

Covid-19 and Role of the Caregivers of the Children with Autism Spectrum Disorder (ASD)

Comment [d1]: Role of the Caregivers of the Children with Autism Spectrum Disorder (ASD) During Covid-19 Pandemic

Abstract

Aims/Background: Children with Autism Spectrum Disorder (ASD) are the most vulnerable group in the society, who have suffered a lot during the Covid-19 pandemic.

Objectives: The main objectives of this study to explore the behavioral changes faced by the ASD children and to find out the strategies taken by the caregivers of the ASD children during the Covid-19 pandemic.

Methodology: The study followed a holistic mixed-method approach. Simple random sampling was used to select the respondents to conduct a survey for the research. For quantitative analysis Chi-square test has been conducted to examine the association between the variables. For the qualitative part of the study, 5 Key Informant Interviews (KIs) were carried out from the experts (such as therapists and teachers) by constructing 15 open-ended questions.

Results: Analysis of data revealed the strategies taken by the caregivers of the ASD children during the Covid-19 pandemic such as- assigning therapist, providing teletherapy, making session plans and taking online classes. It has also disclosed the behavioral changes noticed by the caregivers of the ASD children such as hyperactivity, lack of attention. In this research, for quantitative analysis total 249 data were collected from the caregivers (parents) of the ASD Children in Dhaka City and most of the respondents (80%) were the mother of the children. 98% of the parents observed some sorts of behavioral changes and 90% of them followed different strategies for their mental and physical development during the Covid-19 pandemic.

Conclusion: To put it simply, sufferings of the ASD children and their caregivers know no bounds during the pandemic. The caregivers fought much more challenges than we can imagine from the outside.

Keywords: Autism Spectrum Disorder (ASD), Role of the caregivers, Behavioral changes, Covid-19 Pandemic.

1. Introduction

Disability is a part of human being and current estimates set the number of persons with substantial disabilities at 1.3 billion, or 16% of the world's population [1]. Like other disabilities, Autism Spectrum Disorder (ASD) is a neuro developmental disorder, and due to the wide range in the type and severity of symptoms, autism is commonly referred to as a "spectrum" condition and symptoms usually appears in the first 2 years [2]. Autism Spectrum Disorders (ASD) affect children's communication and social interaction, and they frequently engage in repetitive behavior[3]. Usually, they tend to follow a particular routine, and do the same thing repeatedly, for example playing with certain objects always[4]. Many parents of children with autism said that it caused an excessive amount of anxiety and stress due to the disruption in regular routines [5]. Moreover, Covid-19 pandemic has intensified their behavioral problems in both developed and developing countries [6][7].

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In the United Kingdom, the resources provided from the schools were not utilized properly to improve their learning according to the caregivers. Also, they mentioned expanded school restrictions resulted in children's academic progress [8] [9][10]. In Canada, during the pandemic children with autism and their parents faced mental health complications, and financial insecurity and service loss were the main factors linked with access to acute mental health care [11]. In the United States, results of a study described the intensity of behavioral problems faced by the children such as sleep disturbance, self-injuries and parents reported that it became laborious for them to manage their children [12]. Besides, the results other researches have shown that parents were also disturbed with the behavioral changes, in case of distance learning, lack of learning tools, adjustment with new routines and so on [13] [14] [15] [16]. Recent works from India and Malaysia showed ASD children have faced a lot of challenges during the lockdown period and various problems like changes in sleeping patterns, lack of sitting behavior, attention, concentration, eye contact and so on [17] [18].

In Bangladesh, studies have been carried out regarding the factors related with stress, anxiety and depression of the people with disability during the coronavirus pandemic [19]. However, researches have been conducted regarding the effects of the coronavirus on the caregivers and the children with autism or other neuro developmental disorders and the findings shows the common problems were parental stress, behavioral implications of the disabled children, lack of online or offline support from the authorities for the development of the children's physical and mental condition [20]. In addition, physiological and behavioral implications of the children such as anxiety, depression, attention deficit hyperactivity are revealed by a study during the quarantine period in Bangladesh [21]. There are many researches have been conducted with the ASD children and their caregivers in many countries, and they discovered the behavioral and psychological problems of the ASD children, mental stress faced by the caregivers during the Covid-19 pandemic[22][23][24][25]. In Bangladesh, studies related to the behavioral problems of the ASD children and their caregiver's role during the lockdown period have not been conducted yet.

