A national study of the prevalence of autism among five-year-old children in Iran

Sayyed Ali Samadi, Ameneh Mahmoodizadeh and Roy McConkey

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Sayyed Ali Samadi
Institute of Nursing Research, University of Ulster, Newtownabbey, Northern Ireland, UK

Ameneh Mahmoodizadeh
Iranian Special Education Organization, Tehran, Iran

Roy McConkey
Institute of Nursing Research, University of Ulster, Newtownabbey, Northern Ireland, UK

Abstract
In Iran, more than 1.3 million five-year olds have been screened for autism over three academic years, with the Social Communication Questionnaire (SCQ). The Autism Diagnostic Interview-Revised (ADI-R) is used to confirm a diagnosis of typical autism. The resulting prevalence of 6.26 per 10,000 for typical autism is in line with rates for certain countries but is lower than those reported recently for some Western nations. This may be due to the younger age range assessed but the suitability of the tools and aspects of Iranian culture could be other reasons for the lower prevalence. International comparisons of prevalence rates is fraught with difficulties, but it is a valuable endeavour as it can identify issues around cultural and societal perceptions of children's development.

Keywords
autism spectrum disorder, Iran, prevalence, typical autism

The prevalence of autism spectrum disorders (ASD) in children has risen steadily in Japan, USA and the European countries over the past three decades. Fombonne (2009) suggests that the best estimates based on recent surveys for ASD is 60 to 70 per 10,000, with 20 per 10,000 a conservative rate for an autistic disorder.

Corresponding author:
Sayyed Ali Samadi, School of Nursing, University of Ulster, Newtownabbey BT37 0QB, Northern Ireland, UK.
Email: samadi-s@email.ulster.ac.uk

However, these figures mask a striking variation in reports across countries. For example, in the systematic review of 40 prevalence studies of ASD by Williams et al. (2006), even those recent studies that used the same International Classification of Diseases (ICD)-10 criteria reported rates per 10,000 for autistic disorder of 3.8 in Norway, 5.4 in France and 5.6 in Finland through to a high of 60 per 10,000 in Sweden. A similar variation was evident in rates for all ASD of 5.2 in Norway to 83 per 10,000 in the UK. However a more recent and thorough study based in London reported a prevalence of 38.9 per 10,000 for autistic disorders and that of other ASD at 77.2 per 10,000 making the total prevalence of all ASD 116.1 per 10,000 (Baird et al., 2006).

Moreover, differences in prevalence is reported within countries even when ascertainment method, age group and reporting period are similar. In the USA, the prevalence of all ASD in eight-year-old children varied across 11 sites from 42 per 10,000 in Florida to 121 per 10,000 in Arizona and Missouri (Autism and Developmental Disabilities Monitoring Network, 2009). Using special education data on students with ASD, Coo et al. (2008) reported a prevalence of 43.1 per 10,000 among four- to nine-year-old school children in the Canadian province of British Colombia, whereas in Quebec Fombonne et al. (2006) reported a prevalence of less than half this at 21.6 per 10,000.

In an attempt to understand the reasons for the variation across countries, Williams et al. (2006) undertook regression analyses and found that diagnostic criteria used, age of child when identified, country of origin and urban/rural location of the sample, all significantly influenced the reported ASD rates.

Nearly all the prevalence studies reviewed by Fombonne (2005, 2009) and Williams et al. (2006) were undertaken in developed countries. Thus, to date, there is limited information on the identification of children with this condition in less affluent countries in which services for children with special needs are less developed. Fombonne (2005) reported only one non-Western study from Indonesia, which stated a prevalence of 11.7 per 10,000 for ASD within a birth cohort born between June 1984 and May 1991 (Wignyosumarto et al., 1992).

A subsequent study in China with 7345 children aged two to six years, also reported a prevalence of 11.0 per 10,000 children for autistic disorder (Zhang and Ji, 2005) whereas Wong and Hui (2008), using government population statistics for ASD, noted an estimated five-year incidence of 7.9 per 10,000 for children under five years in Hong Kong in the period 2001to 2005. However in those years, there was an overall incidence in excess of 25 per 10,000 among all children younger than 15 years old.

