## Kertas Asli/Original Articles

# A Survey of Lay Knowledge of Autism Spectrum Disorder in Malaysia (Soal Selidik Pengetahuan Awam tentang *Autism Spectrum Disorder* di Malaysia)

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#### ABSTRACT

Today, increasingly more people worldwide are aware about Autism Spectrum Disorder (ASD). However, their actual knowledge about ASD is yet unknown. The lack of knowledge about ASD is especially apparent among the lay people in the community. In this study, the lay knowledge of ASD was investigated using a brief survey involving a community sample in Malaysia. The survey findings revealed that the vast majority of the respondents could relate to ASD as a type of learning disability. However, they were less familiar with the diagnostic features and remedial needs of ASD. They also reported limited knowledge about the social communication and language deficits of ASD. Another noteworthy finding was that the respondents reported different sources of obtaining ASD knowledge according to their demographic profiles (namely age, gender, education and occupation), which correspondingly led to variability in the type of knowledge they obtained. Together, the findings implied that content-specific ASD awareness programs through the right channels are warranted for optimizing efficacy in knowledge transfer and minimizing redundancy in existing ASD awareness campaigns. Increased lay knowledge on ASD will provide a public guardian ground for children with ASD to ensure that the challenges faced by them can be identified at an early age for optimizing the remedial outcomes.

Keywords: Autism spectrum disorder; Malaysia; lay knowledge; social communication; language

#### ABSTRAK

Kini, semakin ramai orang di seluruh dunia mengetahui tentang Masalah Spektrum Autisme (ASD). Namun, tahap pemahaman sebenar orang ramai tentang ASD masih belum diketahui. Kekurangan pengetahuan tentang ASD adalah paling ketara dalam kalangan masyarakat awam. Dalam kajian ini, pengetahuan awam tentang masalah komunikasi sosial dan bahasa bagi ASD disiasat melalui satu soal selidik yang melibatkan satu sampel masyarakat awam di Malaysia. Hasil kajian menunjukkan bahawa secara am, responden tahu bahawa ASD ialah sejenis masalah pembelajaran. Namun, mereka kurang tahu tentang aspek diagnostik dan keperluan pemulihan ASD secara spesifik. Mereka juga mempunyai pengetahuan yang cetek mengenai masalah bahasa dan komunikasi dalam kalangan kanak-kanak ASD. Satu lagi penemuan penting ialah responden melaporkan bahawa mereka mendapat pengetahuan tentang ASD melalui sumber yang berbeza, dipengaruhi oleh profil demografi mereka (iaitu umur; jantina, pendidikan dan pekerjaan). Selanjutnya, jenis pengetahuan yang mereka perolehi turut dipengaruhi oleh sumber pengetahuan mereka. Hasil kajian ini menunjukkan bahawa program kesedaran ASD yang mempunyai kandungan spesifik melalui saluran yang betul adalah penting untuk mengoptimumkan keberkesanan pemindahan pengetahuan dan meminimumkan kos yang terlibat. Peningkatan ilmu pengetahuan mengenai ASD akan menjana satu persekitaran awam yang selamat dan mempunyai sokongan yang sesuai untuk kanak-kanak dengan ASD. Ini dapat memastikan bahawa cabaran yang dihadapi oleh mereka dapat dikenal pasti pada usia awal untuk mengoptimumkan hasil pemulihan.

Kata Kunci: Masalah spektrum autisme; Malaysia; ilmu pengetahuan; komunikasi sosial; bahasa

### INTRODUCTION

Today, international statistics show that 1-2% of the world population is identifiable with Autism Spectrum Disorder (ASD) (Hahler & Elsabbagh 2015). Two diagnostic features of ASD are social communication deficits and restricted repetitive behaviours (APA 2013; WHO 2013). These two deficit areas affect the life functionality of individuals with ASD, resulting in high disease management cost (Kornack et al. 2014). For example, in 2015, the United States spent around USD268 billion of their public funding on ASD management (Leigh & Du 2015). This amount has exceeded the costs of stroke and hypertension management. The ASD management cost was predicted to rise up to USD461 billion in 2025, and it would then also exceed the costs of diabetes and ADHD management. Globally, the financial burden of families affected by ASD is enormous (Rogge & Janssen 2019). In Malaysia, it is estimated that each family is spending around RM25000 - RM35000 annual for the remediation, education, treatment and living costs of a child with ASD (Kamaralzaman et al. 2018; Najib & Juni 2019). The financial impact is severe since the estimated expenses are near one third of the average household income in Malaysia (average annual income=RM94,812) (Department of Statistics Malaysia 2020).

