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### Title

Parenting Children With Autism Spectrum Disorder (Asd) In The Covid- 19 Pandemic: A Cross-cultural Comparison

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### Author

Moynihan, Johannah

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PARENTING CHILDREN WITH AUTISM SPECTRUM DISORDER (ASD) IN THE COVID-19 PANDEMIC: A CROSS-CULTURAL COMPARISON

By

Johannah Emily Moynihan

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APPROVED

Dr. Katherine Stavropoulos  
Department of Education

Dr. Richard Cardullo, Howard H Hays Jr. Chair  
University Honors

## **Abstract**

The COVID-19 pandemic has brought unparalleled uncertainty, anxiety, and distress into daily life, especially for parents of individuals with autism spectrum disorder (ASD). Children with ASD often struggle in the face of interrupted routines and display difficulty with change, as indicated by the ASD diagnostic components of impaired social interaction and restricted, repetitive behavior patterns. The current review involves an inquiry into the parental distress of caregivers worldwide as they navigate how to support the mental health of themselves and their children. Study objectives are nested in their cultural context on the social acceptance, support service provision, and (mal)adaptiveness of certain behaviors characteristic of ASD. A systematic review of fourteen studies sought to understand the parental stress of raising an individual with ASD in the unprecedented, turbulent context of the COVID-19 pandemic. Given the overrepresentation of Western perspectives in the academic literature about ASD, the current study focused on a cross-cultural view of what familial and social models protect against or exacerbate parental distress. Accordingly, the deleterious impact of parental distress was mitigated in countries equipped with well-established support service infrastructure, as well as a cultural context that destigmatizes ASD, supports caregivers' mental health needs, and promotes adaptive coping strategies. Reliant on study findings, successful cultural protective practices that parents may incorporate to ameliorate their own and their child's well-being are highlighted.

*Keywords:* autism spectrum disorder, mental health, cross-cultural psychology

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## Table of Contents

ABSTRACT .....	2
ACKNOWLEDGEMENTS .....	3
INTRODUCTION .....	6
BACKGROUND .....	8
<b>PARENTAL MENTAL HEALTH</b> .....	8
<b>ROLE OF CULTURE</b> .....	9
METHODS .....	12
PRESENT FINDINGS.....	13
<b>THE MIDDLE EAST</b> .....	14
<b>ASIA</b> .....	16
<b>EUROPE</b> .....	19
<b>NORTH AMERICA</b> .....	22
<b>AFRICA</b> .....	23
DISCUSSION.....	24
<b>EXACERBATION OF ALREADY HIGH DISTRESS</b> .....	25
<b>ADOPTING MULTIPLE ROLES</b> .....	25
<b>MENTAL HEALTH AND AUTISM RESOURCE INFRASTRUCTURE</b> .....	26
<b>COPING STRATEGIES</b> .....	27
<b>COUNTEREVIDENCE: DECREASES IN DISTRESS</b> .....	28
<b>CULTURAL CONTEXT</b> .....	28
LIMITATIONS.....	32
<b>EXCLUSION OF MEANINGFUL SCHOLARSHIP</b> .....	32
<b>ACCESSIBILITY OF RESEARCH DESIGNS</b> .....	33
FUTURE DIRECTIONS .....	33
<b>SECONDARY CAREGIVERS</b> .....	33
<b>DISCRIT LENS</b> .....	34
<b>LONGITUDINAL MENTAL HEALTH OUTCOMES</b> .....	34
CONCLUSION.....	35
REFERENCES .....	36

# **Parenting Children with Autism Spectrum Disorder (ASD) in the COVID-19 Pandemic: A Cross-Cultural Comparison of Parental Distress**

## **Note**

In this review, several terms describe children with ASD, including "affected by ASD," "children with autism," and "autistic children," to encapsulate both the person-first and identity-first models of representing autism in the academic literature and to add a variety to the text. The author recognizes the clinical precedent to describe individuals as people with symptoms of a disorder as well as to validate the identity of autistic scholars and community members that moves away from autistic as a stigma or a deficit (see Botha et al., 2020; Chu et al., 2020; Milton, 2012). This paper advocates dually for the agency and celebration of the autistic identity while considering the psychological consequences of severe ASD symptoms on family dynamics.

## **Introduction**

The COVID-19 pandemic has ushered in a wave of uncertainty, fear, and anxiety, especially for parents of children with autism spectrum disorder (ASD). These youth often struggle in the face of lost routines and display difficulty with change, as indicated by the ASD diagnostic components of impaired social interaction and restricted, repetitive behavior patterns (American Psychiatric Association [APA], 2022). Impaired social communication and interactions may translate to difficulty understanding and responding appropriately to others' emotions, responding to nonverbal cues such as body language, and forming, maintaining, or understanding relationships (APA, 2022). Restricted and repetitive behaviors may look like repetitively lining up toys, repeating phrases from a parent or television show, difficulty with change and routine disruption, hyper-fixated interests, or being under or overstimulated by

sensory information such as light and noise (APA, 2022). Although not innately harmful, these behaviors may be considered disruptive, especially in social situations where they may draw unwanted attention to parents' perceived inability to manage their child's behaviors.

Consequently, the added routine disruptions, context of anxiety and fear, and difficulty with maintaining a sense of normalcy and consistency for individuals with ASD from the pandemic set the stage for increased parental distress, as delineated by stress, anxiety, and depression (see Wang et al., 2021).

Autism spectrum disorder is becoming more frequently diagnosed due to an increase in autism awareness and acceptance, with a prevalence of approximately 1 in 44 individuals, which replicates in many countries even if the diagnostic rates are lower in some countries without as much ASD visibility (see Maenner et al., 2021; Wang et al., 2021). However, much is unknown about autism and its neural mechanisms, which may lead to misconceptions of people with autism as not interested in social relationships, inherently dangerous, or affected by autism because their parents were cold and uncaring (see John et al., 2018). When these misconceptions permeate society, it becomes more difficult for families of individuals with autism to access support service resources and gain a community understanding of the complexities of their lived experience. Accordingly, cultural context determines support for individuals affected by ASD and their families and may minimize or worsen parental distress. These distress appraisals are nested in their cultural context on the social acceptance, support service provision, and (mal)adaptiveness of certain behaviors characteristic of ASD.

