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**RESEARCH PAPER**

**Parenting Role in Delivering Home Based Sexual Education for Adolescents with Autism Spectrum Disorder**

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**ABSTRACT**

The adolescent with spectrum disorder (ASD) and their parents experience much differently in their lives as compared to the parents of normal adolescents. This study aimed at seeking the challenges which their parents experience during the provision of home-based sexual education. This study was exploratory and qualitative. There were 12 parents of adolescent with autism spectrum disorder (ASD) who were the sample of this study. This study used purposive sampling from the group of non-probability sampling technique. A self-developed semi-structured interview protocol was administered to collect data. There were 03 expert who validated the instrument through their expert opinion. An extensive literature review helped the researchers in the reliability of the instrument. The thematic analysis technique was applied for data analysis. Thematic analysis revealed four major themes including parents' perception, challenges for parents, efforts by parents, and strategies for parents. This study's findings revealed that majority participants reported that sexual education at home is right of adolescent with ASD. The study recommended special orientation sessions for parents of ASD on home-based sexual education.

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**KEYWORDS** Adolescent, Autism Spectrum Disorder, Home, Parents, Sexual Education

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**Introduction**

According to needs and interests, all adolescents should learn about relationships and sexual education (Unis & Sällström, 2019). From the time that children are infants, sexual education is provided. The main objective is to more accurately measure the relationship between social or emotional development and school readiness in young children with the single question of how these skills support a child's overall development from middle childhood or later (Kristen et al., 2016).

Healthy sexual education features of children with autism spectrum disorder (ASD) include partner violence prevention, dating support, sexual diversity appreciation, developments in relationships, child sexual abuse prevention, learning to express emotions socially, and social media or print media influence (Goldfarb & Lieberman, 2021).

To ensure their children's development, parents are crucial (Juliet, Graham, 2016). Every child, whether they have autism spectrum disorder or not, should understand their body parts, relationships, the distinctions between bad or good touch, and various body parts.

However, parents face the same challenges when trying to teach their autistic adolescent about appropriate or inappropriate touch, body parts, personal hygiene, and other topics. The family's duty is to educate themselves on the child on the child's developmental characteristics and recognize the child sexual maturation. Child school is requested to support and provide sexual education (Çalışandemir et al., 2008). Sexual development is a part of the development process that takes into account the interactions between social, cognitive, religious, ethical, cultural, mental, physical, and relational factors (Michielsen and Brockschmidt, 2021).

In order to promote self-protection, prevent exploitation, and teach healthy sexual behavior at a young age, sexuality education is crucial (Sravanti, 2021). Children can only receive sexual education from their parents (NurAzira et al., 2020).

When children with autism spectrum disorder (ASD) really try to talk about sex, it is extremely challenging for the parents to explain things to their kids about sex. Such interactions produce misinterpreted messages as a result. With open communication about sex with their parents, autistic children create safer relationships in future with sexual initiative first by birth control and other safety-related measures (Looze et al., 2015).

The condition of autism where children struggle in communicate effectively with both their parents and other members of their social environment. ASD is a condition of neuro-development that has a profound impact on a child's ability to communicate, develop relationships and interpersonal. According to the person with disabilities rights act in India (2016), these are typically concerned with unusual and stereotypical traditions and social mores (Narayan & John, 2017).

Furthermore, when compared to children who are typically developing, children with ASD exhibit very few behavioral issues, very few cues, and are less responsive (Vilaseca et al., 2019).

Due to their isolation from younger children their age, autistic children face challenges when trying out sexual activities and engaging in social interactions. Lack of education also extends to their own sexuality (Woodard, 2010).

There is the significant parents in the daily lives of autistic children as compatible careers and sexuality educators. Parents perform the actions of gripping, touching, changing diaper, and washing in order to begin sexuality education, which typically begins at birth.

## **Literature Review**

"Autism spectrum disorder" is the term, used to exhibiting the particular type of repetitive behavior expressed by the people, highly forced the commencement of sensory behaviors early in life (Lord, 2020).

Regardless of general population, Autistic individuals' siblings and monozygotic twins have the higher risk of diagnosis with ASD (Kim et al., 2019). Genetic factors play a role in ASD susceptibility.

