Parents’ perceptions of autism and their challenges in China

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Abstract: Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by social communication deficits and restricted or repetitive behaviors. Parents play a significant role in research, clinical practice and policy development on autism. Parents’ perceptions of autism can affect not only their own well-being, but also their children’s development. Nevertheless, few studies have examined the parents’ perception of autism in Chinese context. The parents’ perception of autism questionnaire was applied to collect information from 171 families of children with ASD, mainly to investigate the knowledge of autistic children and the difficulties the family facing. The following conclusions were drawn from this study: (1) Mother as the primary caregiver for children with ASD; (2) Parents’ perception of ASD were various parents of autistic children have a good understanding of the symptoms, causes, age of onset and interventions, and their expectations of the prognosis and the future life of their autistic children are high; (3) The difficulties that faced by the parents are mainly composed of low social acceptance, family pressure and concerns about the effectiveness of interventions for their children. In consideration of the future development of children with autism and the mental health development of their parents, it is particularly crucial to support their parents with multifaceted support.

Keywords: parents of children with autism, social awareness, family difficulties, parental perceptions

1 Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by social-emotional impairment and restrictive, repetitive behaviors (Association, 2013). A meta-analysis found that ASD already topped the mental disability rate for children under 5 years old (Baxter et al., 2015). According to the latest data from the United States Centers for Disease Control and Prevention (CDC) in 2020, the current prevalence of autism has risen to 1 in 54, more than the world’s top three diseases (AIDS, cancer, diabetes) combined (CDC, 2020). In China, the estimated prevalence of ASD is increasing to more than 1 % of the total population (Clark et al., 2019). At the same time, ASD is a polygenic disorder that can last up to a lifetime with difficulty of reversal, with the incidence and prevalence increasing year by year, which is and will continue to be a huge burden to families and society (Duan et al., 2015; Papadopoulos., 2021).

1.1 The impact and challenges of autism on families

Due to the social interaction deficits, communication impairments, narrow interests and stereotypical repetitive behavioral patterns, sensory abnormalities, intellectual and cognitive deficits exhibited by children with autism (Deng & Lao, 2016), which seriously affect their quality of life on the one hand and their families on the other. According to research, compared to ordinary families, their parents bear the pressure from many aspects of parenting, mainly suffering from multiple loads such as material and mental, and they bear two to three times higher parenting pressure than raising ordinary children (Lee, 2013; DesChamps et al., 2020; Natalie et al., 2021).

To begin with, parents of children with ASD show role specialization, with mothers taking on parenting responsibilities and fathers working on the outside (Dyer et al., 2009; Rankin et al., 2019). This decreases the employment rate of the family to some extent, which makes the family income decrease. The shrinking of household income sources reduces the living standards of households to some extent, which is not conducive to maintaining the indicators
of family well-being. Moreover, due to the low income and benefits as well as the high cost of rehabilitation treatment, which puts a heavy burden on family survival. Secondly, there was a significant relationship between the diagnosis of a child with autism and parenting stress (DesChamps et al., 2020). Parents of children with autism experience higher levels of stress after their child is diagnosed with autism than if their child is diagnosed with another disability (Meisschaut et al., 2010), and are more likely to suffer from depression (Benson & Karlof, 2009; Marshall et al., 2018; Barańczuk & Pisula, 2020). When families are raising children with autism, family caregivers experience negative emotions such as depression, anxiety, and impatience due to chronic stress of varying degrees, and the stress associated with caring for an adult with autism who is not intellectually disabled is comparable to the stress experienced by individuals with schizophrenia or severe depression (Grootscholten et al., 2018). Up to 50% of parents report suffering from anxiety (Kuuskiko-Gauffin et al., 2013), and up to 60% of parents suffer from depression (Carter et al., 2009). In particular, mothers usually bear more stress than other family members (Ingersoll & Dworczak, 2006; Ang & Loh, 2019; Vernhet et al., 2021).