The current review will examine which cultural perspectives influence parental distress with the hopes of bolstering future mental health interventions. As many individuals with severe manifestations of autism cannot self-advocate, parents must champion their child's best interests



and fight for acceptance on top of their caregiving responsibilities. However, when parents face inundating distress, they begin to doubt their ability to care for themselves or their children, especially during COVID-19, a time of overarching uncertainty and social isolation. This review may yield results that can help decrease the stigma associated with autism and assist parents of children with autism to feel less isolated from their friends, family, and community who do not share the same lived experiences.

Given the overrepresentation of Western perspectives in the academic literature about ASD, it is vital to take a cross-cultural view of what familial and social models protect against or exacerbate parental distress. Accordingly, the researcher expects less parental distress in non-Western cultures that embrace a collectivist, family-oriented approach to caregiving for individuals with autism. Similarly, in countries with more shame accompanying an autism diagnosis, caregivers are predicted to experience more alienation and accompanying maladaptive mental health outcomes. Based on the study findings, the researcher will present recommendations on what successful cultural protective practices parents may incorporate to ameliorate the family's welfare and coping strategies in a holistic intervention program that supports families with ASD.

## **Background**

### **Parental Mental Health**

Parents of children with ASD must contend with societal stigmas about their children's diagnoses, the possibility of disruptive behavioral challenges from their children, and the inundation of unsolicited advice and microaggressions from well-meaning community members. It is well-established that parents of autistic children experience higher levels of baseline distress, defined as anxiety, depression, and stress, compared to parents of typically developing children (see Alnazly & Abojedi, 2019; Kütük et al., 2021; Sanner & Neece, 2018). Compared to parents

of typically developing children, parents of children with autism may encounter more perceived burdens of taking care of their children, who may present communication differences, display loud or repetitive behavioral patterns, and struggle with aggression in periods of transition or sensory overload (Alnazly & Abojedi, 2019). Additionally, parents of children with autism may have difficulty connecting with their children using typical avenues of child-initiated joint attention and conversations which may contribute to a strained relationship between parents and children that exacerbates parental distress (Sanner & Neece, 2018).

Furthermore, parental psychological distress affects the quality of parent-child and parent-parent relationships, as Kütük and colleagues (2021) present evidence that parental psychopathologies as a result of supporting a child affected by ASD are associated with more severe psychopathology in the other parent in a two-parent household, and with heightened ASD symptom severity for the child, creating a deleterious positive feedback loop. In this positive feedback loop, the child exhibits disruptive behavior, which stresses out the parent, making parents more stressed and worse equipped to respond to the child's needs, compounding the child's behavioral difficulties (Kütük et al., 2021). Consequently, this population is notably at risk for the additive effect of stressors, in which the manifold demands of caregiving for an individual with autism combine with financial, parental mental health, and other stressors to reach an unbearable accumulative distress experience (Bradshaw et al., 2021). Accordingly, parents of autistic children are primed for an accumulation of stressors from their day-to-day life, culminating in a risk factor of acute distress during stressful crises such as job loss or marital discord (Bradshaw et al., 2021).

## **Role of Culture**

Cultural conceptions of disability play a crucial role in the awareness and acceptance of individuals with ASD, the level of government infrastructure dedicated to supporting the family's mental health, and the comfort with which parents feel free to disclose if they are struggling. Given that autism spectrum disorders affect individuals across the globe, supporting families with autism is an issue of global importance. Accordingly, cultural contexts influence the degree of shame, guilt, anger, or frustration accompanying an ASD diagnosis.

For example, in Romania, a southeastern European country, an autism diagnosis is a reason for families to mourn the devastating notion that their child will never be the perfect child they had envisioned (Dobre & Topala, 2020). However, Dobre and Topala (2020) suggest that parents may overcome this shame, embarrassment, and culturally dictated disappointment by engaging in active coping strategies that accept their child's diagnosis and the therapeutic interventions their child needs to thrive as facts of life. Although viewing an autism diagnosis as a death sentence may seem harsh and discriminatory, it is integral for researchers to understand the cultural context of these families and responsively adapt their intervention implementation. Also, understanding cultural perspectives around disability can help mental health professionals tailor their communication to connect families with available resources and acknowledge their cultural beliefs while encouraging parents to look at their child's assets and growth potential.

However, this discriminatory view of autism is not universal, and support provision relies heavily on cultural context. For example, Paula and colleagues (2020) highlight the cultural conceptions of autism across Brazil, Argentina, Chile, Uruguay, Venezuela, and the Dominican Republic by assessing caregiver needs facilitated by the *Red Espectro Autista Latinoamerica* network of almost 3,000 participants. A principal concern across all six countries was the desire for more community awareness of autism, reducing social stigma surrounding autism, and the

lack of support service and behavioral therapy infrastructure. Similarly, many families reported emotional and psychological distress and perceptions of helplessness regarding the future or supporting their autistic child. Caregivers also noted stress relating to the financial burden, often paying out of pocket for behavioral therapies and reducing work hours to attend to their child's needs. In light of the dominance of Western perspectives on autism research, studies such as Paula et al. (2020) provide valuable insight into the cultural stigma around severe autism symptoms and the cultural strengths of familism in Latin American cultural contexts.

### **Need For Current Review**

Some systematic reviews have performed cross-cultural comparisons of parental distress of parents of children with autism during the COVID-19 pandemic, but only between two or three countries (e.g., Burnett et al., 2021; Sharma et al., 2021). Larger scale reviews such as Alonso-Esteban et al. (2021) and Yilmaz et al. (2021) have investigated parental distress of parents of autistic children during the lockdown orders but have had a limited geographic range of studies. No review has investigated this parental distress concerning the cultural context in the literature on the newly emergent and ongoing pandemic in fourteen geographically diverse countries. Accordingly, this review strives to identify which countries have built infrastructure to meet the needs of their families with ASD responsively and responsibly to identify models for expanding support networks in the wake of global stressors.

Given the known mental health ramifications of accumulated stressors on parents of children with ASD, it is integral to investigate parents' experiences in the face of new and worsened stressors brought on by the COVID-19 pandemic, for example, encouraging their children to comply with the new sensory stimuli or masking and frequently washing their hands necessitated by social distancing guidelines. Furthermore, due to the timely nature of the

lockdown mandates, it is necessary to look for trends in coping with parental distress that could support current families with autism as the pandemic designation draws to a close, but the mental health effects linger. In this way, this review can summarize coping strategies, supportive cultural contexts, and infrastructure that helped parents survive the pandemic challenges and investigate any potential factors to consider moving forward to look for ways to best support parents through periods of acute stress and the demands of everyday life.

