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The Application of the First Year Inventory for ASD Screening in China

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ABSTRACT

Purpose: The First Year Inventory (FYI) is a parent-report instrument, and is developed to assess behaviors of 12-month-old infants that could suggest risk for an eventual diagnosis of autism. This study was designed to examine the application of the FYI in the Chinese community.
Design and methods: FYIs were completed at a community health center by 541 families during the child's physical examination at 12 months of age from 2013 to 2015. The weighted risk scores used in this study were based on US norms, and compared the FYI differences between China and the U.S.
Results: The total risk scores ranged from 5 to 42 points; the 95th percentile cutoff was 27.00(9.8 points higher than the 95th percentile cutoff in the US), the 98th percentile cutoff was 29.66(7.04 points higher than the 98th percentile cutoff in the US), and the 99th percentile cutoff was 31.83. Higher risk scores were found for boys than girls. Mothers with a junior college education reported significantly higher FYI risk scores than other three groups including high school, college graduates and post-graduates.
Conclusions: There were no significant effects of birth parity, investigator, or investigation year on risk scores. Large-scale longitudinal research is encouraged in the future to develop an early detection model of autism in China.

Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder found in children, and it is generally marked by social communication disorders and repetitive or narrowly restricted behaviors. These impairments are present throughout the course of life. In recent years, there has been an increase in the global prevalence of ASD. In November 2015, The United States (US) Centers for Disease Control and Prevention (CDC) used data from 2014 to determine an estimated ASD prevalence of 2.24%, which was a significant increase from the estimated annualized prevalence of 1.25% based on 2011–2013 data (Zablotsky, Black, Maenner, Schieve, & Blumberg, 2015). Studies in Japan showed that the prevalence had increased to 181 per 10,000 in 2008 (Kawamura, Takahashi, & Ishii, 2008). A study in South Korea reported that the prevalence was estimated to be 2.64% among 7- to 12 years old children in 2011 (Kim et al., 2011). Five years later, Pantelis and Kennedy (2016)reconstructed this study's methodology and demonstrated that there was an overestimation due to flaws in methodology in the previous study, and a more reasonable confidence interval would be approximately twice as large as originally reported. In China, a sampling investigation report on 0 to 6 years old Chinese children with disabilities in 2001 indicated ASD as the most common impairment (Ministry of Health of the People's Republic of China, 2003; Xiu, 2013). A meta-analysis published in 2013 showed that the pooled prevalence of childhood autism was 11.8 per 10,000 individuals in mainland China, and the pooled prevalence of ASD was 26.6 per 10,000 in mainland China, Hong Kong and Taiwan (Sun et al., 2013). Another meta-analysis conducted in 2016 indicated that the mean global coverage of prevalence data for ASD in 5 to 17 years old children was 16.1% (Erskine et al., 2016). The application of the First Year Inventory (FYI) which is a screening tool for ASD may improve to find clues in advance for detection of autism later, thus leading to more accurate prevalence rates of autism in China.

Children with ASD present with delays and/or impairments in communication and social skills, as well as engage in ritualistic or stereotypical patterns of behavior. The symptoms can range from mild to severe. As a phenomenological disorder, ASD is diagnosed by observation of characteristic behaviors and clinical features. Symptoms of ASD are usually first seen in the second year of life but can emerge earlier or later (Jin, 2016). Clinical signs are sometimes evident as early as the age of 12 months (Ozonoff et al., 2010), but diagnosis typically does not occur until the preschool years. Few studies have identified factors that may delay diagnosis. Mandell, Novak, and Zubritsky (2005) reported that the average age of diagnosis in Pennsylvania was 3.1 years

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old for children with autistic disorder, and 3.9 years old for pervasive developmental disorder not otherwise specified, and 7.2 years old for Asperger's disorder. In 2010, another report showed the age was approximately 4 years old in the US (Centers for Disease Control and Prevention, 2014). Definitive diagnosis occurring before the age of two is rare (Turner-Brown, Baranek, Reznick, Watson, & Crais, 2013).

However, there is evidence supporting the benefit of early treatment for ASD, especially before three years of age (Baranek et al., 2015). It is commonly believed that early intervention for children with ASD can significantly reduce the severity of the disorder and may help direct them toward a more well-balanced developmental trajectory. Earlier and more effective interventions rely on early identification (Howlin, Magiati, & Charman, 2009), but early screening for ASD has not been a routine for pediatricians in most Chinese child health care institutions (Xie, Sun, Zheng, & Zhao, 2012), as most pediatricians are not trained to use screening tools to detect ASD. Therefore, the application of the FYI was examined in this study to better understand its viability and potential to identify children as early as one year of age at risk for an eventual diagnosis of autism.