In a recent study in Iran, Ghanizadeh (2008) tried to estimate the prevalence of pervasive developmental disorders such as ASD in Shiraz, a major city in a central province of Iran. An eight-item, self-completion questionnaire derived from the *Diagnostic and Statistical Manual of Mental Disorders* (DSM)-IV was devised and responses sought solely from the parents of a population sample of 1680 school children aged seven to 12 years (mean = 9.1 years). A prevalence rate of 190 per 10,000 was found. This is nearly three times as high as that reported in some Western countries. But as the author noted, the checklist covered ASD-like behaviours that overlap with other types of developmental disorder. Moreover the rates were not different between males and females which is very different from other studies, in which boys tend to outnumber girls by four to one. Therefore the very high rate may have been due to parents reporting unusual behaviours that overlap with features of ASD.

Difficult though it may seem, there are several reasons for obtaining information on the identification of children with ASD in different countries and cultures. First, it can alert governments to the need to adapt or extend education and other services to meet the particular needs of these children and their families in line with the population requirements. Second, international comparisons

of prevalence may confirm the extent to which the identification of this condition is affected by cultural influences (Williams et al., 2006) as well as aetiological factors or a combination of both. To date, studies on cultural factors and ASD have received little attention (Matson and Kozlowski, 2011). Third, suitable procedures for identifying children with this condition in particular cultures can be tested rather than presuming that assessment tools developed in other countries will be adequate in all settings (Greenfield, 1997).

This paper describes the procedures adopted in Iran to screen five-year-old children for ASD prior to school entry and reports the findings from the first three years of operations. Using data obtained from the national screening programme, the prevalence of suspected ASD identified at the screening stage and for those given a confirmed diagnosis of autistic disorder based on Autism Diagnostic Interview-Revised (ADI-R) criteria can be compared. Based on the analyses, the paper identifies implications for refinements to the screening programme, which could be followed up in further research. The Iranian experiences and data obtained may have implications for screening programmes in other countries.

Methods

Iranian national screening programme for special needs

In 1993, a compulsory national screening programme started in Iran for all five- to six-year-old children whose parents wanted to register them in the first grade of elementary school (Iranian Special Education Organization (ISEO), 2006). The screening of children is done by a general physician and a health professional, who assess the children's physical health, height and weight, vision and hearing plus a dental check. An educational counsellor evaluates children's school readiness using a specially devised scale called 'The First Step'. Each assessor sees every individual child. All the information obtained is recorded in a 'Health Identification Booklet', which parents must show for their child to be enrolled in school (primary schooling is free for all children in Iran). This information aims to help schools provide for the children's health and educational needs. However, children with special educational needs are referred to special schools.

The screening programme attempts to cover children of all backgrounds within a locality, namely all ethnic and religious groups, and all urban and rural children. In 2005 there were 749 centres at which the screening took place. The programme operated from June to the end of July (for 60 days) in 560 cities (ISEO, 2006). Further evaluation and diagnosis continued between August and the end of November. Screening for autism was added to the programme in 2005 but only in the major cities of 18 provinces. By 2009, 24 provinces had been included in the programme. These provinces were chosen because the capital city had at least one special school to accept children with autistic disorder and had trained personnel available to undertake the assessments (at least two trained experts for administering the ADI-R). Thus six provinces are currently outside the national screening programme for autism plus the many children who live outside the major cities in the 24 provinces in which screening occurs. Nonetheless, as Table 1 shows, around 40% of five-year-old children have been screened for autism, a total of 1.32 million over the past three years.

