Association of psychosocial risk screening in pediatric cancer with psychosocial services provided

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Abstract

Objective: How screening for psychosocial risk in pediatric oncology may relate to the number and type of psychosocial services provided is a critical step in linking screening with treatment. We predicted that screening at diagnosis would be associated with the delivery of more psychosocial services over 8 weeks and that these services would be consistent with Universal, Targeted, or Clinical psychosocial risk level based on the Pediatric Psychosocial Preventative Health Model (PPPHM).

Methods: Parents of children newly diagnosed with cancer received either the Psychosocial Assessment Tool (PAT; n = 49) or psychosocial care as usual (PAU; n = 47), based on their date of diagnosis and an alternating monthly schedule. Medical record review and surveys completed by social workers and child life specialists were used to determine psychosocial services provided to patients and their families over the first eight weeks of treatment.

Results: As predicted, families in the PAT condition received more services than those in PAU based on social worker and child life specialist report and medical record review. Within the PAT group, families at the Targeted and Clinical levels of risk received more intensive services than those at the Universal level.

Conclusions: This initial report shows how psychosocial risk screening may impact psychosocial care in pediatric cancer, supporting the importance of screening as well as matching services to risk level.

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Keywords: psychosocial; risk; screening; parents; cancer; pediatric oncology; Psychosocial Assessment Tool (PAT)

Introduction

Screening for distress in oncology care is recognized as an essential component of comprehensive treatment and designated as the 6th vital sign [1]. Screening for distress is now included in recommendations from the Institute of Medicine [2], the American Society of Clinical Oncology and the Oncology Nursing Society [3], and the International Psycho-Oncology Society [4]. Distress management is also a new standard of care in the National Comprehensive Cancer Network (NCCN) guidelines, which indicate that ‘distress should be recognized, documented, and treated promptly at all stages of disease and in all settings’ and that ‘all patients should be screened’ [5].

The mandate to screen has highlighted the need for psychometrically strong screeners. A meta-analysis of short screening tools used with adults identified 45 [6]. Of these, only six are validated and most primarily screened for depression. The importance of screening in pediatric cancer is also recognized [7]. One of the most widely used screeners, the Distress Thermometer (DT), has been used in a pediatric setting [8] where scores were correlated with measures of depression and quality of life. There are, however, considerations specific to children that warrant attention.

Screening for distress in the individual child with cancer is complicated for several reasons. First, the majority of children newly diagnosed with cancer are four years old or younger [9], and many are therefore not able to self-report reliably in relation to concepts related to psychosocial wellbeing [10]. Indeed, most evidence-based distress measures focus on specific child-relevant aspects of treatment such as pain or anxiety about procedures [11], rather than psychosocial risks of the family. In addition, many children (and their families) cope quite well over time with the demands of the disease and treatment [12]. Perhaps most importantly, the wellbeing of children is closely linked to
the psychosocial health of their families. The psychosocial risks associated with their families (many of which may not even be known to the child, such as parental emotional problems, financial difficulties, etc.) can impact the child’s adjustment to treatment across treatment and afterwards.

It is critically important to quickly and effectively identify the subset of children and families at greatest risk for ongoing and/or escalating difficulties. Screening is a necessary first step, with the goal of linking screening results to evidence-based care. Although the findings from the adult literature are inconsistent and difficult to interpret, given variability in the goals of screening and heterogeneity in designs and outcomes selected [13–15], relevant research is emerging. Patel et al. [8] found that efforts to link screening results to psychosocial care in pediatric cancer were complicated by the lack of specificity of Distress Thermometer scores and by discrepant perceptions of the child, parent, and staff. Although psychosocial care for children and their families is a widely held expectation in pediatric oncology, models of assessment and delivery of services vary widely across centers, as does the availability of psychosocial staff [16]. Clearly more research is needed linking screening to care in order to build models of assessment and service delivery.

