

Prioritizing Problem-Solving Strategies in Parents of Children with Autism Spectrum Disorder; Initial Report from the SMART Initiative, Shiraz, Iran

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Abstract

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The importance of education through interactive discussion-forums and seminars on family skills in coping with stress of having a child with Autistic Spectrum Disorder (ASD) seems to be under-attended. This prompted a local initiative entitled SMART (Shiraz Multidisciplinary Autism Research Team), to document the personal impact of autism on a preliminary group of parents and identify the correlates of stress and emotional well-being of having a child with ASD. Seventeen parents (11 mothers and 6 fathers) from 17 families who had a child with ASD volunteered to take part in the study. Each participant completed the general health questionnaire (GHQ-28). They were invited to an interactive forum during the 'Brain Awareness Week-2016', where they engaged in discussions and small-group activities to share and rank their top-ten challenges with regard to emotional well-being and family functioning as well as rating their child's autistic symptoms, including stereotyped behaviors. The practice was done through audience-response analysis and post-it note technique for individual counseling with interdisciplinary experts' supervision. Mothers had significantly higher scores than fathers on measures of stress and emotional well-being. Results identified that the poorer health was associated with more behavioral problems of the child. This narrow sample of Iranian parents showed to experience broadly similar responses to parents in other countries, which suggests that the impact of ASD may outweigh cultural disparities. Family counseling and education is planned to be strategized and attempted by SMART, based on the priority challenges documented in this sample group.

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Introduction

To date, most research with families who have a child with autism spectrum disorder (ASD) have been undertaken in English-speaking countries.

Moreover, the increased level of stress allied with poorer health has been commonly reported for mothers, with less attention paid to fathers. Today,

increasing number of children are being diagnosed with ASD worldwide(1-3). A growing body of research from Western countries has documented the impact these children have on their families, notably in terms of the stresses parents experience and their emotional wellbeing (4-7).

The purpose of this study was to investigate the same impact on a narrow sample of parents of ASD children from Shiraz, Iran. This investigation was practiced within a recent initiative introduced during the Brain Awareness Week, March 2016, entitled SMART (Shiraz Multidisciplinary Autism Research Team).

Significantly elevated levels of stress have been consistently reported across many different studies (8) including those involving large-scale populations(9). Mothers appear to show higher levels of stress than fathers, a difference that is less likely to arise with parents whose children have other developmental disabilities such as Down syndrome(10). However, the difference between mothers and fathers in levels of stress seems to become more pronounced as the child gets older as it is less apparent with newly diagnosed toddlers(11). However, as with other developmental disabilities, a clear relationship has been established between increased parental stress and the severity of behavioral problems demonstrated by children with ASD, such as conduct disorders(12). Moreover, there is evidence that parental stress and behavioral problems in children with ASD aggravate each other over time (13).

The emotional well-being of parents has also received attention. A meta-analysis of 18 studies identified a greatly increased risk of depression among mothers of children with developmental disabilities compared to those with typically developing children(3). Moreover, their depression scores were also significantly higher than those of mothers whose children had other developmental disabilities(14). Indeed, mothers bringing up children with autism reported poorer mental health in general(9,15) and those whose children exhibited higher levels of behavioral problems experienced significant psychological distress(16). The emotional well-being of fathers has received less consideration with no differences reported between parents of toddlers(11), whereas studies reported that mothers were significantly more depressed than fathers. Likewise, mothers but not fathers who are caregivers of school-age children with ASD, were at increased risk of poorer health although the differences were more apparent with physical illnesses(14,17).

A small number of studies have explored the

relationship between parental stress and emotional well-being in which increased stress is associated with poorer emotional health(3). Furthermore, research found that stress proliferation over time accentuated parental depression. Few studies have investigated the inter-relationship between mothers and fathers in terms of stress and emotional well-being(17,18).

