Psychosocial Functioning in Pediatric Cancer

Andrea Farkas Patenaude,[1] PhD, and Mary Jo Kupst,[2] PhD
[1]*Dana-Farber Cancer Institute, Children's Hospital, and Harvard Medical School, Boston, and*
[2]*Medical College of Wisconsin, Milwaukee*

Objective To describe the emergence of pediatric psycho-oncology and to summarize research on psychosocial aspects of childhood cancer and survivorship. **Methods** To review research into illness communication and informed consent, procedural pain, late effects, psychological distress, coping and adjustment, and special risk populations. Methodological challenges, appropriate methodology, and directions for future research are discussed. **Results** The past 30 years have seen change from avoidance of communication about cancer to an emphasis on straightforward discussion of diagnosis and prognosis. Behavioral research has led to interventions to reduce procedural distress. Late effects have been observed in social functioning. Although average levels of distress in survivors of pediatric cancer are typical, subsets of more vulnerable patients and family members exist. Factors predicting positive and negative coping have been identified. **Conclusions** As the numbers of pediatric cancer survivors increase, psychosocial researchers will be better able to conduct longitudinal studies not only of adjustment and its predictors but also of the impact of the emerging medical treatments and interventions to ameliorate late effects of treatment. Additional funding, improving methodology, and multi-institutional cooperation will aid future pediatric psycho-oncology investigators.

Over the past 30 years, the field of pediatric psycho-oncology has emerged and evolved. Much has been learned about the behavioral and psychosocial functioning of children with cancer and their families (Patenaude & Last, 2001). Research in this field has attempted to answer the questions, How do children and their families deal with the myriad of stressors that are initiated by the diagnosis of pediatric cancer and the treatment that ensues? and What can we do to improve the adaptation of patients and family members? This paper addresses the psychosocial adaptation of pediatric cancer survivors. Although we briefly mention some of the relevant patient interventions, the paper by Kazak (2005) broadly addresses the psychological treatment approaches for patients and families. For the most part, this paper avoids discussion of research on the neurocognitive impact of pediatric cancer treatments, deferring instead to the excellent papers by Moore (2005) and Butler and Mulhern (2005). We focus our review on areas where research has affected practice and illuminated important psychosocial aspects of survivorship. These include communication about cancer and informed consent, psychological distress, coping and adjustment, and populations at special risk. We further discuss methodological challenges in pediatric psycho-oncology and directions for future work.

Communication and Consent

Our understanding of the psychological aspects of childhood cancer has developed during a period of stunning progress in the medical treatment of cancer in children. In the 1960s most children with cancer died. The 5-year survival rate was only 28% (Ries, Harras, Edwards, & Blot, 1996). Now three out of four children diagnosed with a malignancy in childhood will survive the disease and treatment (Greenlee, Murray, Bolden, & Wingo, 2000). Advancing medical treatment has certainly affected

All correspondence should be sent to Andrea Farkas Patenaude, PhD, Dana-Farber Cancer Institute, 44 Binney Street, Boston MA 02115. E-mail: andrea_patenaude@dfci.harvard.edu. The work of the co-authors should be considered equal in preparation of this manuscript. *This manuscript was managed by Raymond Mulhern, Associate Editor.*

Journal of Pediatric Psychology 30(1) pp. 9–27, 2005
doi:10.1093/jpepsy/jsi012

the focus of pediatric psycho-oncology research. Psychosocial research has in turn influenced the emotional environment in which hospitalized and home-based children with cancer experience their disease. Presently, 1 in 900 people in the United States between the ages of 15 and 45 is a survivor of pediatric cancer (Robison, 2003). With increasing survival has come increased focus on the quality of life of children who survive cancer. As we go forward, this emphasis will only become more important.

Science proceeds from observation to experimentation and theory (Berkson, 1987; Putnam, 1973). Psychosocial research in pediatric *psycho-oncology*, a relatively recent term, began in the 1960s and continued into the early 1970s with studies that were predominately observational of parents' mourning and their psychological reactions to the death of the child (e.g., Binger et al., 1969; Chodoff, Friedman, & Hamburg, 1964; Futterman & Hoffman, 1973; Natterson & Knudson, 1960). The research subjects were mainly parents since children were not routinely informed about the name or nature of the diseases they suffered. It is probably not accidental that our attitudes toward open communication about diagnosis and prognosis with pediatric cancer patients changed markedly at the same time as survival rates were beginning to improve, especially for acute lymphoblastic leukemia (the survival of which had risen to 50–60% by the mid-1970s; Smith & Ries 2002). It is certainly more difficult to openly discuss a condition that is rapidly fatal than it is to discuss a cancer for which treatments exist, offering at least some hope of long-term survival.

Changes in attitude regarding hospital practice and communication with children were influenced by studies whose innovative research designs were based on astute observation of the behavior of children on cancer wards. These studies showed that children were not deceived by the avoidance of discussion of their diseases or by false reassurance about their prognosis. We learned that children understood much more than was originally thought and that they usually knew the seriousness of their condition as well as its name (Spinetta, 1974; Waechter, 1968). The adults' silence about the central topic—the child's imminent death—left the children to cope with their fears alone. The ultimate outcome of dissemination of findings from these studies was that open communication about cancer began to be emphasized by pediatric oncology health care professionals who talked directly to children about their illnesses and who strongly encouraged parents to talk more openly with their children.

The change toward open communication also helped fuel the inclusion of mental health professionals on treatment teams for children with cancer. If there was to be open communication about the difficult emotions of life-threatening illness or imminent death, then it was advisable to have psychological experts close at hand to help families explore and cope with these intimate and challenging issues. The presence of psychologists, social workers, and psychiatrists on pediatric cancer services in turn fostered an awareness of the behavioral challenges faced by children with cancer—notably, how to deal with the isolation of hospitalization and the pain and suffering associated with treatment procedures. The presence of mental health staff also fostered an awareness of cancer's impact on the whole family, including parents and siblings as well as the child with cancer.

Over the past 30 years, it was the courage of many parents and physicians in pursuing new treatments that led to the resounding improvements in survival for children with cancer. Because most children with cancer are placed on a clinical trials protocol (Gurney et al., 1996; Ross, Severson, Pollock, & Robison, 1996), parents and, more recently, pediatric oncology patients have been asked to make difficult decisions between a treatment with known effects but not completely satisfactory outcomes and an experimental treatment with possibly improved potential for cure or survival but with less certain or potentially more ominous side effects. It is in the tension between the known and the unknown, between progress and safety, that advances occur in pediatric oncology or with any disease. How parents understand and make these decisions has itself become the focus of research. Parents tend to focus more than professionals do on the nature of the treatment offered and what it will entail for their child and less on the fact that the treatment is a research effort (Kupst, Patenaude, Walco, & Sterling, 2003; Levi, Marsick, Drotar, & Kodish, 2000; Ruccione, Kramer, Moore, & Perrin, 1991). Parents' lack of awareness that their child's treatment is under a research protocol could cause difficulties in later discussions with physicians, as the parents may not understand limits to the flexibility of treatment options by which the physician researcher is bound.

From continued research on the informed consent process, improvements in provider–parent and provider–patient communication are likely to be forthcoming. The goal of interventions in this area is reduced distress for parents and patients and a greater understanding by medical personnel and parents of the likely areas of misunderstandings and differential emphasis that could leave significant gaps in communication. Particularly important is the discussion of recent findings regarding late effects, as parents and patients must

weigh the risks and benefits of treatment in light of future functioning. Rich areas for future research include assessment of the value of tailoring informed consent discussions according to patient–parent characteristics and of providing revisitable materials using computer technologies that review choices offered and the rights of parents in making treatment decisions for their child. Future research may also include further investigation of the ethical quandaries that arise in trying to maximize autonomy and involvement of young patients while recognizing the legal rights of parents. Psychologists are in a good position to educate physicians and others about the developmental and emotional factors that may in some cases complicate informed consent decision making. We also need a better understanding of proxy decision making, and we need improvements in our understanding the impact of socioeconomic status and cultural and ethnic background on the ways dyadic couples and single parents make such decisions. Other areas for further inquiry include research on preferred methods of involving older children in treatment and in end-of-treatment decisions. The involvement of children in assent and consent discussions marks clearly how far we have advanced from the silent days of the 1950s and 1960s in pediatric psycho-oncology.

Physical Symptoms and Distress During and After Treatment

Treatment Effects

In the late 1970s and early 1980s, there was increased research interest in helping the child with cancer who was undergoing treatment involving painful procedures and side effects (see reviews by Peterson, Harbeck, Chaney, Farmer, & Thomas, 1990; Zeltzer, 1994). Well-designed behavioral observation studies increased our understanding of children's distress (Blount, Davis, Powers, & Roberts, 1991; Dahlquist, Gil, Armstrong, Ginsberg, & Jones, 1985; Jay, Ozolins, Elliott, & Caldwell, 1983; Katz, Kellerman, & Siegel, 1980; Manne et al., 1990). From these studies, we learned that children do not necessarily habituate to the stressors and that coping does not always improve with time (Dahlquist et al., 1985; Jay et al., 1983). Previous experiences, age and developmental level, level of parental anxiety or distress, level of social support, current coping skills, and perceived control were all found to be related to the child's pain and distress (Zeltzer, 1994). The need to help children deal with anticipatory anxiety, pain, and nausea and vomiting (Morrow, Hoagland, & Morse, 1982; Redd & Andrykowksi, 1982) triggered the development of effective interventions that became common practice in pediatric oncology clinics (Dahlquist et al., 1985; Jay & Elliott, 1990; Redd, 1989; Zeltzer, 1994). As noted by Kazak (2005), subsequent improvements in pharmacologic aids for reducing distress and the integration of psychological and pharmacologic interventions have reduced the burden of pain and suffering for children undergoing cancer treatment.

