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Study on the Social Adaptation of Chinese Children with Down Syndrome

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Purpose: To evaluate social adjustment and related factors among Chinese children with Down syndrome (DS). **Patients and Methods:** A structured interview and Peabody Picture Vocabulary Test (PPVT) were conducted with a group of 36 DS children with a mean age of 106.28 months, a group of 30 normally-developing children matched for mental age (MA) and a group of 40 normally-developing children matched for chronological age (CA). Mean scores of social adjustment were compared between the three groups, and partial correlations and stepwise multiple regression models were used to further explore related factors. **Results:** There was no difference between the DS group and the MA group in terms of communication skills. However, the DS group scored much better than the MA group in self-dependence, locomotion, work skills, socialization and self-management. Children in the CA group achieved significantly higher scores in all aspects of social adjustment than the DS children. Partial correlations indicate a relationship between social adjustment and the PPVT raw score and also between social adjustment and age (significant r ranging between 0.24 and 0.92). A stepwise linear regression analysis showed that family structure was the main predictor of social adjustment. Newborn history was also a predictor of work skills, communication, socialization and self-management. Parental education was found to account for 8% of self-dependence. Maternal education explained 6% of the variation in locomotion. **Conclusion:** Although limited by the small sample size, these results indicate that Chinese DS children have better social adjustment skills when compared to their mental-age-matched normally-developing peers, but that the Chinese DS children showed aspects of adaptive development that differed from Western DS children. Analyses of factors related to social adjustment suggest that effective early intervention may improve social adaptability.

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INTRODUCTION

Most studies on the development of children with disabilities focus either on clinical findings or on mechanistic models of learning. With recent theoretical advances in the field of child development research, a broader view on the skills of children with inherited developmental retardation is needed. Studying atypical developmental patterns may contribute considerably to the understanding of human adaptive processes.

Down syndrome (DS), also known as trisomy 21, is the most common cause of inherited intellectual disability. The syndrome is clinically characterized by congenital malformations (especially of the heart and the gastrointestinal tract) which result in a high mortality early in life. As a result of many advancements in the medical treatment of individuals with DS, long-term survival has considerably improved. Estimates of life expectancy in Western countries suggest that about 44% of patients with DS reach the age of 60 and 14% reach the age of 68.[1]

Delayed development of cognitive capacity is a primary consequence of DS.[2,3] Study results show a slowed cognitive development over the first three years of life[4-7] so that by early childhood most children with DS have standard cognitive performance scores at least two standard deviations below the mean reference scores. Their cognitive skills grow at a lower rate than that found in normally-developing children. Other results

show a general decline in standard cognitive scores in the late adolescent period.[8]

Investigations on the emergence of other skills in specific areas of development have revealed typical patterns. Some researchers reported that children with DS appear to exhibit a particular weakness in communication, especially with respect to expressive (i.e., spoken) language.[9-15] In contrast, social development and the mastery of adaptive skills associated with the tasks of daily living are far less affected.[15,16] However, development in these areas also takes place at a slower rate than in normally-developing children.

DS provides a unique opportunity to study a group of children with a type of developmental retardation that is etiologically distinct and homogeneous yet functionally heterogeneous.[17,18] In order to explore the potential for social adaptability and development in children with DS more systematically, DS patients should be studied in comparison with normal children matched for both mental age and chronological age. To our knowledge, no such studies have been reported on DS children of Chinese ethnicity. How do the typical profiles of cognitive retardation affect the social development of Chinese children with DS? Do the same patterns found in Western DS children exist in Chinese children with DS? The exploratory study presented here focuses on the question of whether an etiology-specific profile exists for social adaptation in Chinese DS using the Infants-Junior Middle School Students' Social-Life Abilities Scale.[19]

