Original Article

Psychological Distress in Parents of Children with Cancer: A Descriptive Correlational Study

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ABSTRACT

Objective: This study aimed to ascertain levels of distress and contributing factors among parent caregivers of pediatric cancer patients in Singapore. **Methods:** In this descriptive correlational study, parental caregivers were recruited via convenience sampling during their child's inpatient admission or outpatient appointment. They were asked to complete a self-administered demographic survey and the Distress Thermometer for Parents (DT-P) tool. Descriptive statistics, Chi-square tests, and correlation analyses were performed. **Results:** The mean DT-P score was 5.07 (standard deviation = 2.78), out of a maximum of 10. Distress was reported among 67.9% (n = 55) of caregivers. The cognitive domain of caregiving problems on the DT-P was found to correlate with distress. Parents most frequently

reported cognitive problems (n = 21, 25.9%) and, least often, social problems (n = 6, 7.4%). Practical (P = 0.040), emotional (P = 0.001), physical (P = 0.026), and cognitive problems (P = 0.001) of caregiving were statistically significantly associated with distress. **Conclusions:** Notable levels of distress and proportions of distressed parents highlighted the heavy burden of caregiving. This may also be attributed to the differences in caregiving challenges. The psychological effects of parental caregiving highlight the need for supportive measures for pediatric cancer caregivers.

Key words: Cancer, caregivers, child, oncology, pediatrics, parents, psychological distress

Introduction

Caring for a child with cancer necessitates heavy parental involvement, with caregivers having to take their child for frequent appointments, administer medications, and provide emotional support through painful procedures.^[1] Alongside trauma and worry elicited by their child's diagnosis,^[2] it is unsurprising that a significant proportion of parents of pediatric cancer patients experience heightened psychological distress during their child's cancer diagnosis

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and treatment. Over 84% of American pediatric cancer caregivers were reported to be highly distressed,^[3] while 67.6% of the parents of children with cancer in Jordan experienced clinically significant levels of anxiety.^[4] Research in other Western^[5-7] and Middle-Eastern countries demonstrate similar worrying patterns.^[8]

Based on the definition by the National Comprehensive Cancer Network, distress is "a multifactorial unpleasant

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emotional experience" ranging from "feelings of vulnerability, sadness, and fears to problems that can become disabling."^[9] This distress not only impacts parents' well-being and caregiving abilities, but also deleteriously affects the mental and physical health of their child. Maternal depression has been found to affect a child's adherence to treatment,^[10] whereas parental symptoms have also been found to be predictive of depression, anxiety, and posttraumatic stress syndrome (PTSS) in their children.^[11,12] Seeking to lower caregiver distress by identifying associated factors may consequently be an important component of improving care and quality of life in pediatric oncology. Nonetheless, no definitive consensus has been reached on the parent- or child-related factors contributing toward this distress. For instance, the age of the child has been found to impact parental distress differently in research conducted in Korea^[13] and Turkey.^[14] This trend is similarly demonstrated with other factors such as parental education levels and type of pediatric malignancy, necessitating further examination into how these factors may impact the psychological status of parental caregivers. Given that caregiver psychological welfare has been extensively linked to that of the pediatric cancer patients they care for, it is evident that supporting caregivers is imperative in improving care outcomes for children with cancer. Existing supportive care programs are currently helmed by health-care institutions in Singapore, in collaboration with relevant organizations such as the Children's Cancer Foundation.[15] However, with limited information on the distress levels among this group of caregivers in Singapore, the efficacy of these measures is unknown. Furthermore, associated parent-child characteristics have been found to impact distress differently across cultural settings, warranting the need for research in the local context. Our study aimed to explore the levels of psychological distress and the contributing factors among parents of children with cancer in Singapore, findings of which would arm health-care professionals with crucial knowledge about specific family needs. This may in turn enable them to provide referrals to the appropriate support systems, as well as aid in early identification of parents who may be at risk for distress. Similarly, the results could shed insights on whether the current efforts to support caregivers are sufficient, and propose consequent areas for improvement.

