



REVIEW

Stress factors in parents of children on the autism spectrum: an integrative model approach

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Abstract

Autism is a neurodevelopmental condition with biological, genetic, environmental and developmental causes whose prevalence has suffered substantial increase over the last decades. Children on the autism spectrum (AS) face unique challenges that arise from their difficulty in understanding social behavior and interaction, difficulty in understanding and effectively using communication, and difficulty with having reduced flexibility of thought and behavior. A large number of studies have reported that parents of children on the AS experience higher levels of stress when compared to parents of typically developing children and children with other developmental disabilities. Such stress levels are dependent on a number of factors which seem to be interrelated and complex. In this review we divided these factors into parent characteristics, child characteristics, family support system, social support/socioeconomic status and professional support, proposing an integrative model for understanding parental stress.

Keywords: Autism spectrum, Parent stress, Stress factors.

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Introduction

Autism is nowadays regarded as a neurodevelopmental condition with biological, genetic, environmental and developmental causes. Substantial increase in the estimated prevalence of autism has been reported over the last decade. The median of prevalence estimates is 62/10,000 worldwide [1], with a prevalence of 1 in 68 children aged 8 having been reported in the United States [2]. Since the early references of autism in literature, its definition has evolved over the years and been included in international and recognized diagnostic manuals. The current Diagnostic and Statistical Manual of Mental Disorders (DSM-5, 2013) uses the term autism spectrum (AS) to encompass the previous diagnoses of autistic disorder, Asperger's disorder, childhood disintegrative disorder and pervasive developmental disorder present in the DSM-IV, thus adopting a dimensional approach and differentiating between individuals by dimensions of severity and associated features. The term autism spectrum will be used throughout this paper to include all individuals within the spectrum, avoiding unnecessary categorization unless otherwise specified by the cited studies.

Children on the AS face challenges that arise from their difficulty in understanding social behavior and interaction, difficulty in understanding and effectively using communication, and difficulty with having reduced flexibility of thought and behavior [3]. Most children on the AS present challenges in these areas (to a greater or lesser extent) and many also experience sensory perceptual differences such as hyper or hyposensitivity, fragmented and distorted perception, delayed perception and sensory overload [4], which impact the way they relate to other people and the world around them.

A large number of studies have reported that parents of children on the AS experience higher levels of stress when compared to parents of typically developing children [5, 6] and children with other developmental disabilities [7, 8]. Parents of children on the AS face unique challenges and their ability to deal with higher stress levels depends on multiple factors. This paper is a review into current research regarding stress factors in parents of children on the AS. We conducted a non-systematic literature review using databases such as Pubmed, Web of Science and the University of Birmingham database. Keyword searches were performed to retrieve relevant information that has been published in English over the last 15 years. Additional studies cited in reference lists and books in the autism field with relevance to the topic were also included (even if published at an earlier date).

The diathesis-stress model is a psychological theory that explains behavior as a result of an interaction between individual vulnerability (diathesis) and environmental stress (life events). The model explains how multiple factors interact in the individual experience of stress and provides a holistic framework for understanding parental stress. It has

been used in many areas of psychology to explain how individuals develop psychopathology, but was first used to explain the development of schizophrenia in the 1960's. The term diathesis derives from the Greek term 'vulnerability or predisposition' which can be a genetic, psychological, biological or situational factor. This model asserts that if the combination of the individual vulnerability and the experienced stress exceeds a certain threshold, the person can develop a psychological disorder such as depression or anxiety.

Lazarus [9] described stress as an external load or demand on a biological, social or psychological system. Appraisal is the process by which the individual evaluates the significance of what is happening in terms of his/her well-being. Individuals vary in how they evaluate the situation, that is, the meaning of the situation is influenced by personality characteristics but also by individual beliefs and motives [9]. In that sense, what one individual would regard as stressful another might not. On the other hand, coping is the process by which an individual makes an effort (either in thought or action) to manage the situation which he has evaluated as challenging or demanding. Coping is highly contextual and in order to be effective it must change over time and according to different situations (what might be effective in one situation might be counterproductive in another).

When appraisal determines that something can be done to change the situation, problem-focused coping occurs and coping actions are directed at changing the individual's relationship with the environment. On the other hand, when appraisal determines that nothing can be done, emotion-focused coping occurs and the individual changes the way in which he attends to or interprets what is happening [9]. Coping strategies are complex and some are more stable and dependent on personality characteristics (for example, thinking positively) while others are less stable and more dependent on social context (for example, seeking social support). Also, when the type of stressor is held constant (work, health or family related stress), it seems that women and men show very similar coping strategies [9]. Finally, protective factors are important when considering the interaction between the diathesis and the stressful event. Factors such as a good social network or family support system, or individual emotional competence (and certain personality characteristics) can help reduce the impact of negative events in an individual's well-being.

Several studies have measured stress in parents of children on the AS, and several factors have been associated with parental stress indices. For the purpose of this review we have divided factors linked to parental stress into the following categories: parent characteristics, child characteristics, family support system, social support and socio-economic status, and professional support (Figure 1).

