



## PARENTS' PRACTICES IN IMPARTING SEXUAL HEALTH EDUCATION TO CHILDREN WITH AUTISM: AN INTERVENTION STUDY

### Home Science

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### ABSTRACT

Children with autism experience typical sexual development, but may lack necessary knowledge and self care skills. Parents ought to train them in aspects of sexual health, but they feel incompetent. A self structured scale was used to assess the practices of parents in imparting sexual health education to children with autism. The sample consisted of 100 parents (50 in control group and 50 in experimental group). The present study used the quasi experimental method and intervention was provided to the parents of the experimental group for a period of eight weeks- on techniques to impart sexual health education. Post test results revealed that parents of the control group did not improve much in their practices, while notable improvement was observed among the parents of the experimental group- indicating that parents of the experimental group are practicing different techniques to impart sexual health education to their children, proving that the intervention program was effective.

### KEYWORDS:

Autism, Intervention, Parents, Practice, Sexual health education

### INTRODUCTION

Autism is considered to be one of the most severe developmental disabilities. It is a complex neurological disorder that affects the functioning of the brain. Children with autism are characterized by deficits in the social (difficulties developing friendships, lack of spontaneous sharing of interests, limited social reciprocity) and communicative (difficulties to start and maintain reciprocal interaction, stereotyped and repetitive use of language) domains, and by stereotyped, repetitive behaviours and interests (preoccupations with specific interests, holding on to non-functional routines) (Levy et al., 2009; APA, 2000; Wing, 1993).

Children and youth with disabilities, including those on the autistic spectrum are often erroneously viewed as being asexual (Di Giulio, 2003). Despite limitations in other developmental areas, they experience physical development i.e. the physical and emotional changes of puberty in the same way as their typical peers (Schroeder, LeBlanc, & Mayo, 1996) and they require sexual health education. Unfortunately, they may lack opportunities to know about it through popular means such as books, magazines, friends or online resources, making them heavily dependent on parents for information regarding sexuality. Parents ought to be the primary sexuality educators for their children (Murphy & Elias, 2006) because they can positively influence their child's beliefs and attitudes about sex and sexuality more than anybody else. Parents and caregivers provide the foundation for sexual development by demonstrating and modeling appropriate relationships within the home (NCASH, 1995).

Although parents stand at an advantageous point with reference to sexual health education in the lives of their children with autism, they hesitate to discuss or teach sexuality related aspects. Parents reported feeling uncomfortable educating their children with disabilities about sexuality (Murphy & Young, 2005) as they feel they are not knowledgeable enough about their child's disability in the context of sexual health education (Perspectives on sexual and reproductive health, 2003). Therefore parents lack in their practices in teaching sexual health education to their children with autism. This paper explores the practices of parents and the influence of an intervention program in making them better sexual health educators for their children.

### METHODOLOGY

**Objective:** The first objective of the study was to assess parents' practices in imparting sexual health education to their children with autism. The second objective was to study the influence of intervention program on the practices of parents.

**Sample:** Through purposive sampling technique, the investigator identified 100 parents of children with autism, of whom 50 parents who

gave their consent to participate in the intervention program were identified as the experimental group, while the rest 50 formed the control group. The respondents belonged to different special schools from across the city of Bangalore.

**Tool used:** A dichotomous scale was framed by the investigator for the purpose of this study. It was used to assess the practices of parents in imparting sexual health education to their children with autism. The scale comprised of 18 items (all of which were positive). The items were categorized under the following four dimensions for the sake of analysis-

- i. Practice to teach children with autism about self care (5 items)
- ii. Practice to teach children with autism about sexual safety (5 items)
- iii. Practice to teach children with autism about puberty (4 items)
- iv. Practice to teach children with autism about basic sexual concepts (4 items)

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 Quasi experimental design.

**Pre-test:** The investigator established rapport with the respondents of both the control and experimental groups 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 structured practice scale to assess 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 from the experimental group -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 on Saturday mornings. The resource persons addressed various concepts relating to sexuality and sexual health and elaborated on the methods that can be used to teach the same. Various teaching techniques such as lectures, group discussions and power-point presentations were employed to explain these concepts to the respondents. Demonstrations on how to teach children with autism were given using visual aids such as flash cards, posters, puppets and

models. After the session the respondents sought clarifications regarding matters they found difficult to deal with. 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 practice scale used at the time of pre-test was re-administered to the respondents of both the control and experimental groups. This was done in order to check the effectiveness of the intervention program by assessing if there was any improvement in the respondents' practice methods in imparting sexual health education to their children with autism.

The data was scored, tabulated and analyzed using appropriate statistical tests.

