The Mental Stress of Immigrant Parents of Children with ASD in the United States During the COVID-19 Pandemics: A Study from Ecological System Perspective

Hui Zhang¹

¹ Gevirtz Graduate School of Education, University of California, Santa Barbara, US

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CORRESPONDING AUTHOR:

Hui Zhang; hui_zhang@ucsb.edu

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ABSTRACT:

Given that researchers interested in the experiences of minority parents of children with special needs sometimes recruit participants solely based on their ethnic origin, despite the huge socioeconomic, and political divide between immigrant and native-born minority parents, little is known about the experiences of immigrant parents in the context of the global pandemic beginning in 2019, even though academics have seen major changes in family life in the context of COVID -19 constraints. By examining through an ecological system perspective and based on the findings of a qualitative interpretive phenomenological analysis (IPA) that sought to understand the experiences of 13 immigrant parents of children with ASD advocating for their children, who immigrated from 7 different countries and regions, this article discusses the mental stress experienced by immigrant parents during the pandemic. The findings about mental stress included coping with mental stress caused by being separated from family support networks, increased miscommunication caused by the shift from in-person to online communication, and increased workload as a home-based intervention provider due to practitioner shortages during the pandemic. This study implies that even though immigrant parents have demonstrated amazing resilience in dealing with the pandemic-related environment, external social support is urgently needed to assist them in managing the impact of pandemic-related stresses and concerns.

Keywords: mental stress, immigrant parents, Autism Spectrum Disorder, Interpretative Phenomenological Analysis, ecological system perspective

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BACKGROUND

Numerous studies of parents of children with autism spectrum disorder (ASD) conducted in many countries concluded that parents of children with ASD suffered a higher degree of mental stress than parents of typically developing children. (e.g., Hayes & Watson, 2013; Putri & Lutfianawati, 2021; Su et al., 2018). McStay and colleagues (2014), for example, found various stressors that influence families of children with ASD as they undergo a process of restructuring family features in response to the implications of the diagnosis of ASD. These stressors include children's maladaptive behaviors, such as echolalia in speech or public tantrum-throwing (e.g., Pakenham et al., 2005; Woodgate et al., 2008), the severity of ASD symptoms, such as level 3 of ASD, according to Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5) (APA, 2013) includes symptoms such as self-segregation, which was found to relate to worse parenting outcomes (Lecavalier et al., 2006), and low adaptive functioning, such as a lack of basic real-world skills including dressing or avoiding danger (Hall & Graff, 2011). These stressors are associated with unfavorable results in families parenting children with ASD and can act as a source of mental stress for parents, resulting in emotional dysregulation or even affective disorders (McStay et al., 2014).

Parental mental stress has historically been one of the most extensively researched aspects of family life in families with children with ASD (Lyons et al., 2010), as the Coronavirus Disease 2019 (COVID-19) has swept the world, posing new and unexpected challenges such as severe family financial losses and mandatory stay-at-home orders disrupting families' daily routines, it is important to investigate on experiences of these families, especially on mental health of their parents in these extraordinary circumstances (Adams, 2021). According to Yilmaz and colleagues (2021), in a systematic review of 12 studies on the mental stress experienced by parents of children with ASD during pandemics, the COVID-19 pandemic affected these parents in 7 different countries mentally, and parents of children with ASD reported higher levels of anxiety than parents of healthy children due to significant disruptions in daily routines, difficulty accessing health services, and inability to access private care. Within this context, the levels of stress typically experienced by immigrant parents, who are daily navigating the cultural and linguistic complexities of living outside their home country, can be further compounded by the challenges of navigating the special education systems in the US (Ijalba, 2016; Shorey & Chan, 2020).

However, researchers interested in understanding the perspectives of minoritized parents of children with special needs often recruit participants based only on their ethnicity (e.g., Chiang, 2014; Jegatheesan, 2011; Zuckerman et al., 2014;). For example, Latino parents' perceptions of special education services (Zuckerman et al., 2014), South Asian Muslim immigrant parents' perceptions of services (Jegatheesan, 2011), or Chinese American parents' experiences with intervention methods for children with ASD (Chiang, 2014) have all been documented. However, given that immigrant status is not completely collinear with race, this strategy would not be sensitive to the challenges immigrant families face, leading to potential biases in findings. Such a concern is supported by researchers who have observed significant social-political differences between immigrant and native-born minority parents (Phinney & Vedder, 2006; Raleigh & Kao, 2010). In addition, combining acculturating and domestic minoritized groups based on race may be misleading as critical characteristics, like ethnic subgroup, social economic position, and duration of residence, are often rendered invisible, which are key factors attributing to parental stress according to previous studies (Bornstein, 2017; Bronfenbrenner, 1979; Nomaguchi & DeMaris, 2013; Song et al., 2012). The present study utilized the description provided by Singh et al. (2008) to elucidate the categorization of immigrant families, which includes three distinct groups: foreign-born children with both immigrant parents (first generation), US-born children with both immigrant parents (first generation), and US-born children with one immigrant parent (first generation) (Singh et al., 2008, p.758). The ecological theory of parenting, as proposed by Bronfenbrenner (1979), holds that parenting is greatly impacted by the structural contexts in which parents and children are embedded. Human behavior within the context of nested structures of the environment, as well as the interactions between humans and environmental occurrences, may be better understood by using ecological framework including the microsystem(the groups that most immediately and directly impact the family, e.g., schools and peers), mesosystem (interconnections between the microsystems, for example, between the family and teachers or between the child's peers and the family), exosystem (links between social settings, for example, parents' work, media, and neighborhood), macrosystem(culture contexts, such as ethnicity, traditions, and social-economic status) and chronosystem (pattern of life course transitions, such as the shift of disability paradigm from the medical model

to social model over the past 30 years) (Bronfenbrenner, 1979).

