

The impact on Iranian mothers and fathers who have children with an autism spectrum disorder

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Abstract

Background To date, most research with families who have a child with autism spectrum disorder (ASD) has been undertaken in English-speaking countries. Increased levels of stress allied with poorer health have been commonly reported for mothers, with less attention paid to fathers. This study aimed to document the personal impact on Iranian mothers and fathers and identify the correlates of increased stress and poorer emotional well-being.

Method In all, 103 parents (58 mothers and 45 fathers) from 74 families who had a child with ASD volunteered to take part in the study. Each participant completed through interview, standardised rating scales of parenting stress, emotional well-being and family functioning as well as rating their child's autistic symptoms, including stereotyped behaviours.

Results Mothers had significantly higher scores than fathers on measures of stress and emotional well-being. Although these variables were highly correlated, binary logistic regression identified that the poorer health was also associated with lower educational levels of the parents, more behavioural problems with the child and fewer autistic symp-

toms overall. A similar regression analysis of stress scores identified no gender differences but found that lower stress was associated with mothers and fathers who were joint caregivers and when the family lived with relatives.

Conclusions Iranian parents experience broadly similar responses to parents in other countries, which suggests that the impact of ASD outweighs any cultural differences that might otherwise be present in parental responses to caring for children. In common with families internationally, these parents are likely to benefit from opportunities to become better informed about ASD and the management of their child at home allied with increased support from families and friends.

Keywords autism spectrum disorder, health, Iran, parents, stress

Introduction

Throughout the world, increasing numbers of children are being diagnosed with autism spectrum disorders (ASD) (Fombonne 2009; Xiang & Carrie 2010). 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 well-being. The purpose of this study is to investigate if this holds for mothers and fathers from other cultures, in this instance Iran.

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Significantly elevated levels of stress have been consistently reported across many different studies (Pisula 2011) including those involving large-scale populations (Montes & Halterman 2007). 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 (Dabrowska & Pisula 2010). 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 (Davis & Carter 2008). But as with other developmental disabilities (e.g. Hastings 2002), a clear relationship has been established between increased parental stress and the severity of behaviour problems exhibited by the child with ASD, such as conduct disorders (Tomanik *et al.* 2004; Lecavalier *et al.* 2006). Moreover, there is evidence that parental stress and behavioural problems in children with ASD aggravate each other over time (Benson & Karlof 2009).

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 (Singer 2006). Moreover, their depression scores were also significantly higher than those of mothers whose children had other developmental disabilities (Olsson & Hwang 2001). Indeed, mothers bringing up children with autism reported poorer mental health in general (Montes & Halterman 2007) and those whose children exhibited higher levels of behavioural problems experienced significant psychological distress (Bromley *et al.* 2004). The emotional well-being of fathers has received less consideration with no differences reported between parents of toddlers (Davis & Carter 2008) whereas Olsson & Hwang (2001) reported that mothers were significantly more depressed than fathers. Likewise, Allik *et al.* (2006) found that 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.

A small number of studies have explored the relationship between parental stress and emotional well-being. Not surprisingly, increased stress is

associated with poorer emotional health (e.g. McConkey *et al.* 2008). Furthermore, Benson & Karlof (2009) found that stress proliferation over time accentuated parental depression. Few studies have investigated the inter-relationships between mothers and fathers in terms of stress and emotional well-being although research conducted by Hastings (2003) is a notable exception. He reported that fathers' mental health contributed to maternal stress but the converse did not hold.

More broadly, Smith *et al.* (2010) suggested that stress is an important predictor of family functioning and various studies have identified the role that social support within families can play in moderating maternal stress (Dempsey *et al.* 2009). Low levels of support have been shown to predict depression and anxiety in mothers (Boyd 2002) and to result in higher ratings of a negative impact of the child on family life (Bishop *et al.* 2007). Altire & von Kluge (2009) proposed that better cohesion within families resulted in more positive coping strategies.