1.1 Research Objectives

The main objective of this research is to explore the role of the caregivers (parents, special educators and therapists) of ASD children during lockdown. Data from this research might be helpful in improving public health policies and measures to lessen the pandemic's effects on vulnerable autistic community population.

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2. Materials and Methods

2.1 Methods

The study has used a mixed method approach to explore the role of the caregivers of the children with Autism Spectrum Disorder (ASD).

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2.2 Study Design and Participants

The quantitative part of the study was a cross-sectional study conducted in Dhaka city. Data was collected from the four conveniently selected special schools – Society for the Welfare of Autistic Children (SWAC), Angel Foundation for Children with Special Needs, Toddlers Point and Beautiful Mind School between January 2022 to April 2022 as the ASD children can hardly express their feelings and conditions, we choose their parents, teachers and therapists as respondents. For the quantitative study, we interviewed 248 parents of the ASD children who are considered as the primary caregiver. The parents of the ASD children participated in the survey questionnaire which was fully structured. The questions were about the demographic information of the ASD children, behavioral changes and the role of parents of the ASD children during lockdown. On the contrary, for qualitative analysis, 5 Key Informant Interviews (KIIs) were conducted from the special educators and therapists of the special schools and care centers to discover their role during the lockdown.

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2.3 Data Collection Procedure

Purposive sampling was used for data collection and face to face interviews were conducted with the participants at special schools and care centers when the institutions reopened after some months of lockdown. Participants were thoroughly briefed about the purpose of the study and confirmed the confidentiality of their information. Though the questionnaire was constructed in English, the interviews were conducted in Bangla as it is the native language of both the data collectors and the respondents.

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2.4 Measures

Demographic information collected included age, number of children, household size, educational level and occupation of the parents. Socio-economic condition was categorized based on income ranges (\leq 30000 Bangladeshi Taka or \$270, 30000-60000 Bangladeshi Taka or \$270-\$542), $>$ 60000 Bangladeshi Taka or $>$ \$542). For quantitative analysis data was edited by Statistical Package for the Social Sciences (SPSS 25) and then R programming language was used to analyze the data. The demographic data was summarized using descriptive statistics (e.g., frequencies, percentages), and Chi-square tests were performed to assess the relationship of the strategies of the caregivers to reduce the behavioral implications. The association between the variables was considered statistically significant, if the two-sided p-value was less than 0.05. For qualitative data analysis NVivo 10 was used to analyze the role of the secondary caregivers, and thematic analysis was carried out in this section.

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2.5 Ethical Considerations

Participants were thoroughly described about the objective of the study and confirmed the confidentiality of their information. At the beginning of the survey, researchers provided a section on informed consent that explained the aims and data use policies of this study.

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The procedure of this study was developed using the Helsinki Declaration on Human Subject Research. Besides, ethical approval of this study was provided by the Department of Communication Disorders Ethics Committee, University of Dhaka, Bangladesh (Reference: DCD-3.7/12/2021).

3. Results and Discussion

3.1 Demographic Information of the Primary Caregivers

As shown in Table 1, most of the respondents (80%) of this research were the mother of the ASD children who were considered as the primary caregiver. Among the ASD children a majority (34%) of their age was 10-12 years old, and 19.8% were between 13-15 years old. A large number (69%) of the fathers of the ASD children were job holders, and 72.6% of the fathers were higher educated (Master's or above). In the case of their mother, 60.6% were housewives, and less than a half (40.7%) of them had a Master's degree. 69.1% ASD children were from higher class families and their monthly family income was =>60,000 BDT. It has been discovered that 83.5% of the parents reported they had 1-3 children and 34.9% respondents said that they had 1-3 members in their family. 63.3% ASD children were from extended families with 4-6 members, and they used to live with their grandparents and uncles in their home.

