

CASE REPORTS

COVID19 PANDEMIC: IMPACT ON QUALITY OF LIFE OF CHILDREN WITH CEREBRAL PALSY- A BRIEF REPORT OF PARENTAL EXPERIENCES, CHALLENGES & SUGGESTIONS

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ABSTRACT

The Covid 19 Pandemic has affected lives of people across the globe. Controlling measures like lockdown, social distancing, schools closure, Parent's working pattern, loss of job and conversion of majority of government hospitals to Covid-19 care facility with limited or no provision of non-emergency & routine medical care has affected the health and health care seeking behaviour of the general population.

The children with different Cerebral Palsy are dependant to a varied extent on the care taker for home care, accessing health care facilities and community intervention services as per their disability severity. Thus, above changes have made them more vulnerable for the untoward consequences on physical and mental health.^{1,2}

This case series describes experiences of parents (of children with Cerebral Palsy) during COVID-19 Pandemic and challenges they faced while taking care of their child.

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Case Report

This case series summarizes the experiences of eight families (having a child with Cerebral Palsy of age group birth to 12 years), who consented to participate in the study. Institutional Ethics Committee (IEC) permission was taken prior to starting study.

These families were selected consecutively who visited to Pediatric Developmental/ Disability OPD of a tertiary care center during study period i.e April 2021 to May 2021 (during 2nd wave of Covid 19 pandemic). Using a pre-designed proforma, Socio-demographic details, diagnosis, parental perceptions about health behaviour, home care, family support system, adaptations and challenges faced in seeking the health care were recorded. At the end, all parents were asked to mention one suggestion/change which will improve health care facility to become more patient friendly. They were given up adequate time and assistance to answer questionnaires and Covid-19 safety protocols were strictly followed.

Statistical Analysis-Descriptive analysis was performed on responses received from parents. The data on demographics, behavioral issues, physical activity, medical follow-up, rehabilitative services, parental concerns, difficulties and needs were analyzed. Quantitative results are expressed as mean and categorical results as numbers.

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I] Demographic details- as mentioned in the Table 1, Total 8 families participated in study and were interviewed. Mean Age was 27 months (range 18 to 30 months). There were 6 males and 2 females. As per topographic classification of CP 4 children were Spastic Quadriplegic Cerebral palsy, 1 was Spastic Diplegic CP while 3 were Hypotonic Cerebral palsy. History received from mothers in 6 cases, Grandmother in 1 case and father in 1 case. 5 of the care takers were House wives, 2 were working as House maid and 1 father was vegetable vendor.

II] The second part of interview explored child's health, physical therapy, difficulties faced by parents in home care and in seeking Health care facilities due to Pandemic restrictions.

Parental responses are mentioned in Table 2.

All parents reported physical health of child being affected most during lock down and Covid-19 Pandemic. All the parents reported interruption of institutional physiotherapy affecting health of child negatively. All the parents of children with spastic CP (5cases) reported increased tightness of limbs and decreased mobility. Three mothers tried to continue exercises at home but could not do regularly due to poor child cooperation in in-house setting and time constrain due to increased household work.

One of the Grand mother reported staying indoor with limited physical activities lead to excessive weight gain in the child. While one father reported weight loss in child due to feeding difficulties because of accidental removal of Nasogastric tube.

Table 1. Demographic details

Family	Demographic detail (Child)	Demographic details (Parents)	Education of Parents	Occupation	Diagnosis
1	2Y /M	28Y/M father	12th Std	Vegetable Vendor	Hypotonic Cerebral Palsy, GDD+ Schizencephaly
2	1.5 /F	51Y/F gr.mother	Illiterate	Housewife	Hypotonic Cerebral Palsy with Cerebellar hypoplasia
3	2.5 /F	23Y/F mother	4th Std	Housemaid	Hypotonic Cerebral palsy (HIE)
4	1.5 /F	27 Y/F mother	12th Std	Housewife	Spastic Diplegic Cerebral Palsy
5	2.5 /M	22Y/F mother	4th Std	Housewife	Spastic Quadriplegic Cerebral Palsy with Seizure disorder
6	2.5 /M	26Y/M mother	Illiterate	Housewife	Spastic quadriplegic Cerebral Palsy (HIE)
7	2.5 /M	24Y/ F mother	4th Std	Housemaid	Spastic Quadriplegic Cerebral Palsy with Seizure Disorder
8	1.5 /M	25Y/F mother	Illiterate	Housewife	Spastic Quadriplegic Cerebral Palsy (HIE)

Table 2. Parental responses and suggestions about child care.