To our knowledge, The Psychosocial Assessment Tool (PAT) is the only brief screener of psychosocial risk developed specifically for pediatric oncology. PAT is based on a social ecological framework [17] and provides an assessment of contextual factors associated with adaptation in childhood cancer. The underlying conceptual model is the Pediatric Psychosocial Preventative Health Model (PPPHM; Figure 1, [18]), a public health framework for conceptualizing psychosocial adjustment in pediatric illness, with associated implications for intervention. In prior research, the majority of families (65–75%) fall, as predicted, within the Universal level of risk, with 20–25% within the Targeted range and <10% in the Clinical range [19–24].

The primary aim of the current paper is to investigate how screening with the PAT may impact the number and type of psychosocial services provided to families. We expected that families screened using the PAT would receive more psychosocial services than families who were not asked to complete the PAT (Hypothesis 1) and that psychosocial services provided, for PAT-screened families, would correspond with their level of risk on the PPPHM (Hypothesis 2).

Patients and methods

Study design

The study design contrasted four-week intervals of delivering the PAT as part of clinical care immediately after a child’s diagnosis with cancer with four-week intervals of psychosocial assessment as usual (PAU), for a total of 12 months (six months for each condition). Eight weeks after diagnosis, medical record abstraction and internet-based surveys completed by social workers and child life specialists were used to collect data on psychosocial risks and services for 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 age 20 years); (b) patient admitted to an inpatient unit; (c) completed family meeting with communication of the cancer diagnosis to the family; and (d) chemotherapy and/or radiation treatment begun or about to begin. Patients who received surgical intervention only were not eligible for this study.

Figure 1. Pediatric Psychosocial Preventative Health Model
The flow of patients in the study is summarized in Figure 2. During PAT months, 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. Eight weeks after study entry, data on psychosocial services provided were collected for families in the PAT group for whom we had a completed returned PAT and a living child \((n = 49)\) and all families \((n = 47)\) in the PAU condition.

Procedures

From March 2009 to February 2010, newly diagnosed patients were identified by a Research Assistant who reviewed the daily inpatient list and communicated with oncology staff. During PAU months, families received routine psychosocial care, consisting of assessment and follow-up by social workers (supportive counseling and financial assistance), child life specialists (education, normative play), and hospital-based teachers. Referral for other services (e.g. creative arts, psychology, psychiatry) were made as required.

During PAT months, in addition to the routine psychosocial care provided to families (as in the PAU months), nursing staff distributed and collected the PAT from newly diagnosed 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. The PAT was administered within 48 hours after diagnosis in 88% of the case [24].

PATs were scored using an Excel program, which exported total scores and clinically relevant information to a Communication of Results Form (CRF). The CRF lists three levels of psychosocial risk and available resources 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.

Figure 2. CONSORT flow diagram

1 The study design contrasted four week intervals of the PAT as part of clinical care immediately after a child’s diagnosis with cancer (PAT) with four week intervals of psychosocial care as usual (PAU), for a total of 12 months (six months for each condition).
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 provided by parents shows that scoring is based on research findings, and that staff should use clinical judgment in using the information in patient care.

The completed PAT, scoring results, and CRF were reviewed by a licensed psychologist prior to sending them via email to the patient’s attending physician, fellow, nurse, and social worker and filing it in the medical record. The CRF was emailed from a dedicated address (PATPROJECT) with the subject line ‘PAT screening results for your patient [patient initials].’ The body of the email read: ‘Enclosed are the results from the PAT screening of ______. A hard copy is available in the mental health section of the patient’s chart. Please let me know if you have any concerns accessing the supplied information.’ The signature on the email was a research assistant (DB) who was known to the clinical team as representing the research project. Prior to the beginning of the study, interventions were conducted with oncology attendings, fellows, and nursing staff to make them aware of the study procedures, including the CRFs. The process of collecting, scoring, and emailing the CRF results, including the review of the PAT by a psychologist (median length of time for this review step was 3.5 h), was completed in less than 48 h for 98% of the patients [24].

