PARENTAL KNOWLEDGE OF AUTISM SPECTRUM DISORDER IN A SPECIALIST UNIVERSITY HOSPITAL: A CROSS-SECTIONAL STUDY

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Abstract. Autism Spectrum Disorder (ASD) is a complex neurodevelopmental disorder that affects communication, social interaction, and behaviour. The prevalence of ASD is rising globally, necessitating greater awareness and knowledge among parents to facilitate early diagnosis and intervention. Parents play a crucial role as primary caregivers in recognising ASD symptoms and ensuring their children receive appropriate healthcare. This study aimed to assess the level of ASD knowledge among parents at a specialist university hospital in Kelantan and examine the association between demographic factors and ASD knowledge. A descriptive cross-sectional study was conducted among 94 parents who did not have an autistic child and were not from a medical profession. The knowledge scores were categorised into low, medium, and high levels. Results indicated that 63.8% of respondents had moderate knowledge of ASD, 34% had low knowledge, and only 2.1% demonstrated a high level of knowledge. Gender ($p = 0.008$), educational level ($p = 0.002$), and monthly income ($p = 0.004$) were significantly associated with knowledge of ASD. These findings highlight the influence of socio-economic status and education on parental understanding of ASD. The study's limitations include the use of convenience sampling and an overrepresentation of mothers. Future research should incorporate a more diverse sample and explore additional sociodemographic variables to gain a deeper understanding of the factors influencing ASD knowledge. Improving parental awareness through targeted interventions is essential for enhancing early diagnosis and intervention outcomes.
Keywords: *autism spectrum disorder, parental knowledge, socioeconomic factors, early intervention*

Introduction

Autism Spectrum Disorder (ASD) is a growing global concern, with prevalence rates increasing significantly over the past two decades. The Centres for Disease Control and Prevention (CDC) reported that 1 in 36 children in the United States has been diagnosed with ASD. Similar trends have been observed in Europe and Australia, where rising ASD diagnoses are attributed to improved screening methods, increased awareness, and broader diagnostic criteria (Matson and Burns, 2019). However, in developing countries such as Malaysia, the prevalence of ASD remains unclear due to limited national-level data and inconsistent diagnostic criteria (MOH, 2014). Despite efforts to improve ASD recognition, many children in Malaysia remain undiagnosed or receive late diagnoses, resulting in delays in early intervention (Rahman et al., 2020). Parental knowledge of ASD plays a crucial role in early identification and intervention. Studies indicate that parents with higher educational attainment are more likely to recognize ASD symptoms and seek timely medical consultations (Sun et al., 2021). A study in China found that university-educated parents had significantly greater ASD awareness than those with lower education levels (Wang et al., 2022). Similarly, in Malaysia, parents with tertiary education actively sought ASD-related healthcare services, whereas those with lower education levels relied on informal sources, such as social media and traditional beliefs.

These findings suggest that parental education is a key factor in ASD awareness and early diagnosis. Cultural beliefs and societal stigma also influence parental perceptions of ASD. In many Asian countries, including Malaysia, ASD symptoms are sometimes misinterpreted as behavioural problems or attributed to supernatural causes. This stigma can discourage parents from seeking medical assistance, resulting in further delays in diagnosis and intervention. Studies have demonstrated that culturally sensitive ASD awareness campaigns can improve parental recognition and acceptance of ASD-related healthcare services. For instance, a community-based ASD education program in Indonesia significantly increased parental knowledge and acceptance of early intervention (Sari et al., 2020). These findings highlight the importance of designing awareness initiatives that align with cultural and societal beliefs to reduce stigma and enhance ASD recognition.

Government initiatives and healthcare policies also play a vital role in ASD awareness and intervention. High-income countries such as Canada and the United Kingdom have successfully integrated ASD screening and parental education programs into their public healthcare systems, leading to earlier diagnoses and improved long-term outcomes for children with ASD (Zwaigenbaum et al., 2019). In Malaysia, efforts by organisations like the National Autism Society of Malaysia (NASOM) have helped raise awareness, but many parents still struggle to access reliable ASD-related resources (Abidin et al., 2022). Research found that urban parents had greater exposure to ASD workshops and online resources, whereas rural parents faced barriers in accessing such information due to geographical and infrastructural constraints. In addition to healthcare initiatives, integrating ASD education into Malaysia's public education system could further enhance parental awareness. Studies from developed countries indicate that embedding ASD screening and awareness programs within early childhood education settings increases parental engagement and improves early detection rates (Zwaigenbaum et al., 2019). Implementing a similar approach in Malaysia, particularly in underserved communities, could help bridge the gap in ASD knowledge and intervention accessibility. Given the critical role of parents in ASD recognition and management, this study seeks to assess their level of ASD knowledge and explore the factors that influence their awareness. By identifying gaps in parental knowledge, this study aims to contribute to the development of targeted educational initiatives and policy recommendations that can improve ASD awareness, diagnosis, and intervention strategies in Malaysia.

