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Validity, specificity, feasibility and acceptability of a brief pediatric distress thermometer in outpatient clinics

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Abstract

***Objective*: Psychosocial distress is under-recognized in children with cancer and other serious medical illnesses because of a focus on pressing medical concerns.**

***Aims*: This study assessed the validity, inter-rater reliability, sensitivity/specificity, acceptability, and feasibility of administration of a pediatric distress thermometer (DT) designed to screen for the presence of psychosocial distress in youth with serious medical illnesses.**

***Materials & Methods*: Two hundred eighty-one patient–caregiver–provider triads were enrolled from two hospital outpatient clinics. Patients diagnosed with cancer and other life-threatening diseases, caregivers, and providers completed the DT and a DT acceptability rating. Patients and caregivers completed standardized measures of anxiety, depression, pain, and fatigue. Providers completed a measure of disease severity. Data collectors completed a feasibility rating.**

***Results*: The DT was significantly correlated with both caregiver and patient reports of depression, anxiety, pain, and fatigue, exhibiting concurrent validity. Parent, child, and caregiver report demonstrated significant, moderate inter-rater reliability, with lower concordance between raters in the youngest age group. The DT is a sensitive instrument for screening of psychosocial distress when compared with the selected gold standard (Brief Symptom Inventory 18 depression subscale and the Children's Depression Inventory). The DT is not highly specific but quickly identifies those in need of further psychosocial assessment.**

***Discussion*: Screening, using an adapted pediatric DT, is valid, feasible, and acceptable to patients, caregivers, and medical providers across chronic medical illnesses.**

***Conclusion*: As patient and caregiver reports are not always concordant, both patient and caregiver report of distress are important for the provider to obtain clinically meaningful information to guide interventions.**

Introduction

New medical therapies and early detection have greatly increased survival rates of children with serious medical illnesses. However, these children often experience both short and long-term stressors that significantly impact their quality of life and coping ability [1,2]. Serious pediatric chronic illness often involves a demanding treatment regimen, adverse effects and disruptions of daily activities. Furthermore, invasive or painful medical procedures may be particularly traumatic for children [3]. As such, children adjusting to a chronic illness often experience significant emotional and behavioral distress [4].

The National Comprehensive Cancer Network (NCCN) [5] describes distress as 'an unpleasant emotional experience of a psychological, social or spiritual nature.' Psychosocial distress may also increase over time. A recent Children's Oncology Group (COG) prospective study showed that children with Standard Risk Acute Lymphoblastic Leukemia (SR-ALL) have a higher than expected risk for anxiety and depression at one month post-diagnosis and the risk of depression persists up to one year post-diagnosis [6]. Anxiety and depression can have negative implications on the quality of life and even survival outcomes, including an increase in physical pain, potential for noncompliance with treatment and higher disease morbidity [7–9]. These findings highlight the importance of early identification and intervention to avoid long-term emotional distress and negative health consequences [6].

The Institute of Medicine recommends prompt identification and the provision of appropriate services for the psychosocial needs of patients with cancer and other complex health problems [10]. In cancer care today, several practice guidelines recommend routine screening for psychological distress as a criterion for cancer center accreditation (the American Psychosocial Oncology Society, the Association of Oncology Social Workers and Oncology Nursing Society) [11]. The American College of Surgeons Commission on Cancer will require cancer centers to implement screening programs for psychosocial distress as a new criterion for accreditation in 2015 [12]. However,

while children in oncology settings usually receive a range of psychosocial services, care is not consistently provided within or between centers. In fact, a study of COG institutions found that only about half of families were offered psychosocial services within the first 30 days after diagnosis [13]. In another example, the Committee on AIDS for the American Academy of Pediatrics has made similar recommendations that provision of medical care must be accompanied by psychosocial services that address psychosocial development, coping and changes in the structural environment to improve outcomes [14], but again implementation of these recommendations varies widely across sites. Given the well-documented evidence for psychosocial risk, a valid screening instrument that is integrated into medical care, and that can quickly identify patients at risk is necessary in order to better address the provision of appropriate care [15]. Recently, research has shifted to the development of psychosocial screening tools to assure that screening is accomplished in an evidence-based practical manner [16].

