Original Ariticle

Family Psychosocial Risk, Distress, and Service Utilization in Pediatric Cancer

Predictive Validity of the Psychosocial Assessment Tool*

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BACKGROUND: The way families negotiate diagnosis and early treatment for pediatric cancer sets the stage for their adaptation throughout treatment and survivorship. The Psychosocial Assessment Tool (PAT) is a brief parent-report screener capable of systematically identifying families at risk for problems of adaptation. The current study evaluated stability and predictive validity of PAT psychosocial risk classification with regard to distress, family functioning, and the use of psychosocial services over the first 4 months of treatment. **METHODS:** Caregivers of children with cancer completed the PAT and measures of distress and family functioning at diagnosis and again 4 months into treatment. At the second time point, social workers completed checklists of services provided and rated the intensity of their work with each family. Referrals to psychologists also were tracked. **RESULTS:** Psychosocial risk classification, based on the PAT, was stable across the first 4 months of cancer treatment; 57% to 69% of families remained at the same level of risk. PAT total scores did not differ across time, but subscale scores indicated increases in family and child (patient) problems and decreases in unhelpful beliefs. Families classified at higher levels of psychosocial risk at diagnosis had more distress, more family problems, and greater psychosocial service use 4 months into treatment. **CONCLUSIONS:** Understanding and identifying risks for psychosocial adjustment difficulties within families of children with cancer, considering changes across treatment and beyond, is very complex. Despite evidence of the predictive validity of PAT, additional research is necessary to find ways to effectively use this screener in practice to guide intervention. **Cancer 2009;115(18 suppl):4339–49. © 2009 American Cancer Society.**

KEY WORDS: psychosocial risk, systematic assessment, empirically based, pediatric cancer, predictive validity, resource utilization.

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Childhood cancers will be diagnosed in an estimated 14,000 families this year.[1] Approximately 75% of these families will have a child who survives; however, at the time of diagnosis, fear that the child may die, knowledge that the child will experience invasive and painful procedures, and uncertainty related to the course of treatment take a severe emotional toll. Furthermore, the demands of cancer treatment (eg, repeated inpatient and outpatient appointments, home management of the child with cancer, and negotiation of the complex medical system) require restructuring of roles and responsibilities at home, at work, and within the community. The ways in which a family negotiates these challenges sets the stage for their adaptation across the entire course of treatment, including survivorship.[2,3] Given the stressful nature of this experience, psychosocial services are recognized as an important component of comprehensive cancer care for families of children with cancer.[4,5]

Unfortunately, there are barriers to providing effective and comprehensive psychosocial care. Common models of psychological dysfunction do not readily apply to families of children with cancer, who often endorse subclinical levels of dysfunction.[6,7] Empirically validated assessment instruments and interventions developed for use with families of children with cancer are rare.[8] Our team has created a conceptual model, devised empirically supported methods of assessment and intervention, and maximized cost effectiveness by carefully targeting the provision of psychosocial services to match the level of need of each family at diagnosis, during treatment, and through survivorship.[8–11]

We adopted a public health model and applied its principles in the Pediatric Psychosocial Preventative Health Model (PPPHM)[12] (Fig. 1) to meet these goals. At the core of the public health approach[13] is concern for the health of an entire population and the provision of education and basic support to all to bolster resilience, reduce risk, and prevent the onset of disease. Systematic screening is implemented to identify those with health concerns or those with increased risk for health problems; then, these individuals are channeled to the appropriate levels of care. The PPPHM recognizes that families of children with cancer represent a cross-section of the general population. Most of these families are resilient and adapt to the diagnosis and treatment of cancer with education and support (universal psychosocial risk level). However, there are other families with specific constellations of individual, family, social, and economic factors that put them at greater risk for developing difficulties in the context of managing childhood cancer (targeted and clinical psychosocial risk levels). These families, at the targeted and clinical psychosocial risk levels, require more intensive psychosocial care that is matched to their specific level of need.

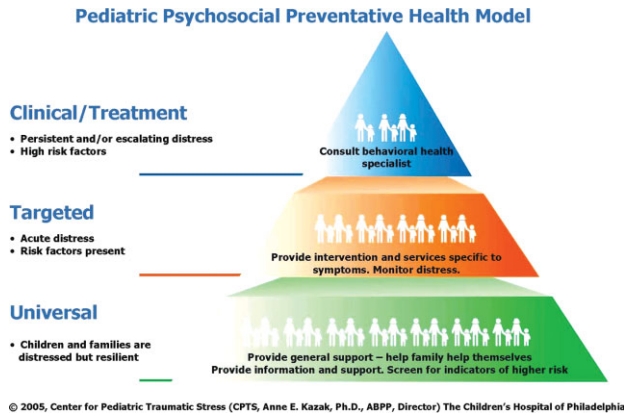

FIGURE 1. This is an illustration of the Pediatric Psychosocial Preventative Health Model.

