The complex information needs of Chinese parents of children with autism spectrum disorder

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Abstract

Purpose – This study aims to explore the information needs of Chinese parents of children with Autism Spectrum Disorder (ASD) and how these needs evolve as their children develop.

Design/methodology/approach – This study collated 17,122 questions regarding raising children with ASD via the Yi Lin website until November 2021.

Findings – The information needs of parents of children with ASD were classified into two categories: 1) Cognition-motivation: related to children with ASD; and 2) Affection-motivation: related to their parents. Child development causes the adaptation of information needs of these parents. Within the first three years, nine different topics of these parents’ information needs were identified. Major information needs at this stage are as follows: intervention content, intervention methods and pre-diagnosis questions. During the ages of three to six years, there were 13 topics of information needs for parents, focusing on three areas: intervention content, intervention methods and diagnosis and examination. There are eight topics of information needs post six years. Parents are more concerned with the three topics of intervention content, life planning and intervention methods.

Originality/value – This novel study indicates the complex and changing information needs of parents of children with ASD in China. It may enhance the understanding of the information needs of these parents at theoretical and practical levels, provide support for them to understand their own information needs and provide a reference for relevant government and social organisations to provide targeted information services for them.

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Keywords Children with ASD, Parents, Information need, Stress coping, Intervention

Paper type Research paper

Introduction

Autism Spectrum Disorder (ASD) is a common neuro-developmental disorder. Its symptoms include social and language communication disorders, parochial interests and repetitive stereotypes (American Psychiatric Association, 2013). Owing to its prevalence and significant impact on children and families, ASD has become a global concern, affecting approximately 78 million people worldwide (Lord et al., 2022). The Centers for Disease Control and Prevention (CDC) states that “approximately one in 44 children in the United States is diagnosed with ASD” (CDC, 2019, p. 1). In the case of China, statistics from Report on the Development of Autism Education and Rehabilitation Industry in China III showed that by 2019 there were about 10 million people with ASD in China. This included approximately two million children under 12 years of age and increasing at nearly 200,000 per year (Chinaorg, 2019). Not only can ASD affect children’s health and life, but it may initiate significant changes for their families. Families whose children are diagnosed with ASD often fall into a stressful state (Gentles et al., 2019; Lu et al., 2015). To alleviate the stress on parents, the provision of professional information support for children and their families has become an
international concern (Lord et al., 2022). Timely and reliable information is a prerequisite for parents to understand ASD and is the key to raising a happy and healthy child and maintaining a healthy and affectively stable family (Hodgetts et al., 2015; King et al., 2006). Previous studies have found that parents of children with ASD need to seek highly specialised information related to health, development, education and an independent life. They will search, browse, organise, store, use and share information (Rodrigue et al., 1992). Active information seeking by parents of autistic children may be used to cope with the stress of raising autistic children (Pifalo et al., 1997).

Owing to the unique and ongoing nature of rehabilitation for children with ASD, the responsibility for their long-term care primarily rests with their parents, particularly in China. Parents who are raising a child with ASD require professional information to reduce their anxiety and uncertainty. This helps to stabilise the family (Lu et al., 2015). As the fundamental factor that triggers and drives human information-seeking behaviour, information needs are the starting point for studying human information behaviour (Haasio et al., 2020). Only two studies have explored the information needs of parents of children with ASD (Murphy and Tierney, 2006; Weissheimer et al., 2020). Previous studies have the following research gaps: First, the number of samples in previous studies is very limited. For example, Martinović and Stričević (2016) have 13 research interviews, and An et al. (2019) have 16 research samples. This may not provide comprehensive coverage of the information needs of parents. Second, as a developmental disorder, parents’ information needs will change with their children’s maturation. However, no previous studies have studied this from a dynamic perspective. Moreover, previous studies on the information needs of this group of people in other countries may be unable to be adapted to the Chinese context. For example, as compared with the rehabilitation environment of children with ASD in the United States (Gibson et al., 2017), parents of children with ASD in China lack official information sources, such as national organisations and relevant websites. This is owing to the inadequate information service system for ASD-related information (An et al., 2019). Thus, the information needs of parents of children with ASD in China may be different. As children with ASD grow, they will encounter new challenges. They and their parents will also have new and evolving information needs on healthcare, education and society. Understanding these changing needs may benefit families and autistic children. Governments and organisations may also provide service information from health, education and social communication perspectives (Gibson et al., 2017). However, there is no detailed study on the information needs of parents of children with ASD in China. Therefore, this study aims to explore the complexity of the information needs of parents of children with ASD in China and identify the types and specific contents of the information needed. This would serve to enable different levels of the sectors of society to understand the information needs of the group and provide professional information assistance.

