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Impact of COVID-19 on psychological well-being of parents of children with autism spectrum disorder in eastern India

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***Abstract*---**Background: COVID-19 outbreak has resulted in adverse psychological effects in children diagnosed with autism, whereas only few research studies are being conducted to study the psychological impact and burden on the parents during this pandemic. Aim: The objectives of the current study were to examine the psychological well-being and the effect in perceived strain among parents during the COVID-19 outbreak in eastern India. Method: Parents of 290 children completed an online survey which investigated variables like demographics, perspective and use of tele-rehabilitation, routine homecare therapy, parent's strain and psychological well-being. Result: Data analysis revealed prevalence of symptoms associated with depression, anxiety and stress factors, which was found to be 65.5 %, 20.6 % and 37.4 % respectively. A significant difference was observed regarding perceived strain among the parents ($p < 0.001$, effect size = 0.92). Parents from rural areas not aware of tele-rehabilitation resulting it as poor mode for rehabilitation indicated higher risks for mental issues whereas a negative perception regarding homecare therapy was strongly associated with higher psychological symptoms and mental strain. Conclusion: Present study associated higher prevalence of depression and significant change in strain exhibited by parents during the sudden COVID-19 outbreak. On the other hand, this study identified several factors related with poor psychological well-being and perceived strain which can be used to guide and

increase awareness among parents and caregivers of children with Autism.

***Keywords*---**Psychological well-being, Mental strain, Parents, Autism, COVID-19, Telerehabilitation.

Introduction

From 2020 the world has been facing the consequences caused due to the sudden outbreak of a novel corona-virus infectious disease i.e. COVID-19 which has led to devastating loss of human lives after its first detection in December 2019 at Wuhan city of central Hubei province of China [1-3]. World Health Organization (WHO) declared COVID-19 as a public health emergency on January 30, 2020 and on March 12, 2020 announced it as a pandemic due to the rapid spread of the corona virus to across various countries [4]. With respect to Indian scenario, the government of India had declared a nationwide lockdown on March 24, 2020 followed which access to all public facilities/services was strictly prohibited [5]. As per the government norms, social distancing was declared as one of the best strategies to avoid the swift transmission of COVID-19. Every citizen focused on children were instructed to stay at home and restrict outdoor activities [6]. Considering the situation, parents of children with autism spectrum disorder (ASD) and similar children with special needs and other chronic disability found it more challenging to manage (parents and other family members). In India, the estimated prevalence of ASD and learning disability seems to be 0.11% [7,8] respectively.

As per 2011 Indian census data the prevalence rate of children suffering from any kind of disability seems to be 1.24 % [9]. These special children require various intensive rehabilitation services such as speech and language therapy, physiotherapy, occupational therapy, behavioral therapy, counseling and/or special education either at clinics or hospital set up. However, to reduce the sharp increase of COVID-19 virus and government policies, children with special needs were not able to be physically visit any of the rehabilitation care providers. Due to such circumstance, the role of parents of children with special needs especially became were extensive and broad which not only included physical care but also rehabilitation goals at home to continue and/or improve their physical and mental function. Research indicates that due to the sudden disruption of normal schedule and social limitation which may lead to increased frustration among children with ASD [10]. Therefore, parents play a vital role in maintaining the daily rehabilitation sessions in order to reduce any increase in their anxiety and frustration.

Previous literature has demonstrated that any kind of similar infectious diseases outbreak including COVID-19 resulted in a negative impact on the psychological wellbeing of general population in India [11]. In a similar study conducted by Zhang et al.(2020) parents of children aged 6-15 years diagnosed with ADHD showed a sharp decline in their psychological state due to COVID-19 [12]. According to WHO Classification of Functioning, Disability and Health (ICF) caregiver strain is considered as a third-party disability[13]. Considering the

current scenario of increasing effect of Covid-19 and omicron caregivers might face challenges in handling self-care and providing specific rehabilitation services in a home environment. In addition to handling for self-care and mobility, providing rehabilitation services in a home environment.

