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Brief Report

Children with autism spectrum disorder from China and the Netherlands: Age of diagnosis, gender and comorbidities

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ABSTRACT

Background: In recent years, an increasing number of studies have highlighted progress in ASD clinical practice and scientific research in China (Zheng & Zheng, 2015). However, little is known about the differences between clinical or scientific approaches to ASD between China and other countries. In our study we explored the impact of gender, comorbidity, parental educational and vocational status on the age of diagnosis in two samples of children with ASD from China and the Netherlands.

Method: 433 children with ASD aged between 6 to 14 from China and 492 age matched children with ASD from the Netherlands were investigated based on national databases on individuals with ASD.

Results: We found a lower diagnosis age in China compared to the Netherlands. The Chinese sample showed a higher male/female ratio and a higher proportion of co-morbid ADHD diagnoses, but lower age of first concern, diagnosis age and shorter delay from first concern to diagnosis. In the Dutch sample only, co-morbid ADHD resulted in lower age of first concern. The differential impact of comorbidity and gender across both countries may be related to cultural and clinical variations.

Conclusions: This study may help us understand ASD from a cross-cultural perspective.

1. Introduction

The first diagnosis of autism in China was reported in the 1980s (Tao, 1987). Since then, an increasing number of studies highlighted the progress of clinical practice and scientific research regarding ASD in China (Zheng & Zheng, 2015). However, little is known about how clinical or scientific progress in China compares with other countries.

Recent reports indicated that ASD is diagnosed increasingly often in eastern countries (primarily Asian countries) (Hsu, Chiang, Lin, & Lin, 2012; Kim et al., 2011). A review of the WHO even suggested that the global prevalence of autism in eastern countries is currently in line with western countries, ranging from 0.02% to 1.8% in eastern countries (China, Japan, South Korea) compared with 0.1% to 1.2% in western countries (Europe, North America, Australia) (Elsabbagh et al., 2012). Besides the prevalence, the severity and symptoms of ASD do seem to vary across eastern and western countries (Matson et al., 2012). For instance, lower nonverbal communication and socialization skills were found in eastern countries (South Korea) compared to western countries (US and UK)

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(Matson et al., 2012).

Adequate care for individuals with ASD relies on early diagnoses. The earlier a child is diagnosed, the better we can offer treatment and care, and prevent the development of additional problems (Lord, 1995). Interestingly, the age of diagnosis varies across eastern and western countries. The mean diagnosis age ranged from 38 to 120 months according to an overview covering 42 studies from eastern and western cultures (US, UK, Europe, India and Taiwan). Note however that the current age of participants ranged from 3 to 50 years old, and only four in 42 studies included adult participants (Daniels & Mandell, 2014). Studies on age of diagnosis in China suggest the average diagnosis age was 3.3 years old, but researchers were relying on participants younger than six years old (Zhou et al., 2014). Most western studies, particularly in North America and Europe, suggest an age of diagnosis in children varying between 3.1 (Mandell, Novak, & Zubritsky, 2005) to 14.5 years old (Mandell et al., 2005). Brett, Warnell, McConachie, and Parr, (2016) found no change of mean age of diagnosis (55 months) in the UK over 10 years across studies. Importantly, the mean age of diagnosis is determined by the age of the population studied. Younger samples were found to have an earlier age of diagnosis, as a logical consequence of their current age (Bent, Dissanayake, & Barbaro, 2015; Bickel, Bridgemohan, Sideridis, & Huntington, 2015) though there are disadvantages of early autism diagnosis, such as it would cause parents' anxiety earlier while not being able to provide further support or solutions especially in countries with limited resources.

