
The Integration of Psychology in Pediatric Oncology Research and Practice

Collaboration to Improve Care and Outcomes for Children and Families

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Childhood cancers are life-threatening diseases that are universally distressing and potentially traumatic for children and their families at diagnosis, during treatment, and beyond. Dramatic improvements in survival have occurred as a result of increasingly aggressive multimodal therapies delivered in the context of clinical research trials. Nonetheless, cancers remain a leading cause of death in children, and their treatments have short- and long-term impacts on health and well-being. For over 35 years, pediatric psychologists have partnered with pediatric oncology teams to make many contributions to our understanding of the impact of cancer and its treatment on children and families and have played prominent roles in providing an understanding of treatment-related late effects and in improving quality of life. After discussing the incidence of cancer in children, its causes, and the treatment approaches to it in pediatric oncology, we present seven key contributions of psychologists to collaborative and integrated care in pediatric cancer: managing procedural pain, nausea, and other symptoms; understanding and reducing neuropsychological effects; treating children in the context of their families and other systems (social ecology); applying a developmental perspective; identifying competence and vulnerability; integrating psychological knowledge into decision making and other clinical care issues; and facilitating the transition to palliative care and bereavement. We conclude with a discussion of the current status of integrating knowledge from psychological research into practice in pediatric cancer.

Keywords: pediatric oncology, childhood cancer, adjustment, psychosocial, intervention

P sychologists have conducted research in pediatric cancer settings since the 1970s, investigating, for example, the psychological impact of isolation rooms (Kellerman et al., 1976) and describing communication among patients, families, and staff and early models of consultation, with insight into issues in evidence-based care that persist today (Kupst et al., 1982; O'Malley & Koocher, 1977). Cancer is one of the very first areas in which pediatric psychologists established themselves. Their accomplishments in understanding the demands of treatment and developing treatment approaches to prevent or reduce the impact of these serious illnesses and treat-

ments on children and their families in the short and long term are among the most prominent accomplishments in pediatric psychology. Subsequent to an introduction to pediatric cancer, we present key accomplishments of psychologists in pediatric cancer. We conclude with a discussion of the translation of research into practice, including current challenges for assuring a sustained collaboration and integration of psychological science and practice in pediatric oncology.

Prevalence, Incidence, and Etiology of Pediatric Cancer

Cancer is the leading cause of death by disease in children. Nearly 12,500 children under the age of 20 (11,000 under age 15) are diagnosed in the United States annually (National Cancer Institute, 2013b), with the most common types of cancer in children being leukemias (blood cell cancers, 37%), brain and other central nervous system (CNS) tumors (25%), and lymphomas (24%; Ries et al., 1999). These cancers are very different from those typically seen in adults, in whom carcinomas are the most common. For many adult cancers, the incidence is much higher in Blacks than in Whites; for childhood cancers, the incidence rates are higher for Whites than for Blacks, Hispanics, or American Indians (Ries et al., 1999).

Cancer in children, unlike many adult cancers, does not typically result from behavior or the milieu of the children or their parents. Pediatric cancers are rare diseases,

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Anne E. Kazak

and obtaining an accurate history of exposures to potential environmental triggers during pregnancy or prior to conception that are associated with subsequent development of cancer has been exceptionally challenging. Certain genetic syndromes (e.g., neurofibromatosis, Gorlin and Li-Fraumeni syndromes), exposure to high levels of ionizing radiation, a history of receiving chemotherapy, and paternal smoking have been associated with increased risk. Ongoing research is investigating early-life exposures to infectious agents, environmental toxins, parental occupational exposures, maternal diet during pregnancy, oral contraceptives, and fertility drugs. A number of potential suspected agents have been investigated with null findings, including power lines, low levels of radiation exposure from radon, ultrasound during pregnancy, pesticides, parent occupations, and maternal smoking (Ries et al., 1999). Learning more about the impact of childhood cancers is an exemplar for understanding the impact of a range of stressful and traumatic events on children and their families.

Treatment of Childhood Cancers

Many of the dramatic treatment gains in pediatric oncology are a result of the development of improved cancer therapies involving the collaborative efforts of clinical and laboratory investigators within clinical research trial groups. Typical care in pediatric cancer involves enrolling in a randomized clinical trial (RCT; Kodish et al., 2004). The advantages of pediatric cancer clinical trial enrollment (treatment outcomes, standards of care, careful monitoring) are seen in the research protocols developed by the National Cancer Institute-funded Children's Oncology Group (COG). COG includes over 200 institutions in the United States, Canada, Australia, and New Zealand and assures that children receive the same medical care on the same

protocols across treatment centers. The majority of children (55%–65%) under the age of 14 participate in clinical trial research studies. Participation is far lower for adolescents (~10%; National Cancer Institute, 2013a), presumably because many adolescents receive care at adult cancer centers or community hospitals.

A child's suspected diagnosis of cancer may start with a pediatrician in an office visit or emergency room with symptoms suspicious of a viral illness or minor injury. Initial tests prompt subsequent evaluations and development of a treatment plan—usually in a pediatric hospital or regional medical center. There is urgency to confirm the diagnosis and initiate treatment; a process that takes at least 2–3 days may minimize prolonged worrying for children and families. However, the compressed time frame surrounding diagnosis is a very stressful period for caregivers. Within days, parents are given extensive information about cancer and are likely offered the opportunity to participate in a randomized phase III clinical trial. The latter necessitates additional discussions with pediatric oncologists and informed consent conferences (ICC) within hours/days after a diagnosis is confirmed (Kodish et al., 2004).

