

## ORIGINAL PAPER

## Are Siblings of Children with Autism More Prone to Behavioural and Psychological Problems as Compared to the General Population?

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### Abstract

**Objective:** To compare the psychological well-being of siblings of autism spectrum disorder (ASD) children versus their parents' and the general population; and social well-being of these siblings versus their parents' perspective and the general population. **Methods:** A cross-sectional study involving siblings aged 11-17 years and parents of ASD children attending paediatric clinics of two hospitals, was conducted in 2017-2018. Controls were secondary school students living with healthy siblings, matched based on gender, ethnicity and geographical location. Study group pairs and controls filled the Depression, Anxiety and Stress scale (DASS-21) and Strength and Difficulties Questionnaire (SDQ). Study group children also answered four open-ended questions. **Results:** We recruited 34 study group pairs and 34 controls. Majority of the participating parents in the study group were mothers (79.4%). Most children were Chinese (58.8%) females (67.6%). There was no significant difference of depression, anxiety or stress in the study group children (26.5%, 52.9%, 17.6%) compared to their parents (23.5%, 52.9%, 32.4%) and controls (32.4%, 52.9%, 23.5%). There was a significant difference in the study group children's SDQ score and their parents' evaluation ( $p=0.039$ ). Most parents (76.5%) evaluated their children to have very high SDQ score compared to self-evaluation (55.9%). There was no significant difference of SDQ levels between study group children and controls ( $p=0.090$ ). **Conclusion:** Living with a child with ASD

**did not significantly alter the behaviour and sense of well-being of their siblings contrary to parental perception.**

**Keywords: Autism, Sibling, Psychological, Social**

## **Introduction**

Autism spectrum disorder (ASD) is a neurodevelopmental disorder that begins in childhood, characterized by impairments in communication, behaviour and social functioning, with a prevalence of 1.6 in 1000 children in Malaysia [1]. Living with a child who has a disability such as autism can result in significant financial, emotional and lifestyle challenges for the family [2]. Studies had suggested that the overall family functioning was more likely to determine sibling adjustment, although financial hardship was one of the social and economic determinants that would negatively impact the family functioning [3]. There were a variety of challenges that siblings of children with ASD might face, such as isolation or resentment, loneliness, confusion, distress or embarrassment from having a sibling with a disability [4].

Although clinicians were seeing the increase rates of diagnosis of autism worldwide over the last four decades [5], few studies were done on the impact of ASD upon siblings. Some studies suggested that siblings were prone to develop internalizing and externalizing problems, peer and conduct problems, hyperactivity, delinquent behaviour, and withdrawal when compared to the general population [6]. Others, however, reported that siblings of individuals with ASD were well adjusted [7]. Kaminsky and Dewey in 2001 had highlighted some positive influences of having a sibling with autism, including greater admiration by their siblings, less quarrelling and less competitiveness [8]. To

date, a sibling's perspective was often demonstrated by the view of a proxy [9]; hence the research question: What is the perspective of a child or adolescent who has a sibling with autism in our local setting as compared to the general population?

Perception of parents may be different from siblings on behavioural characteristics of siblings of children with ASD. Parents may be unaware that siblings are affected by the child with autism. This is part of the investigators' interest in this study.

This study aimed to evaluate the impact of children with ASD on the psychological and social well-being of their siblings. The specific objectives included: (i) to compare the levels of depression, anxiety and stress among parents and siblings of children with ASD; (ii) to evaluate the levels of depression, anxiety and stress among siblings of children with ASD in comparison with children living with healthy siblings; (iii) to identify the behavioural characteristics among siblings of children with ASD in comparison with the perspective of their parent; and (iv) to compare the behavioural characteristics between siblings of children with ASD and children living with healthy siblings. Information gained from this study would provide a better understanding of the psychological and social well-being of siblings of children ASD. This would facilitate more holistic approach in managing families of autistic children.

## **Methods**

### ***Study design, setting & population***

This was a cross-sectional involving siblings and parents of children with ASD attending paediatric clinics in Hospital Raja Permaisuri Bainun (HRPB), Ipoh and Hospital Seri Manjung (HSM), Perak, conducted from December 2017 till July 2018. The participants recruited in the study group were the siblings and parents of autistic children seen in paediatric clinics of both hospitals from 2017 to 2018. This study also involved the participation of children living with healthy siblings. This group of children served as the control group and they were selected from secondary school students in Kinta and Manjung district. They were matched with the study group based on gender, ethnicity and geographical location.

