

Effectiveness of sexual health training to parents with children of autism spectrum disorder

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ABSTRACT

Introduction: Sexual health education among individuals with autism spectrum disorder (ASD) is unique and may not be adequately addressed both at home and at school. Parents have an important role in delivering sexual health education to their children. This is a pilot study to evaluate parental awareness and effectiveness of parent sexual health training for children with ASD.

Materials and Methods: Parents of 30 children with ASD with ages ranging from 8 to 12 years attending Child Development Clinic, Hospital Pulau Pinang (CDC HPP) were recruited. Parents attended two-hour virtual parent sexual health training and educational materials were provided to be utilised at home. Follow-up via phone consultation were done at three and six months to ensure training was carried out. Both structured interview and Vineland adaptive behaviour scales (VABS-3) were done at recruitment and at eight months via phone consultation. Wilcoxon-signed rank test was used to analyse differences between pre- and post-intervention outcome measures.

Results: Statistically significant increase in number of sexual health topics taught by parents and appropriate socio-sexual behaviours of children were found. Intellectual function of children with ASD influenced the study outcomes.

Conclusion: Parent sexual health training can be done to empower parents to educate children with ASD and promote appropriate socio-sexual behaviours.

KEYWORDS:

Autism spectrum disorder, puberty, parent training, sexual health education

INTRODUCTION

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterised by persistent deficits in social communication and interaction, restricted and repetitive patterns of behaviours, interests and activities causing significant impairment across multiple settings. The US Centres for Disease Control and Prevention reported 1 in 36 children aged 8 years was estimated to have ASD in 2020.¹

Children of ASD will reach the pubertal stage just as neurotypical peers; however, they experience more emotional and social challenges during this complex period.² There has been extensive research on intervention therapy to improve

social deficits but research is relatively lacking in the aspect of sexual health among individuals with ASD.³ The reported social challenges include difficulty interpreting social cues, understanding personal boundaries and socially-appropriate behaviours.⁴ Consequently, these social challenges are frequently misinterpreted as inappropriate sexual behaviours with their mature physique. Additionally, systematic review revealed that individuals with ASD have greater difficulty adhering to privacy norms and receive less formal and informal sexual health education, leaving them more disadvantaged.⁵

Barnett et al., found that those individuals with ASD in special education placement were not receiving formal sexuality education.⁶ In addition, adolescents with ASD often have fewer friends and lesser informal learning from peers compared to neurotypical peers.⁷

The American Academy of Pediatrics recommends that parents help their children, both those with and without disabilities, understand sexuality in a healthy way, at early ages as they grow to adulthood.⁸ Ample studies recommend parents as the primary provider of sexual education for their children or adolescents with ASD.^{4,9,10} However, parents are often clueless about approach, timing, information and strategies to discuss with their children.^{3,10} Healthcare providers and educators are in a better position to provide training, resources, and encouragement to these parents.^{9,11} Wight D et al. showed that parents who received training on sexual education had better communication with their adolescents regarding sexual health as compared with those who did not.¹²

Recommended sexual health topics for adolescents with ASD by Beddows N et al., are puberty body changes, social rules, personal boundaries and touch, differences between public and private places and behaviours. Again, it highlighted that parents need to provide continuity of sexual education.¹³ This recommendation was supported by Davies AWJ et al. with emphasis that children should be educated before puberty.¹⁴

Current research suggests that children should be prepared for physical changes associated with puberty before onset of menarche, erection, and nocturnal emissions. For girls with ASD, education on puberty should preferably take place between eight and ten years, before onset of menarche. This may shift to earlier years as girls are reported as having earlier puberty these days.¹⁵⁻¹⁷ Teaching proper hygiene prior to menarche is essential to prepare girls with ASD to manage menstruation.¹⁰ Parent-child communication and education

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on sexuality should ideally begin in early childhood and continue through early adulthood and be given at appropriate levels for individuals' with ASD's development and functioning.¹⁸

Two local studies which explored maternal perspectives on sexual education for their children with intellectual disability showed variable degrees of maternal awareness. These studies highlighted the need to increase parental awareness and appropriate delivery of sexual education, possibly with shared responsibility among all relevant stakeholders.^{19,20}

There is a need to increase the parental awareness as the primary provider of sexual health education for their children with ASD. Sexual health training by health care professionals to parents of children with ASD can provide the necessary guidance and framework for parents to be empowered to educate their children in preparing for adolescence. To our knowledge, this is a first local study to evaluate awareness on sexual health education among parents of children with ASD. We also aim to ascertain the effectiveness of parental training on sexual health education for their children with ASD at Child Development Clinic, Hospital Pulau Pinang.