Using this ecological system theory as a foundation, researchers suggested that the contexts of nested structures are significant sources of mental stress that impact parental experiences. For instance, empirical investigations were done in accordance with ecological system frameworks discovered and validated relationships between socioeconomic environment, social support, and parent mental health (Conger & Conger, 2002; Wade et al., 2015). Additionally, because children with disabilities are more reliant on their parents and surroundings than typically developing children (Belsky, 1984; Wade et al., 2015), mental stress among parents of disabled children is clinically significantly higher than that of typically developing children, and parents of children with ASD experience significantly more stress than parents of children with other disabilities, such as Down Syndrome or other intellectual disabilities (Bellone et al., 2021; Hayes & Watson, 2013).

To date, limited research has taken an in-depth look regarding the experiences and mental stress of immigrant parents of children with disabilities during the COVID-19 pandemic in the United States from a source-response ecological perspective. Given that immigrant parents face disruptions to daily routines during COVID-19 in addition to their roles as newcomers adjusting to life in a new country, it is critical to examine the subjective experiences, including mental stress, that immigrant parents encountered while raising their children with special needs.

Objectives

Starting from the winter of 2021, a qualitative study aimed at understanding the experiences and perspectives of immigrant parents of children with ASD was conducted by phone and virtually, with 13 immigrant parents of children with ASD advocating for their children, who came from 7 different countries and regions and currently resided in 5 different states throughout the United States. One finding that stood out was that immigrant parents experienced mental stress as a result of the COVID-19 pandemic restrictions, including dealing with loneliness from being kept away from family support and coping with additional parental obligations and demands due to the closure of public education.

As such, this study aims to explore and characterize the mental stress endured by immigrant parents of children with ASD living in the United States during the pandemic. The study's overarching questions include 1) What mental stress experiences of immigrant parents of children with ASD in the United States have during the Covid-19 pandemic and 2) how are they coping with the pandemic-related stresses?

METHOD

Participants

As stated above, the subjects for this study are the first-generation immigrant parent(s) with child(ren) diagnosed with ASD who were born either in the US or abroad. Parents who were born in the US were excluded from this study. 13 immigrant parents from widely distributed racial backgrounds were recruited as a representation of immigrant parents from 7 different countries in Asia, Europe, South America, and the Middle East.

Recruitment

The recruitment process included purposeful sampling (Patton, 2007) and snowballing (Goodman,1961). Purposeful sampling is a technique widely used in qualitative research to identify and choose information-rich cases for the most effective use of limited resources (Patton, 2007), while snowballing is a recruiting strategy that allows existing participants to recruit individuals they know who are already enrolled in the research, and those new participants, in turn, recruit people they know who are already enrolled in the study (Goodman, 1961; Lakhanpaul et al., 2020). Two criteria were applied for parents' recruitment: (1) Parents from first-generation immigrant families in the US, and (2) parents' children who have a diagnosis of ASD.

Procedures

The human subject committee (HSC) approved this study in December 2021(protocol number:7-21-0754). In this study, immigrant parents of children with ASD were recruited by using social media platforms, including Facebook, Weixin (the most popular instant messaging app for Mandarin speakers), and Twitter. Recruitment flyers were distributed to these social media platforms, and the participants contacted the researcher showing their willingness to take part in the study. Semi-structured interviews (each for about one hour) were performed via phone or online based on participant availability, and an online demographic information survey based on Qualtrics about parents and their children with ASD was filled out by each participant.

In semi-structured interviews, parents were asked about their thoughts and experiences about (1) their chil-

Table 1. Participants' Characteristics

Total number of participating parents	13	Number of children described in parents'	13
Women	12	interviews	
Men	1	Girls	2
Educational background of parents		Boys	11
Attended college (no degree) Bachelor's degree Graduate degree	1 2 10	Age 5-7 Age 8-12 Age 13-15	2 6 2
Parents' age		Age 16-18 Age 19-22	2
30-39 40-49	3 8	Marital status	
50-59	2	Married	11
Annual household income		Divorced	2
0-\$10,000	2	Racial background	
\$10,000-\$50,000 \$50,000-\$100,000 \$100,000-\$200,000 \$200,000-\$300,000	3 2 4 2	Hispanic Asian White Persian	1 10 1
Employment status		Services received outside school	
Employed, working 1-39 hours per week Employed, working 40 hours per week or more Not employed, looking for work Not employed, not looking for a job	8 2 1 2	(number of times mentioned) Occupational therapy Speech therapy	2 4
Services received at school (number of times mentioned)		After-school program Applied behavior-based therapy Social skill therapy	5 1
Occupational therapy	8	Physical therapy	2
Speech therapy Applied behavior-based therapy	11 11	Years of Immigration	
Social skill therapy Physical therapy Sensory integration therapy	1 1	Less than 5 years 4 to 10 years more than 10 years	2 3 8

dren's diagnoses and services, (2) their schooling choices, (3) their expectations and worries about services, and (4) their lived experiences as caregivers during COVID-19. Parents' comments throughout the interviews revealed the presence of mental stress related to parental responsibilities, and the current study was based on the emerging theme of mental stress of parents during COVID-19 and corresponding restrictions.

The online poll was done in English, and the author and participants conducted interviews in Mandarin Chinese (with 7 parents from mainland China) and English (with 6 parents, respectively from Hongkong, Taiwan, Germany, Korea, Iran, and Bolivia). Excerpted transcribed responses by participants (identified by first and last name initials) were translated into English for accessibility. All participants gave permission for the author to record their talks during the interview, and the author transcribed and coded the interviews. Table 1 presents more details of the participants' characteristics.