ASD is considered to have a substantial functional and financial impact on affected individuals and their families. Early identification and intervention can serve to optimize developmental outcomes, decrease disability, and ultimately reduce associated burdens on families and society (Baranek et al., 2015). The early detection of children with ASD mainly depends on screening scales due to the lack of an ideal experimental diagnostic approach (Falkmer, Anderson, Falkmer, & Horlin, 2013). Most ASD screening measures rely upon parent-report. A commonly used tool is the Modified Checklist for Autism in Toddlers-Revised with Follow-up (M-CHAT-R/F), which is a questionnaire completed by parents, with a follow-up questionnaire administered by a health care professional if needed (Jin, 2016). The CHAT-23 screening scale is the Chinese version of the M-CHAT. One study in Shanghai showed that the sensitivity and specificity of the CHAT-23 were both high (0.941, 0.884) (Wu, Xu, Liu, Xia, & Cao, 2010). Wang, Wang, Yan, and Pan (2014) combined the CHAT-23 and Clancy Autism Behavior Rating Scale (CABRS, Schopler, Reichler, Devellis, & Daly, 1980) as a first autism screening tool, which showed a sensitivity and specificity of 0.85 and 0.99.However, these screening tools are used for 18 to 24 months old children. The Communication and Symbolic Behavior Scales Developmental Profile Infant-Toddler Checklist (CSBS-DP-ITC) focuses on children's social and communication skills and is completed by caregivers when the child is between the age of 6 and 24 months. Although the CSBS-DP-ITC has been used to screen for infants at risk for ASD, findings from some studies note the tool better serves as a screening tool for identifying 12 to 24 months old children with developmental delays than a screening tool for ASD (Dudova et al., 2014; Huang et al., 2016; Wetherby, Allen, Cleary, Kublin, & Goldstein, 2002).

Other tools, such as the Parents' Evaluation of Developmental Status (PEDS) and the Ages and Stages Questionnaires (ASQ), are both parent-report screening tools that detect common developmental problems. They can be used on infants less than 1 year old, but neither is specific to ASD (Velikonja et al., 2016; Wantanakorn, Sawangworachart, Roongpraiwan, & Chuthapisith, 2016).

The FYI is a unique ASD screening tool, as this version of the FYI (v2.0) is specifically geared toward 12 months old children (Baranek, Watson, Crais, & Reznick, 2003). This age seems to map onto a period of critical developmental and neurobiological changes that occur in many infants who will eventually be diagnosed with ASD (Ozonoff et al., 2010; Turner-Brown et al., 2013; Webb, Monk, & Nelson, 2001). The FYI consists of 61 Likert-type or multiple-choice questions that represent social communication and sensory-regulatory domains, and it provides parents with multiple response options rather than limiting them to 'yes' or 'no' answers regarding the presence or absence of a behavior. The FYI was normed on a sample of 1496 12 months old infants from the general population in one state in the US (Reznick, Baranek, Reavis, Watson, & Crais, 2007).

It has been translated into several languages, including Hebrew, Spanish, Italian, Korean and Chinese. Watson et al. (2007) used the FYI retrospective version (FYI-R) and found that children with ASD had significantly higher risk scores than children with a developmental delay (DD) or with typical development. More than 50% of children with ASD scored above the 99th percentile on the FYI-R risk score by retrospective report. One prospective study in Israel showed that infants in the risk group assessed by FYI obtained significantly higher scores on the Autism Observation Scale for Infants (AOSI) (Ben-Sasson & Carter, 2012). In a follow-up study of the normative sample for the FYI in the US, a receiver operator curve (ROC) analysis determined that the two-domain cutoff scores (i.e., in both the social-communication and sensory-regulatory domains) yielded an optimal classification of children based on their diagnostic outcomes at 3.5 years old, with 31% of 12 months old children with high risk scores subsequently being diagnosed with ASD as preschoolers, and 85% of 12 months old children with high risk scores showing later developmental concerns (including ASD). Also, some studies suggested that the FYI is an effective ASD screening measure at 12 months of age (Rowberry et al., 2015). Thus, the FYI has shown promise in identifying 1 year olds at risk for later developmental problems, specifically ASD, in other countries (Hao, Layton, Zou, & Li, 2014). However, no studies have examined early screening for ASD with the FYI among Chinese infants.

