Université de Montréal

Stabilité temporelle du Thermomètre de détresse et de l'Échelle d'évaluation des symptômes d'Edmonton-révisée chez des parents de survivants d'une tumeur pédiatrique

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Résumé

Objectif Les parents d'enfants diagnostiqués avec un cancer rapportent de la détresse psychologique. Des instruments dotés d'une bonne fidélité sont requis pour évaluer les niveaux de détresse parentale au cours de la trajectoire de soins. L'objectif de cette étude est d'estimer la stabilité temporelle (fidélité test-retest) du Thermomètre de détresse (TD) et des items de Dépression et d'Anxiété de l'Échelle d'évaluation des symptômes d'Edmonton-révisée (EESE-r-D; -A) chez des parents d'enfants diagnostiqués avec un cancer.

Méthode Cinquante parents (28 mères, âge médian = 44) de survivants de tumeurs solides ou cérébrale pédiatrique (médiane 9 ans post-diagnostic) en situation clinique stable ont rempli des questionnaires sur leur détresse (TD, EESE-r-D et -A, Brief Symptom Inventory-18: BSI-18, Patient Health Questionnaire-9: PHQ-9, Generalized Anxiety Disorder-7: GAD-7) et la qualité de vie (QdV) de leur enfant (Peds Quality of Life: PedsQL) à deux reprises, à un mois d'intervalle. Au retest, les parents ont aussi évalué les évènements de vie survenus entre les deux temps de mesure. Des régressions hiérarchiques ont exploré les facteurs modérateurs de la stabilité des mesures à l'étude.

Résultats La fidélité test-retest était de r = .79 pour le TD, .55 pour l'EESE-r-D, et .47 pour l'EESE-r-A. Le TD était plus stable que l'EESE-r-D, -A, et le GAD-7. L'accord test/retest en ce qui a trait aux cas de détresse potentiels était bon pour le TD, mitigé pour l'EESE-r-D, et faible pour l'EESE-r-A. L'instabilité du TD a été expliquée par des changements de QdV physique de l'enfant, mais pas d'autres aspects de sa QdV ou par les évènements de vie. Nous n'avons pas identifié de facteurs modérateurs de la stabilité des items de l'EESE-r.

Conclusions Le TD semble être un instrument de mesure stable quand les conditions de vie du participant sont stables. Des fluctuations de construits associés à la détresse peuvent avoir un impact sur la stabilité du TD. La stabilité plus modeste des items de l'EESE-r pourrait être expliquée par les différentes périodes de temps ciblées dans les instructions. Les résultats incitent à poursuivre la validation du TD auprès des aidants naturels dans la période de rémission de l'enfant.

Mots clés: psychologie clinique, dépistage de la détresse, fidélité, aidants naturels, oncologie pédiatrique

Abstract

Purpose Parents report psychological distress in association with their child's cancer. Reliable tools are needed to measure parental distress over the cancer trajectory. This study aimed to estimate the temporal stability (test-retest reliability) of the Distress Thermometer (DT) and the Depression and Anxiety items of the Edmonton Symptom Assessment System-revised (ESAS-r-D; -A) in parents of children diagnosed with cancer.

Method Fifty parents (28 mothers, median age = 44) of clinically stable survivors of childhood solid and brain tumours (median 9 years post-diagnosis) completed questionnaires about their own distress (DT, ESAS-r-D and -A, Brief Symptom Inventory-18: BSI-18, Patient Health Questionnaire-9: PHQ-9, Generalized Anxiety Disorder-7: GAD-7) and their children's quality of life (QoL; Peds Quality of Life: PedsQL) twice, with a month interval between the two assessments. At retest, parents also evaluated life events, which occurred between the two time points. Hierarchical regressions explored moderators for the stability of test measures.

Results Test-retest reliability was r = .79 for the DT, .55 for the ESAS-r-D, and .47 for the ESAS-r-A. The DT was more stable than the ESAS-r-D, -A, and GAD-7. Caseness agreement between test and retest was substantial for the DT, fair for the ESAS-r-D, and slight for the ESAS-r-A. Instability of the DT could be explained by changes in child physical QoL, but not by other components of QoL or life events. No moderators of stability could be identified for the ESAS-r items.

Conclusion The DT appears to be a stable measure when the respondent's condition is stable. Fluctuations in distress-related constructs may affect the temporal stability of the DT. The lower stability of ESAS-r items may result from different time-lapse instructions. Findings support future validation research on the DT with caregivers in the child's survivorship period.

Key words: clinical psychology, distress screening, reliability, caregivers, paediatric oncology

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Liste des sigles et abréviations

