Antonovsky's Sense of Coherence and Resistance Resources reduce perception of burden in family carers of people with Alzheimer's disease.

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ABSTRACT

Objectives: Taking care of people with dementia (PWD) has been associated with some degree of burden. The variability of the carer's burden can be partially explained by their personal characteristics. Antonovsky's model of health defined the resistance resources (RRs) as essential mechanisms to cope with stressors, and to shape the personal sense of coherence (SOC). This study identifies the RRs related with carer's SOC, and their implications in the perception of burden in family dementia carers.

Methods: A sample of 308 participants from the 'SOC & DEM study' (154 carers and 154 PWD) was recruited from two memory clinics. Carer's personal characteristics of burden, SOC, self-efficacy, coping strategies, perceived social support, and depression were evaluated using standardized instruments. PWD's degree of dependence and behaviour and psychological symptoms of dementia (BPSD) were assessed too. A path analysis was used to test the relationship between caregiver burden and SOC including the personal RRs of the carers and clinical data of PWD.

Results: The path model identified SOC as a major factor related to carer's burden perception ($r=-.327$). Self-efficacy ($r=.285$), two coping strategies, 'use instrumental support' ($r=-.235$) and 'behavioural disengagement' ($r=-.219$), and social support perceived ($r=0.304$) were the main carer's personal characteristics directly related with SOC. Caring experience ($r=-.281$) was the main carer factor related with burden while dependence ($r=.156$) and BPSD ($r=.157$) were the dementia factors.

Conclusion: The SOC has previously related with carer's burden. The results contributed to identify relevant and modifiable personal characteristics as RRs that could reduce this burden.

INTRODUCTION

Dementia is a clinical syndrome characterized by progressive cognitive decline that interferes with the ability to perform the activities of daily living (Brodaty, Woodward, Boundy, Ames, & Balshaw, 2014). Even though it can have different aetiologies the main major causes are neurodegenerative, with Alzheimer's disease (AD) being the most frequent subtype, with approximately 55-60% of all the cases with dementia (Nowrangi, Rao, & Lyketsos, 2011).

World population projections for the year 2050 indicate that the number of people aged 60 and over will have increased by 1.25 billion, and will represent 22% of the global population. A large meta-analysis estimated that 35.6 million people around the world had dementia in 2010, and according to the expected demographic changes, these figures will double every 20 years, reaching 65.7 million in 2030 and 115.4 million in 2050 (Prince et al., 2014).

Dementia causes disability and dependence, and the care and support needed by the patients have wide-ranging consequences for families, health-care systems, and society as a whole (Vos et al.2012). In our context, it has been estimated that 89% of people with dementia (PWD) live in the community at the time of diagnosis, and they are assisted by their family (Calvó-Perxas et al., 2012). Providing care to a relative with dementia has been associated with worsening physical and emotional health (García-Alberca, Lara, & Berthier, 2011; Gaugier, Kane, Kane, & Newcomer, 2005; Germain et al., 2009). Cognitive impairment, functional disability and neuropsychiatric disorders are the main symptoms of AD that relate to the burden perceived by the carer (Brodaty et al., 2014; Garre-Olmo et al., 2016; Sousa et al., 2016). However, there are some discrepancies in the literature about the effects of anxiety and depression in family carers. Some socio-

demographic factors, such as gender, have been reported to be relevant. Women generally spend more time on care tasks and report more burden, anxiety and depression (Mahoney, 2005; Rudd, Viney, & Preston, 1999). Cohabitation is another factor that increases the burden, although adult-children who do not live with the relative with dementia have greater feelings of guilt (J.L. Conde-Sala et al., 2013; Viñas-Diez et al., 2017). Some authors point to a reduction of these negative symptoms due to a progressive adaptation to the situation (Arai, Zarit, Sugiura, & Washio, 2002), while others suggest that the average levels of depression and emotional exhaustion worsen with the course of the disease (Sugihara, Sugisawa, Nakatani, & Hougham, 2004). There are also discrepancies in burden perception between spouses and adult-children (Conde-Sala, Garre-Olmo, Turró-Garriga, Vilalta-Franch, & López-Pousa, 2010; Martin Pinquart & Sörensen, 2011).

Salutogenesis is a health model defined in opposition to the pathogenic model. It is based on a dynamic approach between stressors and protective health factors and, currently, it is a referent model of health promotion (Aaron Antonovsky, 1996; Eriksson & Lindström, 2007). This health model incorporates two key elements: the sense of coherence (SOC) and the resources of resistance (RRs). SOC is the ability to maintain a global orientation, with a persistent and dynamic feeling of confidence, to face the internal and external stimuli in a predictable and structured manner (comprehensibility), with the necessary accessible resources and the ability to manage them (capacity of management) and, finally, with the conviction that providing a solution or response to the present challenge is something worth doing (meaningfulness) (Aaron Antonovsky, 1993; Lindström & Eriksson, 2005). The SOC is the ability to make sense of life (because it is comprehensible, manageable and meaningful) and maintain the skills to face changes and interact with the environment. Greater RRs facilitate coping with stressors and increase the SOC. Resources of resistance describe personal capabilities and may facilitate the

management of tensions by using available resources. They can be of a diverse nature including education, coping strategies and social support (Mittelmark, Bull, Daniel, & Urke, 2016).

Current studies have also detected, in general population, positive correlations between SOC and cognitive function, education, self-healing skills and coping capabilities (Koelen, Eriksson, & Cattan, 2016; Read, Aunola, Feldt, Leinonen, & Ruoppila, 2005). Regarding dementia carers, there is an increasing number of studies associating low SOC with high burden perception (del-Pino-Casado, Espinosa-Medina, López-Martínez, & Orgeta, 2019). In addition, a greater vulnerability in carers with lower SOC has been observed and associated with a greater risk of health worsening (Matsushita et al., 2014; Wiesmann & Hannich, 2008). This loss of health, related to the provision of care, has been associated with greater symptoms of depression, stress and anxiety, greater social isolation, and loss of economic position (M. Pinquart & Sörensen, 2004).