A vital component in the effective implementation of the PPPHM for families of children who are diagnosed with cancer is a reliable and valid tool to systematically assess the level of need for psychosocial services shortly after diagnosis. We developed and subsequently revised the Psychosocial Assessment Tool (PAT),[11,14,15] a brief, parent-report screener that can be completed at diagnosis and beyond. The PAT assesses 7 specific areas of psychosocial risk and classifies each family into 1 of the 3 risk levels of the PPPHM: universal, targeted, or clinical. The ability of the PAT to identify families with different levels of vulnerability shortly after diagnosis has been established.

However, adapting to pediatric cancer is a dynamic process that continues over time. Distress declines over the first year after diagnosis,[7] but initial psychosocial status remains critical in predicting long-term well being.[2,3] Based on the PPPHM, families at specific levels of risk at diagnosis may respond differentially to the challenges of cancer diagnosis and treatment and require distinct types and intensity of psychosocial services. Therefore, to gain a better understanding of the psychosocial risk in families of children with cancer and to further evaluate and establish the predictive validity of the PAT and PPPHM

classification, we report on a prospective study that assessed families with the PAT and measures of distress and adjustment at diagnosis (T1) and approximately 4 months later (T2).

Our first objective was to examine changes in PPPHM classification of psychosocial risk level and variation in PAT total and subscale scores from T1 to T2. Our second objective was to evaluate the predictive validity of PPPHM classification of risk level, based on PAT scores at T1, by comparing families at each level of psychosocial risk on measures of distress, family functioning, and use of psychosocial service resources at T2. We expected that families with higher risk level classification at diagnosis would report greater distress, poorer family functioning, and more use of psychosocial service resources.

MATERIALS AND METHODS

Procedure

Families were enrolled in this study over the course of 15 months (from middle January 2005 to middle April 2006) following the procedures approved by the Committees for the Protection of Human Subjects at our institution. Inclusion criteria were 1) a confirmed diagnosis of a pediatric malignancy in a child aged <18 years without prior chronic or life-threatening illness and 2) fluency in English or Spanish. Caregivers (ie, both mothers and fathers, when available) were approached regarding participation shortly after the diagnostic family meeting, at which time the cancer diagnosis was first discussed and treatment options presented. One or 2 caregivers per family could participate. Subsequent to providing written informed consent, participants completed the PAT and a battery of self-report measures that assessed personal distress, parenting stress, family functioning, and child adjustment. For the T1 assessment, forms typically were completed within 2 weeks of diagnosis (mean ± standard deviation [SD], 7.2 ± 7.2 days; median, 4.5 days; range, 0-49 days). The T2 assessment, which involved a similar battery of measures, occurred approximately 4 months later (mean ± SD, 125 ± 20.2 days; median, 117 days; range, 94-189 days). To assess psychosocial services resource use, the social worker assigned to each participating family completed an inventory of the services they provided to the family since the time of diagnosis, and we tracked whether or not families received services from psychologists in our Division of Oncology. Finally, to account for the contribution of intensity of cancer treatment to family risk, we objectively assessed treatment intensity for each patient.

Measures

Psychosocial Assessment Tool 2.0

The PAT is a brief screening tool that was designed to measure psychosocial risk in families that have a child newly diagnosed with cancer. The PAT 2.0[11] is comprised of 7 subscales: Family Structure and Resources, Family Social Support, Family Problems, Parent Stress Reactions, Family Beliefs, Child Problems, and Sibling Problems. Based on the available literature and expert consensus, each item response is classified dichotomously as indicative of risk or no risk, and 7 subscale scores and a total score are calculated. Subscale scores are created by calculating the proportion of items on the scale endorsed as "high-risk." The total score, which ranges from 0 to 7, is created by summing the subscale scores. Universal, the lowest risk category, which indicates few stressors, is categorized by a total score <1. Targeted, a higher risk category, which indicates some stressors, is categorized by a total score ≥1 but <2. A total score ≥2 is categorized as clinical, the highest risk category, which indicates many stressors.

The PAT has strong internal consistency (alpha = .81), good test-retest reliability correlations over a 2-week period (*r*s, .78-.87), and inter-rater reliability evidenced by significant correlations of PAT total scores for mothers and fathers within the same families.[11] Content validity has been established through significant correlations between specific subscale scores and standardized measures designed to assess similar constructs (eg, child problems and the Behavioral Assessment Scale for Children-Parent Report, second edition [BASC-2] Behavioral Symptoms Index [BSI]).[11] Furthermore, criterion validity has been established; PAT 2.0 total scores are correlated significantly with measures of distress and poorer family functioning measured concomitantly and families that were categorized at the targeted and clinical levels displayed more distress and greater difficulties than families that were categorized at the universal level. Finally, receiver-operator characteristic curve analyses have

demonstrated preliminary evidence for the sensitivity and specificity of the categorization scheme (universal, targeted, and clinical) for the cross-sectional prediction of clinically significant levels of child and parent distress.[11]

