e-Bangi Faculty of Social Sciences and Humanities
Universiti Kebangsaan Malaysia
Journal of Social Sciences and Humanities

eISSN: 1823-884x

Volume 21, Issue 3, DOI: https://doi.org/10.17576/ebangi.2024.2103.08

Article

Assessing Parents' Understanding of Autism Spectrum Disorder (ASD) in Malaysia: A Cross-Sectional Study

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Received: 21 February 2024
Accepted: 16 July 2024

Abstract: The current understanding of autism among parents of children with Autism Spectrum Disorder (ASD) in Malaysia reflects a multifaceted perspective marked by various challenges including confusion, financial constraints, limited resources, and a shortage of trained special needs teachers and affordable centers. This study aims to assess the level of autism knowledge among parents of individuals with ASD in Malaysia. A cross-sectional study involving 471 parents was conducted in the Klang Valley between May 2022 and June 2023, utilizing an online survey tool. The study found that most parents exhibited limited understanding in crucial areas related to autism such as its causes, diagnosis, and treatment options. Moreover, there was a significant relationship between the level of education and knowledge of ASD. The findings underscore the importance of comprehensive parental training to provide enduring support for children with ASD. This highlights the necessity for ongoing efforts to enhance parental knowledge and support systems for individuals with autism in Malaysia.

Keywords: Autism; chi-square test; knowledge; Malaysia; parents

Introduction

Addressing the unique challenges of Autism Spectrum Disorder (ASD) requires a comprehensive approach. In Malaysia, ASD is categorized under learning disabilities alongside other cognitive and developmental disorders (Department of Social Welfare, 2019). Early recognition of perplexing behaviours typically observed around the age of three facilitates timely diagnosis (Zwaigenbaum et al., 2015). Once a formal diagnosis is made, gaining a deep understanding of the diverse symptoms and behavioural patterns associated with autism becomes crucial (American Psychiatric Association, 2013).

With this knowledge, suitable treatments and interventions can be pursued to address the individual's specific needs(Lavelle et al., 2014). In Malaysia, families of children with ASD are estimated to spend approximately RM25,000 - RM35,000 annually on remediation, education, treatment, and living expenses (Kamaralzaman et al., 2018). This financial burden is significant, as it accounts for nearly one-third of the average household income in Malaysia, which is RM94,812 per year (Department of Statistics Malaysia, 2020). Undoubtedly, expertise and infrastructure constraints are major barriers that lead to delayed identification and intervention of ASD in Malaysia (Hui et al., 2021). Additionally, reduced public knowledge on ASD further hinders the progress of early identification and intervention in the country (Hui et al., 2021; Ilias et al., 2017). The increased prevalence of ASD has resulted in more people encountering individuals with the condition and becoming aware of its behavioural manifestations. For instance, a study involving medical students in Malaysia found that 19% of the participants (N=83) had prior knowledge of ASD due to having relatives with the condition (Low & Zailan, 2018).

Globally, numerous studies have investigated the knowledge and attitudes toward children with autism spectrum disorder (ASD) among various populations involved in managing ASD children directly or indirectly(Kaman et al., 2023). Some studies have revealed that the level of knowledge about ASD among parents is still inadequate and needs improvement(Effatpanah et al., 2019; Luleci et al., 2016). Some local studies conducted among the general population revealed a broad spectrum of knowledge levels(Kaman et al., 2023). Further research (Anwar et al., 2018; Kaman et al., 2023) explored factors influencing caregivers' knowledge and attitudes toward ASD. Maternal age, maternal depression, and the child's birth order among siblings significantly impacted caregivers' attitudes (Andoy Galvan et al., 2020; Kaman et al., 2023).

In recent years, there has been a growing emphasis on providing training to parents of children with Autism Spectrum Disorder (ASD). The recognition that there is no one-size-fits-all approach in ASD intervention, coupled with the variability in the presentation of autism across individuals, emphasizes the need for empowering parents with knowledge. Parents are increasingly seen as pivotal collaborators in the support system for individuals with ASD, starting from the early stages of understanding autism to identifying and implementing the most suitable interventions.

