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Addressing Puberty Challenges for Adolescents with Autism Spectrum Disorder in Delhi-NCR: Occupational Therapy Perspectives

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Abstract: Significant physical, emotional, and social changes occur during adolescence. Particularly during puberty, these changes might pose special difficulties for those with autism spectrum disorder (ASD).

Objective: The purpose of the study was to evaluate the opinions of occupational therapists in Delhi-NCR on the difficulties that adolescents with ASD encounter throughout puberty and the strategies they employ to help them.

Methods: Targeting occupational therapists in Delhi-NCR who work with adolescents having ASD, a descriptive survey study was carried out using the OT-APS survey. Both quantitative and qualitative techniques were applied to the data analysis.

Results: The survey was completed by sixty occupational therapists in total. The majority of respondents cited parent concerns (n=42, 70%), social expectations (n=26, 43.3%), and sexual changes (n=19, 31.6%) were the most commonly addressed challenges. Ayres Sensory integration treatment approaches and parent training approaches were the most commonly used intervention strategies, followed by behavioral strategies and behavioral skills training.

Conclusions: Puberty is a crucial and difficult developmental stage for teenagers with ASD. The results underscore the need for focused, customized interventions that target social skills, emotional regulation, and sensory processing.

Keywords: Autism Spectrum Disorder, Adolescents with ASD, Adaptive functioning, Occupational Therapy, Puberty challenges.

1. Introduction

Autism Spectrum Disorder (ASD) is a type of neurodevelopmental disorder that affects a person's ability to communicate and interact socially.[1] The Centre for Disease Control estimated that the prevalence of ASD ranges from 1 in 500 (2/1,000) to 1 in 166 children (6/1,000) globally. In India, it is believed that more than 2,160,000 individuals are affected by ASD, with an incidence rate of approximately 1 in 90,666 or

11,914 people.[2] People with ASD frequently exhibit limited and repetitive activities as a result of their struggles with imaginative play, social and emotional reciprocity, and sensory processing.[1]

Puberty is a complicated transition including physical, emotional, and social changes[3,4], which is especially problematic for those with ASD due to difficulty in coping with these developments.[5]

Children with ASD experience typical puberty[5] but struggle with sensory processing, adaptive skills[6], and social norms[7], often leading to difficulties with hygiene, sexual behaviors, and social interactions[8]. They may display inappropriate sexual behaviors due to a lack of understanding and face emotional challenges such as anxiety, depression, and aggression[9] and PCOD in females[11]. Puberty can also lead to social isolation and maladaptive behaviors[10], including bullying and rejection[14]. Many adolescents with ASD lack experience in intimate relationships, making them vulnerable to exploitation[12,13]. Parents worry about managing new hygiene needs, sexual behaviors, and societal perceptions of their child's sexuality.[15,16]

Practitioners of occupational therapy are essential in helping people with ASD with everyday living activities, education, social interaction, and skill development. They employ a range of interventions, such as cognitive-behavioural techniques, social-emotional development, sensory integration, and work-readiness skills.[17] There aren't many practice recommendations, meanwhile, that particularly address puberty-related problems for people with ASD. Individualized instruction emphasizing social skills, personal limits, and healthy sexuality is recommended by the literature currently in publication.[7,8] A 2013 study indicated that behavior and antecedent methods were the most widely employed interventions for adolescents with ASD.[18] A study by Larson et al. (2021) provides insights into the practices of U.S.-based occupational therapy (OT) practitioners in addressing puberty-related challenges in adolescents with autism spectrum disorder (ASD). The study surveyed 71 OT professionals, predominantly white women with an average of 16 years of experience. She found that emotional regulation and personal hygiene are the most addressed issues(47%), while menstruation, safety, and masturbation remained the least addressed issues(26%). Social learning approaches and behavioural strategies were the most commonly employed interventions (92%).[19] This study is an attempt to bridge the gap in the literature by widening the horizon of the previous study by Larson et al(2021) by including the population from Delhi-NCR, India, and paves the way to provide a better understanding and guidelines for intervention of puberty-related challenges in Adolescents with ASD.

1.1 Rationale

There is little evidence on how occupational therapy can help adolescents with ASD deal with the particular difficulties they confront throughout puberty, particularly in the Delhi-NCR area.

1.2 Aim of the study

The study intends to determine commonly utilized therapies, evaluate the resources that are accessible, and provide suggestions to enhance support for adolescents with ASD by investigating occupational therapy practitioners' perspectives on managing puberty-related problems in these individuals.