Because of past sudden events of prolonged lockdown, providing homecare therapies by parents would become challenging. Although home based intervention seems to play a vital role in rehabilitation [13,14] but there is high probability that parents are not so skilled to learn and administer the techniques in a proper well framed manner to achieve the desired functional goals of children with ASD. There are many underlying factors due to which caregivers or parents find it difficult to implement the intervention sessions successfully at home environment, some of the factors are lack of support from family members and healthcare providers in form of intensive session, low self-efficacy, lack of awareness, poor knowledge of homecare therapy and poor functioning of child[14,15] .One of the most emerging alternatives which has come in existence is the role of tele-rehabilitation which has proved to be extremely beneficial [16-19]. Thus, tele-rehabilitation played as a substitute in the field of rehabilitation during the current phase which seems to reduce stress and burden on caregivers. However, India is still a developing country where technological upliftment is in budding phase and tele-rehabilitation steeply growing, there are various potential barriers to tele rehabilitation such as many potential barriers to tele-rehabilitation such as poverty, accessibility, cross-cultural acceptance, lack of awareness, illiteracy and large rural population which don't know the usage of smartphones are present[20]. Apart from all these factors, other issues like understanding and patience regarding implementation of tele-rehabilitation between parents and professionals is also required to establish tele-rehabilitation as a successful mode of intervention considering the current scenario. There is a high probability regarding utility of tele-rehabilitation associated with poor psychological well-being, mental strain and hence greater action may be required.

Research studies reveal that children with special needs especially intellectual and developmental disabilities tend to be at higher risk of COVID-19 virus [21,22,26]. Apart from these, globally delayed development children or children suffering from any other similar kind of chronic neurological related disability face some harder challenges due to their functional inability to cope up with the situation functional limitations and this might further lead to increased stress to their caregivers [23,24]. Apart from handling children diagnosed with ASD there is another budding issue which is also somewhere responsible for increased strain among parents is managing their elders. Research has shown that elders with co-morbidities tend to be more vulnerable to COVID-19 infection [26]. As observed, there is a trend showing a steep increase of nuclear elders is increasing, according to a national survey, 2% aged people tend to live alone and 11% stay along with their spouse or their adult children while 55 % reside either with the nuclear family of their children or in multi-generational household[27]. Taking care of elders and exposure to sever infection and/or sudden death of elders may also adversely affect the psychological well-being and increased strain of caregivers.

Considering the research findings, the objectives of current study is:
To investigate and examine the mental health condition of parents handling children diagnosed with ASD during COVID-19 quarantine period and also examine the impact of the COVID-19 outbreak on the parents' mental strain.
To examine the demographic, social and other related factors associated with mental health status and strain of caregivers.

Method

Study design and participants
The survey for current study was conducted in collaboration with rehabilitation professionals mostly working in pediatric clinics and hospital set up across eastern India. A network of speech language pathologists, few physiotherapists and occupational therapists were contacted to collect adequate target population details by explaining the study in details. All the necessary contact details of parents having children with ASD hereby satisfying the inclusion criteria were collected from the rehabilitation professionals expecting that parents have the basic understanding of English before participating in the survey.

An online questionnaire was formulated by the authors for data collection. Considering the pandemic scenario rather than physically visiting the centers, the authors circulated the questionnaire in the form of link among the parents via digital mode (e.g., WhatsApp, emails and other significant social media) thus, reducing the risk of exposure to virus both for participants and the authors.

Data collection
Data was collected from October 29, 2020 to December 22, 2020. The inclusion criteria for the present study was as follows:

1. All the participants must be parents of children diagnosed with ASD by an experienced rehabilitation professional.
2. All the participants must be proficient in English (both read and write) along with their permission to provide informed consent.
3. All parents must have access to smart phones/gadgets and aware of internet connectivity

On the other hand, exclusion criteria for the present study were:
Parents of children aged diagnosed with other disability other than autism were not included in the study. Parents who did not have basic knowledge of English were excluded from the study. Parents who didn't know to handle smart gadgets/mobile phones.