An increase in autism spectrum disorder awareness between the common public and development of well-organized support for ASD groups can be given useful tools of accessing for parents and help them past such mentioned difficulties and obstacles. To

better support families of children with ASD, future research should identify coping mechanisms and solutions to these problems (Shin et al., 2020).

As parents work to comprehend the children issues and get an identification, an autism spectrum disorder can cause them a great deal of stress and confusion.

The diagnostic process involved five coping experiences for parents of autistic children: (1) difficulty and uncertainty in understanding the behavior of their child before the phase of diagnosis; (2) compulsion for obtaining services of professionals; (3) concerned for seeking 2<sup>nd</sup> opinion during the phase of diagnosis; (4) strength of acceptance in the phase of post diagnosis; (5) Extra accommodation in the phase of post diagnosis. The findings revealed that how parents perceive diagnostic procedure, that may enhance the support and counseling that medical professionals provide to parents (Chao et al., 2018).

It's a common misconception about people with disabilities that they can't have sex or are uninterested in having it. It is particularly crucial that inclusive sex education need because there is limitations of access for them in sexual education for being a sexual minority rather than considered as general population (Samantha et al., 2022).

Generally, comprehensive sexual education describes cognitive, social, emotional, and physical development (Bialystok et al., 2020).

For more welcoming of children and addressing the need for sexual education by creating an inclusive environment, it is crucial to deconstruct the stigmatization of youth and children with special needs in relation to sexuality education (Davies & Kenneally, 2020).

When it comes to provide complete sexual education for supporting autistic individuals or children, care providers and parents frequently lack confidence and knowledge (Donnelly 2023).

New relationships and their establishment and becoming much sensitive with the opposite sex related to sexual education is the initial developmental task in which he or she should be mastered to deal with. The point of interest comply a particular pattern especially for opposite sex, just as adolescents with ASD see their sensual areas develop. Emotional integration, desires and needs known as sexuality reveals a propensity for person's for being female or male to shape their individual personality. On the other hand, sex is known as physical relationship or other related activities or sex.

Autism-affected adolescents dislike their adolescent years. Autism-affected parents face unique difficulties, particularly when it comes to educate their children about sexuality. Sexual education is crucial for autistic adolescents because sexual harassment is more likely to be experienced for them. The proper understanding of the transformation in mental, physical, and maturity of emotions related with sexual problems is another reason why it is significant for autistic adolescent to get sexual education. This will also enable them to safeguard oppose to the manipulation which could harm their mental and physical well-being.

The reality is that the restrictions imposed by their sex, adolescents with autism are not able to recognize the issues with ease. Everything points to the problems with children's sexuality who have autism. For instance, they don't feel self-conscious about removing their clothes in front of people, or about seeing and touching their own genitalia. Even though they need to masturbate, autistic children rarely touch other people's private parts.

If it is not done, they will experience depression. When children act out in public, new parents will be acutely aware of the issue (Ria et al., 2019).

Parents believe that providing sexual education to autistic children as they enter adolescence is important, but they lack sufficient knowledge of the resources and teaching strategies that are suitable for these kids. Additionally, the traits and skills that autistic children possess force parents to resourcefully provide sexual education in line with the child's sexual maturation. As a result, parents of ASD children who are starting to enter teenage need to receive training and mentoring on sexual education (Atien & Santiaur, 2017).

Discussing sexual issues with a child is never a simple task. These sexual issues include gender differences, pregnancy, the spread of AIDS, and various physical changes. The prevention of child's sexual abuse, the development of healthy relationships, promotion of media literacy, and emotional and social learning are all the characteristics of Healthy sexual education (Goldfarb & Lieberman, 2021).

A complete sexual education for children emphasizes bodily autonomy, respect for differences, evidence based instructions, diversity, and a holistic view of social, cognitive, physical, and emotional development (Bialystok et al., 2020).

Teenagers and children with special needs are frequently ignored. Nonetheless, helpful differentiated instruction and guidance for students with special needs are not facilitated accordingly. Additional work must be put into educating all educators on handling of sexual education for autistic adolescent and children (Davies, 2020).

## **Material and Methods**

### **Research Design**

The study was exploratory and qualitative.

### **Study's Population**

The population of the study was consisted of parents of children with autism spectrum disorder (ASD). Both from urban and rural context living in different cities of Punjab including Lahore.

