

Mental Health of Families with Autism Spectrum Disorder: A Systematic Review

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Abstract

Introduction: This study explores parental and sibling mental health challenges associated with a child having autism spectrum disorder (ASD). Potential moderator and mediator effects of the association between ASD and family mental health are also considered, along with interventions and potential positive effects associated with ASD children.

Methods: A systematic review was conducted of peer-reviewed manuscripts involving mental health effects on mothers, fathers, and siblings of children with ASD. The accessed literature came from an electronic search conducted through October 2021. Well-known databases were used to access literature.

Findings: Because of behavioral problems of children with ASD, as well as additional emotional, communication, sleep, and delayed social problems, parents of children with ASD experience greater familial stress. Mothers tend to experience more stress, anxiety, and depression than fathers do. Fathers tend to experience stress due to the mother's mental health challenges as well as a lack of confidence in raising a child with ASD. Added stress for both parties comes from strained marital relationships and other factors. Studies of siblings of children with ASD have shown positive effects in terms of self-concept and social competence, whereas other studies have shown negative effects such as low levels of prosocial behaviors, feelings of loneliness, and delays in developing social skills. Older male siblings have greater risk for behavioral and emotional difficulties and siblings later in the birth order have greater risk of feeling lonely and socially dissatisfied.

Discussion: Mothers gain greater positive outcomes by receiving assistance from family, friends, and professionals. Fathers feel empowered when involved in educational interventions that demonstrate how to care for their child with ASD. Constructive outcomes are achieved for parents of children with ASD through interventions.

Keywords: *Anxiety; Caregiver; Depression; Intervention; Mental Health; Parents; Siblings; Stress*

Introduction

Autism derives from the word autos, signifying a person who keeps to him/herself, isolated from surrounding interactions [1]. The term "autism" was first used in 1908 to describe a group of schizophrenic patients who were unaware of the world around them. In the 1940s, Leo Kanner observed 11 different cases of impaired development in language and social interactions in children. This was the primary observational insight in acknowledging autism as a definite syndrome [2]. Now, more than 80 years later, a stronger definition and understanding of autism has been established. Autism is a neurodevelopmental disorder characterized by continual deficits in social communication and social interactions across different contexts, restricted and repetitive patterns of behavior, and unusual responses to sensory stimuli [3]. Social challenges include avoiding personal interactions and having difficulty expressing emotion [4]. Commu-

nication challenges consist of delayed or absent speech [5]. Behavioral challenges may range from repetitive patterns to aggressive or disruptive behavior [6-8].

In the United States, approximately 1 in 54 children are diagnosed with autism according to a Centers for Disease Control and Prevention (CDC) report based on data in 2016 [3]. Autism is more common in whites and males [3]. It is classified as a developmental disorder because of its manifestations in the initial years of life, most commonly at 20-30 months, but can be detected as early as 18 months [5]. From ages 0-3, children typically hit certain milestones (e.g. walking, talking, sharing, and expressing emotions) [9]. Delays in these milestones indicates the possibility of autism [9]. Children with autism spectrum disorder (ASD) face unique encounters throughout the school years, such as a change of routine and familiarity due to change in classmates, teachers, or subjects, which may cause disruption and discouragement for

children with ASD [9]. Improved education and increased awareness of the special challenges faced by autistic children enhances an educational system's knowledge and effectiveness of working alongside families who have children with special needs [10].

There is no known cure for ASD, but some of the symptoms may be effectively regulated. Therapies and testing are underway to govern the core deficits of ASD [11]. Some therapies include neuro-feedback training and speech therapy to enhance cognitive skills, virtual assessment tools (entertainment technology) to develop speech communication, and interactive skills, psycho-education therapy to increase learning rate and attention control, and assistive tools to develop reading and comprehending skills [1]. Treatments and studies regarding the subject are well documented and advancing rapidly [1]. Treatment outcomes demonstrate various effects on children with ASD, but often overlook how the impact of the outcomes may differ if caregiver involvement is integrated [12].

Researchers have found that parents of children with ASD are at greater risk of stress proliferation (i.e., a tendency of stressors to cause more stressors in other domains of life) [13]. It has long been recognized that autism is associated with several family stressors such as communication problems, marital conflict, lack of bonding, erratic sleep patterns, problems with changes in routine, splinter effects, reduced ability to socialize, need for respite, future related worry, and unique financial matters [14]. The arrival of a child with a disability has the potential to either weaken family relationships or be a source of unity in the family [15]. Responses may differ between mothers, fathers, and siblings as they work to understand, teach, and care for a child with ASD. Identifying differences in responses among the mother, father, and siblings may allow for further emphasis to be placed on positive interventions that can improve possible mental health challenges [14]. Families are encouraged to participate as a group in making program decisions for the affected child and to receive coping and training skills through counseling services [14].

With mental pressures associated with raising a child with ASD, studies have predominantly been focused on mothers of children with ASD [16-18], which is consistent with women most often being the primary care provider. One study found that caregivers of children with ASD are mostly the biological parents (95%), and predominately the mother (89%) [19]. However, the father is sometimes the primary care provider and, likewise, plays an equally important role in raising a child with ASD [20]. In addition to parents, it is important to consider how siblings of those with ASD are affected and ways in which they cope [21]. The ASD child's age, gender, family circumstances, life-course perspectives, marital satisfaction, social support, cultural issues, and more may influence the family's overall mental health outcomes [21-28].

The primary purpose of the current study was to identify parental and sibling mental health outcomes associated with ASD children; identify moderator (e.g., age and gender of the child) and mediator (e.g., parenting stress, marital conflict,

family and economic pressure, future-related worry) effects of the association between ASD and family mental health; and review interventions and positive effects associated with ASD children.

Methods

English-language peer-reviewed literature on mental health effects on mothers, fathers, and siblings of children with ASD were reviewed. The accessed literature was found through an electronic search that was conducted through 2021. Literature was accessed using four well-known databases (i.e., Medline, Embase, Cochrane, and Scopus). Search terms included depression in parents OR anxiety in parents OR depression in mothers OR depression in fathers OR anxiety in mothers OR anxiety in fathers OR mental health effects of parents OR siblings OR stress in siblings OR parental stress OR AND children with autism spectrum disorder OR children with ASD. The authors independently reviewed the titles and abstracts of articles to identify relevant studies for full-text review. Additionally, the authors sought to distinguish certain characteristics of the mothers, fathers, and siblings of children with ASD (e.g, mental health, age and gender of the ASD child, and the parental gender of focus) and the behavioral characteristics of children with ASD.

A total of 84 studies published in the scientific literature during the period 2000 to 2021 were included in the current study (Table 1).

Results

Study designs identified in this paper were primarily cross-sectional surveys ($n = 67$), followed by literature reviews ($n = 5$), longitudinal studies ($n = 4$), meta-analyses ($n = 5$), diary studies ($n = 2$), and a case-control study ($n = 1$). The surveys incorporated several validated instruments for measuring autism; behavioral problems; parental stress, anxiety, and depression; adaptability; resilience; coping; and more. The literature reviews identified an increased risk of family mental health problems in homes with ASD children, that stigma negatively influenced parental mental health, and that ASD children have an increased risk of sleep disorders [23, 29-32]. The longitudinal studies identified higher mental health problems in parents of ASD children and found that home training, interventions, and coping strategies can lower parental stress and other mental health problems [33-36]. The meta-analyses focused on interventions that do not require a specialist in treating individuals with ASD [37]; identified higher risk of depression and psychiatric difficulties in parents of children with ASD [38, 39]; correlated short- and long-term sleep duration with depression [40]; showed that parental stress can be significantly reduced through mindfulness or relaxation training; and that parent style and satisfaction can be improved through parental education [41]. The two diary studies covered different topics. The first identified poorer partner relationships in parents of ASD children [42], and the second found that mothers of ASD children had higher rates of mental health problems, in part because of greater time pressure, but social support was an effective means for lowering maternal mental health

problems [43]. The case-control study identified factors associated with stress in mothers of children with autism [44]. Parental mental health is directly related to ASD.

Among the 84 studies, 21 focused on comparing mental health outcomes of mothers and fathers of children with ASD; 33 assessed the direct relationship between parental mental health and ASD; 33 assessed indirect relationships between parental mental health and ASD; 8 considered sibling mental health; 23 presented ways to reduce mental health problems; and 5 explored positive outcomes linked to being in a family with an ASD child.

The primary outcome variables considered in the studies were stress ($n = 42$), anxiety ($n = 16$), depression ($n = 28$), and other (e.g., family unity, happiness and fulfillment, personal strength, personal maturity and growth, greater social network, physical health) ($n = 53$). Research indicates that stress mediates the association between having a child with ASD and anxiety or depression [45-47]. In the current study, several papers found an increased risk of both stress and anxiety [45, 47-49, 52, 54, 55] and stress and depression [30, 45, 47, 49-57] among mothers and/or fathers of children with ASD.