Many interventions and programs are focused to reduce this burden in carers, to extend the stay of PWD at home. However, since the personal carers' RRs are usually not taken into account, the effectiveness of these institutional homogeneous actions may be limited, especially regarding burden reduction (Thompson et al., 2007). Thus, the objective of this study was to identify the RRs linked to the SOC that have an association with a greater or a lower perception of burden in carers.

METHOD

Design and Population

The 'Sense of coherence and Dementia Study' (SOC & DEM study) is a prospective observational study of family carers of people with AD living in the community. The main purpose of the study was to analyze how relevant is the SOC in the personal and financial

evolution of the caregiver throughout 24 months. This is a cross-sectional study using baseline data of people enrolled from March to December 2018.

Ethical considerations

The 'SOC & DEM study' protocol was approved by the hospital's Clinical Ethics Committee (Ref v2:18/12/147).

Sample

Convenience sample of people with Alzheimer's disease and their family carers attended in two memory clinics; centre 'La República' in Salt and 'CSS Bernat Jaume' in Figueres (Catalonia).

Inclusion and exclusion criteria

Inclusion Criteria:

1) Persons who have a primary carer, defined as the family person who attends and supervises the patient in the activities of daily life a minimum of 4h / week.

2) People with a diagnosis of mild to moderate AD (4-6a according to the Global Deterioration Scale-FAST scale) (Reisberg, Ferris, De Leon, & Crook, 1982).

3) Persons who agree to participate and signed the informed consent.

Exclusion criteria:

1) PWD with expressive aphasia and / or moderate-severe comprehension.

2) Carers with vision or hearing impairment or who do not have a minimum capacity of reading and writing (illiteracy).

3) PWD attended itinerantly by different family carers in different homes.

4) Primary carers who provide care to more than one dependent elderly person.

Procedure

Patients and carers were informed in the outpatient memory clinics of the two centres ("La República" –Salt– and "CSS Bernat Jaume" –Figueres–) and visits to participate in the study were scheduled by telephone. The interviews were conducted by experienced psychologists in the facilities of the centres.

Variables and instruments

Socio-demographic variables: An *ad hoc* questionnaire was developed to collect information on both patients and carers. Age, gender, education level or patient-carer relationship were recorded.

Carer's variables

Sense of Coherence (SOC): The Orientation to Life Questionnaire (OLQ-13) scale consists of 13 items covering the three domains of the SOC construct: meaningfulness (score range: 4-28), comprehensibility (score range: 5-35), and manageability (score range: 4- 28) (A Antonovsky, 1987). The items are scored over a seven-point Likert scale (e.g., 1 = never, 7 = always). Negatively-worded items are reverse coded (items 1, 2, 3, 7, 10). Higher scores indicate higher levels in any of the three SOC domains. The scale has shown appropriate internal consistency and high construction and cross-cultural validity (Eriksson & Lindström, 2007). The OLQ-13 has been adapted to the Spanish elderly population (Virués-Ortega et al., 2007). The three domains of the scale were scored separately for all analyses in this study due to the evidence supporting the multidimensional nature of the construct (Langius & Björvell, 1993; Virués-Ortega et al., 2007).

Carer's burden perception: The Burden Interview (BI) by Zarit was administered for the evaluation of the physical and emotional burden perception of the carers (Zarit, Reever, & Bach-Peterson, 1980). The scale is composed of twenty-two items with a 5-point Likert response (never, rarely, sometimes, many times, always / almost always) with a score range of 22-110, and a greater score meaning a greater burden perception.

Quality of life: The abbreviated scale of the World Health Organization WHOQOL-BREF was administered to assess the perception of the quality of life of the carers (Skevington, Lotfy, & O'Connell, 2004). The scale is composed of 26 items with 5-point Likert type response (1 - 5), one of them inquiring about the general quality of life, another about satisfaction with health, and the remaining 24 items group into four domains of the quality of life: physical health (7 questions), psychological health (6) questions), social relations (3 questions) and environment (8 questions). The score is obtained using a correction table and equated to a scale of 0 to 100 where a higher score means a higher quality of life (World Health Organization, 2002).

Caring experience: The sense of well-being was assessed using the Carer Experience Scale (CES), a specific scale for carers. This scale is composed of 6 items with 3 response options (range = 6-18), and evaluates the following domains: activities, support (from family and friends), assistance (from organizations), fulfilment, control, and getting-on (with the care recipient). A higher score means a greater perceived caring experience (Goranitis, Coast, & Al-Janabi, 2014).

Self-efficacy: The General Self-Efficacy Scale (GSE) was administered to assess the stable feeling of personal competence to effectively handle a wide variety of stressful situations. It is a 10 Likert-type response items of 4 points (range = 0 - 40), with higher scores

indicating greater perception of self-efficacy (Sanjuán Suárez, Pérez García, & Bermúdez Moreno, 2000).

Self-esteem: The Global Self-Esteem scale (SES) is a 10-item scale well-validated measure for global self-esteem with Likert-type response items of 4 points (range = 0 – 40) with higher scores indicating greater perception of self-efficacy (Rosenberg, Schooler, Schoenbach, & Rosenberg, 2006).

Perceived Social Support: The social support was evaluated through the Medical Outcomes Study Social Support Survey (MOS-SSS), a scale of 19 Likert type response items of 5 points (never / almost never, few times, sometimes, often, always / almost always) (range: 19-95), with higher scores indicating higher perceived social support (Sherbourne & Stewart, 1991).

Depression: To evaluate the presence of depressive symptoms in the carer, the Geriatric Depression Scale (GDS) of 15 items and binary answer yes/no was administered. The cut-off for presence of depressive symptoms is more than 6 points (De et al., 2002; Yesavage et al., 1982).

Coping style: The Coping Orientations To Problems Experienced Scale (Brief-COPE) evaluates the strategies of coping and avoidance or denial of the carer based on 14 sub-scales (28 items) of 4-point Likert type response (I never do this, I do this a few times, I do this sometimes, I do this frequently) (range: 2-10 per response, with higher scores indicating a greater use of the given coping strategy) (Perczek, Carver, Price, & Pozo-Kaderman, 2000). The subscales are computed as follows (with no reversals of coding): Self-distraction (items 1 and 19); Active coping (items 2 and 7); Denial (items 3 and 8); Substance use (items 4 and 11); Use of emotional support (items 5 and 15); Use of instrumental support (items 10 and 23); Behavioural disengagement (items 6 and 16);

Venting (items 9 and 21); Positive reframing (items 12 and 17); Planning (items 14 and 25); Humour (items 18 and 28); Acceptance (items 20 and 24); Religion (items 22 and 27); Self-blame (items 13 and 26).

