

Challenges and suggestions for raising children with autism spectrum disorder: A literature review

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Abstract

Being a parent is a journey that is both rewarding and challenging; however, this journey can be particularly challenging for parents who are raising a child with autism spectrum disorder (ASD). Drawing on secondary sources, this review article aims to synthesize findings from previous research to examine the key challenges encountered by parents of children with ASD. Key challenges identified are related to psychological, social, marital, physical, financial, and behavioral challenges. The review also discusses practical suggestions to mitigate these challenges, focusing on prioritizing well-being, building strong social networks, strengthening marital relationships, exploring different financial resources, and managing behavioral challenges. By discussing both the challenges and solutions, this review article provides valuable insights into how to raise a child with ASD, helping parents navigate this difficult journey with resilience and hope. The article concludes by discussing its limitations and providing suggestions for future research.

Keywords: *Autism Spectrum Disorder (ASD), children with ASD; autism, parenting challenges; suggestions*

INTRODUCTION

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterized by social and communication deficits, restricted behaviors, and restricted activities (American Psychiatric Association, 2000; Hodges et al., 2020). ASD is a lifelong disability affecting social interaction, language, communication, and behavior (American Psychiatric Association, 2013; Kluth & Marcus, 2010). Children with ASD often struggle with joint attention, relationship understanding, language and comprehension, expressive gestures, eye gaze recognition, normal behaviors, and good imagination and adaptive skills (Sano et al., 2021). They also experience challenges in intellectual disabilities (American Psychiatric Association, 2013).

Parenting or raising a child with special needs or ASD presents significant challenges because of the unique and unpredictable demands of the child with such a condition (Angold et al., 2011; Paster et al., 2009). Bashir et al. (2014) noted that there are a few factors associated with the increased burden experienced by mothers of children with ASD, including limited informal and professional support, perceived loss of personal control, and a lack of awareness in society. There is also social stigma, resulting from a lack of awareness about autism, experienced by mothers of autistic children (Baba, 2014). Research on mothers raising children with ASD found that these mothers were at higher risk for poor mental health and high-stress levels compared to those with normal children (Zablotsky et al., 2013).

In developing contexts, such as Cambodia, ASD appears to be on the rise due to limited public awareness and knowledge about ASD, often resulting in misdiagnosis, delayed diagnosis, and a lack of appropriate support services (Rose et al., 2022). These challenges hinder the provision of essential resources and opportunities for providing effective frameworks for early identification, intervention, and social inclusion of children with ASD (Heng, 2023a). While the number of ASD children in the United States was estimated at 2.8% in 2020 (Maenner et al., 2023), the number of ASD children in developing countries like Cambodia remains unclear, which contributes to delaying the development of effective policies and the provision of necessary resources (Heng, 2023b). Consequently, providing

appropriate support to children with ASD and parents raising such children remains a major challenge (Heng, 2023a).

There are two primary approaches to catering to the needs of children with disabilities: special education schools, which offer individualized curricula and tailored teaching methods for students with specific disabilities, and inclusive education, which aims to integrate students with disabilities into mainstream classrooms to promote social interaction and equal learning opportunities (MoEYS, 2018). However, both systems cannot be fully equipped for meeting the specific needs of children with ASD (Heng, 2024). As previously mentioned, a major challenge for parents raising children with ASD in developing countries stems from limited data on children with ASD and a lack of clear guidelines and resources for intervention and support, which continue to hinder the development of effective policies and the provision of individualized support to children with ASD (Heng, 2023b). As a result, parents often struggle to provide appropriate interventions to support their ASD children (Gupta, 2020).

Within this context, this article is intended to provide a better understanding of the key challenges faced by parents raising children with ASD and to offer suggestions to address these challenges. The article begins with a brief overview of the origin and characteristics of ASD. It then discusses six key challenges commonly experienced by parents, including psychological, social, marital, physical, and financial challenges. The article also proposes suggestions for parents to cope with the challenges of raising children with ASD, emphasizing the need to prioritize well-being, strengthen social networks, improve relationships, enhance access to financial resources, and manage behavioral challenges. The article concludes by underscoring the need for providing comprehensive support systems to help parents raise their children with ASD.

