



Parents' knowledge and attitude and behavior toward autism: a survey of Chinese families having children with autism spectrum disorder

Fang Wang^{1#}, U-Chong Lao^{1#}, Yi-Pei Xing¹, Ping Zhou², Wen-Lin Deng³, Yu Wang¹, Yue Ji¹, Miao-Ying Chen¹, Hai Li², Xiao-Bing Zou¹

¹Child Development and Behavior Center, The Third Affiliated Hospital, Sun Yat-Sen University, Guangzhou, China; ²Rehabilitation Medicine Department, Shenzhen Hospital, Southern Medical University, Shenzhen, China; ³Department of Pediatrics, The Sixth Affiliated Hospital, Sun Yat-Sen University, Guangzhou, China

Contributions: (I) Conception and design: XB Zou, H Li, F Wang, UC Lao; (II) Administrative support: XB Zou; (III) Provision of study materials or patients: F Wang, YP Xing, WL Deng, Y Wang, Y Ji, MY Chen; (IV) Collection and assembly of data: F Wang, YP Xing, WL Deng, Y Wang, Y Ji, MY Chen, P Zhou; (V) Data analysis and interpretation: F Wang, H Li, UC Lao; (VI) Manuscript writing: All authors; (VII) Final approval of manuscript: All authors.

[#]These authors contributed equally to this work.

Correspondence to: Xiao-Bing Zou. Child Development and Behavior Center, The Third Affiliated Hospital, Sun Yat-Sen University, 2693 Kai Chuang Avenue, Huangpu District, Guangzhou, China. Email: zouxb@mail.sysu.edu.cn; Hai Li. Shenzhen Hospital, Southern Medical University, 1333 Xinhua Road, Shenzhen, China. Email: lihaili2018@smu.edu.cn.

Background: In recent years, parent-mediated intervention for children with autism spectrum disorder (ASD) has increased. Therefore, implementing effective parent training programs for parents of children with autism is of paramount importance, particularly in low- and middle-income countries. However, little is known about the status of and gaps in parents' knowledge on ASD, which may hinder the development of valid parental training programs. Herein, we aimed at exploring the status of Chinese parents' knowledge, attitude and behavior toward ASD, and potential factors affecting the acquisition of correct knowledge.

Methods: This study used a self-designed parental knowledge questionnaire of autism (PKQA) comprising 20 questions alongside another questionnaire comprising additional 17 questions covering the aspects of family demographics, attitudes, and behaviors of parents. In total, we included 394 parents who visited the outpatient department of the Child's Development and Behavior Center of the Third Affiliated Hospital of Sun Yat-Sen University between December 2018 and May 2019, with their children meeting the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) diagnostic criteria for ASD.

Results: The median knowledge score in the PKQA was 15 [interquartile range (IQR), 13–17]. Advanced paternal age and longer time interval from diagnosis to enrolling into the parent training program were associated with a lower total knowledge score (all $P < 0.001$). Higher maternal education attainment, higher family income, child being currently under intervention, and family members sharing a common perception of the diagnosis were associated with a higher total knowledge score (all $P < 0.01$). Reading autism-related books ($P < 0.001$) or attending professional lectures ($P = 0.019$) were also associated with a higher total knowledge score.

Conclusions: Taken together, this study revealed that family demographics and parents' attitudes and behaviors toward ASD may significantly influence their knowledge about autism, suggesting the need for promoting more targeted parental skills training programs.

Keywords: Autism spectrum disorder (ASD); parental knowledge; Chinese; questionnaires; the generalized linear model (GLM)

Submitted Mar 23, 2022. Accepted for publication Aug 18, 2022.

doi: 10.21037/tp-22-113

View this article at: <https://dx.doi.org/10.21037/tp-22-113>

Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by social interaction deficits, narrow interests, and repetitive stereotyped behaviors. Dr. Sucharewa, a Soviet psychiatrist, first reported and recorded autism in 1926 (1). Over the last few years, studies have been reporting an increasing trend in the prevalence of ASD (2,3), the most recently reported alarming prevalence rate being 1 in 54 individuals, which was reported by the American Centers for Disease Control (4). The reported prevalence rate of autism in children in China was 39.23 per 10,000 in 2018 (5), and the actual prevalence rate is expected to be much higher. In China, families of children with autism often face significant barriers with understanding the condition and availing the ideal intervention for the child. Education in China is clearly perplexing when it comes to meeting the needs of children with ASD (6). Families tend to have very limited resources (7), including insufficient access to education about the diagnosis of autism, and they are uncertain about the ways in which they can implement appropriate interventions in their child's development (6). Moreover, the level of knowledge about autism varies greatly even among the general population (8), healthcare education professionals (9), and parents of children with autism.

In China, the following departments are included in the diagnosis and treatment of autism: (I) the children's basic healthcare department, which is mainly responsible for early screening and early treatment; (II) the department of child and adolescent psychiatry, which is mainly for children with ASD the age of at least 6, particularly for children with comorbid emotional problems; (III) the developmental behavioral pediatrics (DBP) department, which is a relative, rapidly developing branch of discipline in China, and it provides relatively comprehensive evaluation, diagnosis, and treatment services for children of different ages having ASD of different severity levels. Notably, even though the abovementioned departments may work in close collaboration with each other, the latter two are predominantly distributed in relatively developed regions. Moreover, although Chinese parents can choose from different departments, the wait time for availing diagnostic and treatment services is often long. Non-governmental

organizations (NGOs) reportedly are the major providers of autism treatment, covering more cases than hospitals and government institutions in China (6). Furthermore, families with autism in China reportedly spend a lot on their children's special education every month (the upper limit of the median range of monthly health expenditures was about 3.5 times of the 2019 per capita wage in China) (10).

With accumulating research on ASD, healthcare professionals' understanding of ASD is constantly updated. However, the general population is still oblivious about the causes, symptoms, and treatment of ASD (11,12). The lack of knowledge and the stigmatization of ASD are particularly prevalent in economically underdeveloped countries (13,14), which imposes a heavy economic and mental burden on families with ASD (15,16).

