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UNCERTAINTY AND PRIMARY APPRAISAL AS PREDICTORS OF ACUTE STRESS  
DISORDER IN PARENTS OF CRITICALLY ILL CHILDREN: A MEDIATIONAL MODEL

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of  
Philosophy at Virginia Commonwealth University

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*Sometimes our light goes out but is blown into flame by another human being. Each of us owes deepest thanks to those who have rekindled this light.*

Albert Schweitzer

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In loving memory of Thomas Fred Harvey, February 11, 1957 – November 1, 1999.

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## Abstract

### UNCERTAINTY AND PRIMARY APPRAISALS AS PREDICTORS OF ACUTE STRESS DISORDER IN PARENTS OF CRITICALLY ILL CHILDREN: A MEDIATIONAL MODEL

By Monica Mary Durette, M.S.

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy at Virginia Commonwealth University.

Virginia Commonwealth University, 2013

Major Director: Marilyn Stern, Ph.D.  
Professor

Departments of Psychology, Pediatrics, Social and Behavioral Health

This study examined illness-related uncertainty and primary appraisals of threat, centrality, and challenge as predictors of acute stress disorder (ASD) symptoms in parents of children hospitalized in a pediatric intensive care unit (PICU). Ultimately, a mediational pathway was tested to determine if primary appraisal was a mechanism that accounted for the impact of uncertainty on ASD symptoms. Ancillary study aims were to assess the degree to which parents perceived uncertainty in the PICU environment, and to determine the prevalence of ASD among parents in this setting. Self-report data was collected from 77 parents (57 mothers, 19 fathers) of children hospitalized in a PICU for a minimum of 48 hours. Descriptive analyses showed that parents perceived a high degree of uncertainty and 57% of parents met



diagnostic criteria for ASD. Unexpected admission was the only objective medical status variable significantly related to uncertainty, threat appraisal, and ASD symptoms. Consistent with hypotheses, results from hierarchical regression analyses showed that perceived uncertainty and primary appraisals of threat accounted for significant variance in parents' ASD symptoms; however, neither centrality nor challenge appraisals were related to parents' ASD symptoms. Because threat was the only appraisal dimension found to be directly related to ASD symptoms, it was the only dimension tested in the mediational model. Consistent with the hypothesis, threat appraisals fully mediated the effect of uncertainty on ASD symptoms; results from a Sobel test confirmed the significance of full mediation. This study is the first to examine uncertainty, primary appraisal, and ASD symptoms in this population. Results clarify that it is not the mere perception of uncertainty that adversely impacts parental adjustment, but rather how it is appraised, and therefore, point to a practical area for in-hospital interventions targeting parents' pediatric medical traumatic stress symptoms. Although a substantial body of empirical research supports a relation between uncertainty and maladaptive outcomes, studies also link uncertainty to positive outcomes. Future research should include positive indicators of adjustment and examine how appraisals vary according to sources of uncertainty.

## Uncertainty and Primary Appraisals as Predictors of Acute Stress Disorder in Parents of Critically Ill Children: A Mediational Model

Approximately 240,000 children in the United States are hospitalized in pediatric intensive care units (PICUs) each year as a result of life-threatening conditions stemming from acute disease, exacerbations of chronic illnesses, neurodevelopmental disabilities, and severe injuries (Himmelstein, Hilden, Boldt, & Weissman, 2004; Randolph, Gonzales, Cortellini, & Yeh, 2004). A child's PICU admission can be a frightening, stressful event for parents, characterized by uncertainty pertaining to diagnoses, difficult medical decisions, treatment options and effectiveness – even uncertainty about where to park the car and where to get something to eat (Board, 2004; Board & Ryan-Wenger, 2003; Bousso & Angelo, 2003; Carter & Miles, 1989; LaMontagne, Hepworth, Johnson, & Deshpande, 1994; Mu & Tomlinson, 1997; Stewart & Mishel, 2000; Turner, Tomlinson, & Harbaugh, 1990; Youngblut & Jay, 1991). Above all, parents may face uncertainty pertaining to the potential for their child to sustain permanent physical disabilities and cognitive impairments, and ultimately, their child's ability to survive (Balluffi et al., 2004; Bousso & Angelo; Noyes, 1998).

To date, only one published study has examined factors that may be related to indicators of short-term parental adjustment to a child's critical care hospitalization (Balluffi et al., 2004). A prospective, longitudinal study found that 32% of parents met diagnostic criteria for acute stress disorder (ASD) within days of their child's PICU admission; moreover, the majority of parents surveyed reported experiencing ASD symptoms of hyperarousal (87%), re-experiencing (75%), dissociation (74%), and avoidance (68%). Follow-up data collected 2 to 11 months after PICU discharge (median 4 months) revealed that virtually every parent reported at least one

symptom of posttraumatic stress (98%), and 21 % of parents met diagnostic criteria for posttraumatic stress disorder (PTSD). Although quantitative empirical research among this population is sparse, qualitative studies show data themes characteristic of acute stress reactions consistent with Balluffi and colleagues findings, thus providing compelling evidence that a child's PICU admission is a potentially traumatic event (Balluffi et al.; Berenbaum & Hatcher, 1992; Board, 2004; Board & Ryan-Wenger, 2003; Tomlinson & Mitchell, 1992).

Even though acute stress reactions manifested as a range of cognitive, emotional, and physical symptoms such as intrusive thoughts, irritability, excessive worry, tearfulness, loss of appetite, and difficulty sleeping are quite normal under this type of circumstance (Balluffi et al. 2004; Board & Ryan-Wenger, 2003), parents of children hospitalized in a PICU experience greater psychological distress than parents of children hospitalized in a general care pediatric unit (Board, 2004; Rees, Gledhill, Garralda, & Nadel, 2004), and their long-term risk for depression and anxiety is increased (e.g., Bronner, Knoester, Bos, Last, & Grootenhuis, 2007; Colville & Gracey, 2006; Rees et al.). Most PICU parents experience one or more PTSD symptoms after their child has been discharged (e.g., Bronner et al.), and they are more likely to be diagnosed with PTSD compared to parents of children treated on a general pediatric unit (Rees et al).

A review of the literature reveals that posttraumatic stress symptoms (PTSS) are common and widespread among parents after numerous types of serious, pediatric medical events including childhood cancers, traffic-related injuries, burns, and diagnoses of type 1 diabetes (e.g., Fuemmeler, Mullins, & Marx, 2001; Hall et al., 2006; Horsch, McManus, Kennedy, & Edge, 2007; Kazak et al., 1998; Landolt, Vollrath, Ribl, Gnehm, & Sennhauser, 2003; Patiño-Fernandez et al., 2008; Winston et al., 2002). Nevertheless, acute stress reactions manifested as

symptoms of irritability, anger, or avoidance have the potential to impede parents' ability to effectively care for their child, or adversely impact communication with medical staff. This may be especially true in a critical care environment where parents must interact with many different teams of specialists and often must make medical decisions quickly, under difficult circumstances (Studdert et al., 2003).

**Pediatric medical traumatic stress.** Pediatric psychology researchers have created a developmental, pediatric medical traumatic stress (PMTS) model that conceptualizes PTSS as a normal spectrum of short- and longer-term responses to a child's life-threatening illness or injury (Kazak et al., 2006). PMTS is defined as a "continuum of key symptoms of PTSD . . . which may be present without meeting criteria for a full diagnosis" (Kazak et al., p. 344). The PMTS model assumes that despite the prevalence of significant PTSS, most children and families facing potentially traumatic medical events are functional and competent; however, some families may be more vulnerable and therefore, are at higher risk for developing significant psychological problems as they negotiate medical demands. The PMTS<sup>1</sup> model comprises three phases that temporally reflect families' experiences of how events typically unfold in the course of a pediatric illness or injury: Phase 1) peri-trauma, Phase 2) early, ongoing (i.e., treatment), and Phase 3) longer-term sequelae. The PMTS model emphasizes the dynamic role of subjective experience of objective aspects of potentially traumatic medical events in determining individual adjustment, especially in one's ability to cope adaptively with immediate challenges in the peri-trauma phase.

---

<sup>1</sup> For a visual depiction of the PMTS model, see Figure 1 in the Literature Review section.

## **Parental Adaptation to Potentially Traumatic Medical Events**

Thus far, most studies of PMTS and factors related to parental adaptation reflect a focus on the active treatment stage (Phase II) and longer-term sequelae (Phase III) among specific, pediatric diagnostic populations. (e.g., Alderfer, Cnaan, Annunziatto, & Kazak, 2005; Fuemmeler et al., 2001; Horsch et al., 2007; Kazak, Boeving, Alderfer, Hwang, & Reilly, 2005; McCarthy, Ashley, Lee, & Anderson, 2012). With the exception of Balluffi and colleagues' work (2004), empirical studies among parents of PICU patients during hospitalization (i.e., the peri-trauma phase) are mainly descriptive (e.g., Tomlinson & Mitchell, 1992; Turner et al., 1990). A limited number of retrospective studies conducted in this population have found positive correlations between parents' PTSD symptoms and their perceptions of illness severity, life threat (Rees et al., 2004), and perceived stress (Colville & Gracey, 2006), but not objective medical status variables, including objective mortality risk and length of PICU stay (Bronner et al., 2007).

**Correlates of parental adjustment.** Results from Balluffi and colleagues' (2004) study conducted among parents of children admitted to a PICU are consistent with the PMTS model's assertion that subjective evaluation of objective aspects of potentially traumatic events play an important role in determining adjustment (Kazak et al., 2006). Moreover, results from the Balluffi study provide empirical support for the portion of the PMTS model linking short- and longer-term indicants of adaptation. Specifically, parents who met diagnostic criteria for ASD shortly after their child was admitted to the PICU experienced significantly more worry their child would die than parents without ASD. Also, severity of parents' ASD symptoms assessed after PICU admission predicted the severity of PTSD symptoms post-discharge, and, parents who met diagnostic criteria for ASD after admission were more likely to develop PTSD after

discharge. Of note is the finding that parents' degree of worry their child would die – which was predictive of ASD – was not related in any meaningful way to an objective measure of mortality risk. Balluffi and colleagues' results are congruent with findings from a retrospective study that documented a positive correlation between parents' perceived stress during PICU hospitalization and symptoms of anxiety, depression, and PTSD 8 months after their child was discharged, but not to objective measures of medical severity (Colville & Gracey, 2006).

A comprehensive synthesis of this portion of the literature points consistently to the conclusions that (a) optimal versus maladaptive adjustment outcomes may depend more on a parent's subjective experiences during a potentially traumatic medical event than on objective indicators of medical severity or treatment intensity, and (b), short-term adaptation is significantly predictive of longer-term adjustment trajectories (e.g., Balluffi et al., 2004; Berenbaum & Hatcher, 1992; Colville & Gracey, 2006; Fuemmeler et al., 2001; Kazak et al., 1998; Kupst & Schulman, 1988; Rini et al., 2008; Stuber & Shemesh, 2006; Youngblut, Brooten, & Kuluz, 2005).

The PMTS model theorizes that parents' subjective experiences during a serious pediatric medical event are influenced by pre-existing, individual difference factors that exert ongoing influences on parents' ability to cope effectively with illness-related demands (Kazak et al., 2006). These differences may be of particular importance in the peri-trauma phase as parents are thrust into a crisis situation for which many are unprepared. Furthermore, because so little research has been done in pediatric critical care populations, we know virtually nothing about individual difference factors that may be especially salient to parental adjustment in the short-term aftermath of a child's PICU admission.

## Subjective Experience

A careful review of extant literature pertaining to health and pediatrics yielded data suggesting that parents' perceptions of illness-related uncertainty and the way they appraise the experience of their child's PICU admission may be particularly salient factors to examine as predictors of adjustment outcomes in the peri-trauma phase (Balluffi et al., 2004; Carpentier, Mullins, Chaney, & Wagner, 2006; Cohen, 1993a, 1993b, 1995; Fuemmeler et al., 2001; Santacroce, 2003; Tomlinson et al., 1995; Stewart & Mishel, 2000).

**Uncertainty in illness.** Uncertainty has emerged as a hallmark, pervasive factor related to short- and longer-term outcomes of parental adjustment to serious pediatric medical events (e.g., Bonner et al., 2006; Carpentier et al., 2006; Fedele et al., 2011; LaMontagne & Pawlak, 1990; Stewart & Mishel, 2000). In Mishel's theoretical model of uncertainty in illness (UIT), uncertainty is defined as "the inability to determine the meaning of events" (Mishel & Braden, 1988; p. 98). The UIT model asserts that uncertainty occurs in situations characterized by a lack of information or schematic cues, thereby impairing an individual's ability to make reasonable sense of an event, or to predict accurate outcomes (Mishel, 1983, 1984, 1990). Perceived uncertainty has been linked to both short- and longer-term indicators of psychological adjustment, including overall psychological distress in parents of children with type 1 diabetes mellitus (Carpentier et al.) and juvenile rheumatic diseases (Fedele et al.), and PTSS in parents of children diagnosed with brain tumors (Bonner et al.; Fuemmeler et al., 2001). Moreover, studies of parent-child adjustment to chronic pediatric conditions have reported that parents' perceptions of illness-related uncertainty are positively correlated with children's depression symptoms (Fedele et al.), problem behaviors, and poorer adaptive functioning (Steele, Aylward, Jensen, & Wu, 2009).

**Primary appraisal.** Lazarus and Folkman's (1984) widely endorsed transactional theory of stress and coping depicts a dynamic adjustment process driven by an individual's ongoing appraisals of his or her relationship to the environment. Appraisal is a process wherein an individual evaluates what, if anything, is personally at stake in a given situation (i.e., *is this situation potentially harmful or beneficial?*) and next, evaluates resources and options for improving benefits or coping with perceived threats (Lazarus, 1999; Lazarus & Folkman, 1984). Lazarus theorized that patterns of appraisal and relational meaning produced a predictable range of both positive and negative emotions. Primary appraisals of situations as threatening, harmful, or challenging have each been identified as reliable predictors of psychological distress and other indicants of emotional adjustment in studies of how adults adapt to serious health challenges (e.g., Kennedy, Evans, & Sandhu, 2009; Pakenham & Rinaldis, 2001; Widows, Jacobsen, & Fields, 2000). Nonetheless, the pivotal role of primary appraisal has been largely overlooked by health psychology researchers in studies of adjustment processes.

**Illness-related uncertainty and appraisal.** According to Mishel's (1983, 1990) cognitive-appraisal theory of uncertainty in illness (UIT), perceived uncertainty is more likely to be appraised as threatening in high stake situations such as a child's PICU hospitalization. Furthermore, researchers theorize that the degree to which uncertainty is perceived will be highest during medical events characterized by ambiguity, lack of clarity, not enough information, and unpredictability (Mishel, 1983; Turner et al., 1990; Stewart & Mishel). Realistically, eliminating all uncertainty is often impossible, and perhaps most importantly, not always necessary or beneficial. Therefore, in high-stakes situations laden with uncertainty, optimal adaptation begins with an individual's ability to reduce perceptions of uncertainty as threatening. It is emphasized here that uncertainty is an essentially neutral perceptual variable; it



can therefore be appraised as threatening, challenging, beneficial, or simply unimportant to one's goals at any given time. Individuals who are unable to appraise uncertainty in less threatening ways exist in a state of prolonged mental duress, which puts them at increased risk for developing psychological problems, particularly PTSS and PTSD (Stewart & Mishel, 2000).

Qualitative studies contain rich descriptions of parents' appraisals of their children's PICU hospitalization as an extremely threatening event made exponentially worse by an unrelenting sense of uncertainty (Miles & Mathes, 1991; Mu & Tomlinson, 1997). Despite the pervasiveness of uncertainty as a source of emotional distress for parents and evidence linking it to indicators of both short- and longer-term adaptation, illness-related uncertainty has not been empirically studied as a potential correlate of adjustment among parents of children admitted to a PICU. Notably, a search of pediatric literature failed to find a single published study examining the potential relations between perceptions of uncertainty, primary appraisals, and parental adaptation during the peri-trauma phase of a potentially traumatic medical event. It is proposed here that the lack of empirical research focused on how illness-related uncertainty and primary appraisals may impact parents' adjustment trajectories in the early stages of a child's serious medical event represents a critical gap in pediatric psychosocial literature.

To sum, a child's PICU hospitalization is a potentially traumatic event for parents, the majority of whom experience a range of acute stress reactions in the days shortly after admission (Balluffi et al., 2004; Board & Ryan-Wenger, 2003). While most families are able to adapt positively and recover gradually from the distressing physical and psychological effects of trauma, documented incidences of ASD and PTSD points to a subset of parents who may be more vulnerable to negative outcomes (Balluffi et al.). Factors related to parents' subjective experiences shortly after their child's PICU admission were important determinants of both

short- and longer-term psychological outcomes, but unrelated to objective indicators of medical severity (Balluffi et al.).

Studies examining psychosocial aspects of parental adaptation to other potentially traumatic pediatric medical events confirm the importance of subjective factors and support the relation between early-stage adjustment and long-term psychological outcomes (Barrera et al., 2004; Best, Streisand, Catania, & Kazak, 2001; Kazak et al., 2005; Kupst & Schulman, 1988; Landolt et al., 2003; McCarthy et al., 2012; Patiño-Fernandez et al., 2008; Rini et al., 2008). However, research thus far has focused primarily on adjustment to specific illnesses and injuries – most notably pediatric cancers – in the treatment and long-term sequelae phases (e.g., Barrera et al.; Best et al.; Fuemmeler et al., 2001; Kazak et al.; Kupst & Schulman; Landolt et al.; Patiño-Fernandez et al.; Rini et al.). Studies conducted among populations that are not disease- or condition-specific, i.e., non-categorical, are rare. Although extant studies of parents of children hospitalized in PICUs are indeed typically non-categorical, data is sparse and limited by retrospective designs (e.g., Bronner et al., 2007; Colville & Gracey, 2006), or purely descriptive methodology (e.g., Tomlinson & Mitchell, 1992).

We lack a clear understanding of risk and protective factors that cross discrete illness and injury boundaries, as well as common factors impacting longer-term adjustment that may be identifiable in the early stages of a pediatric medical crisis. The literature calls for future studies to address these gaps by (a) beginning to examine potential, common predictors of optimal and maladaptive family adjustment trajectories in non-categorical populations and (b) identify risk and protective factors operating in the short-term that are linked to longer-term consequences (e.g., Balluffi et al., 2004; Colville & Gracey, 2006; Landolt et al., 2003; Ward-Begnoche, 2007). A review and synthesis of relevant literature indicates that illness-related uncertainty and primary

appraisals may be particularly salient variables to examine as potential correlates of adjustment among this population in the peri-trauma phase (Carpentier et al., 2006; Cohen, 1993a, 1993b, 1995; Santacroce, 2003; Tomlinson et al., 1995; Stewart & Mishel, 2000).

Based on cognitive-relational theories of adjustment (Lazarus & Folkman, 1984; Lazarus, 1999; Mishel, 1983, 1990) and findings gleaned from the literature, the aims of the proposed study are to address this gap by examining (a) the extent to which parents of children admitted to a PICU perceive illness-related uncertainty in the peri-trauma stage, (b) how parents' appraise the PICU experience, (c) how uncertainty and appraisals may each be directly related to acute stress reactions, and (d) how the combination of uncertainty and appraisals impact short-term adjustment outcomes.

## **Literature Review**

### **Pediatric Intensive Care**

Pediatric intensive care units (PICUs) provide comprehensive care to children whose lives are in imminent danger as a result of serious illness or severe injury (Odetola, Clark, Freed, Bratton, & Davis, 2005). The focus of care in a PICU is to stabilize and maintain physiological functions vital to a child's life (Meyer, Snelling, & Myren-Manbeck, 1998; Odetola et al.). PICUs developed out of necessity as advances in medicine and medical technologies enabled physicians to provide enhanced respiratory care, perform increasingly complex surgical procedures, and maintain complex, high-tech life-supporting protocols. Prior to 1993, the general term *pediatric critical care* was considered sufficient to describe the level of care provided. However, in response to general advances in the medical field and the eventual establishment of pediatric critical care as a subspecialty, in 1993 the American Academy of Pediatrics' (AAP) Committee on Hospital Care and the Pediatric Section of the Society of

Critical Care Medicine (SCCM) recommended that PICUs be classified as either level 1, 2, or 3 based upon the care each was able to provide. The sophisticated level of care provided within a PICU is made possible by high-tech medical equipment and the practice of cutting-edge procedural techniques, all designed to preserve life.

Most PICU admissions are unexpected and originate from emergency departments, other in-hospital pediatric units, or from other hospitals (Aldridge, 2005). PICUs typically function as “transitional units” where children are treated until their medical prognosis improves and they are able to be cared for in a less intensive setting (e.g., Latour, van Goudoever, & Hazelet, 2008). PICU discharges usually involve transfer to general pediatric care units or rehabilitation facilities. Compared to children hospitalized in general pediatric units, children hospitalized in PICUs average longer hospital stays (Landolt et al., 2003; Rees et al., 2004; Shears et al., 2005), undergo significantly more invasive procedures (Rennick, Johnston, Dougherty, Platt, & Ritchie, 2002), and are more likely to have a history of prior hospitalizations (Rees et al.).

Since 1955, when the first PICU opened in Sweden, the number of PICUs worldwide has grown exponentially; surveys of pediatric critical care resources conducted within the last decade estimate that the number of PICUs in the United States alone ranges from 337 (Odetola et al., 2005) to 349 (Randolph et al., 2004). An analysis of PICU trends between the years 1995 and 2001 reveals that the number of PICUs grew 14% and the number of available PICU beds grew 24% as the number of general pediatric care unit beds declined (Randolph et al.). Within the United States, approximately 240,000 children are admitted to a PICU every year (Himelstein et al., 2004; Randolph et al.). Reasons for admission vary widely, but commonly include severe respiratory distress, neurologic problems, diabetes, heart conditions, injuries resulting from

accidental and non-accidental trauma, and infections (Balluffi et al., 2004; Briassoulis, Filipou, Natsi, Mavrikiou, & Hatzis, 2004; Melnyk et al., 2004; Miles & Mathes, 1991).

**Parents' reactions.** Parents have been described as “near panic” on the day of PICU admission (Aldridge, 2005); some parents talk about feeling blindsided at the moment they first realize something is seriously wrong with their child (name withheld, personal communication, August 2008). Most PICU admissions occur without warning (Aldridge); therefore, parents typically have no opportunity to prepare for the deluge of challenges they face stemming from their child's uncertain, tenuous prognosis, as well as the high-tech PICU environment itself (e.g., Johnson, Nelson, & Brunnquell, 1988; Board, 2004). Parents' reactions commonly include intrusive thoughts, excessive worry, sadness, irritability, tearfulness, loss of appetite, low energy, and difficulty sleeping (Aldridge, 2005; Balluffi et al., 2004; Board & Ryan-Wenger, 2003; Rees et al., 2004; Studdert et al., 2003).

In a study conducted by Williams & Koocher (1999), virtually every parent surveyed was fearful that their child was going to die and reported feeling depressed, angry, and afraid that they had lost control of their lives, their ability to parent, and their independence. These early reactions are characteristic of a normal, expectable constellation of symptoms experienced by individuals in the immediate aftermath of a traumatic event (Bryant, 2005; Janoff-Bulman, 1992).

### **Pediatric Medical Traumatic Stress**

In the psychological literature, trauma is broadly conceptualized as exposure to an event that exceeds the bounds of normal, human experience during which one experiences extreme fear or terror, a sense of helplessness, and a loss of control (Janoff-Bulman, 1992; McNally, 1999).

