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**Title:** Resilience and social support as protective factors against abuse of people with dementia:

a study on family caregivers.

**Short Running Title:** Protective factors against abuse

Abstract

**Objective.** Scientific literature has identified different vulnerability factors associated to

abuse in people with dementia (PWD), but little is known about the psychosocial

protective variables against abuse. The main objective of this study is to investigate a

set of caregiver and patient factors linked to abuse-related behavior (ARB) of PWD.

Methods. A total of 326 primary and family caregivers, residents of the Castilla and

León community (Spain), were evaluated. All participants filled out a standardized

protocol, which assessed the sociodemographic characteristics, patient and care related

variables, as well as the perceived burden, resilience and social support. ARB was

evaluated using the Caregiver Abuse Screen (CASE). Results. Results show that the

severity of cognitive impairment and behavior disorders of PWD, a greater number of

caregiving hours, a worse previous relationship with the caregiver, and perceived

burden are positively related with abuse. However, resilience and social support showed

a negative relationship with CASE scores, suggesting a protective effect on abuse, even

after controlling the effect of a number of covariates. Indeed, resilience was the only

variable that remained significant after including the effect of burden. Conclusions.

This paper states the role of burden in abuse of PWD, while resilience and social

support are abuse protective factors. These variables should be considered in future

guidelines for the prevention of abuse against PWD.

**Key words:** Dementia; Family Caregivers, Burden, Abuse, Resilience, Social support

### **INTRODUCTION**

Elder abuse has been defined as "(a) intentional actions that cause harm or create a serious risk of harm (whether or not harm is intended) to a vulnerable elder by a caregiver who stands in a trust relationship or (b) failure by a caregiver to satisfy the elder's basic needs or to protect the elder from harm" (Doron & Apter, 2010). It is well known that people with dementia (PWD) may be more vulnerable to abuse, showing an increased risk of suffering this experience, due to their inability to discuss feelings or remember experiences (Cooper et al., 2008). Basically, abuse has been linked to risk factors related to clinical aspects of the person receiving care (e.g., cognitive impairment), to the caregiver (e.g., stress), their relationship (family disharmony) and the environment (e.g., low social support) of the person receiving care (Johannesen & LoGiudice, 2013).

Family caregivers of PWD look after the dependent person voluntarily without pay, complementing the professional services available (Hoffmann & Rodrigues, 2010). The care given to the patient requires time and dedication by the caregiver, which significantly interferes in their quality of life (Farina et al., 2017). Accordingly, previous literature has indicated that stress and subjective burden associated with caregiving are factors related to the appearance of abuse (Yan & Kwok, 2011). For this reason, the caregiver stress-process theory has been proposed as an overarching conceptual model for elder abuse (Pearlin, Mullan, Semple, & Skaff, 1990). Under this conceptual framework, abuse is an outcome related to the response to stressors faced by family members when providing care for a PWD (Pearlin et al., 1990; Cooper, Selwood, Blanchard, Walker, Blizard, & Livingston, 2009; Yon, Wister, Mitchell, & Gutman, 2014). Thus, it seems that the nature and magnitude of the care demands (e.g., hours of caring, behavioral disturbances) will be reflected in the stress and strain experienced by

the caregivers, which in turn, will negatively affect their ability to provide effective care both to themselves and to the older adult, increasing the risk of abuse (Roberto & Teaster, 2017). However, caregivers' psychological aspects (aggressiveness, subjective burden and negative coping strategies) may act as potential mediators of the relationship between care demands and abuse in PWD (Cooper, Selwood, Blanchard, Walker, Blizard, & Livingston, 2010; Compton, 1997; Cooney & Wrigley, 1996). It is noteworthy that protective factors against the abuse of PWD have received limited attention in research (Gaugler et al., 2007).