Table 1: Socio-Demographic characteristics of the respondents (primary caregivers) (N=248)

Variables	Level	N	%
Child's Age	1-3	21	8.5
	4-6	36	14.5
	7-9	48	19.4
	10-12	84	33.9
	13-15	49	19.8
Father's occupation	16-18	10	4.0
	Job holder	172	69.4
	House-wife	0	0.0
	Businessman	70	28.2
	Others	6	2.4
Mother's occupation	Job holder	78	31.5
	House-wife	151	60.9
	Businessman	16	6.5
	Others	3	1.2
Father's education	P.S.C (05)	1	0.4
	S.S.C (10)	6	2.4
	H.S.C (12)	9	3.6
	Hon's (16)	52	21.0
	Masters (17 and above)	180	72.6
Mother's education	P.S.C (05)	11	4.4
	S.S.C (10)	23	9.3
	H.S.C (12)	48	19.4
	Hon's (16)	65	26.2
	Masters (17 and above)	101	40.7
Income (per month)	<=30000	15	6.1
	31000-60000	61	24.8

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 Infant
 Toddler
 Preschool
 School age
 Adolescent

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	60000+	170	69.1
Number of children	1-2	207	83.5
	3-4	41	16.5
	5-6	0	0.0
Household size	1-3	87	35.1
	4-6	157	63.3
	7-9	4	1.6
	9+	0	0.0

3.2 Behavioral Changes of the ASD Children

Across the entire sample of participants, a significant portion of them (98%) observed behavioral changes of the ASD children during the pandemic whereas, a recent estimate from USA where 74% of the respondents reported that they noticed moderate to large behavioral changes post- Covid-19 regulations [26]. Among the children a majority of them (82%) received therapy services from special schools and care centers before the pandemic. However, from the multiple responses of the primary caregivers (parents) revealed that hyperactivity was noticed by a significant number of parents (78%) and lack of attention was found among 71% of the ASD children. Other behavioral changes such as breaking household things was observed among 36% ASD children and self-attacking was noticed by 35% of the respondents. During Covid-19 outbreak, some of the children became so furious and they used to break household things such as glass, plates and other household things and their toys as well. Apart from these, 29% parents reported that screaming was common among their children when they got bored and very few (16%) of the respondents said that their children did not want to go outside or meet any outsiders such as relatives and neighbors during lockdown. Due to the disruption of the daily routine of the ASD children, their diet chart was not followed properly by the parents, and according to the parents, children became more hype than before because of the changes of their eating habits and sleep disturbance. During the lockdown period, children became very much addicted to the digital devices and 93% of the parents confirmed that their children used mobile, tablet and laptop, and they used to watch cartoons and played games. As, during the lockdown period most of the working people worked from home so in this research, we found 78% working parents of the ASD children got an opportunity to spend more time with their children. They used to play with their children, helped to do exercises and tried to provide some basic therapy to their child. From Table 2, we can see that there is a significant relationship between the parent's interaction with children and using digital devices. On the other hand, there exists a strong association between parents' interaction and behavioral changes during the lockdown of Covid-19 in Bangladesh.

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Table 2: Association between the behavioral changes and factors

Parent's interaction with children	Same as before	More interaction than before	Less interaction than before	No opinion	Total	P value
Total N (%)	N (%) =33 (13.3)	N (%) =193 (77.8)	N (%) =14 (5.6)	N (%) =8 (3.2)	N (%) =248	
Did your child use digital devices?	4 (12.1)	7 (3.6)	0 (0.0)	5 (62.5)	16 (6.5)	<0.001
Yes	29 (87.9)	186 (96.4)	14 (100.0)	3 (37.5)	232 (93.5)	
Did you notice behavioral changes?	2 (6.1)	1 (0.5)	0 (0.0)	3 (37.5)	6 (2.4)	<0.001
Yes	31 (93.9)	192 (99.5)	14 (100.0)	5 (62.5)	242 (97.6)	

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P-values calculated using Chi-square analysis

3.3 Role of the Primary Caregivers (Parents)

Behavioral implications of the ASD children were the main concern for the primary caregivers of the ASD children, and most of them took different strategies to cope up with the problem. It has revealed that 89% of the parents followed some strategy to reduce the hyperactivity of their children such as providing therapy at home, teaching some easy exercises, and stopped providing soft drinks and chocolates to their children. Apart from these they took teletherapy for their children from the therapists of the special schools and the care centers. Almost half of the parents said that their children received teletherapy during the lockdown, as all the educational institutions and therapy centers were closed at that time. Table 3 indicates that the *P* value of two variables (monthly income and received teletherapy) is *P*= 0.438 which means there exists a relationship between the monthly income of the parents and receiving teletherapy.