Methods used for screening and assessment of autism

The screening of children for autism is undertaken using an Iranian translation of the Social Communication Questionnaire (SCQ) (Rutter et al., 2003, translated by Sasanfar and Ghadami, 2006). The SCQ is a 40-item, parent-report questionnaire that rates the child on characteristic

autistic behaviours derived from the ADI-R (see below). The reported Cronbach's alpha coefficient for the Iranian sample was 0.82, based on sample of 712 children aged six to 13 years (Sasanfar and Ghadami, 2006), which is acceptable but lower than the alpha of 0.90 reported for the English scale. Each item is scored 0 or 1 with total scores ranging from 0 to 39. (Note: the first item is a language screening question that is not included in the total score.) Nineteen items rate current behaviour and 20 rate behaviour when the child was four to five years old. The recommended cut-off score for an ASD or pervasive developmental disorder is ≥15. Children who score above the cut-off are referred for further assessment. A study by Chandler et al. (2007) with samples of British children with special needs, with ASD and from the general population, confirmed the utility of the SCQ as a first-level screen with at-risk, school-age children and it was also used by Baird et al. (2006) in their population study in London.

The Persian version of the ADI-R (Le Couteur et al., 2003, translated by Sasanfar and Toloie, 2006) is used by the special education experts in ISEO to assess children who screened positive on the SCQ. The ADI-R is administered in the form of a semi-structured interview with the child's primary caregivers and covers the child's early and current development. It is based on both ICD-10 and DSM-IV criteria for autistic disorder. Most of the items ask about a condition that is displayed currently or if it ever has occurred. The interviewer uses the caregiver's descriptions of the child to code the behaviour on a scale from 0 to 3, with 0 being absence of behaviour and 3 representing extreme severity. The criteria for a diagnosis of autistic disorder were followed, namely that when the child's scores in the three domains of communication, social interaction and patterns of behaviour meet or exceed the specified cut-offs, and that onset of the disorder is evident by 36 months of age.

The test–retest reliabilities of ADI-R range from 0.97 to 0.93 (Cicchetti et al., 2008). The Persian version of this scale was standardized in 2005 on a sample of 209 children aged four to 14 years. The reported Cronbach's alpha for the Iranian sample was 0.86 for the diagnostic part which asks questions about the child's previous behaviours, whereas 0.85 has been reported for the child's current behaviours (Sasanfar and Toloie, 2006). However the training provided in Iran is not as extensive as that recommended in the West.

Training for staff undertaking screening and assessments

The testing and evaluation department of the ISEO provides annual training sessions and workshops in screening and diagnosis for autism for professionals working in the evaluation centres. In addition, psychological and therapy staff from the professional assessment clinics in the provinces participated in the screening programme. The training is of two to three days' duration and covers theoretical and practical aspects of undertaking screening assessments.

When the screening results in a suspected ASD, the child is referred for further assessment, which is undertaken by special education experts from ISEO's testing and evaluation department who have received training in psychological assessment for developmental disabilities. At present, 60 professionals from 24 provinces have been trained in the use of the Persian version of the ADI-R for the diagnosis of autistic disorders in the programme. In the three-year period from 2006 to 2009, over 3000 children were referred for further assessment, 76% of whom were boys (see Table 1). Of these, a total of 826 children aged five years were assessed as having autistic disorder, of whom 81% were boys (see Table 1). These children were then referred to special schools for such pupils or to other special schools for children with different types of disability, which have a special class for students with autism. Information was not available on those children who had screened positive on SCQ but had not been given a diagnosis of autistic disorder on ADI-R.

Data gathered

The total number of the students screened for autism in the 24 provinces during June to November of three academic years (2006–07; 2007–08; 2008–09) was collected from the Ministry of Education's annual report booklet. Information on suspected cases in whom the SCQ was positive ($n = 3181$) and the identified cases of autistic disorder by ADI-R ($n = 826$) from the screened group was obtained from records held by the ISEO's department of evaluation. These data were cross-checked with the ISEO's evaluation departments in the participating capital cities of the different provinces via fax and telephone, and later double checked when further information on the gender of the students was obtained.

Findings

Table 1 summarizes data on the boys and girls who were screened for autism: both the number and prevalence of children who were identified by the SCQ screening and those who were diagnosed as having autistic disorder using ADI-R. The information is presented separately for three academic years as well as for the three-year period from 2006 to 2009.