The Distress Thermometer (DT) is a brief screening tool endorsed by the NCCN to assess for distress in adult cancer patients [17]. The DT has been widely validated in adult (>18) cancer patients, and has been recognized as a good alternative to many of the longer measures commonly used to screen for distress in cancer patients [18]. While the DT was developed for adult cancer patients, Patel *et al.* conducted a study that investigated the validity and utility of an adapted DT to screen for distress in a pediatric oncology inpatient setting [19]. Concurrent validity was demonstrated by reasonable agreement between the pediatric distress rating tool and standardized measures. Additionally, reasonable agreement was found among multiple raters of the child's distress [19]. These data suggest that the DT has promise as a time-efficient screen of distress in a pediatric oncology setting. The authors subsequently examined the potential to detect change in distress for those patients who were approaching end of life [20]. They found that the tool was sensitive in detecting increased distress in pediatric patients who became terminal and eventually died, as patients had increased distress from baseline to the last obtained assessment relative to survivors. However, a cross-sectional rating was not as informative in that group as it was not consistently elevated and thus had less utility in predicting need for services [20]. Another recent report has described 21 patients, aged 9–18 years with sarcoma, who took part in a single site feasibility study of the pediatric DT with an adapted symptom checklist, which reported that it was feasible and acceptable to young people to complete screening measures during a clinic visit [21]. Nearly half of the study group reported worries about lifestyle, practical and emotional issues as well as about physical problems. Sensitivity and specificity data were not evaluated.

Use of the pediatric DT within different pediatric cohorts that receive intense and prolonged outpatient treatment for complex medical conditions has not been described. We sought to determine the validity, acceptability and feasibility of using the DT and symptom checklist with youth (ages 7–21) living with a diverse set of serious and complex medical conditions in an outpatient setting. Additionally, as the level of agreement between caregivers, medical staff and patients in rating distress symptoms (i.e. pain, fatigue, nausea and insomnia) has been found to vary greatly [19], the current study sought to assess the inter-rater reliability of DT ratings between pediatric patients, their caregivers and medical providers as well as the acceptability and feasibility of completing the DT for patients, primary caregivers and medical providers during an outpatient medical appointment.

Methods

Sample

Outpatients ages 7–21 years old, enrolled in a medical research study at the National Institutes of Health or being treated at MedStar Georgetown University Hospital with a diagnosis of pediatric cancer, neurofibromatosis type 1 (NF1), human immunodeficiency virus (HIV), primary immune deficiencies (PIDs), DNA repair disease, sickle cell disease and Li–Fraumeni syndrome, and their medical providers were invited to participate, along with their primary caregiver. Additional inclusion criteria included the ability to speak English. Exclusion criteria included the presence of psychotic symptoms or cognitive impairment in the child, which in the judgment of the Principal or Associate Investigator, or consulting psychiatrist, would compromise the child's ability to accurately complete the measures. Two hundred eighty one patient–caregiver dyads participated in the study. Six families (three at each site) refused participation when approached, resulting in a 98% response rate. Demographic and disease characteristics are included Table 1.

Measures

Distress Thermometer

The NCCN DT is a self-report tool that asks patients to rate their emotional distress (and caregivers and medical providers, about the patients) on a visual analog scale designed to appear as a thermometer. Distress ratings range from 0 ('No Distress') to 10 ('Extreme Distress'). This thermometer has been validated in screening for distress in adult cancer and bone marrow transplant patients [22] and recently adapted for use in pediatric oncology settings [19]. According to Patel *et al.* [19], the DT was adapted into three developmental relevant versions based on foundational work done by developers of other established pediatric measures. In addition, they incorporated

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Table 1. Description of sample ($N = 289$)