The key contribution of this article lies in its synthesis of the complex and interrelated challenges faced by parents raising children with ASD. In particular, this review offers a multidimensional synthesis of the psychological, social, marital, physical, financial, and behavioral challenges parents face when raising a child with ASD, especially in under-researched regions. In addition, the article provides practical suggestions to help parents cope with the challenges of raising a child with ASD, focusing on enhancing well-being, strengthening social networks, improving marital relationships, enhancing access to financial resources, and managing behavioral challenges.

The Origin and Characteristics of Autism Spectrum Disorder

The literature on psychiatry has reported isolated cases of autism since the 18th century, but relationships between cases were not noted until the 19th century (Da Silva & Lebrun, 2023; Wing, 1997). It was initially surprising when Henry Maudsley, a British psychiatrist, stated in 1867 that children exhibiting odd behavior may be diagnosed as having childhood psychosis (Da Silva & Lebrun, 2023). In 1911, Eugen Bleuler, a Swiss psychiatrist, used the term 'autism' for the first time, which was derived from the Greek word 'autos,' meaning 'self'. He described 'autism' based on the specific characteristics of schizophrenia (Alharbi, 2023). In 1920, Fritz Kunkel, a German psychiatrist, used the word 'autism' in European medical literature to characterize schizophrenic children as restless, closed, and socially isolated (Kanner, 1944). Kanner (1943), an Austrian-American psychiatrist, characterized autism as a distinct neurodevelopmental condition that impairs social communication in the early stages of children's development and persists throughout childhood.

According to Kanner (1944), autism is a rare neurodevelopmental condition in children aged 2–8 years, characterized by attachment to routines, extreme isolation, and a noticeable preference for inanimate objects. He identified the characteristics of autism as non-communicative language use, echolalia (repetition of speech), the use of reverse pronouns, engagement with repetitive games, and a lack of inventiveness. Children with ASD can display naivete, repetitive language, poor communication, motor incapacity, poor coordination, and diminished verbal and cognitive capacities (Asperger, 1991). They also tend to have language defects, repetitive behaviors, and learning difficulties, even in basic areas such as nursery rhymes, while also being highly sensitive (Kanner, 1943).

In 1994, the American Psychiatric Association published the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders, which identified ASD as a developmental disability characterized by social and communication impairments, as well as restricted interests and repetitive

behaviors that occur in all racial, ethnic, and socioeconomic groups and can usually be detected when children are between 2 and 3 years (American Psychiatric Association, 1994). Previous research has indicated that ASD is a multiplex neurodevelopmental disorder that affects the nervous system, characterized by restricted and repetitive behaviors, as well as impairment in the social communication of the affected individuals, which makes them unable to interact with others (Baio et al., 2018; Eshraghi et al., 2018; Lo & Lai, 2020). Historically, ASD was more common in males than females, with a ratio of 4:1 (Demily et al., 2017; Tartaglia et al., 2017); however, in a recent meta-analysis by Loomes et al. (2017), the true male-to-female ratio is closer to 3:1. Overall, ASD is a diverse group of neurodevelopmental conditions characterized by varying degrees of difficulty with social interaction and communication, with its prevalence having increased globally in recent years (World Health Organization [WHO], 2022).

Challenges in Raising Children with Autism Spectrum Disorder

Psychological Challenges

Parenting a child with ASD has a substantial impact on parents' psychological well-being, often leading to a high level of depression, anxiety, and stress, typically among parents in developing countries (Serrata, 2012). Parents of children with ASD often experience a high level of psychological challenges, including persistent feelings of guilt, helplessness, anger, self-blame, and depression (Gupta, 2020). Children with ASD may exhibit little to no emotions; disruptive and challenging behaviors, such as continuous periods of screaming as well as aggressive and violent behaviors; suicidal tendencies; and emotional meltdowns (McClintock et al., 2003). These challenging behaviors, especially aggression and self-injury (Kanne & Mazurek, 2011), place additional strain on parents, causing higher levels of stress and other psychological challenges (Hayes & Watson, 2013).

