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A concise and informative title: **Foot prints of Covid 19 Lockdown on Well Being of Caregivers and their Children with Disabilities**

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Foot prints of Covid 19 Lockdown on Well Being of Caregivers and their Children with Disabilities

Abstract: COVID19 was the time when all educational institutions as well as other services were shut down all of a sudden, with limited or no access, in order to minimize the outspread of the pandemic. This study was undertaken during the lockdown period time to understand the emotional well-being of children with disabilities and their caregivers. It was based on the presumption that education and support services such as physiotherapy, occupational therapy to name a few are of critical importance for children with disabilities. When this sudden lock down happened, it may have impacted the children and their caregivers who may not have the know-how or necessary support needed. 34 Caregivers of children with disability, residents of Delhi-NCR comprised the sample size. The disabilities of the children varied from intellectual impairment, autism spectrum disorder and so on. The data collection was largely done through electronic media and social media messaging apps and supplemented with follow up calls if required for clarity. The research findings report the challenges faced by the caregivers during such unprecedented times. Increased workload, in terms of household work along with taking care of the special needs of the children, limited mobility and access to special need services emerged as some of the major factors impacting the emotional well-being of caregivers. The families coping plan post lockdown period was also viewed through the conclusions.

Keywords: Parenting, Special education, COVID, well-being, Disability

1. Introduction

The emergence of coronavirus infection (COVID-19) has led to sudden and profound effect on the entire world such that no Country is left from its impact. In this difficult time as a precautionary step, lockdown was enacted to reduce the spread of the virus leading to closure of schools, special schools, colleges and workplaces. Coping with the COVID-19 pandemic has been challenging for everyone especially for families with children with disabilities (Warner et.al, 2020). It has been more stressful and challenging for families due to loss of economic and psychological support which they had earlier (Patrick et.al, 2020).

1.1 Challenges of COVID19

With the outburst of the pandemic, each and every household in our Country has been impacted. The families with children with disability were impacted the most due to the closure of the educational institutions, the education and support services such as physiotherapy, occupational therapy etc. which are of critical importance. As per a study in USc (Patrick et.al, 2020), the pandemic situation has massively impacted the mental health of parents and children. Another study concluded diminished access to health care by children because of loss of school-based services, increasing parental unemployment, loss of health insurance, and avoidance of health care settings (Masonbrink et.al, 2020).

1.2 Childhood disability in India

As per 2011 Census of India, there are 7,862,921 children with disability in the below 19 year age group, which includes children with visual impairment, hearing impairment, speech disorder, movement disorder, intellectual disability, multiple disability, and other disabilities. Apart from these, the other types of disabilities observed in children include autism spectrum disorder and specific learning disabilities (i.e., dyslexia or auditory processing disorder) and so on. For all these children access to early intervention and special education is critical to their development and learning. These children in our country attend different types of services such as inclusive school system, special schools run by government and non-governmental organizations or home based care depending on the severity of the disability. Each child with disability require individualized planning depending on his/her needs and goals set up, for which they rely on school based services. But as a result of the pandemic, these children and their families may face greater challenges. (Warner et.al, 2020)

Another study carried out on autistic children revealed that it is really challenging to bring change in young children routine in-order to inculcate good habits on regular basis i.e., disinfect your hands, do not touch your eyes or nose, and cover your mouth. These changing routines could result in profound suffering among autistic children. (Narzisi, 2020)

In addition, children with disability due to COVID situation were unable to access in-person therapy services (can be physical and occupational therapy), special education accommodations and adapted materials which helps in catering the individual needs of the child. The families need to take up a critical measure to provide therapy and educate the child while working simultaneously. A further challenge for families supporting children's learning is that, they lack expertise in special education, an in-depth understanding of how to adapt activities or the ability to navigate technology to meet their child's needs (Warner et.al, 2020). So, with understanding of all these challenges the current study has tried to assess the emotional well-being of children with disabilities and their caregivers.

2. Review of Literature

Lot of researches viewed the pandemic as an opportunity to cultivate resilience in-order to be able to cope up with the situations in the future. Resilience refers to the ability to adapt, which facilitates coping in challenging situations (Feder, 2019).