Methods

Design and study population

A descriptive correlational study was used in our study. All participants (n = 81) were recruited between May 2018 and December 2019 via convenience sampling from a children's cancer center comprising an inpatient ward, a day-therapy center, and outpatient clinics. This center was situated within a large, academic tertiary hospital in Singapore. The hospital also admits children with cancer of nonresident Singaporeans living in the neighboring country such as Malaysia. Inclusion criteria included Singaporean and non-resident Singaporean parent caregivers of children who, at the time of recruitment, were: (1) currently receiving treatment for newly diagnosed or a relapse of pediatric cancer, and (2) between the ages of 0 to 18 years. Conversely, parents below 21 years of age have reportedly distinctive parenting challenges and greater susceptibility to psychological symptoms unrelated to caregiving burden^[16] and were consequently not invited to participate in the study. Parent caregivers with insufficient fluency in English to complete the survey measures were similarly excluded from enrollment. Prior to the commencement of the study, ethical approval was sought from the National Healthcare Group Domain-Specific Review Board (Approval No. NHG-DSRB 2016/00713-SRF0002). One parent per pediatric cancer patient was approached during their child's outpatient appointment, day-treatment session, or inpatient admission stay at the cancer center. Informed written consent was obtained from the individuals who agreed to participate. Pen-and-paper survey measures were self-administered to prevent social desirability bias,[17] and returned at participants' convenience to the study team.

Outcome measures

A survey developed for the study was used to retrieve information on participant characteristics including parent's gender, age, educational level, employment status, ethnicity and nationality, relationship to child, as well as child's age. Illness-related data relating to the child's type of cancer diagnosis, age at diagnosis, chemotherapy protocol, number of hospitalizations within the past year, and whether the family was receiving support from a medical social worker or experiencing challenges in medication adherence were collected.

Participants' levels of general distress were measured using the Distress Thermometer for Parents (DT-P) instrument developed by Haverman *et al.*^[10] to identify psychological distress in parents of a chronically ill child [Appendix] The three-part instrument consists of firstly, a thermometer scale between 0 (no distress) and 10 (extreme distress) to indicate parents' overall distress in the past week. Secondly, the tool contains six problems (physical, social, emotional, cognitive, practical, and parenting) potentially contributing to their distress. The items are scored dichotomously (yes or no), based on whether parents deemed them as problematic. The final section pertains to perceived social support and desire for referral to psychosocial services. Previous studies reported the tool to display good internal consistency for overall problem domains.^[6,18] In our study, the overall Content Validity Index was 0.95. The internal consistency reliability of the total domain score across the DT-P problem list was Cronbach's 0.89, while that of the individual problem list domains ranged from 0.65 to 0.76.

Statistical analysis

IBM SPSS Statistics for Windows, Version 25.0. Armonk, NY was used to analyze the data. Descriptive statistics were used to depict participants' characteristics and parental scores on the DT-P. For the problem list component of the DT-P, a score of 1 was given for every item checked as problematic. Parents were arbitrarily considered to be facing challenges in a problem domain if they checked >50% of the total number of items. This meant that for the cognitive problem domain, which contained only two items (memory and concentration), both had to be checked for a parent to be considered as facing problems in the cognitive domain. Given the binary nature of data, the Pearson's Chi-square test of independence examined the associations of distress with participant characteristics as well as caregiving problems from the DT-P problem list. Statistically significant items (P < 0.05) were thereafter keyed into a logistic regression model to identify the predictors of parental distress. To determine if reported distress levels in this study could be explained by differences in the caregiving problems among the participants, Chi-square tests were likewise employed. The P value of the Fisher's exact test was used in the place of Chi-square tests in all variables having small expected cell counts (<5).