Characteristics	N (%)
Child gender	
Female	139 (48.1)
Male	150 (51.9)
Child age	
7–12	88 (30.4)
13–17	133 (46.0)
18+	68 (23.5)
Relationship to child	
Mom	215 (74.4%)
Dad	57 (19.7%)
Grandparent	1 (0.3%)
Aunt/uncle—legal guardian	6 (2.1%)
Other	1(0.3%)
Child race	
White	173 (59.9%)
Black or African American	69 (23.9%)
Asian/Pacific Islander	7 (2.4%)
Biracial	17 (5.9%)
Other	5 (1.7%)
Missing	3 (1.0%)
Child ethnicity	
Latino	15 (5.2%)
Household income	
Less than $1000 per month	24 (8.3%)
$1000–$1999 per month	39 (13.5%)
$2000–$2999 per month	39 (13.5%)
$3000–$3900 per month	43 (14.9%)
$4000–$4900 per month	32 (11.1%)
$5000–$5999 per month	24 (8.3%)
More than $6000 per month	77 (26.6%)
Missing	1 (3.8%)
Diagnosis	
Cancer	136 (47.1)
NF1	80 (27.7)
HIV	36 (12.5)
PID	13 (4.5)
DNA repair diseases	3 (1.0)
Sickle cell disease	19 (6.6)
Li–Fraumeni syndrome	2 (0.7)
Disease severity	Mean (range)
Lansky (<18 years)	90.4 (60–100)
Karnofsky (18+ years)	87.4 (50–100)

recommendations from a multidisciplinary panel of child experts (social work, neuropsychology recreational therapy, child life, pediatric nursing, clinical psychology and chaplaincy) focused on the measure, which also guided development of the tool's problem check-list tailored to a pediatric population (Personal Communication, 9/28/2015). The ratings in the pediatric DT range from 0 ('No Distress') to 10 ('High Distress'). The screening tool includes a short symptom checklist where raters can indicate the reasons for their (or their child's or patient's) distress.

Distress Thermometer Acceptability and Feasibility Scales

Acceptability: Patients, primary caregivers and the child's primary medical provider rated on a scale of 1–4 how easy or difficult the DT was to complete during an outpatient visit and also indicated, on a three point scale, to what extent completing the DT bothered them.

Feasibility: After each administration of the DT to patients and caregivers, the data collector recorded how feasible the DT was to administer on a four-point scale. The DT Acceptability and Feasibility Scales were developed by the study investigators for the purpose of this study.

Children's Depression Inventory (CDI-S and CDI-P)

The CDI-S [23] is a 10-item self-report measure for depression in children, ages 7 to 17 years. The CDI is widely used, reliable and valid. It has been noted to have a bias towards cognitive symptoms [24] and has few questions on physical symptoms, potentially making it more appropriate for children with medical illness whose illness symptoms can be confounded with physical manifestations of depression [24]. The CDI Parent Version (CDI-P) is derived directly from the CDI, is scored identically and has similar psychometric properties [23]. The CDI-P was completed by caregivers of all patients, ages 7–21.

The Brief Symptom Inventory 18 (BSI-18)

The BSI-18 [25] is an 18-item self-report measure to screen for psychological distress and psychiatric disorders in medically ill patients in the community or hospital settings. The BSI-18 assesses three dimensions of emotional functioning, depression, anxiety and somatization. Because the CDI-S was only designed for patients up to age 17, patients ages 18–21 were administered the Depression dimension of the BSI-18 (6 items). The BSI-18 has excellent psychometric properties [26].

The State-Trait Anxiety Inventory for Children (STAI-C), State Scale

The STAI [27] State Anxiety Scale is a 20-item self-report measure of state-related anxiety (subjective feelings of anxiety and tension at a particular moment in time). The STAI for Children (STAI-C) can be used in individual's ages 9 to 12 years and has been used as young as age 7, while the STAI-C is appropriate for individual's ages 13 and older. The authors received permission from the author of the STAI to create a parent-report version of the STAI-C, specifically for the purposes of this study. Parent-report items were derived directly from the STAI-C.