Research background

Theory of information need

Information need is a core concept of human information behaviour (Wilson, 1997). Scholars have discussed this concept since the 1960s. Cole (2012) and Wilson (1981) argued that people’s need to locate and use information is motivated by the desire to orient their knowledge and behaviour. Belkin et al. (1982) and others affirmed the role of information needs in reducing uncertainty. Kuhlthau (1991) considered information need a state of uncertainty in knowledge, characterised by vague ideas and uncertainty; she extended the conceptualisation of information need to affective dimensions. Lin et al. (2015, p. 912) stated that information needs are the “state or process whereby an individual perceives a gap between information and knowledge to deal with an event or problem”. In general, the connotation of information needs has included incentives, reduced uncertainty and problem-solving.
Researchers have also explored the combination of information needs and information-seeking behaviour using context- or user-centred methods. For example, physiological, affective and cognitive needs are direct drivers of information needs at lower levels (Mniszak et al., 2020; Wilson, 1981). Cole’s (2012) information need theory posited that the structure of information needs might help explain why people seek information. Some scholars say that information needs trigger people’s information-seeking. For example, Wilson’s (1997) information-seeking model held that information need was the root cause of information-seeking behaviours. He said that information need does not immediately trigger information-seeking but is affected by coping strategies, costs, self-efficacy and intervention variables. Savolainen (2017) argued that information needs might provide the driving force for longer-term information-seeking, driving the next cycle and extending the process forward. In addition, several studies have used information-seeking processes and outputs to understand information needs (Shenton and Dixon, 2005; Shih et al., 2012).

Studies have found that information needs are hierarchical and categorical (Cole, 2020; Ruthven, 2019; Taylor, 1968; Wilson, 1981). Taylor (1968) identified four levels of question-formation along an information-seeking spectrum: visceral, conscious, formalised and compromised. As pioneer work on information needs, this model has greatly contributed to the research on hierarchical concepts in this field (Chang, 2013). Ruthven’s (2019) analyses of linguistic differences revealed that descriptions of conscious needs are more affective, involve more sensory perceptions and contain different temporal dimensions than descriptions of formal needs. Thus, we could distinguish levels of information needs based on linguistic patterns, and the language used to express information needs might reflect individuals’ understanding of their information needs.

In summary, information need research has deepened our understanding of its concept, level, characteristics and triggering and driving effects on information-seeking. Information need has become an invaluable starting point for investigating information-seeking and use by specific groups.

Interventions for children with ASD in China
The first case of ASD in China was acknowledged in 1984 (Ai, 2013), far later than the earliest diagnoses in the West (Wang, 2016; Xiao, 2020). Thus, the country has relatively few professional institutions that can meet the needs of the growing number of autistic children (An et al., 2019; Yan, 2017). Most are nongovernment institutions with high costs to families (Wucaili Center for Children with Autism, 2015). Although China advocates inclusive education, its implementation and development have been relatively slow and its effects suboptimal (Xiao, 2020; Zhang, 2019).

Nevertheless, China has some large professional rehabilitation institutions, including Yi Lin, dedicated to the rehabilitation, training and research related to children with ASD. After more than a decade of development to increase its professional competence and teaching resources, Yi Lin has become one of the largest such institutions in China. The institution has created the largest online forum for ASD in China, the Yi Lin ASD forum (Yi Lin, 2022). Most of its registered members are parents of children with diagnosed or suspected ASD. The forum allows parents to share and exchange knowledge, training intervention ideas and intervention methods. As of 20 November 2021, the Yi Lin ASD forum had 55,223 registered members and 512,062 communication posts.

Information behaviour of parents of children with ASD
Few studies have researched the information needs of parents of children with ASD. Most have focused on treatments, rehabilitation and rights and primarily used interviews to collect data. For example, An et al. (2019) reported that the information needs of parents of children
with ASD had four themes: independent living, puberty, language development and policies and regulation. Murphy and Tierney (2006) refined the parents’ information needs into eight topics: dealing with diagnoses, next steps, health services, education, financial resources, legal issues, explaining ASD to children or significant others and future concerns. Weissheimer et al.’s (2020) literature review of 41 articles found that parents most frequently sought information about treatments, behaviour management, prospects, children’s rights and information resources.

Exploring the characteristics of parents’ information needs is essential for understanding this group because parents’ information behaviour and needs are always changing (An et al., 2019). Parents’ preferences for sources of information change over time (Martinović and Strićević, 2016). Gentles et al. (2019) found that parents’ motivation to participate in interventions changed along a three-stage trajectory: coming to understand their child has ASD, becoming more active and intense and having their intensity gradually dissipate. The changing intensity corresponds to a change in their information needs. Furthermore, An et al. (2019) found that parents’ information needs change as their children’s life skills improve. Parental information needs also change with the children’s ages. Parents of younger children pay more attention to physical growth and educational information, while parents of older children care more about independent living, work and higher education (Gibson et al., 2017).

The relative lack of reliable information motivates parents to seek as much information as possible. Thus, much current research has focused on sources of and barriers to information-seeking. Gibson et al. (2017) found that parents preferred nonlocal sources (e.g. Internet) despite relying heavily on local sources. Different-aged parents showed similar information-seeking patterns, and information availability decreased with the increase in the child’s age (Gibson et al., 2017). Chávez and Sabelli’s (2020) studies on the information behaviours of parents of autistic children identified obstacles and difficulties in obtaining reliable information sources. They shared information with the closest people and social networks to compensate for the lack of organisational information, especially peers in the same situation. Mansour (2021) found that more than three-quarters of parents of autistic children used informal resources, and one-quarter of parents used library resources. Parents also emphasised the lack of government centres’ basic services and specialised treatments. They often communicated (online and otherwise) with other parents with autistic children, psychologists, psychiatrists, language therapists and special education teachers, and they often read relevant books and articles (Martinović and Strićević, 2016).

