PICU/CICU. For example, although the ranking of stressors was different for each racial/ethnic group, the highest four stressors were the same across groups and the lowest three stressors were the same across groups. Results suggest that interventions should continue to focus on minimizing the stress associated with the top four stressors: altered parental role, the child's behaviors and emotions, the child's appearance, and procedures done to the child.

One consideration in expanding research in this area is participant burden. With that in mind, Rodriguez-Rey & Alonso-Tapia (2015) developed an abbreviated version of the PSS:PICU, the A-PSS:PICU. Researchers combined the list of items in each subscale of the PSS:PICU into a single question with the items listed as examples at the end of the question. This makes both practical and empirical sense and results in a seven question measure of parental stressors. The measure is available in both English and Spanish. The exploratory factor analysis on the A-PSS:PICU resulted in a two factor solution, with staff behavior and communication making up its own factor (Rodriguez-Rey & Alonso-Tapia, 2015). Since staff behavior and communication are consistently among the lowest stressors for mothers, as they were in the current sample, it may even be practical to remove those items from the measure, depending on the focus of the research. This would result in a five question measure focusing specifically on PICU/CICU environmental stressors and at the same time would further minimize participant burden.

### **Race/Ethnicity and Coping Behaviors**

In this study, the theory-driven relationships between coping behaviors and both stressors and level of distress were investigated. The Brief COPE scale was used to assess three types of coping behaviors: a) problem focused, b) emotion focused and c)

avoidance coping. Problem focused coping includes behaviors such as active coping, seeking instructional support and planning. Emotion focused coping includes strategies such as getting emotional support, positive thinking, acceptance, religion, and humor. Avoidance coping includes such strategies as self-distraction, denial, disengagement, venting, self-blame and substance use.

In the current study, avoidance coping behaviors were used very little across all racial/ethnic groups. One explanation for this could be sampling bias. Mothers using avoidance coping may not have been at the patient's bedside, thus minimizing their participation. Of those surveyed, there was one mother out of 103 that scored in the "high use" category for avoidance coping. It was observed during data collection, that mothers who were present remained primarily at the bedside and only pulled the privacy curtain closed when they were sleeping. In this sample of mothers, avoidance coping was not a viable or frequently sought strategy. The family-centered care environment made it quite comfortable for parents to remain at the bedside, which is an amazing and positive advance in pediatric critical care. However, it could be suggested that the family-centered care environment, with all of the activity surrounding the care of the child, may not have allowed mothers the opportunity to engage in avoidance coping behaviors.

In this study, both problem and emotion focused coping behaviors were used by mothers of all racial/ethnic groups. However, only problem focused coping was found to fully mediate the relationship between stressors and level of distress. In other words, the effect of the PICU/CICU stressors on the mothers' level of distress is best explained by the mothers' use of problem focused coping behaviors. The mediating effect of problem focused coping behaviors held true regardless of race/ethnicity in this sample.

Problem focused coping behaviors in the Brief COPE include items such as “taking action to try to make the situation better”, “getting advice or help from others about what to do” and “trying to come up with a strategy.” In looking at racial/ethnic differences in the specific types of problem focused coping behaviors being utilized, AAs focused on “getting advice from others” or “getting help from others.” WNHs focused on both “getting help from others” and “taking action”. Hispanics focused on “taking action” and thinking “about what steps to take”. These item differences may provide an opportunity to evaluate which type, or “dose”, of problem focused coping would more positively improve outcomes.

Further analyses focused on racial/ethnic differences between groups found that AA mothers used more problem and emotion focused coping behaviors than both Hispanic and WNH mothers. The magnitude of differences between AA and WNH mothers use of problem focused coping behaviors was small, while there was a medium difference between AAs and Hispanics. The magnitude of difference in emotion focused coping between AA and WNH mothers was small, while the magnitude of difference between AA and Hispanic mothers’ use of emotion focused coping behaviors was medium. Results are supported by previous studies that found that emotion focused coping behaviors are used significantly more by AAs compared to WNHs (Brantley, 2002; Yeates et al., 2002). In addition, it is suggested that AA women experience a greater number of chronic, daily stressors related to their race and gender. As a result, when faced with an additional, serious stressor such as having a child in the PICU/CICU, AA mothers tend to use of a wider range of coping behaviors in managing their distress (Brantley et al., 2002).

