



Internalization of stigma for parents of children with autism spectrum disorder in Hong Kong

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ABSTRACT

An attribution model was tested to explain the internalization of stigma among parents of children with Autism Spectrum Disorder (ASD). In the model, the internalization paths from courtesy stigma to affiliate stigma and the impact of three types of social support on affiliate stigma and psychological well-being were examined. The study was conducted in Hong Kong, China; one hundred and eighty-eight parents of children with ASD were recruited to complete the questionnaire. The model showed excellent fit to the data. Path analysis suggested three possible paths of internalizing courtesy stigma, including the direct path to affiliate stigma, through perceived controllability, or through perceived responsibility and self-blame. Support from family, significant others, friends, or professionals was found to be related to affiliate stigma and psychological well-being differentially. The internalization of stigma among parents of ASD children was severe. The path model sheds light on possible ways to reduce stigma in future services.

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Stigma not only impacts the discredited individuals themselves; it can affect individuals who are closely associated with these stigmatized individuals (i.e., family members, caregivers, friends, or service providers). Previous studies have found family members encountering various forms of stigmatization and discrimination as a result of their children having autism (Gray, 2002), intellectual disability (Green, 2003), ADHD (Koro-Ljungberg & Bussing, 2009; Norvilitis, Scime, & Lee, 2002), schizophrenia or other mental illness (Angermeyer, Schulze, & Dietrich, 2003; Muhlbaier, 2002; Östman & Kjellin, 2002; Phelan, Bromet, & Link, 1998; Schulze & Angermeyer, 2003). These studies generally focused on the extent of courtesy stigma (Goffman, 1963) that the family members perceive from the general public towards themselves.

To distinguish courtesy stigma from self-stigma experienced by the family members, we refer to this self-stigmatization of family members as affiliate stigma (Mak & Cheung, 2008). In the process of internalizing stigma, family members might develop negative self-evaluation, experience heightened negative emotions, and behaviorally withdraw and conceal their stigmatized status from others (Corrigan & Watson, 2002). Although the concept of affiliate stigma has been proposed (Mak & Cheung, 2008), the process in which associates internalize courtesy stigma into affiliate stigma and its

consequences remain unknown. The present study examined the internalization process of courtesy stigma using Weiner's attribution model (1993) and its impact on psychological well-being among parents of children with Autism Spectrum Disorder (ASD or simply autism) in Hong Kong. In addition, the effects of different types of social support on affiliate stigma and psychological well-being were also investigated.

Stigmatized autistic features and the local context

According to the DSM-IV-TR (APA, 2000), the diagnostic features of Autism Spectrum Disorder (ASD) include impaired social interactions, impaired communication, as well as restricted, repetitive, and stereotyped behavior patterns. Among people with mental illness, those who lack proper social skills and perform inappropriate affective behaviors are considered impolite and dangerous (Pugliesi, 1987). As such, their parents are often subjected to stigma due to the public's misconception of their lack of control or discipline over their children with mental illness (Penn, Kohlmaier, & Corrigan, 2000). In the case of children with autism, parental stress has been shown to become heightened when their children show behavioral oddities in the form of self-stimulation and inappropriate use of their bodies through flapping, smelling and mouthing objects, rocking and twirling and finger-gazing (Konstantareas & Homatidis, 1989). Their children's display of behavioral oddities may expose parents to courtesy stigma, which in turn may become internalized as affiliate stigma.

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In 2009, the overall prevalence of autism in Hong Kong was around 3800, which constituted a prevalence of .1% in the general population (Census and Statistical Department of Hong Kong, 2009). There are about thirty non-governmental organizations (NGOs) providing supportive services to local children with autism (Autism Hong Kong, 2007). However, only about one-third of the NGOs provide services to the parents of children, and thus many parents do not receive any services. Consequently, many of their needs, including protection from stigma, are being overlooked.

Parents of children with autism

Among parents raising children with disabilities such as intellectual disability, cerebral palsy, genetic and chromosomal disorders, parents of children with autism report significantly higher levels of stress and dysphoria (Dumas, Wolf, Fisman, & Culligan, 1991; Sanders & Morgan, 1997), significantly lower well-being (Blacher & McIntyre, 2006) and are more likely to experience depression (Olsson & Hwang, 2001). One of the underlying sources of caregiving stress is the frequency and breadth of children's maladaptive behaviors (Tomanik, Harris, & Hawkins, 2004). Children with autism engage in comparatively more atypical behaviors and have elevated sensory and regulatory difficulties (Carter, Irwin, Skuban, Davis, & Briggs-Gowan, 2005). Thus, their parents may experience greater levels of stress.

