

Evidence-based Assessment, Intervention and Psychosocial Care in Pediatric Oncology: A Blueprint for Comprehensive Services Across Treatment

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Objective This paper describes the translation of psychological research into clinical services in pediatric oncology, based on two decades of research and clinical services in the Division of Oncology at The Children's Hospital of Philadelphia (CHOP). **Method** Two models helpful in conceptualizing clinical care underlying intervention work at CHOP are summarized: The Pediatric Psychosocial Preventative Health Model (PPPHM; Kazak, 2006) and the Medical Traumatic Stress Model, specific to pediatric illness and injury (Kazak, Kassam-Adams et al., 2006). **Results** Integration of these two models offers a "blueprint" for development and evaluation of services to children with cancer and their families relevant for all families across the complete spectrum of disease and treatment. **Conclusion** The dissemination of evidence-based psychosocial practice in pediatric oncology remains a large and challenging goal. The proposed blueprint may facilitate collaborative work to help assure that children with cancer and their families have access to evidence-based care.

Key words assessment; childhood cancer; families; intervention; pediatric oncology; post-traumatic stress; psychological outcomes; psychosocial; survival.

The remarkable history of treatment successes in childhood cancer over the past 30 years has changed the landscape for oncology psychosocial care. Over this same period of time, evidence of the psychological aspects of childhood cancer has also increased substantially with strong knowledge bases for neuropsychological (Moore, 2005) and psychosocial (Patenaude & Kupst, 2005) outcomes. The increasing emphasis on the need for evidence-based psychological interventions and concurrent calls for the integration of behavioral health specialists on pediatric oncology care teams (AAP, 2004; Noll & Kazak, 2004) indicate significant opportunities to incorporate behavioral health care in the treatment plan for all oncology patients. Yet, dissemination of psychosocial empirically supported interventions remains at a rudimentary level (Kazak, 2005). The psychosocial care provided to children and families is not standardized and is often variable between institutions and even within settings.

This paper offers an overarching framework for providing psychosocial care to children and families

experiencing childhood cancer, based on research and clinical work conducted in the Division of Oncology at The Children's Hospital of Philadelphia (CHOP).¹ The goals of this paper are to (a) discuss the application of science to clinical service in pediatric oncology; (b) summarize two models that are helpful in conceptualizing child and family adjustment and the delivery of evidence-based interventions—the Pediatric Psychosocial Preventative Health Model (PPPHM; Kazak, 2006) and the Medical Traumatic Stress Model (Kazak, Kassam-Adams et al., 2006); and (c) integrate these two models in a "blueprint" that may

¹This paper reflects the experiences at one center. In summarizing our work there is no intention to suggest that it is superior to approaches taken at other centers. The research and clinical care models that we have developed and refined over the past two decades may be helpful to others in conceptualizing psychosocial care and in advocating for these or other approaches to benefit their patients, families and services.

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serve as a guide for transcending some of the common barriers to evidence-based care delivery.

Applying Science to Clinical Practice

The growing scientific database in pediatric psychology has consistently and systematically dismantled the idea that children with cancer and their families are necessarily at risk for psychopathology or other adverse psychosocial outcomes. Early research on children with a broad array of childhood illnesses and disabilities was designed to detect psychological difficulties and evidence of family dysfunction. *Over the past 20 years, findings from these studies have indicated that most families with a child with cancer (or other pediatric health issue) are competent and able to cope and adjust well over time despite initial and/or recurrent periods of extreme distress.*

This shift from a deficit-based to a competence-based conceptualization of the reactions to childhood cancer calls for a corresponding change in our intervention paradigms. Specifically, there is a need for a model that can provide a map for treatments that are preventative, innovative, and targeted to the true needs of the child, family, and health-care system. Such a model would include broad-based educational interventions to foster the competence of families. Simultaneously, it would identify those children and families with elevated and/or escalating psychological distress, and provide tailored services to support their adjustment. This approach offers the potential for evidence-based assessment and intervention (applying treatments with scientific evidence), addressing concerns about access to care (serving all families appropriately based on their needs), *and* attending to cost efficiency (assuring that limited resources are used to help the widest range of families feasible).

Two Models

Developed as a competence-based framework, our intervention work at CHOP is based on the integration of two conceptual models, the PPPHM and the Medical Traumatic Stress model. Below, we present both models, including a brief overview of the background for each and examples of its application to clinical care. We will then discuss how these models can be integrated into a single paradigm to inform clinical practice.

Pediatric Psychosocial Preventative Health Model (PPPHM)

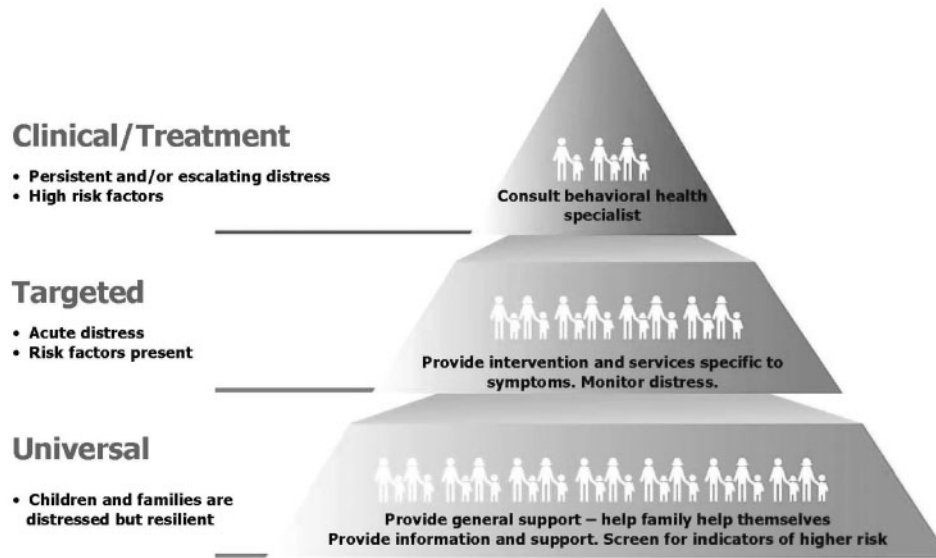
The PPPHM builds on the assumption that the majority of families with a child with cancer are competent and adaptively organized families, without any elevations in their

