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Understanding the effect of COVID-19 on two children with autism and their caregivers: a case study research design

Dalena Dillman Taylor¹, Kaleb Thompson², Caitlin Frawley¹, Sarah Mendoza¹ and Ashley Blount³

¹Department of Counselor Education and School Psychology, University of Central Florida, Orange County, Florida, USA; ²Department of Counseling and Higher Education, University of North Texas, Denton, Texas, USA; ³Department of Counseling, University of Nebraska Omaha, Omaha, Nebraska, USA

Concerns regarding the COVID-19 pandemic include threat to one's physical health and shifts in daily routine, which are considered significant life stressors. The COVID-19 outbreak can be considered a global disaster, and exposure associated with disasters has been linked to negative psychological outcomes (e.g. symptoms of depression, anxiety, post-traumatic stress disorder). The COVID-19 pandemic has affected various communities in unique ways, including the neurodivergent community; therefore, we explored the experience of two children with autism spectrum disorder (ASD) and their parents throughout the pandemic to increase awareness of the specific needs of this population. Utilizing a case study research design, we identified eight core themes across their experience and explored effects on targeted areas of child functioning (i.e. behaviors). For one participant, visual data indicated decreases in each behavioral area (i.e. positive interactions, negative interactions, and repetitive behaviors), whereas for the second participant, visual data indicated increases in each behavioral area. These findings support that autism is a heterogeneous condition in which youth with ASD will experience and respond to emergency situations in unique ways. With this study, we aim to support the growing body of literature narrating the experience of children with ASD and their caregivers during natural disasters.

Keywords: COVID-19; children; caregivers; natural disasters; autism spectrum disorder

Introduction

The COVID-19 outbreak is viewed as a global disaster due to the lasting impacts on children and families. Previously, limited research examined the disaster-related experiences of individuals with autism spectrum disorder (ASD), despite knowledge that people with ASD endure more significant distress during emergency conditions (Edmonds 2017). In response to the COVID-19 pandemic, researchers have taken this opportunity to better understand vulnerable populations. Children living with ASD benefit from behavioral routines (Leaf *et al.* 2021) and can face unique struggles in forming social connections (Marsh *et al.* 2017), and COVID-19 put a stop to accessing their usual routine education, therapeutic support, and social communities. Larsen *et al.* (2022) found that children who missed their friends due to school closures reported significantly higher levels of negative

emotional reactions than children who reported less social isolation from friends. Meral (2022) examined parental views and family functioning during the pandemic and revealed both positive (e.g. child verbal expression, increased family quality time) and negative (e.g. educational disparities) impacts of the pandemic. These findings shed light on unique experiences of children with ASD and their families during emergency situations; however, more research is needed to gain a fuller view of the effects of the COVID-19 pandemic on children with ASD and their caregivers.

Caregiver influence during COVID-19 pandemic

Relationships with caregivers strongly influence children's resilience levels (Osofsky and Osofsky 2018). Hausman *et al.* (2020) found significant associations between mother and child disaster responses, stating that maternal depressive symptoms served as predictors for children's level of depressive symptoms post-disaster, regardless of the level of exposure to the disaster.

Corresponding to: Dalena Dillman Taylor, Department of Counselor Education and School Psychology, University of Central Florida, 12494 University Blvd., Suite 322-R, Orlando, FL 32816, USA. Email: dalena.taylor@ucf.edu

For young children exhibiting behavioral issues during disasters, parents can be a source of safety. Children who receive caring and sensitive responses from their caregivers may experience fewer symptoms during disasters (Osofsky and Osofsky 2018). The same has also been found in adolescents in which caregiver support buffered PTSD symptomology, mediating the effects of negative psychological outcomes (i.e. substance-use behaviors; Hicks *et al.* 2022). Compas *et al.* (2001) noted that children develop patterns of coping skills in childhood that follow them throughout adulthood. Through emotional coregulation and dyadic coping, children can engage in regulatory behaviors alongside their caregivers. In caregivers and young children with ASD, Valentovich *et al.* (2018) found dyadic flexibility and mutual-positive engagements (e.g. child and caregiver are both in positive states) to be significantly associated with lower levels of negative outcomes. Alternatively, lack of dyadic flexibility is associated with increased risk of problem behaviors (Hollenstein *et al.* 2004). Therefore, caregiver reactions have the potential to be either risk factors of these negative effects or protective factors against them.

The COVID-19 outbreak shifted the lives and responsibilities of parents around the world. Many parents were faced with the need to make difficult decisions, in efforts to balance demands of assisting their children with remote education and continue working to provide resources for their families (Uzun *et al.* 2021). Parents who are exposed to persistent and chronic parenting stress may suffer from parental burnout (Mikolajczak and Roskam 2018). Parental burnout refers to ‘a state of intense exhaustion related to one’s parental role,’ which involves doubt in one’s ability to be a good parent and meet the child’s needs (Mikolajczak *et al.* 2019, p. 1319). This burnout often leads to significant distress associated with parental roles, decreased attention to the child-parent relationship, and emotional detachment from one’s child.

Protective factors for parental burnout include higher self-efficacy beliefs and positive parenting practices (Mikolajczak *et al.* 2019). Brown *et al.* (2020) found that parents with higher levels of emotional and social support had lower levels of parenting stress and child maltreatment during the COVID-19 pandemic. Despite the new roles and increased stress among parents during this pandemic, some families report positive experiences during this time. In one study examining caregiving experiences during the COVID-19 pandemic, nearly 54% of parents reported hugging their children more during this time (Lee *et al.* 2021). Families have not only been affected in various ways by the COVID-19 pandemic but have also responded to its impact in ways that best meet their unique needs and circumstances. For the autistic community, these needs and circumstances may look different throughout the pandemic.

Autism spectrum conditions

The neurodivergent community has changed the narrative for autism over the past few years and continues to be more affirming and empowering. Recent researchers indicate favorable effects on caregiver stress when autism is viewed as one specific type of mind within a diverse world rather than a disorder (Ferenc *et al.* 2023). As a diagnosis, ASD has been characterized by social impairments and repetitive engagement in activities, patterns, and/or interests (American Psychiatric Association 2013). ASD, also known as autism spectrum conditions, ‘is a complex, heterogeneous condition with a wide range of developmental trajectories, outcomes, causes, and responses to therapy’ (Ferenc *et al.* 2023, p. 54). When researching language preference among major ASD stakeholders (e.g. autistic adults, parents of children with ASD, professionals who work with individuals diagnosed with ASD), Taboas *et al.* (2023) found that adults were more likely to use identity-first language (i.e. autistic person), and parents were more likely to use identity-first and person-first language (i.e. person with autism) interchangeably. Further, they found that while professionals tend to use person-first language more often, it is important to inquire what terminology their clients prefer and respect that language (Taboas *et al.* 2023). This research team is composed of Counselor Educators, licensed mental health counselors, and play therapists who worked in collaboration with caregivers who attested and documented that their children are diagnosed with ASD. The research team has used the diagnostic term of ASD in this article because ASD coincides with the researcher’s disciplinary use of the DSM-5-TR (APA 2013), participant inclusion for this study, prior literature, public health recommendations, and participant empowerment.

