

Affiliate stigma and related factors among parents of autism spectrum condition: A pilot study from mainland China

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Abstract

Background: Autistic individuals show differences in social and behavioral performances. Autism-related stigma affects autistic children as well as their caregivers (e.g., parents). Research has shown that stigmatizing reactions from others toward caregivers of autistic children are common and that these caregivers suffer from affiliate stigma.

Aims: To examine the level of affiliate stigma among parents of autistic children and its predictive factors in mainland China.

Methods: This was a cross-sectional study involving parents of autistic children from mainland China. The sample consisted of 183 parents (mean age = 36.5 years). The measures assessed included demographic characteristics, and parents completed two questionnaires. The Social Responsiveness Scale (SRS) was used to evaluate the characteristics of children by their parent's subjective assessments, and the Affiliate Stigma Scale (ASS) was used to investigate the affiliate stigma level of parents.

Results: The affiliate stigma levels of parents of autistic children were high, and the mean score of the affect subscale was higher than those of the other subscales. The mean ASS score differed significantly between employed and unemployed parents, those aged under 40 and over 40, and high- and low-income parents. The hierarchical regression analysis showed that parents' age, monthly household income, and mean SRS score were significant predictors of the mean ASS score. The results indicated that parents of autistic children and their children need more social support and inclusion in mainland China.

Conclusion: The present study confirms the importance of studying primary caregivers (i.e., parents) in the context of traditional mainland Chinese culture. Although preliminarily, findings showed that the affiliate stigma levels of parents are high in mainland China, probably due to the influence of traditional cultural values. Moreover, considering the importance

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of autistic child characteristics, our results suggest that we should increase public knowledge of autism, enrich the general understanding of autism, and reduce the autism-related stigma of parents in mainland Chinese societies.

Keywords

Affiliate stigma, autism spectrum condition, parents

Introduction

Autism spectrum condition shows differences in social and behavioral performances, such as social communication and interactions, and restricted and repetitive behaviors, interests, and activities (American Psychiatric Association, 2013). Despite recent studies showing that individuals with autism mask these differences for proper integration into society and maintaining interpersonal relationships, an autism-related stigma persists (Botha et al., 2022; Cage et al., 2018; Perry et al., 2022). Researchers have found that parents of autistic children often encounter stigmatizing reactions from the public (Baxter, 1989; Gray, 1993). Stigma refers to a major group's negative attitude or belief against a minority group perceived as different (Corrigan, 2000). Generally, the most common type of stigma is public stigma, which refers to the general public's negative attitudes and reactions toward stigmatized individuals who are different (Corrigan & Watson, 2002). Public stigma leads to two other types of stigmas: self-stigma and affiliate stigma. Self-stigma refers to the internalization of perceived public stigma by individuals with a particular condition (Corrigan & Watson, 2002). Affiliate stigma is defined as a caregiver's internalized public stigma toward stigmatized individuals rather than based on their own qualities (Mak & Cheung, 2008). In fact, self-stigma and affiliate stigma are both evidence of the internalization of stigma by the individual, which results from a transformation of public stigma (Link & Phelan, 2001; Meyer et al., 2008). The difference between the two in autism research is that self-stigma is directed at the autistic individual, while affiliate stigma is directed at their caregiver. Autism research has thus far been primarily focused on public attitudes and the stigma internalized by autistic individuals. This study investigated the affiliate stigma, specifically the affiliate stigma of parents of autistic children in mainland China. For several reasons, (1) Chinese traditional values usually emphasize social relations and suppressing negative emotions to maintain social ties, whereas Western culture prominently emphasizes the independent self and encourages self-motional expression (Butler et al., 2007). Chinese people might suppress their feelings and blame themselves for troubling others. (2) Mainland Chinese culture is typically collectivistic, emphasizing "face" and family shame (Mak & Chen, 2006). Such culture may easily trigger individuals to internalize negative public attitudes. (3) The public has little knowledge of autism in mainland China (Yu et al., 2020). People who do

not understand autistic children's behaviors probably would not associate them with mental conditions but question their caregivers instead. This may put extra pressure on caregivers and, thus, lead to autism-related stigmatization.

Previously, affiliate stigma was mostly observed among mixed caregivers of autistic children. For example, caregivers are a mix of primary caregivers (i.e., parents) and secondary caregivers (i.e., grandparents) (Chiu et al., 2013; Lovell & Wetherell, 2018; Werner & Shulman, 2015; Wong et al., 2016). Of note, one study involving parents of autistic children found that compared to parents of children with physical or intellectual conditions, parents of autistic children had a higher level of affiliate stigma (Werner & Shulman, 2015). To our knowledge, little research has focused on the affiliate stigma of parents of autistic children in mainland China. Given the large population of autistic individuals in mainland China (Sun et al., 2019), exploring the status of affiliate stigma among parents is necessary. As mentioned above, most previous studies were conducted with mixed caregivers of autistic children. Parents are the primary caregivers for their children. They spend the longest amount of time caring for autistic children, significantly influencing them. Therefore, the present study focused on the affiliate stigma of parents of autistic children in mainland China.

Previous studies on the affiliate stigma of caregivers have focused on developmental disorders, including autism. Research has found inconsistent results regarding the relationship between caregiver affiliate stigma and sociodemographic factors. Some studies have shown that sociodemographic variables are not associated with affiliate stigma. For example, affiliate stigma does not vary with caregiver gender (Mak & Cheung, 2008), education level (Chiu et al., 2013), parents' age, or children's age (Mak & Kwok, 2010). Other studies have demonstrated that sociodemographic variables, such as being an older caregiver and being a caregiver of older children, are associated with affiliate stigma (Chiu et al., 2013; Mak & Kwok, 2010). The relationship between affiliate stigma and sociodemographic variables, especially for parents of autistic children, remains to be examined.