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Table 3: Association between socio-economic status (income) and role of primary caregivers

Income (per month)		<=30000	31000-60000	60000+	Total	<i>P</i> values
Total N (%)		N (%) =15 (6.1)	N (%) =61 (24.8)	N (%) =170 (69.1)	N (%) =246	
Received Teletherapy	No	8 (53.3)	34 (55.7)	79 (46.5)	121 (49.2)	0.438
	Yes	7 (46.7)	27 (44.3)	91 (53.5)	125 (50.8)	
Assigned Caregivers	No	6 (40.0)	37 (60.7)	61 (35.9)	104 (42.3)	0.003
	Yes	9 (60.0)	24 (39.3)	109 (64.1)	142 (57.7)	

P-values calculated using Chi-square analysis

Parents whose income was high intended to receive teletherapy services from the therapists during the lockdown. On the other hand, there was found a strong relationship between monthly income and assigning extra caregivers (Table 3). Parents appointed an extra caregiver who were concerned about the mental and physical development of their children. Though it was very costly to appoint an extra caregiver and receive teletherapy for the ASD children, 57% parents were capable of assigning a caregiver and 50% received teletherapy.

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Apart from these, parents tried to make their child's daily life easier and more structured, and they played multiple roles to manage their child such as providing learning tools, special food, medicine and making new routines. The study has discovered that 92% of parents provided learning tools such as picture books, flash cards, puzzles and cue cards so that they could spend some productive time during lockdown. According to the parents, these strategies helped their children to be calm for some time in a day. Besides, parents also provided some special foods for example dry fruits, food contains protein, calorie and vitamin C to protect them from coronavirus. 83% parents complained that their food habit was changed a lot, and most of them stated that the food consumption reduced due to lack of outdoor activities, therapy and services.

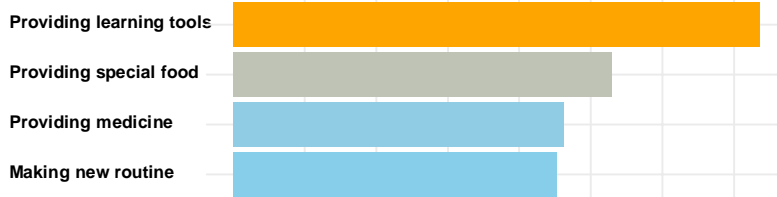


Fig. 1. Other role of the primary caregivers (Multiple response)

65% parents claimed that they observed the sleeping problems, and to handle the situation, 58% parents consulted with the doctors about the hyper activity and sleeping problem and they provided medicines such as sleeping pills according to doctor's prescription. Another thing was making new routines during lockdown for the ASD children, especially parents tried to habituate their children with new routines including breakfast, lunch and dinner time, hand washing, using masks and sanitizer etc.

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In the case of giving therapy to the ASD children, financial scarcity was one of the most important barriers for the parents during coronavirus pandemic [27]. In this study 35.5% of the parents reported that they faced economic hardship during lockdown in case of providing medicine, therapy and services as these are expensive enough. Among the respondents, a minority (20.2%) had to borrow money from their relatives and neighbors to manage the cost of their child's medicine and therapy (speech and physiotherapy). Studies have found that it was a burden for the caregivers of the ASD children to take care of them and sometimes society made them isolated and stigmatized [28]. In this study, another significant challenge for the parents was mental stress and depression and 97% parents agreed that they were worried about their special child. The consequences were alarming among 31.9% of the parents as they had to go to the psychiatric for counselling and took medicine as well.

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Table 4: Percentage of challenges faced by the caregivers (parents)(N=248)

Variables		N	%
Did you go for counselling?	No	169	68.1
	Yes	79	31.9
Did you face any financial crisis?	No	160	64.5
	Yes	88	35.5
Did you borrow money?	No	198	79.8
	Yes	50	20.2

3.4 Qualitative Analysis

3.5 Theme 1: Behavioral Changes Noticed by the Special Educators and Therapists

During the lockdown, most of the ASD children were confined to their home as the schools and care centers were closed. The ASD children did not get their necessary services and therapies during that period. All the 5 experts claimed that hyperactivity was very common to these children but in pandemic it increased. As their regular routine was hampered, most of the children became very angry, stubborn and hyper.¹ The experts talked about the absence of their less motor developmental training during Covid-19 pandemic. Gross motor development refers to the movement of their limb movement. As most of the

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¹ "Children were not engaged with their regular exercises. Motor development was absent as the care-center was closed. During Covid-19 children were not comfortable with their parents for their exercise. They became very hyper and inattentive than before" (Telephone interview, April, 2022).

