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## Self-stigma among parents of children with autism spectrum disorder

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### ABSTRACT

**Background:** Parents of children with autism spectrum disorder (ASD) vary in not only the extent to which they endorse their self-stigmatizing thoughts, referred to as self-stigma “content”, but also the extent to which they think about their self-stigmatizing thoughts repetitively and automatically as a mental habit, referred to as self-stigma “process”. Existing measures of self-stigma, however, focus almost solely on self-stigma content. No measures are available for assessing self-stigma process among parents of children with ASD. The present study examined the psychometric properties of a recently developed measure of self-stigma process, the Self-Stigmatizing Thinking’s Automaticity and Repetition Scale (STARS), among parents of children with ASD.

**Method:** Cross-sectional, questionnaire data were collected from 424 parents of children with ASD residing in Hong Kong, China.

**Results:** Confirmatory factor analyses supported the originally proposed, two-factor model of the STARS. The entire scale, as well as its two subscales, had excellent internal consistency. The STARS demonstrated construct validity by being correlated with self-stigma content. It also showed criterion validity by being correlated with mental health (as indicated by life satisfaction and depression) and caregiving experiences (as indicated by caregiving gain and caregiving burden). Furthermore, the STARS exhibited incremental validity by explaining life satisfaction, depression, caregiving gain, and caregiving burden, even after adjusting for self-stigma content.

**Conclusions:** Our findings provided evidence for the reliability, and the factorial, construct, criterion, and incremental validity, of the STARS among parents of children with ASD. Our findings highlighted the content-process distinction of self-stigma, and provided important insights on the design of effective anti-self-stigma interventions.

### 1. Introduction

Public stigma refers to stereotypical beliefs and prejudicial attitudes endorsed by a sizeable group in society toward a discredited subgroup (Corrigan & Watson 2002). Public stigma adversely affects children with autism spectrum disorder (ASD) in different cultural contexts (World Health Organization, 2016). Due to the absence of conspicuous physical markers of ASD, when children with ASD display socially inappropriate behaviors in public (e.g., flapping, twirling, throwing tantrums, smelling and mouthing objects,

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engaging in self-destructive acts), they are often blamed for being willfully disobedient and disruptive (Gray, 1993; Ling, Mak, & Cheng, 2010). These children may be humiliated, neglected, or excluded by their peers (Kinnear, Link, Ballan, & Fischbach, 2016). They may also be unwelcomed or treated with less empathy by their therapists and teachers in clinical and educational settings (Helps, Newsom-Davis, & Callias, 1999; Nissenbaum, Tollefson, & Reese, 2002).

Stigma harms not only children with ASD, but also their parents (Lam, 2016, 2017;). In fact, many parents of children with ASD are subjected to what Goffman (1963) defined as courtesy stigma: the stereotypes and prejudice directed to individuals not because of their own attributes but rather their associations with other individuals that are publicly stigmatized (Farrugia, 2009; Gill & Liamputtong, 2011; Kinnear et al., 2016; Neely-Barnes, Hall, Roberts, & Graff, 2011; Woodgate, Ateah, & Secco, 2008). Previous studies have shown that parents of children with ASD may be blamed for “causing” their children’s disabilities by passing on bad genes (Wong, Mak, & Liao, 2016). Moreover, due to their children’s social and behavioral oddities, these parents may be criticized for being incompetent, or incapable of controlling and disciplining their children (Gray, 1993). These stigmatizing experiences typically leave parents of children with ASD feeling humiliated, judged, and isolated (Broady, Stoyles, & Morse, 2017).