Another critical factor closely related to stigma is autistic characteristics. Chinese people, as previously discussed, might have negative attitudes toward autistic individuals due to misconceptions about their behavior. Gray and

colleagues (2002) found that most parents thought those around them considered them to be different because their child was autistic. Parents reported that their children were disinterested in social interactions and felt socially isolated (Woodgate et al., 2008). They believed others were critical of their parenting abilities and were not accepting of them, which embarrassed them. The stigma associated with autism comes from the public's construction of autism from the perspective of a disorder rather than neurodiversity (Kapp et al., 2013; Ridout, 2017). The public misperceptions about children's autism-related behaviors lead to poor understanding and acceptance (Kinnear et al., 2016). As a result, the more prominent the characteristics of autistic children in the social environment, the more susceptible parents are to the effect of public stigma, which may influence their affiliate stigma. This may also be why the emphasis is placed on engaging in pleasant and frequent interactions with autistic individuals in a social environment (Kim et al., 2022). Caregiver-affiliate stigma arises from the perception and internalization of public stigma (Mak & Cheung, 2008; Mitter et al., 2019). Parent's perceptions of their children's characteristics may contribute to the formation of affiliate stigma. One of the reasons is that autistic characteristics may trigger negative attitudes and treatment from others, thus, will impart caregivers' well-being and social behaviors (Turnock et al., 2022; Werner & Shulman, 2013) and trigger them to develop affiliate stigma. However, few studies have focused on the direct relationship between children's autistic characteristics on parents' affiliate stigma. Understanding this relationship can help facilitate social support and inform effective interventions to reduce affiliate stigma.

Thus, the goal of the present study was to expand research on affiliate stigma toward parents of autistic children in mainland China. We aimed to (1) determine the level of affiliate stigma among parents of autistic children in mainland China and (2) identify the parent- or child-related factors that predict affiliate stigma in mainland China. This study would further complement the research on affiliate stigma. Moreover, it would provide preliminary data support for reducing autism-related stigma in mainland Chinese society.

Methods

Participants

A total of 197 participants completed an online survey. Participants were recruited from autism services in mainland China (Anhui Province, Beijing, Guangdong Province, Shanghai City, Zhejiang Province). The inclusion criteria were as follows: (1) children with autism diagnosed by a licensed clinician, (2) children aged 4–18 years old, and (3) children whose parents were as eligible guardians.

Eligible parents signed written consent forms and completed questionnaires about themselves and their children. The participants were informed that their answers would be anonymous and that they would receive payment for their participation.

We excluded 14 participants (social demographics, $n = 10$ and missing data, $n = 4$) who did not finish the survey, resulting in a final sample of 183 participants. We used G*Power (Faul et al., 2007) to test sample size and effect size. With a power of 0.80, 159 participants are required for a medium effect size of 0.25. The number of participants in this study exceeded the minimum sample size. The Institutional Review Board and Ethics Committee of Human Participant Protection, Faculty of Psychology at Beijing Normal University approved the study.

Measures

Social Responsiveness Scale. The Social Responsiveness Scale (SRS) was developed by Constantino and validated in autism (Constantino et al., 2003). It comprises 65 items divided into five subscales: social awareness, social cognition, social communication, social motivation, and autistic mannerisms. Items examples include the following: "Walks between people who are talking"; "Takes things too literally"; "Difficulty making friends"; "Is too tense in social settings"; and "Has repetitive, odd behaviors." The scale was designed to assess the characteristics of autistic children aged 4–18 years. The SRS uses a 4-point Likert-type scale, with responses reported by caregivers according to how often each behavior occurs (0 = not true, 1 = sometimes true, 2 = often true, 3 = always true). A higher score indicates more characteristics of autism. The Chinese version of the SRS has been proven to have good reliability, internal consistency, and convergent validity, with Cronbach's $\alpha = 0.95$ (Gau et al., 2013). In the present study, Cronbach's $\alpha = 0.84$.

Affiliate stigma scale. We used the Chinese version of the Affiliate Stigma Scale (ASS), which was developed by Mak et al. (2009) and validated for caregivers of autistic children (Mak & Kwok, 2010). The ASS comprises 22 items with three domains: Affect, Behavior, and Cognitive. Example items include the following: "I feel emotionally disturbed because I have a family member with autism"; "Given that I have a family member with autism, I've cut down on contacts with my neighbors"; and "Having a family member with autism imposes a negative impact on me." For each item, parents self-rated their agreement from 1 (strongly disagree) to 4 (strongly agree) using a 4-point Likert scale. A higher score indicates that caregivers have a higher level of self-stigma. The ASS has excellent internal consistency with a Cronbach's $\alpha = 0.87$ for the Affect domain score, 0.85 for the Behavior domain score, 0.90 for the Cognitive domain

score, and 0.94 for the total score (Chang et al., 2015). In the current study, Cronbach's alpha was 0.88 for the Affect domain score, 0.86 for the Behavior domain score, 0.85 for the Cognitive domain score, and 0.93 for the total score.

Sociodemographic variables. We selected age, gender, location, employment, education, monthly household income, and family type as sociodemographic variables based on studies investigating affiliate stigma in other caregiving populations (Mak & Cheung, 2008).