During PAU intervals, families received routine psychosocial care, consisting of assessment and follow-up by a social worker (supportive counseling, financial assistance), a child life specialist (education, normative play) and a hospital school teacher. Referral for other services (e.g., creative arts therapy, psychology, psychiatry) were made as required.

Two approaches to measuring psychosocial services provided were used. First, two trained research assistants (RAs) were provided with a list of patient medical record numbers in random order, extracted medical and psychosocial treatment information from inpatient and outpatient medical records for the 8 week duration following diagnosis, using a procedure manual and data collection charts (Services Checklist [SC-MedRecord] see below). The RAs were experienced in psychosocial research in oncology, had previously abstracted data from our medical records, and were specifically trained to identify references to the 35 services listed on the form. Abstracted data were reviewed on a biweekly basis with the RAs to provide continued education regarding types of services and identify and to correct any potential problems in the abstraction process. Data were checked by a third research assistant to assure accuracy of coding. Second, social workers and child life specialists also provided data on the services they rendered to families using internet-based surveys (SC-Social Work, SC-Child Life, see below).

The number of inpatient oncology admissions, days in the hospital, and outpatient oncology visits from diagnosis to 8 weeks later were recorded. Data for rating treatment intensity were extracted from the medical record by a pediatric oncologist (A. R.) and rated independently by two pediatric oncologists (L. K., A. L.).

Measures

The PAT [21,22] is a brief parent-report screening tool of psychosocial risk in families with a child with cancer. The PAT consists of 15 item sets and is completed in 5–10 min. There are seven subscales: Structure/Resources, Family Problems, Social Support, Stress Reactions, Child Problems, Sibling Problems, and Family Beliefs. Subscales scores are created by calculating the proportion of items on the subscale endorsed as ‘high-risk’ (each individual item is scored dichotomously as risk or no risk). A total score (0–7) is created by summing the subscale scores and interpreted as Universal (<1.00), Targeted (≥1 and <2), and Clinical (≥2). Cronbach’s Alpha is 0.81 for the total score and 0.62–0.81 for the subscales. Test–retest reliability was strong for mothers (r = 0.78) and fathers (r = 0.87) [18] and risk classification is stable over 4 months [22]. In addition, receiver operator curve analyses support the sensitivity and specificity of the PAT to predict clinically significant levels of parental anxiety and child problems [22].

Services checklists (SC)

In order to measure psychosocial services provided to each family from diagnosis to 8 weeks later a checklist was developed. In order to do so, each of the 35 specific services utilized by the Psychosocial Services staff (social workers, child life specialists, psychologists) in the Division of Oncology were classified into a PPPHM level by experts (A. K., L. B.; for a general overview of services provided at our hospital please see http://www.chop.edu/service/ontology/psychosocial-services/). Eight members of the multidisciplinary PAT team rated each of the 35 services in terms of whether, in our oncology program, the service was Universal, Targeted, or Clinical. The raters were provided with brief definitions for each level of services corresponding to the PPPHM (Universal services are ‘for all patients and families to bolster resources, address expected distress and promote resilience,’ Targeted services were those ‘provided for patients and their families who are at risk for or demonstrating difficulties with adaptation;’ and, clinical services are those ‘for patients and families with severe distress, pain, and/or pre-existing
vulnerabilities.\textsuperscript{1}) For 28 of 35 psychosocial services (80%), the majority of the eight raters agreed with the expert classification. When there was a discrepancy between the raters and the experts, it was decided on closer examination that the items may have been ambiguous and were subsequently clarified and classified as intended by the experts (e.g. ‘school visit/reintegration’ was rewritten as ‘school visit’ to indicate a higher level of service than ‘reintegration’). Services were then collapsed to reduce the number of categories within each PPPHM level (Table 1).

