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AN EXAMINATION OF PARENTAL STRESS AND COPING IN THE PEDIATRIC INTENSIVE CARE UNIT (PICU)

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AN EXAMINATION OF PARENTAL STRESS AND COPING IN THE PEDIATRIC INTENSIVE CARE UNIT (PICU)

BY

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BSN, University of Alberta, 1995
MSN, University of Alberta, 2004

DISSERTATION

Submitted in Partial Fulfillment of the
Requirements for the Degree of

Doctor of Philosophy

Nursing

The University of New Mexico
Albuquerque, New Mexico

December, 2010

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ABSTRACT

Advances in medical science have increased the number of children surviving illnesses and injuries that would have otherwise been fatal. Parents who have a critically ill child in the Pediatric Intensive Care Unit (PICU) often experience extreme levels of stress and poor coping.

The purpose of this exploratory study was to explore parental stress and coping in a diverse group of parents of a critically ill child. This exploratory study used a descriptive-comparative and correlational research design. The Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1993) was used as a theoretical framework for the study. A convenience sample consisted of 86 participants (84 parents, one aunt, and one foster parent) and of the participants, 48 were lone respondents and 38 were from 19 2-parent dyads.

Data were collected in a large freestanding children's hospital in the Southwest. Parental stress was measured by the Parental Stressor Scale:PICU (PSS:PICU; Carter &

Miles, 1983). Parental coping was measured by the Coping Health Inventory for Parents (CHIP) (McCubbin, McCubbin et al., 1983).

Results demonstrated that both mothers and fathers rated the PICU experience as stressful and rated parent roles and child behaviors/emotions as the most stressful aspects of having a critically ill child. There was no statistical difference between mothers and fathers in total stressor scores. Both mothers and fathers used three coping patterns of CHIP, listed from most helpful to least helpful: Coping Pattern I, II, and III. There was a statistically significant difference in the mean scores on Coping Pattern I and Coping Pattern II between mothers and fathers which indicated that mothers found the coping strategies more helpful than fathers. Regression results indicated that income and whether the hospitalization was planned accounted for 19% of the total stressor score. In terms of coping, gender, income, and child age accounted 41% of the variance in Coping Pattern I scores. Whereas, income, parent gender, and nursing acuity accounted for 40% of the variance in Coping Pattern II scores. Neither the parent demographic variables nor the child demographic or clinical variables significantly predicted Coping Pattern III scores.

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INTRODUCTION

Advances in medical science have increased the number of children surviving illnesses and injuries that otherwise would have been fatal several years ago. Between 1980 and 2003, child mortality rates decreased by 46 percent for infants, 51 percent for children ages one to four, 44 percent for children ages 5 to 14, and 32 percent for teens ages 15 to 19 (Child Trends, 2006). Each year, approximately 150,000 to 200,000 children are admitted to pediatric intensive care units in the US (Board & Ryan-Wenger, 2002). The decrease in mortality has increased the number of children living with chronic healthcare needs and recent data suggest that nearly 30 percent of all children have serious, chronic healthcare needs and 90 percent of these children are now surviving into adulthood (Newacheck & Stoddard, 1994).

The majority of pediatric critical care admissions are unplanned, caused by life threatening illnesses or accidents, and evoke feelings of fear and helplessness in parents. It is clearly understood that the sickest and most unstable children require intensive care (Meyer, Snelling, & Myren-Manbeck, 1998). The intensive care setting is a busy and intimidating place dominated by sick children, advanced medical technology, bright lights and shrill monitors (Meyer et al, 1998). Initially, parents experience extreme levels of anxiety that approach near-panic level, followed by a reduction of anxiety in subsequent days. Huckabay and Tilem-Kessler (1999) found that parental anxiety is at the 98th percentile on the first day of admission and decreases to the 84th percentile by the fourth day. Parental coping is less understood and a paucity of research exists regarding the strategies parents employ to cope with their child's critical illness and whether these techniques are successful. A growing body of evidence identifies the negative consequences of ineffective parental coping, not only for the parent-child dyad, but for the entire family.

Significance of the Problem

Investigators have identified that parents experience numerous physical, environmental, psychological, and social stressors when their child is admitted to the Pediatric Intensive Care Unit (PICU). A child's illness and hospitalization may stir up intense emotions for parents: concern and anxiety are often mixed with feelings of insecurity, guilt, fear and grief (Kristensson-Hallstrom, 2000; Shields, 2001). When the child is critically ill, parents may also experience overwhelming shock, helplessness, and guilt (Rothstein, 1980). Miles and Carter (1983) suggest parents' responses are results of the interactions between the following factors: situational variables, personal characteristics, and environmental stressors. Situational stressors can be described as factors relating to the ill child such as the stress of an emergency admission, acuity of the illness, and fear of the unknown. A parent brings historical personal factors to the illness situation which contributes to the present context. These can include family stressors such as perceived changes to the parental role, feelings of helplessness, education level, other life stressors, and personality factors (e.g., propensity for anxiety). Environmental stressors such as technical equipment, the parent seeing their child, atmosphere of tension, and the parent's perception of the nurse's competence are factors which arise from the physical and psychosocial aspects of the PICU environment. Researchers have found that parents of critically ill children find the total intensive care experience stressful (Miles et al., 1984; Board & Ryan-Wenger, 2002); the following specific stressors have been identified as the most frequently reported: alteration or loss of the parental role (Board & Ryan-Wenger, 2002; Carter, Miles, & Buford, 1985; Holditch-Davis & Miles, 2000; Seideman et al., 1997; Weitzman, Chee, & Levkoff, 1997), painful procedures (Seideman et al., 1997), the child's appearance and behavior (Miles, Funk, & Kasper, 1991; Miles, Funk, & Kasper, 1992; Wereszczak, Miles, & Holditch-Davis, 1997), and other sources such as the unfamiliar machinery, noise, lack of privacy (Lewandowski, 1980), and staff communication and behavior (Board & Ryan-Wenger, 2002).

One of the greatest stressors for parents in the PICU is the alteration or loss of the parental role (Board & Ryan-Wenger, 2002; Carter et al., 1985). Under normal circumstances, parents provide a safe and nurturing environment which includes protecting, educating, advocating, and providing for their child (Meyer et al., 1998). An acute critical illness threatens the parents' ability to perform and fulfill their role; they are no longer the major caregiver for their child. Parents are required to make the transition from parents of a well child to parents of an acutely ill child. This can be an extremely difficult process. Parents need time to grieve the loss of their previous familiar role and adapt to a new role where other people are in control of their child's life. This adjustment, which is influenced by personalities, circumstances of the admission, and the family's previous experience with illness and loss, can be difficult (Meyer et al., 1998). The PICU setting can undermine a parent's sense of competence and control as they find themselves dependent upon health care staff (Meyer, DeMaso, Koocher, 1996; Meyer et al., 1998). Health care professionals control access to the child and the new parenting role in the PICU is highly dependent on health care professionals relinquishing some of the control back to the parents. It occurs gradually as nurses educate the family on appropriate interventions and help parents to model the behavior of health care professionals (Meyer et al., 1998). A study by Seideman and colleagues (1997) identified that parents of children in PICU were most stressed from not knowing how to help their child, seeing their child frightened or in pain, and not being able to be with their crying child. Several researchers (Heuer, 1993; Miles et al.,1989; Philichi, 1988) each found that procedures were highly stressful and many parents were overwhelmed with procedures performed in the PICU; however, Heuer (1993) found that more fathers than mothers identified suctioning of their child to be significantly more stressful. Many parents have reported that the child's appearance and behavior, such as inactivity and response to procedures, are the most stressful aspects of their PICU hospitalization (Miles et al., 1991; Miles et al., 1992; Wereszczak et al., 1997).

Although these studies have contributed to the body of knowledge surrounding parental stress, a significant gap in the literature still exists. The majority of studies are more than a decade old and were performed in samples largely consisting of white, middle class mothers who were married to the father of the child in the intensive care unit. Significant advances in medicine have changed the nature of intensive care units and life expectancy of critically ill children throughout the last decade. It is possible these medical advances have altered the stressors experienced by parents (Noyes, 1998). Advances in technology have resulted in a decreasing pediatric mortality, while increasing morbidity. Estimates indicate approximately 30 percent of all children in the United States are affected with one or more chronic illnesses (Newacheck, 1994).

Many of the studies surrounding parental stress and coping have been performed in homogenous samples. The changing demographics of the United States are reflected in recent census reports and the increase in diversity is expected to continue so that by mid-century. People categorized in minority groups will, as a whole, constitute a national majority (U.S. Census Bureau, 2008). Minorities currently constitute one-third of the population and are expected to become the majority in 2042 (US Census Bureau, 2008). The non-Hispanic white category is expected to decrease from 66 percent of the population (199.8 million) to 46 percent (203.3 million), whereas the Hispanic or Latino population is projected to nearly triple, from 15 percent (46.7 million) of the population to 30 percent (132.8 million) of the population. The African American population is also expected to increase from 14 percent (41.1 million) to 15 percent (65.7 million) of the population (US Census Bureau, 2008).

Data from the US Census Bureau suggests 12.4 percent of the population (33.9 million people) reported family incomes below the poverty line, which was down slightly from previous reports (Bishaw & Iceland, 2003). According to the National Center for Children in Poverty (NCCP) (2010), nearly 39 percent or 28.8 million children in the

United States are considered low income (income is less than twice the federal poverty threshold). Poverty rates vary across the child's age, with younger children experiencing more poverty than older children (NCCP, 2008). Poverty rates vary considerably across geographic regions with the West and South regions experiencing the highest poverty (13.0 percent and 13.9 percent, respectively) (Bishaw & Iceland, 2003). Poverty rates also vary considerably based upon race and ethnicity. Non-Hispanic Whites experience the lowest poverty rate (8.1 percent), whereas, Hispanics or Latinos (22.6 percent), Blacks or African Americans (24.9 percent), and American Indians or Alaska Natives (24.9 percent) continue to experience poverty rates almost double the national averages (Bishaw & Iceland, 2003). Naclerio et al. (1999) found that children who are emergently admitted to the PICU are poorer than the local population and income was negatively correlated with admission rates and severity of illness (Naclerio et al., 1999).

A paucity of literature exists regarding parental coping in response to a child's acute critical illness. The majority of research has revolved around assessing parental functioning and coping with caring for a chronically ill child (Baird et al., 2000; Florian & Findler, 2001; Lin, 2000; McCubbin, 1989; Raina et al., 2004). To date, with the exception of two studies (Curley, 1988; Curley & Wallace, 1992), Melnyk and colleagues (Melnyk et al., 1997; Melnyk & Alpert-Gillis, 1998; Melnyk & Feinstein, 2001; Melnyk, Small, & Carno, 2004; Melnyk, Alpert-Gillis et al., 2004; Melnyk, Feinstein, & Fairbanks, 2006) have been the primary investigators of parental coping in the PICU. In a randomized controlled study, Melynk et al. (2004b) investigated the effects of a program titled "Creating Opportunities for Parental Empowerment (COPE)" and found significant positive effects for both mother and child. The program focuses on increasing the parent’s knowledge and understanding of the range of behaviors and emotions young children typically display during and after hospitalization while also encouraging participation in their child’s emotional and physical care (Melnyk, Alpert-Gillis et al., 2004). Results confirmed that mothers in the intervention group (n = 87) demonstrated improved maternal function and emotional coping and the children experienced less internalizing (i.e. depression) and externalizing disorders (i.e. Attention Deficit Hyperactivity Disorder) compared with the control group (n = 76). Interestingly, at three and six months post discharge, mothers’ reports of PTSD symptoms only approached significance; however, at one year post discharge, mothers in the intervention group reported significantly less PTSD symptoms. A limitation of this study is the homogenous sample, which included primarily Caucasian (71.2%) and African American (20.3%) and very limited Hispanic (1.8%) and Native American (1.2%) mothers, and high attrition rate, losing nearly half of the participants at follow-up.

Researchers are becoming increasingly interested in the psychological sequelae that parents and children experience post hospital discharge. There is a growing body of literature suggesting parents may be at risk for developing posttraumatic stress disorder (PTSD) several months to years after a child’s discharge from the PICU (Baluffi et al., 2004; Melnyk, Alpert-Gillis et al., 2004; Rees et al., 2004). According to the American Psychiatric Association’s *Diagnostic and Statistical Manual of Mental Disorders IV-TR* (APA, 2000), PTSD is a psychological disorder that develops within 3 months of an exposure to a traumatic event involving the threat of death or serious injury to the individual or another that is accompanied by feelings of horror, helplessness, or intense fear. Individuals with PTSD experience three clusters of symptoms: re-experiencing the trauma, persistent increased arousal and avoidance of reminders and numbing of responses. Reliving the trauma is evident by recurrent intrusive and distressing thoughts or dreams, a feeling the event is being relived, and extreme distress at reminders of the event. Increased arousal is evident by difficulties sleeping or concentrating, excessive anger, or generalized anxiety. Individuals with PTSD avoid situations similar to the event, feel detached from others, and demonstrate decreased participation in regular activities (APA, 2000).

Recent estimates suggest that nearly 30 percent of parents will develop PTSD after a child’s critical illness (Baluffi et al., 2004; Rees et al., 2004). Colville and Gracey (2006) found slightly lower rates of PTSD; however, they found that 53 percent of parents have significant levels of other forms of psychological distress up to 8 months after their child’s discharge. These statistics are alarming given the negative effects PTSD may have on not only the mother-child dyad, but family functioning as a whole. Although it is beyond the scope of this study, PTSD is becoming an increasingly common outcome for parents of critically ill children. It is extremely important to completely understand the stressors experienced by parents as well as the coping strategies useful during a child’s critical illness.

Purpose of the Study

The purpose of this study is to explore parental stress and coping in a diverse group of families experiencing hospitalization of their child in a pediatric intensive care unit.

The specific aims for this study are:

1. To identify common parental stressors during their child's critical illness in a diverse sample.
2. To identify parental coping strategies that parents utilize during their child's critical illness in a diverse sample
3. To examine the relationship of parent demographic variables (race, ethnicity, socioeconomic status, gender, age) and child demographic and clinical variables (age, planned versus unplanned admission, prior hospitalization, and illness severity) with parental stress and coping during a child's critical illness in a diverse sample.

Research Questions

Three research questions will be used to guide this study. The research questions are as follows:

1. What stressors do parents identify when their child is critically ill, using the Parental Stressor Scale: PICU (PSS:PICU), and do stressors differ between mothers and fathers?

2. What coping strategies do parents identify when their child is critically ill, using the Coping Health Inventory for Parents (CHIP), and do coping strategies differ between mothers and fathers?
3. What are the joint and independent influences of parent demographic variables (race, ethnicity, socioeconomic status, age, and gender) and child demographic and clinical variables (age, planned versus unplanned admission, prior hospitalization, and illness severity) on parental stress and coping?

Theoretical Model

The Resiliency Model of Family Stress, Adjustment and Adaptation (Figure 1) is a theoretical framework developed by McCubbin and McCubbin (1993) to assess adjustment and adaptation to stressors and will be utilized as the conceptual framework. The theoretical framework was developed in an attempt to explain why some families are more resilient and able to adjust and adapt to stress and crises (McCubbin & McCubbin, 1993) and is based upon previous work by Hill (1949) and McCubbin & Patterson (1983). The model consists of two phases, the adjustment phase and the adaptation phase. The adjustment phase of the model occurs when the family experiences a stressor that has minimal impact on the family and does not create a hardship for the family; whereas the adaptation phase occurs when the family experiences a stressor that places major demands on the family (Pinelli, 2000; Svavarsdottir & McCubbin, 1996).

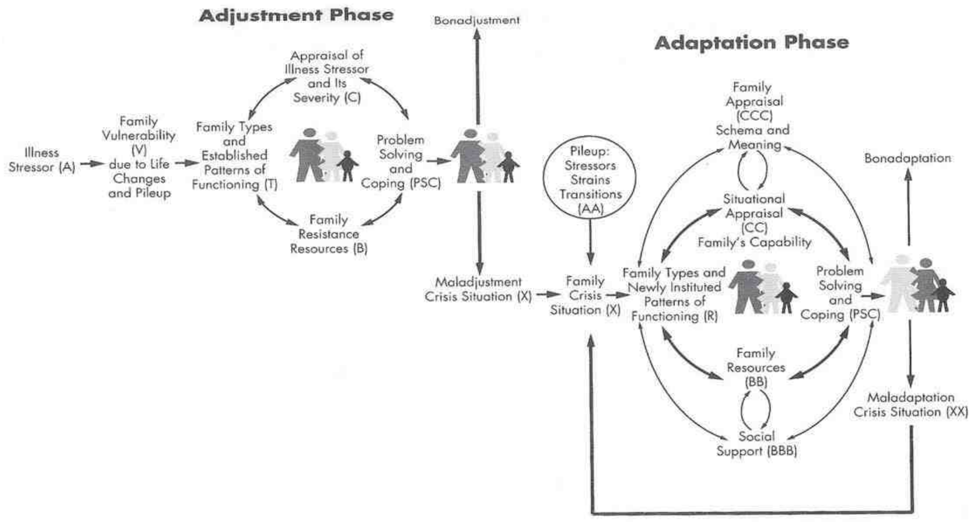

Figure 1. The Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin & McCubbin, 1993)[1].

Application of Resiliency Model for this Study

The conceptual framework for this research is guided by both the adjustment and adaptation phase of the Resiliency Model (Figure 2). Although the average length of stay for a child in the PICU is less than one week, there are some children who stay in the intensive care unit for a much longer period of time (Marcin, Shembri, He, & Romano, 2001). It is desirable for parents to adjust to the stressor without making any lasting changes to the family's established patterns of functioning system; however, some families may need to progress from the adjustment phase to the adaptation phase. The family may move into a crisis state or a period of family disorganization where major changes are required to manage the stressor (Svavarsdottir & McCubbin, 1996). Family adaptation

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[1] From *Families Health and Illness* (p. 23), by M. McCubbin & H. McCubbin, 1993, St. Loius: Mosby. Copyright (1993) by M. McCubbin. Reprinted with permission.

occurs when a change needs to be made to established family patterns of functioning to manage the stressor (Pinelli, 2000).

The focus of this study is stress and coping whereby stress is a situation that disturbs the normal physiological or psychological functioning of an individual and coping is to contend with, face, or encounter dangers and difficulties and to manage or deal competently with a situation or problem. The modifying variables utilized for this study are the demographic variables which may influence adjustment or adaptation indirectly and directly and include: child demographic and clinical variables (diagnosis, planned versus unplanned admission, child's acuity, age of child) and parent demographic variables (gender, ethnicity, race, and socioeconomic status). The goal of both phases of the Resiliency Model of Family Stress, Adjustment and Adaptation, is successful coping in response to a stressor. Parents who have a child in the pediatric intensive care unit may be required to change the way they function in order to manage the increased tension associated with the stressor. For example, the family routine may need to be modified to include arranging childcare for siblings while visiting the sick child, having somebody complete household chores, arranging time off work, and so forth. Whether the family is able to adjust or adapt to a child's critical illness is dependent upon several interacting variables: environment, illness severity, pre-existing stressors such as financial strain, prior experiences with healthcare, social support, existing coping strategies and so forth. The outcome of the adjustment phase is either bonadjustment or maladjustment. If a parent experiences maladjustment, they would progress to the adaptation phase and either experience bonadaptation or maladaptation in which case they would experience a crisis and move through the adaptation phase again.

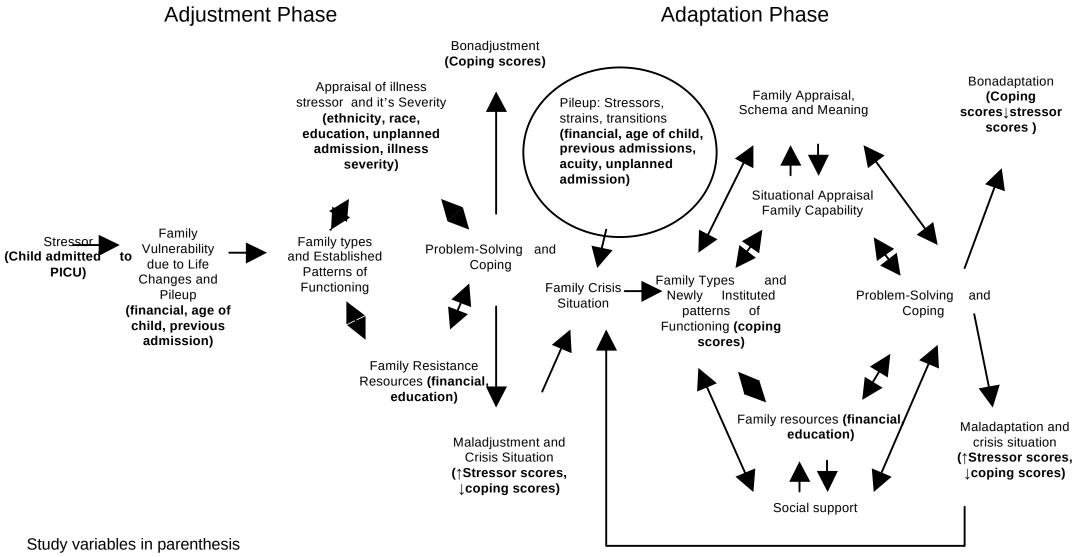

Figure 2. The Resiliency Model of Family Stress, Adjustment and Adaptation (Adapted from McCubbin & McCubbin, 1993)[2].

Assumptions

1. Admission of a child to the Pediatric Intensive Care Unit (PICU) is a stressful experience for parents.
2. Parents may utilize a variety of coping strategies, both positive and/or negative, to adjust to the demands of a child's critical illness.
3. The family is a complex system and when one member of the system is affected, it affects the whole system.

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[2] From *Families Health and Illness* (p. 23), by M. McCubbin & H. McCubbin, 1993, St. Loius: Mosby. Copyright (1993) by M. McCubbin. Adapted with permission.

Definition of Terms

The conceptual and operational definition for the study variables are as follows:

Parent.

Conceptual Definition. A person who is responsible for rearing a child, regardless of whether it is the father, mother, protector, or guardian.

Operational Definition. The person, regardless of gender or biological relationship to the child, who identifies themselves as the caregiver and signs the consent for participation in the study.

Stress.

Conceptual Definition. A demand placed on the family that produces, or has the potential of producing, changes in the functioning of family system (McCubbin & McCubbin,1993) and includes interactions between the following factors: situational variables, personal characteristics, and environmental stressors of the PICU (Miles & Carter, 1983).

Operational Definition. The rating on the Parental Stressor Scale: Pediatric Intensive Care Unit (PSS:PICU).

Coping.

Conceptual Definition. *S*pecific cognitive and behavioral efforts by which an individual and the family attempt to reduce or manage the demands on the family system (Tak & McCubbin, 2002).

Operational Definition. The rating on the Coping Health Inventory for Parents (CHIP).

Illness Severity.

Conceptual Definition. Levels of severity predict morbidity and mortality are determined by various measurement criteria. Levels of severity will include a nursing acuity score.

Operational Definition. The nursing acuity score (see Appendix B) from a tool developed at the hospital will be obtained from the Clinical Supervisor at the time of the interview with the parents.

Socioeconomic Status (SES).

Conceptual Definition. A multidimensional construct that is indexed by three parental factors: occupational status, educational achievement, and financial income (Duncan & Magnuson, 2003; Edwards & Bagozzi, 2000; National Center for Education Statistics, 2008).

Operational Definition. The parent's SES will be determined utilizing the information (income and education only) from the demographic form provided by the parents.

CHAPTER II

LITERATURE REVIEW

The key concepts that guide this literature review are the environment of the pediatric intensive care unit, parental stress, parental coping, and diversity. This review will be organized into five sections. The first section will provide a discussion of the environment of the pediatric intensive care unit. The second section will provide a discussion of stress and, specifically, parental stress in the PICU. The third section will provide a discussion of coping and, specifically parental coping in the PICU. The fourth section will provide a discussion on the impact of diversity on child health. Finally, the fifth section will provide a discussion of the theoretical framework which guided this study.

Pediatric Intensive Care Unit

Advances in technology have increased the number of ill or injured children and acuity level of children admitted to a PICU. From 1980 to 1990, the number of pediatric intensive care units and beds has increased by 59 and 76 percent, respectively (Pollack, 1993). Each year, approximately 150,000 to 200,000 children are admitted to a PICU in the US (Board & Ryan-Wenger, 2002). The majority of these admissions are unplanned, caused by life threatening illnesses or accidents. Admission to a pediatric intensive care unit evokes feelings of fear and helplessness in parents and “it is generally understood that the sickest most unstable children require intensive care, and that preservation of life is clearly the most important function of the unit” (Meyer, Snelling, & Myren-Manbeck, 1998, p. 64).

Stress

Several authors have sought to describe the term stress and many theoretical frameworks have been developed in an attempt to explain the antecedents, defining attributes, and consequences of stress. According to McCubbin & McCubbin (1993), a stressor is “a demand placed on the family that produces, or has the potential of producing, changes in the family system” (p. 28). The severity of the stressor is determined by the degree to which it threatens the stability of the family or places significant demands on the family’s resources and capabilities (McCubbin & McCubbin, 1989; Tak & McCubbin, 2002).

Lipman-Blumen (1975) developed a classification system that characterizes the dimensions of an illness stressor and its ability to cause family strain, stress, and crisis. First, the stressor can originate inside the family system, such as an actual illness of a family member, or outside of the family, such as an ill friend. Illnesses originating outside of the family tend to cause less stress and strain than those originating within the family. The severity of the stressor and the extent to which the stressor impacts the family can vary from mild to severe. For example, a child’s sore throat insignificantly impacts the family, whereas a child’s hospitalization can significantly impact all members of the family.

The onset of the stressor can be gradual or sudden and the duration of the stressor can be short term or long term. Gradual onset of an illness does not produce the same overwhelming feelings of disorganization as sudden onset (Danielson, Hamel-Bissell, & Winstead-Fry, 1993). Duration of a stressor is positively associated with individual and family difficulties (Danielson et al., 1993). A long-term illness often depletes family resources and requires permanent family changes, such as increased financial burden, increased sibling responsibilities and so forth (Danielson et al., 1993). For example, a prolonged hospitalization due to a critically ill child significantly affects all family members including parents, siblings, grandparents, and other relatives.

Control of the stressor can be classified as manageable versus unmanageable (Danielson et al., 1993). Cause of the stressor can be classified as natural, such as a viral or bacterial infection; man-made, such as a car crash; and unknown, such as cancer (Danielson et al., 1993). An illness stressor that occurs unexpectedly causes more strain and stress than an illness that is predictable. For example, a family is usually better prepared to cope with the stressor of a child who will be admitted to the hospital for cardiac surgery versus a child who has a sudden, unplanned hospitalization. The resource demands of the stressor can be classified as great versus small (Danielson et al., 1993). Family resources play an important role in the family's ability to cope with a stressor. Finally, the family may have to cope with the stigma of an illness. Some illnesses, such as Human Immunodeficiency Virus (HIV), mental illness, and mental retardation may cause shame, fear, and social isolation (Danielson et al., 1993).

Parental Stress and the PICU

The intensive care setting is a busy and intimidating place dominated by critically ill children, advanced medical technology, bright lights, and shrill monitors (Meyer et al., 1998). Initially, parents experience extreme levels of anxiety that approach near-panic level, followed by a reduction of anxiety on subsequent days. Miles & Carter (1983) suggest that parents' responses are the results of the interactions between the following factors: situational variables, personal characteristics, and environmental stressors. Situational stressors can be described as factors relating to the ill child such as the stress of an emergency admission, acuity of the illness, and fear of the unknown. A parent brings historical personal factors to the illness situation that contributes to the present context. These can include family stressors such as perceived changes to the parental role, feelings of helplessness, education level, other life stressors, and personality factors (e.g., propensity for anxiety). Environmental stressors are factors that arise from the physical and psychosocial aspects of the PICU environment such as technical equipment, sight of the child, atmosphere of tension, and the parent’s perception of the nurse’s competence. Parental stress in response to a child’s critical illness is a normal and inevitable response. Board & Ryan-Wenger (2002) found that all mothers of critically ill children identified the “total experience” as stressful; however, the following are common stressors experienced by parents of a critically ill child.

One of the greatest stressors for parents in the PICU is the alteration in parental role (Board & Ryan-Wenger, 2002; Carter, Miles, & Buford, 1985). Under normal circumstances, parents provide a safe and nurturing environment which includes protecting, educating, advocating, and providing for their child (Meyer et al., 1998). An acute critical illness threatens the parents’ ability to perform and fulfill their role; they are no longer a major caregiver for their child. Parents are required to make the transition from parents of a well child to parents of an acutely ill child; this can be an extremely difficult process. Parents need time to grieve the loss of their previous familiar role and adapt to a new role where other people are in control of their child’s life. This adjustment can be difficult; it is influenced by their personalities, circumstances of the admission, and the family’s previous experience with illness and loss (Meyer et al., 1998). The PICU setting can undermine a parent’s sense of competence and control as they find themselves dependent upon health care staff (Meyer, DeMaso, Koocher, 1996; Meyer et al., 1998). Parents are often restricted from holding, feeding, and bathing the baby unless the nurse gives the parent permission. Parents may even feel that they lose the ability to act as an advocate for their child. In a study by Holditch-Davis & Miles (2000), one mother, a Jehovah’s Witness, describes her experience:

> They went against our religious beliefs by giving the baby a blood transfusion. I felt like it was sneaky. That day when we went in, one of the practitioners came over, and she started talking to me about their concerns and that they wanted to do the blood transfusion. I was saying that I wouldn’t give my consent, and my husband wouldn’t either. But all the while, they had already gotten consent from Social Services…” (Holditch-Davis & Miles, 2000, p. 18).

Health care professionals control access to the child and the new parenting role in the PICU is highly dependent on health care professionals relinquishing some of the control back to the parents. It occurs gradually as nurses educate the family on appropriate interventions and help parents to model the behavior of health care professionals (Meyer et al., 1998).

Typically, the parenting role includes protecting a child from pain; therefore, it is not surprising that parents identify painful procedures as one of the highest sources of stress. A study by Seideman et al. (1997) identified that parents of children in PICU were most stressed from not knowing how to help their child, seeing their child frightened or in pain, and not being able to be with their crying child. It is well documented that most parents prefer and are able to tolerate the sight of their child undergoing painful procedures or lifesaving procedures, such as resuscitation (Bauchner, Waring, & Vinci, 1991; Shaner & Eckle, 1997). Until recently, all parents were asked to leave during any sort of procedure or resuscitation; however the American Heart Association (AHA) now recommends that parents be involved during resuscitation attempts whenever possible (AHA, 2002).

Children who are critically ill may be medically paralyzed, sedated, and attached to several different machines and monitors as well as physically restrained to prevent them from dislodging or removing equipment. Many parents report that the child's appearance and behavior, such as inactivity and response to procedures is one of the most stressful aspects of their PICU hospitalization (Miles, Funk, & Kasper, 1991,1992; Wereszczak et al., 1997). A child who is hospitalized may develop uncharacteristic behaviors such as separation anxiety, regression, withdrawal, aggression, and sleep disturbances (Jones et al., 1992). However, Heuer (1993) found that parents, when questioned 48 hours after their initial visit, did not experience significant stress from the child's appearance if they were adequately prepared.

Other sources of stress include unfamiliar machinery, noise, lack of privacy, disrupted sleep and eating patterns (Lewandowski, 1980), staff communication and behavior, and procedures (Board & Ryan-Wenger, 2002). The intensive care setting is a highly stressful and emotionally charged atmosphere. Parents have a difficult time adjusting to the noise and commotion of a pediatric ICU and experience distress from the sights and sounds of the intensive care unit (Board & Ryan-Wenger, 2003; Haines, Perger, & Nagy, 1995). All children admitted to a PICU are monitored and many children have various invasive devices inserted for monitoring and treatment. In a study by Board and Ryan-Wenger (2002), parents identified that monitors and invasive lines, 100 percent and 90 percent, respectively, were a source of stress. Another source of stress relating to monitoring is seeing the child's vital signs on the monitor (Board & Ryan-Wenger, 2002; 2003). Parents experience high stress from painful procedures (Board & Ryan-Wenger, 2002; 2003); however, given the opportunity, many parents want to stay and support their child during a procedure (Bauchner et al, 1991).

Coping

The concept of coping evolved in the 1940s and 1950s with roots in two distinct areas: animal experimentation and psychoanalytic ego psychology (Lazarus & Folkman, 1984). Coping defined in terms of animal experimentation was influenced by Darwinian thought and is defined as "acts that control aversive environmental conditions, thereby lowering psychophysiological disturbance" (Lazarus & Folkman, 1984, p. 118). However, the animal model provides a unidimensional concept of drive or arousal and is too simplistic, lacking in cognitive and emotional depth and complexity which are integral elements of human functioning (Lazarus & Folkman, 1984). The alternative approach is derived from psychoanalytic ego psychology in which coping is defined as "realistic and flexible thoughts and acts that solve problems and thereby reduce stress" (Lazarus & Folkman, 1984, p. 118).

Traditional psychoanalytic ego psychology models described coping in terms of traits (properties of persons that predispose them to react in a certain manner), styles (broad and encompassing way of relating to particular types of people), and cognitive styles (automatic rather than effortful responses) which did not predict how people actually coped with the threat as it occurred and underestimated the complexity and variability of actual coping efforts (Lazarus & Folkman, 1984). Lazarus, a well known researcher of stress and coping, defines coping in terms of a process versus traits or styles and states that coping is a “process of constantly changing cognitive and behavioral efforts to manage specific external and internal demands that are appraised as taxing or exceeding the resources of the person” (Lazarus & Folkman, p. 141). According to Lazarus and Folkman, two primary functions of coping include regulation of emotional responses and solving of problems.

