C-21

Psychological and Behavioural Impact of Autism Spectrum Disorder on Siblings

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

Introduction & Objectives

Autism spectrum disorder (ASD) neurodevelopmental disorder that begins in childhood, characterized by impairments in communication, behaviour & social functioning, with a prevalence of 1.6 in 1000 children in Malaysia. Living with a child with ASD can result in significant financial, emotional and lifestyle challenges for the family and siblings. This study aimed to compare the psychological well-being of these siblings versus their parents' and general population; and their social well-being versus parents' perspective and general population.

Methodology

Study design: Cross-sectional study.

Figure 1: Methodology flow diagram

Study Group: Children with ASD attending paediatric clinics in HRPB Ipoh and HSM were identified.

Records of these children were searched to look for family tree. Siblings aged 11-17 years old were identified. A name list of eligible participant was created.

Parents of these children were contacted & an appointment was scheduled to meet the parents and siblings in Paediatric Clinic.

Parental consent and assent were obtained for siblings'. Informed consent was obtained from parents.

One parent and sibling filled in the self-administered DASS-21 and SDQ.

The sibling(s) were asked 4 additional questions on:

- 1. How has your sibling's problem affected you? 2. What are the good things
- that you have learnt from your sibling's problem?
- 3. What are your fears for your sibling?
- 4. How can your parents help you to cope better with your sibling's problem?

Control Group: 4 schools in Kinta and 1 school in Manjung district in Perak were identified and permission to conduct the study was obtained from Ministry of Education.

Appointment with principal and counsellor at selected schools was made to identify the potential students matched based on ethnicity, gender and geographical location.

Parental information sheet, consent form and first sheet of questionnaire were distributed to students to be taken home.

The researcher met again with the students, who brought signed parental consent & filled in demographic details on the questionnaire.

Assent was obtained for students' participation in the study. A copy of the parental consent and assent form were given to the students.

Students filled the selfadministered DASS-21 and SDQ.

If the participating child has 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.

Data collected and analysed.

Acknowledgement

We would like to thank all parents and children who participated in the study. The authors are grateful to the Director General of Health Ministry for his permission to present this poster.

Results

- We recruited **34 study group** pairs & **34 controls**.

A. Socio-demographics:

- 33 families in the study group (97.1%) had one child 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 & semi-routine workers while 38 (55.9%) had secondary education level.
- Majority of the mothers in both groups (n=38, 55.9%) were full time housewives while 38 (55.9%) had secondary education level.
- A total of 47 families (69.2%) in both groups had a combined monthly income of below RM5000.
- Most children were Chinese (58.8%) females (67.6%).

B. Comparison of depression, anxiety and stress (DASS) level among parents and siblings of children with ASD (Table 1)

| Characteristics | Parents, n (%) | Siblings of children with ASD, n (%) | p value* |
|-----------------|-------------------|--------------------------------------|----------|
| Depressed | 8 (23.5) | 9 (26.5) | 0.779 |
| Anxiety | 18 (52.9) | 18 (52.9) | 1.000 |
| Stressed | 11 (32.4) | 6 (17.6) | 0.161 |

* Analysed using Chi-square test

C. Comparison of DASS among siblings of children with ASD and children living with healthy siblings (Table 2)

| Characteristics | Siblings of children | Children with | p value* |
|-----------------|----------------------|---------------------|----------|
| | with ASD, n (%) | healthy siblings, n | |
| | | (%) | |
| Depressed | 9 (26.5) | 11 (32.4) | 0.594 |
| Anxiety | 18 (52.9) | 18 (52.9) | 1.000 |
| Stress | 6 (17.6) | 8 (23.5) | 0.548 |

* Analysed using Chi-square test

D. The behavioural difficulties level among siblings of children with ASD in comparison with the perspective of their parent (Table 3)

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

* Analysed using Fisher's exact test

E. Children evaluation of strength and difficulties level between groups (Table 4)

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

* Analysed using Chi-square test

F. Qualitative feedback of children on the impact of their ASD siblings:

Negative response Positive outcomes

- Having a sibling with ASD taught them kindness, tolerance, patience, as well as effective communication & listening skills.
- Some children learnt to be more grateful, independent and responsible, by appreciating their siblings and also guiding them
- difficulty to focus in their studies as they were often overwhelmed with the situation of having an autistic sibling.
- worried about the safety of their siblings and whether their behaviour could affect the public negatively

Discussion & Conclusion

Psychological well-being of siblings of ASD children were similar to their parents and controls, but poorer than the general adolescent population (NHMS 2017). Their social well-being was similar to the controls. Their parents perceived them to have higher SDQ scores.