

Psychological Support for Parents of Children with Autism Spectrum Disorder and Special Needs in Hubei Province

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Abstract

To understand the parents' burden of children with special needs, we conducted a survey on parents of 186 children in a rehabilitation center in central China. We surveyed and analyzed the parents' needs, the result suggested that parents of children with autism spectrum disorder and special needs faced tremendous pressures and are in urgent need of psychological support and intervention. The language problem is a key issue for children with ASD and special needs, and it is also the parents' biggest worry. The government, educational institutions, rehabilitation institutions and social personnel can reduce the burden on parents of children with ASD and special needs by various forms of support.

Keywords: autism spectrum disorder, psychological demands, primary caregiver

Introduction

Autism Spectrum Disorder (ASD) is a spectrum disorder characterized by language development disorders, social communication difficulties, repetitive and stereotyped behaviors, often accompanied by comorbidity such as attention deficit hyperactivity disorder (ADHD), intellectual disability, epilepsy, and gastrointestinal disorders (American Psychiatric Association, 2013). According to the Centers for Disease Control and Prevention (CDC) in the United States, the prevalence of ASD has increased from 1 in 54 in 2018 (Christensen et al., 2016) to 1 in 36 in 2023 (Maenner et al., 2023). The global prevalence of ASD was estimated to be around 1% (Lai et al., 2014), while the prevalence of ASD in China was 0.7% (Zhou et al., 2020). The accurate prevalence, etiology and pathogenesis of ASD are still unknown, and there are no effective medications for treating the key symptoms of ASD. Early intervention training is the primary approach for addressing ASD.

Due to the communication and learning difficulties, people with ASD struggle with social integration and independent living in life. Parents of children with ASD face significant psychological stress caused by long-term caregiving pressures, economic burdens of rehabilitation, and the unsatisfactory rehabilitation outcomes. These can lead to anxiety, depression, and even suicidal tendencies, and impact on the care of children with ASD. Psychological problems of parents and caregivers needs to be diagnosed then treated timely. Without timely support, families could enter into a vicious cycle of psychological distress. Some ASD parents may even become desperate and resort to suicide along with their children, resulting in tragic incidents related to ASD. Several studies in China have confirmed that parents of ASD face parenting pressure and mental health problems (Gong et al., 2015).

From the news, we heard several tragedies about caring for children with ASD. In 2012, the New Beijing News reported the case of an autistic boy who was

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kept in a cage by his father for 10 years. In March 2016, a father in Danyang City, Jiangsu Province, killed his 19-year-old daughter with autism. In April 2017, a couple from Hunan jumped off a bridge with their autistic child, resulting in the child's death, the father's disappearance, just the mother survived. These cases reflect the immense challenges faced by families with autistic children. The reasons for these incidents lie not only in the lack of targeted treatments currently available for ASD but also in the significant long-term psychological pressure on caregivers and the insufficient social and environmental support they receive (Qi et al., 2023).

Many studies confirmed the critical role of parenting children with special needs and the mental health of parents, but there is little research on the psychological needs of parents of children with special needs, especially in areas with large groups of special needs children in mainland China. This study aimed to further understand their parents' psychological burden using a questionnaire survey. The study respondents are parents of children at a rehabilitation institution located in Central China. The area is a poverty-stricken region with a combination of old districts, reservoir areas, and mountainous areas. The economy is mainly supported by agriculture, forestry, animal husbandry, and fishing. As of 2022, the per capita GDP of the city ranks below average among the provinces in China, and the per capita consumption level is relatively low. There are also a significant number of migrant workers and their accompanying children in the city. This study hopes to gain insights into the psychological burdens of parents through authentic survey data analysis.

Methods

Participants

The study is based on a cross-sectional survey conducted in a rehabilitation center in Xianning City, Hubei Province, China. The participants were parents of children with rehabilitation special needs, majorly ASD.