Parental Coping and the PICU

The majority of research surrounding parental coping has been performed by Melnyk and colleagues; however, a few other researchers have also examined parental coping in the PICU. Curley (1988) examined the effectiveness of the “Nursing Mutual Participation Model of Care (NMPMC)” on parental stress in PICU. The NMPMC consists of a four step process in which a clinical nurse specialist performs daily parental visits and includes: open ended questions, direct questioning, assessment of individual perception of illness, seriousness, stage of recovery, and individual beliefs and attitudes toward health; and eliciting parents informed suggestions and preferences, negotiating any disagreements, and inviting parental participation in care. This was a quasi-experimental study that utilized sequential sampling and the sample (n = 33) obtained was fairly homogenous. The PSS:PICU was administered within 24 to 48 hours after admission and re-administered every 48 hours thereafter until 24 hours after discharge. The results of the study demonstrated that parents in the intervention group reported significantly less stress than the control group and post hoc analyses demonstrated that parents of children with unplanned PICU admission perceived significantly more stress and demonstrated more positive effects from the intervention. A follow-up study was performed by Curley and Wallace (1992) to examine the results of the intervention when administered by a bedside nurse versus a clinical nurse specialist. This was a quasi-experimental study that utilized convenience sampling, and again, the sample (n = 56) was very homogenous. The PSS:PICU was administered within 24 to 48 hours after admission and re-administered every 48 hours thereafter until 24 hours after discharge. The results of the follow-up study also demonstrated a decrease in parental stress for those in the intervention group both during and after hospitalization.

Melnyk and colleagues (1997) performed a randomized controlled pilot study of mothers of one to six year old critically ill children to test the effects of the "Creating Opportunities for Parent Empowerment (COPE)" Program on maternal and child outcomes during and after hospitalization. The COPE program consists of educational information delivered in audio taped and written form that included: child behavioral information, parental role information, and therapeutic medical play. They utilized a convenience sample (n = 30) that was more heterogeneous than previous studies. Mothers were asked to complete study measures between 10 and 24 hours after admission to the PICU, 24 to 36 hours after transfer to the pediatric unit, and at four weeks after discharge. The intervention group reported significantly less negative mood state and less parental stress, provided more support to their critically ill child as rated by the primary nurse blinded to the study, and reported less post-traumatic stress symptoms after discharge. In a follow-up study, Melnyk and Feinstein (2001) conducted a randomized controlled trial to examine the effects of the COPE program on a convenience sample of 174 mothers and their two to seven year old critically ill child. The COPE Program and the study measures were the same as the previous pilot study with the addition of follow-up measures conducted at three, six, and twelve months following discharge. Their most recent study (Melnyk, Alpert-Gillis, et al., 2004) was a randomized controlled trial (n = 163) with follow up at one, three, six, and twelve months after hospitalization and focused on outcome measures such as maternal anxiety, negative mood state, depression, maternal beliefs, parental stress, and parent participation as well as child adjustment. They found that the COPE mothers reported significantly less parental stress, as measured by PSS:PICU and participated more in the child's care. They also reported less negative mood state, depression, and fewer post-traumatic stress disorder symptoms (PTSD) at the twelve month assessment. The critically ill children also significantly benefited from the study and demonstrated fewer negative behavioral symptoms and externalizing symptoms at twelve months.

Several studies have demonstrated that ineffective parental coping may lead to the development of post traumatic stress disorder (PTSD) after discharge from the hospital. Many of these studies have focused on parents of childhood cancer survivors (Best et al, 2001; Kazak et al, 2004; Stuber et al, 1997), children who have experienced a traffic injury or are critically ill (Baluffi et al, 2004; deVries et al, 1999), and mothers of premature infants (Holditch-Davis et al, 2003). According to the American Psychiatric Association's (APA) *Diagnostic and Statistical Manual of Mental Disorders IV-TR*, posttraumatic stress disorder is a psychological disorder that develops within 3 months of an exposure to a traumatic event involving the threat of death or serious injury to the individual or another that is accompanied by feelings of horror, helplessness, or intense fear (APA, 2000). Individuals with PTSD experience three clusters of symptoms: re-experiencing the trauma, persistent increased arousal, and avoidance of reminders and numbing of responses. Reliving the trauma is evident by recurrent intrusive and distressing thoughts or dreams, a feeling that the event is being relived, and extreme distress at reminders of the event. Increased arousal is evident by difficulties sleeping or concentrating, excessive anger, or generalized anxiety. Individuals with PTSD avoid situations similar to the event, feel detached from others, and demonstrate decreased participation in regular activities (APA, 2000).

The development of posttraumatic stress symptoms and/or disorder has only recently been investigated in families of critically ill children and requires further investigation. Early research of PTSD reported that 6 to 8 percent of parents met criteria for a diagnosis of PTSD (Manne et al, 2002). However, recent preliminary data demonstrates that parents of critically ill children are at high risk for psychological distress. Hall et al. (2006) examined parents of children admitted for burns and found that nearly 50 percent of parents reported experiencing significant posttraumatic stress symptoms three months after discharge. Baluffi et al. (2004) examined the correlation between parental perception of illness and the severity of acute stress disorder (ASD) and PTSD. Both ASD and PTSD share the psychological responses of re-experiencing the traumatic event, avoiding reminders of it, and hyperarousal; however, ASD describes the early responses to trauma whereas PTSD is diagnosed when severe symptoms persist for at least one month (Baluffi et al., 2004). Baluffi et al. found that 32 percent of parents met the symptom criteria for

ASD at the initial assessment and during follow up, 21 percent met the criteria for PTSD. Perceived life threat by the parents, not the child's severity of illness (measured by PRISM-III) was found to be the most important factor in the development of both ASD and PTSD.

Understanding parental stress and coping while a child is critically ill is crucial so that interventions can be developed to decrease parental stress and/or improve parental coping. If the current health care trends continue, more children will be admitted to the PICU and, thus, more parents will experience the stressors of a pediatric critical care unit. If parents are not given the resources to assist them during their child's hospitalization, many are lost to follow-up and do not have the resources to deal the psychological sequelae after discharge. Pediatric critical care practitioners will need to provide interventions to decrease the stress and provide assistance for the parents to cope with their child's critical illness. Preliminary research has demonstrated the positive effects of interventions; however, these interventions are not consistently provided and have only been tested in limited populations. Nurses must be educated on simple and cost-effective interventions that can easily be provided to all parents; however, in order to do so, a better understanding of parental stress and coping in diverse samples is required.

Diversity

The United States is becoming a very diverse country and continues to experience changing demographics in which diversity is more frequently encountered. Thus, it is important to understand various cultural differences, especially as they pertain to child and family health. This section provides a description of the rapidly growing population of the United States as well as a discussion of the concepts of race, ethnicity, and socioeconomic status. The changing demographics of the United States are reflected in recent census reports which suggest that minorities who currently comprise one-third of the population are expected to become the majority in 2042 (US Census Bureau, 2008). According the United States Census Bureau (2008), based on increases in population estimates, non-Hispanic Whites are expected to decrease from 66 percent of the population (199.8 million) to 46 percent (203.3 million), whereas the Hispanic or Latino population is projected to nearly triple, from 15 percent (46.7 million) to 30 percent (132.8 million) of the population. The African American or black population is also expected to increase from 14 percent (41.1 million) to 15 percent (65.7 million) of the population (US Census Bureau, 2008). It is also important to mention that in the United States, the poverty rates vary considerably based upon race/ethnicity. Non-Hispanic Whites experience the lowest poverty rate (8.1 percent), whereas, Hispanics or Latinos (22.6 percent), Blacks or African Americans (24.9 percent), and American Indians or Alaska Natives (24.9 percent) continue to experience poverty rates that are almost double national averages (Bishaw & Iceland, 2003).

The terms race and ethnicity, although different, are overlapping concepts often used synonymously, a trend fostered by increasing use, particularly in the United States, of the compound word race/ethnicity (Bhopal, 2004). Ethnicity is a multi-faceted quality referring to a group of people who are perceived to share certain characteristics including geographical and ancestral origins, but particularly cultural traditions and languages (Bhopal, 2004). More specifically, ethnicity is an adjective used to denote origin by birth or descent and acknowledges the place of history, language, and culture in the construction of identity (Thompson, 1998; Fernando, 2003). The biologic conceptualization of race divides people mainly on the basis of their genetically transmitted physical characteristics (Bhopal, 2004) and can be defined as a local geographic or global human population distinguished as a more or less distinct group by genetically transmitted physical characteristics (*American Heritage Stedman's Medical Dictionary*, 2008). Racial classification of individuals gained popularity during the early 19th century and its usage worldwide has steadily declined (Bhopal, 2004). Many countries now utilize the term ethnicity to classify individuals. However, in the United States race and ethnicity continue to be utilized synonymously contributing to the confusion. In the United States, the modern concept of race emphasizes the terms social origins rather than its biological basis. Even though the aspects of social origin may be used to identify populations which look different and have different ancestral roots, race is ultimately based on physical characteristics and hence biological factors (Bhopal, 2004).

Minorities often experience barriers to accessing the health care system and when they do, they rely on emergency medical department for care (Weitzman et al., 1999). Several studies have documented increased rates of injury and injury mortality among children who are from racial and/or ethnic minority groups, who lack medical insurance, who reside in low-income communities (Cubbin, LeClere, & Smith, 2000; Faelker, Pickett, & Brison, 2000) and whose mothers have fewer years of education (Scholer, Mitchel, & Ray, 1997). Chamberlain et al., (2007) examined pediatric admission rates based upon ethnicity and found both crude and severity-adjusted admission rates were lower for African-American and Hispanic children when compared with Caucasian children, even after controlling for illness severity. However, they did find that the results represented overadmitting white patients who are less severely ill than underadmitting black and Hispanic patients who are more severely ill.

Relatively little is known about ethnic/racial or socioeconomic differences and the impact they may have on general stress and coping. To date, there are no reports that examine whether differences exist between ethnic/racial groups in terms of parental stress and coping. Much of the research focuses on differences in health status, acculturation stress, caregiver stress, and socioeconomic differences. A small body of evidence supports the notion that there are differences in general health perceptions and coping with adverse events. For example, blacks when compared with whites are more likely to assess their health status (Navarro, 1991; Ren & Amick, 1996) and their child’s health status (Weitzman et al., 1999) as poor even when controlling for income. Among lower income samples, blacks when compared to whites, report more distress with stressful life events and are more likely to rely upon religion to cope with stress. Yeates et al. (2002) found that race was a significant moderator of parent and family outcomes during the first year following a pediatric traumatic injury. The sample consisted of 73 white and 18 black children with traumatic brain injury (TBI) and 32 white/Caucasian and 23 black/African-American children with only orthopedic injuries. Interestingly, they found that, at baseline, the negative effects (psychological distress and perceived family burden) of traumatic injury was less pronounced for the families of black children; however, at the two follow up periods, the negative effects became more pronounced for families of black children. They also found significant differences in coping strategies and that families of black children used denial, religion, mental disengagement, and less acceptance as coping mechanisms. Higher SES was associated with more active coping, planning, and seeking social support and less behavioral disengagement and denial. Currently, there is a paucity of literature surrounding parental stress and coping in culturally diverse populations. The majority of studies have been performed with samples that are predominantly middle class Caucasian and although valid, the results are not an accurate representation of the American population as a whole and thus, should not be presented as generalizations.

Socioeconomic status (SES) has been linked to disparities in health and access to health care; however definitions of SES continue to be fraught with confusion and there appears to be no consensus on how to define socioeconomic status. Some investigators use only one measure to assess SES or create their own composites. For example, Neupert, Soederberg, and Lachman (2006) defined SES in terms of years of education to investigate physiologic variations of reactivity to cognitive stressors based on age and SES; whereas Marcin and colleagues (2003) utilize three variables (US Census median household income, US Census proportion of families below the poverty line, and insurance status) to examine the effect of SES on pediatric trauma and hospitalization rates. Braveman and colleagues (2005) state that “most studies include SES variables without justifying why a given measure was selected over others, without explaining its meaning for a given analysis, and without discussing how unmeasured socioeconomic differences might have affected findings” (p. 2880). Deonandan et al. (2000) identified seven common methods for estimating SES in Canada: four based on data specific to individuals (Blishen, Pineo-Porter, British Registrar General, Hollingshead) and three specific to the postal code in which people live (income alone, education alone, and income and education combined). The first four are based upon a classification of occupation and also take income into consideration. The last three are based upon information (education, income and the product of education and income) associated with the postal code. Interestingly, Deonandan et al. (2000) found that all methods based on data specific to individuals were significantly strongly correlated with each other whereas the postal code method did not estimate SES and was not strongly correlated with any other method.

According to Dutton and Levine (1989), socioeconomic status is defined as a "composite measure that typically incorporates economic status, measured by income; social status measured by education; and work status, measured by occupation" (p. 30; cited in Adler et al., 1994). Although many researchers attempt to classify socioeconomic status with only one indicator, SES should be a combination of economic resources, education, and occupation for several reasons (Duncan & Magnuson, 2003). First, education and income do not correlate strongly enough to use education as a proxy for income and vice versa (Braveman et al., 2005). For example, Braveman et al. (2005) found that at every educational level, black and Mexican adults had significantly lower incomes than their white counterparts. Second, income is not a proxy for wealth and in fact, wealth is more strongly linked to social class than income but is more difficult to calculate (Shavers, 2007). Finally, occupation is a structural link between education and income (Shavers, 2007), however, in the United States, there is an inadequacy of standardization of occupational categories which is problematic when attempting to evaluate the prestige of an occupation (Braveman et al., 2005).

Economic resources consist of household income, wealth, poverty, hourly income, and human capital. Household income is the sum of income from all sources received by all members of the household and tends to be quite volatile across the family life cycle (Duncan & Magnuson, 2003). Wealth is a point-in-time analysis of the financial assets, both liquid (money in a savings account), and illiquid (money from equity in a house) (Duncan & Magnuson, 2003). The definition of poverty varies with family size and inflation; however, most experts will agree that the poverty line set by the U.S. Bureau and Census is much less than what most people require to live decently or avoid hardship (Duncan & Magnuson, 2003).

Human capital is the collection of skills and is most commonly measured by educational attainment (Duncan & Magnuson, 2003). Education is an easy to measure variable and is quite stable after early adulthood (Shavers, 2007). It is one of the indicators that may be most likely to capture aspects of lifestyle and behavior. However, one of the main disadvantages with education is that level of education does not necessarily correlate with level of income (Shavers, 2007).

A given SES measure may have different meanings in different social groups and thus, multiple methods of measuring SES are documented in the literature. Individual measures have been utilized; however the significant limitations discussed previously make this method very undesirable. Composite measures (occupation, education, and income) and contextual measures (neighborhoods and other geographic areas) have also been utilized to measure SES. Several limitations exist with composite methods: correlation between income and education is low and vary by ethnicity and/or race (Braveman et al., 2001), standard classifications of occupations are based on occupations that commonly employ men (Reid, 2002), and the variable to assess education only captures formal education (Shavers, 2007). Limitations also exist with the contextual methods: contextual variables do not correlate well with individual measures (Deonandan et al., 2000).

Theoretical Framework

The adjustment phase of the model occurs when the family experiences a stressor that has minimal impact on the family and does not create a hardship for the family; only minor adjustments need to be made to established family patterns of functioning (Svavarsdottir & McCubbin, 1996). When a stressor or crises occurs, successful family adjustment is determined by many interacting components: *the stressor and it's severity* (A), *family vulnerabilities* (V), *family types* (T), *family resistance resources* (B), *family appraisal of the stressor* (C), *family problem solving and coping* (PSC), and *family response* (X) (McCubbin & McCubbin, 1993).

The stressor. According to McCubbin and McCubbin (1993), a stressor "is a demand placed on the family that produces, or has the potential of producing, changes in the family system" (p. 28). The severity of the stressor is determined by the degree to which it threatens the stability of the family or places significant demands on the family's resources and capabilities (McCubbin, 1989; McCubbin & McCubbin, 1989; Tak & McCubbin, 2002).

Family vulnerability. Family vulnerability (V) is defined by McCubbin and McCubbin (1993) as the “fragile and organizational condition of the family system” (p. 28). It is determined by the accumulation of pileup of demands (i.e. financial debts, change in work status, poor health status of other relatives) and the tribulations associated with the family’s particular life cycle stage (McCubbin & McCubbin, 1993).

Family typology and resistance resources. A family’s typology (T) is a set of attributes that explains how the family system operates or behaves. These patterns are predictable and discernable patterns of family functioning, but can change as the family matures or when adaptation is needed (McCubbin & McCubbin, 1993). The resilient family typology exhibits patterns of flexibility (the degree to which the family can change roles, rules, and boundaries) and family bonding (the degree of emotional bonding to form a meaningful and integral family) (McCubbin & McCubbin, 1993). The family’s resistance resources (B) are the tangible and intangible abilities and capabilities of the family to address and manage the stressor and its demands (McCubbin & McCubbin, 1993).

Family appraisal. The family’s appraisal (C) is a subjective definition of the severity of the stressor and its hardships (McCubbin & McCubbin, 1993). Families can interpret the stressor as a challenge to be conquered or as uncontrollable.

Family problem solving and coping. The family manages the illness through the use of problem solving and coping skills. Problem solving includes the family’s ability to organize a stressor into manageable components, identify alternative courses of action, and initiate a solution to resolve the issues (McCubbin & McCubbin, 1993). Coping refers to a wide range of strategies, patterns, or behaviors that strengthen the family as a whole. Parental stress and coping strategies may differ between parents depending upon the severity of their child's illness.

Family response. Illness of a child produces a family response that can be defined as eustress or distress. Eustress is a positive state whereby the family defines the demands-resources imbalance as desirable and a challenge to be accepted, whereas distress is a negative state that is characterized as unpleasant, destabilizing, and threatening to the current stability of the family (McCubbin & McCubbin, 1993). Family bonadjustment occurs when the family's typology, resources, coping and problem solving abilities, appraisals, and strengths mediate the stressor. The stressor does not create major hardships for the family system and the family is able to move through the situation without making major changes or adjustments in the family system. Families that are able to adapt successfully have the following characteristics: resources that meet the demands of the illness, form a positive appraisal of the stressor event, typologies with characteristics that successfully meet demands of the specific illness, low in vulnerability, pileup, and life cycle stressors, and good problem-solving capabilities (McCubbin & McCubbin, 1993). Maladjustment occurs when disruption of established patterns and substantial changes in the family system are required in response to a stressor. Families in crisis are unable to restore balance without making basic changes in the family patterns of functioning to restore stability, order, and a sense of coherence (McCubbin & McCubbin, 1993).

The adaptation phase occurs when the family experiences a stressor that places major demands on the family. The family may move into a crisis state which is defined as a period of family disorganization where major changes are required to manage the stressor (Svavarsdottir & McCubbin, 1996). Similar to the adjustment phase, the adaptation phase has several components which include: *pileup of demands* (AA), *family types and newly instituted patterns of functioning* (R), *family resources* (BB), *social support* (BBB), *family appraisal-situational* (CC), *family appraisal-schema and meaning* (CCC), *problem solving and coping* (PSC), and the *family adaptation process* (XX).

Pileup of demands (AA). Illness, especially a critical illness of a child, is an added stressor to the many other stresses experienced by the family. Pileup of demands is a critical factor of how well the family will adapt and must be thoroughly assessed. Pileup of demands falls into six categories: the *illness and hardships over time, normative transitions* in individual family members and the family as a whole, *prior family strains accumulated over time*, *situational demands and contextual difficulties, the consequences of family efforts to cope,* and *intrafamily and social ambiguity* that provides inadequate guidelines on how families should act or cope effectively (McCubbin & McCubbin, 1993).

Illness and hardships over time. Parents, especially those of chronically ill children, experience the stressors associated with the illness over the duration of the child's life (McCubbin & McCubbin, 1993). There may be ambiguity surrounding the diagnosis, course of illness, treatment, and outcome. The medical needs of the child may change, or worsen, over the course of the child’s life. Healthcare professionals must attempt to assess all the life changes, hardships, concurrent hassles, prior strains, situational demands, as well as the family’s efforts to cope (McCubbin & McCubbin, 1993).

Normative transitions. Families are not static social units; they go through predictable transitions as the result of the normal growth and development of the members (McCubbin & McCubbin, 1993). These normal transitions occur at the same time as the illness or crisis. Healthcare professionals must assess the severity of the stressor and its impact on the normal growth and development of each family member. Healthcare professionals must also attempt to assess all the life changes, hardships, concurrent hassles, prior strains, situational demands, as well as the family’s efforts to cope (McCubbin & McCubbin, 1993).

Prior family strains accumulated over time. Most families carry residual strains from previous stressors which may be exacerbated in the face of a new illness stressor (McCubbin & McCubbin, 1993).

Situational demands and contextual difficulties. Decisions regarding medical care of a critically ill child can be very confusing and difficult for parents. Patterns of health care delivery may change; children are transferred from an intensive care unit to a general pediatric unit, and then discharged home. Basic care may need to be transferred from a pediatrician, who has developed a relationship with the family and the child, to a “less informed” specialist (McCubbin & McCubbin, 1993).

Consequences of family efforts to cope. Families, in efforts to cope, may make poor decisions that, instead of encouraging coping, produce additional demands on the family system (McCubbin & McCubbin, 1993). Health care professionals must support and guide families to make decisions that will foster positive long-term outcomes.

Intrafamily and social ambiguity. Every illness induced crises has a certain amount of ambiguity and uncertainty and family structure, roles, responsibilities, and rules must change (McCubbin & McCubbin, 1993). Family structure, roles, responsibilities, and rules can change several times during and after a child's critical illness. While the child is in the hospital, the family may have one set of roles, whereas when the child returns home, another set of roles may apply.

Family types and newly instituted patterns of functioning (R). Families who adapt successfully to an illness stressor have similar characteristics which include having the resources to meet the demands of the illness, forming a positive appraisal of the stressor, having good problem-solving capabilities, demonstrating low vulnerability, pileup, and life cycle stressors (McCubbin & McCubbin, 1993). There are three family typologies that demonstrate the characteristics that provide more successful adjustment and adaptation to stress. The regenerative typology demonstrates high family hardiness and cohesiveness; the rhythmic typology values family time and routines; and the resilient family demonstrates high family flexibility and bonding (McCubbin & McCubbin, 1993).

Family resources (BB). Family resources include the strengths and capabilities that the family possesses. There are three potential sources for resources: individual family members, the family working as a unit, and the community. There are six kinds of individual family or personal resources which include: the innate intelligence of family members; knowledge and skills acquired from education, training, and experience; personality traits; physical and emotional health; a sense of mastery over the circumstances of one's life; and self-esteem (McCubbin & McCubbin, 1993). The family system resources include family cohesion and adaptability, family hardiness, and family organization. Family cohesion is defined as the bonds of unity running through the family and adaptability is the family's capacity to meet obstacles and shift course (McCubbin & McCubbin, 1993). Family hardiness refers to the internal strengths and durability of the family unit that is characterized by a sense of control over the outcome of life events and hardships (McCubbin & McCubbin, 1993). Family organization includes agreement, clarity, and consistency in the family role and rule structure (McCubbin & McCubbin, 1993). The resources become part of the family's capability for resisting a crisis and promoting family adjustment.

Social support (BBB). Social support has been identified as one of the primary buffers of stress and is defined as emotional support, esteem support, network support, appraisal support, and altruistic support (McCubbin & McCubbin, 1993).

Family appraisal-situational (CC). In the adjustment phase, the family's appraisal was limited to the stressor. In the adaptation phase, the family's appraisal has been expanded to include two additional levels. The family's appraisal of their capabilities in handling the situation is a critical factor as to whether the family will be able to successfully adapt to the illness stressor. Families are constantly in the process of evaluating their strengths and choosing strategies to deal with the demands of the stressor (McCubbin & McCubbin, 1993).

Family appraisal-schema and meaning (CCC). In the third level of appraisal, the family is required to appraise the illness stressor and give meaning to the illness and to the resulting changes in the family system (McCubbin & McCubbin, 1993). This third level of appraisal is essential and serves to foster a congruency between changes in the family's schema and instituted patterns of family functioning. The family's schema can be challenged by changes such as a mother's return to work after caring for a chronically ill child. The health care professional must assess whether the changes made by the family fit with their schema (McCubbin & McCubbin, 1993).

Problem solving and coping (PSC). Problem solving is the family's ability to organize the stressor into manageable components, identify alternative courses of action, initiate steps to resolve the issues, and to develop patterns of problem solving communication (McCubbin & McCubbin, 1993). Families tend to use three main coping strategies to adapt to stressful situations: avoidance, elimination, and assimilation. Avoidance is characterized by an attempt to ignore or deny a stressor in the hope that it will resolve itself; elimination is characterized by the family's attempt to rid itself of the stressor by changing, removing, or redefining the stressor; and assimilation is characterized by an attempt to absorb the demands of the stressor with minimal changes in the family structure and interactions (Danielson et al., 1993).

Coping, in the resiliency model, is defined as "specific cognitive and behavioral efforts by which an individual and the family attempt to reduce or manage the demands on the family system” (Tak & McCubbin, 2002, p.192). It is a coordinated problem-solving behavior of the whole system that creates and maintains a balance between demands and stressors (McCubbin & McCubbin, 1993). Coping is a process by which families recognize that systemic changes are required to maintain stability in response to excessive demands and depleted resources (Tak & McCubbin, 2002). McCubbin and McCubbin (1993) identify four characteristics in which coping facilitates adaptation: a direct action that may reduce or eliminate the demands of the stressor, a direct action to acquire additional resources not available to the family, managing the increased tension associated with the stressor, and involve the family creating a positive appraisal of the situation.

Family adaptation process - bonadaptation, maladaptation, and crises (XX). Family adaptation is “the process in which families engage in direct response to excessive demands, depleted resources, and the realization that systematic changes are needed to restore functional stability and improve family satisfaction” (Kosciulek, McCubbin, & McCubbin, 1993, p. 44). There are two levels of adaptation: bonadjustment and maladaptation. The goal of the family adaptation is bonadaptation; however, many families are unable to adapt successfully to a child’s critical illness. Bonadaptation is a process of restructuring and making changes in rules, boundaries, and patterns of functioning and valuing, accepting, and affirming the changes (McCubbin & McCubbin, 1993). According to McCubbin and McCubbin (1993) successful adaptation is:

> “achieved when the family’s schema and patterns of functioning are congruent, family’s members’ personal growth and development are supported, the family’s integrity maintained, the family’s relationship with

> the community is mutually supportive, and the family develops a shared sense of coherence" (p. 59).

Maladaptation occurs when families cannot achieve a satisfactory level of adaptation. These families return to a crisis situation and must find a new way to adapt (McCubbin & McCubbin, 1993). Coping strategies facilitate the family's ability to work together interdependently which is critical in adaptation. Adaptation is not confined to internal changes within the family, but also maintaining a level of rapport with the community. It is essential for parents to develop a network within the community for social support services (i.e. respite, support groups) (Kosciulek, McCubbin & McCubbin, 1993; McCubbin & McCubbin, 1993).

The Resiliency Model has been utilized extensively to describe adjustment and adaptation in children with chronic illness (Tak, 1995), or more specifically, epilepsy (Mu, 2005), cancer (Orbuch, Parry, Chesler, Fritz, & Repetto, 2005), asthma (Svavarsdottir, 2005; Svavarsdottir, McCubbin, & Kane, 2000), developmental disability (Boyle, 2004), and congenital heart disease (Tak & McCubbin, 2002) as well as parental adjustment following discharge from the hospital (Board & Ryan-Wenger, 2000; Doucette & Pinelli, 2004; Mitchell, 1999; Pinelli, 2000). The Resiliency model has also been utilized to describe issues affecting adults, such as breast cancer (Radina & Armer, 2004), schizophrenia (Rungreangkulkij, 2000;Rungreangkulkij, Chafetz, Chesla, & Gilliss, 2002), and mental retardation (Lustig, 1999; Lustig & Thomas, 1997).

Kosciulek et al. (2001) examined the family's response to head injury from the perspective of the Resiliency model and found that it was useful for describing the impact of head injury on the family and provides a guide for health care professionals to understand the process of family adaptation to head injury. Brody and Simmons (2007) utilized a qualitative approach to understand the experience of fathers (n = 8) during childhood cancer and found that fathers were more likely to display resilient characteristics which enabled coping when they utilized their social supports in combination with constructive communication. Mu (2005) examined the stressors that fathers (n = 210) experience when caring for a child with epilepsy and found that paternal uncertainty was negatively associated with the total CHIP score. Doucette and Pinelli (2004) performed a longitudinal correlational study in the NICU to examine the relationship of family coping, resources, and strains on family adjustment over time and found that mothers reported improved family functioning, whereas fathers reported the opposite finding. Family resources were related to positive family adjustment and decreased for both parents, but particularly for fathers. Chen & Rankin (2002) examined the delivery of culturally sensitive care to Chinese families who have a child with a congenital heart defect (CHD) and found that the concepts in the Resiliency Model can be applied in caring with Chinese families. Leske & Jiricka (1998) investigated the impact of family demands, family strengths, and capabilities on family well-being and adaptation after critical injury and found that increases in family demands were negatively associated with family strengths and adaptation, and that family demands are an important indicator of the amount of assistance a family many require. Saied (2006) utilized the Resiliency model to explore the relationship between child and parent demographic characteristics, stress, coping, and adjustment in patients undergoing cardiac surgery and found that the accumulation of stressors led to poorer family functioning.

Summary

Parental anxiety is a normal and expected response to a child's critical illness; however, it is also a significant predictor of parental development of a psychological disorder, such as depression and PTSD. Nurse researchers have investigated parental stress and coping in the PICU for nearly three decades and have made significant gains in understanding the stressors that parents experience when their child is critically ill. However, there continues to be some significant gaps in the knowledge which is mostly associated with small or homogenous samples. Currently, there is some evidence to suggest that in other settings, race, ethnicity, and socioeconomic status does impact health and the utilization of resources. However, to the author's knowledge, research of parental stress and coping in the PICU in a diverse sample is very limited. Health care professionals must be able to adequately assess the parent's response to their child's critical illness and provide the family with resources to facilitate adjustment and bonadaptation. The next section outlines the methods that will be utilized to examine parental stress and coping in a culturally diverse sample.

CHAPTER III

METHODS

The purpose of this study was to explore parental stress and coping in a diverse sample. This chapter describes the methodology for this study, including the study design, sampling methods, instrumentation, data collection procedures, data management, data analysis, and protection of human subjects.

The specific aims of the study included:

1. To identify common parental stressors during their child's critical illness in a culturally diverse sample.
2. To identify parental coping strategies that parents utilize during their child's critical illness in a culturally diverse sample.
3. To examine the relationship of parent demographic variables (race, ethnicity, socioeconomic status, and gender) and child demographic and clinical variables (age, planned admission, prior hospitalization, and illness severity) with parental stress and coping during a child's critical illness in a diverse sample.

The research questions included:

1. What stressors do parents identify when their child is critically ill (using the PSS:PICU), and do stressors differ between mothers and fathers?
2. What coping strategies do parents identify when their child is critically ill (using the CHIPS) and do coping strategies differ between mothers and fathers?

3. What are the joint and independent influences of parent demographic variables (race, ethnicity, socioeconomic status, age, and gender) and child demographic and clinical variables (age, planned admission, prior hospitalization, and illness severity) on parental stress and coping?

Design

To answer the research questions, an exploratory study with a descriptive-comparative and correlational research design was used; data collection was cross-sectional, while the child was in the PICU. Although many studies have examined parental stress, none specifically utilized a racially and ethnically heterogeneous sample nor have they examined parental stress and coping simultaneously. The study measures tested parental stress and coping at one point in time during the hospitalization of the child. Although it would have been preferable to choose a longitudinal design to explore parental stress and coping over time, practical considerations such as costs and the time involved in such a design precluded a longitudinal study. This study utilized the McCubbin & McCubbin’s (1993) Resiliency Model of Family Stress, Adjustment, and Adaptation as a framework to examine the relationships between stress and coping and the demographic variables. Total stress scores and coping strategy scores were the dependent variables and the demographic (parent and child) and clinical (child) variables were the independent variables.

The Setting and Sample

Participants were recruited from the pediatric intensive care unit at a large freestanding children’s hospital in the Southwest. The hospital is one of the largest freestanding pediatric hospitals in the United States and serves a diverse population. The PICU consists of a total of forty beds which are separated into three pods: cardiac (12 beds), medical surgical (16), and neurological/trauma (12). In 2008, there were a total of 2728 patients admitted to the PICU and of those admissions, 1548 (57%) were less than five years of age and 1180 (43%) were greater than five years of age.

Inclusion and Exclusion Criteria

The subjects in this study were parents of children (1 day to 17 years of age) in the PICU. The parents had to be at least 18 years old and able to understand enough English as to understand the benefits and risks associated with the study, sign a consent form, and answer the questions in the research instruments. Parents of children, who have experienced non-accidental trauma, regardless of whether a parent was involved, were excluded from the study.

A convenience sampling strategy was utilized and parents of children in the PICU were approached if they met the inclusion criteria. Convenience sampling is inexpensive, accessible, and requires less time than other types of samples (Burns & Groves, 1997); however, it also provides limited opportunity to control for bias.

Recruitment of Subjects

Parents were recruited to participate in the study if they met the inclusion criteria. If both parents were available, they were both offered the opportunity to participate. If both parents completed the surveys, they were considered one subject and coded in a manner identifying them as a dyad (for example the mother’s surveys were coded with an “a” and the father’s surveys were coded with a “b”).

