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Distress Screening in Parents of Children with Cancer During Active Treatment: A Pilot Study

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ABSTRACT

Introduction: *A cancer diagnosis during childhood is associated with significant psychological distress in parents. While distress screening is now recognized as a standard of care in pediatric oncology, few programs have effectively implemented this practice—particularly for caregivers of children newly diagnosed with cancer.*

Objective: *In this pilot study, we gathered caregiver distress screening results at two different timepoints (T1 and T2), as part of an initiative to implement systematic distress screening by Oncology Nurse Navigators (ONNs) in a large pediatric oncology centre.*

Method: *Data were analyzed from the Distress Detection Tool (DDT) using a standard quantitative descriptive approach. The DDT includes two validated measures: the Distress Thermometer (DT) with an accompanying Problem List (DT-P) and the Edmonton Symptom Assessment System–Revised (ESAS-r).*

Results: *Fourteen parents agreed to participate and completed assessments at both timepoints, resulting in a total of 28 DDT assessments analyzed. At the time of assessment, parents were approximately 3.6 months post-diagnosis of their child at T1 and 8.3 months at T2. The mean distress score on the DT was 3.57 (SD = 2.35, range = 0–9), with an average of 6.89 problems reported on the Problem List (SD = 4.79, range = 0–18). A total of 42.9% (n = 12) of participants scored above the clinical cut-off of 4 on the DT. Comparison of results between T1 and T2 revealed a decrease in distress scores, with a large to very large effect size (Cohen's d = -1.01). Additionally, there was a 28.5% reduction in the number of parents reporting clinically significant distress. On the ESAS-r, a substantial proportion of parents continued to report clinically significant scores at T2, particularly for fatigue (64.3%, n = 9), drowsiness (57.1%, n = 8), and anxiety (57.1%, n = 8).*

Conclusion: *To our knowledge, this is the first study to examine ESAS-r results and referral rates following distress screening in this population. While distress generally decreases over time, many parents continue to experience significant distress and psychosocial issues. These findings align with previous research and underscore the importance of systematic distress screening to ensure equitable access to care. The DT-P is a practical and effective tool; however, further research is needed before the ESAS-r can be fully integrated as a screening tool for parents of children with cancer.*

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INTRODUCTION

Each year, more than 300 children are diagnosed with cancer in Quebec and more than 1,000 in Canada, with an overall survival rate of 82% (Agence de la santé publique du Canada, 2017; Gouvernement du Québec, 2022). Although the survival rate is relatively high in the pediatric population, the diagnosis, treatments, side effects, and complications represent significant stressors for patients and their families. Caring for a sick child is a challenging experience that affects parents both in the short and long term. While most parents eventually adapt to their new reality, a small but substantial proportion develop psychosocial or psychological problems (Kazak et al., 2015; Pierce et al., 2017; Schepers et al., 2018).

In most cases, parents must reorganize their daily lives and stop working. Typically, one parent stays at the hospital with the sick child while the other remains at home with siblings or continues working to maintain financial stability. Moreover, since most parents lack a medical background, they are required to rapidly acquire a range of caregiving and medical skills. These include administering medication, oral chemotherapy, handling central venous catheters, and delivering subcutaneous injections. Parents frequently face financial, emotional, practical, and functional challenges. Numerous studies have demonstrated that anxiety, depression, post-traumatic stress, and other psychosocial issues are significantly associated with parenting a child undergoing cancer treatment (Katz et al., 2018; Nam et al., 2016; Pierce et al., 2017).

Distress screening for these parents is now recognized as a standard of care (Kazak et al., 2015) and is associated with reduced distress and improved quality of life (Barrera et al., 2018). To ensure the highest possible quality of care, a group of experts and decision-makers from Quebec's two largest pediatric oncology centres, conceptualized and introduced a tool called the "Distress Detection Tool" (DDT). This tool combines two well-established and validated psychosocial scales used in oncology: the Distress Thermometer with Problem list (DT-P) and the Edmonton Symptom Assessment System Revised (ESAS-r).