During the COVID-19 pandemic, the Center for Disease and Control (CDC) outlined specific considerations for individuals with neurodevelopmental conditions, such as ASD (CDC 2020). Youth with ASD may experience greater difficulty wearing masks, and may require additional reminders to maintain social distancing. The CDC (2020) recommended extra words of reassurance and explanation of disasters because youth with ASD are more likely to experience worry, distress, and anger. In Portugal, Amorim *et al.* (2020) discovered that changes in daily routines from COVID-19 resulted in significant increases in anxiety among children with ASD. While some may argue that most people experienced increased anxiety during the pandemic, Toseeb and Asbury (2023) found that COVID-19 disproportionately affected the anxiety levels of youth with ASD in the United Kingdom. For youth with ASD, returning to school may have become a new source of anxiety as many institutions implemented new safety measures, and attending mainstream schooling was associated

with higher anxiety levels than other educational modalities (Toseeb and Asbury 2023). Vasa *et al.* (2021) surveyed parents of children with ASD and found that 59% of children experienced worsening psychiatric symptoms as a direct result of the pandemic. These worsening symptoms may be related to the extreme disruption of access to services and therapies (White *et al.* 2021). Caregivers also experienced extreme to moderate stress related to service closures out of fear for their children, indicating a need for additional support for both children with ASD and their families (White *et al.* 2021).

Parents reported challenges with children's social isolation, lack of outdoor playtime, and online schooling during the pandemic (Amorim *et al.* 2020). In a recent qualitative study, Tokatly Latzer *et al.* (2021) revealed several unmet needs and fears of families of children with ASD during the pandemic. Parents expressed fears associated with the closure of special education systems and shortages of resources. Additionally, parents expressed concerns that their children may experience developmental regression due to the pause in behavioral and therapeutic services (Tokatly Latzer *et al.* 2021). Manning *et al.* (2021) identified social isolation, finances, and lack of support as the greatest stressors among individuals with ASD and their families during the pandemic. Understanding stressors in this population, we summarize the purpose of this study in the following section.

Purpose

Neurodivergent children tend to be more sensitive to changes in their environments and rely on predictable routines (Hillman 2018); therefore, we explored the experiences of two children with ASD and their caregivers from March 2020 through September 2020 to increase awareness of the specific needs of this population and their caregivers. Both children were involved in a previous project that was halted due to the COVID-19 pandemic in March 2020. The previous project, a single case research design (SCRD) investigating a play therapy intervention with children diagnosed with ASD, was in the recruitment and baseline line data collection phase immediately preceding the pandemic. We collected daily behavioral data for two weeks prior to the initial lockdown; therefore, we opted to transition to case study research for the two participants already engaged in the research project to examine parents' perceptions of the pandemic through their responses *via* a daily questionnaire regarding their child's behaviors before and during the pandemic, as well as to identify themes from qualitative interviews.

Therefore, in this case study research, we sought to answer the following research questions:

1. How has the pandemic affected two Hispanic children with autism over a period of six months?
2. What themes did researchers identify from caregiver interviews to inform their experience of parenting during a pandemic?

Method

Research design

We approached this research from a postpositivist orientation (Yin 2018), indicating that the reality of the participants in this study can be imperfectly known. We attempted to capture their experiences during the first six months of the pandemic and yet, the fullness of their experiences may be incomplete. We examined data using an intrinsic case study research design (Dillman Taylor and Blount 2021). Case study research is a type of qualitative research in which the investigator explores a bounded case or cases over time (Creswell and Poth 2016), through 'detailed, in-depth data collection involving multiple sources of information... and reports a case description and case-based themes' (Creswell 2007, p. 73). Our research aimed at understanding the effect of the COVID-19 pandemic on two children with autism and their caregivers over the course of six months; therefore, we chose to employ an intrinsic case study design. For this study, we followed the sequential procedures in case study research methodology: an eight-step process (Dillman Taylor and Blount 2021, Yin 2018). By implementing this multi-step process, Dillman Taylor and Blount (2021) noted that researchers are more likely to minimize errors and bias in their work, increasing credibility of the research presented.

Sequential procedures

We followed the eight-step process outlined by Dillman Taylor and Blount (2021). See Dillman Taylor and Blount (2021) for more details regarding each step. Steps 1 and 2 consist of the planning process: setting the stage and determining what we know. For these steps, we selected an event (e.g. case) for the study (i.e. influence of pandemic on two children with autism and their caregivers) (Yin 2018) and conducted a thorough review of the literature to determine what we already know, what we need/want to know, and what has been previously done (i.e. propositions; Yin 2018). In Step 3, we determined the appropriateness of this design and specified the type of case study (e.g. intrinsic; Dillman Taylor and Blount 2021), and bound the case within time and activity (e.g. March 2020 – September 2020; Stake 1995). We determined that this case (i.e. COVID-19 pandemic) is a single case with embedded units (i.e. daily data, parent interviews). Given that the COVID-19 pandemic was phenomenon at the time of the research conducted, limited research existed on the effect it had on children and their caregivers. This study is unique in that a baseline of children's behavioral responses was collected prior to the onset of the

pandemic due to the participants qualifying for a different study. After university lockdown, all of these procedures were initiated and conducted virtually by the research team.

To prepare for the implementation of case study research (Step 4), we solidified the process: outlined the protocol for this research, set procedures for data collection, and prepared the qualitative interviews and daily questions for each child (Dillman Taylor and Blount 2021). Next, we collected data from parents on their children's behaviors daily for six months and in qualitative interviews (Step 5; see [Supplemental Materials](#) for each set of questions), thus meeting the recommendations of utilizing multiple sources of data to understand the influence of this phenomenon (Hays and Singh 2012, Yin 2018). For the last steps (analyze [Step 6], share [Step 7 and 8]), we interpreted the data and reported the findings in the results and discussion to provide context to the findings.

Involving the caregivers of the two participants was an intentional decision to promote the co-production of this study; although parents were not involved in the development or implementation of this study, their qualitative interviews aided in an accurate interpretation, and therefore dissemination, of the study's findings.

Description of participants

Two child participants were originally referred to a larger research study that was to investigate the effect of play therapy on children with autism, presenting with externalizing behaviors. The researchers received approval from the university's institutional review board (IRB Study # 00000912) and all participants completed a written informed consent (parents) and/or an assent (children) prior to their involvement in the research. Due to the COVID-19 pandemic and the university's policy to pause all in-person research in mid-March 2020, the researchers opted to continue daily data collection and to conduct qualitative interviews virtually with the parents after receiving approval for this addendum. This approval allowed the researchers to follow these two participants and their caregivers over the duration of the first six months of the pandemic. To maintain privacy, all participant names are pseudonyms.

Participant 1 and their caregiver

Participant 1, Manuel, an only child, is an 8-year-old Hispanic boy in the third grade. He was referred to play therapy to address concerns such as low self-confidence, anxiety, and frequent attention-seeking behaviors. Manuel was previously diagnosed with ASD, attention-deficit hyperactivity disorder (ADHD), and obsessive-compulsive disorder (OCD). The *child-behavior checklist* (CBCL 6-18; Achenbach and Rescorla

2001) assessment was completed by his mother, Erica, at the time of referral. The CBCL assessment revealed clinically significant concerns on the following subscales: (a) Social, (b) School, (c) Total Competence, (d) Withdrawn/Depressed, (e) Thought Problems, (f) Attention Problems, (g) Internalizing Problems, and (h) Total Problems. Additionally, Manuel scored in the borderline clinical range on the Externalizing Behaviors subscale. Manuel's mother noted that her son's self-esteem has been low because of peer rejection this past year.

Erica, Manuel's mother, is a Hispanic cisgender, married woman. She resigned from her job during the beginning of the pandemic to provide the support that her son needed. Prior to the pandemic, Erica reported that they traveled to visit family in Mexico frequently: eight times in the past five years. However, they were unable to visit their family during the COVID-19 pandemic which created more isolation. During the duration of the study, Manuel and Erica also lost a family member to the COVID-19 virus.

