Teaching Sexuality Education to Children with Autism Spectrum Disorder from Muslim Mothers' Perspectives

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Abstract

Sexuality education is an extremely crucial and sensitive issue, especially in Eastern countries such as Malaysia. Muslim parents are struggling with issues surrounding the sexuality of their children with autism spectrum disorder (ASD). This article presents a study conducted to explore Muslim mothers' perspectives on teaching sexuality education to their children with mild ASD. The study used semi-structured interviews with five mothers selected via a purposive sampling technique following three main criteria. The findings analysed using Interpretative Phenomenological Analysis (IPA) have identified several strategies which mothers used, namely: (1) social stories; (2) repetition and reminders; (3) visual aids and demonstrations; (4) seeking help from other people and experts; and (5) spiritual approach or Islamic teachings. Overall, the experiences were meaningful as reported by the Muslim mothers involved in this study. Therefore, this article aims to disseminate an awareness on the role of mothers of children with ASD in teaching informal sexuality education at home, and that the mothers' experiences in this matter are vital to shedding light on the issue of misunderstandings related to the sexuality of individuals with ASD.

Keywords:

Autism spectrum disorder (ASD), Muslim mothers, sexuality education, teaching strategies.

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Introduction

Autism spectrum disorder (ASD) or autism is related to the development of the brain that involves a diverse group of conditions. Individuals with ASD are characterised by a certain degree of impairment in social skills, communication, and atypical patterns of behaviour such as restrictive, repetitive behaviour, and unusual reactions to sensations.² According to the National Autism Society of Malaysia (NASOM), the approximate number of children born with ASD is 9,000 every year.³ According to the data as of 30th June 2022, there are 36,601 individuals diagnosed with autism in Malaysia, and from that number, it is reported that 24,748 individuals are children under the age of 12.4 Individuals with ASD also have the desire to form intimate relationships with others and participate in various forms of sexual behaviours like most young individuals.⁵ Thus, providing sufficient knowledge and understanding on sexuality to these individuals is crucial as they are exposed to many negative experiences such as inappropriate behaviour, sexual abuse, and loneliness among others.⁶ Unfortunately, many parents are unprepared for the kinds of expression that individuals with ASD portray to convey their behaviours, thoughts, and desires pertaining to sexuality just like individuals with typical neurodevelopment. Parents also reported having little knowledge about sexuality themselves, with limited resources and teaching materials as well as a lack of confidence to teach their children with ASD about sexuality education.

Sexuality is a fundamental component of human life. It is defined as "an expression of identity through gender (male and female). It is a personal and private feeling that involves understanding of one's own sexual responses

^{1.} WHO, "Autism," World Health Organisation, 15th November 2023, https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders.

Ibid.

Ruth Selvaranee Arunasalam and Rohana Jani, "Understanding autism through intervention programs," *International Journal for Studies on Children, Women, the Elderly and Disabled* 4 (2018): 53–62.

^{4.} Bernama, "Kerajaan berhasrat tubuh lebih banyak PPDK fokus anak autism," *Bernama*. com, 10th Septembe 2022, https://www.bernama.com/bm/ekonomi/news_pemerkasa. php?id=2119293

See Hillary H. Bush, Lindsey W. Williams and Eva Mendes, "Brief report: Asexuality and young women on the autism spectrum," *Journal of Autism and Developmental Disorders* 51 (2021): 725–733.

See Kathrin Hartmann et al. "Sexuality in the autism spectrum study (sass): Reports from young adults and parents," *Journal of Autism and Developmental Disorders* 49 (2019): 3638–3655.

Nawal Nabilah Kamaludin et al., "Barriers and concerns in providing sex education among children with intellectual disabilities: Experiences from Malay mothers," *International Journal* of Environmental Research and Public Health 19, no. 3 (2022): 1070.

and emotions." It is a natural right of all persons regardless of their physical and cognitive disabilities to receive sexuality education that is free of coercion, discrimination, and violence. Sexuality education, on the other hand, is a new concept that aligns itself with the notion of human rights of the new era which prioritise education and public health. It is known by different labels such as Comprehensive Sexuality Education (CSE); Relationships and Sex Education (RSE); Sexuality and Reproductive Health (SRH); Holistic Sexuality Education, Life and Living Skills; Sex Education; and Sexuality Education. Sexuality education addresses a broad range of the different dimensions of sexuality—ranging from biological, socio-cultural, psychological, and spiritual dimensions to cognitive, affective, and behavioural dimensions which include the skills for effective communication and making an informed or responsible decision. A sexuality education that is embedded with Islamic values could provide the right information needed by individuals with ASD, delivered via the most proper channel, that is, their parents, to avoid misconducts.

Sexuality Education in Malaysia

In Malaysia, sexuality education has been included in the national curriculum since 1989, to be taught twice a week. ¹⁰ This topic is taught only marginally in subjects such as Islamic Studies, Physical Education, and Biology in Malaysian schools. ¹¹ Furthermore, it only covers limited aspects of the topic such as the physical developments of sex organs, the fertilisation of the male and female gametes, the lawfulness and unlawfulness of behaviours surrounding the topic of sexual intercourse, the virtue and importance of abstinence, and so on without any relatable values imparted in the lessons. The information given in sexuality education in Malaysian schools is said to be lacking, unclear, limited, and inadequate to guide students and young individuals. ¹² In 2011, after the debates revolving around the inadequate trainings received by teachers in implementing the teaching of sexuality education became a cause for concern, the sexuality module was renamed to Reproductive Health and Social Education or *Pendidikan Kesihatan Reproduktif dan Social* (PEERS), and is presently taught as

^{8.} Nik Rubiah Nik Abd. Rashid and Lim Siow Yen, "Understanding sexuality," *MyHealth Ministry of Health Malaysia*, 27th April 2012, http://myhealth.moh.gov.my/en/understanding-sexuality/

^{9.} Muhammad Aftab Khan et al., "Chapter One: An overview of sexuality education in the modern world," in *Sexuality Education from An Islamic Perspective* (Newcastle: Cambridge Scholars Publishing, 2020), 3.

