

Mental Health of Families with Autism Spectrum Disorder

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ABSTRACT

Introduction: This study explores positive and negative mental health challenges for mothers, fathers, and siblings associated with a child having Autism Spectrum Disorder (ASD).

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 from an electronic search was conducted through April 2020. Well-known databases were used to access literature.

Findings: Because of behavioral problems of a child 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 do fathers. 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. The mental health effects on siblings of children with ASD remains uncertain.

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; Stress

INTRODUCTION

Autism derives from the word autos, signifying a person who keeps to him/herself, isolated from surrounding interactions [1]. Autism was a term 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, 80 years later, a stronger definition and understanding of autism has been established. Autism is a neurodevelopmental disorder characterized by social, communication, and behavioral challenges [3]. Social challenges include avoiding personal interactions and having difficulty expressing emotion [4]. Communication challenges consist of delayed or absent speech [3]. Behavioral challenges may range from repetitive patterns to

aggressive or disruptive behavior [5-7].

In the United States, approximately 1 out of 68 children born are diagnosed with autism [1]. Autism is more common in Caucasians and males [1]. 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 [3].

From ages 0-3, children typically hit certain milestones (e.g. walking, talking, sharing, and expressing emotions) [8]. Delay in these milestones indicates the possibility of autism [8]. Children with Autism Spectrum Disorder (ASD) face unique encounters throughout the school years [8]. Unique encounters involve a change of routine and familiarity, due to change in classmates, teachers, or subjects, may cause disruption and discouragement for children with ASD [8]. Improved education and increased awareness of the special challenges faced by the autistic children

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Received: 17-Nov-2020, Manuscript No. AYO-20-001-PreQC-22; **Editor assigned:** 23-Nov-2020, PreQC No. AYO-20-001-PreQC-22 (PQ); **Reviewed:** 24-Dec-2020, QC No. AYO-20-001-PreQC-22; **Revised:** 30-Jun-2022, Manuscript No. AYO-20-001-PreQC-22 (R); **Published:** 04-Aug-2022, DOI: 10.35248/2165-7890.22.12.329

Citation: Merrill RM, Smith A, Schenk CC (2022) Mental Health of Families with Autism Spectrum Disorder. Autism Open Access. 12:329

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enhances an educational system's knowledge and effectiveness of working alongside families who have children with special needs [9].

There is no known cure for the disorder, but some of the symptoms may be effectively regulated. Therapies and testing are underway to govern the core deficits of ASD [10]. Some therapies include neuro-feedback training and speech therapy to enhance cognitive skills and virtual assessment tools (entertainment technology) to develop speech communication, 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 a child with ASD, but often overlook how the impact of the outcomes may differ if caregiver involvement is integrated [11].

Researchers have found that parents of children with ASD are at greater risk of having mental health problems, such as anxiety and depression [12-16]. With these mental pressures in mind, studies have predominantly been focused on mothers of children with ASD [17-19]. This focus is consistent with women most often being the primary care provider [20]. However, the father is sometimes the primary care provider and, likewise, plays an equally important role in raising a child with ASD [21-22]. In addition to parents, it is important to consider how siblings of those with ASD are affected and ways in which they cope.

The primary purpose of the current study is to review the literature for both the negative and positive ways in which a child with ASD may affect the mental health of their parents and siblings. The child's age, gender, family circumstances, life-course perspectives, and cultural issues may influence the families overall mental health outcomes [19,23].

When a child is given a diagnosis of ASD, the outcomes of the diagnosis can have long-term effects on the family unit [24]. In this paper, emphasis is given to identifying response differences between mothers, fathers, and siblings as they work to understand, teach, and care for a child with ASD.

Understanding if there are differences in responses among the mother, father, and sibling(s) may allow for further emphasis to be placed on positive interventions that can improve possible mental health challenges [24]. 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 [24].

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 was conducted through April 2020. Literature was accessed using four well-known databases (e.g, Medline, Embase, Cochrane, and Scopus). The search resulted in 67 articles. 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 children with autism spectrum or children with ASD. 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 of ASD child, and the parental gender of focus) and the behavioral characteristics of children with ASD. Articles included in the review were published in years ranging from 2000 through 2020.

LITERATURE REVIEW

Cross-sectional study designs were typically used to measure the amount of stress parents experience from raising a child with ASD [25-27]. Many of these studies indicate that the stress of raising a child with ASD increases the risk of anxiety and depression, resulting in poorer physical health in parents [28,29]. Stress may alter an individual's life path with long-term consequences [30]. With a focus on clarifying stress-internalizing associations, one study found that perceived lack of control over stressors (e.g., unpredictable behavior and financial challenges) was specifically associated with depression [31]. Additionally, the study found that the number of high-severity stressors correlated more strongly with anxiety than depression. Both of these outcomes are common among parents of children with ASD. Other common outcomes, highlighted in additional studies regarding parents of ASD children, are strained marital relationships, poor self-worth, and physical health problems [21,32,33]. However, not all outcomes are negative. Positive outcomes identified in raising a child with ASD included strengthened family relationships and feelings of accomplishment as the child with ASD progresses [34-36].

