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Traumatic Stress Responses in Mothers and Fathers to Pediatric Intensive Care Treatment: The Role of Beliefs

Carla Cirilli
Philadelphia College of Osteopathic Medicine, Carlaci@pcom.edu

Philadelphia College of Osteopathic Medicine

Department of Psychology

TRAUMATIC STRESS RESPONSES IN MOTHERS AND FATHERS TO

PEDIATRIC INTENSIVE CARE TREATMENT: THE ROLE OF BELIEFS

By Carla Cirilli

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Dissertation Approval

This is to certify that the thesis presented to us by _Carla Cirilli_

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requirements for the degree of Doctor of Psychology, has been examined and is

acceptable in both scholarship and literary quality.

Committee Members' Signatures:

Susan Mindel, PhD, Chairperson

Elizabeth Gosch, PhD

Chiara Baxt, PhD

Robert A DiTomasso, PhD, ABPP, Chair, Department of Psychology

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Abstract

The aim of this study was to examine the prevalence of traumatic stress responses in parents of

children treated in a pediatric intensive care unit, specifically parental beliefs about their child's

illness and their own coping self-efficacy as related to the severity of parental acute and

posttraumatic stress. Archival data from a study conducted August 2004 through July 2005 in the

Children's Hospital of Philadelphia PICU were used. Two hundred and forty-five parents were

assessed at 48 hours after admission, and 180 parents were assessed 3 months postdischarge. At

Time 1, parents completed a screening measure assessing psychosocial factors and an acute

stress disorder (ASD) questionnaire. At Time 2, parents completed a posttraumatic stress

disorder (PTSD) questionnaire. Descriptive analyses examined rates of ASD and PTSD. Chi-

square analyses examined gender differences in these rates. Correlations and hierarchical

multiple regression analyses examined the relationships between parental risk factors and ASD

and PTSD severity. Twenty-seven percent of parents developed ASD and 37% met

subsyndromal criteria, with mothers endorsing higher rates of ASD. Four percent of parents

developed PTSD and 14% met subsyndromal criteria, with no gender differences in these rates.

Numerous psychosocial risk factors correlated with ASD symptom severity in all parents, but

with PTSD symptom severity only in mothers. Maladaptive illness beliefs and low coping self-

efficacy explained a significant amount of variance in ASD and PTSD symptom severity. While

two specific beliefs were highly correlated with ASD and PTSD symptom severity in all parents,

differences were found in the type of beliefs correlated with maternal and paternal ASD and

PTSD symptom severity. Assessments and interventions should be targeted to appropriately

support traumatic stress responses in PICU mothers and fathers of children in PICUs.

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Chapter One

Introduction

Overview

Approximately 200,000 children are admitted annually to pediatric intensive care units (PICU) in the United States (Colville, 2008; Odetola, Clark, Freed, Bratton, & Davis, 2005). The PICU serves as the highest level of acute care available for the most critically ill and injured children who are facing life-threatening circumstances. A child's hospitalization in the PICU is a stressful experience that impacts not only the child, but also the whole family. Numerous studies have described the initial parental response as a crisis, a shock, or a "shattering of their normal lives" (Huckabay & Tilem-Kessler, 1999; Jay, 1977; Miles, 1979; Noyes, 1999, p. 430). The parental response to a child's PICU experience has been of particular concern because of its immediate and lasting impact on the child's and family's functioning and quality of life (Shudy et al., 2006). Studies have demonstrated myriad detrimental effects, such as weaker marital and family cohesion, negative socioeconomic impact, and even deteriorated physical health of parents after pediatric trauma (Shudy et al., 2006; Winthrop et al., 2005; Youngblut & Shiao, 1993).

Pediatric psychology research has been investigating the parental experience of PICU hospitalization for decades, identifying common stressors related to environmental, situational, and interpersonal factors (Board & Ryan-Wenger, 2003; Etzler, 1984; Miles, Carter, Riddle, Hennessey, & Eberly, 1989b). In response to findings that largely demonstrated parental feelings of fear and helplessness accompanied by impaired functioning, more attention was paid to this particular population (Miles, Carter, Riddle,

et al., 1989; Miles & Carter, 1982). Most recently, a child's hospitalization for illness or

injury has been conceptualized as a potentially traumatic event for parents, allowing for

the application of a traumatic stress framework to describe the parental stress response

(de Vries et al., 1999; Kazak, Boeving, Alderfer, Hwang, & Reilly, 2005).

      The immediate stress experienced by parents in response to a child's acute critical

illness or injury and associated PICU hospitalization can be measured and described on a

continuum of acute stress symptomatology. As currently defined in the American

Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders, 4th*

Edition, Text Revision (*DSM-IV-TR*), this acute stress response includes symptoms of

dissociation, re-experiencing, avoidance, and hyperarousal within 2 days and 4 weeks of

a traumatic event, such as a child's PICU admission. With the exception of dissociation,

the persistence of these symptoms in individuals for more than 1 month after the

traumatic event can be measured and described on a continuum of posttraumatic stress

symptomatology (*DSM IV-TR*; American Psychiatric Association, 2000).

      Past studies have demonstrated that parents with children admitted to the PICU do

indeed endorse both acute traumatic stress symptoms during the hospitalization and

persistently after several months (Balluffi et al., 2004; Colville, 2008). Approximately

one third (32%) of parents have been found to meet symptom criteria for acute stress

disorder (ASD) during a child's PICU admission, while a range of 12 to 48% of parents

have been found to meet symptom criteria for posttraumatic stress disorder (PTSD) 2

months or more following discharge (Balluffi et al., 2004; Bronner et al., 2009; Bronner,

Knoester, Bos, Last, & Grootenhuis, 2008; Rees, Gledhill, Garralda, & Nadel, 2004).

Although no significant differences have been found in parental development of ASD, mothers have been found to develop PTSD more often than fathers, with one recent study reporting rates of 24% and 4%, respectively (Balluffi et al., 2004; Bronner et al., 2008; Bronner et al., 2010). This finding corroborates a well-established statistic in the literature regarding higher PTSD prevalence in women than men within the general population of the United States, with rates of full and subsyndromal PTSD in women reaching almost double the rates in men (Pietrzak, Goldstein, Southwick, & Grant, 2011).

Few studies have investigated the relationship between parental factors (e.g., gender, age, ethnicity) as well as situational factors (e.g., unexpected PICU admission, child diagnosis, length of hospitalization) and the development of acute and posttraumatic stress in PICU parents (Balluffi et al., 2004; Bronner et al., 2008; Bronner et al., 2010; Miles, Carter, Hennessey, Eberly, & Riddle, 1989a). Research findings consistently demonstrate that parental perceptions about the situation play a significant role in determining the severity of the parental stress response (Carnevale, 1990; LaMontagne & Pawlak, 1990; Miles, Carter, Riddle, et al., 1989; Youngblut & Shiao, 1993). More specifically, it has been demonstrated that parents' subjective perceptions about their child's illness or injury and associated life-threat, rather than objective characteristics, are strongly related to the development of parental ASD and PTSD (Balluffi et al., 2004).

The course of the parental traumatic stress response to a child's PICU admission remains unclear, as only a small number of studies have begun to identify risk factors for traumatic stress in PICU parents (Balluffi et al., 2004; Rees et al., 2004). Furthermore, recent studies have begun to investigate the predictive validity of acute stress symptoms

in determining risk for PTSD in parents after pediatric trauma (Balluffi et al., 2004;

Bronner et al., 2010). Persistent PTSD symptoms in PICU parents have been found to be

associated with prior trauma exposure, prior psychopathology, and more severe acute

stress symptom severity (Balluffi et al., 2004; Bronner et al., 2010).

While parental beliefs about their own ability to cope with a crisis situation such

as a child's PICU hospitalization have not been investigated prior to this current study,

previous research has demonstrated that coping self-efficacy beliefs are strongly

predictive of posttrauma psychological adjustment, with some findings suggesting a

mediating role between negative cognitions and the development of posttraumatic stress

in other trauma-exposed populations (Cieslak, Benight, & Lehman, 2008). These findings

suggest that parental beliefs about their own coping self-efficacy play a significant role,

along with parental beliefs about their child's illness or injury, in determining who is at

risk for the development of acute and posttraumatic stress.

Purpose of the Study

The purpose of the current study was three-fold. First, prevalence rates of parental

acute and posttraumatic stress symptoms relating to a child's PICU treatment at a large

urban children's hospital were examined and compared to rates reported in the literature.

Furthermore, these rates of parental acute and posttraumatic stress were examined to

determine if differences existed between mothers and fathers. A second purpose of the

current study was to examine the relationship between maternal and paternal beliefs

about (a) their child's condition and (b) their own coping self-efficacy with parental acute

and posttraumatic stress reactions. Finally, this study investigated the predictive

relationship between these same parental beliefs at the time of a child's PICU

hospitalization and subsequent parental posttraumatic stress reactions3 months

postdischarge.

A better understanding of the prevalence and nature of the stress response in

parents following a child's PICU admission is necessary to raise awareness among

medical and mental-health professionals and to inform psychosocial services that can

support families during and after a child's PICU admission. Furthermore, a better

understanding of the relationship between parental beliefs and traumatic stress

symptomatology is necessary to develop and implement appropriate and effective

therapeutic assessment and interventions.

The results of the current study contribute to the broad and general knowledge

base that informs the profession of pediatric psychology. With the advent of this and

other studies, the field of pediatric psychology moves toward a more precise

understanding of the parental experience and response to a child's PICU hospitalization.

Ultimately, these advancements serve to increase awareness, inform practice, and

facilitate collaboration among medical and mental-health professionals who care for

children and families during and after PICU hospitalization.

Chapter Two

Literature Review

Early Studies on the Parental Experience

Early research into the parental PICU experience was prompted by consistent clinical findings of parental distress in the PICU setting. Critical-care professionals, especially nurses, sought ways to better understand and adequately respond to the needs of PICU patients and their families (Etzler, 1984; Jay, 1977; Miles, 1979; Miles & Carter, 1982). This early research focused on anecdotal accounts of the parental experience in order to identify the major causes of parental stress and devise interventions to alleviate this distress. One early descriptive study identified nearly 300 needs of PICU parents, with more than 50% being categorized as psychological needs, such as emotional support and reassurance (Kasper & Nyamathi, 1988). LaMontagne, Johnson, and Hepworth (1995) incorporated theoretical and research findings from these early studies to design a framework for critical-care practice, emphasizing the need for assessment of parental stress and for interventions that reduced distress and supported adaptive coping.

As the literature accumulated, studies became more sophisticated, and conceptual frameworks were modified. For instance, a "hierarchy of parental needs in the PICU" was developed, based on Maslow's hierarchy of needs, as a method of prioritizing parents' physiological needs, such as sleeping and eating, over their need for parental role fulfillment (Meyer, Snelling, & Myren-Manbeck, 1998, p. 64). As conceptualization and methodology evolved, however, the same main themes continued to emerge when describing the PICU parental experience. Indeed, categories of parental PICU stressors

that were identified early-on are still relevant in organizing the current conceptualization

of the parental experience (Carter & Miles, 1989; Melnyk, 2000).

Environmental Stressors

The physical PICU setting in and of itself has been identified as a source of stress

for parents, especially when admission is unplanned (Miles, 1979). In particular, the

unfamiliar sights, smells, and sounds of monitors, alarms and a "frightening array of

technological equipment" contribute to a sense of urgency and distress for parents

(Haines, Perger, & Nagy, 1995, p. 350; Miles, Carter, Hennessey, et al., 1989).

Additionally, parents have reported that the unfamiliar layout, rules, routines and staff

organization of the hospital unit contribute to their uncertainty and distress (Turner,

Tomlinson, & Harbaugh, 1990). Finally, parents can become distressed simply as a result

of their exposure to other pediatric patients' life-threatening conditions, traumatic

treatment procedures, and death (Ward-Begnoche, 2007).