In regards to this, amassing evidence indicated that early identification and intervention is one way to reduce the ASD disease management cost (Koegel et al. 2014; Rogge & Janssen 2019). Evidence indicates that early identification and intervention was effective in bringing positive changes in the life qualities of the affected individuals and their families; including the benefits associated with improved life functionalities, the prevention of secondary symptoms, fiscal savings, reduced parental stress, and the potential of overcoming the disability (Koegel et al. 2014). However, early identification and intervention of ASD is yet to be attained in many low and middle income countries in the Asia Pacific region (Neik et al. 2014. Available statistics show that the mean age of ASD diagnosis in many low and middle-income countries is at 45-57 months, which so much later than the mean age of 37 months in high-income countries (Samms-Vaughan 2014). In Malaysia, the diagnosis of ASD is typically made at the average age of 46-66 months (Ramachandram 2019; Apok & Mohd Salleh 2020), pointing to a prominent delay in ASD diagnosis.

Expertise and infrastructure constraints are undoubtedly the major hindering factors of delayed identification and intervention of ASD in Malaysia (Neik et al. 2014; Tan 2015). Another possible factor which hinders the progress of early identification and intervention of ASD in Malaysia is the reduced public knowledge on ASD (Ilias 2017). Today, the increased prevalence of ASD has contributed to increasingly more people having had encountered someone with ASD, and hence have come to realize the behavioural manifestation of this condition. For example, in a study involved a sample of medical students in Malaysia, it was found that as many as 19% of the studied sample (N=83) reported that they know about ASD prior to their enrolment in the medical program because they have relative(s) with ASD (Low & Zailan 2018).

Despite a notably increase of public awareness of ASD in Malaysia, having had known or heard about ASD does not necessarily translate into having had adequate understanding and knowledge about ASD. In a phenomenological analysis study, it was found that inadequate knowledge of ASD had led to some lay people in the Malaysian community to rely on cultural beliefs such as karma or religious mysticism to explain for the cause of this condition (Ilias et al. 2017). The lack of adequate public knowledge about ASD can adversely affects early identification and intervention of ASD. Firstly, it might lead to tardiness in seeking professional help. Montiel-Nava, Chacín and González-Ávila (2017) collected demographic date from 103 children between 2 and 7 years of age in Venezuela, South America. They found that many children in the sample were diagnosed 36 months later, even parents were aware of developmental difficulties that their child experienced before the second year of life. The lack of adequate knowledge about ASD is undeniably one of the most prominent reasons which had caused the delay in seeking diagnosis and professional help.

Lower education level and lower socioeconomic status are amongst the main reasons which had caused inadequate knowledge about ASD in the community (Pickard & Ingersoll 2016; Kelly et al. 2019). To ensure accessibility of services to young children with ASD, it is important that actions are taken to improve the knowledge of ASD among the public. Pertaining to this, media plays an important role in disseminating accurate ASD-related knowledge to the lay people in the community. However, the critical discourse interpretation of the media coverage has indicated that the leading media in the Asia Pacific region had the tendency to portray victimized images of individuals with ASD and their families; while revealing only limited factual information about ASD (Bie & Tang 2015; Jones & Harwood 2009).

In the discourse analysis of media representation of ASD in China, Tang and Bie (2015) found that the media predominantly discussed ASD as a condition that is affecting children and infants. Such practice might mislead the general public to assume that ASD is only a paediatric disorder. Secondly, the media predominantly reported personal stories which portrayed ASD as a cause of family struggle. Such media coverage might lead the general public to feel that ASD is merely a family matter rather than a societal issue (Bie & Tang 2015). The findings from media representation of ASD in the United States resonated with the above findings that media tended to highlight more on the 'conflict' and 'moral' aspects in ASD, while much less in portraying the associated resources and services for the developmental needs of children with ASD (Wendorf Muhamad & Yang 2017).