### ***Inclusion & exclusion criteria***

For the study group, the inclusion criteria included children: (i) aged 11-17 years, (ii) having a sibling diagnosed with ASD, (iii) with assent and parental consent to participate, as well as (iv) the ability to complete the questionnaires without parental proxy. Parents of children who fulfilled the inclusion criteria were recruited in the study. The children were excluded from study participation if they or their ASD siblings had other chronic medical illnesses, such as cerebral palsy, childhood malignancy, asthma, epilepsy, nephrotic syndrome or autoimmune disorders.

For the control group, the inclusion criteria included children: (i) aged 11-17 years, (ii) attending secondary school, (iii) have siblings without ASD or other chronic medical illnesses, (iv) with assent and parental consent to participate, as well as (v) the ability to complete the questionnaires without parental proxy. The children were excluded from study participation if they

had chronic medical illnesses. Children from boarding schools were not sampled in this study.

### ***Sample size calculation***

Minimum sample size required for this study was calculated based on the SDQ score. To compare the mean SDQ score between the study and control group, we required 34 participants in each group (i.e. total = 68) to detect the SDQ score difference of 4.00 between groups, estimated SD of 5.76, with 80% certainty (power) and alpha 0.05. This figure was arrived using Power & Sample Size Calculation, Dupont and Plummer, 1997. SD of the SDQ score among the study group in research conducted by Giallo R et al [10] was used as the reference for the sample size calculation.

### ***Consent taking***

For the study group, parents of the siblings who fulfilled the inclusion criteria were contacted for an appointment with the investigator in paediatric clinics. During the visit, the parents and siblings were given adequate time for detailed consent and assent taking process. Refusal of study participation would not affect the treatment of their autistic children. The siblings were informed that the study results would be revealed to their parents if there was any concern or if treatment was needed.

For the control group, the Parental Information Sheet, Parental Consent Forms and first sheet of the questionnaires were distributed to the students during investigators' first visit to the school and were brought home by the students. Parents signed the parental consent form if they agreed for their children's participation. The parents then filled the demographic details of the questionnaire. Detailed assent taking

process took place during the investigators' second visit to the school. Students were allowed to fill the demographic details if it was incompletely filled by their parents. The students were informed that the results of the study would be revealed to their parents if there was any concern or if treatment was needed. The results would not be revealed to the teachers and other students in the school.

### ***Data collection***

A self-administered questionnaire was used to collect the following information in both study and control group. Demographic sections included data such as age, gender, race, birth order of the participating child and autistic child, number of children within the same family that was participating in this study, number of autistic children in the family, birth history, parental occupation, education level of both parents and the participating child, gross household income, whether the participating child as well as other child has any chronic illnesses. The parents in both groups filled in this information.

For the study group, two sets of Depression, Anxiety and Stress scale (DASS-21) [11] as well as two sets of Strength and Difficulties Questionnaire (SDQ) [12] were given. One set was filled by the siblings while another set was filled by the parents. The responses for the DASS-21 questionnaire were self-reported for both the parents and siblings. The responses for the SDQ reflected the participating children's own perception on their strength and difficulties, and the parents' perception on their participating children's well-being. The siblings were then asked four additional open-ended questions to assess their perception on coping with a sibling diagnosed with ASD. Data collection was conducted in the paediatric clinics of both hospitals.

For the control group, one set of DASS-21 and one set of SDQ were filled by the students at school. In the event where the participating child in either group had a moderate to extremely severe DASS-21 score or any other medical condition requiring treatment, the child would be referred to a healthcare professional for further management. Each questionnaire required approximately 10 minutes to complete.

### ***Pre-test***

Prior to data collection, the questionnaires were pre-tested among 10 children and their parents to assess the feasibility of the questionnaires. The children might or might not fulfil the inclusion criteria. The results of pre-testing were excluded from the data analysis.

