

Managing Puberty among Children with Autism Spectrum Disorder: Parents' Voices about a Less Explored Transition

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Abstract

Puberty presents unique challenges for children with Autism Spectrum Disorder (ASD) and their families, yet there's a dearth of research exploring parental perspectives on issues in puberty. This condition is more challenging in a country like Pakistan where awareness, acceptance and support for managing ASD is a lifelong challenge for parents. This research aims to explore the experiences of parents while their children undergo puberty in terms of challenges, access and coping resources, and perceptions. A quantitative approach employed a structured questionnaire to assess 100 parents of children aged from 10 to 18 who had ASD. The findings revealed that most parents experience difficulties in three main themes: the changes in the physical body, sensory sensitivity of children, and the resources for necessary support. Most parents feel confident and effective in communicating, but the competition with puberty continues to be an issue. Findings from this study point out the need for well-designed support systems and interventions for families during this critical period in their child's life.

Keywords: *Autism Spectrum Disorder, puberty, parental perspectives, challenges, resource availability, coping strategies.*

Introduction

Especially for the children with Autism Spectrum Disorder (ASD), puberty is a vital aspect of development, bringing along profound physical, emotional, and social changes. It often becomes a problem for such children and their parents (Clawson et al., 2020). The specific experience that autistic children encounter during puberty is needed for specific support and understanding needed by their caregivers. Although, with the ever-increasing recognition of the diverse needs concerning autism, puberty and the whole effect of autism have remained largely unexplored from a parent's point of view (Corbett et al., 2019). This research highlights an understanding gap within these issues, looking at parents' perspectives on what their children are going through during puberty. Most likely, it will be showing the need for specific educational and supportive strategies. Children with ASD are expected to experience puberty differently from others who

are neurotypical due to the variations in sensory processing, social communication, and how they understand changes in the body (Rimington, 2023)

Add even more the complicated anxiety that makes it. It is this confusion that actually intensifies it. Clearer, more consistent, and supportive message types from both parents and teachers are thus necessary (Gao et al., 2024). They alone have become fighting over offering all these changes to parents, and most of them state that they do not have enough research backup while seeking (O'Connor Bones et al., 2022). It is also well noted in the literature that the children and parents do have some conversations regarding sexuality and bodily changes; however, perhaps due to the individual needs of their child or just because it is rather sensitive, most parents of children with ASD thus fail to bring up such discussions (Smusz et al., 2024). The study employed the quantitative assessment approach to systematically assess the challenged waged by parents and strategy parents adapt to bring their children through puberty. Through this, it expects to put into practice useful data and recommendations for practitioners, educators, and policy creators on how best to engage families during this critical developmental stage.

Literature Review

Autism Spectrum Disorder refers to a neurodevelopmental disorder characterized by persistent challenges in social communication, comparative and stereotypic restricted behaviors. Predominantly, children with such disorders have typical experiences, like hypersensitivity, problems understanding social cues, and different levels of intellectual functioning (American Psychiatric Association, 2013). Much impact will be seen in the child's developmental trajectory over time, as behavior makes each developmental milestone much more complex. Puberty constitutes a very complex period in development during which a person undergoes major physical, emotional, and social changes-shifts. The main problems are hormonal changes, development of secondary sexual characteristics, coupled with increased emotional variability (Pfeifer et al., 2021). Adolescents face some very new problems in terms of identity, peer relationship, and, very specifically, independence. This has all been made extremely easy by healthy and effective communication and counseling by parents and teachers to the adolescents in this form of change (Hashmi & Fayyaz, 2022). Children with autism spectrum disorder tend to deal with problems associated with the anxiety of puberty, which could be compounded with their already existing developmental issues related to communication, sensory processing, and social interactions. The results of research indicated those children have a tendency to have increased anxiety, if confused about bodily changes, and, all-in-all, increased difficulty coping with the new social dynamics (Khaledi et al., 2022).

