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Case Series

COVID-19 pandemic: maker or breaker for families having children with autism spectrum disorder-case series of maternal experiences, strategies and suggestions

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ABSTRACT

The COVID-19 pandemic due to prioritization of emergency and COVID-19 patient care at hospitals and disruption of daily routines and finances, impacted significantly families having people with special needs. This case series highlights the problems faced and strategies used by mothers of children having autism spectrum disorder (ASD). It summarizes the experiences of nine families of ASD children (2 to 9 years), selected consecutively from pediatric developmental/disability outpatient department (OPD) of a tertiary care center during i.e. April 2021 to May 2021 (2nd wave of COVID-19 pandemic) using a pre-designed proforma. Socio-demographic details, maternal experiences about challenges faced in child's home care, special therapies, managing child's behaviour, family support system, adaptations and their suggestions were recorded. The age group was 2 to 9 years and 8 were males. 7 out of 9 mothers reported that their child's interaction with father and other family members improved. Institutional therapy was discontinued by all mothers. Two mothers reported increased aggression in the child. Mothers from joint family and having supportive families reported less stress. Children who had company of parents/grandparents/sibling and availability of indoor games, art and craft and storytelling, reported less screen time and less behavioural disturbances though all the mothers reported increased screen time compared to pre COVID times. Mother's empowerment is key to success. Indoor physical games, unstructured play, increasing social awareness, supportive families, tele-rehabilitation services can improve overall progress in ASD children. Health care practices need to be revised from time to time for special needs/situations.

Keywords: COVID-19 pandemic, Children with ASD, Rehabilitation, Maternal stress, Coping strategies, Indoor games

INTRODUCTION

The COVID-19 pandemic proved to be a global challenge. The loss of institutional services and supports, fear about increased infection rates, and disruption of daily routines affected the well-being of each and every one, but the impact was more on families having people with special needs/chronic medical conditions requiring regular medical care and follow up.[1] The children with different neurodevelopmental disorders (NDDs) are dependant to a varied extent on the care taker for home care, accessing health care facilities/therapies and community intervention services as per their disability type and severity.

Everyone knows that no one can be better than a mother in providing love, care and helping a child to achieve their maximum best potential. Unfortunately, many a times, this commendable work done by the mothers remains

unappreciated and is not supported. Though mothers are skilled to do multitasking but during lock down they had bigger challenges with increased household work, financial constraints, many uncertainties and handling the additional burden of newly arising behavioral issues along with providing rehabilitation to their children with ASD. Acknowledging the great work done by mothers on all fronts of child care and rehabilitation is the least they deserve. Raising awareness amongst the community will bring realization that small efforts, support and empathy towards such parents and families can be empowering.

This study will bring to light that the unrelenting efforts of these mothers played a vital role in survival of such children in global disasters like COVID-19 pandemic and lock down with limited community support and restricted medical services. Maternal experiences/strategies/ suggestions will help in making health care services, work places and families more friendly and helpful for such families having child with special need. These could prove to be of great help for other mothers, families and caretakers having child with special need during any such pandemic situation in the future.

CASE SERIES

This case series summarizes the experiences of nine families (having a child with ASD of age group 2 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, maternal experiences about challenges faced in child's home care, home based-special therapies like occupational therapy/speech therapy, child's behaviour at home, family support system and adaptations were recorded. At the end, all mothers were asked to mention one suggestion/change which would help to improve the health care facility to become more accessible and supportive. They were given adequate time and assistance to answer questionnaires and COVID-19 safety protocols were strictly followed.

Descriptive analysis was performed on responses received from mothers. The data on demographics, maternal experiences and difficulties in managing child's home care, behavioral issues, medical follow-up, rehabilitative services and needs were analyzed. Quantitative results are expressed as numbers and maternal responses presented as frequency and percentages.

This case series summarizes the information received through parental interviews about the experiences during COVID-19 pandemic, of nine families having children with autism spectrum disorders. History received from mothers in all 9 cases. In the Table 1, sociodemographic details of families have been summarized.