In 1987, Stone designed the autism knowledge scale (17) and used it to investigate the knowledge status of parents and teachers about ASD (18). Since then, questionnaires examining the status of knowledge on ASD tailored for specific personnel, such as professionals (15,19), teachers (9,20), and the general population (11,12), have revealed that knowledge about ASD is widely lacking. Golson *et al.* conducted a knowledge survey of 318 individuals with no ASD professional training from the general population in the United States in 2022, and 64% of the questions were answered correctly on an average (21). In 2019, Xu Xiu's team conducted the Early Start Denver Model intervention skills training for 55 Chinese families, through a self-designed questionnaire survey and found that the accuracy of caregivers' knowledge about the intervention increased from 54.5% (before the training) to 81.8% (after the training) (22). Although reports on this field have been accumulating in the past five years, these reports have had many shortcomings, such as limited psychometric properties and undocumented cross-cultural adaptations (23–26). There have been several other deficiencies as well. First, few studies have focused on the knowledge level of the parents of children with ASD (27). Second, the sample size of these studies was generally inadequate. For example, Ebrahimi *et al.* investigated the knowledge status of 115 mothers of children with autism in 2013 (28). In addition, most of these studies have been aimed at only the knowledge level of different populations (11,29), and few studies have reported

on the correlation between the knowledge level and various influencing factors.

Parents are an important element of family intervention (28,30). Meanwhile parents' knowledge and awareness will affect the diagnosis (31), treatment, and prognosis of children with ASD (32). Elaborate investigation and research on parents' knowledge of ASD can help us understand and identify specific gaps in their knowledge, which will help develop personalized parental training programs. Most importantly, it can also help us identify whether knowledge training was helpful (25). Strongly emphasizing on parents' knowledge of ASD and using it as a determinant of the effects of training are important aspects of teaching parents to carry out family training. Using a questionnaire, this research sought to identify the status of autism-related knowledge in parents of children with ASD and the factors affecting parents' knowledge status of ASD in China. More specifically, although many factors may contribute to parents' knowledge level, some of them may be fairly static, such as parents' education level, whereas the others may be relatively dynamic, such as parents' attitudes and behaviors. Therefore, our goal herein is to identify factors that can be altered by parent training and thus help clinicians design better training strategies for parents to prepare them for family interventions in the future. We present the following article in accordance with the SURGE reporting checklist (available at <https://tp.amegroups.com/article/view/10.21037/tp-22-113/rc>).

Methods

Study design and sample size calculation

A cross-sectional, convenience sampling method was adopted to process this study. An equation

$$\left(N = \frac{\frac{p(1-p) \times Z^2}{e^2}}{1 + \frac{p(1-p) \times Z^2}{ne^2}} \right) \text{ for the calculation of the}$$

sample size for a cross-sectional questionnaire study was adopted (33), where N was the sample size, p was the population proportion, Z was the Z -score, n was the population size, and e was the margin of error (precision). According to the data from a study conducted by Wang *et al.* (5), the prevalence of ASD in China was about 39.23 per 10,000 individuals with a mean age of 1.6–8 years (p). The population size of Guangdong province was estimated to be about 115.21 million people in 2018 (n). The Z -score

was 1.96 for $\alpha=0.05$, and the margin of error was set as 0.05. The estimated minimal sample size was $N=366$.

Participants

In this study, we recruited parents of children with ASD from 402 families in the outpatient department from December 2018 to May 2019. All children had a diagnosis of ASD by at least 2 developmental and behavioral pediatricians according to the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) (34). The children were outpatients of the Child's Development and Behavior Center of the tertiary hospital named the Third Affiliated Hospital of Sun Yat-Sen University, which is well-known for its high level of diagnosis and treatment of ASD in China. The center has more than 20 years of experience in diagnosis and treatment of ASD. Among the 402 questionnaires collected, 8 were not included in statistical analyses as they had too many missing values. In total, 394 valid questionnaires were collected.

Ethical approval

The research was carried out in line with the Declaration of Helsinki (as revised in 2013). The study was approved by the Ethics Committee of the Third Affiliated Hospital of Sun Yat-Sen University (approval No. [2019] 02-329-01) and informed consent was taken from all the participants.

Materials and procedure

Upon referring to previous reports (24,25,35), the knowledge survey on ASD should cover the aspects of etiology, symptoms, diagnosis, and treatment. Incorporating the cultural perceptions of ASD in China, a self-developed questionnaire to estimate parental knowledge should be developed as well. After thorough discussion, screening, and trial by expert groups, two questionnaires were prepared (see *Figure 1*): a parental knowledge questionnaire of autism (PKQA) comprising 20 questions on etiology, symptoms, diagnosis and treatment and an attached list with 17 additional questions covering the aspects of family demographics and attitudes and behaviors of parents toward ASD (*Tables S1,S2*). The family demographics include family economic level, family location, and parents' education and age. Parents' attitudes mainly pertained to their willingness to hold family interventions and family members sharing a common perception of the diagnosis.

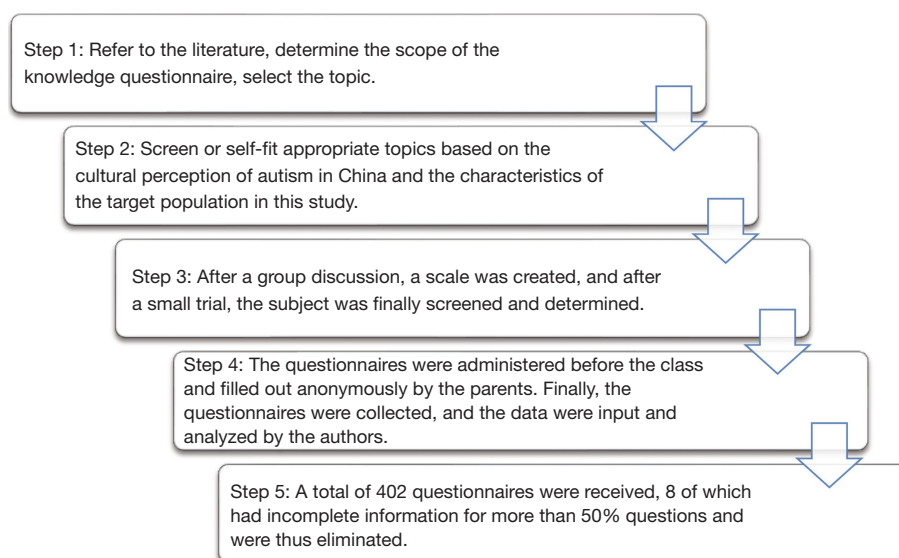


Figure 1 Recruitment and analysis flowchart.

