The Effect of Caregiver Posttraumatic Stress on Newly Diagnosed Pediatric Cancer Patients

BY

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DISSEvation

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<tr>
<td>ANOVA</td>
<td>Analyses of Variance</td>
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<tr>
<td>ASD</td>
<td>Acute Stress Disorder</td>
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<td>D</td>
<td>Kolmogorov–Smirnov test statistic</td>
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<td>DSM-IV-TR</td>
<td>Diagnostic and Statistical Manual of Mental Disorders - Fourth Edition (Text Revision)</td>
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<td>HRQOL</td>
<td>Health-Related Quality of Life</td>
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<tr>
<td>ICD-10</td>
<td>International Statistical Classification of Diseases and Related Health Problems, 10th Revision</td>
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<td>IES-R</td>
<td>Impact of Events Scale - Revised</td>
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<td>K-SADS-PL</td>
<td>Schedule for Affective Disorders and Schizophrenia for School Aged Children - Present and Lifetime Version</td>
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<td>MINI</td>
<td>Mini-International Neuropsychiatric Interview</td>
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<tr>
<td>MINI-KID</td>
<td>Mini-International Neuropsychiatric Interview for Children and Adolescents</td>
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<tr>
<td>PCL</td>
<td>Posttraumatic Stress Disorder Checklist</td>
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<td>PedsQL</td>
<td>Pediatric Quality of Life Inventory</td>
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<td>PMTS</td>
<td>Pediatric Medical Traumatic Stress</td>
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<td>PPCI</td>
<td>Pediatric Pain Coping Inventory</td>
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<td>PPQ-VAS</td>
<td>Pediatric Pain Questionnaire - Visual Analogue Scale</td>
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<td>PTSD</td>
<td>Posttraumatic Stress Disorder</td>
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<td>PTSDI</td>
<td>UCLA PTSD Index for DSM-IV</td>
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<td>PTSS</td>
<td>Posttraumatic Stress Symptoms</td>
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SUMMARY

Despite medical advances in the treatment of pediatric cancers, a pediatric cancer diagnosis remains associated with a threat to life and often precedes painful and potentially traumatic medical procedures. The current study examined posttraumatic stress, pain, and health-related quality of life in newly diagnosed pediatric cancer patients, as well as the associations between these constructs and caregiver posttraumatic stress. Participants were newly diagnosed pediatric cancer patients ($n = 21$, 6 to 23 years old) and their primary caregivers ($n = 21$). Patients completed self-report questionnaires rating their posttraumatic stress symptoms (PTSS), pain severity, use of pain coping strategies, and overall and cancer-related health-related quality of life (HRQOL). Caregivers also rated their own PTSS. Results revealed that although neither patients nor caregivers experienced elevated levels of PTSS compared to normative samples, patients did report poorer HRQOL relative to healthy control participants. Results also provided evidence of inverse relationships between patient PTSS and patient HRQOL, caregiver PTSS and patient HRQOL, and patient pain and patient HRQOL, as well as positive relationships between patient pain and both caregiver PTSS and seeking social support (a pain coping strategy). Results also provided preliminary evidence that caregiver PTSS may moderate the relationship between patient pain and patient PTSS. Theoretical findings are discussed in regards to previous studies, with particular emphasis on the potential impact of caregiver PTSS on patients’ psychological and physical functioning. Recommendations regarding important areas of assessment and potential prevention and intervention targets for pediatric cancer patients and their caregivers are also provided.
1. INTRODUCTION

1.1. Background

The American Cancer Society predicts that approximately 15,800 children under the age of 15 will be diagnosed with cancer in 2014 (American Cancer Society, 2014). Because of substantial treatment advances in recent years, close to 80% of children with cancer are expected to survive for five years or longer after the date of their original diagnosis. As the survival rate has improved, there has been an increased focus on examining the short- and long-term physical and psychological effects of cancer on pediatric cancer patients and their families.

Despite medical advances in the treatment of pediatric cancers, a pediatric cancer diagnosis remains associated with a threat to life and often precedes painful and potentially traumatic medical procedures. The stress and uncertainty surrounding pediatric cancer diagnosis and treatment can be experienced as traumatic by both patients and their parents (Landolt et al., 2003; Stuber, Christakis, Houskamp, & Kazak, 1996; Stuber, Gonzalez, Meeske, Houskamp, & Pynoos, 1994). Although previous studies have demonstrated an association between patient and parental posttraumatic stress in pediatric cancer (e.g., Pelcovitz et al., 1998), less work has focused on the presence and strength of this relationship among newly diagnosed pediatric cancer patients and their parents.

In addition to the distress associated with receiving news of a cancer diagnosis, patients and their families face other potential stressors around the time of diagnosis. For example, the experience of physical pain is common and often perceived as traumatic among newly diagnosed cancer patients (Hëdstrom, Haglund, Skolin, & von Essen, 2003; Ljungman, Gordh, Sörensen, & Kreuger, 1999), indicating a possible relationship between patients’ experiences of pain and posttraumatic stress. Moreover, perceiving one’s child as experiencing physical distress can also
be traumatic for parents (Pöder, Ljungman, & von Essen, 2010). As such, patient pain may also be related to parental posttraumatic stress.

Given the substantial psychological and physical effects of cancer on patients, broader indicators of patients’ overall health and well-being are also important areas of study. Specifically, health-related quality of life (HRQOL), a multidimensional construct that includes physical, emotional, social, and role functioning, has been assessed in pediatric cancer patients over the course of the cancer experience. Because pediatric cancer patients’ ratings of their overall HRQOL are related to their psychological and physical functioning (Roddenbery & Renk, 2008), patient HRQOL may be related to patient posttraumatic stress and patient pain as well. Furthermore, there is growing evidence that pediatric cancer patients’ parents’ psychological adjustment is associated with patient HRQOL (Vance, Jenney, Eiser, & Morse 2001), indicating that parent posttraumatic stress may be related to patient HRQOL.

1.2. Posttraumatic Stress in Pediatric Cancer Patients and their Parents

1.2.1. Patient Posttraumatic Stress.

Early research reports describe many pediatric cancer patients as meeting full criteria for posttraumatic stress disorder (PTSD; Nir, 1985). However, it was not until the publication of the *DSM-IV* (American Psychiatric Association, 1994), when the definition of a Criterion A traumatic event was expanded to include the diagnosis of a life threatening illness, that increased research attention was directed toward the prevalence of PTSD in pediatric cancer patients. In contrast to early reports, recent research has consistently found that the majority of pediatric cancer patients do not develop the full syndrome (Brown, Madan-Swain, & Lambert, 2003). The rates of PTSD in childhood cancer survivors are more consistent with those among healthy age-matched populations (Barakat et al., 1997; Kazak et al., 1997; Stuber et al., 2010) than with other
populations that have experienced traumatic events such as acute physical injuries or natural disasters (Aaron, Zaglul, & Emery, 1999; LaGreca, Silverman, & Wasserstein, 1998). These reports are encouraging and suggest that many children may be psychologically resilient to the stress and trauma associated with childhood cancer.

Alternatively, these low rates may reflect the challenges of applying the diagnostic criteria for PTSD to youth and to chronic medical illnesses in general. The DSM-IV-TR PTSD criteria (American Psychiatric Association, 2000) may not be appropriate for children who experience medically-related traumatic events such as cancer. Indeed, there is some debate about the applicability of DSM-IV-TR PTSD criteria to children, particularly in regards to symptomatic expression. For example, children tend to exhibit fewer cognitive symptoms of PTSD and less avoidance (Salmon & Bryant, 2002). The appropriateness of applying DSM-IV-TR PTSD criteria to cancer may also be problematic. For example, meeting criteria for avoidance symptoms (Criterion C) may be impossible for pediatric cancer patients, due to the necessity of frequent treatments and medical appointments. Similarly, given the ongoing nature of cancer treatment, the re-experiencing symptom cluster (Criterion B) is difficult to assess as well (Phipps, Long, Hudson, & Rail, 2005). There is also disagreement about what aspect of the cancer experience should be considered the traumatic event (Criterion A; Bruce 2006).

Because PTSD diagnostic criteria may not correspond with patients’ reactions to cancer and other medical illnesses, some investigators have adopted the pediatric medical traumatic stress model (PMTS; Kazak, Schneider, & Kassam-Adams, 2009) to better understand the experience of pediatric patients and their families in medical settings. 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 (Kazak et
Although it is related to traumatic stress disorders, PMTS is not limited to diagnostic entities such as acute stress disorder (ASD) and PTSD. Rather, it is conceptualized as a continuum of posttraumatic stress symptoms (PTSS) which may be present with or without meeting full criteria for ASD or PTSD. Pediatric patients are considered within the context of their family, as family members are also experiencing potentially traumatic events. Both the objective nature and an individual’s subjective interpretations of an event contribute to whether an event is perceived as traumatic.

The PMTS model includes three phases: the occurrence of a potentially traumatic event and its immediate aftermath (e.g., cancer diagnosis); the acute, evolving traumatic stress responses (e.g., cancer treatment); and longer-term traumatic responses when the physical sequelae and medical treatment have resolved (e.g., late effects; Pai & Kazak, 2006). Support for this model is primarily provided by research demonstrating high prevalence rates (Erickson & Steiner, 2001; Kazak et al., 1997; Kazak et al., 2004; Kazak et al., 2005; Stuber et al. 1997) and PTSS severity (Kazak et al., 2005; Langeveld et al., 2004) among childhood cancer survivors and their parents.

In response to this theoretical shift in the conceptualization of traumatic stress in pediatric cancer, recent studies have focused on PTSS rather than PTSD diagnoses. Pediatric cancer patients endorse a range of PTSS including re-experiencing of the traumatic event, persistent avoidance of trauma-related stimuli, and hyperarousal (Lee & Santacroce, 2007). Some studies have documented increased levels of PTSS in childhood cancer survivors (patients who were off-treatment for an average of about three years) relative to healthy, age-matched controls (Butler, Rizzi, & Handwerger, 1996; Pelcovitz et al., 1998), whereas others have found no difference between the two populations (Barakat et al., 1997; Brown et al., 2003; Kazak et al., 1997).
Furthermore, the rates of PTSS among children with cancer may be lower than among children who have experienced other stressful events such as acute physical injuries or natural disasters (Aaron et al., 1999; LaGreca et al., 1998).

Because of the inconsistent results regarding overall rates of PTSS and increased interest in understanding the experience of pediatric cancer patients during specific phases of the cancer course, recent investigations have examined levels of PTSS reported by pediatric cancer patients as a function of time since diagnosis (e.g., during active treatment, five years post-treatment completion). For example, in studies of childhood cancer survivors who were at least one year post-diagnosis, 36% of survivors experienced mild PTSS (Brown et al., 2003), 12.1% experienced moderate PTSS, and 2.6% experienced severe PTSS (Barakat et al., 1997). In a study of cancer survivors who completed treatment at least five years prior to the assessment, 12.6% of patients reported moderate PTSS, and 1.6% of patients reported severe PTSS (Kazak et al., 1997).1 Phipps and colleagues (2005) found that children who had recently received a cancer diagnosis had significantly greater levels of PTSS relative to long-term survivors (patients more than five years post-diagnosis). Additional research is needed to extend these findings by comparing the rates of PTSS among newly diagnosed pediatric cancer patients to those of age-matched controls.

1.2.2. **Parent Posttraumatic Stress.**

Contrary to the inconsistent findings regarding elevated levels of PTSS in pediatric cancer patients, numerous empirical studies provide consistent evidence of increased emotional distress among parents of pediatric cancer patients, particularly in the form of elevated anxiety, depression, and posttraumatic stress (Barrera et al., 2004; Brown et al., 2003; Dahlquist, 2003).

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1 Severity of symptoms was categorized based on published cutoffs of PTSD Reaction Index total scores (Pynoos, Frederick, Nader, & Arroyo, 1987).
Rates of traumatic stress in parents tend to be high in the days and weeks following a child’s cancer diagnosis. Within two weeks of a child’s diagnosis, 51% of mothers and 40% of fathers met criteria for ASD (a disorder with many symptoms that overlap with those of PTSD but that occur within one month following a trauma; Patiño-Fernández et al., 2008). Posttraumatic stress is also elevated in parents of children currently receiving cancer treatment. Between one-half and two-thirds of parents of children receiving cancer treatment reported cancer-related PTSS within the moderate to severe range (Kazak, Boeving, Alderfer, Hwang, & Reilly, 2005). Parents of childhood cancer survivors (patients who completed treatment on average five years prior to the assessment) endorsed moderate to severe levels of PTSS (43.7% of mothers and 35.3% of fathers), with the majority of parents endorsing clinically significant re-experiencing symptoms (Kazak et al., 2004).

Parental PTSS tends to decrease as time since diagnosis increases. For example, parents of long-term survivors (defined as parents of patients who were at least five years post-diagnosis and two years post-completion of cancer treatment) reported significantly lower levels of PTSS than did parents of more recently diagnosed patients (Phipps et al., 2005). Although the majority of parents who experience PTSS report a linear decrease in PTSS over time (Pöder, Ljungman, & von Essen, 2008), some parents experience persistent distress (Dolgin et al., 2007). Parents who experienced persistent distress tended to be more neurotic, poorer problem solvers, less agreeable, and less extraverted than parents who experienced low, stable distress or declining distress (Dolgin et al., 2007).
1.2.3. **The Relationship Between Patient Posttraumatic Stress and Parent Posttraumatic Stress.**

Overall, research on PTSS in pediatric cancer patients and their parents demonstrates that a subset of this population experiences significant levels of PTSS. To help identify those individuals who are at increased risk, researchers have examined numerous predictors of PTSS in pediatric cancer patients and their parents including disease severity, demographic factors, and psychosocial factors (Bruce, 2006). Parental PTSS is a consistent predictor of cancer-related PTSS in children. In general, pediatric cancer patients whose parents experience high levels of posttraumatic stress are more likely to have elevated levels of psychological distress such as anxiety or PTSS themselves (Pelcovitz, Goldenberg, Kaplan, & Weinblatt, 1996; Pelcovitz et al., 1998). For example, adolescent cancer survivors are seven times more likely to develop PTSD if their mothers have a current PTSD diagnosis (Pelcovitz et al., 1998). Although parents tend to experience higher rates of PTSS than do pediatric cancer patients (Brown et al., 2003; Kazak et al., 2004), levels of parental PTSS are significantly correlated with child-reported PTSS in families surviving childhood cancer (Barakat et al., 1997; Kazak et al., 1997; Stuber et al., 1994; Stuber et al., 1996) and across the course of cancer (Phipps et al., 2005). Among those patient-parent dyads with elevated PTSS, the pattern of PTSS is similar: Parent and adolescent cancer survivors’ ratings of different clusters of PTSS are concordant (Kazak et al., 2004). These findings point to a consistent and specific relationship between parental and pediatric cancer survivors’ PTSS. Although there is some research on the strength of this relationship within the first six months after diagnosis, no studies to our knowledge have examined this relationship among more recently diagnosed pediatric cancer patients and their parents.
The relational model of PTSD (Scheeringa & Zeanah, 2001) is a heuristic model for conceptualizing the relationship between parent and pediatric cancer patients’ posttraumatic stress. This model posits that elevated parental PTSS and subsequent compromised responsiveness to their children may contribute to children’s PTSS (Scheeringa & Zeanah, 2001). Specifically, parents experiencing elevated PTSS may be less able to accurately perceive their children’s distress (Dumas & Serketich, 1994; Scheeringa & Zeanah, 2001) and, in turn, may be less able to provide appropriate support to facilitate children’s psychological recovery from a traumatic event (Kassam-Adams, García-España, Miller, & Winston, 2006; Scheeringa & Zeanah, 2001). This lack of support could lead to increases in children’s distress which could further perpetuate parental distress. Of note, this model does not posit that parents are to blame for their children’s PTSS; rather, children’s responses to a traumatic event may be intensified or reduced by parental behavior.

