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An exploration of the psychosocial needs of children diagnosed with cancer and their parents in Singapore: a cross-sectional study

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INTRODUCTION

The management of psychosocial functioning in children with cancer and their families forms an important part of the cancer treatment.⁽¹⁻³⁾ Although the survivor rates of childhood cancers in Singapore have significantly improved in the past decades,⁽⁴⁾ these improvements are often accompanied with late effects of chronic treatment including physical, cognitive and mental health conditions.⁽⁵⁾

Regrettably, in the recently published cancer monograph in Singapore,⁽⁴⁾ there were no reported trends in the quality of life or other psychosocial functioning indicators in children with cancer. Specifically, the research development in this area has been limited. Past paediatric psychosocial-oncology studies in Singapore had involved non-Singaporean populations,^(6,7) or were dated.^(8,9) These studies had focused on the health-related quality of life (HRQoL) in children with cancer,⁽⁷⁾ those of their parents,^(6,9) or both.⁽⁸⁾ Overall, these studies highlighted that children with cancer and their parents experienced poor psychosocial functioning, especially within the first 6–12 months of the cancer diagnosis.

Considering the existing Singapore studies, except for two qualitative studies^(9,10) that explored psychological needs of parents, no other known studies had specifically examined psychological distress in children with cancer and/or their parents. Moreover, previous Singapore studies had mostly focused on acute phases of cancer (i.e. less than a year of diagnosis). Information on the psychosocial needs is necessary for the development of targeted psychosocial services or programmes to address these needs beyond the first year of the cancer diagnosis. This study aims to explore the psychological distress and HRQoL of children with cancer and their parents after one year of cancer diagnosis.

METHODS

This study was part of a multidisciplinary research project that investigated the psychosocial impact of childhood cancer in Singapore. It was approved by the SingHealth Centralised Institution Review Board (CIRB, reference no. 2017/2873). Informed consent was obtained from 26 children with cancer and 26 main caregiving parents. The mean duration since cancer diagnosis was 13.92 ± 70.24 (range 10.47–18.20) months. The study included Singaporean and permanent resident children aged 2–17 years who were receiving treatment at KK Women’s and Children’s Hospital (KKH), Singapore. Additionally, participants were required to be fluent in English. Children with cancer relapse, those who were critically ill, and/or were unable to self-report independently on the questionnaires were excluded from this study. Participants’ demographic details are presented in Tables I and II.

Table I. Demographics of child participants (n = 26).

Characteristic	No. (%) / Mean \pm SD
Mean age (yr)	9.39 \pm 4.72
Gender	
Female	9 (34.6)
Male	17 (65.4)
Ethnicity	
Chinese	15 (57.7)
Malay	3 (11.5)
Indian	4 (15.4)
Others	4 (15.4)
Educational level	
Preschool	8 (30.8)
Primary	5 (19.2)
Secondary	8 (30.8)
Tertiary	1 (3.8)
Not in school	4 (15.4)
Cancer type	
Blood	14 (54.0)
Solid	7 (27.0)
Brain	5 (19.0)

SD: standard deviation

Table II. Demographics of parent participants (n = 26).

Characteristic	No. (%) / Mean \pm SD
Mean age (yr)	40.38 \pm 6.53

Gender	
Female	21 (80.8)
Male	5 (19.2)
Marital status	
Married	24 (92.3)
Divorce	2 (7.7)
Employment	
Employed	20 (76.9)
Unemployed	6 (23.1)
Monthly household income (SGD)	
< 2,000	3 (11.5)
2,000–3,999	5 (19.2)
4,000–5,999	5 (19.2)
6,000–9,999	5 (19.2)
> 10,000	6 (23.1)
Preferred not to disclose	2 (7.7)