On the other hand, in case of children with disability it was felt that disruption in routines due to corona virus can be detrimental. Further, the importance of special schools and special educators in treatment as well as early identification of children with disability was also emphasized (Warner et.al, 2020). Due to school closure, the special educators are limited in their capacity to provide emotional support, observe warning signs, and offer intervention for at-risk children. (Masonbrink et.al, 2020)

In this situation the handling of young children with special needs can be really challenging for families or caregivers. Usually these children attend interventions for several hours with special therapists in dedicated hospitals and institutes. However at the current moment, both the families and the children are not physically supported by their therapists and they cannot attend the outside interventions. (Narzisi, 2020).

The lack of such measures can lead to increase in parental stress and an increase in children's behavioral problems. There are no allocated funds for learning capacity building and use of technology for online classes for addressing the educational gaps after reopening. (Masonbrink et.al, 2020). On the basis of review of literature, the research study was carried out to understand challenges faced by the caregivers during such unprecedented times.

3. Methodology

50 families of children with different types of disabilities were identified through snow ball sampling technique. These were all children with disabilities attending special/ inclusive schools in Delhi and NCR. The main approach used to identify these families was through coordinators of the special school/ institute or special educators whom these children were visiting for specialized services on a regular basis before the lock down. An online survey was developed to seek information about demographic profile of the family, everyday allocation of work and responsibilities among the members, how sudden lockdown due to Co-vid had impacted their routines, bonding and stress for the members. The coping strategies during and post lock down period were also probed into. The presumption was that lockdown would have increased the workload and stress of the family members. The on line survey was shared through social media for a limited time period during April 2020. It included an undertaking that the information collated through this form would be kept confidential and that the participants are agreeing to take part in the study. Quite a few parents could not read English, so the survey was translated in Hindi and sent across through social media app (Whatsapp) to facilitate their responses. In a few cases follow up calls were done for clarity in information. Of the 50 forms forwarded, completely filled data was obtained from 34 families only and has been the basis of the study.

4. Result / Discussion

The results from the study have been divided into four sections. The first section reflects demographic profile of the participants of the study followed by the second section which refers to the impact of Covid 19 on routine and well -being of the caregivers. The third and fourth section depicts the coping skills of the families as observed during the lockdown period of the pandemic along with preparation for post Covid period.

4.1 Demographic profile of the Sample

This section covers the demographic profile of the children with disability along with their parents. It includes indicators such as age, sex as well nature of disability of the children.

4.1.1 Demographic profile of Parents

The participants were young parents mostly in the age group of 30-40 years (50%), followed by 40-50 years (26%). The family structure was nuclear with very few in joint families (32%). The socio-economic status was lower middle or middle income group (88%). The educational qualifications were mostly graduation or above (62%).

Table 1: Profile of parents

Age and gender of parent	Male	Female	Total
20-30 years	1	3	4
30 -40 years	2	15	17
40 - 50 years	4	5	9
50 years and above	3	1	4
Total	10	24	34

4.1.2 Demographic profile of Children with disability

The following table and pie chart gives the description of children with disabilities with reference to their age, sex and functional skills. There were more boys than girls in the sample. The special needs varied from multiple, intellectual challenge to loco-motor disability and sensory impairments. Half of the children covered under the study were in the age group of 12 years and above, followed by 3-7 years (29%).

Around 50% of the parents with children with disability felt their daily living activities were the most impacted during the lock down period, many also felt academic performance being obstructed.

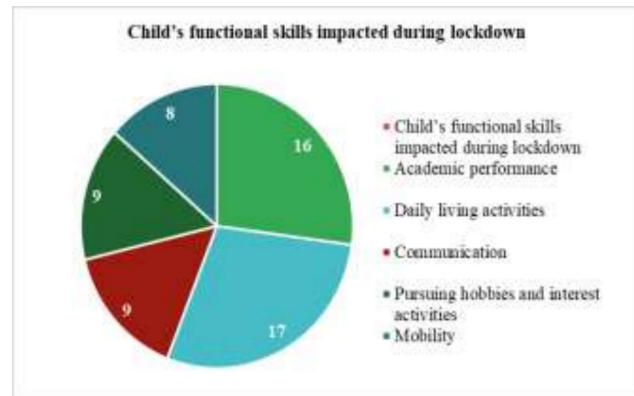


Figure 1: Lockdown's impact on functional skills of children

Table 2: Age, Sex and nature of disability

Age & Sex		Loco-motor disability	Sensory impairment	Intellectual/cognitive disability	Multiple disability	Total
3-7yrs	Boy		2		5	7
	Girl	1		1	1	3
7 – 12 years	Boy	1		1	5	7
	Girl					
12 years & above	Boy	4		6	1	11
	Girl		1	3	2	6
Total		6	3	11	14	34

4.2 Impact of Covid 19 on routine and allocation of responsibilities

How Covid19 had impacted the families was of interest, hence questions were structured around allocation of responsibilities and any changes during the lockdown, family routines and how time was being spent. The responses on daily routine and allocation of responsibilities indicated that mothers continued to be the primary caregivers of their children (63%). In a few cases (29%) fathers supported for medicine or therapy. Very few cases reported support from the child's sibling or grandparents (10%).