Based upon years of psychosocial research among pediatric cancer patients, survivors, and their families, Anne Kazak and colleagues developed a theoretical, traumatic stress model to explain the psychological impact on both children and families of acute and chronic pediatric medical events (2006). The pediatric medical traumatic stress (PMTS) model depicts the overall, temporal course of events most families experience during a serious, pediatric medical event. PMTS is defined as “a set of psychological and physiological responses of children and their families to pain, injury, serious illness, medical procedures, and invasive or frightening treatment experiences” (National Child Traumatic Stress Network, 2003). The model aims to provide a framework for (a) conceptualizing how children and families adapt to pediatric medical challenges across time, and (b), guiding the development of phase-specific interventions targeting the prevalence and severity of PMTS.

**ASD and PTSD.** *The Diagnostic and Statistical Manual of Mental Disorders* (4<sup>th</sup> ed., text revision, American Psychiatric Association [APA], 2000) currently contains diagnostic criteria for two anxiety disorders related to patterns of traumatic stress symptoms: acute stress disorder (ASD) and posttraumatic stress disorder (PTSD; see Appendices F & G). Diagnostic criteria for ASD and PTSD is similar in terms of shared symptom clusters of arousal, re-experiencing, and avoidance, as well as the definition of a traumatic event as one during which an individual has “experienced, witnessed, or was confronted with an event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others” (American Psychiatric Association, *DSM-IV-TR*, 2000, p. 467).

ASD and PTSD are diagnostically distinct in terms of the timing of symptom onset and symptom resolution, as well as the role of dissociative symptoms in ASD. Specifically, a diagnosis of ASD is made when symptoms related to dissociation, re-experiencing, avoidance,

and arousal, appear within four weeks of a potentially traumatic event and cause impairment; ASD symptoms must resolve during that month-long time span as well (APA, 2000). PTSD is defined as an anxiety disorder brought on by a traumatic event with symptoms of re-experiencing, hypervigilance, and avoidance of stimuli reminiscent of the trauma. On average, symptoms appear within 3 months of an individual's exposure to a potentially traumatic event (PTE), but delayed onset with symptoms manifesting many months or years later is not uncommon (APA, 2000).

Within the PMTS model, posttraumatic stress symptoms (PTSS) are conceptualized as a "continuum of key symptoms" (Kazak et al, 2006; p. 344) related to ASD and PTSD, but posit that these two diagnostic categories are not the best fit in terms of a broad understanding of the psychological needs of children and families. A pivotal difference between the clinical, diagnostic conceptualizations of PTSS and the PTMS model is the definition of a potentially traumatic event as a one-time event (*DSM-IV-TR, 2000*) versus multiple, traumatic events likely to be experienced by children and families over time, during a pediatric medical event; PTSS can occur at any stage. The PMTS model (Kazak et al., 2006) is structurally organized around three phases (see Figure 1) that are intended to reflect the sequence of events that occur across time during a serious, pediatric medical event: Phase I (peri-trauma), Phase II (early, ongoing, evolving), and Phase III (longer-term). Brief descriptions of the PMTS model's phases and theoretical assumptions are presented next.

**Phase I: peri-trauma.** The peri-trauma phase begins with the first realization that something related to a child's health may be seriously wrong (Kazak et al., 2006). Awareness

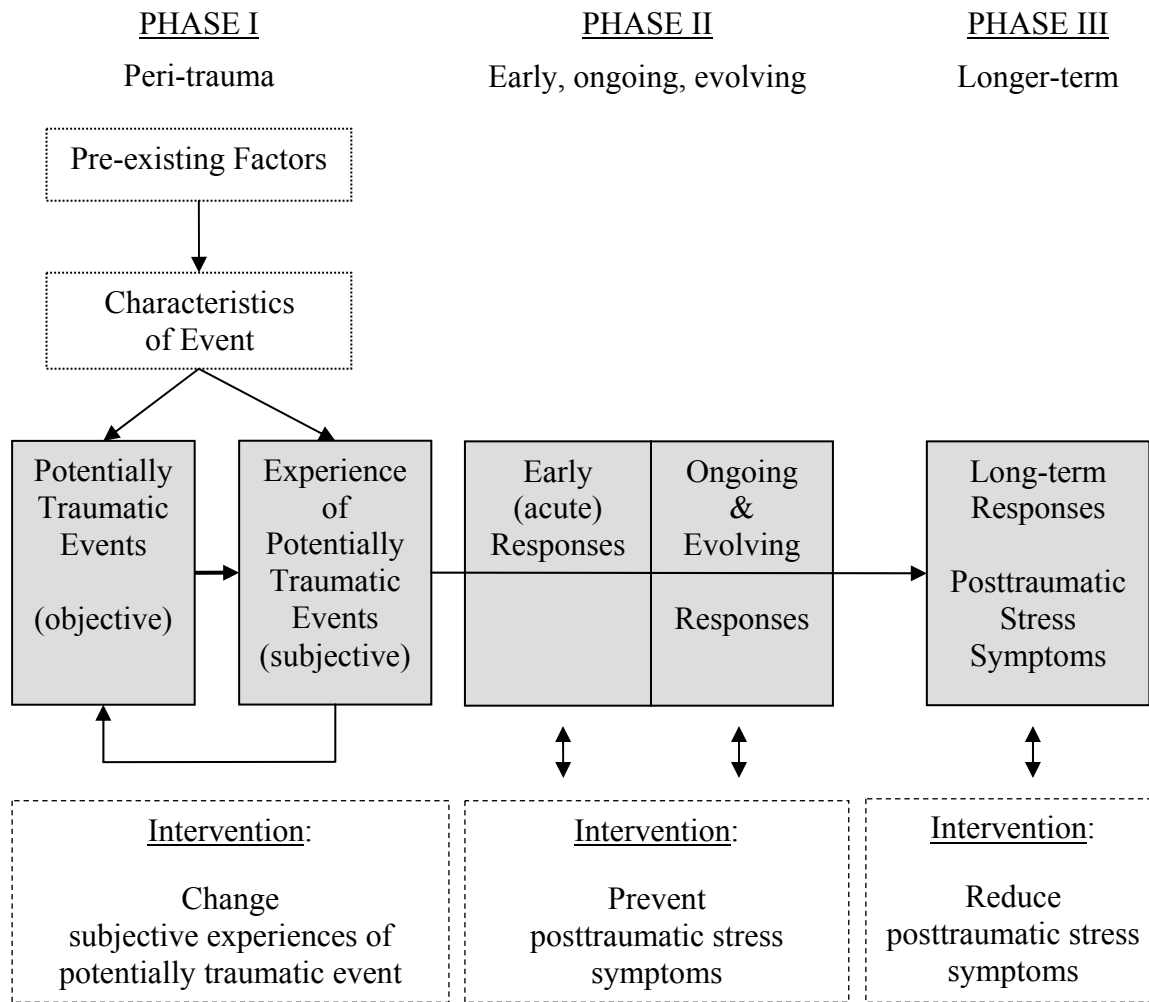


Figure 1. Model of Pediatric Medical Traumatic Stress (Kazak et al., 2006).



that a potentially life-threatening medical problem exists typically marks the first of many, rapidly occurring potentially traumatic stressors families then encounter at this stage. For example, when a constellation of symptoms points to the possibility of cancer in a previously healthy child, immediate hospitalization may be ordered; and multiple, invasive diagnostic procedures ensue. The focus of the peri-trauma phase is on an individual's subjective experiences of potentially traumatic medical events (PTEs) and how those experiences may impact adaptation across time. Kazak and colleagues (2006) emphasized that most research about PMTS to that point assumed that various events were inherently traumatic and failed to examine individual differences in perception.

**Phase II: early, ongoing, evolving.** As time goes on, families are faced with challenges directly related to the demands of their child's medical status. Parents must meet and form new, trusting relationships with medical specialists involved in their child's care, and often they must adhere to treatment protocols that are complicated, extraordinarily time consuming, and may be painful or uncomfortable for their child. Children who require frequent or extended hospitalization must adjust to being separated from home, and parents must negotiate the practical and psychological consequences of disruptions in their roles at home and at work (Melamed, Kaplan, & Fogel, 2001).

**Phase III: longer-term.** The longer-term phase of the PMTS model emphasizes that PTSS often persist, and even begin to develop, after pediatric medical events have been resolved. After treatments end, longer-term sequelae pertain to children and their families, as well as to the families of children who died (Kazak et al., 2006). Longer-term PMTS responses highlight the complex and powerful impact that pediatric medical events can have on families and children, even when treatment has been successful.

**PMTS model assumptions.** First, the PMTS model is predicated on the belief that PTEs have certain common features irrespective of the specific medical problem or threat to health. These factors include a definable moment of awareness that an actual life threat exists, and subsequent feelings of horror and helplessness that may ensue. Second, as with other potentially traumatic events, an expectable range of normal responses to a PTE exists that are characterized by acute physical and psychological distress; however, symptoms of distress do not imply a clinical, psychological disorder. Third, most children and families are functional, competent, and resilient, but pre-existing factors may place some parents and children at higher risk for problems adjusting to medical demands. Fourth, children continue to grow, mature, and face normal, developmental tasks in the midst of negotiating a life-threatening illness or injury. Therefore, a developmental approach to trauma must prevail in pediatric medical settings. Last, children and families facing potentially traumatic medical events are best served by taking the multiple contexts of a child's life into consideration when determining appropriate interventions.

**Parental adaptation.** Consistent with PMTS model assumptions, health and pediatric psychology literature provides compelling evidence of both the resilience of families, as well as the potential for the development of severe short- and longer-term PTSS in a subset of parents (e.g., Balluffi et al., 2004; Kassam-Adans et al., 2009; Kazak et al., 2006; Manne, DuHamel, Galleli, Sorgen, & Redd, 1998; McCarthy, Ashley, Lee, & Anderson, 2012). Parents with PTSS meeting diagnostic criteria for either ASD or PTSD have been documented across all phases of pediatric medical events (see Table 1), including ASD in parents of children newly diagnosed with cancer (McCarthy et al. Patiño-Fernández et al., 2008), PTSD in parents of children receiving active cancer treatment (Kazak et al., 2005), and PTSD in parents of pediatric cancer survivors (Kazak et al., 1997; Manne et al., 2000).

Table 1.

*Prevalence Rates of ASD and PTSD in Parents of Seriously Ill or Injured Children*

Study	Pediatric Medical Event	ASD (%)			PTSD (%)		
		Parents	Mothers	Fathers	Parents	Mothers	Fathers
Balluffi et al., 2006	PICU hospitalization	32%			21%		
Bronner et al., 2007	PICU hospitalization					15%	9.3%
Colville & Gracey, 2006	PICU hospitalization					18%	
Horsch et al., 2007	Type 1 diabetes mellitus					10%	10%
Jubenville et al., 2012	Premature birth		28%				
Kassam-Adams et al., 2009	Traffic-related injuries	12%			8%		
Kazak et al., 1997	Leukemia survivors					10.2%	9.8%
Kazak et al., 2005	Cancer treatment (active)						
Manne et al. 2000	Cancer survivors					12.5%	
McCarthy et al., 2012	New cancer diagnosis	61.6%					

(continued)

Table 1 (continued).

*Prevalence Rates of ASD and PTSD in Parents of Seriously Ill or Injured Children*

Study	Pediatric Medical Event	ASD (%)			PTSD (%)		
		Parents	Mothers	Fathers	Parents	Mothers	Fathers
Patiño-Fernández et al., 2008	New cancer diagnosis	47.2%	51%	40%			
Rees et al., 2004	PICU hospitalization				27%		
Rees et al., 2004	General hospitalization				7%		
Ward-Begnoche, 2007	PICU hospitalization					15%	9.3%

In the only prospective, longitudinal study of ASD and PTSD among parents whose children were hospitalized in a PICU (Balluffi et al., 2004), 32% of parents met diagnostic criteria for ASD shortly after admission, and a solid majority reported symptoms of dissociation (74%), re-experiencing (75%), avoidance (68%), and arousal (69%). Six months after their child was discharged, 20% of parents met diagnostic criteria for PTSD and most reported subclinical levels of PTSD symptoms. Parents' PTSD symptoms post-discharge were positively correlated with ASD symptoms assessed shortly after admission and during PICU hospitalization. Thus far, it appears that Balluffi and colleagues' research is the only published study that documents the prevalence rate of ASD in this population. However, other studies have reported prevalence rates of PTSD in PICU-parent populations ranging from 18% in a mixed sample of mothers and fathers (Colville & Gracey, 2006), to 15% of mothers and 9.3% of fathers in a gender-specific sample (Bronner et al., 2007). These rates are particularly significant given that the lifetime prevalence rate of chronic posttraumatic stress disorders among adults living in the United States is approximately 8% (*DSM-IV-TR*, 2000).

Consistent with the peri-trauma phase described within the PMTS model (Kazak et al., 2006), a child's actual admission to the PICU is likely just one of many rapidly occurring PTEs parents will experience while their child is hospitalized. The consensus reached by researchers is that (a) parents of PICU patients are at high risk for developing chronic PTSD; and (b), studies designed to increase understanding of potential risk and protective factors associated with ASD and PTSD are needed to inform the development of phase-specific interventions to reduce PMTS and facilitate optimal adjustment (Balluffi et al.; Bronner et al., 2007; Colville & Gracey, 2006; Rees et al., 2004).

***The PICU environment as a potentially traumatic event.*** Early nursing studies identified seven primary sources of traumatic stress within the PICU environment related to parents' symptoms of psychological distress: 1) changes in child's appearance, 2) sights and sounds in the PICU environment, 3) medical procedures, 4) altered parental role, 5) changes in child's behavior, 6) staff behavior, and 7) communication with PICU staff (Carter & Miles, 1989; Miles & Carter, 1982, 1983, 1985; Miles et al., 1989; Miles & Mathes, 1991). Over the years, efforts to address and ameliorate these sources of stress have resulted in laudable successes in some areas, but other sources are simply not amenable to change (Aldridge, 2005; Board & Ryan-Wenger, 2003; Colville & Gracey, 2006; Tomlinson, Swiggum, & Harbaugh, 1999; Youngblut & Brooten, 2006). For example, a recent exploratory study of perceived sources of parental stress showed that staff behaviors and communication with staff had been virtually eliminated as sources of stress; but, sights and sounds experienced within the PICU, as well as witnessing medical procedures, persisted as sources of extreme stress (Colville and Gracey). Parents consistently report that the most frightening aspect of having their child in the PICU is seeing their child intubated, attached to machines, and constant alarm warnings from various monitors (e.g., Balluffi et al., 2004; personal communication, name withheld, September 2009).

Ironically, certain changes made over time regarding hospital policies that were explicitly intended to reduce parents' distress have actually increased – albeit, inadvertently – the extent to which parents are exposed to these particular stressors. For example, standard procedure now allows and encourages parents to remain at the bedside with their child in the PICU around the clock, including during invasive medical procedures (Latour, van Goudoever, & Hazelzet, 2008; Smith, Hefley, & Anand, 2007). Virtually all PICU patients are connected to monitors of some

sort, and unfortunately, alarm sounds do not distinguish between relatively benign events such as a pulse oximeter warning prompted by the sensor slipping off a child's toe versus a warning prompted by a trach collar becoming dislodged and impeding the flow of oxygen. Moreover, medical procedures often perceived as traumatic by parents such as suctioning and insertion of various lines, are routine, basic elements of pediatric critical care medicine. Parents are a valuable, irreplaceable component of a child's care, but clearly the PICU environment has the potential to be psychologically overwhelming.

### **Parental Adjustment to the PICU**

Empirical evidence of factors related to parents' adjustment to a child's PICU hospitalization is extremely limited. A careful search of the literature produced only one published empirical study wherein individual and environmental difference factors were examined as potential correlates of short-term indicators of psychological adjustment, i.e., ASD symptoms, in this population (Balluffi et al., 2004). Extant nursing literature contains a number of descriptive studies devoted to the phenomenology of parents' experiences following PICU admission that have yielded both qualitative and quantitative data, albeit not in connection to any type of outcome measure (Meiers & Tomlinson, 2003; Miles & Carter, 1982, 1985; Miles & Mathes, 1991; Mu & Tomlinson, 1997; Tomlinson & Mitchell, 1992; Tomlinson et al., 1999). Finally, results from retrospective studies have identified and documented relations between certain individual and environmental difference factors and a limited range of post-discharge adjustment outcomes (e.g., Bronner et al., 2007; Colville & Gracey, 2006; Rees et al., 2004). However, even though extant data from this population is sparse, a careful synthesis of available literature provides a reasonably sound basis for determining potentially salient variables upon which to focus further research. Detailed results of Balluffi and colleagues' study are presented

next and discussed within the context of relevant pediatric psychology and general trauma literature.

In a prospective cohort study, Balluffi and colleagues (2004) surveyed parents within 3 days of their child's PICU admission and conducted follow-ups an average of 6 months post-discharge to assess the prevalence of ASD and PTSD and begin to identify correlates of adjustment. The researchers looked at both objective and subjective factors including parents' demographics, children's objective medical status, parents' perceptions of the seriousness of their child's condition, and the degree to which they worried that their child might die. Results from data gathered after admission showed that virtually every parent endorsed at least one ASD symptom and 32% ( $N = 272$ ) met diagnostic criteria for ASD. Severity of parents' ASD symptoms were associated with an unplanned PICU admission and the degree to which parents were worried that their child was going to die; but, full diagnostic criteria for ASD was linked only to parents' subjective degree of worry that their child would die. Neither outcome variable – ASD symptom severity, nor ASD diagnosis – was associated with an objective measure of mortality risk, a history of prior pediatric general hospital or PICU admissions, children's demographics, or parents' perceptions of illness severity. Notably, there was no significant relation whatsoever between a child's objective mortality risk and parents' level of worry that their child would die.

Data gathered on average of 6 months post-discharge revealed that 21% of parents met diagnostic criteria for PTSD, 61% were experiencing symptoms of hyperarousal, 43% reported dissociation symptoms, and 40% endorsed symptoms of reexperiencing ( $N = 161$ ). PTSD symptom severity and PTSD diagnoses were each significantly related to factors assessed during PICU hospitalization, i.e., during the peri-trauma phase. Specifically, an unexpected PICU



admission was linked to PTSD symptom severity; parents' degree of worry that their child would die was related to both PTSD symptom severity and PTSD diagnoses. Post-discharge PTSD symptoms and diagnoses were unrelated to objective mortality risk assessed at PICU admission, parents' perceptions of illness severity, or children's demographics (length of PICU stay was included at Time 2). Post-discharge data showed that mothers were more likely to develop PTSD than fathers, and Black parents were at greater psychological risk than White parents. Hierarchical regression analyses revealed that 41% of the variance in PTSD symptom severity 6 months after discharge was accounted for by factors assessed shortly after PICU admission, with ASD symptom severity and parents' degree of worry their child would die identified as significant, unique predictors.

Results from Balluffi and colleagues' study (2004) are consistent with findings from retrospective studies of adjustment to PICU hospitalization (Colville & Gracey, 2006; Rees et al., 2004), as well as results from studies of parental adaptation to specific, life-threatening pediatric medical conditions such as cancer and head trauma (Carpentier et al., 2006; Fuemmeler et al., 2001; Kazak et al., 1998; Kupst & Schulman, 1988; Rini et al., 2008; Youngblut & Brooten, 2006). As an example, a study of parents of preschool-aged children admitted to hospital for treatment of head injuries, parents' level of general psychological distress two weeks after discharge was related to their perception of injury severity, perceived stress stemming from medical procedures, degree of psychological distress, and overall sense of well-being assessed just 24 to 48 hours after admission (Youngblut & Brooten, 2006).

**ASD as a predictor of PTSD.** It should be emphasized that the presence of severe ASD symptoms, even those meeting diagnostic criteria for ASD, in the early aftermath of a potentially traumatic event may represent a "red herring" in terms of predicting risk for longer-term

adjustment (Bryant, 2005). First, not everyone diagnosed with clinically significant ASD goes on to develop PTSD; second, many individuals diagnosed with PTSD have no history of ASD (e.g., Baluffi et al., 2004; Kassam-Adams, 2009). Researchers suggest that this discrepancy may be due in part to the emphasis on dissociative symptoms in the diagnostic criteria for ASD diagnosis (*DSM-IV-TR*, 2000) despite evidence these early symptoms are common after exposure to a traumatic event (Bryant, 2005; Harvey & Bryant, 2002). Bryant theorizes that dissociation may in fact be an adaptive, short-term mechanism that serves to limit emotionally overwhelming stimuli, thereby reducing an individual's perception of danger. To illustrate, parents' perceptions of the severity of their child's illness shortly after PICU admission were considered moderate ( $M = 3.28$  on a scale of 1 to 5), but increased significantly ( $M = 4.67$ ) after discharge (Miles & Mathes, 1991). Researchers posit that the significance of currently established criteria for an ASD diagnosis may lie more in the opportunities to screen for risk factors for PTSD and to understand the score of normal acute stress reactions (Bryant).

A synthesis of the literature cited thus far highlights the following conclusions: (a) parents' short-term adjustment is significantly related to adaptation in the longer-term; (b) adjustment outcomes are more strongly associated with parents' subjective experiences than with objective aspects of potentially traumatic medical events; and (c) subjective factors operating in the early, peri-trauma phase show strong relations to both short- and longer-term indicators of psychological adaptation.

**Subjective versus objective factors.** The *DSM-IV-TR* (APA, 2000) states that objective indicators of event severity are predictive of subsequent PTSS. Findings from research examining objective versus subjective predictors of parents' PTSS reflects mixed results, but primarily point to the importance of subjective factors (e.g., Balluffi et al., 2004; Kazak et al.,

2006). For example, objective ratings of the severity of children's injuries sustained in a traffic accident were indeed related to parents' PTSS (Sturms et al., 2005), and children admitted to hospital for trauma reasons reported more psychological distress one month after discharge than children admitted for non-trauma reasons (Murray, Kennedy, & Spence, 2007).

In a study wherein researchers compared prevalence rates of PTSS between groups of parents of children (a) newly diagnosed with cancer, (b) newly diagnosed with diabetes mellitus type 1, and (c), injured in an automobile accident (Landolt et al., 2003); all children had been hospitalized and parents were assessed after discharge. Landolt and colleagues used an index of objective medical severity based on length of hospital stay and children's functional status 5 to 6 weeks after discharge. They found a significant, positive relation between objective medical severity and PTSS based on diagnostic groups: PTSS in parents were most severe in parents of children newly diagnosed with cancer, followed by parents of children newly diagnosed with type I diabetes group. PTSS were least severe among parents of children with traffic-related injuries. Based on these results, Landolt and colleagues concluded that the objective severity of the three diagnostic conditions was indeed predictive of PTSD in accordance with *DSM-IV-TR* (2000) clinical guidelines. However, it should be noted that the researchers failed to control for a key group difference that given extant empirical evidence, likely played a significant role in parents' subjective experience of their child's hospitalization and subsequent PTSS. Specifically, parents of newly diagnosed pediatric cancer patients were told that their child's condition was life threatening; parents of accident victims knew their child's condition was not life-threatening; and potential life-threats to children diagnosed with diabetes were never discussed with parents because there were none. Based on this potential confound, it is argued

here that Landolt and colleagues' conclusion that their results point to objective indicators of medical severity as a reliable predictor of parental adaptation is erroneous.

