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An Analysis of Families' Experiences with Young Children with Intellectual and Developmental Disabilities (IDDs) during COVID-19 Lockdown in Pakistan

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Abstract

The shadow impacts of the COVID-19 pandemic are critical, especially for children with intellectual and/or developmental disabilities (IDDs). Financial constraints and home confinement have increased the challenges for caregivers to meet the educational and health needs of children with IDD. Hence, this research examines the impact of COVID-19 lockdown on families with IDD children in rural Pakistan. Overall, 176 parents participated in this study and provided valuable responses through interview technique. Parents responded to five (05) open-ended questions. Results indicated that parents of children with IDD are facing various challenges including financial constraints, social lockdown, deteriorated health conditions of their children, reduced or no health services, closure of educational institutes, negative behavioral impacts, and slow mental development. Still, a subset of parents also reported the positive side of lockdown, indicating that staying at home resulted in improved relationships. The findings of the study suggest that parents of children with IDD are confronted with significant challenges that increase their stress.

Keywords: COVID-19, lockdown, pandemic, children, Pakistan

Un Análisis de la Experiencia de Familias con Niños Pequeños con Discapacidades Intelectuales y del Desarrollo (IDD) durante el Confinamiento por COVID-19 en Pakistán

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Resumen

Los impactos oscuros de la pandemia de COVID-19 son críticos, especialmente para niños y niñas con discapacidades intelectuales y/o del desarrollo (IDD). Las limitaciones financieras y el confinamiento en el hogar han aumentado los desafíos para que los cuidadores satisfagan las necesidades educativas y de salud de los niños con IDD. Esta investigación examina el impacto del confinamiento por COVID-19 en familias con niños con IDD en las zonas rurales de Pakistán. 176 padres y madres participaron en este estudio y proporcionaron respuestas valiosas en entrevistas. Los padres y madres respondieron a cinco preguntas abiertas. Los resultados indicaron que se enfrentan a varios desafíos, que incluyen restricciones financieras, bloqueo social, deterioro de las condiciones de salud de sus hijos, servicios de salud reducido o nulo, cierre de instituciones educativas, impactos negativos en el comportamiento y desarrollo mental lento. Aún así, un subconjunto de padres también informó el lado positivo del encierro, lo que indica que quedarse en casa resultó en mejores relaciones. Los hallazgos sugieren que los padres de niños con IDD se enfrentan a desafíos importantes que aumentan su estrés.

Palabras clave: COVID-19, confinamiento, pandemia, niños, Pakistán

A The COVID-19 pandemic has been deemed not only the most significant worldwide health crisis of today, but the greatest global challenge since World War II (Roesch, Amin, Gupta & Moreno, 2020). The COVID-19 virus has affected individuals on all continents of the globe (Neece, McIntyre & Fenning, 2020). The medical science community has struggled to create the cure against COVID-19 and ended up with the formula of social distancing and preventive steps to avert its spread (World Health Organization, 2020). Besides posing the greatest health challenge, COVID-19 has also provided the unprecedented socio-economic crisis (Centres for Disease Control, 2020). Stressing developed countries in general and developing states in particular, COVID-19 has the potential to generate negative social effects which will leave longstanding and deep scars (Adom, 2020; Fontanesi et al., 2020; Schuengel, Tummers, Embregts & Leusink, 2020).

Closing down of schools and day care centres due to COVID-19 lockdown has put extra pressure on the parents to teach their children at home in addition to managing the caregiving duties, family activities, and work needs (Neece et al., 2020; Özdemir & Kerse, 2020; Redquest, Tint, Ries & Lunskey, 2021). According to Fontanesi et al. (2020), working parents have reported implausible strain on their resources, time, and efficiency to manage the everyday needs of home schooling and parenting. Moreover, researchers have documented the negative effect of COVID-19 lockdown on mental health (Almeida, 2020; Mazza et al., 2020; Zaagsma et al., 2020). According to a recent survey, the psychological effects of COVID-19 lockdown upon families, mainly include financial stress, boredom, stigma, confusion, frustration, anger, and post-traumatic stress symptoms (Brooks et al., 2020; Pulido Rodríguez, Villarejo Carballido, Redondo Sama, Guo, Ramis & Flecha, 2020).

Youth, particularly children, are also the victims of these psychological effects (Redquest, Tint, Ries & Lunskey, 2020). This is evidenced by the negative impact of COVID-19 lockdown on youth (aged between 3 to 18 years) reported in a study conducted in Italian and Spanish families (Orgiles et al., 2020). In a sample of 1143 families, 85.7 percent reported that due to shutdown of schools, the child's social interaction has been restrained and their emotional state has altered. Children are becoming subject to irritability,

boredom, impatience, learning difficulty, and nervousness. Besides, these increasing emotional symptoms of children exacerbate the parenting stress (Orgiles et al., 2020). These findings affirm the philosophy of interdependence in parent-child adjustment and transactional parent-child effects on substantial negative worldly activities for example, natural disasters (Juth et al., 2015; Özdemir & Kerse, 2020).

