Experiences of Parents of Children with Autism in Online Health Information Seeking: A Qualitative Study

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Abstract

Background: With the development of medical treatment, according to current research, there is an increasing trend of children with autism. Parents of children with autism are their main caregivers. With the deep integration of information technology and the health field, the Internet has become the preferred channel for obtaining health information due to its rich resources, convenient use and concealment, attracting more patients and their caregivers to participate in the online health information search process to assist health decision-making.

Objective: This study aims to elucidate the psychological experiences of parents of children with autism during their online health information searches. The findings are intended to inform the development of targeted intervention strategies by clinical healthcare providers.

Methods: Semi-structured interviews were utilized to delve into the online health information search behaviors of parents of children with autism, capturing their subjective experiences.

Results: Analysis revealed three primary themes: Positive experiences of parents participating in online health information searches (promoting cognitive changes about the disease, convenient access to effective disease information, alleviating personal psychological anxiety); Negative experiences of online health information searches (fatigue caused by information overload, helplessness in decision-making due to homogenized information);Further expectations for online health search behavior.

Conclusions: The current online health information search experiences of parents of children with autism are suboptimal and require enhancement. There is a critical need to develop specialized online platforms that cater to the diverse needs of these parents.

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Keywords: Autism; Parents; Online health information seeking behavior; Experience study

Online health information seeking behavior (OHISB) refers to the process by which individuals actively utilize the internet to obtain health-related information to meet their cognitive and informational health needs[1]. With the deep integration of information technology into the health sector, the internet, due to its abundant resources, convenience, and anonymity, has become the preferred channel for obtaining health information. This trend has attracted an increasing number of patients and their caregivers to engage in online health information seeking to assist in health decision-making. Autism, a common developmental disorder in children, necessitates long-term rehabilitation treatment. Parents of autistic children assume multiple roles, including those of caregiver, playmate, and therapist. However, the majority of these parents possess limited knowledge and skills regarding the education and rehabilitation of autistic children and lack experience in family education[2]. This deficiency results in a diminished capacity to effectively address their children's behavioral issues. Research indicates that some parents of autistic children bear a heavy caregiving burden[3]. While many parents acquire relevant knowledge through online health information, they often question the credibility of the information obtained and hesitate to take action[4]. Additionally, some parents prioritize authoritative information, expert advice, and the experiences shared by other parents[5]. As societal attention to parents of special needs populations increases, parents of autistic children encounter varying degrees of psychological stress at different stages of their children's development. Although there has been substantial research on the psychological stress experienced by parents of autistic children, studies on their participation in online health information seeking and their actual interactive experiences with their surrounding environment remain scarce. To further explore and develop precise and systematic intervention strategies for parents of autistic children, our research team conducted interviews with several parents of autistic children at a tertiary hospital in Zhengzhou, Henan Province. The findings are reported as follows.

1 Participants

Participants for this study were selected using purposive sampling from parents of children diagnosed with autism at a tertiary hospital in Zhengzhou, Henan Province. The inclusion criteria were as follows: 1. Parents of children aged 0-8 years diagnosed with autism by a pediatrician; 2. Duration of autism diagnosis exceeding one month; 3. Clear verbal communication abilities; 4. Informed consent and voluntary participation in the study. Exclusion criteria were: 1. Children with severe physical or organic comorbidities (e.g., cerebral palsy, epilepsy) or other mental disorders (e.g., ADHD); children with simple mental retardation or language development disorders; 2. Families with other major physical or mental illnesses. Data saturation was reached at interview F14, with an additional two interviews conducted to ensure meaning saturation. Thus, the final sample size was 16 participants. Demographic Characteristics of the respondents is presented in Table 1.

