

---

## Mini Review

---

# Helping Families for Caring Children with Autistic Spectrum Disorders

Ahmad Ghanizadeh MD\*, Mohammad-Javad Alishahi MD\*,  
Hamid Ashkani MD\*

---

**Many families are directly involved in caring of their children with the lifelong autistic spectrum disorders. Sometimes, they are the victims of their children's behaviors.**

**The family, including siblings, may have to explain the children's behaviors to others. Their mothers have poorer mental health with difficulties in family adaptability and cohesion.**

**Its burden is not just limited to psychologic aspects but on the quality of life, economic aspects, and parent-child relationship.**

**This is a narrative review of some of the aspects that families of children with autistic spectrum disorders are facing.**

---

*Archives of Iranian Medicine, Volume 12, Number 5, 2009: 478 – 482.*

---

**Keywords:** Autism • autistic spectrum disorders • children

## Introduction

There is a dramatic increase in the incidence of autism from 1970s through 2008. This incidence increased from one in 10,000 before the 1970s to one in 150 in the last year.<sup>1</sup> This indicates that a considerable number of parents are directly involved in caring of the children with autism.<sup>2</sup> Furthermore, autistic spectrum disorders (ASD) are lifelong disorders that most of the families have to live and care their children on their own forever. In recent years, it is emphasized that these children should not be separated from their own families. Children with ASD are less adaptable.<sup>3</sup> Sometimes, the families have to explicate the reason or justify the behaviors of the children to others that it is not easy at all. A large amount of energy must be spent to make a balance between their needs and those of their children. This is not also an easy task. Authoritative parenting is weaker.<sup>4</sup> The parents are

usually really tired and depressed, showing their reactions among family and even in professional life.<sup>5</sup> They have to spend a lot of time with the child; so, they have less social contacts with the family members, relatives, and community. On occasion, the family is the victim of physical aggression of the children. Many of performance and behavior problems of children with ASD are preserved even with receiving proper health services.<sup>6</sup> Moreover, community understanding from the behavioral characteristics of children with ASD is limited or they do not understand it.<sup>7</sup>

The parents are worried more than control groups for their children's learning problems and being bullied by others.<sup>8</sup> There is an emphasis that the parents should be equipped to engage, communicate with, and teach their own children.<sup>9</sup> Also, counseling and helping such a family to regulate their deficits in different areas of the problem are recommended.<sup>10</sup>

## Siblings

Since siblings may provide opportunities for social interactions, the siblings of children with autism may also have an important role in this regards. The presence of a child with autism may have some unfavorable effects on the siblings.<sup>11</sup> Other kids in the family have stressful life

---

**Authors' affiliation:** \*Department of Psychiatry, Hafez Hospital, Shiraz University of Medical Sciences, Shiraz, Iran.

**•Corresponding author and reprints:** Ahmad Ghanizadeh MD, Department of Psychiatry, Hafez Hospital, Research center for Ssychiatry and Behavioral Sciences, Shiraz University of Medical Sciences, Shiraz, Iran.

Telefax: +98-711-627-93-19

E-mail: ghanizad@sina.tums.ac.ir

Accepted for publication: 1 June 2009

conditions.<sup>10</sup> Temperament profile including lower positive affect and higher negative affect differentiates children with ASD from non-ASD siblings and the control group.<sup>12</sup> ASD children with less behavioral problems have more positive affect and share activities with their brothers and sisters.<sup>13</sup> The siblings of these children may have more social and behavioral adjustment problems that last long for older ages.<sup>14</sup> The siblings of the children are facing precocious responsibility, feeling sorry, observing, and involving in scary behaviors. Even, their relationships with their friends are affected.<sup>10</sup> Also, the risk of developing internalizing behavior problems is higher in them.<sup>15</sup> They have less intimacy and nurturance than the control group.<sup>16</sup>

Higher parental support predicts higher positive affect in sibling relationships.<sup>13</sup> Sibling dissatisfaction from different parental care may compromise sibling relationship.<sup>17</sup> Training such parents can improve positive and decrease negative social interactions with the siblings.<sup>18</sup> Also, managing parenting stress improves the effectiveness of teaching interventions for the children.<sup>19</sup> So, these relationships should be strengthened and the family counseling of siblings is recommended.<sup>10</sup>