### **Methods**

This project involves a systematic review of the present literature on the effect of the pandemic on parents of children with ASD from countries across North America, Asia, the Middle East, Africa, and Europe. Preliminary searches for English-language, peer-reviewed articles published between 2019 and 2023 pertaining to parental stress in the COVID-19 pandemic employed the EBSCOhost, Academic Search Complete, and APA PsycInfo databases, respectively. The researcher searched for relevant, full-text available articles by using search terms “autism OR asd OR autism spectrum disorder,” “parent stress OR caregiver stress OR parent distress OR caregiver distress,” and “covid-19 OR coronavirus OR sars-cov-2 OR 2019 pandemic.” Studies that depict parental and child distress are allowed, but articles focused on the child's experiences alone are excluded from the current review for clarity. Additionally, the researcher focused on parents' experiences with autistic children, not other neurodevelopmental disabilities, to investigate the influence of the pandemic specifically on the need for consistent routines and other ASD-related symptomatology.

After reviewing the literature spanning the last four years, the author selected fourteen studies to highlight in-depth from geographically diverse study locations. Although the author found additional European studies capturing lockdown parental distress for caregivers of

children with autism in France (Miniarikova et al., 2022), the United Kingdom (Toseeb & Asbury, 2023), and Greece (Papanikolaou et al., 2022), as well as additional articles from the United States (Kalb et al., 2021) and Canada (Jacques et al., 2022), these studies were excluded to avoid the overrepresentation of Western perspectives. In this way, the researcher oversampled studies from Non-Western perspectives, such that eight of the fourteen studies (57%) represented countries typically excluded from Eurocentric systematic reviews. Additionally, studies not captured by Alonso-Esteban et al. (2021) and Yilmaz et al. (2021) are reviewed, especially those recently published in 2022.

After reading these fourteen papers, the author uncovered prominent themes based on each study's empirical findings. These key themes, consistent across one or more studies, helped to shape the compilation of trends and to form recommendations for future research. The researcher noted data about the study authors, publication year, study location, child age range, parent participant sample size, parental distress/well-being measurement, and methodology to contextualize each generated theme.

### **Present Findings**

Initial exploration into the parental distress appraisals from fourteen different cultural contexts revealed an exacerbation of parental stress across the board during the COVID-19 pandemic, influenced by the surrounding cultural context. Accordingly, the researcher organized the current findings by geographical location, which provides insight into the geopolitical contexts of each highlighted country; however, there is also variability in parental experiences within each geographical area. In the present findings section, further detail uncovers the cultural contexts, support service networks, main parental concerns, and coping mechanisms parents used to navigate the pandemic.

## **The Middle East**

### ***Saudi Arabia***

Alhuzimi (2021) noted increased stress and deteriorated well-being in parents of children with ASD associated with the lockdown mandate and a lack of governmental support structures to facilitate their own and their child's mental health needs ( $N=150$ ,  $M_{Child\ Age}=2.33$  years).

Parents in this study struggled with their well-being and a lack of support from the government of Saudi Arabia. In the cultural context of associating autism with shame, evil, and overall ill-repute on the family status in Saudi Arabia and not looking into the biological foundations of autism, parenting a child with autism becomes unduly stressful and isolating, which may lead to parents not seeking out social and governmental support for fear of judgment (Alhuzimi, 2021). Initiatives in Saudi Arabia and other conservative cultural contexts to explore the scientific basis of autism to supplement their religious and cultural beliefs could craft a more empathetic attitude towards families with autism.

### ***Qatar***

Qatari families, described by Khan et al. (2021), reported heightened levels of psychological and emotional strain, quantified as caregiver burden, for approximately 46% of parents, even when their child's aggression was not exacerbated or decreased ( $N=26$ ,  $M_{Child\ Age}=14.8$  years). As a result of the increased roles and responsibilities, parents must care for their child in the home for an increased number of hours per day, leading to the accrual of physical and mental fatigue. However, notably, 54% of caregivers noted a decrease or no change in their distress, potentially coinciding with their child's decline in symptomatology with increased routines (Khan et al., 2021). One potential contributing factor to this protective outcome is the well-established and well-funded National Autism Strategy framework, which actively promotes

resources and support for families, and directs behavior support initiatives and mental health for parents (Azeem, 2018; Khan et al., 2021). By taking an active approach to facilitate mental health support for caregivers and establishing a comprehensive framework for individuals with autism to access behavioral health services, Qatar may serve as a role model for other countries to develop a detailed, collaborative national plan that supports the mental health needs of the whole family. Since this context of proactive support has been enacted since 2017, although the pandemic brought on novel challenges in establishing new routines and maintaining children's comfort levels, parents mitigated their caregiving burden and their child's aggression (Azeem, 2018; Khan et al., 2021).

### *Israel*

Employing an immersion/crystallization narrative method, Tokatly Latzer et al. (2021) extracted key themes from parents regarding their experiences with the pandemic, including their stress appraisals, coping strategies, and concerns ( $N=31$ , Median child age=5 years, 11 months). A substantial source of anxiety revolved around interruptions to their child's special education services, potential regressions and loss of academic and life skills, the resurgence or emergence of repetitive behaviors, and a lack of specific developmental knowledge and educational strategies to address their child's learning needs (Tokatly Latzer et al., 2021). Furthermore, some parents experienced helplessness due to difficulty fulfilling their child's sensory, outdoor activity, space, sleep, routine structure, and food preference needs. However, despite accounts of stress due to child regression, destructive behaviors, and difficulty paying attention in a virtual educational setting, some parents reported hope and growth associated with positive parental coping strategies and outlooks (Tokatly Latzer et al., 2021). Parents who endorsed the lowest stress were flexible, seized opportunities to exert agency over setbacks such as limited living



space and resources, and were grateful for extra family time and interactions with their children (Tokatly Latzer et al., 2021). In response to these findings, future interventions may teach parents how to positively reframe stressors to minimize detrimental responses to and frustration with their child while strengthening familial bonds and supporting families with the financial and social resources to foster their children's interests.