Parents' behaviors mainly pertained to their sources for acquiring knowledge and their participation in intervention. All questions could be answered with "yes" or "no". The respondents were awarded 1 point for each correct answer, with a maximum possible score of 20 points of the PKQA. Two chief physicians with extensive clinical experience in ASD diagnosis and treatment collaborated on determining what the correct responses were.

The parents herein were respondents of anonymous self-administered questionnaires, which were distributed, answered, and collected before the start of a training program for parents of children with ASD held by the Child Development Behavior Center of the Third Affiliated Hospital of Sun Yat-Sen University. The main contents of the training course for parents were: (I) understanding ASD from the aspects of symptoms, diagnosis, and treatment; (II) introduction of the behavior-structure-relationship model (36) intervention training; (III) correcting problematic behaviors and emotional management; and (IV) training the children for self-care. The course lasted 2 days and was administered as parent group programs.

Statistical analysis

All statistical analyses were performed using Stata version 16 (College Station, TX: StataCorp LLC). The level of statistical significance set at $P < 0.05$ (two-tailed) for all tests. Cramer's V correlation tests were first conducted for

the knowledge items. The correlation coefficients of the items were indicative of very weak to strong relationships (0.001–0.377; see Table S3 and Figure S1) (37). Then, exploratory factor analysis was performed, and a scree plot was obtained. The results supported the questionnaire as a unidimensional test measuring the same latent trait (i.e., knowledge of ASD), and therefore, the core assumption of latent monotonicity in item response theory models was met (see Table S4 and Figure S2) (38). Cronbach's α revealed that the internal consistency of the PKQA was acceptable (Cronbach's $\alpha = 0.703$).

The PKQA was examined on an item-specific level by a two-parameter logistic model. Using the model, for each item, a difficulty (b) parameter and a discrimination (a) parameter were generated. The difficulty parameter identifies the ability level needed to have 50% of the respondents endorsing a response category [here: answered as yes/no of each item], and higher values of this parameter indicate easier items. The discrimination parameter indicates the abilities of the items to distinguish between individuals at different levels, and higher values of this parameter suggest better discrimination along the latent trait (i.e., parental knowledge on ASD).

The observed distribution revealed that the total questionnaire score was negatively skewed (Shapiro-Wilk test: $W = 0.95574$, $P < 0.001$; Skewness: -0.853 ; kurtosis: 3.53); therefore, sociodemographic data for each category were presented as the number of participants (%), and the

total questionnaire score was represented as the median [interquartile range (IQR)]. The responses of each item of the questionnaire were shown in percentage (%). We used either the Wilcoxon rank-sum test (dichotomous variables) or the Kruskal-Wallis test (nominal variables) to determine between-group differences in the total questionnaire score for different child's and family demographics, service availability, and participants' attitudes and behaviors. For variables that demonstrated significant group differences, follow-up Dunn's *post-hoc* analyses were conducted. Next, Kendall's tau b correlations were used to analyze the relationship between the total knowledge score and the child's and family's demographics, service availability, and participants' attitudes and behaviors. Then, in the regression analysis that followed, significant variables of the correlation analyses were included. To further explore the potential relationship between knowledge scores and these factors, the generalized linear model (GLM) of the binomial family with the logit function was used, with the total PKQA score as the dependent variable and significant variables from the correlation analyses as independent variables (see [Table S5](#)). Several models were established for comparison. The comparison was aimed at verifying how the models predicted by different categories of influencing factors (i.e., child's and family demographics, service availability, and participants' attitudes and behaviors) compared to the complete model or the modified model using goodness-of-fit (GoF) statistics. GoF statistics included log likelihood/deviance, Pearson Chi-square, Akaike information criterion (AIC), and Bayesian information criterion (BIC). Like log likelihood/deviance, Chi-square is also sensitive to the sample size and the number of variables, and therefore, the model corresponding to the smallest value of AIC and BIC would be considered the most appropriate. Residual diagnostic plots suggested that the assumptions of linear regression were not violated (see [Figure S3](#)) (39).

Results

Distribution of the participants

Among the 394 respondents, more than 4/5 had a child with male gender. Nearly 80% of the major caregivers were mothers, while less than 4% of children were taken care of majorly by their fathers. The means of age were 32.75 [standard deviation (SD) =4.35] for mothers and 35.13 (SD =5.28) for fathers. Moreover, the sample comprised approximately 40% each lived in Guangzhou city and

Guangdong province outside Guangzhou, and the remain 21.6% lived outside Guangdong province. Details of the participants characteristics were reported in [Table S1](#).

Service availability

In general, the sample was able to receive relatively adequate level of service availability. On average, the median month interval from diagnosis to the parent training program was 4 (IQR, 0–7; range, 0–48). By the time the parents participated in the training program, more than 80% of children with ASD had already received training.

Parental attitudes and behaviors toward ASD intervention

Nearly 70% of the participants were optimistic about the prognosis for their children with ASD. In total, 81.2% of parents were willing to carry out family training. Notably, 53.3% of the parents hold such a concept that they lacked knowledge of the direction of training. More seriously, 70.3% of the parents thought that they lacked knowledge of methods to address the problematic behaviors of children with ASD. In terms of access to information sources, the most common means was through the Internet (78.7%), followed by reading books (67.8%), professional lectures ranked third (52.8%), and word of mouth was the least common choices (15.5%) (see [Tables S1,S2](#)).

Parental knowledge related to ASD

The median knowledge score in the PKQA was 15 (IQR, 13–17; range, 3–20). Although most parents showed good understanding of the etiology and clinical manifestations of ASD, 64.5% of parents had incorrect answers regarding the prevalence of ASD. Concerningly, 47.2% of parents believed sensory integration therapy as the main treatment for ASD, which lacks sufficient scientific evidence (see [Table S2](#)).