### **Mothers**

The mothers of children with ASD have poorer mental health than the general population.<sup>20</sup> The mothers have negative feelings<sup>21</sup> and the burnout effect of having such a child with ASD for the mothers is even stronger than the fathers.<sup>22</sup>

Less severe maladaptive behaviors and less social impairments of the child with ASD and also lower level of pessimism in the mothers predict more positive mother-child relationship.<sup>23</sup> The greater positive affect and warmth of mother-child relationship is associated with greater caregiving gains.<sup>23</sup> Meanwhile, the feeling of the mothers is related to the quality of their lives.<sup>24</sup> Those who have difficulties in family adaptability and cohesion<sup>25</sup> have higher levels of depressive symptoms and anxiety.<sup>25</sup>

### **Coping**

Couples with children suffering from ASD have more conflicts<sup>26</sup> and the family's quality of life should be improved.<sup>7</sup> The parents of children with ASD have somewhat lower marital happiness and family cohesion. In addition, their family adaptability is less than normal groups.<sup>7</sup> Moreover,

lower level of coping mechanism of family is related with higher level of stress and tension.<sup>22</sup> Parental coping does not differ with the age of the child with autism.<sup>27</sup> However, the coping strategies of the parents change over the time.<sup>28</sup> Aging of parents is associated with less coping through reliance on service providers, family support, social withdrawal, and individualism. They usually cope by their religious beliefs and some other emotion-focused strategies.<sup>28</sup> Acquiring social support is a coping strategy which is frequently used by the families and should be encouraged.<sup>29</sup> Coping style can moderate parental stress and it decreases the rate of negative outcomes such as depression, social isolation, and spousal relationship problems.<sup>30</sup> The parents of children with autism should be aware whether or not they are using healthy coping mechanisms. They need a social network support to be able to adjust themselves for their long and difficult journey of caring for the children.<sup>31</sup> Avoidance should be reduced and the use of positive coping strategies should be increased.<sup>27</sup>

### **Sleep**

Children with autism usually have sleep problems, mostly insomnia. Screening and management of their sleep problems improve family functioning.<sup>32</sup> The parents of children with autism suffer from greater sleep problems than those of typically developing children.<sup>33</sup> Sleep quality of the parents is poorer and their sleep quantity is lower than the parents of children without ASD.<sup>34</sup> Level of symptoms of these children is not related to the parents' sleep problems. However, children's sleep problems are in association with parents' sleep problems.<sup>33</sup>

### **Feeding problems**

Feeding problems and gastrointestinal disturbances are more common in these children and many of the parents might be worried about such problems.<sup>35</sup> Being a picky eater and resistance for trying new foods are more common in children with autism.<sup>36</sup> The parents should be trained about the management of these behaviors to decrease family stress.

### **Sensory problems**

Sensory impairments such as taste, smell, visual, and auditory processing problems are another features of some children with ASD.<sup>37,38</sup> Sometimes these impairments are not detected by

clinicians but they are reported by the parents.<sup>39,40</sup> For example, they are defensive to tactile or auditory stimulation.<sup>41</sup> The deficits of sensory motor gating might be associated with restrictive and repetitive behaviors.<sup>40,42</sup> Unfortunately, there are not enough empirical supports for effective treatments for some of these problems.<sup>41</sup> Implications for the presence of sensory problems in the children should be considered in parents' and families' counseling and management.<sup>43</sup>

### Quality of life

Quality of life of families with ASD children is seriously less than the other families.<sup>8</sup> In developed countries, the quality of life rather than a financial burden affects family members.<sup>44</sup> A study reported that the health-related quality of life of the mothers "but not the fathers" of children with high-functioning Asperger syndrome is impaired.<sup>45</sup>

### Economic aspect

The families of children with ASD usually have a lower level of income. They have to spend a part of their income on the child with ASD.<sup>46</sup> Their families more likely have financial problems and they need additional income for the costs of child's medical care. The families usually decrease work hours or stop it to care for the children. It is reported that the family have to spend many hours to receive care.<sup>47</sup> It should be noticed that the facilities and cares might not be available in some regions or cities, or all of the affected children might not have access to the mental health services. Most of the families who need for participation for psycho-educational early intervention program do not participate for the reasons such as a long waiting time.<sup>48</sup> The parents have to spend about 1000 hours each year for caring and supporting of the child with ASD.<sup>44</sup> Meanwhile, there is a discrepancy between different regions regarding policies and practices for the screening and care of the children.<sup>49</sup>