² "During Covid-19 pandemic, one day a guardian called me around 12 A.M. She wanted to bring her child to my school the next morning. The child became very angry, stubborn and she could not manage her child anymore. Actually, for staying at home for a long period of time, the child became so hyper and the guardian (mother) became very exhausted. I was very shocked by this incident" (Telephone interview, 15th April, 2022).

schools and care-centers were closed for a long period, their fine motor exercises and oral motor exercises (communication skill) were also disrupted during the lockdown. Some of them said that during the lockdown period when they conducted with the parents of the ASD children who complained about the sleeping problems of their children. It was very difficult for the parents to control their children's hyperactivity and other behavioral changes as they were not trained up to overcome this situation.²

3.6 Theme 2: Strategies Taken by the Specialized Schools

For developing communication skills and physical condition, the authority of the care-centers and schools took some effective initiatives (online class, IEP, teletherapy, session plan) during the Covid-19 pandemic that helped also in the post pandemic situation to develop the behavioral problem.

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3.6.1 Online Class

During Covid-19 pandemic, the specialized schools made the decision to carry on the classes online (Zoom meeting). There was a precondition that every parent must attend with their children during the class time. The teachers took the classes and the therapists guided the parents about the exercises and therapies parents can provide at home. Teachers and children were engaged in a group (Facebook page or messenger) where teachers used to provide the class link. Respondents said that they continued weekly meetings with the parents to know the updates of their children. They also mentioned that they worked on motor development of the child like trying to talk with the children during classes for increasing their communication skill.³ The children were also cooperative in this case and they enjoyed the classes as they could communicate with their teachers and other peer groups through online classes. Most of the teachers and therapists of the specialized schools and care-centers were satisfied with the online classes.

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3.6.2 Individualized Educational Plan (IEP)

Individualized Educational Plan (IEP) is a long-term plan for the development of communication, verbal and also planning for the physical development of ASD children. The teachers of the care-centers made specific educational plan for the development of the ASD children both during pandemic and post pandemic period. During Covid-19 pandemic, the social interaction of the ASD children was disrupted, and they could not maintain their regular exercises and therapies. So, their mental and physical well-being were hampered during that period. According to the special educators, most of the children became very hyper and inattentive to staying at home. As a result, for developing their mental and physical state, an individualized educational plan was mandatory.⁴

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³ "Children's condition was improved by online classes. I discussed motor development (limb movement) with the parents and tried to train them with some easy exercises that will help to improve their motor skill gradually. I somehow managed to convince and train the parents during covid-19 pandemic" (Telephone interview, 15th April, 2022).

⁴ "As a senior teacher, I made individualized educational plans for the ASD children according to the level of their development. First, I had to identify the developmental stage of a child. Then I made individual plans for all of them. I included different activities including communication activities, art and

3.7 Theme 3: Initiatives Taken by the Care-centers

3.7.1 Teletherapy

Teletherapy was another activity that was carried out by the therapists of the care-centers during Covid-19 pandemic. It added extra value for improving the communication skills of the ASD children during the lockdown period. When most of the institutions were closed due to the pandemic, the children became very bored and their limb movement and verbal practice were disrupted. Their interaction with other society members decreased a lot. At this time, most of the schools and care-centers took the initiative to conduct teletherapy by the therapists of the institutions.⁵

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In the process of teletherapy, the therapists suggested different therapies and exercises according to the condition of the ASD children. The therapists assigned different therapies and exercises to the parents of the children on the basis of their developmental growth and the parents tried to follow the instructions of the therapists. According to the therapists, teletherapy was effective to reduce behavioral problems in ASD children during the lockdown. However, the therapists had a good experience by providing teletherapy to the ASD children during Covid-19 pandemic.

3.7.2 Session Plan

During Covid-19 pandemic, the therapists of the care centers made new session plans for giving them proper services. Therapists used to prepare both weekly and monthly session plans where they included the daily activities that should be performed by the ASD children over the month or week. They used to provide 2 sessions per week where they included different activities such as art, song, exercises and specific therapies on the basis of the current level of the ASD children.