a priori risk (as a group) for psychopathology. Existing clinical models, interventions or modes of delivery, typically focused upon ameliorating psychopathology, may not effectively address the needs of these families. All of these families have understandable distress associated with the diagnosis of their child's cancer. Some families develop difficulties negotiating the specific challenges of children during cancer treatment (e.g., needle phobias, adherence concerns). A small set have pre-existing vulnerabilities or difficulties that may be exacerbated by the diagnosis of cancer, resulting in increased risk for clinically significant levels of distress and deterioration of functioning. The PPPHM (Fig. 1) attends to this range of adaptation in the population by applying the public health concepts of Universal, Selective, and Indicated levels of need or risk to children with pediatric illnesses and injuries (Kazak, 2006). In this way, the PPPHM provides a model to guide screening and services for *all* families of children entering the pediatric healthcare system, with higher levels of care directed to those families most at risk. We retain use of the term *Universal* for the largest group of families, but use *Targeted* to indicate those families at higher risk and in need of services and *Clinical/Treatment* to highlight those families at highest risk. More details about the PPPHM and its applications can be found in other papers (e.g., Kazak, 2006; Kazak & Noll, 2004).

The goal of assessing the level of family risk is to build an optimal fit between patient/family need and psychosocial care. This kind of empirically-defined fit not only provides good preventative patient care, but also represents an efficient and cost-effective approach to the allocation of resources within the health care environment. In contrast to more traditional clinical models that are activated by referrals for consultation with patients/families having problems, the PPPHM is a proactive and preventative model that directs the provision of both broad and targeted interventions, differentially based on patient risk. PPPHM levels are not static or impermeable. Rather, families may move from level to level (in either direction). Effective intervention may move families to a lower risk level. Characteristics of or changes in the child's medical condition and treatment may influence movement between levels, as well. For example, a recurrence of cancer or side effects (e.g., toxicity necessitating an admission to an intensive care unit) may add sufficient additional stress to the family system and increase the family's vulnerability.

Medical Traumatic Stress Model

One helpful approach, supported by a growing database of empirical research, for understanding the experience of



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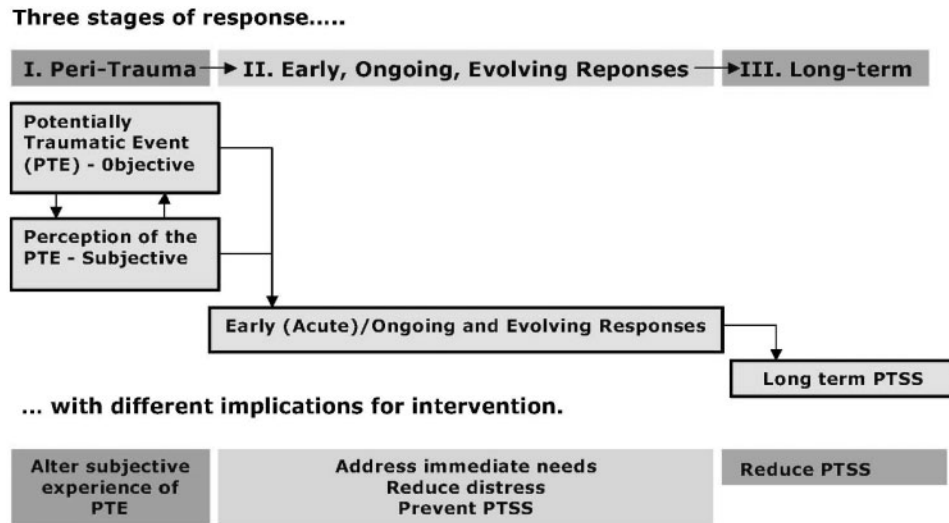
Figure 1. Pediatric Psychosocial Preventative Health Model (PPPHM).

families throughout the course of their child's diagnosis with cancer is a traumatic stress model.² The model we have adapted (Fig. 2) is guided by a developmental conceptualization of traumatic experience across the illness trajectory, with three stages—peri-trauma (I), during treatment (II), and long-term sequelae (III; Kazak, Kassam-Adams et al., 2006). We refer to medical events that may be traumatic (e.g., diagnosis, emergent medical care) as Potentially Traumatic Events (PTE) to underscore that it is the interaction between the objective nature of the event and the subjective interpretation of an event that renders a particular event as traumatic, or not. The peri-trauma phase (Phase I) is the immediate time period around a traumatic event, which often includes multiple PTEs (e.g., learning one's child has cancer, early days of medical workups and treatment initiation, waiting for the results of initial diagnostic workups). Phase II represents the period of time during treatment. It is variable in length and course and continues to expose patients and families to ongoing PTEs (e.g., side effects/complications of treatment, pain, death of other children from cancer, concerns about relapse, relapse). The third phase is long-term traumatic stress.

²There is some controversy regarding the applicability of PTSD to adults with medical illness. Although there is significant empirical support for a traumatic stress model for understanding family responses to pediatric cancer and other pediatric illnesses and injuries, this field of research is at an early stage of development. Readers interested in more detailed discussions of traumatic stress in the context of pediatric illness may find papers by Bruce (2006) and Stuber, Shemesh & Saxe (2003) of interest.

Families in this developmental phase include those whose children have completed treatment as well as families of children who have died.

Evidence supports the conceptualization of childhood cancer and treatment as a series of PTEs that can lead to trauma symptoms such as intrusive memories, physiological arousal, avoidance, numbing, and helplessness. For example, in 140 families of children newly diagnosed with cancer (Phase I), half of mothers and 40% of fathers met full criteria for Acute Stress Disorder (ASD; Patino-Fernandez et al., in press). In another sample of 125 families of children currently in treatment, all parents except one reported Post-traumatic Stress Symptoms (PTSS) and mean scores on the Post-traumatic Stress Disorder (PTSD) Reaction Index were in the moderate range and higher than those found in survivor samples (Phase II; Kazak, Boeving et al., 2005). Support for Phase III of the PTSS model in families of childhood cancer survivors is particularly striking (Barakat et al., 1997; Brown, Madan-Swain, & Lambert, 2003; Fuemmeler, Mullins, & Marx, 2001; Kazak, Alderfer et al., 2004; Kazak, Barakat, Meeske et al., 1997; Manne, DuHamel, Gallelli, Sorgen, & Redd, 1998; Manne et al., 2002, 2004; Stuber et al., 1997). 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 re-experiencing and 20% of the families had at least one parent with current PTSD (Kazak, Alderfer, Rourke et al., 2004). In terms of the



Kazak, A., Kassam-Adams, N., Schneider, S., Alderfer, M., Zelikovsky, N., & Rourke, M. (2006). An integrative model of pediatric medical traumatic stress. *Journal of Pediatric Psychology*.