In addition, mothers of children with autism could experience high levels of psychological distress that are up to four times higher than those of mothers with children in other groups (Silva & Schalock, 2012). Parents of autistic children often face embarrassment, hostile reactions, and negative stereotypes from the public, due to their children's inappropriate behaviors in public settings (Bashir et al., 2014). Parents of autistic children also face challenges in achieving a successful career due to childcare demands and depression, often due to social stigma (REF?). They are also often faced with a prevalence of psychological disorders such as depression, anxiety, and obsessive-compulsive disorder (Schnabel et al., 2020). In addition, they tend to experience a higher frequency of depression, fragility, exhaustion, and hopelessness (Rfat et al., 2023). Research by Omar et al. (2017) about the Egyptian context found that mothers of children with ASD faced various psychological challenges, including sadness, anger, nervousness, stress, and anhedonia, due to uncertainty about their child's future and health. They also experienced psychological challenges concerning childcare responsibilities, financial burdens, and communication difficulties with their autistic children. Similarly, Acharya and Sharma (2021) reported that some parents felt overwhelmed by the financial demands associated with caring for ASD children, while others experienced anxiety due to initial rejection or lack of support from their husbands. Jackson et al. (2018) also reported that parents often experienced depression and distress due to the rejection of their children by peers and the public.

Social Challenges

ASD is a complex neurological disorder that affects brain function and causes impairments in multiple areas of development, including social interaction, communication, and behavior, often referred to as the triad of impairments (Centers for Disease Control and Prevention, 2009). Due to these impairments, ASD children often face social challenges in social visits and recreational activities (Gobrial, 2018), while their parents face challenges with family socialization (Greeff & Van der Walt, 2010). Most parents were found to avoid meeting other families and relatives with typically developing children, which negatively affects the social life of the family and children (Omar et al., 2017). Many parents with ASD children also reported experiencing negative social stereotypes associated with mental illness and disability (Kinnear et al., 2016). As a result, they tend to suffer from social isolation due to the difficulty of visiting friends and relatives, forcing them to remain at home more frequently than going out (Gupta, 2020). Research has also shown a decrease in the quantity and

quality of these parents' social ties and relationships, as they tended to avoid attending public or social events due to the difficulty in finding trusted nannies (Gobrial, 2018). They also find it hard to relate to old friends who do not share similar challenges. In addition, they also have limited opportunities to join social events due to concerns about their behaviors (Papadopoulos, 2021). Parents also find it difficult to maintain good relationships with their autistic children's siblings who may feel jealous or unfairly treated (Gobrial, 2018; Gupta, 2020; Omar et al., 2017).

Marital Challenges

Having ASD children often causes profound changes to the family dynamic, as the whole family has to adapt to a new reality requiring special parental treatment and long-term care (Papadopoulos, 2021). Parents with ASD children usually face marital challenges (Gupta, 2020). They often described how having a child with ASD influenced their relationship. For example, following their child's diagnosis with ASD, the relationship within the family, especially the spousal relationship, changed (Bashir et al., 2014). Raising a child with ASD often causes a big problem for a couple's emotional connection, leading to reduced marital love (Sim et al., 2019). ASD children usually demand special care that could lead to reduced time and energy for intimacy, increased irritability and conflict, and a shift in focus from the couple to the child (Chan & Leung, 2020). Many parents felt that they had neglected the needs of their spouse, leading to emotional distancing and deterioration of their previously healthy relationships (Bluth et al., 2013). Other marital challenges included increased stress and communication issues; unequal distribution of responsibilities; financial strain due to therapy, medication, and equipment costs; a lack of social support; and different coping mechanisms, which can lead to misunderstandings and conflict (Gupta, 2020). Some parents do not show understanding or support for each other; instead, they blame each other, making the couple's relationship worse (Bluth et al., 2013). The divorce rate among families having an autistic child was found to be higher compared to couples with typical children (Hartley et al., 2010).

