Mediating effect of social support on the relationship between resilience and burden in caregivers of people with dementia

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Highlights

- Resilience and social support protect family caregivers of people with dementia against burden.
- The protective effect remained robust after controlling for multiple variables related with caregivers and people with dementia.
- Social support moderated the protective effect of resilience over burden.

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Abstract

Objective. This study examined different predictive factors of burden in sample of family caregivers of patients with dementia (PWD). In particular, the influence of social support and resilience on burden are tested considering potential mediation effects. **Methods**. A total of 283 primary and family caregivers in Spain were evaluated using a standardized protocol to assess sociodemographic characteristics, clinical state of PWD and specific variables of caregiving and care providers. **Results**. The role of caregiver of PWD was more common in women, reporting significantly higher levels of burden than men. Resilience and social support accounted for the most variance of burden. Furthermore, social support partially mediated the relationship between resilience and burden in caregivers. **Discussion**. Caregivers' resilience and social support are protective factors against burden in family caregivers of PWD. Both factors should be considered for tailored interventions aimed at reducing the health costs of burden in caregivers of PWD.

Key words: burden; caregiving; stress; dementia; psychological and social support.

Introduction

Over 600,000 people—about 1.9% of the overall population—are estimated to be living with dementia in Spain (above EU average of 1.5%), a number which is expected to triple by 2050 (Parés-Badell et al., 2014). In this context, the role of family caregivers becomes crucial due to the limited access to formal caregiving support and rehabilitation programs. Hence, 71% of the annual cost per individuals with dementia falls on family members who are the cornerstone of the long-term caring (The Economist, 2017). It is well-known that providing care for PWD often results in burden and poor quality of life (Adelman, Tmanova, Delgado, Dion & Lachs, 2014; Ruisoto, Contador, Fernandez-Calvo, Palenzuela & Ramos, 2018), which may lead to health problems (Bevans, & Stenberg, 2012) and even an earlier death (Schulz & Beach, 1999). These consequences have been traditionally overlooked by clinicians, and caregivers currently remain as invisible patients (Martín et al., 2002; Schoenmakers, Buntinx, & Delepeleire, 2009).

The term burden was originally defined as "*the extent to which caregivers perceived their emotional or physical health, social life, and financial status as suffering as a result of caring for their relative*" (Zarit, Todd, & Zarit, 1986). Considering caring for PWD as a highly demanding situation, Pearlin, Mullan, Semple, and Skaff, (1990) provided an overarching conceptual model to explain caregivers stress and health outcomes as one process comprising many interrelated conditions such as caregivers´resources and the stressors (primary and secondary) to which they are exposed. Following this model, the assessment of burden in family caregivers of PWD requires both the identification of the demands (nature and magnitude) involved in providing care and the resources to successfully manage them (Collins, & Swartz, 2011). A lack of sufficient internal and external resources to cope with the demands involved in providing care to PWD would increase the risk of burden (Adelman et al., 2014; Kim, Chang, Rose, & Kim, 2012). However, providing care to PWD may lead to

positive experiences (i.e., feeling useful or strengthening relationships) when caregivers' resources and demands are balanced (Tarlow et al., 2004).

Accordingly, different authors have claimed that grounded optimism, (Contador, Fernández-Calvo, Palenzuela, Miguéis & Ramos, 2012), or resilience (Bekhet & Sjostedt, 2018; Fernández-Calvo et al., 2016; Ruisoto et al., 2018) as control-related intrapsychic variables may promote a more successful adaptation to the demands involved in providing care to PWD, reducing the risk of burden and negative health outcomes. Moreover, control-related intrapsychic variables increase the engagement for caregiving demands (Menezes de Lucena, Fernández, Hernández, Ramos & Contador, 2006), ameliorating the probability of institutionalization or abuse of PWD (Gaugler, Kane, Newcomer, 2007; Serra et al., 2018).

Finally, social support (external resources) may also play a protective role in caregivers' burden of PWD (Fauth et al, 2012; Rodakowski, Skidmore, Rogers, & Schulz, 2012; Shiba, Kondo & Kondo, 2016). In spite of this, the scientific literature has been mainly focused on the relationship between primary stressors (e.g., hour of caring) and negative outcomes (e.g., burden), whereas the importance of psychological and contextual factors as protective elements against stress and its negative consequences have received lesser attention. Beyond this point, psychological constructs as resilience have been traditionally conceptualized as personality traits, but broader approaches underline the importance of relational and situational contexts for resilience behavior (see Perkins, & Whittington, 2014).