Participant 2 and their caregiver

Participant 2, Lucas, is an 8-year-old Hispanic boy in the second grade. He was previously diagnosed with ASD. Lucas was referred to play therapy services because of difficulties focusing and frequent disruptive behaviors in the classroom. In the previous year, Lucas experienced changes in housing and school districts. At the time of referral, Lucas' mother, Cara, completed the CBCL, revealing clinically significant concerns in the school and total competence subscales as well as borderline clinical concerns on the social subscale.

Lucas' caregivers, Cara (mother, Hispanic cisgender woman) and Rick (father, Hispanic cisgender man), were relocated due to Rick's job site shift in the Spring of 2020 (beginning of COVID-19 pandemic). Cara stayed home with Lucas and Lucas' new brother, Gabriel. Gabriel was born a few months before the pandemic. Rick worked from home during this time.

Data collection and analysis

We asked parents three questions daily to determine their lived experience prior to the pandemic and during the first few months of the pandemic. In addition, we interviewed parents about their experience and their perceptions of their child during this transitory period.

Research question 1

We followed sequential procedures for case study research to obtain daily data from caregivers one and two on targeted child behaviors (Dillman Taylor and Blount 2021, Yin 2018). Questions one through three focused on parent-child interactions, such as how likely the child was to complete a task (e.g. Q1 Based on today's behavior, indicate the number of incidents in

which your child POSITIVELY connected with others.). To analyze the daily caregiver reports, we used descriptive statistics (e.g. mean) to assess if any changes occurred over the six months of daily data collection (Hahs-Vaughn and Lomax 2020). We plotted each child's results for the daily three-item questionnaire and described the data across two segments of data: pre-COVID (26 daily data points) and post-COVID (160 daily data points).

Interviews

We conducted qualitative, semi-structured interviews with three of the four caregivers of the participants. Three caregivers provided consent to be interviewed; one caregiver did not. We developed questions that allowed caregivers to confirm, expand, or challenge existing data regarding child and parental experiences during the pandemic. We minimized researcher and response bias by asking questions that could elicit both positive/negative responses. The research team reviewed questions for clarity and sequencing to enhance succinctness and flow. Interviews were recorded using a HIPPA-protected video platform: Zoom for medical use. We employed an outside company to transcribe de-identified transcripts.

To analyze the interviews for themes, we utilized the consensual qualitative research (CQR; Hill *et al.* 2005, Hill *et al.* 1997) approach for a foundation. Per previous researchers (e.g. Doughty Horn *et al.* 2016, Hanks and Hill 2015), when researchers employ case study as their methodology and another qualitative tradition, researchers tend to follow the data analysis steps of the secondary tradition; therefore, we opted to use CQR to analyze interviews. CQR analysis comprises a team of researchers attaining 'consensus of themes through a systematic process of examining the representativeness across cases' (Barden *et al.* 2021, p. 367). Although CQR is typically used for larger samples, we found this approach useful in determining common themes among these three caregivers (two mothers, one father) and to provide a structure for analyzing themes. CQR is consistent with inductive thematic analysis, 'allowing for themes to emerge direct from the [textual] data' (Fereday and Muir-Cochrane 2006, p. 83). This approach is different from a deductive approach that utilizes a priori codes, which may unintentionally reinforce biases as codes are often value-bound (Roberts *et al.* 2019). Given this methodology is case study research, however, we caution the generalization of the themes beyond these caregivers' experiences.

Role of the researcher. To minimize research bias and create a complex understanding of the caregivers' experience of the pandemic, the CQR process maintains key methodological components. Hill *et al.* (2005) identified that this process is grounded in the assumption

that multiple views are more comprehensive than a single individual's perception; therefore, reaching consensus involves equal involvement, mutual respect, and shared power (Hill *et al.* 1997, 2005). We accomplished this process through developing a research team that consisted of three individuals and an external auditor. The lead research team member, who has extensive experience with CQR, utilized Hill's *et al.* (1997) step-by-step process to train the rest of the research team. Prior to analysis, we bracketed our expectations, previous experiences, and biases related to the pandemic that may create issues for the research team, meaning that we notated our experiences to help refrain from judgment and separate our experiences from those of our participants (Creswell 2007, Moustakas 1994). The bracketing process created opportunities for the team to demonstrate openness in their data exploration, minimizing their own biases. During the first meeting, the team wrote down possible biases. For example, their own pandemic experiences, being a parent during the pandemic, and highlighting either the negative over the positive experiences or vice versa. Therefore, we followed Hill's *et al.* (1997, 2005) recommendations for conducting CQR: use of external auditor, bracketing, and consensus.

Trustworthiness, validity, and objectivity. To obtain trustworthiness of methods, we adhered to Hill's *et al.* (2005) recommendations to script interview questions for consistency across caregivers while allowing for adequate time during the interviews. In addition, the research team was observant to a) the composition of the sample, b) the consensus process among team members (e.g. monitoring disproportionate input, balance, disagreement), c) the application of consistent rules across all caregivers, and d) the use of an external auditor and their feedback. We also utilized triangulation, or the implementation of multiple sources (i.e. targeted areas of child functioning) during data collection to achieve coherence of results (Patton 2002). Coherence of results is critical as it enables researchers to acknowledge that the results are logical and answer the desired research questions. Using labels for each finding (e.g. general, typical), we were able determine the usefulness of findings (Hill *et al.* 2005, Patton 2002). In this case study research, the combination of targeted areas of child functioning and themes from the qualitative interviews creates an illustration of the experiences of the pandemic on children and their caregivers.

Data analysis. We implemented Hill's *et al.* (1997) three main steps for data analysis: (a) develop domains to group the data, (b) create core ideas to summarize caregivers' main ideas, and (c) conduct a cross analysis of data to categorize themes that were consistent across caregivers. We adhered to CQR data analysis

recommendations, which consisted of discussing each domain, core idea, and similar themes to reach consensus among team members. Upon consensus, the external auditor reviewed the results to check the accuracy of the grouping of the raw data, noting the importance of core ideas based on caregivers' words (Hill et al. 2005).

Results

The caregiver's daily data offers information on their lived experience prior to (Days 1-26) and during the COVID-19 pandemic (Days 27-186) and not a pre-post analysis of an intervention. Manuel and Lucas had varying experiences according to their daily data reports. For a summary of their means prior to and during the pandemic, we reported their mean scores for Questions 1, 2, and 3 pre-COVID-19 and during COVID-19 (see Table 1). For Manuel, his scores for positively connecting with others slightly decreased, negative interactions with others decreased by 1.4 points, and he engaged in less repetitive behaviors over the course of the study. Overall, Manuel demonstrated declines in all behaviors over time. The opposite appeared to be true for Lucas. Based on his parental reports, Lucas more than doubled this mean score for positive interactions with others, and increased in his negative interactions with others and repetitive behaviors. Individual changes can be examined visually in Figures 1–6 for daily Questions 1, 2, and 3. For context of their experiences, we look to research question two.

Caregiver domains

CQR data analysis revealed eight domains/topic areas from caregiver responses: behavioral changes, child experience, engagement, external stressors, caregiver experience, resources, routine, and social connection. We provide context per domain below. As per guidelines developed by previous researchers (Hill et al. 2005), we organized the data into categories: six categories labeled 'general' ($n=3$), two categories labeled 'typical' ($n=2$), and no categories were labeled 'variant' or 'rare' ($n=1$).

Behavioral changes

Caregivers described both positive and negative changes that occurred for their child over the course of six months of the pandemic ($n=3$; *general*). Cara noted at the beginning of the pandemic she noticed negative behavioral changes, 'He started to try to gather more negative attention and so much energy that he doesn't

know how to redirect, because there's not much to do.' Whereas six months into the pandemic, she noted positive shifts in Lucas' behavior, 'At this point, we feel that he is able to actually understand emotionally and socially what's happening. He's just not able to articulate properly.'

