PREVALENCE, DIAGNOSIS, TREATMENT AND RESEARCH ON AUTISM SPECTRUM DISORDERS (ASD) IN SINGAPORE AND MALAYSIA

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The prevalence of autism is increasing globally. While most of the published works are done in the Western and European countries, the trend in autism research is shifting towards the Asian continent recently. In this review, we aimed to highlight the current prevalence, diagnosis, treatment and research on Autism Spectrum Disorders (ASD) in Singapore and Malaysia. Based on database searches, we found that the awareness about autism among lay and professional public is higher in Singapore compared to Malaysia. The special education system and approach towards autism treatment is also different between both societies although the culture is similar and the geographic location is close. Main findings and implications were discussed in this review. The lack of study on autism prevalence in this part of the world commands a critical need for further research. Perhaps more collaborative work between both countries could be done to expand the knowledge in autism.

Autistic Spectrum Disorder (ASD) is a type of neurodevelopmental disorder affecting the mental, emotion, learning and memory of a person (McCary et al., 2012). According to the Diagnostic and Statistical Manual of Mental Disorders Fourth Edition (DSM-IV) (American Psychiatric Association, 2000), ASD is characterized by three features. Firstly, impairment of social interaction, which includes but not limited to impairment in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body postures and gestures to regular social interaction. Secondly, impairment in communication, which includes but not limited to delay in or total lack of the development of spoken language, or impairment in the ability to initiate or sustain a conversation with others. Thirdly, there is restricted, repetitive and stereotyped pattern of behaviour, interests, and activities, which include but not limited to inflexible adherence to specific, nonfunctional routines or rituals (APA, 2000). Many official health reports on ASD have shown that there is an increase in the number of ASD cases over the years. One of the most comprehensive ASD prevalence study done so far is the one done by the US Centers for Disease Control and Prevention (CDC)'s Autism and Developmental Disabilities Monitoring (ADDM) Network (Autism and Developmental Disabilities Monitoring Network, 2012). In its latest study in 2008, the rate of US cases rose from one in 110 in 2006 to about one in 88 children in 2008. In fact, the autism numbers skyrocketed since 2002(Autism Spectrum Disorders – Data & Statistics, 2014). This number has caused a public health concern worldwide. Health officials attribute the increase in autism cases through greater awareness, wider screening and better diagnosis (Weintraub, 2011). But the numbers increase at a rate so fast that researchers start to question if these are the true factors that justify the increase (Weintraub, 2011). Growing evidences have shown that environmental and epigenetic factors could contribute towards autism incidence (Persico & Bourgeron, 2006),which include possible causal factors such as genetic mutations (Freitag, 2007) and various environmental agents that would cause birth defects (Arndt, Stodgell, & Rodier, 2005). Yet in all its efforts to understand the underlying cause of ASD which

knows no bounds in affecting children across racial, ethnic and socioeconomic groups, scientists are yet to identify a way to prevent this developmental disorder from happening. Nevertheless, due to its high incidence rate recently, ASD should be treated as a public health emergency that demands immediate attention globally.

Overview of Autism Prevalence Study Done Globally

A quick search on the prevalence study of ASD was done through databases including Science Direct, ProQuest and Web of Science and Medline. Results from these databases showed that prevalence studies were mainly done in the Western and European countries. A systematic review on global prevalence of autism has confirmed this (Elsabbagh et al., 2012). Another review paper report the countries where such study was performed, which included United Arab Emirates, United States, Norway, Canada, Germany, Sweden, France, Iran, Iceland, Finland, Israel, and Britain (Matson & Kozlowski, 2011). For Asia, autism prevalence studies mostly came from Japan, China, Taiwan and Indonesia (Elsabbagh et al., 2012; Sun & Allison, 2010). In a related review paper, Hong Kong was also included (Sun et al., 2013). More recently, a national prevalence study conducted from 2005-2009 in the South Korean community among children aged 7 to 12 was reported (Kim et al., 2011). China is also catching up with the launching of their first nationwide study on autism prevalence starting July this year. This three year project involves collaboration between Fudan Children's Hospital in Shanghai and national health authorities with a sample size of up to 200,000 with geographical diverse middle school pupils aged 6 to 12 (Compton, 2013).