Late Effects

With markedly increased numbers of pediatric cancer survivors, increased funding opportunities, and improving methodologies, we have learned more about the physical and psychosocial functioning of survivors. The field of late effects has burgeoned, and there is now a formidable late-effects literature (see review by Friedman & Meadows, 2002). Long-term effects of treatment vary and can include neurocognitive deficits (see Butler and Mulhern, 2005), organ damage, decreased growth, and infertility (Oberfield & Sklar, 2002). Not surprising, these physical sequelae can affect social functioning and relationships (Boman & Bodegard, 2004; Byrne et al., 1989); academic success (Hays et al., 1992; Katz, Rubinstein, Hubert, & Blew, 1988); employment (Hays et al., 1997; Mackie, Hill, Kiomdryn, & McNally, 2000; Zeltzer et al., 1997), personal functioning (Greenberg, Kazak, & Meadows, 1989; Madan-Swain et al., 2000; Mulhern, Wasserman, Friedman, & Fairclough, 1989; Smith, Ostroff, Tan, & Lesko, 1991), and family functioning (Kazak et al., 2001; Kupst & Schulman, 1988). Recent attention to the genetic transmission of some cancers likely confounds concern among survivors about cancer risk for their children, even though hereditary etiology for childhood cancers is rare (Ganjavi & Malkin, 2002; Patenaude, 2003). From these studies emerging over the past two decades, we have learned with increasing specificity that no child with cancer remains unchanged by the experience.

Psychological Adjustment

Early behavioral studies paved the way for more intensive investigation of psychological responses to the diagnosis, treatment, and late effects of pediatric cancer. In the mid-1970s and 1980s, the National Cancer Institute increased the level of funding to address these questions in adult and pediatric cancer patients. In addition to studies examining treatment-related stressors—such as procedural distress, pain, nausea and vomiting, and anticipatory anxiety—researchers began examining the intrapersonal effects of the disease and treatment on the patient's

psychological status and were able to study the child's functioning outside the hospital. Several well-designed programs of research emerged to study the impact of the disease and treatment on the patients' school functioning (Katz, Varni, Rubenstein, & Blew, 1998), on their families (Kazak, 1992), and on their peer and social functioning (Noll, Bukowski, Davies, Koontz, & Kulkarni, 1993; Noll, LeRoy, Bukowksi, Rogosch, & Kulkarni, 1991). The findings of these studies supported the need to better understand psychological and medical issues affecting the quality of life of children with cancer during and after treatment.

Until the early 1980s little was known about the psychological adjustment of long-term survivors. One of the first questions to be addressed was the degree to which children with cancer experience distress and pathological psychological symptoms as they traversed the path from diagnosis through treatment to hoped-for cures. Although the survival rate was improving, it was still difficult to accrue large samples of children who were surviving cancer in any one center, making work on long-term outcomes particularly challenging. There was a gradual movement from case studies and clinical observations to the use of more-controlled study design and measurement. The seminal work of Koocher and O'Malley (1981) and their colleagues was the first to study a large number of survivors, using a combination of clinical interviews and standardized measures (n = 117; participants were at least 5 years old and were on average 12 years postdiagnosis). In this group, about half of the survivors were found to be functioning relatively well compared to controls. About a quarter were rated as *impaired* on the basis of their symptoms. Socioeconomic status correlated positively with adjustment. Treatments with more uncertain outcomes were associated with higher distress. It became clear from this and other early studies that despite life-threatening circumstances and fatal outcomes, significant psychopathology in children with cancer was not the normative outcome but was in fact relatively rare (Cella & Tross, 1986; Fritz, Williams, & Amylon, 1988; Greenberg et al., 1989; Kupst & Schulman, 1988).

Most studies have found little evidence of serious maladjustment or maladaptation in pediatric cancer patients. A review of chronic illness studies (Lavigne & Faier-Routman, 1992) found that children with cancer were at lower risk for problems than were children with most other chronic illnesses. Many studies have found that most survivors show good adjustment on psychological self-report measures and that their scores are not significantly different from those of norms, controls, or comparison groups (Boman & Bodegard, 1995; Gray et al., 1992; Kazak, 1994; Kazak et al., 1997; Kupst et al., 1995; Mackie et al., 2000; Madan-Swain et al., 1994; Radcliffe, Bennett, Kazak, Foley, & Phillips, 1996; Simms, Kazak, Golomb, Goldwein, & Bunin, 2002;). Similarly, they tend to have fewer emotional and behavioral problems based on report of others (e.g., teachers, parents, and peers; Noll et al., 1997). A recent literature review of 20 studies of survivors of pediatric cancer (Eiser, Hill, & Vance, 2000) found that survivors did not show deficits on measures of anxiety, depression, or self-esteem when compared with population norms or matched controls. In a study emerging from the Childhood Cancer Survivor Study (Zebrack & Zeltzer, 2003), a questionnaire was sent to the largest number of pediatric survivors surveyed to date (over 5,000). The researchers found that rates of depression among survivors in this group were similar to those of the general population.

Areas of Psychosocial Problems and Factors Associated with Adjustment

Although overall mean adjustment in pediatric cancer patients and survivors, as measured by standardized psychological tests, has been found to be near normal levels, evidence suggests that more subtle or specific areas may be adversely affected in long-term survivors. In studies of pediatric psycho-oncology outcomes, there is consistently a small but significant group of children and family members (estimated to be 25–30%) who do not cope well or who have significant personal, family, and social difficulties (Boman & Bodegard, 1995; Friedman & Meadows, 2002; Koocher & O'Malley, 1981; Kupst et al., 1995). Areas that have been found to be problematic for pediatric survivors include academic achievement (Fritz et al., 1988; Haupt et al., 1992; Hays et al., 1997); employment difficulties (Hays et al., 1997); impaired or decreased social relationships (Boman & Bodegard, 1995; Mackie et al., 2000; Mulhern et al., 1989); and self-concept, self-esteem, or identity (Greenberg et al., 1989; Koocher & O'Malley, 1981; Madan-Swain et al., 2000). Similarly, recent work examining prevalence of posttraumatic stress symptoms (Erickson & Steiner, 2001; Kazak et al., 2001; Meeske, Ruccione, Globe, & Stuber, 2001) has found that moderate-to-severe symptoms are present in about 5–20% of survivors, with, surprisingly, young adult survivors experiencing more posttraumatic stress symptoms than younger survivors (Hobbie et al., 2000). Research on stressors and adverse outcomes for pediatric oncology has found that distress in one area may occur despite generally good functioning

in other domains. As Simms et al. (2002) have noted, "clinically relevant distress (not necessarily psychopathology) and adaptive functioning may be interrelated concurrent outcomes" in long-term survivors.

Positive Outcomes

Some studies have found not only a lack of problems but also a set of positive outcomes. It is a fairly common finding that survivors recount problems associated with their having had cancer as well as some associated positive outcomes, including positively perceived changes in focus, a reordering of life priorities, an increased resilience, and a greater appreciation of life and relationships (Eiser et al., 2000; Zebrack & Chesler, 2002). In a study of 161 young adult survivors of pediatric cancer, Elkin, Phipps, Mulhern, and Fairclough (1997) found low levels of psychological distress and significantly better psychological health than would be expected given normative comparisons. Similarly, and in a departure from the usual focus on internalizing problems, Verill, Schafer, Vannatta, and Noll (2000) found that pediatric cancer survivors reported lower levels of aggressiveness, antisocial behavior, and substance abuse outcomes than did case controls.

Coping and Adaptation

The findings that psychopathology was not a typical outcome for children with cancer triggered an important shift in emphasis and approach to studying long-term survivors. The change in orientation came from no longer viewing cancer treatment as a necessarily pathology-inducing experience but, instead, focusing on the skills and resilience of people who were struggling with a difficult situation or a difficult set of situations. This led investigators to the next question: What do children and families do to cope effectively with a child's cancer and cancer treatment?

Several studies of children with cancer (e.g., Bull & Drotar, 1991; Kupst & Schulman, 1988) focused on the process and situational aspects of coping with cancer in children and found that children and families showed a variety of coping strategies, each depending on the situation. Whereas many of the coping studies focused on coping during active treatment, the longitudinal studies of Kupst and colleagues (Kupst et al., 1995; Kupst & Schulman, 1988; Natta, 1995), which followed children and families from diagnosis through long-term survival, focused on coping during specific phases of treatment and beyond and assessed coping strategy (means) and adequacy of coping (outcome). These studies found a wide variety of individual differences in the use of coping strategies in children and parents and no consistently significant predictors of adaptation. A recent study (Grootenhuis & Last, 2001) asked whether coping strategies differed depending on the status of the child's cancer (remission vs. relapse or second malignancy). Comparing 84 children with differing survival expectations, they found that disease status did not predict children's defensiveness or use of cognitive control strategies.

A more recent trend in coping research involves less orientation toward classification of survivors' strategies (which has not been particularly fruitful) and more interest in finding correlates or predictors of adaptation and adjustment. Several researchers have posited a repressive adaptive style to explain the common findings that children with cancer typically show lower levels of distress on self-report measures. Similar findings of low distress and indications of repressive adaptive style have been suggested in studies of long-term survivors (Elkin et al., 1997; Erickson & Steiner, 2000). Results of earlier work indicate that avoidance and even denial, for example, may be adaptive in some situations but not in others (Beisser, 1979; Compas, Worsham, & Ey, 1992; Koocher & O'Malley, 1981; Lazarus, 1981). More work needs to be done to determine the appropriateness of these coping styles and strategies under a variety of circumstances.

Although some studies have found support for one type of strategy over another, no strategy has emerged as the optimal coping mechanism (Phipps, Fairclough, Tyc, & Mulhern, 1998; Rudolph, Dennig, & Weisz, 1995). Our early optimism about finding coping styles or strategies that would predict optimal adjustment has not been well supported (Sloper, 2000). We know that the adaptiveness or maladaptiveness of a given strategy depends on characteristics of the individuals; the existing coping resources; and the characteristics of the situation, including specific demands and time (Spirito, Stark, & Knapp, 1992; Thompson & Gustafson, 1996). However, in pediatric cancer, as in adult cancer (Parle, Jones, & Maguire, 1996), there has been little attention paid to the specific demands or coping tasks involved in a given situation and how changing situational or emotional demands affect coping.