## **Asia**

### ***India***

However, this reduction of child aggression and parental distress was not experienced in every cultural context, as Joseph and Delariarte (2022) highlight in their investigation of parental anxiety, stress, and depression ( $N=100$ ,  $M_{Child\ Age}=9.09$  years). In a harrowing display of statistics, Joseph and Delariarte (2022) revealed staggeringly high distress self-reports for caregivers, with ratings of moderate, severe, or extremely severe distress for depression (82% of participants), anxiety (74%), and stress (84%). Compounding these alarming trends, low-income participants, and caregivers of children with moderate and severe behavioral challenges associated with their ASD diagnosis, elicited the highest depression, anxiety, and stress levels (Joseph & Delariarte, 2022). In effect, the caregivers who faced the most intense situational and environmental stressors particularly suffered from difficulty accessing professional health or mental health resources, the closure of specialized schools, and the overall breakdown in the chain of child behavioral intervention services (Joseph & Delariarte, 2022). In the absence of an established safety net to identify families needing supplemental financial or psychosocial support, the daily worries of these families are compounded by the global stress of the pandemic and produce dire mental health effects.

### ***Malaysia***

Similarly, Anuar et al. (2022) observed an uptick in stress for Malaysian parents as caregivers became the sole support for their children and themselves during the confines of the stay-at-home movement control order ( $N=230$ ,  $M_{Child\ Age}=8.6$  years). Given the pattern of unchecked parental stress transforming into caregiver burnout, resentment towards the child, or guilt, it is critically important for caregivers to focus on stress management and adopting active coping strategies (Anuar et al., 2022). One such approach is connecting with fellow parents via social media such as Facebook. In the highlighted study, participants were from the *Autisme Malaysia* Facebook group, through which parents can casually share their experiences with quarantine, their caregiver stress, and potential suggestions for making the quarantine a smoother experience for the whole family (Anuar et al., 2022). With the rise of digital connectivity and communication, national and regional mental health services should consider online support groups and expand the reach of their current services by offering telehealth services for parents and children and facilitating social support for parents. These interventions may work particularly well in cultural contexts such as Malaysia, where there is already groundwork for some specific autism intervention and caregiver social support programs.

### ***China***

Wang and colleagues (2021) noted heightened anxiety, depression, a more difficult time coping with the new challenges elicited by the pandemic, and a weaker sense of resilience for Chinese parents of children with ASD ( $N=1764$ , 45% three-six years old) versus parents of typically developing children ( $N=4962$ , 42% three-six years old). Exacerbated disruptive symptoms contributed to a positive feedback loop of parental stress, particularly for mothers. Frustration and anxiety over the child's behavioral issues contributed to hopelessness, leading to less attentive care that furthered the child's behavioral struggles (Wang et al., 2021). Given the

pattern of utilizing negative coping strategies and demonstrating less resilience, Chinese government intervention strategies may focus on imparting these skills to families with ASD. Interventions may help them cope with the added challenges of raising a child with ASD in the face of uncertainty and retain hope for the future, working with the community and rehabilitative services. Accordingly, Wang and colleagues (2021) suggest a cultural emphasis on the rehabilitation of individuals with ASD, which assumes the position that autism needs a cure instead of adopting a greater focus on the benefits of neurodiversity. This cultural context may contribute to parental stress if parents feel they cannot ‘fix’ their child alone. Thus, parents may focus more on their child’s socially undesirable behaviors, potentially contributing to amplified parental stress than parents from other cultures.

### ***Turkey***

Situated between European and Asian cultural contexts, Kaba and collaborators (2022) investigated Turkish parental burnout and stress, finding a protective factor of the national collectivist culture in promoting adaptive coping strategies ( $N=79$ ,  $M_{Child\ Age}=9.34$  years). Kaba et al. (2022) noted an increase in parental exhaustion and depression symptoms accompanying a concurrent rise in culturally stigmatized child behavioral symptoms. Accordingly, the parents who experienced the most distress engaged in the maladaptive coping strategies of avoidance and emotion suppression in response to elevated child aggression, irritability, and stereotypic behaviors following school closures and therapeutic intervention disruption (Kaba et al., 2022). However, most parents in this study indicated adaptive coping strategies aligned with their collectivist cultural values that helped to mitigate the effects of distress and isolation and effectively address their concerns about their children and lockdown conditions. Overall, Turkey serves as a prime example of how cultural context matters. Parents are more likely to practice

adaptive coping strategies when they have a solid infrastructure of preventative mental health services and secure home support systems. These frameworks allow parents to ask for help when their children struggle with uncertainty, restrictions to their daily routines, and elevations of frustration.

## **Europe**

### ***Slovakia***

Polónyiová et al. (2021) observed that heightened parental anxiety was associated with a rise in children's behavioral concerns and caregiving responsibilities and was especially severe for parents of children with ASD ( $N=84$ , Boys:  $M_{Child\ Age}=7.73$  years, Girls:  $M_{Child\ Age}=7.70$  years) compared to parents of typically developing children in Slovakia ( $N=95$ , Boys:  $M_{Child\ Age}=8.37$  years, Girls:  $M_{Child\ Age}=9.30$  years). In the second wave of the pandemic spanning November to December 2020, parents experienced the most intense anxiety, depression, and stress in alignment with an intensification of maladaptive internalizing behaviors for autistic children ( $N=71$ , Boys:  $M_{Child\ Age}=8.62$  years, Girls:  $M_{Child\ Age}=10.83$  years) such as withdrawal and isolation from their families, anxiety, and irritability in association with later bedtimes (Polónyiová et al., 2021). During the first and second waves, two focal concerns for parents of children with ASD were more demanding childcare and insufficient or unclear information regarding national quarantine and social distancing regulations (Polónyiová et al., 2021). Stringent first-wave lockdown policies and a high second-wave national death toll exacerbated these stressors (Polónyiová et al., 2021). Although ABA therapy, speech-language services, and psychotherapy services were already established pre-pandemic, interruption of these services in person was particularly disruptive for caregivers and their children. Thus, it is integral to expand the range,

affordability, and accessibility of telehealth services to help provide consistent care to children and their parents.

