

Raising a Child with Autism Spectrum Disorder: Examining Parental Factors

Otizm Spektrum Bozukluğu Tanılı Çocuk Yetiştirmek: Ebeveyn Faktörlerinin İncelenmesi

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ABSTRACT

Autism spectrum disorder is a neurodevelopmental disorder that is quite common today. Although being diagnosed with autism spectrum disorder causes children to face with various difficulties in their lives, raising a child with autism spectrum disorder also poses several difficulties for the parents and families. Studies showed that parents raising children with autism spectrum disorder may perceive their parenting as inadequate and may experience stress, depression and anxiety due to their children's health, behavioral, social and emotional problems. Parents cannot devote enough time to themselves and therefore report intense fatigue. At the same time, raising a child diagnosed with autism spectrum disorder also differentiates the relationship between parent and child. Within the family system, marriage and sibling relationships are also affected and parents report high divorce rates due to difficulties experienced within the family. Lack of access to sufficient financial resources and time also causes various difficulties within the family. All these difficulties negatively affect parents' quality of life. The necessity of interventions specific to the needs of parents in all these areas is inevitable. In this review study, it is aimed to examine difficulties parents experience with their children diagnosed with autism spectrum disorder and, to discuss the limitations of studies examining the impact of autism spectrum disorder on parents.

Keywords: Autism spectrum disorder, parents, families, autism and family

ÖZ

Otizm spektrum bozukluğu günümüzde oldukça yaygın görülen nörogelişimsel bir bozukluktur. Otizm spektrum bozukluğu tanısı almak çocukların yaşamlarında pek çok zorlukla karşı karşıya kalmalarına neden olmakla birlikte otizm spektrum bozukluğu tanılı bir çocuk yetiştirmek de çocuğun ebeveynleri ve aile sistemi üzerinde çeşitli zorluklar barındırmaktadır. Otizm spektrum bozukluğu tanılı çocuk yetiştiren ebeveynler kendi ebeveynliklerini yetersiz algılayabilmekte, çocuklarının davranış problemlerinden dolayı stres, depresyon ve kaygı yaşayabilmektedir. Ebeveynler kendilerine yeterli vakit ayıramamakta, bundan dolayı yoğun yorgunluk bildirmektedir. Aynı zamanda otizm spektrum bozukluğu tanılı çocuk yetiştirmek ebeveyn ve çocuk arasındaki ilişkiyi de farklılaştırmaktadır. Aile sistemi içerisinde ise evlilik ve kardeş ilişkileri etkilenmekte, aile içerisinde yaşanan zorluklardan dolayı ebeveynler yüksek boşanma oranları bildirmektedir. Yeterli maddi kaynağa ve zamana erişimin olmaması da aile içerisinde çeşitli zorluklara neden olmaktadır. Yaşanan tüm bu zorluklar ebeveynlerin yaşam kalitesini olumsuz etkilemektedir. Tüm bu alanlara ilişkin ebeveynlerin ihtiyaçlarına özgü oluşturulacak müdahalelerin gerekliliği ise kaçınılmazdır. Bu derleme çalışmasında otizm spektrum bozukluğu tanılı çocuk yetiştiren ebeveynlerin yaşamlarının farklı alanlarındaki zorlukların incelenmesi ve otizm spektrum bozukluğunun ebeveynler üzerindeki etkisini inceleyen çalışmaların kısıtlılıklarının tartışılması amaçlanmıştır.

Anahtar sözcükler: Otizm spektrum bozukluğu, ebeveynler, aileler, otizm ve aile

Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by deficiencies in social communication, restricted interests, and repetitive behaviors (APA 2013). The "autism" term was first introduced by Leo Kanner as "early infantile autism" in 1943. Kanner identified three characteristic features of ASD: "loneliness, be against to change, and obvious differences in abilities". After Kanner's definition, the diagnostic criteria for autism were included in international classification systems for the first time in 1967 with the ICD-8. These criteria have changed many times until the publication of DSM-5 in 2013 (Kaba and Soykan Aysev 2020). Recently, DSM-5 diagnosis and criteria is based on for diagnosis of ASD. Prevalence of ASD has been ascending in recent years. Published latest report by the American Center for Disease Control and Prevention (CDC 2023), it was reported that one in every 36 children was diagnosed with ASD in 2023.

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According to DSM-5, symptoms of autism spectrum disorder (ASD) are categorized as “deficiencies in social communication and social interaction” and “repetitive behaviors and interests” (APA 2013). Some of the early signs of ASD include difficulty in making eye contact, inability to establish joint attention, not responding to one's name and showing repetitive behaviors. Among these early signs, difficulty in making eye contact and not responding to one's name become visible within the first 12 months. Showing obsessive and repetitive behaviors, as well as the inability to establish joint attention become noticeable between 12 and 24 months. Additionally, children diagnosed with ASD show limited language skills those of their typically developing peers. While most of these early signs emerge between 0 and 3 years of age, they continue to be seen in children's older ages.