Outcome measures:
Demographics: The questionnaire was adopted from similar kind of study conducted by Dhiman et al., (2020) which is mentioned in Appendix A. In the questionnaire, the initial section was in- formation on demographics including child's age, relation with child, occupation of caregiver, diagnosis, and any elder (> 60 years) living at home. Then questions regarding presence of steady financial

status, current workload, relationship between workload and care and whether the primary caregiver worked from home or the workplace were asked.
Status of Children's functional ability and perception regarding tele-rehabilitation: Under this part, each child's independent skills like eating, dressing, hygiene and mobility were assessed. The response for each skill except mobility was divided into independent or dependent status and mobility on other hand was categorized to sub-levels. Other significant areas like caregiver's perception regarding homecare therapy and tele-rehabilitation were also assessed.

Psychological wellbeing: Depression Anxiety Stress-21scale (DASS-21) was used [28] to assess mental health symptom like depression, stress and anxiety during the pandemic scenario. All the participants were instructed to fill the 21 item Depression anxiety scale (DASS-21). DASS-21 generally consisted three sections (stress, anxiety and depression), wherein each domain consists of 7 sub-items. Each participant had to score the response on a 4 item Linkert rating scale which varies from "0"-denotes did not apply to me at all" to "3"-applied to me very much or most of u time. The scores thus, obtained for each domain were calculated by summing the scores for the items being marked. Finally, DASS-21 scores were multiplied by 2 to find the severity of depression, anxiety and stress symptoms. In DASS-21, depression, anxiety and stress subscale is categorized as mild, moderate, severe and extremely severe with different scoring range pattern for each domain respectively. The test-retest validity of this scale measuring depression, anxiety and stress symptoms was has been tested[29].

Caregiver strain: Caregiver's strain regarding pre and post COVID-19 outbreak was analyzed by using a validated caregiver strain index (CSI) questionnaire. CSI is a 13-item questionnaire which measures strain perceived by parents/caregivers related to child care and maintenance provided by them. This questionnaire comprises at least one question related to areas such as social and time, financial, physical, employment. Items were recorded in the form of yes/no response as 0- "no" and 1- "yes". The total score varies from 0-13, higher score indicated greater level of strain. The test was developed and validated to examine the amount of strain perceived by caregivers who took care of children suffering with various neurological conditions like developmental delays (Cerebral palsy) and other serious illnesses[30,31,32].

Data analysis:
Collected data was analyzed using SPSS version 26.0. Descriptive statistics revealed prevalence of depression, anxiety and stress symptoms along with demographics of factors. To examine the impact of COVID-19 outbreak on CSI paired t-test was used. On other side, to find the relationship among depression, anxiety, stress symptoms and CSI Bivariate Pearson correlation testing was conducted. Multivariate ANOVA (MANOVA) and analysis of covariance (ANCOVA) was used, wherein the former was conducted to analyze the demographic, social and care related factors associated with DASS indices (depression, anxiety and stress symptoms) and latter was used to examine demographic, social and care related factors associated with CSI, where the CSI score one month before the pandemic outbreak (retrospective data) respectively.

Results

General characteristics

Data was collected from 295 parents of children diagnosed with autism who satisfied the inclusion criteria from various rehabilitation professionals from eastern India. Two parents denied participating in the study due their lack of awareness with respect to internet and three parents due to their inability of comprehend English. Finally, 290 respondents who fulfilled the inclusion criteria of the study were asked to complete the online form and responses were analyzed. Almost all the parents' minimum educational qualification was bachelor degree qualification and 80 % of present study sample had acquired above bachelor level education. As mentioned in Table 1, among the parents 85 % of caregivers were the mother, 10 %were the father and only 5% were other family member who took care of children as a caregiver. As per the data, the mean age of children was 5.25 ±3.05 (mean ±SD) years and participants were from 5 major eastern cities of India.