### ***Description of DASS-21 and SDQ***

DASS-21 is a set of three self-report scales designed to measure the emotional states of depression, anxiety and stress. Each of the three DASS-21 scales contains seven items, divided into subscales with similar content [13]. DASS-21 is used to measure depression (items: dysphoria, hopelessness, devaluation of life, self-deprecation, lack of interest/involvement, anhedonia, and inertia); anxiety (items: autonomic arousal, skeletal muscle effects, situational anxiety, and subjective experience of anxious affect) and stress (items: present level of arousal as orthogonal to relaxation, agitation and irritability). Four-point Likert scale ranging from zero ("Did not apply to me at all") to three ("Applied to me very much or most of the time") are the options of answer. The DASS-21 of three languages, namely English, Malay and Simplified Chinese were used in this study. The English version of DASS-21 has a good reliability and validity

reported from Hispanic American, British, and Australian adults. However, there is a lack of appropriate validation among Asian populations. Result of the Malay DASS-21 has very good Cronbach's alpha values of .84, .74 and .79, respectively, for depression, anxiety and stress [14].

SDQ is used to measure five subscales including emotional symptoms, conduct problems, hyperactivity, peer problems and prosocial behaviour. A total difficulties score is calculated using the SDQ, which ranges from 0-40. Each 1 point increase in the total difficulties score corresponds with an increase in the risk of developing a mental health disorder. For SDQ, (i) single-sided version without impact supplement for parents in languages of English (UK), Malay and Simplified Chinese AND (ii) single-sided version without impact supplement, self-rated by children aged 11-17 years old in languages of English (UK), Indonesian (as there is no Malay translation) and Simplified Chinese were used in this study. Investigators could not obtain permission to translate the SDQ into the Malay language [15].

### ***Ethical Consideration***

Ethical approval was obtained from the Medical Research and Ethics Committee (MREC) of Ministry of Health (MOH), Malaysia. Approval from Ministry of Education was obtained. Study participation was voluntary. Refusal of participation and withdrawal from study without any reason was allowed. No identifier of participant was collected. All responses were kept confidential. National Medical Research

Register (NMRR) No.: NMRR-17-940-35416. MREC approval letter: (10) KKM/NIHSEC/P17-954 dated 7 July 2017.

### ***Data Analysis and Interpretation***

All statistical tests were analysed using SPSS version 20 (IBM Corp. Released 2011. IBM SPSS Statistics for Windows, Version 20.0. Armonk, NY: IBM Corp). Parental occupation was coded based on Standard Occupational Classification 2010 [16]. Descriptive analysis (means and frequencies) was used to summarise participants' characteristics. Chi square test was used to compare results of DASS and SDQ score among the participants. A significant *p* value was taken as less than 0.05.

For DASS-21 [13], the score of each domain was summed and multiplied by 2 to calculate the final score. The number and percentage of siblings of each severity of depression, anxiety and stress were calculated. In each domain (depression/anxiety/stress), the cut-off scores used in this study were the scores that correspond to the category of mild and above, which is a score of more than 9 for depression, more than 7 for anxiety and more than 14 for stress. The children were grouped as to whether they are: depressed (YES/NO), anxious (YES/NO) and stressed (YES/NO).

For SDQ [15], total difficulties score was calculated by summing scores from all the scales, to identify any area of difficulty. Both parent and self-completed SDQ were categorized as 'close to average', 'slightly raised', 'high' and 'very high'.