Traditionally, research has predominantly concentrated on educators and therapists as the primary source of support for individuals with ASD. However, the evolving understanding of the diverse and multifaceted nature of autism has prompted a redirection of attention towards parents of children with ASD. The recognition that there is no one-size-fits-all approach in ASD intervention, coupled with the variability in the presentation of autism across individuals, emphasizes the need for empowering parents with knowledge. Parents are increasingly seen as pivotal collaborators in the support system for individuals with ASD, starting from the early stages of understanding autism to identifying and implementing the most suitable interventions.

This question probes into the notion that parents with higher education levels might possess a different cognitive framework or analytical skills that could shape their understanding of the complexities associated with ASD. The study aims to uncover whether there is a correlation between educational background and a clearer comprehension of autism, potentially influencing the way parents approach interventions, advocacy, and collaboration within the support system.

Literature Review

Autism, a cognitive neurodevelopmental condition, has undergone varied conceptualizations over time. The historical trajectory of autism traces back to its initial recognition as early as 1747 in Borgue, Scotland where Hugh Blair found himself entangled in a legal dispute where the brother of another individual aimed to secure Hugh Blair's inheritance and its evolution has taken diverse paths (Houston & Frith, 2000). In Malaysia, ASD is categorized under learning disabilities alongside other cognitive and developmental disorders (Department of Social Welfare, 2020). This endorsement is crucial as the definition of persons with disabilities, as outlined in section 2 of the Persons with Disabilities Act 2008, explicitly incorporates individuals with autism under the category of disabled persons. The definition specifies that disabilities encompass long-term physical, mental, intellectual, or sensory impairments, which, when coupled with various barriers, may impede their complete and effective participation in society. As a result, the Ministry of Social Welfare issues Disabled Person cards to individuals diagnosed with autism, serving as a legal document to verify their disability status, as highlighted by (Tahir et al., 2023). In Western societies, the diagnosis of autism in children often occurs as early as 14 to 19 months (Hyman et al., 2020). An indicator that raises concern is the inclination of most children towards anthropomorphism. This tendency is highlighted by heightened rates of personification reported among individuals with autism in the U.K. (White & Remington, 2019).

In Malaysia, the diagnosis of Autism Spectrum Disorder (ASD) is typically established at an average age ranging from 46 to 66 months indicating a notable delay in the identification of ASD(Sathyabama, 2019). However, in Malaysia there is a significant lack of awareness among parents regarding Autism Spectrum Disorder (ASD) when they first learn of their child's diagnosis, revealing a deficiency in information and understanding(Indera Luthfi et al., 2023). This situation is further compounded by parents reporting encounters with social stigma from their own community due to their child's behavior (Chu et al., 2020). Unfortunately, this can lead to social rejection which poses a global concern, particularly impacting children with Autism Spectrum Disorder (ASD), as it can lead to their increased reluctance to participate in society (Kwan et al., 2020). The initiation of the diagnosis process for Autism Spectrum Disorder (ASD) in Malaysia is predominantly carried out by the medical fraternity. However, it was found that lay individuals, as per findings from another study, were found to attribute the cause of autism to factors such as karma or mysticism (Ilias et al., 2019). As a result, the interplay between cultural beliefs, stigma, religious practices, and values in Malaysia can give rise to distinctive perceptions of caregiver burden and stress when compared to other nations (Indera Luthfi et al., 2023).

Crucially, a key obstacle in this journey is the diverse perspectives on autism, contributing to a knowledge gap. Viewed from various angles, this lack of understanding becomes a significant barrier, hindering parents from confidently embarking on the diagnosis and subsequent treatment of autism. This study examines the knowledge level of parents of children with autism spectrum disorder against their education level (ASD) in Malaysia. This could facilitate the delivery of a training module that can better resonate with and meet the diverse needs of families impacted by ASD in the Malaysian cultural context. The hypothesis is that there is a significant association between their education level and knowledge in this population.

Methodology

1. Research Design

This study was conducted in the form of a survey with data being gathered via convenience sampling as per a recent study (HUI et al., 2021). This mode of gathering data via a survey form is convenient, cost effective considering many parents of ASD commonly experience elevated levels of stress compared to those with typically developing children, as evidenced in various studies(Schnabel et al., 2020).