As Table 1 shows, out of 1.32 million five-year-old Iranian children who went through the screening programme for autism in the three academic years from 2006 to 2009, 3181 (24.09 per 10,000) were suspected as having autism, but the number of the children subsequently given a diagnosis of autistic disorder by means of ADI-R was around a quarter of this total ($n = 826$ (6.26 per 10,000)). Comparison of the prevalence across the three years suggests a reduction of numbers in 2007–08 compared with the other two years. The reasons for this are not clear and data from screenings in future years may help to identify the extent of variation in prevalence rates across years.

In all three years, more boys than girls were suspected as having autism or were diagnosed with it. The proportion of around 4:1 is comparable with studies in other countries. A similar distribution is also noted in the prevalence for boys and girls, with an average for boys of close to 10 per 10,000 but of 2.4 per 10,000 for girls.

In Table 2, the variation in prevalence between the less- and well-developed provinces in Iran is presented over the three-year period. Although there are no official criteria for the socio-economic classification of provinces and cities in Iran, an informal classification into less and well developed is possible based on available educational and health services data, geographical location, and levels of unemployment and industrialization as reported by the Iran Statistic Centre in its statistical yearbook (2008). The less-developed provinces are located in border areas and, except for Fars Province, generally represent ethnic minorities such as Turkish, Balouchi, Gilak and Arabs, whereas the more developed provinces are generally located in the central part of Iran. Moreover the screening programme for autism commenced in the more developed provinces because of their geographical proximity to the capital city of Iran (Tehran) and their ease of accessibility for training and supervision of screening personnel. Indeed the six western and eastern border provinces that are still not included in the screening programme are also among the less-developed provinces.

As Table 2 shows, the prevalence of children assessed as having ASD is twice as high in the more developed provinces (8.81 per 10,000) than in the less-developed provinces (3.88 per 10,000); a finding also found in other countries as noted by Williams et al. (2006). However, the rates of those identified by the SCQ are not so different between the two groups and the overall numbers of children participating in the screening programme were broadly comparable across the two groups of provinces.

Table 1. The number of children screened for autism in Iran and the estimated rates for all children and for girls and boys from 2006 to 2009

	2006–2007			2006–2008			2006–2009			2006–2009 combined totals		
	Total	Girls	Boys	Total	Girls	Boys	Total	Girls	Boys	Total	Girls	Boys
Total number of five-year-old children in Iran	1,215,325	586,593	628,732	1,156,503	560,157	596,346	1,164,448	564,930	599,518	3,536,276	1,711,680	1,824,596
Total number screened for autism (% of total)	443,333 36.5%	212,312 36.1%	231,021 36.7%	451,202 39%	220,348 39.3%	230,854 38.7%	425,799 36.6%	208,973 36.9%	216,826 36.1%	1,320,334 37.3%	641,633 37.5%	678,701 37.2%
Number suspected to have autism by SCQ (% total children suspected)	1266	368 29%	898 71%	766	168 22%	598 78%	1149	234 20%	915 80%	3181	770 24%	2411 76%
Autism suspected as a proportion per 10,000 screened	28.55	17.33	38.87	16.97	7.62	25.90	26.98	11.19	42.19	24.09	12	35.52
Confidence interval (95%)	27.01– 30.17	15.61– 19.20	36.37– 41.49	15.80– 18.22	6.52– 8.87	23.87– 28.06	25.45– 28.59	9.81– 12.73	39.51– 45.02	23.26– 24.94	11.17– 12.88	34.12– 36.97
Number identified by ADI-R (% total children identified)	324	64 20%	260 80%	231	55 24%	176 76%	289	56 19%	233 81%	826	157 19%	669 81%
Proportion per 10,000 screened identified as autism by ADI-R	7.30	3.01	11.25	5.11	2.49	7.62	6.78	2.67	10.74	6.26	2.44	9.86
Confidence interval (95%)	6.53– 8.15	2.32– 3.85	9.93– 12.71	4.48– 5.82	1.88– 3.25	6.54– 8.84	6.05– 7.62	2.02– 3.48	9.41– 12.22	5.84– 6.70	2.08– 2.86	9.12– 10.63

ADI-R: Autism Diagnostic Interview-Revised, SCQ, Social Communication Questionnaire.

