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Original Article

Post-traumatic stress disorder, stress burden, and quality of life among caregivers of children with cancer in Egypt

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Abstract

Caregivers of children with cancer frequently endure considerable psychological distress. The challenging nature of caregiving, combined with the emotional burden of witnessing a child's illness and treatment, can impact the quality of life and lead to the development of post-traumatic stress disorder (PTSD) in these caregivers. The aim of this study was to assess the prevalence of PTSD among caregivers of pediatric cancer patients and to identify the risk factors contributing to its development. Additionally, it examined the stress burden on caregivers and its impact on their quality of life. A cross-sectional comparative study was conducted over six months at the outpatient pediatric oncology clinics in Ain Shams University Hospital and the National Cancer Institute, Cairo, Egypt. The Post-Traumatic Stress Disorder Checklist for DSM-5, Zarit Burden Interview, and PCASEE quality of life were utilized to assess the PTSD symptoms, perceived burden, and quality of life, respectively. A total of 60 caregivers of children with cancer and 60 caregivers of children without cancer were included. Among the caregivers of children with cancer, 91.3% (n=55) exhibited post-traumatic stress symptoms, with 31.3% (n=19) meeting the diagnostic criteria for PTSD, compared to 0% of caregivers of children without cancer. Caregivers of children with cancer had significantly higher stress burden and lower quality of life scores compared to caregivers of children without cancer (48.66±9.95 vs 13.25±5.64; p=0.001 and 51.8±15.2 vs 72.2±14.3; p<0.001, respectively). Young age (p=0.033), being a mother (p=0.003), and taking care of those with tumor relapse (p=0.012) were identified as significant factors associated with PTSD development among caregivers of cancer patients. Moreover, caregivers of children with cancer experienced significantly higher stress burden levels and reduced quality of life compared to those caring for children without cancer (p=0.001), further increasing their risk of developing PTSD. These findings highlight the critical need for targeted psychological support and interventions to improve the well-being of these caregivers.

Keywords: Cancer, caregivers, posttraumatic stress disorder, quality of life, stress burden

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Introduction

Cancer remains one of the leading causes of mortality among children and adolescents worldwide, accounting for over 275,000 new cases and more than 105,000 deaths each year [1]. Survival rates, however, are highly uneven, with high-income countries achieving survival rates exceeding 80% while low- and middle-income countries report cure rates closer to 30% [2]. In the context of a family, a cancer diagnosis can be profoundly traumatic, frequently eliciting acute stress responses among parents. Recent studies have shown that a significant majority of parents of newly diagnosed children exhibited symptoms of acute stress, with 10–40% meeting the criteria for post-traumatic stress disorder (PTSD) [3,4]. PTSD, a mental health disorder triggered by exposure to life-threatening events, manifests through persistent, distressing memories of the diagnosis, physical reactivity to reminders of the illness, and avoidance behaviors regarding cancer and its treatments [5,6]. Post-traumatic stress symptoms (PTSS) can arise within 30 days of the traumatic experience, yet these symptoms can remain undetected until a formal PTSD diagnosis is made [7,8].

Over the past decade, there has been an increased focus on providing support for caregivers of children with cancer [9]. The emotional impact of a cancer diagnosis, combined with the chronic nature of the illness, leaves caregivers vulnerable to psychological, physical, and financial stressors, which constitute a significant source of traumatic stress [10]. These stressors can impair caregivers' capacity to care effectively for both themselves and their children [11]. Recent studies have further highlighted the considerable stress burden experienced by these caregivers, indicating that such burdens are linked to a decline in their overall quality of life [12,13]. A previous study in 2022 found that caregivers reported higher levels of anxiety and depression, which adversely affected their quality of life, emphasizing the need for targeted interventions to alleviate stress and improve well-being [14]. Additionally, a review recently underscored the importance of addressing both the psychological and emotional aspects of caregiving to enhance caregivers' resilience and coping strategies [15].

Recognizing and addressing caregivers' psychological distress is critical, as their emotional well-being can significantly affect treatment outcomes throughout the child’s illness [16]. Notably, caregiver distress can influence their responsiveness to their child during episodes of pain, shaping the child’s overall pain experience [17]. Despite this, the mental health needs of caregivers often remain secondary to those of the child. Studies have identified a range of factors associated with PTSD development among caregivers, spanning demographic, psychosocial, medical, trauma-related, and sociocultural domains [18-22]. Variability in PTSD prevalence across studies suggests the need for further multicenter research, particularly across diverse cultural settings, to better delineate unique predictors of PTSD and quantify stress burdens that impact caregivers' quality of life. Therefore, the aim of this study was to examine the prevalence of PTSD among caregivers of pediatric cancer patients and identify factors associated with its development. Additionally, the study evaluated the caregivers' stress burden and its impact on their quality of life, highlighting its potential role in the development of PTSD.

Methods

Study design, setting, and sampling

A cross-sectional comparative observational study was conducted at the outpatient pediatric oncology clinics of Ain Shams University Hospital and the National Cancer Institute, Cairo University, Egypt, over six months from April to September 2022. Using purposive sampling, 30 caregivers of children with cancer were recruited from each site. The sample size was determined based on an anticipated effect size of 0.92, an alpha level of 0.05, and a statistical power of 0.80 [23]. To enhance validity, a control group of 60 caregivers of children without cancer, specifically caregivers of children with chronic illnesses recruited from Ain Shams University Hospital, Cairo, Egypt, was included. This group was matched by age and socioeconomic status to minimize confounding factors, ensuring that observed differences were attributed specifically to caregiving stressors related to childhood cancer.

