

Autism awareness and attitudes towards treatment in caregivers of children aged 3–6 years in Harbin, China

Jia Wang · Xue Zhou · Wei Xia · CaiHong Sun ·
LiJie Wu · JianLi Wang

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Abstract

Objective To (1) estimate the proportion of people in the community who could correctly recognize autism spectrum disorders (ASD); (2) describe the attitudes towards various treatments for ASD; and (3) identify factors associated with ASD recognition.

Methods A population-based cross-sectional survey was conducted in Harbin, China ($n = 4,947$). We estimated the proportions of participants who were at different levels of knowledge about ASD and of their attitudes towards mental health service use. Multivariate logistic regression modeling was used to identify factors associated with the recognition of ASD.

Results Overall, 2,786 (57.8%) of the respondents could recognize the ASD. Recognition of autism depended on gender, residing areas, age and educational levels. With respect to the attitudes towards mental health service use for ASD, 4,007 respondents (84.6%) chose to visit a health organization for treatment; 2,470 (68.2%) made the choice of consulting a psychotherapist.

Conclusions There is a large room for improvement in awareness about ASD and treatment in the Chinese communities. Insufficient knowledge about ASD and inappropriate attitudes towards mental health service use may impede the efforts of early identification and intervention.

Health education and promotion are needed to improve people's knowledge about ASD and available mental health services.

Keywords Awareness · Attitudes · Autism spectrum disorders · Caregivers

Abbreviations

ASD Autism spectrum disorders
OR Odds ratio
CI Confidence interval

Introduction

Autism is a neurodevelopmental disorder that has initial onset during infancy or childhood, and usually follows a predetermined course without remission [1, 2]. It is characterized by impairments in social interaction and communication, and restricted interests and repetitive behaviors [2, 3]. Autism had been considered as a rare condition. However, epidemiological studies have found that the prevalence of autism has increased substantially, from 4 to 5 per 10,000 in 1960s to approximately 1–2% today [4–10]. The increase in the estimated prevalence may be due to many reasons including changes in diagnostic practice and differences in survey methodology [11–13].

Autism was first reported in China in 1982. Since then, the number of children with autism spectrum disorders (ASD) has been increasing. Because relevant monitoring system is not available in China, the prevalence of ASD at the national level is unknown. Several regional studies reported relatively low prevalence, including 1.10 per 1,000 in Tianjin (2004) [14], 1.25 per 1,000 in Jiangsu

J. Wang · X. Zhou · W. Xia · C. Sun · L. Wu (✉)
Department of Children's and Adolescent Health, Public Health
College of Harbin Medical University, 157 Baojian Road,
Nangang District, Harbin 150086, People's Republic of China
e-mail: wljhyd@ems.hrbmu.edu.cn

J. Wang
Departments of Psychiatry and of Community Health Sciences,
Faculty of Medicine, University of Calgary,
Calgary T2N 4Z6, Canada

Province (2001) [15], 1.34 per 1,000 in Beijing (2007) [16] and 2.27 per 1,000 in Harbin City (2010) [17]. It was estimated that there were about 7.8 million individuals with ASD in China in 2008 [18]. However, the prevalence could have been underestimated, since there were no specific surveillance network or case registries for autistic children in China.

ASD can benefit from interventions that may improve developmental trajectories and outcomes. Many studies showed that early intervention for ASD children aged 3–6 years could improve their communication and social skills [19–21]. Early identification and intervention is the key for better outcome. However, the length of time from parent's first notice of autistic symptoms to the time of diagnosis is relatively long, leading to delayed diagnosis and treatment. For example, several studies found that parents noticed autistic symptoms of their children as early as 6–18 months of age. However, they did not seek professional assessment for diagnosis until the children were 3–6 years old [21, 22]. Other studies suggested that the average length of delay for diagnosis was 4 years [19, 23]. Similarly, our study in Heilongjiang Province of China found that the average age of receiving a diagnosis in children with ASD was 3.91 years, and the mean time of delay for diagnosis was 14 months [24]. Therefore, it is important to improve the process of early diagnosis and referral for intervention. Early diagnosis is critical for earlier intervention, appropriate education planning, and the arrangement of family support services [21]. However, early identification and intervention will largely depend on parents' or caregivers' knowledge and awareness about ASD and their attitudes towards treatments.

