

Problems in treatment and training of autistic children growing up in China: A follow-up case report

Fuquan Liu¹ | Shijie Liu² | Jiabao Chai³

¹The Sixth Psychiatric Ward, Beijing Changping District Hospital of Integrated Traditional Chinese and Western Medicine, Beijing, China

²Xibeiwang Community Health Center in Haidian District, Beijing, China

³Art Performance Therapy Center, Hui Long Guan Clinical Medical School, Peking University, Beijing, China

Correspondence

Jiabao Chai, Art Performance Therapy Center, Hui Long Guan Clinical Medical College, Peking University, Beijing 100096, China
Email: 13241007575@163.com

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ABSTRACT

Introduction: Currently, interventions for children with autism spectrum disorders (ASD) in China are mainly carried out by professionals in rehabilitation institutions and special schools. However, when autistic children are older, they do not receive effective training and treatment, and there is no specific place in society to accommodate autistic adults. Mental hospitals are usually their ultimate home.

Case presentation: We report a 22-year-old male with ASD. The manifestation and/or intervention from the age of 3 years to now were recorded. He has been hospitalized in the closed ward of a mental hospital since 2015.

Conclusion: This report typically present the current problems in treatment and training of autistic children growing up in China. Life-long rehabilitation training is important for every patient with ASD. Relevant policies and resources in China should be optimized in terms of medical treatment and health care, education and training, social assistance, social security, labor employment, and social culture.

KEYWORDS

Autism Spectrum Disorders, Training of autistic children, Parents Training, China

INTRODUCTION

Autism spectrum disorders (ASD) are a group of heterogeneous neurodevelopmental disorders clinically characterized by persistent deficits in social communication and social interaction, a restricted range of activities and interests, and repetitive and stereotyped behavior patterns.^{1,2} As a result, autistic children mainly manifest with younger mental ages, difficulties in controlling themselves and managing frustration, and severe problems in language, cognition, behavior, and social interaction.³ In recent years, the number of children diagnosed with ASD has increased in China, with a concomitant increased burden.⁴ In 2018, a meta-analysis based on a Chinese sample showed that the prevalence of ASD in China was 39.23/10 000.⁵ ASD has become the fastest-growing disease worldwide, placing a

heavy disease burden on families and governments, and creating social problems. ASD has become a global public health concern.

Unfortunately, despite rapid advances in brain sciences and genetics, the etiology of ASD remains unclear.⁶ Accordingly, there is no direct and effective medical treatment for this disease.² Currently, interventions for children with ASD in China are mainly carried out by professionals in rehabilitation institutions and special schools. Although the role of parents in the training of ASD children has been gradually recognized, there are no guidelines on family intervention.⁷ As autistic children grow up, their emotions and behaviors gradually become difficult to control, and their parents become old. These autistic adults can no longer easily live at home or in

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their communities. Lack of professional care skills, poor financial conditions, and many other factors make family care for autistic individuals even more difficult. Many autistic children do not receive effective training and treatment when they are older, and there is no specific place in society to accommodate autistic adults. Thus, autistic adults may have to choose mental hospitals as their ultimate home. Even if treatments by professional psychiatrists are available, the emergence of comorbidities, antipsychotic side effects, and impulsive and aggressive behaviors pose substantial challenges for psychiatrists.

This article presents a retrospective analysis of the treatment and interventions provided to one typical patient with autism. This case scenario may elucidate the challenges of autism treatment and intervention in China, and thus inform future interventions for autistic individuals across their life span.

CASE REPORT

The patient is a 22-year-old male. When he was a child, he preferred to be alone and showed delayed speech and walking skills. At the age of 3 years, he was refused entry by many kindergartens owing to poor communication ability and aggressive behavior. During his stay in kindergarten, he kept shouting the names of girls, did not follow the teacher's instructions, and did not obey the rules. His parents had never sought treatment for these behaviors, as they always believed that the problems would automatically disappear once the child grew up. At the age of 5 years, the patient liked to play with his eyebrows, and had muscle twitches in the arms and legs. The latter appeared intermittently but became obvious when he felt nervous and angry. He played the same game at home; he would throw a plastic bag into the air repeatedly and beat it with a rope and his mother can not stop him. He had an extraordinary ability to memorize the numbers of car license plates. The child showed timidity and fear and dared not try new foods; he always ate foods that he was familiar with. He had an extremely poor ability to take care of himself. He only liked watching the TV series *Princess Pearl*. He also liked to wear girl's clothes and headwear. When a guest visited his home, he imitated the TV series and greeted the guest by kneeling, which he would not stop even after repeated requests by his parents. When he was 7 years old, the patient started elementary school. He often left his seat during class and went outside without listening to the teacher's instructions. His teacher suggested that the parents take him to a professional hospital, where he was diagnosed with autism and Tourette syndrome and was recommended for rehabilitation training. However, his parents failed to find a suitable training institution for him, and the child continued to attend school under the care of his parents. He was later dismissed by the school for violating the rules and was unable to adapt to school life. At the age of 8 years, when he was in the second grade, his parents