Correlates of Psychosocial Functioning

What are the factors that make a difference in the adjustment and coping of long-term survivors? With increased survival, several studies have emerged that examine the relationship of disease and treatment, personal, and family/environmental variables on adjustment or adaptation of

survivors and their families. Table I shows the variables, results, and related references.

Eiser (1998) has pointed out an important finding regarding survivors of childhood cancer compared to controls. Outcomes that are assumed to be consequences of physical deficits secondary to treatment, such as lower vocational achievement or reduced birth rates, may more accurately be seen as interactions between physical consequences of illness and treatment and the altered psychological attitudes and beliefs of survivors. For example, whereas a study showed that the number of live births to pediatric oncology survivors was 57% of that of population controls (Hawkins, Smith, & Curtis, 1988), reasons for this difference may include not only problems with impaired fertility but also psychological factors, such as reluctance to parent (based on fears for the health of potential children), reduced marriage opportunities, and fears of premature death due to cancer recurrence and about leaving young children behind. Similarly, reduced achievement and income could reflect some survivors' altered values regarding achievement by themselves or their parents as well as cognitive problems occurring secondary to treatment. Much more attention should be paid to the developmental stage at which the child is diagnosed and to the impact of attendant interruptions in normal developmental tasks and the resulting effects on later functioning (Zebrack and Zeltzer, 2003).

Populations at Particular Risk

Research to date has identified various subgroups of pediatric cancer survivors with more-than-average adverse psychological sequelae of their illness. Children with brain tumors and those who experience insults to their central nervous system as a result of cancer or cancer treatment have been shown to be at considerably high risk for adverse psychosocial outcomes (Boman & Bodegard, 2000; Mulhern, 1994). More specifically, survivors who have had brain or central nervous system tumors or who have had intensive central nervous system therapy appear to be most at risk for cognitive,

Table I. Correlates of Psychosocial Functioning in Pediatric Cancer Survivors

Variables	Results	References
Disease and Treatment		
Diagnosis involving CNS	Lower cognitive and academic functioning	Armstrong & Mulhern, 2000 review
	More difficulties in psychosocial functioning	Boman & Bodegard, 2000; Mulhern et al., 1994; Vannatta et al., 1998
Bone-tumors	More-difficulties-in-adjustment	Eiser et al., 1998; Langeveld et al., 2002
Type of treatment:		
CNS Irradiation	Lower cognitive and academic functioning	Armstrong & Mulhern, 2000 (review)
Chemotherapy	More intensive, lower adjustment	Zebrack & Zeltzer, 2002 review
Physical sequelae/ functional impairment	More severe, lower psychological functioning	Elkin et al., 1997; Fritz et al, 1988; Greenberg et al., 1989; Koocher & O'Malley, 1981
Time since diagnosis	Longer, better adjustment	Cella & Tross, 1986; Koocher & O'Malley, 1981; Kupst & Schulman, 1988
Duration of treatment	Shorter, better adjustment	Koocher & O'Malley, 1981
Personal		
Age at diagnosis	Older, better adjustment	Cella et al., 1987; Mulhern et al., 1989
	Younger, better adjustment	Barakat et al., 1997; Elkin et al., 1997; Slavin et al., 1982
Previous functioning	Previous adjustment related to long-term adjustment	Kupst & Schulman, 1988; Kupst et al., 1995
Degree of perceived stress	Lower, better adjustment	Last & Grootenhuis, 1998; Varni et al., 1994
Level of cognitive functioning	Higher, better adjustment	Boman & Bodegard, 2000; Kupst et al., 1995; Mackie et al., 2000; Levin Newby et al., 2002
Family/Environmental		
Adaptability/cohesiveness	Higher, better adjustment	Kazak & Meadows, 1989; Levin Newby et al., 2002; Rait et al., 1992
Open communication	More open, better adjustment	Fritz et al., 1988; Koocher & O'Malley, 1981; Kupst & Schulman, 1988
Family and social support	More support, better adjustment	Fritz et al., 1988; Kupst & Schulman, 1988; Trask et al., 2003
Coping/adjustment/family	Higher level, better adjustment	Carlson-Greene et al., 1995; Kupst & Schulman, 1988; Kupst et al., 1995; Sahler et al., 1997
Socioeconomic resources	Higher, better adjustment	Koocher & O'Malley, 1981; Kupst et al., 1995

social, and adjustment difficulties (Armstrong & Mulhern, 2000; Vannatta, Gartstein, Short, & Noll, 1998; Zevon, Neubauer, & Green, 1990). Ironically, many outcome studies in pediatric psycho-oncology have excluded brain tumor patients from study participation, as their experiences were considered atypical to that of the majority of pediatric survivors. Pediatric brain tumor patients are a particularly challenging group to study because of the relatively small number of patients, the diversity of brain tumors, the varying functional impact of the tumors, and the range of surgical and treatment effects that can occur. Beyond the extensive neuropsychological studies of children with brain tumors (see Butler & Mulhern, 2005), recent work has focused on the social outcomes of brain tumor patients (Vannatta et al., 1998). Studies have noted that the social skills of brain tumor patients tend to be adversely affected by treatment and that patients with cognitive impairments tend to feel and be perceived as more isolated than peers (Vannatta et al., 1998) and to have more behavioral problems to a degree that is much higher than that of other pediatric cancer survivors (Carpentieri, Mulhern, Douglas, Hanna, & Fairclough 1993).

Pediatric bone tumor patients are another group that has been noted to have greater-than-average difficulties in adjustment following cancer treatment (Eiser et al., 1997; Langeveld, Stam, Grootenhuis, & Last, 2002). Whereas treatments have improved for these patients, some of the newer limb-sparing surgeries have involved more complicated recovery and reduced functionality so that quality of life may actually be reduced with the less-invasive surgery (Nagarajan, Neglia, Clohisy, & Robison, 2002). Such diverse outcomes pose challenging questions about how to present information about physical and psychosocial outcomes to patients in ways that aid decision making about the irreversible and difficult choices bone tumor patients and their families face.

As originally noted by Koocher and O'Malley (1981), children for whom treatment outcome involve uncertainty suffer more psychological distress than do children who receive treatment with predictable outcomes. When children undergo relatively new, complex procedures, it is likely that they experience heightened, often prolonged vulnerability with potential for negative long-term outcomes—as demonstrated by those who underwent bone marrow transplantation in the early 1970s or stem cell transplants in the 1990s. Similarly, parents may be especially stressed by the opposing desires of wanting to offer their child every possibility for cure while also wanting to protect the child to the furthest degree possible. The excellent research done by Pot-Mees (1989) and, more recently, by Phipps and colleagues (Phipps, Dunavant, Garvie, Lensing, & Rai, 2002; Phipps, Dunavant, Lensing, & Rai, 2002; Phipps, Dunavant, Srivastava, Bowman, & Mulhern, 2000) and Streisand, Rodrigue, Houck, Graham-Pole, and Berlant (2000), illustrate the novel challenges that bone marrow transplant involves and the powerful impact the treatment has on patients.

Methodological Difficulties in Pediatric Psycho-oncology Research

While in the past three decades psychological research on children with cancer has come of age, we continue to struggle with difficult methodological and conceptual issues. Many challenges in pediatric psycho-oncology research remain unsolved, and it is often difficult to compare studies, as they differ in patient diagnoses, time since diagnosis, sampling of participants, inclusion of controls or comparison subjects, variables studied and the measures used to study them. Unsolved methodological problems clearly retard the rate of progress toward answering questions of interest.

Sample Size

A frequent methodological problem is sample size limitation owing to the relatively small pediatric oncology patient populations in any one institution. In some cases these problems can be reduced by multi-institutional studies, but then issues regarding comparability of care (even when patients are treated on the same protocol) and increased study cost replace small numbers as potential problems. Multi-institutional studies increase personnel costs and require some duplication of efforts, such as institutional review board approval and data management. Research conducted within the Children's Oncology Group offers large numbers of potential patients, but other problems may occur, such as long lag time for multistage research approval within such a large group (see Armstrong & Reaman, 2005). Psychological studies within the Children's Oncology Group have usually been limited to those that address questions regarding the neurocognitive impact of a treatment protocol or other quality-of-life issues that bear directly on comparison of treatment protocols. There have been to date relatively few studies on psychosocial (i.e., nonneuropsychological) outcomes conducted within the framework of the Children's Oncology Group. As a result, it is often faster and easier to form informal, limited institutional collaborations to try to answer psychosocial questions of interest.

Large, carefully constructed cohort studies allow for broad assessment of health-related outcomes but may be limited in the depth of variables that can be assessed, an issue that may be particularly important in psychosocial studies. In recent years there has been a large collaboration that has produced research on some aspects of long-term pediatric cancer survivorship. The Childhood Cancer Survivor Study (CCSS) is a near decade-long project that approached 20,276 survivors of pediatric or adolescent cancers (or their proxies, if deceased) from 25 institutions, who were treated between 1970 and 1986 and were at least 5 years postdiagnosis (Hudson et al., 2003; Robison, 2003). Unfortunately, the CCSS included very few psychosocial questions. However, research among defined subpopulations of the CCSS sample is possible, and some involving behavioral topics are underway, including smoking cessation and health care utilization and risk taking (Institute of Medicine [IOM], 2003). A major challenge for the CCSS (and for most survivor studies) was difficulty locating subjects: 39% of subjects required tracing beyond letters to last known address and attempts to locate them via telephone directory assistance (Robison, 2003). In spite of the ability to use computer databases to locate participants, the mobility of American young adults and the gaps in medical continuity that often occur during the transition from pediatric to adult providers make tracing long-term pediatric oncology survivors difficult and expensive. The problem of locating subjects adds another burden to the difficulties of doing longitudinal studies that attempt to assess patients at intervals over the course of their adolescent and young adult years.