Resilience refers to the abilities and personal resources of individuals that allows them to successfully deal with adverse situations (Fernández-Calvo et al., 2016). When resilience is present in caregivers of PWD, it allows them to meet the demands of care in a positive and adaptive way. The most resilient formal caregivers are more flexible and better overcome adverse situations compared to those with low resilience (Menezes de Lucena et al., 2006). The reduction of abuse has been related to self-efficacy, expectations and support received from caregivers (Pérez-Rojo et al., 2009). But there are no studies on relationship between resilience and abuse of PWD. Considering that resilience and control constructs, such as optimism, are related to lower burden (Contador et al., 2012; Menezes de Lucena et al., 2006) which is a risk factor for abuse (Yan & Kwok, 2011), resilience is expected to decrease the possibility of abuse. Further, social support may help to confront daily problems or other more serious situations and to integrate the subject into their community and society (Walker, Wasserman & Wellman, 1994), and therefore, people who perceive they have social support are less likely to initiate abuse (Lee, 2008).

The main objective of this study is to understand the key factors of the caregivers and PWD, associated with the appearance of ARB. Currently, the impact of

potential protective factors in family caregivers of PWD is almost unknown. The potential effects of mediation among the different variables present in abuse of PWD are analyzed, and, in particular, burden is examined to see if it has a mediating effect on the resilience or social support relationship with abuse.

#### **METHOD**

### **Participants**

A convenience sample of 326 family caregivers, mainly women (67.2%), of PWD residing in the community of Castilla and León (Northwest Spain) took part in this multicenter study. All participants were selected from the referral user lists of the associations of relatives of people with AD and other dementias (in 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 Alzheimer's disease (Salamanca). All caregivers living at home with PWD were eligible for this study, whereas caregivers of institutionalized people or those living in cities far from their relatives with dementia were excluded. All of them were primary caregivers that offered to participate voluntarily and gave their written informed consent before enrollment in the study. Of the 326 caregivers evaluated for the study, those who had been performing caregiving tasks less than three months (N = 9) were excluded. The study was approved by the Bioethics Committee of the University of Salamanca.

# Instruments

All caregivers underwent a complete structured interview to gather sociodemographic characteristics (of the caregiver and patient), family structure and caregiving characteristics. For the evaluation of the person with dementia, the Informant Questionnaire Cognitive Decline in the Elderly (IQCODE; S-IQCODE, Spanish

version; Morales, González-Montalvo, Del Ser & Bermejo, 1992) was administered to assesses the patient's cognitive changes in recent years. The Neuropsychiatric Inventory (NPI, abbreviated Spanish version; Boada, Cejudo, Tárraga, López & Kaufer, 2002) was used to gather information on the existence of psychological and behavioral symptoms of dementia (PBSD). The Katz Scale (Katz, Ford, Moscowitz, Jackson & Jaffe, 1963) was used to measure the level of dependence and functionality of PWD in activities of daily living and the Spanish 11 items version of Pfeffer Scale (FAQ, Spanish version; Olazarán et al., 2005) to evaluate the instrumental activities of daily living. In the case of the caregiver, the Caregiver Abuse Screen (CASE; Reis & Nahmiash, 1995; Pérez-Rojo, Nuevo, Sancho & Penhale, 2014) was used to measure ARB exerted on the patient by the caregiver. In addition, the following instruments were administered: abbreviated version of the Caregiver Burden Interview (Spanish version; Gort et al., 2005); Hospital Anxiety and Depression Scale (HAD, Spanish version; Quintana et al., 2003) and the General Health Questionnaire (SF-12, Spanish version; Alonso, Prieto & Anto, 1995). Finally, the participants completed the Connor-Davidson Resilience Scale (CD-RISC; Connor & Davidson, 2003) and the Duke-Unc Social Support Questionnaire (Spanish version; De la Revilla et al., 1991) to measure perceived 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. The caregivers were informed of the study's objectives and 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 gather the main

sociodemographic, clinical and caregiving related data of the patient. Subsequently, a standardized protocol was applied to the caregiver who evaluated the characteristics of the person receiving care (cognitive-functional impairment and behavior disorder) and caregiver aspects such as burden, resilience and perceived social support.