Perception of gain: The perception of gain linked to the provision of assistance was evaluated using the Gain in Alzheimer care INstrument (GAIN) scale (Fabà & Villar, 2013). The GAIN is composed by 10 statements about the positive aspects of caregiving assessed using a Likert scale of 1 = disagree to lot, 2 = disagree to little, 3 = neither agree nor disagree, 4 = agree a little, and 5 = agree a lot (range = 10-50). Higher score means higher perception of gain.

Patient's clinical variables

Disability of the patient: It was evaluated with the Dependence Scale, which has 13 items to identify the dependence degree from minimum (1 = the patient needs help to find objects) to maximum (13 = the patient has to be fed) (Stern et al., 1994).

Behavioural and Psychological Symptoms of Dementia (BPSD): The presence of BPSD was evaluated through the Neuropsychiatric Inventory - Questionnaire (NPI-Q) (Boada, Cejudo, Tàrraga, López, & Kaufer, 2002). The NPI-Q was designed to be a self-administered questionnaire completed by the carer. Each of the 12 NPI-Q domains contains a survey question that reflects cardinal symptoms of this particular domain. Initial responses to each domain question are "Yes" (present) or "No" (absent). If the response to the domain question is "No", carers move to the next question. If "Yes", carers then rate both the severity of the symptoms present within the last month on a 3-point scale, and the impact that the given symptoms had on themselves (i.e. Carer Distress) using a 5-point scale. The NPI-Q provides symptom severity and distress ratings for each symptom

reported, and total severity and distress scores reflecting the sum of individual domain scores. A higher score means more symptoms and related distress (range = 0-96).

Statistical analysis

A descriptive analysis was performed for the clinical and socio-demographic characteristics; absolute and relative frequencies were used for the qualitative variables, and central tendency and dispersion measures were used for the quantitative variables. Parametric and non-parametric tests were used for quantitative variables, and chi-squared test was used for qualitative variables. Bivariate analyses were conducted to compare measures of sense of coherence scale and perceived burden by categorical variables. A correlation analysis was performed for OLQ-13, BI and main study continuous variables (GDS, Dependent scale, MOS-SSS, Brief-Coping, GSE, SES, NPI, GAIN and CES).

Two linear regression models were adjusted with the OLQ-13 and BI scales as dependent variables to identify the most relevant associated variables. All variables included in the regression analysis were significant in previous analyses.

We fit a path model according to the theoretical model of Salutogenesis [RR → ↑ SOC → ↑ use of RR → ↑ HEALTH] (Aaron Antonovsky, 1996). We also directed the study and adapted our model to fulfil previous analyses where the SOC had been seen to play an important role as a mediator of the person's wellness and mental health showed in figure 1 (Jaracz, Grabowska-Fudala, & Kozubski, 2012; Pearlin, Mullan, Semple, & Skaff, 1990) .

The first path model was built including only variables of carer's personal resistance resources and social resistance resources. The second path was built including the same measures and all the other significant variables resulted of the 2 linear regressions. All variables were linked as covariance between them and directly to SOC and BI. Also a direct path had drawn from SOC to BI.

All statistical contrasts were bilateral, and confidence intervals were calculated using a 95% reliability level. Data processing and analysis were performed using IBM-SPSS v.20 and SPSS-AMOSS for windows. The goodness of fit of the model was verified by statistics: χ^2>.05 (df<3); RMSEA<.08; CFI≥.95, TLI≥.95 (Schreiber, Stage, King, Nora, & Barlow, 2006). Effect size was evaluated according to the following criteria: 'small' (<0.10), 'typical' or 'medium' (0.30) or 'large' (≥ 0.50) (Kline, 2011).

RESULTS

Sample characteristics

Sample of 308 participants (154 PWD & 154 carers) of which 60.8% of the PWD were men and 60.6% of the carers were women. Of the carers in this study, 54.2% were the spouse/couple of the PWD, and the rest (42.3%) were their adult-child and, in only 8 cases, were nephew/niece or brother/sister. The mean age of the carers was 64.9 years (SD=13.1; range=25-90) and the PWD were 78.5 years old (SD=6.0; range=59.2-92.0). Most of the PWD (67.7%) shared home with their carer, the 100% of the spouse carers and 29.6% of the adult-child or other family member. Other significant differences were observed among carers according to some socio-demographic and relational characteristics. Regarding education, while 71% of the spouses/couples had only completed primary school grades (6-8 years of schooling), 31.9% of the adult-child carers had degree studies (χ2=22.2; df=1; *p*<0.001). Concerning employment status, only 4 spouses/couples (4.8%) still had a paid job, while this percentage rose to 80% within adult-child carers (78.9%). Table 1 shows personal variables of carers and comparative analyses according to gender and kinship.

Analysis of the relationship between burden, sense of coherence and carers' personal characteristics

In the comparative analyses shown in table 1, burden was higher in women while SOC was higher in men and in adult-child than spouses. Also differences were observed in coping strategies and perception of gain or quality of life due the kinship. Correlation analysis showed that the main variables related to carer's burden were: GDS (rho=.416; $p<.001$), CES (rho=–.523; $p<.001$), GSE (rho=-.286; $p<.001$), SES (rho=-.362; $p<.001$), GAIN (rho=–.243; $p<.001$); BRIEF-COPE (rho=.272; $p<.001$); MOS-SSS (rho=–.404; $p<.001$), and an inverse correlation with SOC (rho=-.514; $p<.001$). In the correlation analysis, the OLQ-13 presented inverse relationships with GDS (rho=-0.344; $p<.001$), while it presented direct relationships with GSE (rho=.444; $p<.001$), SES (rho=-.495; $p<.001$), MOS-SSS (rho=.432; $p<.001$), BRIEF-COPE (rho=-.256; $p<.001$); GAIN (rho=.227; $p<.001$), and CES (rho=.327; $p<.001$); carer's age (rho=.164; $p=.044$). Both, the SOC and BI correlated with cope subscales of: Self-distraction (Cope1), denial (Cope3), substance use (Cope4), behavioural disengagement (Cope6), venting (Cope7), use instrumental support (Cope9), acceptance (Cope12), and self-blame (Cope14).

