

PARENTS' KNOWLEDGE, ATTITUDES, AND PRACTICES TOWARDS THE UTILIZATION OF HEALTHCARE SERVICES FOR CHILDREN WITH AUTISM SPECTRUM DISORDER: A CROSS-SECTIONAL DESCRIPTIVE STUDY IN VIETNAM

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ABSTRACT

OBJECTIVE:

This study aimed to describe knowledge, attitude, practice, and some impact factors regarding the utilization of healthcare services for children with autism spectrum disorder (ASD) among parents in Hanoi, Vietnam, in 2024.

METHODS:

The cross-sectional descriptive study was conducted on 191 parents of children with ASD who were using care services at five healthcare facilities in Hanoi from October 2023 to March 2024.

RESULTS:

Only 23.6% of parents had good knowledge, while up to 67.2% had moderate knowledge regarding ASD. The prevalence of parents with positive attitudes towards childcare services was 84.7%, and only 2.3% had a negative attitude. Special education services and inclusive education support were the most frequently used, with over 70% of parents using them regularly. Parents of first-born children and those whose children were diagnosed immediately after abnormalities were detected had higher knowledge and attitude scores ($p < 0.05$).

CONCLUSION:

Most parents had moderate knowledge about ASD but the majority had a positive attitude with respect for childcare services. First-born children and those who were diagnosed immediately after the detection of abnormalities were associated with higher knowledge and attitudes among parents.

KEYWORDS

knowledge-attitude-practice; healthcare services; autism spectrum disorder; Vietnam

INTRODUCTION

Autism Spectrum Disorder (ASD) is a developmental disability characterized by impairments in communication and social interaction, as well as restricted, repetitive patterns of behavior, interests or activities that may persist throughout an individual's life [1]. Research has consistently shown a rising prevalence of ASD among children globally. In 2017, the World Health Organization (WHO) reported the global prevalence rate of ASD was 1:160 children [2]. By 2022, this rate was estimated to have increased, with a current average prevalence of 1:100 children, with boys consistently affected more often than girls, at an average ratio of 4.2 boys to 1 girl [3]. In Vietnam, the prevalence of ASD was estimated at approximately 1:100 children in 2018 [4].

Children with ASD and their families need access to information, services, referrals, and practical support tailored to their individual needs, which requires a comprehensive, integrated service, including health promotion, care, rehabilitation, and collaboration with other sectors such as education, employment, and social services [5]. Unfortunately, a lack of awareness and limited access to care services for children with ASD can significantly delay early diagnosis, assessment, and treatment. This disparity between the needs of caregivers and the availability of services, resources, or community support is particularly prominent in rural and suburban areas or communities where religious beliefs, cultural norms, and limited knowledge prevail. Stigma among families and society further compounds these challenges. Moreover, the concentration of care and intervention centers for children with ASD in urban centers also limits accessibility and increases waiting times for healthcare facilities [6].

Recently, growing awareness of ASD has led to an increase in the number of children diagnosed, with parents becoming more proactive in seeking early screening and medical care for their children [7]. For children with ASD, treatment plans are individualized and adjusted based on each child's unique circumstances, requiring parental involvement. Consequently, understanding parents' knowledge, attitudes, and practices regarding ASD is crucial, as it significantly influences early screening, access to care services, diagnosis, and timely intervention. This study was conducted to describe the knowledge, attitude, practice, and influencing factors regarding the utilization of ASD care services among parents.

METHODS

POPULATION AND SETTING

The study was conducted on 191 parents of children under 15 years old diagnosed with ASD who are currently enrolled in and receiving interventions and treatment at five autism care and intervention centers in Hanoi. These centers include two public institutions (National Hospital of Acupuncture; Binh Minh Primary School) and three private centers (Anh Sang Psychological Therapy Research and Counseling Center, Dai Nghia Integration Center, and Sao Mai Center). Participants were recruited based on their normal mental health, capable to communication, and ability to respond to interviews. Exclusion criteria included parents of children with other co-occurring neurological conditions such as cerebral palsy, hearing impairment, Down syndrome, etc., and those who did not consent to participate in the study.

Data collection period: from October 2023 to March 2024.