Children with ASD are likely to need a more detailed and repetitive guidance dealing with the changes emphasized around adolescence due to the impairment with their understanding of abstract and social aspects (Phan, 2020). Parents of children with ASD often feel unprepared and unsupported in helping their children through the phase of puberty. They face unique challenges in explaining bodily changes and managing their children's increased anxiety about and sensitivity to sensory issues (Cribb et al., 2019). In the case of Ballan (2012), so many of the parents said that they have difficulty talking to their autistic children concerning sexuality and personal hygiene, often due to the hurdles of communication and the highly sensitive nature of such topics. Many parents feel they lack the resources and support systems needed to come

through this transitional period with their children (Holmes et al., 2014). Parental support is essentially a long-preached aspect of managing such issues for children with autism during puberty. Effective strategies are clear, refer literal explanations, social stories about concepts, and have open talks about body changes and social expectations (Higgins et al., 2023). External resources such as health professionals, teachers, and specialized support programs are needed in providing holistic services for families (de Lima et al., 2023; Mestre et al., 2024). There is need for developing more such resource which will be tailored specifically to address the concerns of autistic children undergoing puberty and equip parents with proper knowledge and skills to guide their children.

Research Objectives

The study intends to:

1. Understanding the hurdles that parents faced during periods of puberty of their children with Autism Spectrum Disorder (ASD).
2. Assessing the extent and effectiveness of internal (e.g., cohesion of family members, knowledge of parents) and external (e.g., professional support, community resources) resources for parents of children with ASD during periods of puberty.
3. Establishing how parents might construe their children's puberty stress and the efficacy of parental coping.
4. Discovering the different coping mechanisms, a parent's life would encompass when trying to manage the stress that comes along with that period of their child.

Research Questions

The research questions are:

1. What kinds of common challenges do parents of children with ASD meet when their children attain puberty?
2. What are the internal resources (family cohesion and parental knowledge) and external resources (professional services and community resources) that aid parents in managing the challenges posed by their children with ASD entering puberty?
3. How do parents change their perception of the stressors brought about by their child's onset of puberty?
4. What coping styles are adopted by the parents facing stressors for their child's puberty?

Research Methodology

Research Design

This study uses a quantitative research design to systematically investigate the perspectives of parents on the issues concerning children with Autism Spectrum Disorder (ASD) during puberty. Survey methodology was adopted to collect data, thus understanding experiences and challenges of parents widely and in a generalizable manner.

Participants

The participants in the study were parents whose children have ASD between the age group of 10-18 years usually correlating with the onset of puberty. Participants will be recruited from autism support groups, special education schools, and online forums for ASD. A purposive sampling method will be adopted for recruitment as it is expected that all respondents have relevant firsthand experiences about the effects of puberty concerning their children.

Data Collection

Structured questionnaires were used for collecting the data in this study. This study also incorporated existential questions designed to solicit quantitative data on the challenges, resources, perceptions, coping strategies of parents, and some insights about their experiences.

Instrument Development

The questionnaire was thoroughly developed through literature review and review of existing validated instruments with respect to parenting stress, coping strategies, and other support needs. And the items were pre-tested against some selected parents to measure clarity, relevance, and comprehensiveness. Changes were made according to their responses to optimize validity and reliability of the questionnaire.

Table 1: Reliability Statistics

Cronbach's Alpha	No. of Items
.815	15

Data Analysis

The quantitative data was analyzed using descriptive and inferential statistics. Summarizing the descriptive statistics, the inferential statistics (t-tests, ANOVA, etc.) analyzed the relationship among variables: severity of challenges, effectiveness of resources, parental perceptions, and coping strategies.

Ethical Considerations

Ethical approval was sought from the relevant ethical institutional review board (IRB) before actual study commencement. Participants were to receive a complete description of the study's purpose, procedures involved, and their rights. Prior to all participants, informed consent will be obtained, ensuring voluntary participation and confidentiality. The data has been analyzed keeping under consideration the anonymity of the participants.

Limitations

Though the quantitative approach permits generalizations on findings, it denies obtaining in-depth understanding of parental experiences. Moreover, it is notable that since study subjects provide information through self-reports, responses may be biased through social desirability. We minimized such biases through sound questionnaire design and data triangulation.

