Autism and Mental Retardation of Young Children in China¹

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Objective To understand the prevalence and rehabilitation status of autism and mental retardation in China. **Methods** Screening test and clinical assessment were conducted for the diagnosis of autism and mental retardation. The assessment included investigation of the histories of medical conditions and development of these two disorders, utilization and needs for the rehabilitation service, and related intellectual and behavioral appraisal. **Results** Among the 7345 children investigated, the prevalence of autism disorder was 1.10 cases per 1000 children aged 2-6 years (95% CI=0.34 to 2.54), and the prevalence of mental retardation was 10.76 cases per 1000 children (95% CI=8.40 to 13.12). All the children suffering from autistic disorder were intellectually disabled, whereas 31.0% of the non-autism mental retardates had other disabilities. The medical conditions prior to birth and perinatal period were important potential factors for autism. Half of the autistic children and 84% of the children with non-autism mental retardation had never received any rehabilitative service. **Conclusions** The prevalence of autistic disorder in children aged 2-6 years in Tianjin is rather high. It is urgent to improve the status of the autistic and intelligently disabled young children in China. In order to upgrade the level of early diagnostic and improve the intervention to autism and mental retardation, public awareness and training courses should be heightened.

Key words: Autism; Mental retardation; Epidemiology; China

INTRODUCTION

Autism is a serious, lifelong neurodevelopment disorder characterized by impaired social interaction, delayed and deviant communication, restricted and repetitive patterns of interests and behaviors^[1]. This kind of triad impairments is often accompanied with cognitive deficits ranging from mild to profound levels^[2]. Individuals from all ethnic and socioeconomic backgrounds might be affected^[3]. Mental retardation is a condition of arrested or incomplete mental development, especially characterized by impairment of skill intelligence, i.e. abilities of cognition, language, motor, and social communication. Intellectual retardation may occur with or without other mental or physical defects^[4]. usually associated Autism is with mental retardation^[5].

Autism as a kind of concept has been studied over the past 60 years since it was first described by Kanner^[6]. At present, autism is recognized as one of the pervasive developmental disorders (PDD)^[7]. DSM-IV and ICD-10 have been used as the diagnostic criteria for autism under the title of pervasive developmental disorders. The prevalence of autism has increased as its concept has been expanded. Early epidemiological studies reported that the rates of autism are about 2-5 cases per 10 000 children^[2]. In the United States, Boyle *et al.*^[8] reported recently that the prevalence of autistic disorder in Brick Township is 40 per 10 000 children aged 3-10 years. Variable estimates of the prevalence reported could reflect the differences in case definition, ascertainment strategy, or demographic characteristics^[9].

In China, both clinical doctors and public health workers are lack of the knowledge and experiences on autism or PDD. Clinical pediatricians usually concern about only individual autistic children, and have little information on the prevalence of this

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Abbreviations: DSM-IV: Diagnostic and Statistical Manual, 4th edition; ICD-10: 10th revision of the International Classification of Diseases.

disorder. Since China has the largest population in the world, it is important to know the population-based prevalence and characteristics of autism. The objectives of this study were to understand the prevalence of autistic disorder and mental retardation in pre-school children in China, to identify the characteristics of autistic disorder and mental retardation and review the medical history of the patients, to estimate the patients' needs for the treatment and intervention and the status of utilizing health care facilities, to explore and establish the appropriate ways for the patients to be diagnosed earlier. An active method of looking for the cases among the children randomly selected from the communities was used in the present study. Although the survey was only a pioneer epidemiological study in Tianjin, it is helpful to understand the prevalence of autistic disorder in the whole country. The knowledge we have got from this survey may give important insights into the pathological signs and the progression of autism, and holds promise for earlier intervention and prevention.

METHODS

Population

Tianjin, the third largest metropolis in China, is located in the east about 120 miles away from Beijing, the capital of China. The area of Tianjin is about 119 000 km² including 6 urban districts and 4 rural regions, and the total population is more than 10 million in the year of 2000. The target population was about 745 000 randomly selected from one urban district and one rural region, whose socioeconomic status reflected the middle level of urban and rural people in Tianjin, respectively.

