



Kendra R. Parris, Jennifer M. Allen,
and Niki Jurbergs

Overview of Pediatric Cancer

Nearly 16,000 children and adolescents ages 0–19 years are diagnosed with cancer each year in the United States. The most common diagnoses include acute lymphoblastic leukemia (ALL) and other blood cancers, medulloblastoma and other brain tumors, and neuroblastoma and other solid tumors, and prevalence rates for each vary across age at diagnosis, sex, and race. Treatment for pediatric cancer might include any combination of surgery, chemotherapy, radiation therapy, immunotherapy, stem cell transplant, and other targeted therapies. Although significant variability in outcomes remains, advances in treatment over the past 50 years have pushed overall survival rates to nearly 80% (National Cancer Institute, 2021). Because of the long-term effects and health risks associated with pediatric cancer and survivorship (e.g., side effects of treatment, increased risk of second cancers, etc.), it is now conceptualized as a chronic illness (Armstrong et al., 2014; Hudson et al., 2013; Robison & Hudson, 2014). The disease itself, as well as the invasive treatments, often produces a variety of acute and long-term (or late) effects that can impact physical, cognitive, emotional, and behavioral functioning.

Psychosocial Care for Pediatric Cancer Patients and Their Families

In addition to the obvious challenges presented by the disease and its often complex treatment, pediatric cancer patients and their families endure disruption to their normal routines and changes in access to their typical supports, which can negatively impact the overall social, emotional and academic development of the child or adolescent (Fuemmeler et al., 2002; Gerhardt et al., 2007; Mancini et al., 1989; Noll et al., 1991; Willard et al., 2017) as well as the emotional and social functioning of caregivers and siblings (Gerhardt et al., 2015; Kearney et al., 2015; Klassen et al., 2008). Integrated behavioral and mental health care is now widely accepted as the gold standard across medical settings

K. R. Parris (✉) · N. Jurbergs

Department of Psychology, St. Jude Children's Research Hospital, Memphis, TN, USA

e-mail: kendra.parris@stjude.org

J. M. Allen

Clinical Pediatrics, St. Louis Children's Hospital, Washington University School of Medicine, St. Louis, Missouri, USA

and is associated with benefits including improved health outcomes and patient experience (Agency for Healthcare Research and Quality, 2018). The pediatric oncology setting is no exception, and the American Academic of Pediatrics (AAP) calls for the integration of psychosocial care in pediatric cancer centers including access to pediatric psychologists, social workers, and child life specialists (AAP Section on Hematology/Oncology, 2004).

Screening, assessment, consultation, intervention, and support services should be provided to patients and their families throughout the cancer trajectory. Providers should seek to deliver care according to the Standards for Psychosocial Care for Children with Cancer and Their Families (Wiener et al., 2015). These 15 empirically based standards serve as a blueprint for the provision of services addressing the range of emotional, social, educational, communication, and even financial needs of these families. Recommendations such as serial psychosocial screening, intervention, neurocognitive assessment, ensuring academic continuity, ongoing assessment of adherence, and facilitation of social interaction are outlined. The Pediatric Psychosocial Preventative Health Model (PPPHM; Kazak, 2006; Kazak et al., 2007) framework illustrates the necessity of screening and providing universal psychoeducation and support to all families facing pediatric cancer. Using the PPPHM, the psychosocial risk falls into one of three categories (i.e., universal, targeted, and clinical/treatment), thereby linking the results of screening to the appropriate intervention path. Pediatric psychologists and neuropsychologists, along with other psychosocial providers, may fill a variety of different roles and address a wide range of needs with pediatric oncology patients and their families depending on diagnosis and prognosis, type of and response to treatment, age or developmental level, family risk factors, and individual factors. Several distinct phases in the pediatric cancer journey are associated with unique patient and family needs, while other areas for psychological intervention remain important across the cancer trajectory, as described below.