ANX : Anxiety

BSI-18 : Brief Symptom Inventory-18

CI : Confidence intervals

DEP : Depression

DT : Distress Thermometer

CHU : Centre Hospitalier Universitaire

ESAS : Edmonton Symptom Assessment System

ESAS-r : Edmonton Symptom Assessment System-revised

ESAS-r-A : Edmonton Symptom Assessment System-revised, Anxiety item

ESAS-r-D : Edmonton Symptom Assessment System-revised, Depression item

GAD-7 : Generalized Anxiety Disorder-7

GSI : Global Severity Index

ICC : Intraclass correlation

LES : Life Experiences Survey

PedsQL : Pediatric Quality of Life Inventory

PHQ-9 : Patient Health Questionnaire-9

QoL : Quality of life

ROC : Receiver Operating Characteristic

SOM : Somatization

US : United States

Dédicace

À tous les parents qui traversent une épreuve avec leur enfant

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Introduction

Le cancer de l'enfant est une expérience difficile pour toute la famille, notamment pour les parents. Une revue systématique de la littérature récente suggère que la détresse émotionnelle parentale tend à culminer au diagnostic et à diminuer au travers des traitements de l'enfant, mais qu'elle est vécue selon différentes trajectoires (Sultan, Leclair, Rondeau, Burns, & Abate, 2015). Entre autre, l'historique clinique de l'enfant, le genre du parent, ses ressources personnelles et le fonctionnement familial sont des facteurs modérateurs des niveaux de détresse parentale en lien avec le cancer pédiatrique. La détresse varie en intensité et en durée selon les parents. En particulier, les études récentes suggèrent que certains parents rapportent des niveaux cliniques de détresse au cours de la période de rémission de l'enfant (Ljungman et al., 2014). Les symptômes de détresse des parents - anxiété, dépression, stress post traumatique, qualité de vie diminuée - peuvent avoir des conséquences significatives sur la qualité de vie de l'enfant déjà malade ou en rémission (Landolt, Ystrom, Sennhauser, Gnehm, & Vollrath, 2012). Compte tenu de la variabilité importante des niveaux de détresse parentale et de ses conséquences négatives potentielles, un dépistage systématique de la détresse permettrait d'identifier les parents potentiellement à risque, lesquels pourraient ensuite recevoir une évaluation plus soutenue, et éventuellement une référence vers des services psychosociaux. Face à la complexité de l'expérience émotionnelle dans un contexte de maladie grave pédiatrique, il est essentiel d'avoir recours à des instruments de dépistage précis bénéficiant de qualités psychométriques appropriées. Afin d'évaluer ces qualités, il convient de procéder à un processus de validation rigoureux, organisé au travers de différentes étapes.

Le processus de validation d'un instrument permet de quantifier et d'interpréter sa fidélité et sa validité et éventuellement son applicabilité dans un contexte donné (Thorndike &

Thorndike-Christ, 2010). La fidélité correspond à la précision d'un instrument. Elle apparaît comme la première étape essentielle du processus car elle est nécessaire à l'analyse de la validité. Il existe plusieurs types de fidélité (i.e., stabilité temporelle ou test-retest, split-half, consistance interne, etc.). La stabilité temporelle indique le degré d'association entre deux administrations d'un même test. S'il n'y a pas de changement dans la situation du répondant et si la mesure est fidèle, on attend que deux évaluations produisent des scores à peu près similaires. Une mesure peut donc être instable parce qu'elle est peu fidèle ou pour d'autres raisons (i.e., changement dans le construit mesuré). Alors que beaucoup d'étude portent sur la validité, peu sont consacrées à la fidélité, notamment temporelle. De plus, ces études font rarement l'objet d'un design et d'une interprétation rigoureuse (Watson, 2004). Au lieu d'utiliser des valeurs préétablies (par ex. : r = .80: bonne stabilité), il serait préférable d'évaluer la stabilité temporelle selon la part de changement attendue. On doit alors y distinguer le « vrai » changement psychologique de l'erreur de mesure. En guise de deuxième étape, la validité ou la pertinence d'un instrument pour mesurer un certain construit est étudiée. Un des indices de validité les plus fréquents est la validité de critère. Celle-ci permet de comparer l'instrument à une autre mesure validée du même construit (i.e., validité convergente) ou d'un construit différent (i.e., validité discriminante). Cet indice est simplement décrit par la taille de l'association (i.e., corrélation faible, moyenne, ou élevée). Dans le cas des mesures de dépistage, on doit aussi calculer un seuil clinique (*cutoff*) qui permette de distinguer au mieux les personnes qui présentent une condition des personnes n'en présentant pas, d'après une mesure critère validée (*gold standard*). Le seuil choisi maximise les qualités psychométriques de sensibilité et de spécificité. La sensibilité correspond à la part de personnes correctement identifiées comme souffrant de la condition selon le *gold standard*, alors que la spécificité

indique la part de personne correctement identifiées comme n'en souffrant pas d'après le *gold standard*. Finalement, l'applicabilité ou l'aspect pratique du test (par ex. : l'aisance à l'administrer et l'interpréter) est aussi éventuellement à investiguer.

Notre étude s'insère dans la validation de deux instruments de dépistage de la détresse, le Thermomètre de détresse (NCCN, 2015) et les items Dépression et Anxiété de l'Échelle d'évaluation des symptômes d'Edmonton-révisée (Watanabe et al., 2011) avec des parents d'enfant diagnostiqués avec un cancer. L'objectif principal de l'étude est d'évaluer la stabilité temporelle des mesures, qui n'a jamais été étudiée auparavant auprès de cette population. La validité convergente et diagnostique est aussi investiguée de manière secondaire. L'étude constitue un indicateur préliminaire de ces qualités psychométriques auprès de cette population, compte tenu de sa taille d'échantillon réduite. L'article décrivant la recherche a été raccourci et soumis à la revue scientifique *Psycho-Oncology* le 6 décembre 2015.

Temporal stability of the Distress Thermometer and the Edmonton Symptom Assessment System-revised with parents of childhood cancer survivors

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Introduction

Caring for a child with cancer is a distressing experience, which can affect parents in the long-term. Long after treatment, parents continue to be exposed to illness-related stressors such as uncertainty about cure/relapse [1], physical or emotional late effects [2], and risk of a second cancer [3]. As a consequence, a recent review suggested that even though most parents are resilient, a substantial subgroup of parents of survivors report clinical levels of distress, severe traumatic stress, and worries regarding their child's health beyond five years post-diagnosis [4]. Studies have described parents' difficult adjustment particularly when their child had received intense treatments, such as in the care of brain tumour patients [5, 6]. With parents being the primary caregivers of their child, it is paramount to address their needs accurately and promote the resilience of the whole family unit. This would start by first identifying vulnerable parents, which involves screening procedures.