**Appraisal: a Subjective Factor**

Appraisal figures prominently in the transactional model of stress and coping (Lazarus & Folkman, 1984; see Figure 2), widely cited by health psychology researchers as a framework for

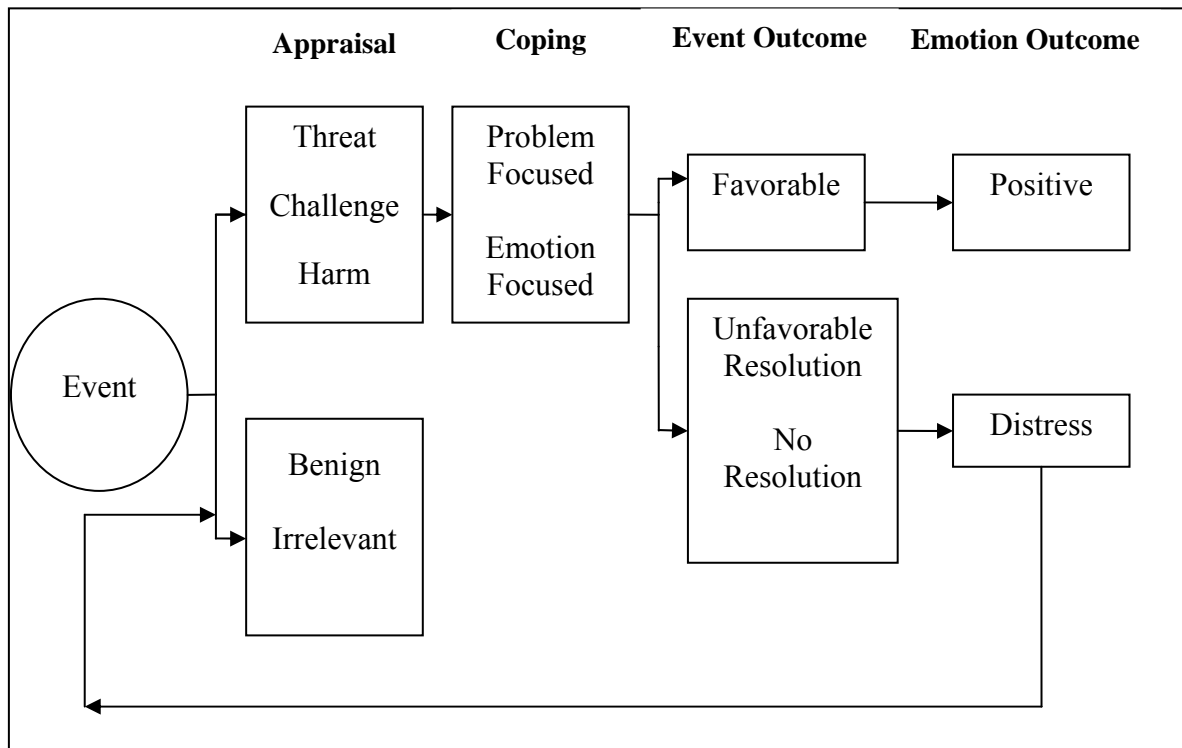


Figure 2. Lazarus and Folkman's Transactional Model of Stress and Coping (1984).

understanding the process of adjustment to medical adversity (e.g., Kennedy, Evans, & Sandhu, 2009; Pakenham & Rinaldis, 2001; Vollrath, Landolt, & Ribi, 2004; Widows et al., 2000).

Appraisal is basically a decision-making process wherein individuals “construe the implications of what is happening in their lives and for their well-being” (Lazarus, 1991, l. 10). Appraisal

occurs both intuitively, or automatically, as well as deliberately with conscious intent and is influenced by environmental characteristics and subjective factors, particularly an individual's goals, values, and beliefs (Lazarus, 1993, 1999). Lazarus's theoretical conceptualizations evolved over time as findings from numerous studies testing portions of the model contributed to a greater understanding of how individuals adapt to stressful situations. He developed a cognitive-motivational-relational theory of stress and emotion (Lazarus, 1999, see Figure 3) that he termed a *sequel* to the original transactional model wherein he conceptualized psychological stress as a subset of emotions and reaffirmed appraisal as crucially important to adjustment processes.

Conceptually, appraisal is organized into two cognitive processes: primary appraisal and secondary appraisal (Lazarus, 1999; Lazarus & Folkman, 1984, 1987). Primary appraisals center on evaluating the personal relevance of a situation or event, i.e., determining what, if anything, is at stake and are broadly grouped into dimensions of harm, threat, and challenge. Harm refers to loss that has already occurred; threat is the anticipation or expectation that harm will likely occur in the future; and challenge represents the sense that situational difficulties can be overcome. Secondary appraisals are evaluations of options for managing stressful demands, i.e., determining how to cope with situational aspects deemed harmful, threatening, or challenging.

**Primary appraisal.** According to Lazarus (1999), individuals are constantly appraising transactions with their environment, and through primary appraisal are constructing relational meanings for events. Relational meaning resulting from appraisal “shapes and defines our emotions” (p.10). Primary appraisals of harm, threat, and challenge are relational meanings inherent in certain emotions. Lazarus (1991) concluded that primary appraisals are the “process

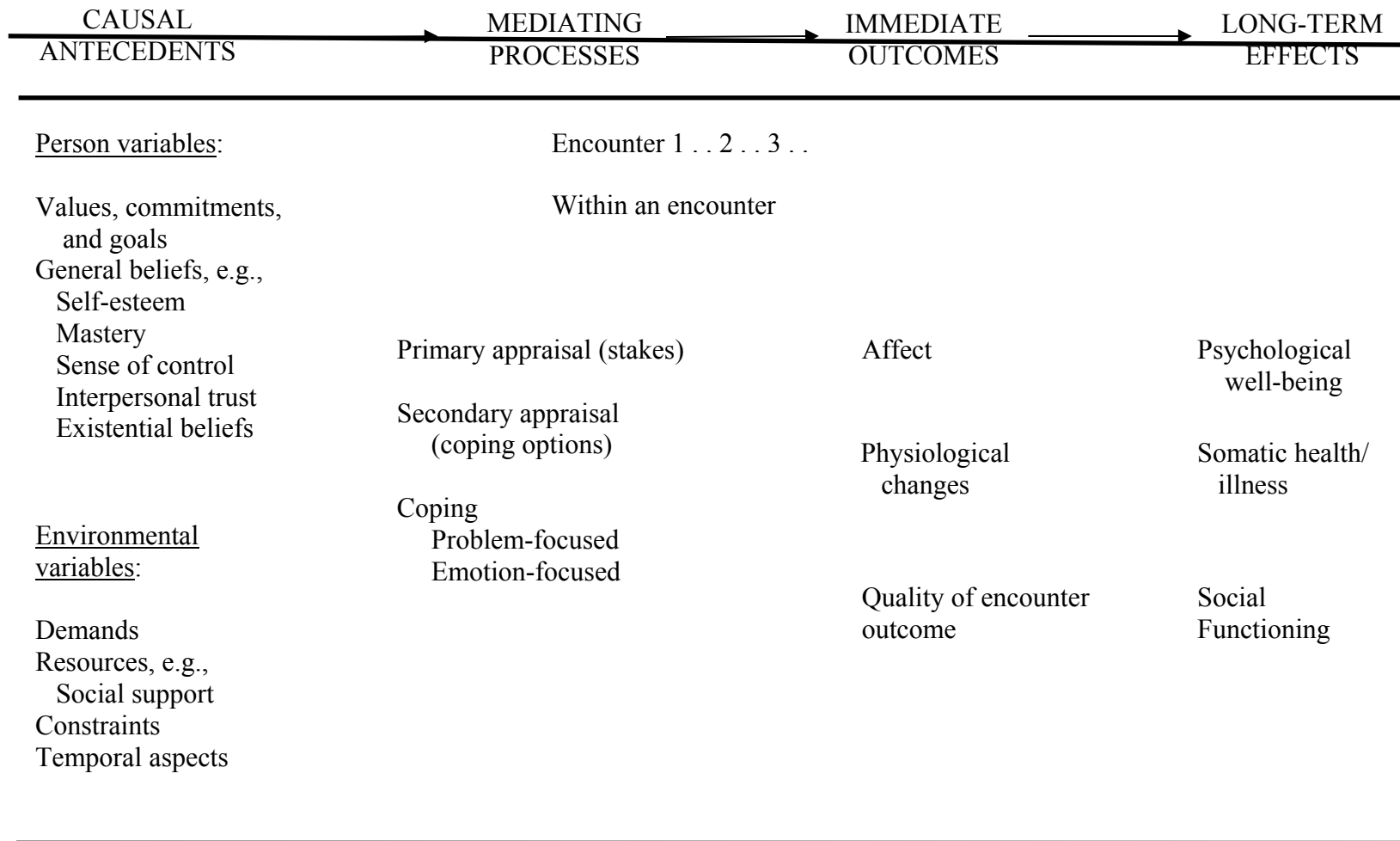


Figure 3. Illustrative system variables for the emotion process (taken from Lazarus, 1999).

most proximal to a person's emotional state" (Lazarus, 1999, p. 2393) because they represent what is important to an individual at a given time in a given situation. He proposed a set of core, relational themes wherein each theme corresponded with a particular emotion. For example, the core relational theme for anxiety is "facing an uncertain, existential threat" (Lazarus, 1999, p. 94). Thus, in Lazarus's model of stress and emotion, primary appraisal acts as a mediator between an individual's environment and emotions.

According to Lazarus (1991), primary appraisals have both state and trait characteristics. Individuals tend to develop habitual appraisal styles that may operate at an unconscious, automatic level, especially when situations are characterized as uncertain. Primary appraisal dimensions have been shown to play a significant role in determining adjustment outcomes among individuals confronted with serious health challenges (e.g., Kennedy, Evans, & Sandhu, 2009; Pakenham & Rinaldis, 2001; Widows et al., 2000). In a study among adults with recent spinal cord injuries, dimensions of primary appraisal emerged as the most reliable predictor of psychological distress, particularly threat appraisals, which accounted for 14.8% and 46.6% of the variance in anxiety and depression symptoms, respectively (Kennedy et al.).

### **Uncertainty in Illness**

Mishel's cognitive appraisal model of uncertainty in illness (UIT) defines uncertainty as "the inability to determine the meaning of illness-related events" (1990, p. 256). UIT was developed as a framework for understanding how individuals living with acute and chronic illnesses perceive and manage illness-related uncertainty (Mishel, 1981, 1988, 1990). According to UIT, uncertainty typically arises in situations where "the decision-maker is unable to assign definite values to objects and events and/or is unable to accurately predict outcomes" (Mishel, 1990; p. 256). Mishel theorizes that uncertainty arises in situations where schematic cues are

lacking, and therefore, “hampers clear appraisal of events” (1983, p. 324). UIT emphasizes the role of appraisal in the creation of relational meanings of illness-related events and theorizes that the goal of successful adaptation to the ubiquitous presence of uncertainty is to reduce the appraisal of threat by creating a revised world view wherein illness-related uncertainty is the “new normal” (Mishel, 1990). Poor adjustment outcomes can result when an individual’s efforts to create a new world view, and hence reduce a sense of danger, are impeded or prolonged by (a) avoiding adjustment tasks, (b) health care environments that value predictability and certainty, (c) social support systems that fail to validate uncertainty as natural, and (d) a lack of supportive interactions with others. In the face of one or more of these barriers, individuals may not be able to effectively reduce the perceived sense of threat and danger associated with uncertainty. Therefore, they endure a prolonged, heightened state of mental duress that places them at high risk for developing psychiatric symptoms and disorders, particularly PTSS and PTSD. This theoretical framework and conceptualization of uncertainty as a cognitive state dominate an extensive body of psychological, pediatric, and nursing literature.

A comprehensive review of current literature points to uncertainty as a pervasive, hallmark characteristic of parents’ experiences with acute and chronic pediatric medical conditions across all phases of adjustment. Parents whose children are seriously ill perceive uncertainty as stemming from multiple sources of medical ambiguity, a lack of clarity, a lack of information, and a general sense of unpredictability (Boman, Viksten, Kogner, & Samuelsson, 2004; Bonner et al., 2006; Carpentier et al., 2006; Fuemmeler et al., 2001; LaMontagne & Pawlak, 1990; DeMaso & Meyer, 1996; Meyer, DeMaso, & Koocher, 1996; Mishel, 1983; Mishel & Braden, 1988; Stewart & Mishel, 2000; Turner et al., 1990). When children require critical care hospitalization, parents are uncertain if their child will survive; what diagnostic tests



will reveal; whether or not viable treatment options exist, and if so, if treatments will work; or if their child's recovery will result in long-lasting cognitive, or other functional impairments.

Moreover, parents of children hospitalized in a PICU describe aspects of illness-related uncertainty generated by the critical care environment itself (Miles & Carter, 1982; Turner et al., 1990).

**Uncertainty and parental adaptation.** Results from extant research in the body of pediatric literature provide empirical support for theoretical conceptualizations (Mishel, 1981, 1990) of the potentially significant relation between uncertainty and parental adaptation, particularly that uncertainty may play a key role in posttrauma adjustment (e.g., Balluffi et al., 2004; Fuemmeler et al., 2001; Stewart & Mishel, 2000). The pathway to adjustment depicted in the reconceptualized UIT model (Mishel, 1990), emphasizes uncertainty as a neutral perceptual variable subject to different interpretations at different times. This pathway is consistent with other process-oriented, cognitive appraisal theories of adaptation wherein outcomes are mediated by appraisal and coping processes (e.g., Lazarus, 1999; Lazarus & Folkman, 1984, 1987; Maes, Leventhal, & de Ridder, 1996; Pakenham, 2005).

Thus far, studies exploring parents' perceptions of uncertainty in a PICU population are purely descriptive; none have attempted to examine the relation between uncertainty and indicators of parental adjustment (e.g., Turner et al., 1990). Therefore, it remains unclear what role parents' perceptions of uncertainty play in the adjustment process among this population. Results from studies among other pediatric populations suggests that uncertainty represents a considerable risk factor for parents' ability to adapt effectively (e.g., Bonner et al., 2006; Carpentier et al., 2006; Fedele et al, 2011; Fuemmeler et al., 2001; Santacroce, 2003; Stuber & Shemesh, 2006). Specifically, perceptions of uncertainty were positively correlated with the

severity of PTSS in parents of pediatric cancer patients during both the initial treatment phase (Bonner et al.), and after treatment ended (Fuemmeler et al.; Stuber & Shemesh). Among parents of children with type 1 diabetes mellitus, the more illness-related uncertainty parents perceived shortly after their child's diagnosis, the more likely they were to experience symptoms of general psychological distress (Carpentier et al.); moreover, parents' levels of perceived uncertainty at diagnosis remained significantly linked to parental adjustment outcomes assessed 5 to 6 years later. In a study of maternal adjustment to premature labor and delivery, mothers who were uncertain about their infant's future and ability to survive, were significantly more likely to report anxiety and depression symptoms even after their infant's discharge from a neonatal intensive care unit (NICU; Reichman, Miller, Gordon, & Hendricks-Munoz, 2000).

Fummeler and colleagues (2001) found that perceptions of uncertainty predicted levels of overall psychological distress in parents of pediatric brain tumor survivors; and perhaps more importantly, uniquely accounted for 30% of the variance in parents' PTSS after controlling for parents' age and time since diagnosis. Clearly, illness-related uncertainty is a crucial component of parents' experiences of a serious pediatric medical event beginning in the early, peri-trauma phase, and remains significant through not only active treatment, but longer-term after initial ambiguities surrounding diagnoses, treatments, and survival have been objectively resolved.

**Appraisals of uncertainty.** Despite the theoretical underpinnings of UIT that highlight the adaptational significance of appraisal processes (Mishel, 1981, 1990), UIT places the onus of adaptive versus maladaptive outcomes on the effectiveness of coping strategies used to manage uncertainty. Although secondary appraisals are key in determining coping strategies, the lack of research focused on how the relation between uncertainty and appraisal impacts adjustment represents a gap in the literature. To explain, the definition of a meditational process variable

presupposes a direct and significant relation between mediator and outcome (Baron & Kenny, 1986). Hence, an individual's appraisal of uncertainty is expected to have a direct impact on indicators of adaptation.

A search of extant pediatric literature within psychology, nursing, and general medical domains did not turn up a single published study examining the relation between parents' appraisals of perceived uncertainty in illness and adjustment outcomes following a child's PICU admission. Therefore, how parents appraise illness-related uncertainty, and how these appraisals may be linked to ASD symptoms following a child's PICU admission are unknown.

In addition to a fundamental lack of empirical data, imprecise interpretations of UIT contained in the literature contribute to theoretical confusion. Uncertainty in and of itself is a neutral construct and therefore, can be appraised in different ways. Yet, some researchers building on UIT have defined illness-related uncertainty as a *pervasive fear* and as *subjective distress* likened to chronic sorrow (Bonner et al., 2006). Other researchers have defined uncertainty as cognitive appraisal and implied negative connotations to the construct by stating that it needs to be reduced in order to improve parental adaptation (Fedele et al., 2011).

Studies among individuals facing various medical challenges document that illness-related uncertainty is not necessarily always appraised as a bad thing, i.e., harmful or threatening (e.g., Brasher et al., 2000; Mishel, 1990; Woodgate & Degner, 2002). For example, pediatric cancer patients and their families judged uncertainty as preferable in situations where "knowing too much" provoked worry and anxiety (Woodgate & Degner). Uncertainty has also been perceived in a positive, hopeful light in that "no news is good news" (Turner et al., 1990). It is argued here that the failure to distinguish uncertainty as a neutral variable, and instead to use definitions that assign an emotional value creates theoretical and conceptual confusion. Based

on the literature reviewed thus far that establishes illness-related uncertainty as a significant correlate of parental adjustment, it is proposed here that examining how parents appraise uncertainty would address a gap in the literature by providing a more complete understanding of how this variable is related to psychological adjustment outcomes.

### **Statement of Problem**

A review of extant pediatric literature yields solid evidence of the emotional trauma inherent in a parent's experience of a child's life-threatening illness. Parents of children who require critical care hospitalization appear to be at greater risk for developing psychological problems as compared to parents of children hospitalized on general care units (Board & Ryan-Wenger, 2003; Rees et al., 2004; Shears et al., 2005). Researchers suggest that the stress, anxiety, and fear provoked by aspects of the high-tech, PICU environment and fears for their child's uncertain prognosis combine to form a uniquely traumatic event over and above challenges related to their child's specific medical condition (Colville & Gracey; Rees et al.; Shears et al.). In fact, parents' memories of sights and sounds within the PICU, as well as witnessing medical procedures considered routine in the practice of pediatric critical care, have been associated with posttraumatic stress symptoms months after discharge (Colville & Gracey). Even though most parents meet the emotional challenges of their child's PICU hospitalization and adapt well over time, the majority report experiencing posttraumatic stress symptoms months after discharge and 21% were found to have PTSD (Balluffi et al., 2004).

Despite ever-increasing numbers of PICUs and PICU beds, research focusing on the psychosocial needs of critical care patients and their families has not kept pace. What little empirical data exists regarding the psychological sequelae of PICU hospitalization is characterized largely by results from descriptive, retrospective studies and those examining

potential correlates of parental adjustment are scarce. Colville and Gracey (2006) linked parents' symptoms of anxiety, depression, and posttraumatic stress 8 months after PICU discharge to the degree of stress perceived from various aspects of the PICU experience, but found no significant relation with objective measures of severity of medical prognosis. In what appears to be the only prospective, cohort study conducted thus far (Balluffi et al., 2004), researchers found that posttraumatic stress symptoms after discharge were positively correlated with factors measured shortly after PICU admission, particularly acute stress symptoms and parents' degree of worry their child would die. Perhaps more importantly, neither acute stress symptoms nor posttraumatic stress symptoms were associated with any objective measure of a child's mortality risk.

Results from extant studies of parental adaptation during a child's life-threatening illness in the larger body of general health and pediatric psychology literature support that (a) how parents are able to adapt during the early stages of a child's potentially traumatic medical event has a significant impact on longer-term adjustment (Crnic, Greenberg, Ragozin, Robinson, & Basham, 1983; Fuemmeler et al., 2001; Landolt et al., 2003; McIntosh et al., 2005; Miceli et al., 2000); (b) objective measures of medical severity are largely unrelated to indicators of parental adjustment, including posttraumatic stress symptoms (e.g., Balluffi et al., 2004; Barrera et al., 2004; Best et al., 2001; Kazak et al., 1998; Kazak et al., 2005; Kupst & Schulman, 1988; Landolt et al., 2003; Patiño-Fernandez et al., 2008; Rini et al., 2008); and (c) parents' subjective experiences are more reliable predictors of both short and long term adjustment outcomes than are objective indicators of medical severity.

Numerous studies provide solid empirical evidence that a major component of parents' subjective experiences throughout each phase of a child's potentially traumatic medical event is

uncertainty stemming from illness-related events (Bonner et al., 2006; Carpentier et al., 2006; Fuemmeler et al., 2001; Stewart & Mishel, 2000; Stuber & Shemesh, 2006; Woodgate & Degner, 2002). In fact, it has been suggested that illness-related uncertainty may represent the single, greatest source of psychological stress for parents (Koocher, 1985). Based on the significant relations between parents' perceptions of uncertainty in illness and indicants of posttrauma adaptation documented in extant pediatric psychology literature, it is argued here that this is a crucial perceptual variable and warrants empirical examination in this population.

Advances in medical science have resulted in high cure rates for many pediatric diseases thereby transforming previously fatal, progressive disorders into survivable, chronic conditions. Children once doomed to tragically short life spans are reaching adulthood and countless parents have been spared the heartbreak of losing a child. However, these medical successes present psychological challenges of a different sort for parents. Parents of previously healthy children suddenly struck with an acute illness, parents of children living with a chronic illness, and parents of children who have survived an illness that has the potential to recur, i.e., cancer, experience varying degrees of uncertainty (Mishel, 1990). Furthermore, non-categorical research, i.e., that which is not based on a specific illness or chronic disease, among pediatric patients and their families is needed to help identify common potential risk and protective factors related to positive and negative adjustment trajectories.

Based on a conceptualization of a child's PICU admission as a peri-trauma stage event (Kazak et al., 2006), this study examines parents' perceptions of illness-related uncertainty and primary appraisals using Lazarus's (1999) theory of stress and emotion and UIT (Mishel, 1983, 1990) as frameworks for exploring how these variables may be linked to short-term parental adjustment. Specifically, this study examines the direct relations between uncertainty and

primary appraisals with acute stress symptoms and ASD. Finally, appraisal is examined as a potential mediator of the association between uncertainty and acute stress symptoms and ASD.

The present study has the potential to make a meaningful contribution to extant pediatric psychology literature. First, acute stress symptoms have the potential to curtail a parent's ability to function on a daily basis and may therefore have a pervasive, detrimental impact on multiple aspects of a child's hospitalization. For example, some parents withdraw from the PICU and are unable to remain with their child for sustained periods of time or even to visit regularly (e.g., Carter & Robinson, 2001); other parents "act out" and express anger towards the PICU staff (e.g., Studdert et al., 2003). Early screening for factors related to acute traumatic stress symptoms could help identify high-risk parents who may need targeted psychosocial support, particularly psychoeducation and interventions designed to support more effective parent-physician relationships. By helping families and PICU staff better understand acute stress responses, potential problems during a family's PICU stay may be averted.

Second, while studies have documented the presence of PTSS in parents following their child's PICU discharge (e.g., Balluffi et al., 2008; Bronner et al., 2007; Colville & Gracey, 2006), to date, only one published study has documented ASD symptoms in this population (Balluffi et al.). Therefore, this study builds on Balluffi and colleagues' work by looking at the extent to which two factors – namely uncertainty and dimensions of primary appraisal – may be related to ASD symptoms and the prevalence of ASD.