The adjusted linear regression model with OLQ-13 as dependent variable (r^2=.586) showed a significant association with the following variables: GSE (standardized beta (β)=.152; $p=.022$), GDS (β=-.175; $p=.028$); COPE 6 –Behaviour disengagement– (β=–.136; $p=.046$), COPE 9 -Instrumental support– (β=–.138; $p=.051$) MOS-SSS (β=.202; $p=.008$), (table supplementary 1). The adjusted model for BI explained more than half of the variance (r^2=.591) and was associated to the following variables: dependency scale (β=.152; $p=.022$); NPI (β=.155; $p=.022$); CES (β=–.259; $p=.001$), and OLQ-13 (β=–.289; $p=.002$) (table supplementary 2).

Path analysis

Finally, based on the results obtained in these regression models with the OLQ-13 and BI as dependent variables, the model of structural equations was elaborated following the basic scheme of the salutogenic health model explained previously. Figure 2 and 3 show the resulting models of the significant direct standardized path coefficients. The first path (figure 2) included the score in GSE, SES, Brief-COPE subscales as personal resources and the score in MOS-SSS as social resources. This model explained 37% of the variance of burden and 43.4% of SOC. The direct effect of SOC on burden was medium close to large (-.430) meaning that a better SOC lower burden perceived.

The final variables included in the second path (figure 3) as covariables were: dependence scale and NPI from PWD, and the age, GDS, GSE, COPE 6, COPE 9, MOS-SSS and CES of carers. The resulting model explain 55.5% of the variance of burden and 52.0% of SOC. The effect of SOC was also the main factor related to burden with a medium effect (r=-.338). The effect of personal and social resources maintained a significant effect, and depression and carer's age increased the explained variability of SOC. Moreover, clinical characteristics of PWD showed lower effect on burden than caring experience perceived. Although, depression did not show a significant direct effect on burden, it was the variable with the highest indirect effect (.09).

DISCUSSION

The relationship between caregiving and perceived burden is widely known, and the relationship between the sense of coherence and perceived burden has also been repeatedly reported. However, as far as we know, there is still a need to identify which of the variables attributable to the carer (RRs) may reduce the perceived burden. The SOC & DEM study assessed a large number of modifiable factors previously reported to be associated with burden, and results showed that the sense of coherence seems to be

determinant of the perceived burden. In addition, our model indicates that SOC is a construct (Aaron Antonovsky, 1996) that correlates with other relevant personal variables, such as age, and that it is linked to the particular resistance resources, such as self-efficacy, social support, and well-being.

Attending to a family member with dementia is a great stressor and not everybody deals with it equally. The avoidance behaviour correlates with a lower SOC when people are placed in these kind of situations (Goldzweig, Merims, Ganon, Peretz, & Baider, 2012). Our study identified negative/avoidance behaviours such as "making jokes" or "trying not to think about the problem" and also "increase alcohol consumption and / or other substances", or "seeking refuge in religion" as strategies to cope with this situation. A recent review concludes that benefits in terms of mental health and depression were generally found for carer coping strategies that involved focusing, accepting and supporting social-emotional problems. Negative outcomes for carers were associated with wishful thinking, denial, and avoidance coping strategies (Gilhooly et al., 2016). Here we saw that disabling behaviours were mainly displayed by non-partner carers, and by carers with lower education. Although schooling has been previously described as a modifier of SOC –and modified the SOC score in our study too- it was not directly linked to the perception of burden (Matsushita et al., 2014; Orgeta & Sterzo, 2013).

Self-efficacy, together with coping capabilities, was a key characteristic associated to higher SOC scores. In line with this, some authors previously identified self-efficacy as one of the main predictors of burden reduction (Van der Lee, Bakker, Duivenvoorden, & Dröes, 2014; Wijngaart, Vernooij-Dassen, & Felling, 2007). A characteristic linked to the control capacity of the situation explains 32% of the variance of the BI (Contador, Fernández-Calvo, Palenzuela, Miguis, & Ramos, 2012). Also, neurotic personality traits (emotional-focused) were associated with weak confrontation behaviours (Riedijk,

Duivenvoorden, Van Swieten, Niermeijer, & Tibben, 2009). The subjective well-being related to different personal and psychological strengths and resistance resources, such as self-esteem and self-efficacy, contribute directly to the sense of coherence and subjective well-being (Wiesmann & Hannich, 2008).

The perception of social support was the non-personal variable linked to the SOC. Previous studies reported benefits of social support interventions for the carers (Dam, De Vugt, Klinkenberg, Verhey, & Van Boxtel, 2016). In addition, the SOC has been linked to a greater perception of available social support and social function development. Among elderly women, social support, such as a favourable marital relationship and / or maintaining a close person at home, was associated with fewer physical health limitations (Nesbitt & Heidrich, 2000). In the same way, another study identified "customizing meaningful activities" as one of the three main strategies that can support, and perhaps enhance, the sense of coherence in people with dementia (Lillekroken, Hauge, & Slettebø, 2015).

The Carer Experience Scale is one of the shorter and more focused instruments available, and it defines well the different contexts of the carers, and where or who can help them. There is an inverse relationship between the perception of burden of the carers and the CES score. At this point, we recently published the effect of different public policies of support to carers on their self-rated health (Calvó-Perxas et al., 2018). Nowadays, the needs of carers are met through more individualized interventions and adequate support for perceived needs (Scales, Bailey, Middleton, & Schneider, 2017). One of the underexplored ways to take care of the carers is to increase their SOC. Increasing the modifiable variables that influence the SOC should increase the strengths of the carers to manage the situation (Stensletten, Bruvik, Espehaug, & Drageset, 2016; Trapp et al., 2015).