### ***Serbia***

Through their examination of parenting in the tumultuous context of the COVID-19 pandemic, Stankovic et al. (2021) discerned parental fears of not being able to take care of their child's exacerbated needs or mediate their behavioral regression, feelings of helplessness, and desires for supplemental education support while educating children at home ( $N=85$ ,  $M_{Child\ Age}=9.2$  years). Overall, parents' main concerns were preventing their child's social skills from slipping away after years of targeted in-person intervention on top of their preexisting worries concerning their child's developmental progress (Stankovic et al., 2021). In addition, this parental stress was intensified through a lack of national structured support services for parents and the underlying cultural context of negative societal stigma regarding an ASD diagnosis (Stankovic et al., 2021). However, since there was no option for free response, only multiple choice of which stressors were pertinent to caregivers, this study did not capture the comparative severity of each concern. Furthermore, this method did not allow parents to voice their organic concerns regarding their lived experiences with lockdown and social distancing restrictions. Due to perceived cultural discrimination for having a child with an autism diagnosis, some caregivers may not reach out for community support for fear of rejection or facing further stigma, preventing them from obtaining the mental health services they need to help their child and themselves. Based on these study findings, a supplemental investigation is needed to investigate how to tailor support programs to meet familial needs and how to reduce societal stigma around ASD.

### ***Italy***

Levante et al. (2021) discovered that children's emotional and behavioral responses to the pandemic restrictions played a crucial role in the amount of parental stress experienced in Italy ( $N=53$ ,  $M_{Child\ Age}=6.94$  years). Poor social support networks among parents were frequently observed and linked with increased stress and anxiety and the diminished potential to cope. Consequently, Levante and colleagues (2021) observed a deteriorated parent-child relationship in which worsened child behavioral problems following routine disruption were associated with heightened parental distress. Additionally, Levante and collaborators (2021) observed a subsequent decrease in child emotion regulation and adaptive behavior through independent play, contributing to a cycle of worsening distress for caregivers and children. This study illustrates the importance of providing mental health support for caregivers. Experiences with depression, anxiety, and stress are detrimental for the parent, and diminished attention to and patience with their children can also intensify child behaviors and contribute to a more stressful pandemic experience for the entire family.

### ***Portugal***

Amorim and collaborators (2020) investigated parents' anxiety appraisals and stress management in Portugal ( $N=43$ ,  $M_{Child\ Age}=9.86$  years). As may be expected, parents of individuals with ASD relayed high levels of anxiety regarding a concomitant increase in their child's anxiety and irritability, the suspension of in-person therapy services for their child, and the added pressure of trying to maintain their child's pre-pandemic routines (Amorim et al., 2020). Anxiety is an insightful dimension of parental well-being that captures the worry of not controlling the future when parenting children who rely on sameness and routine to thrive. Especially in light of the additional challenges to parents, for example, constant caregiving without the typical respites of school or extracurricular activities, the addition of their role as the

child's teacher, and inadequate mental health infrastructure, the lockdown period involved all of the ingredients to provoke an anxiety spiral for parents. Based on the findings from Amorim and collaborators (2020), there is a need for more comprehensive therapeutic and behavioral health interventions that can help parents manage their anxiety, provide strategies for parents to talk with their children about stressors, and cope with uncertainty in an adaptive manner.

## **North America**

### *United States of America*

Corbett and colleagues (2021) presented insight into the higher levels of stress and anxiety of American parents of children with ASD ( $N=61$ ,  $M_{Child\ Age}=13.23$  years) compared with parents of typically developing children ( $N=61$ ,  $M_{Child\ Age}=13.39$  years). These findings highlight the need for more mental health services for parents of children with ASD that similarly experience higher stress levels during normal conditions than their counterparts with typically developing children. In light of the American cultural context of domineering individualism combined with a substantial number of available resources, many American parents may feel they must figure out how to navigate the pandemic by themselves and consequently do not take full advantage of the mental health infrastructure available to them to deal with their concerns about their child's safety and future (Corbett et al., 2021). This study yields insight into parents' reported use of disengagement coping and questioning their ability to help their children overcome adversity or calm their children's anxieties about becoming infected with the virus (Corbett et al., 2021). These maladaptive coping strategies are linked with worse parental distress outcomes and prevent parents from tackling their concerns directly, giving insight into the need for current American support infrastructure to incorporate adaptive coping strategies into their parental resource services (Corbett et al., 2021). In this way, parents may receive more direct

instruction in coping with pandemic stressors and develop a sense of resilience against adversity that may extend beyond the end of the COVID-19 pandemic.

### ***Canada***

Further evidence for the potentially harmful effects of an individualistic cultural context on increasing parental distress is presented by Friesen and collaborators (2021), in which the researchers detail the stress, anxiety, and coping methods of Canadian caregivers ( $N=616$ ,  $M_{Child\ Age}=8.7$  years). The preponderance of caregivers in the study reported heightened stress and anxiety and poor coping skills- a combination providing evidence of an exacerbation of anxiety for already-stressed caregivers (Friesen et al., 2021). These results stress the need to foster resilient coping strategies, such as optimism and confidence in their caregiving abilities, to adequately care for their children as a tool to deal with the added stresses of the pandemic on top of their high baseline stress (Friesen et al., 2021). Additionally, these findings suggest that established social services must extend their programs and allocate resources to teach parents adaptive coping strategies and networks, such as social support networks, as well as interventions to address the complexities of parents' additive stressors and help parents reframe their familial and caregiving challenges in a more positive, productive light.

### **Africa**

#### ***South Africa***

In South Africa, Adams and collaborators (2022) demonstrate a prime example of accumulative stress through interviews with caregivers of autistic children, many of whom often struggle to access or afford support services such as teletherapy and are situated in the national context of high-poverty rates and societal divides stemming from the legacy of apartheid ( $N=21$ ,  $M_{Child\ Age}=5.9$  years). Consequently, these caregivers entered the pandemic without a solid



foundation of governmental services for their children. Participants who lost their jobs during this time or had not received a university degree had to rely on the variable quality public health care system to seek behavioral support for their children (Adams et al., 2022). Through qualitative semi-structured interviews, parents revealed feelings of hopelessness and frustration for not maintaining a sense of normalcy and consistency for their children, such as struggling to find appropriate alternatives at home for their children's routine activities and favorite restaurants or fast foods (Adams et al., 2022). Parents also shared a profound sadness over their children's regressions in academic, social, and emotional regulation skills, especially given the lack of national support in smaller provinces. By suddenly being thrust into the role of teacher, behavioral interventionist, and speech therapist, many parents elicited feeling overwhelmed by their newfound responsibilities and their difficulty transitioning their relationship with their children from one of rest and respite at home to working during the school day, especially when parents were struggling to make ends meet (Adams et al., 2022). However, despite all these obstacles, primary caregivers, mainly mothers, persisted through these setbacks through the support of other caregivers in the home, such as fathers, grandmothers, and great-grandmothers, all of which helped to provide some informal mental health support. Overall, this study demonstrates the ability of informal, community, and intergenerational support to compensate for a lack of national infrastructure.