To our knowledge, there is no published report on nationwide autism prevalence study in the Southeast Asia so far. Singapore and Malaysia, both located at the same geographic region, share a number of common features of being multi-ethnicity with rich cultural diversity. These two countries would serve as a good representation of Southeast Asian context in many types of research studies. This literature review aims to fill the gap in knowledge by providing what has been done so far for autism studies in these two countries. In particular, we will discuss about the prevalence, diagnosis, treatment and types of autism research done with implications highlighted at the end of the paper.

Prevalence

In Singapore, although the first overview study about autism in children was done in 2001 (Bernard-Opitz, Kwook, & Sapuan, 2001), a search from the government official website such as Ministry of Health (MOH) (Singapore Ministry of Health, 2013), Ministry of Education (MOE) (Singapore Ministry of Education, 2013)as well as autism official website such as Autism Resource Centre (ARC) Singapore (Autism Resource Centre Singapore, 2013), and Autism Association Singapore (AAS) (Autism Association Singapore, 2013) found no official records of total number of local children with autism. However, health records from 2003-2004 from the Department of Child Development, Kendang Kerbau Women's and Children's Hospital (KKH) revealed that ASD is the most common clinical development diagnosis among young children (Lian et al., 2012).

Similarly, in Malaysia, there is no official registry for the number of children with autism (See, 2012). This is partly because autism is categorized under learning disabilities along with other cognitive and developmental disabilities (The Ministry of Education Malaysia, 2012).However, a local survey conducted revealed that one in every 625 Malaysian children has autism (Azizan, 2008).This local survey is not accessible at the time of this literature review and the data may not be the most current. However, just like anywhere else in the world, the fact that there is indeed an increase in local ASD cases is undeniable. According to the National Autism Society of Malaysia (NASOM) (The National Autism Society of Malaysia, 2013), there has been a 30% increase in the organization's intake of individual's with autism in the past three years (Cheong, 2009).

Diagnosis

In Singapore, the diagnosis of autism is done by developmental pediatricians and child psychology departments in private or national hospitals (Autistic Spectrum Disorder for Child, 2013) such as the Child Development Unit (CDU) at KK's Women and Children's Hospital. A strong support network for autism in the community has also allowed many parents to seek help from specific autism centre such as ARC, Singapore where services like assessment and diagnosis are provided. Some of these facilities offer subsidies for diagnosis and treatment to affected families too (Autism Association Singapore, 2013; Autism Resource Centre Singapore, 2013). The availability of adequate autistic diagnosis centers with affordable treatment cost also demonstrates that there is a certain level of public awareness on the importance of early diagnosis and intervention of ASD in the society.

Unlike Singapore, Malaysia covers a much wider geographical area. Malaysia has a total landscape of 329,847 square kilometres (Malaysia Department of Statistics, 2011), compared to a size of 716.1 square kilometers in Singapore (Singapore Department of Statistics, 2013). The facilities available for children with ASD in the urban and rural areas could be quite drastically different. In the urban areas such as the capital city Kuala Lumpur and the surroundings, there are public and private medical centres which offer various intervention programs for children with ASD. One of the centres is Child Development Centre (CDC) in Hospital Universiti Kebangsaan Malaysia (HUKM) which offers diagnosis services to children with special needs, including children with ASD (Yoga, 2012). Besides, the National Autism Society of Malaysia (NASOM) is an example of non-governmental organizations (NGOs) dedicated for autism, which plays an important role in offering assessment and diagnosis services to the affected children (The National Autism Society of Malaysia, 2013).

Due to the lack of facilities in the rural areas, these centres are forced to serve a wider population than intended, which includes children and families who travel from inlands and other states. This causes a long waiting list at the specialists, especially those in the public services (Azizan, 2008; Hew, 2000).