Screening for distress stands as a first step in psychosocial care, which allows professionals to efficiently rule-out those who would not need further psychological assessment and concentrate their efforts on those who may have clear unmet needs [7]. However, in spite of paediatric standards of care which recommend family support, no systematic distress screening strategy is currently being implemented in paediatric oncology [8, 9]. This may potentially leave many families with untreated psychosocial difficulties. Governmental agencies in the U.S. and Canada [10, 11] have recommended using the Distress Thermometer (DT) [10] and the Edmonton Symptom Assessment System (ESAS) [12] to screen for distress in adult oncology. The single item DT and Depression and Anxiety items of the ESAS (ESAS-D and ESAS-A) are considered efficient rule-out tools with adult patients of cancer [7, 13]. The DT has been used with caregivers both in adult [14,15] and paediatric

oncology [16-18]. The ESAS has been employed as a caregiver proxy measure to describe patient distress but not caregiver status (except in an unpublished preliminary report [19]). Most research thus far on the DT has addressed its validity and feasibility, with only one study being dedicated to its reliability. This study assessed temporal stability (test-retest reliability) with cancer patients over a one-week period. A stability of $r = .80$ was reported, which was considered an "acceptable" level [20]. The stability of the ESAS and its revised version ESAS-r [21] has been studied in a number of reports. Stability over a one-week period was $\rho = .53$ (ESAS-D) and $\rho = .35$ (ESAS-A) [22]. Logically, coefficients were larger for a one-day interval [22-24]. Importantly, the interpretations of these stability levels were not based on a detailed analysis of the measured construct, participant characteristics, or time intervals [25]. Furthermore, considering the variability reported in the literature on parental distress with childhood cancer, as reported by our previous systematic review [26], stable screening instruments are all the more so required to prevent additional instability from blurring assessments. Many factors may influence the tests' stability of such tools, including changes in distress in relation to the child's status, other occurring life events during the time-lapse, or factors associated with the measures' reliability or inherent sensitivity. For example, poor child quality of life has been associated with parental post-traumatic stress symptoms [27].

Table I.

Examples of studies on the temporal stability of the DT and ESAS-D and -A

Measure	Study	Participants (adult cancers)	Temporal stability		Interval
DT	Tang et al. (2011)	$N = 106$; in remission	$r = .80$		7-10 days
ESAS			-D	-A	
	Chang et al (2000)	$N = 23$ (11 inpatients, 12 outpatients)	$\rho = .81$	$\rho = .62$	1 day
		$N = 19$ (9 inpatients, 10 outpatients)	$\rho = .54$	$\rho = .35$	1 week
	Kwon et al. (2013)	$N = 163$ (152 inpatient, 11 outpatients)*	$r = .86$	$r = .82$	2-4 hours

Note. DT: Distress thermometer, ESAS: Edmonton Symptom Assessment System, -D: Depression, -A: Anxiety,
* advanced cancer

This study had two objectives. Objective 1: To evaluate the temporal stability of the DT and the ESAS-r-D and -A (i.e., *test measures*) in parents of children survivors of cancer, and to compare it with the stability of other oncology distress-screening tools (i.e., *validity measures*). Objective 2: To explore stability moderators, by assessing the effect of changes in the child's quality of life (QoL) and life events over the time interval. We expected stability levels with parents to be larger than those observed with patients, as the latter are more likely to change as a consequence of their condition. Therefore, consistent with our study design and the test measures' time frame (DT: one week, ESAS-r: one day), we hypothesised that the DT would show strong stability ($r \geq .80$), whereas the ESAS-r items would have mild stability over a month ($r = .35$-$.55$) over a one-month period. We expected that instability in test measures would be associated with changes in children's QoL and life events during the month's period.

Methods

Participants and procedure

Data were collected between July and December 2014 at the Hematology-Oncology department of a Canadian paediatric hospital (CHU Sainte-Justine, Montreal). Sixty-one cancer survivors were randomly selected from a list of 187 eligible patients, diagnosed between 1999 and 2009. All patients on the list were younger than 18 years at time of assessment, had been diagnosed with solid or brain tumour for at least five years, and were in remission. We contacted their parents (i.e., any adult responsible for the child) by telephone ($N = 80$). To be eligible, parents had to have been involved in the child's treatment since diagnosis, and be able to read French or English. Sixty-five parents agreed to participate (81% acceptance rate) and were sent the questionnaires by surface mail. Non-responders were

parents who did not return calls. Two parents declined participation. Fifty-six parents returned the test assessment (87% response rate). Fifty-three parents returned the retest assessment (5% attrition). Three parents were excluded at retest, because they either did not provide responses for test measures or because their child had not been clinically stable between the two time points. Consequently, analyses include 50 participants (Table II and III). The project was approved by the CHU Sainte-Justine ethics committee (Project number 3910).

Materials

Demographic information. This included parents' demographics and psychological health (i.e., antecedents, past and current difficulties), family information, and child medical history and current health status. A child was clinically stable when the parent reported: 1) no current relapse, 2) stable or better health condition in the last month, 3) no health complications in the last month.

Test measures.