Situational Factors

In a review of the literature, Ward-Begnoche (2007) distinguished between

condition-related trauma, or distress pertaining to the illness or injury itself, and

treatment-related trauma, or distress in reaction to the invasive, painful and often

frightening procedures that occur in the PICU. These two types of trauma may be

experienced not only by the child as patient, but also by the parents. Past studies

demonstrate that parents identify numerous distressing factors, such as the child's

appearance and behavior, the child's experience of pain and painful procedures, such as

needle sticks and injections, and parental fear of the child's death or severe disability

(Miles, 1979; Miles, Carter, Riddle, et al., 1989). Indeed, concerns over their child's

immediate safety and degree of worry over their child's life threat have been consistently

described as main sources of stress for PICU parents (Balluffi et al., 2004; Carnevale,

1990; LaMontagne & Pawlak, 1990; Youngblut & Shiao, 1993). Parents experience a

sense of helplessness and guilt when witnessing their child's altered appearance,

experience of pain, and emotional sense of fear or sadness (Miles, Carter, Riddle, et al.,

1989; Miles & Carter, 1982). Moreover, uncertainty over their child's treatment plan,

prognosis, and overall healthcare management has been found to contribute to distress

(Turner et al., 1990).

Disruption of the Parent-Child Relationship

Relational disruptions are also a considerable source of stress for PICU parents,

including displacement from typical familial roles and disruptions to the parent-child

relationship (Huckabay & Tilem-Kessler, 1999; Meyer et al., 1998; Miles, 1979;

Rennick, 1986). In an unfamiliar and threatening PICU setting, parents confront an

undermined sense of competence, control, and stability (Meyer, Snelling, & Myren-

Manbeck, 1998). In response to the forced displacement of the familiar role as protector

and primary caretaker of their child, parents undergo a "role revision process of giving up

the role of being parent to a well child and taking on the role of parent to an acutely ill

child" (Jay, 1977, p. 196). This reaction has been described more powerfully as a

grieving process during which parents mourn the loss of their healthy child (Etzler, 1984;

Jay 1977). Necessary adjustments are made to a new PICU parenting role, which

encompasses physical separation from the child, limited direct-care opportunities, and a

relinquishing of decision-making authority and direct care (Jay, 1977; Miles, Carter,

Riddle, et al., 1989).

Interaction with the Medical Team

As parents become more accustomed to the PICU environment during their

child's stay, difficulties in communicating with the medical team become a more salient

stressor. Parents inquire more about their child's condition and desire greater

involvement in his or her care, which is often met with unsatisfactory results (Meyer et

al., 1998). Lack of clear, adequate, and consistent information from members of the

medical team regarding their child's condition was found to be a predominant stressor in

a small sample of PICU parents (LaMontagne & Pawlak, 1990; Turner et al., 1990). In a

cross-sectional cohort study, Colville et al. (2009) found that a minority of parents

retroactively ranked "communication with the medical staff" as a major stressor during

their child's PICU stay several months earlier. Parents reported particular dissatisfaction

with providers' "inappropriate body language and poor timing, especially in relation to

bad news," as well as inconsistent information across members of the medical team

(Colville et al., p. 75). At the time of follow-up assessment 8 months postdischarge, this

subset of parents reported higher rates of distress when describing their earlier PICU

experience.

Interestingly, transition from the PICU to a general pediatric unit also has been

shown to be a source of stress for parents (Colville et al., 2009; Huckabay & Tilem-

Kessler, 1999). Although parents seem to be able to perceive the transition as a positive

development in their child's care, most express concern over an anticipated decline in the

intensity and quality of medical care. For example, Huckabay and Tilem-Kessler (1999) noted that "on the day of transfer, several parents asked if general pediatric unit nurses were as competent as the PICU nurses in case an emergency arose" (p. 38).

Comparisons of Maternal and Paternal Experiences

In a small, early quantitative study examining both the maternal and the paternal response to the PICU experience, no significant difference was found between mothers' and fathers' overall stress response, including their reactions to PICU sights and sounds, the child's appearance, medical procedures, and staff interaction (Miles, Carter, Spicher, & Hassanein, 1984). However, mothers demonstrated higher levels of state anxiety in response to the child's emotions and behaviors, such as crying, whining, or withdrawing, while fathers demonstrated higher levels of anxiety in response to the parental role alteration, such as not being able to protect the child from pain, ease the child's fear, or provide direct care (Miles et al., 1984).

Following this initial study, a larger quantitative study of PICU parents across the midwestern United States found that mothers endorsed significantly higher levels of overall state anxiety than those of fathers (Riddle, Hennessey, Eberly, Carter, & Miles, 1989). More specifically, mothers reported higher anxiety than fathers in response to their child's emotions and behavior, as well as to the parental role alteration, PICU environment, and medical procedures (Riddle et al., 1989).

More recently, Board and Ryan-Wenger (2003) conducted two longitudinal studies with PICU parents. They first compared sources of stress and stress symptoms in mothers with children in the PICU and mothers with children in the general-care unit

(GCU), and then compared the same variables in PICU and GCU fathers. When ranking

the most frequently experienced maternal stressors, the PICU and GCU groups had only

one common source of stress: "putting needles in the child" (Board & Ryan-Wenger,

2003, p. 198). The PICU mothers shared similar stressors related to the PICU

environment, such as sights and sounds of equipment and stressful interactions with the

medical team (e.g., "too many different people talking to me"; Board & Ryan-Wenger,

2003, p. 198). In reaction to these stressors, PICU mothers endorsed more stress

symptoms than GCU mothers up to 6 months postdischarge, with at least 75% of GCU

mothers reporting no distressing symptoms at 3 to 6 months postdischarge. Overall, PICU

mothers endorsed more cognitive and physiologic reactions such as "worrying too much

about things," "repeated unpleasant thoughts," "feeling low in energy," and "easily

annoyed or irritated" (Board & Ryan-Wenger, 2003, p. 200).

In a subsequent study comparing sources of stress and stress symptoms in PICU

and GCU fathers, results indicated that PICU fathers reported significantly more

stressors, with the greatest sources of stress related to procedures (e.g., "putting needles

in my child for fluids, procedures or tests"; Board, 2004, p. 246) and changes in parental

role (e.g., "not knowing how best to help my child during this crisis"; Board, 2004, p.

246). In reaction to these stressors, PICU fathers reported higher frequencies for

cognitive and physiologic stress symptoms, including "headache," "low in energy,"

"repeating unpleasant thoughts," "easily annoyed," and "worrying too much about

things" (Board, 2004, p. 247). One important finding from this data was the stressful

impact of disruptions to caretaking. PICU fathers endorsed higher rates of stress for "not

being able to hold my child" and "not taking care of my child myself" than GCU fathers, which contributes to a richer understanding of the paternal PICU experience (Board, 2004, p. 247).

Most recently, Colville et al. (2009) conducted a mixed-methods cross-sectional study that investigated the differences in maternal and paternal recollections approximately 8 months after their child's discharge from a London-based PICU. Various themes emerged among the parents' responses to open-ended questions about their memories of the PICU experience. One noteworthy qualitative finding is that both mothers and fathers described extremely vivid memories relating to the PICU environment, their child's physical appearance, and their concern over their child's life-threat at the time. Despite this similarity, mothers "were more likely [than fathers] to describe a need to be with their child as much as possible," indicating a greater potential for trauma exposure (Colville et al., 2009, p. 76). Moreover, mothers endorsed a greater perception of child life-threat, as evidenced by voicing stronger beliefs than those of fathers that their child could have died. These qualitative findings serve to enrich the related quantitative data which demonstrated that mothers endorsed significantly higher rates of acute stress at the time of admission and posttraumatic stress 8 months later (Colville et al., 2009).

Recent Studies on the Parental Traumatic Stress Response

Recent studies have served to better quantify the PICU parental experience through the use of more comprehensive conceptualization and assessment measures. Pediatric psychological research has recently begun to look more closely at the

prevalence, severity, and predictors of stress in parents of ill and injured children through a traumatic stress framework.

Pediatric Medical Traumatic Stress

Kazak et al. (2006) have defined pediatric medical traumatic stress (PMTS) as "a constellation of psychological and physiological responses of children and their families to pain, injury, serious illness, medical procedures, and invasive or frightening treatment experiences" (p. 343). This framework allows the conceptualization of a child's PICU treatment as a "potentially traumatic event (PTE)" for the child and parents (Kazak, Schneider, & Kassam-Adams, 2009). PMTS is not limited to a clinical diagnosis, such as ASD or PTSD, but instead describes a cluster of traumatic stress reactions on a continuum (Kazak et al., 2006; Kazak et al., 2009). Furthermore, this framework supports a distinction between what most resilient families experience— normal reactions to an abnormal circumstance— and those families that demonstrate a significantly impairing traumatic reaction to their child's medical event (Kazak, 2006). Finally, a PMTS conceptualization highlights the importance of the PICU parents' subjective response as opposed to objective characteristics of their child's condition (Kazak et al., 2009).

Diagnostic Criteria of ASD and PTSD

According to the *DSM-IV-TR* (2000), one must experience, witness, or be exposed to an event that involves threatened death or serious injury (Criterion A1) and respond to that traumatic stressor with intense fear, helplessness or horror in order to meet criteria for ASD or PTSD (Criterion A2). A traumatic event that leads to a child's PICU hospitalization (e.g., an automobile accident or severe illness) or elements of the

hospitalization itself (e.g., being separated from parents or experiencing a frightening and invasive medical procedure) can constitute a traumatic stressor thus defined.

The remaining ASD diagnostic criteria include symptoms of dissociation (Criterion B) along with three additional symptom clusters that cause functional impairment within 2 days and 4 weeks of the traumatic event (Criterion G). After 1 month, PTSD diagnostic criteria eliminate dissociative symptoms but endorse the same three symptom clusters that impair functioning: (a) persistently re-experiencing the trauma (Criterion B), (b) marked avoidance of trauma reminders (Criterion C), and (c) increased anxiety or arousal (Criterion D).

In PICU parents, dissociation commonly presents as a sense of derealization or dissociative amnesia ("Sometimes I still look at her and think 'Did it happen? Was it a dream?', like I was someone else"; Colville et al., 2009, p. 76). Re-experiencing often presents as intrusive recollections of the trauma that cause distress, such as flashbacks or nightmares ("I can't stand to hear suction [at the dentist] because that floods it back quicker than anything else"; Colville et al., 2009, p. 76). Avoidance of traumatic reminders can present cognitively, emotionally, or behaviorally, such as avoiding thoughts of the trauma or people, objects, or places that serve as reminders of the event ("The thought of passing [the hospital]—I can't, I don't look at that side. If I go to [that part of town] I don't look on the left"; Colville et al., 2009, p. 76). Hyperarousal in PICU parents typically presents as an exaggerated startle response and/or hypervigilance regarding their child's health and safety (*"I just feel like my whole life revolves around just making sure [my child] is OK";* Colville et al., 2009, p. 76).

Dichotomous versus Continuous Stress Responses

The diagnostic criteria for the traumatic stress disorders have undergone

numerous revisions since the initial introduction of a "gross stress reaction" in *DSM-I*

(APA, 1952). Since then, the validity of the PTSD diagnosis has become well

established. Controversy remains, however, over whether PTSD is best conceptualized in

a categorical or a dimensional manner. A plethora of studies demonstrate that individuals

who fail to meet full criteria for PTSD may still suffer from clinically meaningful levels

of functional impairment (Marshall et al., 2001; Moreau & Zisook, 2003; Stein, Walker,

Hazen, & Forde, 1997). These findings support the conceptualization of PTSD on a

continuum of symptom severity and call for assessment measures and interventions to

focus more broadly on those suffering from "subclinical" PTSD. Subclinical PTSD has

been defined in various ways, but most commonly it encompasses individuals who

endorse at least one symptom in each of the three categories: re-experiencing the trauma,

avoidance of trauma reminders, and hyperarousal (Moreau & Zisook, 2003). Additional

studies into subclinical ASD show that ASD symptoms without dissociation may be

strong predictors of subsequent PTSD (Brewin, Andrews, Rose, & Kirk, 1999; Harvey &

Bryant, 1998), with one study finding that subclinical ASD is "almost three times more

sensitive than full ASD in predicting PTSD" in children after traumatic injury (Dalgleish

et al., 2008, p. 392). This inclusion of subclinical traumatic stress has been adopted in the

pediatric psychology literature, where scores for "subclinical ASD" are positive when all

symptom criteria excluding dissociation are met and scores for "subclinical PTSD" are

positive when at least one symptom in each category is met (Kassam-Adams & Winston, 2004).