One study involving female caregivers found that stress was associated with avoidance strategies (self-blame, denial, emotional venting, and disengagement) [57]. One study involving male caregivers found that stress was associated with nervousness, hopelessness, and worthlessness [58]. Increased physical health problems associated with having an ASD child may further contribute to parental stress [19, 28, 58]. Several studies found that parental stress was positively associated with the severity of their child's ASD [59-61]. Other factors contributing to parental stress include behavioral problems [24, 55, 58, 62-66]; social disability [50, 61, 66, 67]; spousal relationship problems and partner depression [51, 68]; being a sole parent or caregiver [60]; economic burden [29]; eating, sleeping, and emotional problems [24, 69]; co-occurring ADHD and OCD [70]; and concern for the child's future, poor health, and permanency of the condition [29, 65]. Parental stress may also be associated with the ASD child's age and sex. One study found that stress was greater if the child was less than age 12 because younger age is more likely associated with the initial diagnosis and treatment [69]. Another study focusing on preschool aged children with ASD found that fathers had greater stress if their child was female [25]. This study of preschoolers also found that age 5 was associated with greater parental stress. More severe depression and lower health-related quality of life was associated with an older child with ASD and diagnosis at an earlier age [26].

Of the studies identified in this paper, 19 involved mothers only, 3 involved fathers only, 53 involved both mothers and fathers, and 9 involved other factors.

Mothers

Mothers are often the focus in studies of children with ASD, as they tend to spend a higher proportion of time with their child. The accumulation of research indicates that mothers experience stress at levels that make them more susceptible

to anxiety, depression, and cellular aging beyond their years [54, 71]. This section highlights selected outcomes, causes of mental health problems, positive outcomes, and interventions and self-redirection for mothers of children with ASD.

Mental Health Problems

Studies have consistently shown that mothers of children with ASD experience higher stress compared with mothers of normally developing children [44, 53-56, 63]. In one study, 42% of mothers hit a clinical level of stress and an additional 28% had moderately elevated stress [34]. In many cases, stress can be severe enough to result in insomnia [72], withdrawal [44], anxiety [27, 46, 49], and depression [49, 51]. However, not all studies found stress to be a precursor of depression in mothers of children with ASD [47].

Causes of Mental Health Problems

Behavioral problems (e.g. hurting others, damaging property, and self-injury) in ASD children have been associated with maternal stress [52, 62], anxiety [66], depression [34, 66], and lower life satisfaction [73]. Behavioral problems in ASD children have been identified as the strongest predictor of maternal psychological distress [55, 59]. Research has shown that child behavior difficulties mediate the association between ASD symptoms and maternal stress [63, 74]. Higher severity of challenging behaviors in children with ASD positively correlates with higher levels of parental stress [66].

In a study linking maternal depression with child behavioral problems, maternal depression was also associated with maternal anxiety symptoms and poor mood, low parenting efficacy and social support, and poor coping styles [34]. When a child's disruptive behavior extends into public settings, levels of maternal stress, anxiety or depression significantly increase [66]. Increased stress may be particularly present when the mother of an ASD child is not able to manage their child's behavior in public places [56].

Studies demonstrate that women find refuge in social interactions, whether it is with organizations or with close friends or family [43, 75, 76]. Research has also shown that for women of children with ASD, social support correlates with greater optimism, which, in turn, leads to lower levels of stress and depression [43, 50]. In a study assessing the association between behavior and emotional problems and maternal life satisfaction, the negative effect of these problems on life satisfaction occurred when there was little or no perceived social support [75]. Having no childcare support, low satisfaction with their healthcare provider, and needing to work outside the home have further been associated with depression in mothers of children with ASD [76].

Positive Outcomes

Although it has been shown that mothers are more inclined than fathers to develop stress, anxiety, and depression while raising a child with ASD [36, 47, 49, 52, 55, 69, 77], it has also been shown that mothers tend to experience more positive outcomes than fathers [48, 51, 55, 78, 79]. Families of children with ASD often experience resilience by making positive meaning of disability, mobilization of resources, be-

coming a closer and more united family, developing a greater appreciation for life and in others, and gaining spiritual strength [80]. One study found that mothers' perceptions of positive contributions of having an ASD child, such as learning by experience, happiness and fulfillment, personal strength and family closeness, understanding the purpose of life, personal maturity and growth, awareness of future issues, greater social network, career and job growth, and pride and correction, are higher than father's perceptions [48].

In a study assessing mental health in mothers with a disabled child, their mental health was positively associated with participation in healthy activity, feelings of empowerment, and the child's psychosocial health [71]. A sense of competence, taking things a day at a time, and emotional support from a spouse can effectively promote maternal well-being when raising a child with ASD [81].

Interventions and Self Redirection

It has been shown that maternal anxiety and depression can decrease by using interventions to monitor and lower core symptoms of children with ASD [82]. Interventions may include promoting healthy activities and empowerment among mothers of ASD children, as well as addressing the psychological needs of the child [71]. They may also focus on regulating severe behavior problems of children with ASD. Researchers say that this requires dedication to a dependable routine of the child's schedule and guidance on proper behavior in order to decrease maternal stress [59]. Interventions aimed to lower maternal stress among mothers of ASD children may consider the child's needs and behaviors; the mother's personal needs and ability to organize; familial and spousal relationships; service availability and adequacy; and the environment in which the family lives [66, 80, 83]. In addition, positive social exchange with one's spouse was shown to be a primary means of lowering depressive symptoms in mothers of ASD children [75].

Mothers of autistic children may redefine what constitutes the fulfillment of various human needs and/or seek to find alternative ways to fulfill them. In one study, mothers of children with ASD placed less emphasis on their own careers and focused more on their parental role; spent more leisure time with extended family members; put less emphasis on what others thought about their child's behavior; put more emphasis on spousal support and the parental role in discussions about marriage; entertained more than one interpretation about their child's behavior; and showed a tendency toward a greater overall tolerance of their child's actions [84].

Fathers

Fewer studies have assessed mental health and social outcomes of fathers of children with ASD. This is likely because fathers are generally less involved than mothers in raising children with ASD [31]. Nevertheless, it has been shown that fathers are fully capable of promoting father-child social interactions wherein the child responds well to them [85]. This section highlights selected mental health outcome measures, with more emphasis on differences between fa-

thers and mothers, and discusses selected interventions and empowerment strategies.

Mental Health Outcomes

Fathers, like mothers of ASD children, experience higher stress [25, 33, 51, 87]. In one study, 17% of fathers of ASD children had higher risk for psychological distress; 16% experienced poor global health; and 16-18% engaged in adverse health behaviors (e.g., alcohol abuse, cigarette smoking) [58]. In another study, father's stress was linked more to the child's externalizing behaviors and mother's stress was linked more to the child's eating, sleeping, and emotional regulation [69].

Research has found that fathers are more likely than mothers of ASD children to ignore their own mental health issues [87], express less emotion, seek less social support, and have poorer coping skills [69]. For example, mothers do better than fathers in coping (e.g., by communicating questions and seeking information), while fathers tend to just avoid the stressful situation (e.g., by going to work) [69]. Both mothers and fathers of ASD children experience significantly higher levels of anxiety and depression [36], but fathers appear to have lower levels of anxiety than mothers [88]. While research has found that fathers also have lower levels of stress than mothers of children with ASD [36, 47, 49, 52, 55, 69, 77, 89], mothers adapt better to stress and stress is a stronger precursor of depression for fathers [33, 47, 48, 55].

Negative social exchange with one's spouse has been shown to have a positive association with depressive symptoms for both fathers and mothers of children with ASD [74]. An older study explained that although mothers may be more susceptible to stress, depression, and parental burnout, if parental roles change (with fathers assuming a greater role in providing direct care) stress levels may become more equally shared [90]. In the same study, three main outcomes were related to increased stress in fathers of children with ASD: strained marriage, poor self-competence, and the challenging behaviors of the ASD child.

One study evaluated parental coping mechanisms such as escape/avoidance, which is a strategy of trying to nullify or forget the challenge at hand [91]. The escape/avoidance mechanism often results in social isolation and neglect of the marital relationship. Stress may arise in the marital relationship when the couple neglects to spend time together [62]. While mothers are often the primary care provider, it is important for fathers to equally care for children with ASD [91]. Studies have shown that the stress of the family unit (e.g. in spousal relationships, sibling relationships, and parent-child relationships) could be eased through an increase of direct father-child nurturing efforts [31].

Intervention

A quasi-experimental research design was used to examine parental stress through the Parenting Stress Index-Short Form (PSI) before and after testing an intervention [33]. The intervention was a father-based initiative, where the father was taught four methods: following the child's lead in play; imitating and exaggerating the child's actions, to prevent

parent-child reciprocity; effective communication through clear signals; and commenting on child's actions rather than asking questions. The father then taught the mother these techniques.