The information collected during parental interview is presented in Table 2.

Table 1: Sociodemographic details of families.

Families	Demographic detail (child) age (years)/sex	Demographic details (parents) age/sex	Education of parents	Family type	Occupation	Diagnosis
Family 1	4/M	28, mother	Illiterate	Nuclear	Housewife	ASD with ADHD
Family 2	7/M	30, mother	10th pass	Joint	Housewife	ASD with epilepsy with intellectual disability
Family 3	4.5/M	24, mother	11th pass	Joint	Home tuitions	ASD with ADHD*
Family 4	2/M	23, mother	Graduate	Nuclear	Work in IT company	ASD
Family 5	8/M	28, mother	12th pass	Joint	Work at office data entry	ASD with ID with seizure disorder+
Family 6	9/M	30, mother	8th pass	Joint	Housewife	ASD with ID with visual impairment
Family 7	7/M	28, mother	12th pass	Joint	Work at office	ASD with ID with seizure disorder
Family 8	7/M	28, mother	Graduate	Nuclear	School teacher	ASD with GDD#
Family 9	8/F	28, mother	Graduate	Nuclear	Work in IT company	Rett syndrome

*ADHD-attention deficit hyperactivity disorder, + ID-intellectual disability, # GDD-global developmental delay

Table 2: Information on parental experiences collected during interview (n=9).

S. no.	Responses	Frequency	Percentage	Reasons /details/effects mentioned for the response
1	**Effect on health**			
a	Positive			
	Increased social interaction	7	78	Due to lock down everyone, was at home
	Toilet training	1	11	Mother found putting toilet training charts inside and outside the toilet helpful
	Increased bonding with parents	2	22	
	Increased bonding between the siblings	2	22	Schools were closed and both kids had an opportunity to interact and play together
b	Negative			
	Increased screen time	3	33	Less recreational activities in indoor setting, unavailability of outdoor games
	Decreased social interaction	2	22	Both parents were working online, child was offered gadgets for a longer time and social interaction with family members was less
	Excessive weight gain	1	11	Sedentary lifestyle, excessive screen time and restriction to any outdoor activities/ recreation.
	Increased agression/ behavioural issues	3	33	One mother reported increased hyperactivity; 2 of the mothers reported increased aggression in the child as daily routine was disrupted, no outdoor activities, limited indoor options for recreation, no access to interventional therapies - unavailability of medications to control aggression without recent prescription from a doctor/ shortage of the drug stock with chemist.
2	**Institutional therapy-IT**			
	Speech therapy/occupational therapy			No access to institutional occupational therapy services (no public transport)
	Continued	0	0	COVID-19 infection related concerns- about child's safety and vulnerability
	Stopped	9	100	Government hospitals were giving COVID care and private hospitals' occupational therapy and speech therapy sessions were very costly. As there was no job, families financial conditions were bad
3	**Parental stress**			
	Increased	4	44	3 parents of nuclear family found it very stressful to manage house hold work, child care, keeping child engaged indoors and earning daily living expenses. 1 mother from the joint family reported that the absence of family support made her very sad and she was exhausted physically as well as mentally.
	Decreased	4	44	4 parents having joint family reported that family support helped them, as child care and household work was shared, their stress was less
	No change	1	11	
4	**Family support**			
	Yes	4	44	Child had less behavioural disturbances; mother's had less stress
	No	5	56	
5	**Health care seeking during lockdown**			
	Yes	2	22	By teleconsultation
	No	7	78	Due to lockdown restrictions
6	**Activities to keep kids engaged in indoor settings**			
a	Indoor games			

Continued.

