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Screening for Family Psychosocial Risk in Pediatric Hematopoietic Stem Cell Transplantation with the Psychosocial Assessment Tool

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Family psychosocial risk screening is an important initial step in delivering evidence-based care in hematopoietic stem cell transplantation (HCT). Establishing an evidence-based screening approach that is acceptable, reliable, and valid is an essential step in psychosocial care delivery. This is a 3-institution multimethod study. In part 1, caregivers of children about to undergo HCT (n = 140) completed the Psychosocial Assessment Tool–Hematopoietic Cell Transplantation (PAT-HCT), a brief parent report screener adapted for HCT, and validating questionnaires. Families received feedback on their risks identified on the PAT-HCT. In part 2, 12 caregivers completed a semistructured interview about their perceptions of the PAT and the feedback process. The reliability and validity of the PAT-HCT total and subscale scores were tested using Kuder-Richardson-20 (KR-20) and Pearson correlations. Thematic content analysis was used to analyze the qualitative interview data. Internal consistency for the total score (KR-20 = .88) and the Child Problems, Sibling Problems, Family Problems, and Stress Reactions subscales were strong (KR-20 >.70). Family Structure, Social Support, and Family Beliefs subscales were adequate (KR-20 = .55 to .63). Moderate to strong correlations with the criteria measures provided validation for the total and subscale scores. Feedback was provided to 97.14% of the families who completed the PAT-HCT, and the mean rating of acceptability was >4.00 (on a 5-point scale). The qualitative data indicate that families appreciate the effort to provide screening and feedback. The PAT-HCT is a psychometrically sound screener for use in HCT. Feedback can be given to families. Both the screener and the feedback process are acceptable to caregivers.

INTRODUCTION

Hematopoietic stem cell transplantation (HCT) is a potentially curative treatment for a wide range of life-threatening pediatric conditions. The intensive treatment regimens often require lengthy hospitalizations and put the patient at risk of life-threatening complications throughout the course of treatment and beyond. Consequently, patients and their families endure the daily uncertainty of the patient's condition, changing employment status for one or more members of the family, disrupted family routines and roles, and disrupted sleep. These and many other stressors place a significant psychosocial burden for the patient and entire family system [1-6]. Patients and their caregivers alike report high rates of depression, anxiety, and traumatic stress symptoms [5,7]. Psychological symptoms decrease over time for many, but for a significant proportion (~30%), psychosocial distress persists [7]. Despite the robust literature demonstrating high rates of psychosocial symptomatology throughout the course of HCT,

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routine and standardized psychosocial screening continues to be limited in practice.

There is strong evidence supporting the value of incorporating standardized psychosocial screening into practice. In the absence of a psychosocial assessment, providers are likely to grossly underestimate patient and family emotional and social distress [8]. Adult HCT patients who receive psychosocial screening are more likely to have a discussion with their providers regarding psychological symptoms and indicate that they prefer psychosocial screening at future visits [9]. Finally, consultation with a psychologist earlier in the course of pediatric HCT is associated with significantly decreased hospitalization costs [10]. Similar findings resulted in the development of the 2015 Standards for Psychosocial Care for Children with Cancer and their Families [11]. The first standard calls for the systematic assessment of psychosocial needs of the patient and family [12], followed by a psychosocial care plan based on identified psychosocial needs. Other standards address the importance of providing psychosocial interventions for patients [13] and also attending to the psychosocial needs of parents [14].

The purpose of this study was to validate the Psychosocial Assessment Tool-Hematopoietic Cell Transplant PAT-HCT). The PAT-HCT is an adaptation of the Psychosocial Assessment Tool 3.0 (PAT 3.0) [15] for use in the HCT population. The PAT 3.0 is used in pediatric oncology in the United States and other countries [16-23] and has been adapted for other pediatric conditions with published reports, including sickle cell disease [24-26], organ transplantation [27,28], and pain[1] [29].

Consistent with the original measure, the PAT-HCT is a parent-report screener of family psychosocial risk that yields an overall score of psychosocial risk and seven subscale scores (Structure/Resources, Social Support, Child Problems, Sibling Problems, Family Problems, Stress Reactions, and Family Beliefs). The PAT-HCT total score categorizes families in a trilevel model of risk, the Pediatric Psychosocial Preventative Health Model (PPPHM) (Supplementary Material) [30]. The PPPHM is a pyramid; the base is Universal Risk, the largest group of families with the least risk, typically one-half to two-thirds of families. The middle tier, Targeted, represents generally one-quarter to one-third of families, with identifiable specific psychosocial risks. The top tier represents Clinical families, the smallest group at up to 15%. The PAT is used in 28.9% of cancer programs in the United States [31]. Determining the family's psychosocial risk is the first step in developing a psychosocial care plan [32].

To facilitate the assessment of familial psychosocial risk among families of children receiving HCT, this multimethod study had two aims. The first aim was to evaluate the psychometric properties of the PAT-HCT. We examined the reliability of the PAT-HCT subscales across its seven theoretically derived risk areas. We hypothesized that internal consistency would be strong for the total score (Kuder-Richardson-20 [KR-20] >.80) and acceptable for the subscale scores (KR-20 >.50). We also assessed the construct validity of the total and subscale scores against established measures. We hypothesized that the PAT-HCT subscale scores would be significantly and positively correlated with the established measure corresponding to the subscale content. The second aim was to establish the acceptability and feasibility of PAT-HCT administration as well as to provide feedback to families on screening results within 4 days of administration. We also sought to identify whether or not families found the feedback helpful at the time of transplantation.