The sample subjects were children aged 2 to 6 years born before June 30, 2000. According to the 5th national census data in 2000, the proportion of 0 to 6 years old children in the total population of Tianjin was approximately 6%, whereas the number of children aged 2 to 6 years in the two regions under study was estimated as 45 000. Based on the estimated population size and 95% level of confidence, the sampling size should be about 7000 children (EpiInfo Software CDC). According to the personal income level ("high", "middle", and "low"), a stratified sampling method was applied in this study. Three communities were randomly sampled from one of the urban districts and one of the rural regions, respectively. A total of 7416 children aged 2 to 6 years were enrolled, and 7345 (99%) of them (3927 males and 3418 females) were actually investigated. The average age was 3.09±1.93 years.

Case Ascertainment

Mental retardation Mental development of the subjects was screened by developmental pediatricians using a standardized DDST (the Denver Development Screening Test-Chinese Revision, standardized in 1982 in China). If a subject was suspected of mental retardation by DDST, a definite diagnosis with the Gesell Developmental Scale (standardized and revised in China in 1985 and 1990) and ICD-10 was conducted. The mental retardation was divided into 4 degrees by development quotient (DQ): mild (DQ 74-57), moderate (DQ 56-41), severe (DQ 40-25) and profound (DQ<25).

Autism All subjects were first screened by CABS-CV (Chinese Version of Clancy Autism Behavior Scale)^[10], which consists of 14 items. If the score of CABS-CV exceeded or was equal to 7, the subject would be considered having a suspected autism, and had to have another definite diagnosis by using CARS-CV (the Chinese version of Childhood Autism Rating Scale)^[11]. The sum of scores ranged from 15 to 60. According to the recommendation of Histeru *et al.*^[12], the cut-off score of CARS-CV for diagnosing autistic disorder was 30 and above in this study. The scores were reexamined and checked by other specialists. Final diagnosis was determined by the consensus of two pediatricians by using DSM-IV. The diagnostic results were effective only when the consensus of the two clinicians was confirmed by *Kapper*≥0.9.

Medical and developmental histories Detailed medical and developmental histories were obtained by questionnaires and face-to-face interviews between the clinicians and parents. During screening, the questionnaire A was completed by the pediatricians who were also specialists in children development. The general socio-demographic information of the children (birthday, sex, nationality, etc.), parents (marriage status, occupation, and education level, etc.), and the family (members, income, and the person bring up the child, etc.), as well as the screening results were collected. In order to check the diagnosis of mental retardation and autism of a suspected child, the pediatrician and psychiatrist completed the questionnaire Β. Information on the medical history, medical events in life, possible affections, the rehabilitation status and the needs for rehabilitation service were included.

The rehabilitation status of autism and mental retardation was the key information collected during the interview. The rehabilitation modalities included hospital therapy which means that the child was receiving medication, operation and physical training in the hospital, family treatment which means that the patient was conducting functional training or associated adjunctive functional training under guidance and doing at home, institution treatment which means that the patient was undertaking special therapy and had training in a special technical rehabilitation center for handicapped persons, and educational treatment which means that the patient was now learning in a nursery or a kindergarten or a general primary school.

Other developmental disabilities, such as hearing, vision, and limb disabilities might be identified through physical examination.

Statistical Analysis

This study used the cluster sampling methods, and P<0.05 was considered statistically significant. Confidence intervals were calculated at the 95% level. Chi-square test was used to compare categorical data and *t* test was used to compare the group means. All calculations and analyses were performed by using SPSS/PC 10.0 software in the Institute of Child and Adolescent Health, Peking University Health Science Center.

RESULTS

Prevalence of Autism and Mental Retardation

Table 1 shows the sex and age distribution of autistic and mentally retarded children. Seventy-nine children, 60 boys (75.9%) and 19 girls (24.1%), were identified as mental retardation. The prevalence of mental retardation was 10.76 cases per 1000 children aged 2 to 6 years (Table 1). No significant difference in mental retardation was found between age groups.