S. no.	Responses	Frequency	Percentage	Reasons /details/effects mentioned for the response
	Carrom board	1	11	One mother said child has ADHD also, waiting for his turn was a difficult task. By playing catch catch ball game and carom board game, child became patient and learnt turn taking
	Ball catch game	1	11	
	Art and craft	4	44	Decreased screen time
	Cards, ludo, building blocks	3	33	
	Others- putting pictures/charts at home for child's learning	1	11	Other mother found putting toilet training charts inside the toilet and regular reminders with following the same routine helped her child to be toilet trained.
b	Watering plants	1	11	
c	Reading story books	1	11	
d	Story telling by grand parents	2	22	One mother reported that night time story telling session by grandparents made child's issue of difficulty in falling asleep easy; it prevented from excessive screen time; one mother reported child's communication improved
7	**Screen time**			
a	Before lockdown			
	None	4	44	
	Less than 30 mins	2	22	
	30-60 mins	3	33	
	1-2 hours	0	0	
	More than 2 hours	0	0	
b	During lockdown			
	None	0	0	Children who had company of parents/grandparents/sibling and availability of indoor games, art and craft and storytelling, reported less screen time and less behavioural disturbances though all the mothers reported increased screen time compared to pre COVID times.
	Less than 30 mins	2	22	
	30-60 mins	1	11	
	1-2 hours	3	33	
	More than 2 hours	3	33	
c	Type of digital devices used			
	Television	5	56	
	Mobile phone	8	89	
	Tablet	1	11	
d	Content of screen time			
	Mobile games	02	22	
	Cartoons	5	56	
	Youtube kid's stories	2	22	
	Youtube poems/rhymes	1	11	

Following are the special adjustments done by parents for child during COVID-19 pandemic: family 1: removed glass table, created a play corner for child to play; family 2: gave him toys after checking wheels and no loose parts, requested grandparents to supervise him when was busy in the kitchen; family 3: put pictures outside and inside the bathroom (steps of brushing), toilet training (steps with pictures). This helped in toilet training; family 4: none; family 5: created play corner at home with coloring, and blocks; family 6: grandparent's involvement proved savior in keeping child engaged and their bonding with child increased; family 7: not much place at home, child was given mobile to watch cartoons; family 8: mother made her routine as per child's routine and home therapy time; and family 9: both the parents tried to take different working shifts whenever possible, so the child is not left unattended.

Following are the parental experiences/suggestions to make health care services and work places more supportive during COVID-19 pandemic or similar situation in future

Family 1

There should be provision of occupational therapy services in remote places too apart from government hospitals at free or at subsidized cost for poor/needy patients.

Family 2

Mother was very sad that everyone talks about inclusive education and acceptance in society but infact there is lot more a mother faces in the family itself. So she said prior to achieving other things there is need of *inclusive families* where in each family member understands and support need of child in achieving the best of the potential possible instead of just labelling and blaming the child and or mother. Family members should support and share child care responsibilities to prevent burnout in mothers.

Family 3

There should be provision of standardized and free mother's guide about home care and therapy of children with Autism in different languages to guide mothers.

Family 4

There should be provision of special leaves and concession in work timing and duration for working parents having child with special needs for child's health related issues/therapies.

Family 5

There should be concession/adjustments in work timing/shifts and duration in private sectors too for parents having child with special need.

Family 6

Creating social awareness to remove stigma from society can help families to provide better care.

Family 7

Family counselling should be done to support & help mother. Mother's efforts should be appreciated and supported for the extra hard work she puts for child's special needs.

Family 8

These children should be allowed to attended medical services on priority basis without waiting in long OPD que with patients having other minor illnesses.

Family 9

There should be provision of extra leaves for the parents having child with special need for the health care/medical emergency and follow ups.

DISCUSSION

This study aimed to explore the experiences, perceptions and suggestions of mothers taking care of children with ASD during COVID-19 pandemic about child's health, well-being, behaviour, home care, rehabilitative services along, with challenges faced and their way of coping.

In our study, 7 out of 9 mothers reported increased child's social interaction. Our findings are consistent with other studies by Bozkus-Genc et al, some parents stated that they had more opportunities for positive interactions with their children and spend quality time with their family members resulting in increased social interaction.[2] In study by Heyworth et al parents were aware they needed support but found it difficult to reach out to their usual social supports they described how their connections with their children grew stronger over lockdown as they focused on nurturing their children's "mental health ahead of everything else".[3]

One mother reported increased hyperactivity in her child. 2 of the mothers reported increased aggression in the child. Our findings are consistent with other studies. In a study on COVID-19 impact on families with ASD by Stadheim et al.[4] 66.4% of participants reported both negative and positive behavioral changes. Thus, 92.6% of participants reported at least one negative behavioral change, whereas 71.3% of the sample reported at least one positive behavioral change.