Studies have suggested that stress is an important predictor of family functioning and various reports have identified the role of social support within families in moderating maternal stress(17,19). Moreover, low levels of support have been shown to predict depression and anxiety in mothers and to result in higher ratings of a negative impact of the child on family life(18)

The present study aimed to investigate the similar variables both in a preliminary sample of mothers and fathers of children with ASD in, Shiraz Iran. Information about the impact on parents would assist with the development of more family-centered support services within SMART and possibly the whole country. In addition, the study would further confirm if ASD has a consistent impact on parental well-being. As such we attempted to: 1- document the extent of parental stress, emotional well-being and family support for a preliminary sample of parents of ASD children; 2- contrast the impact of a child with ASD on mothers and on fathers as the latter in particular have often been neglected in past studies and play a particularly significant role in Iranian society; and 3- identify for this sample the variables that are associated with parental stress and emotional well-being, notably the child's behaviors and level of functioning, the mutual supports within families.

Method

- Enrollment

The following inclusion criteria were used in recruiting families. The child had a confirmed diagnosis of ASD and was aged between 3 and 19 years; the parents currently lived with their child and they were resident in Fars Province. Initial recruitment was through a notice by SMART within the Fars-branch of the Iranian Autism Society distributed to parents. In all, 30 parents who expressed an interest, were contacted by telephone and briefed more about the discussions, educational forum, workshop and the related study.

Eventually, 17 parents (11 mothers and 6 fathers) from 17 families who had a child with ASD volunteered to take part in the study. From the participants, over half lived in privately owned

accommodation (n = 9: 53%) and others in rented accommodation or lived with families. In most families, the primary caregiver was the mother (n = 14: 84%) while others reported that it was shared equally with mothers and fathers.

- **Measures**

The GHQ-28 (General Health Questionnaire by Goldberg & Williams 1991) was employed to gather data on parents' physical symptoms, anxiety and sleep disorders, social function and depressive symptoms. This is a 28-item questionnaire recommended for screening the assessment of psychiatric morbidity that has been translated into Persian and the reported Cronbach's alpha for the Iranian population was 0.85(20). A higher score is indicative of poorer health with a score of 7 and above seen as the threshold that warrants further investigation. Example items include: 'been feeling run down and out of sorts', 'lost much sleep over worry', 'been taking longer over the things you do' and 'felt that life isn't worth living'.

The basic demographic information was gathered on the parents using a structured questionnaire.

- **Procedure**

The attendees were invited to an interactive forum where they engaged in discussions and small-group activities to share and rank their top-ten challenges with regard to emotional well-being and family functioning as well as rating their child's autistic symptoms, including stereotyped behaviors. The practice was done through audience-response analysis and post-it note technique for individual counseling with interdisciplinary experts' supervision(21). All participants completed the GHQ-28 and demographic questionnaires (20). They provided informed consent allowing the use of their input in the present and further analyses. Descriptive and analytical assessments were done using the MedCalc statistical package v. 16.8.

Results

Comparisons of mothers and fathers

Table 1 summarizes the means and SDs for the subscales and global score in GHQ-28. As such, the mothers as a whole rated themselves as having significantly poorer health than fathers (Table 2). All participants had scores that were above the cut-off of 7. During the small-group discussions and post-it affirmation practice, some participants commented:

[Mother #3] I think that I have lost my energy and I need some type of medications. [Father #8] Sometimes I felt pain but generally I ignore it. I must be healthy because of my family and daughter.

Mothers also had significantly higher scores in terms of parenting stress and more mothers scored above the median than fathers did. Two mothers commented. [Mother #10] declared: "I have stress. I blame myself because of my son's late diagnosis". [Mother #13] commented: "I have stress because of my child. I cannot pretend that her future will be normal".

A father observed: [Father #2] How can you stop being worried when you know that your child is in trouble and you cannot do anything. I love my son but I do not know how to help him. My wife is a fulltime mother now but all that she can do is to bring him to different clinics, we even tried acupuncture (based on one of the other parent's suggestion) which was useless for him.

Another father [Father #8] commented: I'm not too much stressed. I have to accept the problem.

It is possible that parental ratings of their health and stress may be significantly related to other variables that could be confounded with gender. These included educational level, whether or not parents were in employment, parental age, if both parents and not just mothers were involved in caring for the child, the child's age and number of children in the family and if they had a relative living with them.

