

Original Research Article

Effect of COVID-19 pandemic on health seeking behavior of children with cerebral palsy and their caregivers

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ABSTRACT

Background: COVID-19 pandemic exacerbated the already existing challenges face by children with cerebral palsy (CP) and their caregivers. This study was conducted to analyze the effect of COVID-19 pandemic on the health seeking behavior of children with CP and their caregivers.

Methods: Parents/ caregivers of sixty-one children, who could be contacted were asked a set of questions using a pre-structured questionnaire including demographic details, information related to change in health status and reasons for change in health seeking behavior during and after pandemic.

Results: Out of 61 caregivers, 34 (55.7%) reported worsening in child's health after COVID-19. 59 (96.7%) caregivers reported decrease in the frequency follow up visits after COVID-19 pandemic. The 38 (62.3%) shifted to rehabilitation at home by self. 59 (96.7%) caregivers reported consultation at hospital and two (3.3%) cases at private clinics during acute illness before COVID-19 pandemic. Fear of COVID infection was cited as most common reason for change followed by closure of health facilities during COVID pandemic. Post covid, irritability increased in 23% cases, tone increased in 54.1% cases, contractures increased in 6.6% cases, seizures increased in 27.9% cases.

Conclusions: Children with CP and their caregivers need special care during major events such as pandemic to avoid negative impact on their health status.

Keyword: COVID-19, Cerebral palsy, Health seeking behavior, Contractures

INTRODUCTION

COVID-19 was declared as a pandemic by WHO on March 12, 2020.¹ Nationwide lockdown was posed by government of India on March 24, 2020. Essential health care services were disrupted due to COVID-19 disease burden.² Children with CP and their caregivers encountered numerous challenges during the pandemic. Children with CP require regular rehabilitation interventions with physiotherapy, occupational therapy, speech therapy, behavioral therapy.¹ During the pandemic, health care services including rehabilitation services were badly affected and children with CP were required to stay away from these services.^{3,8} Prolonged interruption in rehabilitation may have negative impact

on functional prognosis in children with CP due to risk of hypertonia, development of irreversible contractures, deformities and psychological issues such as irritability, anger and even aggression.⁴ Caregivers of CP faced negative effects of lockdown including economic burden and effects on mental health during and after the pandemic, which might have changed their health seeking behavior after pandemic.⁸ We conducted this study with aim to find out impact of COVID-19 pandemic on health seeking behavior of the caregivers of children with CP.

METHODS

This cross-sectional observational study was conducted in child development clinic in the outpatient department of

University College of Medical Sciences and Guru Tegh Bahadur Hospital Delhi from January 2021 to December 2021. An approval from the institutional ethical committee (IECHR/2020/PG/46/72-R1) was obtained. Consent was obtained from the parents or legal guardian of all the participants. Caregivers of 61 children already enrolled in child developmental clinic with a clinical diagnosis of CP were contacted telephonically and were asked a set of questions using a pre-structured questionnaire. Caregivers not understanding English or Hindi were excluded from the study. Questionnaire included demographic details of children with CP and their caregivers including age, gender, address, education level, income and occupation. Socioeconomic status was determined using modified Kuppuswamy scale. Details related to clinical profile including type of CP; examination details were noted from the medical records. Change in the health status was categorizing as: same as before COVID pandemic, improved after COVID pandemic and deteriorated after COVID pandemic. Follow-up visits were categorized as frequency reduced after COVID pandemic and same as before COVID pandemic. Mode of facility used for rehabilitation (physiotherapy and occupational therapy) and for acute illness before COVID pandemic were categorized as: self at home, private clinic, hospital and others. Change in rehabilitation was categorized as: remained unaffected and reduced during and after COVID pandemic. Reasons for change from pre-COVID to the post-COVID were asked.

Data were entered in excel sheet. Data was analyzed using SPSS v26.0 (IBM, SPSS statistics for windows, Armonk, NY: IBM Corp, USA). Descriptive statistics in terms of mean and standard deviation were used for age. Frequency tables were used for qualitative data. For the purpose of analysis socio-economic status was determined using student's t test.

For the purpose of comparison between two periods, age variable was recoded into age categories. Chi-square test was used to determine significance of difference between proportions of two periods for variable such as age categories, gender, causes of the CP, comorbidities in the CP.