Figure 2. Traumatic stress model.

survivors (children) themselves, 5–10% have PTSD (Butler, Rizzi, & Handwerker, 1996; Erickson & Steiner, 2002; Kazak, Alderfer, Rourke et al., 2004; Pelcovitz et al., 1998; Phipps, Long, Hudson, & Rai, 2005), with considerably more experiencing PTSS (Brown et al., 2003; Erickson & Steiner, 2002; Kazak, Barakat, Alderfer et al., 2001; Kazak, Stuber et al., 1998). Evidence for significant levels of PTSS in young adult survivors of childhood cancer is also increasing (Langeveld, Grootenhuis, Voute, & De Hann, 2004; Rourke, Hobbie, Kazak et al., 2002; Hobbie et al., 2000; Rourke, Hobbie, Schwartz et al., in press; Santacroce & Lee, 2006; Schwartz & Drotar, 2006; Zebrack et al., 2002). Moderate to severe PTSS has also been reported in approximately one-third of siblings of survivors (Alderfer, Labay & Kazak, 2003).

The normative and understandable experience of a trauma reaction after childhood cancer is not always a pathological response or one with singularly negative implications. Indeed, some forms of traumatic stress responses may be viewed as potentially adaptive. The overt distress and arousal experienced by parents of newly diagnosed patients, for example, communicates to family, friends, community and providers that support and assistance are needed. In addition, re-experiencing is a natural means by which experiences are processed and by which traumatic experiences are ultimately (and often) resolved. Finally, avoidance behaviors may help people tolerate distress and accomplish their parental responsibilities in the face of potentially overwhelming emotional demands (Kazak, Kassam-Adams et al., 2006).

An advantage of this developmental trauma model is that different intervention strategies can be tailored for the clinical needs specific to each phase of this model. Peri-trauma care includes general trauma-informed care, while interventions during treatment most often aim to reduce the traumatic potential of events common during childhood cancer treatment (pain, procedural distress, anxiety, separations from caregivers). Clinical interventions during the long-term phase generally must be tailored to an individual's presenting issues, and often involve a complex and longer-term treatment plan.

Blending the PPPHM and Medical Traumatic Stress Model: A Blueprint

The PPPHM provides a broad framework with three levels of risk. Similarly, the traumatic stress model has three phases. Integrated, these two models, visualized as a 3 (levels of risk) by 3 (trauma phases) grid, renders a "blueprint" to guide the development of risk-based clinical interventions from initial diagnosis through survivorship, inclusive of varying levels of distress (Fig. 3). We begin with the premise that services should be provided across all nine cells. The types and intensity of care will vary, but providing appropriate services to *all* families is the goal.

The first step in effectively implementing this framework is assessing the family's level of psychosocial risk. To do this in a reliable and valid way, a two-page screener was developed [*The Psychosocial Assessment Tool (PAT)*;

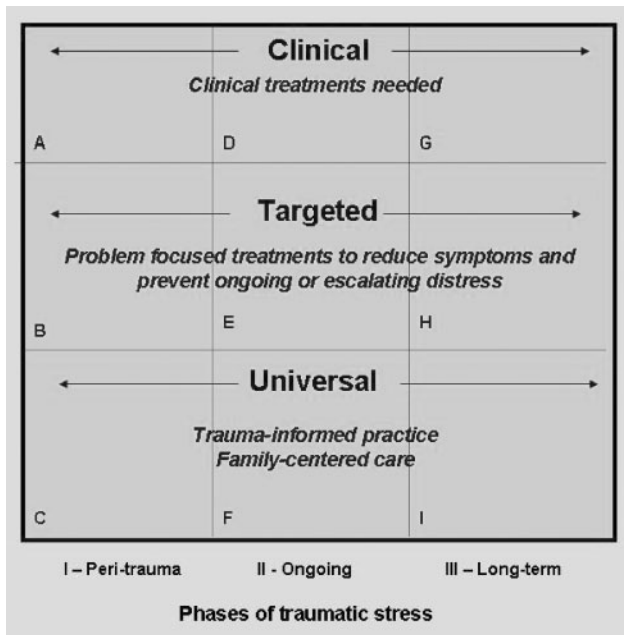


Figure 3. PPPHM combined with traumatic stress model provides a blueprint for psychosocial care in pediatric oncology.

Kazak, Cant et al., 2003; Kazak, Prusak et al., 2001]. A series of studies using the PAT shortly after diagnosis (in the peri-trauma phase) has validated its ability to categorize families into PPPHM risk categories. That is, about two-thirds of families fall in the Universal risk category, endorsing three or fewer risk items and, by self and staff (oncologist, nurse) report are psychologically quite healthy and functioning well. Approximately 25% of families fall in the Targeted category and endorse items (e.g., family stressors, child adjustment difficulties, financial concerns, etc.) that place them at moderate psychosocial risk. Less than 10% fall in the Clinical/Targeted category. These families experience the most severe difficulties, including severe psychopathology and/or significant social or financial difficulties (e.g., homelessness, child foster placement issues; Kazak, Cant et al., 2003; Kazak, Prusak et al., 2001; Patino-Fernandez et al., 2006). Given the potential for PPPHM levels to change, reassessment of risk, particularly following critical events during treatment (Phase II of the Medical Traumatic Stress Model) or at treatment junctures (e.g., entering Phase III) is also recommended.