The main objective of this study was to examine the relationship between resilience and social support as predictors of burden in a large sample of family caregivers of PWD. In particular, we examined the potential effect of social support in the relationship between resilience and burden, controlling the effects of the characteristics of PWD and of their care providers.

Methods

Participants

A convenience sample of 326 family caregivers (67.2% women and 32.8% men) of PWD residing in the community of Castilla and León (northwest Spain) were recruited for this multicenter study. All participants were selected from the referral user lists of the associations of relatives of people with Alzheimer's disease (AD) and other dementias (Valladolid, Burgos, Aranda del Duero, Zamora, Merindades area, and Arévalo), neurology outpatient clinics (Hospital Divino Vallés in Burgos and University Hospital Rio Hortega in Valladolid) and the National Reference Center of AD (Salamanca). As inclusion criteria, all caregivers were relatives or had a close relationship with the patients, assuming the role of primary caregiver without receiving any retribution for this service. Caregivers of institutionalized people and those living in cities far from their relatives with dementia were excluded. Of the 326 caregivers evaluated for the study, those who had been performing caregiving tasks for less than 3 months (n=9) were also excluded. All participants were gave their written informed consent before enrolment in the study. This research was approved by the Bioethics Committee of the University of Salamanca.

Measures

All caregivers underwent a complete structured interview to determine the characteristics of PWD, care-related variables and data about sociodemographic and heath factors of family caregivers. The following scales were included in the assessment protocol:

a) The Informant Questionnaire Cognitive Decline in the Elderly (S-IQCODE, Morales González, González-Montalvo, Del Ser Quijano, & Bermejo-Pareja, 1992). The brief version was used, consisting of 26 items assessing the care recipient's cognitive changes in the last 10 years. Participants respond on a five-point ordinal hierarchical scale ranging from 1 ('has become much better') to 5 ('has become much worse'). This questionnaire showed good diagnostic validity for detection of mild dementia (sensitivity of 86%, specificity of 92%), with higher scores indicating greater decline.

b) The Neuropsychiatric Inventory–Questionnaire (NPI-Q, Boada, Cejudo, Tàrraga, López, & Kaufer, 2002). It consists of a brief 12-item version of the Neuropsychiatric Inventory (NPI), which assesses the severity of psychological and behavioral symptoms of dementia (PBSD) and caregiver distress. The scores range from 1 to 3 points. It has shown good test-retest reliability (r = .89) and convergent validity (r = 0.87 for total symptom) with NPI.

c) Pfeffer Functional Activity Questionnaire (FAQ; Olazarán, Mouronte, & Bermejo, 2005). This version rates performance on 11 items, with responses ranging from 0 to 3 (3 = dependent, 2 = requires external assistance, 1 = has problems but does it without help, 0 = normal). The total score ranges from 0 to 33, with higher scores indicating higher functional dependence for Instrumental Activities of Daily Living (IADL). The FAQ is a valid and reliable tool for the assessment of patients with Alzheimer´s disease, reaching a sensitivity (0.95) and a specificity (0.88) for dementia screening.

d) Abbreviated version of the Zarit Caregiver Burden Interview (Gort et al., 2005). It consists of 7 items to assess the severity of burden. Items are scored on a five-point ordinal Likert-type scale, ranging from 1 (*never*) to 5 (*nearly always*). It has been useful for the identification and follow-up of caregivers´ burden in palliative care patients. The 7– item brief version is frequently used in caregivers of PWD because it shows good psychometric properties (Bédard, Pedlar, Martin, Malott, & Stones, 2000).

e) Hospital Anxiety and Depression Scale (HADS, Quintana et al., 2003). It is a 14-item, self-reporting screening scale, containing two 7-item Likert scales, one for anxiety and one for depression. The scores of both scales range from 0 to 21; total HAD score is obtained by summing items of each subscale. It has a good internal consistency (Cronbach's alpha value for Anxiety was .86 and, 0.86 for Depression). Concurrent validity with the Beck Depression Inventory and State-Trait Anxiety Inventory were also high.