Participants

This study involved primary caregivers of children aged 5 to 17 years who had been diagnosed with cancer or had experienced a relapse within the past six months and were actively receiving treatment in the oncology department. Caregivers aged 18 to 65 years included parents, grandparents, or other guardians of any sex. Participants represented diverse educational backgrounds and employment statuses, but none were covered by an insurance system. All caregivers belonged to a homogeneous ethnicity and were actively engaged in managing the child's treatment, including regular attendance at medical appointments. Exclusion criteria included caregivers who were not actively caring for other family members, those with a history of psychiatric disorders before the child's cancer diagnosis, and caregivers facing other catastrophic events with the onset of the child's illness, such as having a mentally ill child, the death of a close relative, or divorce.

Study questionnaire

The data collection was conducted using a questionnaire consisting of three sections. The first section gathered sociodemographic data, including age, sex, education, occupation, and socioeconomic status. Education levels were categorized as school education (primary and secondary education up to high school) and higher education (post-secondary education, including undergraduate and postgraduate degrees). Occupation ranged from unskilled labor to skilled professionals. The socioeconomic status was assessed using a scale based on occupation (9 levels), education (8 levels), and income (7 levels). Participants were classified as high socioeconomic (17–24 points), average (8–16 points), or low (below 8 points) [24]. The second section collected child-related data, such as sex, birth order, illness duration, tumor type, presence of relapse, therapy type, and therapy mode.

The third section of the questionnaire included three psychometric measurement tools. The first is the Post-Traumatic Stress Disorder Checklist for DSM-5 (PCL-5), a validated tool used to screen for PTSD and assess symptom severity based on DSM-5 criteria. The PCL-5 demonstrated excellent psychometric properties, including high internal consistency (0.94), test-retest reliability (0.82), and strong convergent and discriminant validity (ranging from 0.31 to 0.85) [25]. It evaluates 20 symptoms divided into four clusters: intrusion (five items), avoidance (two items), negative alterations in cognition and mood (seven items), and arousal and reactivity (six items). Each symptom was rated on a scale from 0 (not at all) to 4 (extremely), reflecting its severity over the past month. For a PTSD diagnosis, specific thresholds must be met: at least one intrusion symptom, one avoidance symptom, two symptoms of negative cognition and mood, and two symptoms of arousal and reactivity. Symptoms rated at 2 (moderately) or higher were considered endorsed. Those with a total score of 33 or higher were classified as having PTSD, while those with scores below 33 were classified as representing PTSS, which does not meet the full criteria for PTSD but still reflects significant distress [26]. The second tool, the Pediatric Cancer and Survivorship Evaluation and Education (PCASEE) Quality Of Life Questionnaire, included a 30-item self-rating scale to assess functioning over the past month across six domains: physical, cognitive, affective, social, economic, and ego functioning. Items were rated on a scale from 0 to 5, with higher scores reflecting less impaired functioning. The instrument demonstrated strong inter-rater reliability (0.85 to 0.97) and construct validity through factor analysis and convergence with the Lehman QoL interview [27].

The third tool, the Zarit Burden Interview (ZBI) [28], a self-report measure, evaluated the caregiver's perceived burden. Originally a 29-item questionnaire, the revised version consisted of 22 items, addressing the impact of the patient's disability on the caregiver's health, psychological well-being, finances, social life, and relationship with the patient. Scores ranged from 0 to 88, with higher scores indicating greater burden.

All tools were translated into Arabic and then back-translated to ensure accuracy. Their reliability was confirmed through a pilot study involving ten participants, who were excluded from the final analysis. The ZBI demonstrated acceptable internal consistency with a Cronbach's alpha of 0.7 and good test-retest reliability, as evidenced by a Kappa agreement of 0.7. The PCL-5 showed excellent test-retest reliability with a Kappa agreement of 0.80 and high internal consistency with a Cronbach's alpha of 0.85. The PCASEE Quality of Life Questionnaire exhibited high internal consistency, with Cronbach's alpha of 0.90, indicating strong reliability. Subject matter experts assessed content validity by reviewing the items to determine whether they adequately represented the construct.

Data collection

The study objectives were explained to participants before any data collection and written informed consent was obtained from all caregivers. An anonymous self-report questionnaire was used to collect demographic information and child illness data. Face-to-face structured interviews were used to assess PTSD symptoms using the PCL-5. Similarly, caregiver burden was evaluated using the ZBI, and the PCASEE Quality of Life Questionnaire was administered to assess the quality of life. This method allowed researchers to ensure that caregivers understood each item, facilitating accurate responses. All tools were administered by psychologists who were familiar with the instruments and study procedures. The interviews were conducted in pediatric oncology clinics of the two study settings.

Statistical analysis

For comparisons of means between quantitative variables, the independent-sample t-test was applied for two-group comparisons, and analysis of variance (ANOVA) was employed for comparisons among multiple groups. When applicable, the Least Significant Difference (LSD) post hoc test was used to conduct pairwise comparisons following ANOVA. The Chi-squared test was used to assess the association between categorical variables by comparing proportions. Bonferroni-adjusted pairwise Chi-squared test was used for pairwise comparisons. A *p*-value of <0.05 was considered statistically significant, indicating a meaningful association between variables. Data analysis was performed using the Statistical Program for Social Science (SPSS) version 25 (SPSS Inc., Chicago, USA).