A wide variety of factors has been associated with the lower age of diagnosis in ASD, including parental concern (Twyman, Maxim, Leet, & Ultmann, 2009), the presence of older siblings (Emerson, Morrell, & Neece, 2016; Mishaal, Ben-Itzhak, & Zachor, 2014), higher socioeconomic status (SES) (Emerson et al., 2016), developmental regression (Mishaal et al., 2014), higher symptom severity at early ages, the health and education systems (Daniels & Mandell, 2014), higher parental age and parental educational status (Emerson et al., 2016) and gender, with males showing lower age of diagnosis compared to females. However, there is no consensus the influence of SES on age of diagnosis. A number of studies linked higher SES to an earlier age at diagnosis (e.g. Goin-Kochel, Mackintosh, & Myers, 2006), but Brett et al. (2016) reported that children diagnosed before 60 months had lower SES than children diagnosed after 60 months. Note also that the male/female ratio is higher in China (6.92:1) (Zhou et al., 2014) compared to western countries (4:1) (Begeer et al., 2013), where it was found to reduce with increasing age (Rutherford et al., 2016). In addition, co-occurring psychiatric disorders are common in children with ASD, with an estimated 70% of individuals with one, and 40% with two comorbid disorders besides their ASD diagnosis (Simonoff et al., 2008). While comorbidity has been shown to influence the age of diagnosis in western countries, it is unclear whether this is the case in eastern countries.

In our current study, we aim to explore the impact of gender, diagnosis age, the presence of highly common comorbidities (ADHD, allergy, epilepsy and sleeping problems) (Doshi-Velez, Ge, & Kohane, 2014; Simonoff et al., 2008) and parental status in two samples of children with ASD from China and the Netherlands. Convenience samples were used from China and the Netherlands, available from national resources of data on individuals with ASD. We expect a higher male to female ratio in both China and the Netherlands. Considering the longer history of clinical care of autism and better SES in western countries, we would expect age of diagnosis in general to be lower in the Netherlands compared to China. However, the current Chinese participants were recruited through clinics aimed at young children, while the Dutch participants were recruited through an open online register. This may lower the age of diagnoses in the Chinese participants considerably. The impact of comorbidity, parental education and vocational status will be explored in both samples.

2. Methods

2.1. Participants

Nine hundred and twenty-five children with ASD from China or the Netherlands, aged 6–14, were investigated in this study (Table 1) during 2013 to 2014. The Dutch participants ($n = 492$) were registered in the Netherlands Autism Register (NAR, <https://www.nederlandsautismeregister.nl/english/>), an online national longitudinal cohort open to all individuals with an ASD diagnosis. The Chinese participants ($n = 433$) were recruited by the China Association of Persons with Psychiatric Disability and their Relatives (CAPPDR), which is the biggest national autism organization in charge of all the services of ASD in China. Both databases were national resources of data on individuals with ASD, which could represent the general picture of children aged 6 to 14 in both countries. Previous research has shown that online research databases have the ability to recruit a representative sample that, on further testing, meet the diagnostic criteria for autism (Lee, Marvin, & Watson, 2010; Warnell, George, & McConachie, 2015). Ethics and participants' informed consent were in accordance with the requirements of Nankai University School of Medicine and the NAR. The Medical Ethical Committee of the Vrije Universiteit Amsterdam approved the NAR data collection (2013/15) which were used for research purposes only.

2.2. Context

All diagnostic measures were administered by trained clinicians according to the Diagnostic and Statistical manual of Mental Disorders, Fourth Edition, DSM-IV-TR (APA, 2001). Since there is no such a developmental surveillance on ASD in most cities in China, a child is usually referred by preschool teachers for further assessment and diagnosis. Once a child has a confirmed diagnosis of ASD by a clinician, the parent will look for support services. In China most support services are for children with ASD younger than six years old, both private and government owned. After seven years old, children with normal IQ will attend typical schools, and those diagnosed with different disabilities will usually attend special schools, including children with ASD. However, children with ASD and normal IQ usually attend typical schools, though there are rarely any services for them. Children with ASD and low IQ

Table 1
The comparisons of cohort between the Netherlands and China.

