



IMPACT OF INTERVENTION ON PARENTS' AWARENESS AND PRACTICES IN IMPARTING SEXUAL HEALTH EDUCATION TO CHILDREN WITH AUTISM

Ms. Gifty Joel

Ph.D. Research Scholar

Department of Human Development and Research Centre

Smt. V.H.D. Central Institute of Home Science (Autonomous), Seshadri Road, Bangalore-560 001

Dr. Venkat Lakshmi H.

Associate Professor

Department of Human Development and Research Centre

Smt. V.H.D. Central Institute of Home Science (Autonomous), Seshadri Road, Bangalore-560 001

ABSTRACT

Parents play a crucial role as sexual health educators for children with autism- because children with autism experience typical sexual development, but lack social skills and understanding of the rules that govern the display of appropriate sexual behaviour. The pre-test post-test method helped assess the awareness and practices of 50 parents in imparting sexual health education to children with autism- before and after an 8 week intervention program. Two dichotomous scales were framed by the investigator for the purpose of this study- to assess the awareness and practices of parents in imparting sexual health education to their children with autism. During pre-test it was found that parents lacked in their awareness and practices. The McNemar's test was used to assess if statistically significant changes in response have occurred after the intervention program. Data reveals a highly significant improvement in their awareness and practices, indicating the effectiveness of the intervention program on sexual health education for parents of children with autism.

Key Words:

Autism, Awareness, Intervention, Parents, Practice, Sexual health education

Introduction:

Autism is a complex and serious neuro-developmental disorder, a lifelong condition, with no cure so far. It causes significant impairment in a child's ability to communicate and socialize; it also involves restricted, repetitive and stereotypic patterns of behavior, interests, and activities that affect social, occupational and other areas of functioning ((DSM-V) American Psychiatric Association, 2014). The estimated prevalence of autism in India at present is 1 in 66, among children between 2 and 9 years of age (Deshmukh, et. al, 2013). Autism spectrum disorders are about 4.5 times more common among boys (1 in 42) than among girls (1 in 189) (Christensen, 2016).

Sexuality of individuals with autism is a rather under-researched aspect. Parents and professionals erroneously regard individuals with autism to be asexual, child-like and lacking interest in sexuality (Stokes & Kaur, 2005; Koller,2000; Van

Bourgondien, Reichle, & Palmer, 1997; Konstantareas & Lunsy, 1997; Ruble & Dalrymple, 1993; Ousley & Mesibov, 1991). Conversely, they are sometimes viewed as inappropriately sexual or as having uncontrollable urges (Neufeld, et. al., 2002). Research proves that they are sexual beings who have the same experiences of pleasure, excitement and passion as their neuro-typical peers. They have age appropriate sexual interests, but possess limited sexual knowledge and experiences (Henault, 2005). They lack the social skills that will enable them to discern how to express their sexuality in socially appropriate ways. Therefore, sexual health education provided within the contexts of human relations (SIECUS, 2001) and a social framework with rules will benefit individuals with autism.

There is a misconception that sexual health education may arouse or excite individuals, and it primarily focuses on the physical act of having sex. But the sexual health education focuses more on personal safety, hygiene and self awareness. Sexual health education is defined as the provision of information about bodily development, sex, sexuality, and relationships, along with skills-building to help young people communicate about and make informed decisions regarding sex and their sexual health (Advocates for youth, 2014). It is a lifelong process of acquiring information and forming attitudes, beliefs, and values not only about sexual development, but also about affection, intimacy, body image, and gender roles (SIECUS, 2001). Therefore, it should be considered an integral element of a comprehensive transition plan for individuals with autism, assuming that the goal of such education is to make them safe, competent, and confident adults to the fullest extent possible (Gerhardt, 2006).