Child experience

During the interview, caregivers noted their perception of the child's experience during this time ($n=2$; *typical*). In particular, the caregivers explained what the child was communicating to the parent about their experience at home without the usual resources and school experiences. For example, Erica noted,

His anxiety levels have increased, sometimes he says that the COVID situation is horrible. "I want it to end." You know, sometimes he says that. He says sometimes he has been asking a lot, this started since the COVID situation has started. He has been asking a lot for a sibling, "Why I am the only one? Why I don't have a sibling? I don't have any anybody who to go play with?"

Engagement

All caregivers commented on the child's increase in engagement at home, expansion of their interests, and increase in ways to be creative ($n=3$; *general*). For example, Rick explained,

He just ask[ed] us for a piano. He used to have one, but at that time, we tried to get into some classes but it was a temporary interest and he forgot about it. And now he has piqued the interest back because he likes making melodies. So, anything that we can get him engaged, and his creativity, we'll try to get. The latest thing that we did get him was a drone. Even, well we found first a little toy one when we realized that those are cheap because they're actually very, very difficult to handle. So, we got him something that was not expensive, quote unquote, but enough for him to learn to use it and stable enough.

External stressors

Two caregivers communicated during the interview about external stressors, or other factors that are contributing to stress at home ($n=2$; *typical*). Rick noted the increase stress of the political climate and instability of jobs stating, 'Unfortunately, mixing the political climate with the availability of jobs, it's become increasingly probable that we might have to move.' Whereas Erica explained the stress of disconnection and impact of COVID directly on their family. She stated, 'It's been difficult because it's difficult to stay at home for so long. We have been trying to keep social distancing because [...] we have a family relative who died from COVID. So that was very, very traumatic experience.'

Caregiver experience

Caregivers reported on their experience from the start of the pandemic ($n=3$; *general*). They reflected on decisions that had to be made to support their family

Table 1. Means scores of parent daily data pre and during COVID.

	Q1	Q2	Q3	Q1	Q2	Q3
Manuel	7.3	2.9	2.4	6.8	1.5	1.9
Lucas	2.9	4.3	5.3	6.5	6.8	8.5

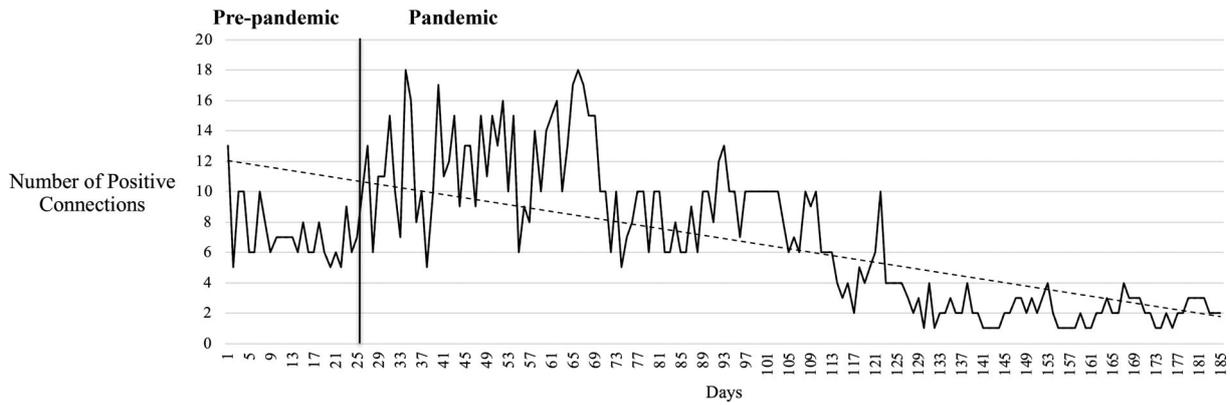


Figure 1. Q1: Manuel's daily positive connections with others.

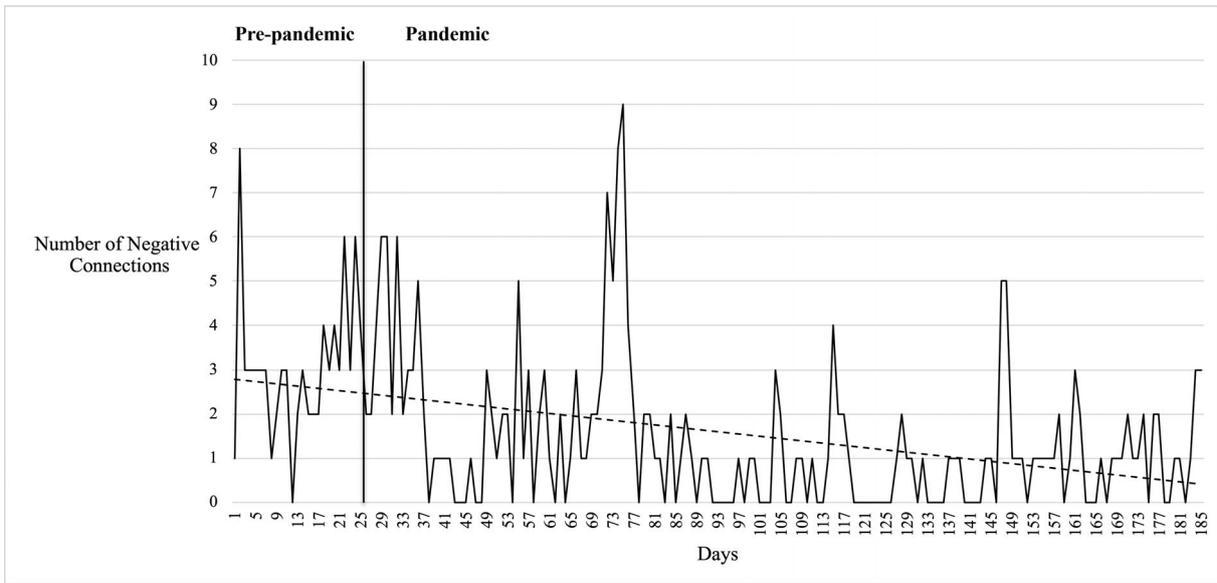


Figure 2. Q2: Manuel's daily incidents involving negative connections with others.

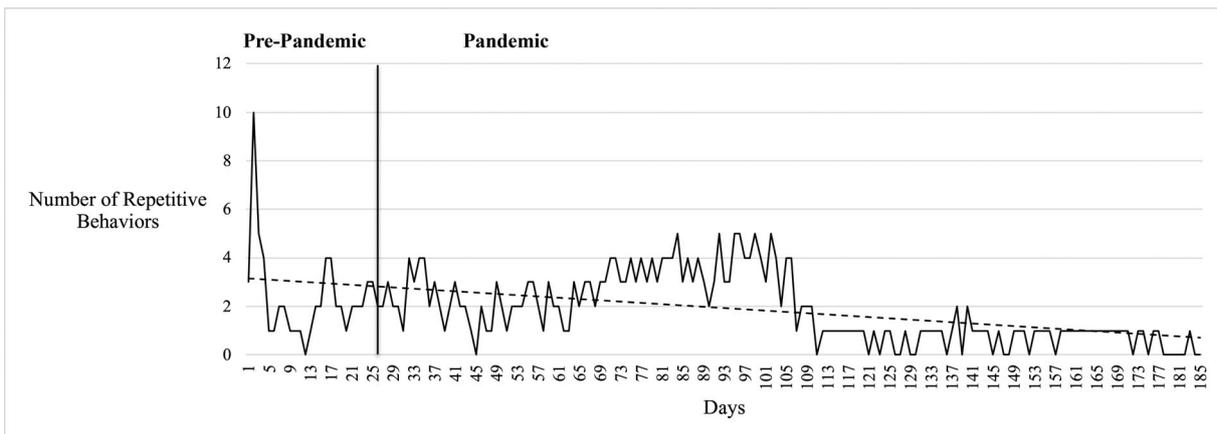


Figure 3. Q3: Manuel's daily incidents involving repetitive behaviors.

and the developmental needs of their children. They also expressed the emotional components of their experience with their families during this time.