Survey Questionnaire

A survey questionnaire was distributed online from July 21, 2022 to July 25, 2022, with a response rate of 93%. The survey collected information on characteristics of the patient population, including disease characteristics, rehabilitation conditions, family information of patients, and the burden and needs of the primary caregivers. This study was approved by the Ethics Committee of Zhongnan Hospital of Wuhan University (Approval number: K2021099). We have

informed the participants that our survey is anonymous, and information collected is kept confidential. And all participants signed informed consent forms.

Results

A total of 186 completed questionnaires were received from parents of patients in the rehabilitation center. The patient population is predominantly ASD (68.8%), with boys accounting for the majority (74.2%). The age range of the patients is 2-16 years old, with an average age of 5.7 ± 2.1 years. The rehabilitation center has a high proportion of preschool children below 6 years old (73.1%). The main reasons of children with special needs for the first visit to the rehabilitation center were language development disorders (86%), followed by lack of social interest (46.2%) and other types of intellectual disabilities (33.3%) (Table 1). The average age at the first visit was 2.8 ± 1.3 years. The children surveyed in this study often had comorbidity, with intellectual developmental delay being the most common (67.7%), followed by attention deficit hyperactivity disorder (19.4%). Movement disorders were also relatively common, and some patients had gastrointestinal diseases.

The age when rehabilitation started for the children ranged from the time of diagnosis after birth to 12 years old. The average age at the start of rehabilitation for all patients was 3.2 years ($SD = 1.6$). As of the end of data collection, the average duration of rehabilitation was 2.5 years ($SD = 1.9$). Almost every patient received sensory integration training (91.9%), while psychological and medication treatments were less common. Sensory integration is one of the most used interventions in ASD, often chosen by parents and often applied by therapists to children with special needs who are predominantly ASD, however, there is a lack of consensus on its evidence base (Schoen et al., 2019). On the contrary, there is currently no effective medication to treat the core symptoms of ASD, the drugs applied to ASD are mainly for the treatment of its symptoms and comorbidity. Most parents had high expectations for their children's rehabilitation, considering the rehabilitation effectiveness to be average (47.8%).

Most patients' primary caregivers are mothers (83.9%). The most common occupations of primary caregivers are full-time homemakers (56.5%), indicating that more than half of the families rely solely on the father's income to support the household. A survey on the patients' family information revealed that most patients are not only children (66.7%), with households having two

children being the most common (54.8%). Among families with multiple children, the affected child usually ranks second (63.7%), and almost none of the other children in the family have similar diseases (96.8%). Please refer to Table 2 for the family information of patients and Figure 2 for the primary caregiver's occupation.

Currently, the biggest concern of parents is their children's language problems (30.1%), as they believe that their children's language abilities are progressing slowly, and they don't know when their children will be able to speak voluntarily. The second common concern is their children's social issues (14.5%). In addition to worrying their children cannot communicate with themselves and their family members, they are more

concerned that their children cannot integrate into peer groups and will have difficulties surviving in society in the future. Other concerns include economic hardship, intervention effects, whether their children can attend school. Parents who believe that the intervention effects are unsatisfactory are more likely to complain about economic hardship. Most parents hope to see improvement in their children's language problems (23.7%), followed by hoping their children can attend school (21.5%). Some parents expressed the need more skilled instructors' help for their children (5.4%), and some parents hope to increase the medical insurance reimbursement for rehabilitation expenses (4.3%). Please refer to Table 3 for parents' concerns and expectations, and Figure 1 for summary of the rehabilitation methods used with the children.