| | The Netherlands | | | China | | |
|---|-----------------------|-------------------------|-------------|-----------------------|------------------------|-------------|
| | Male (n = 386; 78.5%) | Female (n = 106, 21.5%) | Total (492) | Male (n = 357, 82.4%) | Female (n = 76, 17.6%) | Total (433) |
| Basic characteristics (in years)¹ | | | | | | |
| Current age | 11.47 (2.2) | 11.46 (2.1) | 11.47 (2.2) | 7.9 (2.2) | 7.64 (1.8) | 7.9 (2.1) |
| Age of first concern | 3.0 (2.2) | 3.8 (2.6) | 3.2 (2.3) | 2.5 (0.9) | 2.5 (1.1) | 2.5 (0.9) |
| Age of diagnosis | 4.9 (2.1) | 5.6 (2.4) | 5.0 (2.2) | 3.3 (1.1) | 3.4 (1.3) | 3.3 (1.1) |
| Gap between first concern and diagnosis | 1.9 (1.8) | 1.8 (1.6) | 1.9 (1.7) | 0.8 (1.0) | 0.9 (1.0) | 0.9 (1.0) |
| Co-occurring conditions (%)² | | | | | | |
| ADHD | 105 (28.5%) | 26 (24.5%) | 131 (26.6%) | 212 (59.4%) | 35 (46.1%) | 247 (57.0%) |
| Allergy | 68 (17.6%) | 21 (19.8%) | 89 (18.1%) | 37 (10.4%) | 9 (11.8%) | 46 (10.6%) |
| Sleeping problem | 106 (27.5%) | 36 (34.0%) | 142 (28.9%) | 110 (30.8%) | 20 (26.3%) | 130 (30.0%) |
| Epilepsy | 4 (1.0%) | 2 (1.9%) | 6 (1.2%) | 35 (9.8%) | 12 (15.8%) | 47 (10.9%) |
| Only child in the family | 22 | 4 | 26 | 252 | 46 | 298 |
| Father's Educational status (%)² | | | | | | |
| Below high school | 4 (0.8%) | 0 | 4 (0.8%) | 30 (6.9%) | 7 (1.6%) | 37 (8.5%) |
| College | 99 (20.1%) | 32 (6.5%) | 131 (26.6%) | 21 (4.8%) | 6 (1.4%) | 27 (6.2%) |
| Bachelor's degree | 72 (14.6%) | 26 (5.3%) | 98 (19.9%) | 15 (3.5%) | 3 (0.7%) | 18 (4.2%) |
| Master and higher | 33 (6.7%) | 5 (1.0%) | 38 (7.7%) | 6 (1.4%) | 1 (0.2%) | 7 (1.6%) |
| Total | 208 | 63 | 271 | 72 | 17 | 89 |
| Mother's Educational status² | | | | | | |
| Below high school | 0 | 0 | 0 | 126 (29.1%) | 26 (6.0%) | 152 (35.1%) |
| College | 110 (22.4%) | 28 (5.7%) | 138 (28.0%) | 98 (22.6%) | 20 (4.6%) | 118 (27.3%) |
| Bachelor's Degree | 74 (15.0%) | 30 (6.1%) | 104 (21.1%) | 55 (12.7%) | 11 (2.5%) | 66 (15.2%) |
| Master and higher | 33 (6.7%) | 6 (1.2%) | 39 (7.9%) | 6 (1.4%) | 2 (0.5%) | 8 (1.8%) |
| Total | 217 | 64 | 281 | 285 | 59 | 344 |
| Father's Vocational status² | | | | | | |
| Unemployed | 19 (3.9%) | 6 (1.2%) | 25 (5.1%) | 44 (10.2%) | 11 (2.5%) | 55 (12.7%) |
| Houseman | 2 (0.4%) | 1 (0.2%) | 3 (0.6%) | 12 (2.8%) | 3 (0.7%) | 15 (3.5%) |
| Employed | 183 (37.2%) | 57 (11.6%) | 240 (48.8%) | 296 (68.4%) | 62 (14.3%) | 358 (82.7%) |
| Other and Not clear | 15 (3.0%) | 2 (0.4%) | 17 (3.5%) | 5 (1.2%) | 0 | 5 (1.2%) |
| Total | 219 | 66 | 285 | 357 | 76 | 433 |
| Mother's Vocational status² | | | | | | |
| Unemployed | 47 (9.5%) | 11 (2.2%) | 58 (11.8%) | 41 (9.5%) | 7 (1.6%) | 48 (11.1%) |
| Housewife | 26 (5.3%) | 12 (2.4%) | 38 (7.7%) | 184 (42.5%) | 45 (10.4%) | 229 (52.9%) |
| Employed | 145 (29.5%) | 41 (8.3%) | 186 (37.8%) | 129 (29.8%) | 23 (5.3%) | 152 (35.1%) |
| Other and Not clear | 3 (0.6%) | 1 (0.2%) | 4 (0.8%) | 3 (0.7%) | 1 (0.2%) | 4 (0.9%) |
| Total | 221 | 65 | 286 | 357 | 76 | 433 |