Parent characteristics

Parent characteristics include factors that are solely dependent on the parent, whether biological (genetic, phys-

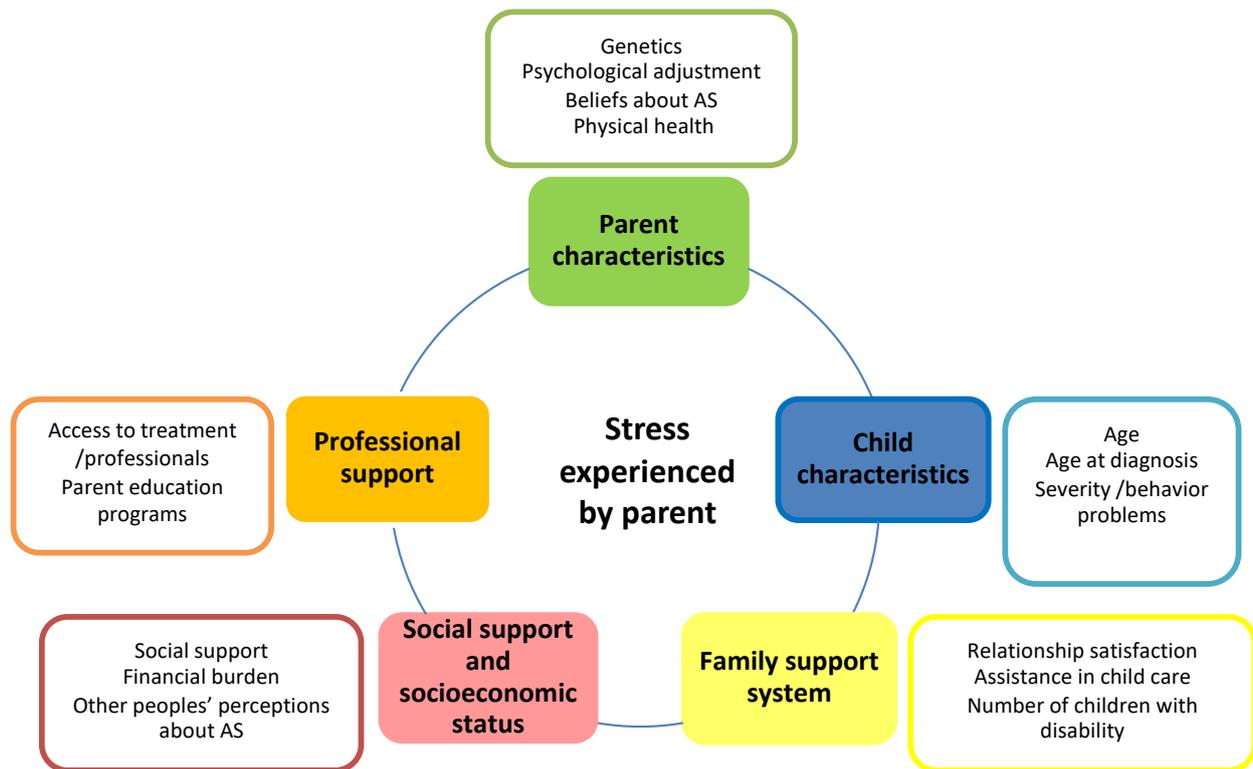


Figure 1. Integrative model of factors that influence parent stress.

ical health) or psychological (psychological adjustment and individual beliefs). It is nowadays known that the AS is highly heritable with a remarkable genetic heterogeneity with several hundred predisposition genes having been identified to date [10]. In an interesting paper by Baron-Cohen [11], the author calls attention to the complexity of the genetics of autism but particularly on the possibility that genes contributing to autism might overlap with other genes that confer a unique 'ability to understand how the world works in detail—to see beauty in patterns inherent in nature, music and math' [11]. Still according to Baron-Cohen [11] systematizing is the drive to analyze or construct a system (whether it is mechanical, natural or abstract), understanding the rules that govern that system making it predictable. Genes responsible for autism could be co-inherited with genes that determine cognitive talents common in people on the AS and technical minded individuals. In that sense, the author has found that children and adults (on the Asperger side of the AS) score higher on self-report and parent report measures of systematizing, and on a test of attention to detail. Further, parents of children with autism were faster and more accurate on a test of attention to detail than parents of typically developing children. Some studies have also suggested that there is a genetic link between mood disorders and the AS [12] and also a genetic link between parental depression and having a child on the AS [13].

Another factor which appears to influence parent stress is the existence of an illness or disability. Parents who had

an illness or disability reported significantly higher anxiety, depression and stress levels than parents who were healthy and/or did not have a disability [14]. Also, in a later study the authors found similar findings, with higher anxiety and depression levels being reported by parents who had a physical disability or illness/disorder [15].

Parental beliefs and concerns regarding the care the child receives, also seems to influence anxiety and depression levels. In their study, Bitsika and Sharpley (2004) found parents' perceptions regarding the expertise of the family caregiver were contributing factors, in that higher anxiety and depression levels were reported by parents who had a poor perception of the caregivers' expertise. In fact, in this study, nearly half of parents had severe anxiety levels and nearly two-thirds were clinically depressed (according to Zung's criteria) which was about four to five times greater than levels reported for the general population. Despite the lack of direct comparability due to the demographic nature of both samples [14, 15] the authors state the greater indices of clinical anxiety and depression found in the 2004 study might be explained by the fact that parents in the earlier study had children who had been diagnosed at an earlier age, accessed respite care more frequently and had greater family support in caring for the child. Zhou and Yi (2014) also reported that parents perceived that their own emotions influenced the emotional reactions of the children as well as their own symptoms [16].