The PSI is a self-report questionnaire that measures stress by assessing the parent's perceptions of both self and child. A PSI score of 90 is considered clinical. At pretest, mothers and fathers reported an average PSI level of 96.4 and 90.5, respectively. After a 12-week training for an intervention program, the mother's average PSI level dropped to 89.9 and the father's PSI fell to 83.7. The results were significant for mothers. Although the decrease in the fathers' mean score was notable, it was not statistically significant because of the large variability in the scores [33].

In general, interventions that educate fathers on caring for their child with ASD that include working alongside their spouse in raising their child have shown positive results in stress relief for both the mother and father [59, 77, 80].

Empowerment

Empowerment (ability to actively satisfy one's needs, gain control of one's life, and overcome obstacles) has been studied in both fathers [92] and mothers [71] of children with ASD. Higher empowerment corresponds with better mental health [71]. Unfortunately, empowerment tends to be lower in fathers of children with ASD than fathers of normal developing children [92]. Social support was not associated with empowerment in these fathers.

Fathers of children with ASD often lack confidence in feeling capable of raising their child [92]. If fathers gain a better understanding of the disorder and the available services for their child and family, they may feel more empowered and confident in fulfilling their role in caring for their child [92]. However, implementing certain coping strategies may help lower paternal stress. For example, researchers found that fathers demonstrated lower levels of stress due to their ability to use different strategies of coping in relation to their child with ASD. Because of these different coping strategies, fathers were able to bear their child's behaviors in an adaptive manner that empowered and reduced the resulting impact of stress [85].

Parental Unit

Sometimes studies do not differentiate by "father" or "mother," but classify parents as a unit. For example, in a study of high-functioning children with autism, parental stress was evaluated along with sibling adjustment and family functioning [86]. Parents of children with high-functioning autism showed greater stress than parents of children with no psychological disorder. The fact that these children were high functioning did not compensate for the increased stress parents experienced because of their child's primary symptoms. In another study, parents of toddlers that had ASD experienced increased stress compared with parents of toddlers with developmental delay without ASD and typical development children [93].

One study found that family support had a direct, positive effect on family quality of life and an indirect effect on fam-

ily quality of life through stress [94]. Another study showed that social support had a positive effect on family cohesion and adaptability [95]. Specifically, social support in the form of subjective support (an individual's level of satisfaction of being supported) and utilization support (degree individuals make use of available social support), but not objective support (visual or actual social support), were found to increase family cohesion and adaptability.

In a study assessing the partner relationship in families with ASD children, individual optimism, benefit finding, coping strategies, and social (instrumental and emotional) support positively related to relationship satisfaction [96]. Note that instrumental support involves seeking advice or assistance from another individual. Emotional support involves seeking moral support (sympathy or understanding).

Though many parents experience hardships from raising a child with ASD, there are some benefits that warrant consideration. Some positive outcomes described by parents of children with ASD are personal growth, empowerment to help others, spiritual growth, stronger couple relationships, a more united family unit, and new career discoveries [78]. Another study found that the greatest factor contributing to positive outcomes in a mother's mental health was when there were informational and emotional social exchanges from both within and outside the family [75].

Divorce

When comparing couples with and without a child with ASD, a significantly higher rate of divorce occurred in families with an autistic child [97]. Divorce remained high through the ASD child's childhood, adolescence, and early adulthood. Divorce was more likely for younger maternal age when the ASD child was born and if the child was born later in the birth order [97].

Sleep

Children with ASD tend to have higher levels of sleep disorders [32, 98], which contributes to disrupted sleep and maternal stress [68, 99]. The majority of children with ASD follow a sleep-wake pattern for sleeping and experience a sleep onset delay [98]. For several reasons, sleep for a child with ASD is a major concern and challenge for parents. Difficulty to sleep interferes with brain development, thus creating additional difficult behaviors for parents to monitor [32]. Difficulty to develop a regular sleep schedule for children with ASD disrupts the parent's sleep cycle. A meta-analysis of prospective cohort studies, which included 25,271 participants for short sleep duration and 23,663 participants for long sleep duration, found that adults who followed short or long sleep duration patterns had a greater risk of depression [40]. The authors indicated that short duration sleep patterns induced depression from a lack of sleep and long duration sleep patterns induced depression from a lack of physical activity [40].

Siblings

Considering siblings is important because they, like their parents, have various experiences of coping with parental stress and individual consequences of working with a sib-

ling who has ASD. Yet the subsystems (mother-father relationship, sibling relationships, and peer relationships) make the sibling relationship complicated. A review study found mixed results with respect to outcome and adjustment variables for siblings of individuals with ASD [23]. While some studies showed positive effects in terms of self-concept and social competence, other studies showed negative effects like low levels of prosocial behaviors (actions to help other people), increased internalizing and externalizing problem behavior, feelings of loneliness, and delays in developing social skills. One study found that siblings of children with ASD without a diagnosed disorder are not at increased risk of psychosocial problems, compared to children in the general population [100]. In another study, siblings of children with ASD had similar emotional/behavioral adjustment but less involvement and more avoidance of their sibling as normally developing children [101]. Older male siblings in this study were at greater risk for behavioral/emotional difficulties. A study of siblings of children with ASD found that while the firstborn child does not experience greater likelihood of feeling lonely and socially dissatisfied, a sibling of an ASD child later in the birth order is more likely to feel lonely and socially dissatisfied [102].

Both mothers and fathers are more likely to rate siblings of ASD children as having more emotional problems and lower prosocial behavior when compared with normally developing children [103, 104]. These studies involving parent's perceptions may differ from sibling's perceptions. For example, one study found that overall, siblings did not feel negative emotions toward the affected sibling while parents often reported a more negative perception of the impact the individual with the disability had on the family [105].

In one paper, sibling relationships were studied by using the Family Systems Framework, which recognizes the interrelatedness and evolving dynamics of the family unit. The authors suggest that siblings function as intervention agents by understanding the perceptions of other children toward their sibling with ASD [106]. In order to promote positive sibling involvement and family functioning the authors identified key features that should be addressed such as developmental level, communication status, and areas of strength, challenge, and interest.

Discussion

Children with ASD bring new life changes for mothers, fathers, and siblings. There have been several studies that have focused on how children with ASD can influence the mental health of their mothers. The mental health of fathers and siblings of children with ASD have received less attention. The aim of this review was to present the mental health effects commonly experienced by parents of children with ASD, identify how ASD affects family mental health, and discuss some of the interventions and positive effects associated with ASD children.

Severity and behavioral problems like self-injury and disruptive public outbursts in ASD children are the primary causes of parental psychological stress [24, 55, 58-66]. There is considerable evidence that a proliferation of stress

results for mothers and fathers of children with ASD [13, 25, 33, 51, 87]. This proliferation relates negatively to hope, confidence, self-worth, communication, marriage, bonding, sleep, socialization, finances, and more [14, 24, 29, 50, 57, 58, 61, 65-67, 69, 70]. Stress also increases the risk of anxiety and/or depression [45-47]. Increased sleep disorders in ASD children and resulting sleep disturbances in parents is a potential mediating cause of parental depression [40]. Research has found that stress-induced depression is caused by vulnerabilities in personality structure and persistent disturbances in the 5-hydroxytryptamine (serotonin) system and other underlying mechanisms [107, 108].

There is some evidence that social support is a moderator of the association between ASD child behavior and maternal depression [73]. The association between ASD and parental stress may also be moderated by the child's age and sex [25-27]. Behavioral difficulties may mediate the association between ASD and maternal stress [63, 74]. In turn, stress may mediate the association between ASD and anxiety and/or depression [36, 46, 48].

Differences were observed in the mental health between mothers and fathers of children with ASD, with mothers more inclined than fathers to experience stress, anxiety, and depression [36, 47, 49, 52, 55, 69, 77, 89]. However, mothers adapt better to stress [33, 47, 48, 55] and experience more positive outcomes (e.g., learning by experience, happiness and fulfillment, personal strength and family closeness, understanding the purpose of life, personal maturity and growth, awareness of future issues, greater social network, higher spiritual strength, career and job growth, and pride and correction) than fathers [48, 51, 55, 78, 79, 80]. This may be because fathers are typically less involved than mothers in raising ASD children [31], are more likely to ignore their own mental health issues [87], express less emotion, seek less social support, have poorer coping skills, and avoid stressful situations [69].

Fewer studies have considered mental health and social factors of siblings of children with ASD. Some studies showed siblings of ASD children to have higher self-concept and social competence, but lower prosocial behaviors, increased behavior problems, feelings of loneliness, less involvement and more avoidance of their siblings, and delays in developing social skills [23, 101]. The risk of negative outcomes may be greater for ASD siblings born later in the birth order [102] and older males [101]. It may be that siblings of ASD children are more likely to have mental health and social problems because they are more likely to be on the spectrum [100]. The promotion of positive sibling involvement and family functioning should consider the ASD sibling's developmental level, communication status, and areas of strength, challenge, and interest [106].