**RESULTS AND DISCUSSION**

The socio-demographic information of the respondents is as follows. A majority of the parents from both the control and experimental groups (54% and 56%) were in the 30-40 years age group and 40 % of the parents from both the groups were in the 40-50 years age group. Eighty percent of the respondents were mothers, only 20% of them were fathers. Considering the aspect of religion, 96% were Hindus, and the rest 4% comprised of Muslims and Christians. The data revealed that half the parents (50%) were graduates, and 14% from the control and 22% from the experimental group had done their higher education. The rest of the respondents had completed only schooling or pre-university. Seventy percent of the parents from both groups were home-makers. Some mothers reported working earlier, but chose to be home makers when their children were diagnosed with autism. Studies show that most frequently, mothers are the full-time primary caregivers of their autistic children, and because of this additional responsibility, they are less likely to work (Cidav, Marcus & Mandell, 2012, et. al., 2012). A majority of the parents from both groups (42%) reportedly had a monthly income of Rs 10,000/- to 25,000/-. Less than 10% of them earned lesser than Rs. 10,000/- per month; 32% of them earned more than Rs. 40,000/- per month.

Most parents are aware of basic sexual health related concepts such as names of the genitals, pubertal changes and personal/menstrual hygiene, yet they feel ill-prepared to practice teaching their child with autism 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 1** reveals parents' pre-test scores for practice. The scores of parents from the control and experimental groups indicated that there was no significant difference in their practices in teaching children about self care, sexual safety, puberty & menstruation, and basic sexual concepts such as names of genitalia.

**TABLE – 1 Pre-test-Practice Scores of Parents (Comparison of control with experimental group)**

Dimensions of Practice – to teach...	Control Group	Exp. Group	Significance of t value
Children about Self care	2.52 ± 1.14	2.42 ± 1.07	0.4522NS
Sexual Safety	2.12 ± 1.09	2.28 ± 1.24	0.6855NS
Puberty & Menstruation	0.90 ± 0.81	0.94 ± 1.16	0.2000NS
Basic sexual Concepts	0.98 ± 0.82	1.04 ± 0.94	0.3401NS
<b>Overall Scores</b>	<b>6.52 ± 1.89</b>	<b>6.68 ± 2.72</b>	<b>0.3415NS</b>

NS Not Significant

They lacked in their practices and had low overall scores (6.52 ± 1.89 and 6.68 ± 2.72) and there was no significant difference between the two groups. They were hesitant and felt they lacked knowledge about how to teach sexuality related concepts at the time of the pre-test. In his research, Hirst (1994), states that there appears to be reluctance amongst parents, particularly fathers, to talk to their sons about sexual matters. 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.

After the intervention program, the post-test data from table 2 reveals that the parents of the control group did not improve much in their practices, with their overall score being 7.14 ± 2.05 while a notable improvement was observed in the practices of the parents of the experimental group, with an overall score of 12.48 ± 2.48.

**TABLE – 2 Post-Test-Practice Scores of Parents (Comparison of control with experimental group)**

Dimensions of Practice – to teach...	Control Group	Exp. Group	Significance of t value
Children about Self care	2.66 ± 1.22	4.24 ± 0.84	7.5453**
Sexual Safety	2.34 ± 1.11	3.90 ± 1.28	6.5108**
Puberty & Menstruation	1.06 ± 0.95	2.06 ± 1.30	4.3917**
Basic sexual Concepts	1.08 ± 0.96	2.28 ± 1.19	5.5504**
<b>Overall Scores</b>	<b>7.14 ± 2.05</b>	<b>12.48 ± 2.48</b>	<b>11.7362**</b>

\*\*Significant at 1% level

There was a highly significant difference between the groups. This indicates that parents of the experimental group have improved in their practices to teach sexual health education to their children with Autism after attending the intervention program. The intervention program has been effective in improving parents' practices as the teaching techniques suggested have been useful to the parents. Research findings suggest that 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 (Roeyers, 1996) as autists are visual learners and learn better when teaching aids are used (Schreibman, Whalen, & Stahmer, 2000).

The findings of the present study are supported by a similar study conducted by Nichols and Blakeley-Smith (2010) who developed an education program for parents, aiming to increase 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 to learn various concepts related to sexuality and were trained in the teaching methods and strategies that can be employed for each concept. The results showed that parents improved greatly in the areas of skill and knowledge in dealing with the sexuality of their growing children.

**CONCLUSION**

Thus it can be concluded that parents lack in their practices in teaching sexual health education to their children with autism. They require teaching and training to be effective sexual health educators of their 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.

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