Hence, it is important to recognise that the increased public awareness of ASD is not equivalent to the increased public knowledge of ASD. Pertaining to this, misconceptions about ASD is notably common in the low and middle-income countries in the Asia Pacific region (Samms-Vaughan 2014; Wallace et al. 2012). The lack of accurate knowledge about ASD is as hazardous as not knowing its existence. As reported in previous public surveys, the common misconceptions about ASD include the association of its etiology to nurturing issues, assuming that children with ASD will outgrow it, and not realizing that children with ASD can attend regular schools (Qi, Zaroff & Bernardo, 2015; Al-Sharbati et al. 2015). Such misconceptions are likely to lead to the wrong management of ASD cases, resulting in negative outcomes and the wasting of public resources. Therefore, as part of a larger study to investigate the knowledge of lay persons about ASD in Malaysia, an exploratory study was conducted with a community sample during a public expo in Kuala Lumpur, Malaysia. This investigation aimed to obtain insights of the community's knowledge about ASD in the context of Malaysia.

## METHODOLOGY

This research was a brief survey which involved a convenient sampling technique. This survey was conducted during a public expo in the city of Kuala Lumpur, Malaysia. The researchers of this paper participated in this expo to showcase a product on teacher and caregiver training to enhance the language skills of students with ASD. The questionnaires were distributed to the public visitors and other researchers in the expo who visited the booth during the period of expo. The written consent of research participations was obtained prior to the participants responding to the questionnaire were distributed and collected.

The questionnaire was a one-page form self-developed by the researchers specifically for the purpose of a brief survey. Some items in this questionnaire were adapted loosely from existing questionnaires developed by Holt and Christensen (2013), Mavropoulus and Padeliadu (2000) and Park, Chitiyo and Choi (2010). The first part of the questionnaire contained demographic questions involving age, gender, education level, occupation, family history of ASD, and source of knowing about ASD. The second part contained 20 Yes/No dichotomous questions with the following themes: general knowledge (4 questions), social communicative deficits (6 questions), special education needs (5 questions), and social communication and language remediation (5 questions). This questionnaire was tested with 120 primary-school teachers in a preliminary study. The international consistency of this form was assessed using Cronbach's alpha coefficient. The alpha value of 0.84 was obtained, indicating satisfactory internal consistency.

## RESULTS

#### DEMOGRAPHIC PROFILES

The demographic data showed that the majority of respondents were young adults between 20 and 39 years of age (83.5%). Of these, 63.2% were females. The majority of the respondents had at least a bachelor degree (85.4%), and they were predominantly students (47.3%) and educators (29.3%) in universities. The demographic data indicated that the current survey involved predominantly the elite members in the Malaysian community. Among the respondents who participated in the survey, 4.3% of them (n=9) reportedly had family members identified with ASD, and 55.5% of them (n=5) reported that the diagnosis was made after the age of 7 years. Next, the respondents identified the Internet (58.1%) and TV (55.7%) as the most common sources of information about ASD, followed by newspapers (27.6%), social acquaintances (26.7%) and books (23.8%).

### OVERVIEW OF KNOWLEDGE

The cumulative scores of the respondents were computed to identify their overall knowledge level. The mean score was 12.95 (SD=2.071). As summarised in Figure 1, the majority of respondents obtained a score of 11-15 for the 20 Yes/No binary questions in the survey (cumulative percent=77.4%), indicating a group representation of moderate knowledge level.

## KNOWLEDGE ABOUT ASD CHARACTERISTICS

Figure 2 shows the respondents' knowledge about social communication and language deficits of ASD, and also the general knowledge of ASD. The results showed that the respondents could relate better to the communication aspect of deficits, rather than the language aspect. More than 80% of the respondents could correctly identify communication and relationship building deficits as ASD features. Comparatively, fewer respondents could relate to the language deficits, especially receptive language deficits (43.7%). The respondents' general knowledge of ASD was poor. Near half of the respondents did not know that reading deficit is not the primary feature of ASD (64.8%). A large majority of them also did not know that ASD persists through to adulthood (46.4%), it has no absolute cure (31.5%) and it affects more males than females (10.0%). This set of findings indicated that the majority of respondents knew that ASD was associated with social communication deficits; but many of them were not aware

