

Article

Navigating Puberty with Special Needs Teenagers: Empowering Parents Through a Sexuality Education Workshop

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Abstract: Adolescence is a crucial phase of development, marked by significant physical, emotional, and social changes. Navigating these changes for teenagers with special needs can be particularly challenging. Addressing these topics is essential to ensure holistic well-being and healthy development of teenagers with special needs. This workshop aimed to equip parents with the necessary knowledge, skills, and strategies to navigate conversations about puberty and sexuality effectively. This paper is to present the findings of this workshop focused on puberty and sexuality education for parents of teenagers with special needs. A diverse group of parents of teenagers with special needs were recruited through Facebook groups, special schools, and community organizations. Prior to the workshop participants were invited to answer questions regarding their concerns about their special needs child sexuality. A total of 150 parents responded to this qualitative survey. The workshop includes a slot for a sexuality education lecture and a hands-on practical session focusing on managing menstruation and masturbation. A total of 69 participants for the workshop were required to answer pre and post-questionnaires – to determine the knowledge, perceptions, dedication, and willingness in delivering sexual information to teenagers with special needs.

Keywords: Sexual education; puberty; teenagers; sexuality; special needs

Introduction

Adolescence is an important phase of development, shown by significant changes in physical, emotional, and social aspects. For teenagers with special needs, navigating these changes can be particularly challenging. Puberty brings various transformations, including the onset of menstruation, hormonal fluctuations, and emerging sexual feelings. Addressing these topics is essential to ensure holistic well-being and healthy development of teenagers with special needs. Cognitive impairment among adolescents with special needs is interrelated to other cognitive abilities such as language skills, social skills, attention and memory skills, and generalization (Schaff and Mohamad, 2019). Teaching or delivering sexuality education to learning disabilities individuals such as Autism, Attention Deficits Hyperactive Disorder (ADHD), and intellectual disability involve unique approaches because they are cognitively, affectively, and physically different from normal individuals. The role of parents plays in providing sex and reproductive education to their children with special needs are significant because their children continued dependence on them for support. However, parents often find themselves ill-prepared to guide their children through these sensitive areas due to a lack of knowledge, resources, and support.

A workshop to educate parents on puberty and sexuality education was designed to assist parents in overcoming these difficulties. Parents or caregivers who have children with disabilities, developmental disorders or special needs that require additional support, care and attention were invited to participate in this workshop. This workshop aimed to equip parents with the necessary knowledge, skills, and strategies to navigate conversations about puberty and sexuality effectively. By empowering parents, this workshop has the potential to foster open communication, promote self-esteem, and enhance the overall well-being of both parents and their special needs teenagers.

This paper is to present the findings of this workshop focused on puberty and sexuality education for parents of teenagers with special needs. The workshop was designed to provide parents with evidence-based information, practical strategies, and a supportive environment to address the unique challenges associated with discussing these topics with their children. The objectives of this study are; i) To explore the concerns that parents have with regards to sexuality of their special needs children/ teenagers and; ii) To identify parents' knowledge, participation, dedication and willingness in delivering sexual information to their children.

Literature Review

Learning difficulties as categorised by Department of Social Welfare Malaysia are including Global Developmental Disorder (GDD), Down Syndrome, Attention Deficit Hyperactive Disorder (ADHD), Autism, intellectual disabilities, and specific learning disabilities: dyslexia, dyscalculia, dysgraphia. Behaviour is the primary form of communication for young generation, and emotional and behavioural signs constitute an important part of the disclosure process (Reitsema et al., 2016). Risky sexual behaviours may potentially resulting from parental relationship, lack of the information and knowledge about sexuality and STIs/HIV; and the cultural values that contribute to the reasons of this population hides their sexual activities from parents and health care providers. Some research concludes that people who have suffered an episode of sexual abuse during childhood present earlier initiation of consensual sex with penetration (Gray & Rarick, 2018), more sexual partners and more inconsistent condom use (Senn et al., 2017).

Brkic-Jovanovic et al. (2021) studied the sexual behaviour in persons with intellectual disability (ID), stated that persons with ID have difficulties in understanding their own sexuality and how to express it appropriately as they have slower memory processes, unstable and fluctuating attention, lower level of speech development, difficulties in the implementation of learned information, difficulties in self-care, and difficulties in communication and social skills; and these difficulties results in poor conceptual, social and practical adaptive skills, consequently these characteristics make engaging in sexual interactions more challenging for persons with ID.