Results also show that race/ethnicity moderated both the relationship between stressors and emotion focused coping behaviors and level of distress and emotion focused coping behaviors in both Hispanics and AAs when compared to WNHs. In other words, AA and Hispanic mothers may use more emotion focused coping behaviors compared to WNHs when experiencing PICU/CICU stressors. In further evaluating the differences in specific types of emotion focused coping behaviors being utilized, AAs in this study focused most highly on “finding comfort in my religion or spiritual beliefs” and prayer, which is supported extensively in the literature (Allen & Marshall, 2010; Brantley et al., 2002; McCreary et al., 2006; Seng, Kohn-Wood, McPherson, & Sperlich, 2011; Utsey, Adams & Bolden, 2000). In a longitudinal study by Yeates et al. (2002), religious coping, mental disengagement and denial were used more by AA parents after a child’s traumatic injury, compared to WNHs who used acceptance most often. This is supported by the current study, in which WNHs focused on both acceptance and getting “comfort and understanding from someone.” Hispanics focused on looking “for something good in what’s happening” and acceptance. It should be noted that humor was the least used emotion focused coping behavior for all mothers across racial/ethnic groups. While it is important to evaluate the similarities and differences in coping behaviors of parents with a child in the PICU/CICU, it is of greater importance to evaluate the relationship between coping behaviors and the mental health outcomes for parents.

### **Race/Ethnicity and Level of Distress**

One unique finding in this study is that Hispanic mothers experienced the least amount of distress. Hispanics were significantly different than AAs and WNHs in regard to this outcome. There was a medium difference/effect size between Hispanics and WNH

and a large difference between Hispanics and AAs. Interestingly, Hispanic and WNH mothers used a comparable amount of coping behaviors but Hispanic mothers had significantly lower level of acute distress than WNH mothers. One rationale may be that Hispanic mothers had less critical children in the PICU/CICU. It could also be suggested that other coping behaviors are being used by Hispanic parents that are not captured in the Brief COPE. For example, Hispanic mothers generally have a larger number of extended family members and friends at the bedside for support, an aspect of Hispanic culture known as familialism. While the Brief COPE has items pertaining to seeking emotional support, perhaps the impact of familialism on the stress and coping process is not fully captured. This might be an area for future research on Hispanic mothers with a child in the PICU/CICU.

AA mothers experienced the most distress in this study, while using more of both problem and emotion focused coping behaviors than either Hispanic or WNH mothers. One explanation may be that AA children were in more critical condition than Hispanic or WNH children. Maybe some aspect of their emotion focused coping behaviors moderated distress in a negative direction. Perhaps unmeasured contextual factors, such as minority status, experiences of discrimination, previous trauma exposures or stait anxiety levels placed AA mothers at higher risk for ASD and PTSD when experiencing the acute trauma of having a child admitted to the PICU/CICU (Ai et al., 2011; Seng et al., 2012; Woods-Giscombe, 2010). In addition to potentially being at higher risk for ASD and PTSD, AA mothers may be less likely to display or to seek help for emotional distress, making it difficult for nurses to assess their mental health status (Woods-Giscombe, 2010).

## **Limitations**

This study used a convenience sampling strategy and was limited to mothers in one institution. These factors impact the generalizability of findings. For example, the study was limited to mothers who were at the bedside, possibly excluding mothers experiencing greater distress. It focused solely on the acute stress and coping experience of mothers at one point in time, so it does not take into consideration the temporal factors related to level of distress and does not allow for causal inferences to be made. The sample sizes for AA and WNH mothers were relatively small, which may have limited statistical power to detect group differences. Also, the experience of racial/ethnic groups in Miami may be different from other parts of the country.

## **Implications**

Importantly, the stressors experienced by mothers in the acute phase of a PICU/CICU admission were universal across racial groups in this study. This suggests that currently available interventions to reduce these stressors would have the same efficacy for mothers, regardless of racial/ethnic background. Interventions should continue to focus on minimizing the distress associated with altered parental role, the child's behaviors and emotions, the child's appearance, and procedures done to the child.

Mothers in this study engaged in numerous coping behaviors in an attempt to deal with the distress of having a child in the PICU/CICU. Problem focused coping was an important strategy across all groups. Utilizing existing evidenced based interventions and resources which actively engage parents in problem coping activities would be the gold standard for improving outcomes. These tools and interventions should be standardized throughout organizations and readily available for acute admissions. Having a standard

protocol in place would guarantee that all mothers are being provided thorough, specific and consistent information. Nurses could then support mothers in using problem focused coping activities such as talking to and touching their child, assisting with bathing and diapering, and supporting their child through medical procedures. These interventions address the areas of highest stress for parents. Nurses can also provide emotional support and access to needed resources to the mothers. Consulting social work, chaplain services, psychological support and encouraging participation in parent support groups will enable mothers to get help or to seek advice from others with similar experiences.