# Statistical Analyses

All data analyses were done using the statistical program SPSS 23 (IBM SPSS Statistics version 23). The descriptive analysis of the sample included the means and standard deviations for the quantitative variables, while the frequencies, with their respective percentages, were used for the nominal variables. A Pearson correlation analysis (quantitative variables) and point-biserial correlation (nominal variables) were performed to analyze the relationship between the variables of the caregiver and patient with the ARB. Variables that showed a significant association with the abuse behavior scale scores were selected as covariates for analyses of multiple regression. First, the capacity of the target variables (resilience, social support and burden) to predict ARB was analyzed, controlling the effect of other variables such as the previous relationship with the patient (good-very good vs. regular or bad), caregiving (number of hours), and behavior disorders of the patient. Afterwards, a relational model was carried out with the results of the stepwise multiple regression analyses, in which social support and resilience act as predictor variables of burden and ARB. In the regression equation, two steps were stablished, in which the different standardized independent variables were added successively. Resilience and support were included in the first step, and burden in the second one. Assumptions of normality and independence of the residuals (Durbin-Watson statistic), and absence of collinearity (tolerance index, condition index and variance inflation factor) among the predictor variables were checked to verify the validity of the models. The general confidence level adopted was p <.05.

The presence of mediation effects among the independent (IV) and dependent (DV) variables were established according to Baron & Kenny (1986). The Medgraph program was later used to check if the mediation effect was significant (Sobel test), the direct and indirect effects of the relationship between the independent, mediator and dependent variables, and the "standardized indirect to total ratio index", showing how much of the total effect of the original relationship (IV over DV) is explained by the indirect effect of the mediator variable.

# **RESULTS**

Sample characteristics

Of the 317 caregivers who met the study criteria, 34 did not fulfill the complete protocol data required and were excluded from the statistical analyses. Table 1 presents the characteristics of caregivers and PWD.

Relationship between caregiver and patient variables with abuse scores

The correlation analyses indicated that higher scores in the abuse scale (CASE) were significantly related with the intensity of the patient's cognitive impairment (r = .19, p = .05) and PBSD (r = .38, p = .01). In caregivers, there was a positive correlation among the CASE scores and the number of caregiving hours (r = .14, p = .05), while having a good or very good previous relationship between the caregiver and the PWD is negatively related with abusive behavior (r = .26, p = .01). Perceived burden (r = .51, p = .01), anxiety symptoms (r = .39, p = .01) and depression (r = .35, p < .01) positively correlated with CASE scores, whereas a better general health condition correlated negatively (r = -.15, p = .05). Finally, CASE scores correlated negatively with social support (r = -.27, p < .001) and resilience (r = -.35, p < .001).

### Prediction of abuse-related behavior

The simple linear regression analysis showed that social support (B = -0.31, p<.001) and resilience (B = -0.37, p<.001) variables were associated with less probability of abuse, with an explained variance ratio (R<sup>2</sup>) of 10% and 13% respectively. On the other hand, burden was associated with more probability of abuse (B = 0.50, p<.001), with an explained variance ratio (R<sup>2</sup>) of 25%. Table 2 include several multiple regression models, considering burden, social support and resilience as predictor variables of ARB. Multiple independent regression models indicate that the three variables (resilience, social support and burden) significantly predict CASE scores, even after controlling the effect of other covariates such as PBSD, caregiving hours and previous relationship with the patient. The resilience and burden models explained a higher variance percentage (Table 2).

Finally, a stepwise multiple regression model was conducted to predict ARB (Figure 1). Resilience and social support predicted CASE scores in the first step. However, when burden was introduced in the second step, only resilience remained a significant predictor of CASE scores and the effect of social support disappeared.

