

Battling Through the Norms of Pakistani Society: Mothers' Apprehension Regarding Puberty of Their Daughters with Autism Spectrum Disorder

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The transition from childhood to adolescence is challenging especially for the youth of Autism Spectrum Disorder (ASD). Girls with autism struggles with menstruation and there is limited data available on sexual and reproductive health of ASD teenagers in Pakistani society, therefore this study aimed to explore mothers' perception of puberty in 10-15 years ASD old girls using the qualitative exploratory design. Phase 1 involve generating interview guide through literature review and subject matter experts' input. Phase 2 aimed to conduct interviews with mothers ($N = 6$) through purposive-convenient sampling. Themes were derived from recorded and transcribed interviews using the [Braun and Clarke \(2019\)](#) model. The Interrater reliability was substantial for mothers' apprehension and the study aligned with international findings, highlighting noteworthy aspects. deficient in menstrual hygiene, rivalry with the same-sex parent, affectionate behavior towards father and uncle, victim of sexual harassment, lack of understanding about the rights and wrongs in religion, unavailability of funds to go for hormone replacement therapy and mood disruption during puberty. Furthermore, this study recognized the mothers' apprehension of societal unacceptable attitudes toward the inappropriate pubertal behavior among the ASD teenagers and identified the need to eavesdrop on future exploration of reproductive health of ASD population in Pakistani society.

Keywords. Autism Spectrum Disorder, puberty, girls

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Transitioning is often closely associated with growth through the pubertal process which includes sexual maturity, and every society has its expectations from its typically developing adolescents to deal with it. Every culture has a subjective concept of going through the pubertal process which varies in time and societal norms (Fatusi & Hindin, 2010). However, it also varies from typically developing peers to an individual with special needs.

Teenagers with special needs go through the same pubertal changes and reach sexual maturity as their peers who are generally developing, but they are unable to advance in their social and cognitive development (Corona et al., 2016). Autism spectrum disorder has been frequently diagnosed as a neurodevelopmental condition (Foote, 2004). The prevalence of ASD among boys is higher than it is in girls (Seltzer et al., 2004). Adolescents with autism spectrum disorder, in particular, struggle with the accompanying social and emotional impairment during puberty as they must deal with their diagnosis.

The idea that adolescents with ASD enter puberty sooner than their normally developing peers is controversial and girls' periods of bodily development and transformation last from 9 to 11 years of age (Nichols et al., 2009). During this time, teenage girls experience breast development, pubic hair growth, acne, body odor, and the beginning of menarche (May et al., 2017). A study conducted on ASD girls by university students reported delays in menarche. However, the online survey reported experiencing precocious puberty in girls with ASD (Hergüner & Hergüner, 2016). Although there are conflicting opinions on whether people with ASD enter puberty earlier or later in life, they often go through the same emotional and behavioral changes as their peers who are typically developing.

For teenagers with ASD, puberty may also signal regression in some behaviors. Puberty brings hormonal changes, mood swings, and menstruation may worsen troublesome conduct in adolescent women with autism since they are unable to communicate their natural discomfort because of their social deficiencies, according to research (Hughes et al., 2010). Puberty may have become too much for women with ASD because they must cope with menstruation hygiene and hormonal changes, which can cause agitation, strong sexual demands before or during the menstrual cycle, and worries about physical changes (Gabriels & Hill, 2010)

Peer interactions may be challenging for girls with ASD, and they frequently struggle with exclusion and harassment from them. They are unable to establish a more profound emotional connection with

anyone (Parchomiuk, 2019). Women with impairments tend to be the targets of sexual offenses. Although women generally engage in less heterosexual activity and more often self-identify as asexual (Gilmour et al., 2012). Lack of sexual knowledge and social exposure was found in ASD in one study comparing peers with ASD with peers who were typically developing in terms of puberty, sexual behavior, and social interaction (Mehzabin & Stokes, 2011). To achieve this goal, a sex education program that is accessible to people with ASD is required (Karal & Wolfe, 2018).

