Pakistan Journal of Statistics and Operation Research

Psychological Impact of COVID-19 on Families of Children with ASD and Typically Developing Children: A Case Study of Pakistan

Ayesha Amir[1], Zamir Hussain[2*], Qurrat Ulain Hamdan[3], Mahnoor Hasan[4], Syeda Aneela Zahra Shamsi[5]

* Corresponding Author

1. Department of Sciences, School of Interdisciplinary Engineering and Sciences, National University of Sciences and Technology, Islamabad, 44000, Pakistan. Email: ayeshaamir2601@gmail.com
2. Department of Sciences, School of Interdisciplinary Engineering and Sciences, National University of Sciences and Technology, Islamabad, 44000, Pakistan. Email: zamir@sines.nust.edu.pk
3. Institute of Psychiatry, Benazir Bhutto Hospital, Rawalpindi, 46000, Pakistan. Email: drqurrat.psy@gmail.com
4. Department of Sciences, School of Interdisciplinary Engineering and Sciences, National University of Sciences and Technology, Islamabad, 44000, Pakistan. Email: mahnoorhasan122@gmail.com
5. Department of Sciences, School of Interdisciplinary Engineering and Sciences, National University of Sciences and Technology, Islamabad, 44000, Pakistan. Email: aneelazara10@gmail.com

Abstract

Children with Autism Spectrum Disorder (ASD) and their parents, being a vulnerable population, were expected to be highly affected by the pandemic and its containment response. This study aims to analyze and compare the impact of COVID-19 on behavioral and mental well-being of ASD and TD (typically developing) individuals and their parents/caregivers in Pakistan. A total of 51 primary data samples from both groups were collected from Rawalpindi and Islamabad using a comprehensively designed survey, consisting of 6 sections related to participants and children demographics, parental exposure to COVID-19, impact of COVID-19 lockdowns, behavioral problems and ASD support during lockdown, parental distress (estimated via DASS21) and 2 open response questions. The study found that ASD families reported increased difficulties and required more commitment than before in nearly all aspects of life as compared to the TD group. Additionally, ASD children showed more behavioral problems in terms of aggressive, repetitive, and transition activities during lockdowns than before. Moreover, comparison of machine learning models ranked 5 significant factors contributing in parental distress which include family income, severity of ASD symptoms, type of ASD therapy, parental exposure to COVID-19, and impact of lockdowns on daily routines. Majority of participants reported the need for financial support, awareness, and proper planning from the government during the pandemic. The findings of this study provide evidence which highlights the necessity of collaborative interventions from both healthcare professionals and government authorities aimed at assisting parents in reducing distress and developing effective coping strategies, especially for individuals with ASD.

Key Words: Autism Spectrum Disorder; Behavioral Problems; COVID-19; Parental Distress; Machine Learning

1. Introduction

The pandemic spread of the novel coronavirus disease (COVID-19) began in early 2020. It rapidly evolved into one of the most disruptive public health crises of the twenty-first century. In addition to the critical health issues of being infected, the pandemic had a widespread effect on the psychological well-being, social engagements, and family dynamics all over the world. Prolonged lockdowns, closures of schools, disruption to routine healthcare services, and the pervasive feeling of uncertainty had an overwhelming effect on children and their caregivers. These circumstances placed considerable strain on families. Although every child was affected by the sudden interruption to daily routine, evidence consistently indicates that children with neurodevelopmental issues, especially Autism Spectrum Disorder

(ASD), and their families were among the most susceptible to the negative consequences of the pandemic (Colizzi et al., 2020; Mutluer et al., 2020).

ASD is a complex neurodevelopmental disorder characterized by impaired social communication, lack of interests, and repetitive behaviors, and has an estimated prevalence across the world of one in every 100 children (WHO, 2022). ASD children normally require extensive educational and behavioral interventions that will enable them to progress in their development. The abruption suspension of these structured services during COVID-19 pandemic posed major challenges for both child and their caregivers. Empirical evidence highlights the magnitude of these difficulties. According to an Italian survey, 93% of parents of ASD children reported that behavioral problems had gone worse during the lockdown, as compared to 35% of parents of children with typical development (TD) (Siracusano et al., 2021). Similarly, a Spanish study found that 80% of families experienced increased irritability, emotional outbursts, and sleep problems among autistic children during confinement (Mumbardó-Adam et al., 2021). Turkey data further revealed that 78% of children with ASD became behaviorally impaired (aggressive and hyperactive) when their structured routines were disrupted (Mutluer et al., 2020). Parents reported increases in hostility, sleeping difficulties and self-care challenges. A cross-country survey illustrated that, 67% of ASD families were found to have regressed in adaptive functioning, versus 22% of TD families (Colizzi et al., 2020). These results showed that children with ASD were much less adaptable to abrupt changes compared to their TD counterparts who were less affected but more flexible to adapt to the changed routine.

The COVID-19 pandemic affected not only autistic children but also their parents and caregivers. Giving care to a child with ASD is a very demanding task even in the normal conditions, but the sudden closure of therapy centers, schools with special education and community support institutions significantly aggravated this task. Parents of children with special needs worldwide had two to three times more stress, depression, and anxiety than parents of TD children (Dhiman et al., 2020; Alhuzimi, 2021). The prevalence of moderate to severe anxiety associated with disruption of routines and professional support was reported by 65% of ASD caregivers in Saudi Arabia (Alhuzimi, 2021). On the same note, 70% of parents with children who had special educational needs and disabilities (SEND) in the United Kingdom also indicated clinically significant mental health problems during lockdowns, in contrast to 45% of parents of TD children (Asbury et al., 2021). This stress was further augmented by the increased responsibility of dealing with the behavioral issues of their child at home, as well as financial insecurity, adapting to working remotely, and constant fear of infection. Many caregivers reported the sense of isolation, helplessness, and burnout due to lack of professional support networks and social outlets that usually mitigate the stress of caregiving (Dhiman et al., 2020).Pakistan represents a particularly concerning context. According to a study carried out in Lahore, 72% of caregivers of children with ASD were in severe psychological distress during lockdowns, in contrast to 38% of caregivers of children with TD (Nadeem et al., 2021). In Pakistan, 80% of parents of ASD children stated that their financial loads have been increased, while 60% noted that their children develop undesirable behaviors, such as self-harm and aggression. Pakistani families (as opposed to high-income countries, where Tele-therapy and remote support partially alleviated gaps in services) were deprived of virtual professional support.

