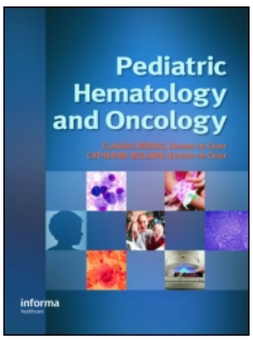

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How to interpret high levels of distress when using the Distress Thermometer in the long-term follow-up clinic? A study with Acute Lymphoblastic Leukemia survivors

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ABSTRACT

Objectives: Recent guidelines recommend to assess emotional distress in pediatric oncology during treatment and in after care. One tool used to do this is the distress thermometer (DT), a simple tool which has almost exclusively been studied in its screening abilities. Given its increased used as a measure of distress per se, it is necessary to document its concurrent validity. The goal of this study was to identify clinical domains (eg, depression, anxiety) and individual symptoms associated with pediatric cancer survivors' rating on the DT. **Participants:** To do so we used data collected from 84 young (≤18 years old), and 120 older (>18 years old) survivors who were treated for pediatric leukemia. **Methods:** Participants responded to self-report questionnaires as part of a research visit. **Results:** Results from stepwise regressions show that in the younger group, high scores on the thermometer were associated with higher negative affectivity only. In adults, high scores were associated with higher anxiety, higher negative affectivity, and lower positive affectivity. When exploring associations with individual items, we found that the main emotional tone reflected by the thermometer score was anxiety. **Conclusions:** Interpreting ratings on the thermometer should probably focus on anxiety in childhood cancer survivors. This widely used tool also does not measure the same domains in young versus older survivors, so that age groups should be considered separately in future work.

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Background

Survivors of pediatric cancer are at high risk for suffering from depressive and anxiety symptoms, behavioral problems, and significant distress [1, 2]. These repercussions affect children, adolescents, and adults who need to be assessed and referred for treatment if necessary. In Canada, following the acknowledgment of distress as the sixth vital sign, the national cancer board (Direction Québécoise de Cancérologie) prescribes the use of a distress evaluation during treatment and in after care, both in adult and pediatric oncology [3].

Among the detection tools of emotional distress routinely used in oncology, the distress thermometer (DT) is one of the most studied, mainly among adults but also in children [5].

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The DT is a single-item, pencil-and-paper self-report on a visual-analog scale, which measures emotional distress over the past week from 0 (*no distress*) to 10 (*extreme distress*) [4, 6]. The DT is quick to respond (2 minutes), it needs no scoring, and is simple to interpret. It is typically used by nurses or other health professionals [6, 7]. Both child/adult versions of the DT have been used with survivors with some success [8, 9]. Based on ongoing research, the DT could be used in the long-term clinics to identify a risk of distress in survivors. With a cut-point of 3, this instrument has shown a sensitivity of 77–88% and a specificity of 72–79% to detect cases of anxiety, depression, and comorbid anxiety-depression, in cancer survivors [8]. In fact, the majority of studies to date focus on the ability to detect anxiety and depression using clinical or subclinical thresholds [9]. However, very few studies have sought to highlight the psychological domains and symptoms associated with DT ratings, particularly following treatments of pediatric cancer [10]. The DT is a useful tool to detect clinical distress, but we do not know exactly which specific symptoms are associated with high scores of distress. Documenting concurrent validity of tools such as the DT is of primary importance as users are increasingly treating distress level on this thermometer as outcomes or predictors of clinical change, independently from their screening abilities. [11, 12].

The aims of this study were to: (a) identify specific symptoms and affects associated with DT scores in a sample of pediatric cancer survivors and (b) compare these symptoms and affects across age groups: children and adolescents ($\leq$18 years old) vs. adults ($>$18 years old).

Materials and methods

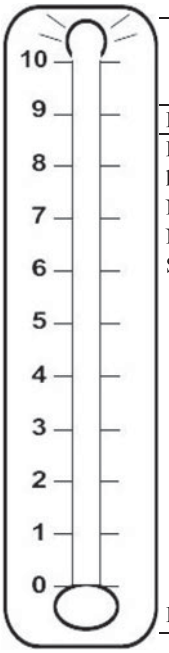
The sample includes 204 pediatric cancer survivors (47% men; 53% women; 41% $\leq$18 years old), from the PETALE-PSY childhood acute lymphoblastic leukemia (ALL) survivor cohort, who have been followed at the Sainte-Justine UHC (Montreal, $N = 176$) and Québec UHC (Quebec, $N = 28$), and treated since 1989 according to the Dana Farber Cancer Institute protocols, without recurrence. This cohort was recruited consecutively from February 2013 to May 2016. Children and adolescents ($N = 84$) had a mean age of 15 ± 2 years (8–18 years), and comprised 44 girls and 40 boys. Adults ($N = 120$) had a mean age of 26 ± 5 years (19–40 years), and comprised 64 women and 56 men. The two groups did not differ in age at diagnosis (6 ± 5 years) or in proportion of individuals with a high risk status (52%). Fifty-seven percent of the sample had undergone radiation therapy, and there was no difference in radiotherapy between age groups.

As part of a research visit to identify early biomarkers of late effects, participants answered the following questionnaires. Children and adolescents: The Beck Youth Inventories depression (20 items, $\alpha = .91$) and anxiety modules (20 items, $\alpha = .89$), the Positive and Negative Affect Scale for Children negative affects (15 items, $\alpha = .85$) and positive affects (15 items, $\alpha = .88$). Adults: Beck Depression Inventory-II (21 items $\alpha = .91$), Beck Anxiety Inventory (21 items $\alpha = .90$), Positive and Negative Affect Scale positive affects (10 items $\alpha = .83$) and negative affects (10 items $\alpha = .81$). In order to explore the associations between the score obtained on the DT and the validity measures, we conducted stepwise regression analyses (p inclusion-exclusion values $= .05$–$.10$). Each age group was analyzed separately, where the DT score was the dependent variable, and the scores and items on the measures of anxiety, depression, positive and negative affects were the independent variables.