Parents of children with ASD expressed concern about their stereotyped conduct, which may be an issue when they act inappropriately in public (Fernandes et al., 2016). In addition, ASD parents and therapists saw puberty as a separate issue in addition to the disorder's other symptoms (Hénault, 2006). For females experiencing puberty and ASD symptoms, it is especially difficult for those who have low language abilities since they are frequently unable to express their pain, and most parents are uninformed of the cause of such conduct (Cummins et al., 2020). Girls with neurodevelopmental difficulties have reported difficulty controlling their periods, which negatively affects their general well-being (Ditchfield & Burns, 2004). As a result, the caregiver may decide to regulate the period medically (Cummins et al., 2020).

Some mothers' have stated their worries about their children entering puberty, including sexual abuse, unintended pregnancies, and improper conduct, while others have noted benefits such as increased independence in daily activities and a sense of control (Zacharin, 2009). One study found that compared to neurotypical females, girls with ASD reported more behavioral, sensory, and emotional issues related to menstruation. Koller (2000) stresses that therapists should provide patients with a tailored strategy for dealing with menarche and that social storytelling and chaining have both been successful in implementing such programs (Veazey et al., 2016).

Pakistani Society's Perspective on Puberty

In contrast to industrialized nations, where adolescents are considered a distinct entity and have legislative restrictions dating back to the 1980s, this notion is still growing in developing nations. One of the top nations with more than 25 million young people between the ages of 14 and 25 is Pakistan (Hennink et al., 2005). Although open discussion of puberty or sexuality is still frowned upon in this indigenous society, especially among young people (Atta et al., 2015).

Sathar et al. (2003) conducted a study in Pakistan about the lack of understanding about puberty and sexual development in Pakistani adolescents. According to the study findings, 90% of boys and 80% of girls were aware of the physical changes that occur throughout puberty among their peers and family members. Boys were also more conscious of these changes than females were. The results also suggest that whereas only 30% of girls were aware of guys' wet dreams, 70% of boys were aware of menstruation. In addition, guys were more knowledgeable than girls about a woman's pregnancy process. The studies also recommended that the teenager be informed directly about puberty and reproductive health before it occurs.

According to studies, parents struggle to teach their kids about sexual health because they feel uncomfortable doing so since it could make them consider premarital behaviors (Corona et al., 2016). They also worry that if they do teach their kids about sexuality and puberty, they might initiate sexual activities earlier. Like studies on typically developing children, there aren't many studies on autism spectrum disorder in Pakistani society. Research on puberty in ASD females and parents' experiences during this critical time appears to be lacking. To build an acceptable curriculum for adolescents and parents with special needs and to address their concerns throughout puberty, this topic must be thoroughly explored in Pakistani society from the perspectives of parents, family, and professionals.

Rationale

The current study is multifaceted and focuses on addressing the critical gaps in understanding and assisting girls with Autism Spectrum Disorder as they approach puberty in Pakistani Society.

Prior studies have mostly examined sexuality or puberty in Western culture (Atta et al., 2015). There is a notable gap present in the literature. Female adolescents with ASD have received less attention in Pakistani culture due to the lack of fundamental-level studies that concentrate on puberty and the sexual health of typically developing adolescents. Recognizing the significance importance of cultural sensitivity, this study aims to fill the void by exploring this phenomenon from the mothers' perspective in Pakistani Society, thereby providing a cultural appropriate insight that might inform tailored interventional strategies.

Additionally, there are studies examining the puberty and sexual development in ASD but the female community has received little to no attention, globally as well as in Pakistan. As the female ASD suffer

from the different experiences than their male peers, this study solely focus on them with in intention to guide through the future endeavors

With the use of an interview guide that provides in-depth information about puberty from mothers' perspectives and struggling through the norms of indigenous society, the current study sought to qualitatively analyze mothers' anxiety about puberty in their ASD daughters. The current study concentrated on the worries that mothers of girls with ASD have about the difficulties that they and their families will encounter as they go through puberty in Pakistani culture. The study tend to equip policy maker and healthcare professional a valuable insight which would be able them to develop a supporting tools for the parents which could make this journey easier for ASD girls.

In conclusion, the goals of the current study include addressing the lack of research on the puberty experiences of people with ASD in the context of Pakistani culture, paying close attention to female adolescents, and comprehending the worries of parents during this crucial time. By doing this, the study hopes to close a knowledge gap, completely examine the problems and requirements of this community, and successfully accomplish its objective of offering culturally sensitive insights. Future research might build on these findings to create comprehensive plans and interventions that will further improve the care and wellbeing of Pakistani teenage ASD adolescents.