Demographic

Table 2: Gender of the Parents

		Frequency	Percent	Cumulative Percent
Valid	Male	50	50.0	50.0
	Female	50	50.0	100.0
	Total	100	100.0	

Table 2 exhibits gender-wise distribution among the participating parents in the study. Totally equal number of male and female parents, 50 each, are surveyed which accounts for 50% of the total sample for both genders. Cumulative percentage assures this entire sample consists of 100 parents, again divided, half in each group: male and female.

Table 3: Education of the Parents

		Frequency	Percent	Cumulative Percent
Valid	Metric	17	17.0	17.0
	Intermediate	16	16.0	33.0
	Graduation	34	34.0	67.0
	Masters	17	17.0	84.0
	Above Master	16	16.0	100.0
	Total	100	100.0	

Table 3 indicates the educational levels of the parents taking part in the study are shown, where a maximum number of parents, that is, 34% have got a graduation level followed by matriculation and master's degree, which is approximately 34%. 16% of parents form intermediate levels of education, while similar percentage is for above-master level education. All these proportions thus give a total of 100 parents from varied educational backgrounds to make the entire sample very diverse.

Table 4: Location of the Parents

		Frequency	Percent	Cumulative Percent
Valid	Urban	34	34.0	34.0
	Suburban	33	33.0	67.0
	Rural	33	33.0	100.0
	Total	100	100.0	

Table 4 presents the distribution of parents' locations in the study. The sample is closely comparable among urban, suburb, and rural places with approximately 34 percent of parents living with the urban society and both suburbs and rural areas capturing 33 percent each, thus ensuring that different environments will be well represented with perspectives, which will contribute towards a holistic understanding of the problems faced by parents of children with ASD during puberty.

Descriptive Data Analysis

Table 5: Perceptions of Parents Regarding Parental Challenges

Statement	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1. My child's puberty has introduced new challenges that I find difficult to manage.	0	16	17	50	17
2. Explaining bodily changes to my child with ASD is particularly challenging.	0	0	16	17	67
3. My child's sensory sensitivities have increased during puberty, making daily routines more difficult.	0	0	33	34	33
4. My child's anxiety has increased during puberty, which has been challenging for our family.	0	0	33	34	33
5. I find it difficult to manage my child's behavioral changes during puberty.	16	17	0	34	33

Table 05 Showcases the Perceptions of Parents towards the Afflictions They Encounter with Their Adolescents During Puberty. The first statement, "Puberty of my child has brought so many problems, which I can't sort out," reflects a very significant part of 50% of parents agreeing and 17% strongly agreeing, suggesting that most consent to puberty being a phase that is quite difficult. Disagreeing is a paltry 16%, while no one strongly disagrees. That in itself shows that the difficulty is generally agreed. For the following "Explaining bodily changes to my daughter with ASD is particularly challenging," the responses are far more telling in their regard. Strongly agreeing, 67% of parents along with 17% also agree to this. Hence, almost all parents struggle majorly with this. And there is no disagreeing parent, which means this is a challenge universally known when it comes to conveying these messages. Parents are then prompted by the statement, "My child's sensory sensitivities have intensified during puberty making daily routines more tough," regarding increased sensory sensitivities wherein the responses are somewhat divided: 34% agree, 33% strongly agree, and 33% neutral. This goes on to suggest that many

parents notice an increase in sensory sensitivities but not all seem to weigh that as particularly problematic or merely undecided according to their answers.

One similar to the statement: "My child has become more anxious during puberty and this is very difficult for our family," which collects comments that is similar to sensory sensitivities. There are 34% agree, 33% strongly agree, with 33% neutral. In light of this, there are those who assert an increase in anxiety as something experienced while others pay lesser attention to or are doubtful about the effect on them. The statement, finally, "I feel it tough to get through my child's behavioral changes during puberty," gives a rather mixed result. 34% agree and 33% strongly agree, while 17% disagree, with 16% being strongly against it. Here, we can see that while many parents have trouble managing children's behavior changes, a fair proportion finds it manageable. Thus, the responses present the picture of parents, indeed all parents having a very hard time with basically such problems during puberty. The real subject mainly deals with explaining bodily changes and increased sensations and anxieties, whereas behavior appears varied mostly among the levels of difference and severity of the same experienced by parents.