### Mental healthcare system

The burden of ASD is not just limited to the families but it also affects the society. Autism is associated with a higher rate of using childcare services that it seriously affects the employment of the parents.<sup>46</sup> Many of them will be unemployed.<sup>50</sup> The growing healthcare expenditures of children with ASD put a burden on mental health services. It threatens access of these children to the proper care.<sup>51</sup> Autism burden for lifetime per capita in the

USA is \$3.2 million, which is increasing.<sup>52</sup> This burden is even higher than the other disabled children groups.<sup>53</sup> Their annual mean number of total clinic visits, hospitalization, and the using of different medications such as psychotherapeutic medications are higher.<sup>54,55</sup> The cost for caring the children with ASD is more than twice of the children without ASD.<sup>54</sup> Therefore, "supported employment programs" and lifelong financial help should be planned not only for the children but also for the families and service providers.<sup>50</sup>

### Parent-child relationship

Higher quality of mother-child relationship such as maternal warmth and praise decreases internalizing and proceeds externalizing problems. It also diminishes impairments in social reciprocity and repetitive behaviors of the children.<sup>56</sup> The training of the parents of children with ASD improves their positive behavioral transactions with their children, increases satisfaction with their parenting, increases social interactions with their children, and decreases parenting stress and aggression.<sup>18</sup> Mothers who accepted the diagnosis of autism and resolved their emotion have a higher cognitive engagement and supportive engagement in play interactions with the children. In other words, their verbal and nonverbal communications with the children are enhanced and stabilize a greater reciprocity.<sup>57</sup>

### References

- 1 Cave SF. The history of vaccinations in the light of the autism epidemic. *Altern Ther Health Med*. 2008; **14**: 54 – 57.
- 2 Ghanizadeh A. A preliminary study on screening prevalence of pervasive developmental disorder in schoolchildren in Iran. *J Autism Dev Disord*. 2008; **38**: 759 – 763.
- 3 Hepburn SL, Stone WL. Using Carey Temperament Scales to assess behavioral style in children with autism spectrum disorders. *J Autism Dev Disord*. 2006; **36**: 637 – 642.
- 4 Rutgers AH, van Ijzendoorn MH, Bakermans-Kranenburg MJ, Swinkels SH, van Daalen E, Dietz C, et al. Autism, attachment, and parenting: a comparison of children with autism spectrum disorder, mental retardation, language disorder, and non-clinical children. *J Abnorm Child Psychol*. 2007; **35**: 859 – 870.
- 5 Benderix Y, Nordstrom B, Sivberg B. Parents' experience of having a child with autism and learning disabilities living in a group home: a case study. *Autism*. 2006; **10**: 629 – 641.
- 6 Montes G, Halterman JS. Characteristics of school-age children with autism. *J Dev Behav Pediatr*. 2006; **27**: 379 – 385.

