An Integrative Model of Pediatric Medical Traumatic Stress

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Objective To guide assessment and intervention for patients and families, a model for assessing and treating pediatric medical traumatic stress (PMTS) is presented that integrates the literature across pediatric conditions. Methods A model with three general phases is outlined—I, peritrauma; II, early, ongoing, and evolving responses; and III, longer-term PMTS. Relevant literature for each is reviewed and discussed with respect to implications for intervention for patients and families. Results Commonalities across conditions, the range of normative responses to potentially traumatic events (PTEs), the importance of preexisting psychological well-being, developmental considerations, and a social ecological orientation are highlighted. Conclusions Growing empirical support exists to guide the development of assessment and intervention related to PMTS for patients with pediatric illness and their parents. The need for interventions across the course of pediatric illness and injury that target patients, families, and/or healthcare teams is apparent. The model provides a basis for further development of evidence-based treatments.

Key words cancer; families; intervention; pediatric illness; pediatric injury; posttraumatic stress disorder; posttraumatic stress; transplantation.

Illness and injury bring children and their families into healthcare settings under adverse and often life-threatening circumstances. Yet psychosocial professionals have had few conceptual models to guide assessment and intervention associated with traumatic medical experiences. This article presents a model of pediatric medical traumatic stress (PMTS) derived from research and clinical reports and intended as a general blueprint to guide trauma-informed practice in pediatric settings.

Pediatric Medical Traumatic Stress

PMTS has been defined as “a set of psychological and physiological responses of children and their families to pain, injury, serious illness, medical procedures, and invasive or frightening treatment experiences” (National Child Traumatic Stress Network, 2003). PMTS includes traumatic stress responses, such as arousal, reexperiencing, and avoidance, which can vary in intensity and may become disruptive to functioning. The research evidence supporting a traumatic stress model for understanding and addressing psychological reactions specific to pediatric illness and injury is growing (Saxe, Vanderbilt, & Zuckerman, 2003; Stuber, Shemesh, & Saxe, 2003). The literature to date has been primarily descriptive, without yet providing consistent important linkages to functional and other health outcomes.

Applying the concept of trauma to pediatric illness and injury represents a departure for both pediatric psychology and traumatic stress studies. Although PMTS is related to traumatic stress disorders [acute stress disorder (ASD) and posttraumatic stress disorder (PTSD; American Psychiatric Association, 1994)], it is not limited to these diagnostic entities. The specific requirements of these diagnoses may not fit the phenomenology of child or family reactions to medical events. Therefore, PMTS is not...
A Model for PMTS

The concept of PMTS grew out of clinical and research efforts to understand the experience of children and families in medical settings. Independent research groups described symptoms of intrusive thoughts, hyperarousal, and avoidance in pediatric samples. The literature that emerged in this relatively young field has been based on specific patient groups. In this article, we propose a developmental model of PMTS, understanding that traumatic stress is a process that may unfold at various points in the course of illness and treatment.\(^1\) We emphasize the importance of viewing PMTS from a family perspective. That is, traumatic medical events happen to children embedded in families. Our focus incorporates

\(^1\)Although existing models of posttraumatic stress have highlighted processes that are relevant to pediatric traumatic stress, most are oriented to adults and are not focused on medical events, hence our need to develop a model specific to PMTS. We appreciate the contribution and relevance of existing developmental models (e.g., Pynoos, Steinberg, & Piacentini, 1999; Pynoos, Goenjian, & Steinberg, 1998) and the application of cognitive models of PTSD to childhood injuries (Ehlers & Clark, 2000; Ehlers, Mayou, & Bryant, 2003). A detailed discussion of these models is beyond the scope of this article.

the examination of the child in the context of the family (Kazak, Rourke, & Crump, 2003).

There are three general phases in the model (Fig. 1).\(^2\) Each represents a segment of the child’s and family’s experience of a potentially traumatic medical event, and each roughly corresponds to a period of time—phase I includes the occurrence of the potentially traumatic event (PTE) and its immediate aftermath, phase II encompasses the early (acute), ongoing, and evolving traumatic stress responses that unfold with physical sequelae of the initial event and treatment, and phase III includes longer-term traumatic responses when immediate physical sequelae, treatment, and acute threat have resolved or ended. The timing and duration of these phases will vary depending on the nature and course of the medical event. Most importantly, PTEs are nonlinear and may be recurrent and/or cyclical, with the possibility of subsequent episodes of trauma. For example, a child diagnosed with renal disease, and the child’s family, may experience traumatic responses around the initial diagnosis. A decade later, they may experience another traumatic episode if they learn, for example, that the child is in chronic renal failure and dialysis is necessary, along with the prospect of later transplantation.