Additionally, ASD involves deficiencies in social communication, social cognition and the ability to perceive social cues (Laugeson et al. 2012). This situation is also related to the concepts of theory of mind and executive functions. Theory of mind (ToM), defined as the capacity to interpret, infer and explain the mental states underlying others' behaviors (Scholl and Leslie 1999). ToM skills are expected to develop during the preschool years. However, children with ASD often exhibit delayed or restricted theory of mind, which can explain the core deficits in social cognition and communication of autism. Besides theory of mind, deficiencies are also observed in executive functions, which are high-level control processes necessary for guiding behavior in constantly changing environments (Jurado and Rosselli 2007). Children with ASD are known to experience difficulties in executive function domains such as planning, mental flexibility, impulse control and self-monitoring (Hill 2004). Consequently, these challenges affect social skills, which are defined as the cognitive, social, emotional and behavioral abilities required to establish, maintain and enhance healthy, effective and quality interactions with others (Çetrez Arıcan et al. 2018).

Since ASD is defined as a spectrum, each child is positioned at different place on the spectrum and thus, each child does not face the same challenges (Ferrioli and Harris 2009). Some children exhibit severe language difficulties and extreme sensitivity to routines, while other children have fewer problems but still experience difficulties with social and communication skills. These challenges, regardless of where the children on the spectrum, can visible from early childhood into adulthood and makes their lives difficult (Karst and Van Hecke 2012). Also, these difficulties are associated with loneliness, depression, anxiety and low self-esteem (Schohl et al. 2014).

Because of the closest system to the child is family, all these challenges not only affect the child but also impact the parents and the family system (Karst and Van Hecke 2012). Parents of children diagnosed with autism spectrum disorder needs may be often neglected (Yassıbaş et al. 2019). Some studies suggest that the child's symptoms, as well as the severity and variety of these symptoms, differentiate the impact on parents and the family (Ekas et al. 2010). Conversely, other studies indicated that raising a child with ASD negatively affects parents and families regardless of the severity of symptoms or the time of diagnosis (Pottie and Ingram 2008). Regardless of symptoms severity, because most children with ASD cannot lead independent lives necessitates, parents and families provide lifelong care to them (Karst and Van Hecke 2012). Approximately 85% of individuals with ASD have cognitive or adaptive limitations that restrict their ability to live independently. This situation leads to lifelong care or assistance from their parents and families (Volkmar and Pauls 2003). According to a longitudinal study on parents of children with neurodevelopmental problems found that over 50% of parents aged 50 and above still lived with their children, compared to 17% of parents of typically developing children (Seltzer et al. 2001). This situation worsens the difficulties faced by families of children with ASD, causing them to feel more pessimistic about their own and their children's futures (Karst and Van Hecke 2012).

Raising a child with ASD also brings certain financial burdens. Parents described raising a child with ASD as challenging due to increased financial burdens and the significant amount of time spent for their children's needs (Myers et al. 2009). Additionally, difficulties in accessing the services and negative attitudes in society are also challenging for parents (Symon 2001). Parents report that raising a child with ASD leads to conflicts between partners, negatively affecting marital satisfaction and their careers (Cavkaytar et al. 2008, Karst and Van Hecke 2012). Besides marital relationships, sibling relationships are also impacted. Moreover, raising a child with ASD affects parental self-efficacy, stress levels, physical and psychological health and the parent-child relationship (Karst and Van Hecke 2012). Therefore, studies for challenges faced by children with ASD and their families are needed. This review aims to address the difficulties experienced by parents and families of children with ASD. In this context, first the impacts of raising a child with ASD on parents, then the effects on the family system will be discussed.

Effects of Raising a Child Diagnosed with ASD on Parents

Parental Self-Efficacy

Parental self-efficacy is defined as the caregiver's belief to their ability of parenting their child. Raising a child with ASD leads to perceive their own parenting skills as inadequate for several reasons (Karst and Van Hecke 2012). Primary and most significant reason is difficulty in establishing reciprocal social communication. This skill is a defining feature of ASD. Deficiency in this skill can result in children with ASD not fully expressing their needs and parents feeling less capable of meeting those needs (Karst and Van Hecke 2012). Particularly due to the delay in diagnosis, parents believe that they have used ineffective parenting strategies for extended periods and may perceive themselves as inadequate in parenting during the early stages of diagnosis (Sofronoff and Farbotko 2002).

Before diagnosis, when the child's receptive and expressive language skills are not sufficiently developed and eye contact is limited, parents may exhibit either permissive behaviors by fulfilling all their child's desires or conversely, more compulsory behaviors to encourage the child to express their needs independently. Parents who use such parenting strategies before diagnosis may blame themselves for their parenting during the post-diagnosis period. Relatedly, Kuhn and Carter (2006) noted that the sense of agency and guilt significantly contribute to parental self-efficacy. Accordingly, parents of children with ASD may perceive their self-efficacy as low due to the feeling of guilt arising from the perception of not being able to fully meet their child's emotional desires and needs. Conversely, a sense of agency, defined as the degree of insistence on actively participating in their child's development, engaging with their child and determining strategies to minimize maladaptive behaviors and maximize adaptive behaviors, can enhance parents' perceptions of their self-efficacy.