Acute Stress in PICU Parents

In an early evaluative, survey-design study conducted at California State University, Huckabay and Tilem-Kessler (1999) investigated the pattern of parental anxiety across the first 4 days of a child's PICU hospitalization for acute trauma that necessitated an emergency admission. Using Peplau's (1963) conceptualization of anxiety on a continuum that ranges from mild to panic levels, this study found that "parental anxiety was at the 98th percentile — near panic — on the first day of their child's admission to the PICU, decreasing to the 84th percentile —still relatively high — on days two, three, and four" (Huckabay & Tilem-Kessler, 1999, p. 37). Significant differences were found between anxiety levels on Day 1 and Day 2, as well as between Day 1 and Day 3, indicating that there exists a clinically meaningful decline and subsequent stabilization in parental anxiety after the first day of "near panic" levels of anxiety. Additional findings demonstrated that parent gender was not significantly correlated with anxiety level, suggesting that mothers and fathers did not differ on their anxiety patterns.

Utilizing the more recent traumatic stress framework, Balluffi et al. (2004) conducted a longitudinal study of parental traumatic stress reactions to a child's PICU hospitalization at a large urban children's hospital in the United States. Of 272 parents, 32% met symptom criteria for an ASD diagnosis at the time of their child's PICU admission (Balluffi et al., 2004). Overall, an overwhelming majority of parents endorsed

specific types of acute stress symptoms, such as hyperarousal (87%), re-experiencing

(75%), dissociation (74%), and avoidance (68%; Balluffi et al., 2004).

No significant differences were found in the rates of ASD diagnosis or level of

ASD severity between mothers and fathers (Balluffi et al., 2004). Parental ASD diagnosis

was found to be associated with the parent's self-reported degree of worry that the child

might die ($r = .20$; $p = .001$), while the severity of parental ASD was associated with the

parent's degree of worry that the child might die ($r = .31$; $p < .005$) and with the child's

unexpected admission to the PICU ($r = .18$; $p = .005$; Balluffi et al., 2004). Interestingly,

no significant associations were found between parental ASD diagnosis or ASD severity

and the child's objective illness severity, suggesting that parental perceptions of their

child's life-threat is more important in determining risk for ASD than are objective

measures of illness severity (Balluffi et al., 2004).

Posttraumatic Stress in PICU Parents

In this same sample of PICU parents, Balluffi et al. (2004) found that 21% of 161

parents who completed follow-up assessment met symptom criteria for a PTSD diagnosis

at 2 months postdischarge. Overall, fewer parents endorsed specific types of

posttraumatic stress symptoms, such as hyperarousal (61%), re-experiencing (43%), and

avoidance (40%; Balluffi et al., 2004). Twenty-four percent of mothers developed PTSD

as compared to only 4% of fathers ($p = .04$; Balluffi et al., 2004).

Parental PTSD diagnosis was found to be associated with the parent's self-

reported degree of worry that the child might die (Balluffi et al., 2004). The severity of

parental PTSD was associated with numerous factors, including the parent's self-reported

degree of worry that the child might die, unexpected admission to the PICU, the presence

of a new hospital admission for the child since PICU discharge, and the presence of a

subsequent traumatic event in the family (Balluffi et al., 2004). Similar to ASD findings,

no significant associations were found between parental PTSD diagnosis or PTSD

severity and the child's objective illness severity, further supporting the importance of

parental perceptions of child life-threat in determining risk for PTSD rather than

objective measures of illness severity (Balluffi et al., 2004).

In a retrospective cohort study comparing the psychiatric outcome of parents of

children in a London-based PICU and those in a general pediatric unit (GPU), 27% of

PICU parents were found to be at high risk for PTSD as compared to only 7% of GPU

parents at 6 to 12 months postdischarge (Rees et al., 2004). More specifically, PICU

parents endorsed significantly more PTSD symptoms than GPU parents, as reflected in

subscale scores for avoidance (20% vs. 8%, respectively) and intrusion (19.5% vs. 11.5%

respectively; Rees et al., 2004). No data were available for parental symptoms of

hyperarousal because of methodological limitations. Additionally, PICU parents reported

higher ratings than those reported by GPU parents on measures of perceived severity of

their child's illness and degree of fear for their child's life (Rees et al., 2004).

A more recent prospective study examined the prevalence of posttraumatic stress

symptoms and a PTSD diagnosis among 140 mothers and 107 fathers at 3 months

following their child's discharge from a PICU in the Netherlands (Bronner et al., 2008).

While 15% of mothers and 9% of fathers received a PTSD diagnosis, substantially more

parents endorsed specific posttraumatic stress symptoms that fulfilled full criteria for a

diagnosis (Bronner et al., 2008). Eighty-four percent of mothers and 73% of fathers

reported one or more intrusion symptoms, 41% of mothers and 22% of fathers reported

two or more hyperarousal symptoms, and 16% of mothers and 12% of fathers reported

three or more avoidance symptoms (Bronner et al., 2008). Overall, mothers were found to

endorse significantly more symptoms than fathers, with a median of four total symptoms

compared to two total symptoms, respectively (Bronner et al., 2008).

In a more recent cohort study, Bronner et al. (2009) found that 17% of mothers

and 4 % of fathers met full criteria for PTSD at 3 months after their child's PICU

admission. Bronner et al. (2010) conducted a subsequent longitudinal study examining

PTSD prevalence in PICU parents at 3 months (T2) and 9 months (T2) after unexpected

PICU treatment in the Netherlands. Out of 140 mothers and 107 fathers assessed by self-

report at T2, nearly 13% endorsed a PTSD diagnosis and 30% met criteria for subclinical

PTSD. Out of 108 mothers and 82 fathers assessed by self-report at T3, 10.5% of parents

continued to endorse a PTSD diagnosis while 18% continued to meet criteria for

subclinical PTSD (Bronner et al., 2010). Although mothers and fathers did not differ in

the prevalence of PTSD diagnosis, mothers endorsed significantly more subclinical

PTSD than fathers at both follow-up assessments (36% of mothers vs. 22% of fathers at

T2; 27% of mothers vs. 6% of fathers at T3; Bronner et al., 2010).

The Course of the PICU Parental Stress Response

An Early Look at Predictors of PICU Parental Stress

Building upon early qualitative studies that elucidated parent-identified sources of

stress in the PICU, Miles et al. (1989a) conducted a study using multiple regression

techniques to evaluate the interaction of these numerous factors and their impact on the

parental stress response, operationalized as state anxiety measured within 1 and 4 days of

PICU admission. More specifically, Miles et al. (1989a) investigated the interaction

between (a) personal factors, such as parental age, role (mothers vs. fathers), educational

level, trait anxiety, and other life stressors; (b) situational variables, such as child age,

admission circumstances (expected vs. unexpected), diagnosis, and parental perception of

illness severity; and (c) PICU environmental variables, such as sights and sounds,

communication with medical staff, procedures, parental role alteration, and the child's

appearance, behavior and emotions. Overall, six variables were found to significantly

predict parental state anxiety, accounting for 33% of the variance: parental trait anxiety,

parental perception of severity of their child's illness, admission circumstances, parental

role alteration, the child's behavior and emotional response, and the child's appearance

(Miles et al., 1989a). This seminal study thus informed further research and practice by

illuminating predictors of the PICU parental stress response. These findings suggest that

assessment and intervention should focus on parents who possess a higher propensity for

anxiety, perceive their child's illness as more serious, have a child unexpectedly admitted

to the PICU, perceive changes to their parenting role, and are distressed by their child's

appearance and response to PICU hospitalization.

Predicting Posttraumatic Stress in PICU Parents

More recently, two studies have investigated predictors of the PICU parental

stress response through a traumatic stress framework. First, Balluffi et al. (2004) found

that ASD symptom severity predicted PTSD symptom severity in that PICU parents who

endorsed an ASD diagnosis within the first 3 days of PICU admission (T1) were more

likely to endorse a PTSD diagnosis at 2 months after discharge (T2). Hierarchical

multiple regression analysis indicated that 41% of the variance in PTSD severity was

accounted for by T1 variables, with parental ASD severity emerging as the strongest

predictor of subsequent parental PTSD severity. Parental degree of worry that the child

might die emerged as a second modest independent predictor (Balluffi et al., 2004). In

further examining risk factors, Balluffi et al. (2004) calculated sensitivity, specificity, and

odds ratios for specific potential predictive tests of later PTSD and determined that

"asking two other simple questions (was this admission unexpected? and how worried are

you that your child might die?) appear to be at least as sensitive, but less specific, in

predicting later PTSD" (Balluffi et al., 2004, pp. 551-552). This study thus confirmed and

further clarified Miles et al.'s (1989) previous assertion that assessment and intervention

should focus on the subset of PICU parents who are experiencing early traumatic stress

symptoms, particularly regarding unexpected PICU admission and parental perception of

child life threat. Possibly the most noteworthy contribution of this study is the

conceptualization and measurement of the course of the PICU parental stress response

through a traumatic stress framework.

Bronner et al.'s (2010) longitudinal study examining the course of posttraumatic

stress symptomatology in PICU mothers and fathers also utilized a traumatic stress

framework to investigate potential predictors of the parental stress response. In order to

identify potential risk factors for developing PTSD at 9 months, data were collected on

demographics; pretrauma factors, such as previous stressful life events; medical factors

pertaining to PICU treatment, such as risk of mortality; and posttraumatic stress

symptomatology at 3 months. Four independent predictors of persistent clinical and

subclinical PTSD emerged through univariate and multivariate logistic regression

analyses: (a) number of previous stressful life events (b) receipt of professional

psychosocial care during the year before PICU admission (c) number of avoidance

symptoms endorsed at the 3-month assessment, and (d) number of hyperarousal

symptoms endorsed at the 3-month assessment (Bronner et al., 2010).

The authors further explicated the finding that a higher number of previous

stressful life events and the receipt of psychosocial care predict PTSD by suggesting that

parents with many lifetime stressors or prior psychological problems make up a subset of

PICU parents who are more vulnerable to poor adjustment in the form of high risk PTSD

(Bronner et al., 2010). This conclusion is in line with Miles et al.'s (1989a) finding that

parental trait anxiety is a predictive factor for state anxiety after PICU treatment of the

child. Additionally, Bronner et al.'s (2009; 2010) findings that the presence of certain

acute and posttraumatic stress symptoms, specifically dissociation, hyperarousal, and

avoidance, are strongly associated with persistent PTSD in PICU parents is in line with

Balluffi et al.'s (2004) finding that ASD severity is a strong predictor of later PTSD

severity in this population.

An Early Model of Stress and Coping

The transactional model of stress and coping (Lazarus, 1966; Lazarus & Cohen,

1977; Lazarus & Launier, 1978) is a framework for conceptualizing an individual's

response to environmental stressors. This framework may be used to better understand

the PICU parental response. When facing a stressor, such as PICU admission, parents

first make a primary appraisal of the situation or an initial evaluation of the threat

(Lazarus, 1966; Lazarus & Cohen, 1977; Lazarus & Launier, 1978). The large majority

of parents initially judge the situation to be stressful in that it is overwhelming and

uncontrollable, as supported by Huckabay and Tilem-Kessler's (1999) findings of "near

panic" levels of parental anxiety on the first day of admission. A secondary appraisal

follows, in which parents assess their own coping resources and options (Cohen, 1984).

At this point, parental appraisal may be determined by a wide variety of factors, such as

individual vulnerability to stress and anxiety, prior psychopathology, and past trauma

exposure (Balluffi et al., 2004; Bronner et al., 2010). Finally, parents engage in coping

efforts that are aimed at managing the problem and regulating emotions (Cohen 1984;

Lazarus & Cohen, 1977). Final outcomes of the coping process vary but may be broadly

categorized as positive adaptation or negative maladaptation (Cohen 1984; Lazarus &

Cohen, 1977).

Parental Coping in Response to PICU Stress

Miles and Carter (1985) applied Lazarus' cognitive phenomenological model of

stress and coping to the PICU context, hypothesizing that parental coping is a variable

that affects parental perception of the "nature, meaning, and power of stress stimuli" in

the PICU setting (Miles & Carter, 1985, p. 15). In order to further examine the types of

coping used by PICU parents, the researchers developed the *Parental Coping Scale*

Pediatric ICU and interviewed parents 5 days after their child's PICU discharge. The

coping strategy found most helpful by 92% of the parents was "being near my child as

much as possible," while four other coping strategies were endorsed by the majority of parents and also rated to be the most helpful: (a) "seeking help or comfort from others," (b) "believing my child is getting the best care possible," (c) "seeking as much information as possible," and (d) "having hope" (Miles & Carter, 1985, p. 17).