What may be most critical with regard to sample size is not the absolute number but the ability to be able to access the most appropriate sample for the research question being asked. Robison (2003) has written, "While cohort studies represent a strong study design for many topics of late effects research, there are other designs, such as case-control, case-case, and cross-sectional studies, that can be employed to answer important questions" (p. 12).

Self-Selection

Questions about self-selection apply to most survivor studies and form an issue for the CCSS sample, in which nearly 3,000 survivors refused invitation to the study (Robison, 2003). It is legitimate to question whether this large sample represents the more compliant survivors and does not include the more disenfranchised and possibly more impaired survivors, who may be most in need of psychosocial intervention. Long-term pediatric cancer survivors vary enormously in the degree to which they wish to be identified as cancer survivors. Some survivors see their cancer status as a defining characteristic of who they are; others wish to put it behind them as they become spouses and parents. Thus, recruitment outreach, no matter how thorough, is more likely to be able to enlist the more adherent, positive, or altruistic group of survivors, whose experience and attitudes may vary significantly from those with more hesitancy to participate in research. In the future, legislation based on the Health Insurance Portability and Accountability Act (HIPAA) and restrictions on the sharing of health information may make it even more difficult to find patients a decade or more after they have been treated for cancer. Given these hurdles, it is easy to understand why prospective studies remain difficult to conduct.

Selection of subjects for participation in research studies necessitates careful attention to specification of eligibility criteria. The absence of universally accepted severity criteria in pediatric oncology and the lack of techniques to calibrate exposure to many treatment modalities make it difficult to compare patients with a variety of diagnoses, treatments, complications, and outcomes. Treatment protocols in pediatric oncology are constantly updated, so longitudinal study of patients with the same disease may involve participants with significantly different treatments. Further, abstraction of medical data from medical records is costly and imperfect, especially with pediatric patients who are likely to be seen in several medical settings over the course of their lives. These problems in turn make it difficult to adequately analyze the relationship between psychosocial outcomes and physical disease.

Controls are also difficult to select for pediatric cancer patients, as there are no clearly comparable life experiences. Even comparison with other chronic diseases is less than optimal. When the question involves comparison with healthy children, siblings have been utilized. However, the use of sibling controls is questionable, as research clearly shows that siblings are influenced by their brother's or sister's cancer experience (Sahler et al., 1994). Selection of classroom peer controls has been used successfully in several studies of social functioning to comparison with healthy age-compatible mates (Noll et al., 1990; Vannatta et al., 1998); however, this methodology is quite labor intensive and requires cooperation of schools and often entire school districts. Other problems to be addressed in sample selection are the bias toward including only English-speaking families, which omits many ethnic and cultural minorities, and difficulty in locating survivors of low socioeconomic

status, who are more likely to move often and are less likely to be reachable through telephone directories or on the Internet.

Few studies have obtained or utilized prospective or longitudinal data, choosing instead single, cross-sectional assessment of long-term survivors at a point many years after diagnosis. One exception includes a 4-year longitudinal study (Sawyer, Antoniou, Toogood, Rice, & Baghurst, 2000) of 39 children aged 2–12 years and diagnosed with cancer, compared to a community cohort. The study found that right after diagnosis, children with cancer and parents had significantly more psychological problems than did the community sample. At subsequent assessments, the two groups did not differ in prevalence of psychological problems. Similarly, a study that followed children and families from diagnosis to 10 years after treatment (Kupst et al., 1995; Kupst & Schulman, 1988), found that despite periods of expected high stress, most of the long-term survivors and their parents continued to adjust well over time.

Ideally, as the value of continuing follow-up with pediatric oncology survivors is increasingly recognized, efforts to maintain contact over time with former patients will be seen as an important priority. The Children's Oncology Group is reportedly planning a long-term follow-up center (IOM, 2003). Robison (2003) believes that continuing contact will not only have research benefits, serving as an "early warning system" for unrecognized late effects, but will also be a means of providing education to survivors about late-effect risks and intervention options. Such two-way interaction will also provide survivors with means of more effectively conveying their needs to the research community.

Measurement Challenges

Measurement in pediatric cancer progressed from clinical impressions and case studies to use of standard measures of anxiety, depression, and behavioral adjustment to determine prevalence of these outcomes. Although such measures have the advantage of being well normed and having good psychometric properties, it is frequently difficult to know how to interpret the results. For example, we have learned that the Child Behavior Checklist, one of the most commonly used measurements of behavioral problems, can show higher average levels of behavioral and social competence problems in children with cancer and other serious illnesses (Perrin, Stein, & Drotar, 1991). Similarly, a significantly high-state anxiety or depression score may occur when a child or parent is facing a new diagnosis of cancer, going off treatment, or discovering late effects of treatment. What scores would be considered appropriate reactions given the situation? And what would be a cutoff score that would indicate a need for further assessment and intervention? For a long time, these standard clinical measures were the only tools that we had to describe the psychological states of pediatric cancer patients and families. If the question of interest concerns comparison to healthy peers or families, these standard measures are useful. However, if the question concerns changes over time in psychosocial functioning in a child or an adolescent with a life-threatening or chronic illness, other measures should be used that are appropriate to these situations. In many cases, it is a question not of comparing pediatric cancer with "normal" controls but of within-group assessment over time or comparison across different types of disease.

Although it is beyond the score of this article to provide a comprehensive list of potentially useful measures, it is worth mentioning some of the measures that have been used frequently in studies of coping and adaptation in children with chronic illness. As an observational measure, the Child–Adult Medical Procedure Interaction Scale–Short Form (CAMPIS–SF; Blount, Bunke, Cohen, & Forbes, 2001) has been used as an assessment of procedure-related distress and behavior and as an assessment of child and adult coping behaviors. As a self-report rating scale, the Kidcope (Spirito, Stark, & Williams, 1988) has been given to children with chronic illnesses to assess types of coping strategies as well as their perceived efficacy.

Pediatric Cancer–Specific Measures

If the question to be answered concerns description of the cancer experience per se, then pediatric cancer–specific measures are more appropriate. In recent years, several quality-of-life measures have emerged for use with pediatric cancer patients, a recent issue of the *International Journal of Cancer* (1999, Suppl. 12) contains a comprehensive review regarding many of the commonly used health-related quality-of-life instruments in pediatric oncology. Among the several well-designed measures, the most commonly used pediatric cancer–related measures cited in recent literature are the Pediatric Cancer Quality of Life Scale (Varni, Burwinkle, Katz, Meeske, & Dickinson, 2002), the Miami Pediatric Quality of Life Questionnaire (Armstrong et al., 1999), and the Pediatric Oncology Quality of Life Scale (Goodwin, Boggs, & Graham-Pole, 1994). In addition, new measures exist that look at specific concerns during and after treatment—for example, fatigue (Hockenberry et al., 2003;

Varni et al., 2002) and acute, somatic, behavioral, and affective experiences during intensive treatment such as bone marrow transplant (Behavioral Affective and Somatic Experiences Scale; Phipps, Dunavant, Jayawardene, & Srivastiva, 1999). Promising data have emerged regarding the Pediatric Inventory for Parents (Streisand, Braniecki, Tercyak, & Kazak, 2001), a measure of stress in parents of children with cancer, and the Psychosocial Assessment Tool (Kazak et al., 2003), a measure to identify psychosocial risk in families of newly diagnosed patients. Although many of these measures have been used early or during active treatment, more work needs to be done in the assessment of long-term psychosocial functioning.

Eiser (1998) commented eloquently on the need to develop research techniques that tap the subtle but important ways in which survivors' lives are affected by their illness experience:

> In reality, there are likely to be limitations to approaches that focus exclusively on either a deficit-centered or coping perspective, with many survivors showing adjustment difficulties in some areas while at the same time coping with other aspects of their lives with greater maturity than might have otherwise been the case. The experience of cancer, with all its implications of trauma, separation, pain, and uncertainty, cannot be reduced to such a simple issue as describing differences from a healthy population on some standardized measure, which is unlikely to be sensitive to the most critical issues. Survivors of childhood cancer have experienced unique disruptions in their childhood, they often continue to need regular medical surveillance and follow-up, and, increasingly, they are confronted with information regarding their vulnerability to both physical and psychological late effects.

Mixed Methodologies

Although the emphasis in our studies is typically on quantification, it may be that in some areas of psychosocial research we have jumped ahead too quickly and do not sufficiently understand many of the concepts of interest. It may be necessary to return to qualitative or mixed methodologies to provide an in-depth observation of the experience and understanding of survivors (Atkins & Patenaude, 1987; Woodgate, 2000). Haase, Heine, Ruccione, and Stutzer (1999), in their well-designed research on resiliency in pediatric cancer, have advocated for and have used meaning-based models that begin with a thorough qualitative assessment and that progress to quantitative measurement. Similarly, little attention has been paid to the role that appraisal and perception play in situations of pediatric cancer (Eiser et al., 2000; Last & Grooenhuis, 1998). One criticism toward many of the research tools used in pediatric psycho-oncology studies is the emphasis on self-report. It would seem that by employing multiple methods and sources—such as behavioral observations, rating scales, and in-depth qualitative interviews of the same individual—our understanding of the survivor's coping abilities would improve; but at present, this is seldom done (Levin Newby, Brown, Pawletko, Gold, & Whitt, 2000). Hypothesis-driven research questions can be applied to both quantitative and qualitative investigation of survivors. Whereas the former may answer questions more specifically about the rate and extent of a psychological or behavioral outcome, the latter may extend our understanding of the personal meaning of the survivor's experience. Furthermore, it may elucidate new problems faced by survivors or or new approaches to coping with long-term stressors related to being a survivor of childhood cancer.