At the same time, there is a lack of knowledge on ASD among many affected parents in Malaysia (Dolah, Yahaya, & Chong, 2011).As a result, the diagnosis is often done much later during the childhood. In 2009, The Malaysian Ministry of Education introduced a screening program during the school entry (Year 1), known as the Literacy and Numeracy Screening (LINUS) programme. (Linus 2.0 programme in all primary schools soon, 2012).Under this programme, students who are identified with learning difficulties would be referred to medical professional for further diagnosis (Every child has potential to succeed, 2012).Therefore, it is possible for children with ASD to be diagnosed via this route. However, it is often too late to diagnosis a child with ASD at this time.

Treatment

Although there is no treatment to cure autism, studies support that early diagnosis of autism followed by early intervention programme (EIP), especially behaviour modification, would help to increase the child's cognitive level (Dawson et al., 2010).In Singapore, the ASD early intervention plan is laid out clearly in the Clinical Practice Guidelines (Bee et al., 2010).In this guideline, it states that the intervention plan starts at pre-school level. The intervention methods include Early Intensive Behaviour Intervention (EIBI) and Developmental Models. Although Sensory Integration (SI) is used, it is not a recommended standard therapy. Similarly, this method is also practiced minimally in Malaysia (Leong, Stephenson, & Carter, 2011). Aside from getting EIPs from the child specialist clinic, most of the EIPs in Singapore are run by specific autism centers that offer different models. For example WeCAN EIP, which is supported by ARC uses Individualized Education Plan (IEP) model (WeCAN Early Intervention Programme, 2013).The other one would be Early Intervention Programs for Infants and Young Children (EIPIC) that is run at 11 centers (Chong et al., 2012).

In Malaysia, due to the long waiting list in the public centres, it is more common for parents to seek treatment from NASOM or privately-owned entities. For example, Early Autism Project Malaysia Sdn Bhd is a private company, which offers both home- and centre-based Applied Behaviour Analysis (ABA) therapy (Early Autism Project Malaysia, 2013).The same therapy is also offered by Autism Link Sdn Bhd through classroom and group programmes for children aged 3-6 years (Autism Link Malaysia, 2013).Parents would need to pay a certain amount of fees for treatments at these centers.

An important aspect in autism treatment is special education (SPED) for children with ASD. In Singapore, as at January 2010, there are 20 SPED schools that are run by Voluntary Welfare Organizations (VWOs), funded by Ministry of Education (MOE) and National Council of Social Service (NCSS). Out of which, three are dedicated for autistic children including Pathlight School, Eden School and Saint Andrew's Autism School (Chia, 2013).These schools run SPED from primary to secondary level. At secondary level, the academic track is offered by Pathlight School while Eden School and St Andrew's Autism School offer vocational track (Chia, 2013).

In Malaysia, the SPED schools cater only for children with hearing and visual impairment. Children with learning disabilities are educated within the Integrated Programmes that are run as segregated classes in mainstream schools (The Ministry of Education Malaysia, 2008). Currently, there are 1,945 regular schools in the country that run such Integrated Programmes throughout the country (Every child has potential to succeed, 2012). Meanwhile, there is no governmental-support autism school but there is a NGO autism school called Hua Ming (Hua Ming Autism Society, 2013). It is the only autism school in the country that is established in 1996 by a group of passionate parents having

children with ASD. It teaches children aged 2 to 15 years old by adopting the Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH) programme as well as Applied Behaviour Analysis (ABA) programme. Besides running academic curriculum, Hua Ming also conducts vocational training for the students (Hua Ming Autism Society, 2013).Many affected families have benefited from this school.

In line with the global trend (Forlin & Lian, 2008; UNESCO, 1990, 1994), the EIPs and special education (SPED) in Singapore and Malaysia are now preparing children with ASD to enter mainstream classes. In Singapore, the MOE has initiated *Support for Special Needs in Mainstream Schools* in which funds were allocated to support students with special needs in mainstream schools (Ho, 2009). This initiative has successfully prepared the mainstream schools with the learning environments supportive of children with ASD when more and more of these children were enrolled into the mainstream schools (Leow & Quek, 2010).