This relational, transactional process could apply to posttraumatic stress in pediatric cancer populations (Goldwin, Lee, Afzal, Drossos, & Karnik, 2014; see Figure 1). Specifically, caregivers experiencing elevated levels of posttraumatic stress may be less likely to effectively respond to the patients’ needs when patients experience psychological and physical stresses associated with the experience of pediatric cancer. (Possible relational patterns will be described in more detail below.) Patients, in turn, may be at increased risk for developing maladaptive coping strategies, poor psychological adjustment, and, more specifically, increased posttraumatic stress. Patients’ increased posttraumatic stress and overall maladjustment could then contribute to higher levels of caregiver posttraumatic stress.
Figure 1. A theoretical model of the reciprocal relationship between posttraumatic stress symptoms in pediatric cancer patients and their parents

There is some empirical evidence to support the application of this model to pediatric cancer patients’ overall psychological well-being. Pediatric cancer patients whose parents experience elevated psychological distress tend to have elevated psychological distress as well. Specifically, pediatric cancer patients whose mothers report higher perceived stress and emotional distress tend to experience higher subsequent emotional distress (mood and behavior problems) and somatic distress (Steele et al., 2004). Also, higher levels of parenting-related stress are associated with increased behavioral and social difficulties among pediatric cancer
patients currently undergoing treatment, and higher levels of parenting stress and perceived child vulnerability are associated with poorer emotional adjustment (Colletti et al., 2008).

As mentioned above, levels of parental PTSS are significantly correlated with child-reported PTSS (Barakat et al., 1997; Currier et al., 2009; Kazak et al., 1997; Landolt et al., 2003; Phipps et al., 2005; Stuber et al., 1994; Stuber et al., 1996), and patterns of PTSS are similar among patient-parent dyads with elevated PTSS (Kazak et al., 2004). Based on the relational PTSD model (Scheeringa & Zeanah, 2001), this association could be due to withdrawn/unresponsive/unavailable parenting. Because of parents’ symptom-related impairments including avoidance, withdrawal, and/or emotional numbness, parents’ ability to accurately perceive and respond to their children’s physical or psychological distress could be compromised. In turn, parents may be less able or available to provide support to their children, which could contribute to an exacerbation of children’s symptoms.

Alternatively, parents with elevated PTSS may be overprotective, in part due to their own hypervigilance to stimuli associated with the cancer-related traumatic event. Because of their own fear and hypervigilance, parents may respond in an overly sensitive manner to perceived cancer-related threats. They may consider any stimulus associated with the cancer-related traumatic event to be potentially dangerous and requiring parental protection or intervention. Patients may interpret parental overprotection as an indicator of their own vulnerability (Mullins et al., 2007) and/or as a signal that they need to remain wary of cues that could indicate future threats in order to increase their own preparedness to respond to these events. Both increased perceptions of their own vulnerability and increased hypervigilance to stimuli associated with a cancer-related traumatic event could contribute to increased fear and PTSS among pediatric cancer patients. Together, these findings indicate that pediatric cancer patients whose parents
exhibit elevated PTSS may experience increased PTSS in part due to maladaptive parental responsiveness to cancer-related traumatic events.

1.3. **Pain in Pediatric Cancer Patients**

As mentioned above, pediatric medical traumatic stress involves a set of responses by children and their families to a variety of potentially traumatic events that may occur as part of pediatric illnesses (Kazak et al., 2009). Pain is one of the many potentially traumatic events related to pediatric illness and treatment. Pain is also a common and distressing symptom throughout all phases of cancer treatment, including the time immediately preceding and following a cancer diagnosis (Ljungman et al., 1999).

1.3.1. **Patient Pain.**

Pain is a common symptom experienced by pediatric cancer patients, with many patients experiencing frequent episodes of severe pain (Zernikow et al., 2005). The experience of pain is pervasive across the course of cancer and, for a large proportion of children and young adults, pain is often a presenting symptom of cancer (Miser, McCalla, Dothage, Wesley, & Miser, 1987). At the time of diagnosis, 60% of children report that they had experienced pain, and 36% of children had experienced pain often or very often (Ljungman et al., 1999). Sixty-two percent of children across different stages of treatment for cancer consider pain a more troublesome symptom than nausea (Ljungman et al., 1999). Causes of cancer-related pain include the cancer itself as well as side effects of treatments including chemotherapy, lumbar punctures, accessing intravenous sites, and phantom pain from amputations (Kestler & LoBiondo-Wood, 2012). Interviews with pediatric cancer patients reveal that patients use a wide variety of words to describe their pain ranging from “annoying” to “stabbing” and “terrifying” (Bossert et al., 1996).
Over half of newly diagnosed pediatric cancer patients report that pain is an unavoidable aspect of cancer and approximately one quarter of pediatric cancer patients do not ask for help managing their pain because they believe that pain is a natural consequence of cancer (Ljungman et al., 1999). Children with cancer tend to experience the most intense pain at the beginning of treatment (Ljungman, Gordh, Sörensen, & Kreuger, 2000). Pain related to procedures and treatments is considered to be one of the worst aspects of cancer by recently diagnosed adolescents (Hëdstrom, Ljungman, & von Essen, 2005). Together, these results indicate that pain contributes to both physical and emotional distress among newly diagnosed pediatric cancer patients.

1.3.2. Pain Coping Strategies.

Children differ in their coping responses to pain, and these differences may impact child and parental responses to the cancer experience. Children’s pain coping strategies may be adaptive or maladaptive depending on the outcome in terms of pain relief, emotional adjustment, and functional status (Varni, 1995). For example, children and adolescents experiencing musculoskeletal pain associated with rheumatologic diseases who actively concentrated away from pain perception reported lower pain intensity and depressive symptoms; parents of children who used this strategy reported that their children experienced less frequent and less intense pain and fewer internalizing problems (Varni et al., 1996). Accordingly, refocusing away from pain was considered an adaptive strategy because it led to positive outcomes (i.e., lower perceived pain intensity, lower emotional distress). Studies with other pediatric populations have identified maladaptive pain coping strategies. Children and adolescents with sickle cell disease who used negative thinking and passive adherence as coping strategies required more health care services and experienced more psychological distress during painful episodes (Gil, Williams, Thompson,
& Kinney, 1991). In addition to predicting variability in their experience of pain perception, pain behavior, and functional status (Varni, 1995), children’s pain coping strategies may mediate the relationship between children’s experience of pain and their overall HRQOL (Varni et al., 1996).

Common pain coping strategies reported by pediatric cancer patients include rest/sleep, analgesics, rubbing, distraction, social support, and application of heat (Bossert et al., 1996). Intervention research supports the utility of parent-driven distraction in reducing pediatric cancer patients’ distress during painful procedures such as repeated chemotherapy injections (Dahlquist, Pendley, Landthrip, Jones, & Steuber, 2002). To our knowledge, no study has examined the association between pain intensity and the use of specific pediatric pain coping strategies in newly diagnosed cancer patients. Because pain coping strategies are theoretically an intervening factor in pediatric pain perception, pain behavior, and functional status (Varni, 1995), the identification of specific pediatric pain coping strategies related to lower pain intensity among newly diagnosed patients could inform future interventions for this population.

1.3.3. The Relationship Between Patient Pain and Patient Posttraumatic Stress.

Cancer-related pain could be considered a traumatic event for children with cancer and, accordingly, may be positively associated with PTSS. Research with other pediatric populations supports positive associations between pain and PTSS (Gold, Kant, & Kim, 2008; Saxe et al., 2005a; Stoddard et al., 2006). For example, pain may be directly or indirectly associated with the development of acute stress disorder in children with burns (Saxe et al., 2005b) and PTSD in hospitalized children and adolescents with injuries (Saxe et al., 2005a).

There is a well-established relationship between cancer-related pain and general emotional distress (Varni, Blount, Waldron, & Smith, 1995; Varni, Burwinkle, & Katz, 2004).
Many children experience anxiety about their cancer-related pain (Enskär, Carlsson, Golsäter, Hamrin, & Kreuger, 1997). In addition to worrying about future pain, children may experience the painful aspects of treatment (e.g., the procedural pain of a bone marrow aspiration, painful side effects that result from chemotherapy or radiation therapy) as highly traumatic (Hedström, et al., 2003; Ljungman et al., 1999). Such repeated traumatic experiences could theoretically lead to increased PTSS and decreased quality of life. Among patients who completed cancer treatment within the past six months, pain and PTSS were positively correlated (Ruccione, Lu, & Meeske, 2013). No studies to our knowledge have examined the relationship between pain and PTSS in newly diagnosed pediatric cancer patients.

1.3.4. **The Relationship Between Patient Pain and Parent Posttraumatic Stress.**

In addition to being a potentially traumatic event for pediatric cancer patients, perceiving one’s child as experiencing intense pain is a stressor for parents and could be experienced as traumatic for parents of children with cancer (Pöder et al., 2010). Although no studies to our knowledge have examined patient pain and parent posttraumatic stress within a pediatric cancer population, evidence from studies of other traumatic medical events provides support for this relationship. Among children with burn injuries, parental acute stress symptoms mediated the relationship between children’s experience of pain and children’s acute stress symptoms (Stoddard et al., 2006). Consistent with the relational model of PTSD described above, the stress of perceiving one’s child to be in intense pain could lead to increased parental PTSS which could, in turn, affect parents’ ability to accurately perceive and effectively respond to their children’s pain and any related psychological distress.

Parents’ emotions and behaviors before and during cancer-related procedures predict how much pain and distress children experience in response to these procedures (Dahlquist, Power, &
Carlson, 1995; Dahlquist, Power, Cox, & Fernbach, 1994). During potentially painful medical procedures, children whose parents encourage positive coping strategies and distraction tend to exhibit reduced distress (Blount et al., 1989; Blount, Landolf-Fritsche, Powers, & Sturges, 1991; Blount, Sturges, & Powers, 1990), whereas children whose parents use apologies, reassurance, and criticism tend to display increased distress (Blount et al., 1989; Blount et al., 1991; Blount et al., 1990). Thus, children’s experience of a particular pain episode may depend on parents’ behavior.

Consistent with the relational model of PTSD, two relational patterns – namely, overprotective/hypervigilant parenting and withdrawn/unresponsive parenting – could help explain how parental responses to pain contribute to patient PTSS. Among children experiencing pain, overprotective parent behaviors that focus children on symptoms leads to increased child distress and pain (Chambers, Craig, & Bennett, 2002; Claar, Simons, & Logan, 2008). Children may interpret parental overprotective behavior as a signal that their pain is more serious and debilitating than they previously thought. Even if parents are aware of effective pain management techniques that could help their children, parental anxiety is associated with child distress during medical procedures (Jacobsen et al., 1990), possibly because parental anxiety may interfere with parents’ ability to effectively implement such techniques (Dahlquist & Pendley, 2005). Hypervigilant parents may also be more likely to focus on patients’ pain. Among children with functional abdominal pain with a high disposition toward pain catastrophizing, higher levels of parents’ symptom-related talk was associated with more symptom complaints during a task that induced visceral discomfort (Williams, Blount, & Walker, 2011). Parent symptom-related talk may serve as a pain antecedent that triggers
threatening thoughts about physical symptoms and, in turn, worsens patients’ pain (Blount et al., 2009).

Parents who are withdrawn/unresponsive, on the other hand, may be less likely to encourage effective pain coping strategies because of a decreased recognition of the need for different responses to their children’s pain. Parents may also minimize their children’s pain symptoms in an attempt to avoid trauma-related stimuli that would exacerbate their own PTSS. Such minimization could lead to increased child-reported pain (Claar et al., 2008), possibly because children whose pain is unrecognized or ignored may attempt to (consciously or unconsciously) magnify their pain in an attempt to gain parental attention. Together, these findings support the possibility that patient pain could contribute to increased parental PTSS and that the relational patterns exhibited by parents with elevated PTSS may be associated with decreased parental responsiveness to children’s needs during experiences of pain. Thus, children of parents with elevated PTSS may not receive the parental help that could alleviate some of their own pain and associated PTSS.

1.4. Health-Related Quality of Life in Pediatric Cancer Patients

In addition to examining specific constructs such as PTSS and pain, pediatric psycho-oncology researchers are increasingly advocating for the inclusion of measures that assess the broader impact of the cancer experience. For example, the marked improvement in the survival rates of pediatric cancer (Ries et al., 2007) has prompted an increased focus on overall quality of pediatric cancer patients’ lives (Mulhern et al., 1989). Quality of life is a multi-dimensional concept that includes physical, mental, and social well-being (World Health Organization, 1948). As mentioned previously, HRQOL refers to physical, emotional, social, and role functioning. Rather than focusing on objective health status alone or on a specific symptom, HRQOL
measures include subjective perceptions and expectations regarding health and one’s ability to cope (Testa & Simonson, 1996). Thorough assessments of both generic and disease-specific dimensions of HRQOL exist for pediatric cancer and are often used to assess the impact of cancer treatments on patients’ overall functioning (Varni et al., 2001; Varni, Burwinkle, Katz, Meeske, & Dickinson, 2002). HRQOL tends to be poorer in pediatric cancer patients relative to healthy, age-matched control participants (Bhat et al., 2005 Eiser et al., 2005; Ruccione et al., 2013; Shanker et al., 2005; Varni et al., 2002a).