Sense of coherence (SOC) is conceptualized as a way of perceiving life events that an individual brings to differ-

ent situations. It encompasses a feeling of confidence that the stimulus is comprehensible, that resources are available to meet demands (the stimulus is manageable) and the demand or challenge is worth investing in (is meaningful) [17]. Sense of coherence may act as a general resilience to stress or as a precursor to other cognitive processes specific to a particular situation, and it has been inversely associated with depression and anxiety [18], and directly associated with psychological health and well-being [19-21]. In a study with parents of children with developmental disabilities, SOC was inversely related to parental depression [22] whilst in another study [23], the parents' level of SOC was predictive of their children's perceived competence and reduced behavioral problems.

Parenting confidence and child acceptance have also been associated with lower parenting stress [21]. Parenting confidence refers to the perception that parents have of themselves as parents. On the other hand, child acceptance refers to how parents understand and accept their child's behavior and feelings, are happy with their child and see their child as an independent individual. In their study of mothers of children on the AS, the authors [21] found that SOC moderated the effect of symptom severity on stress. Symptom severity was associated with increased levels of stress in mothers with low SOC. On the other hand, mothers with a strong SOC perceived lower stress even when their children presented with more severe autistic symptoms. Also, mothers with a higher SOC showed more confidence and greater acceptance which in turn related to lower parenting stress. The authors also found that a negative perception of the child's disability was associated with high levels of parenting stress [21].

Certain aspects of parental mental health have been found to impact child outcome. Specifically, parent depression may contribute to less parental responsiveness with the child during play, which in turn, is associated with decreased child engagement, social interaction, and socio-emotional functioning [24]. Decreased parental responsiveness has also been associated with delay in language development and joint attention [25]. Nock and Kazdin (2001) found that high levels of parenting stress and depression were associated with low expectations regarding treatment, which in turn predicted greater obstacles throughout the treatment process, lower attendance, and early termination of therapy [26].

Child characteristics

Several characteristics which are related to the child have been associated with increased parent stress and reduced well-being, namely, core autism symptoms (social communication impairments and repetitive behaviors), poor cognitive and adaptive skills, and emotional and behavioral difficulties [27]. Both higher levels of AS symptoms and severity of impairment have been associated with higher levels of parent stress [28]. Several studies have consistently

found that child behavior problems contribute to increased parent stress [29, 30]. Lecavalier et al., (2006) found that a specific group of externalized behaviors, such as conduct problems were strongly associated with caregiver stress. In the study by Bitsika and Sharpley (2004) most of the parents considered behavioral difficulties to be the most challenging, followed by cognitive/learning difficulties, poor communication skills and lack of independence. About one in five parents rated their self-confidence in dealing with such daily behavioral issues as low. Over 90% of parents felt unable to deal with these issues and felt 'stretched beyond their limits' with nearly 40% of parents stating that they felt like that about every three days [15]. Poor expression of affect and little interest in people also contributed to maternal stress levels [31] and another study found that social interaction skills independently predicted maternal child-related stress in mothers of AS children [32].

The subtypes of AS diagnoses have also been linked to different parent stress levels. In a study by Mori et al., (2009) [33] parents of children with Asperger's reported the highest levels of stress and in another study [34], parents of children with autism reported higher levels of stress than those of children with pervasive developmental disorder (not otherwise specified). Higher autism symptomatology and a greater number of co-occurring psychiatric disorders (in the child) were associated with an increased risk for current treatment of maternal depression and lower maternal quality of life [35]. Blatcher and McIntyre (2006) examined whether behavior problems and adaptive behavior of low functioning young adults, and well-being of their families, varied by diagnostic group (intellectual disability only, cerebral palsy, Down syndrome, autism). Even though they found that autism was associated with the highest scores in multiple behavior problem areas and lower maternal well-being, when behavior problems were controlled for there was no additional variance in maternal stress or depression by diagnostic groups [36]. Other studies did not find an association between autism severity and stress levels in caregivers [27, 37]. On the other hand, the association between higher rates of child emotional and behavioral problems and poorer parental psychological well-being are more consistent [30, 38, 39].

Age of the child has been associated with parent stress, and it has been suggested that parents of older children have higher levels of stress when compared to parents of younger children [40]. It could be that the maturational changes that occur in middle childhood combined with increased exposure to social situations, demand major adjustments in parents' expectations which, in turn, may be associated with higher risk for stress [27, 41]. Also, the age of diagnosis has been associated with parent stress. Gray and Holden (1992) found a later diagnosis to be associated with higher depression levels [42]. Another study [43] found that parents of children who had been diagnosed for 1 to <2 years reported a higher caregiving burden than others (<1 and ≥2 years since diagnosis) [43] and according

to Zablotsky et al., (2013) [44], mothers of older children were less likely to be receiving treatment for depression. However, other studies have found no significant effects according to age of diagnosis or age of the child [14].

Family support system

Family factors are also probable determinants of parental stress, and include aspects such as satisfaction with relationships (marital or family), assistance in caring for the child and parents' perceptions regarding the expertise of other family caregivers. Parents of children on the AS face unique caretaking challenges within these complex and important relationships, and tend to report less marital satisfaction compared with married parents of typically developing children [45]. According to Gau et al., (2012) lower dyadic consensus, or agreement between parents, and lower levels of positive affective expression contribute to decreased marital satisfaction in parents of AS children. Importantly, divorce rates seem to be twice as high in families with children on the AS compared to families with typically developing children [46].