Distress Thermometer [10]. The DT is a screening measure of distress. It consists of an 11-point numeral scale (0 = *No distress*; 10 = *High distress*) on which subjects are asked to: "Check how much distress you have been experiencing in the past week (including today)". We used the French adaptation of the DT of the Centre Hospitalier Universitaire de Québec [28]. The DT was strongly associated with the total score of the Hospital Anxiety and Depression Scale (r = .61), yielding a cutoff of ≥ 4 for parents of children in treatment [16].

Note. The DT Problem list is not the focus of the present work. Frequencies and stability of reported problems are available on request.

Table II.

Participant information

Parents ($N = 50$)	*M (SD)*	*N*	*%*
Mothers		28	56
Fathers		20	40
Other*		2	4
Individual parents		16	32
Parents in couple		34	68
Age**	44.06 (5.71)		
30-39		10	21
40-49		30	63
50-59		8	16
Origin			
Canadian		45	90
Other		5	10
Education (obtained diploma)			
None		1	2
Secondary		14	28
College		14	28
University		20	40
Missing		1	2
Income			
< 20,000 $		9	18
20,000 - 40,000 $		8	16
40,000 - 60,000 $		20	40
60,000 - 80,000 $		4	8
> 80,000 $		7	14
Missing		2	4
Consultation for psychosocial difficulties		16	33
During child treatment		13	81
Post child treatment		3	19
Missing		1	6
Medical treatment for psychosocial difficulties (since child diagnosis)		5	10

Note. * grand-parents primary caregivers of the child since diagnosis, **: excluding grand-parents (age: 59 and 63)

Table III.

Participants' children information

Children ($N = 33$)	*M (SD)*	*N*	%
Girl		12	36
Boy		21	64
Age (years)	11.70 (3.05)		
5-7		2	6
8-12		16	49
13-17		15	45
Age at diagnosis (years)	2.79 (2.48)		
< 1		3	9
1		11	34
2-3		9	27
4-6		8	24
9-10		2	6
Time since diagnosis (years)	8.91 (2.44)		
Solid tumours		25	76
Hepatoblastoma		2	6
Histiocytosis		4	12
Neuroblastoma		8	25
Retinoblastoma		1	3
Germ cell tumour		3	9
Wilm's tumour		7	21
Brain tumours		8	24
Astrocytoma glioma		1	3
Craniopharyngioma		2	6
Gliome des voies		1	3
Medulloblastoma		3	10
Primitive neuroectodermal tumour		1	3
Treatment			
Chimiotherapy		24	73
Radiotherapy		15	45
Surgery		29	88

Edmonton Symptom Assessment System-revised (ESAS-r) [21]. The ESAS-r is a screening measure for physical/psychological symptoms. It includes nine items, answered on 11-point numeral scales, and an optional blank item for patient-specific symptoms (0 = *No symptom*; 10 = *Worst possible symptom*). Participants are asked to "Circle the number that best describes how you feel now". We used the Depression and Anxiety items. These items have

validated cutoffs of ≥ 2 and ≥ 3 in outpatients, and were strongly associated with the Patient Health Questionnaire-9 ($\rho = .72$) and the Generalized Anxiety Disorder-7 ($\rho = .74$) [13]. The ESAS has been validated in French [29].

Note. Instability in test measures was obtained by partialing out the variance of test from retest assessments in a simple linear regression and saving residuals.

Validity measures.

Brief Symptom Inventory-18 (BSI-18) [30]. The BSI-18 is a screening measure of anxiety and depression symptoms. It assesses distress over the last week on 18 items on 5-point scales (0 = *Not at all*; 4 = *Extremely*). The measure yields three subscales of six items: Somatization (SOM), Depression (DEP), Anxiety (ANX), and a general distress score (Global Severity Index, GSI). Standard cutoffs are available to evaluate the risk of caseness. High internal consistency has been reported (subscales: α = .74-.84, GSI: α = .89), which was comparable in our sample (subscales: α = .80-.87, GSI: .94). The GSI appeared to have moderate stability (r = .76, N = 103, i = 15 days) and was strongly associated with the Beck Anxiety Inventory (r = .82) and the Beck Depression Inventory (r = .75) in outpatients [31].

Patient Health Questionnaire-9 (PHQ-9) and Generalized Anxiety Disorder-7 (GAD-7) [35]. The PHQ-9 (nine items) and the GAD-7 (seven items) are screening measures that evaluate the intensity of depressive and anxious symptoms over the last two weeks on 4-point scales (0 = *Not at all*; 3 = *Nearly every day*). Scores to items are summed and totals of ≥ 10 are indicative of *moderate* symptoms. Moderate to high reliability was reported for the PHQ-9 (r = .84, N = 6000, i = 2 days, α = .89) [33] and the GAD-7 (r = .83, N = 591, α = .92 [34]. Internal consistency in our sample was also high (PHQ-9: α = .84, GAD-7: α = .86). In the general population, the PHQ-9 was strongly associated with the Brief Beck Depression

Inventory (r = .73) [35] and the GAD-7 was moderately associated with the Rosenberg Self-Esteem Scale (r = -.41) [36].

Moderators of stability of test-measures.

