





CLINICAL CORRESPONDENCE

Caregiver's perspective on psychosocial issues of paediatric cancer patients during COVID 19 pandemic lockdown

Vidhya Gopalakrishnan¹  | Surendran Veeraiah¹  |
Sundaramoorthy Chidambaram¹ | Revathy Sudhakar¹  |
Venkatraman Radhakrishnan² 

¹Department of Psycho-oncology, Cancer Institute (WIA), Chennai, India

²Department of Medical Oncology, Cancer Institute (WIA), Chennai, India

Correspondence

Surendran Veeraiah, Department of Psycho-oncology and Resource Centre for Tobacco Control, Cancer Institute (WIA), Chennai, 600036, India.

Email: suren.psy@gmail.com and v.surendran@cancerinstitutewia.org

KEYWORDS

COVID-19, lockdown, paediatric cancer, psycho-oncology, psychosocial issues, treatment interruption

Key points

- The unprecedented pandemic crisis has caused serious changes in the medical care for cancer patients, thereby mandating research studies to focus and understand the psychosocial issues faced by paediatric cancer patients during the pandemic lockdown in India.
- Paediatric cancer patients irrespective of diagnosis and treatment status were assessed for psychosocial issues ($N = 103$) and distress ($n = 74$).
- Caregivers were chosen as the primary respondents except for distress score in order to obtain data with better clarity and comprehension.
- The data was summarized using descriptive statistics; chi square analysis was adopted to find the association between psychosocial issues and outcome variables; multivariate logistic regression was used to find the predictors of treatment status and distress.
- Paediatric cancer patients experienced significant physical and psychological issues pertaining to the unprecedented pandemic lockdown and its associated changes with the cancer treatment and interruptions.

1 | INTRODUCTION

As a measure of containing the spread of COVID-19, India announced a nationwide lockdown from March 24; 2020. This unprecedented crisis resulted in disruption of medical care to patients with chronic diseases, especially in oncology where continued hospital visits and follow-ups are warranted. In addition to the uncertainty about the transmissibility of COVID-19, worrying about treatment continuation was found to be more stressful for cancer patients and caregivers.¹ Caregivers experienced anxiety related to children contracting COVID-19 and hospitals were no longer felt to be a safer place.² The COVID-19 pandemic has caused greater impact on the mental health of paediatric patients, requiring professional mental health support.^{3,4} Although studies are being published around the pandemic situation in oncology with reference to psychosocial concerns, across different countries, there is scarce resources on psychosocial impact of COVID-19 pandemic in low-middle income countries, especially from India. In

order to more fully understand the psychosocial issues and concerns of paediatric cancer patients during COVID-19 pandemic, this study was undertaken in a regional comprehensive cancer centre.

2 | METHOD

This study employed a cross-sectional survey design. Paediatric cancer patients below 18 years, irrespective of the diagnosis and stage, visited the paediatric out-patients department (OPD) from 1st September to 30th October 2020 were considered eligible. A structured interview schedule, developed and face-validated with experts, consisting 24 items comprising physical ($n = 1$), psychological ($n = 9$), logistic ($n = 6$), social ($n = 6$) and informational ($n = 2$) domains was used. The interview schedule was administered to the primary caregivers and the distress score was assessed from patients between 7 and 18 years using Paediatric Distress Thermometer.⁵ Caregivers were chosen as the primary respondents except for

distress score in order to obtain data with better clarity and comprehension. In order to validate the responses of the caregivers, patients were made to sit alongside during interview. For those, who were unable to respond in OPD, the data was collected over telephone at their convenient time. The caregivers were initially briefed about the study and written/oral consent was obtained. Average time taken for each caregiver was 30 min. The demographics and clinical details were obtained from hospital case record form. The data was double entered and validated using EpiData entry (V.3.0)⁶ and analysed using Statistical Package for Social Sciences (Ver.20). Of all the outcome variables, only those which were reported by more than 10% of respondents were considered for analysis. Key outcome indicators namely distress and psychosocial concerns were summarized using frequency and percentage. Chi square analysis was carried out to find the association of treatment status (interrupted vs. uninterrupted) and distress with psychosocial concerns. Multivariate logistic regression was used to find the psychosocial predictors of treatment status and distress. The significance level for all analyses was set at $p < 0.05$, two-tailed. The study was approved by Institutional Ethics Committee (IEC), Cancer Institute (WIA) (Ref. No.: IEC/2020/Sep/14).