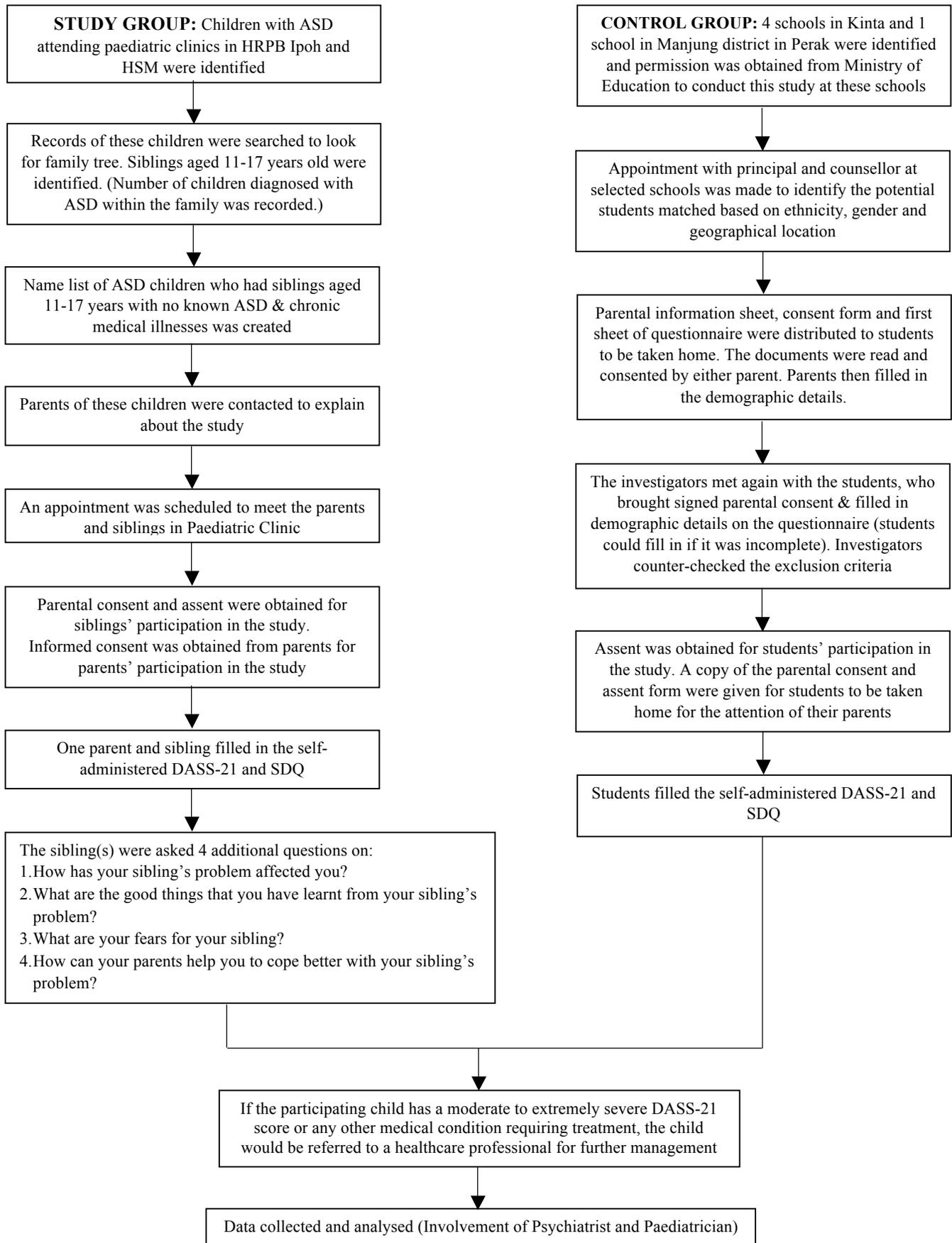


Figure 1: Methodology Flow Chart

## Results

### Response Rate

Among the children in the study group, 50 parents were approached however only 36 children agreed to participate. Two children were excluded as they were 10 and 18 years old, leaving a total of 34 children in the study group. For the control group, 34 school students were matched with the gender, ethnicity and geographical location of the study group.

### Socio-demographics

Among the study group participants, 33 families (97.1%) had one child with ASD. One of the participating families had two children with ASD. Majority of the participating parents in the study group were mothers (n=27, 79.4%). Among the fathers in both groups, almost two-fifth of them (n=27, 39.7%) were routine and semi-routine workers while 38 (55.9%) had secondary education as their highest

education level. Majority of the mothers in both groups (n=38, 55.9%) were full time housewives while 38 (55.9%) had secondary education as their highest education level. A total of 47 families (69.2%) in both groups had a combined monthly income of below RM5000.

In the study group, majority of the children with autistic siblings were females (n=23, 67.6%) and of Chinese ethnicity (n=20, 58.8%) with a mean age of 13 years (SD 2.1). Approximately two-thirds of the children (n=22, 64.7%) were in secondary school, more than half of them were the eldest in the family (n=21, 61.8%), while 21 (61.8%) were delivered normally.

Among the controls, the mean age of the participating siblings was 15 years (SD 1.1). All of the children were in secondary school, almost one-third of them (n=11, 32.4%) were the eldest in the family, while most of these children (n=30, 88.2%) were delivered normally (Table 1).