Decisions. Caregivers considered screen time limits, job changes, expectations of their children among other

decisions in order to parent during this time. Erica noted that ‘I had to resign to my job to be able to stay at home with him.’ Cara made allowances of screen time use as indicated by her statement,

So, I allowed him to have a little bit more screen time. I would say maybe five, maybe six hours a day. But then after

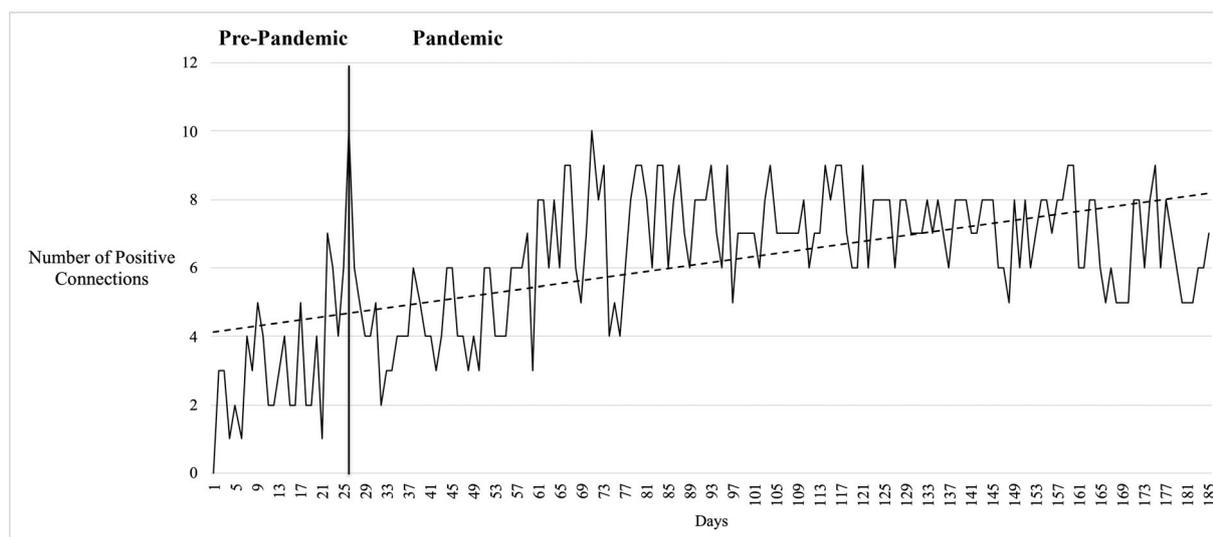


Figure 4. Q1: Lucas' daily positive connections with others.

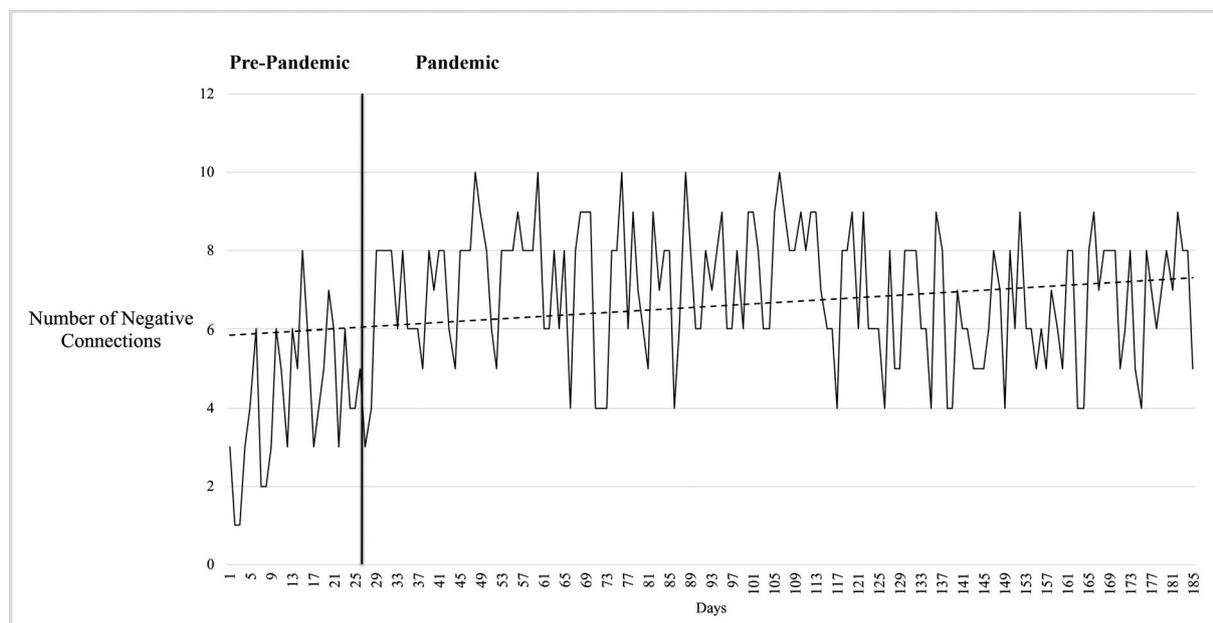


Figure 5. Q2: Lucas' daily incidents involving negative connections with others.

the pandemic, basically he wakes up and he grabs his phone or he goes to the TV. It's very, very hard for us to make him do something else. I mean basically since he wakes up until he goes to bed he's using something. The laptop, it could be the phone, TV... whatever.

Emotional. Emotions were also apparent in both interviews. Caregivers noted anxious feelings, increased sadness, and higher levels of frustration from the start of the pandemic. Erica noted her feelings of guilt that her emotions or reactions may be influencing Manuel's emotional wellbeing, as she indicated:

I recognize that part of his anxiety increase was my fault. There is a part that is not. I know that part of my issue. My fault because I was anxious also about COVID... My emotional reactions are more when I have an anxiety attack. For example, I see something scary about COVID on the news and I start getting anxious. Basically, in those moments,

I feel like I can't think in a rational way. But the rest of the day, emotionally, I cry. I felt like I was getting depressed, but I try not to cry in front of Manuel.

Rick indicated a lack of previous experience that would help him navigate how to support Lucas during this unprecedented time. He stated:

There's not this has happened before or we know what to do, it's for everyone, right? So, there's no reference. And initially...the expectations are unrealistic. I think for most people, you know, generally speaking, I'm going to start a new personal project. Or so we will start off with these expectations. And then if you start feeling frustrated, because in theory, you have more free time and more time with family but in reality, a whole new way of interacting, and it is.