Jorm's [25] Mental Health Literacy model points out that insufficient knowledge about a health condition and inappropriate attitudes towards causes and treatments may hinder help-seeking and response to treatment. Andersen's [26] Behavioral Model of Health Services Use also suggests that health beliefs and demographic factors (gender and education) are predisposing factors for health service use; geographic access and severity of illness are the enabling factors. Therefore, it is very important for the parents and other caregivers, especially in the developing countries like China, to obtain adequate knowledge and awareness about ASD, which would ensure early identification and intervention of ASD. However, the levels of awareness about ASD and attitudes towards treatment in China are unknown.

Given this background, in this study we aimed to: (1) estimate the proportions of people in the community who could correctly identify ASD; (2) describe the attitudes towards various treatments for ASD; and (3) identify factors associated with ASD recognition.

Methods

Study population

Between October 2009 and January 2010, we conducted a cross-sectional study among caregivers of children who were between the ages of 3 and 6 years and who attended kindergartens in Harbin, Heilongjiang, China. In China, because of the one-child policy, parents often expect their only child to be exposed to early education. As such, a vast majority of children attend kindergartens at 3 years, except those with learning and developmental disabilities. The target population of this study included parents or caregivers of children who attended kindergartens at the time of study. Harbin is the provincial capital with a population of 9.89 million in the metropolitan area. Because of the large population and the feasibility of operation, we randomly selected 44 of the 985 kindergartens in all 8 districts of Harbin City and all selected kindergartens agreed to participate. This study was approved by the ethics review committee of Harbin Medical University.

Data were collected by questionnaire survey. We developed a survey questionnaire based upon previous studies about ASD knowledge [27–30] and our research objectives. The questionnaire was first pilot tested for clarity in a small sample of caregivers. With the support of the directors of the selected kindergartens, we invited all caregivers who looked after the children ($n = 5,515$) to participate in a questionnaire survey. Of them, 5,240 agreed to participate. The survey team organized the participants to complete the questionnaires at the meeting rooms provided by the kindergartens. At the end, 4,947 completed and returned the questionnaires (response rate = 94.4%).

ASD awareness and attitudes towards mental health service use

We used one question to determine participants' ability to recognize ASD—"what are the symptoms of autism?" ASD symptoms in communication, language, and repetitive behaviors were provided after the question. If participant could recognize the manifestations in all three aspects, they were considered as knowledgeable about ASD. We also asked six additional questions to assess their general knowledge about ASD (see "Appendix").

We asked two questions about their attitudes towards mental health service use. Specifically, we asked "what would you do if you find that your child cannot speak and make eye contact with you by 2 years old?" and "which of the following health professionals would you contact for diagnostic evaluation?" The options of answer to each

question are in “[Appendix](#)”. Attitudes which show recognition and appropriate help-seeking are regarded as positive.

Other variables included gender, education levels, ethnic background (Han vs. non-Han), relationship with the child, whether they had heard of autism (yes or no), whether they had personal contact with individuals with ASD, and whether there were autistic children in their family. Although Han is the majority group of the Chinese population, Han and non-Han people receive the same education. Employment does not depend on ethnic background in China.

Statistical analysis

We estimated the proportions of the ability to recognize ASD, general knowledge and attitudes toward mental health service use for ASD. We conducted bi-variate analyses to identify variables that were significantly associated with the recognition. We used logistic regression modeling to examine potential effect modifications between selected variables in relation to ASD recognition by including a product term in model. If effect modification was found, stratified analysis was conducted. Significant variables in bi-variate analysis were included in multivariate logistic regression modeling with the perceived ability to recognize ASD as dependent variable. The associations between the selected variable and the ability to recognize ASD were estimated in form of odds ratio (OR) and related 95% confidence interval (95% CI). All of the statistical analyses were performed using the Statistical Package for Social Sciences version 17.0 (SPSS Inc, Chicago, IL, USA). All *P* values reported are 2-sided and *P* values of less than 0.05 were considered statistically significant.