Table 6: Perceptions of Parents Regarding Resource Availability and Effectiveness

Statement	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1. I have sufficient knowledge to help my child navigate puberty.	16	16	0	34	34
2. I can easily access professional support for my child during puberty.	16	17	17	33	17
3. Community resources are available to assist me in supporting my child during puberty.	17	16	17	17	33
4. Our family has a strong support system to help us during this transition.	16	17	17	33	17
5. The resources I have accessed have been effective in helping my child during puberty.	16	17	17	33	17

Table 06 elucidates the perceptions of parents concerning resources, availability, and effectiveness for their children to be navigated through the transitional stage of puberty. The very first statement, "I have enough knowledge to guide my child through puberty," does imply that 34% of the parents seem to be in agreement while another 34% strongly agree, thus, signifying that the majority feel very knowledgeable. On the contrary, 16% strongly disagree and another 16% disagree, indicating that a sizeable minority feel to be without sufficient knowledge. To the statement, "I can easily access professional support for my child during puberty," the responses were apparently rather mixed. 33%-agree, and 17%-strongly agree, while 17%-neutral, but 17%-disagree, and 16%-strongly disagree. This shows that the views of the parents are unfortunately

not all uniform, thus being far from the picture of working with ease as available to some of them in accessing such professional support. Like that, "There are community resources available to assist me in supporting my child during puberty," also shows varying types of responses from respondents. Emphatically, 33% strongly agree, and the other 17%-agree would imply that there are some parents who do find helpful community resources. However, there are still neutral-17%, and the remaining 33%-disagree or strongly disagree signifying inadequate community resources on the part of a substantial number of parents. In the case of a statement on "Our family has a strong support system to help us during this transition," it states that 33% of parents agree and 17% strongly agree. This strongly indicates that nearly half of the respondents are assured of being supported by their family systems.

Thus, out of that remaining half, 17% of respondents are neutral and 33% disagree or strongly disagree, which means they are simply having weak or nonexistent family support systems. Finally, on the statement "The resources I have accessed have been effective in helping my child during puberty," there were 33% who answered agree and 17% who answered strongly agree, which indicates that half of the parents find the resources effective; on the other hand, there were 17% who remain neutral while 33% answered disagree or strongly disagree, indicating that a significant amount does not find effectiveness in the available resources for parents. Overall, it shows that there is a classic divide in the parents' experiences with resource availability and effectiveness; some parents consider themselves well-informed, supported, and having access to really effective resources, whereas a large number of parents are having a hard time accessing and using these resources effectively. And so 17% are neutral, while 33% disagree or strongly disagree-in which case the rest do have either weak or no family support systems. Finally, for the statement "The resources I have accessed have been effective in helping my child during puberty," 33% agree, and 17% strongly agree, showing that half the parents find the resources effective; meanwhile, 17% remain neutral, and 33% disagree or strongly disagree, indicating the lack of effectiveness of such resources for the majority of the parents. Collectively, all these responses show the duality of experiences among parents in as far as resource availability and resource effectiveness are concerned. Some parents feel knowledgeable about good support with some very effective resources, while a large proportion of parents struggle to access and use the resources effectively.