Mothers

Mothers are often the focus in studies of children with autism, as they are more commonly known to spend larger quantities 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 [18,37]. This section highlights selected outcome measures for mothers caring for a child with ASD.

Clinical attention: Studies have consistently shown that mothers of children with ASD experience higher stress compared with mothers of normally developing children [38]. Other research has examined what distinguishes mothers who experience chronic high stress from mothers who do not [39]. In one study, 42% of mothers hit a clinical level of stress and an additional 28% had moderately elevated stress [40]. In many cases, stress could be considered to be severe enough to require clinical attention from a medical professional.

Behavior of child with ASD: After testing a series of child-related factors using two different scales (e.g. Pediatric Quality of Life 4.0 Generic Core Scales Parent Report and the Pediatric Evaluation of Disability Inventory Caregiver Scales), those factors statistically significantly correlated with the mother's mental health were the child's behavior, their emotional functioning

ability, and their psychosocial health [39]. Other research has shown that the age and behavioral problems of the child with ASD were positively associated with an increased risk of maternal depression [41]. Another study also found that higher severity of challenging behaviors in children with ASD positively correlated with higher levels of parenting stress [25]. The study concluded that reducing those challenging behaviors relates to lower stress. When a child's disruptive behavior extends into public settings, levels of maternal stress, anxiety and/or depression significantly increase [25]. Research has found that mothers of children with ASD reported that stress was triggered by having less personal time and not being able to manage their child's behavior in public places [20]. Interventions that focus on regulating the severe behavior of children with ASD requires dedication to a dependable routine of the child's schedule and guidance on proper behavior can result in a decrease in stress and a pathway that the child can self-regulate an otherwise anxious mind [42].

Social interactions and positive outcomes: Studies demonstrate that women find refuge in social interactions, whether it is with organizations or with close friends or family [43-45]. For women with a child that has ASD, social support correlated with greater optimism led to lower levels of stress and depression [45,46].

Although it has been determined that mothers are more inclined than fathers to develop depression while raising a child with ASD [43], studies have also found that mothers tend to experience more positive outcomes than fathers [17,34-37]. Some researchers suggest that as a family exhibits resilience (ability to do well while facing adversity), they are able to find increased joy in raising a child with ASD [47]. In a qualitative investigation, mothers of children with ASD said that even though their life plans had changed (e.g, not returning to the workplace), they were grateful to be able to spend more time at home with their child [48].

Fathers

Few studies have evaluated the negative and/or positive outcomes in fathers of children with ASD. Often, if they are included in a study, it is by classifying parents as a unit rather than differentiating by "father" or "mother." Nevertheless, it has been shown that fathers are often affected differently than mothers, both negatively and positively [49]. This section highlights selected outcome measures for fathers caring for a child with ASD.

Stress: Fathers describe parenting a child with ASD as a stressful experience. Yet research has found that fathers have lower stress levels than mothers of children with ASD, but mothers adapt better to stress and stress is a stronger precursor of depression for fathers [17,27,32]. Some researchers 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 [50]. 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. When comparing couples

with and without a child with ASD, one study found that stress arises in the marital relationship when the couple neglects to spend time together [51]. Another study evaluated parental coping mechanisms such as escape/avoidance, which is a strategy of trying to avoid or forget the challenge at hand [52]. The escape/avoidance mechanism often results in social isolation and neglect of the marital relationship. While mothers are often the primary care provider, it is important for fathers to equally care for children with ASD [52]. Studies have shown that the stress of the family unit (e.g. spousal relationship, sibling relationship, parent-child relationship) could be eased through an increase of direct father-child nurturing efforts [49].

Lack of confidence and stress level: Researchers found that fathers of children with ASD often lack confidence of feeling capable of raising their child [53]. The study concluded that if fathers gain a better understanding of the disorder and the available services for their child and family, they would feel more empowered and confident in fulfilling their role as a co-care provider. In one study, researchers showed that fathers demonstrated lower levels of stress due to their ability to use different strategies of coping with unknown circumstances in relation to their child with ASD. Because of these different coping strategies, fathers can bear their child's behaviors in an adaptive manner that reduces the resulting impact of stress [47].

