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Affiliate stigma and depression in caregivers of children with Autism Spectrum Disorders in China: Effects of self-esteem, shame and family functioning



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ABSTRACT

The present study aimed to investigate affiliate stigma and depression in caregivers of children with Autism Spectrum Disorders (ASD) in China and to examine the predictive effects of self-esteem, shame proneness and family functioning. Two hundred and sixty-three primary caregivers of children with autism in Mainland China participated in the survey. The results suggested that affiliate stigma in caregivers of children with autism was prevalent and severe; their depressive symptoms were significantly more severe than the national norm of the similar age group. Low self-esteem, high shame proneness and poor family adaptability were associated with experience of affiliate stigma and heightened depressive symptoms. Affiliate stigma partially mediated the links between self-esteem/ shame proneness/family adaptability and depression levels. This study was the first one to measure affiliate stigma on caregivers of children with ASD in mainland China using a quantitative method. The results highlight the necessity and importance of de-stigmatization for the caregivers of children with autism and suggest that interventions to improve self-esteem, reduce experience of shame and to enhance family functioning might be effective.

1. Introduction

Autism Spectrum Disorders (ASD) is a neurodevelopmental disorder with increasing morbidity in recent years. Children diagnosed with ASD often have deficits in social functioning, exhibit repetitive, stereotyped and self-stimulatory behavior and typically show marked delay in the development of verbal language (American Psychiatric Association, 2013). Rearing a child with ASD is a great challenge for parents. These parents report greater stress and poorer mental health than the parents of children without disabilities and those with other disabilities (Ingersoll and Hambrick, 2011; Rao and Beidel, 2009; Weiss, 2002).

Affiliate stigma has been identified as an important predictor of psychological problems of caregivers of children with developmental disabilities including ASD (Ali et al., 2012; Cantwell et al., 2015; Chan and Lam, 2017; Chou et al., 2009; Green, 2003; Mak and Kwok, 2010; Wong et al., 2016). Affiliate stigma refers to internalized stigma for family members of a stigmatized individual (Corrigan and Watson, 2002; Mak and Cheung, 2008). People with affiliate stigma may develop negative self-evaluation, experience heightened negative emotions such as anger and despair, behaviorally withdraw and tend to

conceal their stigmatized status from others (Corrigan and Watson 2002). Results of previous research suggest that the experience of affiliate stigma is prevalent and severe in caregivers of children with ASD (Gray, 1993; Farrugia, 2009; Mak and Kwok, 2010; Wong et al., 2016). Impropriate social behaviors of children with ASD in public pose one of the greatest challenges for their caregivers. People's reactions, such as shock, anger and blame, to such children usually make their parents feel embarrassed and ashamed (Gray, 1993,2002).

The issue of affiliate stigma in caregivers of children with ASD should be emphasized in China for several reasons. First, Chinese people have an especially negative stereotype to individuals with mental illness and consider children with mental illness as "bad seeds" (Mak and Cheung, 2008). ASD is not yet well-known in our society and public stigma attached to ASD is common (Mak and Cheung, 2008; Mak and Kwok, 2010). Second, Chinese parents of children with mental illness are more likely to internalize stigma. Chinese culture, along with other East Asian cultures, is considered to be a shame-socialized culture. Individuals are socialized to "have a sense of shame" and are encouraged to act so as to maximize the positive evaluation granted by others (Fung, 1999). Chinese parents of children with ASD tend to

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emphasize on their social identity and value (Chiu et al., 2013; Fung et al., 2007; Mak and Chen, 2006; Yang, 2015). Third, Chinese parents of children with ASD may experience strong affiliate stigma since the experience of shame is more of a group concern rather than an individual concern and people tend to feel ashamed by behaviors of their families, friends, and relatives (Chiu et al., 2013; Li et al., 2004; Stipek, 1908)

Affiliate stigma is closely associated with shame. Shame is a self-related social emotion accompanied by self-evaluated failures and shortcomings (Tangney and Fischer, 1995; Fung, 1999). People high in shame proneness are sensitive to others' attention and evaluation. They tend to have negative interpretation on ambiguous social cues and are more likely to experience "loss of face" (Shi and Qian, 1998; Yang, 2015). Moreover, they tend to attribute negative events to internal and stable factors so they are more likely to internalize stigma (Mak and Kwok, 2010). Therefore, proneness to shame was used as a proxy to predict affiliate stigma in the caregivers of children with ASD in the present study.