There has been increased interest in examining whether HRQOL is compromised soon after a child is diagnosed and during the acute phase of cancer treatment (Eiser et al., 2005) and how HRQOL varies as a function of time since diagnosis (Meeske, Katz, Palmer, Burwinkle, & Varni, 2004). In a prospective study of pediatric cancer patients during the first year after diagnosis, patients reported poorer HRQOL in multiple domains six weeks after diagnosis (including physical complaints, motor autonomy, and emotional functioning) and, although HRQOL generally increased as time since diagnosis increased, patients continued to report reduced HRQOL in some domains one year after diagnosis (Landolt et al., 2006). Consistent with the trend of improving HRQOL as a function of time since diagnosis, pediatric cancer patients within one month of receiving a diagnosis reported poorer HRQOL at diagnosis relative to their own reports three months after initiation of treatment (Yaris, Yavuz, Yavuz, & Okten, 2001). Furthermore, HRQOL in children during the acute phase of therapy tends to be lower than that of survivors who have completed treatment (Shankar et al., 2005; Varni et al., 2002a). Notably, many of the aforementioned studies rely on proxy-report measures of HRQOL. There is a need for research comparing self-reported HRQOL of newly diagnosed pediatric cancer
patients to that of healthy individuals in order to clarify whether patients themselves perceive their HRQOL as being compromised.

1.4.1. **Relationship Between Patient Health-Related Quality of Life and Patient Posttraumatic Stress.**

Pediatric cancer patients’ ratings of their overall HRQOL are related to their psychological and physical functioning (Roddenbery & Renk, 2008). Although there is evidence that survivors of childhood cancer with PTSD tend to have poorer HRQOL (Schwartz & Drotar, 2006; Meeske, Ruccione, Globe, & Stuber, 2001), posttraumatic stress and HRQOL have not been examined extensively in newly diagnosed pediatric cancer patients. PTSS and HRQOL tend to be negatively associated in other pediatric populations who have recently experienced a potentially traumatic event. For example, among children assessed within two weeks of the occurrence of an accident or a diagnosis of a severe chronic illness (including cancer), PTSS severity was significantly associated with lower functional status (ability to participate in physical activities of daily life; Landolt et al., 2003). There is also evidence that PTSS experienced soon after a potentially traumatic event predicts subsequent HRQOL. In a prospective study of adolescent survivors of traumatic injuries, meeting criteria for ASD prior to discharge from the hospital predicted poorer overall quality of life at both short- and long-term follow-up assessments (Holbrook, Hoyt, Coimbra, Potenza, Sise, & Anderson, 2005). Similarly, among child survivors of road traffic accidents, child PTSS one month after the accident predicted lower overall HRQOL one year after the accident (Landolt, Vollrath, Gnehm, & Sennhauser, 2009). In sum, posttraumatic stress and HRQOL tend to be related among childhood cancer survivors and pediatric patients who have experienced potentially traumatic
events. However, the presence and strength of this association among newly diagnosed pediatric cancer patients remains understudied.

1.4.2. **Relationship Between Patient Health-Related Quality of Life and Patient Pain.**

Pain and HRQOL tend to be negatively related among children and adolescents with a variety of medical conditions including autoimmune liver disease (Gulati et al., 2013), juvenile idiopathic arthritis (Sawyer, Antoniou, Toogood, & Rice, 2004), neurofibromatosis type 1 (Krab et al., 2009), sickle cell disease (Dampier et al., 2010), and spina bifida (Bellin et al., 2013). Pain and HRQOL are also related in pediatric cancer patients who are not currently receiving treatment for cancer. Among pediatric cancer patients who completed treatment within six months of the assessment, pain was negatively associated with psychosocial HRQOL (Ruccione et al., 2013). Childhood cancer survivors report that pain continues to negatively affect their quality of life years after treatment was completed (Zebrack & Chesler, 2002). Together, these studies demonstrate a negative association between pain and HRQOL among medically ill youth, including those who have completed cancer treatment. There is a need for further research examining whether pain is negatively associated with HRQOL among recently diagnosed pediatric cancer patients and those currently undergoing cancer treatment.

1.4.3. **Relationship between Patient Health-Related Quality of Life and Parent Posttraumatic Stress.**

Consistent with evidence that less adaptive parental functioning following traumas tends to be associated with less adaptive child functioning (e.g., Scheeringa & Zeanah, 2001), parents’ psychological adjustment and pediatric cancer patients’ HRQOL appear to be related. For example, six weeks after a cancer diagnosis, better parental adjustment was associated with
better patient HRQOL (Landolt, Vollrath, Niggli, Gnehm, & Sennhauser, 2006). Some studies have examined the associations between patient HRQOL and more specific measures of parental adjustment. In a study of newly diagnosed cancer patients (approximately three months post-diagnosis), mothers with more worries and poorer quality of life rated their children’s HRQOL as being poorer (Eiser, Eiser, and Stride, 2005). Similarly, among pediatric cancer patients currently undergoing cancer treatment, increased maternal symptoms of depression and anxiety were related to poorer maternal report of patients’ cancer-specific quality of life (Roddenbery & Renk, 2008). In a study of children currently receiving treatment for cancer, maternal depression was associated with poorer self-reported patient HRQOL (Vance et al., 2001). Among survivors of hematopoietic stem cell transplant, maternal depressive symptoms were negatively associated with maternal report of patient HRQOL (Barrera, Atenafu & Pinto, 2009). The interpretation of the findings from many of these studies are confounded by the reliance on maternal report of child’s HRQOL, given the tendency for mothers experiencing psychological difficulties to rate their children as experiencing higher levels of emotional and behavioral problems (e.g., Najman, et al., 2000).

Given the theoretical effect of parental PTSS on parental responsiveness to pediatric cancer patients’ needs (Goldwin et al., 2014), increased parental PTSS is likely associated with poorer patient HRQOL. Specifically, without sufficient parental emotional and pragmatic support, pediatric cancer patients’ overall quality of life is likely to be adversely affected. Although there have been no studies to our knowledge examining the relationship between parental PTSS and child HRQOL among pediatric cancer patients specifically, in a study of pediatric patients within the first two weeks after the occurrence of an accident or the diagnosis of severe chronic illness (including cancer), severity of parental PTSS was significantly
associated with lower functional status of child (ability to participate in physical activities of daily life; Landolt et al., 2003).

1.5. **Current Study**

In the current study, we conducted assessments of newly diagnosed pediatric cancer patients and their primary caregivers. Specifically, we assessed PTSS severity, pain intensity, use of pain coping strategies, and both general and cancer-specific HRQOL among pediatric patients. We also assessed the severity of PTSS experienced by patients’ primary caregivers.

The current study has five aims. First, we will compare the level of posttraumatic stress reported by pediatric cancer patients and their caregivers to available normative data from healthy control participants. Second, we will compare pediatric cancer patients’ HRQOL to that of healthy control participants. Third, we will examine the strength of the relationships between patient posttraumatic stress, caregiver posttraumatic stress, patient pain, and patient HRQOL. Fourth, we will examine whether pain intensity is related to the use of specific pain coping strategies. Fifth, we will examine whether caregiver PTSS is associated with the strength of the relationship between patient pain and patient PTSS.

We tested the following five hypotheses:

1) Consistent with previous findings that children recently diagnosed with cancer and their parents experience more elevated levels of PTSS than do long-term survivors (Phipps et al., 2005), we expected that pediatric patients and their caregivers would show elevated levels of PTSS as compared to established normative levels for healthy control participants and parents of healthy children.

2) Consistent with previous research that HRQOL tends to be poorer in pediatric cancer patients relative to healthy, age-matched control participants (Varni et al., 2002a) and that HRQOL
tends to be compromised among newly diagnosed cancer patients (Landolt et al., 2006), we expected that patient HRQOL would be significantly lower in our sample relative to established normative levels for healthy control participants.

3) We expected that (a) patient PTSS would be positively associated with caregiver PTSS and patient pain intensity and inversely associated with patient HRQOL; (b) caregiver PTSS would be positively associated with patient pain intensity and inversely associated with patient HRQOL; and (c) patient pain intensity would be inversely associated with patient HRQOL.

4) Consistent with evidence from other pediatric populations that specific pain coping strategies are related to pain intensity (Varni et al. 1996), we expected that pain intensity would be related to the use of specific pain coping strategies.

5) Finally, consistent with evidence that patients who experience pain and have parents with elevated PTSS tend to report higher levels of stress-related symptoms (Stoddard et al., 2006), we expected that caregiver PTSS would moderate the relationship between patient pain and patient PTSS. Specifically, we predicted that the association between patient pain and patient PTSS would be stronger in patients whose caregivers experienced higher levels of PTSS (see Figure 2 for a model of the hypothesized relationships among study variables).
Figure 2. Hypothesized relationships among study variables.
2. METHOD

2.1. **Participants**

Participants were recruited from the University of Chicago Comer Children’s Hospital. Inclusion criteria for the patients were: (1) ages 6-24; (2) diagnosis of cancer within the last 90 days; (3) planning to undergo treatment or follow-up at Comer Children’s Hospital; and (4) sufficient understanding of English language (by both patients and caregivers) in order to complete study measures. Exclusion criteria were: (1) prior diagnosis of cancer or relapse of cancer, and (2) current diagnosis of an intellectual disability. Twenty-eight eligible patient-caregiver pairs were approached about the study, and 22 (78.57%) of the patient-caregiver pairs consented to participate. Additionally, one young adult consented to participate but no caregiver was consented due to lack of family interest. Reasons for declining to participate in the study included lack of direct benefit to participants, not wanting to talk about the psychological effects of their cancer diagnosis, and having “nothing negative to say.” One caregiver withdrew participation for both herself and her son due to concerns about her son talking to members of the Psychiatry Department given past personal experiences with mental health providers. All other patient-caregiver pairs (n = 21) who consented completed the study.

The current study, which focuses on a single time point, was part of a proposed longitudinal study designed to examine whether there were significant relationships between patient PTSS, patient pain, patient HRQOL, and caregiver PTSS and whether these relationships change over time. The statistical consultant for the project (Dr. Robert Gibbons) assisted in the computation of the sample size needed to conduct the analyses for this longitudinal study. Because the proposed longitudinal study sought to assess the relationship between PTSS and pain over time, we utilized data from a longitudinal study of pain and emotional distress in
pediatric cancer to conduct the following analyses (Varni et al., 2004). This longitudinal study examined the concurrent and prospective correlations of emotional distress and pain. All correlations were significant. Based on these data, we estimated that the mean correlation between the measures utilized in our study would be 0.50, on average. We then calculated the confidence interval for a study with a correlation coefficient of 0.50, a sample size of 50 participants, and a 95% confidence interval. In such a study, the true correlation would be between 0.25 – 0.68, which “has reasonable precision” (R. Gibbons, personal communication, January 6, 2012). For higher correlations, the confidence interval would be more precise. In order to meet this participation rate, we planned to recruit and screen 67-70 patient-caregiver pairs.

2.2. **Measures**

2.2.1. **Demographic and medical variables.**

Patient age, gender, ethnicity, date of diagnosis, and cancer type were collected from patients’ electronic medical records. Patient insurance type (private versus public) was also collected from patients’ electronic medical records to serve as a proxy for socioeconomic status. Time since diagnosis was calculated by computing the number of days between date of diagnosis and the date of assessment. Patients’ caregiver type (i.e., mother, sibling) was recorded at the time of the assessment.

2.2.2. **Mini-International Neuropsychiatric Interview (MINI) and Mini-International Interview for Children and Adolescents (MINI-KID; Sheehan et al., 1998; Sheehan et al., 2010).**

The MINI and MINI-KID are brief, semi-structured diagnostic interviews designed to screen for the presence of the major diagnostic disorders in the *DSM-IV* and the *ICD-10*. The
structured format of the MINI allows for rapid exclusion of diagnoses. The MINI and MINI-KID have good psychometric properties, including good concordance with other structured psychiatric interviews (between 78-100% with the Schedule for Affective Disorders and Schizophrenia for School Aged Children – Present and Lifetime Version; K-SADS-PL; Kaufman et al., 1997) and good to very good interrater (Cohen’s Kappa values of 0.65-1.00) reliability and moderate to very good test-retest (Cohen’s Kappa values of 0.41-1.00) reliability (Sheehan et al., 1998; Sheehan et al., 2010). Based on measure guidelines, during interviews of 6-12 year old patients, questions were directed to patients in the presence of caregivers; caregivers were encouraged to interject if patients’ answers were inaccurate. For 13-17 year old patients, questions from the MINI-KID were directed to the patient; for 18-24 year old patients, questions from the MINI were directed to the patient. Caregivers were not present during interviews of patients 13 years and older.

2.2.3. **Pediatric Pain Coping Inventory – Child and Teen Report (PPCI; Varni et al., 1996).**

The PPCI assesses the frequency with which pediatric pain coping strategies are implemented. The PPCI has developmentally appropriate child (5-12 year olds) and teen (13-18 year olds) versions; because a young adult version was unavailable, the teen version was administered to all patients 13 years and older. Items are answered on a 3-point Likert scale from 0 (not at all) to 2 (a lot). The PPCI has five factors: (1) Cognitive Self-Instruction (internal self-statements that deal with an individual’s cognitions regarding pain; e.g., “tell myself to be brave”); (2) Seeks Social Support (seeking aid, comfort, or understanding from parents, peers, or others; e.g., “have a parent or friend sit with me”); (3) Strives to Rest and Be Alone (e.g., “lie down” and “ask to stay by myself”); (4) Cognitive Refocusing (actively focusing one’s attention
away from pain perception; e.g., “think about happy things”); and (5) Problem-Solving Self-Efficacy (engaging in overt acts that are intended to manage pain; e.g., “know I can ask for something that will make me feel better”). Internal consistency for the overall score (α = .85) was good with weaker internal consistencies for the five subscales (α = .67 - .77); factor analysis supports the five-factor structure (Varni et al., 1996). The overall internal consistency of the PPCI in the current sample was excellent (α = .93); however, the internal consistencies of the five subscales were slightly weaker (αs ranging from .62 to .74).