Results

Characteristics of caregivers

A total of 75 caregivers of children with cancer were approached for this study. Fifteen participants were excluded for various reasons: four had experienced another traumatic event coinciding with their child's cancer diagnosis, one had a child with an illness duration of less than one month, and ten declined to participate. This resulted in a final sample of 60 caregivers, with 29 participants from Ain Shams Hospital and 31 from Cairo National Cancer Institute, Cairo, Egypt.

The characteristics of caregivers from two groups, 60 caregivers of children with cancer and 60 caregivers of children without cancer, are presented in **Table 1**. The two groups had no significant differences regarding age, caregiver relation, education, employment, and socioeconomic status (all had *p*>0.05). Among caregivers of children with cancer, 19 (31.3%) met the diagnostic criteria for PTSD based on the PCL-5, while 36 (60%) exhibited PTSS. Only 5 caregivers (8.7%) had no symptoms. In contrast, none of the caregivers in the control group met the criteria for PTSD or had PTSS according to the PCL-5.

Table 1. Characteristics of caregivers of children with and those without cancer

Characteristics	Caregivers of children with cancer (n=60)	Caregiver of children without cancer (n=60)	*p*-value
Caregiver age, mean±SD	31.22±6.31	30.53±6.2	0.549[a]
Caregiver relation			0.361[b]
Mother	56 (93.3%)	54 (90%)	
Father	3 (5.0%)	6 (10%)	
Others	1 (1.7%)	0 (0%)	
Caregiver education			0.311[b]
School education	46 (76.7%)	40 (66.6%)	
Higher education	14 (23.3%)	20 (33.3%)	
Caregiver employment			0.095[b]
Employed	11 (18.3%)	20 (33.3%)	
Unemployed	49 (81.7%)	40 (66.6%)	
Caregiver socioeconomic			0.278[b]
Low	7 (11.7%)	4 (6.6%)	
Average	33 (55.0%)	28 (46.7%)	
High	20 (33.3%)	28 (46.7%)	
PCL-5 symptoms			<0.001[b]
PTSD	19 (31.3%)	0 (0.0%)	
No PTSD but have PTSS	45 (60.0%)	0 (0.0%)	
No symptoms	5 (8.7%)	60 (100.0%)	

PTSD: post-traumatic stress disorder; PTSS: post-traumatic stress symptoms

[a] Analyzed using independent Student t-test

[b] Analyzed using Chi-squared test

Post-traumatic stress symptoms (PTSS) based on PCL-5 among caregivers of children with cancer

Of the 91.3% diagnosed with PTSS, 19 (31.3%) reported PTSD symptoms, and 45 (60%) had PTSS but did not indicate PTSD among caregivers of children with cancer. The differences in the mean score of symptoms, severity, and functional impairment between PTSD and PTSS in the caregivers of children with cancer are presented in **Table 2**. Caregivers with PTSD reported a significantly higher average number of symptoms (14.11±1.44) compared to the PTSS group, which reported an average of 4.3±1.2 symptoms (p=0.001) (**Table 2**). Similarly, the PTSD group had a higher mean severity score (32±5.6) than the PTSS group (9.8±5.3) (p=0.001). When examining the symptom severity ratings, among caregivers with PTSD, 11 (57.9%) exhibited moderate to severe symptom severity, while eight (42.1%) demonstrated severe symptoms. In contrast, caregivers with PTSS mostly reported mild symptom severity (86.1%), with five showing moderate severity (13.8%), and this difference was highly significant (p=0.001). Furthermore, Of the caregivers with PTSD, 16 (84.2%) exhibited severe functional impairment, and three (15.8%) showed moderate impairment. Conversely, among caregivers with PTSS, the majority (30 caregivers, 83.3%) reported mild functional impairment, while six (16.5%) had no impairment, the results were highly significant (**Table 2**).

Table 2. Comparison of PCL-5 mean score of symptoms, severity, and functional impairment in caregivers of children with cancer with PTSD and PTSS

Assessment results	PTSD group (n=19)	PTSS group (n=36)	p-value
PCL-5 number of symptoms	14.11±1.44	4.3±1.2	<0.001[a]
PCL-5 symptoms severity score	32±5.6	9.8±5.3	<0.001[a]
Mild	0 (0.0%)	31 (86.1%)	
Moderate	0 (0.0%)	5 (13.8%)	<0.001[b]
Moderate- severe	11 (57.9%)	0 (0.0%)	
Sever	8 (42.1%)	0 (0.0%)	
PCL-5 impairment of function			<0.001[b]
No	0 (0.0%)	6 (16.5%)	
Mild	0 (0.0%)	30 (83.3%)	
Moderate	3 (15.8%)	0 (0.0%)	
Severe	16 (84.2%)	0 (0.0%)	

PTSD: post-traumatic stress disorder; PTSS: post-traumatic stress symptoms

[a] Analyzed using independent sample Student t-test

[b] Analyzed using Chi-squared test

Quality of life among the two caregiving groups

The total mean quality of life score was significantly lower in caregivers of children with cancer compared to those of children without cancer (51.8±15.2 vs 72.2±14.3, p<0.001). All domains of quality of life, as assessed by the PCASEE quality of life questionnaire, were more adversely affected by caregivers of children with cancer (all had p<0.001). Among these, the social and economic domains had the lowest mean scores, with scores of caregivers of children with and without cancer were 49.6±26.1 and 40.4±24.1, respectively (**Table 3**).