MATERIALS AND METHODS

This study included children with ASD and their parents who attended Child Developmental Clinic, Hospital Pulau Pinang (CDC HPP) from November 2020 to April 2022. Inclusion criteria were children aged 8-12 years old with ASD. Exclusion criteria were children with ASD with visual or hearing impairment. Diagnosis of ASD was made by a developmental paediatrician by meeting the Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-5; American Psychiatric Association (APA), 2013) criteria. 70 children were identified, of which 33 children and their parents were recruited. All parents provided written consent for their participation. Thirty parents completed the study at the final stage.

This is a quasi-experimental pre- and post-intervention study without a control group. The intervention is a two-hour virtual sexual health training given by CDC HPP team with the presence of a developmental paediatrician. Training materials from the virtual sexual health training were given to parents to supplement training of their children at home. Training progress, utilisation of training materials and other parental concerns were enquired during telephone consultations at three and six months after intervention.

As this study was designed during the COVID-19 pandemic with enforced social distancing, sexual health training, follow-ups and data collections were conducted via telehealth (mainly telephone consultation without physical contact). Parents underwent two interview sessions, before and eight months after intervention. Parental interview which was based on a self-designed questionnaire on sexual health (Appendix 2 and 3) and Vineland Adaptive Behaviour Scale-3 Comprehensive Interview Forms (VABS- 3) were conducted by the principal investigator who is proficient in Malay, English and Mandarin language. These interviews were done before intervention and at eight months after intervention.

The Vineland Adaptive Behaviour Scale-3 (VABS-3) is a standardised assessment tool that measures adaptive functions which include communication, daily living skills and socialisation in daily life. Parent satisfaction scale was completed at the end of study period at eight months (attached in Appendix 3).

The content of the parent sexual health training was obtained from two resources, 'Training module "Live life, stay safe" reproductive health for children and adolescents with disabilities' by Family Division Development Division, Ministry of Health, Malaysia and 'The Healthy Bodies Toolkit for boys and girls - Parent's Guide on Puberty for Boys and girls with Disabilities' by Vanderbilt Leadership Education in Neurodevelopmental Disabilities (LEND).

The topics covered during the parent sexual health training were as follows:

- I. Body parts including public and private parts.
- II. Puberty changes in males and female including menstruation.
- III. Personal hygiene.
- IV. Differentiate public and private places and behaviours.
- V. Circle of relationship.
- VI. Differentiate safe and unsafe touch.
- VII. Safety skills when encountering unsafe touch.

Each topic contained directions and activities supported by visual representations to enhance comprehension among individuals with ASD.

This study obtained approval from the Medical Review & Ethics Committee (MREC), Ministry of Health Malaysia, NMRR – 20 -1993 – 56284. Recruited children and parents were provided code numbers throughout study period and these codes were used in all the research documents with no mention of names or identity numbers to ensure privacy and confidentiality. All the study data including the pen drive with electronic files were stored securely at CDC HPP.

Data Analysis

In view of the small number of subjects (N=30) and non-normally distributed data, non-parametric tests of statistical analysis were selected. Wilcoxon-signed rank test was used to analyse the differences between pre- and post-intervention outcome measures. Mann-Whitney U test was used to analyse the relationship between two independent variables. Spearman rho's coefficient was used to explore potential correlation between the outcome measures. Statistical analysis was performed using SPSS Statistic-28.

RESULTS

Demographic data

The demographic data of both children and parents are presented in Table I.

For this study, the ASD severity was categorised into three levels by integrating the severity specifier of both social communication (SC) and restricted, repetitive behaviours (RRB) domains. Children with similar severity specifiers of level 1, 2 and 3 for both SC and RRB domains were categorised as mild, moderate and severe ASD respectively.

Table I: Characteristics of children and parents who participated in parent sexual health training.

Characteristic of children	N=30	%
Age (years)		
8-9	14	46.7
10-12	16	53.3
Gender		
Male	24	80
Female	6	20
ASD severity		
Mild	7	23.3
Moderate	20	66.7
Severe	3	10
Intellectual function		
Intellectual disability	22	73.3
Without intellectual disability	8	26.7
School		
Integrated Special Education Program	16	53.3
Inclusive Education Program	4	13.3
Mainstream	8	26.7
Home-school	2	6.7
Characteristic of parents (N=30 parents)		
Participation in parents training		
Mother	25	83.3
Father	5	16.7
Age of parents (years)		
<40	11	36.7
40-50	19	63.3
Education level		
Secondary education	8	26.7
Diploma equivalent	8	26.7
Bachelor's degree	13	43.3
Master's degree	1	3.3

Table II: Parental perception and satisfaction about sexual health education.