Parental unit

One study focused on identifying which child variable (e.g. age, gender, clinical profile) and/or family characteristic (income, education, and waiting time for services) contributed most to parental stress [54]. Parental stress was associated with waiting time for services and maternal education level, in addition to the child's age, gender, intelligence level, symptom severity, and adaptive behaviors. In general, the father's stress stemmed from the mother's stress, and the mother's stress stemmed from the child's behavior. A different study identified social exchanges with one's spouse as the primary factor related to depressive symptoms [44]. Another study used a scale that measured depression levels and hypothesized that mothers who felt that they had no time for their own personal needs or leisure activities experienced greater levels of depression [55]. The study also hypothesized that factors such as career, family dynamics, marital roles, and attitudes about child rearing could contribute to these higher levels of depression.

Children with ASD tend to have higher levels of sleep disorders, which contributes to greater maternal stress [56]. The majority of children with ASD follow a sleep-wake pattern for sleeping and experience a sleep onset delay. 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 [57]. Difficulty to develop a regular sleep schedule for children with ASD disrupts the parent's sleep cycle. One study concluded that after conducting a meta-analysis of prospective cohort studies, which included 25,271 participants for short sleep duration and 23,663 participants for long sleep duration, adults who followed short or long sleep duration patterns had a greater

risk of depression. The authors indicated that short duration sleep patterns induced depression from a lack of sleep and long duration sleep patterns were induced from a lack of physical activity [58].

Communication impairments, poor social relationships, and challenging behavior (e.g, hurting others, damaging property, and self-injury) in a child posed the greatest correlation with parenting stress [42]. A quasi-experimental research design was used to examine parental stress through the Parenting Stress Index-Short Form (PSI) before and after testing a certain intervention [32]. 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; 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 [32]. Interventions that educate fathers on caring for their child with ASD that include working alongside their spouse in raising their child with ASD has shown positive results in stress relief for both the mother and father [22,36,42].

Though many parents experience hardships from raising a child with ASD, there are some benefits that warrant being mentioned. Research has identified some positive outcomes described by parents of children with ASD as personal growth, empowerment to help others, spiritual growth, stronger couple relationships, a more united family unit, and new career discoveries [34]. 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 [44].

Siblings

Little research has explored the mental health of siblings to children with ASD. However, considering siblings is important because they also have various experiences of coping with parental stress and individual consequences of working with a sibling who has ASD. These subsystems (mother-father relationship, sibling relationships, and peer relationships) make the sibling relationship complicated and difficult to understand. Some researchers conclude that siblings of a child with ASD display more emotional and behavioral problems than do siblings of children that have not been diagnosed with ASD [59]. Siblings of individuals with ASD are less involved and have more avoidant relationships [60].

Other research compared the positive and negative perceptions of parents and siblings toward a child with ASD in the home. Specifically, it was found that siblings of children with ASD do not feel negative emotions toward their sibling, but parents

often report a more negative perception of the influence the child with ASD has on the family [61]. In one research study, 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 should be considered as intervention agents by understanding the perceptions of children toward their sibling with ASD [62].

DISCUSSION

Children with ASD bring new life changes for mothers, fathers, and siblings [42]. There have been several studies that have focused on how children with ASD can influence the mental health of their mothers [27]. The mental health of fathers and siblings of children with ASD have received less attention [44]. The aim of this review was to present positive and negative mental health outcomes for mothers, fathers, and siblings who are involved in raising a child with ASD [44]. Similar and dissimilar responses among these individuals were described and effective interventions identified [63].

Studies are not consistent as to whether siblings of children with ASD have more emotional or behavioral problems. They appear to experience lower levels of stress than their parents [23]. A common theme in the reviewed literature was that children with ASD generate stress in the family, which, in turn, contributes to greater risk of anxiety and depression [42]. Both mothers and fathers experience stress when their child displays challenging behavior like self-injury and disruptive public outbursts [44].

Studies involving mothers of children with ASD found that their mental health was directly related to the child's emotional functional ability, social health, communication impairment, and challenging behaviors. Challenging behaviors directly correspond to maternal anxiety and depression [44]. Fathers had greater stress if the mothers experienced depression and were more likely to escape/avoid the challenges at home, which further contributes to stress by putting strain on the marital relationship [52].

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 [47]. Additionally, fathers who invest time in being involved 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 [47]. 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 [47]. Mothers appear to require more social support from counselors, organizations, family and friends than fathers [43]. Parent and family focused interventions may be effective in improving parental well-being and familial quality of life [63-65].

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, and joy in raising their child with ASD [35].

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 exists. These studies are also limited in being able to identify 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 done 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.).

CONCLUSION

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 eliminating some of the potential confounding influences. Testing for specific variables may be the best approach to understanding the effects that children with ASD have on their families.

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