**Table 1. Socio-demographics of cases and controls**

Characteristics	Cases (study group), n (%)	Control, n (%)	Total, n (%)
<b>PARENT</b>			
Age (mean year, SD)	45 (8.0)	NA	-
Gender			
Male	7 (20.6)	9 (26.5)	16 (23.5)
Female	27 (79.4)	25 (73.5)	52 (76.5)
Father's occupation*			
Higher & lower management	-	3 (8.8)	3 (4.4)
Intermediate	7 (20.6)	7 (20.6)	14 (20.6)
Small employers & own account workers	5 (14.7)	8 (23.5)	13 (19.1)
Lower supervisory and technical	5 (14.7)	1 (2.9)	6 (8.8)
Routine & semi-routine	15 (44.1)	12 (35.3)	27 (39.7)
Never worked & long-term unemployed	2 (5.9)	3 (8.8)	5 (7.4)
Mother's occupation*			
Higher & lower management	4 (11.8)	4 (11.8)	8 (11.8)
Intermediate	5 (14.7)	8 (23.5)	13 (19.1)
Small employers & own account workers	-	3 (8.8)	3 (4.4)
Lower supervisory and technical	-	-	-
Routine & semi-routine	3 (8.8)	3 (8.8)	6 (8.8)
Never worked & long-term unemployed	22 (64.7)	16 (47.1)	38 (55.9)
Father's highest education level			

No formal education	-	-	-
Primary	4 (11.8)	2 (5.9)	6 (8.8)
Secondary	15 (44.1)	23 (67.6)	38 (55.9)
Tertiary	15 (44.1)	9 (26.5)	24 (35.3)
Mother's highest education level			
No formal education	2 (5.9)	-	2 (2.9)
Primary	3 (8.8)	-	3 (4.4)
Secondary	19 (55.9)	19 (55.9)	38 (55.9)
Tertiary	10 (29.4)	15 (44.1)	25 (36.8)
Gross household income			
Less than RM 1000	3 (8.8)	1 (2.9)	4 (5.9)
RM 1000 to 2999	11 (32.4)	10 (29.4)	21 (30.9)
RM 3000 to 4999	8 (23.5)	14 (41.2)	22 (32.4)
RM 5000 to 6999	3 (8.8)	6 (17.6)	9 (13.2)
RM 7000 to 8999	5 (14.7)	1 (2.9)	6 (8.8)
RM 9000 and above	4 (11.8)	2 (5.9)	6 (8.8)
<b>CHILDREN</b>			
Age (mean year, SD)	13 (2.1)	15 (1.1)	14 (1.9)
Gender			
Boy	11 (32.4)	11 (32.4)	22 (32.4)
Girl	23 (67.6)	23 (67.6)	46 (67.6)
Ethnicity			
Malay	14 (41.2)	14 (41.2)	28 (41.2)
Chinese	20 (58.8)	20 (58.8)	40 (58.8)
Child's education level			
Primary	12 (35.3)	-	12 (17.6)
Secondary	22 (64.7)	34 (100.0)	56 (82.4)
Number of participating child			
1	18 (52.9)	31 (91.2)	49 (72.1)
2	16 (47.1)	3 (8.8)	19 (27.9)
Child birth order			
1	21 (61.8)	11 (32.4)	32 (47.1)
2	8 (23.5)	13 (38.2)	21 (30.9)
3	3 (8.8)	7 (20.6)	10 (14.7)
4	1 (2.9)	2 (5.9)	3 (4.4)
5	1 (2.9)	1 (2.9)	2 (2.9)
Number of autistic children in the family			
1	33 (97.1)	NA	-
2	1 (2.9)	NA	-
Autistic child birth order			
Younger than participant	30 (88.2)	NA	-
Older than participant	4 (11.8)	NA	-
Is the participating child being delivered normally			
Yes	21 (61.8)	30 (88.2)	51 (75.0)
No	13 (38.2)	4 (11.8)	17 (25.0)
Does the participating child have chronic illness			
Yes	-	-	-
No	34 (100.0)	34 (100.0)	68 (100.0)

\* The National Statistics Socio-economic Classification: Rebased on the Standard Occupational Classification 2010 (SOC2010) User Manual [16]

***Comparison of depression, anxiety and stress level among parents and siblings of children with ASD***

Among the participating parents and siblings of children with ASD, a quarter of them had depression, half had anxiety, while one third

of the parents experienced stress and one fifth of the siblings of children with ASD experienced stress. There was no statistically

significant difference when comparing the DASS scores between parents and siblings of children with ASD (Table 2).