## **Discussion**

After reviewing these fourteen studies, the author discerns six essential themes: an exacerbation of already high parental distress, parents adopting multiple roles, the protective impact of mental health and autism resource infrastructure, the utilization and emergence of coping strategies, counterevidence supporting a decrease in parental distress after acclimating to

lockdown conditions, and the impact of cultural context. Many of these trends transcend cultures, whereas others were linked with other studies from the same geographic region, giving evidence for the dual pattern of culturally specific and universal protective factors. Table 1 details each study location, the age range of children, the total number of parent participants, how the researchers measure parental distress or well-being, the methodology, and the prominent themes elicited from each paper.

### **Exacerbation of Already High Distress**

Universally across all studies analyzed, parents reported an increase in their already elevated distress levels. Caregivers were forced to rapidly adapt to new lockdown restrictions, which often disrupted their established routines for themselves and their children, prevented them from acquiring the foods and toys their children requested with stay-at-home mandates, and obliged them to take care of their children without respite (Adams et al., 2022; Anuar et al., 2022; Khan et al., 2021). In some cases, parental distress levels became so overwhelming that children's distress also increased in the form of heightened aggression and irritability, with both parent and child trapped in a positive feedback loop (Joseph & Delariarte, 2022; Kaba et al., 2022; Wang et al., 2021). Furthermore, parents often felt more isolated from their community and alienated from society with the physical isolation requirements, compounding their feelings of isolation and lack of community acceptance experienced before the onset of the COVID-19 pandemic (Stankovic et al., 2021). Overall, the lockdown period was linked to a worsening of parental mental health outcomes and a frequent worsening of child behavioral outcomes, illustrating the deleterious ramifications of a global stressor combined with day-to-day stressors to push parents to their breaking point (Levante et al., 2021; Polónyiová et al., 2021).

### **Adopting Multiple Roles**

With the closure of in-person behavioral therapies, schools, and other support service centers, children's expanded needs compelled parents to adopt many roles beyond their baseline caregiving responsibilities. Without formal training or expertise, many parents assumed the position of teacher, behavioral therapist, speech-language pathologist, and more overnight (Adams et al., 2022; Amorim et al., 2020). If the pre-pandemic stresses of parenting were not enough, parents suddenly had to evolve their parenting practices to help their children pay attention during virtual lessons, help them with homework, and desperately try to keep their children from losing the academic and behavioral progress they had made (Adams et al., 2022; Tokatly Latzer et al., 2021). This assumption of countless responsibilities sometimes impacted the parent-child relationship as children struggled to accept their parents as stricter instructors at home compared with the more relaxed, lenient caregivers children knew them to be (Adams et al., 2022). Additionally, although some parents took time off or lost their jobs, most parents across studies had to continue to manage their professional responsibilities while facilitating their own and their child's productivity (Adam et al., 2022; Amorim et al., 2020). As a general pattern, parents who did not feel supported expanding into more roles struggled more with distress, suggesting that this additional set of responsibilities made the pandemic experience much more stressful for parents and children (Anuar et al., 2022).

### **Mental Health and Autism Resource Infrastructure**

Pre-established mental health and autism resource infrastructure was observed to be a protective factor against severe parental distress (Corbett et al., 2021; Friesen et al., 2021; Khan et al., 2021). By knowing whom to contact to continue their child's behavioral services and telehealth support and address their personal mental health needs, parents in countries with a solid resource infrastructure were equipped with the psychological tools needed to thrive (Khan

et al., 2021). Parents already connected with other parents of autistic children and who had easy access to reputable resources about how to explain the pandemic restrictions and regulations to their children, how to minimize triggers for the child, and how to find alternatives to meet their children's needs, were able to reduce some of the anxiety, depression, and stress introduced by the pandemic (Anuar et al., 2022; Corbett et al., 2021). However, unsupported parents reported alarming anxiety, depression, and stress appraisals (Alhuzimi, 2021; Joseph & Delariarte, 2022). Interestingly, middle-to-high income countries sometimes displayed well-planned, well-executed, and accessible autism and mental health resource infrastructure, such as Canada, China, and Qatar, while other countries, especially many in Europe, left parents unsatisfied and desiring more formal support for their children and themselves (Friesen et al., 2021, Khan et al., 2021; Wang et al., 2021). Across the board, all fourteen studies demonstrated the need for either the implementation, modification, or expansion of national support networks so that parents and children alike may have reliable and reputable access to the tools, services, and resources to navigate life, both in everyday tribulations and in the light of the chaos and unpredictability of crises.

### **Coping Strategies**

In the six studies that explicitly mentioned coping strategies, although adaptive coping strategies such as using positive framing or breaking down a challenge in a stepwise fashion could help buffer some parental distress, many parents did not employ these strategies or instead employed less constructive coping strategies such as disengagement or suppressing their emotions (Adams et al., 2022; Anuar et al., 2022; Corbett et al., 2021; Friesen et al., 2021; Kaba et al., 2022; Tokatly Latzer et al., 2021). Productive coping strategies strengthened parents' resilience, such that they persevered through the setbacks introduced by the pandemic and

prioritized their mental health needs (Anuar et al., 2022; Friesen et al., 2021; Tokatly Latzer et al., 2021). Based on the trends observed by Kaba and colleagues (2021), it would be productive to explicitly teach parents healthy ways to cope with their stress to protect parents' mental health and prevent parental distress from spilling over onto their children.

### **Counterevidence: Decreases in Distress**

Despite the chaotic and unprecedented nature of the pandemic and the proliferation of potential stressors, Khan and collaborators (2021) and Tokatly Latzer and colleagues (2021) noted an overall decrease in parental distress, despite the initial learning curve with the implementation of lockdown guidelines, such that the pandemic experience offered some unique silver linings. In part due to increased family time, less time devoted to concerns such as transport to and from school, and the improved ability to maintain routines and exert control over one's home environment, in some cases, the pandemic allowed some parents to strengthen their relationships with their children (Khan et al., 2021). Aligned with coping strategies and strengthening support networks for parents, future interventions may consider these principles to give parents strategies to reframe stressful situations to look for potentially positive outcomes and to continue to facilitate trust and fun with their children (Khan et al., 2021; Tokatly Latzer et al., 2021).