Procedure for Data Collection

The procedures and instruments are outlined as follows. Prior to initiating the project, the study was approved by the Institutional Review Board at the hospital. Prospective parents were identified by the pediatric admissions logbook kept in each pod. Parent(s) were approached if they met the inclusion criteria and were asked if they had a few minutes to talk with the researcher. If they agreed, the study was explained, including the purpose, risks and benefits, data collection procedures, and confidentiality. All information was provided in verbal and written form. Once the parent(s) agreed to participate and signed a written consent form, they received a packet which included: a copy of the consent form (Appendix C) and authorization to release protected health information (Appendix D), demographic information sheet (Appendix E), and both questionnaires , the PSS: PICU (Appendix F) and the CHIP (Appendix G).

Data collection for this study was primarily self-administered. Parents were given the opportunity to ask questions regarding the study and drop out at any point during the study. The questionnaires were filled out by the parents. If parents wanted to participate in the study and were unable to understand or read the questions/statements in the instrument, the instrument was verbally administered by the researcher. The completed packets were collected after the parents had time to complete them.

Measures

Parent demographic variables.

Socioeconomic status. The parent's SES was determined utilizing income and education information from the demographic form provided by the parents. Income was documented numerically as reported by the US Census Bureau. Education was documented by number of years completed and highest grade achieved.

Race. Race was documented on the parent demographic sheet per U.S. Census Bureau guidelines (American Indian or Alaskan native, Asian, Black or African American, Native Hawaiian or other Pacific Islander, and White).

Ethnicity. Categories of ethnicity were “Hispanic or Latino” and “not Hispanic or Latino”. Hispanic or Latino includes persons of "Cuban, Mexican, Puerto Rican, Cuban, South or Central American, or other Spanish culture or origin, regardless of race" (Office of Management & Budget, 1997, Categories and Definitions). Ethnicity was obtained by parent self-report on the demographics sheet.

Age. Age was obtained from the parent demographic sheet

Gender. Gender was obtained from the parent demographic sheet.

Child demographic and clinical variables.

Age. Age was documented in months and obtained from the medical record.

Illness acuity. Illness acuity was determined by a nursing acuity score (0-4) obtained from the bedside nurse or Clinical Supervisor at the time of the interview with the parents. Patients are assigned a number based on meeting 3 or more of the criteria to fit with a given score.

Unplanned versus planned admission. The parents were asked whether admission to the PICU was planned, such as cardiac surgery, or unplanned such as an illness or accident and was documented in a yes/no response.

Previous admissions. The parents were asked to document whether their child had been previously hospitalized, and if so, how many times in a numerical response with none documented as zero.

Stress

Stress for this study was conceptualized as a demand placed on the family that produces, or has the potential of producing, changes in the family system (McCubbin & McCubbin, 1993) and includes interactions between the following factors: situational variables, personal characteristics, and environmental stressors of the PICU (Miles & Carter, 1983). Parental stress was measured by the total stress score on the Parental Stressor Scale:PICU (PSS:PICU; Carter & Miles, 1983, 1989)(See Appendix C).

The PSS:PICU, developed by Carter and Miles (1983), is a 37-item instrument designed to measure parental perception of the intensive care unit environmental stressors experienced during their child's hospitalization in a pediatric intensive care unit. The PSS:PICU has seven subscales covering three broad areas: personal-family, situational, and environmental stressors. The stressors are grouped under seven dimensions: (1) Child's appearance: descriptions of the child's appearance in the intensive care unit (3 items); (2) Sights and sounds: sounds of alarms and other equipment that may have been attached to the child (3 items); (3) Procedures: procedures that may have been done to the child (6 items); (4) Staff behavior: behaviors of physicians and nurses that the parent may have observed while caring for the child (4 items); (5) Parental role alteration: parent's perception of not being able to care for the child (6 items); (6) Staff communication: how physicians and nurses may communicate with the parents about the child's illness (5 items); (7) Child's behavior and emotions: behavioral and emotional responses the child may exhibit while in the intensive care unit (10 items). Each item is scored from 1 (*not stressful*) to 5 (*extremely stressful*) or as 0 (*not experienced*). It is recommended by the authors that the mean dimension or total score for each subject be computed by dividing the sum of the dimension or total scores by the number of items rated "1" or above. This compensates for the "0-Not Experienced" scores and for any missing data. The group means are then calculated from the individual mean scores (Carter & Miles, 1983). The possible range of scores is 0 to 185 for the total stressor score (Carter & Miles, 1983). Alpha coefficients for the revised instrument and each of the seven dimensions are as follows: Child's Appearance .92; Sights and Sounds .83; Procedures .86; Staff Communication .99; Child's Behavior & Emotions .97; Parental Role Alteration .99; and for the total instrument .95 (Carter & Miles, 1983). The high alpha coefficients indicate that each subscale is measuring one construct, and the very high alpha coefficient for the total scale indicates the subscale constructs are related to a higher order construct (e.g., stress) and that there is probably some redundancy among the items and subscales (Norman & Streiner, 2004). The test-retest correlations range from r = .58 to .92 within a 48 hour period (Carter & Miles, 1989). Only one subscale, sights and sounds, demonstrated a test-retest coefficient less than .73 (Carter & Miles, 1989). Validity was assessed through several different methods. First, the instrument developers consulted with several experts involved in pediatric critical care including parents, bedside nurses, and doctorally-prepared pediatric nursing faculty. The original instrument consisted of 79 items and eight dimensions (Miles & Carter, 1983). An initial factor analysis indicated that six factors accounted for 68% of item variance (Carter & Miles, 1989). A second factor analysis of 62 items indicated that seven factors accounted for 68% of item variance. Items that were highly correlated or that did not load saliently were deleted resulting in a 37 item questionnaire. All 36 items loaded primarily on one of the seven factors, and factors were assumed to be orthogonal. The authors also administered Spielberg's State-trait Anxiety Inventory in conjunction with the PSS: PICU to test for criterion-related validity. State anxiety scores correlated significantly ($p \leq .0001$) with all of the subscales, and the correlations were only weak to moderate in magnitude.

The PSS:PICU exhibits strong psychometric properties; however, it does have some limitations. First, it was originally developed in the mid 1980s prior to the many medical advances currently being practiced in the PICU. The instrument was originally tested in a very homogenous population. The majority of participants were female parents or step-parents of the child in the PICU and were White, in their mid-thirties, married, and middle class. The major strengths of the PSS:PICU are simplicity and strong psychometric properties. The PSS: PICU items are short, clear, and easily comprehensible without requiring a high reading level. It has been reported frequently in recent literature. It has also been translated into Chinese (Yam, Lopez, & Thompson, 2004) and Spanish (Rei & Fong, 1996) and has demonstrated similar structure and psychometric properties to the original instrument.

Coping

Coping for this study was conceptualized as specific cognitive and behavioral efforts by which an individual and the family attempt to reduce or manage the demands on the family system (Tak & McCubbin, 2002). Parental coping was measured by the Coping Health Inventory for Parents (CHIP). (See Appendix D)

The CHIP, developed by McCubbin, McCubbin, et al. (1983), is a 45-item instrument designed to measure parent's response to management of family life when they have a child who is seriously or chronically ill. Items use Likert-type ratings with 4 response categories: 0 = *not helpful*; 1 = *minimally helpful*; 2 = *moderately helpful*; 3 = *extremely helpful*. It is also possible to mark the coping strategies that the parent chose not to use or that were not possible (unscored).

The original instrument consisted of 100 items developed through consultation with several experts involved in coping research and parents of a chronically ill child. The 80-item version was given to 100 parents to eliminate unnecessary items. The items were reduced to 45 items and an initial factor analysis identified 3 factors that explained 71% of item variance (McCubbin, McCubbin, et al., 1983). Three clear coping patterns were identified: Coping Pattern I (maintaining family integration, cooperation, and an optimistic definition of the situation) which includes 19 items that measure behaviors centered around family life and relationships and the parents outlook on life; Coping Pattern II (maintaining social support, self esteem, and psychological stability) which includes 18 items that measure behaviors focusing on the parents' effort to maintain a sense of well-being through social relationships; and Coping Pattern III (understanding the medical situation through communication with other parents and consultation of the medical staff) which includes 8 items that focus on the relationship between other parents with an ill child and the medical staff (McCubbin, McCubbin, et al., 1983).

A Coping score is obtained by summing the numbers circled by the respondent (0 = *not helpful*; 1 = *minimally helpful*; 2 = *moderately helpful*; 3 = *extremely helpful*) and disregarding the "*I do not cope this way*" statements since they are equivalent to 0. A subscale score (the authors provide a list to determine which items belong to each subscale) may also be calculated in the same manner (McCubbin, Thompson, & McCubbin, 1996). Alpha coefficients for each of the three subscales are as follows: (1) maintaining family integration, cooperation, and an optimistic definition of the situation, α = .79; (2) maintaining social support, self esteem, and psychological stability , α = .79; and (3) understanding the medical situation through communication with other parents and consultation of the medical staff, α = .71 (McCubbin, McCubbin, et al, 1983)

The CHIP exhibits adequate psychometric properties; however, it does have some limitations. The CHIP was originally developed in the mid-1980s prior to the many medical advances currently being practice in the PICU and it was originally tested in a very homogenous population. The CHIP has been tested mostly with parents of chronically ill children and has not been tested in a sample of parents with critically ill children. However, it has recently been utilized in a sample of pediatric critically ill cardiac patients with the following alpha coefficients are: Coping pattern I .77, Coping pattern II .77, and Coping pattern III .64 (Saied, 2006). In the proposed study, further testing of internal consistency reliability will be conducted.

Data Management

Rigorous data management strategies were employed to avoid any inconsistencies in data collection and/or documentation. Once participants had consented to participating in the study, basic demographic information was obtained. Each participant's study documents were placed in a separate file folder which included their signed consent, demographic information, PSS:PICU and CHIP questionnaires. The demographic information and questionnaires were collected by the principal investigator and immediately filed in a locked file cabinet. All forms were assessed for completeness prior to filing. Data coding and entry was done on a computer with a secure server and password protected by one person to eliminate error and identify missing data in a timely fashion. Hard copies were stored in a locked file cabinet.

Data Analysis

Data were analyzed for completeness and distribution anomalies. Data were screened prior to analysis for missing data, outliers, and distributional characteristics. Data were analyzed with SPSS Version 17.

Missing data can occur when measurement equipment fails, subjects do not complete all trials or respond to all items, or errors occur during data entry (Mertler & Vannatta, 2002). While surveys were assessed for completeness as they were collected, there was some missing data. Data entry was performed frequently and all entries were double checked after entering the variables into the computer. Missing data were identified and analyzed for patterns since the pattern may be more crucial than the actual presence of missing data (Mertler & Vannatta, 2005). The amount of missing data on any of the dependent variables ranged from 2 to 5 cases (3.0% to 7.5%), and the data appeared to be missing at random.

Extreme values were assessed and the reason for the outlier was examined. The outliers in this study appeared to be related to the extreme situation with which the parents were placed in (i.e. the PICU). According to Tabachnick and Fidell (1996), there are three causes for outliers: data entry errors, the subject is not a member of the population for which the sample is intended, and the subject is simply different from the rest of the sample.

Normality was assessed graphically (e.g., with histograms and normal probability plots) and with skewness and kurtosis coefficients. The continuous variables did not depart substantially from a normal distribution, and thus, did not need to be recoded or transformed (Mertler & Vannatta, 2005).

Linearity assesses the presupposition that there is a straight line relationship between two variables (Mertler & Vannatta, 2005). This is important in multivariate analyses because many techniques are based on linear combinations of variables (Mertler & Vannatta). Linearity was assessed with bivariate scatterplots and scatterplot matrices and residual plots.

Homoscedasticity refers to the assumption that the variability in scores for one continuous dependent variable is roughly the same at all values of a categorical (i.e., grouping) variable (Mertler & Vannatta, 2002). Homoscedasticity was assessed through the Levene’s test in univariate analyses of group differences such as an independent t-test or one-way analysis of variance.

Statistical Analysis

Descriptive statistics (for example, means, medians, modes, and standard deviation [SD]) were calculated for all demographic variables of the parent (income, education, and age) and child (illness severity, and age) as well as for stress (PSS:PICU) and coping (CHIP) scores. For any inferential analyses, a *p*-value < .05 was taken to be statistically significant. Because the study is exploratory, no adjustment was made for multiple comparisons. As much as possible, results were reported with a 95% confidence interval or an appropriate effect size estimate, not just a significance level. Because for some cases only one parent will participate, whereas for others two will participate, there is a potential issue of lack of independence of observations. Therefore, for these analyses, if two parents of a child both completed the study measures, a coin toss was used to determine which parent to include in the independent groups analyses.

Univariate Analyses

Analyses of differences in stress and coping scales by parental gender and ethnicity and by child type of admission (planned / unplanned) and prior hospitalization (yes / no) used a two-sample (independent) Mann-Whitney test because of the differences in sample size of independent mothers and fathers. In addition, a sub-analysis was conducted for the two-parent families using either a Wilcoxon signed ranks test for dependent samples.

Multivariable Analyses

Hierarchical multiple regression analysis was used to assess the joint and independent influences of the parent independent variables (race, ethnicity, socioeconomic status, age, and gender) and child independent variables (age, planned admission, prior hospitalization, and illness severity) on the Total PSS:PICU score and the Total CHIP score.

Nominal categorical independent variables with more than 2 levels (categories, groups, e.g., race) were converted to a series of binary dummy variables (one less than the number of levels of the variable). Dichotomous, ordinal, and continuous predictors were used ‘as is.’ The parent block was entered first, followed by the child block. Simultaneous entry was used for each block.

Sample Size

Although this was an exploratory study, it was important to obtain a sufficient sample size to detect a significant effect, therefore, a power analysis (Cohen, 1988) was utilized to estimate the number of subjects required. A power analysis consists of four components: the significance level (alpha), an appropriate effect size estimate for the type of analysis that corresponds to a clinically meaningful impact on the dependent variable power (1-β, where β is the maximum Type II error rate one is willing to tolerate), and sample size (Burns & Grove, 2004). When three of the four parameters are known, the fourth can be calculated using a power analysis.

The significance level or alpha-error is set by the researcher; the larger the alpha, the easier it is to attain significance (Lipsey, 1990). Typically, the alpha is set at .05 which corresponds to 95% confidence (1-alpha error) and a long run Type I error rate of no more than 5%, meaning that over the long run, in no more than 5% of instances would one expect rejection of a null hypothesis when the null hypothesis is actually true of the population being sampled (or, conversely, at least 95% of the time when the null hypothesis is true of the population being sampled, it will not be rejected) (Lipsey, 1990).

Effect size is defined as the magnitude of the relationship between independent and dependent variables (e.g., a correlation coefficient, multiple correlation coefficient or an estimate of variance accounted for) or magnitude of difference (e.g., in means or proportions) in a dependent variable between groups (Polit & Beck 2004). Effect size is important in reducing a type II error; as effect size increases, sample size requirements decrease. Various kinds of effect sizes differ according to the type of design and statistical analysis. For example, in a two-group experimental design with a continuous dependent variable, effect size is usually expressed as a standardized difference in means, essentially a z-score for the difference in means. In a correlational design, the absolute value of a conventional correlation coefficient (or a model multiple correlation coefficient, R, in multiple regression) is a dimensionless effect size, however the squared multiple correlation (R^2, i.e., the variance in the dependent variable accounted for by the model) may be used, making the necessary corrections for squaring. Recommendations for effect size for a correlation coefficient in behavioral science are: .1 for a small effect, .3 for a medium effect, and .5 for a large effect (Cohen, 1988, p. 532); however, if enough previous research exists, a researcher should use the results from previous studies to determine the magnitude of effect that has practical or clinical importance (Lipsey, 1990).

Melnyk and colleagues utilized the PSS:PICU to examine the effects of an intervention on parental stress and reported effect sizes ranging from .29 (not statistically significant) to .40 ($p \le .01$; Melnyk, Alpert-Gillis, et al., 2004, Table 4, p. e602). Therefore, a standardized effect size of .4 for the PSS:PICU was used to estimate sample size for this study. This would correspond to a multiple correlation coefficient ($R = .4$) for a regression model, hence an unadjusted R^2 of .16 was considered large enough to be of practical or clinical importance for purposes of this study. The CHIP measure has not been used sufficiently with acutely ill children in a PICU to have an adequate sense of a meaningful effect size.

According to Lipsey (1990) “statistical power is the probability that a statistical test of the null hypothesis upon sample data will (correctly) yield statistical significance when the null hypothesis is, in fact, false for the population from which the sample is drawn” (p. 28). In other words, a power analysis is a method to reduce the likelihood of committing a Type II error. Cohen (1977, 1988) recommends that at minimum, the power is set at .80; however, a power of .90 or .95 may be reasonable in some research contexts (Lipsey, 1990). Power analysis based on Cohen (1988, Equation 9.2.3, p. 410 and Table 9.3.2, p. 420) indicated that a sample size of 92 children would be sufficient for at least 80% power to detect a large effect (i.e., model R-square $\ge .25$ for the full model assuming an R-sq $\le 9\%$ for the parent factors; or a model R-square $\ge .30$ for the full model assuming an R-sq of $\le .16$ for the parent factor). However, due to administrative changes at the study site, data collection had to stop after only 86 participants.

Protection of Human Subjects

Risks to the subjects

Human subjects involvement and characteristics. The study population was composed of parents of critically ill children in one tertiary hospital in a Southwestern city. All parents who met the inclusion criteria were invited to participate in the research study. The parents were various ages, ethnicity, and came from varied socioeconomic backgrounds. The inclusion criteria for participation were: (1) have a child (ages 0-16) in the PICU (2) be able to speak and understand English (3) be 18 years of age. The only exclusion criterion was if non-accidental trauma injury was suspected, regardless of whether the parent is involved. Parents who agreed to participate were required to answer one demographic information sheet and two questionnaires, the Parental Stressor Scale: PICU (PSS:PICU) and the Coping Health Inventory for Parents (CHIP). A convenience sampling strategy was utilized and any parent whose child was critically ill and met the inclusion criteria was approached by the Principal Investigator (PI) or a research assistant who has been trained in the procedures for this study. The hospital's Institutional Review Board (IRB) was the governing board of approval for this study. Once the study was approved, the PI met with the nursing leaders, physicians, and bedside nurses to explain the aims, inclusion criteria, methods, and data collection procedures.

Sources of Materials. No physiological specimens were obtained for use in this study. Demographic data from the parent (race/ethnicity, income, age, education, marital status, occupation, and gender) and the child (age, diagnosis, planned or unplanned admission, prior hospitalization, and illness severity) were obtained and the participants were given the questionnaires, Parental Stressor Scale: PICU (PSS: PICU) and the Coping Health Inventory for Parents (CHIP). Only the PI had access to the demographic data and questionnaires and once completed were stored in a locked cabinet.

Potential Risks. The risks for participation in this study were minimal. There were no identified risks for the child. Parents did not report increased stress from having to answer the questionnaires during their child's hospitalization.

Adequacy of Protection Against Risks

Recruitment and informed consent. A convenience sampling strategy was utilized and all parents who met the inclusion criteria were invited to participate in this study. It has been documented that parents experience extreme stress levels, approaching near panic levels during the first 24 to 48 hours and decreases significantly after the first 24 hours and thus parents were not approached within 24 hours of admission. Once participants were identified, they were approached and the study was explained to them. Each participant was encouraged to ask any questions and was informed of their right to privacy and anonymity as well as their right to decline or be removed from the study at any time for any reason. It was also explained that participation was voluntary and that participation or lack thereof, would not affect their child's medical or nursing care. The researcher's name and number was provided for any further questions. Once the participant verbally agreed to participate, a signed consent that thoroughly explains the study's aims, data collection procedures, and potential risks and benefits was obtained.

Protection against risk. Confidentiality was protected by maintaining records in a locked cabinet that only the PI had access to. Parents did not report that participation in this study caused added stress; however, social work was available for consultation to evaluate the situation and identify resources for the parent at no additional cost to the parent.

Potential benefits of the proposed research to the subjects and others. There are no direct benefits for participation in this study.

Importance of Knowledge to be Gained

The knowledge gained from this study will significantly add to a limited body of knowledge regarding parental coping during a child’s critical illness. The knowledge will assist healthcare providers to have a better understanding of the stressors that parents experience during their hospitalization and the strategies that parents employ to cope with the stressors. Healthcare institutions are continually striving to provide family-centered care in a cost-effective manner. This study will assist healthcare providers to have a better understanding and thus provide better care to families who are coping with the stressors of a critically ill child. This study will also add to the paucity of research that exists regarding parental coping during a child’s critical illness. Understanding how parents cope with the various stressors will provide healthcare professionals with the knowledge required to assist parents to better cope. Improving parental coping is crucial to improving both the child’s outcomes after discharge, such as decreasing the incidence of internalizing disorders (for example, sadness, anxiety, depression, etc) and externalizing disorders (for example, oppositional defiant disorder, attention deficit hyperactivity disorder, etc).

CHAPTER IV

ANALYSIS OF DATA

The purpose of this study was to explore parental stress and coping in a diverse group of families experiencing hospitalization of their child in a pediatric intensive care unit. This chapter presents the demographic characteristics of the participants and a description of the major study variables. Next, analyses for the three research questions are presented. All analyses were conducted using SPSS 17.0 for Windows to evaluate all assumptions and to derive the findings.

Parent Demographic Characteristics

Subjects were recruited from a large PICU in a freestanding children's hospital in the Southwest. The sample for this study (*N* = 86) consisted of 84 parents, one aunt, and one foster parent: 48 were lone respondents; 38 were from 19 2-parent dyads. Of the total sample, 30 percent (*n* = 26) were male and 70 percent (*n* = 60) were female. All of the male participants were fathers, and all but 2 of the female participants were mothers of children admitted to the PICU. Because those 2 participants (both female) were in a parenting role for the hospitalized child, they will be labeled as among the mothers throughout the analysis.

The demographic characteristics of the total sample of parents are presented in Table 1. The parents ranged in age from 18 to 56 years (M = 33.9; SD = 9.8), the majority of respondents were married (*n* = 55; 64.0 %), Caucasian (*n* = 59; 68.6%), and approximately 23% were Hispanic or Latino in ethnicity. Parental education levels ranged from elementary/middle school to graduate degrees; 87% of participants reported having attained at least a high school diploma or GED. One third of participants self reported that they were either unemployed (*n* = 12) or homemakers (*n* = 18).

Table 1

Parent Demographic Characteristics (N = 86)

Demographic Characteristics	**Mothers (N = 60)**	**Fathers (N = 26)**	**Total (N = 86)**
Age, M (SD), years	33.4 (9.1)	35.3 (11.4)	33.9 (9.8)
Education, M (SD), years	14.3 (3.16)	14.7 (2.64)	14.5 (2.9)
Education, n (%)			
Elementary/Middle School	1 (1.7)	0	1 (1.2)
Some High school	7 (11.7)	2 (7.7)	9 (10.5)
High school graduate/GED	10 (16.7)	7 (26.9)	17 (19.8)
Some college/technical school	23 (38.3)	7 (26.9)	30 (34.9)
University degree	10 (16.7)	6 (23.1)	16 (18.6)
Graduate degree/Professional	9 (15.0)	4 (15.4)	13 (15.1)
Missing	0	0	0
Income Level, n (%)			
<15,000	13 (22.4)	3 (11.5)	16 (18.6)
15,000-24,999	5 (8.3)	3 (11.5)	8 (9.3)
25, 000-34,999	6 (10.0)	3 (11.5)	9 (10.5)
35,000-49,999	8 (13.3)	6 (23.1)	14 (16.3)
50,000-74,999	13 (21.7)	2 (7.7)	15 (17.4)
75,000-99,999	7 (11.7)	5 (19.2)	12 (14)
>100,000	6 (10.0)	4 (15.4)	10 (11.6)
Missing	2 (3.3)	0	2 (2.3)
Marital Status, n (%)			
Married	35 (58.3)	20 (76.9)	55 (61.2)
Not Married, Living with Partner	15 (25.0)	4 (15.4)	19 (22.4)
Divorced/Separated	5 (8.3)	2 (7.7)	7 (9)
Never Married	5 (8.3)	0 (0)	5 (7.5)
Missing	0	0	0
Race/Ethnicity*, n (% within gender)			
White/Caucasian (not Hispanic)	41 (68.3)	18 (69.2)	59 (68.6)
Black/African American	4 (6.7)	0	4 (4.7)
American Indian/Alaskan Native	5 (8.3)	1 (3.8)	6 (7.0)
Asian	1 (1.7)	2 (7.7)	3 (3.5)
Hawaiian Native/Pacifica Islander	1 (1.7)	0	1 (1.2)
Hispanic*	8 (13.3)	5 (19.2)	13 (15.1)
Ethnicity only**, n (%)			
Hispanic or Latino	13 (21.7)	7 (26.9)	20 (23.3)
Not Hispanic or Latino	47 (78.3)	19 (73.1)	66 (76.7)

Percentages in the Mothers and Fathers colums are percentages within gender
***responses limited to one category**
****Ethnicity without considering race**

Child Demographic Characteristics

To account for the parent dyad responses, if both parents participated, one parent was randomly removed for analysis. Of the 67 children involved, the majority were male (58%) and their ages ranged from less than one month to 204 months (17 years). The demographic characteristics of the children are presented in Table 2. More than half (n = 39; 58.2%) of the children had been previously hospitalized and of these children, 64% (n = 25) had been previously hospitalized in the PICU. In the PICU, a nursing acuity score (see Appendix B for description of the nursing acuity tool) based on several key indicators was utilized to categorize patients in increasing nursing acuity: floor status, stable ICU, unstable ICU, critical ICU, and 2 nurses to 1 patient. Of those for whom an acuity rating was documented (n = 61; 91%), a majority (n = 31; 51%) were stable.

Table 2

Child Demographic Characteristics (N = 67)

Variable	Female	Male	Missing	Total
Sex				
N	27	39	1	67
%	40.3%	58.2%	1.5%	
Age (Months)				
Mean (SD)	58.1 (76.3)	53.4 (68.3)	< 1 mo	54.7 (70.8)
Median (25th, 75th %ile)	12 (3, 144)	12 (3, 96)		12 (3, 96)
Planned admission, n (%)				
No	13 (19.4)	20 (29.9)		33 (49.3)
Yes	14 (20.9)	19 (28.4)	1 (1.5)	34 (50.7)
Prior Hospitalization, n (%)				
No	14 (20.9)	14 (20.9)		28 (41.8)
Yes	13 (19.4)	25 (37.3)	1 (1.5)	39 (58.2)
Prior PICU, n (%)				
No	20 (29.9)	22 (32.8)		42 (62.7)
Yes	7 (10.4)	17 (25.4)	1 (1.5)	25 (37.3)
Diagnosis, n (%)				
Respiratory	7 (10.4)	14 (20.9)		21 (31.3)
Cardiac	9 (13.4)	8 (11.9)		17 (25.4)
Neuro	7 (10.4)	5 (7.5)	1 (1.5)	13 (19.4)
Hematology / Oncology	3 (4.5)	3 (4.5)		6 (9.0)
Surgical (non-cardiac)	0	5 (7.5)		5 (7.5)
Genitourinary	0	3 (4.5)		3 (4.5)
Gastrointestinal	0	1 (1.5)		1 (1.5)
Missing	1 (1.5)	0		1 (1.5)
Nursing Acuity , n (%)				
Floor/Stable ICU	13 (19.4)	18 (26.9)	1 (1.5)	32 (47.8)
Critical ICU	4 (6.0)	11 (16.4)		15 (22.4)
Unstable ICU	7 (10.4)	5 (7.5)		12 (17.9)
2 nurses : 1 patient	2 (3.0)	0 (0)		2 (3.0)
Missing	1 (1.5)	5 (7.5)		6 (9.0)
Length of Stay (days), n (%)				
< 3	9 (13.4)	13 (19.4)	1 (1.5)	23 (34.3)
3 to 7	6 (9.0)	11 (16.4)		17 (25.4)
8 to 14	5 (7.5)	7 (10.4)		12 (17.9)

>14	6 (9.0)	4 (6.0)	10 (14.9)
Missing	1 (1.5)	4 (6.0)	5 (7.5)

Data Analysis

The inital data analysis included the frequencies and descriptive statistics for all of the variables.

Descriptions of study variables. Parental stressors were measured utilizing the Parental Stressor Scale: PICU (Carter & Miles, 1983). For the individual items and subscales, a Likert scale that ranged from 0, meaning “not experienced,” to 5, meaning “extremely stressful” was utilized. The authors recommend using the total score and subscales to describe the stressors parents experience while their child is critically ill. The total stress score is a summation of the 37 items, and the scores ranged from 19 to 128. The mean total stress score was 77.0 (SD = 28.0). Descriptive data (sample size, mean, SD, quartiles), the number of items, and Cronbach’s alpha are presented in Table 3.

Table 3

Summary of PSS:PICU and Scale Reliabilities for All Parents (N = 86)

					Percentiles			
Scale	**N**	**# of items**	**Mean**	**SD**	**25th**	**50th**	**75th**	**Cronbach’s α**
PSS:PICU Total Score	82	37	77.0	28.0	57.0	73.5	95.8	0.89
Appearance	85	3	3.0	1.0	2.3	3.0	3.7	0.50
Sights & Sounds	85	3	2.8	1.2	2.0	2.7	3.7	0.85
Procedures	86	6	3.0	1.1	2.3	2.8	3.7	0.82
Staff Behaviors	78	4	2.0	1.0	1.2	1.8	2.5	0.74
Parent Roles	86	6	3.3	1.1	2.5	3.5	4.3	0.84
Communications	68	5	2.5	1.2	1.5	2.0	3.6	0.84

Child Behaviors & Emotions	83	10	3.3	1.1	2.7	3.4	4.0	0.85

The Coping Health Inventory for Parents (CHIP) was used to measure coping strategies utilized by the parents. Descriptive data (n, mean, SD, quartiles), the number of items, and Cronbach's alpha are presented in Table 4. Coping Pattern I, which involves maintaining family integration, cooperation, and an optimistic definition of the situation was rated the most helpful. Coping Pattern II, which involves social support, self-esteem, and psychological stability was rated helpful as well. Coping Pattern III, which involves understanding the medical situation through communication with other parents and consultation with medical staff, was identified as the least helpful coping pattern. These results are consistent with Saied's (2004) study of families in the PICU after their child's surgery for congenital heart defect.

Table 4

Summary of CHIP and Scale Reliabilities for All Parents (N = 86)

					Percentiles			
Scale	**N**	**# of items**	**Mean**	**SD**	**25th**	**50th**	**75th**	**Cronbach's α**
Coping I[a]	84	16	33.0	8.2	28.3	34.0	39.0	0.81
Coping II[b]	80	19	22.3	9.8	13.3	21.0	29.8	0.79
Coping III[c]	82	19	14.3	5.0	10.0	14.5	17.3	0.71

a = maintaining family integration
b= maintaining social support
c = understanding the medical situation

Research Questions

Data analysis is organized around the following research questions:

1. What stressors do parents identify when their child is critically ill (using the PSS:PICU), and do stressors differ between mothers and fathers?
2. What coping strategies do parents identify when their child is critically ill (using the CHIP) and do coping strategies differ between mothers and fathers?
3. What are the joint and independent influences of parent demographic variables (race, ethnicity, socioeconomic status, age, and gender) and child demographic and clinical variables (age, planned admission, prior hospitalization, and illness severity) on parental stress and coping?
4. What stressors do parents identify when their child is critically ill (using the PSS:PICU), and do stressors differ between mothers and fathers?

To answer the first research question, what stressors do parents identify when their child is critically ill (using the PSS:PICU), and do they differ between mothers and fathers, descriptive statistics (means, standard deviation, and quartiles) were utilized to answer the first part of this question on all parents who participated. Parents identified the following individual stressors as most stressful: sudden sounds of monitor alarms (M = 3.4; SD = 1.4); acting or looking like in pain (M = 3.4; SD = 1.8); tubes in my child (M = 3.3; SD = 1.4), not being able to hold my child (M = 3.2; SD = 2.0). Conversely, parents identified the following stressors as least stressful: staff behaviors such as joking (M = 1.2; SD = 0.9), and staff not stating their names (M = 1.2; SD = 1.5); staff communication such as explaining things to fast (M = 1.0; SD = 1.2) and not talking to me enough (M=1.1; SD=1.6); and child behaviors such as demanding behavior (M = 0.7; SD = 1.1) or anger (M = 1.4; SD = 1.8).

Mothers reported the following as most stressful: acting or looking as if in pain (M = 3.5, SD = 1.8), the sudden sound of monitor alarms (M = 3.4; SD = 1.5), and tubes in my child (M = 3.3, SD = 1.6), not being able to hold my child (M = 3.1; SD = 2.1). Fathers reported the following items as most stressful: the sudden sound of monitor alarms (M = 3.6; SD = 1.1), not being able to hold my child (M = 3.5; SD = 1.9), tubes in my child (M = 3.4, SD = 0.9), and acting or looking as if in pain (M = 3.3; SD = 1.8). The mean scores and standard deviations for the individual parental stressors are found in Appendix E. The mean scores of the parental stress subscales for all parents are presented in Table 5.

Table 5

Mean Scores for PSS:PICU for All Mothers (N = 60) and Fathers (N = 26)

Variable	Mothers Mean (SD)	Fathers Mean (SD)	Total Sample Mean (SD)
Stress Total Score	76.9 (26.8)	77.2 (30.8)	77.0 (28.0)
Appearance	3.1 (1.0)	2.9 (1.1)	3.0 (1.0)
Sights and Sounds	2.8 (1.3)	2.7 (0.8)	2.8 (1.2)
Procedures	3.0 (1.1)	3.0 (0.9)	3.0 (1.1)
Staff Behaviors	2.0 (1.0)	1.9 (1.0)	2.0 (1.0)
Parent Roles	3.3 (1.2)	3.4 (1.0)	3.3(1.1)
Communication	2.4 (1.2)	2.6 (1.2)	2.5 (1.2)
Child Behaviors and Emotions	3.3 (1.0)	3.3 (1.1)	3.3 (1.1)

The demographic characteristics of the independent mothers and fathers are presented in Table 6. The mean scores for the independent mothers and fathers are presented graphically in Figure 3. To answer whether stressors differed between mothers and fathers a Mann-Whitney test was conducted to compare whether independent mothers and fathers differed in their scores of the parental stressor subscales and total score (See Table 7).