The comparative approach between the ASD and the TD populations is essential in order to demonstrate the disproportionate pandemic burdens. Although parents of TD children mentioned the challenges related to homeschooling, the work-life balance, and screen time of children, the majority of these stress factors were temporally dynamic and reduced with time (Asbury et al., 2021). In comparison, parents of children with ASD had to cope with multidimensional problems, which did not just involve educational adaptation efforts, but also behavioral crises, therapy lapses, and the worsening of pre-existing emotional and social deficits (Siracusano et al., 2021). Comparative analysis indicate that families of ASD children had higher stress, anxiety, and burnout rates, and 60–80% of ASD caregivers experienced clinical distress levels in relation to 30%-40% of TD caregivers (Dhiman et al., 2020; Nadeem et al., 2021).These challenges were different in their severity in sociocultural and economic conditions. Even in high-income countries where online therapy, remote counseling, and telehealth services rapidly became widespread, families with ASD children, at the same time, noted that they still had a lot of troubles, but at least partially alleviated by technological means (Mutluer et al., 2020; Mumbardo-Adam et al., 2021). Low- and middle-income countries (LMICs), such as those in the South Asian region, however, had much less to call on. Inaccessibility to digital infrastructure, a lack of specialized mental health practitioners and firmly rooted stigma around neurodevelopmental issues complicated the problems of the families living within these areas (Nadeem et al., 2021). In the context of Pakistan particularly where the rates of ASD are estimated to be under-reported because of the difficulty in diagnosing and reporting, families already operate within weak support systems. The pandemic also placed an extra burden on

such families by reducing access to already scarce therapy services, increasing the feeling of isolation, and revealing the lack of institutional preparedness to work with vulnerable groups.

The overlapping of mental health, developmental disorders, and pandemic-related stressors is especially acute in the low- and middle-income countries (LMICs), whose responses to pandemics tend to ignore the needs of the special populations. Emerging trends from Pakistan highlight the importance of exploring how containment practices have impacted differently on families of children with ASD compared to those with TD children. This knowledge is essential in creating culturally sensitive and contextually appropriate interventions to support families during future crises. Comparative studies on the groups of ASD and TD participants give significant information about the overall effects of pandemic stressors and the peculiarities of vulnerability that require specific policy consideration. The proposed study will address this gap by comparing and contrasting the effect of COVID-19 on the mental and behavioral health of children with ASD and those with TD status, their parents and caregivers, in Pakistan. Locating the experiences of both the ASD families and the TD households, this study is not only helping to reveal the overrepresented burden to vulnerable groups but can also offer significant knowledge that can be used to create comprehensive and inclusive health promotion policies and models of intervention.

The major objectives of this research include (1) A survey analysis to determine the effectiveness of complete/smart lockdown during pandemics for children having neurological and developmental disorders and their parents. (2) Measuring and comparing the degree of depression, anxiety and stress of parents of affected children during pandemics. (3) Highlighting significant factors for improvement in dealing strategies to overcome routine difficulties, hence, supporting data driven decision making.

2. Methods

2.1 Study Design and procedure:

The study received ethical approval from the Institutional Review Board at National University of Sciences and Technology under Case Number: 2023-IRB-A-06/06 on 22-02-2023. All research was conducted in accordance with the Declaration of Helsinki. Data from 51 participants were collected between February to July 2023, through direct face-to-face interviews and online formats. Access to parents of children with ASD was obtained from Benazir Bhutto Hospital in Rawalpindi and Step to Learn School in Islamabad. Parents of TD children were also recruited as controls from regular schools and other sources. Even though in population-based surveys, larger sample size is usually advised, methodological literature indicates that sample size of about 50 is typically satisfactory in both exploratory and applied health research. As an example, the review of the studies on the agreement revealed that 50 is the median sample size when continuous endpoints are considered; thus, the similar figures are common in the publication (Han et al., 2022). Pilot and feasibility studies can also be guided methodologically where samples of 30-50 respondents usually suffice in studying feasibility, making parameter estimates, and creating initial results (Hertzog, 2008). Similarly, Julious (2015) suggested a basic rule-of-thumb, which is that about 59 individuals are sufficient to conduct pilot studies to give preliminary estimates with a reasonable degree of confidence. Based on this, the 51 parents sampled in the current study can be discussed as being methodologically justified, as it can provide significant information, but it must be admitted that there are some limitations in terms of generalizability.
The children with ASD were designated as those who had received a prior diagnosis after evaluation from the recruitment center or were regularly enrolled in therapy at the recruitment center. Typically developing children were age and gender matched from regular schools with history of overt behavioral concerns prior to the data collection as reported by the school. The study design was cross-sectional, and parents were requested to retrospectively consider the same lockdown period when they were compelled to stay at home due to the pandemic. Participation was pursued only with the parents' agreement via consent forms. The questionnaire was specifically designed in English and Urdu, by taking consultation from relevant professors, psychologists, and adapting the finding of previous researches. A copy of the questionnaire is provided in Supplementary Files (Questionnaire.pdf). To be included in the study, participants needed to meet the following criteria: (1) being a parent or guardian of a child with an ASD diagnosis aged between 4 to 18 years or being a parent or guardian of a typically developing child aged between 4 to 18 years; (2) possessing the ability to read and understand the English or Urdu language; and (3) being a Pakistani citizen.