Treatments for childhood cancer vary in length and intensity but typically have significant acute health and psychosocial implications of at least one year's duration and often longer. During this time children and their families receive specialized care from health care teams including some, but not necessarily all, of the following specialties: pediatric oncologists, surgeons, radiation oncologists, nurses, consulting pediatric subspecialists, psychiatrists, psychologists, social workers, nutritionists, occupational and physical therapists, and child life specialists. Children may be hospitalized for portions of their treatment (e.g., surgery, early stages of chemotherapy, stem cell transplantation, infections), although much treatment is delivered in outpatient clinics and at home, with monitoring from the cancer center, local health care providers, and home care teams.

Pediatric Cancer Survivorship

Although there are multiple definitions of cancer survivorship and some organizations suggest that survivorship begins at diagnosis (Centers for Disease Control and Prevention & LIVESTRONG Foundation, 2004), within the pediatric cancer community, survivorship is often defined as surviving at least five years from diagnosis and at least two years from the child's last treatment (Meadows, 2003). The overall five-year survival rate for all childhood cancers is an important medical accomplishment, having increased from under 60% in 1975–1977 to greater than 80% (Ries et al., 1999). Adult survivors of pediatric cancers will eventually comprise 1 in 430 adults (Meadows, 2003). However, there are disparities in pediatric cancer survival outcomes, with Hispanic and Black children having poorer outcomes than White children, likely related to a complex interplay of disease biology, pharmacogenetics, socioeconomic status (SES), and cultural factors that may impact access to care and adherence to cancer treatment (Bhatia, 2011).



Robert B. Noll

Despite improved survival rates, cancer treatments can be arduous, with significant associated morbidities and lasting health and psychosocial implications throughout childhood and into adulthood. Almost 70% of pediatric cancer survivors develop “late effects” that can be chronic or even life threatening (e.g., infertility, cardiovascular/lung disease, renal dysfunction, severe musculoskeletal problems, endocrinopathies, second cancers, cognitive impairments), often emerging in early adulthood (Oeffinger, Nathan, & Kremer, 2008). The morbidity and mortality associated with many late effects can be mitigated through targeted surveillance, adoption of health-promoting behaviors, and early management/treatment. Unfortunately, about two thirds of young adult survivors of childhood cancer do not follow through with recommended health monitoring or health promoting behaviors (Nathan et al., 2008).

The Childhood Cancer Survivor Study (CCSS; see <http://ccss.stjude.org>) is an epidemiological retrospective study of over 20,000 adult survivors of childhood cancer and their siblings. CCSS data provide information about the many potential sequelae of cancer from this large cohort, including health behaviors (Nathan et al., 2009). As a group, childhood cancer survivors tend to engage in less physical activity relative to controls, smoke at rates comparable to their peers, and fall short of recommended nutritional standards. Neurocognitive and psychosocial late effects are also observed (Zeltzer et al., 2009). A subset of survivors have poor quality of life and ongoing psychological late effects and struggle with normative developmental tasks and the establishment of adult identities (Gurney et al., 2009). Compared with the general population and with their siblings, they are less likely to have educational plans beyond high school, to attend college, and to secure em-

ployment. They also have more difficulty leaving home, achieving romantic/sexual relationships, and finding marriage partners, compared with their siblings and normative data. Many of these late effects are more evident in brain tumor survivors, even those children with nonmalignant brain tumors.

Key Psychological Contributions to Pediatric Oncology Care

Psychologists have been influential in collaborations that have improved care and outcomes for children with cancer and their families. In this section, we briefly review seven major areas of accomplishment.¹

Managing Procedural Pain, Nausea, and Other Symptoms

An important early area of accomplishment was establishing evidence-based interventions for pain from bone marrow aspirates, IVs, lumbar punctures, and chemotherapy-induced nausea, as well as for general symptom management. There are several common sources of pain (e.g., disease, procedural) that can affect children with cancer. Since the experience of pain commonly has biological, cognitive, and emotional components (Hilgard & LeBaron, 1984), psychologists have played a key role in alleviating suffering. Pain and distress are often intertwined as children undergo medical procedures such as bone marrow aspirates and biopsies, insertion of “lines,” and invasive tests and examinations. A number of evidence-based behavioral and cognitive-behavioral interventions were established to reduce pain and distress and to facilitate coping during procedures, including distraction, relaxation, hypnotherapy, cognitive-behavioral approaches, and treatment approaches that integrate psychological and pharmacologic interventions (Patterson & Jensen, 2003; Spirito & Kazak, 2006).

This body of work has included a focus on developmental issues and tailored interventions based on the child’s development. For example, distraction is more effective with younger children, whereas guided imagery, relaxation, and self-hypnosis are better with older children and adolescents (Cohen, 2008). The increasing use of short-acting general anesthesia and central lines and the use of fewer invasive procedures have reduced anticipatory anxiety and pain, although some concerns have been raised regarding the neurotoxicity of these short-acting anesthetics on the developing brain (Stratmann, 2011). Other distressing symptoms associated with disease and side effects of treatment such as nausea and vomiting can also be

¹ The first two accomplishments (managing procedural pain, nausea, and other symptoms, understanding and reducing neuropsychological effects) are the earliest but remain highly salient today. The next three (treating children in the context of their families and other systems; applying a developmental perspective; and identifying competence and vulnerability) are foundational to this work across time. The final two (integrating psychological knowledge in treatment adherence, decision making and other clinical care issues; facilitating the transition to palliative care and bereavement) encompass more current research that advances clinical issues that have been recognized for many years.

effectively treated with behavioral approaches. Interestingly, advances in supportive treatments in recent years (e.g., use of short-acting general anesthesia for procedures and new classes of anti-emetic medications) have lessened the overall demand for behavioral intervention in these areas. However, for some patients, ongoing pain and distress may persist and can be effectively treated with these behavioral and cognitive-behavioral approaches. This early research by pediatric psychologists in pediatric oncology established the foundation for current evidence-based practices, often provided by child life specialists, related to helping all children with injections or other invasive procedures.