Phase I. Peritrauma: During and Immediately Following the Potentially Traumatic Medical Event

In medical settings, many events may be considered traumatic. We call these PTEs because the same objective event (e.g., the child was intubated, parents are told their child has a life-threatening condition) is not uniformly traumatogenic across individuals or families. Rather, there is a growing evidence that it is the subjective experience of the PTE that renders it traumatic (Balluffi et al., 2004; Stuber et al., 1997).

Most literature on PMTS has focused on reactions to events that are presumed to be traumatic. An unanswered question is what may contribute to an event being perceived as traumatic for a patient or one or more parents. We propose that preexisting factors are important. For example, prospective studies of adjustment to pediatric illness indicate that psychological adjustment and coping skills are quite stable across the course of

\(^2\)The phases proposed are based on our clinical experiences, are consistent with existing empirical data, and build on a framework of three general phases of illness (diagnostic, treatment, long-term outcomes) within a biopsychosocial framework in which medical and psychosocial events are intertwined over the course of time. We acknowledge that alternative phases or stages may be appropriate as well.
childhood cancer treatment and survivorship and that parental distress during treatment is predictive of later PTSS (Best, Streisand, Catania, & Kazak, 2002; Kazak & Barakat, 1997). Family and other social support are also related to PTSS in survivors of childhood cancer and their parents and in parents of organ transplantation survivors (Kazak et al., 1998; Stuber et al., 1997; Young et al., 2003). Preexisting psychopathology has been found to be associated with PTSD outcomes in traumatically injured children (Daviss, Mooney et al., 2000), and preexisting anxiety and/or other psychological difficulties also appear predictive of PTSS in parents of cancer survivors (Kazak et al., 1998; Manne et al., 2004). The traumatic stress responses of parents of organ transplant recipients are associated with parents' general attitudes toward healthcare services and their perceptions of the child's health (Young et al., 2003).

There are also characteristics of the event that may contribute to PMTS. Basic to a traumatic stress framework are the hallmarks of precipitants of PTSD—life threat and/or the likelihood of an event evoking fear, horror, and helplessness (American Psychiatric Association, 1994). To be considered trauma engendering, it is important that these characteristics be present. However, evidence across studies of PMTS suggests that objective characteristics of the medical illness (e.g., staging, severity, complexity) and related treatments (intensity, duration, type) are not strongly related to subsequent PTSS.

Investigations of PMTS in ED and intensive care unit (ICU) settings have shown that child and parent responses immediately following the trauma can help to predict the course of PTSS over time. For example, child and adolescent ASD symptoms assessed in the ED within a few hours of a violent injury have been linked with the severity of PTSS months later (Fein et al., 2002). Early physiological arousal in injured children (elevated heart rate in the ED) has also been linked to child PTSD outcome (Kassam-Adams, Garcia-Espana, Fein, & Winston, 2005), suggesting that the trajectory toward more problematic outcomes after a PTE may be evidenced quite early after trauma. Additionally, traumatic stress responses in children who had cardiac surgery have been shown to relate to the length of hospitalization in intensive care (Connolly, McClowry, Hayman, Mahony, & Artman, 2004), and children who are younger at the time of ICU admission, more seriously ill, and had more procedures were more likely to evidence PTSS 6 months after hospitalization (Rennick, Johnston, Dougherty, Platt, & Ritchie, 2002). Finally, in a prospective study of ASD and PTSD in 272 families of children admitted to an ICU, one-third of the parents met symptom criteria for ASD in the days following their child’s hospitalization and one-fifth of the sample met criteria for PTSD 4 months later. The presence and severity of ASD during the admission was predictive of later PTSD as was the parent’s subjective appraisal of life threat to the child (Balluffi et al., 2004).