Table 2. Estimated rates of prevalence in Iran according to the division of the provinces into more and less developed (2006 to 2009; per 10,000)

	More developed Provinces[a] (n = 11)	Less developed Provinces[b] (n = 13)
Total number of children screened	636,472	683,862
Number with suspected autism by SCQ	1,611	1,570
Proportion per 10,000 screened	25.31	22.95
Confidence interval (5%)	24.09–26.58	21.84–24.12
Identified autism by ADI-R	561	265
Proportion per 10,000 identified	8.81	3.88
Confidence interval (5%)	8.10–9.57	3.42–4.37

[a]Central and Eastern provinces: that is, Tehran, Qom, Qazvin, Zanjan, Yazd, Esfahan, Semnan, Hamadan, Markazi, Razavi Khorasan, South Khorasan.
[b]Northern, Western and Southern provinces: that is, Ardabil, East Azarbayjan, Gilan, Mazandaran, Golestan, Kermanshah, Ilam, Lorestan, Chahrmahal va Bakhtiari, Fars, Kerman, Hormozgan, Khuzestan.
ADI-R: Autism Diagnostic Interview-Revised, SCQ, Social Communication Questionnaire.

Finally, it is possible to estimate the likely numbers of children with autistic disorder in Iran by applying each year's gender-specific ASD prevalence estimate to that year's population of boys and girls. This suggests that more than 2500 children aged five to seven years will have an autistic disorder.

Discussion

Few, if any, countries screen children for ASD to the same extent as in Iran. This screening is done as part of a national Iranian screening programme linked with school entry, hence it is obligatory on families to participate, although to date the screening for autism has involved approximately 40% of five year olds nationally, but a much higher proportion of those living in the major cities. The prevalence of 6.26 per 10,000 for five year olds assessed by ADI-R criteria for autistic disorder over the three-year period is similar to that previously reported for certain European countries and for Hong Kong, as noted earlier. Hence this study challenges the assumption made by some authors that autism is rare in non-Western cultures (e.g. Dyches et al., 2004; Zhang et al., 2006). Nonetheless, the rates obtained for Iran in the present study are much lower than those reported for Sweden (Kadesjo et al., 1999), the USA (Bertrand et al., 2001) and England (Baird et al., 2006), with rates of up to 40 per 10,000 for children with autistic disorder. Likewise, the prevalence of all ASD based on the SCQ screening is also much lower than those reported in more developed countries (i.e. 35 per 10,000 compared with 121 per 10,000 in the USA (Autism and Developmental Disabilities Monitoring Network Principal Investigators, 2009).

A variety of factors might explain the lower prevalence of autism in less-developed countries such as Iran. In Iranian culture, a diagnosis of disability is likely to be seen as stigmatizing (Samadi, 2008). When parents are keen for their child to attend a mainstream school rather than being referred to a special school, they may under-report the child's difficulties to assessors even though they are aware of them. The screening tools that are used in Iran rely heavily on parental reports, with limited time and opportunity for assessors to observe and interact with the child and for them to make consensus decisions (Baird et al., 2006). By contrast, in Western countries parents may be eager to obtain a diagnosis for their child's difficulties as this enables them to access additional services, which are not readily available in Iran.

A second reason for the lower prevalence rates in the present study is that children who have associated conditions such as intellectual disabilities and epilepsy may have been diverted from educational services at an earlier age and therefore are not included in the screening for pupils enrolling in elementary schools. In addition, childhood mortality among the more severely affected children may be greater, especially in poorer areas (Hosseinpoor et al., 2005). All these factors would reduce the prevalence of ASD compared with Western countries with more developed health and education services.

