

# Parental Outlook and Problems Faced during Lockdown in COVID-19 Pandemic: Experience from a Paediatric Haematology-Oncology Unit in a Developing Country- A Questionnaire Based Survey

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## ABSTRACT

**Introduction:** Corona Virus Disease 2019 (COVID-19) pandemic has resulted in disruption of essential healthcare services. Children with cancer are very vulnerable group and delay in seeking treatment or defaulting scheduled medications adversely affects the outcome.

**Aim:** To obtain insight into barriers and to evaluate concerns, outlook and challenges faced by parents of children suffering with malignancy in accessing the healthcare services during lockdown imposed due to COVID-19 pandemic.

**Materials and Methods:** A questionnaire-based survey was conducted from parents of children newly diagnosed (during lockdown restrictions) with malignancy and previously diagnosed and under treatment at Paediatric Haematology Oncology unit in a Tertiary care centre. The responses were recorded in predesigned proforma during 15 days period after restrictions were relaxed.

**Results:** Fifty-five responses were recorded and analysed. Father was the respondent in most cases. Acute Leukaemia (n=37) and Lymphoma (n=14) patients comprised majority of the patients. Major challenges faced were transportation (98.2%), financial burden (96.4%) and loss of job (65.4%). Fear of contracting COVID-19 infection was a primary barrier in seeking treatment for most respondents.

**Conclusion:** The success and outcome of children with malignancy has been suboptimal in low-income and middle-income countries due to effect of lack of timely access of healthcare services, delayed diagnosis, treatment abandonment, poor compliance and financial constraints. The COVID-19 pandemic and associated setbacks have accentuated these factors and may have long term impact in final outcome for such patients.

**Keywords:** Financial burden, Lymphoma, Malignancy, Parental concern

## INTRODUCTION

Due to COVID-19 pandemic and alarming rise in the number of cases, a countrywide lockdown was imposed from 25<sup>th</sup> March 2020 till 31<sup>st</sup> May 2020 to limit the spread of infection as a part of preventive strategy. A number of restrictions were imposed with exemption of healthcare services. However, most of these facilities primarily focussed on dealing with patients of COVID-19. The fear of acquiring COVID-19 infections, loss of source of income, widespread travel restrictions and disruption of routine medical services during this period may adversely affect outcome of children suffering with cancer. Timely diagnosis and continuation of therapy protocol is cornerstone for successful outcome of these patients. Due to diversion of already scarce medical resources and lack of availability of affordable cancer care centres, the care of patients with non COVID illnesses is highly likely to be compromised [1-7]. Though, these concerns and challenges have been identified, there is paucity of adequate literature on parental perspectives and outlook of parents of children suffering from malignancy in accessing the health services during this period.

The main objectives of the present study were to obtain insight into barriers and to evaluate concerns, outlook and challenges faced by parents of children suffering with malignancy in accessing the healthcare services during lockdown imposed due to COVID-19 pandemic.

## MATERIALS AND METHODS

A questionnaire based survey (Google Form) was designed for the study conducted in the Haematology-Oncology unit in the Department of Paediatrics, Safdarjung Hospital, New Delhi, India.

The ethical clearance was obtained from Institute Ethics Committee IEC/MMC/SJH/PROJECT-2020-07/CC-26.

**Inclusion and Exclusion criteria:** The parents of children under 12 years age who had been newly diagnosed with malignancy during last three months and those who were under follow-up at the centre were consecutively recruited over a period of 15 days in July 2020 soon after lockdown restrictions were relaxed. Those who were referred to another centre were excluded.

**Predesign performa:** The responses from parents were recorded in predesigned proforma after obtaining consent. An oncology nurse and medical social worker assisted the parents who explained them all questions. A total of 41 questions (31 compulsory and 10 optional questions) were included in the form and were distributed under four major headings: 1) Demographic data of the patient (child) and parent; 2) Diagnosis and related data; 3) Parental Fears; 4) Problems faced in lockdown. Both open ended questions (17) and closed ended questions (24) were included in the form. Two questions required the answer in terms of grade on a scale of five (1 to 5). About half of the closed ended questions were "Yes/No" type.

## STATISTICAL ANALYSIS

The data was tabulated as mean and percentages and analysed using Microsoft Excel.

