



## Short communication

## Affiliate stigma among parents of children with autism in eastern India

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## ABSTRACT

Parents of children with autism experience high levels of stigma. They often internalize stigma which results in high psychological distress and has negative impact on seeking and providing care. Qualitative methodology has been used to study stigma in Indian population while quantitative studies have not been reported. The authors report affiliate stigma perception among parents of children with autism in a tertiary care medical centre using Affiliate Stigma Scale. Thirty-eight parents participated in this cross-sectional study. We discuss predictors of stigma in terms of caregiver characteristics and symptom profile. Identification of predictors of stigma perception can help in identifying populations at risk.

## 1. Introduction

Absence of physical disability and presence of behavioural problems makes autism an invisible form of disability. Abnormal behaviour is often blamed to bad parenting and parents are frequently subjected to societal stigma. Stigma perception in autism is reportedly more than any other developmental disability or childhood psychiatric disorder (Zhou et al., 2018). Hostile public reactions in terms of angry stares, name calling, targeted exclusion often results in feelings of shame and rejection among individuals with autism as well their caregivers (World Health Organization, 2016). Experience of social stigma often leads parents to internalize the attribute through believing in the public stereotype resulting in low self-esteem and social withdrawal (Mukolo et al., 2010; Grover et al., 2017).

Affiliate stigma or courtesy stigma is experience of social stigma on account of association with a person who is stigmatized (Zhou et al., 2018). Parents of children with autism experience sequential process of stigmatization which begins with negative stereotyping, loss of societal status, separation and isolation and culminates into discrimination (Mukolo et al., 2010). Internalization of societal stigma results in devaluation and feelings of rejection. Feelings of shame and low self-esteem together with agreement to negative stereotype of child's autism reduces care-seeking behaviour. Even the process of taking care of the child is compromised (Lowell and A Wetherell, 2018). Affiliate stigma has been reported to be very high in caregivers of autism from China and Hong Kong (Lowell and A Wetherell, 2018; Mak and Kwok, 2010). Stigma in Indian population with autism has been studied using qualitative methodology (Minhas et al., 2015). Parents experience tremendous strain, burden and discrimination during the process of caring

for their child with autism. Minhas et al, in their research on lived experiences of parents of children with autism in Goa, reported feeling of extreme strain due to absence of care provisions as well as lack of awareness of the condition in the community as well as among service-providers. Parents experienced social stigma in terms of negative labelling, negative comments and exclusion from society. Experience of stigma and discrimination having a negative impact on help seeking behaviour.

As there is paucity of quantitative research in this area, we explored affiliate stigma among parents of children with autism and its predictors in our speciality Child Psychiatry Out Patient Department.

## 2. Materials &amp; methods

## 2.1. Participants

Parents of children diagnosed with Autism Spectrum Disorder as per INCLIN diagnostic criteria were invited to participate in the study. Consecutive patients seeking care for ASD in the Child Guidance Clinic of a tertiary care hospital were enrolled after they gave their consent. There were no exclusion criteria.

## 2.2. Study instruments

INCLIN: This tool based on DSM IV diagnostic criteria for Autism Spectrum Disorder was indigenously developed and is available free of cost for clinical and research use (Juneja et al., 2014). It has been recommended by the Government of India and has documented psychometric properties. The tool is divided into two sections: Section A and

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B. Section A includes questions and behavioural observation about socialization interaction, communication and restricted interest and activities. Section B generates a diagnosis of category of Autism Spectrum Disorder.

Childhood Autism Rating Scale (CARS): CARS is a screening as well as diagnostic instrument for autism; it also generates a severity score. It includes 14 items addressing different domains of autism and a separate domain on general impression of autism. Scoring is done from 1 to 4; higher score indicating more severe symptoms. Total scores range from 15 to 60 with 30 being cut off score for diagnosis of autism. Scores from 30 to 36.5 indicate mild- moderate autism whereas higher scores indicate severe autism (Schopler and Reichler, 1980). The psychometric property of CARS has been well documented in Indian population (Russell et al., 2010).

Affiliate Stigma Scale: This scale was developed for measuring affiliate stigma in caregivers of people with intellectual disability or mental illness (Mak and Cheung, 2008). The scale has also been used in caregivers of children with autism and has been reported with good psychometric properties (Lowell and A Wetherell, 2018). Affiliate stigma scale consists of 22 items scored on four-point likert type scale with 1 = strongly disagree and 4 = strongly agree. Total scores on 22 items is added up to generate scale score; higher scores implicating higher stigma.