Results

Participant characteristics

Parents (n = 81) comprised 58 mothers, 19 fathers, and four other family members. There were more females (n = 60, 74.1%) than male participants. Approximately half of the parents were older parents above the age of 40 (n = 41, 50.6%), were nonresidents (n = 45, 55.6%), and were college graduates (n = 50, 61.7%). Some parents were employed on a full-time basis (n = 37, 45.7%). The children with cancer were between the ages of 12 and 18 years (n = 30, 37.0%) and having a diagnosis of acute lymphoblastic leukemia (n = 42, 51.9%). At the point of the survey, 55.6% (n = 45) of the children had not been admitted for any inpatient hospitalization over the past 12 months. Most parents were receiving social worker assistance (n = 64, 79.0%). Most of them (n = 74, 91.4%) frequently reported that they felt adequately supported, especially in terms of practical and emotional aspects (n = 53, 65.4%). Over half of the parents (n = 55, 67.9%) did not request referral to additional psychosocial services and nearly half of them (n = 49, 60.5%) did not report facing challenges in their child's medication administration [Table 1]. No significant associations were found between distress and any of the participant characteristics, namely parental or child age and gender, parental education level and employment status, the child's type of diagnosis, as well as the utilization of social services.

Parental distress and caregiving problems

The mean DT-P thermometer score of parents was 5.07 (standard deviation [SD] = 2.78, range = 0–10). More

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More than 6 6 (7.4) Missing 18 (22.2)	1–5	12 (14.8)			
Missing 18 (22.2)	More than 6	6 (7.4)			
	Missing	18 (22.2)			

than half (n = 55, 67.9%) were found to be distressed, having given a score of 4 and above. The proportions of parents facing caregiving problems in each domain (checked more than half of the total number of items) were likewise presented. The domain of parenting problems for parents of children below 2 years old, however, was excluded due to the small number of parents under the category (n = 3). Parents most frequently reported cognitive problems (n = 21, 25.9%), and the least often was social problems (n = 6, 7.4%) [Table 2].

The practical (P = 0.040), emotional (P = 0.001), physical (P = 0.026), and cognitive problems (P = 0.001) from the DT-P caregiving problem list were significantly associated with distressed and nondistressed parents [Table 3]. The statistically significant items were further analyzed using a backward logistic regression model to identify predictors of distress, which showed that only the

Table 2: Participant caregiving problems $(n=78)$			
Domain scores	Mean (SD)	Caregivers facing problems, <i>n</i> (%)	
Practical problems (7 items)	2.07 (1.79)	17 (21.0)	
Social problems (4 items)	0.61 (1.04)	6 (7.4)	
Emotional problems (9 items)	2.49 (2.17)	17 (21.0)	
Physical problems (7 items)	1.62 (1.64)	10 (12.3)	
Cognitive problems (2 items)	0.72 (0.87)	21 (25.9)	
Parenting problems (2 years and above) (5 items)	1.51 (1.60)	18 (22.2)	
Total domain score (34 items)	8.94 (6.70)	8 (9.9)	
SD: Standard deviation			

Table 3: Associations between caregiving problems and distress

Facing problems in domain	Not distressed (%), n=26	Distressed (%), n=55	χ^2	Р
Practical				
Yes	2 (7.69)	16 (29.09)	4.231	0.040*
No	24 (92.31)	24 (92.31) 39 (70.91)		
Social				
Yes	4 (15.38)	6 (10.91)	3.123	0.170^{\dagger}
No	22 (84.62)	48 (89.09)		
Emotional				
Yes	1 (3.85)	17 (30.90)	10.869	0.001*
No	25 (96.15)	35 (69.10)		
Physical				
Yes	2 (7.69)	10 (18.18)	5.617	0.026†,*
No	24 (92.31)	43 (81.82)		
Cognitive				
Yes	3 (11.53)	20 (36.36)	10.556	0.001*
No	23 (88.47)	32 (3 (11.53)		
Parenting				
Yes	4 (15.38)	15 (27.27)	3.829	0.050
No	22 (84.62)	30 (72.73)		
[†] P-value of Fisher's e	exact test reported instead	of Chi-square test, du	e to small e	xpected

¹P-value of Fisher's exact test reported instead of Chi-square test, due to small expecte count for variable (<5); *Significant (P<0.05)

cognitive problem domain remained statistically significant (odds ratio = 5.195, 95% confidence interval = 1.481–18.216, P = 0.010). Correlations between practical (P = 0.047), emotional (P = 0.019), as well as cognitive (P = 0.008) problems and distress were found among nonresident Singaporean parents. Emotional problems were linked with distress for both younger (P = 0.036) and older parents (P = 0.034). However, statistically significant relationships between cognitive problems and distress were only reported among older (P = 0.003) but not younger parents. Practical (P = 0.009), emotional (P = 0.008), physical (P = 0.034) problems were found to be correlated with distress in university graduates.