Burden as mediator factor of the relationship between social support and abuse-related behavior

According to Baron and Kenny<sup>30</sup>, burden mediates the relationship between social support and risk of abuse, since the effect of social support on the risk of abuse was no longer significant (c') after the inclusion of burden in the model (Figure 2). In addition, the Sobel Test indicated that this mediator effect of burden over the original relationship was significant (z-value = 4.269, p < .001). The indirect effect of social support on the

risk of abuse, through burden, was 0.21 with a "standardized indirect to total ratio" of 0.67. This shows that 67% of the relationship between social support and risk of abuse was accounted for by the burden level of individuals, leaving the other 33% to other possible mediators.

#### **DISCUSSION**

Our findings demonstrate that there are different variables related with the patient, the care context, and the caregiver, which are linked to ARB towards PWD. Specifically, we verified that there is a significant positive relationship between the intensity of cognitive impairment and PBSD of the patient with the probability of suffering abuse. Different studies have also established a relationship between the intensity of cognitive impairment and the risk of abuse (Vandeweerd & Paveza, 2005). Vandeweerd et al. (2013) confirm a positive relationship between the behavior disorders of the patient and the appearance of abuse. The PBSD in PWD are a demanding challenge for caregivers, greatly reducing the quality of life of the patient and caregiver (Khoo, Chen, Ang & Yap, 2013). Despite this, we have not found a relationship between functional alteration and abuse behavior, confirming the results obtained in previous studies (Pérez-Rojo et al., 2009).

Sociodemographic variables of caregivers did not have a significant relationship with the risk of abuse towards PWD. Previous studies support these results showing that gender is not associated with the risk of abuse (Pillemer & Suitor, 1992). Even when some studies have found a higher risk of abuse in men with lower education (Cooper et al., 2008; Kishimoto el al., 2013); an abuser profile based on sociodemographic characteristics still remains unclear (Downes, Fealy, Phelan, Donnelly & Lafferty, 2013). These differences found among studies regarding the existence or lack of relationship between the caregiver's sociodemographic characteristics and abuse can be

justified by social and cultural differences in the population studied (Kishimoto et al., 2013; Yan & Kwok, 2011).

Regarding caregiver's characteristics, results showed a positive relationship between the number of daily caregiving hours and risk of abuse, while a previous quality relationship (good or very good) had a negative relationship. As reported by previous studies, caregiving creates emotional bonds between caregiver and patient that can reduce the effects of negative factors associated with care (Sbern, 2005). Some studies confirm that when the relationship between caregiver and patient is less than good, the risk of abuse increases (Cooney et al., 2006). Similarly, when care activities require more hours (objective burden), the risk of abuse increases as well (Yan & Kwok, 2011). However, Kishimoto et al. (2013) failed to find a positive relationship between the number of caregiving hours and the risk of abuse in people with mild dementia. This result may be explained by the fact that the number of hours increases with the severity of deterioration and its effect depends on mediators factors such as the level of social support received (Dong, 2015; Yan & Kwok, 2011).

The results have also proven that perceived burden in the caregiver significantly increases the risk of abuse. These results are supported by different studies such as those by Pérez-Rojo et al. (2009) and Yan (2014). Burden may increase the risk of a more severe abuse, specifically negligence, towards the PWD (Lee, 2008). However, the risk of abuse decrease with resilient caregiver of PWD. In this sense, Gallicchio, Siddiqi, Langenberg & Baumgarten (2002) indicate that resilient caregivers may be less susceptible to negative behavior triggers in stressful situations. Finally, we found that the risk of abuse towards the person with dementia decreases when caregivers perceive

social support. Previously, other studies showed that the risk of verbal and physical abuse is reduced when social support is perceived. These results are also consistent with Lee (2008), who indicated that low level of formal social support was associated with abuse. According to Acierno et al. (2010), almost all types of abuse (psychological, physical, sexual, economic and negligence) would be associated with lower social support.