The aim of this study is to eventually develop a screening tool to identify younger infants in the general Chinese population who are at risk for atypical development, especially for ASD and to utilize it as a routine screening tool among community centers. The first goal of the present study is to survey the initial use of the FYI among Chinese parents, and to examine the response patterns between Chinese and American participants. Because these items are designed under different educational and cultural backgrounds, many items may be culturally and linguistically inappropriate. The first aim is to determine whether Chinese parents understand the items and are able to easily complete the scale. The preferred approach is to verify the screening tool for Chinese children by Chinese professionals in China (Turner-Brown et al., 2013). The second aim is to explore FYI scoring data for Chinese infants and to compare the scores to that of American infants. By establishing such data, in future work, we will aim to identify a majority of the infants who are at risk for an eventual diagnosis of ASD, while also ensuring that a high percentage of children identified have ASD or another developmental disability, thus minimizing false positive rates.

Method

Participants

Participating families live in the Jianggan district in Hangzhou of Zhejiang Province, China. This district is located in the east of the city and has high socioeconomic groups. In the Chinese child healthcare system, each child receives a health check-up at 12monthsof age at a community health center, during which questionnaires can be completed. We started the investigation in January 2013 and completed it at the end of September 2015. All families with 12 months old infants who visited the Kaixuan Community Health Center filled out the forms. The pediatricians of the clinic assisted with the administration and collection of all the forms and were trained to clarify the items and answer questions raised by participants. The total number of participating families was 541. Questionnaires of 14 participants were incomplete and excluded from analysis, which resulted in an overall completion rate of 97.41%. In addition, nine preterm infants were excluded, resulting in a total of 518 eligible families.

This study was approved by the Institutional Review Board of the Children's Hospital Zhejiang University School of Medicine, and written informed consent was obtained from the caregiver of each participant.

Measures

The FYI is a parent-report instrument that is developed to assess the behaviors of 12 months old infants for potential risk of an eventual ASD diagnosis. The instrument consists of the following two domains: social-communication and sensory-regulatory functions. The social-communication domain is comprised of the following four constructs: social orienting and receptive communication, social-affective engagement, imitation, and expressive communication. The sensory-regulatory functions domain also has four constructs: sensory processing, regulatory patterns, reactivity and repetitive behaviors. The eight constructs are combined to establish a general risk index. Cronbach's alpha for the US English version is 0.81 across the 61 questions of the FYI, 0.71 for the social-communication domain, and 0.63 for the sensory-regulatory domain (Reznick et al., 2007).

The Chinese version of the FYI was translated from the original FYI English version independently by an English-Chinese Bilingual SLP and a graduate student. The two translations were compared and the two translators discussed the minor differences before agreeing on the final Chinese version of FYI. This translation was then back-translated and submitted to the original test developers for review and approval to ensure the accuracy of the translation. After the back-translated version was approved, FYI-C was recognized by the original testing development experts to start collecting the pilot data.

The Chinese version of the FYI comprises a total of 63 questions, including 46 questions with response alternatives of “never”, “seldom”, “sometimes”, and “often”;14 questions with three or four multiple choice answers; one question in which parents select sounds from a list of consonants (p, b, t, d, k, g, m, n, w, y, h, s) that infants have been heard to produce; and two open-ended questions regarding parental concerns and unusual physical or medical characteristics. All the questions are same as American Version. The method for computing the risk score of the Chinese version follows the process used for the US version. The answers of two open-ended questions (question 62, 63) were collected and classified by keywords (growth, development, allergy, physical disease, etc.), then analyzed.

Results

We have obtained some basic information of the questionnaires and scored the FYI based US norm, then compare groups on the basis of sex, birth parity, type of respondents, data collection period and education level of mothers. Finally, we will explore the characteristics of open-ended questions to find out whether the parents' concerns are related to the content of the questionnaire.

Basic Information

Among the eligible FYIs, 52.12% were completed for males and 47.88% were completed for females, with a mean chronological age of 12.25 ± 0.43 months. The mean birth weight of these children was 3.42 ± 0.44 kg, and the mean gestation period was 40.45 ± 0.44 weeks.The infants were classified as follows: firstborn in a one-child family (92.67%), firstborn in a two-child family (3.86%), or second-born in a two-child family (3.47%). Most of the FYIs were completed by mothers (71.04%), 21.81% were completed by fathers, 5.02% were completed by both parents, and 2.12% were completed by caregivers, most of whom were grandparents of the infants.

The mean age of the mothers was 29.27 ± 2.95 years, and the mean age of the fathers was 30.82 ± 3.70 years. The ethnicity and education levels of the mothers were nearly identical to those of the fathers, and 98.46% of families identified their ethnicity as Han. Additionally, academic degrees were held by 72.97% of mothers and 73.16% of fathers.