Table 7: Perceptions of Parents Regarding their Abilities and Strategies

Statement	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1. I feel confident in my ability to support my child during puberty.	0	0	16	68	16
2. The stress associated with my child's puberty is manageable.	16	33	17	17	17
3. I perceive the challenges of my child's puberty as a normal part of development.	0	17	0	50	33
4. I use clear and literal explanations to help my child understand bodily changes.	0	0	17	49	34

5. Encouragement and positive reinforcement help my child feel more confident during puberty.	0	0	16	33	51
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Parents' reflections concerning their support ability to children during puberty: For the first question, "I feel I can support my children through puberty," parents were largely (68%) or moderately agreed (16%) without reporting any disagreement or strongly disagreeing; 16% reported a neutral response. Thus, the majority of these subjects appear to be optimistic about their roles as supporters. However, with regard to the statement "The stress associated with my child's puberty is manageable," responses go in varied ratios. It shows that while 17% either agree or strongly agree, there are those who remain neutral at 17%. However, there is a significant contradiction between those who disagreed at 33% with another 16% strongly disagreeing. This means half of the parents feel the pressure could actually not be manageable. The statement which reads, "I view the challenges of my child's puberty as normal aspects of development," received scores with 50% agreement and 33% strong agreement showing that the majority see puberty challenges as developmental. Only 17% are neutral, while there are no parents in the disagree agreement. Last but not least, for "Encouragement and positive reinforcement help my child feel confident," we recorded 51% strong agreement while 33% simply agreed. These strategies drew on effective favor for that statement, with only 16% neutral on the issue and no indication of disagreement. With that in mind, it can be seen that for most of the parents, positives perceptions about their confidence, stress management, and effective use of communication and reinforcement strategies have been displayed during their child's puberty.

Inferential Data Analysis

Table 8: Independent Samples Test

Gender Of the Respondent	N	M	S.D	t	Df	Sig.
Female	50	56.8800	11.86599	1.239	98	.000
Male	50	54.7400	2.87714			

*p>.05 Level of Significance

An independent samples t-test was conducted to compare the female and male response to a variable. The table 08 contains the output of t-tests. Each row indicates the gender groups defined according to number of respondents (N), Mean (M), Standard Deviation (S.D.), t Value, Degrees of Freedom (Df) and Significance Levels (Sig.). The difference in the mean score of female students (N=50, M=56.88, S.D.=11.87) was found to be statistically greater than that of male students (N=50, M=54.74, S.D.=2.88) with a t-value of 1.239 and p-value (Sig.) less than 0.001. This shows that the difference is not by mere chance. The findings point toward significant gender-based differences in this variable form, indicating a possible future research direction on the factors that lead to these differences.

Table 9: One-way ANOVA on Education Basis

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	4665.390	4	1166.347	40.233	.000
Within Groups	2754.000	95	28.989		
Total	7419.390	99			

*p>.05 Level of Significance

One Way ANOVA depicts that the independent variable is significantly varied concerning the dependent variable values according to the different education bases as shown in Table No. 09. It was found statistically significant differences among the groups classified as per education basis ($F(4, 95) = 40.233, p < .001$). This leads to a major difference concerning the parameter used for the outcome. Between-group shows a substantial between-group sum of squares ($SS = 4665.390$) and a mean square ($MS=1166.347$). That indicates substantial variation attributable to differences across the educational categories. Conversely, within groups, while variance ($SS = 2754.000, MS = 28.989$) also prevailed, it was much smaller compared to that between groups. The results indicate how important the educational context is on the outcome variable and recommended the exploration of contributing factors behind these differences.

Table 10: One-way ANOVA on Location Basis

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	870.784	2	435.392	6.449	.002
Within Groups	6548.606	97	67.511		
Total	7419.390	99			

*p>.05 Level of Significance

The data analyzed by one-way ANOVA, shown in Table No. 10, indicated that there are significant differences across different basis of location concerning the dependent variable. Generally speaking, significant differences occur statistically based on the location basis grouping ($F(2, 97) = 6.449, p = .002$). Thus, it implies huge impact of the finding by an actual geographical location. Its result indicated that it shows a very large ss ($SS=870.784$), and a mean square ($MS=435.392$), which accounts for between-group difference thus indicating a very influential variance that attributed to locations on account. Along these lines, there is also some existing within-group variance ($SS=6548.606, MS=67.511$) but not nearly as much as the variation between groups-the importance of geography comes through in empirically determining the outcome variable investigated in this respect. Investigating specific factors operating at various locations may yield further insight into the disparities.

