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Running Head: Predictors of affiliate stigma in ASD caregivers

Caregivers' Characteristics and Family Constellation Variables as Predictors of Affiliate Stigma in
Caregivers of Children with ASD

Abstract

Affiliate stigma is one risk factor for psychological distress in familial caregivers. Few studies however, and none involving caregivers in the UK and US, have explored caregivers' characteristics and family constellation variables as risk and protective factors for affiliate stigma. This study aimed to fill this gap. Moreover, we believe this study is only second to explore these relationships among caregivers of children with autism spectrum disorder (ASD), a group particularly vulnerable to affiliate stigma. A sample of $n=192$ caregivers of children with ASD completed an online survey assessing caregivers' characteristics and family factors, and affiliate stigma. Non-partnered caregivers were more likely to report affiliate stigma, as were caregivers with shorter sleep duration. These findings might help clinicians and other health professionals identify caregivers at risk for affiliate stigma and concomitant psychological distress.

Keywords: Affiliate Stigma; Autism Spectrum Disorder; Caregivers; Risk Factors

Introduction

Individuals with developmental disabilities, particularly autism spectrum disorder (ASD), often experience stigmatising public reactions (Ali et al., 2012; Broady et al., 2017; Eaton et al., 2016; Marsack et al., 2018; Tudose et al., 2017). This stigma can spill over to care providers who, by virtue of associating with the stigmatised person, also experience negative reactions from the public (Abojabel et al., 2016; Koshorke et al., 2014). This has been labelled courtesy stigma. The lived experience of stigma among caregivers of children with ASD has been the topic of much qualitative research. Results suggest caregivers' experience of stigma, which manifests as hostile stares, insensitive comments and social exclusion, to be underpinned by lack of knowledge about ASD. Across several studies, caregivers commented that schools, even family and close friends, did not know enough about ASD. Caregivers perceived this ultimately led to stigma, characterised by feeling judged (i.e., as an unskilled or incapable parent) and rejected (i.e., from schools), and receiving inadequate support (Broady et al., 2017; Eaton et al., 2016).

Research has reported that caregivers often internalise, and come to believe, external criticism (Mak et al., 2008). This affiliate (or self) stigma appears to be particularly problematic for caregivers of children with ASD. Indeed, relative to parents of children with physical and/or intellectual disabilities, reports of affiliate stigma tend to be higher in caregivers of children with ASD (Gill and Liamputtong, 2013, Griffith et al., 2012; Werner & Schulman, 2015). This might be explained in part by the invisible nature of ASD. In the absence of physical signs of disability, members of the public often perceive socially inappropriate behaviours (e.g., flapping, flailing, self-injury) of the child with ASD to be the result of inadequate parenting (Werner et al., 2013). A plethora of correlational research found affiliate stigma to be a robust, positive predictor of psychological distress among familial caregivers (Chiu et al., 2013; Banga et al., 2016; Dalky et al., 2017; Kim-Wan et al., 2016; Kwok et al., 2014; Magana et al., 2007; Mikami et al., 2014). Again, however, it is among caregivers of children with ASD where the negative psychological impact of affiliate stigma appears to be most salient (Werner and Schulman, 2013). Moreover, in addition to its influence on caregivers' psychological well-being, affiliate stigma has also been linked with a various quality of care

outcomes. For example, in a study involving caregivers of children with developmental disabilities, including ASD, children whose parents reported greater affiliate stigma were less likely to interact with age related peers (Green, 2003).