STUDY DESIGN AND SAMPLE SIZE

This cross-sectional descriptive study was part of a community intervention study in its initial investigative phase. The sample size formula for pre-post comparison community intervention studies, was determined as

$$n = \frac{\{Z_{(1-\alpha/2)}\sqrt{2\bar{p}(1-\bar{p})} + Z_{(1-\beta)}\sqrt{P_1(1-P_1) + P_2(1-P_2)}\}^2}{(P_1 - P_2)^2}$$

Specifically, the estimated pre-intervention knowledge rate of parents on care for children with ASD was $P_1 = 50\%$, and the estimate targeted post-intervention rate was $P_2 = 60\%$; $\bar{p} = (P_1 + P_2)/2$; $Z_{1-\alpha/2}$ represents the Confidence coefficient at

95% probability and $Z_{1-\beta}$ represents the study power at 95%. According to the formula, the required sample size was calculated to be $n = 178$. However, 191 eligible parents were ultimately recruited to participate in the study.

The sampling process involved two stages. First, we intentionally selected 05 care and intervention centers for children with ASD in Hanoi. Subsequently, participants were chosen for the study using convenience sampling methods.

MEASUREMENT

The initial scale comprised 50 items, which were developed by referring to documents and translating items from other international studies [8–10]. A pilot study was conducted with a sample of 30 individuals to evaluate the reliability of Cronbach's Alpha. Questions exhibiting a total correlation coefficient exceeding 0.3 and a Cronbach's Alpha coefficient higher than 0.7 were retained [11,12]. Following validation and expert consultation, the finalized scale for the official study encompassed the following sections:

- Section 1: Parental characteristics – Includes details about parents or primary caregivers, such as age, sex, education, economic status, care services utilized for the child, and any challenges encountered.
- Section 2: Children characteristics – Includes birth order, time of abnormality detection, time of diagnosis, time of initial intervention, and improvement level of the child.
- Section 3: Parents' knowledge regarding autism spectrum disorder: Consists of 14 True/False questions, referenced from the studies of Liu Y (2016) and Hamad S (2022) [8,9].
- Section 4: Parents' attitude toward care service for children with autism spectrum disorder: Includes 12 questions assessed on a 5-level Likert scale (from 1-Strongly Disagree to 5-Strongly Agree), based on the studies of Liu Y (2016) and Hamad (2022) [8,9].
- Section 5: Care service usage frequency: Comprises 9 questions evaluated on a 5-level Likert scale (from 1-Strongly Disagree to 5-Strongly Agree), adapted from the study of Jon Baio (2018) [10].

DATA COLLECTION AND STATISTICAL ANALYSIS

The interviewers were staff members at five facilities for children with ASD involved in the study. They participated in a training session on the questionnaire and conducted face-to-face interviews with study participants for the official research. The supervisor was the principal investigator from Hanoi Medical University.

The data was cleaned and coded using Epi Data version 3.1 software. Data analysis was performed using SPSS version 20.0.

Descriptive statistics were used to describe the current state of knowledge, attitude, and frequency of utilizing various care services for children with ASD. The knowledge and attitude of parents regarding care services were classified into two levels according to Norman's assessment guidelines (2010) [13]:

- Inadequate knowledge/ Negative attitude: scoring <75% of overall
- Sufficient knowledge/ Positive attitude: scoring $\geq 75\%$ of overall

To compare the average scores of knowledge and attitude toward care services for ASD children among parents. Independent T-test was employed to compare mean scores of knowledge and attitudes between two groups, and ANOVA test was applied to compare three or more groups. Statistical significance was established at $p < 0.05$.

RESEARCH ETHICS

This study was approved by Decision No. 6812/QĐ-ĐHYHN, issued by Hanoi Medical University on December 29, 2022, and was received approval by Certificate No. 162/HĐĐĐ-VKC, issued by the ethics committee on June 23, 2023. The research was conducted with the voluntary participation of parents after being fully informed about the purpose and content of the study. Data collection was approved by the institution directly responsible for the management, care and treatment of the children. All personal information of participants was encoded and maintained in strict confidentiality, and was utilized solely for research purposes.

RESULTS

Table 1 shows that the majority of parents in the study had insufficient knowledge about ASD, with only 24.6% demonstrating sufficient knowledge, which equates to nearly a quarter of participants. Over 90% of parents correctly identified ASD as a developmental disorder, the majority also mistakenly believed it to be a psychological problem, with only 31.4% answering this question correctly. Regarding signs of ASD, over half of the parents correctly answered questions related to identifying children with ASD through manifestations such as processing better visual input than auditory input (79.6%), hyperactive and inattentive (78.5%), delayed speech/language development (66.5%), did not show social attachment (63.9%) and reduced manifest physical pain (51.8%). In terms of future development for children with ASD, 84.8% and 75.9% of parents, respectively, understood that ASD cannot develop into schizophrenia and that children can attend university. However, when coming to treatment, only 31.9% of parents were aware that ASD cannot be cured, even with early diagnosis and intervention.