**Phase II. Early, Ongoing, and Evolving Responses**

After the peritrauma phase, patients and families face ongoing demands and challenges related to their medical condition and treatment. These psychological responses...
secondary to the PTE may persist over time and could affect treatment adherence, reactions to procedures and pain, and other health outcomes. PMTS may provide a means by which the ongoing experiences and reactions of families may be understood. For example, children with cancer undergo invasive medical procedures, endure pain, lose their hair, and may need to be admitted to the hospital repeatedly. After cancer treatment ends, survivors report upsetting memories of these experiences (Kazak et al., 2001). Furthermore, parental anxiety during treatment around fearing that their child would die and worrying about relapse is related to later PTSS (Best et al., 2002; Kazak & Barakat, 1997), highlighting the importance of addressing PMTS during acute treatment. Such data are just beginning to emerge in childhood cancer, as reported by Santacroce (2002) in a small sample of parents. In a larger sample of 119 mothers and 52 fathers, all but one of the parents reported PTSS and two-thirds of mothers and one half of the fathers reported PMTS in the moderate to severe range (Kazak, Boeving, Alderfer, Hwang, & Reilly, in press).

A recent study of 209 children hospitalized for newly diagnosed diabetes, newly diagnosed cancer, or accident-related injuries supports the notion that children and parents can have quite different experience of the same PTE and subsequent medical treatment. When assessed about 6 weeks after accident or after diagnosis, the child’s functional status was related to PTSS severity for both children and parents. However, the children with accident-related injuries had higher rates of PTSS than those with newly diagnosed diabetes or cancer, whereas the parents of cancer patients had significantly higher rates of PTSS than the other two parent groups (Landolt, Vollrath, Ribi, Gnehm, & Sennhasuer, 2003).

The experience of acute stress may be normative. For example, the vast majority (more than 80%) of children and parents report at least one severe ASD symptom in the first month after the child’s traumatic injury (Winston et al., 2002). Nevertheless, once the acute impact associated with a traumatic injury or a new diagnosis subsides, the potential for PTSS to persist and to impair the child’s or parent’s everyday functioning is of concern. Studies of injured children have suggested that ASD symptoms in the first month, while not a sufficiently sensitive single predictor of later PTSD, are consistently correlated with later PTSS severity (Daviss, Mooney et al., 2000; Kassam-Adams & Winston, 2004).

As the early medical phases of treating an illness or injury begin to resolve, the family may be returning to its more “normal” life, but demands of longer-term treatment, complications, or ramifications of the illness/injury may precipitate ongoing distress. Importantly, there are many opportunities for intervention during this phase, but there are also many barriers to identification of those in need. For example, after an unexpected hospitalization for an acute injury, a patient may be discharged from the hospital but have little contact with hospital-based staff. Rather, they may be monitored by their primary care pediatrician during this time when they may have limitations on their activities and are readjusting to life at home and in school. Primary care healthcare providers may play an important role in recognizing ongoing or escalating symptoms of PMTS that may not be apparent to others in the neighborhood or school, who may be less aware of the child’s medical history.

**Phase III. Longer-Term PMTS**

The first studies on PMTS were conducted with long-term survivors of childhood cancer, establishing that traumatic responses do not necessarily subside over time and pointing to the importance of considering long-term reactions separately from more acute treatment. Indeed, long-term PMTS has been reported in pediatric cancer, transplantation, and burns many years after the onset of the illness and the end of treatment. Studies of pediatric injury have generally had shorter follow-up times, but here too there is support for PTSS and related impairment in day-to-day functioning 6 months to more than 1 year after the injury. For all of these types of medical events, the data also support the presence of PTSS in family members in addition to the patient, in some cases highlighting that parents may be more symptomatic than children. Clinically, long-term PMTS might affect the patient and/or family’s likelihood to seek follow-up care (e.g., PMTS-related avoidance could prompt delays in seeking medical treatment).

With regard to longer-term child PTSS and PTSD after potentially traumatic medical events, the most robust evidence (multiple large sample studies) exists for child cancer survivors and injured children. Low rates of PTSD are typically found for child cancer survivors, in the range of 5–10% (Butler, Rizzi, & Handwerger, 1996; Erickson & Steiner, 2002; Kazak, Alderfer, Rourke et al., 2004; Pelcovitz et al., 1998), although considerably more survivors meet criteria for distinct PTSD symptom clusters (e.g., reexperiencing, arousal; Brown, Madan-Swain, & Lambert, 2003; Erickson & Steiner, 2002; Kazak, Barakat et al., 2001; Kazak et al., 1998). The prevalence of PTSD in longer-term studies of children with injuries ranges from 6 to 25%, with more of these children experiencing PTSS and functional impairment (DeVries et al., 1999; Kassam-Adams & Winston, 2004; Levi, Drotar, Yeates, & Taylor, 1999).
Many smaller studies suggest the occurrence of longer-term PTSS and PTSD in children with other conditions, such as liver transplantation (Shemesh et al., 2000; Walker, Harris, Baker, Kelly, & Houghton, 1999), and burns (Stoddard, Norman, & Murphy, 1989; Stoddard, Norman, Murphy, & Beardslee, 1989).