Other measures

To validate the PAT at T1,[11] assess for biases in the sample because of dropout between T1 and T2, and evaluate the predictive validity of the PAT, parents completed the following battery of measures: Basic demographic information was collected as part of the PAT. Socioeconomic status was assessed using the Hollingshead Four-Factor Scale of Social Status,[16] a calculation based on parent report of education and occupation. Anxiety was assessed with the State-Trait Anxiety Inventory (STAI-Y),[17] a 40-item self-report questionnaire that assesses symptoms of anxiety currently (state) and generally (trait). The Acute Stress Disorder Scale (ASDS)[18] was used at T1, and the Post-Traumatic Stress Disorder Checklist-Specific Version[19,20] was used at T2 to assess traumatic stress symptoms. The Parenting Stress Index-Short Form (PSI-SF)[21] was completed by parents of children aged $\leq$12 years to assess difficulties in the parent-child relationship, and the Family Environment Scale (FES) Conflict and Cohesion Scales[22] and Family Life Scales (FLS) Family Coherence Subscale[23] were used to assess family functioning. Finally, the BASC-2[24] was used to assess the psychosocial competence of patients between ages 2.5 years and 18 years.

The social worker who was assigned to the family also completed the Social Work Summary Form (SWSF), a summary of all social work services provided to a child/family between T1 and T2 in the following areas: supportive counseling, medical care issues, resources, safety/legal issues, community/financial organizations, child welfare, and behavioral health/family referrals. The social worker indicated whether or not they provided each service and then rated the intensity of their work with the family relative to work with other families in each area on a 5-point Likert scale (1, much less; 3, typical; 5, much more). The SWSF total score was calculated by weighting each endorsed item by the intensity score for that domain and summing the weighted scores. The total score had an alpha of .92 in our sample. Two subscale scores also were calculated: total number of services and average intensity score.

A pediatric oncologist (A.T.R.) who was blinded to patient identity completed the Intensity of Treatment Rating scale (ITR-2)[25] for each patient based on disease and treatment data extracted by chart review. The ITR-2 provides a categorization of the intensity of pediatric cancer treatment from least intensive (Level 1) through most intensive (Level 4) based on treatment modality (radiation, chemotherapy, surgery) and stage/risk level for the patient. A second pediatric oncologist rated 45% of the sample (n = 63 patients), and inter-rater reliability on the current sample was .89.

Statistical Analysis

SPSS version 16.0 (SPSS Inc., Chicago, Ill) was used for all statistical analyses. Preliminary analyses were conducted to examine differences between participants who completed the second data point and those who were lost to follow-up. These groups were compared on sociodemographic variables (race/ethnicity, parental relationship status, socioeconomic status, patient age), cancer-related variables (diagnosis, intensity of treatment), the validation measures at T1 (STAI, ASDS, PSI-SF, FES, FLS, and BASC-BSI), and PAT scores and PPPHM classification at T1 using *t* tests and Pearson chi-square tests. A *P* value $\leq$.01 was used as the indicator of statistical significance to account for multiple comparisons.

To use all available PAT information provided by caregivers, we created a family PPPHM classification based on total PAT scores as follows: when data were available from 2 caregivers, the higher of the 2 risk categorizations was used; in single-parent families or in 2-parent families in which only 1 parent participated, that parent's score was used. A family PAT score also was created by using either the higher of the 2 scores or the only score available. Analyses were conducted on the family classification and family PAT score and also on mother and father data separately when possible. The lower participation rate for fathers precluded some of their analyses.

McNemar-Bowker tests were used to examine change in PPPHM classification across time. The percentages of families remaining at the same level, decreasing in risk, and increasing in risk were calculated and reported. Pearson chi-square analyses and *t* tests were used to examine whether demographic and cancer-related variables

were associated with changes in risk over time. To examine changes in the amount of risk across time, T1 and T2 PAT total and subscale scores were compared through Student *t* tests for paired data. Again, a *P* value $\leq$.01 was considered statistically significant.

To evaluate the predictive validity of PPPHM classification at T1, a series of Kruskal-Wallis nonparametric statistics were calculated with Mann Whitney *U* post hoc comparisons to determine whether the universal, targeted, and clinical groups differed at T2 on measures of distress, family functioning, and child behavioral problems. Nonparametric statistics were used because of skewed distributions on the T2 outcome measures. Finally, Kruskal-Wallis analyses with Mann-Whitney *U* follow-up tests and Pearson chi-square analysis were used to explore differences in psychosocial resource use as a function of PPPHM classification at diagnosis. These predictive validity analyses could not be conducted with fathers' outcomes, because data were available from too few fathers from families that were classified as clinical.