In developing countries, particularly Pakistan, the negative impact of COVID-19 is still unfolding and less is known about it. Thus, limited knowledge is available to see the psychological effects on households having children with intellectual and developmental disabilities (IDDs). Existing literature in European context argued that the negative impact of COVID-19 is more on parents caring for children with IDD's in comparison to the general population (Nearchou, Flinn, Niland, Subramaniam & Hennessy, 2020; Neece et al., 2020). For instance, a survey was conducted by Fontanesi et al. (2020) on a sample of 1126 families to understand the COVID-19 impact on families in Italy. The outcomes suggested that parents of children with physical or mental disabilities perceived less social support and signify a high degree of parental burnout in comparison to parents of children with no handicap. Moreover, parents of children with physical or mental disabilities have reported psychological changes in their child's behavior such as inability to concentrate, general discomfort, distractibility, and fussiness. Thus, Fontanesi et al.'s (2020) study concluded that COVID-19 pandemic has increased stress on parents of children with physical or mental impairments.

The associated disorders in routine and obvious implausibility due to COVID-19 pandemic may be adverse particularly for children with IDD's (Nearchou et al., 2020; Redquest et al., 2021). Before this pandemic, life for children with IDD's was with clear expectations, heightened structure, and an array of services (Ho, Perry & Koudys, 2021; Mazza et al., 2020). However, the substantial changes in the routine during the pandemic may be difficult to absorb by these children, thus aggravating parents' stress levels (Brooks et al., 2020; Schuengel et al., 2020). Parents of children with IDD's are required to execute diverse functions for their children during this pandemic, mainly speech-language pathologist, social skills coach, special educator, and behavioral health therapist (Eshraghi et al., 2020; Jeste et al., 2020). This is because intensive support and services are needed for children with IDD's (McIntyre, 2020; Nearchou et al., 2020). The intensive support and services

become the exclusive duty of the parents and it generally includes specialized coaching in the pattern of speech therapy, physical therapy, behavioral programming, special training, and social skills tutoring (National Research Council, 2001). This eventually intensifies the degree of stress on parents (Neece et al., 2020; Zaagsma et al., 2020). Even in the absence of this pandemic, parents of children with IDD struggle with the parenting stress (Almeida, 2020; Ho et al., 2021; Woodman, Mawdsley & Hauser-Cram, 2015). Children's challenging behavior is another factor which heightens parenting stress (Baker, McIntyre, Blacher, Crnic, Edelbrock & Low, 2003), which affects the parents' adjustment and vice versa (Shivers, 2019; Woodman et al., 2015).

Developing nations like Pakistan hold additional challenges for parents of children with IDDs due to their weak economic and legislative structure (Shafi, Liu & Ren, 2020). According to World Health Organization (2020) estimates, 15 percent of Pakistan's children population consists of children with IDDs and the country struggles to mainstream the limited constitutional cover and sketchy definitions for children with IDDs. Parents of children with IDDs challenges escalates in Pakistan due to deficiency of government funding in terms of policy making (Shafi et al., 2020). Since 1960s, the regime in the country is unable to establish consensus over the internal definition of children with IDDs. And after 18th Amendment, the central governmental control for policy making in Pakistan has declined and provinces failed to draft the national definition of children with IDDs in accordance with the UN Convention on the Rights of People with Disability.

Therefore, considering these contextual risks that parents of children with IDDs are facing, particularly those families having financial constraints, and physical/mental health challenges of the COVID-19, the present study attempts to investigate the parents' perspectives of COVID-19's impact in a sample of families of children with IDDs living in the rural part of Pakistan.

Method

Pakistan has a population of 220 million. 70% of the country's population resides in the rural part of the country, which differs socio-cultural and economic from the urban part. The income level is generally low and the

primary income earners are associated with the agricultural sector. In addition to the national language, people in rural areas prefer to speak their native language and practice a different culture from other villages. A sample of 176 parents of children (aged between 3 to 5 years) with IDD from rural areas of two principal cities (Lahore and Karachi) of Pakistan participated in the present study. These two cities were selected since both (Lahore and Karachi) are the central capitals of highest population provinces (Punjab and Sindh respectively) in the country. Both of these provinces are technologically more advanced than other provinces and have a mixed cultural approach to the country. People are comparatively educated and understand the living standards of the country.

Maximum variation sampling technique was used to select the present study participants. In Pakistan, community health workers (CHWs) system exists. CHWs' primary role is to offer basic health care facilities as well as information to the families to meet with the daily health-related challenges, particularly to women in rural parts of the country. For this reason, CHWs were contacted to identify and approach the families with children with IDD. The present study therefore used the stratified random sampling technique to identify such families and they are readily available for study participation (Neece et al., 2020). 235 parents of children with IDD were approached in the rural parts of Lahore and Karachi. Ultimately, 176 parents agreed to participate in the research study. The decline rate was 25 percent. The major grounds of refusal were due to hesitation to participate in any research study, COVID-19 social distancing measures, time constraints, and frustration with government policies. The interview technique was used to collect the relevant information and open-ended interview questions were asked to gather maximum input.