Table 1. Demographic Characteristics of the respondents

No.	respondents									Child				
	Age	**Gender**	**Educational Level**	**Residence Location**	**Currently employed or not**	**Marital Status**	**Monthly household income (in Chinese yuan)**	**Method of payment for medical expenses**	**Attitude towards child's illness**	**Gender**	**Age**	**Time of autism diagnosis**	**Severity of autism**	**Whether or not an only child**
F1	35	Female	Senior high school	Rural Area	Not Employed	Married	4000~8000	Medical insurance	Negative	Male	3	Two years old	Moderate	No
F2	25	Male	Bachelor’s Degree	City	Employed	Married	10000~15000	Medical insurance	Positive	Female	3	One and a half years old	Moderate	Yes
F3	36	Female	College diploma	City	Not Employed	Married	4000~8000	Medical insurance	Positive	Male	3	One and a half years old	Moderate	No
F4	27	Female	College diploma	City	Not Employed	Married	4000~8000	Medical insurance	Positive	Male	4	Two years old	Mild	No
F5	26	Female	Bachelor’s Degree	City	Not Employed	Divorced	Less than 4000	Medical insurance	Positive	Male	3	Two years old	Moderate	Yes
F6	27	Female	College diploma	County town	Not Employed	Married	Less than 4000	Self-pay	Positive	Male	4	One and a half years old	Moderate	No
F7	28	Female	College diploma	County town	Not Employed	Married	4000~8000	Medical insurance	Negative	Female	2	One year old	Severe	No
F8	24	Female	Bachelor’s Degree	City	Not Employed	Married	8000~10000	Medical insurance	Positive	Female	2	One and a half years old	Severe	Yes
F9	27	Female	Bachelor’s Degree	City	Not Employed	Married	10000~15000	Medical insurance	Negative	Female	4	Two and a half years old	Moderate	No

F10	30	Female	College diploma	County town	Not Employed	Divorced	4000~8000	Medical insurance	Negative	Male	3	One year old	Moderate	Yes
F11	31	Male	Bachelor’s Degree	City	Not Employed	Married	10000~15000	Medical insurance	Positive	Male	4	Two years old	Moderate	No
F12	30	Female	College diploma	Rural Area	Not Employed	Married	8000~10000	Medical insurance	Positive	Female	2	One and a half years old	Moderate	No
F13	33	Male	College diploma	County town	Not Employed	Married	8000~10000	Self-pay	Negative	Male	5	Two years old	Mild	Yes
F14	38	Female	Senior high school	County town	Not Employed	Married	Less than 4000	Medical insurance	Negative	Male	3	One year old	Mild	No
F15	25	Female	Bachelor’s Degree	City	Not Employed	Married	10000~15000	Medical insurance	Positive	Male	3	Two years old	Moderate	Yes
F16	45	Female	□□	City	Not Employed	Married	4000~8000	Medical insurance	Positive	Male	4	Two years old	Moderate	No

2 Methods

2.1 Development of Interview Guide

Before conducting the formal interviews, researchers developed an interview guide based on the study's objectives, a literature review, and expert opinions. The guide included the following questions:

1. What is your overall experience when searching for disease-related information online?
2. What difficulties have you encountered while searching for disease-related information online, and how did you overcome them?
3. What kind of assistance do you hope to receive when searching for disease-related information online? Do you have any suggestions for improving the online health information seeking process?

2.2 Data Collection and Quality Control

Prior to the interviews, parents of autistic children were invited to participate in the study through introductions by the responsible nurses. The study's purpose and significance were explained to them, with assurances of strict adherence to confidentiality principles. Informed consent was obtained, and interview times and locations were scheduled in advance to avoid treatment periods, ensuring a private, relaxed, and comfortable interview environment. During the interviews, researchers followed the interview guide, listened attentively, and engaged in timely follow-up questions, paraphrasing, and summarizing. They maintained an objective attitude without leading, evaluating, or interrupting the respondents. With the respondents' consent, interviews were recorded using a voice recorder, and non-verbal behaviors and emotional changes of the respondents were noted. Each interview lasted between 10-30 minutes.

2.3 Data Organization and Analysis

Within 24 hours of each interview, researchers replayed the recordings and transcribed them into text. The Colaizzi seven-step analysis method was employed to organize, summarize, and extract themes from the interview data, with NVivo14 software used for coding. The steps were as follows: 1. Thoroughly read the interview data; 2. Identify meaningful statements related to the online health information seeking behavior of parents of autistic children; 3. Code recurring viewpoints; 4. Summarize and extract themes from the coded information; 5. Describe the themes in detail; 6. Identify similar viewpoints; 7. Verify the research results with the respondents.

3. Results

3.1 Theme 1: Positive Experiences of Parents Engaging in Online Health Information Seeking Behavior

3.1.1 Enhancing Cognitive Understanding of the Disease

Several respondents reported that due to limited rehabilitation time and methods at hospitals, they proactively sought health information online. This approach highlighted the importance of family education, prompting parents to gradually become more involved in the rehabilitation process. Many parents initially had limited knowledge of the disease. Through online searches, they increased their awareness and understanding of their child's behavior in various areas such as clothing, diet, and daily activities. F8:*We were diagnosed not long ago, so we didn't really understand the disease at first. We kept searching online to know what the disease is about. Initially, we felt very scared and anxious, but with more understanding, we feel better now."* F6: *"Coming from a small county, we had only seen it on TV. There are no cases of this disease where we live. We couldn't understand much of what the doctor said, so we searched online to figure out what was going on."* F11: *"We discovered it quite late. Initially, we just thought our child was introverted and didn't like to talk. Later, we found out through research that it was autism. We've been doing rehabilitation for two years now and have been learning about this disease online. We realized he wasn't just introverted. We used to scold him for repeating the same sentence."*