The broader objectives of the study were to explore the apprehension of mothers regarding puberty and sexual development in a female adolescent with ASD. In addition, it is also intended to explore the stereotypical norms of society and limitations for ASD females growing through puberty.

Method

This study employs semi-structured interviews to investigate the stated research topics in-depth. It is a qualitative exploratory study. Exploratory research allows freedom to examine a subject in depth that has not been thoroughly examined ([Kashif & Khanum, 2022](#)).

Sample

The mothers of girls who were diagnosed with ASD at puberty provided the information for this qualitative research. Random-purposive sampling was used to choose the participants. Five mothers, ranging in age from 30 to 45 years, were interviewed for the study

($N = 5$). The data was audio-recorded after obtaining informed consent from the participants which was later transcribed.

Material and Procedure

The semi-structured interview guide, which was created with the aid of academic research and the advice of subject-matter experts, was employed. The interviewing process included questions examining the moms' perspectives on how ASD girls are coping with the changes and limits that Pakistan as a nation is facing. The specific group, i.e. girls with ASD, and their experiences going through puberty in Pakistani society from the perspective of their mothers, was the focus of the inquiry. To ensure that the interview questions were acceptable, they were administered to a 35-year-old mother in a mock trial. The input was then included to create the final interview guide.

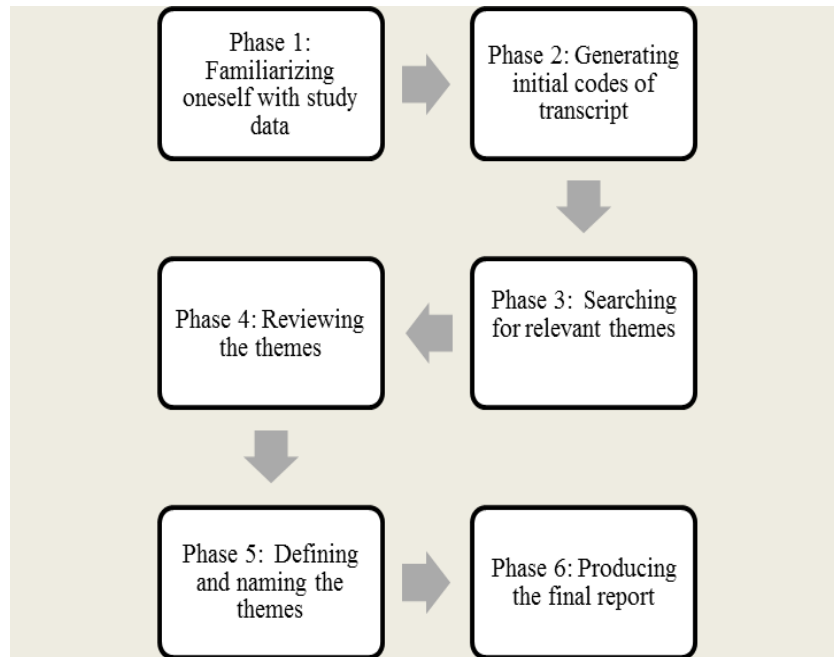
In the current study, the mothers were interviewed during one in-person visit and one online appointment. An initial Zoom conference was held to discuss the purpose of the study, have participants sign an informed consent form, and determine whether the moms could be contacted in person. With the participants' permission, all interviews were audio recorded. The participants were informed that the recordings would be kept secret and would only be used for transcription before being deleted.

Results

The six-phase [Braun and Clark \(2019\)](#) analysis method was used to thematically analyze the current investigation. Thematic analysis is a versatile technique for detecting, evaluating, and reporting themes across data, according to ([Braun & Clarke, 2019](#)). As seen in [Figure 1](#), it proceeds via a six-phase procedure. With the assistance of the second author, the inter-rater reliability was evaluated, and Cohen-Kappa values of .82, .81, .80, and .83 for the themes derived from mothers' anxiety were determined to be significant. Any discrepancy between the authors' interpretations of the codes was clarified by additional discussion and the presentation of data and statistics.

Figure 1.

Process of thematic analysis based on [Braun and Clarke \(2019\)](#).



Focusing on the phenomenological approach, four themes—poor menstrual hygiene, conflict with the same-sex parent, victim of sexual harassment, ignorance of the good and bad in religion, lack of funds for hormone replacement therapy, and mood disruption during puberty were taken from therapists' perspectives. Each topic was followed, but there were also several subthemes, as illustrated in [Table 1](#).