In a study with mothers of children on the AS, the authors studied the contributions of child behaviors, parenting stress and relationship satisfaction to maternal depressive symptoms [47]. Although diagnostic severity and behavior problems significantly predicted depressive symptoms, relationship satisfaction and parental distress did so above and beyond child characteristics. Also, results suggested that relationship satisfaction may buffer (to some extent) the impact of parent stress on maternal depression [47]. Importantly, caregiver depression can not only impact day to day family life but also limit intervention access and benefit [48].

In a study by Sharpley et al., (1997) parents with access to other family members for assistance in caring for their child had lower stress levels than parents who did not have such assistance. Lower levels of anxiety and depression were found in parents who considered that family members who gave assistance had a clear understanding of the child's needs and difficulties. This was replicated in a later study [15] where the authors found that parents' perceptions regarding the expertise of the family caregiver contributed to anxiety and depressive symptoms, with higher anxiety and depression levels being present in parents who had poor perceptions. In another study family support was associated with increased psychological well-being in mothers of children on the AS [49].

The number of children with a disability in the family is also an important factor in parent stress [50] and Kuhlthau et al., (2014) reported that families with more than two children with special needs had lower health-related quality of life and higher caregiver burden and depression. Whether the child attended a special school or not was a significant factor in determining parents' daily stress in the Bitsika and Sharpley (2004) study. The reduction in the

care that can be provided to other siblings, when there is a child on the AS in the family, has also been reported as a factor that contributes to parent stress [40].

Social support and socioeconomic status

Social support is a critical factor in reducing the negative psychological impact of raising a child on the AS or other developmental disabilities [49, 51]. Social support has been shown to be associated with decreased psychological distress [52, 53], reduced feelings of depression, improved overall mood, and decreased parenting stress [49], as well as increased parenting efficacy [54] in parents of children on the AS [55].

Informal social support, such as the support received from friends and family, reduces stress among mothers of children with AS. In a study by Ekas et al., (2010), the authors evaluated how each source of support (spouse, family and friends) related to optimism and maternal well-being. Each source of social support was associated with lower levels of depression, negative affect, and parenting stress. Further, while support from spouse was associated with increased life satisfaction and psychological well-being, support received from friends was associated with increased life satisfaction, positive affect, and psychological well-being. On the other hand, support received from other family members was associated only with increased psychological well-being. The authors also found that higher levels of optimism were associated with increased positive outcomes and decreased negative outcomes [49].

Persistent parenting stress has been associated with lowered perceptions of social support [56] so it could be that parents might not always be aware of or use available resources to them [55]. Also, parents of children on the AS may have decreased social contacts partly because of the challenges they face but also because the emotional support and understanding they need may be difficult to find in families with typically developing children [55]. Other factors that have been found to contribute to parent stress are the unlikely remission of behaviors that cause social criticism and the lack of understanding among the public about the nature of AS [15].

Financial burden and economic impact is also considered to be a factor contributing to parent stress [55] and annual expenses for taking care of children on the AS are significantly higher than those for non-affected children [57]. Parents of children with special health care needs are at increased risk for not being employed and having financial stress [43, 58, 59]. In a study by Kuhlthau et al., (2014) where parent health-related quality of life was studied on a quantitative and qualitative perspective, the majority of parents reported direct and indirect financial strains related to parenting a child on the AS; over half of parents reported at least some problems with combining care tasks with daily activities and financial problems because of care tasks; and many parents referred to the inability to work

or difficulty in maintaining a job [43]. Such issues are important to be considered as they may reduce family income and social connection due to loss of work.

Finally, the degree of expertise demonstrated by alternate caregivers in respite care (regarding AS) has been shown to influence parent stress. Low levels of caregiver expertise may contribute to parental distress due to poor behavior management skills and strategies being implemented during the parents' absence, with consequently extra demands when they resume their primary caregiver roles [15].

Professional support

One of the most significant aspects of the AS is its clinical heterogeneity and diversity, with substantial differences also being apparent in treatment outcome. Not all children and families derive the same benefits from similar interventions and there is little research so far as to what variables (child or other) predict response to treatment [60]. In absence of this important information, the choice of early intervention and education programs by families and clinicians is largely dependent on factors such as availability and proximity of services rather than on scientific information regarding which intervention will result best taking into account the individual characteristics of the child and family [60]. In a study by Shepherd et al., (2018), the authors found that funding was a major determinant of intervention engagement as was influence from medical professionals. Also, parental perceptions of their child's symptom severity were related to intervention engagement [61]. Understanding why parents choose some interventions over others, which factors influence decisions and barriers or reasons behind intervention rejection or discontinuation will result in better service provision [61]. Professionals in clinical settings need to take parents' concerns about future outcomes into consideration and address such concerns, when communicating with families.

Despite the various treatment options available, only a small proportion of interventions have scientific evidence of efficacy, and early intensive interventions are currently recommended as the treatment of choice for children on the AS. However, evidence also suggests that such programs are not equally beneficial for all children (60). How a child on the AS responds to intervention over time is certainly dependent on numerous variables and possibly complex interactions between such variables, some of which are related to the child's characteristics but also to the environment they live in. A detailed analysis of these aspects is beyond the scope of this review. However, reference to studies regarding the impact of family factors, such as parent stress, are significant to the subject of this paper.

