

ORIGINAL ARTICLE

Psychological distress in primary caregivers of children with cancer during COVID-19 pandemic-A single tertiary care center experience

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Abstract

Objective: Families of children with cancer undergoing treatment during COVID-19 pandemic represent a vulnerable population for psychological distress and early identification and remedial measures are imperative for wellbeing of both the children and the caregivers. This article reports the results of assessment of psychological distress in primary caregivers of children with cancer undergoing treatment at a tertiary care center.

Methods: Primary caregivers of children with cancer (≤ 15 years) taking treatment at our institute during the period of July 2020 to August 2020 were prospectively evaluated for psychological distress using Patient Health Questionnaire-9 (PHQ-9) and Generalized Anxiety Disorder-7 (GAD-7) tools over a telephonic call. There were 2 cohorts, A and B (50 participants each) depending on whether child was diagnosed with COVID-19 or not respectively during the study period.

Results: The assessment tool, PHQ-9 showed a score of ≥ 10 in 13% ($n = 13$) participants (95%CI:7.1%–21.2%) in the entire cohort and in 16% ($n = 8$, 95%CI:5.8%–26.2%) and 10% ($n = 5$, 95%CI:1.7%–18.3%) participants in cohort A and cohort B respectively. GAD-7 showed a score of ≥ 8 in 18% ($n = 18$) participants (95% CI:11.0%–27.0%) in the entire cohort and in 20% ($n = 10$, 95%CI:8.9%–31.1%) and 16% ($n = 8$, 95%CI:5.8%–26.2%) participants in cohort A and cohort B respectively. All participants were assessed, and supportive psychotherapeutic interventions administered over telephonic call.

Conclusions: Primary caregivers should be assessed and followed up for psychological distress irrespective of other co-existing factors. Robust support systems built over time could help withstand the exceptional strain of a major surge during a pandemic.

KEYWORDS

caregivers, children with cancer, COVID-19, pandemic, psychological Distress, psycho-oncology

1 | INTRODUCTION

The pandemic caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), that causes coronavirus disease-2019 (COVID-19) has had a tremendous impact on the health systems worldwide. Initial global focus was on testing, treating and containing the virus through lockdowns and restrictions in public life has inflicted fear, anxiety and considerable psychological stress in the general population. The degree of impact is likely to vary between different population groups depending on the circumstances. Families of children undergoing treatment for cancer are amongst the most vulnerable groups plagued by this unprecedented pandemic not only due to the threat of COVID-19 infection but also due to the primary malignancy, its treatment and related complications, in these times of restricted logistics and accessibility to healthcare services and drugs.

Early in the pandemic, guidelines and policies to address the physical consequences of infection in the population were formulated and with time, world organizations and institutes have laid down guidelines pertaining to mental health and also necessary psychosocial support needed for different population groups trying to navigate this pandemic.¹⁻³ Though there have been very recent studies addressing the psychological aspect of patients with COVID-19, their caregivers as well as healthcare workers and general population, there is dearth of such information in primary caregivers of the pediatric cancer patients.⁴⁻⁸ Psychological Distress (PD) is a state of emotional suffering typically characterized by symptoms of depression and anxiety which often co-exist and co-occur with common somatic complaints usually brought on by stressors and demands.^{9,10} As PD may be a forerunner to mental, physical and emotional exhaustion, there is a need for early initiation of measures to avoid burnout in such individuals.¹¹ This is more so relevant during the current pandemic where early interventions may be necessary in primary caregivers of pediatric cancer patients to enable them to effectively carry out their roles as caregivers of this very vulnerable group of patients. We, herein, report the results of assessment of psychological distress in primary caregivers of children with cancer undergoing treatment at one of the largest tertiary care cancer centers in India.

