

Challenges for Primary Caregivers during the COVID-19 Pandemic in Accessing Health Care of Children with Chronic Diseases under Periodic Follow-up at a Tertiary Care Hospital in South India

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Abstract

Introduction: Challenges faced by the primary caregivers during the COVID-19 pandemic help to identify their needs and health seeking behavior during pandemic. **Objectives:** (1) To describe the factors associated with periodic follow-up at the hospital which posed as difficulties to their primary caregivers during the COVID-19 pandemic. (2) To identify the measures adopted by these primary caregivers to overcome those difficulties. **Materials and Methods:** This hospital-based cross-sectional observational study was conducted from May to August 2021 among 57 primary caregivers of children with chronic diseases registered before March 1, 2020, who were under periodic follow-up in our pediatrics department. Data were collected by direct or telephonic interview using a predesigned semi-structured questionnaire and analyzed using descriptive and inferential statistics like mean, standard deviation, proportions and paired “t”-test using Epi info and IBM SPSS trial version 28.0. **Results:** Frequency of hospital visits of 14 (24.6%) subjects were reduced during the COVID pandemic compared to the prepandemic period. During the COVID pandemic, 42 (73.7%) subjects had faced transportation difficulties, 23 (40.3%) had faced financial difficulties, 22 (38.6%) had skipped their scheduled follow-up visits and around 31.6% of them have feared of contracting COVID. None had availed telemedicine consultation for their children either before or during the pandemic. **Conclusions:** Difficulties faced in transportation, fear of contracting COVID, financial difficulties, and lack of awareness of teleconsultation services were identified as their major obstacles.

Keywords: Challenges, chronic diseases, COVID-19, follow-up, primary caregivers, telehealth

INTRODUCTION

COVID-19 caused by the severe acute respiratory syndrome coronavirus 2 is a potentially fatal disease.^[1,2] In India the first case of COVID-19 was reported on January 30, 2020 after which the cases have spread nationwide. India has so far witnessed three waves of the COVID-19 pandemic.^[3] Tamil Nadu, a state in southern India, reported its first case on March 7, 2020, and then the pandemic had spread to all districts.^[4] On March 11, 2020, World Health Organization declared the COVID outbreak, a pandemic following which the Government of India declared COVID a “notified disaster” under the Disaster Management Act of 2005 and appealed power under the Epidemic Diseases Act of 1897 to augment the preparedness and repression of the virus.^[5,6]

During disasters like the COVID pandemic, accessing the health-care facilities would be of utmost importance to the people affected, especially to those who need continuity in health care. Kendzerska *et al.* observed that due to fear of potential COVID infection, patients with chronic conditions avoided in-person medical visits to hospitals and clinics.^[7] The ECIE-2020 study described that the disease measures

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adopted during lockdown caused a significant fall in the number of both pediatric ED consultations and hospital admissions.^[8] Drentea defines “caregiving” as the act of assisting and supporting family members or acquaintances who have physical, psychological, or developmental needs without acquiring any monetary benefits. Caregivers may be family members, friends, or neighbors.^[9] Primary caregivers play an important role in the health care of children with chronic diseases who are under periodic follow-up at Hospitals. High contagiousness of the virus during the pandemic posed a risk of infection among caregivers, which would limit health-care services significantly.^[10]

Therefore, the challenges faced by the primary caregivers during the COVID-19 pandemic would help us understand their needs and health-seeking behavioral patterns. Hence, the objectives of this study were (1) to describe the factors associated with periodic follow-up at the hospital, which posed difficulties to their primary caregivers during the COVID-19 pandemic and (2) to identify the measures adopted by these primary caregivers to overcome the difficulties in accessing health care for these children during the COVID-19 pandemic.

MATERIALS AND METHODS

Study design, study setting, and duration

This hospital-based cross-sectional observational study was conducted for a period of 4 months from May to August 2021, at the outpatient clinic and inpatient ward of the pediatrics department of our tertiary care hospital.