Past research has insufficiently refined the information topics, the proportion of each information type and changing information needs over time. Thus, there is an urgent need for research clarifying these literature gaps.

**Problem statement**

Relevant and appropriate information can help reduce stress in parents of children with ASD and encourage parents to actively engage in decision-making about their children’s health (Martinović and Strićević, 2016). Information provides needed social support for stressed parents, helping them achieve psychological growth and reduce anxiety (Shontz, 1975). Therefore, exploring what information this group needs is imperative. This study analysed parents’ questions in the Yi Lin ASD forum as an information-search coping behaviour. We also considered the parents’ information need as reflecting their current knowledge deficiencies for coping with stress and the questions’ content as representative of their information need. Therefore, the first research question was as follows:

*RQ1.* What information needs topics were expressed by the parents of children with ASD in the forum?
Children with ASD are a highly heterogeneous group. The challenges and pressures experienced by their parents are not immutable; as the children age, their parents’ new information needs change with the developing environment (Gibson et al., 2017). Therefore, studying their information needs from a dynamic perspective provides a deeper understanding of parents’ information needs (Kuhlthau, 1991; Stroebe et al., 2017). Scholars have used the concept of stages to understand parents’ experiences. DePape and Lindsay (2015) applied the family life cycle model to divide the parental experience into two stages: before and after diagnosis. However, Gentles et al. (2019) argued that the stage changes in parental information needs should not be tied to external events (e.g. before and after a diagnosis) because only the parents’ meaning construction process is mapped to these external events. Therefore, this study explored parents’ changing information needs based on the ages of the children with ASD. This enabled us to trace the changing needs and the changes’ underlying causes. Thus, the second research question was as follows:

**RQ2.** How do the information needs of parents of children with ASD change during their children’s growth stages?

**Methodology**

**Data collection**

There are significant advantages to using the online forum data to represent information needs (Ruthven, 2019). First, users express their information needs according to their authentic feelings. Questions are usually narratives of immediate needs rather than later reflections on experiences. Therefore, these information situations are immediate. Second, online forums provide more sample data than interviews on users’ information needs.

“Yi Lin” ASD forum’s permanent question section includes “Help Me”, “ABA Behaviour Problem Management”, “Family and Marriage & Society”, “My Baby Has Made Progress!”, “Education and Training”, “Recommended” and “Information Exchange”. As “My Baby Has Made Progress!” and “Information Exchange” are mostly life records, they belong to information sharing rather than information needs. Therefore, this study selected five blocks as data sources. We then crawled five pages of user questions in the section using the “Hou Yi” crawler tool. The crawler was set to crawl all the pages, with no restrictions on the posting time nor language. The data were crawled from the first post published in the forum (the earliest of which was posted on 23 November 2001) until 20 November 2021. We obtained a total of 17,122 questions asked by users. We then saved these data in a text format that could be processed by the NVivo11 Plus software. Subsequently, the researchers manually cleaned the obtained data. As most of the questions which reflected the needs are in the form of questions, this study had “how to do”(怎么办), “what happened”(怎么了), “how to deal with”(怎么处理), “whether”(是不是), “ask for help”(求救), “ask for teaching”(求教), “help me”(帮我), “can we (me) . . . ?(可以 . . . 吗?) and “will he (she) . . . ?(会不会 . . . ?) as the main form of expression needs. Therefore, we retained the data containing these phrases. Then, in the data cleansing, we removed duplicate, vacant, semantically unknown posts, advertising posts, newsletters and non-parent posts. After this process, we were left with 8,533 questions. Additionally, we excluded questions that did not pertain to the information needs of parents raising children with ASD, such as “how to use the forum?” or “how to operate the computer?”. This resulted in 7,232 valid data sets.

**Data analysis**

**Analysis process for the identification of information needs topics.** Owing to the lack of reliable classification of information needs topics for parents of children with ASD, we used thematic content analysis and open coding and the NVivo11 Plus software for auxiliary coding. First,
2,000 data participants were randomly selected as the initial samples in the overall data set. The reading analysis was conducted by two researchers and a basic coding mode was formed. This included the following categories: aetiology and basic knowledge, disease, diagnosis and identification, examination, treatment, behavioural intervention, learning and training, diet and health, complications, life, emotion, prevention, future development, education and research, rights and policies, family, second child and work.

Thereafter, the entire data set was independently coded by two researchers, and the inconsistent coding results were discussed until all the differences were resolved. In the coding process, we found that the initial coding model could not cover all the information needs. Some unreflected topics emerged, such as parents’ social interaction. In addition, some topics could not be classified into one category, such as children’s and parents’ emotion, and their information needs on emotional issues were not the same. Parents required emotional support, while children required more emotional training and control. Therefore, the information needs of parents were separated into two categories: related to children with ASD and related to the needs of parents. This classification is more conducive to an in-depth analysis of the group. In addition, we adjusted the category name and structure of the coding scheme. For example, we combined aetiology and basic knowledge with knowledge of ASD and grouped it into four sub-topics, including rehabilitation knowledge, pathological knowledge, popular science knowledge and etiological knowledge. Treatment, behavioural intervention, learning and training were combined as intervention contents, as they are all about behavioural intervention and training for children with ASD. Methodological issues were separately listed as methods of intervention, and drugs were also incorporated into this topic. We integrated disease into the complication because the latter could better encompass other conditions associated with ASD. Thereafter, the resources required for interventions on ASD were separated from learning and training and were called intervention resources. In addition, we removed sub-topics, such as renting houses and computer information technology since these contents are not directly related to the information needs of parents of children with autism. Hereafter, we calculated the agreement (Cohen’s kappa) between the two coders to be 0.83, which shows an acceptable conclusion level (Landis and Koch, 1977). The final encoding mode is indicated in Tables 1 and 2.

