Psychosocial Risk, Symptom Burden, and Concerns in Families Affected by Childhood Cancer

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Abstract

PURPOSE: The revised Psychosocial Assessment Tool (PATrev) is a common family-level risk-based screening tool for pediatric oncology that has gained support for its ability to predict, at diagnosis, the degree of psychosocial support a family may require throughout the treatment trajectory. However, ongoing screening for symptoms and concerns (e.g., feeling alone, understanding treatment) remain underutilized. Resource limitations necessitate triaging and intervention based on need and risk. Given the widespread use of the PATrev, we sought to explore the association between family psychosocial risk, symptom burden (as measured by the revised Edmonton Symptom Assessment System; ESAS-r), and concerns (as measured by the Canadian Problem Checklist; CPC).

METHODS: Families ($n = 85$) with children between 2–18 years of age ($M = 11.98$, male: 62.4%) on or off treatment for cancer were recruited from the Alberta Children's Hospital. One parent from each family completed the PATrev and the CPC. Participants 8–18 years of age completed the ESAS-r.

RESULTS: Risk category (universal/low risk = 67.1%, targeted/intermediate risk = 21.1%, clinical/high risk = 5.9%), predicted symptom burden ($F[2, 63.07] = 4.57, p = .014$) and concerns ($F[2, 80.08] = 16.34, p < .001$), such that universal risk was associated with significantly lower symptom burden and fewer concerns.

CONCLUSION: Family psychosocial risk is associated with cross-sectionally identified concerns and symptom burden, suggesting that resources might be prioritized for families with the greatest predicted need. Future research should evaluate the predictive validity of the PATrev to identify longitudinal concerns and symptom burden throughout the cancer trajectory.

Background

While a diagnosis of childhood cancer is often extremely distressing to those families affected, the majority of families adjust well. Yet, for some, this distress persists well into treatment and survivorship [1]. For this subset of families, psychosocial concerns and burdensome symptoms can dramatically decrease quality of life [2, 3]. Left unaddressed, these challenges may negatively affect satisfaction with care, a family's ability to cope, long-term mental health, and potentially mortality of the child [3–6]. Even after treatment has ended, symptoms such as pain and fatigue may persist for many years into adulthood [7–10]. In response, standards for the psychosocial care of children with cancer and their families were published in 2015. These 15 evidence-based standards advocate for routine screening and assessment of psychosocial health needs within pediatric oncology [11, 12]. While these standards represent an important step forward for psychosocial care, there remains little guidance to direct health care professionals about how psychosocial difficulties should be assessed.

In contrast, routine screening of psychosocial health is well established within adult oncology and implemented widely in countries such as Canada and Australia [13, 14]. Here, psychosocial screening has primarily focused on ongoing assessment of practical and biopsychosocial concerns (e.g., difficulty

making treatment decisions, feeling like a burden to others, etc., via the Canadian Problem Checklist) as well as symptom burden (e.g., pain, fatigue, etc., via the Edmonton Symptom Assessment System). For adults, effective screening using these two tools is associated with fewer emergency room visits, increased patient engagement in treatment, and potentially improved survival [15–17].

While distress screening is less well established within pediatric oncology, there has been advocacy for a family-centered approach, given the important social context of family dynamic for children and adolescents undergoing treatment [1, 18]. How a family is coping may not be evident by their outward expression of distress, which may in itself vary significantly between family members, all of whom may also have a significant impact on a child's functioning and wellbeing. In response to this, the Psychosocial Assessment Tool (PAT) was developed as a screening tool to be used at diagnosis, to identify families likely to require greater psychosocial support and intervention [19]. Families are differentiated by three tiers of psychosocial risk: Universal (distressed but resilient); Targeted (acute or elevated distress); and Clinical (severe, escalating, or persistent distress). The three tiers of psychosocial risk are then used to facilitate referral to appropriate resources and treatment. Indeed, the PAT has shown feasibility and a strong ability to predictively differentiate families by the degree of psychosocial support required throughout treatment and into survivorship [20–23]. What remains underutilized within pediatric oncology is ongoing screening for psychosocial concerns, as well as symptom burden using patient-reported outcomes, as is advocated for in the 2015 practice guidelines and is widely implemented in adult care [3, 24]. In fact, Screening for Distress and distress management has become an accreditation standard in many countries (Accreditation Canada).