Beyond the observed resistance resources, we obtained a relationship between SOC and depression. This relationship has been seen to be an element of greater vulnerability among female carers and among those with a lower sense of coherence (del-Pino-Casado et al., 2019; Valimaki, Vehviläinen-Julkunen, Pietilä, & Pirttilä, 2009). As in previous studies, the most severe depressive symptoms in our study were observed in female carers who assisted their partners (Kim, 2017). However, in contrast with other studies, depressive symptoms have not been seen to have a direct link to the perceived burden (Han et al., 2014; Kim, 2017), and depression was instead a covariable correlating both with the main variables of the model that affect both SOC and burden. The association of depression and burden seems to have a link with the evolution of the caregiving process too. In this case, personal competences and SOC may be factors that justify the discrepancy and variability in the evolution of the caregiving process (Matsushita et al., 2014; M. Pinquart & Sörensen, 2004; Thompson et al., 2007). However, the purpose of this work was not to observe the link between SOC and depression of the carers, but to identify the RRs that were more relevant in the reduction of the perception of burden.

Some limitations should be taken into account when interpreting the results of this study: First, we used the GDS, which is a scale to assess depression in geriatric people, while part of the carers was not older than 65 years. Even though some carer's depressive symptoms may have been left out, we used the GDS as screening measure and there is enough evidence about its usefulness (J.L. Conde-Sala et al., 2014; Rosness, Mjørud, & Engedal, 2011). Second, this study has a cross-sectional design, which prevents attributing causal relationships between the SOC and the perceived burden and it is only indicates an association. Third, the sample of 125 carers may not be representative of all-kind of carers, because we recruited most of them shortly after the confirmation of the diagnosis of dementia, and all of them agreed to participate. In addition, this study may not be directly

applicable to all-kind of carers because our sample was mainly composed of Mediterranean people and cultural differences may exist (Konerding et al., 2018). Finally, the study does not have a probabilistic sample, so we missed less frequent cases, with more complicated patient-carer relationships, busy carers who lack time, those who have accessibility problems, etc.

This is, to our knowledge, the first study that provides complementary data to the relationship between the sense of coherence and the perceived burden; the relationship between the personal resistance resources, the personal and social cost of caring for a loved one in a degenerative process. Unfortunately, previous studies have shown little empirical consistency of the psychosocial interventions, due mainly to methodological differences such as the heterogeneity of the samples (Gilhooly et al., 2016; Selwood, Johnston, Katona, Lyketsos, & Livingston, 2007). A recent systematic review found increasing the Cognitive Behaviour Therapy and the Acceptance and Commitment Therapy, seemed to be particularly beneficial for carers experiencing high levels of anxiety (Kishita, Hammond, Dietrich, & Mioshi, 2018). In our opinion, the application of the health model based on the study of the specificity of carers (SOC & RRs) may give a different perspective to the intervention projects and modulate the type of actions based on the background of the person (Wennerberg, Lundgren, & Danielson, 2012). In other words, not all carers have the same personal needs as each other (support, training, etc.) and not all people have the same contextual circumstances (previous relationship, work, family responsibilities, etc.) which may determine both the burden and the sense of coherence.

These are factors that should be considered in futures studies, especially as they may affect, directly or indirectly, the use of limited social and healthcare resources. In addition, future research should include two considerations: having more personal parameters to analyze the characteristics of the carers who will attend their relative with dementia for a

long time, and expore the implications of these findings for services and support for carers by Health care systems. Available healthcare and social resources are limited, and increasing the carers' resistance resources may be a new action capable of providing benefits to both the carers and the people with dementia.

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Table 1. Description of the main characteristics of the caregivers, and a comparative analysis by gender and type of kinship (spouse/child).

VARIABLES	MEAN (SD)						
	Total (n=154)	WOMEN (n=77)	MEN (n=48)		SPOUSE (n=72)	CHILD (n=47[a])	
BI	46.9 (14.7)	49.4 (14.2)	43.1 (14.7)	*	45.5 (15.4)	48.7 (13.6)	*
OLQ-13	73.1 (11.5)	72.4 (11.6)	74.3 (11.4)		74.6 (10.5)	71.4 (12.5)	
SES	32.9 (4.1)	32.7 (4.4)	33.4 (3.7)		33.1 (4.1)	32.9 (4.2)	
GSE	30.7 (4.3)	30.2 (4.6)	31.5 (3.5)		30.7 (3.8)	30.8 (4.8)	
GAIN	26.1 (7.6)	24.6 (7.8)	28.4 (9.2)	*	26.8 (7.3)	25.0 (7.9)	
COPE*	52.8 (8.6)	52.6 (9.1)	52.2 (9.2)		49.9 (8.2)	55.5 (9.3)	*†
Self distraction	4.0 (1.4)	4.1 ()1.4	3.9 (1.5)		3.8 (1.5)	4.2 (1.4)	
Active coping	5.0 (1.6)	4.9 (1.6)	5.0 (1.5)		4.6 (1.6)	5.3 (1.5)	*
Denial	2.8 (1.2)	2.9 (1.2)	2.7 (1.1)		2.9 (1.1)	2.7 (1.2)	
Substance use	2.1 (0.5)	2.1 (0.6)	2.2 (0.5)		2.1 (0.4)	2.2 (0.7)	*
Use emotional support	3.9 (1.2)	4.0 (1.2)	3.9 (1.1)		3.7 (1.1)	4.2 (1.2)	*
Behavioural disengagement	2.4 (0.8)	2.4 (0.7)	2.5 (0.8)		2.4 (0.7)	2.5 (0.8)	
Venting	3.6 (1.3)	3.7 (1.5)	3.5 (1.2)		3.3 (1.2)	4.0 (1.3)	*
Positive reframing	4.6 (1.6)	4.5 (1.6)	4.6 (1.6)		4.3 (1.6)	5.0 (1.6)	*
Use instrumental support	3.8 (1.3)	3.6 (1.5)	3.4 (1.4)		3.2 (1.4)	3.9 (1.4)	*
Planning	4.7 (1.6)	4.5 (1.6)	4.7 (1.6)		4.1 (1.6)	5.2 (1.4)	*
Humor	3.8 (1.2)	3.7 (1.2)	3.9 (1.4)		3.5 (1.1)	4.1 (1.4)	*
Acceptance	6.1 (1.5)	6.0 (1.5)	6.3 (1.5)		6.1 (1.6)	6.1 (1.4)	
Religion	4.0 (1.4)	4.0 (1.4)	3.9 (1.3)		3.9 (1.4)	4.1 (1.3)	
Self-blame	2.9 (1.0)	2.9 (1.0)	2.8 (0.9)		2.7 (0.9)	3.0 (1.0)	
MOS-SSS	65.8 (26.6)	62.8 (25.8)	70.3 (27.4)		61.1 (27.5)	74.5 (24.4)	*
CES	13.1 (2.3)	13 (2.4)	13.4 (2.2)		13.1 (2.3)	13.2 (2.3)	
WHOQOL-Brief	25.9 (0.4)	25.9 (0.6)	26 (1.0)	*	25.9 (0.5)	25.9 (0.2)	
GDS	5.6 (1.8)	5.8 (1.7)	5.3 (1.9)	*	5.9 (1.7)	5.1 (1.8)	*