### **Cultural Context**

As supported by prior trends in cross-cultural research, cultural context heavily influenced families' pandemic experiences. Although the author did not observe a traditional Western vs. non-Western dichotomy in pandemic experiences, cultural conceptualizations of dis/ability did impact parents' distress, especially in countries where stigma accompanies an ASD diagnosis versus contexts where there is prominent visibility of autistic individuals (Alhuzimi,

2021; Kaba et al., 2022; Stankovic et al., 2021; Wang et al., 2021). While it is not accurate to directly compare highlighted studies, it is noteworthy that parents particularly struggled with distress and feelings of alienation in countries such as Saudi Arabia, where autism is dishonorable to the family name and shameful (Alhuzimi, 2021). However, this trend was not always associated with countries in the same geographic region or other so-called collectivist countries (Adams et al., 2022; Kaba et al., 2022; Khan et al., 2021; Tokatly Latzer et al., 2021). Thus, when considering culture in this sampling of fourteen studies, it is insightful to move beyond Western/non-Western, collectivist/individualistic, and broad geographic labels to consider the unique geospatial, financial, religious, and political contexts shaping each country's commitment to building support infrastructure, perceptions about mental health, and beliefs around ASD. In this way, no cultural context is valued or emphasized above another nor judged by Western standards. Each study offers unique strategies, insights, or theories that can help inform interventions to make the world more supportive of families with ASD.

**Table 1**

*Descriptives of Studies Reviewed*

In-Text Citation	Location of Study	Child Age Range (In years)	N Parents	Measurement of parental distress/ well-being	Methodology	Main Themes
Adams et al. (2022)	South Africa	$M_{Age}=5.9$ , $SD=2.0$	21	parental stress and well-being	Qualitative semi-structured interviews	Adopting multiple roles Exacerbation of already high distress Inadequate structured mental health support Power of adaptive coping strategies Supportive cultural context
Alhuzimi (2021)	Saudi Arabia	$M_{Age}=2.33$ , $SD=0.82$	150	parental stress and well-being	Parent Stress Index Short Form, PSI-SF (Abdin, 1995) General Health Questionnaire, GHQ-12 (Goldberg, 1992)	Exacerbation of already high distress Cultural stigma contributing to heightened parental distress Inadequate structured mental health support

Amorim et al. (2020)	Portugal	$M_{Age}=9.86$ , $SD=3.08$	43	parental anxiety, adaptation to quarantine	0-10 rating of anxiety and adaptation	Adopting multiple roles Exacerbation of already high distress Inadequate structured mental health support
Anuar et al. (2022)	Malaysia	$M_{Age}=8.6$ , $SD=4.2$	230	parental stress	Malay version Perceived Stress Scale, PSS-10 (Cohen & Williamson, 1988)	Adopting multiple roles Exacerbation of already high distress Power of adaptive coping strategies
Corbett et al. (2021)	United States	$M_{Age}=13.23$ $SD=1.16$	122	parental stress, parental anxiety	Responses to Stress Questionnaire COVID-19 (Connor-Smith et al., 2000) State-Trait Anxiety Inventory for Adults, STAI-A (Spielberger, 1973)	Exacerbation of already high distress Protective nature of national autism infrastructure Maladaptive coping strategies
Friesen et al. (2021)	Canada	$M_{Age}=8.7$ $SD=4.2$	616	parental stress, anxiety, and resilient coping	Perceived Stress Scale, PSS-10 (Cohen & Williamson, 1988) State-Trait Anxiety Inventory, STAI-6 (Marteau & Bekker, 1992) Brief Resilient Coping Scale, BRCS (Sinclair & Wallston, 2004)	Exacerbation of already high distress Power of adaptive coping strategies Protective nature of national autism infrastructure
Joseph and Delariarte (2022)	India	$M_{Age}=9.09$ $SD=2.67$	100	parental stress, anxiety, and depression	Depression Anxiety and Stress Scale, DASS-42 (Lovibond & Lovibond, 1995)	Exacerbation of already high distress Inadequate structured mental health support
Kaba et al. (2022)	Turkey	$M_{Age}=9.34$ $SD=3.99$	79	parental distress and burnout	Maslach Burnout Inventory, MBI (Maslach & Jackson, 1981) Depression Anxiety Stress Scale, DASS-21 (Lovibond & Lovibond, 1995) Brief COPE Inventory (Carver, 1997)	Exacerbation of already high distress Power of adaptive coping strategies Supportive cultural context
Khan et al. (2021)	Qatar	$M_{Age}=14.8$	26	parental strain and stress appraisals	Caregiver Burden Interview, CBI (Zarit et al., 1985)	Adopting multiple roles Exacerbation of already high distress Protective nature of national autism infrastructure Counterevidence: decrease in parental distress
Levante et al. (2021)	Italy	$M_{Age}=6.94$ $SD=1.6$	53	parental distress	Depression, Anxiety, and Stress Scale, DASS-21 (Bottesi et al., 2015)	Exacerbation of already high distress Inadequate structured mental health support
Polónyiová et al. (2021)	Slovakia	First wave:	155	parental depression,	Depression Anxiety and Stress Scale, DASS-42 (Lovibond &	Adopting multiple roles Exacerbation of already high distress

