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Autism in East Malaysia: A Survey Among Parents of Children with ASD in Kota Kinabalu Sabah

Prescilla C. Apok, Norshidah Mohd Salleh

National University of Malaysia 43600 Bangi, Selangor
joannberyl@gmail.com. 0109330688

Abstract: The aim of this study is to understand the characteristics ASD children, past and present service utilization, parental stigma, and support networks received by families raising ASD children in Kota Kinabalu Sabah. A quantitative study was conducted on 44 parents of children with ASD using the Affiliate Stigma Scale and the Family Support Scale (FSS). In general, the children first show ASD symptoms at the average age of 28.1 months (SD 17.3) and the average age of diagnosis is 46 months (SD 23.4). The validity of the instruments in this study is high with the Cronbach's alpha value of 0.93 for stigma and 0.81 for family support. 56.8% children with ASD in this study have no-verbal ability or able to use single words. The findings show that the average age of children with ASD in this study is 7.7 years. The most common characteristic of ASD children is showing no response when their name is called, no eye contact, lack of speech ability compared other children of the same age, delayed speech, difficulty in interacting with others, and behavioral problems. Most diagnoses were done by psychiatrists and pediatricians. Occupational therapy is the most widely used therapy, followed by speech and language therapy, sensory integration therapy, and behavior al therapy. Behaviorists and psychiatrists are the commonly used specialists. Half of parents say they sometimes experience frustration when it comes to providing services for their children. Overall, the levels of stigma and family support network are low.

Keywords: autism (ASD); child characteristics perceive stigma; family support network

INTRODUCTION

Autism Spectrum Disorder (ASD)

Autism Spectrum Disorder (ASD) or Autism is two common terms that represent a cluster of complex brain growth disorders. The number of children diagnosed with ASD has gradually grown over the years and this might be due to the changes in diagnostic criteria, change of policy and practice and increasing knowledge and understanding of this disorder (McPartland, J. C., Reichow, B., & Volkmar, F. R., 2012).

The dramatic increase of ASD diagnostics in the last two decades has driven many parents to become caregivers and their roles growing as their children move from childhood to adolescence and later into adulthood (Marsack, C. N., 2016). According to recent studies, parents of children with ASD have reported greater challenges than parents of normal children or those diagnosed with other types of developmental disorders (Ilias, K., Cornish, K., Kummar, A. S., Park, M. S. A., & Golden, K. J., 2018; Picardi, A., Gigantesco, A., Tarolla, E., Stoppioni, V., Cerbo, R., Cremonte, M., Alessandri, G., Lega, I. & Nardocci, F., 2018; Porter, N., & Loveland, K. A., 2019).

In recent decades, there is a hike in the global awareness towards autism and the number of autism related research has increased in Malaysia. However, despite the increasing number of studies on autism in Malaysia, there is still a lack of studies on the documentation of life experiences and needs of families raising autism children. This indicates the need to conduct a research on the experiences of parents raising ASD children, including the process of diagnosis, selection of specialists and therapists, and the types of social support provided to these families.

A study conducted in Southeast Europe, specifically Albania reported that Autistic children have little access to social services and inclusive education. Children in the country also face great barriers in accessing these services. (Daniels, A. M., Como, A., Herguner, S., Kostadinova, k., Stosic, J., and Shih, A., 2017). Furthermore, there is also a lack of comprehensive studies on ASD in countries like Bulgaria (Levterova, D., 2010).

There are several studies conducted on the stress level and quality of life of parents with autistic children in Malaysia (Abdul Manan A., A.I., Amit, N., Said, Z. & Ahmad, M., 2018; Ilias, K. et al., 2018; Lee, J. X., Ong, S. I., Lee, V. Y.; dan Fairuz Nazri A. R., 2017; Wei, W., Tze, L., Goh, J., Oei, T. P. S., & Sung, M., 2015). However, there is still little understanding of the characteristics of ASD children in relation to diagnosis, service use experience, and the family support network received by parents with ASD children and such studies are particularly rare in East Malaysia.

Therefore, the purpose of this study is to examine the experience of parents with ASD children, parents' perception of the characteristics of ASD children, the stigma and social support received by parents with ASD children in Kota Kinabalu Sabah. The research is intended to gather relevant information and can serve as a guide for the public, especially educators and mental health professionals, to better understand the challenges facing families with ASD children, and to help build and strengthen support systems to help families in need.