Understanding and Reducing Neuropsychological Effects

Certain cancers (e.g., brain tumors) and treatments (e.g., chemotherapies that cross the blood–brain barrier, cranial irradiation, surgical resection) have neurotoxic effects on the developing brain that may result in short- and long-term impairment of neurocognition and school performance (Campbell et al., 2007; Robinson et al., 2010). Impacts on IQ, verbal and nonverbal reasoning, memory, attention, processing speed, and executive functioning remain significant concerns (Hocking & Alderfer, 2012). Data from pediatric psychologists and neuropsychologists have been instrumental in altering treatment protocols to reduce the risk of neurocognitive damage (e.g., Rowland et al., 1984). Survivors with CNS involvement are at higher risk for ongoing social concerns, presumably as a result of their cognitive challenges (Vannatta, Gerhardt, Wells, & Noll, 2007).

Neurocognitive effects of treatment may emerge early in treatment or years later, necessitating evaluation and attention to interventions to optimize quality of life and school performance (see www.survivorshipguidelines.org). Cognitive remediation approaches, adapted from the adult and pediatric brain injury literatures, have been tested in pediatric cancer survivors, and there is also some evidence that stimulant medication may be helpful for attentional concerns; methylphenidate has been shown to be well tolerated by childhood cancer survivors (Conklin et al., 2009) and to be associated with sustained attention and more positive parent ratings of social skills and behavior problems (Conklin et al., 2010). Caution regarding the use of stimulant medication for social functioning of cancer survivors is important, given the disappointing social outcomes for children with attention problems in the Multimodal Treatment Study of Children with Attention Deficit Hyperactivity Disorder (Hoza et al., 2005) and the extremely low correspondence between parent or teacher ratings of children's social skills or competence and actual peer reports (Noll & Bukowski, 2012).

A cognitive remediation approach that has been examined for cancer survivors in a multisite randomized trial is the cognitive remediation program (CRP; Butler et al., 2008). CRP utilizes a cognitive rehabilitation model, delivered in 20 two-hour sessions, directed at the most commonly described domains of cognitive vulnerability asso-

ciated with academic problems (i.e., brief focused attention, working memory, memory recall, vigilance) in pediatric cancer survivors. CRP utilizes paper-and-pencil tasks to improve a child's attention, concentration, and memory and teaches meta-strategies to help with generalization of abilities to home and school. The trial provided evidence that CRP improved academic test performance and parent-reported attention in survivors.

CRP and other face-to-face interventions (i.e., Patel, Katz, Richardson, Rimmer, & Kilian, 2009) require significant time and are often only provided in a hospital setting. Intensive, therapist-directed interventions may not be practical for many families. Computer-based cognitive training offers the potential to improve targeted cognitive skills with less burden, since this type of training can be conducted at home at any time. Like CRP, these computerized approaches are associated with less risk for side effects, especially compared with pharmacologic interventions. Recent work has demonstrated that computer-based training, CogmedRM, was feasible and demonstrated some preliminary evidence of efficacy for a small group of survivors of brain tumors or acute lymphocytic leukemia (ALL; Hardy, Willard, Allen & Bonner, 2013).

Ongoing work within COG has established that psychologists can administer a one-hour standardized neuropsychological battery to 90% of eligible patients to monitor neurocognitive functioning of high-risk patients (Embry et al., 2012). This emerging work will complete these evaluations over three time points during the course of a child's therapy and into survivorship. Additional work within COG is examining the usefulness of brief computerized assessments administered by nurses or child life specialists to provide sensitive ongoing monitoring of a child's neurocognitive functioning during treatment. Research establishing the validity of these approaches relative to face-to-face CRP or assessments is necessary and underway within the COG.

Treating Children in the Context of Their Families and Other Systems (Social Ecology)

Pediatric cancer is inherently a family disease, impacting all facets of the world of the child and his or her family and doing so over an extended period of time. In many cases, the child with cancer is very young and not able to understand or consent to treatment, highlighting the important role of parents as they receive the news that their child has a life-threatening illness and make treatment-related decisions. A social ecological model (Kazak, Rourke, & Navsaria, 2009) is often used to understand the multiple influences on the child and family, highlighting the importance of looking at subsystems of the child's social world that play prominent roles in adjustment and outcomes. Pediatric cancers and their treatments are part of the social ecology because they are important factors that enter into the lives of children and families. They vary considerably in intensity, duration, and impact, dimensions that can impact child and family functioning. Most children are able to cope and adjust to the demands of treatment without demonstrating psychological dysfunction, typically with

the support of family, community (i.e., neighbors, schools), and health care team members. However, there are expected short-term reactions of distress (often associated with potential separation from parents; fear of needles and procedures; fear of the unknown and novelty of the treatment environments; treatment side effects; and impact on daily routines, including peers and school) across the course of treatment (Kazak et al., 2009). Notably, children with CNS tumors appear to be at highest risk for longer term problems with adjustment (Vannatta et al., 2007).

Meta-analyses document that parents—both mothers and fathers—experience considerable distress and burden at the time of diagnosis, with a trajectory of improved adjustment over one year (Vrijmoet-Wiersma et al., 2008). A persistent myth is that the experience of having an ill child will necessarily be destructive to parents' marriages; this has repeatedly been shown to be unsubstantiated (Syse, Loge, & Lyngstad, 2010), although family structure is important and there is evidence that lone parents experience more strain and distress than those with partners (Iobst et al., 2009). While having a child with cancer can strain relationships and patterns of coping and adjustment, it may also foster family connection. Families are complex systems, and there are many ways in which family functioning may be either a hindrance or an asset in the context of childhood cancer. Based on a large empirical literature from pediatric oncology and developmental psychopathology, factors associated with ongoing distress include pre-existing characteristics of the child (age, temperament, behavior); the illness and treatment (notably, brain tumors); family structure (lone parent, teenaged parent); financial concerns that can be exacerbated by cancer and its treatment; psychopathology of family members; a history of family dysfunction and lack of social support; and parental beliefs about the course and outcomes of treatment (Kazak et al., 2009).