RESULTS

The sample at T1 consisted of 132 mothers and 72 fathers of 141 children newly diagnosed with cancer, representing 89% of eligible families. Parents were in their late 30s and early 40s (mean age $\pm$ SD: mothers, 38.1 $\pm$ 7.3 years; fathers, 41.1 $\pm$ 7 years). In terms of educational level, the sample was diverse: Twenty-three percent of mothers (n = 31) and 16% of fathers (n = 12) had a high school education or less, 58% of mothers (n = 77) and 57% of fathers (n = 42) had college courses or a college degree, and 18% of mothers (n = 34) and 27% of fathers (n = 20) had some postgraduate education. The patients ranged in age from 5 weeks to 18 years (mean age $\pm$ SD, 8.2 $\pm$ 5.6 years), and 60% of patients were male (n = 84). Ethnic background was as follows: Caucasian (n = 111 patients; 79%), African American (n = 13 patients; 9%), Hispanic (n = 7 patients; 5%), Asian (n = 3 patients; 2%), and biracial (n = 7 patients; 5%). Cancer diagnoses were: hematologic malignancies (acute lymphocytic leukemia, acute myeloid leukemia, chronic myeloid leukemia, lymphoma, and Hodgkin disease; n = 79 patients; 56%), brain tumors (n = 31 patients; 22%), and solid tumors (neuroblastoma, sarcomas, germ cell tumors, Wilms tumor, and carcinoma; n = 30 patients; 21%).

In total, 97 mothers (63% of eligible mothers who were approached at T1) and 39 fathers (44% of eligible fathers who were approached at T1), representing 102 families, provided data at both T1 and T2. Demographic variables are presented in Table 1. Those who dropped out of the study were compared with those who remained, and there were no significant differences observed on any of the demographic or T1 variables, including PAT 2.0 scores and PPPHM classification. These finding suggest that, overall, there was no bias introduced into the final sample from attrition.

Stability and Change in Psychosocial Risk Across Time

In general, psychosocial risk over time was stable. The percentages classified at each PPPHM level at T1 and T2 for family data, mother data, and father data are presented in Table 2. McNemar-Bowker tests revealed that PPPHM categorization did not differ significantly within families or parents between T1 and T2 (*P* values [*P*s] > .56). Family data indicated that 58% (n = 59) remained in the same classification, 24% (n = 24) reduced in their level of risk, and 19% (n = 19) increased in risk. Based on mothers' reports of risk, 64% (n = 62) remained at the same PPPHM level across time, 21% (n = 20) reduced their level of risk, and the remaining 15% (n = 15) increased in level of risk. Based on fathers' reports, 69% (n = 27) remained at the same level across time, 13% (n = 5) reduced their level of risk, and the remaining 18% (n = 7) increased in risk. Changes in risk status across time were not associated significantly with race/ethnicity, socioeconomic status, patient sex, cancer diagnosis, or intensity of cancer treatment.

To further understand changes over time, PAT total and subscale scores were examined from T1 to T2 for families, mothers, and fathers. Although total scores did not differ significantly across time (*P*s > .46), there were significant changes (both increases and decreases) on the PAT subscales (Fig. 2) from T1 to T2. Significant increases were observed in Family Problems (for family and father scores; *P*s = .006) and Child Problems (for family and mother scores; *P*s < .01), and significant decreases were observed in Unhelpful Beliefs (all scores; *P*s < .001). Fathers reported significant increases in

Table 1. Demographic Characteristics of the Sample that Completed the Psychosocial Assessment Tool at Both Diagnosis and 4 Months Later

	% (n)	
Characteristic	Mothers	Fathers
Race/ethnicity		
Caucasian	81 (79)	87 (34)
African American	8 (8)	8 (3)
Hispanic	4 (4)	3 (1)
Asian	1 (1)	0 (0)
Biracial	5 (5)	3 (1)
Marital status		
Partnered	77 (75)	92 (36)
Single, separated, or divorced	23 (22)	8 (3)
Educational status		
High school or less	24 (23)	18 (7)
Some college/college degree	57 (55)	59 (23)
Postgraduate education	20 (19)	24 (9)
Patient gender		
Female	39 (38)	44 (17)
Male	61 (59)	56 (22)
Cancer diagnoses		
Hematologic malignancies (leukemias, lymphoma, etc)	59 (57)	64 (25)
Brain tumors	21 (20)	26 (10)
Solid tumors (neuroblastoma, sarcoma, etc)	21 (20)	10 (4)
Treatment intensity		
Level I (least intensive treatments)	1 (1)	0 (0)
Level II (moderately intensive treatments)	30 (29)	29 (11)
Level III (very intensive treatments)	51 (48)	53 (20)
Level IV (most intensive treatments)	14 (14)	18 (7)
Unrated	4 (4)	3 (1)

Table 2. Pediatric Psychosocial Preventative Health Model Classification Based on Family, Mother, and Father Psychosocial Assessment Tool Data at Diagnosis and 4 Months Later

	PPPHM Classification at T2: % (n)			
Classification at T1	Universal	Targeted	Clinical	Total
Family PPPHM				
Universal	35 (36)	14 (14)	1 (1)	50 (51)
Targeted	20 (20)	18 (18)	4 (4)	41 (42)
Clinical	0 (0)	4 (4)	5 (5)	9 (9)
Total	55 (56)	35 (36)	10 (10)	100 (102)
Mother PPPHM				
Universal	43 (42)	11 (11)	1 (1)	56 (54)
Targeted	17 (16)	16 (15)	3 (3)	35 (34)
Clinical	0 (0)	4 (4)	5 (5)	9 (9)
Total	60 (58)	31 (30)	9 (9)	100 (97)
Father PPPHM				
Universal	59 (23)	13 (5)	0 (0)	72 (28)
Targeted	10 (4)	10 (4)	5 (2)	26 (10)
Clinical	0 (0)	3 (1)	0 (0)	3 (1)
Total	69 (27)	26 (10)	5 (2)	100 (39)

PPPHM indicates Pediatric Psychosocial Preventative Health Model; Universal, the lowest risk category indicating few stressors (categorized by a total score <1); Targeted, a higher risk category indicating some stressors (categorized by a total score ≥ 1 but <2; Clinical, the highest risk category, indicating many stressors (categorized by a total score ≥ 2); T2, 4 months after initial diagnosis; T1, the time of diagnosis.

