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Abstract

Five-year survival rates for children with cancer have increased dramatically since the 1970s, but cancer remains a traumatic experience for many children with cancer and their families. Moreover, many treatment options for children with cancer remain highly toxic, with lifelong medical and neurocognitive consequences. In addition to the child with cancer, parents and siblings also commonly report psychosocial distress related to cancer diagnosis and treatment. Psychosocial screening helps to identify areas of concern for children with cancer and their families, and psychosocial interventions provide critical support to help families navigate the many

challenges associated with cancer diagnosis and treatment. Psychosocial cancer care must extend beyond diagnosis and treatment into survivorship and, when indicated, through death and bereavement. Interdisciplinary collaboration is essential when providing holistic cancer care, and multidisciplinary care teams often include individuals with medical and psychosocial backgrounds, as well as members of the community, such as teachers. Future directions for pediatric cancer care include the development of new medical treatments to improve outcomes and decrease adverse side effects, and a greater reliance on technology for the provision of psychosocial and follow-up care.

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Background

Over 15,000 children under age 19 are diagnosed with cancer each year in the United States (Siegel, Miller, & Jemal, 2017). Five-year survival rates in children with cancer increased dramatically from 58% in the mid-1970s to 83% in the early 2010s (Siegel et al., 2017). Due to these advances in treatment, there are over 400,000 survivors of childhood cancer in the United States (Howlader et al., 2017). However, treatment remains toxic and cancer remains the leading cause of death from disease in childhood (Siegel et al., 2017). Treatments may include combinations of chemotherapy, immunotherapy, radiation therapy, surgery, and stem cell transplantation and are tailored to the specific cancer type and stage. Duration of cancer therapy can last from several weeks to many years.

The types of cancer diagnosed in children vary by age. The most common cancers for children aged 0–14 years include leukemia (29%), brain and central nervous system cancers (26%), lymphomas (11%), soft tissue sarcomas (6%), neuroblastoma (6%), and kidney cancers (5%). Lymphomas (21%), brain and central nervous system tumors (17%), leukemias (14%), germ cell and gonadal tumors (12%), thyroid cancer (11%), and melanoma (5%) are most common in adolescents aged 15–19 years.

Direct toxic effects of chemotherapy occur in every organ system (Chavhan, Babyn, Nathan, & Kaste, 2016; Cordelli et al., 2017; Riachy et al., 2014; Thu Huynh & Bergeron, 2017). Short-term side effects typically resolve quickly and often include nausea, vomiting, hair loss, and increased susceptibility to infection. Radiation toxicity is dose and location dependent but includes fatigue, bone marrow suppression, and direct damage to surrounding tissue (Selo et al., 2010). Surgical treatment to remove a tumor results in post-operative pain and physical changes from scarring or amputation.

“Late effects” are long-term side effects that do not resolve after completion of therapy or may not appear until months or years later. Late effects vary based on age, type of cancer, type of treatment and may be physical, cognitive, or psycho-

social. Potential late effects may impact every organ system (Bottomley & Kassner, 2003; Diller et al., 2009) and may include learning disabilities or other neurologic problems (Cheung et al., 2018), abnormal growth or development (Chow et al., 2007), hearing loss (Bass et al., 2016), cardiac dysfunction (Scholz-Kreisel et al., 2017), impaired fertility or reproductive health (Overbeek et al., 2017), and increased risk of secondary cancers (Neglia et al., 2001). Like chemotherapy, the late effects of radiation therapy depend on dose, location, and age of child (Ishida et al., 2010).

As the number of long-term cancer survivors increases, attention to late effects is critical. Because of this, the Children’s Oncology Group created long-term follow-up guidelines for survivors of childhood cancer (<http://www.survivorshipguidelines.org/>) and recommends ongoing monitoring by someone familiar with pediatric oncology and late effects. Though the cause of most pediatric cancers is unknown, more than 5–10% of children with cancer may have a cancer predisposition syndrome such as LiFraumeni syndrome (Brodeur, Nichols, Plon, Schiffman, & Malkin, 2017). In addition to monitoring for relapse of disease and long-term side effects from initial cancer therapy, children with cancer predisposition syndromes often require additional screening measures. As therapies advance, efforts to decrease toxicity while increasing survival continue.