Siblings of children with cancer are similarly resilient despite having potential vulnerabilities. Like other members of the family, siblings do not have a preponderance of difficulties but rather have understandable and potentially persistent reactions to their brother's or sister's illness and treatment, including fear, worry, sadness, school difficulties, and struggles with perceived lack of attention and status in the family (Alderfer et al., 2010), findings that are supported for siblings of long-term survivors as well (Buchbinder et al., 2011). Data regarding greater risk for siblings are unclear and may be dependent upon the type of cancer (e.g., are siblings of children surviving brain tumors at higher risk?).

Over the course of the past 20 years, there has been considerable interest in establishing evidence-based practices that have the potential to facilitate coping and minimize psychological late effects for children and their families. Due to the low incidence of pediatric cancers, the Chambless criteria (Chambless & Hollon, 1998) can be modified to measure effectiveness (Spirito & Kazak, 2006). Two interventions for families of children with cancer (see below) are also registered on the National Cancer Insti-

tute's Research Tested Intervention Programs website (<http://rtips.cancer.gov>).

Since mothers of children diagnosed with cancer are typically the primary caregivers and their functioning is central to the overall well-being of their ill child and family, coping strategies to facilitate maternal adjustment are important. The adjustment of mothers after learning their child had been diagnosed with cancer has been improved using Bright IDEAS: Problem-Solving Skills Training (PSST; Sahler et al. 2005, 2013). PSST can be delivered to the majority of mothers weeks after diagnosis despite medical and logistical challenges. Within the framework of resilience research, teaching coping behavioral skills shortly after diagnosis not only alleviates distress for mothers but also has the potential to provide broader benefits to children with cancer and other family members over the course of treatment and survivorship. Significantly, PSST was found to be most effective for mothers from disadvantaged backgrounds (i.e., low-income, minority single parents; Askins et al., 2009; Iobst et al., 2009). It is more effective than both "care as usual" and nondirective supportive psychotherapy (Sahler et al., 2013). As a result of two large multisite trials with over 800 mothers of children with cancer, PSST is a well-established intervention that is efficacious and specific.

A second evidence-based approach uses cognitive-behavioral and family therapy approaches within a medical trauma framework to reduce or prevent posttraumatic stress symptoms and enhance family functioning. This intervention, the Surviving Cancer Competently Intervention Program (SCCIP), has two versions that have been tested using a wait list control design. An RCT of SCCIP, delivered in a one-day multiple-family intervention format, with 150 adolescent cancer survivors and their parents and siblings showed significant reductions in intrusive thoughts among fathers and in arousal among survivors (Kazak et al., 2004). SCCIP was adapted for use with families at diagnosis, in a three-session format that incorporated video discussions and was directed toward caregivers. While SCCIP was well received at diagnosis, the challenges of recruiting families for an RCT at diagnosis were a barrier (Stehl et al., 2009).

Applying a Developmental Perspective

The challenges of cancer typically vary by the age of the patient and the stage of family development, necessitating a developmentally grounded approach. Many children with cancer are very young (e.g., the median age for the diagnosis of ALL is four years). Their understanding of cancer and treatment is minimal, but their vulnerabilities associated with the impact of treatment on growth and development are very evident. With preschoolers, behavioral concerns can complicate the delivery of treatment and present parenting challenges. For children of school age, determining how best to assure ongoing school attendance, completion of academic work, and the sustaining of friendships are common concerns. Similarly, parents of a young child may be in a very different stage of family development than parents of an adolescent.

For children with cancer, two domains of functioning have received considerable scrutiny: emotional well-being and peer relationships (two key domains of quality of life). Early work raised concerns about the ability of children with cancer to fit in with peers (Deasy-Spinetta, 1981). Across development, considerable theoretical and empirical work has highlighted the importance of peer relationships for healthy psychological development for children and adolescents regardless of health status or race (Bukowski, Rubin, & Parker, 2002). Assessment of social functioning focuses on social reputation, friendships, and likability. When these domains of social functioning are evaluated using standardized measures from the child's peer group, they are stable and predict school dropout, depressive symptoms, delinquent behavior, and social functioning and economic success in adulthood (see Bukowski, Cillessen, & Velasquez, 2012, for a review). Data collected directly from their peers show that children with cancer, despite missing days of school, numerous treatment-related restrictions on their activities, and changes in their appearance (weight loss or gain, hair loss), generally fit in well with their peers, both during and after treatment (Noll et al., 1999; Reiter-Purtill, Vannatta, Gerhardt, Correll, & Noll, 2003). In contrast, children surviving brain tumors and children with pediatric cancers that require treatment focused on the central nervous system (Vannatta et al., 2007) are more likely to be isolated, be victimized, have few friends, and be less well liked. These findings from peers highlight the resiliency of children with cancer and the increased risk for children with brain tumors. Interventions that promote school reentry (see Canter & Roberts, 2012, for a review) and coordinated partnerships of patients, families, and school personnel are important to promote adaptive adjustment (Power, DuPaul, Shapiro, & Kazak, 2003).