2. Methodology

Research Design: Descriptive Survey Design

Sample Size: 30-100 Occupational Therapists qualified with at least a graduation degree.

Source of Study: Community

Population: Occupational Therapist Working in Delhi NCR.

Sampling Method: Convenience Random Sampling

Inclusion Criteria:

- Occupational Therapists working in Delhi-NCR
- Occupational Therapists working with adolescents with ASD

Exclusion Criteria:

- Occupational Therapists working with the adult population
- Occupational Therapists are not willing to disclose the information or are uncomfortable discussing these issues.

Measuring Instrument Used: A quantitative survey instrument, Occupational

Therapy for Autism and Puberty Survey (OT - APS), (Larson S. K. et al, 2021), developed using a thorough literature review and will be administered to Occupational Therapy Practitioners to gather data for this study. [19]

Occupational therapists working with adolescent ASD were selected using convenience random sampling in Delhi-NCR. The participants were informed about the objectives of the study, and informed consent was taken from them. Respondents completed the OT-APS survey form in physical form, and data were collected by the author, an occupational therapist. Data collected was quantitatively and qualitatively analysed.

3. Results

60 occupational therapists from Delhi-NCR working with adolescents with ASD completed the OT-APS over 2.5 months from January 2023 to March 2023. A majority of participants were females (n=40, 66.7%), while males accounted for 33.3% (n=20) of the population. Gurgaon had the maximum number of participants (n=12), followed by East Delhi (n=11), Noida (n=11), West Delhi (n=8), Ghaziabad (n=7), North Delhi (n=4), South Delhi (n=4), and Faridabad (n=3).

The training of therapists in various interventions (Fig 1) and types of assessment used with children and adolescents with ASD aged 8-16 years for puberty-related challenges were also addressed in this survey (Fig 2).