3 | RESULTS

Totally 165 paediatric patients reported to the OPD of which, 103 caregivers completed the survey. Sixty-two were unreachable due to either wrong contact or no response to the call. Nearly 77.6% of the paediatric patients were above 6 years and 63.2% were receiving formal education. Nearly 78.6% were from a nuclear family and 78.6% hired vehicles to reach the hospital. Totally, 51.5% were diagnosed as high-risk group under risk stratification (patients who have a blast count more than 1000/micro litre on day 8 of induction). Of the 103 patients, 76.9% were diagnosed with haematological malignancies and 26.1% with solid tumours. Three-fourth (70.9%) had uninterrupted treatment during the lockdown (Supplementary Table S1).

While, pain (26.2%), fatigue (16.5%), nausea/vomiting (18.4%), appetite (14.6%) and fever (10.8%) were reported as common physical symptoms, fear (10.8%), low mood (17.5%), helplessness (10.9%) and sleep difficulty (19.4%) were reported as common psychological concerns experienced by paediatric patients. Patients reported logistic issues including transportation (52.4%), challenges in getting medical care (23.3%), financial constraints (82.5%) and challenges in meeting daily needs (77.7%). In total, 81.6% had adequate family support and 48.5% reported support from relatives/friends. Nearly 56.3% sought informational support pertaining to COVID-19 and cancer care from the hospital. With regard to distress, 72.9% of the patients aged between 7 and 18 years reported no distress, while 12.6%, 8.7% and 5.8% reported mild, moderate and severe distress, respectively.

Pain ($p = 0.012$), appetite ($p = 0.013$), fever ($p = 0.028$), low mood ($p = 0.053$), sleep difficulty ($p = 0.022$), challenges in meeting daily

needs ($p = 0.046$) and information support ($p < 0.001$) experienced by patients with uninterrupted treatment differed significantly from those with treatment interruption (Supplementary Table S2). Fear ($p = 0.006$), low mood ($p < 0.001$), helplessness ($p = 0.001$), sleep difficulty ($p = 0.007$), challenges in getting medical care ($p = 0.029$), challenges in meeting daily needs ($p = 0.016$) were found to be significantly associated with distress (Supplementary Table S3).

Multivariate regression analysis was performed between treatment status (Interruption/Uninterrupted) and psychosocial issues (physical, psychological, logistic and informational). Results revealed that informational support ($\beta = 0.015$) emerged as an independent predictor of treatment status (Table 1). In Univariate analysis of distress and psychosocial issues, factors emerging significant amongst psychological issues (fear, low mood, helplessness and sleep difficulty) and logistic issues (challenges in getting medical care and challenges in meeting daily needs) were interdependent and likely to neutralize the independent effect. To overcome this, multivariate analysis was performed by each adjusting each factor in the psychological issues with challenges in daily needs. The results revealed that fear ($\beta = 0.028$), low mood ($\beta = 0.003$) and sleep difficulty ($\beta = 0.039$) emerged as predictors of distress. Similarly, each factor in logistic issues is adjusted with helplessness and challenges in getting medical care ($\beta = 0.036$) and challenges in meeting daily needs ($\beta = 0.028$) emerged as predictors of distress (Table 2).

4 | DISCUSSION

This is the first study that we are aware of, to attempt assessing the psychosocial issues and its association with distress among paediatric cancer patients during a pandemic in India. A major strength of this study is the attempt to assess the psychosocial concerns of paediatric patients in a hospital setting when the intensity of COVID-19 spread was rapid. Paediatric cancer patients experienced significant psychosocial issues with respect to physical, psychological and logistic domains as reported by caregivers. One-fourth of the patients experienced some level of distress.

Patients experienced significant challenges in commuting to the hospital during lockdown due to restrictions in transportation. Government transportation was curbed during lockdown period; hence caregivers had to hire private vehicles to reach the hospital. Patients across Tamil Nadu and nearby states travel for treatment, resulting in additional financial burden particularly during a pandemic situation, when the families themselves are deprived of adequate financial support. Recent literature report that low- and middle-income countries have lack of timely access to health care services, delayed treatment, abandonment of treatment, poor compliance and financial constraints in general. In addition, the pandemic has enhanced these issues and have caused a long term impact on the quality of life and survival of these patients.⁷

However, despite pandemic lockdown and travel restrictions, nearly half of the patients were on treatment without interruption.

TABLE 1 Psychosocial issues predicting treatment status (interrupted vs. uninterrupted) of paediatric cancer patients ($n = 103$) during COVID 19 pandemic lockdown

