Screening for Psychosocial Risk at Pediatric Cancer Diagnosis: The Psychosocial Assessment Tool

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Background: To investigate the feasibility of integrating an evidence-based screening tool of psychosocial risk in pediatric cancer care at diagnosis.

Methods: Parents of children newly diagnosed with cancer received either the Psychosocial Assessment Tool (PAT; n = 52) or psychosocial care as usual (n = 47; PAU), based on their date of diagnosis and an alternating monthly schedule. Time to completion of the PAT, time to communication of PAT results to clinical care teams, distribution of PAT risk scores, and identification of psychosocial risks in the medical record were examined.

Results: Of families receiving the PAT, 88% completed it within 48 hours. PAT was scored and results communicated within 48 hours in 98% of cases. Most families (72%) were classified as Universal risk based on the underlying Pediatric Psychosocial Preventative Health Model, 24% were classified as Targeted risk, and 4% scored in the Clinical range. Significantly more psychosocial risks were recorded in the medical record during PAT intervals than during PAU.

Conclusions: An evidence-based psychosocial screener is feasible in pediatric oncology care and is associated with documentation of psychosocial risks in the medical record. Although the majority of families report low levels of psychosocial risk, about one-quarter report problems.

Key Words: psychosocial, risk, screening, parents, pediatric oncology

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Comprehensive cancer care should include systematic assessment of psychosocial risks and delivery of evidence-based care to address identified risks associated with cancer and its treatment. Recognition of these facts has resulted in recent calls for implementation of systematic psychosocial screening, as the first step in the provision of psychosocial care[1,2] and as an integral part of chemotherapy administration.[3] However, there are 2 key barriers to evidence-based screening. First is the availability of easy to administer, reliable, and valid screening tools. Second is the slow uptake for integrating screening in routine oncology care.[4]

Learning of the diagnosis of cancer in a child is distressing to the child and family members. All families have psychosocial needs at the time of diagnosis and throughout treatment. Although the majority of families respond over time in an adaptive manner, some children and families are at risk for escalating problems.[5] Although most pediatric cancer treatment centers provide some services, a recent survey from the Children's Oncology Group[6] shows that psychosocial staffing and services are inconsistent within and across centers. Social workers, child-life specialists, and psychologists may each conduct evaluations as part of their work with patients and families, but these assessments may not be integrated and screening is generally not conducted in a standardized manner.

Current approaches for screening, based largely on adult cancers, have limitations that restrict their clinical utility. Standardized measures of psychological distress[7] may identify seriously distressed individuals; however, the measures or battery may be relatively long, necessitate scoring and/or interpretation by a mental health professional, and are unlikely to identify those with mild-to-moderate distress who require supportive interventions. Alternatively, very brief screening instruments, such as the Distress Thermometer, have strong psychometric properties and the advantage of ease of administration.[8,9] Yet, they may be relatively imprecise in identifying high-risk individuals reliably and in providing sufficient specificity to identify subsequent interventions.[10]

The Psychosocial Assessment Tool (PAT) is a brief screener of psychosocial risk in pediatric oncology based on a social ecologic framework[11] and provides an assessment of contextual factors that may affect adaptation in childhood illness. The conceptual model underlying PAT is the Pediatric Psychosocial Preventative Health Model (PPPHM; Fig. 1),[12] a public health framework for conceptualizing psychosocial adjustment in pediatric illness, with associated implications for intervention. In earlier research, the majority of families (65% to 75%) fall, as predicted, within the Universal level of risk, with 20% to 25% within the Targeted range and $\leq 10\%$ in the Clinically distressed range.[13–17] Thus, PAT shows promise as a feasible, useful screener of psychosocial risk in pediatric cancer.