Najihah Shuib, Nurfitrianti Misheila and Nur Hidayah Zabarani, "Implementation of sexuality education for students with special needs (learning disabilities)," *International Journal of Education and Pedagogy (IJEAP)* 2, no. 4 (2020): 379–390.

^{11.} Johari Talib et al., "Analysis on sex education in schools across Malaysia," *Procedia-Social and Behavioral Sciences* 59 (2012): 340–348.

^{12.} Ibid.

one of many chapters in the Health Education subject. ¹³ In the same year, the curriculum was formally established in the Special Education (*Pendidikan Khas*) to be taught in the Special Education Schools (*Sekolah Pendidikan Khas*). ¹⁴ Some elements of sexuality education are taught at the Special Education Schools, but, unfortunately, they are not fully taught by the teachers, and even the ones that are taught are done so rather vaguely. Hence, the effort to teach sexuality education to individuals with learning disabilities is found to be less effective because the problem of sexual misconduct among students with special needs is still widely reported by the local media. ¹⁵

Malaysia is a country populated largely by Muslims which created a rather conservative religious ambience. ¹⁶ This has been the cultural and religious canvas which envelops the norms of the Malaysian society. As such, the term "sex education" is not officially used in our education system since it conveys a negative connotation and is still perceived as a taboo due to the concern somewhat unjustifiably—that the information would encourage young people to act out their sexual knowledge. It is against this background that Muslim parents are struggling to teach proper sexuality education to their children especially those with children with ASD. Islamic inputs in this sensitive subject are sought after as a guide for teaching values surrounding sexuality to young individuals with ASD. Children with ASD, just like other children, rely entirely on their parents and caregivers for information pertaining to sexuality education from an early age before they reach puberty. According to a Muslim scholar specialised in the topic of children education, Abdullah Nasih Ulwan, there are three stages of teaching sexuality education to young children: (1) the tamyīz stage, (2) the murāhagah stage, and (3) and the bāligh stage as shown in Table 1. 17

^{13.} Nawal Nabilah et al., "Barriers and concerns."

^{14.} Chai Tin Ang and Lau Wah Lee, "Sexuality education curriculum content for Malaysian students with learning disabilities," *Sexuality and Disability* 34 (2016): 255–267.

^{15.} Shariza Said, "Pembangunan modul latihan pendidikan seksualiti untuk guru program pendidikan khas integrasi (PPKI) peringkat sekolah rendah," PhD thesis, Universiti Malaya, 2017.

^{16.} Refer to "Stats Geoportal," *Jabatan Perangkaan Malaysia*, accessed on 18th October 2023, https://statsgeo.mycensus.gov.my/geostats/mapv2.php#

^{17.} Abdullah Nasih Ulwan, *Pendidikan Anak-Anak dalam Islam*, trans. Syed Ahmad Semait (Singapore: Pustaka Nasional Pte. Ltd., 1988).

Table 1 Sexuality topics according to stages for teaching sexuality education in Islam.

Stage (age)	Topics on sexuality
Tamyīz (7–10 years old)	1) Identifying self-identity and self-value regarding the reproductive organ/ biology; 2) Identifying and distinguishing between sexes—males and females; 3) Cleanliness before and after relieving oneself; 4) Bedroom separation between siblings of different sexes; 5) Permission-seeking before entering parents' room; 6) The manner of the eyes and the virtue of lowering one's gaze.
Murāhaqah (10—14 years old)	 The functions of different body parts; Awrah between males and females; The social limits between males and females; Modesty and honour; Avoiding sexually arousing topics.
Bāligh (14–16 years old)	1) Understanding puberty; 2) The religious, health, psychological, and emotional consequences of premarital sex.

Puberty and the Sexuality of Individuals with ASD

Puberty, or *bāligh* in Islam, is a normal developmental process in the physical, emotional, and psychological terms. It occurs to all healthy individuals, marking the healthy development of the ability to reproduce and become active sexually. It is an *ijmā* among the *fuqahā* that, for females, puberty is attained upon the first menstruation (*hayd*); meanwhile, for males, it is indicated by the experience of their first "wet dreams" or nocturnal emissions. For females, puberty can take place as early as nine years old and as late as fifteen years old; while, for males, the age range is between nine and sixteen years old. On average, the age of puberty begins between eight and thirteen years old in females, and between nine and fourteen years old in males. For individuals with ASD, the age range for puberty is no different from normal individuals. During the adolescence period, physical and sexual maturity takes place. This period is

^{18.} Logen Breehl and Omar Caban, "Physiology, puberty," in *StatPearls* (Treasure Island (FL): StatPearls Publishing, 2023).

^{19.} Wan Azhar Wan Ahmad, "Religious status of minors," *The Star*, 18th August 2009, accessed on 19th October 2023, https://www.ikim.gov.my/index.php/2009/08/18/22426/

^{20.} Aina Mazwin Mohamed Radzi, "Persediaan emosi menghadapi akil baligh: remaja Perempuan," MYHEALTH Official Portal, Ministry of Health Malaysia, 4th January 2016, accessed on 19th October 2023, http://www.myhealth.gov.my/persediaan-emosi-menghadapi-akil-baligh-remaja-perempuan/

^{21.} Breehl and Caban, "Physiology, puberty."

also marked by an increase in the adolescents' sense of personal autonomy and social immaturity as can be observed in their risk-taking behaviour, as well as an increase in spontaneity which makes them more susceptible to various issues regarding sexual and reproductive health.²² At this critical stage of their development, parents must attend to their children's inquiries and needs because their bodily changes can be quite an uncomfortable experience for them.