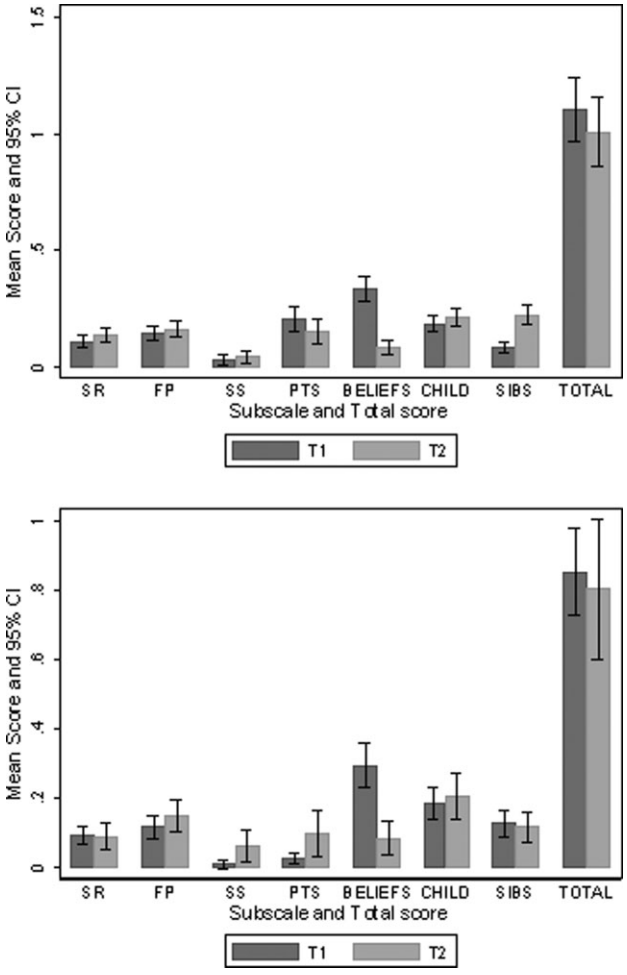

FIGURE 2. These charts illustrate Psychosocial Assessment Tool subscale scores and total scale scores at diagnosis (T1) and 4 months later (T2) for mothers (*Top*) and fathers (*Bottom*). CI indicates confidence interval; SR, Family Structure and Resources; FP, Family Problems; SS, Family Social Support; PTS, Parent Stress Reactions; Beliefs, Family Beliefs; CHILD, Child Problems; SIBS, Sibling Problems.

Traumatic Stress Symptoms ($P = .01$) and decreases in Social Support (increased risk; $P = .01$).

Pediatric Psychosocial Preventative Health Model Risk at Diagnosis and Distress and Family Functioning 4 Months into Treatment

There were significant differences in mother-reported T2 traumatic stress symptoms, parenting stress, family conflict and coherence, and child behavioral problems between families at different T1 PPPHM classifications across family and mother PPPHM classifications, as predicted. The universal and targeted groups tended to be similar. and the universal group was consistently better functioning than the clinical group (see the post hoc analyses presented in Table 3). Father outcomes, as mentioned above, could not be evaluated because of limited numbers in the clinical group.

Pediatric Psychosocial Preventative Health Model Classification at Diagnosis and Psychosocial Services Resource Use

Social work services resource use differed by PPPHM classification based on family data ($P = .006$) and mother data ($P = .003$). Families classified at the clinical level of risk used more social work resources than those in the universal group (see Table 4). PPPHM classification was associated marginally with the number and associated significantly with the intensity of social work services provided. The universal group required the least intensive services, the targeted group required more intensive services, and the clinical group required the most intensive services. Consistent with these data, psychological services were provided to families in the targeted and clinical groups at increased rates compared with families in the universal group. A significant difference was observed in the family data ($P = .009$); 19% of the universal families ($n = 11$), 42% of the targeted families ($n = 18$), and 47% of the clinical families ($n = 6$) received referrals for psychological services.