Results

Among the children and adolescents, 11% ($N = 9$) reported high levels of anxiety (moderate or severe) and 8% ($N = 7$) displayed high levels of depression (moderate or severe).

Children and adolescents (≤ 18 years) (N = 84)		
Item	**ΔR^2**	***p***
Sad (PANAS-C)	.261	.000
Nervous (PANAS-C)	.105	.001



Adults (> 18 years) (N = 120)		
Item	**ΔR^2**	***p***
Fear of the worst happening (BAI)	.271	.000
Nervous (BAI)	.052	.008
Nervous (PANAS)	.179	.000
Scared (PANAS)	.057	.002
Interested (PANAS)	.097	.010

Note: ΔR^2 values are semi-partial correlations for regression models explaining scores on the DT using anxiety and depressive symptoms, negative and positive affects as independent variables. Only significant results are displayed based on p values corrected for multiple models (α = .05/4 models = .125).

Figure 1. Specific depressive and anxiety symptoms, and negative and positive affects associated with emotional distress measured with the DT.

Thirty-three percent ($N = 28$) of children and adolescents had a DT score ≥3, and 25% ($N = 21$) obtained scores ≥4. Among the adults, 8% ($N = 10$) reported moderate to severe symptoms of anxiety and 10% ($N = 12$) had moderate to severe symptoms of depression. Thirty-three percent ($N = 39$) had a score ≥3, and 23% ($N = 28$) had ≥4.

When examining the associations between the DT scores and scores on the scales, we found that the children and adolescents' scores were exclusively associated with the Negative Affect domain ($\beta = 0.523$, $p < .001$; $\Delta R^2 = 0.273$, $p < .001$). In adults, however, DT scores were associated with Anxiety ($\beta = 0.343$, $p = .001$; $\Delta R^2 = 0.291$, $p < .001$), Positive Affect ($\beta = -0.209$, $p = .008$; $\Delta R^2 = 0{,}045$, $p = .006$), and Negative Affect ($\beta = 0.210$, $p = .045$; $\Delta R^2 = 0{,}023$, $p = .045$), but not with Depression. In additional analyses, Exposure to radiotherapy (0 = no; 1 = yes) and Risk status (1 = SR; 2 = HR) were not significantly associated to DT scores or any depression or anxiety measures, in both groups (data not shown). To identify emotions and symptoms that could explain these associations we applied the same analysis to items of domains previously identified as being associated with the DT scores (Figure 1). In children and adolescents, feeling Sad and feeling Nervous were positively associated with the DT ratings. In adults, Fear of the worst happening, feeling Nervous, and feeling Scared were positively associated with DT scores, while the positive affect of being Interested was negatively associated with DT scores.

Conclusion

This study indicates that the DT rating in the children/adolescents and adult groups was consistently associated with the affects and symptoms of anxiety. As observed for other instruments, it is possible that the DT rating is more a reflection of emotions or mood, rather than

psychological symptoms [13]. It is also noted that the depression domain was *not* associated with the thermometer rating in either of the two age groups, while positive affects explained a small part of scores in adults, beyond the effect of anxiety and negative affect. Thus, the anxious tone is more present than the depressive tone in the DT scores (Figure 1). One explanation is that emotional distress in our sample was more characterized by anxiety than depression. However, distress domain frequencies were comparable with normative groups. It is also possible that the thermometer rating mode is more in line with the dimensional scores on anxiety, and less with the more categorical scores of the concept of depression (preliminary analyses showed that the distribution of depression was more skewed than anxiety, especially in adolescents).

When comparing the associations across age groups, we observed important differences. This could be due to emotional development, such as ways of expressing distress that are perhaps less typical or consistent in children and adolescents than in adults. An explanation would be that the instructions given to children and adolescents to rate the DT emphasized on certain emotions (*sadness*, *worry,* and *anger*) to define distress, which could explain the associations observed here.

Some factors limit the external validity of these results. First, the sample was consecutive and not randomized, even though it represents almost 50% of all individuals treated for ALL in both centers. Second, despite the corrections of the significance levels adopted for the analyses of items, given the high number of independent variables, it is possible that the detected associations could be due to chance. Finally, it is important to note that these differences in associations do not mean that the DT is a better tool to detect clinical conditions of one domain rather than another as our goal was not to yield screening cut-points for the identification of conditions such as anxiety or depression.

Despite these limitations, our study suggests that affects probably have a significant influence on the DT scores (eg, feeling nervous), and more so than psychological symptoms (eg, tremors, sleep problems, having trouble concentrating). The anxiety domain may have a more important role than the depression domain when scoring the thermometer. These findings may partly explain why it is difficult to identify positive cases for clinical conditions with this instrument [14]. The results may have important future applications in the long-term follow-up clinic. First, the use of the thermometer is supported especially if one wishes to evaluate anxiety in both age groups, and more so than depression. Second, the absence of distress on the thermometer could be interpreted as a sign of positive affectivity or well-being, but only in adults. These results are important if we are to use the DT as a traditional outcome measure and not just a screening tool as is increasingly the case [11, 12]. Future work should further investigate validity and sensitivity to change of this tool [15].

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