Discussion

Parental distress was notably elevated, with the mean distress thermometer score in this study falling above the DT-P cutoff for distress. This was found to be comparable to the results of other studies which utilized the same tool. In Pierce et al.'s research, participants from the USA had an average DT-P mean score of 4.9 (SD 2.70).^[5] Schepers et al. also found higher distress among parental caregivers of pediatric cancer patients than parents of healthy children, in the Netherlands.^[6] This may suggest that pediatric cancer caregiving is a universally distressing experience for parents of children with cancer regardless of the cultural context. In our study, the elevated distress may also be attributed to the substantial proportions of older, nonresident parent caregivers who were university graduates, as this subset of parents were found to have more caregiving problems than their counterparts.

Out of the six problem lists in the DT-P, only the category of cognitive problem (concentration and memory) was found to predict distress. The above result could be attributed to the fact that over half of the caregivers were older adults (aged 40 and above), who tend to report difficulties in concentration and memory more frequently than their younger counterparts as a consequence of aging.^[19] The above finding could also be explained by the stress and burden of caregiving, which has been shown to negatively impact one's cognitive functioning.^[20] This is further supported by a study by Schepers et al., which reported that participants faced significantly greater concentration and memory problems on the DT-P as compared to parents of healthy children,^[6] highlighting the relationship between the pediatric cancer caregiving burden and cognitive problems for parents of children with cancer.

Interventions in our study site and relevant organizations could have explained why other caregiving problems were not found as predictors of parental distress. In Singapore, current efforts include practical assistance in terms of financial aid and referrals to social workers, counseling for emotional support, as well as massage therapy to promote physical wellness. Such support to parents was found to be helpful in more ways than one.^[21,22]

Previous studies have drawn associations between parental distress and parent-child demographic, medical, and psychosocial factors.^[1,14,21,23] However, in our study, none of the caregivers' characteristics were linked with distress, including their utilization of social services. This result may suggest that parents in our study were not distressed by the people or situation surrounding them. Rather, it was having to personally cope with the mental and cognitive strain of caregiving, which remained in spite of external circumstances and supportive measures that contributed to their distress. Pierce et al. studied the predictors of psychological adjustment in parents of children with cancer and found that demographics and medical variables such as gender, child's diagnosis, intensity of treatment, and time since diagnosis were not substantially interrelated with caregiver distress. As such, they emphasized the universal burden of caregiving and importance of early psychosocial screening and support for all parents of children with cancer.^[5]

While no participant characteristics were found to be related to distress, caregiving problems were found to differ among various groups of parents, which could have accounted for reported distress levels in our study. Practical, emotional, and cognitive problems were associated with distress in nonresident Singaporean parent caregivers. These problems could stem from the challenges associated with being away from one's home country. Similarly, Sultan *et al.* found that pediatric cancer caregivers with immigrant status had higher distress levels than their local counterparts.^[22] A similar finding was reported by Ben-Zur and Khoury and explained that having fewer resources to cope with the child's diagnosis among Arabian caregivers in Israel translated to their higher distress levels, when compared against their native Hebrew counterparts.^[24]

Practical, emotional, physical, cognitive, and parenting problems were found to be correlated with distress in university graduates, but not in parents having primary to vocational levels of education. Aziza *et al.* found that parents with higher education levels tend to have greater demands for information as well as express stronger opinions about the care of their child to the medical team.^[25] When they perceive their informational needs or expectations of their child's care to be unmet, it could consequently translate to their frustrations and perceived problems. This potentially explains the significant relationship between caregiving problems and distress in parents with higher education levels in this study. For both younger and older parents, emotional problems contributed substantially toward their distress. However, cognitive problems were notably associated with distress only in the older caregivers. This is corroborated by earlier research, which found emotional problems to be associated with higher parental distress.^[22,26,27] In these studies, parents who engaged in disengagement, withdrawal, avoidance, repetitive thinking, or experienced guilt and worry in terms of their child's disease were found to have greater depressive and PTSS symptoms. On the other hand, associations between cognitive problems and distress only in older parents support the earlier postulation that aging is interrelated with higher incidence of cognitive problems.