Young adolescents were at risk of having improper attitudes towards sexual behaviours, but good knowledge on sexual and reproductive health may protect them from it (Rahman *et al.*, 2015). Holmes, Strassberg and Himle (2019) supported that knowledge is the foundation for sexual and reproductive health and also healthy romantic relationships. The curiosity to explore their bodies, identities and personalities are common to all adolescents, regardless of if they have any special disability or if they are normal developmental adolescents (Schaff and Mohamad, 2019). Knowledge on sexual and reproductive health is a major defence mechanism against permissive sexual attitude and this can be improved by specific education programs (Rahman et al., 2015). However, adolescents with special disabilities do not have the chances to ask their peers, nor do they have the opportunity to observe, develop good values, and practice healthy social and sexual behaviour.

Stokes & Kaur (2005) reported that adolescents with high functioning autism display poorer social behaviours, have poorer knowledge and behaviours regarding privacy issues, have less exposure towards sexual knowledge and sexual education, display more inappropriate sexual behaviours, and greater parental concerns. In addition, parents in their study reported that their children with autism engaged in a wide range of inappropriate sexual behaviour, i.e., touching their private body areas in public and removed clothing in public, masturbating in public and touching opposite sex inappropriately. The lack of social understanding causes young individual with special disabilities may engage in inappropriate sexual behaviours; although

90% of parents involved in the study reported that their child had been taught rules governing private behaviour (Stokes & Kaur, 2005).

Sexuality education interventions can prevent or reduce the risk of adolescent pregnancy, HIV, and STIs for adolescents with and without chronic health conditions and disabilities. Adolescents need to receive accurate education about sexuality to understand ultimately how to practice healthy sexual behavior. Ihwani *et al.* (2016) stated that sex education should be taught according to age level because the children's age development varies; at the age of 7-10 years old, children should be taught about the "adab" (manner) of asking for permission and the "adab" of sight, and at the age of 10-14 years old, children should be taught to avoid and hinder themselves from lusts; and "adab" or manner in sexual relationship can be exposed to them at the age of 14-16 years old. Based on these three stages, children and adolescents should be given exposure in matters related to sex according to their age, and if they are not educated and supervised well in every stage, it might cause them to be involved in activities related to sexual misconduct.

However, the general population has negative attitudes and low level of knowledge regarding the sexuality of persons with disabilities and point to the need for educating parents and professionals on this subject (Brkic-Jovanovic *et al.*, 2021). Mackin *et al.* (2016) found that some level of sexual education was necessary and important, and all adolescents had been introduced to sexual information but in varying degrees, and the topic preferences included those that would increase the recognition of healthy relationships, provide a measure of self-protection, and reducing undesirable consequences of sexual activity. Sex education needs involvement between family, friends, educators and media to be effective, however, effective sex education program is tremendously challenging especially in Muslim country such Iran, Saudi Arabia, Pakistan, Malaysia and Indonesia, and sex education is still not being taught widely in the countries. The challenges of addressing young generations about the sexuality health include various aspects of religious, cultural, social and community attitudes.

Societal stigmas may overshadow people with disabilities and may hinder positive sexual experiences (Van Hees *et al.*, 2017). When an individual internalizes negative stigmas and attitudes surrounding their disability and sexuality it may result in decreased self-image, lower self-esteem, role loss, decreased sexual satisfaction, and depression (Eglseder *et al.*, 2018). In Malaysia, many still uphold the traditional ideas that considering sex-related issues to be taboo. The emphasize on the need of sex education starts to show when statistic related to moral issues such as free mixing, baby born out of wedlock, drug abuse and addiction, rape, theft, prostitution, and sex out of wedlock start to increase rapidly from time to time.

Engelen *et al.* (2019) also mentioned that patients, parents, and healthcare professionals experienced sexual health as a taboo topic and felt not comfortable talking about it. Breuner *et al.* (2016) added that parent-focused child sexual abuse prevention offers potential as a public health approach to prevention of child sexual abuse, and it is time that we devote resources toward developing and studying this important area. Resources that guide and advise parents by providing training, resources, understanding, and encouragement included health care providers, schools, faith-based institutions, the media, and professional sexuality educators. Ihwani *et al.* (2016) listed some barriers to communicate in sexual issues are lack of communication skills, language, obstacles, limited sexual knowledge of parents, lack of available time, and traditional way (not receiving any sex education from their own parents). Breuner *et al.*, (2016) identified factors including lack of knowledge, skills or comfort, that may impede a parent's or caregiver's successful fulfilment of that role.