Table 6

Independent Parent Demographics (N = 67)

Demographic Characteristics	**Mothers (N = 49)**	**Fathers (N = 18)**	**Total (N = 67)**
Age, M (SD), years	33.7 (9.7)	36.8 (10.6)	34.6 (10.0)
Education, M (SD), years	14.2 (3.2)	15.1 (3.2)	14.4 (3.2)
Education, n (%)			
Elementary/Middle School	1 (2.0)	0	1 (1.5)
Some High school	6 (12.2)	2 (11.1)	8 (11.9)
High school graduate/GED	8 (16.3)	3 (16.7)	11 (16.4)
Some college/technical school	19 (38.8)	4 (22.2)	23 (34.3)
University degree	8 (16.3)	6 (33.3)	14 (20.9)
Graduate degree/Professional	7 (14.3)	3 (16.7)	10 (14.9)
Income Level, n (%)			
<15,000	13 (27.7)	2 (11.1)	15 (13.8)
15,000-24,999	4 (8.5)	1 (5.6)	5 (7.7)
25,000-34,999	4 (8.5)	3 (16.7)	7 (10.8)
35,000-49,999	6 (12.8)	4 (22.2)	10 (15.4)
50,000-74,999	10 (21.3)	1 (5.6)	11 (16.9)
75,000-99,999	7 (14.9)	4 (22.2)	11 (16.9)
>100,000	3 (6.4)	3 (16.7)	6 (9.2)
Missing	2 (4.1)	0	2 (3.0)
Marital Status, n (%)			
Married	28 (57.1)	13 (72.2)	41 (61.2)
Not Married, Living with Partner	12 (24.5)	3 (16.7)	15 (22.4)
Divorced/Separated	4 (8.1)	2 (11.1)	6 (9.0)
Never Married	5 (10.2)	0	5 (7.5)
Race/Ethnicity, n (%)			
White/Caucasian	33 (67.3)	9 (50.0)	42 (62.7)
Black/African American	3 (6.1)	1 (5.6)	4 (6.0)
American Indian/Alaskan Native	4 (8.2)	1 (5.6)	5 (7.5)
Asian	1 (2.0)	2 (11.1)	3 (4.5)
Hawaiian Native/Pacifica Islander	1 (2.0)	0	1 (1.5)
Hispanic	7 (14.3)	5 (27.8)	12 (17.9)

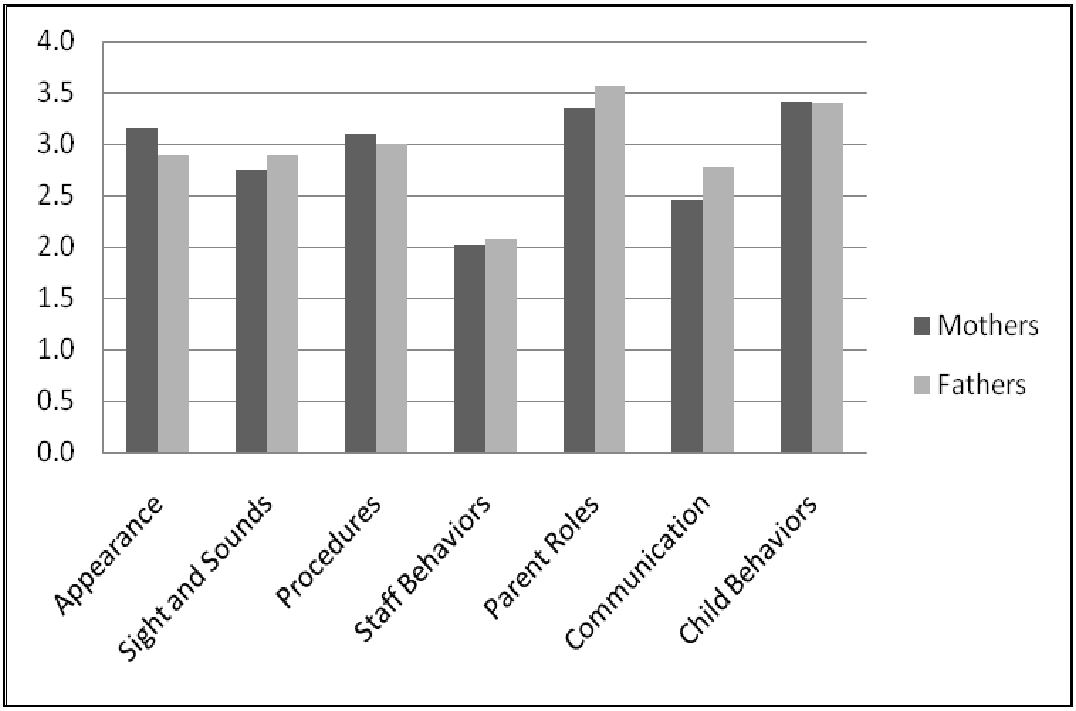

Figure 3. PSS:PICU Subscale Mean Scores for Independent Mothers (N = 49) and Fathers (N = 18)

Table 7

Comparison of Independent Mothers' (N = 49) and Fathers' (N = 18) Mean Scores on the PSS:PICU

Scale	Mean	Median	SD	Percentiles		Mann Whitney	
				25	75	Z score	p
Total Score						-.184	.854
Mothers	77.1	77.1	25.7	54.0	94.0		
Fathers	81.1	73.0	33.1	55.5	118.3		
Appearance						-.433	.665
Mothers	3.2	3.0	1.0	2.4	4.0		
Fathers	2.9	3.4	1.2	4.0	3.7		
Sights and Sounds						-.668	.504
Mothers	2.7	2.7	1.3	1.7	3.7		
Fathers	2.9	3.0	0.6	2.3	3.3		
Procedures						-.595	.552
Mothers	3.1	3.0	1.1	2.4	3.8		
Fathers	3.0	2.8	0.9	2.4	3.4		
Staff Behaviors						-.292	.770
Mothers	2.0	2.0	0.9	1.3	2.4		
Fathers	2.1	2.0	1.0	1.3	2.7		
Parent Roles						-1.608	.108
Mothers	3.4	3.6	1.2	2.2	4.3		
Fathers	3.6	3.7	0.9	3.0	4.3		
Communication						-1.32	.187
Mothers	2.5	2.5	1.0	2.0	3.0		
Fathers	2.8	2.8	1.0	2.3	3.6		
Child Behaviors						-.382	.702
Mothers	3.4	3.1	1.0	2.7	4.2		
Fathers	3.4	3.3	1.0	2.8	4.0		

The mean subscale scores for partnered mothers and fathers are presented in Figure 4. To examine whether differences exist between mothers and fathers who are partners, a Wilcoxon signed ranks test was performed on all mother-father dyads (n = 19). The results of the Wilcoxon signed ranks test indicated there were no differences in the total stressor score or the subscales between mother-father pairs (see Table 8). These results suggest that parents in the same household identify similar stressors.

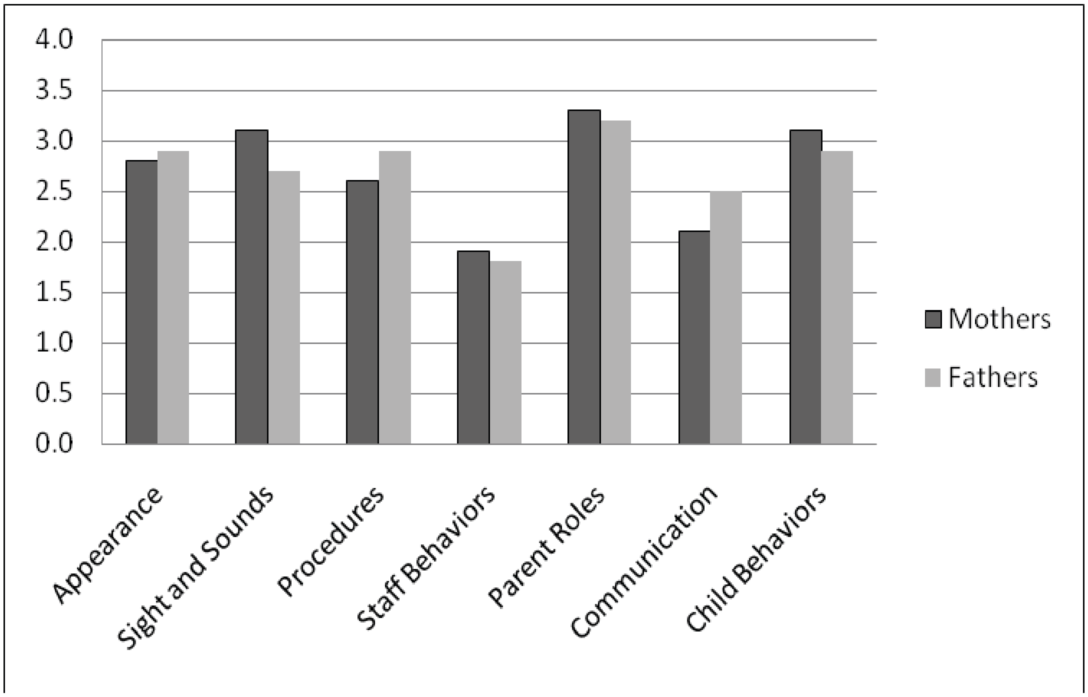

Figure 4. PSS:PICU Subscale Means for Partnered Mothers (N = 19) and Fathers (N = 19)

Table 8

Comparison of Partnered Mothers' (N =19) and Fathers'(N = 19) Mean PSS:PICU Scores

Scale	Mean	Median	SD	Percentiles 25	Percentiles 75	z	p
Total Score						-.382	.702
Mothers	74.9	70.0	27.8	59	86		
Fathers	75.1	72.0	31.1	45	100.0		
Appearance						-.065	.948
Mothers	2.8	2.7	0.8	2.3	3.3		
Fathers	2.9	2.7	1.0	2.0	3.5		
Sights and Sounds						-1.11	.266
Mothers	3.1	3.0	1.2	2.3	3.7		
Fathers	2.7	2.7	0.9	2.0	3.3		
Procedures						-1.55	.121
Mothers	2.6	2.3	1.0	2.0	3.6		
Fathers	2.9	2.8	1.0	2.4	3.7		
Staff Behaviors						-.925	.355
Mothers	1.9	1.5	1.0	1.0	3.0		
Fathers	1.75	1.5	1.0	1.0	2.0		
Parent Roles						-.545	.586
Mothers	3.3	3.3	0.9	2.7	4.2		
Fathers	3.2	3.3	0.9	2.3	3.7		
Communication						-1.14	.255
Mothers	2.1	2.0	1.1	1.3	2.7		
Fathers	2.5	2.0	1.0	1.0	3.5		
Child Behaviors						-.947	.344
Mothers	3.1	3.2	1.1	2.5	4.4		
Fathers	2.9	3.0	0.8	2.3	3.6		

In addition to the PSS:PICU, two open-ended questions were asked of parents completing the surveys: 1) Why is your child in the PICU and 2) In your own words, what is the most stressful aspect of the PICU? The majority of participants (n = 75) responded to the open-ended questions. According to their responses, all parents were able to correctly describe why their child was in the PICU. The responses from the second question were transcribed into a document and tallied for similar content. The top five content areas that emerged were: uncertainty, helplessness, child's pain/discomfort, equipment, and nursing interventions. One-third of parents responded that the most stressful aspect of the PICU was the uncertainty of the outcome and a feeling of helplessness. One-third of parents responded that it was very stressful “not knowing” the diagnosis, treatment, or outcome. One parent stated “not knowing when it will end and not being able to do anything to help her recovery” while another parent stated “not knowing if she will survive, pneumonia is typically the cause of death for children with [Metachromatic Leukodystrophy] MLD”. Nearly one-third of parents reported that not being able to hold, comfort, or relieve their child’s pain as the most stressful aspect of the PICU. One parent stated “keeping her comfortable, trying to figure out why she is crying, where her pain is, keeping her calm” while another parent stated “not being able to do anything for my child. Not being able to hold my child…”. Equipment continues to be identified as a major stressor and one parent stated, “Everything in this unit scares me, even in the room. The machine he’s hooked on, all the tubes that are running into him, just everything, even the sound of the machines scare me. Not being able to hold him because of all the tubes”. Nursing interventions were identified as being very stressful by a few parents. Parents stated “when the nurses do things that make my baby cry” or “when the IV specialist shoved an IV in his head when she said she was just looking”.

To answer the second research question, what coping strategies do parents identify when their child is critically ill (using the CHIP) and do they differ between mothers and fathers, descriptive statistics (means, standard deviation, and quartiles) were utilized to identify the individual coping strategies of all parents who participated (see Appendix F). Parents identified the following individual coping strategies as most helpful: believing that my child is getting the best medical care possible (M = 2.8; SD = 0.6), believing my child will get better (M = 2.7; SD = 0.7), believing that the hospital has my family's best interest in mind (M = 2.7; SD = 0.6), and talking with the doctor about my concerns (M = 2.6; SD = 0.8). Parents found the following coping strategies least helpful: entertaining friends in our home (M = 0.5; SD = 0.9), purchasing gifts for myself or family members (M = 0.5; SD = 0.8), and involvement in social activities with friends (M = 0.6; SD = 1.0).

Mothers reported the following coping strategies as most helpful: believing that my child is getting the best medical care possible (M = 2.9; SD = 0.5), believing that the hospital has my family's best interest in mind (M = 2.8; SD = 0.5), believing my child will get better (M = 2.7; SD = 0.6), and talking with the doctor about my concerns (M = 2.6; SD = 0.8). Although fathers reported similar coping strategies, they did not find them as helpful as mothers did. Fathers reported the following coping strategies as most helpful: believing my child will get better (M = 2.7; SD = 0.9), believing that my child is getting the best medical care possible (M = 2.6; SD = 0.8), talking with the doctor about my concerns (M = 2.4; SD = 0.8), and believing that the hospital has my family's best interest in mind (M = 2.4; SD = 0.8).

The means and SD for the parental coping subscales for all mothers and fathers are presented in Table 9.

Table 9

Mean Scores for CHIP for All Mothers (N = 60) and Fathers (N = 26)

Variable	Mothers Mean (SD)	Fathers Mean (SD)	Total Sample Mean (SD)
Coping Pattern I[a]	35.2 (7.2)	29.6 (8.6)	33.6 (7.9)
Coping Pattern II [b]	24.7 (9.88)	17.7 (9.5)	22.8 (10.2)
Coping Pattern III [c]	15.3 (4.5)	12.6 (5.5)	14.6 (4.9)

a = maintaining family integration
b= maintaining social support
c = understanding the medical situation

To answer whether coping strategies differed between mothers and fathers, a Mann-Whitney test was conducted to compare whether males and females differed in their scores of the coping subscales. The CHIP subscales mean scores (see Table 10) of the independent mothers and fathers are presented graphically in Figure 5.

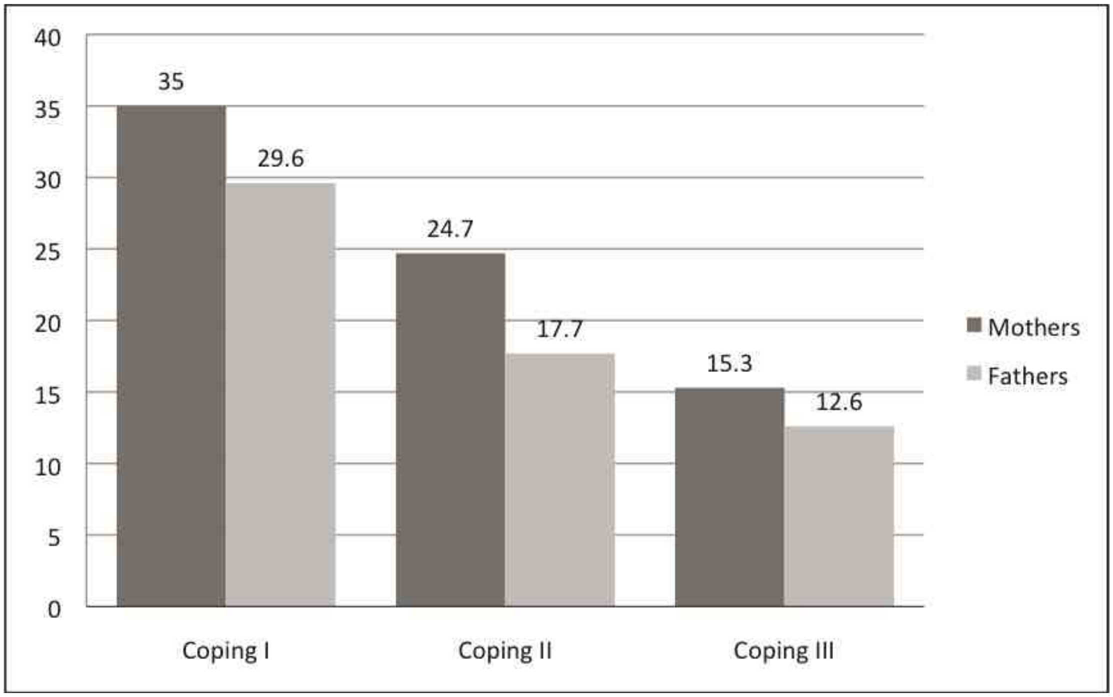

Figure 5. CHIP Subscale Mean Scores for Independent Mothers (N = 49) and Fathers (N = 18)

The results of the Mann-Whitney test indicated males and females differ significantly in the Coping Pattern I subscale (*z* = -2.15, *p* = .032), which involved coping strategies aimed at maintaining family integration and the Coping Pattern II subscale (*z* = -2.39, *p* = .017), which involved aspects related to social support (see Table 10). The third subscale, Coping Pattern III, which involved coping strategies aimed at understanding the medical situation through communication with the healthcare providers, was not statistically significant (*z* = -1.91, *p* = .057). Overall, the results suggest mothers find coping strategies aimed at family integration and social support more helpful than fathers do. The mean scores of the CHIP subscales are presented in Figure 6.

Table 10

Comparison of Independent Mothers' (N=49) and Fathers'(N = 18) Mean Scores on the CHIP

Scale	**Mean**	**Median**	**SD**	**Percentiles**		**Mann Whitney**	
				25	75	*Z* score	*p*
Coping I[a]						-2.2	.032
Mothers	35.0	35.0	7.2	30.0	41.0		
Fathers	29.6	31.0	8.6	25.3	35.0		
Coping II[b]						-2.4	.017
Mothers	24.7	26.0	9.9	16.5	34.0		
Fathers	17.7	18.5	9.5	8.0	25.0		
Coping III[c]						-1.9	.057
Mothers	15.3	15.0	4.5	25.3	35.0		
Fathers	12.6	12.5	5. 6	8.0	16.3		

a = Coping Pattern I, maintaining family integration
b= Coping Pattern II, maintaining social support
c= Coping Pattern III, understanding the medical situation

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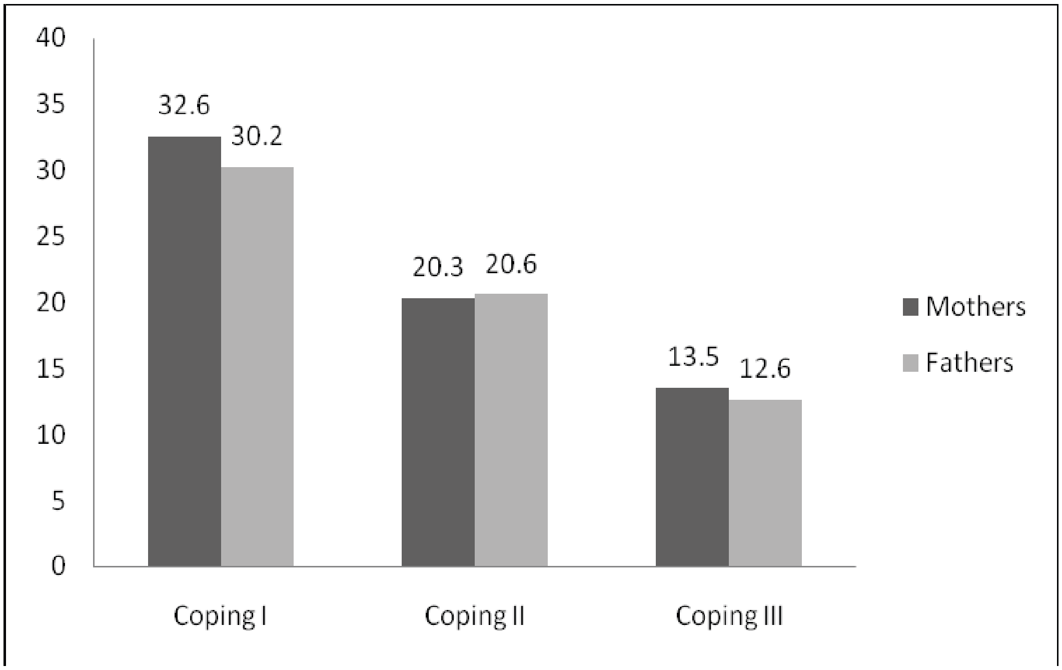

Figure 6. CHIP Subscale Mean Scores for Partnered Mothers (N = 19) and Fathers (N = 19)

Within partner dyads, differences in coping patterns were negligible, and results of a paired Wilcoxon signed ranks test indicated that there were no statistically significant differences in any of the coping subscales between mother-father pairs (see Table 11). These results suggest that, despite differences between the sexes overall, parents in the same household use similar coping strategies.

Table 11

Comparison of Partnered Mothers' (N = 19) and Fathers' (N = 19) Mean Scores on the CHIP

Scale	Mean	Median	SD	Percentiles		*Z* Score	*p*
				25	75		
Coping I[a]						-.63	.527
Mothers	32.6	32.0	7.25	28.0	38.0		
Fathers	30.2	32.98	9.72	18.0	38.0		
Coping II[b]						-.46	.647
Mothers	20.3	20.0	9.2	12.0	27.0		
Fathers	20.6	22.3	8.8	13.0	28.0		
Coping III[c]						-.88	.381
Mothers	13.5	14.0	4.3	10.0	17.0		
Fathers	12.6	10.0	6.5	7.0	17.0		

a = Coping Pattern I, maintaining family integration
b= Coping Pattern II, maintaining social support
c= Coping Pattern III, understanding the medical situation

To answer the third research question, what are the joint and independent influences of parent demographic variables (race/ethnicity, socioeconomic status [income and education], age, and gender) and child demographic and clinical variables (age, planned versus unplanned admission, prior hospitalization, and illness severity) on parental stress and coping, correlations of the study variables were first used to examine if relationships exist between the major study variables. Correlations between the demographic variables, the stressor scores (total score and subscale scores) and the coping patterns are presented in Table 12. In terms of parent demographic variables, there were some statistically significant relationships between parent education, age, and income and stressor scores and coping scores. Parent age was weakly negatively correlated with two of the stressor subscales: procedures (r = -.24, p < .01) and parent role (r = -.28, p < .01). Parent education is weakly correlated with two of the stressor subscales: sights and sounds (*r* = -.28, *p* < .01) and procedures (*r* = -.40, *p* < .01). Income was negatively correlated with procedures (*r* = -.36, *p* < .01) and weakly correlated with Coping Pattern II scores (*r* = -.24, *p* < .05). Illness severity was weakly correlated with parent role (*r* = .23, *p* < .05) and Coping Pattern II scores (*r* = -.27, *p* < .05).

Table 12

Correlations between Parent (Income, Education, and Age,) and Child Demographic Variables (Age, Illness severity) and Stress and Coping Scores

Variables	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
1. Total Stress	.49**	.40**	.67**	.50**	.56**	.47**	.52**	.07	-.08	-.12	-.14	-.17	-.15	-.03	.01
2. Appearance	-	.36**	.48**	.37**	.42**	.20	.22*	-.05	-.12	-.08	-.16	-.20	-.21	-.06	.04
3. Sights and Sounds		-	.49**	.14	.30**	-.01	.04	.02	-.07	.14	-.16	-.28**	-.15	-.07	.07
4. Procedures			-	.30**	.47**	.29*	.27*	.10	-.13	-.04	-.24*	-.40**	-.36**	-.17	-.07
5. Staff Behaviors				-	.25*	.52**	.35**	-.11	.05	-.01	.07	-.06	-.17	.08	-.23
6. Parent Roles					-	.36**	.38**	.02	-.18	-.07	-.28**	-.16	-.11	-.09	.23*
7. Communication						-	.39**	-.03	-.01	-.01	-.22	-.12	-.23	.09	-.04
8. Child Behaviors/ Emotions							-	-.01	-.09	-.18	-.15	.17	.03	-.10	-.13
9. Coping I								-	.50**	.57**	.02	-.00	.18	-.17	.08
10. Coping II									-	.59**	.16	.18	.24*	.07	-.27*
11. Coping III										-	.17	-.03	.16	-.02	-.02
12. Parent's Age											-	.33**	.37**	.65**	-.07
13. Education												-	.62**	.24*	-.012
14. Income													-	.19	.17
15. Child's age														-	-.02
16. Illness severity															-

*Correlation is significant at the 0.05 level
**Correlation significant at the .01 level

For the total stress score and each of the three coping subscale scores, hierarchical multiple regression was conducted to determine the joint and independent influences of parent demographic variables (Race, Ethnicity, education, income, gender, & age) as the first block and child demographic and clinical variables (age, planned admission, previous admission, and acuity score) as the second block using simultaneous entry for both blocks. Dummy coding was used for Race (White / Other), Ethnicity (Not Hispanic / Hispanic) and sex of the parent (Female / Male), with White, Not Hispanic, and Female as reference categories (coded 0); for Planned admission and Previous hospitalization (No / Yes), the reference category was No (coded 0). Parental income and education were collapsed to 4 ordinal categories. For education, categories were: Less than high school diploma, high school diploma / GED, some college, and bachelor's degree or higher. For income, categories were in intervals of $25,000/year with the lowest category < $25,000 and the highest category > $75,000. For each of the 4 dependent variables, the parent block was entered first, followed by the child block.

For the PSS:PICU, the parent block, by itself, did not account for significant variance in the total score. However, the full model (parent + child block) together accounted for approximately 19% of variance (after adjustment) in the total stress score at a statistically significant level and with statistically significant change in R-square (Table 13). For the full model, income and planned admissions were significantly and negatively associated with stress. Examination of unstandardized coefficients indicated that the independent effect of income, holding the other variables constant, was an approximate 9 point decrease for each $25,000 increase in income, and the independent effect of a planned admission was a decrease of approximately 19 points in the total stress score. Beta coefficients for race and parental age were similar in magnitude, but did not reach statistical significance.

Table 13

Regression of PSS:PICU Total Stress Score on Parent Demographic and Child Demographic and Clinical Variables (n = 55)

	R^2	R^2_{adj}	B	SE	β	*t*	F	df	*p*	95% CI	
										Lower	Upper
Model 1	0.157	0.052					1.49	(6, 48)	.201		
(Constant)			112.42	18.37		6.12			<.001	75.48	149.35
Race			-8.18	11.33	-0.14	-0.72			.474	-30.97	14.60
Ethnicity			-18.10	11.40	-0.28	-1.59			.119	-41.01	4.81
Education			-2.35	5.02	-0.09	-0.47			.642	-12.45	7.74
Income			-5.72	4.43	-0.24	-1.29			.203	-14.62	3.19
Gender of Parent			11.40	8.91	0.19	1.28			.207	-6.52	29.31
age of parent			-0.30	0.49	-0.10	-0.61			.544	-1.29	0.69
Model 2*	**0.337**	**0.186**					**2.23**	**(10, 44)**	**.033**		
(Constant)			127.59	19.56		6.52			<.001	88.17	167.01
Race			-20.35	11.55	-0.34	-1.76			.085	-43.62	2.92
Ethnicity			-14.00	10.86	-0.21	-1.29			.204	-35.89	7.90
Education			-0.88	4.74	-0.03	-0.18			.854	-10.44	8.69
Income			**-8.98**	**4.37**	**-0.38**	**-2.05**			**.046**	**-17.80**	**-0.17**
Gender of Parent			14.77	8.35	0.24	1.77			.084	-2.06	31.60
Age of Parent			-0.98	0.65	-0.34	-1.51			.139	-2.29	0.33
Age of child (months)			0.04	0.08	0.11	0.56			.581	-0.11	0.20
Planned Admit			**-18.73**	**7.61**	**-0.34**	**-2.46**			**.018**	**-34.06**	**-3.40**
Prior Hospital			15.23	7.85	0.27	1.94			.059	-0.59	31.04
Acuity			6.89	4.23	0.22	1.63			.110	-1.63	15.42

***Δ R^2 = .179, F (4, 44) = 2.97, p = .029**

For Coping Pattern I (Family Integration), parent level variables accounted for approximately 18% of score variance (p = .012), with significant independent contributions of income and parent gender (Table 14). Each $25,000 increase in income was associated with an approximate 3 point increase in scores. On average, scores for fathers were approximately 7 points less than for mothers. Adding the child level variables significantly increased explained variance. The effects of income and parent gender were comparable to their independent contributions to the parent level alone. The only other significant predictor for the full model was the age of the child; Each year of age was associated with an approximate 0.6 point decrease in scores, holding the other variables in the model constant. Beta coefficients for income, parent gender, and child age were similar in magnitude. Overall, the full model accounted for approximately 28% of score variance in family integration scores after R-square adjustment.

Table 14

Regression of CHIP Coping Pattern I (Family Integration) on Parent Demographic and Child Demographic and Clinical Variables (n = 58)

	R^2	R^2_{adj}	B	SE	β	*t*	F	df	*p*	95% CI	
										Lower	Upper
Model 1	**0.267**	**0.181**					**3.099**	**(6, 51)**	**0.012**		
(Constant)			33.29	4.56		7.31			<0.001	24.15	42.44
Race			0.75	2.88	0.04	0.26			0.795	-5.03	6.53
Ethnicity			0.54	2.95	0.03	0.18			0.855	-5.39	6.47
Education			-0.57	1.30	-0.08	-0.44			0.660	-3.19	2.04
Income			**3.03**	**1.17**	**0.44**	**2.58**			**0.013**	**0.67**	**5.39**
Gender of Parent			**-7.61**	**2.31**	**-0.42**	**-3.30**			**0.002**	**-12.25**	**-2.98**
Age of parent			-0.10	0.12	-0.12	-0.82			0.414	-0.33	0.14
Model 2*	**0.408**	**0.282**					**3.237**	**(10, 47)**	**0.003**		
(Constant)			32.85	5.01		6.56			<0.001	22.77	42.93
Race			-0.90	2.79	-0.05	-0.32			0.747	-6.52	4.71
Ethnicity			0.77	2.81	0.04	0.27			0.785	-4.88	6.43
Education			-1.15	1.24	-0.15	-0.93			0.357	-3.64	1.34
Income			**3.28**	**1.16**	**0.48**	**2.83**			**0.007**	**0.95**	**5.62**
Gender of Parent			**-7.55**	**2.17**	**-0.42**	**-3.47**			**0.001**	**-11.92**	**-3.17**
Age of Parent			0.17	0.16	0.21	1.08			0.284	-0.15	0.50
Age of child (months)			**-0.05**	**0.02**	**-0.42**	**-2.47**			**0.017**	**-0.09**	**-0.01**
Planned Admit			-3.48	1.92	-0.22	-1.81			0.077	-7.35	0.39
Prior Hospital			-0.72	2.05	-0.04	-0.35			0.726	-4.85	3.41
Acuity			-1.60	1.09	-0.17	-1.46			0.151	-3.80	0.60

***ΔR^2 = .141, F (4, 47) = 2.79, p = .037**

For Coping Pattern II (Social Support), the parent level variables did not account for statistically significant score variance, but addition of the child level variables was associated with a statistically significant increase in explained variance. The full model (parent + child level) accounted for approximately 26.5% of variance after adjustment (Table 15). Income was associated with an approximate 4 point increase in scores for each $25,000 increment. The independent effect of parent gender was an approximate 7 point decrease in scores for male compared with female parents, and each level increase in the child's acuity was associated with an approximate 4 point decrease in scores, holding the other variables in the model constant. Income had the largest standardized independent effect ($\beta = .51$); the beta coefficients for parent gender and child acuity were similar ($\beta = -.31$ to $-.34$). The standardized effects of parent age and child age were comparable in absolute value to the effects of parent gender and acuity, but neither made a statistically significant contribution to the overall model.

For Coping Pattern III (understanding the situation), neither the parent level nor the child level variables made a statistically significant contribution (Table 16). However, compared with female parents, male parents had significantly lower scores, on average, approximately 4 points less; and the difference was approximately the same magnitude for the parent level variables alone or the full model. Across all 4 dependent variables, the most consistently observed statistically significant effects were for income (less stress, improved coping) and parent gender (lower coping scores for male parents).

For all regression models for all 4 dependent variables, regression diagnostics were satisfactory. Variable Inflation Factors were all between 1.0 and 3.0 and Tolerance statistics were all greater than .29, suggesting no substantial multicollinearity. Durbin-Watson statistics were all close to 2.0 (± 0.3), indicating that residuals were uncorrelated. The number of standardized residuals > 2 for any model was either 0 or 1, and residuals plots did not suggest any serious departure from normality or from homoscedasticity.