Psycho-social issues	Categories	Response	Frequency	Univariate analysis		Multivariate analysis	
				OR (95% CI)	p-value	Adj. OR (95% CI)	p-value
Physical	Pain	Yes	27	0.28 (0.10–0.78)	0.015*	0.46 (0.15–1.43)	0.182
		No	76	1 (reference)		1 (reference)	
	Appetite	Yes	15	0.16 (0.03–0.79)	0.024*	0.28 (0.05–1.63)	0.159
		No	88	1			
	Fever	Yes	59	0.12 (0.01–1.06)	0.057	-	-
		No	44	1 (reference)		-	-
Psychological	Sleep difficulty	Yes	20	0.26 (0.08–0.87)	0.029*	0.42 (0.11–1.58)	0.203
		No	83	1 (reference)		1 (reference)	
Logistic issues	Challenges in meeting daily needs	Yes	80	0.38 (0.14–0.99)	0.050*	-	-
		No	23	1 (reference)		-	-
Informational	Informational support	Yes	71	0.20 (0.83–0.50)	0.001**	0.28 (0.10–0.78)	0.015*
		No	32	1 (reference)		1 (reference)	

Note: OR = odds Ratio, CI = Confidence Interval, * $p < 0.05$, ** $p < 0.01$.

TABLE 2 Psychosocial issues predicting distress of paediatric cancer patients ($n = 74$) during COVID 19 pandemic lockdown

Psycho-social issues	Categories	Response	Frequency	Univariate analysis		Multivariate analysis	
				OR (95% CI)	p-value	Adj. OR (95% CI)	p-value
Psychological	Fear	Yes	17	4.69 (1.48–14.84)	0.008**	3.75 (1.15–12.23)	0.028 ^a
		No	57	1 (reference)		1 (reference)	
	Low mood	Yes	18	7.80 (2.35–25.78)	0.001**	6.34 (1.86–21.53)	0.003 ^{***a}
		No	56	1 (reference)		1 (reference)	
	Helplessness	Yes	11	11.25 (2.21–57.23)	0.004**	1.29 (0.07–21.72)	0.859 ^a
		No	63	1 (reference)		1 (reference)	
Sleep difficulty	Yes	13	3.53 (1.02–12.24)	0.046*	4.15 (1.07–16.07)	0.039 ^a	
	No	61	1 (reference)		1 (reference)		
Logistic issues	Challenges in getting medical care	Yes	17	3.36 (1.09–10.30)	0.034*	3.32 (1.07–10.25)	0.036 ^b
		No	57	1 (reference)		1 (reference)	
	Challenges in meeting daily needs	Yes	57	5.85 (1.22–28.03)	0.027*	5.80 (1.21–27.87)	0.028 ^b
		No	17	1 (reference)		1 (reference)	

Note: OR = odds Ratio, CI = Confidence Interval, * $p < 0.05$, ** $p < 0.01$.

^aFactor adjusted with challenges in meeting daily needs.

^bFactor adjusted with helplessness.

This may be attributed to the fact that few patients were staying near the hospital which enabled uninterrupted treatment. Also, there was provision of accommodations provided by NGOs. This was a significant finding of this study as the treatment protocol for paediatric patients warrants continued care without delay or interruptions. Studies conducted have also emphasised on the importance of having continued treatment without interruption.^{8,9}

Although nearly half of the patients were receiving treatment irrespective of the pandemic situation, the treatment interruption

among the remaining patients was inevitable. Patients with treatment interruption were found to experience profound physical symptoms including pain, fever and reduced appetite. These symptoms were attributed to the result of disease interference in the general health of the patient, owing to the break in the treatment. Similarly, the study revealed that patients with psychological symptoms experienced significant distress. Studies have reported that paediatric patients and youth experience psychosocial issues due to pandemic, impacting their mental health resulting in frequent referrals to psychologist.^{3,10}

While informational support emerged as a predictor of treatment status among paediatric cancer patients, this could be justified as provision of more information regarding an uncertain situation from a reliable source may provide confidence and motivate patients to continue cancer treatment without interruption. This study highlights that modifiable factors namely challenges in getting medical care and challenges in meeting daily needs increases the distress of cancer patients, which mandates necessary action and support from government and health communities.

Overall, paediatric patients experienced physical and psychological issues related to the pandemic and changes in the medical care at the time of COVID-19 pandemic lockdown in India. The results of this study could help in tailoring appropriate psychosocial intervention to cater to the needs of the cancer patients and their families during such scenario at present and in the future. This finding could also be incorporated into strengthening cancer care in other low-middle income countries as the impact of the pandemic is assumed to be similar in terms of practical, social and financial challenges. Government and medical institutions need to develop strategies to ensure that treatment for cancer patients are provided without interruption. This study had two limitations. First, only the symptoms of psychological issues were assessed. Standardized tools might have provided more information on psychological domains. Second, patients who were either lost-to-follow up or defaulted were not included in the study.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

ORCID

Vidhya Gopalakrishnan  <https://orcid.org/0000-0001-8268-3383>

Surendran Veeraiah  <https://orcid.org/0000-0002-6747-7423>

Revathy Sudhakar  <https://orcid.org/0000-0002-3012-6136>

Venkatraman Radhakrishnan  <https://orcid.org/0000-0002-7557-5816>

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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