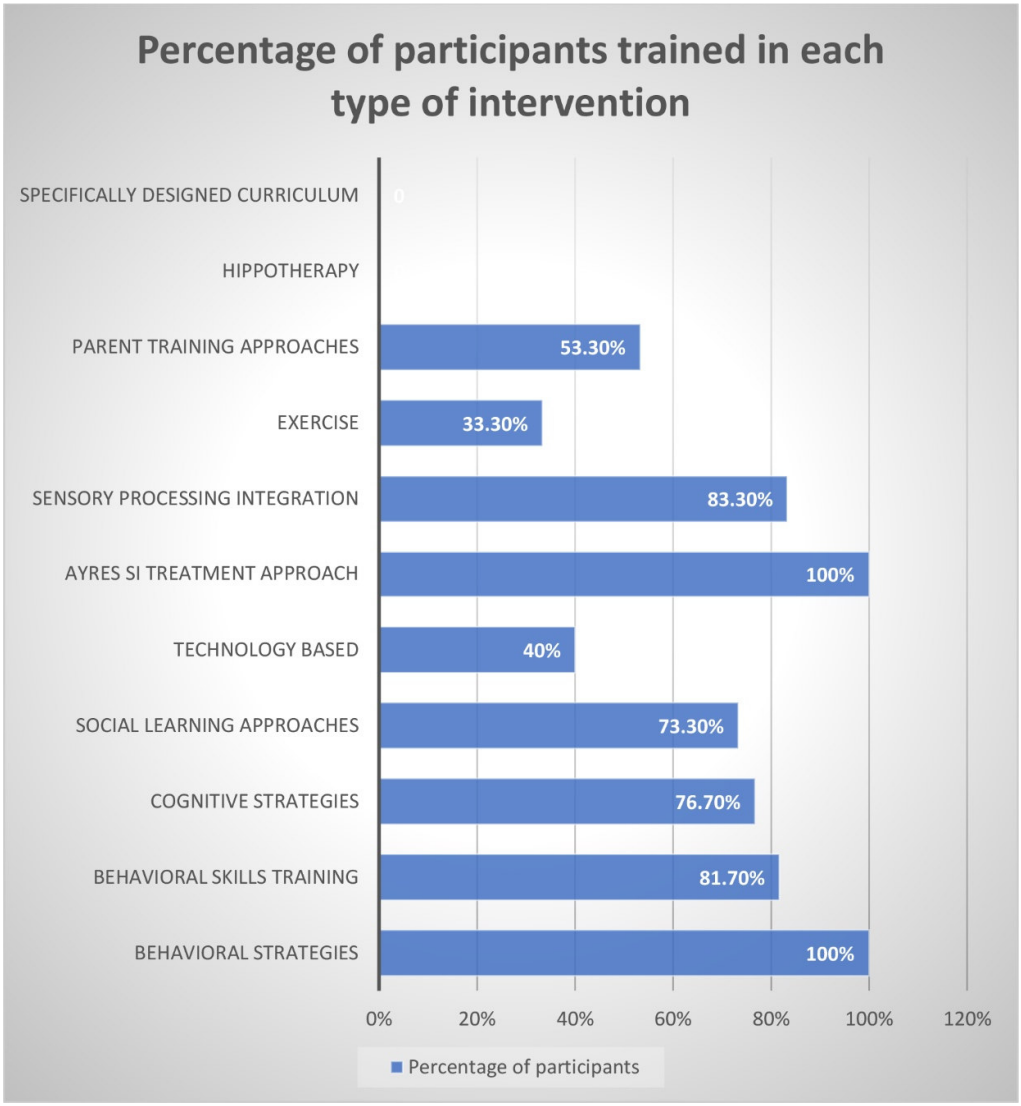


Fig 1: Percentage of participants trained in different intervention techniques

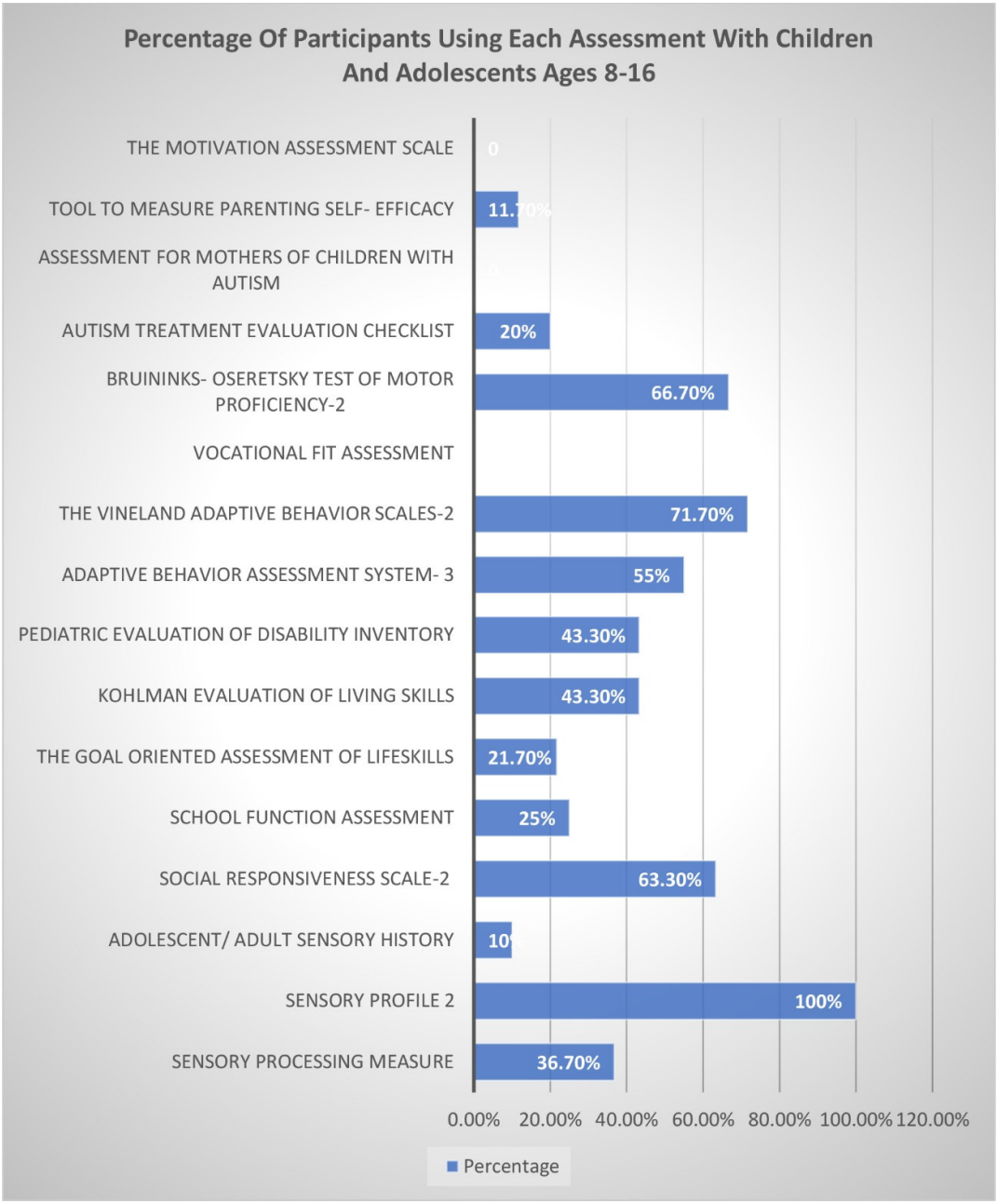


Fig 2: Percentage of participants using each assessment with children and adolescents aged 8-16 years