Third, extant studies of parental adaptation to PMTS focus primarily on specific pediatric populations (e.g., Horsch et al., 2007; Kazak et al., 2005). Therefore, our understanding of common factors that may operate during the initial phase of a pediatric medical crisis to promote or impede optimal adjustment is very limited; research among non-categorical diagnostic

populations is needed. Non-categorical findings based on empirically-designed studies maximize the potential applicability of results in hospital settings, such as PICUs and GCUs, where medical teams care for pediatric patients suffering from a broad range of illnesses and injuries. This study addressed calls in the literature emphasizing the need for empirical studies that cross specific illness and injury boundaries in an effort to identify common predictors of both optimal and maladaptive family adjustment trajectories (e.g., Colville & Gracey, 2006; Vandolt et al., 2003).

### **Hypotheses**

Based on the common theoretical foundations of process-oriented, cognitive appraisal models of adjustment (Lazarus & Folkman, 1984, 1987; Lazarus, 1999; Mishel, 1983, 1990), the literature review presented, and the specific aims of the proposed study, three sets of hypotheses were developed (see Figure 4): (a) parents would perceive a high degree of uncertainty related to their child's PICU admission; (b) parents' primary appraisals were expected to be directly related to short-term outcomes (immediate effects) as measured by acute posttraumatic stress symptoms; and (c) parents' primary appraisals were expected to mediate the relation between uncertainty and acute posttraumatic stress symptoms (short-term outcome). Mediators can be explained as the middle link in a causal chain of three or more variables wherein the mediator variable accounts for some (partial mediation) or all (full mediation) of the impact of the initial variable on a dependent variable (DV; Baron & Kenny, 1986). In the current study, the mediator variable was primary appraisal, the initial variable was uncertainty, and the dependent variable was ASD symptoms.



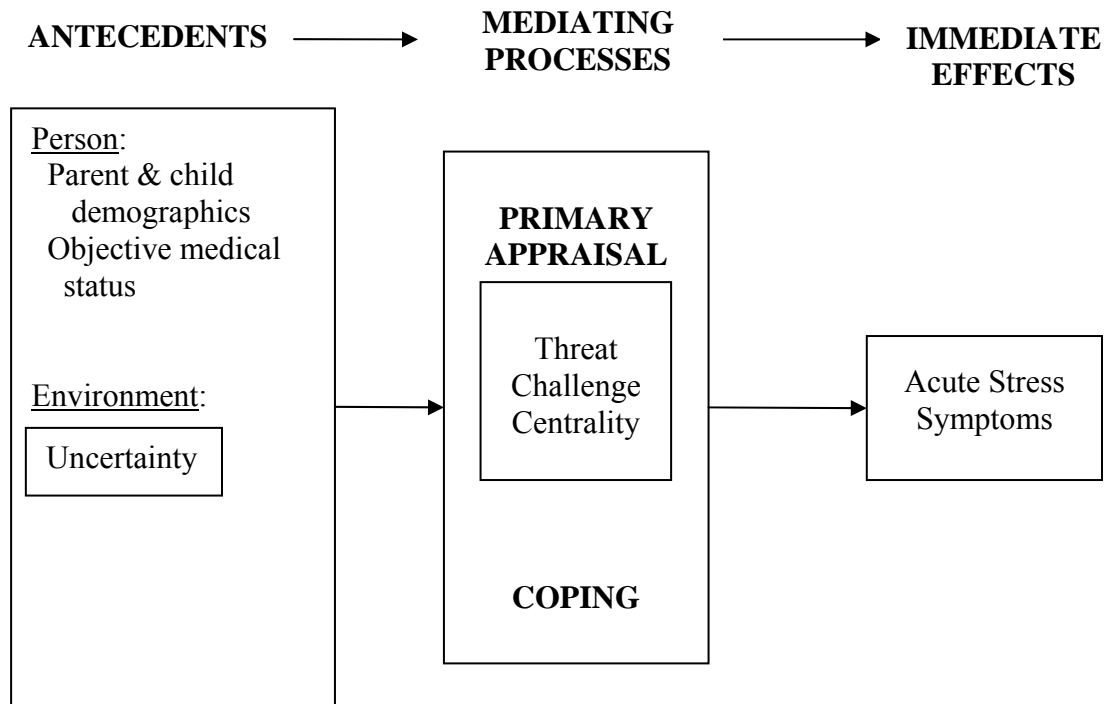


Figure 4. Model of current study.

**Hypothesis 1:** Parents' perceptions of uncertainty will account for a portion of the variance in ASD symptoms; specifically, greater degrees of uncertainty will be related to more severe ASD symptoms.

**Hypothesis 2:** Appraisals of threat, centrality, and challenge will account for a portion of variance in ASD symptoms:

- 2a) Increased threat appraisals will be associated with greater ASD symptom severity.
- 2b) Increased centrality appraisals will be associated with greater ASD symptom severity.
- 2c) Increased challenge appraisals will be associated with less severe ASD symptoms.

**Hypothesis 3:** Primary appraisals will mediate the relation between perceived uncertainty and acute stress symptoms.

## Method

### Participants

Participants were 56 mothers, 19 fathers, one custodial grandmother, and one custodial grandfather ( $N = 77$ ) of children hospitalized for a minimum of 48 hours in a Level-I pediatric intensive care unit (PICU)<sup>2</sup>. Demographic information for parents and children is summarized and presented in Tables 2 and 3, respectively. To be eligible for inclusion, participants had to be at least 18 years of age; be a primary caretaker or legal guardian with primary physical custody of the hospitalized child; and be able to speak and read English at a level that enabled them to provide informed consent and complete the questionnaire packet. Parents of children whose death was deemed imminent and parents of children admitted to the PICU for non-accidental injuries (e.g., child abuse, attempted suicide) or drug overdoses were not approached for inclusion.

Parents ranged in age from 18 to 61 years ( $M = 35.86$ ,  $SD = 8.70$ ). Most described themselves as either White ( $n = 47$ , 61%) or Black ( $n = 23$ , 29.9%). Two parents identified as Asian (2.6%), two as biracial (2.6%), one as multiracial (1.3%), and one as Hispanic (1.3%). The majority of parents were married or partnered ( $n = 50$ , 64.9%); sixteen were single (20.8%), and 11 were as separated or divorced (14.3%). Parents' educational backgrounds ranged from

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<sup>2</sup> Both grandparents had had primary physical and legal custody of their grandchild since birth; for brevity, all participants are herein referred to as "parents."

Table 2.

*Parents' Demographic Characteristics (N = 77)*

Variable	<i>n</i>	Percent
Participant's relationship to child		
Mother	56	72.7
Father	19	24.7
Grandmother	1	1.3
Grandfather	1	1.3
Ethnicity		
White	47	61.0
Black	23	29.9
Asian	2	2.6
Biracial	2	2.6
Hispanic/Latino(a)	1	1.3
Multiracial	1	1.3
Missing	1	1.3
Relationship status		
Single	16	20.8
Married/Partnered	50	64.9
Separated/Divorced	11	14.3
Education		
Less than high school	5	6.5
High school diploma or GED	17	22.1
Some college or vocational training	20	(median) 26.0
Graduated college or vocational school	25	32.5
Some graduate school	2	2.6
Graduate or professional degree	8	10.4
Annual Household Income		
< 10,000	9	11.7
\$10,000 - \$14,999	6	7.8
\$15,000 - \$24,999	7	9.1
\$25,000 - \$34,999	4	5.2
\$35,000 - \$49,999	5	6.5
\$50,000 - \$74,999	19	(median) 24.7
\$75,000 - \$99,999	13	16.9

(continued)

Table 2 (continued).

*Parents Demographic Characteristics*

Variable	<i>n</i>	Percent
\$100,000 – \$149,999	8	10.4
\$150,000 - \$199,999	2	2.6
≥ \$200,000	1	1.3
Missing	3	3.9

Table 3.

*Children's Demographics and Medical Status Characteristics (N = 77)*

Variable	Number of children	Percent
Child's gender		
Male	44	57.1
Female	33	42.9
Status of current admission		
Planned	17	22.1
Unexpected	60	77.9
Hospital history		
No previous hospital admissions	21	27.3
1 or more previous hospital admissions	56	72.7
1 or more previous PICU admissions	31	40.3
Primary diagnostic reasons for PICU admission <sup>3</sup>		
Circulatory	13	16.8
Endocrine	10	12.9
Gastro-intestinal	4	5
Neurological	25	32.3
Respiratory	38	49.3

(continued)

<sup>3</sup> Percentages for diagnoses exceed 100% of sample because children are often admitted to the PICU for multiple reasons; primary reasons for admission are life-threatening conditions pertaining to an area of physiological functioning necessary to support life.

Table 3 (continued).

*Children's Demographics and Medical Status Characteristics (N = 77)*

Variable	Number of children	Percent
Injury	4	5
Post-operative recovery	28	36.3

having obtained a graduate or professional degree ( $n = 8, 10.4\%$ ) to not having earned a high school diploma or equivalency ( $n = 5, 6.5\%$ ); most parents reported having attended either some college or vocational training ( $n = 20, 26\%$ ), or having completed college or vocational training ( $n = 25, 32.5\%$ ).

Children's ages ranged from two months to 18 years ( $M = 6.72$  years,  $SD = 5.09$  years). Most parents reported that their child's PICU admission was unexpected ( $n = 60, 77.9\%$ ), and although the majority of children had a history of previous hospitalizations ( $n = 56, 72.7\%$ ), most had never been admitted to a PICU ( $n = 46, 59.7\%$ ). Diagnoses and reasons for PICU admissions are summarized and included in Table 3.

**Power analyses.** A power analysis was conducted prior to data collection to determine the sample size needed to test the hypotheses. Based on Model 1 error estimates,<sup>4</sup> an estimated medium effect size of .15, a desired power level of .80, and an alpha of 0.05 (Cohen, Cohen, West, & Aiken, 2003), a sample size of 91 was optimal, assuming two predictor variables (primary appraisal and uncertainty) and up to three covariates in the hierarchical regression

<sup>4</sup> Model 1 error is the SPSS default approach and is recommended for exploratory research or when the number of IVs is large.

equations used in the main analyses. Post hoc power was analyzed for each hypothesis based on the actual sample size ( $N = 77$ ), obtained effect sizes, and alpha set at .05. For hypothesis 1, with a medium effect size ( $f^2 = .15$ ), six covariates and one predictor, power was .90. For hypotheses 2a, 2b, and 2c, with six covariates and one predictor variable, observed power for 2a was  $> .99$  ( $f^2 = .48$ ); power for 2b was .39 ( $f^2 = .04$ ), and power for 2c was only .13 ( $f^2 = .01$ ). For the hierarchical regression equations used to evaluate Steps 1 – 4 of the mediational model in hypothesis 3, observed power was .90 for Step 1 (uncertainty predicting ASD symptoms,  $f^2 = .15$ ); .96 for Step 2 (uncertainty predicting threat appraisals,  $f^2 = .19$ );  $> .99$  for Step 3 (threat appraisals predicting ASD symptoms,  $f^2 = .48$ ); and .92 for Step 4 ( $f^2 = .20$ ).

## **Procedure**

Participants were recruited from the PICU at Children's Hospital of Richmond (CHoR), located within Virginia Commonwealth University's Health System (VCUHS). Virginia Commonwealth University's Institutional Review Board approved the research protocol. CHoR's PICU is a 14-bed, Level – 1 pediatric critical care facility situated in an urban area; it serves the greater Richmond area and is also the pediatric referral center for the central Virginia area. Approximately 900 – 1000 children are admitted to CHoR's PICU each year. Admissions originate from multiple sources within VCUHS, as well as from other health facilities and hospitals throughout the state that may be unable to provide the level of critical care a particular child requires.

During the data collection phase, an open letter to families from the researcher (see Appendix H) was included in the *Welcome Packet* given to all parents as part of the PICU's routine admissions process. The letter notified parents that (a) a research study was being conducted in the PICU; (b) they may be approached by study staff and invited to participate; (c)

participation was completely voluntary; and (d) if they preferred *not* to be approached and invited to participate, they could “opt out” of the study by signing the bottom of the letter and giving it to their child’s primary care nurse, or to the PICU receptionist. A computer-generated Patient Status Report was used on a daily basis to identify families whose children had been in the PICU for a minimum of 48 hours. The researcher then consulted with an on-duty PICU staff member (e.g., the child’s primary care nurse, attending, or resident) to ensure that parents met all other eligibility criteria and to ascertain that there was no ongoing situation (e.g., pending CPS investigation or other situation identified by PICU staff) that would preclude parents from participating. Eligible parents were approached in the PICU by the researcher, typically at their child’s bedside, and invited to participate. Once informed consent was properly reviewed and written consent obtained, parents were given a questionnaire packet to complete and return. The packet required approximately 20 – 25 minutes to complete; however, many parents required more time because of frequent interruptions necessary to the care of their child.

Of 199 families that met study criteria, 91 agreed to participate and provided informed consent. Three families declined, one parent signed the opt-out letter, and 81 families were missed before they could be approached (e.g., were being discharged, involved in consults, sleeping, not present). Twenty-three families were not approached due to extenuating circumstances; specifically, five children were in the PICU for treatment of injuries sustained during a motor vehicle accident wherein a parent had died or was also hospitalized; seven families had children being withdrawn from life support; six families had posted Do Not Disturb signs; and PICU staff recommended not approaching five families whose children were medically unstable (i.e., seizing and coding) on a specific day.

Of the 91 parents who agreed to participate in the study and provided informed consent, 14 parents did not return completed questionnaire packets for the following reasons: (a) four parents said they were too distracted to complete the measures, (b) seven parents said they were



unable to follow through because of frequent interruptions pertaining to the care of their child, and (c) three parents were told their child was being discharged before they began the packet. Results of independent samples *t*-tests showed that there were no significant differences between parents who returned a completed questionnaire packet versus those who did not based on children's objective medical status (PIM2 scores),  $t(89) = 0.65, p = .52$ ; children's age,  $t(89) = -0.89, p = .38$ ; or number of days in the PICU,  $t(56.72) = 1.4, p = .17$ . A chi-square test for independence (with Yates' Correction for Continuity) revealed no significant difference in children's gender between parents who did not return a completed packet and those who did,  $\chi^2(1, n = 91) = 2.81, p = .09$ . Data from these 14 cases was excluded from further analyses.

## Measures

**Demographics** (Parent Information Form, Appendix A). Participants filled out a one-page demographic questionnaire that elicited information about their age, gender, relationship to the child admitted (i.e., biological parent, stepparent, legal custodial guardian, custodial grandparent), race/ethnicity, level of education, and annual household income. Additional questions on the Parent Information form pertained to the reason for the current admission, child's history of previous hospitalizations, and whether the current PICU admission had been expected (e.g., post-operative care following elective surgery) or had occurred unexpectedly. Parents were also asked to briefly describe what their child's PICU hospitalization had been like for them up to that point. Children's age, gender, number of previous hospitalizations<sup>5</sup>, and date and reason for current admission were obtained from the child's medical records.

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<sup>5</sup> Chart review for information pertaining to children's hospital history was limited to PICU admissions' notes.

**Pediatric Index of Mortality<sup>2</sup>** (PIM2; Slater, Shann, & Pearson, 2003; see Appendix B).

The PIM2 was used as an objective indicator of the severity of each child's medical status.

PIM2 scores are calculated based on information from 10 medical variables (e.g., systolic blood pressure, pupil reactivity, need for respiratory support) charted during a patient's first face-to-face contact with critical care providers. Numerical values for each variable are entered into a logit formula and scores are expressed as a percentage representing probability of death. For example, a PIM2 score of 0.1969 is interpreted as a 19.7% chance of death, i.e., the probability of survival is approximately 80%. None of the medical information needed to calculate a reliable PIM2 score requires subjecting a child to any extra or unnecessary invasive procedures.

The researcher received training from PICU attendings regarding how to retrieve needed information from the medical chart, and how to ensure accurate representation of variables. For example, one variable contained in the PIM2 equation is the ratio of partial pressure of oxygen in arterial blood to the fraction of inspired oxygen ( $\text{PaO}_2/\text{FiO}_2$ ); these values are entered separately and usually at different times, into the medical chart. In order to calculate an accurate ratio, the values used must be measurements taken at the same moment in time. The researcher consulted frequently with PICU staff to determine appropriate classifications of high risk versus low risk diagnoses. All PIM2 scores were calculated using an online scoring calculator<sup>6</sup> and were regularly checked for accuracy using random review and recalculation by a member of the PICU staff.

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<sup>6</sup><http://www.sfar.org/scores2/pim22.html>

The PIM2 (Slater et al., 2003) is an updated version of the PIM (Shann, Pearson, Slater, & Wilkinson, 1997) that reflects the ways in which improvements and changes in medical care since the original PIM formula was developed have altered the relation between a child's physiological status upon presentation and estimated mortality risk. The revised version is based on physiological data collected from over 20,500 admissions to 14 PICUs located in the UK, Australia, and New Zealand. In the revision study, the PIM2 produced an acceptable estimate of goodness-of-fit ( $\chi^2$  11.56,  $p = 0.17$ ) and demonstrated a good ability to discriminate mortality outcomes (Slater et al., 2003; area 0.90, 0.89 – 0.91 based on a 95% confidence interval). In a study comparing the predictive ability of the PIM2 to the PIM and the PRISM III, the PIM2 demonstrated the highest degree of accuracy and the best goodness-of-fit values across all diagnostic groups (Slater & Shann, 2004).

**Parental Perceptions of Uncertainty in Illness Scale (PPUS; Mishel, 1983; see Appendix C).** The PPUS is a 31-item measure that assesses the degree to which parents perceive uncertainty related to their child's medical status. Twenty scale items are positively-valenced (e.g., *I have a lot of questions without answers*) and 11 are negatively-valenced (e.g., *The doctors and nurses use everyday language so I can understand what they are saying*). Respondents are asked to indicate their level of agreement with each statement on a Likert-type scale ranging from 1 to 5. Corresponding descriptors vary depending on whether the item is positively or negatively valenced in terms of uncertainty. For example, on positively valenced items, 1 = *strongly disagree* and 5 = *strongly agree*; on negatively valenced items, 1 = *strongly agree* and 5 = *strongly disagree*. All 31 items were summed to produce a total uncertainty score ranging from 31 – 155; higher scores represent a greater degree of perceived uncertainty.

Factor analyses conducted during the original scale development study yielded four factors: Ambiguity (13 items), Lack of Clarity (9 items), Lack of Information (5 items), and Unpredictability (4 items; Mishel, 1983). Ambiguity, defined as “the inability to place an event within a comprehensive gestalt” (p. 325), is considered the broadest aspect of uncertainty and emerged as the strongest factor on the PPUS, accounting for 64.7% of variance. A separate score for each factor (subscale) can be calculated by summing the subset of items pertaining to each factor. Only total PPUS scores were used in the present study.

Preliminary internal consistency reliability estimates for the PPUS based on a population of parents of children hospitalized for either medical treatment, surgery, or diagnostic work-ups produced a Cronbach’s alpha of .91 for the total scale (Mishel, 1983); factor estimates ranged from .87 (Ambiguity) to .72 (Unpredictability). Subsequent studies using the PPUS have documented strong reliability among parents of critically ill children in samples from mixed pediatric diagnoses ( $\alpha = .92$  and  $.93$ , Mishel, 1997;  $\alpha = .90$ , Page et al., 2011) and disease-specific diagnoses, including parents of children with spina bifida ( $\alpha = .81$ ), leukemia ( $\alpha = .90$ ), cystic fibrosis ( $\alpha = .89$ ; Mishel, 1997), diabetes mellitus type 1 ( $\alpha = .88$ ; Carpentier et al., 2006), and juvenile rheumatic diseases ( $\alpha = .88$ ; Fedele et al., 2011). Construct validity for the PPUS among parents of hospitalized children was supported by results of factor analyses consistent with theoretical predictions (Mishel, 1983).

**Stress Appraisal Measure (SAM; Peacock & Wong, 1990).** Parents’ primary appraisals were assessed using the SAM, a 28-item, self-report index of primary and secondary appraisal dimensions. The SAM was developed based upon cognitive-relational theories of stress and coping and is conceptually very well-suited to the present study. Respondents are asked to indicate their level of agreement with each item on a 5-point Likert-type scale ranging from 1

(*not at all*) to 5 (*extremely*). The SAM comprises 7 subscales representing three dimensions of primary appraisal: Threat (anticipated harm or loss in the future), Challenge (anticipated benefit or personal growth from the experience), and Centrality (the perception of how important a particular event is for one's well-being), three dimensions of secondary appraisal (Controllable-by-self, Controllable-by-others, Uncontrollable), and a Stressfulness subscale which measures the amount of overall stress perceived in a given situation at a given moment. For purposes of this study, only the three primary appraisal subscales and the Stressfulness subscale were used.

In scale development studies conducted among undergraduate college populations, Peacock and Wong found internal consistency estimates for the primary appraisal subscales ranging from .84 to .90 (Centrality), .65 to .75 (Threat), .66 to .74 (Challenge) and .75 to .81 (Stressfulness), indicating good reliability. A longitudinal study that examined parental stress and coping after the birth of a preterm infant reported Cronbach's alphas of .69, .73, .78, and .73 for the Threat, Challenge, Centrality, and Stressfulness subscales, respectively (Rowe & Jones, 2010). In a study conducted among parents of infant children born with Down Syndrome or cleft lip/palate, researchers reported Cronbach's alpha for all seven subscales ranging from .73 to .86 (Pelchat, Bisson, Ricard, Perreault, & Bouchard, 1999).

**Acute Stress Disorder Scale (ASDS; Bryant, Moulds, & Guthrie, 2000).** The ASDS is a 19-item, self-report inventory that screens for the presence (or absence) of ASD and provides a measure of acute stress symptom severity. Respondents are asked to provide a brief, written description of a recent traumatic experience and then rate on a 5-point Likert-type scale (1 = *not at all*, 5 = *very much*) the extent to which they have subsequently experienced certain symptoms based on *DSM-IV* criteria (1994). The ASDS yields a total score and four subscale scores based on acute stress symptom clusters: Dissociation (e.g., *During or after the trauma, did things*

*around you ever feel unreal or dreamlike?*), Reexperiencing (e.g., *Have memories of the trauma kept entering your mind?*), Avoidance (e.g., *Have you tried not to think about the trauma?*), and Arousal (e.g., *Have you become jumpy since the trauma?*). A total score indicating overall symptom severity is calculated by summing all items; subscale scores are calculated by summing the items specific to each subscale. Clinically significant ASD is determined by a score  $\geq 9$  on the Dissociative symptoms subscale and a combined score  $\geq 28$  on the other three subscales. Higher scores indicate greater symptom severity, with a total score  $\geq 56$  indicating high risk for the development of PTSD.

In the original scale development study conducted among adult survivors of wildfires, internal consistency estimates for the ASDS produced Cronbach's alphas of .96 for the total score, .84 for the Dissociation subscale, .87 for the Reexperiencing subscale, .92 for the Avoidance subscale, and .93 for the Arousal subscale (Bryant et al., 2000). Test-retest reliability estimates conducted after 2 to 7 days resulted in an alpha of .94 for total scale scores; symptom cluster alphas were strong at .85 (Dissociation), .94 (Reexperiencing), .89 (Avoidance), and .94 (Arousal). The ASDS has been deemed reliable in subsequent studies of family adaptation following a potentially traumatic medical event, including parental adaptation to a child's PICU admission (Balluffi et al., 2004), family adjustment to an adult family member's admission to an intensive care unit (Auerbach et al., 2005), and parental adaptation following a child's cancer diagnosis (Patiño-Fernández et al., 2008).

## **Results**

This section presents details of the statistical analyses used to address the specific aims of the present study and test the hypotheses put forth herein. All analyses were conducted using SPSS, Version 21.