Statistical validity and reliability of the questionnaire was also assessed using Cronbach's alpha. This is a statistical measure that quantifies the overall quality of a questionnaire or survey in terms of the correlation of constituent statements. Ideally, statements of a questionnaire should relate to each other so that the questionnaire is focused on

the particular domain or construct being analyzed. However, the statements should not be so similar that they impart redundancy or repetition. Generally, values of Cronbach's alpha above 0.7 indicate that items of the questionnaire correlate adequately with each other. Although the designed questionnaire is a set of various scales, it was treated as one cohesive item to calculate Cronbach's alpha. This allows us to assess the overall validity of all questions. For our designed questionnaire, the Cronbach's alpha for whole sample was 0.911, indicating that the items of the questionnaire are significantly correlated to be structured together, constituting a reliable and valid questionnaire.

The following sections describe the questionnaire design in detail:

2.1.1 Demographic data

This section included questions covering aspects such as participant's gender and age, place of residence, family status, relationship with the child, educational qualifications, family income, total number of children, child's age and gender, as well as the child's educational status (e.g., regular school, special education, or at home). Parents of children on the Autism spectrum were additionally required to provide supplementary data regarding their child's disorder. This includes information on the specific type of neurodevelopmental disorder, the severity of symptoms, and the type of therapy the child is receiving.

2.1.2 Parental Exposure to COVID-19

In this section, parents were asked whether they, their partner, their relatives, or their friends had tested positive for COVID-19 or shown similar symptoms, and an additional question asked if any of their relatives, friends, or colleagues had died because of COVID-19. A cumulative score was obtained for both questions, with higher scores indicating a higher level of parental exposure.

2.1.3 Impact of COVID-19 lockdown

Participants were queried about the challenges they encountered during the crisis, encompassing 12 items distributed across six categories: (1) Daily routines, (2) Educational conditions, (3) Social development, (4) Economic/working conditions, (5) Behavior issues, and (6) Child's physiological distress. Each item's response option was measured on a scale ranging from 0 ("Not at all") to 3 ("Very much").

2.1.4 Questions related to Behavioural problems in ASD children and ASD support during COVID-19

This segment of the survey comprises two parts, specifically designed for parents of children with ASD. Part I consists of three formulated questions aimed at exploring behavioral problems (aggression, repetition, and transition activities) in children with ASD. Parents were asked to rate each question on a scale from 0 ("Not at all") to 3 ("Very much") to assess the severity of these behaviors during the lockdown period in comparison to their lifestyle before lockdowns (Levante et al., 2021). Part II focuses on gathering information related to the availability and satisfaction of ASD support and services during the COVID-19 pandemic, specifically from school, local healthcare services, and private therapists. Responses were measured on a scale ranging from 0 ("Strongly agree") to 3 ("Strongly disagree").

2.1.5 Parental stress and mental health during COVID-19

Parental distress was evaluated using the 21-item, self-reported Depression, Anxiety, and Stress Scale questionnaire (henceforth referred to as DASS-21). Each subscale of Depression, Anxiety, and Stress comprises seven items, and participants rated each item on a Likert scale ranging from 0 ("Did not apply to me at all") to 3 ("Applied to me very much or most of the time"). A higher score on the scale indicates a higher level of depression or anxiety symptoms. To simplify the process of data collection, only the primary caregiver of the children was asked to fill this portion of the questionnaire. For all participants, mothers were the primary caregiver for the children. Therefore, the term "parental stress" has been referred to as "maternal stress" subsequently.

2.1.6 Open response questions

These questions aim to gather additional information from parents regarding the challenges they encountered during the COVID-19 lockdown, beyond those already mentioned, and the potential strategies that could prove helpful in addressing such global emergencies in the future.

2.2 Data Analysis

Data analyses were performed on preprocessed dataset using IBM SPSS software (Version 20) (IBM Corp, 2011) and the programming language Python (Version 3.10) (McKinney, 2022). Prior to the main analysis, the primary data were examined for missing and duplicate values. Simple descriptive statistics were utilized to deliver baseline information regarding survey participants and their children. Continuous variables were described using the mean (M) and standard deviation (SD), while categorical variables were presented as frequencies with corresponding percentages. Further inferential statistics such as Independent t-test, chi-square test and Paired sample t-tests were utilized to perform comparison between families with ASD and TD children. For each of these tests, p-value was compared with the predefined significance level ($\alpha = 0.05$) to determine the statistical significance of the obtained results.

2.3 Evaluation of significant contributing factors to parental distress during the pandemic

In this study, three different Machine Learning (ML) models, including Logistic Regression, Decision Tree, and Random Forest have been implemented to determine whether potential explanatory variables could predict heightened distress (measured by DASS-21) among parents of children with Autism Spectrum Disorder and typically developing children. Each model was developed with two different subsets of features as covariates using IBM SPSS software and Python. Subsequently, these predictor variables were integrated into all the developed models, following these steps:

- **In Model I,** all demographic variables were included as dependent features.
- **In Model II**, "Parental Exposure to COVID-19" and "Impact of COVID-19 lockdown" were used as predictor variables.

2.3.1 Assessment of ML Models:

The developed models were evaluated using different standardized evaluation estimates for each model, with their comparison highlighting potential factors that play a major role in exacerbating distress experienced by parents of individuals with ASD and TD children due to the restrictions imposed by the pandemic. In case of Logistic Regression model, the standardized estimates level of significance (p-value) and Beta (β coefficient) determine the association of potential explanatory variables and the incremental predicted variance for any given set of variables. For Decision Tree and Random Forest, the significance of all individual features were identified using feature importance or Gini importance, which is calculated as the reduction in impurity upon splitting of features at nodes.