METHODS

Design

The data were drawn from a multimethod, multisite study validating the PAT-HCT. Study sites were the Alfred I. du Pont Hospital for Children (Wilmington, Delaware), Children's of Alabama/University of Alabama (Birmingham, Alabama), and Cincinnati Children's Hospital Medical Center (Cincinnati, Ohio). In part 1 of the study, caregivers (age ≥19 years) completed the PAT-HCT and validating self-report questionnaires between signing consent for transplantation up to 24 hours before the stem cell infusion. Families were provided with verbal and written feedback on their psychosocial risks, as determined by the PAT-HCT, within 72 hours of completing the PAT-HCT. Data from the electronic health record were extracted to measure medical- and treatment-related variables. In part 2, 12 caregivers who completed part 1 participated in semistructured interviews regarding their perceptions of the PAT-HCT and the feedback process.

Participants

Part 1

Participants were the primary caregivers of 140 patients (119 females and 21 males). Families in which caregivers did not speak English were excluded. The patients ranged in age from under 1 year to 18 years (mean age, 5.94 ± 5.14 years). A slight majority of the patients were male (55.7%). The race and ethnicity of the caregiver participants and patients are presented in Table 1. Patients had the following conditions: leukemias/lymphomas, n = 40 (28.6%); brain tumors, n = 10 (7.1%); other solid tumors, n = 30 (21.4%); anemias and hematologic disorders, n = 30 (21.4%); immune disorders, n = 25 (17.9%); metabolic disorders, n = 4 (2.9%); and infantile malignant osteopetrosis, n = 1 (.7%). The total median duration of the patients' hospital stay for transplantation was 45 days (range, 15 to 406 days). Additional information on HCT treatment is provided in Table 2.

Part 2

The sample comprised 8 female and 4 male caregivers, all age >21 years, including 7 Caucasians (58.3%) and 5 African Americans (41.7%). All were non-Hispanic. Their children (ie, the HCT patients) included 3 females and 9 males (7 Caucasian [58.3%], 4 African American [33.3%], and 1 multiracial [8.3%]), with a mean age of 8.17 ± 5.52 years. Patient diagnoses included leukemias/lymphomas, n = 3 (25.0%); other solid tumors, n = 3 (25.0%); anemias/hematologic disorders, n = 3 (25.0%); immune disorders, n = 2 (16.7%); and metabolic disorders, n = 1 (8.3%). In terms of family psychosocial risk, all 3 levels of the PPPHM were represented (8 Universal, 2 Targeted, and 2 Clinical).

Procedure

This study was approved by the Institutional Review Board at each study site.

Part 1

Families from all 3 sites were enrolled over the course of 28 months (March 1, 2016, to June 30, 2018). Transplantation coordinators at each site worked with study staff to identify candidates for HCT. Once the HCT treatment consent conference was completed, the research coordinator at each site worked with the patient's medical team to approach the family in person at the hospital before the initiation of HCT to obtain informed consent for this study. Caregivers completed a 30- to 45-minute battery of self-report measures administered through a REDCap portal on a tablet computer. Each family received a $20 gift card after completion of the questionnaires.

Feedback on PAT scores and risks was provided by a member of the psychosocial staff who was trained to use the form as part of clinical care.[2] Participants also completed a brief questionnaire about the feedback process.

Part 2

Participants from Part 1 (4 from each site) were selected using purposive criterion-based sampling [33]. In purposive sampling, investigators select participants based on the main study phenomenon, to identify participants who will add depth and expand the ability of the data to inform the study questions [34]. We included primary caregivers from families who were diverse in terms of patient age, diagnosis, and race/ethnicity. All 12

[1] The PAT has been adapted for a variety of other pediatric conditions. More information about the other versions and related publications is available at www.psychosocialassessmenttool.org.

[2] The PAT has "red flag" items that require a prompt response (eg, suicidality). The study protocol for responding to these items necessitated prompt action consistent with the standards of the clinical service at each site.

Table 1
Demographic Data

Characteristic	Part 1 (N = 140)				Part 2 (N = 12)			
	Caregivers		Patients		Caregivers		Patients	
	n	%	n	%	n	%	n	%
Sex								
Female	119	85.0	62	44.3	8	66.7	3	25.0
Male	21	15.0	78	55.7	4	33.3	9	75.0
Race								
Caucasian	104	74.3	95	67.9	7	58.3	7	58.3
African American	20	14.3	21	15.0	5	41.7	4	33.3
Native American	2	1.4	1	.7	0	0	0	0
Asian	4	2.9	3	2.1	0	0	0	0
Multiracial	4	2.9	14	10.0	0	0	1	8.3
Hawaiian	1	.7	0	0	0	0	0	0
Other	5	3.6	6	4.3	0	0	0	0
Ethnicity								
Hispanic or Latino	6	4.3	9	6.4	0	0	0	0
Non-Hispanic	134	95.7	131	93.6	12	100.0	12	100.0
Education								
< Grade 12	13	9.3			0	0		
High school	30	21.4			3	25.0		
Some college	35	25.0			2	16.7		
BA or equivalent	42	30.0			5	41.7		
Some graduate school	7	5.0			1	8.3		
Finished graduate school	13	9.3			1	8.3		
Marital status								
Single	24	17.1			3	25.0		
Married/partnered	96	68.6			7	58.3		
Separated/divorced	14	10.0			2	16.7		
Widowed	2	1.4			0	0		
Other	4	2.9			0	0		

participants approached consented to participate in part 2. Using a script developed by the investigative team, these 12 caregivers participated in a qualitative interview about psychosocial care during HCT [35]. A series of questions from this longer interview is reported here. The questions relate to participants' recall of completing the PAT-HCT and receiving feedback, including the PPPHM pyramid with risk level indicated. Each participant received a $100 gift card after completion of the interview.