2.2.4. **Pediatric Quality of Life Inventory Version 4.0 Generic Core Scales—Young Child, Child, Adolescent, and Young Adult Report (PedsQL – Generic Core Scale; Varni, Burkwinkle, Seid, & Skarr, 2003; Varni & Limbers, 2009; Varni, Seid, Knight, Uzark, & Szer 2002; Varni, Seid, & Kurtin, 2001).**

The PedsQL – Generic Core Scale assesses health-related quality of life in children and adolescents in the areas of physical, emotional, social, and school functioning. The 23-item generic core measure was developed for use in healthy populations and in pediatric populations with acute or chronic health conditions. Items are answered on a 5-point Likert scale ranging from 0 (*never a problem*) to 4 (*almost always a problem*). Items are reverse-scored and linearly transformed to a 0-100 scale such that higher scores indicate better HRQOL. In addition to the Total Score, the PedsQL encompasses four scales: Physical Functioning, Emotional Functioning, Social Functioning, and School Functioning. Also, two summary scores can be calculated: Physical Functioning and Psychosocial Functioning (which includes all items from the Emotional, Social, and School Functioning Scales). Scale, summary, and total scores are computed as the sum of the items divided by the number of items completed. Scale, summary, and total scores range from 0-100. Scores one standard deviation below the population mean
have been proposed as a meaningful cut-off point for at-risk status for impaired HRQOL (Varni, Burkwinkle, & Seid, 2005). Developmentally appropriate versions were administered to patients based on chronological age (see Table I). In a population of cancer patients, the scale had good construct validity (as measured by significant differences \( ps < .05 \) on all scales between children with cancer and healthy children) and good internal consistency (\( \alpha = 0.88; \) Varni et al., 2002b). In the current study, the internal consistencies for the different versions were acceptable and ranged from .71 to .94.
<table>
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<tr>
<th>Measures Administered to Patients Based on Patient Age</th>
<th>Ages 6-7</th>
<th>Ages 8-12</th>
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<td>PPCI Child</td>
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2.2.5. **Pediatric Quality of Life Inventory Cancer Module– Young Child, Child, Adolescent, and Young Adult Report (PedsQL 3.0 Cancer Module; Varni, Burkwinkle, Katz, Meeske, & Dickinson, 2002).**

The PedsQL Cancer Module assesses health-related quality of life and consists of items specifically tailored for pediatric cancer patients. The 27-item multidimensional measure has 8 scales: Pain and Hurt, Nausea, Procedural Anxiety, Treatment Anxiety, Worry, Cognitive Problems, Perceived Physical Appearance, and Communication. The Likert responses and scoring procedures are identical to the PedsQL Generic Core Scale. Developmentally appropriate versions were administered to patients based on chronological age (see Table I). In a population of cancer patients, the module demonstrated good construct validity (as measured by significant differences $[ps < .05]$ on the Nausea, Treatment Anxiety, and Worry Scales between children currently receiving treatment versus those who had completed at least 12 months prior to the assessment) and good internal consistency ($\alpha = 0.72$ child; Varni et al., 2002a). In the current study, the internal consistencies for the different versions were acceptable and ranged from .85 to .98.

2.2.6. **Posttraumatic Stress Disorder Checklist – Specific Stressor (PCL-S; Weathers, Litz, Huska, & Keane, 1994).**

The PCL is a 17-item self-report measure of the *DSM-IV* symptoms associated with a diagnosis of PTSD. Items are answered on a 1 (*not at all*) to 5 (*extremely*) Likert scale to indicate how much an individual has been bothered by a problem in the last month. The PCL has good internal consistency ($\alpha = .94$) and convergent validity ($r = .93$; Blanchard, Jones-Alexander, Buckley, & Forneris, 1996). The PCL can be used to screen individuals for PTSD, to diagnose PTSD, or to monitor symptom change. The PCL-S is a version of the PCL that asks
about symptoms related to a specific, identified “stressful experience.” Scores on the PCL-S range from 17 to 85. A cut-off of 44 has high sensitivity and specificity in predicting PTSD (Blanchard et al., 1996). Item scores of 3 (“moderately”), 4 (“quite a bit”), and 5 (“extremely”) are used as cutoffs of symptom presence. In the current study, caregivers completed this measure and were directed to rate their symptoms in relation to the patient’s recent cancer diagnosis. The PCL-S was found to have internal consistency in the current sample (α = .91).

2.2.7. **UCLA PTSD Index for DSM-IV (PTSDI; Pynoos, Rodriguez, Steinberg, Stuber, & Frederick, 1998).**

The PTSDI is a series of self-report instruments that screen both for exposure to traumatic events and for DSM-IV PTSD symptoms in children and adolescents. Items assessing how often symptoms have been present over the past month are answered on a 5-point Likert scale ranging from 0 (none) to 4 (most). Item scores of 3 (“much of the time”) and 4 (“most of the time”) are used as cutoffs of symptom presence. Patients were instructed to complete the PTSDI referring to their symptoms following their cancer diagnosis. The PTSDI has developmentally appropriate child (5-12 year olds) and adolescent (13-18 year olds) versions; because a young adult version was unavailable, the adolescent version was administered to all patients 13 years and above. The PTSDI has good internal consistency (α = .90) and convergent validity (r = 0.75; Steinberg et al., 2013), as well as good retest reliability (r = .84; Rodriguez, Steinberg, Saltzman, & Pynoos, 2001b). Items are grouped into DSM-IV criteria clusters B (re-experiencing/intrusion), C (avoidance/numbing), and D (arousal). The PTSDI also includes two additional questions assessing fear of recurrence of the traumatic event and trauma-related guilt. Scores on the PTSDI range from 0 to 68. A cut-off of 38 has high sensitivity and specificity in detecting PTSD (Rodriguez et al., 2001a, 2001b). The instrument has been used in the
assessment of pediatric cancer (Brown et al., 2003; Currier et al., 2009; Phipps et al., 2005). The child ($\alpha = .96$) and adolescent ($\alpha = .89$) versions of the PTSDI were found to be internally consistent in the current study.

2.2.8. **Varni-Thompson Pediatric Pain Questionnaire - Visual Analogue Scale**

**(PPQ-VAS; Varni, Thompson, & Hanson, 1987).**

The PPQ-VAS measures present pain and worst pain intensity during the last week. The PPQ-VAS consists of two 100mm horizontal lines, one representing present pain intensity and one representing worst pain intensity during the last week. Each line is without markings, numbers, or words, representing a continuum of pain. The PPQ-VAS is anchored with developmentally appropriate pain descriptors (“not hurting, no discomfort, no pain” accompanied by a happy face at one end, and “hurting a whole lot, very uncomfortable, severe pain” accompanied by a sad face at the other end). Patients rate their pain intensity by marking the point corresponding to their pain intensity on each horizontal line of the PPQ-VAS. Pain intensity scores are calculated by measuring the distance (in mm) from the left end point of the scale to the patient’s mark. The PPQ-VAS has been shown to have good construct validity ($r = .35, p < .05$ between present pain intensity and disease activity; Thompson et al., 1987).

2.3. **Procedure**

Participants were recruited from the Pediatric Hematology-Oncology Service at Comer Children’s Hospital at the University of Chicago. Consent was obtained from the parent or legal guardian of all patients under 18 years old. Consent was obtained from all patients over 18, and assent was obtained from all patients under 18 years old. Consent was also obtained from patients’ primary caregivers regarding their own participation in the study. Participation in the study was entirely voluntary and without remuneration. The MINI-KID and MINI were
administered as structured diagnostic interviews by psychology graduate students with extensive assessment training as well as by a medical student and two advanced undergraduate students who received training by Ms. Goldwin. Assessors discussed ambiguous responses with study principal investigators (which included a pediatric psychologist and child psychiatrist). All other questionnaires were completed by the participants. Patients completed age-specific versions of the PTSDI, PPQ-VAS, PPCI, and PedsQL (Generic Core Scales and the Cancer Module).² Caregivers completed the PCL-S to rate their own PTSS, specifically in relation to the patients’ cancer diagnoses. Table I indicates the specific versions of all measures administered to patients in each age range.

2.4. **Statistical Analyses**

Descriptive analyses of demographic and medical variables were conducted to characterize the current sample. Means and standard deviations for all study variables were calculated, as was the frequency with which patients endorsed symptoms of PTSD (as determined by measure cutoffs of symptom presence). Kolmogorov-Smirnov tests of normality were conducted to assess whether variables deviated significantly from normality.

To examine whether pediatric cancer patients and their caregivers reported elevated levels of PTSS as compared to established normative data for appropriate comparison groups, independent samples t-tests were conducted. We also calculated the percentage of patients and caregivers who reported scores above the recommended cutoff scores on the PTSDI and PCL. A series of independent samples t-tests were also conducted to examine whether newly diagnosed

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² The order in which the protocol was administered varied across participants. Whereas some patients completed questionnaires first, the MINI was administered first for others. Attempts were made to administer the questionnaires in a consistent order, with measures of overall health-related quality of life (HRQOL) completed first, followed by measures assessing pain, pain coping, posttraumatic stress symptoms, and then cancer-related HRQOL.
pediatric cancer patients’ HRQOL was significantly lower than established normative data for healthy controls. Welch’s $t$-tests were used if the variances between the two groups were unequal.

To examine the relationships between patient PTSS, caregiver PTSS, patient pain intensity, and patient HRQOL, Pearson product-moment correlation coefficients were calculated. Separate correlations were calculated for physical HRQOL, psychosocial HRQOL, and cancer-specific HRQOL. To explore whether patient pain was associated with any of the five pain coping strategies from the PPCI, Pearson product-moment correlation coefficients were calculated. Finally, to test whether caregiver PTSS moderated the relationship between patient pain and patient PTSS, moderated regression analyses were conducted using standard multiple regression following procedures suggested by Aiken and West (1991). Correlation effect sizes are designated as small (0.10 – 0.29), moderate (0.30 – 0.49), and large (≥ 0.50) based on Cohen’s (1992) conventions. Given the exploratory nature of this study and the small sample size, data interpretation will focus on the size of correlation, rather than the level of significance.
3. RESULTS

3.1. Tests of Normality

Patient PTSS ($D[20] = .20, p = .03$), present pain scores ($D[21] = .20, p = .02$), and time since diagnosis ($D[21] = .20, p = .03$) were significantly non-normal. Thus, these variables were transformed by calculating the square root. Transformed variables did not deviate significantly from normal ($ps < .05$) and were used in all subsequent analyses.

3.2. Demographic and Medical Characteristics

Table II displays the demographic and medical characteristics for the pediatric cancer patients. Table III displays the means and standard deviations for all study variables. Figures 3 and 4 display the frequency with which patients and caregivers endorsed PTSS (as determined by measure cutoff scores).
TABLE II

DEMOGRAPHIC AND MEDICAL CHARACTERISTICS OF PEDIATRIC CANCER PATIENTS

<table>
<thead>
<tr>
<th></th>
<th>M (SD); Mdn</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (Years)</td>
<td>14.62 (5.35); 15.00</td>
<td>6 – 23</td>
</tr>
<tr>
<td>Days since Diagnosis</td>
<td>26.43 (22.19); 24.00</td>
<td>2 – 85</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>52.4</td>
<td>11</td>
</tr>
<tr>
<td>Female</td>
<td>47.6</td>
<td>10</td>
</tr>
<tr>
<td>Ethnicity</td>
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<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>33.3</td>
<td>7</td>
</tr>
<tr>
<td>Non-Hispanic White</td>
<td>28.6</td>
<td>6</td>
</tr>
<tr>
<td>Black</td>
<td>23.8</td>
<td>5</td>
</tr>
<tr>
<td>Other</td>
<td>14.3</td>
<td>3</td>
</tr>
<tr>
<td>Caregiver Type</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>80.95</td>
<td>17</td>
</tr>
<tr>
<td>Other</td>
<td>19.05</td>
<td>4</td>
</tr>
<tr>
<td>Insurance Type</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Private</td>
<td>66.67</td>
<td>14</td>
</tr>
<tr>
<td>Public/None</td>
<td>33.33</td>
<td>7</td>
</tr>
<tr>
<td>Treatment Status</td>
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<td></td>
</tr>
<tr>
<td>Active Treatment</td>
<td>95.24</td>
<td>20</td>
</tr>
<tr>
<td>Not on Active Treatment</td>
<td>4.76</td>
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<tr>
<td>Cancer Type</td>
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<td></td>
</tr>
<tr>
<td>Solid Tumors</td>
<td>47.62</td>
<td>10</td>
</tr>
<tr>
<td>Leukemia</td>
<td>38.10</td>
<td>8</td>
</tr>
<tr>
<td>Other</td>
<td>14.29</td>
<td>3</td>
</tr>
<tr>
<td>Psychiatric Diagnoses</td>
<td>%</td>
<td>n</td>
</tr>
<tr>
<td>-----------------------</td>
<td>-----</td>
<td>---</td>
</tr>
<tr>
<td>Agoraphobia</td>
<td>28.57</td>
<td>6</td>
</tr>
<tr>
<td>Major Depressive Disorder</td>
<td>19.05</td>
<td>4</td>
</tr>
<tr>
<td>Alcohol Abuse</td>
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<td>3</td>
</tr>
<tr>
<td>Substance Dependence</td>
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<td>2</td>
</tr>
<tr>
<td>ADHD, Inattentive Type</td>
<td>9.52</td>
<td>2</td>
</tr>
<tr>
<td>ADHD, Combined Type</td>
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</tr>
<tr>
<td>Bipolar II Disorder, Past</td>
<td>4.76</td>
<td>1</td>
</tr>
<tr>
<td>Bipolar Disorder, NOS</td>
<td>4.76</td>
<td>1</td>
</tr>
<tr>
<td>Conduct Disorder</td>
<td>4.76</td>
<td>1</td>
</tr>
<tr>
<td>Obsessive Compulsive Disorder</td>
<td>4.76</td>
<td>1</td>
</tr>
<tr>
<td>Posttraumatic Stress Disorder</td>
<td>4.76</td>
<td>1</td>
</tr>
<tr>
<td>Social Phobia, Generalized</td>
<td>4.76</td>
<td>1</td>
</tr>
<tr>
<td>Specific Phobia</td>
<td>4.76</td>
<td>1</td>
</tr>
<tr>
<td>Substance Abuse</td>
<td>4.76</td>
<td>1</td>
</tr>
<tr>
<td>Any Psychiatric Diagnosis</td>
<td>57.14</td>
<td>12</td>
</tr>
</tbody>
</table>

* M: mean; SD: standard deviation; Mdn: median; n: sample size; ADHD: Attention Deficit Hyperactivity Disorder; NOS: Not Otherwise Specified.