Parent interview questionnaires	Parents, N=30 (%)	
	Yes	No
Do you think that sexual health education is important for your child with ASD?	25(83.3)	5(16.7)
In your opinion, who should deliver sexual health education to children of ASD?		
Parent	27 (90)	
Teacher	3 (10)	
When is the suitable time for you to educate your child with ASD on sexual health education?		
8-12 years old	16 (53.3)	
13-17 years old	14 (46.7)	
Parental satisfaction with sexual health training	25(83.3)	5(16.7)

Table III: Median scores for outcome measures in pre- and post-intervention.

Outcome measures	Pre-intervention		Post-intervention		p-value
	Median	25th-75th percentiles	Median	25-75th percentiles	
Numbers of sexual health topics covered by parents	0	0-3.3	2.5	0-8	<0.001 ^b
Parent-reported appropriate socio-sexual behaviours	4.5	4-7	8.5	4.8-10	<0.001 ^b
VABS-3					
Socialisation domain	59	39.5-63.3	59	40-65	0.011 ^b
Adaptive behaviour composite	62	50.8-68.3	63	53.5-68	0.568

^b p <0.05, statistical significance from paired-sample Wilcoxon-signed rank test

Table IV: Predictor factors affecting the outcome measures.

Predictor factors	Outcome measures, p-values			
	Numbers of sexual health topics covered by parents	Parent-reported Socio-sexual behaviours	VABS-3	
			Socialisation domain	Adaptive behaviour composite
Subjects				
Intellectual function	<0.001 ^c	<0.001 ^c	0.04 ^c	0.01 ^c
Age	0.697	0.294	0.313	0.275
Gender	0.104	0.900	0.143	0.158
Parents				
Education level	0.667	0.918	0.334	0.637

^c p<0.05, statistical significance from independent-samples Mann-Whitney U Test

For those with variable severity specifiers for both domains, the categorisation was based on the higher severity specifier of either domain.

Parents who felt that sexual health training is not important cited training for daily living skills and academic skills as a higher priority for their children. Among parents who voiced dissatisfaction with sexual health training, three parents of children with moderate to severe ASD and significant intellectual disability indicated no benefit while two parents were concerned that sexual health education may expose their children to sexual information and arouse curiosity toward sexuality.

Protection from sexual victimisation or exploitation (40%) and worries about inappropriate sexual behaviours in public (30%) were the two main concerns stated among parents in our cohort. Understanding social boundaries and preparation for marriage were indicated among 26.7% and 3.3% of our parents respectively.

Outcome measures

As observed from Table III, the intervention produced consistent and statistical significant improvement across most of the outcome measures, except for Adaptive Behaviour Composite in VABS-3.

Intellectual function of the subjects was the only statistically significant predictor factor of the outcome measures as indicated in Table IV.

We administered additional analysis with Spearman' correlation to determine the relationship between the study intervention and outcome measures. There were moderate positive and statistically significant correlation between the numbers of sexual health topics covered by parents in the study intervention with all the outcome measures at post-intervention ($r=0.822$, $r=0.828$, $r=0.721$, $p<0.001$).

DISCUSSION

To our knowledge, this is the first local study assessing outcomes of parent training on sexual health among children with ASD at Child Development Clinic. Our findings were consistent with previous research regarding parental awareness.^{3-4,9,11,21} Majority of parents in this study are aware of the importance of sexual health education (83.3%) and that they played a major role in educating their children

(90%). Parents of our study reported limited knowledge, professional support, and available resources on sexual health education.

Concerns about children with ASD having inappropriate sexual behaviours and being at risk of sexual abuse or victimisation were addressed by parents of this study group. Even though there has been a proliferation of evidence-based autism-related intervention, resources on sexual health education among children with ASD is limited. Parents across different regions faced similar concerns and challenges in supporting children with ASD.^{3-4,9,10,21} Improvement in parental engagement after the training is expected and our results are no different from other similar studies.^{3-4,21} Parents will be empowered to discuss sexual health topics with their children once they have appropriate training and support from professionals. 83.3% of parents of this study expressed their satisfaction and benefited from this intervention. A few parents of this study would like to have more complex sexuality topics in the future which include intimacy and pregnancy.

With better parental engagement on sexual health topics, parents in our cohort reported a significant decrease in inappropriate socio-sexual behaviours among their children at the end of the study period. This positive correlation between the intervention and socio-sexual behaviours was statistically significant. Again, it strongly supports that parent sexual health training with professional support can promote better socio-sexual behaviours among children with ASD.²² This short-term parent sexual health training is effective in helping our parents to guide their children with ASD in understanding basic sexual health before embarking to more complicated areas of sexuality such as romantic relationships and pregnancy.