Family sexual communication according to Breuner *et al.* (2016) can begin with questions the family might have about the child and his or her body as well as about self-stimulation and "safe touch", with insights into the typical stages of child and adolescent sexual development, parents can better understand their own child's behaviours.

Methodology

The workshop was conducted with a diverse group of parents of teenagers with special needs. Purposive sampling was used for this study. Parents who have special needs children aged between 10 years old and above were invited to participate in this survey. The participants were recruited through Facebook groups, special schools, and community organizations. Prior to the workshop participants were invited to answer questions regarding their concerns about their special needs child sexuality. Content analysis was then used

to analyse the text to identify the themes, patterns, and trends presented in the data. A total of 150 parents responded to this qualitative survey.

A pair sample t-test was conducted to determine the knowledge, perceptions, dedication, and willingness in delivering sexual information to teenagers with special needs during the workshop. The workshop included a slot for a sexuality education lecture and a hands-on practical session focusing on managing menstruation and masturbation, as requested by the majority of the participants before the workshop. Participants were required to answer pre- and post-questionnaires on their knowledge, perceptions, dedication, and willingness in delivering sexual information to their children, and a total of 69 participants completed both surveys.

Results and Discussion

The qualitative part of the study prior to the workshop yields three themes on parents' concerns about their special needs children; i) Puberty and Sexual Development; ii) Communications and Relationships; iii) Understanding boundaries and manners. Table 1 summarized the theme and supporting comments responded by the parents.

Table 1. Theme and supporting comments regarding parents' concerns about their special needs children

Themes	Supporting Comments/ Quotes
Puberty and Sexual Development	<i>Curious why his penis erected</i>
	<i>Worried his body parts are getting bigger</i>
	<i>Worried if family members saw him and find out</i>
Communications and Relationship	<i>Whenever she is having her menstruation, she cannot control her emotion</i>
	<i>My daughter is aware of her menstruation cycle, and how to use sanitary pad and clean it, but she doesn't feel comfortable changing it in the toilet and washroom</i>
Understanding boundaries and Manners	<i>I noticed it and asked him, but he denies it while having a red face from embarrassment and scared.</i>
	<i>Keep on calling the person she has romantic feelings for despite stopping her.</i>
	<i>Differentiating the love between sibling and friends</i> <i>Boundaries in communication, manner as a girl</i>

The themes that emerged from the content analysis shed light on crucial aspects of teenagers, particularly concerning puberty, sexual development, communication and boundaries. Understanding these themes can provide valuable insights into the challenges and concerns faced by young individuals during this transformative phase of life.

Teenagers experiencing physical changes, such as erections may encounter feelings of embarrassment, confusion, and curiosity. It is essential to acknowledge and address these emotions sensitively, as they play a vital role in shaping adolescents' understanding of their changing bodies and emerging sexuality. Providing accurate and age-appropriate sexuality education and open communication channels with parents, caregivers, or educators can help adolescents navigate this stage with confidence and comfort (Pechmann et al., 2020). The emotional fluctuations during menstruation can be overwhelming and may affect girls' well-being and self-esteem. Promoting awareness and understanding of menstrual health, along with emotional support, can aid girls in managing their emotions during this phase (Liang et al., 2019; Munro et al., 2022). Educators and parents should create a nurturing environment where girls can freely discuss their menstrual experiences and receive guidance on coping strategies for emotional changes.

Lack of information, misinformation, or perception of societal judgments may create anxieties during puberty. Teenagers may experience difficulty discussing intimate topics, such as sexual development or romantic feelings, due to fear or uncertainty. Addressing these concerns through comprehensive sexuality education and fostering a supportive environment can alleviate anxieties and empower adolescents to cope effectively with the challenges of puberty (Akatuwasa et al. 2023) Encouraging healthy communication patterns early on can positively impact adolescents' ability to build meaningful relationships and navigate social interactions throughout their lives. As adolescents explore friendships and romantic feelings, they must develop a clear understanding of appropriate boundaries (Van Ouytsel, 2019). Educating adolescents on

respecting personal boundaries and fostering empathy can facilitate the development of healthy relationships based on mutual respect and consent.

