CITATION:

Recio, P., Molero, F., García-Ael, C. y Pérez-Garín, D. (2020). Perceived discrimination and self-esteem among family caregivers of children with autism spectrum disorders (ASD) and children with intellectual disabilities (ID) in Spain: The mediational role of affiliate stigma and social support. *Research in Developmental Disabilities*, *105*. <u>https://doi.org/10.1016/j.ridd.2020.103737</u>

Perceived discrimination and self-esteem among family caregivers of children with autism spectrum disorders (ASD) and children with intellectual disabilities (ID) in Spain: The mediational role of affiliate stigma and social support

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Funding: This research received a grant from the Spanish Ministry of Economy and Industry PSI2017-88455-R.

Conflict of Interest Statement. The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as potential conflicts of interest.

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Running head: Affiliate stigma and self-esteem in caregivers

Abstract

Background. People with autism spectrum disorders (ASD) and people with intellectual disabilities (ID) are stigmatized, and therefore discriminated against worldwide and, on many occasions, this stigma and discrimination are expanded to include their family caregivers. The main objective of this research was to examine the consequences of perceived discrimination on family caregivers of children with ASD and children with ID. Methods. The sample consisted of 109 Spanish caregivers of children with ASD and 83 caregivers of children with ID. They completed four questionnaires: Multidimensional Perceived Discrimination Scale, Affiliate Stigma Scale, Social Support Questionnaire and Rosenberg Self-Esteem Scale. Results. Using path analysis, we found support for a model in which personal discrimination perceived by caregivers was positively associated with affiliate stigma, which, in turn, was negatively related to caregivers' self-esteem. The model also shows the total mediational role of affiliate stigma in the association between perceived discrimination and self-esteem and the partial mediational role that social support plays in the association between perceived discrimination and caregivers' self-esteem. Conclusions: Caregivers' perceived discrimination negatively influences caregivers' self-esteem, but

this relationship is mediated by both affiliate stigma (totally) and social support (partially). These results have theoretical and practical implications and may contribute to improving the quality of life of parents of children with ASD and ID that in turn would result in an improvement of the quality of life of their children.

Keywords: Affiliate stigma, Self-esteem, Social support, Autism spectrum disorders, Intellectual disabilities, Family caregivers

What this paper adds

This study explores, through path analysis, the mediational role that affiliate stigma and social support may play in the association between perceived discrimination and self-esteem among mothers and fathers of children with ASD and ID in a Spanish sample. This research is new in at least two aspects. First, because it focuses on one of the antecedents of affiliate stigma, which is parents' perceived discrimination. As far as we know, it is the first study exploring this antecedent of affiliate stigma. Second, because the proposed model explores how caregivers' perceived discrimination impacts an important psychological variable—caregiver self-esteem—and the protective role that social support may play.

We found that caregivers' perceived discrimination negatively influences their selfesteem, but this relationship is mediated by both affiliate stigma (totally) and social support (partially). These results have theoretical and practical implications and may contribute to improving the quality of life of parents of children with ASD and ID that in turn would result in an improvement of the quality of life of their children.

1. Introduction

There is a great amount of research showing that people with autism spectrum disorders (ASD) and people with intellectual disabilities (ID) are stigmatized, and therefore discriminated against worldwide (Lowell & Wetherell, 2018; Scior & Werner, 2016; Ting, Yiting, & Chunli, 2018). Stigmatized individuals are those that possess (or are believed to possess) some attribute or characteristic that conveys a social identity that is devaluated in some particular context (Crocker, Major, & Steele, 1998). In the case of people with ASD, perceived or experienced stigma has been reported in several countries, both by people with ASD and by their parents (Obeid, Daou, DeNigris, Shane-Simpson, Brooks & Gillespie-Lynch, 2015). In some cases, the performance of disruptive behaviors (such as flapping, flailing, or self-injury) may lead to the social rejection both of children and parents of people with ASD (Obeid et al., 2015). In other cases, the absence of visible markers may contribute to stigma because people may perceive an apparently "normal" person behaving in a socially inappropriate manner (Gray, 2002). Regarding people with ID, mixed reactions are reported. Some observers may respond to intellectual disability with compassion or sympathy, but in other cases ID elicits negative stigmatizing emotions such as pity, anxiety, or hostility, which can lead to the rejection and avoidance of interaction with people with ID (Scior, 2016). Nonetheless, the stigmatization experienced is very detrimental for the psychological well-being of both children and their parents (Ali et al., 2012).