Psychosocial Concomitants and Consequences

Despite improvements in survival rates for children with cancer, the perceived life threat, physical toll, and logistical demands of treatment have psychosocial implications for the entire family. Qualitative research provides vivid accounts of families’ experiences with pediatric cancer diagnosis, treatment, and survivorship, highlighting great uncertainty, feelings of chaos and helplessness, distress, physical and emotional pain, fatigue, and social isolation (e.g., Gibbins, Steinhardt, & Beinart, 2012; Hedstrom, Haglund, Skolin, & Von Essen, 2003; Wakefield, McLoone,

Butow, Lenthen, & Cohn, 2011; Yang, Mu, Sheng, Chen, & Hung, 2016).

The experience often starts prior to diagnosis with concern and uncertainty regarding the child's sometimes vague or common symptoms, repeated medical appointments before cancer is suspected, and then invasive, painful and/or frightening diagnostic tests, usually in an unfamiliar medical setting. When a cancer diagnosis is made, the threat to the child's life becomes real and shock and devastation sets in. The intense treatment has many physical side effects, may disrupt school attendance, and requires changes in family roles and responsibilities (e.g., parental employment; household tasks) to accommodate frequent appointments and hospitalizations. Eventually, routines are established and most families adapt to their new situation; however, managing treatment is difficult for families to sustain and it is often punctuated with stressful events (e.g., invasive procedures, waiting for test results), emergencies, and other possible set-backs.

Once the cancer is eradicated and the treatment protocol completed, the end of treatment is often an ambivalent time—the joy of completing treatment and conquering the cancer is combined with fear that stopping treatment may result in relapse, that late effects may now emerge, and that these new challenges may arise without the safety net of the healthcare team. Finally, as the patient and family moves into survivorship, they need to establish a “new normal” and integrate the cancer experience into the continuing evolution of their family.

Given the stressful nature of the cancer experience, much attention has been paid to the psychosocial consequences for children with cancer and their family members. Some treatments that children with cancer receive (i.e., corticosteroids) are linked to side effects such as mood swings, irritability, depression, anxiety, and problems with behavior (Hochhauser, Lewis, Kamen, & Cole, 2005; Mrakotsky et al., 2011). Repeated, painful, invasive procedures often result in procedural distress (Shockey et al., 2013). Physical decline related to cancer, treatment side effects, and physical late effects leads to decrements in quality of life (Momani, Hathaway, & Mandrell,

2016). Absences from school and cognitive effects of treatment raise concerns about social functioning and long-term educational achievement (Lum et al., 2017; Pinquart & Tuebert, 2012). However, children with cancer and childhood cancer survivors are typically resilient; meta-analyses indicate that, on average, as a group, they score within normal ranges on standardized measures of emotional, social, and behavioral problems (e.g., Pinquart & Shen, 2011; Wechsler & Sánchez-Iglesias, 2013).

Still, there is a subset that experiences difficulties. Prospective studies reveal that the percentage of children with cancer experiencing at-risk/clinical levels of anxiety, depression symptoms, and poor quality of life is significantly elevated within one month following diagnosis (Furlong et al., 2012; Jorngarten, Mattsson, & von Essen, 2007; Marcoux, Robaey, Krajcinovic, Moghrabi, & Laverdière, 2012; Mitchell et al., 2016; Myers et al., 2014; Sawyer, Antoniou, Toogood, Rice, & Baghurst, 2000). Generally, improvements are seen with time, but 20–30% continue to experience depressive symptoms and decrements in quality of life throughout treatment and into early survivorship (Kunin-Batson et al., 2016; Mitchell et al., 2016; Myers et al., 2014). After a decline to normative levels, there also seems to be an increase in anxiety after treatment ends (Ander et al., 2016; Kunin-Batson et al., 2016). This anxiety may persist or re-emerge for survivors during specific developmental stages or transitions (McDonnell et al., 2017). Cancer-related post-traumatic stress symptoms also occur in approximately 20% of children who have been diagnosed with cancer (Kazak et al., 2004; Bruce, 2006; Price, Kassam-Adams, Alderfer, Christofferson, & Kazak, 2016).