The current study's main aim was to investigate the impact of a sexuality education seminar on the knowledge, perceptions, dedications, and willingness to change practices among a sample of 69 participants. The majority of the participants, comprising 89.9% of the total, identified as female, suggesting a female-centric focus in the study. This gender distribution allows for a deeper exploration of females' perspectives on sexuality education, which is particularly relevant given the significance of addressing gender-specific concerns and disparities in sexual health education (Ulin et al., 2020). Understanding females' attitudes towards sexuality education is essential, as they often play a crucial role in facilitating open discussions about sex and reproductive health within families and communities (Madlala, 2021). The insights gained from this study can contribute to tailoring sexuality education programs to meet the specific needs and preferences of young women.

Examining the age distribution, it is notable that 62.3% of the participants fell within the 20 to 30 years old range. This indicates that the study primarily involves a relatively young adult population, which may contribute to an exploration of the attitudes and understanding of sexuality education among this specific age group. Understanding the attitudes and knowledge of sexuality education among young adults can inform interventions and policies to address potential gaps and challenges during this critical stage of life.

In terms of educational background, a considerable proportion of the participants, 59.4% in total, hold a degree. This suggests that the study involves a sample with a relatively high level of education, potentially influencing their baseline knowledge and ability to critically engage with the topic of sexuality education. Education is associated with improved sexual health outcomes and better access to accurate information (Yu et al., 2019; Kaczkowski et al., 2020). Participants' higher educational attainment may influence their baseline knowledge and ability to critically engage with the topic of sexuality education, possibly affecting their perceptions and willingness to change practices. It is crucial to consider the potential impact of education on the participants' responses and tailor sexuality education interventions accordingly.

Table 2. Demographic characteristics of the participants

Variables	N(%)
Gender	
Male	7 (10.1)
Female	62 (89.9)
Age	
20 – 30 years old	43 (62.3)
31 – 40 years old	20 (29.0)
41 years old and above	6 (8.7)
Education	
Secondary School	1 (1.4)
Diploma	21 (30.4)
Degree	41 (59.4)
Master and above	6 (8.7)

A paired-sample t-test was conducted to evaluate the impact of the sexuality seminars on participants' scores on knowledge about sexuality. There was a statistically significant increase in knowledge in all questions (Question 1 to Question 6) at $p < .001$ (two-tailed) with eta square statistics ranging from 0.11 to 0.32 indicating a large effect size. In addition, overall there is an increase in knowledge about sexuality from before the seminar ($M = 4.28$, $SD = 0.60$) to after the seminar ($M = 4.66$, $SD = 0.47$), $t(68) = -5.69$, $p < .001$ (two-tailed). The mean knowledge increase was -0.38 with a 95% confidence interval ranging from -0.52 to -0.25 . The eta squared statistic (0.32) indicated a large effect size as shown in Table 3.

The observed increase in knowledge about sexuality is an encouraging outcome, as it highlights the efficacy of the workshop in delivering valuable and evidence-based information to parents of teenagers with special needs. Sexuality education is often a sensitive and challenging topic to discuss, particularly for parents of special needs teenagers who may require specialized support and guidance. Therefore, the significant

knowledge gained resulting from the seminars is a promising step towards empowering parents to address these important matters with their children effectively.

The mean knowledge increase of -0.38, as indicated by the paired-sample t-test, reinforces the positive impact of the seminars on participants' understanding of sexuality-related issues. This result signifies that, on average, participants' knowledge scores improved by 0.38 points after attending the workshop. The 95% confidence interval (-0.52 to -0.25) further supports the reliability of this finding, suggesting that the actual knowledge increase is likely to fall within this range.

Furthermore, the large effect size (eta squared = 0.32) found in this study underscores the substantial influence of the seminars on participants' knowledge outcomes. Effect sizes provide valuable information about the practical significance of an intervention, and a value of 0.32 indicates a strong and meaningful impact of the workshops on parents' understanding of sexuality. This finding is consistent with previous research that emphasizes the significance of tailored interventions in promoting parental education and support (Leung et al., 2019).

The overall mean knowledge score before the seminar (M = 4.28, SD = 0.60) and after the seminar (M = 4.66, SD = 0.47) further confirms the efficacy of the workshops in enhancing participants' knowledge about sexuality. The increase of 0.38 in knowledge scores suggests that the seminars successfully addressed key gaps in participants' understanding of puberty issues, menstruation, and other aspects of sexuality that are vital for the development and well-being of their special needs teenagers.