Discussion

The various socio-familial barriers that affect the management of puberty in children with ASD. During puberty, children with ASD face unique challenges that are also shared with their parents. The research shows that existing difficulties are accentuated at this stage and also explains the following reasons; increased sensory sensitivities, challenges in social communication, and

emotional regulation issues related to these (Clawson et al., 2020; Mukherjee & Beresford, 2023). From a parent's point of view, a study highlighted the proactive nature of communication about bodily changes; thus it needs to start early and directly with the purpose of demystifying these changes (Martin & Steinbeck, 2017). Such emotional turmoil can lead to better chances of greater anxiety and depression in children with ASD and thus calls for effective coping strategies from parents (Efstratopoulou et al., 2022). A particular qualitative research on this problem stated that children certainly require their parents to go through management for their own sensory sensitivity during adolescents, and these factors play a great role in making this very hard to discuss hygiene or privacy in this case (Tadesse et al., 2024). In many countries, for instance, Pakistan, the absence of easily accessible supportive resources culminates into poor adaptation of interventions, because it does not consider the cultural and parental contextual differences (Saeed et al., 2024).

If we are to focus on literature in general, it indicates the need for an all-embracing support system. It's not enough to equip a parent with the tools for effective communication; there must also be structured environments for the children as they try to navigate these changes (Ahmed et al., 2024). For instance, visual aids, role-plays of social interactions, or interaction with professionals who work with children with ASD may be some of the tools that parents could use to help their children cope through the experience of puberty. Understanding the multifaceted nature of this transition will serve to better support families through what can potentially be viewed as a critical transition in their children's lives (Hart Barnett, 2018). Hence, dealing with these issues can substantially improve these children's outcomes at puberty from targeted research and community support. Parent perspectives will remain critical for further understanding specific needs and effective means to ensure smoother transitions into adolescence.

Conclusion

Through this study, we gathered perspectives on the difficulties that parents face during this transitional stage in the lives of their children who suffer from Autism Spectrum Disorder (ASD). In general, the findings from this study point out the major challenges that parents face in regards to explaining bodily changes, managing sensory sensitivities and anxiety, and finally getting enough resource support. These challenges are also influenced by varied levels of parental knowledge and with how effective the available resources are in reaching their points. However, there is also a lot of evidence on resilience and adaptive strategies of many parents toward such an issue. Most have learned how to better manage and understand things in puberty and what this means for their children. They feel they can help their children successfully navigate this time and maintain a focus on communication and positive reinforcement in the process. This study indicates, however, that managing puberty stress is quite overwhelming for some parents. Therefore, targeted stress discovery management is essential. The study was grounded in the theoretical frameworks of: Bronfenbrenner's Ecological Systems Theory, the Double ABCX Model of Family Stress and Adaptation, and Social Cognitive Theory. These theoretical frameworks articulated the rich understandings of multi-dimensional complexities of puberty in children with ASD. They brought out the multiple facets of the environmental, family stress processes, and learning mechanisms in parent experiences and coping strategies. Moving

forward, perfectly tailored interventions and support programs should address some specific needs identified in this study, such as better access to professional and community resources, improved parental education and support, as well as stress management strategies. It will ultimately support better outcomes in development for the child and family in terms of quality of life. Ultimately, practitioners, educators, and policymakers can address the concerns and facilitate support for families in meeting challenges arising from puberty among children with ASD.

Recommendations

On the basis of findings, following recommendations are made:

1. Develop and carry out special materials and workshops for children with autism spectrum disorders. This would advise valuable methods for talking about bodily changes; sensory sensitivities and anxiety coping strategies.
2. Increase the number and the accessibility of healthcare professionals dealing with autism spectrum disorders that can provide guidance and counseling services during adolescence periods.
3. Raise community-oriented networks and resources to fit the experiences of the parents with transforming children from puberty. These include support groups for parents, respite care services, and recreational activities that would consider their sensory needs.
4. Family resources to promote cohesion and support in clear and communicative understanding might include peer support groups, family therapy sessions, and workshops on parenting skills.

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