**Table 2. Depression/Anxiety/Stress (DASS) level among parents and siblings of children with ASD**

Characteristics	Parents, n (%)	Siblings of children with ASD, n (%)	<i>p</i> value*
Depression			
Yes	8 (23.5)	9 (26.5)	0.779
No	26 (76.5)	25 (73.5)	
Anxiety			
Yes	18 (52.9)	18 (52.9)	1.000
No	16 (47.1)	16 (47.1)	
Stress			
Yes	11 (32.4)	6 (17.6)	0.161
No	23 (67.6)	28 (82.4)	

\* Chi-square test

***Comparison of Depression/Anxiety/Stress (DASS) among siblings of children with ASD and children living with healthy siblings***

DASS scores between the two groups of participating children. There was no statistically significant difference of depression, anxiety and stress between both groups.

Table 3 summarises the comparison of

**Table 3. Children evaluation of having depression, anxiety and stress between groups**

Characteristics	Siblings of children with ASD, n (%)	Children with healthy siblings, n (%)	<i>p</i> value*
Depression			
Yes	9 (26.5)	11 (32.4)	0.594
No	25 (73.5)	23 (67.6)	
Anxiety			
Yes	18 (52.9)	18 (52.9)	1.000
No	16 (47.1)	16 (47.1)	
Stress			
Yes	6 (17.6)	8 (23.5)	0.548
No	28 (82.4)	26 (76.5)	

\* Chi-square test

***The behavioural difficulties level among siblings of children with ASD in comparison with the perspective of their parent***

There was a statistically significant difference in the parental perception of the

strength and difficulties level compared to self-evaluation of siblings of children with ASD ( $p=0.039$ ). Most of the parents evaluated their children to have a very high strength and difficulties score ( $n=26$ , 76.5%) compared to the siblings of autistic children ( $n=19$ , 55.9%) (Table 4).

**Table 4. Strength and difficulties level of siblings of children with ASD (parental versus self-evaluation)**

Strength and difficulties level	Parental evaluation, n (%)	Siblings of children with ASD, n (%)	p value*
Close to average	0	7 (20.6)	0.039
Slightly raised	5 (14.7)	6 (17.6)	
High	3 (8.8)	2 (5.9)	
Very high	26 (76.5)	19 (55.9)	

\* Fisher's exact test

Among the five components of psychological attributes of the strength and difficulties questionnaire, most of the parents and siblings' evaluation were close to the average level for emotional problems, conduct problems and hyperactivity. Peer problems were rated as very high among 44.1% of parents as well as siblings of children with ASD. Half of the siblings of children with ASD rated themselves to be close to average (52.9%) and none scored very high in the prosocial score domain, while 41.2% of parents perceived their children to have a very high score in this domain.

#### *The behavioural difficulties level between*

#### *siblings of children with ASD and children living with healthy siblings*

There was no statistically significant difference of strength and difficulties level between children with autistic siblings and healthy siblings ( $p=0.090$ ). Among the five components of psychological attributes of strength and difficulties questionnaire, most of the autistic siblings and healthy siblings' children evaluation were close to the average level except for the peer problem component, where 44.1% of siblings of autistic children and 41.2% of children with healthy siblings scored themselves as very high (Table 5).

**Table 5. Children evaluation of strength and difficulties level between groups**

Strength and difficulties level	Siblings of children with ASD, n (%)	Children with healthy siblings, n (%)	p value*
Close to average	7 (20.6)	3 (8.8)	0.090
Slightly raised	6 (17.6)	4 (11.8)	
High	2 (5.9)	9 (26.5)	
Very high	19 (55.9)	18 (52.9)	

\* Chi-square test

#### *Qualitative feedback of children on the impact of their ASD siblings*

Feedback was sought from siblings of the autistic children who were included in this study by means of four open-ended questions. Areas covered included questions on how their autistic sibling's problem affected them, what are the positive outcomes of having an autistic sibling, fears

of having a sibling with autism, and the role of their parents in helping them to cope better.

When asked on how their sibling's condition had affected them, 19 responded negatively, 6 were positive, 7 provided a neutral response, and 2 children did not provide a response to this question. The negative response was regarding difficulty to focus in

their studies as they were often overwhelmed with the situation of having an autistic sibling. They also reported difficulty in sharing of interests and dealing with the manifested behavioural problems. They were worried regarding the constant attention and guidance required in managing their siblings' daily activities as well as play time. They also expressed difficulty in understanding their autistic sibling. Respondents who gave a positive feedback mentioned that they were privileged to be able to teach their sibling thus teaching them the value of patience and tolerance.