MATERIALS AND METHODS

Participants

A total of 106 individuals participated in the study, including 36 DS children, 30 children matched for mental age (MA group) and 40 children matched for chronological age (CA group). DS children with moderate to severe levels of cognitive disability were recruited at the Children's Health Care outpatient clinic of the Children's Hospital (Zhejiang University, School of Medicine) between September 2004 and August 2006. With the exception of three children, the IQs of Chinese DS children could not be measured with the Chinese Revised Version of the Wechsler Intelligence Scale for Children (WISC-R). The highest IQ was found to be 47. The clinical diagnosis of DS was cytogenetically confirmed and 35 (97.2%) of the children were found to have complete trisomy 21 and only one (2.8%) had a mosaic form. Controls were recruited from kindergarten groups and primary schools. All parents or guardians of controls reported their children to be in good physical and mental health, and there were no known previous or current neurological or psychiatric diseases or current drug intake among the controls.

The mean age was 106.28 ± 35.58 months (range 52 - 167 months) for DS patients, 36.17 ± 10.66 months (range 20 - 65 months) in the MA group and 92.15 ± 30.83 months (range 43-144 months) in the CA group. All of the children lived at home, although three DS children (8.3%) were not living with their genetic parents. Thirteen of the study participants (11 DS children, two children in the CA group) had one sibling. There were no significant differences in terms of the child's sex, family income or parental marital status (Table 1).

Written informed consent was obtained from the legal representative (relatives and/or guardians) of each study participant.

Procedures

Structured interviews with the child and his/her parents or guardians were conducted by trained doctors in a quiet room at the outpatient department of our institution. Verbal mental age was tested with the Peabody Picture Vocabulary Test (PPVT).[20] The participant was seated in front of a computer touch screen at an eye-to-screen distance of approximately 40 cm and was requested to point at the appropriate picture with his/her finger. Results were automatically recorded by the computer. Thereafter, a 132-item Infants-Junior Middle School Students' Social-Life Abilities Scale was used to assess the child's social adjustment. Parents or guardians were interviewed about the performance of their children. A variety of socio-demographic and medical history variables, including sex, age, family structure, family income,

parental marital status, parents' education, mode of delivery and newborn history were also obtained at the same time.

Measures

Social adjustment

Social adjustment was the outcome of interest in this investigation. The interview form of the Infants-Junior Middle School Students' Social-Life Abilities Scales was used to assess six dimensions: self-dependence, locomotion, work skills, communication, socialization and self-management. This scale is a 132-item questionnaire measuring an individual's personal and social competence from six months of age through junior middle school. Each item is worth one point. A perfect score is 132, which includes 31 points in self-dependence, 18 in locomotion, 20 in work skills, 23 in communication, 22 in socialization, and 18 in self-management. Data on this questionnaire were gathered through a structured interview that was conducted with parents or guardians. The interviewer asked the parents or guardians to identify the skills their children demonstrated on a regular basis. Self-dependence included skills such as drinking, putting on clothes and bathing. Locomotion included sitting, running, going to school, and traveling. Work skills included drawing, opening a bottle and cooking. Communication included speaking, reading and writing. Socialization included showing an interest in others, having a preferred friend and engaging in school activities. Self- management included doing something by oneself, taking care of elderly and younger people, saving money, and planning. For example, if the child could put on clothes by himself he passed the item and got one point, or if the child failed he got no points for that item. The Infants-Junior Middle School Students' Social-Life Abilities Scale has excellent test-retest and equivalence reliability and excellent concurrent validity.

Cognitive development

Matching on verbal mental age was performed using the Chinese Revised Version of the PPVT. There are 120 trials in the test and each consists of four pictures. The child was asked to select the one picture from a set of pictures that was related to what the interviewer said. For example, when the interviewer said "banana" the child should choose the picture showing a banana. The total score was 120 points, and the raw score was the total number of correct choices. When raw score is beyond or equal to 30, it means that the mental age of the child is beyond three years three months old. If the raw score is below 30, the mental age can not be found out. In our study, the raw score on the PPVT was adopted for measuring cognitive development.