2. Participant

The study employed a survey method using convenience sampling to gather data from 471 parents of children with Autism Spectrum Disorder (ASD), utilizing the Autism Spectrum Knowledge Scale General Version for Parents (ASKSG) questionnaire to assess parental knowledge across various domains related to ASD. The questionnaire was distributed via email, WhatsApp groups, NGOs, and special needs schools that catered to the needs of children with ASD, reaching out to the parents of children with ASD. The data collection involved the administration of a validated questionnaire known as "The Autism Spectrum Knowledge Scale General Version for Parents (ASKSG)." (Benallie et al., 2020).

3. Instrument

The survey employed in this research was originally created by McClain et al., 2019, and its domains align with the criteria outlined in the DSM-5. Respondents were presented with questions requiring them to choose from "true," "false," or "don't know" responses. The initial portion of the questionnaire gathered demographic information, encompassing details such as age, race, religion, marital status, and others. The knowledge assessment segment encompassed six subcategories, covering aspects like the causes and prevalence, symptoms and related behaviors, assessment and diagnosis, treatment options, and prognosis, amounting to a total of 31 items.

The ASKSG score was computed by comparing the number of correct responses to the total of 31 questions, following the approach established by (McClain et al., 2019) A similar research assessing the knowledge level of pre school teachers used the ASKSG in the year 2022 by Jessica Prizer. These responses were recorded using a binary format consistent with previous studies, where "correct" was assigned a value of 1, "incorrect" a value of 0, and "don't know". Higher ASKSG scores indicated a greater understanding of ASD. "Having knowledge" was defined as selecting the correct answer, while "no knowledge" referred to choosing the wrong answer. Therefore, a higher score signified a higher level of knowledge.

4. Data Collection Process

The data collection procedure involved administering the validated ASKSG questionnaire, comprising demographic information and knowledge assessment sections, with respondents choosing from "true," "false," or "don't know" responses. ASKSG scores were computed based on the number of correct responses, providing a measure of parents' understanding of ASD. Parents of children with ASD received a Google link that directed their responses to the researcher's email, securely collecting the data. The Google form included elements of consent and confidentiality. Participants were given approximately three weeks to respond, taking into account their challenges and time constraints, which the researcher considered when setting the time frame.

5. Data Analysis

The data in this study was processed and analyzed utilizing Statistical Package for Social Sciences 16.0 (SPSS). For categorical data, the analysis involved reporting frequencies and percentages based on Bloom's taxonomy cutoff point. This means that if a participant scored below 59%, their knowledge about autism was considered inadequate. If they scored between 60%-79%, their knowledge was considered moderate, and if they scored 80 - 100%, their knowledge was considered adequate. Additionally, the study computed the mean and standard deviation. To examine the relationship between the level of education and knowledge of autism, the Chi-square test of independence was applied.

6. Ethical Consideration

Participation in this research is entirely voluntary, anonymous, and confidential, with the option to withdraw at any time without any negative consequences. All personal information and collected data will be kept confidential and only accessible to the researcher.

Findings

1. Demographic Profile of Participants

Table 1 presents a comprehensive overview of the personal characteristics of the survey participants, encompassing various demographic factors.

Table 1. Demographic Details of Survey Samples (n=471)

Demographic variables	**Frequency**	**Percent %**
Gender		
Male	111	23.6
Female	360	76.4
Age Group		
18 – 24	5	1.1
25 – 39	198	42.3
40 – 59	252	53.8
≥ 60	13	2.8
Level of Education		
No formal education	4	0.9
Primary School	12	2.6
Secondary School	91	20.0
College / University / Institution	347	76.4
Ethnicity		
Malay	286	60.7
Chinese	80	17.0
Indian	52	11.0
Others	53	11.3
Religion		
Islam	313	66.5
Christian	67	14.2
Buddha	58	12.3
Hindu	33	7.0
Marital Status		
Single	48	10.2
Married	423	89.8

The sample consists of 471 individuals, and it is evident that there is a diverse representation across these characteristics. The gender distribution shows that 76.4% of the respondents identified as female, while 23.6% identified as male. Regarding age, the largest proportion (53.8%) falls within the 40-59 age group, followed by 25-39-year-olds comprising 42.3% of the sample. The largest age group among the respondents was 40-59, accounting for 53.5% of the sample, while 42.0% belonged to the 25-39 age group. In terms of ethnicity, the majority of respondents (60.7%) identified as Malay, followed by Chinese (17.0%) and Indian (11.0%). Muslim was the most commonly reported religion (66.5%), followed by Christian (14.2%) and Buddhist (12.3%). Finally, the majority of respondents (89.8%) identified as married, while only 10.2% reported being single.