Unlike most children and adolescents, those on the autism spectrum are limited or no access to the books or friends through whom they may learn about sex and sexuality. For them sexual health education mostly takes place at home, and parents are the primary sexuality educators of their children (Murphy & Elias, 2006). However, many parents may believe that they lack awareness, and report feeling uncomfortable and awkward educating their children about sexuality (Byers, Sears, & Weaver, 2008). When parents lack awareness, they may not employ healthy practices in teaching children with autism about the body, sexual changes and hygiene. Parents of youth with autism spectrum disorders have reported needing guidance to effectively provide sex education, and state that they are not receiving such guidance from schools, healthcare providers, or communities (Ballan, 2012; Nichols & Blakeley-Smith, 2010). Therefore, there is a need to educate parents on aspects of sexual health education, especially catering to the unique social needs of their children, in order to increase their awareness and help them inculcate better practices as sexual health educators for their children.

Hence, the present study was undertaken to study the impact of an educational intervention program on parents' awareness and practices in imparting sexual health education to children with autism.

Methodology:

Objective: The study aimed to assess the impact of intervention on parents' awareness and practices in imparting sexual health education to their children with autism.

Sample: Through purposive sampling technique, the investigator identified 50 parents of children with autism, from Bangalore city, as sample for the present study.

Tool used: Two nominal (dichotomous) scales were framed by the investigator for the purpose of this study- to assess the awareness and practices of parents in imparting sexual health education to their children with autism. The scales had twelve and ten items respectively, all of which were positive. The response options given to the respondents were a direct 'yes' or 'no', in order to reduce the ambiguity of their responses. Each item that was marked 'yes' was given a score of 1 and a 'no' was given a 0 score.

Method: The method adopted for the present study was the pre-test post-test experimental method with an intervention program.

The investigator conducted a survey in the city of Bangalore to identify the special schools catering to the needs of children with autism. With the help and support of the special school authorities, the investigator contacted parents of children with autism to provide data before and after intervention, and attend an 8 week intervention program on sexual health education.

Pre-test: The investigator established rapport with the respondents and explained to them the need and importance of the study and sought consent from them to gather data. The respondents were assured that the data obtained from them will be only used for the purpose of research. The pre-test was conducted by administering the self developed awareness and practice scales to assess their existing awareness on sexual health and the practices they were employing to teach sexual health education to their children with autism.

Intervention Program: The intervention program was designed by the investigator for the parents of children with autism -to create awareness among them on the various issues related to sexual health and to familiarize them to different practices that they may inculcate in order to teach their children about sexual health effectively. The intervention program on sexual health education was conducted by the investigator for a period of 8 weeks, covering 8 different modules that lasted three hours each. The concepts to be taught to the children and the methodologies that can be employed to teach the same to children with autism were addressed. At the end of each session the respondents sought clarifications regarding matters they found difficult to deal with. Various teaching

techniques such as lectures, group discussions and power-point presentations, and visual aids such as flash cards, posters, puppets and models were employed to explain these concepts to the respondents. Respondents were also given home assignments, to ensure that they begin to practice what they learnt during the program. The investigator addressed the following topics during the intervention program:

1. Understanding sexuality and the need for sexual health education
2. Characteristics and behaviours of children with autism in relation to sexuality
3. Healthy lifestyle: hygiene, nutrition and fitness
4. Puberty and changes that accompany it in males
5. Puberty and changes that accompany it in females
6. Masturbation and its management
7. Sexual safety skills and prevention of abuse
8. Importance of leisure activities in reducing undesirable sexual behaviours

Post-test: On completion of the intervention program, the awareness and practice scales used at the time of pre-test were re-administered to the respondents. This was done in order to check the effectiveness of the intervention program by assessing if there was any improvement in the respondents' awareness and practice methods in imparting sexual health education to their children with autism.

The data was scored, tabulated and analyzed using a non-parametric statistical test as the data was obtained using nominal scales. The McNemar's test- a non-parametric (distribution free) test was used to assess if statistically significant changes in response have occurred on the series of dichotomous test items, before and after the intervention program.

Results and Discussion:

The socio-demographic information of the respondents and their children is discussed below. Most of the respondents were females (80%) as they are the full-time caregivers of their children. They accompany their children to school where they act as shadow teachers and they also take their children for various therapies during the day. Fathers spend considerably lesser time with their children and only a few fathers (20%) have an inclination to involve fully in the child's upbringing. All the respondents were Hindu (100%). A majority of the respondents were aged between 35 and 45 years (54%). Half of the respondents were graduates (50%) and a substantial number (22%) have done their higher education. Considering their occupational status, 68% of them were home makers, and only 32% of them worked in the government sector, private sector or had their own business establishments. Many families (42%) had a monthly income between Rs 10,000/- and Rs 25,000/- and fewer (32%) had a monthly income of more than Rs 40,000/-.