Sixteen (0.22%) children were identified having suspected autism and 8 of them were diagnosed as autistic disorder by using CARS and DMS-IV criteria. The prevalence of autistic disorder was 1.10 cases per 1000 children aged 2 to 6 years. There were 7 (87.5%) autistic disorder boys, and the male-to-female ratio was 7:1, and 5 (62.5%) from the urban district and 3 (37.5%) from the rural region. The prevalence of autistic disorder tended to be higher among the 2-3 year-old children (Table 1).

Crowna		Autistic Disorder		Mental Retardation	
Groups	n —	п	‰ (95% CI)	п	‰ (95% CI)
Age (year)					
2	1428	3	2.10 (0.6-8.8)	17	11.9 (6.28-17.5)
3	1455	3	2.06 (0.6-8.8)	13	8.93 (4.10-13.7)
4	1489	1	0.67 (0.1-5.6)	13	8.73 (4.00-13.46)
5	1679	0	0	19	11.32 (6.26-16.38)
6	1294	1	0.77 (0.67-5.6)	17	13.14 (6.93-19.34)
Total	7345	8	1.10 (0.34-2.54)	79	10.76 (8.40-13.12)
Sex					
Male	3927	7	1.78 (0.46-3.10) ^a	60	15.28 (11.44-19.12) ^b
Female	3418	1	0.29 (0.6-8.8) ^a	19	5.56 (3.07-8.05) ^b
Regions					
Urban	3606	5	1.37 (0.16-2.6) ^c	41	11.37 (7.91to14.83) ^d
Suburban	3739	3	$0.80(0.6-8.8)^{c}$	38	10.16 (6.95to13.37) ^d

TABLE 1

Note. ^a Male autism vs. female autism, fisher exact χ^2 test P > 0.05; ^b Male MR vs. female MR, Chi-square test $\chi^2 = 15.89$, P < 0.01; ^c Autism in urban vs. autism in suburban, fisher exact χ^2 text P > 0.05; ^d MR in urban vs. MR in suburban, Chi-square test $\chi^2 = 0.25$, P > 0.05.

The total CARS-CV score was significantly higher in the autistic disorder group (39.4 ± 7.8) than in the suspected autism group (22.3 ± 2.9) . Among the 8 patients with autistic disorder assessed by CARS-CV, 7 (87.5%) were mild-moderate, and 1 (12.5%) severe.

The development quotient (DQ) of autistic disorder children (34.75) was lower than that of the non-autism mental retardation group (60.38) and the

suspected autism group (52.57). The degree of mental retardation in the autistic disorder group (12.5% mild and 37.5% profound) and in the non-autism mental retardation group (50.7% mild and 11.8% profound) was different, too.

Medical Conditions and Histories

The medical conditions are listed in Table 2. Evident disease histories were found in 56 cases in

the non-autism group, and 35 (62.5%) of them suffered from prenatal diseases. On the other hand, among the five (62.5%) autistic patients suffering from postnatal diseases, one had epilepsy and the other had high fever and twitch, the remaining 3 had other pediatric common diseases such as pneumonia and diarrhea.

Table 3 shows other developmental disorders

through sensory-perceived examination. Among the eight autistic children, only one was diagnosed as cerebral palsy. On the other hand, 22 (31.0%) of the 71 children with non-autistic mental retardation had other developmental disorders; 4 had congenital cataract, retinal optic neuropathy or other vision disabilities; and 18 had cerebral palsy, congenital osteoarthropathia and other extremity disabilities.

TABL	JE 2	

Specific Medical Conditions in Children With Autism and Non-autistic Mental Retardation					
Madical Conditions	Autistic Disorder		Mental Retardation		
Medical Columnis	n	(%)	n	(%)	
Before Birth					
Chromosomal Abnormality	-	-	2	2.8	
Hereditary Syndrome	-	-	1	1.4	
Hereditary Disease	-	-	1	1.4	
Antepartum Infection	-	-	2	2.8	
Premature Infant	1	12.5	13	18.3	
Intrauterine Asphyxia	1	12.5	7	9.9	
Other Antepartum Diseases	-	-	9	12.7	
Perinatal Period					
Intrapartum Apnoea	1	12.5	9	12.7	
After Birth					
Kernicterus	-	-	1	1.4	
Cerebrovascular Disease	-	-	2	0.8	
Other Diseases	5	62.5	9	12.7	
No Medical Condition			15	21.1	
Time Stage Total (Medical Conditions)*					
Before Birth Problem	2	25.0	35	62.5	
Perinatal Problem	1	12.5	9	16.1	
After Birth Problem	5	62.5	12	21.4	

Note. *In different time stage group of MR vs. group of autism, Chi-square test χ^2 =7.88, *P*=0.02.