It is important to acknowledge that this study does not provide evidence that problem focused coping leads to improved outcomes. However, previous interventional research states that mental health outcomes for parents were improved when problem focused coping was enhanced. Specifically, providing mothers with information about what behaviors and emotions their child will experience and providing them with strategies for how to comfort and emotionally support their child through stressful medical procedures may improve mental health outcomes in the long term (Melnyk, 1994; Melnyk, 1995; Melnyk, Feinstein & Fairbanks, 2006; Shudy et al., 2006).

In this study, race/ethnicity was a significant moderator for emotion focused coping behaviors in AAs and Hispanics, compared to WNHs. Interestingly, the type and frequency of use for emotion focused coping behaviors varied between AA and Hispanic mothers, as did their acute level of distress. This suggests that more research is needed on the types and utilization of emotion focused coping and how specific behaviors might impact the level of distress both over time and between race/ethnicities.

Education for PICU/CICU nurses should include information about the prevalence and outcomes of ASD and PTSD in this population of parents. It should also include the identification of high-risk groups, such as women and AAs. Knowledge about assessment tools and interventions for ASD and PTSD should be provided. Even when tools are provided to nurses, they may not be routinely implemented. One strategy to improve resource utilization by nurses, would be to have ASD assessment tools incorporated into the electronic medical record for all admissions to the PICU/CICU. These could be accompanied by a reference list of specific interventions based on different patient criteria, such as age, intubation status or severity of illness scores.

The trend toward parents consistently being at the bedside of their child is generally viewed in a positive manner. Yet, it may also have unintended consequences on parental stress and coping which should be considered in future research. For example, avoidance coping and humor were used very little in this sample of mothers. Sampling bias may be a factor, but constantly being in the PICU/CICU may minimize the opportunity for parents to use some of the positive avoidance coping behaviors, including distraction and venting negative feelings. It may also minimize the use of some positive emotion focused coping behaviors, such as humor. Lastly, in this setting, mothers were much more isolated from other mothers, which may diminish opportunities to engage in problem focused coping behaviors, such as getting support, advice and understanding from other parents in the same situation.

### **Future Research**

Future research on parental stress should focus on increasing the size and number of racially/ethnically diverse mothers in samples, with a specific focus on AA mothers

who may be at the highest risk for ASD and PTSD. Data from this research can provide a baseline for future studies to compare stressors in racially/ethnically diverse mothers with a child in the PICU/CICU. Research should test whether coping variables predict ASD and PTSD over time so that causal effects can be evaluated. Further testing should be done on the moderating effect of racial/ethnic variances on emotion focused coping behaviors and level of distress outcomes. Randomized, longitudinal, interventional studies which include measures on stressors, coping behaviors and level of distress over time in a diverse population of mothers would be a good next step in moving research on parental stress and coping forward.

### **Conclusion**

This study found no racial/ethnic differences in the stressors experienced by mothers with a child newly admitted to the PICU/CICU. However, race/ethnicity did moderate the relationship between stressors, emotion focused coping, and level of distress. AA mothers were found to use more emotion and problem focused coping behaviors than Hispanic or WNH mothers, and experienced higher levels of distress. A unique finding in this study, was that Hispanic mothers who used comparable amounts of problem and emotion focused coping behaviors as WNH mothers, had lower levels of distress. The continued study of ethnically diverse mothers is critical to minimizing the negative effects of ASD and PTSD in mothers with a child in the PICU/CICU.

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## Appendix A

### Stress and Coping Survey

#### Self-Report Anonymous Survey

You are being asked to participate in a study to learn more about the stress you feel, how you are managing the stress and outcomes of mothers with a child in the Pediatric Intensive Care Unit (PICU). Taking part in this study is completely voluntary. You may skip any question or stop participating at any time. Your child's care at Nicklaus Children's Hospital will not be impacted by any decision you make about this survey. All of the data will be collected anonymously. That means, we are NOT collecting any information that will allow us, or anyone else, to identify you.

If you choose to participate, you will take a survey, answering questions about what things have been stressful for you, how you have coped with the situation, and how the experience has impacted you. The survey will take less than 15 minutes to complete.

There are no known direct benefits associated with participating in this research. If you experience increased emotional upset please let a study staff member know and we can connect you with the unit social worker at Nicklaus Children's Hospital to assist you during this time.