Universal Care Across the Trauma Stages (Cells C, F, and I)

Universal care requires the collaboration of psychosocial, medical, and nursing professionals to address the most common needs of families facing childhood cancer. Given

the high rates of ASD and symptoms of acute stress (SAS) in parents of newly diagnosed patients (e.g., Patino-Fernandez et al., in press), efficient and appropriate goals of Universal intervention are to reduce the experience of trauma for all patients and family members and to increase patients' and parents' experience of safety and control. While the intent of many psychosocial pediatric oncology programs is to use existing hospital resources (e.g., child life, social work, family-centered care programs, chaplains) to address many of these needs, these resources are often diverted "upward" to families presenting with greater needs.

Universal care that is consistent with this model can be achieved with somewhat of a shift in the traditional role of a pediatric psychologist. First, the pediatric psychologist may be a facilitator of collaboration across psychosocial providers. These collaborations can provide opportunities for the development of programs and approaches consistent with family-centered care and likely to benefit many families (e.g., parent groups, psychoeducational programs, sibling groups). This is most feasible when the psychologist is embedded as a member of the team and is able to devote the time necessary to developing services and facilitating referral to programs. Second, pediatric psychologists working at this level of care may take the role of coach or trainer and provide education, resources, and problem-solving that will allow nurses, support staff, physicians, and trainees to integrate psychosocial care into their daily work. Examples include participating in medical rounds to provide input on psychosocial care and facilitating psychosocial rounding for medical and nursing staff.

The Medical Traumatic Stress Toolkit (http://www.ncsnet.org/nccts/nav.do?pid=typ_mt_ptlkt; Stuber et al., 2006) is an example of a Universal Care intervention for the peri-trauma and treatment phases of the Medical Traumatic Stress model. The toolkit provides background information to guide trauma-informed practice. It contains materials that can be used by physicians, nurses, and other healthcare providers in busy pediatric oncology centers. For example, the Toolkit includes D-E-F (distress, emotional support, family) pocket cards that may be useful in cueing providers to ask basic questions assessing these critical dimensions of patient/family well-being after assessing A-B-C (airways, breathing, circulation). In addition to providing background materials to foster an appreciation for potentially traumatic aspects of oncology care, sample questions are provided that allow providers to ask directly about risk factors (e.g., does the child have a history of other

traumatic experiences?), symptoms (e.g., does the child/parent startle easily?) when it is appropriate to do so and to provide education and guidance more generally (Pai & Kazak, 2006).

Survivors of childhood cancer (Phase III: Long-term Traumatic Stress Responses) present additional opportunities for Universal intervention. Here universal care might include assessing PTSS in survivors as a routine part of care, and providing anticipatory guidance on PTSS and other emotional late effects as a standard part of end of treatment education and subsequent survivorship visits (Rourke et al., in press). Finally, an underused resource by many pediatric oncology centers is partnerships with community cancer-based organizations that may reach survivors and their family members, offering the opportunity to provide anticipatory guidance and assessment.

The PPPHM and Phase III also apply to families whose child has died (Kazak & Noll, 2004). Much of the literature on families whose child has died is based on clinical samples, and informs us only about the appropriateness of clinical level interventions. Looking more broadly at this population of families can provide a different perspective, and is necessary in order to inform broader intervention approaches. The first step toward developing interventions at this level is to better understand normative family needs immediately before the child's death, at the time of death and just after, and in the weeks, months, and years afterward. Current treatments, based mostly on clinical experience, include intensive interventions at the peri-trauma phase (i.e., the days and weeks leading up to a child's anticipated death). These efforts most often are accomplished with the assistance of child life specialists, and include working with parents and siblings to make mementos of a child (e.g., handprints), or helping families discuss the impending death with siblings or extended family members. Recent calls for increased (and earlier) involvement of formal pediatric palliative care, with a focus on better management of a dying child's physical and emotional symptoms (Wolfe, Grier, Klar et al., 2000) is another example of this level of intervention, as it aims to minimize the potential for trauma by maximizing a child's comfort and providing families with the experience of a "good" death.

Targeted Care Across Trauma Stages (Cells B, E and H)

Psychosocial services for children/families at the Targeted level include evidence-based interventions typically used

by pediatric psychologists in oncology. For example, interventions addressing procedural distress and other pain, reduce the traumatic potential of medical events. These interventions, as well as those that target symptom-related distress, anxiety and/or depression, and family stress also address symptoms seen during treatment (Level B, E). Maternal problem-solving (Sahler et al., 2002, 2005) and parental stress reduction approaches (Streisand, Rodrigue, Houck, Graham-Pole, & Berland, 2000) may similarly be most helpful for those families with some identified need for assistance, but who are, nonetheless, receptive to intervention and able to engage in treatment and organize themselves to attend interventions.

To address Targeted psychosocial needs during treatment and in the Survivorship phases, the Surviving Cancer Competently Intervention Program (SCCIP), with intervention modules specific to parents of newly diagnosed children (Phase II) and survivors (Phase III), was developed. SCCIP-ND (Newly Diagnosed) is a three-session intervention for parents that integrates cognitive behavioral and family systems techniques to reduce traumatic stress symptoms. Given that higher levels of parental distress during treatment are associated with later PTSS (Kazak & Barakat, 1997; Best, Streisand, Catania, & Kazak, 2001), the early months of treatment provide an important window to intervene to reduce short and longer-term PTSS. Pilot data from SCCIP-ND documented the feasibility and acceptability of the intervention and showed changes in outcomes in the expected direction (Kazak, Simms et al., 2005). SCCIP-ND is now being evaluated in a larger randomized clinical trial (RCT). SCCIP was originally developed for adolescent survivors of childhood cancer and their families (Kazak et al., 1999). In this version, the intervention is a one-day (weekend) group intervention in which cognitive behavioral approaches are used in a family context to identify how beliefs about cancer affect families over time. SCCIP was tested using a waitlist control RCT with 150 families (Kazak et al., 2004). The results showed significant treatment effects for survivors, mothers and fathers, in particular decreases in arousal and intrusive thoughts.