METHODOLOGY

Study Sample

Due to the lack of accurate statistical information on the number of people with ASD in Kota Kinabalu Sabah, random sampling approach was used in this study. The sets of questionnaire were distributed in several private schools and therapy centers throughout Kota Kinabalu. An online version of the questionnaire was distributed to members of the Parents Support Group "*Anak-Anak Syurga".* Parents who agreed to participate in the study filled out the questionnaire form manually and online. The option of filling out the online was given to parents who want to get involved in the research but are still hesitant to fill out the manual questionnaire. In addition to the parents of the Parents Support Group "*Anak-Anak Syurga*", the study's sample consisted of parents of children attending four private schools in Kota Kinabalu, Taska Mesra Cheshire, Seri Mengasih Centre, the Matahari Learning Centre, the Stepping Stone Education Centre, De Loving Early Intervention Centre, and the Nelson Occupational Therapy Centre.

Ethical Considerations

To address the possible ethical issues prior to distributing the questionnaire, written consents were sent to the headmasters/principals of the private schools involved. A letter verifying that the researcher is a student of the National University of Malaysia, as well as letter of permission to collect data were included in the application form for the study. Once consent was obtained from each school principal, the manual questionnaire was distributed through the instructor. Permission has also been granted to distribute questionnaires through google form. A research note was distributed to the study participants to inform them that the participation in this questionnaire is entirely voluntary and that there will be no punishment for refusing to participate. Participants may withdraw at any time and are not bound to any rules.

Measures

A research involves the use of several instruments as tools to test the research hypotheses. The instrument used in this study helps the researcher to understand the process of childhood diagnosis and was adapted from the Interactive Autism Network's (IAN) Child with ASD Questionnaire (IAN Community 2016). Current diagnosis of ASD, current age, and verbal ability were adapted from the COST-ESSEA study (T. Charman; personal communication, 2012). Questions regarding the age of the child when the characteristic disorder was detected, the early diagnosis, the earliest known diagnosis, and the age of diagnosis were adapted from the Survey of Pathways to Diagnosis and Services (CDC, 2015) (Daniels, A. M, et al., 2017). In addition, the main instrument used is the Affiliate Stigma Scale (Mak & Cheung, 2008) to assess self-stigma or perceive stigma. The Family Support Scale (FFS) (Dunst, C. J., Jenkins, V., & Trivette, C., M., 1984) is used to assess the social support received by the families in this study. Basic descriptive statistics will be presented for the demographic variables and the primary study variables. For the primary study variables, Shapiro Wilk's test used to assess the data normality.

FINDINGS AND DISCUSSION

Findings

Background of Parents of Children with ASD

A total of 44 parents with ASD children were included in this study. Table 1 shows the demographic characteristics of parents of ASD children. The majority of parents (77.3%) in this study are aged 31-40 years. The majority of the study participants (59.1%) are biological mothers while the remaining (40.9%) are biological fathers. In terms of the ethnic groups distribution, the majority (59.1%) of the participants are from Kadazan/Dusun ethnic group followed by other Bumiputera (15.9%), Malay (11.4%), Bajau and other ethnic with 4.5%, respectively, as well as Chinese and Indian with 2.3%, respectively. Almost half (45.5%) of parents have a Bachelor's degree and only a minority (6.8%) of parents has SPM level education. About 50.1% reported that they earn a monthly income exceeding RM4500 (approximately 1086 USD) while 29.5% earn a monthly income below RM3000 (approximately 724 USD). Most ASD children (81.8%) have at least one or two siblings (68.2%) while 13.6% have 3 or 4 or more siblings. To be specific, 79.5 percent of the parents have one child with disability, 15.9% have two children with disability and 4.5% have more than 2 children with disability.

The Characteristics of Children with ASD

Table 2 details the characteristics of ASD children. 47.7% of the ASD children involved in this study were aged between 7-12 years old, 45.5% were aged 1-6 years old, and 6.8% were aged 18 years and above. The majority of the children are male (77.3%) and only 22.7 percent are female.

The verbal ability of the ASD children varied from non-verbal (29.5%), use single words only (27.3%), uses-two or three-word phrases (18.2%), uses sentences with / more than 4 words (20.5%), and able to using complex sentences (4.5%). The mean age for the ASD children overall was 7.7 years (See Table 2).

The mean age of first concern is 28.1 months (SD 17.3), which indicates that most parents are well aware of their children's disorder before they reach 2 and half years old.