For more information concerning this study you may contact the Student Investigator, Mary E. Ernst, at 305-282-9305, under the supervision of Dr. Jessica Williams, at 305-284-3072, at the University of Miami School of Nursing and Health Studies. If you have any questions about your rights as a research participant, you may contact the Director of the Research Institute, at 305-666-6511, Ext. 3540 or the University of Miami Human Subject Research Office at 305-243-3195.

Your completion of this survey implies your consent to participation in this research.

The questions below ask about you and your family. It helps us to better understand other factors that might influence how you cope with the stress of having a child in the Pediatric Intensive Care Unit (PICU).

Q1 What is your age?

Q2 What is the age of the child in the PICU?

Q3 What is your relationship to the child in the PICU?

- Mother (1)
- Grandmother (2)
- Stepmother (3)
- Other (please describe) (4) \_\_\_\_\_

Q4 What is your marital status?

- Married (1)
- Single, never married (2)
- Widowed (3)
- Divorced (4)
- Separated (5)
- Living with partner, not married (6)

Q5 Which one or more of the following would you say is your race?

- White or Caucasian (1)
- Black or African American (2)
- Other Black (please describe) (6) \_\_\_\_\_
- American Indian or Alaska Native (7)
- Asian (9)
- Other Asian (please describe) (15) \_\_\_\_\_
- Native Hawaiian or Other Pacific Islander (16)
- Some Other Race (please describe) (20) \_\_\_\_\_

Display This Question:

If Which one or more of the following would you say is your race?

q://QID9/SelectedChoicesCount Is Greater Than or Equal to 2

Q5a Which one of these groups would you say best represents your race?

- White or Caucasian (1)
- Black or African American (2)
- Other Black (please describe) (3) \_\_\_\_\_
- American Indian or Alaska Native (4)
- Asian (5)
- Other Asian (please describe) (6) \_\_\_\_\_
- Native Hawaiian or Other Pacific Islander (7)
- Some Other Race (please describe) (8) \_\_\_\_\_

Q6 Are you of Hispanic, Latina, or Spanish origin?

- Yes (1)
- No (2)

If Yes Is Selected, Then Skip To Which of the following best describes...If No Is Selected, Then Skip To Were you born in the United States?

Q6a Which of the following best describes you? (select all that apply)

- Cuban (1)
- Puerto Rican (2)
- Colombian (3)
- Mexican (4)
- Nicaraguan (5)
- Venezuelan (6)
- Other (please describe) (7) \_\_\_\_\_

Q7 Were you born in the United States?

- Yes (1)
- No (2)

If Yes Is Selected, Then Skip To What type of household are you living...

Q7a What country were you born in? (Drop down list provided)

Q7b How many years have you lived in the United States?

Q8 What best describes the household of the child in the PICU?

- Single parent household (1)
- Two parent household (2)
- Other (please describe) (3) \_\_\_\_\_

Q9 What is your annual household income from all sources before taxes?

- Less than \$14, 999 (1)
- \$15,000 to \$24,999 (2)
- \$25,000 to \$34,999 (3)
- \$35,000 to \$49, 999 (4)
- \$50,000 to \$74,999 (5)
- \$75,000 to \$99,999 (6)
- \$100,000 to \$149,999 (7)
- Greater than \$150,000 (8)

Q10 How many people live in your household, including you and the child in the PICU?

Q11 What is the highest grade or year of school that you have completed?

- Less than 9th grade (1)
- Grades 9-11 (some high school) (2)
- Grade 12 or GED (high school graduate) (3)
- College 1-3 years (some college or technical school) (4)
- College 4 years (college graduate) (5)
- Graduate or Professional school (advanced degree) (6)

Q11a What is the highest grade or year of school that your spouse/partner has completed? (if applicable)

- Less than 9th grade (1)
- Grades 9-11 (some high school) (2)
- Grade 12 or GED (high school graduate) (3)
- College 1-3 years (some college or technical school) (4)
- College 4 years (college graduate) (5)
- Graduate or Professional school (advanced degree) (6)
- Not applicable (7)

Q12 What, if any, is your religious preference?

- Christian (please describe) (1) \_\_\_\_\_
- Hindu (2)
- Jewish (3)
- Buddhist (4)
- Islam (5)
- Other non-Christian (please describe) (6) \_\_\_\_\_
- None, no religious preference (7)

If None, no religious preference Is Selected, Then Skip To End of Block

Q12a How important is your religion to you as a person?

