Assessing Family Psychosocial Risks in Pediatric Cancer

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Anne E. Kazak, Stephen DiDonato,
Stephanie J. Schneider, and Ahna L.H. Pai

Introduction

Although psychosocial interventions and care in pediatric cancer, based on strong scientific evidence from more than 30 years of research on youth and families, has prospered and been refined over recent decades, these findings are not consistently translated into the clinical delivery of psychosocial care for children with cancer and their families (Kazak and Noll 2015). For example, in a study of Children's Oncology Group (COG) institutions, about half of families were offered psychosocial services within the first 30 days after diagnosis. Only 9 % of institutions used empirically supported psychosocial evaluations and less than 11 % implemented empirically based treatments (Selove et al. 2012). Notably, no published data are available addressing the type or frequency of services at other points during the treatment trajectory.

There is little empirical data that documents psychosocial care and outcomes in pediatric cancer. Clinical experience and professional collaborations portray a situation in which psychosocial care is highly variable between, and even within, pediatric cancer programs. While most centers have access to some psychosocial staff, models for integrating psychosocial care in pediatric oncology programs have not been clearly articulated nor implemented consistently. Most pediatric cancer centers rely on existing psychosocial resources at a given institution and referral patterns are based on provider judgments of need. Ongoing concerns about staffing, time, and finances are pervasive.

Therefore, it is difficult to answer the basic question "What are the standards of psychosocial care in pediatric cancer?" A recent review on this point identified that, despite calls from professional organizations to screen for psychosocial distress (COC 2012; IOM 2007; Noll et al. 2013), none of the current published guidelines or stan-

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A.E. Kazak, PhD, ABPP (✉)
Nemours Biomedical Research,
Nemours Center for Healthcare Delivery Science/
Alfred I. duPont Hospital for Children,
Wilmington, DE, USA
e-mail: anne.kazak@nemours.org

S. DiDonato, MS
Nemours Biomedical Research,
Center for Pediatric Traumatic Stress at the Nemours/
Alfred I. duPont Hospital for Children,
RC1 – 167, 1600 Rockland Road,
Wilmington, DE 19803, USA
e-mail: stephen.didonato@nemours.org

S.J. Schneider, MS
Nemours Biomedical Research, Nemours/
Alfred I duPont Hospital for Children,
RC1-160G, 1600 Rockland Road,
Wilmington, DE 19803, USA
e-mail: Stephanie.J.Schneider@gmail.com

A.L.H. Pai, PhD
Department of Behavioral Medicine and Clinical
Psychology, Blood Diseases Institute, Cincinnati
Children's Hospital Medical Center,
MLC 7039, Cincinnati, OH 45229-3039, USA
e-mail: ahna.pai@cchmc.org

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dards meet the comprehensive and evidenced-based criteria necessary to serve as psychosocial standards of care for pediatric cancer today (Wiener et al. 2015).

Screening to determine the level and nature of a patient and family's psychosocial status is a reasonable first step in the process of delivering care. Screening, usually for depression or distress, has become more common in adult oncology. The Commission on Cancer guidelines (COC 2012) requires distress screening but indicates that the treating institution should decide upon the method and tool for screening. Standardized and validated screening measures have preference. The COC also recommends that screening should occur at times of highest distress (i.e., at diagnosis, family meeting with oncologist to discuss treatment, transitions off treatment).

These existing recommendations for screening do not translate easily to pediatric settings. Many screening or assessment approaches are focused on the individual adult patient and are neither sufficiently broad nor inclusive of many key aspects of families and the broader social context necessary in pediatrics. In addition, there is a history of family-centered care and psychosocial support for families in pediatrics that is not typical in adult settings. Therefore, screening that corresponds to the types of services available to children and families in healthcare settings is also important.

Indeed, it is reasonable to assert that *all* families entering a pediatric healthcare setting should receive care attuned to their specific needs, including psychosocial care related to their health condition. There are distinct practice models for providing psychosocial care to children in pediatric settings. These approaches are generally aimed at treating the more severe problems identified by medical and nursing staff. For example, consultation liaison teams and referral to community providers are common approaches. However, care may be based primarily on clinical referral patterns that are not systematic but rather selective, based on individual clinical judgment and response to crisis. The availability of an "on-site" psychosocial professional integrated into the healthcare team may facilitate care to a broader range of patients and families. A population health model, looking at the needs of all patients and families and screening systematically, has the potential to overcome stigma associated with behavioral health services, change non-systematic provider-determined referral patterns, and facilitate more evidence-based and cost-effective allocation of finite resources, including more preventative care, when appropriate.

Screeners of psychosocial risk should include questions based on key research findings (e.g., factors related to adjustment over time and the need for intervention) and be administered efficiently in order to pair screening results with appropriate clinical interventions. Given the large literature on family factors that impact child functioning and well-being in both primary and tertiary healthcare settings, a contextual social ecological approach to screening offers a broad array of potential targets for intervention and provides an opportunity to appreciate the strengths as well as vulnerabilities of families (Ungar 2012).

Figure 4.1 illustrates the social ecology of child health and provides examples of how these map on to screening items. At the center are the child, the illness/condition, and the family microsystems. Family assessments/screening focuses heavily on these interrelated systems with questions about the child, family, and illness prominent. At the next level of the model are systems intimately linked to successful adaptation and child health outcomes: healthcare settings, schools, social relationships, and communities. Figure 4.1 illustrates the complex interrelationships among elements of the social ecology. The more distal macrosystem includes other influences, such as culture, laws, and social class that provide a context for a thorough conceptualization of risk and resilience. Therefore, a comprehensive screen should include quick evaluation of relevant topics of the child's social ecology and in the context of a broader systemic model in order to identify factors impacting the child's functioning and to identify and prioritize interventions.