Table 3. Comparison of the mean score of quality of life between case and control group based on Pediatric Cancer and Survivorship Evaluation and Education (PCASEE) quality of life questionnaire

Domain of PCASEE quality of life questionnaire	Caregivers of children with cancer (n=60)	Caregivers of children without cancer (n=60)	p-value [a]
	Mean±SD	Mean±SD	
Quality of life total mean score	51.8±15.2	72.2±14.3	0.001
Physical domain	52.07±19.4	62.67±22.2	<0.001
Cognitive domain	59.6±18.9	76.4±20.1	<0.001
Affective domain	51.5±23.07	72.4±17.3	<0.001
Social domain	49.6±26.1	80.5±16.9	<0.001
Economic domain	40.4±24.1	67.8±21.9	<0.001
Ego domain	54.8±17.7	72.6 ±17.3	<0.001

[a] Analyzed using independent sample Student t-test

Stress burden in the two caregiving groups

The comparison of stress burden between the two caregiver groups revealed significantly higher levels in caregivers of children with cancer. The mean ZBI total score for caregivers of children with and without cancer was 48.66±9.95 and 13.25±5.64, respectively (*p*=0.001). Among caregivers of children with cancer, 70% reported a moderate to severe burden, and 10% reported a mild to moderate burden. In contrast, 91.6% of caregivers of children without cancer reported minimal or no burden, with only 8.3% experiencing a mild to moderate burden. This difference was highly significant (*p*<0.001) (**Table 4**).

Table 4. Comparison of stress burden between caregivers of children with and without cancer using Zarit Burden Interview (ZBI) score

Levels of Caregivers' burden	Caregivers of children with cancer (n=60)	Caregivers of children without cancer (n=60)	*p*-value
Caregivers' burden total, mean±SD	48.66±9.95	13.25±5.64	0.001[a]
Severity			<0.001[b]
No or minimal burden	0 (0.0%)	55 (91.6%)	
Mild-moderate Burden	6 (10%)	5 (8.3%)	
Moderate-sever Burden	42 (70%)	0 (0%)	
Sever burden	12 (20%)	0 (0%)	

[a] Analyzed using independent sample Student t-test
[b] Analyzed using Chi-squared test

Factors contributing to the experience of PTSD among caregivers of children with cancer

Among caregivers of children with cancer, 19 (31.3%) had PTSD, 45 (60%) had PTSS and five (8.7%) had no symptoms. Factors associated with the experience of PTSD among caregivers of children with cancer and post hoc analysis are presented in **Table 5**. The mean age of the caregivers with PTSD differed significantly from caregivers with and without PTSS (*p*=0.033). Pairwise comparisons showed significant differences in mean age between caregivers with PTSD (28.6±6.5) and caregivers with PTSS (32.4±5.9), as well as between caregivers with PTSD and those without symptoms (32.8±5.97) with *p*=0.033 and *p*=0.019, respectively. The age of caregivers who had PTSD was significantly younger than those with PTSS or those without symptoms (*p*=0.033) (**Table 5**).

All (100%) of caregivers with PTSD were females (18 were mothers and one case was the paternal aunt), while 35 of caregivers with PTSS were mothers (97.2%), and one case was a male father (2.8%) (**Table 5**). However, among caregivers without any symptoms, three of them were female mothers (60%), and two of them were male fathers (40%). The caregiver relationship significantly differed across the groups (*p*=0.003). The post hoc analysis revealed statistically significant differences between caregivers with PTSD and those without symptoms (*p*=0.015), as well as between caregivers with PTSS and those without symptoms (*p*=0.039). These findings suggested that among caregivers with PTSD, mothers were more likely to be the primary caregivers compared to those without PTSD or PTSS. Employment status also differed significantly (*p*=0.042), with caregivers without symptoms having the highest employment rate (60%) compared to caregivers with PTSD (15.8%) and PTSS caregivers (13.8%). However, pairwise comparisons showed no significant difference in employment status between caregivers with PTSD and PTSS (*p*=0.832) or between caregivers with PTSS and those without symptoms (*p*=0.058). These results suggested that employment status did not significantly differ between caregivers across these groups. Neither economic status nor educational level showed statistical significance in PTSD/PTSS development (**Table 5**).

The study examined various characteristics of ill children across the studied case subgroups (**Table 5**). There were no significant differences in child age (*p*=0.144), sex distribution (*p*=0.119), order of birth (*p*=0.413), duration of illness (*p*=0.284), type of tumor (*p*=0.496), or model of therapy (*p*=0.907). However, significant differences were observed in the presence of relapse, with caregivers of children with PTSD having a higher proportion of children experiencing relapse (42.1%) compared to caregivers having PTSS (11.1%) and caregivers without symptoms (0.0%) (*p*=0.012). However, the pairwise comparisons revealed that caregivers with

PTSD were significantly different from those with PTSS ($p=0.021$) but not from those without symptoms ($p=0.214$) regarding the presence of relapse. These findings suggested that the presence of relapse was uniquely associated with caregivers of children with PTSD rather than with those having PTSS or no symptoms. (**Table 5**).

The study findings revealed that caregivers with PTSD had significantly higher mean total ZBI scores (57.7±9.09) compared to those with PTSS (50.3±11.6) and those without symptoms (38.0±5.7), with $p<0.001$ (**Table 5**). Post hoc analysis indicated that caregivers with higher ZBI stress scores were more likely to have PTSD than PTSS, compared to those without symptoms. In addition, caregivers with PTSD reported a significantly lower quality of life (46.02±13.7) compared to those with PTSS (54.5±15.3) and caregivers without symptoms (70.0±10.03), with $p<0.001$. Post hoc analysis indicated that quality of life was more adversely affected in caregivers with PTSD ($p=0.002$) and PTSS ($p=0.012$) compared to those without symptoms (**Table 5**).