\_\_\_\_\_ Slide scale to rate











Q20 The following questions focus on ways you've been coping with the stress of having a child in the PICU. Obviously, different people deal with things in different ways, but I am interested in how you are dealing with it. I want to know to what extent you are doing what the item says - how much or how frequently. Don't answer on the basis of whether it seems to be working or not - just whether or not you are doing it. Try to rate each item separately in your mind from the others. Make your answers as true for you as you can.

	I am not doing this at all (1)	I am doing this a little bit since admission (2)	I am doing this a medium amount since admission (3)	I am doing this frequently since admission (4)
I turn to work or other activities to take my mind off things (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I concentrate my efforts on doing something about the situation I am in (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I tell myself "this isn't real" (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I get emotional support from others (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I just give up trying to deal with it (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I say things to let my unpleasant feelings escape (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I get help and advice from other people (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Q21 What ways have you been coping with the stress of having a child in the PICU?

	I am not doing this at all (1)	I am doing this a little bit since admission (2)	I am doing this a medium amount since admission (3)	I am doing this frequently since admission (4)
I try to see it in a different light, to make it seem more positive (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I criticize myself (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I try to come up with a strategy about what to do (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I accept the reality of the fact that this has happened (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I try to find comfort in my religion or spiritual beliefs (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I make jokes about things (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I use alcohol to make myself feel better (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Q22 What ways have you been coping with the stress of having a child in the PICU?

	I am not doing this at all (1)	I am doing this a little bit since admission (2)	I am doing this a medium amount since admission (3)	I am doing this frequently since admission (4)
I do something to think about it less, like watch TV, read or sleep (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I take action to try to make the situation better (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I just refuse to believe that this has happened (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I get comfort and understanding from someone (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I give up the attempt to cope (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I express my negative feelings (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I try to get advice or help from others about what to do (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q23 What ways have you been coping with the stress of having a child in the PICU?

	I am not doing this at all (1)	I am doing this a little bit since admission (2)	I am doing this a medium amount since admission (3)	I am doing this frequently since admission (4)
I look for something good in what's happening (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I blame myself for things that happen (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I think hard about what steps to take (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I try to learn to live with it (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I pray or meditate (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I make fun of the situation (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I use drugs to help me get through it (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q24 Did the experience of having your child admitted to the Pediatric Intensive Care Unit (PICU) frighten you?

- Yes (1)  
 No (2)

Q25 The following questions ask about your experiences surrounding "the trauma". The trauma, for the purposes of this study, refers to having a child admitted to the PICU. Please answer each question in the context of what you have experienced since your child was admitted.

	Not at all (1)	Mildly (2)	Medium (3)	Quite a bit (4)	Very much (5)
During or after the trauma, did you ever feel numb or distant from your emotions? (1)	<input type="radio"/>				
During or after the trauma, did you ever feel in a daze? (2)	<input type="radio"/>				
During or after the trauma, did things around you ever feel unreal or dreamlike? (3)	<input type="radio"/>				
During or after the trauma, did you ever feel distant from your normal self or like you were watching it happen from outside? (4)	<input type="radio"/>				
Have you been unable to recall important aspects of the trauma? (5)	<input type="radio"/>				
Have memories of the trauma kept entering your mind? (6)	<input type="radio"/>				
Have you had bad dreams or nightmares about the trauma? (7)	<input type="radio"/>				
Have you felt as if the trauma was about to happen again? (8)	<input type="radio"/>				
Do you feel very upset when you are reminded of the trauma? (9)	<input type="radio"/>				

Q26 Please answer each question in the context of what you have experienced since your child was admitted.

	Not at all (1)	Mildly (2)	Medium (3)	Quite a bit (4)	Very much (5)
Have you tried not to think about the trauma? (1)	<input type="radio"/>				
Have you tried not to talk about the trauma? (2)	<input type="radio"/>				
Have you tried to avoid situations or people that remind you of the trauma? (3)	<input type="radio"/>				
Have you tried not to feel upset or distressed about the trauma? (4)	<input type="radio"/>				
Have you had trouble sleeping since the trauma? (5)	<input type="radio"/>				
Have you felt more irritable since the trauma? (6)	<input type="radio"/>				
Have you had difficulty concentration since the trauma? (7)	<input type="radio"/>				
Have you become more alert to danger since the trauma? (8)	<input type="radio"/>				
Have you become jumpy since the trauma? (9)	<input type="radio"/>				
When you are reminded of the trauma, do you sweat or tremble or does your heart beat faster? (10)	<input type="radio"/>				