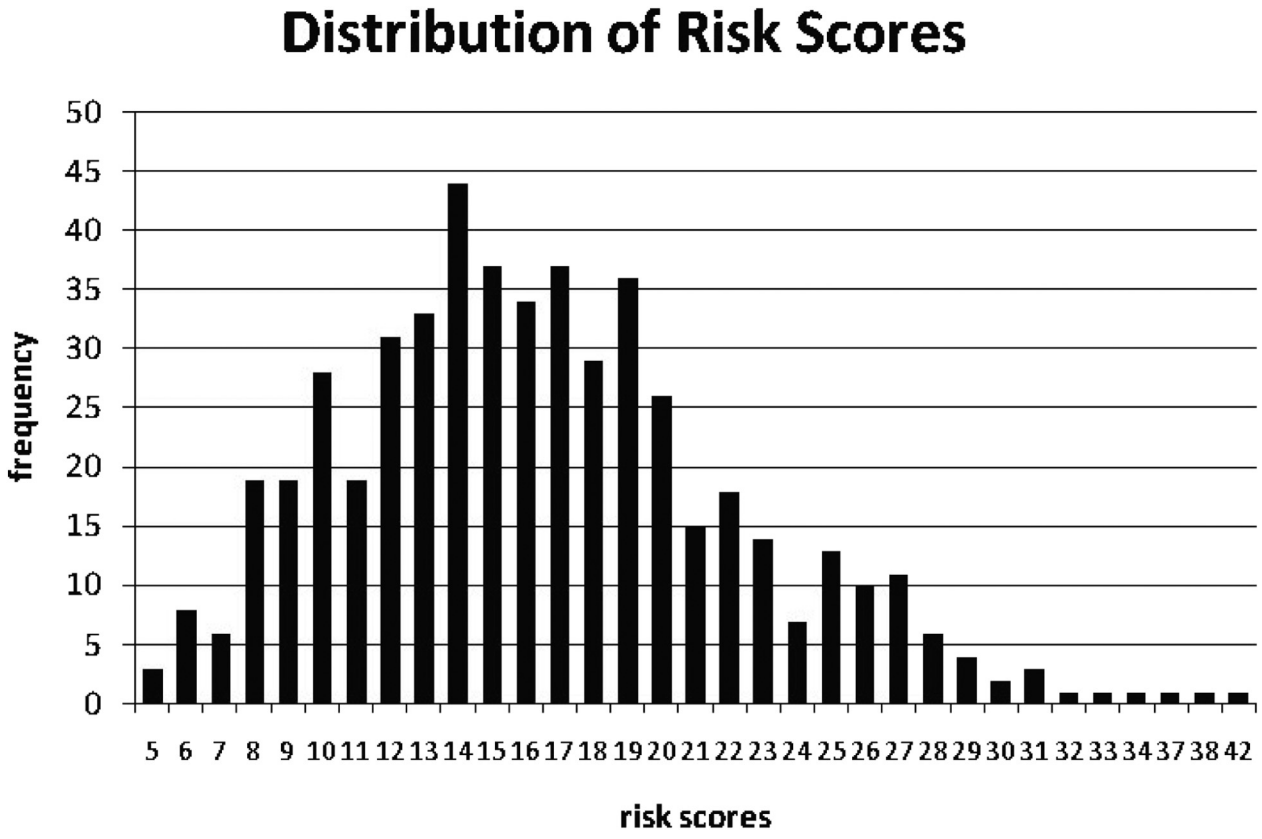

Fig. 1. Distribution of FYI risk scores.

Risk Score Distribution

The total risk scores on the Chinese FYI ranged from 5 to 42, with a mean of 16.46 (SD = 5.85) and a median of 16. Fig. 1 shows the frequency distribution of risk scores. Most children obtained scores around the median. The Chinese total risk cutoff for the 95th percentile was 27.00(9.8 points higher than the 95th percentile cutoff in the US), the 98th percentile cutoff was 29.66(7.04 points higher than the 98th percentile cutoff in the US), and the 99th percentile cutoff was 31.83. Eleven (2.12%) children obtained scores higher than the 98th percentile cutoff. Fig. 2 showed the frequency distribution of risk scores between social-communication domain and sensory-regulatory functions domain. The risk scores of social-communication domain had wider spans than the other domain.