There are three parallel versions of the SC. The SC-MedRecord was used for chart review. For each of the 35 services, notes documenting that service in the medical record, written by a social worker, nurse, child life specialist, psychologist, or other provider, were counted. The sum of notes about each service was computed and separate scores were calculated for the total of Universal, Targeted, and Clinical Services. Two separate internet surveys (SC-Social Work, SC-Child Life) were used for social workers and child life specialists to report retrospectively, 8 weeks after the patient’s diagnosis, on the frequency with which services were provided to each family. The surveys were developed based on forms used in prior research on the PAT to collect data on psychosocial services provided\textsuperscript{[20,22]}. There were slightly different versions for social workers and child life specialists that included only services that were relevant to each profession (e.g. on the child life form intervention for procedural distress was included, but clinical services were not included).

The Intensity of Treatment Rating scale [ITR-2; 25] 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. Statistical analysis

Demographic, disease and treatment characteristics were compared between PAT and PAU families using \( t \)-tests or Mann–Whitney tests for continuous variables and Pearson’s chi-square test for categorical variables. Because only two families were classified at the Clinical level, Clinical and Targeted families and services were combined for all analyses. SC-MedRecord, SC-Social Work, and SC-Child Life data were examined separately. The ordinal scale on the SC-Social Work and SC-Child Life Surveys was transposed to an interval metric to facilitate analysis of the quantity of services (None = 0; Once = 1; 2–4 = 3; 5–8 = 6; 9+ = 9). The majority of families had data on services provided by a social worker (76%) or a child life specialist (91%) and, in most cases (66%), from both disciplines. The number of missing surveys (a total of four) was comparable for PAT and PAU. There were no missing data for the medical record checklist. The relationship between the PAT score and the ITR was tested using ANOVA.

For the first hypothesis, differences in services provided (universal, targeted/clinical, total [sum of universal+targeted/clinical]) between groups (PAT, PAU) were tested separately for each type of data collection (SC-MedRecord, SC-Social Work, SC-Child Life) using \( t \)-tests with unequal variances. Because the sample size available does not provide sufficient power for these tests, we interpreted effect sizes and the direction of effects rather than statistical significance. By convention, Cohen’s \( d \) of 0.2–0.3 is interpreted as a small effect, around 0.5 a medium effect, and \( >0.8 \) a large effect [26].

The second hypothesis evaluates whether social work services delivered correspond to the family’s level of risk on the PAT (e.g. did Targeted/Clinical families receive primarily Targeted/Clinical care?). The quantity of Universal and Targeted/Clinical

<table>
<thead>
<tr>
<th>Universal</th>
<th>Targeted</th>
<th>Clinical</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychosocial Education</td>
<td>Play and Creative Arts Therapies</td>
<td>Intensive Interventions (e.g. crisis management, escalating problems)</td>
</tr>
<tr>
<td>Supportive Counseling</td>
<td>Interventions (e.g. adherence, adaptation, pain, intensive counseling, psychological testing, family therapy)</td>
<td>Legal (e.g. security, child abuse)</td>
</tr>
<tr>
<td>Normative Medical Play</td>
<td>School Consultation</td>
<td>Nursing Interventions for psycho-socially challenging circumstances</td>
</tr>
<tr>
<td>Resources (e.g. language services, housing, meals, transportation, financial, insurance, employment assistance)</td>
<td>Patient Care Conferences</td>
<td>Consultation-Liaison and Medication</td>
</tr>
<tr>
<td></td>
<td></td>
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</tbody>
</table>

\textsuperscript{1}The original 35 services, which are used on the Services Checklist are: psychosocial education; supportive counseling—general; supportive counseling—intensive; medical play—normative or group setting; medical play—for problem; psychological interventions for adherence to treatment; interventions for divorce/custody; psychological interventions for pain/procedural distress; psychological interventions related to adaptation to diagnosis and treatment; family interventions; psychological interventions for severe and/or escalating psychosocial symptoms; crisis management; consultation-liaison team; medication for behavioral problem; psychological testing; creative arts therapy (music and art); pastoral counseling, consultation with teachers; letters to school; school visit; language services; housing/meals/transportation; financial assistance; insurance assistance; employment issues; buddy system; admission prompted/lengthened for non-medical reason; I:1 staffing; patient care conference; complex care team; involvement of security; involvement of CHOP case management; involvement of legal; child abuse/neglect/child welfare involvement; guardianship/consent to treatment issues.