Children with CP were categorized into spastic quadriplegic CP, spastic hemiplegic CP, Spastic diplegic CP, dystonic CP and mixed CP to compare between two periods. Proportions of types of CP were compared during two periods. To determine significance of difference between proportions during two periods, CP patients were categorized into ambulatory (GMFCS level 1-3) and non-ambulatory (GMFCS level 4-5). Findings of neuroimaging were compared using proportions. Fischer's exact test was used for variables involving less than five patients. the $p < 0.05$ was considered as significant.

RESULTS

Table 1 displays the demographic characteristics of children with CP and their caregivers. Out of 61 caregivers, 34 (55.7%) reported deterioration of clinical condition and general health status after COVID-19 whereas 27 (44.3%) reported as same before pandemic.

Table 1: Demographic characteristics of children with CP and their caregivers.

Demographic variables	N (%)
Age of children (years)	9.88±2.31
Type of residence	
Urban	54 (88.5)
Rural	11 (11.5)
Socioeconomic status	
Upper and middle	22 (36.1)
Lower	39 (63.9)
Education of caregiver	
Below or up to 5 th standard	44 (36.1)
Above 5 th standard	78 (63.9)
Type of CP	
Spastic quadriparetic	41 (67.2)
Spastic diplegic	8 (13.1)
Spastic hemiparetic	9 (14.8)
Dystonic	3 (4.9)

*N=number of cases, %=percentage of cases, SD=standard deviation

The 48 caregivers (78.7%) did not visit any medical facility for follow up during the pandemic while 59 (96.7%) caregivers reported decrease in the frequency follow up visits after COVID-19 pandemic. Change in rehabilitation was reported as reduced in 39 (63.9%) cases. Out of 61 caregivers, 38 (62.3%) reported to get rehabilitation services at home by self, 12 (19.7%) at hospital and 11 (18%) at private clinic before pandemic. Figure 1 displays the mode of facility used before and after COVID for acute illness.

Caregivers cited fear of COVID infection as the most common reason for change during COVID pandemic in 24 (39.3%) cases. Closure of health facilities was the second most common reason cited in 22 (36.1%) cases. Other reason cited were availability of teleconsultation services (4.9%), lack of transport (6.6%) and other reasons (13.1%). The 98.4% children with CP were continuing long term medications before the pandemic, whereas only 82% were taking long term medication during COVID pandemic.

Reasons stated for discontinuation or change in long term medication were lack of availability of free medicines (73.8%), decreased per capita income (11.5%) and loss of job/ unemployment (6.6%) during COVID pandemic. Only 23% caregivers had a valid disability certificate for their children with CP. The 98.4% cases did not receive disability financial assistance during the pandemic.

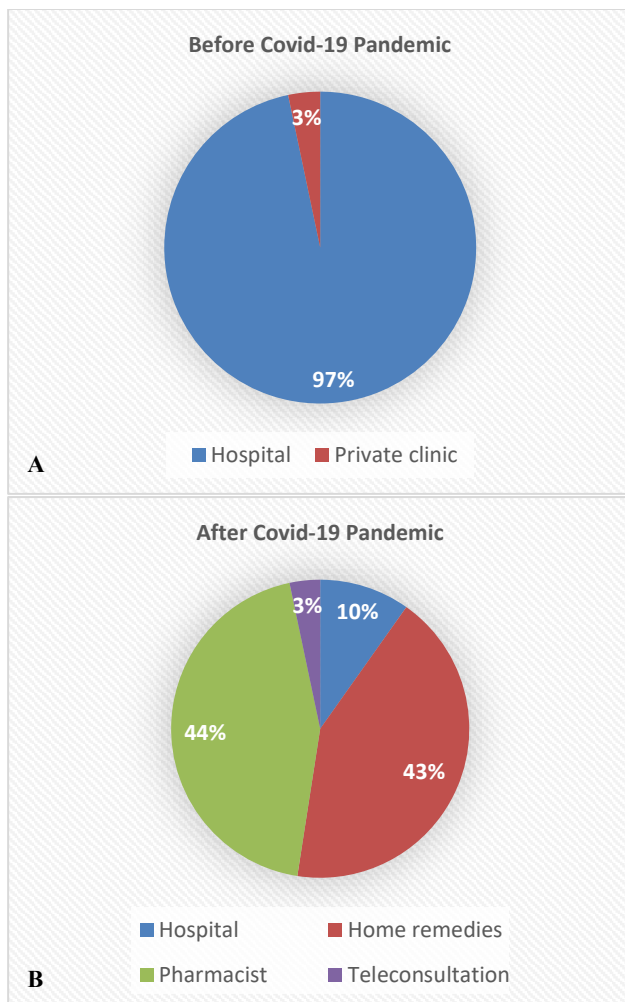


Figure 1 (A and B): Mode of facility used for consultation before and after pandemic.