DISCUSSION

Psychosocial care provided to families during the difficult time around a child's diagnosis of cancer may impact both short-term and long-term adaptation. Highlighting the potential benefit of early, effective psychosocial interventions, 1 of the few longitudinal investigations of families of children with cancer demonstrated that adjustment and coping at diagnosis were predictive of long-term adjustment during survivorship.[3] Although the pediatric cancer experience is recognized as a time when psychosocial support is needed, the lack of consistent services matched to the specific needs of families remains a troublesome aspect of cancer care. The current study provides data with regard to an evidence-based screener, the PAT, and

Table 3. Mother-Reported Outcomes 4 Months After Diagnosis for Pediatric Psychosocial Preventative Health Model Risk Categories at Diagnosis

Outcome Measured	PPPHM Classification: Median Score (Range)*			
	Universal	Targeted	Clinical	Statistical Test Chi-Square [*P*]
Family PPPHM				
No.	50	42	9	
State anxiety, STAI-Y	38.5 (55)	43 (56)	51 (53)	4.87 [.09]
PTS total, PCL-S	28 (37)[a]	28 (47)[a]	45 (46)[b]	8.45 [.02]
Parenting stress, PSI-SF†	59 (76)[a]	70.5 (72)[b]	93.5 (67)[b]	9.99 [.007]
Family cohesion, FES	9 (8)	8 (4)	7 (5)	5.55 [.06]
Family conflict, FES	1 (7)[a]	2 (6)[a,b]	3 (5)[b]	12.91 [.002]
Family coherence, FLS	66 (38)[a]	61.5 (41)[a,b]	57 (28)[b]	12.24 [.002]
Behavioral symptoms, BASC‡	42.5 (26)[a]	47 (32)[b]	53 (33)[b]	11.64 [.003]
Mother PPPHM				
No.	54	34	9	
State anxiety, STAI-Y	38.5 (55)	47 (56)	51 (53)	8.03 [.02]
PTS total, PCL-S	28 (37)[a]	35.5 (47)[a]	45 (46)[b]	9.04 [.01]
Parenting stress, PSI-SF§	60 (76)	70.5 (72)	93.5 (67)	7.76 [.02]
Family cohesion, FES	9 (8)	9 (4)	7 (5)	5.41 [.07]
Family conflict, FES	1.5 (7)[a]	2 (6)[a]	3 (5)[b]	11.73 [.003]
Family coherence, FLS	67 (38)[a]	61 (41)[a]	57 (28)[b]	13.59 [.001]
Behavioral symptoms, BASC‖	43.5 (26)[a]	46 (32)[a]	53 (33)[b]	7.75 [.02]

PPPHM indicates Pediatric Psychosocial Preventative Health Model; Universal, the lowest risk category indicating few stressors (categorized by a total score <1); Targeted, a higher risk category indicating some stressors (categorized by a total score ≥1 but <2; Clinical, the highest risk category, indicating many stressors (categorized by a total score ≥2); STAI-Y, the State-Trait Anxiety Inventory; PTS, post-traumatic stress; PCL-S, Post-Traumatic Stress Disorder Checklist-Specific Version; PSI-SF, Parenting Stress Index-Short Form; FES, Family Environment Scale; FLS, Family Life Scales-Family Coherence Subscale; BASC, Behavioral Assessment Scale for Children-Parent Report.

* Within rows, median scores with different superscript letters differed significantly according to follow-up Mann-Whitney *U* -up tests (*P* value <.01).

† Only applied to patients aged ≤12 years: universal, n=36; targeted, n=26; clinical, n=4.

‡ Only applied to patients between ages 2 years and 18 years: universal, n=32; targeted, n=33, clinical, n=7.

§ Universal, n=40; targeted, n=20; clinical, n=4.

‖Universal, n=36; targeted, n=25; clinical, n=7.

Table 4. Social Work Service Resources Used by Pediatric Psychosocial Preventative Health Model Risk Categories at Diagnosis

Resources	PPPHM Classification: Median Score (Range)*			
	Universal	Targeted	Clinical	Statistical Test Chi-Square [*P*]
Family PPPHM				
No.	55	43	13	
SWSF total score†	20 (127)[a]	34 (111)[a,b]	51 (98)[b]	10.29 [.003]
No. of services‡	9 (34)[a]	11 (27)[a,b]	15 (22)[b]	7.99 [.02]
Intensity of work§	2.3 (3.3)[a]	2.7 (2.4)[b]	3.4 (2.4)[c]	17.43 [<.001]
Mother PPPHM				
No.	59	33	13	
SWSF total score†	20 (127)[a]	36 (87)[a,b]	51 (98)[b]	11.46 [.003]
No. of services‡	9 (34)[a]	12 (24)[a,b]	15 (22)[b]	8.34 [.02]
Intensity of work§	2.3 (3.3)[a]	2.7 (2.3)[b]	3.4 (2.4)[c]	16.86 [<.001]

PPPHM indicates Pediatric Psychosocial Preventative Health Model; Universal, the lowest risk category indicating few stressors (categorized by a total score <1); Targeted, a higher risk category indicating some stressors (categorized by a total score ≥1 but <2; Clinical, the highest risk category, indicating many stressors (categorized by a total score ≥2); SWSF, Social Work Summary Form.

* Within rows, median scores with different superscript letters differed significantly according to follow-up Mann-Whitney *U* tests (*P* value <.01).