The positive outcomes of this study align with previous research that highlights the importance of parental involvement in promoting healthy development during adolescence (Sala et al., 2019). By equipping parents with accurate and comprehensive information about sexuality, the seminars empower them to engage in meaningful and supportive conversations with their special needs teenagers. These discussions are critical for fostering positive self-esteem, healthy relationships, and responsible sexual behavior (Wu et al., 2020).

Table 3. Results of the paired sample t-test on knowledge pre and post workshop

Questions	Pre (Mean/SD)	Post (Mean/SD)	95% CI		t	df	p	r
			Upper	Lower				
Current knowledge about the topics in the workshop	3.89 (0.9)	4.50 (0.79)	-0.81	-0.39	-5.75	68	0.00	0.32
Benefits of the symposium to your career development and learning process	4.50 (0.67)	4.72 (0.48)	-0.37	-0.06	-2.82	68	0.00	0.11
Familiarity and your skills with the topics in the workshop	4.02 (0.82)	4.56 (0.65)	-0.72	-0.34	-5.72	68	0.00	0.32
Perception/attitude about the topics in the workshop	4.42 (0.65)	4.72 (0.48)	-0.46	-0.14	-3.89	68	0.00	0.18
Dedications to develop the activities related to the workshop	4.40 (0.75)	4.72 (0.48)	-0.47	-0.16	-4.05	68	0.00	0.19
Willingness to adopt changes in your practices in relations to the topics in the workshop	4.43 (0.67)	4.76 (0.42)	-0.47	-0.18	-4.53	68	0.00	0.23
Total	4.28 (0.60)	4.66 (0.47)	-0.52	-0.25	-5.69	68	0.00	0.32

Conclusion and Recommendations

The qualitative findings revealed several key themes that are pertinent to understanding and addressing the needs of adolescents during their journey through puberty and sexual development. This study sheds light on the unique challenges and concerns faced by adolescents during puberty and sexual development. The themes identified emphasize the crucial role of comprehensive sexuality education, open communication, and supportive environments in facilitating positive outcomes during this transformative phase of life. By addressing these themes, parents, caregivers, educators, and policymakers can play a pivotal role in supporting adolescents' well-being and healthy development, ultimately empowering them to navigate adolescence with confidence, resilience, and a positive outlook on their sexual and emotional health.

In conclusion, this study delved into the impact of a sexuality education workshop on the knowledge, perceptions, dedication, and willingness to change practices among a diverse sample of 69 participants. The results demonstrate a statistically significant increase in participants' knowledge about sexuality, indicating the effectiveness of the seminar in enhancing their understanding of puberty-related issues. The increased knowledge observed in all questions, along with the large effect sizes, highlights the significance of providing targeted and comprehensive sexuality education to parents of teenagers with special needs. By equipping parents with accurate information and practical guidance on addressing puberty-related topics such as masturbation, menstruation, and general changes during adolescence, they can better support their children's sexual development. Moreover, the positive changes in perceptions, dedications, and willingness to change practices suggest that the workshop had a broader impact beyond mere knowledge gain. Participants' attitudes towards sexuality issues likely shifted positively, and they became more committed to effectively addressing these topics with their teenagers.

It is important to note that this study's scope and sample size may have limitations, and further research is warranted to explore these themes in a broader context and with more diverse populations. Nevertheless, the insights gained from this study serve as a foundation for implementing evidence-based interventions and support systems that cater to the unique needs of teenagers with special needs during this crucial stage of their development. By addressing the themes identified in this study, society can foster a more informed, empathetic, and supportive environment that nurtures the well-being and healthy development of all adolescents as they journey through puberty and sexual maturation. Furthermore, the study's sample was drawn from a specific geographical area, which may limit the generalizability of the findings to different cultural or regional contexts. Additionally, while parents play a vital role in adolescents' sexual education, including the perspective of adolescents with special needs themselves could provide more holistic understanding. Finally, this study did not delve deeply into the long-term effects of the workshop on teenagers with special needs' development. Further research could follow up with both parents and their teenagers with special needs to assess the workshop's sustained impact on their knowledge, attitudes and practices regarding puberty and sexuality.

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