These children were also asked on the positive outcomes of having a sibling with ASD, to which 30 out of 34 children (88.2%) responded positively, 3 participants mentioned that they did not learn much and 1 provided a neutral response. Many children felt that having a sibling with ASD taught them kindness, tolerance, patience, as well as effective communication and listening skills. Some children learnt to be more grateful, independent and responsible, by appreciating their siblings and also guiding them.

When these children were asked regarding any fears that they had, 28 out of 34 children responded to this question, of which 22 out of 28 children (78.6%) expressed their fears. The children feared the future of their autistic siblings in terms of studies and career, whether their siblings will be able to lead independent lives and overcome their behavioural difficulties. Some respondents worried about the safety of their siblings and whether their behaviour could affect the public negatively.

When asked on how their parents played a role in helping them to cope with their autistic siblings, 33 out of 34 children responded to this question, of which 29 out

of 33 children (87.9%) responded positively, stating that their parents were actively involved in occupational therapy, speech therapy and special educational classes. Their parents also allocated extra attention to the autistic siblings and played an important role in teaching family members to be more understanding. Some children also mentioned that their parents encouraged and guided them to adapt. These parents also taught them how to communicate and handle problems concerning their sibling with ASD.

## **Discussion**

In Malaysia, the National Health and Morbidity Survey (NHMS) 2011 quoted a lifetime prevalence of 2.4% for depression and 1.7% for anxiety in adults [17]. A systematic review by Shivers et al on functioning of siblings of children with ASD [18] found inconsistent results, with some studies reporting negative outcomes, while others had no significant difference. Our study focused on behavioural and psychological issues related to ASD, and found that there were higher levels of depression, anxiety and stress among siblings of children with ASD compared to the general adolescent population, as reported in the NHMS 2017 [19]. We also found higher levels of depression and anxiety among parents of children with ASD as compared to general population, as reported in NHMS 2011 [17]. A study published by Al-Farsi et al in 2016 demonstrated higher levels of depression (48.6%), anxiety (45.9%) and stress (45.9%) among caregivers of children with ASD [20]. Other studies also reported higher levels of depression, anxiety and stress among caregivers [21-24], however these studies did not explore the psychological impact on the siblings of the autistic child.

A study by Orsmond and Seltzer in USA had looked into the impact of having a child with ASD on their mothers and adolescent siblings [25]. This study reported that 36% of siblings had depressive symptoms on the Centre of Epidemiological Studies Depression Scale (CES-D) compared to 19.2% of their mothers. Another study by Melli et al in 2016 which used the psychological general well being index (PGWBI) reported severe distress among 23% of parents and 47% of siblings of children with ASD [26]. Our study observed similar levels of depression and anxiety among parents and siblings of ASD children. In addition, there were more stressed parents than siblings of ASD children, although the difference was statistically insignificant.

We found a higher level of depression and stress in children with typically developing siblings as compared to siblings of children with ASD, although this difference was not statistically significant. This was contrary to a meta-analysis by Shivers et al in 2018, which found that siblings of children with ASD had significantly worse outcomes, although small in magnitudes [18]. A study by Gold utilizing the Children's Depression Inventory (CDI) as a study tool, demonstrated that the mean CDI score among siblings of boys with ASD were significantly higher than siblings of typically developing children [27]. Another study by Lovell and Wetherell in the UK which utilized CDI found that siblings of children with ASD had greater emotional and depressive symptoms compared to controls [28]. In our study, most of the children recruited were older than their autistic sibling, and this could represent a better understanding of caring for a child with ASD. These group of children were also able to reason logically, cope and relate to the situation better as compared to their younger siblings [29].

This study also explored the behavioural characteristics among siblings of children with ASD by means of the Strengths and Difficulties Questionnaire (SDQ), and found that the SDQ levels were perceived to be significantly higher by their parents compared to the self-evaluation. However, there was no statistically significant difference of strength and difficulties level between children with autistic siblings and healthy siblings via self-evaluation. A study done by Benson and Karlof found that siblings of children with ASD were perceived by their parents to have a higher rate of behavioural problems compared to the general population [30]. Another study by Hastings in 2003 reported that siblings of children with ASD were perceived by their mothers to face more difficulties in terms of peer problems, overall adjustment and prosocial behaviour compared to siblings of children with normal development [7]. However, reliance on parental report might lead to incomplete conclusions about the experiences of the siblings themselves [31]. There were limited studies where siblings of children with ASD self-evaluated the SDQ, as most studies involved a parental proxy to do so [7, 30, 32]. Our study found that the difference between the parental evaluation and self-evaluation was in the prosocial score. The result demonstrated that parents were assuming that their typically developing children were having difficulties in this domain. However, the current study did not explore the perception of other adults such as school teachers who might have evaluated the SDQ score differently.