Symptom screening may be especially important within pediatric oncology settings, as children may not report symptoms until they become severely problematic [25, 26]. Some children may believe debilitating symptoms are necessary to cure their cancer, be reluctant to worry their family, or worry about burdening their healthcare team [24]. When symptoms are known by families, greater symptom burden and unaddressed concerns may contribute to difficulty making treatment decisions and adhering to treatment recommendations [18, 27]. In survivorship, unmet needs pertaining to symptom management are prevalent and associated with increased fear of cancer recurrence [10]. As such, it is exceedingly important that concerns and symptoms are identified systematically and early to ensure families can be given the appropriate resources and tools to address symptoms and concerns, and navigate treatment and survivorship.

Given the use of familial level psychosocial risk screening in pediatric oncology, we sought to explore the association between psychosocial family risk, parent-identified concerns, and patient-reported symptom burden in a pediatric oncology sample. We hypothesized that higher psychosocial risk category would correspond to more parent-identified concerns and greater symptom burden as reported by patients.

Methods

Participants

Ethics approval was obtained from the Health Research Ethics Board of Alberta: Cancer Committee (HREBA.CC-16-0274). Participants were recruited from the Alberta Children's Hospital over a 24-month period, as part of a larger study. Families were eligible to participate if patients were: 18 years of age or younger; on active treatment for cancer, or, had completed cancer therapy; were fluent in English; and had at least one parent who was fluent in English and was willing to participate. Informed written consent was obtained from all participating parents and patients who were 18 years of age, and verbal assent was obtained from participating children and adolescents who were 8–18 years of age. Parents completed a demographics questionnaire, the PAT-revised edition (adapted for families in Canada), and the CPC. Children and adolescents completed the ESAS-revised edition.

Measures

Psychosocial Assessment Tool (PATrev) [19, 28]. The PATrev is a comprehensive family-level psychosocial risk assessment tool that was developed for use in pediatric oncology settings and has been adapted for a Canadian setting. The PATrev contains 57 items across seven domains: family structure and resources; social support; child problems; sibling problems; caregiver stress reactions; family problems; and family beliefs. Total scores range from 0–7, with higher scores indicating higher psychosocial family risk. Families are classified as belonging to one of three categories: Universal (lowest risk, scores 0.00-0.99), Targeted (elevated risk, scores 1.00-1.99) or Clinical (highest risk, scores 2.00–7.00). The PATrev has strong internal consistency and test-retest reliability.

Edmonton Symptom Assessment System (ESAS-r) [29]. The ESAS-r is a 10-item self-report measure of the most common symptoms experienced by cancer patients including: Pain, Tiredness, Nausea, Depression, Anxiety, Drowsiness, Appetite, Wellbeing, Shortness of Breath, and Other. Each item is rated on a 10-point scale of severity and can be summed to provide a total score for each patient (scale: 0–100). Patient self-report data were collected for participants aged 8–18. The ESAS-r is widely used in both clinical practice and research worldwide, and it has been translated into over 20 languages (Hui & Bruera, 2017). While the ESAS-r was developed for use with adults, available evidence suggests children ≥ 8 years of age can provide valid responses on self-report symptom measures [30]. Previous research has found the ESAS-r to produce good internal reliability (0.79), test-retest reliability (0.86), and convergent validity (0.56–0.85) (Chang, Hwang, & Feuerman, 2000).

Canadian Problem Checklist (CPC) [15]. The CPC is an evidence-based [31, 32]) 21-item self-report checklist designed to query common concerns that cancer patients experience. It includes six broad domains: Emotional, Spiritual, Practical, Social/Family, Informational, and Physical. This tool is intended to be used in conjunction with the ESAS-r, and measures concerns over the week preceding completion [14, 15]. A summary score was calculated by summing the number of items endorsed on this checklist, as has been previously described [33]. Patient self-report data were collected. Although the CPC is used across Canada as a part of a Screening for Distress toolkit, its psychometric properties have yet to be established. However, psychometric evaluation may be of limited value given the checklist format [34].