3.1.2 Easy Access to Effective Information on Autism

Several respondents noted that the internet has become an essential resource for obtaining comprehensive information about autism. Through search engines, entertainment platforms, forums, and social media, they can quickly access a vast amount of information. This includes details on autism symptoms, diagnosis, treatment methods, and rehabilitation training, which significantly supports parents in participating in their child's treatment process. F2: *"Sometimes you have minor questions and feel embarrassed to bother the doctors since they are quite busy. So, I search online. You wouldn't believe the variety of methods available online."* F9: *"I often come across rehabilitation methods online and think it's worth learning whatever I can. I taught him myself, and it actually worked. Last time, I managed to teach him how to complete a puzzle on his own (laughs)."* F5: *"I don't have time to search myself, so my husband looks up information online and sends it to me. The information he finds has been incredibly helpful."*

3.1.3 Reducing Personal Psychological Anxiety

Several respondents expressed that discovering the extensive autism community online alleviated their anxiety and despair. Interacting with other parents, learning from successful rehabilitation cases, and sharing experiences helped parents gradually shift their mindset. They no longer felt that their child belonged to a rare group and became better psychologically prepared for long-term rehabilitation. F4: *"When we first received the diagnosis, it felt like the world was falling apart. I cried for a whole week. Then, seeing many children with autism achieving great rehabilitation results online made me feel less hopeless."* F1: *"There are many fellow parents online, and I often communicate with them. They share their experiences, which teaches me a lot. Although my child's progress is slow, I am confident about his future rehabilitation."*

3.2 Theme 2: Negative Experiences of Parents Engaging in Online Health Information Seeking Behavior

3.2.1 Fatigue Due to Information Overload

Many respondents reported feeling overwhelmed by the sheer volume of information available online, despite their eagerness to find helpful resources. They not only have to sift through information of varying credibility but also need to understand numerous technical terms and complex treatment principles, significantly increasing their cognitive load. Prolonged periods of searching and filtering information left parents feeling exhausted and frustrated. F1: *"Honestly, sometimes I wonder if I'm doing it wrong. Every time I search, I'm bombarded with a ton of information. It's overwhelming, and I feel like very little of it is actually useful."* F16: *"I find a lot of information online, but I can't tell if it's accurate or useful. I don't have the time to verify it all, so I just try whatever I find on my child."* F14: *I come across seemingly professional articles or videos, but the technical jargon and complex treatment principles are exhausting. I'm not a doctor or an expert, and it makes me not want to continue."*

3.2.2 Helplessness Due to Homogeneous Information

Despite the certification of most rehabilitation methods as effective for children with autism, the heterogeneous nature of autism means that some respondents found much of the online health information inapplicable to their children, making it difficult to find a fully suitable rehabilitation plan. F7: *"My child always needs new methods. If we use a method once, he won't use it again, so we have to keep changing methods. But we never know which one will be effective, so we just keep trying different ones."* F13: *"Rehabilitation therapists often teach various methods, but they are the same for every child. For instance, one method might work well for my child, and he shows significant improvement that week. If the method doesn't suit him, there won't be much change. With so many children, therapists can't tailor methods to each child individually every day."* F10 : *"I have to work every day, so I don't have much time to search online for methods. When I do find something, I try to learn it, but* *whether it works for my child is not something I pay close attention to. Finding a method that is particularly useful is rare."*

3.3 Theme 3: Parents' Further Expectations for Online Health Information Seeking Behavior

Numerous parents reported that they only began to understand the disease after their child's diagnosis, resulting in a high dependence on hospitals and medical institutions for rehabilitation. Many respondents expressed uncertainty about how to acquire knowledge on family education and rehabilitation for their autistic child. Most parents aspire to gain rehabilitation knowledge that they can apply at home and in the long term. Additionally, some respondents acknowledged a need to enhance their online health information searching skills and expressed a desire for standardized guidance from hospitals or relevant institutions.F12: *"Since we are currently hospitalized, we primarily rely on therapists and doctors for rehabilitation. Although I try to learn a bit myself, it's superficial. Once his symptoms improve and we are discharged, I will be responsible for most of his rehabilitation. However, with my current capabilities, I can't conduct rehabilitation on my own. I want to learn more about home rehabilitation."* F15: *"I also want to find more information online, but taking care of my child and working leaves me with little energy to search. I am not very familiar with resources in this area. If possible, I hope the hospital can provide more platforms like this. Or even give me a flyer with instructions on how to search online if I have questions."* F3: *"Our department does distribute many meeting notices in the group, but I don't understand them—they are too technical. It would be helpful if our department could hold special lectures or activities for parents, teaching us how to search for information online. I think this is feasible, and we could also ask questions on the spot."*