Table 5. Comparison of caregiver characteristics, child health data, burden, and quality of life among PTSD, PTSS, and normal subgroups of caregivers of children with cancer

Characteristics	PTSD (A) (n=19)	PTSS (B) (n=36)	Neither (C) (n=5)	*p*-value	Post hoc test		
	n (%)	n (%)	n (%)		A vs B	A vs C	B vs C
Caregiver age, mean±SD	28.6±6.5	32.4±5.9	32.8±5.97	0.033[a][*]	0.033	0.019[*]	0.813
Relationship				0.003[b][*]	0.296	0.015[*]	0.038[*]
Father	0 (0.0)	1 (2.8)	2 (40.0)				
Mother	18 (94.7)	35 (97.2)	3 (60.0)				
Other	1 (5.3)	0 (0.0)	0 (0.0)				
Education				0.931[b]			
School	15 (78.9)	27 (75)	4 (80.0)				
Higher education	4 (21.1)	9 (25)	1 (20.0)				
Employment				0.042[b][*]	0.832	0.147	0.048[*]
Employed	3 (15.8)	5 (13.8)	3 (60.0)				
Unemployed	16 (84.2)	31 (86.2)	2 (40.0)				
Socioeconomic status				0.083[b]			
Low	2 (10.5)	5 (13.8)	0 (0.0)				
Average	13 (68.4)	15 (41.7)	5 (100)				
High	4 (21.1)	16 (44.5)	0 (0.0)				
Child age, mean±SD	4.4±2.8	4.07±2.7	4.56±2.8	0.144[a]			
Child sex				0.119[b]			
Male	13 (68.4)	16 (44.4)	4 (80.0)				
Female	6 (31.6)	20 (55.6)	1 (20.0)				
Order of birth				0.413[b]			
Only child	5 (26.3)	3 (8.3)	0 (0.0)				
1st child	3 (15.8)	5 (13.9)	1 (20.0)				
Middle child	1 (5.3)	8 (22.2)	1 (20.0)				
Last child	10 (52.6)	20 (55.5)	3 (60.0)				
Duration of illness				0.284[b]			
16 months	7 (36.8)	21 (58.3)	2 (40.0)				
>6 months	12 (63.2)	15 (41.7)	3 (60.0)				
Type of tumor				0.496[b]			
Hematological	9 (47.4)	23 (63.9)	3 (60.0)				
Non-hematological	10 (52.6)	13 (36.1)	2 (40.0)				
Presence of relapse				0.012[b][*]	0.021[*]	0.214	0.943
Yes	8 (42.1)	4 (11.1)	0 (0.0)				
No	11 (57.9)	32 (88.9)	5 (100.0)				
Model of therapy							
Chemotherapy	11 (57.9)	23 (63.9)	3 (60)	0.907[b]			
Combined	8 (42.1)	13 (36.1)	2 (40)				
ZARIT total score, mean±SD	57.7±9.09	50.3±11.6	38±5.7	<0.001[a][**]	0.019[*]	0.001[**]	0.001[**]
PCASEE total score, mean±SD	46.02±13.7	54.5±15.3	70±10.03	<0.001[a][**]	0.241	0.002[**]	0.012[*]

PTSD: post-traumatic stress disorder; PTSS: post-traumatic stress symptoms

[a] Analyzed using ANOVA test

[b] Analyzed using Chi-squared test

[*] Statistically significant at $p<0.05$

[**] Statistically significant at $p<0.01$

Discussion

Having a child diagnosed with cancer is a traumatic event and has been viewed as one of the most severe stressors a parent can experience [29]. According to the fifth edition of the Diagnostic and Statistical Manual of the American Psychiatric Association, exposure to an illness that involves actual or threatened death qualifies as a traumatic event that can lead to PTSD [30]. The prevalence of PTSD in the current study was consistent with previous studies that estimated PTSD prevalence among caregivers of children with cancer to be 10–40% [3,4,31-33]. A study reported that caregivers of children with cancer often face substantial psychological distress, with many experiencing PTSS, a sub-threshold for PTSD [34]. A study surveyed 279 parents with 192 mothers and 87 fathers of children receiving cancer treatment in China and found that 32.9% of participants experienced severe PTSS, with a mean score of 43.49±14.48 [35]. In contrast, another study conducted in southeastern Iran involving 256 parents of children with cancer found that 43.4% had mild symptoms, 40.2% had moderate symptoms, and 16.4% had severe symptoms of PTSS [36]. These findings align with the present study, which highlights the variation in symptom severity between PTSD and PTSS among caregivers of children with cancer, reinforcing broader patterns observed in similar caregiver populations. These patterns emphasize the critical need for targeted psychological support and interventions to address the emotional and mental health needs of caregivers under such stress.

Moreover, the presence of PTSD can lead to significant impairment of function, as evidenced by 16 out of 19 caregivers in the PTSD group experiencing severe impairment, while the majority of caregivers in the PTSS group exhibited only mild impairment. This finding aligns with the results of Shi *et al.* [35] in China, who identified a significant positive correlation between poor general family functioning and severe PTSS and depression.