Table 1*Themes, Sub-Themes and Codes from the Transcribed Interviews*

Themes	Sub-themes	Codes
Deficit in menstrual hygiene	<ul style="list-style-type: none"> • Pubertal hygiene • Bathroom training 	<ul style="list-style-type: none"> • Difficulty in shaving. • Razor cuts. • Toilet training difficulties. • Unable to wear pads.
Rivalry with the same sex parent	<ul style="list-style-type: none"> • Affectionate behavior towards uncle and father. 	<ul style="list-style-type: none"> • Restraining the child from affectionate techniques. • Positive bonding with male figure of the family.
Sexual Harassment	<ul style="list-style-type: none"> • Safety and security of the child 	<ul style="list-style-type: none"> • Unable to identify safe unsafe figures. • Perfect catch for victimization.
Religious Social aspect.	<ul style="list-style-type: none"> • Religious restrictions • Social pressure 	<ul style="list-style-type: none"> • Lacking practical judgement. • Unable to control sexual urges.
Unavailability of funds	<ul style="list-style-type: none"> • Expenses of therapies • Hormonal replacement therapies 	<ul style="list-style-type: none"> • Lack of resource from the Govt. • Medical assistance being too expensive.
Transitioning period	<ul style="list-style-type: none"> • Mood swings • Hormonal changes 	<ul style="list-style-type: none"> • Hormonal changes. • Emotional dysregulations.

Following a thematic analysis of the data, six main themes and seven subthemes with different codes were identified. The outcomes have their justification and corroborating evidence.

Theme 1: Deficit in Menstrual Hygiene

The themes highlighted various aspects of puberty in female adolescents with ASD and the challenges associated with it.

Bathroom Training. Puberty is difficult for people with ASD not just because it affects them personally but also because it is a period of crisis for the family (Nichols & Blakeley-Smith, 2009). The findings showed that parents expressed their anxiety when thinking about puberty since they are generally unprepared for the changes their kid would experience (Holmes, 2005; Lang, 2005), as parent A noted; *“It is very hard for me during the time of puberty because she is hardly trained even potty trained and tasks during puberty requires a lot of independence.”*

Pubertal Hygiene. Even typically developing girls have emotional ups and downs throughout puberty as far girls with ASD are concerned, (Nichols & Blakeley-Smith, 2009) they find it difficult to control their feelings. Understanding and controlling the hormonal changes and pubertal hygiene as they get older is challenging for them (Gilmour et al., 2012). *“As she is also becoming stronger and bigger, I have this fear what if she tries to shave and cut herself with the razor because she obviously won’t let me touch her private parts due to privacy reasons.”* Another parent highlighted the most important aspect she noted; *“I and my daughter struggle a lot during her period’s cycle. She gets very agitated and shows a lot of tantrums. The main problem arises when she has to wear pad and I always must model it for her, and she gets frustrated because of it”.*

Theme 2: Rivalry With Same Sex Parents

During the interview, the mother she recommended claimed that parents were confused about the associated issues with puberty in ASD. The family is also going through a critical moment right now. Parents experience extreme anxiety when their child enters puberty (Nichols & Blakeley-Smith, 2009). Parents are aware, yet they are not conscious. Parents were perplexed by the concomitant issues of puberty, so they tried to reassure their child in their unique methods. Through modelling and parenting techniques, parents have an impact on their children's ability to regulate their emotions. (2017) Morris et al. They fail to see that their child is growing older and that some norms and boundaries need to be established, as a mother also said; *my daughter show more affection to her father then to me and at times she doesn’t listen to me but she would listen to her father about the same thing, I have realize she have become more close to her father during this time”*

Another mother mentioned; *“as the child gets older, parents must define the boundaries for how much physical affection they may exhibit. For example, if you want to demonstrate physical affection, you might maybe give someone a hand kiss or a hug, but that should only come from your parents and siblings. Such actions ought to be modelled for the youngster”.*

Theme 3: Sexual Harassment

This theme identified the vulnerability and exploitation that could cause a lot of damage to female adolescent with ASD, safety and security of the child was an evident subtheme during the interviews with the mother.