In order to examine parental perceptions, feelings, and coping responses to the PICU experience, LaMontagne and Pawlak (1990) interviewed a small sample of parents within the first 2 days of their child's PICU admission. Findings from the *Ways of Coping Questionnaire* (Folkman & Lazarus, 1988) revealed that the parents used a combination of emotion- and problem-focused forms of coping. Emotion-focused strategies included positive reappraisal, emotional self-control, escape/avoidance, accepting responsibility, and distancing. Problem-focused strategies included seeking social support, planful problem solving, and a confrontative approach to emotional expression. In this sample, the two most common coping strategies used by all parents were positive reappraisal and seeking social support.

Subsequent studies further demonstrated that certain parental variables, such as age, locus of control, and state anxiety level, as well as the strength of the family unit, can influence parental coping strategies and activities within the first 2 days of a child's PICU admission (LaMontagne et al., 1995; LaMontagne, Hepworth, Pawlak, & Chiafery, 1992). Findings from a small cross-sectional study indicated that older parents with a greater internal locus of control and less state anxiety utilized more problem-focused coping strategies and were more likely to participate in their child's care (LaMontagne et al., 1992).

In another preliminary descriptive study, Carnevale (1990) asked a small sample of parents about perceived stressors and subsequent coping strategies used within 1 week of their child's discharge from a PICU at an urban children's hospital in Canada. Parents identified five overall categories of coping strategies used in response to common PICU stressors: (a) cognitive coping strategies, defined as "things you think about to deal with the situation," (b) interpersonal coping strategies, defined as "actions directed toward other people such as staff, family and friends," (c) social-support coping strategies, defined as "drawing on support from others [including] family and friends," (d) behavioral coping strategies, defined as "things you do . . . particular behaviors that alter the environment favorably," and (5) environmental coping strategies, defined as "drawing on aspects of the environment that helped you deal with the situation" (Carnevale, 1990, p. 7).

An emphasis on the role of cognitions in PICU parents' perceptions of stressors and subsequent coping strategies was a new and significant addition to this area of research. Carnevale's (1990) assertion that "cognitive appraisal processes contribute to wide inter-individual variation in coping responses to similar situations" (p. 6) was an early indication that targeting cognitions would be an essential part of accurate assessment and effective interventions for PICU parents.

The Role of Parental Beliefs

Illness Beliefs

In investigating family needs in the hospital, early qualitative studies preliminarily established the importance of family perception of critical illness and

injury. Reeder (1991) analyzed qualitative data from 112 family members during the first

3 days of a child's or adult family member's critical hospitalization in order to highlight

the importance of the subjective experience that develops in reaction to another family

member's illness or injury. As opposed to objective measures of the patient's state of

health, this subjective experience is influenced by numerous factors, including past

experiences with illness, family roles, family traditions, and past coping strategies

(Reeder, 1991). Utilizing the Double ABCX Model of Family Adjustment and

Adaptation (McCubbin & Patterson, 1981), Reeder (1991) presented the injury or illness

as the stressor event (A) that interacts with existing family resources (B) and the family's

perception of the event (C) to produce a crisis (X). Based on the family's level of

functioning and coping skills, adaptation to the crisis experience occurs on a continuum.

Part C of the model, the family's perception of the event, can be considered the

"definition or meaning that families have of the injury event. Past experiences,

interpretations of current cues, cultural and religious beliefs and family traditions all have

an impact on the meaning or perception" (p. 190) that a family develops in response to a

critical injury or illness. Extrapolating these early findings to the parental perception of a

child's condition and treatment in the PICU suggests that parental perception of the

child's illness or injury may be considered an essential aspect of the parental response

from a psychological standpoint, thereby forming the crux of effective intervention.

Further studies began to investigate the importance of parental illness beliefs

regarding their child's condition in the context of the PICU. In an early study piloting the

Parental Concerns Scale with 17 parents, Youngblut and Jay (1991) found that the

highest rated parental concern for both PICU mothers and fathers was concern for their

child's survival, followed by concern for their child's possible mental or physical

impairment. Moreover, parents who had a previous experience with a family member in

the ICU maintained a higher level of concern across the first 36 hours of PICU

hospitalization, while other parents without past ICU exposure demonstrated a reduction

in their level of concern. Although this finding could not be explained clearly, the

investigators suggested that it could be "due to an unsatisfactory resolution of the prior

ICU experience or to a more realistic perception of what lies ahead" (Youngblut & Jay,

1991, p. 335). In a later study sampling 16 mothers and 13 fathers of PICU-admitted

children, Youngblut and Shiao (1993) found that parents' reactions to their child's PICU

admission and critical illness were, in fact, not related to objective characteristics of the

child's condition as measured by his or her score on the Pediatric Risk of Mortality scale.

This finding was one of the first to support the notion that the subjective, rather than

objective, experience is more indicative of risk for parental distress regarding a child's

illness or injury.

Balluffi et al.'s (2004) findings confirmed the importance of parental beliefs about

child life-threat in determining parental risk for ASD and PTSD. In the initial assessment

(T1), parents reported the extent to which they worried that their child might die, using a

5-point Likert-type scale. This variable was found to be strongly associated with both the

presence and severity of ASD, as well as the presence and severity of PTSD (Balluffi et

al., 2004). The importance of parental illness beliefs was further demonstrated when this

variable emerged as one of two independent predictors of parental PTSD severity using

hierarchical multiple regression analysis (Balluffi et al., 2004). The authors asserted that

assessing parental perceptions of their child's life-threat in the PICU can serve an integral

role in predictive tests that identify the subset of parents who are at higher risk for PTSD

symptoms. Caution is also advised against using objective measures of illness severity in

determining risk. The authors emphasized that, in contrast to parental *subjective*

perception of life-threat, no association was found between *objective* hospital-based

measures of mortality risk and development of ASD or PTSD (Balluffi et al., 2004).

More research into the crucial role of parental illness beliefs in the course of

parental stress and coping has been conducted in the pediatric oncology population.

Qualitative studies suggest that parental appraisals of their child's cancer experience play

an important role in the family's stress response. Parents who perceive their child's

cancer experience as a comprehensible, manageable, and meaningful experience, through

spiritual or religious beliefs, for example, demonstrate a more resilient response as

evidenced by rapid mobilization, appropriate family reorganization, and procurement of

support from the healthcare team and other social support resources (McCubbin, Balling,

Possin, Frierdich, & Byrne, 2002; Spilka & Hartmen, 2000). Conversely, parents who

struggle to make sense of the experience and appraise their child's illness as consistently

life-threatening or out of their control demonstrate less resilient and more distressed

responses, as evidenced by elevated posttraumatic stress symptoms (Kazak, 1998). In

sum, this research shows that the identification of these parental illness beliefs is essential

in understanding and treating the course of the parental stress response to a child's life-

threatening medical condition.

Building upon these findings, Kazak et al. (2004) created and conducted a

psychometric study of the Family Illness Beliefs Inventory (FIBI), an assessment tool

that measures cancer-related beliefs that may facilitate or inhibit appropriate family

adaptation to a child's cancer diagnosis and treatment. One hundred and nineteen mothers

and 56 fathers were assessed with the FIBI at a large children's hospital in the United

States, with time since their child's cancer diagnosis ranging from 2 to 44 months (Kazak

et al., 2004). T-tests with maternal and paternal data indicated that there were no

statistically significant gender differences in FIBI item responses (Kazak et al., 2004). In

examining the latent structure of the FIBI, five factors emerged from a principal-

components analysis of maternal data: (a) treatment-related suffering, (b) death and

devastation, (c) caregiver competence, (d) connection, and (e) finding meaning. This

study's findings serve to underscore the importance of parental beliefs regarding a child's

illness and perceived ability to competently manage the traumatic situation. As of yet, no

further studies have investigated the correlation between FIBI scores and parental ASD,

nor the predictive relationship between FIBI scores and subsequent parental PTSD in the

PICU setting.

Coping Self-Efficacy Beliefs

Various parent variables have been shown to be associated with parental coping

strategies and activities in the PICU. As previously discussed, one early study found a

relationship between parental locus of control and forms of coping, in that the more a

parent exhibited an external locus of control, the less they utilized problem-solving or

sought social support (LaMontagne et al., 1992). At the same time, these parents were

more likely to use coping strategies, such as distancing, accepting responsibility, and

escape-avoidance (LaMontagne et al., 1992). Overall, these parents were less likely to

perform and/or maintain active involvement in their child's care, regardless of the child's

age. Thus, parental sense of control over situational outcomes, operationalized here as

locus of control, has a significant effect on the type and success of parental coping

strategies and related childcare activities in the PICU.

Coping self-efficacy (CSE) is a related construct used to operationalize an

individual's "perceived capability to manage one's personal functioning and the myriad

environmental demands of the aftermath occasioned by a traumatic event" (Benight &

Bandura, 2004, p. 1130). Perceived coping self-efficacy mediates an individual's

traumatic stress response in that a high sense of coping self-efficacy, indicating strong

belief in one's capability to exert control over some aspects of a traumatic situation,

serves as a protective factor against the development of PTSD (Benight & Bandura,

2003). Researchers have posited that higher levels of coping self-efficacy provide an

internal sense of control that supports "self-affirming cognitions, steadfast motivation,

effective self-management of emotions, and effective decision making" (Bandura, 1997;

Benight, Cieslak, Molton, & Johnson, 2008, p. 678).Through this research, coping self-

efficacy has been further divided into four main areas of coping demands: thoughts,

images, emotions, and behaviors (Benight & Bandura, 2004; Benight et al., 2008). Thus,

coping self-efficacy has been assessed via self-report questionnaires that measure

confidence in one's ability to control cognitions and related mental imagery, as well as

affective and behavioral responses.

Numerous studies have demonstrated a negative correlation between coping self-efficacy and PTSD in adult survivors of trauma (Benight et al., 2008; Cieslak et al., 2008; Flatten, Walte, & Perlitz, 2008). Moreover, the independent contribution of coping self-efficacy in determining the intensity and persistence of acute and posttraumatic stress reactions is well established in studies of adults exposed to diverse types of trauma (Benight & Bandura, 2004). In one sample of adult survivors following natural disasters, acute coping self-efficacy perceptions accounted for a significant proportion of the variance of ASD at 3 to 8 weeks and additionally served as a significant predictor of PTSD symptoms at 1 year postdisaster (Benight & Harper, 2002).

Summary and Critique of Literature

After 3 decades of investigation, a better understanding of the PICU parental response has emerged, including parent-identified stressors, levels of stress, and the effectiveness of commonly used coping strategies (Board & Ryan-Wenger, 2003; Etzler, 1984; Miles, Carter, Riddle, et al., 1989). Great strides have been made in moving from early anecdotal reports that focused mostly on mothers to more recent methodologically sound quantitative studies. Along the way, the conceptualization of the PICU parental experience has also matured, as it is now viewed through a traumatic stress framework (Balluffi et al., 2004; Kazak et al., 2006). At the present time, most studies remain cross-sectional in nature, often asking a small sample of parents to report retrospectively on their earlier PICU experience (Colville et al., 2009; Rees et al., 2004). As a result, these small studies fail to grasp a precise assessment of parental functioning at the time of their child's PICU treatment and run the risk of numerous flaws, such as limited statistical

power and self-selection biases. Although much progress has been made in the inclusion

of paternal data, small sample sizes remain a limitation of many current studies and

restricts generalizability.

More recently, prospective studies that include larger samples of both mothers

and fathers have begun to explore the course of the PICU parental stress response. In

these studies, parental acute stress reactions and degree of worry about their child's life-

threat have consistently emerged as independent predictors of subsequent parental PTSD

severity (Balluffi et al., 2004; Bronner et al., 2009; Bronner et al., 2010). As a result, the

parental perception of their child's condition now is considered key to understanding and

predicting the parental stress response. However, no further analyses have investigated

the role of more general parental illness beliefs and PTSD outcomes.