Data Analysis

All analyses were performed using SPSS 24.0. Descriptive analyses were performed to describe participant characteristics and distributions of items endorsed on the ESAS-r and CPC. Multilevel modelling was used to account for dependence of data within phase of cancer trajectory (on treatment vs off treatment). Multilevel modelling assumes that micro-level data (i.e., response data) is dependent within macro-level groups (i.e., treatment phase), and thus simultaneously estimates variability at each level. Two multilevel models were conducted to evaluate the association between family psychosocial risk (via PATrev) and symptoms (via self-reported ESAS-r), as well as between family psychosocial risk (via PATrev) and concerns (via parent-reported CPC). Survivors' sex and age were included as covariates in all analyses.

Results

Participants

A sample of 87 families were included in the final analyses (on treatment $n = 40$; off treatment $n = 47$). Patient participants (62.4% male) were on average 11.98 years of age at participation. The most common diagnoses were leukemia and lymphoma (45.9%), followed by solid tumors (29.4%) and malignancies of the central nervous system (15.3%). Parent respondents included mothers (91.9%), fathers (7.0%), and one grandparent (1.2%). Of 186 families identified as eligible and invited to participate (on treatment $n=76$; off treatment $n=110$), 50 declined (on treatment $n=19$; off treatment $n=31$) due to disinterest in study ($n=33$), no time to participate ($n=11$), and already participating in too many studies ($n=6$). An additional forty-eight consenting families did not return their survey package (on treatment $n=14$; off treatment $n=27$) or returned packages with incomplete PATrev or CPC/ESAS-r data (on treatment $n=3$; off treatment $n=5$). There were no significant differences between participants and those who declined or did not complete packages with respect to gender, age, or age at diagnosis.

For families undergoing active treatment, 27 (67.5%) were classified into the universal risk category, 12 (30.0%) were classified into the targeted risk category, and one family (2.5%) was classified into the clinical risk category. For those families who had completed therapy, 32 (68.1%) were classified into the universal risk category, 11 (23.4%) were classified into the targeted risk category, and four (8.5%) were classified into the clinical risk category (see Figure 1). Additional patient and family demographics can be found in Table 1.

Edmonton Symptom Assessment System

Out of a possible score of 100, children and adolescents in the universal risk category reported an average symptom summary score of 11.02. The most highly rated symptom was tiredness ($M = 2.26$, $SD = 2.05$), followed by lack of appetite ($M = 1.55$, $SD = 2.18$), and anxiety ($M = 1.45$, $SD = 2.69$). Those in the targeted risk category reported an average symptom summary score of 20.42. The most highly rated symptom was tiredness ($M = 3.37$, $SD = 2.09$), followed by pain ($M = 3.00$, $SD = 4.45$), and wellbeing ($M =$

2.47, $SD = 2.46$). Finally, those in the clinical risk category reported an average symptom summary score of 25.20. The most highly rated symptom was tiredness ($M = 4.80$, $SD = 2.39$), followed by anxiety ($M = 4.00$, $SD = 4.62$), and pain ($M = 3.00$, $SD = 3.94$). Additional symptom information can be found in Table 2.

Results of the multilevel model indicated that PATrev risk category was significantly associated with survivors' self-reported ESAS-r summary score $F(2, 63.07) = 4.57$, $p = .014$. Exploring further, there was a significant difference in ESAS-r summary scores between those in the universal and targeted risk categories ($b = 8.01$, $SE = 3.83$, 95% CI = 0.34, 15.67), as well as between those in the universal and clinical risk categories ($b = 16.27$, $SE = 6.44$, 95% CI = 3.39, 29.14), such that those in the universal risk category had significantly lower symptom burden. The difference between summary scores for those in the targeted and clinical risk categories did not reach significance ($b = 8.26$, $SE = 6.88$, 95% CI = -5.49, 22.01).