f) Questionnaire of Health SF-12 (Vilagut et al., 2005). It consists of 12 items obtained from a broader version (SF36). Scores s range from 0 to 100 and the higher values indicate a greater level of physical and mental health. It showed acceptable reliability with a Cronbach alpha value of 0.70 and high correlations with other health indicators.

g) Connor-Davidson Resilience Scale (CD-RISC, Connor & Davidson, 2003). It comprises 25 items, each rated on a scale ranging from 0 to 4 points, with higher scores reflecting greater resilience. It shows good internal consistency (Cronbach's alpha value was 0.89) and test–retest reliability, with intraclass correlation coefficient of 0.87. It also presents good convergent validity with the Kobasa hardiness measure (Kobasa, 1979) and divergent validity with Cohen stress measure (Cohen, Kamarck, & Mermelstein, 1983).

h) Duke-Unc Social Support Questionnaire (De la Revilla Ahumada et al., 1991). It consists of 11 items to measure the individuals´ perception of the amount and type of personal social support. Participants respond on a 5-point scale ranging from 1 (*much less than I would like*) to 5 (*as much as I would like*). The instrument showed high internal consistency and convergent validity. Test-retest reliability was .85. The factorial analysis confirmed the existence of two components: Confidant and Affective Social Support.

Procedure

Initially, the cooperation of family caregivers in the study was requested through a letter and an authorization to contact them in person. Then, eligible participants were informed of the study's objectives, and the confidentiality of their data was guaranteed. Their participation in the study was made effective after signing the informed consent. In the initial phase, an interview was conducted with the caregivers to register the characteristics of the care recipients (e.g., severity of cognitive- functional impairment, presence of psychological and behavioral symptoms) and care-related variables. Subsequently, a standardized protocol was applied to the family caregiver to assess basic sociodemographic information, health-related factors, and diverse aspects such as burden, resilience, and perceived social support.

Statistical Analyses

All data analyses were performed using the Statistical Package for the Social Sciences, version 21 for Mac (IBM Spain, Madrid, Spain). The descriptive analysis of the sample included the means and standard deviations ($M \pm SD$) for the quantitative variables, while frequencies and percentages were used for the nominal variables. Pearson's correlation analysis between variables was used to explore the relation between quantitative variables, *t*-tests were used to examine differences between two independent samples. One-way analysis of variance (ANOVA) were used to compare groups, and Levene's test to examine equality of variance across groups. Subsequently, independent hierarchical multiple regression were conducted to examine the effect of resilience or social support (Step 2) on burden, controlling for different covariates significantly associated with the outcome (Step 1). Detection of multicollinearity was performed using the Variance Inflation Factor (VIF), with VIF > 5 as cut-off point for diagnosis of collinearity (Sheather, 2009). The multiple determination coefficient for multiple regression (R^2) was evaluated in conjunction with residual plots to assess goodness of fit of the regression model to the data and rule out potential biases. Finally, indirect and interaction effects of social support on the effect of resilience on burden were examined using the bootstrap method with the Process macro version 3.3 (Hayes, 2017) for SPSS. The number of bootstrap samples was set at 10,000. The Sobel test was also conducted to test mediation effect of social support on the relationship between resilience and burden. Complementary, Baron and Kenny´s (1986) mediational triangle was used to visually display the mediation effects. The general significance adopted in the statistical analysis was $p < .05$.

Results

Sample characteristics.

Out of 317 eligible individuals, 34 were excluded from statistical analyses because they did not fully complete the protocol. The final sample was made up of 283 family caregivers with their respective PWD (Table 1).

[INSERT HERE TABLE 1]

Overall, caregivers were family members (mainly women), cohabiting at home, who had provided care for almost 4 years on average, with a good prior relationship with the PWD. At least, 97.9% of caregivers reported primary education or higher. Significant sex differences were found in caregivers age, $t_{(281)} = 7.167$, $p < .001$, with men being older (67.85 ± 13.90) than women (55.81 ± 13.15). On average, women become caregivers a decade earlier than men.