Parents or guardians of children with ASD often face overwhelming adversity in taking care of their children's needs, especially mothers, as they seem to be carrying the heavier burden of caring for the child.²³ However, because of their position as the primary caregivers to individuals with ASD, parents or guardians are considered the most relevant party to teach sexuality education. It is assumed that a mother can be a good assistant to a daughter with ASD, while a father to a son with ASD. However, there should be a limit to the extent of help offered by parents. In Islamic teaching, it is not advisable even for parents or any adults to touch their children's genitalia or private body parts unnecessarily or directly with their hands even when they are still babies or toddlers, and it is even more strictly prohibited when the touch appears to be sexual.²⁴ Therefore, this matter should be handled with great care because inappropriate or unnecessary touch can affect children's sexuality psychologically and emotionally. Of course, parents are required to educate or supervise their children, but the implementation must be conducted by the children themselves, with both their public and private concerns being safeguarded cautiously.

The approach to teaching sexuality education to individuals with ASD is different from that of typical neurodevelopmental individuals. Thus, it is essential to learn about the experiences of teaching sexuality education from mothers of children with ASD themselves to plan for future interventions suitable for this group of individuals. Notably, many mothers/parents have done their homework, and that they may be knowledgeable about children with ASD as well as the pedagogy required.²⁵ However, in Malaysia, there is a limited number of studies conducted to explore parents' involvement in the teaching of sexuality education to their children with ASD, especially at home.

^{22.} Donna M. Denno, Andrea J. Hoopes, and Venkatraman Chandra-Mouli, "Effective strategies to provide adolescent sexual and reproductive health services and to increase demand and community support," *Journal of Adolescent Health* 56 (2015): 22–41.

^{23.} See Sigan L. Hartley, Leann Smith DaWalt, and Haley M. Schultz, "Daily couple experiences and parent affect in families of children with versus without autism," *Journal of Autism and Developmental Disorders* 47, no. 6 (2017): 1645–1658; Hazlina Abdullah et al., "The challenges in raising autistic children: the voices of mothers," *International Journal of Evaluation and Research in Education (IJERE)* 11, no. 1 (2022): 78–87.

^{24.} Stephen R. Munzer, "Examining nontherapeutic circumcision," *Health Matrix: The Journal of Law-Medicine* 28, no. 1 (2018): 1–77.

Andrea Reupert, Joanne M. Deppeler, and Umesh Sharma, "Enablers for inclusion: The perspectives of parents of children with autism spectrum disorder," *Australasian Journal of Special Education* 39, no. 1 (2015): 85–96.

Much research that has been carried out focuses only on the experiences of teachers, ²⁶ and not that of parents as the primary caregivers. Previous studies in Malaysia related to sexuality education also do not focus on individuals with ASD specifically but the individuals or students with special needs or learning disabilities in general. ²⁷ For this reason, this article aims to fill this gap with the study conducted to learn the experience of teaching sexuality education to children with ASD from Muslim mothers' perspectives, particularly in terms of the strategies used.

Methodology

This study made use of a qualitative approach wherein semi-structured interviews with an Interpretative Phenomenological Analysis (IPA) were conducted to explore Muslim mother's experiences in teaching sexuality education to their children with ASD. The qualitative method allows the researcher to study the phenomenon of interest without being restricted by any predetermined framework and enables the participants to freely narrate their life experiences on this matter. IPA is a contemporary method in qualitative research that allows the researcher to get detailed examinations of positive psychological phenomena which are, in this case, the experiences of Muslim mothers in teaching sexuality education to their children with ASD.

Settings

This study was carried out in the states of Selangor and Kuala Lumpur involving participants who live around these regions. This is mainly due to the high prevalence of autism in Selangor as compared to other states of Malaysia. The location was also chosen because of the high population density of the region, mainly Malay Muslims.

^{26.} Najihah Shuib, Nurfitrianti Misheila, and Nur Hidayah Zabarani, "Implementation of sexuality education for students with special needs (learning disabilities)," International Journal of Education and Pedagogy (IJEAP) 2, no. 4 (2020): 379–390; Adibah Hanim Ab Latif, Mohd Hanafi Mohd Yasin, and Mohd Mokhtar Tahar, "Tahap pengetahuan pedagogi isi kandungan (PPIK) guru pendidikan khas mengenai pendidikan seksualiti," Proceedings International Conference on Special Education in Southeast Asia Region 8th Series (ICSAR 2018) (2018): 9–16.

^{27.} Ruayah@Doren Herman, "Model kesediaan guru Pendidikan kesihatan dan seksualiti Pendidikan khas program integrasi murid bermasalah pembelajaran sekolah rendah," PhD thesis, Universiti Pendidikan Sultan Idris, 2017.

^{28.} Muhammad Aminnuraliff, "Autisme catat bilangan tertinggi di Selangor," *Sinar Harian*, 6th April 2019. https://www.sinarharian.com.my/article/22123/edisi/selangor-kl/autisme-catat-bilangan-tertinggi-di-selangor.

Participants

There are five Muslim mothers of children diagnosed with mild ASD aged 7–26 years old who were involved in this study. Only the mothers were involved in this study, and this choice was made based on the premise that they actively play the role of primary caregiver to their children.²⁹ Since these mothers spend the most time with their children, they are the ones who have the most opportunities to provide sexuality education at home. The description of the participants involved in this study is shown in Table 2.

Table 2 Background of the research's participants

Participant/ Mother (M)	Marital Status	No. of children diagnosed with ASD	Age of children during the time of the interview (2022)	Sex of children
M1	Mother (married)	1	12 years old	Boy
M2	Mother (married)	1	15 years old	Boy
M3	Mother (married)	1	7 years old	Boy
M4	Single mother	1	13 years old	Boy
M5	Single mother	3	26 years old* 25 years old 20 years old	Girl/Female Boy/Male Girl/Female

Note: *The eldest daughter of M5 had passed away at the age of 26 years old.