PedsQL 4.0 Generic Core scales: parent proxy-report (PedsQL) [37]. The PedsQL assesses the child's quality of life over the past month. It includes a total of 23 items distributed on four scales: Physical (eight items; e.g., "Taking a bath or shower by himself"), Emotional (five items; e.g., "Worrying about what will happen to him or her"), Social (five items; e.g., "Keeping up when playing with other children") and School (five items; e.g., "Keeping up with school activities"), rated on 5-point scales (0 = *Never*; 4 = *Almost always*). Internal consistency for the total score is very high in paediatric cancer (α = .93) [38], and similar in our sample (α = .92; scales: α = .74-89). Stability of the scales appeared high with children hospitalized for traumatic brain injury (r = .75-.90, N = 95, i = 8 days) [39]. The measure distinguished children with cancer from healthy children and children on-treatment from those off-treatment children [38]. Change in child QoL was calculated as the difference between test and retest levels.

Life Experiences Survey (LES) [40]. The LES is a life events inventory that measures exposure to life stress. We used the general events section of 47 items. Participants are asked to check off life events that they have experienced over the last year (e.g., New job), and to rate their impact on a 7-point scale (-3: *Extremely negative*, 3: *Extremely positive*). Negative and positive items are summed to yield a Negative and a Positive change score [41]. The Negative counterpart was moderately associated with the State-Trait Anxiety Inventory (r = .29 and .46) and the Positive counterpart to a measure of introversion-extroversion (r = .28).

The LES differentiated students who had asked for psychological help from those who had not. The time interval was adapted to the purposes of the current study (one month).

Statistical analysis

As preliminary analyses, we conducted Receiver Operating Characteristic (ROC) curve analyses to determine sample-specific optimal cutoffs for the DT and the ESAS-r to detect depression, anxiety and distress on the BSI-18, PHQ-9, and GAD-7. We performed descriptive statistics for all measures at test and retest (*M*, *SD*). For Objective 1, we used Pearson's correlations to estimate test and validity measures' relative stability, and tested the difference between these non-independent stability correlations [42]. We used paired samples *t*-tests and Cohen's *d* to estimate absolute mean-level stability. Absolute agreement between test and retest was measured by intraclass correlation coefficients (ICCs) for individual scores. To examine stability of caseness, we used cross tables with Kappa coefficients. Caseness was defined in reference to pre-validated cutoffs and using sample-specific cutoffs. For Objective 2, we used correlations to examine the association between instability in test measures and life events and change in child QoL. Then, we examined the impact of potential moderators on instability for each test measure with hierarchical regressions. Test measures (retest) were entered as the dependent variable, test measures (test) as the first block, in order to partial out the common variance between test and retest, and life events and change in child QoL were entered as alternate second blocks.

Results

Preliminary analyses

At baseline, 8% of parents met case criteria on the BSI-18, 12% on the PHQ-9, and 6% on the GAD-7, in comparison to 10% [30], 9% [35], and 3% [36] in the general population.

Following ROC curve analyses, optimal cutoffs in our sample were: ≥ 3 for the DT when detecting distress on the BSI-18, PHQ-9, and GAD-7, ≥ 3 for the ESAS-r-D when detecting depression on the PHQ-9, and ≥ 5 for the ESAS-r-A when detecting anxiety on the GAD-7 (full analysis available on request). Consequently, 32%, 36%, and 18% of parents reported case levels of distress on the DT, ESAS-D and ESAS-A, respectively (Table IV). Test measures were strongly associated at both times (*r*s = .75-.88), and they were also closely associated with validity measures (*r*s = .68-.83).

Objective 1: Temporal stability

Relative stability. Large test-retest correlation coefficients were found for the DT (r = .79, 95% CI [.65-.88]) and the ESAS-r-D (r = .55, 95% CI [.32-.72]; ρ = .68), whereas a moderate correlation was found for the ESAS-r-A (r = .47, 95% CI [.22-.66]; ρ = .52) [43]. The DT test-retest coefficient was larger than those of both ESAS-r items ($p < .01$). There was no difference between the test-retest coefficients of the ESAS-r-D and -A. Interestingly, the DT test-retest coefficient appeared larger than those of validity measures (BSI-18: r = .65, PHQ-9: r = .72, GAD-7: r = .63), but the difference was only significant with the GAD-7 test-retest coefficient (p = .018). In contrast, the test-retest coefficients of the ESAS-r items both appeared smaller than those of validity measures. Yet, only the difference between the ESAS-r-D and the PHQ-9 was significant (p = .029).

Table IV.