Measures

The Psychosocial Assessment Tool – Hematopoietic Cell Transplant (PAT-HCT)[3]

The PAT-HCT is a brief (10 minute) parent-report screener of family psychosocial risk adapted from the PAT 3.0 [15]. To adapt the PAT for HCT, we completed a review of the literature to ensure that all relevant topics in this population were considered and asked 7 families to complete the PAT and provide feedback. Based on this process, the following changes were made: (1) questions were focused on the previous 30 days, (2) questions differentiated between donor and nondonor siblings, and (3) 5 new family beliefs items were added. Consistent with PAT 3.0, the purpose and structure of the PAT-HCT is to assess psychosocial risks across the child's social environment via seven subscale scores: Structure/Resources, Social Support, Child Problems, Sibling Problems, Family Problems, Stress Reactions, and Family Beliefs. The total score, a sum of the subscales ranging from 0 to 7, maps onto the 3 tiers of the PPPHM [30].

Caregiver-Report Validation Measures

Barratt Simplified Measure of Socioeconomic Status (BSMSS). The BSMSS [36] is a self-report updated variation of the Hollingshead Four-Factor Index of Social Status [37]. The BSMSS was used to validate the Structure/Resources subscale of the PAT. The total score sums 2 items: education (7 levels) and occupation (9 levels). The total score ranges from 8 to 66. The BSMSS has been used in pediatric oncology [38] with scores used to define 5 levels of socioeconomic status (SES).

Medical Outcomes Study Social Support Survey (MOS-SSS). The MOS-SSS [39] is a 19-item scale. Items are rated on a 5-point Likert scale ranging from 1 (none of the time) to 5 (all of the time). Higher scores represent greater social support. The MOS-SSS has excellent internal consistency and concurrent validity and has been used in pediatric oncology [40]. Cronbach's α for the present sample was .97. The MOS-SSS was used to validate the Social Support subscale.

Strengths and Difficulties Questionnaire (SDQ). The SDQ [41,42] is a 25-item measure of child adjustment for children age 3 to 17 years. A total difficulties score (0 to 40) is derived. The SDQ has strong psychometrics and has been used in pediatric oncology [43]. Cronbach's α values for the present sample were .79 (child) and .77 (sibling). The SDQ was used to validate the Child and Sibling subscales.

McMaster Family Assessment Device-General Functioning Subscale (FAD-GF). The FAD-GF [44] is a 12-item self-report scale rated on a 4-point Likert scale from 1 (strongly agree) to 4 (strongly disagree). Lower scores indicate better family functioning. It has been used in families with a child with cancer [44]. Cronbach's α for the present sample was .91. The FAD-GF was used to validate the Family Problems subscale.

PTSD Checklist-Civilian-6 (PCL-C-6). The PCL-C-6 [45] is a 6-item self-report screening instrument for assessing post-traumatic stress symptoms and severity [46]. It uses a 5-point Likert scale ranging from 0 (not at all) to 5 (extremely) and has excellent concurrent validity and strong specificity and sensitivity. Cronbach's α for the present sample was .87. The PCL-C-6 was used to validate the Stress Reactions subscale.

Children's Hospital of Philadelphia-Self Efficacy Scale (CHOP-SES-12).. The CHOP-SES-12 is a brief version of the CHOP-SES [47] that assesses parent perceptions of self-efficacy specific to medical care for their child. Responses are rated on a 5-point Likert scale ranging from 1 (not at all confident) to 5

[3] The PAT is a copyrighted instrument and may not be used without written permission. Please contact the authors at psychosocialassessmenttool@nemours.org for information about using the PAT, as well as the scripts and feedback forms used as part of this study.

Table 2
Disease and Transplantation Characteristics

Characteristic	Part 1 (N = 140)		Part 2 (N = 12)	
	n	%	n	%
Type of transplantation				
Allogenic	96	67.1	8	66.7
Autologous	44	30.9	4	33.3
Number of transplantations per protocol				
1	117	83.6	10	83.3
>1	23	16.4	2	16.7
GVHD				
No	108	77.1	9	75.0
Yes	31	22.1	3	25.0
Unknown	1	0.7	0	0
GVHD grade				
I or II	21	67.7	2	66.7
III or IV	10	32.3	1	33.3
Donor type				
Related	28	20.0	1	8.3
Unrelated	68	48.6	8	66.7
Self	44	31.4	3	25.0
Sibling donor (if related)				
No	9	32.1	0	0
Yes	19	67.9	1	100.0
BMT regimen				
Myeloablative	115	82.1	10	83.3
Reduced intensity	25	17.9	2	16.7
Total body irradiation	18	12.9	0	0
Chemotherapy	127	91.4	11	91.7
Serotherapy	66	47.5	6	50.0
Number of readmissions within 3 months of transplantation				
None	81	57.9	7	58.3
1	38	27.1	2	16.7
>1	20	14.3	3	25.0
Unknown	1	.7	0	0
PICU admissions within 3 months of transplantation				
None	112	80.0	11	91.7
1	18	12.9	1	8.3
>1	9	6.4	0	0
Unknown	1	.7	0	0
Emergency department visits within 3 months of transplantation				
None	113	80.7	11	91.7
1	19	13.6	1	8.3
>1	7	5.0	0	0
Unknown	1	.7	0	0

BMT indicates bone marrow transplantation; PICU, pediatric intensive care unit.

(extremely confident). Internal consistency for the present sample was .86. The CHOP-SES was used to validate the Family Beliefs subscale.

Distress Thermometer (DT). The DT [48] is a very brief self-report visual analog measure of psychological distress with scores ranging from 0 (no distress) to 10 (extreme distress). The DT is used widely in distress screening and was used in the present study to validate the PAT total score [49-51].