Randomized Clinical Trials

In pediatric psycho-oncology, as in the rest of psychological and medical research, there is an increasing interest in evidence-based practice and in randomized clinical trials (Stinson, McGrath, & Yamada, 2003). As survival rates continue to improve, there will be increasing primary interest in psychosocial outcomes in studies of differential medical treatments. As more psychosocial interventions are proposed and tested for use with pediatric cancer survivors, there will be some increased opportunities for using the "gold standard" of empiric scientific research—the randomized clinical trial (RCT). Currently, however, RCTs are rare in pediatric psychology. Stinson et al. (2003) found that about 5% of articles in the *Journal of Pediatric Psychology* and the *Journal of Consulting and Clinical Psychology* were reports of pediatric RCTs. Of the 28 studies reviewed, 3 concerned pediatric oncology patients. An accompanying editorial (Brown, 2003) offered help from senior investigators in the challenge of planning of RCTs and in the priority publication for the results of studies that conform to Consolidated Standards of Reporting Trials guidelines (Altman et al., 2001; Begg et al., 1996). Recent attention toward the use of such guidelines in pediatric research suggests that additional or amended items may be needed in applying these standards to the reporting of psychosocial research (Davidson et al., in press) and that there may be special challenges in studies using pediatric populations (Drotar, 2002). Use of the guidelines in pediatric journals will, however, have a number of advantages (McGrath, Stinson, & Davidson, 2003), including facilitating the comparison of future studies. As has been pointed out (Stinson, McGrath, &

Yamada, 2003), it is important to differentiate clinical significance (i.e., whether there is value to the patient) from statistical significance in the findings from RCTs.

Discussion

Directions for Future Research

We are still at the beginning, perhaps at the end of the beginning, of our understanding of psychosocial aspects of childhood cancer. As the third generation of pediatric psycho-oncologists begins their work, survival of children with cancer is much improved but not ensured. Pediatric cancer remains a life-threatening illness. One area for abundant future work is the development of interventions to address the fear of recurrence, which lingers in many patients despite good psychological functioning. Entering the 21st century, the medical community understands a great deal more about late effects, but there is still much work to be done in understanding the interdependence of physical and psychosocial impact, especially for vulnerable subpopulations, and in developing targeted interventions (see Kazak, 2005). Zebrack and Zeltzer (2003) suggest that the current goal in pediatric psycho-oncology research is to define "who might benefit from which intervention when." As an example, they point to infertility as an area where knowledge of late effects needs much-deeper exploration. They discuss the fact that we have known for many years about the reproductive problems associated with pediatric oncology treatment protocols. Despite this, there is a lack of research about how cancer survivors experience and deal with the resulting infertility and about possible educational interventions that might aid consideration of alternative reproductive technologies. The authors caution, however, that such research would have to include ethical and economic discussion about whether most survivors would have the resources to make use of these technologies.

We know that there are individual differences in the effectiveness of treatments and the outcomes of patients who appear medically similar. Genetic studies may ultimately help identify patients with similar illnesses who fare well physically and psychologically and who do not. We also understand some of the emotional and behavioral ways in which survivors react to their treatments and late effects. It will be as important to study adverse psychosocial reactions as it will be to understand interventions that enhance positive outcomes (Zebrack & Zeltzer, 2003). Our research efforts will be enhanced if, in at least some cases, we return to the first step in the scientific process—observation—and plan research that appropriately incorporates qualitative and quantitative measures. If we can design research that makes use of optimal samples, if we develop measures that work for patients as well as survivors, if we test interventions that come out of observed need for improvement in outcomes, then we may ultimately be able to develop workable theories for the relative success of one patient versus others that incorporates biological and psychological factors. Such research would be of tremendous benefit to patients, parents, and long-term survivors.

Psychosocial research questions will change with changes in the treatment of childhood cancer and with increased understanding of the late effects of treatment and the links between biological and psychological phenomenon. Research on the biological underpinnings of stress and the relationship between stress and immune function—or research on biomarkers that may predict the utility of a certain treatment or prognosis—will suggest the need for psychosocial interventions to incorporate empirical findings into the treatment of patients and survivors and to help them to understand limits to the interventions. The same is true with the increasing interest in alternative or complementary treatments. Interventions that may work to reduce distress should be tested and, if successful, integrated into the options offered to patients and survivors. However, care must be taken to avoid transferring to patients and survivors the responsibility for their own survival. Patients whose expectations for self-efficacy in affecting their own mortality are raised beyond what is proven realistic often suffer double burdens when cancer recurs, experiencing a threat to their survival and a sense of failure. This scenario can be avoided with sensitive and accurate integration of only those interventions with confirmed patient benefits.

It is likely that in the future, treatment of children with cancer with involve pharmacogenomics and gene therapy. In the latter case, genetic analysis will determine which treatments work best for which patients. This may confound psychosocial research by further dividing already small groups of patients with the same disease into many smaller groups of patients undergoing identical treatments. Gene therapy, the introduction of vectors that actually repair deleterious mutations in disease genes, has great promise but remains at present a frightening prospect for patients and parents. Research on the understanding of what gene therapy is and the acceptability of the treatments will be necessary forerunners of widespread acceptance of such treatments.

Future Opportunities

Evidence for the importance of continued work relating to psychosocial concerns of survivors of pediatric malignancy comes from the findings of two recent reports. First, the "National Action Plan for Childhood Cancer" (Arceci et al., 2002) recommends increased and improved screening, education, and treatment for children and adolescents who are at risk for late effects. One of the research priorities frequently cited by this group—one comprising over 30 medical, psychosocial, patient, and parent organizations—was additional psychosocial and quality-of-life research with pediatric cancer survivors to provide research-based evidence for the establishment of a national standard for care of survivors that takes into account physical, neurocognitive, and psychosocial functioning. Second, the recent Institute of Medicine report (August 2003) "Childhood Cancer Survivorship: Improving Care and Quality of Life" specifically mentions the "paucity of studies of survivors and their families regarding the psychosocial burden and economic costs associated with late effects." Among the general recommendations made by the authors of this report are

> to develop evidence-based clinical practice guidelines for care of survivors;
> to define a minimum set of standards for comprehensive, multidisciplinary care;
> to improve awareness of late effects among children and their families;
> to improve education and training of professionals who work with long-term survivors; and
> to increase support for research in survivorship.

The latter report stresses that only with large cohorts of survivors can the full extent of late effects be understood. Such research could measure prevalence of late effects, identify etiology of late effects, and evaluate effectiveness of interventions to ameliorate late effects. It will be essential to include psychosocial research in the assessment of late effects and in the studies documenting the efficacy of interventions to improve quality of life. Looking at the functioning of the pediatric cancer survivor in schools and jobs, in their roles as spouses and parents, and as utilizers of health care resources will help to develop a well-rounded picture of the benefits and costs of success in the medical treatment of children with cancer.

The pediatric cancer survivor is a vivid and important illustration of the power of medicine to conquer cancer. Psychosocial studies can enlarge our image of the ways in which the costs of that success are absorbed into the daily lives of those who survive. They can also help illustrate the ways in which our understanding of those costs can be used to develop interventions that reduce adverse treatment effects, minimize distress, and encourage positive outcomes for survivors of pediatric cancers.

A further encouraging step for psychosocial research in pediatric oncology is the designation of cancer survivorship as an "extraordinary opportunity for investment" in the 2004 budget requests from the National Cancer Institute. The request for $46 million dollars aims to support research that would accelerate the pace of intervention research, aid in measurement development, enhance the capacity for the institute to follow and track long-term survivors, and improve understanding of psychological and social mechanisms that affect a patient's response to disease, treatment, and recovery. The National Cancer Institute is the home of the Office of Cancer Survivorship, which was created in 1996 to further the needs of pediatric and adult cancer survivors. Since its inception, the office has provided ongoing research funding as well as offered several requests for application on topics of particular interest to survivors.

Conclusion

The newest generation of researchers in pediatric psycho-oncology need not fear that all the interesting questions are solved. On the contrary, it seems likely that these investigators will have many interesting and important research agendas to pursue. They will be able to stand on the shoulders of the researchers who came into this field before it had a name, before there were many survivors to study, and before there were many funding sources to appeal to for support. Although still lagging behind the funding for adult survivorship, improved funding for pediatric psycho-oncology research is now available from not only federal sources but also the American Cancer Society and private foundations, including the more recently created Lance Armstrong Foundation, which has support of survivorship research as one of its specific aims. Despite the hurdles, it will become easier to create cohorts of patients who may be longitudinally followed. It will also, ideally, become easier to create alliances of researchers to develop multi-institutional studies that can answer many of the particular questions in this area. Studies of positive outcomes will be mixed with an awareness of the continuing handicap in some groups of survivors. Utilization of

Internet- and computer-based methodologies may improve researchers' access to pediatric cancer survivors and enhance the scope of potential interventions. The work on psychosocial aspects of pediatric cancer survivorship will continue to engage and fascinate psychological researchers for many decades to come, perhaps long after pediatric cancer ceases to be a life-threatening condition.

References

Altman, D. G., Schulz, K. F., Moher, D., Egger, M., Davidoff, F., Elbourne, D., et al. (2001). The revised CONSORT statement for reporting randomized trials: Explanation and elaboration. *Annals of Internal Medicine*, *134*, 663–694.

Arceci, R., Ettinger, A., Forman, E., Haase, G. M., Hammond, G. D., Hoffman, R., et al. (2002). National action plan for childhood cancer: Report of the national summit meetings on childhood cancer. *CA: A Cancer Journal for Clinicians*, *52*, 377–379.

Armstrong, F. D., & Mulhern, R. K. (2000). Acute lymphoblastic leukemia and brain tumors. In R. T. Brown (Ed.), *Cognitive aspects of chronic illness in children* (pp. 47–77). New York: Guilford.

Armstrong, F. D., Toledano, S., Miloslavich, S. B., Lackman-Zeman, L., Levy, J. D., Gay, C. L., et al. (1999). The Miami pediatric quality of life questionnaire: Parent scale. *International Journal of Cancer*, *83*(Suppl. 12), 11–17.