Most families (96%) had only one child on the spectrum, but 4% of them had two children with autism. 66% of the children were between 10 and 15 years of age, while 34% of them were younger. In keeping with the universal sex ratio of autism (4 males:1 female), 82% of the children were males and only 18% were females. It was reported that 36% of children had attained puberty, and 42% had not. But a significant number of respondents (22%) were not sure if their child had attained puberty or not. This was true especially of mothers who were not sure about their sons' pubertal status- because spermatarche is not as apparent as menarche in girls.

Table 1: Parents' pre and post test scores for items on Awareness
(Ordered according to the χ^2 value - significance of McNemar test)

Items of Awareness	Pre test (N=50)		Post test (N=50)		Significance of McNemar test
	Yes	No	Yes	No	
Children with autism can be taught concepts related to Sexual Health Education	41	9	50	0	9.00**
I know how to teach a girl with autism about menstrual hygiene	31	19	44	6	13.00**
Masturbation is a healthy sexual outlet	29	21	47	3	18.00**
I know how to teach a child with autism about sexual modesty	26	24	45	5	19.00**
Children with autism vary in the display of their sexual behavior	23	27	43	7	20.00**

I am aware of the concepts of 'good touch' and 'bad touch'	26	24	47	3	21.00**
I am aware of various ways to keep my child occupied, - so as to prevent any occurrence of inappropriate sexual behavior	21	29	43	7	22.00**
It is not harmful for my child with autism to masturbate behind closed doors in my home	22	28	46	4	24.00**
I am aware that even a child with autism requires personal space and privacy	19	31	45	5	26.00**
I know how to teach a boy with autism about personal and sexual hygiene	11	39	42	8	31.00**
I am aware of techniques to modify the undesirable sexual behaviour of children with autism	6	44	39	11	33.00**
I know of effective ways to teach children with autism about good touch and bad touch	14	36	48	2	34.00**

** Significant at 1% level

Awareness is defined as the state of knowing something or being aware of a particular issue. Irrespective of their backgrounds, parents are generally aware of ways to bring up their children- because parenting is instinctual. However, raising a child with autism can sometimes be more challenging. Parents of special children may require extra help, training and skill-building in order to cope with the difficulties they face in effectively parenting their offspring. Dealing with sexual health education is a particularly difficult task for parents, as most parents feel awkward discussing sexuality related topics with their children, especially with their children with disabilities (Murphy and Young, 2005).

Table 1 reveals parents' pre and post-test scores for awareness. Most parents were aware that sexual health concepts can be taught to children with autism, based on their level of understanding. During pre-test itself many parents reported that they knew how to train a girl child about menstrual hygiene. This can be attributed to the fact that most respondents were mothers and would have basic knowledge about menstrual hygiene and care by the mere virtue of being females themselves. Research shows that mothers tend to provide most of the sexual education of their children, and are also seen by their youth to be more emotionally accessible, capable and knowledgeable about matters that relate to sex (Rosenthal et al, 2001; Downie & Coates 1999; King & Lorusso, 1997).