There have been some reports that parental stress can predict the developmental level of children with intellectual disabilities [62] and that high levels of parenting stress can counteract the effectiveness of early teaching interventions in children with autism spectrum disorders [48, 63]. Par-

ents are frequently expected to engage alongside therapists across a variety of interventions which demands a great amount of time, dedication, energy and financial resource. Parents are included directly or indirectly in the majority of interventions even though the intensity, the form and function of such involvement varies [64]. Alongside this therapist or coach role, parents are usually the primary caregivers for their children and the essential link between home and school environments.

Parent training and education programs provide parents with information or skills to help them cope with their child's particular challenges. Studies on the effects of such programs have reported decrease in parent stress and increase in parental confidence and quality of life [65, 66]. Involving parents in the intervention being delivered to the child on the AS has several benefits. Not only does it provide increased insight into the individual child but more easily facilitates the incorporation of therapy into the child's own environment, facilitates the generalization of learned skills and reduces parent stress [67, 68].

Several studies have highlighted that including parents and other family members in the intervention process can benefit the whole family, decrease parent mental health concerns, promote greater parental understanding of their child's difficulties, and improve social behavior and communication skills [55, 68, 69]. Further, improved responsiveness and emotional regulation, reduced levels of stress and depression, overall improved mental and physical health, and greater parenting self-efficacy have also been described as benefits of parent training programs [68, 70].

Conclusions

Stress in parents of children on the AS is dependent on a number of factors which seem to be interrelated and complex. For the purpose of this review we have divided these factors into parent characteristics, child characteristics, family support system, social support and socioeconomic status, and professional support and propose an integrative model for understanding parental stress (Figure 1). The way in which these factors interact is still not fully understood, and available studies have methodological and statistical limitations that make causal connections and definite trajectories related to both parent and child well-being difficult to establish [55]. Further, the heterogeneity of clinical samples and small sample sizes, the lack of longitudinal studies and randomized controlled trials, the limited availability of standardized measures for social and non-social variables, the use of parent-rating measures or self-report, and the complexity in finding appropriate control groups makes comparisons across studies difficult [55].

Children on the AS face challenges that require long-term care, both of which have a profound impact on parents and family. The identification and understanding of the factors that contribute to parent stress is necessary to effectively address the psychological needs of parents as

part of any intervention program. If parents feel supported, educated and more confident in their ability to help their child, they will become better advocates for their child's needs and a better foundational support.

Abbreviations

AS: Autism spectrum; DSM-5: Diagnostic and Statistical Manual of Mental Disorders; SOC: Sense of coherence

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Competing interests

The authors declare that there are no conflicts of interests.