Family Feedback Measures

Family Feedback Letter (FFL). The FFL is a 1-page form that explains the purpose of the PAT and illustrates the PPPHM levels graphically: Universal ("needing a little support"), Targeted ("needing some support"), and Clinical ("needing more support"). It includes 10 areas in which support or resources can be provided that match the information on the PAT: Family Resources, Financial, Transportation, Social Support, Child Concerns, Sibling Concerns, Donor Sibling Concerns, Caregiver/Family Concerns, Caregiver Distress, and Caregiver Beliefs. The FFL is provided to the family during a feedback session, can be used to develop a psychosocial treatment plan with the family.

Feedback Form. This 5-question survey elicited participant feedback about the FFL (eg, was it helpful, understandable, did it provide specific ways to help, was the process of reviewing the letter helpful). Each item was endorsed using a 5-point Likert-type scale, with responses ranging from strongly disagree to strongly agree. The form also provided space for other open-ended responses about the FFL.

Data Analysis

Part 1: Psychometric Properties of the PAT-HCT

The primary purpose of the analysis was to establish the reliability and validity of the HCT version of the PAT, using the theoretically and clinically derived subscales found to be psychometrically sound in the present version that has been validated in childhood cancer [15]. Descriptive statistics were used to summarize participant and family characteristics. Each binary item on the PAT was scored using prespecified risk/no risk criteria, either 1 (endorsed) or 0 (not endorsed). Risk area-specific subscale scores were calculated by summing binary items, weighted by the number of items in the subscale. The total score was the sum of the subscale score. The range for each subscale score is 0 to 1.00 and that for the total score is 1.00 to 7.00. The KR-20 coefficient was used to calculate internal consistency. For construct validity, the total and relevant subscales are correlated with criteria variables using Pearson product moment correlations. PAT-HCT cutoff scores were used to classify families into the three levels of the PPPHM. Scores on the outcome measures were compared across the three PPPHM levels using one-way analysis of variance (ANOVA). Statistical analyses were performed with SPSS version 24 (IBM, Armonk, NY).

Part 2: Acceptability of the PAT-HCT Measure and the Feedback Process

The transcribed interviews were uploaded into Altas.ti. Initial analytic activities were based on principles of thematic content analysis to inductively analyze the data and identify themes [52]. The sample size of 12 was sufficient to achieve redundancy and saturation [53]. The rigor of the iterative analytic process was guided by NIH and other national standards for qualitative research [54,55]. Coders were trained to rigorously and systematically gather, manage, analyze, and interpret data. This training and subsequent in-person supervision of the qualitative analyses were conducted by an expert qualitative researcher (J.D.). The two primary reviewers (G.V. and O.C.) co-coded the first three interviews (80% congruence) and then continued to co-code each interview. All coded data were reviewed by the complete multisite research team during an all-day in person meeting in April 2018.

RESULTS

Part 1

PAT-HCT Descriptive Statistics and Internal Consistency

One hundred seventy-two families were approached for participation, of which 144 (83.7%) agreed to participate. Participation rates ranged from 78.0% to 93.9% across sites. There were no differences between participants and nonparticipants with respect to patient age, gender, ethnicity, or diagnosis. With respect to race, the participants were more diverse (ie, more nonwhite participants) than nonparticipants ($P < .005$). Ultimately, 144 (83.7%) were consented and 4 withdrew before T1 due to time constraints (families decided they did not have time during the transplantation procedure). Descriptive

Table 3
Descriptive Statistics and Internal Consistency Coefficients for PAT-HCT Total and Subscale Scores

Scale/Total Score	Mean ± SD	Range	α
Family Structure/Resource	.19 ± .20	0-.83	.55
Social Support	.06 ± .14	0-.80	.63
Child Problems	.29 ± .23	0-1.00	.72
Sibling Problems	.11 ± .18	0-.73	.81
Family Problems	.19 ± .17	0-.69	.76
Stress Reactions	.15 ± .30	0-1.00	.79
Family Beliefs	.14 ± .14	0-.54	.63
Total score	1.14 ± .79	0-3.58	.88

Binary items were used to compute sum subscale score and weighted total score.

Table 4
Relationships of PAT-HCT Total and Subscale Scores with Validation Measures

	Total Score	Family Structure	Social Support	Child Problems	Sibling Problems	Family Problems	Stress Reactions	Family Beliefs
MOS-SSS	-.41‡	-.23†	-.25†	-.17*	(-.14)	-.37‡	-.23*	-.37†
SDQ-C	.54‡	(.11)	(.19)	.61†	.49‡	.28†	.24*	.37†
SDQ-S	.51‡	(.23)	(.09)	.35†	.57‡	(.13)	.28*	.35†
FAD-GF	.42‡	(.17)	(.16)	.21*	(.07)	.30†	.24†	.33‡
PCL-6	.62‡	.21*	(.08)	.18*	.36‡	.49‡	.61‡	.46‡
CHOP-SES	-.35‡	(-.13)	(-.08)	(-.17)	(-.11)	-.22†	-.30‡	-.41‡
BSMSS	-.17*	-.36‡	(-.15)	(.02)	(-.08)	(-.08)	(-.05)	(-.06)
DT	.56‡	.21*	(.14)	.27†	.29†	.42‡	.47‡	.45‡

* $P < .05$.
† $P < .01$.
‡ $P < .001$.

statistics for the total PAT score and the 7 subscale scores are presented in Table 3. Internal consistency for the total score was strong (KR-20 = .88). KR-20 scores for Child Problems, Sibling Problems, Social Support and Stress Reactions were >.70, and those for Family Structure/Resources, Social Support, and Family Beliefs were adequate but lower, ranging from .55 to .63.