Results

Of the total of 5,240 questionnaires distributed to the participants, 4,947 were completed and were eligible for being included in the analysis (94.4%). The demographic characteristics of the respondents are shown in Table 1. Females accounted for 72.6% of the respondents. Most of the respondents were parents of the children (4,679, 95.1%), and Han Chinese (4,622, 93.8%). The average age of respondents was 34.07 (SD = 8.37) years. Over 63.1% of the participants had a university degree or higher education (>13 years). Of the 4,947 respondents, 4,564 (93.9%) reported that they had heard of ASD; 275 (5.8%) had been in contact with ASD children; 40 (0.8%) reported that there was an ASD case in his/her family.

Among the participants, 2,786 (57.8%) could correctly recognize ASD. The proportions of correct responses to the items about ASD children were 84.7% (ability to communicate),

68.6% (active language), 55.9% (eye contact and closeness with family members), 45.9% (narrow interests and stereotyped behaviors) and 36.7% (soliloquizing).

Bi-variate analyses revealed that women, parents, resident people, those who lived in urban areas, those who had previous contact with ASD and those who were at a higher educational level were more likely to correctly recognize ASD than others (Table 2). We found a statistically significant effect modification between relationship with child and educational levels ($P < 0.001$) (see Table 3). Among participants who were grandparents or other relatives of the children, educational levels were not associated with ASD recognition; among parents, the odds of ASD recognition increased with the increase of educational levels (10–13 years education: OR = 2.04, 95% CI 1.63, 2.56; 13–17 years education: OR = 5.39, 95% CI 4.38, 6.63; 17+ years education: OR = 9.12, 95% CI 6.17, 13.48).

Multivariate logistic regression model showed that women, participants who lived in urban areas and who had contact with ASD cases were more likely to recognize ASD than others (Table 3). Of the six questions about general knowledge of ASD, over 50% of participants reported correct answers for three questions; for the remaining three questions, the percentages of correct answers ranged from 17.1 to 38.1%. The proportions of those who selected “Don’t know” ranged from 23.0 to 47.8% (Table 4).

When participants were asked “What are you going to do if you find out that your kids cannot speak and make eye contact with you by 2 years old?”, 4,007 (84.6%) reported “visiting a health organization” (Table 5). Women were more likely to provide such an answer than men. Among the participants, 2,470 (68.2%) reported that they would like to consult the psychotherapist for diagnostic evaluation. There was no gender difference in the answer to this question. However, women were more likely to consult a physiotherapist than men for diagnostic evaluation (Table 5).

Discussion

To our knowledge, this was the first study to describe awareness about ASD and their attitudes towards mental health service use among the care givers of children aged 3–6 years in China. This study, which was based on a large random sample of care givers, provided important descriptive information about the current levels of awareness and attitudes toward ASD in the Chinese general population. In this study, majority of our participants (93.9%) had heard of ASD, but only 57.8% could accurately recognize ASD. Recognition of autism depended on gender and residing areas, previous contact with ASD and educational levels of the parents. With respect to the attitudes towards mental

Table 1 Demographic characteristics of the respondents ($n = 4,947$)

Variable	Subjects (%)
Gender	
Male	1,347 (27.4)
Female	3,561 (72.6)
Ethnic group	
Han Chinese	4,622 (93.8)
Non-Han Chinese	304 (6.2)
Residence	
Countryside	4,247 (89.6)
City/town	495 (10.4)
Relationship with the child	
Father	1,262 (25.8)
Mother	3,417 (69.6)
Grandfather	85 (1.7)
Grandmother	105 (2.1)
Other relatives	39 (0.8)
Education levels	
<9	620 (12.7)
10–13	1,186 (24.2)
13–17	2,883 (58.9)
≥ 17	203 (4.2)

The percentage of missing data for the variables ranged from 0.4% for Ethnic group to 4.1% for Residence

health service use for ASD, 84.6% appeared to trust health organizations for diagnosis and treatment. But 68.2% of them made the choice of consulting a psychotherapist.