In Malaysia, selective placement of children with special needs in mainstream classes occurs on a child-specific basis (Lee, 2010). However, such placement is not mandatory and the decision lies solely on the school's administration prerogative based on advice by the school's special education teachers (The Ministry of Education Malaysia, 2008).This gives rise to a situation whichLee and Low (2013) describes as 'unconscious inclusion' of students with special needs. At both preschool (Razali, Toran, Kamaralzaman, Salleh, & Yasin, 2013) and primary school levels (Lee & Low, 2013), students with ASD in Malaysia are found to be included into mainstream education after mutual decision between the school administrative and the parents. This laid-back attitude towards inclusion is about to change as 30% of children with special needs are targeted for enrolment in mainstream classes by 2015, and 75% by 2025under the National Education Blueprint (The Ministry of Education Malaysia, 2012) initiatives.

Current Autism Research

A quick search on autism research was done through Web of Knowledge database using *Autism Singapore* and *Autism Malaysia* as keywords. Previous studies on ASD conducted by Singapore and Malaysia with its key findings are tabulated in Appendices 1 and 2 respectively.

From Appendices 1 and 2, it is evident that there are more published journals in autism research in Singapore compared to Malaysia. The majority of the studies conducted in Singapore are more focused on the disability. These include parents' perspective and expectations, studying challenging behaviours and testing usefulness of screening tools and intervention methods of children with ASD. While those conducted in Malaysia are more general which covers a range of disabilities with limited focus on ASD study. The number of citations for Singapore studies is comparatively higher than that of Malaysia, suggesting a wider accessibility and greater impact globally.

As mentioned, scholarly research on ASD in Malaysia is limited and this has been highlighted repeatedly in the local press (Azizan, 2008; Dolah, Yahaya, Chong & Mohamed, 2012). This scarcity is reflected from the citation in the limited scholarly published work done locally, which cited sources from local press such as Money and Distance Letting Down Children with Autism (2010) as cited in Pohand Tan (2012), and The Burden of Autism by Azizan (2008) as cited in Dolah et al. (2011); Dolah et al. (2012). There is a lack of primary data on autism where publication is concern. Researchers who are involved in autism find it difficult to obtain data from the national registry. For example, the number of registered autism cases or child developmental disorders cannot be found anywhere from the Social Welfare Department, MOH nor MOE websites in the course of this literature review. Nevertheless, there is one published work to find out about autism awareness in the society, and another one to gather data on the incidence of autism amongst undergraduate students in a local university (Dolah et al, 2011; Dolah et al., 2012). In both these studies, primary data was collected.

Implications of Study

By comparing the current status on what had been done for autism in both countries, gaps in knowledge can be identified. For example, the urgent need for expansion of autism research especially in Malaysia is spotted. Although Singapore also lacks in epidemiological studies on autism, the scholarly research is comparatively better in terms of quantity, depth and scope. The endorsement of government guidelines in autism such as the Clinical Practice Guidelines has increased the credibility of the research (Bee et al., 2010). Guidelines in the Malaysian context are still much broader and less differentiated for specific disabilities.

However, regardless of developmental status, in both nations, data collection, diagnosis and treatment are still primarily driven by private entities, which suggest that there is still a lot to be done for autism research in both countries. As a start, more current prevalence studies should be done locally for better understanding of how widespread autism is in this part of the world compared to other regions. Some other potential topics that can be researched on following this literature review would be the impact of ethnicity on autism incidence, considering the cultural diversity in both Malaysia and Singapore. This would add value to the current knowledge of autism research.

Conclusion

This review compiled numerous previously published studies on the prevalence, diagnosis, treatment and research on ASD in Singapore and Malaysia and demonstrated their respective current trends of development in ASD research at different levels. In Malaysia, the awareness level on autism is still quite low. Due to the limited public awareness, children and adults alike who suffer from this developmental disorder are often not given their due dignity but treated as people with mental problem (Hew, 2000). The plight to restore this ignorance through a better education system (Amar-Singh, 2012; Amar-Singh, Wong, & Toh, 2013a, 2013b; Hopeful-Teacher, 2012) such as more initiatives from the government to set up EIP and partnership with relevant NGOs (Amar-Singh, 2011), as well as more job opportunities for occupational therapists, and speech-language therapists especially in schools (Azizan, 2008; Low, 2012; Veera, 2002) were all reported in the local press by the respective special education specialists.