All the participants in this study evaluated a close to average SDQ score on the domains of emotional problems, conduct problems and hyperactivity, however they evaluated a very high score in the peer problem domain. A study by Hastings and Petalas in 2014

found that more than four times the number of siblings in the study sample reported peer problems at a level within the abnormal range compared with the normative British sample [31]. A very high score on the peer problem domain could be attributed to various factors such as more time spent on the internet, social isolation or bullying in school [33]. Future research in this area could explore in further detail the reason behind the issues in the peer problem domain of the SDQ.

The subjects recruited in this study were predominantly Chinese, followed by Malays. This observation was not consistent with the NHMS 2016 maternal and child health survey which reported that the prevalence of autism in children were predominantly among Malays, followed by Chinese and Indians [34]. In our study, the Chinese children were the predominant ethnic group as the others did not meet the inclusion criteria of 11 to 17 years age range. More than half of the participants in this study were from households with a monthly income of less than RM5000.

Our study had also evaluated the social, emotional and behavioural aspects of living with a sibling with ASD. More than half of the participants had responded negatively by expressing that they are often overwhelmed when dealing with their autistic sibling. One fifth of the sib-lings of children with ASD reported positive experiences such as feelings of kindness and tolerance when dealing with their autistic sibling. A review of literature by Meadan et al in 2009 showed mixed results on adjustments by typically developing siblings of children with ASD [35]. Some of the negative outcomes in this study included a low prosocial behaviour, feelings of loneliness and fear for the future of their sibling with ASD.

*Strength and weakness of the study:* Siblings are a valuable component of a family unit, and looking into their health and development is of research and clinical significance. This study evaluated the psychological and social well-being of siblings of autistic children by obtaining the perspective of the sibling instead of only a parental proxy. The authors used a validated instrument of DASS-21 questionnaire of English and Malay language Cronbach's alpha values of .84, .74 and .79, respectively, for depression, anxiety and stress [14]. The strengths and difficulties (SDQ) questionnaire used in the study shows good concurrent validity and the internal consistency coefficients were generally satisfactory (mean Cronbach's alphas was 0.70 for the parent version and 0.64 for the self-report version) [36]. Four additional open-ended questions also elicited qualitative data which further provided a better understanding of the impact of living with a sibling with ASD.

International literature generally does not recommend the use of DASS-21 below 14 years [11]. However, with limited scales validated in 3 languages for this age group, DASS-21 is probably a reasonable option. NHMS 2017 used DASS-21 for age group of 13-17 years old [19]. We used the age group of 11-17 years old as SDQ is specific for this age group. This questionnaire was self-administered but investigators were available to assist the children if necessary. The data collection went well with the participants.

A larger sample size involving more geographical regions would be more representative and may influence the accuracy of the results. The children of Chinese ethnicity were over-represented in this study, due to unavailability of subjects of other ethnicities, thus not reflecting the

ethnic composition of the Malaysian population. The severity of ASD was not included in the design of this study. The perspective of school teachers in providing an SDQ score would have added valuable feedback.

### **Recommendation**

It would be desirable in future studies to embrace the challenge of assessing the well-being of the whole family for a more holistic approach to better manage autistic children. Clinicians and health care professionals should conduct regular assessments and be made aware of face-to-face support groups for siblings and parents.

We hope that future studies would include a wider assessment of the autistic child in terms of severity of the condition, as living with a child with severe autism may have a greater impact on the well-being of the family as compared to living with a child with mild autism. A follow up study in future involving multiple centres may yield more accurate results. We would also like to assess the well-being of siblings of a wider age group, comprising of both primary and secondary school siblings, as their perception may vary.

We wish to continue exploring and improving the experience of these siblings who will be the next generation of adults as well as parents. The aim is to allow these children to enjoy being a sibling, to optimise their development, encourage resilience, and in the long term maximise their contribution to their family as well as the community.

### **Conclusion**

The psychological well-being of siblings of children with ASD was similar to their parents and children with healthy siblings,

but poorer than general adolescent population as reported in NHMS 2017. The social well-being of siblings of children with ASD was similar to children with healthy siblings. These siblings were perceived by their parents to have higher strength and difficulties problem compared to self-evaluation.

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