A series of reports has documented long-term PTSS and/or PTSD in parents of childhood cancer survivors (Barakat et al., 1997; Brown et al., 2003; Kazak, Alderfer, Rourke et al., 2004; Kazak et al., 1997; Manne, DuHamel, Gallerelli, Sorgen, & Redd, 1998; Manne et al., 2002; Manne et al., 2004), parents of transplant recipients (Young et al., 2003), parents of burn patients (Fukunishi, 1998; Rizzone, Stoddard, Murphy, & Kruger, 1994), and parents of injured children (DeVries et al., 1999). The prevalence of these symptoms can be marked; for example, in a study of 150 families of adolescent survivors of childhood cancer, nearly all families (99%) had at least one parent meet symptom criteria for reexperiencing and 20% of the families had at least one parent with current PTSD (Kazak, Alderfer, Rourke et al., 2004). A growing body of literature suggests PTSS/PTSD responses of parents of transplant recipients are consistent in magnitude with those in the cancer literature. About half of a sample of 111 primary caregivers of children who had cardiac, renal, and liver transplantations reported PTSS in the moderate to severe range, with 27% meeting criteria for PTSD (Young et al., 2003). A better understanding is needed of the mechanisms through which long-term parent and child PTSS are related, including the role that parental responses and coping assistance play in children’s longer-term adaptation after a PTE.

Koocher and O’Malley (1981) likened the experience of cancer survivorship to that of the Greek character Damocles, with a sword hanging over his head while sitting at a banquet in his honor. This analogy may be broadly applicable to the experiences of children and family members with regard to life-threatening pediatric medical conditions in which more intensive treatments have enhanced survival but where survivorship brings with it the potential for later medical problems, as is recognized in childhood cancer survival (Friedman & Meadows, 2002). The Damocles analogy also aptly characterizes the nonlinearity of traumatic stress processes and is a stark reminder that the reaction and adaptation of children and parents to medical events may be complex and long lasting.

**Underlying Assumptions of the Model**

Our PMTS model is grounded by five assumptions that are fundamental to our understanding of child and family adjustment in pediatric healthcare and instrumental in our formulation of interventions to prevent and/or reduce PMTS.

**Potentially Traumatic Medical Events have Commonalities that Cut Across Illness or Injury Groups**

Regardless of type of illness or injury, there is often a moment for parents and older children and adolescents during which one realizes that there is a life threat. This could involve hearing a car horn and seeing a car slide toward you/your child, seeing your child losing consciousness from poorly controlled diabetes, or hearing that you/your child has cancer. Regardless of the nature of the medical event, feelings of fear, horror, and helplessness may arise from the apparent or understood life threat, the observed or experienced pain of the child, and uncertainty of the outcome of the situation. These feelings may also arise in response to the demands of the situation (e.g., separation from parent, making treatment decisions in a highly stressed state, entrusting previously unknown healthcare providers with the child’s life). As all serious medically-related events challenge beliefs about safety and invulnerability, there is the opportunity to develop interventions that address this common core element of experiences.

There are also differences among medical events, which we propose fall along some dimensions that can be identified across diagnostic or patient groups. Medically-related events vary in their degree of acuity, onset, length of exposure, and intensity. They also differ in the threat of reoccurrence, follow-up complications, obviousness, and the number of family members directly involved. Finally, medical events may differ in the presence or degree of human agency or responsibility for the event. These differences influence the ways in which core content of interventions might be applied and also speak to the importance of considering the specific traumatic aspects of any pediatric condition.