Table 15

Regression of CHIP Coping Pattern II (Social Support) on Parent Demographic and Child Demographic and Clinical Variables (n = 58)

	R^2	R^2_{adj}	B	SE	β	*t*	F	df	*p*	95% CI	
										Lower	Upper
Model 1	0.212	0.114					2.16	(6, 48)	0.064		
(Constant)			19.71	6.53		3.02			0.004	6.58	32.83
Race			-3.09	4.22	-0.14	-0.73			0.468	-11.58	5.40
Ethnicity			0.73	4.59	0.03	0.16			0.874	-8.49	9.95
Education			-0.22	2.02	-0.02	-0.11			0.915	-4.28	3.85
Income			3.09	1.63	0.35	1.90			0.063	-0.18	6.36
Gender of Parent			**-6.88**	**3.40**	**-0.29**	**-2.02**			**0.049**	**-13.72**	**-0.04**
Age of parent			-0.03	0.17	-0.03	-0.19			0.853	-0.37	0.31
Model 2*	**0.401**	**0.265**					**2.95**	**(10, 44)**	**0.006**		
(Constant)			18.83	7.16		2.63			0.012	4.39	33.26
Race			-2.35	3.95	-0.10	-0.59			0.555	-10.31	5.61
Ethnicity			0.18	4.21	0.01	0.04			0.966	-8.30	8.66
Education			-1.58	1.88	-0.15	-0.84			0.405	-5.37	2.21
Income			**4.44**	**1.58**	**0.50**	**2.81**			**0.007**	**1.26**	**7.63**
Gender of Parent			**-7.32**	**3.13**	**-0.31**	**-2.34**			**0.024**	**-13.63**	**-1.01**
Age of Parent			0.33	0.23	0.31	1.47			0.149	-0.12	0.79
Age of child (months)			-0.05	0.03	-0.34	-1.88			0.067	-0.11	0.00
Planned Admit			1.73	2.65	0.08	0.65			0.516	-3.60	7.06

Prior Hospital			-3.79	2.80	-0.18	-1.36			0.182	-9.43	1.85
Acuity			**-4.01**	**1.49**	**-0.34**	**-2.70**			**0.010**	**-7.00**	**-1.01**

***Δ R^2 = .189, F (4, 44) = 3.48, p = .015**

Table 16

Regression of CHIP Coping Pattern III (Family Integration) on Parent Demographic and Child Demographic and Clinical Variables (n = 58)

	R^2	R^2_{adj}	B	SE	β	*t*	F	df	*p*	95% CI	
										Lower	upper
Model 1	0.183	0.081					1.79	(6, 48)	0.120		
(Constant)			12.39	3.12		3.97			0.000	6.11	18.67
Race			2.49	1.99	0.24	1.25			0.216	-1.50	6.48
Ethnicity			-0.14	2.18	-0.01	-0.06			0.950	-4.51	4.24
Education			-1.07	0.84	-0.24	-1.27			0.210	-2.77	0.63
Income			1.33	0.76	0.32	1.74			0.088	-0.21	2.86
Gender of Parent			-3.90	1.55	-0.35	-2.51			0.016	-7.02	-0.77
Age of parent			0.07	0.08	0.14	0.92			0.360	-0.08	0.23
Model 2*	0.282	0.118					1.72	(10, 44)	0.105		
(Constant)			10.55	3.52		3.00			0.004	3.46	17.64
Race			1.98	2.03	0.19	0.98			0.334	-2.11	6.08
Ethnicity			-0.17	2.18	-0.02	-0.08			0.939	-4.56	4.22
Education			-1.42	0.84	-0.32	-1.69			0.098	-3.12	0.27
Income			1.48	0.80	0.36	1.86			0.070	-0.12	3.09
Gender of Parent			-4.19	1.54	-0.38	-2.73			0.009	-7.29	-1.10
Age of Parent			0.25	0.11	0.48	2.31			0.025	0.03	0.47
Age of child (months)			-0.03	0.01	-0.39	-2.07			0.044	-0.06	0.00
Planned Admit			-0.62	1.34	-0.06	-0.47			0.644	-3.33	2.08
Prior Hospital			-1.58	1.39	-0.16	-1.13			0.264	-4.39	1.23
Acuity			-0.52	0.78	-0.09	-0.67			0.508	-2.10	1.05

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*$\Delta R^2 = .098$, $F(4, 44) = 1.51$, $p = .217$

CHAPTER V

DISCUSSION

The purpose of this exploratory pilot study was to examine parental stress and coping in a diverse group of families experiencing hospitalization of their child in a pediatric intensive care unit. McCubbin and McCubbin's (1993) Resiliency Model of Family Stress, Adjustment, and Adaptation served as the theoretical model for the conceptualization of stress and coping. Data analysis involved both descriptive and inferential statistics to answer the following research questions:

1. What stressors do parents identify when their child is critically ill (using the PSS:PICU), and do stressors differ between mothers and fathers?
2. What coping strategies do parents identify when their child is critically ill (using the CHIP) and do coping strategies differ between mothers and fathers?
3. What are the joint and independent influences of parent demographic variables (race/ethnicity, socioeconomic status [income and education], age, and gender) and child demographic and clinical variables (age, planned versus unplanned admission, prior hospitalization, and illness severity) on parental stress and coping?

This chapter is organized around the following topics of discussion: interpretation of findings, evaluation of the study model, strengths, limitations, implications for nursing practice, and recommendations for future research.

Interpretation of the Findings

This section provides a discussion of the findings from the study. The findings of this exploratory study both confirmed previous research as well as provided new information.

Description of Parental Stressors for All Parents

Stress in this study was measured by the Parental Stressor Scale: PICU (Miles & Carter, 1983). It has been utilized extensively to describe parental stressors in the PICU and is comprised of a total stressor score and seven subscales: appearance, environment, procedures, staff behaviors, parenting roles, staff communication, and child behaviors. In addition, one open- ended question was asked of parents and will be discussed at the end of this section.

Parents reported the following subscales from most to least stressful: parent roles, child behaviors/emotion, appearance, sights and sounds, procedures, staff communication, and staff behaviors. Alteration of parenting role (Eberly et al., 1985; LaMontange & Pawlack, 1990; Miles & Carter, 1982, 1983) and staff communication (Eberly et al, 1985; Youngblut & Jay, 1991) have consistently been identified as the greatest sources of distress to parents. In the current study, alteration of the parenting role was rated as the top stressor; however, staff communication was rated as sixth. One possible explanation for this may be that over the past 30 years, the adoption of family centered care (FCC) has become increasingly widespread in pediatric institutions and is viewed, by many, as one of the most important movements in pediatric care for the 21st century (Frazier, Frazier, & Warren, 2010). Historically, parents were not encouraged to participate in their child's care and the PICU had extremely restrictive visitation hours. Family-centered care, in essence, acknowledges the central role of the family in the delivery of health care to pediatric patients and is defined as an "approach to the planning, delivery, and evaluation of health care that is governed by mutually beneficial partnerships between health care providers, patients, and families" (Institute for Family-Centered Care, 2004). One of the main tenets of FCC is to facilitate collaboration among patients, family members, and providers in all aspects of the delivery of care (Institute for Family-Centered Care, 2004).

The subscale means in this study were higher than previous studies (Haines, Perger, & Nagy, 1995; Youngblut, Brooten, & Kuluz, 2005). Technology has evolved during the past thirty years and children are surviving illnesses and accidents that they otherwise would not have survived, even just a few years ago. Data for this study were collected at the only freestanding children's hospital in a southwestern state. Both the higher acuity in the hospital and the changes in healthcare technology may be responsible for the increase in mean stressor scores for parents involved in this study.

Although not typically reported in the literature, the individual scale items were examined to provide additional information regarding stressors as well as to provide further information to determine the usefulness of the instrument. Parents identified the following individual stressors as most stressful: sudden sounds of monitor alarms, acting or looking like in pain, tubes in my child, and not being able to hold my child. Conversely, parents identified the following stressors as least stressful: staff behaviors, such as joking and not stating their names; staff communication, such as explaining things too fast and not talking to me enough; and child behaviors such as demanding behavior or anger. It is apparent that both the environment and parental role continues to be a stressor for parents.

It is interesting to note that staff behaviors and staff communication have become less of a stressor. This information may be useful in revising the instrument. Child behaviors such as demanding behavior and/or anger scored very low. Given the acuity of children in the PICU today versus when this instrument was developed, these sorts of behaviors may no longer be relevant and it may be worthwhile to examine whether these types of behaviors occur in the PICU or do they occur after transfer to the pediatric units. The other issue with the instrument is the low reliability with the appearance subscale. This is the first study to report such a low reliability; however, there are only three items in the particular subscale. One explanation for this may be that the questions asked may be inappropriate. Advances in technology have allowed healthcare professionals to better control many aspects of a child’s physiological state and thus, parents may not witness color changes in their child or may not view color and changes in color as stressful. For example, poor perfusion can be improved with medications and temperature can controlled with either warming or cooling blankets. In fact, children with illnesses may have, at baseline, an abnormal color (children with cyanotic congenital heart defects normally have bluish color to their lips and skin etc). Also, a majority of the children had been previously hospitalized, so it is plausible that the parents rated appearance as less stressful since they were familiar with their child’s experience in the PICU.

In addition to the PSS:PICU, two open-ended question were asked of parents completing the surveys: (1) *Why is your child in the PICU* and (2) *In your own words, what is the most stressful aspect of the PICU?* The majority of participants (n = 75) responded to the open-ended questions. According to their responses, all parents correctly identified why their child was in the PICU. Parents identified the following content areas that parents as stressful: uncertainty, helplessness, child's pain/discomfort, equipment, and nursing interventions.

One-third of parents responded that it was very stressful "not knowing" the diagnosis, treatment, or outcome. One parent stated "not knowing when it will end and not being able to do anything to help her recovery" while another parent also stated "not knowing if she will survive; pneumonia is typically the cause of death for children with MLD." The parents' statements reiterated the parental themes of uncertainty and helplessness. The notion of uncertainty surrounding a child's critical illness has briefly been discussed and the recent research on interventions (Melnyk, Alpert-Gillis et al., 2004) has not included any measure of parental uncertainty as a source of stress. *Illness uncertainty* was first defined by Mishel (1981, 1984) and is a complex concept that results from an illness-related experience that is characterized by ambiguity such as unpredictability of symptoms, perceived lack of information about the medical condition, and perceived lack of clarity regarding possible treatment outcomes. Mishel (1984) further suggested that illness uncertainty may impede one's analysis of the medical event and prevent adaptive coping strategies resulting in higher levels of distress and decreased psychosocial functioning.

Research addressing parental uncertainty was primarily performed on parents of chronically ill children (Bonner et al., 2006; Grootenhuis & Last, 1997; Mu, 2005; Mu, Ma, Hwang, & Chao, 2002; Mu, Ma, et al., 2001; Mu, Wong, Chang, & Kwan, 2001). However, a few researchers have examined parental uncertainty in parents of critically ill children (Kirschbaum, 1990; Scott, 1998; Tomlinson, Kirschbaum, Harbaugh, & Anderson, 1998). The results found in the current study supported findings from previous studies on parental uncertainty. Medical advances during the past 30 years have made it possible for children to survive illnesses and injuries they would have otherwise not survived; resulting in greater acuity, prolonged hospitalization, and greater exposure of parents to uncertainties and stress (Tomlinson et al., 1999). Nurses spend a substantial amount of time with parents and can contribute to parents' perceptions of uncertainty (Mischel, 1988). In fact, Kirschbaum (1990) recommends that parents are updated by the nurse frequently and by the physician on a daily basis in language and terms that are easy to understand.

Nearly one-third of parents reported that not being able to hold, comfort, or relieve their child's pain as the most stressful aspects of the PICU. One parent stated "keeping her comfortable, trying to figure out why she is crying, where her pain is, keeping her calm" while another parent stated "not being able to do anything for my child. Not being able to hold my child". This confirms both the previous research as well as the findings from the PSS:PICU in the current study. However, it would be interesting to note whether parental stress related to a child's discomfort decreases if nurses provide the parent with educational information. The educational information involves many non-invasive interventions which encourage a parent to either distract their child or, if the child is medically sedated and paralyzed, hold their child’s hand, read to the child, and so forth.

Equipment continues to be identified as a major stressor reiterated by one parent’s statement, “Everything in this unit scares me, even in the room. The machine he’s hooked on, all the tubes that are running into him, just everything, even the sound of the machines scare me. Not being able to hold him because of all the tubes”. This has also been recognized in the literature supporting the findings from the PSS:PICU in the current study. Again, it would be interesting to examine whether the major stressor of equipment could be decreased with educational information or to examine if it is an inherent stressor in the PICU.

Nursing interventions were identified as being very stressful by only a few parents. Parents stated “when the nurses do things that make my baby cry” or “when the IV specialist shoved an IV in his head when she said she was just looking”. Nursing interventions may be medically essential, at the same time making a child uncomfortable. For example, suctioning or starting an intravenous line may cause the child discomfort and be inherently stressful procedures in the PICU or it may be related to a lack of parental understanding or communication between the nurse and parent. Parental uncertainty decreases with information and it would be interesting to note whether parents’ perceptions of nursing interventions would change if parents were educated about and understood the reason behind the interventions.

Stressor Differences between Independent Parents

Data analysis of the independent mothers and fathers indicated there were no statistically significant differences in parental stressor subscales or total stressor score. Although no significant statistical differences were found, fathers' total stress scores were slightly higher than mothers' scores and there were small differences between mothers and fathers. Mothers rated the sights and sounds as more stressful than fathers, whereas, fathers rated that procedures were more stressful than mothers.

The individual items of all parents were further examined to provide additional information as to the specific stressors identified by mothers and fathers of critically ill children (see Appendix A). In terms of specific individual items, mothers reported the following as most stressful: acting or looking as if in pain, the sudden sound of monitor alarms, tubes in my child, and not being able to hold my child. Fathers reported the following individual items as most stressful: the sudden sound of monitor alarms, not being able to hold my child, tubes in my child, and acting or looking as if in pain. Interestingly, fathers rated many of the items more stressful than mothers.

Although the current study's sample size was small, it does have a higher proportion of fathers and partnered mothers and fathers. Previous researchers have found conflicting results on gender differences and stress: no differences between mothers and fathers (Miles et al., 1984), fathers experiencing more stress than mothers (Heuer, 1993; Johnson, Nelson, & Brunnquell, 1988), and mothers experiencing more stress than fathers (Graves & Ware, 1990; Younblut, Brooten, & Kuluz, 2005). Youngblut, Brooten, & Kulutz (2005) reported mothers experienced statistically significantly higher stress scores on three of the seven subscales (child's behavior and emotions, staff communication, and parental role). However, in the present study, on average, after accounting for all other variables in the model, total stress scores for men were, on average, almost 15 points higher than for women (14.8 points, 95% CI -2.1 to 31.6; Table 13). The width of the 95% CI is consistent with a large standard error. Thus, it may be the case that, although the sample size was sufficient for the model as a whole to be statistically significant, it may not have had adequate power for some coefficients to be statistically significant.

Stressor Differences between Partnered Parents

Data analysis of the partnered mothers and fathers indicated there were no statistically significant differences in parental stressor subscales or total stressor score. This is consistent with the findings of independent mothers and fathers. It implies that other variables, such as income, race/ethnicity, or perhaps unmeasured variables, may impact partnered parents identification of stressors to a greater extent than parental gender.

Coping Strategies and Differences between Parents

Coping in this study was measured by the Coping Health Inventory for Parents (CHIP) (McCubbin & McCubbin, 1983) which has been utilized extensively to examine coping strategies in parents of a chronically ill child (McCubbin et al, 1996, p. 432). The CHIP is composed of three coping patterns: Coping Pattern I which includes strategies aimed at maintaining family integration, cooperation and an optimistic definition of the situation; Coping Pattern II which includes strategies aimed at maintaining social support, self-esteem, and psychological stability; and finally, Coping Pattern III which includes strategies aimed at understanding the health care situation through communication with other parents and consultation with medical staff.

Coping Differences between Independent Mothers and Fathers

The sample of independent mothers and fathers found the coping strategies associated with family integration to be most helpful, followed by strategies aimed at social support. Mothers and fathers identified coping strategies aimed at understanding the medical situation through communication to be the least helpful pattern. Although mothers and fathers ranked each of the coping patterns similarly in helpfulness, mothers were statistically significantly more likely than fathers report or rate as helpful strategies aimed at maintaining family integration and social support. Fathers consistently found the coping patterns less helpful than mothers. Tamres, Janicki, & Helgeson (2002), in a meta-analysis of sex differences in coping, also found that women reported greater use of coping behaviors than men. The results of this study, combined with previous research, lead the author to believe that researchers and health care providers do not adequately understand fathers' coping. The instruments to measure parental coping were developed with a sample of mothers and researchers may not even have the tools necessary for evaluating fathers' coping. For example, both mothers and fathers found Coping Pattern I was the most helpful, followed by Coping Pattern II, and finally, Coping Pattern III; however, fathers consistently found the Coping Patterns to be less helpful than mothers found them.

Second, the Coping Pattern III (understanding the medical situation through communication) received a marginal Cronbach alpha, and was not significantly predicted by the parent level variables or by the full model. It could be possible that this subscale does not adequately measure what it is supposed to measure.There may also be differences in ability to access information (for example, internet) or expectations of communication (collaborative versus authoritarian). When both of the instruments were developed nearly two decades ago, communication between parents and healthcare providers may be different. Lastly, it may be that attempts to understand the situation are less relevant to parents of children in a PICU compared to parents of a child with a chronic condition.

The results of this study indicated that the mean score (M = 77.3) for the total CHIP scale was slightly lower than both Saied's (2004) study in parents of critically ill children and McCubbin et al. (1996) study in chronically ill children. The mean score for Coping Pattern I was also slightly lower in this study than in previous studies (Cavallo, Feldman, Swaine, & Meshefedjian, 2009; McCubbin et al, 1996; Saied, 2004). The mean scores for Coping Pattern II and Coping Pattern III are consistent with Saied's results, yet lower than Cavallo and colleagues (2009). Cavallo et al. (2009) recently reported higher subscale means (M = 40.1) for Coping Pattern II in comparison with the current study (M = 33.0). Several explanations for this phenomenon may be plausible. Parents of critically ill children in the PICU are at near panic levels of anxiety and are using any method possible to understand the situation and are hoping and praying for their child's survival (Youngblut, Brooten, & Kuluz, 2005). It may be challenging for parents in the PICU to develop relationships with other parents in similar situations. The parent might not know or accept their child’s outcome and parents in similar situations may be difficult to identify or not even be present in the PICU during the same time period. On the other hand, many parents of chronically ill children are involved in support groups and require various levels of social support to cope with the reality of day-to-day life. While in the PICU, parents are trying to cope with the uncertainty of their child’s outcome and hoping for the best possible outcome. They are using any method possible to understand the situation; whereas parents of chronically ill children already understand the medical situation and to cope with the reality of day-to-day life, require coping strategies aimed at maintaining social support, self esteem, and psychological stability.

To further explore the coping strategies used by parents, the individual items in the CHIP were examined. Interestingly, mothers and fathers identified similar coping strategies; however, fathers consistently reported that the strategies were less helpful than mothers reported. Parents found the following individual coping strategies most helpful: believing that my child is getting the best medical care possible, believing my child will get better, believing that the hospital has my family’s best interest in mind, and talking with the doctor about my concerns. Parents found the following individual coping strategies least helpful: entertaining friends in our home, purchasing gifts for myself or family members and involvement in social activities with friends. It may be more reasonable to expect that a parent of a child with a chronic illness entertains friends or participates in social activities, whereas, parents of a critically ill child are unable to socialize or find socializing as helpful coping strategies.

Differences in Coping Strategies between Partnered Mothers and Fathers

Statistical analysis revealed that there was no significant differences in coping strategies between mothers and fathers who are partners (n = 19). This suggests that mothers and fathers in the same household use similar coping strategies. This has not been previously reported in the literature and needs to be re-examined in a larger sample; however, the results from this study provide a preliminary foundation for future research to understand coping in parents of critically ill children.

Effect of Demographic Variables on Parental Stress and Coping

This section provides a discussion of the effect of key parent and child demographic variables on parental stress and coping strategies. The parent demographic variables that were examined include: age, race/ethnicity, education, income, and gender. The child demographic and clinical variables include: child age, planned admission, prior hospitalization, and nursing acuity.

Correlations of the study variables were first used to examine if any relationships exists between the major study variables. Correlations between the demographic variables, the stressor scores (total score and subscale scores) and the coping patterns were analyzed. In terms of parent demographic variables, there were some statistically significant relationships between parent education, age, and income and stressor scores and coping scores. Parental age was weakly negatively correlated with two of the stressor subscales (procedures and parent role) meaning that as parents age, the stress associated with their child receiving procedures and the alteration of parental role decreases. Parent education was negatively correlated with two of the stressor subscales (sights and sounds and procedures) which indicates that as education increases, parents find the sights and sounds of the ICU less stressful and they also find procedures on their child less stressful. Income was negatively correlated with procedures and positively correlated with Coping Pattern II scores which indicate that as income increases, parents find procedures less stressful and use more coping strategies related to social support. The only child demographic and clinical variable that was statistically significant was illness severity. Illness severity was positively correlated with parent roles and negatively correlated with Coping Pattern II which indicates that the higher the child's acuity, the less useful they find coping strategies related to social support.

There are several explanations why these relationships may have occurred. As parent's age, they may have had the opportunity to pursue additional education which may assist them in understanding the reason for the various procedures and their role change. As education increases, parents are able to better understand why certain procedures are being performed on their child. Age and education may also impact the level of communication between the nurses and physicians and the parent. In many cases education and income and education are linked together. This is especially true when discussing differences between obtaining a high school diploma versus obtaining an undergraduate 4 year degree. According to the U. S. Census Bureau (2002), the average income was $25,900 for a high school graduate, $45,400 for a college graduate, and nearly $100,000 for those with professional degrees. In the current study, education and income were strongly correlated (r = .62). Finally, in terms of illness acuity, there was only a weak positive relationship between acuity and parental role stress, possibly because as the child’s illness acuity increases, so does the nursing presence and, hopefully, communication between nurses and parents. Parents may be more stressed about other aspects, such as uncertainty regarding their child’s outcome, guilt, and so forth. There was a weak negative relationship between acuity and Coping Pattern II, suggesting that parents find social support less useful for coping as acuity increases.

Effect of Demographic Variables on Parental Stress

The examination of demographic variables on the total parental stressor score was performed on the sample of independent mothers and fathers (n = 55). The parent demographic variables and child demographic and clinical variables were entered into a regression model. The final model accounted for nearly 19% of the variance in total stressor score. Income and whether the admission was planned accounted for significant portions of the variance, with both increasing income and planned admission being associated with significantly less stress. Parent gender, race, and whether the child had been previously hospitalized were associated with substantial differences in total stress scores, but that did not reach statistical significance. Compared with mothers, fathers reported greater stress on average. Compared with White parents, parents of other races reported less stress on average, and a history of prior hospitalization was associated with greater stress.

A large body of evidence suggests that individuals in low socioeconomic environments experience a disproportionate burden of stressful life conditions (Lynch, Kaplan, & Salonen, 1997; Ross & Wu, 1996). Socioeconomic status, income in particular, appears to play an important role in identification of stressors during a child’s critical illness. Vandsburger & Biggerstaff (2004) utilized the ABCX Model to study the effect of economic pressure and family functioning and found that the experience of economic pressure is negatively associated with family functioning and that race/ethnicity was a significant variable in predicting stressor scores. There is a paucity of information regarding racial/ethnic differences in stress appraisal; however, the present study provides preliminary evidence that stress appraisal may be more related to socioeconomic status than race or ethnicity. However, it should be noted that the effects of race and ethnicity on total stress in the present study were relatively large, albeit not statistically significant. Moreover, the direction of the relationship was negative (i.e., Whites and non-Hispanics had higher total stress scores on average than Non-Whites or Hispanics)

Effect of Demographic Variables on Parental Coping

The examination of demographic variables on the coping subscales was performed on the sample of independent mothers and fathers (n = 55).The parent and child demographic variables of the independent mothers and fathers were entered into a regression model. The parent and child demographic variables significantly impacted coping strategies, specifically Coping Patterns I and II, used by parents. For Coping Pattern I, the parent variables accounted for 18% of adjusted score variance, with parent gender and income as statistically significant predictors. In the full model, in addition to those two predictors, child age was statistically significant, but in practical terms the effect was small. It appeared that the statistical significance of child age was due largely to a very small standard error for the regression coefficient. Race/ethnicity, age of parent, education, planned hospitalization, previous hospitalization, and nursing acuity were not significantly related to Coping Pattern I, and beta coefficients for these variables suggested negligible contributions to explained variance of Coping Pattern I scores. For Coping Pattern II, the parent variables did not significantly predict the coping scores; however, adding the child demographic variables in the overall model did significantly predict coping scores. The overall model accounted for 27% of the adjusted score variance in Coping Pattern II scores. Income was positively associated with the social support coping pattern, and was the strongest predictor overall. Nursing acuity and being a father were negatively ssociated with this coping pattern. Parent age was positively associated with social support coping, and the beta coefficient for parent age was approximately equal in absolute value to the beta coefficient for gender. However, parent age was not a statistically significant predictor, and a 10 year difference in age was equivalent to less than half the difference between mothers and fathers. Race/ethnicity, education, age of child, previous hospitalization, and planned hospitalization were not significantly related to Coping Pattern II, and had small to negligible effects.

For Coping Pattern III, both the first model (parent demographic variables) and the overall model did not significantly predict parent coping scores. For the full model, parent age was positively and significantly associated with this coping pattern, whereas parent gender and the age of the child were negatively and significantly associated with Coping Pattern III. The strongest beta coefficient was for parent age, and the beta coefficient for child age was approximately equal to the beta coefficient for parent gender. However, unstandardized coefficients for parent age and child age were small. It would have taken an approximate 16 year age difference among parents of an 11 year age difference among children to achieve a socre difference equivalent to the difference between mothers and fathers in absolute value.

The results of this study suggest that parent gender significantly impacts Coping Patterns I and II. A substantial body of literature regarding sex differences supports this finding. However, several researchers assert that the study of coping is complex and that sex differences have not yet been established conclusively (Porter & Stone, 1995; Tamres, Janicki, & Helgeson, 2002; Thoits, 1991). Some researchers (Billings & Moos, 1981; Folkman & Lazarus, 1980; Hamilton & Fagot, 1988) suggest that women tend to use more emotion-oriented coping behaviors and to seek social support, whereas men use more problem-confronting coping behaviors or, alternatively, avoid or deny the stressor (Pearlin & Schooler, 1978; Stone & Neale, 1984). Although it is well-documented that women, have in the past, used emotion-focused coping strategies and seek out others for social support, it is unclear whether differences are innate or learned (Tamres, Janicki, & Helgeson, 2002). In fact, Rosario et al. (1988) proposes the role constraint theory in which sex differences in coping behaviors are more related to the different roles that men and women assume.

The results of this study suggest that income impacted Coping Patterns I and II. In contrast, education was not a significant predictor of stress or coping, and the standardized effect size (beta coefficients) for education were consistently much smaller than for income across both models for all four dependent variables. Socio-economic status (SES) may be an indication of the amount of resources available or the likelihood that an individual is able to accumulate resources (Ouwehand, de Ridder, & Bensing, 2009). Individuals living in a low-SES environment may be less able to process information and develop coping strategies because of the chronic exposure to difficult life circumstances. Researchers have suggested that people develop problem solving skills through education (Ross & Wu, 1988); however, evidence in the present study suggest thtat income was far more important than education in predicting stress and coping for parents of children hospitalized in a PICU.

Evaluation of the Resiliency Model

The Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin & McCubbin, 1993) was used as the conceptual framework for this study. It was developed in an attempt to explain why some families are more resilient and are able to adjust and adapt to stress and crises (McCubbin & McCubbin, 1993). Although researchers are beginning to understand the effects on parents of having a critically ill child, coping in parents of a critically ill child, remains less understood. However, the Resiliency Model does appear to theoretically explain many of the key components of coping. According to McCubbin & McCubbin (1993), coping is a coordinated problem-solving behavior of the whole family system that creates and maintains a balance between demands and stressors. To achieve bonadaptation, families must recognize that systemic changes are required to maintain stability in response to excessive demands and depleted resources (Tak & McCubbin (2002).

The findings from this study support the the premise that stress and coping is determined by many interacting factors (McCubbin & McCubbin, 1993). According to the results of this study, there does appear to be some protective effect of socioeconomic status, specifically income, which is consistent with the model, specifically family resistance resources or decreased vulnerability. Gender was the most consistent predictor of stress and coping in this study. There is some evidence that gender does play a role in how one appraises a stressor or patterns of functioning when a stressor occurs. Nursing acuity played a limited role in coping (Coping Pattern II; sociall support) which, according the model could be considered an aspect of stressor severity. The study variables that were significant in this study are outlined in Figure 7.

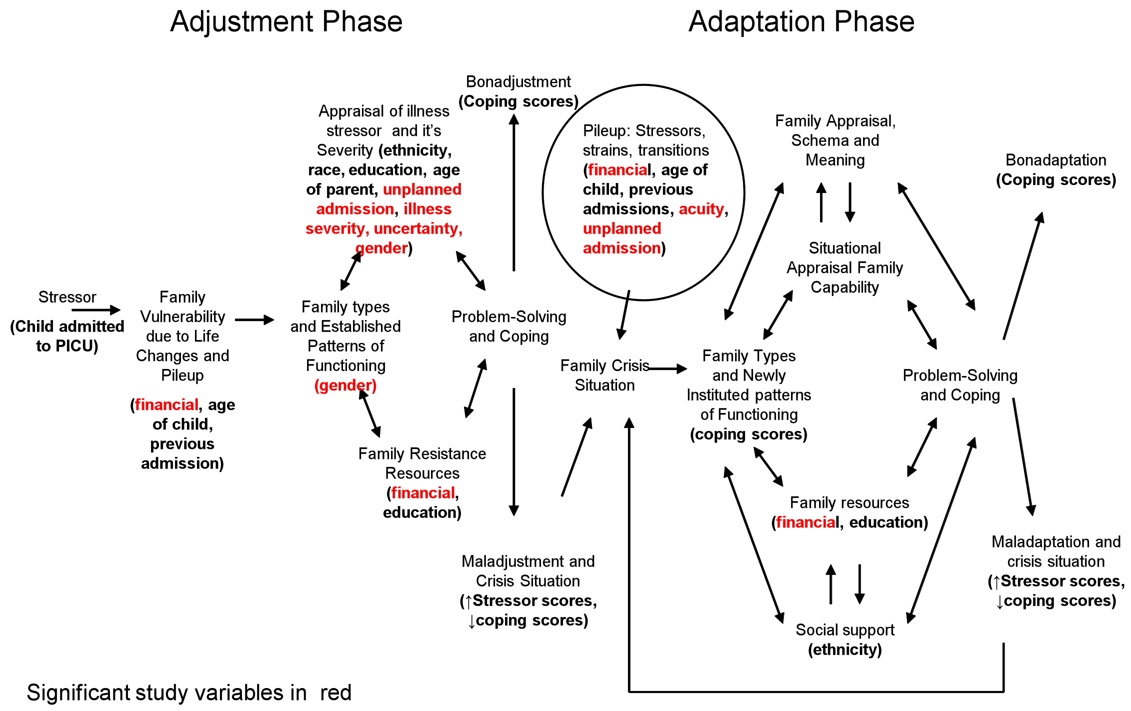


Figure 7. Application of Study Variables to Resiliency Model

Strengths of Study

The strengths of this study are related to the diversity of participants. The study site was a very large, well established children's hospital serving families from across the region. To the author's knowledge, this is one of the first studies to obtain a sample with a large percentage of parents reporting Hispanic race/ethnicity. It is one of the first studies on parental stress and coping in parents of critically ill children to enroll a significant number of fathers. It is one of the first studies to examine parental stressors and coping in parents of critically ill children and compare differences between mothers and fathers.

Limitations of Study

The main limitations of this study were related to sampling and instrumentation. A convenience sample (n = 86) was used, consisting of parents of critically ill children. The use of a convenience sample, although practical may limit the generalizability of the study results (Polit & Beck, 2004; Shadish, Cook, & Campbell, 2002). Also, the sample size was relatively small (n = 86) and may not have had adequate power to detect effects that might have been statistically significant in a larger sample. The study had adequate power to detect a statistically significant model that could explain a clinical significant amount of variance in stress or coping patterns, but may have resulted in some predictors associated with clinically meaningful differences in stress and coping failing to cross the threshold for statistical significance. The goal sample size was not achieved due to several issues. At this particular institution, a doctoral nursing student had never acted as a primary investigator. After relocating to a different state and terminating employment, access to the study site was no longer permitted. In addition, the use of a cross-sectional design was also a limitation; a longitudinal study would have described the trajectory of stress and coping over the duration of a child's critical illness revealing if variables associated with stress and coping change over time.

Both instruments have been utilized and tested extensively and demonstrate strong psychometric properties. However, both instruments were developed more than twenty years ago and significant changes have occurred in pediatric critical care. Although the PSS:PICU has been utilized recently as by Melnyk et al. (2004), it may not accurately measure the stressors experienced by parents in the PICU. Similarly, although the CHIP demonstrates strong psychometric properties, it has never been utilized in this specific population and may not measure the coping strategies utilized by parents while their child is critically ill. However, despite these limitations, the findings of the current study have important implications for nurses and other professionals who work with families of critically ill children.