Group Comparisons

Sex

Higher risk scores were seen in boys than girls ($z = -4.306$, $p = 0.000$) (Fig. 3). This sex difference was more dramatic at extreme values, and 10 of the 11 highest risk scores were assigned to boys. Scores across constructs were analyzed using Mann-Whitney *U* test. Fig. 4 indicates significant differences in the social-communication domain between boys and girls. The scores of boys were all higher than those of girls across the four constructs, but only two showed statistically significant differences (social orienting and receptive communication: $z = -2.641$, $p = 0.008$, expressive communication: $z = -2.633$, $p = 0.008$) (Fig. 4). In the sensory-regulatory domain, risk scores were higher in boys than girls in the repetitive behavior construct ($z = -2.112$, $p = 0.035$) (Fig. 4).

Birth Parity

Due to the Chinese family planning policy prior to 2016, most families only have one child. Therefore, the question of birth order allowed us to categorize children into the following two types: first born (96.53%) and second born (3.47%). For the large discrepancies of group sample sizes, Mann-Whitney U test was applied for statistical treatment, and finding that the mean risk scores were not significantly different between the two groups ($z = -0.825$, $p = 0.409$) (Fig. 3).

Type of Respondents

Four types of respondents completed the questionnaire: fathers, mothers, both parents, and others who helped caring for the infant. The mean risk score (17.58 ± 5.93) of the questionnaires obtained by fathers was higher than those of the other three groups, and the both parent groups had the lowest score (15.92 ± 5.53). However, these differences among respondents were not statistically significant ($H = 6.162$, $p = 0.104$) (Fig. 3).

Data Collection Period

From 2013 to 2015, we received 222, 160, and 136 questionnaires in each of the three years, respectively. We also calculated the average risk score for each year, which revealed no significant difference among each of the years ($H = 0.270$, $p = 0.874$) (Fig. 3).

Education Level of Mothers

Most FYIs were completed by mothers; therefore, we focused on examining whether the mother's education level was related to the infant's risk score. Only 6.76% of the mothers had a high school education or lower, 20.27% of mothers had a junior college degree, and there were higher percentages of college graduates (59.65%) and postgraduates (13.32%). Excluding the group with an education level of high school or lower, higher educational attainment resulted in lower risk scores. Significantly higher FYI risk was reported by informants with a junior college degree than the other three groups ($H = 11.750$, $p = 0.008$) (Fig. 3).