Targeted interventions have generally been focused on reducing symptoms after they develop. The blueprint suggests that this focus be broadened such that prevention-oriented services are included; families at higher levels of risk may also benefit from interventions with a preventative focus. For example, SCCIP-ND targets

beliefs during the initial weeks after diagnosis that may be malleable, in an attempt to prevent long-term distress. In order to advance preventative care in this area, innovation in delivery models is necessary, including use of technology (e.g., internet, web-based approaches) that facilitate dissemination. A recent pilot study showed the feasibility and interest of families of children with cancer in an intervention with a web-based format (Svacarsdottir & Sigurdardottir, 2005). There may be other brief intervention models that could target the well-being of multiple members of the family and be delivered during treatment. These approaches might also incorporate interventions that balance the reduction of problems with fostering positive outcomes.

Clinical Levels of Care (Cells A, D, G)

Interventions at the Clinical level are the most intensive and expensive, and are most often focused on meeting the significant needs of patients and families with multiple pre-existing difficulties. Treatment at this level often involves extensive collaboration with the medical and nursing team and may include consultation from psychiatrists and other hospital services, including security and hospital administration under some circumstances.

In our setting, we have two treatment approaches for families of children during active cancer treatment at this level (Cells A and D). The first is a family systems oriented consultation model (Kazak, Simms & Rourke, 2002) that views the child as one part of the patient–family–staff triad. Although an individual child or adolescent may be the target of the intervention, the emphasis is on providing the structure necessary for all participants in the triad to function more competently. The intervention approach is highly focused, reflecting realistic goals of assuring that medical care is provided safely and that acute distress is reduced, without attempting to “cure” more severe and chronic family problems that may contribute to the presenting problem.

A second approach is a protocol implemented in our hospital when “difficult” family situations arise. A survey of oncologists, nurses, and psychosocial staff in our setting highlighted the types of situations that are most difficult for providers (Rourke et al., 2006). Not surprisingly, these include verbal or physical aggression, perceived interference of family members in the delivery of medical care, and nonadherence to treatment. Providing as much consistency as possible in the team

members caring for the patient, creating strong team leadership, having frequent team meetings and solid support of staff for one another are effective parts of a protocol for working with these families. Engagement of families in treatment can be challenging and the seriousness of problems at this level often warrants close and intensive intervention from multiple team members. At the same time, and despite the resources expended, the outcomes are often the least satisfying and difficult to measure.

Patients with traumatic stress (or other) difficulties during survivorship (Phase III) may or may not come to the attention of the oncology treatment teams. Increasing calls to attend to psychological late effects within the context of follow-up/survivorship visits may increase the identification of these issues by medical teams. Cancer survivors may not associate their ongoing difficulties with their cancer treatment, however, or may seek care from medical providers who are not aware of traumatic stress during survivorship. Survivors with persistent and intense PTSS present unique and worrisome challenges. That is, survivors with chronic PTSS tend to be older (e.g., young adults) and have suffered with PTSS and other psychological symptoms over time (Rourke et al., in press). Their identification and treatment may come at the time of a crisis (e.g., transition from school to work, change in family, interpersonal difficulties) or may not be readily detected when avoidance (a symptom of PTSS) limits interactions with healthcare professionals who could identify problems. The SCCIP treatment model is helpful for formulating intervention approaches for these survivors. Our team has adapted this model to a group workshop format that targets PTSS and adaptation in young adult survivors of childhood cancer. To date, the two-session workshop series is highly accepted by participants. Data analysis is ongoing, but trends indicate that anxiety and post-traumatic stress ratings are lower after the workshop. Formal analysis and a more rigorous test of this program are necessary.

Advantages, Challenges and Next Steps in Implementation

Advantages of this integrated framework include the opportunity to differentiate the needs of families and to conceptualize the families’ needs within the framework of the traumatic stress process from the onset of the potentially traumatic event through long-term responses.

This is unique in mental health care where trauma is addressed often years after a PTE. The traumatic stress model is highly acceptable to families and survivors, applicable to nearly all families, and provides many directions for intervention. Combining these approaches gives us a framework in which we have the opportunity to consider what types and levels of intervention may be most useful given the psychosocial risk of the specific family, within the midst of their traumatic exposures [e.g., diagnosis, receiving complex information about treatment options and survival, seeing and meeting other children with cancer and their parents, early days of treatment and related hospital (emergency department, pediatric intensive care unit) experiences]. Also, the model provides a framework for attention to larger numbers of patients than traditional referral-based approaches.

In addition, there is increasing evidence for resilience (Luthar, Cichchetti, & Becker, 2000) and enhanced growth and positive outcomes after trauma (Bonanno, 2004). Post-traumatic growth (PTG) and benefit finding describe ways in which cancer patients and their families identify a “silver lining” associated with their cancer-related experiences. Childhood cancer survivors have been shown to report increased maturity, greater compassion and empathy, new values and priorities, new strengths, and recognition of one’s vulnerabilities and appreciation for life (Jones et al., 2006; Parry and Chesler, 2005). PTG and PTSS are both seen in survivors, with positive outcomes coexisting with distress (Barakat, Alderfer & Kazak, 2006). Bereaved parents (Polantinsky & Esprey, 2000) and mothers of children undergoing bone marrow transplants (Rini et al., 2004) have also reported perceived benefits following their experience. Collectively, these studies highlight the relevance of PTG for survivors and family members.

Considering systems broader than families is also important in preventively oriented work. That is, traumatic stress responses among caregivers in medical settings, often called secondary traumatic stress responses, are prevalent (Robins, Meltzer & Zelikovsky, 2006). Interventions that support staff and provide tools to facilitate their caregiving under repeated stressful circumstances may have indirect benefits for patient care as well as staff morale and retention.

There are very real challenges, however, to how the proposed blueprint for psychosocial services in oncology might be received and/or implemented. Translating research into practice is an iterative process, beginning with rigorous, conceptually guided research on the most

appropriate targets of clinical intervention as well as the mechanisms believed to be essential to achieving treatment outcomes. Assuring that “basic” research is rigorous while also being clinically meaningful and related to relevant outcomes is necessary in order to develop and refine intervention models. In pediatric psychology, we have strong bases of work that are guiding the development of pilot interventions. We are seeing increasing reports of relatively small studies with conceptually and empirically guided interventions (Spirito & Kazak, 2006; Pai et al., 2006).