Although rates of psychiatric diagnoses appear high, it should be noted that the Mini-International Neuropsychiatric Interview (MINI) is a research instrument and not a diagnostic tool used in clinical settings. The MINI was designed to err on the side of false positives (Sheehan et al., 1998). As such, endorsement of symptoms on the MINI indicates a need for subsequent follow-up and further clinical assessment.
### TABLE III

**MEANS AND STANDARD DEVIATIONS FOR MEASURES OF POSTTRAUMATIC STRESS, PAIN, AND QUALITY OF LIFE**

<table>
<thead>
<tr>
<th></th>
<th>M (SD)</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Posttraumatic Stress Symptoms</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Patient</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cluster B (Re-Experiencing)</td>
<td>5.75 (5.21)</td>
<td>0.00 – 17.00</td>
</tr>
<tr>
<td>Cluster C (Avoidance)</td>
<td>7.05 (6.17)</td>
<td>0.00 – 24.00</td>
</tr>
<tr>
<td>Cluster D (Increased Arousal)</td>
<td>7.95 (3.97)</td>
<td>0.00 – 17.00</td>
</tr>
<tr>
<td>Total</td>
<td>20.75 (14.20)</td>
<td>0.00 – 57.00</td>
</tr>
<tr>
<td><strong>Caregiver</strong></td>
<td>30.52 (11.00)</td>
<td>17.00 – 62.00</td>
</tr>
<tr>
<td><strong>Pain Intensity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Current pain</td>
<td>24.05 (26.56)</td>
<td>0 – 80</td>
</tr>
<tr>
<td>Worst pain in past week</td>
<td>54.57 (30.61)</td>
<td>3 – 100</td>
</tr>
<tr>
<td><strong>Pain Coping Strategies</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cognitive Self-Instruction</td>
<td>1.12 (0.45)</td>
<td>0.00 – 1.86</td>
</tr>
<tr>
<td>Problem-Solving</td>
<td>1.10 (0.37)</td>
<td>0.30 – 1.80</td>
</tr>
<tr>
<td>Distraction</td>
<td>0.89 (0.36)</td>
<td>0.10 – 1.60</td>
</tr>
<tr>
<td>Seeks Social Support</td>
<td>1.07 (0.39)</td>
<td>0.00 – 1.67</td>
</tr>
<tr>
<td>Catastrophizing/Helplessness</td>
<td>0.96 (0.45)</td>
<td>00.00 – 2.00</td>
</tr>
<tr>
<td><strong>HRQOL: General</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>60.46 (17.77)</td>
<td>32.61 – 100.00</td>
</tr>
<tr>
<td>Physical Functioning</td>
<td>50.00 (23.76)</td>
<td>15.63 – 100.00</td>
</tr>
<tr>
<td>Psychosocial Functioning</td>
<td>66.03 (16.49)</td>
<td>33.33 – 100.00</td>
</tr>
<tr>
<td>Emotional Functioning</td>
<td>62.62 (23.27)</td>
<td>20.00 – 100.00</td>
</tr>
<tr>
<td>Social Functioning</td>
<td>71.67 (24.36)</td>
<td>10.00 – 100.00</td>
</tr>
<tr>
<td>School Functioning</td>
<td>63.81 (21.33)</td>
<td>15.00 – 100.00</td>
</tr>
<tr>
<td><strong>HRQOL: Cancer-Specific</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>61.86 (18.33)</td>
<td>21.90 – 99.07</td>
</tr>
<tr>
<td>Pain/Hurt</td>
<td>60.71 (31.94)</td>
<td>0.00 – 100.00</td>
</tr>
<tr>
<td>Nausea</td>
<td>55.65 (22.16)</td>
<td>20.00 – 100.00</td>
</tr>
<tr>
<td>Procedural Anxiety</td>
<td>58.73 (31.01)</td>
<td>0.00 – 100.00</td>
</tr>
<tr>
<td>Treatment Anxiety</td>
<td>69.05 (30.18)</td>
<td>0.00 – 100.00</td>
</tr>
<tr>
<td>Worry</td>
<td>51.19 (28.29)</td>
<td>0.00 – 100.00</td>
</tr>
<tr>
<td>Cognitive Problems</td>
<td>67.26 (21.42)</td>
<td>1.00 – 100.00</td>
</tr>
<tr>
<td>Perceived Physical Appearance</td>
<td>63.10 (31.24)</td>
<td>0.00 – 100.00</td>
</tr>
<tr>
<td>Communication</td>
<td>68.65 (28.49)</td>
<td>0.00 – 100.00</td>
</tr>
</tbody>
</table>

a **M**: mean; **SD**: standard deviation; **HRQOL**: Health-related quality of life.
3.3. **Comparison between Participants and Non-Participants**

Patients who participated in the study \((n = 21)\) were compared to patients who were approached and declined to participate and patients who withdrew their consent (non-participants; \(n = 7\)) for all available demographic and medical variables. No group differences emerged. Specifically, participants and non-participants did not significantly differ by patient gender \((\chi^2(1) = 1.85, p = .17)\), patient age \((t(25) = 0.88, p = .39)\), patient ethnicity \((\chi^2(3) = 4.85, p = .18)\), caregiver type \((\chi^2(1) = 0.02, p = .90)\), cancer type \((\chi^2(2) = 3.54, p = .17)\), days since diagnosis \((t(25) = 1.42, p = .17)\), or insurance type \((\chi^2(1) = 0.56, p = .46)\).

3.4. **Baseline Differences for Demographic and Medical Variables**

Bivariate correlation analyses were conducted to examine associations between patient age and patient PTSS, patient pain, patient HRQL, and caregiver PTSS. Patient age was not significantly correlated with any study variables \((ps > .05)\), although there was a positive moderate relationship between patient age and worst pain in the past week, \(r(19) = .32, p = .16\). Next, patient gender, patient ethnicity, and caregiver type were examined for group differences across patient PTSS, patient pain, patient HRQOL, and caregiver PTSS. A series of independent samples \(t\)-tests to examine group differences by patient gender did not field significant differences \((ps > .05)\). A series of one-way analyses of variance (ANOVAs) to examine group differences by patient ethnicity did not reveal any significant differences \((ps > .05)\). Finally, a series of independent samples \(t\)-tests to examine group differences by caregiver type revealed that patients whose primary caregivers were their mothers reported significantly greater levels of PTSS \((n = 17, M = 23.25, SD = 13.86)\) than patients whose primary caregivers were not their
mothers ($n = 4, M = 10.75, SD = 12.20), t(18) = 2.34, p = .03. No other group differences by

caregiver type were found ($ps > .05$).

Correlational analyses were conducted to examine the association between time since
diagnosis and patient PTSS, patient pain, patient HRQOL, and caregiver PTSS. Time since
diagnosis was not significantly correlated with any study variables ($ps > .05$). Next, cancer type,
insurance status, and presence of past or current psychiatric diagnoses were examined for group
differences across patient PTSS, patient pain, patient HRQOL, and caregiver PTSS. A series of
one-way ANOVAs to examine differences by cancer type did not reveal significant differences
($ps > .05$). A series of independent samples $t$-tests to examine differences by insurance status
indicated that caregivers of patients receiving public aid reported higher levels of PTSS ($M =
40.43, SD = 13.58$) relative to caregivers of patients with private insurance ($M = 25.57, SD =
4.69$), $t(6) = 2.81, p = .03$. No other significant differences were found ($ps > .05$). A series of
independent-samples $t$-tests to examine group differences by presence versus absence of a
lifetime psychiatric diagnosis did not reveal significant differences on any of the study variables
($ps > .05$).

3.5. **Comparisons with Established Normative Means**

To compare the levels of PTSS in our sample relative to those of healthy controls, a
literature review was conducted to find the most appropriate comparison groups for both patients
and caregivers. A sample of healthy children recruited to serve as an acquaintance control group
in Phipps, Jurbergs, & Long’s (2009) study of PTSS was selected as the comparison group for
the patients in the current study. Children in the comparison group ranged in age from 7 to 18
years old ($M = 12.38, SD = 3.0$) and were predominantly female (59.3%). Children in the
comparison group were 91.7% Caucasian, 5.6% African-American, and 2.7% identified as “Other.” Contrary to our hypothesis, results from an independent samples t-test indicated that newly diagnosed pediatric cancer patients \((n = 20, M = 20.75, SD = 14.20)\) did not report significantly higher levels of PTSS compared to healthy controls \((n = 108, M = 17.15, SD = 14.80)\), \(t(126) = 1.01, p = .32\). We also found that only 10% \((n = 2)\) of patients reported PTSDI scores above the recommended cutoff score of 38.

No publicly available normative means for healthy controls were available for the Specific Stressor version of the PCL (PCL-S) that was administered to the caregivers in the current study. As such, we were unable to directly test our hypothesis that caregivers of newly diagnosed cancer patients would report elevated levels of PTSS as compared to established normative means for parents of healthy children. However, we utilized data from a study that administered the PCL – Civilian Version (PCL-C) to a sample of women enrolled in an HMO (Walker, Newman, Dobie, Ciechanowski, & Katon, 2002). The questions and scoring for the PCL-S and the PCL-C are identical, with the PCL-C asking about symptoms in relation to “stressful experiences” rather than a single specified event. The individuals in our selected comparison group were 18 to 65 years old \((M = 41.8, SD = 11.5)\). Individuals in the comparison group were 79% Caucasian, 6% African-American, 8% Asian, 2% Hispanic, and 1% Native American. Results from an independent samples t-test indicated that caregivers of newly diagnosed pediatric cancer patients \((n = 21, M = 30.52, SD = 11.00)\) did not report significantly different levels of PTSS compared to a sample of women enrolled in an HMO \((n = 1161, M = 27.2, SD = 10.3)\), \(t(1180) = 2.27, p = .14\). We also found that only 9.52% \((n = 2)\) of caregivers who reported PCL scores above the recommended cutoff score of 44 or greater.
To compare the HRQOL in our sample relative to those of healthy control participants, we utilized data from a field trial that examined child-reported PedsQL scores in chronically ill, acutely ill, and healthy children (Varni et al., 2001). Although demographic information was not reported separately for the three groups of healthy children, combined information for all study participants was available. Among those children who completed self-report measures, subjects were ages 5 to 18 years ($n = 401, M = 10.78, SD = 3.61$); 49.5% of the children were female, 48.6% were male, and 1.9% did not report their gender. Across the entire sample of children, 39.8% of the children were Hispanic, 36.5% were Non-Hispanic White, 7.0% were Non-Hispanic Black, 2.9% were Asian/Pacific Islander, 1.1% were American Indian or Alaskan Native, 5.9% identified as “Other,” and 6.9% did not report their ethnicity. Regarding insurance type, 56% of subjects were covered by Medicaid; 31% had commercial insurance; and 13% reported self-pay, “Other,” or did not respond. Overall, the sample was ethnically diverse and represented a range of socioeconomic statuses. Independent samples $t$-tests were conducted to examine group differences between the HRQOL total and scale scores of the current study sample and those of the healthy children recruited by Varni et al. (2001). For every comparison, pediatric cancer patients reported poorer HRQOL than did healthy control children (Table IV). Two-thirds of the current sample reported total HRQOL scores above cut-off scores for at-risk status for impaired HRQOL. Rates of impaired HRQOL for total, summary, and scale scores are reported in Table IV.
TABLE IV

COMPARISON BETWEEN HEALTH-RELATED QUALITY OF LIFE OF NEWLY DIAGNOSED PEDIATRIC CANCER PATIENTS AND HEALTHY CONTROL SUBJECTS  

<table>
<thead>
<tr>
<th></th>
<th>Current study</th>
<th>Healthy sample</th>
<th>Independent Samples t-test</th>
<th>Percent of current sample at-risk for impaired HRQOL</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>M</td>
<td>SD</td>
<td>n</td>
</tr>
<tr>
<td>Total Score</td>
<td>21</td>
<td>60.45</td>
<td>17.77</td>
<td>401</td>
</tr>
<tr>
<td>Physical</td>
<td>21</td>
<td>50.00</td>
<td>23.76</td>
<td>400</td>
</tr>
<tr>
<td>Psychosocial</td>
<td>21</td>
<td>66.03</td>
<td>16.49</td>
<td>399</td>
</tr>
<tr>
<td>Emotional</td>
<td>21</td>
<td>62.62</td>
<td>23.27</td>
<td>400</td>
</tr>
<tr>
<td>Social</td>
<td>21</td>
<td>71.67</td>
<td>24.36</td>
<td>399</td>
</tr>
<tr>
<td>School</td>
<td>21</td>
<td>63.81</td>
<td>21.33</td>
<td>386</td>
</tr>
</tbody>
</table>

a  n: sample size; M: mean; SD: standard deviation. HRQOL: health-related quality of life. ** p < .01, *** p < .001. Welch’s t-tests were used if the variances between the two groups were unequal.

b  Healthy sample includes self-report for children 5-18 years old (Varni, Seid, & Kurtin, 2001).
3.6. **Relationships Between Patient Posttraumatic Stress, Patient Pain, Patient Health-Related Quality of Life and Caregiver Posttraumatic Stress**

There was a small, positive correlation between patient PTSS and caregiver PTSS, $r(18) = .25, p = .30$. Although the correlation between patient PTSS and present pain was weak, there was a small positive relationship between patient PTSS and worst pain in the past week, $r(18) = .24, p = .32$. Higher levels of patient PTSS were associated with poorer patient HRQOL. Specifically, greater patient PTSS severity was negatively correlated with physical functioning ($r(18) = -.21, p = .38$), psychosocial functioning ($r(18) = -.52, p = .02$), and cancer-specific HRQOL ($r(18) = -.86, p < .001$).

There was a moderate positive correlation between caregiver PTSS and patients’ worst pain in the past week. Specifically, higher levels of caregiver PTSS were associated with higher levels of patients’ worst pain in the past week, $r(19) = .32, p = .16$. In contrast, caregiver PTSS was weakly correlated with patients’ present pain. Higher levels of caregiver PTSS were associated with poorer patient HRQOL. Specifically, higher levels of caregiver PTSS were negatively correlated with physical functioning ($r(19) = -.34, p = .13$), psychosocial functioning ($r(19) = -.35, p = .12$), and cancer-specific HRQOL ($r(19) = -.24, p = .31$).