Analysis of the PKQA

Figures 2,3 show the results of the analysis of item information and characteristics. For each item, a difficulty parameter and discrimination parameter were generated from the model. From the results, the factor loadings were revealed to be around 0.139–0.505. Item 7 (autism can be cured by drugs), item 8 (autism can be diagnosed only after a child enters kindergarten), and item 11 (autism is caused by a lack of parental love) had the highest discrimination

(indicating these items were correctly answered by most participants). Conversely, item 2 (autism cannot be cured, once diagnosed will be permanently disabled) and item 18 (once children are crying during the treatment, we should stop treatments immediately) had the lowest discrimination. Items with low discrimination parameters were not in an S-shape, suggesting that these items were difficult to discriminate by parents with different knowledge levels. Item 4 (the prevalence of autism is close to 1%) and item 10 (sensory integration is the main treatment for autism) were the most difficult items for parents (suggesting participants with higher knowledge levels could endorse correct responses) (see Table S4). As could be seen from

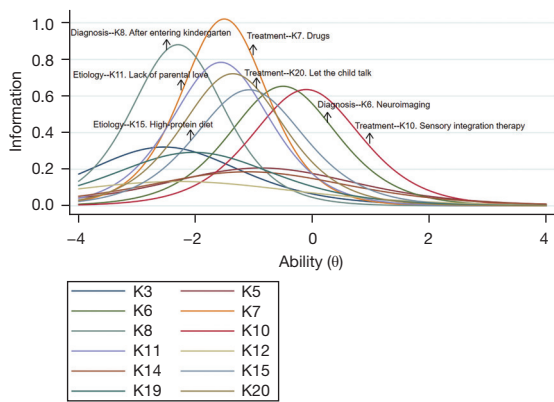


Figure 2 Item information function plot. K, items of knowledge questionnaire.

Figure 4 and Figure 5, greater amounts of information were given at the left part of the trait, with information precision peaking near -1.8 and the corresponding expected true score to be 10 (mid-true score). Moreover, the test characteristic curve lay more to the left on the ability (θ) continuum. Therefore, the PKQA may be the most suitable for discriminating the knowledge of parents whose child has recently been diagnosed with autism, i.e., parents who had lesser knowledge about ASD.

Analysis of influencing factors of parental knowledge

A preliminary analysis was conducted using the Kendall’s correlation method. Results indicated that variables came from family demographics, service availability, participants’ behaviors and attitudes were correlated with the PKQA score (see Table 1). The correlation analyses were followed by GLM analysis. The final refined model had the lowest GoF values, which supported the use of the final model (see Table 2, M8). The results of the refined model revealed that neither the gender nor the major caregiver contributed to the variations in the PKQA score (child’s characteristics, all $P>0.05$). Regarding family demographics, while advanced paternal age [family demographics, odds ratio (OR) =0.98, 95% confidence interval (CI): 0.97–0.99, $P<0.001$] was associated with a lower total knowledge score, higher maternal education [i.e., a college degree (OR =1.26, 95% CI: 1.09–1.45, $P<0.001$), bachelor’s degree (OR =1.41, 95% CI: 1.23–1.60), and master’s degree or above (OR =1.70, 95% CI: 1.33–2.13)] and a higher family income (OR =1.29, 95% CI: 1.12–1.49) were associated with a better

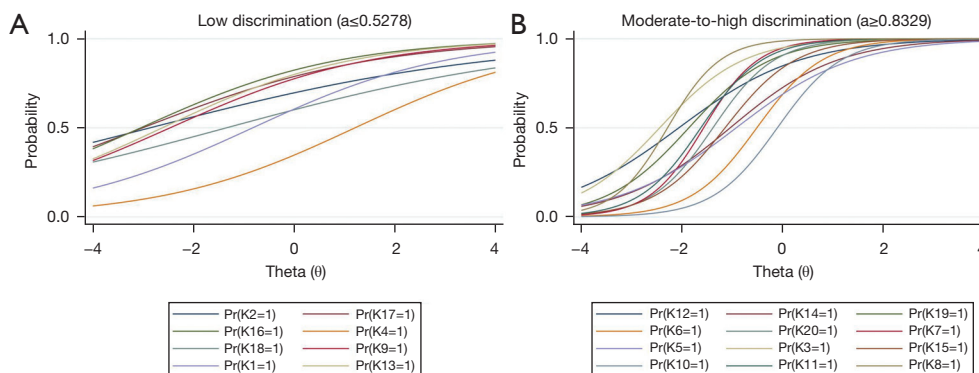


Figure 3 Item characteristic curves. (A) Item characteristic curve with low discrimination; (B) item characteristic curve with moderate-to-high discrimination. K, items of knowledge questionnaire; Pr, probability.

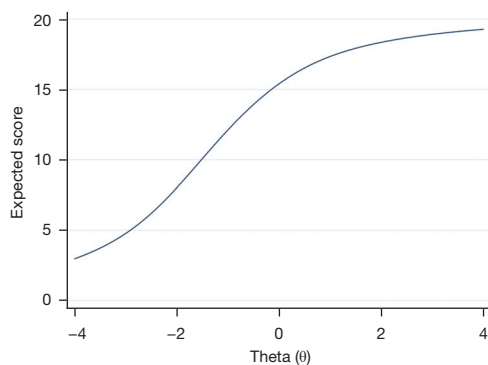


Figure 4 Test characteristic curve.

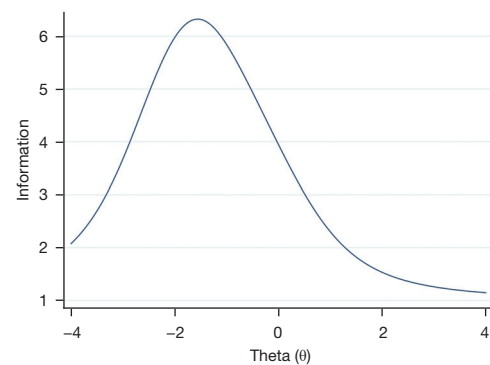


Figure 5 Test information curve.