Analysis process for the identification of changes in information needs. Although general injuries usually persist, the clinical manifestations of ASD are heterogeneous and change with the development of children (Georgiades et al., 2017). Children with ASD usually begin to manifest symptoms within three years of age, and the severity of most children with ASD traits decrease from three to six years of age. However, after the age of six, the improvement of ASD in nearly three-quarters of children will decline. Therefore, before the age of six is the optimal period for early intervention. This age may be a key turning point for autistic children (Georgiades et al., 2021). Therefore, the researchers selected the two time-nodes of three years old and six years old, and divided children with ASD into three stages according to age: before three years old, three to six years old, and after six years old. Accordingly, changes in parents’ information needs are also considered from these three stages. The researchers extracted posts with age characteristics in the data set, that is, with “one”, “two”, “three”, “four”, “five”, “six”, “seven”, “eight”, “nine”, “ten” and “zero”. After deleting the posts that did not reflect age, a total of 538 post data were obtained. There were 325 posts before three years old, 164 posts during three to six years old, and 79 posts after six years old. Based on the above coding mode, the two researchers coded the data of the three stages and discussed the inconsistent coding results until they reached an agreement. After the test of the same method above, the agreement (Cohen’s kappa) between the two coders was 0.97 (Landis and Koch, 1977). This study simultaneously conducted descriptive statistical analysis on the frequency and proportion of needs.
<table>
<thead>
<tr>
<th>Topics</th>
<th>Descriptions/Examples</th>
<th>Number</th>
<th>Proportion</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1 Intervention contents</strong></td>
<td>Information about challenging behaviours and interventions for children with ASD</td>
<td>3,389</td>
<td>46.86%</td>
</tr>
<tr>
<td>1.1 Challenging behaviours</td>
<td>What to do since my baby likes to look at lights?</td>
<td>1,950</td>
<td>26.96%</td>
</tr>
<tr>
<td>1.2 Cognition</td>
<td>How to help children establish the concept of property rights?</td>
<td>478</td>
<td>6.61%</td>
</tr>
<tr>
<td>1.3 Language</td>
<td>How to teach kids pronunciation?</td>
<td>323</td>
<td>4.47%</td>
</tr>
<tr>
<td>1.4 Social intercourse</td>
<td>How to guide child play with other children?</td>
<td>306</td>
<td>4.23%</td>
</tr>
<tr>
<td>1.5 Fine motor</td>
<td>How to train children’s finger fine movements?</td>
<td>153</td>
<td>2.12%</td>
</tr>
<tr>
<td>1.6 Self-care</td>
<td>How do I potty train my child?</td>
<td>112</td>
<td>1.55%</td>
</tr>
<tr>
<td>1.7 Gross motor</td>
<td>How to teach my baby to bounce a ball?</td>
<td>67</td>
<td>0.93%</td>
</tr>
<tr>
<td><strong>2 Intervention methods</strong></td>
<td>Information about options and questions on rehabilitation methods of ASD</td>
<td>709</td>
<td>9.80%</td>
</tr>
<tr>
<td>2.1 Therapy</td>
<td>Is stem cell therapy effective for ASD?</td>
<td>211</td>
<td>2.92%</td>
</tr>
<tr>
<td>2.2 Questions about methods</td>
<td>How should I train my child who has just turned one year old?</td>
<td>169</td>
<td>2.34%</td>
</tr>
<tr>
<td>2.3 Drugs</td>
<td>Is VB6 and magnesium reliable for treating ASD?</td>
<td>158</td>
<td>2.18%</td>
</tr>
<tr>
<td>2.4 Planning advice</td>
<td>What’s next for my baby?</td>
<td>120</td>
<td>1.66%</td>
</tr>
<tr>
<td>2.5 Family intervention</td>
<td>Looking for a family training program for a one year and three months old child with ASD</td>
<td>51</td>
<td>0.71%</td>
</tr>
<tr>
<td><strong>3 Diagnosis and examination</strong></td>
<td>Information about diagnosing and screening for ASD</td>
<td>398</td>
<td>5.50%</td>
</tr>
<tr>
<td>3.1 Judgement of symptoms</td>
<td>Please help me to see the level of autism in my 2.5 year old girl</td>
<td>328</td>
<td>4.54%</td>
</tr>
<tr>
<td>3.2 Medical examination</td>
<td>If my child needs an MRI of the brain?</td>
<td>70</td>
<td>0.97%</td>
</tr>
<tr>
<td><strong>4 Intervention providers</strong></td>
<td>Information about selection of intervention sites and personnel</td>
<td>398</td>
<td>5.50%</td>
</tr>
<tr>
<td>4.1 Institutions</td>
<td>Ask for recommendations for training institutions in Shanghai</td>
<td>207</td>
<td>2.86%</td>
</tr>
<tr>
<td>4.2 Teachers and Tutors</td>
<td>Looking for a tutor</td>
<td>111</td>
<td>1.53%</td>
</tr>
<tr>
<td>4.3 Hospitals</td>
<td>Which hospital is good in Beijing?</td>
<td>80</td>
<td>1.11%</td>
</tr>
<tr>
<td><strong>5 Intervention resources</strong></td>
<td>Information about resources needed for the rehabilitation of children with ASD</td>
<td>381</td>
<td>5.27%</td>
</tr>
<tr>
<td>5.1 Learning materials</td>
<td>Request information on RDI</td>
<td>299</td>
<td>4.13%</td>
</tr>
<tr>
<td>5.2 Teaching aids</td>
<td>Buy recognition cards</td>
<td>75</td>
<td>1.04%</td>
</tr>
<tr>
<td>5.3 Economic support</td>
<td>Would like to find out about the monthly expenses of raising a child with ASD</td>
<td>7</td>
<td>0.10%</td>
</tr>
<tr>
<td><strong>6 Knowledge of ASD</strong></td>
<td>Information about basic and specialist knowledge</td>
<td>371</td>
<td>5.13%</td>
</tr>
<tr>
<td>6.1 Rehabilitation knowledge</td>
<td>What exactly is ABA, and can someone explain it to me in layman’s terms?</td>
<td>146</td>
<td>2.02%</td>
</tr>
<tr>
<td>6.2 Pathological knowledge</td>
<td>What is the difference between ASD and growth retardation?</td>
<td>105</td>
<td>1.45%</td>
</tr>
<tr>
<td>6.3 Popular science knowledge</td>
<td>How old should a child be considered autistic?</td>
<td>71</td>
<td>0.98%</td>
</tr>
<tr>
<td>6.4 Etiological knowledge</td>
<td>Is ASD linked to genes?</td>
<td>49</td>
<td>0.68%</td>
</tr>
<tr>
<td><strong>7 Education</strong></td>
<td>Information about learning and education for children with ASD</td>
<td>355</td>
<td>4.91%</td>
</tr>
<tr>
<td>7.1 Schooling issues</td>
<td>Can my son go to primary school?</td>
<td>277</td>
<td>3.83%</td>
</tr>
<tr>
<td>7.2 Enrolment issues</td>
<td>What to do since my child is rejected from kindergarten?</td>
<td>44</td>
<td>0.61%</td>
</tr>
<tr>
<td>7.3 Foreign Education</td>
<td>Please tell us about autism education in Canada</td>
<td>17</td>
<td>0.24%</td>
</tr>
</tbody>
</table>