In addition, characteristics of the children were also correlated with parental ratings of health and stress as noted previously. There may also be differences between those parents who participated as couples and those who took part singly.

In order to control for these possible confounding variables, stepwise binary logistic regressions analyses were undertaken based on the cut-off scores for poorer health.

The resulting model was significant with five significant predictors. Poorer health was nearly five times more likely to occur for parents whose children showed stereotyped behaviors, four times more likely with mothers than fathers, nearly four times more likely for those parents who had not attended university, 3.5 times more likely if parents were stressed and three times more likely if the child had lower autism index scores.

Table1. General health measures and related subscales in mothers and fathers of children with autistic spectrum disorder

Participant	Physical symptoms	Anxiety and Sleep Disorders	Social functions	Depressive symptoms	Sum
1	6	7	14	0	27
2	7	4	7	4	22
3	9	13	6	5	33
4	8	12	8	1	29
5	6	5	9	0	20
6	4	9	9	8	30
7	8	9	6	3	26
8	5	7	5	1	18
9	2	8	11	6	27
10	13	13	5	12	43
11	7	10	7	1	25
12	4	6	7	1	18
13	8	9	9	3	29
14	5	6	16	1	28
15	2	3	12	1	18
16	5	6	7	8	26
17	4	6	6	12	28
Mean	6.2	8.06	8.7	3.1	26.2
M±SEM	6.2±0.73	8.06±0.79	8.7±0.84	3.1±0.87	26.2±1.7

Table2. The comparison of general health measures between mothers and fathers of children with autistic spectrum disorder

Rating scales	Mothers (n = 11)	Fathers (n = 6)	Sample t test
General health			
Mean (SD)	29.63 (7.7)	20.16 (5.9)	$t = 4.46, P < 0.001$
times above cut-off of 7	4.23	2.88	$C^2 = 10.5, P < 0.001$

The other variables noted above such as age of child, parental employment and participant couples were not significant. Table 1 demonstrates means and standard errors of mean scores for mother and fathers on measures of general health and its subscales. Table 2 demonstrated the differences between mother and fathers.

Comments

The insights emerged from the present study in two-fold. First, in common with findings from other countries, Iranian mothers seem to report increased stress and poorer health arising from parenting a child with ASD. Fathers' health is also affected although not to the same extent as mothers. However, in comparison with two previous studies that have used the same measure of stress, our sample had a higher overall stress scores than

Japanese parents of young people with ASD(22) and Lebanese parents of children with intellectual disabilities(23). In part this could be an artefact of the recruitment strategies used in our study. Parents who are more stressed may be more eager to participate in a study if they felt it could be of benefit to them.

A second issue relates to the correlates of poorer health experienced by Iranian parents in addition to the stresses of parenting. As previously reported in the literature, mothers reported poorer health more so than fathers(14). In addition, higher levels of stereotyped behaviors shown by their child result in poorer health and indirectly increase parental stress, a well-established finding across various cultures and different developmental disabilities(24).

An underlying rationale for undertaking this particular study was to gain an insight into the personal supports that Iranian families may require if they have a child with ASD. Or instance, given the high scores obtained with regard to parents' anxiety and sleep disorders, the SMART initiative conducted a workshop focusing on "How to improve sleep in ASD children and their parents" few weeks after the initial discussion forum.

International experience suggests that the strains of caring for a child can be alleviated through use of particular coping strategies such as problem-focused coping and that parental predisposition to use certain coping strategies may mediate the cultural differences reported among parents(25). Nevertheless, our understanding remains limited as to how parents from diverse cultural backgrounds can be guided in their use of coping strategies, although the provision of accurate information regarding the child's condition and advice on managing the child's behaviors at home are likely to be important ingredients. Further research into the coping strategies of Iranian parents of ASD children would be beneficial in this respect.

Conclusion

Family counseling and education efforts for parents of children with ASD would potentially better be strategized and attempted based on the priority challenges documented in the present sample group.

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