



NEEDS OF PRESCHOOL CHILDREN WITH AUTISM SPECTRUM DISORDER AND THEIR PARENTS IN THE INDIAN CULTURAL CONTEXT: A QUALITATIVE STUDY

Amit kumar,

Ph.D. Research scholar,
Dept. of Psychology,
Banasthali Vidyapith,
Banasthali, Rajasthan

Dr. Santoshmeena

Associate Professor,
Dept. of Psychology,
Banasthali Vidyapith,
Banasthali, Rajasthan

Abstract:

The researchers investigated diverse aspects which affect 25 preschool children diagnosed with Autism Spectrum Disorder (ASD) and their parents based on Indian cultural norms through a qualitative study. The research population included members from PGIMER located in Chandigarh. The research method included observation of parent-child interaction in combination with semi-structured parental interviews. The results from thematic analysis produced fundamental themes that demonstrated the special difficulties family members face. These included significant communication deficits (non-responsiveness to name, limited verbal and non-verbal communication, inability to express basic needs), behavioral difficulties (disruptive behavior, hyperactivity, repetitive behaviors), educational disparities (lack of KG school enrollment and engagement in learning activities), limited access to services (lack of diagnosis, therapeutic interventions, and parental support groups), and emotional and social challenges (reduced emotional expression, reactivity, and limited emotional connection with outsiders). The study reveals the pressing requirement to develop diagnostic methods and treatment solutions and educational programs as well as support systems for families that care for children with ASD throughout India. This research emphasizes the significance of cultural factors when developing interventions for people with autism spectrum disorder.

Keywords: *Autism Spectrum Disorder, Preschool Children, India, Parental Needs, Cultural Context, Qualitative Research, Communication Deficits, Behavioral Challenges, Service Gaps.*

Introduction:

The complex neurological development of Autism Spectrum Disorder leads to difficulties in communication and interaction between people with the disorder. Two defining elements define Autism Spectrum Disorder because it causes continuous social interaction and communication problems alongside strict behavioral patterns. These characteristics manifest differently in each individual, hence the term "spectrum." Royal American Psychiatric Association through its Diagnostic and Statistical Manual section 5 (DSM-5) delivers the professional framework to diagnose and comprehend ASD. The overall experience of living with ASD among young children depends on their



developmental level alongside their personal abilities and difficulties and the societal environment where they reside. ASD exists as a globally recognized condition but its incidence together with appreciation and intervention approaches differ substantially between different cultural backgrounds. Several influential elements determine these disparities including medical diagnostic procedures together with community awareness about ASD plus the presence of specific service facilities and cultural interpretations of developmental delays and disability enablements. Elsabbagh et al. (2012) stressed that research on ASD prevalence and needs requires attention to cultural elements. The use of different diagnostic tools along with varying cultural interpretations related to social and communication behaviors leads to different reported ASD prevalence numbers. An additional barrier to identification exists when cultural stigma about mental health problems stops families from seeking help because it reduces their access to needed support treatments.

The vast heterogeneous population of India produces special circumstances when examining and addressing Autistic Spectrum Disorder needs among children together with their families. Universal experiences of ASD do not exist in India since cultural differences and economic variations create substantial differences in the ASD journey of each family unit. People from various regions across India experience difficulties finding expert diagnosis and specialized services and therapeutic assistance for their children with ASD because ASD knowledge remains minimal in these areas. Traditional customs concerning child development and disability create influences on how families interpret their child's needs alongside their responses. The current facilities designed to support children with developmental disabilities fall short of addressing the increasing requirement for service delivery.

The research analyzes the requirements of ASD-afflicted preschool kids together with their parents in the Indian environment. Early intervention during the preschool years holds great importance because it creates significant long-term effects for children with ASD regarding their development. The research directs its attention toward understanding the particular difficulties of Indian ASD children between three to five years old together with their families along with developing appropriate interventions. Education about the population needs dynamics enables better delivery of adequate assistance for children to achieve their highest potential. The research targets the particular requirements that the investigated preschool children with ASD demonstrate. Young children with ASD experience specific development needs through four core areas which include communication development as well as social interaction skills and behavioral patterns along with their learning abilities. A main barrier exists specifically in the area of non-response when addressed by name. Parents and caregivers feel distress when their child does not respond to their name because it creates challenges for bonding and communication with the child. Among the typical concerns about children with ASD



disruptive behavior targets different activities including temper tantrums along with physical aggression and harmful self-harming conduct. The child's undesirable behaviors become problematic for their families to control because these behaviors create barriers to their social and educational engagements. The inability to express basic needs stands as one of the crucial obstacles facing young children who have ASD. The inability of young children with ASD to express their needs through communication causes frustration among both the child and their caregivers. The child faces challenges to their learning and social contact because of communication problems.