Finally, the adult trauma literature has been examining associations between one's

level of coping self-efficacy and one's traumatic stress response (Benight et al., 2008;

Cieslak, et al., 2008; Flatten, et al., 2008). In diverse samples of trauma survivors, the

individual perception of coping self-efficacy has been found to be a significant predictor

of later PTSD symptoms (Benight & Bandura, 2004; Benight & Harper, 2002). This

concept has not yet been introduced in the PICU literature, and studies of PICU parental

coping strategies remain limited to basic descriptive analyses identifying the techniques

used and their perceived helpfulness. An application of the concept of coping self-

efficacy in the PICU setting holds great potential in linking parental beliefs about their

child's PICU hospitalization and their ability to manage this trauma.

Conclusion

The current study aimed to advance the current understanding of the PICU

parental traumatic stress response in a unique way. Examining data from a prospective

study with two time points, first within 48 hours of a child's PICU admission and then 3

months postdischarge, provided a plethora of data from which multiple hypotheses were

tested. First, prevalence rates of ASD and PTSD were examined, with comparisons made

between maternal and paternal rates. Secondly, associations between parental illness

beliefs about their child's condition and their own ability to cope with the trauma were

explored. Finally, drawing on findings from the adult trauma literature, a potential

predictive relationship between parental beliefs at the time of their child's PICU

hospitalization and subsequent development of posttraumatic stress was investigated.

Findings from this study present the field with a more in-depth look at the role of parental

beliefs in the course of the PICU parental stress response and, in turn, serve to inform

assessment and intervention efforts aimed at identifying at-risk parents and providing

appropriate support.

Chapter Three

Hypotheses

Hypothesis 1

A first hypothesis held that the prevalence of parental ASD and PTSD would be

consistent with rates in other PICU populations as documented in the current literature.

Approximately one third (32%) of parents have been found to meet symptom criteria for

ASD during a child's PICU admission, while a range of 12 to 48% have been found to

meet symptom criteria for PTSD 2 months or more following discharge (Balluffi et al.,

2004; Bronner et al., 2008; Bronner et al., 2009; Rees et al., 2004).

Hypothesis 2

A second hypothesis held that that there would be no statistically significant

differences between maternal and paternal rates of ASD, based on the findings of one

past study of PICU parents (Balluffi et al., 2004). However, it was hypothesized that

mothers would endorse higher rates of PTSD in comparison to fathers, as supported by

numerous study findings (Balluffi et al., 2004; Bronner et al., 2008; Bronner et al., 2010).

Hypothesis 3

Based on previous research findings, numerous parental risk factors, such as

female gender, past trauma history, and subjective assessment of the child's condition as

life-threatening, were expected to correlate positively with ASD and PTSD severity

(Balluffi et al., 2004; Pietrzak et al., 2011). Additionally, it was hypothesized that

endorsement of maladaptive parental illness beliefs would correlate positively with ASD

and PTSD severity, while endorsement of adaptive coping self-efficacy beliefs would

correlate negatively with ASD and PTSD severity (Balluffi et al., 2004, Benight & Harper, 2002, Kazak et al., 2004).

Hypothesis 4

A final hypothesis held that greater endorsement of parental illness beliefs and lower endorsement of coping self-efficacy beliefs at T1 would explain a significant amount of the variance in ASD and PTSD severity, as supported by previous findings that parental degree of worry about their child's life-threat and parental degree of coping self-efficacy are significant predictors of subsequent PTSD severity (Balluffi et al., 2004; Benight & Harper, 2002).

Chapter Four

Methodology

Overview

Archival data from a prospective cohort study design were used to describe the

prevalence of traumatic stress reactions in parents with a child in the PICU and to

examine the association between parental beliefs surrounding this admission and the

development of traumatic stress symptoms.

Design and Design Justification

Data from the original study were collected from a sample of parents at two points

in time: an initial assessment (T1) within 48 hours of PICU admission and a second

assessment (T2) at 3 months postdischarge. A longitudinal cohort study at these two time

points allowed for the examination of a predictive relationship between parental beliefs at

the time of PICU hospitalization and subsequent development of posttraumatic stress.

Participants

An archival data set was used in the current study. The T1 sample included 245

parents (including legal guardians and primary caregivers) of children admitted to the

PICU at the Children's Hospital of Philadelphia between August 1, 2004, and July 31,

2005. Although attempts were made to contact parents 3 months postdischarge, the time

lapse from T1 to T2 ranged from 3 months to 20 months, with a mean time to follow-up

of 5 months. Sixty-five parents were lost to follow-up, resulting in 180 parents who fully

completed all required measures. Between those parents who completed both T1 and T2

assessments and those who completed only T1 assessments, no differences were found in

parental level of acute stress symptom severity, parent or child age, child gender, parent

or child ethnicity, parental relationship status or parental education level. However,

mothers were more likely than fathers to complete follow-up (80% vs. 60%; $p = .001$).

In both the T1 and T2 samples, mothers represented a majority, as did Caucasian

parents, parents with at least some college education or beyond, and parents who were

married or living with a partner (Table 1). The age range of participating parents was 19

to 60 years, with a mean of 38 years and a mode of 42 years.

Table 1

Frequency Distributions of Parental Demographic Characteristics

Demographic Characteristic	T1 Sample (N = 245)		T2 Sample (N = 180)	
	N	%	*N*	%
Parent gender				
Female	163	67	131	73
Male	82	33	49	27
Parent ethnicity				
Caucasian	192	80	146	82
African American	23	10	17	10
Hispanic	11	5	6	3
Asian	6	2.5	5	3
Other (e.g., biracial)	6	2.5	3	2
Parent relationship status				
Married or living with partner	204	84	148	82
Separated or divorced	20	8	18	10
Single	17	7	11	6
Other (e.g. engaged, widowed)	3	1	3	2
Parent educational level				
High school graduation or less	56	23	37	20
At least some/ completed college	134	55	101	56
At least some/ completed graduate school	54	22	42	24

The majority of children of both T1 and T2 samples were boys (64%), and ages ranged from 2 weeks to 17 years, with a mean of 7 years and a mode of 2 years. Objective characteristics of the patients' medical conditions and treatments were obtained for a subset of all children (76 of 179 total children). Of this subset, the median length of stay in the PICU was 4 days (Range = 0 to 48 days), the mean Pediatric Risk of Mortality (PRISM) score at 12 hours was 3.3 (Range = 0 to 28), the mean PRISM score at 24 hours was 5.3 (Range = 0 to 29) and the most common reasons for admission included hydrocephalus, seizures, and shunt malfunctions.

Inclusion and Exclusion Criteria

An archival data set was used in the current study. In the original study, parents were eligible to participate if they had a child 17 years old or younger admitted for at least 48 hours to the PICU at CHOP. Parents were excluded from the study if they did not speak sufficient English to complete a questionnaire, if the child's death appeared imminent, or if child abuse or neglect was suspected as a precipitant to the admission. Parents of children who were discharged fewer than 48 hours from PICU admission also were excluded.

Recruitment

An archival data set was used in the current study. In the original study, parents were recruited for participation while their child was in the PICU. All eligible parents were identified and approached in the PICU by a research assistant.

Informed Consent Procedures

An archival data set was used in the current study. In the original study, eligible parents were informed about the study and invited to participate as soon as possible after the second day of a child's PICU admission. Written informed consent was obtained from each parent before he or she completed the first assessment.

Measures

Child Characteristics

Demographic data about the participants' children were gathered by parent report, including child age, gender, and ethnicity. Medical characteristics about the child's condition and treatment were gathered from the patients' medical records for a subset of children (76 of 179 total children). These characteristics included reason for admission, length of stay in the PICU, and PRISM scores at 12 and 24 hours after admission. PRISM scores are well-established, validated, physiology-based scores for measuring mortality risk in pediatric patients (Pollack, Patel, & Ruttimann, 1996).

Screener for the Development of a Response Posttrauma (SDRP)

The SDRP was piloted in the original study from which the current study drew archival data. The SDRP is a 54-item self-report screening measure designed to assess a variety of psychosocial risk factors that could potentially impact the parental traumatic stress reaction to a child's PICU hospitalization. The psychosocial risk factors included demographics, parental psychosocial history, parental subjective assessment of their child's condition, parental illness beliefs, and parental coping self-efficacy beliefs.

Demographic information included parent gender, age, ethnicity, relationship

status, and educational level. Four parental psychosocial history factors were

dichotomously assessed, with parents endorsing whether or not they had ever experienced

(a) an event that made the parent feel scared, helpless, and/or horrified; (b) period(s) of

excessive worry, fear, and/or anxiety; (c) period(s) of prolonged sadness or depression;

and (d) an extremely frightening event that still troubled him or her. Parents were asked

to subjectively assess their child's condition via four Likert-scale questions (0 = not at all

and 3 = very much) that asked (a) was your child's hospital stay unexpected? (b) has

having your child in the hospital been a burden for your child and/or family? (c) how sick

or hurt is your child? and (d) how worried are you that your child might die?

The SDRP also assessed eight parental illness beliefs on a Likert-scale (0 = not at

all true and 3 = very true). In this way, parental illness beliefs could be examined via a

continuous score, with higher scores reflecting endorsement of more maladaptive beliefs

that foster distress. In developing the SDRP, parental illness belief items were selected

carefully from the FIBI (Kazak et al., 2004) to ensure inclusion of the most empirically

supported items demonstrating high correlations with posttraumatic stress outcomes as

measured by the Posttraumatic Stress Disorder Reaction Index (PTSD-RI; Pynoos et al.,

1987). For example, the belief item *This is a disaster* loaded highly on Factor I of the

FIBI "treatment-related suffering," thus demonstrating a strong positive correlation with

posttraumatic stress symptoms ($r = .43$, $p < .001$). Additional parental illness belief items

from the remaining four FIBI factors, including "death and devastation," "caregiver

competence," "connection," and "finding meaning," also were selected to broaden the

representation of other illness beliefs experienced by parents of an ill or injured child.

Lastly, the SDRP assessed 15 parental coping self-efficacy beliefs on a Likert

scale (0 = not at all confident and 3 = very confident). In this way, coping self-efficacy

beliefs could be examined via a continuous score, with higher scores reflecting higher

confidence in one's ability to cope with a potentially traumatic event, or via a simple

frequency count of each item's score. In developing the SDRP, coping self-efficacy items

were modeled on well-established measures presented in the literature on adult traumatic

stress responses to various events, such as sexual assault and natural disasters (Benight &

Bandura, 2004; Benight, Ironson, & Durham, 1999; Benight et al., 2008). While the four

domains of coping self-efficacy were retained (thought control, behavioral, emotional,

and imagery), the SDRP items utilized wording that addressed the specific trauma of a

child's PICU hospitalization for use in this particular sample. For example, a previously

utilized item asking participants to rate how confident they are that they can *cope with the*

emotional stress caused by the hurricane was reworded to *cope with the emotional stress*

of having a sick/injured child.

Acute Stress Disorder Scale (ASDS)

The ASDS is a 19-item self-report questionnaire designed to identify ASD in

adult individuals exposed to traumatic events (Bryant, Moulds, & Guthrie, 2000).

Respondents rate items that measure specific ASD symptoms on a 5-point Likert scale

ranging from 1 ("not at all") to 5 ("very much"; Bryant et al., 2000). The ASDS has

demonstrated excellent internal consistency, test-retest reliability, and convergent validity

as well as good sensitivity and specificity for identifying ASD in adult trauma survivors (Bryant et al., 2000).

   Full ASD diagnosis. In the present study, the ASDS was used to determine diagnostic status via a symptom count method according to *DSM-IV-TR* (2000) diagnostic criteria requiring the presence of at least three dissociation symptoms, at least one re-experiencing symptom, at least one avoidance symptom, and at least one hyperarousal symptom. In addition to this dichotomous determination of ASD diagnostic status, the severity of acute stress symptoms was examined via a continuous ASDS total score ranging from 19 to 95, with higher scores indicating greater severity (Bryant et al., 2000).

   Subsyndromal ASD diagnosis. To determine the presence of subsyndromal ASD, a modified symptom count method was utilized, requiring at least one symptom to be present in each of the four clusters, as used in previous research (Friedman, 2009).

