

Prevalence of self-stigma and psychological distress among parents of children with autism spectrum disorder: A cross-sectional study

Harshavardhana Anandakumar, Raghuram Pattusamy*, Loganathan Shanmugam, Deepika Pakkiri

Faculty of Occupational Therapy, Sri Ramachandra Institute of Higher Education and Research (DU), Chennai, Tamil Nadu, India.

ARTICLE INFO

Article history:

Received 20 February 2026

Accepted as revised 6 July 2026

Available online 22 July 2026

Keywords:

Autism spectrum disorder, mental health, psychological distress, social stigma

ABSTRACT

Background: Autism Spectrum Disorder (ASD) is a lifelong neurodevelopmental disorder characterized by challenges in social communication and restricted behaviors. Parents of children with ASD often face self-stigma-the internalization of negative societal attitudes which contributes to psychological distress. Given the multifaceted caregiving demands associated with ASD, these parents are particularly vulnerable to stress and psychological burden across the developmental course of their child.

Objectives: To investigate the prevalence of, and relationship between, self-stigma and psychological distress among parents of children diagnosed with ASD.

Materials and methods: A cross-sectional study was conducted among 138 parents recruited from special educational centers in Chennai, India. Data were collected using the Parents' Self-Stigma Scale (PSSS) and the Kessler Psychological Distress Scale (K10) and analyzed using IBM SPSS Statistics (Version 26).

Results: Among the parents, 4.3% reported severe self-stigma, 57.2% moderate, and 37.7% mild. Regarding psychological distress, 21% exhibited severe distress, 18.8% moderate, 20.3% mild, and 39.9% were classified as 'well'. A statistically significant positive correlation was observed between self-stigma and psychological distress ($r=0.311$, $p<0.001$).

Conclusion: Higher levels of self-stigma among parents are significantly associated with elevated psychological distress. Interventions targeting self-stigma reduction, including cognitive reframing, acceptance-based therapeutic strategies, and peer-facilitated support, could mitigate psychological distress and enhance parental well-being.

Introduction

Autism spectrum disorder (ASD) is a lifelong neurodevelopmental disorder, which is characterized by deficits in social communication and the use of language, as well as by restricted interests and repetitive behaviors. According to the Fifth Edition of the Diagnostic and Statistical Manual of Mental Disorders, ASD was defined by integrating distinct subcategories, namely autistic disorder, Asperger's syndrome, and pervasive developmental disorder-not otherwise specified (PDD-NOS).¹ The symptoms observed in ASD vary with age, language capability (with/without speech), IQ, and gender. In infancy and early childhood, common presenting symptoms and signs include delays in language development, regression of language, or a

*Corresponding contributor.

Author's Address: Faculty of Occupational Therapy, Sri Ramachandra Institute of Higher Education and Research (DU), Chennai, Tamil Nadu, India.

E-mail address: raghurammot@sriramachandra.edu.in

doi: 10.66285/JAMS.2026.103

E-ISSN: 2539-6056

lack of development of language and communicative gestures.²⁻⁴ Children with ASD may not have many noticeable physical signs but demonstrate behaviors that can be socially misinterpreted, such as flapping, twirling, or having tantrums. Consequently, they may be perceived as 'rebellious' or 'disruptively behaving'.⁵

The global prevalence of ASD has increased substantially over recent decades. Whereas early estimates placed prevalence at approximately 0.2 per 1,000 children, contemporary figures indicate a prevalence of approximately 1 in 100 children worldwide, representing an increase attributable in part to broader diagnostic criteria, improved awareness, and enhanced surveillance methodologies.⁶ In India specifically, a systematic review and meta-analysis by Chauhan *et al.* estimated the prevalence of ASD at 0.09% in urban settings and 0.11% in rural settings, with regional and methodological variation warranting continued epidemiological investigation.⁷

Stigma can be defined as a mark of social distinction that is assumed to imply undesirable characteristics or behaviors considered unfavorable in society. Goffman further noted that stigma is situational; the perception of such stigma can produce a deleterious effect on the physical, psycho-social, and communal well-being not only of the person with disability but of his or her family and relatives as well.⁸ Parents experience negative attitudes held by society and attribute their child's condition to themselves, which is more evident among parents of children with ASD.^{9,10} This internalization only compounds feelings of self-stigma, which stem from societal opinions alongside the notion that it is the parent's responsibility to mold the child into an acceptable social participant.¹¹⁻¹³ Parents and caregivers of a child with ASD may feel that they are inadequate parents, ashamed, guilty, and unable to help the situation. These feelings may be exacerbated by judgments from the outside world and misunderstanding, which further adds to the sense of parental incompetence.¹⁴

The lived experience of self-stigma among parents of children with ASD may manifest across multiple domains of daily life. For example, a parent who avoids taking their child to a public space out of fear that others will judge their child's atypical behavior or who internalizes such judgment as evidence of their own parental failure exemplifies the behavioral and emotional consequences of internalized stigma.¹¹ These everyday experiences, repeated across social, educational, and healthcare encounters, compound over time and may translate into measurable psychological burden.