[a] 6 cases were brother/sister or nephew/niece of the patient.* $p<0.05$; † Cohen's $d \geq 0.6$; **BI**: burden interview; **OLQ-13**: Sense of Coherence scale; **SES**: global Self Esteem Scale; **GSE**: General Self-Efficacy scale; **CES**: Carers Experience scale; **GAIN**: Gain in Alzheimer; **BRIEF-COPE**: Brief coping scale; **MOS-SSS**: Social Support Scale; **WHOQOL-Brief**: Quality of life questionnaire **GDS**: Geriatric Depression Scale.
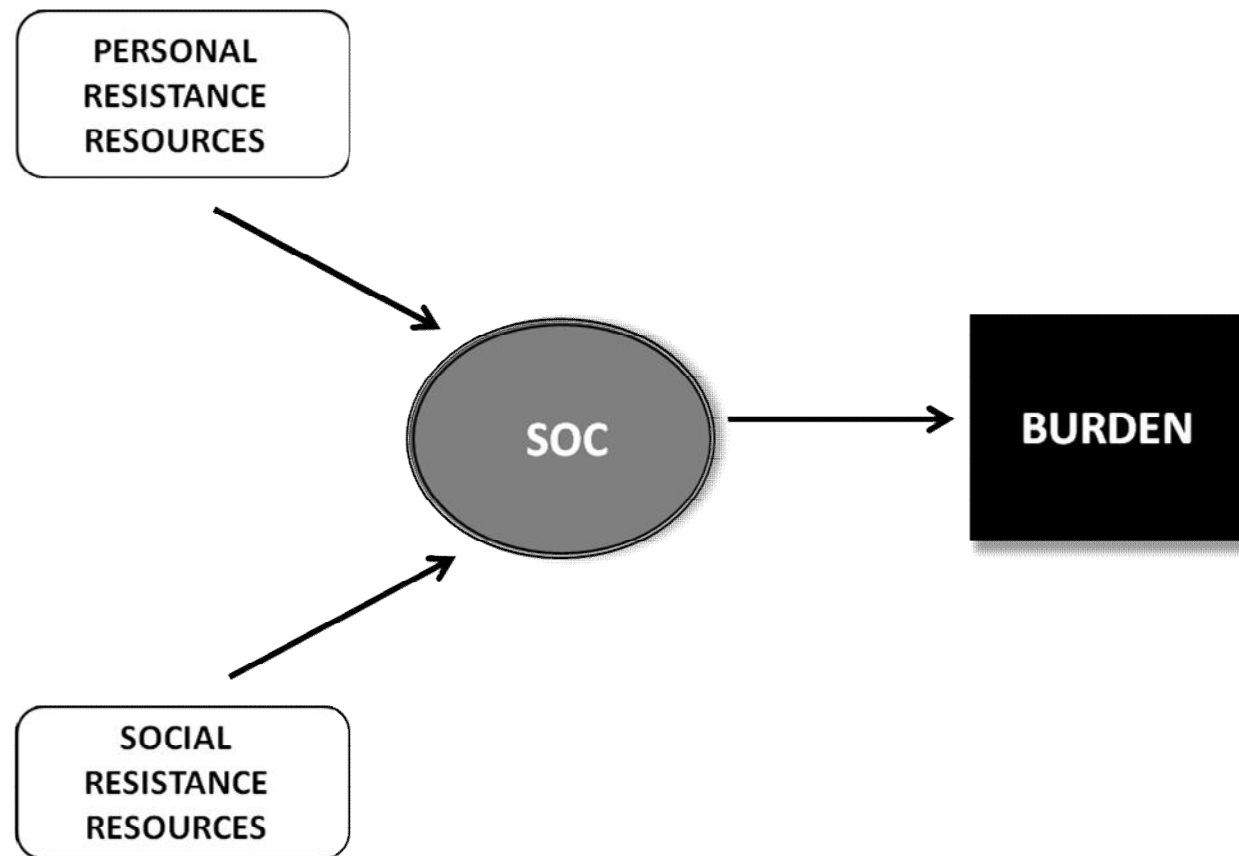
Figure 1. Theoretical model of the relationship between SOC and Burden adapted of Jaracz, Grabowska-Fudala, & Kozubski model (2012) and Pearlin, Mullan, Semple, & Skaff model (1990).
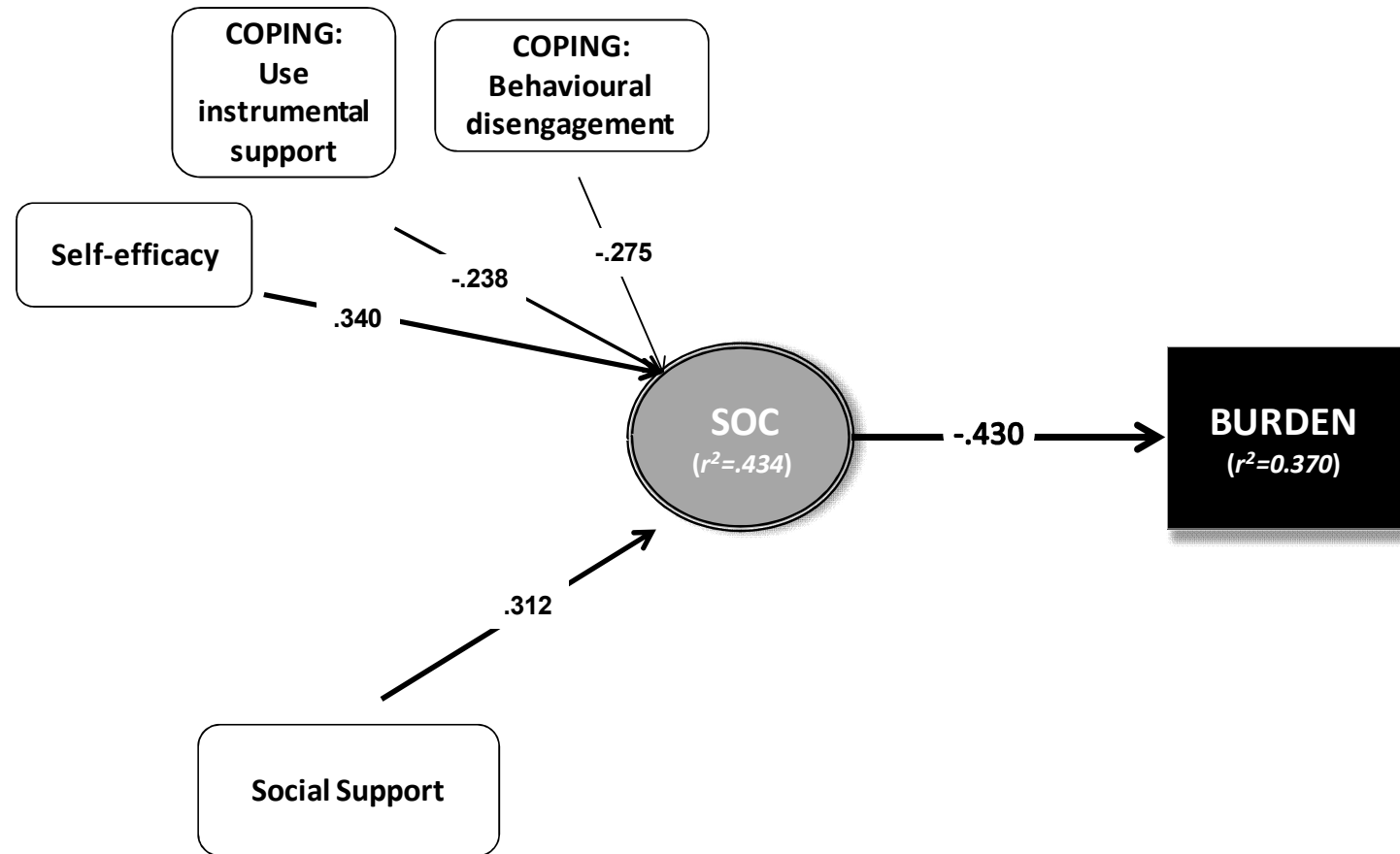
Figure 2. Standardized path coefficients of direct effects of Sense of coherence and burden perceived as dependent varaibles. χ^2=0.552; *df*=1; *p*=0.457; **CFI**= 1.0; **TLI**=1.062; **RMSEA**<0.001; **AIC**= 52.5; **SOC**: Sense of Coherence (Orientation to Life Questionnaire -13) **BURDEN**: Burden Interview; **Social Support**: Medical Outcomes Study Social Support Survey (MOS-SSS); **Self-efficacy**: General self-efficacy scale; **COPING**: Brief-COPE scale .