Among the significant challenges of children is the problem of hyperactivity which causes difficulties in focusing and paying attention to tasks. Their educational growth together with their social competence becomes limited when hyperactivity occurs. The lack of kids going to KG schools along with their disinterest in studying poses a critical problem because early schooling remains essential for child development. The communication and behavioral issues of children with ASD create challenges for their admission into regular educational programs. Parents should monitor their children's participation in games because lack of game involvement represents a potential concern. Children require play as an important avenue that develops their social abilities and emotional conduct and intellectual processes. Children with ASD experience challenges when they participate in imaginative gameplay along with social interaction with classmates during school playtime. A person with ASD will show limited difficulties in the expression of speech and language abilities. The condition manifests differently in each case from delayed verbal abilities to total speech incapability. Missing verbal communication along with nonverbal methods becomes an additional barrier which hinders children from interacting with others so they cannot express their needs effectively. India faces a large-scale challenge because many regions have no available services for children and parents. Children and their families face problems identifying suitable healthcare providers offering diagnosis and assessment and intervention services. Children cannot get necessary support or required proper interventions when a diagnosis is not available because they do not receive the needed diagnostic services. Some children with ASD face challenges because they have limited ability to comprehend emotions. People with autism spectrum disorder encounter difficulties recognizing their emotions as well as the emotions felt by others. Their social connections with others along with their relationship-building abilities suffer consequences. An individual's reactive behavior without proper reaction analysis tends to produce spontaneous actions which makes emotional management challenging. Children find it difficult to derive learning from their experiences and build appropriate social skills because of this condition. Children who lack emotional attachment outside their family environment struggle to build friendships with outsiders. Social isolation becomes a problem for these children as they gain fewer opportunities to learn and develop. Autistic Spectrum

Disorder often brings about enjoyment through repetitious actions. Some autistic children experience comfort through repetitive movements yet these behaviors prevent them from participating in new activities which are necessary for skill acquisition. The investigation of these particular needs in India's cultural framework aims to furnish enhanced knowledge about ASD-related obstacles which affect children in preschool and their families. The research results will support developing customized interventions and support programs that address the specific needs of this ethnic group. The final objective exists to enhance the quality of life for ASD children together with giving their families tools to handle their difficulties.

Overview of Literature

The current body of research about Autism Spectrum Disorder in India demonstrates how investigations on preschool child needs and Indian family circumstances specifically remains insufficient (Patra&Kar, 2020). The research field suffers from insufficient information about both family experiences and cultural factors affecting parents whose children display ASD symptoms in India despite several clinical reports (Kommu et al., 2017; Mhatre et al., 2016). The worldwide experience by ASD parents share similar difficulties such as stress elevation, social alienation and financial strains (Smith et al., 2014). The Indian environment requires special attention because joint families are common and disabilities receive limited acknowledgment from society and the available specialized services remain scarce (Krishnamurthy 2008, Desai et al. 2012). There should be more research to understand how cultural beliefs affect recognition of conditions along with help-seeking actions and selection of treatments (Daley &Sigman, 2002). The current scarcity of tools and interventions adapted to Indian culture acts as a major impediment to obtaining quality healthcare (Juneja et al., 2014; Patra&Arun, 2011). Early developmental interventions designed for Indian settings need to be developed because they would help reduce the current challenges faced by Indian families dealing with autism spectrum disorder. The educational requirements of Indian university students with ASD remain underexplored according to YingRu et al. (2015) so researchers must conduct ongoing studies following ASD children from kindergarten to maturation. Wilson and Landa (2019) described how evidence-based intervention implementation barriers exist in preschool education along with the details about educator preparedness and engagement and administrator support and time/resource constraints and teaching complexity for ASD students in preschool.