Given the necessity to implement distress screening tools rapidly in pediatric oncology, a larger study was launched in 2021 to implement the DDT (Bernier et al., 2026). As part of this broader initiative, the objectives of the present pilot study are to explore the psychological distress in parents of children

undergoing active cancer treatments by 1) measuring outcomes using the DDT, 2) exploring changes in distress level over time, and 3) investigating whether screening leads to an increased referral rate.

To our knowledge, this is the first study to explore the distress in parents of children with cancer using DDT. While the DT-P has been used previously in this population, the ESAS-r has not yet been applied in this specific context.

METHOD

This study was conducted at Canada's second-largest pediatric teaching hospital, located in the metropolitan region of Montreal in Quebec. The caregiver data presented here are part of a larger study that explored distress screening using the DDT and gathered feedback from both parents and Oncology Nurse Navigators (ONNs; Bernier et al., 2026).

It was determined that the involvement of ONNs was essential for the early detection of caregiver distress. Their unique role enables them to build trusting relationships with families, facilitate open communication, and ensure timely access to psychosocial resources. Parents were identified by their ONN and invited to participate in the study by a member of the research team. Once informed consent was obtained, the ONN invited parents to complete the DDT, regardless of the time since diagnosis (T1). As a reminder, the primary aim of the larger study was to implement the DDT rather than to analyze specific outcomes tied to specific timing. Following the completion of the DDT, the ONN met privately with the parents to review the results, gain a deeper understanding of their experience, provide emotional support, and offer referrals to professional services when appropriate.

Participating parents were asked to complete the DDT at a second timepoint (T2). The ONN determined both timepoints based on their clinical judgment, considering individual diagnoses, treatment plans, and key moments in the care trajectory. Although ONNs had discretion in identifying optimal screening moments, the research team recommended that no more than 6 months elapse between T1 and T2. The first author (PB) monitored the interval between DDT completions and acted as the super-user, offering technical and procedural support to ONNs, as needed.

Participants

The inclusion criteria were being a parent of a child diagnosed with cancer during the active treatment phase and fluency in spoken and written French. Parents of children receiving palliative care were excluded from the study.

Of the 21 parents who agreed to participate in the larger study, only the 14 parents (mothers $n = 8$) of children with cancer who completed the DDT at both timepoints were included in this analysis, yielding a total of 28 DDT assessments. This selection was made to reduce the influence of the small sample size on the exploratory comparisons between T1 and T2.

Measures

The DDT comprises two validated scales, the DT-P and the ESAS-r. The DT-P includes a distress thermometer (DT) ranging from 0 (no distress) to 10 (extreme distress), together with a list of 38 potential problems that parents are asked to check if they are experiencing them. The DT-P has demonstrated good psychometric properties across various contexts and medical settings, including pediatric oncology showing high levels of stability, sensitivity, and specificity (Haverman et al., 2013; Leclair et al., 2016; van Oers et al., 2017). As noted by Haverman et al. (2013), a cut-off score of 4 or higher on the DT is indicative of clinically significant psychological distress. The ESAS-r consists of nine symptoms – physical pain, fatigue, sleepiness, nausea, appetite, shortness of breath, depression, anxiety, and well-being. Parents are asked to rate each symptom on a scale from 0 (symptom not present) to 10 (worst). In this study, a cut-off score of 4 or greater for all ESAS-r items was used. As reported by Seow et al. (2012), a score of 3–4 or greater is considered as "moderate" and 6–7 as "severe" in the adult population undergoing cancer treatments. To our knowledge, the ESAS-r has not yet been fully validated for assessing symptom burden in parents of children undergoing cancer treatments.

Analysis

Based on the three objectives of this study, we employed a quantitative descriptive design to assess psychological distress in parents. Accordingly, we conducted an exploratory analysis of the results obtained from each participant's DDT.

For the first objective, we calculated the mean distress score, its standard deviation measure, and the percentage of parents who scored at or above the established cut-off score. We also identified the most frequently reported problems by determining the number (n) of parents and corresponding percentage of parents who endorsed each item. For the ESAS-r, we reported the mean scores and standard deviations of the most significant symptoms, as well as the percentage of parents scoring at or above the cut-off score.