Given that self-stigmatising caregivers are more vulnerable to emotional distress, and given both stigma and distress predict quality of provided care, it is perhaps surprising only a handful of studies, and only one involving ASD caregivers, have explored predictors of affiliate stigma. To date, in a series of studies involving caregivers of adults with schizophrenia, characteristics of the care provider and other family variables accounted for a significant amount of variance in affiliate stigma. In particular, younger, female, non-earning caregivers, and caregivers of younger patients with greater disease severity, were more likely to report affiliate stigma. Caregivers of patients with longer treatment durations were also more likely to report affiliate stigma (Grover et al., 2017; Kim-Wan et al., 2016; Koshorke et al., 2014, 2017; Singh et al., 2016; Thara et al., 2000; Yin et al., 2014). These results however might not be generalised to caregivers of children with ASD, who not only commence with the caretaking role much earlier, but also can expect it to last considerably longer (Greenberg et al., 2004). In addition, while behaviour problems of children with ASD tend to decline with age, this is not the same for schizophrenia patients, where behavioural problems tend to be more stable over time (Shattuck et al., 2007). Moreover, psychological distress, which is predicted by affiliate stigma, was found to be higher in caregivers of patients with schizophrenia relative to caregivers of children with ASD (Magaña, et al., 2007).

To date, we can identify only two studies, none of which involve caregivers from the UK or US, which explore predictors of affiliate stigma in the context of caring for a child with developmental disabilities, including ASD. Findings, based on a small sample of caregivers from Ethiopia, found caregivers of an orthodox, Christian faith to be at greater risk for affiliate stigma. Caregivers who prescribed to a supernatural explanation for their child's condition were also more likely to report affiliate stigma (Tilahun et al., 2016). More recently, in a group of ASD caregivers from China, self-esteem negatively, and feelings of shame positively, predicted reports of affiliate stigma (Zhou et al., 2018). These studies however, much like earlier research involving caregivers of

schizophrenia patients, recruited predominately from China and India, with one study recruiting from Ethiopia. These findings therefore might not be generalised to caregivers in the UK and US, where cultural values are very different. Indeed, familial caregivers in China and India, because of the strong emphasis placed on social position and cultural value, tend to be particularly vulnerable to affiliate stigma (Fung et al., 2007). Moreover, face concern, which refers to maintaining social position through satisfying social roles, tends to be much less emphasised among caregivers in western countries such as the UK and US, where rates of affiliate stigma are comparably high (West et al., 2011). Several studies involving familial caregivers have also found affiliate stigma to be predicted by socio-cultural context (Lam et al., 2011; Yang, 2007).

Given the paucity of research in this area, this study explores how affiliate stigma among caregivers of children with ASD living in the UK and US might vary according to a range of caregivers' characteristics and family variables. The paucity of research in this area, coupled with the cultural differences in the sample populations, means we make no *a priori* hypotheses; the study is exploratory.

Methods

Participants & Procedure

A convenience sample of $n=212$ caregivers of children with clinically verified (by GP, paediatrician or other health professional) ASD was recruited via adverts posted on UK and US caregiving information/support pages of social media sites. Participants were recruited against strict criteria: a) caring for a child, aged 3-21 years, living at home full time and with clinically verified ASD, b) not caring for another person (i.e., partner, parent, friend or other relative) with chronic illness, and c) not managing any clinically recognised psychological condition such as depression. Consenting participants were asked to complete an online survey, with questions asking about characteristics of the care provider (e.g., gender, age, exercise, sleep duration), family variables (e.g., single parent, number of children, age of child with ASD), and affiliate stigma. The institutional ethics committee approved the study. Participants received no recompense for taking part. Data were

removed for $n=20$ participants who failed to provide consent for survey completion. Statistical analysis therefore was conducted on final sample of $n=192$.

The sample was predominately female (97%) and partnered (82%), with an average age of 42.7 years ($SD = 7.8$). The majority were non-smokers (88%), slept an average 6.3 hours per night ($SD = 1.3$) and exercised between 0-7 times per week ($M = 1.54$, $SD = 1.74$). Most were employed (57%) and caring for more than one child (73%). Median age of the child with ASD was 11 years ($SD = 5.0$), with caregivers having provided care for an average, 4.8 years (range, 1-21 years). Sample characteristics are displayed in Table 1.

INSERT TABLE 1 HERE

Measures

Predictor Variables

Data were collected with respect to caregivers' characteristics (gender, age, employment and relationship status, caregiving duration, exercise and sleep duration) and family variables (number of children, age of the child with ASD) that might serve as protective or risk factors for affiliate stigma. Selection of predictor variables was informed by studies involving other caregiving populations that also explored how affiliate stigma might be differentially affected by caregivers' characteristics and family factors (Grover et al., 2017; Koshorke et al., 2017; Singh et al., 2016;).