Canadian Problem Checklist

Of a possible 21 concerns, parents in the universal risk category endorsed, on average, 2.63 ($SD = 3.18$). The most common concerns in this group were fears ($n = 22$, 37.3%) and sleep ($n = 15$, 25.4%). Parents in the targeted risk category endorsed 6.43 items on average. Their most common concerns were fears ($n = 17$, 73.9%), followed by sleep ($n = 15$, 65.2%), sadness ($n = 15$, 65.2%), and work/school ($n = 15$, 65.2%). Finally, parents in the clinical risk group endorsed 8.50 concerns on average. Their most common concerns were fears ($n = 4$, 80.0%), and sleep ($n = 4$, 80.0%). Additional information about concerns endorsed can be found in Table 2.

Results of the multilevel model indicated that PATrev risk category was significantly associated with parent-reported CPC summary score $F(2, 82.06) = 16.79$, $p < .001$. Exploring further, there was a significant difference in CPC summary scores between those in the universal and targeted risk categories ($b = 3.72$, $SE = 0.80$, 95% CI = 2.14, 5.30), as well as between the universal and clinical risk categories ($b = 6.73$, $SE = 1.68$, 95% CI = 3.40, 10.07), such that those in the universal risk category endorsed significantly fewer concerns than those in the targeted or clinical risk categories. The difference between summary scores for those in the targeted and clinical risk categories did not reach significance ($b = 3.01$, $SE = 1.75$, 95% CI = -0.48, 6.50).

Discussion

The aim of the current study was to assess the association between psychosocial family risk, parent-identified concerns, and patient-reported symptom burden in a pediatric oncology sample. Our hypothesis that greater psychosocial family risk would be associated with more parent-reported concerns and greater patient-reported symptom burden using cross-sectional data was partly supported by the data. Results indicated that those in the targeted and clinical levels of familial risk on the PATrev reported more concerns and higher symptom burden than those in the universal risk category during both active

treatment and after treatment completion. No statistical differences in symptom burden between families in the targeted and clinical risk categories were present in the current sample.

Our findings that the majority of families were identified as belonging to the universal risk category, followed by targeted and clinical risk categories are consistent with the broader literature [18, 19, 35]. Though comprehensive research on child and teen symptoms in pediatric oncology is scant, the most commonly evaluated and reported symptoms in the literature include fatigue, sleep, pain, and psychosocial distress [7, 24, 36]. While our results reflect some of these symptoms (e.g., fatigue, pain, and anxiety) as the most intensely experienced, it is unclear which symptoms patients find most *distressing*, which may differ. Certainly, there is evidence for the association between the symptom frequency and worry among survivors of childhood cancer, but this does not always align [37]. Bottom-up research is also needed to identify which symptoms are most relevant for children and teens, as these symptoms may differ from the most frequently reported adult symptoms captured by the ESAS-r. Finally, future research should also work to better characterize the multidimensional aspects of symptoms experienced by this population (e.g., frequency, duration, distress, interference) [24].

Our results expand previous findings that familial psychosocial risk is related to psychosocial distress [12, 38] by identifying relationships with symptom burden as well as other practical and psychosocial concerns. Previous research has explored the relationship between family factors (e.g., family cohesion, parent distress) and symptom burden as well as health-related quality of life, and found that family and parent factors are related to health outcomes [39]. The relationship between family risk and child health has been well-established in the general population [40, 41]. Results of this work have called for a need to identify interventions focused on family function and parent distress as potential moderators of child health, although interventions focused on parent or family functioning within pediatric oncology are relatively rare [42–44].

The results of this study have important clinical implications. Regular screening for symptoms and concerns is needed to systematically identify and intervene as these challenges arise. The need for screening is further emphasized by the fact that symptoms and concerns were present during both active treatment and after treatment completion, and especially given that nearly a quarter of families in our study on active treatment indicated that they did not know about available resources. The PATrev can easily be administered to families of children currently undergoing treatment as well as to families of survivors to assess risk of psychosocial distress. Evidence for the feasibility of administration of the PATrev has previously been established [2]. Knowing that high familial risk is associated with larger numbers of total symptoms and higher levels of burden due to these symptoms, physicians can follow up with families who score in higher risk categories with an assessment of symptom burden.

