Exploring Barriers to Early Diagnoses and Interventions for Autism in South India: A Community-Based Study

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Abstract

Background: In recent years, research studies have shown that in South India there is a significant delay (about 2 years) between the first recognition of symptoms to the actual initiation of treatments for children on the autism spectrum disorder (ASD).
Scientific literature reveals these delays exist, yet there is little research exploring the causes for such delays. The primary aim of this study is to identify barriers that prevent families in South India from receiving early ASD diagnoses and interventions. The secondary aim of this study is to investigate the mental well-being of the primary caregivers and/or parents of autistic children.
Methods: 38 semi-structured qualitative interviews were conducted with adult men and women from the greater Puducherry region in India. Primary caregiver/parent participants also completed the Depression, Anxiety and Stress Scale (DASS-21) questionnaire (in Tamil, English, or Hindi). Qualitative thematic data analysis was used to categorize the findings and interpret the results of the interviews. Mean, standard deviation, and correlation values of the DASS-21 variables were determined.
Results: On average, this population fell into the moderately depressed range (X̄depression= 14.94), the moderately anxious range (X̄anxiety= 10.31), and the mildly stressed range (X̄stress= 15.88). Strong positive correlations between depression and stress scores (r=0.79), strong positive correlations between depression and anxiety scores (r=0.71), and strong positive correlations between stress and anxiety (r=0.85) were found. 2 main parent themes emerged from the interviews: Bureaucratic and Cultural Barriers.
Conclusions: Based on the data, more exposure and education are necessary to expand knowledge and verbiage about ASD. More support and emphasis on ASD early detection from the local government is needed, including mental health support for primary caregivers.

Background

- ASD is a neurodevelopmental disorder primarily affecting social communication, and early diagnosis—as early as 14 months—can significantly improve developmental outcomes (Pierce et al., 2019).
- While ASD prevalence is estimated at ~2% globally, accurate prevalence data for India is lacking due to limited diagnostic tools, low awareness, and stigma (Talantseva et al., 2023; Rudra et al., 2017).
- Studies show an average two-year delay between initial symptom recognition and intervention in India, adversely impacting child development (Kommu et al., 2017; Malhi et al., 2023).
- There is limited research on the causes of diagnostic delays and the mental well- being of caregivers, particularly in South India (Renford et al., 2020).
- This study investigates barriers to early ASD diagnosis and intervention in Puducherry, South India, and examines caregiver stress and anxiety as potential contributing factors to delays.



Above are pictures from various speech and occupational therapy centers and special schools visited in the greater Puducherry area.

Methods

Participants: The study included 38 individuals aged 18 or older, categorized as primary caregivers/parents, community organization leaders, and/or providers/professionals. Participants were standardized by region of origin, specifically Puducherry, India. **Recruitment Strategy:** Initial recruitment focused on community leaders and professionals to leverage their connections for reaching families of children with ASD. Participants were recruited via email and/or phone calls.
Community-Based Research: The study integrated local perspectives into data analysis, aiming to build trust and enhance study relevance.
Qualitative Component: Semi-structured interviews were used for flexibility to explore emerging topics. Interviews were conducted either in-person or over Zoom, lasted 30 minutes to 1 hour, and were recorded for transcription and analysis. Interviews were conducted in Tamil, English, or Hindi, depending on participants' language preferences. **Quantitative Component:** A total of 32 primary caregivers completed the **DASS-21** questionnaire to assess levels of depression, anxiety, and stress, with Tamil and Hindi versions used when needed for non-English speakers.
Data Analysis: Quantitative data from the DASS-21 was analyzed in R, while qualitative interview data was transcribed, cleaned, coded, and analyzed using inductive thematic analysis in NVivo, with all participant names anonymized.

Results

Quantitative Results:
Participant Demographics: 38 adult participants (≥18 years) from the Puducherry region; 90% identified as female, 10% as male (Table 1).