PKQA score (all except college degree, $P < 0.001$). Service availability variables were also related to the PKQA score, with longer time interval from establishing the diagnosis to starting the parent training program (OR = 0.98, 95% CI: 0.97–0.98) being associated with a lower score and child being currently under intervention (OR = 1.32, 95% CI: 1.14–1.52) being associated with a higher score (all $P < 0.001$). With regard to participants' attitudes, family members sharing a common perception of the diagnosis of ASD (OR = 1.18, 95% CI: 1.04–1.34) was associated with a higher score (all $P < 0.01$). Moreover, the means of knowledge acquisition had an impact on the knowledge score, wherein reading autism-related books (OR = 1.24, 95% CI: 1.11–1.38, $P < 0.001$) or receiving professional lectures (OR = 1.14, 95% CI: 1.02–1.27, $P = 0.019$) were associated with a better score.

Discussion

In this study, we preliminarily investigated the knowledge status of parents of children with autism in China using a self-designed questionnaire and performed a detailed analysis of the factors affecting their knowledge about ASD. PKQA, a brief questionnaire covering several core aspects of autism-related knowledge, showed acceptable psychometric properties and may be appropriate to apply to parents of children newly diagnosed as having ASD. Since this has been a relatively unexplored aspect, our findings fill a knowledge gap in this regard in China. The results revealed that parents of children with autism had a relatively acceptable level of autism-related professional knowledge in China, which was seemingly better than that of the general populations and parents of non-autistic children reported in previous studies (21,23). This could be attributed to

the fact that parents of children with ASD have more opportunities and stronger motivations to gain professional knowledge about ASD. This result was also closely related to the government's vigorous publicity in recent years (such as the screening of autism-related public welfare movies and promotional films and the promulgation of relevant policies), the strengthening of professional doctor training, the improvement in early screening work, and the expansion of intervention training resources (40).

The results of the analysis of the impact of the family demographics on parents' knowledge of ASD was consistent with other foreign studies. First, maternal education had a prominent impact on ASD knowledge, and mothers with higher education had higher knowledge scores (28). Second, better economic condition of the family was associated with a higher level of parents' knowledge (41). In addition, the location of family's residence may have a certain impact on the level of knowledge; however, the results in this regard are almost non-significant ($P = 0.075$). In 2016, Professor Yuantao Hao's team conducted a questionnaire-based survey on the knowledge of ASD among kindergarten teachers and found that teachers' geographical location impacted the knowledge level (9). Therefore, in the future, expanding the diversity of samples for further investigation is warranted. Different from Ebrahimi *et al.*'s study (28), we found that mother's age did not affect the knowledge level, but father's age was correlated with knowledge level, with younger fathers exhibiting a higher knowledge score. This result was also consistent with our clinical experience. Younger fathers have more passion and greater learning ability, and thus, we encourage young fathers to participate more in family training.

More importantly, this study unveiled that relatively modifiable factors, including service availability and parental

Table 1 Kendall's correlation between the PKQA score and other variables of the sample (N=394)

Variables	tau-b	P value ^a
Children's gender (0= male)	0.0139	0.7466
Time to diagnosis	-0.095	0.0102
Major caregiver ^b	-0.0168	0.6925
Home location ^c	-0.158	<0.0001
Maternal education ^d	-0.2821	<0.0001
Maternal age	-0.0511	0.1617
Paternal education ^d	-0.2275	<0.0001
Paternal age	-0.0983	0.007
Financial status ^e	0.1901	<0.0001
Parents' relationship ^f	0.0689	0.087
Attitude toward diagnosis (0= consistent)	-0.1194	0.0056
Attitude toward prognosis ^g	-0.0393	0.351
Willing to do family-based intervention ^h	-0.0269	0.5322
Direction for ASD intervention (0= yes)	-0.1467	0.0007
Ways to deal with children's challenging behaviors (0= yes)	-0.0854	0.0476
Currently under intervention (0= yes)	-0.1286	0.0029
Barriers to family intervention (0= no)		
Insufficient ASD knowledge	0.0177	0.6813
Economic burden	-0.0434	0.3141
Insufficient time	0.0921	0.0326
Count of barriers of family intervention	0.0509	0.2199
Access to ASD knowledge (0= no)		
Internet	0.0959	0.0261
Book	0.1972	<0.0001
Word of mouth	0.0453	0.2934
Professional lecture	0.1663	<0.0001
Count of ways to access ASD knowledge	0.2056	<0.0001

^a, P values were continuity corrected; P values lesser than 0.05 were marked in bold; ^b, major caregiver: 0= mother, 1= father, 2= other; ^c, home location: 0= Guangzhou, 1= Guangdong province, 2= Outside Guangdong province; ^d, education level: 0= master or above, 1= bachelor, 2= college, 3= high school or below; ^e, financial status: 0= bad, 1= general, 2= fair/good; ^f, parents' relationship: 0= bad, 1= general, 2= fair, 3= good; ^g, attitude toward prognosis: 0= optimistic, 1= uncertain, 2= pessimistic; ^h, willing to do family-based intervention: 0= willing and able, 1= willing but cannot/not willing. PKQA, parental knowledge questionnaire of autism; ASD, autism spectrum disorder.

attitude and behavior, may have a crucial impact on parental knowledge levels. In terms of parental attitudes, family members sharing a common perception of the diagnosis, an important component of the family ecosystem of children with ASD, affected parental knowledge scores (OR

=1.18). Therefore, we paid greater attention to this aspect in the family intervention training of parents as parents' willingness to acquire knowledge would have weakened otherwise. However, 53.3% of the parents thought that they lacked knowledge of the direction of training, and 70.3% of

Table 2 Summaries of the final selected regression model (M8) with the PKQA score as the dependent variable (N=394)