Procedure

The participants above were selected through a purposive sampling technique based on the following criteria: (1) the mothers have experience in teaching their children about sexuality; (2) their children have been diagnosed with mild ASD; and (3) the children's ages are 25 years and below. The participants were also selected from the snowball sampling technique whereby the researcher was introduced to the other potential participants by the mothers themselves. Then, all the participants were briefed on the purpose of this study and that their information would be used for research purposes only. For this reason, the researcher only used pseudonyms for every participant, and data analysis was

^{29.} Valerie L. Braunstein et al., "The inclusion of fathers in investigations of autistic spectrum disorders," *Research in Autism Spectrum Disorders* 7, no. 7 (2013): 858–865.

made accordingly. The data collected were kept confidential by the researcher throughout the study and even upon completion. The interview sessions with every research participant commenced as soon as the participants agreed to be interviewed. The interview sessions were conducted flexibly and most lasted usually around 60 minutes. The interviews were conducted in either one of two forms: face-to-face interview and, upon the participants' request, online interview. Audio and video recordings as well as notetaking were done with the participants' consents. Then after, transcriptions of the interviews were made, reread, and analysed by identifying certain words or terms that were regularly used to be grouped as a theme. The exact same processes were repeated for all participants. All the transcriptions were done within a short period of time to allow for verification by the participants as well as to follow-up for further explanations or clarifications from the participants regarding the data to ensure the validity of the data collected.

Findings and Discussion

The findings from the study have identified a few themes regarding the strategies that the mothers of children with ASD have utilised to teach sexuality education, namely (1) social story, (2) repetition and reminder, (3) visual aids and demonstrations, (4) seeking help from the experts and other people, and (5) spiritual approach.

Social Story

Social stories are commonly used by parents and therapists to teach children with ASD a variety of knowledge, skills, and behaviours.³⁰ The aim of social stories is also to outline some special situations or events that prepare the children for a specific topic, skill, or event since they need to be prepared for unexpected circumstances and would be struggling in such situations. The social stories used by mothers of children with ASD cover various topics such as the differences between male and female, body parts, privacy, safe and unsafe touch, menses, and so on. For example, the M4 mentioned that her son needed to know what to expect because he could easily get anxious. Hence, M4 utilised social stories to prepare his son for the changes that would occur during puberty. Among the sexuality topics she had covered were safe and unsafe touch, relationships, as well as public and private places, in which she said, in transcript:

^{30.} Salmihah Che Mud, Fariza Md Sham, and Manisah Mohd Ali, "Kaedah pengawalan tingkah laku bagi anak mengalami autism," *Al-Irsyad: Journal of Islamic and Contemporary Issues* 6, no. 2 (2021): 733–744.

Close the door, this is dangerous for people to see, you know we must give more social stories. In fact, social story is non-stop with him. He can't be surprised; he has an anxiety disorder. So, we like to be prepared for anything we don't want, (or) want to explain to him. For example, "When you grow up you cannot touch, not when grow up only, you go to school, make sure you play, with girls or boys, you cannot touch this or that. Ok, you cannot touch their private parts; you cannot touch their bodies. You can play but there are limits, ok. You can touch a shoulder but do not touch..." you know. The courtesy is something that we (I) have taught him since small.

The second mother (M2) also incorporated social stories as a tool to educate her son about touch as well as public and private matters. In this context, M2 explained:

In terms of sexuality, we have not yet gone in deep about that. But we have given him a social story like what he can do, he cannot do. Like when he meets a girl/woman, he should not shake her hand, hold or touch (her). There is one time when he suddenly follows (on Instagram) someone who is quite sexy...So, from there, we do a social story... He washes himself. He enters the toilet; he will bring all his clothes. Meaning that he steps out from the toilet fully covered. He never goes out with boxers only. He used to be naked, but we do social stories. So, now he goes in with the towel and clothes, and he goes out in new clothes...My son, everything must be made into a social story. If verbalised, he cannot quite understand it...

In fact, social stories have been used widely to teach children with ASD to understand social situations.³¹ The method of social stories was developed by Carol Gray in 1991.³² It was used to exchange information that is personalised and illustrated with individuals with ASD. Social stories are commonly simple, and short, and have defined criteria to be called "social stories."³³ It can be created by anyone as long as they include specific elements in it. Social stories also help in managing expectations among individuals with ASD by sharing exact information, promoting social understanding, and reducing inappropriate

^{31.} Parisa Ghanouni et al., "Social stories for children with autism spectrum disorder: Validating the content of a virtual reality program," *Journal of Autism and Developmental Disorders* 49, no. 2 (2019): 660–668.

^{32.} Zuliza Mohd Kusrin et al., "Intervensi individu dengan autism berkaitan tingkah laku seksual," *MANU* 31, no. 1 (2020): 121–137.

^{33.} National Autistic Society, "Social stories and comic strip conversations," *National Autistic Society*, 21st August 2020, https://www.autism.org.uk/advice-and-guidance/topics/communication/communication-tools/social-stories-and-comic-strip-coversations (accessed on 10th September 2023).

sexual behaviours.³⁴ Parents who used social stories in their effort to teach their children with ASD found that social stories were quite helpful in describing events, activities, and social norms about which they wanted the child to know. This is in parallel with the findings from the previous studies which show that social stories used in sexuality education to individuals with ASD have resulted in significantly improved knowledge pertaining to aspects of sexuality.³⁵ A pilot study following three women with ASD also found that social stories are effective in explaining menstrual care, increasing knowledge about reproductive development in women, and promoting independence in managing menses.³⁶

Repetition and Reminder

Most parents stressed the need to consistently repeat and remind children with ASD about everything that they should know or understand. Thus, most mothers mentioned repetition and reminders to teach their children with ASD about sexuality, as the latter might not learn the skills or activities straight away. Children with ASD also easily forget what they have been told, so parents need to repeat it from time to time whenever necessary. For example, M1 described her experience as follows:

Repeat many times until at one stage he can differentiate. It must be told every day, not just that one time only. Every day or often when have time, remind him...So, for children with special needs, we must remind them. When they forget, we must remind them again...I will tell (him) that "this is your younger sister. So, you must take care of your sister. If your sister falls sick, she may not wear any clothes, you must take care of her, and you must bathe her if she cannot get up. So, you should not have any feelings towards your sister." That is how I remind him.