Family	Effect on health Positive/Negative	Medical Care	Health care seeking	Physiotherapy	Parental Stress / Family support/ health seeking behavior	Indoor games/ Screen time before/ during lockdown	Parental Suggestions
1	Negative/ Weight Loss & Increased tightness all 4 limbs	Continued only Medication	No	Stopped completely	Less/Yes/No	mobile games and cartoons/30 mins/2 hours	Separate Que for disabled at all hospital services
2	Negative/ Weight Gain	Continued only Medication	No	Only stretching exercises	More/Yes/No	Colouring, doll game, toys and clay. 50 mnt/3 hours	Toll free helpline for parent of children with special need
3	Negative/ Decreased Mobility	Continued only Medication	Yes for pneumonia	Only stretching exercises	Less/Yes/No	None/2 hours-4 hours	Financial assistance for therapy for single poor parent
4	Negative/ Increased tightness both lower limbs	Continued only Medication	No	Only stretching exercise	More/No/No	None/30 to 60 mins/2 hours	Mobile App by Government with videos on physical therapy
5	Negative/ Increased tightness all 4 limbs	Continued only Medication	No	Stopped completely	More/No/No	None/None/1 hour	Awareness programmes in the society to remove social stigma and increase acceptability
6	Negative/ Increased tightness all 4 limbs	Continued only medication	No	Only stretching exercise	Less/Yes/No	None/ None/1-2 hour	Occupational therapies at remote places too

Family	Effect on health Positive/Negative	Medical Care	Health care seeking	Physiotherapy	Parental Stress / Family support/ health seeking behavior	Indoor games/ Screen time before/ during lockdown	Parental Suggestions
7	Negative/ Increased tightness all 4 limbs	Discontinued Medication	Yes for convulsion	Only stretching exercises	Less/Yes/No	Mobile games and poems/30 to 60 mins/2 to 3 hours	Mother support group/ social workers for guidance and financial assistance for mothers in unsupportive families
8	Negative/ Increased tightness all 4 limbs	Continued only Medication	No	Stopped completely	Less/Yes/No	Mobile games and poems/2 hours/6 to 8 hours daily	Free OPD consultation and Physiotherapy at both Government and private hospital

II.a) Health care and Rehabilitation at home

All parents observed change in behaviour of child in form of increased agitation and aggressiveness, and most of them attributed it to less recreational activities in indoor setting, no interaction with other kids, absence of regular follow up, increased screen time with less mobility/ physical activity as the possible causes.

II.b) Health care seeking

Two of the parents visited the hospital during this time for medical emergency. One child had pneumonia while other had break through convulsions. Both parents were satisfied with treatment received, though they were worried with Covid-19 testing and one parent refuse admission for the same. Six parents who did not report to health care facility reported non availability of public transport, concerns of child’s safety and vulnerability in health care settings, uncertainty of the disease and its outcome, fear of getting quarantine, financial constrain as reasons for not seeking health care facility.

II.c) Parental difficulties and concerns during the lockdown

All the parents found child care at home difficult during this period due to lack of regular medical assistance and follow up. Four parents reported home care easy and less stressful due to help and support of spouse, other family members and siblings, while other 4 parents were over burdened with increased house hold work and lack of family support, so home care of child was more challenging for them.

Only one mother played with child indoor games, while all other parents used mobile games, cartoons, you tube videos to keep child engaged. Thus screen time of all kids increased during Covid Pandemic. One grandmother reported excess weight gain due to decrease physical activity and increased mobile use while other mother felt child was dependent on mobile for all routine activities i.e. eating, sleeping, doing

stretching exercises.