Relationship between burden and caregiver or PWD variables

Burden scores were significantly higher in women than in men (10.41±6.89 vs. 7.830 ± 5.86, $t_{(281)} = -3.370$, $p < .001$), particularly among those caregivers who rated their previous relationship with the PWD as "bad" versus caregivers with a "good" relationship (15.26 ± 7.07 vs. 8.92 ± 6.49, $t_{(281)} = 4.08$, $p < .001$). No significant differences were found in burden when taking into account the following variables: PWD kinship, educational attainment or sex of caregiver or PWD, living status, marital status, and type of dementia. In addition, burden scores correlated significantly with the intensity of PWDs' cognitive decline ($r = .217$, $p < .001$), the presence of PBSD ($r = .268$, $p < .001$), and their degree of dependence in daily life activities ($r = .242$, $p < .001$). Caregivers' burden scores were also associated with anxiety ($r = .306$, $p < .001$) and depressive symptoms ($r = .286$, $p < .001$). In contrast, caregivers' burden correlated negatively with age ($r = -.189$, $p < .001$), general health ($r = -.325$, $p < .001$) and perception of social support ($r = -.277$, $p < .001$) or resilience ($r = - .218$, $p < .001$). Finally, burden scores failed to correlate with the number of hours providing care per day.

Prediction of burden.

The hierarchical multiple regression showed that caregiver's age, quality of the previous relationship, and PBSD were significant predictors on burden scores (Step 1). Moreover, both resilience ($\Delta F_{1, 276}$ =32.24, p<.001) and social support ($\Delta F_{1, 276}$ =55.25, p<.001) scores (Step 2) were also significant after controlling the effects of previous covariates (Table 2). Residual plots (x=standardized regression predicted value, and y= standardized regression residual) were randomly dispersed around the horizontal axis, supporting the appropriateness of the regression model.

[INSERT HERE TABLE 2]

Mediation and moderation analysis

After controlling for significant covariates in the regression models (caregiver´s age, prior relationship, and PBSD), resilience significantly predicted social support (path *a*), b = .205, $t_{(278)}$ = 6.567, p < .001, explaining 18.70% of the variance of social support (p<.001). Social support significantly predicted burden (path *b*), b = -.247, $t_{(286)}$ = -5.699, p < .001, accounting for 46.11% of the variance of burden (p<.001). The direct effect of resilience on caregivers´ burden, ignoring the mediator (path *c*), was significant, b = -.097, $t_{(286)}$ = -4.023, p < .001. Finally, the indirect effect of resilience on burden (path *c´*) after controlling for social support as mediator and for covariates was significant, b = -.051, p < .001, 95% confidence interval (CI) ranging from -.0816 to .0250.

The Sobel test indicated partial mediation (z = -.5116, p < .001) of social support in the relationship between resilience and caregivers' burden. Thus, the difference between indirect (path *c´*) and direct (path *c*) effects was statistically significant, b = -.058 (SE = -.014), 95% CI [-.088, -.03]. However, moderation effects were discarded, as no significant interaction effects were found between resilience and social support (b= -.005, $t_{(286)}$= -1.801, p=.073). Following Baron and Kenny´s (1986) recommendation (Figure 1) visually displays the mediational triangle for the relationship between resilience and caregivers' burden mediated by social support.

[INSERT HERE FIGURE 1]

Discussion

The main contribution of this study is to highlight the role of both resilience and social support as protective variables against burden in family caregivers of PWD. Interestingly, social support mediated the relationship between resilience and burden in caregivers, accounting for a significant amount of variance in this relationship. The link between resilience and social support is consistent with previous research (Bonanno, 2005). Indeed, our findings suggest that resilience is influenced by experience (caregivers' age) and the situational contexts. These results are consistent with the view of other authors indicating that personality traits such as resilience depend on the context and situational cues (Mischel, 2004; Perkins, & Whittington, 2014).

This study also shows the importance of resilience and social support in preventing negative consequences of caring for PWD. Over and beyond the main primary stressors (hours of caring, PBSD, cognitive and functional impairment), our findings underline the importance of positive psychological variables such as resilience to reduce the risk of burden and increase well-being in family caregivers of PWD (Scott, 2013; Van der Lee J, Bakker, Duivenvoorden, & Dröes, 2017;). In particular, this research strengthens the central role of intrapsychic control-related resources to prevent burden (Contador et al., 2012). Furthermore, the subjective appraisal of personal and social resources may facilitate keeping or gaining control, improving the adjustment or coping strategies when facing the high demands inherent in providing care to PWD (Ong, Bergeman, & Boker, 2009).