Furthermore, parental self-efficacy also plays important role in the psychological well-being and problem behaviors of children. Parental self-efficacy was found that partially mediate the relationship between parental stress, depression and anxiety exhibited by parents (Rezendes and Scarpa 2011). Similarly, Hastings and Brown (2002) are examined the relationship between parental self-efficacy, anxiety, and depression levels among 26 mothers and 20 fathers of children diagnosed with ASD. It was revealed that parental self-efficacy mediated the relationship between the child's problem behaviors, mother's anxiety, depression and the experienced stress was associated with a decrease in parental self-efficacy. However, the same result was not found for fathers. In another study, it was found that greater behavior problems were associated with lower parental self-efficacy, which in turn affected parental stress (Stephenson et al. 2022). Thus, children's problem behaviors lead parents to perceive their parenting as inadequate and increase stress levels. This results parents reports higher levels of depression and anxiety..

Herein, perceived social support by parents and their collaboration in childcare are supportive for parental self-efficacy. Feng et al. (2022) examined whether social support mediates the relationship between parental self-efficacy and quality of life among parents of children diagnosed with ASD. Results indicated that parental self-efficacy has both direct and indirect effects on quality of life, while social support only has an indirect effect. Moreover, it is noted that both mothers and fathers taking responsibility for their children's care and collaborating in childcare (co-parenting) directly or indirectly contribute to an increase in parental self-efficacy (May et al. 2015). In line with this, Almendingen and Pilkington (2024) examined the relationship between co-parenting as a predictor of parental self-efficacy and psychological distress among 122 parents. The results showed that engaging in co-parenting resulted in higher reported parental self-efficacy and reduced level of psychological distress. Thus, when considering the unique challenges of raising a child with ASD, collaboration in childcare (co-parenting) also provides social support. This perceived social support serves as a protective factor for parental physical and psychological health, including parental self-efficacy. Therefore, co-parenting in childcare will positively impact parents' psychological health and self-efficacy.

As a result, parental self-efficacy emerges as a significant concept directly or indirectly associated with the challenges faced by parents raising a child with ASD. Therefore, considering parental self-efficacy seems important for understanding the impact of raising a child with ASD on parents and families. Interventions aimed to enhancing parental self-efficacy will not only support parents in coping with behaviors associated with their child's diagnosis but also help reduce psychological health problems such as stress, anxiety and depression (Almendingen and Pilkington 2024). However, most parents of children with ASD experience difficulty accessing appropriate services for their children, which can affect their self-efficacy. Weiss et al. (2016) examined the role of demographic variables in relation to parental self-efficacy experiences among parents of adolescents and young adults with ASD. They found that parental self-efficacy was associated not only with the child's clinical condition but also with various other variables such as the child's age, the parent's internal or external migration

status and limited access to services (e.g., insurance coverage, difficulty in accessing and utilizing services). Considering the significant role parents play in the lives of children with ASD, supporting parental efforts and ensuring all parents have access to necessary interventions are highly important.

Parental Stress

Parental stress is one of the most primary factor studies focused on the challenges experienced by parents raising a child with ASD (Bonis 2016). Research indicated that parents of children with ASD experience higher levels of parental stress compared to parents of typically developing children (Hoffman et al. 2009, Hayes and Watson 2013) and parents of children with other neurodevelopmental problems (Estes et al. 2009, Dabrowska and Pisula 2010, Hayes and Watson 2013). Furthermore, some studies express positive relationship between ASD symptoms and parental stress (Davis and Carter 2008). Domains where children with ASD experience difficulties such as communication, socialization and self-care deficiencies can be another source of stress for parents (Tomanik et al. 2004). Additionally, parental stress can arise from limited access to services and financial burdens (Dardas and Ahmad 2014, Vohra et al. 2014).

Moreover, parental stress can also be influenced by the presence of attention deficit and hyperactivity disorder (ADHD) symptoms, internalizing and externalizing problem behaviors in addition to ASD symptoms (McStay et al. 2014). Studies indicated high prevalence of behavioral and emotional problems among children with ASD. This cause to parents reporting higher levels of stress (Estes et al. 2009). For instance, since ASD and ADHD symptoms may often comorbid (Reiersen and Todd 2008), it is likely that parents of children with both ASD and ADHD symptoms experience more parental stress compared to parents of children with only ASD symptoms. Hence, it can be suggested that comorbid psychiatric diagnoses predict higher levels of parental stress among parents of children with ASD (Hastings 2003, Orsmond et al. 2006).