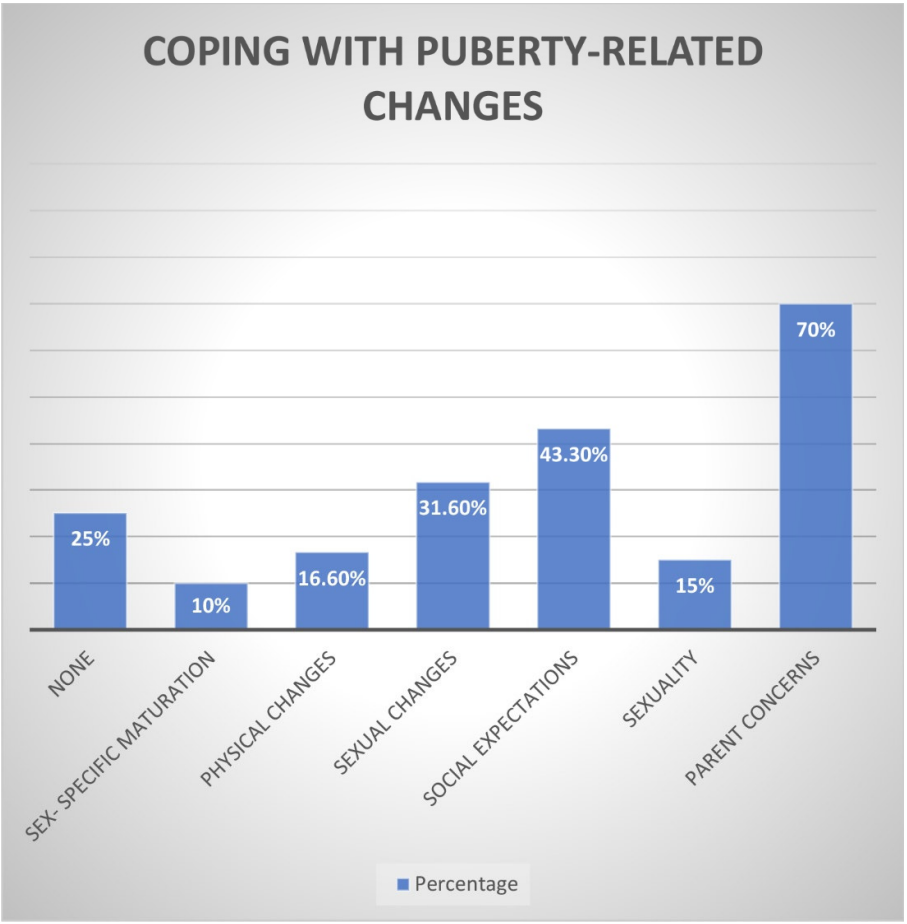


Fig 3: Percentage of response to coping with puberty-related changes

A total of 9 puberty challenges, further divided into sub-challenges, were surveyed. (Fig 3).

The results were analysed and it was found that, in regard to coping with puberty-related changes, parent concerns (n=42, 70%), social expectations (n=26, 43.3%), and sexual changes (n=19, 31.6%) were the most commonly addressed challenges.

The most addressed sub challenge for each problem were: for menstruation- hygiene management (n=28, 46.6%), masturbation- touching genitals in public (n=37, 61.6%) and engagement in the presence of others (n=24, 40%), Personal Hygiene and self- care -Dressing (n=59, 98.3%)), family routines- behavioral management (n=20, 33.3%) and transitioning from dependence to independence (n=18, 30%), in regards to safety- avoiding vulnerable situations (n=10, 16.6%) and healthy relationships (n=7, 11.6%), emotion regulation- aggression (n=51, 85%), anger (n=49, 81.6%), moodiness (n=43, 71.6%), unpredictability (n=42, 70%) and anxiety (n=38, 63.3%), behavior management- obsessive and compulsive behavior (n=42, 70%) and self-stimming behaviors (n=38, 63.3%), social participation- nonverbal communication (n=42, 70%) and awareness of boundaries (n=30, 50%).