Subscale Validation

Descriptive statistics for the validation measures and relationships with the PAT-HCT total score and subscale scores are presented in Table 4. Moderate to strong correlations were found among the 7 specific risk area subscales and the corresponding validation measures. The total score was correlated in the expected direction with measures of parental distress (DT and PCL-6), child (patient) and sibling behavior (SDQ), family functioning (FAD-GF), self-efficacy (CHOP-SES), and SES (BSMSS) (P <.001 for all). Each of the predicted associations between subscales and validation measures were supported, although some measures were strongly correlated with more than one risk area (eg, FAD-GF had a higher correlation with Family Beliefs than with Family Problems). Moreover, divergent validity of the subscales was supported, in that low correlations were observed between the subscale scores and unrelated measures.

Validation of PPPHM Levels

Using PAT total scores, 54.3% of the sample scored at the Universal tier of the PPPHM (total score <1.0), 30.0% were at the Targeted tier (total score 1.0 to 2.0), and 15.7% were in the Clinical tier (total score >2). Mean scores of the validation measures of each tier of the PPPHM were significantly different for all outcomes except SES (BSMSS; Table 5).

Part 2

Providing PAT-HCT Feedback

Feedback on the scored PAT-HCT was provided to 136 of the 140 families (97.1%). Nearly two-thirds (63.2%; n = 86) received feedback within 4 days (n = 43; 31.6% within 1 day), and 84.6% (n = 115) did so within 1 week. All families (100%) received feedback in <2 weeks (mean, 3.91 ± 3.51 days). The remaining 4 caregivers completed the PAT but did not receive feedback. Of these, 2 withdrew from the study. One family was withdrawn because the caregiver was not at the hospital after transplantation. One family did not have time to complete the full battery of measures before transplantation.

Participants described the feedback process as acceptable and provided useful feedback about receiving feedback. On the feedback form, the mean for all items was ≥4.00 on a scale of 1 to 5, indicating acceptability of the feedback process (Table 6). Most participants (10 of 12; 83.33%) who completed the interviews remembered completing the PAT, although fewer recalled seeing the PPPHM pyramid (7 of 12; 58.33%). When asked how they felt when they saw the pyramid, they indicated that they were pleased (6 of 7; 85.71%), surprised (1 of 7; 14.29%), or overwhelmed (2 of 7; 28.57%). The qualitative data show that although caregivers remembered the PAT-HCT, they admitted feeling overwhelmed and did not recall specifics. ("I don't remember what I put down for them, but I know those questions.") Participants were able to identify what it was like to complete the PAT, its usefulness, what issues were most important (eg, financial assistance, social support, emotional concerns) and what they felt was missing (Table 7).

DISCUSSION

This is the first study to assess the reliability and validity of the PAT-HCT, a novel caregiver-report measure that systematically assesses the needs and resources for families with a child

Table 5
Validation Measures by PPPHM Category

	Universal	Targeted	Clinical	F	*P* Value
PCL-6	9.34_a	13.22_b	18.00_c	43.76	.000
FAD-GF	1.43_a	1.90_{bc}	1.96_c	17.76	.000
SDQ (patient)	24.30_a	29.62_{bc}	31.50_c	19.63	.000
SDQ (sibling)	27.08_a	30.08_{bc}	33.44_c	11.38	.000
CHOP-SES	55.93_a	51.02_{bc}	50.14_c	10.81	.000
MOS-SSS	26.96_a	22.99_{bc}	21.96_c	15.29	.000
BSMSS	38.44	32.86	32.93	2.50	.086
DT	4.20_a	6.02_b	8.38_c	28.12	.000

Values are means. Means that share the same subscript are not significantly different from each other at $P < .05$.
Five new PAT-HCT items have been added.

Table 6
Caregiver Acceptability of Receiving Feedback on Psychosocial Risk Screening with the FFL

FFL item	Mean ± SD
The letter was helpful	4.02 ± .95
The letter was easy to understand	4.34 ± .84
The letter helped identify specific ways to help my family	4.04 ± .95
It was helpful to go over the letter with a member of the team	4.21 ± .92
Representative comments from open-ended responses	
"It's nice that someone wants to take the time to help families. . ..I am overjoyed to see how much everyone here cares about not only the patient but also the families."	
"It would be helpful to have more specific information about the resources available that our PAT-BMT indicated we may need."	
"I felt like a number when I was taking the survey and wasn't clear on social work's involvement. The feedback turned me from a number back to a person. I liked the survey and think it would be helpful for others."	
"Hey, here's what, as the parent, this is what I'm seeing. Let's listen to me and let's partner to come up with the plan together."	
"The letter was very helpful as it stands."	

Table 7
Caregiver Perspectives on the PAT-HCT

Theme	Example quotes
Usefulness of PAT	• I do remember the questions mattering to me, as far as, like, how to help people in our situation.
	• It was very direct, very to the point. It was user-friendly.
	• It asks questions that no one else had even asked me up until that point.
	• To me it means a lot that you guys care about the patients and the families enough to go through that process. . .it is such a whirlwind.
	• It really helped me think about how I felt and how I was processing everything.
	• Maybe made me realize that I do have family that would help me.
	• A lot of it didn't apply to us.
Most important types of items	• Specific financial resources, transportation, things like that
	• Social support, financial support, more financial support because of the length of time it may take.
	• Definitely emotional support. You know that social support is very important because you're kind of isolated from a lot of people during that time.
	• Definitely support toward the patient.
	• What you think about the diagnosis, what you think about the treatment.
	• My expectations about what's going to happen during treatment; those are things that you don't think about.
	• About the childcare, and, you know, the siblings.
Areas not addressed	• Method of helping after transplant. . .transitioning back out of the hospital.
	• Social areas, post-transplantation care.
	• Once your kid is out of treatment, it's like, oh well, there's nothing we can do.
	• I would say most resources were needed after.
	• Um, I think, well, the care needs to be delivered long after.
	• Different outcomes or issues, especially for older children.
	• Certain things I didn't find out until later, like how he would, he's going to learn differently.
	• Somethings about your relationship with (patient) and how cancer was impacting that.
	• I think it would be good to ask, maybe, about the family's past history.
	• What to hide from [patient] and what not to hide from [patient].
	• A few of these questions might be able to be more specific to siblings.
	• Preparation for transplant.