Furthermore, parental stress is significantly influenced by the type of coping strategies used and the dimension of social support received by parents (Lee et al. 2008, Pottie and Ingram 2008). However, this effect may be different between mothers and fathers (Tehee et al. 2009). Particularly social support provided by friends and family was shown to be effective in reducing stress among mothers of children with ASD (Ekas et al. 2010). While raising a child with ASD, parents often dedicate themselves mainly to caregiving, which may lead to social withdrawal from the community. It is thought that this might cause burden to parents. Dunn et al. (2001) found that social support plays significant regulatory role in the relationship between stressors and feelings of isolation among parents. Consequently, decrease in perceived social support leads parents to report more stress associated with feelings of isolation. According to a longitudinal study examining the relationships between child problem behaviors, coping strategies, social support sources and parental stress among parents of children with ASD, it was noted that perceived high levels of social support from the time of diagnosis were associated with lower levels of parental stress (Zaidman-Zait et al. 2017). Two years later, high levels of parental stress at the time of diagnosis predicted an increase in parental stress, while high or increased levels of social support predicted a decrease in parental stress (Zaidman-Zait et al. 2017). Therefore, providing social support to parents is crucial to reduce the effect of factors such as the severity of ASD symptoms, children' problem behaviors and limited access to services to parental stress.

Additionally, mothers of children with ASD tend to report higher levels of parental stress compared to fathers (Davis and Carter 2008, Rivard et al. 2014). Similar results were found in a study conducted in China with mothers of children with ASD (Wang et al. 2013). This is related to fact that mothers show higher levels of parental involvement to childcare compared to fathers (Karst and Van Hecke 2012). Thus, the size of parental involvement showed by caregivers is related to parental stress and it is suggested that parental involvement may partially or fully mediate the relationship between parental gender and stress (Tehee et al. 2009). Considering the increased time and effort required to raise children with ASD, it is noted that increased paternal involvement in childcare and providing co-parenting are important to reduce childcare burdens, parental stress and enhancing parental self-efficacy (May et al. 2015). Research also indicated that increased paternal involvement in childcare is associated with lower parental stress in both mothers and fathers and the quality of co-parenting mediates the relationship between parental self-efficacy and stress (May et al. 2015).

Consequently, there are numerous factors that influence parental stress. Therefore, understanding not only the factors affecting parental stress but also the mediating effects will help to develop intervention programs aimed at reducing parental stress levels (Enea and Rusu 2020). Also, more longitudinal studies are needed to support the relationship between child and parent characteristics, environmental variables and parental stress.

Parental Psychological Well-being and Physical Health

Raising a child with ASD, leads to decreases in parental psychological well-being and increases in concerns about physical and psychological health (Ekas et al. 2010). Psychological well-being refers to an individual's state of emotional, mental and social health. Accordingly, parents raising children with ASD tend to pay much less attention to their own health under the burden of caring for their children. Moreover, children's behavioral problems require constant attention from mothers, leads to less time to address their own needs (Dardas and Ahmad 2014). This negatively impacts the psychological well-being of parents.

Parents of children with ASD, who cannot take enough time for their own health, report higher levels of fatigue compared to parents of typically developing children and children with other neurodevelopmental problems (Smith et al. 2010). Mothers of children with ASD reported that experience fatigue twice as much as mothers of typically developing children during 50% of the day over an eight-day period (Smith et al. 2010). Also, while 19% of mothers of children with ASD reported fatigue throughout the entire eight days, only 3% of mothers of typically developing children reported experience fatigue throughout the same period. Additionally, Giallo et al. (2013) found that mothers reporting high levels of fatigue also reported higher levels of depression, anxiety and stress.

Numerous stressful events while they try to provide the necessary care for their children that have to face in their daily lives. These events may include leaving their jobs, reducing their work hours, struggling to balance between other responsibilities within the household and inadequate time for socialize (Smith et al. 2010). Mothers of children with ASD were three times more likely to experience at least one stressful event in a day compared to mothers of typically developing children (Smith et al. 2010). Furthermore, several child and parent factors such as lower education level, more intense child behavior problems, poorer quality of nutrition, exercise, sleep and perceived high levels of social support needs are associated with fatigue (Giallo et al. 2013). It was also stated that mothers reporting high levels of fatigue perceived themselves less effective in their parenting roles and were less satisfied with their parenting roles. Therefore, fatigue also negatively affects parents' self-efficacy.

In addition to fatigue, parents of children with ASD are more likely to experience mental health issues. Davis and Carter (2008) found that 33% of mothers and 17% of fathers among 54 mother-father dyads were within the clinical range for depression. Similarly, Hastings (2003) reported that mothers had higher levels of anxiety compared to fathers and expressed more concerns about their children's health. This difference could be less involvement of fathers in their children's care. This also results being less affected by their children's problems (Hastings 2003). Similarly, in a longitudinal study from infancy to early childhood conducted by Carter et al. (2009), it was reported that mothers' depression symptoms became more stable over time but individual differences in parental anxiety, self-efficacy, coping strategies and dimensions of social support were effective for parents' physical and psychological health. Hisoğlu (2018) stated that social support influenced parents' life satisfaction and levels of depression. Accordingly, families receiving social support from sources such as spouses and friends experienced decreased levels of depression and increased life satisfaction. All these studies highlight the importance of parents' resources of social support.