## Appendix B

### Spanish PICU Stress and Coping Survey

#### Encuesta sobre Auto Informe Anónimo

Se le solicita participar en un estudio para aprender más sobre el estrés que usted siente, cómo está sobrellevando el estrés y los resultados una madre con un niño/a en una Unidad de Cuidados Intensivos Pediátricos (PICU, en su sigla en inglés). La participación en el estudio es absolutamente voluntaria. Puede saltarse cualquier pregunta o dejar de participar en cualquier momento. El cuidado de su hijo/a en el Nicklaus Children's Hospital no se verá impactado por ninguna decisión que usted tome con relación a este estudio. Toda la información será recopilada en forma anónima. Eso significa que NO estamos recopilando ningún tipo de información que nos permita a nosotros ni a ninguna otra persona, identificarla.

Si usted decide participar, usted hará la encuesta, respondiendo preguntas sobre qué cosas han sido estresantes para usted, cómo ha podido sobrellevar la situación, y cómo han impactado en usted las experiencias. La encuesta le tomará menos de 15 minutos para completarla.

No existen ningún tipo de beneficios directos conocidos asociados a la participación en esta investigación. Si usted experimenta un incremento en el trastorno emocional por favor infórmele a nuestro personal del estudio para que podamos ponerla en contacto con la trabajadora social de la unidad en el Nicklaus Children's Hospital para que pueda asistirle durante este tiempo.

Para mayor información relacionada con este estudio puede contactarse con la Estudiante Investigadora, Mary E. Ernst, en el 305-282-9305, bajo la supervisión de la Dra. Jessica Williams, en el 305-284-3072, en la Facultad de Enfermería y Estudios de Salud de la Universidad de Miami. Si tiene alguna pregunta sobre sus derechos como participante de una investigación, puede ponerse en contacto con el Director del Instituto de Investigación, en el 305-666-6511, Int. 3540, o con la Oficina de Investigación de Sujetos Humanos de la Universidad de Miami en el 305-243-3195.

Completar la siguiente encuesta implica su consentimiento de participar en esta investigación.

Las siguientes preguntas son acerca de usted y su familia. Nos ayudan a comprender mejor otros factores que pueden influir en cómo usted sobrelleva el estrés de tener un niño/a en la Unidad de Cuidados Intensivos Pediátricos (PICU, en su sigla en inglés).

Q1 ¿Cuál es su edad?

Q2 ¿Cuál es la edad del niño/a en la PICU?

Q3 ¿Cuál es su relación con el niño/a en la PICU?

- Madre
- Abuela
- Madrastra
- Otro (por favor describir) \_\_\_\_\_

Q4 ¿Cuál es su estado civil?

- Casada
- Soltera, nunca casada
- Viuda
- Divorciada
- Separada
- Viviendo en pareja, no casada

Q5 ¿Cuál o cuáles de las siguientes diría usted que es su raza?

- Blanca o caucásica
- Negra o Afro Americana
- Otra raza Negra (por favor describir) \_\_\_\_\_
- India Americana o Nativa de Alaska
- Asiática
- Otra raza Asiática (por favor describir) \_\_\_\_\_
- Hawaiana Nativa o de otra Isla del Pacífico
- Alguna otra Raza (por favor describir) \_\_\_\_\_

Display This Question:

If Which one or more of the following would you say is your race?

q://QID9/SelectedChoicesCount Is Greater Than or Equal to 2

Q5a ¿Cuál de estos grupos diría que mejor representa su raza?

- Blanca o Caucásica
- Negra o Afro Americana
- Otra raza Negra (por favor describir) \_\_\_\_\_
- India Americana o Nativa de Alaska
- Asiática
- Otra raza Asiática (por favor describir) \_\_\_\_\_
- Hawaiana Nativa o de otra Isla del Pacífico
- Alguna otra Raza (por favor describir) \_\_\_\_\_

Q6 ¿Eres Hispana, Latina o de origen español?

- Sí
- No

If Yes Is Selected, Then Skip To Which of the following best describes...If No Is Selected, Then Skip To Were you born in the United States?

Q6a ¿Cuál de las siguientes la describe mejor? (seleccione todas las que correspondan)

- Cubana
- Puertorriqueña
- Colombiana
- Mexicana
- Nicaragüense
- Venezolana
- Otras (por favor describir) \_\_\_\_\_

Q7 ¿Nació usted en los Estados Unidos?

- Sí
- No

If Yes Is Selected, Then Skip To What type of household are you living...

Q7a ¿En qué país nació usted?

Q7b ¿Cuántos años ha vivido en los Estados Unidos?

Q8 ¿Qué describe mejor el hogar del niño/a en la PICU?