3. Results

3.1 Demographic Characteristics:

A total of 51 candidates participated in the study, comprising 21 parents/guardians of children diagnosed with Autism Spectrum Disorder and 30 parents/guardians of typically developing children. Among the parents/guardians of children with ASD, 16 (76.2%) were females, while 5 (23.8%) were males. The mean age of this group was 42.10 years, with a standard deviation (SD) of 10.054 years. In the group of parents/guardians with typically developing children, 22 (73.3%) were females, while 8 (26.7%) were males. This group had a mean age of 38.80 years, with an SD of 8.323 years. The statistical evaluation of categorical variables using Chi-square tests, shows that only the variable "Child's Gender" exhibits a statistically significant variation in distribution (p=0.007) between individuals with ASD and those in the typically developing group. Regarding continuous variables, t-test was used for comparative analysis. The statistical evaluation indicates that the variables "Participant's Age" and "Child's Age" showed insignificant difference between the means of ASD and TD cases. The characteristics of the sample along with the results of the comparisons between the two groups are presented in Table 1.

Table 1: Descriptive and comparative analysis of demographics of ASD and TD samples

Variable	Categories	ASD cases (n=21)	TD cases (n=30)	Comparisons	p-value
Participant's Gender n (%)	Male	5 (23.8%)	8 (26.7%)	X^2 (1)=0.053	p=0.818
	Female	16 (76.2%)	22 (73.3%)		
Participant's Age M (SD)		42.10 (10.054)	38.80 (8.323)	t(49)=-1.277	p=0.208
Place of living n (%)	City	18 (85.7%)	27 (90%)	X^2 (1)=0.219	p=0.640
	Village	3 (14.3%)	3 (10%)		
Family situation n (%)	Joint Family	5 (23.8%)	12 (40%)	X^2 (1)=1.457	p=0.227
	Nuclear Family	16 (76.2%)	18 (60%)		
Relationship with child n (%)	Father	7 (33.3%)	8 (26.7%)	X^2 (2)=1.850	p=0.396
	Mother	13 (61.9%)	22 (73.3%)		
	Guardian	1 (4.8%)	0 (0%)		
Educational qualification n (%)	Uneducated or under matriculation	1 (4.8%)	3 (10%)	X^2 (2)=3.300	p=0.192
	Matriculation or Intermediate	5 (23.8%)	2 (6.7%)		
	Bachelors or Above	15 (71.4%)	25 (83.3%)		
Monthly income n (%)	Less than 20,000	2 (9.5%)	0 (0%)	X^2 (2)=3.235	p=0.198
	20,000 to 40,000	5 (23.8%)	6 (20%)		
	Greater than 40,000	14 (66.7%)	24 (80%)		
Total children n (%)	1	4 (19%)	5 (16.7%)	X^2 (3)=1.714	p=0.634
	2	2 (9.5%)	7 (23.3%)		
	3	11 (52.4%)	14 (46.7%)		
	=>4	4 (19%)	4 (13.3%)		
Child's Age M (SD)		8.69 (3.509)	10.83 (5.032)		
Child's gender n (%)	Male	17 (81%)	13 (56.7%)	t(49)= 1.684	=0.099
	Female	4 (19%)	17 (43.3%)	X^2 (1)=7.217	p=0.007
Child's educational status n (%)	At Home	6 (28.6%)	2 (6.7%)		
	Regular School	6 (28.6%)	28 (93.3%)		
	Special School	9 (42.9%)			
Symptoms n (%)	Mild	5 (23.8%)			
	Moderate	11 (52.4%)			
	Severe	5 (23.8%)			
Type of therapy child is receiving n (%)	Rehabilitation Center	6 (28.6%)			
	Home guidance Therapy	1 (4.8%)			
	Private therapy	2 (9.5%)			
	Other	12 (57.1%)			
Parental exposure to Covid-19 M (SD)		2.42 (1.71)	2.16 (1.51)		
				t(49)=-0.576	p=0.568

3.2 Parental Exposure to COVID-19:

The second section of the survey, "Parental Exposure to COVID-19," underwent both descriptive and comparative analyses (Table 1). A cumulative score was derived from the items, signifying parental exposure levels in both ASD group (M = 1.84; SD = 1.650; range 0–5) and the TD group (M = 0.86; SD = 0.690; range 0–5). This cumulative score, indicating exposure intensity, was calculated by summing the individual item scores. The comparison of the cumulative scores was conducted using an independent t-test (t = 0.576, p = 0.568). Notably, the calculated p-value for the Parental

Exposure score was greater than the 5% significance level, representing a statistically insignificant difference in means between the ASD and TD cases. This shows that the extent of parental exposure was not affected by the neurological state (ASD or TD) of the children.

3.3 Impact of COVID-19 Lockdown:

A significant percentage of parents reported that during the lockdown period, they sometimes faced challenging situation in managing various aspects of daily life activities (Table 2).

Table 2: Descriptive statistics of Impact of COVID-19 lockdown

Dimensions	Variables	Not at all	Sometimes	Often	Very Much
Daily routines	Meal	23.5%	**45.1%**	17.6%	13.7%
	Free-time	19.6%	**35.3%**	31.4%	13.7%
	Sleep routine	29.4%	**31.4%**	27.5%	11.8%
Educational condition	Online tools	31.4%	**41.2%**	17.6%	9.8%
	School work	15.7%	**49%**	15.7%	19.6%
Social development	Social interaction	19.6%	25.5%	**33.3%**	21.6%
Economic /Employment Condition	Work	23.5%	**39.2%**	9.8%	27.5%
	Finances	27.5%	**37.3%**	11.8%	23.5%
Behavior issues	Aggression	13.7%	**45.1%**	13.7%	27.5%
	Temper issues	15.7%	**49%**	17.6%	17.6%
Child's Physiological Distress	Fears	27.5%	**51%**	17.6%	3.9%
	Anxiety	**35.3%**	33.3%	25.5%	5.9%

Furthermore, the comparison of COVID-19 impacts on both ASD and TD groups was done by performing independent sample t-test between the proposed 6 categories of this section. A cumulative score for each category was obtained by summing the individual item scores, with greater score indicating greater difficulty regarding that aspect during lockdown. Results of comparisons are shown in Table 3, which indicate that a significant difference exists in means of three categories i.e. daily routines, social development, and behavior issues ($p<0.05$) among ASD and TD group. This shows that parents of ASD children faced more daunting challenges in managing their child's daily routine, social development and behavior issues as compared to parents of TD children.