Table 1. Psychosocial services categorized by PPPHM level

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services was compared for families scoring at the Universal and Targeted/Clinical levels using t-tests and interpreting effect sizes, as noted above. The association between the quantity of services provided and number of days in the hospital was tested using Spearman’s correlations. To test whether families at the Targeted/Clinical level received more Targeted/Clinical services than families at the Universal level, linear regression models were used; an indicator variable for the risk level (Universal vs Targeted/Clinical) was included as a predictor, while the number of Universal services provided to the family and number of days in the hospital were used as control variables. Effect size in multiple linear regression models was measured by Cohen’s $f^2$ [26]. The analyses were performed with SPSS, Version 18.

Results

Demographic and disease characteristics

There were no significant differences in demographic or disease/treatment characteristics between patients and families in PAT and PAU (Table 2). Total PAT scores ranged from 0.00 (no risks) to 2.42 ($M_{\text{PAT}} = 0.77$, Median $= 0.58$, SD $= 0.61$). As expected, the distribution is skewed, with the majority of families ($n = 35$, 71%) scoring at the Universal level of the PPPHM, 25% ($n = 12$) in the Targeted range and a subset in the Clinical range ($n = 2$, 4%). PAT scores did not differ significantly by ITR level ($p = 0.73$).

Psychosocial services by screening condition (Hypothesis 1)

As predicted, families in the PAT condition received more services than those in the PAU condition for Universal ($M_{\text{PAT}} = 2.7$, $M_{\text{PAU}} = 1.8$), Targeted/Clinical ($M_{\text{PAT}} = 4.1$, $M_{\text{PAU}} = 2.5$), and Total ($M_{\text{PAT}} = 6.9$, $M_{\text{PAU}} = 4.3$) services, based on SC-MedRecord, with effect sizes (Cohen’s $d$) ranging from 0.24 to 0.37 (Table 3). The data collected directly from social workers (SC-Social Work) show a similar pattern but a higher level of services provided than was identified in the medical

### Table 2. Demographic and disease/treatment characteristics by group

| Psychosocial Assessment Tool (PAT) | Psychosocial Assessment as Usual (PAU) | n | M | SD | Mdn | n | M | SD | Mdn | $p^*$ |
|-----------------------------------|--------------------------------------|---|---|---|----|---|---|---|----|----|-----|
| Patient age in years $M$ (SD)     | 9.4 (6.5)                            | 49 |    |    |    | 9.6 (6.4) | 47 |    |    |    | 0.85 |
| Frequency (%)                     | 23 (46.9)                            |    | 19 (40.4) |    |    | 0.52 |
| Ethnicity/Race                    | 7 (14.9)                             |    | 12 (31.9) |    |    | 0.79 |
| African-American                  | 10 (20.4)                            |    | 7 (14.9) |    |    | 0.52 |
| Caucasian                         | 33 (67.3)                            |    | 34 (72.3) |    |    | 0.79 |
| Other                             | 6 (12.2)                             |    | 6 (12.8) |    |    | 0.79 |
| Intensity of Treatment (ITR)      |                                     |    |      |    |    | 0.61 |
| Moderately Intense               | 13 (26.5)                            |    | 15 (31.9) |    |    |      |
| Very Intense                     | 25 (51)                              |    | 25 (53.2) |    |    |      |
| Most Intense                     | 11 (22.4)                            |    | 7 (14.9) |    |    |      |
| Cancer Diagnosis                 |                                     |    |      |    |    | 0.79 |
| Leukemias/Lymphomas              | 28 (57.1)                            |    | 30 (63.8) |    |    |      |
| Solid Tumors                     | 17 (34.7)                            |    | 14 (29.8) |    |    |      |
| Brain Tumors                     | 4 (8.2)                              |    | 3 (6.4) |    |    | 0.79 |
| Number of inpatient oncology admissions/8 weeks | 2 (0–5) |    | 2 (0–6) |    |    | 0.92 |
| Number of days in hospital/8 weeks | 25 (1–71) |    | 23 (3–63) |    |    | 0.83 |
| Outpatient oncology visits/8 weeks | 6 (0–13) |    | 6 (0–16) |    |    | 0.79 |

