

## PARENTS' PERSPECTIVES ON SEXUAL BEHAVIOURS OF CHILDREN WITH AUTISM AND THE BARRIERS IN IMPARTING SEXUAL HEALTH EDUCATION

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**Abstract:** This study was undertaken to explore parents' perspectives on the sexual behaviour of their children with autism and understand the barriers they faced in teaching them sexual health education. The survey method was used to identify fifty parents of children with autism from various special schools in Bangalore. A self-developed observation checklist was used to obtain information from parents regarding the sexual behaviors of their children with autism. Additionally, the investigator interacted with them to understand the barriers they faced while trying to teach their children about sexual health education. The data obtained was analyzed and the results showed that every child displayed some form of inappropriate sexual behavior or the other; and, most parents have not attempted to teach their child about socially appropriate sexual behaviour due to many reasons-which they perceived as barriers. They felt inadequate to deal with the subject of sexuality, not knowing when to start, how to teach and how much to reveal to their children. Therefore, there is a need to educate parents and help them overcome the barriers and effectively teach children with autism about sexual health education and socially appropriate sexual behaviours.

**Keywords:** Autism, Parental perspectives, Sexual behaviours, Sexual health education

**Introduction:** Autism spectrum disorders are clinically heterogeneous neuro-developmental disorders with prominent impairments in social reciprocity, language impairment and restricted repetitive behaviours or interests [1]. It is considered to be one of the most severe disabilities affecting young children, because it adversely impacts almost every aspect of the child's development [2-4]. Parenting a child with autism spectrum disorder requires an inordinate amount of time, effort and energy [5]; it becomes a central commitment in the lives of parents [6]. Even though it is frequently noticed that in the parental dyad, mothers assume the role of the primary caregiver [7], both parents play multiple crucial roles in the lives of their children with autism as caregivers, shadow teachers, therapists and much more.

Parents spend the most amount of time with their children, looking after them and even caring for their most private and intimate needs. Because they do this on a regular basis, they tend to infantilize their children and fail to see their growing children as emerging sexual beings. The aspect of sexual development is overlooked, until such time that the child begins manifesting behaviours that are deemed inappropriate by societal standards. Children with autism spectrum disorders frequently exhibit a wide range of problematic and socially deviant characteristics and behaviours [8] owing to their lack of social skills, need for repetition, and the other core features of autism. Ruble and Dalrymple [9], in their study titled "Social/Sexual Awareness of Persons with Autism: A Parental Perspective" analyzed data obtained from 100 respondents and reported that individuals with autism engage in a wide range of sexual behaviors. Sixty-five percent have touched

their private parts in public, 28% removed clothing in public, 23% masturbated in public, and 18% touched the opposite-sex inappropriately; 18% mentioned other things such as talking about inappropriate subjects, looking up shorts and down shirts, and touching parents inappropriately. Fourteen percent have masturbated with unusual objects such as a pair of socks, 4% display private pictures in public, and 2% refuse to touch their penis. In another study addressing the sexuality and sex education of individuals with Autism Spectrum Disorders, reported a high frequency of sexual behaviours among individuals with autism spectrum disorders, of which a number of them may become problematic for caregivers and service providers because they violate societal norms regarding appropriate interpersonal behavior [10].

For much of known history, the concept of individuals with any disability being accepted as sexual beings was unthinkable [11]; although, that notion is gradually changing, parents still find it the hard to accept the overt sexual behaviours of their children and they find it harder to teach them appropriate sexual behaviours. Most parents are not aware of the importance of commencing sexual discussions in the early years of a child's development for the establishment of a strong foundation for open discussions during adolescence [12]. A possible explanation why parents hesitate to provide sexuality education may be that they do not expect that their child will develop sexual relationships and thus do not expect that their child will need or benefit from sex education [13]. Guest highlights this perception in his recollection of growing up with a disability - where his father believed that he would not be able to engage in sexual activity, and so he should not

receive any sexual information[14]. Additionally, many parents believe that the schools have the primary responsibility for educating their children about sexual health, and thus take a passive role. They may also feel they lack knowledge, and hesitate to discuss sexual health with their child. Parents cite a number of reasons as barriers that prevent them from effectively imparting sexual health education to their children with autism.

#### Methodology:

**Objectives:** The first objective was to explore parents' perspectives on the sexual behaviours of their children with autism. The second objective was to understand the barriers parents faced in imparting sexual health education to their children with autism.