Affiliate Stigma

The 22 item Affiliate Stigma Scale (ASS), which incorporates a 4 point Likert type scale (1 = *strongly disagree* - 4 = *strongly agree*), was used to measure caregivers' affiliate stigma (Mak and Cheung, 2008). A total score is generated by summing across 22 items (e.g., *'I feel helpless for having a family member with developmental disability, 'I avoid communicating with a family member having developmental disability'*) with higher scores reflecting greater affiliate stigma. The ASS showed

good internal consistency ($\alpha = .98$) in other recent studies (Grover et al., 2017); this was also the case here ($\alpha = .93$).

Statistical Analysis

Bivariate and, for binary variables, point-biserial correlations were used to explore whether caregivers' characteristics and family variables might be associated with affiliate stigma. Variables significant in correlations were taken forward to multiple regression to explore their unique predictive value.

Results

Correlation Analysis

Affiliate stigma was inversely related to caregivers' sleep duration ($r = -.16, p = .03$). In addition, compared to partnered caregivers ($M = 46.0, SD = 10.6$), non-partnered (i.e., single) caregivers ($M = 50.6, SD = 13.6$) were more likely to report affiliate stigma ($t = 2.1, df = 190, p = .04$). No relationships were found between affiliate stigma and other caregivers' characteristics or family variables (all $ps > .14$). A correlation matrix displaying relationships between study variables is presented in Table 2.

INSERT TABLE 2 HERE

Multiple Regression

In competing analysis, where variables were entered simultaneously, relationship status ($\beta = -.14, t = -2.0, SE = 2.11, p = .05$) and sleep duration ($\beta = -.14, t = -2.0, SE = .61, p = .05$) independently predicted affiliate stigma. The overall model accounted for 4% of the variation ($F(2, 191) = 4.33, p < .05$). These data suggest non-partnered caregivers with shorter sleep duration to be at greater risk for affiliate stigma.

Discussion

This study explored the extent to which caregivers' characteristics and family constellation variables might predict affiliate stigma in UK and US caregivers of children with ASD. Findings are commensurate with other recent studies, in which caregivers' characteristics and other family factors accounted for a significant portion of the variation in affiliate stigma (Kolshorke et al., 2014, 2017; Singh et al., 2016; Thara et al., 2000). Previous research however highlighted caregivers' age, gender, ethnicity, and earning potential, as predictors of affiliate stigma (Singh et al., 2016; Tilahun et al., 2016). This was not the case in the current study. Here, it was other characteristics of the care provider, particularly relationship status and sleep, which emerged as predictors of affiliate stigma. That affiliate stigma appears to be greater among non-partnered (i.e., single) caregivers might not be surprising. Indeed, in other studies involving caregivers of children with ASD, social support inversely predicted reports of stigma (Elafros et al., 2013; Mak et al., 2010). It might be that single caregivers, by virtue of not being able to offload stigmatising reactions of the public to a partner, are more susceptible to affiliate stigma. Moreover, research has demonstrated that individuals respond more adaptively to stressful situations, especially those involving social evaluation, when accompanied by a partner (Hennessey et al., 2009; Kirschbaum et al., 1995). That affiliate stigma is more likely in those reporting shorter, and possibly poorer, sleep might also not be surprising. Indeed, while not in the context of familial caregiving, studies have reported on the negative relationship between sleep duration and stigma consciousness (Ong et al., 2017). Moreover, while the current study is first to explore sleep in relation to caregivers' affiliate stigma, other studies have observed links between sleep and closely related constructs. For example, resilience, a known protective factor against the negative psychological effects of stigma (Bockting et al., 2013), was found to be higher in those with longer sleep duration (Segovia et al., 2013). As such, shorter sleep, by reducing levels of resilience, might increase susceptibility to affiliate stigma.