As Goffman (1963) pointed out, even in his earliest work, the stigma borne by an individual can spill over to people associated with them (friends, relatives). This phenomenon has received several names, such as courtesy stigma, family stigma, stigma by association, and, more recently, affiliate stigma. In this research we focus on the concept of affiliate stigma (or internalized stigma by association) as experienced by family caregivers of children with ASD and ID.

The aim of this study is to explore, through path analysis, the mediational role that affiliate stigma and social support may play in the association between perceived discrimination and self-esteem among the mothers and fathers of children with ASD and ID in a Spanish sample. This research is new, at least in two aspects. First, because it focusses on one of the antecedents of affiliate stigma, which is parents' perceived discrimination. As far as we know it is the first study exploring this antecedent of affiliate stigma. Second, because the proposed model explores how caregivers' perceived discrimination impacts on an important psychological variable—caregivers' self-esteem—and the protective role that social support may play.

2. Perceived discrimination, affiliate stigma, social support and self-esteem in family caregivers

Perceived discrimination may be defined as the awareness of public stereotypes and discrimination that exists toward members of a group. The meta-analysis of Schmitt, Branscombe, Postmes, and Garcia (2014) shows that perceived discrimination has significant negative effects on several aspects of the health and well-being of members of various stigmatized groups (African Americans, gays and lesbians, people with mental illness, and people with physical disabilities, among others). Moreover, perceived discrimination has been found to be related to the internalization of stigma (the individual's endorsement of negative social stereotypes and self-blame for them) among people with physical disabilities (Molero, Recio, García-Ael, & Pérez-Garín, 2019) or people with mental illness (Pérez-Garín, Molero, & Bos, 2017). In the study of Molero et al. (2019) it was also found that internalized stigma was negatively associated with the self-esteem of people with physical disabilities. In the aforementioned literature, the focus of interest was the discrimination perceived by the stigmatized individuals. In the current research we are going to focus on the discrimination experienced by the family caregivers (mothers and fathers) of children with ASD or ID. Perceived discrimination and stigma has been reported both by parents of children with ASD (Gray, 2002, Lowell & Wetherell, 2018; Obeid et al., 2015) and ID (Banga & Ghosh, 2017; Chiu, Yang, Woing, Li, & Li, 2013). We assume that, in the same way that stigmatized individuals internalize the public stigma against them, family caregivers also internalize the public stigma borne by their children (for example, feeling guilty or embarrassed for their child's behaviour or disability). Mak and Cheung (2008) coined the concept of affiliate stigma as a construct different to courtesy or associative stigma which refers specifically to the self-stigma (and corresponding psychological responses) of the parents or caregivers of stigmatized groups.

Since then, several studies have shown the negative effects of caregivers' affiliate stigma on their stress, psychological and emotional well-being, and subjective burden (Mak & Cheung, 2008, 2012; Mitter, Ali, & Scior, 2019; Ting et al., 2018 and Werner & Shulman, 2015). One of the variables that has been found strongly (and negatively) associated with affiliate stigma is caregiver's self-esteem (Shi et al., 2018). This association should not be surprising because affiliate stigma is the caregiver's self-identification with the negative public stereotypes about ASD or ID disabilities. Thus, it is not strange that, to the extent the caregiver feels guilty or ashamed for their child's disability, their sense of self-worth or self-esteem is diminished. Self-esteem can be defined as an individual's attitude about him or herself, involving self-evaluation along a positive/negative dimension (Baron & Byrne, 1991). The importance of self-esteem in caregivers' psychological well-being is shown in several studies. For example, Cantwell

et al. (2015) found that self-esteem mediated the relation between stigma and depression symptoms in parents of children with ASD/ID. Similarly, the study of Werner and Shulman (2013) shows that self-esteem contributes to the subjective well-being of parents with children with ASD.

Traditionally, social support has been considered a buffer or protective variable on the negative effects of discrimination on the health and well-being of stigmatized people. Social network support and high-quality interpersonal relationships are considered essential for reducing the effects of stress produced by discrimination. In the above-mentioned meta-analysis (Pascoe & Smart Richman, 2009), it was found that social support was a moderating variable between perceived discrimination and negative effects on mental health in various discriminated groups. Ma and Mak (2016) found that perceived social support contributes to reducing affiliate stigma and preventing psychological distress in family caregivers of children with physical disability (PD).