Our results showed that intellectual function was the only statistically significant predictor outcome for outcome measures where children with ASD without intellectual disability showed significant improvement in numbers of sexual health topics covered by parents, parent-reported socio-sexual behaviours, socialisation domain and adaptive behaviour composite of VABS-3. In our study, children without intellectual disability were taught by their parents about puberty changes, circle of relationship and menstruation for girls. Children with intellectual disability were taught on recognition of public and private body part, public and private places, and appropriate behaviours. These

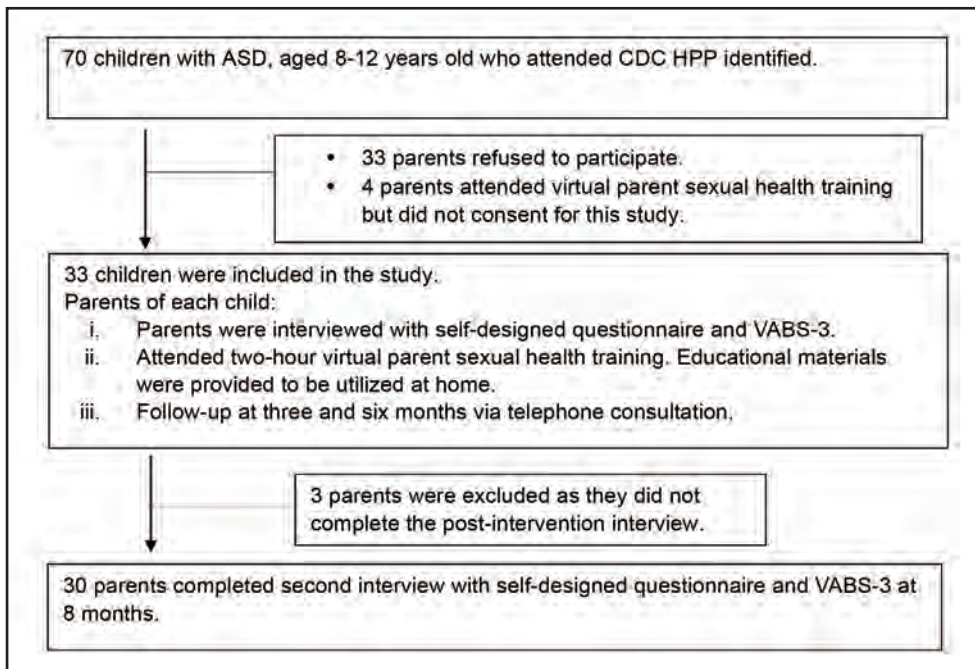


Fig. 1: Flow chart on patient recruitment

findings were consistent from previous studies indicating that the intellectual capacity of children with ASD influenced parental communication on sophisticated sexuality-related topics.^{3,9} This could be due to parental perception that certain sexual health topics were irrelevant for their children with intellectual disability.³ Perhaps the approach and materials of the sexual health education may not be suitable for children with lower intellectual capacity. There is a need to address these concerns in future studies.

We also found positive changes and correlations in the socialisation domain of VABS-3. VABS-3 has not been utilised as a measurement tool for socio-sexual behaviours in previous research on sexual education. The socialisation domain of VABS-3 includes interpersonal relationship, play and leisure and coping skills. We postulated that the basic concepts of appropriate socio-sexual behaviours at private and public places and behaviours and ‘safe and unsafe touch’ from the intervention had positively influenced interpersonal relationship skills.

LIMITATIONS

This study has several limitations. The small sample size may affect generalisation of results to general population. There is a likelihood of recall bias as the occurrence of appropriate socio-sexual behaviours was based on parental report. Apart from that, during the COVID-19 pandemic there was limited social situations in general. In fact, a large majority of children were highly vigilant about ‘social distancing’, as healthcare providers repeatedly emphasised this during the pandemic. The rather short study duration is another limitation.

CONCLUSION

Our findings suggest that parent sexual health training is effective in empowering parents to teach their children with ASD. This basic sexual health training can be provided to parents by trained healthcare provider at various healthcare sites either virtually or physically, providing an early start to communication and education on sexual health between parents and their children with ASD. It is important to tailor the training and resource materials according to the intellectual capacity of children with ASD.

Future studies with a larger sample and stratification based on intellectual function may provide more data on effectiveness of parent training that can be carried out not only in CDCs but also at general paediatric and primary health clinics for children with special needs.

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