Patient pain was negatively correlated with patient HRQOL. Specifically, present pain was negatively correlated with physical functioning ($r(19) = -.49, p = .02$), psychosocial functioning ($r(19) = -.32, p = .16$), and cancer-related HRQOL ($r(19) = -.18, p = .44$). Similarly, patients’ worst pain in the past week was negatively correlated with physical functioning ($r(19) = -.31, p = .18$), psychosocial functioning ($r(19) = -.14, p = .54$), and cancer-related patient HRQOL ($r(19) = -.20, p = .40$). (See Table V for correlation coefficients.)
TABLE V

CORRELATIONS BETWEEN CAREGIVER POSTTRAUMATIC STRESS SYMPTOMS AND PATIENT POSTTRAUMATIC STRESS SYMPTOMS, PRESENT PAIN, WORST PAIN IN THE PAST WEEK, PHYSICAL FUNCTIONING, PSYCHOSOCIAL FUNCTIONING, AND CANCER-SPECIFIC HEALTH-RELATED QUALITY OF LIFE* a

<table>
<thead>
<tr>
<th></th>
<th>Patient PTSS</th>
<th>Caregiver PTSS</th>
<th>Present Pain</th>
<th>Worst Pain</th>
<th>HRQOL: Physical</th>
<th>HRQOL: Psychosocial</th>
<th>HRQOL: Cancer-specific</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient PTSS</td>
<td>1</td>
<td>.25</td>
<td>.06</td>
<td>.24</td>
<td>-.21</td>
<td>-.52*</td>
<td>-.86***</td>
</tr>
<tr>
<td>Caregiver PTSS</td>
<td>--</td>
<td>1</td>
<td>.09</td>
<td>.32</td>
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<tr>
<td>Worst Pain</td>
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<td>1</td>
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<td>.65**</td>
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<td>HRQOL: Cancer-specific</td>
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* PTSS: Posttraumatic Stress Symptoms; HRQOL: Health-related quality of life. * p < .05. ** p < .01. *** p < .001. Moderate and large correlations are printed in bold. Correlation coefficients were calculated using square root transformed patient PTSS and patient present pain.
3.7. **Relationship Between Pain and Pain Coping Strategies**

There was a moderate positive relationship between present pain and reported use of the strategy of seeking social support, $r(19) = .34, p = .13$. There were also small positive relationships between present pain and reported use of the following strategies: cognitive self-instruction ($r(19) = .17, p = .47$), problem solving ($r(19) = .17, p = .48$), and catastrophizing/helplessness ($r(19) = .24, p = .30$). There were small positive relationships between patients’ worst pain in the past week and reported use of cognitive self-instruction ($r(19) = .23, p = .32$) and seeking social support ($r(19) = .16, p = .48$). (See Table VI for all correlation coefficients.)

### TABLE VI

<table>
<thead>
<tr>
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<th>Present Pain</th>
<th>Worst Pain</th>
<th>Cognitive Self-Instruction</th>
<th>Problem Solving</th>
<th>Distraction</th>
<th>Seeks Social Support</th>
<th>Catastrophizing/Helplessness</th>
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<td>.23</td>
<td>.03</td>
<td>.04</td>
<td>.16</td>
<td>.07</td>
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*a Moderate and large correlations are printed in bold. Correlation coefficients were calculated using square root transformed patient pain.*

3.8. **Moderation Analyses**

We completed moderated regression analyses using standard multiple regression. Following procedures suggested by Aiken and West (1991), centered scores representing
caregiver PTSS and patient pain, and the interaction of these two variables, were used to predict levels of patient PTSS. Separate regressions were conducted for present pain and worst pain in the past week. Results indicated that neither caregiver PTSS nor present pain was significantly associated with increased patient PTSS \((B = .59, \, t(19) = 1.45, \, p = .17)\) and \((B = -.04, \, t(19) = -0.35, \, p = .73)\), respectively. Furthermore, the interaction of caregiver PTSS and present pain did not significantly predict patient PTSS, \((B = .21, \, t(19) = 1.41, \, p = .18)\). Although the interaction was not significant, given the small sample size, simple slopes of present pain on patient PTSS at high versus low levels of caregiver PTSS were examined to further examine the interaction. Results indicated that when caregiver PTSS was high, present pain tended to be positively related to patient PTSS, \((B = .15, \, t(19) = 0.95, \, p = .36)\). When caregiver PTSS was low, present pain tended to be inversely related to patient PTSS, \((B = -.24, \, t(19) = -1.09, \, p = .29)\) (see Figure 3).

![Figure 3. Simple slopes of patient present pain on patient posttraumatic stress symptoms as a function of caregiver posttraumatic stress symptoms. PTSS = posttraumatic stress symptoms. SD = standard deviation. Analyses were conducted using transformed variables. As such, y-axis values reflect square root of UCLA PTSD Index scores.](image)
Parallel analyses were conducted with worst pain in the past week as a predictor. Neither caregiver PTSS nor worst pain in the past week was associated with increased patient PTSS ($B = .41, t(19) = .93, p = .37$ and $B = .01, t(19) = .64, p = .53$, respectively). The interaction between caregiver PTSS and worst pain in the past week did not significantly predict patient PTSS, $B = - .002, t(19) = -0.11, p = .92$. 
4. DISCUSSION

The current study examined posttraumatic stress, pain, and health-related quality of life in newly diagnosed pediatric cancer patients, as well as the relationships between these constructs and caregiver posttraumatic stress. Our results provide important information about the experience of pediatric cancer patients and their primary caregivers within the first three months after diagnosis. Although neither patients nor caregivers experienced elevated levels of PTSS compared to normative samples, patients did report poorer HRQOL relative to healthy control participants. The current study also provided evidence of inverse relationships between patient PTSS and patient HRQOL, caregiver PTSS and patient HRQOL, and patient pain and patient HRQOL. Results also indicated positive relationships between patient pain and both caregiver PTSS and seeking social support (a pain coping strategy). Finally, results provided preliminary evidence that caregiver PTSS may moderate the relationship between patient pain and patient PTSS.
4.1. **Pediatric Cancer Patients and Caregivers’ Posttraumatic Stress**

PTSS severity was not higher among pediatric cancer patients and their caregivers relative to available normative data for healthy comparison groups. PTSS severity scores for both the current sample and the healthy comparison group fell 1 to 1.5 standard deviations below the cutoff score for likely PTSD, indicating the absence of elevated PTSS in either group. Given that patients in the current sample were assessed in the treatment setting, support and resources offered within pediatric cancer units may have contributed to the low rates of PTSS in the current sample.

Although our findings are inconsistent with expectations from Kazak and colleagues’ PMTS model (Kazak et al., 2009), other studies have also failed to demonstrate increased PTSS severity among pediatric cancer patients relative to healthy children (Barakat et al., 1997; Brown et al., 2003; Schwartz & Drotar, 2006) and to children who experienced other stressful events including natural disasters, accidents, serious physical injury, or the death of a parent (Salmon & Bryant, 2002). Notably, the rate of likely PTSD in our current sample is lower than that reported for physically healthy children in other studies (Barakat et al., 1997).

Phipps and colleagues have recently concluded that PTSS is “not a widespread problem or one that occurs in unusually high frequency” among pediatric cancer patients (Phipps et al., 2009, p. 1000). In a recent study of a large cohort of children with cancer, pediatric cancer patients completed assessments of PTSD and PTSS based on the event that they spontaneously identified as their most traumatic (Phipps et al., 2014). Almost half of the patients selected a non-cancer related event as their most traumatic event, and over two-thirds of the PTSD cases were associated with traumatic events not related to cancer. Similarly, in the current study, the patient who met criteria for PTSD (based on the MINI) did not report a cancer-related event as
the Criterion A traumatic event. Phipps and colleagues also found that when patients who did not identify cancer as their most traumatic event were asked to rate their PTSS in relation to their cancer experience, they reported lower levels of PTSS when referring to cancer-related traumatic events relative to non-cancer related events (Phipps et al., 2014). Phipps asserts that other researchers have had trouble accepting “good news” regarding the absence of elevated PTSS and PTSD in pediatric cancer patients and instead continue to “question whether we are missing something” (Phipps, 2005; p. 42). Rather than continuing to focus on posttraumatic stress and negative outcomes of cancer, Phipps (2007) recommends that researchers shift their focus toward the nature and mechanisms associated with the positive adjustment outcomes of pediatric cancer patients including optimism, posttraumatic growth, and benefit finding.

Closer examination of the specific PTSS endorsed by newly diagnosed pediatric cancer patients reveals that one-third of the patients in the current study endorsed clinically significant levels of sleep disturbance and irritability/anger (see Figure 4). Although these symptoms could be stress-related, they may also be associated with side effects of treatment (e.g., dexamethasone; Hinds et al., 2007), environmental changes (e.g., frequent hospitalizations, irregular school attendance), or appropriate, expected emotional reactions (e.g., anger about cancer-related disruptions in one’s life). Approximately one-quarter of the patients also endorsed clinically significant symptoms of hyperarousal (specifically hypervigilance) and re-experiencing of the traumatic event. Lower rates of avoidance symptoms, relative to hyperarousal and re-experiencing symptoms (particularly reactivity to event-related cues), are unsurprising given the necessity of ongoing treatments and medical appointments, particularly in the time immediately following a new cancer diagnosis.
Figure 4. Percentage of patients who endorsed each DSM-IV-TR posttraumatic stress disorder symptom at a clinical level. Percentages are calculated based on the total number of participants who completed each item. All patients did not complete all items.
Although we were unable to directly test our hypothesis that caregivers of pediatric cancer patients would experience higher levels of PTSS relative to parents of healthy children, we compared the rates of PTSS among caregivers of pediatric cancer patients to available comparison data. Our results did not reveal elevated PTSS among caregivers of newly diagnosed pediatric cancer patients. The rate of likely PTSD in caregivers (9.52%) was substantially lower than rates reported in other studies of parents of recently diagnosed pediatric cancer patients (e.g., 37.46%, Dunn et al., 2012). Interestingly, we did find that caregivers tended to endorse certain PTSS more frequently than others (see Figure 5). Specifically, almost half of the caregivers in our sample reported that they were at least moderately bothered by their tendency to be hypervigilant following their child’s pediatric cancer diagnosis. It may be that relative to other PTSS, hypervigilance to cancer-related stimuli arises soon after finding out that one’s child has cancer, possibly as an understandable response to warnings by the medical team to watch for treatment-related side effects and other adverse events (e.g., fever).
Figure 5. Percentage of caregivers who endorsed each *DSM-IV-TR* posttraumatic stress disorder symptoms at a clinical level.
Given that many of the presenting symptoms of cancer are similar to those of typical childhood illnesses (e.g., fatigue, fevers), caregivers may not immediately recognize that their children’s symptoms are areas of serious concern. Accordingly, following the cancer diagnosis, caregivers may feel compelled to be “superalert” to any changes in their children’s wellbeing. Notably, consistent with previous research that parent and pediatric cancer patients’ ratings of different clusters of PTSS are concordant (Kazak et al., 2004), patients also endorsed elevated levels of hypervigilance, a response that may be reinforced by medical personnel and setting.

There are two notable methodological differences between our study and those that have consistently found elevated parent or caregiver PTSS. First, we administered the PCL-S whereas most other researchers administered the Impact of Events Scale – Revised (IES-R). Although these measures tend to be correlated (Weathers, Litz, Herman, Huska, & Keane, 1993), the PCL may be less applicable to the experiences of caregivers of pediatric cancer patients (Manne, Du Hamel, Gallelli, Sorgen, & Redd, 1998). Also, these measures assess different time periods, with the IES-R assessing symptoms over the past week and the PCL-S assessing symptoms over the past month. Second, whereas some studies demonstrating elevated rates of parent PTSS provided broader instructions related to the nature of the traumatic event (i.e., “with respect to your child’s cancer,” Dolgin et al., 2007, p.774), caregivers in the current study were instructed to think about their child’s cancer diagnosis as the specific stressful event. Parents in other studies likely recalled symptoms related to a wider range of cancer-related experiences (including those that are potentially more traumatic than the news of a cancer diagnosis), potentially leading to increased reporting of PTSS. Given the limitations of our comparison groups (which are described in more detail below) and consistent evidence from previous studies of increased rates of PTSS among parents of children recently diagnosed with cancer (Dunn et
al., 2012; Patino-Fernandez et al., 2008; c.f., Jurbergs, Long, Ticona, & Phipps, 2009), our results should be interpreted with caution.

4.2. **Pediatric Cancer Patients’ Health-Related Quality of Life**

Although patients in the current study did not endorse elevated PTSS, HRQOL does appear to be compromised during the time immediately following diagnosis. Consistent with our hypothesis and with findings from other studies (e.g., Eiser et al., 2005; Landolt et al., 2006; Yaris et al., 2001), newly diagnosed cancer patients manifested lower HRQOL relative to healthy children. Whereas previous studies have relied on proxy-report measures of HRQOL (e.g., Yaris et al., 2001), the current study provides evidence that pediatric cancer patients’ subjective perceptions and expectations regarding their health and ability to cope are compromised as well. Specifically, newly diagnosed cancer patients self-reported poorer HRQOL across total, summary, and scale PedsQL scores.

In addition to examining overall HRQOL, we separately examined patients’ physical and psychosocial HRQOL. Two-thirds of the current sample evidenced impaired HRQOL and more patients evidenced impaired physical HRQOL relative to psychosocial HRQOL. Whereas impairments in psychosocial HRQOL may not occur immediately following diagnosis, the impact of diagnostic procedures and initial treatments on patients’ physical HRQOL (including low energy and pain related to illness and treatment) is immediate and concrete. Many patients and their families recognize and attempt to address patients’ physical discomfort prior to focusing on psychosocial difficulties that patients may encounter (i.e., missing school due to medical appointments, not being able to participate in the same activities as their same-age peers, feeling isolated). Overall, newly diagnosed patients perceive more adverse impacts of cancer and its treatment on physical relative to psychosocial functioning.
4.3. **Relationships between Patient Posttraumatic Stress, Caregiver Posttraumatic Stress, Patient Pain, and Patient Health-Related Quality of Life**

4.3.1. **Relationship between Patient Posttraumatic Stress and Caregiver Posttraumatic Stress.**

In contrast to previous work demonstrating a relationship between patient and parental PTSS in pediatric cancer patients (e.g., Phipps et al., 2005), patient and caregiver PTSS were only weakly correlated in the current study. One explanation for the discrepancy between our findings and those of previous studies may be the time since diagnosis across studies. Whereas our study examined PTSS in newly diagnosed patients, the majority of support for this relationship comes from studies of survivors of pediatric cancer and their parents who were assessed many years after the initial diagnosis (Barakat et al., 1997; Kazak et al., 1997; Stuber et al., 1994; Stuber et al., 1996). To our knowledge, ours is the first study to have examined whether this relationship exists among newly diagnosed pediatric cancer patients. Consistent with our findings, studies examining the relationship between parental and child PTSS within three months of a potentially traumatic event found that parent PTSS and children’s self-reported PTSS were not strongly related (Koplewicz et al., 2002; Landolt et al., 2003; McDermott & Cvitanovich, 2000). The strength of this relationship tended to increase as time since the traumatic event increased (Koplewicz et al., 2002), indicating that the “contagion of stress” (Pfefferbaum & Pfefferbaum, 1998) may require more time to evolve. Accordingly, it may be that the reciprocal influence between pediatric cancer patient and caregiver PTSS develops over the course of the cancer experience. For example, caregiver PTSS soon after diagnosis could predict subsequent but not concurrent patient PTSS.