SD: standard deviation

Two outcome measures were used for this study: psychological distress and HRQoL. Psychological distress was measured using an adapted self-report distress thermometer.⁽¹¹⁾ Children and parent participants self-reported on their own psychological distress levels on an 11-point Likert scale from 0 to 10, with 0 indicating no distress and 10 indicating the most distress. A self-reported score of 5 was considered a significant cut-off for psychological distress. Parents self-reported on six measures including psychological distress, anxious/fearful, depressed/feeling down, angry, world has fallen apart and needing help. Children aged five years and above self-reported on their own level of psychological distress, and were given the option to endorse on a list of common problems experienced across psychological, physical, practical and family/social domains. Children aged less than five years self-reported on a simple distress thermometer with a 3-point Likert scale depicting happy (0), neutral (1) and sad (2) faces. These young children were not presented with the list of common problems owing to their young age.

The HRQoL was measured with the Paediatric Quality of Life Inventory (PedsQL) including the Generic Core Scale, version 4.0 (English for Singapore, standard version),⁽¹²⁾ Cancer Module, version 3.0 (English for United Kingdom, standard version)⁽¹³⁾ and the Family Impact Module, version 2.0 (English for Singapore).⁽¹⁴⁾ The questionnaires were administered via paper-and-pen format to child and parent participants, and scored on a 5-point Likert scale ranging from 0 to 4.⁽¹⁵⁾ These questionnaires have very good psychometric properties ($\alpha_{\min} > 0.70$) and are widely used in paediatric oncology.^(13,16)

Distress thermometer and PedsQL questionnaires were completed by the children and their main caregiving parent concurrently and independently during their outpatient oncology appointments or hospital admissions at one year after cancer diagnosis (Table III) from July 2018 to March 2019. Children and parents were not permitted to discuss their responses on the questionnaires during the administration. These questionnaires were administered by the associate psychologist and a clinical coordinator who were trained on these measures. A sample question on the instruction page of the PedsQL was read to the child participants; administration was stopped if the child could not understand/respond to the sample question (Note: All children were able to answer the sample questions). Participants who scored 5 and above on the distress thermometer were referred to the clinical psychologists for further evaluation.

SPSS version 19.0 (IBM Corp, Armonk, NY, USA) was used to conduct the analyses, and the alpha value was set at $p < 0.05$. The two main dependent variables were distress thermometer and HRQoL measures. Student's *t*-test for independent samples, Pearson's correlation analysis and relative risk index were used. Effect sizes r and r^2 were reported to provide an estimate of the observed effect. Cronbach's alpha for the PedsQL inventory used in this study were found to reach acceptable reliability (mean $\alpha = 0.74$ – 0.85). As there were no self-report measures for children

aged less than five years on the PedsQL, data was not available for seven young children in the main analysis stage. Hence, data was available for a total of 19 child participants. However, the parental proxy-data for these young children was available for analysis (n = 26).

Table III. Overall study design with outcome measures and type of respondents.

Questionnaires/rating scales	Respondents		
	Child self-report	Parent self-report	Parent proxy report
Psychological distress			
Distress thermometer	Yes	Yes	
Health-related Quality of Life			
PedsQL Generic Core Scale	Yes		Yes
PedsQL Cancer Module	Yes		Yes
PedsQL Family Impact Module		Yes	

PedsQL: Paediatric Quality of Life Inventory

RESULTS

On average, each child participant endorsed three problems on the list of common problems (mean 3.00 ± 3.50). The most endorsed items were physical and practical problems, followed by psychological problems and family/social problems (Table IV). For children who reported significant psychological distress on the distress thermometer, the relative risk of endorsing having problems was 1.8 times that of children who did not report significant psychological distress. In other words, children were 45% less likely to report having problems if they were not in significant psychological distress.

Table IV. Summary of the highest number of endorsed items in each domain of the problem list (n = 19).

Problem domain	No. (%)
Physical problems	
Feeling tired	5 (26.32)
Practical problems	
School/tutoring	5 (26.32)

Psychological problems	
Feeling worried/anxious	4 (21.05)
Feeling sad/depressed	4 (21.05)
Bored/not wanting to do anything	4 (21.05)
Family/social problems	
Dealing with siblings	2 (10.53)

Only the highest number of endorsements in each domain were reported.