For the second objective, we exploratively compared the results obtained at T1 and T2 using independent samples t-test, reporting both the direction and magnitude of the effect using Cohen's d (small = 0.2, medium = 0.5, large = 0.8, very large = 1.20). A negative Cohen's d indicates a decrease in item scores over time, while a positive value indicates an increase.

For the third objective, we explored the impact of distress screening and the ONN's review of the DDT on the number of referrals made at each timepoint. Specifically, we examined whether completion of the DDT was associated with an increase in referrals initiated by the ONN.

RESULTS

Selected demographics

The mean age of participants was 39.1 years [31–48], and the interval between the two timepoints was 143.3 days (SD 39.42; [94–231]; approximately 4.8 months). The mean time since diagnosis was 106.8 days (SD 103.2; [12–391]; around 3.6 months) at T1 and 250.1 days (SD 104.9; [148–485]; around 8.3 months) at T2. Table 1 presents the relevant sociodemographic characteristics of participants.

Table 1

Sociodemographic of Participating Parents (n = 14)

Fathers	*n* = 6 (42.9%)
Mothers	*n* = 8 (57.1%)
Age	Mean 39.1 [31–48]
Ethnic	Caucasian *n* = 12 (85.7%) Afro-American *n* = 1 (7.1%) Latin America *n* = 1 (7.1%)
Education	Elementary *n* = 1 (7.1%) High School or Professional Education *n* = 4 (28.6%) College/CEGEP *n* = 3 (21.4%) Undergraduate *n* = 4 (28.6%) Graduate *n* = 2 (14.3%)
Religious affiliation	Catholic *n* = 2 (14.3%) Christian *n* = 1 (7.1%) None *n* = 7 (50%) Missing *n* = 4 (28.5%)
Marital situation	Single parent *n* = 2 (14.3%) Partnered *n* = 6 (42.9%) Married *n* = 5 (35.7%) Separated/Divorced *n* = 1 (7.1%)
Family situation	Still with the father/mother of my child *n* = 10 (71.4%) In a relationship, but not with my child's other parent *n* = 3 (21.4%) Single *n* = 1 (7.1%)
No. of children in the family	Mean 2.45 [2–3]
Distance from hospital	50 km or less *n* = 6 (42.9%) More than 50 km *n* = 8 (57.1%)
Work	Actually working *n* = 4 (28.6%) I have a job but actually in sick leave *n* = 10 (71.4%)
Family income	25–45k *n* = 3 (21.4%) 45–60k *n* = 2 (14.3%) 75–100k *n* = 3 (21.4%) More than 100k *n* = 6 (42.9%)
Child age	Mean 8.79 [1–16]
Child sex	Boy *n* = 13 (92.9%) Girl *n* = 1 (7.1%)
Child diagnosis	Lymphoma *n* = 7 (50%) Neuroblastoma *n* = 3 (21.4%) Osteosarcoma *n* = 1 (7.1%) Sarcoma *n* = 1 (7.1%) Rare tumours *n* = 2 (14.2%)
Treatment received	Chemotherapy *n* = 14 (100%) Radiation therapy *n* = 6 (42.9%) Immune Therapy *n* = 3 (21.4%) Surgery *n* = 5 (35.7%) Bone marrow transplant *n* = 3 (21.4%) MIBG *n* = 1 (7.1%)
Time since diagnosis	
T1	106.8 days (3.6 months; [12–391])
T2	250.1 days (8.3 months; [148–485])
Mean time between T1 et T2	143.3 days; (ET 39.42; 4.8 months; [94–231])

First objective: Measuring psychological distress in parents using DDT

Distress thermometer and list of problems (DT-P)

Overall, participating parents indicated a mean DT score of 3.57 (SD 2.35; [0–9]), with 42.9% (*n* = 12) scoring at or above the established cut-off score for significant distress. As shown in Table 2, parents endorsed an average of 6.89 problems (SD 4.79; [0–18]) out of a possible 38 on the problem list. The most frequently reported issues were fatigue (*n* = 14; 50.0%), concentration (*n* = 13; 46.4%), interacting with children (*n* = 11; 39.3%), fears (*n* = 11; 39.3%), sleep (*n* = 11; 39.3%), nervousness (*n* = 10; 35.7%), work/insurance (*n* = 10; 35.7%), dealing with child's emotions (*n* = 9; 32.1%), and memory (*n* = 8; 28.6%).