The study was not without limitations. First, the cross-sectional nature of the study impedes the ability to draw causal conclusions based on the findings. Without longitudinal data, it is unknown if the reported symptoms were due to cancer and its treatment or if they were present before diagnosis. Moreover, it is unclear whether familial risk leads to greater symptom burden or vice versa. Although the PAT has been

designed to determine premorbid familial functioning, it may be that the experience of greater symptom burden leads to the reporting of greater psychosocial distress. Likely these relationships are bidirectional. Second, 47% of invited participants either declined to participate or did not complete the questionnaire; though, this is only noted as a minor limitation as those who completed the questionnaires did not significantly differ on demographic variables from those who did not complete the questionnaires. However, it is possible that symptom burden could have differed between groups in that individuals with lower symptom burden and lower family-level stressors may have been more likely to participate in the study. Third, the ESAS-r and the CPC do not yet have evidence of validity in younger populations. Since this study was conducted, pediatric symptom screening tools have been established for use in pediatric oncology (e.g., the SSPedi, O'Sullivan, Dupuis [45]). As such, future studies should utilize larger sample sizes with longitudinal data to increase the confidence that the PATrev administered at diagnosis can predict higher symptom burden at a later time during treatment and survivorship using screening tools for a pediatric setting. It may be beneficial to design studies that follow families through treatment and into survivorship to assess symptom burden over time. In addition, given that the ages of survivors who completed their own survey spanned from 8–18, it is possible that some of the young children in our study may have completed the ESAS with the help of their parents, which may have influenced reporting. Unfortunately, we do not have documentation of if and when this occurred. Our sample was also limited by the number of families in the targeted and clinical PAT categories, and as such, our analyses may have been underpowered.

Finally, it is important to highlight that all participants in our study were fluent in English, the majority of our sample identified as white (79%), nearly all respondents were mothers (92%), and mean income of fathers was quite high. Taken together, these characteristics reflect a sample largely comprised of families of high socioeconomic status. As such, our results may not be generalizable to other, more diverse populations. Related to this and of particular importance, there is a significant need for psychosocial screening tools that are appropriate for a pediatric health setting and can be completed by non-English speaking patients and families. These families may include new immigrants, those who are unfamiliar with our healthcare system, or may have added challenges identifying and engaging in needed resources due to language barriers. As such, it is especially critical that we work to identify and support these families.

In sum, we found that familial psychosocial risk, as measured by the PAT, was significantly associated with the number of symptoms reported and overall burden on the patient and their family, as measured by the ESAS-r and CPC, respectively. Institutions already using the PATrev to assess familial psychosocial risk should follow up with families who fall within the targeted and clinical risk categories to assess the patient's symptom burden and ensure appropriate interventions are provided.

Declarations

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Availability of data and material: Data can be made available upon request to the corresponding author.

Code availability: Not applicable

Authors' contributions: All authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by Brooke Russell and Fiona Schulte. The first draft of the manuscript was written by Brooke Russell and Fiona Schulte and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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Consent to participate: Informed written consent was obtained from all participating parents and patients who were 18 years of age. Verbal assent was obtained from participating children and adolescents who were 8-18 years of age.

Consent for publication: Not applicable

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Tables

Table 1. Participant demographics

	All Participants (n = 87)
	N (%) or M (SD)
Child age at Participation (years)	11.72 (4.22)
Child age at Diagnosis (years)	6.05 (5.09)
Child time Since Diagnosis (years)	5.67 (5.04)
Gender	
Male	54 (62.1%)
Female	33 (37.9%)
Ethnicity	
White	69 (79.3%)
Asian	7 (8.0%)
Black	1 (1.1%)
Hispanic	1 (1.1%)
Other	7 (8.0%)
Other	15 (17.6%)
Diagnosis	
Leukemias	30 (34.5%)
Lymphomas	10 (11.5%)
Solid Tumor	25 (28.7%)
CNS	14 (16.1%)
Other/Mixed	8 (9.2%)
Father's Age	43.72 (7.04)
Mother's Age	41.73 (7.06)
Father's Income	\$113,870 (\$111,217)
Mother's Income	\$37,511 (\$40,708)
Father's Education	
High School or Less	22 (25.3%)
Some Post-Secondary	39 (44.7%)
Graduate or	17 (19.5%)