Independent predictor variables	β (SE)	95% CI	OR	95% CI	Z	P
Control variables						
Child's major caregiver = father/others	0.0164 (0.0654)	-0.1118, 0.1445	1.0165	0.8942, 1.1554	0.25	0.802
Child's gender = female	0.0264 (0.0708)	-0.1124, 0.1652	1.0268	0.8937, 1.1797	0.37	0.709
Children's characteristics						
Time interval from diagnosis to parent training program	-0.0241 (0.0041)	-0.0321, -0.0161	0.9762	0.9684, 0.9840	-5.90	<0.001
Currently under intervention = yes	0.2749 (0.0721)	0.1337, 0.4161	1.3164	1.1430, 1.5161	3.82	<0.001
Family demographics						
Paternal age	-0.0229 (0.0050)	-0.0326, -0.0132	0.9774	0.9679, 0.9869	-4.62	<0.001
Maternal education ^a						
College	0.2303 (0.0725)	0.0882, 0.3724	1.2590	1.0922, 1.4512	4.37	<0.001
Bachelor	0.3403 (0.0670)	0.2090, 0.4716	1.4054	1.2325, 1.6026	5.08	<0.001
Master degree or above	0.5219 (0.1195)	0.2876, 0.7562	1.6952	1.3332, 2.1302	3.18	0.001
Home location ^b						
Guangdong province	-0.1136 (0.0638)	-0.2387, 0.0115	0.8926	0.7876, 1.0116	-1.78	0.075
Outside Guangdong province	-0.1318 (0.0733)	-0.2755, 0.0119	0.8765	0.7592, 1.0120	-1.80	0.072
Financial status = fair/good ^c	0.2564 (0.0713)	0.1167, 0.3961	1.2922	1.1237, 1.4860	3.60	<0.001
Participants' attitudes						
Attitude toward diagnosis = consistent	0.1691 (0.0648)	0.0422, 0.2960	1.1842	1.0431, 1.3445	2.61	0.009
Direction of ASD intervention = yes	0.1725 (0.0553)	0.0641, 0.2808	1.1882	1.0662, 1.3242	3.12	0.002
Participants' behaviors						
Access to ASD knowledge = yes						
Books	0.2131 (0.0571)	0.1013, 0.3250	1.2376	1.1066, 1.3840	3.73	<0.001
Professional lecture	0.1308 (0.0559)	0.0212, 0.2403	1.1397	1.0214, 1.2717	2.34	0.019
Constant	1.1678 (0.1970)	0.7816, 1.5539	3.2148	2.1850, 4.7300	5.93	<0.001

^a, high school or below was defined as the reference group; ^b, Guangzhou was defined as the reference group; ^c, bad/general was defined as the reference group. PKQA, parental knowledge questionnaire of autism; ASD, autism spectrum disorder; SE, standard error; CI, confidence interval; OR, odds ratio.

the parents thought that they lacked knowledge of methods to address the problematic behaviors of children with ASD, both reflecting insufficient parental efficacy. Parenting self-efficacy (PSE), reflecting caregivers' belief in their own ability to effectively parent their children, may predict the level of parenting competence and impact actual parenting behaviors (42). Notably, by modifying the negative attitudes of parents, the family will be better empowered to approach a child with ASD, which helps the family unit become more competent and capable in itself and less dependent on

service providers (41).

In the terms of service availability, the time interval from diagnosis to enrolling into the parent training program was negatively correlated with parental knowledge, and a shorter time interval from diagnosis to parent training program was associated with better parental knowledge. Besides, whether or not the child participated in intervention training significantly influenced the knowledge of his or her parents as they could observe their child's training and learn. Both these aspects showed that the relatively adequate level

of service availability and providing early intervention to children were greatly helpful for better knowledge acquisition of parents. As mentioned above, the main intervention resources in China are provided by NGOs. NGOs are often criticized for their lack of professionalism and the lack of evidence-based approach to interventions. Instead of focusing on quality and effectiveness or taking the time to train parents for family intervention, NGOs prioritize speed and scale of treatment. Besides, parents generally hold the concept that “something is better than nothing”, which leads to them making a blind choice when it comes to such institutions (43). Taken together, the government and professionals need to take positive actions to provide more family intervention training resources for parents to better improve parents’ intervention knowledge and parenting self-efficiency.

This study also demonstrated that the sources from where parents acquired knowledge impacted their knowledge level. Parents who accessed information via books and professional lectures had higher knowledge levels. The results are not surprising as ASD-related books or parent training programs aimed at facilitating parents’ understanding of ASD knowledge and intervention methods are written and published by autism professionals (44,45). Although the Internet did not have a significant effect on parents’ knowledge, the Internet was the most chosen means for obtaining information for parents, possibly due to the ease of accessing information on the Internet (78.68%). Considering that online resources are not necessarily credible or accurate in China, it is difficult to assess their scientific accuracy. However, leveraging Internet resources may facilitate service delivery, particularly in the wake of the COVID-19 outbreak. The development of online parent education and training programs and electronic information leaflets and support tools may alleviate the problem of there being few reliable resources for parents (46). For example, the World Health Organization (WHO) has developed and is validating a virtual Caregiver Skills Training (eCST) program for families having children with developmental delays and disabilities, including ASD. The program has been translated into mandarin Chinese and will be available for Chinese families in the near future.

Limitations

In this study, a self-made questionnaire prepared using existing literature-based knowledge was found to be suitable for parents of children with ASD initially diagnosed

in accordance with Chinese cultural background. The results show that the scale has good validity (Cronbach’s $\alpha=0.703$). However, this study still had many shortcomings. Although the process was clear, the entire scale lacked a psychological measurement basis, and its validity needs further improvement. Some of the questions in the questionnaire were perhaps controversial, such as the one about vaccination leading to autism. Although some scholars proposed that vaccination may lead to autism many years ago, the study was later proved to be fraudulent and misleading. In recent years, more literature and reviews have refuted this view (47,48). Despite strong evidence of its safety, some parents were still hesitant to accept the measles, mumps, and rubella vaccine for their children.

Most subjects included in this study were from Guangzhou and its surrounding areas; there was a lack of samples from other parts of China. Currently, under the promotion of Professor Xiao-Bing Zou’s team, the diagnosis and treatment level of ASD in Guangdong province is at the leading level in China. The characteristics of this sample may lead to some bias in the results.

