

Autism spectrum disorder: Status of primary care in China

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SUMMARY Primary care serves as the cornerstone to ensure positive health outcomes for diseases. Autism spectrum disorder (ASD) has attracted more attention as a lifelong neurodevelopmental disorder with a prevalence that is increasing yearly. Although the demand for primary care for ASD is rapidly expanding, there are many challenges that need to be faced. Here, the current status of primary care for ASD in China is described. *i*) Identification of and care for ASD includes pre-diagnosis, diagnosis and evaluation, and treatment; the complexity of the disease and the lack of public understanding increase delays in diagnosis and treatment. *ii*) Most instruments, which are indispensable for diagnosing and evaluating ASD, are of foreign origin. *iii*) Treatments for ASD are based on mainstream Western interventions with complementary approaches. *iv*) The scale of rehabilitation and educational institutions has gradually grown and their expertise has gradually increased but rehabilitation costs are relatively high.

Keywords autism spectrum disorder, primary care, diagnosis, treatment

1. Introduction

Autism spectrum disorder (ASD), characterized by difficult social interaction and communication, narrow interests, and stereotyped repetitive behaviors, is a neurodevelopmental disorder that originates in early childhood (1,2). A nationwide multi-center population study found that the prevalence of ASD in children ages 6-12 was about 0.70% on the Chinese mainland (3), which was similar to a global prevalence of 0.76% (4). ASD is a lifelong disorder with a prevalence that is increasing yearly, and patients require long-term care and support in areas such as healthcare, education, and community services, posing a heavy economic burden to their families and society (5,6). In addition, the long-term stigma suffered by family members negatively affects their physical and mental health (7).

Primary care broadly refers to a type of public health and is narrowly a healthcare approach that provides medical care to the public (8). An important guarantee is that people with ASD can obtain long-term medical support, which not only increases access to medical care but also reduces the negative impact of economic concerns on health (9). Here, the current status of primary care for ASD in China is described in terms of

approaches to and methods of diagnosing and treating ASD and rehabilitation and educational institutions.

2. Current status of ASD diagnosis and treatment in China

Generally, most patients need to undergo three complex processes: pre-diagnosis, diagnosis and evaluation, and treatment (Figure 1). Unlike diseases such as Down syndrome that can be diagnosed early by prenatal and postpartum chromosomal tests (10), ASD can only be diagnosed via an assessment of abnormal behaviors, which may be not well understood by many Chinese parents or doctors in primary hospitals (11). In addition, the number of doctors cannot meet the ever-increasing demand for care (12), and psychiatrists and psychologists specializing in diagnosing and treating children with ASD are especially in short supply, resulting in a limited capacity for primary care in local hospitals, private practices, and community centers (11). Consequently, the complexity of ASD and the lack of understanding of the disorder results in an average delay of one year from identification of symptoms to proper treatment (13-15). Although an expert consensus on early screening and intervention for Chinese children with ASD was reached