Table 1.
Characteristics of Participants (N = 186)

Items	Number of answers	%
Gender		
Boy	138	74.2
Girl	48	25.8
Age		
0-3.0 years	11	5.9
3.1-6.0 years	125	67.2
6.1-16.0 years	50	26.9
Main diagnosis		
ASD	128	68.8
Developmental delay	27	14.5
Intellectual disability	8	4.3
Down syndrome	3	1.6
Epilepsy	1	0.5
Movement disorders	1	0.5
Other	9	4.8
Reasons for first visit		
Language development disorder	160	86.0
Social communication deficits	86	46.2
Intellectual disability	62	33.3
Emotional and behavioral problems	48	25.8
Stereotyped and repetitive behaviors	42	22.6
Motor developmental dysfunction	39	21.1
Comorbidity		
Intellectual disability	126	67.7
ADHD	36	19.3
Movement disorders	29	15.6
Gastrointestinal diseases	16	8.6
Psychiatric disorders	5	2.7
Epilepsy	5	2.7

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Table 2.
Family Background of Patients (N = 186)

Items	Number of answers	Proportion (%)
Primary caregiver		
Mother	156	83.9
Father	19	10.2
Grandma	10	5.4
Others	1	0.5
Only child		
Yes	62	33.3
No	124	66.7
Number of children in the family		
One	62	33.4
Two	102	54.8
Three	19	10.2
Four	3	1.6
Patient's birth order		
First	31	25.0
Second	79	63.7
Third	12	9.7
Fourth	2	1.6
Other children in the family have similar illnesses		
Yes	4	3.2
No	120	96.8
Satisfaction with progress in rehabilitation		
Moderately satisfied	89	47.8
Satisfied	69	37.1
Very satisfied	14	7.5
Not very satisfied	10	5.4
Unsatisfied	4	2.2

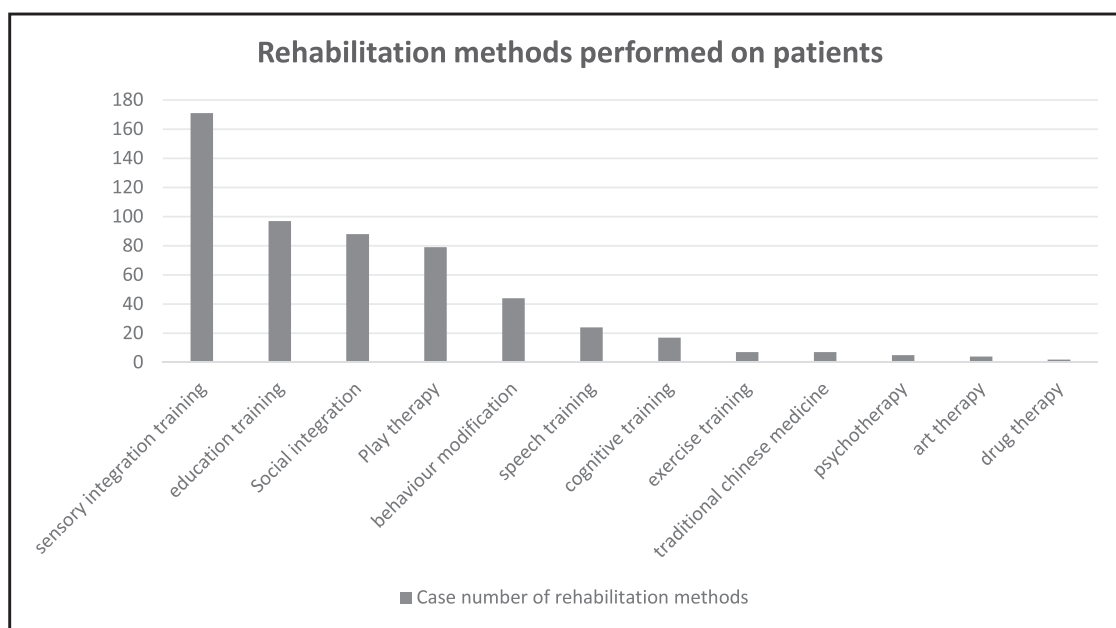
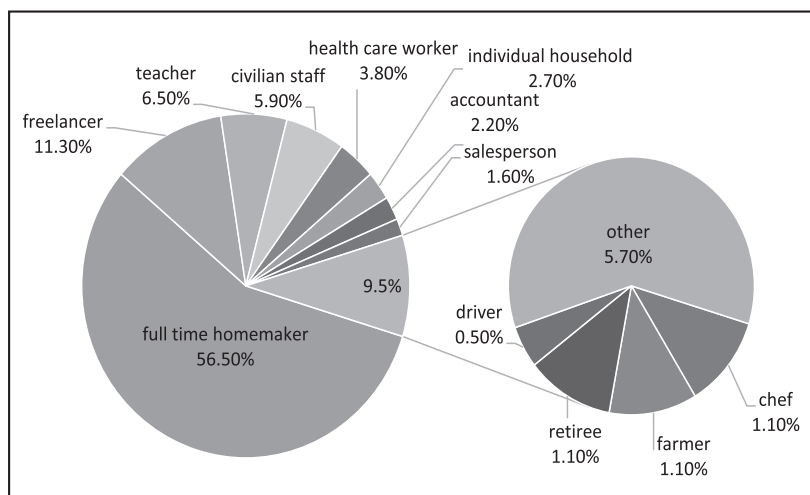