As interventions are developed, the field will continually be faced with questions regarding dissemination. Pediatric oncology has been an optimal setting for dissemination. Cancer has long been recognized as extremely stressful for children and families. Identification of neurocognitive sequelae of treatment further solidified the importance of including psychologists in the care of children with cancer. There is little doubt that evidence-based care has been provided to children with cancer, particularly with respect to interventions related to procedural pain (Powers, 1999) and identification of cognitive and learning difficulties (Mulhern & Butler, 2006). However, in order to provide more comprehensive evidence-based care, conscious decisions at the leadership level in healthcare systems must be made to support research and dissemination. And, the effectiveness of interventions must be linked to patient care outcomes, many of which have yet to be measured effectively. The model described in this paper is one that advocates for integration of psychologists on the cancer treatment team, sometimes referred to as “embedded psychologists” as contrasted with a consultancy model. This model provides more opportunity for the development of services that are integral to patient care and facilitates multidisciplinary exchanges that foster collaborations on research, practice, and teaching. These opportunities tend to be more limited in consultation models where services are typically provided to individual patients and the consultant’s role is defined more narrowly.

Perhaps most evident among the challenges to the work described in this paper are considerations for the cost of providing comprehensive preventative services, even at relatively well-resourced tertiary care hospitals. Expense-related barriers include the upfront cost of providing care to more patients and the inadequacy of current billing and reimbursement policies for services provided by psychologists and social workers for pediatric (nonpsychiatric) patients (Kazak, 2006). Health and

behavior codes are promising sources of revenue (Brosig & Zahart, 2006; Noll & Fischer, 2004), but are not likely, alone, to cover the costs of the kind of “embedded” model proposed here. Instead, psychosocial professionals and our medical and nursing colleagues must be challenged to think differently about the kinds of outcomes that may be associated with preventative interventions. That is, interventions that promote family adaptation to childhood cancer and facilitate adherence to treatment have the potential for cost offset and savings in multiple ways, and may, for example, reduce days in the hospital and clinic visits and avert morbidities, and even potential mortalities, related to noncompliance with treatment. Creating empirical ways to demonstrate more of these unconventional cost savings may open up the potential for different funding mechanisms. Other potential barriers to the models described in this paper include resistance that may emerge from any or all members of the multidisciplinary team when changes are introduced (Kazak, 2006). That is, the model requires the coordination of care among behavioral health specialists. This coordination can necessitate flexibility in professional roles, but ultimately may be a cost effective alternative to multiple parallel services and consultations.

In acknowledging these challenges, we maintain that an aspirational blueprint is important in providing an overview of the needs and possibilities for intervention development. There are many multidisciplinary teams working in pediatric oncology nationally and internationally. A combination of multisite and smaller studies will both be needed to advance intervention development. A collective and collaborative framework will be needed to advance practice in this area. For instance, multisite studies will be needed to promote the process of intervention development and dissemination, while smaller studies will be needed to make inroads in the portions of the blueprint in which interventions are just beginning to be developed. Regardless, the products of this research, empirically supported intervention approaches, must ultimately be cost effective and readily disseminated.

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References

- Alderfer, M., Labay, L., & Kazak, A. (2003). Brief Report: Does posttraumatic stress apply to siblings of childhood cancer survivors? *Journal of Pediatric Psychology*, 28, 281–286.
- American Academy of Pediatrics (2004). Guidelines for pediatric cancer centers. *Pediatrics*, 113, 1833–1835.
- Barakat, L., Alderfer, M., & Kazak, A. (2006). Posttraumatic growth in adolescent survivors of cancer and their families. *Journal of Pediatric Psychology*, 31, 413–419.
- Barakat, L., Kazak, A., Meadows, A., Casey, R., Meeske, K., & Stuber, M. (1997). Families surviving childhood cancer: A comparison of post-traumatic stress symptoms with families of healthy children. *Journal of Pediatric Psychology*, 22, 843–859.
- Best, M., Streisand, R., Catania, L., & Kazak, A. (2001). Parental distress during pediatric leukemia and parental post-traumatic stress symptoms after treatment ends. *Journal of Pediatric Psychology*, 26, 299–307.
- Bonanno, G. (2004). Loss, trauma and human resilience: Have we underestimated the human capacity to thrive after extremely aversive events? *American Psychologist*, 59, 20–28.
- Brown, R., Madan-Swain, A., & Lambert, R. (2003). Posttraumatic stress symptoms in adolescent survivors of childhood cancer and their mothers. *Journal of Traumatic Stress*, 16, 309–318.
- Brosig, C., & Zahart, D. (2006). Evolution of an inpatient pediatric psychology consultation service: Issues related to reimbursement and the use of health and behavior codes. *Journal of Clinical Psychology in Medical Settings*, 13, 425–429.
- Bruce, M. (2006). A systematic and conceptual review of posttraumatic stress in childhood cancer survivors and their parents. *Clinical Psychology Review*, 26, 233–256.