To date nearly all these research studies have been undertaken with predominantly middle-class, English-speaking, White parents who had access to a range of professional supports for their child (Singer 2006). The applicability of the findings to parents in other societies around the world cannot be assumed (Ghosh & Magana 2009). The concept of disability differs across cultures as does the way in which children's behaviours are construed (Cho *et al.* 2003). Moreover, societal influences may affect the way parents appraise the stressors they experience and their styles of coping (Dyches *et al.* 2004). For example, Latina mothers in the USA reported lower levels of stress and better psychological well-being than non-Latina mothers caring for youth or adults with autism (Magana & Smith 2006). By contrast, Taiwanese parents of youth and adults with ASD had higher levels of depression compared to USA mothers, which the authors attributed to differences in coping strategies (Lin *et al.* 2011). These studies have prompted a growing appreciation of the need in Western countries to adjust family support services to the eco-culture of immigrant families (Welterlin & LaRue 2007), an argument that carries even greater weight when it comes to developing services in non-Western societies (Samadi & McConkey 2011). These need to reflect

the values and cultures of the society and families (Crabtree 2007).

Nonetheless, several recent studies in Japan (Mori *et al.* 2009), Malaysia (Norizan & Shamsuddin 2010) and Turkey (Bilgin & Kucuk 2010) have reported similar findings to those noted for Western countries, namely high levels of stress among mothers whose children had developmental disabilities such as ASD and Down syndrome which were exacerbated by the child's behaviours and by maternal depression. Similarly, a cross-cultural comparison of Irish, Taiwanese and Jordanian mothers found that problem behaviours exhibited by the child were correlated with poorer maternal well-being and stress (McConkey *et al.* 2008).

Mother–father differences have been rarely studied although Rimmerman *et al.* (2003) reported no differences between Israeli mothers and fathers in levels of child-related stress, a finding also confirmed by Azar & Badr (2010) with Lebanese parents of children with intellectual disabilities (ID). However in both studies, access to informal support was associated with less stress, particularly with mothers, a relationship also endorsed with Arab mothers of children with ID living in Northern Israel (Duvdevany & Abboud 2003) and by the reports from Turkish mothers as to how they coped with stress arising from a child with ASD (Bilgin & Kucuk 2010).

The present study aimed to add to the international literature by focussing on both mothers and fathers of children with ASD in Iran. Iranian society is distinct from other Islamic societies of the Middle-East and Central Eurasia in terms of its long history of civilisation, its geographical location, separate language (Persian) and religious denomination (Shia Muslim). Information about the impact on parents would assist with the development of more family-centred support services within Iran and possibly with Iranian immigrants in Western countries (Welterlin & LaRue 2007). In addition, the study would further confirm if ASD has a consistent impact on parental well-being across cultures.

Hence, the specific aims of the study were:

- to document the extent of parental stress, emotional well-being and family support for a sample of families drawn from a distinct culture that has not been previously studied;

- to 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
- to identify for this sample the variables that are associated with parental stress and emotional well-being, notably the child's behaviours and level of functioning, the mutual supports within families and overall ratings of family functioning.

Method

Recruitment

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 Tehran city so as to facilitate travel to the family home. Initial recruitment was through a notice distributed to all parents whose children attended six special schools for ASD children and through three mother and child clinics in the city. In all, 55 parents expressed an interest and they were contacted by telephone and told more about the study. Twelve parents subsequently declined to participate citing various reasons such as lack of time, poor health and uncertainty as to whether or not their child had ASD. In addition, an advertisement about the study appeared in a local magazine with contact details for the first researcher. This yielded 100 enquiries from different cities around Iran from which 60 parents who met the inclusion criteria of living in Tehran were recruited.

In all, 103 parents from 74 families who had a child with ASD took part in the study: 29 couples (both mothers and fathers), 29 mothers only and 16 fathers only.