Diagnosis and Treatment

The receipt of a pediatric cancer diagnosis is an overwhelming experience for patients and their families as they navigate shock, struggle to understand novel medical information, make rapid treatment decisions, and begin to learn complex treatment regimens. Pediatric psychologists play key roles in assisting with communication around the time of diagnosis, assessing patient and family coping, conducting early screening and prevention efforts, and providing necessary support throughout the child's treatment.

Communication with healthcare providers occurs across the cancer trajectory, though it is particularly important at the time of diagnosis when critical treatment decisions are made. Effective communication and involvement of patients and families in discussion about diagnosis and medical care are integral to improved patient health outcomes, adherence, and satisfaction (see Coyne et al., 2016 for a review). Facilitating a collaborative relationship between patient and medical team can enhance internal locus of control (Tiffenberg et al., 2000), decrease fears and concerns (Runeson et al., 2002), enhance preparedness, and promote belief that patient preferences are important (Coyne & Gallagher, 2011).

Psychological Functioning and Adjustment of Patients

Pediatric patients newly diagnosed with cancer must quickly adjust to novel situations that can be quite challenging, including hospitalization, initiation of intensive treatment regimens, and painful procedures. Indeed, one of the most common referrals to psychologists is adjustment to new diagnosis

(Clerici et al., 2008), with over half of Children's Oncology Group (COG) institutions reporting that they provide multiple psychosocial supports to patients and families within 30 days of new diagnosis (Selove et al., 2012). Importantly, the length and intensity of cancer treatments are highly variable and will depend on diagnosis, disease status, age, and other factors. For some patients, treatment can be profoundly difficult and characterized by long hospitalizations, complex treatments, medication side effects, and invasive and painful procedures. As a result, some patients can experience increased levels of distress compared to healthy peers (Price et al., 2016; Sawyer et al., 2000). Yet, the majority of patients adjust to treatment adequately and do not experience significant emotional or behavioral problems (Price et al., 2016; Sawyer et al., 2000; Van Schoors et al., 2015). Consistent with the PPPHM framework (Kazak, 2006), most patients function well with the universal supports provided in most children's hospitals (e.g., chaplain support, Child Life services, etc.), with smaller percentages of patients requiring more individualized and targeted interventions.

Screening and Prevention

Because of the variability in coping with diagnosis and treatment, early and ongoing psychosocial screening and prevention efforts are now considered essential in pediatric cancer care (Kazak et al., 2015). Early in the treatment process, most patients and families benefit from anticipatory guidance, psychoeducation, and information related to illness, treatment, potential side effects, and psychosocial factors (Thompson & Young-Saleme, 2015). Key areas to assess of both the patient and family include patient developmental history, emotional and behavioral functioning, social functioning and social supports, understanding of diagnosis and treatment, coping and adjustment to diagnosis, and health behaviors (e.g., sleep, diet). This information is often gathered from psychosocial providers via interview and structured assessment methods and can be obtained routinely throughout the cancer trajectory. Some examples of commonly used rating scales in a pediatric oncology setting include (but are not limited to) the Pediatric Quality of Life Inventory™ (PedsQL™; Varni et al., 2001), the Patient-Reported Outcomes Measurement Information Systems® (PROMIS®; DeWalt et al., 2015), the Psychosocial Assessment Tool 2.0™ (PAT 2.0™; Pai et al., 2008), and the NIH Toolbox for Assessment of Neurological and Behavioral Function® (NIH Toolbox®; Gershon et al., 2013). Ongoing and regular screening and assessment of individual patient and family coping can help determine risk level and design more targeted interventions and supports when appropriate.