There is one mother who mentioned that her children, aside for their ASD, had epilepsy and would usually forget whatever they had learned before their episodes of epilepsy. Hence, continuous practice and lessons to nurture children with ASD pertaining to their knowledge and skills on sexuality are critically needed. For example, M5 explained: "This epilepsy, when they learn a new word, (and) when the epilepsy attacks, it will be gone (forgotten)." M5 also mentioned

^{34.} Jenna M. Gutierrez, "Social skills training targeting inappropriate sexual behavior for adolescents with autism," Master's Theses, California State University, 2016, 16.

^{35.} Tanja Stankova and Vladimir E. Trajkovski, "Sexual education of persons with autistic spectrum disorders: Use of the technique: 'Social stories," *Sexuality and Disability* 39, no. 2 (2020): 377–393.

^{36.} Lesley S. Klett and Yasemin Turan, "Generalized effects of social stories with task analysis for teaching menstrual care to three young girls with autism," *Sexuality and Disability* 30, no. 3 (2012): 319–336.

that repetition in teaching and nurturing young individuals with ASD about sexuality education was inadvertent because they had limited cognitive ability to understand such matters easily, whereby she remarked: "Even though they don't understand, we must *tell* them. For how many times, it's okay. Every time they did, we tell him, so long as he understands."

There is also a mother who would check on the understanding of her son by asking or giving exemplary questions. If her son answered correctly, then it meant he had understood correctly. The lesson was continuous, and parents would keep on telling, reminding, and explaining the concepts surrounding the topic of sexuality until their children internalise the lessons. In this case, M4 detailed as follows:

After finished talking, "Do you understand what Mummy has said? Do you understand? Do you want to ask a question?" You know, ok I will *check* on his understanding. "So, after this, you can touch it or not? Where cannot you touch?" Just to see whether it is right.

M4 also would always remind her son about certain relationship barriers with his cousin of the opposite sex when they joked and played together. For example, M4 remarked further:

It's an ongoing *reminder*. As I said, he is close to his cousin. So, from time to time they joke, they play together. So, until now, we (I) don't allow them to sleep on the same bed. His cousin has (gone through) a period (menstruation). And then what is a period? I explain to him about girls this and that.

This is coherent with the statement that the communication on sexuality between parents and children should be a continuous, ongoing, and bidirectional process beginning early in life.³⁷ A study published in *Nature Neuroscience* suggests that too much repetition may limit the scope of skills in people with autism in applying the learned skills to new situations.³⁸ However, another study carried out by Behrmann and her colleagues found that repetition helps individuals with autism to perform better on new tasks, but hardly so in new contexts.³⁹ In this context, the research's participants mentioned that they had to always repeat and remind their children regarding the lessons on sexuality whenever necessary—for

Laura G. Holmes, Michael B. Himle, and Donald S. Strassberg, "Parental sexuality-related concerns for adolescents with autism spectrum disorders and average or above IQ," Research in Autism Spectrum Disorders 21 (2016): 84–93.

^{38.} Hila Harris et al., "Perceptual learning in autism: Over-specificity and possible remedies," *Natural Neuroscience* 18, no. 11 (2016): 1574–1576.

^{39.} The study involves ten people with autism and nine people with age-matched controls for a visual discrimination task. See Nicholette Zeliadt, "Repetition may limit scope of skills in people with autism," *Spectrum News*, 13th November 2015, https://www.spectrumnews.org/news/repetition-may-limit-scope-of-skills-in-people-with-autism/ (accessed on 19th October 2023).

example, when children with ASD touched or stared inappropriately at other people's bodies, or showed interest in the opposite sex, and so on. In any case, children must indeed be reminded all the time as they easily forget due to a lack in retentive cognitive ability to understand and comprehend this matter.

Applied Behaviour Analysis (ABA) is one of the treatments or intervention methods for children with ASD. One of the principles of ABA is repetition since children with ASD learn better through repetitive behaviours. However, in developmental approaches, children who continuously learn a skill in one situation may not be able to adapt to a new situation with the newly acquired skill. 40 Intense repetitive behaviours in children with ASD hinder their ability to engage in an important activity or learning in school.⁴¹ Learning and generalisation can be fostered among children with ASD by limiting the number of repetitions by breaking the activities up into different sub-activities while practising the same task that the child needs to perform. ⁴² Thus, in this regard, the mothers who participated in this study had played an important role in helping their children develop by teaching sexuality knowledge and skills through repetition within their children's zones of development following Vygotsky's sociocultural theory of cognitive development. M3 also informed the researcher that according to psychiatrists, children with ASD require at least two weeks to adapt or learn a new skill, and the key was consistency in the teaching and learning process:

This is all up to us, up to parents. We must teach every day. According to a psychiatrist, kids like this just give him two weeks for him to adapt to a new situation, but it must be done *consistently*. He was diaper-free at the age of 4 years old. When we teach him, we open his diaper and bring him (to the toilet), (so) every time he wants or every hour, we ask him. After two weeks, he learned that.