Table 1
Demographics and general characteristics (N = 290)

Characteristics	N (%)
Primary caregiver	
Mother	232(80%)
Father	30 (10.3%)
Other family member	15(5.17%)
Age of child	
<6 years	150(51.72%)
≥ 6 years	140(48.27%)
Steady financial status	
Yes	210 (72.4%)
No	80(27.5%)
Elder living at home	
Yes	128 (44.1%)
No	136(46.8%)
Working from home	
Yes	96(33.1%)
No	67(23.1%)
Not Applicable	127(43.7%)
Work load increased	
Yes	150(51.7%)
No	42(14.4%)
Not applicable	98(33.7%)
Increased workload affecting child care	
Yes	147(50.6%)
No	64 (22.06%)
Not applicable	79(27.2%)

Prevalence of depression, anxiety, stress symptoms and CSI among caregivers
The prevalence of psychological symptoms with their severity is presented in Table 2 and Fig.1. Result analysis reveals prevalence of depression, anxiety and stress symptoms as 66.14 %, 29.1 % and 38.4 % respectively.

Table 2
Prevalence of psychological symptoms (depression, anxiety and stress symptoms) with severity level among parents of children with autism (N = 290)

Variables	Prevalence No (%)
Depression	
Normal	98 (33.7%)
Mild	89 (30.6%)
Moderate	59 (20.34%)
Severe	36 (12.4%)
Extremely severe	8 (2.8%)
Anxiety	
Normal	205 (70.7%)
Mild	35(12%)
Moderate	23(7.9%)
Severe	9(3%)
Extremely Severe	18(6.2%)
Stress	
Normal	164 (56.5%)
Mild	66 (22.7%)
Moderate	38 (13.1%)
Severe	12 (41.3%)
Extremely severe	10 (3.4%)

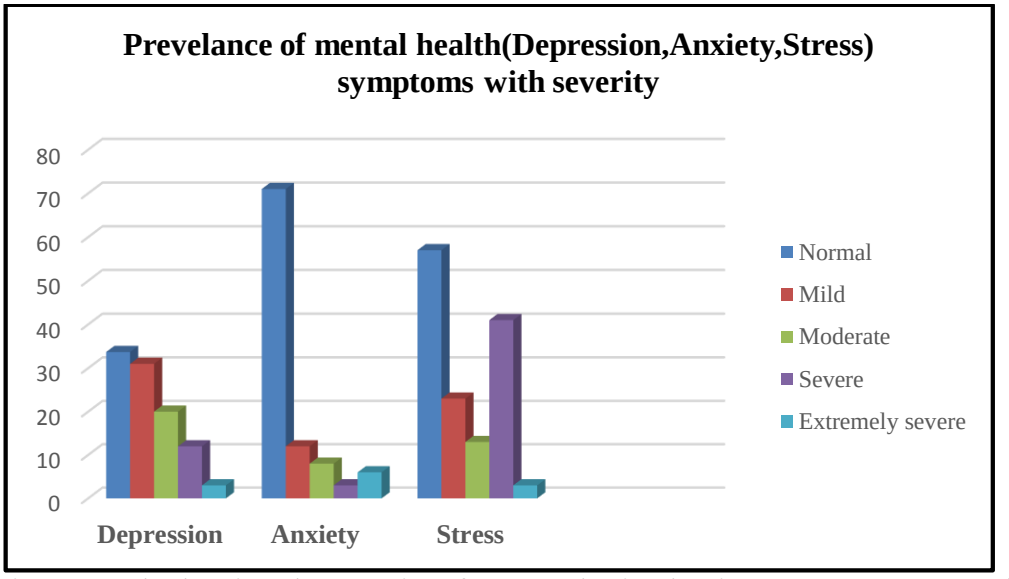

Fig 1: Graph showing the severity of scores obtained using DASS-21 on overall psychological symptoms of parents of children with ASD (N=290)

Impact on CSI during COVID-19 outbreak

To examine the impact of COVID-19 outbreak on CSI on parents of children with ASD, the scores of CSI during the outbreak was compared with the retrospective CSI scores collected 1month before the outbreak by using paired t-test. The result analysis has been presented in Table 3 and Fig. 2 which suggests a statistically significant ($p < 0.001$) with large effect size (0.92) pre and post COVID-19 outbreak and a mean difference of 2.89±3.85.