## Data Screening

Prior to performing preliminary or main analyses, the data set was inspected for errors and accuracy. Descriptive statistics were used to examine the minimum, maximum, and mean values of the continuous variables. Frequencies showing the range of values for the categorical variables were examined to verify that all values fell within the range of possible responses. All values were found to be within specified parameters; no errors were detected.

**Missing data.** The data set was checked for missing values by examining frequencies and descriptive statistics for all variables at the item level. Missing item-level data was extrapolated from the mean of the participant's responses to other items on that particular subscale if the number of missing items was less than 20% (Tabachnick & Fidell, 1996). If the number of items missing on a scale exceeded 20%, participant responses for that particular scale were excluded from further analyses. Two cases were missing one data point each – one from the SAM and one from the PPUS; these values were replaced by the respective subscale mean as previously described. In one case, information about a child's hospital history was missing from the Parent Information form; history of previous hospitalizations was contained in the PICU admission note used to calculate the PIM2 score and therefore, replaced.

**Outliers.** The data was checked for univariate outliers by examining the range of standardized scores for each measured variable, and by visual inspection of histograms and boxplots. A score was considered a univariate outlier if it exceeded 3 standard deviations from the mean. When univariate outliers were identified, the participant's questionnaire packet was first checked to see if the outlier was caused by a data entry error. The distribution of PIM2 scores revealed three univariate outliers. PIM2 scores for these three cases were checked, recalculated, and found to be accurate; therefore, these scores were considered a legitimate part

of the target population. Appropriate steps were taken to reduce their impact so that these cases could be retained in the sample (logarithm transformation of PIM2 scores is detailed in the next section, *Normality of Distributions*).

**Normality of distributions.** The distributions of all measured variables were examined for normality and to ensure that the assumptions of multiple regression analyses were met. The means, standard deviations, ranges, and values for skewness and kurtosis were calculated; histograms, boxplots, and normal probability plots of distributions were generated and visually inspected. With the exception of the distribution of PIM2 scores, no violations of normality were detected. The distribution of PIM2 scores showed strong, positive skewness (3.13), as well as significant kurtosis (11.17), indicating that although children in the PICU needed critical care, the probability of death occurring was very low for most children. A Normal Q-Q probability plot showed all PIM2 scores reasonably clustered along a straight line with the exception of the three extreme scores previously identified as univariate outliers. While there are no clear definitions of acceptable skewness and kurtosis values, absolute values less than two are preferred. A logarithm transformation of PIM2 scores was performed to reduce the impact of the three outliers, resulting in acceptable skewness and kurtosis values of 0.26 and -.89, respectively (Tabachnick & Fidell, 2007). Transformed PIM2 scores were used in all subsequent analyses. Final distributions for all scales and subscales, including both original and transformed PIM2 scores, are presented in Table 4.

### **Preliminary Analyses**

**Reliability of measures.** To evaluate the internal consistency of the measures among the current sample, Cronbach's alpha coefficients were calculated for all scales and subscales used in



Table 4.

*Final Distributions of Scales and Subscales*

Measure	Range	Mean	SD	95% CI	Skewness	Kurtosis
<b>ASD</b>						
Total score	19 – 84	44.57	14.94	41.18 – 47.96	.45	-.28
Dissociation	5 – 23	10.87	4.61	9.82 – 11.91	.68	-.25
Reexperiencing	4 – 18	8.99	3.85	8.11 – 9.86	.46	-.69
Arousal	6 – 30	15.92	5.64	14.64 – 17.20	.48	-.27
Avoidance	4 – 20	8.79	3.99	7.89 – 9.70	.98	.76
<b>PPUS</b>						
Total score	38 – 123	76.91	20.88	72.17 – 81.64	.02	-.75
Lack of clarity	9 – 34	18.62	6.18	17.22 – 20.03	.50	.27
Ambiguity	13 – 58	34.45	10.96	31.97 – 36.94	-.12	-.75
Lack of information	5 – 22	11.05	4.16	10.12 – 11.99	.54	-.49
Unpredictability	4 – 20	12.78	3.56	11.97 – 13.59	-.25	-.60
<b>SAM</b>						
Threat	4 – 20	10.55	3.44	9.76 – 11.32	.01	-.30
Challenge	8 – 20	16.10	3.07	15.41 – 16.80	-.86	.14
Centrality	4 – 20	15.35	4.28	14.38 – 16.32	-.93	.03
Stressfulness	4 – 20	13.57	3.48	12.78 – 14.36	-.43	-.42
<b>PIM2</b>						
Original score	.20 – 83.60	8.56	14.73	5.22 – 11.91	3.17	11.52
Transformed score	-.70 – 1.92	.46	.67	.31 – .68	.22	-.89

the main analyses (see Table 5). Internal consistency values based on the current sample for the PPUS total scale ( $\alpha = .94$ ) and the ASDS total ( $\alpha = .91$ ) were both very good (DeVellis, 2003) and were similar to those reported in other studies. Reliability estimates for each of the subscales comprising the ASDS were respectable and ranged from .74 (Reexperiencing subscale) to .83 (Arousal subscale). Cronbach's alpha coefficients for the SAM total also fell within the respectable range ( $\alpha = .78$ ), as did SAM subscales for Threat ( $\alpha = .73$ ), Centrality ( $\alpha = .80$ ), and Stressfulness ( $\alpha = .72$ ). The reliability estimate for the SAM's Challenge subscale was not as good ( $\alpha = .67$ ), but fell within a range considered minimally acceptable (DeVellis) and was consistent with alphas reported in previous studies. Further examination of the Challenge subscale showed that inter-item correlations ranged from .30 to .48, with an average of .35. Cronbach's alpha for the Challenge subscale with the lowest correlated item removed (*To what extent am I excited thinking about the outcome of this situation?*) weakened the subscale's internal consistency further and produced an unacceptable alpha coefficient ( $\alpha = .56$ ); therefore, this item was retained. Results from hypotheses testing using the Challenge subscale were interpreted with caution.

**Descriptives.** Means, standard deviations, ranges, confidence intervals for the means, and skewness and kurtosis values for all study measures are presented in Table 4. Pearson correlation coefficients for all variables used in hypotheses testing are reported and summarized in Table 6.

**Uncertainty (PPUS).** The mean for PPUS total scores measuring parents' perceptions of uncertainty related to their child's medical situation ( $M = 76.91$ ,  $SD = 20.88$ , possible range 31 – 155) was very similar to that reported in the original scale development study conducted among parents of children hospitalized for surgery, medical treatment, or diagnostic evaluations

Table 5.

*Internal Consistency Reliability Estimates for Scales and Subscales*

Instrument	Alpha
Parental Perceptions of Uncertainty in Illness Scale (PPUS)	
Total	.94
Clarity	.82
Ambiguity	.92
Information	.75
Unpredictability	.79
Stress Appraisal Measure (SAM)	
Total	.78
Threat	.73
Challenge	.67
Centrality	.80
Stressfulness	.72
Acute Stress Disorder Scale (ASDS)	
Total	.91
Dissociation	.80
Reexperiencing	.74
Avoidance	.81
Arousal	.83

Table 6.

*Zero-Order Correlations of Variables Used in Hypotheses Testing*

	1	2	3	4	5	6	7
1. ASD symptoms (total)	-----	.48**	.52**	-.13	.15	.59**	.08
2. Perceived Uncertainty (total)	.48**	-----	.49**	-.21	.28*	.58**	.17
3. Threat Appraisal	.51**	.49**	-----	-.11	.62**	.67**	.17
4. Challenge Appraisal	-.13	-.21	-.11	-----	.02	.05	-.07
5. Centrality Appraisal	.15	.28*	.62**	.02	-----	.55**	.22
6. Stressfulness Appraisal	.59**	.58**	.67**	.05	.55**	-----	.16
7. PIM2 (transformed score)	.08	.17	.17	-.07	.22	.16	-----

Note: \*  $p < .05$ , \*\*  $p < .001$ .

(Mishel, 1983;  $M = 78.8$ ,  $SD = 18.9$ ). The mean among the current sample is higher than means reported among parents of pediatric liver and renal transplant recipients (Maikranz et al., 2007;  $M = 58.35$ ,  $SD = 13.19$ ), parents of children with juvenile rheumatic diseases (Fedele et al., 2011;  $M = 59.88$ ,  $SD = 14.18$ ), and somewhat higher than in a sample of mothers of chronically ill children (Page, et al., 2011;  $M = 67.30$ ,  $SD = 15.53$ ).

**Acute stress disorder (ASD) symptoms.** Most parents reported that the experience of having their child admitted to the PICU was frightening ( $n = 52$ , 67.5%). The mean for total scale scores measuring severity of ASD symptoms in the current sample of parents was 44.57 ( $SD = 14.94$ , possible range 19 – 84). ASD scale means for mothers ( $M = 46.88$ ,  $SD = 15.47$ ) and fathers in the present sample ( $M = 38.00$ ,  $SD = 11.25$ ) were similar, albeit somewhat lower, than means reported in separate studies among parents of children newly diagnosed with

pediatric cancer (Patiño-Fernández, et al., 2008; mothers:  $M = 50.2$ ,  $SD = 16.0$ ; fathers:  $M = 46.1$ ,  $SD = 14.8$ ; McCarthy et al., 2012; mothers:  $M = 50.95$ ,  $SD = 15.33$ ; fathers:  $M = 45.86$ ,  $SD = 15.24$ ).

Based on scoring guidelines for the ASDS, 57.1% (95% CI: 46.01% – 67.5%) of parents in the present sample met all diagnostic criteria for ASD ( $n = 44$ ; 81.8% mothers, 18.2% fathers) and 24.6% (95% CI: 16.41% – 35.3%) had total scores  $\geq 56$  ( $n = 19$ ; 94.7% mothers, 5.3% fathers), indicating potential risk for PTSD. Sixty-nine percent of parents (95% CI: 57.8% – 78.1%) met criteria for partial ASD<sup>7</sup> ( $n = 53$ ; 77.3% mothers, 20.7% fathers, 1% grandfather). The prevalence rate of parents meeting diagnostic criteria for ASD in the present sample was higher than that reported in a study using the ASDS among a similar population (32%; Balluffi et al., 2004); however, because Balluffi and colleagues did not report means, ranges, and standard deviations for ASDS scores, no further comparisons can be made. Two studies examining parental adjustment to newly diagnosed pediatric cancer reported prevalence rates of ASD similar to those among the current sample (McCarthy et al., 2012; 61.6%; Patiño-Fernández, et al., 2008; 47.2%), as well as similar percentages of parents deemed at risk for PTSD (McCarthy et al., 2012; 29.6%; Patiño-Fernández, et al., 2008; 33%).

**Potential covariates.** Independent-samples *t*-tests were conducted to examine the relations between the outcome variables (ASD symptoms and uncertainty) and (a) parents' gender, (b) children's gender, and (c) admission status (planned or unexpected). Mothers (female gender) had significantly higher mean scores for ASD symptoms ( $M = 46.88$ ,  $SD =$

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<sup>7</sup> Diagnostic criteria for partial ASD is defined as meeting all criteria except dissociation; as assessed in this study, parents with combined scores of  $\geq 28$  on the Reexperiencing, Arousal, and Avoidance subscales met criteria for partial ASD.

15.47) than fathers (male gender;  $M = 38$ ,  $SD = 11.25$ ),  $t(75) = 2.35$ ,  $p = .02$ . The effect size of the mean difference in scores (8.88, 95%  $CI$ : 1.36 – 16.39) was moderate ( $\eta^2 = .07$ ). Parents' gender was therefore entered as a control variable in subsequent hierarchical regression analyses used to test hypotheses. There were no significant differences based on children's gender in parents' reported ASD symptoms [ $t(75) = 0.25$ ,  $p = .805$ ] or levels of perceived uncertainty [ $t(75) = 0.06$ ,  $p = .956$ ]. Parents whose children were admitted to the PICU unexpectedly had significantly higher total scores on both the ASDS ( $M = 47.48$ ,  $SD = 14.18$ ) and the PPUS ( $M = 82.02$ ,  $SD = 18.99$ ) than parents of children whose admission was planned or expected (ASDS:  $M = 34.39$ ,  $SD = 14.18$ ; PPUS:  $M = 58.88$ ,  $SD = 17.26$ ),  $t(75) = -3.43$ ,  $p = .001$  (ASDS),  $t(75) = -4.52$ ,  $p = .000$  (PPUS). The effect sizes of the mean differences in ASDS scores (-13.19, 95%  $CI$ : -20.84 to -5.53) and PPUS scores (-23.13, 95%  $CI$ : -33.33 to -12.93) were moderately large (ASDS:  $\eta^2 = .13$ ) and large (PPUS:  $\eta^2 = .21$ ). Children's admission status was controlled for in subsequent hypotheses testing.

Pearson product-moment correlation coefficients were calculated and used to identify significant relations between parent's age, child's age, annual household income, number of days in the PICU at the time of data collection, children's objective medical status (transformed PIM2 scores), number of previous hospitalizations, number of previous PICU admissions, and the outcome variables (ASD symptoms and perceived uncertainty). Parents' age showed a significant, negative correlation with ASD symptoms ( $r = -.24$ ,  $p = .03$ ), with more severe ASD symptoms associated with younger parents. There was also a marginally significant, negative correlation between ASD symptoms and annual household income ( $r = -.23$ ,  $p = .053$ ). According to established guidelines for determining the strength of a relation between two variables, this value is considered small (Cohen, 1988). There were no significant correlations

between ASD symptoms and number of days in the PICU at the time of data collection ( $r = -.08$ ,  $p = .47$ ), children's objective medical status (transformed PIM2 scores;  $r = .08$ ,  $p = .52$ ), number of previous hospitalizations ( $r = -.08$ ,  $p = .49$ ), or number of previous PICU admissions ( $r = 0.8$ ,  $p = .51$ ). Parents' age and annual household income were controlled for in the main analyses.

Parents' perceptions of uncertainty were not significantly correlated with any of the demographic variables or medical status characteristics: parent's age,  $r = -.05$ ,  $p = .68$ ; child's age,  $r = .03$ ,  $p = .81$ ; annual household income,  $r = -.11$ ,  $p = .33$ ; number of days in the PICU at the time of data collection,  $r = .17$ ,  $p = .17$ ; children's objective medical status (transformed PIM2 scores),  $r = .17$ ,  $p = .14$ , number of previous hospitalizations,  $r = .09$ ,  $p = .47$ ; and number of previous PICU admissions,  $r = .19$ ,  $p = .10$ .

One-way, between-groups analyses of variance (ANOVAs) were used to examine the impact of parents' ethnicity, level of education, and relationship status, respectively, on ASD symptoms and levels of perceived uncertainty. Variability within some cells of reported ethnicity was very limited; specifically, only one participant identified as Hispanic/Latino(a) and just two participants identified as Asian. Therefore, ethnicity was collapsed into *White*, *Black*, and *Other* to create fewer categories and a more even distribution. Results showed that neither parents' ethnicity [ $F(2, 73) = 0.41$ ,  $p = .67$ ], nor educational background [ $F(5, 71) = 0.57$ ,  $p = .72$ ] were significantly related to ASD symptoms. Parents' relationship status was grouped into three categories: *Married/Partnered*, *Separated/Divorced*, and *Single*. Results revealed significant differences in ASD symptoms based on parents' relationship status,  $F(2, 74) = 4.46$ ,  $p = .02$ . A Tukey post hoc analysis showed that single parents had significantly higher total scores on the ASD scale ( $M = 54.00$ ,  $SD = 17.25$ ) than did parents who were married or partnered ( $M = 42.42$ ,  $SD = 13.71$ ). The effect size, estimated using eta squared, is considered

moderately large ( $\eta^2 = .11$ ). ASD symptom scores for parents who were separated or divorced ( $M = 40.64, SD = 12.11$ ) were not significantly different from either of the other groups. Two dummy variables were created and used to control for parents' relationship status in subsequent hypotheses testing. There were no significant differences in parents' perceptions of uncertainty (total PPUS scores) based on parents' ethnicity [ $F(2, 73) = 1.46, p = .24$ ], level of education [ $F(5, 71) = 0.54, p = .75$ ], or relationship status [ $F(2, 74) = 0.65, p = .52$ ].

### **Hypotheses Testing**

**Hypothesis 1.** Parents' perceptions of uncertainty related to their child's medical status will account for a significant portion of the variance in the severity of parents' ASD symptoms. Specifically, it was hypothesized that greater degrees of perceived uncertainty would be associated with higher levels of ASD symptoms.

**Analysis of hypothesis 1.** A hierarchical regression analysis was conducted to examine the relation between perceived illness-related uncertainty and ASD symptoms after controlling for the influence of parents' age, gender, relationship status, annual household income, and children's admission status (planned or unexpected). Results showed that the overall model was significant,  $F(7, 66) = 5.86, p = .000$ , and accounted for 38.3% of the variance in ASD symptoms (see Table 7). After the covariates were controlled for, the variance accounted for by perceived uncertainty was significant,  $\Delta R^2 = .09, \Delta F(1, 66) = 10.08, p = .002$ . An examination of beta weights showed that perceived uncertainty was the only variable that made a unique, significant contribution to the overall model ( $\beta = .35, t = 3.18, p = .002$ ). Therefore, this hypothesis was supported.

**Hypothesis 2.** Dimensions of primary appraisal – threat, centrality, and challenge – will each account for a significant portion of variation in parents' self-reported ASD symptoms.



Table 7.

*Summary of Hierarchical Regression Analysis with Uncertainty as a Predictor of ASD Symptoms.*

Variable	<i>df</i>	<i>R</i> <sup>2</sup>	$\Delta R^2$	$\Delta F$	<i>B</i>	<i>SE B</i>	$\beta$	<i>t</i>
Step 1	6, 67	.29	.29	4.54**				
Parents' gender					-5.86	3.96	-.17	-1.48
Parents' age					-.15	.20	-.09	-.76
Dummy for relationship (single)					9.31	5.76	.26	1.61
Dummy for relationship (M/P)					-.41	4.73	-.01	-.09
Annual Income					.12	.89	.02	.12
Admission status					13.69	3.74	.38	3.66***
Step 2	1, 66	.38	.09	10.08**				
Perceived uncertainty					.25	.08	.35	3.18**

*Note.* \*\* $p = .002$ ; \*\*\* $p = .000$ .

Specifically, parents who appraise their child's PICU hospitalization as very threatening, with the potential for harm or loss (Threat subscale), and as having more long-term consequences (Centrality subscale), are expected to report more severe ASD symptoms. The degree to which parents appraise their child's medical status as a positively-valenced challenge with opportunities for personal growth or benefit (Challenge subscale) is expected to be associated with less severe ASD symptoms. Three separate hierarchical regression analyses were conducted to examine the relation of each dimension of primary appraisal with ASD symptoms after controlling for the influence of parents' age, gender, relationship status, annual household income, and admission status (planned or unexpected).

**Hypothesis 2a.** Appraisals of threat will account for a significant portion of the variance in ASD symptoms.

**Analysis of hypothesis 2a.** Previously identified covariates were controlled for by entering them as a set in Step 1 of the regression equation; parents' scores on the Threat subscale of the SAM were entered as the predictor variable in Step 2. The overall model was significant,  $F(7, 66) = 10.24, p = .000$ , and accounted for 52.1% of the variance in ASD scale scores (see Table 8). The variance in ASD symptoms accounted for by the covariates (parents' age, gender,

Table 8.

*Hierarchical Multiple Regression Analysis Predicting Acute Stress Disorder Symptoms from Threat Appraisals*

Variable	<i>df</i>	$R^2$	$\Delta R^2$	$\Delta F$	<i>B</i>	<i>SE B</i>	$\beta$	<i>t</i>
Step 1	6, 67	.29	.29	4.56				
Parents' gender					-5.86	3.96	-.17	-1.48
Parents' age					-.15	.20	-.09	-.76
Dummy for relationship (single)					9.31	5.76	.26	1.61
Dummy for relationship (M/P)					-.41	4.73	-.01	-.09
Annual Income					.12	.89	.02	.12
Admission status					13.69	3.74	.38	3.66**
Step 2	1, 66	.52	.23	31.93**				
Threat appraisals					2.29	.41	.53	5.65**

Note: \*\*  $p = .000$ .

relationship status, annual household income, and admission status) entered as a set in Step 1 of the model was significant [ $R^2 = .29, F(6, 67) = 4.54, p = .001$ ]. Step 2 of the model showed that threat appraisals accounted for 23.2% of the variance in ASD symptoms after controlling for the covariates,  $\Delta R^2 = .23, \Delta F(1, 66) = 31.96, p = .000$ . An examination of the beta weights showed that parents who tended to appraise their child's PICU hospitalization as threatening reported

more severe ASD symptoms ( $\beta = .53$ ,  $t = 5.65$ ,  $p = .000$ ). Therefore, this hypothesis was supported.

**Hypothesis 2b.** Appraisals of centrality will account for a significant portion of the variance in total ASD symptom scores.

*Analysis of hypothesis 2b.* Covariates (parents' age, gender, relationship status, annual household income, and admission status) were controlled for by entering them as a set in Step 1 of the equation; parents' scores on the Centrality subscale of the SAM were entered as the predictor variable in Step 2. The overall model was significant,  $F(7, 66) = 4.42$ ,  $p = .000$ , and accounted for 31.9% of the variance in ASD symptoms. The covariates entered in Step 1 accounted for a significant portion of the variance in ASD symptoms (28%;  $R^2 = .29$ ,  $F(6, 67) = 4.56$ ,  $p = .001$ ). After controlling for parents' age, gender, relationship status, annual household income, and admission status, the 3% of variance accounted for by Centrality appraisals was not significant,  $\Delta R^2 = .03$ ,  $\Delta F(1, 66) = 2.93$ ,  $p = .09$  (see Table 9). In the final model, children's admission status was the only variable that accounted for a significant portion of unique variance ( $\beta = .34$ ,  $t = 3.16$ ,  $p = .002$ ). Therefore, this hypothesis was not supported.

**Hypothesis 2c.** Challenge appraisals will be associated with less severe ASD symptom severity.

*Analysis of hypothesis 2c.* Demographic covariates (parents' age, gender, relationship status, annual household income, and admission status) were controlled for by entering them as a set in Step 1; parents' scores on the Challenge subscale of the SAM were entered in Step 2 as the predictor variable. Results of the overall model were significant [ $F(7, 66) = 4.01$ ,  $p = .001$ ] and accounted for 29.8% of the variance in severity of ASD symptoms ( $R^2 = .30$ ). However, once the portion of variance accounted for by the covariates was controlled [ $R^2 = .29$ ,  $F(6, 67) = 4.56$ ,

Table 9.

*Summary of Hierarchical Regression Analysis for Centrality Appraisals as a Predictor of Acute Stress Disorder Symptoms*

Variable	<i>df</i>	<i>R</i> <sup>2</sup>	$\Delta R^2$	$\Delta F$	<i>B</i>	<i>SE B</i>	$\beta$	<i>t</i>
Step 1	6, 67	.29	.29	4.56				
Parents' gender					-5.86	3.96	-.17	-1.48
Parents' age					-.15	.20	-.09	-.76
Dummy for relationship (single)					9.31	5.78	.26	1.61
Dummy for relationship (M/P)					-.41	4.73	-.01	-.09
Annual income					.11	.89	.02	.12
Admission status					13.69	3.74	.38	3.66**
Step 2	1, 66	.32	.03	2.93				
Centrality appraisals					.68	.39	.19	1.71

Note: \*\*  $p = .000$ .