Resources

Caregivers indicated a range of resources, noting some resources were easy to find *via* the internet while others

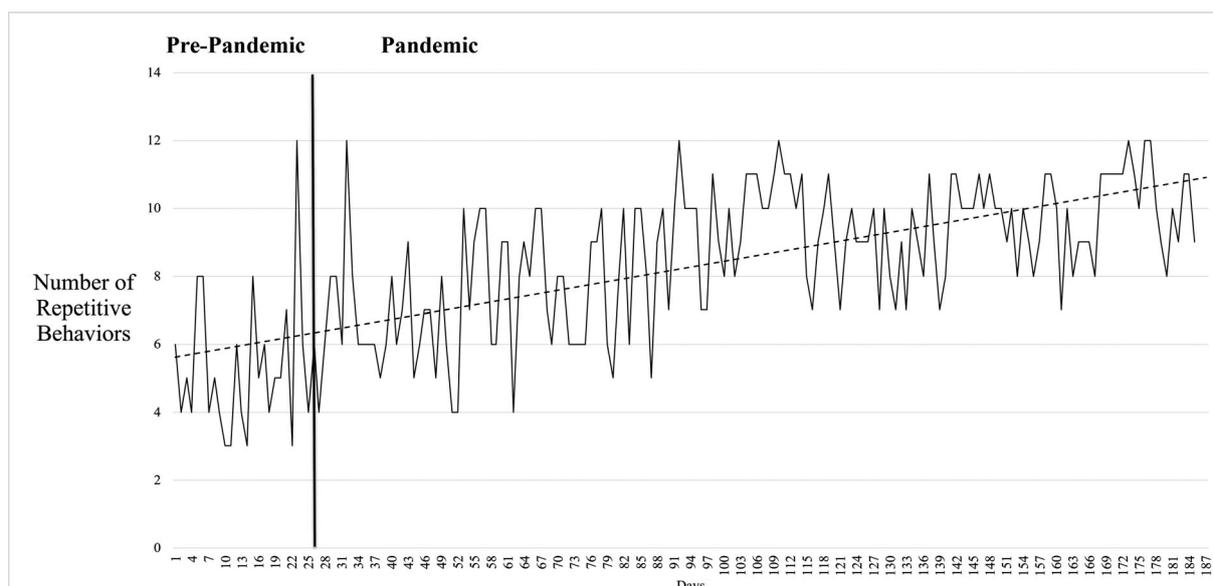


Figure 6. Q3: Lucas’ daily incidents involving repetitive behaviors.

(e.g. in-person counseling, behavioral specialists) were more challenging, especially early in the pandemic ($n = 3$; *general*). Some caregivers were more resourceful and spent time and energy searching for specific resources. Not all caregivers could afford the time to spend on tracking down services. Rick summarized their experience:

You’d say at least this because we have the support. I mean, we had access to yourself via email. Even the previous service for Lucas from years ago was available to us. I mean, we know where to look. And we have the support. Correct? But there are other resources that were not there, especially physically present- whether it’s access to therapy that’s face to face. This school was also not presently there so those were resources that were valuable when they were still having them. So, we don’t we don’t feel abandoned or insufficient. I just say it’s just circumstances that won’t allow us to have access.

Routine

Caregivers noted difficulty in creating and maintaining a structure during this time, especially without the outside forces (i.e. school) that help create a semblance of routine ($n = 3$; *general*). For example, Rick stated, ‘There’s no structure, there’s just... all those little things that you did that force you to have a schedule, cleaner structure are no longer there.’

Social connection

According to caregivers, children also missed social interaction with children their own age ($n = 3$; *general*). Erica indicated, ‘Manuel was missing his friends from school and his teacher.’ Rick stated, ‘Lucas doesn’t have much interaction with children right now. He doesn’t have the opportunity to do that.’ Rick further noted that Lucas would try to talk to adults along their outside walk to build connection.

Discussion

Through case study research, we have conceptualized the experience of two children with ASD during the pandemic and the experiences of their caregivers as they faced unforeseen circumstances. Facilitating qualitative interviews provided a space for caregivers to share about their own experience of the pandemic in a way that would have been lost with just the daily behavioral child questionnaire. We identified through the CQR analysis (i.e. behavioral changes, child experience, engagement, external stressors, caregiver experience, resources, routine, and social connection) the eight caregiver domains that reflected similar child outcomes as other disasters (i.e. behavioral changes, disruptions to routine), which are known to be dysregulating for individuals with ASD (Amorim *et al.* 2020, Meral 2022; Vasa *et al.* 2021). Collectively, caregiver interviews provided additional context for the child’s daily behavioral data to better understand what was happening within each family.

In this study, Manuel’s positive behaviors did not improve through prolonged exposure from the pandemic; however, he reduced his frequency of daily incidents involving negative interactions with others, as well as his daily incidents of repetitive behaviors. Manuel’s visual data of repetitive behaviors (Figure 3) shows a temporary increase in repetitive behaviors during the early stages of the pandemic and then a quick decrease to below their pre-pandemic frequency. These observations indicate Manuel’s ability to adjust to the significant environmental shifts without prolonged negative effects even during the absence of services. Further, Manuel’s visual data of positive interactions with others (Figure 1) shows an immediate increase in daily positive interactions at the onset of the pandemic, which decreased at approximately a month and a half

into quarantine. An important factor to consider in its contribution to these behaviors—or the perception of these behaviors—is that Erica, Manuel’s mother, resigned from her job, and the two were spending more time together. More frequent contact allowed for increased interactions, both positive and negative, and over time may be viewed differently (e.g. connection-seeking versus attention-seeking behaviors).

On the other hand, while Lucas’ negative interactions and repetitive behaviors increased during the pandemic, so did the frequency of positive interactions. Daily data revealed no major outliers for Lucas after the shutdown, indicating that he successfully navigated transitions without a spike in negative behaviors, even after significant events, such as the family’s move or the recent birth of his baby brother. An increase in behaviors for all questions (i.e. positive interactions, negative interactions, repetitive behaviors) for Lucas was observed pre-pandemic (Day 1-26), indicating that after the pandemic, these behaviors followed a previously established trajectory. Without play therapy services to interfere with this trajectory, Lucas’ frequency of negative interactions and repetitive actions continued to increase; however, Cara and Rick expressed wanting to be realistic in their expectations of Lucas.

Developmental considerations

While both children demonstrated relative occurrences of negative behavioral changes, it is imperative to consider the chronological and developmental age of both children and note that these responses are developmentally appropriate (Ray 2016). Many children during this time lost a main source of social interaction: their classroom. Without access to peers, children lose out on creative expression and social engagement, which we know to be crucial aspects of child development (Larsen et al. 2022). Caregivers were forced to find alternative ways to provide engagement for their children, possibly to curb the increase in repetitive behaviors and negative interactions beginning to take place in the home. Autism research often indicates lack of desire or interest towards social interactions, which is in direct opposition to these caregivers’ reports. According to the caregiver participants, both children expressed a longing towards peers and teachers and acted on this desire to meet their social needs. For Lucas, this experience included conversing with strangers and creating a video channel with his uncle, and for Manuel, this request included asking his mother for a new sibling; both children found unique ways to attempt to meet their needs during this time.

Cultural considerations

Many have viewed childhood as a cultural identity itself based on the assertion by Bronfenbrenner (1995) that childhood is a web of practices and norms within one’s

culture that influences all of their early developmental experiences. When individuals discuss childhood as a time period, it is often generalized as a universal experience that has been conceptualized through a Western lens (Bronfenbrenner 1995). In this study, both families are Hispanic and may have different values, practices, or experiences that significantly shaped this time period for both children; to ignore this would be deleterious to all participants involved and ultimately, inimical to the interpretation of our results.