Materials and Methods

The cross-sectional study design is used to assess parental knowledge of ASD in a specialist university hospital in Kelantan. The study setting was conducted after received an approval from the Human Ethics Committee, USM (USM/JEPeM/KK/23120946). The sampling method used in this study is convenience sampling. The sample was selected from parents, either fathers or mothers, or caregivers of children who were continuing for paediatric follow-up in the Paediatric Clinic. The instrument used in this study was a structured, self-administered questionnaire adapted from a previous study and reviewed for its accuracy. The permission for the questionnaire used in this study was granted by the original author (Shrestha et al., 2021). The instrument consists of two sections: demographic information (gender, education level, and income) and ASD knowledge (22 items assessing awareness of

symptoms, diagnosis, and intervention strategies). All items had three response choices: “agree”, “disagree”, and “do not know”. Each item had a predetermined correct answer. Agreement was considered correct for items 1, 2, 5, 7, 8, 11–17, and 20–22, while disagreement was considered correct for items 3, 4, 6, 9, 10, 18, and 19. Correct responses were scored as 1, whereas incorrect and “do not know” responses were scored as 0, reflecting a lack of knowledge. Total ASD knowledge scores ranged from 0 to 22. Knowledge levels were categorised based on percentage scores, as proposed by Shrestha et al. (2021): high (80–100%, scores 18–22), moderate (60–79%, scores 13–17), and low (<60%, scores <13).

Results and Discussion

Sociodemographic characteristics

A total of 94 respondents from a specialist healthcare setting in Kelantan participated in this study. More than half of the respondents (n = 58, 61.7%) were female, while the remaining respondents (n = 36, 38.3%) were male. Respondents between the ages of 18 and 70 have been selected, and most of the respondents (n = 51, 54.3%) fell within the 31- to 40-year-old age range. The majority of respondents had a higher education level (n = 53, 56.4%), while a lower educational level was represented (n = 41, 43.6%). Most of the respondents had a monthly income between RM 2001 and RM 4000, representing 42 respondents (44.7%). Meanwhile, 39 respondents (41.5%) had a monthly income below RM 2000. *Table 1* presents a detailed summary of the sociodemographic characteristics of the respondents.

Table 1. *Sociodemographic characteristics of respondents.*

Variables	Frequency (Percentage)
Gender	
Male	36 (61.7)
Female	58 (38.3)
Age (Year)	
20 years old and below	1 (1.1)
21-30 years	25 (26.6)
31-40 years	52 (55.3)
41-60 years	16 (17.0)
Level of Education	
High Level of Education	53 (56.4)
Low Level of Education	41 (43.6)
Monthly Income	
Below RM 2000	39 (41.5%)
RM 2001 - RM 4000	42 (44.7%)
RM 4001 - RM 6000	13 (13.8%)
RM 6001 - RM 8000	0 (0%)

ASD knowledge

According to the results presented in *Table 2*, parents' correct responses across the 22 ASD knowledge items indicated overall moderate knowledge, with low knowledge observed for several specific items. The mean percentage of correct responses across all items was 63.68%. All respondents (94, 100%) had heard of the term autism. More than

90% of respondents correctly identified that children with ASD experience difficulties in communication (97.9%) and in forming friendships (94.7%). The majority of respondents (93, 98.9%) recognised the importance of early diagnosis, and all respondents (94, 100%) agreed that early intervention is crucial for children with ASD. In contrast, misconceptions were evident in several areas. Only 9 respondents (9.6%) correctly disagreed with the statement that ASD is merely an intellectual disability. Similarly, only 10 respondents (10.6%) correctly disagreed that children with ASD understand and use gestures effectively in communication. Furthermore, only 24 respondents (25.5%) correctly agreed that children with ASD do not typically display unusual interests or strong attachments to objects. Approximately half of the respondents (48, 51.1%) correctly identified that ASD occurs more frequently in boys than in girls.