### **Sample of the Study**

The participants of the study included 12 parents of children with autism spectrum disorder associated with various educational backgrounds and socioeconomic. Among 12 parents, there were males (N=06) and females (N=06). Parents from Lahore city were 2 (16.66%) whereas 6 (50%) were from Rawalpindi, 2 (16.66%) parents were from Faisalabad, Shahdara, and parents from Bhakkar were 2 (16.66%). The sampling technique used in this study was purposive sampling technique.

### **Instrument of the Study**

A self-developed semi-structured interview protocol was administered to collect data. In-depth, interviews questions guided the researchers as primary method of data collection.

### Validity and Reliability of the Instrument

The instrument's validity was assured through the opinion of the expert (N=03). The instrument's reliability was assured through the extensive literature review.

**Table 1**  
**Samples' Demographics**

Characteristics	f(%)	M	Minimum	Maximum
Age		45.66	35	56
Qualification of mother				
Bachelor	4(33.33%)			
M.A	7(58.33%)			
MPhil	1(8.33%)			
Qualification of father				
Bachelor	2(16.66%)			
M.A	10(83.33%)			
Level of child with ASD				
Mild	3(25%)			
Moderate	2(16.66%)			
Mild to moderate	4(33.33%)			
Moderate to severe	1(8.33%)			
Severe	2(16.66%)			
Children school going	8(66.66%)			
Children not going school	4(33.33%)			
Family from				
Urban	6(50%)			
Rural	6(50%)			
Family system				
Joint	4(33.33%)			
Nuclear	8(66.66%)			

### Procedure for Data Analysis

The thematic analysis technique was applied for the analysis of the data. Four broader themes were generated from the categories that were drawn from the interview transcription. There were sub-themes that were defined to explain the categories. The participants of the study were approached with great efforts. As the first author of the study, participants of the study were approached. It took three weeks to contact and get the consent of all of the participants.

### Ethical Considerations

This is the basic ethic of research to ensure ethics. A permission was taken from the participants. It was assured to all participants that information will remain private and would be dealt only for the purpose of the research. All participants had also the option to refuse any question and leaving this study at any stage. The study's participants were not asked for any secret information as it was not desired according to this topic of research.

## **Results and Discussion**

### **Qualitative Data Analysis**

Research Question 1: What is the perception of the parents regarding sexual education of their autistic children?

#### **Theme 1: Parents Perception**

This theme reflects that how the parents of autistic children perceive the sexual education for their autistic children. This theme is emerged from the categories of guidance, communication gap, inadequate materials, reaction, and schools' responsibility. The parents reported non-comprehension of the words due to poor communication ability, is shown from the autistic children irrespective of age appropriate emotional expressiveness is restricted. Therefore, children are unable to express or control their age appropriate emotions (Rea et al., 2019).

#### **Category 1: Guidance**

This category shows that only few participants expressed they guide their autistic children about differences among genders. These participants also stated giving information about various body parts and advice for not touching the private parts is important for their autistic children. One of the participants said that

"I guide my son repeatedly than he go through gradually."

#### **Category 2: Communicational Breach**

This category displays that only few participants said that it is difficult to talk about sexual education. Their children became secluded if we talk. They have communication gap towards their children. They cannot control sexual aggression. In addition, one of the participants said that

"My son doesn't communicate he just laying on bed."

#### **Category 3: Inadequate Materials**

This category shows that less than half of the participants stated that more material is needed to learn as they teach these teen-agers but without proper material, it is difficult to make understand their autistic adolescent. Furthermore, one participants stated that

"I tried to find out more materials for my child but I could not find the desired material."

#### **Category 4: Reaction**

This category depicts that maximum of the participants stated that there is no behavioural change of their autistic children. They like to watch videos and celebrities. They have limited socialization and don't show interest. These participants also stated that their children want to touch and hug the people they like. However, one of the participants said that

"He does not show attraction he has no social reaction."

### Category 5: Schools' Responsibility

This category depicts that few of the participants expressed that schools are expected to teach the child with autism spectrum disorder about sexual education but there are no such activities regarding their development. They also stated that sexual abuse of autistic children is mostly done by the servant. They tell that teachers do not pay attention to their children. Moreover, one of the participants narrated that

“There is no school strategy about controlling sexual abuses and give proper sexual education.”