Sociodemographic variables included age, gender, location, employment, education, monthly household income, and family type. The age of the children was recoded into three categories, 4–7 years (preschool), 8–12 years (primary school), and 13–18 years (secondary school), which were based on the education schedule in mainland China (Alshaigi et al., 2020; Song et al., 2020). Parent age was recoded into two categories, under 40 and above

40 years, based on population research in China (Luo, 2017). Employment was recoded into employed and not employed. Education was recoded into three levels: elementary (namely, from preschool to middle school), secondary (namely, professional schools), and higher education (university bachelor's, master's, and doctoral degree programs). Monthly household income was recoded into three levels: lower (namely, <RMB5000), middle (RMB5000-10000), and upper (\geq RMB 10000). The family type was recoded into three types: a joint family (grandparents, father, mother, and children), a core family (two parents and their children), and a single-family (one parent and his or her child).

Data analyses

The data were inputted into and analyzed using the Statistical Package for Social Science (SPSS) version 19.0 (SPSS, Inc., Chicago, IL, USA). Descriptive statistical analysis was used for the primary sociodemographic variables data. The mean score and standard deviation of the SRS and ASS were calculated. The reliability of the SRS and ASS was evaluated with Cronbach's alpha. Independent *t*-tests and analysis of variance (ANOVA) were used to investigate the differences between the sociodemographic variables in the ASS scores. We performed a correlation analysis between variables. Finally, regression analysis was conducted to evaluate the relationship between each variable and affiliate stigma. Statistical significances reported in the present study are at the level of $p < .05$.

Results

The mean score and standard deviation of the SRS and ASS were calculated. Independent *t*-tests and analyses of variance were used to investigate the differences between the demographic variables in the ASS scores. We also performed a correlation analysis (parents' variables of gender, age, location, education, employment, income, family type, and mean ASS score and children's variables of age, gender, and mean SRS score). Finally, linear regression analysis was conducted to evaluate the relationship between each variable and affiliate stigma.

Sample characteristics

Table 1 shows the demographic characteristics of the parents and children. The mean age of the children was 8.4 years ($SD = 3.51$, range = 4–18), and 58.5% were male. The mean age of the parents was 36.5 years ($SD = 6.04$, range = 26–60). Mothers accounted for 55.7% of the parents. A total of 84.2% of the parents were under 40 years old, and 83.1% lived in urban areas. 51.4% of the parents had a higher education degree (i.e., bachelor's degree or above).

Table 1. Sociodemographic characteristics of participants.

Variable	<i>n</i>	%
Children		
Gender		
Male	107	58.5
Female	76	41.5
Age		
4–7	88	48.1
8–12	69	37.7
≥ 13	26	14.2
Parents		
Gender		
Father	81	44.3
Mother	102	55.7
Age		
< 40	154	84.2
≥ 40	29	15.8
Location		
Urban	152	83.1
Rural	31	16.9
Employment		
Employed	123	67.2
Not employed	60	32.8
Education		
High	94	51.4
Secondary	58	31.7
Elementary	31	16.9
Income		
Upper	63	34.4
Middle	72	39.3
Lower	48	26.2
Family		
Joint family	87	47.5
Core family	87	47.5
Single family	9	4.9

Affiliate stigma results

The independent *t*-test results showed that the mean ASS score of the parents differed significantly between employed and unemployed individuals ($t(181) = 2.26, p = .03$, Cohen's $d = 0.34$) and between those aged under 40 and over 40 years ($t(181) = 2.23, p = .03$, Cohen's $d = 0.33$). The mean ASS score did not differ significantly based on the gender of the parents ($t(181) = 0.75, p = .46$), the gender of children with ASC ($t(181) = 1.24, p = .22$) or location ($t(181) = 1.49, p = 0.14$).

The results of one-way ANOVA revealed a marginal main effect of monthly household income on the mean ASS score ($F(2,180) = 2.87, p = .06, \eta_p^2 = 0.031$), and the least significant difference (LSD) post-hoc test revealed a significant difference between high- and low-income individuals ($p = .02$).

Age had a marginal main effect on the mean ASS score ($F(2,180) = 2.83, p = .06, \eta_p^2 = 0.03$). The LSD post-hoc test revealed that the mean ASS score in children aged 13–18 years was much higher than that in children aged 4–7 ($p = .03$) and 8–12 years ($p = .03$). There was no significant difference in the mean ASS score based on education level or family ($F_{education}(2,180) = 1.39, p_{education} = .25, F_{family}(2,180) = 0.12, p_{family} = .89$, respectively).

We used repeated-measures ANOVA to assess the difference among the three subscales of the ASS. According to the box plot, there was no difference in the subscale scores. The Shapiro–Wilk test revealed that the data from each group were distributed normally ($p = .75$). Mauchly's spherical hypothesis test indicated that the dependent variable's variance-covariance matrix was not equal ($\chi^2(2) = 63.27, p < .001$), which we corrected using the Greenhouse and Geisser method. One-way repeated-measures ANOVA revealed significant differences in the three subscales of the ASS ($F(2,180) = 40.48, p < .001, \eta_p^2 = 0.31$). The LSD post-hoc test showed that the mean score of the affect subscale was significantly higher than the scores of the behavior ($p < .001$) and cognition subscales ($p < .001$).

Correlation analysis

As shown in Table 2, we assessed the associations between demographic and primary study variables with Pearson and Spearman correlation analyses. Spearman correlation analysis showed that the parent's employment status, monthly household income, and age were significantly positively correlated with the mean ASS score ($r = .18, p = .02$; $r = .17, p = .02$; $r = -.15, p = .04$, respectively). Pearson correlation analysis showed that the mean SRS score was significantly positively correlated with the mean ASS score ($r = .22, p = .003$). The other demographic variables were not significantly associated with the mean ASS score.