References

- Elsabbagh M, Divan G, Koh Y-J, Kim YS, Kauchali S, Marcín C, et al. Global Prevalence of Autism and Other Pervasive Developmental Disorders. *Autism Research* 2012; 5(3):160-79. <https://doi.org/10.1002/aur.239>
- Christensen D, Baio J, Braun K, Bilder D, Charles J, Constantino J, et al. Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2012. *MMWR Surveill Summ* 2016; 65(No. SS-3):1-23. <https://doi.org/10.15585/mmwr.ss6503a1>
- Wing L, Gould J, Gillberg C. Autism spectrum disorders in the DSM-V: Better or worse than the DSM-IV? *Research in Developmental Disabilities* 2011; 32(2):768-73. <https://doi.org/10.1016/j.ridd.2010.11.003>
- Bogdashina O. *Sensory Perceptual Issues in Autism and Asperger Syndrome : Different Sensory Experiences - Different Perceptual Worlds*. London, GB: Jessica Kingsley Publishers; 2003.
- Rodrigue JR, Morgan SB, Geffken GR. Psychosocial adaptation of fathers of children with autism, Down syndrome, and normal development. *J Autism Dev Disord* 1992; 22(2):249-63. <https://doi.org/10.1007/BF01058154>
- Keenan BM, Newman LK, Gray KM, Rinehart NJ. Parents of Children with ASD Experience More Psychological Distress, Parenting Stress, and Attachment-Related Anxiety. *J Autism Dev Disord* 2016; 46(9):2979-91. <https://doi.org/10.1007/s10803-016-2836-z>
- Dabrowska A, Pisula E. Parenting stress and coping styles in mothers and fathers of pre-school children with autism and Down syndrome. *J Intellect Disabil Res* 2010; 54(3):266-80. <https://doi.org/10.1111/j.1365-2788.2010.01258.x>
- Yamada A, Suzuki M, Kato M, Suzuki M, Tanaka S, Shindo T, et al. Emotional distress and its correlates among parents of children with pervasive developmental disorders. *Psychiatry and clinical neurosciences* 2007; 61(6):651-7. <https://doi.org/10.1111/j.1440-1819.2007.01736.x>
- Lazarus RS. From psychological stress to the emotions: a history of changing outlooks. *Annual review of psychology* 1993; 44:1-21. <https://doi.org/10.1146/annurev.ps.44.020193.000245>
- Grayson DR, Guidotti A. Merging data from genetic and epigenetic approaches to better understand autistic spectrum disorder. *Epigenomics* 2016; 8(1):85-104. <https://doi.org/10.2217/epi.15.92>
- Baron-Cohen S. Autism and the technical mind: children of scientists and engineers may inherit genes that not only confer intellectual talents but also predispose them to autism. *Scientific American* 2012; 307(5):72-5. <https://doi.org/10.1038/scientificamerican1112-72>
- DeLong R. Autism and familial major mood disorder: are they related? *The Journal of neuropsychiatry and clinical neurosciences* 2004; 16(2):199-213. <https://doi.org/10.1176/jnp.16.2.199>
- Cohen, Tsiouris J. Maternal recurrent mood disorders and high-functioning autism. *J Autism Dev Disord* 2006; 36(8):1077-88. <https://doi.org/10.1007/s10803-006-0145-7>
- Sharpley CF, Bitsika V, Efremidis B. Influence of gender, parental health, and perceived expertise of assistance upon stress, anxiety, and depression among parents of children with autism. *Journal of Intellectual & Developmental Disability* 1997; 22(1):19-28. <https://doi.org/10.1080/13668259700033261>
- Bitsika V, Sharpley CF. Stress, Anxiety and Depression Among Parents of Children With Autism Spectrum Disorder. *Australian Journal of Guidance and Counselling* 2004; 14(2):151-61. <https://doi.org/10.1017/S1037291100002466>
- Zhou T, Yi C. Parenting styles and parents' perspectives on how their own emotions affect the functioning of children with autism spectrum disorders. *Family process* 2014; 53(1):67-79. <https://doi.org/10.1111/famp.12058>
- Antonovsky A. The structure and properties of the sense of coherence scale. *Soc Sci Med* 1993; 36(6):725-33. [https://doi.org/10.1016/0277-9536\(93\)90033-Z](https://doi.org/10.1016/0277-9536(93)90033-Z)
- McSherry WC, Holm JE. Sense of coherence: Its effects on psychological and physiological processes prior to, during, and after a stressful situation. *Journal of Clinical Psychology* 1994; 50(4):476-87. [https://doi.org/10.1002/1097-4679\(199407\)50:4<476::AID-JCLP2270500402>3.0.CO;2-9](https://doi.org/10.1002/1097-4679(199407)50:4<476::AID-JCLP2270500402>3.0.CO;2-9)
- Cohen, Dekel. Sense of Coherence, Ways of Coping, and Well Being of Married and Divorced Mothers. *Contemporary Family Therapy* 2000; 22(4):467-86. <https://doi.org/10.1023/A:1007853002549>
- Kivimäki M, Feldt T, Vahtera J, Nurmi J-E. Sense of coherence and health: evidence from two cross-lagged longitudinal samples. *Soc Sci Med* 2000; 50(4):583-97. [https://doi.org/10.1016/S0277-9536\(99\)00326-3](https://doi.org/10.1016/S0277-9536(99)00326-3)
- Mak WWS, Ho AHY, Law RW. Sense of Coherence, Parenting Attitudes and Stress among Mothers of Children with Autism in Hong Kong. *Journal of Applied Research in Intellectual Disabilities* 2007; 20(2):157-67. <https://doi.org/10.1111/j.1468-3148.2006.00315.x>
- Olsson MB, Hwang CP. Sense of coherence in parents of children with different developmental disabilities. *Journal of Intellectual Disability Research* 2002; 46(7):548-59. <https://doi.org/10.1046/j.1365-2788.2002.00414.x>
- Cederblad M, Pruksachatkunakorn P, Boripunkul T, Intraprasert S, Hook B. Sense of coherence in a Thai sample. *Transcultural psychiatry* 2003; 40(4):585-600. <https://doi.org/10.1177/1363461503404007>
- Kim J-M, Mahoney G. The Effects of Mother's Style of Interaction on Children's Engagement. *Topics in Early Childhood Special Education* 2004; 24(1):31-8. <https://doi.org/10.1177/02711214040240010301>
- Ruble L, McDuffie A, King AS, Lorenz D. Caregiver Responsiveness and Social Interaction Behaviors of Young Children With Autism. *Topics in Early Childhood Special Education* 2008; 28(3):158-70. <https://doi.org/10.1177/0271121408323009>
- Nock MK, Kazdin AE. Parent Expectancies for Child Therapy: Assessment and Relation to Participation in Treatment. *Journal of Child and Family Studies* 2001; 10(2):155-80. <https://doi.org/10.1023/A:1016699424731>