Investigations on the influencing factors of parental knowledge were not comprehensive enough, such as the severity of ASD and number of siblings. Future research will continue to expand the sample source and sample size, increase the accuracy of the scale, and make the survey results more representative of the actual situation in China. In addition, in this study, questionnaires were distributed to and collected from parents before the start of the training program to gain an understanding of their knowledge status before they received professional training. However, we did not conduct a study comparing their knowledge status before and after the training. We have planned a follow-up study to compare the knowledge of parents before and after the training which will help understand the effect of parent training.

Conclusions

Parents of children with ASD had good general awareness of and knowledge about autism. The influence of family demographics on this knowledge was mainly reflected in the following aspects: higher educational level of the mother, lower age of the father, and higher family income were associated with better knowledge and understanding of ASD. If more family members share a common perception of the diagnosis, the knowledge level of parents increases. Active participation in children’s intervention training and

reading professional books may elevate parents' knowledge level. In a nutshell, this article provides evidence for the potential impact of relatively variable factors, including service availability and parents' attitudes and behaviors, on parental knowledge of ASD, suggesting that greater efforts need to be devoted to promoting more targeted parental skills training programs.

Acknowledgments

The authors would like to thank all participants for their time answering the questionnaire and their openness to share their thoughts, attitude, and information about their families with us.

Funding: This work was funded by National Natural Science Foundation of China (No. 81873801) and Science and Technology Planning Project of Guangdong Province, China (No. 20160914), and Shenzhen Science and Technology Program (No. JHZ20190823115412789).

Footnote

Reporting Checklist: The authors have completed the SURGE reporting checklist. Available at <https://tp.amegroups.com/article/view/10.21037/tp-22-113/rc>

Data Sharing Statement: Available at <https://tp.amegroups.com/article/view/10.21037/tp-22-113/dss>

Conflicts of Interest: All authors have completed the ICMJE uniform disclosure form (available at <https://tp.amegroups.com/article/view/10.21037/tp-22-113/coif>). The authors have no conflicts of interest to declare.

Ethical Statement: The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. The research was carried out in line with the Declaration of Helsinki (as revised in 2013). The study was approved by the Ethics Committee of the Third Affiliated Hospital of Sun Yat-Sen University (approval No. [2019] 02-329-01) and informed consent was taken from all the participants.

Open Access Statement: This is an Open Access article distributed in accordance with the Creative Commons Attribution-NonCommercial-NoDerivs 4.0 International License (CC BY-NC-ND 4.0), which permits the non-

commercial replication and distribution of the article with the strict proviso that no changes or edits are made and the original work is properly cited (including links to both the formal publication through the relevant DOI and the license). See: <https://creativecommons.org/licenses/by-nc-nd/4.0/>.

References

1. Ssucharewa GE, Wolff S. The first account of the syndrome Asperger described? Translation of a paper entitled "Die schizoiden Psychopathien im Kindesalter" by Dr. G.E. Ssucharewa; scientific assistant, which appeared in 1926 in the *Monatsschrift für Psychiatrie und Neurologie* 60:235-261. *Eur Child Adolesc Psychiatry* 1996;5:119-32.
2. Kim YS, Leventhal BL, Koh YJ, et al. Prevalence of autism spectrum disorders in a total population sample. *Am J Psychiatry* 2011;168:904-12.
3. Baio J, Wiggins L, Christensen DL, et al. Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014. *MMWR Surveill Summ* 2018;67:1-23.
4. Maenner MJ, Shaw KA, Baio J, et al. Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2016. *MMWR Surveill Summ* 2020;69:1-12.
5. Wang F, Lu L, Wang SB, et al. The prevalence of autism spectrum disorders in China: a comprehensive meta-analysis. *Int J Biol Sci* 2018;14:717-25.
6. Clark E, Zhou Z, Du L. Autism in China: Progress and challenges in addressing the needs of children and families. *International Journal of School & Educational Psychology* 2019;7:135-46.
7. Sun X, Allison C, Auyeung B, et al. Service provision for autism in mainland China: a service providers' perspective. *Res Dev Disabil* 2013;34:440-51.
8. Wang J, Zhou X, Xia W, et al. Autism awareness and attitudes towards treatment in caregivers of children aged 3-6 years in Harbin, China. *Soc Psychiatry Psychiatr Epidemiol* 2012;47:1301-8.
9. Liu Y, Li J, Zheng Q, et al. Knowledge, attitudes, and perceptions of autism spectrum disorder in a stratified sampling of preschool teachers in China. *BMC Psychiatry* 2016;16:142.
10. Zhou L, Wang J, Huang J. Brief Report: Health Expenditures for Children with Autism and Family Financial Well-Being in China. *J Autism Dev Disord*