undergoing HCT. Analyses demonstrated that the psychometrics of the PAT-HCT are strong and, as anticipated, similar to those of its parent measure, the PAT 3.0 [15]. The total PAT-HCT score and the subscale scores had strong internal consistency and associations with the validation measures. The distribution of scores across the PPPHM was mostly consistent with that seen in other samples. Although the majority of families were at the Universal level of risk, a greater proportion of families scored at the Targeted and Clinical levels (45.7%) than in other samples (37.5%) [15,19,56-58]. Given the demands of treatment and the previous illness experiences of many HCT patients, it is not surprising that the level of risk is somewhat elevated over that in the pediatric oncology population.

Caregivers found the PAT-HCT acceptable as a means to identify psychosocial risks across patient and caregiver social ecology. They reported that the PAT-HCT was user-friendly and useful, and that it helped them think about their experiences in ways that they might not have otherwise considered. They appreciated having the opportunity to provide information on their psychosocial well-being. The questions related to social support, emotional reactions, and financial concerns were viewed as most important by caregivers. It is notable, however, that some caregivers indicated that they did not recall many details about completing the PAT-HCT, and not all found the items entirely relevant. This is likely due to the acute stress and volumes of novel information typically experienced in the days around HCT, raising the question of when it would

be most helpful to screen with the PAT-HCT. Future research should evaluate whether the timing of screening (eg, after the transplant infusion rather than before) impacts the quality of data obtained and the usefulness of the information in terms of treatment planning, to delay screening. Repeated screening across the transplantation process also may be helpful in capturing the changing medical and psychosocial experiences. Indeed, in terms of areas not covered by the PAT-HCT, caregivers underscored the importance of questions addressing ongoing support over the entire course of treatment and beyond, as well as attention to the impact of late effects. We also recognize that the PAT-HCT is a parent-report measure and does not assess the experience of the patient. Psychosocial risk from the patient perspective is particularly important particularly in adolescents and young adults; therefore, future research should explore the development and validation of a patient-reported version for adolescents and young adults undergoing HCT.

In the context of HCT, providing direct feedback to caregivers on their PAT-HCT scores was an innovative and feasible process that families welcomed to develop a psychosocial care plan. Whereas screening is viewed by healthcare providers as important in identifying psychosocial treatment needs for families, the process of providing feedback and its acceptability to families has not been previously reported in HCT. We found that families were very in interested in feedback on their psychosocial risks; however, >40% of families did not remember seeing the simple graphic representation of their risk level, suggesting the need for further studies examining both the mode of presentation to the families and the value of the graphic representation of risk during the feedback discussion. A very small number of families did not receive feedback, due to the intensive treatments that were underway or to staff oversight. Overall, caregivers were very positive about the use of the feedback letter and indicated that they saw it as a step that acknowledged the broader impact of the HCT experience within a family-centered care framework that promotes collaboration care among patients, caregivers, and healthcare teams.

The PAT-HCT demonstrated excellent preliminary psychometrics that are largely consistent with the findings in other pediatric populations. Importantly, families found the measure and the feedback they received helpful. Of course, given the acute stress experienced by parents at the time of transplantation, they may feel overwhelmed when completing the PAT-HCT and receiving feedback. Simplifying the approach and attending to timing and delivery may be helpful. Although our findings are promising, this study is not without limitations. For instance, the sample was relatively homogeneous, with larger proportions of female caregivers and those identifying as Caucasian. In addition, the sample size prohibited the use of more sophisticated analyses to confirm the factor structure of the PAT-HCT and to assess the sensitivity and specificity of the scores. Importantly, the PAT-HCT should continue to be evaluated with larger and more diverse populations and in multiple languages, to more fully understand the potential utility of the measure.

The PAT-HCT can help bridge a significant gap in the psychosocial care of patients and their families by providing a systematic and efficient way to assess psychosocial risk. The broader implementation of reliable and relevant psychosocial screening is critical for advancing HCT models of care and that are consistent with the care standards [12] set forth for many diagnostic groups treated with HCT. Therefore, training multidisciplinary teams on how to administer the PAT-HCT, interpret the scores, and deliver interventions based on the identified needs are critical next steps. In addition, the efficacy and benefits of interventions provided to families based on the PAT-HCT should be evaluated. Use of the PAT-HCT could facilitate the development of efficient and targeted clinical pathways that are specific to multidisciplinary teams and their particular health care setting to deliver the right psychosocial care to the right family at the right time.