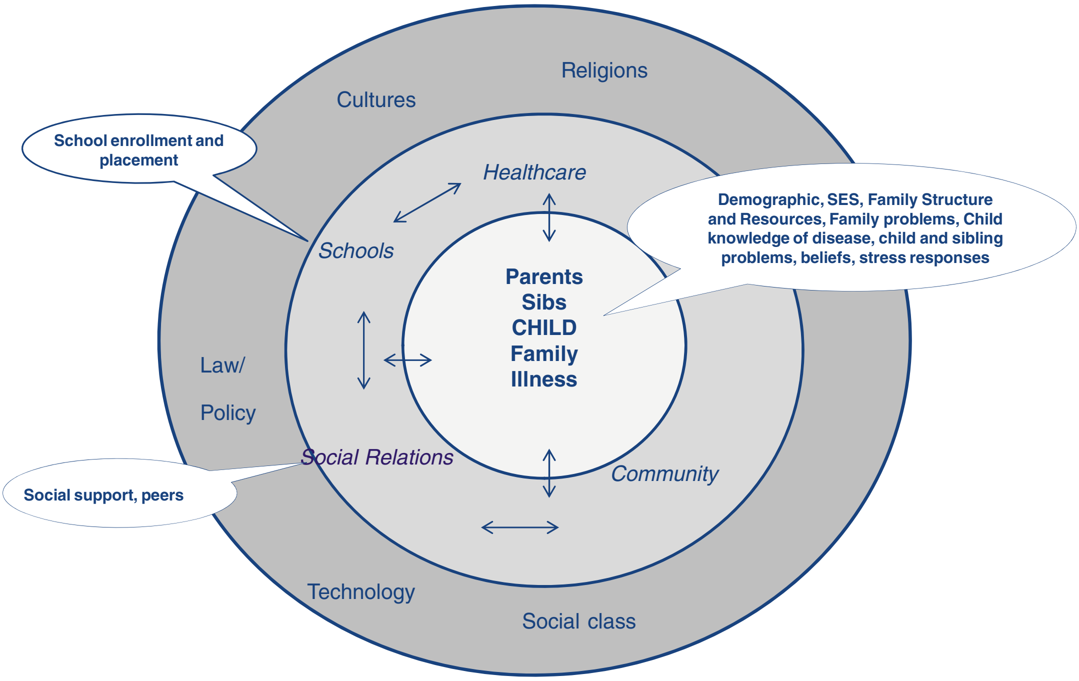

Fig. 4.1 Screening in a social ecological context

Timely screening for multifaceted family psychosocial risk is a means by which treatment needs and follow-up care for the patient and family can be identified in an effective and inclusive manner to facilitate efficient assessment and delivery of evidence-based care matched to patient and family need. In light of a recent comprehensive review of the literature on screening in pediatric cancer (Kazak et al. 2012), this chapter includes an updated search, completed in October 2014, to identify recent papers on psychosocial screening in pediatric cancer. We used the same keywords as the earlier review ("pediatric oncology" or "pediatric cancer" or "childhood cancer") AND (screen* or tool* or assess* or classify* or categorize or evaluate or "psychosocial risk" or "psychosocial need" or "psychosocial care" or at risk" or "level of risk" or "identify risk" or distress or parents) AND (NOT survivor*) and databases (PsycInfo, Cinahl, PubMed, and Health and Psychosocial Instruments Database). In addition, authors of recent papers were contacted to obtain copies of relevant presentations and prepublication work.

Models for Standardized Screening

Three primary models of risk screening were identified in a previous review (Kazak et al. 2012) – 1) the *P*ediatric *P*reventative *P*sychosocial *H*ealth *M*odel (PPPHM), 2) the Family APGAR (*A*daptability, *P*artnership, *G*rowth, *A*ffection, and *R*esolve) approach, and 3) the HEADSS (*H*ome, *E*ducation, *A*ctivities, *D*rugs, *S*exuality, and *S*uicide/Depression) framework. No additional models of psychosocial risk screening in pediatric cancer were found in the literature between 2011 and 2014.

The Pediatric Psychosocial Preventative Health Model (PPPHM; Fig. 4.2) is based on a public health framework and used to conceptualize families with varying levels of psychosocial risk along with interventions matched to risk (Kazak 2006). Each of the PPPHM levels is described below followed by a case example.

At the base of the pyramid are Universal families, who are understandably concerned or distressed about their child's health problem but who are generally resilient and able to

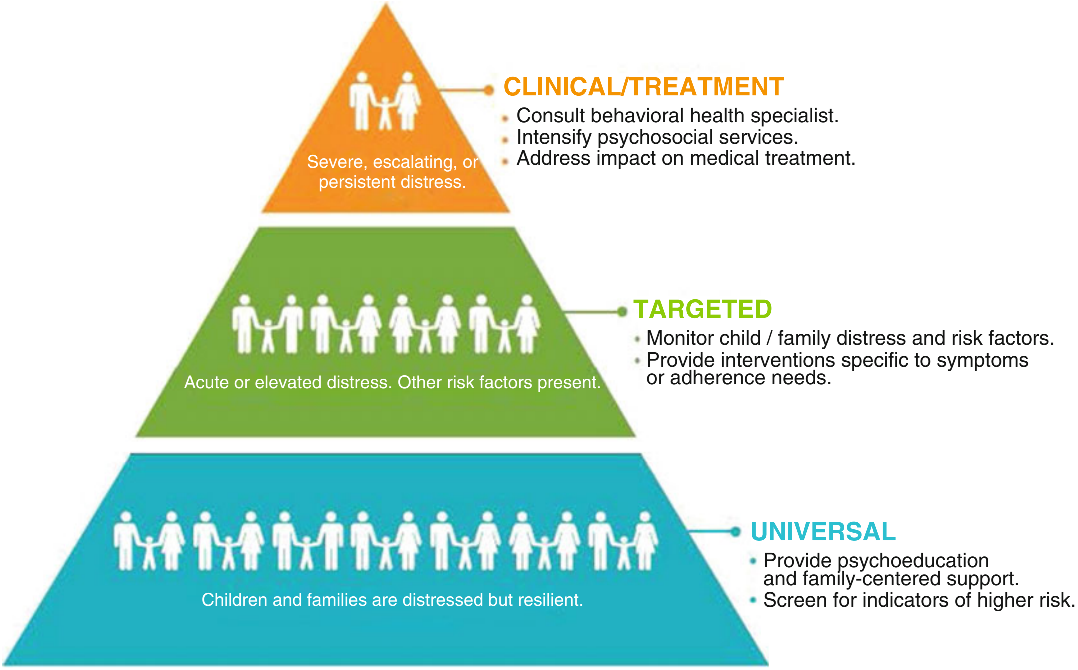

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Fig. 4.2 Pediatric Psychosocial Preventative Health Model (PPPHM) (Reproduced with permission from the Center for Pediatric Traumatic Stress (CPTS) at Nemours Children's Health System © 2011. All rights reserved. The PPPHM may not be reproduced in any form for any purpose without the express written permission of CPTS. To obtain permission to use reproduce the PPPHM, contact Anne Kazak, PhD ABPP at anne.kazak@nemours.org)

cope and adapt to their child's illness and treatment.