Safety and Security of the Child. Finally, moms emphasize the child's safety and security concerns as they get them ready for puberty. Due to the delicate nature of the issue, therapists or other family members cannot discuss puberty directly. Because young people with ASD are more likely to be sexually abused (Mandell et al., 2005). Due to the kid's fragility and the fact that parents are a child's safest figure, as one mother said, the knowledge should be given to the parents, who should then instill it in the youngster; *“Targeting things like puberty not only requires you to know the knowledge, but we also need to be taught to prevent our children from becoming abuse victims. Unfortunately, this is a restriction in Pakistan, where it is frequently for the child's protection and safety”*.

Theme 4: Religious/Social Aspect

Another crucial issue that was further investigated is how society views ASD and the developmental difficulties it presents. The results of the interviews revealed two subthemes: social pressure and religious restrictions.

Social Pressure. According to a parent survey, people with ASD exhibited a lack of social knowledge, which is vital to recognize when it comes to puberty (Hancock et al., 2020, Ginevra et al., 2016). Parents expressed concern about being judged and cut out from their social group. *“As your child grows up, you feel uncomfortable, people start to shun you, and they start to exclude you from social occasions,”* mother B said.

Religious Restriction. The moms' are also significantly constrained by the religious factor. Due to religious factors in Pakistan, a lack of knowledge, and the possibility that religion may occasionally cause parents to become radicals, many avoid discussing puberty. Mothers claim that religious practice is only appropriate for individuals who can discern right from wrong on a practical level. Additionally, their inability to control their sexual cravings will make them aggressive and frustrated if their parents try to stop them. A mother mentioned; *“my daughter doesn't know what religion is or what is right and wrong in our religion. So how can I expect her not to indulge in self-satisfactory activities?”*

Theme 5: Unavailability of Funds

The following sub-theme was highlighted during the interview with the mothers'.

Expense of the Therapies. The mothers also bring up the fact that some therapies are expensive for parents, which led them to initially refuse to continue them due to a lack of funding and insurance coverage in Pakistan, leaving the ASD unaddressed and resulting in the child's disruptive behavior as well as issues for the parents and those around them (Koegel et al., 2014). A mother reported; *“medical assistance like hormonal replacement therapy or ABA in our country is so expensive that we must think twice to opt for it. We can somehow afford it but these therapies are only for specific class, parents with low income suffer on the hands of general education teachers”*

Theme 6: Transitioning Period

Transitioning often becoming overwhelming for girls with ASD while going through pubertal phase. Adolescents with developmental delays in particular face twice as many difficulties due to these issues. Their brain doesn't have the same capacity as norm population to grab the concept of puberty. Transitioning period highlighted another important aspect which is a concern for a number of mothers' i.e. hormonal changes and mood swings that their child has to bear.

Hormonal Changes. During the times of puberty, even the typically developing individuals go through the emotional roller coaster as for ASD, they are unable to manage their emotional response during puberty. As they are growing up, understanding, and managing the hormonal changes and pubertal hygiene becomes difficult for them (Nichols & Blakeley-Smith, 2009). A mother reported; *“My daughter doesn't understand these hormonal shifts that she is experiencing, and I don't know how to explain to them because she needs logical explanation for everything, and I don't think so I have answers to her questions. So, I haven't explained to them.”*

Discussion

The purpose of the current study is to qualitatively investigate the phenomenon of female ASD puberty from the moms' perspective and the struggles they face in this stereotyped culture. The small but expanding corpus of literature was carefully and methodically studied. The findings of this study offer the chance to gain a peek of other components that are related to puberty. Additionally, the stakeholder's data supports the argument that adolescents with ASD experience puberty differently from teenagers who are typically developing. Even if these changes are seen as normal for teenagers, moms with ASD nonetheless indicated a lack of readiness and anxiety about it.

The safety and security of the kid and how the general public views their child's conduct came to light through the literature study and interview transcription. These results conflict with those of the earlier research (Nichols & Blakeley-Smith, 2009). It also highlights the degree to which their child is vulnerable to abuse and the likelihood that their actions will be taken seriously by the social group in the form of legal action. The aforementioned features brought to light Pakistan's lack of a broad population-wide educational program on sexual development and puberty

According to the results of the recent studies, women with ASDs have a tendency to establish connections but are unable to grasp the complexities of a social interaction (Stokes et al., 2007). It is caused by a lack of access to appropriate knowledge about puberty, reproductive health, and romantic relationships (Mehzabin & Stokes, 2011). Even though this research has shown the value of educational programs for parents and their adolescents with ASD, these programs should include all aspects of puberty and sexuality in ASD.