Table 1: The demography of parents with ASD children in Kota Kinabalu Sabah

Parents' Background	Percentage (%)
Age (years)	
21-30	2.3 %
31-40	77.3%
41-50	15.9%
51-60	4.5%
Gender	
Male	40.9%
Female	59.1%
Number of Children	
1	18.2%
2	36.4%
3	31.8%
4	9.1%
> 5	4.5%
Number of Children with Disability	
1	79.5%
2	15.9%
>2	4.5%
Education Background	
SRP/PMR (Lower Cert. of Education / Lower Secondary Assesment	-
SPM (Malaysian Cert. of Education)	6.8%
STPM (Malaysian Higher School Cert.) / Diploma	29.5%
Bachelor's Degree	45.5%
Master's Degree	18.2%
Doctors of Philosophy (PHD)	-
Monthly Income (RM)	
1500 – 3000	29.5%
3000 – 4500	20.5%
4500 – 6000	20.5%
6000 – 7500	11.4%

7500 and above	18.2%

Table 2. Parents-reported characteristics of children with ASD in Kota Kinabalu Sabah

Ciri Kanak-Kanak	Mean (SD)/%
Child age (years)	7.7 (SD 4.7)
Child gender (%)]	
Male	77.3%
Female	22.7%
Current verbal ability (%)]	
Non-verbal	29.5%
Uses single words only	27.3%
Uses two-or-three word phrases	18.2%
Uses sentences with / more 4 words	20.5%
Uses complex sentences	4.5%
Age at first concern (months) mean (SD)	28 (SD 17.3)
Nature of first concerned N (%)]	
Medical problem	9 (20.5)
No eye contact	33 (75)
No response to name	35 (80)
Did not understand non-verbal Communication	14 (32)
Behavioral difficulties	20 (45)
Gross motor problems	6 (14)
Delayed speech	27 (61)
No speech	17 (39)
Did not talk like other children same Age	31 (70.5)
Lost speech or other skills	11 (25)
Did not understand verbal Communication	18 (41)
Fine motor problems	5 (11)
Difficulty interacting with others	23 (52)
Interested in sameness	14 (32)
Difficulty learning new skills	8 (18)
Difficulty learning new things	8 (18)
Unusual gestures/movements	16 (36)
Age at diagnosis (months) mean (SD)	46 (SD 23.4)
Current diagnosis (%)	
Autism/autistic disorder	70%
ASD	29.5%
Diagnosis person (%)	
Psychiatrist	37%
Team of professionals	9%
Neurologist	34%
Pediatric specialist	11%
Other/ multiple	8%
Distance to diagnosis (%)]	
<25 km	63.6%
25 and 50 km	36.4%
50 and 100 km	-
>100 km	-
Travelled outside the country	-

The first person to detect autistic symptoms shown by their children is the mother (59%). According to the parents, the most noticeable features of a child's disorder are not responding when their name was called (80%); lack of eye contact (75%); unable to speak at the same level with their peers (70.5%); speech delay (61%); difficulty to interact with other people (52%); behavioral problems (45%); unable to understand verbal communication (41%); and no speech (39%). Children with ASD showed unusual gestures/movements (36%);

preferences of repetitive actions (interested in sameness) and unable to understand non-verbal communication respectively 32%; lost speech or other skills (25%); difficulty to learn new skills or new things respectively 18%; and have a weak motor (14%) and fine motor skills (11%). The mean age for diagnosis is 46 months (SD 23.4).

Most of the ASD children are diagnosed before they are 4 years old. Majority of the diagnosis is Autistic disorder/ Autism (70%) and the remaining is ASD (29.5%). None of this study's participants were diagnosed with Asperger's, PDD and PDD-NOS disorders. Most diagnosis were performed either by a psychiatrist (37%), a neurologist (34%), a pediatric specialist (11%), team of professionals (9%), and by other/multiple medical practitioners (8%). Most of the participants travelled less than 25km to be diagnosed (63.6%) while the remaining (36.4%) travelled more than 25km to be diagnosed.

Table 3. Past and present service and provider utilization of children with ASD in Kota Kinabalu, Sabah

Past and present service and provider utilization	N (%)
Past service	
Behavioral therapy	19 (43)
Sensory integration therapy	22 (50)
Occupational therapy	37 (84)
Physical therapy	8 (18)
Speech and language therapy	34 (77)
Medication	6 (14)
Present service	
Behavioral therapy	16 (36)
Sensory integration therapy	22 (50)
Occupational therapy	33 (75)
Physical therapy	6 (14)
Speech and language therapy	30 (68)
Medication	6 (14)
Past provider	
Audiologist	21 (50)
Behaviorist	10 (23)
Neurologist	5 (11)
Nutritionist	3 (7)
Psychiatrist	22 (50)
Psychologist	7 (16)
Current provider	
Audiologist	7 (16)
Behaviorist	12 (27)
Neurologist	3 (7)
Nutritionist	4 (9)
Psychiatrist	21 (50)
Psychologist	6 (14)

Past and Present Service Utilization

The past and present services reported for ASD children are presented in detail in Table 3. In this regard, 43% received behavioral therapy services in the past while 36% are currently attending behavioral therapy. Meanwhile, 50% of the participants have attended sensory integration therapy in the past and at present; and 84% underwent occupational therapies while 75% attend occupational therapies at present. 18% attended physical therapy in the past as opposed to 14% at present while 77% attended language and speech therapy in the past and at present, 68%; and 14% used medication based treatment in the past and at present, respectively. From this result, occupational therapy is the most widely used therapy, followed by language and speech therapy, followed by sensory integration therapy and behavioral therapy. The least used therapies are physical therapy and medication-based treatment.