In this study, women represent the majority of caregivers, playing a primary role in terms of assuming duties associated with caring for PWD (Rivera, Bermejo, Franco, Morales-González, & Benito León, 2009). Moreover, we found greater levels of burden in women caregivers than in men, which is consistent with previous studies (Pöysti et al., 2012; Sharma, Chakrabarti, & Grover, 2016). Although women reported a longer time of caring than men, the increased levels of burden in women may also explained by sociocultural differences in terms of demands on women to assume the main responsibilities of caring. Male caregivers may be less attentive to their emotions, failing to recognize or report distress, or women may apply less effective coping strategies to relieve distress (Papastavrou, Tsangari, Kalokerinou, Papacostas, & Sourtzi, 2009; Pöysti et al., 2012).

This study has some limitations to consider. First, information was collected using self-report instruments, which are subject to social-desirability bias. However, selected scales are well-recognized tools and have reported good psychometric properties. Second, finding of this selected sample might not reflect the whole population of Spanish family caregivers due to the recruitment procedure, which was not based on population census. Nevertheless, the multicenter nature of the study and the large sample size ensure its statistical power to establish reliable inferences and findings. Prospective studies based on mixed methodological approaches (self-report instruments and expert interviews) may help to improve the accuracy of different predictors of burden in family caregivers of PWD.

In conclusion, this study looks into the protective role of resilience and social support against burden in family caregivers of PWD. Resilience and social support were associated with a lower probability of burden, even after controlling the effect of all covariates. Furthermore, social support mediated the effect of resilience on caregivers´ burden. These findings show the need to consider intrapsychic control-related resources and social support as essential components of intervention programs aimed to reduce burden in family caregivers of PWD. Previous investigations have suggested that increasing skills for social problem-solving improve health and well-being in caregivers (Elliot, & Schewchuk, 2003; Elliott, & Pezent, 2008). Likewise, other studies have focused on increasing resourcefulness to deal with caregiving demands (Zauszniewski, Lekhak, Yolpant, & Morris, 2015), reducing burden and negative health consequences in terms of health (Livingston et al., 2014). Future interventions should promote resilience, combining individual and contextual approaches, in order to improve the health of caregivers and quality of life.

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CReditT authorship contribution statement

Pablo Ruisoto: Data curation, Formal analysis, Writing – original draft. **Israel Contador:** Conceptualization, Methodology, Formal analysis, Funding acquisition, Investigation, Project administration, Resources, Writing - review & editing. **Bernardino Fernández-Calvo:** Data curation, Formal analysis, Writing - original draft. **Lídia Serra:** Methodology, Investigation, Writing - review & editing. **Cristina Jenaro:** Conceptualization, Supervision, Writing - review & editing. **Noelia Flores:** Conceptualization, Supervision, Writing - review & editing. **Francisco Ramos:** Conceptualization, Supervision, Writing - review & editing. **Jesús Rivera-Navarro:** Conceptualization, Supervision, Writing - review & editing.

Declaration of Competing interest

The authors declare no conflict of interest.

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Table 1.

Clinical and sociodemographic characteristics of caregivers and people with dementia.

Family Caregivers (N =283)	
Age	59.93 ± 14.56
Sex men/women[a] (% women)	186/97 (65.72)
Relationship[a] (%)	
Son/ daughter/ son or daughter-in-law	157 (55.5)
Husband/wife	115 (40.6)
Other	11 (3.9)
Education attainment[a] (%)	
No education certificate	6 (2.1)
Primary education	92 (32.5)
Secondary/technical education	103 (36.4)
Higher education	82 (29.0)
Previous relationship (% good-very good) [a]	264 (93.3)
Time of care (years)	3.93 ± 3.33
Caregiving per day (hours)	12.59 ± 8.28
Burden (Zarit)	9.35 ± 6.70
Resilience (CD-RISC)	73.90 ± 13.66
Social support (Duke)	27.90 ±7.57
Anxiety (HADS Scale)	6.68 ± 4.44
Depression (HADS Scale)	4.31 ± 3.80
General Health Questionnaire (SF-12)	1.89 ± 0.88
People with Dementia	
Age	83.92 ± 5.37
Sex M/W (% women)	197/86 (69.61)
Education attainment[a] (%)	
No education certificate	97 (34.3)
Primary education	134 (47.3)
Secondary/technical education	29 (10.2)
Higher education	23 (8.1)
Type of Dementia [a] (%)	