Universal Level Case Example: Max is a 15-year-old recently diagnosed with resilient leukemia. His parents are married. They work full time outside the home but expect that their employers will afford them some flexibility over the next few months. Max has two siblings, ages 12 and 17, and a large family support system available for help. Max's parents consider him a bit of a worrier but otherwise a popular student who learns easily. His mother reports a history of frequent migraine headaches and appears sad and tired at clinic visits.

The middle tier consists of Targeted families, with preexisting concerns or difficulties that may contribute to continuing or escalating vulnerability during treatment.

Targeted Level Case Example: Aiden is a 9-year-old recently diagnosed with a rhabdomyosarcoma. His teachers have noted difficulties in attention and some challenges in learning last year and this year. His parents are executives in local businesses who separated last year and have occasional disputes about custody and child support. Both parents are present at clinic visits.

At the tip of the pyramid are Clinical families, with one or more preexisting, chronic, and complex problems and resulting greatest need for prompt and often intensive intervention.

Clinical Level Case Example: Sophia is a 5-year-old recently diagnosed with a medulloblastoma. She has three younger siblings, ages 3 and 2 years and 8 months. Her parents have many financial worries (e.g., concerns about paying phone and utility bills, rent, etc.), few people to assist them, and general apprehensiveness about treatment and its impact on their daughter and family. Sophia's parents indicate that she has several behavioral and developmental concerns (e.g., moodiness, anxiety, problems in kindergarten) and, on screening, endorses a number of behavioral concerns for at least one of the siblings. In addition, her mother has a history of anxiety and endorsed symptoms of acute stress since her daughter's diagnosis.

Using the PPPHM as a guide, treatment options vary by level. Many of the services currently provided in pediatric settings (e.g., social workers, child life specialists, chaplains, creative arts programs, family-centered care programs, financial counselors, etc.) provide a broad undergirding of care that will address many of the needs of Universal families. There are many evidence-based interventions developed that are appropriate for families at the Targeted level. These include cognitive behavioral therapy for pain and behavioral or multicomponent interventions for adherence to medical regimens (see http://www.apadivisions.org/division-54/evidence-based/). At the Clinical level, behavioral medicine teams are usually necessary to assess and provide generally more intensive interventions in addition to Universal services that families would receive. The PPPHM provides a "snapshot" of the family's risks and resilience. Screening always necessitates clinical follow-up assessment to determine a treatment plan. Continued monitoring of risk for all families is critical to capture changes in risk over time. The literature review identified eight papers that referred to the PPPHM as a model or guide for pediatric populations.

The Family APGAR (*A*daptability, *P*artnership, *G*rowth, *A*ffection, and *R*esolve) provides quantitative data on individual family member's satisfaction with their family's functioning based on the APGAR components. The items are intended to measure individual family member's perception of family functioning. The Family APGAR also allows for the integration of physician knowledge of the family and follow-up discussions with the family member to gain qualitative data of the individual family member's satisfaction and family functioning based on the quantitative APGAR data (Smilkstein 1978).

The HEADSS framework (*H*ome, *E*ducation, *A*ctivities, *D*rugs, *S*exuality, and *S*uicide/Depression) interview guide aims to engage adolescents and young adults (AYAs) in preventative healthcare throughout the course of their cancer treatment (Yeo and Sawyer 2009). Providing physicians with a developmentally appropriate guide to engage adolescents and young adults in queries of specific areas of psychosocial risk is important in building rapport and ensuring patient-centered care. Although there is limited empirical basis for the HEADSS interview, the content is consistent with general adolescent preventative care (Goldenring and Rosen 2004).

Screening Methods and Evidence-Based Tools

There are potentially many different means of conducting screening. Before discussing specific approaches and measures, the results of a listserv posting conducted as part of the Psychosocial Standards of Care Project for Childhood Cancer (PSCPCC) are noted (Kupst MJ, 2015, Personal Communication). Queries were posted in July 2013 to listservs of the Society of Pediatric Psychology (SPP) and the International Society of Pediatric Oncology (SIOP) asking what measures were used in clinical care for screening and assessment of children, adolescents, and young adults with cancer. Although not a scientific survey, the results indicated that the most frequently used screeners were the Psychosocial Assessment Tool (PAT; Pai et al. 2008), the Strengths and Difficulties Questionnaire (SDQ; Goodman 2001), the Child Behavior Checklist (CBCL; ASEBA 2015), the Distress Thermometer (DT; National Comprehensive Cancer Network® (NCCN®) 2003), the Behavior Assessment System for Children (BASC/BASC-2; Reynolds and Kamphaus 2004), and the Brief Symptom Inventory (BSI; Derogatis 2000).

Methods for Screening

One method of risk assessment is to use a battery of validated measures (e.g., well-known measures of depression, anxiety, child behavior).[1]

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[1] There are many validated instruments that have been used in pediatric oncology. A review of all of them is beyond the scope of this chapter.

The advantage of these approaches is the use of established psychometrically strong instruments, usually specific to a construct (e.g., quality of life, behavior, depression) and often with clinical cutoff scores. The disadvantages are that multiple measures are often necessary to assess relevant outcomes. The number of items on these batteries can be significant and the participant burden and administration time can become longer than is feasible in a medical setting. Scoring and interpretation may also necessitate a mental health professional; adding another step can slow the communication of results and may be problematic in some settings without such staff. One of the more creative applications of this approach, measuring quality of life in the Netherlands, is KLIK, a Dutch acronym roughly translated in English as *Mapping Quality of Life in Clinical Practice*, which provides a patient and family ePROfile developed from generic and illness-related questionnaires. KLIK provides the health-care team with direct access to patient responses, which increases communication and provider satisfaction in care (Haverman et al. 2014).

A second approach is the very brief screeners, exemplified by the Distress Thermometer (DT) and discussed below.