Study subjects

Around 76 primary caregivers of children with chronic diseases registered before the March 1, 2020, whose children were under periodic follow-up for investigations and treatment at the outpatient clinic or inpatient ward of the pediatrics department of our hospital, were included as study subjects.

Study tool and method of data collection

Data were collected by direct interview or telephonically using a predesigned semi-structured questionnaire. Face-to-face interview of the primary caregiver of the children in the line listing was done during their visit to the outpatient clinic or inpatient ward for their periodic follow-up during the study period. A telephonic interview was done for those primary caregivers who did not turn up for follow-up even after 2 months from the beginning of the study. Study subjects who did not consent and those in the line listing who neither visited the follow-up clinic nor could be contacted telephonically until completion of the study period were excluded.

Statistical analysis

Data collected were entered into a Microsoft Office Excel worksheet and analyzed with descriptive statistics like mean, standard deviation, proportions, and inferential statistics like 95% confidence interval (95% CI) and paired “*t*-test using statistical software like Epi Info and SPSS trial version 28.0.(IBM Corp., Armonk, NY., USA). At

95% confidence level, $P \leq 0.05$ was considered statistically significant.

Ethical issues

Approval from our institutional ethics committee (IEC) was obtained prior to data collection vide letter no. ESICMCPGIMSR/IEC/2021/1/13 dated: May 4, 2021. Written informed consent was obtained from parents of the children prior to their interview on explaining the aims and research procedure. The research followed the guidelines laid down in the Declaration of Helsinki.

RESULTS

Among the 76 Primary Caregivers of all the children with chronic diseases who were registered before March 2020 and in the line listing of the follow-up clinic in the pediatric department, only 57 participated in the study. Nineteen were excluded as a few did not consent and most of them were not able to be contacted directly or telephonically until the completion of the study period. Of the 57 study participants, 51 (89.5%) were directly interviewed and 6 (10.5%) were interviewed through telephone.

Sociodemographic characteristics of the children

Table 1 shows that almost 35 (61.4%) children with the chronic diseases under follow-up were males and the majority 31 (54.4%) were in the age group of 11–15 years. The mean (95% CI) age of children was 9.9 (9.1–10.8) years. Most of the children were under treatment for chronic diseases of the central nervous system 14 (24.6%), genitourinary system 13 (22.8%), and hematological 11 (19.3%) disorders. Seizure disorders, chronic kidney diseases, hemophilia, thalassemia, immunodeficiencies, and Type I diabetes mellitus were the majority of diseases diagnosed for which they were under follow-up. Of the children studied 33 (57.9%) were availing tablets and 15 (26.3%) were availing injections as their treatment during follow-up visits at the hospital. Around 26 (45.6%) children were under follow-up for <3 years. During the COVID pandemic, only 3 (5.3%) children were affected due to COVID while 10 (17.5%) of the household members had been affected due to COVID in the past.

Sociodemographic characteristics of the primary caregivers

As seen in Table 2, of the Primary caregivers 26 (45.6%) were in the age group of 41–50 years and most of them were mothers. The mean (95% CI) age of Primary caregivers was 38.5 (36.8–40.2) years. Around 19 (33.3%) Primary caregivers had completed high school while 37 (64.9%) were employed. The majority 52 (91.2%) were residing in urban localities and 42 (73.7%) lived in nuclear type of families. Most Primary caregivers 32 (56.1%) belonged to the upper-middle socioeconomic class as per the modified B. G Prasad scale. Thirty-seven (64.9%) study participants resided within 25 km from the hospital.