Physical Challenges

Raising children with ASD can be physically and mentally exhausting, leading to a higher prevalence of physical and mental health problems among parents (Karst & VanHecke, 2012). Approximately 92% of the children with autism have psychiatric problems, including attention-deficit, hyperactivity disorder, oppositional defiant disorder, and anxiety disorder (Helland & Helland, 2017). They also exhibit behavioral problems, including noncompliance and defiance (McStay et al., 2015). In such cases, parents tend to experience elevated stress (Miranda et al., 2019) and mental tiredness (Cadman et al., 2012) in managing their children's behaviors. ASD is a heterogeneous disorder, commonly characterized by co-occurring conditions such as hyperactivity, self-injurious or aggressive behaviors, cognitive impairments, changes in sensory perceptions, frequent outbursts, and sleep disturbances (Micai et al., 2023). These challenges impose substantial physical demands on parents who tend to encounter a lack of sleep, physical exhaustion, heightened risk of injury, and insufficient time for exercises (Factor et al., 2019). Mothers of autistic children often face physical challenges, due to excessive caregiving demands, often including nighttime awakenings to attend to their ASD child's needs (Omar et al., 2017).

Financial Challenges

Raising a child with ASD can negatively affect the financial level of families. Research has shown the financial burden encountered by parents of children with ASD (Rao & Beidel, 2009). Autistic children often require specialized therapies and educational activities, assistive technologies, and other support, which can prove costly for families of low socioeconomic status (Aylaz et al., 2012). Parents with ASD children often need up to three times more financial resources due to high medical and therapeutic costs, potential job resignations, and possible spousal abandonment (Befkadu & Adamek, 2022). In some cases, parents need to spend a significant amount of money to seek treatment from private organizations or therapy centers for their ASD children. Thus, they need to make sacrifices to ensure they can have enough money to pay for good treatments for their children. This sometimes means sacrificing their careers to focus on their ASD children (Matin et al., 2022). Mothers

of autistic children often need to make personal sacrifices by quitting their jobs, working extra hours, or holding multiple jobs to afford the costs of daycare services (Gobrial, 2018). In addition, the financial burden and the need for securing extra income to cover the ongoing costs of providing special education, therapies, and care to ASD children frequently lead to increased levels of parental fatigue, specifically for low-income households (Montes & Cianca, 2014).

Behavioral Challenges

Children with ASD often exhibit aggressive behaviors toward themselves or others, with self-abusive behaviors being the strongest predictor of stress for parents (Koceski et al., 2023). These challenging behaviors can include tantrums, mood swings, repetitive behaviors, and self-injurious behaviors (Koceski et al., 2023). These behaviors were reported as highly challenging, unpredictable, and out of control, leading to feelings of embarrassment in public settings (Kodak & Bergmann, 2020) and increased parental stress (Paster et al., 2009). Common challenging behaviors of children with ASD include temper tantrums and repetitive and aggressive behaviors (Papadopoulos, 2021), with tantrums often being described as unpredictable and difficult to manage (Potegal & Davidson, 2003; Yalim & Mohamed, 2023). Autistic children can also exhibit aggression (at times quite violent) directed toward siblings and themselves (Fitzpatrick et al., 2016). As a result, parents of autistic children often need to deal with these behavioral challenges that are difficult and emotionally exhausting to manage (Papadopoulos, 2021).

Suggestions for Raising Children with Autism Spectrum Disorder

This section outlines the suggestions for supporting parents in raising their children with ASD. Although the suggestions are primarily directed at parents with ASD children, the involvement of relevant stakeholders across multiple levels, including government agencies, non-governmental organizations, educational institutions, communities, families, as well as other actors such as the private sector and development partners, is essential. These stakeholders can work together to develop and implement policies and initiatives that offer support to parents who have children with ASD so that they can better navigate the complex and multifaceted challenges of raising children with autistic conditions.