Management of Somatic Symptoms

Many forms of cancer treatment are associated with aversive physical side effects, with most common short- and long-term side effects including nausea, vomiting, pain, and fatigue (Collins et al., 2000; Olson & Amari, 2015). Moreover, many pediatric patients with cancer routinely undergo painful and invasive medical procedures (e.g., venipunctures, intravenous line insertions, bone marrow aspirates, lumbar punctures, etc.) that can incite significant psychological distress (Stevens et al., 2011; Twycross et al., 2015). As a result, patients can develop anticipatory symptoms (e.g., nausea), procedural distress, and nonadherence to necessary components of their medical treatment (DuHamel et al., 1999). Sleep disturbance and fatigue are also common both during and following cancer treatment. These symptoms are described as distressing and can negatively impact behavioral, social, emotional, and daily functioning (Crabtree et al., 2015), making this another important area of functioning to regularly assess.

Effective use of cognitive-behavioral treatments to address physical symptoms (e.g., nausea, pain, and anticipatory symptoms) is well documented in the literature, including the use of distraction, hypnosis, diaphragmatic breathing, progressive muscle relaxation, biofeedback, guided imagery, and other mindfulness-based interventions such as yoga and music therapy (AAP Section on Integrative Medicine, 2016; Birnie et al., 2018; Kanitz et al., 2012). Engagement in cognitive-behavioral interventions can also enhance youth's sense of self-efficacy in managing pain and other distressful symptoms (Kanitz et al., 2012; Kuppenheimer & Brown, 2002). Parents and caregivers play key roles in helping patients utilize learned coping techniques, and it is well documented that caregivers contribute to a pediatric patient's experience of and management of distress (Caes et al., 2014; Harper et al., 2013). Pediatric psychologists work with patients and caregivers throughout a patient's treatment in implementing interventions that lessen pain, distress, discomfort, and fatigue.

Management of Emotional and Behavioral Symptoms

Again, diagnosis and treatment of pediatric cancer can contribute to the onset of emotional and behavioral problems; however, some patients bring premorbid emotional and behavioral concerns to the cancer experience. And, again, early screening can assist in identifying these needs. It is recommended that pediatric cancer patients have access to psychosocial interventions throughout the cancer trajectory to address these difficulties (Steele et al., 2015). Most often, evidence-based treatments for childhood internalizing and externalizing disorders (e.g., cognitive-behavioral, behavioral, social skills, problem-solving, etc.) are utilized to address both premorbid and new-onset mood and behavior problems; however, these interventions often require flexibility in implementation due to medical treatment variables such as side effects of medical treatment, timing of hospitalizations, and other factors (Salley & Catarozoli, 2019).

Risk and Resilience Factors

Developing an understanding of specific risk and resilience factors aids pediatric psychologists in determining the level of risk and matching supports accordingly. For example, disease status (e.g., relapse and prognosis), involvement of the central nervous system, and certain medical treatments (e.g., cranial irradiation and intrathecal chemotherapy) can negatively impact adjustment and neuro-cognitive outcomes (Reddick et al., 2014; Phipps et al., 2009). In addition, family risk factors, such as lower socioeconomic status, poor parental coping, and parental experience of prior trauma have been shown to impact patient and family coping (Kupst et al., 1995; Boman et al., 2013). Individual resilience factors (e.g., self-esteem, perceived competence, temperament, and effortful control) and social factors (e.g., social support and strong family cohesion) account for variability in distress, can aid in positive adaptation, and can contribute to better outcomes (Harper et al., 2019; Hoekstra-Weebers et al., 2001; Howard Sharp et al., 2015; Tillery et al., 2019). Attention should also be given to other vulnerable populations, including young children who are at heightened risk for disturbances in their development as a result of both their medical diagnoses/treatments and missed opportunities at a critical time in development (Kenney et al., 2020; Willard et al., 2017).