The American Psychological Association defines psychological distress as a set of painful mental and physical symptoms that are associated with normal fluctuations of mood. Parenting children with ASD can provide daily stressors and possible challenges, including the child's behavioral difficulties and impaired communicative functioning.¹⁵ Parents of children with

ASD may be more vulnerable to high levels of stress and psychological discomfort throughout the toddler and preschool years because of the special demands and stresses that accompany these developmental stages.^{16,17}

The mental health of the parent has an impact on the standard of care and the long-term rehabilitation results of their child. Psychologically distressed caregivers are more likely to engage in less responsive, less consistent, and less stimulating parenting behaviors, which in turn may impede the child's communicative and social development.¹⁸ Moreover, parental stress and depression have been associated with reduced implementation fidelity of home-based intervention programs, diminished advocacy for the child's educational and therapeutic needs, and lower rates of participation in caregiver training initiatives.¹⁹ Supporting parental psychological well-being improves treatment adherence and fosters a stable home environment, leading to better developmental outcomes for children with ASD.²⁰ These findings highlight the need to address parental mental health as part of comprehensive, family-centered rehabilitation. The stigma stress model, which implies that awareness and agreement with stigmatizing public attitudes, followed by their application to the self, results in diminished self-esteem and increased emotional suffering, can help explain the relationship between self-stigma and psychological distress.²¹

The process known as "courtesy stigma" or "stigma by association", in which caregivers internalize the stigma directed at their child, exacerbates this pathway in parents of children with ASD.⁸ Previous studies by Mak and Kwok showed a positive correlation between poor mental health outcomes and parental self-stigma in Hong Kong.¹⁴ However, similar data from the Indian subcontinent are still scarce. In the context of the significant cultural, familial, and systemic disparities that influence caregiving experiences in India, this study was intended to address that gap by exploring the prevalence of self-stigma and psychological distress among parents of children with ASD in Chennai. The results will ultimately help develop more thorough rehabilitation plans for those impacted families.

Materials and methods

Study design and setting

This cross-sectional study was conducted in four specialized educational centers in Chennai, India: Kumaran Special School (Ennore), Sankalp Special School (Kolappancheri), Maithree Special School (Perambur), and B.K.N Opportunity School (Egmore), in August 2024, over a period of 3 weeks. The selection of these sites was intended to collect a representative sample of parents from varying urban/suburban and socioeconomic/educational backgrounds. All eligible parents were provided with a participant information document prior to data collection, which explained the purpose of the study, the voluntary nature of

participation, and anonymity. Written consent was also obtained from each parent. For parents who were more confident communicating in their own language, a validated Tamil version of the consent form and questionnaires was used to ensure that they had fully understood the study's protocols.

Participants

A total of 138 parents of children and adolescents with a diagnosis of ASD aged 4-17 years were recruited. This age group has been chosen to reflect the population enrolled in the participating special educational centers and aligns with the eligibility criteria defined under the Persons with Disabilities Act, India (2016). The World Health Organization states that adolescence lasts until age 19, but the 17-year age limit in this study aligns with the participating schools' policies on admission to their institutions.

Sampling size

The targeted sample size was determined based on the prevalence of internalized stigma identified in previous studies by Mak and Kwok,¹⁴ who investigated self-stigma among parents of children with neurodevelopmental impairments. For statistical validity, a power analysis was performed using their reported prevalence rate of 41% as a baseline. The minimum sample size required was determined to be 138 individuals with a confidence level of 95% and a predetermined margin of error of 8%.

Sampling method

A total of 138 parents of children diagnosed with ASD were recruited using a convenience sampling method.

Inclusion criteria

1. Must be the primary parent or legal guardian providing direct care to the child.
2. Parents of children and adolescents aged between 4 and 17 years diagnosed with Autism Spectrum Disorder.
3. Parents able to read and write Tamil or English.

Exclusion criteria

1. Parents who are not the child's primary caregivers.
2. Parents of a child with siblings who also have any other physical and orthopedic conditions.