Findings reported here might have implications for identifying caregivers at risk for psychological distress. Indeed, the negative relationship between affiliate stigma and caregivers' psychological well-being has been widely reported (Chiu et al., 2013; Kwok et al., 2014), as have the

possible implications of caregivers' poorer psychological well-being for quality of provided care (Hutchison et al., 2016; Wong and Heriot, 2008). Encouragingly however, affiliate stigma appears to be amenable to improvement via intervention, especially education-based intervention. For example, following several weeks of a psycho-educational intervention, caregivers of patients with schizophrenia reported marked reductions in internalised (i.e., affiliate) stigma compared with a control group (Vaghee et al., 2015). Other studies have also highlighted how caregivers' stigma was inversely related to both formal education and knowledge about the disorder (Elafros et al., 2013). Whether education based interventions might reduce affiliate stigma in non-partnered caregivers with shorter sleep, and whether any positive effects might lead to concomitant improvements in quality of provided care, might be the subject of future studies.

Findings reported here must be tempered by study limitations. First, the cross sectional nature of the work makes it impossible to draw causal inferences. These relationships might be bidirectional, with stigma found to predict greater sleep problems in a recent study (Ruff et al., 2016). Future studies might use longitudinal designs to better tease apart the direction of these relationships. Second, caregivers' affiliate stigma has been shown to vary according to characteristics of the care recipient, particularly level of functioning and disease severity (Koshorke et al., 2017). That care recipients' characteristics were not measured here represents a notable limitation of the current study. Third, given our sample recruited from the UK and US, and given that previous research has tended to recruit almost exclusively from China and India, cross-cultural comparisons, which were beyond the scope of this paper, might be interesting. Future research, in addition to exploring culture related disparities in caregivers' affiliate stigma, might consider whether the predictive value of caregivers' characteristics and family factors for affiliate stigma is culturally consistent.

In conclusion, on-partnered caregivers, as well as those with shorter sleep, appear to be particularly vulnerable for affiliate stigma. Whether interventions that mitigate affiliate stigma might also be advantageous improving caregivers' psychological well-being, and how this relates to quality of provided care, might be explored in future studies. Non-partnered caregivers with poorer sleep might be targeted in particular.

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Table 1.

Sample Characteristics

	Caregivers
	<i>n</i>=192
Mean age	42.7 (7.8)
Mean exercise (occasions per week)	1.5 (1.7)
Mean age of child with ASD	11.2 (5.0)
Mean hours sleep (per night)	6.3 (1.3)
Mean years caregiving	4.8 (4.2)
Gender	
<i>Male</i>	6 (3%)
<i>Female</i>	184 (97%)
Smoker	
<i>Yes</i>	22 (12%)
<i>No</i>	169 (88%)
Employment status	
<i>Employed</i>	110 (57%)
<i>Not employed</i>	81 (43%)
Relationship status	
<i>Partnered</i>	158 (82%)
<i>Not partnered</i>	34 (18%)
Number of children	
<i>One</i>	51 (27%)
<i>Two or Three</i>	131 (69%)
<i>Four or more</i>	10 (4%)

Table 2

Correlations among Study Variables

	1	2	3	4	5	6	7	8	9	10	11
1. Affiliate stigma	-										
2. Age	-.11	-									
3. Gender	-.09	.25**	-								
4. Employment	.01	-.01	-.03	-							
5. Number of children	.07	-.24**	-.12	-.18*	-						
6. Age of child with ASD	-.03	.65**	.15*	.00	-.12	-					
7. Years caregiving	-.02	.44**	.17*	-.03	-.04	.64**	-				
8. Single parent	-.15*	-.03	.08	.01	.06	-.06	.01	-			
9. Sleep duration	-.16*	.08	.00	-.01	-.18*	.067	-.15*	.08	-		
10. Exercise	-.06	-.15*	.03	-.07	-.05	-.13	-.05	.08	.05	-	
11. Smoking	.04	-.06	-.07	-.01	-.10	-.06	-.00	-.05	-.09	-.12	-

Note: N=192. Point-biserial correlations were used for binary variables: gender (1 = F, 2 = M), employment status (1 = Y, 2 = N), single parent (1 = Y, 2 = N), smoking (1 = Y, 2 = N).

* $p < 0.05$

** $p < 0.01$