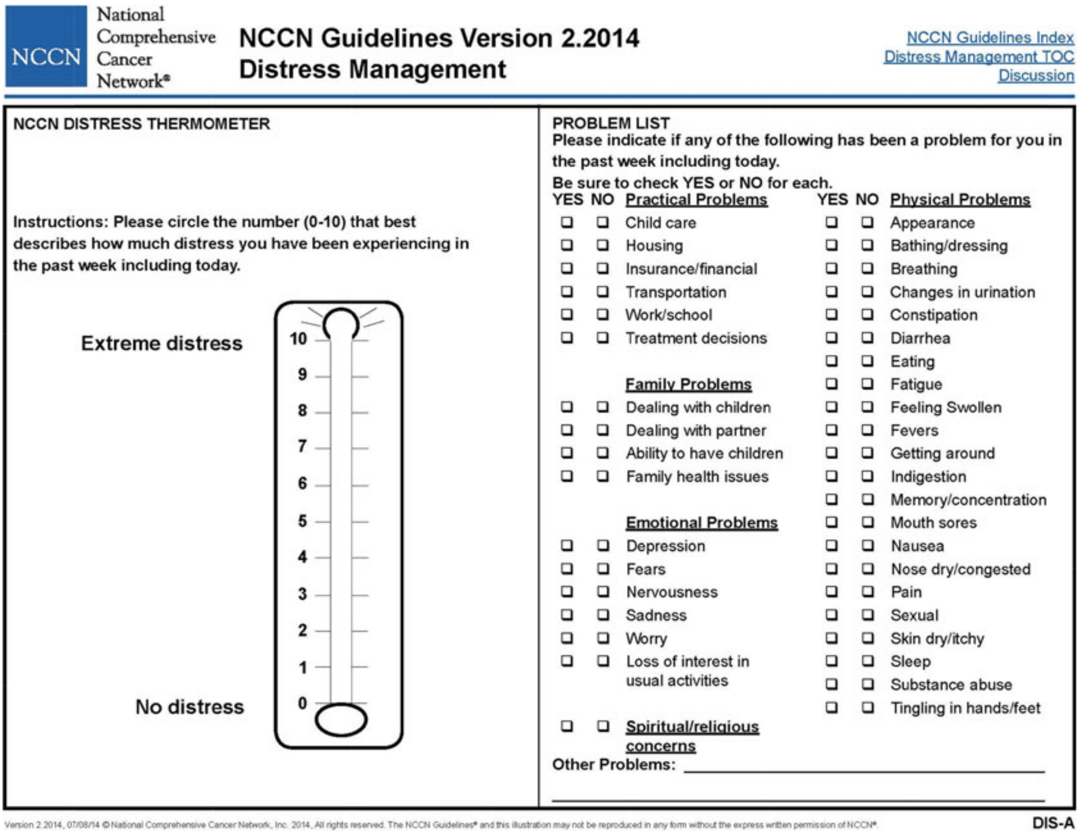
Another method is structured clinical interviews. Such interviews typically include standardized questions about the nature, severity, and duration of symptoms, often with the goal of determining a diagnosis. Exemplified by the HEADSS, discussed above (e.g., HEADSS 3.0; Goldenring and Rosen 2004), structured clinical interviews assess a broad range of topics in detail and facilitate rapport. Although they provide clinicians with guidance regarding which questions to ask and how to ask them, they tend to be susceptible to interviewer drift and social desirability. The standardized structured clinical interview such as HEADSS also requires trained staff and increases the burden on clinical staff, and the administration time can be problematic in health-care settings. The structured clinical interview differs from a clinical assessment in which the clinician is asking questions about particular areas of interest but using a less formally structured protocol to do so.

Yet another approach is the use of single relatively short standardized instruments. Most focus solely on child behavior (e.g., the Pediatric Symptom Checklist) or parenting stress (e.g., the Parenting Stress Index). The Beck Youth Inventory II was found to be a feasible approach for screening depression and anxiety in adolescents in oncology treatment (Kersun et al. 2009). SCREEM-RES (*S*ocial, *C*ultural, *R*eligious, *E*conomic, *E*ducation, and *M*edical) Family Resource Survey questionnaire was developed to identify areas that families need support in order to increase the family's capacity to cope with the child's cancer (Panganiban-Corales and Medina 2011).

The Psychosocial Assessment Tool (PAT) is the only measure developed specifically for pediatric oncology, guided by research evidence and clinical experience to assess (parental report) a range of potential risks across the family's social ecology. The PAT is discussed below in more detail.

Two Empirically Supported Tools

The Distress Thermometer (DT; Fig. 4.3; NCCN® 2014) uses a graphic representation of a thermometer, generating a 1–10 unidimensional rating of how distressed the respondent has felt in the past week. The DT may also be used with a problem list of practical problems (e.g., housing, insurance), family problems (e.g., dealing with partner, children), emotional problems (e.g.., worry, sadness), spiritual and religious concerns (e.g., relating to God, loss of faith), and physical problems (e.g., pain, nausea) (NCCN 2003). The DT has been used quite extensively in adult oncology and more recently in pediatric cancer (Patel et al. 2011). Data from Patel et al. (2011) were extracted for patients and their mothers at the end of life, indicating that the DT was helpful in tracking changes at this point in treatment (Patel et al. 2011). The DT is feasible in screening for distress in children with cancer or other chronic illness and correlated with both child and parent measures of depression, anxiety, pain, and fatigue (Zadeh et al. 2014). The Distress Thermometer for Parents (DT-P) was also developed and validated for parents of children with



NCCN National Comprehensive Cancer Network®

NCCN Guidelines Version 2.2014
Distress Management

NCCN Guidelines Index
Distress Management TOC
Discussion

NCCN DISTRESS THERMOMETER

Instructions: Please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.

PROBLEM LIST
Please indicate if any of the following has been a problem for you in the past week including today.
Be sure to check YES or NO for each.

YES NO **Practical Problems**
☐ ☐ Child care
☐ ☐ Housing
☐ ☐ Insurance/financial
☐ ☐ Transportation
☐ ☐ Work/school
☐ ☐ Treatment decisions

Family Problems
☐ ☐ Dealing with children
☐ ☐ Dealing with partner
☐ ☐ Ability to have children
☐ ☐ Family health issues

Emotional Problems
☐ ☐ Depression
☐ ☐ Fears
☐ ☐ Nervousness
☐ ☐ Sadness
☐ ☐ Worry
☐ ☐ Loss of interest in usual activities

☐ ☐ **Spiritual/religious concerns**

YES NO **Physical Problems**
☐ ☐ Appearance
☐ ☐ Bathing/dressing
☐ ☐ Breathing
☐ ☐ Changes in urination
☐ ☐ Constipation
☐ ☐ Diarrhea
☐ ☐ Eating
☐ ☐ Fatigue
☐ ☐ Feeling Swollen
☐ ☐ Fevers
☐ ☐ Getting around
☐ ☐ Indigestion
☐ ☐ Memory/concentration
☐ ☐ Mouth sores
☐ ☐ Nausea
☐ ☐ Nose dry/congested
☐ ☐ Pain
☐ ☐ Sexual
☐ ☐ Skin dry/itchy
☐ ☐ Sleep
☐ ☐ Substance abuse
☐ ☐ Tingling in hands/feet