End of Treatment and Survivorship

Many imagine that achieving cure and completing treatment for cancer would come with an overwhelming sense of relief, but that is not always the case for pediatric cancer survivors and their families who often struggle to establish a “new normal” in the face of ongoing side effects and uncertainty while adjusting to decreased contact with their oncology team. Survivors and caregivers turn their attention from treatment to reintegrating at school and with peers while families attempt to resume their pre-diagnosis roles and routines, and this transition often brings significant stress (Karst et al., 2018). Pediatric cancer survivors report mixed emotional experiences, including anxiety, as they transition off therapy (Nathan et al., 2011). Likewise, caregivers report anxiety and fear of relapse (Wakefield et al., 2011). Moreover, youth with cancer often face functional consequences associated with their treatment, including missed academic and social opportunities, physical changes and limitations, neurocognitive deficits, and disruptions to family functioning that extend well past the end of treatment (Husson et al., 2017; Long & Marsland, 2011; Mulhern et al., 2004; Reddick & Conklin, 2014). As such, screening for psychosocial needs and providing developmentally appropriate preparation including psychoeducation and anticipatory guidance are essential to a successful end-of-therapy transition (Kazak et al., 2015; Thompson & Young-Saleme, 2015). Survivors should be provided with screening and support throughout long-term survivorship as well (Lown et al., 2015), related to medical care (e.g., transition from pediatric to adult care) and psychosocial functioning (e.g., educational transition after high school and transition to independent living). Nathan et al. (2011) set out six domains of functioning in which childhood cancer survivors should receive support: physical health and function, sexual/reproductive health, mental health, health behaviors, health education, and social competence (including education and employment). The Children’s Oncology Group (COG, 2018) has published clinical practice guidelines that outline recommendations for screening and management of potential medical and psychosocial late effects for providers working with long-term survivors of childhood cancer.

Cognitive and Academic Functioning

School Reintegration Many children and adolescents return to school following treatment, highlighting the importance of academic continuity during cancer-directed therapy and support to facilitate academic and social aspects of school re-entry (Thompson et al., 2015). Survivors may continue to experience pain, fatigue, decreased immune functioning, changes in physical appearance (e.g., hair loss, amputation, and weight loss/gain), changes in physical functioning (e.g., decreased mobility and fine motor weakness), and changes in cognitive functioning as they reintegrate into the classroom. Nearly all cancer survivors will require accommodations or interventions, including rehabilitation services such as physical, occupational, and speech and language therapies, to address individual needs, which may be best delivered via formal educational plans such as 504 Plans and Individualized Educational Programs (IEP). Common accommodations include preferential seating, provision of teacher notes, shortened school day, allowance of rest breaks, shortened assignments and/or extended time for test taking, and support for social reintegration into the classroom. Please see Harman et al. (2019) for a comprehensive list of common needs and accommodations.

Cognitive Late Effects Patients with central nervous system disease or directed therapy (e.g., cranial radiation and intrathecal chemotherapy), such as patients with brain tumors and ALL, are at higher risk for long-lasting cognitive late effects such as attention, working memory and processing speed

difficulties (Jacola et al., 2016; Knight et al., 2014; Reddick et al., 2014; Winter et al., 2014). These core deficits can lead to secondary deficits in global cognitive functioning (i.e., IQ) and academic skills. Young age at diagnosis, greater treatment intensity, and neurological complications (e.g., hydrocephalus and stroke) are also associated with increased risk for developing cognitive difficulties, which typically emerge following treatment and may worsen over time. Prevalence rates for cognitive effects in childhood cancer survivors vary across studies, but at least 35% experience impairment in at least one domain (Krull et al., 2018; Michel et al., 2020). Given these risks and their potential impact on academic functioning, serial monitoring of cognitive functioning is recommended in these high-risk populations (Annett et al., 2015). At a minimum, these survivors should be routinely screened for weaknesses or changes in cognitive functioning via interview and/or questionnaires and should be assessed with comprehensive cognitive evaluation at the time of school re-entry and every 2–3 years or with notable changes in status. The standard for assessment of neuropsychological outcomes suggests assessment of intelligence, attention, memory, language, executive functioning, and processing speed. Assessment results should inform classroom services (Harman et al., 2019) and may reveal the need for additional intervention as well. It is important to keep in mind that these cognitive late effects are long-lasting and continue to impact survivors' functioning beyond school and throughout adulthood (Krull et al., 2018; Michel et al., 2020; Ullrich & Embry, 2012).