The DT-P also includes additional questions related to perceived support and the desire for further resources. Results indicated that the majority of parents felt supported by their surroundings (*n* = 26; 92.9%) and believed that those around them understood their situation (*n* = 21; 75.0%). Only a few parents reported having a concerning health problem (*n* = 4; 14.3%). Notably, all parents indicated having a positive/good relationship with their medical team (*n* = 28; 100%).

Edmonton Symptom Assessment System Revised (ESAS-r)

As shown in Table 2, the symptoms with the highest mean scores were fatigue (5.25, SD 1.96), anxiety (4.18, SD 2.84), and sleepiness (3.42, SD 2.30). The mean score for the perceived impact of symptoms on daily functioning was 5.20 (SD 2.14). A clinically significant level of fatigue, anxiety, and sleepiness was reported by 78.6% (*n* = 22), 60.7% (*n* = 17), and 57.1% (*n* = 16) of parents, respectively. Although only eight parents completed this question at both T1 and T2, 75% (*n* = 12) of them indicated that the symptoms reported on the ESAS-r had a significant impact on their daily functioning.

Second objective: Exploratory comparison between timepoints

DT-P

When comparing the results between T1 and T2, a large and clinically significant negative effect size (*d* = -1.01) was observed for the DT score, as shown in Table 2. Specifically, there was a 46.1% reduction in distress intensity (T1 4.64; T2 2.50), along with a 28.5% decrease in the proportion of parents reporting clinically significant distress. A moderate negative effect size was also noted for the total number of problems reported by parents (*d* = -0.53). Additionally, moderate to large negative effect sizes were observed in specific problem domains: practical (*d* = -0.61), emotional (*d* = -0.63), and parenting (*d* = -0.75). Furthermore, there were moderate to large positive effect sizes for the number of parents reporting no problems in the practical (*d* = 1.04), emotional (*d* = 0.80), parenting (*d* = 0.76), and cognitive (*d* = 0.58) domains between T1 and T2, suggesting notable improvements in these areas over time.

More specifically, when comparing T1 and T2, moderate to large negative effect sizes were observed for several items on the DT-P: Leisure-Relaxation (*d* = -0.87), Housing (*d* = -0.71), Finance-Insurance (*d* = -0.06), Expressing Emotions (*d* = -0.56), Repetitive Thought (*d* = -0.56), Talking About the Disease with