TABLE 3

Other Developmental Disorders in Mental Retardation Children With and Without Autistic Disorder

Other Developmental Disorders	Mental Retardation (n)			
Other Developmental Disorders	Autism n=8	Non-autism <i>n</i> =71		
Hearing Disability	0	0		
Vision Disability				
Congenital Cataract	0	1		
Retinal Optic Neuropathy	0	3		
Subtotal	0	4		
Extremity Disability				
Cerebral Palsy	1	15		
Congenital Osteoarthropathia	0	1		
Others	0	2		
Subtotal	1	18		
Total	1	22		

Rehabilitation and Health Service

The rehabilitation of the children with autistic and mental disorder is shown in Table 4. Sixty-one (88.41%) children with non-autism mental retardation and 4 (50%) children with autistic disorder received no rehabilitative service. Only four children with autistic disorder received some intervention and rehabilitation service.

The factors affecting patients' access to health care service are shown in Table 5. Dwelling region, mother's education and family income had significant influences. The patients living in urban areas, whose mothers had higher education and higher family income had more opportunities to get health care and rehabilitation services.

TABLE 4

Utilization Of Health Care Service in Children With Autistic Disorder and Non-autistic Mental Retardat
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Rehabilitation Status	Non-autism ^c n=69 ^b	Autism n=8	Total n=77
No Treatment	61 (88.41%) ^a	4 (50%) ^a	65 (84.42%)
Treatment	8 (11.59%) ^a	4 (50%) ^a	12 (15.58%)
At Hospital	4	2	6
At Special Institution	3	0	3
At Educational Institution	1	1	2
Intervention at Home	0	1	1

Note. ^a Autism group versus non-autism MR group, Chi-square test χ^2 =8.04, *P*=0.0046. ^b Two parents did not provide this information. ^c Non-autism, non-autistic mental retardation.

TABLE 5

Factors Influencing Rehabilitation Service of Patients					
Rehabilitation Service					
Factors	Yes	No	Total	χ^2	Р
Region:				5.60	0.018
Urban	10	31	41		
Suburban	2	36	38		
Gender:				1.68	0.195
Male	11	1	12		
Female	50	17	67		
Fathers' Educational Level:				7.20	0.126
University	3	6	9		
High School	6	18	24		
Middle School	3	33	36		
Primary School	0	9	9		
Illiterate	0	1	1		
Mothers' Educational Level:				12.72	0.013
University	5	6	11		
High School	3	13	16		
Middle School	3	32	35		
Primary School	0	12	12		
Illiterate	0	4	4		
Family Income:				10.76	0.001
Below 2000 Yuan	1	40	41		
Above 2000 Yuan	11	27	38		

When the parents were inquired about the needs for rehabilitation services, 50% (4 cases) and 37.5% (3 cases) of them chose to have treatment and rehabilitation at hospitals and to get intervention at home, respectively. One parent hoped to let his child receive care in a specialized institution. However, no parents of the children with non-autistic mental retardation hoped to let their children have therapy at hospitals, but 82.3% of them preferred to get intervention for their children at home, and 19.7% of them preferred to have rehabilitation of their children in specialized institutions.