Table 3: Comparative analysis of Impacts of COVID-19 lockdown

Categories	Group	Mean	T	p-value
Daily routines	**TD**	**3.13**	**-2.50**	**0.01**
	ASD	**4.80**		
Educational condition	TD	2.30	-0.71	0.48
	ASD	2.66		
Social development	**TD**	**1.23**	**-2.99**	**0.004**
	ASD	**2.04**		
Economic/ working condition	TD	2.26	-1.89	0.06
	ASD	3.38		
Behavior issues	**TD**	**2.16**	**-3.88**	**0.001**
	ASD	**4.00**		
Child's physiological distress	TD	1.70	-1.72	0.09
	ASD	2.42		

3.4 Behavioural Problems among ASD children before and during Lockdown:

For the comparison of children's behavioral problems prior to and during the lockdown, paired-sample t-tests were conducted. The results presented in the Table 4 demonstrate significant distinctions concerning parental perceptions of children's aggressive behaviors, repetitive behaviors, and the transition between activities.

Table 4: Paired Samples test between children's behavioral problems before and during lockdowns

	Paired items	Mean	Std. Deviation	T	P –value
Pair 1	Was your child aggressive towards him/herself before the lockdown? - Was your child aggressive towards him/herself during the lockdown?	-0.810	0.680	-5.458	**0.000**
Pair 2	Did your child show repetitive behaviors before the lockdown? - Did your child show repetitive behaviors during the lockdown?	-0.619	0.590	-4.812	**0.000**
Pair 3	Had your child faced difficulties in managing the transition from one activity to another before the lockdown? - Had your child faced difficulties in managing the transition from one activity to another during the lockdown?	-0.905	0.768	-5.396	**0.000**

Children showed more aggressive and repetitive behaviors towards themselves during the lockdown compared to before it. The tests indicate a significant difference with p-values of 0.000. This suggests that the increase in aggressive and repetitive behaviors during the lockdown is unlikely to be a random occurrence. Similarly, significant differences were found regarding the transition from one activity to another. Children with ASD faced more difficulties in this regard during the lockdown compared to before it, with a statistically significant result (p-value = 0.000). This suggests that the increase in transition between activities during the lockdown is unlikely to be a random occurrence.

3.5 ASD Support during COVID-19 Lockdown:

Following the emergency outbreak, a substantial portion of parents indicated their partial dissatisfaction with the available support from local and private healthcare services, as well as support from educational centers. The majority of these parents expressed disagreement (Hospitals/rehabilitation centers: Disagree = 47.6%, Therapist/doctors: Disagree = 57.1%, Schools/academic centers: Disagree = 38.1%, Private tutors/teachers: Disagree = 42.9%) during the pandemic. Conversely, a slightly lesser proportion of parents showed agreement for each type of support (Hospitals/rehabilitation centers: Agree = 33.3%, Therapist/doctors: Agree = 23.8%, Schools/academic centers: Agree = 28.6%, Private tutors/teachers: Agree = 28.6%) during the emergency outbreak.

3.6 Maternal Stress:

This section of the questionnaire facilitates the assessment of distress experienced by mothers throughout the COVID-19 period, which, in the context of this study, aligns with the lockdown timeframe. The total distress score in parents was calculated as the mean of all items of DASS 21. This score represents higher levels of distress as reflected by elevated scores. Moreover, the independent samples t-test indicates a significant difference in paternal distress between the two distinct groups (ASD and TD). Table 5 shows that the p-value falls below the 5% threshold of significance ($t(49) = 2.618$, $p = 0.012$) suggesting that mothers of children with ASD ($M = 16.4$; $SD = 9.97$) experienced higher levels of distress in comparison to mothers of TD children ($M = 9.83$; $SD = 7.99$).

Table 5: Independent sample t-test for comparison between maternal stress in ASD and TD parents

Variable	Mean		t	p-value
Total Distress Score	TD	9.83	2.618	**0.012**
	ASD	**16.43**		

3.7 Model Development:

After analysis and comparison of the results, one of the primary objectives of this survey based research is to find out the features that are significant in increasing parental distress with the help of developing various models i.e. Linear

Regression, Logistic Regression, Decision Tree, and Random Forest. For this purpose, the distress score was converted in to categorical variable of "level/ severity of distress". Levels of parental distress calculated from the score are described in Table 6.

Table 6: Levels of maternal distress calculated from the score

Levels of Distress	Distress score
Normal	0-9
Mild	10-13
Moderate	14-20
Severe	21-27
Extremely Severe	28+

For modeling, the level of distress is further converted in to binary variable with only two categories, i.e. Normal to Moderated (encoded as 0) and Severe to Extremely Severe (encoded as 1). The comparison of binary distress level using chi square test shows significant difference in distribution between ASD and TD groups as shown in Table 7. The continuous variable "Total Distress Score" was used as outcome feature for development of linear regression models. Whereas, for all the other models categorical variable "Binary level of distress" was used as dependent feature.

Table 7: Chi-square test for comparison between binary levels of maternal Distress in ASD and TD groups

Variable	Categories	ASD N (%)	TD N (%)	Chi-square	p-value
Binary level of distress	Normal to Moderate	12 (57.1%)	26 (86.7%)	5.669	0.017
	Severe to Extremely Severe	**9 (42.9%)**	**4 (13.3%)**		

3.7.1 Development of Logistic Regression models:

Two binary Logistic Regression models were also developed using Enter method in SPSS software. The significance and insignificance of variables were estimated using Wald value, Wald significance value (p value), and odds ratio (Exp (B)). The details of theses regression models to determine the association of predictor variables with dependent variable (Binary level of distress) are discussed in Tables 8 and 9.