To address potential barriers for implementing psychosocial screening, research must establish that screening is feasible and that it represents "value added." Screening requires acceptance of its importance, identification of

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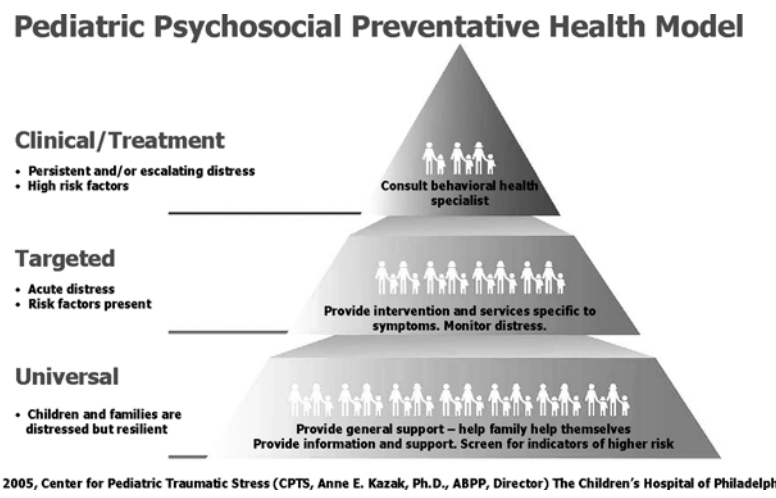

FIGURE 1. Pediatric Psychosocial Preventative Health Model (PPPHM).

patients/families to screen, administration of the screener (to all those eligible), scoring and interpretation, and communication of the results back to the healthcare team in a usable form. To our knowledge, this is the first study to examine a psychosocial screener at each stage of this process.

The primary aim of this study was to establish the feasibility of administering the PAT at diagnosis and communicating the results to the treatment team. We hypothesized that 80% of families of children newly diagnosed with cancer would complete the screener within 48 hours of their diagnostic meeting (Hypothesis 1) and that 90% of these would have the PAT collected, scored, and results communicated to treatment team within 48 hours (Hypothesis 2). We also expected that PAT scores, when categorized into the 3 levels of the PPPHM, would approximate other samples (Hypothesis 3). A second aim was to examine how screening adds to clinical care. We hypothesized that, compared with the families receiving psychosocial care as usual (PAU), screened families would have more information in the medical record about their psychosocial risks than families who were not screened (Hypothesis 4).

MATERIALS AND METHODS

Study Design

The study design contrasted 4-week intervals of delivering the PAT as part of clinical care immediately after a child's diagnosis with cancer with 4-week intervals of PAU, for a total of 12 months (6 mo for each condition). Eight weeks after diagnosis, medical record abstraction was used to evaluate the impact of screening on clinical care for all participants. The study was approved by the Committees for the Protection of Human Subjects at The Children's Hospital of Philadelphia. A waiver of consent was granted.

Participants

Eligibility for the study included: (a) a first diagnosis of cancer in a child (birth to the age of 20 y); (b) patient admitted to an inpatient unit; (c) communication of the cancer diagnosis to the family in a "family meeting" has been completed; and (d) chemotherapy and/or radiation treatment has begun or is imminent. The flow of patients in the study is summarized in Figure 2. During PAT intervals, a total of 53 families were identified as eligible for screening. During PAU intervals, 47 newly diagnosed patients were tracked as part of this study.

Procedures

From March 2009 to February 2010, newly diagnosed patients were identified by research assistants (D.B. and I.M.) who reviewed the daily inpatient list and communicated with oncology staff. Then, during PAT months, clinical (bedside) nursing staff administered and collected the PAT from newly diagnosed families, recording the time of distribution and collection. Nursing staff were integrally involved in the project. Nurses participated in all aspects of planning and implementing the project, and all oncology nursing staff received training for the study, including a script to assist in presenting the PAT to families. Families were told that the PAT "asks questions that help us get to know you and your family better" and that a summary of the information would be placed in their medical record. Collecting the completed PATs from the families was the responsibility of the nurses. Completed PATs were placed in a sealed envelope in a bin on the inpatient unit and retrieved by the research assistant.

PATs were scored using an Excel program[1] which exported total scores and clinically relevant information to a Communication of Results Form (CRF)[2] The completed PAT, scoring results, and CRF were reviewed by a licensed psychologist (A.E.K., L.P.B., M.A.A.). The CRF was then

[1]The PAT, its manual, an Excel scoring program (and an alternative hand scoring template), and access to a PAT-users group may be obtained by contacting the first author. The PAT has been translated into several languages and adapted for use in other English speaking countries. Consultation on the design of web-based administration is also available.