Table 1. Participant Demographic Data

Participant Type[a]	Primary Caregiver/Parent	Community Organization Leader	Provider/ Professional
Male	3	1	3
Female	30	3	3

[a]Some participants fell into more than one category

On average, this population fell into the **moderately depressed** range (X̄depression= 14.94), the **moderately anxious** range (X̄anxiety= 10.31), and the **mildly stressed** range (X̄stress= 15.88) (Table 2). Strong positive correlations between depression and stress scores (r=0.79), strong positive correlations between depression and anxiety scores (r=0.71), and strong positive correlations between stress and anxiety (r=0.85) were found (Table 3).

Table 2. Descriptive Statistics for DASS-21 Variables

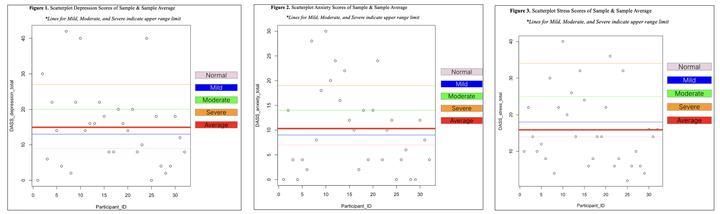
Measure	Mean	SD	% Mild and Above
Depression	14.94	11.21	62.5%
Anxiety	10.31	8.77	59.4%
Stress	15.88	10.15	40.6%

Table 3. Correlations Between DASS-21 Variables

Measure	1	2	3
1. Depression	---		
2. Anxiety	0.71*	---	
3. Stress	0.79*	0.85*	---

[a]p<0.01

Figures 1–3 illustrate the average DASS-21 scores compared to standardized severity ranges.



Qualitative Results:
Bureaucratic Barriers Identified: Participants cited long wait times, limited access to ASD resources, lack of language support, and funding issues as major obstacles.
Cultural Barriers Identified: Stigma, absence of ASD-related terms in native languages, gender discrimination, and mistrust in medical/institutional systems were prevalent.
Dual Barrier System: Findings indicate both **bureaucratic and cultural barriers** significantly delay early diagnosis and care for ASD in Puducherry.

Discussion

- Caregivers consistently reported long wait times for specialist appointments, often exceeding a year, due to a critical shortage of trained developmental professionals in the region.
- The availability of ASD-specific services in Puducherry and surrounding areas remains extremely limited, with most mainstream schools lacking special educators or inclusive infrastructure.
- 98% of caregivers were unaware of autism prior to their child's diagnosis, underscoring a profound need for public health education and early developmental screening campaigns.
- The lack of Tamil-language resources and regionally adapted diagnostic tools significantly impedes access, particularly among families with limited formal education.
- High out-of-pocket costs for therapy, transportation, and assessments, combined with minimal insurance coverage, contribute to substantial care delays and increased caregiver stress.
- Social stigma and gendered caregiving roles contribute to diagnostic hesitancy, with mothers often facing blame and isolation, which further delays help-seeking behavior.
- School-level data revealed an extremely low ASD identification rate (0.05%), reflecting both under-diagnosis and poor integration of neurodiverse children into mainstream education.
- The absence of culturally appropriate and linguistically relevant terminology for ASD results in mislabeling and confusion, limiting community understanding and acceptance.
- Recurrent reports of misdiagnosis, dismissal, and poor communication with providers contribute to institutional mistrust, especially among marginalized caregivers.
- Poor coordination between medical, educational, and social services exacerbates caregiver burden and limits the effectiveness of interventions.

Conclusion

- **Multiple Barriers Delay Care:** Bureaucratic inefficiencies (e.g., long wait times, cost, lack of services) and cultural factors (e.g., stigma, gender bias, mistrust) jointly delay ASD diagnosis and intervention in Puducherry.
- **Language and Literacy Gaps:** The lack of Tamil-language materials and culturally adapted ASD terminology hinders awareness, screening accuracy, and caregiver understanding.
- **Disproportionate Impact on Marginalized Groups:** Rural and low-income families face barriers, resulting in missed intervention windows and heightened caregiver stress.
- **Urgent Need for Systemic Change:** Integration of ASD services into primary healthcare, teacher training, and policy subsidies is essential to improve access and affordability.
- **Empowering Families is Key:** Community outreach, maternal support, and culturally relevant education are critical to reducing stigma and fostering inclusive, early support systems.

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