Hence, consistency and routine are essential to children with ASD in their learning and development processes. Most participants in this study reported that their children preferred preparation since they easily got anxious if something were to happen unexpectedly. Thus, a consistent approach used by mothers or caregivers can help ensure that their children know what to expect and how to address them;⁴³ meanwhile, inconsistency can be confusing and can trigger anxiety among children with ASD.

^{40.} D. Brown, "Repetition in autism therapy: A closer look," We Chose Play, 4th December 2017. https://affectautism.com/2017/12/04/repetition/

^{41.} Sarah Deweerdt, "Repetitive behaviours and 'stimming' in autism, explained," *Spectrum News*, 31st January 2020, https://www.spectrumnews.org/news/repetitive-behaviors-and-stimming-in-autism-explained/

^{42.} Nicholette Zeliadt, "Repetition may limit scope of skills in people with autism."

^{43.} Steph Reed, "The impact of successful parent and teacher relationships on autistic children," *Autism Spectrum Teacher*, 9th May 2018, https://autismspectrumteacher.com/successful-autism-parent-and-teacher-relationships-parent-and-teacher-perspectives/

Visual Aids and Demonstrations

The use of visual aids and demonstrations in teaching sexuality education is equally efficient as reported by the participants. For example, the M1 elaborated that she made use of videos to teach her son about touch and how to express love or compassion to others.

One easy way is through *video*. I mean about what can be touched, cannot be touched, what we love, what we don't love, like that. We must do practically like for example cannot touch; we must *demonstrate* it to him "cannot touch" like that. If we love, we hug our siblings, we must mention "if kiss, kiss on the cheek, to show your love," like that.

Meanwhile, M2 mentioned that she used pictures to make social stories about what she wanted to teach her son: "There are *pictures* in a booklet, we printed out. We put *pictures* of what we want him to know." M4 made use of visual materials found on the internet and encyclopaedias as teaching aids for her son. She emphasised the importance of visual-based learning to children with ASD who could hardly understand verbal instruction.

So, even for the body, we have a lot of aids at home, *visual* (aids) like an encyclopaedia, on the internet and everything we can show, this is the body of a child. Because to tell him like this, he cannot imagine it but *visually* is helpful. If we only tell him what I have said, that doesn't help him to understand, we have to say with the aid of *visuals*, with a social story like a *movie*. There is a movie I saw that is helpful, for example when someone wants to kiss the other person and that person refuses, "You see this is one example that you cannot simply kiss people."

M5 talked about her strategy to help her son releases his sexual needs by using a certain video from YouTube. She stressed the importance of privacy and that parents should not be involved directly; instead, her son would be left alone in his bedroom with minimal supervision.

My own experience is with a son with ASD who does not understand, he has his room and I let him watch one *video* that he likes to watch. The *video* that I gave him is on YouTube. There is a sexy lady, not showing the real body which people say, the original of it, and the way... but just a sexy appearance because my son likes Hindustan. Hindustan, they dance sexily, right? So, I let him watch it...Let him do it himself. We should not do it. Because the mistake is when we help him, he will continuously depend on us.

M5 also made use of demonstrations as a strategy to teach her daughter how to wear and clean her sanitary pads during menstruation. She explained:

I taught, I *showed* the pad in the way that I have mentioned, put syrup on it, and then I cleaned it. I took her to the bathroom. I bathed her (continuously) until she had her menses. There are also *pictures*. I drew it myself (on) how to wear, put the plus sign, at the bathroom, I made it, I placed the dustbin, I used some *pictures*... After we (I) finished bathing her, we (I) took her panties, we (I) placed (the pad), made her wear it, brought her to the bathroom again, took off her pants, cleaned (the pad), and *showed* her how to wrap it (the pad), even that has to be taught. If we only give *pictures*, she cannot understand. She must be taught the right way so that she can understand.

All participants involved in this study agreed that visual aids were helpful in enhancing their children's understanding on sexuality. This corresponds to the previous finding which stated that the instruction given to individuals with ASD regarding positive sexual education should incorporate imitation and role play in a naturalistic setting, and it must be specific, brief, as well as repetitive. 44 Visual supports such as pictures, visual schedules, and items that can be seen/touched help increase independence among children with ASD. Visual aids are found to be effective in teaching new skills, including self-care, social, and behaviour to individuals with ASD. 45 These individuals often have no or limited spoken language because of a lack of natural ability to understand spoken words. Therefore, visual strategies are effective in compensating their difficulties in retaining their attention, following a normal conversation, or deriving meaning from social events. Also, their ability to remember nonverbal materials is better than remembering verbal ones. As such, for instance, a demonstration in managing menstruation is also vital since the information not only educates these young women with ASD but also helps reduce their anxiety, prevent sexual abuse and sexual illnesses, and empower them in terms of sexual and reproductive health. 46 Hence, in this study, it is found that the participants have applied various kinds of visual materials that they obtained from the internet and books to aid their effort to teach their children with ASD at home on sexuality.

^{44.} Laurie McLay et al., "A systematic review of interventions for inappropriate sexual behavior of children and adolescents with developmental disabilities," *Review Journal of Autism and Developmental Disorders* 2, no. 4 (2015): 357–373.

^{45.} Erin Kostigen, "Human sexuality instruction for individuals with autism spectrum disorders: A case study," PhD Thesis, Northeastern University, 2020, 36.

Dasha Solomon, David W. Pantalone, and Susan Faja, "Autism and adult sex education: A literature review using the information-motivation-behavioral skills framework," Sexuality and Disability, 37, no. 3 (2019): 339–351.