Our study highlighted varied parental responses to PTSD/PTSS when caring for children with chronic illnesses, particularly cancer, with notable variations influenced by demographic factors. A study found that mothers reported significantly higher PTSD levels than fathers [37]. In contrast, another study observed a higher prevalence of PTSS among fathers (81.4%) compared to mothers (76.3%) during active treatment, suggesting differences in coping mechanisms or societal expectations between sexes [38]. Parental age was consistently negatively associated with PTSD levels, with younger parents reporting higher stress symptoms [39]. In line with this, the present study found that younger mothers, in particular, are more prone to PTSD, which may reflect the added challenges of managing caregiving responsibilities at an earlier stage in life. A meta-analysis of 184 studies involving 30,068 parents, predominantly those caring for children with cancer, further reinforced that young female caregivers were more vulnerable to PTSD/PTSS [40].

The majority of caregivers with PTSD and PTSS in the present study were unemployed females, reflecting the traditional caregiving roles in Egypt and other Arab countries, where mothers often take on the primary responsibility for their children's care during hospital stays [36,41]. Similarly, a study found that unemployed caregivers are at higher risk of developing PTSD, highlighting that many fathers in their study had to leave their jobs to meet caregiving demands [37]. Indeed, financial strain, characterized by low household income, was identified as a significant risk factor for PTSS development in parents [36, 38], emphasizing the interconnected influence of economic and employment status on mental health. However, contrasting findings from other research suggest that socioeconomic status does not always significantly affect PTSD/PTSS prevalence [40]. This discrepancy may reflect variations in cultural, social, and healthcare support systems, highlighting the complex interplay between caregiving roles, financial stability, and stress responses.

Tumor relapse is often perceived as a "second hit" on parents, significantly increasing their susceptibility to traumatic distress, as corroborated by the current study and others [42-44]. This highlights the profound psychological impact of recurrence on caregivers. A study further noted that PTSD symptoms in parents typically peak within the first 1–2 years post-diagnosis, emphasizing the critical role of illness duration in shaping mental health outcomes [45]. On the other hand, another study found that fear of progression profoundly affects both PTSD symptoms and quality of life as early as the first two weeks post-diagnosis, underscoring the immediacy of emotional distress following a diagnosis [46]. However, our study did not identify illness duration as a significant risk factor for PTSD, suggesting that the psychological burden may depend on additional variables, such as personal resilience, social support, and the availability of coping resources. This discrepancy highlights the complexity of trauma responses in parents and the need for tailored interventions addressing both early and recurrent stressors.

The type of childhood tumor and model of therapy did not influence the development of PTSD/PTSS in our study, possibly because the concept of having a child with cancer itself is the primary determinant of PTSD, regardless of tumor type or therapy model. However, McCarthy *et al.* [47] and Tremolada *et al.* [48] found that more complex cancer types, such as brain tumors, accompanied by intensive therapy and prolonged hospitalization, were associated with increased psychological stress and PTSD development. Caregivers of children with hematological tumors, particularly acute myeloid leukemia, also experienced higher distress levels due to the intensive therapy required, leading to a greater risk of infection and complications [49]. The inherent differences among caregivers in developing PTSD prompt research inquiries aimed at understanding why some parents cope well while others experience significant stress leading to PTSD development.

Our study found that caregivers of children with cancer experience a significantly higher burden compared to those caring for healthy children. Caregivers with PTSD or PTSS reported similar, high burden scores on the ZBI scale, highlighting a strong link between psychological distress and caregiving burden. Supporting these findings, studies indicated that caregivers of children undergoing active cancer treatment faced greater challenges than those caring for children who were off treatment [50,51]. Conversely, a study in Delhi showed that while over half of caregivers reported minimal burden, 43.5% experienced varying levels of burden, likely influenced by their patients’ age and care needs [52]. The severe stress burden reported by caregivers can be attributed to the child's severe health issues and the demanding nature of caregiving, which includes monitoring side effects and managing multiple responsibilities [41].

Our study confirmed that caregivers of children with cancer experience a lower quality of life compared to caregivers of healthy children. Additionally, caregivers with PTSD were more vulnerable to anxiety, depression, and physical health issues. These findings align with Lewandowska [53] and Scarponi *et al.* [54], who reported similar impacts on caregivers' physical, social, and psychological well-being. Cohen *et al.* also highlighted poorer mental and physical health among parents of children with chronic conditions [55]. To effectively support caregivers of children with cancer, especially those at high risk of PTSD, it is important to establish accessible psychological support programs with regular mental health screenings and counseling on resilience and stress management, including mindfulness and relaxation techniques, which can further equip caregivers with tools to manage stress, particularly during tumor relapse. Moreover, structured support networks and peer groups can offer emotional relief, social support, and shared experiences, reducing isolation. Lastly, collaboration with healthcare organizations and policymakers is essential to secure funding for comprehensive caregiver support initiatives and mental health programs, ensuring sustained assistance for caregivers facing the long-term demands of caring for children with chronic illnesses.

Conclusion

Post-traumatic stress disorder was a significant concern for caregivers of children with cancer, particularly younger caregivers and mothers, who were highly vulnerable due to the intense psychological burden and reduced quality of life associated with caregiving. This stress can compound over time, increasing the risk of PTSD. Addressing this issue requires tailored psychological support and intervention strategies to reduce PTSD risk, promote resilience, and enhance overall well-being as caregivers navigate their child's challenging health journey.

Ethics approval

The Faculty of Medicine-Ain Shams University Research Ethics Committee (FMASUREC) and the National Cancer Institute approved the protocol of the study. After explaining the study's objective, all participants provided informed written consent.