   PTSD Checklist (PCL)

   The PCL is a 17-item self-report checklist that assesses for posttraumatic stress reactions to general stressful experiences in adult individuals (Weathers, Litz, Herman, & Keane, 1993). Respondents rate "how much they have been bothered by" a stressful experience from the past within the preceding month. Items are rated on a 5-point Likert scale ranging from 1 ("not at all") to 5 ("extremely"; Weathers et al., 1993). The PCL has demonstrated excellent internal consistency, test-retest reliability, and convergent validity, as well as adequate sensitivity and specificity in adults exposed to various types

of trauma (Blanchard, Jones-Alexander, Buckley, & Forneris, 1996; Weathers et al., 1993; Ruggiero, Del Ben, Scotti, & Rabalais, 2003).

Full PTSD diagnosis. In the present study, the PCL was used to determine diagnostic status via a symptom count method according to *DSM-IV-TR* (2000) diagnostic criteria requiring the presence of at least one re-experiencing symptom, at least three avoidance symptoms, and at least two hyperarousal symptoms. In addition to this dichotomous determination of PTSD diagnostic status, the severity of posttraumatic stress symptoms was examined via a continuous PCL total score ranging from 17 to 85, with higher scores indicating greater severity (Weathers et al., 1993).

Subsyndromal PTSD diagnosis. To determine the presence of subsyndromal PTSD, a modified symptom count method was utilized, requiring at least one symptom to be present in each of the three clusters, as used in previous research (Friedman, 2009).

Procedure

An archival data set was used in the current study. After securing consent for participation, parents were given a paper-and-pencil screening measure (SDRP) and a measure of ASD symptoms (ASDS). Parents were given the option of having a researcher administer the T1 measures verbally, if they preferred. At 3 months postdischarge, a researcher contacted each parent by telephone and administered a brief telephone assessment to measure PTSD symptoms (PCL) and inquire about interim hospitalizations and other potentially traumatic events. When telephone contact could not be made, follow-up questionnaires were mailed to parents with an accompanying explanatory letter and stamped, self-addressed return envelope.

Analysis of Risk/Benefit Ratio

Potential Risk to Study Participants

This study possessed no risk to participants because of the use of archival data.

Procedures for Minimization of Risk

This study possessed no risk to participants because of the use of archival data.

Potential Benefits to Study Participants/ Others

Societal benefits include expanding the understanding of parental responses to a child's serious medical traumatic event, the development of effective identification procedures of those parents at risk for the development of traumatic stress responses, and ultimately the development of preventive and/or treatment interventions.

Procedures for Maintaining Confidentiality

Access to original data and study materials was limited to the investigative team. Raw data were stored in a locked storage cabinet within a secured office space. Computer files containing confidential data were protected with use of unique assigned study identification (ID) codes. A master key linking identifying patient information with the study ID code was secured similarly to the raw data but in a different location.

Chapter Five

Results

Statistical Analyses

Data were analyzed using the Statistical Package for Social Sciences (SPSS)

Version 19.0. All analyses were carried out separately for mothers and fathers. Both

continuous and categorical variables were analyzed to accomplish the study objectives.

For continuous variables, a sample size of 120 would detect a correlation as low as .25

(small to moderate sized) when the alpha is set .05 on a two-tailed test, with a power of

.80. For categorical variables, a sample size of 126 would be required to meet a power of

.80 with the same set of parameters. Both the T1 and T2 samples exceed this required

minimum sample size.

Descriptive analyses were conducted to examine rates of clinical and

subsyndromal parental ASD and PTSD, with continuous ASDS and PCL scores

determining the severity of ASD and PTSD, respectively. Chi-square tests for

independence were conducted to determine whether mothers and fathers differed in the

presence of ASD and PTSD, while independent-samples t-tests were conducted to

explore any differences in ASD and PTSD symptom severity.

Pearson product moment correlations were used to examine the relationships

between parental risk factors (demographics, psychosocial history, subjective assessment

of child's condition, parental illness beliefs, and coping self-efficacy beliefs) and ASD

symptom severity at T1, while Spearman's rank order correlations were used to examine

these relationships with PTSD symptom severity in the T2 sample. Because correlational

hypotheses were directional, one-tailed tests were used at a significance level of $p < .05$

to increase statistical power. One-way between-groups multivariate analyses of variance

were then performed to examine more closely differences in mothers' and fathers'

individual parental illness beliefs and coping self-efficacy beliefs in both samples.

Finally, three-stage hierarchical multiple regression analyses were performed

separately for mothers and fathers to explore the relative contributions of the most highly

correlated parental risk factors in predicting ASD and PTSD symptom severity.

Results

Assessment of Normality

Normality of the distribution of ASDS and PCL scores was assessed by obtaining

skewness and kurtosis values. The significance values for both samples suggest violation

of the assumption of normality. All parental ASDS scores fell within generally accepted

skewness values between -1 and 1 and kurtosis values between -3 and 3, while parental

PCL scores fell outside of the generally accepted ranges of expected values for normal

distributions (Maxwell & Delaney, 2004). Parametric statistical tests for the T1 sample

were conducted, and alternative nonparametric analyses were utilized for the smaller T2

sample.

Prevalence of ASD

At 48 hours after their child's PICU admission, 27% of parents met full criteria

for ASD, while 37% of parents met subsyndromal criteria. Almost identical rates were

found in the T2 sample, with 28% meeting full criteria and 39% meeting subsyndromal

criteria. More mothers endorsed both full and subsyndromal ASD across both samples. In

the T1 sample, mothers endorsed full ASD at double the rate of fathers (33% compared to 15%) with a similar discrepancy for subsyndromal ASD (42% compared to 28%). Gender differences were also substantial in the T2 sample, with mothers endorsing full ASD at triple the rate of fathers (35% compared to 10%) and greater rates of subsyndromal ASD as well (44% compared to 25%).

Chi-square statistics determined that the presence of ASD diagnosis did differ by gender, in that mothers were much more likely than fathers to meet full criteria for ASD in both the T1 sample [c^2 (1, N = 245) = 9.481, p = .002] and the T2 sample [c^2 (1, N = 180) = 10.898, p = .001]. Additionally, mothers were much more likely than fathers to meet subsyndromal criteria in both the T1 sample [c^2 (1, N = 245) = 4.366, p = .037] and the T2 sample [c^2 (1, N = 180) = 5.912, p = .015]. In examining each of the four symptom clusters as defined by the *DSM-IV-TR* (2000), mothers were significantly more likely than fathers to endorse the required three dissociation symptoms in both the T1 sample [c^2 (1, N = 245) = 7.116, p = .008] and the T2 sample [c^2 (1, N = 180) = 7.664, p = .006]. No gender differences were found in endorsement of the remaining diagnostic requirements (i.e., one re-experiencing, one avoidance, one arousal symptom).

Independent-samples t-tests determined that mothers reported significantly higher ASDS scores (M = 42.43, SD = 16.19) than those reported by fathers (M = 35.56, SD = 13.13; t(195) = -3.57, p = .000). The magnitude of differences in the means was small, with only 5% of the variance in ASDS severity explained by gender (eta squared = .050).

Prevalence of PTSD

Seven parents (4%) met full PTSD criteria while 26 parents (14%) met

subsyndromal criteria. While no gender differences were demonstrated in endorsement of

full PTSD (4% of mothers; 4% of fathers), more mothers endorsed subsyndromal PTSD

(16% compared to 10%).

Chi-square statistics determined no differences in the presence of full or

subsyndromal PTSD across gender. Similarly, no gender differences were found in

parental endorsement of the three PTSD symptom clusters defined by the *DSM-IV-TR*

(2000).

In examining gender differences in posttraumatic stress symptom severity, a

Mann-Whitney U test for independent samples determined that maternal PCL scores (*M*

= 25.1, *SD* = 9.8, *Mdn* = 22.0) were significantly higher than paternal scores (*M* = 22.1,

SD = 7.8, *Mdn* = 20.0; *N* = 180, *z* = 4.619, *p* = .032).

Association Between Risk Factors and Traumatic Stress Outcomes

The relationships between specific parental risk factors and ASD/ PTSD

symptom severity were investigated via correlations (Table 2).

Table 2

Correlations Between Potential Parent Risk Factors and Traumatic Stress Severity

Potential parent risk factors	Correlation (r) with ASDS score			Correlation (ρ) with PCL score		
	T1Parents $N = 245$	Mothers $N = 163$	Fathers $N = 82$	T2Parents $N = 180$	Mothers $N = 132$	Fathers $N = 48$
Psychosocial history (Have you ever experienced…)						
an event that made you feel scared, helpless, horrified	.31***	.26***	.34**	.22***	.25**	.05
a period of excessive worry, fear and/or anxiety	.30***	.29***	.23*	.27***	.28***	.10
a period of prolonged sadness or depression	.32***	.35***	.10	.25***	.31***	-.16
something extremely frightening that still troubles you	.43***	.38***	.47***	.31***	.29***	.25*
Subjective assessment of child's condition						
Was your child's hospital stay unexpected?	.28***	.32***	.21*	.25***	.27***	.10
Has having your child in the hospital been a burden?	.30***	.28***	.44***	.23***	.30***	.06
How sick or hurt is your child?	.37***	.36***	.36***	.16*	.19*	.14
How worried are you that your child might die?	.40***	.40***	.37***	.37***	.41***	.13
Objective assessment of child's condition						
Child 12- hr PRISM score[†]	.19			.06		
Child 24- hr PRISM score[†]	.09			.17		
Child length of PICU stay[†]	.24*			.09		
ASD symptom severity						
Total ASDS score				.61***	.63***	.47***

*$p < .05$. ** $p < .01$. *** $p \leq .001$ (1-tailed) . [†] Correlations conducted on limited subset ($N = 76$).

First, risk factors pertaining to parental psychosocial history were examined. A majority of all parents (69%) reported having experienced an event that made them feel really scared, helpless, or horrified, and while this variable correlated positively with ASD symptom severity in all parents, it correlated positively with PTSD symptom severity only in mothers. Similarly, 61% of all parents reported having experienced periods of excessive worry, fear, and/or anxiety, and while this variable demonstrated a

stronger correlation with ASD symptom severity in mothers as compared to fathers, it

correlated positively with PTSD symptom severity only in mothers. Just over one third of

all parents (36%) reported having experienced a period of prolonged sadness or

depression, and this variable demonstrated a positive correlation with ASD symptom

severity and PTSD symptom severity only in mothers. Finally, one quarter of all parents

(26%) reported having experienced an extremely frightening event that was still

troubling, and this variable demonstrated a positive correlation with both ASD and PTSD

symptom severity in all parents.

Next, subjective parental assessments of their child's condition were examined.

More than half of all parents (59%) reported that their child's hospital stay was

unexpected, and while this variable demonstrated a stronger correlation with ASD

symptom severity in mothers as compared to fathers, it correlated positively with PTSD

symptom severity only in mothers. The remaining three variables were all strongly

associated with ASD symptom severity for all parents but demonstrated statistically

significant correlations with PTSD symptom severity only in mothers. These three

variables were: considering their child's hospital stay as a burden for the child/family

(44%), parental rating of the severity of their child's condition (80% endorsed "very

sick/hurt"), and parental worry about child life-threat (34% endorsed "very worried my

child might die").

Among the subset of 76 children whose medical records were evaluated, only the

child's length of stay was weakly associated with parental ASDS score. Finally, level of

ASD symptom severity was strongly associated with level of PTSD symptom severity in all parents, demonstrating a greater correlation in mothers than fathers.

Gender, Parental Illness Beliefs, and Traumatic Stress Outcomes

The three most frequently endorsed parental illness beliefs included the following: *There are people I can turn to for help* (70%), *Faith or prayer will get me through this* (60%), and *The doctors will know what to do* (60%). Just over 40% of parents endorsed the beliefs *Everything happens for a reason* and *It's okay to take care of myself*, while only 14% of parents believed *This is a disaster*.

One-way between-groups MANOVA using a Bonferroni adjusted alpha level of .006 determined that mothers and fathers differed only in their frequencies of the two least endorsed illness beliefs: *I can't bear to think the treatment might not work* [17% of mothers and 7% of fathers; $F(1, 224) = 12.58$, $p = .000$, partial eta squared = .053] and *I may fall apart emotionally* [9% of mothers and 0% of fathers; $F(1, 224) = 26.80$, $p = .000$, partial eta squared = .107]. These same two parental illness beliefs were strongly associated with ASD symptom severity and moderately associated with PTSD symptom severity in all parents (Table 3).