Childhood cancer is stressful for parents. They must take in complicated information, make difficult treatment decisions, ensure adherence, reorganize their lives to accommodate treatment among their other demands, and face financial burdens while fearing for the life of their child. As a group, parents of children with cancer demonstrate elevated scores on indices of anxiety, depression, and cancer-related traumatic stress around the time of diagnosis. Most are resilient

and improve with time; however, it can take months or years before distress levels return to normal and a substantial subset is at-risk for marked, prolonged distress (Kearney, Salley, & Muriel, 2015). For example, estimates indicate that 40–83% of parents report significant traumatic stress near the time of diagnosis (Price et al., 2016) with 20–41% reporting these levels during and after treatment (Ljungman et al., 2014). Marital and family strains (e.g., conflict) are also common, but with time, most are resilient (Van Schoors, Caes, Alderfer, Goubert, & Verhofstadt, 2017; Van Schoors, Caes, Verhofstadt, Goubert, & Alderfer, 2015).

Siblings of children with cancer are also impacted by the cancer diagnosis and treatment (Alderfer et al., 2010; Gerhardt, Lehmann, Long, & Alderfer, 2015). Like children with cancer, on average, as a group, siblings score within norms on standardized measures of emotional, social, and behavioral problems; however, an important subset reports cancer-related traumatic stress (Kaplan, Kaal, Bradley, & Alderfer, 2013), anxiety, depression and poor quality of life (Gerhardt et al., 2015), poor academic functioning (Alderfer et al., 2015), various unmet needs related to social and emotional support, cancer-related information, and treatment involvement (O’Shea, Shea, Robert, & Cavanaugh, 2012; Patterson et al., 2014; Samson, Rourke, & Alderfer, 2016)

Standards for Psychosocial Care for Children with Cancer and Their Families

Psychosocial care has long been recognized as an important component of pediatric cancer care, and psychosocial staff have been important partners in providing clinical care and shaping research agendas in pediatric cancer for several decades (Kazak & Noll, 2015). However, research has described great variability between sites with regard to the provision of care (Selove, Kroll, Coppes, & Cheng, 2012). In order to develop a set of evidence-based standards for providing optimal psychosocial care for children with cancer and their families, the multidisciplinary

Psychosocial Standards of Care Project for Childhood Cancer (PSCPCC) was initiated in 2012 (Wiener, Kazak, Noll, Patenaude, & Kupst, 2015). Supported by the Mattie Miracle Foundation (www.mattiemiracle.com), this workgroup conducted comprehensive literature reviews that supported 15 standards for psychosocial care that can be used to develop and evaluate psychosocial programs at pediatric cancer centers. Several of these standards focus on screening, assessment, and intervention in this population, which are discussed in more detail later in this chapter. Refer to Table 9.1 for a complete list of the psychosocial standards. These standards were published as a special issue of *Pediatric Blood & Cancer* in 2015 (<http://onlinelibrary.wiley.com/doi/10.1002/pbc.v62.S5/issuetoc>).

Psychosocial Screening and Assessment

When considering “core” psychosocial services that are often offered to children with cancer and their families, screening and assessment is important as it identifies patient and family needs and guides the provision of psychosocial care to the family. Data suggests that screening is most often provided via informal discussion, followed by the use of structured interviews and evidence-based assessment tools, such as the Psychosocial Assessment Tool (Pai et al., 2008) and Distress Thermometer (National Comprehensive Cancer Network, 2013; Scialla et al., 2017a). While many pediatric cancer centers report that screening and assessment of psychosocial need occurs at diagnosis, the majority of centers indicated that assessment occurs in response to an identified problem (Scialla et al., 2017a). This is potentially problematic, as identifying potential problems preemptively allows for faster and more effective provision of services. Additionally, a lack of systematic screening procedures allows some families with difficulties that could be remedied to “fall through the cracks.”