Data Analysis

The semi-structured interviews' qualitative data were analyzed using a combination of interpretive phenomenological analysis (IPA) and Bronfenbrenner's ecological systems theory (1979) to guide the data analysis and theme identification. The purpose of IPA is to elicit an in-depth examination of the participant's perspective on the subject at hand, and the technique is heavily influenced by Merleau-philosophy Ponty's that people's perceptions must always be interpreted in relation to their immediate surroundings, which may include specific legislation (Sohn et al., 2017). The ecological system theory was used in structuring the coding scheme by connecting the interview data to the ecological system theory. A three-step analytic technique was applied to assess data from the semi-structured parent interviews, as shown in figure 1.

The analysis began with reviewing the original transcripts of parents' interviews and creating memoranda

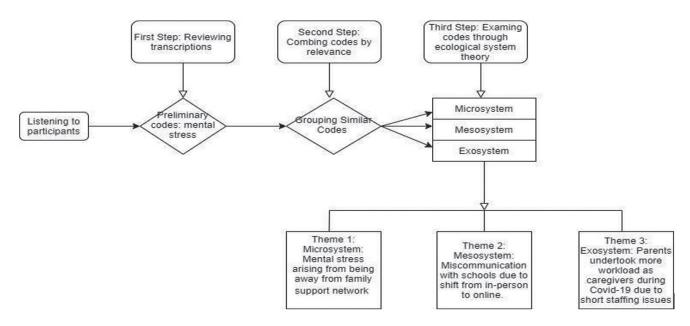


Figure 1. Data Analysis Procedure

on emergent excerpts relating to mental stress during COVID-19. Following up the review throughout transcriptions, the author then compared and grouped quotes about mental stress into codes in line with the coding book on parental mental stress during COVID-19 developed by Asbury and colleagues (2021), in which the au-

thors classified the essential terms associated with mental stress into 48 categories, such as anxiety, lonely, fear and frustration. Table 2 shows the formation of codes. The third stage examined and integrated findings by refining and summarizing codes into three themes through the frameworks of ecological system theory.

Table 2. Formation of Codes and Themes

Themes	Codes	Sub-category	Examples of excerpts
Mental stress arising from being away from family support network	Anxiety	Anxiety for self	'I don't know how long I could handle it on my own, and it made me anxious from time to time'.
	Loss	Anxiety for others	'My parents are still in China, and if anything comes up now, I cannot come back.'
	LOSS	Loss of support from family	'I wish I had a relative around so I could have some help'
	Worry	Worries for self	'I am worried that I will have to quit my job eventually if my parents cannot come over to help me'.
		Worries for their children	'I hope I have a relative around that I could arrange a playdate for him coz it is difficult to do it with others, you know, people are afraid of get contracted by virus'
Mental stress because of the communication shift from in-person to online	Frustration	Frustration occurred in communication	'And online meetings make everything much more difficult; I meanfeel like you're talking to your computer.'
		Frustration in advocacy	'You can image how frustrated we were when you tried to advocate for their right, but the network suddenly got spotty, and the conversation was interrupted.'

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Themes	Codes	Sub-category	Examples of excerpts
Mental stress because of the communication shift from in-person to	Confusion	Confusion occurred in communication Confusion occurred in understanding rules	'You know how sometimes you can't find the right word to communicate your feelings in a Zoom meeting.'
online			'You stammered and had to say something to fill the silence, and you said something that isn't exactly what you meant to say and made everyone confused.'
Mental stress due to insufficient staffing and frequent changes of routine.	due to insufficient Changes in routine workload staffing and frequent		'I honestly don't know how other parents did when they had to work at home and care for autistic children at the same time It's been quite stressful I cook for him and his sister, and I have to keep an eye on him when he's playing and teach him his assignments when paraprofessionals or therapists are unable to be at our place.'
		Lack of support from practitioners High turnover of practitioners	'We have had 6 different occupational therapists working with us since COVID-19, and none of them worked a long time with my son, so we have to make adjustments often according to their availabilities.'

RESULTS

The ecological theory of parenting (Bronfenbrenner,1979) helps interpret parents' experiences under a contextual ecological system where they are embedded in. Research has supported the contexts of nested structures as significant sources of mental stress that impact parental experiences (e.g., Belsky, 1984; Conger & Conger, 2002; Wade et al., 2015). Following the analytical steps from an ecological system perspective, mental stress-related themes emerged as follows: 1) Immigrant parents dealt with mental stress arising from being away from family support networks, 2) The shift from in-person to online communication complicated communication and increased the possibility of miscommunication between immigrant parents and school for issues regarding their children, which resulted in increased mental stress, and 3) Due to insufficient staffing and frequent changes in intervention practitioners during COVID-19, parents assumed more of the workload as home-based intervention provider, which added their mental stress.

Being Away from Family Support Network Increased Mental Stress

8 out of 13 immigrant parents reported that they have not seen other family members (including spouses, parents, grandparents, and relatives) residing in other countries since the worldwide outbreak of COVID-19 in 2020 due to travel bans and restrictions. During interviews, when asked about their experience during the pandemic, par-

ents reported the insecurity and isolation because of the COVID-19-related restrictions and the mental stress as a result of staying away from family support.

"...we don't have family members to support us, like grandparents, you know, because of COVID, they could not fly over, so it is all on me..." (QC, mother of a 10-year-old boy)

"...it is not that we chose to be stressed out...we simply don't get help from family members, for example, pick him up from therapy when we are both at work..." (FA, mother of a 9-year-old boy)

Additionally, parents expressed their insecurity and loneliness as a result of COVID-19 social restrictions, which they must balance with their desire to provide social interactions for their children with ASD, whose social communication deficit is widely regarded as one of two core manifestations (along with restricted and competitive behavior) for diagnosis criteria (Lord et al., 2000).