Table 1. Information needs related to children with ASD (continued)
Results

Topics of the information needs of parents of children with ASD
The topics of the information needs of parents gradually emerged in two parts. In the following, we also separately present the two parts of information needs.

Information needs related to children with ASD
Thirteen topics and 52 sub-topics related to children’s information needs were identified. This type of information need accounted for 93.32% of all the information needs of parents of children with ASD, as per Table 1.

Intervention contents. This topic accounted for 46.86% of all information needs, which is parents’ most concerned topic. Parents expressed concern involving cognitive disorder, language disorder, social disorder, sports, self-care and other aspects. Therefore, information needs about these challenging behaviours also account for a large proportion (26.96%). Intervention information mainly involves six areas: cognition, language, social intercourse, fine motor, self-care and large muscles. Among them, the information need for cognitive training is the strongest, accounting for 6.61%.

Intervention methods. As children with ASD are highly heterogeneous, individualised intervention-based approaches are correspondingly in high demand by parents, accounting for
9.80% of all information needs. When parents encounter difficulties in rehabilitation training, they seek relevant information. This includes guidance and assistance, whether the intervention method is feasible and how to conduct intervention training at home. Parents also seek planning information for the next steps when they complete a training stage or problems arise.

**Diagnosis and examination.** Parents’ questions about ASD diagnoses and examinations accounted for 5.50% of their queries. Parents seek recommendations for doctors for professional diagnoses and medical examinations to assess their children’s ASD and identify complications.

**Intervention providers.** This need accounts for 5.50%. It mainly includes reviewing and selecting appropriate intervention institutions or hospitals. Parents will refer to the strength of the institution’s intervention projects, distance and costs for comprehensive consideration, and decide on whether to go there. Simultaneously, parents have the need to find special education teachers, individual training teachers and tutors to compensate for their lack of training knowledge and conduct more timely and convenient intervention training at home.

**Intervention resources.** Information needs on resources accounts for 5.27% of all requirements. Parents seek various auxiliary resources for support and to help them acquire better training for interventions and training. Parents also seek economic support and resources to cover institutional training and hospital costs.