Moreover, parents' coping strategies can play a significant role for their psychological well-being and stress levels (Costa et al. 2016). Using positive coping strategies can reduce the risk of high stress among parents (Zablotsky et al. 2013). However, many of these parents do not have positive coping strategies (Zablotsky et al. 2013). For instance, Lai et al. (2015) found that parents of children diagnosed with ASD reported higher levels of parental stress and depression compared to parents of typically developing children and used more negative coping strategies. Parents of children with ASD who use more negative coping strategies such as avoidance (Dunn et al. 2001, Hastings et al. 2005) or blame (Pottie and Ingram 2008) report more negative psychological well-being and health outcomes. On the other hand, parents who use more positive coping strategies such as distraction, problem-solving and reappraisal report more positive psychological well-being and health outcomes (Dunn et al. 2001, Pottie and Ingram 2008). Hastings et al. (2005) reported that avoidance coping strategy was associated with more stress, anxiety and depression for both mothers and fathers. Conversely, positive coping strategies were associated with lower levels of depression (Hastings et al. 2005) and lower levels of parental stress (Zaitman-Zait et al. 2017) for both mothers and fathers. Increasing the use of negative coping strategies over time and decreasing the use of positive coping strategies predicted higher levels of parental stress. For this reason, helping parents change their cognitive frameworks related to their children's problem behaviors will contribute to increasing parental psychological well-being, reducing stress and reporting more positive health outcomes (Costa et al. 2016). Therefore, reducing the use of avoidance coping strategies and encouraging parents to engage in positive reappraisal methods are important (Dunn et al. 2001).

Namely, it can be said that raising a child with ASD causes parents to experience physical and psychological fatigue. When parents are physically and psychologically tired, they struggle to use their personal resources caring for their children (Giallo et al. 2013). This situation can lead to parental burnout (Ardıç 2020). Like in physical and psychological health, parental burnout is also associated with perceived social support. Ardıç (2020) examined the relationship between parental burnout and parents' perceived levels of social support and satisfaction with this support. A negative relationship was found between the level of social support perceived by parents and levels of parental burnout, negative spouse and marital relationship and emotional exhaustion (Ardıç 2020). In other words, parental burnout decreases when parents perceive social support while caring for their child. Another finding is that the burnout reported by parents of children with ASD is more strongly associated with their satisfaction of perceived social support compared to their perceived level of social support. Thus, parents' satisfaction with the social support they receive has greater impact on parental burnout. Similarly, Smith et al. (2012) reported that perceived social support had a lower correlation with psychological well-being compared to satisfaction with perceived social support. This indicated that it is more important for interventions aimed at parents to be planned taking into account their needs (Ardıç 2020).

Parent-Child Relationship

Relationship between parents and children with ASD may differ with typically developing children, because the needs of a child with ASD are not the same as typically developing children. However, despite challenges that parents faced, differences in the level of closeness in the relationship are not observed. Montes and Halterman (2007) noted that mothers of children with ASD reported high levels of relationship closeness with their children despite increased stress levels and decreased communication quality. Similarly, Hoffman et al. (2009) reported that mothers of children with ASD maintained close relationships with their children despite the stress of parenting challenges. Conversely, fathers' parenting experiences are influenced by factors such as the child's age and characteristics and the child spend at home. When the time spent at home by adolescents or adult children with ASD decreases, fathers report a closer father-child relationship (Hartley et al. 2011). Therefore, for fathers living with adolescents or adult children with ASD, their children spending time away from home and engaging in daily activities may enable to closer father-child relationship.

Additionally, Montes and Halterman (2007) noted that parents of children with ASD being less likely to show anger toward their children even though they are disturbed by their behaviors. On the other hand, Hoffman et al. (2009) suggested that the ASD diagnosis itself could serve as a protective factor in the parent-child relationship because parents perceive their children as less responsible for their problem behaviors. This may be cause of parents of children with ASD often attribute all of their children's behavioral problems to ASD symptoms rather than their child's personality or temperament. They may also blame themselves rather than their children for their behavioral issues (Whittingham et al. 2008). Therefore, while high levels of closeness in parent-child relationship may have positive effects, parents also need to be careful interpret and respond to their children's behavioral problems. Because parents who blame themselves for their children's behaviors based on ASD symptoms may also experience negative effects on their own psychological well-being.

Effects of Raising a Child Diagnosed with ASD on Family System

Impact on Marital Relationship and Marital Satisfaction

Because of the negative effects of raising a child diagnosed with ASD, many spouses may also experience difficulties in their marriages. A seven-year longitudinal study found that mothers' marital satisfaction decreased after the birth of a child diagnosed with ASD. Furthermore, it was observed that mothers' marital satisfaction changed over the years depending on the severity of the child's behavior problems (Hartley et al. 2012). Also, mothers who reported a close relationship with their child reported higher levels of marital satisfaction.