- Butler, R., Rizzi, L., & Handwerger, B. (1996). Brief Report: The assessment of posttraumatic stress disorder in pediatric cancer patients and survivors. *Journal of Pediatric Psychology, 21*, 499–504.
- Erickson, S., & Steiner, H. (2002). Trauma and personality correlates in long term pediatric cancer survivors. *Child Psychiatry and Human Development, 31*, 195–213.
- Fuemmeler, B., Mullins, L., & Marx, B. (2001). Posttraumatic stress and general distress among parents of children surviving a brain tumor. *Children's Health Care, 30*, 169–182.
- Hobbie, W., Stuber, M., Meeske, K., Wissler, K., Rourke, M., Ruccione, K., et al. (2000). Symptoms of posttraumatic stress in young adult survivors of childhood cancer. *Journal of Clinical Oncology, 18*, 4060–4066.
- Jones, B., Volker, D., Vinajeras, Y., & Sampson, M. (2006, October). *The meaning of survival for Hispanic adolescents: A qualitative study*. Poster, "Cancer Survivorship: Embracing the Future," National Cancer Institute, American Cancer Society, Lance Armstrong Foundation National Cancer Survivorship Conference, Bethesda, MD.
- Kazak, A. E. (2005). Evidence based interventions for survivors of childhood cancer and their families. *Journal of Pediatric Psychology, 30*, 29–39.
- Kazak, A. (2006). Pediatric Psychosocial Preventative Health Model (PPPHM): Research, practice and collaboration in pediatric family systems medicine. *Families, Systems and Health*.
- Kazak, A., Alderfer, M., Streisand, R., Simms, S., Rourke, M., Barakat, L., et al. (2004). Treatment of posttraumatic stress symptoms in adolescent survivors of childhood cancer and their families: A randomized clinical trial. *Journal of Family Psychology, 18*, 493–504.
- Kazak, A., Alderfer, M., Rourke, M., Simms, S., Streisand, R., & Grossman, J. (2004). Posttraumatic stress symptoms (PTSS) and posttraumatic stress disorder (PTSD) in families of adolescent childhood cancer survivors. *Journal of Pediatric Psychology, 29*, 211–219.
- Kazak, A., & Barakat, L. (1997). Parenting stress and quality of life during treatment for childhood leukemia predicts child and parent adjustment after treatment ends. *Journal of Pediatric Psychology, 22*, 749–758.
- Kazak, A., Barakat, L., Meeske, K., Christakis, D., Meadows, A., Casey, R., et al. (1997). Posttraumatic stress, family functioning, and social support in survivors of childhood leukemia and their mothers and fathers. *Journal of Consulting and Clinical Psychology, 65*, 120–129.
- Kazak, A., Boeving, A., Alderfer, M., Hwang, W. T., & Reilly, A. (2005). Posttraumatic stress symptoms in parents of pediatric oncology patients during treatment. *Journal of Clinical Oncology, 23*, 7405–7410.
- Kazak, A., Cant, M. C., Jensen, M., McSherry, M., Rourke, M., Hwang, W. T., et al. (2003). Identifying psychosocial risk indicative of subsequent resource utilization in families of newly diagnosed pediatric oncology patients. *Journal of Clinical Oncology, 21*, 3220–3225.
- Kazak, A., Kassam-Adams, N., Schneider, S., Zelikovsky, N., Alderfer, M., & Rourke, M. (2006). An integrative model of pediatric medical traumatic stress. *Journal of Pediatric Psychology, 31*, 343–355.
- Kazak, A., & Noll, R. (2004). Child death from pediatric illness: Conceptualizing intervention approaches from a family/systems and public health perspective. *Professional Psychology, 35*, 219–226.
- Kazak, A., Prusak, A., McSherry, M., Simms, S., Beele, D., Rourke, M., et al. (2001). The Psychosocial Assessment Tool (PAT): Development of a brief screening instrument for identifying high risk families in pediatric oncology. *Families, Systems and Health, 19*, 303–317.
- Kazak, A., Simms, S., Alderfer, M., Rourke, M., Crump, T., McClure, K., et al. (2005). Feasibility and preliminary outcomes from a pilot study of a brief psychological intervention for families of children newly diagnosed with cancer. *Journal of Pediatric Psychology, 30*, 644–655.
- Kazak, A., Simms, S., & Rourke, M. (2002). Family systems in pediatric psychology. *Journal Pediatric Psychology, 27*, 133–143.
- Kazak, A., Stuber, M., Barakat, L., Meeske, K., Guthrie, D., & Meadows, A. (1998). Predicting posttraumatic stress symptoms in mothers and fathers of survivors of childhood cancer. *Journal of the American Academy of Child and Adolescent Psychiatry, 37*, 823–831.
- Langeveld, N., Grootenhuis, M., Voute, P., & De Hann, R. (2004). Posttraumatic stress symptoms in adult survivors of childhood cancer. *Pediatric Blood and Cancer, 42*, 604–610.
- Luthar, S., Cichchetti, D., & Becker, B. (2000). The construct of resilience: A critical evaluation and

- guidelines for future work. *Child Development*, 71, 543–562.
- Manne, S., DuHamel, K., Gallelli, K., Sorgen, K., & Redd, W. (1998). Posttraumatic stress disorder among mothers of pediatric cancer survivors: Diagnosis, comorbidity, and utility of the PTSD Checklists as a screening instrument. *Journal of Pediatric Psychology*, 23, 357–366.
- Manne, S., DuHamel, K., Nereo, N., Ostroff, J., Parsons, S., Martini, R., et al. (2002). Predictors of PTSD in mothers of children undergoing bone marrow transplantation: The role of cognitive and social processes. *Journal of Pediatric Psychology*, 27, 607–617.
- Manne, S., DuHamel, K., Ostroff, J., Parsons, S., Martini, D., Williams, S., et al. (2004). Anxiety, depressive, and posttraumatic stress disorders among mothers of pediatric hematopoietic stem cell transplantation. *Pediatrics*, 113, 1700–1708.
- Moore, B. (2005). Neurocognitive outcomes in survivors of childhood cancer. *Journal of Pediatric Psychology*, 30, 65–78.
- Mulhern, R., & Butler, R. (2006). Neuropsychological late effects. In R. Brown (Ed.), *Comprehensive Handbook of Childhood Cancer and Sickle Cell Disease* (pp. 262–278). NY: Oxford.
- Noll, R., & Fischer, M. (2004). Commentary: Health and behavior CPT codes: An opportunity to revolutionize reimbursement in pediatric psychology. *Journal of Pediatric Psychology*, 29, 571–578.
- Noll, R., & Kazak, A. (2004). Psychosocial care. In A. Altman (Ed.), *Supportive care of children with cancer: Current therapy and guidelines from the Children's Oncology Group* (pp. 337–353). Baltimore MD: Johns Hopkins University Press.
- Pai, A. L. H., Drotar, D., Zebracki, K., Moore, M., & Youngstrom, E. (2006). A meta-analysis of the effects of psychological interventions in pediatric oncology on outcomes of psychological distress and adjustment. *Journal of Pediatric Psychology*, 31, 978–988.
- Pai, A., & Kazak, A. (2006). Family systems interventions to mitigate pediatric medical traumatic stress in pediatric oncology. *Current Opinions in Pediatrics*, 18, 558–562.
- Parry, C., & Chesler, M. (2005). Thematic evidence of psychosocial thriving in childhood cancer survivors. *Qualitative Health Research*, 15, 1055–1073.
- Patenaude, A., & Kupst, M. J. (2005). Psychosocial functioning in pediatric cancer. *Journal of Pediatric Psychology*, 30, 9–28.
- Patino-Fernandez, A. M., Pai, A., Alderfer, M., Hwang, W.T., Reilly, A., & Kazak, A. (in press). Acute stress in parents of children newly diagnosed with cancer. *Pediatric Blood and Cancer*.
- Patino-Fernandez, A. M., Pai, A., Alderfer, M., Jensen-Pace, M., Reilly, A., & Kazak, A. (2006b, September). *Assessing psychosocial risk: Mother, physician, nurse report*. Paper presented at the annual meeting of the Society for Developmental and Behavioral Pediatrics, Philadelphia, PA.
- Pelcovitz, D., Libov, B., Mandel, F., Kaplan, S., Weinblatt, M., & Septimus, A. (1998). Posttraumatic stress disorder and family functioning in adolescent cancer. *Journal of Traumatic Stress*, 11, 205–221.
- Phipps, S., Long, A., Hudson, M., & Rai, S. N. (2005). Symptoms of post-traumatic stress in children with cancer and their parents: Effects of informant and time from diagnosis. *Pediatric Blood and Cancer*, 45, 952–959.
- Polantinsky, S., & Esprey, Y. (2000). An assessment of gender differences in the perception of benefit resulting from the loss of a child. *Journal of Traumatic Stress*, 13, 709–718.
- Powers, S. (1999). Empirically supported treatments in pediatric psychology: Procedure-related pain. *Journal of Pediatric Psychology*, 18, 681–695.
- Rini, C., Manne, S., DuHamel, K., Austin, J., Ostroff, J., Bouland, F., et al. (2004). Mothers' perceptions of benefit following pediatric stem cell transplantation: A longitudinal investigation of the roles of optimism, medical risk, and sociodemographic resources. *Annals of Behavioral Medicine*, 28, 132–141.
- Robins, P. M., Meltzer, L., & Zelikovsky, N. (2006). The experience of secondary traumatic stress upon care providers working within a children's hospital. *Under editorial review*.
- Rourke, M. T., Reilly, A., Kersun, L. S., McSherry, M., Ingram, M., & Tracy, E. (February 2006). Understanding and managing challenging families in pediatric oncology. Poster presented at the American Psychosocial Oncology Society (APOS) 3rd Annual Conference, Amelia Island, FL.
- Rourke, M. T., Hobbie, W. L., Labay, L., & Kazak, A. E. (2002). Posttraumatic stress and other distress in young adult survivors of childhood cancer. Poster presented at the 7th International Conference on