"...It hurts to see his social skills decrease so drastically during COVID, and there is nothing we can do because we have no relatives here, and it is difficult to arrange any kind of play date for him..." (LKN, mother of a 12-year-old boy)

"...I'm worried and exhausted all at the same time... I feel like I need more alone time, and I also need to play with him more because I am the only one, he can play with at home, and everything is closed now, and I wish we had a relative around whom he could play with..." (WQ, mother of an 8-year-old)

However, two parents with children ages 18 to 22 claimed that the stay-at-home order is even preferable for their children with ASD because they are not socially engaged and being at home is rather fitting for their personality.

"...My son is relieved that he can stay at home and has no issue maintaining a social distance from others because that is his thing: avoiding people. His younger sister, who is socially active, couldn't stand it and grieved when she couldn't hang out with friends, but my son is completely OK with it." (BF, father of a 22-year-old son)

"... The Covid thing doesn't seem to bother her at all, and she'll simply do her thing while I'm working at home. I cook for her, and that's about it, and I'm relieved because I don't have to drive her to school..."

(AM, mother of an 18-year-old daughter)

Both parents have children of legal age to work, and one of them is already employed. Compared to parents of younger children, their attitudes are substantially more relaxed and less stressful.

According to the findings, parents of young children with ASD are experiencing mental stress as a result of being away from family support, and they are finding it difficult to balance the need to maintain social distance with the need to provide intervention-oriented social interaction arrangements for their children when family support is not available.

Miscommunication Due to the Shift from In-person to Online Model

All the parents who took part in the study spoke about the kindness and professionalism shown by practitioners (e.g., nurses, schoolteachers, and intervention providers) who were particularly helpful to them, as well as the positive impact that this kindness and professionalism had on their own as well as on their children with ASD. However, some participants (6 out of 13) in this study reported a rising number of miscommunications that caused mental stress that occurred when they communicated with schools regarding the education plan of their children, and parents ascribed the increasing number of miscommunications to a shift in the way they communicate, from face-to-face meetings in the past to online meetings in the present, which compounded their difficulty communicating with the school.

"...We had a discussion with the school district during COVID about their decision to lay off more than 20 special education instructors because they thought it would be a waste of money when school was closed, and you can imagine how furious we were... And online meetings make everything much more difficult; I mean, it's always more productive and related when you chat to someone face to face, but online meetings now feel like you're talking to your computer." (IC, mother of a 10-year-old boy)

Additionally, parents mentioned how, due to the limits of online meetings, teachers occasionally logged off and never returned, or abruptly ended the conference when the time went off, even though the meeting agenda was not completely covered, which made them feel disrespected and stressed as if it had something to do with them being not proficient in English.

"...I remember one time when we had the annual IEP meeting, and we were in the middle of it, and the teacher simply told me that time is up for this meeting, and she had another meeting to catch up, so we just finished it like that..." (LH, mother of a 17-year-old girl)

"... You know how sometimes you can't find the right word to communicate your feelings in a Zoom meeting or over the phone coz you cannot use your body language to get yourself understood, and you stammered and have to say something to fill the silence, and you said something that isn't exactly what you meant to say..." (FL, mother of an 8-year-old boy)

Even though immigrant parents demonstrated remarkable resilience in dealing with the pandemic-related restrictions, the findings revealed that as the model of communication with schools regarding their children's education shifted from in-person to online, the stress experienced by immigrant parents grew steadily worse.

Increased Parental Childcare Burden Due to Staffing Shortages During COVID-19

According to previous research of parenting issues during the COVID-19 pandemic, parents of school-aged children are experiencing changes in their everyday lives, such as increased parenting time, but are also experiencing higher levels of fear, despair, and stress because of those changes (e.g., Cameron et al., 2020; Davenport et al., 2020). The findings of this study echo these statements, as most parents (10 out of 13) reported that they have to spend more time on parenting, not only as caregivers but also as intervention providers during the pandemic, because of staff shortages of practitioners in special education.

"...I honestly don't know how other parents did when they had to work at home and care for autistic children at the same time... It's been quite stressful... I cook for him and his sister, and I must keep an eye on him when he's playing and teach him his assignments when paraprofessionals or therapists are unable to be at our place... I experienced a panic attack not long ago and was terrified, and I am now on antidepressant medication...' (IC, mother of a 10-year-old boy)

"...I sometimes feel helpless and cry a lot, and I'm not sure what will happen to him in the future if this continues... I feel like there is so much I need to do right now and so little I can do...." (FL, mother of an 8-year-old boy)

FL, the mother of an 8-year-old boy, was at home for quarantine with her son, who tested positive for COVID-19 at the time of the interview, and her comments indicated that under COVID-related restrictions, it is even more difficult for parents to manage and balance their roles as primary caregivers and intervention providers when professional support is no longer available.

Other parents expressed similar concerns and anxieties about the COVID-related restrictions, which resulted in the inaccessibility of specialists critical to their children's intervention, and how the tension was alleviated once these services were restored.

"...he was doing quite well before the pandemic; but, once the pandemic began, I saw his social and academic step back so badly staying at home, and I was also under a lot of pressure, so I paid for an outside behavior therapist to come home to accompany him...it is out of pocket, but I feel much relieved from all these stress..." (QZ, mother of a 10-year-old boy)

Additionally, it is noteworthy that due to adjustments to attendance policies, as a result of staffing shortages in public schools (including schoolteachers and nurses) as well as safety concerns because of COVID-19, parents of children with ASD are more likely to be contacted by schools to pick up their children due to physical or behavioral issues at school, such as eating disorders or tantrum throwing. This frequent 'recalling' of their children exacerbated parents' mental stress.