Table 2

Distress Thermometer with Problems Scores

Distress Thermometer				Scores	CI 95%	
		Mean	SD	d cohens	Lower	Higher
DT score	T1	4.64	2.24	-1.01	-1.79	-0.21
	T2	2.5	1.99			
List of problems					**CI 95%**	
		Mean	**SD**	**d cohens**	**Lower**	**Higher**
Total n of problems [0–38]	T1	8.14	3.94	-0.53	-1.28	0.23
	T2	5.64	5.36			
Total n of practical problems [0–6]	T1	1.93	1.27	-0.61	-1.36	0.16
	T2	1.07	1.54			
Leisure-Relaxation [0–1]	T1	0.43	0.51	-0.87	-1.64	-0.09
	T2	0.07	0.27			
Cleaning [0–1]	T1	0.29	0.47	-0.16	-0.9	0.58
	T2	0.21	0.43			
Housing [0–1]	T1	0.21	0.43	-0.71	-1.47	0.06
	T2	0	0			
Finance-Insurance [0–1]	T1	0.5	0.52	-0.6	-1.35	0.16
	T2	0.21	0.43			
Child Care [0–1]	T1	0.29	0.47	-0.16	-0.9	0.58
	T2	0.21	0.43			
Work-Study [0–1]	T1	0.21	0.43	0.31	-0.44	1.05
	T2	0.36	0.5			
No Practical Problem [0–1]	T1	0.07	0.27	1.04	0.24	1.82
	T2	0.5	0.52			
Total n of Emotional Problems [0–10]	T1	2	1.3	-0.63	-1.39	0.13
	T2	1.14	1.41			
Nervousness [0–1]	T1	0.36	0.5	0		
	T2	0.36	0.5			
Expressing Emotions [0–1]	T1	0.29	0.47	-0.56	-1.31	0.2
	T2	0.07	0.27			
Controling Emotions [0–1]	T1	0.21	0.43	-0.18	-0.92	0.56
	T2	0.14	0.36			
Fears [0–1]	T1	0.5	0.52	-0.43	-1.18	0.32
	T2	0.29	0.47			
Guilt [0–1]	T1	0.07	0.27	-0.38	-1.12	0.37
	T2	0	0			
Self-confidence [0–1]	T1	0	0	0.38	-0.37	1.12
	T2	0.07	0.27			
Depression [0–1]	T1	0.14	0.36	-0.22	-0.97	0.52
	T2	0.07	0.27			
Substance use [0–1]	T1	0	0	0		
	T2	0	0			
Repetitive thoughts [0–1]	T1	0.29	0.47	-0.56	-1.31	0.2
	T2	0.07	0.27			

Loneliness [0–1]	T1	0.14	0.36	-0.22	-0.97	0.52
	T2	0.07	0.27			
No Emotional Problem [0–1]	T1	0.14	0.36	0.8	0.02	1.56
	T2	0.5	0.52			
Total n of parenting problems [0-5]	T1	1.14	0.77	-0.75	-1.51	0.03
	T2	0.57	0.76			
Dealing With Child Emotions [0–1]	T1	0.43	0.51	-0.45	-1.2	0.3
	T2	0.21	0.43			
Dealing With Child Autonomy [0–1]	T1	0.21	0.43	-0.4	-1.15	0.35
	T2	0.07	0.27			
Following Professional Advice [0–1]	T1	0.14	0.36	0		
	T2	0.14	0.36			
Talking About Disease With My Child [0–1]	T1	0.36	0.5	-0.72	-1.48	0.06
	T2	0.07	0.27			
Relation With Child [0–1]	T1	0	0	0.38	-0.37	1.12
	T2	0.07	0.27			
No Parenting Problem [0–1]	T1	0.21	0.43	0.76	-0.02	1.52
	T2	0.57	0.51			
Total n of Family Problems [0–4]	T1	0.79	0.8	0		
	T2	0.79	1.12			
Interacting With Children [0–1]	T1	0.36	0.5	0.14	-0.6	0.88
	T2	0.43	0.51			
Marital Relationship [0–1]	T1	0.21	0.43	0		
	T2	0.21	0.43			
Relation With Family [0–1]	T1	0.07	0.27	0		
	T2	0.07	0.27			
Relation With Friends [0–1]	T1	0.14	0.36	-0.56	-1.31	0.2
	T2	0	0			
No Family Problem [0–1]	T1	0.42	0.51	0.16	-0.61	0.93
	T2	0.5	0.52			
Total n of Physical Problems [0–11]	T1	1.5	1.09	-0.13	-0.87	0.62
	T2	1.36	1.15			
Fatigue [0–1]	T1	0.5	0.52	0		
	T2	0.5	0.52			
Sleep [0–1]	T1	0.43	0.51	-0.14	-0.88	0.6
	T2	0.36	0.36			
Physical Condition [0–1]	T1	0.21	0.5	-0.18	-0.92	0.56
	T2	0.14	0.43			
Eating [0–1]	T1	0.21	0.43	-0.4	-1.15	0.35
	T2	0.07	0.27			
Weight [0–1]	T1	0.14	0.36	-0.22	-0.97	0.52
	T2	0.07	0.27			
Pain [0–1]	T1	0	0	0.56	-0.2	1.31
	T2	0.14	0.36			
Sexuality [0–1]	T1	0	0	0.38	-0.37	1.12
	T2	0.07	0.27			