Other Problems: ______________________

____

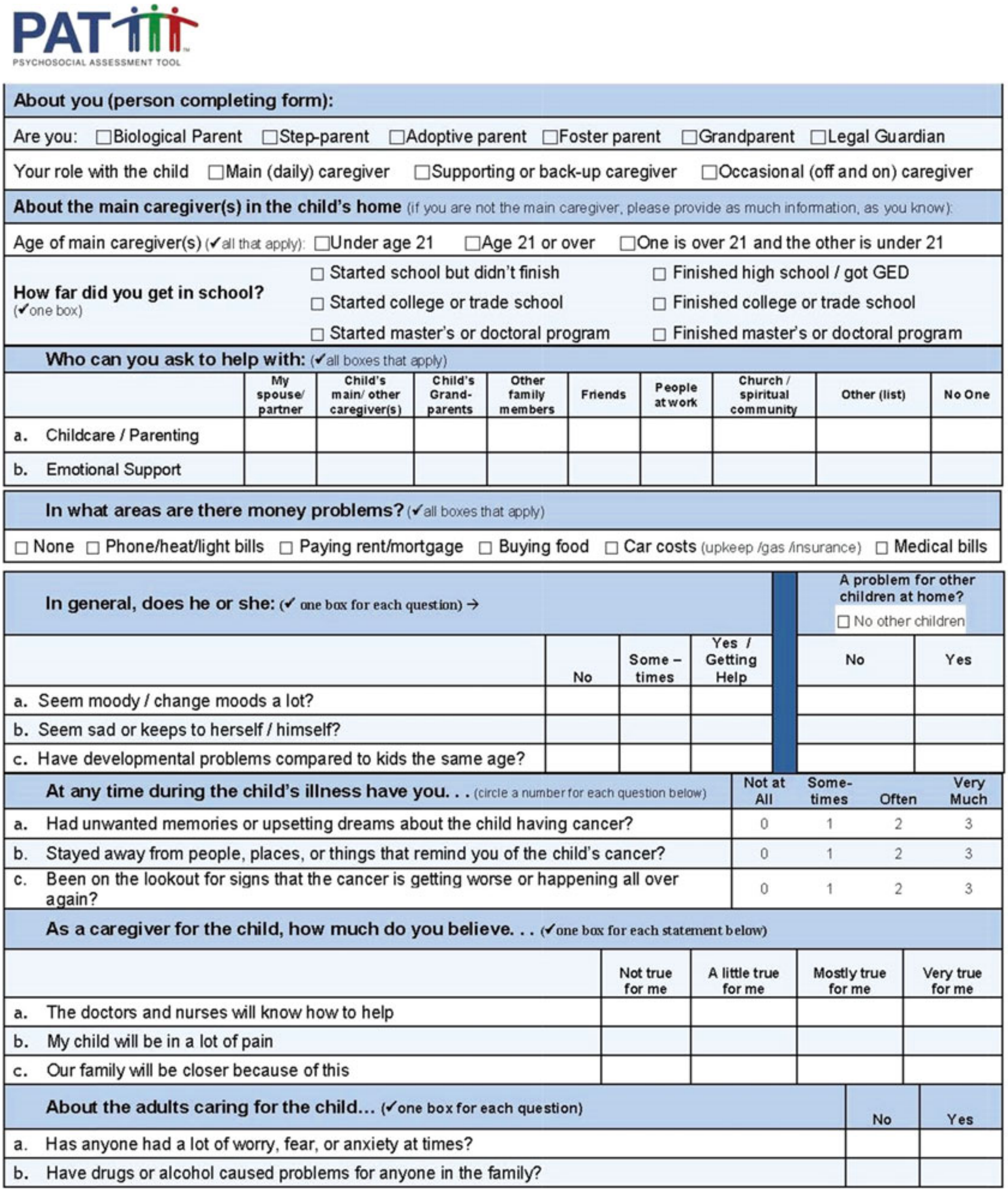
DIS-A

Fig. 4.3 NCCN® Distress Thermometer (Reproduced with permission from the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Distress Management V.2.2014. © 2014 National Comprehensive Cancer Network, Inc. All rights reserved. The NCCN Guidelines® and illustrations herein may not be reproduced in any form for any purpose without the express written permission of the NCCN. To view the most recent and complete version of the NCCN Guidelines, go online to NCCN.org. NATIONAL COMPREHENSIVE CANCER NETWORK®, NCCN®, NCCN GUIDELINES®, and all other NCCN Content are trademarks owned by the National Comprehensive Cancer Network, Inc.)

chronic illnesses, showing associations of its 10-point Likert scale with parental distress (Haverman et al. 2013).

The advantages of the DT are brevity, simplicity, and focus on the self-reported distress of the respondent. Its simplicity allows for it to be completed by children and parents. However, a single score of one dimension (distress) may provide limited clinical information and is not highly specific in providing direction for needed intervention. The use of problem lists on the DT contributes information about areas of concern, although it adds slightly to the length, which is usually 3–5 minutes.

The Psychosocial Assessment Tool (PAT; Fig. 4.4; Pai et al. 2008), a brief (5–10 minutes administration time) screener of family psychosocial risk based on the PPPHM's trilevel of risk classification, was developed for families of children with cancer. In addition to the total score, there are seven subscales (structure/resources, family problems, social support, stress reactions, family beliefs, child problems, and sibling problems). The psychometric properties of the PAT are strong (Pai et al. 2008) and PPPHM risk classification is generally stable across 4 months (Alderfer et al. 2009). Detailed information about the history, use, and research on the PAT is detailed in a recent paper (Kazak et al. 2015). The all-literacy English and Spanish versions of the PAT (4th-grade reading level) are



PAT™
PSYCHOSOCIAL ASSESSMENT TOOL

About you (person completing form):

Are you: ☐Biological Parent ☐Step-parent ☐Adoptive parent ☐Foster parent ☐Grandparent ☐Legal Guardian

Your role with the child ☐Main (daily) caregiver ☐Supporting or back-up caregiver ☐Occasional (off and on) caregiver

About the main caregiver(s) in the child's home (if you are not the main caregiver, please provide as much information, as you know):

Age of main caregiver(s) (✓all that apply): ☐Under age 21 ☐Age 21 or over ☐One is over 21 and the other is under 21

How far did you get in school? (✓one box)