Atkins, D. M., & Patenaude, A. F. (1987). Psychosocial preparation and follow-up for pediatric bone marrow transplant patients. *American Journal of Orthopsychiatry*, *57*, 246–252.

Barakat, L., Kazak, A., Meadows, A. T., 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*(6), 843–859.

Begg, C., Cho, M., Eastwood, S., Horton, R., Moher, D., Olkin, I., et al. (1996). Improving the quality of reporting randomized controlled trials: The CONSORT statement. *Journal of the American Medical Association*, *276*, 637–639.

Beisser, A. R. (1979). Denial and affirmation in illness and health. *American Journal of Psychiatry*, *136*, 1026–1030.

Berkson, W. (1987). Research problems and the understanding of science. In N. J. Nersessian (Ed.), *The process of science: Contemporary philosophical approaches to understanding scientific practice* (pp. 83–93). Dordrecht, Netherlands: Marinus Nijhoff.

Binger, C. M., Ablin, A. R., Feuerstein, R. C., Kushner, J. H., Zoger, S., & Mikkelsen, C. (1969). Childhood leukemia: Emotional impact on patient and family. *New England Journal of Medicine*, *280*, 414–418.

Blount, R. L., Bunke, V., Cohen, L. L., & Forbes, C. J. (2001). The Child–Adult Medical Procedure Interaction Scale–Short Form (CAMPIS–SF): Validation of a rating scale for children's and adults' behaviors during painful procedures. *Journal of Pain & Symptom Management*, *22*, 591–599.

Blount, R. L., Davis, N., Powers, S. W., & Roberts, M. C. (1991). The influence of environmental factors and coping style on children's coping and distress. *Clinical Psychology Review*, *11*, 93–116.

Boman, K., & Bodegard G. (2000). Long-term coping in childhood cancer survivors: influence of illness, treatment and demographic background factors. *Acta Paediatr., 89*, 105–111.

Boman, K., & Bodegard, G. (1995). Psychological long-term coping with experiences of disease and treatment in childhood cancer survivors. *Acta Paediatrica*, *84*, 1395–1402.

Brown, R. T. (2003). Editorial: The *Journal of Pediatric Psychology* will support the publication of clinical trials. *Journal of Pediatric Psychology*, *28*, 173.

Bull, B. A., & Drotar, D. (1991). Coping with cancer in remission: Stressors and strategies reported by children and adolescents. *Journal of Pediatric Psychology*, *16*, 767–782.

Butler, R. W., & Mulhern, R. K. (2005). Neurocognitive interventions for children and adolescents surviving cancer. *Journal of Pediatric Psychology*, *30*(1), 65–78.

Byrne, J., Fears, T. R., Steinhorn, S. C., Mulvihill, J. J., Connelly, R. R., Austin, D. F., et al. (1989). Marriage and divorce after childhood and adolescent cancer. *Journal of the American Medical Association*, *262*, 2693–2699.

Carlson-Greene, B., Morris, R. D., & Krawiecki, N. (1995). Family and illness predictors of outcome in pediatric brain tumors. *Journal of Pediatric Psychology*, *20*(6), 769–784.

Carpentieri, S. C., Mulhern, R. K., Douglas, S., Hanna, S., & Fairclough, D. L. (1993). Behavioral resiliency among children surviving brain tumors: A longitudinal study. *Journal of Clinical Child Psychology*, *22*, 236–246.

Cella, D. F., Tan, C., Sullivan, M., Weinstock, L., Alter, R., & Jow, D. (1987). Identifying survivors of pediatric Hodgkin's disease who need psychological interventions. *Journal of Psychosocial Oncology*, *5*, 83–96.

Cella, D. F., & Tross, S. (1986). Psychological adjustment to survival from Hodgkin's disease. *Journal of Consulting and Clinical Psychology*, *54*, 616–622.

Chodoff, R., Friedman, S. B., & Hamburg, D. A. (1964). Stress, defenses, and coping behavior: Observations in parents of children with malignant disease. *American Journal of Psychiatry*, *120*, 743–749.

Compas, B. E., Wordsham, N. L., & Ey, S. (1992). Conceptual and developmental issues in children's coping with stress. In A. LaGreca, L. J. Siegel, J. L. Wallander, & C. E. Walker (Eds.), *Stress and coping in child health* (pp. 7–24). New York: Guilford.

Dahlquist, L., Gil, K. M., Amrstrong, F. D., Ginsberg, A., & Jones, B. (1985). Behavioral management of children's distress during chemotherapy. *Journal of Behavior Therapy and Experimental Psychiatry*, *16*, 325–329.

Davidson, K., Goldstein, M., Kaplan, R., Kaufmann, P., Genell Knatterud, G., & Orleans, T. (in press). Evidence-based behavioral medicine: What it is and how do we get there? *Annals of Behavioral Medicine*.

Drotar, D. (2002). Enhancing reviews of psychological treatments with pediatric populations: Thought on next steps. *Journal of Pediatric Psychology*, *27*, 167–176.

Eiser, C. (1998). Practitioner review: Long-term consequences of childhood cancer. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, *39*, 621–633.

Eiser, C., Cool, P., Grimer, R., Carter, S., Cotter, I., Ellis, A., et al. (1997). Quality of life in skeletally immature children following treatment for a malignant primary bone tumor around the knee. *Sarcoma*, *1*, 39–45.

Eiser, C., Hill, J. J., & Vance, Y. H. (2000). Examining the psychological consequences of surviving childhood cancer: Systematic review as a research method in pediatric psychology. *Journal of Pediatric Psychology*, *25*(6), 449–460.

Elkin, T. D., Phipps. S., Mulhern, R. K., & Fairclough, D. (1997). Psychological functioning of adolescent and young adult survivors of pediatric malignancy. *Medical and Pediatric Oncology*, *29*(6), 582–588.

Erickson, S. J., & Steiner, H. (2001). Trauma and personality correlates in long-term pediatric cancer survivors. *Child Psychiatry and Human Development*, *31*(3), 195–213.

Friedman, D., & Meadows, A. (2002). Late effects of childhood cancer therapy. In E. Vichinsky, M. Waters, & J. Feusner (Eds.), *Pediatric clinics of North America*. Philadelphia: Saunders.

Futterman, E. H., & Hoffman, I. (1973). Crisis and adaptation in families of fatally ill children. In E. G. Anthony & C. Koupernik (Eds.), *The child in his family: The impact of disease and death* (Vol. 2, pp. 127–142). New York: Wiley.

Ganjavi, H., & Malkin, D. (2002). Genetics of childhood cancer. *Clinical Orthopaedics & Related Research*, *401*, 75–87.

Goodwin, D. A., Boggs, S. R., & Graham-Pole, F. (1994). Development and validation of the pediatric oncology quality of life scale. *Psychological Assessment*, *6*, 321–328.

Greenberg, H., Kazak, A. E., & Meadows, A. (1989). Psychological adjustment in 8–16 year old cancer survivors and their parents. *Journal of Pediatrics*, *114*, 488–493.

Greenlee, R. T., Murray, T., Bolden, S., & Wingo, P. A. (2000). Cancer Statistics 2000. *CA: A Cancer Journal for Clinicians*, *50*, 7–33.

Grootenhuis, M. A., & Last, B. F. (2001). Children with cancer with different survival perspectives: Defensiveness, control strategies, and psychological adjustment. *Psycho-Oncology*, *10*(4), 305–314.

Gray, R. E., Doan, B. D., Shermer, P., FitzGerald, A. V., Berry, M. P., Jenkin, D., et al. (1992). Psychologic adaptation of survivors of childhood cancer. *Cancer*, *70*, 2713–2721.

Gurney, J. G., Davis, S., Severson, R. K., Fang, J. Y., Ross, J. A., & Robison, L. L. (1996). Trends in cancer incidence among children in the U.S. *Cancer*, *78*, 532–541.

Haase, J. E., Heine, S. P., Ruccione, K. S., & Stutzer, C. (1999). Research triangulation to derive meaning-based quality of life theory: Adolescent resilience model and instrument development. *International Journal of Cancer*, *83*(Suppl. 12), 125–131.

Haupt, R., Byrne, J., Connelly, R., Mostow, E., Austin, A. D., Holmes, G., et al. (1992). Smoking habits in survivors of childhood and adolescent cancer. *Medical and Pediatric Oncology*, *20*, 301–306.

Hawkins, M. M., Smith, R. A., & Curtis, L. J. (1988). Childhood cancer survivors and their offspring studied through a postal survey of general

practitioners: Preliminary results. *Journal of the Royal College of General Practitioners*, *38*, 102–105.

Hays, D. M., Dolgin, M., Steele, L. L., Patenaude, A. F., Hewett, K. D., Ruymann, F., et al. (1997). Educational achievement, employment and workplace experience of adult survivors of childhood cancer. *International Journal of Pediatric Hematology/Oncology*, *4*, 327–337.

Hays, D. M., Landsverk, J., Sallan, S. E., Hewett, K. D., Patenaude, A. F., Schoonover, D., et al. (1992). Educational, occupational, and insurance status of childhood cancer survivors in their fourth and fifth decades of life. *Journal of Clinical Oncology*, 10, 1397–1406.

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.

Hockenberry, M. J., Hinds, P. S., Barrera, P., Bryant, R., Adams-McNeill, J., Hooke, C., et al. (2003). Three instruments to assess fatigue in children with cancer: The child, parent, and staff perspectives. *Journal of Pain and Symptom Management*, *25*, 319–328.

Hudson, M. M., Mertens, A. C., Yasui, Y., Hobbie, W., Chen, H., Gurney, J. G., et al. (2003). Health status of adult long-term survivors of childhood cancer: A report from the Childhood Cancer Survivor Study. *Journal of the American Medical Association*, *290*, 1583–1592.