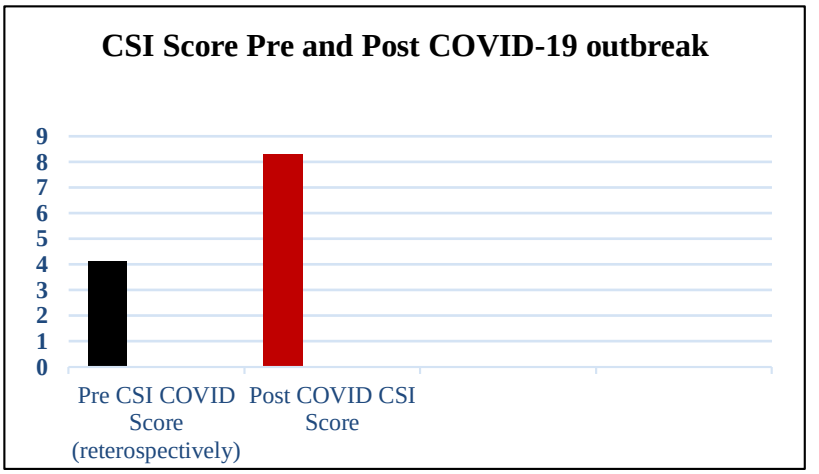

Fig. 2. Graph showing mean change in CSI score before the outbreak and during the COVID-19 outbreak.

Table 3
Impact of COVID-19 outbreak on CSI using paired *t*-test

Variable	Before outbreak (mean ±SD)	During outbreak (mean ±SD)	Mean change ±	95% CI	*T*	*p*	Effect Size
Caregiver Strain Index (CSI)	4.13 ± 1.43	8.29 ± 3.48	—2.98 ± 3.85	-3.45- -2.52	— 12.664	< 0.001*	0.92

*Significance kept at p<0.05, Effect Size=Cohen's *d*

Correlation between psychological symptoms (depression, anxiety and stress) and CSI among the parents =

Bivariate correlation testing was administered to examine the correlation between psychological symptoms and CSI. The results revealed poor but statistically significant correlation between depression (r 0.21, P < 0.001) and anxiety symptoms (r 0.25, P < 0.001) with CSI, while correlation between stress and CSI indicated moderate significant correlation (r 0.42, P < 0.001). However, statistically significant and strong correlation were observed between the core psychological symptoms like depression and anxiety symptoms (r 0.62, P <

0.001), stress and depression symptoms (r 0.65, P < 0.001) and between stress and anxiety symptoms (r 0.72, P < 0.001).

Table 4
Bivariate correlation analysis among psychological symptoms and CSI

	Depression	Anxiety	Stress	CSI
Depression	1			
Anxiety	0.62**	1		
Stress	0.65**	0.72**	1	
CSI	0.21**	0.25**	0.42**	1

** Correlation is significant at 0.01 level (2 tailed).

Factors associated with psychological (depression, stress, anxiety) symptoms among caregivers of children with special needs

MANOVA statistical tool was used to explore factors associated with DASS indices such as demographic, social and care on depression, anxiety and stress. Certain assumptions regarding MANOVA some of which were absence of outliers, linear relationship between each dependent and independent variables satisfying the assumptions were considered to be analyzed. Result of One-way MANOVA analysis with Wilk's lamda (Λ), p value and effect sizes (partial Eta squared) has been represented in Table 5, which reveals the difference across the levels with respect to various factors when depression, anxiety and stress symptoms taken into consideration as a dependent variable. To establish an association of each independent factor on depression, anxiety and stress symptoms separately Analysis of variance (ANOVA) was conducted which is represented in Table 6.

Table 5
MANOVAs – Differences in depression, anxiety and stress symptoms interaction levels of demographic, social and care related factors

Factors	Value	*F*	*Df*	*P*	η^2_p
Child's age	0.912	7.658	3	<0.001***	0.082
Continuation of tele-rehabilitation	0.882	10.142	3	<0.001***	0.110
Parents perception on tele-rehabilitation as alternate option	0.911	8.713	3	<0.001***	0.094
Learning of homecare therapy skills	0.960	3.614	3	0.013*	0.041
Perception of parents regarding homecare therapy	0.908	4.929	5	<0.001***	0.046
Elder living at home	0.989	1.261	3	0.293	0.013
Steady financial income	0.963	2.569	3	0.014*	0.040
Working from home	0.906	4.526	5	<0.001***	0.052