Regression for the parents' ASS scores

Hierarchical regression analyses were conducted to examine the predictive validity of autistic characteristics on affiliate stigma by step-to-step entering age, income, employment, and autistic characteristics (Table 3). The results showed that the parents' age, income, and mean SRS score were significant predictors of the mean ASS score. No other variables or models were significant in predicting the mean ASS score. These data suggest that parents who (a) were older, (b) had higher income, and (c) had children with prominent characteristics of autism were at greater risk for affiliate stigma.

Discussion

The present study focused on affiliate stigma among parents of autistic children in mainland China. We had two main findings: (a) the parents' age, monthly household income, and autistic characteristics were predictors of affiliate stigma, and (b) parents of autistic children were experiencing severe affiliate stigma in mainland China.

Factors that affect affiliate stigma among parents

The present study explored the factors related to affiliate stigma among parents of autistic children in mainland China. We identified three factors (i.e., parents' age, monthly household income, and children's characteristics) predicting affiliate stigma toward parents.

Parents' Age. Inconsistent results were reported in previous studies. Singh et al. (2016) found that parents' age was associated with the level of affiliate stigma. However, no correlations between parents' age and affiliate stigma of parents were reported in other studies (e.g., Lovell & Wetherell, 2018; Mak & Cheung, 2008; Mak & Kwok, 2010; Werner & Shulman, 2015). In the present study, we found that the affiliate stigma of younger parents was higher than that of older parents. Cultural differences might partly account for the inconsistency. Chinese culture emphasizes family responsibility (Stalder, 1996), and the public tends to attribute children's problems to poor parenting (Werner & Shulman, 2013). Moreover, Confucianism greatly influences Chinese culture, emphasizing the importance of different age group. It places a more excellent value and emphasis on age group, such as "at 30, standing firmly in one's convictions; at 40, being free of confusion; at 50, understanding one's destiny" in "Lun Yu" (Confucius, 300 BC; see the translated version by Edward Slingerland, 2006. The essential Analects: Selected passages with traditional commentary). Recent research also revealed a significant age gap between those under 40 and those over 40 (Luo, 2017). Younger parents may be more inclined to seek the approval of others and uphold a favorable reputation, while older parents

Table 2. Correlation between measures.

Variable	M	SD	1	2	3	4	5	6	7	8	9	10	11
Parents													
1.Gender			-										
2.Age	36.5	6.04	-.07	-									
3.Location			-.02	-.00	-								
4.Education			-.02	-.10	.30**	-							
5.Employment			.06	-.11	.27**	.38**	-						
6.Income			-.12	-.13	.25**	.38**	.22**	-					
7.Family			-.11	.13	-.07	.05	.09	.15*	-				
8.AS mean score	2.3	0.5	.06	-.15*	.12	.06	.18*	.17*	-.02	-			
Children													
9.Age	8.4	3.5	-.05	.34**	-.16	-.09	-.08	-.14	-.03	-.11	-		
10.Gender			.22**	-.12	-.00	.06	.09	.09	-.02	.09	.01	-	
11.SRS mean score	1.4	0.2	-.08	-.09	-.11	-.09	.12	.07	-.05	.22**	-.05	-.06	-

Note. The following variables were dummy coded: gender (1 = female), location (1 = urban), education (1 = high), employment (1 = employed), income (1 = upper), and family (1 = core family). One is the reference category for dummy coded variables.

* $p < .05$, ** $p < .01$.

Table 3. Hierarchical regression output for ASS mean score.

	Step 1	Step 2	Step 3	Step 4
	β	β	β	β
Parents age	-.022*	-.020	-.018	-.018
Income		0.10*	0.09	0.09
Employment			0.13	0.11
SRS mean score				0.46**
F	4.95*	4.92**	4.19**	5.28**
R ²	0.027	0.052	0.066	0.106
Adjusted R ²	0.021	0.041	0.050	0.086
R ² change	0.027	0.025	0.014	0.041

Note. The following variables were dummy coded: parents' age (1 = over 40), income (1 = upper), and employment (1 = employed). One is the reference category for dummy coded variables.

* $p < .05$, ** $p < .01$.

may be less concerned with how others perceive them. Reassuringly, attitudes toward autism have shifted from a deficit model to a neurodiversity perspective (Botha et al., 2022). This shift comes mainly from an increased understanding of the science behind autism and growing acceptance of diversity in general.

Another possible explanation for this discrepancy may be different ranges of participants. The current study focuses on primary caregivers of autistic children only. However, the previous studies were on parents of children with needs, not restricted to autistic children. Research has reported that caregivers of autistic children have higher levels of affiliate stigma than caregivers of children with intellectual conditions (Lovell & Wetherell, 2018).

Household income. The present study showed that parents with high-income suffered more severe affiliate stigma than parents with low-income and unemployed parents. This result is consistent with the study of Ngo et al. (2012), which showed that caregivers of higher

socioeconomic status perceived and internalized more stigma than those of lower socioeconomic status. This result was inconsistent with some prior research (Werner & Shulman, 2015; Zhou et al., 2018), which showed no relationship with family income. This inconsistency might be partly explained by socioeconomic status. High socioeconomic status individuals are more engaged in social and economic activities (Tora et al., 2011). It is generally the case that wealthier households are more committed to maintaining the current status and normative behaviors to follow the social norms in their activities. In this way, wealthier families might face more rigid social standards than those with lower incomes. They may be more sensitive to negative evaluations and attitudes from others due to being judged by others for being different from their children (Gray, 2002). This result indicated that the public urgently needs to increase autism awareness and understanding in mainland China. Provide social support, assistance, and acceptance to parents of autistic children, and give them the courage to expose their children to seek help to integrate into society better.