Figure 1: Rehabilitation Methods Performed on Patients

Table 3.
Parents' Concerns and Expectation

Items	Number of answers	Proportion (%)
Parents' concerns		
Language ability	54	30.1
Social Issues	27	14.5
Economic problems	22	11.8
Understanding and cognitive ability	16	8.6
Poor intervention effect	15	8.0
Go to school/get involved in school	15	8.0
Hyperactivity/behavioral problems	11	5.9
Emotional problems	9	4.8
Family intervention methods	8	4.3
Parents' expectation		
Language problems improvement	44	23.7
Attending school/Fusion Schooling	40	21.5
Improvement in social	21	11.3
Comprehension skills improvement	18	9.7
Cognitive improvement	16	8.6
Self caring skills improvement	10	5.4
Needs more skilled instructors' help	10	5.4
Medical insurance reimbursement	8	4.3



Note. 9.5% is the overall percentages of chef, farmer, retiree, driver and other occupations.

Figure 2: Primary Caregivers Occupation

Discussion

Research has shown that parents of children with special needs, particularly those with ASD, face greater stresses in the process of raising their children (Estes et al., 2009). Compared to parents of children with other developmental disorders, parents of children with ASD often experience greater parenting stress and lower emotional well-being (Valicenti-McDermott

et al., 2015). A national survey in the United States in 2008 found that the costs associated with ASD are 3-6 times higher than those of typically developing children (Shimabukuro et al., 2007). Based on our survey results, we found that parents of children with special needs face problems such as overwhelming anxiety due to lack of understanding about their child's condition, economic hardship, and a need for better rehabilitation programmes, family intervention, and

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reimbursement of medical expenses. The underlying causes of these problems are a combination of the nature of the child's illness, family factors, and social factors.

Illness-related Factors

ASD and other developmental disorders are usually lifelong disabilities, and current therapy and rehabilitation for children with ASD is to guide them to learn life skills using individualized and adapted learning approaches, and to overcome common difficulties, e.g. communication skills training. (Kodak et al., 2020). Our research suggests that most children in this institution have comorbidities, leading to more severe conditions and increasing the difficulty of intervention. Additionally, existing intervention methods often show effect slowly in a short term, which further adds to the anxiety of parents.

Family Factors

The primary caregivers for most children in this institution are female, as females generally have lower physical and coping abilities compared to males (Miranda et al., 2019). Under long-term stress, they are more likely to experience physical and psychological problems. More than half of the caregivers are full-time housekeeping, and the main source of income for the family relies on the father's sole efforts. Most families have two children, with another child needing to be cared for, and potential financial difficulties may exacerbate anxiety for both parents, affecting the quality of their relationship and marriage. Many families also cannot get rehabilitation timely or even lose the chance of rehabilitation. There is a relationship between parents' views on children's treatment choices, and parental stress (Dale et al., 2006). The rehabilitation, education, and future development of special needs children largely depend on the support from their parents (Cohen et al., 2013). We found that many parents are still concerned about their child's language and social problems and have not clearly understood the nature of their child's illness. They are unable to anticipate the specific duration required for recovery and lack knowledge about the disease, resulting in overly high expectations for their child's rehabilitation. When these expectations are not met, it often leads to more anxiety and depression.