## RESULTS

A total of 55 responses were recorded. Father was the respondent in majority of cases (51%). The mean age of children was 7.7 years

(range 1-12 years). Acute Leukaemia and Hodgkin's Lymphoma comprised the majority of diagnosis. The caregivers were primarily daily wage workers and most of them have travelled from other states to seek specialised care and travelled distances beyond 500 km. Many parents had travelled long distances from their native state and hence, faced problems related to boarding and lodging. All parents received support from Non-Government Organisation (NGO) but many had out of pocket expenditures as well [Table/Fig-1]. During the lockdown period, problems arising due to restrictions imposed for transportation were almost a universal issue. The financial burden, constraints and loss of job were other problems in two-thirds of respondents. Arranging blood and blood products donation was a minor concern in the respondents [Table/Fig-2]. In order of priority, maximum parents ranked lack of job/loss of job as their most common problem affecting their source of income. A vast majority of parents had fear of acquiring COVID-19 infection while visiting the hospital during the lockdown and were also concerned going to quarantine in case they get infected with COVID-19. When asked to grade the difficulty level of lockdown period for them and their child on a scale of 1 to 5, 72.7% of the parents graded 5 out of 5 while 27.3% graded 4 out of 5. Most of the parents felt helpless at some point during the lockdown (92.7%) and negative thoughts (89.1%) as well. However, at the same time maximum parents were satisfied after spending more time with their ward (63.6% graded 5 on 5 and 36.4% graded 4 on 5 on a scale

Socio-demographic status	Number (n) Percentages (%)
Mean age of the child (in years)	7.7
Range of age (in years)	1-12
<b>Age distribution (years)</b>	
<5	12 (21.8%)
5-10	26 (47.3%)
>10 to 12	17 (30.9%)
<b>Diagnosis (n=55) (%)</b>	
Leukemia (ALL and AML)	37 (67.3%)
Lymphoma	14 (25.5%)
Rhabdomyosarcoma	1 (1.8%)
Osteosarcoma	1 (1.8%)
Hepatoblastoma	1 (1.8%)
Hemophagocytic Lymphangiohistiocytosis (HLH)	1 (1.8%)
<b>Respondents</b>	
Mother	18 (33%)
Father	28 (51%)
Guardian	9 (16%)
<b>Caregiver's characteristics</b>	
Mean age (in years)	34.3
Range of age (in years)	23-50
<b>Occupation</b>	
Daily wage worker	36.4%
House wife	27.3%
Farmer	11%
<b>Distance of residence from hospital</b>	
Less than 100 km	21 (38%)
Between 100 km to 500 km	24 (44%)
More than 500 km	10 (18%)
<b>Source of funding (for fooding, lodging, travel)</b>	
Out of pocket	41 (74.5%)
NGO aided	55 (100%)
Borrowed from someone	3 (5.45%)

**[Table/Fig-1]:** Socio-demographic profile of the study participants and caregivers characteristics.

of 1-5). A very small number of parents saw their child in pain or his/her condition deteriorating. Delay in diagnosis (subjective opinion) of their child was reported by 61% of the parents [Table/Fig-3]. Majority of the parents had average number of 1-2 visits to other healthcare setups before coming to this hospital (n=45, 81%), nine parents had made 3-4 visits while one parent directly came to our institute. However, the result is not statistically significant (p-value <0.05). All the parents told that they had used protective measures for their kids as well as themselves in one form or the other and also in combination, while in hospital premises and out of home. Personal protective measures used in decreasing order of frequency were: sanitisers (100%), facemasks (98.1%), frequent hand-washing (67.3%) and social distancing (38.1%). Being a public care hospital, chemotherapy medications were provided free of cost. However, 40% parents reported some difficulty in procurement of drugs not available in hospital supply.

Issues of concern	(n=55) (%)
Transportation	54 (98.2)
Financial burden and constraints	53 (96.4)
Food arrangements	50 (91)
Job/Employment	35 (65.7)
Boarding/lodging and stay	30 (55)
Procurement of medicines	22 (40)
Arranging blood and blood products	16 (29)
Lab tests/Investigations	6 (11)

**[Table/Fig-2]:** Challenges and problems faced by caregivers of children with cancer.

Parental perception (n=55)	Percentage
Afraid of hospital visit/fear of contracting illness	92.7
Feeling helpless	92.7
Had negative thoughts	89.1
Hardship and difficult time*	72.7
Satisfaction of spending time with child*	63.6
Delayed diagnosis	61
Deterioration of health status of child	5.5

**[Table/Fig-3]:** Psychological concerns, fears, and apprehensions of caregivers of children with cancer; \*(Grade 5 on scale 1-5).

## DISCUSSION

Oncologists worldwide are perplexed to choose between cancer chemotherapy vs risk of COVID-19 infection. Patients suffering from malignancies form a high risk immunocompromised vulnerable group and providing care during COVID-19 pandemic is difficult and challenging task. Delay in accessing appropriate healthcare for children suffering from malignancy is significant issue in resource poor settings and the situation is made worse due to ignorance of caregivers [2,5,8-11]. COVID-19 pandemic restrictions have a deep impact on livelihood of population and can offset the gains made in treatment of such patients. This study tried to explore these issues to gain an insight of major challenges faced by caregivers during this period of crisis. In this study, we found that parental concerns and hardships during an unprecedented situation are compounded and have deep psychological impacts. Their perceptions are many times underestimated and remain unattended, though they are closely associated with comprehensive care of their child.