Table 1: Distribution of children with the chronic disease based on system involved and treatment availed

Characteristic	Frequency
Age group of children (years)	
1-5	6 (10.5)
6-10	20 (35.1)
11-15	31 (54.4)
Sex of children	
Male	35 (61.4)
Female	22 (38.6)
System involved due to chronic disease for which periodic treatment is availed	
CVS	3 (5.3)
CNS	14 (24.6)
RS	2 (3.5)
GIT	2 (3.5)
GUT	13 (22.8)
Endocrine	4 (7.0)
Hematology	11 (19.3)
Musculoskeletal	2 (3.5)
Multisystem	6 (10.5)
Treatment availed by the child on periodic interval at the hospital	
Tablets	33 (57.9)
Injections	15 (26.3)
Chemotherapy	1 (1.8)
Radiotherapy	1 (1.8)
Blood transfusion	3 (5.3)
Dialysis	4 (7.0)
Number of years the child is on periodic treatment for the chronic health condition in our hospital (years)	
≤3	26 (45.6)
3-6	16 (28.1)
>6	15 (26.3)
Child was ever affected by COVID-19	
Affected	3 (5.3)
Not affected	54 (94.7)
Household members of the child ever affected by COVID-19	
Affected	10 (17.5)
Not affected	47 (82.5)

Figures in parentheses denotes percentages. CVS: Cardio vascular system, CNS: Central nervous system, RS: Respiratory system, GIT: Gastro intestinal tract, GUT: Genito urinary system

Frequency of hospital visits and mode of transportation used

Before the COVID pandemic, majority 39 (68.4%) of them had utilized public transportation like buses or trains to reach the hospital for availing treatment. During the COVID, the proportion of those who utilized public transport reduced to 11 (19.3%) while as many as 17 (29.8%) switched to own vehicle like bikes and scooters. The frequency of hospital visits of 14 (24.6%) subjects was reduced during the COVID pandemic compared to the prepandemic period. As evident from Table 3, among the study subjects, eight (14.0%) had visited the hospital twice a month for treatment before the

Table 2: Distribution of primary caregivers of children with chronic disease based on sociodemographic characteristics

Sociodemographic characteristic	Frequency
Primary caregiver to the children	
Mother	37 (64.9)
Father	20 (35.1)
Age group of primary care giver (years)	
21-30	8 (14.0)
31-40	22 (38.6)
41-50	26 (45.6)
51-60	1 (1.8)
Marital status of the primary caregiver	
Married	54 (94.7)
Widowed	1 (1.8)
Separated	2 (3.5)
Educational status of primary caregiver	
Primary school	2 (3.5)
Middle school	13 (22.8)
High school	19 (33.3)
Higher-secondary	8 (14.0)
Diploma	4 (7.0)
Under-graduate degree	10 (17.5)
Postgraduate degree	1 (1.8)
Occupational status of primary caregiver	
Unemployed	20 (35.1)
Employed	37 (64.9)
Type of family	
Nuclear	42 (73.7)
Joint	15 (26.3)
Residential locality	
Urban	52 (91.2)
Rural	5 (8.8)
Socioeconomic status of the family	
Upper class	6 (10.5)
Upper middle class	32 (56.1)
Lower middle class	19 (33.3)
Upper lower class	None
Lower class	None
Distance between residence and hospital (km)	
≤25	37 (64.9)
26-50	17 (29.8)
51-75	2 (3.5)
>75	1 (1.8)

Figures in parentheses denote percentages

pandemic while during the pandemic period only five (8.8%) of them were able to visit the hospital twice a month. Two (3.5%) study participants reported that they did not visit the hospital during the COVID pandemic period. The mean (95% CI) number of visits to the hospital reduced from 13 (11 to 16) before the COVID pandemic to 11 (9–13) during the COVID pandemic. This mean difference was found to be statistically significant ($P < 0.001$, $t = 3.385$, paired t -test). Around 18 (31.6%) primary caregivers have feared contracting COVID to their children or to themselves either

during transportation or within the hospital premises during the treatment process.