Only 29 respondents were aware that masturbation was a healthy sexual outlet. Many parents were anxious and worried about their child's masturbatory behaviours, especially because of their own strict upbringing and conservative values. A child with autism may never have a satisfying sexual relationship with another individual. Therefore the only permissible and safe sexual outlet for the child or adolescent would be through masturbation. But the sexuality of persons with autism is a major concern for parents (DeMeyer, 1979). Only about half the respondents said they were aware of how to teach their child about sexual modesty. Many parents assume that their child cannot comprehend what is being taught, especially about appropriate behaviour and modesty. Not many parents were aware of the fact that children with autism vary in the display of their sexual behaviour. But research has shown that certain inappropriate sexual behaviors including touching self, touching others, masturbating in public, and disrobing (Ruble & Dalrymple, 1993; Haracopos & Pedersen, 1992) are commonly seen among individuals with autism. However, these seemingly inappropriate sexual behaviours may not be stemming from sexual deviancy or obsession, but merely from the core features of autism such as their predisposition for self-stimulatory behavior (Dalldorf, 1983), impairment in social awareness, and their lack of ability to empathize (Charman et. al., 1997). Owing to these varied contributing factors, individuals with autism may be ignorant of the inappropriateness of their varied sexual behaviours. Few parents were aware of the concept of 'good and bad touch', fewer parents were aware of effective ways to teach their child the same. Only 19 parents (38%) were aware that their child needed privacy and personal space. Many parents were worried for their child's safety and hence felt it necessary to stay beside them at all times during the day, and made the children sleep beside them even at night. Only 11 parents (22%) knew how to teach a boy about pubertal changes, sexual hygiene and wet dreams. Many respondents were female, and they reported feeling hesitant to talk about or seek information on male reproductive health.

After the parents attended the intervention program, they gained awareness on sexual health issues that concern their children. The post test scores show that they have become more aware than they were earlier during the pre-test. The McNemar test showed a highly significant improvement for all the 12 items tested. But just awareness is of no value, unless what is known is put into practice.

Table 2: Parents' pre and post test scores for items on Practice
(Ordered according to the χ^2 value - significance of McNemar test)

Items of Practice	Pre test (N=50)		Post test (N=50)		Significance of McNemar test
	Yes	No	Yes	No	
I speak to the child with autism about pubertal changes and growing up	21	29	30	20	9.00**
I give the child with autism privacy on a daily basis	8	42	22	28	14.00**
I have taught the child with autism leisure time activities that he enjoys	32	18	46	4	14.00**
I train the child with autism to differentiate between a good touch and a bad touch	23	27	38	12	15.00**
I have taught the child with autism how to maintain sexual hygiene	28	22	43	7	15.00**
I have taught the child with autism about the opposite gender	11	39	27	23	16.00**
I have spoken to the child with autism about getting a period/ wet dream	11	39	27	23	16.00**
I have addressed the topic of masturbation with the child with autism	7	43	24	26	17.00**
I use teaching aids to explain sexuality related concepts to the child with autism	9	41	26	24	17.00**
When I teach a child with autism about the parts of the body, I teach about the sexual parts too	11	39	28	22	17.00**

** Significant at 1% level

Despite being aware of basic sexual health related concepts, parents feel ill-prepared to practice what they know. They also tend to put off talking about sexual health, assuming that their child is still young to know about sexual matters. Sometimes, parents tend to believe that their child cannot learn and therefore do not make an attempt to teach. Table 2 reveals parents' pre and post-test scores for practice. The demographical data of children discussed earlier indicates that 33 children were between 10 and 15 years of age. Yet, during pre-test only 21 parents (42%) had spoken to their children about puberty. Autism is seen more among males, but fathers often shirk the responsibility of educating their sons on sexual health and hygiene. In his research, Hirst (1994), states that there appears to be a reluctance amongst parents, particularly fathers, to talk to their sons about sexual matters.

Although in Table 1, 38% of the parents had reported being aware that their child needs privacy on a regular basis, table 2 reveals that only 16% parents made provision for it. About half the respondents practiced teaching their child to differentiate between a good and bad touch, and taught the children to maintain personal and sexual hygiene. Some parents reported that they have not made an attempt to teach the child, but rather find it easier to look after the personal hygiene of their children by themselves. They reasoned saying they fear their child may not do a thorough job and may also take a longer period of time for self care.

During pre-test a large number of parents (64%) said that they have taught their child leisure activities that the child enjoys. Because of their tendency to be sedentary and idle, children with autism sometimes tend to obsess with their bodies and masturbate more frequently than their peers. According to research by Lee in 2004, children with autism may have an excessive curiosity about the human body and the way it functions. Therefore it is very important to keep them engaged in purposeful activities while growing up, in order to prevent them from indulging in frequent sexual behaviours. Only 22% of the parents taught their children the names of the sexual parts of the body while teaching them the other parts of the body, spoke to their children about the opposite gender, and

taught the child about getting a period or wet dream. Only seven parents (14%) had addressed the issue of masturbation with their children. And 18% of them used various teaching aids such as charts and books to teach their children about the body and sexuality. Some of the effective methods for teaching social skills to individuals with autism include video-taping real or acted situations for playback and discussion and specifically developed books that depict social situations (Wing, 1992; Roeyers, 1996). They are visual learners and learn better when teaching aids are used.