"...My son has a number of health challenges, and I get a lot of calls from school, whether it's about his eating habits or his behavior issues... They called me even more after COVID, I did everything I could to cooperate with schools, he takes his own lunch box and prescriptions for the medicine he is taking, and I asked them if they could stop calling me for things I have explained numerous times, but I still get calls if the nurse who knows my son was not at school that day and they want me to take him home just in case..." (BJD, mother of a 7-year-old boy)

The experiences and hardships of participating parents demonstrate that COVID-19 restrictions have had a detrimental influence on the mental health of immigrant parents of children with ASD. Additionally, responses suggest that parents suffered compounded anxiety, stress, and fatigue as a result of the resulting changes to school policy and staff shortages in both public and private sectors, which play important roles in providing services and intervention practices to families of children with ASD.

DISCUSSIONS

The purpose of this study was to acquire a better understanding of immigrant parents of children with ASD's mental health during the COVID-19 pandemic. The study's limitations include the fact that the study's primary channel of recruitment (online networking and snowballing) excludes parents who do not have access to online resources or are uninterested in both online and in-person networking. As a result, our findings may not be generalizable to immigrant parents in all cultural and socioeconomic circumstances, as the participants do not represent all ethnic groups equally. This constraint results in an inability to comprehend the entire picture of social reality for immigrant parents of children with ASD from a multi-ethnic perspective. Another limitation is the relatively small sample size recruited for this study, thus precluding the ability to make any generalizations or group-level claims (e.g., parents with high-functioning ASD children vs. low-functioning ASD children). Given these limitations, this study is viewed as an initial phase of a larger exploration to make visible what immigrant parents of children with ASD in the United States may experience during the COVID-19 pandemic.

Findings from the analysis offer some insight into the mental stress that immigrant parents of children with ASD—even those within the top socioeconomic sphere—face when raising their children during the pandemic. Analytic uses of the ecological system lens have been instructive in previous studies on probing the relationship between social environment and parental mental health (e.g., Conger & Conger, 2002; Wade et al., 2015). As such, this ecological framework guided data analysis and three major findings emerged from the exploration of recorded interviews with 13 immigrant parents of children with ASD, each of which is addressed in turn.

Microsystem: During a pandemic, family support is critical for immigrant parents of young children with ASD

Although research has shown that family conflict is associated with worse parental mental health during COVID-19 (Feinberg et al., 2021; Moulin et al., 2021) and that parents of young children suffer from mental health problems worldwide because an increased time of co-parenting decreased their ability to buffer COVID-related stresses and deteriorated quality of family relationships, including co-parenting and parenting quality (Cohodes et al., 2021; Racine et al., 2021), the findings of this study suggested that during COVID-19, isolated family life and lack of support for parents due to COVID-related travel bans and border closures contributed to the increased mental stress of immigrant parents of children with ASD, especially those families with young children.

While this finding is not surprising, it is consistent with those of a recent systematic review focusing on the mental health of parents of children with ASD during pandemics, which concluded that parents might feel stressed and anxious as they struggle to manage the process and require family support to cope with routine changes in their children's lives (Yilmaz et al., 2021). Similarly, the findings that a lack of social support from family members is associated with a higher level of mental stress are consistent with previous studies of immigrant parents in the United States that have found that social support from family has both direct and indirect effects on mental health through parenting stress among different immigrant populations from a variety of racial and ethnic backgrounds (e.g., Harker, 2001; Rusch et al., 2020; Zeng et al., 2020).

It is noteworthy that there may be group variations in terms of mental stress levels between immigrant families with adult children and those with young children during COVID-19. As indicated by interviews, immigrant parents of younger school-aged children with ASD felt greater worry than parents of older children due to their secluded family life and lack of family support. This also presents a potential avenue for future investigation.

Mesosystem: The shift from in-person to online interaction increased the mental stress of immigrant parents

The findings suggested that, in the midst of these changes and obstacles, immigrant parents of children with ASD have shown their adaptability and creativity in order to facilitate the adjustment in their daily routine during COVID-19. However, when most communication migrated from in-person to online, this transition aggravated the already-existing communication issues, such as

miscommunication occurring during meetings between parents and their children's schools.

Prior studies had shown that language-minority parents and schools struggled to communicate effectively with one another, particularly when it came to teaching and learning decisions about children with special needs (e.g., Archer, 2010; Crozier & Davies, 2007). Furthermore, when it came to communications aimed at resolving critical issues affecting children with ASD, such as annual IEP (individual education plan) meetings, which researchers identified as venues for conflict in the parent-school partnership (Harry et al., 1995), miscommunication occurred frequently between parents and school personnel, owing to the fact that parents lack the necessary information or expertise for constructive communication (Kalyanpur et al., 2000).

Adding to the existing difficulties, the COVID-19 pandemic is a game changer in interpersonal communications, as offline in-person communication has been widely replaced by online meetings in a variety of workplaces (Kolakowski et al., 2021; Stefanoudis et al., 2021). Researchers have also discovered that online meetings are less effective than personal meetings at fostering interpersonal understanding, as social cues necessary for mutual communication have been lost under online communication (Kohnke & Moorhouse, 2020; Ren et al., 2016).

According to the findings of this study, the mental stress experienced by parents of children with ASD as a result of increased miscommunication between themselves and schools may be explained by their dual-identity status as both parents of children with ASD and members of first-generation immigrant families in a new country, which was exacerbated by significant shifts in communication patterns during the pandemic.