Adolescents and young adults with cancer are a group of particular concern because gains in survival commensurate with those of younger patients have not been achieved (National Cancer Institute & LIVESTRONG Young Adult Alliance, 2006). The reasons for this include access to care, delayed diagnosis, low levels of participation in clinical trials (Parsons, Harlan, Seibel, Stevens, & Keegan, 2011), and the unique psychosocial considerations attendant to this age range. Adolescents and young adults, relative to younger patients, are more likely to talk directly with their health care team about their illness and treatment, participate in treatment decisions, and understand the broader implications of their illness and treatment. The disruption to their lives may be particularly stressful, and side effects of treatment (e.g., hair loss, weight gain or loss) can have significant effects on appearance at an age when looking different can be particularly difficult. In addition, parent-adolescent conflicts and struggles over autonomy and independence can be impacted by the demands of cancer and its treatment (Schwartz, Kazak, & Mougianis, 2009).

Young adult survivors (YAS) of childhood cancer are no longer uncommon. However, persistent and potentially escalating health concerns (i.e., late effects of treatment and disease) are a reality for this population. The Institute

of Medicine (2007) and pediatric oncology providers recommend long-term follow-up for survivors to prevent or delay, detect, and effectively manage late effects (Hewitt, Weiner, & Simone, 2003). Unfortunately, about two thirds of YAS do not follow through with recommended health monitoring or health promoting behaviors (Nathan et al., 2008). Furthermore, a subset of YAS, brain tumor survivors, have poor quality of life, ongoing psychological late effects, and challenges in living independently. Reasons for poor psychosocial outcomes and the lack of healthy behaviors among YAS are not well understood and are undoubtedly complex. Further, parents of YAS, who for many years have been advised to advocate for their children, may question whether or how to alter their parenting roles as their child survivor reaches young adulthood (Hardy et al., 2008). Appropriately, parents of YAS continue to be involved with their child's care, and many attend medical appointments with their child during long-term follow-up care (Ressler, Cash, McNeill, Joy, & Rosoff, 2003). Like survivors of other pediatric conditions, survivors of childhood cancer experience a transition to health care in adult settings that is important but challenging. Factors that influence this process, including many key psychological considerations such as self-efficacy, maturation, and family support, are outlined in the social ecological model of adolescent and young adult readiness to transition (Schwartz, Tuchman, Hobbie, & Ginsberg, 2011).

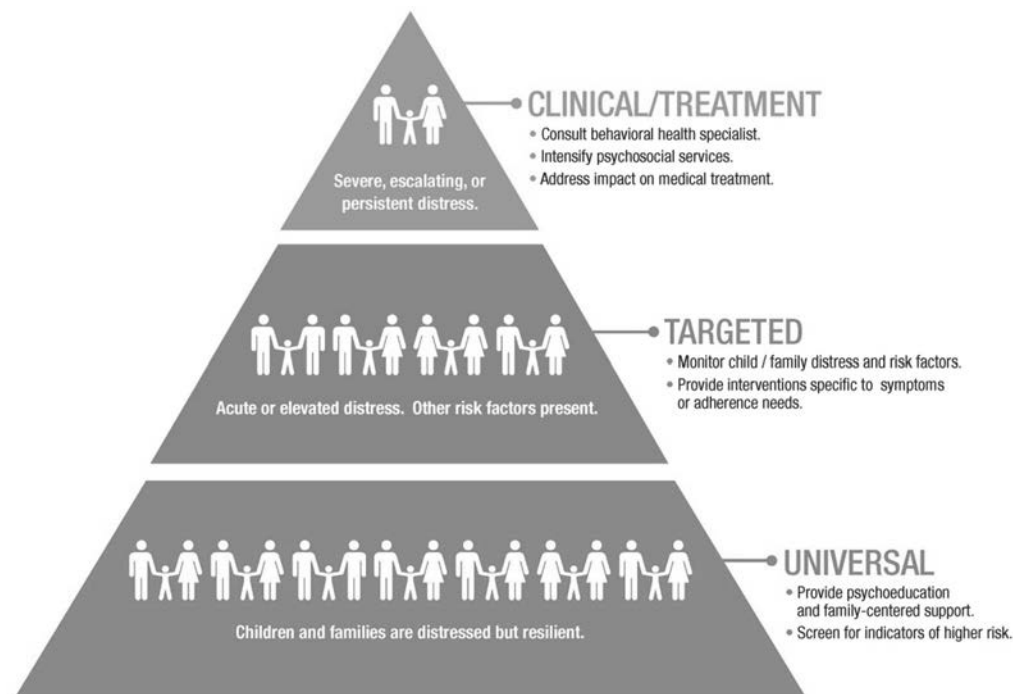
Identifying Competence and Vulnerability

Research data support the overall positive adjustment/resilience of children with cancer and their families (Noll & Kupst, 2007). Distress occurs around the time of diagnosis across members of the family but generally lessens over time as family members adjust to the demands of treatment (Dolgin et al., 2007). Despite this overall adaptive trajectory, treatment-related events are known to impact adjustment and to increase distress. The most significant event is, understandably, a relapse or potential referral to palliative care. However, even events that are positive (e.g., ending treatment) can result in anxiety (Wakefield et al., 2010).

A conceptual model that builds on the research evidence for adaptive functioning is the pediatric preventative psychosocial health model (PPPHM; Kazak, 2006) shown in Figure 1. Using a public health framework, the PPPHM was conceptualized to distinguish among levels of family risk, with matched treatment strategies proposed. The majority of families of children with cancer experience temporary distress but have minimal pre-existing risk factors and sufficient resources that help them cope successfully and adapt to their child's illness (the Universal level in Figure 1, ~65%). The intervention approach for these families is basic psychosocial care (e.g., education, resources, assistance with treatment demands), although brief behavioral interventions are effective at helping parents to avoid distress (Sahler et al., 2005, 2013). A smaller group of families (the Targeted level, ~20%–25%) have some identified areas of pre-existing risk and moderate resources and are likely to benefit from targeted interventions to reduce symptoms (e.g., pain, excessive child anxiety, par-

Figure 1

Pediatric Psychosocial Preventive Health Model: Addressing Traumatic Stress in the Pediatric Health Care Setting



Note. Adapted from "Pediatric Psychosocial Preventive Health Model (PPPHM): Research, Practice, and Collaboration in Pediatric Family Systems Medicine" by A. E. Kazak, 2006, *Families, Systems, & Health*, 24, p. 385. Copyright 2005 and 2011 by the Center for Pediatric Traumatic Stress, The Children's Hospital of Philadelphia.

ent distress) and promote more adaptive adjustment across the family system. At the top of the pyramid are families with more severe problems, many pre-existing risk factors (e.g., child or parent psychopathology, child behavior problems), and few resources (the Clinical level, < 10%) who generally warrant multipronged intensive evidence-based treatments. Factors contributing to classification at a level of risk can change over time, resulting in potential changes in PPPHM risk levels and interventions.