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REFERENCES

1. Bingen K, Kent MW, Rodday AM, Ratichek SJ, Kupst MJ, Parsons SK. Children's coping with hematopoietic stem cell transplant stressors: results from the Journey to Recovery Study. *Children's Health Care*. 2012;41(2):145–161.
2. Chang G, Ratichek S, Recklitis C, et al. Children's psychological distress during pediatric HSCT: parent and child perspectives. *Pediatr Blood Cancer*. 2012;58:289–296.
3. Norberg AL, Forinder U. Different aspects of psychological ill health in a national sample of Swedish parents after successful paediatric stem cell transplantation. *Pediatr Blood Cancer*. 2016;63:1065–1069.
4. Riva R, Forinder U, Arvidson J, et al. Patterns of psychological responses in parents of children that underwent stem cell transplantation. *Psychooncology*. 2014;23:1307–1313.
5. Rodday AM, Terrin N, Leslie LK, Graham RJ, Parsons SK. Understanding the relationship between child health-related quality of life and parent emotional functioning in pediatric hematopoietic stem cell transplant. *J Pediatr Psychol*. 2017;42:804–814.
6. Virtue SM, Manne SL, Mee L, et al. Psychological distress and psychiatric diagnoses among primary caregivers of children undergoing hematopoietic stem cell transplant: an examination of prevalence, correlates and racial/ethnic differences. *Gen Hosp Psychiatry*. 2014;36:620–626.
7. Sands SA, Mee L, Bartell A, et al. Group-based trajectory modeling of distress and well-being among caregivers of children undergoing hematopoietic stem cell transplant. *J Pediatr Psychol*. 2017;42:283–295.
8. Barata A, Martino R, Gich I, et al. Do patients and physicians agree when they assess quality of life? *Biol Blood Marrow Transplant*. 2017;23:1005–1010.
9. Hoodin F, Zhao L, Carey J, Levine JE, Kitko C. Impact of psychosocial screening on routine outpatient care of hematopoietic cell transplantation survivors. *Biol Blood Marrow Transplant*. 2013;19:1493–1497.
10. McGrady ME, Joffe NE, Pai AL. Earlier pediatric psychology consultation predicts lower stem cell transplantation hospital costs. *J Pediatr Psychol*. 2018;43:434–442.
11. Wiener L, Kazak AE, Noll RB, Patenaude AF, Kupst MJ. Standards for psychosocial care for children with cancer and their families: an introduction to the special issue. *Pediatr Blood Cancer*. 2015;62(suppl 5):S419–S424.
12. Kazak AE, Abrams AN, Banks J, et al. Psychosocial assessment as a standard of care in pediatric cancer. *Pediatr Blood Cancer*. 2015;62(suppl 5):S426–S459.
13. Steele AC, Mullins LL, Mullins AJ, Muriel AC. Psychosocial interventions and therapeutic support as a standard of care in pediatric oncology. *Pediatr Blood Cancer*. 2015;62(suppl 5):S585–S618.
14. Kearney JA, Salley CG, Muriel AC. Standards of psychosocial care for parents of children with cancer. *Pediatr Blood Cancer*. 2015;62(suppl 5):S632–S683.
15. Kazak AE, Hwang WT, Chen FF, et al. Screening for family psychosocial risk in pediatric cancer: validation of the Psychosocial Assessment Tool (PAT) Version 3. *J Pediatr Psychol*. 2018;43:737–748.