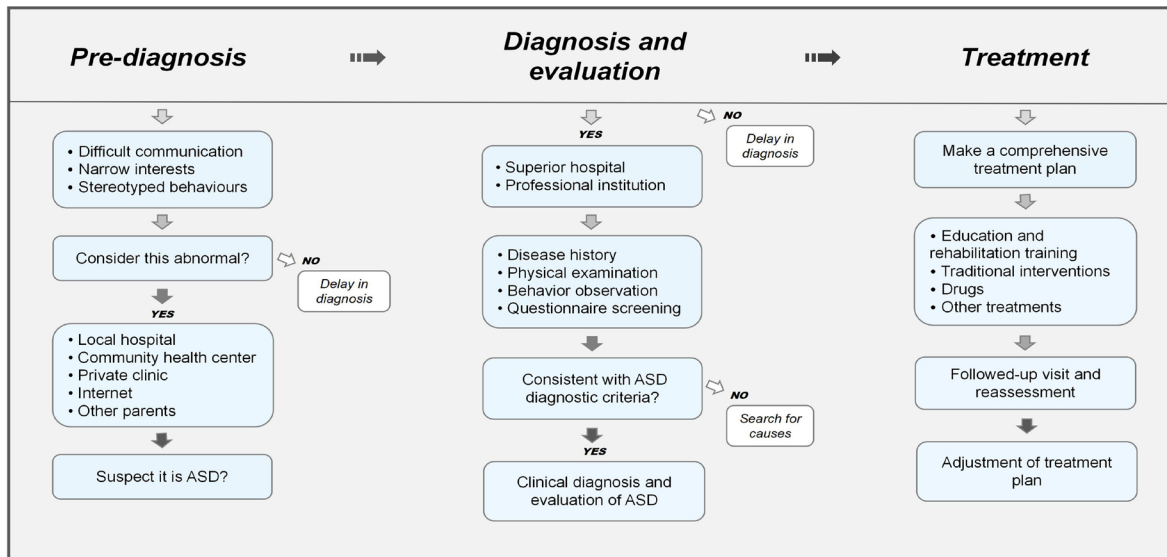


Figure 1. Flowchart for primary care for ASD in China. Identification of and care for Chinese patients with ASD can be summarized into three processes: Pre-diagnosis, diagnosis and evaluation, and treatment. ASD, autism spectrum disorder.

Table 1. ASD screening and diagnostic tools commonly used in China

Category	Tool name	Applicable age groups	Main purpose	Features
Screening tools	CHCIA, M-CHAT, SORF	Infant	Screening or initial diagnosis of patients with ASD	<ul style="list-style-type: none"> • Relatively easy to use; • Filled in by the caregiver; • Positive results require further testing.
	ASSS, CABS ABC	Child Infant to adult		
Diagnostic and assessment tools	CARS	Child	Diagnosis and differential diagnosis or assessment of ASD	<ul style="list-style-type: none"> • Used by professionals; • Time-consuming; • Larger population covered.
	C-PEP-3	Infant, child		
	ADI-R, ADOS, SRS-2	Infant to adult		

Data source: Reference (19). Infant, < 4 years of age; Child, 5-13 years of age; Infant to adult, including infants, children, adolescents, and adults. ABC, Autism Behavior Checklist; ADI-R, Autism Diagnostic Interview-Revised; ADOS, Autism Diagnostic Observation Schedule; ASD, autism spectrum disorder; ASSS, Asperger's Syndrome Screening Scale; CABS, Clancy Autism Behavior Scale; CARS, Childhood Autism Rating Scale; CHCIA, Checklist for China's Infants With Autism; C-PEP-3, Third Edition of the Revised Chinese Version of the Psycho-Educational Profile for Children with ASD & Developmental Disabilities; M-CHAT, Modified Checklist for Autism in Toddlers; SORF, Systematic Observation of Red Flags; SRS-2, Social Responsiveness Scale, Second Edition.

in 2017 (16), early ASD screening has unfortunately not been included in the public health projects of community health service centers, and only a few large cities have implemented such a program through cooperative projects (11).

3. Screening and diagnosis of ASD in China

Early diagnosis and treatment are more conducive to alleviating the symptoms of patients with ASD and integrating them into society as much as possible (16,17). Methods of diagnosing ASD via imaging studies or blood biochemistry are still in the preclinical study phase (18). Presently, the diagnosis of ASD by domestic medical personnel is mainly based on the diagnostic criteria in the Diagnostic and Statistical Manual of Mental Disorders, 5th ed, which is dependent on the caregiver's description of unusual behaviors and the physician's evaluation of symptoms using special instruments (16). These instruments are divided into screening tools and

diagnostic evaluation tools depending on their functions (Table 1) (19). Most of these instruments are of foreign origin, translated, and revised, so the translations may be biased. More importantly, the applicability of these instruments to China needs to be confirmed. Encouragingly, the level of primary care for ASD has improved with the gradual standardization of screening and diagnostic tools. A point worth noting is that the currently recommended diagnostic methods include information from a clinical assessment, the educational environment, and standardized tools rather than blindly accepting the diagnosis and implementing treatment (20).