Table 3

Correlations Between Parental Illness Beliefs and Traumatic Stress Severity

Parental Illness Beliefs (How much do you believe….)	Correlation (*r*) with ASDS score			Correlation (*ρ*) with PCL score		
	T1Parents $N = 245$	Mothers $N = 163$	Fathers $N = 82$	T2Parents $N = 180$	Mothers $N = 132$	Fathers $N = 48$
I can't bear to think the treatment might not work	.56***	.56***	.49***	.37***	.35***	.27*
I may fall apart emotionally	.54***	.50***	.57***	.37***	.36***	.25*
This is a disaster	.52***	.54***	.47***	.45***	.50***	.22
It's okay to take care of myself†	.07	.04	.21*	.11	.05	.33**
Everything happens for a reason†	.02	.05	.05	-.02	.06	-.12
The doctors will know what to do†	.12	.16*	.10	.06	.04	.05
Faith or prayer will get me through this†	-.04	-.01	-.04	-.09	-.06	-.18
There are people I can turn to for help†	.19**	.18*	.19*	.18**	.19*	.12
Total mean PIB score (Range = 0 – 24)	.51***	.53***	.45***	.38***	.40***	.19

† reverse coded items. *$p < .05$. ** $p < .01$. *** $p ≤ .001$ (1-tailed).

The belief *This is a disaster* demonstrated a strong association with ASD symptom severity in all parents, but this finding held true with PTSD symptom severity only in mothers. Conversely, the belief *It's ok to take care of myself* demonstrated a small positive correlation with both ASD and PTSD symptom severity in fathers but not in mothers.

Finally, mean parental illness belief scores among all parents (*M* = 6.2, *SD* = 3.5) were quite low, indicating few maladaptive beliefs. Although mothers endorsed higher mean parental illness belief scores (*M* = 6.5, *SD* = 3.5) than those of fathers (*M* = 5.8, *SD* = 3.5), this difference was not statistically significant [*t*(224) = -.148, *p* = .142]. While

total parental illness belief score was associated strongly with ASD symptom severity in all parents, it was correlated positively with PTSD symptom severity only in mothers.

Gender, Coping Self-Efficacy Beliefs, and Traumatic Stress Outcomes

The three most frequently endorsed coping self-efficacy beliefs included confidence to *be strong for child* (82%), *express thoughts and needs to the medical team* (71%), and *be optimistic about child's recovery* (71%). Nearly 70% of all parents felt very confident that they could *support child's coping/adjustment*, *understand information about child's treatment*, *make complex decisions about child's health*, and *readily accept help from others*. About half of all parents felt very confident that they could *deal with child's medical problems effectively, help child cope when in pain/upset*, and *remain calm when faced with upsetting sights/sounds.* A minority of parents endorsed the remaining coping self-efficacy beliefs, including confidence to *control upsetting thoughts about child being ill/injured* (45%), *keep distressing images in my mind from overwhelming me* (42%), *cope with the emotional stress of having a sick/injured child* (41%), and *handle times of uncertainty about child's health* (35%).

One-way between-groups MANOVA using a Bonferroni adjusted alpha level of .003 determined that mothers and fathers differed in their frequencies of only one coping self-efficacy belief: *Keep my emotions in check* [46% of fathers and 30% of mothers; $F(1, 231) = 9.86$, $p = .002$, partial eta squared = .041].

Two coping self-efficacy beliefs, *Keep distressing images in my mind from overwhelming me* and *Understand information about child's treatments,* were strongly

associated with ASD symptom severity and moderately associated with PTSD symptom

severity in all parents (Table 4).

Table 4

Correlations Between Coping Self-Efficacy Beliefs and Traumatic Stress Severity

Coping Self-Efficacy Beliefs (How confident are you that you can….)	Correlation (r) with ASDS score			Correlation (ρ) with PCL score		
	T1Parents $N = 245$	Mothers $N = 163$	Fathers $N = 82$	T2Parents $N = 180$	Mothers $N = 132$	Fathers $N = 48$
Keep distressing images from overwhelming you	-.45***	-.49***	-.32**	-.30***	-.29***	-.27*
Control upsetting thoughts about child being ill/injured	-.36***	-.40***	-.33***	-.29***	-.35***	-.07
Handle times of uncertainty about child's health	-.35***	-.40***	-.21*	-.24***	-.26***	-.18
Remain calm when faced with upsetting sights/sounds	-.34***	-.35***	-.24*	-.27***	-.33***	.06
Keep your emotions in check	-.30***	-.31***	-.14	-.25***	-.24**	-.18
Be optimistic about child's recovery	-.30***	-.30***	-.27**	-.27***	-.28***	-.17
Cope with emotional stress of having sick/injured child	-.28***	-.30***	.15	-.16*	-.16*	-.07
Deal with child's medical problems/issues effectively	-.28***	-.28***	-.40***	-.14*	-.15*	-.13
Help child cope when in pain/ upset while in hospital	-.27***	-.29***	-.36***	-.22**	-.29***	.01
Understand information about child's health/ treatments	-.26***	-.25***	-.33**	-.27***	-.27***	-.24*
Make complex decisions about child's health care	-.24***	-.27***	-.23*	-.14*	-.18*	.04
Express your thoughts and needs to medical team	-.22**	-.22**	-.27**	-.28***	-.33***	-.13
Be strong for your child	-.18**	-.20*	-.12	-.22***	-.23**	-.12
Accept help from others while child is ill/injured	-.16**	-.12	-.23*	-.16*	-.16	-.01
Support child's coping/ adjustment while in hospital	-.11*	-.13	-.16	-.07	-.11	-.02
Total mean CSE score (Range = 0 – 45)	-.42***	-.45***	-.37***	-.35***	-.39***	.19

*p < .0. ** p < .01. *** p ≤ .001 (1-tailed).

All but two coping self-efficacy beliefs were associated with ASD and PTSD symptom severity in mothers. All but four coping self-efficacy beliefs were associated with ASD symptom severity in fathers, however, only two were associated with paternal PTSD symptom severity.

Overall, mean coping self-efficacy scores among all parents ($M = 37.0$, $SD = 6.4$) were quite high, reflecting high levels of confidence in the ability to cope with their child's condition. Although fathers endorsed higher mean scores of coping self-efficacy beliefs ($M = 37.2$, $SD = 6.8$) than mothers ($M = 36.9$, $SD = 6.2$), this was not a statistically significant difference [$t(231) = .365$, $p = .715$). Total coping self-efficacy score was correlated strongly and negatively with ASD symptom severity across all parents, but negatively correlated with PTSD symptom severity only in mothers.

Relationship Between Parental Risk Factors and ASD Outcomes

Three-stage hierarchical multiple regression analyses were performed separately for mothers and fathers to explore the relative contributions of the most highly correlated parental risk factors to ASD symptom severity. Fourteen predictor variables were entered, meeting sample-size requirements as proposed in the literature (Tabachnick & Fidell, 1996). The assumption of collinearity was not violated for any of the predictor variables, and no major deviations from normality were observed.

Four demographic variables were entered on Step I, four psychosocial variables correlating most highly with maternal/paternal ASD symptom severity were entered on Step II, and three parental illness beliefs/ three coping self-efficacy beliefs correlating

most highly with maternal/paternal ASD symptom severity were entered on Step III

(Table 5).

Table 5

Predictors of Parental ASD Symptom Severity: Hierarchical Multiple Regression

Step	Variables	Mothers (N = 154)				Fathers (N = 74)			
		R^2	ΔR^2	F	p	R^2	ΔR^2	F	p
I	Age	.133	.133			.048	.048		
	Ethnicity								
	Marital status								
	Educational level								
II	Experienced something frightening that is still troubling	.388	.255			.386	.338		
	How sick or hurt is your child?								
	How worried are you that your child might die?								
	Period of prolonged sadness or depression[a]								
	Has having your child in the hospital been a burden?[b]								
III	I may fall apart emotionally	.599	.211	14.97	.000	.678	.292	9.03	.000
	I can't bear to think the treatment might not work								
	This is a disaster								
	Control upsetting thoughts about child being ill/injured								
	Handle times of uncertainty about child's health[a]								
	Keep distressing images from overwhelming me[a]								
	Help child cope while in pain or upset [b]								
	Deal with child's medical problems/ issues effectively [b]								

[a] Included only in mothers' analysis. [b] Included only in fathers' analysis.

Results indicated that, after block I demographic variables were entered, the

overall model explained 13.3% of the variance in maternal ASD symptom severity and

4.8% of the variance in paternal ASD symptom severity. After block II psychosocial

variables were entered, the model as a whole explained 38.8% of the variance in maternal

ASD symptom severity and 38.6% of the variance in paternal ASD symptom severity.

Finally, after block III parental illness beliefs and coping self-efficacy beliefs were

entered, the model as a whole explained 59.9% of the variance in maternal ASD

symptom severity and 67.8% of the variance in paternal ASD symptom severity.

Thus, after controlling for demographics, psychosocial history, and subjective

assessment, the selected parental illness beliefs and coping self-efficacy beliefs explained

an additional 21.1% of the variance in maternal ASD symptom severity and an additional

29.2% of the variance in paternal ASD symptom severity, both of which are statistically

significant contributions [$F(14, 140) = 14.97$, $p < .0005$; $F(14, 60) = 9.03$, $p < .0005$)].

In evaluating each of the predictor variables, four variables were shown to make a

statistically significant contribution for mothers: maternal age (beta = -.17), period(s) of

prolonged sadness or depression (beta = .13), the parental illness belief *I can't bear to

think that the treatment might not work* (beta = .25), and confidence in the ability to *Keep

distressing images in my mind from upsetting or overwhelming me* (beta = -.17). Five

variables were shown to make a statistically significant contribution for fathers: paternal

age (beta = -.21), having experienced something frightening that still troubles him (beta =

.25), and the three parental illness beliefs *I can't bear to think the treatment might not*

work (beta = .23), *This is a disaster* (beta = .20), and *I may fall apart emotionally* (beta =

.41).

Relationship Between Parental Risk Factors and PTSD Outcomes

Three-stage hierarchical multiple regression analyses were performed separately

for mothers and fathers to explore the relative contributions of the most highly correlated

parental risk factors to PTSD symptom severity. Fifteen predictor variables were entered

for mothers and 11 for fathers, meeting sample-size requirements as proposed in the

literature (Tabachnick & Fidell, 1996). The assumption of collinearity was not violated

for any of the predictor variables, and no major deviations from normality were observed.

Four demographic variables were entered on Step I, ASDS score and psychosocial

variables correlating most highly with maternal/paternal PTSD symptom severity were

entered on Step II, and three parental illness beliefs/ three coping self-efficacy beliefs

correlating most highly with maternal/paternal PTSD symptom severity were entered on

Step III (Table 6).

Table 6

Predictors of Parental PTSD Symptom Severity: Hierarchical Multiple Regression

Step	Variables	Mothers (N = 124)				Fathers (N = 47)			
		R^2	ΔR^2	F	p	R^2	ΔR^2	F	p
I	Age	.104	.104			.131	.131		
	Ethnicity								
	Marital status								
	Educational level								
II	Experienced something frightening that is still troubling	.380	.276			.433	.302		
	Total ASDS score								
	Period of prolonged sadness or depression[a]								
	Was your child's hospital stay unexpected?[a]								
	How worried are you that your child might die?[a]								
III	I may fall apart emotionally	.497	.117	7.18	.000	.488	.055	3.12	.005
	I can't bear to think the treatment might not work								
	This is a disaster [a]								
	Control upsetting thoughts about child being ill/injured[a]								
	Remain calm when faced with upsetting sights/sounds[a]								
	Express my thoughts and needs to the medical team[a]								
	It's ok to take care of myself[b]								
	Keep distressing images from overwhelming me[b]								
	Understand information about child's treatment[b]								

[a] Included only in mothers' analysis. [b] Included only in fathers' analysis.