Table 8: Outcome of Binary Logistic Regression using demographic variables (Model I)

Variables	B	Wald	p-value	Exp(B)
Participant Gender	-20.688	.000	.999	.000
Participant's Age	-.062	.250	.617	.940
Place of living	-1.821	1.159	.282	.162
Family situation	-.547	.250	.617	.578
Relationship with child	21.889	.000	.999	3207993821.357
Educational qualification	-2.936	5.421	**.020**	**.053**
Family Monthly income	3.539	4.407	**.036**	**34.446**
Total children	.047	.005	.944	1.048
Child's Age	.002	.000	.991	1.002
Child's gender	-2.554	2.819	.093	.078
Child's educational status	.477	.338	.561	1.611
Severity of Symptoms	.773	1.307	.253	2.165
Type of therapy child is Receiving	-1.159	4.777	**.029**	**.314**
Group Label (TD /ASD)	1.584	5.197	**.023**	**4.875**
Note: Accuracy = 82.4, X^2 = 24.410, p= 0.028				

Table 9: Results of logistic regression model using PE and impacts of COVID-19 (Model II)

Variables	B	Wald	p-value	Exp(B)
Parental Exposure Score	.331	1.277	.258	**1.392**
Daily routines	.714	6.703	**.010**	2.041
Educational condition	-.015	.003	.959	**.985**
Social development	-.258	.178	.673	**.773**
Economic/working Condition	.142	.341	.559	**1.153**
Behavior issues	.031	.010	.920	**1.031**
Child's physiological Distress	-.191	.329	.566	**.826**

Note: Accuracy= 82.4, X^2 = 15.569, p= 0.029

The results of the developed models reveal that variables including educational qualification, family monthly income, type of therapy child is receiving, group label, and daily routines significantly influenced maternal distress.

3.7.2 Development of Decision Tree and Random Forest models:

The same process has been repeated for Decision Tree and Random Forest models, where the association of demographic features and features of parental exposure and impact of lockdowns with the target feature (binary level of distress) has been evaluated separately. Features with non-zero feature importance were selected as best features. Detailed outcomes of all the developed models are discussed in Tables 10 to 13.

Table 10: Outcome of Decision Tree with demographic features (Model I).

Feature	Importance
Participant's age (years)	0.43
Child's educational status	0.33
Symptoms	0.13
Child's age	0.09
Group Label (TD / ASD)	0.07
Gender	**0**
Place of living	**0**
Family situation	**0**
Relationship with child	**0**
Educational qualification	**0**
Family monthly income (PKR)	**0**
Total children	**0**
Child's gender	**0**
Type of therapy child receiving	**0**

Note: Accuracy of model = 0.69

Table 11: Outcome of Decision Tree with features of PE and Impact of COVID-19 Lockdowns (Model II).

Name	Importance
Daily routine	0.34
Social development	0.18
Parental Exposure Score	0.15
Child's physiological distress	0.12
Educational condition	0.10
Behavior issues	0.08
Economic/ working condition	**0**

Note: Accuracy of model = 0.76

Table 12: Outcome of Random Forest with demographic features (Model I).

Name	Importance
Child's educational status	0.45
Family monthly income	0.14
Relationship with child	0.11
Family situation	0.04
Child's gender	0.04
Type of therapy child receiving	0.04
Group Label (TD / ASD)	0.04
Child's age	0.04
Severity of Symptoms	0.04
Total children	0.03
Participant's Age	0.03
Participant's Gender	**0**
Place of living	**0**
Educational qualification	**0**
Note: Accuracy of model = 0.84	

Table 13: Outcome of Random Forest with features of PE and Impact of COVID-19 Lockdowns (Model II).

Name	Importance
Daily routine	0.29
Social development	0.17
Educational condition	0.15
Child's physiological distress	0.13
Parental Exposure Score	0.10
Economic/ working condition	0.07
Behavior issues	0.04
Note: Accuracy of model = 0.69	

3.8 Comparative analysis

A comparative analysis of all the developed models has been performed to identify the survey features which significantly associated with parental distress. The demographic variables that are selected by majority of the developed models (2 or more) include Participants age, family monthly income, child age, child education status, severity of symptoms, and the type of therapy child is receiving are both statistically significant and have high feature importance (Table 14). Table 15 demonstrates the selection of significant features from the second subset of features in parental distress. These features include parental exposure score and daily routine of children.

Table 14: Significant features revealed by all models trained on demographic features.

Features	Logistic Regression	Decision Tree	Random Forest	Selected
Participant Gender	×	×	×	**0/3**
Participant's Age	×	✓	✓	**2/3**
Place of living	×	×	×	**0/3**
Family situation	×	×	✓	**1/3**
Relationship with Child	×	×	✓	**1/3**
Educational Qualification	✓	×	×	**1/3**

Family Monthly Income	✓	×	✓	**2/3**
Total children	×	×	✓	**1/3**
Child's Age	×	✓	✓	**2/3**
Child's gender	×	×	✓	**1/3**
Child's educational Status	×	✓	✓	**2/3**
Severity of Symptoms	✓	✓	✓	**3/3**
Type of therapy child is receiving	✓	×	✓	**2/3**

Table 15: Significant features revealed by all models trained on features of PE and Impact of COVID-19 Lockdown.

Features	Logistic Regression	Decision Tree	Random Forest	Selected
Parental Exposure Score	×	✓	✓	2/3
Daily routines	✓	✓	✓	3/3
Educational Condition	×	✓	✓	2/3
Social development	×	✓	✓	2/3
Economic/ working Condition	×	×	✓	1/3
Behavior issues	×	✓	✓	2/3
Child's physiological Distress	×	✓	✓	2/3

3.9 Open response Questions

Nearly all the survey participants responded to the open-ended question. The predominant response, indicated by 37.3% of participants, was "nothing," indicating that many participants did not perceive additional challenges other than those already mentioned in the questionnaire. This was followed by the response "lack of financial family support" at 17.6%. In regards to strategies to manage such global emergencies, the most frequent response was "proper planning instead of a complete lockdown," mentioned by 37.3% of participants followed by higher demand for "awareness programs and proper planning to educate and train people to deal with such emergencies" at 35.3%.