The family members had allocated responsibilities among themselves and were engaging with children in tasks of daily living or pass time. These were usually families wherein both parents had shared responsibilities of child care, education and special therapies among themselves. "I am able to spend quality time like playing games, watching programmes with kids", was reported by one such parent. Interestingly, this seemed to add to their well-being, as 53% parents reported they were enjoying doing what they never got time for.

Table 3: Allocation of responsibilities among family members

Allocation of responsibilities for the child with disability	Father	Mother	Others (grandparents & sibling)
Activities of daily living (bathing, feeding)	4	30	-
Educational guidance (reading, teaching concepts)	2	24	8
Spending quality play time	8	15	11
Taking care of medicines, exercise and therapy needs	10	24	-

4.3 Stress Causing Factors and Coping skills of families

4.3.1 Stress causing factors

The parents reported feelings of stress due to limited mobility at home (n=25) and largely thinking about income (n=20). A change in eating and sleep pattern was also reported in these cases. "Responsibilities have exponentially increased with no input from external sources" was reported by a parent. "There is a lot of frustration with constantly having to do therapy without external help" was a feeling reported by yet another. They were parents who also admitted that their children became irritable due to limited mobility and changed routine.

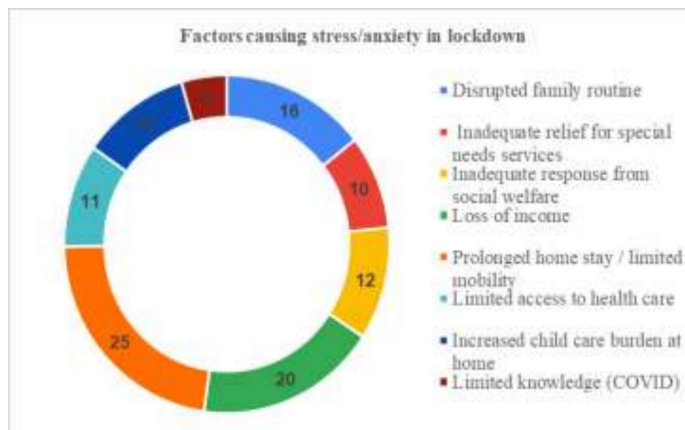


Figure 2: Reasons of stress during lockdown

4.3.2 Coping Skills of families

Coping skills of the parents were analyzed with respect to their age, specific disability of the child and support available. It was found that 47% of families covering all age groups had difficulty in coping. In other words, around 53% of parents reported positive resilience as they were able to cope well during the lockdown situation of the pandemic.

Further, when nature of disability and the coping abilities of the family was compared, it was found that families with cognitive, locomotor and multiple disability children were able to meet the challenges and reflected good coping skills (refer Table 4).

A few parents reported that the children were irritable due to imposed restrictions, lack of space or change of routine. The parent's inability to engage them in meaningful activities could be one of the reasons as only 24.7% of the parents reported that they were able to engage children in small tasks.

Table 4: Nature of disability and family coping

	Coping well	Unable to cope	Grand Total
Intellectual / Cognitive disability	6	5	11
Multiple disability	7	7	14
Loco-motor disability	4	2	6
Sensory impairment	1	2	3
	18	16	34

Analyzing the various activities adopted by families during the lock down period to maintain well-being (Fig 3), it emerged that around 28% of parents worshiped and continued with their belief on god to maintain positive outlook during the pandemic situation.