### 2.3. Ethical considerations

The study received approval from Institutional Ethics Committee vide IEC No. T/IM-NF/Psych15/2. Written informed consent was obtained from parents in a pre-designed proforma who agreed to participate in the study.

### 2.4. Statistical analysis

Descriptive statistics was carried out using SPSS 20. Mean and standard deviations were calculated for parametric variables. Independent *t*-test and correlation analysis was carried out for identifying socio-demographic and clinical predictors of stigma. Cronbach's  $\alpha$  was calculated to test for internal consistency in our sample.

## 3. Results & discussion

A total of 38 parents participated in the study, 24 mothers and 14 fathers completed the study questionnaire. Mean age was 43 years, majority belonged to upper middle socioeconomic status (Gadhav and Nagarkar, 2015) and had a single child; socioeconomic details are provided in Table 1. Mean age of children was 4.7 years; age range 3-7years, majority were males and single child. Parents reported that in the care seeking pathway, they had chosen a medical care provider as the first care agency which emphasizes their biomedical orientation towards autism.

### 3.1. Affiliate stigma scores

We used the version of Affiliate Stigma Scale used by Lovell & Wetherell with parents of children with autism in which the term 'developmental disability' was replaced with 'autism'. Cronbach's  $\alpha$  for our sample was 0.92 which means there was high internal consistency of the scale in our patient population. Our Cronbach's  $\alpha$  score is similar 0.93 as reported in similar populations (Lovell and A Wetherell, 2018). Mean total score on Affiliate Stigma Scale was 45.54 ( $\pm$  13.01), range 24-73. A large proportion of our sample reported higher scores in attitude domain whereas a comparatively lower proportion experienced stigma in behavioural domains of Affiliate Stigma Scale (Table 2).

**Table 1**  
Participant profile.

Variable	n(%)
<b>Gender child</b>	
Male	34 (89)
Female	4(11)
<b>Religion</b>	
Hindu	36(95)
Christian	1(2.5)
Muslim	1(2.5)
<b>Locality</b>	
Urban	20(53)
Semi-urban	4(10)
Rural	14(37)
<b>Socio economic status</b>	
Upper	22(58)
Upper middle	15(40)
Upper lower	1(2)
<b>Number of siblings of child</b>	
Single child	24(63)
One sibling	11(29)
Two siblings	3(8)

**Table 2**

Parental affiliate stigma scores in attitudinal and behavioural domains.

Item no	Item	n (%)
<b>Attitudes</b>		
1.	Feelings of inferiority due to child's autism	19(50)
10.	Sour attitude of people due to child's autism	15(39)
6.	Worries if other people would know of child's autism	10(26)
9.	Damaged self-reputation because of child's autism	10(26)
<b>Behaviour</b>		
18.	Have cut down contacts with others	8(21)
16.	Dare not tell others about child's autism	7(18)
21.	Dare not participate in autism related activities	4(11)
17.	Reduced going out with child with autism	3(8)

### 3.2. Sociodemographic and clinical predictors of affiliate stigma scores

Among the various sociodemographic predictors, gender of the participant showed significant statistical correlation with stigma scores,  $r = 0.827$ , ( $p = 0.01$ ), higher stigma scores were seen in parents having a girl child with autism. Mean stigma score of mothers was ( $53.14 \pm 10.46$ ) as compared to ( $33.36 \pm 4.73$ ) in fathers. No other socio-demographic variable showed correlation with stigma scores. Higher severity of symptoms of autism was associated with higher stigma scores; independent *t*-test showed statistically significant association with total Affiliate stigma score ( $p = 0.015$ ). Total CARS score was associated with higher mean stigma scores on Affiliate Stigma scale. High stigma scores in our sample is comparable to Chinese population. High face concern ie., value placed over social position is common to Indian and Chinese population which can explain the similarity in affiliate stigma scores (Fung et al., 2007). Higher stigma perception in mothers and correlation with severity of autism scores have been reported by Lovell & Wetherell in Chinese population. High stigma scores in attitudinal domain is a cause of concern as these may be associated with low self-esteem and feelings of distress with an adverse impact on providing care to the child. Lower scores in behavioural domains in our population is an encouraging finding as this underscores the parent's continuous efforts in seeking and providing care to the affected child. Only a small proportion had stopped going out with their child or had reduced participation in autism related activities. Concept and nosology of autism is continuously evolving with an impact on diagnostic labelling which in turn may impact the perception of stigma (Gyawali and Patra, 2019).