Autistic characteristics. We found that autistic characteristics were predictors of affiliate stigma toward parents in mainland China. This finding indicated that the more obvious the autistic characteristics of children, the greater the stigma attached to their families. It is a novel predictor that has not been reported in previous studies. This result indicated that parents' evaluation of autistic characteristics of their children directly affected parents' affiliate stigma. It is common for the public to evaluate the behavior of a minority group (such as an individual with autism) based on the majority group's social norms without considering neurodiversity, which is human variation characterized by diversity in the brain (Botha et al., 2022; Kapp et al., 2013). Also, parents may not consider the neurodiverse perspective of children with autism, resulting in the more

prominent the parents' evaluation of autistic characteristics, the greater the risk of affiliate stigma. Indeed, parents' positive views could influence their children's social connections and reduce their affiliate stigma because they would no longer consider their children's behavior to be "abnormal" (Jaswal et al., 2020). Moreover, stigma is a social-constructed product derived from social interactions between the individual self and others (Yang et al., 2007). The present study used parents' self-reported characteristics of their children, describing the event in a social context (e.g., not interacting with others). Consequently, parents may worry about rejection and prejudice when their children display different behaviors in social situations. Due to their close relationships with their children, parents consciously or unconsciously internalize the discrimination and prejudice they encounter from others and slowly form affiliate stigma. Mainly, this result may be closely related to Chinese culture. A recent cross-cultural comparative study showed that autism stigma is different between different cultural settings, which is a greater degree of autism stigma is more likely to occur in collectivist cultural contexts (Kim et al., 2022). The typical characteristic of Chinese culture is collectivism, and Chinese people pay more attention to "face" (Yang, 2015). The self-reporting of parents whose children's characteristics differed from those of typical children may feel "face loss" (i.e., embarrassed) and negatively impact their self-esteem, leading to parents' automatic and unconscious production of affiliate stigma. It should be noted that we have made the above possible explanation of the prediction of the autistic characteristics to the affiliate stigma. Still, the explanatory variables are responsible for a small percentage (8.6%) of affiliate stigma, which is necessary to emphasize. In other words, the effect of children's characteristics on affiliate stigma is small, and there are likely to be other variables influencing it more, such as traditional culture, "face concern," community services, and social support. Future studies could explore the possible factors that affect affiliate stigma in the context of mainland Chinese culture.

In addition, we found that the scores of affiliate stigma among parents differed across the three subscales of cognition (e.g., "Other people would discriminate against me if I am with a child with autism," "Having a child with autism imposes a negative impact on me"), affect (e.g., "I feel inferior because my child has autism," "I feel helpless for having an autistic child"), and behavior (e.g., "I limit going out with my child with autism," "I do not date to tell others that I have a child with autism"). Scores on the affect subscale of affiliate stigma were higher than scores on the behavioral and cognitive subscales. This intriguing finding could result from "face concern" cognition in Chinese culture. Concerns about losing "face" are a unique Chinese cultural concept representing the loss of respect and status in society (Chiu et al., 2014; Lu et al., 2015; Mak & Chen, 2006; Mak & Cheung, 2008).

Parents of autistic children who were worried about losing face and being isolated from society received higher scores on the affect subscale with higher scores, which could explain why the parents resisted seeking treatment and social and professional support (Gill & Liamputtong, 2011). Based on the findings between autistic characteristics and affiliate stigma relationship, we suggest increasing autism knowledge in the public because misunderstanding autism would lead to more significant autism stigma (Kim et al., 2022). At the same time, we suggest improving public education about autism and fostering counter-stereotypes about autism, shifting the general people's perception of autism as a disorder and replacing it with a neurodiversity continuum (Cage et al., 2018; Kapp et al., 2013). Furthermore, to reduce stigma, social-based social contact interventions should be employed to create a good social space with the participation of autistic individuals and their families due to stigma being generated in social interaction (Link & Phelan, 2001). Previous research showed that social contact-based interventions reduce public stigma and promote interpersonal interaction (Corrigan et al., 2003).

The level of affiliate stigma toward parents in mainland China

The present study is the first conducted in mainland China, and it is of great interest to compare our results to previous results from the Hong Kong region and Western countries.

As we did not specifically analyze the differences between the current results and previous studies, the discussion regarding these differences should be considered with caution. Similar to previous research in Hong Kong (Mak & Cheung, 2008; Mak & Kwok, 2010), our participants' affiliate stigma was relatively high in mainland China. This finding is also in line with three systematic reviews (Ali et al., 2012; Mitter et al., 2019; Werner et al., 2012), indicating that family members in Asian countries are mainly subjected to adverse treatment by members of their community and family (Ali et al., 2012). However, these results are not similar to those of previous studies from Western countries (Recio et al., 2020; Werner & Shulman, 2015), which showed low values. The difference may result from different cultural contexts and social representations of disability. Asian countries were more interested in family stigma than public stigma research, according to Western studies (Werner et al., 2012). Another possible explanation is a different way of thinking about things. Western culture is characterized by individualism and analytical thinking (Nisbett et al., 2001). However, the culture of mainland China is characterized by collectivism and holistic thinking, which emphasizes social evaluation, the evaluation of others, and a strong sense of social and family responsibility (Stalder, 1996). As a result, others see children with disabilities as "bad seeds" (with bad genes) who bring shame to their families

(Sue & Sue, 1987), making it easier to blame the behavior of autistic children on their parents (Wong et al., 2016). This finding may provide essential data support within a mainland Chinese cultural context for the anti-stigma intervention, which may be based on specific cultures such as face culture. Meanwhile, autistic people have gradually integrated into mainland China's public health care system. It still needs to strengthen community support and general publicity to reduce the stigma associated with autism.