Additionally, weak marital relationship serves as an additional source of difficulty and distress for parents, thereby leading to an increase in the burden of parenting. Conversely, strong marital relationship is associated with lower levels of parenting stress (Hartley et al. 2011). Also, because it reduces the time spouses can take to their personal relationships, the quality of the parent-child relationship (the time parents spend caring for their children) can have a direct negative impact on the quality of the relationship. However, high levels of family support serve as an important resource to cope challenges raising a child with ASD. (He et al. 2022). While spouses perceived social support serves as a protective factor for marriage; children's behavior problems,

parental stress and psychological health conditions are identified as risk factors for the relationship between spouses (Wilkes-Gillan and Bourke-Taylor 2017). Thus, it is believed that child's problem behaviors cause high levels of stress in spouses, leading to increased marital conflict among spouses who cannot engage in co-parenting resulting in decreased marital satisfaction (Chan and Leung 2020).

Furthermore, inadequate social support and high levels of other negative factors cause higher divorce rates (Hartley et al. 2010). Hartley et al. (2010) reported that divorce rate among parents of children with ASD was 24%. This rate is significantly higher than the divorce rate among parents of typically developing children (14%). Additionally, research suggests that while the divorce risk decreases for parents of typically developing children in the late childhood period, the divorce risk remains high for parents of children with ASD throughout adolescence and early adulthood (Hartley et al. 2010). Therefore, parents of children with ASD continue to have a high risk of divorce throughout all developmental stages.

Taken together, it can be said that the marital relationship serves as a significant resource to help parents cope with the challenges of parenting a child with ASD (Hartley 2011). Especially considering the negative impact of parental stress on the marital relationship, it is important to help parents to engage in positive marital interactions when under stress (Chan and Leung 2020). Therefore, providing services to parents helping reduce their parenting burdens and enhance emotion regulation skills. Also teaching stress management techniques to decrease caregiving stress and psychological distress would be beneficial (Da Paz and Wallander 2017, Tehee et al. 2009).

Impact on Siblings

Raising a child with ASD within the family not only affects the parents but also influences sibling relationships. Sibling pairs with typical development often serve as a social comparison source for each other and try to develop social skills together (Bascoe et al. 2012). However, when one of the siblings diagnosed with ASD, the dynamics and relationships among siblings are changed due to the social and communication deficits caused ASD (Perlman and Howe 2023). Because social and communication deficiencies affect not only interactions with peers but also relationships with siblings (Coffmann et al. 2021).

As typically developing siblings older, they tend to spend more time outside the home and peer relationship become more important (La Greca and Harrison 2005). This often cause weakening the relationships between siblings. Kaufmann et al. (2021) were proved the idea that sibling relationships changes with age. Specifically, as the age of the typically developing sibling increases, both hostility and warmth perception toward the sibling with ASD decreases. This shows that how sibling relationships has changed from early childhood to adolescence. As siblings grow older, peer relationships and social approval become more important, this cause decrease in warmth toward the sibling with ASD. However, as awareness and sensitivity toward ASD and the diagnosed sibling increases, hostility toward the sibling with ASD also decreases.

Additionally, it has been reported that typically developing sibling takes caregiving roles regardless of birth order (Perlman and Howe 2023). Typically developing siblings, despite being chronologically younger, can assume the role of the "older sibling" (Ferraioli and Harris 2009). As a result, siblings of individuals with ASD report intense stress due to responsibilities placed on them (Ferraioli and Harris 2009). Typically developing siblings are also at risk of internalizing behaviors such as depression and anxiety in long term (Rossiter and Sharpe 2011). Furthermore, typically developing sibling express feelings of jealousy and resentment due to the extra responsibilities and receiving less parental attention compared to their siblings with ASD (Ward et al. 2016).

Molinario et al. (2020) conducted semi-structured interviews with both siblings and parents to explore the experiences of families living with a child diagnosed with ASD. In these interviews, most siblings and parents reported that typically developing children had to mature quickly and receive less attention from their parents due to having siblings with ASD. Similarly, Petalas et al. (2012) stated that siblings of children with ASD experienced increased responsibilities within the family and received less attention from their parents due to child with ASD needs.

In addition to these negative effects, there are also positive effects for both siblings. Relationships with siblings with ASD are not always negative. Qualitative study about mother's perceptions of the quality of sibling relationships, children's development, harmony and influence on each other, mothers described typically developing siblings as caring and loving toward their siblings with ASD, but also reported experiencing daily challenges related to family relationships and dynamics (Perlman and Howe 2023). The most commonly reported positive behaviors were supporting each other, feeling proud, helping, being kind and showing affection; while the most common negative behaviors included arguing, fighting over belongings, controlling,

and teasing each other (Perlman and Howe 2023). Additionally, it has been reported that as typically developing siblings grow older, they take a protective role for their siblings with ASD and protecting them from bullying or teasing (Ferraioli and Harris 2009).