16. Barrera M, Hancock K, Rokeach A, et al. Does the use of the revised Psychosocial Assessment Tool (PATrev) result in improved quality of life and reduced psychosocial risk in Canadian families with a child newly diagnosed with cancer? *Psychooncology*. 2014;23:165–172.
17. Gilleland J, Reed-Knight B, Brand S, et al. Assessment of family psychosocial functioning in survivors of pediatric cancer using the PAT2.0. *Psychooncology*. 2013;22:2133–2139.
18. Karlson CW, Leist-Haynes S, Smith M, Faith MA, Elkin TD, Megason G. Examination of risk and resiliency in a pediatric sickle cell disease population using the Psychosocial Assessment Tool 2.0. *J Pediatr Psychol*. 2012;37:1031–1040.
19. McCarthy MC, Clarke NE, Vance A, Ashley DM, Heath JA, Anderson VA. Measuring psychosocial risk in families caring for a child with cancer: the Psychosocial Assessment Tool (PAT2.0). *Pediatr Blood Cancer*. 2009;53:78–83.
20. Sint Nicolaas SM, Schepers SA, Hoogerbrugge PM, et al. Screening for psychosocial risk in Dutch families of a child with cancer: reliability, validity, and usability of the psychosocial assessment tool. *J Pediatr Psychol*. 2016;41:810–819.
21. McCarthy MC, DeGraves S, Wakefield CE, Bowden MJ, Marks LV, Williams LK. The association of psychosocial screening and service provision in pediatric oncology: the Psychosocial Assessment Tool (PAT2.0) into clinical practice. *Support Care Cancer*. 2016;24:2945–2952.
22. McCarthy M, Hearps SJC, Muscara F, et al. Family psychosocial risk screening in infants and older children in the acute pediatric hospital setting using the Psychosocial Assessment Tool. *J Pediatr Psychol*. 2016;41:820–829.
23. Schepers SA, Sint Nicolaas SM, Maurice-Stam H, Haverman L, Verhaak CM, Grootenhuis MA. Parental distress 6 months after a pediatric cancer diagnosis in relation to family psychosocial risk at diagnosis. *Cancer*. 2018;124:381–390.
24. Crosby LE, Joffe NE, Reynolds N, Peugh JL, Manegold E, Pai AL. Psychometric properties of the Psychosocial Assessment Tool-General in adolescents and young adults with sickle cell disease. *J Pediatr Psychol*. 2016;41:397–405.
25. Karlson CW, Faith M, Pierce J, Elkin TD, Megason G. Risk for psychosocial problems in pediatric cancer: impact of socioeconomics. *Children's Health Care*. 2013;42:231–247.
26. Reader SK, Ruppe NM, Deatrick JA, et al. Caregiver perspectives on family psychosocial risks and resiliencies in pediatric sickle cell disease: informing the adaptation of the Psychosocial Assessment Tool. *Clin Pract Pediatr Psychol*. 2017;5:330–341.
27. Cousino MK, Schumacher KR, Rea KE, et al. Psychosocial functioning in pediatric heart transplant recipients and their families. *Pediatr Transplant*. 2018;22:e13110.
28. Pai AL, Tackett A, Ittenbach RF, Goebel J. Psychosocial Assessment Tool 2.0_General: validity of a psychosocial risk screener in a pediatric kidney transplant sample. *Pediatr Transplant*. 2012;16:92–98.
29. Woods K, Ostrowski-Delahanty S. Psychometric properties of the Psychosocial Assessment Tool-Chronic Pain version in families of children with headache. *J Child Neurol*. 2017;32:766–773.
30. Kazak A. Pediatric Psychosocial Preventative Health Model (PPPHM): research, practice and collaboration in pediatric family systems medicine. *Fam Syst Health*. 2006;24:381–395.
31. Scialla M, Canter KS, Chen FF. Delivery of care consistent with the psychosocial standards in pediatric cancer: current practices in the United States. *Pediatr Blood Cancer*. 2018;65:e26869.
32. Kazak AE, Barakat LP, Askins MA. Provider perspectives on the implementation of psychosocial risk screening in pediatric cancer. *J Pediatr Psychol*. 2017;42:700–710.
33. Patton MQ. *Qualitative Research and Evaluation Methods*. Thousand Oaks, CA: Sage; 2002.
34. Wu YP, Thompson D, Aroian KJ, McQuaid EL, Deatrick JA. Commentary: Writing and evaluating qualitative research reports. *J Pediatr Psychol*. 2016;41:493–505.
35. Kazak AE, Swain AM, Pai ALH, Canter K, Carlson O, Vega G, Deatrick J. Caregiver perspectives on psychosocial care in pediatric hematopoietic stem cell transplantation (HSCT). *Clin Pract Pediatr Psychol*. 2019. http://dx.doi.org/10.1037/cpp0000278. [Advance online publication].
36. Barratt W. *The Barratt Simplified Measure of Social Status (BSMSS)*. Terre Haute, IN: Indiana State University; 2006.
37. Hollingshead AB. *Four Factor Index of Social Status*. New Haven, CT: Yale University Press; 1975.
38. Tillery R, Long A, Phipps S. Child perceptions of parental care and overprotection in children with cancer and healthy children. *J Clin Psychol Med Settings*. 2014;21:165–172.
39. Sherbourne CD, Stewart AL. The MOS social support survey. *Soc Sci Med*. 1991;32:705–714.
40. Rosenberg AR, Wolfe J, Bradford MC. Resilience and psychosocial outcomes in parents of children with cancer. *Pediatr Blood Cancer*. 2014;61:552–557.
41. Goodman R. The Strengths and Difficulties Questionnaire: a research note. *J Child Psychol Psychiatry*. 1997;38:581–586.
42. Goodman R, Meltzer H, Bailey V. The Strengths and Difficulties Questionnaire: a pilot study on the validity of the self-report version. *Eur Child Adolesc Psychiatry*. 1998;7:125–130.
43. Roberts RM, Robins T, Gannoni AF, Tapp H. Survivors of childhood cancer in South Australia attending a late-effects clinic: a descriptive report of psychological, cognitive, and academic late-effects. *J Psychosoc Oncol*. 2014;32:152–166.
44. Epstein NB, Baldwin LM, Bishop DS. The McMaster Family Assessment Device. *J Marital Fam Ther*. 1983;9:171–180.
45. Lang AJ, Stein MB. An abbreviated PTSD checklist for use as a screening instrument in primary care. *Behav Res Ther*. 2005;43:585–594.
46. Weathers FW, Litz BT, Herman DS, Huska JA, Keane TM. The PTSD Checklist: reliability, validity, and diagnostic utility. *Presented at: Annual Meeting of the International Society for Traumatic Stress Studies*. San Antonio, TX.1993. October 24-27.
47. Best M, Streisand R, Catania L, Kazak AE. Parental distress during pediatric leukemia and posttraumatic stress symptoms (PTSS) after treatment ends. *J Pediatr Psychol*. 2001;26:299–307.
48. National Comprehensive Cancer Network. Distress management. Clinical practice guidelines. *J Natl Compr Canc Netw*. 2003;1:344–374.
49. Haverman L, van Oers HA, Limperg PF. Development and validation of the distress thermometer for parents of a chronically ill child. *J Pediatr*. 2013;163:1140.e2–1146.e2.
50. Patel SK, Mullins W, Turk A, Dekel N, Kinjo C, Sato JK. Distress screening, rater agreement, and services in pediatric oncology. *Psychooncology*. 2011;20:1324–1333.
51. Wiener L, Battles H, Zadeh S, Widemann BC, Pao M. Validity, specificity, feasibility and acceptability of a brief pediatric distress thermometer in outpatient clinics. *Psychooncology*. 2017;26:461–468.
52. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Heath Res*. 2005;15:1277–1288.
53. Sandelowski M. Sample size in qualitative research. *Res Nurs Health*. 1995;18:179–183.
54. Levitt HM, Bamberg M, Creswell JW, Frost DM, Josselson R, Suárez-Orozco C. Journal article reporting standards for qualitative primary, qualitative meta-analytic and mixed methods research in psychology: the APA Publications and Communications Board task force report. *Am Psychol*. 2018;73:26–46.
55. National Institutes of Health, Office of Behavioral and Social Sciences Research. Qualitative methods in health research: opportunities and considerations in application and review. Washington, DC; 2001.
56. Pai AL, Patiño Fernández AM, McSherry M, et al. The Psychosocial Assessment Tool (PAT2.0): Psychometric properties of a screener for psychosocial distress in families of children newly diagnosed with cancer. *J Pediatr Psychol*. 2008;33:50–62.
57. Schepers SA, Sint Nicolaas SM, Maurice-Stam H, et al. First experience with electronic feedback of the Psychosocial Assessment Tool in pediatric cancer care. *Support Care Cancer*. 2017;25:3113–3121.
58. Barrera M, Hancock K, Rokeach A, et al. External validity and reliability of the Psychosocial Assessment Tool (PAT) among Canadian parents of children newly diagnosed with cancer. *Pediatr Blood Cancer*. 2014;61:165–170.