A common theme among the possible interventions is that fathers who co-care for their child with ASD are able to increase in direct father-child nurturing [51]. Additionally, fathers who invest time in gaining education and a larger understanding of ASD, are then able to implement the learned resources that are available for assisting in the care of their child with ASD [51]. As a result, fathers

will be more empowered, less likely to avoid caring for the child with ASD, and stronger marriages will ensue, thereby contributing to a unified effort in the child rearing process [51]. Mothers appear to require more social support from counselors, organizations, and family and friends than fathers do [73]. Parent and family focused interventions may be effective in improving parental well-being and familial quality of life [33, 37, 41, 59, 66, 71, 75, 77, 80, 82, 83, 94].

Notwithstanding the many challenges, studies have also identified positive aspects of raising a child with ASD. These include stronger family perceived relationships, a sense of accomplishment by the parents as they see their child progress, a greater sense of personal growth and empowerment, a closer and more united family, a greater appreciation for life and in others, spiritual strength, and joy in raising their child with ASD [79, 80]. Mothers' perceptions of positive contributions of their ASD children are greater than fathers [48, 51, 55, 78, 79].

Some limitations and recommendations are in order. First, most studies are based on cross-sectional designs, which may be prone to misrepresentation if low response rates and recall bias exist. These studies are not effective at identifying temporal sequences of events. Second, some studies reviewed used small sample sizes or convenience samples. Small sample size and lack of random selection may cause misleading results. Hence, generalization of these studies should be made with caution. Third, some studies were susceptible to confounding factors, although several of the studies adjusted their results for potential confounders (e.g., child's age, socioeconomic status, employment status, education levels of parents, family systems and relationships apart from the child with ASD, marital relationship, and definitions of stress levels, etc.). Despite these limitations, there were several strengths to the reviewed studies. Many of the studies were able to test specific interventions to evaluate how they affected the mental health of mothers, fathers, and siblings. Some of the studies tested for a specific variable (i.e., child's age, certain behaviors), which allowed for assessment of potential mediating or moderating effects.

Table 1: Summary of Autism Spectrum Disorder Studies

Source	Measurement	Study Design	Population	Child Factors	Outcome Variables	Summary
Alshekaili et al., 2019 [60] BC	Patient Healthcare Questionnaire-9	Cross-sectional	Random sample of 80 parents with children with ASD (Oman)	Severe disability	Depression	Prevalence of depressive symptoms among caregivers of children with ASD was 71%. The high percent could be due to the child having severe disability. Unemployment and being the sole parent/caregiver correlated with depression.
Ang & Loh, 2019 [47] AE	Diagnostic Statistical Manual of Mental Disorders—Fifth Edition (DSM-5); depression, anxiety, stress (self-reported questionnaires); COPE	Cross-sectional	106 mothers and 97 fathers from Asia. 97% were married (Asia)	Ages 7-17 years. Most with ASD, some with Asperger's disorder, and some with pervasive developmental disorder	Stress Anxiety Depression	Active-avoidance coping was the most common approach for adjusting, and this correlated highest with greater depression, anxiety and stress. Mothers experienced significantly greater stress levels than fathers. Although stress was a major precursor to depression for fathers, it was not for mothers.
Argumedes et al., 2018 [59] BE	Sociodemographic questionnaire; Childhood rating Scale; Parenting Stress Index-3 ed.	Cross-sectional	42 families; 10 fathers; 27 mothers; 5 couples (Canada)	ASD child had to present at least one challenging behavior (e.g. hitting, property damage, self-injury)	Stress	High severity of ASD and challenging behaviors were associated with increased risk of stress. Reductions in challenging child behavior with family centered support correlated with reduced parenting stress.
Bayat 2007 [80] F	Walsh's Resilience Theory.	Cross-sectional	175 parents and other primary caregivers (USA)	Ages 2-18; 53% had severe autism. 60% had some sort of aggressive behavior.	Positive outcomes Family unity	Families of children with ASD often experience resilience by making positive meaning of disability, mobilization of resources, becoming a closer and more united family, developing a greater appreciation for life and in others, and gaining spiritual strength.
Bendixen et al., 2011 [33] AE	Parenting Stress Index-Short Form; The Family Adaptability and Cohesion Evaluation Scales	Longitudinal	18 male and 1 female with ASD and their parents recruited from Florida's Center for Autism and Related Disabilities (USA)	Mean age = 4.5	Stress	Fathers and mothers were studied separately and as a partnership before and after the 12-week in home training and intervention. Mothers and fathers reported high stress prior to the intervention. The intervention lowered the stress level, but not significantly. Mothers were more flexible and easy to adapt to new developmental stressors. Fathers reported that they liked structures where they established rules.
Benson, Karlof, 2008 [100] D	Autism Diagnostic Interview-Revised; Strengths and Difficulties Questionnaire (SDQ); Parenting Stress Index; Family Climate Index	Cross-sectional	72 parents of children with ASD (USA)	Ages 3-7 (Mean = 4.7)	Psychosocial effects	Siblings of children with ASD who do not have a diagnosed disorder are not at increased risk of psychosocial problems, compared to children in the general population.
Bourke-Taylor et al., 2012 [71] BC	Short Form 36 V.2; Pediatric Quality of Life Parent Report	Cross-sectional	152 mothers (94 with ASD, 29 with cerebral palsy, and 19 with attention deficit hyperactivity disorder) (Australia)	Ages 5-18	Mother's mental health	Maternal mental health was negatively associated with their child's unmet service needs and challenging behaviors, but positively associated with maternal participation in healthy activity, maternal empowerment, and the child's psychosocial health.

Bourke-Taylor et al., 2010 [83] BC	Qualitative assessment	Cross-sectional	Purposive sample of 8 participants (Australia)		Emotional distress (e.g. daily challenges to mental health)	The five main categories that were associated with maternal mental health were (1) the child's needs and behaviors; (2) the mother's personal needs and ability to organize; (3) familial and spousal relationships; (4) service availability and adequacy; (5) and the environment in which the family lives. The study aimed to find solutions to these five issues. A study limitation was its small sample size.
Brobst et al., 2009 [62] A	Parental Stress Index Short Form (PSI-SF); Eyberg Child Behavior Inventory (ECBI); Relationship Assessment Scale (RAS); Social Support Scale (SSQ6); Respect Toward Partner scale; Commitment scale	Cross-sectional	25 couples with ASD children; 20 couples with children who have no developmental disorders (USA)	Mild severity	Stress	Parents of ASD children experienced more stress and greater challenges with child behavior problems, as well as poorer social support and relationship satisfaction than parents of normal functioning children. Mothers of children with ASD having the most intense behavior problems had lower levels of spousal support, respect for their spouse, and commitment to their marriage.
Bujnowska et al., 2019 [88] A	Future Anxiety Scale-FAS1	Cross-sectional	167 parents of children with disabilities (majority had ASD) and 103 parents of children with normal development (Poland)		Future anxiety (about health and meaning of their life)	Mothers of children with disabilities had higher general levels of future anxiety than fathers of children with disabilities.
Carter et al., 2009 [34] BC	Several scales to measure behavior, family environment, maternal efficacy, etc.	Longitudinal	143 mothers of newly diagnosed toddlers with ASD (USA)	Ages 2-3 years	Depression	Maternal depression was associated with child behavioral problems, maternal anxiety symptoms and poor mood, low parenting efficacy, social supports, and coping styles.
Chan et al., 2018 [45] BC	40-item Social Communication Questionnaire; 13-item Maternal Worry Scale for children with chronic illness; 15-item Parenting Stress Index-Short Form; 9-item Patient Health Questionnaire; 7-item Generalized Anxiety Disorder Scale.	Cross-sectional	375 parents of children with ASD (China)		Stress Anxiety Depression	There is a positive association between child autism symptoms and depression and anxiety in parents. The associations were mediated by parenting stress, marital conflicts, family and economic pressure, and future-related worry.
Chen et al., 2021[98] E	SDM-5 and Child Autism Rating Scale (CARS); Social Responsiveness Scale (SRS); Autism Behavior Checklist (ABC); Children's Sleep Habits Questionnaire (CSHQ)	Cross-sectional	1310 with ASD and 1158 normally developing children (China)	Ages 2-7	Sleep disorder	Sleep disorders in ASD children were significantly higher than in normally developing children. The highest prevalence of sleep problems in ASD children were bedtime resistance, sleep anxiety, sleep onset delay, and daytime sleepiness.
Davis & Carter, 2008 [49] ABC	Beck Anxiety Index (BAI); Center for Epidemiologic Studies Depression Inventory (CES-D); Parent Stress Index-Short Form (PSI-SF)	Cross-sectional	108 parents (54 mothers, 54 fathers) (USA)	Toddlers (M = 26.9 months) with ASD	Stress Anxiety Depression	Anxiety and depression highly correlated with stress. Mothers' stress and depression scores were uniformly higher than fathers' scores. There was no significant difference in anxiety between mothers and fathers.
Duarte et al., 2005 [44] BC		Case-control	Mothers of 31 children with autism and 31 without autism (USA)	29 boys and 2 girls. Mean age 6.8 years.	Stress	Having a child with autism was a main cause of stress. Other factors responsible for stress were little interest in people, being an older mother, and having a younger child.