Informed consent for voluntarily participation in the present research was also taken from the families. 176 families' interviews were conducted in their houses as per their convenience due to COVID-19 movement restriction. Each interview lasted from 30 to 40 minutes and they were audio recorded for further coding. The total duration for collection of information of the present research comprised of 6 months (July to December, 2020). The following modified questions were adopted from study of Neece et al. (2020) and questioned in native language (Urdu) to the parents of children with IDD;

1. Please explain your life experience and major difficulties during COVID-19 lockdown in the country.
2. What effects COVID-19 has brought to your children with IDD and their life?
3. Have you received any benefits or services for your children with IDD during this pandemic?
4. What strategies have you adopted to cope with the COVID-19 challenges?
5. How do you see the long-term impacts of COVID-19 pandemic on your family life?

Considering the social norms and boundaries of the women in the rural parts of the country, one female interview assistant was recruited from the university in Lahore. After imparting necessary training to the interview assistant, the interviews were conducted with the parents of children with IDD. After collection of necessary information from the interviews, the recorded interviews were transcribed through NVIVO-10 software for qualitative data analysis (Neece et al., 2020). All interviews were then analyzed carefully to generate nodes and coding of information into relevant nodes. This systematic review of interviews enabled generation of themes for summary (Berg, 2009; Corbin & Strauss, 2008). In order to achieve greater accuracy in generating themes, the principal researcher and interview assistant independently coded the interview responses according to interview questions (Neece et al., 2020). The reliability among the two coders was then checked and to remove any disagreements in the ratings, the coders' discussion was carried out to reach consensus. Hence, the two independent coder reliability improved and correlation coefficients of 0.95 was reached. The discussion of the present research is based on the consensus codes and they are reported descriptively.

Participants' Demographics

From the present study participants (176 parents), the majority were mothers of children with IDD (77.27%). Table 1 represents the complete demographics of the study participants. The majority of participant were married (90.91%) with 2 or more children. The majority of children with IDD

in the present study sample were male (68.18%) and diagnosed with intellectual impairment.

Table 1.

Sociodemographic Characteristics of In-depth Interviews (N=22) Participants

Demographic Variable	n	%
Parents Characteristics		
Age		
Less than 30 years	16	9.09
30 to 40 years	136	77.27
More than 40 years	24	13.64
Gender		
Mother/Female	136	77.27
Father/Male	40	22.73
Marital Status		
Married	160	90.91
Single Parent	16	9.09
Family Monthly Income (PKR)*		
Less than 20,000	72	40.91
20,000 to 40,000	64	36.36
More than 40,000	40	22.73
Education		
No Schooling	8	4.55
Up to 10 years of Schooling	56	31.82
More than 10 years of Schooling	112	63.64
Source of Income		
Private Sector Job	88	50.00
Government Sector Job	56	31.82
Own Business	32	18.18
Number of Children		
0 to 2 Children	8	4.55
3 to 4 Children	120	68.18
More than 4 Children	48	27.27
Child Characteristics		
Age		
Less than 02 years	16	9.09
3 to 4 years	144	81.82
More than 4 years	16	9.09
Gender		
Male	120	68.18
Female	56	31.82

* 01 USD = 165 PKR

Table 2.

Parents Challenges and difficulties during COVID-19 lockdown (n=176)

Type of Challenge	n	%	Illustrative Quote
Financial Constraint			
Losing Job and Closing Down of Businesses	48	27.27	"The job helps to earn the basic necessities of life. COVID-19 makes it difficult to keep up with your monthly salary"
Expensive Medical Facilities	24	13.64	"Medication and other associated facilities were employed to be approachable, but at present they are really expensive to buy"
Accessibility to Consumable Items	16	9.09	"The lockdown has offered the shortage of consumable items supply at the stores thus, making them expensive for a home"
Inadequate Govt. Funding	8	4.55	"In the absence of Govt. level support, it has become so hard to oversee the events relevant to my child with IDDs"
Staying at Home			
Balancing Work	8	4.55	"My spouse use to work wholeheartedly for the family, but now my spouse stays more at home due to lockdown and feels demotivated"
Changes in Routine	8	4.55	"I use to wake up ahead of time in the morning and use to go for exercise, but the lockdown is changing my everyday procedure and increased my sleeping habits"
Childcare	16	9.09	"It has become difficult to offer the good childcare at home rather we use to give them at day care or at hospitals"
Boredom for Kids	8	4.55	"Due to closure of public places and parks, my kids feels boredom at home. Kids use to play with other children at the parks, but now no such routine"
Health Conditions			
Avoidance of COVID - 19	24	13.64	"The major challenge which I see is to keep the health conditions upright and to avoid the COVID-19 in our home as it has no cure"
Disparity in Child's daily routine			
Child's Behavior	16	9.09	"At that place is a substantial impact of COVID-19 lockdown on the child's behavior because they feel frightened and irritated while staying at home"