Psychosocial and neurocognitive screening through survivorship is also critically important.

Table 9.1 Psychosocial standards of care for children with cancer and their families

Psychosocial standards
Youth with cancer and their family members should routinely receive systematic assessments of their psychosocial healthcare needs
Patients with brain tumors and others at high risk for neuropsychological deficits as a result of cancer treatment should be monitored for neuropsychological deficits during and after treatment
Long-term survivors of child and adolescent cancers should receive yearly psychosocial screening for: (a) adverse educational and/or vocational progress, social and relationship difficulties; (b) distress, anxiety, and depression, and (c) risky health behaviors. Adolescent and young adult survivors and their parents should receive anticipatory guidance on the need for life-long follow-up care by the time treatment ends and repeated at each follow-up visit
Youth with cancer and their family members should have access to psychosocial support and interventions throughout the cancer trajectory and access to psychiatry as needed
Assessment of risk for financial hardship should be incorporated at time of diagnosis for all pediatric oncology families... Targeted referral for financial counseling and supportive resources (including both governmental and charitable supports) should be offered based on results of family assessment. Longitudinal reassessment and intervention should occur throughout the cancer treatment trajectory and into survivorship or bereavement
Parents and caregivers of children with cancer should have early and ongoing assessment of their mental health needs. Access to appropriate interventions for parents and caregivers should be facilitated to optimize parent, child, and family well-being
Youth with cancer and their family members should be provided with psychoeducation, information, and anticipatory guidance related to disease, treatment, acute and long-term effects, hospitalization, procedures, and psychosocial adaptation. Guidance should be tailored to the specific needs and preferences of individual patients and families and be provided throughout the trajectory of cancer care
Youth with cancer should receive developmentally appropriate preparatory information about invasive medical procedures. All youth should receive psychological interventions for these procedures
Children and adolescents with cancer should be provided opportunities for social interaction during cancer therapy and into survivorship following careful consideration of the patients' unique characteristics, including developmental level, preferences for social interaction, and health status
Siblings of children with cancer are a psychosocially at-risk group and should be provided with appropriate supportive services
In collaboration with parents, school-age youth diagnosed with cancer should receive school reentry support that focuses on providing information to school personnel about the patient's diagnosis, treatment, and implications for the school environment and provides recommendations to support the child's school experience
Adherence should be assessed routinely and monitored throughout treatment
Youth with cancer and their families should be introduced to palliative care concepts to reduce suffering throughout the disease process regardless of disease status. When necessary, youth and families should receive developmentally appropriate end of life care [which includes bereavement care after the child's death]
A member of the healthcare team should contact the family after a child's death to assess family needs, to identify those for negative psychosocial sequelae, to continue care, and to provide resources for bereavement support
Open, respectful communication and collaboration among medical and psychosocial providers, patients, and families is essential to effective patient- and family-centered care. Psychosocial professionals should be integrated into pediatric oncology care settings as integral team members and be participants in patient care rounds/meetings... Pediatric psychosocial providers must have specialized training and education and be credentialed in their discipline to provide developmentally appropriate assessment and treatment for children with cancer and their families. Experience working with children with serious, chronic illness is crucial as well as ongoing relevant supervision/peer support

Note: Adapted and abbreviated from *Pediatric Blood & Cancer*, Volume 62, Issue S5

Survivors of pediatric cancer are at high risk for a number of adverse educational, vocational, social, and psychosocial difficulties. In addition, survivors of pediatric cancer report levels of risky health behavior (e.g., heavy drinking, tobacco use) that are often similar to national norms, despite increased risk for adverse health out-

comes such as secondary malignancies (Hudson et al., 2003; Lown, Phillips, Schwartz, Rosenberg, & Jones, 2015). Systematic psychosocial screening allows for the identification of problems and the provision of appropriate services. Abbreviated neurocognitive batteries have proven to be feasible (Pejnovic et al., 2012; Embrey et al., 2012)

and useful in terms of identifying potential neurocognitive and neurobehavioral concerns early in treatment (Pejnovic et al., 2012) and into survivorship (Krull et al., 2008).