**There is a Range of Normative Reactions to Medical Traumatic Events**

In the face of a significant and potentially traumatic medical event, nearly all children, parents, and families will experience a period of adjustment and challenge, likely including some acute stress reactions (Daviss, Racusin et al., 2000; Winston et al., 2002). Not all traumatic stress reactions to medical events are pathological or appropriately interpreted as symptoms of PTSD. Some reactions, although they may be upsetting, can serve adaptive purposes in the early stages of dealing
with a frightening and life-threatening event. For example, frequent thoughts about a new diagnosis can be useful in processing it and beginning to fit it into one’s identity and world view, whereas periodic attempts to distract oneself from these thoughts can be a useful way of titrating the exposure to keep one’s level of distress manageable. It is only when these “reexperiencing” or “avoidance” reactions are extreme, distressing, and persistent that they fall in the realm of ASD or PTSD.

Of growing interest are positive outcomes to a traumatic event, sometimes called posttraumatic growth (PTG). Adolescent survivors of childhood cancer and their mothers and fathers report PTG from the experience, including positive changes in self, relationships with others, and in plans for the future (Barakat, Alderfer, & Kazak, 2005). PTG and posttraumatic stress were correlated with one another, suggesting that these outcomes are not independent. Both posttraumatic stress and PTG were more common in survivors who were diagnosed after age 5 compared with those younger at diagnosis (Barakat et al., 2005). Very similar findings reported are related to children who had been in a road accident—42% reported PTG, with indications that both PTSS and PTG were evident (Salter & Stallard, 2004). Viewing the response to a PTE as possibly having both positive and negative outcomes offers the ability to help patients and families balance their understanding of the event and their experiences of it. It accepts their competence in dealing with adversity while allowing for discussion of more upsetting aspects. Attending to all of the normative aspects of traumatic responses can help to guide preventative intervention approaches, applicable to a broad range of patients and families.

**Patients and Families have a Range of Preexisting Psychological Functioning**

Most families of children who enter the healthcare system because of a serious illness or injury are normally functioning and competent individuals and families. Given the consistency in adjustment across the course of pediatric illness, early and accurate assessment of competence and risk is important and can guide the content and format of interventions. Our understanding of traumatic stress responses should ideally build on the competence of families, although remaining sensitive to those families who experience more significant distress or psychological difficulties. In our work in pediatric oncology, for example, a psychosocial screening measure is used to identify families at three levels of risk for ongoing psychological difficulties. Results of screening show that most families function quite well and that a subset (about 25%) have some preexisting difficulties that may be associated with ongoing distress (Kazak, Cant et al., 2003). Approximately 6–7% of families have multiple serious psychosocial difficulties that indicate the need for the most intensive level of services (Kazak et al., 2003). These data indicate the importance of a model for understanding medical traumatic stress that provides for competent as well as less functional responses over time.

**A Developmental Lens on Trauma is Essential**

A sustained focus on processes of growth and development is critical in working with children and families and can ground intervention approaches in PMTS. Assessment and intervention approaches must be appropriate to the child’s developmental stage and must take into account that the child continues to change and develop over time. For example, in pediatric cancer, higher rates of PTSS are seen in young adults who survived cancer as children compared with rates of PTSS in child survivors, suggesting that there may be developmental processes that alter the meaning of one’s past medical experiences (Hobbie et al., 2000; Langeveld, Grootenhuis, Voute, & De Hann, 2004; Rourke, Hobbie, & Kazak, 2002). In the aftermath of traffic-related injuries, younger school-age children were more likely to experience significant acute distress (ASD symptoms) than adolescents, but this difference did not persist when PTSD was assessed months later (Kassam-Adams & Winston, 2004). In some cases, particularly when children are very young, attention may appropriately be focused on the parents or family, as parents are more likely to experience PTSS than are the children and their responses are key for the child’s and family’s ongoing development.

**A Social Ecological or Contextual Approach is Optimal for Intervention**

Viewing the child across multiple contexts, beginning with the family and moving outward to broader systems, allows for consideration of the complex interactions that affect the well-being of children in pediatric healthcare (Kazak, Rourke et al., 2003). We know, for example, that parent–child interactions are critically important during invasive procedures and that the triadic interactions among patients, families, and healthcare teams impact the provision of many aspects of healthcare, including adherence to treatment (Power, DuPaul, Shapiro, & Kazak, 2003). Other community leaders, including clergy and mental health workers, are also critical in facilitating the long-term adjustment of children
PMTS during the peritraumatic phase in burn patients. The dose of morphine administered to pediatric burn patients has been found to be inversely associated with PTSS 6 months later (Saxe et al., 2001), and imipramine has been used to reduce ASD symptoms (Robert et al., 1999). This is consistent with the philosophy of delivering maximum safe sedation at the time of initial procedures to help prevent conditioned maladaptive responses to subsequent procedures.