Results

Major Difficulties during COVID-19 Lockdown

Parents were asked to identify the most difficult aspects of COVID-19 lockdown. Table 2 provides the difficult things identified by the parents during interviews. The most frequent issue identified was the financial constraint during the pandemic. Among those parents who identified the financial constraint, the bulk (27.27%) said that losing their job and closing down of businesses were most challenging in order to satisfy the basic demands of households, followed by the need for expensive medical facilities (13.64%) due to limited medical workforce in hospitals. Other challenges relevant to financial constraints identified include accessibility to consumable items (9.09%) and inadequate government funding (4.20%). Parents of children with IDD's also reported that staying at home has created challenges relevant to balancing work, changes in routine, childcare, and boredom for their children. All this new challenging routine generated the stoppage of development services for children with IDD's and scarcity of progressive educational demands. Moreover, a few parents (13.64%) emphasized the health conditions and avoidance of COVID-19 for their children with IDD's as of central importance. Lastly, a subset of parents (9.09%) stated that COVID-19 has offered the substantial changes in the child's behavior due to a disparity in the child daily routine and inability to leave the house.

COVID-19 Effects on Children with IDD's and their Life

The parents in the rural parts of the two cities (Lahore and Karachi) reported that children with IDD's are suffering the most. The behavior of the children has changed due to spending the majority of their time at home. The children with IDD's use to visit coaching and educational centres where they had the opportunity to interact with other children. However, COVID-19 restrictions have isolated these children in homes and their learning abilities have declined (54.55%). Table 3 provides the percentage of feedback received from various parents regarding the effects of COVID-19 on children with IDD's.

Table 3.

COVID-19 Effects on Children with IDD and their Life (n=176)

Type of Challenge	n	%	Illustrative Quote
Educational Services			
Reduction in Learning Capabilities	96	54.55	"My child used to earn many new things at coaching school. However, COVID-19 has taken our hopes for his fast recovery"
Inadequate Health Education and Services	40	22.73	"We receive limited and challenging health education for children with IDDs in the rural regions of the metropolis"
Decrease in Services			
Limited Social Interaction	24	13.64	"My child is stuck at home. She has many friends at school. However, COVID-19 has restricted her social interaction with her friends and learning habits"
Closure of Health Facilities	16	9.09	"The basic health facilities have stopped all operations and engaged in fighting against COVID-19 thus created a challenge for us"

Perceived Benefits for Children with IDDs during COVID-19

The parents reported that in rural parts of the country, the government support was available inadequately (95.45%). Government owns a basic health facility network in the fringes of the rural areas where hospital services are not approachable. Still, these basic health facilities were lacking medical staff as well as resources to counter the pandemic. Even the new-born child vaccination was stopped, and parents had to rely on private hospitals, which were expensive to impose for a financially challenged family.

On the other hand, the time parents had with the children at home was beneficial in various ways during the pandemic as shown in Table 4. For example, half of the parents reported that they had more chance to interact with their children with IDDs and teach them the basic cultural values of their respective communities (50.00%). Other parents had the opportunity to teach the basic native language skills (31.82%). Moreover, a subset of parents also reported that the children with IDDs have showed development gains because of increased interaction with all household members (18.18%).

Table 4.

Perceived Benefits for Children with IDD's during COVID-19

Type of Benefit	n	%	Illustrative Quote
Governmental Support			
Adequate government health facility	8	4.55	"We experience a basic health facility center in our area and lady health worker occasionally visits our place for our child care instructions"
Inadequate government health facility	168	95.45	"COVID-19 has restricted the movement of the people in the community and therefore, the government temporarily converted all basic health facilities into quarantine centers"
Other Benefits			
Increased interaction and inculcating basic cultural values	88	50.00	"I was mostly in office during the daytime, but now I get the opportunity to play with my child with IDD's and teach her the basic cultural values of our society"
Teaching language skills	56	31.82	"Children learn fast in the growing years. I am practicing and speaking my native language mostly so that my child could also learn it"
Development gains	32	18.18	"Although I have perceived major challenges for my child with IDD's during this lockdown, still due to majority of time at home my child is responding well which is a good news for me"

Coping Strategies

Parents of the children with IDD's were also asked about coping skills parents have adopted during this challenging time of COVID-19. Table 5 describes the response percentages with reference to each coping strategy. Although people residing in rural regions have limited knowledge regarding such coping strategies, parents were still able to develop few based on their experiences and cultural practices to productively engage their children with IDD's.

A range of coping strategies were identified during the in-depth interviews of the parents. The bulk of the respondents talked about the reinforcement system as a major tool as well as meshing with the family members in various enjoyable activities (e.g. playing outside, family games). Additionally, parents also identified eating healthy, exercising, meditation, getting in touch with

other family relatives, and watching entertaining programs on television as helping to act as coping strategies for children with IDD during pandemic.

A subset of parents (18.18%) was not familiar with coping strategies because of limited access to the necessities of life such as basic education, awareness of social rights, medical facilities etc. These parents also identified challenges in terms of financial ability and awareness in order to care for their children with IDD in rural Pakistan.