The Psychosocial Assessment Tool (PAT) is a brief parent-report screener based on social ecological theory which maps on to the PPPHM and generates a trilevel classification of families into Universal, Targeted, or Clinical risk. The PAT has strong psychometric properties and excellent sensitivity and specificity for child behavior and parent stress (Pai et al., 2008), and risk classification is consistent with that of the PPPHM (McCarthy et al., 2009) and generally stable across treatment (Alderfer et al., 2009). It is feasible to screen with the PAT within 48 hours of a child's diagnosis (Kazak, Barakat, Ditaranto, et al., 2011), and there is evidence that families screened with the PAT were provided psychosocial care consistent with their psychosocial risk (Kazak, Barakat, Hwang, et al., 2011).

Also consistent with a competency-based approach to cancer-related stress is a medical traumatic stress model.

That is, given the life threat associated with a diagnosis of childhood cancer, traumatic stress responses are normative, not pathological. Traumatic stress responses include psychological and physiological reactions of children and their families to pain, injury, medical procedures, and invasive or frightening treatment experiences. Traumatic stress responses are more common for parents than for patients. Although posttraumatic stress symptoms are common in mothers and fathers of children with cancer across the spectrum from diagnosis through survivorship (Kazak, Schneider, & Kassam-Adams, 2009), diagnoses of posttraumatic stress disorder are more rare. Significant traumatic stress responses have also been found in siblings, across two independent studies (Alderfer, Labay & Kazak, 2003; Kaplan, Kaal, Bradley, & Alderfer, 2013), and there is also evidence of posttraumatic growth for survivors (Zebrack et al., 2012) and parents (Barakat, Alderfer, & Kazak, 2006).

Despite the obvious challenges and trauma, the prevalence of psychosocial dysfunction in youth with cancer (i.e., psychopathology or social dysfunction) is similar to that found in the general population when appropriate comparison groups are used (Noll & Kupst, 2007). Cancer survivorship research has increasingly suggested that cancer survivors exhibit remarkable psychological resilience

despite multiple challenges (Rowland & Baker, 2005). Indeed, deficit-focused models do not fit the majority of findings related to children and adolescents with cancer. Despite the intense impact for children, parents, and treatment teams when a child is diagnosed, there is a remarkable lack of psychopathology or social dysfunction in children or their parents (Bonanno, 2004; Noll & Kupst, 2007). Many instances of situational responses (i.e., distress at diagnosis, difficulties with procedures, poor adjustment to hospitalization) exist, but overall functioning is remarkably sound. The cancer experience may have a subclinical impact on multiple domains of the life of a child and his or her parents and can change developmental trajectories. Given the extreme challenges, stressors, and even trauma posed to children and their families by the diagnosis of cancer, Masten's (2001) observation of a lack of dysfunction for children growing up in the face of adversity is highly relevant for children with cancer.

Applying Psychological Knowledge to Decision Making and Other Clinical Care Issues

Adherence to treatment recommendations is a critical area in which psychological expertise is warranted. Nonadherence to treatment is common in youth, with rates of nonadherence across diseases typically exceeding 50% (La Greca & Mackey, 2009). In cancer, the risks associated with not taking chemotherapy as prescribed are known to be potentially life threatening. Adherence to taking chemotherapy is lower among Hispanics, children from single-parent families, and adolescents and is related to disease relapse (Bhatia et al., 2012). Adherence is a very complex phenomenon in children and youth (Butow et al., 2010) and necessitates study of factors related to engagement in care, understanding and communication, as well as developmental factors and parent-child interactions. Across pediatric illnesses, interventions with a specific focus on addressing behaviors associated with adherence are helpful in improving adherence and supporting related health behaviors (Graves, Roberts, Rapoff, & Boyer, 2010).

The majority of pediatric oncology patients are involved with RCTs, and psychologists have been involved in research related to difficulties with understanding multiple fundamental elements of treatment and informed consent, including randomization, the role of choice in participation, and differences between a clinical trial and off-study treatment. Considerable time is devoted to ICCs: For a child diagnosed with ALL, the average meeting with a pediatric oncologist lasts 79 minutes (range = 25 to 183 minutes; Kodish et al., 2004). That said, a multisite trial of parental understanding of the elements of informed consent showed that 50% of parents did not understand randomization (Kodish et al., 2004). This was especially problematic for low-SES and minority parents.