Data analysis

The children were divided into three groups for analysis (the DS group and the MA and CA groups). All information from the questionnaire was entered into an SPSS database and analyzed with the SPSS 13.0 software package for Windows. Statistical tests were performed as two-sided tests. A p-value of 0.05 or less indicated statistical significance. T-tests were used to compare two continuously distributed variables, and a non-parametric test (Mann-Whitney U-test) was used for variables with distributions other than normal, i.e. for all factors of social adjustment. Chi-squared tests were based on one or more degrees of freedom as indicated in Table 1. A partial correlation was used to further explore the relationship between cognition and social adjustment. Stepwise multiple linear regression models were employed to identify factors of family environment that could influence social adjustment.

RESULTS

Socio-demographic profile of the study participants

The sociodemographic characteristics and the newborn history are shown in Table 1. As a result of the matching procedure, the subjects in the MA and DS groups showed no significant difference in terms of PPVT raw score, sex, family income or parental marital status. Similarly, no differences in age, sex, mode of delivery, family income or parental marital status were found between the DS and the CA groups.

Table 1. Sociodemographic Profile of the Sample

Characteristics	DS group (n = 36)	MA group (n = 30)				CA group (n = 40)			
		Mean ± SD/n	t/ χ^2	df	*p* value	Mean ± SD/n	t/ χ^2	df	*p* value
Age	106.28 ± 35.58	36.17 ± 10.66	t = 11.23	64	0.000	92.15 ± 30.83	t = 1.84	74	0.069
Sex			χ^2 = 3.62	1	0.057		χ^2 = 2.16	1	0.142
Male	24	13				20			
Female	12	17				20			
PPVT raw score	22.72 ± 14.63	28.30 ± 13.81	t = 1.58	64	0.119	83.25 ± 24.02	t = 13.41	74	0.000
Mode of delivery			χ^2 = 13.34	1	0.001		χ^2 = 4.04	1	0.133
Vaginal delivery	24	7				22			
Caesarean section	12	23				18			
Newborn history			χ^2 = 9.47	1	0.002		χ^2 = 13.79	1	0.000
Illness	16	3				3			
Health	20	27				37			
Family characteristics			χ^2 = 8.16	2	0.017		χ^2 = 19.53	2	0.000
Nuclear family, only child	11	13				32			
Nuclear family, multiple children	11	1				2			
Extended family	14	16				6			
Family income (yuan/month)			χ^2 = 4.64	2	0.098		χ^2 = 3.62	2	0.163
> 7500	21	16				20			
3000 - 7500	6	11				14			
< 3000	9	3				6			
Parental marital status			χ^2 = 0.73	2	0.693		χ^2 = 3.03	2	0.220
Married, spouse present	33	27				37			
Married, separated	1	2				2			
Divorced	2	1				1			
Father's education (yrs)			χ^2 = 14.03	3	0.003		χ^2 = 18.33	3	0.000
> 16	3	6				11			
12 - 16	8	17				13			
9 - 12	9	2				1			
< 9	16	5				15			
Mother's education (yrs)			χ^2 = 14.46	3	0.002		χ^2 = 13.81	3	0.003
> 16	1	2				9			
12 - 16	6	16				14			
9 - 12	10	8				7			
< 9	19	4				10			

Data are shown as mean ± standard deviation.
The *p* values are calculated with the t-test or the χ^2 test.
DS, Down syndrome; MA, mental age; CA, chronological age.

A higher percentage of delivery by caesarean section was shown for the children in the MA group. DS newborns were reported to have had more diseases when they were born than controls. DS families showed a different family structure compared with controls: one-third of DS families had more than one child. Most families with DS children had a high income of more than 7500 RMB per month and most children in the entire study lived with their parents. Two DS families were divorced, and one family in each of the control groups was divorced as well. The educational level of parents with DS children was much lower than that of the parents of the controls.