4. Discussions

The COVID -19 pandemic and lockdowns have led researchers throughout the world to investigate its consequences on vulnerable populations especially children with ASD and their parents. Overall, the results of the present research showed that complete/smart lockdown were more emotionally and mentally challenging for children with Autism Spectrum Disorder and their families as they reported a higher frequency of challenges and difficulties over the course of the pandemic. The survey highlights significant increase in behavior problems among ASD children during lockdown period as compared to before it and the dissatisfaction of parents with the availability of ASD support during the crisis. Other similar studies from various regions of the world also report an increase in behavioral and sensory problems in ASD children before and during or after lockdowns (Althiabi, 2021; Colizzi et al., 2020; Fazil et al., 2023; Isensee et al., 2022). It was already well known that the stress level of parents of ASD children is greater than the parents of typically developing children because of additional parenting challenges. Moreover, pandemic implication increases burden on parents/caregivers of ASD children as the constant monitoring of the children can become increasingly overwhelming and stressful. Therefore, the most relevant finding of this study confirmed the increased parental distress in Parents of ASD children as compared to the TD group during the lockdown phase. This study also highlights the areas that significantly contribute to heightened parental distress. Factors including monthly income, severity of ASD symptoms, type of therapy child is receiving, parental exposure to COVID-19, and the impact of

COVID-19 on daily routines of ASD children and their families play a role in impacting parental stress. One similar study from Pakistan also reports that the financial conditions of families had an impact on their level of stress (Ali et al., 2023). A few studies also describe a correlation between the severity of ASD symptoms and parental stress and attribute this effect to the fact that more diligent care and attention is required for children with more intense restrictive and repetitive behaviors (Alhuzimi, 2021; Eshraghi et al., 2022; Lyons et al., 2010). With regards to the factor of "type of therapy child is receiving", it may be inferred that the regular administration of these therapies and their effectiveness at managing ASD symptoms impact parental stress (Isensee et al., 2022). Parental exposure to COVID-19 is a self-explanatory contributor to increased stress owing to the widespread devastation and anxiety perpetuated by the pandemic (Vigo et al., 2020). Lastly, the disruption of daily activities due to lockdowns has also been reported as a contributor to parental stress by other researchers (Levante et al., 2021). Overall, the significant contributing factors elucidated by the ML models in this study are consistent with reported literature regarding ASD and the mental health of parents. Regarding the open response questions in the survey, majority of participants reported the need of financial support, awareness, and proper planning from the government. Almost half of the parents showed disagreement towards stringent restrictions and lockdown during the pandemic. Consequently, the study insists on the importance of interventions designed to assist parents in reducing distress and developing effective coping strategies, particularly for families with ASD.

Certain limitations exist in our study. Firstly, a comparatively small sample size has been used, as the primary data was collected from participants of Islamabad and Rawalpindi only. The impact of COVID-19 should be explored in other cities as well. Secondly, the study is cross-sectional and of retrospective nature as it was conducted during the months of February and July 2023, after some time of the pandemic. This increases the possibility of biasness in results as the parents may not have been able to properly recall the lockdown period. Lastly, less data on female children with ASD was collected, thus making it difficult to understand the impact of COVID-19 lockdowns on ASD female individuals.

5. Future Implications

The pandemic compelled researchers to focus on specific pertinent issues relating to the psychological support of children with ASD and their families in order to assist them in managing their distress and disrupted daily routines. Although ASD is a neurological condition, some family and environmental factors can influence outcomes (Lord et al., 2020). For instance, the mental health of parents during the pandemic effects parenting behaviors and styles, potentially affecting their child's ASD symptoms and behavioral problems. It was concluded that children with ASD and their families had greater distress as a result of the outbreak, and the prevalence of stereotyped and repetitive behaviors among the children increased compared to the earlier time. Moreover, many of these families received little to no support during COVID-19 lockdown. Consequently, it is essential to provide mental health services and support from the government and community stakeholders to these families during times of crisis to ensure the overall well-being of the family. Research in this area could highlight and contribute to the development of online parent-coaching interventions. The intervention programs might include advice to parents on how to play and engage with their children better, as well as how to speak to them more effectively. These interventions may lessen distress and aid in the development of effective coping mechanisms, and they may also indirectly influence children's adaptive behavior through their emotional regulation. Conclusively, specific attention must be placed on the well-being of families with neurodevelopmental disorders, with a particular focus on parental mental health. Furthermore, long-term effective intervention programs that are targeted towards parents of children with ASD should be promoted around Pakistan especially during such global emergencies.

References

1. Alhuzimi, T. (2021). Stress and emotional wellbeing of parents due to change in routine for children with Autism Spectrum Disorder (ASD) at home during COVID-19 pandemic in Saudi Arabia. Research in Developmental Disabilities, 108, 103822. https://doi.org/10.1016/j.ridd.2020.103822
2. Ali, A., Nauman, M., & Maqbool, S. (2023). Preventive practices and parents' psychological health of children with disabilities after COVID-19 lockdown in Pakistan. Journal of Paediatrics and Child Health, 59(6), 814–821. https://doi.org/10.1111/jpc.16397
3. Althiabi, Y. (2021). Attitude, anxiety and perceived mental health care needs among parents of children with Autism Spectrum Disorder (ASD) in Saudi Arabia during COVID-19 pandemic. Research in Developmental Disabilities, 111, 103873. https://doi.org/10.1016/j.ridd.2021.103873