Demographic items		Percent	No of responses	Total no. of responses
Age	< 20 years old	4.7%	10	213
	20-29 years old	59.6%	127	
	30-39 years old	23.9%	51	
	40-49 years old	8.9%	19	
	$\geq$ 50 years old	2.8%	6	
Gender	Female	63.2%	120	190
	Male	36.8%	70	
Education	Diploma and below	14.6%	31	213
	Bachelor degree	39.0%	83	
	Master degree	27.2%	58	
	Doctoral degree	19.2%	41	
Occupation	Students	47.3%	89	
	Research assistants	6.4%	12	
	Educators	29.3%	55	188
	Others	17.0%	32	
Family History with ASD	Yes	4.3%	9	210
	No	95.7%	201	
Sources of information	Internet	58.1%	122	679
	TV	55.7%	117	
	Newspaper	27.6%	58	
	Friends/Neighbors	26.7%	56	
	Books	23.8%	50	
	School	19.5%	41	
	Hospital	19.5%	41	
	Magazines	17.6%	37	
	Brochures	16.7%	35	
	Family	12.9%	27	
	Radio	12.4%	26	
	Personal experience	10.0%	21	
	Doctors	8.1%	17	
	Clinics	6.7%	14	
	Courses	5.2%	11	
	Professional training	2.9%	6	

TABLE 1. The Demographic Representations of the Respondents

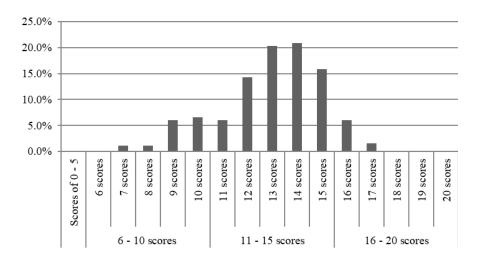


FIGURE 1. Overall Knowledge Scores

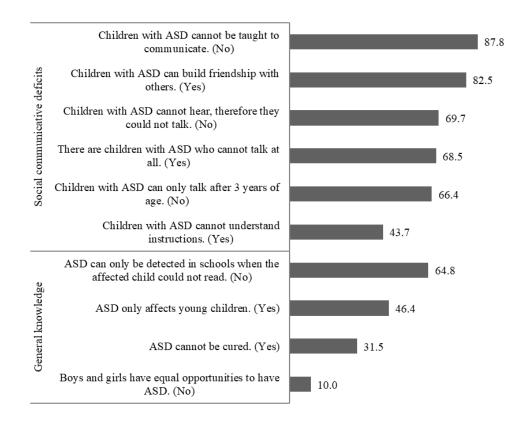


FIGURE 2. Knowledge about ASD characteristics

about the lifelong manifestations of ASD and the aspect of language impairments.

### KNOWLEDGE ON EDUCATION AND REMEDIATION

As shown in Figure 3, the majority of respondents could relate to the special education needs and prospects of students with ASD in schools. However, only 36.0% agreed that inclusive education was possible for these students. Pertaining to social communication and language remedial strategies, the vast majority of them could relate to the relevance of following the child's lead, such as using the things that the child likes to encourage him or her to talk (93.4%), and asking questions (91.9%). Comparatively, only two thirds of them could relate to the relevance of using common materials and adult imitation in stimulating children with ASD to communicate. Further, very few of them (6.6%) perceived the relevance of spontaneous incidental teaching. This set of findings revealed that even though the respondents could identify the general aspects of special education and remedial needs for young children with ASD, they were less able to relate to the contemporary methods of educating and remediating children with ASD, namely inclusive education and incidental teaching.