Also, the more complex the behavioral problems of children with autism, the more pressure their families feel (Miranda et al., 2019). The parenting stress directly affects parents’ emotional well-being, parent-child relationships, and children’s emotional and social development (Deater-Deckard et al., 2006; Kousgaard et al., 2018; Hickey et al., 2020). In family life, parental stress can negatively affect the parent-child relationship (Del Bianco et al., 2018; Costa et al., 2019). According to the results of an Iranian study, repetitive, impulsive, destructive and harassing behavior of children can harm the mother-child relationship (Samadi et al., 2018). In daily life, some autistic parents are reluctant to participate in their children’s intervention and rehabilitation programs due to poor parent-child relationships (Noyan Erbasa et al., 2020). Poor parent-child relationships can affect the subsequent development of children with autism. At the same time, parents’ marital happiness decreases dramatically due to the long period of time in a stressful family environment. Studies have proven that parents of children with autism in the family are much more prone to divorce (Hartley et al., 2010; Hartley et al., 2018; Kousgaard et al., 2018). As a person with autism grows up, the ultimate destination for the autistic person is to enter the mainstream of society, where he or she must work, live and study independently. Parents begin to worry about their children’s future development, which further increases their psychological burden. In addition, poor recovery outcomes also affect the level of parental mental health.

Last but not least, among parents of children with autism, parental stress is associated with a lack of social support and effective coping strategies (Weiss, 2002; Lu et al., 2018; Shepherd et al., 2020). As autism requires understanding and respect from the people in society, and an inclusive social environment, inclusion is the best option for children with autism. However, due to the lack of knowledge about autism and the characteristics of autistic children, they are not easily accepted by ordinary schools and a certain proportion of autistic students are rejected (Craig, 2015). School attendance for children with autism has become an area of concern for their parents. For students with autism who are already enrolled in regular schools, parents are still concerned about their children’s development at school due to the lack of knowledge about autism among the teachers and the lack of empathy for students with autism (Ebadi et al., 2021). The vast majority of parents of children with autism believe that there is a lack of inclusive educational settings and they desire inclusive educational and community settings that are supportive. At the same time, the general public does not know enough about autism, and the acceptance level is low. Parents of autistic children are ashamed to talk about their children in front of others, and they often feel embarrassed and ashamed because they are misunderstood and criticized (David et al., 2000; Torbet et al., 2019; Oduyemi et al., 2021). The associated stigma adds to the psychological stress of parents of children with autism.

1.2 Parents’ awareness of autism and its impact

Raising a child with autism can be a daunting challenge for families. During the preschool years, parents play a key role in seeking assessment and diagnosis, selecting and coordinating treatment options, managing atypical behaviors, and working to improve their child’s developmental and educational skills (Estes et al., 2013; Sharabi & Marom-Golan, 2018; Nordahl-Hansen et al., 2018). As parents spend a lot of time with their children, it is pivotal for parents of children with autism to have knowledge about autism. Chinese parents of children with autism have always stressed the importance of learning from other parents who have children with autism, and advocated for learning from other families’ experiences in parenting (McCabe, 2008). At the early stage of diagnosis, most parents do not take into account the specific implications that professionals imply when they diagnose a child with autism. Almost all parents had never or only heard of ASD before receiving a diagnosis. A small number of
Parents realize the seriousness of the situation immediately after hearing the diagnosis (Divan, 2012). Parents with higher levels of education are more knowledgeable about autism (Zhou et al., 2014; Rosenbrock et al. 2021). Parents’ perceptions of ASD affect not only their own well-being but also their children’s performance. Parents who have received intervention training are able to deal more positively with their children’s problem behaviors (Shyu et al., 2010; Zhou et al., 2019; Rodriguez et al. 2019). Research shows that parents and caregivers are the most effective primary interventionists because they are spending more time with their children than professional clinicians (McConachie & Diggle, 2007; Landa, 2018). Because of the modeling nature of parental behavior, parents are better able to reinforce positive behaviors as they happen and to sustain the therapeutic effects over time. The parents of children with autism have been learning about the disorder in a variety of ways to acquire some relevant knowledge. As the rate of autism continues to rise and the need for cost-effective autism interventions grows, researchers increasingly see parent training as an affordable intervention (Steiner et al., 2012; Zhou et al., 2018). Successful behavior change and the acquisition of new skills require consistent learning opportunities across different settings, people and environments (Dogan et al., 2017). Therefore, it is crucial for parents to be involved in teaching and intervening during their children’s childhood. Parents participate in interventions to improve their own knowledge about autism on the one hand, and to improve their ability to help their children and their effectiveness in using evidence-based strategies on the other (Magaz et al., 2015; Noyan et al., 2021). Involving parents in interventions benefits children and their parents by saving time and resources, can overcome some of the barriers that limit family involvement in interventions. For example, cost, availability, and operability.Drew et al. administered an intensive, family environment-based behavioral intervention to 24 preschool children with ASD, and a one-year follow-up found that children in the parent intervention group made greater progress in language comprehension and expression than the control group (Drew et al., 2002). Kickles et al. tracked the long-term effects of parental mediation, showing that children in the parent-trained group had more communication with their parents and sustained improvements in ASD symptoms compared to children in the control group whose parents did not receive training (Pickles et al., 2016). Consequently, for parents of children with autism spectrum disorder (ASD), it is beneficial for both the child with ASD and the parents to be trained to intervene in their child’s intervention process.