- 7 Higgins DJ, Bailey SR, Pearce JC. Factors associated with functioning style and coping strategies of families with a child with an autism spectrum disorder. *Autism*. 2005; **9**: 125 – 137.
- 8 Lee LC, Harrington RA, Louie BB, Newschaffer CJ. Children with autism: quality of life and parental concerns. *J Autism Dev Disord*. 2008; **38**: 1147 – 1160.
- 9 Vismara LA, Colombi C, Rogers SJ. Can one hour per week of therapy lead to lasting changes in young children with autism? *Autism*. 2009; **13**: 93 – 115.
- 10 Benderix Y, Sivberg B. Siblings' experiences of having a brother or sister with autism and mental retardation: a case study of 14 siblings from five families. *J Pediatr Nurs*. 2007; **22**: 410 – 418.
- 11 Macks RJ, Reeve RE. The adjustment of non-disabled siblings of children with autism. *J Autism Dev Disord*. 2007; **37**: 1060 – 1067.
- 12 Garon N, Bryson SE, Zwaigenbaum L, Smith IM, Brian J, Roberts W, et al. Temperament and its relationship to autistic symptoms in a high-risk infant sib cohort. *J Abnorm Child Psychol*. 2009; **37**: 59 – 78.
- 13 Orsmond GI, Kuo HY, Seltzer MM. Siblings of individuals with an autism spectrum disorder: sibling relationships and wellbeing in adolescence and adulthood. *Autism*. 2009; **13**: 59 – 80.
- 14 Orsmond GI, Seltzer MM. Siblings of individuals with autism spectrum disorders across the life course. *Ment Retard Dev Disabil Res Rev*. 2007; **13**: 313 – 320.
- 15 Ross P, Cuskelly M. Adjustment, sibling problems, and coping strategies of brothers and sisters of children with autistic spectrum disorder. *J Intellect Dev Disabil*. 2006; **31**: 77 – 86.
- 16 Kaminsky L, Dewey D. Siblings relationships of children with autism. *J Autism Dev Disord*. 2001; **31**: 399 – 410.
- 17 Rivers JW, Stoneman Z. Child temperaments, differential parenting, and the sibling relationships of children with autism spectrum disorder. *J Autism Dev Disord*. 2008; **38**: 1740 – 1750.
- 18 Singh NN, Lancioni GE, Winton AS, Singh J, Curtis WJ, Wahler RG, et al. Mindful parenting decreases aggression and increases social behavior in children with developmental disabilities. *Behav Modif*. 2007; **31**: 749 – 771.
- 19 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**: 1092 – 1103.
- 20 Montes G, Halterman JS. Psychological functioning and coping among mothers of children with autism: a population-based study. *Pediatrics*. 2007; **119**: e1040 – 1046.
- 21 Monteiro CF, Batista DO, Moraes EG, Magalhães Tde S, Nunes BM, Moura ME. Maternal experiences in the reality of having an autistic son: an understanding for nursing. *Rev Bras Enferm*. 2008; **61**: 330 – 335.
- 22 Sivberg B. Family system and coping behaviors: a comparison between parents of children with autistic spectrum disorders and parents with non-autistic children. *Autism*. 2002; **6**: 397 – 409.
- 23 Orsmond GI, Seltzer MM, Greenberg JS, Krauss MW. Mother-child relationship quality among adolescents and adults with autism. *Am J Ment Retard*. 2006; **111**: 121 – 137.
- 24 Shu BC. Quality of life of family caregivers of children with autism: the mother's perspective. *Autism*. 2009; **13**: 81 – 91.
- 25 Orsmond GI, Lin LY, Seltzer MM. Mothers of adolescents and adults with autism: parenting multiple children with disabilities. *Intellect Dev Disabil*. 2007; **45**: 257 – 270.
- 26 Kelly AB, Garnett MS, Attwood T, Peterson C. Autism spectrum symptomatology in children: the impact of family and peer relationships. *J Abnorm Child Psychol*. 2008; **36**: 1069 – 1081.
- 27 Hastings RP, Kovshoff H, Brown T, Ward NJ, Espinosa FD, Remington B. Coping strategies in mothers and fathers of preschool and school-age children with autism. *Autism*. 2005; **9**: 377 – 391.
- 28 Gray DE. Coping over time: the parents of children with autism. *J Intellect Disabil Res*. 2006; **50**: 970 – 976.
- 29 Luther EH, Canham DL, Young Cureton V. Coping and social support for parents of children with autism. *J Sch Nurs*. 2005; **21**: 40 – 47.
- 30 Dunn ME, Burbine T, Bowers CA, Tantleff-Dunn S. Moderators of stress in parents of children with autism. *Community Ment Health J*. 2001; **37**: 39 – 52.
- 31 Lin CR, Tsai YF, Chang HL. Coping mechanisms of parents of children recently diagnosed with autism in Taiwan: a qualitative study. *J Clin Nurs*. 2008; **17**: 2733 – 2740.
- 32 Johnson KP, Malow BA. Sleep in children with autism spectrum disorders. *Curr Treat Options Neurol*. 2008; **10**: 350 – 359.
- 33 Lopez-Wagner MC, Hoffman CD, Sweeney DP, Hodge D, Gilliam JE. Sleep problems of parents of typically developing children and parents of children with autism. *J Genet Psychol*. 2008; **169**: 245 – 259.
- 34 Meltzer LJ. Brief report: sleep in parents of children with autism spectrum disorders. *J Pediatr Psychol*. 2008; **33**: 380 – 386.
- 35 Kodak T, Piazza CC. Assessment and behavioral treatment of feeding and sleeping disorders in children with autism spectrum disorders. *Child Adolesc Psychiatr Clin N Am*. 2008; **17**: 887 – 905, x-xi.
- 36 Lockner DW, Crowe TK, Skipper BJ. Dietary intake and parents' perception of mealtime behaviors in preschool-age children with autism spectrum disorder and in typically developing children. *J Am Diet Assoc*. 2008; **108**: 1360 – 1363.
- 37 Rogers SJ, Hepburn S, Wehner E. Parent reports of sensory symptoms in toddlers with autism and those with other developmental disorders. *J Autism Dev Disord*. 2003; **33**: 631 – 642.
- 38 Ghanizadeh A. Autism: is it all in the head? *Altern Ther Health Med*. 2009; **15**: 8; author reply 8.
- 39 Ben-Sasson A, Cermak SA, Orsmond GI, Tager-Flusberg H, Carter AS, Kadlec MB, et al. Extreme sensory modulation behaviors in toddlers with autism spectrum disorders. *Am J Occup Ther*. 2007; **61**: 584 – 592.
- 40 Ghanizadeh A. Is thermal regulation processing involved in the etiology of self injury of skin in autism? *Iran J Pediatr*. 2009; **19**: 81 – 83.
- 41 Ghanizadeh A. Does risperidone improve hyperacusia in children with autism? *Psychopharmacol Bull*. 2009; **42**: 108 – 110.
- 42 Perry W, Minassian A, Lopez B, Maron L, Lincoln A. Sensorimotor gating deficits in adults with autism. *Biol Psychiatry*. 2007; **61**: 482 – 486.