† Scores could range from 0 to 270.

‡ Scores could range from 0 to 54.

§ Scores could range from 1 to 5, with a score of 3 indicating a typical level of work intensity relative to other families.

information on the course of adjustment for families, illustrating the utility of early assessment of psychosocial risk.

Matching needs and targeting the intensity of psychosocial services has been limited by a lack of brief, evidence-based, psychometrically sound assessment tools that are sensitive to the relevant needs of families of children with cancer. The PAT, with content based on predictors of adjustment to childhood cancer and cutoff scores that allow for risk classification consistent with a public health-based, conceptual model (the PPPHM), demonstrated feasibility, reliability, and validity in previous investigations.[11] In the current study, we established the consistency of risk across time and the predictive validity of PPPHM classification based on PAT scores at diagnosis.

PPPHM classification of families at diagnosis (based on PAT scores) was quite reliable across the first 4 months of cancer treatment. Risk was low (at the universal level) and stable for many families (range, 35%-59%, depending on the reporter); however, risk consistently was elevated (at the targeted and clinical levels) for some (range, 10%-23%). These data are similar to those reported in an independent study of the PAT based in Australia.[26] In that study, risk classifications remained stable over 6 months, although an increase in actual PAT total scores over time was observed. This measure is designed such that we expect some variation in PAT scores and item-level responses across time but relative stability in the broad psychosocial risk classification levels.

Although PPPHM classifications primarily were stable across time, an important minority of families (range, 16%-19%) increased in risk over the first few months of cancer treatment, indicating a clear need for psychosocial care at this time. Furthermore, a similar percentage (range, 13%-24%) decreased in risk. Finding predictors of change in risk status across time will be important for better targeting of services. Although both increases and decreases in risk are of interest, assuring the delivery of clinical care to those most in need (those whose risk increases) is necessarily a priority. In the current investigation, demographic characteristics and cancer-related variables (including diagnosis and treatment intensity) did not distinguish those families that remained stable, decreased, or increased in risk over time.

Changes in subscale scores provide clues regarding the nature of risks that may change over time. Fathers reported increases in family problems and mothers reported increases in child (patient) problems over this period, perhaps reflecting the demands associated with the initiation and continuation of intensive treatment during this period and its impact on the family. The decrease in unhelpful family beliefs highlights the involvement of medical, nursing, and psychosocial team members, who provide support and information, and increases in self-efficacy as parents become actively involved in treatment.

In terms of predictive validity, PPPHM classification of risk at diagnosis was related to distress, family functioning, and child adjustment 4 months into treatment, with significant differences observed between the high-risk clinical group and the low-risk universal group. Moreover, these findings were consistent with regard to psychosocial service resource use, because the high-risk clinical families received more varied and intensive social work services as well as referrals for treatment by a psychologist.

There are several limitations of the current study. Despite efforts to recruit and retain both fathers and mothers in this study, only 56 of the 107 2-parent families (52%) provided data from fathers, and the distribution of nonparticipating fathers varied as a function of mother-reported PPPHM level at T1: 39% of the universal families, 55% of the targeted families and 89% of the clinical families were missing father data ($P = .01$) at T1. Furthermore, only 24% of families classified at the highest level of risk at T1 ($n = 17$) provided father data at T2, precluding predictive validity analyses using fathers' data. It is noteworthy that the marital status of the parents was not related statistically to whether or not the father's data were available at T2. In fact, of the 4 fathers classified in the clinical group at T1 (based on family data) who provided data at T2, 3 fathers were not married to the mother of the patient. It is important to continue to seek out fathers when conducting studies of psychosocial risk and adaptation and to attend to their psychosocial needs. Additional investigation also is necessary to ascertain the optimal way of obtaining and using risk data from multiple members of the family (eg, 2 parents/caregivers, when available).

The findings of this study address the clinical utility of the PAT in terms of offering pediatric oncology treatment teams an assessment approach that can be used to

identify those families whose distress will remain elevated over time and will require more intensive interventions. The PAT also may be used to target psychosocial services to areas of need, such as parent distress, child problems, or sibling issues. Although the current study cannot address the longer term psychosocial outcomes (eg, during survivorship), providing early interventions that are matched to the level of family risk may promote adaptive adjustment over time in both the short term and the longer term. Translational research examining the effectiveness of the PAT as a clinical tool with which to channel families of children newly diagnosed with cancer into different levels of psychosocial care are important ongoing next steps.

Understanding and identifying risk for psychosocial adjustment problems, with an eye toward changes across treatment transitions from diagnosis through survivorship, is very complex. Despite support for the use of the PAT and its predictive validity, additional research is necessary to understand how and why levels of risk may change over time, necessitating particular attention to risk factors associated with survivorship, such as late effects and their potential associated impairment. Findings to date support the overall adaptive competence of youth with cancer and their families. Ongoing attention to the use of evidence-based assessment during active treatment and survivorship phases to reduce risk and maintain adaptive functioning remains an important challenge for ongoing research and clinical care.