The percentage of participants who could correctly recognize ASD was higher than that reported in a Japanese study [29] (57.8 vs. 45.8%). The discrepancy may be due to the differences in survey methodology. The Japanese study used a case vignette to examine participants' mental health literacy on ASD, whereas we presented the symptoms of ASD to the participants. Although over half of our participants could recognize ASD given that the prevalence of ASD is less than 1% in the communities, there is still a large room for improvement. The awareness of specific health conditions in the community depends on many factors including the efforts of health promotion and education at the population level, stigma and regional differences. For example, the prevalence of schizophrenia is also less than 1% in the general population. A recent multinational study showed that the percentage of individuals who could correctly recognize schizophrenia based on a case vignette varied from 15.7% in Hungary to 68.2% in Cyprus and the percentage of individuals who considered schizophrenic case vignette as mental illness ranged from 79.7% in Spain to 95.9% in Cyprus [31].

Koyama and colleagues [29] also reported that a larger number of females than males had accurate knowledge and

Table 2 Bi-variate statistical analyses for predictors of recognition of ASD

Variables	<i>B</i>	SE	Wals	<i>df</i>	OR (95%CI)	<i>P</i> value
Ethnic group						
Han Chinese					1	
Non-Han Chinese	0.08	0.12	0.40	1	1.08 (0.85–1.37)	0.53
Residence						
Countryside					1	
City/town	1.34	0.11	162.25	1	3.80 (3.10–4.67)	<0.001
Gender						
Male					1	
Female	0.41	0.07	39.16	1	1.51 (1.33–1.71)	<0.001
Relationship with the child						
Grandparents					1	
Parents	0.79	0.16	25.73	1	2.20 (1.62–2.98)	<0.001
Education status (year)						
<9			399.28	3	1	<0.001
10–12	0.64	0.11	34.71	1	1.89 (1.53–2.33)	<0.001
13–16	1.60	0.10	264.30	1	4.97 (4.09–6.02)	<0.001
≥ 17	2.17	0.20	122.62	1	8.74 (5.95–12.82)	<0.001
Previous contact with ASD						
No					1	
Yes	0.57	0.14	17.97	1	1.77 (1.36–2.31)	<0.001

beliefs of ASD. The gender difference may be due to that women are primarily responsible for children's education and well-being in daily lives and parents had higher educational levels than grandparents. Similarly, urban residents were more likely to recognize ASD than those who resided in suburban areas, which may be due to different socio-economic status and different levels of access to information about ASD.

An interesting result of our study was that there was an effect modification between relationship with children and participants' educational levels. Recognition of ASD depended on parents' educational levels, rather than grandparents' educational levels. One possible explanation is that parents' educational levels were generally higher than those of grandparents. In our participants, few grandparents reported having university or higher education. The difference in education and the fact that parents are more likely to be exposed to various health information than grandparents and may contribute to the observed effect modification.

It is worrisome that large proportions of respondents reported "do not know" to questions regarding symptoms of autism. It was estimated that there are at least 7 million patients with ASD in China [18, 32]. In Harbin City, the prevalence of ASD was 2.27 per 1,000 in 2010 [17], indicating that autism is not a rare disease, which is consistent with Koyama's research [29]. In our participants, a large

Table 3 Results of multivariate logistic regression modeling with recognition of ASD as dependent variable

Variables	<i>B</i>	SE	Wals	<i>df</i>	OR (95%CI)	<i>P</i> value
Residence						
Countryside					1	
City/town	0.50	0.127	15.89	1	1.66 (1.29–2.12)	<0.001
Gender						
Male					1	
Female	0.29	0.07	16.18	1	1.34 (1.16–1.54)	<0.001
Previous contact with ASD						
No					1	
Yes	0.40	0.15	7.65	1	1.50 (1.12–1.99)	0.006
Education level × relationship with the child						
Grand parents						
Education level			1.13	2		0.57
Level 0 (<9 years)					1	
Level 1 (10–13 years)	−0.08	0.38	0.05	1	0.92 (0.44–1.95)	0.83
Level 2 (13–17 years)	0.30	0.40	0.56	1	1.35 (0.62–2.97)	0.45
Parents						
Education level			383.29	3		<0.001
Level 0 (<9 years)					1	
Level 1 (10–13 years)	0.71	0.12	38.39	1	2.04 (1.63–2.56)	<0.001
Level 2 (13–17 years)	1.68	0.11	254.26	1	5.39 (4.38–6.63)	<0.001
Level 3 (>17 years)	2.21	0.20	122.80	1	9.12 (6.17–13.48)	<0.001