Finally, the results from multiple regression models indicate that resilience and social support predict ARB independently, even after controlling the effect of different covariates. When burden was considered in the model, the effect of resilience continued to be significant, but the effect of social support on ARB disappeared. Thus, regardless of burden, the resilient caregiver has less probability of abuse, even considering the effect of all covariates. These results are in accordance with the results of other studies, whose findings show that high levels of resilience reduce abusive behavior in the families (Bolger, Thomas & Eckenrode, 1997). Further, only some types social support (e.g., social interaction) are effective in highly demands situations. When social support is not sufficiently relevant (e.g. lack of meaningful support), its effect can disappear due to the mediation effect of other powerful predictors such as burden (Shiba, Kondo & Kondo, 2016).

This study has some limitations. First, the CASE is a brief self-report measure and the sensitivity of the information provided may have led to the loss of relevant information and influenced its veracity. However, two studies of validation has shown that the CASE has adequate psychometric properties to detect risk of abuse in Spanish elders with dementia (Pérez-Rojo et al., 2014; Rivera et al., 2017). Second, the CASE emphasizes physical items (excluding emotional or financial forms), and no external

resources (e.g., hospital records) were available to corroborate the ARB. However, CASE is a well recognized tool, not only suggestive of different forms of abuse (interpersonal and neglect), but also indicative of stress that could lead to abusive behavior in the future (Reis & Nahmiash, 1995; Rivera et al., 2017). Besides, detection of abuse, a hidden phenomenon, remains a challenge itself and there is no established gold standard for detection. Third, the effects of the different types of social support (formal vs. informal) received by caregivers were not distinguished, and differential effects on ARB prevention should be clarified. Finally, caregivers were selected from hospitals or centers seeking support, which potentially limits the generalization of the results.

This study looks into the risk and protective factors of ARB in family caregivers of PWD. Specifically, this research contributes to understanding the relationships between variables related with the patient, the care context and the caregiver and the risk of abuse towards the PWD. Factors such as severity of cognitive impairment, the presence of psychological and behavioral symptoms in the PWD, a greater number of caregiving hours, a worse previous relationship between the person cared for and the caregiver, and the caregiver's perceived burden, predict ARB. On the contrary, resilience and social support in caregivers are protective factors of abuse. It should be noted that resilience was associated with a lower probability of abuse, even after controlling the effect of all covariates including burden, which mediated the effect of caregiver's social support and the risk of abuse.

This study can help associations or other social and health services create educational and informative programs on abuse aimed at family caregivers of PWD. To clarify and stimulate the training of family caregivers on this issue is key to adequately discriminate and prevent abuse. This also requires appropriate social policies and

awareness programs on caregiver needs and the abuse of PWD. Future longitudinal studies in diverse sociocultural populations will allow a better understanding of the manifestations of abuse in time and create robust theoretical models that can predict abuse in PWD.

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**Table 1.** Clinical and sociodemographic characteristics of informal caregivers and people with dementia

Informal Caregivers	
Age	59,9±14,6
Sex (% women)	186 (65,7)
Relationship* (%)	
Son/ daughter	115 (40,6)
Husband/wife	157 (55,5)
Other	11 (3,9)
Education level * (%)	, · · · ,
No education	6 (2,1)
Primary education	92 (32,5)
Secondary/technical education	103 (36,4)
Higher education	82 (29,0)
Previous relationship (% good-very good)*	264 (92,7)
Time of care (years)	$3.9 \pm 3.3$
Caregiving per day (hours)	$12,6\pm8,3$
Burden (Zarit)	$9,4\pm 6,7$
Resilience (Connor-Davidson)	$73.9 \pm 13.7$
Hospital Scale	
Anxiety	$6,7\pm4,4$
Depression	4,3±3,8
General Health (SF-12)	$1,89\pm0,88$
Caregiver Abuse Screen (CASE)	$6,72\pm4,8$
People with Dementia	
Age	83,9±5,4
Sex (% women)	197 (69,6)
Type of Dementia * (%)	
Alzheimer's Disease	242 (85,5)
Other dementias ¥	41 (14,5)
Marital status * (%)	
Married	166 (58,7)
Widow	109 (38,5)
Others (widow/separated)	8 (2,8)
Living status * (%)	
Alone	26 (9,2)
Several people (one house)	247 (87,3)
Several houses (rotation)	10 (3,5)
Informant Test (S-IQCODE)	$97,9\pm20,6$
Neuropsychiatric Inventory (NPI)	$9,1\pm6,2$
Functional evaluation questionnaire (FAQ)	$24,3\pm 9,3$
Katz Index (quantitative)	$3,8 \pm 2,1$