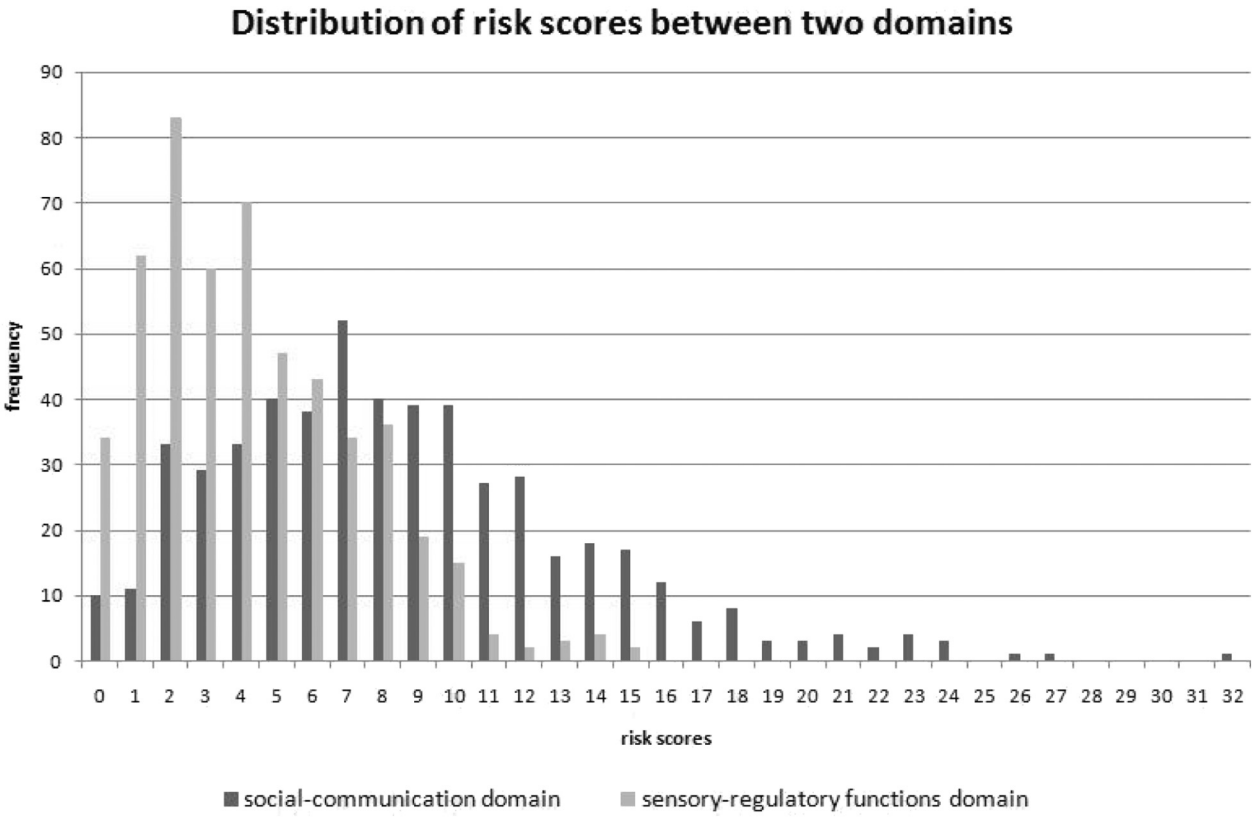

Fig. 2. Distribution of risk scores between two domains.

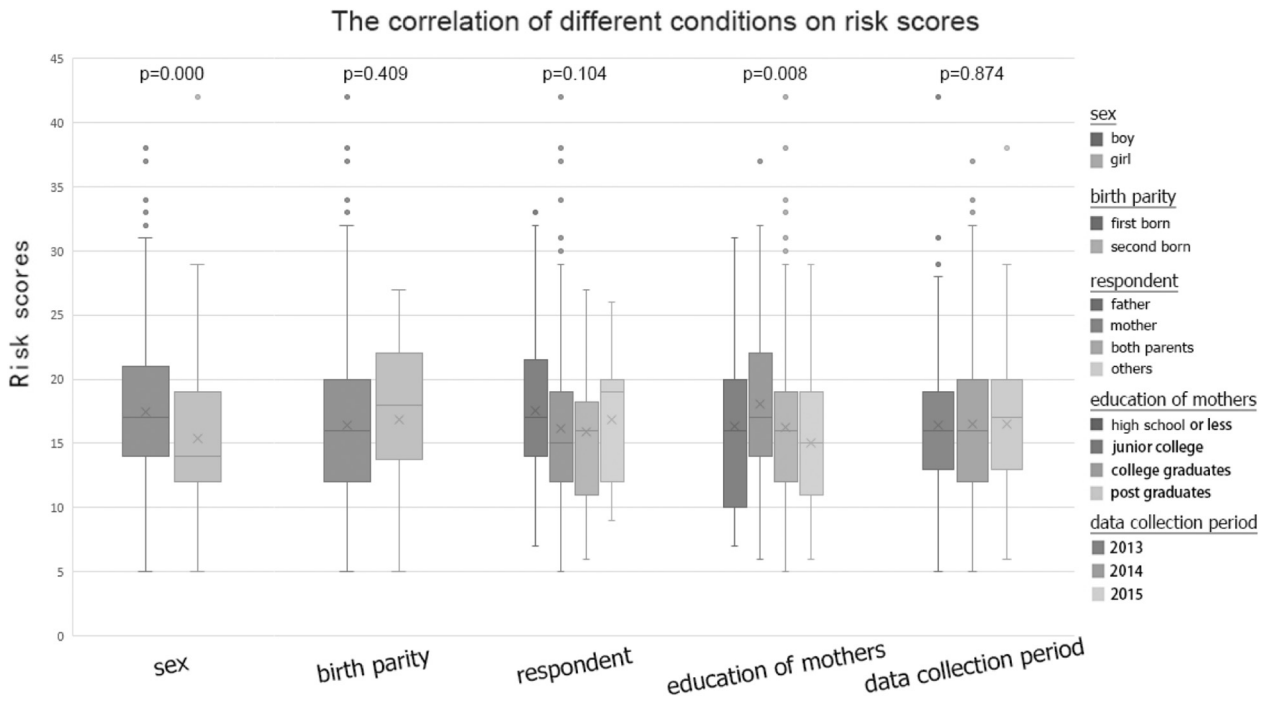

Fig. 3. Total risk scores by demographic variables.

Open-ended Questions

Questions 62 and 63 were open-ended questions regarding concerns with the infant's development or any unusual physical or medical characteristics (Reznick et al., 2007). Upon combining all responses to the two questions, there were 150 responses covering a wide range of problems, such as growth issues (weight: 30.00%, height: 30.00%, micronutrients: 11.33%), progress toward language milestones (3.33%), motor (8%) or cognitive development (8.00%), families concerned with allergies (2.00%), and various physical anomalies (anemia, pneumonia, etc.) (7.33%). Concerns were expressed for 37.50% of the infants with the highest 5% of risk scores, which was similar to US data (40%). In this group, one infant with a risk score of 30 was described as unafraid of strangers and unresponsive to a parent's calling, but this infant reportedly enjoyed laughing.