Figure 3. Standardized path coefficients of direct effects of Sense of coherence and burden perceived as dependent varaibles. χ^2=0.302; *df*=3; *p*=0.960; **CFI**= 1.0; **TLI**=1.176; **RMSEA**<0.001; **AIC**= 159.1; **SOC**: Sense of Coherence (Orientation to Life Questionnaire -13) **BURDEN**: Burden Interview; **BPSD**: Neuropsychiatric inventory; **Dependence**: Dependence scale; **Caring experience**: Carer's Experience Scale**; Depression**: Geriatric Depression Scale; **Social Support**: Medical Outcomes Study Social Support Survey (MOS-SSS); **Self-efficacy**: General self-efficacy scale; **COPING**: Brief-COPE scale .
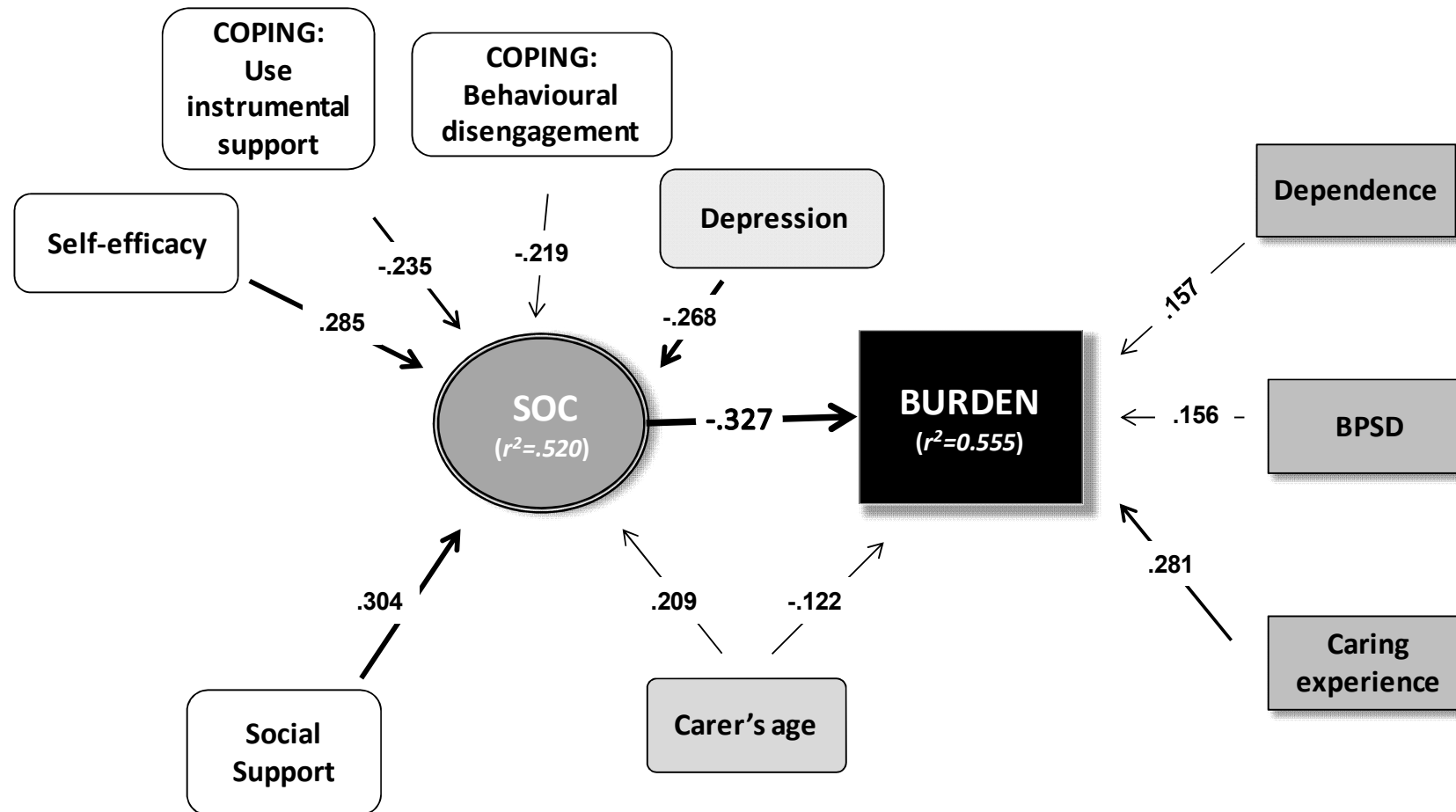
Supplementary Table 1. Linear regression with SOC as dependent variable (r^2=.586).