The challenges faced by parents of children suffering with malignancies have been aptly described in various studies. It is postulated that due to inherent vulnerable state, cancer patients are likely to fare worse than general population [11,12]. But there is limited data available regarding concerns and outlook of parents of children suffering from malignancy. Most of the parents in present study expressed the fear of going to the hospital during lockdown and were afraid of going to quarantine if they get infected with

COVID-19, strikingly similar to other study done in UK [1]. However, being resource limited setting many patients in the present study travelled distances more than 500 km to access services at the centre. This may be attributed to lack of widespread availability of specialised cancer care centres in our country. This highlights the pertinent issue which needs serious attention of policy makers as more and more children are being diagnosed in peripheral centres but are unable to receive chemotherapy and treatment services.

Like adults, children may also suffer mental stress and emotional issues. Again, this issue has been largely ignored altogether or remain unrecognised. Due to imposed restrictions, children had limited avenues to relive from stressful situation. These children were more likely to be quarantined due to their immune-compromised state. Appropriate psychiatric care and counselling formed part of their treatment plan [13]. Fear and anxiety, emotional stress, monetary issues, availability of medications coupled with financial hardship due to loss of jobs can have widespread implications on parents [14]. In present study, we have tried to explore these problems as per parent's perspective. Cancer treatment per se tends to bring financial hardships on people. As reported in a study, on an average 50% of low wealth quintile households in our country face financial distress due to cancer treatments [15]. In contrast to this study, present survey monetary issues were reported by 96.4% parents. This may indicate that lockdown situation and loss of jobs aggravated the financial hardships of parents (majority of who belonged to low income groups). In current study, nearly one-third of parents faced problem in arranging blood products attributed to the lack of blood donors. Similar challenges have been highlighted in other studies as well [16,17]. It has been suggested that effective communication strategies and community awareness is required to mitigate the effects of shortage of donors in crisis situations. But due to false beliefs and fear of transmission of COVID infections, blood donation programmes during this pandemic has suffered serious setbacks. Delayed diagnosis of illness was perceived by 61% of the respondents. This could be attributed to other healthcare setup visits prior to coming to the hospital in study and also because of travel restrictions and lack of access to appropriate resources during lockdown [12,18]. This is aggravation of previously well-identified concern in cancer treatment [19].

Majority of parents felt helpless and insecure probably because lockdown created a socially isolated environment. In this survey, negative thoughts were also seen in study participants who were the caregivers (89%). These issues can also have a long-term impact on care of these children as many parents lack access to suitable counselling. These patients may be non-compliant and are more likely to default [1,20-23]. Another, parameter was the level of satisfaction which was found to be high after spending more time with the child as most of the working parents would have got the chance to stay for long with child due to lockdown. Very few parents (n=3, 5.5%) reported to have seen their child in pain or his/her condition deteriorating during the lockdown period, which could be because of the fact that study recorded experiences of parents who attended the hospital even during difficult time of lockdown.

It is advocated that avoiding non-essential visits to hospital and use of telemedicine can be beneficial in some cases to avoid default in treatment. But such consultations are limited again due to lack of suitable facilities. Most of our study participants belonged to lower or middle class and lacked knowledge and access for such services. Moreover, these consultations are suitable in a limited number of cases of children with malignancy and in otherwise healthy follow-up patients only. Only, 42% of parents had made use of phone calls to inquire about the hospital visit and OPD functioning in our study [24,25]. Due to restrictions of the pandemic, defaulting of chemotherapy poses a higher risk

of treatment failures [7,26]. Timely access to services is pertinent to chances of good clinical outcome.

### Limitation(s)

Present study had certain limitations as well. Despite all odds 55 parents were included in the study. The patient number reduced during and after lockdown period, but it still reflects parental attitude towards seeking care despite hardship. Nevertheless, a larger sample size would have reflected the spectrum of issues faced in a better manner. The study could not record the experience of other parents of children with cancer who were unable to visit the institute during this period. Some patients defaulted on scheduled visits or were lost to follow-up were also not included. It is expected that these parents may have suffered more serious hardships. Also, the study did not include further follow-up of these patients regarding completion of treatment or outcome. Since, social issues continue to play an important role in compliance to long term treatment protocols, this study did not ascertain all of these factors.

### CONCLUSION(S)

Care of children suffering from malignancies has various aspects which not only includes medical services but psychological, emotional and other support as well. It is a multidisciplinary approach which forms a part of comprehensive care of such children. Role of NGO and similar agencies is vital for such services. Present study was designed to explore the perceptions of caregivers so that effective solutions and strategies can be explored to limit the challenges faced by families of such vulnerable population. The impact and repercussions of disruption of these services are still not known. Parental expectations and perspectives may be an unmet need and can be effectively handled, once we gain a detailed insight into these issues. If these issues are addressed simultaneously along with treatment plan, the overall compliance to therapy can be greatly improved.

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