Institute of Medicine (2003). Childhood cancer survivorship: Improving care and quality of life. *Institute of Medicine Report,* Washington D.C.

Jay, S. M., & Elliott, C. H. (1990). A stress inoculation program for parents whose children are undergoing painful medical procedures. *Journal of Consulting and Clinical Psychology*, *58*, 799–804.

Jay, S. M., Ozolins, M., Elliott, C. H., & Caldwell, S. (1983). Assessment of children's distress during painful medical procedures. *Health Psychology*, *2*, 139–149.

Katz, E. R., Kellerman, J., & Siegel, S. W. (1980). Behavioral distress in children with cancer undergoing medical procedures: Developmental considerations. *Journal of Consulting and Clinical Psychology*, *48*, 356–365.

Katz, E. R., Rubinstein, C. L., Hubert, N. C., & Blew, A. (1988). School and social reintegration of children with cancer. *Journal of Psychosocial Oncology*, *6*, 123–140.

Katz, E. R., Varni, J. W., Rubinstein C. L., et al. (1998). Teacher, parent, and child evaluative ratings of a school reintegration intervention for children newly diagnosed with cancer. *Children's Health Care, 21,* 69–75.

Kazak, A. E. (1992). The social context of coping with childhood chronic illness: Family systems and social support. In A. LaGreca, L. Siegel, J. Wallander, & C. E. Walker (Eds.), *Stress and coping in child health* (pp. 262–278). New York: Guilford Press.

Kazak, A. E. (1994). Implications of survival: Pediatric oncology patients and their families, pp. 171–192. In D. J. Bearison & R. K. Mulhern (Eds.). *Pediatric Psychooncology,* New York: Oxford University Press.

Kazak, A. E. (2005). Evidence-based interventions for survivors of childhood cancer and their families. *Journal of Pediatric Psychology*, *30*(1), 29–39.

Kazak, A., Barakat, L., Alderfer, M., Rourke, M., Meeske, K., Gallagher, P., et al. (2001). Posttraumatic stress in survivors of childhood cancer and mothers. *Journal of Clinical Psychology in Medical Settings*, *8*, 307–323.

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. E., Cant, M. C., Jensen, M. M., McSherry, M., Rourke, M. T., Hwang, W. T., et al. (2003). Identifying psychosocial risk indicative of subsequent resource use in families of newly diagnosed pediatric oncology patients. *Journal of Clinical Oncology*, *21*, 3220–3225.

Kazak, A. E., & Meadows A.T. (1989). Families of young adolescents who have survived cancer: social-emotional adjustment, adaptability, and social support. *J Pediatr Psychol., 14,* 175–91.

Koocher, G. P., & O'Malley, J. E. (Eds.). (1981). *The Damocles syndrome: Psychological consequences of surviving childhood cancer.* New York: McGraw-Hill.

Kupst, M. J., Natta, M. B., Richardson, C. C., Schulman, J. L., Lavigne, J. V., & Das, L. (1995). Family coping with pediatric leukemia: Ten years after treatment. *Journal of Pediatric Psychology*, *20*, 601–617.

Kupst, M. J., Patenaude, A. F., Walco, G. A., & Sterling, C. (2003). Clinical trials in pediatric cancer: Parental perspectives on informed consent. *Journal of Pediatric Hematology/Oncology*, *25*, 787–790.

Kupst, M. J., & Schulman, J. L. (1988). Long-term coping with pediatric leukemia: A six-year follow-up study. *Journal of Pediatric Psychology*, *13*, 7–22.

Langeveld, N. E., Stam, H., Grootenhuis, M. A., & Last, B. F. (2002). Quality of life in young adult survivors of childhood cancer. *Supportive Care in Cancer*, *10*, 579–600.

Last, B. F., & Grootenhuis, M. A. (1998). Emotions, coping and the need for support in families of children with cancer: A model for psychosocial care. *Patient Education and Counseling*, *33*(2), 169–179.

Lavigne, J. V., & Faier-Routman, J. (1992). Psychological adjustment to pediatric physician disorders: A meta-analytic review. *Journal of Pediatric Psychology*, *17*, 133–158.

Lazarus, R. S. (1981). The costs and benefits of denial. In J. J. Spinetta & P. Deasy-Spinetta (Eds.), *Living with childhood cancer* (pp. 50–67). St. Louis, MO: C. V. Mosby.

Levi, R. B., Marsick, R., Drotar, D., & Kodish, E. D. (2000). Diagnosis, disclosure and informed consent: Learning from parents of children with cancer. *Journal of Pediatric Hematology/Oncology*, *22*, 3–12.

Levin, Newby, W., Brown, R. T., Pawletko, M., Gold, S. H., & Whitt, J. K. (2000). Social skills and psychological adjustment of child and adolescent cancer survivors, *Psycho-Oncology*, *9*(2), 113–126.

Levin, Newby, W., Brown, R. T., Pawletko, T. M., Gold, S. H., Whitt, J. K. (2000). Social skills and psychological adjustment of child and adolescent cancer survivors. *Psychooncology, 9,* 113–26.

Mackie, E., Hill, J., Kiomdryn, H., & McNally, R. (2000). Adult psychosocial outcomes in long-term survivors of acute lymphoblastic leukemia and Wilms' tumor: A controlled study. *Lancet*, *355*, 1310–1314.

Madan-Swain, A., Brown, R. T., Foster, M. A., Vega, R., Byars, K., Rodenberger, W., et al. (2000). Identity in adolescent survivors of childhood cancer. *Journal of Pediatric Psychology*, *25*, 105–115.

Madan-Swain, A., Brown, R. T., Sexson, S. B. et al. (1994). Adolescent cancer survivors: Psychological and family adaptation. *Psychosomatics, 35,* 453–459.

Manne, S. L., Redd, W. H., Jacobsen, P. B., Gorfinkle, K., Schorr, O., & Rapkin, B. (1990). Behavioral intervention to reduce child and parent distress during venipuncture. *Journal of Consulting and Clinical Psychology*, *58*, 565–572.

McGrath, P. J., Stinson, J., & Davidson, K. (2003). Commentary: The *Journal of Pediatric Psychology* should adopt the CONSORT statement as a way of improving the evidence base in pediatric psychology. *Journal of Pediatric Psychology*, *29*, 169–171.

Meeske, K. A., Ruccione, K., Globe, D. R., & Stuber, M. L. (2001). Posttraumatic stress, quality of lie, and psychological distress in young adult survivors of childhood cancer. *Oncology Nursing Forum*, *28*(3), 481–489.

Morrow, G. R., Hoagland, A. C., & Morse, I. P. (1982). Sources of support perceived by parents of children with cancer: Implications for counseling. *Patient Counseling and Health Education*, *4*, 36–40.

Mulhern, R. K. (1994). Neuropsychological late effects. In D. Bearison & R. K. Mulhern (Eds.), *Pediatric psychooncology* (pp. 99–121). New York: Oxford University Press.

Mulhern, R. K., Wasserman, A. L., Friedman, A. G., & Fairclough, D. (1989). Social competence and behavioral adjustment of children who are long-term survivors of cancer. *Pediatrics*, *83*, 18–25.

Nagarajan, R., Neglia, J. P., Clohisy, D. R., & Robison, L. L. (2002). Limb salvage and amputation in survivors of pediatric lower-extremity bone tumors: What are the long-term implications? *Journal of Clinical Oncology*, *20*(22), 4493–4501.

Natta, M. B. (1995). Coping strategies, psychological distress experience, and perceived adjustment of long-term survivors of pediatric leukemia. *Dissertation Abstracts International*, *55*(9-B), 4127.

Natterson, J. M., & Knudson, A. G. (1960). Observations concerning fear of death in fatally ill children and their mothers. *Psychosomatic Medicine*, *22*, 456–465.

Noll, R. B., Bukowski, W. M., Davies, W. H., Koontz, K., & Kulkarni, R. (1993). Adjustment in the peer system of adolescents with cancer. *Journal of Pediatric Psychology*, *18*, 351–354.

Noll, R. B., LeRoy, S., Bukowski, W. M., Rogosch, F. A., & Kulkarni, R. (1991). Peer relationships and adjustment in children with cancer. *Journal of Pediatric Psychology*, *16*, 307–326.

Noll, R. B., MacLean, W. E., Whitt, J. K., Kaleita, T. A., Stehbens, J. A., Waskerwitz, M. J., et al. (1997). Behavioral adjustment and social functioning of long-term survivors of childhood leukemia: Parent and teacher reports. *Journal of Pediatric Psychology*, *22*, 827–841.

Oberfield, S. E., & Sklar, C. A. (2002). Endocrine sequelae in survivors of childhood cancer. *Adolescent Medicine*, *13*, 161–169.

Parle, M., Jones, B., Maguire, P. (1996). Maladaptive coping and affective disorders among cancer patients. *Psychological Medicine*, *26*, 735–744.

Patenaude, A. F. (2003). Pediatric psychology training and genetics: What will 21st century pediatric psychologists need to know? *Journal of Pediatric Psychology*, *28*, 135–145.

Patenaude, A. F., & Last, B. (2001). Cancer and children: Where are we coming from? Where are we going? [Editorial]. *Psycho-Oncology*, *10*, 281–283.

Perrin, E. C., Stein, R. E. K., & Drotar, D. (1991). Cautions in using the Child Behavior Checklist: Observations based on research about children with a chronic illness. *Journal of Pediatric Psychology*, *16*, 411–422.

Peterson, L., Harbeck, C., Chaney, J., Farmer, J., & Thomas, A. M. (1990). Children's coping with medical procedures: A conceptual overview and integration. *Behavioral Assessment*, *12*, 197–212.

Phipps, S., Dunavant, M., Garvie, P. A. et al., (2002). Acute health-related quality of life in children undergoing stem cell transplant. I.: Descriptive outcomes. *Bone Marrow Transplant, 29,* 425–434.