Social adjustment

A perfect score is 132 points. Each item is worth

Table 2. Social Adjustment in the DS Group and in the MA Group

Task groups	DS group		MA group		Z	*p* value
	Mean ± SD	Mean rank	Mean ± SD	Mean rank		
Self-dependence	19.97 ± 4.80	43.53	13.27 ± 4.68	21.47	-4.658	0.000
Locomotion	7.50 ± 1.40	39.44	6.37 ± 1.56	26.37	-2.806	0.005
Work skills	8.17 ± 2.36	40.68	6.17 ± 1.98	24.88	-3.360	0.001
Communication	8.31 ± 3.57	34.28	7.57 ± 2.49	32.57	-0.364	0.715
Socialization	9.58 ± 2.30	37.81	8.50 ± 2.16	28.33	-2.017	0.044
Self-management	5.92 ± 2.59	38.82	4.60 ± 1.99	27.12	-2.504	0.012

Data are shown as mean ± standard deviation and mean rank.
The *p* values are calculated with the Mann-Whitney U test.
DS, Down syndrome; MA, mental age.

Table 3. Social Adjustment in the DS Group and in the CA Group

Task groups	DS group		CA group		Z	*p* value
	Mean ± SD	Mean rank	Mean ± SD	Mean rank		
Self-dependence	19.97 ± 4.80	25.15	26.45 ± 4.86	50.51	-5.009	0.000
Locomotion	7.50 ± 1.40	24.18	11.35 ± 3.29	51.39	-5.416	0.000
Work skills	8.17 ± 2.36	22.15	14.40 ± 3.88	53.21	-6.141	0.000
Communication	8.31 ± 3.57	21.00	18.33 ± 4.81	54.25	-6.581	0.000
Socialization	9.58 ± 2.30	21.56	17.13 ± 4.24	53.75	-6.363	0.000
Self-management	5.92 ± 2.59	22.35	13.78 ± 4.63	53.04	-6.082	0.000

Data are shown as mean ± standard deviation and mean rank.
The *p* values are calculated with the Mann-Whitney U test.
DS, Down syndrome; CA, chronological age.

one point. The score for each dimension is the total number of items in the dimension that the children passed. There was no difference in communicational skills between the DS group and the MA group ($Z = -0.36$, $p = 0.715$). DS children scored higher than the MA group in self- dependence ($Z = -4.66$, $p = 0.000$), locomotion ($Z = -2.81$, $p = 0.005$), work skills ($Z = -3.36$, $p = 0.000$), socialization ($Z = -2.02$, $p = 0.044$) and self-management ($Z = -2.50$, $p = 0.012$) (Table 2). Children in the CA group achieved higher scores than DS patients in all dimensions of social adjustment (Table 3).

The relationship between scores of social adjustment and PPVT raw score or age

A perfect score on the PPVT is 120 points. The raw score was the total number of correct choices that the children made. The partial correlations between the PPVT raw score and the six dimensions of social adjustment (controlling for age), as well as the partial correlation between age and the six dimensions of social adjustment (controlling for PPVT and excluding the DS group) were all significant. The correlation coefficients ranged from 0.24 to 0.92 (Table 4).

The relationship between socio-demographic variables and scores of social adjustment

A stepwise linear regression model was employed to explore the relationship between socio-demographic variables and the dimensions of social adjustment. This analysis showed that family structure was the main predictor of social adjustment. Birth history was also a predictor of work skills, communication, socialization and self-management. Using this analysis, parental education was also found to account for 8% of self-dependence, and the mother's educational level

Table 4. Partial Correlation between Dimensions of Social Adjustment and PPVT Raw Score/Age

Task groups	PPVT raw score (controlling for age, n = 106)		Age (controlling for PPVT, n = 70)	
	R	*p* value	R	*p* value
Self-dependence	0.73	0.000	0.26	0.030
Locomotion	0.82	0.000	0.56	0.000
Work skills	0.84	0.000	0.31	0.011
Communication	0.92	0.000	0.42	0.000
Socialization	0.88	0.000	0.24	0.047
Self-management	0.87	0.000	0.30	0.013

The *p* values are calculated with the partial correlation analysis.
PPVT, Peabody Picture Vocabulary Test.