Our study has a limitation of small sample size which could bias the results. Generalizability of our study findings remain questionable. However, people seeking care at our centre belonged to higher middle socio-economic status and shared a bio-medical model for causation of stigma which was apparent in their help seeking behaviour. High levels of stigma even in people with good awareness of autism is a cause of concern and underlines the need for understanding the contributors and correlates of stigma in autism with longitudinal population- based studies. Higher severity of autism and female gender of the child are important correlates of high stigma perception in our set-up and hence need provision for targeted interventions.

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#### References

- Fung, K.M.T., Tsang, H.W.H., Corrigan, P.W., Lam, C.S., Cheung, W., Cheng, W., 2007. Measuring self-stigma of mental illness in China and its implications for recovery. *The International Journal of Social Psychiatry* 53 (5), 408–418. <https://doi.org/10.1177/0020764007078342>.
- Gadhave, S., Nagarkar, A., 2015. Kuppaswamy scale for measuring socio-economic status: revised monthly income figures for 2015. *Indian J. Pediatr.* 82 (12), 1175–1176. <https://doi.org/10.1007/s12098-015-1753-z>.
- Grover, S., Avasthi, A., Singh, A., Dan, A., Neogi, R., Kaur, D., et al., 2017. Stigma experienced by caregivers of patients with severe mental disorders: a nationwide multicentric study. *Int. J. Soc. Psychiatry* 63 (5), 407–417. <https://doi.org/10.1177/0020764017709484>.
- Gyawali, S., Patra, B.N., 2019. Trends in concept and nosology of autism spectrum disorder: a review. *Asian J. Psychiatr.* 40, 92–99. <https://doi.org/10.1016/j.ajp.2019.01.021>.
- Juneja, M., Mishra, D., Russell, P.S.S., Gulati, S., Deshmukh, V., Tudu, P., et al., 2014. INCLIN Diagnostic Tool for Autism Spectrum disorder (INDT-ASD): development and validation. *Indian Pediatr.* 51 (5), 359–365.
- Lovell, B., A Wetherell, M., 2018. Caregivers' characteristics and family constellation variables as predictors of affiliate stigma in caregivers of children with ASD. *Psychiatry Res.* 270, 426–429. <https://doi.org/10.1016/j.psychres.2018.09.055>.
- Mak, W.W.S., Cheung, R.Y.M., 2008. Affiliate stigma among caregivers of people with intellectual disability or mental illness. *J. Appl. Res. Intellect. Disabil.* 21 (6), 532–545. <https://doi.org/10.1111/j.1468-3148.2008.00426.x>.
- Mak, W.W.S., Kwok, Y.T.Y., 2010. Internalization of stigma for parents of children with autism spectrum disorder in Hong Kong. *Social Science & Medicine* (1982) 70 (12), 2045–2051. <https://doi.org/10.1016/j.socscimed.2010.02.023>.
- Minhas, A., Vajaratkar, V., Divan, G., Hamdani, S.U., Leadbitter, K., Taylor, C., et al., 2015. Parents' perspectives on care of children with autistic spectrum disorder in South Asia - Views from Pakistan and India. *Int. Rev. Psychiatry (Abingdon Engl.)* 27 (3), 247–256. <https://doi.org/10.3109/09540261.2015.1049128>.
- Mukolo, A., Heflinger, C.A., Wallston, K.A., 2010. The stigma of childhood mental disorders: a conceptual framework. *J. Am. Acad. Child Adolesc. Psychiatry* 49 (2), 92–103 quiz 198.
- Russell, P.S.S., Daniel, A., Russell, S., Mammen, P., Abel, J.S., Raj, L.E., et al., 2010. Diagnostic accuracy, reliability and validity of Childhood Autism Rating Scale in India. *World J. Pediatr.: WJP* 6 (2), 141–147. <https://doi.org/10.1007/s12519-010-0029-y>.
- Schopler, E., Reichler, R.J., DeVellis, R.F., Daly, K., 1980. Toward objective classification of childhood autism: Childhood Autism Rating Scale (CARS). *J. Autism Dev. Disord.* 10 (1), 91–103.
- Zhou, T., Wang, Y., Yi, C., 2018. Affiliate stigma and depression in caregivers of children with Autism Spectrum Disorders in China: effects of self-esteem, shame and family functioning. *Psychiatry Res.* 264, 260–265. <https://doi.org/10.1016/j.psychres.2018.03.071>.
- World Health Organization, 2016. Autism Spectrum Disorders: Fact Sheet. Retrieved from <http://www.who.int/mediacentre/factsheets/autism-spectrum-disorders/en/>.