Challenges faced by primary caregivers

As seen in Table 4, majority 42 (73.7%) subjects had faced transportation difficulty to and from our Hospital during the COVID pandemic. Almost 23 (40.3%) had faced financial

Table 3: Frequency of visit to hospital and mode of transportation used before and during the COVID pandemic

Frequency of hospital visit and mode of transportation used	Before COVID pandemic	During the COVID pandemic
Periodic visits to this hospital for the child's treatment		
Not visited	None	2 (3.5)
Once a week	2 (3.5)	1 (1.8)
Twice a month	8 (14.0)	5 (8.8)
Once a month	36 (63.2)	35 (61.4)
Once in 2 months	3 (5.3)	3 (5.3)
Once in 3 months	8 (14.0)	9 (15.8)
Once in 4 months	None	1 (1.8)
Once in 6 months	None	1 (1.8)
Mode of transport used regularly to reach this hospital		
Public transport	39 (68.4)	11 (19.3)
Private transport	None	17 (29.8)
Own vehicle	18 (31.6)	29 (50.9)
Walkable	None	None

Figures in parentheses denote percentages

Table 4: Challenges faced by primary caregivers during the COVID pandemic

Challenges faced by primary caregivers	Before COVID pandemic	During the COVID pandemic
Faced difficulty in transportation to and from this hospital	1 (1.8)	42 (73.7)
Faced difficulty in attending outpatient clinic periodically	None	22 (38.6)
Faced difficulty in availing in-patient treatment periodically	None	10 (17.5)
Faced difficulty in contacting HCP for queries	None	21 (36.8)
Faced difficulty in availing laboratory investigations	None	19 (33.3)
Faced difficulty in availing radiological investigations	None	4 (7.0)
Faced difficulty in availing surgical intervention	None	None
Faced difficulty in availing immunization scheduled for the child	None	2 (3.5)
Faced financial difficulties in treatment of the child's health condition	12 (21.0)	23 (40.3)
Ever skipped the periodic follow-up scheduled for the child's treatment at this hospital	None	22 (38.6)

Figures in parentheses denote percentages. HCP: Health-care provider

difficulties during the treatment process while 22 (38.6%) had skipped their scheduled periodic follow-up visits.

Alternate measures adopted to ensure treatment for children and their reasons

None of them had availed treatment in alternate systems of medicine like Ayurveda, Siddha, Unani, homeopathy, etc., before and during the COVID pandemic. Before the pandemic, none had self-medicated their children but at least 4 (7.0%) of them had self-medicated their children for their Chronic health conditions during the pandemic. Table 5 shows the reason cited for self-medication by the primary caregivers was that medicines were available in a nearby pharmacy upon showing the prescription of the previous visits. One (1.8%) subject had availed treatment for their child in another public health institution before the pandemic while 2 (3.5%) had availed treatment during the pandemic period. None reported availing treatment for their child in private health-care institutions before the pandemic but during the pandemic period, 6 (10.5%) had taken treatment in private institution. From Table 5 it is evident that the major reasons cited for skipping the follow-up visits during the pandemic were difficulty in getting a mode of transportation, difficulty in reaching the hospital due to lockdown measures and fear of the child contracting COVID during the hospital visit by 17 (29.8%), 4 (7.0%) and 4 (7.0%) subjects respectively.

Measures adopted to overcome the challenges faced before and during a pandemic

Table 6 shows that a treatment certificate provided at our hospital for the patients helped them to overcome transportation difficulties, especially when the complete lockdown was enforced during the pandemic as a part of COVID control measures. Almost 30 (52.6%) of them were able to travel to and from our hospital without restrictions using the treatment certificate during the pandemic. Only eight (14.0%) of them were unable to overcome the transportation difficulty. Not many had faced difficulty in accessing immunization as they had already completed immunizations due for their age.