Conflict of Interest Disclosures

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References

1. Ries LAG, Melbert D, Krapcho M, et al, eds. SEER Cancer Statistics Review, 1975-2005. Bethesda, Md: National Cancer Institute; 2008. Available at: http://seer.cancer.gov/csr/1975-2005/ Accessed August 1, 2008.
2. 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.
3. Kupst MJ, Schulman JL.Long-term coping with pediatric leukemia: a 6-year follow-up study. *J Pediatr Psychol.* 1988;13:7-22.
4. American Academy of Pediatrics.Guidelines for the pediatric cancer centers. *Pediatrics.* 2004;113:1833-1835.
5. Institute of Medicine. Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs. Washington, DC: National Academies Press; 2007.
6. Phipps S.Adaptive style in children with cancer: implications for a positive psychology approach. *J Pediatr Psychol.* 2007;32:1055-1066.
7. Vrijmoet-Wiersma CMJ, van Klink JMM, Kolk AM, et al. Assessment of parental psychological stress in pediatric cancer: a review. *J Pediatr Psychol.* 2008;33:694-706.
8. Stehl ML, Kazak AE, Alderfer MA, et al.Conducting a randomized clinical trial of an psychological intervention for parents/caregivers of children with cancer shortly after diagnosis. *J Pediatr Psychol.* 2008. Dec 17 [Epub ahead of print].
9. Kazak AE, Alderfer MA, Streisand R, et al. Treatment of posttraumatic stress symptoms in adolescent survivors of childhood cancer and their families: a randomized clinical trial. *J Fam Psychol.* 2004;18:493-504.
10. Kazak AE, Rourke MT, Alderfer MA, Pai AL, Reilly AF, Meadows AT. Evidence-based assessment, intervention and psychosocial care in pediatric oncology: a blueprint for comprehensive services across treatment. *J Pediatr Psychol.* 2007;32:1099-1110.
11. Pai AL, Patino-Fernandez AM, McSherry M, et al. The Psychosocial Assessment Tool (PAT 2.0): psychometric properties of a screener for psychosocial distress in families of children newly diagnosed with cancer. *J Pediatr Psychol.* 2008;33:50-62.
12. Kazak AE. Pediatric Psychosocial Preventative Health Model (PPPHM): research, practice and collaboration in pediatric family systems medicine. *Fam Syst Health.* 2006;24:381-395.
13. US Department of Health and Human Services. Mental Health: A Report of the Surgeon General. Rockville, Md: US Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute of Mental Health; 1999. Available at: http://www.surgeongeneral.gov/library/mentalhealth/home.html Accessed November 18, 2008.
14. Kazak AE, Cant MC, Jensen MM, et al. Identifying psychosocial risk indicative of subsequent resource use in families of newly diagnosed pediatric oncology patients. *J Clin Oncol.* 2003;21:3220-3225.
15. Kazak AE, Prusak A, McSherry M, et al. The Psychosocial Assessment Tool (PAT): pilot data on a brief screening instrument for identifying high risk families in pediatric oncology. *Fam Syst Health.* 2001;19:303-317.
16. Hollingshead A. The Four-Factor Index of Social Position. New Haven, Conn: Yale University Press; 1975.

17. Speilberger C. Manual for the State-Trait Anxiety Inventory. Palo Alto, Calif: Consulting Psychologists Press; 1983.
18. Bryant RA, Moulds ML, Guthrie RM. Acute Stress Disorder Scale: a self report measure of acute stress disorder. *Psychol Assess.* 2000;12:61-68.
19. Weathers F, Litz B, Herman D, Juska J, Keane T. The PTSD Checklist (PCL): reliability, validity, and diagnostic utility. Poster presented at: Ninth Annual Meeting of the International Society for Traumatic Stress Studies, San Antonio, Texas, October 24-27, 1993.
20. Smith MY, Redd W, DuHamel K, Vickberg SJ, Ricketts P.Validation of the PTSD Checklist-Civilian Version in survivors of bone marrow transplantation. *J Trauma Stress*.1999;12:485-499.
21. Abidin R. Parenting Stress Index. 3rd ed. Lutz, Fla: Psychological Assessment Resources;1995.
22. Moos RH, Moos BS. Family Environment Scale. Palo Alto, Calif: Consulting Psychologists Press; 1974.
23. Ransom DC, Fisher L, Terry HE.The California Family Health Project: II. Family worldview and adult health. *Fam Process.* 1992;31:251-267.
24. Reynolds CR, Kamphaus RW. Manual for the Behavior Assessment System for Children. 2nd ed. Circle Pines, MN: AGS Publishing; 2004.
25. Werba B, Hobbie W, Kazak AE, et al. Classifying the intensity of pediatric cancer treatment protocols: the Intensity of Treatment Rating Scale 2.0 (ITR-2). *Pediatr Blood Cancer*. 2007;48:673-677.
26. McCarthy MC, Clarke NE, Vance A, et al. Measuring psychosocial risk in families caring for a child with cancer: the Psychosocial Assessment Tool (PAT 2.0). *Pediatr Blood Cancer*. 2009;53:78-83.