Different child-rearing practices, and adult tolerance of and expectations around children's behaviours, could also be other reasons for the difference in the prevalence rates of autism noted above. Iranian culture and families might be more tolerant of behaviours in children that in Western societies may be seen as 'abnormal'. DeGiacomo and Fombonne (1998) found that the most common parental concerns were for delay in speech and language development, followed by abnormal signs of socio-emotional behaviour and medical problems or delay in reaching milestones. In contrast, Daley (2004) reported that Indian parents rated social difficulties such as lack of interest in people, poor eye contact and showing no interest in playing with other children as their primary concern.

Also the environmental influences that trigger ASD-like behaviours in children may differ among different cultures. Seo (1992, cited in Weru, 2003) compared three groups of children with ASD from South Korean, Korean American and American backgrounds to explore the influences of culture with reference to the behaviours of autism. She found differences in social impairments and developmental disturbances between the South Korean and American children. She concluded that these differences might have been the result of differences in symptoms rather than just the result of parental perception.

The foregoing discussion has implications for the assessment of autism in different cultures. It is possible that the screening tool used in Iraq (the SCQ) is not sensitive enough to pick up cues for autism in children living within an Iranian culture and this may also apply to the ADI-R. As Triandis (1995, cited in Greenfield, 1997) noted, when cultures are very dissimilar, different assessment methods may have to be used in each culture. An ongoing study is analysing the ADI-R item data (on which SCQ is based) on 250 Iranian children to establish if any behaviours are less commonly found in Iranian parental reports compared with British samples with a diagnosis of autistic disorder and to track the extent to which these items are also included in the SCQ (Samadi et al., unpublished data). This may result in a screening tool for autism that is more sensitive to Iranian culture. Moreover, Iranian assessors may benefit from more extensive training in the use of ADI-R.

Further research is also required into the sensitivity and specificity of the SCQ as a screening tool in a general population of five year olds as its previous use has been with children perceived to have a high risk for ASD (e.g. Chandler et al., 2007). For example, the programme only assesses on the ADI-R those children scoring 15 or above on the SCQ and the sensitivity of the scale needs to be evaluated with respect to this cut-off. A random sample of children who screen on SCQ at just below the threshold for ASD (e.g. scores of 13 and 14) should be assessed using ADI-R in order to check for false negatives. In addition children who screened as positive on SCQ but who were not given an ADI-R diagnosis, should be followed up in school to monitor their subsequent development and the presence of Asperger's syndrome or other pervasive developmental disabilities not otherwise specified (PDD-NOS). As yet the ISEO has not developed services for children with these conditions, and these children are generally mixed with other students with special needs or they attend mainstream schools with little or no extra support. Moreover, there could be a case for delaying or repeating the screening for ASD when the child is older (Williams et al., 2006). In this instance teachers could be trained to undertake screening to identify and refer children for diagnostic assessment.

Nonetheless, the Iranian data replicates two findings from the international literature: namely the much higher prevalence of ASD among boys and in more developed, urban areas. The latter finding is often attributed to greater availability in urban areas of better trained professionals who are more skilled in assessing children for ASD along with better access to child development services such as clinics, preschools and therapeutic services than is the case in less developed and rural regions (Mandell and Palmer, 2005). Parental literacy may also be a factor. As the Iranian screening programme is extended to other provinces and into rural areas, these factors may need particular attention if uniform screening and assessment procedures are to be established nationally. Moreover, assessors from different disciplines should have opportunities to observe and interact with the children as part of the diagnostic process so as reduce the current reliance on parental reports.

A strength of the Iranian procedures is that changes in prevalence rates can be monitored over time. It is too early as yet to determine any trends although there was some variation in prevalence year by year but this may represent a statistically insignificant variation.

Conclusions

A national screening programme for autism in Iran over a three-year period identified a prevalence of 6.26 per 10,000 for autistic disorder, which is comparable with rates reported for some countries but lower than recent estimates in more developed countries. Various reasons are given as to why the Iranian figure may be an under-estimate. However, further research is needed into cultural influences on parental perceptions of children's difficulties and how screening and assessment tools should be adapted to allow for this and to ensure comparability with procedures used in other countries.

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