**Knowledge of ASD.** Parents’ knowledge of ASD was minimal, and 5.13% of the needs seek information about interventions and four general types of knowledge: rehabilitation, pathological, popular science and etiological.
**Education.** Parents have questions about choosing schools for their children and whether their children had the relevant standards for schooling. Many children with ASD find it difficult to adapt to mainstream schooling. Specifically, parents have questions about delaying enrolment, choosing classes and choosing between institutions and schools. Parents also wanted to understand the education levels of children abroad to choose a better education for their children. In addition, interest-based education was also a parental concern.

**Pre-diagnosis questions.** Before a diagnosis is made, parents find that their children have a tendency toward ASD, and they will need relevant information to help them identify whether their children do have it.

**Complications.** ASD may have some complications. Parents need information about these diseases to help their children treat and recover from it. At the forum, some parents raised issues related to low muscle tension, indigestion, hyperactivity, epilepsy and other complications: teeth problems, intellectual development and sleep disorders.

**Rights and policies.** Parents also need legal and social support. Parents said they need to safeguard their right to education when children are bullied and unable to participate in activities, when they needed insurance, or needed legal aid. Parents also seek ASD information from the China Disabled Persons’ Federation (CDPF) to help them manage their children’s disability certificates and apply for subsidies. They also request for all sectors of society to provide care to autistic children and families and help children with ASD solve their work and more security problems. In addition, parents will also pray when they encounter confusion and hope to seek support from religious beliefs.

**Diet and health.** The parents have questions about fasting, nutrition and physical fitness. Some parents need information about the food intolerances common in children with ASD and alternative foods to provide an appropriate, healthy daily diet. Most parents hope that improving their children’s diet, exercise and other health habits will improve their physical fitness and disease resistance.

**Future development.** The parents’ concerns about their children’s future include development trajectories, personal and sexual relationships and work prospects. They wonder if their children will recover or adapt well enough to work, live independently or have families.

**Life planning.** The parents have questions about living environments and lifestyle issues, including immigration policies and preparations when they are considering emigrating. They also have practical questions about everyday life, such as the impact of bed separation on children with ASD.

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**Information needs related to parents themselves**

Six topics and 11 sub-topics related to the information needs of the parents themselves were identified, which accounted for 6.68% of all the needs, as per Table 2 below.

**Social intercourse.** The parents’ social information needs accounted for 2.93% of all the posts. First, they communicate with other parents of children with ASD to learn about child training and find emotional and psychological support, especially from parents nearby. They also communicate with teachers (including rehabilitation teachers) about training challenges and schooling. Some parents try to hide their children’s ASD from teachers. Some parents need information to help them explain their children’s ASD to friends and neighbours.

**A second child.** Some parents need help deciding whether to have a second child. The questions are related to the policy of having a second child, medical examinations, preparations, risks and whether having a second child will benefit their autistic children.

**Family relationships.** Parents often have family conflicts owing to anxiety, pain and disagreement about interventions. Some parents seek advice about marriage and family relationships.
Construction of mentality. Parents are prone to negative emotions in long-term training, so they need useful suggestions for emotional control and psychological construction to maintain a stable emotional and psychological state.

Learning and Work. Caring for children with ASD consumes significant time, which affects the parents’ work to varying degrees. Some parents seek advice about whether they should quit their jobs or change their work–life balance or childcare arrangements. They also need information about ASD and other expertise.

Health. Health information needs refer to parents’ health information on sleep problems and physical problems. Parents want to keep fit by exercising and sleeping better and indicate that their own health is key to long-term care for their children.

Changes in information needs of parents of children with ASD

Figures 1 and 2 present the topics and changes in the information needs of the parents of children with ASD during the three stages. The percentage indicates the proportion of this type of need to the total needs during a specific stage; thus, 0.00% means there was no need. The three different colours identify the different stages.

Figure 1 shows the changes in the information needs focused on the children with ASD. It shows that parents of children with ASD have eight topics of information needs related to children before their children are three years old. Among them, intervention contents, intervention methods and questions before diagnosis were their main needs at that stage, which accounted for 30.77%, 30.77% and 18.46%, respectively. The diagnosis and examination and intervention providers also accounted for a significant proportion at 9.23% and 7.08%, respectively. Under the topic of intervention content, information regarding the challenging behaviours was most required by parents. Regarding

Source(s): Figure by authors
rehabilitation, training language accounted for the highest proportion, followed by social intercourse, cognition, self-care and gross motor. Under the topic of the methods of intervention, parents had the highest need for methodological questions, while parents were also in dire need of more planning advice. Parents had less need for the information on the knowledge of ASD, resources for intervention and life planning. From three to six years old, parents’ information needs covered 11 topics. The focus was on the three topics of intervention contents, intervention methods and diagnosis and examination. This accounted for 57.32%, 17.07% and 6.71%, respectively. Regarding the sub-topics of intervention content, parents still pay the most attention to challenging behaviours. The needs for rehabilitation content were in the order of language, self-care, social intercourse, cognition, gross motor and fine motor. Regarding the sub-topics of intervention methods, there were four main sub-topics of needs: planning advice, methodological guidance, medication and family intervention. After the age of six, parents’ information needs gradually decreased and included seven topics. At this stage, parents’ information needs mainly focused on three sub-topics of intervention content, life planning and methods of intervention. This accounted for 49.37%, 12.66% and 11.39%, respectively, and focused more on the rehabilitation of children’s social intercourse, cognition and language. Concurrently, parents are concerned about their children’s education, future development and complications.