## CORRELATION BETWEEN THE SOURCE OF INFORMATION WITH KNOWLEDGE AND DEMOGRAPHIC PROFILES

The point-biserial correlation coefficient was used to examine the relationship between different aspects of ASD knowledge and sources of obtaining information about ASD, while chi-square analyses were used to examine the relationships between the selection of sources and respondents' demographic profiles. Table 2 summarizes the results for the top 10 sources identified by the respondents and the significant correlation results recorded. As shown in Table 2, it can be interpreted that the respondents' general knowledge about ASD was obtained from TV ( $r_{pb}$ = -.132, p<.05), books ( $r_{pb}$ =.130, p < .05) and school ( $r_{pb} = .146, p < .05$ ); while their knowledge about the social communicative deficits of ASD was predominantly obtained from TV ( $r_{pb}$  = -.129, p<.05), books  $(r_{\rm pb}=.116, p<.05)$  and social acquaintances, i.e., friends and neighbours ( $r_{pb}$ =.203, p<.05). On the other hand, they knew about the special education needs of ASD through brochures ( $r_{pb}$ =.118, p<.05) while they were aware of the social communicative remediation of ASD through the Internet  $(r_{ph}=.150, p<.05)$  and magazines  $(r_{ph}=.140, p<.05)$ .

Negative correlations were noted for the relationships between TV as the source of information and two

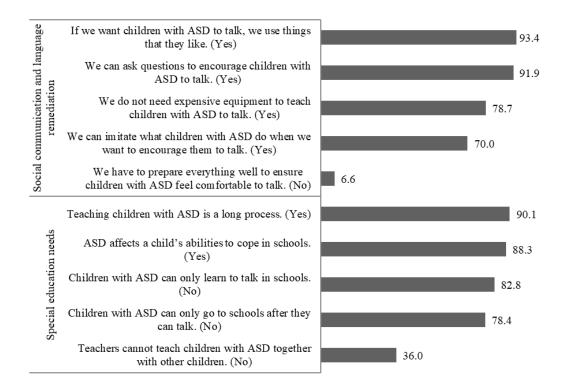


FIGURE 3: Knowledge about education and remediation

knowledge sub-scales, namely general knowledge ( $r_{pb}^{=}$  -.132, p<.05) and social communication and language deficits ( $r_{pb}^{=}$  -.129, p<.05). Pertaining to this, respondents who reported TV as the source of information were found to score lower in general knowledge (M=1.42, SD=.945) than those who did not (M=1.66, SD=.918). Similarly, respondents who reported TV as the source of information scored lower in knowledge about social communicative behaviors (M=4.07, SD=1.033) than those who did not (M=4.35, SD=1.099). The findings revealed the possibility that TV might actually have aversive effects on the respondents' knowledge about ASD characteristics. This raised the concern that TV might produce nonfactual information about ASD which lead to misconceptions about ASD.

As shown in Table 2, Chi-Square analyses revealed that significant relationships were recorded for four sets of demographic variables and sources of information: (1) respondents' age and having had known about ASD from brochure ( $\chi^2$ =14.605, p<.01), (2) respondents' occupation and having had known about ASD from brochure ( $\chi^2$ =10.126, p<.01), (3) respondents' gender and having had known about ASD from book ( $\chi^2$ =4.409, p<.05), and (4) respondents' education level and having had known about ASD from brochure ( $\chi^2$ =13.056, p<.05). The findings as summarised in Figure 4 provided a further insight that older respondents tended to obtain information about ASD mainly through brochure. For example, as many as 42.1% of those between 40-49 years old reportedly knew about ASD from brochure. At the same time, obtaining information about ASD from brochure is a popular option among educators, such as lecturers (28.1%) and teachers (27.3%). On the other hand, there were more females (27.5%) than males (14.3%) who have had learnt about ASD from books. Last but not least, having had learnt about ASD from TV was popular among respondents with certificate (100.0%) and diploma (71.4%) academic qualifications. This set of findings provided important insights to plan content-specific and cost-effective ASD awareness campaigns for people from different demographic backgrounds.

## DISCUSSION

A public survey of the knowledge on Autism Spectrum Disorder (ASD) of lay persons was conducted in Kuala Lumpur, Malaysia. The results showed that the knowledge of lay persons about speech and language deficits, education inclusion and the factual aspects of ASD is still limited. The majority of the respondents in this study could only relate to ASD as a category of children with special educational needs. However, many of them could not relate to the specific symptoms and manifestations of ASD. The findings indicated the urgency of disseminating factual knowledge about ASD to the general public in Malaysia.