Research Question 2: Which are the challenges that parents of autistic children experienced during home-based sexual education?

### Theme 2: Challenges for Parents

The theme reflects the challenges that become the hurdles for the parents of autistic adolescent. This theme depicts the relevant challenges emerged from the interview of the participants. The theme has been appeared from the categories of food availability, hyper activeness, and nudeness. Parents experience various challenges among their children with ASD. Restricted comprehension difficulties, non-verbal & verbal communication, including sensory processing disorder are experienced by the children with autism spectrum disorder (Pektaş, 2016; Rustioğlu et al., 2018).

#### Category1: Food Availability

This category shows that few of the participants indicated that they can handle their children with autism spectrum disorder by giving low potential food. They also stated that they are aware Pakistani perspective issues and can handle it. Moreover, one of the participants said that

“We try to give him the food which he remains cool so that his body parts could remain normal.”

#### Category 2: Hyper activeness

This category shows that less than half of the participants reported that they are unable to control their children with autism spectrum disorder. They also stated that big challenge is to deal with rubbing or sexual aggression in a function. They also tell that under shaving is a big task or them. However, one of the participants said that

“On many occasions in my life, I felt much difficulties to accommodate my son in his genital areas hygiene.”

#### Category 3: Nudeness

This category highlights less than half of the participants declared that their children with autism spectrum disorder have no concept of nudity. They take off their pants or dress in front of anybody. They also stated that her autistic child totally depend on them for personal hygiene. They tell that they taught them time to time. One of the participants said that,

“He often take off his pent in front of anybody.”

Research Question 3: What are efforts delineated from parents of autistic children for delivering sexual education at home?

### Theme 3: Efforts by Parents

This theme has been emerged from the categories of the concept of good and bad touch, developing interest, and marital relations. The autistic children's needs are **preferably full filled by mothers through coping up the challenges in childhood that are resulted by the family dynamics change** (Papadopoulos 2021).

#### Category 1: Concept of Good and Bad Touch

This category shows that maximum parents narrated that they taught autistic child about good and bad touch time to time. Participants also that their children have conceptual learning of nudity. One of the participants said that,

"I have told him about good and bad touch and tell nobody should touch you."

#### Category 2: Developing Interest

This category indicates that few of the participants reported that it is very difficult to teach them about sexual education. They stated that their children don't take interest in it. It is difficult to communicate with autistic children. These participants reported that developing interest among children with autism to learn about sexual education is the real efforts of the parents. However, one of the participants said that

"There is no flexible behaviour of autistic child."

#### Category 3: Marital Relations

This category displays that only few of the participants responded that they tried to deliver the conceptual learning of marriage to their autistic children. However, these parents also expressed that at the situation, they talk about marriage their children with autism spectrum disorder remain calm and do not show interest. These participants narrated that they tried to tell their son or daughter regarding married relationship as part of sexual education. These participants also said that it is high concept to teach them. Moreover, one of the participants expressed that

"We are not able to delivered concept about marriage."

Research Question 4: What are strategies beneficial for parents for provision of sexual education to their autistic children?

### Theme 4: Strategies for Parents

The theme is occurred through the categories mentioned below. This theme represents the strategies that are much beneficial for the parents of autistic adolescent. The theme reflects a comprehensive understanding of the parents for using undermentioned strategies to give overt concept of learning sexual education. The categories include demonstrative approach, counselling, visualization, discussion method, and written content. **Families require much orientation or education of autistic adolescent about handling of sexual problems** (Shakuri & Alzahrani 2023).

#### Category 1: Demonstrative Approach



This category highlights that half of the participants indicates that their autistic children do not learn verbally so they use demonstrative approach. They also stated that they can learn through animation, pictorial and by practically manner. They tell that through visual cues and social media they can learn better. However, one of the participants said that

“The help of animation, we can develop interest for learning sexual education.”

#### Category 2: Counselling

This category indicates that few of the participants reported that through proper counselling they can develop the interest in their autistic children. Moreover, one of the participants said that

“One to one counselling is the best way.”

#### Category 3: Visualization

This category shows that only few of the participants shows that their children with autism spectrum disorder has self-understanding through see into their eyes. However, one of the participants said that

“He is able to understand what the father want to say.”