Wong-Baker FACES Pain Scale

The FACES Pain Scale [28] is a widely used, highly reliable and valid visual analogue scale used to quickly assess for pain. The scale has been used in young children up to the elderly and asks the patient to identify their pain from a series of five cartoon faces. Children have indicated a preference for the FACES scale over verbal analogue scales [29]. Patients and caregivers completed the same form related to the patient's pain.

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The Childhood Fatigue Scales

The Childhood Fatigue Scales (CFS) [30] are instruments designed to measure fatigue in pediatric oncology patients, ages 7–18 years. Youth ages 7–12 completed the child self-report form (14 items), adolescents/young adults completed the adolescent self-report form (14 items) and caregivers completed a 17 item form to assess their perceptions of their child's fatigue. All forms use a 5-point Likert scale. The instruments have demonstrated strong validity and reliability [30] and have been used in patients up to the age of 21.

Lansky and Karnofsky scores

Medical providers completed a Lansky score for patients 17 years and younger and a Karnofsky score for patients 18 years and older. Lansky and Karnofsky scores range from 0 to 100 in increments of 10, with 0 indicating unresponsiveness/death to 100 indicating perfect health. These scores indicate the disease severity and functional capabilities of the patient [31,32]. These scores were obtained in order to assess the disease severity of the patients completing the DT.

Procedure

Patients were recruited by a study investigator at either hospital, and all data collection was completed in a single clinic visit. After reviewing and signing the assent or consent, each patient was given a self-administered DT, CDI-S or BSI-18, STAI-C, CFS, FACES and DT Acceptability Scale. Primary caregivers also consented to the study for their minor children and themselves, and completed the same scales on the child. Patient and caregiver data collection occurred simultaneously and separately and took 30 min or less each. Primary medical providers (physicians or nurse practitioner) completed the DT, giving their estimation of the patient's distress on the same day the patient and primary caregiver completed the measure. They also completed the DT Acceptability Scale and the Lansky and Karnofsky scales. Data collectors completed the DT Acceptability and Feasibility Scale after each administration of the DT to patients and caregivers.

If the patient endorsed items on the CDI-S or BSI-18 that indicated suicidal ideation, the primary protocol PI was notified, and referrals were made for further mental health evaluation. This study was approved by the Combined Neuroscience Institutional Review Board at the National Institute of Mental Health.

Analysis

To assess concurrent validity between the DT and the CDI-S/BSI-18, STAI-C, FACES and the CFS, correlation coefficients for each of the four standardized measures were assessed with that of the DT. Specific DT checklist items (sad/depressed, worried/anxious, pain and fatigue) were compared with the standardized measures with independent samples *t*-tests, with the checklist item itself used as the binary variable (symptom checked or not) and the standardized measure as the continuous variable.

To examine the inter-rater reliability of DT ratings of the patient by patient, caregiver and medical provider report, intra-class correlation coefficients were computed with two-way mixed models and absolute agreement for all three raters and for each pairing of raters (patient/caregiver, patient/medical provider and caregiver/medical provider). To examine the nature of the differences between ratings, a repeated measures ANOVA was conducted. While repeated measures ANOVA is typically conducted for longitudinal data, because the intent was to examine differences in mean DT ratings within patient subjects (caregiver, medical provider and patient DT ratings for a single patient subject), it was deemed appropriate for the current analysis.

In order to assess the acceptability of completing the DT, a cutoff was established to indicate low acceptability. Low acceptability was determined by observing whether the percent of patients, caregivers or providers indicated that the DT was difficult to complete ('somewhat hard' or 'very hard') or bothersome ('it bothered me a lot') exceeded 25% of administrations within a particular respondent type (patient, caregiver or provider). Analyses for this scale are descriptive.

To assess the feasibility of administering the DT in the outpatient clinic setting, a similar cutoff for feasibility was established. If more than 25% of administrations in any of the settings were marked somewhat or very infeasible, the instrument was considered not feasible in the clinical setting. Analyses for this scale are descriptive.