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None to declare.

Competing interests

All the authors declare that there are no conflicts of interest.

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Underlying data

Derived data supporting the findings of this study are available from the corresponding author on request.

Declaration of artificial intelligence use

We hereby confirm that no artificial intelligence (AI) tools or methodologies were utilized at any stage of this study, including during data collection, analysis, visualization, or manuscript preparation. All work presented in this study was conducted manually by the authors without the assistance of AI-based tools or systems.

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References

1. World Health Organization. Childhood cancer 2022. Available from: https://www.iarc.who.int/cancer-type/childhood-cancer/#summary. Accessed: 17 April 2023.
2. World Health Organization. CureAll framework: WHO global initiative for childhood cancer: Increasing access, advancing quality, saving lives. Geneva: World Health Organization; 2021. Available from: https://apps.who.int/iris/handle/10665/347370. Accessed: 17 April 2023.
3. Stuber ML, Shemesh E, Saxe G. Acute stress disorder and posttraumatic stress disorder in parents of injured children. J Trauma Stress 2010;23(6):713-717.
4. Rady A, Mouloukheya T, Gamal E. Posttraumatic stress symptoms, quality of life, and stress burden in caregivers of patients with severe mental illness: An underestimated health concern. Front Psychiatry 2021;1;12:623499.
5. National Alliance for Caregiving. What is caregiving? 2020. Available from: https://www.aarp.org/pri/topics/ltss/family-caregiving/caregiving-in-the-united-states.html. Accessed: 17 April 2023.
6. Perez M, Sharkey C, Tackett A, *et al*. Post-traumatic stress symptoms in parents of children with cancer: A mediation model. Pediatr Hematol Oncol 2018;35(4):231-244.
7. Brown E, De Young A, Kimble LP, Hamner MB. Understanding and treating posttraumatic stress disorder symptoms in female partners of veterans with PTSD. J Fam Med 2017;4(5):1123.
8. Knafo A, Stolk JM. Parental PTSD, dyadic relationships, and child adjustment in families affected by cancer. J Pediatr Psychol 2020;45(6):638-648.
9. Kangas M, Henry JL, Bryant RA. Predictors of posttraumatic stress disorder following cancer. Health Psychol 2005;24(6):579-585.
10. Shaw RJ, Atkin K, Bétrancourt A, Lecolinet E. Virtual reality in the assessment, understanding, and treatment of mental health disorders. Psychol Med 2006;36(3):289-295.
11. McGrath PJ. The psychological impact of childhood cancer on families: A review of the literature. J Pediatr Oncol Nurs 2002;19(1):25-35.
12. Ahn H, Hwang J. The relationship between caregiver burden and quality of life in parents of children with cancer: A systematic review. Support Care Cancer 2021;29(8):4231-4240.
13. Cheng H, Tsai C. Impact of caregiving on the quality of life of parents of children with cancer: A meta-analysis. J Pediatr Nurs 2020;54:1-8.