Table 5.

Coping Strategies for Children with IDD during COVID-19 (n=176)

Type of Benefit	n	%	Illustrative Quote
Reinforcement System	48	27.27	"My child was attending special school prior to the COVID-19 containment. So I set up the same learning schedule for him at home to give him the impression that his routine has not changed."
Engaging in Enjoyable Activities	24	13.64	"Planning various gaming activities with friends and family engages my child with IDD and provides a refreshing attitude in his personality"
Eating Healthy	24	13.64	"Good food and balanced nutrition is a fundamental part of growing and grooming children. I am therefore focusing on developing good eating habits for my IDD-affected child so that she can develop a good mental health"
Exercising	16	9.09	"I take my child to our fields and we do various exercises in the mud so that my child feels entertained and can also be physically fit".
Meditation	8	4.55	"I speak to my child every day and every night about the positive side of life, engaging his mind to reflect on the optimistic side of life so he feels more confident".
Getting in Touch with Other Relatives	8	4.55	"I take my child with IDD to visit the related neighbouring houses and we spend time so that his environment changes and he should not feel like his movement is limited to home only".
Watching Entertaining Programs	16	9.09	"I find quality time during this lockdown to see various entertaining programs, particularly cartoons with my child at home. Practicing this, he passes his time with me equally comfortably as he sees his favourite cartoons"

Table 6.

Long Term Impacts for Children with IDD’s during COVID-19 (n=176)

Type of Benefit	n	%	Illustrative Quote
Changes in Emotional Status			
Engagement at Schools and Hospitals	48	27.27	“My child was used to spending quality time in school where his learning abilities were increasing. However, his emotional condition is changing because of his more time at home now.”
Practical and Social Skills	40	22.73	“As my child stays at home more often because of a pandemic, his practical and social skills are affected. It makes him feel alone and sad”.
Behavioral Status			
Feelings of Happiness and Sadness	24	13.64	"Since the lockdown has started, my child’s behavioral conditions have shifted significantly. She is more sad and irritated".
Mental Growth	16	9.09	“My child’s mental growth has been affected by a lack of education. He has become lazy and now his interests in learning new words have fallen”
Other Long Term Impacts			
Social Changes	24	13.64	“As a result of the change in routine of all the surrounding activities, my child began to feel that he is in a different state of time where most of the people around him are ill. He understands the fear of the COVID-19 virus.”
No Impact	24	13.64	"The COVID-19 pandemic is a temporary illness that does not impact the life of my child with IDD’s."

Long-Term Impact

During the interviews, parents were also asked how they perceived the long-term impact of COVID-19 on the lives of children with IDD’s. Table 6 describes the response percentages of the long-term effect of COVID-19. Few parents (13.64%) reported that the pandemic would have no impact on children with IDD’s.

Most parents described changes in the emotional status of children with IDD’s due to pandemic lockdown. Children were engaged in various activities in schools and hospitals for grooming (27.27%) and to address challenges

related to physical and mental impairment. However, pandemic lockdown resulted in children staying at home, which affected their understanding of practical and social skills (22.73%). In addition, parents have also identified the behavioral status of children with IDD as a major concern. Behavioural status is usually derived from a child's feelings of happiness and sadness (13.64%). Children with IDD respond positively if they are happy and excited with their new routine, particularly, staying at home and spending time with family members. In addition, few parents (9.09%) reported that if lockdown continued longer (e.g. 6 months longer) the pandemic would have a wide range of negative impacts on children with IDDs. In particular, parents expressed that if special schools for children failed to resume, a lack of developmental and educational progress would have long-term impacts on children's mental growth.

The social changes (13.64%) which include early closure of markets, shutting down all common play areas and parks, wearing of face masks, meeting each other with social distancing, and not shaking hands are likewise the key drivers for the long term impact of pandemic on children with IDDs.

Discussion

This study sample identified a variety of concerns related to lockdown as part of the COVID-19 pandemic and their effect on the lives of children with IDDs in rural Pakistan. Precisely, staying in the home affects the children's behavior, social and emotional status, environmental and cultural changes, and the growth of intellectual development. In addition, parents were also affected by lockdown related to COVID-19. Parents are facing financial challenges, stress issues, child grooming burden, limited health facilities for children, and inadequate government funding. To cope with these challenges, parents are able to develop few in house plans for the children. For instance, healthy food, exercising, engaging in enjoyable activities, gaming, and meeting with relatives. On the other hand, a few parents also expressed the benefits of COVID-19 lockdown by spending more time with their children, which reinforces their family ties.