☐ Started school but didn't finish
☐ Finished high school / got GED
☐ Started college or trade school
☐ Finished college or trade school
☐ Started master's or doctoral program
☐ Finished master's or doctoral program

Who can you ask to help with: (✓all boxes that apply)

	My spouse/ partner	Child's main/ other caregiver(s)	Child's Grand-parents	Other family members	Friends	People at work	Church / spiritual community	Other (list)	No One
a. Childcare / Parenting									
b. Emotional Support									

In what areas are there money problems? (✓all boxes that apply)

☐ None ☐ Phone/heat/light bills ☐ Paying rent/mortgage ☐ Buying food ☐ Car costs (upkeep /gas /insurance) ☐ Medical bills

In general, does he or she: (✓ one box for each question) →				A problem for other children at home? ☐ No other children	
	No	Some – times	Yes / Getting Help	No	Yes
a. Seem moody / change moods a lot?					
b. Seem sad or keeps to herself / himself?					
c. Have developmental problems compared to kids the same age?					

At any time during the child's illness have you. . . (circle a number for each question below)	Not at All	Some- times	Often	Very Much
a. Had unwanted memories or upsetting dreams about the child having cancer?	0	1	2	3
b. Stayed away from people, places, or things that remind you of the child's cancer?	0	1	2	3
c. Been on the lookout for signs that the cancer is getting worse or happening all over again?	0	1	2	3

As a caregiver for the child, how much do you believe. . . (✓one box for each statement below)

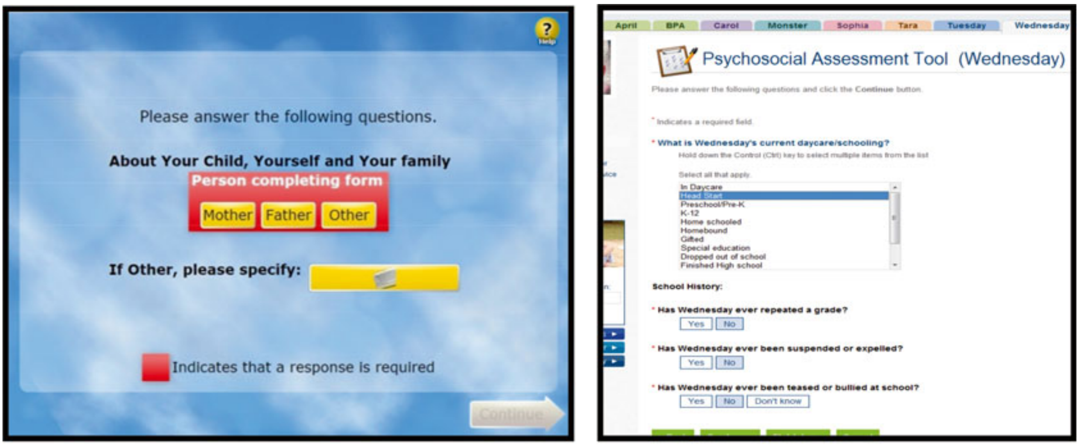
	Not true for me	A little true for me	Mostly true for me	Very true for me
a. The doctors and nurses will know how to help				
b. My child will be in a lot of pain				
c. Our family will be closer because of this				

About the adults caring for the child... (✓one box for each question)	No	Yes
a. Has anyone had a lot of worry, fear, or anxiety at times?		
b. Have drugs or alcohol caused problems for anyone in the family?		

Fig. 4.4 Sample items from the Psychosocial Assessment Tool (PAT) (Reproduced with permission from the Center for Pediatric Traumatic Stress (CPTS) at Nemours Children's Health System © 2014–2015. All rights reserved. The PAT image above is comprised of sample items from each of the PAT subscales. The PAT image may not be reproduced in any form for any purpose without the express written permission of CPTS. To obtain permission to use or view the most recent version of the PAT, please contact CPTS at psychosocialassessmenttool@nemours.org)

being tested in a current multisite study (ACS RSG-13-015).

Recent papers support the use of a Canadian adaptation of the PAT (Barrera et al. 2014), associations between socioeconomic variables and overall risk level over a 1-year period (Karlson et al. 2013), and feasibility in survivorship care (Gilleland et al. 2013). PAT can be administered in



Please answer the following questions.

About Your Child, Yourself and Your family

Person completing form

Mother Father Other

If Other, please specify:

Indicates that a response is required

EPIC Template
Cincinnati Children's Hospital Medical Center

Psychosocial Assessment Tool (Wednesday)

Please answer the following questions and click the **Continue** button.

* Indicates a required field.

* **What is Wednesday's current daycare/schooling?**

Hold down the Control (Ctrl) key to select multiple items from the list

Select all that apply.

- In Daycare
- Head Start
- Preschool/Pre-K
- K-12
- Home schooled
- Homebound
- Gifted
- Special education
- Dropped out of school
- Finished High school

School History:

* **Has Wednesday ever repeated a grade?**

Yes No

* **Has Wednesday ever been suspended or expelled?**

Yes No

* **Has Wednesday ever been teased or bullied at school?**

Yes No Don't know

Patient Portal/EPIC
www.MyNemours.org

Fig. 4.5 Examples of integration into electronic health records (EPIC) at two hospitals (Reproduced with permission from Cincinnati Children's Hospital Medical Center and Nemours Children's Health System)

paper and pencil, via REDCap on a tablet computer, or using a web-based version. Interfaces with electronic health records (EHRs), specifically (EPIC; www.epic.com) at Nemours Children's Health System and Cincinnati Children's Hospital Medical Center, and in the patient/family portal at Nemours (Fig. 4.5), are available as well.

Across sites and patient groups, the distribution of patients across risk levels for the PPPHM, based on PAT scores, is reassuring in terms of the overall competence of families and also quite consistent across settings and patient populations (Kazak et al. 2015). In general, one-half to two-thirds of samples score in the Universal tier on the PAT, one-quarter to one-third in the Targeted range, and up to 15 % fall in the Clinical tier. This is generally less than anticipated by healthcare providers who fear that screening will identify a large number of previously unidentified families for whom services would have to be provided.

Implementing Psychosocial Risk Screening

Although psychosocial screening is not utilized in a consistent or systematic manner in pediatric cancer treatment programs, there are options for screening that could be implemented. For example, either the DT or the PAT could be used as a brief screener. Or other validated questionnaires could be implemented to assess more specific areas of function. Parent report measures could be augmented by inclusion of a child-report screener. For example, targeted selection of the child-report screeners could minimize the response burden on children undergoing treatment. Given the recognized importance of screening and the availability of approaches and of validated instruments, the barriers to implementation are important to address.