Limitations

The small sample size of participants in this study, which was conducted at a single site, potentially limited generalizability and contributed to nonsignificant associations between participant characteristics and distress. Nonetheless, the number of participants was comparable to that of other studies found in literature.^[2,6,13,16,21,26] Future studies may be expanded to involve multiple sites across pediatric cancer treatment centers in Singapore. The inclusion of responses from more caregivers could provide a more holistic and accurate depiction of caregiver distress among the study population.

The DT-P tool was based on distress experienced by parents over the past week from the point of survey. The acute, situational nature of this short-term self-reported distress could have culminated in the lack of significant correlations between caregiving problems or participant characteristics and distress. Furthermore, as a result of the descriptive correlational nature of the study, no definitive conclusions can be drawn on the causal relationships between study variables. Although there may be a possibility that the domain of cognitive problems extracted from the logistic regression model is the result rather than the cause of caregiving distress,^[28] its significant association with distress nonetheless underscores the heavy burden and repercussions of pediatric oncology caregiving. Future longitudinal studies, where participants' distress are prospectively studied from the time of their child's diagnosis to survivorship, may also be beneficial in establishing temporal precedence.^[29]

Moreover, questionnaires were utilized to attain information about the distress levels of pediatric cancer caregivers. However, this may have restricted explorations of participant opinions and experiences, which could be further investigated through open-ended questions or interviews to attain richer data of the specific factors causing parental caregiving distress. Another significant limitation of the study was that the cognitive problem domain of the DT-P tool utilized only contained two items. As such, this may affect the validity of the correlation between cognitive problems and parental distress in this study. Nonetheless, based on Cronbachvalues, the internal consistency of all problem domains on the DT-P problem list was found to be satisfactory as well as comparable to that of earlier studies,^[5,6,10] supporting the utility of the tool in encapsulating distress as a complex, multidimensional concept.

In spite of its limitations, the study encapsulated a spectrum of emotional concerns through the measurement of participants' general distress. Furthermore, the DT-P incorporated broader constructs of distress through the problem list, which covered a comprehensive range of caregiving challenges. This provided valuable insights to adaptation to their caregiving role and child's disease. In contrast to earlier research, there was also greater representativeness among the participants in the present study, in comparison to most articles,^[6,13,14,23,24] whereby participants' gender, nationality, and ethnicity were largely homogenous.

Implications for nursing practice

The results of the present study have primarily shown two main implications for practice, namely (1) implementation of distress screening services and (2) expanding current supportive care programs. A considerable proportion of parents of children with cancer in this study were found to be distressed, which pronounces the need for psychosocial screening. Brief psychosocial tools, such as the DT-P, can be potentially implemented in the pediatric cancer setting as a quick and easy method to screen for caregiver distress. This would enable health-care professionals to identify parents who may require assistance with adjustment to their child's cancer and promptly allocate resources as appropriate. Among participants, cognitive problems were found to be significantly associated with distress, highlighting the strain of caregiving. It could be beneficial to explore the possibility of supplementing the existing supportive measures with respite care programs in order to give parents a break from their caregiving duties and potentially alleviate the burden of caring for their child. Although such programs have been widely implemented in palliative care settings, this is currently not prevalent in our pediatric cancer setting. Cognitive-based therapy, particularly mindfulness-based interventions, has also demonstrated success in reducing concentration and memory problems in caregivers of oncology patients.^[20] Accordingly, pilot testing of mindfulness-based cognitive therapy sessions could be undertaken, to determine its suitability for use in the local pediatric cancer context. In this study, older, nonresident

participants who were college graduates were found to have more caregiving problems contributing toward their psychological distress, in comparison to their counterparts. Given that the existing supportive care interventions are in place, a qualitative study can be undertaken to further examine the caregiving challenges among these specific groups of parents. This would shed light on their adaptation processes, sources of distress, and how current efforts can be tailored to their needs.

Conclusions

The present research underscores the substantial burden of pediatric cancer caregiving. Supporting caregivers in their psychological adjustment to their child's disease is consequently emphasized as an imperative cornerstone of providing quality care and improving treatment outcomes for pediatric cancer patients.