To sum up, despite having a sibling with ASD may cause greater burden and responsibility for typically developing sibling, findings showed that the relationship of typically developing siblings with their ASD siblings is similar to the relationship between typically developing sibling dyads (Molinaro et al. 2020). However, there is still need for services aimed supporting sibling and family relationships (Perlman and Howe 2023).

Impact on Family Resources and Quality of Life

Besides emotional burden parents of children with ASD also have to spend more time and money for their child compared to parents of typically developing children (Sharpe and Baker 2007). Parents of child with ASD reported more time and money related burden than parents of children with other neurodevelopmental problems (Vohra et al. 2014). Parents need take time to care for their child with ASD and also carry significant financial burden to cover their treatment and services (Karst and Van Hecke 2012). Additionally, one or both parents often need to reduce their working hours or quit their jobs (Sharpe and Baker 2007). This is because parents of children with ASD are reported to spend ten or more hours per week planning or organizing childcare at home, compared to parents of children with other neurodevelopmental problems (Vohra et al. 2014). Furthermore, it is noted that mothers of children with ASD spend more time on childcare, household work and much less time on leisure activities (Smith et al. 2010). This increases financial stress factors on families and decreases both their social and emotional support resources (Karst and Van Hecke 2012).

Moreover, most studies have found that there is significant relationship between income and quality of life (Karst and Van Hecke 2012). Similarly, it was found that, low-income level was identified as a factor that affect negatively parents' quality of life and mental health (Güller and Yaylacı 2022). Thus, inadequate income levels can lead to decrease in parents' quality of life by limiting the resources necessary for their child's education and healthcare expenses (Özgür et al. 2017). This is because the financial and emotional caregiving burdens faced by parents of children with ASD inevitably impact their level of satisfaction with their quality of life (Dardas and Ahmad 2014, Vasilopoulou and Nisbet 2016).

Quality of life is defined as an individual's perception of their position in life related to their goals, expectations, standards and concerns within the context of the culture and value systems they live in (WHOQOL 1998). Studies indicated that parents of children with ASD report lower quality of life compared to parents of typically developing children (Vasilopoulou and Nisbet 2016) and parents of children diagnosed with ADHD (Lee et al. 2008). Also, they frequently show concern regarding their children's well-being (Lee et al. 2008). Examined studies emphasize the importance of social resources and participation in activities outside the home on parents' quality of life (Vasilopoulou and Nisbet 2016). However, it is reported that parents of children with ASD participate in activities less frequently compared to parents of children with ADHD or typically developing children (Lee et al. 2008).

There is a positive relationship between family quality of life and social support (Feng et al. 2022). Social support is defined as the love, care, trust, respect, information and material assistance received from one's social network (Hsiao 2018). Studies indicate that families of child with ASD do not identify anyone as their primary source of social support (Sencar 2007); mothers mostly identify their spouses for primary support, followed by immediate family members and finally parents of other children with ASD who face similar challenges (Boyd 2002). Research suggests that emotional support and social support from the community (e.g., neighborhood) can protect against families' psychological health problems (Zablotsky et al. 2013). Perceived family support can also reduce the impact of child's ASD-related behaviors on parents' psychological health (Lai et al. 2015). Both family and friend support are associated with positive psychological well-being (Ekas et al. 2010). Gönültaş (2019) also found that providing adequate social support to parents lead to positive changes in their quality of life. It is known that single mothers report lower levels of social support (Bromley et al. 2004). Therefore, perceived social support from their immediate environment will not only affect parents' quality of life but also lead to less stress, depression and parental burnout.

Further, both the quantity and quality of social support are important. For example, although primary social support sources of mothers may be their spouses (Boyd 2002), spouses may not always be the most effective source of support (Ekas et al. 2010). When spouses are equally distressed and unable to provide effective social support (Coyne et al. 1990), it may be more beneficial for mothers of children with ASD to seek social support from extended family members or close friends. Ekas et al. (2010) were examined various sources of social

support (spouse, family, friends). It was found that social support from friends was associated with increased life satisfaction, positive affect and psychological well-being, while spousal support was only associated with increased life satisfaction and psychological well-being. With respect to a longitudinal study to examine the quantity and type of perceived support (positive support and negative support), it was found that higher levels of negative social support were found to be associated with an increase in depressive symptoms and negative affect and a decrease in positive affect (Smith et al. 2012). After controlling for all child-related factors at 18-month follow-up measurements, it was found that increasing in positive social support was associated with higher levels of positive effect and lower depressive symptoms.