Seeking Help from the Experts and Others

The participants also mentioned that one of their strategies was to seek help from experts and other people. They consulted psychiatrists, initiated discussions with teachers, and engaged the cooperation of male figures regarding male children with ASD. This is supported by the previous studies that showed how family members sought external professional help to address these issues. Families also believe that professionals such as doctors and psychiatrists were the most credible sources in dealing with the subject. The research participants in this study also mentioned the difficulty in helping their sons made sense of experiences surrounding sexuality, especially wet dreams. This is similar to the findings in a study carried out by Cohen, Byers, and Sears which states that topics requiring explicit explanations such as wet dreams, masturbation, and sexual climax are difficult subjects to teach to children with a learning disability. Therefore, this research's participants sought help from other family members such as father, brother(s), and uncle(s) to explain and teach about the mentioned topics instead. M1 described it as follows:

I ask for help from my *husband* and his *brother* to guide (him) a lot. At the same time, I asked for an opinion from a *psychiatrist* about sex. I asked about how when he grows up, how he pees and one more is about his penis, how he can control his sex (sexual desire).

Meanwhile, M4 remarked pertaining to her child:

Any inquiry about feeling, I always raise about feelings, or "you think about something that you are embarrassed to ask mommy or if you ask mommy, but mommy cannot answer, mommy will tell you to ask Pak Lang (his uncle)." So, one way if I cannot answer him, I will tell him "You can ask your *uncle* or your *father*"...I asked for advice from *experts*. I would ask from time to time from experts such as Dr. Harlina, you know, autism *experts* and everything...But if not in front of our eyes, we can ask for help from a *caregiver* or *teacher* to monitor. This is why I think it's good for him to stay at PPKI (Program Pendidikan Khas Integrasi/Integrated Special Education Programme).

See Jordi Torralbas-Ortega et al., "Affectivity, sexuality, and autism spectrum disorder: Qualitative analysis of the experiences of autistic young adults and their families," BMC Psychiatry 23, no. 858 (2023).

^{48.} Jacqueline N. Cohen, E. Sandra Byers, and Heather A. Sears, "Factors affecting Canadian teachers' willingness to teach sexual health education," *Sex Education* 12, no. 3 (2012): 299–316.

In this regard, M3 made a similar remark pertaining to her child:

I also discussed this with his *teacher*. Luckily, his teacher is a male. So, his teacher asked me "If your child is a boy, do you allow me to clean him (after poo), Madam?" I said yes, but he is not used to cleaning from the front, so we must clean from behind. Because we don't want to touch his private parts. The most helpful are the *therapists*.

A study conducted by Holmes, Stressberg, and Himle reported that parents also feel that teaching sexual and reproductive health topics were more effective among healthcare providers or educators. 49 This corresponds to the finding from this present study in which one of the participants mentioned the role of teachers and schools to better educate individuals with ASD about sexuality. For example, M1 expressed: "In my opinion, at first I thought that it (sexuality education) is something negative but actually it is best taught in school, but with a good and clear explanation." Help-seeking is common among parents and caregivers of children with ASD. It is defined as a behaviour in which after a person has attained awareness and accepted the problem, he or she seeks help from others.⁵⁰ Social comparison frequently occurs in selfhelp groups that oftens lead an individual to seek help from other people who have experienced similar situations.⁵¹ In this study, the participants reported that they joined various support groups on social media such as Facebook to acquire relevant information and help from various groups regarding ASD. For example, M3 and M4 described respectively:

I also joined many groups on *Facebook* such as Hope for Autism, The Nemecheck Protocol...Most parents share there (in the group)... they are from all over the world...they support each other. So, every Sunday, we are asked to share our accomplishments, small or big doesn't matter, even a small thing is considered as an achievement. So, it is really best to join the group.

I am a part of the community Autism Malaysia, I am one of the members and being in that group, you can always freely ask these. We can say coming from different backgrounds. There are *religious people, psychology expert*, and also *teachers*. So, we can ask from a few angles...I think that staying in *jamā'ah*, staying in community is really helpful... When I found out that my son has autism, immediately I searched on *Facebook*, on the *internet* about autism community in Malaysia.

Laura Graham Holmes, Donald S. Strassberg, and Michael B. Himle, "Family sexuality communication: Parent report for autistic young adults versus a comparison group," *Journal* of Autism and Developmental Disorders 50, no. 2 (2020): 3018–3031.

^{50.} Elise Pattyn et al., "Public stigma and self-stigma: Differential association with attitudes toward formal and informal help seeking," *Psychiatric Services* 65, no. 2 (2014): 232–238.

Marjan Mohamadi et al., "The correlation between help-seeking behavior, social comparison and stigma in caregivers of children with autism," Medical Science 23, no. 96 (2019): 146–151.

Spiritual Approach

Lastly, the strategy that mothers of children with ASD use to nurture values surrounding sexuality in their children is through Islamic teachings or spiritual approaches. The participants involved in this study cited Islamic medicine, Islamic school, and Islamic teachings related to private body parts, among others. For example, M1 described: "There are many efforts that we have done, in terms of *traditional Islamic medicine* and then I mean hospital, we still brought him (there)." Meanwhile, M2 related her experience as follows:

...(therapy) actually (at) Universiti Malaya. It is for children with special needs. They taught everything, from prayer to daily *dhikr*, even obligatory baths also taught there...Sometimes I noticed that he woke up and immediately washed himself. I think he learned that in FAQEH.⁵² I think from there even, *dhikr* therapy, spiritual therapy is important for children's puberty because for normal people like us, if we do *spiritual therapy*, we can be...more in control, right...I think spiritual is still the best therapy for autism...I always think that *spiritual therapy* is important. Not just for him, for us in his family as well.

Furthermore, M3 also highlighted the importance of teaching sexuality education to children with ASD by first equipping the child with sufficient religious knowledge to guide them about their 'awrah, appropriate behaviour, limitations in relationships, and so on. M3 added:

So, in educating children like this, we have to first make him understand about his 'awrah', on the limit of what can be touched by others even (when) joking...This matter of sexuality education is important, but if we have provided sufficient religious knowledge, he will not easily fall astray...of course, Islamic religion has explained the issue of sexuality.