Implications for Nursing Practice

The knowledge gained from this study adds to a limited body of knowledge regarding parental stressors experienced and coping strategies utilized during a child's critical illness. This study provides knowledge that assists healthcare providers to have a better understanding of the stressors that parents experience during their child's hospitalization in the PICU. The current study found that increasing income and parents whose child had a planned admission reported less stress. Nurses should consider that parents of lower socioeconomic status and parents of children whose hospitalizations were not planned to be at risk for greater stress while the child is in the PICU.

Previous researchers found that mothers and fathers differed significantly in their identification of stressors. However, this trend may be changing and healthcare providers must be prepared to communicate effectively with fathers of critically ill children. One of the areas frequently identified as a major stressor for parents was their child’s pain (Board & Ryan-Wenger, 2002; Seideman, 1997) and their inability to help their child. Responses to the open-ended questions and to the procedures and sights and sounds subscales of the PS:PICU in the present study are consistent with the premise that the child’s pain and parental feelings of helplessness are important stressors. Nurses need to provide parents with the necessary tools to empower them to care for their child during their PICU experience. This may include simple interventions, such as holding the child’s hand, reading a book, telling a story, talking softly, and so forth, that the parent can perform while at their child’s beside.

Improving parental coping is crucial to improving child and parent outcomes both during and after discharge. There is growing evidence to suggest that critically ill children develop more internalizing (for example, sadness, anxiety, depression, etc) and externalizing disorders (for example, oppositional defiant disorder, attention deficit hyperactivity disorder, etc) if their parent is stressed (Melnyk, Alpert-Gillis et al., 2004). There is also growing evidence to suggest that many parents, especially mothers, develop post-traumatic stress symptoms (PTSS) or post-traumatic stress disorder (PTSD) after their child has been discharged from the PICU (Baluffi et al., 2004; Melnyk, Alpert-Gillis et al., 2004; Rees et al., 2004). The stress that these parents continue to deal with affects not only the child who was critically ill, but the entire family including siblings, spouse, and so forth. This study adds to the paucity of research that exists regarding parental coping during a child's critical illness. This is the second study (Saied, 2004) that has demonstrated coping patterns utilized by parents of critically ill children. However, the results of this study suggest that healthcare providers and researchers do not understand fathers' coping as well as they understand mothers' coping. Understanding how parents cope with the various stressors will provide healthcare professionals with the knowledge required to support parents during their PICU experience. Nurses are in a unique situation to build relationships with parents and can offer suggestions on effective coping strategies. Parents need interventions aimed at maintaining family integration, cooperation, and an optimistic definition of the situation. Nurses can offer support and encourage parents to fulfill their own personal needs when possible (Katz, 2002). Parents require information aimed at encouraging social support strategies. Nurses can provide information to parents regarding the various organizations, both local and web based, to assist parents with their child's illness or injury.

Recommendations for Future Research

Based on the findings of this study, there are several areas in which future research should be focused. This section provides recommendations for future research in several key areas: instrumentation, research design, and interventions.

- Both of the instruments, PSS: PICU and CHIPS, need to be re-examined. First, each questionnaire's items need to be examined to make sure they are consistent with current practice and there may be items that either need to be added or removed due to the age of the instrument. Second, each instrument should be examined from a gender and/or role perspective.

- Parental stress and coping should be examined using a longitudinal mixed methods design which would identify the trajectory of parental stressors and coping strategies over time. A mixed methods design would enable investigators to identify stressors and coping strategies not addressed by the instruments. It would provide information on whether certain resources or interventions are more important at specific time points.
- Intervention studies are desperately needed for parents of a critically ill child. Interventions that improve communication between healthcare providers and parents need to be identified and examined. Other interventions, such as on-site support groups and activities for the parents may improve psychological functioning and need to be examined.
- Research should be aimed at understanding stress and coping in mothers and fathers from diverse backgrounds to examine the role of race/ethnicity, income, education, and so forth.
- More studies on both mothers and fathers are needed to understand whether the identification of stress and coping differences exist for partnered couples.
- Few studies have examined nurses’ perceptions of parental stress and coping. This area needs to be further developed so that misconceptions can be clarified and

nursing interventions can be developed aimed at assisting parents to cope with the PICU environment and parenting a critically ill child.

- Further research on the impact of parental uncertainty on stress and coping needs to be performed and whether improved communication and/or informational programs has any effect on stress and coping.

Conclusion

The purpose of this exploratory study was to explore parental stress and coping in a diverse group of families experiencing hospitalization of their child in a pediatric intensive care unit. McCubbin and McCubbin's (1993) Resiliency Model of Family Stress, Adjustment, and Adaptation served as the theoretical model for the conceptualization of stress and coping

Findings of this study indicated that parents rated the parent roles and child behaviors and emotions as the most stressful dimensions of their PICU experience. Mothers and fathers did not differ significantly in their rating of stress (total score or subscales). However, mothers and fathers ranked the individual items differently. Seeing their child in pain and feeling helpless was a common theme when parents were asked to describe their most stressful experience. Uncertainty about the child's outcome and how to cope at home was another common theme that parents identified as stressful.

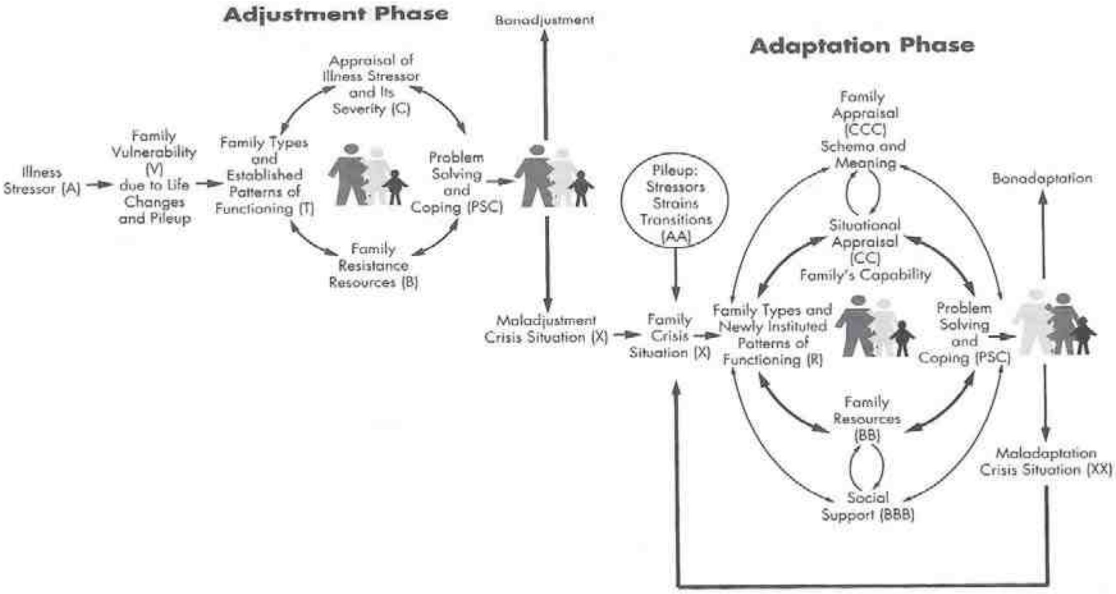
The participants in this study used the three coping patterns of CHIP in varying degrees to cope with their situation. Coping Pattern I, which involves family integration, cooperation and having an optimistic definition of the situation, was rated as more useful, and coping patterns pertaining to social support (Coping Pattern II) were also useful. In contrast, coping patterns related to attempts to understand the situation (Coping Pattern III) were less useful. This study provides further information regarding the impact of parent demographic and child demographic and clinical variables.

This study provides evidence that researchers understand mother's stress and coping better than they understand father's stress and coping. Significant advances have been made in terms of identifying what stressors parents experience, but there continues to be a critical need to develop interventions that are effective in either reducing parental stress or improving parental coping. In fact, almost a decade ago, Melnyk and colleagues issued an urgent call to action for more studies on interventions aimed at reducing parental stress and improve parental coping in the PICU. Unfortunately, to date, this has not occurred and the opportunity to improve the experience of the PICU continues to be unmet.

LIST OF APPENDICES

APPENDIX A

THE RESILIENCY MODEL OF FAMILY STRESS, ADJUSTMENT AND ADAPTATION



From *Families Health and Illness* (p. 23), by M. McCubbin & H. McCubbin, 1993, St. Loius: Mosby. Copyright (1993) by M. McCubbin. Reprinted with permission.

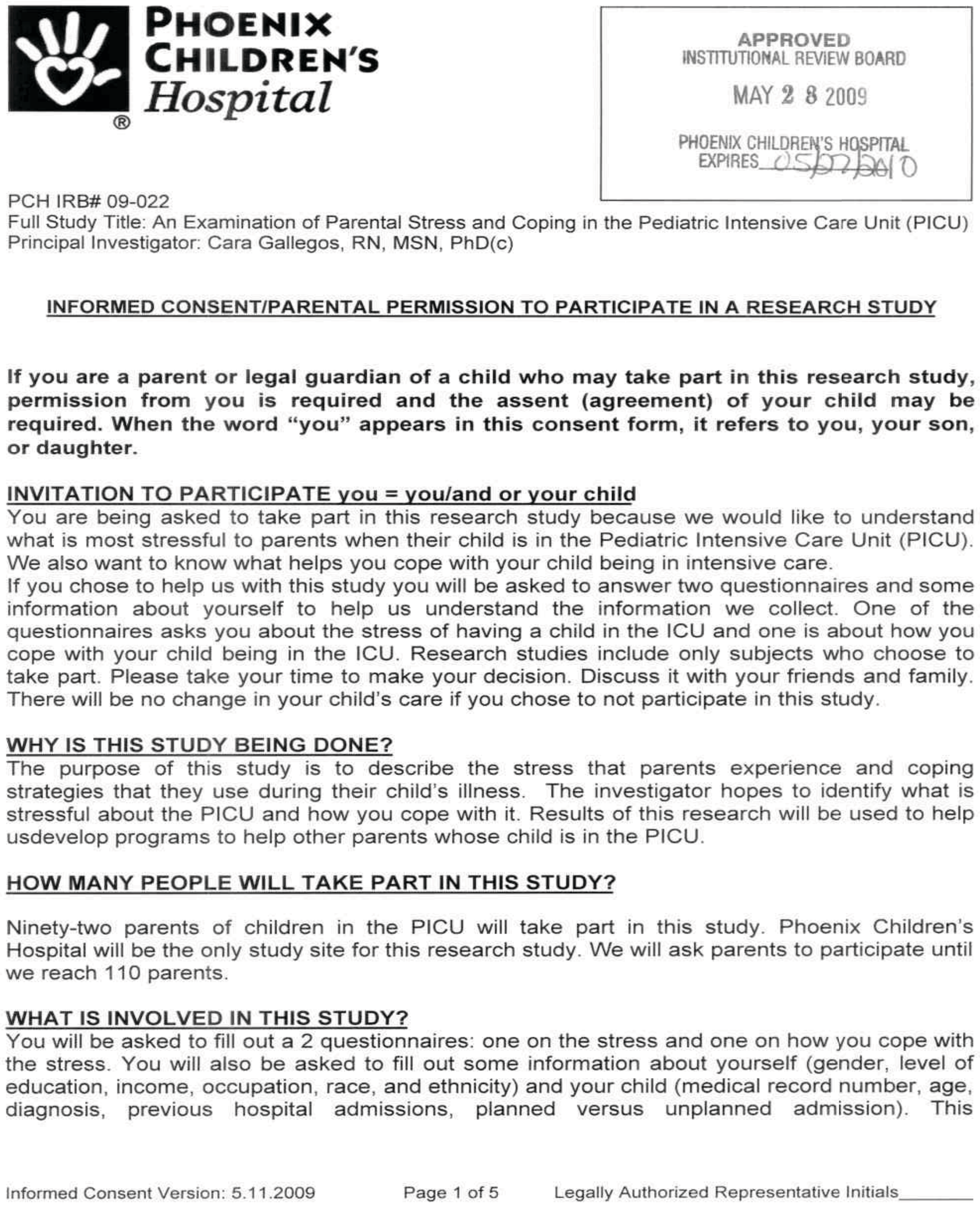
APPENDIX B

NURSING ACUITY TOOL

LEVEL 1 **1:2**	**LEVEL 2** **1:2**	**LEVEL 3** **1:1**	**LEVEL 4** **2:1**
Vital signs/ assessments/ interventions q 2h	Vital signs/ assessments/ interventions q 1-2h	Vital signs/ assessments/ interventions q 1h or more frequently	Vital signs/ assessments/ interventions q 30 min or more frequently
IV therapy 1-2	IV therapy 2-4	IV therapy >4	Meeting three criteria from Level 3 plus: • Start up of ECMO • Start up of CVVH • Admission of post-op complex heart • Any complex admission (s/p code, trauma)
Require cardiac monitor	ART-CVP-ICP Monitoring		
	Mechanical ventilation	Not meeting targets for mechanical ventilation	
Meds 4-6x in 24 hrs	Meds 6-10x in 24 hrs	Meds 10-18x in 24 hrs	
	Stable drips/pressors	Drips/pressors requiring titration	
Stable patients with EVDs	External pacing		
Post op patients requiring close observation		The following patients: • ECMO • CVVH • BMT • First day of complex heart surgery • New onset GCS<8 for first 24 hours	
Requiring < 90 minutes/shift of emotional support or education	Requiring > 90 minutes/shift of emotional support or education	Requiring > 3 hours/shift of emotional support or education	

APPENDIX C

CONSENT FORM



PHOENIX CHILDREN'S Hospital ®

APPROVED
INSTITUTIONAL REVIEW BOARD
MAY 2 8 2009
PHOENIX CHILDREN'S HOSPITAL
EXPIRES 05/27/2010

PCH IRB# 09-022
Full Study Title: An Examination of Parental Stress and Coping in the Pediatric Intensive Care Unit (PICU)
Principal Investigator: Cara Gallegos, RN, MSN, PhD(c)

INFORMED CONSENT/PARENTAL PERMISSION TO PARTICIPATE IN A RESEARCH STUDY

If you are a parent or legal guardian of a child who may take part in this research study, permission from you is required and the assent (agreement) of your child may be required. When the word "you" appears in this consent form, it refers to you, your son, or daughter.

INVITATION TO PARTICIPATE you = you/and or your child

You are being asked to take part in this research study because we would like to understand what is most stressful to parents when their child is in the Pediatric Intensive Care Unit (PICU). We also want to know what helps you cope with your child being in intensive care.

If you chose to help us with this study you will be asked to answer two questionnaires and some information about yourself to help us understand the information we collect. One of the questionnaires asks you about the stress of having a child in the ICU and one is about how you cope with your child being in the ICU. Research studies include only subjects who choose to take part. Please take your time to make your decision. Discuss it with your friends and family. There will be no change in your child's care if you chose to not participate in this study.

WHY IS THIS STUDY BEING DONE?

The purpose of this study is to describe the stress that parents experience and coping strategies that they use during their child's illness. The investigator hopes to identify what is stressful about the PICU and how you cope with it. Results of this research will be used to help usdevelop programs to help other parents whose child is in the PICU.

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?

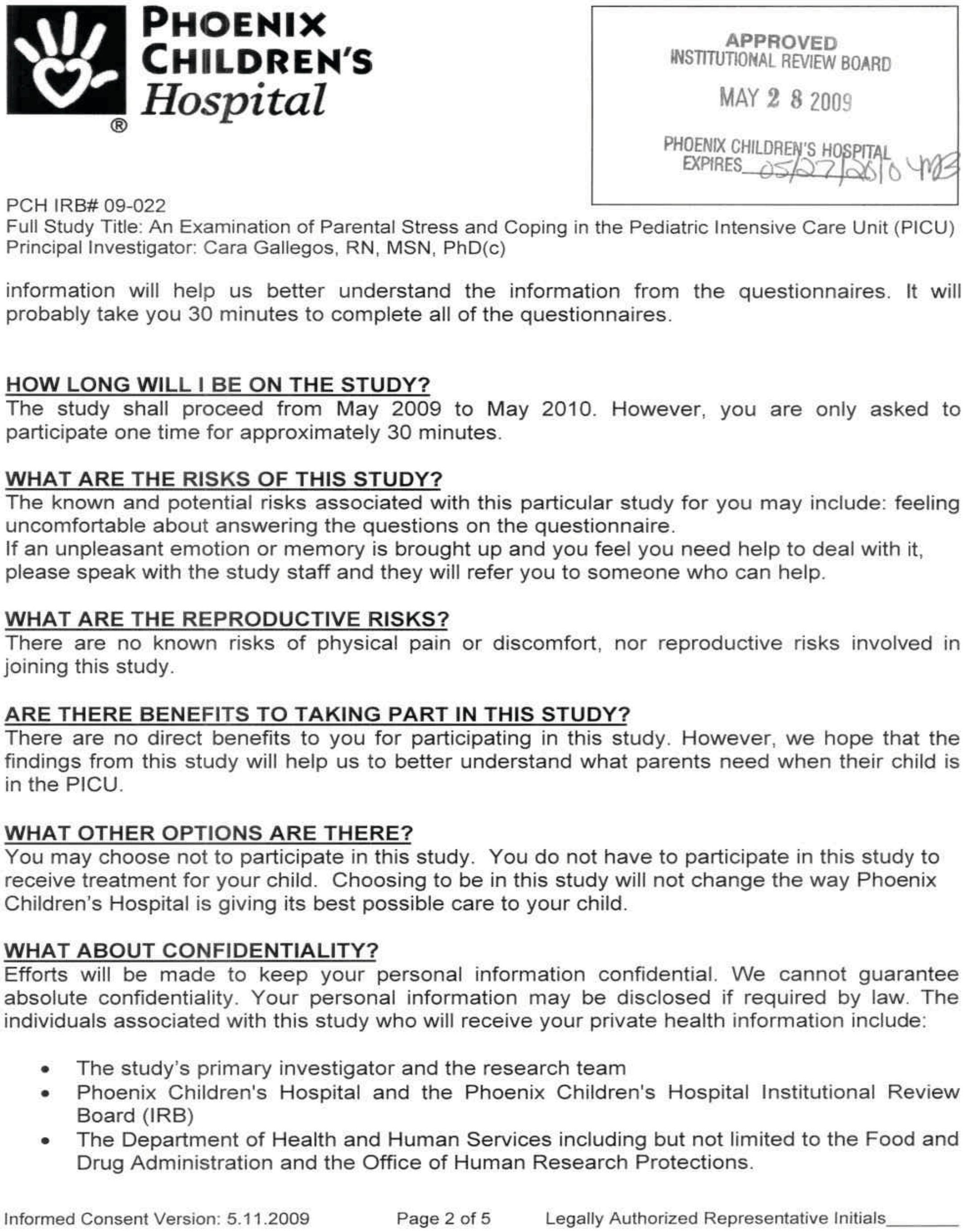
Ninety-two parents of children in the PICU will take part in this study. Phoenix Children's Hospital will be the only study site for this research study. We will ask parents to participate until we reach 110 parents.

WHAT IS INVOLVED IN THIS STUDY?

You will be asked to fill out a 2 questionnaires: one on the stress and one on how you cope with the stress. You will also be asked to fill out some information about yourself (gender, level of education, income, occupation, race, and ethnicity) and your child (medical record number, age, diagnosis, previous hospital admissions, planned versus unplanned admission). This

APPENDIX C (CONT.)

CONSENT FORM



PHOENIX CHILDREN'S Hospital

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PHOENIX CHILDREN'S HOSPITAL
EXPIRES 05/27/2010

PCH IRB# 09-022
Full Study Title: An Examination of Parental Stress and Coping in the Pediatric Intensive Care Unit (PICU)
Principal Investigator: Cara Gallegos, RN, MSN, PhD(c)

information will help us better understand the information from the questionnaires. It will probably take you 30 minutes to complete all of the questionnaires.

HOW LONG WILL I BE ON THE STUDY?

The study shall proceed from May 2009 to May 2010. However, you are only asked to participate one time for approximately 30 minutes.

WHAT ARE THE RISKS OF THIS STUDY?

The known and potential risks associated with this particular study for you may include: feeling uncomfortable about answering the questions on the questionnaire.
If an unpleasant emotion or memory is brought up and you feel you need help to deal with it, please speak with the study staff and they will refer you to someone who can help.

WHAT ARE THE REPRODUCTIVE RISKS?

There are no known risks of physical pain or discomfort, nor reproductive risks involved in joining this study.

ARE THERE BENEFITS TO TAKING PART IN THIS STUDY?

There are no direct benefits to you for participating in this study. However, we hope that the findings from this study will help us to better understand what parents need when their child is in the PICU.

WHAT OTHER OPTIONS ARE THERE?

You may choose not to participate in this study. You do not have to participate in this study to receive treatment for your child. Choosing to be in this study will not change the way Phoenix Children's Hospital is giving its best possible care to your child.

WHAT ABOUT CONFIDENTIALITY?

Efforts will be made to keep your personal information confidential. We cannot guarantee absolute confidentiality. Your personal information may be disclosed if required by law. The individuals associated with this study who will receive your private health information include:

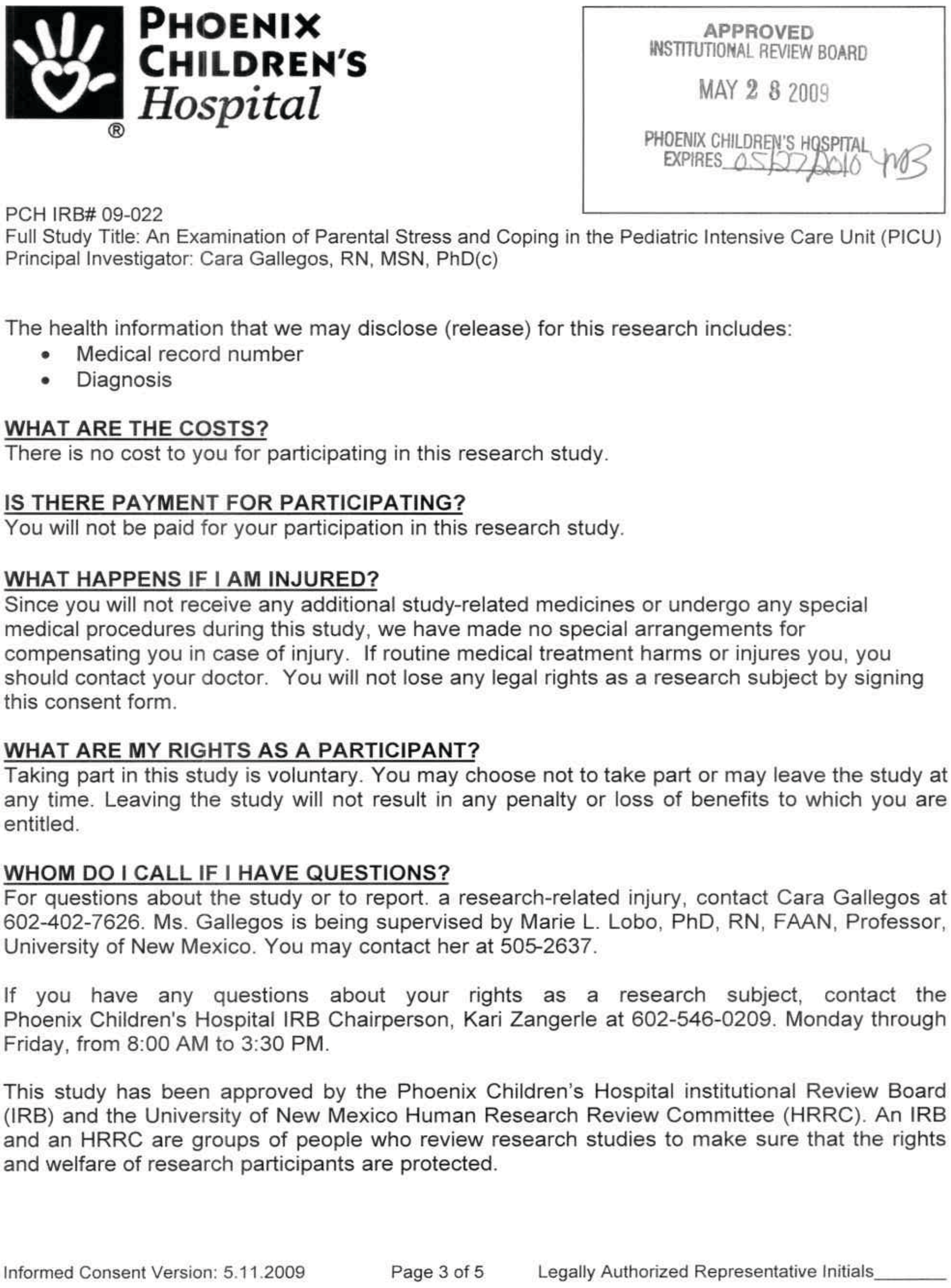
- The study's primary investigator and the research team
- Phoenix Children's Hospital and the Phoenix Children's Hospital Institutional Review Board (IRB)
- The Department of Health and Human Services including but not limited to the Food and Drug Administration and the Office of Human Research Protections.

Informed Consent Version: 5.11.2009 Page 2 of 5 Legally Authorized Representative Initials_______

APPENDIX C (CONT.)

CONSENT

FORM



PHOENIX CHILDREN'S *Hospital*

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INSTITUTIONAL REVIEW BOARD
MAY 28 2009
PHOENIX CHILDREN'S HOSPITAL
EXPIRES 05/27/2010

PCH IRB# 09-022
Full Study Title: An Examination of Parental Stress and Coping in the Pediatric Intensive Care Unit (PICU)
Principal Investigator: Cara Gallegos, RN, MSN, PhD(c)

The health information that we may disclose (release) for this research includes:

- Medical record number
- Diagnosis

WHAT ARE THE COSTS?

There is no cost to you for participating in this research study.

IS THERE PAYMENT FOR PARTICIPATING?

You will not be paid for your participation in this research study.

WHAT HAPPENS IF I AM INJURED?

Since you will not receive any additional study-related medicines or undergo any special medical procedures during this study, we have made no special arrangements for compensating you in case of injury. If routine medical treatment harms or injures you, you should contact your doctor. You will not lose any legal rights as a research subject by signing this consent form.

WHAT ARE MY RIGHTS AS A PARTICIPANT?

Taking part in this study is voluntary. You may choose not to take part or may leave the study at any time. Leaving the study will not result in any penalty or loss of benefits to which you are entitled.

WHOM DO I CALL IF I HAVE QUESTIONS?

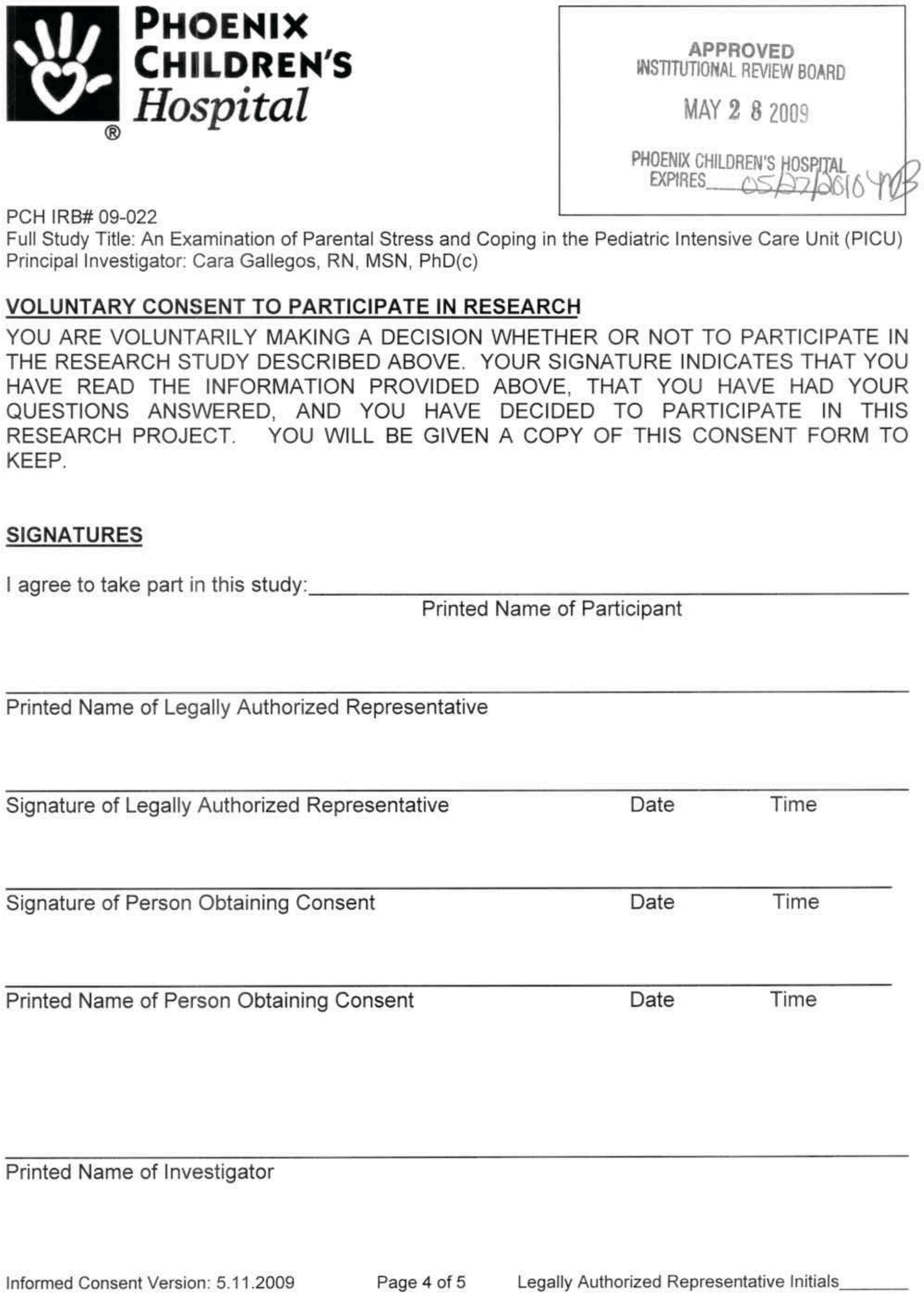
For questions about the study or to report. a research-related injury, contact Cara Gallegos at 602-402-7626. Ms. Gallegos is being supervised by Marie L. Lobo, PhD, RN, FAAN, Professor, University of New Mexico. You may contact her at 505-2637.

If you have any questions about your rights as a research subject, contact the Phoenix Children's Hospital IRB Chairperson, Kari Zangerle at 602-546-0209. Monday through Friday, from 8:00 AM to 3:30 PM.

This study has been approved by the Phoenix Children's Hospital institutional Review Board (IRB) and the University of New Mexico Human Research Review Committee (HRRC). An IRB and an HRRC are groups of people who review research studies to make sure that the rights and welfare of research participants are protected.

APPENDIX C (CONT.)

CONSENT FORM



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EXPIRES 05/27/2010 MB

PCH IRB# 09-022
Full Study Title: An Examination of Parental Stress and Coping in the Pediatric Intensive Care Unit (PICU)
Principal Investigator: Cara Gallegos, RN, MSN, PhD(c)

VOLUNTARY CONSENT TO PARTICIPATE IN RESEARCH

YOU ARE VOLUNTARILY MAKING A DECISION WHETHER OR NOT TO PARTICIPATE IN THE RESEARCH STUDY DESCRIBED ABOVE. YOUR SIGNATURE INDICATES THAT YOU HAVE READ THE INFORMATION PROVIDED ABOVE, THAT YOU HAVE HAD YOUR QUESTIONS ANSWERED, AND YOU HAVE DECIDED TO PARTICIPATE IN THIS RESEARCH PROJECT. YOU WILL BE GIVEN A COPY OF THIS CONSENT FORM TO KEEP.