proportion of them did not know the prevalence of ASD or underestimated the prevalence. Autistic patients do not have special physical characteristics, which makes people neglect the possibility that their children may have autism. Our results showed that participants had some misunderstandings about autism, i.e., some considered that ASD existed only in children or that individuals with ASD had superpower, which were consistent with Heidgerken's study [27]. The misperceptions about autism may be due to the influence of public media which often shows autistic people with high IQ, super power, excellent mathematical talent or artistic talent. Insufficient knowledge and misconceptions about ASD among parents will have negative impacts on early identification and intervention of ASD [33]. Thus, it is important that general public should be informed by professionals to understand the nature of ASD and the difficulties experienced by individuals with ASD.

It is critical to seek help from specialists for ASD diagnosis and treatment. Presently, the Chinese health professionals who have clinical knowledge about autism are pediatricians, psychiatrists and child health care doctors. Unlike developed countries, seeking clinical treatment does not need referrals from family doctors in China. Our data showed that participants had positive attitudes towards seeing a specialist if their children showed abnormal behaviors. But they had misunderstanding about the appropriate health professionals whom they should contact

for diagnosis and treatment. Over 68% would contact a psychotherapist—a type of health professional with insufficient knowledge and skills about ASD in China. Only about 20% would contact specialists in ASD. This was consistent with studies in other countries [29]. Our previous studies found that children with autism in China have visited many health professionals before a diagnosis is made. About 34.0% of children with autism have met three different types of health professionals before receiving a diagnosis [24]. Seeking help from health professionals with insufficient knowledge and skills will lead to delayed or incorrect diagnosis, which in turn may lead to reduced parental confidence in the health professional and delayed recovery [34].

Limitations

First, this study was based on a self-administered questionnaire. Reporting bias and desirability for providing right answers were possible. Second, about 5.6% of eligible participants did not complete the questionnaire. Although any refusals in cross-sectional studies may lead to the possibility of selection bias, the extent to which selection bias affects the estimates in the studies decreases with the increase of response rate. We considered that selection bias may not have a significant impact on the results given the high response rate

Table 4 Results of general knowledge about autism

Items	Respondents (%)	Male (%)	Female (%)	χ^2	<i>P</i> value
1. Autism is rare (the prevalence of autism is lower than 0.1%)					
Yes	688 (14.3)	195 (14.9)	493 (14.1)	11.34	0.003
No	3,009 (62.7)	771 (59.0)	2,238 (64.0)		
Do not know	1,105 (23.0)	340 (26.0)	765 (21.9)		
2. Severity of autism					
From mild to severe	2,719 (57.1)	640 (49.6)	2,079 (59.9)	56.55	0.000
Usually mild	528 (11.1)	198 (15.3)	330 (9.5)		
Usually severe	245 (5.1)	60 (4.7)	185 (5.3)		
Do not know	1,268 (26.6)	392 (30.4)	876 (25.2)		
3. IQ level of autistic child					
High	126 (2.7)	20 (1.6)	106 (3.1)	24.38	0.000
Low	357 (7.6)	102 (8.0)	255 (7.4)		
Normal	1,084 (23.0)	318 (25.0)	766 (22.3)		
All mentioned above	1,792 (38.1)	431 (33.9)	1,361 (39.6)		
Do not know	1,345 (28.6)	400 (31.5)	945 (27.5)		
4. Onset of autism is usually in childhood					
Yes	408 (8.6)	120 (9.3)	288 (8.3)	12.39	0.002
No	3,184 (67.1)	815 (63.2)	2,369 (68.6)		
Do not know	1,152 (24.3)	354 (27.5)	798 (23.1)		
5. Autistic children have special talent					
Yes	1,723 (36.6)	398 (31.0)	1,325 (38.6)	23.12	0.000
No	806 (17.1)	236 (18.4)	570 (16.6)		
Do not know	2,184 (46.3)	648 (50.5)	1,536 (44.8)		
6. Autistic children usually grow up in high-income and high-educated family					
Yes	734 (15.3)	186 (14.3)	548 (15.7)	2.35	0.309
No	1,767 (36.9)	474 (36.4)	1,293 (37.1)		
Do not know	2,288 (47.8)	643 (49.3)	1,645 (47.2)		