TABLE 1. PARENTS' KNOWLEDGE REGARDING AUTISM SPECTRUM DISORDER (N=191)

Contents	Participants with inadequate answers (n)	Rate of correct answers (%)
ASD is a developmental disorder	172	90.1
ASD is a psychological problem	60	31.4
ASD is caused by poor parenting skills or inadequate home care	149	78.0
Children with ASD often delayed speech and language development until the age of 3	127	66.5
It is normal for children from one to one-and-a-half-year-old to have already developed definite hand preference	115	60.2
Children with delayed speech often have accompanying hyperactivity and reduced concentration	150	78.5
Children with ASD can not show social attachments, with their parents	122	63.9
ASD does not manifest as physical pain	99	51.8
Children with ASD are deliberately negative and non-compliant	87	45.5
Children with ASD often process better visual input than auditory input	152	79.6
Children with ASD do not usually grow up to be adults with schizophrenia	162	84.8
All children with ASD will be able to pursue further education at the university level	145	75.9
ASD is not curable even with early diagnosis and appropriate intervention provided	61	31.9
It is important that children with ASD receive special education services at school	159	83.2
Inadequate general knowledge	47	24.6%

About 90% of parents had a positive attitude toward care services for children with ASD as demonstrated in Table 2. The majority of parents were supportive of the need for intervention programs for children with ASD (94.2%) and regular health check-ups (91.6%). Other services, such as one-on-one therapy or scheduled therapy sessions, attending intervention

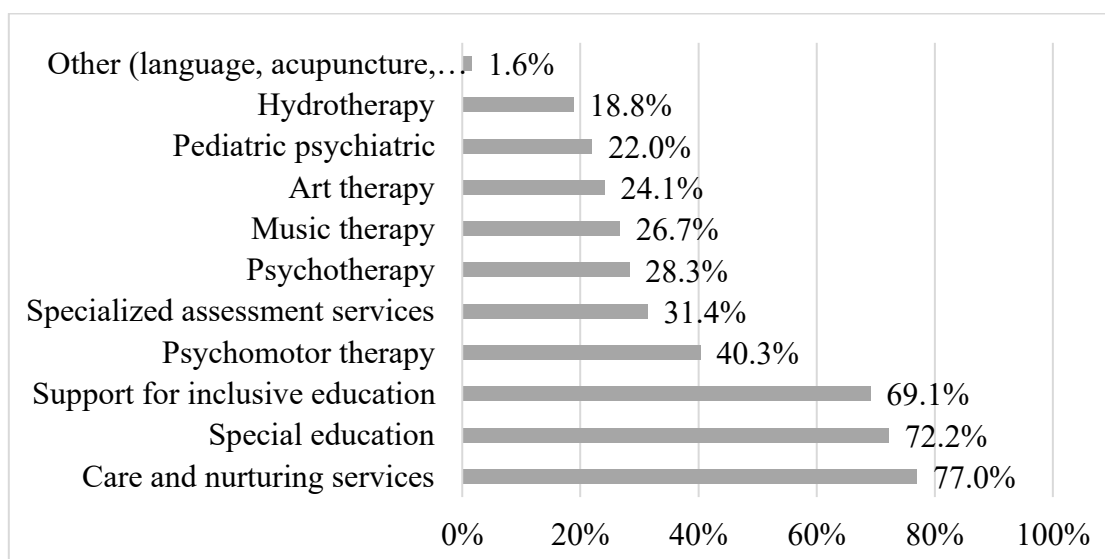
classes, studying at specialized centers or schools, and inclusive education were also well-supported by a significant portion of parents. Additionally, parents highly valued the importance of support from both family and society.

TABLE 2. PARENTS' ATTITUDE TOWARD CARE SERVICE FOR CHILDREN WITH AUTISM SPECTRUM DISORDER (N=191)

Contents	Participants with positive attitude(n)	Rate of participants with positive attitude (%)
Children diagnosed with ASD require interventions	180	94.2
Parents should schedule regular follow-up evaluations for their child to ensure timely and appropriate interventions	175	91.6
Children with ASD should receive one-on-one intervention sessions or participate in scheduled hourly sessions	168	88.0
Parents should attend intervention classes for children with ASD	164	85.9
Children with ASD should receive specialized education provided at dedicated centers or schools	160	83.8
Children with ASD should be encouraged to participate in inclusive education	157	82.2
Children with ASD should be integrated into mainstream school	134	70.2
Children with ASD should be started in kindergarten early	117	61.3
Partial financial assistance from social insurance is necessary for families with children with ASD	168	88.0
A government-provided intervention program for children with ASD is necessary	165	86.4
Parents should guide other family members regarding the intervention strategies for their child	165	86.4
Parents should observe instructional videos through mass media	147	77.0
Positive general attitude	169	88.5