- 43 Ghanizadeh A. Should tactile sensation impairment be considered in pharmacotherapy of pervasive developmental disorders? A case report. *Neuro Endocrinol Lett.* 2008; **29**: 877 – 888.
- 44 Jarbrink K. The economic consequences of autistic spectrum disorder among children in a Swedish municipality. *Autism.* 2007; **11**: 453 – 463.
- 45 Allik H, Larsson JO, Smedje H. Health-related quality of life in parents of school-age children with Asperger Syndrome or High-Functioning Autism. *Health Qual Life Outcomes.* 2006; **4**: 1.
- 46 Montes G, Halterman JS. Child care problems and employment among families with preschool-aged children with autism in the United States. *Pediatrics.* 2008; **122**: e202 – e208.
- 47 Kogan MD, Strickland BB, Blumberg SJ, Singh GK, Perrin JM, van Dyck PC. A national profile of the health-care experiences and family impact of autism spectrum disorder among children in the United States, 2005 – 2006. *Pediatrics.* 2008; **122**: e1149 – e1158.
- 48 Birkin C, Anderson A, Seymour F, Moore DW. A parent-focused early intervention program for autism: who gets access? *J Intellect Dev Disabil.* 2008; **33**: 108 – 116.
- 49 Stahmer AC, Mandell DS. State infant/toddler program policies for eligibility and services provision for young children with autism. *Adm Policy Ment Health.* 2007; **34**: 29 – 37.
- 50 Järbrink K, McCrone P, Fombonne E, Zandén H, Knapp M. Cost-impact of young adults with high-functioning autistic spectrum disorder. *Res Dev Disabil.* 2007; **28**: 94 – 104.
- 51 Leslie DL, Martin A. Healthcare expenditures associated with autism spectrum disorders. *Arch Pediatr Adolesc Med.* 2007; **161**: 350 – 355.
- 52 Ganz ML. The lifetime distribution of the incremental societal costs of autism. *Arch Pediatr Adolesc Med.* 2007; **161**: 343 – 349.
- 53 Bebbington A, Beecham J. Social services support and expenditure for children with autism. *Autism.* 2007; **11**: 43 – 61.
- 54 Croen LA, Najjar DV, Ray GT, Lotspeich L, Bernal P. A comparison of healthcare utilization and costs of children with and without autism spectrum disorders in a large group-model health plan. *Pediatrics.* 2006; **118**: e1203 – e1211.
- 55 Liptak GS, Stuart T, Auinger P. Healthcare utilization and expenditures for children with autism: data from U.S. national samples. *J Autism Dev Disord.* 2006; **36**: 871 – 879.
- 56 Smith LE, Greenberg JS, Seltzer MM, Hong J. Symptoms and behavior problems of adolescents and adults with autism: effects of mother-child relationship quality, warmth, and praise. *Am J Ment Retard.* 2008; **113**: 387 – 402.
- 57 Wachtel K, Carter AS. Reaction to diagnosis and parenting styles among mothers of young children with ASDs. *Autism.* 2008; **12**: 575 – 594.