Overall, there are numerous studies pay attention on the parenting stress of parents having children with ASD, including in China (Zhou et al., 2014; Guan et al, 2021). While the perception of autism was neglected, which directly determines parents’ confidence, activity and investment in education and rehabilitation intervention for children with autism, affects the effect of education and rehabilitation. Evidence has found the important role of parents in family education and rehabilitation for children with ASD. To address the gaps, we investigated the parents’ perception of ASD in China. Through this survey, we wanted to find out: (a) what parents know about their children with autism in China today; (b) What are the real-life dilemmas that families are facing currently?

2 Methods

2.1 Participants and procedure

We contacted with the principals of a autism intervention agency, special schools for students with developmental disabilities to get their permission to issue questionnaires in site. After agreed upon when and where to distribute the questionnaires, we delivered questionnaires to parents of children with ASD in autism training institutions, a early intervention center for family having children with autism in a university and a special education school for children with developmental disabilities. Each parent was told to participate voluntary and they could withdraw at any time. For those who completed the whole questionnaire, they would be given a small gift like pencil, bookmark and so on. The questionnaires were completed and collected on the spot, and a total of 171 valid questionnaires were recovered. The demographic information was shown in Table 1.

The 88.4% of the surveyed participants who are parents of children for autism are mainly mothers, and the remaining 11.6% are other family members of children with autism, which is basically consistent with the later data that 80.2% of the primary caregivers of children with autism are mothers. In addition, about 84.2% of the parents in this survey have junior college education or above, which shows that parents of children with autism have a high level of education.
Table 1  Demographic information of parents

| Characteristics       | Frequency (n) | Ratio (%) |
|-----------------------|--------------|-----------|
| Gender                |              |           |
| Male                  | 27           | 15.8      |
| Female                | 144          | 84.2      |
| Total                 | 171          | 100.0     |
| Age (years)           |              |           |
| 20-30                 | 27           | 15.8      |
| 31-40                 | 129          | 73.7      |
| > 60                  | 18           | 10.5      |
| Total                 | 171          | 100.0     |
| Relationship          |              |           |
| Father                | 18           | 10.5      |
| Mother                | 138          | 78.9      |
| Other family numbers  | 18           | 10.5      |
| Total                 | 171          | 100.0     |
| Education level       |              |           |
| Secondary School      | 27           | 15.8      |
| Junior college        | 99           | 57.9      |
| Undergraduate college | 45           | 26.3      |
| Total                 | 171          | 100.0     |

2.2 Measurements

The questionnaire was developed by the Autism Research Centre on parents’ perception of autism (Hua, Yang, 2013). The questionnaire was divided into three sections. The first part (6 items) is basic information about the parents of children with ASD (including age, gender, education level, child training institution, etc.); the second part (17 items) is the parents’ knowledge of autism (including autism symptoms, age of onset, intervention methods, intervention effects and expectations of it, etc.). It include the parents’ knowledge on the characteristics, causes of autism and the Understanding and attitude to autism intervention (e.g., what factors does the effect of autism intervention depend on, including timely intervention, intervention strategies, types and degrees of autism, the importance of parents). The third section (10 items) is about the stresses parents facing of (e.g., your child’s most disturbing behavior, major emotional distress; What happens to your family after your child was diagnosed with ASD, including one of the parents gave up or changed jobs, the couple divorced, more spears and shields between the members of the family, families work together to support the child with ASD, etc.)