- Hogar de madre soltera
- Hogar con dos padres
- Otro (por favor describir) \_\_\_\_\_

Q9 ¿Cuál es el ingreso anual proveniente de todas las fuentes del hogar libre de impuestos?

- Menos de \$14, 999
- \$15,000 a \$24,999
- \$25,000 a \$34,999
- \$35,000 a \$49, 999
- \$50,000 a \$74,999
- \$75,000 a \$99,999
- \$100,000 a \$149,999
- Superior a \$150,000

Q10 ¿Cuántas personas viven en su hogar, incluyendo al niño/a en la PICU?

Q11 ¿Cuál es el grado más alto o el año escolar que usted ha completado?

- Menor al 9° grado
- Grados 9-11 (algunos años de preparatoria)
- Grado 12 o GED (graduada de preparatoria)
- Universidad 1-3 años (algunos años de Universidad o escuela técnica)
- Universidad 4 años (graduada universitaria)
- Graduada o escuela Profesional (estudios de postgrado)

Q11a ¿Cuál es el grado más alto o el año escolar que su cónyuge/pareja ha completado? (si correspondiera)

- Menor al 9° grado
- Grados 9-11 (algunos años de preparatoria)
- Grado 12 o GED (graduada de preparatoria)
- Universidad 1-3 años (algunos años de Universidad o escuela técnica)
- Universidad 4 años (graduada universitaria)
- Graduada o escuela Profesional (estudios de postgrado)
- No corresponde

Q12 ¿Cuál es su preferencia religiosa, si la tuviera?

- Cristiana (por favor describir) \_\_\_\_\_
- Hindú
- Judía
- Budista
- Islámica
- Otras no-cristianas (por favor describir) \_\_\_\_\_
- Ninguna, sin preferencia religiosa

If Ninguna, sin preferencia re... Is Selected, Then Skip To End of Block













Q20 Las siguientes preguntas se enfocan en las formas como usted ha estado manejando el estrés de tener a un niño/a en la PICU. Obviamente, diferentes personas lidian con las cosas en diferentes maneras, pero yo estoy interesada en saber cómo usted está lidiando con ello. Deseo saber en qué medida usted está haciendo lo que el ítem dice – qué tanto o con qué frecuencia. No responda sobre la base de si parece que está funcionando o no – sino si usted lo está haciendo o no. Trate de calificar cada ítem por separado de los otros en su mente. Que sus respuestas sean lo más verídicas que usted pueda.

	No estoy haciendo esto para nada	Estoy haciendo esto un poco desde la internación	Estoy haciendo esto medianamente desde la internación	Estoy haciendo esto frecuentemente desde la internación
Me enfoco en el trabajo o en otras actividades para despejarme	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Concentro mis esfuerzos en hacer algo con respecto a la situación en la que me encuentro	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Me digo a mí misma “esto no es real”	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Recibo apoyo emocional de otras personas	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Desisto de tratar de manejarlo	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Digo cosas para que mis sentimientos desagradables escapen	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Recibo ayuda y consejo de otras personas	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q21 ¿En qué maneras ha estado manejando el estrés de tener un niño/a en la PICU?

	No estoy haciendo esto para nada	Estoy haciendo esto un poco desde la internación	Estoy haciendo esto medianamente desde la internación	Estoy haciendo esto frecuentemente desde la internación
Trato de verlo desde otra perspectiva, para que parezca más positivo	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Me critico a mí misma	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Trato de idear una estrategia sobre qué hacer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Acepto la realidad del hecho de que esto ha ocurrido	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Trato de encontrar consuelo en mi religión o creencias espirituales	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hago chistes sobre las cosas	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Uso el alcohol para que me haga sentir mejor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q22 ¿En qué maneras ha estado manejando el estrés de tener un niño/a en la PICU?

	No estoy haciendo esto para nada	Estoy haciendo esto un poco desde la internación	Estoy haciendo esto medianamente desde la internación	Estoy haciendo esto frecuentemente desde la internación
Hago algo para pensar menos en eso, como mirar televisión, leer o dormir	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hago algo para intentar que la situación mejore	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Simplemente me niego a creer que esto ha ocurrido	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Obtengo consuelo y comprensión de alguien	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Desisto en mi intento de manejarlo	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Expreso mis sentimientos negativos	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Trato de obtener consejo o ayuda de otros con respecto a qué hacer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q23 ¿En qué maneras ha estado manejando el estrés de tener un niño/a en la PICU?