Phipps, S., Dunavant, M., Jayawardene, D., & Srivastiva, D. K. (1999). Assessment of health quality of life in acute in-patient settings: Use of the BASES instrument in children undergoing bone marrow transplantation. *International Journal of Cancer*, *83*(Suppl. 12), 18–24.

Phipps, S., Dunavant, M., Lensing, S. et al., (2002). Patterns of distress in parents of children undergoing stem cell transplantation. *Pediatric. Blood Cancer, 43,* 267–274.

Phipps, S., Dunavant, M., Srivastava, D. K., Bowman, L., & Mulhern, R. K. (2000). Cognitive and academic functioning in survivors of pediatric bone marrow transplantation. *Journal of Clinical Oncology*, *18*, 1004–1011.

Phipps, S., Fairclough, D., Tyc, V., & Mulhern, R. K. (1998). Assessment of coping with invasive procedures in children with cancer: State-trait and approach avoidance dimensions. *Children's Health Care*, *27*(3), 147–156.

Pot-Mees, C. C. (1989). *The psychological effects of bone marrow transplantation in children.* Delft, Netherlands: Eburon.

Putnam, H. (1973). What theories are not. In R. E. Grandy (Ed.), *Theories and observation in science* (pp. 11–123). Atascadero, CA: Ridgeview.

Radcliffe, J., Bennett, D., Kazak, A. E., Foley, B., & Phillips, P. C. (1996). Adjustment in childhood brain tumor survival: Child, mother, and teacher report. *Journal of Pediatric Psychology*, *21*, 529–539.

Rait, D. S., Ostroff, J. S., Smith, K., Cella, D. F., Tan, C., & Lesko, L. M. (1992). Lives in a balance: Perceived family functioning and the psychosocial adjustment of adolescent cancer survivors. *Family Process*, *31*, 383–397.

Redd, W. (1989). Behavioral interventions to reduce child distress. In J. C. Holland & J. H. Rowland (Eds.), *Handbook of psycho-oncology* (pp. 573–584). New York: Oxford University Press.

Redd, W. H., & Andrykowski, M. A. (1982). Behavioral intervention in cancer treatment: Controlling aversion reactions to chemotherapy. *Journal of Consulting & Clinical Psychology*, *50*, 1018–1029.

Ries, L. A., Harras, A., Edwards, B. K., & Blot, W. J. (1996). *Cancer rates and risks* (4th ed.). Washington, DC: National Institutes of Health, National Cancer Institute.

Robison, L. L. (2003). Research involving long-term survivors of childhood and adolescent cancer: Methodologic considerations. Background paper for the Institute of Medicine. Retrieved September 16, 2004, from http://www.iom.edu/file.asp?id=15238

Ross, J. A., Severson, R. K., Pollock, B. H., & Robison, L. (1996). Childhood cancer in the United States: A geographical analysis of cases from the Pediatric Cooperative Clinical Trials Groups. *Cancer*, *77*, 201–207.

Ruccione, K., Kramer, R. F., Moore, I. K., & Perin, G. (1991). Informed consent for treatment of childhood cancer: Factors affecting parents' decision-making. *Journal of Pediatric Oncology Nursing*, *8*, 112–121.

Rudolph, K. D., Dennig, M. D., & Weisz, J. R. (1995). Determinants and consequences of children's coping in the medical setting: Conceptualization, review, and critique. *Psychological Bulletin*, *118*, 328–357.

Sahler, O. J., Roghmann, K. J., Mulhern, R. K., Carpenter, P. J., Sargent, J. R., Copeland, D. R., Barbarin, O. A., Zeltzer, L. K., Dolgin, M. J. (1997). Sibling adaptation to childhood cancer collaborative study: The association of sibling adaptation with maternal well-being, physical health, and resource use. *J Dev Behav Pediatr., 18,* 233–243.

Sahler, O. J., Roghmann, K. J., Carpenter, P. J., Mulhern, R. K., Dolgin, M. J., Sargent, J. R., et al. (1994). Sibling adaptation to childhood cancer collaborative study: Prevalence of sibling distress and definition of adaptation levels. *Journal of Developmental and Behavioral Pediatrics*, *15*, 353–366.

Sawyer, M., Antoniou, G., Toogood, I., Rice, M., & Baghurst, P. (2000). Childhood cancer: A 4-year prospective study of the psychological adjustment of children and parents. *Journal of Pediatric Hematology/Oncology*, *22*(3), 214–220.

Simms, S., Kazak, A. E., Golomb, V., Goldwein, J., & Bunin, N. (2002). Cognitive, behavioral, and social outcome in survivors of childhood stem cell transplantation. *Journal of Pediatric Hematology/Oncology*, *24*, 115–119.

Slavin, L. A., O'Malley, J. E., Koocher, G. P., & Foster, D. J. (1982). Communication of the cancer diagnosis to pediatric patients: Impact on long-term adjustment. *American Journal of Psychiatry*, *139*, 179–183.

Sloper, P. (2000). Predictors of distress in parents of children with cancer: A prospective study. *Journal of Pediatric Psychology*, *25*, 79–92.

Smith, K., Ostroff, J., Tan, C., & Lesko, L. (1991). Alterations in self-perceptions among adolescent cancer survivors. *Cancer Investigation*, *9*, 581–588.

Smith, M. A., & Ries, L. A. (2002). Childhood cancer: Incidence, survival, and mortality. In P. A. Pizzo & D. G. Poplack (Eds.), *Principles and practice of pediatric oncology* (4th ed., pp. 1–12). Philadelphia: Lippincott, Williams, & Wilkins.

Spinetta, J. J. (1974). The dying child's awareness of death. *Psychological Bulletin*, *81*, 256–260.

Spirito, A., Stark, L. J., & Knapp, L. G. (1992). The assessment of coping in chronically ill children. In A. LaGreca, L. J. Siegel, J. L. Wallander, & C. E. Walker (Eds.), *Stress and coping in child health* (pp. 327–344). New York: Guilford.

Spirito, A., Stark, L. J., & Williams, C. (1988). Development of a brief checklist to assess coping in pediatric patients. *Journal of Pediatric Psychology*, *13*, 555–574.

Stinson, J. N., McGrath, P. J., & Yamada, J. T. (2003). Clinical trials in the *Journal of Pediatric Psychology*: Applying the CONSORT statement. *Journal of Pediatric Psychology*, *28*, 159–167.

Streisand, R., Braniecki, S., Tercyak, K. P., & Kazak, A. E. (2001). Childhood illness-related parenting stress: The pediatric inventory for parents. *Journal of Pediatric Psychology*, *26*, 155–162.

Streisand, R., Rodrique, J., Houck, C., Graham-Pole, J., & Berlant, N. (2000). Brief report: Parents of children undergoing bone marrow transplantation: Documenting stress and piloting a psychological intervention program. *Journal of Pediatric Psychology*, *25*, 331–337.

Thompson, R. J., & Gustafson, K. E. (1996). *Adaptation to chronic illness*. Washington, DC: American Psychological Association.

Trask, P. C., Paterson, A. G., Trask, C. L., Bares, C. B., Birt, J., & Maan, C. (2003). Parent and adolescent adjustment to pediatric cancer: Associations with coping, social support, and family function. *Journal of Pediatric Oncology Nursing*, *20*(1), 36–47.

Vannatta, K., Gartstein, M. A., Short, A., & Noll, R. B. (1998). A controlled study of peer relationships of children surviving brain tumors: Teacher, peer, and self-ratings. *Journal of Pediatric Psychology*, *23*, 279–287.

Varni, J. W., Burwinkle, T. M., Katz, E. R., Meeske, K., & Dickinson, P. (2002). The PedsQL in pediatric cancer: Reliability and validity of the Pediatric Quality of Life Inventory Generic Core Scales, Multidimensional Fatigue Scale, and Cancer Module. *Cancer*, *94*, 2090–2106.

Varni, J. W., Katz, E. R., Colegrove, R., Jr., & Dolgin, M. (1994). Perceived social support and adjustment of children with newly diagnosed cancer. *Journal of Developmental & Behavioral Pediatrics*, *15*, 20–26.

Verill, J. R., Schafer, J., Vannatta, K., & Noll, R. B. (2000). Aggression, antisocial behavior, and substance abuse in survivors of pediatric cancer: Possible protective effects of cancer and its treatment. *Journal of Pediatric Psychology*, *25*, 493–502.

Waechter, E. H. (1968). *Death anxiety in children with fatal illness*. Unpublished doctoral dissertation, Stanford University, Palo Alto, California.

Woodgate, R. L. (2000). A critical review of qualitative research related to children's experiences with cancer. *Journal of Pediatric Oncology Nursing*, *17*, 207–228.

Zebrack, B. J., & Chesler, M. A. (2002). Quality of life in childhood cancer survivors. *Psycho-Oncology 11*, 132–141.

Zebrack, B., & Zeltzer, L. (2002). Quality of life issues and cancer survivorship. Report prepared for the Institute of Medicine. Retrieved September 16, 2004, from http://www.iom.edu/file.asp?id=15236

Zebrack, B., & Zeltzer, L. (2003). Quality of life issues and cancer survivorship. *Current Problems in Cancer*, *27*(4), 198–211.

Zeltzer, L. K. (1994). Symptom management. In D. Bearison & R. K. Mulhern (Eds.), *Pediatric psycho-oncology*. New York: Oxford University Press.

Zeltzer, L. K., Chen, E., Weiss, R., Matthre, D. G., Robison, L. L., Meadows, A. T., et al. (1997). Comparison of psychologic outcome in adult survivors of childhood acute lymphoblastic leukemia versus sibling controls: A Cooperative Children's Cancer Group and National Institutes of Health study. *Journal of Clinical Oncology*, *15*, 547–556.

Zevon, M. A., Neubauer, N. A., & Green, D. M. (1990). Adjustment and vocational satisfaction of patients treated during childhood or adolescence for acute lymphoblastic leukemia. *American Journal of Pediatric Hematology-Oncology*, *12*(4), 454–461.