2.3 Data processing

SPSS 17.0 was used for statistical analysis and processing.

3 Results

3.1 Knowledge of autism among parents of children with autism

The findings show that parents of children with autism have good knowledge of autism information such as symptoms of autism, optimal intervention period, intervention tasks and factors influencing the intervention effect precautions, with a correct rate of over 70%. The answer was various referring to prognosis of the disorder and their expectation of children with ASD (see Table 2).

Table 2 showed that parents’ perception of the prognosis of the disorder in children with autism is that 21.1% of parents believe it can be completely cured, 26.3% believe it is a lifelong disorder but can reach a normal level of living through intervention, and 47.4% believe that autism cannot be completely cure and that some effectiveness can be obtained through intervention. This indicates that parents have a relatively objective understanding of the prognosis for autism, but a significant number of parents (about 47%) still have high expectations of the prognosis for autism, which may cause adverse internal experiences for parents during the intervention process.

In terms of parents’ expectations for the future of their children with ASD, 57.9% of parents expect their children with autism to lead a normal life, and 36.8% of parents expect their children to develop special talents and work despite still having autistic symptoms. The above data
Table 2  Prognosis of ASD and expectation of children with ASD

| Options                                      | Ratio (%) |
|----------------------------------------------|-----------|
| Prognosis of ASD                             |           |
| Can be cured                                 | 21.1      |
| Lifelong disorders which can be normalized by intervention | 26.3      |
| Not completely curable, but interventions have some effects | 47.4      |
| Incurable, a burden to the family and society| 5.3       |
| Total                                        | 100.0     |
| Expectations of children with ASD            |           |
| Living as a normal person, having a family and a career, having achievements | 57.9      |
| May have lifelong autistic symptoms and be able to develop special talents and work | 36.8      |
| Can take care of themselves, but have difficulty in working | 5.3       |
| Total                                        | 100.0     |

indicate that parents are optimistic about the prognosis of their autistic child’s disorder and have high expectations for their child’s future life, which makes parents prone to psychological disparity and aggravates psychological stress.

For the intervention for children with ASD, parents were prone to disagreement among themselves in their attitudes toward autism intervention (Table 3) as well. There were 52.6% of parents agree with the practice of promoting strengths and complementing weaknesses in intervention, while 36.8% of parents believe that the aim of intervention is to eliminate symptoms of ASD.

Table 3  The aim and effective intervention for children with ASD in parents’ perception

| Options                                      | Ratio (%) |
|----------------------------------------------|-----------|
| Aim of intervention for children with ASD    |           |
| Develop their advantages                     | 52.6      |
| Eliminating symptoms                        | 36.8      |
| Unclear                                      | 5.3       |
| Both develop advantages and eliminate symptoms| 5.3      |
| Interventions perceived as effective by parents (multiple selections) |         |
| Behavioral interventions, such as ABA       | 73.7      |
| Sensory Integration Training                 | 63.2      |
| Structured Teaching                          | 21.1      |
| RDI or DIR (Flooring Time)                   | 5.3       |
| Medication                                   | 10.5      |

Parents had a conservative understanding of the effectiveness of interventions, and parental choice of interventions has an important influence on the child’s intervention process. The current interventions for children with autism are very diverse, and the survey found that the two main types of interventions that parents consider effective are behavioral interventions such as ABA and sensory training. These two types of interventions are also the most used by domestic training institutions, and both of them are relatively single in content and parents agree with the traditional training programs. For some emerging interventions (e.g., RDI or DIR) are relatively uncommon in the institutional training, with a small number of parents finding them effective.