#### Category 4: Discussion Method

This category shows that maximum participants depicts that they taught about sexual education from puberty age. They also narrated that their autistic children are able for understanding good or bad touch. Moreover, one of the participants expressed that

“He is slowly understanding these things.”

#### Category 5: Written Content

This category shows that only few of the participants expressed that there should be need of telling about body parts and negative sexual activities in the society by strangers. These participants also stated that material regarding sexual educational awareness should be included in age appropriate books for autistic children. One of the participants narrated that

“I think the need is to put such content in the books so that children with ASD could get a comprehensive understanding from it.”

#### Findings

The findings of the study have been given below;

#### **Parents Perception**

This study found parents of autistic adolescent perceive that guidance by the parents is given to their children with ASD. It also includes that parents feel difficulty to discuss about sexual education to their autistic children. Parents also perceive there is inadequate material regarding guidance for sexual education to their autistic children.

Additionally, maximum of the participants perceive that this is the school responsibility to educate their children with ASD about sexual education.

### **Challenges for Parents**

This study found that parents of autistic adolescent experience various challenges including the challenge for providing suitable food, hyperactivity or aggressive behavior of their child with ASD, and the nudeness in-front of anyone.

### **Efforts by Parents**

This study found that parents develop the concept of good & bad touch, interest to listen regarding the body parts and marital relationship.

### **Strategies for Parents**

This study found that strategies for parents to guide them about sexual education are telling the adolescent with ASD through the demonstrative approach, counseling of the Adolescent with ASD, visual learning, discussion, and using of book based content.

### **Discussion**

Sexual education is sensitive phenomenon to discuss with anyone but if the matter is of teen-agers with autism spectrum disorder then it becomes much challenging especially for parents to discuss with their children with ASD. As they are already passing through a social communication disorder. When an autistic individual's capacity is surpassed with social demands, then individuals may involve in the mechanism of coping (Monk et al., 2022), in which stimming (movement with repetitive behavior but limited) is most common (Bottema-Beutel et al., 2021; Möhrle et al., 2020). Parents perceive the sexual education for their autistic children as need of the era but it is quite difficult for them to discuss such important matter with their children due to non-developed culture of telling the children about sexual education. Families and their autistic children may be marginalized by the prescribed treatment and it becomes a struggling endeavor for them (Salgado, 2020).

Therefore, parents face much challenges in discussing or dealing with their children or adolescent with autism spectrum disorder. These challenges are related to aggressive behavior of their autistic children who are passing through adolescent stage. Families with low socioeconomic status experience challenging situation while having financial struggle for the provision of such resources that are therapy (occupational, speech, or other therapies), social interactions, and especially education (Kudaibergenova, 2018).

Parents at some extent, do effort to deliver sexual education to their children with ASD by telling about various body parts, marital relationships, good or bad touch or even male or females. There is no doubt that various approaches and resources are used by the parents to tell them about sexual education. Financial Burdon is Three times larger for families of autistic individuals' as compare to the families of allistics children (Nuri et al., 2018).

Additionally, parents use various strategies in guiding their autistic children by using demonstration approach, time-time counseling for good or bad and provision of opportunities regarding visual learning. All these strategies make their child with ASD to understand much the sexual education. Autistic individuals require apex support for acquiring services relevant that are employment accessibility, abilities development for living independent life, strength-based programs with effective adult life (Lee et al., 2020).

**Conclusion**

The study is concluded herewith parents has a significant role in giving the concept of sexual education to autistic children. Parents may guide their children with ASD by giving them time to time instructions by using demonstrative approach. The performance of responsibility through the use of effective strategies by the parents brings their children or adolescent with autism spectrum disorder to a conceptual and lifelong learning.

**Recommendations**

The study recommends the followings:

1. Special education department should conduct regular trainings sessions for the parents of autistic adolescent about awareness of sexual education for autistic children.
2. Comprehensive content on guidance for parents of autistic children about sexual education must be prepared by collaboration between special education department and universities' scholars.
3. Schools having enrolled autistic children must deliver orientation based discussion and guidance in their weekly programmes for autistic children.
4. Government should commence the campaign through social media on regular grounds for awareness of the general society regarding responsibility of parents and its significance.
5. Researchers in future should conduct studies on the same phenomenon by using quantitative and mixed method approaches.

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