Although medical care is free of cost in our hospital for the insured persons and their dependents, financial difficulties may arise toward transportation, food, loss of daily wages along with other direct and indirect expenditures during the treatment process. To overcome such financial difficulties, 11 (19.3%) of them had taken debt before the pandemic which increased to 22 (38.6%) during the pandemic period. To overcome the difficulty in contacting the health-care providers (HCPs) during the pandemic, five (8.7%) of them had contacted the HCP through their personal phone while two (3.5%) had contacted the HCP through the hospital telephone while 14 (24.6%) were not able to contact the HCP for queries related to the child's treatment. None had availed telemedicine consultation for their children either before or during the pandemic. Of the reasons cited, 29 (50.9%) primary caregivers were unaware of the telemedicine services and 15 (26.3%) of them did not have the required facilities for teleconsultation services.

Table 5: Distribution of study subjects based on reasons for adopting alternate measures

Reasons for adopting alternate measures	During the COVID pandemic
For availing treatment for the child in any other public health institution for this health condition	
As child's health worsened and unable to access this hospital during lockdown	2 (3.5)
For availing treatment for the child in private health institution for this health condition	
As it was nearby to our residence	3 (5.3)
As the child's health worsened	1 (1.8)
Was not able to access the periodic treatment at this hospital during lockdown	4 (7.0)
For skipping the periodic treatment in this hospital	
Difficulty in getting transportation	17 (29.8)
Difficulty in reaching the hospital due to lockdown measures	4 (7.0)
As child was out of station	1 (1.8)
Due to fear of contracting COVID to care taker during transportation	2 (3.5)
Due to fear of contracting COVID to care taker during child's treatment process within the Hospital	3 (5.3)
Due to fear of contracting COVID to the child during transportation	2 (3.5)
Due to fear of contracting COVID to the child during the treatment process within the Hospital	4 (7.0)
For not availing telemedicine consultation	
Not aware of such services	29 (50.9)
Did not have the required facilities for tele consultation services	15 (26.3)
Not affordable	1 (1.8)
Cannot avail treatment procedures in teleconsultation	12 (21.0)

Figures in parentheses denote percentages

Table 6: Distribution of study subjects based on measures adopted to overcome the challenges faced

Measures adopted to overcome challenges	Before COVID pandemic	During the COVID pandemic
To overcome the transportation difficulty		
Managed to hire a vehicle	None	4 (7.0)
Treatment certificate of this hospital helped	1 (1.8)	30 (52.6)
Unable to overcome the transportation difficulty	None	8 (14.0)
To overcome the difficulty in contacting HCP for queries		
Contacted HCP through their personal phone	None	5 (8.7)
Contacted HCP through the hospital phone	None	2 (3.5)
Unable to contact HCP	None	14 (24.6)
Not applicable	57 (100.0)	36 (63.2)
To overcome the challenges in availing immunization		
Delayed the vaccination	None	1 (1.8)
Got vaccinated in another public health institution	None	1 (1.8)
Got vaccinated in another private health institution	None	None
To overcome the financial difficulties toward treatment process of the child's health condition		
Borrowing debt	11 (19.3)	22 (38.6)
Sold their jewelry	1 (1.8)	2 (3.5)

Figures in parentheses denotes percentages. HCP: Health-care provider

DISCUSSION

COVID-19 pandemic and its control measures like lockdown, travel restrictions, lifestyle alteration have caused an impact on the health-care delivery in many countries. Modifications in the health-care availability is very crucial and has significant implications in children with chronic diseases who require frequent follow to health-care facility.^[11] The needs of patients with chronic diseases are being neglected during the pandemic.^[12] Patients deferred treatment and many health-care providers cancelled appointments. The outpatient facilities were modified to only emergency cases and inpatient services

were also reduced.^[13] Around 70% of patients cancelled their appointments due to limited access to health-care facilities.^[14] During the pandemic, patients with chronic conditions are at risk of serious COVID infection and also at risk of missing the routine care which could lead to poor outcome in health.^[12] Caregivers of children with chronic diseases who need frequent visits to hospital faced many challenges in accessing health care due to COVID-19 pandemic. To decide between delaying the treatment for the existing disease and the risk of COVID infection during the process would be one of the toughest decisions for the caregivers.^[15]