3.2 Challenges for parents of children with autism

It showed parents experience low social acceptance of children with ASD. There were 73.1% of parents felt that the current situation of autistic children in China was isolated and helpless, and they did not know where to seek social help. Only 3 parents having children with ASD thought they could get help, accounting for only 5.3% of the surveyed population. Such a situation makes parents feel isolated and helpless, suggesting the necessity of strengthening social support for parents of children with autism. Table 4 showed that 31.6% of parents believe that the public’s attitude toward autism was ignoring, 52.6% of parents believed that the public discriminates against children with ASD, accounting for more than half of the total, while only 5.3% of parents believe that the public can understand and accept children with ASD.

Family pressure was a big challenge for parents as well. When investigating the impact of the arrival of a child with autism on the family, 73.7% of parents reported that one of them gave up or changed jobs as a result; 31.6% of families experienced an increase in conflicts and contradictions among family members; and 52.6% of families experienced a greater unity of effort and solidarity among all members. Of particular note were the 31.6% of families with increased conflict. Family members may be conflicted due to etiological attribution,
disagreement about intervention methods and unclear roles, while the solidarity and cooperation of family members are significant factors affecting the educational rehabilitation of children.

According to the survey, 78.9% of the surveyed parents of children with ASD were troubled by anxiety, 63.2% were depressed, and 36.8% were experiencing guilt, which according to the data shows that some parents were troubled by multiple negative emotions at the same time, seriously affecting their mental health. The biggest challenge faced by parents was their child’s enrollment in school and later life, followed by the excessive long-term cost of rehabilitation training, and then the effectiveness of their child’s training. Parents were very concerned about the enrollment and life of their school-aged children. For parents, the short-term goal of intervention is for the child to attend school and the long-term goal is for the child to live independently.

Besides, parents reported the worries about the effectiveness of the intervention. The diversity of autism intervention training methods and the lack of authoritative data showing its effectiveness have left parents confused and helpless when choosing intervention methods for their children, and they have to keep trying to get information on their own way. The fact that 73.7% of parents were more interested in learning about advanced intervention strategies reflects that parents are very concerned about training methods for their children, expect proper guidance and advice, and are somewhat concerned about the training effects of current training strategies.

For the help they needed mostly, 89.5% of parents most want their children to receive systematic intervention programs, and 68.4% expect their children to receive timely and effective professional guidance.

4 Discussion

4.1 Mother as the primary caregiver for children with autism

When analyzing the primary caregivers of children with autism, the statistical results showed that the primary caregiver of 135 children with autism out of 171 respondents was the mother, accounting for 78.9% of the total. It’s consistent with the previous studies (Samadi et al., 2014; Naheed et al., 2020; Hu et al., 2020). It is evident that mothers are still the primary caregivers of children with autism. Because of the heavy caregiving burden and constant attention to the child’s progress intervention effects, etc., they are under a high level of life and psychological stress for a long time. It has been shown that the survival environment of children with autism is not optimistic, such as discrimination, ignoring, poor rehabilitation environment and social support, resulting in more emotional problems for parents (Xiong, et al., 2009).

4.2 Parents’ perception of ASD were various

We found nearly 40% of the participants felt that the focus of intervention was on eliminating symptoms. Autistic symptoms cannot be eliminated, and interventions can be used to alleviate the stereotypical behaviors of children with autism, improve their social interaction skills, alleviate their symptoms to a certain extent, and thus improve their level of social adjustment. It’s in agreement with prior studies (Winter-Messiers et al., 2007; Donaldson et al., 2017; Mottron, 2017).