Descriptive statistics

	T1			T2			Comparisons			
	N	*M* (SD)	Case *N* (%)	*N*	*M* (SD)	Case *N* (%)	*t*	*d*	*ICC* [95% CI]	κ [95% CI]
Test measures										
DT	50	1.72 (2.01)	16 (32)	48	1.90 (2.46)	13 (27)	-.67	.10	.88*** [.78-.93]	.75*** [.55-.95]
ESAS-r-D	50	1.90 (1.99)	18 (36)	49	1.55 (1.87)	12 (24)	1.39	.20	.70*** [.48-.83]	.34* [.07-.61]
ESAS-r-A	50	2.40 (2.17)	9 (18)	49	2.20 (2.34)	8 (16)	.74	.10	.64*** [.37-.80]	.08 [-.23-.39]
Validity measures										
BSI-18										
Somatization	50	49.24 (9.15)	7 (14)	50	48.26 (8.89)	7 (14)	1.19	.2	.88*** [.80-.93]	.83*** [.61-1.05]
Depression	50	48.32 (8.72)	6 (12)	50	47.06 (8.40)	4 (8)	1.16	.16	.75*** [.56-.86]	.56*** [.17-.95]
Anxiety	50	47.98 (9.90)	6 (12)	50	45.54 (8.28)	2 (4)	1.75	.25	.58** [.26-.76]	.20 [-.19-.59]
GSI	50	47.58 (10.57)	4 (8)	50	45.88 (10.07)	2 (4)	1.31	.18	.78*** [.62-.88]	.30* [-.19-.79]
PHQ-9	50	3.89 (3.98)	6 (12)	50	3.65 (3.94)	5 (10)	.57	.08	.84*** [.71-.91]	.49*** [.10-.88]
GAD-7	50	3.14 (3.39)	3 (6)	50	3.08 (3.29)	3 (6)	.15	.02	.78*** [.61-.87]	.29* [-.22-.80]
Reliability moderators										
PedsQL										
Physical	50	81.54 (23.65)	-	50	83.28 (21.50)	-	-1.09	.15	.93*** [.88-.96]	-
Emotional	49	78.16 (18.84)	-	50	83.54 (15.57)	-	-2.36*	.34	.75*** [.56-.86]	-
Social	50	76.65 (24.06)	-	49	78.57 (24.77)	-	-.53	.08	.90*** [.82-.94]	-
School	50	68.50 (20.11)	-	49	75.92 (19.97)	-	-2.93**	.42	.74*** [.52-.86]	-
Total	49	76.71 (16.61)	-	49	80.63 (16.38)	-	-2.68*	.38	.88*** [.78-.94]	-
LES										
Positive	-	-	-	42	2.31 (3.67)	-	-	-	-	-
Negative	-	-	-	42	-4.88 (5.42)	-	-	-	-	-

Note. DT = Distress thermometer; Problem list 5 domains include Practical, Social, Emotional, Physical, and Cognitive Problems; Problem list 6 domains includes all problems listed and Parenting problems; ESAS-r-D = Edmonton Symptom Assessment System-revised-Depression; ESAS-r-A = Edmonton Symptom Assessment System-revised-Anxiety; Sample-specific cutoffs for the DT, ESAS-r-D and ESAS-r-A are reported; BSI-18 = Brief Symptom Inventory-18; GSI = Global Severity Index; PHQ-9 = Patient Health Questionnaire-9; GAD-7 = General Anxiety Disorder-7; PedsQL = Peds Quality of life Inventory; LES = Life Experiences Survey.
* $p < .05$, ** $p < .01$, *** $p < .001$.

Absolute stability. There were no differences between mean scores on test measures over time, which indicated negligible change in distress at the group level between test and retest. This was also observed when examining change in validity measures. Absolute score agreement between test and retest was good for the DT (*ICC* = .88) and the ESAS-r-D (*ICC* = .70), but limited for the ESAS-r-A (*ICC* = .64). Importantly, when looking at caseness on test-measures with our sample-specific cutoffs, Kappas indicated substantial agreement between test and retest for the DT, fair agreement for the ESAS-r-D, and slight agreement for the ESAS-r-A (Table IV) [44]. Agreement with pre-validated cutoffs [13, 16] was also substantial for the DT, but was moderate for the ESAS-r items. Stability for non-cases with the ESAS-r-D and -A (87 and 85%) was higher than stability for cases (44-22%). In other words, cases at test assessment were more likely to become non-cases at retest (7 and 10%) than initial non-cases to become cases at retest (4 and 6%; Table V). This observation was not consistent when examining pre-validated cutoffs.

Table V.

Stability of test measures using cutoffs

			Time 2				
			Non case	Case	Total	% Stability	% Difference [95% CI]
Time 1	DT (3+)	Non case	31	1	32	97	
		Case	4	12	16	75	22 [0-44]
		Total	35	13	48	90	
	ESAS-r-D (3+)	Non case	27	4	31	87	
		Case	10	8	18	44	43 [27-59]
		Total	37	12	49	71	
	ESAS-r-A (5+)	Non case	34	6	40	85	
		Case	7	2	9	22	63 [34-92]
		Total	41	8	49	73	

Note. DT: Distress Thermometer, ESAS-r-D: Edmonton Symptom Assessment-revised-Depression, ESAS-r-A: Edmonton Symptom Assessment-revised-Anxiety. The cutoffs are derived from preliminary analyses identifying optimal cutoffs to identify anxiety, depression and distress on validated measures (see Method section). Non case (DT = 0-2; ESAS-r-D = 0-2; ESAS-r-A = 0-4); Case (DT = 3-10; ESAS-r-D = 3-10; ESAS-r-A = 5-10), % of stability for Total were obtained by dividing the sum of stable Non case and stable case by total N. For example, for DT: (31+12)/48 = .90. CI = Confidence Intervals.

Objective 2: Moderators of stability on test measures

There was a significant increase in child total QoL between test and retest, particularly on the Emotional and School QoL subscales (Table IV). Instability on test measures was moderately associated with change in child QoL. An increase in child Physical QoL was associated with a decrease in parental distress (DT; r = -.39). An increase in child Social QoL was associated with a decrease in parental distress (DT; r = -.41), depression (ESAS-r-D; r = -.35) and anxiety symptoms (ESAS-r-A; r = -.34). An increase in child School QoL was associated with a decrease in parental anxiety (ESAS-r-A; r = -.35). There were no associations between instability and negative or positive life events. Hierarchical regressions

indicated that positive or negative life events did not predict instability in test measures. However, an improvement of the child's QoL predicted a decrease parental distress (DT) over time, with an additional 12% of variance explained. This was due to increases in Physical QoL being associated with a decrease in DT over time. Stability levels for the ESAS-r items were unrelated to life events or child QoL (Table VI).

Table VI.