Integrated care rests on successful partnerships with healthcare providers and systems and care delivery models that facilitate treatment outcomes and are acceptable to patients and families. With regard to partnerships, screening is highly congruent with healthcare practice because it is quick and can be incorporated into the flow of clinical care. The brief assessment of a patient's or family's status guides treatment plans and clinical pathways. Our experience has been that physicians and nurses readily appreciate the rationale for screening and will collaborate with psychosocial staff on implementation of brief screening tools. Screening is particularly appealing when results can be readily communicated to multidisciplinary healthcare teams, patients, and families and ideally transmitted into

Table 4.1 Barriers to screening and associated strategies to overcome them

Barriers	Strategies to overcome barriers
Stigma associated with psychosocial care	Assure acceptability of screening items to families
	Make screening standard across all patients
	Provide education on comprehensive patient care
	Document patient/family satisfaction with screening
	Track items that are skipped or other evidence of concern
Need for psychosocial care not recognized	Emphasize how information gained from screening aids effective management of the child's condition
	Show the family how information collected will directly inform the child's care
	Discuss with healthcare team how information can improve care and outcomes
	Address discipline-specific concerns and facilitate coordinated support for screening
Time	Determine actual time necessary for screening
	Integrate screening into routine clinical processes
	Schedule appointments to account for time needed to complete screening
Concern about responding to needs identified	Create algorithms that match specific high-risk items with existing system resources
	Use aggregate screening data to argue for increase in psychosocial services
Impact on processes and work flow	Determine format (e.g., EHR, web) and who administers
	Create alerts for high-risk responses that require immediate action
	Identify who reviews and coordinates response
	Develop approach to provide feedback to family
	Integrate results into EHR
Sustaining screening	After processes are defined, train relevant providers to implement
	Monitor clinical pathways of care from screening to services
	Generate data to show results and further refine approaches
	Consider use of health and behavior codes to bill for screening time

EHR records for healthcare providers to consider as they treat patients and families. An example of how screening results can be communicated is shown in Fig. 4.3. Using the example of the PAT and the PPPHM, the PAT is scored quickly by computer and the overall risk level and specific high-risk responses are conveyed to the team. In this way, clinical pathways at the site can be activated immediately to match areas of risk with evidence-based treatments.

There are barriers to implementing systematic screening (Table 4.1). For example, treatment options can be limited in many, if not most, settings. That is, in many settings qualified clinicians are not perceived as available to provide care and treatment. This is a realistic concern ("should we screen if we do not have good treatment options?"). However, regardless of the size and resources of the treatment setting, problems do exist and algorithms can be created to address specific high-risk items or levels of need so that the healthcare system can predictably manage any increased burden due to issues uncovered by screening. In addition, our experiences with screening have been that fewer problems are actually found than are anticipated. And early identification of problems can facilitate earlier, less intensive, potentially more cost-effective interventions than when problems escalate and are treated later. Importantly as well, screening is a type of patient (family)-reported outcome (PRO) and also consistent with family-centered care in incorporating family input early in the treatment process. In our studies, screening tools have been acceptable to caregivers and therefore may contribute to overall positive patient experiences in healthcare settings (Table 4.2).

Table 4.2 Sample of how screening results can be communicated to treatment teams

PAT™
PSYCHOSOCIAL ASSESSMENT TOOL

The family of________completed the PAT on________The items the family endorsed on the PAT are consistent with the following level of psychosocial risk and resource availability.

Overall Psychosocial Risk Level:

☐ **Low Risk:** The family reports many supportive resources and relatively low psychosocial risk (in number or severity). Any at-risk items are listed below. Recommendation: Universal interventions are recommended, including education about psychosocial impact of diagnosis / treatment, focusing on positive coping strategies and support-seeking among family members when needed.

☐ **Moderate Risk:** The family reports some supportive resources but also some psychosocial risk factors, which may impact illness adjustment or treatment adherence. Specific at-risk items are listed below. Recommendation: Further evaluation or close monitoring may be necessary. Targeted interventions are recommended, focusing on specific family problems, parent / child stress reactions, or parent beliefs that can negatively impact adjustment or adherence.

☐ **High Risk:** The family reports few supportive resources and multiple areas of difficulty that may impede illness adjustment or treatment adherence. Specific areas of difficulty are listed below. Recommendation: Clinical interventions, including mental health evaluation and more intensive family-based psychosocial services may be necessary. A team-based approach may be needed to ensure treatment adherence.

Specific areas of risk endorsed by the family: (positively scored items listed)

Family Structure / Family Resources:
Social / Family Support:
Child (Patient) Problems:
Sibling Problems:
Caregiver Problems: A caregiver in the home has experienced:
Caregiver Stress Reactions:
Caregiver beliefs that may impact treatment:
Other Notes:

Screen, Assess, Treat, Test, and Track (SATTT)

Screening is not intended to replace in-depth clinical assessment or treatment. It is the first step in a process of care delivery. A new model of *S*creen, *A*ssess, *T*reat, *T*est, and *T*rack (SATTT) has been proposed. *S*creening is a quick overview to identify families at risk (e.g., using the parent report of the DT or the PAT) and identifies "hot spots" that warrant more detailed evaluation. Therefore, screening must be followed by a more in-depth *A*ssessment/evaluation by appropriate psychosocial staff members, which then leads to implementation of the relevant evidence-based treatment. Using the subscales of the PAT as a guide, Table 4.3 provides examples of assessment topics, questions, and approaches that flow from screening. In each case, the clinician can start from an endorsed high-risk screening item to expand and understand the patient and family concerns while attending to strengths as well as challenges in each area. Standardized instruments may also be used to provide an in-depth detailed assessment. Clinical judgment and, as needed, peer and supervisory support are always