SIGNATURES

I agree to take part in this study:____
Printed Name of Participant

____
Printed Name of Legally Authorized Representative

____
Signature of Legally Authorized Representative Date Time

____
Signature of Person Obtaining Consent Date Time

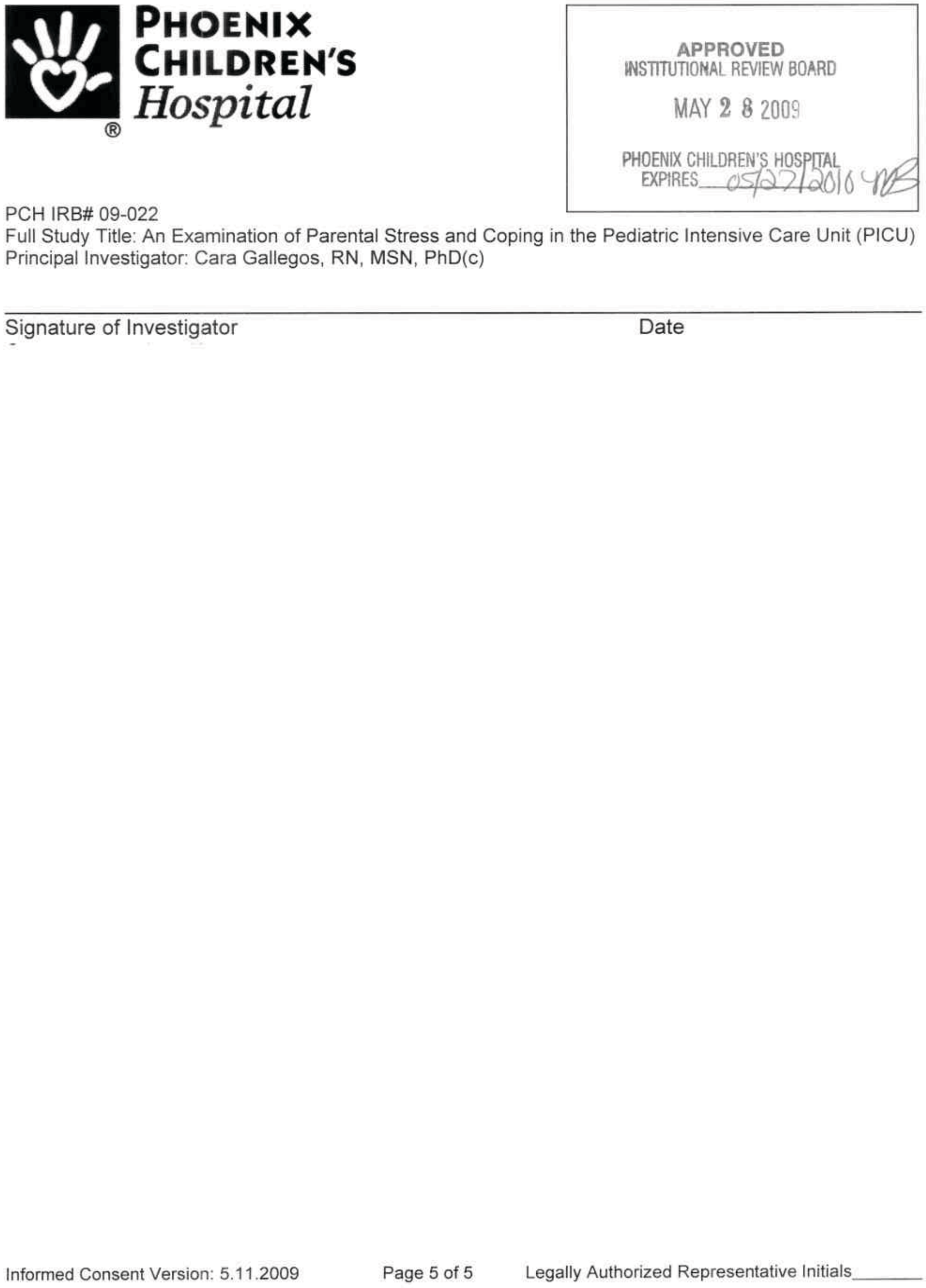
____
Printed Name of Person Obtaining Consent Date Time

____
Printed Name of Investigator

Informed Consent Version: 5.11.2009 Page 4 of 5 Legally Authorized Representative Initials_______

APPENDIX C (CONT.)

CONSENT FORM



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EXPIRES 05/27/2010

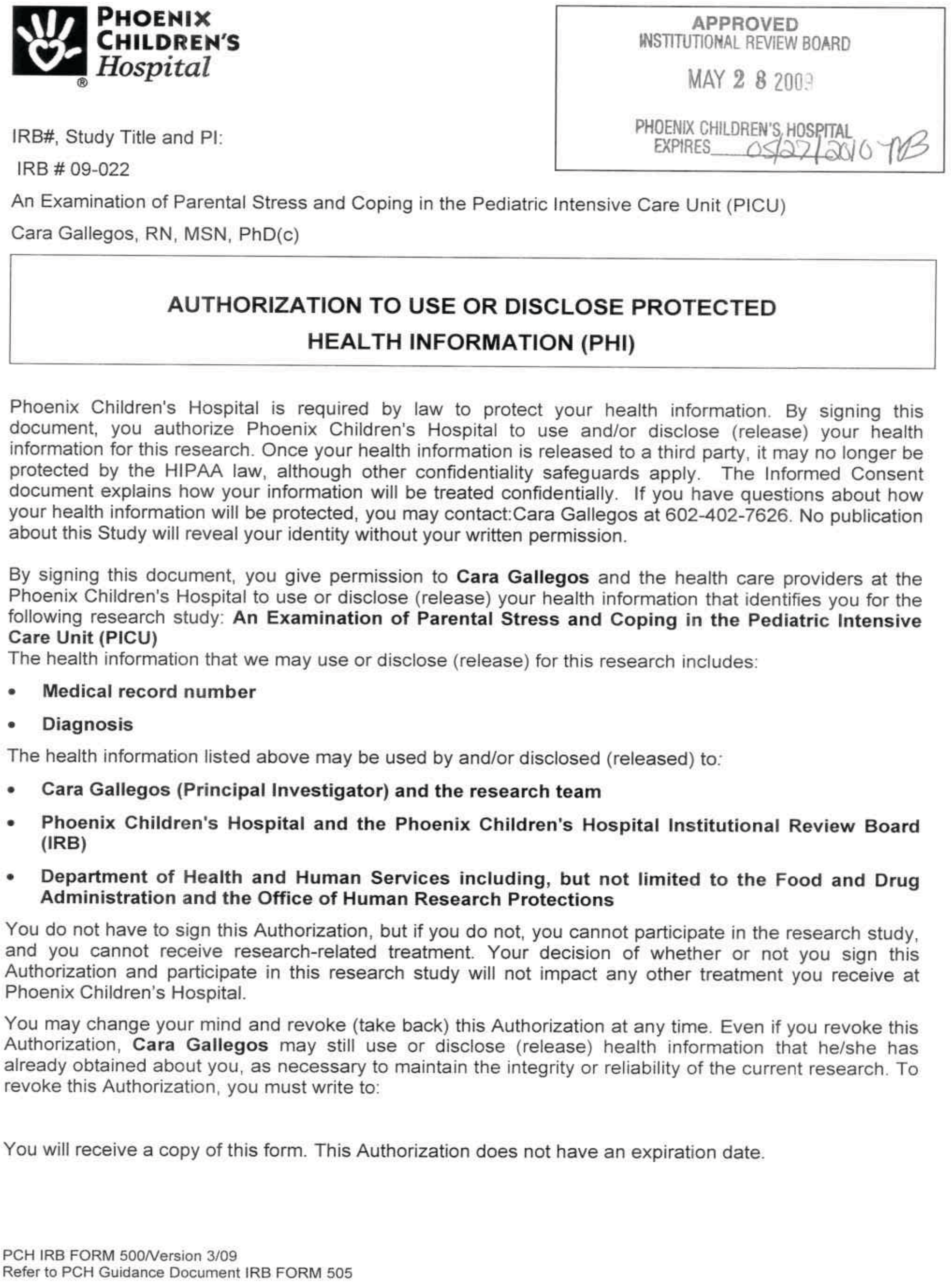
PCH IRB# 09-022
Full Study Title: An Examination of Parental Stress and Coping in the Pediatric Intensive Care Unit (PICU)
Principal Investigator: Cara Gallegos, RN, MSN, PhD(c)

Signature of Investigator Date

Informed Consent Version: 5.11.2009 Page 5 of 5 Legally Authorized Representative Initials_______

APPENDIX D

AUTHORIZATION FORM



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PHOENIX CHILDREN'S HOSPITAL
EXPIRES 05/27/2010 MB

IRB#, Study Title and PI:
IRB # 09-022
An Examination of Parental Stress and Coping in the Pediatric Intensive Care Unit (PICU)
Cara Gallegos, RN, MSN, PhD(c)

AUTHORIZATION TO USE OR DISCLOSE PROTECTED HEALTH INFORMATION (PHI)

Phoenix Children's Hospital is required by law to protect your health information. By signing this document, you authorize Phoenix Children's Hospital to use and/or disclose (release) your health information for this research. Once your health information is released to a third party, it may no longer be protected by the HIPAA law, although other confidentiality safeguards apply. The Informed Consent document explains how your information will be treated confidentially. If you have questions about how your health information will be protected, you may contact:Cara Gallegos at 602-402-7626. No publication about this Study will reveal your identity without your written permission.

By signing this document, you give permission to **Cara Gallegos** and the health care providers at the Phoenix Children's Hospital to use or disclose (release) your health information that identifies you for the following research study: **An Examination of Parental Stress and Coping in the Pediatric Intensive Care Unit (PICU)**
The health information that we may use or disclose (release) for this research includes:

- **Medical record number**
- **Diagnosis**

The health information listed above may be used by and/or disclosed (released) to:

- **Cara Gallegos (Principal Investigator) and the research team**
- **Phoenix Children's Hospital and the Phoenix Children's Hospital Institutional Review Board (IRB)**
- **Department of Health and Human Services including, but not limited to the Food and Drug Administration and the Office of Human Research Protections**

You do not have to sign this Authorization, but if you do not, you cannot participate in the research study, and you cannot receive research-related treatment. Your decision of whether or not you sign this Authorization and participate in this research study will not impact any other treatment you receive at Phoenix Children's Hospital.

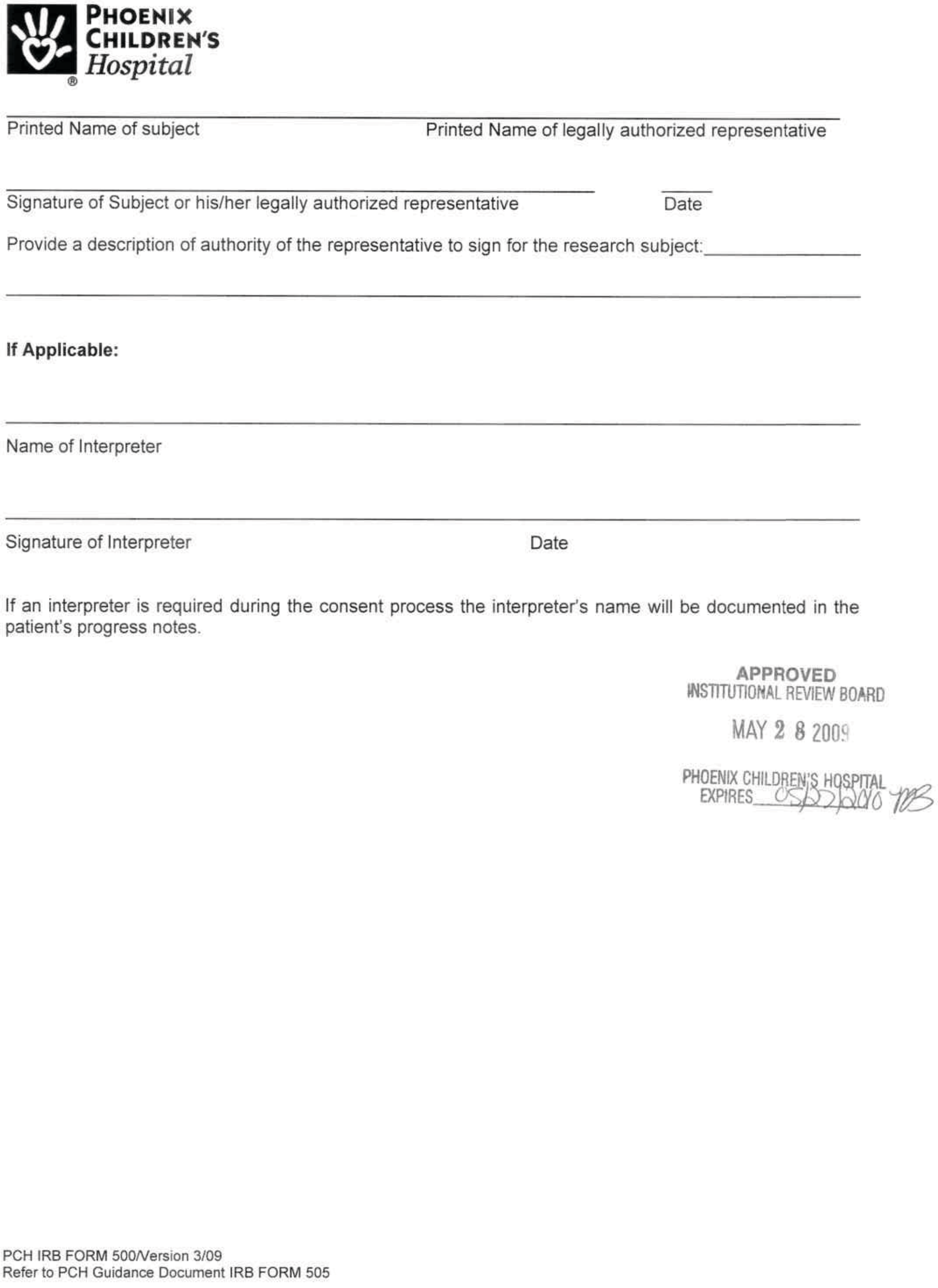
You may change your mind and revoke (take back) this Authorization at any time. Even if you revoke this Authorization, **Cara Gallegos** may still use or disclose (release) health information that he/she has already obtained about you, as necessary to maintain the integrity or reliability of the current research. To revoke this Authorization, you must write to:

You will receive a copy of this form. This Authorization does not have an expiration date.

PCH IRB FORM 500/Version 3/09
Refer to PCH Guidance Document IRB FORM 505

APPENDIX D (CONT.)

AUTHORIZATION FORM



PHOENIX CHILDREN'S Hospital

Printed Name of subject   Printed Name of legally authorized representative

Signature of Subject or his/her legally authorized representative   Date

Provide a description of authority of the representative to sign for the research subject:________________

If Applicable:

Name of Interpreter

Signature of Interpreter   Date

If an interpreter is required during the consent process the interpreter's name will be documented in the patient's progress notes.

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PCH IRB FORM 500/Version 3/09
Refer to PCH Guidance Document IRB FORM 505

APPENDIX E

FAMILY DEMOGRAPHIC FORM

This section asks about you or your family. This helps us better understand the answers on the questionnaires we are asking you to complete. Please fill in the blank or place an X on the line that best describes you. Please answer all questions.

1. What is your gender?
   a. _______Male
   b. _______ Female

2. What is your relationship to the child in the pediatric intensive care unit?
   a. _______ Mother
   b. _______ Father
   c. _______ Grandmother
   d. _______ Aunt
   e. _______ Other (Please explain)______________

3. Are you the person who takes care of the child most of the time?
   a. _______ Yes
   b. _______ No

4. What is your age at your last birthday? _________

5. How many people live in your household, including you? _______

	Age last birthday	Gender of Child	Years of schooling to date
Mother/wife		▨	
Father/Husband		▨	
			Current Grade
Child 1 (In PICU)		M F	
Child 2		M F	
Child 3		M F	
Child 4		M F	

Child 5		M F	
Others living in your home/ relationship			
		M F	

6. Are you?
   a. ______Married
   b. ______Never Married
   c. ______Divorced
   d. ______Living with partner, not married
   e. ______Separated
   f. ______Widowed

7. How do you describe yourself? Check all that apply.
   a. ____White (non Hispanic/Latino)
   b. ____Black or African American (non Hispanic/Latino)
   c. ____American Indian/Alaskan Native
   d. ____Asian
   e. ____Hawaiian Native/Pacifica Islander
   f. ____ Other (Please clarify)______________________________

8. Do you consider yourself:
   a. ______Mexican/American
   b. ______Puerto Rican
   c. ______Cuban
   d. ______Other Spanish/Hispanic/Latino
   e. ______none of the above

9. What is your occupation? ____________________________

10. What is the highest grade or year of school that you completed? ______

11. Would you classify your last year of school to be:
   a. ______Grades 1-8 (Elementary/middle school)
   b. ______Grades 9-11 (Some high school)
   c. ______Grade 12 or GED
   d. ______College 1-3 years (Some college or technical school)

  e. ______College 4 years (College graduate)
  f. ______Graduate or Professional School (Advanced degree)

12. What is your household's total annual income for the most recent calendar year, before taxes?
    a. _____< $9,999
    b. _____$10,000-$14,999
    c. _____ $15,000-$24,999
    d. _____$25,000-$34,999
    e. _____ $35,000-$49,999
    f. _____$50,000-$74,999
    g. _____$75,000-$99,000
    h. _____$100,000+

This section asks information about your child. This will help us understand more about what happens to parents when their child is in the Pediatric Intensive Care Unit.

1. Was this admission planned?
    a. ______Yes
    b. ______No

2. Has your child been hospitalized before?
    a. ______Yes → If yes, how many times? __________
    b. ______No

3. Has your child been hospitalized in the PICU before?
    a. ______Yes → If yes, how many times? __________
    b. ______No

4. Why is your child in the Pediatric Intensive Care Unit?

5. In your own words, can you describe what you think is most stressful about having your child in the Pediatric Intensive Care Unit?

APPENDIX F

PARENTAL STRESSOR SCALE: PICU

Directions:

Of great concern to nurses and others who work in a Pediatric Intensive care Unit (PICU) is the effect of this environment and experience on parents. This questionnaire contains a number of items that may be stressful to parents while their child in PICU. I am interested in your view of these stressors. **By stressful, I mean an experience that caused you to feel anxious, upset, or tense.** On the questionnaire, you are asked to circle the number that best expresses how stressful each item was for you.

Below is a list of items that might describe your **CHILD'S APPEARANCE.** Using the rating scale on the right, circle the number that <u>best</u> expresses how stressful these things have been for you.

	Not Experienced	**Not Stressful**	**Minimally Stressful**	**Moderately Stressful**	**Very Stressful**	**Extremely stressful**
1. Puffiness of my child	0	1	2	3	4	5
2. Color changes in my child (pale, blue or yellow)	0	1	2	3	4	5
3. Child appearing cold	0	1	2	3	4	5

Below is a list of **SIGHTS AND SOUNDS** in an intensive care unit (ICU). Circle the number that <u>best</u> expresses how stressful each of these items has been for you.

1. Seeing the heart beat on the monitors	0	1	2	3	4	5
2. The sound of monitors and equipment	0	1	2	3	4	5
3. The sudden sounds of	0	1	2	3	4	5

monitor alarms

Below is a list of **PROCEDURES** that may have been done to your child. Circle the number that best expresses how stressful these procedures have been for you.

1. Injections/shots	0	1	2	3	4	5
2. Tubes in my child	0	1	2	3	4	5
3. Suctioning	0	1	2	3	4	5
4. Putting needles in my child for fluids, procedures or tests	0	1	2	3	4	5
5.Making my child cough and deep breath/pounding and clapping on my child's chest	0	1	2	3	4	5
6. Bruises, cuts, incisions on my child	0	1	2	3	4	5

Below is a list of **BEHAVIORS** of the **PROFESSIONAL STAFF** (doctors and nurses) that you may have observed. Circle the number that best expresses how stressful these items have been for you.

1. Joking, laughing or talking loudly	0	1	2	3	4	5
2. Not talking to me enough	0	1	2	3	4	5
3. Too many different people (doctors, nurses, staff) talking to me	0	1	2	3	4	5
4. Not telling me their names	0	1	2	3	4	5

or who they are

These items relate to **PARENTAL ROLES.** How stressful have the following been for you?

	Not Experienced	**Not Stressful**	**Minimally Stressful**	**Moderately Stressful**	**Very Stressful**	**Extremely stressful**
1. Not taking care of my child myself	0	1	2	3	4	5
2. Not being able to visit my child when I wanted	0	1	2	3	4	5
3. Not being able to see my child when I wanted	0	1	2	3	4	5
4. Not being able to be with my crying child	0	1	2	3	4	5
5.Not being able to hold my child	0	1	2	3	4	5
6. Using the same rating scale, how stressful, in general, has the total intensive care unit experience been for you?	0	1	2	3	4	5

Below is a list of items that relate to how the professional staff (doctors and nurses) may **COMMUNICATE** with you about your child's illness. Please indicate the stress level of these items.

1. Explaining things too fast	0	1	2	3	4	5

2. Using words I don't understand	0	1	2	3	4	5
3. Telling me different things about my child's condition	0	1	2	3	4	5
4. Not telling me what is definitely wrong with my child	0	1	2	3	4	5
5.Not talking to me enough	0	1	2	3	4	5

Below is a list of **BEHAVIORS AND EMOTIONAL RESPONSES** that your child may have exhibited while in the intensive care unit. Using the same rating scale as above, how stressful were these things for you?

1. Confusion	0	1	2	3	4	5
2. Rebellious or uncooperative behavior	0	1	2	3	4	5
3. Crying or whining	0	1	2	3	4	5
4. Demanding	0	1	2	3	4	5
5.Acting or looking as if in pain	0	1	2	3	4	5
6. Restlessness	0	1	2	3	4	5
7. Inability to talk or cry	0	1	2	3	4	5
8. Fright	0	1	2	3	4	5
9. Anger	0	1	2	3	4	5
10. Sadness or depression	0	1	2	3	4	5

APPENDIX G

COPING HEALTH INVENTORY FOR PARENTS

Directions:

To complete this inventory you are asked to read the list of "Coping Behaviors" below, one at a time**.** For each coping behavior you used**,** please indicate by circling a number how helpful this belief or action is for you in managing family life right now with your child.

0 = Not helpful
1 = Minimally helpful
2 = Moderately helpful
3= Extremely helpful

For each Coping Behavior you **Did Not** use, please record your "Reason" (Chose not to or Not possible).

					I do not cope this way because	
Coping Behaviors	**Extremely helpful**	**Moderately helpful**	**Minimally helpful**	**Not helpful**	**Chose not to**	**Not possible**
1. Talking over personal feelings and concerns with spouse/partner	3	2	1	0	4	5
2. Engaging in relationships and friendships which help me to feel important and appreciated	3	2	1	0	4	5
3. Trusting my spouse/partner (or	3	2	1	0	4	5

former) to help support me and my child(ren)						
4. Sleeping	3	2	1	0	4	5
5. Talking with the medical staff (nurses, social worker etc) when we visit the medical center	3	2	1	0	4	5
6. Believing that my child(ren) will get better	3	2	1	0	4	5
7. Working, outside employment	3	2	1	0	4	5
8. Showing that I am strong	3	2	1	0	4	5
9. Purchasing gifts for myself and/or other family members	3	2	1	0	4	5
10. Talking with other individuals/parents in my same situation	3	2	1	0	4	5
11. Taking good care of all the medical equipment at home	3	2	1	0	4	5
11. Eating	3	2	1	0	4	5
12. Getting other members of the family to help with chores and tasks at home	3	2	1	0	4	5
14. Getting away by myself	3	2	1	0	4	5
15. Talking with the doctor about my concerns about my child(ren) with	3	2	1	0	4	5

the medical condition						
16. Believing that the medical center/hospital has my family's best interest in mind	3	2	1	0	4	5
17. Building close relationships with people	3	2	1	0	4	5
18. Believing in God	3	2	1	0	4	5
19. Develop myself as a person	3	2	1	0	4	5
20. Talking with other parents in the same type of situation and learning about their experience	3	2	1	0	4	5
21. Doing this together as a family (involving all members of the family)	3	2	1	0	4	5
22. Investing time and energy in my job	3	2	1	0	4	5
23. Believing that my child is getting the best medical care possible	3	2	1	0	4	5
24. Entertaining friends in our home	3	2	1	0	4	5
25. Reading about how other persons in my situation handle things	3	2	1	0	4	5
26. Doing things with family relatives	3	2	1	0	4	5
27. Becoming	3	2	1	0	4	5

more self reliant and independent						
28. Telling myself that I have many things I should be thankful for	3	2	1	0	4	5
29. Concentrating on hobbies (art, music, jogging, etc)	3	2	1	0	4	5
30. Explaining family situation to friends and neighbors so they will understand us.	3	2	1	0	4	5
31. Encouraging child(ren) with medical condition to be more independent	3	2	1	0	4	5
32. Keeping myself in shape and well groomed	3	2	1	0	4	5
33. Involvement in social activities (parties etc) with friends	3	2	1	0	4	5
34. Going out with my spouse/partner on a regular basis	3	2	1	0	4	5
35. Being sure prescribed medical treatments for child(ren) are carried out at home on a daily basis	3	2	1	0	4	5
36. Building a closer relationship with my spouse	3	2	1	0	4	5
37. Allowing myself to get angry	3	2	1	0	4	5

38. Investing myself in my child(ren)	3	2	1	0	4	5
39. Talking to someone(not professional counselor/doctor) about how I feel	3	2	1	0	4	5
40. Reading more about the medical problem which concerns me	3	2	1	0	4	5
41. Trying to maintain family stability	3	2	1	0	4	5
42. Being able to get away from the home care tasks and responsibilities for some relief	3	2	1	0	4	5
43.Having my child with the medical condition seen at the clinic/hospital on a regular basis	3	2	1	0	4	5
44. Believing that things will always work out	3	2	1	0	4	5
45. Doing things with my children	3	2	1	0	4	5

APPENDIX H

INDIVIDUAL PARENTAL STRESSOR SCALE ITEMS

Subscale Item	Females (N=60)			Males (N=26)			Total (N=86)		
	Mean	Percentiles		Mean	Percentiles		Mean	Percentiles	
	(SD)	25th	75th	(SD)	25th	75th	(SD)	25th	75th
Appearance							3.0 (1.0)	2	4
Puffiness of my child	2.3 (1.6)	1	3	2.5 (1.3)	2	3	2.3 (1.5)	1	3
Color changes	2.7 (1.8)	2	4	2.9 (1.3)	2	4	2.7 (1.6)	2	4
Child appearing cold	2.6 (1.6)	1	4	2.3 (1.4)	1	3	2.5 (1.6)	1	4
Environment							2.8 (1.2)	2	4
Seeing heartbeat on monitors	2.1 (1.4)	1	3	1.9 (1.2)	1	3	2.0 (1.3)	1	3
Sound of monitors and equipment	2.6 (1.5)	1	4	2.7 (1.2)	2	4	2.6 (1.4)	1	4
Sudden sound of monitor alarms	3.4 (1.5)	2	5	3.6 (1.1)	3	4	3.4 (1.4)	3	5
Procedures							3.0 (1.1)	2.3	3.7
Injections/shots	2.4 (1.6)	1	4	2.4 (1.3)	1	3	2.4 (1.5)	1	3
Tubes in my child	3.3 (1.6)	2	5	3.4 (1.0)	3	4	3.3 (1.4)	3	5
Suctioning	2.2 (1.7)	1	3	2.4 (1.9)	1	5	2.3 (1.7)	1	3
Putting needles in my child	3.0 (1.6)	2	5	3.0 (1.5)	2	4	3.0 (1.6)	2	5
Making my child cough/clapping on my child's chest	2.2 (1.8)	1	3	1.8 (1.9)	0	3	2.09 (1.8)	0	3
Bruises, cuts, incisions	3.0 (1.8)	2	5	3.1 (1.6)	2	4	3.0 (1.8)	2	5
Staff Behaviors							2.0 (1.0)	1.2	2.5
Joking, laughing or talking loudly	1.15 (.9)	1	1	1.3 (0.9)	1	2	1.2 (0.9)	1	2
Not talking to me enough	1.5 (1.6)	0	3	1.3 (1.6)	0	2	1.4 (1.6)	0	3
Too many people (staff) talking to me	1.7 (1.4)	1	2	1.6 (1.6)	1	3	1.7 (1.4)	1	2
Not telling me names/ who they are	1.3 (1.6)	0	2	.96 (1.4)	0	2	1.21 (1.5)	0	2
Parenting Roles							3.3 (1.1)	2.5	4.3
Not taking care of my child	2.4 (1.7)	1	4	2.6 (1.4)	2	4	2.4 (1.6)	1	4
Not being able to	1.4 (2.0)	0	3	1.5 (2.2)	0	4	1.4 (2.1)	0	4

visit when I wanted									
Not being able to see my child	1.5 (2.0)	0	3	1.7 (2.1)	0	4	1.5 (2.0)	0	4
Not being able to be with my crying child	1. 7 (2.1)	0	4	2.1 (2.5)	0	5	1.8 (2.2)	0	4
Not being able to hold my child	3.1 (2.1)	0	5	3.5 (1.9)	2	5	3.2 (2.0)	2	5
How stressful is the total ICU experience	3.1 (1.4)	2	4	3.3 (1.0)	3	4	3.2 (1.3)	2	4
Staff Communication							2.5 (1.2)	1.5	3.6
Explaining things to fast	1.0 (1.2)	0	2	1.0 (1.2)	0	2	1.0 (1.2)	0	2
Using words I don’t understand	1.4 (1.4)	0	2	1.1 (1.3)	0	2	1.3 (1.4)	0	2
Telling me conflicting things about my child’s condition	1.6 (1.8)	0	3	1.4 (1.6)	0	3	1.4 (1.9)	0	3
Not telling me what is wrong with my child	1.3 (1.9)	0	2	1.9 (2.0)	0	4	1.4 (1.9)	0	3
Not talking to me enough	1.2 (1.6)	0	2	.92 (1.5)	0	3	1.1 (1.6)	0	2
Child behaviors							3.3 (1.1)	2.7	4.0
Confusion	1.7 (1.8)	0	3	1.4 (1.7)	0	3	1.6 (1.7)	0	3
Rebellious or uncooperative behavior	1.4 (1.7)	0	3	1.2 (1.6)	0	3	1.3 (1.7)	0	3
Crying or whining	2.7 (1.7)	1	4	2.5 (2.0)	0	4	2.6 (1.8)	1	4
Demanding behavior	0.8 (1.1)	0	1	0.7 (1.2)	0	1	0.7 (1.1)	0	1
Acting or looking as if pain	3.5 (1.8)	2	5	3.3 (1.8)	2	5	3.4 (1.8)	2	5
Restlessness	3.0 (1.5)	2	4	2.4 (1.8)	1	4	2.8 (1.6)	2	4
Inability to talk or cry	2.5 (2.0)	0	5	2.8 (2.0)	0	5	2.6 (2.0)	0	5
Fright	2.1 (2.1)	0	4	2.0 (2.1)	0	4	2.1 (2.1)	0	4
Anger	1.4 (1.9)	0	3	1.4 (1.8)	0	3	1.4 (1.8)	0	3
Sadness or depression	1.6 (2.0)	0	4	1.5 (1.9)	0	3	1.5 (2.0)	0	3

APPENDIX I

INDIVIDUAL PARENTAL COPING STRATEGIES

Subscale Item	Females (N=60)			Males (N=26)			Total (N=86)		
	Mean (SD)	Percentiles		Mean (SD)	Percentiles		Mean (SD)	Percentiles	
		25th	75th		25th	75th		25th	75th
Talking over feelings/ concerns with spouse	2.3 (0.9)	2	3	2.2 (1.0)	1	3	2.3 (1.0)	2	3
Engaging in relationships which help make me feel important and appreciated	2.1 (1.1)	1	3	1.7 (1.1)	1	3	1.9 (1.1)	1	3
Trusting my spouse/ partner (or former) to help support me and my children	2.5 (0.9)	2	3	2.4 (0.9)	2	3	2.4 (0.9)	2	3
Sleeping	2.0 (1.2)	1	3	1.9 (1.1)	1	3	2.0 (1.2)	1	3
Talking with the medical staff when we visit the medical center	2.6 (0.6)	2	3	2.0 (1.0)	1	3	2. 5 (0.8)	2	3
Believing that my child will get better	2.7 (0.7)	3	3	2.7 (0.9)	3	3	2.7 (0.7)	3	3
Work. Outside employment	0.8 (1.1)	0	1	0.6 (1.0)	0	1	0.7 (1.1)	0	1
Showing that I am strong	1.8 (1.2)	1	3	1.2 (1.8)	0	2	1.6 (1.2)	0	3
Purchasing gifts for myself or family members	0.5 (0.9)	0	1	0.4 (0.6)	0	1	0.5 (0.8)	0	1
Talking with other individuals in same situation	1.7 (1.1)	1	3	1.0 (1.2)	0	2	1.5 (1.2)	0	3
Taking good care of the medical equipment at home	1.2 (1.4)	0	3	0.7 (1.2)	0	1	1.1 (1.3)	0	3
Eating	1.8 (1.0)	1	2	1.2 (0.9)	0	3	1.6 (1.0)	1	2
Getting other family members to help	2.1 (1.1)	1	3	1.5 (1.2)	0	3	1.9 (1.2)	1	3

with chores at home									
Getting away by myself	1.3 (1.2)	0	2	1.50 (1.1)	0	2.25	1.3 (1.2)	0	2
Talking with doctor about my concerns	2.6 (0.8)	3	3	2.4 (0.8)	2	3	2.6 (1.8)	2	3
Believing that the hospital has my family's best interest in mind	2.8 (0.5)	3	3	2.4 (0.7)	2	3	2.7 (0.6)	2	3
Building close relationships with people	2.0 (1.1)	1	3	1.7 (1.1)	1	3	1.9 (1.1)	1	3
Believing in God	2.4 (1.0)	2	3	1.7 (1.3)	0	3	2.2 (1.2)	1.75	3
Develop myself as a person	1.8 (1.1)	1	3	1.1 (1.3)	0	3	1.6 (1.2)	0	3
Talking with other parents and learning about their experience	1.6 (1.2)	0	3	1.2 (1.3)	0	3	1.5 (1.3)	0	3
Doing this together as a family	2.3 (1.0)	2	3	1.9 (1.3)	0.5	3	2.1 (1.1)	2	3
Investing time and energy in my job	0.8 (1.2)	0	1	0.5 (0.8)	0	1	0.7 (1.1)	0	1
Believing that my child is getting the best medical care possible	2.9 (0.5)	3	3	2.6 (0.8)	2	3	2.8 (0.6)	3	3
Entertaining friends in our home	0.6 (1.0)	0	1	0.3 (0.5)	0	0.25	0.5 (0.9)	0	1
Reading about how other people in my situation handle things	1.5 (1.1)	0	2.75	0.7 (1.1)	0	2	1.3 (1.2)	0	2
Doing things with family relatives	1.5 (1.1)	0	2	1.2 (1.1)	0	2	1.4 (1.1)	0	2
Becoming more self reliant and independent	1.7 (1.1)	1	3	1.0 (1.1)	0	2	1.5 (1.1)	0	3
Telling myself that I have many thing I should be thankful for	2.2 (1.0)	1	3	1.6 (1.2)	0.75	3	2.0 (1.1)	1	3
Concentrating on hobbies	1.1 (1.1)	0	2	0.7 (0.9)	0	2	1.0 (1.0)	0	2
Explaining family	1.4	0	3	1.0	0	2	1.3	0	3

situation to friends so they will understand us	(1.2)			(1.2)			(1.2)		
Encouraging child with medical condition to be more independent	1.0 (1.2)	0	2	0.5 (1.0)	0	1	0.9 (1.2)	0	2
Keeping myself in shape and well groomed	1.5 (1.1)	0	2	1.12 (1.1)	0	2	1.4 (1.1)	0	2
Involvement in social activities with friends	0.7 (1.0)	0	1	0.5 (0.9)	0	0.25	0.6 (1.0)	0	1
Going out with my spouse/partner on a regular basis	0.9 (0.9)	0	2	1.2 (1.3)	0	2.25	1.0 (1.1)	0	2
Being sure prescribed medical treatments are carried out at home	1.8 (1.4)	0	3	1.8 (1.3)	0	3	1.8 (1.4)	0	3
Building a closer relationship with my spouse	2.0 (1.2)	1	3	2.4 (1.1)	2	3	2.1 (1.2)	1	3
Allowing myself to get angry	1.6 (0.8)	0	2	0.5 (1.0)	0	1.25	0.9 (1.2)	0	2
Investing myself in child	2.6 (0.7)	2	3	2.3 (1.1)	1.75	3	2.5 (0.9)	2	3
Talking to someone (not professional) about how I feel	2.1 (2.9)	1	3	1.3 (1.2)	0	1.25	1.9 (2.5)	0	3
Reading more about the medical problem	2.2 (1.0)	2	3	1.3 (1.1)	0	2.25	1.9 (1.1)	1	3
Trying to maintain family stability	2.5 (0.8)	2	3	1.9 (1.3)	0	2	2.4 (1.0)	2	3
Being able to get away from the homecare tasks/responsibilities for some relief	1.7 (1.1)	1	3	1.0 (1.1)	0	2	1.5 (1.2)	0	3
Having my child with the medical condition seen at the clinic on a regular basis	2.2 (1.0)	2	3	1.7 (1.1)	0.75	3	2.0 (1.1)	1	3
Believing that things will always work out	2.3 (0.7)	2	3	2.0 (1.1)	1	3	2.4 (0.9)	2	3
Doing things with my children	2.6 (0.8)	2	3	2.2 (1.2)	1.75	3	2.5 (0.9)	2	3

APPENDIX J

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Myron B. Thompson School of Social Work

July 27, 2010

Cara Gallegos RN, MSN, PhD(c)
Assistant Professor- Marshfield Site
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Marshfield, WI 54449Cara Gallegos RN, MSN, PhD(c)

Dear Professor Gallegos

The purpose of this correspondence is to confirm permission for your use of the Figure of the Resilience Model of Family Stress, Adjustment and Adaptation. This permission is granted contingent on our receipt of a copy of what you are including and citation being sent by email to my office for filing.