In regard to specialist services, 50% of the participants consulted audiologists in the past while only 16% consult audiologists at present; 23% visited behaviorist in the past and 27% visit behavioral experts at present while only 11% visited neurologists in the past and 7% visit neurologists at present. Moreover, 7% and 9% visited nutritionists in the past and at present, respectively and 50% of the parents visited psychiatrist in the past and at present. Lastly, 16% of the participants consulted psychologists in the past and 14% consult psychologists at present. The result shows that most parents consulted audiologists in the past but the number declined drastically at present. In addition, the help of psychiatrists is the most demanded so far and that the demand for behaviorists and nutritionists are on the rise while the demand for services offered by neurologists and psychologists are declining.

Parents' Needs and Perceptions

The current study provides the information of past 12 months access and unmet needs for services (data not shown). 11% of the parents said they face difficulties in getting services because they are not eligible for the services, while 16% mentioned that they are not able to access the services as the centers are located far from them. 36% agreed that they need to wait a long time to access treatment as well as due to the cost of getting these treatments, respectively. Half of the parents (50%) said that they sometimes feel frustrated in their efforts to get services for their children; while 23% said they always feel frustrated in their efforts to get services for their children. Only 14% responded that they never experienced disappointment in getting services for their children.

Table 4. Perceive stigma among parents of children with ASD children in Kota Kinabalu Sabah

Perceive Stigma	Percentage (%)
I feel helpless for having a child with autism	
Strongly disagree	34.1
Disagree	40.9
Agree	20.5
Strongly agree	4.5
I worry if other people know that I have a child with autism	
Strongly disagree	54.5
Disagree	36.4
Agree	4.5
Strongly agree	4.5
Other people will discriminate against me because I have a child with autism	
Strongly disagree	36.4
Disagree	43.2
Agree	13.6
Strongly agree	6.8
Having a child with autism imposes a negative impact on me	
Strongly disagree	40.9
Disagree	43.2
Agree	9.1
Strongly agree	6.8

Family Support Network

The family support network illustrated in Table 5 lists several types of support received by families raising ASD children. Family support is divided into 4 sections, "Informal Kinship", "Spouse/Partner Support; "Social Organizations", "Formal Kinship", and "Professional Services".

Informal Kinship include friends, spouse's/partner's friends, own children, other parents, and church. 9% of the parents believe that friends are very helpful and extremely helpful, while 27.3% believe that friends are generally helpful, 36.4% agree that they are sometimes helpful. On the other hand, 11.4% percent of the parents think that friends are totally unhelpful while 15.9% reported that support from their friends is not available. Furthermore, 9.1% of the parents agreed that their own children are the most helpful, extremely helpful (20.5%), generally helpful (13.6%), sometimes helpful (25%). Meanwhile, 2.3% respondents that their other children are totally unhelpful and do not offer any help (29.5%). Besides that, 6.8% of the parents responded that the other parent is most helpful, 13.6% of the other parent is very helpful, 47.7% is sometimes helpful, and only 2.3% responded that the other parents are totally unhelpful (2.3%). 45.5% of parents received support from the religious group while 54.6% do not get any support from the religious group.

Spouse/Partner Support includes support from their own spouse/partner, spouse/partner parents, and spouse/partner relatives/kin. 31.8% agree that their own spouse/partner is extremely helpful and only 4.5% stated that their spouse is not helpful at all. In regards to the support from their spouse's parents, only 18.2% of the respondents agree that their parents in law are the most helpful while 27.3% believe that they are very helpful, generally helpful (13.6%), sometimes helpful (20.5%), not helpful at all (6.8%) and not available (13.6%). On the other hand, respondents believe that their spouse relatives/kin are extremely helpful (6.8%), very helpful (15.9%), generally helpful (18.2%), and sometimes helpful (29.5); while 13.6% responded that their spouse's relatives/kin never helped.

Table 5: Family support network for parents with ASD children in Kota Kinabalu, Sabah, Malaysia.