4.3.2. **Relationship between Patient Posttraumatic Stress and Patient Pain.**
Newly diagnosed pediatric cancer patients endorsed a range of pain intensity levels, with scores ranging from the low to high end of the measure. We did not find evidence of a relationship between patient pain and patient PTSS in the current sample. Although previous studies have demonstrated a relationship between pain and general emotional distress, these studies included more heterogeneous populations in regards to time since diagnosis; previous studies also utilized different measures of both emotional distress and pain (e.g., Hedström, et al., 2003; Varni et al., 1995). For example, Varni and colleagues (2004) used the Emotional Functioning Scale from the PedsQL Generic Scales and the Pain Scale from the PedsQL Cancer Module to assess emotional functioning and pain-related disability, respectively. In the present study, we assessed more specific psychological (PTSS) and physical (current pain and worst pain in the past week) constructs.

As will be described below, patient pain and psychosocial HRQOL were inversely related in the current study. It may be that broader measures of newly diagnosed pediatric cancer patients’ emotional functioning better capture affective reactions to cancer-related pain. Additionally, the relationship between pain and posttraumatic stress may develop over time or following the completion of the initial phases of treatment. For example, pain during the acute phase of treatment may be a risk factor for subsequent PTSS.

4.3.3. **Relationship between Caregiver Posttraumatic Stress and Patient Pain.**

Consistent with our hypothesis, patient pain was positively associated with caregiver PTSS; however, this relationship was only present when examining the relationship between caregiver PTSS and patients’ ratings of their worst pain intensity in the past week. Our findings are consistent with previous research demonstrating that perceiving one’s child as experiencing intense pain is a stressor for parents and could be experienced as traumatic for parents of children.
with cancer (Pöder et al., 2010). Alternatively, in line with the relational model of PTSD (Scheeringa & Zeanah, 2001), caregivers with elevated PTSS may be less likely to respond effectively to patients’ needs during their experience of pain relative to psychologically healthy caregivers. For example, hypervigilant/overprotective caregivers may be less likely to redirect their children’s attention away from the pain, an effective coping strategy; instead, these caregivers may engage in higher levels of symptom-related talk, a possible pain antecedent that could trigger threatening thoughts about physical symptoms and, in turn, worsen patients’ pain (Blount et al., 2009). Alternatively, pediatric cancer patients whose caregivers have elevated PTSS and a withdrawn/unresponsive relational pattern may report higher levels of pain in an attempt to gain attention and support from caregivers (Claar et al., 2008).

4.3.4. **Relationship between Patient Posttraumatic Stress and Patient Health-Related Quality of Life.**

There was a strong, negative correlation between patient PTSS and psychosocial HRQOL. Said otherwise, increased PTSS severity was associated with poorer emotional, school, and social functioning. In contrast, consistent with the absence of a relationship between patient PTSS and patient pain, the relationship between patient PTSS and physical HRQOL was weak. This is the first study to our knowledge to demonstrate that patient PTSS is negatively associated with psychosocial HRQOL among newly diagnosed pediatric cancer patients. Our results are consistent with findings from longitudinal studies of pediatric patients following traumatic injuries (Holbrook et al., 2005; Landolt et al., 2009) and of childhood cancer survivors (Meeske et al., 2001). Although our results are correlational in nature, we suspect that consistent with findings from the aforementioned longitudinal studies, elevated PTSS precedes impairments in psychosocial functioning. Over one-quarter of the patients in the present study reported
clinically significant hyperarousal symptoms (e.g., irritability and sleep problems). These difficulties could adversely affect patients’ emotional well-being, their ability to get along with peers, and their school performance. However, it is also possible that poorer HRQOL precedes increased PTSS. Future studies should examine the relationship between PTSS and psychosocial HRQOL over time, with initial assessments occurring soon after diagnosis, to clarify the temporal relationship between these constructs.

4.3.5. Relationship between Patient Pain and Patient Health-Related Quality of Life.

Consistent with our hypothesis, newly diagnosed pediatric cancer patients who reported higher levels of pain (specifically pain at the time of the assessment) tended to report poorer physical and psychosocial HRQOL. Although it is unsurprising that pain is associated with patients’ physical functioning (e.g., their abilities to engage in sports activities and activities of daily living), the relationship between pain and psychosocial HRQOL requires additional explanation. Cancer-related pain and associated fatigue and lack of energy could impact psychosocial HRQOL due to increased psychological distress associated with pain, missed opportunities for peer socialization (e.g., playing on sports teams, dating), and difficulties concentrating at school and/or frequent school absences. Furthermore, given their increased reliance on caregivers to help manage pain and associated functional impairments, adolescents in particular may report lower psychosocial HRQOL because of reduced opportunities to develop and maintain autonomy and independence relative to their peers and their own premorbid functioning. Alternatively, impaired psychosocial HRQOL may directly or indirectly impact pain intensity. Whereas involvement in pleasurable activities could help distract patients from
thinking about their pain, limited engagement in such activities may lead to increased pain-related thinking and, in turn, higher levels of pain intensity.

4.3.6. **Relationship between Caregiver Posttraumatic Stress and Patient Health-Related Quality of Life.**

To our knowledge, this is the first study to examine the relationship between caregiver PTSS and newly diagnosed pediatric cancer patients’ HRQOL. Consistent with previous findings that parental psychological adjustment is associated with pediatric cancer patients’ HRQOL (e.g. Eiser et al., 2005), caregiver PTSS was inversely associated with both physical and psychosocial HRQOL. It may be that caregiver PTSS increases in response to caregivers noticing patients’ reduced HRQOL. Alternatively, caregivers with elevated PTSS may be less able to effectively respond to patients’ emotional and pragmatic needs, thus leading to reductions in HRQOL. For example, caregivers with PTSS may be hypervigilant about the risk of infection or injury. Accordingly, they may explicitly or implicitly discourage patients from attending school, playing sports, or spending time with peers, thus limiting patients’ opportunities to engage in activities typically associated with positive HRQOL. As mentioned above, caregivers with elevated PTSS may also be avoidant or withdrawn and thus less likely to perceive and respond to patients’ social and emotional needs (which would impact psychosocial HRQOL).

4.4. **Relationship between Pain Intensity and Use of Specific Pain Coping Strategies**

Patients endorsed utilizing each of the five pain coping strategies at similar frequencies, with the mean ratings indicating that patients “sometimes” used each of the five strategies. However, patients who endorsed higher levels of pain intensity reported that they coped with pain by seeking social support. Given the cross-sectional and correlational nature of our study, we are unable to determine whether use of this strategy led to increased pain (and thus could be considered an ineffective coping strategy) or whether this association is better explained by other
factors. It may be that patients who endorsed higher levels of pain engaged in this strategy more frequently because of the relative ease of seeking social support as compared to more active, internally-driven coping strategies (e.g., cognitive self-instruction). Alternatively, caregivers’ responses to patients’ pain could contribute to increased reports of pain (Walker et al., 2006). Patients who have a tendency to engage in attention-seeking behaviors may be more likely to both seek social support as a way to cope with pain and to report higher levels of pain. As such, patients’ complaints of pain and associated elicitations for social support may be positively reinforced by increased caregiver attention. Future research is needed to clarify whether seeking social support is a maladaptive strategy and whether patients with greater pain intensity utilize pain coping strategies differentially.
4.5. **Caregiver Posttraumatic Stress as a Moderator of the Relationship between Patient Pain and Patient Posttraumatic Stress**

Results provided preliminary support for our hypothesis that caregiver PTSS moderated the relationship between patient pain and patient PTSS; this relationship was only present when examining the relationship between caregiver PTSS and patients’ present pain. Specifically, among patients whose caregivers reported higher levels of PTSS, as pain increased, PTSS also tended to increase. In contrast, among patients whose caregivers reported lower levels of PTSS, as pain increased, PTSS tended to decrease. Closer examination of the simple slopes reveals that when patient pain is low, caregiver PTSS does not appear to impact the relationship between pain and PTSS. However, as patient pain increases, level of caregiver PTSS becomes more meaningful, possibly due to patients’ increased need for caregiver help, involvement, and emotional attunement.

Consistent with research that patients whose parents encourage positive coping strategies experience less distress (Blount et al., 1990), caregivers who are more responsive to patients’ needs may promote better coping and, accordingly, lower psychological distress. Also, having the experience of being supported by caregivers during a stressful experience may increase patient’s sense of safety and security as well as their belief that with their caregivers support, they will be able to manage future cancer-related stressors. In contrast, caregivers experiencing increased PTSS may be hypervigilant or avoidant in response to patients’ pain and, accordingly, less adaptively responsive to patients’ pragmatic and emotional needs during painful experiences. Patients may model their caregivers’ PTSS in response to pain; interpret caregiver behavior as a signal that their pain is more serious, debilitating, and anxiety-provoking than they previously thought; and/or engage in less adaptive coping in response to pain. These patients
may ultimately experience pain as more traumatic and report higher levels of PTSS relative to patients whose caregivers are less symptomatic.

Given the study’s small sample size and the absence of indirect or observational measures of caregivers’ responses to pain, these results should be interpreted with caution. Definitive conclusions should be postponed until these analyses can be repeated in a larger sample. Our results support the need for future research exploring whether caregivers’ perceptions of and responses to childhood cancer patients’ pain varies among caregivers with higher and lower levels of PTSS. It will be especially important to measure these constructs over time. Just as the relationship between patient and caregiver PTSS seems to arise over the course of the cancer experience, the effect of caregiver PTSS on the relationship between pain and PTSS may evolve and strengthen over time. The stress of perceiving one’s child to be in intense pain soon after diagnosis (i.e., during lumbar punctures or port placements) or the effects of ongoing cancer-related pain not associated with procedures could lead to increased caregiver PTSS.

4.6. **Limitations**

The current study has several limitations. First, our sample is small, making statistically significant findings more difficult to achieve and limiting comparisons of subgroups based on cancer diagnosis, gender, age, and other key variables. Second, the cross-sectional design precludes our ability to assess the relationships between our study variables over time. Future studies should use longitudinal designs to examine the relationships between study variables over time. Third, two of our study measures (the PTSDI and PPCI) were not normed for individuals over 18 years old. Members of the research team carefully reviewed each item on the adolescent versions of these measures and did not find any items that appeared inappropriate or unsuitable for young adults. Also, the four participants who were over 18 years did not skip any items on
either of the two measures. However, the use of measures outside of the population for which they were normed remains a limitation. Future studies should examine PTSS and pain coping strategies among young adults recently diagnosed with cancer using measures normed for this age group.

Finally, we did not include a comparison group for either patients or caregivers and, as such, were limited to published data that most closely matched our sample demographics. The age range of normative controls (7-18 years old in Phipps et al., 2009 and 5-18 years old in Varni et al., 2001) was somewhat restricted relative to the age range of patients in the current study (6-23 years old). Whereas patients in the current study were more ethnically diverse relative to the normative controls for the PTSS comparison (Phipps et al., 2009), the ethnic make-up was similarly diverse among normative controls for comparisons of HRQOL (with a relative underrepresentation of black participants; Varni et al., 2001). Also, although the HRQOL comparison group and the current sample had relatively equal gender distributions, the PTSS comparison group had a higher proportion of females.

We were also unable to find published studies in which the PCL was administered to parents of healthy children; as such, we could not directly test our hypothesis that caregivers of pediatric cancer patients would show elevated levels of PTSS as compared to established norms for parents of healthy children. Furthermore, the version of the PCL we administered asked participants to refer to a specific stressor which had occurred (PCL-S). No studies to our knowledge have administered the PCL-S to a sample of healthy controls. Rather, the Civilian version of the PCL (the PCL-C, which instructs subjects to rate symptoms related to “stressful experiences” more broadly) has been administered to populations who may or may not have experienced a specific stressful event. Whereas the comparison sample consisted entirely of
females, the current study included male caregivers. We did not collect additional demographic data on caregivers for further comparisons. Despite these limitations, our findings contribute to the field of pediatric psycho-oncology by providing descriptive data about the experience of PTSS in newly diagnosed pediatric cancer patients and their caregivers. Our results may prove to be useful in future studies that seek to compare the experiences of pediatric cancer patients and their caregivers as a function of time since diagnosis and in comparison to healthy controls.

4.7. **Clinical Implications and Future Directions**

Although most pediatric cancer patients and their caregivers ultimately function well and experience normal levels of distress, families who experience the most risk factors (e.g., financial difficulties, preexisting emotional problems in the family) at the time of diagnosis are most likely to continue to experience psychological distress and, accordingly, to require psychosocial support in the future (Kazak et al., 2003). Furthermore, those families who have the most difficulty adjusting to a cancer diagnosis continue to experience the highest levels of distress after treatment ends (Kupst & Schulman, 1988; Kupst et al., 1995). Results of the current study could contribute to the systematic identification of patients and families at increased risk for psychological distress and in need of additional psychosocial support. Such targeted, early intervention could contribute to reduced future psychological distress and reduced healthcare costs.

Although our study did not fully test the relational model of PTSD in the pediatric cancer population, we did find that caregiver PTSS tends to moderate the relationship between patient pain and patient PTSS and that caregiver PTSS was related to patient pain and patient HRQOL. Interventions focused on targeting caregiver PTSS and enhancing caregivers’ abilities to appropriately respond to patients’ physical and psychosocial needs may lead to reductions in patient pain and PTSS and improvements in patient HRQOL. Alternatively, clinicians could
provide all caregivers of newly diagnosed patients with information on caregiver stress management techniques and recommendations for how to respond to patients’ physical and psychological needs. Caregivers who implement this advice throughout their child’s cancer experience may be better able to manage future cancer-related traumatic events and less likely to develop PTSS; to the degree to which caregiver PTSS may impact child PTSS, caregivers may also be less likely to unintentionally contribute to or maintain their child’s experience of physical or psychological distress. Caregivers who are exposed to information normalizing the presence and discussing the risks of caregiver PTSS may be better positioned to identify the need for and seek out psychosocial support. Future prevention and treatment studies should examine the effects of early caregiver support and education on patients’ functioning.

Future research should also explore the applicability of the relational model of PTSD to the pediatric cancer population. Rather than examining associations between patient and caregiver PTSS at a single time point, longitudinal studies should examine whether the relationship between patient and caregiver PTSS changes over time and whether caregiver PTSS predicts subsequent child PTSS. Furthermore, longitudinal research examining specific relational patterns, caregiver PTSS, and patient PTSS could provide information on the stability of parent-child relational patterns over time and the predictive strength of specific relational patterns for subsequent posttraumatic stress. Findings from such studies could help determine possible points of intervention and identify families who require earlier and more intensive psychological interventions targeting parent-child communication.