It showed that systematic intervention programs as well as timely and effective professional guidance are two of the most essential in the minds of parents. And among the interventions, parents prefer behavioral intervention strategies (e.g., ABA) and sensory integration training. This is in line with a prior study (Zhou et al., 2014; Chang & Zaroff, 2017). The popularity of
these two interventions among parents is due to their promotion in the agencies in China. First of all, parents are looking forward to a systematic intervention program and effective professional guidance. However, as it stands now, it is difficult for hospitals and schools to provide an individualized set of services for children with autism. The autism training institutions are indeed more accessible to parents. Although the quality of autism training institutions in China varies, many parents have no choice but to choose these training institutions because of the limited training resources provided by the government and schools. Sensory integration training, which is exceptionally popular among domestic training institutions. In a research, it was found that although the effectiveness of sensory integration therapy is still controversial at domestic and abroad, in China, the efficacy of sensory integration is exaggerated to the extent that it can cure the core disorders of sensory, behavioral and cognitive disorders in children with ASD (Han & Deng, 2019). Many institutions provide sensory integration training programs and promote only partial knowledge, which leads most parents to believe in the project. Behavioral intervention strategies have been developed over a long period of time and have accumulated experience with many successful cases (He, 2013; Hu & Fan, 2014; Hu et al., 2015). At the same time, more books on this aspect of training have been published in recent years and are known to many parents of children with autism. Therefore, behavioral intervention strategies are also favored by many parents.

4.3 High family distress of having children with ASD

Firstly, the public’s attitude towards acceptance of ASD children is not optimistic. The survey found parents felt negative attitude from the public for children with ASD. Due to the neurological deficits of autism, most children with autism experience sensory dissonance in their lives. This impaired sensory regulation leads to deficits in their ability to perceive the world and process information (Zhang et al., 2015). The public does not have a deep awareness of autism and understand the poor academic performance, employment difficulties and social problems that they present. Also, the stereotypical behaviors and emotional problems exhibited by people with autism are considered to be somewhat damaging (Li et al., 2020). It’s consistent with the previous studies (Craig, 2015; Xu, 2019). It is easy to see that in today’s rapidly growing economy and accumulation of wealth, the development of social literacy is slow, and current social attitudes are unable to accept the autistic group, or even the disabled population. As a result, there is a tendency to ignore, or look at these groups in a discriminatory light. This is one of the reasons why most parents of autistic children feel depressed and anxious.

Secondly, the survey found parents bear considerable psychological pressure to care for ASD children. It’s consistent with the previous study (Samadi & Onkey, 2014; Marshall et al., 2018; Baraníczuk & Pisula, 2020). The negative emotions are common among parents of children with autism. Their psychological guidance, catharsis has the value of further research. It can be seen that the difficulties faced by the parents of autistic children are mainly composed of four dimensions: low social acceptance, financial burden, family pressure, and concerns about the effectiveness of interventions for their children. Families of children with autism urgently need social support, including psychological and financial help, and an increase in the number of training institutions run by the government and professionals that can provide systematic and effective intervention programs. In addition, family solidarity and collaboration are also important for the education and rehabilitation of these children.

Even though the high pressures, parents have optimistic and high expectations about the prognosis of children with ASD. The survey on parents’ expectations for the future of their autistic children showed that 57.9% of parents expect their children to lead a normal life, and 36.8% of parents hope that their children will develop special talents and work although they still have autistic symptoms. It is in line with the previous study (Finke et al., 2019). This is evident that parents are generally optimistic that their children with autism will be able to achieve a normal standard of living. It was found that parenting efficacy was positively correlated with the frequency of problem behavior presentation in children with ASD (Yao & Liu, 2015; Schrott et al., 2019). On the one hand, in China, with the continuous promotion of inclusive education, children with ASD are able to study in regular classroom with increasing opportunities and more communication between home and school, which creates conditions for further development of children with ASD. On the other hand, with the increased opportunities for parents of children with ASD to be more knowledgeable about autism, an aspect of the child with autism is developed and the parents’ sense of parenting efficacy improves. With the continuous innovation of advanced intervention methods in domestic and foreign countries and the increasing number of places for the rehabilitation of children with autism. It creates conditions for the rehabilitation of ASD children while also providing a chance for their parents to learn advanced knowledge. It can be seen that increased parenting efficacy is beneficial in improving problem behaviors.
among ASD children, thus helping parents to develop a positive parenting mindset. While some limitations need to be addressed. Firstly, the sample of participants are not national, and it is conducted in a developed city in China, which can’t represent the whole level of Parents’ perceptions of autism and their challenges in China. Following studies, can expand the scope of the study subjects. In addition, the questionnaire was mainly distributed to autism training institutions, early intervention centers, and a special education school. Future studies can be conducted in general primary and secondary schools.