Family Support	**Percentage (%)**					
How helpful has each of the following been to you in terms of raising your child?						
	Not available	Not at all helpful	Sometimes helpful	Generally helpful	Very helpful	Extremely helpful
Factor I						
Informal Kinship						
Friends	15.9	11.4	36.4	27.3	4.5	4.5
Spouse’s/Partner’s Friends	31.8	15.9	27.3	18.2	4.5	2.3
Own Children	29.5	2.3	25	13.6	20.5	9.1
Other Parents	29.5	2.3	47.7	13.6	6.8	-
Church	45.5	9.1	27.3	11.4	6.8	-
Faktor II						
Spouse/Partner Support						
Spouse/Partner	-	4.5	20.5	13.6	29.5	31.8
Spouse/Partner Parents	13.6	6.8	20.5	13.6	27.3	18.2
Spouse/Partner Relatives/Kin	15.9	13.6	29.5	18.2	15.9	6.8
Factor III						
Sosial Organizations						
Social Groups/Clubs	27.3	6.8	29.5	20.5	13.6	2.3
Parents Groups	20.5	6.8	40.9	22.7	6.8	2.3
School /Day Care	-	-	15.9	11.4	47.7	25
Co-Workers	31.8	4.5	31.8	22.7	9.1	-
Factor IV						
Formal Kinship						
Relatives/Kin	9.1	9.1	27.3	25	22.7	6.8
Own Parents	15.9	4.5	20.5	20.5	25	13.6
Factor V						
Professional Services						
Early Intervention Programs	4.5	2.3	22.7	27.3	34	9.1
Professional Helpers	11.4	4.5	20.5	11.4	29.5	22.7
Family/Child’s Physician	20.5	4.5	25	18.2	25	6.8
Professional Agencies	18.2	2.3	27.3	27.3	20.5	4.5

The "Social Organizations" family support network consists of social groups/clubs, parent group, schools/day care centers and co-workers. 2.3% said that social groups/clubs are extremely helpful, very helpful (13.6%), generally helpful (20.5%), sometimes helpful (29.5%), totally unhelpful (6.8%) and not available (27.3%). 2.3% believe that the parents' group is most helpful, very helpful (6.8%), generally helpful (22.7), sometimes helpful (40.9%), totally unhelpful (6.8%) and not available (20.5%). In regard to schools or day care, 25% of parents said this type of support is extremely helpful, very helpful (47.7%), generally helpful (11.4%), and sometimes helpful (15.9%). Furthermore, the respondents agree that co-workers are extremely helpful (9.1%), generally helpful (22.7%), sometimes helpful (31.8%), totally unhelpful (4.5%) and not available (31.8%).

The "Formal Kinship" is composed of relatives/kin and own parents. 6.8% of the respondents mentioned that their relatives/kin are really helpful, very helpful (22.7%), generally helpful (25%), sometimes helpful (27.3%). Meanwhile, 9.1% of parents think that their relatives are totally unhelpful and not available (9.1%), respectively. Furthermore, 13.6% agree that their own parents are extremely helpful, very helpful (25%), generally helpful (20.5%), sometimes helpful (20.5%) while 4.5% think that their own parents are totally unhelpful and 15.9% is not available.

Professional Services include early intervention centres, professional helpers, family physicians, and professional agencies. 34% of the respondents agree that early intervention program for children is very helpful "Professional Services" followed by consultations with a professional helper (social workers, therapists, teachers etc.) at 29.5%, family doctors (25%), and specialist agencies (20.5%). Overall, the highest support received is from the professional helpers (social workers, therapists, teachers etc.) with 22.7%.

Discussion

Previous research in Southeast Europe provides a valuable picture of families affected by ASD including characteristics of children with ASD, professional services received in past and present, as well as the challenges and needs of families with ASD (Daniels, A.M., et al., 2017). It is hoped that this study could provide comprehensive overview of families caring for and raising ASD children in East Malaysia as an effort to address the needs of families affected by ASD.

This study found that the mean age of diagnosis is 46 months (SD 23.4). Previous studies have also shown that the age of diagnosis is after 3 years. Thus, the mean diagnosis age in this study is consistent with the mean age of diagnosis of 46.6 months in Bulgaria (Daniels, A. et al., 2017); 46.59 months (SD 13.45) in Ireland; 47.88 months (SD 12.37) in Hungary; dan 48.44 months (SD 10.98) in Germany (Salomone, E., Charman, T., McConachie, H., and Warreyn, P., 2015).

The age of diagnosis is influenced by factors such as family structure and frequency of family members' interactions. According to Sicherman, N., Loewenstein, G., Tavassoli, T., & Buxbaum, J. D. (2018), interactions with grandparents reduced the age of diagnosis by 5 months. In addition, children whose parents had concerns about their child’s nonverbal communication or unusual gestures/movements received an earlier diagnosis than children whose parents did not have these specific (Zablotsky, B., Colpe, L. J., Pringle, B. A., Kogan, M. D., Rice, C., & Blumberg, S. J., 2017).