Trauma-informed medical practice (by all healthcare providers) that skillfully addresses both child and parent needs in the course of a potentially traumatic medical event is consistent with the notion of family-centered care that is central to the philosophy of many pediatric healthcare settings (Baren, 2001) and consistent with findings from pediatric ICUs (Melnyk, Alpert-Gillis, Hensel, Cable-Beiling, & Rubenstein, 1997; Powers & Rubenstein, 1999). A recent policy statement from the American Academy of Pediatrics’ Committee on hospital care and the Institute for Family-Centered Care notes that parent involvement in child hospital care can improve patient and family outcomes and recommends that parents “should be offered the option to be present with their child during medical procedures and offered support before, during, and after the procedure” (American Academy of Pediatrics Committee on Hospital Care and Institute for Family-Centered Care, 2003).

PMTS provides important opportunities for prevention of traumatic stress through promotion of trauma-informed practice in the medical system (Horowitz, Kassam-Adams, & Bergstein, 2001; Ruzek & Garay, 1996). An important role for pediatric psychologists may be to provide consultation regarding delivery of care in ways that reduce the likelihood for PTEs to be traumatic or that may prevent the onset of a traumatic response. The Medical Traumatic Stress Working Group of the National Child Traumatic Stress Network has developed a compendium of practical tools and training materials to support trauma-informed medical and nursing practice (available from the network at www.NCTSNet.org). This toolkit provides user-friendly materials to prompt healthcare providers to assess for the D–E–F of trauma (Distress, Emotional support, and Family needs) specific to traumatic stress. Such materials provide important opportunities for research to establish the feasibility and utility of early interventions.

From a systemic perspective, patient, parents, and staff are all operating in the face of PTEs. Burnout and compassion fatigue, as well as compassion satisfaction, are prevalent among multidisciplinary staff in pediatric hospitals (Robins, Meltzer, & Zelikovsky, submitted for...
Phase II. Assessing, Preventing, and/or Reducing PMTS

During phase II, the assessment of PMTS is a key goal (National Child Traumatic Stress Network, 2004). We also encourage attention to the competence of families, the beliefs and resources available to address psychological difficulties and reactions, and the multiple contexts in which patients and families function. Potential targets for intervention include factors that may moderate or mediate the relationship between the PTE and PTSS, including social support, beliefs about the medical experience, and physiological factors. Early in the course of treatment, screening for risk of persistent PMTS or other psychosocial concerns may help to identify patients and families who can benefit from intervention.

In pediatric injury, the Screening Tool for Early Predictors of PTSD (STEPP; Winston et al., 2003) is a 12-item screener designed to identify, during the course of acute medical care, those patients and families who might benefit from preventive interventions. In the development sample, the STEPP had good sensitivity and moderate specificity for prediction of PTSS; further field testing of this measure is underway. Risk predictors for child PTSS on the STEPP include early behavioral concerns, separation from parents during the injury or emergency medical treatment, exposure to the injury or death of others, peritraumatic fear and subjective life threat, presence of an extremity fracture, elevated acute heart rate, and being female. Risk predictors for parent PTSS include exposure to child’s injury and emergency treatment (eyewitness to injury event, riding in ambulance with child), feelings of helplessness in the peritraumatic phase, early behavioral concerns about the child, and child extremity fracture.

The Psychosocial Assessment Tool (PAT; Kazak, Prusak et al., 2001; Kazak, Cant et al., 2003) is a 20-item measure for families of children newly diagnosed with cancer. The PAT has been tested in two studies of over 100 families each. Although the current version is not specific to PMTS, the PAT describes three levels of risk for ongoing psychosocial problems and is predictive of ongoing distress and utilization of psychosocial resources during cancer treatment. To identify parents’ beliefs that may be related to PMTS, the Family Illness Beliefs Inventory was developed (FIBI; Kazak et al., 2004). Two FIBI factors reflecting beliefs about the child’s treatment-related suffering and whether the child will die and/or the family will be damaged—death and devastation—were positively correlated with PMTS. Connection was inversely correlated, indicating an expected association between isolation and PMTS. These beliefs are hypothesized to be important in mediating the relationship between cancer-related adversities faced and psychological outcome (prevention or reduction of PMTS).