Finally, to assess the discriminatory power of the DT as an instrument to identify elevated levels of distress, receiver operating characteristic (ROC) analysis was used, with the BSI-18 depression scale and CDI-S/CDI-P scales selected as the gold standard measures (or state) against which to measure the DT. As no broad pediatric diagnostic measure of distress exists, we included in this study measures of commonly occurring types of distress in the study population (depression, anxiety, fatigue and pain). Of these four measures, only the depression measures met criteria for inclusion in ROC analysis, in that they contain diagnostic cutoffs. ROC analyses were completed for both parent and child-report measures. Cutoffs for the state variables were consistent with those indicated in the scoring manuals and are as follows: for the CDI-S and CDI-P, a cutoff of $t = 66$ was used, indicating 'much above average' [31] for the BSI-18, a cutoff of $t = 63$ was used, indicating 'caseness' [33]. Sensitivity refers to a screening test's ability to accurately identify the condition it is testing for, producing a positive screening result for individuals who actually have the condition and specificity refers to a test's ability to correctly identify individuals who do not have the condition, and produce a negative result [34]. The goal of a screening instrument is to identify most or all of patients

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Table 2. Associations between the DT rating, DT checklist items and standardized measures

	DT rating		DT checklist item[a]	
Standardized measure	**Patient**	**Caregiver**	**Patient**	**Caregiver**
Children's Depression Inventory DT checklist item: Sadness/Depression	$r = .40$**	$r = .53$**	$t = 2.6$*	$t = 8.9$**
Brief Symptom Inventory—Depression DT checklist item: Sadness/Depression	$r = .61$**	n/a	$t = 6.6$**	n/a
State-Trait Anxiety Index (State only) DT checklist item: Worried/Anxious	$r = .52$**	$r = .54$**	$t = 6.1$**	$t = 6.4$**
FACES DT checklist item: Pain	$r = .25$**	$r = .28$**	$t = 8.5$**	$t = 9.9$**
Children Chronic Fatigue Scales DT checklist item: Fatigue	$r = .41$**	$r = .47$**	$t = 5.8$**	$t = 7.5$**

*$p < .01$.
**$p < .001$.
[a]For the independent samples *t*-tests, those who checked a particular symptom on the DT were compared with those who did not.

with a particular condition, in order for additional screening to take place. Criteria for establishing high discriminatory power were set at area under the curve (AUC) $> .75$, consistent with the literature on screening [35]. Analyses were completed using SPSS 12.0.1 (Chicago, IL).

Results

Concurrent validity

Table 2 shows the correlations between DT ratings and the CDI-S, BSI-18, STAI-C, FACES pain scale and the CFS. The DT patient and caregiver ratings were significantly, moderately correlated with validated measures of depression ($r = .40$ and $r = .53$, respectively), anxiety ($r = .52$ and $r = .54$) and fatigue ($r = .41$ and $r = .47$). DT ratings were also significantly correlated with the FACES pain scale, but to a lesser extent ($r = .25$ and $r = .28$). The table also shows associations between each of the standardized measures and their related DT checklist item, which all show significant associations. For depression, the related DT checklist item was 'sad/depressed'; for anxiety it was 'worried/anxious', for pain it was 'pain' and for fatigue it was 'fatigue'. All correlations and all but one *t*-test were significant at the $p < .001$ level (*t*-test for patient CDI-S and DT checklist item was $p < .01$).

Of note, six patients (ages 18–21) endorsed thoughts of ending their life on the BSI-18 (two a little bit, one moderately, two quite a bit and one extremely) and 18 patients (ages 7–17) on the CDI-S (17 thoughts of killing self, one want to kill self). All but one of these patients also scored in the clinical range on the DT. All were evaluated by the study mental health team and triaged for appropriate follow-up services. No patients required psychiatric hospitalization. Patients were in relatively stable medical condition as rated by the medical providers on the Lansky–Karnofsky scores (mean Lansky 90.4, range 60–100; mean Karnofsky 87.4, range 50–100). No significant associations were found between DT ratings and Lansky/Karnofsky scores.