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Conflicts of interest

There are no conflicts of interest.

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Appendix Could you please indicate for the questions below which answer is most applicable to your situation? Do you feel you receive enough support from people around you? \bigcirc Yes \bigcirc No (if yes) What kind of support do you receive? Completed by: ○ Practical ○ Father C Emotional O Mother O Practical as well as emotional Other, namely..... Do people often react to your situation with a lack of understanding? ○ Yes O No functioning. 1. Do you have a (chronic) disease? ○ Yes O No 10 = extreme distress). How do you get along with the medical staff? O Verv well ○ Well ○ Fair O Poor Would you like to talk to a professional about your situation? O Yes O Maybe O No Please explain: _____ Do you have any further comments/questions about this questionnaire or anything you would like to add about your responses? _____ THANK YOU VERY MUCH FOR COMPLETING THIS **QUESTIONNAIRE!**

Distress Thermometer for Parents (DT-P)

The DT-P is for parents/caregivers of a child who is (has been) receiving treatment in the (children's) hospital.

Your name:

Your date of birth:.....

Date of completion:

Child's name:.....

○ Other, namely.....

The DT-P questions are about how you feel. First, we will ask you to indicate, on the thermometer, how you are doing in general. Next, we will ask how you are doing related to day-today practical, emotional, physical and cognitive

Please indicate on the thermometer which number best describes how much distress you have been experiencing in the past week (including today) physically, emotionally, socially and practically in general. (0 = no distress at all -



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3.

(children's) hospital.

When the question is about <u>your child</u>, we are r the child that is (has been) receiving treatment

2.

Please indicate by checking YES or NO if any of the following has been a problem for you in the past week (including today). Be sure to check YES or NO for each item.

YES	NO	Practical problems	In case receivi in mine	In case you have more than one child that is (ha receiving treatment in the hospital, please keep in mind whose disease/condition is influencing t		
0	\bigcirc	Housing	day fu	day functioning the most.		
0	0	Work/study				
0	\bigcirc		ls your	child 2 ye	ears or older?	
Finance	es/insuranc	eOO Housekeeping				
0	\bigcirc	Transport		<u>YES, my</u>	child is 2 years or older:	
0	\bigcirc	Child care/child supervision		For the	following domain, please indicat	
\bigcirc	0	Leisure activities/relaxing		has been a problem for you in the past (including today). Please make sure you		
YES	NO	Family / social problems		or NU to	r each item.	
0	\bigcirc	Dealing with (ex)partner				
0	\bigcirc	Dealing with family			Parenting your child that is (has been) receiving treatme	
\bigcirc	\bigcirc	Dealing with friends	YES	NO	in the (children's) hospital	
\bigcirc	0	Interacting with your child(ren)	0	0	Dealing with your child	
YES	NO	Emotional problems	\bigcirc	0	Dealing with the feelings of ye	
0	0	Keeping emotions under control	0	0	Talking about the disease/cor with your child	
0	0	Self-confidence	\bigcirc	\bigcirc	Independence of your child	
0	\circ	Fears	\bigcirc	\bigcirc	Following advice about treatn	
0	\circ	Depression	0	U	giving your child his/her medi	
0	\circ	Feeling tense or nervous				
0	\bigcirc	Loneliness		NO. mv	child is vounger than 2 years:	
0	\bigcirc	Feelings of guilt			<u> </u>	
0	0	Use of substances (e.g. use of alcohol, drugs, and/or medication)		For the following questions, please indic has been a problem for you in the past v (including today). Please make sure you or NO for each item.		
0	0	Intrusive/recurrent thoughts about a specific event			Parenting your child that it	
YES	NO	Physical problems	YES	NO	(has been) receiving treatr	
0	0	Eating			in the (children's) hospital	
0	0	Weight	0	0	Feeling connected with you	
0	0	Sleep	\circ	\circ	Caring for your child	
0	0	Fatigue	\bigcirc	\bigcirc	Feeding your child	
0	0	Out of shape/condition	\bigcirc	\bigcirc	Development of your child	
0	0	Pain	0	0	Following advice about trea	