Data collection tools

Parents' Self-Stigma Scale (PSSS)

The Parents' Self-Stigma Scale (PSSS) is a standardized psychometric instrument developed by Mak and Kwok to measure the extent to which parents of children with neurodevelopmental conditions internalize societal stigma.¹⁴ Self-blame, shame, social disengagement, and perceived inadequacy are the four key psychological characteristics assessed by

the self-report instrument. Using a Likert scale with responses ranging from "strongly disagree" to "strongly agree," participants answer a series of items, enabling both a composite self-stigma score as well as specific subscale insights. The validation study reported a Cronbach's alpha of 0.89, indicating excellent internal consistency. Construct validity was demonstrated through confirmatory factor analysis.

Kessler Psychological Distress scale (K10)

This 10-item self-report instrument has been validated to screen for anxiety or depressive disorders and general psychological distress. Respondents are asked to report how often they experience feelings such as anxiety, sadness, restlessness, and exhaustion during the last 30 days using a 5-point Likert scale. Psychometric evaluation showed excellent internal consistency (Cronbach's $\alpha=0.92-0.93$) and strong criterion validity with sensitivity of 0.87 and specificity of 0.70 for identifying serious mental illness against ICD-10 criteria. Scores are grouped into 4 levels of distress: low (10-19), moderate (20-24), high (25-29), and very high (30-50), and provide an effective means of identifying individuals who may require further clinical assessment.²²

Procedure

This cross-sectional study was conducted among parents of children with ASD from Special schools in Chennai. The parents were selected based on the selection criteria using convenience sampling. Prior to participation in the study, informed consent was obtained. The PSSS and K10 were administered to all participants. The collected data were analyzed, and results were inferred.

Data analysis

Data were analyzed using IBM SPSS Statistics (Version 26). Descriptive statistics including frequencies, percentages, means, and standard deviations were computed to summarize sociodemographic and outcome variables. Prior to inferential analysis, normality was assessed using the Shapiro-Wilk test, which revealed that both the PSSS and K10 score distributions deviated significantly from normality ($p<0.05$). Accordingly, Spearman's rank-order correlation coefficient (r_s) was used to examine the association between parental self-stigma and psychological distress. Chi-square (χ^2) tests were applied to explore associations between categorical demographic variables and categorical outcome groups.

Results

Sociodemographic characteristics of participants

Of the 138 participants, the majority ($N=78, 56.5\%$) were between 36 and 45 years of age. A smaller proportion fell within the 25-35 ($N=36, 26.1\%$), 46-55 ($N=23, 16.7\%$), and 56-65 ($N=1, 0.7\%$) age groups.

Mothers constituted the predominant respondents (N=113, 81.9%), with fathers representing 18.1% (N=25) of the sample (Table 1).

Prevalence of self-stigma and psychological distress

Analysis of the PSSS scores revealed that 57.2% (N=79) of parents experienced moderate self-stigma, 37.7% (N=52) mild, 4.3% (N=6) severe, and only 0.7% (N=1) scored in the normal range. With regard to psychological distress, 39.9% (N=55) of participants scored in the 'well' category, while 20.2% (N=28) reported mild distress, 18.8% (N=26) moderate distress, and 21.1% (N=29) severe distress, indicating that approximately 60% of the sample experienced

some degree of psychological distress. These findings are presented in Table 2.

Association between self-stigma and psychological distress

Spearman's rank correlation analysis revealed a statistically significant positive association between parental self-stigma and psychological distress ($r_s=0.311$, $p<0.001$). Although the magnitude of the correlation is modest, its significance across the full sample indicates that parents reporting higher levels of internalized stigma are consistently more likely to experience elevated psychological distress. (Table 3).

Table 1. Distribution of demographic characteristics of parents

Demographic characteristics of parents	Category	Number of participants
Age range (years)	25-35	36
	36-45	78
	46-55	23
	56-65	1
Gender distribution (N, %)	Mother	113 (81.9%)
	Father	25 (18.1%)

Table 2. Distribution of PSSS and K10 scores.

Measure	Score category	Frequency	Percentage
PSSS score	Normal	1	0.7
	Mild	52	37.7
	Moderate	79	57.2
	Severe	6	4.3
K10 score	Well	55	39.9
	Mild	28	20.2
	Moderate	26	18.8
	Severe	29	21.1

Table 3. Association between self-stigma and psychological distress within participants.