The findings of this study are aligned with the recent reports on the impact of COVID-19 on families. For example, the burden of the COVID-19

pandemic is greater for parents with IDD-challenged children than the parents of non-IDD-challenged children (Coyne et al., 2020; Masters et al., 2020). The reason for this is that parents of children with IDD are more susceptible to social and educational vulnerabilities (Adom, 2020; Fontanesi et al., 2020; Jeste et al., 2020). Particularly, in developing countries like Pakistan, rural regions have comparatively more socioeconomic, linguistic, and ethnic issues than urban parts of the country (Shafi et al., 2020). As a result, raising children with IDD is a difficult job in rural Pakistan. According to Hayes and Watson (2013), increased challenges, which primarily include increased caregiving burden and parenting stress, are identified among parents of children with IDD compared to families with typical developing children. As a result, this transactional relationship between the child's challenging behaviour and parental stress increases parents' difficulties during the COVID-19 pandemic and their ability to cope (Fontanesi et al., 2020; Woodman et al., 2015). Consequently, this translates into an overall reduction in services for children with IDD in rural Pakistan and likely detrimental short and long-term effects on child development (Reichow & Wolery, 2009). The report by the National Institute of Child Health and Human Development (2017) states that;

The early years are a critical window of intervention because of the plasticity of the brain and the possibility of rapid development gains.

Participants in this study were socio-economically, linguistically and ethnically diverse because rural practices are different from urban culture in Pakistan and the rural population speaks their local 'Punjabi' language (Shafi et al., 2020). This diverse participant's background is unusual for urban and modernized families with IDD (Safer-Lichtenstein et al., 2019). Based on the existing literature review, the value of modernized families (e.g., familismo) is generally associated with human adaptation and improved well-being, especially in difficult environments (Ayón et al., 2010). Improved well-being for modernized families allows them to better adapt (Perez & Cruess, 2014). As a result, the better adaption is helping these families improve their family relationships and spend quality time with other family members, which translates into unintended benefits from the pandemic. However, the rural families are unaware of their basic civil rights and their limited knowledge

hinders them to overcome the stressful situation through mobilizing available resources. Hence, rural families struggle for improved well-being and to attain solutions for their problems.

According to Hooper et al. (2020), in developed countries like the US, resilient perspectives have identified different characteristics of families during COVID-19 based on their socioeconomic and health disparities. These disparities significantly affect individuals from cultural minority and racial backgrounds during the pandemic in the USA. Therefore, the results of the present study can be generalized and tested to other similar population where socio-economic and health conditions can have a considerable impact (positive/negative) on families due to strong familial linkages. Hence, the present study represents a snapshot of the difficulties experienced by parents of children with IDD in rural Pakistan in the year 2020. However, the long-term impacts of the pandemic are yet to be fully studied by academicians and researchers.

Healthcare workers or community workers in rural Pakistan are currently the only source for remote health service platforms and in their absence, medical assistance is scarce for children with IDDs. More research is needed to highlight the short and long-term impacts of COVID-19 lockdown on children with IDDs. This research has attempted to identify the perceived concerns of parents of children with IDDs during the pandemic and their views on how it affects their children. The study could serve as a baseline for future researchers and academics to further investigate what the Pakistan government is doing to eliminate these pandemic problems for children with IDDs. This study has highlighted the concerns of parents for their children with IDDs during the pandemic about closing schools and health institutions using qualitative data collection technique. All these identified challenges associated with being at home, providing full-time care to children, and implementing home learning mechanisms for children with IDDs could further be tested quantitatively in urban settings.

Recommendations

The present study has attempted to highlight the concerns of families with children with IDDs during the COVID-19 pandemic. It is recommended that

health care professionals and other government agencies should actively support these families in rural regions of Pakistan. The support will be in the form of guidance, counselling, and offering opportunities for parents as well as children with IDD to improve their social environment to appropriately overcome their issues during this distress time of COVID-19 lockdown. While social distancing and self-quarantine are effective means of preventing the spread of a pandemic, they may have a negative impact on people's well-being. Therefore, media through informative programs and public organizations through CHWs may offer procedures to adopt for improvement of physical health of children with IDD which may eventually improve the children immunity as well as their leaning abilities. In fact, stable health conditions are key to fighting this pandemic and reducing parents' mental stress. For this reason, government and health professionals' focus should be on the well-being of parents and their children with IDD and it should be a continuous process because this pandemic could have long lasting implications. According to Bowlby (1988):

Man and woman power devoted to the production of material goods counts a plus in all our economic indices. Man and woman power devoted to the production of happy, healthy, and self-reliant children in their own homes does not count at all. We have created a topsy-turvy world (Bowlby, 1988).

References

- Adom, D. (2020). Cultural and Educational Implications of the COVID-19 Global Pandemic in Ghana. *International and Multidisciplinary Journal of Social Sciences*, 9(3), 202-229. <http://doi.org/10.17583/rimcis.2020.5416>
- Almeida, F. (2020). The Concept Of Human2Human In The Response To COVID-19. *International and Multidisciplinary Journal of Social Sciences*, 9(2), 129-151. <http://dx.doi.org/10.17583/rimcis.2020.5524>
- Ayón, C., Marsiglia, F. F., & Bermudez-Parsai, M. (2010). Latino family mental health: exploring the role of discrimination and familismo. *Journal of Community Psychology*, 38, 742-756. <https://doi.org/10.1002/jcop.20392>