A recent found that early ASD diagnosis was associated with epilepsy-related conditions, whereas a later diagnosis was associated with psychiatric conditions study (Failla, M. D., Schwartz, K. L., Chaganti, S., Cutting, L. E., Landman, B. A., and Cascio, C. J., 2019). According to Petrou, A. M., Parr, J. R., & McConachie, H. (2018), male received diagnosis an average of one year earlier than female. A study in Scotland found that girls continue to be referred and diagnosed later than boys and that this delay occurs prior to referral for specialist assessment (Rutherford, M., McKenzie, K., Johnson, T., Catchpole, C., O’Hare, A., McClure, I., Murray, A., 2016). This finding is supported by Wang, K., Wang, C., Guo, D., Wijngaarden, M., & Begeer, S. (2018) which found lower diagnosis age for girls in the Chinese sample.

In this regard, diagnosis after a child reaches 3 years old is considered as a late diagnosis. In this light, diagnosis delays are mostly due to low parental education levels, low socioeconomic status, limited ASD knowledge, and poor knowledge on health care (Montiel-Nava, C., et al., 2017). Early diagnosis of Autism Spectrum Disorders is considered as best practice as it could improve the children’s access to early intervention. Clark, MLE, Vinen, Z., Barbaro, J., Dissanayake, C. (2018) argued that children who are diagnosed earlier than 3 years old usually have more intervention, show greater verbal and cognitive abilities in school age, are more likely to attend mainstream schools and require less ongoing support than children who are diagnosed later. Early diagnosis is important and may promote more positive outcomes at school-age because of the increased opportunities for early intervention.

Based on the previous study, there is a big difference when the child diagnosed before the age of 3 than children who are diagnosed later. In relation to the delay of diagnosis, a study by Montiel-Nava, C., Chacin, J. A., Gonzalez-Avila, Z. (2017) on Latino children diagnosed after 4 years of age showed more serious autistic symptoms and lower IQ compared to ASD children with earlier diagnosis. However, the mean age of diagnosis of 46 months in this study is consistent with previous studies. The current study was conducted in urban areas where awareness of autism is relatively good, and the average age of diagnosis is below 48 months.

Early detection of the features of ASD enables early diagnosis. The current study reported a high percentage (70.5%) of children with ASD showed limited verbal communication / non-verbal ability. This is in line with the previous studies that found that children with significant difficulties in communication often receive an earlier diagnosis (Zablotsky, B., Colpe, LJ, Pringle, BA, Kogan, MD, Rice, C., and Blumberg, S.J. , 2017).

This study found that the age of first concern is 28 months (SD 17.3). This is in line with studies in India (K, D. P., Srinath, D. S., Seshadri, D. S. P., Girimaji, D. S. C., & Kommu, D. J. V. S., 2017), Southeast Europe (Daniels, A. et al., 2017), and in the U.S. (Zablotsky, B., Colpe, L., Pringle, B. A., Kogan, M. D., Rice, C., & Blumberg, S. J., 2017). However, age of first concern not necessarily leads to early diagnosis. For instance, current study showed 18 months difference between the age of first concern and the age of diagnosis.

The level of stigma towards families with ASD children in Kota Kinabalu, Sabah is not relatively high. This finding is in line studies in Southeast Europe also reported that many parents or guardians feel helpless in raising ASD children and think that others will discriminate against their children for having ASD (Daniels, A. et al., 2017). Studies on parents with austistic children in Asian countries found high stigma towards caregivers of autistic children in China and India (Lovell, B., and Wetherell, M. A., 2018; Patra, S. and Patro, B. K., 2019).

In India, high stigma scores could be associated with low self-esteem and anxiety among caregivers of ASD children. In contrast, not all stigma scores were high, as parents continue their efforts to find and provide care for their children and only a small percentage do not dare go out with their autism child or limit their involvement to autism-related activities (Patra, S. and Patro, BK, 2019).

Studies on affiliated stigma in the US and the UK have also found that single parents who act as caregivers for disabled children experience higher stigma. Unsurprisingly, the single caregivers might not have the support of the spouse. On the other hand, the current study found that the level of stigma among the parents is lower. This could be due to the fact that this study only involved parents from urban areas and most or almost all of the parents have sufficient awareness and knowledge of their children's disability and help their children to overcome stigma. Furthermore, the participants of this study, for the most part, over 90% are non-single parents and receive the support of their spouse.

Other studies have shown that stigma levels can be reduced through intervention. These studies have emphasized how guardianship stigma is reduced through formal education and knowledge of such disorders (Elafros, M. A., Sakubita-Simasiku, C., Atadzhanov, M., Haworth, A., Chomba, E., Birbeck, G. L., 2013). In addition, government and community-based organizations need to maximize the use of the internet as a source of information, particularly social media to increase awareness and acceptance of ASD (Daniels, A. et al., 2017).