We wish you the best

Let us know if we can be of assistance.

Sincerely,

Hamilton I. McCubbin Ph.D.
Professor and Director of Research
Center for Training, Evaluation and Research of the Pacific

CC: Dr. Marilyn McCubbin
CC: Dr. Laurie McCubbin

REFERENCES

Adler, N.E., Boyce, T., Chesney, M.A., Cohen, S., Folkman, S., Kahn, L., & Syme, S.L. (1994). Socioeconomic status and health. The challenge of the gradient. *American Psychologist, 49*(1), 15-24.

American Heart Association, American Academy of Pediatrics. (2002). *PALS provider manual.* Dallas, TX: American Heart Association.

American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders,* (4th ed.). Washington, DC: Author.

American Heritage Stedman's Medical Dictionary. (2008). Race. Retrieved online May 2009 from: http://www.thefreedictionary.com/Race.

Baluffi, A., Kassam-Adams, N., Kazak, A., Tucker, M., Dominguez, T., & Helfaer, M. (2004). Traumatic stress in parents of children admitted to the pediatric intensive care unit. *Pediatric Critical Care Medicine, 5*(6), 547-553.

Baird, G., McConachie, H. & Scrutton, D. (2000). Parents' perceptionsof disclosure of the diagnosis of cerebral palsy. *Archives of Disease in Childhood*, 83, 475–480.

Bauchner, H., Waring, C. & Vinci R. (1991). Parental presence during procedures in an emergency room: results from 50 observations. *Pediatrics, 87,* 544-548.

Best, M., Streissand, R., Catania, L., & Kazak, A. (2001). Parental distress during pediatric leukemia and posttraumatic stress symptoms (PTSS) after treatment ends. *Journal of Pediatric Psychology, 26*(5), 299-307.

Bhopal, R. (2004). Glossary of terms relating to ethnicity and race: for reflection and debate. *Journal of Epidemiology and Community Health,* 58, 441-445.

Billings, A. G., & Moos, R. H. (1981). The role of coping responses and social resources in attenuating the stress of life events. *Journal of Behavioral Medicine, 4,* 139–157.

Bishaw, A. & Iceland, J. (2003). *Poverty: 1999*. Census 2000 Brief. U.S. Department of Commerce.

Board, R. & Ryan-Wenger, N. (2000). State of the science of parental stress and family functioning in pediatric intensive care units. *American Journal of Critical Care, 9*(2), 106-24.

Board, R. & Ryan-Wenger, N. (2002). Long-term effects of pediatric intensive care unit hospitalization on families with young children. *Heart & Lung: The Journal of Acute and Critical Care, 31*(1), 53-66.

Board, R. & Ryan-Wenger, N. (2003). Stressors and stress symptoms of mothers with children in the PICU. *Journal of Pediatric Nursing, 18* (3), 195-202.

Bonner, M. J., Hardy, K. K., Guill, A. B.,McLaughlin, C., Schweitzer, H., & Carter, K. (2006). Development and validation of the Parent Experience of Child Illness. *Journal of Pediatric Psychology, 31,* 310–321.

Braveman, P., Cubbin, C., Egerter, S., Chideya, S., Marchi, K., Metzler, M., & Posner, S. (2005). Socioeconomic status in health research: One size does not fit all. *Journal of the American Medical Association,* 294(22), 2879-2888.

Brody, A. & Simmons, L. (2007). Family resiliency during childhood cancer: The father’s perspective. *Journal of Pediatric Oncology Nursing, 24* (3), 152-165.

Burns, N. & Groves, S. (2004). *The practice of nursing research: Conduct, critique, and utilization (5th Ed).* New York. Saunders.

Carter, M. & Miles M. (1983). *Parental stressor scale: Pediatric intensive care unit*. Kansas City, KS: University of Kansas.

Carter M. & Miles M. (1989). The parental stressor scale: pediatric intensive care unit. *Maternal-Child Health Nursing Journal 18*(3), 187–198.

Carter, M., Miles, M., & Buford, T. (1985). Parental environmental stress in pediatric intensive care units. *Dimensions in Critical Care Nursing, 4,* 180-88.

Cavallo, S., Feldman, D., Swaine, B., Meshefedjian, G. (2009). Is parental coping associated with the level of function in children with physical disabilities? *Child: Care, Health & Development*, *35*(1), 33-40.

Chamberlain, J., Joseph, J., Patel, K.M., & Pollack, M. (1997). Differences in severity-adjusted pediatric hospitalization rates are associated with Race/Ethnicity. *Pediatrics, 19* (6), e1319-e1324.

Chen, J. & Rankin, S. (2002). Using the Resiliency Model to deliver culturally sensitive care to Chinese families. *Journal of Pediatric Nursing, 17* (3), 157-166.

Child Trends. (2006). Retrieved August 15, 2008 from: http://www.childtrendsdatabank.org/indicators/63ChildMortality.cfm

Cohen, J. (1977). *Statistical power analysis for behavioral sciences.* New York. Academic Press.

Cohen, J. (1988). *Statistical power analysis for behavioral sciences* (2nd ed). Hillsdale, NJ. Lawrence Erlbaum.

Colville, G., & Gracey, D. (2006). Mothers' recollections of the Paediatric Intensive Care Unit: associations with psychopathology and views on follow up. *Intensive & Critical Care Nursing, 22*(1), 49-55.

Cubbin, C., LeClere, F.B. & Smith, G.S. (2000). Socioeconomic status and occurrence of fatal and non fatal injury in the United States. *American Journal of Public Health, 90* (1), 70-77.

Curley, M. (1988). Effects of the nursing mutual participation model of care on parental stress in the pediatric intensive care unit. *Heart & Lung, 17*(6), 682-688.

Curley, M. & Wallace, J. (1992). Effects of the nursing mutual participation model of care on parental stress in the pediatric intensive care unit: A replication. *Journal of Pediatric Nursing, 7*(6), 377-84.

Danielson, C., Hamel-Bissell, B., & Winstead-Fry, P. (1993). *Families, health, and illness*. St. Louis: Mosby.

Deonandan, R., Campbell, K., Ostbye, T., Trummon, I., & Robertson, J. (2000). A comparison of methods for measuring socio-economic status by occupation or postal area. 21(3), 1-8. Retrieved online January 30, 2009 from: http://www.phac-aspc.gc.ca/publicat/cdic-mcc/21-3/c_e.html.

De Vries, A., Kassam-Adams, N., Cnaan, A., Sherman-Slate, E., Gallagher, P., & Winston, F. (1999). Looking beyond the physical injury: Posttraumatic stress disorder in children and parents after pediatric traffic injury. *Pediatrics, 104*(6), 1293-1299.

Doucette, J. & Pinelli, J. (2004). The effects of family resources, coping, and strains on family adjustment 18 to 24 months after the NICU experience. *Advances in Neonatal Care, 4*(2): 92-104.

Duncan, G. & Magnuson, K. (2003). Off with Hollingshead: Socioeconomic resources, parenting, and child development (pp.83-105). In M. Bornstein & R. Bradley (Eds) *Socioeconomic Status, Parenting, and Child Development*. Hillsdale, NJ. Lawrence Erlbaum Associates

Eberly, T., Miles, M., Carter, M., Hennessey, J. & Riddle, I. (1985) Parental stress after the unexpected admission of a child to the intensive care unit. *Critical Care Quarterly 8(*1), 57–65.

Edwards, J. R., & Bagozzi, R. P. (2000). On the nature and direction of relationships between constructs and measure. *Psychological Methods, 5*, 155-174.

Faelker, T., Picket, W., & Brison, R. J. (2000). Socioeconomic differences in childhood injury: A population based epidemiologie study in Ontario, Canada. *Injury Prevention, 6*, 203-208.

Fernando, S. (2003). *Cultural diversity, mental health, a psychiatry: The struggle against racism.* New York: Brunner-Routledge.

Folkman, S., & Lazarus, R. (1980). An analysis of coping in a middle-aged community sample. *Journal of Health and Social Behavior, 21*, 219-239.

Florian, V. & Findler, L. (2001). Mental health and marital adaptation among mothers of children with cerebral palsy. *American Journal of Orthopsychiatry*, 71(3), 358-367.

Frazier, A., Frazier, H., & Warren, N. (2010). A discussion of family-centered care within the pediatric intensive care unit. *Critical Care Nursing Quarterly, 33*(1), 82-86.

Graves, J. & Ware, M. (1990). Parents' and health professionals' perceptions concerning parental stress during a child's hospitalization. *Children's Health Care, 19*(1), 37-42.

Grootenhuis, M. A., & Last, B. F. (1997). Predictors of parental emotional adjustment to childhood cancer. *Psycho-Oncology, 6,* 115– 128.

Hall, E., Saxe, G., Stoddard, F., Kaplow, J., Koenen, K., Chawla, N., Lopez, C., King, L., & King, D. (2006). Posttraumatic stress symptoms in parents of children with acute burns. *Journal of Pediatric Psychology, 31* (4), 403-412.

Haines, C., Perger, C., & Nagy, S. (1995). A comparison of the stressors experienced by parents of intubated and non-intubated children. *Journal of Advanced Nursing, 21*(2), 350-355. Retrieved September 3, 2008, from CINAHL Plus with Full Text database.

Hamilton, S. & Fagot, B. (1988). Chronic stress and coping styles: A comparison of male and female undergraduates. *Journal of Personality and Social Psychology, 55*(5), 819-823.

Heuer, L. (1993). Parental stressors in a pediatric intensive care unit. *Pediatric Nursing, 19*(2), 128-133. Retrieved September 3, 2008, from CINAHL Plus with Full Text database.

Hill, R. (1949). *Families under stress*. New York. Harper & Brothers.

Holditch-Davis, D. & Miles, M. (2000). Mother’s stories about their experience in the neonatal intensive care unit. *Neonatal Network*, *19*(3), 13-21.

Huckabay, L. & Tilem- Kessler, D. (1999). Patterns of parental stress in PICU emergency admission. *Dimensions of Critical Care Nursing*, *18*(2), 36-42.

Institute for Family-Centered Care. (2004). Family-Centered Care: Questions and answers. Retrieved June 13, 2004 from http//www.familycenteredcare.org.

Johnson P., Nelson G., & Brunnquell D. (1988). Parent and nurse perceptions of parent stress in the pediatric intensive care unit. *Children's Health Care 17*(2), 98–105.

Jones, S., Fiser, D., & Livingston, R. (1992). Behavioral Changes in Pediatric Intensive Care Units. *American Journal of Diseases of Children*, 146(3), 375-379.

Kasper, J. & Nyamathi, A. (1988). Parents of children in the pediatric intensive care unit: what are their needs? *Heart & Lung*, *17*(5), 574-581. Retrieved September 3, 2008, from CINAHL Plus with Full Text database.

Katz, S. (2002). When the child's illness is life threatening: impact on the parents. *Pediatric Nursing*, *28*(5), 453.

Kazak, A., Alderfer, M., Rourke, M., Simms, S., Streisand, R., & Grossman, J. (2004). Posttraumatic stress disorder (PTSD) and posttraumatic stress symptoms (PTSS) in families of adolescent childhood cancer survivors. *Journal of Pediatric Psychology*, *29*(3), 211-219.

Kirschbaum, M. (1990). Needs of parents of critically ill children. *Dimensions of Critical Care Nursing*, *9*(6), 344–352.

Kosciulek, J., McCubbin, M. & McCubbin, H. (1993). A theoretical framework for family adaptation to head injury. *Journal of Rehabilitation*, 59, 40-45.

Kristensson-Hallstrom, I. (2000). Parental participation in pediatric surgical care. *Association of Operating Room Nurses Journal, 71*(5), 1021.

LaMontagne, L. & Pawlak, R. (1990). Stress and coping of parents and children in a pediatric intensive care unit. *Heart Lung*, 19, 416–421.

Lazarus, R. S. & Folkman, S. (1984). *Stress, appraisal, and coping.* New York: Springer Publishing Company.

Leske, J. & Jiricka, (1998). Impact of family demands and family strengths and capabilities on family well-being and adaptation after critical injury. *American Journal of Critical Care, 7(*5), 383-92.

Lewandowski L. (1980). Stresses and coping styles of parents and children undergoing open heart surgery. *Critical Care Quarterly 3*, 75–84.

Lin, S. L. (2000). Coping and adaptation in families of children with cerebral palsy. *Exceptional Children*, 66, 201–218.

Lipman-Blumen, J. (1975). A crisis framework applied to macrosociological family changes: Marriage, divorce, occupational trends associated with World War II. *Journal of Marriage and the Family, 3,* 889-902.

Lipsey, M. (1990). Design Sensitivity: Statistical Power for Experimental Research. Thousand Oaks, CA. Sage.

Lustig, D. (1999). Families with an adult with mental retardation: Predictors of family adjustment. *Journal of Applied Rehabilitation Counseling, 30*(3), 11-18.

Lustig, D. & Thomas, K. (1997). Adaptation of families to the entry of young adults with mental retardation into supported employment. *Education & Training in Mental Retardation & Developmental Disabilities, 32*(1), 21-31.

Lynch, W., Kaplan, G., & Salonen, J. (1997). Why do poor people behave poorly? Variation in adult health behaviours and psychosocial characteristics by stages of the socioeconomic lifecourse. *Social Science & Medicine, 44*(6), 809-819.

Manne, S., DuHamel, K., Nereo, N, Ostroff, P., Parsons, S., Martini, R., Williams, S., Mee, L., Sexson, S., Wu, L., Difede, J., & Redd, W. (2002). Predictors of PTSD in mothers of children undergoing bone marrow transplantation: The role of cognitive and social processes. *Journal of Pediatric Psychology, 27*(7), 607-617.

Marcin, J., Shembri, M., He, J. & Romano, P. (2003). A population based analysis of socioeconomic status and insurance status and their relationship with pediatric trauma and hospitalization rates. *American Journal of Public Health, 93,* 461-466.

McCubbin, M. (1989). Family stress and family strengths: a comparison of single- and two-parent families with handicapped children. *Research in Nursing and Health, 12*, 101–110.

McCubbin, M., & McCubbin, H. (1989). Theoretical orientations to family stress and coping. In C.R. Figley (Ed.), *Treating stress in families* (p.3-43). New York: Brunner/Mazel.

McCubbin, M., & McCubbin, H. (1993). Families coping with Illness: The resiliency model of family stress, adjustment, and adaptation. In C. Danielson, B. Hamel-Bissell, & P. Winstead-Fry (Eds.), *Families Health and Illness* (pp. 21-63*).* St. Louis: Mosby.

McCubbin, M., McCubbin, H., Patterson, J., Cauble, E., Wilson, L. & Warwick, W. (1983). CHIP. Coping health inventory for parents: An assessment of parental coping patterns in the care of the chronically ill child. *Journal of Marriage and the Family, 45*(2), 359-370.

McCubbin, H. & Patterson, J. (1983). Family transitions: Adaptation to stress. In H. McCubbin & C. Figley (Eds), *Stress and the Family Volume I: Coping with Normative Transitions* (pp. 5-25). New York: Brunner/Mazel Inc.

McCubbin, H., Thompson, A., & McCubbin, M. (1996). *Family assessment: Resiliency, coping and adaptation. Inventories for research and practice.* Madison: University of Wisconsin System.

Melnyk, M. & Alpert-Gillis, L. (1998). The COPE program: a strategy to improve outcomes of critically ill young children and their parents. *Pediatric Nursing, 24* (6), 521-7.

Melnyk, B., Alpert-Gillis, L., Hensel, P., Cable-Beiling, R., & Rubenstein, J. (1997). Helping mothers cope with a critically ill child: a pilot test of the COPE intervention. *Research in Nursing & Health, 20*(1), 3-14.

Melnyk, B., Alpert-Gillis, L., Feinstein, N., Crean, H., Johnson, J., Fairbanks, E., Small, L., Rubenstein, J., Slota, M., & Corbo-Richert, B. (2004). Creating opportunities for parent empowerment: program effects on the mental health/coping outcomes of critically ill young children and their mothers. *Pediatrics, 113*(6 part 1), e597-607. Retrieved September 3, 2008, from CINAHL Plus with Full Text database.

Melnyk, B. & Feinstein, N. (2001). Mediating functions of maternal anxiety and participation in care on young children's posthospital adjustment. *Research in Nursing & Health, 24(*1), 18-26.

Melnyk, B., Feinstein, N., & Fairbanks, E. (2006). Two decades of evidence to support implementation of the COPE program as standard practice with parents of young unexpectedly hospitalized/critically ill children and premature infants. *Pediatric Nursing, 32*(5), 475-81.

Melnyk, B., Small, L., & Carno, M. (2004). The effectiveness of parent-focused interventions in improving coping/mental health outcomes of critically ill children and their parents: an evidence base to guide clinical practice. *Pediatric Nursing, 30* (2), 143-8.

Mertler, C. A. & Vannatta, R.A. (2001). *Advanced and Multivariate Statistical Methods*: Practical Application and Interpretation.(2nd Ed). Los Angeles, CA. Pyrczak Publishing.

Meyer, E., DeMaso, D., & Koocher, G. (1996). Mental health consultation in pediatric intensive care unit. *Professional Psychology Research & Practice*, *27* (2), 130–136.

Meyer, E., Snelling, L., & Myren-Manbeck, L. (1998). Pediatric intensive care: the parent's experience. *AACN Clinical Issues: Advanced Practice in Acute & Critical Care, 9*(1), 64-74. Retrieved September 3, 2008, from CINAHL Plus with Full Text database.

Miles M. & Carter M. (1982). Sources of parental stress in pediatric intensive care units. *Children's Health Care 11*(2), 65–69.

Miles M. & Carter M. (1983). Assessing parental stress in the intensive care unit. *Maternal-Child Health Nursing 8,* 354–359.

Miles M., Carter M., Riddle I., Hennessey J. & Eberly T. (1989). The pediatric intensive care unit environment as a source of stress for parents. *Maternal Child Health Journal 18*(3), 199–206.

Miles M., Carter M., Spicher C. & Hassanein R. (1984). Maternal and paternal stress reactions when a child is hospitalised in a pediatric intensive care unit. *Issues in Comprehensive Pediatric Nursing 7,* 333–342.

Miles, M., Funk, S., & Kasper, M. (1991). The neonatal intensive care unit environment: Sources of stress for parents. *AACN Clinical Issues*, *2*(2), 346-354.

Miles, M., Funk, S., & Kasper, M. (1992). The stress response of mothers and fathers of preterm infants. *Research in Nursing & Health*, *15*(4), 261-269.

Mishel, M. H. (1981). The measurement of uncertainty in illness. *Nursing Research, 30,* 258–263.

Mishel, M. H. (1984). Perceived uncertainty and stress in illness. *Research in Nursing and Health, 7,* 163–171.

Mishel, M. H. (1988). Uncertainty in illness. *IMAGE: Journal of Nursing Scholarship, 20,* 225–232.

Mitchell, M. (1999). Prospective study of family adjustment and adaptation following pediatric hospitalization. Unpublished doctoral dissertation. Vanderbilt University.

Mu, P. F. (2005). Paternal reactions to a child with epilepsy: Uncertainty, coping strategies, and depression. *Journal of Advanced Nursing, 49,* 367–376.

Mu, P., Ma, F. C., Hwang, B., & Chao, Y. M. (2002). Families of children with cancer: The impact on anxiety experienced by fathers. *Cancer Nursing, 25,* 66–73.

Mu, P., Ma, F., Ku, S., Shu, H., Hwang, B., & Ku, B. I. (2001). Families of Chinese children with malignancy: The factors impact on mother's anxiety. *Journal of Pediatric Nursing, 16,* 287–295.

Mu, P. F., Wong, T. T., Chang, K. P., & Kwan, S. Y. (2001). Predictors of maternal depression for families having a child with epilepsy. *Journal of Nursing Research, 9,* 116–126.

Naclerio A., Gardner, J., & Pollack, M. (1999). Socioeconomic factors and emergency pediatric ICU admissions. *Annals of the New York Academy of Sciences, 896,* 379– 382.

National Center for Children in Poverty. (2010). Who are America's Poor Children? Retrieved July 25, 2010 from: http://nccp.org/publications/pub_912.html.

National Center for Educational Statistics. (2008). Glossary. Retrieved March 31, 2008 from: http://nces.ed.gov/programs/coe/glossary/s.asp

Navarro, V. (1991). Race or class or race and class: Growing mortality differentials in the United States. *International Journal of Health Services, 21*, 229-235.

Neupert, S., Soederberg, L., & Lachman, M. (2006). Physiological reactivity to cognitive stressors: Variations by age and socioeconomic status. *The International Journal of Aging and Human Development, 62*(3), 221-235.

Newacheck, P. & Stoddard, J. (1994). Prevalence and impact of multiple childhood chronic illnesses. *Journal of Pediatrics*, *124*, 40-48.

Noyes, J. (1998). A critique of studies exploring the experiences and needs of parents of children admitted to paediatric intensive care units. *Journal of Advanced Nursing, 28*(1), 134-141. Retrieved September 3, 2008, from CINAHL Plus with Full Text database.

Norman, G. & Streiner, D. (2004). *PDQ Statistics* (2nd Ed). Philadelphia, PA. B.C. Decker.

Office of Management & Budget. (1997). *Revisions to the standards for the classification of federal data on race and ethnicity*. Retrieved August 29, 2010, from http://www.whitehouse.gov/omb/fedreg_1997standards.

Orbuch, T.,Parry, C., Chesler, M., Fritz, J. & Repetto, P. (2005). Parent-child relationships and quality of life: Resilience among childhood cancer survivors. *Family Relations, 54*(2), 171-183.

Ouwehand, C., de Ridder, D., & Bensing, J. (2009). Who can afford to look to the future? The relationship between socio-economic status and proactive coping. *European Journal of Public Health, 19*(4), 412-417.

Pearlin, L. I., & Schooler, C. (1978). The structure of coping. *Journal of Health and Social Behavior, 19,* 2–21.

Philichi, L. (1988). Supporting the parents when the child requires intensive care. *Focus on Critical Care, 15*(2), 34-38.

Pinelli, J. (2000). Effects of family coping and resources on family adjustment and parental stress in the acute phase of the NICU experience. *Neonatal Network, 19*(6), 27-37.

Polit, D. & Beck, C. (2004) *Nursing Research: Principles and Methods* (7th Ed). Philadelphia. Lippincott Williams & Wilkins.

Pollack, M. (1993). Outcome assessment. *Critical Care Medicine, 21*(9), 395-396.

Porter, L. S., & Stone, A. A. (1995). Are there really gender differences in coping? A reconsideration of previous data and results from a daily study. *Journal of Social and Clinical Psychology, 14,* 184–202.

Radina, M. & Armer, J. (2004). Surviving breast cancer and living with lymphedema: resiliency among women in the context of their families. *Journal of Family Nursing, 10*(4), 485-505.

Raina P., O’Donnell, M., Schwellnus, H., Rosenbaum, P., King, G., Brehaut, J., Russell, D., Swinton, M., King, S., Wong, M., Walter, S. & Wood, E. (2004). Caregiving process and caregiver burden: conceptual models to guide research and practice. *Biomed Central Pediatrics, 4*(1). Retrieved online January 18, 2009 from: http:// http://www.biomedcentral.com/content/pdf/1471-2431-4-1.pdf.

Rees, G., Gledhill, J., Garralda, M. E. & Nadel, S. (2004). Psychiatric outcome following paediatric intensive care unit (PICU) admission: a cohort study. *Intensive Care Medicine*, 30, 1607-1614.

Rei, R., & Fong, C. (1996). The Spanish version of the Parental Stressor Scale: Pediatric Intensive Care Unit. *Journal of Pediatric Nursing, 11*(1), 3-9. Retrieved September 3, 2008, from CINAHL Plus with Full Text database.

Reid, C. (2002). A full measure: A women's occupational stand health status. *Centre of Excellence for Women's Health Research Bulletin, 2*(3). Retrieved online January 28, 2009 from: www.cewh-cesf.ca/bulletin/v2n3/page2.html.

Ren, X.S. & Amick, B.C. (1996). Race and self assessed helath status: The role of socioeconomic factors in the USA. *Journal of Epidemiology and Community Health, 50*, 269-273.

Riddle I., Hennessey J., Eberly T., Carter M. & Miles M. (1989). Stressors in the pediatric intensive care unit as perceived by mothers and fathers. *Maternal-Child Nursing Journal 18*(3), 221–234.

Rosario, M., Shinn, M., Morch, H., & Huckabee, C. B. (1988). Gender differences in coping and social supports: Testing socialization and role constraint theories. *Journal of Community Psychology, 16*, 55–69.

Ross C. E., Wu, C. (1995). The links between education and health. *American Sociology Review*, 60, 719–45.

Rothstein, P. (1980). Psychological stress in families of children on a pediatric intensive care unit. *Pediatric Clinics of North America, 27*(3), 613-620.

Rungreangkulkij, S. (2000). *Experience of Thai families of a person with schizophrenia: Family stress and adaptation*. Unpublished doctoral dissertation. University of California, San Francisco.

Rungreangkulkij, S.,Chafetz, L., Chelsa, C., & Gilliss, C. (2002). Psychological morbidity of Thai families of a person with schizophrenia. *International Journal of Nursing Studies, 39* (1), 35-50.

Saied, H. (2006). *Stress, coping, and social support and adjustment among families of CHD children in PICU after heart surgery*. Case Western Reserve University. Cleveland, OH. Retrieved September 3, 2008, from CINAHL Plus with Full Text database.

Scholer, S., Mitchel, E., & Ray, W. (1997). Predictors of injury mortality in early childhood. *Pediatrics, 100*(3), 342-347.

Scott, L. (1998). Perceived needs of parents of critically ill children. *Journal of the Society of Pediatric Nurse, 3*(1), 4-12.

Seideman, R., Watson, M., Corff, K., Odle, P., Haase, J., & Bowerman, J. (1997). Parent stress and coping in NICU and PICU. *Journal of Pediatric Nursing, 12(*3), 169-177. Retrieved September 3, 2008, from CINAHL Plus with Full Text database.

Shadish, W., Cook, T., & Campbell, D. (2001). *Experimental and Quasi-Experimental Designs for Generalized Causal Inference*. Boston. Houghton Mifflin.

Shaner K. & Eckle N. (1997). Implementing a program to support the option of family presence during resuscitation. *ACCH Advocate*, 3(1), 3-7.

Shavers, V. (2007). Measurement of socioeconomic status in health disparities research. *Journal of the National Medical Association, 99*(9), 1013-1023.

Shields, J. (2001). The NAS earlybird programme: Partnership with parents in early intervention. *Autism, 5,* 49–56.

Stone, A. A., & Neale, J. M. (1984). New measure of daily coping: Development and preliminary results. *Journal of Personality and Social Psychology, 46,* 892–906.

Stuber, M., Kazak, A., Meeske, K., Barakat, L., Guthrie, D., Garnier, H., Pynoos, R., & Meadows, A. (1997). Predictors of posttraumatic stress symptoms in childhood cancer survivors. *Pediatrics, 100*(6), 958-964.

Svavarsdottir, E. (2005). Caring for a child with cancer: a longitudinal perspective. *Journal of Advanced Nursing 50*(2), 153–161.

Svavarsdottir, E. & McCubbin, M. (1996). Parenthood transition for parents of an infant diagnosed with a congenital heart condition. *Journal of Pediatric Nursing, 11*(4), 207-216.

Svavarsdottir, E., McCubbin, M., & Kane, J. (2000). Well being of parents of young children with asthma. *Research in Nursing & Health, 23*(5), 346-358.

Tabachnick, B. & Fidell, (1996). *Using multivariate statistics* (3rd ed). New York. Harper Collins Publishers.

Tak, Y. (1995). Family stress, perceived social support, and coping of family who has a child with chronic illness. *Dissertation Abstracts International: Section B: The Sciences and Engineering, 55*(10-B), 4624.

Tak, Y. & McCubbin, M. (2002). Family stress, perceived social support and coping following the diagnosis of a child’s congenital heart disease. *Journal of Advanced Nursing, 39*(2), 190-198.

Tamres, L., Janicki, D., & Helgeson, V. (2002). Sex differences in coping behavior: A meta-analytic review and an examination of relative coping. *Personality and Social Psychology Review, 6*(1), 2-30.

Thoits, P. A. (1994). Stressors and problem-solving: The individual as psychological activist. *Journal of Health and Social Behavior, 35,* 143–160.

Thompson, D. (Ed.) (1998). *Oxford dictionary of current English.* New York. Oxford University Press.

Tomlinson, P., Kirschbaum, M., Harbaugh, B., & Anderson, K. (1996). The influence of illness severity and family resources on maternal uncertainty during critical pediatric hospitalization. *American Journal of Critical Care, 5*(2): 140-6.

Tomlinson, P., Swiggum, P., & Harbaugh, B. (1999). Identification of nurse-family intervention sites to decrease health-related family boundary ambiguity in PICU. *Issues in Comprehensive Pediatric Nursing, 22*(1), 27-47. Retrieved September 3, 2008, from CINAHL Plus with Full Text database.

U.S. Census Bureau. (2002). *The big payoff: Educational attainment and synthetic estimates of work-life earnings*. Retrieved online June 2010 from: http://www.census.gov/prod/2002pubs/p23-210.pdf

U.S. Census Bureau. (2005). *Race and Ethnicity Identification*. Retrieved August 31, 2008 from: http://www.census.gov/hrd/www/new_emp/sf181.pdf

U.S. Census Bureau. (2008). *U.S. Census Bureau News: An Older and More Diverse Nation by Midcentury*. Retrieved online August 21, 2008 fromhttp://www.census.gov/Press-Release/www/releases/archives/population/012496.html.

Vandsburger, E & Biggerstaff, M. (2004). Evaluation of the Stress Adjustment and Adaption Model among families reporting economic pressure. *Journal of Family Social Work.*, 8(2), 65-84.

Weitzman, P.F., Chee, Y.K., & Levkoff, S.E. (1999). A social and cognitive examination of responses to family conflict by African-American and Chinese-American caregivers. *American Journal of Alzheimer's Disease, 14,* 343-350.

Wereszczak, J., Miles, M.S., & Holditch-Davis, D. (1997). Maternal recall of the neonatal intensive care unit. *Neonatal Network,* 16(4), 33-40.

Yam, B., Lopez, V., & Thompson, D. (2004). The Chinese version of the PSS:PICU. *Nursing Research, 53*(1), 19-27. Retrieved September 3, 2008, from CINAHL Plus with Full Text database.

Yeates, K., Taylor, G., Woodrome, S., Wade, S., Stancin, T., & Drotar, D. (2002). Race as a moderator of parent and family outcomes following pediatric traumatic brain injury. *Journal of Pediatric Psychology, 27*(4), 393-403.

Youngblut, J., Brooten, D., & Kuluz, J. (2005). Parents' reactions at 24-48 hrs after a preschool child's head injury. *Pediatric Critical Care Medicine, 6*(5), 550-556. Retrieved September 3, 2008, from CINAHL Plus with Full Text database.

Youngblut J. & Jay S. (1991). Emergent admission to the pediatric intensive care unit: parental concerns. *AACN Clinical Issues*, *2*(2), 329–337.