3. The present research

The main objective of this research was to examine the consequences of perceived discrimination in family caregivers (mothers and fathers) of children with ASD and children with ID. We used path analysis to test a model in which personal discrimination perceived by caregivers is associated (positively) with affiliate stigma, which, in turn, is negatively related to caregivers' self-esteem. We predict a negative association between perceived discrimination and social support, and a positive association between perceived social support and caregivers' self-esteem. Both affiliate stigma and social support would play a mediational role in the relationships between caregivers' perceived discrimination and caregivers.

This model (see Figure 1) was derived from the literature and, as far as we know, has not been tested previously in family caregivers of people with disability.

4. Method

4.1. Participants

The sample consisted of 192 caregivers (fathers and mothers) of children with autism spectrum disorders (109) and of children with intellectual disabilities (83) ranging from 25 to 61 years (M = 41.82; SD = 6.81). Caregivers were not partners and they each provided information about their perceived discrimination regarding a different child. As in previous studies (Mak & Kwok, 2010), the inclusion criteria were (1) to have a child with ASD or ID (2) that the child's age was up to 18 years (age of the legal majority). The distribution of participants' demographic characteristics may be found in Table 1.

According to the information reported by their parents, children's ages ranged from 2 to 18 years (M = 10.65; SD = 4.01). Eighty-seven of the children had an autism spectrum disorder, and 22 had Asperger diagnoses (Asperger Syndrome AS). Regarding the children with individual disabilities, 51 of them had Down's Syndrome (DS), while 32 of them had unspecified intellectual disabilities or developmental disorders. Most of the children had a similar recognized level of disability (70.74%).

4.2.Measures

To measure perceived discrimination, we used the *Multidimensional Perceived Discrimination Scale* (Molero et al., 2013). This 20-item scale measures the perception of four different types of discrimination: blatant group discrimination, subtle group discrimination, blatant personal discrimination, and subtle personal discrimination. For the purposes of this study, however, we took only the two personal discrimination factors (which show the highest associations with well-being) and grouped them into a single perceived personal discrimination score (e.g., "I have felt personally rejected for having a child with autism spectrum/ with intellectual disability"). For the purposes of this study, we took the two subscales of personal discrimination (10 items) and obtained a single perceived personal discrimination score. The scale showed a high internal consistency ($\alpha = .92$), similar to the one it showed in the original sample ($\alpha = .94$).

Affiliate stigma was measured using Mak and Cheung's (2008) *Affiliate Stigma Scale*, a 19-item instrument that measures the internalized stigma of caregivers of children with disabilities (e.g., "Having a child with a disability makes me feel that I am incompetent compared with other people"). As a preliminary step, a Spanish version of this scale was produced by blind back-translation. Then, two experts (in methodology and in stigma) evaluated, methodologically and substantively, the items of the original scale and of the final translated version. The Cronbach's *alpha* for our sample was .90 (quite similar to the .94 obtained by Mak and Cheung (2008)), indicating good internal consistency.

The Spanish adaptation (Bellón, Delgado, Luna & Lardelli, 1996) of the *Duke-UNC Functional Social Support Questionnaire* (Broadhead, Gehlbach, Degruy & Kaplan, 1988) was used to measure perceived functional social support (e. g., " I have the opportunity to talk to someone about my personal and family problems"). This 11-item scale had a good internal consistency ($\alpha = .91$).

Self-esteem was measured using the Spanish adaptation (Expósito & Moya, 1999) of the *Rosenberg Self-Esteem Scale* (Rosenberg, 1965), which is a 10-item scale (e.g., "Sometimes I feel useless"). This showed a satisfactory internal consistency (α = .86), considerably higher than the one obtained by Expósito & Moya (1999): α = .75). *4.3. Procedure*

Answers to the study were collected through an online questionnaire designed and hosted at www.qualtrics.com. Participants were recruited by undergraduate students, who were asked to send the link to caregivers of children with disabilities in exchange for extra course credits. Once they accessed the link, participants first completed the consent form and then filled out the self-administered questionnaire. Anonymity and confidentiality were guaranteed. Completing the questionnaire took approximately 20 minutes. The study received approval from the National University of Distance Education Ethics Committee and was performed in accordance with the ethical standards of the Declaration of Helsinki.

4.4. Data analyses

First, preliminary data analysis and correlation analysis were performed to explore data adequacy and examine the relationships between the variables using SPSS 25. Next, the proposed model was evaluated through path analysis. Path analysis allows the simultaneous examination of structural relationships, as well as the examination of direct and indirect paths (e.g., Schumacker & Lomax, 2004). After checking the multivariate normality, using Mardia's (1970) multivariate kurtosis coefficient, we used the maximum likelihood estimation method in the path analysis, using AMOS 25 (Arbuckle, 2017). Various goodness-of-fit measures and recommended cut-points were used to assess model fit (Kline 2011): Chi-Square (χ^2), Normed Chi-Square (χ^2 /d.f.), Comparative Fit Index (CFI > .90 acceptable and > .95 desirable), Normed Fit Index (NFI > .90 acceptable and > .95 desirable), Standard Root Mean Square Residual (SRMR < .08 acceptable fit and < .06 good fit).

The mediation effects were analyzed using a bootstrap procedure (5000 resamples) with 95% bias-corrected confidence interval. It is considered that if zero is not included on the interval between the lower and the upper bound the effect is statistically significant at p < 0.05. The bootstrap procedure is useful for assessing mediation effects because it provides reliable estimates of direct and indirect effects, and more valid

confidence intervals than those calculated through the traditional Sobel test (Cheung & Lau, 2008). The direct effect is analyzed before and after introducing the mediator variable, to determine whether doing so eliminates the direct path (total mediation) or reduces it significantly (partial mediation).

5. Results

5.1. Preliminary data analysis

The percentage of missing values did not exceed 2% for most items and so no imputation was performed. Only one participant was excluded from the final sample because of missing data (more than four items missing from at least one of the subscales), so the sample size for descriptive, correlation, and path analysis was 191.

In Structural Equation Modelling (SEM) sample size depends on model complexity but also on many other factors (e.g., normality of the data, missing patterns). Most researchers would recommend using sample sizes of at least a ratio of 10 cases per parameter estimated (for an overview, see Kline, 2011). We estimated nine parameters in our model, so according to this standard, our sample size (191 participants) was appropriate.

There were no differences according to the type of disability of the child (p > .05) in any of the variables studied in the model (perceived personal discrimination, affiliate stigma, perceived social support and self-esteem). Likewise, the pattern of correlations between the variables was similar in parents of children with ASD and parents of children with ID. With respect to the children's age, considering four age groups, we did not find significant differences in any of the dependent variables. Regarding parents' gender, no differences were found in the study variables, except for the case of self-esteem (F(1,188)= 7.36, p = .007, $\eta^2 = .038$), which was higher in men than in women, as is usual in the literature (for reviews, see for example, Kling et al., 1999). The correlation pattern was similar for both genders. Finally, with reference to socioeconomic status (educational level and employment), we found no differences depending on the educational level (p > .05) or employment (p > .05) in any of the variables, which is in line with the data obtained by Zhou et al. (2018) with a sample of caregivers of children with Autism Spectrum Disorders.

5.2. Descriptive analysis and correlations

Descriptive analysis and Pearson's correlation coefficients for all variables in the study are presented in Table 2. Bivariate Pearson correlation analysis showed that all variables were significantly correlated. The correlation pattern was consistent with expectations. Thus, personal discrimination was positively related to affiliate stigma and negatively to social support and self-esteem. On the other hand, perceived social support and self-esteem correlated positively with each other and negatively with affiliate stigma. *5.3. Model testing and mediation analysis*

The standardised coefficients of all paths of the model were significant (see Figure 1). Overall, the model presented an excellent model fit (χ^2 /df = 0.14, CFI = 1.000, NFI = .999, SRMR = .006, RMSEA = .000). The results indicated that, for parents of people with ASD or ID, personal perceived discrimination predicts affiliate stigma (β = .53, *p* = .000), which predicts self-esteem (β = -.33, *p* = .000). Moreover, we found a significant and negative association between personal perceived discrimination and perceived social support (β = -.32, *p* = .000) which, in turn, was negatively related to affiliate stigma (β = -.23, *p* = .000) and positively related to self-esteem (β = .24, *p* = .000).

To examine the mediating effect of each mediator, the path from perceived personal discrimination to the other mediator was eliminated such that there was only one mediator at a time. The summary of direct and indirect effects is provided in Table 3. The direct effect between perceived personal discrimination and self-esteem was $\beta = -.0.25$. When affiliate stigma was introduced as a mediator, the direct effect dropped to $\beta = -.01$. This decrease in direct effect, which was no longer significant, indicated a total mediating effect. The bootstrapping results revealed that the mediating effect of affiliate stigma gave rise to significant indirect relationships ($\beta = -.26$, p = .00; 95% CI: -.40, -.16).

Similarly, when perceived social support was introduced as a mediator, the direct effect decreased from -.25 to -.15. This decrease in direct effect, while remaining statistically significant, indicates a partial mediating effect. Perceived social support was a significant partial mediator on the relationship between perceived personal discrimination and self-esteem, with an indirect effect of $\beta = -.10$, p = .00; 95% CI: -.18, -.05.

There was a third mediation in our model since social support mediated the relationship between personal discrimination and affiliate stigma. The direct effect between perceived personal discrimination and affiliate stigma was $\beta = .60$ (p = .00) and it decreased to $\beta = .05$ (p = .00) when perceived social support was introduced to the model (partial mediation). Perceived social support was also a significant partial mediator on the relationship between perceived personal discrimination and affiliate stigma, with positive and statistically significant indirect effects ($\beta = .07$, p = .00; 95% CI: .03, .14).

6. Discussion

Worldwide, children with ASD and ID and their families experience stigma and discrimination in many aspects of their lives. This stigmatization is very detrimental for the psychological well-being of both children and their parents (Ali et al., 2012). In this research we focus on the effects of discrimination and stigma on children's caregivers. We propose a model in which caregivers' perceived discrimination is positively

associated with experienced affiliate stigma, which in turn is detrimental for caregivers' self-esteem. The model also predicts that social support will play a protective role, both in the generation of affiliate stigma and on the negative association between perceived personal discrimination and self-esteem.

The proposed model shows a good fit for the data. As predicted, we found a high association between parents' perceived discrimination and affiliate stigma. As far as we know, this is the first time that this relationship has been empirically tested. However, studies conducted with other stigmatized groups, such as people with mental illness (Pérez-Garín, Molero y Bos, 2017) and people with physical disabilities (Molero et al., 2019) have already found an association between perceived discrimination and internalization of stigma by stigmatized individuals. We also found that affiliate stigma negatively influences caregivers' self-esteem. Although the research on affiliate stigma is currently limited the studies of Cantwell et al. (2015), in a sample of parents of children with ASD/ID, and Werner and Shulman, (2013) in a sample of parents of affiliate stigma on caregivers' self-esteem.

The mediation of affiliate stigma in the association between perceived discrimination and caregivers' self-esteem is total. That means that when family caregivers perceive the existence of public stigma (for example, when they are rejected or excluded from a social relationship for having a child with ASD or ID), this perception may easily lead to the internalization of the stigma (affiliate stigma) that in turn leads to a decline in their self-esteem. Finally, the model shows a double protective effect of social support. On the one hand, social support exerts a buffer effect (partial mediation) on the association between perceived discrimination and affiliate stigma, while on the other hand social support mediates the association between perceived personal discrimination and parents' self-esteem. These results are consistent with the literature because, traditionally, social support has been considered a moderating variable of the negative effects of discrimination and stigma on health and well-being in several stigmatized groups (e.g., Pascoe & Smart Richman, 2009). Social network support and high-quality interpersonal relationships are considered essential for reducing the effects of stress produced by discrimination (Pisula & Banasiak, 2019). In the same way, with a sample of caregivers of children with physical disability, Ma and Mak (2016) found that social support decreased participants' level of worry, affiliate stigma, and psychological distress.

In summary, this research contributes to better knowledge of the affiliate stigma in parents of children with ASD and ID and its association with some important psychosocial variables such as perceived discrimination, social support and self-esteem. In future research, it will be necessary to explore the directionality of the influence between affiliate stigma and self-esteem. Does low self-esteem facilitate the emergence of affiliate stigma or is it affiliate stigma that diminishes caregiver self-esteem? Both statements are probably true, but only thorough longitudinal studies will be able to discern the predominant direction of the association between these variables. In this research, not unlike the model of Watson, Corrigan, Larson, and Sells, (2007), which is commonly used to explain the effects of internalized stigma in mental illness, we consider affiliate stigma as a predictor of self-esteem.

This study contains some methodological limitations that need to be taken into consideration. On the one hand are limitations related to the selection of the sample, which only included parents of children with ASD and children with ID who had the motivation and time to participate in the study. Another possible limitation is that we recruited the opinion of only one parent. It would be interesting to have the perceptions of both parents to study the actor and partner effects with a dyadic analysis (García-López et al., 2016). Finally, our model can be considered limited because other variables may also contribute to mediate the relationship between perceived personal discrimination and self-esteem or affiliate stigma.

Despite these limitations, the results of this study highlight the pattern of relationships between important psychological variables from the perspective of parents of children with ASD and children with ID. These findings yield relevant implications for theory, and practice. Regarding theory, we have confirmed empirically that, at least in the Spanish sample to which we had access, affiliate stigma is strongly related to caregivers' perceived discrimination (or public stigma) present in the society in relation to ASD and ID disabilities. Assuming that social attitudes towards these disabilities are difficult to change in the short term, future interventions aimed at improving caregivers' well-being should be addressed, first to measure the family's perceived social support and, when necessary, to actively help them to maintain an adequate social network support and high-quality interpersonal relationships. Indeed, that will contribute to reduce the internalization of social stigma and to maintaining a good level of selfesteem among mothers and fathers of children with ASD and ID.

7. Conclusions

In this research, we focus on the effects of discrimination and stigma on the caregivers of children with ASD and ID. We propose a model in which caregivers' perceived discrimination is positively associated with experienced affiliate stigma, which in turn is detrimental for caregivers' self-esteem. The model also predicts that social support will play a protective role, both in the generation of affiliate stigma and on the negative association between perceived personal discrimination and self-esteem.

The proposed model presents a good fit for the data, and all predicted associations between variables are significant. The mediation of affiliate stigma in the association between perceived discrimination and caregivers' self-esteem is total. Moreover, we found a double protective effect of social support. On the one hand, social support exerts a buffer effect (partial mediation) on the association between perceived discrimination and affiliate stigma, while on the other hand social support mediates the association between perceived personal discrimination and parents' self-esteem.

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Figure 1. Standardised path coefficients among variables. All path coefficients are statistically significant.

Table 1.

Participants' sociodemographic characteristics

	Mothers	Fathers	
	75.3%	24.7%	Children
	(n = 143)	(<i>n</i> = 47)	
Education level			
Primary school	7 (10)	10.6 (5)	
Secondary school	50.3 (72)	57.4 (27)	
University grade	42.7 (61)	31.9 (15)	
Employment			
Employed	73.2 (104)	90 (42)	
Unemployed	26.8 (38)	6 (3)	
Retired	0 (0)	4 (2)	
Main Diagnosis			
Autism Spectrum Disorder (ASD)			
Autism			47.3 (87)
Asperger Syndrome (AS)			9.9 (22)
Intellectual Disability (ID)			
Down's syndrome (DS)			29.1 (51)
Unspecified intellectual disabilities			13.7 (32)
Origin of disability			
Innate disability			90.5(172)
Acquired disability			9.5 (18)

Table 2.

Means (M), Standard Deviations (SD) and Pearson correlation coefficients between the variables in the study (n=191).

	М	SD	2	3	4
1. Perceived personal Discrimination	1.98	.73	.60**	32**	26**
2. Affiliate stigma	1.52	.43		40**	43**
3. Perceived social support	2.73	.60			.37**
4. Self-esteem	3.33	.53			

Note. Scores range from 1 to 4.

* *p* < .05; ** *p* <.01.

Table 3.

Resul	ts of	med	liational	anal	lvsis
	···· J				

Mediation	Direct β without mediator	Direct β with mediator	Indirect β	95% [CI]	Type of mediation
$PPD \rightarrow AS \rightarrow SE$	25***	01	26***	[40,16]	Total
PPD → PPS → SE	25***	15*	10***	[18,05]	Partial
$PPD \rightarrow PPS \rightarrow AS$.60***	.53***	.073***	[.03, .14]	Partial

Note: PPD = Perceived Personal Discrimination, AS = Affiliate Stigma, SE = Self-esteem, PSS = Perceived Social Support, CI = Confidence Interval. *p < .05 **p < .01, ***p < .001