Limitations

This study had a few limitations. First, the samples were drawn from training institutions for children with ASC, not ordinary schools. The selection criteria can lead to bias in the analysis and results. Second, this study's selection of factors influencing affiliate stigma was limited because it is a preliminary investigation. Future studies should consider more variables to explore the factors influencing affiliate stigma. Finally, this study used parents' self-reports, which indicate subjective evaluation, to predict affiliate stigma. Nevertheless, there is a lack of data for assessing how these feelings translate into specific interactions with the child or affect family functioning, which future research should consider.

Conclusions

Findings from this sample showed that parents of autistic children have a high affiliate stigma level in mainland China, especially since the emotional aspect of affiliate stigma is more prominent than the others. Our findings extend the existing literature by revealing affiliate stigma-related factors of parents of autistic children in mainland China's geographical and cultural context. The most significant results were that parents' age, monthly household income, and autistic characteristics affected parents' affiliate stigma. It indicated an urgent need to expand the knowledge of autism in mainland China so that the public and parents themselves may better understand the characteristics of autism to reduce autism-related stigma and promote the social integration of autistic individuals.

Declaration of conflicting interests


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References

- Ali, A., Hassiotis, A., Strydom, A., & King, M. (2012). Self stigma in people with intellectual disabilities and courtesy stigma in family carers: A systematic review. *Research in Developmental Disabilities, 33*(6), 2122–2140. <https://doi.org/10.1016/j.ridd.2012.06.013>
- Alshaigi, K., Albraheem, R., Alsaleem, K., Zakaria, M., Jobeir, A., & Aldhalaan, H. (2020). Stigmatization among parents of autism spectrum disorder children in Riyadh, Saudi Arabia. *International Journal of Pediatrics & Adolescent Medicine, 7*(3), 140–146. <https://doi.org/10.1016/j.ijpam.2019.06.003>
- American Psychiatric Association (2013). *Diagnostic and statistical manual of mental disorders*. American Psychiatric Association.
- Baxter, C. (1989). Investigating stigma as stress in social interactions of parents. *Journal of Mental Deficiency Research, 33*(Pt 6), 455–466. <https://doi.org/10.1111/j.1365-2788.1989.tb01501.x>
- Botha, M., Dibb, B., & Frost, D. M. (2022). “Autism is me”: An investigation of how autistic individuals make sense of autism and stigma. *Disability & Society, 37*(3), 427–453 <https://doi.org/10.1080/09687599.2020.1822782>.
- Butler, E. A., Lee, T. L., & Gross, J. J. (2007). Emotion regulation and culture: Are the social consequences of emotion suppression culture-specific? *Emotion, 7*(1), 30–48. <https://doi.org/10.1037/1528-3542.7.1.30>
- Cage, E., Di Monaco, J., & Newell, V. (2018). Experiences of autism acceptance and mental health in autistic adults. *Journal of Autism and Developmental Disorders, 48*(2), 473–484. <https://doi.org/10.1007/s10803-017-3342-7>
- Chang, C. C., Su, J. A., Tsai, C. S., Yen, C. F., Liu, J. H., & Lin, C. Y. (2015). Rasch analysis suggested three unidimensional domains for affiliate stigma scale: Additional psychometric evaluation. *Journal of Clinical Epidemiology, 68*(6), 674–683. <https://doi.org/10.1016/j.jclinepi.2015.01.018>
- Chiu, M. Y. L., Yang, X., Wong, F. H. T., Li, J. H., & Li, J. (2013). Caregiving of children with intellectual disabilities in China - an examination of affiliate stigma and the cultural thesis: Chinese caregivers - stigma and cultural thesis. *Journal of Intellectual Disability Research: JIDR, 57*(12), 1117–1129. <https://doi.org/10.1111/j.1365-2788.2012.01624.x>
- Chiu, M. Y. L., Yang, X., Wong, H. T., & Li, J. H. (2014). The mediating effect of affective stigma between face concern and general mental health - the case of Chinese caregivers of children with intellectual disability. *Research in Developmental Disabilities, 36*(6), 437–446. <https://doi.org/10.1016/j.ridd.2014.10.024>
- Constantino, J. N., Davis, S. A., Todd, R. D., Schindler, M. K., Gross, M. M., Brophy, S. L., Metzger, L. M., Shoushtari, C. S., Splinter, R., & Reich, W. (2003). Validation of a brief quantitative measure of autistic traits: Comparison of the social responsiveness scale