Additionally, the research found that mothers expressed anxiety about their teenager not being recognized as a contributing member of society and the pressure from others to raise awareness of their child's impairment. Educating people about their children's sexuality and puberty, as well as locating the best programs for them, is a mother's primary issue. Recognizing that social groups and schools would likely react cautiously since the topic is taboo (Nichols & Blakeley-Smith, 2009).

Parents and teenagers should get training about healthy sexuality and coping with puberty, which includes educating parents about acceptable and inappropriate touch, educating kids about bodily parts, and strengthening their awareness of proper boundaries and behavior. The thorough and methodical assessment of the literature also revealed that there is little knowledge about puberty and sexual development in indigenous cultures. By carefully examining the experiences of moms of ASD, the current study aims to close the gap and provides context for future research.

Limitation and Future Research

The study comprises of important findings but it is essential to acknowledge the limitations of the study. First and foremost, given that the sample in the current study was a purposive sample, which might not be able to cover the diverse pubertal experiences of ASD's and their families. Future research can focus on diversifying the

sample of the study so that the results could be applicable to the broader population.

Lastly, this study primarily focuses on mothers' perspective, which does give the valuable insight on the topic but doesn't necessarily cover the broader context. The father may have their own concerns and it will be of significance to identify the common concerns of both parents as well as unique concerns of each parent. Future research should focus on including the perspective of fathers, firsthand experience of girls with ASD, as well as their family members, teachers, and other health professionals to gain a more holistic understanding on this critical developmental phase of ASD girls.

Looking ahead, future research in this area should address this limitation and explore diverse sample, implement standardized measures, investigate cross-culture differences, conduct longitudinal and intervention studies and include broader range of stakeholders. These steps will contribute to a more comprehensive understanding of the challenges and support needs related to puberty and sexual development in individuals with ASD, ultimately leading to more effective interventions and support programs.

Implications

The implication extracted from this study carry important relevance on various aspect for helping ASD navigating through pubertal development in Pakistani context. Healthcare profession can utilize the findings and develop an interventional plan focusing on the areas of essential life skills that is personal hygiene, social interaction, and emotional regulation. The study also highlights the crucial role of parental supervision and the necessity to provide essential tools especially to mothers to accompany their daughter in this challenging phase of development. Policy maker and educator must take into consideration the absence of comprehensive sexuality education program in their curriculum and integrate culturally sensitive curricula into the education system and ensure its availability to all the adolescents other than ASD.

Furthermore, the research also highlights urgent needs, such as the development of standardized measures to comprehensively assess concerns related to puberty and the experiences of individuals with ASD during this phase. Future studies should focus on filling these gaps, to form evidence-based practices and policies. Understanding the impact of societal norms and beliefs on how these issues are seen is crucial when tackling puberty and sexuality education in Pakistani

society. This knowledge can help professionals and policymakers develop inclusive support systems in communities, healthcare settings, and educational institutions that will enable adolescents with ASD to learn and develop with the help they need.

Finally, this study can serve as a foundation for advocacy campaigns targeting public awareness on this topic experienced by the population with ASD during puberty. These research results can be used by advocacy groups, educators, and healthcare organizations to promote better resources, services, and policies that help this vulnerable population, progressing towards improvement of their general well-being and quality of life during this crucial period of social development in Pakistani society.

Conclusion

In conclusion, the study highlights the important aspect of puberty in Pakistani society for girls with ASD. It reveals the key findings which indicate the significant challenges of menstrual hygiene, conflicts within same-sex parent relationships, vulnerability to sexual harassment, lack of awareness about religious and social norms, financial constraints hindering therapy options, and the impact of hormonal changes on mood. These findings give direction to healthcare professionals, educators and parents. By addressing the particular concerns of this group tailored intervention and support programs can be developed. Furthermore, this study emphasizes the value of culturally appropriate methods for comprehending and supporting adolescents with ASD during puberty. It signifies the broader understanding of puberty in girls with ASD. It also highlights the need for comprehensive plan, advocacy and further research to enhance the quality of life and well-being of this population during this crucial developmental stage in the Pakistani context.

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