4. Interventions commonly used in China

ASD has a complex etiology, and 75% of patients have additional neurological or psychiatric disorders, making treatment more challenging (21). Current therapies for ASD include pharmacological treatments and non-pharmacological interventions. Commonly used drugs

include antidepressants, atypical antipsychotics, and psychostimulants (21), which are limited to treating concomitant conditions rather than ASD itself (22). Traditional Chinese medicine interventions such as acupuncture, massage, and herbal remedies seem to have some effect on partial symptoms, but further research is needed to confirm these results (21,23). In contrast, behavioral and educational rehabilitation is an evidence-based intervention for core symptoms of ASD and is widely accepted for its demonstrable effects.

Interventions cited by the National Autism Center (NAC) in 2015 are domestic mainstream treatments for ASD (24). A survey of 1,136 Chinese rehabilitation facilities found that 57 interventions for ASD were used in China, the 3 most often used of which were behavioral interventions, language training and production, and natural teaching strategies. Others were complementary therapies such as traditional Chinese medicine and play therapy (25). Generally speaking, a wide variety of interventions are used in China, and the most common intervention strategy is to combine conventional rehabilitation training with other traditional adjuvant therapies.

5. Current status of rehabilitation and educational institutions for patients with ASD in China

At present, medical care for patients with ASD is supported by the government, including rehabilitation facilities belonging to the China Disable Persons' Federation (CDPF), research institutions, and public hospitals, as well as private rehabilitation and educational institutions (26). Although China's policy stipulates that children under 6 years of age with ASD can receive rehabilitation subsidies, the shortage of domestic rehabilitation therapists means that most doctors in public hospitals can only diagnose, evaluate, and advise patients rather than providing one-to-one rehabilitation training (18). Therefore, parents often choose rehabilitation and educational institutions for their expert quality services. However, a large proportion of these institutions are private organizations, and rehabilitation expenses of patients are mainly borne by patients' families instead of government subsidies, contributing to the heavy financial burden on families of patients with ASD (18,26).

With attention to ASD and improved policies for patients with disabilities, ASD education and rehabilitation in China has developed rapidly in recent years. According to data from the CDPF, 2,681 institutions provided rehabilitation services for people with ASD throughout the country by the end of 2020, and the number of staff and patients in these institutions has continued to grow (27). Nonetheless, there are still large gaps in service capacity between different institutions (25). As an example, daily training sessions can be conducted for up to 300 patients, but the minimum is only 8 (25).

6. Suggestions

China's capacity for primary care for ASD has generally tended to increase, and especially in the improved management of rehabilitation and education for patients with ASD (27). These changes will help to provide basic services to patients, rationally allocate national resources, and promote the standardized operation of institutions. But more needs to be done. An ASD screening and monitoring system needs to be created in accordance with the needs of Chinese patients as soon as possible; disseminating knowledge about ASD and enhancing psychiatrist training are essential to improving the early diagnosis of the disorder. In addition, ASD is classified as a mental disability in China, so national policies and subsidies are not directly targeted at patients with ASD but at the total population of patients with mental disabilities. Thus, more policies need to be implemented and funds need to be earmarked for patients with ASD and autism research.

Acknowledgements

The authors wish to sincerely thank Peng Li and Suna Tian for their assistance in preparing the figures in this manuscript.

Funding: This work was supported by grants from the 2018 Program to Guide Medicine ("Yixue Yindao") of the Shanghai Municipal Science and Technology Commission (grant no.18401902200 to L Wang), a project under the Scientific and Technological Innovation Action Plan of the Shanghai Natural Science Fund (grant no. 20ZR1409100 to L Wang), a project of the Chinese Association of Integration of Traditional and Western Medicine special foundation for Obstetrics and Gynecology-PuZheng Pharmaceutical Foundation (grant no. FCK-PZ-08 to L Wang), a project for hospital management of the Shanghai Hospital Association (grant no. X2021046 to L Wang), a clinical trial project (L Wang) of the Special Foundation for Healthcare Research of the Shanghai Municipal Health Commission, a project under the Hubei Provincial Natural Science Foundation of China (grant no. 2020CFB140 to S Chen), and a project (S Chen) of the One Hundred Million Personnel Program to Carry on and Spur Innovation in Traditional Chinese Medicine.

Conflict of Interest: The authors have no conflicts of interest to disclose.

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- Received February 25, 2022; Revised March 9, 2022; Accepted March 10, 2022.
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- Released online in J-STAGE as advance publication March 12, 2022.