**Sample:** The investigator surveyed the special schools within the city of Bangalore and sought permission to interact with the parents of children with autism. Through purposive sampling technique, 50 parents of children with Autism were selected based on their willingness to participate in the present study.

**Tool used:** A dichotomous observation checklist was framed by the investigator for the purpose of this study, to record the sexual behaviours manifested by children with autism. It contained 17 items, of which 4 were pertaining to positive and 13 pertaining to negative behaviors. The items were categorized under the following three dimensions for the sake of analysis-

- i. Gender and body awareness(5 items)
- ii. Socio-sexual behaviors (6 items)
- iii. Sexual behaviors (6 items)

The response options given to the respondents were a direct 'yes' or 'no', in order to reduce the ambiguity of their responses. Positive items that were marked 'yes' were given a score of 1 and a 'no' was given a 0 score. Negative items were reverse scored.

**Method:** The survey method was adopted for the present study. The investigator established rapport with the respondents and assured them that the data obtained from them will be used only for the purpose of research. The investigator also explained the need for the study and sought written consent from the respondents. A self developed tool was utilized to collect the socio-demographic information of the respondents, and specific information about their children. Parents were then asked to indicate the presence or absence of sexual behaviours of their child with Autism by marking yes or no in the tools provided to them. The data collected was scored, tabulated and analyzed using simple descriptive statistical measures. Further, the investigator interacted with the parents to understand the barriers that prevented them from effectively imparting sexual health education to their children with autism. The findings of the study were

discussed, in the light of existing literature on sexual health education for children with autism.

**Results and Discussion:** The socio-demographic information of the respondents and their children is discussed below. Eighty percent of the respondents were mothers, as they are the full-time caregivers of their children. Only a few fathers (20%) participated in the present study. Because of the additional responsibility of care giving, mothers are less likely to work and fathers are often forced to work overtime in order to compensate for the decrease in the family income [15]; hence, few fathers have the time and the inclination to be involved in the child's upbringing. All the respondents were Hindus (100%). A majority of the respondents were middle-aged adults (54%). Half of the respondents were graduates (50%) and a substantial number (22%) have done their higher education.

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 spermatheca in boys is not as apparent as menarche in girls.

**Table 1a** indicates parents' perceptions of their child's gender and body awareness. About half the parents were not sure if their children (44%) were sure of their gender.

**Table- 1a: Gender and body awareness of children with Autism**

Gender and Body awareness	Number (N=50)	Percentage (%)
Is sure of his/her own gender	28	56
Behaves in a gender appropriate manner	37	74
Is pre-occupied with the pubertal changes occurring in the body	18	36
Maintains hygiene while having periods/ wet dreams and ejaculations	8	16
Is able to handle his/her personal (toileting) needs independently	28	56

They reported that they have not made an intentional observation to see if their child was aware of gender

differences. Although 74% of the children were reported to behave in a gender appropriate manner, the rest of them showed some ambiguity from time to time in the choices they made with regard to clothing, accessories, etc. Data showed that 66% of the children were between 10 and 15 years of age, and 36% of them seemed to be preoccupied with the changes they saw in their bodies. One parent reported that her daughter was very worried by the appearance of pubic hair and thought she could get rid of it by scrubbing herself during bath. Studies show that children with Autism may have an excessive curiosity about the human body and the way it functions [16]. Parents reported that 36% of the children had attained puberty but only 16% of them maintained adequate menstrual and personal cleanliness. Some children required help, but some parents felt their children liked certain odours and hence refused to be clean. One father reported that his 14 year old son liked to rub his genitals and then smell his fingers. He disliked being clean because his body odours were not pungent enough for his liking. Parents assisted 44% of the children in handling their personal and toileting needs on a regular basis.