Ayres Sensory integration treatment approaches and parent training approaches were the most commonly used intervention strategies, followed by behavioral strategies and behavioral skills training (Table 1).

Table 1: Interventions used by various occupational therapists to address these issues.

	BEHAVIORAL STRATEGIES	BEHAVIORAL SKILLS TRAINING	COGNITIVE STRATEGIES	SOCIAL LEARNING APPROACHES	TECHNOLOGY-BASED	AYRES SENSORY INTEGRATION TREATMENT APPROACH	SENSORY PROCESSING INTEGRATION	EXERCISE	PARENT TRAINING APPROACHES	EQUINE ASSISTED/	SPECIFIC CURRICULUM
COPING WITH PUBERTY-RELATED CHANGES	31.6% (n=19)	26.6% (n=16)	31.6% (n=19)	16.6% (n=10)	1.6% (n=1)	40% (n=24)	18.3% (n=11)	0	70% (n=42)	0	0
MENSTRUATION	5% (n=3)	6.6% (n=4)	8.3% (n=5)	3.3% (n=2)	21.6% (n=13)	11.6% (n=7)	0	0	51.6% (n=31)	0	0
MASTURBATION	50% (n=30)	28.3% (n=17)	5% (n=3)	1.6% (n=1)	0	76.6% (n=46)	33.3% (n=20)	0	40% (n=24)	0	0
PERSONAL HYGIENE AND SELF-CARE	93.3% (n=56)	40% (n=24)	16.6% (n=10)	0	1.6% (n=1)	98.3% (n=59)	36.6% (n=22)	41.6%(n=25)	23.3% (n=14)	0	1.6 % (n= 1)
FAMILY ROUTINE	20%(n= 12)	26.6%(n=16)	28.3%(n=17)	5%(n=3)	3.3%(n=2)	15%(n= 9)	1.6%(n =1)	3.3%(n =2)	45%(n= 27)	0	0
SAFETY	0	3.3%(n =2)	5%(n=3)	0	0	0	0	0	28.3%(n=17)	0	0
EMOTION REGULATION	96.6%(n=58)	98.3%(n=59)	70%(n= 42)	38.3%(n=23)	1.6%(n=1)	80%(n= 48)	28.3%(n=17)	3.3%(n =2)	28.3%(n=17)	0	0
BEHAVIOR MANAGEMENT	98.3%(n=59)	96.6%(n=58)	13.3%(n=8)	11.6%(n=7)	0	71.6%(n=43)	30%(n= 18)	0	21.6%(n=13)	0	0
SOCIAL PARTICIPATION	21.6%(n=13)	25%(n= 15)	23.3%(n=14)	96.6%(n=58)	0	60%(n= 36)	3.3%(n =2)	1.6%(n =1)	38.3%(n=23)	0	0

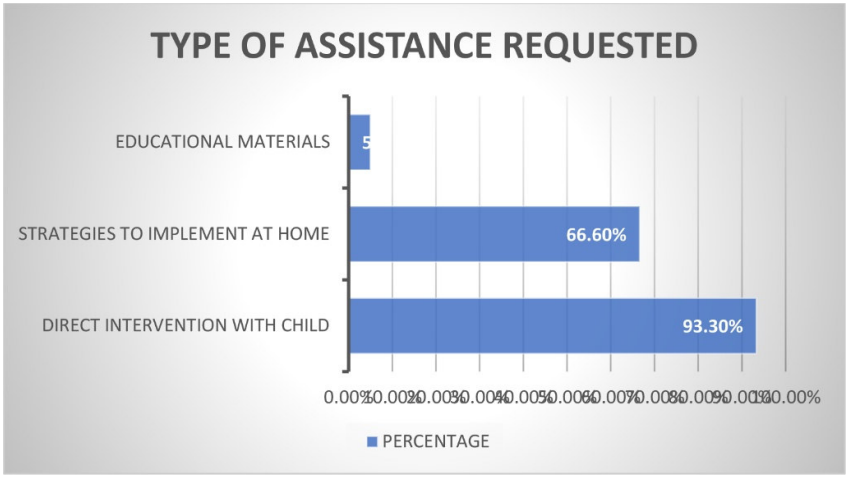


Fig 4: Type of assistance requested

A majority of respondents (30% with children/adolescents with ASD and 50% with parents) reported feeling "very comfortable" discussing puberty-related changes and challenges using a 5-point Likert scale. Respondents reported that parents most often requested direct intervention with the child (n=56, 93.3%) and strategies to implement at home (n=40, 66.6%) to work on puberty challenges (Fig 4).