Psychosocial Intervention

Preventive interventions and evidence-based interventions are critical components of psychosocial care for children with cancer and their families, as these services help families cope with the significant stress associated with pediatric cancer. Moreover, some of these symptoms may persist long after the conclusion of cancer treatment, highlighting the need for appropriate support and intervention through treatment.

Interventions vary greatly between and among sites, depending on factors such as patient needs, staffing, and resources. Data suggests that pediatric cancer centers deliver psychosocial interventions via a range of different approaches, although many centers rely most commonly on informal discussion as opposed to evidence-based interventions. Many centers also report utilizing supportive psychotherapy and cognitive behavioral therapy (Scialla et al., 2017a). Problem-Solving Skills Training is a highly utilized intervention strategy with a strong evidence-base supporting its efficacy for mothers of newly diagnosed patients (Sahler et al., 2005, 2013). This intervention consists of eight 1-h intervention sessions that are focused on learning and practicing a structured approach to identifying and solving problems (Sahler et al., 2002). The treatment manual is available through the National Cancer Institute's Research-Tested Intervention Programs (RTIPs) website (Varni et al., 2002; <https://rtips.cancer.gov/rtips/programDetails.do?programId=546012>). The Surviving Cancer Competently Intervention Program (SCCIP) and Surviving Cancer Competently Intervention Program—Newly Diagnosed (SCCIP-ND) are additional research-based interventions which incorporate cognitive-behavioral skills and family systems therapy to help parents cope with pediatric cancer (Kazak et al., 1999, 2005). SCCIP is a group intervention, and SCCIP-ND

utilizes a pre-recorded multifamily video discussion group as a proxy for a group session. Both interventions include cognitive-behavioral skills such as thought reframing.

Intervention services should follow the child and family beyond the cancer diagnosis and treatment, extending to include survivorship or bereavement care. While data suggests that there is great variability in terms of how and when this care is delivered, most pediatric cancer centers reported providing survivorship care via informal discussion as opposed to utilizing a standardized program or approach (Scialla et al., 2017a). The lack of formalized approaches to survivorship care is unfortunately not surprising, as data suggests that many childhood cancer survivors do not receive recommended cancer-related follow-up care as they transition to young adulthood (e.g., Szalda et al., 2016). Encouragingly, there is important work being done to develop and test models of care for successfully transitioning survivors of pediatric cancer into the adult health-care sphere (e.g., the social-ecological model of adolescent and young adult readiness to transition; Schwartz, Tuchman, Hobbie, & Ginsberg, 2011). Several intervention programs are also available and in development to help improve modifiable health behaviors of adolescent and young adult cancer survivors given their increased risk for ongoing chronic health conditions (Kopp et al., 2016).

Despite recommendations to integrate palliative care into cancer treatment regardless of prognosis—for example, introducing palliative care early on to assist with medical decision making, symptom alleviation and provide pain management support—this is not a widespread practice in pediatric oncology care. Grounded in a comprehensive literature review, the psychosocial standard related to palliative care underscores the importance of early integration of palliative care concepts to reduce suffering and help with symptom management (Weaver et al., 2015). Recent work by Weaver et al. (2016) introduces a conceptual framework for moving towards standardized interventions in psychosocial pediatric palliative cancer care. This framework highlights five “quality care factors” (i.e., communication,