27. Salomone E, Leadbitter K, Aldred C, Barrett B, Byford S, Charman T, et al. The Association Between Child and Family Characteristics and the Mental Health and Wellbeing of Caregivers of Children with Autism in Mid-Childhood. *Journal of Autism and Developmental Disorders* 2018; 48(4):1189-98. <https://doi.org/10.1007/s10803-017-3392-x>
28. Benson PR. The impact of child symptom severity on depressed mood among parents of children with ASD: the mediating role of stress proliferation. *J Autism Dev Disord* 2006; 36(5):685-95. <https://doi.org/10.1007/s10803-006-0112-3>
29. Davis NO, Carter AS. Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: associations with child characteristics. *J Autism Dev Disord* 2008; 38(7):1278-91. <https://doi.org/10.1007/s10803-007-0512-z>
30. Lecavalier L, Leone S, Wiltz J. The impact of behaviour problems on caregiver stress in young people with autism spectrum disorders. *J Intellect Disabil Res* 2006; 50(Pt 3):172-83. <https://doi.org/10.1111/j.1365-2788.2005.00732.x>
31. Duarte CS, Bordin IA, Yazigi L, Mooney J. Factors associated with stress in mothers of children with autism. *Autism* 2005; 9(4):416-27. <https://doi.org/10.1177/1362361305056081>
32. Baker-Ericzén MJ, Brookman-Frazee L, Stahmer A. Stress Levels and Adaptability in Parents of Toddlers with and without Autism Spectrum Disorders. *Research and Practice for Persons with Severe Disabilities* 2005; 30(4):194-204. <https://doi.org/10.2511/rpsd.30.4.194>
33. Mori K, Ujiie T, Smith A, Howlin P. Parental stress associated with caring for children with Asperger's syndrome or autism. *Pediatrics international : official journal of the Japan Pediatric Society* 2009; 51(3):364-70. <https://doi.org/10.1111/j.1442-200X.2008.02728.x>
34. Tobing LE, Glenwick DS. Relation of the childhood autism rating scale-parent version to diagnosis, stress, and age. *Res Dev Disabil* 2002; 23(3):211-23. [https://doi.org/10.1016/S0891-4222\(02\)00099-9](https://doi.org/10.1016/S0891-4222(02)00099-9)
35. Zablotsky B, Bradshaw CP, Stuart EA. The Association Between Mental Health, Stress, and Coping Supports in Mothers of Children with Autism Spectrum Disorders. 2013:1380-93.
36. Blacher J, McIntyre LL. Syndrome specificity and behavioural disorders in young adults with intellectual disability: cultural differences in family impact. *J Intellect Disabil Res* 2006; 50(Pt 3):184-98. <https://doi.org/10.1111/j.1365-2788.2005.00768.x>
37. McStay RL, Dissanayake C, Scheeren A, Koot HM, Begeer S. Parenting stress and autism: The role of age, autism severity, quality of life and problem behaviour of children and adolescents with autism. *Autism* 2014; 18(5):502-10. <https://doi.org/10.1177/1362361313485163>
38. Estes A, Olson E, Sullivan K, Greenson J, Winter J, Dawson G, et al. Parenting-related stress and psychological distress in mothers of toddlers with autism spectrum disorders. *Brain & development* 2013; 35(2):133-8. <https://doi.org/10.1016/j.braindev.2012.10.004>
39. Peters-Scheffer N, Didden R, Korzilius H. Maternal stress predicted by characteristics of children with autism spectrum disorder and intellectual disability. *Research in Autism Spectrum Disorders* 2012; 6(2):696-706. <https://doi.org/10.1016/j.rasd.2011.10.003>
40. Holroyd J, Brown N, Wikler L, Simmons JQ, 3rd. Stress in families of institutionalized and noninstitutionalized autistic children. *Journal of community psychology* 1975; 3(1):26-31. [https://doi.org/10.1002/1520-6629\(197501\)3:1<26::AID-JCOP2290030105>3.0.CO;2-Y](https://doi.org/10.1002/1520-6629(197501)3:1<26::AID-JCOP2290030105>3.0.CO;2-Y)
41. Orr RR, Cameron SJ, Dobson LA, Day DM. Age-related changes in stress experienced by families with a child who has developmental delays. *Mental retardation* 1993; 31(3):171-6.
42. Gray DE, Holden WJ. Psycho-social well-being among the parents of children with autism. *Australia and New Zealand Journal of Developmental Disabilities* 1992; 18(2):83-93. <https://doi.org/10.1080/07263869200034841>
43. Kuhlthau, Payakachat N, Delahaye J, Hurson J, Pyne JM, Kovacs E, et al. Quality of life for parents of children with autism spectrum disorders. *Research in Autism Spectrum Disorders* 2014; 8(10):1339-50. <https://doi.org/10.1016/j.rasd.2014.07.002>
44. Zablotsky B, Anderson C. The Association Between Child Autism Symptomatology, Maternal Quality of Life, and Risk for Depression. 2013:1946-55.
45. Gau SS-F, Chou M-C, Chiang H-L, Lee J-C, Wong C-C, Chou W-J, et al. Parental adjustment, marital relationship, and family function in families of children with autism. *Research in Autism Spectrum Disorders* 2012; 6(1):263-70. <https://doi.org/10.1016/j.rasd.2011.05.007>
46. Hartley SL, Barker ET, Seltzer MM, Floyd F, Greenberg J, Orsmond G, et al. The relative risk and timing of divorce in families of children with an autism spectrum disorder. *Journal of Family Psychology* 2010; 24(4):449-57. <https://doi.org/10.1037/a0019847>
47. Weitlauf AS, Vehorn AC, Taylor JL, Warren ZE. Relationship satisfaction, parenting stress, and depression in mothers of children with autism. *Autism: the international journal of research and practice* 2014; 18(2):194-8. <https://doi.org/10.1177/1362361312458039>
48. Osborne LA, McHugh L, Saunders J, Reed P. Parenting stress reduces the effectiveness of early teaching interventions for autistic spectrum disorders. *J Autism Dev Disord* 2008; 38(6):1092-103. <https://doi.org/10.1007/s10803-007-0497-7>
49. Ekas, Lickenbrock, Whitman. Optimism, social support, and well-being in mothers of children with autism spectrum disorder. *J Autism Dev Disord* 2010; 40(10):1274-84. <https://doi.org/10.1007/s10803-010-0986-y>
50. Orsmond GI, Lin L-Y, Seltzer MM. Mothers of Adolescents and Adults With Autism: Parenting Multiple Children With Disabilities. *Intellectual and Developmental Disabilities* 2007; 45(4):257-70. [https://doi.org/10.1352/1934-9556\(2007\)45\[257:MOAAA\]2.0.CO;2](https://doi.org/10.1352/1934-9556(2007)45[257:MOAAA]2.0.CO;2)
51. Bishop SL, Richler J, Cain AC, Lord C. Predictors of perceived negative impact in mothers of children with autism spectrum disorder. *American journal of mental retardation: AJMR* 2007; 112(6):450-61. [https://doi.org/10.1352/0895-8017\(2007\)112\[450:POPNI\]2.0.CO;2](https://doi.org/10.1352/0895-8017(2007)112[450:POPNI]2.0.CO;2)
52. Bromley J, Hare DJ, Davison K, Emerson E. Mothers supporting children with autistic spectrum disorders: social support, mental health status and satisfaction with services. *Autism* 2004; 8(4):409-23. <https://doi.org/10.1177/1362361304047224>
53. Lindsey RA, Barry TD. Protective Factors Against Distress for Caregivers of a Child with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders* 2018; 48(4):1092-107. <https://doi.org/10.1007/s10803-017-3372-1>
54. Weiss MJ. Harrdiness and social support as predictors of stress in mothers of typical children, children with autism, and children with mental retardation. *Autism* 2002; 6(1):115-30. <https://doi.org/10.1177/1362361302006001009>
55. Karst JS, Van Hecke AV. Parent and family impact of autism spectrum disorders: a review and proposed model for intervention evaluation. *Clinical child and family psychology review* 2012; 15(3):247-77. <https://doi.org/10.1007/s10567-012-0119-6>
56. Quittner AL, Glueckauf RL, Jackson DN. Chronic parenting stress: Moderating versus mediating effects of social support. *Journal of Personality and Social Psychology* 1990; 59(6):1266-78. <https://doi.org/10.1037/0022-3514.59.6.1266>