Summary of hierarchical regressions predicting instability of test measures with change in child QoL and life events

	Time 2					
	DT		ESAS-r-D		ESAS-r-A	
Predictor	ΔR^2	β	ΔR^2	β	ΔR^2	β
Block 1	.58***		.22**		.15*	
Time 1		.76***		.47**		.38*
Block 2a	.01		.05		.08	
Negative life events		-.08		-.21		-.27
Positive life events		-.05		-.11		-.10
Block 2b	.12*		.14		.15	
Change in Physical QoL		-.23*		-.17		.01
Change in Emotional QoL		.08		-.11		.02
Change in Social QoL		-.17		-.22		-.25
Change in School QoL		-.11		.02		-.24

Note. DT: Distress Thermometer, ESAS-r-D: Edmonton Symptom Assessment-revised-Depression, ESAS-r-A: Edmonton Symptom Assessment-revised-Anxiety, * $p < .05$, ** $p < .01$, *** $p < .001$. Change is defined as T2-T1 for child QoL.

Discussion

Reliability refers to a measurement's precision and when combined with validity, is a necessary factor for accurate measurement. This study was the first to investigate test-retest reliability or temporal stability in the DT and the Depression and Anxiety items of the ESAS-r with parents of paediatric cancer survivors. As hypothesized at a month interval, we found strong stability levels for the DT and mild stability levels for the ESAS-r-D, but lower stability level for the ESAS-r-A. Changes in children's QoL over time, particularly on the physical

component, predicted instability on the DT.

The level of stability observed on test measures may be due to a variety of factors: psychological change over time, time intervals, instructions of test measures, and should be interpreted in comparison to measures of similar and different constructs [25]. Consistent with our study design minimizing change in distress, we found no significant change in test measures' levels over time. The capacity of the design to control for changes in distress was confirmed by the consistency of validity measures over time. As the measured constructs appear stable over time, explanations for instability probably lie with measurement sensitivity or measurement error. Parents with different levels of distress also tended to remain at the same overall level of distress over time, as described by caseness stability on the DT, but less so on the ESAS-r-D and ESAS-r-A. Parents who did not report clinical levels of distress were more likely to stay in that category, as opposed to parents who first reported clinical levels of distress. This may be accounted for by the lower base rate for cases, but it could also describe that parental distress is experienced as a normative transitory phenomenon at this stage of the cancer trajectory.

Taking into account the impact of time on stability, it is coherent that the DT test-retest coefficient with caregivers at a month interval was similar to the one reported with adult patients in remission with only a week interval [20]. This speaks in favour of a good test-retest reliability of the DT in our sample. Unexpectedly, test-retest coefficients for the ESAS-r-D and -A items in this study were larger than those with adult patients at a week interval [22]. This may result from changes in distress levels in patients over time in the latter study, which mechanically decreased the stability coefficient.

The different levels of stability of the DT and the ESAS-r items are probably due to the

time frames of the measures [25]. On the DT, participants are asked to consider their average distress level over a week. In contrast, they are asked to focus on their present distress when responding to the ESAS-r. As a consequence, higher sensitivity or lower stability is expected on the ESAS-r. The ESAS was originally designed to be used twice a day [12] and most studies investigating its stability have selected hours to days interval [22-24, 45-47]. This stresses the fact that lower stability for such an instrument is a sought-after property and certainly not a limitation of the instrument. Yet, with the present design it was not possible to disentangle measurement error from change in experienced anxiety and depression. In addition, the DT's larger stability coefficient might be partially explained by the overarching term of *distress*, which allows participants to include various manifestations of emotional difficulties, as opposed to specific symptoms on the ESAS-r. We expect broader categories to be more stable than specific transient symptoms.

When comparing our findings to other test-retest coefficients, it is important to keep in mind that test-retest coefficients for emotional experience (i.e., *state*) are not likely to be as strong as those of more enduring personality constructs (i.e., *traits*), such as Extraversion (stability over two months: .89 [48]), since the proportion of expected true change is greater for the former [25]. Moreover, although larger tests usually show stronger stability than shorter tests because they are less vulnerable to chance or settings elements [49], the one-item DT test-retest coefficient was significantly larger than the coefficient of a multi-item measure like the GAD-7.

The DT appeared as a stable instrument with parents of survivors, beyond some longer screeners, which speaks in favour of its reliability. Our findings also confirm that this tool has good convergent validity. Therefore, although the use of the DT with caregivers is still rare,

our data support future research with this population in paediatric oncology [9]. As for the ESAS-r items, our data and design are not able to disentangle a desired sensitivity from a lack of stability of the scales. Future research should use appropriate time-lapses (i.e., one day). Given their lower stability, the ESAS-r-D and -A should probably be used in situations where day-to-day changes are expected. In contrast, the DT would be more appropriate in contexts where changes are expected on a longer period.

When exploring factors associated with stability, we found that variations in parental distress on test measures were related to changes in children's QoL. Although children were clinically stable throughout the study, their emotional and school QoL increased over time. With test assessments being taken over the summer and retests once school had resumed, it is possible that a more structured routine contributed to improvements on these domains of children's QoL. Changes in children's physical, social, and school QoL between test and retest were moderately associated with instability in test measures, implying that an increase in child QoL was associated with a decrease in parental distress in the survivorship period. Although expected, this association suggests that the test measures under examination could be particularly sensitive to small changes in the parent's environment and that attention should be given to families when the child's status changes. Children's physical health appeared to have a high level of impact on parents' well-being over time, consistent with a previous report [50]. It is possible that a more observable ability (physical QoL) stands as a stronger factor of distress change as opposed to psychological QoL. Parents of cancer survivors may also be more attuned to subtle physical changes in their child's health, considering their significant and durable involvement during treatment.