Race and ethnicity may impact autistic children in unique ways, including prevalence, access to services, differential diagnosis, and caregiver outcomes. For example, in a sample of over 100,000 eight-year-old children, Pedersen and colleagues (2012) found an increase in ASD prevalence for both groups, (i.e. Hispanic and Non-Hispanic White) across a five-year period but also found that the prevalence rate was lower for the Hispanic group than for their counterparts. This association has been cautioned in the past, highlighting the difference between reporting rates and prevalence rates (Overton et al. 2007), especially as autism may be underdiagnosed in Hispanic families (CDC 2006). Diagnosticians may experience confusion during the assessment process as the ASD criteria and literature has shifted over time, but researchers have noted that the process is even more complex when diagnosing Hispanic children from bilingual Spanish/English homes and monolingual Spanish homes (Overton et al. 2007). Diagnostic disparities, exposure to knowledge about ASD, and access to services may also be associated with lower socioeconomic status (Colbert et al. 2017), which disproportionately affects Hispanic individuals. During the COVID-19 pandemic, financial insecurity affected Hispanic families at greater rates than other racial and ethnic groups (Gonzalez et al. 2020).

According to *Caregiver Experience* and *External Stressors*, both families in this study were impacted by job insecurity during the COVID-19 pandemic, which Gonzalez and colleagues (2020) found impacted nearly six in 10 Hispanic adults by early April 2020. Undocumented families living in the United States are more likely to experience additional concerns regarding visa status and international travel restrictions, which was a reality for both families involved in this study. To continue, researchers have also explored gender and ethnic differences in coping styles and investigated how Hispanic caregivers of children with ASD navigate their own parenting stress. Willis and others (2016) found that Hispanic mothers may report greater depressive symptoms than Hispanic fathers, which—through caregiver interviews—we discovered Erica was experiencing. Hispanic fathers may also utilize problem solving skills and emotional coping strategies less than Hispanic mothers, but both groups equally engaged in

avoidant coping strategies. Willis and colleagues (2016) also found religion to be a supportive factor for parental well-being, and while supportive coping did not mediate the relationship between optimism and depressive symptoms, Hispanic mothers and fathers reported similar levels of optimism—which was observed for Lucas' parents through their caregiver interviews.

These factors must all be taken into consideration when conceptualizing the findings of this study, making the use of both qualitative and quantitative measures crucial for understanding the complexity of these experiences.

Limitations

A limitation of this study is that the initial research design and research questions were modified; however, the research team would argue this change is also a strength of this study. Following exposure to the original intervention, we can still observe the absence and/or regression of immediate effects due to the impact of the pandemic on the participants. Additionally, the participants of this study included two Hispanic, eight-year-old males both diagnosed with ASD, and the similarities in participant demographics could be viewed as a limitation. This overlap prohibited a more diverse illustration of children with ASD during this time, however, it does allow the two participants and their families to be more comparable to each other. Due to the nature of this research design, and the similarity in demographics between Lucas and Manuel, our intentions are not to generalize these findings to other children with autism, but rather to provide descriptive data for how the pandemic uniquely impacted these families. Additional research is still warranted to expand these findings to other children with autism.

Conclusion

The COVID-19 global pandemic has impacted communities in unique ways, and researchers continue to avidly study its continued impact. Children and families were especially challenged by organizational closures that created barriers to resources such as school, mental health services, and child-care, and children with ASD face even greater risks associated with the pandemic. Pivoting from the original empirical investigation, we chose to continue monitoring two participants and their families, anticipating a need for increased support during this time.

We utilized both qualitative and quantitative measures for this case study approach so caregiver interviews could provide context for the behavioral changes that occurred throughout the pandemic. This study provides an example of how to collect qualitative data as a mechanism to explain the results found *via* quantitative data and how to involve other stakeholders (i.e. parents) in autism research to prevent the inaccurate

interpretation of data. This step is especially important when the researchers are non-autistic in order to mitigate the potential for neurotypical bias (Holt *et al.* 2022). Through targeted aspects of child functioning and qualitative interviews, this study documented positive and negative outcomes for two children with ASD and their families during the COVID-19 pandemic. Additional research and interventions are needed to continue to understand how to best support this community during ambiguous and challenging events.

Disclosure statement

No potential conflict of interest was reported by the authors.

Data availability statement

The data that support the findings of this study are available from the corresponding author, [DDT], upon reasonable request.

References

- Achenbach, T. M. and Rescorla, L. A. 2001. *Manual for the ASEBA school-age forms & profiles*. University of Vermont, Research Center for Children, Youth, and Families. Available at: <https://aseba.org/wp-content/uploads/2019/01/ASEBA-Reliability-and-Validity-School-Age.pdf>.
- American Psychiatric Association. 2013. *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: American psychiatric association.
- Amorim, R., Catarino, S., Miragaia, P., Ferreras, C., Viana, V. and Guardiano, M. 2020. The impact of COVID-19 on children with autism spectrum disorder. *Revista de Neurologia*, 71, 285–291.
- Barden, S. M., Dillman Taylor, D., Silverio, N., Carlson, R. G., Whitbeck, M., Carroll, N. and Velez, M. 2021. Motivations to enroll and engage in relationship education programs: A qualitative investigation of key process factors. *Journal of Couple & Relationship Therapy*, 20, 365–383.
- Bronfenbrenner, U. 1995. Developmental ecology through space and time: A future perspective. In P. Moen, G. H. Elder, Jr., & K. Luscher (Eds.), *Examining lives in context: Perspectives on the ecology of human development* (pp. 619–647). Washington, DC: American Psychological Association.
- Brown, S. M., Doom, J. R., Lechuga-Pena, S., Watamura, S. E. and Koppels, T. 2020. Stress and parenting during the global COVID-19 pandemic. *Child Abuse & Neglect*, 110, 104699.
- Centers for Disease and Prevention Control (CDC). 2020. *Guidance for direct service providers, caregivers, parents, and people with developmental and behavioral disorders*.
- Colbert, A. M., Webber, J. and Graham, R. 2017. Factors that influence autism knowledge in Hispanic cultures: A pilot study. *Journal of Racial and Ethnic Health Disparities*, 4, 156–164.
- Compas, B. E., Connor-Smith, J. K., Saltzman, H., Thomsen, A. H. and Wadsworth, M. E. 2001. Coping with stress during childhood and adolescence: Problems, progress, and potential in theory and research. *Psychological Bulletin*, 127, 87–127.
- Creswell, J. W. 2007. *Qualitative inquiry and research design: Choosing among five approaches* (3rd ed.). Thousand Oaks, CA: SAGE.
- Creswell, J. W. and Poth, C. N. 2016. *Qualitative inquiry and research design: Choosing among five approaches*. SAGE.
- Dillman Taylor, D., & Blount, A. J. 2021. Case study research. In S. Flynn (Ed.), *Research design for the behavioral sciences: An applied approach*. Danvers, Massachusetts: Springer Publishing Company.
- Doughty Horn, E. A., Crews, J. A., Guryan, B. A. and Katsilometes, B. M. 2016. Identifying and addressing grief and loss issues in a person with aphasia: A single-case study. *Journal of Counseling & Development*, 94, 225–233.
- Edmonds, C. O. 2017. Designing emergency preparedness resources for children with autism. *International Journal of Disability, Development and Education*, 64, 404–419.