Previous studies have linked social support with better well-being among parents of special needs children (Minnes, P., Perry, A., and Weiss, J. A., 2015). Support is something that is needed throughout the life of a family raising ASD children. Low support or unmet needs are associated with emotional distress. In the current study, the highest support came from social organizations namely schools and day care centers; followed by spousal support (spouse / spouse), specialist help, parent's spouse, early intervention program, and support from the parents themselves. This is in line with previous studies that indicated that support from family members, especially one's partner, is one of the most important forms of support because a partner is the first individual to reach out for support, provide physical or emotional support (Robinson, S., Weiss, J. A., Lunsky, Y., and Quellette-Kuntz, H., 2016).

Support from parents and spouse parents also helped to reduce the burden. In this regard, despite the importance of support from both parents, such support might not be sufficient because as parents and grandparents will grow older and gradually, their physical support capacity will become limited due to sickness and old age. Other support is needed to help them ease the burden in the future (Robinson, S., et al., 2016).

There are several limitations to this study. First, the sample of this study was chosen by using simple random sampling and limited to the Kota Kinabalu area. This sample may also be insufficient compared to the actual population. Thus, the findings cannot be generalized to all parents with ASD children in Sabah. Second, it is possible that the respondents in the study provided feedback that is less honest without realizing it as they provide feedback that they feel as appropriate rather than expressing their own feeling. This could be due to cultural factors.

Furthermore, some respondents might rely on their existing knowledge to respond to the questions and this could reduce the accuracy of the answer. They may be reluctant to provide the most accurate and honest answer. In addition, it is difficult to obtain a more diverse sample of the study as not all parents or administrators in the schools are open about their children's ASD. Furthermore, they are some centers that refused to participate in this study as they believe that this study will violate the privacy rights of the parents and their children. Consequently, the researchers were unable to convince some parents to participate in this study.

CONCLUSION

Overall, the findings of the current study are similar with the previous studies, specifically in terms of the mean age of diagnostics, characteristics of children with ASD and the mean age of diagnosis. The difficulty in obtaining specialist treatment and therapies also not at the lowest level even though some parents sometimes have difficulty in getting specialist services and therapies. The level of awareness and acceptance of autism children is considered as good as the study was conducted in the urban area of Kota Kinabalu, which is the state capital of Sabah. Another significant finding is that parental stigma is at a low level and schools and day care centers are the most important sources of support network available to the parents. Although the current study was limited to the Sabahan context in the urban area, this finding will extend our knowledge related to experience of the families raising a child with ASD in diverse social-cultural contexts. Future research could extend the current study by doing more research widely in rural areas in East Malaysia.

REFERENCES

ABDUL MANAN, A. I., AMIT, N., SAID, Z., & AHMAD, M. (2018). The Influences of Parenting Stress, Children Behavioral Problems and Children Quality of Life on Depression Symptoms Among Parents of Children with Autism: Preliminary Findings. *Jurnal Sains Kesihatan Malaysia*, *16*(si), 137–143. https://doi.org/10.17576/jskm-2018-19

Clark, M. L. E., Vinen, Z., Barbaro, J., & Dissanayake, C. (2018). School Age Outcomes of Children Diagnosed Early and Later with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, *48*(1), 92–102. https://doi.org/10.1007/s10803-017-3279-x

Daniels, A. M., Como, A., Hergüner, S., Kostadinova, K., Stosic, J., & Shih, A. (2017). Autism in Southeast Europe: A Survey of Caregivers of Children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, *47*(8), 2314–2325. https://doi.org/10.1007/s10803-017-3145-x

Elafros, M. A., Sakubita-Simasiku, C., Atadzhanov, M., Haworth, A., Chomba, E., & Birbeck, G. L. (2013). Stigma and psychiatric morbidity among mothers of children with epilepsy in Zambia. *International Health*, *5*(4), 288–294. https://doi.org/10.1093/inthealth/iht028

Failla, M. D., Schwartz, K. L., Chaganti, S., Cutting, L. E., Landman, B. A., dan Cascio, C. J., (2019). Characterizing co-occurring conditions by age at diagnosis in autism spectrum disorders. 0–34.

Haziq, M., & Akma, N. (2019). Cabaran Ibu Bapa Bersama Kanak-Kanak Kecelaruan Spektrum Parents Challenges With Children Autism Spectrum Disorders (Asd): Literature Review, *4*(1), 33–43.