The mean psychological distress level in child participants was 2.79 ± 2.53 (range 0–8). 6 (31.58%) children reported significant psychological distress equal to or above the cut-off score of 5. In parent participants, the mean psychological distress level was 2.81 ± 2.67 (range 0–8), and 8 (30.77%) parents reported significant psychological distress equal to or higher than the cut-off score of 5. There was no statistically significant difference in psychological distress levels between children and their parents ($t[40.09] = -0.02$, $p = 0.98$, $r = 0.003$). Additionally, the relative risks of significant psychological distress were similar in both children (1.03) and their parents (0.97). Other psychological indicators of parent participants are presented in Table V. Parent self-rated scores on the psychological scales (i.e. distress, anxiety/fearful, depressed, anger, world has fallen apart) were also positively correlated with parents needing help ($r_{\text{range}} 0.51\text{--}0.69$, $r^2_{\text{range}} 0.26\text{--}0.48$, $p < 0.01$).

Table V. Summary of psychological distress indicators in parent participants (n = 26).

Psychological indicators	Mean \pm SD	Range of scores	n > cut-off* (%)
Anxiety/Fearful	3.00 ± 2.67	0–8	8 (30.77)
Depressed	2.58 ± 2.53	0–8	6 (23.08)
Anger	2.31 ± 2.85	0–9	5 (19.23)
World fallen	0.50 ± 1.18	0–5	1 (3.85)
Needing help	1.69 ± 2.40	0–7	6 (23.08)

**Refers to scores ≥ 5 on the distress thermometer (parents).*

There were significant relationships between children's age and the psychosocial functioning of their parents. In particular, children's age was significantly related to parent-rated

anxiety ($r = -0.40$, $p = 0.04$, $r^2 = 0.16$); parents of younger children were found to have higher anxiety levels. Furthermore, younger children were significantly associated with having parents with poorer HRQoL ($r = 0.55$, $p = 0.004$, $r^2 = 0.30$, including physical [$r = 0.64$, $p < 0.001$, $r^2 = 0.41$] and psychological functioning [$r = 0.47$, $p = 0.02$, $r^2 = 0.19$]). Additionally, parents of younger children also tended to report more problems in worrying about their child's health status ($r = 0.40$, $p = 0.045$, $r^2 = 0.16$).

Children who self-rated more problems in experiencing physical pain, nausea and procedural anxiety were significantly correlated with poor psychological coping in their parents ($r^2_{\text{range}} 0.24\text{--}0.40$, $p < 0.05$). Specifically, these problems were significantly related to a parent-reported feeling that their world has fallen (Table VI). Additionally, children who reported experiencing more nausea symptoms were also significantly correlated with parent-reported feelings of anger ($r = -0.48$, $p = 0.04$, $r^2 = 0.23$).

Table VI. Correlations between child-reported health-related quality of life and parental Distress Thermometer.

Variable	Pain	Nausea	Procedural anxiety	World crushed
Child self-report				
Pain	–			
Nausea	0.55*	–		
Procedural anxiety	0.63†	0.47*	–	
Parent self-report				
World crushed	-0.63†	-0.49*	-0.56*	–

* $p < 0.05$. † $p < 0.01$.

DISCUSSION

This study sought to explore the psychosocial needs of children with cancer and their main caregiving parent one year after receiving the diagnosis. The most common problems rated by

11%–26% of the children in our study were fatigue, academic stress, worrying or anxiousness, sadness, boredom and family relationships. These problems were similar to those reported in the literature,^(16,17) although sleep problems were not reported in our study.