¹ Data are given as mean (SD).

² Data are given as number (%).

sometimes attend typical schools depending on the available services in the schools in China. However, in the Netherlands, depending on child's symptom severity, educational settings either promote the inclusion of children with ASD in regular education classrooms or provide a wider array of services in special education settings (European Agency for Special Needs and Inclusive Education (2016)).

2.3. Surveys

In both countries the surveys were intended for parents or primary caregivers of children with a professional diagnosis of ASD. They could be completed online, via an interview or in person. Surveys included the age of first concern (the first-time parents noticed that there was something unusual about their child before they contacted a professional), the diagnosis age, the diagnostic delay (the time lag between the first concern and diagnosis) and common comorbidities (ADHD, allergy, epilepsy and sleeping problems) (Table 1).

3. Results

3.1. Gender

A higher male to female ratio was found both in Chinese (4.7:1) and Dutch samples (3.6:1). Significant differences were found in the Chinese male to female ratio compared to the Dutch sample ($p < .05$), indicating relatively more males in our Chinese sample.

Table 2
The means and SDs of comorbidities between the Netherlands and China¹.

| Comorbidities | The Netherlands | | | China | | |
|-------------------------|----------------------|------------------|------------|----------------------|------------------|------------|
| | Age of first concern | Age of diagnosis | Delay | Age of first concern | Age of diagnosis | Delay |
| ADHD | 3.39(2.15) | 5.23(2.00) | 1.83(1.72) | 2.39(.90) | 3.27(1.17) | .88(1.00) |
| Allergy | 3.14(2.25) | 4.99(2.13) | 1.84(1.75) | 2.46(.92) | 3.32(1.14) | .86(.97) |
| Sleeping problem | 3.24(2.40) | 5.28(2.17) | 2.04(1.84) | 2.54(.87) | 3.31(1.12) | .77(.88) |
| Epilepsy | 2.22(1.71) | 4.53(2.58) | 2.31(2.34) | 2.27(1.09) | 3.38(1.03) | 1.11(1.17) |

¹ Data are given as mean (SD).

3.2. Diagnosis age

A lower diagnosis age was found in the Chinese sample ($M = 3.3$, $SD = 1.1$) compared to the Dutch sample ($M = 5.0$, $SD = 2.2$) ($F = 32.59$, $p < .001$, $\eta^2 = .034$). Also, children in the Chinese sample ($M = 0.85$, $SD = 0.9$) had shorter delays of diagnosis ($F = 18.6$, $p < .001$, $\eta^2 = .020$). A higher diagnosis age of females ($F = 9.7$, $p < .001$, $\eta^2 = .053$) was also found in Dutch ($M = 3.8$, $SD = 2.6$) sample (see Table 1). In addition, a lower age of first concern was found in Chinese sample ($M = 2.5$, $SD = 0.9$) compared to the Dutch sample ($M = 3.2$, $SD = 2.3$) ($F = 216.9$, $p < .001$, $\eta^2 = .002$).