Findings from this review suggest that continuous efforts are needed toward raising awareness on autism and improving the quality of life of the affected families in both Singapore and Malaysia. Collaboration between stakeholders in Malaysia and Singapore can be expanded in such efforts. This collaboration can occur at multiple levels for example the NGOs with strong support from parents, and also at the academic research levels. Efforts and supports should extend beyond childhood so that the individuals with ASD may one day become valuable members of our community. Finally, the authors hope that this review paper will help to promote future ASD-related research in Asia as this region continues to raise its standard of living in all aspects.

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Appendix 1. Current Studies on Autism in Singapore

Authors(s) Year	Research Design/Aim/Participants	Main Findings
Poon (2013)	Qualitative research (interview method) to investigate Singaporean parents' expectations on their adolescent with ASD future/20 parents	Majority expected their children to be unemployed or working in sheltered workshops. All parents cited that their children would stay with them and half wished that relatives can care for them.
Chong et al. (2012)	Mixed method research (exploratory factor analysis and focus group discussion) to evaluate the extent to which the 11 EIPIC programs for children with moderate and severe disabilities in Singapore provided a family-oriented service / 310 parents of whose children participate in the program	Results from factor analysis suggested that parents perceived family-centered practices to be carried out to a moderate or great extent in the program. The focus group interviews suggested that families wanted more parent-to-parent support by providing a platform to share common grief, interests, information and resources.
Koh and Milne (2012)	Quantitative research (standardized questionnaire) to assess cultural influence (Singapore and England) on perceptual style that is field dependent or field independent in children with ASD / 104 children from both countries including control group	Found increased field-independence in English participants with ASD compared with their Singaporean counterpart.
Lian et al. (2012)	Quantitative research (referral reports) to establish the first regional database for CDABD by evaluating profiles & outcomes of children referred to CDU in KKH from 2003	Most common clinical developmental diagnosis was ASD (30%). ASD remained the most common definitive developmental diagnosis with 31% at one year.

	to 2004	
Moh and Magiati (2012)	Quantitative research (survey method) to find out parental experiences of the process of diagnosis of ASD and to explore possible factors associated with parental stress and satisfaction / 102 parents of affected children with diagnosis period since 2001, 17 professionals from both private and public organizations providing ASD diagnostic service	High parental stress was related with more professionals consulted. Parents were more satisfied when they collaborated closely with professionals and received better or more helpful information. As part of the diagnostic process, parents whose children presented more severe ASD symptomatology reported lower levels of satisfaction.
Poon (2012)	Quantitative research (standardized questionnaire) to understand factors that impact the challenging behaviours of children with ASD and MD/Teachers of 322 and 132 children with ASD & MD respectively	Children with ASD showed higher levels of challenging behaviours as compared to children with MD. Age, diagnosis and gender were significantly associated with challenging behaviours.
Ooi, Rescorla, Ang, Woo, and Fung (2011)	Quantitative research (standardized questionnaire) to assess utility of CBCL to differentiate ASD group from non-referred group (school group), ADHD-IA, ADHD-HI/C, and undiagnosed/ 1265 individuals	Moderate to high sensitivity (68-78%) & specificity (73-92%) was found in nine CBCL items for the identification of ASD with respect to four different comparison groups. Overall, this study provides strong support for using CBCL as a screening tool for ASD.
Poon (2011)	Quantitative research (standardized questionnaire) to describe activities and participation of adolescents with ASD and to examine the suitability of the Activity and Participation component of the ICF in achieving this purpose / 20 parents of affected children	By using the APRS rating score (part of the ICF and developed for this study), adolescents found more difficulties with participation than with engaging activities. Concurrent results from a standardized VABS-II measuring adaptive skills of ASD individuals support the use of APRS as a measure of adaptive skills.
Lian et al. (2008)	Quantitative research (survey method) to explore the knowledge, attitudes and practices amongst pre-school teachers concerning CDABD / 503 pre-school teachers	Overall knowledge of CDABD amongst pre-school teachers was inadequate. However, it is encouraging that most of them were interested to be trained on how to help CDABD.
Bernard-Opitz, Ing, and Kong (2004) Bernard-Opitz et al. (2004)	Mixed method research (standardized questionnaire and video-recording) to compare beneficial effects of traditional behavioural approach and natural play approach as intervention in ASD children/ 8 ASD children and their parents, and therapists	Children in both groups showed improvements in play, attention, compliance, and communication with therapists and parents. These beneficial effects vary with the two interventions, their sequence (cross-over design) and interaction partners.
Bernard-Opitz et al. (2001)	Quantitative research (survey method) to examine the epidemiology of autism in children, focusing on the child's background, behaviour problems and skill profile, home and school situation as well as linguistic and social background / 176 parents of affected children	Findings suggested that autism is diagnosed before 3 years of age, much earlier than the UK, which is a positive sign. Majority of the children have behaviour problems, which is mainly contributed by high prevalence of working parents and involvement of foreign maids as caregivers. Lack of conducive home environment for the affected child also