Table 5. Stepwise Linear Regression Analysis of the Sociodemographic Profile and Factors of Social Adjustment

Task groups	Predictors	R	R2	F	B	t	*p* value
Self-dependence	(Constant)				24.75	12.65	0.000
	Family structure	0.35	0.12	14.35	- 2.98	- 4.31	0.000
	Father's education	0.41	0.17	10.45	- 0.61	- 2.85	0.005
	Mother's education	0.45	0.20	8.59	1.16	2.06	0.042
Locomotion	(Constant)				11.60	16.49	0.000
	Family structure	0.33	0.11	12.56	- 1.18	- 3.38	0.000
	Mother's education	0.42	0.17	10.83	- 0.27	- 2.87	0.005
Work skills	(Constant)				16.65	11.48	0.000
	Family structure	0.38	0.15	18.02	- 1.83	- 4.16	0.000
	Newborn history	0.46	0.21	13.53	- 2.79	- 2.80	0.006
Communication	(Constant)				21.31	10.81	0.000
	Family structure	0.40	0.16	19.77	- 2.61	- 4.37	0.000
	Newborn history	0.47	0.22	14.68	- 3.88	- 2.87	0.005
Socialization	(Constant)				20.11	13.05	0.000
	Family structure	0.41	0.17	21.25	- 2.13	- 4.56	0.000
	Newborn history	0.50	0.25	16.78	- 3.41	- 3.22	0.002
Self-management	(Constant)				17.11	10.45	0.000
	Family structure	0.41	0.17	20.53	- 2.22	- 4.49	0.000
	Newborn history	0.50	0.25	16.89	- 3.77	- 3.35	0.001

accounted for 6% of locomotion (Table 5).

DISCUSSION

The aim of the present study was to gain more information about the social adjustment of children with Down syndrome in China. It is important to acknowledge the limitation of the assessment tools and the fact that there are no well-validated instruments for measuring cognitive development in Chinese children with DS. In Western countries, mental retardation is common in DS, with IQs typically in the range of mild (50-70) to moderate (35-50) retardation.[21] In this study, the IQs of only three children could be measured using the WISC-R, and the highest score achieved was 47. PPVT was employed in this study as it has been used in previous studies on developmental disorders, and it seems more suitable than the WISC-R for testing children with DS. Even so, it was not possible to calculate an individual IQ and mental age in most DS patients because their chronological ages exceeded the age

range of the test as the range was from three years six months to eight years six months. Therefore, the PPVT raw score had to be adopted as the measurement of verbal mental age in our study.

An increasing number of women in China choose caesarean section as a less painful mode of delivery, since most of women only have one baby due to the family planning policy. The quality of medical service at a hospital is considered very important in China, and in recent years a high rate of selective caesarean sections has occurred as it is widely accepted as a proper way to avoid injuries of the mother and the newborn during labor and delivery. In this study the caesarean birth rate was higher in the MA group than in the two other groups.

DS children are more susceptible to certain diseases than are normally-developing children, and these diseases include congenital heart disease, intestinal abnormalities and infectious diseases.[22] DS children often have a history of postnatal illness, which can greatly contribute to the mental retardation.

Family structure plays an important role in the cognitive and social development of DS children. Since the implementation of the family planning policy in China, family characteristics have undergone great changes. In urban areas, most families are only-child nuclear families, except those who have handicapped children. In rural areas, most couples are permitted to have a second child, especially if the first is female. Yet with the progress of society, many couples who are permitted to have a second child choose to have only one child.[23] The nuclear family with one child has become the mainstream of society. When a family has a baby or toddler, or has a handicapped child, grandparents usually are invited to live together with the young family, for economic reasons or as a matter of custom. As the child grows up, the grandparents return to live by themselves, while the MA group are still young, and the DS group are handicapped so the grandparents still live with them Therefore, the nuclear family with one child was the main social living environment for children in the CA group, but not in the DS or the MA groups. The handicapped child usually was the most important member and the center of the family. The practice of spoiling handicapped children may aggravate the retardation of social adjustment abilities because DS children have no chance to practice their skills.