3.3. Comorbidity

In Table 2, higher proportions of children with ASD reporting comorbid ADHD ($F = 97.3$, $p < .001$, $\eta^2 = .31$), eating disorder ($F = 262.1$, $p < .001$, $\eta^2 = .47$) and epilepsy ($F = 41.3$, $p < .001$, $\eta^2 = .21$) were found in the Chinese sample, while more ASD allergies ($F = 10.4$, $p < .05$, $\eta^2 = .106$) were found in the Dutch sample. The logistic regression suggested that in the Chinese sample a higher age of first concern among ASD children with ADHD was found compared to those without ADHD ($p < .05$). Besides, the age of first concern and sleeping problems were correlated ($p < .05$, $r = .058$) in Chinese sample. In Dutch sample, children with both ADHD and ASD had a lower age of first concern compared to those children with only ASD ($p < .05$).

3.4. Parental status

Parents' educational and vocational status did not affect any outcomes across both samples. The educational level of parents, employment status and occupation of parents did not affect the diagnosis age of their ASD children in our study.

3.5. Other factors

In the Chinese sample, 309 participants (71.4%) were diagnosed in or after 2008. The participants in China diagnosed in or after 2008 had a higher average age of diagnosis ($M = 3.4$) ($F = 14.1$, $p < .001$, $\eta^2 = .178$) than those who diagnosed before 2008 ($M = 3.0$). The IQ score was not collected in Chinese sample, but 388 Dutch participants (78.9%) were found to have a normal IQ (> 85).

4. Discussion

The current study explored factors related to ASD diagnosis between China and the Netherlands. The age of diagnosis was lower in China compared to the Netherlands. A higher male to female ratio was found in Chinese samples though there was a high male to female ratio in both countries. There were differences in the incidence of comorbidity in both countries. ASD Children with ADHD had different age of first concern in both countries. Sleeping problems were found correlated with the age of first concern in China.

4.1. Diagnosis age

The lower age of diagnosis of ASD in the Chinese sample compared to the Dutch sample may be attributed to several factors. The primary explanation for our finding is related to recruitment differences, which occurred through clinics for children in China, while the Dutch participants were recruited through an online open survey, also suitable for older participants. The short delay of diagnosis in China may be related to increasing numbers of hospitals where ASD can be diagnosed, service availability, parents anxiety, high kindergarten attendance or sample differences. Zhou et al. (2014) has reported that "The total number of hospitals where the children received their diagnoses of ASD or 'autistic tendencies' increased steadily over time, from just a few hospitals in the early 1990s to 267 hospitals in 2012". More and more hospitals have professionals who are able to diagnose children with ASD now. There are around 1600 centers for children with ASD in China. In big cities or economically more developed provinces like Beijing, Shanghai and Guangdong province, there are more than 100 centers in each place. Therefore, children with ASD may be referred and get diagnosed earlier in more developed cities or provinces. In addition, the belief that parents are the cause of ASD is more frequently observed in studies conducted in Asia compared to western cultures (Qi, Zaroff, & Bernardo, 2016), which in turn could make parents

more anxious and willing to get their children assessed earlier. In addition, 75% of Chinese preschool-age children attend kindergartens (China National Bureau of Statistics) at the age between 2 to 6, compared to 65% in the Netherlands (Dutch Central Bureau of Statistics, CBS). Kindergartens or other baby care facilities create a social environment for young kids, which may increase the likelihood of recognition of those with ASD. However, it should also be noted that the Dutch data were collected through an open online database, allowing participants to respond that were not necessarily under treatment or assessments in clinics. In contrast, the Chinese data were recruited from various services for people with ASD around China, and most of these participants were identified at a younger age. However, the two groups of participants were age matched.