		hinders their developmental progress.

Note: ASD: Autism Spectrum Disorder; CDABD: Childhood Developmental and Behavioural Disorders; CDU: Child Development Unit; KKH: KK Women's and Children's Hospital; MD: Multiple Disabilities; EIPIC: Early Intervention Programme for Infants and Children; CBCL: Child Behavior Checklist; ADHD-IA: Attention Deficit Hyperactivity Disorder-Inattentive type; ADHD-HI/C: Attention Deficit Hyperactivity Disorder-Hyperactive and Impulsive or Combined type; APRS: Activities and Participation Rating Scale; ICF: International Classification of Functioning, Disability and Health; VABS-II: Vineland Adaptive Behavioural Scales-Second edition

Appendix 2. Current Studies on Autism in Malaysia

Authors(s) Year	Research Design/Aim/Participants	Main Findings
Dolah et al. (2012)	Quantitative research (survey method) to find out the probability of detecting autism symptoms among adults with average intelligence by using ASQ / 76 undergraduate students of different race	Findings from this study showed that majority of the respondents scored average points for autism symptoms. This finding can be used to develop educational materials to educate the public about autism symptoms.
Joginder-Singh, Iacono, and Gray (2011)	Quantitative study (standardized questionnaire) to compare practices by SLPs from two different countries with children with developmental disabilities who are pre-symbolic / 65 and 157 SLPs from Malaysia and Australia respectively	SLPs from both countries were most likely to rely on informal assessments rather than structured assessments. SLPs from both countries focused on enhancing the children's pre-verbal, play, and requesting skills, as well as educating parents about how to facilitate their child's communication. More Australian than Malaysian SLPs introduce AAC system as initial therapy goal. Similar challenges were reported by SLPs from both countries when conducting assessment and providing intervention.
Leong et al. (2011)	Qualitative study (interview) to explore the perceived effectiveness of using SI therapy in improving the behaviour of children with special needs / 10 teachers and supervisors from intervention centres for children with special needs	Findings showed that the implementation of SI therapy was limited and largely unstructured in the intervention centres. There was a lack of policy on the use, assessment, monitoring and planning of SI therapy. Besides, many of the forms of SI therapy described could not be easily differentiated from the regular activities in educational programmes.
Iradah and Rabiah (2011)	A book chapter on testing of learning performance of high-functioning autism students using multimedia approach (*EduTism* educational system).	Results supported that teachers agreed that *EduTism* is a good educational tool to help autistic students learn better. The students were also excited to learn from the software. This software is useful for teachers and parents to track the learning progress of affected students.
Yusoff, Wahab, Aziz, and Asha'ari (2009)	A book chapter on testing of the usage of ESSE system to help teachers identify children with ASD and dyslexia.	This system is able to assist special education teachers in screening and diagnosis of children with special needs.

Note: ASQ: Autism Spectrum Quotient; SLPs: Speech and Language Pathologists; AAC: Augmentative and Alternative Communication; SI: Sensory Integration; ESSE: Expert System for Special Education