DISCUSSION

The present study was conducted to assess change in the health seeking behavior of children with CP during COVID pandemic. This study highlights the challenges faced during the pandemic affecting psychological, social and financial aspects. Our results suggest that caregivers could not visit rehabilitation facility during pandemic due to closed facility and frequency of follow up visits declined even after COVID pandemic.

There have been studies highlighting the impact on the healthcare services related to children with CP during the pandemic. However, very few studies have shown the change in health seeking behavior after COVID-19 pandemic. Consistent with the results obtained from our study, a study by Khan et al conducted in adult patients, revealed that there was a significant change in the behavior of the individuals towards any health issue they faced after the COVID-19 pandemic ($p < 0.0001$). In this study, 37% cases self-medicated during the pandemic and preferred method of taking medication after consulting a physician before and after the pandemic were 67.3% and

61.8% respectively.⁵ Similarly, in a study conducted by Arichi et al 66.7% children with CP missed their hospital appointments due to lockdown.⁷ The 57.9% continued to have contact with their physiotherapist whereas only 25.7% of them could avail their occupational therapy services. In 26.2% had difficulties in accessing medications. Cankurtaran et al in another study from Turkey, reported that 45.7% of the caregivers observed worsening of the general health of their children with CP during the pandemic.⁸ The 86.1% reported that their children had irregular follow up visits with the most common reason of fear of contracting COVID 19. According to a study conducted by Cadwgan et al parents of children with neuro-disability were concerned about seeking health care only during acutely illness due to fear of contracting COVID-19 during the pandemic.⁹ In our study, Irritability and behavioral problems increased in 23% cases, tone increased in 54.1% cases, seizure frequency increased in 27.9% cases. Consistent with our results authors have shown that physiotherapy and occupational therapy were discontinued during the pandemic and co-morbidities such as tone abnormalities, epilepsy increased after the pandemic.⁷⁻¹² Families of children with CP are already a vulnerable population who faced various challenges such as economic hardships and lack of public services including transport during pandemic.⁶ In our study, 6.6% caregivers revealed lack of transport as a reason for decreased follow up visits during and after pandemic. In developing countries, socioeconomic disadvantages arising after the pandemic have resulted in difficulty in transport especially for those children who have poor gross motor function, particularly for families who relying on public transport.⁶ This is a possible explanation for change in health seeking behavior after the pandemic.

It has been shown that many conspiracy theories and misinformation among people led to mistrust towards the healthcare institutions. Moreover, fear of contracting COVID-19 infection contributed to change the health seeking behavior of people.⁵ In our study, 38 (62.3%) continued rehabilitation at home by self. Due to sudden lockdown, caregivers might not have learned rehabilitation techniques and therefore it was challenging for them to provide homecare in appropriate manner to achieve desired functional outcome.¹

Role of tele-rehabilitation can be extremely useful in chronic conditions such as in CP especially during pandemics. However, authors have shown poor utilization and acceptance of tele-consultation in Indian population.¹ In our study, only 2 (3.3%) caregivers utilized tele-consultation services. Barriers like poverty, lack of technical support, lack of awareness and lack of proper health policies regarding tele-consultation services also contribute towards decreased utilization of tele-consultation services.

This study was able to highlight the various challenges faced by children with CP and their caregivers. Small

sample size, single-centered study and retrospective design were some of the limitations of our study. The study was based on the responses obtained telephonically, so those caregivers who could be contacted were included in the study. This may have resulted in selection bias.

CONCLUSION

COVID-19 pandemic badly affected the health seeking behavior of parents or caregivers of children with CP which led to a decrease in follow up visits and availing rehabilitation services even after pandemic was over. Children with disabilities and their caregivers require special care during such pandemic to avoid negative impact on the health status.

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Conflict of interest: None declared

Ethical approval: The study was approved by the Institutional Ethics Committee IECHR/2020/PG/46/72-R1

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