4. Asbury, K., Fox, L., Deniz, E., Code, A., & Toseeb, U. (2021). How is COVID-19 affecting the mental health of children with special educational needs and disabilities and their families? Journal of Autism and Developmental Disorders, 51, 1772–1780. https://doi.org/10.1007/s10803-020-04577-2
5. Colizzi, M., Sironi, E., Antonini, F., Ciceri, M. L., Bovo, C., & Zoccante, L. (2020). Psychosocial and Behavioral Impact of COVID-19 in Autism Spectrum Disorder: An Online Parent Survey. Brain Sciences, 10(6), 341. https://doi.org/10.3390/brainsci10060341
6. Dhiman, S., Sahu, P. K., Reed, W. R., Ganesh, G. S., Goyal, R. K., & Jain, S. (2020). Impact of COVID-19 outbreak on mental health and perceived strain among caregivers tending children with special needs. Research in Developmental Disabilities, 107, 103790. https://doi.org/10.1016/j.ridd.2020.103790
7. Eshraghi, A. A., Cavalcante, L., Furar, E., Alessandri, M., Eshraghi, R. S., Armstrong, F. D., & Mittal, R. (2022). Implications of parental stress on worsening of behavioral problems in children with autism during COVID-19 pandemic: "The spillover hypothesis." Molecular Psychiatry, 27(4), 1869–1870. https://doi.org/10.1038/s41380-021-01433-2
8. Fazil, H., Nisar, F., & Mushtaq, T. (2023). Differences between the Sensory and Behavioral Problems of Children with Autism Spectrum Disorder before and after Pandemic Condition of Covid-19: Fathers' Perspective. Journal of Development and Social Sciences, 4(2), 49–57.
9. Han, O., Tan, H. W., Julious, S., Sutton, L., Jacques, R., Lee, E., & Walters, S., et al. (2022). A descriptive study of sample sizes used in agreement studies published in the PubMed repository. BMC Medical Research Methodology, 22, Article 242. https://doi.org/10.1186/s12874-022-01723-5 SpringerLink Hertzog, M. A. (2008). Considerations in determining sample size for pilot studies. Research in Nursing & Health, 31(2), 180-191. https://doi.org/10.1002/nur.20247 ouci.dntb.gov.ua
10. IBM Corp. (2011). IBM SPSS Statistics for Windows (Version Version 20) [Computer software]. IBM Corp.
11. Isensee, C., Schmid, B., Marschik, P. B., Zhang, D., & Poustka, L. (2022). Impact of COVID-19 pandemic on families living with autism: An online survey. Research in Developmental Disabilities, 129, 104307. https://doi.org/10.1016/j.ridd.2022.104307
12. Julious, S. A. (2015). A simple formula for the calculation of sample size in pilot studies. Journal of Clinical Epidemiology, 68(12), 1355-1359. https://doi.org/10.1016/j.jclinepi.2015.04.014 PubMed
13. Levante, A., Petrocchi, S., Bianco, F., Castelli, I., Colombi, C., Keller, R., Narzisi, A., Masi, G., & Lecciso, F. (2021). Psychological Impact of COVID-19 Outbreak on Families of Children with Autism Spectrum Disorder and Typically Developing Peers: An Online Survey. Brain Sciences, 11(6), 808. https://doi.org/10.3390/brainsci11060808
14. Lord, C., Brugha, T. S., Charman, T., Cusack, J., Dumas, G., Frazier, T., Jones, E. J., Jones, R. M., Pickles, A., & State, M. W. (2020). Autism spectrum disorder. Nature Reviews Disease Primers, 6(1), 1–23.
15. Lyons, A. M., Leon, S. C., Roecker Phelps, C. E., & Dunleavy, A. M. (2010). The Impact of Child Symptom Severity on Stress Among Parents of Children with ASD: The Moderating Role of Coping Styles. Journal of Child and Family Studies, 19(4), 516–524. https://doi.org/10.1007/s10826-009-9323-5
16. Mumbardó-Adam, C., Barnet-López, S., & Balboni, G. (2021). How have youth with autism spectrum disorder managed quarantine derived from COVID-19 pandemic? An approach to families' perspectives. Research in Developmental Disabilities, 110, 103860. https://doi.org/10.1016/j.ridd.2021.103860
17. McKinney, W. (2022). Python for data analysis. O'Reilly Media, Inc.
18. Munir, D. M. M., Rubaca, U., Munir, M. H., & Munir, B. (2021). An Analysis of Families Experiences with Young Children with Intellectual and Developmental Disabilities (IDDs) during COVID-19
19. Mutluer, T., Doenyas, C., & Genc, H. A. (2020). Behavioral implications of the COVID-19 process for autism spectrum disorder, and individuals' comprehension of and reactions to the pandemic conditions. Frontiers in Psychiatry, 11, 561882. https://doi.org/10.3389/fpsyt.2020.561882
20. Nadeem, M., Arshad, M., & Saleem, H. (2021). Mental health outcomes among parents of children with autism spectrum disorder during COVID-19 pandemic in Pakistan. Pakistan Journal of Medical Sciences, 37(6), 1624–1629. https://doi.org/10.12669/pjms.37.6-WIT.4652
21. Siracusano, M., Segatori, E., Riccioni, A., Curatolo, P., & Mazzone, L. (2021). The impact of COVID-19 on the adaptive functioning, behavioral problems, and repetitive behaviors of Italian children with autism spectrum disorder: Comparison before and during lockdown. Journal of Autism and Developmental Disorders, 51, 459–465. https://doi.org/10.1007/s10803-020-04807-3
22. Vigo, D., Patten, S., Pajer, K., Krausz, M., Taylor, S., Rush, B., Raviola, G., Saxena, S., Thornicroft, G., & Yatham, L. N. (2020). Mental Health of Communities during the COVID-19 Pandemic. The Canadian Journal of Psychiatry, 65(10), 681–687. https://doi.org/10.1177/0706743720926676
23. World Health Organization (WHO). (2022). Autism spectrum disorders. https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders