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Citation: Lovell, Brian and Wetherell, Mark (2019) Affiliate stigma, perceived social support and perceived stress in caregivers of children with autism spectrum disorder: A multiple mediation study. Archives of Psychiatric Nursing, 33 (5). pp. 31-35. ISSN 0883-9417

Published by: Elsevier

URL: <https://doi.org/10.1016/j.apnu.2019.08.012> <<https://doi.org/10.1016/j.apnu.2019.08.012>>

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**Affiliate Stigma, Perceived Social Support and Perceived Stress in Caregivers of
Children with Autism Spectrum Disorder: A Multiple Mediation Study**

Abstract

Background: Affiliate stigma negatively predicts social support, and positively predicts psychological distress, in caregivers of children with ASD. Whether the affiliate stigma-distress relationship occurs indirectly via social support however has not been explored.

Methods: A correlational design was used. A sample of $n=124$ caregivers of children with ASD completed an online survey assessing affiliate stigma, perceived support from family, friends and significant others, and perceived stress.

Results: The relationship between greater affiliate stigma and increased perceived stress occurred indirectly via lower perceived support from family, but not from friends or significant others.

Conclusions: These findings underscore the importance of increasing caregivers' perceived family support. Whether interventions that alleviate affiliate stigma are beneficial for reducing perceived stress, and whether this effect is mediated by increased perceived availability of support, might be the subject of future research.

KEYWORDS: affiliate stigma; ASD; caregiving; perceived stress; social support

Introduction

Caregivers of children with developmental disabilities (DD), particularly autism spectrum disorder (ASD), experience stigmatising public reactions such as insensitive comments and hostile stares, even physical aggression (Ali et al., 2012; Broady et al., 2017; Tudose et al., 2017). Behaviourally, ASD can manifest as tantrums, flapping and self-injury, and in the absence of physical markers of disability, members of the public often misattribute these socially inappropriate child behaviours to ‘bad’ parenting (Werner et al., 2013). Indeed, themes of inadequate and unskilled parenting are prominent in qualitative research exploring the lived experience of stigma in caregivers of children with ASD (Broady et al., 2017; Green, 2003).

Stigma can affect caregivers’ psychological health. This is particularly true of affiliate, or self, stigma, which describes the process of internalising, and coming to believe, criticism from others (Mak and Cheung, 2008). A plethora of cross sectional research has found psychological outcomes such as depression and anxiety, and most recently perceived stress, to be elevated among self-stigmatising caregivers (Banga et al., 2017; Dalky et al., 2017; Young et al., 2016; Kwok et al., 2014; Mikami et al., 2015). Themes of psychological distress are also common in qualitative research exploring the psychological consequences of caregiving related stigma (Broady et al., 2017; Eaton et al., 2016). The affiliate stigma-distress relationship however appears to vary as a function of individual difference variables, particularly those related to personality. Indeed, in two recent studies involving caregivers of children with ASD, affiliate stigma was found to positively predict psychological distress, but only in the context of lower levels of self-compassion and self-esteem. Higher levels of self-esteem and self-compassion buffered caregivers against the negative psychological impact of affiliate stigma (Cantwell et al., 2015; Chen et al., 2016). Affiliate stigma has also been

linked with quality of provided care, with one recent study finding caregivers' affiliate stigma to be inversely associated with child social functioning (Mikami et al., 2015).

The negative impact of affiliate stigma on caregivers' social functioning has also been documented. For example, in addition to reporting lower levels of social support (dosReis et al., 2010), self-stigmatising caregivers are less likely to access support when available to them (Hinshaw & Stier, 2008). Moreover, caregivers, and particularly ASD caregivers, not only experience stigma from members of the public, but from family and close friends (Broady et al., 2017). This might partially explain why self-stigmatising caregivers report lower levels of, and are less likely to access, available support. Indeed, along with other coping behaviours, caregivers often use social withdrawal as a way to avoid judgemental comments from the public, and from close relatives (Eaton et al., 2016; Green, 2003). Correlational studies have widely reported on the inverse association between caregivers' social support and psychological distress (Bozo et al., 2010; Lovell et al., 2012; Halstead et al., 2017). Most recently, in a study involving caregivers of children with ASD, lower perceived support, especially from close family, predicted greater depressive symptomology (Singh et al., 2017).

To date, research has tended to focus on the direct relationship between stigma and caregivers' psychosocial health, with very few studies, and only one measuring affiliate stigma, assessing indirect (or mediation) effects. Indeed, in a recent study involving caregivers of children with DD, including ASD, higher levels of subjective burden partially mediated the relationship between greater affiliate stigma and poorer psychological well-being (Banga et al., 2017). Other studies, including those with caregivers, found the relationship between increased stigma and greater psychological distress occurred indirectly via lower social support. (Perlick et al., 2007). Crucially however, these studies focussed on

perceived or courtesy, not affiliate, stigma. Moreover, these studies did not consider the indirect effect of stigma on psychological functioning via multiple types of social support.

Here, we use a multiple mediational model to explore direct and indirect (mediating) relationships between caregivers' affiliate stigma, perceived stress, and perceived support from family, friends and significant others. We hypothesised caregivers who report greater affiliate stigma would also report higher perceived stress, and this relationship would occur indirectly via lower perceived support from family, friends, and significant others.

Methods

Participants & Procedure

A sample of $n=159$ caregivers of children with clinically verified (by paediatrician, GP, or other health professional) ASD was recruited via adverts posted in caregiving support groups on social media sites. Participants were recruited according to strict criteria: a) aged 18 years or older, b) caring for a child aged 3-21 years, living at home full time, with clinically verified ASD, and c) not caring for another person (i.e., parent, partner, friend, or other relative) with chronic illness. Consenting participants completed an online survey assessing basic socio-demographic (e.g., gender, age, relationship status), lifestyle and family (e.g., exercise, smoking, number of children) information, and details about the child with ASD (e.g., age, time since diagnosis). Participants also completed questionnaires assessing affiliate stigma, perceived social support, and perceived stress. The Faculty of Health and Life Sciences Ethics Committee approved the study, and all participants provided informed consent.

Of $n=159$ participants who consented to take part, $n=5$ provided no data and, therefore, were removed from the study, as were $n=2$ who failed to confirm caring for a child with ASD. Data was also removed for $n=19$ participants who provided only partial responses to one or

more of the questionnaires. z scores were generated for predictor and outcome variables to identify outliers. As per the recommendations of Tabachnick and Fidel (2007), data were removed for $n=9$ participants with z scores ± 3.29 .

The final sample of $n=124$ caregivers was predominately female (96%), cohabiting or married (77%), with an average age of 42.4 years ($SD = 7.3$). The majority had more than one child under 21 years of age living at home (70%). Most parents were non-smokers (78%), exercised an average twice per week ($SD = 1.0$), and slept an average 6.5 hours ($SD = 6.2$). 50% of the sample were employed full or part time. The median age of the child with ASD was 10.5 years (range = 3-21), and mean age at diagnosis was 5.6 years ($SD = 3.3$).

Measures

Potential confounds

Socio-demographic (gender, age, relationship status, employment status), lifestyle and family (exercise, smoking, sleep, number of children) data, and data about the child with ASD (age, time since diagnosis), was collected to safeguard against spurious relationships emerging between study variables.

Affiliate stigma

The 22 item Affiliate Stigma Scale (ASS), which incorporates a five point Likert type scale (1 = strongly disagree, 5 = strongly agree), was used to assess affiliate stigma (Mak & Cheung, 2008). A total score, generated by averaging responses from all 22 items, ranges from 1-4, with higher scores reflecting greater affiliate stigma. The ASS achieved excellent internal consistency ($\alpha = .98$) in recent studies (Grover et al., 2017), as was the case here ($\alpha = .91$).

Perceived social support

The Multidimensional Scale of Perceived Social Support (MPSS), a 12-item questionnaire incorporating a seven point Likert type scale (1 = very strongly disagree, 7 = very strongly agree), was used to measure perceived support from family (e.g., I get the emotional help and support I need from my family), friends (e.g., I can talk about my problems with my friends) and significant others (e.g., There is a special person who is around when I am in need). Total scores for each support subscale range from 1-28, with higher scores reflecting greater perceived support (Zimet et al., 1988). MSPSS subscales showed good psychometrics ($\alpha = .84$) in recent studies (Civitci, 2015), as was the case here (all alphas $> .90$).

Perceived Stress

The 10 item Perceived Stress Scale (PSS), which uses a five point Likert type scale (0 = never, 4 = very often), was used to quantify psychological distress (Cohen et al., 1983). A total score, generated by summing across items, ranges from 0-40, with higher scores reflecting higher perceived stress. The PSS achieved good reliability in the current sample ($\alpha = .83$), which was in accord with other recent studies (Lovell et al., 2014).

Statistical analysis

A series of bivariate correlations were used to assess whether caregivers' perceived levels of stress might be related to the socio-demographic, lifestyle and family variables, and characteristics of child with ASD. Bivariate correlation was also used to explore whether perceived stress might be related to perceived support from family, friends and significant others, and affiliate stigma. The SPSS PROCESS macro (model 6) with bootstrapping, as per

Hayes (2012), was used to explore whether the relationship between affiliate stigma and perceived stress might occur indirectly via multiple types of perceived social support.

Results

Potential confounds

Employed caregivers ($M = 23.2$, $SD = 6.3$) reported lower perceived stress compared with unemployed ($M = 25.7$, $SD = 5.9$) caregivers ($r = .21$, $p = .02$). Perceived stress was unrelated to the other sociodemographic, lifestyle and family variables, (all $ps > .13$), and characteristics of the child with ASD (all $ps > .08$). Employment status therefore was controlled in subsequent analyses.

Correlations between affiliate stigma, perceived stress and perceived support

Inverse associations emerged between affiliate stigma and all three social support measures (all $ps < .01$). Perceived stress, which was positively associated with affiliate stigma ($r = .49$, $p < .001$), was inversely associated with all three social support measures (all $ps < .001$). A correlation matrix displaying relationships between study variables is presented in Table 1.

INSERT TABLE 1 HERE

Multiple mediation model

Affiliate stigma predicted support from family ($\beta = -3.31$, $t = -3.54$, $SE = .93$, $p < .001$) and significant others ($\beta = -4.59$, $t = -4.59$, $SE = .99$, $p < .0001$), but not from friends ($\beta = -.94$, $t = -1.17$, $SE = .81$, $p = .24$). Adjusting for affiliate stigma, family support ($\beta = -.26$, $t = -4.39$, $SE = .06$, $p < .0001$), but not support from friends ($\beta = .04$, $t = .67$, $SE = .06$, $p = .51$) or

significant others ($\beta = .00, t = -.00, SE = .06, p = .99$), predicted perceived stress. The total effect of affiliate stigma on perceived stress was significant; greater affiliate stigma predicted higher perceived stress ($\beta = 7.33, t = 9.05, SE = .81, p < .0001$). The direct effect of affiliate stigma on perceived stress, after adjusting for all three types of support, was significant ($\beta = 6.04, p < .0001$); however, the magnitude of the effect was reduced by 19.5%. These data satisfy criteria for partial mediation as per Baron and Kenny (1986). The overall model, including affiliate stigma and three types of social support, accounted for 31% of the variation in caregivers' perceived stress ($F(4, 256) = 29.06, p < .0001$).

An indirect effect of affiliate stigma on perceived stress via family support ($CI_{95} = .24, 1.86$), but not support from friends ($CI_{95} = -.61, .12$) or significant others ($CI_{95} = -.87, .74$), was observed. These data implicate lower support from family as one mechanism by which greater affiliate stigma might translated into higher perceived stress for caregivers of children with ASD. Figure 1 displays results from the multiple mediation model.

INSERT FIGURE 1 HERE

Discussion

This study explored whether the relationship between affiliate stigma and perceived stress in caregivers of children with ASD might occur indirectly via multiple types of social support. Results resonate with other recent studies involving caregivers of children with ASD, in which affiliate stigma positively, and perceived social support negatively, predicted psychological distress (Banga et al., 2017; Dalky et al., 2017; dosReis et al., 2012; Hinshaw & Stier, 2008; Young et al., 2016). In the current study, it was lower perceived support from family, not friends or significant others, that predicted greater perceived stress. This finding might not be surprising given it tends to be family, particularly parents and grandparents, that

caregivers rely on to assist with their caretaking responsibilities (White et al., 2004). Findings reported here are also commensurate with research, both quantitative and qualitative, that found self-stigmatising caregivers use social withdrawal to cope with judgemental reactions from the public, and from family (Broady et al., 2017). Indeed, self-stigmatising have been shown to be less likely to access support when it is available (Eaton et al., 2016).

Here, data revealed an indirect effect of affiliate stigma on perceived stress via family support. That is, caregivers who reported greater affiliate stigma perceived support from their family to be lower, and this was associated with higher perceived stress. These findings might inform intervention efforts. Indeed, with a view to reducing perceived stress, psychotherapeutic interventions might do well to target caregivers with higher affiliate stigma and lower perceived family support. To date, psychotherapeutic, and particularly psychoeducational, interventions have been shown to be associated reductions in affiliate stigma for both care provider and care recipient (Perlick et al., 2011; Mittal et al., 2014). Most recently, in one study involving caregivers of loved ones with schizophrenia, peer led (i.e., by another caregiver) psychoeducation, which involved caregivers sharing their experiences of, and ways of coping with, stigma, was associated with marked reductions in affiliate stigma two months post intervention (Vahgee et al., 2015). Other studies also found psychoeducation, using a peer-led format, to be effective for reducing caregivers' affiliate stigma (Yang et al., 2013). Collectively, these findings suggest ASD caregivers might benefit from family, peer led interventions that allow for sharing their experiences of, and methods for coping with, affiliate stigma. Moreover, in addition to reduced self-stigma, caregivers who engage with peer led interventions also report increased perceived availability of social support. Researchers speculate it might be via these new support networks that affiliate stigma is reduced (McFarlane et al., 2002). In addition, by challenging stereotypes, and by hearing their peers speak positively about support from relatives, caregivers who engage with

these interventions might also be more likely to seek out support from family. The effectiveness of psychoeducational, particularly peer led, interventions for reducing affiliate stigma, and the possible mediating role of increased perceived availability of support, might be the subject of future research with ASD caregivers.

In conclusion, this study implicates lower perceived support from family, but not from friends or significant others, as one pathway that partially mediates the association between greater affiliate stigma and higher perceived stress in caregivers of children with ASD. These findings have implications for identifying caregivers who, by virtue of experiencing higher perceived stress, might be at risk for providing lower quality care. Whether interventions that reduce affiliate stigma are advantageous for reducing caregivers' psychological distress, and whether increased perceived availability of support might underlie this effect, might be the subject of future research.

Conflict of Interests

Authors declare no conflict of interest.

Acknowledgements

The research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

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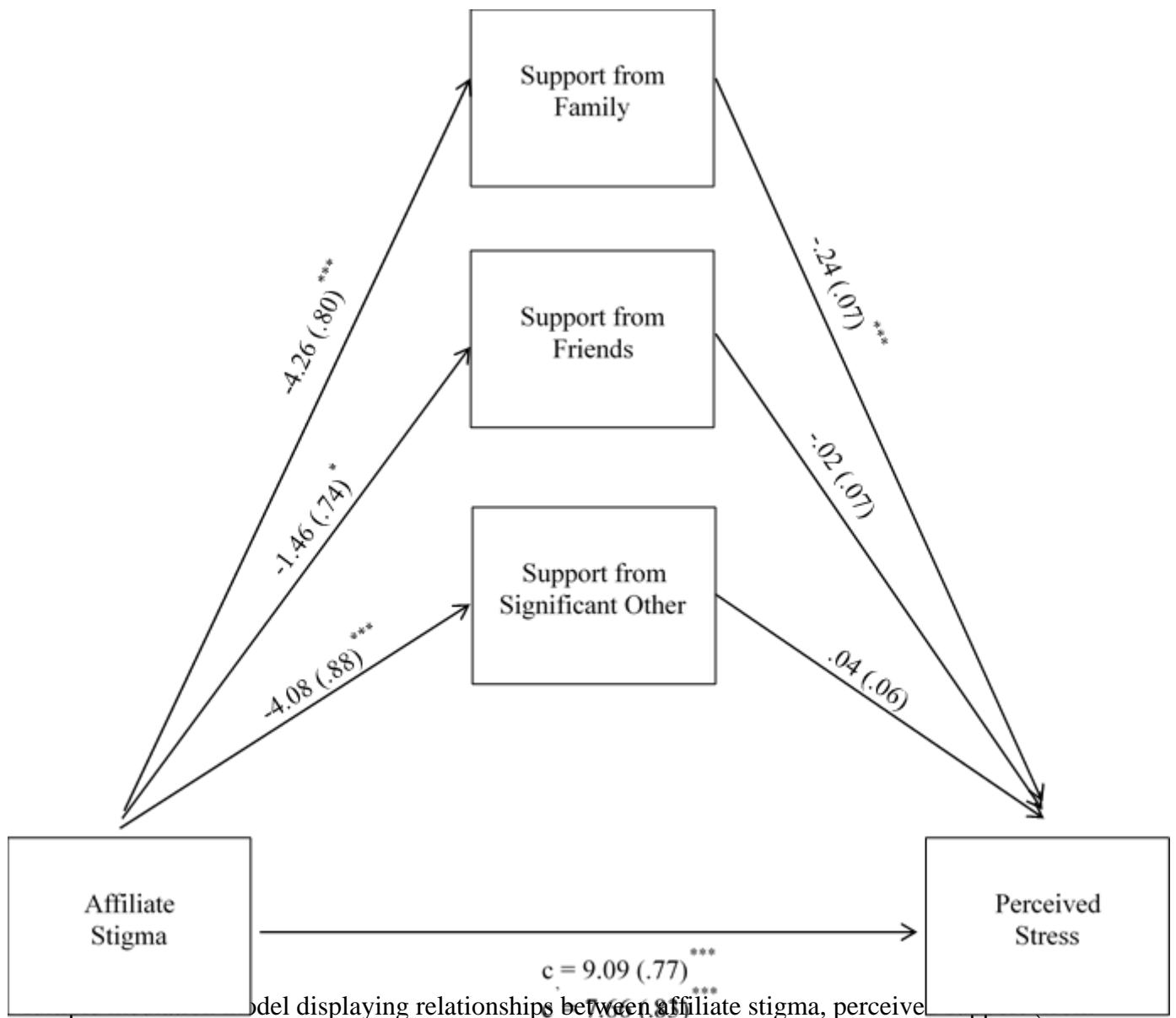
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Table 1

Descriptive Statistics and Correlation Coefficients for Affiliate Stigma, Perceived Support from Family, Friends and Significant Others, and Perceived Stress

	<i>M</i>	<i>(SD)</i>	1	2	3	4	5
1. Affiliate stigma	2.0	.29	-				
2. Perceived stress	25.5	4.3	.49**	-			
3. Perceived support (significant other)	18.7	4.8	-.27**	-.25**	-		
4. Perceived support (family)	13.9	5.0	-.32**	-.41**	.53**	-	
5. Perceived support (friends)	14.5	4.5	-.27**	-.25**	.50**	.60**	-

Note: $n=124$ ** $p < 0.01$



Model displaying relationships between affiliate stigma, perceived stress, and support (from family, friends and significant others) and perceived stress