Research Methodology

The researchers utilized grounded theory as their method for qualitative research to study the needs and requirements of Indian preschool children with Autism Spectrum Disorder (ASD) alongside their parents in their cultural environment. Methodologically grounded theory generates new theory by analyzing collected data instead of testing previously established hypotheses. Research teams selected this method because it enabled them to investigate participant reports and understandances which led to the identification of



meaningful patterns about their requirements. The research placed priority on Indian social context due to cultural beliefs and society structures which profoundly impact families who have children with ASD. The research base in its native cultural environment allowed the study to develop contextual insights that were meaningful for the local culture. The research explored Northern India families who had preschool children diagnosed with ASD. The total research participant group consisted of twenty-five families. Early intervention becomes essential at this developmental stage which spans from 3 to 5 years among the children. PGIMER Chandigarh selected families as participants through its recruitment process at the prominent medical institution of this region. The recruitment tactics allowed researchers to reach families whose children underwent formal diagnosis of ASD from medical facilities. Through a recognized medical institution families could join the research who had already participated in support services or learned the procedures for developmental assistance. The study included these research criteria to preserve the sample's homogeneity and validate collected data. Participation needed a formal clinical verification of ASD diagnosis before enrollment. Participation in the study required children to demonstrate diagnosis records that specified ASD criteria thus improving research reliability and validity. The authors employed two diagnostic instruments: Autism Diagnostic Interview-Revised (ADI-R) and Autism Diagnostic Observation Schedule (ADOS) to verify ASD diagnoses. The ADI-R functions as a structured conversation strategy which helps providers collect deep information from guardians regarding their child's developmental history while focusing on communication abilities and social relationships together with repetitive behavioral patterns. The ADI-R along with ADOS serves as an extensive diagnostic instrument recognized as superior in ASD diagnosis when used in research environments. The ADOS represents an observational evaluation method that specializes in measuring child performance through standardized interactions and tasks. The assessment tool evaluates communication along with social interaction and play functions and restricted and repetitive behaviors to obtain essential information about how the child functions at present. The concurrent administration of ADI-R and ADOS provided laboratories with a thorough evaluation method to guarantee precise ASD diagnoses among their research subjects. Age was critical because all selected participants needed to fit between 3 and 5 years old. This age range was mandatory for inclusion in the study. The researchers chose this age group as it stands as a vital time for implementing early developmental interventions. The early development stages of preschool child development can be affected substantially through effective early intervention programs for ASD patients. This focused study examined ASD-related challenges and needs of parents of preschool children to help develop suitable interventions for this age group. This concentrated method helped researchers analyze the data with precision to recognize developmental requirements that match this particular stage. The study selected children within this



specific age group because researchers wanted to evaluate data matches with a specific developmental phase while reducing any effects or changes resulting from age-related developmental differences.

Data Collection

The research data collection utilized semi-structure interviews together with parent-child interaction observations. These research methods provided complete knowledge about the lives and requirements of parents raising children with Autism Spectrum Disorder (ASD). Using interview and observational data together created enhanced understanding because it combined findings from multiple data sources and resulted in discoveries which one method might have missed. Semi-structured interviews acted as the main method for gathering research data. The researcher interviewed parents to collect detailed firsthand accounts which revealed their ASD-related experiences while exploring their encountered challenges along with their necessity requirements. Research teams used semi-structured interviews as their data collection method which created adaptable guidelines for interviews that let them study identified themes and discover emerging themes and individual experiences simultaneously. A set of open-ended questions on the interview guide helped researchers investigate the necessary areas during the process. These areas encompassed a broad spectrum of the parents' lives, starting with the child's developmental milestones and progressing through behavioral challenges, communication difficulties, and access to necessary services. The interviews explored emotional aspects impacting children with ASD along with their families since ASD modifies the way families interact with each other. The parents held the freedom to choose between English and Hindi during interviews thus creating an environment where they felt better able to communicate openly. All interviews gained approval from parents before being audio-recorded to aid further analysis together with maintaining accuracy in the obtained data. The ethical measure gained critical importance because it allowed participants to understand recording reasons while preserving their rights to their collected data. Research observations added to the interview data as researchers observed parent-child interactions throughout ordinary environments. Researchers selected family residences as well as clinical environments to study interactions naturally because this approach increased the scientific value of their observational research. Researchers used these observations to explore the child's actual behavioral patterns together with their communication methods as well as to study their parent-child relational complexity. Observational researchers prepared extensive notes in order to document their observations instead of adopting a standardized methodology. The observational technique provided an inclusive view of interactions by including both mentioned parental behaviors throughout interviews and significant aspects which parents had not foreseen originally. The observational findings allowed researchers to validate the parents' interview statements while obtaining better comprehension of the behaviors and



their environmental context. Interview data together with observational data delivered an extensive insight that led to improved understanding of ASD family experiences and their related needs and challenges.