- with the autism diagnostic interview-revised. *Journal of Autism and Developmental Disorders*, 33(4), 427–433. <https://doi.org/10.1023/a:1025014929212>
- Corrigan, P., Markowitz, F. E., Watson, A., Rowan, D., & Kubiak, M. A. (2003). An attribution model of public discrimination towards persons with mental illness. *Journal of Health and Social Behavior*, 44(2), 162–179. <https://doi.org/10.2307/1519806>
- Corrigan, P. W. (2000). Mental health stigma as social attribution: Implications for research methods and attitude change. *Clinical Psychology: A Publication of the Division of Clinical Psychology of the American Psychological Association*, 7(1), 48–67. <https://doi.org/10.1093/clipsy.7.1.48>
- Corrigan, P. W., & Watson, A. C. (2002). The paradox of self-stigma and mental illness. *Clinical Psychology: A Publication of the Division of Clinical Psychology of the American Psychological Association*, 9(1), 35–53. <https://doi.org/10.1093/clipsy.9.1.35>
- Faul, F., Erdfelder, E., Lang, A. G., & Buchner, A. (2007). G*Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods*, 39(2), 175–191. <https://doi.org/10.3758/bf03193146>
- Gau, S. S. F., Liu, L. T., Wu, Y. Y., Chiu, Y. N., & Tsai, W. C. (2013). Psychometric properties of the Chinese version of the Social Responsiveness Scale. *Research in Autism Spectrum Disorders*, 7(2), 349–360. <http://dx.doi.org/10.1016/j.rasd.2012.10.004>
- Gill, J., & Liamputtong, P. (2011). Being the mother of a child with Asperger's syndrome: Women's experiences of stigma. *Health Care for Women International*, 32(8), 708–722. <https://doi.org/10.1080/07399332.2011.555830>
- Gray, D. E. (1993). Perceptions of stigma: The parents of autistic children. *Sociology of Health & Illness*, 15(1), 102–120. <https://doi.org/10.1111/1467-9566.ep11343802>
- Gray, D. E. (2002). Everybody just freezes. Everybody is just embarrassed": Felt and enacted stigma among parents of children with high functioning autism. *Sociology of Health & Illness*, 24(6), 734–749. <https://doi.org/10.1111/1467-9566.00316>
- Jaswal, V. K., Dinishak, J., Stephan, C., & Akhtar, N. (2020). Experiencing social connection: A qualitative study of mothers of nonspeaking autistic children. *PLoS One*, 15(11), e0242661. <https://doi.org/10.1371/journal.pone.0242661>
- Kapp, S. K., Gillespie Lynch, K., Sherman, L. E., & Hutman, T. (2013). Deficit, difference, or both? Autism and neurodiversity. *Developmental Psychology*, 49(1), 59–71. <https://doi.org/10.1037/a0028353>
- Kim, S. Y., Cheon, J. E., Gillespie Lynch, K., & Kim, Y. H. (2022). Is autism stigma higher in South Korea than the United States? Examining cultural tightness, intergroup bias, and concerns about heredity as contributors to heightened autism stigma. *Autism: The International Journal of Research and Practice*, 26(2), 460–472. <https://doi.org/10.1177/13623613211029520>
- Kinney, S. H., Link, B. G., Ballan, M. S., & Fischbach, R. L. (2016). Understanding the experience of stigma for parents of children with autism spectrum disorder and the role stigma plays in families' lives. *Journal of Autism and Developmental Disorders*, 46(3), 942–953. <https://doi.org/10.1007/s10803-015-2637-9>
- Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual Review of Sociology*, 27(1), 363–385. <https://doi.org/10.1146/annurev.soc.27.1.363>
- Lovell, B., & Wetherell, M. A. (2018). Caregivers' characteristics and family constellation variables as predictors of affiliate stigma in caregivers of children with ASD. *Psychiatry Research*, 270, 426–429. <https://doi.org/10.1016/j.psychres.2018.09.055>
- Lu, M., Yang, G., Skora, E., Wang, G., Cai, Y., Sun, Q., & Li, W. (2015). Self-esteem, social support, and life satisfaction in Chinese parents of children with autism spectrum disorder. *Research in Autism Spectrum Disorders*, 17, 70–77. <https://doi.org/10.1016/j.rasd.2015.05.003>
- Luo, C. (2017). Re-partitioning population age group and its implications. *Population Research (in Chinese)*, 41(5), 16–25.
- Mak, W. W. S., & Cheung, R. Y. M. (2008). Affiliate stigma among caregivers of people with intellectual disability or mental illness. *Journal of Applied Research in Intellectual Disabilities*, 21(6), 532–545. <http://dx.doi.org/10.1111/jar.2008.21.issue-6>
- Mak, W. W. S., & Chen, S. X. (2006). Face concern: Its role on stress–distress relationships among Chinese Americans. *Personality and Individual Differences*, 41(1), 143–153. <https://doi.org/10.1016/j.paid.2005.12.016>
- Mak, W. W. S., Chen, S. X., Lam, A. G., & Yiu, V. F. L. (2009). Understanding distress: The role of face concern among Chinese Americans, European Americans, Hong Kong Chinese, and mainland Chinese. *The Counseling Psychologist*, 37(2), 219–248. <https://doi.org/10.1177/0011000008316378>
- Mak, W. W. S., & Cheung, R. Y. M. (2008). Affiliate stigma among caregivers of people with intellectual disability or mental illness. *Journal of Applied Research in Intellectual Disabilities: JARID*, 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>
- Meyer, I. H., Schwartz, S., & Frost, D. M. (2008). Social patterning of stress and coping: Does disadvantaged social statuses confer more stress and fewer coping resources? *Social Science & Medicine (1982)*, 67(3), 368–379. <https://doi.org/10.1016/j.socscimed.2008.03.012>
- Mitter, N., Ali, A., & Scior, K. (2019). Stigma experienced by families of individuals with intellectual disabilities and autism: A systematic review. *Research in Developmental Disabilities*, 89, 10–21. <https://doi.org/10.1016/j.ridd.2019.03.001>
- Ngo, H., Shin, J. Y., Nhan, N. V., & Yang, L. H. (2012). Stigma and restriction on the social life of families of children with intellectual disabilities in Vietnam. *Singapore Medical Journal*, 53(7), 451–457.
- Nisbett, R. E., Peng, K., Choi, I., & Norenzayan, A. (2001). Culture and systems of thought: Holistic versus analytic cognition. *Psychological Review*, 108(2), 291–310. <https://doi.org/10.1037/0033-295x.108.2.291>
- Perry, E., Mandy, W., Hull, L., & Cage, E. (2022). Understanding camouflaging as a response to autism-related stigma: A social