Based on these findings, raising a child with ASD brings many financial and emotional difficulties, also cause negative quality of life. However, studies have reported positive relationships between quality of life and perceived social support. In this context, decreasing exposure to negative social support and increasing positive social support will positively affect parents' well-being. Findings also suggest that decreasing parental stress and increasing social support may increase parental resilience (Zhao et al. 2021). Therefore high, quality and satisfying social support will benefit parents in many areas where they experience challenges when raising a child with ASD. Hence, there is need for professional support services, social support groups, intervention programs and parent education to contribute to better psychological health and quality of life for parents raising a child with ASD. Helping parents to recognize and reduce negative social support they receive (Smith 2012) in future intervention programs and parent educations will also be important for parents' psychological well-being and resilience.

Conclusion

Overall, raising a child with ASD presents many challenges, which significantly impact both parenting behaviors and family life. Parents of children with ASD report decreased belief in their ability to parent effectively (Karst and Van Hecke 2012) and exhibit higher levels of physical and psychological health concerns (Ekas et al. 2010). Additionally, these parents report higher levels of parental stress compared to parents of typically developing children or children with other neurodevelopmental problems (Hayes and Watson 2013). Furthermore, raising a child with ASD is associated with decrease in parents' quality of life (Lee et al. 2008), as well as an increase in marital (Hartley et al. 2012) and sibling relationship problems (Coffmann et al. 2021). Moreover, insufficient perceived social support from the environment aggravates all these factors (Smith et al. 2012).

In a qualitative study aiming to describe the experiences of parents of children with ASD, parents expressed their experiences using the phrase "living in our own world." They reported that feelings of loneliness cause lack of understanding in society, unsupportive systems and sense of disconnection from their families (Woodgate et al. 2008). Parents feel isolated from their families and communities, which lack understanding of what they are going through (Woodgate et al. 2008). This situation shows that the society and the parents' relatives do not understand and support ASD sufficiently. However, high quantity and quality of perceived social support serve as protective factors for parents in many areas where they experience difficulties. At this point, social policies should be implemented to transform the system into embraces parents of children with ASD. Additionally, families from disadvantaged backgrounds such as those with low socioeconomic status, immigrant status or residing in disadvantaged areas have limited access to services. This leads them to experience double disadvantage. Therefore, it is important to consider families with limited access to services and make service accessibilities universally available for everyone.

Additionally, there is need for parent-focused intervention and parent education programs aimed to support parents in various areas where they face difficulties. These intervention programs must critically consider factors such as marital relationships, sibling relationships, social support resources, coping strategies and children's problem behaviors. Consistent and frequent implementation of the methods learned in these programs by parents in their daily lives will be beneficial in managing the child's problem behaviors and improving social and communication skills.

As well as parent-focused interventions, involvement of parents in intervention programs implemented for children also facilitates the generalization of learned skills and increases the impact of intervention received by the child. Moreover, this benefit is not only for children. A review study on parental involvement of intervention programs for children with ASD showed that the inclusion of parents in interventions benefits both the child and the parents (Burrell and Barrego 2012). Involving parents in intervention programs also increases parental and family functionality and parents report greater parental self-efficacy when they feel more involved in interventions (Kurzkrok et al. 2021). Furthermore, it is known that when given the opportunity to learn and

implement skills that will increase their child's functionality, positive emotional states increase (Solomon et al. 2008), stress decreases (Symon, 2001), and parental self-efficacy increases (Sofronoff and Farbotko 2002).

Finally, as in this review study, studies aimed at examining the impact of raising a child with ASD on parents also have some limitations. Addressing these limitations within this review would be beneficial for future studies. Firstly, autism is a spectrum, making it difficult to understand parental and family factors comprehensively. Since not all children experience similar difficulties, all parents and family systems are not affected in the same way. This complicates comparison of results across studies. Therefore, it is important to conduct studies that take into account the differences between parents and family systems of children at different parts of the spectrum. Secondly, longitudinal studies concerning parents and family systems are inadequate. Even though cross-sectional studies provide information about effects of raising a child with ASD on parents and the family system, they could not give any information about events that happen over time. Therefore, longitudinal studies will be important to provide comprehensive understanding of the parent-child relationship. Thirdly, comparative studies with parents of typically developing children will help to understand the areas where parents of children with ASD experience difficulties. Fourthly, as highlighted in this review, all the difficulties experienced by parents appear to be related to each other. Therefore, it is not possible to clearly describe the difficulties experienced by parents raising children with ASD. Hence, causal relationships should be considered and appropriate statistical methods should be used. Fifthly, in most studies, the results are based on mothers' self-reports. However, because it may be challenging for mothers to provide an objective assessment of their child's abilities and limitations, mothers may report their lives as either more difficult or easier. Additionally, there are a limited number of studies focusing on fathers. Including both parents in future studies and using different measurement methods will help us to understand better both parents. Moreover, the fundamental biological, neurological and psychological differences between parents and siblings of children with ASD are not fully examined. Considering autism spectrum disorder as a neurodevelopmental difference, future studies need to include genetic factors associated with ASD. In conclusion, despite the increasing understanding of raising a child with ASD, there is a need for more comprehensive and numerous studies on the impact of raising a child with ASD on parents. Considering these limitations in future studies will make significant contributions to the relevant literature.

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