4 Discussion

4.1 Enhancing Online Health Information Seeking Behavior Among Parents of Children with Autism

The interviews reveal that an increasing number of parents of children with autism are using the internet to access valuable health information, reflecting a shift in family education perspectives. However, both positive and negative experiences were reported. Notably, some parents experienced fatigue from information overload and a sense of helplessness due to homogenized information. This underscores the need for attention from various stakeholders. Han Jiawei et al. [6] emphasized that parents' access to and application of information is closely linked to the development of children with autism and their families. Our study identified a critical need to improve the online health information seeking behavior of these parents, likely due to insufficient e-health literacy and a scarcity of dedicated online platforms for specific diseases.

Healthcare professionals could address this by developing systematic online courses and offline community promotion classes to enhance parents' online health information seeking skills. Yuan Hong [7] stressed that high-quality health information, based on scientific research or expert opinion, should be presented in non-technical language to reduce cognitive load. Furthermore, studies indicate that information provided by doctors and medical institutions is the most trusted and valued by patients [8]. Therefore, hospital websites and academic institutions should regularly publish research progress reports or authoritative recommendations related to autism.

Additionally, Pan Wei et al. [9] noted that sharing experiences within similar groups can effectively buffer stress. Providing parents of children with autism ample opportunities to share experiences can significantly reduce their psychological stress. Healthcare professionals could facilitate this by organizing parents to participate in online discussions and share experiences, implementing organized online health information seeking behavior management. Establishing regional online communities, such as "Virtual Parent Salons" or "Family Meeting Rooms," where healthcare professionals host activities, would allow parents to share insights and receive professional feedback and guidance. Incorporating design aesthetics and health navigation elements into web design can further enhance the online search experience for parents.

4.2 Developing a Precise Online Service Platform to Meet Parents' Multidimensional Needs

The study results indicate that parents of children with autism face challenges in searching for and selecting online information, distinguishing its authenticity, and have strong needs for online knowledge regarding rehabilitation, home care, and education. However, there is currently a lack of quality assessment standards for online health information [2]. Many online health information platforms are highly commercialized, and the absence of health information regulatory bodies results in a lack of authoritative information, inaccurate service information, and inadequate regulatory measures [10]. Ni Chidan [11] found that autism significantly affects the "common sense knowledge base" of typical families, creating an urgent need for parents to understand treatment, rehabilitation, education, social services, and future development for their children. Additionally, parent support organizations help rebuild hope for parents and provide guidance on emotional and behavioral development [12].

Therefore, relevant authorities should develop a precise online service platform based on the multidimensional needs of parents, integrating artificial intelligence technology to create a knowledge graph suitable for parents of children with autism. Data mining techniques could analyze and provide targeted guidance on the "home care profiles" of children and their parents, reducing cognitive load during information searches and ensuring access to accurate, reliable, high-quality online health information. Liao Hualin et al. [13] proposed user context aggregation and user group aggregation models to address the lack of focus on user information needs and health information services, suggesting thematic and semantic association aggregation models to improve online health information organization. These approaches could enhance the online health information seeking experience for parents of children with autism.

Moreover, our study found that most respondents hope that educators and healthcare experts will deeply understand their children and tailor educational plans based on their characteristics and needs. Current treatments for autism focus on improving core symptoms and intellectual levels [14], but each child's personality, symptoms, and abilities vary, necessitating individualized rehabilitation strategies. Thus, obtaining effective personalized strategies for addressing their children's behavioral problems through online health information searches is a key concern for parents. This indicates that healthcare professionals should guide parents to systematically learn how to assess changes in their children's emotions, behaviors, and learning attitudes, identify the impact of different rehabilitation methods, and discuss personalized, precise intervention plans through online interactions. Consequently, a precise online service platform for autism could include more remote video assessments, communications, and online family interventions, continuously improving parents' experiences in online health information seeking behavior.

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Conflicts of Interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Supplementary Files