- Baker, B. L., McIntyre, L. L., Blacher, J., Crnic, K., Edelbrock, C., & Low, C. (2003). Preschool children with and without developmental delay: behavioral problems and parenting stress over time. *Journal of Intellectual Disability Research*, 47, 217-230. <https://doi.org/10.1046/j.1365-2788.2003.00484.x>
- Berg, B. L. (2009). *Qualitative research methods for the social sciences*. Allyn and Bacon.
- Bowlby, J. (1988). *A Secure Base: Parent-Child Attachment and Healthy Human Development*. London: Routledge.
- Brooks, S., Webster, R. K., Smith, L. E., Woodland, L., Wessely, S., Greenberg, N., & Rubin, G. J. (2020). The psychological impact of quarantine and how to reduce it: rapid review of the evidence. *Lancet*, 395, 912-920. [https://doi.org/10.1016/S0140-6736\(20\)30460-8](https://doi.org/10.1016/S0140-6736(20)30460-8)
- Centers for Disease Control (2020). Cases in the U.S. Centers for Disease Control website <https://www.cdc.gov/coronavirus/2019-ncov/cases-updates/cases-in-us.html>
- Corbin, J. M., & Strauss, A. L. (2008). Basics of qualitative research: techniques and procedures for developing grounded theory. *Sage Publications, Inc.*, Los Angeles. <https://dx.doi.org/10.4135/9781452230153>
- Coyne, L. W., Gould, E. R., Grimaldi, M., Wilson, K. G., Baffuto, G., & Biglan A. (2020). First things first: Parent psychological flexibility and self-compassion during COVID-19. *Behavior Analysis in Practice*. <https://doi.org/10.1007/s40617-020-00435-w>
- Eshraghi, A. A., Li, C., Alessandri, M., Messinger, D. S., Eshraghi, R. S., Mittal, R., & Armstrong, F. D. (2020). COVID-19: overcoming the challenges faced by individuals with autism and their families. *The Lancet. Psychiatry*, 7(20), 481-483. [https://doi.org/10.1016/S2215-0366\(20\)30197-8](https://doi.org/10.1016/S2215-0366(20)30197-8)
- Fontanesi, L., Marchetti, D., Mazza, C., Di Giandomenico, S., Roma, P. & Verrocchio, M. C. (2020). The effect of the COVID-19 lockdown on parents: a call to adopt urgent measures. *Psychological Trauma: Theory, Research, Practice, and Policy*, 12, S79-S81. <http://dx.doi.org/10.1037/tra0000672>
- Hayes, S. A., & Watson, S. L. (2013). The impact of parenting stress: a meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum

- disorder. *Journal of Autism and Developmental Disorders*, 43, 629-642. <https://doi.org/10.1007/s10803-012-1604-y>
- Ho, H., Perry, A., & Koudys, J. (2021). A systematic review of behaviour analytic interventions for young children with intellectual disabilities. *Journal of Intellectual Disability Research*, 65(1), 11-31. <https://doi.org/10.1111/jir.12780>
- Hooper, W., M., Nápoles, A. M., & Pérez-Stable, E. J. (2020). COVID-19 and racial/ethnic disparities. *JAMA*, 323, 2466-2467. <https://doi.org/10.1001/jama.2020.8598>
- Jeste, S., Hyde, C., Distefano, C., Halladay, A., Ray, S., Porath, M., Wilson, R. B., & Thurm, A. (2020). Changes in access to educational and healthcare services for individuals with intellectual and developmental disabilities during COVID-19 restrictions. *Journal of Intellectual Disability Research*, 64(12), 825-833. <https://doi.org/10.1111/jir.12776>
- Juth, V., Silver, R. C., Seyle, D. C., Widyatmoko, C. S., & Tan, E. T. (2015). Post-disaster mental health among parent-child dyads after a major earthquake in Indonesia. *Journal of Abnormal Child Psychology*, 43, 1309-1318. <https://doi.org/10.1007/s10802-015-0009-8>
- Masters, G. N., Taylor-Guy, P., Fraillon, J., & Chase, A. (2020). *Ministerial Briefing Paper on Evidence of the Likely Impact on Educational Outcomes of Vulnerable Children Learning at Home during COVID-19*. Australian Government Department of Education, Skills and Employment.
- Mazza, C., Ricci, E., Biondi, S., Colasanti, M., Ferracuti, S., & Napoli, C. et al. (2020). Nationwide survey of psychological distress among Italian people during the COVID-19 pandemic: immediate psychological responses and associated factors. *International Journal of Environmental Research and Public Health*, 17, 1-14. <https://doi.org/10.3390/ijerph17093165>
- McIntyre, L. L. (2020). Family-Based Practices to Promote Well-Being. *American Journal on Intellectual and Development Disabilities*, 125(5), 349-352. <https://doi.org/10.1352/1944-7558-125.5.349>
- National Institute of Child Health and Human Development (2017). *Early intervention and autism*. National Institute of Child Health and Human Development
- National Research Council (2001). *Educating Children with Autism*. The National Academies Press.