The sample

Parents

Of the 103 parents who volunteered to participate, 58 (56%) were mothers and 45 (44%) fathers. Nearly all were married ($n = 98$: 95%) but five single mothers (5%) were also included. Two-thirds ($n = 69$) were Fars and one-third ($n = 34$) were from other ethnic backgrounds of which the most

common was Turkish. All were Muslim. Over half lived in privately owned accommodation ($n = 57$: 55%) and others in rented accommodation ($n = 38$: 37%) or lived with families ($n = 8$: 8%). In all, 18 (17%) had another dependent living with them such as grandparent and 33 (32%) had a relative living nearby. In most families, the primary carer was the mother ($n = 87$: 84%) but others reported that it was shared equally with mothers and fathers ($n = 16$: 16%).

Over half of the parents ($n = 53$: 51%) were university educated with no differences between mothers and fathers. However, significantly more fathers ($n = 26$: 58%) were aged 40 years and over than were mothers ($n = 18$: 31%) ($\chi^2 = 7.4$: d.f. 1; $P < 0.01$). Also fathers ($n = 44$: 98%) were more likely than mothers ($n = 18$: 31%) to be in paid employment ($\chi^2 = 47.1$; d.f. 1; $P < 0.001$).

Only limited comparisons could be made between the sample and national data on the Iranian population as reported by the Iranian Statistical Centre (http://amar.sci.org.ir/index_e.aspx). The most striking difference was in terms of university education with over half the parents (51%) in the sample having attended university compared to the national average of around 13%. Also a higher proportion of mothers (31%) were in employment compared to an estimated 13% nationally. The proportion of non-Fars in the present sample (34%) tended to be higher than the national figure of 25% and fewer parents in the sample (55%) lived in privately owned accommodation compared to 73% nationally.

Children

As 29 married couples participated in the study, this meant that 74 children with ASD were included in the sample. For school-age children the diagnosis had been made by special education experts in the Iranian Special Education Organisation trained in administering the Persian version of the Autism Diagnostic Interview – Revised (ADI-R) (Le Couteur *et al.* 2003; translated by Sasanfar & Toloie 2006). The ADI-R takes the form of a structured interview with parents and consists of 93 items arranged in three functional domains: Language/Communication; Reciprocal Social Interactions and Restricted, Repetitive, and Stereotyped Behaviors and Interests. A Chronbach alpha of 0.85 (for

present behaviours) was reported for the Iranian version. The test–retest reliability on a sample of 33 children with a 4- to 6-week interval was 0.99 for items relating to unusual social interaction, 0.99 for language and communication and 0.96 for repetitive and stereotyped behaviours.

Clinicians (usually paediatricians) in the mother and child clinics had made the diagnosis for the eight pre-school children in the sample.

Of the 74 children, 59 (80%) were boys and 15 (20%) were girls. Their ages ranged from 3 to 19 years with a mean of 7.4 years. One-third ($n = 35$) were only children and 60 (58%) had one or two sibling(s) with only eight (7.8%) having three or more siblings. Around half of the children ($n = 38$: 51%) attended a special unit; 21 (29%) went to a special school and seven (8%) to a mainstream school or nursery. The remainder were too young for school ($n = 8$: 11%).

Measures

Three scales used in international research with families were selected.

General Health Questionnaire (Goldberg & Williams 1991)

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 (calculated on a 751-member sample) was 0.85 (Homan 1998). The calculated Cronbach's alpha in the present study was 0.91. 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 Short Form of the Parenting Stress Index

This is a 36-item short version of the full Parenting Stress Index (PSI) (Abidin 1983). The total stress score on the Short Form of the Parenting Stress Index (PSI-SF) provides an indication of the overall level of parenting stress a parent is experiencing. The short-form score has a 0.94 correlation with

the total stress score of the full-length PSI, an internal consistency coefficient alpha of 0.91, and a test-retest reliability coefficient of 0.84 over a 6-month retest interval was reported (Abidin 1983). In this study Cronbach's alpha was 0.87. Higher scores indicate higher parent stress levels. Those parents whose scores fell above the 99 percentile were rated as highly stressed. Example items include: 'since having this child, I have been unable to do new and different things', 'sometimes I feel my child doesn't like me and doesn't want to be close to me' and 'my child gets upset easily over the smallest thing'.