symptom control, cognitive understanding, pragmatic needs, and maintaining relationships) as they relate to the patient, parent, family, and clinician. Additionally, and of critical importance, palliative care support should be tantamount when providing end of life and bereavement care to the child with cancer and his/her family (Lichtenthal et al., 2015; Weaver et al., 2015). Many bereaved family members are at-risk for long-lasting negative psychosocial outcomes following the death of a child from cancer, and indicate that continued contact with the healthcare team is desired (Lichtenthal et al., 2015). Despite this, data suggests that many centers send a card or letter following the death of a child, while only a small minority offer in person meetings or therapy (Scialla et al., 2017a). While it is likely challenging for staff to manage the needs of bereaved families in addition to the needs of current patients, this is an area of critical importance that should be included in comprehensive cancer care plans.

Implications for Interprofessional Care

In addition to the child with cancer and their family, there are a number of other individuals who are central to the treatment and adjustment of the family system after a cancer diagnosis (e.g., oncologists, social workers, teachers). As the healthcare landscape in the United States continues to shift and alternative models for service delivery and reimbursement are considered, the importance of interdisciplinary care becomes apparent. Interdisciplinary care, highlighted as an integral component of a changing healthcare system almost two decades ago (Institute of Medicine, 2001), utilizes a team-based approach where providers from different disciplines (e.g., oncology, psychology, social work, nutrition) collaborate to provide holistic care for patients. For children with cancer, these interdisciplinary teams are often comprised of a number of individuals from different psychosocial disciplines (e.g., social work, psychology, child life), although teams vary greatly across sites (Selove

et al., 2012; Scialla et al., 2017b). Recent data suggests that the “typical” psychosocial team is comprised of two social workers, one psychologist, and two child life specialists (Scialla et al., 2017b). Work patterns also vary greatly between sites, with the level of integration between the medical and psychosocial team predicting perceptions of providing “state of the art” psychosocial care (Scialla et al., 2017a). These data highlight the importance of providing integrated, interprofessional care to children with cancer and their families.

In addition to interdisciplinary care within the hospital system, a systems-level approach to healthcare mandates the consideration of the life of the child and family outside of and beyond the cancer diagnosis. A thorough assessment of the other systems affecting the child and family allows the interdisciplinary team to better understand the family’s needs and provide care that is consistent with these needs. Recent data from Scialla et al. (2017a) again highlights the wide range of methods used to understand and assess each family’s unique background following the initial cancer diagnosis. For example, some centers reported relying on structured interviews or institution specific tools to evaluate family needs and identify areas where additional support would be useful. In contrast, many centers reported relying on informal discussion to evaluate the strengths and needs of a family following a cancer diagnosis. In order to facilitate and coordinate care within and between systems (e.g., hospital, school, community), as well as to ensure that all families are treated with the same level of care, standardized instruments and/or procedures are likely beneficial.

One particularly salient example of interprofessional care and collaboration for children with cancer involves the interface between the school and hospital system. School is often described as the most essential “job” of childhood, as this is the primary sphere where children learn and develop critical social skills. Data suggests that children with cancer miss many days of school during cancer treatment (Charlton et al., 1991) and into survivorship (French et al., 2013). This can contribute to social and emotional challenges, as

children are often isolated from peers when they are not able to attend school consistently or participate fully in activities with peers. Moreover, while several models for school reentry programs exist (Harris, 2009; Power, DuPaul, Shapiro, & Kazak, 2003), school is not always a high priority in the context of working to save the child's life and addressing more "pressing" psychosocial concerns. Meta-analytic data also suggests that knowledge may be more amenable to change than attitudes for peers of children with cancer, which may further complicate the return to school (Canter & Roberts, 2012). For example, there may be social and emotional challenges if classmates are unsure about how to interact with the child with cancer when they return to the classroom. An increased reliance on technology in the classroom may facilitate more integration of the child with cancer into the classroom, although this remains an understudied area. Video conferencing programs may allow children with cancer to "join" their classmates from home or the hospital, and online platforms are utilized by many schools to assign and complete work.