II.d) Parental suggestions to improve Health Care Services during Covid-19 Pandemic

- There should be more centers for providing Physiotherapy services even at remote places and services should be affordable for poor & needy patients.
- There should be separate Que for hospital services (both OPD & IPD) for patients with disability.
- All the medications including anti-epileptic and anti spastic drugs should be available at Government Hospital.
- There should be provision of financial assistance for single parent/ parent with poor family support for child’s medications, therapies (OT/PT/ST) and other health care needs.
- There is need to increase awareness about disabilities in society to remove social stigma and increasing acceptability and support in society
- All family members should help mother-by sharing household work and child care

Discussion

This study aimed to explore experiences of parents having children with Cerebral palsy during COVID-19 Pandemic about Health, well being, Behaviour, home care of their Child and challenges faced and their way of coping.

The results showed a significant affection of health of children as well as their care takers, as they were faced with the burden of managing the child’s daily life as well as providing rehabilitation.

The results of the current study are in line with few other research studies.

Four of our patients reported increased tone due to interruption of institutional physiotherapy. These findings are similar to a study conducted by Daiki

Asano et al. Daiki Asano et al³, reported decline in motor function due to Pandemic restriction, which took double time to improve to Pre pandemic status. Hence it emphasizes the crucial role of frequent physical therapy for maintaining motor function in non-ambulatory children with CP. As a corrective step for the future, urgent efforts are needed for making these services more accessible and affordable.

In the ECHO French survey⁴, it was found that Rehabilitation services were massively interrupted, and this was the main parental concern.

The mother in joint families and having family support reported less stress. The extended family probably helped to share household work, child care and helps avoid burnout. Our findings are similar to study by Ardic A⁵ which reported rising numbers of cases of disturbances in psychological well-being of parents and burnout in families who have children with NDDs.

Only one mother played physical indoor games with child while other parents used gadgets to keep child engaged. Indoor games are becoming forgotten entity in this digital era. There is need to emphasize role of indoor games, family time, storytelling, unstructured play and other strategies in child's motor and cognitive development.

Study done by Erkan Y et al⁶ during Covid Pandemic, it is found that promotion of physical activity in place of gadget use proved beneficial in children with Autism Spectrum disorder.

None of the Parents reported seeking medical help for their physical/ mental health issues, despite 4 mothers reported feeling low and burnout.

Cerebral palsy (CP) is the most common Neurodevelopmental disability in childhood requiring more care and supervision than the normally developing children. Due to extra responsibilities to meet child's special needs and to provide medical care and therapy in addition to parenting job it's distressing for parents, especially mother. The studies done by Barreto TM et al⁷ and Kaya K et al⁸ have reported prevalence of anxiety, depression in such mothers. In a study by Dhiman S et al⁹ found significant impact of Covid-19 pandemic on the mental health and increase in anxiety level of care givers of children with special needs.

Conclusion

During Covid-19 Pandemic which was an unexpected disaster, health care system was challenged by this pandemic all over the globe. Care of chronically ill patients got neglected because of the whole focus shifted to saving lives of patients suffering from Covid 19. We have to learnt lot of lesson from this Pandemic

- There is need to increase awareness about Tele rehabilitation and, tele-mental health services.
- Active participation of the mother in the rehabilitation of a child with CP can ensure the therapy even during lockdown and other natural calamity.
- Protecting mother's mental and physical health has vital role in improving the Child's outcome.
- Parents must also plan strategies to prevent burnout, which will negatively impact children.

- Indoor physical activities/ games and unstructured play, has a vital role in child's motor and cognitive development and should be encouraged.
- Excess Screen time / media exposure can prove detrimental for child's growth and development.
- Health Professionals need to design more accessible, productive and family directed care even during Pandemic situation like Covid-19 in future.

Limitations: The study had a relatively small sample size.

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Compliance with Ethical Standards

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Conflict of Interest None

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