Figure 1 revealed that care and nurturing services, special education, and support for inclusive education were the most frequently used services, with utilization rates of 77.0%, 72.2%, and 69.1%, respectively. In contrast, the regular utilization of other services was significantly lower, such as psychomotor therapy (40.3%), specialized assessment services (31.4%), and psychotherapy (28.3%). Hydrotherapy was the least used service, with a utilization rate of just 18.8%.

FIGURE 1. CARE SERVICE USAGE FREQUENCY (N=191)



In Table 3, our findings did not indicate significant differences between knowledge scores and general parental characteristics (including age, education level, monthly income, current care facility, and challenges in accessing services). However, notable discrepancies in knowledge and attitude scores were observed that were related to specific characteristics of the children. Parents of firstborn children diagnosed with the disorder exhibited an average knowledge score higher than those with a second child, who scored $8.90 \pm 1.91/14$. Parents of children assessed immediately after abnormalities were detected displayed a more positive attitude, scoring an average of $50.95 \pm 5.32/60$, surpassing the $48.62 \pm 7.35/60$ of parents who waited one month or more. These differences were statistically significant, with $p < 0.05$.

TABLE 3. DEMOGRAPHIC CHARACTERISTICS RELATED TO PARENTS' KNOWLEDGE AND ATTITUDE REGARDING HEALTHCARE SERVICES FOR CHILDREN WITH AUTISM SPECTRUM DISORDER (N=191)

Characteristics	Knowledge		Attitude		
	Mean±SD	p	Mean±SD	p	
Characteristics of parents					
Age	<30 years old	9.09±2.33	0.745 ^a	49.27±8.95	0.809 ^a
	≥30 years old	9.23±1.84		49.64±6.34	
Level of education	<High school	8.85±1.91	0.468 ^a	49.69±5.12	0.483 ^a
	≥High school	9.24±1.89		49.59±6.77	
Monthly income	<10 million VND	8.87±2.60	0.489 ^a	48.83±7.27	0.555 ^a
	≥10 million VND	9.26±1.78		49.70±6.59	
Current care facility	Education facility	9.16±1.95	0.418 ^b	49.74±6.26	0.750 ^b
	Healthcare facility	8.57±1.51		47.86±5.93	
	Both	9.48±1.76		49.41±7.99	
Challenges in accessing services	Yes	9.31±1.62	0.475 ^a	48.83±7.30	0.112 ^a
	No	9.12±2.14		50.37±5.89	
Characteristics of the child					
Birth order	First-born	9.63±1.79	0.008^a	50.63±6.81	0.061 ^a
	Other	8.90±1.91		48.81±6.47	
Time of abnormality detection	<1 year old	9.26±1.81	0.099 ^b	48.89±7.31	0.396 ^b
	1-3 years old	9.33±1.81		49.96±6.81	
	>3 years old	8.38±2.40		48.05±4.38	
Time of diagnosis	Immediately	9.50±1.53	0.063 ^a	50.95±5.32	0.017^a
	After ≥1 month	9.01±2.10		48.62±7.35	
Time of initial intervention	Immediately	9.34±1.93	0.209 ^a	50.25±6.12	0.070 ^a
	After ≥1 month	8.99±1.82		48.43±7.43	
Improvement level	Not improved	9.40±2.07	0.825 ^a	53.00±5.39	0.248 ^a
	Improved	9.21±1.89		49.51±6.68	

^aT test; ^bANOVA test

DISCUSSION

Raising a child with autism spectrum disorder presents significant psychological challenges for parents, with a lack of knowledge being the initial problem they must overcome to take care of their child [6].

In our study, the majority of parents possessed only an average level of knowledge about ASD. Notably, only about one-fourth of the participants understood the disorder well. These findings were consistent with the study by Yaacob et al (2021), which reported that parents self-assessed their knowledge of ASD in the community as poor with nearly 50% of parents admitting to never seeking information about the said disorder. Even those who had heard of ASD did not delve deeper into understanding it until their child was diagnosed [6]. Wang F et al (2022) discovered that in China, the average

knowledge score about ASD among parents was 15 out of 20, with the highest score being 17 out of 20 [14]. Furthermore, a study conducted in Saudi Arabia in 2022 involving 500 adults revealed that over 80% of respondents had a moderate to high level of knowledge about ASD, with an average score of 20.6 out of 34 [15]. In Vietnam, Thai THP et al (2017) noted that mothers often lacked sufficient knowledge about ASD [16]. Collectively, these studies illustrate that parental knowledge of ASD was generally at an average level. Common gaps in parental understanding of ASD include misconceptions about the causes and prevalence of the disorder [14,15].