Social Factors

Many parents face economic hardship, and they expect more reimbursement for rehabilitation treatment

from health insurance. The level of insurance coverage depends on the economic level of the country and the government's attention to individuals with special needs. Society often attributes abnormal behaviors of children with ASD to the educational shortcomings of the parents, leading to stigmatization of both the parents and their child, which further burdens the caregivers psychologically (Pang et al., 2023).

In summary, parents of children with ASD require urgent psychological support. How can we meet the needs of these parents and alleviate their burden? The following suggestions are proposed:

Supports for the Children with ASD

Educational institutions can designate policies to ensure that children with ASD's right to education is protected. Rehabilitation institutions should provide advanced rehabilitation equipment and technology, train more competent teachers, and develop personalized treatment methods for children. Family and school should develop partnerships to train autistic children, parents consolidate the teaching content of the teacher and apply the knowledge learned in school to the life of the children. The treatment for ASD was mainly based on behavioral training, supplemented by drug therapy, and guided normal children to help autistic children. Training should be provided to enhance the child's daily living skills and psychological resilience, improving their abilities to take care of themselves and cope with stress. Play therapy should be optimized, with an emphasis on including parent-child play to foster emotional connection between the children and their parents, enabling them to implement parent-child play therapy at home. Furthermore, it has been observed that psychological therapy and medication are not widely utilized in the treatment of children, some of whom also have prominent attention deficits that could be addressed through medication. In the future, it is important to explore and develop more suitable psychological treatment methods for children with special needs and to develop medications that target the core symptoms of ASD. There is a need to increased research on interventions for children with ASD.

Supports for Parents

Help parents understand that their anxiety about their child's language skills should be channeled into collaboration with therapists for home-based interventions, with the core of language improvement being improved communication skills. Provide parents and society with more knowledge about ASD through lectures, promotional videos, etc., and offer

them more family intervention methods to encourage greater involvement of parents and teachers in the rehabilitation of children with ASD. For example, the Early Bird Programme founded by the National Autistic Society provides strategies for parents to understand the developmental process of autism, learn how to communicate with children with autism, and increase their confidence (Shields, 2001). Research has found that parental education can improve children's cognition, academic performance, and social skills by enhancing parents' skills in educating their children (Kaminski et al., 2008). In general, parents, teachers, and therapists need to work together as partners. Teachers and therapists should share with or train parents on how to teach the child at home, and to carry out interventions that are done in therapy or schools. Additionally, provide psychological counseling services to parents, providing them with a place to express themselves and release their stress, ultimately alleviating their anxiety and increasing their psychological resilience.

Suggestions for Enhancing Social Supports

Studies have shown that social support can effectively reduce the caregiving stress on parents of children with ASD and improve their quality of life (Shu et al., 2005). We strongly advocate for the integration of medical and educational approaches, the government can provide protection for children with special needs and their parents by improving laws and regulations, while also offering appropriate subsidies to rehabilitation institutions. The society should provide financial or material assistance for families with economic disadvantage and promote greater understanding and acceptance of children with ASD. Parents of children with special needs can develop communication networks of supporting each other, with proper guidance from professional social worker or other type of help.

Therefore, the government, educational institutions, rehabilitation institutions, teacher and social personnel can reduce the burden on parents of children with ASD and special needs by various forms of support.

摘要

湖北地區以孤獨症譜系障礙為主的康復兒童家長心理需求

為了解以孤獨症譜系障礙為主的特殊需求兒童家長的心理負擔，我們對中國中部地區一家康復中心正在治療中的 186 名兒童的家長

進行了調查。我們收集並分析了家長當前面臨的困難及需求，證實了以孤獨症譜系障礙為主的特殊需求兒童的家長面臨著巨大的壓力，迫切需要進行心理干預。

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