Exosystem: Short staffing of practitioners in special education during COVID-19 increased parental workload and led to more mental stress

Participants indicated that, because of a lack of special education practitioners ready to provide at-home assistance during the pandemic, parents must dedicate additional time to parenting, not just as caregivers but also as intervention providers. This finding is consistent with those of previous studies examining the staff shortage during COVID-19, which found that staff shortage issues and frequent staff turnover existed globally prior to the pandemic, particularly in professions such as nursing and occupational caregivers, but were exacerbated and deteriorated during COVID-19 as a result of pandemic-related social restrictions and practitioner burnout as

a result of increased workload (e.g., Cristina et al., 2021; Khatiwada et al., 2021; Nie et al., 2020).

Studies also suggested possible reasons for the shortage issues as teachers and the fear of contracting the coronavirus, social isolation, and overburdened work contributed to the high turnover of staff working in the field of special education (Asghar et al., 2021; Patel, 2020)

Having a dual identity as both parents of children with ASD and members of first-generation immigrant families in a new country, compounded with significant shifts affecting many aspects of daily life during the pandemic, has been shown to increase mental stress among immigrant parents of children with ASD when raising their children who require constant and regular intervention and services, necessitating consequent and stable collaboration. However, just a few studies have been conducted to date on the scarcity of practitioners and employees in special education and the resulting impact on parents of children with special needs. This finding suggests a viable avenue for future study.

CONCLUSIONS

Responses from 13 immigrant parents of children with ASD about their experiences during COVID-19 demonstrated that COVID-19 restrictions have had a detrimental influence on the mental health of immigrant parents of children with ASD. Additionally, responses suggest that parents suffered compounded anxiety, stress, and loss as a result of changes to ways of communication, social restrictions, school policies and staff shortages in both public and private sectors, all of which have played important roles in providing services and intervention practices to families of children with ASD. The findings of this study align with perspectives of the ecological system that parenting experiences are greatly impacted by the structural contexts in which parents and children are embedded. One of the most significant findings from this study is the uniqueness of the situation of immigrant parents of children with ASD that is revealed: In addition to the stresses that most parents of children with special needs face during the COVID-19 pandemic, they also face challenges associated with their identities as immigrants adjusted in a new country.

IMPLICATIONS

The implications of this study emphasize the importance of studying immigrant parents from a multidimensional perspective, as immigrant status is not completely collinear with race, and a race-based strategy would be blind to the challenges faced by immigrant families, resulting in a potential bias in findings, as researchers who have observed significant social-political differences between immigrant and native-born minority parents have observed (Bornstein, 2017; Phinney & Vedder, 2006; Raleigh & Kao, 2010). The current study also offers insights for prospective investigations in the field of family and parenting, such as exploring the determinants that impact the psychological strain experienced by parents of diverse ethnicities. This study elucidates that immigrant parents from diverse ethnic backgrounds frequently associate their reported mental stress with shared experiences, including the severity of ASD, the age of their child, the presence of supportive family members, and other relevant factors. Moreover, even though immigrant parents have adapted to these changes and challenges through incredible resilience in dealing with the pandemic-related environment, this study suggests that external social support is urgently required to assist them in managing the impact of pandemic-related stresses and concerns.

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DECLARATION OF INTEREST STATEMENT

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REFERENCES

Adams, E., Smith, D., Caccavale, L., & Bean, M. K. (2021). Parents are Stressed! Factors that Influence Parenting During COVID-19. *Annals of Behavioral Medicine*, Vol. 55, pp. S340-S340). https://doi.org/10.21203/rs.3.rs-66730/v1

- APA, (2013). Diagnostic and statistical manual of mental disorders (Vol. 3). Washington, DC: American Psychiatric Association.
- Archer, L. (2010). 'We raised it with the Head': the educational practices of minority ethnic, middle-class families. *British Journal of Sociology of Education*, 31(4), 449–469. https://doi.org/10.1080/01425692.2010.484921
- 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(5), 1772-1780. https://doi.org/10.1007/s10803-020-04577-2
- Asghar, M. Z., Arif, S., Barbera, E., Seitamaa-Hakkarainen, P., & Kocayoruk, E. (2021). Support through Social Media and Online Class Participation to Enhance Psychological Resilience. *International Journal of Environmental Research and Public Health*, 18(22), 11962. https://doi.org/10.3390/ijerph182211962
- Bellone, K. M., Elliott, S. C., Hynan, L. S., Warren, B., & Jarrett, R. B. (2021). Mindful Self-Care for Caregivers: A Proof of Concept Study Investigating a Model for Embedded Caregiver Support in a Pediatric Setting. *Journal of Autism and Developmental Disorders*, 1-14. https://doi.org/10.1007/s10803-021-05113-6
- Belsky, J. (1984). The determinants of parenting: A process model. *Child development*, 55(1), 83–96. https://doi.org/10.2307/1129836
- Bornstein, M. H. (2017). The specificity principle in acculturation science. *Perspectives on Psychological Science*, 12(1), 3-45. https://doi.org/10.1177%2F1745691616655997
- Bronfenbrenner, U. (1979). The ecology of human development: Experiments by nature and design. Harvard University Press.
- Chiang, H. M. (2014). A parent education program for parents of Chinese American children with autism spectrum disorders (ASDs) a pilot study. *Focus on Autism and Other Developmental Disabilities*, 29(2), 88-94. https://doi.org/10.1177/1088357613504990
- Cohodes, E.M., McCauley, S., & Gee, D. G. Parental Buffering of Stress in the Time of COVID-19: Family-Level Factors May Moderate the Association Between Pandemic-Related Stress and Youth Symptomatology (2021). Research on Child and Adolescent Psychopathology 49, 935–948. https://doi.org/10.1007/s10802-020-00732-6
- Conger, R. D., & Conger, K. J. (2002). Resilience in Midwestern families: Selected findings from the first decade of a prospective, longitudinal study. *Journal of marriage and family*, 64(2), 361–373. https://doi.org/10.1111/j.1741-3737.2002.00361.x
- Cristina, M. L., Spagnolo, A. M., Giribone, L., Demartini, A., & Sartini, M. (2021). Epidemiology and Prevention of Healthcare-Associated Infections in Geriatric Patients: A Narrative Review. *International Journal of Environmental Research and Public Health*, 18(10), 5333. https://doi.org/10.3390/ijerph18105333
- Crozier, G., & Davies, J. (2007). Hard to reach parents or hard to reach schools? A discussion of home—school relations, with particular reference to Bangladeshi and Pakistani parents. *British educational research journal*, 33(3), 295-313.