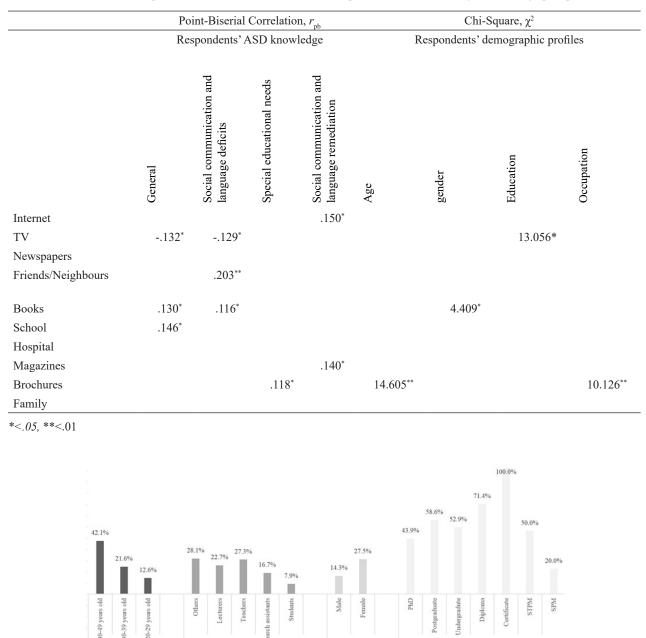


TABLE 2. Relationships between scores of information and respondents' ASD knowledge and demographic profiles

FIGURE 4. Knowledge about education and remediation

Gender group who learns

about ASD from book

Edu

who learnt about ASD from

From the insights obtained in the current survey, the mass media including the Internet, TV, and newspapers are the most suitable media to transmit information related to ASD. It is important that these media have to transmit accurate information about ASD.

up who learnt about ASD

from brochure

Occu

In the current study, the sample was skewed towards representing educators and academicians with higher levels of educational qualification due to the context in which the survey was conducted. Therefore, the findings from the current survey mainly reflected the knowledge of the elite community. The knowledge level of the general public is estimated to be lower when a more diversified sample is considered. This prediction is made since the evidence in the current study and past studies (Mitchell & Locke 2015; Holt & Christensen 2013) had proven that ASD knowledge is closely related to one's educational level. However, as profiled in the current study, academic qualification only explained for a small percentage of variance in knowledge scores. Hence, researchers such as Tipton and Blacher (2014) posited that it is unnecessary

on group who learnt about ASD from TV

to focus on any particular group during the dissemination of public knowledge about ASD.

On the other hand, it is more essential to focus on the source factors during the knowledge dissemination. Consistent with past studies, the TV media was identified as one of the most common sources of obtaining information about ASD (Holt & Christensen 2013). However, the current study offered the insight that the TV media had adverse effects on the knowledge related to ASD manifestations and deficits. As pinpointed by the mass media researchers, the TV media might portray the extreme representations of ASD as profoundly disabled persons or savants which lead to public misconceptions about ASD (Garner, Jones & Harwood 2015). Therefore, the authorities need to be aware that the TV media is not disseminating enough factual information about ASD.

To move forward, the general public requires more information related to the identification of ASD, including the behavioral symptoms, the medical manifestations, and the education and remedial needs of ASD. Such information is a crucial to pathway for early identification and remediation of ASD in early childhood, and also to ensure that opportunities of educational inclusion are available for children with ASD. The findings from the study also provided the insights that internet and TV are the two most popular information sources which the public obtained information about ASD. Specifically, females, older people and people in the academic professions tended to rely more on printed sources like books and brochures to obtain knowledge about ASD. On the other hand, people with lower academic qualifications tended to get information about ASD from TV. The findings highlighted the importance of duplicating knowledge about ASD in different sources and languages to meet the needs of different community members (Holt & Christensen 2013).

## CONCLUSION

The findings from this study revealed that the public knowledge of ASD is still low in Malaysia, and the leading media in Malaysia is not disseminating enough factual information about ASD. Continual efforts are warranted to improve public knowledge about ASD. In Malaysia and globally, with increased public knowledge about ASD, it is hoped that the general public can act as the collective guardians for children with ASD and their families to protect them from the violation of rights and the waste of time and money in non-evidence-based treatments. Besides that, increased public knowledge will also prevent overdiagnosis due to the increased awareness of ASD but not

understanding the actual manifestations and implications of ASD. In some places, false labelling of ASD might become commonplace for reasons of monetary benefits (Leonard, Dixon & Whitehouse 2010).

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