Data Analysis

The analysis method used methods that systematically examined family experiences. The transcripts from audio-talk interviews received detailed verbatim transcriptions because they served as the main data source. Each spoken word underwent an accurate transcription procedure that offered a strong basis for assessment purposes. The verbatim transcripts functioned as the basic information needed to understand the subtle aspects of the family accounts. Thematic analysis became the main data analysis technique to identify fundamental patterns and themes among interviewed responses after transcription ended. The researchers employed this method to transcend simple summary reports so they could reveal the main themes and reoccurring ideas which emerged from participant responses. The flexible research method of thematic analysis lets researchers determine data patterns through systematic organization and interpretation of qualitative data findings.

The research analysis required independent selection of coding for interview transcripts and field note documentation by different researchers to maintain validity and reliability. The analysts performed separate reviews of recorded data which led them to apply specific labels to text segments that illustrated emerging concepts or themes. The independent coding procedure reduced personal interpretation errors and improved the possibility of detecting diverse perspectives which appeared in the gathered data. The study included a system to solve any differences in coding identified by its two involved researchers. The researchers resolved their conflicting interpretations or labels for data segments through cooperative discussions to reach mutual consensus. Through comparing their findings continuously the researchers conducted discussions leading to mutual agreement about interpreting major themes. Teamwork during data analysis strengthened both the research's methodological strength and the legitimation of its results. The research team did not view individual themes independently instead they constructed a hierarchical arrangement to relate the themes to each other. The research team developed a structural representation to showcase the complex family dynamics which illustrated how various themes connected to each other as well as larger themes related to their specific subcategories. The hierarchical structure enabled researchers to develop a substantive in-depth understanding of how families experienced their situations in a layered fashion.

Research took special consideration of the Indian cultural environment due to its vital context. The researchers studied the effect of cultural beliefs alongside organizational practices alongside societal attitudes on families' experiences and their encountered difficulties. Understanding the cultural background of these families allowed researchers



to produce observations that respectfully followed their community-specific environment rather than applying generalized analytical frameworks. The researchers used their contextual understanding to both interpret the results and extract meaningful cultural and individual connections between each other. Data saturation was achieved through the research method of constant comparative method when combined with the process of refining emerging themes. The researchers conducted multiple data comparisons between fresh findings and established themes until they detected similar elements between all the dataset information. The constant comparative method helped develop the themes by validating connections between new and established data which directly reflected participant experiences. Data saturation occurred when new information ceased to unveil significant themes or insights and thus marked the termination of the analytical work because it demonstrated sufficient comprehension of family experiences.

Major Findings

This research investigated the multiple requirements of preschool children with ASD and their parents from an Indian cultural point of view which yielded essential thematic findings. Data showed multiple family difficulties together with evidence supporting the necessity for better knowledge along with support and resources. A notable finding showed major communication problems among the children. The data showed that lots of children failed to respond when their names were mentioned which suggested problems with both auditory signal processing and social understanding. The child's inability to respond demonstrated inadequate connection to external stimuli which might affect their relationship-building skills and learning capabilities. A considerable number of children showed minimal verbal skills as several among them displayed no speaking abilities at all.

The communication problem spread into unspoken messages since the children had severe difficulties with non-verbal communication. Due to their handicap in verbal and non-verbal communication systems the children struggled to effectively communicate or make meaningful social connections. Their disability in communicating requirements resulted in failure to convey simple needs such as thirst or hunger alongside bodily discomfort. Disabled communication skills between the children and their caregivers created frustrating situations causing both groups to display disruptive behaviors expressing unmet needs.

The research demonstrated how frequently behavioral issues occurred among the studied children. Research showed multiple cases of disruptive behaviors consisting of tantrums and aggression together with self-harming behaviors. Children's disordered behaviors brought extensive difficulties to their parents and caregivers through their daily routines while making their environments stressful. The examined children frequently experienced hyperactivity as a shared trait which impaired their ability to pay attention and join organized activities. The students faced challenges keeping their attention which



interfered with their educational performance in classroom activities. Both hand flapping and rocking patterns occurred as repetitive behaviors among these children. The children often used these behaviors to experience sensory stimulation but they simultaneously created social isolation and disruptiveness.