Similarly, M4 mentioned that she used an *Islamic approach* such as sending her son to a class that taught the basics of what could and could not be done in Islam. She detailed: "I used the Islamic approach...KAFA (Kelas al-Quran Fardu Ain). My son has been taught about the basics of the do's and the don'ts, what is allowed and not allowed."

Most of the participants in this study highlighted spiritual or Islamic approach as one of the approaches which they incorporated when teaching sexuality education to their children. Religious obligations such as prayer, reciting the Quran, daily *dhikr, ādāb* (manners), covering their *'awrah*, and the

^{52.} FAQEH or Yayasan Pendidikan Al-Quran Bagi Anak Istimewa was co-founded by FAQEH Foundation and Universiti Malaya Centre of Quranic Research. It serves as an Islamic daily school for teaching the Quran to children with special needs. See https://www.facebook.com/yayasanFAQEH?locale=ms_MY.

relationship between family and other people, among others, were common concepts that were taught. A study carried out by Hersinta reported that parents who were committed to getting their children with special needs be involved in religious and social activities. Even though children might not understand the basic principles of religious obligations, parents felt that their children would eventually practise religion as part of their routine by getting their children accustomed to it.⁵³ This is consistent with the finding from this study in which participants believed that their children also deserved to be equipped with religious knowledge. Parents or mothers involved in this study also highlighted that religious belief and its values could nurture positive knowledge of what was right or wrong as well as protect their children from engaging in self-harm or inappropriate behaviours.

In an article on youth and self-management, Robiah states that religious belief is a great force in preventing negative elements in a youth's life.⁵⁴ Religious knowledge taught to children at a young age can lead to positive development and nurture good attributes in their lives. Previous studies also reported that individuals who have strong religious faith were less likely to involve in risky behaviours, including high-risk sexual acts.⁵⁵ Acts of worship such as prayer and *dhikr* also showed a significant impact on the development of children with autism.⁵⁶ A study carried out by Salmihah and colleagues also reported that teaching the Quran was vital for the psychological development in children with ASD wherein it served as a cure (*shifā*) that provided tranquility and reduced behavioural issues such as tantrum and sexual problems.⁵⁷ This study confirms the abovementioned findings wherein learning and practising religious knowledge such as reciting the Quran, *dhikr*, performing prayers, covering the *'awrah*, and so on have resulted in positive sexual behaviour in the participants' children.

^{53.} Hersinta, "How religious beliefs influence understanding on disability: A study of Muslim family's perception on autism" (Paper presented at the Jogja International Conference on Communication: Communication in Culture; Whose Culture? UPN Yogyakarta, 21st November 2012), https://www.researchgate.net/publication/305072743_How_Religious_Beliefs_Influence_Understanding_on_Disability_A_Study_of_Muslim_Family's_Perception_on_Autism (accessed on 19th October 2023).

^{54.} See Robiah Kulop Hamzah, *Remaja dan Pengurusan Diri* (Kuala Lumpur: Dewan Bahasa dan Pustaka, 2001).

Fauziah Ibrahim et al., "Memperkasakan pengetahuan agama dalam kalangan remaja bermasalah tingkah laku: Ke arah pembentukan akhlak remaja Sejahtera," *Journal of Social Sciences and Humanities* 7, no. 1 (2012): 84–93.

Mohd Syukri Zainal Abidin, Che Zarrina Sa'ari, and Syed Mohammad Hilmi Syed Abdul Rahman, "Pendekatan psikoterapi terhadap kanak-kanak Muslim autistic," *Akademika* 88, no.1 (2018): 65–73.

^{57.} Salmihah Che Mud et al., "Kepentingan pengajaran al-Quran untuk perkembangan psikologi anak-anak autism," *International Journal for Studies on Children, Women, the Elderly and Disabled* 4 (2018): 24–31.

In Islam, sexuality and sexual education are framed in a morality which has the elements of rights and obligations, justice, and equity.⁵⁸ Islamic teachings are not confined only to daily prayers and rituals, instead they also provide guidance in all dimensions of daily activities, practices, and lifestyles, including sexuality and the specific rules surrounding it.⁵⁹ In Islam, premarital sexual relationship is not allowed. The concept of abstinence is pertinent in Islam. Furthermore, Islamic sexuality education also includes elements such as hygiene, puberty, relationships, religious obligations, responsibilities, among others.

Conclusion

The strategies used by mothers in teaching sexuality education to their children with ASD is essential in providing guidance for many other parents who face similar situation. The experiences of these mothers in this matter can also help shed some light on the issue of misunderstanding of sexuality pertaining to individuals with ASD. The role of mothers or parents is indeed critical in teaching and educating their children about cultures, religions, and values of a society. Throughout the upbringing process of children with ASD, parents may inculcate different knowledge and skills regarding sexuality according to the Islamic values. Thus, parents' experiences, especially in teaching sexuality education, are significant and relevant for the dissemination of knowledge that is meaningful to the life of individuals with special needs, or with ASD in particular.

Limitations

One of the limitations of this study is that the findings do not allow for the generalisation of the result to other categories of special needs other than individuals with ASD. Another limitation pertains to the observability of the processes employed by the participants, wherein only reports are available as a result of interviews.

Implications

Based on the findings of this study, it is clear that teaching sexuality education to children with ASD as early as possible is necessary. And the experiences of the mothers in performing this task are significant and meaningful for other Muslim mothers or parents in order for them to relate the phenomenon of interest with their respective situations.

^{58.} Muhammad Aftab Khan et al., Sexuality Education from an Islamic Perspective (Newcastle: Cambridge Scholars Publishing, 2020).

^{59.} Ibid.

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