Correlations (Spearman's rho)		PSSS score	K10 score
PSSS score	Correlation coefficient	1.000	0.311***
	Sig. (2-tailed)	-	<0.001
K10 score	Correlation coefficient	0.311***	1.000
	Sig. (2-tailed)	<0.001	-

Discussion

The findings reveal significant insights into how societal perceptions and internalized stigma contribute to the psychological well-being of these parents. The current study found that 4.3% of parents have severe self-stigma; these parents likely face intense societal judgment, lack sufficient support, and may have limited resources or understanding about ASD. This group might also include parents who are more socially or emotionally isolated, making them more vulnerable to severe internalized stigma. Most parents experienced moderate self-stigma 57.2%. This suggests that while they are affected by stereotypical reactions and internalized blame, they are not overwhelmed by these feelings. These parents likely encounter regular challenges related to societal attitudes and may have internal conflicts about their role as a parent; however, they may also possess some coping strategies that prevent these feelings from escalating.

A significant portion of parents falls into the mild self-stigma category, at 37.7%. These parents may experience some societal pressures and occasional feelings of inadequacy or guilt, but they are generally able to manage these emotions. Factors such as moderate social support, education, and understanding of ASD could contribute to a lower level of internalized stigma. Only 0.7% of parents in the study reported a normal level of self-stigma. This could be attributed to strong resilience, a highly supportive environment, or effective coping mechanisms. These parents may have a deep understanding of ASD, access to resources, or a strong social support network that shields them from internalizing stigma.

Mittal *et al.* stated that parents could employ unhealthy coping mechanisms like hiding and social disengagement, which exacerbate the stigma.²³ Additionally, they could adopt adaptive coping mechanisms, including seeking spiritual or religious support, seeking social support, accessing social networks, actively seeking knowledge about ASD, and participating in advocacy and education campaigns. Adaptive coping enables caregivers to avoid being constrained by social stereotypes and judgments about their children's conduct.¹⁸

Among the parents, 21.0% experienced severe psychological distress, likely due to high caregiving demands, limited support, and persistent stress from managing their child's needs and societal stigma. Moderate distress (18.8%) may reflect partial support from family or community, which helps but does not fully alleviate stress. Mild distress (20.3%) could be attributed to effective coping strategies, such as self-care, professional help, and realistic expectations. 39.9% who were likely to be well appeared to benefit from strong support systems and effective problem-solving skills, helping them maintain better mental health.

The results from the current study show that mothers experience higher levels of self-stigma (severe

and extremely severe) compared to fathers, who experience moderate self-stigma. This difference can be attributed to traditional caregiving roles, societal expectations, cultural norms, and the different ways in which mothers and fathers cope with the challenges of raising a child with ASD. Mothers, who constituted 81.9% of respondents, have been shown in multiple studies to assume primary caregiving responsibilities and are therefore disproportionately exposed to stigma-generating social interactions.²⁴ Cultural norms in India further reinforce maternal caregiving roles, amplifying the social visibility and hence the stigma exposure of mothers in this context.²⁵

Association between self-stigma and psychological distress

The analysis reveals a statistically significant, positive correlation between parental self-stigma and psychological distress ($r_s = 0.311, p < 0.001$). This means that parents who score higher on the self-stigma scale are significantly more likely to also report higher levels of psychological distress. This finding is consistent with existing evidence by Eaton *et al.*, who found a positive association between parental awareness of stigma, self-stigma, and emotional suffering.²⁶

The observed Spearman's correlation ($r_s = 0.311, p < 0.001$) falls within the moderate range according to Cohen's conventional criteria, where values between 0.30-0.49 indicate a moderate association. While this coefficient may appear modest in absolute terms, it is important to contextualize its practical significance. Psychological distress is a complex, multidetermined outcome shaped by factors including social support, coping style, severity of the child's ASD symptoms, socioeconomic status, and marital functioning- none of which were controlled for in the present analysis. Within this context, self-stigma independently accounting for approximately 9.7% of the variance in psychological distress ($r_s^2 = 0.097$) is both statistically meaningful and clinically relevant. These findings underscore the importance of addressing internalized stigma as one modifiable contributor to parental psychological burden.