Regarding attitudes, a study in China in 2022 showed that nearly 70% of parents were optimistic about their child's prognosis. However, many admitted their lack of knowledge on how to approach behavioral issues associated with ASD [14]. Thai THP et al (2017) also observed that parents frequently felt sadness and fear that their child would struggle to integrate with peers, leading to social isolation and communication difficulties. Some parents even reported experiencing overwhelming stress due to their child's condition, with a minority expressing suicidal thoughts [16]. As a result, parents believed that ensuring their child receives the necessary care services were crucial for the child's health and the family's overall well-being. Although most parents in our study did not demonstrate a high level of knowledge about ASD, they generally held positive attitudes toward the importance of care services and the need for support from family and the community.

Previous studies had shown that demographic factors such as age, level of education, place of residence, and income are related to parents' knowledge and attitudes about ASD and the care services for affected children. Generally, parents with higher education, better income, and urban residency tend to have better knowledge and attitudes [6,14,17]. A study conducted by Yaacob et al in 2021 revealed that parents in rural areas remarkably rated their knowledge of ASD as poor [6]. Besides, Wang F et al. (2022) reported that mothers with higher education levels and better family income had a better understanding of ASD. Conversely, fathers' knowledge was inversely related to their age. Moreover, families with higher knowledge scores typically had a collective awareness of the disorder, often engaged in reading about ASD, or attended professional talks on the subject. Zhou M (2023) synthesized findings and concluded that knowledge of ASD positively correlates with educational attainment, the number of children with ASD in the community, and socio-economic status. Additionally, caregivers who received information directly from healthcare professionals rather than other sources had a better understanding of the disorder [17]. Thai THP et al (2017) also found that maternal age and education level were associated with psychological difficulties and attitudes when facing their child's ASD diagnosis ($p < 0.05$) [16].

However, some researchers have presented contrasting hypotheses. For instance, a study done by Hamad et al in 2022 found no significant correlation between parents' educational level and their knowledge about ASD [9]. In China, the longer the duration from diagnosis to access to services, the lower the parents' knowledge scores [14].

Our study did not find significant differences in parents' knowledge and attitudes based on demographic characteristics. The only factors that positively influenced average knowledge scores about ASD and attitudes toward care services were whether the child was the firstborn and if the child was diagnosed immediately after the detection of abnormalities. This difference may be attributed to our study's relatively small sample size. Furthermore, the study was primarily conducted at private care facilities, where parents using these services tend to have relatively similar education and income levels.

The findings of this study provide critical insights that can be applied to policy development, enhancing parental support initiatives, and advancing healthcare services for children with ASD. Given the identified gaps in parental knowledge, national awareness campaigns and structured educational programs should be implemented to improve understanding and reduce misconceptions. Policymakers should integrate autism-related healthcare services into public health infrastructure to ensure equitable access across both urban and rural areas. Additionally, healthcare facilities and special education centers can utilize these findings to develop tailored workshops that equip parents with essential skills for early intervention and caregiving. This study also highlights the necessity for future research to examine the long-term effects of parental education on ASD awareness and attitudes. Expanding investigations to rural regions and conducting

international comparisons would offer deeper insights into disparities in autism care. Furthermore, evaluating the effectiveness of digital training programs and remote support services could facilitate broader access to ASD-related resources. Moreover, we encourage further exploration of socioeconomic barriers that hinder access to ASD-related services, including financial constraints, insurance coverage limitations, and the adequacy of government assistance. Investigating the psychological impact on parents and families is equally vital for informing mental health policies and fostering community-based support networks. Such research will be instrumental in refining ASD services and strengthening support systems for affected families.

LIMITATIONS OF THE STUDY

There were some limitations to this study. The study was conducted exclusively at care and intervention centers for children with ASD within Hanoi. We encountered difficulties gaining access to these centers, resulting in only two public institutions agreeing to provide patient information, while three private centers were involved.

CONCLUSION

This study indicated most parents had a moderate level of knowledge about ASD, yet the majority display a positive attitude towards care services. Parents of first-born children and children who sought a diagnosis promptly after detecting abnormalities tend to have a higher level of knowledge and a more favorable attitude.

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