4.2. Gender

Confirming previous studies, more males with ASD were found in both China and the Netherlands (Begeer et al., 2013; Sun et al., 2014), however relatively more males than females were found affected with ASD in China (such as, Zhou et al., 2014) compared to the Netherlands. The gender ratio differences were all statistically significant. This could be explained by parents attending more to the functioning of boys compared to girls (Huang, Jia, & Wheeler, 2013) due to the Family Planning Policy. Also known as the One Child Policy, this act was introduced in 1979 in China to control the birth rate in China in the past seventy-eight years. Drawbacks of this policy included skewed sex ratio at birth. After the first "one child" generation were born, the 4-2-1 family structure became the norm (4 grandparents, 2 parents, 1 child). The Chinese traditional idea "to carry on the family line" was deeply rooted and a baby boy was valued higher than a girl. Therefore, we can assume boys got more attention and are diagnosed relatively more than girls in China compared to western countries though we need to test this assumption further (Chen & Rao, 2011). In addition, the gender difference (6.92:1) found in Zhou et al. (2014) study was based on data collected from 1993 to 2012, and our study was conducted during 2013 to 2014, so the decreasing male to female ratio (4.7:1) found in Chinese sample could be explained that girls got more attention and more easily diagnosed now than the last decade in China.

4.3. Comorbidity

Previous studies suggested a later diagnosis age of children with both ASD and ADHD (Stevens, Peng, & Barnard-Brak, 2016), which is different from our Chinese results. Children with both ASD and ID were diagnosed with ASD at a younger age compared to those who have ASD only (Daniels & Mandell, 2014). This is relevant because different cultures have different perceptions on ASD. As ASD is regarded a mental disability in China, it would be easier for Chinese parents to accept that the child has ADHD when the child has both ADHD and ASD because mental disability is still discriminated against and parents generally believe that ADHD is not a mental disability but rather a behavior problem. Moreover, the ASD children without ID in the Netherlands could have increased the average diagnosis age. Our Chinese dataset did not include information on cognitive abilities of the participants, but we assume that ASD children without ID might relatively more often attend typical schools and would not appear in our samples from the service institutions.

4.4. Parental status

Diagnosis age of ASD could be influenced by parents' social status. Parents with higher social class have been found to express more concern for their children with ASD than those from lower social classes (Williams et al., 2014). In the current study, we did not find any relationship between parental status (educational or vocational) and diagnosis age in both Chinese and Dutch samples.

4.5. Other factors

ASD children in the Chinese sample were younger compared to the Dutch sample in our study. This could be attributed to the focus of the current service or benefits for autism in China largely on the younger ASD children, while in the Netherlands, this focus on younger children is less explicit. Services for children over age 18 were available in only 12 centers across the whole of China (Zhou et al., 2014). While obtaining information through services is currently the most direct and efficient way to get information on autism, it may result in a bias. Previous studies have indeed suggested that younger samples, by default, get diagnosed earlier than older samples (Mandell et al., 2005). It could also influence the gender ratio as the male/female ratio has been found to reduce with increasing age (Rutherford et al., 2016), which implied there would be more females diagnosed with ASD as the age increases. Therefore, the samples with lower age (just like the samples in our study) would have a larger male to female ratio compared to those older samples.

While autism gradually received public awareness in North America and Europe over last century, autism in China became widely known almost instantaneously since 2008. From that time, both the government and the public started to pay attention to mental disabilities with a specific focus on autism. The growth of the universal knowledge of autism might contribute to the bloom of the diagnosis of ASD after 2008. What surprised us was that participants diagnosed before 2008 had a lower average age of diagnosis than those who were diagnosed in or after 2008. This may be related to increased attention for autism in older children.

This study has various limitations. Findings from this study are based on comparatively small samples from both countries and cannot be generalized to all children with ASD in both countries. Moreover, younger children with ASD participated in China than in the Netherlands, so we had to limit our current study sample to those aged 6 to 14. Future research, including IQ scores and additional information, may provide a better comparison across eastern and western autism care.

5. Conclusion

This study is the first systematic assessment exploring differences in features of ASD children between an eastern country (China) and a western country (the Netherlands), and may help us understand ASD from a cross-cultural perspective across nations.

Conflict of interest

The authors have no conflict of interest to declare.

Ethical approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committees and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent

Informed consent was obtained from all individual participants included in the current study.

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