Professional Degree	
Mother's Education	
High School or Less	17 (19.5%)
Some Post-Secondary	52 (59.7%)
Graduate or Professional Degree	16 (18.4%)
PATrev Risk Category	
Universal	59 (67.8%)
Targeted	23 (26.4%)
Clinical	5 (5.7%)

Table 2. ESAS and CPC Descriptives by PATrev Risk Category.

	Universal Risk	Targeted Risk	Clinical Risk
ESAS (self-report)			
Pain	1.17 (1.90)	2.53 (2.25)	3.00 (3.94)
Tired	2.26 (2.05)	3.37 (2.09)	4.80 (2.39)
Nausea	0.71 (1.70)	1.58 (2.69)	0.80 (1.30)
Depressed	0.69 (2.00)	1.84 (2.87)	2.60 (2.70)
Anxiety	1.45 (2.69)	2.42 (2.65)	4.00 (4.62)
Drowsy	1.24 (1.86)	1.68 (1.57)	2.80 (3.35)
Appetite	1.55 (2.18)	2.26 (2.31)	2.60 (3.20)
Wellbeing	1.38 (2.19)	2.47 (2.46)	2.80 (3.42)
Shortness of Breath	0.31 (0.72)	0.53 (1.07)	1.20 (2.68)
Other	0.63 (1.70)	3.00 (4.45)	1.75 (3.50)
ESAS Summary Score	11.02 (13.39)	20.42 (15.82)	25.20 (27.62)
CPC (parent-report)			
Fears	22 (37.3%)	17 (73.9%)	4 (80.0%)
Sadness	14 (23.7%)	15 (65.2%)	2 (40.0%)
Frustration	12 (20.3%)	7 (30.4%)	3 (60.0%)
Appearance	5 (8.5%)	2 (8.7%)	2 (40.0%)
Intimacy	4 (6.8%)	3 (13.0%)	0 (0.0%)
Meaning	3 (5.1%)	4 (17.4%)	1 (20.0%)
Faith	2 (3.4%)	2 (8.7%)	2 (40.0%)
Work or School	14 (23.7%)	15 (65.2%)	2 (40.0%)
Finances	11 (18.6%)	9 (39.1%)	3 (60.0%)
Appointment Transportation	5 (8.5%)	1 (4.3%)	2 (40.0%)
Accommodation	2 (3.4%)	2 (8.7%)	0 (0.0%)
Burden to others	2 (3.4%)	5 (21.7%)	2 (40.0%)
Worry	10 (16.9%)	11 (47.8%)	3 (60.0%)
Feeling Alone	4 (6.8%)	7 (30.4%)	2 (40.0%)
Understanding my illness	4 (6.8%)	2 (8.7%)	1 (20.0%)

Talking to healthcare team	1 (1.7%)	1 (4.3%)	1 (20.0%)
Making treatment decisions	6 (10.2%)	3 (13.0%)	1 (20.0%)
Access to resources	4 (6.8%)	6 (26.1%)	1 (20.0%)
Concentration	3 (5.1%)	13 (56.5%)	1 (20.0%)
Sleep	15 (25.4%)	15 (65.2%)	4 (80.0%)
Weight	7 (11.9%)	8 (34.8%)	3 (60.0%)
CPC Summary Score	2.63 (3.18)	6.43 (4.24)	8.50 (6.45)

Figures

Figure 1

For families undergoing active treatment, 27 (67.5%) were classified into the universal risk category, 12 (30.0%) were classified into the targeted risk category, and one family (2.5%) was classified into the clinical risk category. For those families who had completed therapy, 32 (68.1%) were classified into the universal risk category, 11 (23.4%) were classified into the targeted risk category, and four (8.5%) were classified into the clinical risk category (see Figure 1).