In the face of constant disapproval from the public, parents of children with ASD may be affected by perceived stigma (Gray, 1993) and self-stigma (also referred to as affiliate stigma; Mak & Kwok, 2010; Zisman-Ilani, Hasson-Ohayon, Levy-Frank, Tuval-Mashiach, & Roe, 2017). Perceived stigma refers to individuals’ awareness of societal negative evaluations toward themselves (Gray, 1993), whereas self-stigma refers to individuals’ acceptance of societal negative evaluations and incorporation of such views into their own value systems (Corrigan, Watson, & Miller, 2006; Hasson-Ohayon, Levy, Kravetz, Vollanski-Narkis, & Roe, 2011; Perlick et al., 2011; Zisman-Ilani et al., 2017). Because self-stigma involves the internalization of societal stigma toward the self and the development of negative self-thoughts, self-stigma tends to damage self-esteem and self-efficacy and have a more detrimental impact on psychological well-being (Corrigan, Rafacz, & Rüsich, 2011).

Self-stigma has long been assessed as a global, unidimensional construct among parents of children with ASD (Mak & Kwok, 2010; Werner & Shulman, 2015; Wong et al., 2016). Recent research, however, shows that self-stigma may be a more differentiated, multifaceted concept. Stigmatized individuals, for example, may vary in not only the extent to which they endorse their self-stigmatizing thoughts, referred to as self-stigma “content”, but also the extent to which they think about their self-stigmatizing thoughts repetitively and automatically as a mental habit, referred to as self-stigma “process” (Chan & Mak, 2017). Because the content of self-stigmatizing thoughts may only partially explain the psychological implications of self-stigma, considering the process through which parents experience these thoughts may enrich our understanding of self-stigma.

Only a handful of studies have examined self-stigma among parents of children with ASD (Mak & Kwok, 2010; Werner & Shulman, 2015; Wong et al., 2016). These studies have also focused on self-stigma content. To our best knowledge, no study has investigated self-stigma process among parents of children with ASD. Guided by the content-process theory of self-stigma (Chan & Mak, 2017), the present study addressed an important gap in the literature by examining both the content and process of self-stigma among parents of children with ASD. The content refers to the extent of attitudinal endorsement of self-stigmatizing thoughts, whereas the process refers to the extent of habitual recurrence of self-stigmatizing thoughts in everyday life.

### 1.1. *Self-stigma content*

Being aware of societal stigmatizing thoughts against them, parents of children with ASD may endorse and internalize the content of such thoughts at various degrees (Corrigan & Watson, 2002). If parents regard stigma as fair and legitimate, they are likely to self-concur with societal stigmatizing thoughts and develop self-stigmatizing ideas (Corrigan & Watson, 2002). Conversely, if parents consider stigma as unfair and illegitimate, they are likely to feel indifferent or even angry in response to societal stigma (Corrigan & Watson, 2002).

Parents who endorse and internalize the content of societal stigmatizing thoughts may develop negative evaluations of themselves and their stigmatized identities (Mak & Cheung, 2008). In particular, they may perceive themselves as incompetent and inferior to others, and experience a diminished sense of purpose and value (Mak & Cheung, 2008). They may also feel ashamed of their stigmatized identities, and begin to denigrate themselves and withdraw from others so as to conceal their stigmatized status (Mak & Cheung, 2008).

### 1.2. *Self-stigma process*

Parents who have self-stigmatizing thoughts may experience different degrees of recurrence of such thoughts, depending on various contextual and individual factors. At the contextual level, when the social environment is marked by profound stigma against ASD, the negative social reactions received by these parents may make their stigmatized status more salient (Mak & Kwok, 2010). Such salience may continue to activate self-stigmatizing thoughts and prompt these parents to adopt a negative view of themselves (Mak & Kwok, 2010). At the individual level, tendencies to ruminate and worry may make these parents think repetitively about negative issues, such as their experienced and anticipated problems associated with their stigmatized identities (Ma & Mak, 2016). This may make self-stigmatizing thoughts more accessible and render these parents preoccupied with negative self-thoughts (Ma & Mak, 2016).

When self-stigmatizing thinking occurs repetitively and persistently, it may become a dominant feature of the mind and develop into a mental habit (Chan & Mak, 2017). A mental habit refers to a thought that has acquired automaticity after repetition (Verplanken, Friberg, Wang, Trafimow, & Woolf, 2007). For parents who have a mental habit of self-stigma, self-stigmatizing thoughts can become so automatic that they may emerge without conscious awareness or willful intent, demand little attention and

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