In interpreting the status of the education level among parents, it was found that the majority of respondents (76.4%) had attended college, university, or other educational institutions, indicating a relatively higher level of education within the sample. Conversely, only a small percentage reported having no formal education at (0.9%) or attending only primary school at a percentage of (2.6%) with (20.0%) having attending secondary school.

2. Understanding of Autism

The mean scores are analysed as shown below (Table 2) with the following analysis. Based on the mean score of overall knowledge (43.6%), it was found that the level of knowledge of the parents towards the ASD is poor. This was attributable by the lower score of Outcome/Prognosis (10.0%), followed by Etiology (37.4%), Assessment/Diagnosis (45.7%) and Treatment (57.7%) indicating low level of knowledge. However, their level of knowledge on Symptoms/Associated behaviour is moderate (68.2%) Using Bloom's cutoff point, the total scores from the knowledge domains were categorized into three levels: low-level knowledge (below 60%), moderate-level knowledge (60% to 79%), and high-level knowledge (80% to 100%). As observed in Table 2, the total knowledge score stands at 43.6%, revealing a limited level of knowledge among the parents regarding autism. When examining specific domains, their knowledge about symptoms and associated behaviours is considered average. However, they demonstrated poor knowledge in areas related to assessment/diagnosis, etiology, and outcomes/prognosis.

Similarly, the median showed that parent's overall knowledge is poor (48.4%). It was due to a low level on Outcome/Prognosis (16.7%), Aetiology (42.9%) and Assessment/Diagnosis (42.9%). Nevertheless, parents had a moderate level of knowledge on Treatment (75.0%) and Symptoms/Associated behaviour (71.4%). The knowledge scores for all domains and overall knowledge were widely scattered as indicated by high standard deviation ranging from 8.16 to 27.78.

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Table 2. Parent Knowledge of Autism Spectrum Disorder

Domain	**Mean Score**	**Median**	**S D**
Ethology	37.4	42.9	21.96
Symptoms/Associated behaviour	68.2	71.4	25.00
Assessment/Diagnosis	45.7	42.9	25.00
Treatment	57.7	75.0	27.78
Outcome/Prognosis	10.0	16.7	8.16
Overall Knowledge	**43.6**	**48.4**	**17.14**

3. Correlation Between Educational Background and Autism Knowledge

Table 3 displays the outcomes of the Chi-Square test examining the association between knowledge domains and educational levels. With the exception of aetiology, all other domains, including overall knowledge, exhibit a significant association with educational levels. Clearly, the results indicate that, regardless of educational background, a majority of respondents scored low across all knowledge domains. This significant finding holds valuable implications for the body of training parents, specifically in the context of enhancing awareness and understanding of Autism Spectrum Disorder (ASD). The identified association between educational levels and knowledge domains underscores the need for targeted interventions in parental training programs. Recognizing the prevalent low scores across various domains, these programs can be tailored to address specific gaps and challenges that parents, regardless of their educational background, may encounter.

In practical terms, the findings suggest that parental training initiatives should be designed with a holistic approach, catering to a broad range of educational backgrounds. By acknowledging and addressing the common areas of limited understanding, such as assessment, treatment, and overall knowledge, training programs can empower parents with the essential insights needed to effectively support their children with ASD. This contributes to creating more inclusive and accessible parent training modules that consider the diverse educational profiles of participants, ultimately fostering a more informed and capable support network for individuals with ASD.

Table 3. Relationship between education level and knowledge of Autism Spectrum Disorder

		Educational level				
Domain	**Knowledge Level**	**Primary School**	**Secondary School**	**College/University**	**Chi-square**	***p*-value**
Ethology	Low	100	93.4	87.9	4.45	0.348
	Moderate	0	4.4	9.2		
	High	0	2.2	2.9		
Symptom	Low	75.0	45.1	23.1	37.6	0.000*
	Moderate	12.5	26.4	24.8		
	High	12.5	28.6	52.2		
Assessment	Low	87.5	83.5	70.0	9.56	0.049*
	Moderate	12.5	13.2	20.2		
	High	0	3.3	9.8		
Treatment	Low	75.0	60.4	43.5	15.6	0.004*
	Moderate	25.0	35.2	43.8		
	High	0	4.4	12.7		
Overall Knowledge	Low	100	94.5	81.8	12.0	0.017*
	Moderate	0	5.5	17.9		
	High	0	0	0.3		

Discussion

The primary research was carried out within the confines of the Klang Valley, with limited involvement from other regions. However, the data analysis has illuminated the necessity for a training module. It is evident that parents assume the central caregiving role, and enhancing their capabilities opens up greater opportunities for a child's successful integration into society.