Institutional therapy was discontinued by all mothers. In the ECHO French survey, it was found that rehabilitation services were massively interrupted, and this was the main parental concern.[5]

All the mothers reported increase stress compared to pre-COVID times. However, mothers from joint family and having supportive families had less stress compared to mothers with nuclear families as their house hold and child care work was shared by other family members. Our findings are similar to study by Ardic which reported rising numbers of cases of disturbances in psychological well-being of parents and burnout in families who have children with NDDs.[6] In study by Kalb et al parents of children with ASD reported higher levels of overall psychological distress.[7]

Due to extra responsibilities to meet child's special needs, medical care and providing therapy in addition to parenting job it's distressing for parents, especially mother. The studies done by Barreto et al and Kaya et al have reported prevalence of anxiety, depression in such mothers.[8,9] In a study by Dhiman et al found significant impact of COVID 19 pandemic on the mental health and increase in anxiety level of care givers of children with special needs.[10]

Children who had company of parents/grandparents/ sibling and availability of indoor games, art and craft and storytelling, reported less screen time and less behavioural disturbances though all the mother's reported increased screen time compared to pre COVID times. Study done by Erkan et al during COVID pandemic, it is found that promotion of physical activity in place of gadget use

proved beneficial in children with autism spectrum disorder.[11] One mother used child's strength as visual learner and could toilet train the child. Other mother used carrom board and ball games to teach turn taking to child. With changing time in this digital era, Indoor games are becoming forgotten entity. There is need to emphasize the role of indoor games, family time, storytelling, unstructured play and other strategies in child's motor and cognitive development.

Limitations

The study had a relatively small sample size. All participants were from middle and lower socioeconomic classes. All the participants were mothers; hence fathers' experiences and suggestions need to be explored.

CONCLUSION

During the COVID-19 pandemic, which was an unexpected disaster, health care system was challenged all over the globe. Care of chronically ill patients was neglected because the primary focus was to save the lives of patients suffering from COVID-19. The maternal experiences in this case series highlight the fact that health care practices need to be revised from time to time for special needs/situations. COVID-19 pandemic proved to be an opportunity for increased interaction and bonding between ASD child and their parents/siblings. Institutional therapy was discontinued by all mothers affecting health and behaviour of children hence tele-rehabilitation services are very important in such situations. Mothers from joint family and having supportive families reported less stress. Children who had company of parents/grandparents/sibling and availability of indoor games, art and craft and storytelling, reported less screen time and less behavioural disturbances though all the mother's reported increased screen time compared to pre COVID times. Thus, mother's empowerment remains the key to success. The strategies used by mothers to make their child's health and care better during COVID-19 pandemic are going to be of great help for other mothers, families and caretakers during any such pandemic in the future. We have to learn a lot of lessons from this pandemic and plan strategies for making health services and workplaces more effective in handling any such disaster in future. Thus, experiences and suggestions by mothers in this case series open many areas of possible improvement, in families, societies, workplaces and the health care system. Following are the recommendations as per the study findings.

Recommendations

Health care practices need to be revised from time to time for special needs/situations and made more accessible, productive and family directed to achieve better outcomes even during pandemic situations like COVID-19 in the future. There is need to increase awareness about Tele rehabilitation and, tele-mental health services. Involvement of fathers and other family members in a child's care and rehabilitation can decrease stress and protect burn out in mothers. As suggested by one mother, inclusive family is need of the hour before correcting external factors. Indoor physical games and unstructured play, has a significant impact on children's learning, behaviour and overall development even, in children with special needs. Replacing it with electronic gadgets will have negative consequences on child's physical as well as mental health. Hence, supervising and maintaining the balance between both can have a better outcome.

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