4. Discussion

The purpose of this study was to investigate occupational therapy approaches for managing puberty changes in children and adolescents with ASD, aged 8 to 16. 60 occupational therapists from Delhi-NCR participated in a descriptive study that examined the tests they utilize daily.

Standard instruments for children with ASD, such as the Bruininks-Oseretsky Test of Motor Proficiency-2, Vineland Adaptive Behavior Scale, and Sensory Profile-2, were found to be the most often used tests.[17] ASD-specific tests, like the Vocational Fit Assessment and Motivation Assessment Scale, were not as widely employed, nevertheless. The results imply that occupational therapy professionals might not have the testing required to completely comprehend and handle the particular pubertal difficulties experienced by teenagers with ASD, which could reduce the efficacy of their interventions. Assessments created especially to examine these problems could be developed or promoted by the occupational therapy profession to address the difficulties faced by adolescents with ASD throughout puberty. To better address puberty-related issues like hygiene, social standards, and emotional regulation, practitioners might also modify current tests.

Adolescents with ASD may find puberty particularly challenging, since they may have trouble managing social expectations, comprehending physical changes, and maintaining personal hygiene, which can leave them vulnerable.[7,10,20] Families and other caregivers need to be prepared with the information and tools necessary to help teenagers through this phase, including instruction on emotional control, hygiene, and sexuality. The results of the study reinforce earlier studies by identifying particular difficulties, including irregular menstruation and inappropriate sexual conduct, which emphasize the need for focused treatments and assistance.[10,21]

Studies on occupational therapy that address puberty-related difficulties for adolescents with ASD are scarce, and many therapists may steer clear of these problems because of cultural differences, a lack of knowledge, and a lack of resources in India, according to the literature. The survey discovered that the most popular methods for addressing these issues in kids and teenagers between the ages of 8 and 16 were parent education, behavioral techniques, and Ayres Sensory Integration. Positive behavioral supports, visual aids, and reinforcement were all part of these interventions; nevertheless, more evidence-based, specialized occupational therapy interventions are required for puberty difficulties associated with ASD. To better address these issues, strategies including hippotherapy, behavioral skills training, and the Cognitive Orientation to Daily Occupational Performance (CO-OP) may be helpful.[6,22-25]

Although non-occupational therapy research identifies several successful treatments, there aren't many particular occupational therapy therapies for puberty difficulties in adolescents with ASD. Research backs the use of social skills training[27], environmental changes[28], parent education, and reinforcement techniques to help adolescents with ASD deal with emotional and behavioral problems during puberty[16,18]. The results of the study support these methods, but they also show that occupational therapists feel more at ease discussing things like hygiene and emotion management than they do discussing delicate subjects like menstruation and masturbation. Lack of specialist training or curriculum on puberty and sexual education for teenagers with ASD may be the cause of this discomfort.

Additionally, the study discovered that although parents usually start conversations about pubertal difficulties, therapists ought to be more involved in helping parents navigate this stage of development.[10,20] The application of specific interventions that have demonstrated promise in non-occupational therapy literature, such as hippotherapy and puberty-focused curriculum, needs more investigation.

5. Conclusion

Occupational therapists in Delhi-NCR acknowledge the substantial obstacles that

adolescents with ASD encounter during puberty, especially in the social, emotional, and sensory domains, according to the study's findings. The poll indicated a lack of clear guidelines and resources to effectively treat puberty-related concerns, despite the recognition of the need for tailored interventions. Although occupational therapy practitioners employ a variety of tactics, such as behavioral approaches, social skills training, and sensory integration techniques, more thorough training and standardized procedures are required to serve adolescents with ASD at this developmental stage. Among the suggestions are the creation of regional guidelines as well as the expansion of knowledge and resources for occupational therapy professionals.

6. Limitations

- Limited Sample Size: Generalizability is impacted by the small number of OT practitioners surveyed.
- Regional Focus: Results might not be applicable outside of Delhi-NCR.
- Self-Reported Data: Responses from practitioners may be biased.
- No Longitudinal Data: No investigation of the effectiveness of the intervention over an extended period.

Considerations for future research: Studies on how taboos impact occupational therapy methods in addressing puberty challenges. Assess the breadth and availability of occupational therapy in clinics and schools. Therapist's Insight on the difficulties, solutions, and obstacles faced during practice. For more thorough grasp, employment of a combination of approaches should be preferred.

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