Family functioning (Epstein et al. 1983)

This scale is taken from the McMaster Family Assessment Device. It consists of 12 items: six of which describe unhealthy functioning and six healthy functioning (such as the way that family members deal with a problem inside the family). A Cronbach's alpha of 0.92 is reported for the English version of this scale although in the present sample it was 0.83. Higher scores are indicative of better family functioning. Example items include: 'planning family activities is difficult because we misunderstand each other', 'we do not get along well together' and 'we express our feelings to each other'.

Parents were also asked to complete the *Gilliam Autism Rating Scale – Second Edition (GARS-2)* (Gilliam 2006) for their child as a means of checking on the children's present autistic behaviours. This is a behaviour checklist developed for use with children and youth aged 3 to 22 years. The scale consists of three sub-scales: Stereotyped Behaviors, Communication and Social Interaction, which are combined into a standard score called the 'autism index' with higher scores indicative of ASD symptoms (based on a normative sample of 1107 individuals with ASD and 328 non-ASD persons and those with other developmental disabilities). Coefficients of reliability (internal consistency and test-retest) for the sub-scales and autism index range from 0.80 to 0.90. In this study Cronbach's alpha was 0.85 for all three sub-scales and 0.77 for the behavioural sub-scale. An autism index can be calculated for each child and scores ranged from 63 to 131 with a median score of 100. Based on US norms, scores of 85 and over indicate that the child

'very likely' has autism and 81% of children ($n = 59$) in the sample fell into this category with a further 13 having scores in the 'likely' range of 70 to 84. Only one child had a score under 70 which indicates that autism is 'unlikely'. However, later reviews of GARS suggest that the indicative scores for autism should be set lower than those recommended in US norms (South *et al.* 2002).

As well as using the autism index score, the raw scores of the stereotyped behaviours were also used in these analyses; the scores ranged from 5 to 41 with a median score of 20.

The Parenting Stress Index, family functioning scale and GARS-2 were translated from English into Persian by the first author with back-translations by bilingual speakers experienced in disability to check on the accuracy of the translation and the relevance to Iranian society. Only a few adjustments were needed to items to make them more culturally appropriate.

Finally, basic demographic information was gathered on the parents and children using a structured questionnaire.

Procedure

The first author arranged by telephone a convenient time to visit the family. Information sheets were prepared in Persian that described the aims of the study and assured parents of anonymity and confidentiality. Contact details for the researcher were provided. If parents were agreeable to participate, a consent form was signed and a copy left with the family.

Most of the interviews were conducted by the first author in the family home ($n = 71$) but one family wanted to be interviewed in their child's school and two fathers preferred to be interviewed in a hotel lobby. The maximum return trip was 80 km. Overall 29 mothers only and 16 fathers only were present, with both mothers and fathers present in 29 instances. The rating scales were given to the parents and if they requested, the questions were read to them along with the choice of answers. In addition, parents were asked to talk in their own words about their health, feelings of stress and family communication. A conversational style was adopted and prompts used to encourage parents to provide a richer account. At the end of the inter-

view parents were free to comment and ask any further questions. An information sheet had been prepared to leave with families that gave details of services for children with ASD in Tehran and details of websites where families could get further information. They were also informed about the possibility of taking part in a short course on ASD to be provided by the first author (see later).

Data analysis

As the sample included mothers and fathers of the same child, the following precautions were taken in the data analyses reported below. Comparisons were first made to ascertain if the data obtained from couples were significantly different from those obtained by single respondents of each gender and in the case of the regression analyses, a variable to this effect was included in the analyses.