		Boys: $M_{Age}=7.73$ $SD=3.51$  Girls: $M_{Age}=7.7$ $SD=2.45$  Second wave:  Boys $M_{Age}=8.62$ $SD=3.87$  Girls: $M_{Age}=10.83$ $SD=5.09$		anxiety, and stress	Lovibond, 1995) Vineland Adaptive Behavior Scales–Third Edition (Sparrow et al., 2016)	
Stankovic et al. (2021)	Serbia	$M_{Age}=9.2$ $SD=4.5$	85	parental stress and major stressors	Modified Caregiver Needs Survey (Daniels, 2016)	Adopting multiple roles Exacerbation of already high distress Cultural stigma contributing to heightened parental distress Inadequate structured mental health support
Tokatly Latzer et al. (2021)	Israel	median age= 5 years 11 months, IQR=4 years 11 months-6 years 11 months	31	parental stress and anxiety	immersion/crystallization narrative method (Miller, 1992)	Adopting multiple roles Exacerbation of already high distress Counterevidence: decrease in parental distress Power of adaptive coping strategies
Wang et al. (2021)	China	18 or younger; 45% 3-6 years old	1764	parental anxiety, depression, and coping	Psychological Stress from COVID-19 Questionnaire, PSCQ (Wang et al. 2021) Connor-Davidson Resilience Scale, CD-RISC (Connor & Davidson, 2003) Simplified Coping Style Questionnaire, SCSQ (Xie, 1998) Self-rating Anxiety Scale, SAS (Zung, 1971) Self-rating Depression Scale, SDS (Zung, 1965)	Exacerbation of already high distress Cultural stigma contributing to heightened parental distress



## **Limitations**

### **Exclusion of Meaningful Scholarship**

One limitation of this review is sorting through the vast literature that may pertain to parental well-being but is not specific enough. For example, in the preliminary research, some studies measured general parent well-being levels, parents of children with developmental disabilities, or parents of children with disabilities, which do not provide specific enough information. For this review, the researcher excluded studies that include parents of children with developmental disabilities broadly or that specify co-occurrences with other neurodevelopmental disorders (i.e., attention-deficit/hyperactivity disorder, intellectual disability). However, the researcher acknowledges the common co-occurring conditions that children with autism face and suggest future investigation of how to support the unique needs of children with co-occurring autism and anxiety, depression, attention-deficit/hyperactivity disorder, intellectual disability, obsessive-compulsive disorder, sleep disorders, and other salient conditions (Al-Beltagi, 2021).

Additionally, this review can only capture a portion of the available literature, given that certain countries may not be heavily involved with autism research, have adequate funding to sponsor projects related to ASD, or do not have available English translations, which leaves out potential voices from this work. Unfortunately, much of the prominent literature on parental well-being published in high-impact journals comes from well-resourced, well-funded research projects in affluent countries, overshadowing diverse global voices. Future research may involve a team of multilingual researchers who may provide a more comprehensive review of studies published in languages other than the prestige language of English. This expansion of reviewed literature is essential to gain more representation for Spanish and Portuguese-speaking countries in Latin America, French-speaking countries in Africa, and local or tribal language perspectives.

## **Accessibility of Research Designs**

On a similar note, many of the studies included in this review included online questionnaires dispersed through a central healthcare center, which excluded families who did not have access to a computer, did not have proficiency in the primary language spoken in each country, or did not have a clinical diagnosis of ASD. It is possible that families who did not have access to any telehealth services or who could not access ASD-specific supports as a result of waiting to receive a clinical diagnosis had a quantifiably different pandemic experience than the parents included in this review or potential other unmet needs that have yet to be addressed by the current ASD literature. Future studies may probe how to ensure scholars capture economically and geographically diverse families in the literature and build rapport with families from rural communities who may be wary of researchers.

## **Future Directions**

### **Secondary Caregivers**

Almost all of the studies reviewed only focused on primary caregiver responses, often not including the option of assessing the secondary caregivers' distress appraisals. In alignment with recent initiatives to highlight secondary caregiver experiences, typically father data, this review recommends that future empirical research on parental distress should include the option for multiple respondents. In this way, future projects may compare how secondary and primary caregiver dynamics are bidirectionally influential in addition to the secondary caregiver's influence on child psychological and behavioral outcomes (see Giannotti et al., 2021; Rankin et al., 2019). Additionally, cultural and geospatial contexts inform which family members are responsible for childcare. For example, Adams and colleagues (2022) conducted ethnographic interviews with mothers, fathers, grandmothers, and great-grandmothers of individuals with

autism in South Africa, all active co-contributors to children's caregiving needs. Contrastingly, the American caregiver sample by Corbett and colleagues (2021) was 96.3% mothers.

### **DisCrit Lens**

This review may also serve as a starting point for a broader discussion on familial levels of support that considers the pandemic experiences of individuals with autism, their parents, and their siblings to form a more comprehensive picture of how parents, siblings, and autistic individuals reciprocally influence the family unit's mental health. By employing a critical dis/ability studies (DisCrit) lens that moves away from infantilizing individuals with autism and towards depicting authentic representations in the academic literature, future work should highlight the lockdown experiences of individuals with autism from their point of view beyond caregiver reports (see Stevenson et al., 2011). Scholarship such as Pellicano and colleagues (2022), a qualitative study that included the pandemic perspectives of autistic adults, autistic children, and parents who were autistic themselves, pave the way for more research that is needed to create space for autistic scholars and better holistic, community-informed representations of autism.

### **Longitudinal Mental Health Outcomes**

The present review focused on the immediate outcomes of the COVID-19 pandemic, assessing the anxiety, depression, and stress of parents during the initial stages of lockdowns, in the first wave, the second wave, and the immediate aftermath of the pandemic once stay-at-home and masking regulations began to ease up. Future research may explore if there are any long-term mental health outcomes for parents of autistic children or coping strategies that they learned during lockdown orders they now implement in their daily lives. Studies such as Asbury and Toseeb (2023) offer an optimistic perspective, observing a decline in parental distress with lifted

restrictions and a return to in-person instruction. However, there is still a need to look at longitudinal outcomes one year, two years, and five years after the official end of the pandemic to ascertain any potential long-term parental distress.

### **Conclusion**

Through introducing increased stressors and caregiving demands by the COVID-19 lockdown mandates, parents of children with autism spectrum disorder faced increased anxiety, depression, and stress as they adapted to the new normal for their children. By comparing fourteen research studies from countries worldwide in a systematic literature review, the author uncovered that a supportive cultural context, solid support service resource network, and adaptive coping strategies mitigated some of the poor mental health effects initiated by lockdown conditions. Culture, infrastructure, and coping worked in tandem to serve as protective factors against parental distress. Often, countries with a culture emphasizing mental health support without substantial stigma accompanying ASD diagnoses built infrastructure to support parental and child's psychological and behavioral health needs and promoted adaptive and resilient coping skills for parents to adapt to their new roles and responsibilities. Future work may build on this review to inform culturally responsive intervention practices to help further strengthen the bond between parent and child, promote ASD visibility and acceptance, and advocate for healthy responses to stressors to facilitate the well-being of the entire family unit.

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