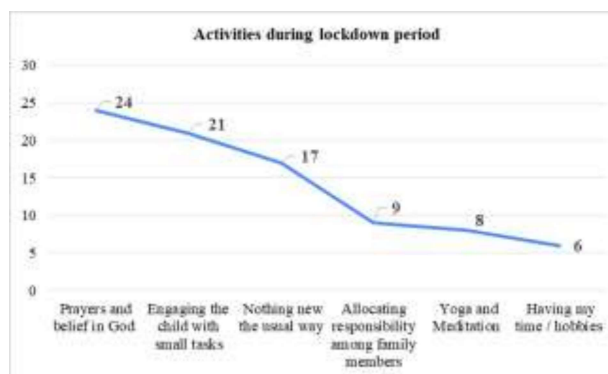


Figure 3: Activities during the Lockdown

4.4 Preparation for post lock -down

Holding discussions, awareness messages, better hygiene practices, encourage use of mask and minimizing social gatherings were some of the strategies reported by almost all parents. The parents made the children watch media reports and discussions on how to avoid spread of corona and the necessary precautions.

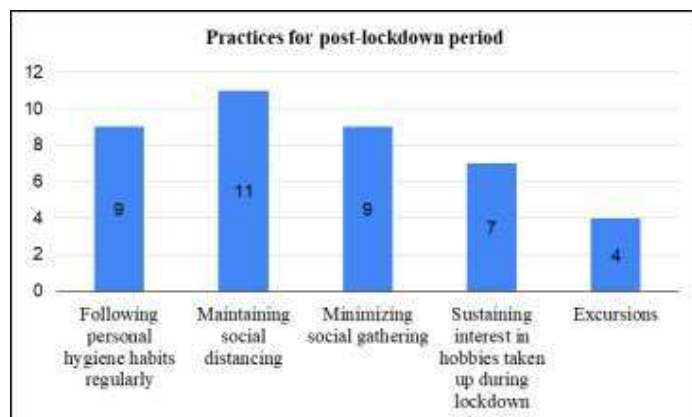


Figure 4: Post-lockdown practices to be adopted

5. Conclusion

Based on the data analysis, it emerged that prolonged stay at home, disrupted routine, lack of access to resources, lack of space and meaningful engagement were some of the factors causing stress. Especially the activity for daily living or academic support of children with disabilities that was facilitated through therapies was impacted. Parents did reallocate a few responsibilities related to the child among themselves. These were to do with education, daily child care and special therapies. This added to their well-being in many cases. However, exponential increase in work without external support was also felt by them. There were a few parents who continued to struggle to engage their children in productive tasks. An increase in prayers and belief in God was reported to add to their positive outlook towards this situation. The parents also reported pro – actively engaging themselves for post lockdown by preparing their children and bringing about necessary changes.

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Author's Profile



Dr Reema Lamba is currently an Associate Professor in the Department of Human Development and Family Empowerment, Aditi Mahavidyalaya, University of Delhi. She has a teaching experience of twenty four years in the area of child development and education. Her doctoral work involves Inclusion of Children with Disabilities in Schools of Delhi. Her interests and expertise are on issues related to ageing, marginalization and inclusion.

She has been associated with various projects namely the Global Fund Project to Fight against HIV-AIDS, Tuberculosis and Malaria. She has been a National Lead Trainer for NGO Envisions working in collaboration with UNICEF on Social Behaviour Change and Communication. She has been actively involved with teacher training and parent counseling programmes. She has contributed in developing IGNOU course material on ECCE, disability and inclusion. She has been an editor of the Integrated Journal for Social Sciences and has written various articles in books and journals.



Swati Bawa Sawhney is currently Assistant Professor at Bharati College, University of Delhi. Prior to this she worked as an Early Childhood Development Consultant at the Ministry of Women and Child development under the Strategic Health and Nutrition Partnership Programme by DFID to provide support to MWCD, GoI through Deloitte led Technical Support Agency. Prior to working with the WCD Ministry, she was a Senior Consultant at PricewaterhouseCoopers (PwC) and worked on multiple projects with GOI and UN. She has also worked at Centre for Early Childhood Care and Education (CECED), Ambedkar University as Research Associate.

Her major area of work has been monitoring the status and implementation of National ECCE Policy across States/UTs, guidelines for Integrating Children with Special Needs, Services for caregivers with children in the age group of 0-3 years on early stimulation and tracking of developmental delay. She also contributed to policy briefs titled 'Unpacking Care – Protecting Early childhood' and 'Brain development in early years' and research projects - 'Preparing teachers for Early Childhood Care and Education', Case study of Uttarakhand Sevanidhi – 'The Balwadi Programme' and Action research in Bihar.