DISCUSSION

Gillberg C used the criteria of DSM-III-R to do survey in Sweden, in which the prevalence of autistic disorder was 0.4 case per 1000 children (95% CI= 0.3-0.52) in 1984^[13], and 0.95 case per 1000 children (95% CI = 0.74-1.12) in $1991^{[14]}$, which are much close to our findings. However, the survey in the USA reported that the prevalence of autistic disorder is 4 cases per 1000 children aged 3 to 10 years^[15] which is much higher than ours. No doubt, different methods for discovering cases may affect the results of epidemiological study. However, the difference in diagnostic criteria, and especially the higher awareness of autism may have stronger effects. There are two differences between our survey and other studies. One is that autistic disorder cases were included in our study and other subsets were excluded, the other is that the diagnostic procedure used to distinguish autistic disorder from suspected autism in our study was \geq 30 scores of CARS as the cut-off point, and DSM-IV was used to diagnose the autistic disorder finally. There may exist some shortcomings in our procedure to discover the cases, and several cues and information, may be missed because the autism awareness in China is much lower than that in the USA, Europe, and other developed countries.

The prevalence of mental retardation in our study is 1.1% in children aged 2 to 6 years, which is quite similar to other latest surveys in the range of 1% to 2% in pre-school children^[16].

The result of our survey showed that all autistic children were intellectually disabled (DQ<75), which is different from some other studies. Most recent epidemiological studies reported that only about 50% to 75% of autistic children have mental retardation^[17-18]. However, using the DMS-III-R criteria for diagnosis, Gillberg *et al.*^[14] found that 80% of autistic children are accompanied with mental

retardation. Using the ICD-10 criteria for diagnosis, Arvidsson *et al.*^[19] also found that 100% of autistic Swedish children suffer from mental retardation. The reason for this phenomenon in these two studies may be due to the fact that they focused only on the typical autistic disorder. Another important reason is that the common people and investigators in China are all lack of knowledge and awareness for autism, and that autistic children with normal or mild intellectual disabilities might be neglected during the screening and case-assortment processes.

Developmental disorders are usually caused by specific medical conditions, and identification of the underlying causes may have important implications for the management, estimation of prognosis and prediction of recurrence of these disorders. In reviewing the surveys related to autistic children, Gillberg *et al.*^[13] and Colman *et al.*^[20] concluded that 11% to 37% of patients are caused by medical conditions. Most of the surveys paid attention to the medical conditions affecting brain and other nervous system. Four autistic cases (50%) in our study had related medical conditions. If common pediatric diseases are neglected, three fourths of them are related to the medical signs that occur during pregnancy and perinatal period. Some authors have suggested that the basic pathology in most autistic spectrum disorder is present before birth^[21]. Most autistic children in the present study suffered from sensory impairment. We found that one (12.5%) autistic child and twenty-two children (31.0%) with non-autistic mental retardation had one or more developmental disabilities as shown in Table 3. A survey from the USA in 1998 showed that about 30% of the children with non-autistic mental retardation younger than 17 years old have one or more developmental disabilities^[22]. These findings are quite similar to our study, but other developmental disabilities are relatively higher than ours.

Autistic disorder and mental retardation are a major public health and social problem, and both have lifelong influence on the patients. Therefore, it is necessary and conducive to start rehabilitative care as early as possible. However, our study showed that even in Tianjin, the third largest metropolis in China, at least 50% of autistic children and 88.4% of mentally retarded children did not receive any kind of intervention or rehabilitative treatment. The earlier the treatment and intervention of the autistic and mentally retarded children, the better the physical and mental development, as well as the improvement of their life quality. Family support is also very important, especially for those living in rural areas. Most of them have low family income, and their

mothers have low education. As for the urban patients who have relatively high family income and higher educated mothers, not only the cause of the disorder, but also the most important resources and the most effective factors in promoting the children's mental health and behavior should be considered. Our investigation showed that all parents hoped to be appropriate intervention accessible to and rehabilitation for their children, but their economic status, cultural factors and the awareness of autism and mental retardation have hampered them to have earlier intervention and rehabilitation, even in the metropolis like Tianjin.

Future efforts should be directed to the following two areas. First, it is important to further analyze the prevalence and changing trend of autism and pervasive developmental disorder in different Chinese populations. Second, the awareness of autism and pervasive developmental disorders should be elevated, the channels and methods to improve early interventions and rehabilitative care should be explored.

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