[2]The CRF lists 3 levels of psychosocial risk and resource availability based on the PPPHM. Each risk level indication also includes general clinical guidance: Some risk factors/many resources (low)—as with all families, monitoring is important; Moderate risk factors/moderate resources (medium)—further evaluation and/or close monitoring may be necessary; and Many risk factors/few resources (high)—further evaluation and determination of treatment options is necessary. In addition, specific items that were endorsed by parents in a manner indicative of high risk, along with any other clinically relevant information from the PAT, are outlined. The CRF indicates that the information is provided by parents, that scoring is based on research findings, and that staff should use clinical judgment in using the information in patient care.

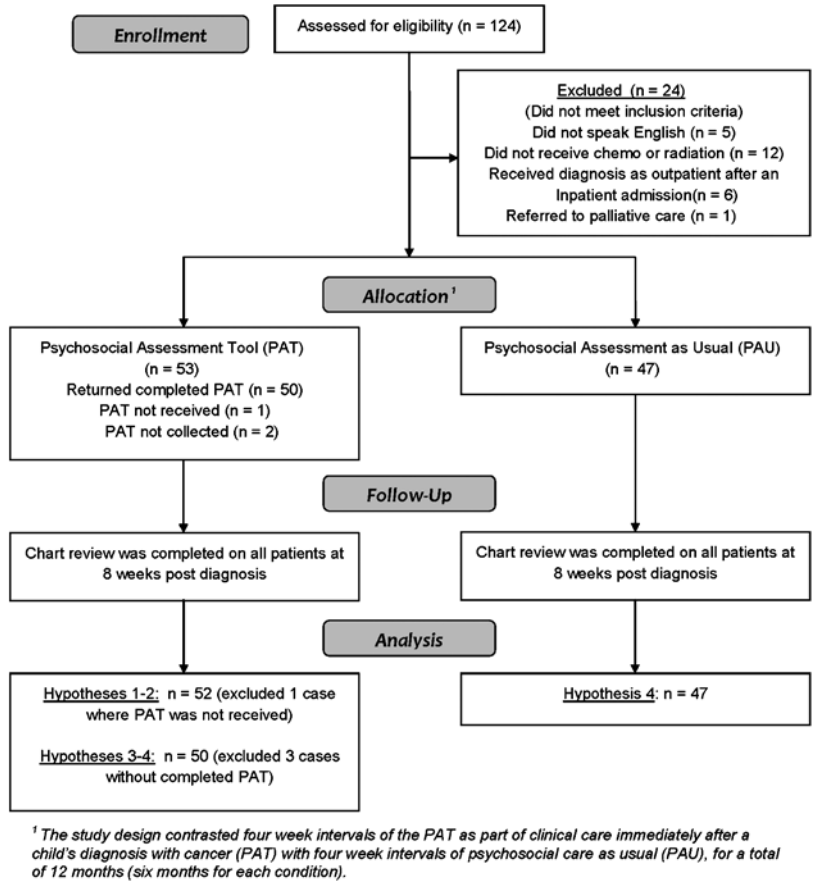

FIGURE 2. Consolidated Standards of Reporting Trials flow diagram.

emailed to the patient's team (attending, fellow, nurse, and social worker) and filed in the medical record. During PAU intervals, families received routine psychosocial care and were typically seen by a social worker and child-life specialist, with referral for other services as needed.

At 8 weeks after diagnosis, a research assistant extracted medical and psychosocial treatment information from inpatient and outpatient medical records by examining all notes written by physicians, nurses, and psychosocial staff members. This process was blinded in that the abstractor was not aware upfront of condition although blinding was not possible when a CRF was found in the record. Data for rating treatment intensity was extracted from the medical record by a pediatric oncologist (A.R.) and then rated independently by 2 additional (2 additional pediatric oncologists) pediatric oncologists.

Measures

The[3] PAT[15,16] is a brief parent-report screening tool (one 2-sided piece of paper) of psychosocial risk in families with a child with cancer. The PAT consists of 15-item sets and is completed in 5 to 10 minutes. There are 7 subscales—structure/resources, family problems, social support, stress reactions, child problems, sibling problems, and family beliefs. The response to each item is classified dichotomously risk or no risk. Subscales scores are created by calculating the proportion of items on the subscale endorsed as "high-risk." A total score (0 to 7) is created by summing the subscale scores and interpreted as Universal (< 1.00), Targeted (≥ 1 and < 2), and Clinical (> 2).