Prioritizing Well-Being

Research has shown that a lack of perceived social support is one of the most significant indicators of mental health problems among parents of children with ASD (Boyd, 2002), leading to parental stress and reduced family socialization (Bishop et al., 2007). Without sufficient social support, parents often face challenges in managing their children's behaviors, which can exacerbate parental stress and depressive symptoms (Sanders & Morgan, 1997). Understanding the emotional challenges of parents with ASD children is therefore vitally important for prioritizing their well-being. From a different perspective, strong protective factors against parental stress include the use of both formal and informal sources of social support, such as professional guidance, groups of friends, extended family members, groups of parents with similar concerns, and online communities (Ilias et al., 2018). In addition, parents of children with ASD should engage in open communication with their spouses, family members, or close friends to break down the walls of isolation and foster supportive networks (Roquette Viana et al., 2021). These strategies help parents maintain a positive mood and improve emotional well-being (Benson & Karlof, 2009), as well as increase the size of their support networks, enabling effective coping strategies in the face of increased distress (Lovell et al., 2012). Research has indicated the relationship between the receipt of social support and the ability of parents to enjoy life and have optimistic outlook (Cetinbakis et al., 2020). Parents should therefore seek leisure activities, such as exercise, meditation, or hobbies, which can significantly improve their emotional resilience and well-being (Smith et al., 2012). The provision of family-focused social support has been found to be a crucial factor that contributes to family adaptation and resilience (Walsh, 2003), which in turn increases the perceived sense of control over life circumstances (Weiss et al., 2012). Thus, it is essential for parents to stay connected with other parents through peer support groups, online forums, and local

organizations to maintain a sense of belonging, receive emotional support, develop a sense of community and shared understanding (National Autistic Society, 2023).

Building Strong Social Networks

Children with ASD often face challenges in self-care, daily life chores, and social communication that rely heavily on their families support in areas such as employment, living, and relationships (Taylor & Seltzer, 2011). The challenges of day-to-day functioning can lead to higher dependency and create a formidable burden for parents and caregivers (Krauss et al., 2005). In this context, appropriate social support is critical for promoting independence of children with ASD (Müller et al., 2008) and decreasing the burden shouldered by their primary caregivers, especially parents (Krauss et al., 2005). Social support is considered as one of the most appropriate and important mechanisms for reducing stress for families with ASD children and improving parental well-being (Bromley et al., 2004). Parents should therefore seek social support to cope with the challenges and stress of raising children with ASD (Shepherd et al., 2020). The support can be categorized into informal and formal sources. Informal support typically consists of family, friends, and other social networks, which are vital sources of emotional support, while formal support often comes from governmental or organizational sources that provide assistance in terms of financial, technical, or material support (Bromley et al., 2004). Thus, there should be support groups for parents of autistic children, with professionals providing social support. It is therefore essential that professionals, including doctors, receive specialized training in autism to provide accurate diagnoses and effective rehabilitation services. Collaboration among parents, schools, and communities is essential for fostering a supportive and rewarding home education environment (Ahmad, 2020). To mitigate social isolation, negative judgment, and complexities associated with raising a child with ASD (Shattnawi et al., 2021), open communication with family and friends is crucial to foster mutual understanding and share experiences in dealing with the challenges (National Autistic Society, 2023; Smith et al., 2012).

Strengthening Marital Relationships

Parents of children with ASD commonly perceive a high risk of divorce (Reeve et al., 2013), with more marriages ending in divorce among parents of children with disabilities compared with those with normal children (Risdaal & Singer, 2004). Previous research has reported high levels of stress (Rivard et al., 2014) and rates of depression among parents (Farmer et al., 2014). The strain on family and couple relationships can be intensified when a child with ASD requires more time and effort for caregiving, especially in managing problematic behaviors (Pozo et al., 2014). To overcome these challenges, it is crucial to establish a strong support system and seek professional therapy from specialists in working with ASD children (Shattnawi et al., 2021). Therapeutic interventions offer a safe space for couples to communicate openly, identify sources of conflict, and develop effective coping strategies. Additionally, it is important to establish clear caregiving roles, providing mutual support, and celebrating achievements together to strengthen the couple's bond (Bluth et al., 2013).