- Nearchou, F., Flinn, C., Niland, R., Subramaniam, S.S., & Hennessy, E. (2020). Exploring the Impact of COVID-19 on Mental Health Outcomes in Children and Adolescents: A Systematic Review. *International Journal of Environmental Research and Public Health*, 17(22), 79-84. <https://doi.org/10.3390/ijerph17228479>
- Neece, C., McIntyre, L.L., & Fenning, R. (2020). Examining the impact of COVID-19 in ethnically diverse families with young children with intellectual and developmental disabilities. *Journal of Intellectual Disability research*, 64(10), 739-749. <https://doi.org/10.1111/jir.12769>
- Orgilés, M., Morales, A., Delveccio, E., Mazzeschi, C., & Espada, J. P. (2020). Immediate psychological effects of COVID-19 quarantine in youth from Italy and Spain. *Frontiers in Psychology*, 11, 2986. <https://doi.org/10.3389/fpsyg.2020.579038>
- Özdemir, S., & Kerse, G. (2020). The Effects of COVID 19 Process on Health Care Workers: Analysing of the Relationships between Optimism, Job Stress and Emotional Exhaustion. *International and Multidisciplinary Journal of Social Sciences*, 9(2), 178-201. <http://dx.doi.org/10.17583/rimcis.2020.5849>
- Perez, G. K., & Cruess, D. (2014). The impact of familism on physical and mental health among Hispanics in the United States. *Health Psychology Review*, 8, 95-127. <https://doi.org/10.1080/17437199.2011.569936>
- Pulido Rodríguez, C., Villarejo Carballido, B., Redondo Sama, G., Guo, M., Ramis, M., & Flecha, R. (2020). False News Around COVID-19 Circulated Less On Sina Weibo Than On Twitter. How To Overcome False Information? *International and Multidisciplinary Journal of Social Sciences*, 9(2), 107-128. <http://dx.doi.org/10.17583/rimcis.2020.5386>
- Redquest, B. K., Tint, A., Ries, H., & Lunsy, Y. (2021). Exploring the experiences of siblings of adults with intellectual/developmental disabilities during the COVID-19 pandemic. *Journal of Intellectual Disability Research*, 65(1), 1-10. <https://doi.org/10.1111/jir.12793>
- Redquest, B.K., Tint, A., Ries, H., & Lunsy, Y. (2020). Exploring the experiences of siblings of adults with intellectual/developmental disabilities during the COVID-19 pandemic. *Journal of Intellectual Disability Research*, 65(1), 1-10. <https://doi.org/10.1111/jir.12793>
- Reichow, B., & Wolery, M. (2009). Comprehensive synthesis of early intensive behavioral interventions for young children with autism

- based on the UCLA young autism project model. *Journal of Autism and Developmental Disorders*, 39, 23-41.
<https://doi.org/10.1007/s10803-008-0596-0>
- Roesch, E., Amin, A., Gupta, J., & Moreno, C.J. (2020). Violence against women during covid-19 pandemic restrictions. *BMJ*, 369.
<https://doi.org/10.1136/bmj.m1712>
- Safer-Lichtenstein, J., Hamilton, J., & McIntyre, L. L. (2019). Examining demographics in randomized control trials of group social skills interventions for individuals with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 49, 3453-3461.
<https://doi.org/10.1007/s10803-019-04063-4>
- Schuengel, C., Tummers, J., Embregts, P. J. C. M., & Leusink, G. L. (2020). Impact of the initial response to COVID-19 on long-term care for people with intellectual disability: an interrupted time series analysis of incident reports. *Journal of Intellectual Disability Research*, 64(II), 817-824. <https://doi.org/10.1111/jir.12778>
- Shafi, M., Liu, J., & Ren, W. (2020). Impact of COVID-19 pandemic on micro, small, and medium-sized Enterprises operating in Pakistan. *Research in Globalization*, 2, 100018.
<https://doi.org/10.1016/j.resglo.2020.100018>
- Shivers, C. M. (2019). Self-Reported Guilt Among Adult Siblings of People With Intellectual and Developmental Disabilities. *American Journal on Intellectual and Development Disabilities*, 124(5), 470-477.
<https://doi.org/10.1352/1944-7558-124.5.470>
- Woodman, A. C., Mawdsley, H. P., & Hauser-Cram, P. (2015). Parenting stress and child behavior problems within families of children with developmental disabilities: transactional relations across 15 years. *Research in Developmental Disabilities*, 36, 264-276.
<https://doi.org/10.1016/j.ridd.2014.10.011>
- World Health Organization (2020). Coronavirus disease (COVID-19) pandemic. World Health Organization website
<https://www.who.int/emergencies/diseases/novel-coronavirus-2019>
- Zaagsma, M., Volkers, K. M., Swart, E. A. K., Schippers, A. P., & Hove, G. V. (2020). The use of online support by people with intellectual disabilities living independently during COVID-19. *Journal of Intellectual Disability Research*, 64(10), 750-756.
<https://doi.org/10.1111/jir.12770>

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