	No estoy haciendo esto para nada	Estoy haciendo esto un poco desde la internación	Estoy haciendo esto medianamente desde la internación	Estoy haciendo esto frecuentemente desde la internación
Busco algo bueno en lo que está ocurriendo	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Me culpo a mí misma por cosas que ocurren	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Medito profundamente sobre qué pasos seguir	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Trato de aprender a vivir con ello	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Rezo o medito	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Me río de la situación	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Uso drogas para que me ayuden a superarlo	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q24 ¿Le causó temor la experiencia de que su hijo/a sea internado en la Unidad de Cuidados Intensivos Pediátricos (PICU)?

- Sí  
 No

Q25 Las siguientes preguntas se relacionan con sus experiencias alrededor del “trauma”. El trauma, para los propósitos de este estudio, se refiere a tener a un niño/a internado en

la PICU. Por favor responda cada pregunta en el contexto de lo que usted ha experimentado desde que su hijo/a fue internado.

	Para nada	Moderadamente	Mediana mente	Bastante	Mucho
Durante o después del trauma, ¿alguna vez se sintió insensible o distante de sus emociones?	<input type="radio"/>				
Durante o después del trauma, ¿alguna vez se sintió aturdida?	<input type="radio"/>				
Durante o después del trauma, ¿alguna vez las cosas a su alrededor le parecieron irreales o como en un sueño?	<input type="radio"/>				
Durante o después del trauma, ¿alguna vez se sintió distante de su ser normal o como si estuviera mirando lo que pasaba desde afuera?	<input type="radio"/>				
¿No ha podido recordar aspectos importantes del trauma?	<input type="radio"/>				
¿Recuerdos del trauma han estado apareciendo en su mente?	<input type="radio"/>				
¿Ha tenido sueños feos o pesadillas sobre el trauma?	<input type="radio"/>				
¿Ha sentido como que el trauma estuviera por ocurrir nuevamente?	<input type="radio"/>				
¿Se siente muy alterada cuando le recuerdan el trauma?	<input type="radio"/>				

Q26 Por favor responda cada pregunta en el contexto de lo que usted ha experimentado desde que su hijo/a fue internado.

	Para nada	Moderadamente	Medianamente	Bastante	Mucho
¿Ha intentado no pensar en el trauma?	<input type="radio"/>				
¿Ha intentado no hablar sobre el trauma?	<input type="radio"/>				
¿Ha intentado evitar situaciones o personas que le recuerdan el trauma?	<input type="radio"/>				
¿Ha intentado no sentirse alterada o angustiada por el trauma?	<input type="radio"/>				
¿Ha tenido dificultad para dormir desde el trauma?	<input type="radio"/>				
¿Se ha sentido más irritable desde el trauma?	<input type="radio"/>				
¿Ha tenido dificultad para concentrarse desde el trauma?	<input type="radio"/>				
¿Ha estado más alerta al peligro desde el trauma?	<input type="radio"/>				
¿Ha estado más nerviosa desde el trauma?	<input type="radio"/>				
Cuando le recuerdan el trauma, ¿suda, tiembla o su corazón late más rápido?	<input type="radio"/>				

Appendix C

Copy of written permission for use of the PSS:PICU scale

To: University of Kansas Medical Center  
School of Nursing  
Office of Grants & Research

From: MARY E. ERNST  
Name PhD Student  
Position 7119 Sw 105<sup>th</sup> Ct. } Please mail back to this  
Address Miami, FL 33173 address ~ thanks!!

I am seeking permission to use the instrument "Parental Stressor Scale: Pediatric Intensive Care Unit" for the following purpose:

I am doing research on parental stress in African American parents with a child in the PICU for my PhD program at the University of Miami.

AND/OR

I am seeking permission to translate this instrument into \_\_\_\_\_ (language). Upon completion, I will forward the translated Parental Stressor Scale: Pediatric Intensive Care Unit" to the University of Kansas Medical Center School of Nursing in exchange for waiver of fee.

I agree upon request to send back to you the raw data from the instrument, along with selected personal data about the subjects (excluding any identifiers, e.g., date of birth) for use in further testing of the reliability and validity of the instrument. It is understood that the data returned by you will not be used for any other purpose than instrument development.

Mary E. Ernst  
Signature

5-6-15  
Date

We hereby grant permission for you to copy and use the "Parental Stressor Scale: Pediatric Intensive Care Unit" with the above noted stipulations.

Marge J. Bott  
Marge J. Bott, RN, PhD  
Associate Dean for Research, SON, Grants & Research

5-13-15  
Date