The psychometric properties of the PAT are strong.[15,16] Cronbach's α for the total score is 0.83. Two week test-retest reliability is strong for mothers ($r = 0.78$, $P < 0.001$) and fathers ($r = 0.87$, $P < 0.001$). Content validity was investigated by correlating scores with measures that assess the same theoretical constructs. These correlations were all in the expected direction. Total scores were correlated in the predicted direction with outcome variables indicative of psychosocial risk.

Risks Checklist

A checklist was developed to determine whether the risks assessed by the PAT were recorded in the medical record. Checklist items were recorded as "positive" if the medical chart contains information that corresponds to risk items. Positive responses are summed for each of the 7 areas corresponding to the subscales of the PAT yielding a total score.

The Intensity of Treatment Rating scale[18] was used to categorize the intensity of pediatric cancer treatment from least intensive (Level 1) through most intensive (Level 4) based on treatment modality and stage/risk level for the patient. Content validity for the Intensity of Treatment

[3]There have been 4 earlier studies published on the PAT by our group. The first two[13,14] were based on an initial version of the PAT. The second 2 articles[15,16] and this report are based on a revision of the PAT which replaced the earlier version. The revision was originally designated as PAT2.0 but is now referred to simply as PAT.

Rating scale-2 was shown in earlier samples by agreement between internal criterion raters and external criterion raters ($r = 0.95$). In this study, no patients were rated as receiving the least-intensive treatment and interrater agreement was 0.93.

Statistical Analysis

Demographic and disease characteristics were compared between PAT and PAU families using *t* tests or Mann-Whitney *U* tests for continuous variables and Pearson χ^2 test for categorical variables. To evaluate the feasibility of screening, the probability of having parents complete the PAT within 48 hours of their family diagnostic meeting was estimated by the proportion of families that completed the PAT within this window. The associated 95% confidence interval (CI) was also calculated. This CI was hypothesized to include a value of 80%. A similar approach was used to analyze the probability of having completed screeners collected, scored, reviewed, and communicated to the treatment team within 48 hours. Data from the Risks Checklist was tabulated, noting the presence/absence of each psychosocial risk. As these distributions were skewed, the comparisons between groups (PAT and PAU) were based on nonparametric Mann-Whitney *U* tests. Using Cliff's delta,[19] effect sizes were calculated to represent the percent of nonoverlap between the two distributions.

RESULTS

There were no significant differences in demographic or disease/treatment characteristics between study patients in the PAT and PAU months (Table 1).

The hypotheses associated with the primary aim were supported. The PAT was completed shortly after diagnosis (mean = 29 h, median = 30 h, SD = 18 h, range: 2 to 87 h, 95% CI: 23.8-33.8). Of the 52 families who received the PAT, 88% (n = 46) completed it within 48 hours exceeding our projected 80% (Hypothesis 1). In 98% of the returned cases, PAT was scored and the results communicated to the treatment team within 48 hours (mean = 23 h, median = 22 h, SD = 15 h, range: 2 to 48 h, 95% CI: 19.1-27.6), again achieving a rate higher than the projected 90% (Hypothesis 2).

Total PAT scores ranged from 0.00 (no risks) to 2.42 (mean = 0.76, median = 0.55, SD = 0.61). Consistent with Hypothesis 3, the distribution is skewed, with the majority of families (n = 36, 72%) scoring at the Universal level of the PPPHM (PAT score 0.00 to 0.99), 24% ($n = 12$) within the Targeted range (PAT score 1.00 to 1.99), and a subset in the Clinical range, with a score above 2.00 (n = 2, 4%).

Hypothesis 4 was also supported. The summed total score of risks (corresponding to PAT scales) found in the medical record was significantly greater for families in the PAT group when compared with the PAU group [7.2 risks on average (PAT) vs 2.7 (PAU)] (Table 2). For the PAT group, significantly more information was found in the medical record for structure/resource, family problems, child problems, and sibling problems. No differences were found with regard to report of social support, stress reactions, and family beliefs.