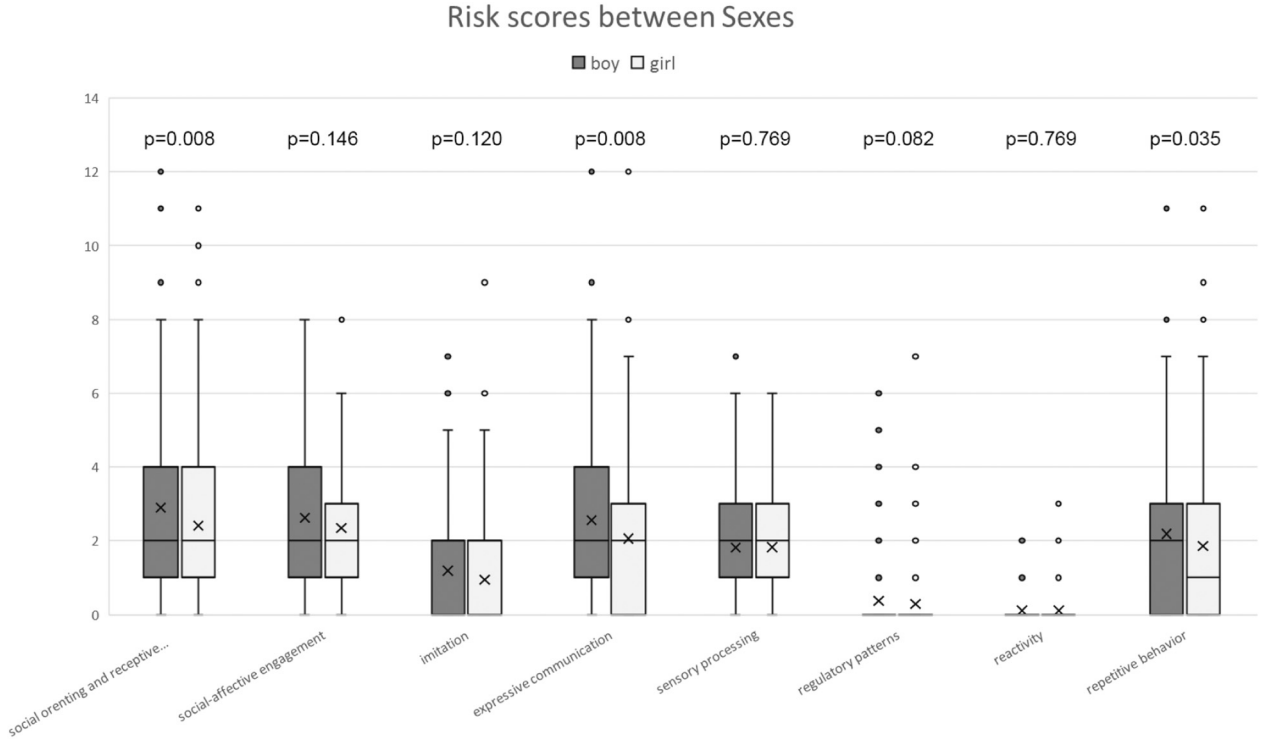

Fig. 4. Construct risk scores by sex.

Discussion

This study is an initial step toward the goal of finding a sensitive ASD screening protocol that is brief, developmentally appropriate, and easily administered and scored by clinicians to screen Chinese infants (Choueiri & Wagner, 2015). The FYI was selected from a variety of screening tools, and there were no previous research data in China. Our goal in this research was to assess the FYI's ease of use, explore Chinese scoring data based on US strategy, and gather preliminary normative data.

Since the Chinese version has not been widely used in China, we do not yet have diagnostic outcome data to examine the viability of this tool for identifying Chinese infants who will later be diagnosed with ASD or determining optimal cutoff scores. The first aim was to assess the ease of use of the FYI. One indication was the lack of missing data. All families were able to easily complete the FYI during the physical examination, but only a few grandparents sought clarification or additional information, which suggested that the questions had considerable clarity. Only 14 questionnaires had invalid answers (e.g., two answers selected for the same question), yielding a 97.41% efficiency for completion of the FYI. Therefore, the FYI could meet our needs in the present study and warrant further testing for usability in other provinces or across the whole country.