In addition to family structure, the educational level of the parents also plays an important role in the development of social adaptation.[24-26] Compared to typically-developing children, the educational level of parents with DS children was significantly lower in our study. In the more prosperous areas of China, prenatal screening has become more popular for well-off parents. To some degree, parents with a low educational level are less likely to participate in routine examinations during pregnancy, so that in this case pregnant women miss the chance of prenatal diagnosis of many genetic diseases. After the birth of a DS child, well-educated parents may provide a better environment for the growth and development of their disabled child and, for example, may more readily participate in early intervention programs. Early intervention can help many children with DS to develop their full cognitive and social potential and live productive lives well into adulthood.[27-29]

The term "behavioral phenotype" may best be described as "the heightened probability that people with a given syndrome will exhibit certain behavioral and developmental sequelae".[30] The results of our study suggest that a differentiated view on cognitive and adaptive development is needed in DS patients, who in this respect differ from what is seen in children with Williams syndrome. Compared to the MA group with a chronological age of around three years, DS children on average scored higher on the Infants-Junior Middle School Students' Social-Life Abilities Scales, at a level that is equivalent to what is expected from normal, four-year-old children. Thus, although the PPVT raw scores in the DS group showed no differences when compared with the MA group, the ability to utilize skills within a general social context tended to be better in DS children. This pattern of results is consistent with the idea that the diagnosis of mental retardation does not define the person: individuals with DS can continue to learn throughout their lives.

While rarely used in China, the Vineland Adaptive Behavior Scales (VABS) have been widely employed in the investigation of developmental

retardation in Western countries.[31-33] The VABS measures adaptive behavior in four domains: communication, daily living skills, socialization, and motor skills. It is difficult to directly compare the results of DS children from Western countries and from China because of the different test instruments used. However, it seems that a particular weakness in communication is seen in both Western and Chinese DS children, while the mastery of adaptive skills associated with the tasks of daily living is far less affected.[16,33] Children with DS often are noted to have speech delays. Understanding or receptive language is often better than speaking or expressive language.[34-36] Poor muscle tone in the oral structures can lead to hypernasality, imprecise consonants, breathiness, a harsh voice, and short phrases, which can make speech difficult to understand.[37] These all greatly contribute to the delay of communication. Because most DS children in Western countries, but not in China, are subject to early intervention after birth, they should show better social adaptability than Chinese DS children. The low levels of cognition and social competence found in this study suggest that families with DS children in China need appropriate professional help to promote the cognitive and social development of their children as early as possible.

Children in the CA group got higher scores than DS patients in all dimensions of social adjustment. This is in agreement with the idea that the development of cognition is associated with the development of social adjustment and quality of life.[38,39] Motor development, language and executive functions are all engaged in the development of social adjustment. To a certain extent, cognition predicts the individual potential and the characteristics of social adaptation, while training and education are often considered to have less of an impact on children with developmental retardation, and therefore they are then more likely to be withheld.[40]

In this study, the development of adaptive behavior was significantly correlated with the development of cognition, even after controlling for age. At the same time, age-related cognitive development was significantly correlated with social adaptive ability, too. An earlier study reported significant age-related developmental progress in adaptive functioning in children with DS from infancy to elementary-school age, whereas in middle school a stagnation of social adjustment was documented.[16] Chinese DS children usually enter elementary school from the ages of 8 to 11. Most of them have had no intervention before that time. Learning in special schools provides sufficient opportunities to develop the children's potential so that social adjustment in DS children of school age should develop continuously. Further investigations are needed that address a possible stagnation of development among Chinese DS children in middle school.

Children with DS require special health care and early interventions to ensure optimal development, which also has a significant impact on their family. Independence training for the affected individuals and advice to their parents for effective intervention might result in adults with DS becoming less dependent on their families for support and more able to utilize those skills and abilities that they undoubtedly possess.

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