2 | AIMS AND OBJECTIVES

The pediatric oncology department at our institute sees more than 2000 new registrations a year with patients referred from in and out of the country who stay locally for the duration of their intensive treatment. Though these children and their families received holistic support including accommodation, nutritional support, in addition to treatment for cancer, the pandemic created an unexpected panic and distress which was increasingly perceptible in this group with time.¹² This study was conceived to evaluate the psychological distress in primary caregivers of children with cancer (with and without COVID-19) during the pandemic as the primary objective so that we have a rapid realistic idea of planning the desired psychological input in

these restricted settings across the different groups. This study compared the scores at baseline among the two cohorts, noted the reassessment scores after delivery of psycho-therapeutic interventions in participants who had baseline high scores and factors predictive of high scores in both cohorts as secondary objectives.

3 | METHODS

3.1 | Participant selection

This was a prospective observational study conducted after approval from the institutional ethics committee (IEC/0720/3509/001 dated 15th July 2020). Primary caregivers, (both mother and father or either of them or other caregiver whoever was involved in the direct care during treatment) of children with cancer (≤ 15 years), taking treatment at our institute during the period of July 2020 to August 2020 were eligible. Caregivers with history of pre-existing psychiatric disorder or cognitive impairment and those unable to comprehend Hindi, Marathi or English were excluded from formal analysis. Verbally consented participants caring for consecutive children with cancer diagnosed with COVID-19 during the period formed cohort A and those caring for children with cancer without COVID-19 formed cohort B. Since there were no assumptions or considerations for calculating sample size, a convenient sample size of 50 was chosen for each cohort to study the primary objective to inform policies and adaptations in a realistic time.

3.2 | Study Procedure

The primary caregiver(s) were contacted over telephone (voice call or video call wherever possible as per the comfort of the caregiver) due to the COVID-19 restrictions to deliver the objective assessment tools for depression and anxiety, Patient Health Questionnaire-9 (PHQ-9) and Generalized Anxiety Disorder-7 (GAD-7) respectively by a team of psycho-oncologists at our institute in the language they comprehended. PHQ-9 consists of nine items measuring depressive symptoms corresponding to the diagnostic criteria for major depressive disorder. Each item is scored on a four-point Likert scale (0-3) with scores ranging from 0 to 27, with higher scores reflecting greater depression severity. Scores above 10 are considered to be in the depressive area.¹³ GAD-7 consists of seven items measuring worry and anxiety symptoms. Each item is scored on a four-point Likert scale (0-3) with total scores ranging from 0 to 21 with higher scores reflecting greater anxiety severity. Scores above 10 are considered to be in the clinical range.¹⁴ Considering heterogeneity of the family and the COVID pandemic, GAD-7 cut-off was selected as 8 for the participants in the study. Scores ≥ 10 on PHQ-9 and ≥ 8 on GAD-7 were considered for diagnosis of moderate to severe depression and anxiety respectively in both the cohorts. Participants with above high scores were administered supportive psychotherapeutic interventions which used a

person-centered approach with components of unconditional positive regard, genuineness, warmth and empathy. Problem solving approaches, stress and anxiety management techniques were used in addition as per need. All interventions were provided telephonically (voice call or video call). Those caregivers with high scores on either one of the tools were reassessed by both the tools delivered in 2–4 weeks' time by the same psycho-oncologist who did the first assessment and intervention to allow for ease of care delivery. Any subject requiring inpatient care for their symptoms were planned for referral to a specialty hospital. If initial scores were not high or normal requiring no intervention, they were counseled to get back if they needed any support or contact if they had any symptoms, and only if required at this point was a repeat formal assessment done to optimize the use of available resources. All patients who were enrolled onto the study were provided emotional support irrespective of the scores, though formal reassessment was done only in those with high scores. Study participants were followed up for a period of 4 weeks from the date of initial contact as part of this study. Other pertaining data inputs were recorded in approved case record forms for subsequent analysis.