57. Croen LA, Najjar DV, Ray GT, Lotspeich L, Bernal P. A comparison of health care utilization and costs of children with and without autism spectrum disorders in a large group-model health plan. *Pediatrics* 2006; 118(4):e1203-11. <https://doi.org/10.1542/peds.2006-0127>
58. Heck KE, Makuc DM. Parental employment and health insurance coverage among school-aged children with special health care needs. *American Journal of Public Health* 2000; 90(12):1856-60. <https://doi.org/10.2105/AJPH.90.12.1856>
59. Kuhlthau, Perrin. Child health status and parental employment. *Archives of Pediatrics & Adolescent Medicine* 2001; 155(12):1346-50. <https://doi.org/10.1001/archpedi.155.12.1346>
60. Vivanti G, Prior M, Williams K, Dissanayake C. Predictors of outcomes in autism early intervention: why don't we know more? *Frontiers in pediatrics* 2014; 2:58. <https://doi.org/10.3389/fped.2014.00058>
61. Shepherd D, Csako R, Landon J, Goedeke S, Ty K. Documenting and Understanding Parent's Intervention Choices for Their Child with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders* 2018; 48(4):988-1001. <https://doi.org/10.1007/s10803-017-3395-7>
62. Brinker RP, Seifer R, Sameroff AJ. Relations among maternal stress, cognitive development, and early intervention in middle- and low-SES infants with developmental disabilities. *American journal of mental retardation : AJMR* 1994; 98(4):463-80.
63. Robbins FR, Dunlap G, Plienis AJ. Family Characteristics, Family Training, and the Progress of Young Children with Autism. *Journal of Early Intervention* 1991; 15(2):173-84. <https://doi.org/10.1177/105381519101500206>
64. Granger S, Rivières-Pigeon C, Sabourin G, Forget J. Mothers' Reports of Their Involvement in Early Intensive Behavioral Intervention. *Topics in Early Childhood Special Education* 2012; 32(2):68-77. <https://doi.org/10.1177/0271121410393285>
65. Todd S, Bromley J, Ioannou K, Harrison J, Mellor C, Taylor E, et al. Using Group-Based Parent Training Interventions with Parents of Children with Disabilities: A Description of Process, Content and Outcomes in Clinical Practice. *Child and Adolescent Mental Health* 2010; 15(3):171-5. <https://doi.org/10.1111/j.1475-3588.2009.00553.x>
66. Iadarola S, Levato L, Harrison B, Smith T, Lecavalier L, Johnson C, et al. Teaching Parents Behavioral Strategies for Autism Spectrum Disorder (ASD): Effects on Stress, Strain, and Competence. *Journal of Autism and Developmental Disorders* 2018; 48(4):1031-40. <https://doi.org/10.1007/s10803-017-3339-2>
67. Kaiser AP, Hancock TB. Teaching Parents New Skills to Support Their Young Children's Development. *Infants & Young Children* 2003; 16(1):9-21. <https://doi.org/10.1097/00001163-200301000-00003>
68. McConachie H, Diggle T. Parent implemented early intervention for young children with autism spectrum disorder: a systematic review. *Journal of Evaluation in Clinical Practice* 2007; 13(1):120-9. <https://doi.org/10.1111/j.1365-2753.2006.00674.x>
69. Matson ML, Mahan S, Matson JL. Parent training: A review of methods for children with autism spectrum disorders. *Research in Autism Spectrum Disorders* 2009; 3(4):868-75. <https://doi.org/10.1016/j.rasd.2009.02.003>
70. Tonge B, Brereton A, Kiomall M, Mackinnon A, King N, Rinehart N. Effects on Parental Mental Health of an Education and Skills Training Program for Parents of Young Children With Autism: A Randomized Controlled Trial. *Journal of the American Academy of Child & Adolescent Psychiatry* 2006; 45(5):561-9. <https://doi.org/10.1097/01.chi.0000205701.48324.26>