- Long-Term Complications of Treatment of Children and Adolescents for Cancer, Niagara-on-the-Lake, Ontario.
- Rourke, M., Hobbie, W., Schwartz, L., & Kazak, A. (in press). Posttraumatic stress disorder (PTSD) in young adult survivors of childhood cancer. *Pediatric Blood and Cancer*.
- Sahler, O. J. Z., Fairclough, D. L., Phipps, S., Mulhern, R. K., Dolgin, M. J., Noll, R. B., et al. (2005). Using problem-solving skills training to reduce negative affectivity in mothers of children with newly diagnosed cancer: Report of a multisite randomized trial. *Journal of Consulting and Clinical Psychology, 73*, 272–283.
- Sahler, O. J. Z., Varni, J. W., Fairclough, D. L., Butler, R. W., Noll, R. B., Dolgin, M. J., et al. (2002). Problem-solving skills training for mothers of children with newly diagnosed cancer: A randomized trial. *Journal of Developmental & Behavioral Pediatrics, 23*, 77–86.
- Santacroce, S., & Lee, Y. (2006). Uncertainty, posttraumatic stress, and health behavior in young adult childhood cancer survivors. *Nursing Research, 55*, 259–266.
- Svavarsdottir, E., & Sigurdardottir, A. (2005). The feasibility of offering a family level intervention to parents of children with cancer. *Scandinavian Journal of Caring Sciences, 19*, 368–372.
- Schwartz, L., & Drotar, D. (2006). Posttraumatic stress and related impairment in survivors of childhood cancer in early adulthood compared to healthy peers. *Journal of Pediatric Psychology, 31*, 356–366.
- Spirito, A., & Kazak, A. E. (2006). *Effective & emerging treatments in pediatric psychology*. New York: Oxford.
- Streisand, R., Rodrigue, J., Houck, C., Graham-Pole, J., & Berland, N. (2000). Brief Report: Parenting of children undergoing bone marrow transplantation: Documenting stress and piloting a psychological intervention program. *Journal of Pediatric Psychology, 25*, 331–337.
- Stuber, M., Kazak, A., Meeske, K., Barakat, L., Guthrie, D., Garnier, H., et al. (1997). Predictors of posttraumatic stress symptoms in childhood cancer survivors. *Pediatrics, 100*, 958–964.
- Stuber, M., Schneider, S., Kassam-Adams, N., Kazak, A., & Saxe, G. (2006). The medical traumatic stress toolkit. *CNS Spectrums, 11*, 1–6.
- Stuber, M., Shemesh, E., & Saxe, G. (2003). Posttraumatic stress responses in children with life-threatening illness. *Child and Adolescent Psychiatric Clinics of North America, 12*, 195–209.
- Svavarsdottir, E., & Sigurdardottir, A. (2005). The feasibility of offering a family level intervention to parents of children with cancer. *Scandinavian Journal of Caring Sciences, 19*, 368–372.
- Tedeschi, R. G., & Calhoun, L. G. (2004). Posttraumatic growth: Conceptual foundations and empirical evidence. *Psychological Inquiry, 15*, 1–18.
- Wolfe, J., Grier, H. E., Klar, N., Levin, S. B., Ellenbogen, J.M., Salem-Schatz, S., et al. (2000). Symptoms and suffering at the end of life in children with cancer. *The New England Journal of Medicine, 342*(5), 326–333.
- Zebrack, B. J., Zeltzer, L. K., Whitton, J., Mertens, A. C., Odom, L., Berkow, R., et al. (2002). Psychological outcomes in long-term survivors of childhood leukemia, Hodgkin's disease, and non-Hodgkin's lymphoma: A report from the Childhood Cancer Survivor Study. *Pediatrics, 110*, 42–52.