Results indicated that, after block I demographic variables were entered, the

overall model explained 10.4% of the variance in maternal PTSD symptom severity and

13.1% of the variance in paternal PTSD symptom severity. After block II psychosocial

variables and ASDS scores were entered, the model as a whole explained 38.0% of the

variance in maternal PTSD symptom severity and 43.3% of the variance in paternal

PTSD symptom severity. Finally, after block III parental illness beliefs and coping self-

efficacy beliefs were entered, the model as a whole explained 49.7% of the variance in

maternal PTSD symptom severity and 48.8% of the variance in paternal PTSD symptom

severity.

Thus, after controlling for demographics, psychosocial history, acute stress

symptomatology and subjective assessment of the situation, the selected parental illness

beliefs and coping self-efficacy beliefs explained an additional 11.7% of the variance in

maternal PTSD symptom severity and an additional 5.5% of the variance in paternal

PTSD symptom severity, both of which are statistically significant contributions [F(15,

109) = 7.18, $p < .0005$); F(11, 36) = 3.12, $p = .005$].

In evaluating each of the predictor variables, three variables were shown to make

a statistically significant contribution for mothers: ASDS score (beta = .46), the illness

belief *This is a disaster* (beta = .19), and confidence in the ability to *Express thoughts*

and needs to the medical team (beta = -.34). Only one variable, ASDS score, was shown

to make a statistically significant contribution for fathers (beta = .64).

Chapter Six

Discussion

Hypothesis 1

As hypothesized, the prevalence of parental ASD in this sample was consistent with rates in other PICU populations as documented in the current literature. Just under one-third of parents in this sample developed full ASD, while a greater number of parents developed subsyndromal ASD. However, this sample's prevalence of PTSD was significantly lower than those documented in the literature, with fewer than 5% of parents developing full PTSD.

Hypothesis 2

Results lacked support for the hypothesis that there would be no statistically significant differences between maternal and paternal ASD rates, with mothers far surpassing fathers in rates of full and subsyndromal ASD. Results also lacked support for the hypothesis that mothers would endorse greater rates of PTSD, as no gender differences were found in PTSD prevalence. However, mothers demonstrated higher mean scores on the ASDS and PCL, indicating greater severity in maternal acute and posttraumatic stress responses.

Hypothesis 3

As hypothesized, numerous risk factors correlated with parental ASD and PTSD severity, with differences noted between mothers and fathers. All risk factors pertaining to parental psychosocial history and subjective assessment of the child's condition correlated with both ASD and PTSD symptom severity for mothers. While all of these

correlated with fathers' ASD symptom severity, only fathers who had experienced "something extremely frightening that is still troubling" had more severe PTSD symptoms. Results also supported that parents with more severe ASD symptoms developed more severe PTSD symptoms and that objective medical characteristics of the child's condition were not associated with ASD or PTSD severity. Finally, greater endorsement of maladaptive parental illness beliefs and lower coping self-efficacy was associated with more severe ASD symptoms for all parents, but with more severe PTSD symptoms only in mothers.

Hypothesis 4

As hypothesized, parental endorsement of maladaptive parental illness beliefs and low coping self-efficacy beliefs explained a significant amount of the variance in ASD symptom severity for both mothers and fathers. To a smaller degree, these beliefs also explained a significant amount of the variance in PTSD symptom severity for both mothers and fathers.

Significance of the Findings

While supporting the current literature on ASD rates in PICU parents, the current study demonstrated a lower rate of PTSD, suggesting that the majority of parents successfully cope with the challenges presented by their child's PICU treatment or resolve more immediate and impairing symptoms after the first month postdischarge. Also in contrast to the literature, this study found that mothers far surpassed fathers in their development and severity of ASD symptoms, with an emphasis on dissociation symptoms. This finding suggests that PICU mothers experience more immediate distress

than fathers surrounding their child's PICU admission and a higher susceptibility to particular symptoms, such as derealization, detachment, difficulty recalling specific details of the traumatic event, or experiencing the world as unreal or dreamlike. With more focused screening and greater attention paid to these specific maternal reactions, pediatric professionals can better support familial needs by tailoring interventions.

Gathering specific parental information, such as a history of trauma, anxiety, or depression, an unexpected PICU admission, and worry that their child might die, is also crucial in identifying mothers and fathers who are at risk for more severe ASD responses. While these risk factors also are associated with more severe PTSD symptoms in mothers, the current study found only one association with increased PTSD severity in fathers: current impaired functioning from a past trauma. As reported in previous studies, while the parents' own subjective assessment of the severity of their child's condition was associated with ASD and PTSD severity, objective medical characteristics were not (Baluffi et al., 2004; Pietrzak et al., 2011).

Overall, the majority of this sample endorsed adaptive beliefs about their child's illness/injury and relatively high confidence in their ability to cope with the situation. The minority of parents who endorsed more maladaptive parental illness beliefs and less coping self-efficacy developed more severe symptoms of ASD. For mothers, these beliefs also were associated with more severe PTSD symptoms; however, this finding did not hold up for fathers. Thus, while assessment and intervention regarding cognitions, images, and assumptions about the situation may be beneficial for all parents within the

first month of the child's PICU admission, they are likely to be helpful only for mothers

who develop longer-term traumatic stress responses.

More specifically, this study found the endorsement of two beliefs to be highly

correlated with traumatic stress severity across all parents: "I may fall apart emotionally"

and "I can't bear to think the treatment might not work." For mothers, those who also

believed that the situation was "a disaster" and had low confidence to handle uncertain

times about their child's health, control upsetting thoughts, or keep distressing images

from upsetting them developed more severe ASD symptoms. Previous literature points to

the PICU environment (e.g., sight of equipment, sound of alarms) and the child's

emotions and behavior (e.g., crying, whining, withdrawing) as the greatest sources of

stress for mothers, and so assessing and treating mothers' initial cognitive responses to

these triggers is vital (e.g., *this situation is overwhelming and out of my control*).

Alternately, fathers who believed that the situation was "a disaster" and had low

confidence to control upsetting thoughts, help their child cope while in pain or upset, and

deal with their child's medical problems effectively developed more severe ASD

symptoms. Previous literature points to medical procedures and changes in parental role

as the greatest sources of stress for fathers, and so separate assessment and treatment of

fathers' initial cognitive responses to these triggers is vital (e.g., *I am not able to care for

my child myself*). As for development of longer term, more severe PTSD symptoms,

mothers with low confidence in being able to express thoughts/needs to the medical team

and fathers with low confidence to understand information about their child's

health/treatment are at risk. Again, pediatric professionals have the opportunity to

respond in a sensitive manner to these issues of communication and collaboration during

and after the child's treatment to better fulfill parental needs and lower the risk of

traumatic stress responses.

Limitations of the Current Study

While utilizing a relatively large sample within 48 hours of a child's PICU

admission, the current study conducted analyses on a smaller T2 sample because many

parents were lost to follow-up. At both time points, the sample was overly representative

of married, well-educated, and Caucasian parents, with twice as many mothers than

fathers, which may be indicative of a self-selection bias. This restricted variability in

sample demographics also limits the study's representation of more general population

parameters in PICU parents across the United States. Overall, parents of this sample

endorsed highly adaptive parental illness beliefs and high confidence in their ability to

cope with the situation, which may limit the utility of these findings to a more distributed

population of parents. For example, within the smaller T2 sample size, very few parents

developed full PTSD, which limited this study's power.

An additional limitation included the accessibility of medical record information

for the children admitted to the PICU; consequently, only ancillary analyses were

conducted on the association of these variables with parental ASD and PTSD symptom

severity. More information on the child's diagnosis, frequency and nature of previous

hospitalizations, and circumstances of the identified trauma that caused PICU admission

could further elucidate differences in the parental traumatic stress trajectory.

Methodologically, the current study utilized self-report measures for assessing the presence and severity of ASD and PTSD which limits the amount of information gathered. A clinical diagnostic interview would reflect broader and possibly more accurate results, and may also illuminate reporting differences in men and women.

Future Directions

Future work can build on the current study's findings by assessing parental illness beliefs and coping self-efficacy at multiple treatment time points among a more diverse and varied parent sample with a larger representation of fathers. Electronic mail may be used to facilitate more continuous participation and serve as an incentive for parents to complete all measures. While this study has elucidated some differences in certain maternal and paternal stress-inducing beliefs, future work can further assess these and other trauma-related cognitions immediately upon PICU admission, throughout treatment, and after discharge to illuminate adaptive and nonadaptive changes in parental belief systems. Furthermore, cognitive behavioral therapy (CBT) interventions aimed at restructuring early nonadaptive parental illness beliefs and promoting more resilience-based appraisals of the situation and coping self-efficacy can be piloted and assessed for efficacy.

Supplementary data about the child's medical condition and possible child self-report of psychosocial functioning also could expand this study's findings to better understand the entire family's traumatic stress responses to a child's PICU treatment. These additional sources of data could enhance the field's perspective on why and how parents develop their beliefs about the situation and their ability to cope. Previous

literature has documented discrepancies between child and parent reports of acute and posttraumatic stress responses to medical trauma, and this study provides a foundation for further illuminating any discrepancies that might exist with PICU treatment.

Finally, this study's findings regarding the role of beliefs in parental traumatic stress outcomes can serve as a building block for the development of more precise assessments and tailored interventions. Psychoeducational materials describing pediatric medical traumatic stress may be disseminated to all families upon PICU admission, or even provided to families in which a PICU hospitalization may be expected, such as children living with congenital or high-risk chronic illnesses. Also upon admission, healthcare professionals can integrate routine assessments of parental illness and coping self-efficacy beliefs so that families at higher risk can be referred to appropriate mental health services. Psychologists, family therapists, and social workers in the hospital then can focus on restructuring maladaptive subjective appraisals of the situation, such as parental overestimation of child life-threat, and on enhancing parental coping self-efficacy by utilizing family resources (e.g., extended family, religious or spiritual leaders).

Findings from the current study can inform more precise interventions for mothers and fathers separately. In order to prevent acute stress symptoms, immediate maternal interventions can integrate mindfulness and commitment/acceptance therapy to reduce symptoms of dissociation or re-experiencing, while paternal interventions may integrate more practical, hands-on behaviors, such as guiding their children in relaxation exercises or other means of caring for their child's psychological, if not medical, needs.

In order to prevent longer term posttraumatic stress symptoms, mental-healthcare professionals can facilitate more effective communication between parents and the healthcare team so that specific needs are expressed and met and information about the child's health and treatment are clearly understood.

Summary and Conclusion

The current study found a prevalence rate of parental ASD that is consistent with the current literature and a prevalence rate of parental PTSD that is substantially lower than previously documented. Mothers were found to far surpass fathers in their rates of full and subsyndromal ASD, while no statistically significant gender differences were found in rates of full and subsyndromal PTSD. Overall, however, mothers reported higher severity of both ASD and PTSD symptoms.

Numerous risk factors, including psychosocial history and subjective assessment of the child's condition, were found to correlate with parental ASD and PTSD severity, with differences noted between mothers and fathers. In support of current literature, more severe ASD symptoms correlated with more severe PTSD symptoms, while objective medical characteristics of the child's condition were not associated with ASD or PTSD severity. This study added to the current literature by demonstrating that greater endorsement of maladaptive parental illness beliefs and lower coping self-efficacy was associated with more severe ASD symptoms for all parents, but with more severe PTSD symptoms only in mothers.

Upon closer examination, two beliefs were found to be correlated highly with traumatic stress severity across all parents: "I may fall apart emotionally" and "I can't

bear to think the treatment might not work." However, differences were noted in the type

of beliefs that were significant for mothers and those that were significant for fathers.

Beliefs focused on the PICU environment and the child's condition correlated with ASD

symptom severity for mothers, while beliefs about the parental role and medical

treatment correlated with ASD symptom severity for fathers. As for development of

longer term symptoms, mothers with low confidence in being able to express thoughts/

needs to the medical team and fathers with low confidence to understand information

about their child's treatment were shown to be at highest risk for PTSD.

  Overall, parental endorsement of maladaptive parental illness beliefs and low

coping self-efficacy beliefs explained a significant amount of the variance in ASD and

PTSD symptom severity for both mothers and fathers. Thus, the findings of the current

study add to the current literature and contribute to a better understanding of the role of

beliefs in maternal and paternal traumatic stress responses after a child's PICU

admission.

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