DISCUSSION

The results of this study are highly responsive to guidelines for screening in cancer care. The data show how

TABLE 1. Demographic and Disease/Treatment Characteristics by Group

	Psychosocial Assessment Tool (n = 52)	Psychosocial Assessment as Usual (n = 47)	*P*†
Patient age (y) [mean (SD)]	9.3 (6.5)	9.6 (6.4)	0.76
	Frequency (%)	Frequency (%)	*p*
Female sex	25 (48.1)	19 (40.4)	0.54
Ethnicity/race*			0.72
African-American	11 (21.2)	7 (14.9)	
White	35 (67.3)	34 (72.3)	
Others	6 (11.5)	6 (12.8)	
ITR			0.72
Moderately intense	16 (30.8)	15 (31.9)	
Very intense	25 (48.1)	25 (53.2)	
Most intense	11 (21.2)	7 (14.9)	
Cancer diagnosis			0.82
Leukemias/lymphomas	30 (57.7)	30 (63.8)	
Solid tumors	18 (34.6)	14 (29.8)	
Brain	4 (7.7)	3 (6.4)	
	Median (Range)	Median (Range)	*p*
No. inpatient oncology admissions/8 wk	2 (0-5)	2 (0-6)	0.79
No. days in hospital/8 wk	24 (1-71)	23 (3-63)	0.81
Outpatient oncology visits/8 wk	6 (0-13)	6 (0-16)	0.87

*Owing to small sample sizes, Hispanic, Asian, and others were combined for analysis.

†For continuous variables, *t* tests (age) and Mann-Whitney *U* tests (admissions, days in hospital, and outpatient visits) were conducted. Chi square analyses were used for all categorical variables (sex, ethnicity, ITR, and diagnosis).

ITR indicates intensity of treatment.

TABLE 2. Psychosocial Risks Identified in the Medical Record by Group

	Psychosocial Assessment Tool (n = 50)				Psychosocial Assessment as Usual (n = 47)					
Risk Domain	**Mdn**	**M**	**SD**	**R**	**Mdn**	**M**	**SD**	**R**	***P***	**ES**
Structure resources	1	1.7	1.3	0-5	0	0.4	0.7	0-3	0.00	1.21
Family problems	0	0.8	1.1	0-4	0	0.2	0.6	0-4	0.00	0.74
Social support	0	0.2	0.4	0-1	0	0.2	0.5	0-2	0.72	0.02
Stress reactions	1	0.8	0.6	0-2	1	0.8	0.4	0-1	0.62	0.06
Child problems	2	2.7	2.9	0-11	1	1.1	1.3	0-4	0.00	0.73
Sibling problems	0	0.9	1.8	0-8	0	0.1	0.3	0-1	0.00	0.66
Family beliefs	0	0.1	0.5	0-3	0	0.0	0.2	0-1	0.34	0.23
Total (sum) risks	6	7.2	5.3	0-23	2	2.7	2.2	0-9	0.00	1.10

ES indicates effect size; M, mean; Mdn, median; *P*, significance level; R, range.

a brief reliable and valid screener of psychosocial risks can be used at diagnosis and offer guidance for how a screener can be integrated into multidisciplinary clinical care. Our approach relied on nurses distributing the PAT to parents, within 48 hours of learning of their child's cancer diagnosis. This was highly feasible, occurring for 88% of the families during the intervals of PAT distribution. The screener was scored, reviewed, and results communicated to the treatment team within another 48 hours in 98% of cases.

The study provides information about steps that can facilitate screening and reduce earlier identified barriers. First, the success of our screening is attributable to significant "buy-in" from the clinical service in Oncology at The Children's Hospital of Philadelphia. The role of nursing leadership and staff in endorsing the importance of the information obtained on the PAT and highlighting its relevance to their practice as well as the broader care of the patient and family was essential and reflects other emerging studies in this area.[20] Second, screening was accomplished without additional burden on the nursing workflow by incorporating it into standard nursing procedures with families of newly diagnosed children. Admittedly, we had additional resources (a grant) to ensure that forms were collected, scored, and communicated to the treatment team. However, with the increasing use of computerization in screening and use of electronic medical records, the administration and scoring of the PAT (and other screeners) can be streamlined to reduce the resources necessary to support its use.