It is interesting that fathers in this study had endorsed slightly higher risk scores than mothers, and all uncompleted FYIs were all obtained from fathers. After reviewing the fathers' backgrounds, we found that they were of Han ethnicity and most had an education level higher than junior college. Compare the two samples (Reznick et al., 2007), the percentage of Chinese fathers (21.81%) filling out the questionnaire was much higher than the percentage in the US (5.00%). In China, mothers play the lead role in raising children, whereas the fathers are responsible for providing financial support. Therefore, fathers may not understand their children's daily performance very well and may be unable to answer some of the questions. The high proportion of fathers involved in this study might account for some of the higher risk scores on average in the China versus US findings. To increase the accuracy rate, we suggest that the mother or both parents will answer the questions to attain more precise responses about the child's performance for future studies.

We computed an overall score for the FYI using the approach of Reznick et al. (2007), which was used for US infants, and speculated to gather preliminary data of risk scores' distribution in China. Most Chinese infants received scores that were distributed around the median, which was in contrast to the US data, in which most children obtained relatively low scores. The lowest risk score among our infants was five, and no infants received a score of zero. The shape of the distribution shown in Fig. 1 suggests an obvious change of inflection at a risk score of 28.00, which defined the upper 4.05% of the distribution and was much higher than that of US infants. The 95th percentile cutoff was 27.00, 9.8 points higher than the 95th percentile cutoff in the US and five points higher than the Israel (Ben-Sasson & Carter, 2012). These findings might have occurred because Chinese families paid increased attention to and have excessive expectations of their children (Liu, 2017), which also contributed to their concerns for their children's developmental and behavioral problems. Another reason may be that the parents completing the questionnaire for the first time might not have had enough experience and felt nervous; thus, they selected higher scores. Also, the risk scores in this study were weighted based on US norms for each item, and not on normative distributions in the Chinese sample. The data were collected at one health care center, and did not include a broad community sample. Thus future studies are needed to establish norms specifically for Chinese children and with a larger and more diverse population.

The sex differences among the infants in this study were the same as those for US infants. We found higher risk scores in boys than in girls, especially in the social communication domain, which was a core deficit in children with ASD. This sex difference was more evident at the extreme values, and 10 of the highest 11 risk scores were assigned to boys. According to the Empathizing-Systemizing (E-S) theory (Baron-Cohen et al., 2011; McClure, 2003),which proposes that females on average have a stronger drive to empathize while males on average have a stronger drive to systemize, men and woman have different brain. This bias also presents in children with ASD (Mandy et al., 2012). Some possible biological mechanism to the male bias could be the masculinizing effect of fetal testosterone (fT), the X- and Y-linked theories and the reduced autosomal penetrance theory (Baron-Cohen et al., 2011). None of these theories has been confirmed, so the causes for this male bias are still unclear.

We explored data from open-ended questions which regarded parental concerns, and found that the open-ended data showed the same contention between higher FYI scores and atypical development with US norms. Most parents paid much more attention on growth and nutrients, and some parents did not mention any concerns about atypical behaviors, even though they reported higher scores. One reason was that parents might not be aware of the symptoms of infants that were identified as atypical behaviors by professionals. From a forward-looking perspective, it is necessary to add effective screening tools to the routine physical examination process in future, and to help detecting in the early days.

Recent evidence-based studies have verified that, in general, earlier intervention for children with ASD results in better outcomes (Schreibman et al., 2015). Early intervention relies on early detection. In this study, we found that the type of respondent, investigation year and birth parity had little influence on the FYI scores, suggesting that scores are not highly influenced by extraneous variables. Furthermore, the operability and efficiency of the FYI show that it may be useful for ASD risk screening among infants as early as one year of age, and for screening those with developmental delays to obtain intervention as soon as possible.

However, the sample size in this study was recruited from one community health care in China, which may have introduced selection bias coming from soliciting range which was not sufficiently large. Additionally, the specificity and sensitivity of the cutoff scores were not clear. In future research, we will aim to increase the number of respondents and expand the geographic areas to obtain more appropriate risk cutoff scores and implement screening in all community health centers to establish an early detection model in China. For infants who were already screened, follow-up evaluations are needed to determine the sensitivity and specificity of the FYI and to determine whether the FYI constructs and risk scores will correlate with a final diagnosis of ASD among Chinese children using an age appropriate tool.

CRediT authorship contribution statement

Wen-Hao Li: Investigation, Data curation, Formal analysis, Writing - original draft, Writing - review & editing. **Li-Fei Hu:** Data curation, Formal analysis. **Li Yuan:** Investigation, Resources. **Grace Hao:** Methodology, Writing - review & editing. **Zhi-Wei Zhu:** Conceptualization, Methodology, Funding acquisition, Project administration, Supervision, Writing - review & editing.

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