**Table- 1b: Socio-sexual behaviors of children with Autism**

Socio-sexual behaviors	Number (N=50)	Percentage (%)
Tries to undress others	6	12
Undresses or tries to undress before others	14	28
Touches others inappropriately- hugging, kissing, etc.	12	24
Touches others' sexual parts against their wish	4	8
Touches himself/herself sexually in the presence of others	9	8
Tries to invite others into the bathroom/toilet with self	5	10

Sexuality is one of the core aspects of one's personality, consisting of values, beliefs and attitudes. Sexual behaviours are the overt expressions of one's sexuality and it is a natural part of an individual's development from infancy to late adult years. A person's sexual behaviour may often involve more than one person, because of the biological need for reproduction and the emotional need for intimacy. When sexual behaviour is directed towards or involves others, it is referred to as socio-sexual behaviour. While young children with autism may have little interest in having physical contact or in

developing relationships with peers, older children and adolescents often have interest but lack social skills [17]. They have the same human needs for intimacy and relationships as anyone else [18]; however, for individuals with autism, sexual development, feelings and urges are not accompanied by adequate social understanding, due to which they tend to indulge in inappropriate sexual behaviours. These behaviours cause concern to parents who themselves feel inadequate to deal with such situations. **Table 1b** clearly depicts the extent to which children with autism indulged in socio-sexual behaviours. About 12% of them tried to undress others or touch them under their clothes, while 28% of them undressed before others; 24% tried to hug or kiss others, while 8% of them tried to touch others in a sexual manner. One parent testified that her son liked soft things that he could squeeze; this often led him to touch women inappropriately. Although he did not have a sexual intent, this behavior stemming from his sensory needs was often misinterpreted to be of a sexual kind. According to parents' reports, 8% of the children touched themselves sexually in the presence of others. Several studies have reported that some individuals with autism develop problematic behaviours such as undressing in public, masturbation in the presence of other people and the initiation of inappropriate physical contact with other individuals [9, 19, 20].

**Table- 1c: Sexual behaviours of children with Autism**

Sexual behaviors	Number (N=50)	Percentage (%)
Tells words that are sexual in nature loudly and inappropriately	3	6
Masturbates at inappropriate times and places	22	44
Rubs body against furniture in a sexual manner	6	12
Uses dolls and items of common use inappropriately for obtaining sexual pleasure	2	4
Tries to look at pictures of naked people or of people wearing revealing clothes	11	22
Behaves in a sexual manner with people of both the genders	4	8

Some sexual behaviors are performed on one's self and do not involve anyone else. Such behaviours are referred to as solitary sexual behaviours. It generally

involves touching one's genitals when aroused, and masturbating in order to orgasm. **Table 1c** reveals the sexual behaviors of children with autism. Parents' report revealed that 44% of children masturbated at inappropriate times and places. Masturbation is the most commonly reported sexual expression for people with autism spectrum disorders [21], and it is a normal part of an individual's sexual development [22]. It is necessary to acknowledge that masturbation may be the only outlet for sexual expression for this group [23]. Although solitary sexual behaviour is healthy for a number of reasons, in the case of individuals with Autism, it is sometimes problematic as they engage in such behaviours in the presence of others, being unmindful of their social environment. Table 1c reveals that 12% of the children rubbed themselves against furniture and 4% of them used toys to obtain some form of sexual pleasure. Parents reasoned that the children had poor motor skills and were often unable to satisfactorily masturbate to the point of orgasm. Therefore they sought out other means such as toys and furniture- merely as aids to help stimulate their bodies. Research bears witness that some individuals with autism spectrum disorders indulge in deviant forms of masturbation, use unusual objects during masturbation, and some hyper-masturbate - masturbate frequently to an extent where it disrupts daily functioning [21, 24]. Parents also found their children (22%) looking at pictures of scantily clad people either in books, newspapers or on their personal electronics. This was most often noticed among adolescent boys. One father shared that he felt jolted when he found that his son attempted to send a nude 'selfie' of himself through a social media application on his mobile phone. Considering the last aspect, 8% of the children behaved in a sexual manner with people of both the genders. Some parents reasoned that because their child was not very sure of the concept of gender differences, they seemed to behave the same way with people of both genders. Sexual identity develops normatively in adolescence related to puberty and overall body changes in the context of societal expectations about partner choices. For most adolescents with autism, this development may occur later than that of their typically developing peers [25].

**Barriers faced by parents in imparting sexual health education:** The data from the present study as well as from recent literature reveals that parents of children with autism who were found to engage in sexual behaviours of concern, were primarily concerned with the child's safety and others' understanding of their children's behaviour [26]. Parents tend to avoid discussing sexuality related issues with their child for as long as possible. But in the event of problematic or inappropriate sexual behaviors, parents feel compelled to impart sexual

health education. However, in the present study parents cited a number of barriers that prevented them from effectively imparting sexual health education to their children with autism.