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The therapists made a list of the ASD children according to their level of development and after that they made their session plans for 3-4 weeks at a time. According to the respondents, they made session plan on the basis of the level of the ASD children.⁶ Parents of the children gave positive feedback about the initiatives taken by the caregivers (therapists and teachers) during the pandemic in Dhaka. In contrast, due to lack of enough capital, many institutions could not provide the best service to the online activities for

academic tasks for the children with ASD. Moreover, I talked with the parents and shared about different plans with them" (Telephone interview, 22th April, 2022).

⁵ "During Covid-19 pandemic when our institution was closed, we provided services through telephone with the help of our experts. Previously most of the guardians were known about different therapies of the special child so assigned them some therapies that will help for the development of their ASD child. We tried to open schools 2/3 days in a week for the motor development of the children. Teletherapy was fruitful as some of the guardians were helpful and cooperative" (Telephone interview, 22th April, 2022).

⁶ "As most of the guardians complained to us that their child's mental and physical states are deteriorating day by day, we planned to take quick strategies for the development of the ASD children during the pandemic. We made a session plan for the improvement of the condition of the ASD children. Before making a session plan, we had to observe the condition very carefully and according to their physical state we made plans for each ASD child." (Telephone interview, 15th April, 2022).

example online class and teletherapy. Many of them complained that parents did not follow up or monitor their children during online class or in case of submission of the assignments.

3.8 Discussion

During the second phase of lockdown, 98% of the parents experienced behavioral problems of their children including sleep disturbance, screaming and most significant was hyperactivity (78%) due to the absence of therapy. A result of a research proved that there exists a close relationship between the absence of speech therapy and increasing repetitive behavior of the ASD children [29], in our study 89% of parents had taken several strategies for reducing hyperactivity and other behavioral problems. Our study revealed that 78% parents considered that their interaction with the children increased more during the lockdown than before, whereas a research result of Turkey shows that, according to parents, the second negative effect of the epidemic on children was their isolation and lack of or minimal engagement with classmates (31.2%) [30].

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From the result of this study, it was found that during lockdown most of the specialized school and care centers were closed, and to minimize the loss they started providing therapy over the phone. 49% of the parents reported that their children received teletherapy service during lockdown. According to a study of the USA, children with disabilities lost access to all therapy services in 42% of cases, whereas 34% of cases had at least one via telemedicine therapy session [31]. However, 43% of the parents in this study regarded teletherapy fruitful for their children. On the contrary, preschool-aged children's families were the least satisfied with online and telehealth therapies, with the majority of participants seeing little to no benefit from services [32]. Moreover, the parents who had financial solvency (monthly income >60,000 BDT) among them 64.1% assigned extra caregivers at home to maintain regularity of exercises and therapies needed for their children. A recent study recommended that parents should follow a daily routine as ASD children prefer a structured routine (Lim et al., 2020), in this study parents also made a new routine for their child as the regular routine disrupted due to lockdown.

Besides, the secondary caregivers including special educators and therapists also observed the same behavioral changes noticed by the parents and so they provided teletherapy, started conducting classes online, made IEP and session plan for the ASD children to improve their condition. Though most of the therapists and special educators were satisfied with the outcome, some of them conveyed the lack of proper monitoring and cooperation of the parents. This study revealed the role of the two types of caregivers—primary (parents) and secondary (special educators and therapists) which made this more reliable.

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4. Conclusion

The findings of this study have broadened understanding of the parental function, special educators and therapists on basis of reducing behavioral problems of the ASD children during a very crucial life event—a pandemic-induced lockdown. Caregivers (primary and secondary) have played significant roles including assigning caregivers, providing learning tools, new routine, medicine and we found that there was a close link between socio economic condition and increase of assigning caregivers and teletherapy service. In terms of the care centers and special schools, they tried their best to serve the ASD children through online class, telehealth service and making short term and long term (IEP and session plan) planning for the ASD children during lockdown. The findings of this research have suggested

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some strategies and policies that should be taken under consideration for the mental and physical development of the ASD children during any future pandemic in Bangladesh. The care centers for the ASD children need to provide free therapy services, free learning tools and free counselling to the underprivileged families having special children. Government should introduce special transport service for the children with special needs in both urban and rural areas for bringing them into the mainstream, and should come up with more financial support for the needy families, care centers and specialized schools.

Limitations

The study's scope was limited to only Dhaka city in Bangladesh due to financial constraints, compounded by the challenges of the COVID-19 pandemic, which resulted in some respondents declining to participate due to health concerns.

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