No Physical Problem [0–1]	T1	0.14	0.36	0.18	-0.56	0.92
	T2	0.21	0.43			
Total n of cognitive problems [0-2]	T1	0.79	0.8	-0.08	-0.82	0.66
	T2	0.71	0.91			
Concentration [0–1]	T1	0.5	0.52	-0.14	-0.88	0.6
	T2	0.43	0.51			
Memory [0–1]	T1	0.29	0.47	0		
	T2	0.29	0.47			
No Cognitive Problem [0–1]	T1	0.29	0.47	0.58	-0.18	1.33
	T2	0.57	0.51			
ESAS-r					**CI 95%**	
		Mean [0–10]	**SD**	**d Cohen**	**Lower**	**Higher**
Pain	T1	1	1.47	0		
	T2	1	2			
Fatigue	T1	5.57	1.4	-0.33	-1.07	0.42
	T2	4.93	2.4			
Sleepiness	T1	3.43	2.34	0		
	T2	3.43	2.34			
Nausea	T1	0.36	0.93	-0.07	-0.81	0.67
	T2	0.27	1.07			
Appetite	T1	1.57	2.06	-0.47	-1.22	0.29
	T2	0.71	1.54			
Shortness of Breath	T1	0.71	1.2	0.15	-0.6	0.89
	T2	0.93	1.69			
Depression	T1	3.14	2.35	-0.58	-1.33	0.18
	T2	1.86	2.07			
Anxiety	T1	4.57	3.03	-0.27	-1.02	0.47
	T2	3.79	2.69			
Well-Being	T1	4.93	1.54	-0.43	-1.18	0.32
	T2	4	2.6			
Impact of the Problems	T1	6.25	1.39	-1.2	-2.3	-0.07
	T2	4	2.31			
Additional Questions					**CI 95%**	
		Mean [0–1]	**SD**	**d Cohen**	**Lower**	**Higher**
I have the support of my surroundings	T1	0.93	0.27	0		
	T2	0.93	0.27			
My surroundings understand my situation	T1	0.79	0.47	-0.16	-0.9	.58
	T2	0.71	0.43			
I have a good relationship with the medical team	T1	1	0	0		
	T2	1	0			
I have a health problem that concerns me	T1	0.14	0.36	0		
	T2	0.14	0.36			

my Child (d = -0.72), Relation with Friends (d = -0.56). Pain (d = 0.56) was the only item to show a positive moderate effect size, suggesting a worsening in parents' experience.

Responses to the additional questions revealed that the majority of participating parents continued to feel supported at both timepoints (T1 and T2: 92.9%; d = 0), and felt understood by those around them, although there was a slight decrease from T1 to T2 (d = -0.16). No changes were observed between T1 and T2 regarding the proportion of parents reporting a concerning health problem (d = 0) or those reporting a good relationship with their medical team (d = 0).

ESAS-r

Among the ESAS-r items, only "depression" (d = -0.58) and the "impact of symptoms on daily functioning" (d = -1.20) showed moderate to large negative effect sizes. Although most effect sizes are small, we still noted a significantly high proportion of parents at both timepoints who scored on or above the cut-off for fatigue (T1: 92.9%; T2: 64.3%; d = -0.33), anxiety (T1: 64.3%; T2: 57.1%; d = -0.27), and sleepiness (T1 and T2: 57.1%; d = 0).

Third objective: Exploring if distress screening leads to an increased rate of referrals

In the DDT, when asked if they would like professional help regarding their situation, 46.4% (n = 13) of responding parents indicated they already had professional help, and 10.7% (n = 3) expressed a desire for such help. After the ONN reviewed the DDT with the parents, a professional referral was completed for 35.7% of them. Considering that 10.7% had already requested a referral before the ONN's assessment, this represents an additional 25% of parents for whom a referral was proposed following the use of DDT.