3.3 | Statistical analysis

Conventional descriptive statistics was used to analyze the data. PHQ-9 and GAD-7 at baseline for the two cohorts were reported as frequency and percentage with 95% exact confidence interval and the scores between the 2 cohorts were compared using Fisher exact test. Covariates were compared between those with high and low scores of PHQ-9 and GAD-7 using Fisher exact test. PHQ-9 and GAD-7 scores measured at baseline and 2–4 weeks were analyzed using McNemar test. p value < 0.05 was considered significant. Data was analyzed using IBM SPSS v25 and RStudio 1.2.5019.

4 | RESULTS

4.1 | Demographic profile

There were 50 primary caregivers of 41 and 40 pediatric cancer patients in cohort A and B respectively. Median age of the caregivers were 37 years (range, 19–60 years) and 32 years (range, 21–52 years) with a male to female ratio of 0.7:1 and 1.4:1 in cohorts A and B respectively. Ninety-six participants (96%) were contacted over voice call and only 4 over video call. Voice call was preferred over video call by many due to different reasons, mainly technical issues like poor network, video call facility not available. The details in Table 1. In cohort A, only two caregivers were attending to a child with severe COVID-19 and rest all were taking care of asymptomatic or mildly symptomatic children. Eighty-three percent of the caregivers were attending to children with hematological malignancies (cohort A-45.8%, cohort B-54.2%) and 17% were attending to children with solid tumors (cohort A-70.6%, cohort B-29.4%). Three caregivers were taking care of two children in cohort A who were on

a palliative track. The remaining children in both cohorts were on curative treatment for their malignancy.

4.2 | Assessment of psychological distress

The assessment tool, PHQ-9 showed a score of ≥ 10 in 13% participants ($n = 13$, 95%CI:7.1%–21.2%) in the entire cohort and in 16% ($n = 8$, 95%CI:5.8%–26.2%) and 10% ($n = 5$, 95%CI:1.7%–18.3%) participants in cohort A and cohort B respectively. GAD-7 showed a score of ≥ 8 in 18% ($n = 18$) participants (95%CI:11.0%–27.0%) in the entire cohort and in 20% ($n = 10$, 95%CI:8.9%–31.1%) and 16% ($n = 8$, 95%CI:5.8%–26.2%) participants in cohort A and cohort B respectively. Nine of these 18 participants had PHQ-9 score ≥ 10 , 4 in cohort A and 5 in cohort B. Details of PHQ-9 and GAD-7 scores in Table 2. There were no significant differences in high PHQ-9 and GAD-7 scores between the 2 cohorts ($p = 0.37$, $p = 0.6$ respectively).

Of the total 22 participants who had high scores on PHQ-9, GAD-7 or both, reassessment at 2–4 weeks was done in 21 (1 child expired while on follow-up due to severe sepsis, COVID-19 pneumonia). PHQ-9 scores in this cohort of 21 participants were ≥ 10 in 7 patients, 6 out of 13 in cohort A (46%, 95%CI:18.9%–73.1%) and one out of eight in cohort B (13%, 95%CI:0%–36.3%), $p = 0.12$. There were 2 patients in cohort A whose initial PHQ-9 scores were < 10 , but GAD-7 scores were ≥ 8 , and at reassessment PHQ-9 scores were ≥ 10 . GAD-7 scores in 21 patients at reassessment were ≥ 8 in 8 participants in cohort A (8/13, 61.5%, 95%CI:35.1%–88.4%) and none in cohort B, $p = 0.004$. There were 3 patients with initial score < 8 in cohort A with a reassessment score ≥ 8 on GAD-7. The initial and post-intervention reassessment scores for GAD-7 and PHQ-9 in the cohort of 21 participants showed a significant difference in the proportion of patients with respect to GAD-7 scores (McNemar $p = 0.035$), but no significance was attained for proportion of patients with respect to PHQ-9 scores (McNemar $p = 0.1$). Details in Table 3.