Alzheimer's Disease	242 (85.5)
Other dementias[b]	41 (14.5)
Marital status [a] (%)	
Married	166 (58.7)
Widow	109 (38.5)
Others (widow/separated)	8 (2.8)
Living status[a] (%)	
Alone	26 (9.2)
Several people (one home)	247 (87.3)
Several homes (rotation)	10 (3.5)
Informant Test (S-IQCODE)	97.90 ± 20.63
Neuropsychiatric Inventory (NPI)	9.13 ± 6.24
Functional Activities Questionnaire (FAQ)	24.09 ± 9.25

Note. Values indicate means and standard deviations.
a = frequencies and percentages in parenthesis for nominal variables.
[b] = vascular dementia, frontotemporal dementia, secondary dementia and dementia of unknown etiology.

Table 2.

Hierarchical regressions examining the effect of resilience and social support on burden.

Regression Models (steps and predictors)	b	Confidence interval (95%)	*p*	*VIF*
Resilience Model				
Step 1 (R^2 = .362)				
Caregiver's age	-.068	-.116/-.020	**.006**	1.241
Caregiver's sex Previous	1.074	-.382/2.529	.148	1.2010
relationships	-4.819	-7.363/-2.275	**<.001**	1.020
PWD´s cognitive decline	.029	-.025/.084	.291	3.203
Functional activity	.108	-.011/.227	.076	3.084
PBSD	.422	.314/.529	**<.001**	1.130
Step 2 (R^2 = .431)				
Caregiver's age	-.067	-.116/-.020	**.006**	1.241
Caregiver's sex	1.327	-.055/2.710	.060	1.206
Previous relationships	-2.981	-.5.475/-.487	**.019**	1.091
PWD´s cognitive decline	.023	-.029/.075	.388	3.100
Functional activity	.084	-.030/.197	.146	3.209
PBSD	.400	-.298/.403	**<.001**	1.136
Resilience	-.134	.181/-.088	**<.001**	1.131
Social Support Model				
Step 1 (R^2 = .369)				
Caregiver's age	-.068	-.116/-.020	**.006**	1.241
Caregiver's sex	1.074	-.382/.2.529	.148	1.201
Previous relationships	-4.819	-7.363/-2.275	**<.001**	1.020
PWD´s cognitive decline	.029	-.025/.084	-.291	3.084
Functional activity	.108	-.011/.227	.0760	3.203
PBSD	.357	.314/.529	**<.001**	1.130
Step 2 (R^2 = .475)				
Caregiver's age	-.052	-.097/-.008	**.021**	1.252

Caregiver's sex	1.562	-.225/2.899	.022	1.212
Previous relationships	-3.931	-6.269/-1.594	**.001**	1.030
PWD´s cognitive decline	.010	-.041/.060	.705	3.237
Functional activity	.118	.009/.237	.034	3.086
PBSD	.357	.257/.457	**<.001**	1.164
Social support	-.301	-.381/-.222	**<.001**	1.097

Note: b= unstandardized Beta Coefficient; PBSD=psychological and behavioral symptoms of dementia.

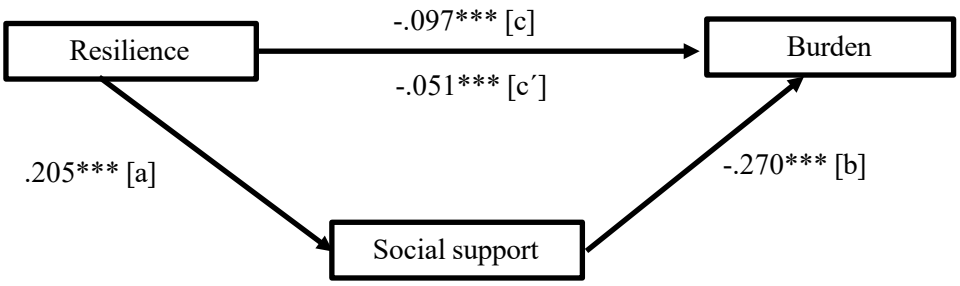

Figure 1. Unstandardized regression coefficients for the mediation effect of social support on the relationship between resilience and burden.

*** = p < .0001