Results

Comparisons of mothers and fathers

Table 1 summarises the means and SDs for the mothers and fathers on the three chosen measures of health, stress and family functioning. On all three measures there were no significant differences within each gender between parents who participated as couples and those who took part singly. However, the mothers as a whole rated themselves as having significantly poorer health than fathers. Over four out of five mothers and over half of the fathers had scores that were above the cut-off. In the interviews one mother commented:

[M.33] I think that I have lost my energy and I need some type of medications.

And a father said:

[F.6] 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.

[M.9] I have stress. I blame myself because of my son's late diagnosis.

[M.15] I have stress because of my child. I cannot pretend that her future will be normal.

A father observed:

[F.83] 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.

But another father stated:

[F.17] I'm not too much stressed. I have to accept the problems.

By contrast there were no significant differences between mothers and fathers in terms of parental

Rating scales	Mothers (n = 58)	Fathers (n = 45)	Statistical tests
General health			
Mean (SD)	15.4 (7.7)	9.2 (5.9)	$t = 4.46, P < 0.001$
% above cut-off of 7	82.8%	53.3%	$\chi^2 = 10.5, P < 0.001$
Parenting stress			
Mean (SD)	121.5 (17.0)	110.2 (17.6)	$t = 3.29, P < 0.001$
% above 99 percentile	58.6%	35.6%	$\chi^2 = 5.4, P < 0.05$
Family functioning			
Mean (SD)	26.2 (5.8)	27.5 (5.7)	$t = 1.18, NS$
% above median	48.3%	55.6%	$\chi^2 = 0.54, NS$

Table 1 Means and standard scores for mother and fathers on measures of parental well-being

ratings of family functioning. Both genders reported positive as well as negative aspects as to how the family functions.

[M.32] My husband ignores things and does not accept his mistakes. I will apologise and he will accept. It is always like this. Our discussion will never come to a conclusion or compromise. He is much too serious, there is no use in discussing with him, it always turn out to be a real quarrel. He is so stubborn but I love him and I love our relationship.

[F.24] We just let the time solve the problem; we do not talk about the problem. We have no energy to waste upon family issues.

[F.26] I have given up; I talk about the problem but let my wife take the final decision.

[M.61] I have stopped talking to my husband just to stop more misunderstandings. Fortunately I have my elder son whom I can talk to and share my pain and sorrows, although he is preparing himself for the university entrance exam.

Inter-relationships among the measures

The inter-relationships among the parental rating scales are shown in Table 2 along with two measures relating to the children's autism. This was first done for mothers and fathers separately. As the pattern of correlations was similar, the two genders were combined and the resulting correlations are shown in Table 2.

The correlation between general health and parental stress was highly significant. But parental stress scores and health scores were not correlated with family functioning. When children showed stereotyped behaviours, parents' health was poorer

and their stress tended to be higher. However, there were no significant relationships between the extent of the child's autistic symptoms and parental ratings of health, stress or family functioning.

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 as Table 3 shows although the confidence intervals are wide given the relatively small sample. Poorer health was nearly five times more likely to occur for parents whose children showed stereotyped behaviours, 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. The other variables noted above such as age of child, parental employment and participant couples were not significant.

A similar stepwise binary logistic regression was also conducted contrasting parents whose stress scores were above the 99 percentile for the Parent-

	Parental stress	Family functioning	Autism index	Stereotyped behaviours
General health	0.589**	-0.141	0.277**	0.263**
Parental stress		-0.186	0.069	0.277**
Family functioning			-0.110	-0.128
Autism index				0.187

Table 2 The inter-correlations between parental scales and child measures ($n = 103$)

* $P < 0.05$, ** $P < 0.01$.

Table 3 Variables related to the poorer parental health

Variable	P	Corrected odds ratio
Child's behaviours		
Below median scores (reference)		1.00
Above median scores	0.009	4.756
Parent gender		
Male (reference)		1.00
Female	0.010	4.140
Parent education		
Attended university (reference)		1.00
Did not attend university	0.028	3.783
Parent stress		
Lower stress		1.00
Higher stress (over 99 percentile)	0.024	3.529
Autism index scores for child		
High autism index (reference)		1.00
Low autism index	0.052	3.058

$n = 103$. Hosmer and Lemeshow test 4.25, d.f. 8, $P < 0.836$; Nagelkerke $r = 0.466$, $\chi^2 = 41.06$, d.f. = 5, $P < 0.001$.