Note: $p \leq 0.05$*, $p \leq 0.01$**, $p \leq 0.001$***.
η^2_p = *Partial Eta Squared*

Table 6
ANOVA tests between the groups with respect to psychological (depression, anxiety and stress) symptoms (N = 290)

Factors	No.	Depression			Anxiety			Stress		
		B	*p*	*ηp2*	B	*p*	*ηp2*	B	*p*	*ηp2*
Child's age				*0.05*			0.033			0.073
<6[a]	137									
≥6	153	-2.871	<0.001***		-2.216	0.003**		-3.96	<0.001***	
Continuation of tele-rehabilitation				0.00			0.026			
Yes	208									
No	82	0.242	0.765		2.249	0.005**		-1.252	0.210	
Parents perception on tele-rehabilitation as alternate option				0.060			0.085			
Yes[a]	172									
No	118	3.61	<0.001***		3.598	<0.001***		2.910	0.003**	
Learning of homecare therapy skills				0.019			0.001			
Yes[a]	230									
No	60	1.953	0.043*	0.563	0.575		—0.816	0.482		

Perception of parents regarding homecare therapy		0.93	0.001		p	0.204	0.013		0.001***	
Easy	23	0.747			— 2.757			-7.065		0.053
Moderate[a]	108									
Difficult	159	0.09			0.241			0.014		
Working from home during lockdown			0.014*	0.032		0.003**	0.041		<0.001***	
Yes	94									
Not applicable (N/A) being homemaker	69	-2.37			-2.783			-3.61		
No	127	-2.34			-0.891			-3.97		
Elder living at home										
Yes[a]	137									
No	153	0.085	0.932		-0.085	0.909		-1.17	0.195	
Steady financial income										
Yes[a]	213									
No	77	-2.48	0.008**		-0.630	0.485		-2.06	0.041	

Note: $p \leq 0.05$*, $p \leq 0.01$**, $p \leq 0.001$***; a - Referent factor ; B = Estimates; $\eta^{2:}$ Partial Eta squared.

Factors associated with CSI among parents of children with ASD

ANCOVA statistical tool was administered in order to examine the association between the demographic, social and care related factors and CSI post COVID outbreak among parents tending children with autism spectrum disorder. The statistical analysis includes estimates (B), p value and effect sizes (partial Eta squared) in Table 7.

Table 7
ANCOVA tests between the groups differences in CSI during outbreak (N = 290)

	d	F	B	T	p	η^2_p
Child's age	1	4.413				0.017
<6[a]			—0.893	—2.153	0.034*	
≥6						
Continuation of tele-rehabilitation	1	4.73				0.015
Yes			—0.821	—2.21	0.036*	
No						
Parents perception on tele-rehabilitation as alternate option	1	11.918				0.036
Yes[a]						
No			—1.412	—3.449	<0.001***	
Learning of homecare therapy skills	1	8.125				
Yes[a]			—1.283	—2.821	0.004**	
No						
Perception of parents regarding homecare therapy	2	21.102				0.154
Easy			-4.204	—5.262	<0.001***	
Moderate[a]			1.452	2.771	0.006**	
Difficult						
Working from home during lockdown	2	17.698				
Yes						
Not applicable (N/A) being homemaker			-1.214	—3.202	0.003**	
No			—3.703	—5.929		
Elder living at home	1	4.742				
Yes[a]			—0.856	—2.182	0.040*	
No						
Steady financial income	1	0.659				
Yes[a]			—0.368	—0.850	0.411	
No						

Note: $p \leq 0.05$*, $p \leq 0.01$**, $p \leq 0.001$***; a - referent factor.
B = Estimates; η_p^2: Partial Eta squared

Discussion

The overall findings of the current study indicate higher prevalence of depressive symptoms among parents of children with ASD during COVID-19 outbreak. With respect to parental strain, a significant difference was observed in caregiver strain during the outbreak. There were various other factors like demographic and social related domains associated to psychological symptoms and perceived strain in parents of children with ASD.