An Example of Standardization of Care: Assessment of Psychosocial Needs at Nemours

The Psychosocial Assessment Tool (PAT; Pai et al., 2008) is a brief parent report screening instrument guided by social ecological approaches to child health to assess psychosocial risk in families of children with cancer. The PAT is used at 28.9% of cancer programs in the United States (Sciallla et al., 2017a). In addition to a total score, the PAT has seven subscales: Family Structure and Resources, Family Social Support, Family Problems, Parent Stress Reactions, Family Beliefs, Child Problems, and Sibling Problems (Pai et al., 2008). The PAT is guided by the Pediatric Psychosocial Preventative Health Model (PPPHM; Kazak, 2006), which utilizes a pyramid model to categorize families into levels of psychosocial risk. Families at the base of the pyramid, or the *Universal* level, are resilient despite some expected distress at diagnosis. Families in the middle of the pyramid, described

as the *Targeted* level, have some risk factors present and likely experience acute distress. The most high-risk families, who have persistent and/or escalating distress, are categorized at the *Clinical* level. Data indicates that the majority of families who have a child with cancer fall into the *Universal* level, with fewer families at the *Targeted* and *Clinical* levels (Kazak, Schneider, Didonato, & Pai, 2015). Levels of intervention, ranging from providing general support to specialized psychosocial intervention, vary based on risk classification.

The PAT is used at our institution, Nemours/Alfred I. duPont Hospital for Children, as a clinical screening tool to evaluate family risk and resilience following a cancer diagnosis. The PAT is available in English and Spanish and is offered to the parents of all newly diagnosed patients who are fluent in either language. The PAT is presented to families as a routine part of care within 45 days of the cancer diagnosis, which normalizes the assessment process and sets the stage for the integration of psychosocial care throughout cancer treatment.

Each eligible family is first identified by social work staff, who approach the family about the PAT within 45 days of cancer diagnosis. The PAT is given online, using a secure web application for research and survey administration (i.e., REDCap), on an iPad and takes 10–15 min to complete. After completion of the PAT, a report including an overall risk score and individual subscale scores is automatically generated. Information about specific item endorsements (e.g., "the caregiver reports that it is 'very true' for me that [the cancer diagnosis] is a disaster") is also provided in this report. A note with information about the instrument and family risk profile is entered into the electronic medical record, and information about psychosocial risk and resilience is discussed during weekly team rounds. If a high-risk item is endorsed (e.g., a question about suicidality) and/or a family screens into the clinical range, a member of the psychosocial team is immediately notified and meets with the family as quickly as possible. Parents typically complete the PAT during an initial inpatient admission, which facilitates rapid identification of any urgent needs and allows the

the psychosocial staff to more readily follow up about any areas of concern. While item endorsements and levels of risk vary greatly, problems related to finances, employment, parental emotional health, and child behavior changes are commonly endorsed. Utilizing the PAT early in the treatment process allows for the psychosocial team to identify appropriate members of the care team to work with individual families. The inclusion of the PAT scores in the EMR also allows the medical team to view critical psychosocial information and address relevant concerns.

Conclusions and Future Directions

Advances in medical treatment have greatly improved the prognosis for many children diagnosed with cancer, although treatment remains highly toxic and the medical and psychosocial impact of cancer on the child and family often persist long into remission. Holistic, interdisciplinary care models help address the many needs of children and families through cancer treatment and into survivorship. Critical roles for psychosocial team members include the provision of assessment and intervention services for the child with cancer, siblings, and caregivers from diagnosis into treatment, survivorship, and bereavement care when needed. Evidence suggests that “best practice” psychosocial care should be research-based and standardized, and should follow patients and their families from diagnosis into survivorship or, if necessary, bereavement. While models and methods of care delivery will undoubtedly change as the healthcare landscape continues to shift, the long history of integration between psychosocial and medical care in pediatric cancer ensures that integrated care will remain a hallmark of pediatric cancer treatment in the future.

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