Table 4 Variables related to the higher parental stress

Variable	P	Corrected odds ratio
Parental health		
Below cut-off (reference)		1.00
Above cut-off	0.001	7.890
Family living arrangements		
Lives with extended family (reference)		1.00
Lives as nuclear family	0.011	4.808
Child's primary carer		
Both parents (reference)		1.00
Mothers only	0.018	4.631

$n = 103$. Hosmer and Lemeshow test 3.030, d.f. 2, $P < 0.219$; Nagelkerke $r = 0.340$, $\chi^2 = 29.45$, d.f. = 3, $P < 0.001$.

ing Stress Index (see Table 4). In this model, the main predictors of stress were non-university education (4.6 times more likely to have elevated stress), living alone rather than with relatives (4.5 times) and the child's stereotyped behaviours (4.3 times). However, when parental health grouping was added to the model, this became the main predictor of stress in that parents who had poor health were nearly eight times more likely to have elevated stress scores. However, parental education and children's

behaviours were no longer significant, which suggests that these variables are more closely associated with parental health than they are with parenting stress. However, living alone remained significant and mothers as the primary carers (rather than both parents) was now also significant. Hence, these two variables are more linked with stress than with health. Parental gender was not significantly associated with stress.

As a summary, Fig. 1 illustrates the parental and child characteristics that were predictive of poorer health and greater stress and includes the accompanying odds ratios.

Discussion

Three main conclusions can be drawn from these findings. First, in common with findings from other countries, Iranian mothers report increased stress and poorer health arising from parenting a child with ASD. Fathers' health is similarly affected although not to the same extent as mothers.

However, in comparison with two previous studies that have used the same measure of stress – the Parenting Stress Index – Iranian mothers and fathers had higher overall stress scores than Japanese parents of young people with ASD (Mori *et al.* 2009) and Lebanese parents of children with ID (Azar & Badr 2010). In part this could be an artefact of the recruitment strategies used in this 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. Equally though, it could reflect the relative dearth of support available to Iranian parents compared to other countries.

A second conclusion 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 (e.g. Olsson & Hwang 2001). In addition, higher levels of stereotyped behaviours shown by their child result in poorer health and indirectly increase parental stress, a well-established finding across various cultures and different developmental disabilities (e.g. Norizan & Shamsuddin 2010; Manning *et al.* 2011). However, Iranian parents who had university education reported better health, a common finding in inter-

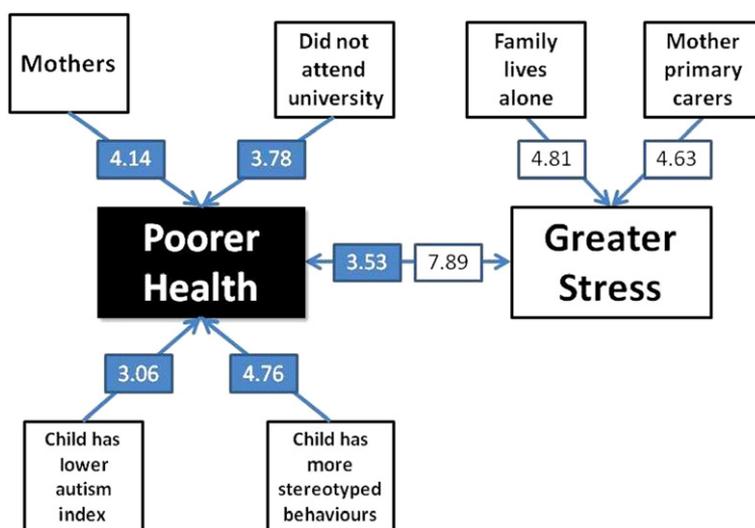


Figure 1 The predictor variables with corrected odds ratio related to poorer parental health and greater stress.

national studies (e.g. Emerson *et al.* 2006). Such parents are also likely to have increased access to information about autism through the Internet and books that less educated parents lack (Samadi *et al.* 2011).