- identity theory approach. *Journal of Autism and Developmental Disorders*, 52(2), 800–810. <https://doi.org/10.1007/s10803-021-04987-w>
- Recio, P., Molero, F., García Ael, C., & Pérez Garín, D. (2020). Perceived discrimination and self-esteem among family caregivers of children with autism spectrum disorders (ASD) and children with intellectual disabilities (ID) in Spain: The mediational role of affiliate stigma and social support. *Research in Developmental Disabilities*, 105(103737), 103737. <https://doi.org/10.1016/j.ridd.2020.103737>
- Ridout, S. (2017). The autistic voice and creative methodologies. *Qualitative Research Journal*, 17(1), 52–64. <https://doi.org/10.1108/QRJ-07-2016-0046>
- Singh, A., Mattoo, S. K., & Grover, S. (2016). Stigma and its correlates among caregivers of schizophrenia: A study from North India. *Psychiatry Research*, 241, 302–308.
- Song, Z., Wang, C., & Bergmann, L. (2020). China's prefectural digital divide: Spatial analysis and multivariate determinants of ICT diffusion. *International Journal of Information Management*, 52(102072), 102072. <https://doi.org/10.1016/j.ijinfomgt.2020.102072>
- Stalder, D. R. (1996). Review of individualism and collectivism: Theory, method, and applications. *Contemporary Psychology*, 41(12), 1219–1219. <https://doi.org/10.1037/003295>
- Sue, D., & Sue, S. (1987). Cultural factors in the clinical assessment of Asian Americans. *Journal of Consulting and Clinical Psychology*, 55(4), 479–487. <https://doi.org/10.1037/0022-006X.55.4.479>
- Sun, X., Allison, C., Wei, L., Matthews, F. E., Auyeung, B., Wu, Y. Y., Griffiths, S., Zhang, J., Baron-Cohen, S., & Brayne, C. (2019). Autism prevalence in China is comparable to western prevalence. *Molecular Autism*, 10(1), 7. <https://doi.org/10.1186/s13229-018-0246-0>
- Tora, A., Davey, G., & Tadele, G. (2011). A qualitative study on stigma and coping strategies of patients with podocoinosis in Wolaita zone, Southern Ethiopia. *International Health*, 3(3), 176–181. <https://doi.org/10.1016/j.inhe.2011.06.006>
- Turnock, A., Langley, K., & Jones, C. R. G. (2022). Understanding stigma in autism: A narrative review and theoretical model. *Autism in Adulthood Knowledge Practice and Policy*, 4(1), 76–91. <https://doi.org/10.1089/aut.2021.0005>
- Werner, S., Corrigan, P., Ditchman, N., & Sokol, K. (2012). Stigma and intellectual disability: A review of related measures and future directions. *Research in Developmental Disabilities*, 33(2), 748–765. <https://doi.org/10.1016/j.ridd.2011.10.009>
- Werner, S., & Shulman, C. (2013). Subjective well-being among family caregivers of individuals with developmental disabilities: The role of affiliate stigma and psychosocial moderating variables. *Research in Developmental Disabilities*, 34(11), 4103–4114. <https://doi.org/10.1016/j.ridd.2013.08.029>
- Werner, S., & Shulman, C. (2015). Does type of disability make a difference in affiliate stigma among family caregivers of individuals with autism, intellectual disability or physical disability?: Affiliate stigma in developmental disability. *Journal of Intellectual Disability Research: JIDR*, 59(3), 272–283. <https://doi.org/10.1111/jir.12136>
- Wong, C. C. Y., Mak, W. W. S., & Liao, K. Y. H. (2016). Self-compassion: A potential buffer against affiliate stigma experienced by parents of children with autism spectrum disorders. *Mindfulness*, 7(6), 1385–1395. <https://doi.org/10.1007/s12671-016-0580-2>
- Woodgate, R. L., Ateah, C., & Secco, L. (2008). Living in a world of our own: The experience of parents who have a child with autism. *Qualitative Health Research*, 18(8), 1075–1083. <https://doi.org/10.1177/1049732308320112>
- Yang, L. H., Kleinman, A., Link, B. G., Phelan, J. C., Lee, S., & Good, B. (2007). Culture and stigma: Adding moral experience to stigma theory. *Social Science & Medicine* (1982), 64(7), 1524–1535. <https://doi.org/10.1016/j.socscimed.2006.11.013>
- Yang, X. (2015). No matter how I think, it already hurts: Self-stigmatized feelings and face concern of Chinese caregivers of people with intellectual disabilities. *Journal of Intellectual Disabilities: JOID*, 19(4), 367–380. <https://doi.org/10.1177/1744629515577909>
- Yu, L., Stronach, S., & Harrison, A. J. (2020). Public knowledge and stigma of autism spectrum disorder: Comparing China with the United States. *Autism: The International Journal of Research and Practice*, 24(6), 1531–1545. <https://doi.org/10.1177/1362361319900839>
- 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 Research*, 264, 260–265. <https://doi.org/10.1016/j.psychres.2018.03.071>