5 | DISCUSSION

Psychological disturbances during natural disasters and pandemics are seen mostly in normal people affected by an extraordinary stressor, and in majority, subside spontaneously or with brief psychological inputs.² Primary caregivers of children with cancer form a cohort in whom there could be a complex interplay of various stressors including diagnosis and treatment of malignancy in the child and concerns and problems related to COVID-19, during this pandemic. An assessment of the psychological health of these participants could inform the burden of the distress and interventions needed to be actively planned and implemented for their physical and mental well-being, that can be extrapolated to any acute emergencies. This is of prime importance being a primary caregiver of a child with cancer for the uninterrupted treatment and continued holistic delivery of care. This also helps identify a subset who would require continued care even after the pandemic subsides.

TABLE 1 Characteristics of the caregivers in the 2 cohorts

Characteristic		Cohort n (%)		p value
		A	B	
Gender	Female	29 (58.0)	21 (42.0)	0.11
	Male	21 (42.0)	29 (58.0)	
Local residence	Own accommodation	2 (4.1)	10 (20.0)	0.026
	Provided accommodation (free)	35 (71.4)	25 (50.0)	
	Rented accommodation	12 (24.5)	15 (30.0)	
Education status	Graduation or post graduation	11 (22.0)	15 (30.0)	0.212
	Junior college	10 (20.0)	4 (8.0)	
	Primary	8 (16.0)	7 (14.0)	
	Secondary	19 (38.0)	24 (48.0)	
	Illiterate	2 (4.0)	0 (0.0)	
Financial stress during pandemic (cohort A, n = 37; cohort B, n = 45)	No	30 (81.1)	37 (82.2)	0.612
	Yes	7 (18.9)	8 (17.8)	
Relationship of caregiver	Parent	42 (84.0)	48 (96.0)	0.092
	Others	8 (16.0)	2 (4.0)	
Phase of the treatment	Intensive	37 (74.0)	48 (96.0)	0.007
	Maintenance	8 (16.0)	2 (4.0)	
	Relapse at diagnosis of COVID-19	5 (10.0)	0 (0.0)	
Comorbid illnesses in caregiver	No	45 (90.0)	45 (90.0)	1.0
	Yes	5 (10.0)	5 (10.0)	
COVID-19 in caregiver during the study	No	28 (56.0)	48 (96.0)	<0.001
	Yes	22 (44.0)	2 (4.0)	

This study identifies moderate to severe depressive and anxiety symptoms in 13% and 18% of primary caregivers respectively which is similar to the reported incidence of moderate to severe depression and anxiety (18% and 16% respectively) in frontline health care workers engaged in COVID-19¹⁵ work, severe depression in adult patients with COVID-19 (19.3%) and general public (14.3%),¹⁶ suggesting that all strata of people are affected equally by the pandemic. Although the participants in our study had multiple additional stressors related to malignancy and treatment of the child, these did not lead to increased psychological distress in the cohort above that observed in different strata of population. These figures in our study cohort are also less when compared to higher levels of clinically relevant distress (49%–60%) noted in caregivers of pediatric cancer patients, before and during the current pandemic though the tools used were different.^{17–19} This could be attributed to the robust psychosocial support systems established in the institute for the holistic delivery of care to the children stricken with cancer, whereby tiered-counseling from the time of diagnosis of cancer is provided to caregivers by volunteers, dedicated social workers and psychologists helping them develop coping and adaptive skills to the medical stress.¹² This coupled with financial,

accommodation, nutritional, educational support could be a main reason for the lower incidence of psychological distress observed in our caregiver cohort. There were no significant differences in psychological distress between the caregivers of children based on the status of COVID-19 either in their child or the caregiver himself, asserting the fact that the assessment for mental health disturbances should be performed across all strata during such crisis irrespective of other factors. The various measures adopted by the department to mitigate the adverse effects of the pandemic on the continuation of treatment in children with cancer, including continuing intensive chemotherapy in asymptomatic and mildly symptomatic children with COVID-19 along with the continued psychosocial support and the awareness that children with cancer had no increased vulnerability to severe COVID-19 could have been attributing factors for the above observation.^{20,21} Rapid institution of measures to combat the challenge of the pandemic by way of adaptive protocols, setting up of outpatient clinics in accommodation centers to minimize hospital footfalls and day care rooms for delivery of chemotherapy to quarantined children helped the cause.