Although we did not find that any specific pain coping strategies were associated with lower pain intensity, the positive association between pain intensity and seeking social support is clinically relevant. Additional research is needed to determine whether seeking social support is
maladaptive and, if it is, whether there are specific cases in which this strategy tends to be more or less effective. Results from future studies could inform pain management interventions for pediatric cancer patients. Clinicians could work with patients and their families to develop more adaptive communication and pain coping strategies and to recognize ineffective strategies that could inadvertently increase pain intensity. By learning about more adaptive coping techniques soon after diagnosis, newly diagnosed pediatric cancer patients could implement these strategies throughout the course of cancer experience and potentially experience less pain and associated deficits in HRQOL.

Finally, our results support previous recommendations regarding the assessment of HRQOL among pediatric cancer patients across the course of cancer, including in newly diagnosed patients (Eiser et al., 2005; Landolt et al. 2006). Previous findings demonstrating lower HRQOL in childhood cancer survivors have led to increased emphasis on the quality of survival among children treated for cancer (Fuemmeler, Elkin, & Mullins, 2002; Langeveld, Stam, Grootenhuis, & Last, 2002; Meeske et al., 2004). In addition to considering the late effects of different cancer treatments when selecting treatment protocols, when possible, physicians and caregivers should consider the impact of diagnostic procedures and early cancer treatments on patients’ quality of life as well. Furthermore, whereas newly diagnosed cancer patients may not experience diagnosis as a traumatic event, there is growing evidence that a significant proportion of patients experience compromised HRQOL. Based on Phipps’ recommendations (2005, 2007) and findings from the current study, future research may better serve patients and their families by focusing more on the how cancer affects newly diagnosed patients’ overall physical, emotional, social, and role functioning. Paralleling this proposed shift in research, clinicians are encouraged to begin assessments with questions related to patients’
overall well-being rather than questions regarding specific psychological symptoms (i.e., depression, posttraumatic stress). If patients report deficits in their HRQOL, clinicians could then follow up with more specific questions to determine whether patients’ difficulties are associated with their physical, emotional, social, and role functioning.


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2008-present  **University of Illinois at Chicago**, Chicago, IL
M.A. in Clinical Psychology, October 2010
Thesis: “The Catalytic Effects of Relaxation on the Inhibitory Qualities of Worry”

Doctoral Candidate, expected graduation in August 2014
Dissertation: “The Relationships between Caregiver Posttraumatic Stress and Newly Diagnosed Pediatric Cancer Patients’ Posttraumatic Stress, Pain, and Quality of Life”

2002-2006  **University of Pennsylvania**, Philadelphia, PA
B.A., Psychology (major), History (minor)
Thesis: “The Etiological Role of Imagery in Specific Phobias”

Fall 2004: Semester abroad at University College London in London, England
Coursework included psychology, art history, and history

HONORS AND AWARDS

2013  St. Jude Children’s Research Hospital National Graduate Student Symposium Participant
2011  Elsie Ramos Memorial Student Poster Award, Association for Behavioral and Cognitive Therapies
2011  Passed Preliminary Examination with Commendation, University of Illinois at Chicago
2006  *Summa cum laude*, University of Pennsylvania
2002-2006  Benjamin Franklin Scholar, University of Pennsylvania
2002-2005  Dean’s List (all eligible years), University of Pennsylvania
2002  Outstanding Young Woman of Memphis, *Memphis Woman Magazine*

CLINICAL EXPERIENCE

2013-present  **Predoctoral Psychology Intern**, Department of Psychology, Children’s Hospitals and Clinics of Minnesota, Minneapolis, MN
Roles: Provide outpatient (individual, family) therapy to children and adolescents with a variety of psychological disorders and medical conditions including generalized anxiety disorder, major depressive disorder, self-injurious behaviors, disruptive mood dysregulation disorder, disruptive, impulse-control, and conduct disorders, encopresis, cancer, and intractable headaches.
Conduct psychological assessments of preschool, school-aged, and high school-aged children and adolescents. Communicate findings and recommendations to families through feedback sessions and written report.
Provide inpatient diagnostic, consultative, intervention, and liaison services to pediatric medical patients and their families with particular focus on patients presenting to the Hematology-Oncology service. Help facilitate a mind-body skills group for adolescents with chronic illnesses.

**Director of Training:** Sharon Berry, Ph.D., L.P.

**2012-2013**  
**Pediatric Neuropsychology Extern,** Pediatric Neuropsychology Program, Department of Psychiatry and Behavioral Neuroscience, University of Chicago Medicine, Chicago, IL  
**Roles:** Conducted comprehensive evaluations of children and adolescents with suspected or known neurocognitive dysfunction. Selected, administered, scored, and interpreted cognitive, neuropsychological, and behavioral measures. Wrote comprehensive reports of assessment results and presented appropriate, empirically-supported recommendations for intervention and learning.  
**Supervisor:** Scott Hunter, Ph.D.

**2011-2012**  
**Psychotherapy Extern,** Child and Adolescent Psychotherapy Program, Department of Psychiatry and Behavioral Neuroscience, University of Chicago Medicine, Chicago, IL  
**Roles:** Provided ongoing outpatient (individual, family) psychotherapy to children and adolescents with a variety of psychological disorders including major depressive disorder, social anxiety disorder, obsessive compulsive disorder, and attention deficit hyperactivity disorder. Provided group therapy to children, adolescents, and their parents focusing on social skills and/or coping with a chronic illness. Evaluated children and adolescents receiving inpatient pediatric services for psychiatric needs pre-transplantation and during acute and chronic medical illness. Presenting medical problems included cancer, sickle cell disease, epilepsy, and conversion disorder. Provided recommendations to patients, families, and physicians.  
**Supervisor:** Tina Drossos, Ph.D.
2010-2013  **Clinic Assistant**, Office of Applied Psychological Services (OAPS), University of Illinois at Chicago, Chicago, IL  
**Roles:** Served as the first line of contact for potential therapy and testing clients and their parents. Assessed clients’ needs, suicidal risk, and homicidal risk.  
Organized intake interviews, assisted with clinician assignments, and provided general administrative support to the clinic’s co-directors.  
**Supervisors:** Nancy Dassoff, Ph.D. and Audrey Ruderman, Ph.D.

2010-2011  **Research Clinician**, Pediatric Mood Disorders Program, Institute for Juvenile Research, University of Illinois at Chicago, Chicago, IL  
**Roles:** Conducted psychological assessments with children diagnosed with bipolar spectrum disorders as part of a randomized control trial comparing a child- and family-focused cognitive behavior therapy to treatment as usual.  
**Supervisors:** Sally Weinstein, Ph.D. and Amy West, Ph.D.

2009-2013  **Psychotherapy Clinician**, Office of Applied Psychological Services, Department of Psychology, University of Illinois at Chicago, Chicago, IL  
**Roles:** Conducted individual psychotherapy with patients presenting with a variety of psychological disorders including major depressive disorder, generalized anxiety disorder, obsessive compulsive disorder, Asperger’s syndrome, sleep difficulties, and attention deficit hyperactivity disorder.  
**Supervisors:** Gloria Balague, Ph.D. and Nancy Dassoff, Ph.D.

2009-2011  **Assessment Clinician**, Office of Applied Psychological Services, Department of Psychology, University of Illinois at Chicago, Chicago, IL  
**Roles:** Conducted psychological assessments with patients presenting with learning disabilities, attention deficit hyperactivity disorder, and other psychological disorders.  
**Supervisor:** Audrey Ruderman, Ph.D.

2009-2010  **Research Therapist**, Building Cultural Bridges for Success, Disruptive Behavior Clinic for Preschoolers, Institute for Juvenile Research, University of Illinois at Chicago, Chicago, IL  
**Roles:** Conducted treatment with preschool-age children with disruptive behavior and their families as part of a protocol intervention designed to increase parental engagement and clinician cultural competence via implementing a culturally enhanced observational feedback.  
**Supervisors:** Barbara Danis, Ph.D. and Miwa Yasui, Ph.D.

2008-2009  **Intake Clinician**, Office of Applied Psychological Services, Department of Psychology, University of Illinois at Chicago, Chicago, IL  
**Roles:** Conducted intake interviews.  
**Supervisors:** Gloria Balague, Ph.D. and Nancy Dassoff, Ph.D.
2006-2008  **Psychological Skills Tutor**, Telephone Tutoring in Psychological Skills
Supervisor: Joseph Strayhorn, M.D.

**RESEARCH EXPERIENCE**

2008-2012  **Graduate Research Assistant**, Laboratory for Emotion and Anxiety Disorders, University of Illinois at Chicago, Chicago, IL
Roles: Administered IRB-approved protocols to examine the characteristics of worry, depressive rumination, and trauma recall and to test the effects of relaxation on emotional processing and cognitive flexibility. Trained undergraduate and graduate students to reliably code concreteness of thought.
Supervisor: Evelyn Behar, Ph.D.

Fall 2010  **Graduate Research Assistant**, Pediatric Intervention Research in Affect Dysregulation and Mood Disorders, University of Illinois at Chicago, Chicago, IL
Roles: Conducted fidelity checks for clinical trial of child- and family-focused cognitive behavioral therapy adjunctive to pharmacotherapy for children with a bipolar spectrum disorder and their families. Trial supported by NIMH K23 awarded to Amy West, Ph.D.
Supervisor: Sally Weinstein, Ph.D.

2009-2010  **Graduate Research Assistant**, Multidimensional Assessment of Preschool Disruptive Behavior, University of Illinois at Chicago, Chicago, IL
Roles: Helped develop a developmentally-sensitive measure of parental report of anxiety and tasks to assess low concern as part of developmentally-sensitive observational assessment for disruptive preschoolers. Supported by NIMH Grant R01MH08280, “Developmental Characterization of Preschool Disruptive Behavior,” awarded to Lauren Wakschlag, Ph.D.
Supervisors: Barbara Danis, Ph.D. and Lauren Wakschlag, Ph.D.

2008-2010  **Graduate Research Assistant**, Developmental Characterization of Anxiety Phenotypes within Observation Contexts: ANX-DOS Measure Validation Study, Institute for Juvenile Research, University of Illinois at Chicago, Chicago, IL
Roles: Collaborated in development and refinement of coding system for developmentally-sensitive observational assessment for anxious preschoolers. Supported by NIMH Grant R21MH074780, “Neural Substrates of Preschool Psychopathology,” awarded to Lauren Wakschlag, Ph.D.
Supervisors: Barbara Danis, Ph.D. and Lauren Wakschlag, Ph.D.
2006-2008 **Postbaccalaureate Intramural Research Training Award**, Section on Development and Affective Neuroscience, Mood and Anxiety Disorders Program, National Institute of Mental Health, National Institutes of Health, Bethesda, MD

**Roles:** Analyzed fMRI and behavioral data using statistical software packages (SPSS, AFNI, SPM, Matlab). Administered cognitive assessments to children with anxiety and/or depression, as well as psychiatrically healthy child and adult volunteers. Recruited, scheduled, and screened subjects on attention and emotional memory.

**Supervisor:** Daniel S. Pine, M.D.

2005-2006 **Undergraduate Thesis**, Department of Psychology, University of Pennsylvania, Philadelphia, PA

**Roles:** Tested effects of fearful snake imagery on non-phobic participants’ behavioral avoidance and subjective fear of snakes. Created behavioral approach test and implicit association test.

**Supervisor:** Melissa Hunt, Ph.D.


**Roles:** Measured effectiveness of positive psychology skills taught in workshops to undergraduate students with pessimistic attributional styles.

**Supervisors:** Angela Duckworth, Ph.D. and Martin E.P. Seligman, Ph.D.

2004-2005 **Research Assistant**, Department of Psychology, University of Pennsylvania, Philadelphia, PA

**Roles:** Tested effects of a directed written disclosure exercise on dreaming and sleep quality as well as mood and physical health symptoms. Tested effects of directed written disclosure interventions on psychosocial and physiological factors among individuals who have suffered a significant interpersonal loss.

**Supervisor:** Dean Cruess, Ph.D.

**Publications**


**Manuscripts Submitted and in Preparation**


**Conference Presentations**


TEACHING EXPERIENCE

Teaching Assistantship Positions (University of Illinois at Chicago)
- Psychological Testing (PSCH 340; Spring 2010, Summer 2010)
- Interviewing (PSCH 381; Fall 2009, Spring 2010)
- Abnormal Psychology (PSCH 270; Summer 2009, Fall 2009)
- Introduction to Psychology (PSCH 100; Fall 2008, Spring 2009)

Guest Lectures
- Process Issues in Long-Term Therapy Clients, graduate Intervention Techniques course, Chicago, IL (October 2011)
- Testing and the Law. University of Illinois at Chicago, undergraduate Psychological Testing course, Chicago, IL (July 2010)
- Interviewing Children. University of Illinois at Chicago, graduate Clinical Interviewing course, Chicago, IL (October 2009, October 2010)

INVITED ADDRESSES


Goldwin, M.A. (2013, April). Pediatric Bipolar Disorders. Lecture presented during Pediatric Clinical Neuroscience Seminar at University of Chicago Medicine, Chicago IL.

Goldwin M.A. (2012, November). Attention. Lecture presented during Pediatric Clinical Neuroscience Seminar at University of Chicago Medicine, Chicago IL.


**EDITORIAL EXPERIENCE**

Children’s Health Care (Editorial Board)

**AD HOC REVIEWER FOR SCIENTIFIC JOURNALS**

Behavior Therapy*
Behavioural and Cognitive Psychotherapy*
Child Psychiatry and Human Development
*conducted under the supervision of Evelyn Behar, Ph.D.

**PROFESSIONAL AFFILIATIONS**

Association for Behavioral and Cognitive Therapies
Association for Psychological Science
Society of Clinical Child and Adolescent Psychology
Society of Pediatric Psychology

**CONTINUING EDUCATION**

The Compassionate Use of Exposure Strategies in ACT, Workshop taught by John Forsyth – November 17, 2012
Neuropsychological Assessment training, certified as Neuropsychology Technician of Service, University of Chicago Medicine – July 2012
Child and Adolescent Cognitive Behavioral Therapy, University of Chicago Medicine – January - March 2012
Cognitive Therapy Training at the Beck Institute for Cognitive Therapy and Research – August 9 - 11, 2010
Mindfulness Based Cognitive Therapy for Prevention of Relapse in Mood Disorders, Workshop taught by Zindel Segal – June 2, 2010
Wechsler Memory Scale - IV (WMS-IV) Workshop – November 24, 2009
Tourette Syndrome Workshop, taught by Doug Woods – May 18, 2009
Wechsler Adult Intelligence Scale - IV (WAIS-IV) Workshop – December 9, 2008
Introduction to the Principles and Practice of Clinical Research, taught by investigators at the NIH Clinical Center, National Institutes of Health – 2007