Empirical evidence supports parent training as an effective intervention for addressing disruptive behavior in children not complicated by Autism Spectrum Disorder (ASD). This form of intervention equips parents with targeted techniques to manage behavioural challenges in their children (Nazir et al., 2024; Oono et al., 2013). According to the Investigators (2012), emphasizing the significance of early diagnosis and intervention is vital for enhancing developmental outcomes in individuals affected by Autism Spectrum Disorder (ASD). Following the establishment of an ASD diagnosis and the initiation of early interventions, it becomes essential to provide parents with training regarding the causative factors and behavioural traits associated with ASD. This training equips parents with the knowledge necessary to comprehend ASD and effectively implement behavioural strategies (Investigators, 2012). Past research has extensively incorporated parental training within interventions, commonly referred to as parent-mediated interventions (Oono et al., 2013). Various countries, including the USA, UK, Australia, Canada, Thailand, and China, have emphasized the pivotal role of these parent-mediated interventions in shaping comprehensive intervention programs (Oono et al., 2013).

However, the current trend is leaning towards a focus on psychoeducational training, aiming for greater individualization that aligns with the child's specific goals, preferences, routines, and traditions (Zhao et al., 2021). This shift reflects a move towards more tailored approaches. The effective implementation of evidence-based interventions in real-world settings, as exemplified in addressing disruptive behaviour (Pickard & Ingersoll, 2016), is becoming the norm. It is proposed that the requisites of Parent-Mediated Intervention (PMI), which necessitate patience and consistency may be more feasible for parents in nuclear families, allowing for increased time dedicated to home interventions. Furthermore, the absence of extended family members cohabiting may streamline the execution of PMI strategies, minimizing interference from external parties.

Additionally, parents within this demographic often benefit from enhanced access to face-to-face or online coaching, possess heightened awareness of their child's challenges, and exhibit greater knowledge, often attributed to their urban residential setting (Deb et al., 2020). Other multiple studies suggest that active parental engagement in interventions can serve as a preventive measure, potentially averting the development of more severe disruptive behaviors in children (Colizzi et al., 2020; Razman & Mohd Hoesni, 2023).

Conclusion

Exploring the association between parents' educational backgrounds and their understanding of Autism Spectrum Disorder (ASD) is pivotal for crafting tailored support initiatives. For instance, parents with lower education levels may benefit from practical approaches, such as videos and role-playing, to enhance their comprehension. On the other hand, parents with higher education levels might engage with a blend of theoretical concepts and practical approaches to grasp the nuances of autism. While the ultimate goal remains consistent, adapting methodologies to align with the cognitive capacities of parents ensures a more effective and personalized approach. Identifying knowledge gaps among parents can inform early intervention strategies. Educating parents about ASD early on can lead to earlier diagnosis and intervention for children, which is crucial for their long-term development and well-being.

Educated parents may be better equipped to advocate for their children within the educational and healthcare systems. Understanding their knowledge level can help in providing them with the necessary tools and resources to navigate these systems effectively and advocate for appropriate services and accommodations for their children. Insights from this study can inform policymaking related to ASD awareness and support programs in Malaysia. Government agencies and policymakers can use this information to allocate resources effectively and develop policies that cater to the diverse needs of families affected by ASD.

Acknowledgement: We wish to thank Jabatan Pendidikan Negeri Selangor for their assistance in sharing the questionnaire through their parent’s groups of special needs children.

Ethical Approval: Ethical approval for this study was granted by Universiti Malaya Research Ethics Committee with protocol code: UM. TNC2/UMREC_1616.

Informed Consent Statement: Informed consent was obtained from all subjects involved in the study.

Conflicts of Interest: The authors declare no conflict of interest.

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