Model	Unstandardized Coefficients		Standardized Coefficients		
	B	Std. Error	Beta	t	p
(Constant)	86,300	101,121		,853	,395
SES	,426	,232	,152	1,834	,069
GSE	,509	,219	,189	2,322	**,022**
GAIN	,137	,109	,088	1,252	,213
WHOQOL_BREF	-1,225	3,911	-,020	-,313	,755
GDS	-1,135	,510	-,175	-2,226	**,028**
COPE_1 Self distraction	-,720	,609	-,086	-1,183	,239
COPE_3 Denial	-1,289	,793	-,122	-1,626	,106
COPE_4 Substance abuse	-1,548	1,516	-,071	-1,021	,309
COPE_6 Behavioral disengagement	-2,084	1,108	-,136	-1,864	**,046**
COPE_7 Venting	,327	,688	,037	,474	,636
COPE_9 Use instrumental support	-1,124	,571	-,138	-1,968	**,051**
COPE_12 Acceptance	-,596	,505	-,077	-1,179	,241
COPE_14 Self-blame	-1,516	,965	-,132	-1,570	,119
Carer's age	,161	,060	,184	2,667	**,009**
Dependence scale	,390	,527	,051	,740	,460
NPI	-,017	,199	-,006	-,086	,932
CES	-,124	,375	-,025	-,330	,742
MOS-SSS	,087	,032	,202	2,717	**,008**

CES: Carer's Experience Scale**; COPE**: Brief-COPE scale; **GAIN**: Gain in Alzheimer care Instrument; **GDS**: Geriatric Depression Scale; **GSE**: General self-efficacy scale; **MOS-SSS:** Medical Outcomes Study Social Support Survey; **NPI**: Neuropsychiatric inventory; **SES**: Global Self-Esteem Scale; **SOC**: Sense of Coherence; **WHOQOL_BREF:** World Health Organization Quality of Life questionnaire.

Supplementary Table 2. Linear regression with BI as dependent variable (r^2=.591).

Model	Unstandardized Coefficients		Standardized Coefficients		
	B	Std. Error	Beta	t	p
(Constant)	286,280	131,195	-,066	2,182	,031
Self-esteem	-,232	,300	,053	-,771	,442
Self-efficacy	,181	,288	-,094	,627	,532
GAIN	-,184	,145	-,096	-1,265	,208
TOTAL_WHOQOL_BREF	-7,620	5,131	,095	-1,485	,140
GDS	,780	,673	,073	1,159	,249
COPE_1 Self distraction	,771	,780	,031	,989	,325
COPE_3 Denial	,414	1,037	,003	,399	,691
COPE_4 Substance abuse	,084	1,944	-,049	,043	,966
COPE_6 Behavioral disengagement	-,940	1,458	,110	-,645	,520
COPE_7 Venting	1,239	,879	-,058	1,409	,161
COPE_9 Use instrumental support	-,591	,744	,028	-,794	,429
COPE_12 Acceptance	,273	,647	,037	,423	,673
COPE_14 Self-blame	,542	1,241	-,018	,436	,663
Carer's age	-,020	,128	,152	-,160	,873
Dependence scale	1,464	,684	,155	2,140	**,034**
NPI	,591	,255	-,259	2,321	**,022**
CES	-1,639	,481	-,060	-3,407	**,001**
MOSSS	-,033	131,195	-,066	-,764	,446
SOC	-.365	.118	-.289	-3.095	**.002**
Carer's genderder	-2.443	2.040	-.081	-1.198	.234
Kindship	1.322	3.408	.045	.388	.699

CES: Carer's Experience Scale**; COPE**: Brief-COPE scale; **GAIN**: Gain in Alzheimer care Instrument; **GDS**: Geriatric Depression Scale; **GSE**: General self-efficacy scale; **MOS-SSS:** Medical Outcomes Study Social Support Survey; **NPI**: Neuropsychiatric inventory; **SES**: Global Self-Esteem Scale; **SOC**: Sense of Coherence; **WHOQOL_BREF:** World Health Organization Quality of Life questionnaire.