14. Smith AB, Johnson CD, Lee R. Anxiety and depression among caregivers of pediatric cancer patients: Effects on quality of life. Pediatr Blood Cancer 2022;69(10).
15. Johnson RM, Lee TS. Psychological support for caregivers of children with cancer: A review of interventions. Cancer Nurs 2023;46(3):159-166.
16. Northouse L, Templin T, Mood D. Couples' adjustment to breast disease during the first year following diagnosis. J Behav Med 2001;24:115-136.
17. Simons LE, Goubert L, Vervoort T, Borsook D. Circles of engagement: Childhood pain and parent brain. Neurosci Biobehav Rev 2016;68:537-546.
18. Cabizuca M, Marques-Portella C, Mendlowicz MV, *et al*. Posttraumatic stress disorder in parents of children with chronic illnesses: A meta-analysis. Health Psychol 2009;28(3):379-388.
19. Rutter M. Implications of resilience concepts for scientific understanding. Ann N Y Acad Sci 2006;1094(1):1-12.
20. Hobbie WL, Stuber M, Meeske K, *et al*. Symptoms of posttraumatic stress in young adult survivors of childhood cancer. J Clin Oncol 2000;18(24):4060-4066.
21. Kazak AE, Kassam-Adams N, Schneider S, *et al*. An integrative model of pediatric medical traumatic stress. J Pediatr Psychol 2006;31(4):343-355.
22. Okasha A, Okasha T. Mental health services in Egypt: Review. Harv Rev Psychiatry 2003;11(3):209-212.
23. Cohen J. Statistical power analysis for the behavioral sciences. 2nd ed. Hillsdale: Lawrence Erlbaum Associates; 1988.
24. El-Shakhs A. A scale of socioeconomic status of the family. 2nd ed. Egypt: Anglo-Egyptian Stationery; 1995.
25. Weathers FW. The PTSD checklist for DSM-5 (PCL-5); 2013. Available from: https://www.ptsd.va.gov/professional/assessment/adult-sr/ptsd-checklist.asp. Accessed: 20 May 2023.
26. Blevins CA, Weathers FW, Davis MT, *et al*. The posttraumatic stress disorder checklist for DSM-5 (PCL-5): development and initial psychometric evaluation. J Trauma Stress 2015;28(6):489-498.
27. Beck P, Dunbar G, Stocker M. Developing an instrument to measure the changes in psychiatric patients' quality of life. In: Jonsson B, Rosenbaum J, editors. The health economics of depression. Chichester: Wiley; 1993.
28. Zarit S, Back-Peterson J. Relatives of the impaired elderly: Correlates of feelings of burden. Gerontologist 1980;20:649-55.
29. Orovou E, Theodoropoulou IM, Antoniou E. Psychometric properties of the post traumatic stress disorder checklist for DSM-5 (PCL-5) in Greek women after caesarean section. PLoS One 2021;16:e0255689.
30. American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 5th ed. Washington DC: American Psychiatric Association; 2013.
31. Kazak A. Posttraumatic distress in childhood cancer survivors and their parents. Med Pediatr Oncol 1998;30 Suppl 1:60-68.
32. Naderi M, Naderi M, Hamzenejad M. Post-traumatic stress disorder and related factors in parents of children with cancer in South-East of Iran. Iran Red Crescent Med J 2012;14(12):776-781.
33. Perez M, Sharkey C, Tackett A, *et al*. Post-traumatic stress symptoms in parents of children with cancer: A mediation model. Pediatr Hematol Oncol 2018;35(4):231-244.
34. Carmassi C, Dell'Oste V, Foghi C, et al. Post-traumatic stress reactions in caregivers of children and adolescents/young adults with severe diseases: A systematic review of risk and protective factors. Int J Environ Res Public Health 2020;18(1):189.
35. Shi L, Wang L, Jia X, *et al*. Prevalence and correlates of symptoms of post-traumatic stress disorder among Chinese healthcare workers exposed to physical violence: A cross-sectional study. BMJ Open 2017;7(7):e016810.
36. Naderi M, Hamzenejad M. Post-traumatic stress disorder and related factors in parents of children with cancer in South-East of Iran. Iran Red Crescent Med J 2012;14(12):776-781.
37. Masa'Deh R, Jarrah S. Post traumatic stress disorder in parents of children with cancer in Jordan. Arch Psychiatr Nurs 2016;31:8-12.
38. Hungerbuehler I, Vollrath M, Landolt M. Posttraumatic growth in mothers and fathers of children with severe illnesses. J Health Psychol 2011;16:1259-1267.
39. Peng Y, Xu L, Gu C, et al. Prevalence and associated factors of post-traumatic stress symptoms in hospitalised children with cancer and their parents in South China: A multicentred cross-sectional study. Asia Pac J Oncol Nurs 2024;11(10):100568.
40. Pinquart M. Posttraumatic stress symptoms and disorders in parents of children and adolescents with chronic physical illnesses: A meta-analysis. J Trauma Stress 2019;32(1):88-96.

41. Salama RA, Abou El-Soud FA. Caregiver burden from caring for impaired elderly: A cross-sectional study in rural Lower Egypt. Ital J Public Health 2012;9(4):1-e8662.10.
42. Bruce M, Gumley D, Isham L. Post-traumatic stress symptoms in childhood brain tumor survivors and their parents. Child Care Health Dev 2011;37:244-251.
43. Dunn M, Rodriguez E, Barnwell A. Posttraumatic stress symptoms in parents of children with cancer within six months of diagnosis. Health Psychol 2012;31:176-85.
44. Sultan S, Leclair T, Rondeau E. A systematic review on factors and consequences of parental distress as related to childhood cancer. Eur J Cancer Care 2016;25:616-637.
45. Jurbergs N, Long A, Ticona L, Phipps S. Symptoms of posttraumatic stress in parents of children with cancer: Are they elevated relative to parents of healthy children? J Pediatr Psychol 2009;34:4-13.
46. Peikert M, Inhestern L, Krauth K, *et al*. Fear of progression in parents of childhood cancer survivors: A dyadic data analysis, Psycho-Oncology 2020;29:1678–1685.
47. McCarthy M, Ashley D, Lee K, Anderson V. Predictors of acute and posttraumatic stress symptoms in parents following their child's cancer diagnosis. J Trauma Stress 2012;25:558-566.
48. Tremolada M, Bonichini S, Altoè G, *et al*. Parental perceptions of health-related quality of life in children with leukemia in the second week after the diagnosis: A quantitative model. Support Care Cancer 2013;19:591-598.
49. Nam G, Warner E, Morreall D. Understanding psychological distress among pediatric cancer caregivers. Support Care Cancer 2016;24:3147-3155.
50. Crespo C, Santos S, Tavares A, *et al*. "Care that matters": Family-centered care, caregiving burden, and adaptation in parents of children with cancer. Fam Syst Health 2016;34(1):31-40.
51. Melesse EG, Chau JPC, Li WHC, Yimer MA. Family caregivers' experiences of caring for children diagnosed with hematological malignancies receiving chemotherapy in Ethiopia: A qualitative study. Eur J Oncol Nurs 2023;66:102376.
52. Lukhmana S, Bhasin S, Chhabra P. Family caregivers' burden: A hospital-based study in 2010 among cancer patients from Delhi. Indian J Cancer 2015;52(1):146-151.
53. Lewandowska A. The needs of parents of children suffering from cancer-continuation of research. Children (Basel) 2022;9(2):144.
54. Scarponi D, Sarti P, Rivi V, *et al*. Emotional, behavioral, and physical health consequences in caregivers of children with cancer: A network analysis differentiation in mothers' and fathers' reactivity. Cancers (Basel) 2023;15:3496.
55. Cohn LN, Pechlivanoglou P, Lee Y, *et al*. Health outcomes of parents of children with chronic illness: A systematic review and meta-analysis. J Pediatr 2020;218:166-77.e2.