Psychologists have collaborated in efforts to improve the presentation of medical treatment options and informed consent, including physician training focused on delivering information in a specific order, encouraging parental involvement, using open-ended questions, encouraging par-

ents to ask questions (Yap et al., 2009), and use of a video prior to the ICC (Hazen et al., 2010). These lines of research related to informed consent represent examples in which psychologists can be involved with issues related to bioethics and communication (Cousino et al., 2012). While many families are initially surprised by their physician's suggesting treatment in an RCT, they soon learn about clinical equipoise. This occurs when there is real uncertainty about whether one treatment is better than another. For example, an RCT for ALL in the 1990s randomized children to receive either 1800 rads of whole brain radiation therapy and intrathecal medications or intrathecal medications alone to prevent ALL of the child's CNS. Findings showed survival rates were nearly identical, resulting in changes in treatment protocols to protect children's brain development. In sharp contrast, when a child is eligible for a Phase I trial, treatment has not been successful and the Phase I trial is experimental, examining outcomes such as maximum tolerated dose and toxicity. The primary benefit in this case to children and their families is the opportunity to help others. Pediatric psychologists have been involved with this research regarding communication and parental understanding within the framework of clinical research. Future work can now focus on best practices to provide information, discerning different methods to provide information, and alternative strategies to alleviate distress for families participating in Phase I trials (Cousino et al., 2012).

Facilitating the Transition to Palliative Care and Bereavement

Despite the important improvements in pediatric cancer survival, approximately 20% of children with cancer will die of their disease or of treatment-related complications. While the initial diagnosis of cancer is conveyed with the grave implications of having a life-threatening illness and enduring intensive, potentially life-threatening treatments, a sense of hope and optimism for a cure is generally conveyed to the child and family. Changes during the course of treatment (e.g., the child's disease does remit or there is a relapse) often prompt discussions of palliative care. In an effort to minimize abrupt transitions in the goal of treatment (e.g., from curative therapy to end-of-life care), pediatric palliative care services are common in pediatric children's hospitals and offer care to a broader range of patients, often related to concerns closely related to the domains of care provided by psychologists.

Collaborative decision making in pediatric palliative care, for example, involves patients (as developmentally appropriate), parents, and health care team members in conversations about the goals of care, the pros and cons of options, and where care will be delivered (Feudtner, 2007). The need for interventions to reduce suffering is important (Wolfe et al., 2000), as are efforts to coordinate care and assure coverage for care at this difficult time for families (Feudtner, 2007). In contrast to adult palliative care programs, there is evidence that children referred to palliative care teams may live for longer periods of time and that parents' patterns of hopeful thinking and emotional well-

being may help in enacting decisions about their child's care (Feudtner et al., 2010).

A child's death is one of the most distressing and difficult to imagine events for families, and the time before, during, and after a child's death from cancer is one of understandable grief and disruption. As at other points in treatment, there is variability in how children and families cope throughout this process and inconsistencies in the extent to which families want and access psychological interventions. We have argued previously that the PPPHM is an example of a public-health-oriented, preventative, and strengths-oriented approach to bereavement (Kazak & Noll, 2004). That is, rather than conducting research only on those families who seek help (clinical samples), examining the full population of families, including those whose children have died, allows for consideration of the ways in which families may ultimately adapt and "survive" the child's death and targets clinical services in a manner that fits with the level of risks for families (also see Bonanno, 2004; Gerhardt et al., 2012).

Integrating and Applying Psychological Knowledge in Research, Clinical Practice, and Policy

Given the strong history of partnership between psychologists and pediatric oncology teams and their many clinically relevant achievements, an overview of current practices and a vision for how clinical care might be further augmented are timely. In pediatric oncology there is a long history of interdisciplinary care, with pediatric psychologists functioning as partners on the treatment team. This integration of psychosocial clinical care and research has facilitated a translational process whereby clinical experiences have led to research accomplishments and research is ready for translation into practice. Psychosocial standards of care are emerging, guidelines intended to assure that evidence-based psychosocial care is provided more consistently across centers, reaching more of the pediatric cancer population (Wiener, Patenaude, Kazak, & Noll, 2013).

The history of integrated, preventative services in pediatric cancer may have contributed to the overall adaptive adjustment seen in families, since the informal standard of care has included psychological services for many years. At the same time, in many pediatric settings, there are few, if any, psychologists available, and challenges to care are ongoing. Psychosocial services are not currently provided in a consistent manner across, or even within, treatment centers. Indeed, care around the time of diagnosis is highly variable and reflects a low level of uptake of evidence-based approaches (Selove, Kroll, Coppes, & Cheng, 2012).

Indeed, clinical care in pediatric cancer is an inherently multidisciplinary endeavor, with hospital-based psychosocial teams comprising social workers, child life specialists, psychologists, creative arts therapists, clergy, and psychiatrists. A multidisciplinary approach is highly consistent with the literature and clinical experience. That is, families are well served by the availability of social workers with expertise in pediatric cancer and child-centered therapists (e.g., child life specialists,

art therapists) to facilitate adaptive coping in youth of all ages. Psychologists have traditionally partnered well with other disciplines and identified areas in which their expertise is helpful while also appreciating the potential overlap in care provided across these disciplines. Many of the current best practices across disciplines have emerged from the research of pediatric psychologists. Community providers with expertise in evidence-based treatments for children with cancer and their families are less common and represent a potential area of expansion for psychosocial professionals in the pediatric oncology community.

Psychosocial screening at diagnosis is the first step in identifying risks (and competences) and determining need for further evaluation and treatments. Some of the children diagnosed with cancer and their families have pre-existing vulnerabilities/deficits that may complicate treatment and benefit from psychological intervention. Screening allows for prompt identification of children and families at various levels of risk who can benefit from various types of services/intervention. Psychosocial risk screening is rarely conducted on a systematic basis. Although many empirical papers note the need for screening, few brief, theoretically grounded, and empirically validated instruments are available (Kazak et al., 2012).