$p = .001$ ], Challenge appraisals did not make a significant contribution in variance,  $\Delta R^2 = .01$ ,  $\Delta F$  (1, 66) = 0.89,  $p = .35$  (see Table 10). In the final model, children's admission status was the only variable that accounted for a significant portion of unique variance ( $\beta = .37$ ,  $t = 3.50$ ,  $p = .001$ ). Therefore, this hypothesis was not supported.

**Hypothesis 3.** Dimensions of primary appraisal (threat, centrality, and challenge) will mediate the relation between the degree to which parents' perceive uncertainty related to their child's PICU hospitalization (total PPUS scores) and ASD symptoms. A mediational model specifies a causal chain, wherein the mediator variable is a mechanism, or process, through which an outcome occurs. In this specific hypothesis, the ways in which parents appraise (mediator variable) their child's PICU hospitalization is expected to mediate the relation between uncertainty (predictor variable), which is inherently benign, and the severity of ASD symptoms (outcome variable; see Figure 5).

Table 10.

*Summary of Hierarchical Regression Analysis for Challenge Appraisals as a Predictor of Acute Stress Disorder Symptoms*

Variable	<i>df</i>	<i>R</i> <sup>2</sup>	$\Delta R^2$	$\Delta F$	<i>B</i>	<i>SE B</i>	$\beta$	<i>t</i>
Step 1	6, 67	.29	.29	4.54				
Parents' gender					-5.86	3.96	-.17	-1.48
Parents' age					-.15	.20	-.09	-.76
Dummy for relationship (single)					9.31	5.78	.26	1.61
Dummy for relationship (M/P)					-.41	4.73	-.01	-.09
Annual household income					.11	.89	.02	.12
Admission status					13.69	3.74	.38	3.66**
Step 2	1, 67	.17	.02	1.76				
Challenge appraisals					-.73	.56	-.15	-1.32

Note: \*\*  $p = .000$ .

**Analysis of hypothesis 3.** This hypothesis was tested using a series of hierarchical regression analyses according to a four-step approach outlined by Baron & Kenny (1986). The objectives of the first three steps are to establish that significant relations exist between (a) the initial variable (uncertainty) and the outcome variable (ASD symptoms), (b) the initial variable (uncertainty) and the mediator (dimensions of primary appraisal), and (c) the mediator (dimensions of primary appraisal) and the outcome variable (ASD symptoms). Results from hierarchical regression equations used to test hypotheses 2a, 2b, and 2c showed that the only dimension of primary appraisal significantly related to ASD symptoms was threat; centrality and challenge appraisals were not. Therefore, only appraisals of threat were tested as a potential mediator in the hypothesized model.

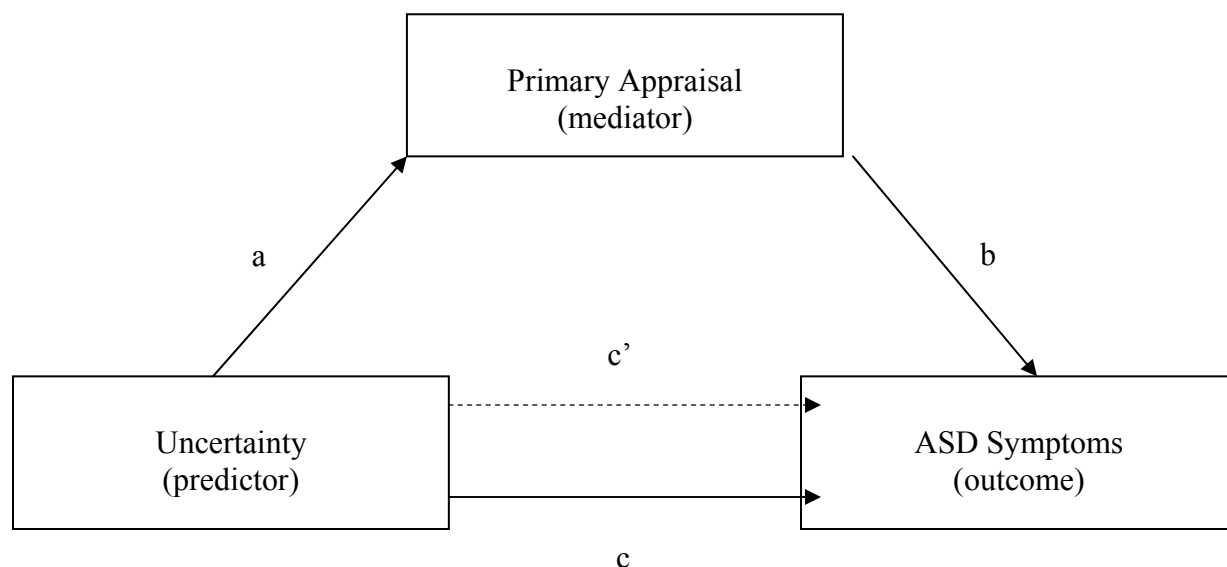


Figure 5. Hypothesized mediational model.

1). Results from hypothesis 1 established that a significant, direct effect existed between uncertainty and ASD symptoms (path c in Figure 5); therefore, the first requirement for testing a mediational model was satisfied.

2). The second step in testing for mediation was to determine if a significant relation existed between perceived uncertainty and threat appraisals (path a in Figure 5). Parents' scores from the Threat subscale were used as the outcome variable in the regression equation, therefore preliminary analyses were conducted first to identify potential covariates. Parents whose children had been admitted to the PICU unexpectedly had significantly higher scores on the Threat appraisal subscale ( $M = 11.13$ ,  $SD = 3.29$ ) than parents of children whose PICU admission had been planned ( $M = 8.47$ ,  $SD = 3.28$ ),  $t(75) = -2.95$ ,  $p = .004$ . Therefore, admission status was controlled for by entering it as a covariate in Step 1 of the regression

equation; perceived uncertainty scores (PPUS total) were entered in Step 2; parents' scores on the Threat subscale were entered as the dependent (outcome) variable.

Results of the overall model examining the impact of perceived uncertainty on threat appraisals were significant [ $F(2, 74) = 12.18, p = .000$ ] and accounted for 24.8% of the variance in parents' threat appraisals (see Table 11). After controlling for admission status, the variance

Table 11.

*Summary of Hierarchical Regression Analysis for Perceived Uncertainty as a Predictor for Threat Appraisals*

Variable	<i>df</i>	$R^2$	$\Delta R^2$	$\Delta F$	<i>B</i>	<i>SE B</i>	$\beta$	<i>t</i>
Step 1	1, 75	.10	.10	8.73**				
Admission status					2.66	.90	.32	2.95**
Step 2	1, 74	.25	.14	14.11***				
Perceived uncertainty scores					.07	.02	.43	3.76***

Note: \*\*  $p = .004$ , \*\*\*  $p = .000$ .

in scores on the Threat subscale accounted for by perceived uncertainty (14.3%) was significant,  $\Delta R^2 = .14, \Delta F(1, 74) = 14.11, p = .002$ . An examination of the beta weights showed that the more uncertainty parents perceived regarding their child's PICU hospitalization, the more they tended to appraise the situation as threatening ( $\beta = .43, t = 3.76, p = .000$ ). These results established a significant, direct effect between perceived uncertainty and appraisals of threat; therefore, it was appropriate to proceed to the third step in the mediational analysis.

3.) In this step, the relation between the mediator (threat appraisal) and the outcome variable (ASD symptoms) was examined for significance (path b). This analysis is identical to the hierarchical regression analysis used to test Hypothesis 2a (see Table 7); therefore, results

from that analysis are used here. Covariates were controlled for by entering them as a set in Step 1; parents' scores on the Threat subscale of the SAM were entered as the predictor variable in Step 2. The overall model was significant,  $F(7, 66) = 10.24, p = .000$ , and accounted for 52.1% of the variance in ASD scale scores. Step 2 of the model showed that Threat appraisals accounted for a significant portion of variance in ASD symptoms after controlling for the covariates,  $\Delta R^2 = .23, \Delta F(1, 66) = 31.96, p = .000$ . An examination of the beta weights showed that the amount of variance in ASD symptoms uniquely attributed to appraisals of threat was significant ( $\beta = .53, p = .000$ ). Therefore, it was appropriate to proceed to the last step in testing for mediation.

4). The purpose of the final step is to determine if the effect of the mediator variable (path b) is still a significant predictor of the dependent variable (ASD symptoms) after controlling for the initial variable (perceived uncertainty). If the initial variable, uncertainty, is no longer significant after controlling for the mediator (threat appraisal), a finding of full mediation is supported. A 3-step hierarchical regression analysis was conducted with ASD symptoms entered as the outcome variable (see Table 12). Covariates (parents' age, gender, annual income, relationship status, and admission status) were entered as a set in Step 1; perceived uncertainty scores were entered in Step 2; and Threat subscale scores were entered in Step 3. Results of the overall model were significant,  $F(8, 65) = 9.26, p = .000$ , and accounted for 53% of the variance in parents' ASD symptoms,  $R^2 = .53$  (see Figure 6). In Step 2 of the model, the amount of unique variance attributed to uncertainty was significant ( $\beta = .35, t = 3.18, p = .002$ ); however, an examination of beta weights in Step 3 of the model revealed that after appraisals of threat were entered, the beta for perceived uncertainty decreased and was no longer significant ( $\beta = .14, t = 1.29, p = .20$ ). Appraisals of threat produced the only significant beta coefficient in the last



Table 12.

*Summary of Hierarchical Regression Analysis Testing Threat Appraisal as Mediator Between Uncertainty and ASD Symptoms.*

Variable	<i>df</i>	<i>R</i> <sup>2</sup>	$\Delta R^2$	$\Delta F$	<i>B</i>	<i>SE B</i>	$\beta$	<i>t</i>
Step 1	6, 67	.29	.29	4.54				
Parents' gender					-5.86	3.96	-.17	-1.48
Parents' age					-.15	.20	-.09	-.76
Dummy for relationship (single)					9.31	5.78	.26	1.61
Dummy for relationship (M/P)					-.41	4.73	-.01	-.09
Annual household income					.11	.89	.02	.12
Admission status					13.69	3.74	.38	3.66***
Step 2								
PPUS total scores	1, 66	.38	.09	10.08**	.25	.08	.35	3.18**
Step 3								
(PPUS total scores)					.10	.08	.14	1.29
Threat subscale scores	1, 65	.53	.15	20.79***	2.039	.45	.47	4.56***

Note: \*\*  $p < .003$ , \*\*\* $p < .001$

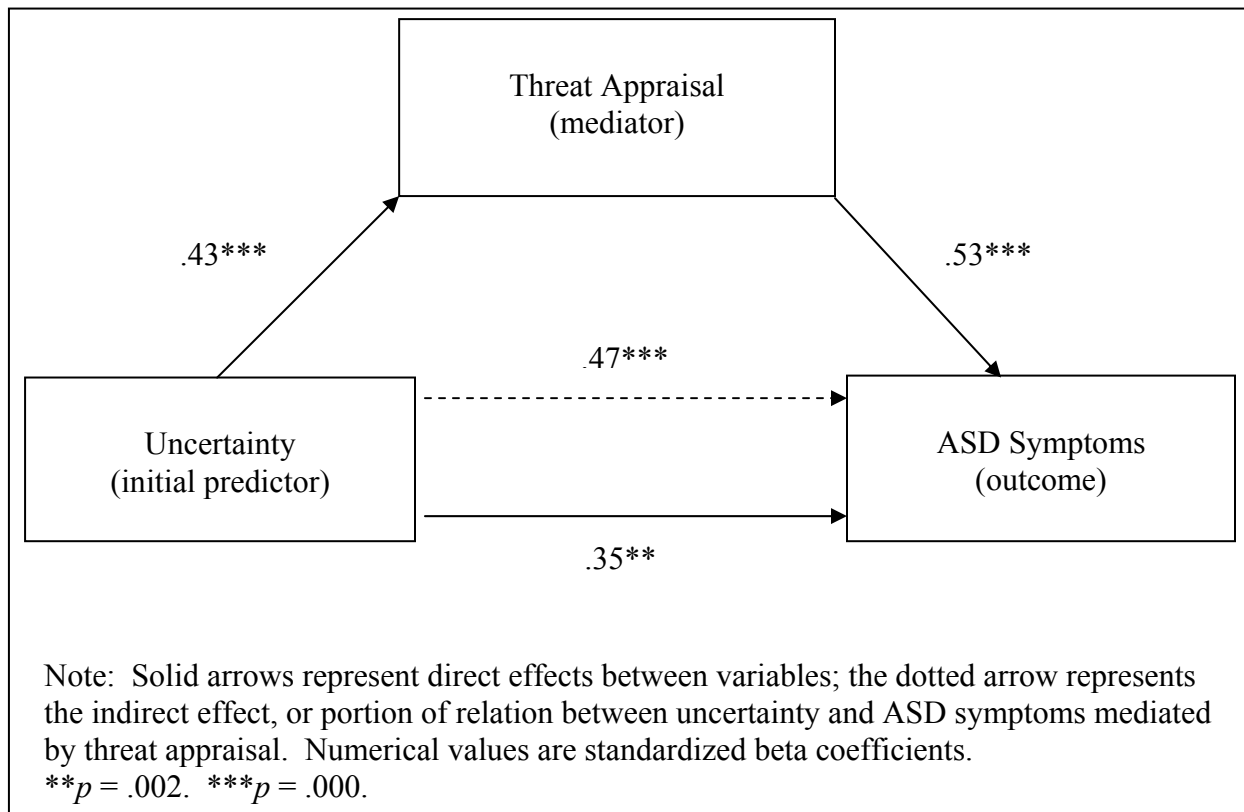


Figure 6. Illustration of mediational pathways between uncertainty, threat appraisal, and ASD symptoms.

step of the model ( $\beta = .47, t = 4.56, p = .000$ ). Because perceived uncertainty was no longer significant after controlling for appraisals of threat, these results support a finding of full mediation. A Sobel test conducted on the indirect effect showed that the portion of the relation between uncertainty and ASD symptoms mediated by threat appraisals was significant (Sobel's  $z = 2.87, p = .004$ ). Therefore, this hypothesis was soundly supported.

### Discussion

The purpose of this study was to examine the relations between illness-related uncertainty, primary appraisal, and symptoms of acute stress in parents of children admitted to a

PICU. Using Lazarus's (1999) theory of emotion and stress as a theoretical framework, and a temporal conceptualization of PICU hospitalization as a peri-traumatic event (Kazak et al., 2006), uncertainty and primary appraisals of threat, challenge, and centrality were examined separately as predictors of ASD symptoms. A mediational model was tested to determine the extent to which primary appraisal mediated the relation between uncertainty and ASD symptoms. Ancillary aims were to assess the degree to which parents perceived uncertainty in the PICU environment, and to determine the prevalence of ASD among parents in this setting.

### **Descriptive Findings**

Results from descriptive analyses confirm a high prevalence rate of ASD in parents shortly after their child's PICU admission. Fifty-seven percent of parents in the current sample met diagnostic criteria for ASD. This prevalence rate is notably higher than the 32% prevalence rate documented in an earlier study conducted among a similar sample of parents (Balluffi et al., 2004). One probable reason for these seemingly discrepant prevalence rates is the difference in the percentages of unexpected admissions versus planned admissions between Balluffi and colleagues' sample and the current study. In both samples, parents of children who were admitted to a PICU unexpectedly experienced significantly more severe ASD symptoms than parents of children whose PICU admission was planned. However, in the Balluffi study, just 30% of admissions were unexpected compared to 77.9% in the current sample. Unexpected admission status was a robust predictor of (a) higher degrees of uncertainty, (b) greater appraisals of threat and centrality, and (c), more severe ASD symptoms. Based on available information, it is not readily apparent why the ratio of unexpected to planned admissions is so different in the two samples. The number of PICU beds in the Balluffi study was greater than the current sample (38 versus 14), but both studies took place in Level I PICUs located within

teaching hospitals. Analyses of hospital trends show that the median number of admissions per bed is not statistically different based on the size of the PICU itself (Odetola et al., 2005), and on average, most PICU admissions occur unexpectedly (Aldridge, 2005). Therefore, the higher prevalence rate of acute stress symptoms and ASD in the current sample may be more accurate.

An additional reason that may account for perhaps a very small amount of the difference in ASD prevalence rates between the two samples is that Balluffi and colleagues (2004) screened potential participants for preexisting, acute psychiatric symptoms prior to enrolling parents in their study; parents who reported a history of psychiatric symptoms were excluded from participating. Pre-existing factors that have been linked to an increased likelihood of developing ASD after a traumatic event include a history of psychiatric symptoms and diagnoses (e.g., Fuglsang, Moergeli & Schnyder, 2004). In the current study, parents' mental health history was not assessed and therefore, it is possible that some parents had preexisting psychiatric symptoms.

Descriptive analyses revealed that parents perceived a high degree of uncertainty associated with their child's PICU hospitalization. Although a moderately high degree of uncertainty appears to be an ongoing component of parents' experiences of both acute and chronic pediatric conditions across all phases, the level of perceived uncertainty in the current sample seems somewhat higher compared to studies of later stages of a pediatric medical event. Cohen (1995) suggests that ongoing, rapid advances in medical technology have increased perceptions of uncertainty as part of the overall illness experience. Therefore, uncertainty may be more pronounced in a PICU setting.

### **Hypotheses Findings**

Three sets of hypotheses were tested to (a) evaluate the extent to which uncertainty and primary appraisal dimensions of threat, centrality, and challenge were predictive of ASD

symptoms, and (b) examine primary appraisal as a mediator of uncertainty and ASD symptoms. The first hypothesis stated that parents' perceptions of illness-related uncertainty would account for a significant portion of variance in parents' ASD symptoms. This hypothesis was soundly supported by the results. These findings are consistent with a theoretical model of parental adaptation to a PTE in the peri-trauma stage that posits pre-existing factors and characteristics of a particular event play a role in the development of PMTS (Kazak et al., 2006), and that conceptualize a link between perceived uncertainty and stress (Mishel, 1984). Uncertainty has been established as a defining characteristic of the PICU experience (e.g., Board, 2004; Turner) and identified as a source of stress for parents (Board). Both parental uncertainty and stress have been qualitatively described in numerous studies of parents of children hospitalized in a PICU (e.g., Turner et al., 1989), but this study is the first in this population to demonstrate the relation between perceived uncertainty to parents' symptoms of ASD.

The strong relations between uncertainty and parents' ASD symptoms revealed in the current study builds on earlier work done by Balluffi and colleagues' (2004) in a similar population by identifying uncertainty as a significant subjective factor related to parents' ASD symptoms. Because parents' symptoms of ASD during their child's PICU hospitalization have been related to PTSS 6 months after discharge, the current findings represent a potential target area for early intervention. Moreover, the current study confirmed unexpected admission status as the only objective, medical factor predictive of ASD symptoms, and revealed it to be significantly related to higher degrees of uncertainty.

The link between uncertainty and symptoms of ASD found in the current study is consistent with results in the broader pediatric psychology literature documenting the positive relation between parents' perceptions of uncertainty and indicators of maladaptive psychological

outcomes during active, ongoing and longer-term phases of a pediatric medical event (e.g., Bonner et al., 2006; Fedele et al., 2011; Fuemmeler et al., 2001; Holm et al., 2008; Stuber & Shemesh, 2006). However, it must be noted here that the literature also contains evidence relating uncertainty to positive indicators of adjustment. For example, long-term uncertainty was related to less overall psychological distress in parents of children diagnosed with brain tumors (Bonner et al., 2006); the researchers concluded that because of the potential for unique physical and psychosocial consequences of a pediatric brain tumor diagnosis, uncertainty about longer-term outcomes represented hope for optimal recovery. These disparate outcomes underscore theoretical conceptualizations of the important role that characteristics of events play in the process of adjustment (Lazarus, 1999), as well as in determining PMTS (Kazak et al., 2006).

In the second set of hypotheses, primary appraisal dimensions of threat, centrality, and challenge were examined as predictors of ASD symptoms. Increased threat and centrality appraisals were expected to be related to more severe ASD symptoms, whereas increased challenge appraisals were posited to predict less severe symptoms. As hypothesized, threat appraisals accounted for a significant portion of variance in parents' ASD symptoms after controlling for covariates; therefore, this specific hypothesis was soundly supported.

The strong relation between threat appraisals and parents' ASD symptoms is consistent with Lazarus's (1999) conceptualization of the direct connection between emotional states and appraisals comprising core relational themes. The core relational theme for the emotional state of anxiety is uncertain, existential threat (Lazarus). Hence, the direct relation documented here between appraisals of threat and parents' ASD symptoms is congruent with emotion and stress theory (Lazarus). Although some studies have not defined perceived threat as a primary appraisal per se, the degree to which parents rated their child's life as threatened by a serious

medical event predicted ASD symptom severity in parents of children hospitalized in a PICU (Balluffi et al., 2004) and parents of children newly diagnosed with cancer (Kassam-Adams et al., 2009).

The role of primary appraisal in parental adjustment to a child's critical care hospitalization is thus far, virtually unstudied. By establishing a link between parents' appraisals of threat and ASD symptoms, this study addressed a gap in the pediatric psychology literature noted by Kazak and colleagues (2008) that most research to that point had assumed certain medical events were traumatic, but had not examined individual differences in perception. The current findings confirm that a child's PICU hospitalization is a threatening, traumatic event for parents, and support the appropriateness of conceptualizing the event within a PMTS framework.

It is interesting to note that once again, unexpected admission status was the only objective medical status variable significantly linked to the variables tested, threat appraisal and ASD symptoms. These findings highlight the transactional dynamic between objective characteristics of an event and individual differences in subjective experience, as well as point to an area for further research.

Neither centrality nor challenge appraisals were significantly related to parents' ASD symptoms. The variance in ASD symptoms accounted for by appraisals of centrality trended towards significance, suggesting the possibility that increased statistical power may have resulted in finding a small, but significant, positive relation between the two variables. Although results from the regression equation testing challenge appraisals as a predictor of ASD symptoms were insignificant, negative beta weights indicated that the direction of the relation between the variables was as hypothesized, i.e., as challenge appraisals increased, ASD symptoms decreased. Again, a larger sample size may have provided enough statistical power to determine more

conclusively whether any significant relation between these dimensions of appraisal and ASD symptoms was there to be found.

Overall, this pattern of results is consistent with findings reported by Reichman and colleagues (2000) and Kennedy and colleagues (2009) wherein threat appraisals were related to psychological adjustment outcomes, but other primary appraisal dimensions were not. One possible explanation for this pattern is the impact that situational factors and characteristics of particular settings may have on the appraisal process (Lazarus & Folkman, 1987; Mishel, 1990; Monat et al., 1972). Objective, situational components that have been associated with appraisals of threat are (a) clear danger, (b) imminence of the event, and (c) how likely something is to occur (Paterson & Neufeld, 1987, cited in Lazarus, 1991). Because the main focus of pediatric critical care is to sustain physiological functions vital to survival, children admitted to a PICU are clearly in some type of imminent danger; therefore, appraisals of threat may be higher, and may supersede appraisals of challenge and centrality at that point.

Another plausible explanation for this pattern of results is suggested by Lazarus's theoretical conceptualizations of emotion and core relational themes, is that the core relational themes of challenge and centrality are incongruent with ASD, i.e., anxiety. Appraisals of centrality are defined as the significance of what is happening in terms of an individual's goals, especially the potential for negative, long-term consequences; challenge appraisals refer to an optimistic sense that adversity can be overcome and positive outcomes will ensue. Appraisals of centrality and challenge are therefore perhaps more congruent with the relational theme of hope: *fearing the worst, but yearning for better* (Lazarus, 1999, p. 96). Since ASD symptoms were the only indicator of psychological adaptation measured, this suggests an area for future research.