Self-esteem is another important self-related concept which refers to a sense of self-respect, worthiness and adequacy (Rosenberg, 1965). A number of studies have suggested that low self-esteem is associated with experience of stigma and poor mental health status for individuals with developmental disabilities (Abraham et al., 2002; Dagnan and Waring, 2004; Paterson et al., 2012). More and more studies suggest self-esteem is a protective factor of affiliate stigma in caregivers of children with developmental disabilities (Cantwell et al., 2015; Mak and Kwok, 2010; Werner and Shulman, 2013). Given the established association between self-esteem and shame proneness (Zhu et al., 1999), shame proneness was hypothesized to mediate the link between self-esteem and affiliate stigma in the present study.

In addition to personal factors like self-esteem and shame proneness, environmental factors are associated with affiliate stigma and psychological adaptation as well. Social support has been used as a protective factor of stigma (Cantwell et al., 2015; Werner and Shulman, 2013). Family plays an important role in social support system and provides direct support to primary caregivers in coping with a child's illness (Mak and Kwok, 2010; Werner and Shulman, 2013). Successful psychological adaption of caregivers to children's physical and/or mental illnesses is associated with family functioning that provides a high level of support (Drotar, 1997; Thompson et al., 1992). While the effects of family functioning on caregivers' mental health have been well-documented, its relation with affiliate stigma remains less understood. Theoretically, trust, respect and instrumental support from family members might help caregivers view children's illnesses relatively positive, reduce their self-blame and increase their sense of control and in turn decrease the level of affiliate stigma. However, a previous study found that family support and affiliate stigma were not significantly correlated (Mak and Kwok, 2010). The present study would further examine the relation between family functioning, affiliate stigma, and caregivers' depression.

In sum, several studies have revealed that caregivers of children with ASD experience high level of affiliate stigma and it is predictive of the mental health of these caregivers. Self-esteem and social support have been identified as factors associated with stigma. However, most studies were conducted in Western countries, leaving affiliate stigma on caregivers of children with ASD in Mainland China largely unknown. Given the shame-socialized cultural tradition, affiliate stigma and its association with psychological adaptation in such caregivers in China deserve more attention. The present study aimed to examine the effects of self-esteem, proneness to shame and family functioning on affiliate stigma and depression with a sample of caregivers of children with ASD in Mainland China. Our hypothesized model is presented in Fig. 1.

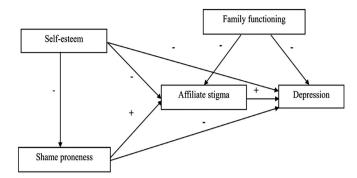


Fig. 1. Hypothesized effects of self-esteem, shame proneness and family functioning on affiliate stigma and depression in caregivers of children with ASD.

2. Method

2.1. Participants

Primary caregivers of children who had been diagnosed with ASD were invited to participate in this study. Convenience sampling method was used. Participants were approached at four rehabilitation centers for children with autism in Beijing and Tianjin. The inclusion criteria were 1) the child had been diagnosed as ASD by a psychiatrist; 2) the primary caregivers were accessible and willing to participate in the survey. No particular exclusion criteria were applied.

As shown in Table 1, the sample consisted of 263 primary caregivers of children with autism, including 61 (23.2%) males and 188 (71.5%) females (14, i.e. 5.3%, participants did not specify their genders). A majority of the participants (n = 212, 80.6%) were parents of children with ASD, 44(16.7%) were grandparents, and 7 participants did not specify the relationship with their children. The average age of caregivers was 34.6 (SD = 5.4) years old. 109 (41.4%) families were from urban areas, 65 (24.7%) families were from rural areas and 89 participants did not report their places of residence. The educational levels of caregivers varied among junior high school (n = 33, 12.5%), senior high school (n = 53, 20.2%), college (n = 48, 18.3%), bachelor's degree (n = 92, 35.0%), and postgraduate degree (n = 27, 10.3%) (10 participants did not report their education attainment).

Table 1 Participants' demographic data.

	N	Percentage(%)
Relationship with the child of AS	D	
Parents	212	80.6
Grandparents	44	15.6
Gender of caregivers		
Male	61	23.2
Female	188	71.5
Age of caregivers	34.60 (SD = 5.40)	
Education level of caregivers		
Junior high school	33	12.5
Senior high school	53	20.2
College	48	18.3
Bachelor's degree	92	35.0
Postgraduate degree	27	10.3
Area of residence		
Urban areas	109	41.4
Rural areas	65	24.7
Gender of the child with ASD		
Male	197	74.9
Female	61	23.6
Age of the child with ASD	5.39 (SD = 2.38)	

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