***Table 2**. Knowledge of ASD.*

No	Knowledge of ASD	True [N(%)]	False [N(%)]
1	I have heard the word autism.	94 (100.0)	0 (0.0)
2	Autism is a neurodevelopment condition.	45 (47.9)	49 (52.1)
3	Autism is just an intellectual disability.	9 (9.6)	85 (90.4)
4	A child with autism makes regular eye contact with others.	72 (76.6)	22 (23.4)
5	A child with autism shows difficulties in communicating with others.	92 (97.9)	2 (2.1)
6	A child with autism understands and uses gestures.	10 (10.6)	84 (89.4)
7	A child with autism has difficulties in making friends.	89 (94.7)	5 (5.3)
8	A child with autism shows repetitive patterns of speech such as repeating words and phrases they hear in the exact tone of the original message.	43 (45.7)	51 (54.3)
9	A child with autism has imaginative play appropriate to his/her developmental level.	3 (3.2)	91 (96.8)
10	A child with autism does not show repetitive patterns of speech such as body rocking, flapping hands.	41 (43.6)	53 (56.4)
11	A child with autism prefers sameness in his/her routine, such as eating the same food or taking the same route to go to school.	63 (67.0)	31 (33.0)
12	A child with autism shows the repetitive use an object, such as lining up toys or spinning objects.	71 (75.5)	23 (24.5)
13	A child with autism shows hyper-sensitivities to the environment around them, such as avoiding loud noises and getting upset in the crowd.	88 (93.6)	6 (6.4)
14	A child with autism does not displays an unusual interest or a strong attachment to an object.	24 (25.5)	70 (74.5)
15	A child with autism shows hypo-sensitivities to the environment around him/her, such as excessive smelling or touching of objects.	48 (51.1)	46 (48.9)
16	A child with can be identified by the age of 24 months.	66 (70.2)	28 (29.8)
17	Autism occurs more in boys than in girls.	48 (51.1)	46 (48.9)
18	Autism occurs more commonly among higher socioeconomic levels.	72 (76.6)	22 (23.4)
19	Autism occurs more commonly in higher educational levels.	74 (78.7)	20 (21.3)
20	If a child has autism, getting a diagnosis is important.	93 (98.9)	1 (1.1)
21	A child with autism can be treated.	78 (83.0)	16 (17.0)
22	Early intervention is important for a child with autism.	94 (100.0)	0 (0.0)

Based on *Table 3*, most respondents had a moderate level of knowledge about ASD, with 60 individuals (63.8%) scoring between 14 and 17. Thirty-two respondents (34.0%) had low knowledge (0–13), and only 2 respondents (2.1%) showed high knowledge (18–22). Overall, parents' understanding of ASD in this study was adequate but not comprehensive. This aligns with previous research in Malaysia. Chu et al. (2023) found that respondents had adequate knowledge and generally positive attitudes toward people with ASD. However, other studies reported gaps in understanding specific aspects, such as recognising signs and symptoms (Shamsudin and Abd Rahman, 2017). Similar trends are seen internationally. In Saudi Arabia, 88% of the public were aware of ASD, but 41% considered their knowledge weak, especially regarding diagnosis and causes (Alyami et al., 2022). Studies in China have found low knowledge of ASD diagnosis, symptoms, causes, and treatment (Yu et al., 2020), whereas research in the United States has shown higher levels of understanding. Among

healthcare personnel in Saudi Arabia, about half had only moderate or poor knowledge, particularly about causes and comorbidities (Hayat et al., 2019). The moderate knowledge in this study may result from limited exposure to children with ASD, inconsistent access to accurate information, and reliance on informal sources. Similar findings were reported in Pakistan, where awareness was common but detailed knowledge was lacking (Anwar et al., 2018). These results indicate that while awareness of ASD is improving, a deeper understanding is still limited. Structured health education programs, information and communication technology-based resources, and media interventions could help improve parental knowledge, supporting earlier recognition and timely intervention (Alsehemi et al., 2017).

***Table 3**. Level of knowledge of ASD.*

Level of knowledge	Frequency (Percentage)
High	2 (2.1)
Medium	60 (63.8)
Low	32 (34)

Associations between sociodemographic characteristics and the level of knowledge of ASD

Table 4 presents the associations between sociodemographic characteristics and the level of knowledge of autism spectrum disorder (ASD) among parents attending specialist healthcare settings in Kelantan. A statistically significant association was observed between gender and level of knowledge of ASD ($p = 0.008$), as well as between monthly income and level of knowledge ($p = 0.004$). Female parents demonstrated a higher proportion of moderate-to-high knowledge compared to male parents. In contrast, no significant associations were found between the level of knowledge of ASD and other sociodemographic variables, including age group and educational level ($p > 0.05$). These findings suggest that gender and household economic capacity play a more prominent role than formal education in shaping parents' knowledge of ASD in this population.