The present study revealed significantly higher prevalence of depression (66.14 %) among parents of children with autism whereas caregivers whereas 29.1 % and 38.4 % for anxiety and stress symptoms respectively. In contrary to the above findings there are two Chinese studies which reported 37.1 % and 20.1 % depressive symptoms among caregivers which was conducted during the initial phase of lockdown among the Chinese population [30-33]. Similar studies were conducted which revealed that an extended period of outbreak didn't affect the depressive symptoms among general Chinese population [1]. In general, parents of children with ASD face unique challenges related to family, reduced social life, sometimes they face stigmatized due to their children's disability. With respect to Indian Scenario, increased death rate and amount of media coverage regarding the pandemic might have led to increased depression level among parents.

In the present study a very evident result was found with indicates that parents who were not attending tele-rehabilitation sessions during the lock down tend to exhibit greater psychological symptoms specially increased anxiety, a very strong correlation was seen between parental perception on the concept of tele-consultation as an alternate option for rehabilitation. It was observed that the parents who responded against the concept of teleconsultation tend to exhibit greater risk for mental health symptoms like depression, anxiety and stress. Technological advancement in the field of tele-rehabilitation has been a boon in health care system to combat the COVID-19 outbreak pandemic. In a developing country like India, there are many barriers like poor utilization, lack of knowledge regarding tele-health service, poverty, cross-cultural strategies of tele-rehabilitation are some of the probable factors which has resulted in negative perception of tele-rehabilitation [32]. However, parental knowledge regarding importance of tele rehabilitation, clinician-patient relationship, proper communication among participants play a very important role in creating positive perception of tele-rehabilitation among parents of children with ASD[33].Thus, the present work encourages greater urgency for policy makers and care providers to implement and strengthen greater use of tele-rehabilitation approaches and to provide better education on the benefits of tele-rehabilitation as a means to reduce depression, stress and anxiety symptoms among caregivers tending children with special needs.

Research studies indicate that parents' participation plays a crucial factor for the positive outcome in rehabilitation field for disabled children especially for children with ASD [34] . Thus, it becomes very necessary for the parents to acquire the required knowledge on homecare therapy techniques from the clinician in order to enhance their child's overall functional skills. During the current study it was observed, sudden lockdown declaration by Government of India has affected

drastically the routine of many parents and as a result of which they are unable to learn the basic homecare techniques in a proper manner which again might have resulted in negative perception regarding homecare therapy. The study reveals that parents who didn't have the knowledge of homecare therapy tend to exhibit symptoms of depression whereas, parents who considered learning homecare therapy is moderate to difficult tend to be associated with stress symptoms.

CSI findings indicate that due to lack of efficient training in homecare therapy and continuation of tele-rehabilitation with little or no knowledge of homecare therapy among parents of children with ASD resulted in physical and mental strain. Similar findings have been found in which it was observed that level of strain was more in caregivers whose concept regarding of homecare therapy was from moderate to difficult. Therefore, it's a high time wherein the rehabilitation professionals should teach the best strategies for better communication in order to reduce strain. Beside this, another triggering factor for increased strain among parents may be the burden related to additional care which they facing due to elderly family members living with them.

Conclusion

The current study concludes that there is a high prevalence of psychological symptoms exhibited by parents of children with ASD. The COVID-19 outbreak scenario has resulted in negative impact on caregiver strain. ack of awareness regarding tele-rehabilitation and its negative perception seems to be associated with anxiety symptoms and poor mental health. On, the other side continuation of tele-rehabilitation without adequate homecare training leads to strain among parents.

Therefore, detailed communication among professionals and caregivers should be carried out in order to remove the external barriers like negative perception of tele-rehabilitation, proper education regarding homecare therapy and better provision for psychological intervention may help in reducing the mental health conditions of parents of children with ASD. Regarding removal of barriers associated with an unfavorable perception of tele-rehabilitation, increasing education on the homecare therapy, and provision of psychological interventions/services may help to diminish mental health issues and strain associated with care-giving. As a whole, better intervention plan will result in better implementations on children with ASD who can receive better care and lead a better quality of life along with their parents by reducing their psychological symptoms and improving their mental health.

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