The data in this study support prior work with the PAT and are consistent with the PPPHM, highlighting the adaptive competence of families of children with cancer. That is, despite the distress and family disruption associated with the diagnosis of cancer in a child, the majority of families report relatively few stressors and the number of families with clinically significant levels of distress is small. The PAT and the PPPHM differ from screening approaches used in adult cancer screening where the focus of screening is often the psychological distress of an individual. The PAT and its underlying model are based on a developmentally grounded approach that incorporates inclusion of multiple factors in the child's social context that may impact short and long-term responses to cancer and its treatment. PAT provides a link between specific risks and the overall level of risk (PPPHM), thereby providing guidance for the delivery of evidence-based interventions matched to families' needs.[21]

Determining the value added of screening is essential to inform future screening efforts. As a first step in addressing this question, we ascertained that families that completed the PAT had more information in their medical records about psychosocial risks in general and about risks related to their family (structure and problems) and behavioral concerns about the patient and siblings. Thus, screening provides the treatment team with access to more information about the family's psychosocial status. It is particularly striking that behavioral concerns about the patient and information about family structure and resources, each of which are areas in which interventions can be identified and applied, were not found in the PAU charts. We recognize that clinically important issues may not be charted. Therefore, we cannot conclude that psychosocial issues were not being identified in the PAU families; however, given the importance of the medical record for patient care and compliance, its absence is noteworthy.

The results of screening have implications for the delivery of psychosocial care and for the inclusion of services by psychosocial teams, typically social workers, child-life specialists, and pediatric psychologists, with consultation from psychiatrists and other behavioral specialists as needed. Levels of risk on the PAT may be matched with evidence-based interventions.[22,23] For example, families at the Universal level of risk may benefit from support and educational approaches. Families at the Targeted and Clinical levels report difficulties that could be addressed with evidence-based treatments appropriate to the concerns raised (eg, pain, adherence to treatment, behavioral concerns, quality of life, and family problems). The results of this study support the importance of screening at diagnosis and the potentially preventative implications of intervening early in treatment to address reported risks. However, future research is necessary to investigate the validity of screening at diagnosis, as opposed to at a later point and in outpatient settings, or repeated psychosocial screening over time. Given that psychosocial risks may change over the course of treatment,[16,17] the risks reported within the first days after diagnosis may not fully reflect psychosocial problems and/or service needs across time.

Although this research included families of all patients who met eligibility criteria over 1 year at a large children's cancer center and provided sufficient opportunity to assess the feasibility of screening, the small sample is nonetheless a limitation of the study. In this study, PAT was completed in an inpatient setting although the services provided spanned inpatient and outpatient care, including that delivered at hospital satellites. We recognize that our hospital, a tertiary

care center where the patient population is skewed toward patients with more intensive treatments and with psychosocial resources, may limit generalizability. We also had a research assistant to assist with patient identification, tracking, and scoring. However, these are steps in screening which could be completed by other team members, or more fully integrated into clinical care systems in future evaluation of the dissemination of screening.

In terms of the cost/benefit ratio of screening, the relatively small number of patients at the Targeted and Clinical levels offers reassurance that screening will not necessarily increase the demand for clinical services. We also recognize that some problems may not be evident at diagnosis, highlighting the potential importance of repeating screening as treatment proceeds. However, early screening (whether at diagnosis or within the first few months) and prompt delivery of evidence-based psychosocial services has the potential to decrease the amount and cost of psychosocial care over time, questions that warrant further investigation. Screening does, of course, entail a clinical and ethical obligation to respond to concerns reported by patients and families and to provide more intensive treatments for those patients and families in greatest need. Screening at diagnosis provides the opportunity to do this at an earlier point rather than allowing unrecognized psychosocial concerns to potentially escalate over time and to provide services in a cost-effective manner by matching need with services.

In conclusion, psychosocial screening at diagnosis in pediatric cancer is feasible, when integrated into clinical care and endorsed by the multidisciplinary treatment team. Systematic screening and the communication of results to the treatment team is associated with documentation of risks in the medical record. These data have important implications for the provision of psychosocial care and facilitate overall patient care and safety by providing direction for early intervention to address psychosocial risks experienced by patients and their families.

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