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

*Due to small sample sizes, Hispanic, Asian, and others were combined for the analysis.
Do services provided correspond to the level of PPPHM risk? (Hypothesis 2)

Within the PAT condition, families at the Targeted/Clinical levels of risk received more Targeted/Clinical services than families at the Universal level of risk, based on medical record data and social work report (Table 4). Cohen’s $d$ effect sizes were small for medical record data (0.24) and large for social work report (0.89). For example, families in the Targeted/Clinical group received, on average, nearly 43 services in contrast to about 19 for families in the Universal group. By social work report, they also received more Universal services while medical record data showed they received less (Table 4). Days in the hospital and number of services provided were significantly correlated for SC-MedRecord (Spearman’s rho = 0.59) but not SC-Social Work (Spearman’s rho = 0.16) or SC-Child Life (Spearman’s rho = 0.24). Controlling for the amount of Universal services received and days in the hospital, families at the Targeted/Clinical levels of risk received on average 1.6 more (Cohen’s $f^2 = 0.12$) Targeted/Clinical services and 4.9 more (Cohen’s $f^2 = 0.39$) Targeted/Clinical services based on SC-MedRecord and SC-Social Work, respectively, than families at the Universal level of risk. Families at the Targeted/Clinical levels of risk received less services based on SC-Child Life but the effect size is very small (Cohen’s $f^2 = 0.05$).

**Discussion**

This report is an initial investigation of how psychosocial screening may be used in pediatric oncology settings. Using an evidence-based screener developed specifically for parents of pediatric cancer patients, the PAT, we addressed a critical issue in the screening field—how does screening impact the delivery of psychosocial care? The results are preliminary but encouraging and supportive of how screening may facilitate psychosocial care corresponding to need. We found that families who completed the PAT received more psychosocial services than families who were diagnosed in months in which we did not screen systematically. And, of families who completed the PAT, those at higher levels of psychosocial risk, those at the Targeted or Clinical level of the PPPHM, received more intensive services than those at the Universal level.

The issues associated with screening are complex and potentially variable across settings. Although the small sample is a limitation, the differences observed may be meaningful and important in terms of future research. There was variability in services provided in the PAT group, reflecting a small number of families who receive relatively more services, as predicted by the PPPHM. For these families, more services may have been used to address the greater number of risks reported. Interestingly, families at the Targeted/Clinical levels of risk not only received more clinical

### Table 4. Services provided to families at Universal and Targeted/Clinical levels of risk

<table>
<thead>
<tr>
<th>Services provided</th>
<th>Universal risk</th>
<th>Targeted/clinical risk</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$M$</td>
<td>$SD$</td>
</tr>
<tr>
<td>Medical Record Data</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Universal</td>
<td>$n=35$</td>
<td>5.8</td>
</tr>
<tr>
<td>Targeted/Clinical</td>
<td>3.7</td>
<td>6.7</td>
</tr>
<tr>
<td>Total Services</td>
<td>6.6</td>
<td>9.6</td>
</tr>
<tr>
<td>Social Work Survey</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Universal</td>
<td>$n=24$</td>
<td>9.7</td>
</tr>
<tr>
<td>Targeted/Clinical</td>
<td>6.0</td>
<td>12.0</td>
</tr>
<tr>
<td>Total</td>
<td>18.5</td>
<td>21.0</td>
</tr>
<tr>
<td>Child Life Survey</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Universal</td>
<td>$n=31$</td>
<td>4.2</td>
</tr>
<tr>
<td>Targeted</td>
<td>11.7</td>
<td>9.8</td>
</tr>
<tr>
<td>Total</td>
<td>17.2</td>
<td>13.0</td>
</tr>
</tbody>
</table>