5 Implications

5.1 Theoretical Implications

As the rate of ASD in China is currently increasing, the issue of rehabilitation of ASD is one of the priorities of the current academic research in China. In stakeholder research, parents are inextricably linked to the intervention of children with autism. In this study, we used questionnaires and interviews to find out the perceptions of parents of children with autism and the situations faced by their families. On the one hand, this study can conduct a step to enrich the relevant theoretical research in China. On the other hand, the theoretical findings of this study can provide theoretical support and guidance for future practice in China.

5.2 Practical Implications

Firstly, improving the social support system for parents of children with ASD. Government should provide more financial support for families having children with ASD. Some parents’ loss of part of the family income source, as well as the expensive rehabilitation costs have put a heavy financial burden on the family, and the government should provide some social security for them. Meanwhile government shall emphasize theoretical and practical research on ASD in universities and research institutions, accelerate the process of frontier theory guidance. In practice, there are many challenges in the research and practice of autism, with delays and uncertainties in diagnosis causing problems for children to receive timely and effective interventions. It is important that children with ASD be provided with timely, continuous, professional and formal early intervention and education. The government should invest more to encourage professionals to set up rehabilitation institutions. Rehabilitation institutions run by public will have better protection in terms of cost, system, and results, which will be more convincing to parents. In addition, public support is very important because public influence permeates through every aspect of the family of children with ASD.

Secondly, strengthen education about ASD for parents having children with ASD. Although parents of children with ASD have some knowledge of autism, however, it is not comprehensive. Parents of children with ASD are most interested in learning about autism-related information about advanced intervention strategies and relevant government policies. It directly affects the effectiveness of interventions for children with ASD and is closely related to the later social life of children with ASD. Therefore, it is significant to educate the parents about this aspect of autism. The process involves parents learning to accept that their children are different and to set reasonable expectations. The birth of a child with autism can have a serious impact on family life and may cause family bias and limit the social life of the whole family. At this time, family solidarity and cooperation are an important factor affecting the education and rehabilitation of children with autism and the mental health of the family. A proper understanding of autism also facilitates internal family unity so that they can take a rational and positive approach to the process of intervention for children with autism.

Besides, promote group support among parents of children with ASD. In the process of a child with autism from suspected autism to diagnosis, parents of children with ASD are mostly plagued by negative emotions such as depression, guilt, and anxiety, which are unreasonable but indeed common. Before parents are in contact with people in the same situation, they often feel abandoned and isolated and don’t know what choices to make. Therefore, groups for parents of children with ASD can provide an extremely important role for them. It provides moral support for parents of autistic children, gives parents a sense of belonging to the group, gives parents in the group a sense of inner identity and security, and relieves psychological stress during the period. What’s more, the establishment of a group for parents of autistic children is also conducive to further understanding of the field by local governments and the public to provide assistance.
6 Limitations and further research

The study surveyed Chinese parents’ perception of ASD in Chinese context, which affects not only their own well-being but also their children’s development. The following conclusions were drawn from this study: (1) Mother as the primary caregiver for children with ASD; (2) Parents’ perception of ASD were various. Parents of children with ASD have a good understanding of the symptoms, causes, age of onset and interventions, and their expectations of the prognosis and the future life of their autistic children are high; (3) The challenges that faced by the parents are mainly composed of low social acceptance, family pressure and concerns about the effectiveness of interventions for their children. While there are some limitations of the study. First, the participants in the study is not a national wide sample. Their perception cannot reflect the parents of ASD in the whole country. Especially in China, which is a wide, uneven developed country. Further study should select a more representative group of parents of children with ASD to deeply analyze their characteristics. Second, the study presents the status of parents’ perception of ASD, while the influencing factors of parents’ perception was not explored. The influencing factors such as social support and personal traits should be studied in the next step, which may contribute to improving parents’ mental health.

Funding

This project was supported by the Grant No. 2021NTSS34 from the Fundamental Research Funds for the Central Universities.

Conflict of interest

The authors declare that they have no conflict of interest.

Ethical approval

Consent was obtained from all participants in the study. No official ethics approval number was provided since the ethic committee in our university was yet to be formed at the time of collecting data.

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