The percentage of missing data for the variable ranged from 2.9% for items 1 to 4.7% for items 5

Table 5 Attitudes towards mental health service use

Items	Respondents (%)	Male (%)	Female (%)	χ^2	<i>P</i> value
1. What are you going to do if you find out your kids can not speak and make eye contact with you by 2 years old?					
Visiting a health organization	4,007 (84.6)	1,034 (80.4)	2,973 (86.1)	29.80	0.000
Wait and see. The kids will “grow out”	467 (9.9)	146 (11.4)	321 (9.3)		
Do not worry. This does not affect development.	33 (0.7)	13 (1.0)	20 (0.6)		
Do not know what to do.	232 (4.9)	93 (7.2)	139 (4.0)		
2. Which specialist would you like to consult for diagnostic evaluation?					
Psychotherapist	2,470 (68.2)	621 (66.0)	1,849 (69.0)	2.84	0.092
Physician for children health care	849 (23.4)	223 (23.7)	626 (23.3)	0.05	0.828
Pediatrician	713 (19.7)	193 (20.5)	520 (19.4)	0.55	0.460
Psychiatrist	590 (16.3)	148 (15.7)	442 (16.5)	0.29	0.588
Physiotherapist	349 (9.6)	63 (6.7)	286 (10.7)	12.63	0.000
Neurosurgeons	286 (7.9)	72 (7.7)	214 (8.0)	0.11	0.746
Other health professionals	81 (2.2)	20 (2.1)	61 (2.3)	0.07	0.789
Do not know	634 (17.5)	165 (17.5)	469 (17.5)	0.001	0.981

The percentage of missing data for the variables ranged from 4.2% for items in 1 to 10.2% for items in 2

(94.4%). Third, some questions related to the general knowledge about ASD may not be easy to understand for the participants, e.g., “autism is rare” and “severity of autism”. There might be reporting bias associated with the answers. However, there were no participants who asked for clarification of these questions in the survey or in the pilot study. Finally, this study was conducted in the metropolitan area of Harbin. The results may not be generalizable to other regions.

In summary, this is one of few studies on the topic of awareness and knowledge about ASD in caregivers of children aged 3–6 years in China. There is lack of awareness about ASD and treatment in the communities, which may impede the efforts of early identification and intervention. Health education and promotion are needed to improve people’s knowledge about ASD and available mental health services.

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Conflict of interest The authors have no conflict of interest to declare.

Appendix: Questions about knowledge and attitudes towards autism spectrum disorders in caregivers

Questionnaire

1. Have you heard of Autism?
(A) Yes, (B) No.
 2. What are the symptoms of the Autism?
(A) Unable to communicate with others, un-cooperative and being isolated,
(B) No eye contact, and not close to family members,
(C) Language barriers,
(D) Talking to themselves, or repetitive talking,
(E) Narrow life interests and repetitive behaviors,
(F) All of the above,
(G) Do not know.
 3. Do you think that Autism is a rare disease?
(A) Yes, (B) No, (C) Don’t Know.
 4. What do you think about the severity of Autism?
(A) From mild to severe, (B) Usually mild,
(C) Usually severe, (D) Do not know.
 5. What do you think about the IQ levels of the Autistic children?
(A) High, (B) Low, (C) Normal, (D) All mentioned above, (E) Do not know.
 6. Do you think that the onset of Autism is only in childhood?
(A) Yes, (B) No, (C) Don’t Know.
 7. Do you think that Autistic children always have special talent?
(A) Yes, (B) No, (C) Don’t Know.
 8. Do you think that Autism is associated with the economic status and educational level of the parents of children?
(A) Yes, (B) No, (C) Don’t Know.
- Attitudes towards mental health service use*
9. What are you going to do if you find out your kids can not speak and make eye contact with you by 2 years old?
(A) Visit health organizations, (B) Wait and see (The kids will “grow out”),
(C) Do not worry, (D) This does not affect development,
(E) Do not know what to do.
 10. If you select to go to consult someone else, which specialist would you like to consult for diagnostic evaluation?
(A) Psychotherapist, (B) Physician for Children Health Care, (C) Pediatrician,
(D) Psychiatrist, (E) Physiotherapist,
(F) Neurosurgeons,
(G) Other health professionals, (H) Do not know.

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