A final hypothesis tested a mediational model wherein primary appraisal was posited to be the mechanism, or process, through which uncertainty was linked to ASD symptoms. In order to test a mediational model, it is first necessary to determine if significant, direct relations exist between the variables. Results established that threat appraisals were related to ASD symptoms, but centrality and challenge appraisals were not. Therefore, only threat appraisals were examined in a mediator role. Consistent with the hypothesis, threat appraisals fully mediated the effect of uncertainty on ASD symptoms. In other words, it is not the mere presence or perception of uncertainty that impacts adjustment, but rather how perceived uncertainty is appraised. The significance of threat appraisal as a mediator between uncertainty and symptoms of ASD is consistent with Lazarus's theory of stress and emotion (1999), as well as his assertion that appraisal, not knowledge (i.e., uncertainty), was most proximal to emotion. He emphasized the importance of differentiating between knowledge and appraisal and explained appraisal as the process of determining the personal significance (or meaning) of whatever knowledge one possesses. Therefore, if uncertainty is defined simply as something one doesn't know, and appraisal as the process that attaches personal meaning to what isn't known, it becomes conceptually clear how uncertainty can be related to a range of both positive and negative indicators of adjustment.

### **Implications for Theory and Research**

Theoretical models used as frames of reference in the current study reflect common conceptualizations of the importance of objective and subjective individual differences related to pre-existing factors and situational characteristics in determining emotional adjustment in both the short- and longer-term (Kazak et al., 2006; Lazarus, 1999; Lazarus & Folkman, 1984). The strong links revealed between unexpected admission status and all three variables used as

outcome measures, i.e., uncertainty, threat appraisal, and ASD symptoms, represents an important contribution to understanding the dynamic interplay between objective and subjective individual differences.

Results of the current study showing the extent to which uncertainty predicted threat appraisals, and in turn, how threat appraisals accounted for the relation between uncertainty and ASD symptoms, highlights a potentially confusing aspect of the conceptual definition of illness-related uncertainty as “inability to assign meaning” (Mishel, 1984, 1990). UIT has evolved over time and at one point, was reconceptualized to incorporate a decade of research findings, but the basic definition of illness-related uncertainty hasn’t changed, i.e., one can’t figure out what something means. A sequential examination of the premises that (a) illness-related uncertainty is the inability to assign meaning, and (b), appraisal is the process wherein meaning is determined, leads one to suppose that uncertainty and appraisal should not show a positive relation. Although results have consistently supported a relation between uncertainty and indicators of maladaptive adjustment, few have been able to explain how an essentially neutral factor becomes so strongly linked to psychological distress. But, results from this study wherein parents perceived a great deal of uncertainty, *and* that uncertainty was directly related to increased appraisals of threat, it is logically reasonable to infer that parents *had* assigned a meaning to uncertainty, and that meaning was fairly ominous.

Uncertainty as defined in the UIT model (Mishel, 1981, 1990) has been the focus of numerous studies of adjustment across a range of health issues (e.g., (Carpentier et al., 2006). It is important to keep in mind that the process of adjustment depicted in UIT (Mishel, 1990) emphasizes uncertainty as a neutral, individual difference variable subject to different interpretations at different times. Unfortunately, a careful review of the literature reveals a

number of instances where the conceptualization of illness-related uncertainty has been misinterpreted and often confounded by attaching an appraisal dimension, i.e., an evaluative component, to what is supposed to be a neutral variable. For example, uncertainty has been defined as subjective distress and pervasive fear (Bonner, et al., 2006), and has been conceptualized as a cognitive appraisal variable (Carpentier et al.) that needs to be reduced in order to facilitate optimal parental adaptation (Fedele et al., 2011).

Studies of illness-related uncertainty often conclude by calling for interventions aimed at reducing uncertainty by providing education about relevant diagnoses, treatments, and controllable aspects of chronic illness, thereby helping parents better manage perceived uncertainty by (e.g., Carpentier et al., 2006). Although parents want accurate, honest information, they are often overwhelmed at crisis points and experience stress from too much information given all at once (Jackson et al., 2007). Further research should focus on examining how various sources of uncertainty are appraised, as well as how different primary appraisal patterns are related to both positive and negative adjustment outcomes.

### **Implications for Clinical Practice**

In health psychology, much of the onus of adaptive versus maladaptive adjustment is placed on the extent to which individuals can cope effectively with medical challenges, including uncertainty (e.g., Mishel, 1990); unfortunately, the time available for interventions with an in-hospital population is unpredictable and typically, very brief. Therefore, it may be more practical for in-hospital interventions to target one or two simple thoughts, rather than attempt to teach new coping skills. The PMTS model provides a framework for (a) conceptualizing and understanding how children and families adapt to pediatric medical challenges across time, and (b), guiding the development of phase-specific interventions aimed at reducing the prevalence

and severity of PMTS. The overall goal of interventions in the peri-trauma phase is to change an individual's subjective experience. By assessing how parents are thinking about uncertainty, it may help both parents and medical staff to discriminate between areas of uncertainty that are realistically somewhat threatening and those that are more benign.

### **Strengths and Limitations**

**Strengths.** A particular strength of this study was that hypothesized relations between variables were solidly grounded in common, core aspects of Lazarus and Folkman's (1984) transactional theory of stress and coping, Lazarus's (1999) theory of stress and emotions, and Mishel's cognitive appraisal model of uncertainty in illness (Mishel, 1984, 1990). Moreover, the PMTS model (Kazak et al., 2006) was used as a temporal reference point for a child's PICU admission to further define the current study in terms of theoretical relevance. Findings added to the body of knowledge pertaining to these theories, especially in terms of commonalities between conceptualizations of pathways to adjustment. Moreover, findings shed light on some potentially confusing interpretations of theoretical definitions in the literature and how this can contribute to seemingly contradictory conclusions.

Another particular strength was the extent to which the study's aims addressed gaps in the pediatric psychology literature. This study examined primary appraisal, a variable that figures prominently in the above referenced theories, but is often overlooked despite solid evidence in the literature that parents' subjective experiences are more reliable predictors of adjustment than objective medical characteristics. Second, there is an unfortunate lack of psychosocial research conducted among heterogeneous pediatric groups focused on understanding common factors related to parents' psychosocial adjustment. Children are admitted to PICUs for medical crises ranging from chronic asthma exacerbations to acute renal

and liver failure. On any given day, it is common to find pediatric critical care providers responsible for treating children with brain tumors and other pediatric cancers, low blood counts stemming from lupus, severe burns, shunt failures, infection, following heart surgery and transplant procedures, massive head injuries, and diabetic ketoacidosis. By concentrating on a particular medical setting, rather than a specific disease or injury group, this study contributed to knowledge of common factors relevant in the peri-trauma phase.

Measures chosen for this study were well-validated and theoretically well-matched to the rationale for the development of the hypotheses tested. Reliability analyses confirmed that measures used performed equally reliably in the present sample. The literature reflects numerous studies where parents' appraisals are assessed with a single item; therefore, results from the current study provide support for extant literature.

**Limitations.** The present study had several limitations. First, the cross-sectional design represents a simple snapshot of a dynamic, reiterative process of adjustment as depicted in Lazarus's theory of stress and emotion (1999). Moreover, this study examined just a small portion of the overall conceptual model. Second, the current sample is best characterized as one of convenience in that a percentage of eligible parents were missed during the data collection phase simply because they weren't in the PICU, or were otherwise unavailable when the researcher was there. For example, parents were sometimes asleep, engaged in telephone conversations, or had stepped away for a break. Some parents were only able to come to the PICU late at night because of work schedules, or because they were needed at home to care for their other children. This is a common challenge for researchers in medical settings, and although every reasonable effort was made to contact all eligible parents, this wasn't possible. Therefore, external validity was somewhat reduced.

Third, statistical power to detect small, meaningful differences was reduced due to a smaller than optimal sample size and more covariates than anticipated. This was particularly true for hypothesis 2b, testing the relation between centrality appraisal and ASD symptoms. Results were trending towards significance, but the observed effect size was small. It is possible that with a larger sample a meaningful difference may have been detected. Also, it should be noted that despite the common statistical terminology used herein describing a mediational model as a causal pathway, causal inferences based on this study's results are inappropriate.

Fourth, with the exception of PIM2 scores, all study variables were measured using self-report instruments. Although a diagnostic interview for ASD would have been methodologically ideal, this was highly impractical given the PICU environment. All the self-report measures used were well-validated, were chosen specifically for their brevity in order to minimize the burden on parents, and performed reliably in this sample.

## **Conclusion**

This study addressed notable gaps in the literature related to parental adjustment in the early, immediate stage of a potentially, traumatic medical event. Results establish that a child's PICU admission is a traumatic event for parents, characterized by a great deal of uncertainty that is appraised as very threatening. Pre-existing factors and characteristics pertaining to specific events or settings are emphasized as important variables in the appraisal process (Lazarus, 1999), and as potential contributors to the development of PMTS (Kazak et al., 2006). Parents' perceptions of illness-related uncertainty measured at various time points across a range of pediatric diagnoses indicate that uncertainty is an inherent part of both acute and chronic pediatric medical conditions. As a pre-existing factor, children's unexpected admission was the only objective medical variable that significantly predicted perceived uncertainty, appraisals of

threat, and symptoms of ASD. These measures of parents' subjective experiences each predicted significant variance in parents' symptoms of ASD; but perhaps most importantly, this study demonstrated that threat appraisals were the process through which uncertainty and ASD were linked.

Furthermore, the current study provided support for key theories of adaptation and contributed to a clearer understanding of certain theoretical conceptualizations. Although there is a substantial body of empirical research that consistently supports a relation between uncertainty and indicators of maladaptive adjustment, there are also studies that link uncertainty to positive outcomes. Results of this study demonstrate that threat appraisal is a crucial cognitive process that acts to mediate the relation between uncertainty and ASD symptoms.

Given the high rate of severe acute stress reactions, and the connection between parents' adjustment and child outcomes, it is imperative that more be done to support parents in this environment. Results from this study identified a meaningful, practical target in terms of subjective experience for intervention in the peri-trauma phase. More effective interventions at this point may help reduce ASD symptoms and ultimately, may be able to reduce rates of longer-term PTSD. It is important to note that only ASD symptoms were examined as an indicator of adjustment outcomes. Future research focused on how various sources of uncertainty are appraised, and how in turn different appraisals are related to other indicators of adjustment, especially positive, is needed. When viewed comprehensively, these findings contribute to the literature establishing the significance of relations between objective and subjective individual differences and pediatric medical traumatic stress.

## List of References

- Alderfer, M. A., Cnaan, A., Annunziato, R. A., & Kazak, A. E. (2005). Patterns of posttraumatic stress symptoms in parents of childhood cancer survivors. *Journal of Family Psychology, 19*(3), 430 – 440.
- Aldridge, M. D. (2005). Decreasing parental stress in the pediatric intensive care unit: One unit's experience. *Critical Care Nurse, 25*(6), 40 – 50.
- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (Revised 4<sup>th</sup> ed.). Washington, DC: Author.
- Balluffi, A., Kassam-Adams, N., Kazak, A., Tucker, M., Dominguez, T., & Helfaer, M. (2004). Traumatic stress in parents of children admitted to the pediatric intensive care unit. *Pediatric Critical Care Medicine, 5*(6), 547 – 553.
- Baron, R. M. & Kenny, D. A. (1986). The moderator-mediator variable distinction in social psychological research: Conceptual, strategic, and statistical considerations. *Journal of Personality and Social Psychology, 51*(6), 1173 – 1182.
- Barrera, M., D'Agostino, N. M., Gibson, J., Gilbert, T., Weksberg, R., & Malkin, D. (2004). Predictors and mediators of psychological adjustment in mothers of children newly diagnosed with cancer. *Psycho-Oncology, 13*, 630 – 641.
- Berenbaum, J. & Hatcher, J. (1992). Emotional distress of mothers of hospitalized children. *Journal of Pediatric Psychology, 17*(3), 359 – 372.
- Best, M., Streisand, R., Catania, L., & Kazak, A. E. (2001). Parental distress during pediatric leukemia and posttraumatic stress symptoms after treatment ends. *Journal of Pediatric Psychology, 26*(5), 299 – 307.
- Board, R. (2004). Father stress during a child's critical care hospitalization. *Journal of Pediatric Health Care, 18*, 244 – 249.
- Board, R. & Ryan-Wenger, N. (2003). Stressors and stress symptoms of mothers with children in the PICU. *Journal of Pediatric Nursing, 18*(3), 195 – 202.
- Boman, K. K., Viksten, J., Kogner, P., & Samuelsson, U. (2004). Serious illness in childhood: The different threats of cancer and diabetes from a parent perspective. *The Journal of Pediatrics, 145*, 373 – 379.
- Bonner, M. J., Hardy, K. K., Guill, A. B., McLaughlin, C., Schweitzer, H., & Carter, K. (2006). Development and validation of the parent experience of child illness. *Journal of Pediatric Psychology, 31*(3), 310 – 321.



- Bouso, R. S. & Angelo, M. (2003). The family in the intensive care unit: Living the possibility of losing a child. *Journal of Family Nursing*, 9(2), 212 – 221.
- Briassoulis, G., Filipou, O., Natsi, L., Mavrikiou, M., & Hatzis, T. (2004). Acute and chronic paediatric intensive care patients: Current trends and perspectives on resource utilization. *QJM*, 97, 507 – 518.
- Bronner, M. B., Knoester, H., Bos, A. P., Last, B. F., & Grootenhuis, M. A. (2007). Follow-up after paediatric intensive care treatment: parental posttraumatic stress. *Acta Paediatrica*, 97, 181 – 186.
- Bryant, R. A. (2005). Predicting posttraumatic stress disorder from acute reaction. *Journal of Trauma and Dissociation*, 6(2), 5 – 15.
- Bryant, R. A., Friedman, M. J., Spiegel, D., Ursano, R., & Strain, J. (2011). A review of acute stress disorder in DSM-5. *Depression and Anxiety*, 28, 802 – 817.
- Bryant, R. A., Moulds, M. L., & Guthrie, R. M. (2000). Acute stress disorder scale: A self-report measure of acute stress disorder. *Psychological Assessment*, 12(1), 61 – 68.
- Carpentier, M. Y., Mullins, L. L., Chaney, J. M., & Wagner, J. L. (2006). The relationship of illness uncertainty and attributional style to long-term psychological distress in parents of children with type 1 diabetes mellitus. *Children's Health Care*, 35(2), 141 – 154.
- Carter, M. C. & Miles, M. S. (1989). The parental stressor scale: Pediatric intensive care unit. *Maternal-Child Nursing Journal*, 18(3), 187 – 198.
- Carter, M. A. & Robinson, S. S. (2001). A narrative approach to the clinical reasoning process in pediatric intensive care: The story of Matthew. *Journal of Medical Humanities*, 22(3), 173 – 194.
- Cohen, M. H. (1993a). Diagnostic closure and the spread of uncertainty. *Issues in Comprehensive Pediatric Nursing*, 16(3), 135 – 146.
- Cohen, M. H. (1993b). The unknown and the unknowable – managing sustained uncertainty. *Western Journal of Nursing Research*, 15(1), 77 – 96.
- Cohen, M. H. (1995). The triggers of heightened parental uncertainty in chronic, life-threatening childhood illness. *Qualitative Health Research*, 5(1), 63 – 77.
- Colville, G. A. & Gracey, D. (2006). Mothers' recollections of the paediatric intensive care unit: Associations with psychopathology and views on follow-up. *Intensive and Critical Care Nursing*, 22, 49 – 55.
- Crnica, K. A., Greenberg, M. T., Ragozin, A. S., Robinson, N. M., & Basham, R. B. (1983).

Effects of stress and social support on mothers and premature and full-term infants. *Child Development*, 54, 209 – 217.

- DeMaso, D. R. & Meyer, E. C. (1996). A psychiatric consultant's survival guide to the pediatric intensive care unit. *Journal of the American Academy of Child & Adolescent Psychiatry*, 34(10), 1411 – 1413.
- Fedele, D. A., Ramsey, R. R., Ryan, J. L., Bonner, M. S., Mullins, L. L., Jarvis, J. N., & Chaney, J. M. (2011). The association of illness uncertainty to parent and youth adjustment in juvenile rheumatic diseases: Effect of youth age. *Journal of Developmental Behavioral Pediatrics*, 32, 361 – 367.
- Fuemmeler, B. F., Mullins, L. L., & Marx, B. P. (2001). Posttraumatic stress and general distress among parents of children surviving a brain tumor. *Children's Health Care*, 30(3), 169 – 182.
- Hall, E., E., Saxe, G., Stoddard, F., Kaplow, J., Koenen, K., Chawla, N., Lopez, C., King, L., & King, D. (2006). Posttraumatic stress symptoms in parents of children with acute burns. *Journal of Pediatric Psychology*, 31(4), 403 – 412.
- Harvey, A. G. & Bryant, R. A. (2002). Acute stress disorder: A synthesis and critique. *Psychological Bulletin*, 128(6), 886 – 902.
- Himmelstein, B. P., Hilden, J. M., Boldt, A. M., & Weissman, D. (2004). Pediatric palliative care. *New England Journal of Medicine*, 350(17), 1752 – 1762.
- Horsch, A., McManus, F., Kennedy, P., & Edge, J. (2007). Anxiety, depressive, and posttraumatic stress symptoms in mothers of children with type 1 diabetes. *Journal of Traumatic Stress*, 20(5), 881 – 891.
- Jackson, A. C., Stewart, H., O'Toole, M., Tokatlian, N., Enderby, K., Miller, J., & Ashley, D. (2007). Pediatric brain tumor patients: Their parents' perceptions of the hospital experience. *Journal of Pediatric Oncology Nursing*, 24(2), 95 – 105.
- Janoff-Bulman, R. (1992). *Shattered assumptions: Towards a new psychology of trauma*. New York: The Free Press.
- Johnson, P. A., Nelson, G. L., & Brunnequell, D. J. (1988). Parent and nurse perceptions of parent stressors in the pediatric intensive care unit. *Child Health Care*, 17(2), 98 – 105.
- Kassam-Adams, N., Fleisher, C. L., & Winston, F. K. (2009). Acute stress disorder and posttraumatic stress disorder in parents of injured children. *Journal of Traumatic Stress*, 22(4), 294 – 302.
- Kazak, A. E., Barakat, L., Meeske, K., Christakis, D., Meadows, A., Casey, R. et al. (1997).

- Posttraumatic stress, family functioning, and social support in survivors of childhood leukemia and their mothers and fathers. *Journal of Consulting & Clinical Psychology*, 65(1), 120 – 129.
- Kazak, A. E., Boeving, C. A., Alderfer, M. A., Hwang, W., & Reilly, A. (2005). Posttraumatic stress symptoms during treatment in parents of children with cancer. *Journal of Clinical Oncology*, 23(30), 7405 – 7410.
- Kazak, A. E., Kassam-Adams, N., Schneider, S., Zelikovsky, N., Alderfer, M. A., & Rourke, M. (2006). An integrative model of pediatric medical traumatic stress. *Journal of Pediatric Psychology*, 31(4), 343 – 355.
- Kazak, A., Stuber, M., Barakat, L., Meeske, K., Guthrie, D., & Meadows, A. (1998). Predicting posttraumatic stress symptoms in mothers and fathers of survivors of childhood cancers. *Journal of the American Academy of Child and Adolescent Psychiatry*, 37(8), 823 – 831.
- Kennedy, P., Evans, M., & Sandhu, N. (2009). Psychological adjustment to spinal cord injury: The contribution of coping, hope, and cognitive appraisals. *Psychology, Health, & Medicine*, 14(1), 17 – 33.
- Koocher, G. P. (1985). Treatment of the child with life-threatening illness. *Psychotherapy in Private Practice*, 3(4), 75 – 87.
- Kupst, M. J. & Schulman, J. L. (1988). Long-term coping with pediatric leukemia: A six-year follow-up study. *Journal of Pediatric Psychology*, 13(1), 7 – 22.
- LaMontagne, L. L., Hepworth, J. T., Johnson, B. D., & Deshpande, J. K. (1994). Psychophysiological responses of parents to pediatric critical care stress. *Clinical Nursing Research*, 3(2), 104 – 118.
- LaMontagne, L. L. & Pawlak, R. (1990). Stress and coping of parents in a pediatric intensive care unit. *Heart Lung*, 19(4), 416 – 421.
- Landolt, M. A., Vollrath, M., Ribi, K., Gnehm, H. E., & Sennhauser, F. H. (2003). Incidence and associations of parental and child posttraumatic stress symptoms in pediatric patients. *Journal of Child Psychology and Psychiatry*, 44(8), 1199 – 1207.
- Latour, J. M., van Goudoever, J. B., & Hazelzet, J. A. (2008). Parent satisfaction in the pediatric ICU. *Pediatric Clinics of North America*, 5, 775 – 790.
- Lazarus, R. S. (1991). *Emotion and adaptation*. New York: Oxford University Press, Inc., [Amazon Kindle Editions version].
- Lazarus, R. S. (1993). From psychological stress to the emotions: A history of changing outlooks. *Annual Review of Psychology*, 44, 1 – 21.

- Lazarus, R. S. (1999). *Stress and emotion: A new synthesis*. New York: Springer.
- Lazarus, R. S. & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer.
- Lazarus, R. S. & Folkman, S. (1987). Transactional theory and research on emotions and coping. *European Journal of Personality*, 1, 141 – 169.
- Maes, S., Leventhal, H., & de Ridder, D. T. (1996). Coping with chronic diseases. In M. Zeidner & N. S. Endler (Eds.) *Handbook of coping: Theory, research, applications*. Oxford: John Wiley & Sons.
- Maikranz, J. M., Steele, R. G., Dreyer, M. L., Stratman, A. C., & Bovaird, J. A. (2007). The relationship of hope and illness-related uncertainty to emotional adjustment and adherence among pediatric renal and liver transplant recipients. *Journal of Pediatric Psychology*, 32(5), 571 – 581.
- Manne, S. L., DuHamel, K., Gallelli, K., Sorgen, K., & Redd, W. H. (1998). Posttraumatic stress disorder among mothers of pediatric cancer survivors: Diagnosis, comorbidity, and utility of the PTSD Checklist as a screening instrument. *Journal of Pediatric Psychology*, 23(6), 357 – 366.
- Manne, S., DuHamel, K., & Redd, W. H. (2000). Association of psychological vulnerability factors to post-traumatic stress symptomatology in mothers of pediatric cancer survivors. *Psycho-Oncology*, 9, 372 – 384.
- McCarthy, M. C., Ashley, D. M., Lee, K. J., & Anderson, V. A. (2012). Predictors of acute and posttraumatic stress symptoms in parents following their child's cancer diagnosis. *Journal of Traumatic Stress*, 25, 558 – 566.
- McNally, R. J. (1999). Posttraumatic stress disorder. In T. Millon, P. H. Blaney, & R. D. Davis (Eds.), *Oxford textbook of psychopathology* (pp. 144 – 165). New York: Oxford University Press.
- Meiers, S. & Tomlinson, P. S. (2003). Family-nurse co-construction of meaning: A central phenomenon of family caring. *Scandinavian Journal of Caring Science*, 17, 193 – 201.
- Melamed, B. G., Kaplan, B., & Fogel, J. (2001). Childhood health issues across the life span. In *Handbook of Health Psychology*, A. Baum, T.A. Revenson, & J. E. Singer (Eds.). New Jersey: Lawrence Erlbaum Associates.
- Melnyk, B. M., Alpert-Gillis, L., Feinstein, N. F., Crean, H. F., Johnson, J., Fairbanks, E., et al. (2004). Creating opportunities for parent empowerment: Program effects on the mental health/coping outcomes of critically ill young children and their mothers. *Pediatrics*, 113(6), 597 – 607.