In addition to compensatory interventions and accommodations provided in the classroom setting as described above, survivors with cognitive deficits may benefit from pharmacological intervention or cognitive rehabilitation. Although multiple pharmacological agents have been studied in this population, the most studied drugs are psychostimulants. In particular, multiple trials have illustrated the efficacy of methylphenidate in improving attention and working memory in leukemia and brain tumor survivors (Conklin et al., 2010; Smithson et al., 2013). Computerized cognitive remediation has shown promise in recent studies in improving working memory performance, though the functional impact of these demonstrated improvements is not yet known (Conklin et al., 2017; Hardy et al., 2013).

Psychological Functioning and Adjustment of Survivors

Overall, pediatric cancer survivors are not at increased risk for psychological problems as compared to their healthy peers, with 80–90% considered psychologically well (Eiser et al., 2000; Mertens & Gilleland Marchak, 2015; Phipps et al., 2009; Stam et al., 2001). However, a subset will experience emotional and related difficulties such as anxiety, depression, and post-traumatic stress symptoms (PTSS; Bitsko et al., 2016; McDonnell et al., 2017; Michel et al., 2020). While models of traumatic stress often influence the conceptualization of pediatric patients' experiences (Kazak et al., 2006), rates of formal post-traumatic stress disorder (PTSD) are actually quite low and commensurate with healthy controls (Allen et al., 2018; Phipps et al., 2014; Tillery et al., 2019). Indeed, pediatric patients with cancer often display remarkable resilience (Tillery et al., 2017; Van Schoors et al., 2015), reporting similar or even lower levels of psychological problems than healthy peers (DeJong & Fombonne, 2006; Eiser et al., 2000; Howard Sharp et al., 2015). Moreover, the concept of post-traumatic growth has been increasingly studied, with results of some studies suggesting that pediatric patients with cancer can experience long-term psychological benefits from their cancer experience (Barakat et al., 2006; Phipps et al., 2014; Van Schoors et al., 2015). Again, brain tumor survivors are at increased risk of struggling with psychosocial functioning following treatment, with some studies identifying higher rates of internalizing and externalizing symptoms (Cox et al., 2019; Fuemmeler et al., 2002). Brain tumor survivors are also at increased long-term risk for social and adaptive functioning difficulties such as lower rates of employment, social relationships, and independent living (Armstrong et al.,

2009). All long-term survivors of childhood cancer should receive annual screening for anxiety, depression, adverse educational and vocational issues, and social functioning following completion of therapy (COG, 2018; Lown et al., 2015).

Disease Recurrence and End-of-Life Care

Patients and families hope they never have to face disease recurrence or death. However, if this happens, pediatric psychologists can help provide support and guide difficult conversations. Different from the time of diagnosis, when communicating about relapsed or refractory disease, these patients have lived experiences that may influence how they wish to proceed with (or without) further treatment. Especially when confronted with limited or no curative options, these conversations and resulting decisions are high-stakes – with a substantial impact on the patient. Although patients, especially adolescents, may not always be included or actively engage in conversations about their advanced cancer status (Frederick & Mack, 2018; Poort et al., 2020) there is precedence to involve the patient in these discussions and the decision-making process (Lövgren et al., 2020; Weaver et al., 2015).

Advance Care Planning

Given that some patients with a diagnosis of cancer still face early death, advance care planning is an integral component of end-of-life (EOL) care and should involve three core components: understanding of values, discussion between patient, caregiver(s) and providers, and completion of written directives (Fried et al., 2010). However, despite international guidelines and recommendations that early conversations regarding goals of care and treatment options happen in pediatrics (AAP Section on Hospice and Palliative Medicine and Committee on Hospital Care, 2013), there appear to be few structured pediatric models to help facilitate these conversations (Lotz et al., 2013), with many approaches limited to single aspects of the advance care planning process (e.g., advance directives; Hein et al., 2020). Goals of advance care planning include improved communication about prognosis and care plans to honor the patient and family values and goals, establishment of advance directives, and outlining of goals for care should a patient acutely decompensate (DeCoursey et al., 2019).