The discrimination in educational experiences between students became the most prominent issue. Communication problems together with behavioral issues prevented numerous children with ASD from attending kindergarten schools. The limited access to early education cut off these children from vital learning experiences together with missing chances for social interaction. School-enrolled children faced difficulties in participating with their educational activities. Their academic progress suffered because of difficulties in engagement thus creating more distance with their typical peers.

The study revealed that restricted access to vital services functioned as a significant discovery among the participants. The lack of formal ASD diagnosis for children prevented their families from obtaining proper therapeutic intervention as well as necessary support. Unidentified ASD leads to the challenging task of obtaining appropriate interventions on time. Children needed therapy services including speech therapy along with occupational therapy as well as behavioral therapy yet these specialized treatments were challenging to reach. Several elements including funding issues and geographical isolation along with insufficient expert professionals combined to create a resource deficiency. There was insufficient access to needed therapy treatments which probably inhibited the development of these children. The research showed that there was no support system matching parents as it restricted their ability to meet other parents who faced comparable difficulties. Students without peer support networks might undergo social isolation and prevent them from accessing mutual experiences with strength-building techniques.

The research investigated the emotional alongside social difficulties which these children experienced. Parents struggled to understand the emotional needs of their children because these children showed limited emotional displays. Expression problems concerning emotions generate situations that frequently create conflicts and annoyance between children and their caregivers. Children displayed reactive behaviors because they reacted without thinking about the outcomes of their actions in response to situations. The emotional impulses of these children caused problems when interacting with others and difficulties managing their actions. Social isolation became a problem for these children because they experienced difficulty developing emotional bonds beyond their family members. Therefore they missed possible relationship-building opportunities. The social and emotional difficulties requiring special interventions that would target the development of social competencies together with emotional management and communication capabilities.

Results and Conclusion



Research examined diverse requirements faced by preschool children with Autism Spectrum Disorder (ASD) together with their parents in the Indian cultural setting to understand their difficulties. The study analyzed multiple vital elements as they interrelated to create a complete representation of the family experiences.

The important theme evident from the findings revealed the serious communication difficulties faced by children with ASD. The research recorded how these deficits manifested across different dimensions which prevented children from effective communication and interaction with their environment. The communication issue affected both children and their families who experienced more difficulties as a result. Behavioral problems created one of the main themes that emerged from the research results. Research showed that parents struggle in dealing with ASD-related behaviors because these behaviors create extensive obstacles for both family life and daily household operations. The children faced added barriers to social interactions because their behavioral issues together with communication problems successfully hindered their pathway into community spaces.

The research study found that educational inequalities constituted a vital issue among its identified concerns. The study exposed an inadequate system for obtaining suitable educational resources as well as support services for preschool children with autism spectrum disorder in India. Such educational disadvantages created developmental setbacks for these children and made it harder for families to obtain suitable educational placements. Research pointed to the necessity of making both parents and professionals more aware of specialized education services which are designed to accommodate individual needs of children with ASD. The study showed that restricted service access became a consistent recurring issue across its investigation. The research studied the obstacles which made it difficult for families to get suitable diagnostic and treatment services on time. Some geographical areas lacked sufficient resources which became an obstacle for families working to develop their children's well-being. Early intervention programs together with speech therapy and occupational therapy and specialized support need to be immediately expanded to meet the growing need of families affected by autism. Research findings showed that emotional together with social difficulties were common among children. The research documented how ASD child parenting produces substantial emotional distress on parents through anxiety alongside social detachment and constant pressure. Research examined social difficulties which children face on their own because they experience problems with social relationships and establishing friendships and managing social surroundings. The identified emotional and social challenges underlined the requirement for full-scale support networks which serve the requirements of children with ASD and their families.

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Discussion

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The limitations of this study include the relatively small sample size and the focus on a specific geographical region in India. Its also because to locate more sample in a institute related to a single concept is not possible. Future research may involve larger samples from various institutions to enhance the generalizability of the findings. Further research is also needed to explore the effectiveness of culturally adapted interventions and support systems in improving the outcomes for children with ASD and their families in India.

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