- 2022;52:3712-7.
11. Durand-Zaleski I, Scott J, Rouillon F, et al. A first national survey of knowledge, attitudes and behaviours towards schizophrenia, bipolar disorders and autism in France. *BMC Psychiatry* 2012;12:128.
 12. Alsehemi MA, Abousaadah MM, Sairafi RA, et al. Public awareness of autism spectrum disorder. *Neurosciences (Riyadh)* 2017;22:213-5.
 13. Bakare MO, Ebigbo PO, Agomoh AO, et al. Knowledge about childhood autism among health workers (KCAHW) questionnaire: description, reliability and internal consistency. *Clin Pract Epidemiol Ment Health* 2008;4:17.
 14. Bakare MO, Ebigbo PO, Agomoh AO, et al. Knowledge about childhood autism and opinion among healthcare workers on availability of facilities and law caring for the needs and rights of children with childhood autism and other developmental disorders in Nigeria. *BMC Pediatr* 2009;9:12.
 15. Igwe MN, Ahanotu AC, Bakare MO, et al. Assessment of knowledge about childhood autism among paediatric and psychiatric nurses in Ebonyi state, Nigeria. *Child Adolesc Psychiatry Ment Health* 2011;5:1.
 16. Catalano D, Holloway L, Mpofu E. Mental Health Interventions for Parent Carers of Children with Autistic Spectrum Disorder: Practice Guidelines from a Critical Interpretive Synthesis (CIS) Systematic Review. *Int J Environ Res Public Health* 2018;15:341.
 17. Stone WL. Cross-disciplinary perspectives on autism. *J Pediatr Psychol* 1987;12:615-30.
 18. Stone WL, Rosenbaum JL. A comparison of teacher and parent views of autism. *J Autism Dev Disord* 1988;18:403-14.
 19. Heidgerken AD, Geffken G, Modi A, et al. A survey of autism knowledge in a health care setting. *J Autism Dev Disord* 2005;35:323-30.
 20. Täresh SM, Ahmad NA, Roslan S, et al. Preschool Teachers' Beliefs towards Children with Autism Spectrum Disorder (ASD) in Yemen. *Children (Basel)* 2020;7:170.
 21. Golson ME, Benallie KJ, Benney CM, et al. Current state of autism knowledge in the general population of the United States. *Research in Autism Spectrum Disorders* 2022;90:101886.
 22. Zhang Y, Xu Q, Lu P, et al. Skill Training for Parents with ASD Children in China. *Pediatr Med* 2019;2:47.
 23. McClain MB, Harris B, Schwartz SE, et al. Brief Report: Development and Validation of the Autism Spectrum Knowledge Scale General Population Version: Preliminary Analyses. *J Autism Dev Disord* 2019;49:3007-15.
 24. Obeid R, Daou N, DeNigris D, et al. A Cross-Cultural Comparison of Knowledge and Stigma Associated with Autism Spectrum Disorder Among College Students in Lebanon and the United States. *J Autism Dev Disord* 2015;45:3520-36.
 25. Harrison AJ, Bradshaw LP, Naqvi NC, et al. Development and Psychometric Evaluation of the Autism Stigma and Knowledge Questionnaire (ASK-Q). *J Autism Dev Disord* 2017;47:3281-95.
 26. Harrison AJ, Slane MM, Hoang L, et al. An international review of autism knowledge assessment measures. *Autism* 2017;21:262-75.
 27. Benallie KJ. Parent knowledge of autism spectrum disorder. All graduate theses and dissertations. 2019. Available online: <https://digitalcommons.usu.edu/etd/7693>
 28. Ebrahimi H, Malek A. Factors associated with the attitude and knowledge and behavior of mothers raising a child with autism spectrum disorder. *International Research Journal of Applied and Basic Sciences* 2013;10:3104-08.
 29. Mitchell GE, Locke KD. Lay beliefs about autism spectrum disorder among the general public and childcare providers. *Autism* 2015;19:553-61.
 30. Meadan H, Ostrosky MM, Zaghawan HY, et al. Promoting the social and communicative behavior of young children with autism spectrum disorders: a review of parent-implemented intervention studies. *Topics in Early Childhood Special Education* 2009;29:90-104.
 31. Zuckerman KE, Sinche B, Mejia A, et al. Latino parents' perspectives on barriers to autism diagnosis. *Acad Pediatr* 2014;14:301-8.
 32. McConachie H, Diggie T. Parent implemented early intervention for young children with autism spectrum disorder: a systematic review. *J Eval Clin Pract* 2007;13:120-9.
 33. Serdar CC, Cihan M, Yücel D, et al. Sample size, power and effect size revisited: simplified and practical approaches in pre-clinical, clinical and laboratory studies. *Biochem Med (Zagreb)* 2021;31:010502.
 34. American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 5th edition. Arlington, VA: American Psychiatric Publishing, 2013:991.
 35. Hansen LK. Development and validation of a survey of knowledge of autism spectrum disorder. Master's Theses. 2015. Available online: http://aquila.usm.edu/masters_theses/141
 36. Zou XB. Intervention principles and BSR models of autism spectrum disorders. *Chinese Journal of Child Health Care* 2019;27:1-6.

37. Akoglu H. User's guide to correlation coefficients. *Turk J Emerg Med* 2018;18:91-3.
38. Linden WJVD, Hambleton RK. *Handbook of modern item response theory*. New York, NY: Springer, 1997.
39. Verma JP, Abdel-Salam ASG. Testing statistical assumptions in research. 2019. Available online: https://www.researchgate.net/publication/331461660_Testing_Statistical_Assumptions_in_Research
40. Zhou WZ, Ye AY, Sun ZK, et al. Statistical analysis of twenty years (1993 to 2012) of data from mainland China's first intervention center for children with autism spectrum disorder. *Mol Autism* 2014;5:52.
41. Graves KN, Shelton TL. Family empowerment as a mediator between family-centered systems of care and changes in child functioning: identifying an important mechanism of change. *Journal of Child and Family Studies* 2007;16:556-66.
42. Karst JS, Van Hecke AV. Parent and family impact of autism spectrum disorders: a review and proposed model for intervention evaluation. *Clin Child Fam Psychol Rev* 2012;15:247-77.
43. McCabe H. Bamboo shoots after the rain: development and challenges of autism intervention in China. *Autism* 2013;17:510-26.
44. Matson ML, Mahan S, Matson JL. Parent training: A review of methods for children with autism spectrum disorders. *Research in Autism Spectrum Disorders* 2009;3:868-75.
45. Ho M, Lin L. Efficacy of parent-training programs for preschool children with autism spectrum disorder: A randomized controlled trial. *Research in Autism Spectrum Disorders* 2020;71:101495.
46. McDevitt SE. While quarantined: An online parent education and training model for families of children with autism in China. *Res Dev Disabil* 2021;109:103851.
47. DeStefano F, Shimabukuro TT. The MMR Vaccine and Autism. *Annu Rev Virol* 2019;6:585-600.
48. Bölte S, Girdler S, Marschik PB. The contribution of environmental exposure to the etiology of autism spectrum disorder. *Cell Mol Life Sci* 2019;76:1275-97.

Cite this article as: Wang F, Lao UC, Xing YP, Zhou P, Deng WL, Wang Y, Ji Y, Chen MY, Li H, Zou XB. Parents' knowledge and attitude and behavior toward autism: a survey of Chinese families having children with autism spectrum disorder. *Transl Pediatr* 2022;11(9):1445-1457. doi: 10.21037/tp-22-113