*Cohen’s $d$ where Universal Risk was used as the reference group.*
services—they tended to receive more of all types of services. Their psychosocial risks may have spanned a variety of areas or, once identified, they may have been offered/encouraged to make use of Universal services as well as Targeted/Clinical services.

An underlying concern is whether routine screening will increase the cost of care and the demand on already overtaxed (or minimal) staff. However, with the majority of families scoring in the Universal level, the importance of more preventative services, which may also be relatively less labor intensive and costly than subsequent more intensive clinical care, is evident. Financing, or absorbing, the costs of providing Targeted/Clinical services is an ongoing concern in healthcare settings. Screening highlights the clinical and ethical mandate of addressing risks that are identified for patient care and safety. Screening can also help clarify the actual needs reported by families and may foster a more efficient use of limited resources.

Methodologically, collecting data on psychosocial services provided is complicated and there is no established reliable and valid approach for doing so. In this study we included both medical chart and staff report data. Consistent with other reports of infrequent and inconsistent psychosocial data in medical records [27], there was less documentation of services provided in the medical record than were reported by staff on surveys. This is concerning and warrants further attention if services are not being documented as intended. Even if recorded reliably, these methods may reflect charting and documentation rather than provide the type of detailed information necessary to evaluate services provided more thoroughly. Although the retrospective staff report used in this study carries its own risks of bias, the endorsements of services provided seemed consistent with those typically utilized in our setting. This is clearly an area for further work to establish reliable and valid metrics for describing the care provided.

The small sample in this single site study is a significant limitation. The study was completed only with patients who were admitted to the hospital, resulting in a smaller sample and not including patients who were diagnosed as outpatients. However, the psychosocial services provided spanned inpatient and outpatient care. We recognize that our hospital, a tertiary care center with psychosocial resources and where the patient population is skewed towards patients with more intensive treatments, may limit generalizability. Our assessments were also restricted to the period immediately after diagnosis although psychosocial adjustment will vary over time and may benefit from repeated screening. We did not collect any other information directly from families or ask them about the services they needed or received. Because we had a waiver of consent, we simply screened families and did not alter their usual access to psychosocial care. Furthermore, we chose to have a psychologist review the screening results to assure the accuracy of the scoring and to attend to any emergent issues that might have been indicated. And, the results were sent to the treatment team via an email from a research assistant. These are examples of the types of issues that warrant further consideration in screening research. That is, it is not clear whether having a professional review is necessary for clinical/ethical reasons and how best to assure that the treatment team attends to the results.

The design of this observational study necessitated the possibly unavoidable complication of psychosocial team members’ reporting on services provided to families when they are not blind to their group assignment. This study did not include an intervention and results of screening were only returned to the healthcare team and filed in the medical record. How the data were used clinically remained at the discretion of clinicians. We were not able to demonstrate in this study that clinicians necessarily read or used the PAT results although we have some anecdotal evidence that the information was reviewed in future research, assuring that screening results are utilized, providing feedback to parents about psychosocial risk, mapping risks to specific intervention approaches, and evaluating the extent to which interventions provided helped child and family adjustment will be important [28].

In conclusion, the use of the PAT, with a total score mapped on to three levels of risk and information about specific areas of risk relevant in pediatric cancer, meets (or exceeds) the spirit of recent recommendations regarding screening in cancer. The data presented in this paper, noting the association of risk screening with psychosocial services provided, are important in beginning to develop clinical pathways in pediatric cancer, linking psychosocial need to care.

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