- Meyer, E. C., DeMaso, D. R., & Koocher, G. P. (1996). Mental health consultation in the pediatric intensive care unit. *Professional Psychology: Research and Practice, 27*(2), 130 – 136.
- Meyer, E. C., Snelling, L. K., & Myren-Manbeck, L. K. (1998). Pediatric intensive care: The parents' experience. *AACN Clinical Issues, 9*(1), 64 – 74.
- Miles, M. S. & Carter, M. C. (1982). Sources of parental stress in pediatric intensive care units. *Child Health Care, 11*(2), 65 – 69.
- Miles, M. S. & Carter, M. C. (1983). Assessing parental stress in intensive care units. *Maternal Child Nursing Journal, 8*, 354 – 359.
- Miles, M. S. & Carter, M. C. (1985). Coping strategies used by parents during their child's hospitalization in an intensive care unit. *Child Health Care, 14*(1), 14 – 21.
- Miles, M. S., Carter, M. C., Eberly, T. W., Hennessey, J., & Riddle, I. I. (1989). Toward an understanding of parent stress in the pediatric intensive care unit: An overview of the program of research. *Maternal-Child Nursing Journal, 18*(3), 181 – 185.
- Miles, M. S. & Mathes, M. (1991). Preparation of parents or the ICU experience: What are we missing? *Child Health Care, 20*(3), 132 – 137.
- Mishel, M. H. (1981). The measurement of uncertainty in illness. *Nursing Research, 30*(5), 258 – 263.
- Mishel, M. H. (1983). Parents' perception of uncertainty concerning their hospitalized child. *Nursing Research, 32*(6), 324 – 330.
- Mishel, M. H. (1984). Perceived uncertainty and stress in illness. *Research in Nursing and Health, 7*, 163 – 171.
- Mishel, M. H. (1988). Uncertainty in illness. *IMAGE: Journal of Nursing Scholarship, 20*(4), 225 – 232.
- Mishel, M. H. (1990). Reconceptualization of the uncertainty in illness theory. *Image – The Journal of Nursing Scholarship, 22*(4), 256 – 62.
- Mishel, M. H. & Braden, C. J. (1988). Finding meaning: Antecedents of uncertainty in illness. *Nursing Research, 37*(2), 98 – 103, 127.
- Mu, P. F. & Tomlinson, P. (1997). Parental experience and meaning construction during a pediatric health crisis. *Western Journal of Nursing Research, 19*(5), 608 – 636.
- National Child Traumatic Stress Network (n.d.). *Medical trauma*. Retrieved September 1, 2008 from [http://nctsnet.org/ncts/nav.do?pid=typ\\_mt](http://nctsnet.org/ncts/nav.do?pid=typ_mt).

- Noyes, J. (1998). A critique of studies exploring the experiences and needs of parents of children admitted to paediatric intensive care units. *Journal of Advanced Nursing*, 28(1), 134 – 141.
- Odetola, F. O., Clark, S. J., Freed, G. L., Bratton, S. L., & Davis, M. M. (2005). A national survey of pediatric critical care resources in the United States. *Pediatrics*, 115(4), e382 – e386.
- Page, M. C., Fedele, D. A., Pai, A. L., Anderson, J., Wolfe-Christensen, C., Ryan, J. L., et al. (2012). The relationship of maternal and child illness uncertainty to child depressive symptomology: A mediational model. *Journal of Pediatric Psychology*, 37(1), 97 – 105.
- Pakenham, K. I. (2005). Benefit finding in multiple sclerosis and associations with positive and negative outcomes. *Health Psychology*, 24(2), 123 – 132.
- Pakenham, K. I. & Rinaldis, M. (2001). The role of illness, resources, appraisal, and coping strategies in adjustment to HIV/AIDS: The direct and buffering effects. *Journal of Behavioral Medicine*, 24(3), 259 – 279.
- Patiño-Fernández, A. M., Pai, A. L., Alderfer, M., Hwang, W. T., Reilly, A., & Kazak, A.E. (2008). Acute stress in parents of children newly diagnosed with cancer. *Pediatric Blood Cancer*, 50, 289 – 292.
- Peacock, E. J. & Wong, P. T. (1990). The stress appraisal measure (SAM): a multidimensional approach to cognitive appraisal. *Stress Medicine*, 6, 227 – 236.
- Randolph, A. G., Gonzales, C. A., Cortellini, L., & Yeh, T. S. (2004). Growth of pediatric intensive care units in the United States from 1995 to 2001. *The Journal of Pediatrics*, 144, 792 – 798.
- Rees, G., Gledhill, J., Garralda, M. E., & Nadel, S. (2004). Psychiatric outcome following paediatric intensive care unit (PICU) admission: A cohort study. *Intensive Care Medicine*, 30, 1607 – 1614.
- Reichman, S. R. F., Miller, A. C., Gordon, R. M., & Hendricks-Munoz, K. D. (2000). Stress appraisal and coping in mothers of NICU infants. *Children's Health Care*, 29(4), 279 – 293.
- Rennick, J. E., Johnston, C. C., Dougherty, G., Platt, R., & Ritchie, J. A. (2002). Children's psychological responses after critical illness and exposure to invasive technology. *Developmental and Behavioral Pediatrics*, 23(3), 133 – 144.
- Rini, C., Manne, S., DuHamel, K., Austin, J., Ostroff, J., Boulad, F. et al. (2008). Social support

from family and friends as a buffer of low spousal support among mothers of critically ill children: A multilevel modeling approach. *Health Psychology*, 27(5), 593 – 603.

- Santacroce, S. J. (2003). Parental uncertainty and posttraumatic stress in serious childhood illness. *Journal of Nursing Scholarship*, 35(1), 45 – 51.
- Shears, D., Nadel, S., Gledhill, J., & Garralda, M. E. (2005). Short-term psychiatric adjustment of children and their parents following meningococcal disease. *Pediatric Critical Care Medicine*, 6(1), 39 – 43.
- Smith, A. B., Hefley, G. C., & Anand, K. J. (2007). Parent bed spaces in the PICU: Effect on parental stress. *Pediatric Nursing*, 33(3), 215 – 221.
- Steele, R. G., Aylward, B. S., Jensen, C. D., & Wu, Y. P. (2009). Parent- and youth-reported illness uncertainty: Associations with distress and psychosocial functioning among recipients of liver and kidney transplantations. *Children's Health Care*, 38(3), 185 – 199.
- Stewart, J. L. & Mishel, M. H. (2000). Uncertainty in childhood illness: A synthesis of the parent and child literature. *Scholarly Inquiry for Nursing Practice*, 14(4), 299 – 319.
- Stuber, M. L. & Shemesh, E. (2006). Post-traumatic stress response to life-threatening illnesses in children and their parents. *Child and Adolescent Psychiatric Clinics of North America*, 15, 597 – 609.
- Studdert, D. M., Burns, J. P., Mello, M. M., Puopolo, A. L., Truog, R. D., & Brennan, T. A. (2003). Nature of conflict in the care of pediatric intensive care patients with prolonged stay. *Pediatrics*, 112, 553 – 558.
- Sturms, L. M., van der Sluis, C. K., Stewart, R. E., Groothoff, J. W., ten Duis, H. J., & Eisma, W. H. (2005). A prospective study on paediatric traffic injuries: Health-related quality of life and post-traumatic stress. *Clinical Rehabilitation*, 19(3), 312 – 322.
- Tomlinson, P. S., Harbaugh, B. L., Kotchevar, J., & Swanson, L. (1995). Caregiver mental health and family health outcomes following critical hospitalization of a child. *Issues in Mental Health Nursing*, 16, 533 – 545.
- Tomlinson, P. S., & Mitchell, K. E. (1992). On the nature of social support for families of critically ill children. *Journal of Pediatric Nursing*, 7(6), 386 – 394.
- Tomlinson, P. S., Swiggum, P., & Harbaugh, B. L. (1999). Identification of nurse-family intervention sites to decrease health-related family boundary ambiguity in PICU. *Issues in Comprehensive Pediatric Nursing*, 22, 27 – 47.
- Turner, M. A., Tomlinson, P. S., & Harbaugh, B. L. (1990). Parental uncertainty in critical care hospitalization of children. *Maternal-Child Nursing Journal*, 19(1), 45 – 62.

- Vollrath, M., Landolt, M. A., & Ribi, K. (2004). Illness appraisals in paediatric patients and their parents: A short scale. *Swiss Journal of Psychology, 63*(1), 3 – 15.
- Ward-Begnoche, W. (2007). Posttraumatic stress symptoms in the pediatric intensive care unit. *Journal for Specialists in Pediatric Nursing, 12*(2), 84 – 92.
- Widows, M. R., Jacobsen, P. B., & Fields, K. K. (2000). Relation of psychological vulnerability factors to posttraumatic stress disorder symptomatology in bone marrow transplant recipients. *Psychosomatic Medicine, 62*, 873 – 882.
- Williams, J. & Koocher, G. P. (1999). Medical crisis counseling on a pediatric intensive care unit: Case examples and clinical utility. *Journal of Clinical Psychology in Medical Settings, 6*(3), 249 – 258.
- Winston, F. K., Kassam-Adams, N., Vivarelli-O'Neill, C., Ford, J., Newman, E., Baxt, C., et al. (2002). Acute stress disorder symptoms in children and their parents after pediatric traffic injury. *Pediatrics, 109*(6), e90 – 97.
- Woodgate, R. L. & Degner, L. F. (2002). “Nothing is carved in stone!”: Uncertainty in children with cancer and their families. *European Journal of Oncology Nursing, 6*(4), 191 – 202.
- Youngblut, J. M. & Brooten, D. (2006). Pediatric head trauma: Parent, parent-child, and family functioning 2 weeks after hospital discharge. *Journal of Pediatric Psychology, 31*(6), 608 – 618.
- Youngblut, J. M., Brooten, D., & Kuluz, J. (2005). Parents' reactions at 24 – 48 hours after a preschool child's head injury. *Pediatric Critical Care Medicine, 6*(5), 550 – 556.
- Youngblut, J. M. & Jay, S. S. (1991). Emergent admission to the pediatric ICU: Parental concerns. *AACN Clinical Issues in Critical Care Nursing, 2*, 329 – 337.



## Appendices

Appendix A

**PARENT INFORMATION FORM**

<b>ABOUT YOURSELF:</b>					
Family Member Completing Form: <input type="checkbox"/> Mother <input type="checkbox"/> Father <input type="checkbox"/> Other (please specify):					
Your Name:		First	MI	Last	
Date of Birth:	Month	Day	Yr	Your Gender:	<input type="checkbox"/> Male <input type="checkbox"/> Female
Ethnicity (please check all that apply to you): <input type="checkbox"/> Black/African Amer. <input type="checkbox"/> White <input type="checkbox"/> Hispanic <input type="checkbox"/> Asian <input type="checkbox"/> Other					
Highest Education Completed:	<input type="checkbox"/> Less than high school <input type="checkbox"/> Graduated High School /GED	<input type="checkbox"/> Some college/vocational school <input type="checkbox"/> Graduated college/vocational school	<input type="checkbox"/> Some professional/graduate school <input type="checkbox"/> Graduated professional/graduate school		
<b>WHAT IS YOUR RELATIONSHIP STATUS:</b> (PLEASE CHECK ONE OF THE BOXES BELOW)					
<input type="checkbox"/> Single	<input type="checkbox"/> Married/Partnered	<input type="checkbox"/> Separated/Divorced	<input type="checkbox"/> Other (describe):		
<b>WHAT IS YOUR APPROXIMATE ANNUAL HOUSEHOLD INCOME:</b> (PLEASE CHECK ONE OF THE BOXES BELOW)					
<input type="checkbox"/> Less than \$15,000	<input type="checkbox"/> \$15,000-\$24,999	<input type="checkbox"/> \$25,000 - \$34,999	<input type="checkbox"/> \$35,000 - \$44,999	<input type="checkbox"/> \$45,000 - \$59,000	<input type="checkbox"/> More than \$60,000
<b>ABOUT YOUR CHILD (THE PATIENT):</b>					
Why was your child admitted to the PICU?					
Was your child's admission to the PICU planned? <input type="checkbox"/> Yes <input type="checkbox"/> No					

(Thank you very much for your participation in this study)

## Appendix B

### Pediatric Index of Mortality<sup>2</sup> (PIM2)

#### PIM2 General Instructions

The PIM2 is calculated from the information collected at the time a child is admitted to an ICU. Observations recorded are those made at or about the time of first face-to-face contact between the patient and a PICU attending (or an attending from a specialist pediatric transport team). Use the first value of each variable measured within the period from the time of first contact to 1 hour after arrival in an ICU. If information is missing (e.g. base excess is not measured) record zero, except for systolic blood pressure, which should be recorded as 120.

- 
1. Systolic blood pressure, mmHg (unknown = 120)<sup>1</sup>
  2. Pupillary reactions to bright light (>3 mm and both fixed = 1, other or unknown = 0)<sup>2</sup>
  3. PaO<sub>2</sub>, mmHg (unknown = 0)  
FIO<sub>2</sub> at the time of PaO<sub>2</sub> if oxygen via ETT or headbox (unknown = 0)
  4. Base excess in arterial or capillary blood, mmol/l (unknown = 0)
  5. Mechanical ventilation at any time during the first hour in ICU (no = 0, yes = 1)<sup>3</sup>
  6. Elective admission to ICU (no = 0, yes = 1)<sup>4</sup>
  7. Recovery from surgery, or a procedure is the main reason for ICU admission (no = 0, yes = 1)<sup>5</sup>
  8. Admitted following cardiac bypass (no = 0, yes = 1)<sup>6</sup>

9. High risk diagnosis. Record the number in brackets; if in doubt record 0.

- [0] None
- [1] Cardiac arrest preceding ICU admission<sup>7</sup>
- [2] Severe combined immune deficiency
- [3] Leukemia or lymphoma after first induction
- [4] Spontaneous cerebral hemorrhage<sup>8</sup>
- [5] Cardiomyopathy or myocarditis
- [6] Hypoplastic left heart syndrome<sup>9</sup>
- [7] HIV infection
- [8] Liver failure is the main reason for ICU admission<sup>10</sup>
- [9] Neuro-degenerative disorder<sup>11</sup>

10. Low risk diagnosis. Record the number in brackets; if in doubt record 0.

- [0] None
- [1] Asthma is the main reason for ICU admission
- [2] Bronchiolitis is the main reason for ICU admission<sup>12</sup>
- [3] Croup is the main reason for ICU admission
- [4] Obstructive sleep apnoea is the main reason for ICU admission<sup>13</sup>
- [5] Diabetic keto-acidosis is the main reason for ICU admission

---

### Coding Rules

(Note: coding rules must be followed carefully for PIM2 to perform reliably.)

- 1) Record SBP as 0 if the patient is in cardiac arrest, record 30 if the patient is shocked and blood pressure is so low that it cannot be measured.
- 2) Pupillary reactions to bright light are used as an index of brain function. Do not record an abnormal finding if this is due to drugs, toxins or local eye injury.
- 3) Mechanical ventilation includes mask or nasal CPAP or BiPAP or negative pressure ventilation.
- 4) Elective admission; include admission after elective surgery or admission for an elective procedure (e.g. insertion of a central line), or elective monitoring, or review of home ventilation. An ICU admission or an operation is considered elective if it could be postponed for more than 6 hours without adverse effect.
- 5) Recovery from surgery or procedure includes a radiology procedure or cardiac catheter. Do not include patients admitted from the operating room where recovery from surgery is not the main reason for ICU admission (e.g. a patient with a head injury who is admitted from theatre after insertion of an ICP monitor; in this patient the main reason for ICU admission is the head injury).

- 6) Cardiac bypass. These patients must also be coded as recovery from surgery.
- 7) Cardiac arrest preceding ICU admission includes both in-hospital and out-of-hospital arrests. Requires either documented absent pulse or the requirement for external cardiac compression. Do not include past history of cardiac arrest.
- 8) Cerebral hemorrhage must be spontaneous (e.g. from aneurysm or AV malformation). Do not include traumatic cerebral hemorrhage or intracranial hemorrhage that is not intracerebral (e.g. subdural hemorrhage).
- 9) Hypoplastic left heart syndrome. Any age, but include only cases where a Norwood procedure or equivalent is or was required in the neonatal period to sustain life.
- 10) Liver failure, acute or chronic, must be the main reason for ICU admission. Include patients admitted for recovery following liver transplantation for acute or chronic liver failure.
- 11) Neurodegenerative disorder. Requires a history of progressive loss of milestones or a diagnosis where this will inevitably occur.
- 12) Bronchiolitis. Include children who present either with respiratory distress or central apnea where the clinical diagnosis is bronchiolitis.
- 13) Obstructive sleep apnea. Include patients admitted following adenoidectomy and/or tonsillectomy in whom obstructive sleep apnea is the main reason for ICU admission (and code as recovery from surgery).

## Appendix C

### Diagnostic Criteria for Acute Stress Disorder (*DSM-IV-TR*, 2000)

- A. The person has been exposed to a traumatic event in which both of the following were present:
- 1) the person experienced, witnessed, or was confronted with an event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others
  - 2) the person's response involved intense fear, helplessness, or horror
- B. Either while experiencing or after experiencing the distressing event, the individual has three (or more) of the following dissociative symptoms:
- 1) a subjective sense of numbing, detachment, or absence of emotional responsiveness
  - 2) a reduction in awareness of his or her surroundings (e.g., "being in a daze")
  - 3) derealization
  - 4) depersonalization
  - 5) dissociative amnesia (i.e., inability to recall an important aspect of the trauma)
- C. The traumatic event is persistently re-experienced in at least one of the following ways: recurrent images, thoughts, dreams, illusions, flashback episodes, or a sense of reliving the experience; or distress on exposure to reminders of the traumatic event.
- D. Marked avoidance of stimuli that arouse recollections of the trauma (e.g., thoughts, feelings, conversations, activities, places, people).
- D. Marked symptoms of anxiety or increased arousal (e.g., difficulty sleeping, irritability, poor concentration, hypervigilance, exaggerated startle response, motor restlessness).
- E. The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning or impairs the individual's ability to pursue some necessary task, such as obtaining necessary assistance or mobilizing personal resources by telling family members about the traumatic experience.
- F. The disturbance lasts for a minimum of 2 days and a maximum of 4 weeks and occurs within 4 weeks of the traumatic event.
- G. The disturbance is not due to the direct physiological effects of a substance (e.g., a drug

of abuse, medication) or a general medical condition, is not better accounted for by Brief Psychotic Disorder, and is not merely an exacerbation of a preexisting Axis I or Axis II disorder.

## Appendix D

### Diagnostic Criteria for Posttraumatic Stress Disorder (*DSM-IV-TR*, 2000)

- A. The person has been exposed to a traumatic event in which both of the following were present:
- 1) the person experienced, witnessed, or was confronted with an event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others;
  - 2) the person's response involved intense fear, helplessness, or horror. **Note:** in children, this may be expressed instead by disorganized or agitated behavior.
- B. The traumatic event is persistently re-experienced in one (or more) of the following ways:
- 1) recurrent and intrusive distressing recollections of the event, including images, thoughts, or perceptions; **note:** in young children, repetitive play may occur in which themes or aspects of the trauma are expressed.
  - 2) recurrent distressing dreams of the event; **note:** in children, there may be frightening dreams without recognizable content;
  - 3) acting or feeling as if the traumatic event were recurring (includes a sense of reliving the experience, illusions, hallucinations, and dissociative flashback episodes, including those that occur on awakening or when intoxicated); **note:** in young children, trauma-specific reenactment may occur;
  - 4) intense psychological distress at exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event;
  - 5) physiological reactivity on exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event.
- C. Persistent avoidance of stimuli associated with the trauma and numbing of general responsiveness (not present before the trauma), as indicated by three (or more) of the following:
- 1) efforts to avoid thoughts, feelings, or conversations associated with the trauma;
  - 2) efforts to avoid activities, places, or people that arouse recollections of the trauma;
  - 3) inability to recall an important aspect of the trauma;
  - 4) markedly diminished interest or participation in significant activities;
  - 5) feeling of detachment or estrangement from others;
  - 6) restricted range of affect (e.g., unable to have loving feelings);
  - 7) sense of foreshortened future (e.g. does not expect to have a career, marriage, children, or a normal life span).



- D. Persistent symptoms of increased arousal (not present before the trauma), as indicated by two or more of the following:
- 1) difficulty falling or staying asleep;
  - 2) irritability or outbursts of anger;
  - 3) difficulty concentrating;
  - 4) hypervigilance;
  - 5) exaggerated startle response.
- E. Duration of the disturbance (symptoms in Criteria B, C, and D) is more than 1 month.
- F. The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.

## Appendix E



Monroe Park Campus

Virginia Commonwealth University

Department of Psychology  
White House  
806 West Franklin Street  
P.O. Box 842018  
Richmond, VA 23284-2018  
804-828-1193  
Fax: 804 828-2237

Dear Families:

My name is Monica Durette and I am a doctoral student at Virginia Commonwealth University in the Department of Psychology's counseling program. I am writing to tell you about a research study that I am currently conducting here in the pediatric intensive care unit (PICU) with the cooperation of the Division of Pediatric Critical Care Medicine. The purpose of the study is to learn more about what it's like for parents to have a child hospitalized in a PICU so that we can increase our understanding of how to support parents in the future. Because not every family is the same, a child's "parent" may also be a stepparent, grandparent, or legal guardian.

If your child stays in the PICU for at least 48 hours, you may be invited to participate in the research study. Your decision to participate, or not participate, is completely voluntary and will not affect the medical care your child receives. If you decide to participate, you will be asked to fill out some questionnaires about things you may have thought or felt since your child was admitted. You will also be asked some questions about yourself, such as how old you are. If you do not want to be invited to participate, you may simply fill out the information requested at the bottom of this letter and give it to your child's nurse, or to the PICU receptionist. The signed letter will be placed in a confidential folder and will serve as your notice that you have decided not to participate.

If you have any questions, or would like further information about the study, you may contact me by email ([durrettemm@vcu.edu](mailto:durrettemm@vcu.edu)) or telephone (804-337-4943). You may also contact the study's Principal Investigator, Marilyn Stern, by email at [mstern@vcu.edu](mailto:mstern@vcu.edu) or by calling 804-827-0400. Thank you very much.

Sincerely,

Monica Durette, MS  
Doctoral Candidate  
Department of Psychology, Counseling Program  
Virginia Commonwealth University

---

I have read this letter and have decided not to participate in the research study.

---

Parent's name (printed)

Parent's signature

Date

Child's name & room number: \_\_\_\_\_

## Vita

Monica Mary Durette (nee Rodenburg) was born on April 18, 1960 in Tucson, Arizona. She earned a General Educational Development Certificate from the Virginia Department of Education in 1993 and an Associate in Arts and Sciences from John Tyler Community College in 1998. Monica received her Bachelor of Science in Psychology from the College of William and Mary in Williamsburg, Virginia in 2002, where she graduated *summa cum laude* and was awarded the Stanley B. Williams Prize for Outstanding Psychology Major. She began her graduate training in Counseling Psychology at Virginia Commonwealth University in 2004, received the Corazzini Award for Therapeutic Group Work in April 2007, and a Master of Science in December 2007. Monica has specialized in health and pediatric psychology throughout her doctoral training and completed a one-year, clinical internship in June 2011 at Georgia Health Sciences University in Augusta, Georgia as the Medical Psychology – HIV/AIDS resident.