Exploring Different Financial Resources

ASD is a very common developmental disability that occurs in 1 out of 110 children globally (WHO, 2022). Children with ASD are more than four times as likely to have educational and school-based services compared to their peers without ASD (Garbacz et al., 2016). They often require special education programs and a variety of other special educational services, such as prolonged day and week times, summer school services, and community-based services designed to support their unique developmental needs (Eskow & Summers, 2019). Parents of children with ASD, therefore, need to spend a lot of money on therapies, specialist resources, and equipment (Milosevic et al., 2022). To alleviate this financial burden, they should find available financial support from various sources, including government agencies, non-profit organizations, and foundations that offer grants or scholarships (Milosevic et al., 2022). Moreover, governments should prioritize the provision of accessible healthcare, inclusive education, and essential social services to ensure that children with ASD receive services covered by public insurance or government programs (Shattnawi et al., 2021).

Managing Behavioral Challenges

From an early age, children with ASD often exhibit high levels of behavioral problems, such as disruptive behavior, aggression, and hyperactivity. These behavioral problems cause parental stress, depression, anxiety, lower family quality of life, and lower life satisfaction (Meleady et al., 2020). It is a big challenge that causes parents of children with ASD to feel worried and stressed about their children's future. However, with appropriate strategies and support, parents can empower their children to manage the challenging behaviors by adopting a positive and structured approach, in collaboration with professionals, to develop a comprehensive behavior intervention plan that targets specific behavioral challenges (Papadopoulos, 2021). Parents should identify the underlying causes of problematic behaviors in their children to find solutions to mitigate them (Gadow et al., 2008). It is also essential for parents to consult behavior analysts or therapists to create a behavior intervention plan that incorporates positive reinforcement strategies tailored to meeting a child's needs (Ithriyah, 2018). In addition, they need to promote effective communication through clear, concise instructions, consistent consequences, the use of non-verbal cues, and alternative communication tools that can empower children to express their needs more effectively, thereby reducing their meltdowns, tantrums, or emotional outbursts (National Autistic Society, 2023).

CONCLUSION

Autism is a life-long neurodevelopmental condition that can significantly affect social interaction and communication, joint attention, and the ability to build and maintain relationships. Parents of children with ASD often face a range of challenges, including psychological, social, marital, physical, financial, and behavioral challenges. Many parents have experienced feelings of helplessness, resentment, and social isolation. Behavioral issues commonly associated with children with ASD, such as aggression, self-injury, and repetitive behaviors, can be particularly difficult for parents to manage. Consequently, many parents have to resign from their jobs or reduce working hours to look after their ASD children, creating a significant financial burden for the family. As the costs associated with providing special education, medical treatment, and behavioral therapy for ASD children with ASD are normally high and often not covered by government programs, there is an urgent need to provide inclusive and accessible services to mitigate the above-mentioned challenges.

Parents of children with ASD need to overcome many challenges in order to provide their children with well-being and quality of life. To achieve this goal, parents need to take an active role in giving support to their children by teaching them to communicate, helping them acquire life skills, and keeping them safe. Within the family setting, parents need to explain to other children about the nature of autism and the challenges in raising children with ASD to ensure they do not feel jealous or neglected. In addition, to overcome the broader social challenges, parents can establish open communication, prioritize healthy social and marital relationships, understand their children's unique needs, establish consistent routines, and prioritize self-care and well-being. They also need to maintain physical and emotional well-being, seek financial support, and collaborate with professionals or experts to effectively manage their children's behavioral challenges.

This review article has examined the key challenges faced by parents of children with ASD. It has also outlined suggestions for providing support to families raising children with ASD. The article underscores the importance of finding mental health support from professionals, families, relatives, friends, and communities. The review also highlights the need for seeking resources and support to strengthen social connections, ensure access to financial assistance, and promote healthy family and social relationships. However, considering the nature of this review article, which is limited to secondary sources, it is recommended that future research explore effective coping strategies and support mechanisms by empirically investigating strategies to mitigate the multifaceted challenges and burdens faced by parents of children with ASD. Future research should also identify effective policies and interventions to support children with ASD, particularly those in developing countries, to help integrate them into mainstream educational systems, thereby providing them with the opportunity to develop essential life and academic skills that enable them to achieve their full potential within society.

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