There can be multiple psychiatric manifestations which can co-exist and warrants close assessment and follow-up. In cohort A,

TABLE 2 (A) Baseline PHQ-9 and GAD-7 scores (B) Variables associated with baseline scores

(A)							
		n (%)			95% CI		
PHQ-9							
Minimal depression		69 (69.0)			59.0%–77.9%		
Mild to moderate depression		28 (28.0)			19.5%–37.9%		
Severe depression		3 (3.0)			0.6%–8.5%		
GAD-7							
None to mild		89 (89.0)			81.2%–94.4%		
Moderate		11 (11.0)			5.6%–18.8%		
(B)							
Variable		PHQ-9			GAD-7		
		<10	≥10	p value	<8	≥8	p value
Gender	Female	44 (50.6)	6 (46.2)	0.766	39 (47.6)	11 (61.1)	0.298
	Male	43 (49.4)	7 (53.8)		43 (52.4)	7 (38.9)	
Local residence	Owned accommodation	11 (12.8)	1 (7.7)	0.152	8 (9.9)	4 (22.2)	0.252
	Provided accommodation (free)	49 (57.0)	11 (84.6)		49 (60.5)	11 (61.1)	
	Rented accommodation	26 (30.2)	1 (7.7)		24 (29.6)	3 (16.7)	
Education of the caregiver	Graduation or post graduation	21 (24.1)	5 (38.5)	0.702	21 (25.6)	5 (27.8)	0.766
	Illiterate	2 (2.3)	0 (0.0)		2 (2.4)	0 (0.0)	
	Junior college	13 (14.9)	1 (7.7)		10 (12.2)	4 (22.2)	
	Primary	14 (16.1)	1 (7.7)		13 (15.9)	2 (11.1)	
	Secondary	37 (42.5)	6 (46.2)		36 (43.9)	7 (38.9)	
Financial stress during pandemic	No	56 (80.0)	11 (91.7)	0.615	55 (82.1)	12 (80.0)	0.851
	Yes	14 (20.0)	1 (8.3)		12 (17.9)	3 (20.0)	
Relationship of caregiver to the patient	Others	10 (11.5)	0 (0.0)	0.351	9 (11.0)	1 (5.6)	0.685
	Parent	77 (88.5)	13 (100)		73 (89.0)	17 (94.4)	
Phase of the treatment	Intensive	74 (85.1)	11 (84.6)	0.554	67 (81.7)	18 (100)	0.144
	Maintenance	8 (9.2)	2 (15.4)		10 (12.2)	0 (0.0)	
	Relapse at diagnosis of COVID-19	5 (5.7)	0 (0.0)		5 (6.1)	0 (0.0)	
Comorbidities	No	80 (92.0)	10 (76.9)	0.120	76 (92.7)	14 (77.8)	0.077
	Yes	7 (8.0)	3 (23.1)		6 (7.3)	4 (22.2)	
COVID-19 in caregiver during the study	No	66 (75.9)	10 (76.9)	1.000	62 (75.6)	14 (77.8)	1.000
	Yes	21 (24.1)	3 (23.1)		20 (24.4)	4 (22.2)	
Cohort	A	42 (48.3)	8 (61.5)	0.372	40 (48.8)	10 (55.6)	0.603
	B	45 (51.7)	5 (38.5)		42 (51.2)	8 (44.4)	

Abbreviations: GAD-7, generalized anxiety disorder-7; PHQ-9, patient health questionnaire-9.