Another possible explanation is that caring for a child with a chronic disability can involve considerable expenditures of time and effort beyond the typical responsibilities of parenting. Studies on parents of children with cystic fibrosis showed that parenting may impose financial and marital strain on the family, which contributes to parents' depression (e.g., Quittner, DiGirolamo, Michel, & Eigen, 1992). According to the revised stress processing model developed for parents of children with anorexia nervosa (Dimitropoulos, Carter, Schachter, & Woodside, 2008), parenting stress and parental stigma are highly correlated and may work together in predicting negative caregiving outcomes such as psychological distress.

Chinese parents, in particular, are subjected to higher parenting stress and stigma. Previous studies have found that Chinese parents of children with mental illness are more likely to self-stigmatize because they focus more on their social identity and value (Fung, Tsang, Corrigan, Lam, & Cheng, 2007). Once they are stigmatized by society, they internalize stigma more easily. Their concern for face also contributes to higher levels of stress and psychological distress (Mak & Chen, 2006). A recent study conducted among family members of people with mental illness in Hong Kong showed that affiliate stigma partially mediated face concern and caregiver distress and fully mediated face concern and subjective burden (Mak & Cheung, *in press*). Thus, raising a child with autism may be particularly stressful for Chinese parents.

Internalization of affiliate stigma using the attribution model

The experience of stigmatization among parents with children with autism may be very complex, as it involves biological differences of the children, the negative evaluation of those differences by others, adverse reactions of others, and negative social and emotional outcomes for parents (Green, Davis, Karshmer, Marsh, & Straight, 2005). The present study extended previous studies by conceptualizing parents' internalization of courtesy stigma using the attribution model (Weiner, 1993). According to Weiner's (1993) attribution theory, one's assignment of the cause of a disorder can affect one's affective and behavioral reaction to the person with the disorder. The target's perceived responsibility for the stigmatizing circumstance predicts either anger and punitive actions (if believed

to be controllable) or pity and helping behaviors towards the target (if believed to be uncontrollable) (Corrigan, Markowitz, Watson, Rowan, & Kubiak, 2003; Corrigan, 2000).

However, research findings on the attribution model have been mixed. Among staff or caregivers of children with challenging behaviors or intellectual disabilities, whereas some studies showed the mediating effect of positive or negative affect on controllability and helping or punitive behaviors (e.g., Dagnan, Trower, & Smith, 1998; Ling, Mak, & Cheng, *in press*; McGuinness & Dagnan, 2001; Stanley & Standen, 2000), others failed to find such mediating effects (e.g., Hill & Dagnan, 2002; Jones & Hastings, 2003; Rose & Rose, 2005; Wanless & Jahoda, 2002). In a recent review of the application of the attribution theory to people with intellectual disability (Willner & Smith, 2008), only partial support for the attribution theory was found. Nevertheless, it is important to note that none of the above studies specifically focused on stigma but rather on its consequences or behavioral reactions.

With respect to testing the attribution explanation of stigma, findings continue to be equivocal. Whereas support of the model from controllability, responsibility, and blame was found among people with serious illness (Mantler, Schellenberg, & Page, 2003), blame was not significantly related to self-stigma among people with HIV/AIDS (Mak et al., 2007). Moreover, Mak et al. (2007) found internal controllability to be negatively related to self-stigma, meaning that the lower the control over the condition perceived by stigmatized individuals, the greater their self-stigma. In the present study, we explored the effects of attributions, including perceived controllability, perceived responsibility, and self-blame on affiliate stigma among parents of children with autism. Based on the previous findings, we hypothesized that controllability would be negatively related to affiliate stigma.

Parents of children with autism may be stigmatized, blamed, and rebuffed by other people in the community, who blame them directly for causing their children's developmental disturbances. In addition to being blamed for causing the problem, parents are also stigmatized because people in society expect them to exert control over their children's atypical behaviors. Fernandez and Arcia (2004) suggested that there are two sources of parents' perception of stigma. One is repeated stigmatizing experiences and the second is parents' belief, like society at large, that they are responsible for their children's behaviors. It is likely that parents agree with these attributions and blame themselves for causing their children's condition. In fact, self-blame is identified as the most common response of parents of children with schizophrenia and developmental disability after their children's illnesses were diagnosed (Awad & Voruganti, 2008; Fernandez & Arcia, 2004). For these reasons, parents may perceive a certain degree of stigmatization towards them and gradually internalize it into affiliate stigma. In the present study, we hypothesized responsibility and self-blame to be positively related to affiliate stigma.

Given individual differences in the attribution process (Anderson, Jennings, & Arnoult, 1988), the present study tested four possible pathways of stigma internalization among parents of children with autism. Specifically, the four pathways included (1) a direct path from courtesy stigma to affiliate stigma; (2) an indirect path from courtesy stigma to affiliate stigma through perceived controllability, perceived responsibility and self-blame; (3) an indirect path from courtesy stigma to affiliate stigma through perceived controllability; and (4) an indirect path from courtesy stigma to affiliate stigma through responsibility and self-blame.

Perceived support & stigma

Social support was included in the model because of its known protective value (Vandervoort, 1999). Among parents of children

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