https://doi.org/10.1080/01411920701243578

Feinberg, M. E., A Mogle, J., Lee, J. K., Tornello, S. L., Hostetler, M. L., Cifelli, J. A., Sunhye, B., & Hotez, E. (2021). Impact of the COVID-19 Pandemic on Parent, Child, and Family Functioning. *Family Process* 61(1), 362-375. https://doi.org/10.1111/famp.12649 Goodman, L. A. (1961). Snowball Sampling. *Annals of Mathematical Statistics*, 32, 148-170.

https://doi.org/10.1214/aoms/1177705148

- Hall, H. R., & Graff, J. C. (2011). The relationships among adaptive behaviors of children with autism, family support, parenting stress, and coping. *Issues in comprehensive pediatric nursing*, 34(1), 4-25. https://doi.org/10.3109/01460862.2011.555270
- Harker, K. (2001). Immigrant generation, assimilation, and adolescent psychological well-being. *Social forces*, 79(3), 969-1004. https://doi.org/10.1353/sof.2001.0010
- Harry, B., Allen, N., & McLaughlin, M. (1995). Communication versus compliance: African American parents' involvement in special education. *Exceptional Children*, 61(4), 364-377. https://doi.org/10.1177/001440299506100405
- 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(3), 629-642. https://doi.org/10.1007/s10803-012-1604-y
- ljalba, E. (2016). Hispanic immigrant mothers of young children with autism spectrum disorders: How do they understand and cope with autism? *American Journal of Speech-Language Pathology*, 25(2), 200-213. https://doi.org/10.1044/2015
 AJSLP-13-0017

- Jegatheesan, B. (2011). Multilingual development in children with autism: Perspectives of South Asian Muslim immigrant parents on raising a child with a communicative disorder in multilingual contexts. *Bilingual Research Journal*, 34(2), 185–200. https://doi.org/10.1080/15235882.2011.597824
- Kalyanpur, M., Harry, B., & Skrtic, T. (2000). Equity and advocacy expectations of culturally diverse families' participation in special education. *International Journal of Disability, Development and Education*, 47(2), 119-136. https://doi.org/10.1080/713671106
- Khatiwada, A. P., Maskey, S., Shrestha, N., Shrestha, S., Khanal, S., Kc, B., & Paudyal, V. (2021). Impact of the first phase of COVID-19 pandemic on childhood routine immunization services in Nepal: a qualitative study on the perspectives of service providers and users. *Journal of pharmaceutical policy and practice*, 14(1), 1-10. https://doi.org/10.1186/s40545-021-00366-z
- Kohnke, L., & Moorhouse, B. L. (2020). Facilitating synchronous online language learning through Zoom. *RELC Journal*. https://doi.org/10.1177/0033688220937235
- Kolakowski, H., Shepley, M. M., Valenzuela-Mendoza, E., & Ziebarth, N. R. (2021). How the COVID-19 Pandemic Will Change Workplaces, Healthcare Markets and Healthy Living: An Overview and Assessment. *Sustainability*, 13(18), 10096. https://doi.org/10.3390/su131810096
- Lakhanpaul, M., Culley, L., Robertson, N., Alexander, E. C., Bird, D., Hudson, N., Johal, N., McFeeters, M., Hamlyn-Williams, C., Manikam, L., Boo, Y. Y, Lakhanpaul, M., & Johnson, M. R. (2020). A structured collaborative approach to intervention design using a modified intervention mapping approach: a case study using the Management and Interventions for Asthma (MIA) project for South Asian children. BMC medical research methodology, 20(1), 1-16. https://doi.org/10.1186/s12874-020-01148-y
- Lecavalier, L., Leone, S., & Wiltz, J. (2006). The impact of behaviour problems on caregiver stress in young people with autism spectrum disorders. *Journal of intellectual disability research*, 50(3), 172-183. https://doi.org/10.1111/j.1365-2788.2005.00732.x
- Lyons, A. M., Leon, S. C., Phelps, C. E. R., & 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
- McStay, R. L., Trembath, D., & Dissanayake, C. (2014). Stress and family quality of life in parents of children with autism spectrum disorder: Parent gender and the double ABCX model. *Journal of autism and developmental disorders*, 44(12), 3101-3118. https://doi.org/10.1007/s10803-014-2178-7
- Moulin, F., El-Aarbaoui, T., Bustamante, J.J.H. et al. Risk and protective factors related to children's symptoms of emotional difficulties and hyperactivity/inattention during the COVID-19-related lockdown in France: results from a community sample (2021). European Child & Adolescent Psychiatry, vol. 31, 1–12. https://doi.org/10.1007/s00787-021-01752-3
- Nie, A., Su, X., Zhang, S., Guan, W., & Li, J. (2020). Psychological impact of COVID-19 outbreak on frontline nurses: A cross-sectional survey study. *Journal of clinical nursing*, 29(21-22), 4217-4226. https://doi.org/10.1111/jocn.15454
- Nomaguchi, K. M., & DeMaris, A. (2013). Nonmaternal care's association with mother's parenting sensitivity: A case of self-selection bias? *Journal of Marriage and Family*, 75(3), 760-777. https://doi.org/10.1111/cfs.12323
- Pakenham, K. I., Samios, C., & Sofronoff, K. (2005). Adjustment in mothers of children with Asperger syndrome: An application of the double ABCX model of family adjustment. *Autism*, 9(2), 191-212. https://doi.org/10.1177/1362361305049033
- Patel, K. (2020). Mental health implications of COVID-19 on children with disabilities. *Asian journal of psychiatry*, 54, 102273. https://doi.org/10.1016/j.ajp.2020.102273
- Patton, M. Q. (2007). Sampling, qualitative (purposive). *The Blackwell encyclopedia of sociology*. https://doi.org/10.1002/9781405165518.wbeoss012
- Phinney, J. S., & Vedder, P. (2006). Family Relationship Values of Adolescents and Parents: *Intergenerational Discrepancies and Adaptation*. https://doi.org/10.4324/9780415963619-7
- Putri, A. and Lutfianawati, D. (2021). Parenting stress, social support and parental characteristics in parents of ASD children. International Journal of Early Childhood Special Education, 13(1), 143-151. https://doi.org/10.9756/int-jecse/v13i1.211017
- Racine, N., Hetherington, E., McArthur, B. A., McDonald, S., Edwards, S., Tough, S., & Madigan, S. (2021). Maternal depressive and anxiety symptoms before and during the COVID-19 pandemic in Canada: a longitudinal analysis. *The Lancet Psychiatry*, 8(5), 405-415. https://doi.org/10.1016/S2215-0366(21)00074-2
- Raleigh, E., & Kao, G. (2010). Do immigrant minority parents have more consistent college aspirations for their children? *Social Science Quarterly*, 91(4), 1083-1102. https://doi.org/10.1111/j.1540-6237.2010.00750.x
- Ren, Y., Chen, J., & Riedl, J. (2016). The impact and evolution of group diversity in online open collaboration. *Management Science*, 62(6), 1668-1686. https://doi.org/10.1287/mnsc.2015.2178