***Table 4**. Associations between sociodemographic characteristics and the level of knowledge of ASD.*

Variable	Level of knowledge			p-value
	Low [N(%)]	Moderate [N(%)]	High [N(%)]	
Gender				
Female	13 (22.4)	43 (74.1)	2 (3.4)	0.008
Male	19 (52.8)	17 (47.2)	0 (0.0)	
Age (years)				0.736
20 years old and below	1 (100)	0 (0.0)	0 (0.0)	
21-30 years	10 (40.0)	14 (56.0)	1 (4.0)	
31-40 years	16 (30.8)	35 (67.3)	1 (1.9)	
41-60 years	5 (31.3)	11 (68.8)	0 (0.0)	
Educational level				0.090
No formal education	1 (100)	0 (0.0)	0 (0.0)	
Primary school	2 (66.7)	1 (33.3)	0 (0.0)	
Secondary school	19 (51.4)	17 (45.9)	1 (2.7)	
Pre-university (diploma, vocational training, etc.)	8 (25.0)	23 (71.9)	1 (3.1)	
Bachelor/Degree	2 (10.5)	17 (89.5)	0 (0.0)	
Master/Ph.D.	0 (0.0)	2 (100)	0 (0.0)	
Monthly income				0.004
Below RM 2000	21 (53.8)	17 (43.6)	1 (2.6)	
RM 2001 - RM 4000	11 (26.2)	30 (71.4)	1 (2.4)	
RM 4001 - RM 6000	0 (0.0)	13 (100)	0 (0.0%)	

Note: Significant difference at $p<0.05$ using Chi-square test.

The present study demonstrates that monthly income is a significant determinant of parents' knowledge of ASD, highlighting the role of socioeconomic factors in shaping health-related knowledge. This finding aligns with extensive evidence indicating that socioeconomic status (SES), commonly operationalised through income, education, and occupation, is closely linked to disparities in health literacy, access to services, and health outcomes. Parents from higher-income households may benefit from greater access to healthcare providers, diagnostic services, educational materials, and support networks, all of which facilitate improved understanding of ASD. Delayed diagnosis of autism remains a global concern, with many children not identified until the age of three or four years (Chu et al., 2023). In resource-limited settings, financial constraints can further exacerbate delays in diagnosis and limit parents' opportunities to acquire accurate information. Studies have consistently reported that parents with higher incomes are more likely to access books, online resources, private assessments, and specialised interventions for their children with ASD (Anwar et al., 2018; Pickard and Ingersoll, 2016). Conversely, parents from lower-income households may face multiple barriers, including limited access to healthcare, transportation difficulties, and competing financial priorities, which collectively hinder their information-seeking behaviours. The finding that the majority of respondents had at least heard the term "autism" suggests a basic level of awareness within the community; however, awareness does not necessarily equate to adequate or accurate knowledge. A Malaysian study reported that while 76.7% of respondents were familiar with the term autism, many were unable to correctly identify its characteristics (Shamsudin and Abd Rahman, 2017). Similar patterns have been observed in other low- and middle-income countries, including Yemen, where a substantial proportion of respondents had limited or no familiarity with ASD terminology (Taresh et al., 2021). These findings collectively indicate that superficial awareness may mask significant gaps in conceptual understanding, underscoring the need for structured and accessible educational interventions.

The significant association between gender and knowledge level observed in this study may reflect traditional caregiving roles, where mothers are more actively involved in child-rearing, healthcare utilisation, and communication with health professionals. Maternal involvement may increase exposure to ASD-related information through clinical encounters and informal support networks. Nevertheless, evolving family dynamics and increasing paternal involvement in childcare may gradually narrow this knowledge gap, suggesting the importance of inclusive parent-focused educational strategies. Furthermore, the psychological and environmental stressors commonly experienced by low-income households, such as housing instability, food insecurity, and employment uncertainty, may limit parents' cognitive and emotional capacity to prioritise learning about ASD. Evidence from China supports this interpretation, demonstrating that better household economic conditions are associated with higher parental knowledge levels (Wang et al., 2022). Similar trends reported in Saudi Arabia indicate that parents within lower- and middle-income categories were less likely to be knowledgeable about ASD (Alyami et al., 2022).

Conclusion

In conclusion, most parents in this study had a moderate level of knowledge about ASD, suggesting that awareness exists, but detailed understanding remains limited. Knowledge levels varied by gender and socioeconomic status, with mothers and parents from higher-income households demonstrating a better understanding, likely due to their greater involvement in caregiving and access to resources. Parents with lower incomes may face barriers in accessing information and services, highlighting the need for targeted educational efforts to improve early detection and support for children with ASD.

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Conflict of interest

The authors declare no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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