Inter-rater reliability

DT ratings between patient, caregiver and medical provider exhibited modest inter-rater reliability, with the overall intra-class correlation coefficient at .55 and the coefficient for each pair of raters at .44–.45. The strength of the inter-rater reliability increased with age for all raters combined as well as the combinations of patient/caregiver and patient/medical provider (Table 3). A repeated measures ANOVA was conducted to compare the mean DT rating between the three raters (measuring three ratings within a single patient subject). While there was no significant difference between patients (3.6) and medical providers (3.5; $t = .64$, ns), there was a significant

Table 3. Inter-rater reliability, overall and by age

	Intra-class correlation
All raters—all ages	*.55*
7–12 years[a]	.38
13–17 years[b]	.55
18+ years[c]	.61
Patient and caregiver—all ages	*.45*
7–12 years	.26
13–17 years	.47
18+ years	.60
Patient and medical provider—all ages	*.44*
7–12 years	.27
13–17 years	.41
18+ years	.51
Caregiver and medical provider—all ages	*.44*
7–12 years	.33
13–17 years	.49
18+ years	.37

[a]$n = 88$.
[b]$n = 133$.
[c]$n = 68$.

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difference between caregivers (4.4) and both patients and medical providers ($t=4.5$, $p<.001$ and $t=5.1$, $p<.001$, respectively; overall $F=15.9$, $p<.001$), with caregivers rating their child's distress approximately one point higher than patients or medical providers. In order to better understand the data, we also looked at between-rater concordance by category of the distress ratings (Low, Moderate and High), which showed 42.7% of the caregivers placed the child's distress in a different category then the child did; 28.1% rated their children as more distressed than the child did and 14.6% rated their children as less distressed than the child did (data not shown).

Feasibility

Data collectors reported that administering the DT in an outpatient setting is highly feasible for 89.3% of patients and 91.3% of caregivers. Challenges to DT administration feasibility for parents included a busy clinic schedule and their child not feeling well and for some younger children, difficulty understanding the language level of the scale.

Acceptability

Patients, caregivers and medical providers all indicated high acceptability of the DT as a tool to be completed in the clinic visit. Ninety four percent of patients, 86.9% of caregivers and 95.8% of medical providers reported that the DT was somewhat easy or very easy to complete. The remainder reported that it was somewhat difficult; no one reported that it was very difficult. Eighty-eight percent of patients, 92.4% of caregivers and 93.8% of medical providers were not bothered at all by completing the DT.

Specificity/sensitivity of DT

DT scores (parent and child) were examined using ROC to determine sensitivity and specificity of the DT relative to the selected gold standard measures of depression, the CDI-S and BSI-18 depression scale. The AUC is the summary measure that averages diagnostic accuracy across the spectrum of the test. When compared to the CDI-S, the DT had high AUC scores of .822 for caregiver rating and .802 for patient rating, indicating good diagnostic utility. For patients ages 18–21, who responded to the BSI-18 Depression subscale, AUC was even higher at .857. According to the literature, a score of 4 on the DT indicates elevated distress [20]. The cutoff of 4 yields very high sensitivity and only moderate specificity. Potentially raising the cutoff to 5 or 6 brings better specificity without substantial loss in sensitivity. Specificity and sensitivity for both measures are displayed in Table 4.