End of Life

Although there has been significant advancement in the treatment of pediatric cancer, approximately 20% of youth diagnosed with cancer in the United States do not survive their disease (Siegel et al., 2016). Though a focus during the EOL period is often on comfort and minimizing symptom burden, children with cancer often suffer physical and psychological symptoms during this time (Jalmsell et al., 2006), with more overall symptoms being associated with decreased health-related quality of life (Eche et al., 2020). Symptom burden tends to differ by diagnosis (e.g., more symptoms in children with brain tumors than those with hematologic malignancies), with symptom prevalence ranging from 2 to 15 symptoms during the EOL period, coupled with heightened fears of being alone and dying (Eche et al., 2020).

Palliative care is defined by the World Health Organization (WHO) as “an approach that improves the quality of life of patients (adult and children) and their families who are facing problems associated with life-threatening illness” (WHO, 2020). Unfortunately, for children with cancer, referral to palliative care specialists often happens late in the care trajectory (Cheng et al., 2019; Kaye et al.,

2016), though earlier initiation of pediatric palliative care within oncology has been found to afford more opportunity to improve symptom burden and quality of life, increase opportunities for advanced care planning, decrease the intensity of medical interventions, and improve the chance of dying within the home setting (Kaye et al., 2016, 2021; Sansom-Daly et al., 2020; Taylor et al., 2020).

Legacy-Making and Bereavement

When faced with EOL, children and adolescents want to know that they will be remembered by their loved ones. Legacy-making is an activity that provides the opportunity for the patient to contribute to or create something for others to serve as a remembrance (Foster et al., 2009). When death is anticipated, engaging in legacy-making activities can decrease symptoms of prolonged grief and increase the perception of support for caregivers (Schaefer et al., 2019). Further, participating in legacy artwork can enhance family bonding, communication, and meaning-making and lessen parental grief following the death of the child (Schaefer et al., 2020).

Across the Cancer Trajectory

Certain aspects of the pediatric cancer experience transcend the specific phases and milestones described above and are relevant across the entire cancer trajectory. These additional factors weave throughout the pediatric cancer experience and can influence a patient's and family's coping, adjustment, and overall outcomes.

Communication and Decision-Making

Pediatric oncology medical providers may struggle to effectively communicate information about prognosis, including deciding when in the care trajectory this information should be relayed. For some medical providers, the perception is that families may not be ready to hear this type of information early in the treatment process (Lövgren et al., 2020; Mack et al., 2007). When information is presented, it is important that it be communicated in a manner commensurate with the patient's developmental and cognitive levels. Psychologists can assess developmental and cognitive functioning, partner with other psychosocial providers to enhance patient and family understanding, help address questions of the pediatric patient, and offer support during difficult conversations. Psychosocial providers can also collaborate with healthcare professionals to enhance communication styles and foster the inclusion of patients and families in relevant decision-making processes. Importantly, understanding patient preference is critical, as pediatric patients with cancer can differ vastly in their desired extent of involvement in treatment decisions (Siembida & Bellizzi, 2015), and factors such as age, developmental level, severity of disease/prognosis, and individual factors may contribute to patient preference. Adolescents, in particular, are often capable of meaningfully contributing to conversations and decision-making related to their cancer-directed treatment and medical preferences (Stegenga & Ward-Smith, 2008), and the presence of the child or adolescent during diagnostic and treatment planning conversations does not seem to negatively impact parental experience or communication with the medical provider (Brand McCarthy et al., 2019). Indeed, open and respectful communication and collaboration between providers, patients, and families are essential to patient-family-centered care, can contribute to a patient's sense of respect, safety, and control (Lin et al., 2020), and are recognized as a key standard in the psychosocial care of pediatric patients with cancer (Patenaude et al., 2015).