Ekas et al., 2015 [96] CD	Brief COPE; Benefit Finding scale; Life Orientation Test-Revised (LOT-R); Couples Satisfaction Index (CSI); Whalen and Lachman scale	Cross-sectional	67 couples (64 married) (USA)	56 males and 11 females	Coping. Benefit finding Optimism Relationship satisfaction Spousal/partner support	Individual optimism, benefit finding, coping strategies, and social (instrumental and emotional) support positively related to their relationship satisfaction. However, only benefit finding and seeking emotional support affected their partner. Note that instrumental support involves seeking advice/assistance from another. Emotional support involves seeking moral support (sympathy or understanding).
Ekas et al., 2010 [50] C	Life Orientation Test; Parental Stress Items scale; Positive and Negative Affect Schedule (PENAS); Center for Epidemiological Studies Depression Scale (CES-D); Satisfaction with Life Scale; Psychological Well-Being Scale (PWB)	Cross-sectional	124 mothers (USA)	Ages under 18	Stress Depression Optimism Social support	Greater family support was associated with increased optimism. Optimism was associated with decreased parenting stress, depression and negative affect. Social support was associated with lower depression, negative affect, and parenting stress. Mediating and moderating roles were discussed.
Elder et al., 2010 [85] E	Autism Diagnostic Interview-Revised (ADI-R); Autism Diagnostic Observation Schedule (ADOS); Vineland Adaptive Behavior Scales-Survey Form;	Cross-sectional	18 dyads (USA)	Ages 3-7 years; 18 males and 1 female with ASD	Four skills associated with training interventions	Four common skills were taught to fathers, based on social interaction theory. Fathers were then asked to teach the mothers what they had learned. They found that fathers and mothers were equally capable of achieving positive social reciprocity in parents and children with autism. The main point emphasized was that fathers are fully capable of promoting father-child social interactions and that the child responds well to them.
Estes et al., 2013[93] B	Questionnaire on Resources and Stress (QRS); Brief Symptom Inventory (BSI); Aberrant Behavior Checklist; Vineland Adaptive Behavior Scales (VABS)	Cross-sectional	Families of 46 ASD, 25 developmentally delayed, and 25 typically developing (USA)	Ages 18-30 months	Stress	Parents of toddlers that had ASD experienced increased stress compared with parents of toddlers with developmental delay without ASD and typical development children.
Fassett-Carman et al., 2020 [46] C	DSM-5 Level 1; Cross Cutting Symptom Measure; Level 2-Depression; Level 2-Anxiety	Cross-sectional	356 (70% female) were recruited from treatment-seeking college students assessed at the Brandeis Counseling Center (USA)	Ages 18-25 (M = 20.8)	Anxiety Depression	This study explains how stress can lead to anxiety and/or depression. Sources of stress or the frequency and level thereof indicate one more than the other. For example, more severe or dramatic stress correlates with anxiety more than depression.
Fida et al., 2019 [37] E		Meta-analysis of 24 studies			Stress Parent-child interaction	This article provides an overview of selected interventions that do not require a specialist in treating individuals with ASD. These interventions show increased parent-child interactions and reduce parental stress.
Gallagher & Hannigan, 2014 [65] BC	25-item Strengths and Difficulties Questionnaire	Cross-sectional	8,568 primary caregivers (Ireland)	9-yr old school children	Depression Physical health	Parents of children with disabilities (9% had autism or Asperger's) have greater risk of depression. Some but not all of this increased risk is attributed to chronic health conditions. However, the increased risk was explained by the child's problem behaviors.

García-López et al., 2021 [48] A	Parental Stress Index (PSI); Hospital Anxiety and Depression Scale (HADS); Kansas Inventory of Parental Perceptions	Cross-sectional	135 father-mother dyads of children with ASD (Spain)	Ages 3-38.	Stress Anxiety Positive contributions	Parents of a child with autism experience increased levels of stress and anxiety. Parents of children with severe ASD experienced lower perceptions of positive contributions (i.e., learning by experience, happiness and fulfillment, personal strength and family closeness, understanding the purpose of life, personal maturity and growth, awareness of future issues, greater social network, career and job growth, pride and correction) compared to parents of mild-moderate ASD. Mothers' perceptions of positive contributions were higher than father's perceptions.
Gray, 2006 [35] E	In-depth semi-structured interviews	Longitudinal study – 1988 through 1990	28 parents (19 mothers and fathers) of children with autism (Australia)	Ages 4-19	Coping strategies	Aging is associated with change in coping strategies from reliance on service providers, family support, and social withdrawal and individualism to coping through religious faith and other emotion-focused strategies.
Grebe et al., 2021 [69] A	Revised Illness Perceptions Questionnaire for ASD (IPQ-R-ASD); Family Adjustment Measure (FAM), Parental Stress Index (PSI)-4; Stress Index for Parents of Adolescents (SIPA)	Cross-sectional	361 biological parents (294 mothers and 67 fathers) of children with ASD (USA)		Stress Coping	Mothers had more and better coping compared with fathers, suggesting mothers had more coping skills (e.g., communicating questions and seeking information) in dealing with their child's ASD. Fathers appear to cope by leaving the home more than mothers (e.g., going to work). Fathers expressed their emotions less and sought less social support than mothers. Mothers reported higher stress than fathers, particularly among teenagers, related to their child's temperament and behavioral characteristics. Mothers' higher stress has been linked with their child's eating, sleeping, and emotional regulation, but fathers stress is linked with their child's externalizing behaviors. Father and mother stress is higher when their child is under 12. Since ASD is typically first diagnosed in children under 12, the higher parental stress may be associated with the initial diagnosis and treatment.
Griffith et al., 2014 [103] E	The Strengths and Difficulties Questionnaire (SDQ)	Cross-sectional	168 mothers and 130 fathers with a child diagnosed with ASD and another child without a diagnosis of ASD (UK)	Ages 4-17 (M = 10.4)	Abnormal behavior	Fathers and mothers were more likely to rate siblings of ASD children as having more emotional problems and lower pro-social behavior when compared with normally developing children. Mothers identified more adjustment problems and conduct problems in siblings of ADHD children than normal developing children.

Halstead et al., 2017 [73] BC	Positive Affect Scale; Life-short scale; Hospital Anxiety and Depression Scale	Cross-sectional	138 mothers (ages 23-57) of children with intellectual developmental disabilities (UK)	Ages 4-18	Depression Life satisfaction Positive affect	Social support has a moderating effect on the relationship between child behavioral and emotional problem and maternal depression. Increased behavior and emotional problems correspond with lower life satisfaction, higher maternal depression, and lower positive effect most profoundly when social support is low.
Hartley et al., 2017 [41] A		Diary-14-day daily	174 couples of children with ASD; 179 couples without children with disabilities (USA)		Time with partner Support of partner Closeness with partner Positive and negative couple interactions	ASD parents spent less time with their partner, had lower partner closeness, and had fewer positive couple interactions than parents of children who are not disabled.
Hartley et al., 2010 [97] C		Cross-sectional	391 parents of children with ASD and matched sample of parents of children without disabilities. (USA)		Divorce	A significantly higher rate of divorce occurred in families with an autistic child. Divorce remained high through the ASD child's childhood, adolescence, and early adulthood but decreased following the normal developing child's childhood (after age 8 years). Divorce was more likely for younger maternal age when the ASD child was born and if the child was born later in the birth order.
Hastings et al., 2005 [51] A	Parent Report version of the Developmental Behavior Checklist (DBC); Autism Screening Questionnaire (ASQ); Hospital Anxiety and Depression scale; Questionnaire on Resources and Stress Friedrich short form (QRS-F); Kansas Inventory of Parental Perceptions Positive Contributions Scale (KIPP-PC)	Cross-sectional	41 mother-father pairs at Southampton Childhood Autism Program (UK)	Preschool age (M=37 months)	Stress Depression	Depression is significantly greater for mothers than fathers of children with autism. There is no difference in elevated stress levels among mothers and fathers, but mothers had more positive perceptions than fathers. Maternal stress is related to their partner's depression and to behavior problems of their child with autism. Mothers are affected more negatively by their child's behavior problems than fathers. Paternal depression predicted their partner's stress.
Hastings, 2003 [52] A	Developmental Behaviour Checklist; Hospital Anxiety and Depression Scale; Parent and Family Problems subscale of the QRS-F	Cross-sectional	18 married couples of children with autism (UK)	Mean age 11.8 years, 13 males and 5 females	Stress Anxiety Depression	Mothers and fathers had similar levels of stress and depression, but mothers experienced greater anxiety than fathers. Mothers' stress was associated with child behavior problems and the fathers' mental health. On the other hand, fathers' stress is less affected by other family members and more by other factors.
Hastings, 2003[104] D	Developmental Behavior Checklist (DBC); Parent and Family Problems subscale of the Friedrich Short Form of the Questionnaire on Resources and Stress (QRS-F); Strengths and Difficulties Questionnaire (SDQ)	Cross-sectional	22 siblings of children with autism	Ages 4-16	Behavioral problems Prosocial behaviors	Mothers rated these children as having more behavior problems and fewer prosocial behaviors. Boys and individuals younger than their sibling with ASD had fewer prosocial behaviors.

Hastings, 2001 [61] C	Autism Behavior Checklist (ABC); Questionnaire on Resources and Stress (QRS); Family Support Scale (FSS); Family Coping Strategies (F-COPES)	Cross-sectional	141 parents (UK)	Mean age = 5.0	Stress	Parents had lower stress if they had adaptive coping strategies, informal social support sources, and beliefs about the efficacy of the intervention. Higher stress was associated with greater autism symptomatology.
Herring et al., 2006 [89] AC	Diagnostic and Statistical Manual of Mental Disorder (DSM)-IV; Psychoeducational Profile; Vineland Adaptive Behaviour Scales parent interview; Adaptive Behaviour Composite; Reynell Developmental Language Scales	Cross-sectional (3 time points)	Parents of 123 children with autistic disorder and pervasive developmental disorder (Australia)	20-51 months	Stress Child behavioral and emotional problems Family functioning Mental health	Child emotional and behavioral problems contributed more to mother stress, parental mental health problems, and perceived family dysfunction. Fathers reported significantly less stress than mothers in relation to parenting their child with ASD.
Hickey et al., 2017 [75] A	PANSE; Center for epidemiological Studies-Depression Scale	Cross-sectional Dyadic Models	176 families (couples that had been in relationship for more than 3 years) (USA)	Ages 5-12; 85% males	Depression Social exchange	Mothers reported more positive and negative social exchanges with family, friends, and health professionals than fathers. Mothers experienced all three social exchanges (informational, emotional, and social); Fathers experienced more informational and emotional; Not having social exchanges was a significant indicator of depression. Positive and negative social exchanges with one's spouse were the biggest factor related to depressive symptoms.
Higgins et al., 2005[] BC	Family Adaptability and Cohesion Evaluation Scales (FACES II); Quality Marriage Index (QMI); Rosenberg Self-Esteem Scale; Coping Health Inventory for Patients (CHIP)	Cross-sectional	53 parents/caregivers of children with ASD (Australia)	Mean = 10 years and 10 months	Marital happiness Family cohesion Family adaptability Coping strategies	Having a child with ASD may lower marital happiness, family adaptability, and family cohesion. No evidence of lower self-esteem. Coping strategies were not associated with marital or family adjustment.
Hoefman et al., 2014 [19] F	Quality of Well-Being Scale (QWB-SA); Primary Caregiver Questionnaire; Centers for Epidemiologic Studies Depression Scale (CES-D); CarerQol-VAS; CarerQol-7D; Self-Rated Burden (SRB) Scale; Family Quality of Life Scale (FQLS)	Cross-sectional	224 families with ASD child (USA)	Ages 4-17	Fulfillment Relationship problems Mental health problems (including depression, problems with daily activities, financial problems, disability-related support, physical health problems).	Many parents had fulfillment in caring for their child with ASD. However, parents often experienced problems balancing care for their child and other daily activities, had financial challenges or suffered from depression. CarerQol was shown to be valid in assessing the impact of caregiving on parents of children with ASD.
Hoffman et al., 2009 [53] BF	Parenting Stress Index	Cross-sectional	Mothers of children with autism (104) and mothers of typically developing children (342) (USA)	20 female ASD children, 84 male ASD children; 136 female normal developing children, 205 male normal developing children (Ages 3-16) (M = 8.6 in the ASD group and 8 in the normal developing group)	Stress Depression	Mothers of children with ASD reported higher levels of stress and depression than mothers of normally developing children. Although mothers of ASD children deal with more stress, they still feel they have a close relationship with their child.

Hu et al., 2019 [87] ABC	Difficulties in Emotion Regulation Scale (DERS); Parenting Stress Inventory-Short Form (PSI-SF); Parenting Bonding Instrument (PBI)	Cross-sectional	211 mother-father pairs (China)	Ages 7-12 (M = 10.4); clinical diagnosis of ASD	Stress	Mothers and fathers who had difficulties coping with emotional challenges had greater perceived stress when caring for their child with ASD. Higher stress perception then resulted in fewer bonding behaviors, more overprotection, and less care for their child. Mothers were more easily overwhelmed by emotional regulation. On the other hand, fathers were more likely to ignore their own mental health issues. Mothers' stress was not associated with their spouses' care behaviors.
Huang et al., 2019 [54] BC	Revised Autism Diagnostic Inventory; Neuropsychiatric inventory; Parenting Stress Index-Short Form; Multidimensional Scale of Perceived Social Support	Cross-sectional	80 mothers of ASD children (China)	34 low-functioning ASD and 46 high-functioning ASD	Stress Anxiety Depression Irritability Agitation Nighttime behavior disturbances	Neuropsychiatric symptoms and parental stress are significantly greater in mothers of ASD children. Low-functioning ASD was associated with significantly higher depression, anxiety, apathy, irritability, agitation, nighttime behavior disturbances, and change in appetite versus the high-functioning ASD group.
Jones et al., 2014 [55] AC	Hospital and Anxiety Depression Scale; Questionnaire on Resources and Stress-Short Form (QRS-F); Positive Gain Scale (PCS); Social Communication Questionnaire (SCQ)	Cross-sectional	161 mother/father couples taken from another study that focused on sibling well-being (UK)	Ages 4-16	Stress Anxiety Depression	Mothers reported higher stress, anxiety, and depression but greater positive gain than did fathers. The child's behavior was the biggest predictor of psychological distress.
Jose et al., 2021 [68] AC	Perceived Stress Scale (PSS-10)	Cross-sectional	99 mothers and 11 fathers (India)		Stress Emotion-based coping strategies Spousal support in care of child with ASD	High stress was associated with low spousal support. Unlike women with strong spousal support, mothers with low spousal support experienced difficulty interacting with others and felt a low level of acceptance.
Karaivazoglou et al., 2019 [26] ABC	Hospital Anxiety and Depression Scale; Short Form 36 Health Survey	Cross-sectional	130 parents; 95 children referred for evaluation, 35 healthy children (Greece)	Any kind of developmental disorder	Anxiety Depression Quality of life	Parents of developmentally impaired children have greater depression, anxiety, worse social functioning and social health. Mothers have greater anxiety, bodily pain, lower vitality, and poorer social function and mental health. More children in the family equates to higher anxiety. Older aged children corresponded with higher parental anxiety, emotional problems, and worse mental health.
Kayfitz et al., 2010 [79] AF	Parenting Stress Index-Short Form, Positive Contributions Survey	Cross-sectional	23 mother/father couples (Canada)	Ages 5-12 (M = 7.4) with ASD, Asperger's disorder, or pervasive developmental disorder	Stress Positive experiences	Mothers experienced more positive experiences than did fathers. Positive experiences (e.g., improved family relationships, source of happiness, personal development, a better understanding of life goals) were negatively associated with reports of parental stress. Positive experiences were negatively associated with their partners' report of parental stress in fathers but not mothers.

Koukouriki et al., 2021 [102] D	Children's Loneliness and Social Dissatisfaction Questionnaire (LSDQ)	Cross-sectional	118 siblings of children with ASD; 115 siblings of normally developing children (Greece)	Ages 9-13	Lonely Social dissatisfaction	A study of siblings of children with ASD found that while the firstborn child does not experience greater likelihood of feeling lonely and socially dissatisfied, a child later in the birth order who is a sibling of a child with ASD is more likely to feel lonely and socially dissatisfied.
Kousha et al., 2015 [27] B	Beck Depression Index, Beck Anxiety Index, WHO Quality of Life-BREF	Cross-sectional	127 mothers of ASD children (Iran)	Ages 2-16 (M = 6.3), living in an urban or rural community	Anxiety Depression	Mothers of children with ASD experience higher levels of depression and anxiety and poorer levels of health-related quality of life. More severe depression and lower health-related quality of life was associated with an older child with ASD and diagnosis at an earlier age.
Kwok et al., 2014 [28] C	Devaluation of Consumer Families scale; Caregiver Burden Inventory; Kansas Marital Satisfaction Scale (KMSS)	Cross-sectional	160 mothers of preschool children with disabilities (Hong Kong)	Ages 2-6	Depression Marital satisfaction Perceived stigma Perceived burden	Negative associations were observed between perceived stigma and marital satisfaction and perceived caregiving burden and marital satisfaction. Perceived burden mediated the association between perceived stigma and marital satisfaction. Stigma negatively predicted caregiving burden. Other mediators of the association between perceived stigma and marital satisfaction were perceived social, emotional, and developmental burdens. Developmental burden was associated with depression. Physical and social burdens were also associated with depression.
Lei & Kantor, 2021 [95] E	Social Support Rating Scale; Family Adaptability and Cohesion Scale	Cross-sectional	167 caregivers of children with ASD recruited through teachers in special education schools (China)	Ages < 18	Social support Family cohesion and adaptability	Social support had a positive effect on family cohesion and adaptability. Social support in the form of subjective support (an individual's level of satisfaction of being supported) and utilization support (degree individuals make use of available social support), but not objective support (visual or actual social support), were found to increase family cohesion and adaptability.
Levin et al., 2016 [99] C	Parenting Stress Index-Short Form; Children's Sleep Habits Questionnaire; Maternal Cognitions about Infant Sleep Questionnaire; Parental Bedtime Behavior Interaction	Cross-sectional	66 mother-child dyads, 35 ASD children 31 normally developing children (Israel)	ASD child ages 29-48 months (M = 39); Normally developing child ages 25-48 months (M = 36); majority of children were males in both groups	Disruption to parental sleep	Children with ASD experienced more sleep problems than normally developing children. Sleep problems in children with ASD contributed to a disruption of sleep in their mothers and increased parental stress.
Marquis et al, 2020 [36] AB		Longitudinal – matched population-level data	Children with developmental disability (Canada)		Depression and other mental health problems	Significantly higher levels of depression and other mental health problems occurred in mothers and fathers of children with developmental disability.

Meadan, Halle, et al., 2010 [29] BCD		Literature Review			Marital stress Parental stress Sibling stress Familial coping strategies Sources of support	Studies on marital stress resulting from having a child with ASD are few and mixed. Stress is greater for parents of children with ASD due to the permanency of the condition, lack of acceptance of behavior, low levels of support available, economic burden, concern for the child's future, challenging behavior, and psychological characteristics of the parents (self-efficacy, locus of control, coping style). Studies assessing sibling stress are few and inconsistent. Use of coping strategies and social support (including respite care) can lower parental and family stress and increase family cohesiveness.
Meadan, Stoner, Angell, 2010a [23] D		Literature Review (n = 12)	Focus on siblings of ASD children	Ages 3-18	Social, emotional, and behavioral adjustment of siblings of individuals with ASD	The reviewed studies showed mixed results with respect to outcome and adjustment variables for siblings of individuals with ASD. While some studies showed positive effects in terms of self-concept and social competence, other studies showed negative effects like low levels of prosocial behavior, increased internalizing and externalizing problem behavior, feelings of loneliness, and delays in developing social skills.
Miranda et al., 2019 [63] E	Parenting stress questionnaire; Coping Orientation to Problems Experienced Scale; Strengths and Difficulties Questionnaire; and Duke-UNC Social Support Questionnaire	Cross-sectional	52 mothers of ASD children (Spain)		Stress	Maternal stress was positively associated with the children's ASD symptoms. Maternal stress was negatively associated with engagement coping and social functioning support. Significant mediators between ASD symptoms and maternal stress were engagement coping and behavioral difficulties.
Naheed et al., 2019 [76] BC	Patient Health Questionnaire (PHQ-9)	Cross-sectional	6 schools in Dhaka metropolitan city. 388 mothers (ages > 18) with ASD children (Bangladesh)		Depression	Major depressive disorder was diagnosed in 45% of mothers, proportionally higher in those who worked outside the home, had no childcare support, and had low satisfaction with their providers when they sought treatment for their ASD child.
Navot et al., 2016 [81] E		Cross-sectional; interviews	22 mothers (USA)	Ages 2-4	Qualitative study focusing on family vision and planning	A sense of competence, taking things a day at a time, and emotional support from a spouse can effectively promote maternal well-being when raising a child with ASD.
Papadopoulos et al., 2019 [30] C		Literature Review	12 papers; autism-related stigma effect on caregivers (primarily mothers) mental health (UK)		Mental health factors	There was a relationship between stigma and depression, psychological distress, psychological wellbeing, psychological burden, and general mental health. Stigma may consist of blaming the caregiver for the onset of autism, poor child development, the caregiver should be ashamed, that they lack competence in their caregiving, that they should be avoided or pitied.

Phetrasuwan and Shandor, 2009 [56] B	Parental Stressor Sale; Childhood Autism Rating Scale-Parent Version; Center for Epidemiologic Studies Depression Scale; Psychological Well-Being Scale	Cross-sectional	108 mothers of ASD children (USA)	Ages 3-10 (M = 6)	Stress Depression	Mothers of ASD children had more stress and depressive symptoms and lower levels of well-being.
Pisula and Banasiak, 2019 [92] E	Family Empowerment Scale; Ways of Coping Questionnaire; Social Support Questionnaire Short Form	Cross-sectional	35 fathers of ASD children; 37 fathers of Downs Syndrome children; 40 fathers of normal developing children (Poland)	Ages 7-17; at least 3 years since diagnosis	Empowerment	Empowerment, defined as the ability to actively satisfy one's needs and gain control of one's life, is key to adapting to having a child with disabilities. Fathers of children with autism had lower empowerment. In fathers of children with ASD, they found no association between social support and empowerment.
Postorino et al., 2019 [66] BC	Vineland Adaptive Behavior Scales, Aberrant Behavior Checklist; Parenting Stress Index	Cross-sectional	Parents of 298 children (259 males, 39 females) (USA)	Ages 4-14 years (M = 5.8), diagnosed with ASD, and have severe behavior problems	Stress	Challenging behavior, social disability, and adaptive functioning are common contributing characteristics to stress for parents of children with ASD.
Rankin et al., 2019 [31] AE		Literature Review				This review focused on the father's role in a family raising a child with ASD. The review found that fathers are less involved than mothers in child rearing activities. The authors also note that fathers are not usually included in research for raising children with ASD. The authors concluded that an intervention that teaches both parents to be equally involved in child rearing could be effective in improving the overall family unit.
Rao & Beidel, 2009 [86] B	Parenting Stress Index, Family Environment Scale; psychological problems; symptom-90-Revised, SF-36; Piers-Harris Children's Self-Concept Scale; Child Behavior Checklist	Cross-sectional	12 mothers and 8 fathers (USA)	Ages 8-14	Stress, family functioning, psychological problems, general physical and mental health, sibling adjustment, child behavior problems	Parents of children with high functioning autism experienced significantly greater stress than parents of children without psychological disorders, depending on the characteristics of the children. Higher intellectual functioning of the high functioning child with autism did not compensate for the greater stress experience by the parents.
Riahi & Izadimazidi, 2012 [72] B	General Health Questionnaire (GHQ)	Cross-sectional	32 mothers of children with autism and 29 mothers of children without the disorder		Mental health Anxiety Insomnia	Mothers of children with autism experienced significantly more mental health problems, anxiety, and insomnia than mothers with normal functioning children.
Rivard et al., 2014 [25] AB	Childhood Autism Rating Scale (CARS); Wechsler Preschool and Primary Scale of Intelligence (WPPSI-III); Adaptive Behavior Assessment System-II (ABAS-II); Parenting Stress Index-Short Form (PSI/SF)	Cross-sectional	118 fathers and 118 mothers (Canada)	Pre-school aged children	Stress	Mothers and fathers had stress reaching a clinical threshold. Fathers' stress was associated with the child's sex and age. Mothers' stress was positively associated with the child's age. The father had greater stress if the autistic child was female.
Rutherford et al. 2019 [41] E		Meta-analysis			Quality of life Parent stress Self efficacy Parenting style and satisfaction	Reduction of parental stress occurred through mindfulness/relaxation training. In addition, parent style and satisfaction was improved through parent training and education.

Sawyer et al., 2010 [43] BCE	Time Crunch Scale; International Support Evaluation List (ISEL); General Health Questionnaire (GHQ); Center for Epidemiological Studies Depression Scale (CES-D)	Diary	216 mothers (Australia)	Ages 6-17 (M = 11); 88% males	Depression	Mothers caring for children with autism had higher rates of mental health problems. Mothers with more social support had fewer mental health problems. Mothers feeling more time pressure reported a higher level of depression.
Scherer et al., 2019 [38] B		Meta-analysis	6 studies		Depression	There was a higher risk of depression among parents of children with autism.
Seymour and Wood, 2017 [58] B	Kessler-6	Cross-sectional	159 fathers of ASD children, 45 fathers of children with a long term disability, and 6,578 fathers of normal developing children (Australia)	Ages 8-9 years	Distress Overall health	Approximately 17% of fathers of ASD children had higher risk for psychological distress (nervousness, hopelessness, and worthlessness); 16% reported poor global health; and 16-18% engaged in adverse health behaviors (e.g., alcohol abuse, cigarette smoking).
Shivers and McGregor, 2019 [105] D	Multiple Affect Adjective Checklist—Revised (MAACL-R); Revised Life Orientation Test (LOT-R); Family Impact Questionnaire (FIQ); Behavior Problems Index (BPI);	Cross-sectional	97 with a brother or sister; 26 participants had a brother or sister with ASD, 23 participants had a brother or sister with a different developmental disorder (USA)	Ages 12-18 (M = 14.4)	Siblings reported on anxiety, hostility, and positive affect. Parents reported on general optimism, child behavior problems, and perceptions of how the child impacts the family (and sibling)	This study focused on siblings' perceptions of their brother or sister with developmental disorders. Parents' perceptions and siblings' perceptions did not always match. Overall, siblings did not feel negative emotions toward the affected sibling while parents often reported a more negative perception of the impact the individual with the disability had on the family.
Sim et al., 2018 [67] BC		Cross-sectional	535 families with one or more children with ASD. Random sample follow-up (6 months later) (Australia)		Response to the question: "How would you rate your family's overall stress due to your child's ASD diagnosis?"	Forty-four percent of parents reported severe family stress associated with raising a child with ASD. Factors associated with severe family stress were reduced ability to socialize, no access to individual therapy, negative spousal relationships, and high out of pocket costs because of the child. The study did not find comorbid conditions, sociodemographic variables, or social support as contributors to severe family stress.
Siu et al., 2019 [74] BC	Strength and Difficulties Questionnaire (SDQ); Parent Stress Index-Short Form (PSI-SF)	Cross-sectional	177 parents of children with ASD and 554 parents of typically developing children (China)	Ages 6-11	Stress Child behavior	Parents of children with ASD have significantly higher stress, with the relationship mediated by child behavioral problems.
Soltanifar et al., 2015 [77] A	Childhood Autism Rating Scale-Parent (CARS-P); Parenting Stress Index	Cross-sectional	42 couples with children with ASD (Iran)	Ages 2-12	Stress	The parental stress index positively correlates with the childhood autism rating scale. Mothers have significantly higher stress than fathers.
Souders et al., 2017 [32] E		Literature Review			Sleep disorder	ASD children are more prone to sleep problems due to arousal dysregulation and sensory hyper-reactivity. Improving sleep in ASD cases may involve sleep education, ecological and behavioral interventions, and exogenous melatonin.

Spratt et al., 2007 [64] E	Parenting Stress Index-Short Form; Family Resource Scale	Cross-sectional	Parents of children with developmental, behavioral, and neurological, and emotional problems (57), intraventricular hemorrhage documented at birth (70), and neural tube defects (45) (USA)	Ages 4-12	Stress	Behavior problems in the ASD child were the greatest factor contributing to high parental stress. They conclude that clinics and mental health professionals need to collaborate to help parents deal with this stress.
Stewart et al., 2015 [70] BC	Parenting Stress Index Short Form (PSI-SF)	Cross-sectional	74 Children with Tourette syndrome, 48 normally developing children (USA)		Stress	Parents of children with Tourette syndrome had increased stress compared with the parents of normally developing children. The increased stress was due to co-occurring ADHD and OCD.
Tunali & Power, 2002 [84] E	Autism Behavior Checklist (ABC); Home/Career Questionnaire; Self-Rating Depression Scale; Short-Marital Adjustment Test (SMAT)	Cross-sectional	58 mothers, 29 children with autism and 29 children without autism	Ages 5-14, 22 boys, 7 girls	Coping and redirection	Mothers of autistic children redefined what constitutes the fulfillment of various human needs and/or they sought to find alternative ways to fulfill them. These mothers placed less emphasis on their careers and focused more on their parental role; spent more leisure time with extended family members; put less emphasis on what others thought about their child's behavior; put more emphasis on spousal support and the parental role in discussions about marriage; open to more than one interpretation about their child's behavior; and showed a tendency toward a greater overall tolerance of their child's behavior.
Twoy et al., 2007 [91] E	Family Crisis Oriented Personal Evaluation Scales (F-COPEs)	Cross-sectional	55 parents of children with autism (USA)	Ages < 12	Stress Family coping	Parents of children with ASD are resilient in their ability to adapt to challenges of raising children with autism. Coping strategies included using social support from close friends and extended families. Stress was high among families of children with autism.
Valicenti-McDermott et al., 2015 [24] BC	Parenting Stress Index-Short Form (PSI-SF); Gastrointestinal Questionnaire, Child Sleep Habits Questionnaire, and Aberrant Behavior Checklist.	Cross-sectional	50 families of children with autism and 50 families of children with other developmental disabilities matched by age/gender (USA)	Ages 2-18 with ASD	Stress Sleep problems Behavioral difficulties Gastrointestinal symptoms	Parents of children with ASD have significantly higher stress. Parental stress was related to child sleep and behavioral problems and gastrointestinal symptoms. Parental stress was not associated with age or time since the child was diagnosed.
Waizbard-Bartov et al., 2018 [78] F	Tedeschi and Calhoun's Crisis-Related Growth Model	Cross-sectional; Interview	19 parents (14 mothers, 5 fathers) (Israel)	Ages 9-26 (M = 15.8), with varying levels of required support	Qualitative growth narratives	The study demonstrated that parents' interaction with their ASD children may have positive perspectives that result in personal growth. Growth experiences were described as personal strength and inner power, insights, more intimate relationships, and stronger marital bonds.
Walton and Ingersoll, 2015 [101] DE	Strengths and Difficulties Questionnaire (SDQ); Social Responsiveness Scale (SRS); Sibling Inventory of Behavior (SIB); Center for Epidemiologic Studies Depression Scale (CES-D); Family Impact Questionnaire (FIQ)	Cross-sectional	163 mothers of two of more children with ASD; 69 siblings of ASD children, 93 siblings of normally developing children, all recruited through Interactive Autism Network (IAN) (USA)	Ages < 18	Behavior Emotion	Siblings of children with ASD had similar emotional/behavioral adjustment but less involvement and were more avoidant of their sibling than normally developing children. Older male siblings were at greater risk for behavioral/emotional difficulties.

Whitehead et al., 2015 [57] E	Depression Anxiety Stress Scales-21 Item (DASS-21); Connor Davidson Resilience Scale (CD-RISC-25); Short Form Developmental Behaviour Checklist (DBC-P24); Locus of Control of Behaviour Scale (LCB); Brief COPE; Social Support Index (SSI); Service Obstacles Scale (SOS)	Cross-sectional; national survey	438 female caregivers (Australia)	Ages < 18 with ASD	Stress Anxiety Depression Resilience	Psychological outcomes primarily related to individual coping responses. Avoidance strategies (self-blame, denial, emotional venting, and disengagement) associated with stress, anxiety, and depression. Planning, acceptance, and positive reframing characterize resilience.
Yirmiya & Shaked, 2005 [39] B		Meta-analysis			Anxiety Depression Mania Obsessions Neuroticism Schizophrenia Psychiatric disorders	Parents of children with ASD experience higher risk of psychiatric difficulties.
Zeng et al., 2020 [94] C	Chinese version of the Beach Center FQOL Scale; Family Support Scale; Parenting Stress Inventory-Short Form (PSI-SF)	Cross-sectional	226 parents (China)	Ages 7-12 (M = 10.3)	Stress Family quality of life	Perceived family support and family quality of life was low and parental stress was high. Family support had a direct, positive effect on family quality of life and an indirect effect on family quality of life through stress.
Zhai et al., 2015 [40] E		Meta-analysis	7 prospective studies resulting in 25,271 participants for a short sleep duration and 23,663 participants for a long sleep duration (China)	Adults	Depression	Short and long sleep duration was significantly associated with increased risk of depression in adults
Zhou et al., 2019 [82] E	9-item Patient Health Questionnaire; 7-item Generalized Anxiety Scale	Cross-sectional	167 mothers who spent at least 4 hours/day with ASD individual (China)	The majority were boys with average age of 5 years	Anxiety Depression	Mothers of ASD children have higher levels of anxiety and depression. The study indicates that maternal anxiety and depression can be lowered by using interventions to monitor and lower core symptoms of children with ASD.

- A. Compared mental health between mothers and fathers
- B. Parental mental health directly related to ASD
- C. Parental mental health indirectly related to ASD
- D. Sibling mental health
- E. Ways to reduce mental health problems
- F. Positive family outcomes associated with ASD children

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