two participants had higher PHQ-9 scores and 3 had higher GAD-7 scores at reassessment, with initial scores below the defined cut-off. There was also a higher proportion of caregivers with persistent high GAD-7 scores in cohort A compared to B. These can probably be attributed to the common stressor of long hospitalization due to COVID-19 and also to the diagnosis of COVID-19 in the other

caregiver. Nevertheless, there was a significant improvement post-intervention administered by the trained Psycho-oncologist with regards to GAD-7 scores, but not PHQ-9 scores. This improvement in anxiety may be due to resolving infection, though the numbers were small. This underlines the importance of continued assessment and delivery of psycho-therapeutic support and care that would be

TABLE 3 (A) Reassessment scores for those with initial high PHQ-9 or GAD-7 scores separately and in 21 participants with initial high scores on PHQ-9 or GAD-7 or both (B) McNemar test for PHQ-9 and GAD-7 in 21 participants who were reassessed

(A)

PHQ-9 Baseline ≥ 10 (n = 13)	N	≥ 10 at Reassessment	%	95% CI	p value
Cohort A	8	4	50%	15.4% - 84.7%	0.27
Cohort B	5	1	20%	0 - 55.0%	
GAD-7 BASELINE ≥ 8 (n = 18)		≥ 8 at reassessment			
Cohort A	10	5	50%	19.0% - 80.9%	0.01
Cohort B	8	0	0%	0 - 0	
PHQ-9 (n = 21)		≥ 10 at reassessment			
Cohort A	13	6	46%	18.9% - 73.1%	0.12
Cohort B	8	1	13%	0 - 36.3%	
GAD-7 (n = 21)		≥ 8 at reassessment			
Cohort A	13	8	61.5%	35.1% - 88.4%	0.004
Cohort B	8	0	0%	0 - 0	

(B)

			PHQ-9 at Baseline		Total	McNemar p value = 0.109
			<10	≥ 10		
PHQ-9 at reassessment	<10	Count	6	8	14	
	≥ 10	Count	2	5	7	
Total		Count	8	13	21	
			GAD-7 at baseline		Total	McNemar p value = 0.035
			<8	≥ 8		
GAD-7 at reassessment	<8	Count	1	12	13	
	≥ 8	Count	3	5	8	
Total		Count	4	17	21	

Abbreviations: GAD-7, generalized anxiety disorder-7; PHQ-9, patient health questionnaire-9.

required to identify ongoing psychiatric morbidity and manage them, which was provided in all the participants with persistent high PHQ-9 scores.

The delivery of the tools and psychotherapeutic interventions wherever necessary were delivered in majority (96%) of the caregivers over a voice call after establishing rapport, as personal direct contact had to be minimized due to COVID restrictions and timely delivery was deemed important. This opportunity had opened up a new avenue of contact where integration of skilled health professional was made available in an emergency despite resource constraints.

5.1 | Study limitations

The limitations of this study are the small sample size, short period of study and follow-up and that we have not assessed all the psychological disturbances that could manifest in the participants including

post-traumatic stress disorder. Though we did exclude those with pre-existing psychiatric disorders, a comprehensive assessment of personality and past or family history could not be done due to urgency of the situation related to the pandemic. The effect of interventions could also be studied in only a limited number of subjects, though it was not the primary objective.

5.2 | Clinical implications

Despite the limitations, the study provides a picture of the incidence of depression and anxiety in a vulnerable targeted population and reiterates the fact that coupling of index and mental health department services are necessary to mitigate these disturbances posed by challenging situations like the current pandemic, even in resource constrained settings with limited trained manpower utilizing the available technologies.

6 | CONCLUSIONS

Primary caregivers should be assessed and followed up for psychological distress irrespective of other coexisting factors. Robust support systems built over time could help withstand the exceptional strain of a major surge during a pandemic delivering care to childhood cancer patients with and without COVID-19.

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DATA AVAILABILITY STATEMENT

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

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