- Fereday, J. and Muir-Cochrane, E. 2006. Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development. *International Journal of Qualitative Methods*, 5, 80–92.
- Ferenc, K., Byrka, K. and Król, M. E. 2023. The spectrum of attitudes towards the spectrum of autism and its relationship to psychological distress in mothers of children with autism. *Autism : The International Journal of Research and Practice*, 27, 54–64.
- Gonzalez, D., Karpman, M., Kenney, G. M. and Zuckerman, S. 2020. Hispanic adults in families with noncitizens disproportionately feel the economic fallout from COVID-19. *Urban Institute*, 13.
- Hahs-Vaughn, D. L. and Lomax, R. G. 2020. *Statistical concepts-a first course*. Routledge.
- Hanks, B. B. and Hill, N. R. 2015. Relational dynamics within the context of deafness: A case study of the supervision triad. *Journal of Counseling & Development*, 93, 299–311.
- Hausman, E. M., Black, S. R., Bromet, E., Carlson, G., Danzig, A., Kotov, R. and Klein, D. N. 2020. Reciprocal effects of maternal and child internalizing symptoms before and after a natural disaster. *Journal of Family Psychology : JFP*, 34, 836–845.
- Hays, D. G. and Singh, A. A. 2012. *Qualitative inquiry in clinical and educational settings*. New York, NY: Guilford Press.
- Hicks, T. A., Bountress, K. E., Resnick, H. S., Ruggiero, K. J. and Amstadter, A. B. 2022. Caregiver support buffers posttraumatic stress disorder symptoms following a natural disaster in relation to binge drinking. *Psychological Trauma : Theory, Research, Practice and Policy*, 14, 1142–1148.
- Hill, C. E., Knox, S., Thompson, B. J., Williams, E. N., Hess, S. A. and Ladany, N. 2005. Consensual qualitative research: An update. *Journal of Counseling Psychology*, 52, 196–205.
- Hill, C. E., Thompson, B. J. and Williams, E. N. 1997. A guide to conducting consensual qualitative research. *The Counseling Psychologist*, 25, 517–522.
- Hillman, H. 2018. Child-centered play therapy as an intervention for children with autism: A literature review. *International Journal of Play Therapy*, 27, 198–204.
- Hollenstein, T., Granic, I., Stoolmiller, M. and Snyder, J. 2004. Rigidity in parent-child interactions and the development of externalizing and internalizing behavior in early childhood. *Journal of Abnormal Child Psychology*, 32, 595–607.
- Holt, A., Bounekhla, K., Welch, C. and Polatajko, H. 2022. Unheard minds, again and again”: Autistic insider perspectives and theory of mind. *Disability and Rehabilitation*, 44, 5887–5897.
- Larsen, L., Helland, M. S. and Holt, T. 2022. The impact of school closure and social isolation on children in vulnerable families during COVID-19: A focus on children’s reactions. *European Child & Adolescent Psychiatry*, 31, 1–11.
- Leaf, J. B., Cihon, J. H., Ferguson, J. L., Milne, C. M., Leaf, R. and McEachin, J. 2021. Advances in our understanding of behavioral intervention: 1980 to 2020 for individuals diagnosed with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 51, 4395–4410.
- Lee, S. J., Ward, K. P., Chang, O. D. and Downing, K. D. 2021. Parenting activities and the transition to home-based education during the COVID-19 pandemic. *Children and Youth Services Review*, 122(, 105585.
- Manning, J., Billian, J., Matson, J., Allen, C. and Soares, N. 2021. Perceptions of families of individuals with autism spectrum disorder during the COVID-19 crisis. *Journal of Autism and Developmental Disorders*, 51, 2920–2928.
- Marsh, A., Spagnol, V., Grove, R. and Eapen, V. 2017. Transition to school for children with autism spectrum disorder: A systematic review. *World Journal of Psychiatry*, 7, 184–196.
- Meral, B. F. 2022. Parental views of families of children with autism spectrum disorder and developmental disorders during the COVID-19 pandemic. *Journal of Autism and Developmental Disorders*, 52, 1712–1724.
- Mikolajczak, M., Gross, J. J. and Roskam, I. 2019. Parental burnout: What is it, and why does it matter? *Clinical Psychological Science*, 7, 1319–1329.
- Mikolajczak, M. and Roskam, I. 2018. A theoretical and clinical framework for parental burnout: The balance between risks and resources (BR2). *Frontiers in Psychology*, 9, 886.
- Moustakas, C. E. 1994. *Phenomenological research methods*. Thousand Oaks, California: Sage Publications, Inc.
- Osofsky, J. D. and Osofsky, H. J. 2018. Challenges in building child and family resilience after disasters. *Journal of Family Social Work*, 21, 115–128.
- Overton, T., Fielding, C. and Garcia de Alba, R. 2007. Differential diagnosis of Hispanic children referred for autism spectrum disorders: Complex issues. *Journal of Autism and Developmental Disorders*, 37, 1996–2007.
- Patton, M. Q. 2002. Two decades of developments in qualitative inquiry: A personal, experiential perspective. *Qualitative Social Work*, 1, 261–283.
- Pedersen, A., Pettygrove, S., Meaney, J., Mancilla, K., Gotschall, K., Kessler, D. B., Grebe, T. A. and Cuniff, C. 2012. Prevalence of autism spectrum disorders in Hispanic and non-Hispanic White children. *Pediatrics*, 129, e629–e635.
- Ray, D. 2016. *Therapist guide to child development: The extraordinarily normal years*. New York, NY: Routledge.
- Roberts, K., Dowell, A. and Nie, J. B. 2019. Attempting rigour and replicability in thematic analysis of qualitative research data: A case study of codebook development. *BMC Medical Research Methodology*, 19, 1–8.
- Schmitt-Grohé, S., Teoh, K. and Uribe, M. 2020. COVID-19: Testing inequality in New York City. *National Bureau of Economic Research* 1–14.
- Stake, R. E. 1995. *The art of case study research*. Thousand Oaks, California: SAGE.
- Taboas, A., Doepke, K. and Zimmerman, C. 2023. Preferences for identity-first versus person-first language in a US sample of autism stakeholders. *Autism : The International Journal of Research and Practice*, 27, 565–570.
- Tokatly Latzer, I., Leitner, Y. and Karnieli-Miller, O. 2021. Core experiences of parents of children with autism during the COVID-19 pandemic lockdown. *Autism : The International Journal of Research and Practice*, 25, 1047–1059.
- Toseeb, U. and Asbury, K. 2023. A longitudinal study of the mental health of autistic children and adolescents and their parents during COVID-19: Part 1, quantitative findings. *Autism : The International Journal of Research and Practice*, 27, 105–116.
- Uzun, H., Karaca, N. H. and Metin, S. 2021. Assessment of parent-child relationship in COVID-19 pandemic. *Children and Youth Services Review*, 120, 105748.
- Vasa, R. A., Singh, V., Hologue, C., Kalb, L. G., Jang, Y. and Keefer, A. 2021. Psychiatric problems during the COVID-19 pandemic in children with autism spectrum disorder. *Autism Research : official Journal of the International Society for Autism Research*, 14, 2113–2119.
- Valentovich, V., Goldberg, W.A., Garfin, D.R. and Guo, Y. 2018. Emotion coregulation processes between mothers and their children with and without autism spectrum disorder: Associations with children’s maladaptive behaviors. *Journal of Autism and Developmental Disorders*, 48, 1235–1248.
- White, L. C., Law, J. K., Daniels, A. M., Toroney, J., Vernoia, B., Xiao, S., Feliciano, P. and Chung, W. K.; SPARK Consortium. 2021. Brief report: Impact of COVID-19 on individuals with ASD and their caregivers: A Perspective from the SPARK cohort. *Journal of Autism and Developmental Disorders*, 51, 3766–3773.
- Willis, K., Timmons, L., Pruitt, M., Schneider, H. L., Alessandri, M. and Ekas, N. V. 2016. The relationship between optimism, coping, and depressive symptoms in Hispanic mothers and fathers of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 46, 2427–2440.
- Yin, R. K. 2018. *Case study research and applications*. Los Angeles, CA: SAGE.