After the intervention program, the post-test data reveals that they have inculcated better practices to teach their children about sexual health. The scores show that they have started practicing what they have learnt during the intervention program. The McNemar test showed a highly significant improvement for all the 10 items tested. If parents are consistent in practicing these methods, their children with autism will learn effectively about their body, sexual changes, sexual hygiene, and appropriate behavior and develop skills necessary for their adult years.

Thus, the post test data of parents on both scales showed that the intervention program has been effective in improving parents' awareness and practices in imparting sexual health education to their children with autism. The findings of the present study are supported by a similar study conducted by Nichols in 2015 for parents, who developed an education program for parents with the aim of decreasing their anxiety and increasing their comfort and competence in addressing their child's sexual development. The parents met once a week for 90 minutes for a period of 10 weeks. They discussed their hopes, fears, values related to the sexuality of their autistic children. They learn various concepts related to sexuality and were trained in the teaching methods and strategies that can be employed for each concept. The results of the study showed that parents' self report on comfort level in discussing issues related to sexuality had increased significantly. They also scored high in the aspects of acceptance, skill, experience, knowledge and competence, with the greatest gains in the areas of skill and knowledge in dealing with the sexuality of their growing children.

Conclusion:

Thus it can be concluded that parents require teaching and training to improve their awareness and practices in order to effectively impart sexual health education to their children with autism. This can be best accomplished through a planned, comprehensive, structured intervention program on sexual health education, specifically designed to cater to the needs of parents of children with autism. Such training should be made available to parents on a regular basis, and parents in turn should be persistent and consistent in training their children in aspects of sexual health, keeping in mind the age appropriateness and developmental needs of the child.

References:

1. Advocates for youth, 2014. <http://www.advocatesforyouth.org/storage/advfy/documents/Factsheets/sexuality-education-2015.pdf> [10th September, 2016].
2. American Psychiatric Association, 2013. *Diagnostic and statistical manual of mental disorders (DSM-5®)*. American Psychiatric Pub.
3. American Psychiatric Association, 2014. Autism spectrum disorder. <http://www.psychiatry.org/dsm5>. [Feb. 24, 2014].
4. Ballan, M.S., 2012. Parental perspectives of communication about sexuality in families of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 42(5), pp.676-684.
5. Byers, E.S., Sears, H.A. and Weaver, A.D., 2008. Parents' reports of sexual communication with children in kindergarten to grade 8. *Journal of Marriage and Family*, 70(1), pp.86-96.
6. Charman, T., Swettenham, J., Baron-Cohen, S., Cox, A., Baird, G. and Drew, A., 1997. Infants with autism: An investigation of empathy, pretend play, joint attention, and imitation. *Developmental psychology*, 33(5), p.781.
7. Christensen, D.L., Bilder, D.A., Zahorodny, W., Pettygrove, S., Durkin, M.S., Fitzgerald, R.T., Rice, C., Kurzius-Spencer, M., Baio, J. and Yeargin-Allsopp, M., 2016. Prevalence and characteristics of autism spectrum disorder among 4-year-old children in the autism and developmental disabilities monitoring network. *Journal of Developmental & Behavioral Pediatrics*, 37(1), pp.1-8.
8. Dalldorf, J.S., 1983. Medical needs of the autistic adolescent. In *Autism in adolescents and adults* (pp. 149-168). Springer, Boston, MA.
9. DeMyer, M.K., 1979. *Parents and children in autism*. VH Winston.
10. Downie, J. and Coates, R., 1999. The impact of gender on parent-child sexuality communication: Has anything changed?. *Sexual and Marital Therapy*, 14(2), pp.109-121.
11. Gerhardt, P., 2006. Sexuality instruction and autism spectrum disorders. *Autism & Asperger's Digest Magazine*, 44-46.
12. Haracopos, D. and Pedersen, L., 1992. Sexuality and autism: Danish report. *United Kingdom: Society for the Autistically Handicapped*. Retrieved September, 15, p.2006.
13. Hénault, I., 2006. *Asperger's syndrome and sexuality: from adolescence through adulthood*. Jessica Kingsley Publishers.
14. Hirst, J., 1994. *Not in Front of the Grown-ups: A Study of the Social and Sexual Lives of 15 and 16 Year Olds*. Pavic Publications.
15. King, B.M. and Lorusso, J., 1997. Discussions in the home about sex: Different recollections by parents and children. *Journal of Sex & Marital Therapy*, 23(1), pp.52-60.
16. Koller, R., 2000. Sexuality and adolescents with autism. *Sexuality and Disability*, 18(2), pp.125-135.