The goal of intervention during phase II is to reduce or prevent PTSS. A three-session manualized intervention for parents/caregivers of children newly diagnosed with cancer has recently been developed and piloted. Surviving Cancer Competently Intervention Program—Newly Diagnosed (SCCIP-ND) has preliminary data supportive of its ability to reduce PTSS (Kazak et al., 2005). SCCIP-ND is based on a treatment model that integrates cognitive-behavioral and family therapy approaches and identifies beliefs of parents that may facilitate adaptive functioning and lessen PTMS.

A stepped model of preventive intervention in the acute care setting aimed at reducing PTSS following pediatric injury is also being developed and piloted by our team (Kassam-Adams et al., 2004). This model is grounded in empirical data regarding the development of child PTSS post injury and links early screening in the emergency or acute care setting with preventive parent–child interventions. Those identified as at risk based on early screening are followed and offered further intervention, if distressing PTSS persist for more than a few weeks. Mixed evidence regarding single session debriefing interventions for adults (Litz, Gray, Bryant, & Adler, 2001) underscores the importance of empirically sound approaches.

Phase III. Reducing PMTS

The goal of intervention during phase III is to reduce symptoms of PTSS. To our knowledge, the only empirically evaluated intervention to reduce PTSS in pediatric illness is the Surviving Cancer Competently Intervention Program (SCCIP; Kazak et al., 1999). SCCIP integrates cognitive-behavioral and family therapy approaches to address symptoms of PMTS in adolescent childhood cancer survivors and their mothers, fathers, and siblings.
SCCIP provides four sessions within one weekend day (Kazak et al., 1999) for groups of families. Two sessions, conducted with separate groups of mothers, fathers, survivors, and siblings, focus on identifying traumatic memories associated with cancer and its treatment and using cognitive-behavioral approaches to reframe beliefs about these adversities. The other two sessions use family therapy approaches to facilitate awareness and communication about the ongoing impact of cancer on families and how beliefs about cancer affect the family at the present time. A randomized clinical trial (RCT) with 150 families showed that SCCIP was effective in reducing PTSS for survivors, mothers, and fathers (Kazak et al., 2004). The model of PMTS suggests that by identifying common elements as well as unique aspects of different illness groups, effective interventions, such as SCCIP, might be usefully adapted and evaluated for survivors of other serious pediatric illnesses (and their families).

Conclusions

Understanding psychological reactions to pediatric illness and injury from a posttraumatic stress framework has strong support from studies of childhood cancer and injury. Growing evidence suggests its relevance for ICUs and for children with burns or undergoing transplantation. The model can be used as a framework for research that may further (a) the documentation of PMTS across medical conditions and stages, (b) the identification of predictors of PMTS across and within phases, and (c) the development of evidence-based assessment and intervention approaches. Several related points may be highlighted.

First, PMTS affects not only pediatric patients but also their families, healthcare teams, schools, and communities. Interventions should include families in an essential and integral manner. Interventions may be conceptualized broadly and include approaches that impact staff and affect healthcare practice and the delivery of multidisciplinary trauma-informed treatment.

Second, a traumatic stress model is consistent with evidence showing that it is the subjective experience of medical events that shapes psychological outcomes rather than more objective markers of the severity of disease or injury, intensity of procedures, or survival statistics. A traumatic stress model is less concerned with verifying whether different experiences are objectively traumatic and more concerned with understanding patient and family experiences of and beliefs about medical events. Third, many patients and families experiencing PMTS are functioning quite well. The essential normality of these patients and families necessitates that interventions be brief, competency-based, and nonstigmatizing. It also argues for the systematic identification of families most at risk to provide interventions that best match the families’ need and risk status and to establish clearer links between PMTS and potential functional impairments for patients and family members. Fourth, although a traumatic stress framework is a useful and empirically supported model, we recognize that other potential psychosocial outcomes (e.g., depression) may also be relevant to assess and treat. It is our intent that the model presented be helpful in conceptualizing and guiding intervention development. We recognize that alternative outcomes or pathways may be identified in relation to specific patient groups or circumstances. We also encourage the further refinement of this model to examine the impact of PMTS on other health outcomes.

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References


Manne, S., DuHamel, K., Ostroff, J., Parsons, S., Martini, D., Williams, S., et al. (2004). Anxiety, depressive,