The relatively moderate correlation may be explained by several factors. Firstly, psychological distress is shaped by numerous variables beyond self-stigma, including child behavior severity, family support, and financial stress. Secondly, the majority of parents scoring in the moderate self-stigma range results in a restricted range in the predictor variable, which typically attenuates correlation estimates. Thirdly, Indian families may have access to extended family support systems that partially buffer against psychological distress despite high self-stigma levels.²⁷

The observed association between self-stigma and psychological distress in this study can be understood through several interrelated mechanisms. According to the cognitive-behavioral model of stigma, when parents internalize negative societal beliefs about their child's

condition, these beliefs activate cognitive schemas of self-blame and inadequacy, which in turn fuel affective states of shame, guilt, and hopelessness.²¹ These emotional consequences are consistent with cognitive appraisal theory by Lazarus & Folkman, wherein caregivers who perceive their situation as beyond their coping capacity report greater emotional distress.²⁸ Furthermore, self-stigma has been shown to reduce help-seeking behavior, thereby limiting access to professional and social support.^{26,29} The resulting social isolation creates a self-reinforcing cycle in which stigma leads to withdrawal, which reduces access to corrective social experiences, further entrenching negative self-perceptions and elevating distress.

Hayes *et al.*'s meta-analysis (N=284 studies) confirmed that parents of children with ASD experience significantly higher stress and depression compared to parents of typically developing children.²⁰ Karst and Van Hecke *et al.* linked parental psychological distress in ASD families to child behavior severity, social isolation, and lack of professional support.¹⁹ Kuhlthau *et al.* documented that unmet service needs independently contribute to parental psychological burden.³⁰ Notably, studies have reported weaker associations between stigma and distress when robust social support is present, highlighting the moderating role of support systems and explaining the modest rather than strong correlation observed here.²⁷

Given the significant association between self-stigma and psychological distress observed in this study, occupational therapy has a specific and valuable role to play in supporting parents of children with ASD. Through role-focused interventions, occupational therapists can help parents reframe their identity beyond the caregiving role, restoring meaningful engagement in occupations such as leisure, social participation, and self-care that may have been relinquished due to the emotional demands of caregiving and the social withdrawal driven by self-stigma.³¹ Family-centered practice models, which position the parent as an active collaborator in the therapeutic process rather than a passive recipient of care, may further reduce feelings of inadequacy and enhance parental self-efficacy, both of which are dimensions of self-stigma assessed in the PSSS.³²

Psychoeducational workshops and individual therapeutic sessions targeting self-stigma reduction have shown promise in analogous populations. Corrigan *et al.* demonstrated that Acceptance and Commitment Therapy (ACT) based approaches significantly reduced internalized stigma in mental health service users.²⁹ Similarly, self-compassion interventions have been associated with lower shame and improved psychological well-being in caregivers of individuals with developmental disabilities.³³ Encouraging parents to maintain engagement in meaningful occupations unrelated to caregiving such as creative pursuits, social activities, or vocational roles may help rebuild a positive self-concept and reduce

the centrality of the stigmatized caregiver identity to overall self-worth.^{31,34}

Limitations

Firstly, the cross-sectional design precludes causal inferences regarding the direction of the association between self-stigma and psychological distress. Secondly, convenience sampling may limit the generalisability of findings to parents from rural settings or those whose children are not enrolled in formal educational programs. Thirdly, potential confounders including parental mental health history, child's severity, and socioeconomic status were not assessed. Future research should address these limitations by employing longitudinal designs, probability-based sampling strategies, structured clinical interviews for parental mental health, and the inclusion of child-level variables such as ASD severity and functional profile.

Conclusion

This study provides novel evidence from an underrepresented South Asian context demonstrating that a substantial majority of parents of children with ASD in Chennai experience moderate-to-severe levels of self-stigma, and that higher internalized stigma is significantly associated with greater psychological distress. To the best of our knowledge, this is the first study in the Indian context to employ the PSSS alongside the K10 to systematically characterize this association.

These findings have direct clinical relevance: healthcare professionals and rehabilitation specialists, including occupational therapists, should adopt family-centered approaches that proactively screen for self-stigma and implement targeted interventions such as cognitive reframing, acceptance-based therapeutic strategies, and peer-facilitated support groups.

Ethical approval

The study was approved by the institutional ethics committee for student proposals [CSP/24/JUN/149/259].

Funding

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

Conflict of interest

The authors declare no conflict of interest.

CRedit authorship contribution statement

Harshavardhana Anandakumar: conceptualization, methodology, investigation, data curation, writing: original draft; **Raghuram Pattusamy:** supervision, methodology, writing: review and edit, validation; **Loganathan Shanmugam:** methodology, writing: review and edit, validation; **Deepika Pakkiri:** methodology, supervision, writing: review and edit.

Acknowledgements

The authors would like to thank the management, staff, and students of the participating special schools for their support and cooperation during data collection. The authors also gratefully acknowledge the parents who participated in this study for their time and willingness to share their experiences.

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