Family Coping and Psychosocial Interventions for Family Members

For many caregivers of pediatric cancer patients, the trajectory of coping is similar to that of their child and marked by transient distress around the time of diagnosis, followed by gradual decline in distress symptoms (Dolgin et al., 2007; Sawyer et al., 2000; Wijnberg-Williams et al., 2006). Yet, for caregivers with pre-existing mental health problems or other risk factors (e.g., prior trauma, relapse of child's disease), their child's cancer diagnosis can be paralyzing (Boman et al., 2013; Jurbergs et al., 2009). Moreover, it is well documented that caregiver mental health problems can cause disruption to a child's medical treatment, impact the parenting and support of the patient and their siblings, and cause disruption to family functioning (Barrera et al., 2004; Fedele et al., 2013; Harper et al., 2019; Pai et al., 2007; Trask et al., 2003). Indeed, distinct patterns of parental coping have been identified (Dolgin et al., 2007; Steele et al., 2004), which underscores the importance of early and ongoing screening and intervention of caregivers (Kearney et al., 2015).

Several interventions have been designed to specifically reduce distress in caregivers of pediatric patients with cancer. The Bright Ideas: Problem-Solving Skills Training (PSST) program has been shown to enhance problem-solving skills and decrease mood disturbance in mothers of children newly diagnosed with cancer (Sahler et al., 2005, 2013). Likewise, parents receiving the Promoting Resilience in Stress Management for Parents (PRISM-P) program displayed improvements in resilience and benefit finding (Rosenberg et al., 2019). Finally, the Surviving Cancer Competently Intervention Program (SCCIP) aims to reduce post-traumatic stress symptoms and reduce cancer-related anxiety while improving coping; however, results of randomized clinical trials show varying success (Kazak et al., 2004; Stehl et al., 2009).

Siblings of pediatric cancer patients face unique challenges and stressors that can impact their coping, including changes in family roles and routines, less contact with the parent caring for the patient, less parental attention, concern for the patient, and less access to psychosocial supports than the patient (Alderfer et al., 2010). Similar to coping patterns of patients and parents, siblings can experience initial problems with mood and other areas of functioning (e.g., academics, social relationships) that typically improve with time (Alderfer et al., 2010; Houtzager et al., 2003). Indeed, many siblings show resilience and positive outcomes (Cordaro et al., 2012). Yet, there is variability in sibling coping and adjustment, and factors including age and gender have been explored (Houtzager et al., 2003; Long et al., 2013). These findings highlight the need for support of siblings as a standard of care in pediatric cancer (Gerhardt et al., 2015). Intervention research with siblings of pediatric cancer patients is more limited but suggests that sibling support groups and camps may help decrease negative mood, improve quality of life, and enhance medical knowledge (Martiniuk et al., 2014; Prchal & Landolt, 2009).

Adherence

Management of pediatric cancer can be arduous for both the patient and the family. Complex and lengthy treatment regimens are common, and many treatment agents are associated with adverse side effects and long-term sequelae. Moreover, some patients will require long-term use of medications for many years (or potentially lifelong) after completion of their medical treatment. As a result, many patients and families struggle to fully adhere to the treatment regimen. Medication adherence is critical to obtaining cure (Bhatia et al., 2012), and medication nonadherence is associated with an increased chance of relapse and decreased survival rates (Lilleyman & Lenard, 1996).

It is increasingly understood that individual patient factors contribute to medication adherence, with adolescents and certain minority groups showing lower rates of adherence (Bhatia et al., 2012;

Butow et al., 2010). Indeed, published medication nonadherence rates in the adolescent oncology population are astonishingly high (25–60%; Butow et al., 2010; Festa et al., 1992; McGrady et al., 2014), and families often struggle with balancing an adolescent's developmentally appropriate need for independence with ensuring compliance with oral medical regimens (Landier et al., 2011). Other risk factors for medication nonadherence include weak family support, lack of open communication, limited understanding of the threat of the illness, psychological distress of the patient and family, limited resources, and adverse side effects of medications (Butow et al., 2010; Spinetta et al., 2002).