Table 4. Specificity and sensitivity of the DT with the CDI-S, CDI-P and BSI-18 depression subscale

DT score cutoff	Sensitivity	Specificity
DT patient (ages 18–21) and BSI Depression Scale		
1	1.0	.065
2	1.0	.152
3	.952	.326
4	.905	.587
5	.810	.717
6	.810	.804
7	.667	.913
8	.429	.957
9	.143	.978
10	.000	.978
DT patient (ages 7–17) and CDI-S		
1	1.0	.129
2	1.0	.268
3	1.0	.435
4	.875	.569
5	.725	.694
6	.500	.813
7	.500	.885
8	.374	.952
9	.125	.971
10	.125	.981
DT caregiver and CDI-P (for patients ages 7–21)		
1	1.0	.029
2	1.0	.157
3	1.0	.273
4	.882	.453
5	.765	.587
6	.706	.791
7	.706	.872
8	.529	.924
9	.353	.965
10	.353	.994

Discussion

Medical teams often first become aware of significant emotional distress once it becomes acute, such as when a child is not adherent to medications, severely depressed or even suicidal [36]. This reactive approach can result in additional trauma to the child and family, jeopardizing their rapport with the team as well as effective participation in their treatment [37]. The DT proved to be a reliable, valid, acceptable, feasible and sensitive measure for quickly assessing for the presence of distress in a pediatric outpatient setting with youth ages 7–21 years. Rapid screening can inform the need for further evaluation and referrals. The DT exhibited moderate concurrent validity with established, standardized screening measures of distress for depression, anxiety, pain and fatigue, for both child and caregiver report. It has good utility as a screening instrument for psychosocial distress, but should be

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followed up with a diagnostic screen for those with positive results. The DT was rated by patients ages 7–21, caregivers and providers as both highly feasible and acceptable in a clinical setting.

There was only moderate, inter-rater reliability between patient, caregiver and medical provider ratings, and the strength of this association increased with patient age. These findings are consistent with Patel's study (2011) in which several patterns of concordance among the different raters of DT (patient, parent, psychosocial team member and medical team member) were described. Our results emphasize the need to gather input on a child's distress not only from the caregiver, but also from the child. Of interest, we also found that caregivers rated their child's distress approximately 1 point higher than the child or medical providers do, particularly for younger children. This may reflect younger children's reduced ability to verbalize their distress to their parents, their lack of understanding of the term distress or confusion in how to use the thermometer. Weiner *et al.* (2015) also found that parents reported more concerns than their children [19]. Additionally, the CDI-S and the BSI-18, the validating measures for depression, identified several patients who were having thoughts of suicide. These findings suggest that future screening measures include a direct question about suicidal thoughts and intent.

Strengths and limitations

One of the primary strengths of this study includes the large sample of children and adolescents with a diverse set of medical conditions in two sites, which helps to demonstrate the overall flexibility and utility of the DT. This sample included children with different sets of symptoms, treatment related adverse effects and therefore, different psychosocial implications. The sample also included a wide pediatric age range, from 7 to 21, which encompasses a diverse set of developmental stages and potential psychosocial stressors.

The study is limited by the cross-sectional nature of the data and the fact that caregivers are largely represented by mothers. Fathers and other types of caregivers were not highly prevalent in this sample; however, the proportion of mothers in the sample resembles that in studies of parent gender and caregiving for an ill child [38]. Approximately 60% of participants are Caucasian, and while this represents a higher rate of inclusion of racial diversity than most pediatric oncology studies, replication in more diverse racial and ethnic populations would be important. Furthermore, while the accompanying symptom checklist provides additional information to contextualize the child's distress, knowing whether these symptoms interfere with the child's daily life cannot be inferred from the DT.

Future directions

Given the ease of administration and valid identification of psychosocial distress, even on repeated intervals [19], this tool may well be useful to monitor psychosocial distress across the trajectory of a variety of illnesses. Future research should consider focusing on the symptom checklist and whether quick, follow-up questions, utilizing skip patterns can efficiently gather more detailed information about specific symptoms and help determine the degree to which particular symptoms/concerns are interfering with the child's current functioning.

Some research suggests that an electronic format compared to a paper version demonstrates greater compliance and accuracy; future distress screening in pediatrics should include electronic versions [39]. To increase clinical utility, a summary report should be developed for the pediatric medical provider to provide real time feedback. This clinical summary can, in turn, improve communication with medical providers about psychosocial needs and, hopefully, prevent chronic distress or more serious problems.

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