transferred him to another elementary school, where his performance improved slightly. He could obey the school rules after repeated persuasion, but often behaved poorly in the classroom and had poor academic performance. His performance was even worse in the third grade at the age of 9 years. He would put his shoes on the table during class, grab the braids of girls sitting in front of him, and shout loudly in the classroom. He would visit the trash bin at midnight to pick up the rubbish discarded by his mother. He kept asking his mother questions and would scold and beat her if her responses were not those he had expected. Later, the patient was sent to Beijing Anding Hospital, where he was diagnosed with autism, obsessive-compulsive disorder, and Tourette syndrome. He was treated with compound sodium valproate and valproic acid sustained-release tablets, sertraline hydrochloride tablets, and aripiprazole tablets; the specific dosages are unknown. He was discharged after about 5 months in hospital. After discharge, his parents tried to find a rehabilitation institution for him and regularly went to Beijing Anding Hospital to obtain medication. While taking this medication, the patient received training at a growth and development center. However, as he grew older, he became increasingly aggressive and lost his temper frequently, leading to his dismissal from the growth and development center. His parents kept him at home, but he still often lost his temper. His mood swings were often accompanied by impulsive and aggressive behaviors. He was again refused admittance by many adolescent growth centers in Beijing. His parents could not take care of him and finally he was admitted to the closed ward of our hospital in 2015 when he was 17 years old.

After admission, the patient showed naive language, impulsive behavior, and emotional instability. He disobeyed the ward rules. When he was quiet, he remained alone in the ward and was unwilling to communicate with other patients. He often attacked the medical staff over small annoyances and often hurt himself for attention. A diagnosis of autism was made based on the patient's past medical histories and current manifestations. He was treated with amisulpride 1000 mg/d combined with modified electroconvulsive therapy (MECT) three times per week. The patient resisted the MECT and cried loudly after returning to the ward. The therapeutic effect was unsatisfactory, and the patient still showed emotional instability and often had impulsive and aggressive behaviors. After consultations within the department, the therapy regime was changed to aripiprazole tablets (an antipsychotic drug) 25 mg/d combined with magnesium valproate (an emotional stabilizer) 1000 mg/d, and the patient's mood instability improved. However, his mood swings persisted, and he still did not follow instructions and attacked other patients. Therefore, 24-hour care by the ward medical staff was often required. Owing to the long-term use of aripiprazole, the patient's body weight increased remarkably from 65 kg (at admission) to 90 kg. His blood triglycerides and cholesterol levels were high. After consultations within the department, metformin

hydrochloride 1000 mg/d was added to alleviate the disordered glycolipid metabolism. Owing to limited resources in the psychiatric ward and the lack of autism rehabilitation skills, the patient's behaviors and emotions could not be changed through professional rehabilitation training. His attacks and self-injuries often frustrated the nursing staff in the ward and thus protective restraints were often required.

DISCUSSION

Because of the poor understanding of the causes of ASD, there is no effective treatment now. Therefore, interventions supplemented by drugs are increasingly used; education and training programs are major interventions for ASD.⁸ However, this case highlights several shortcomings in the diagnosis and treatment of ASD in China.

Firstly, early screening for ASD is far from satisfactory. ASD interventions and treatments are based on early screening and early diagnosis. Owing to a lack of awareness and insufficient knowledge about ASD among parents, diagnosis of ASD is often delayed, which leads directly to delayed treatment during the critical period for recovery.

Secondly, defective rehabilitation training facilities. Most rehabilitation training facilities in China are private institutions that only enroll children younger than 6 years. When children with ASD reach school age, they face the difficult situation of being refused by both schools and institutions and there is often no caregiver at home. Some parents choose to leave work and take care of the children by themselves, but experience resulting economic pressures. Although some adolescent growth and development centers are available in a few big cities, they mainly offer nursing and care services and there are no well-designed rehabilitation training programs.

Thirdly, autistic adults have nowhere to go. When an autistic child grows up, there are no appropriate institutions to accommodate them. As their parents get older and autistic adults develop new behavioral problems, the difficulty of obtaining adequate care become more prominent. Many parents have to send their children to closed mental hospitals.

Finally, difficulties in treating ASD in mental hospitals. Owing to a lack of professional technical guidance, care for patients with ASD places greater pressure on hospitals. In addition, the self-injury and aggressive behavior of ASD patients often make medical staff feel helpless. Antipsychotic drugs can reduce these symptoms, but the side effects of such drugs cause new problems.

To conclude, proper rehabilitation and education are important for ASD children to achieve their full development and experience improved prognoses. We call

for life-long rehabilitation training for every autistic child. However, long-term, high-intensity rehabilitation training poses a high economic burden and huge challenges to all families that have a child with ASD. The case reported here is not untypical. Therefore, society as a whole should place great importance on the care of these vulnerable individuals and their families. Relevant policies and resources should be optimized in terms of medical treatment and health care, education and training, social assistance, social security, labor employment, and social culture. Such multilevel and multidimensional efforts may enable adult patients with ASD to receive more standardized and systematic training and treatment.

CONSENT FOR PUBLICATION

Consent was obtained from the patient and his guardian.

CONFLICT OF INTEREST

None.

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