17. Konstantareas, M.M. and Lunsby, Y.J., 1997. Sociosexual knowledge, experience, attitudes, and interests of individuals with autistic disorder and developmental delay. *Journal of Autism and Developmental Disorders*, 27(4), pp.397-413.
18. Lee, D.O., 2004. Menstrually related self-injurious behavior in adolescents with autism. *Journal of the American Academy of Child & Adolescent Psychiatry*, 43(10), p.1193.
19. Mukherjee, S.B., Malhotra, M.K., Aneja, S., Chakraborty, S. and Deshpande, S., 2015. Diagnostic accuracy of Indian Scale for Assessment of Autism (ISAA) in children aged 2–9 years. *Indian pediatrics*, 52(3), pp.212-216.
20. Murphy, N. and Young, P.C., 2005. Sexuality in children and adolescents with disabilities. *Developmental Medicine & Child Neurology*, 47(9), pp.640-644.
21. Murphy, N.A. and Elias, E.R., 2006. Sexuality of children and adolescents with developmental disabilities. *Pediatrics*, 118(1), pp.398-403.
22. Neufeld, J.A., Klingbeil, F., Bryen, D.N., Silverman, B. and Thomas, A., 2002. Adolescent sexuality and disability. *Physical medicine and rehabilitation clinics of North America*, 13(4), pp.857-873.
23. Nichols, S. and Blakeley-Smith, A., 2009. "I'm not sure we're ready for this...": Working with families toward facilitating healthy sexuality for individuals with autism spectrum disorders. *Social Work in Mental Health*, 8(1), pp.72-91.
24. Nichols, S., 2007. Growing Up on the Autism Spectrum: A Parent Education and Skill Building Curriculum, [Online] Available: <https://researchautism.org/growing-up-on-the-autism-spectrum-developing-a-parent-education-and-skill-building-curriculum/> [13 February 2018].
25. Ousley, O.Y. and Mesibov, G.B., 1991. Sexual attitudes and knowledge of high-functioning adolescents and adults with autism. *Journal of autism and developmental disorders*, 21(4), pp.471-481.
26. Roeyers, H., 1996. The influence of nonhandicapped peers on the social interactions of children with a pervasive developmental disorder. *Journal of Autism and Developmental Disorders*, 26(3), pp.303-320.
27. Rosenthal, D., Senserrick, T. and Feldman, S., 2001. A typology approach to describing parents as communicators about sexuality. *Archives of Sexual Behavior*, 30(5), pp.463-482.
28. Ruble, L.A. and Dalrymple, N.J., 1993. Social/sexual awareness of persons with autism: A parental perspective. *Archives of sexual behavior*, 22(3), pp.229-240.
29. Sexuality Education Information Council of the United States SIECUS.(2001). Issues and answers: fact sheet on sexuality education. *SIECUS Report Supplement*, 29(6), pp.1-8.
30. Stokes, M.A. and Kaur, A., 2005. High-functioning autism and sexuality: A parental perspective. *Autism*, 9(3), pp.266-289.
31. Van Bourgondien, M.E., Reichle, N.C. and Palmer, A., 1997. Sexual behavior in adults with autism. *Journal of Autism and Developmental Disorders*, 27(2), pp.113-125.
32. Wing, L., 1992. Manifestations of social problems in high-functioning autistic people. In *High-functioning individuals with autism* (pp. 129-142). Springer, Boston, MA.