Rusch, D., Walden, A. L., & DeCarlo Santiago, C. (2020). A community-based organization model to promote Latinx immigrant mental health through advocacy skills and universal parenting supports. *American Journal of Community Psychology*, 66(3-4), 337-346. https://doi.org/10.1002/ajcp.12458

- Singh, G. K., Stella, M. Y., Siahpush, M., & Kogan, M. D. (2008). High levels of physical inactivity and sedentary behaviors among US immigrant children and adolescents. *Archives of pediatrics & adolescent medicine*, 162(8), 756-763.
- Shorey, S., & Chan, V. (2020). Lessons from past epidemics and pandemics and a way forward for pregnant women, midwives and nurses during COVID-19 and beyond: A meta-synthesis. *Midwifery*, 90, 102821. https://doi.org/10.1016/j.midw.2020.102821
- Sohn, B. K., Thomas, S. P., Greenberg, K. H., & Pollio, H. R. (2017). Hearing the Voices of Students and Teachers: A Phenomenological Approach to Educational Research. *Qualitative Research in Education*, 6(2), 121. https://doi.org/10.17583/gre.2017.2374
- Song, L., Tamis-LeMonda, C. S., Yoshikawa, H., Kahana-Kalman, R., & Wu, I. (2012). Language experiences and vocabulary development in Dominican and Mexican infants across the first 2 years. *Developmental psychology*, 48(4), 1106. https://doi.org/10.1037/a0026401
- Stefanoudis, P. V., Biancani, L. M., Cambronero-Solano, S., Clark, M. R., Copley, J. T., Easton, E., ... & Glover, A. G. (2021). Moving conferences online: lessons learned from an international virtual meeting. *Proceedings of the Royal Society* B, 288(1961), 20211769. https://doi.org/10.1098/rspb.2021.1769
- Su, X., Cai, R. Y., & Uljarević, M. (2018). Predictors of mental health in Chinese parents of children with autism spectrum disorder (ASD). *Journal of autism and developmental disorders*, 48(4), 1159-1168.
- Wade, C., Llewellyn, G., & Matthews, J. (2015). Parent mental health as a mediator of contextual effects on parents with intellectual disabilities and their children. *Clinical Psychologist*, 19(1), 28-38.
- Woodgate, R. L., Ateah, C., & Secco, L. (2008). Living in a world of our own: The experience of parents who have a child with autism. *Qualitative health research*, 18(8), 1075-1083. https://doi.org/10.1177/1049732308320112
- Yılmaz, B., Azak, M., & Şahin, N. (2021). Mental health of parents of children with autism spectrum disorder during COVID-19 pandemic: A systematic review. *World Journal of Psychiatry*, 11(7), 388. https://doi.org/10.5498/wjp.v11.i7.388
- Zeng, S., Hu, X., Zhao, H., & Stone-MacDonald, A. K. (2020). Examining the relationships of parental stress, family support and family quality of life: A structural equation modeling approach. *Research in developmental disabilities*, 96, 103523. https://doi.org/10.1016/j.ridd.2019.103523
- Zuckerman, K. E., Sinche, B., Mejia, A., Cobian, M., Becker, T., & Nicolaidis, C. (2014). Latino parents' perspectives on barriers to autism diagnosis. *Academic pediatrics*, 14(3), 301-308. https://doi.org/10.1016/j.acap.2013.12.004

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