Finally, our study adds to the literature by providing information about the emotional state of an understudied group of parents. Consistent with the literature describing that parental distress tends to decrease along the cancer trajectory [26], parents of survivors of solid tumours reported normative levels of distress on average [51]. Yet, almost a fifth of parents reported clinical levels of distress. Parents also reported higher depressive and anxiety symptoms than in the general population. This provides further evidence that at-risk parents should be identified as early as possible to prevent distress from persisting in the long run and promote family resilience.

We must however acknowledge the limitations of this study. First, the sample size is relatively small in comparison to suggested *N*s for stability research. Small samples will yield less accurate stability estimates, as indicated by large confidence intervals [25]. However, this sample size is typical of clinical research, especially in paediatric oncology where numbers are low. Moreover, this study was conducted with a homogeneous group of parents showing mostly low levels of distress. Since greater group variability tends to increase test-retest coefficients [49], stability levels might have been higher with a group of parents with a wider range of distress levels. Second, although participants received separate envelopes and were instructed to respond individually, we cannot assert that this was the case when both parents of the same child participated. Further, 16% of parents seemed to have had difficulty understanding the LES instructions. Consequently, the absence of association with this instrument should not be taken as an absence of impact of life events in future studies, and alternate instructions or another instrument could be used. Finally, one limitation of the study deals with the validity of the QoL proxy measure, which may reflect how parents perceive their child' QoL, instead of the child's QoL. This perception could well be influenced by

parental distress [52]. Therefore, it is possible that changes in distress influenced responses on the QoL inventory, a phenomenon that our design cannot positively identify. Despite these limitations, the assets of the present study relate to the inclusion of a population with a stable status, a theoretically-based time interval and expected associations, and comparisons with validated reference measures.

Conclusions

Reliable and valid tools are required to identify distress in families in paediatric oncology. In a sample of 50 parents of cancer survivors, we studied the temporal stability of the DT, ESAS-r-D and ESAS-r-A. We found that the DT was highly stable and more stable than the ESAS-r items, which was consistent with the different time frames of the instruments. We found that stability levels were associated with changes in children's status as reported by parents. No impact of life events was reported. The results are in favour of conducting larger stability studies on the DT with this population. Future studies could examine other moderators of stability such as gender and investigate the impact of different time-lapses between measures.

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Conclusion

Certains parents éprouveront de la détresse psychologique à des niveaux cliniques au long de la trajectoire de soins de cancer de leur enfant, d'où la pertinence d'intégrer des procédures de dépistage de la détresse efficaces et adaptées au contexte hospitalier. Nous avons évalué la stabilité temporelle et la validité convergente et diagnostique du Thermomètre de détresse et des items Dépression et Anxiété de l'Échelle d'évaluation des symptômes d'Edmonton-révisée avec des parents d'enfants diagnostiqués avec un cancer. Malgré sa taille d'échantillon réduite, l'étude a permis d'analyser le niveau de stabilité de ces échelles de manière rigoureuse, en départageant les différentes sources de l'instabilité temporelle (changement psychologique ou erreur de mesure) par le biais de son devis et de ses analyses. Les résultats de cette première étape du processus de validation soutiennent que le TD est un outil stable de dépistage de la détresse à long terme des parents et que les items de Dépression et d'Anxiété de l'EESE-r répondent à une stabilité plus réduite. En plus des aspects reliés à la fidélité, l'étude a permis d'étudier la validité des instruments par l'intermédiaire d'associations avec des mesures de la détresse (BSI-18, PHQ-9 ET GAD-7). Les instruments ont ainsi fait preuve de validité convergente élevée. Il est possible que la différence observée entre les seuils cliniques de l'étude et ceux précédemment validés soit en partie le reflet de différents niveaux de détresse, les parents d'enfants en rémission ayant tendance à rapporter moins de détresse que ceux dont les enfants sont encore en traitement. Le dépistage de la détresse doit être effectué avec un seuil approprié aux caractéristiques de la population ciblée. Afin de compléter le processus de validation des instruments, il conviendrait de répliquer cette étude avec un échantillon plus étendu (Watson, 2004). Une mesure de qualité de vie des parents pourrait être ajoutée au protocole afin d'étudier la validité discriminante. Finalement, des

études d'applicabilité tenant compte de l'appréciation des professionnels et des parents pourraient être effectuées avant d'implanter le TD dans les soins de routine en oncologie pédiatrique. Nous espérons que notre étude incitera d'autres chercheurs à compléter le processus de validation avec précision afin de faciliter l'intégration du dépistage systématiques de la détresse dans les cliniques externes. Nous souhaitons ainsi permettre aux équipes de pouvoir encore mieux aider les parents qui en auraient besoin. Une fois validé avec cette population, le TD pourrait être utilisé pour étudier les associations entre la détresse parentale et le développement des survivants. Comme ces derniers rencontrent davantage de difficultés scolaires et sociales que des enfants n'ayant pas eu cette maladie (Barrera, Shaw, Speechley, Maunsell & Pogany, 2005), des études pourraient investiguer l'impact de la détresse parentale via le TD sur le sentiment de confiance en soi du survivant. Au-delà des objectifs psychométriques, la présente étude représente une étape importante dans l'établissement de recherches et d'applications cliniques de qualité.

Références de l'introduction et de la conclusion

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