Among parents’ information needs, interventions for challenging behaviours have been the focus of attention. This sub-topic is the core information need and shows an upward trend with the development of the child’s age. The focus on rehabilitation also varies by stage, with language, social intercourse and cognition being the more important issues for parents in all three stages. The proportion of parents’ information needs regarding intervention method topics showed a gradual decrease with the development of the child’s age. There was also a gradual decrease in the sub-topic of instructional needs for intervention methods. Planning advice was a constant need for parents and remained largely stable throughout the three stages. The need for therapy was only present in the stages before age three and after age six. The need for family intervention was only present in the stages before age three and from age three to six, with a gradually decreasing share. The need for parents to identify their child as autistic before the diagnosis is made is greater before the age of three years and less in the three-six years stage, and it disappears after the age of six years. The choice of intervention is mainly related to the issue of institutions. This need exists in the first two stages and gradually declines. The need for schooling is present in the first two stages after the age of three years, and it increases from 4.27% to 8.86% in the change from three-six years to after six years. As children age, parents’ concerns about their children’s future situation gradually emerge, with the need accounting for 2.44% at ages three-six years, and having risen to 7.59% after six years. Parents’ concerns about the life issues of their children were gradually

![Figure 2](image-url)

**Figure 2.** Changes in information needs related to parents themselves in the three stages

**Source(s):** Figure by authors
considered after the age of six years, accounting for 12.66% of the needs. However, this need did not manifest itself in the first two stages. Parents’ concerns about the developmental problems and other complications became progressively more evident as the children grew older. Resources were an ever-present need and were only a smaller percentage.

Figure 2 shows the information need changes focused on the parents. Before the age of 3, parents of children with ASD mainly have one topic of information needs related to themselves, namely social intercourse, which accounts for 0.62%. From three to six years old, parents’ information needs about themselves covered two topics, and the proportion of social intercourse, learning and work were all 0.61%. After the age of six, parents’ information needs about themselves include only social intercourse, which accounts for 3.80%.

Information needs about the parents themselves changed less. Learning and work appear only at the age of three to six years. The need for social information has always existed in three stages. This topic accounted for a small proportion in the first two stages and increased slightly after the age of six.

Discussion

Complex information needs of parents of children with ASD

The information needs of parents of children with ASD may be classified into two parts, including 13 topics of information needs related to children and six topics of information needs related to the parents. Among them, the information needs of these children are more complex. They occupy the main part of the information needs of this special group. However, there are also unique information needs related to the parents of children with ASD themselves, which have not been addressed in previous research and differs from the information needs of other groups (Hersberger, 2001; Ruthven et al., 2018). In addition, the classification of the information needs in this study is more refined than that in previous studies (An et al., 2019; Murphy and Tierney, 2006) and may more comprehensively cover the information needs of parents of children with ASD at different ages.

Parents’ information needs related their children are primarily cognitive-driven. This study’s findings confirm that parents mainly need information to cope with the lack of knowledge in the rehabilitation process (Grant et al., 2015; Murphy and Tierney, 2006). The behavioural interventions and child’s rehabilitation are the focus of parents’ attention. What has not been mentioned in previous studies is that parents in China emphasise the comprehensive training of abilities, and not solely for one aspect. Parents urgently need guidance and planning advice, especially at the beginning of the diagnosis. This is because most families do not begin to understand ASD until the child is diagnosed (Chávez and Sabelli, 2020; Grant et al., 2015). In addition, parents have concerns about their child’s future development. This is because parents have difficulty finding information on how to help their children transition to adulthood (Gibson et al., 2017). Moreover, this study found that many parents in China were unable to accurately determine their child’s condition. These findings are consistent with the study of Heys et al. (2017). This study identifies several information needs that have not yet been identified, including: information about the child’s diet and health, immigration issues, information about complications of disorders, sleep problems, religious beliefs and teaching aids. It is important to note that while a parent’s need is often triggered by a current concern, it may also be triggered by a positive or future issue. Parents want their children to have access to make greater progress, or they may have concerns about their future development (Gentles et al., 2019).

The information needs of the parents themselves are largely affection-driven. The study’s results showed that parents of children with ASD prefer to interact with other parents in the same situation nearby. This is because they can gain referable information, and psychological support and comfort (Derguy et al., 2015). They are keen to be acknowledged, accepted and understood by the public (An et al., 2019) and by family
members, especially their partners, which was not mentioned in previous studies. In addition, long-term rehabilitation may also lead to personal financial risks, sleep deprivation and other forms of physical functioning, and affective impairment (Gentles et al., 2019). The need for information on second child issues is also unique to this group, as they desire information on the risks of having a second child and whether having a second child will assist with the first.

Overall, there is an urgent need for parents to learn about ASD, rehabilitation knowledge and skills to better manage the challenges encountered during their child’s intervention. This validates the mechanism of information needs reflected in a state of information scarcity and sought in forums (Belkin et al., 1982; Cole, 2012; Lin et al., 2015; Wilson, 1981). Moreover, the information needs of parents coping with parenting stress are simultaneously cognitively and affection-driven. They need information and knowledge about parenting their children and need emotional support. This study further supports Wilson’s (1981) understanding of the characteristics of information needs, which include emotional and cognitive needs. Therefore, needs may be that they include their own needs and needs related to the object of their attention. This may also provide some inspiration for the study of the types of information needs.