Ilias, K., Cornish, K., Kummar, A. S., Park, M. S. A., & Golden, K. J. (2018). Parenting stress and resilience in parents of children with autism spectrum disorder (ASD) in Southeast Asia: A systematic review. *Frontiers in Psychology*, *9*(APR). https://doi.org/10.3389/fpsyg.2018.00280

K, D. P., Srinath, D. S., Seshadri, D. S. P., Girimaji, D. S. C., & Kommu, D. J. V. S. (2017). Lost time—Need for more awareness in early intervention of autism spectrum disorder. *Asian Journal of Psychiatry*, *25*, 13–15. https://doi.org/10.1016/j.ajp.2016.07.021

Lovell, B., & A. Wetherell, M. (2018). Caregivers' characteristics and family constellation variables as predictors of affiliate stigma in caregivers of children with ASD. *Psychiatry Research*, *270*(February), 426–429. https://doi.org/10.1016/j.psychres.2018.09.055

Mak, W. W. S., & Kwok, Y. T. Y. (2010). Internalization of stigma for parents of children with autism spectrum disorder in Hong Kong. *Social Science and Medicine*, *70*(12), 2045–2051. https://doi.org/10.1016/j.socscimed.2010.02.023

McPartland, J. C., Reichow, B., & Volkmar, F. R. (2012). Sensitivity and specificity of proposed DSM-5 diagnostic criteria for autism spectrum disorder. *Journal of the American Academy of Child and Adolescent Psychiatry*, *51*(4), 368–383. https://doi.org/10.1016/j.jaac.2012.01.007

Minnes, P., Perry, A., & Weiss, J. A. (2015). Predictors of distress and well-being in parents of young children with developmental delays and disabilities: The importance of parent perceptions. *Journal of Intellectual Disability Research*, *59*(6), 551–560. https://doi.org/10.1111/jir.12160

Montiel-Nava, C., Chacín, J. A., & González-Ávila, Z. (2017). Age of diagnosis of autism spectrum disorder in Latino children: The case of Venezuelan children. *Autism*, *21*(5), 573–580. https://doi.org/10.1177/1362361317701267

Patra, S., & Kumar Patro, B. (2019). Affiliate stigma among parents of children with autism in eastern India. *Asian Journal of Psychiatry*, *44*(July), 45–47. https://doi.org/10.1016/j.ajp.2019.07.018

Petrou, A. M., Parr, J. R., & McConachie, H. (2018). Gender differences in parent-reported age at diagnosis of children with autism spectrum disorder. *Research in Autism Spectrum Disorders*, *50*(January), 32–42. https://doi.org/10.1016/j.rasd.2018.02.003

Robinson, S., Weiss, J. A., Lunsky, Y., & Ouellette-Kuntz, H. (2016). Informal Support and Burden among Parents of Adults with Intellectual and/or Developmental Disabilities. *Journal of Applied Research in Intellectual Disabilities : JARID*, *29*(4), 356–365. https://doi.org/10.1111/jar.12184

Rutherford, M., McKenzie, K., Johnson, T., Catchpole, C., O'Hare, A., McClure, I., … Murray, A. (2016). Gender ratio in a clinical population sample, age of diagnosis and duration of assessment in children and adults with autism spectrum disorder. *Autism*, *20*(5), 628–634. https://doi.org/10.1177/1362361315617879

Salomone, E., Charman, T., Mcconachie, H., & Warreyn, P. (2016). Child's verbal ability and gender are associated with age at diagnosis in a sample of young children with ASD in Europe. *Child: Care, Health and Development*, *42*(1), 141–145. https://doi.org/10.1111/cch.12261

Sicherman, N., Loewenstein, G., Tavassoli, T., & Buxbaum, J. D. (2018). Grandma knows best: Family structure and age of diagnosis of autism spectrum disorder. *Autism*, *22*(3), 368–376. https://doi.org/10.1177/1362361316679632

Wang, K., Wang, C., Guo, D., van Wijngaarden, M., & Begeer, S. (2018). Children with autism spectrum disorder from China and the Netherlands: Age of diagnosis, gender and comorbidities. *Research in Autism Spectrum Disorders*, *54*(July), 76–82. https://doi.org/10.1016/j.rasd.2018.07.004

Xiang Neik, T. T., Lee, L. W., Low, H. M., Kok Hwee Chia, N., & Chee Keong Chua, A. (2014). Prevalence, diagnosis, treatment and research on autism spectrum disorders (ASD) in Singapore and Malaysia. *International Journal of Special Education*, *29*(3), 1–10.

Zablotsky, B., Colpe, L. J., Pringle, B. A., Kogan, M. D., Rice, C., & Blumberg, S. J. (2017). Age of parental concern, diagnosis, and service initiation among children with autism spectrum disorder. *American Journal on Intellectual and Developmental Disabilities*, *122*(1), 49–61. https://doi.org/10.1352/1944-7558-122.1.49

Zwaigenbaum, L., Duku, E., Fombonne, E., Szatmari, P., Smith, I. M., Bryson, S. E., … Bruno, R. (2019). Developmental functioning and symptom severity influence age of diagnosis in Canadian preschool children with autism. *Paediatrics and Child Health (Canada)*, *24*(1), E57–E65. https://doi.org/10.1093/pch/pxy076