Rather surprisingly, parents whose children had fewer autism traits as measured by the autism index scores also rated their health as poorer. Indeed, somewhat similar findings have been reported by Mori *et al.* (2009) in that Japanese mothers and fathers of young people with Asperger's syndrome had higher stress levels than parents whose children had more marked forms of autism. This variation may derive from the ambiguities parents experience when their child has milder forms of ASD and as to how they should respond to their more unusual traits. Further studies are needed to understand more fully the mutual impact of children's behaviours and parental well-being.

A third conclusion to emerge from this study is that certain variables may accentuate or moderate parental stress separately from health ratings. Parents who lived with extended families and parents both of whom were involved in the care of the child reported lower stress scores although neither of these variables influenced parental health ratings. This concurs with previous international research into the importance of intra-family support with Japanese families (Mori *et al.* 2009) or more

broadly the availability of informal supports for Lebanese (Azar & Badr 2010) and UK families (Bromley *et al.* 2004). Moreover, single parenting has been linked with higher stress (e.g. Norizan & Shamsuddin 2010) although this was not the case in the present study possibly due to the small number of single parents who were recruited.

More puzzling is the lack of relationship in these data between family functioning and parental measures of stress and emotional well-being reported in other studies (e.g. McConkey *et al.* 2008; Lin *et al.* 2011). It could be that the chosen measure of family functioning may not have been sufficiently sensitive to detect differences among the parents and certainly the qualitative comments reported by some mothers especially bear out the added stress they experienced from poor communication within the family.

A number of further cautions need to be expressed with regard to the study. A self-selected sample of better educated parents drawn mainly from the capital city was recruited and these findings may not be representative for all Iranian families who have a child with ASD. However, it is conceivable that less educated families living in more rural areas may show even poorer health and higher levels of stress based on the findings from this sample. But these shortcomings also serve to highlight the caution that needs to be exercised when comparing results from studies undertaken in

different countries (Hatton 2004). Equally international understanding of the impact of ASD on families would be greatly facilitated by studies that endeavoured to obtain more representative samples of parents, ensured that common criteria were used to assess the children's autism and utilised common measures of parental stress, emotional well-being and family functioning along with pertinent demographic data. Even so this study is further confirmation that children with ASD adversely affect their parents' well-being irrespective of their cultural background and to a greater extent than for other developmental disabilities.

Finally, 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. International experience suggests that the strains of caring for a child can be alleviated through use of particular coping strategies such as problem-focussed coping (e.g. Dabrowska & Pisula 2010) and that parental predisposition to use certain coping strategies may mediate the cultural differences reported among parents (Lin *et al.* 2011). Nevertheless, our understanding remains limited as to how parents from diverse cultural backgrounds can be guided in their use of coping strategies (Ghosh & Magana 2009), although the provision of accurate information regarding the child's condition and advice on managing the child's behaviours at home are likely to be important ingredients (Samadi *et al.* 2011). Further research into the coping strategies of Iranian parents would be helpful.

Families across all cultures also seem to benefit from greater access to formal and informal supports (Manning *et al.* 2011) and notably opportunities for parents to learn from one another (Singer 2006). Given the professional culture and practices in Iran, it is a particular challenge to provide such family-centred services but a recent study has shown how improved parental well-being and better family functioning resulted from a seven-session, group-based course for parents and these changes were sustained up to 12 months later particularly from parents who maintained contact with one another after the course (McConkey & Samadi 2012). Hence, a priority for professionals in health and educational services in Iran, and indeed internationally, is to become better informed about ASD and

the ways in which they can support parents to achieve better health and well-being.

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