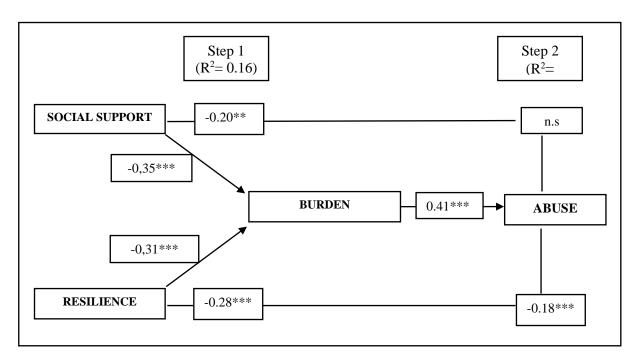
Note. Values indicate means and standard deviations. \* = frequencies and percentages in parenthesis for nominal variables. ¥ = vascular dementia, frontotemporal dementia, secondary dementia and dementia with unknown etiology.

**Table 2.** Multiple regression models to predict abuse-related behavior.

Regression models	Exp (B)*	Confidence interval (95%)	p
<b>Model 1</b> $(R^2 = 0.25)$			
Previous relationship	-0.19	-0.99, -0.29	<.001
Caregiving hours	0.06	-0.00-0.00	0.23
PBSD	0.33	0.07-0.15	<.001
Social support	-0.20	-0.08,-0.02	<.001
<b>Model 2</b> ( $R^2 = 0.29$ )			
Previous relationship	-0.15	-0.87, -0.17	<.01
Caregiving hours	0.06	-0.00-0.00	0.21
PBSD	0.34	0.08-0.15	<.001
Resilience	-0.28	-0.06,-0.02	<.001
<b>Model 3</b> $(R^2 = 0.30)$			
Previous relationship	-0.16	-0.88, -0.21	<.01
Caregiving hours	0.05	-0.00-0.00	0.24
PBSD	0.19	0.02-0.10	<.01
Burden	0.37	0.08-0.15	<.001

Note.  $R^2$  = explained variance; Exp (B) = Standardized Beta Coefficient; PBSD = psychological and behavioral symptoms of dementia

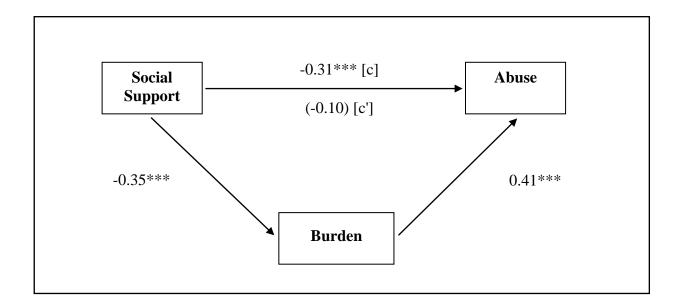
Figure 1. Stepwise multiple regression model to predict abuse-related behavior



Note. Numerical values indicate standardized beta coefficients.

p < .05. \*p < .01. \*\*\*p < .001

**Figure 2.** Burden analysis as mediator in the relationship between social support and abuse-related behavior



Note. [c] = total effect of social support on abuse without the mediator variable. [c'] = direct effect of social support on abuse-related behavior considering the effect of the mediator variable (burden). \*p < .05. \*\*p < .01. \*\*\*p < .001