At T1, 21.4% (n = 3) of parents requested a referral for professional services, and 42.9% (n = 6) were already receiving services. At T2, no parent asked for professional help, but 50% (n = 7) were already receiving services. After the ONN's review, professional referrals were offered to 50% of parents at T1 (n = 7) and 21.4% at T2 (n = 3). Taking into account those who had already requested referral before the ONN's review, this indicates that an additional 28.6% at T1 and 21.4% at T2 received a referral following DDT.

Although we did not systematically track the outcome of each referral, we were informed that most referrals initiated by ONNs were to social workers, community services (e.g., LEUCAN), or family physicians.

DISCUSSION

The present study aimed to explore the psychological distress experienced by parents of children diagnosed with cancer during the active treatment period. As previously mentioned, ONNs play a crucial role in supporting families of children with cancer. Their proximity to families places them in an optimal position to assess parental distress and to identify key moments in the cancer care trajectory. Previous studies have shown that these parents often experience significant levels of psychological distress (Katz et al., 2018; Nam et al., 2016; Schepers et al., 2018). Additionally, research has demonstrated the clinical effectiveness and relevance of the DT-P in this population (Haverman et al., 2013; Leclair et al., 2016; van Oers et al., 2017). For example, Haverman et al. (2013) reported a mean DT score of 3.7 (SD 3.0) in parents of children undergoing treatment for chronic conditions (including cancer), which aligns with our finding of a mean DT score of 3.57 (SD 2.35).

Schepers et al. (2018) measured distress 6 months post-diagnosis and found that 59% of parents had a significant score. This is comparable to our result at T1 (3.6 months post-diagnosis; 57.1%) but not at T2 (8.3 months post-diagnosis; 28.6%). This difference may be due to the small sample in our study and the fact that 50% of parents received a referral for professional services at T1. Based on our experience, we believe that the distress screening itself at T1 may also have contributed to the reduced proportion of parents reporting high distress at T2. This interpretation aligns with other studies showing that distress screening can be beneficial and is associated with a decrease in distress over time (Barrera et al., 2018; Barrera et al., 2022). Consistent with this, we observed between T1 and T2 a reduction in the mean DT score, the percentage of parents above the cut-off, and a large negative Cohen's d effect size (T1: 4.64, 57.1%; T2: 2.50, 28.6%; d = -1.01, 95% CI [-1.79, -0.21]). As noted by Patel et al. (2011), caregiver distress scores tend to decrease over time. Nevertheless, a substantial proportion of parents still experience psychological distress compared to parents of healthy children (Schepers et al., 2018), underscoring the importance of ongoing monitoring and timely identification of distress in caregivers.

Based on the DT-P problem list, Isabel Tan et al. (2021) reported a mean of 8.94 problems in parents of children newly diagnosed or in relapse of cancer, which is consistent with our result at T1 (8.14; SD 3.94). Similarly, Schepers et al. (2018) found that 6 months post-diagnosis, parents reported a mean of 6.87 problems (SD 6.46) and a higher number of problems in emotional (2.18; SD 2.27), physical (1.78; 1.80), practical (1.59; SD 1.85) and cognitive (.70; SD .98) domains, which are congruent with our results at T1 but not T2. This indicates the importance of screening in this population, as it is an effective intervention to support parents and reduce distress levels. In our study, depression, fatigue, and anxiety items remained significantly, consistent with other studies showing that anxiety and depression are highly prevalent in parents of children with cancer (Katz et al., 2018; Scarponi et al., 2023; Shi et al., 2017). Caregivers may also experience more post-traumatic stress symptoms (Nam et al., 2016), higher stress levels, and greater sleep disturbances (Santacroce et al., 2020). Furthermore, it is well established that higher parental psychological distress negatively affects children's well-being (Bakula et al., 2019). These findings reinforce the need for systematic distress screening in this population, not only to support parents but also to promote better outcomes for children and adolescents undergoing cancer treatment. Another noteworthy finding is the increased number of parents reporting pain-related issues at T2, which may suggest that more physical problems emerge following a pediatric cancer diagnosis. However, the tool does not assess whether the reported pain was pre-existing, making it impossible at this stage to draw any reliable conclusions.

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