One of the conundrums in providing psychological care in an integrated model in pediatric cancer is adapting psychologists' roles to fit the challenges associated with various cancers and treatments and identifying targets for intervention given the lack of psychopathology in this population. Psychologists who are integrated into treatment teams have opportunities to provide preventative care in collaboration with other key team members (oncologists, nurses, social workers, child life specialists). For example, a psychologist can initially meet a family at or shortly after a child's diagnosis, use the PAT to screen for "hot spots" and strengths in the family, and provide PSST or SCCIP. If this child experiences relapses several years later, the same psychologist may provide support during the crisis and may have an opportunity to work with the child and family during the end of life, either when the child is an inpatient or when the child is at home. Such services are highly unlikely when psychologists are based outside of the pediatric cancer setting. Integrated psychologists often have their faculty appointments in the division of hematology/oncology within the department of pediatrics to facilitate their integration as key faculty members in the division. In contrast, nonintegrated psychologists are more likely to be called on occasions when behaviors or symptoms exceed the treatment team's threshold for managing them. This perpetuates a system in which the smallest number of patients (based on the PPPHM) receive the most psychological care, while others (at the Targeted or Universal levels) may not be detected as appropriate for available interventions.

Early clinical work by psychologists in pediatric oncology was not dependent on billing. A number of prominent psychologists in pediatric cancer entered the field conducting clinical research that emerged from their provision of direct clinical care. These integrated psycholo-

gists were funded by hospital clinical programs with the strong support of oncologist leaders; in these programs they had the flexibility to participate in activities such as rounds with the treating team, care conferences, oncology journal clubs and tumor boards, training fellows in pediatric oncology, and initiating programs of clinical research, in addition to providing direct care to the patient and family. With ready access to treatment teams, integrated models facilitate coordination of care and foster a family-centered approach. In addition, barriers to locating psychological services are diminished considerably for families. This is critical for families returning repeatedly to clinics and hospitals, where they can be seen by the same psychologist. Integrated care is less burdensome and stigmatic.

Over the past 10 years, with the rise of health care costs and far greater attention to billing for each encounter, integration of pediatric psychologists has become increasingly challenging. However, health and behavior assessment and intervention codes in the Current Procedural Terminology (CPT) system provide pediatric psychologists a means of providing services that emphasize physical health, address psychological factors that affect or interfere with treatment, and encourage collaboration between the medical team and the pediatric psychologist (Noll & Fischer, 2004). The health and behavior service codes are in contrast to psychotherapy codes, which emphasize mental illness, privacy, and remediation of symptoms of mental illness. Within this framework, evidence-based interventions (i.e., SCCIP, PSST, CRP) can be provided without a psychiatric diagnosis and with far less stigma.

The use of health and behavior codes also avoids ethical issues related to providing psychological services to children and their families at times when distress is normative without making a psychiatric diagnosis. It avoids placing a psychiatric diagnosis into an electronic medical record and encourages integration of the psychologist's notes into the electronic medical record. A known problem in using these codes is that reimbursements for them often lag behind those for psychotherapy service codes, although they require detailed knowledge of pediatric cancers and their treatments and a sound knowledge of appropriate evidence-based treatments (Drotar, 2012). Even with alternative methods for billing, pressures to ensure billable hours present barriers to pediatric psychology practice, potential innovation, and training.

Research related to procedural distress, maternal coping, family interventions, physician-family communications, ethical issues related to communication, and cognitive remediation, among other topics, has influenced not only pediatric cancer care but also research and clinical care in other pediatric populations. Many pediatric psychologists "cover" more than one medical service, and research in pediatric cancer and clinical interventions "translates" quite easily to other pediatric illness groups. Often the developmental considerations (e.g., treating a three-year-old or an adolescent) and the presenting problem (e.g., nonadherence, family distress) are more important in the choice of psychological intervention than the medical disease itself. Given the challenges in conducting research

in (relatively) low-incidence pediatric diseases and the commonalities in the impact of illness and treatment on children and families, investigating the potential generalization of interventions to other illness groups is warranted. In addition, the knowledge gained about the adaptive competence of children with cancer and their families may become a model for understanding adjustment to other types of potentially traumatic events experienced by children and their families.

While the psychological functioning of children with cancer and their families is cause for optimism and suggestive of considerable evidence for resilience, the vulnerabilities associated with brain tumors and/or treatments that impact the CNS are significant and important. These children are at risk for neurocognitive deficits (i.e., lower IQ, processing speed, attention/concentration, learning and memory, and executive functioning) and social problems with peers. Establishing evidence-based practices to ameliorate these problems for children surviving brain tumors and their families and delivering evidence-based care for this population are important priorities.

Other areas for future research should focus on the "costs" of and value added by the integration of pediatric psychologists into teams providing care for children with cancer. Such research can guide the development of policies that support psychosocial care if, for example, pediatric psychologists' services contribute to patient satisfaction, to reduced physician/nursing burnout, or to the direct reduction in health care cost if, for example, a parent uses problem-solving skills around a nonurgent medical issue and avoids a trip to the emergency department.

One of the key contributions that psychologists can make is to assure that the large research literature on children with cancer and their families is accurately recognized and translated into effective and accessible treatments. In pediatric cancer we have learned a tremendous amount from the prior three decades of research on psychosocial distress, strengths, and the needs of children with cancer, pediatric survivors, and their parents and siblings. We also have developed empirically supported treatments for children with cancer and their families. What is necessary are effective strategies to develop and implement standards of psychosocial care in pediatric cancer that reflect this knowledge base. Pediatric oncology has a long history of utilizing evidence-based medical care; within this culture psychologists have an opportunity to promote evidence-based supportive care. In doing so, psychosocial care will inevitably need to anticipate changes in health care delivery and related issues associated with costs of care and reimbursement and deliver care using models that minimize disparities in access. Standards of care might articulate psychosocial interventions matched to level of patient and family risk and assure that pediatric patients are considered in the context of their families, with an appreciation for their risks and resiliencies. The continued close partnership of psychologists with pediatric oncology teams will likely continue to facilitate positive outcomes in cancer, with necessary attention to the full range of issues that emerge in the course of treatment.

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