A study done by Ahmed *et al.* showed that access to all health-care facilities were reduced during the COVID pandemic. Barriers to access health-care facilities were multiple causes like reduced income, fear of infection, stigmatization and physical barriers in reaching the health facility.^[16]

In our study, frequency of visits to our health facility decreased to 24.6% during the pandemic whereas Rathore *et al.* showed a 65%–70% decrease in the outpatients.^[17] In our study transportation difficulties were experienced by 73.7% of caregivers which was reported only by 21% of them in Micheal *et al.* study.^[14] In our study 36.8% had difficulty in contacting health-care providers. Sharma *et al.* and Micheal *et al.* studies had reported difficulty in medical consultation among patients as 40.5% and 28% respectively.^[14,18] Around 33.3% of patients had difficulty in availing laboratory investigations in our study, which was experienced by 55% of patients in Sharma *et al.* study and 61.7% of patients by Enver *et al.* study.^[18,19]

In spite of availability of our social security scheme such as health insurance, in our study 40.3% caregivers reported financial difficulties which was in comparable to Zorcec *et al.* study where 47% had faced similar obstacles.^[11] Although only 3.5% of the children in our study faced difficulties in availing immunization, it amounted to 33% of the children under 5 years of age which was comparable to the study done by Baghdadi *et al.* who revealed vaccine delay in 37% of children under 2 years of age.^[20] In our study 38.6% subjects skipped their periodic treatment which was similar to Zorcec *et al.* study which showed missed visits in 37.7% subjects and was in contrast to the Micheal *et al.* study where 70% of patients cancelled their treatments.^[11,14]

None of them in our study switched to alternate therapy which was in contrast to the study done by Micheal *et al.* who declared that 23% of immunology patients and 19% cancer patients switched to alternate therapy.^[14] With difficulty in routine health-care visits, patients with chronic diseases tend to adopt various telemedicine services such as video consultations.^[12] None had availed teleconsultations in our study whereas Micheal *et al.* showed that 37% of patients started to use virtual health services.^[14] In our study 5.3% of children and 17.5% of caregivers were affected due to COVID infection, while the Rathore *et al.* study showed that incidence of COVID infection among patients with epilepsy and their family members as 4% and 8% respectively.^[17] Patients with chronic diseases tend to avoid their routine health-care services due to fear of COVID infection and its related complications.^[12] In our study around 31.6% of the primary care givers have feared of contracting COVID to the children or to themselves either during transportation or within hospital premises during treatment process. Similar barriers were reported as low as 36% in Micheal *et al.* study and as high as 96% in Sharma *et al.* study.^[14,18]

CONCLUSIONS

In pediatric patients their primary caregivers play a major role in planning the health-care needs, hence challenges faced by

them in accessing the health-care services and measures they undertook to overcome them during the COVID-19 pandemic are vital. These challenges provide an insight for planning our health-care services to ensure continuity of care as a part of disaster and pandemic preparedness. Difficulties faced in transportation especially during lockdown, fear of contracting COVID infection, financial difficulties during the COVID and lack of awareness of teleconsultation services were identified as major obstacles for primary caregivers.

Recommendations

In order to balance between prevention of COVID infection among chronic disease patients under periodic follow-up and maintenance of their continuity of care, there is a need for strengthening of services like telemedicine, door step dispensing of medicines, creation of dedicated non-COVID wards with strict COVID screening procedure for those in need of parenteral medication, ensuring adequate personal protective measures at the hospital, pediatric COVID vaccination and establishing mobile medical teams.

Limitations

Though 76 study subjects were in line listing only 57 participated in the study which may be considered as a limitation. Strict lockdown measures were enforced from March to August 2020 and then between May and June 2021 in the state of Tamil Nadu as a part of COVID control measures. Most of the challenges answered by the primary caregivers pertain to the lockdown restrictions period during the COVID pandemic and may not reflect the entire period of the pandemic.

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Conflicts of interest

There are no conflicts of interest.

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