Additionally, we found that children who are psychologically distressed are 1.8 times more likely to report having problems in the physical, practical, psychological and family/social domains relative to those who are not in distress. In other words, children who are not in distress are 45% less likely to report having problems in these domains. Indeed, large-scale childhood cancer survivor studies have shown that survivors who experienced significant psychological distress were more susceptible to neurocognitive problems,⁽¹⁶⁾ and distress is also related to fatigue and poor psychosocial functioning.⁽¹⁷⁾ These findings highlighted the importance of monitoring psychological distress in children with cancer.

Studies have shown both short- and long-term psychosocial risk in children with cancer^(5,18) and their parents.^(1,2) A recent meta-analysis⁽¹⁹⁾ found an overall moderate effect size in the relationship between psychological distress in children with cancer and their parents. Indeed, the current study shows that the relative risks of developing psychological distress were similar in children with cancer and their parents. Specifically, we found that around 30% of the children with cancer and their main caregiving parent in Singapore experienced significant psychological distress requiring psychological support, after one-year of cancer diagnosis. This percentage is similar to those reported in Western studies.⁽²⁰⁾ Although there are no prior studies examining psychological distress in Singaporean children with cancer, a study on older adult Singaporeans with cancer has found that 33% of them experienced significant distress.⁽²¹⁾

Haverman et al⁽²²⁾ found that 47% of parents reported significant psychological distress, which is higher than the proportion in the current study. However, this difference may be

attributable to the cut-off score used (i.e. 4),⁽²²⁾ which is different from that used in our study (i.e. 5). The issue of determining cut-off scores is not straightforward, as existing studies supported cut-off scores of both 4⁽²²⁾ and 5.⁽²¹⁾ Although no validation studies have evaluated the use of distress thermometer in Singaporean children with cancer, a study on older Singaporean adults with cancer found better balance between specificity and sensitivity when the cut-off score of 5 was used compared to a score of 4.⁽²¹⁾

The current study found that parent-rated psychological distress, including anxiety and depressed feelings, correlates with parent-reported need for support. Furthermore, the age of the child is significantly correlated with parental distress, especially for younger children; this finding is consistent with the literature.⁽²³⁾ Our study revealed that parents of younger children with cancer have poorer HRQoL. Specifically, these parents are more likely to report higher anxiety level and worrying for their child's health. Additionally, poorer psychological coping in parents is found to be related to children who experience problems such as physical pain, nausea and procedural anxiety. Taken together, these findings supported the mutual relationship between psychological distress and HRQoL in children with cancer and their parents.^(19,24-26)

To our knowledge, this is the first study to concurrently examine psychological distress and quality of life of Singaporean children with cancer and their parents. Nevertheless, the study results should be interpreted in light of the limitations. First, this study is based on a cross-sectional correlational design. Hence, the associations between various factors cannot be interpreted as causative. Second, similar to most paediatric oncology studies,⁽²⁷⁾ this study included mostly mothers as they are the primary caregivers; future studies should explore the psychosocial needs of Singaporean fathers. Third, future studies could consider including a list of common problems for parents to identify the areas of support required.⁽²²⁾ Fourth, the effect of diagnosis on

psychological distress and HRQoL was not evaluated because of unequal sample sizes among the cancer diagnoses. Although our main findings were largely consistent with the literature, our sample size was limited by the inherently small clinical population of interest in Singapore (i.e. childhood cancers).⁽⁴⁾ Hence, future studies with larger equal sample sizes are required to validate our findings (e.g. via meta-analysis) and further explore the impact of diagnosis on psychosocial functioning. Lastly, future studies could investigate the specificity and sensitivity of the cut-off scores of the distress thermometer in Singaporean children with cancer.

In conclusion, poor psychosocial functioning in children was associated with poor psychosocial functioning in their parents, especially for parents with younger children. Hence, psychosocial programme or services for children with cancer in Singapore must consider proactive screening of psychological distress and extend the support to both the children and their parents beyond the first year of the cancer treatment.

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study forms part of a larger research project exploring late effects and the psychosocial impact of childhood cancer in Singapore. We declare that there is no potential conflict of interest.

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