Identification of parents’ information needs topics could inform the designers and administrators of ASD forums to help optimise the navigation and expand or refine the board topics. We recommend that ASD forums organise their information and posts according to the users’ specific information needs and by the children’s ages to make it easier for parents of children with ASD to find the information they need when they need it. This would also help parents anticipate their own information needs based on others’ posts sorted by age. All ASD-related service providers (e.g. government and nongovernment agencies, foundations, institutions, etc.) would benefit from recognising and differentiation between child- and parent-related information needs; more parent-related information is needed overall, including information on parents’ psychological, emotional and physical health and legal and financial resources.

Changes in the information needs of parents of children with ASD
The dynamic changes of the information need of parents of children with ASD are mainly reflected in the topics of information needs about children. This category of information needs may show great variation with the age of the child. In contrast, information needs about the parents themselves do not significantly change across the three stages. Since this category of needs is more affection-driven, this group requires long-term affective support (Martinović and Strićević, 2016). This study also explores how needs change as the child ages, rather than by reference to external conditions, and thus provides greater insight into the dynamics of parents’ information needs (DePape and Lindsay, 2015).

Since the behaviour of children with ASD is constantly changing (Seltzer et al., 2003), the intervention issues faced by parents are not static. Intervention and rehabilitation are a major source of stress for parents. This results in changes in parental stressors, and ultimately in the dynamics of parents’ information needs. These changes were evident in the 11 topics of information needs. Second, these changes are also related to the way parents cope with the intensity of their information seeking decreasing as the critical period fades (Gentles et al., 2019). In the early stages of ASD, parents commonly have questions about the diagnosis, and the need for diagnosis and examination is very urgent (Sen and Spring, 2013). Post diagnosis, this need dissipates. It is thereafter related to the knowledge reserve and mastery of parents. Before the age of three, parents need initial and regular guidance as newcomers to dealing with ASD (Chávez and Sabelli, 2020). As rehabilitation progressed, parents gradually acquire knowledge and skills, and thus the need for this information gradually decreases. When new problems arise, parents need new ways and resources to help them navigate them. The focus of parents’ attention on the content of child’s intervention changes at different stages.
However, regardless of the age, interventions for the child’s challenging behaviours and competency training are still the most important concerns for parents. This is also related to the fact that there is currently no complete cure for ASD. Children with ASD need long-term rehabilitation (Gibson et al., 2017).

Our findings provide valuable information for relevant government and rehabilitation agencies. First, government agencies in China, such as the National Health Commission (NHC) and the CDPF, need to provide integrated policy planning support for the entire life cycle of children with ASD, even before they have been diagnosed. This will meet the dynamic needs of families with ASD at different ages and developmental stages of children. For example, the NHC needs to develop a scientific policy on autism screening for children 0–6 years of age and ensure that parents of newborns aware of the importance of early screening information for ASD. The CDPF should focus on guiding current rehabilitation institutions to provide standardized rehabilitation policies for children diagnosed with ASD that fit the developmental patterns of children. Besides, it needs to develop a comprehensive living security policy for the older ASD group to maintain their equal civil rights in political, economic, cultural and social aspects. Second, rehabilitation institutions need to develop individualized information service plans based on the child’s stage of development and the changing information needs and provide comprehensive rehabilitation measures for each stage. For example, institutions need to focus on the different needs of children with ASD at different ages in terms of language and cognitive and social intercourse training, to develop targeted information service plans and training programs and to maintain dynamic adjustments.

Limitations
There are some limitations in this study: First, regarding the data sources, this study only analysed data from the “Yi Lin” forum and did not cover other Chinese online communities about ASD. Second, the subset of posts mentioning age groups was smaller than the overall dataset. Hence, limited data were available for exploring the changes in information needs. Therefore, future studies should use interview and questionnaire methods to better reveal the changes in information needs. Third, although our study had a greater sample size than previous studies, the forum data did not enable us to explore the cognitive and affective levels of parents of children with ASD beyond the most basic inferences of what triggered or drove the information needs. Future studies should undertake qualitative explorations of the triggering mechanisms of the information needs of parents of children with ASD (e.g. the role of cognition and affect). There should also be more quantitative analyses of the individual differences in the population’s information needs and the association between their information needs and information-seeking. Only after these fundamental issues are fully clarified can we provide targeted professional information support to parents of children with ASD to help them cope with their various challenges.

Conclusions
This study provides the first comprehensive and detailed insight into the information and adaptation needs of parents of children with ASD in China. Understanding the unique information needs of these parents will help relevant organisations provide the child- and parent-related information they need to cope with the pressures of raising children with ASD. The need for information about children is mainly cognition-driven, while the need for information about parents themselves is mainly affection-driven. Regardless of the ages of their children, the ASD forum parents’ always seek information about rehabilitation training and behaviour interventions. However, their other information needs vary according to the children’s ages. Our findings provide valuable support for those providing information for the parents of children with ASD in China and purveyors of ASD information in general.
References


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