They felt awkward and were uncertain about how much these adolescents can understand, and what is developmentally appropriate for them. They feared revealing too much, so as to not arouse them or awaken their sexual feelings. The Committee on Children with Disabilities suggested that parents may be reluctant to discuss sexuality with their adolescents with developmental disabilities for fear that it may promote sexual behavior or lead to sexual exploitation [27].

Some parents felt they lacked knowledge on aspects related to sexual health and hence felt inadequate to deal with the emerging sexual behaviors of their children. This was especially true of mothers who were looking after adolescent boys, without much spousal support. A single mother shared that she is solely responsible for teaching and training her son about everything that he must know as an adolescent. She herself grew up in a conservative family with no male siblings. Her own sexual and intimate experiences were limited to a short span of time with an adult man. Now she feels incompetent in both knowledge and skill to manage the sexual behaviours of her adolescent son and teach him sexual health education. Byers, Sears, & Weaver found that many parents believed they lack knowledge or are not at ease discussing sexual health knowledge with their child [28].

In the Indian context, even though many live in nuclear families, they still reside in close proximity to their extended family. Quite often elderly relatives may stay for extended periods of time and relatives may frequent the house. Parents reported not having adequate privacy in their own homes to initiate discussions or training pertaining to sexual health with their child. They said they were anxious about being judged by their relatives, as many hold conservative views and open talk about sexuality is still considered a taboo. A parent revealed that her elderly in-laws would not approve of any talk about sexual health. If ever they give their consent, they may agree to discuss the biological process of puberty in brief and tell the child facts about growing up. However, as a mother of an autistic child, she knows well that her child will not benefit so much from knowing about the body, but he requires training in functional skills to manage his personal hygiene and self stimulatory behaviours, and socio-sexual skills training in order to interact and behave appropriately with others. But she could do neither, as she found others coming in the way of training her son in these aspects.

Those whose children were non-verbal felt clueless about how they can teach the complex aspects of sexual health to their children. They expressed that the teaching material available to them in books and websites were suitable to teach the child about the physical aspects of growing up and puberty. But they felt it is impossible to teach children behavioural and emotional aspects of sexuality, including the nuances of appropriate socio-sexual and sexual behaviour without direct oral communication. They also stated a lack of suitable teaching materials and visual aids that are educational but not offensive.

On the other hand, parents of children who were verbal expressed that they could not judge how much their children actually understood. Sometimes, due to existing echolalic behaviours, the child repeated what was told to him or her. A mother conveyed that her 11 year old daughter showed interest when she taught her about sexual health. But she soon had to stop because her daughter repeated certain phrases out of context, causing embarrassment and inviting unnecessary attention to herself. She repeated phrases such as “my breasts” and “no boys” frequently. Stokes and Kaur in their study of high functioning adolescents with autism reported that when compared with typical adolescents, adolescents with HFA were found to display more inappropriate sexual behaviours, including speaking about sexual activities in a way that was not typically discussed by their peers [29].

Parents expressed that imparting sexuality education for individuals with autism is emotionally taxing, and they would like to delay it for as long as possible.

Their own and others’ beliefs and attitudes towards sexuality of the child, hindered them from discussing sexuality related issues. As one parent expressed, he said “as a parent, I not only have to evaluate but also alter my morals and beliefs about sexuality, in order to accommodate my child’s sexuality- because I know that our society is not ready to accept the sexual needs of any child with special needs. I must be willing to stand strong against all odds”. Parents must prepare to deal with their own feelings about the child, and accept that the child is growing up and will experience sexual feelings and urges too. Mesibov cautions that “because most autistic people will not form our society’s traditional sexual unions consisting of marriage and a family, we must evaluate our feelings about possible alternatives, weighing the needs of autistic people for appropriate sexual outlets against the values and morals of society” [30].

**Conclusion:** Owing to a number of reasons, children with autism display a number of sexual behaviours that cause concern to their parents. Parents recognize the need to teach and train their children in aspects of sexual health education, but report various barriers that impede them from addressing sexuality issues in their children. Yet, they must take constructive steps to overcome these barriers and train their children. Because sexuality is a primary dimension of the human experience and sexual health education will enable individuals with autism be independent, express their sexuality in socially appropriate ways and gain both self esteem and social acceptance.

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