Other types of adherence are also crucial to the well-being of pediatric cancer patients both during and after treatment, including engagement in positive health behaviors (Klosky et al., 2012) and routine attendance at ancillary appointments that promote physical and emotional health (e.g., rehabilitation therapies, nutrition consults, psychological intervention, etc.). As such, more routine and objective assessment of adherence has been recommended, and the critical need for effective adherence interventions in pediatric oncology is apparent. A number of interventions have been developed to enhance adherence more generally in pediatric psychology, including educational interventions that provide illness-specific instruction, cognitive-behavioral interventions (e.g., reminders, incentives, and addressing illness attitudes), and family-based interventions (see Hommel et al., 2017 for an overview), and ongoing evaluation in the pediatric cancer population is needed.

Promotion of Health Behaviors

Health behaviors are generally modifiable behaviors that can be improved using targeted interventions and/or psychoeducation. Among pediatric cancer patients and survivors, it is important to assess for risky health behaviors, such as sun exposure, low physical activity, poor diet and nutrition, poor sleep behaviors, substance use (e.g., tobacco, marijuana, and illicit substances), and risky sexual behavior. Patients receiving cancer treatment are encouraged to cease smoking and drinking, to engage in physical activity, and to adopt a healthy diet and healthy sleep behaviors in order to optimize medical outcomes (Pinto & Trunzo, 2005). Cancer survivors are at heightened risk for secondary cancers and other medical problems (e.g., cardiovascular disease, pulmonary disease, endocrine dysfunction, nervous system abnormalities) due to their receipt of toxic medical treatments (Hudson et al., 2013), and engagement in unhealthy behaviors can exacerbate these vulnerabilities. While survivors appear to engage in risky health behaviors at a comparable rate to controls (Brinkman et al., 2018; Klosky et al., 2012), their heightened medical risk underscores the importance of ensuring a healthy lifestyle. Certainly, pediatric psychologists play a crucial role in providing education on long-term health risks and assisting in modifying risky behaviors.

Summary

Along with the significant advances in medical treatment of pediatric cancer over the past 50 years, the field has seen striking progress in the development and implementation of comprehensive psychosocial care for pediatric patients and their family members. Yet, gaps remain in our understanding of aspects of the patient and family experience during and after treatment for pediatric cancer, as well as specific factors that may contribute to variable psychosocial outcomes. It is increasingly documented that most patients and family members are resilient during the pediatric cancer trajectory, and routine screening and assessment can help identify those who may require additional supports. With the wide acceptance of the need for comprehensive and preventative approaches to psychosocial care, psychologists will continue to play key roles in developing and researching evidence-informed programs

and models of psychosocial care. In addition, pediatric psychologists have tremendous opportunity and responsibility to engage in advocacy efforts for youth with cancer to ensure that the psychosocial needs of patients and families are met throughout the cancer trajectory (see Parris et al., 2020).

Resources

Websites

Together: Your Home Base to Face Cancer: www.together.stjude.org

Teen Cancer America: www.teencanceramerica.org

Children's Oncology Group: www.childrensoncologygroup.org

Children's Cancer Web: www.cancerindex.org/ccw

National Cancer Institute: www.cancer.gov

American Cancer Society: www.cancer.org

CancerCare: www.cancercare.org

Leukemia & Lymphoma Society: www.lls.org

National Brain Tumor Society: www.braintumor.org

Guides and Tools

Voicing My CHOICES- Five Wishes™: www.fivewishes.org

OncoLife™ Survivorship Care Plan: oncolife.oncolink.org

Passport for Care®: www.passportforcare.org/en/

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