Table 4.3 Guidance for further assessment of positive screening responses

Area of risk	Topics, questions, and approaches
Family structure/family resources	Discuss, in detail, family members, those living in home, and elsewhere and role in caregiving and support
	Appraise any issues related to child custody and support
	Inquire about concrete financial concerns, employment status, transportation, etc.
Social and family support	Discuss who is available to support family throughout illness and treatment course
	Identify coping strategies used by the family
	Explore potential isolation of family or specific family members
Child (patient) problems	Ask about any child behavior items endorsed on screening
	Assess child's developmental status and any concerns
	Consider using a validated measure of child behavior, development, emotional, or social functioning to gather more detailed and normative information
	Anticipate how child and family will cope with treatment-related challenges
	Determine child's school status and identify concerns related to attendance and academic and social functioning
Sibling problems	Cover topics above
	Ask about siblings' knowledge of their brother/sister's illness/treatment and expected reactions
	Identify plans for caregiving for siblings
Caregiver problems	Obtain more information about all high-risk responses
	Consider using validated measures or structured clinical interviews to evaluate mental health concerns in detail
	Evaluate seriousness and need for referral for parents and other family members
Stress reactions	Evaluate symptoms of acute stress/traumatic stress using validated measures
	Normalize reactions and evaluate appropriateness of interventions to reduce distress and provide support
	Monitor stress reactions periodically
Family beliefs	Probe with family members about all high-risk beliefs and identify how beliefs may impact coping and interactions with the treatment team

critical in a comprehensive and accurate assessment process. It is also essential in the screening/assessment process to assure that responses that may be particularly clinically salient are addressed in a prompt and appropriate manner. While any number of items on the PAT, for example, might warrant timely clinical intervention (behavior problems, financial strains, family problems), reports of acute distress or suicidality, for example, require immediate implementation of associated clinical protocols for these concerns.

The outcome of the *T*reatment must be evaluated in a timely manner in order to determine whether to continue, discontinue, or change treatments (Test). And Tracking of psychosocial well-being over time is critical for all families, as risks can change with changes in medical treatment or with other stressors that the family may experience. Ideally, a screener should be appropriate for use at various time points in treatment and also sensitive to change over time. Both the DT and the PAT have been used at different points in care and seem applicable across the course of treatment. With a focus on current distress, the DT provides data that would be expected to reflect current events and identify elevated distress at different time points. The PAT has some subscales which are less likely to change (e.g., family structure) and others where clinically important information may reflect changes over time (e.g., child behavior, parent distress). How often screening should be repeated, which psychosocial risk factors are most associated with ongoing problems, and how screening data could be used to document clinically relevant changes are essential questions to investigate further.

There are important considerations in the refinement of screening instruments and processes for the future. Once screened, the process of SATTT should include collaboration with families. For example, families could be provided with the results of screening and participate collaboratively in subsequent care and treatment plans. The role that the child himself/herself could play in screening is another area worthy of additional consideration. Including the child's perspective is particularly important for child behavior, school issues, and adjustment to illness and treatment. Assuring that screening is responsive to the needs of families from infants through young adults is another important future consideration in screening.

Screening Within Systems of Care

While it is reasonable to think that delivering evidence-based treatments in a timely and focused manner will improve overall patient and family outcomes, this remains an area for future investigation. For example, does screening improve access to appropriate evidence-based care and patient/family satisfaction with the care received? Can we impact quality of life or other outcomes that are important to patients and families?

The PPPHM also raises interesting questions for the design of psychosocial care at a healthcare setting/system level. There is great variability in psychosocial care across medical settings, but concerns about equity in access to care, delivery of optimal interventions, and cost are common across all. Based on the PPPHM, care to families at the tip of the pyramid (Clinical) is the most expensive (e.g., psychiatric consultations, additional demands on nursing staff, physician time, patient care meetings focused on behavioral concerns, one-on-one monitoring of patients, involvement of hospital security or administration, more days in the hospital, and more clinic visits). Care at the Targeted tier is likely less intensive and less expensive and has the potential to be valuable over time, by reducing or preventing difficulties that impact healthcare (e.g., interventions related to pain, adherence to treatment, child behavior). Services at the Universal level are least expensive (e.g., social work, child life, family resources centers and programs, chaplaincy, etc.) but delivered as part of family-centered care and add value by impacting family satisfaction with care received.

The smallest number of patients (Clinical) receives the most intensive and expensive services and the largest number of patients (Universal) receives comparatively less. While clinical families must receive care to address their pressing problems, it is interesting to consider whether this scenario is optimal or whether resources could be distributed more evenly across tiers of the PPPHM and what is the perceived value in doing so. Implementation of screening would suggest that risk and services might be distributed differently, specifically with more allocation to families at the targeted tier.

Risk factors such as socioeconomic status, child difficulties, parental distress, and cultural values and beliefs may contribute to disparities by limiting engagement in care or adherence to treatment (Sato et al. 2013). Many of the areas assessed by the PAT map directly or indirectly on to areas associated with health disparities (Bhatia 2011), such as income, health insurance, knowledge, sociocultural factors, health behaviors, adherence to treatment, and health access. More effective identification of family risks can foster earlier interventions to address factors that may contribute to health disparities.

Although Electronic Health Record (EHR) systems were not designed to support psychosocial care, psychosocial risk screening can be introduced when healthcare team members endorse the concept and if screening modalities are easy to use, integrated with clinical care, and associated with improvements in care delivery. Providing screeners in user-friendly formats reduces some of the demand on the personnel responsible for conducting the screening. Tablet technology may be employed by healthcare systems to facilitate medical and psychosocial screening. And the transmission of data into the EHR has the potential to further simplify screening and facilitate integration of the results into patient records.

The Affordable Care Act mandates screening as part of preventative care without additional costs for patients. The targets for screening as described in the law, while not specifically described as psychosocial risk, include many relevant topics (e.g., developmental and behavioral concerns, obesity https://www.healthcare.gov/what-are-my-preventive-care-benefits/#part=3). We have the opportunity to assure that psychometrically strong, clinically important and family-friendly approaches are used that will not only identify risk, but guide psychosocial intervention in the pediatric oncology population.

Conclusions

Screening is the first step in assuring that the psychosocial risks and resiliencies of all families entering pediatric healthcare systems are detected early in the course of care. When linked to a conceptual model for delivering care, such as the PPPHM, clinical pathways can be developed and tested. Ideally screening is a clinical activity supported by all members of the healthcare team, including the patient and family, and can be completed in a manner that is consistent with family-centered care and appreciative of the variability in resources available across settings.

Clinical Pearls

- Screening is the first step in assuring that the psychosocial risks and resiliencies of all families entering pediatric healthcare systems are detected early in the course of care.
- Screen families early in treatment to identify and initiate interventions linked to specific patient and family risks.
- Facilitate the delivery of care to *all* families (not just those more obviously in need) by screening everyone.
- Put processes in place to complete screening systematically and to assure that results are integrated with relevant clinical information.

Appreciate that, consistent with the PPPHM, screening will necessitate immediate action for a small group of families but will promote more preventative interventions for others.

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