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Title

Coping strategies and psychological distress in family carers of frail older people: a longitudinal study.

Running title

Coping and psychological distress in family carers

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Conflict of interest statement

No conflict of interest has been declared by the authors.

Key points:

- Active/approach and passive coping strategies modulate carer psychological distress.
- Positive reframing and self-distraction predict lower levels of carer distress a year later.
- Interventions that focus on approach coping may prevent future psychological distress in carers.

Abstract

Background. Carers of dependent older people experience high levels of psychological distress. However, little is known about the effects of coping on carer distress over time. In this one year longitudinal study we investigated the relationship between distress, and coping strategies in a representative sample of family carers living in Spain.

Methods. Primary carers of older people were recruited (*N* = 200). We used probability sampling and collected data via individual interviews from 2013 to 2015. Variables investigated included psychological distress, coping, and levels of objective and subjective burden. Panel data analysis was used to test a model of association of psychological distress, and coping strategies controlling for key confounders.

Results. Acceptance and emotional support were the most frequently used strategies, whereas behavioural disengagement and humour were the least used. In the panel data regressions, positive reframing ($B = -0.79$, $p < 0.001$), self-distraction ($B = -0.46$, $p = 0.034$), substance use ($B = 0.57$, $p < 0.001$) and denial ($B = 0.57$, p = 0,049) were significantly related to psychological distress at one year follow-up.

Limitations. Limitations include participant drop out and assessing substance use coping via a brief measure.

Conclusions. Positive reframing and self-distraction were longitudinally associated with lower levels of carer psychological distress. Using denial and substance use coping increased distress long-term. Our results suggest that interventions that focus on positive reframing and assisting carers in decreasing dysfunctional coping may be useful therapeutic targets mitigating carer psychological morbidity.

Key words: carers; older people; coping; psychological distress; longitudinal design.

1. Introduction

The number of older people living with chronic and neurodegenerative diseases is increasing globally with projections indicating that prevalence will continue to increase for the next 50 years (Prince et al., 2016; The King's Fund, 2012). This means that the number of family carers looking after dependent older people will also increase (OECD, 2013). Caring for an older relative is a significant source of psychological distress for carers (Pinquart and Sorensen, 2003; van der Lee et al., 2014), and is associated with experiencing high rates of anxiety and depression (Loh et al., 2017; Sallim et al., 2015). Understanding which factors predict family carer distress is important as it will allow early detection and prevention of symptoms.

Coping and psychological distress in carers

Stress process models (Pearlin et al., 1990) propose that carer distress is influenced by contextual variables (carer sex or kinship), objective stressors (care-recipient needs and care provided), subjective burden (a state characterised by fatigue, stress, perceived limited social contact and self-esteem; (Zarit et al., 1980), and psychological resources such as coping. Although several classifications have been proposed, coping strategies are generally classified as a) problem or solution-focused (findings solutions, and planning), sometimes also referred to as active or approach coping (attempts to solve, or re-evaluate the problem), b) emotion-focused (aimed at managing emotions and acceptance-based), and c) dysfunctional or passive coping responses (avoidance of the problem, denial or emotional discharge) (Del-Pino-Casado et al., 2011).

Studies investigating coping and caregiver distress have shown that coping mechanisms are strongly and differentially associated to carer psychological morbidity (Garcia-Alberca et al., 2012a). Use of dysfunctional coping such as denial or avoidance have been consistently associated with higher levels of depression and anxiety (Cooper et al., 2010; Huang et al., 2015; Khalaila and Cohen, 2016). Acceptance-focused coping and accessing emotional support predict better psychological health but to a lesser degree (Li et al., 2012). Research on the relationship between carer psychological morbidity and problem-focused coping however remains contradictory. For example, although some studies find that solution focused coping is protective for carers' psychological health (Batt-Leiba et al., 1998; Roche et al., 2015), others report that problem-focused coping predicts higher carer distress (Cooper et al., 2008b; Shaw et al., 1997). The meta-analysis by Li et al. (2012) concluded that generally solution-focused coping is not cross-sectionally associated with caregiver anxiety or depression.

Coping and caregiving over time

An important limitation of current research is that most studies to date remain cross-sectional with only a few examining the longitudinal association between coping and carer psychological morbidity (Li et al., 2012). At least three longitudinal studies have found that carers reporting higher use of dysfunctional coping experience higher levels of depression at 6 months (Matson, 1994; Powers et al., 2002), one year later (Vedhara et al., 2001) and greater anxiety (Vedhara et al., 2000). Emotion focused coping such as acceptance and emotional support protects carers from anxiety at 1 year follow-up (Cooper et al., 2008b). Similarly, in the one year longitudinal study by Romero-Moreno et al. (2012) carers' higher use of cognitive reappraisal predicted lower depressive symptoms over time.

As with cross-sectional studies results on the longitudinal relationship between problem-focused coping and carer distress remain conflicting. Although solution-focused coping has been found to predict lower depression scores at 6 to 24 months (Goode et al., 1998; Vedhara et al., 2000; Wright, 1994), at least one study reports that using more solution-focused coping predicts higher anxiety a year later (Cooper et al., 2008b). It appears therefore that the contribution of at least some coping resources on explaining carer distress over time remains inconclusive.

Cross-sectional or repeated measures studies testing relationships among variables at the same time point, cannot address causality or examine changes over time. In contrast, longitudinal data allow investigating intra-individual changes, addressing causality and reducing the problem of unobserved heterogeneity (Brüderl and Ludwig, 2015; Romswinkel et al., 2018). Given the advantages and strengths of longitudinal studies (Romswinkel et al., 2018), the primary aim of this study was to examine the longitudinal association between carers' coping styles and psychological distress. We used probability sampling and controlled for key confounders in the literature, which may explain contradictory findings. Drawing upon stress process models of caregiving (Litman (2006), we hypothesised that greater use of approach coping strategies such as acceptance, planning, and positive reframing will predict lower levels of carer distress over time and that dysfunctional coping would predict higher levels of psychological morbidity.

The objectives of our study were: 1) to describe and identify the most frequent coping strategies used by carers, 2) to identify which coping mechanisms predict carers' psychological distress after controlling for key confounders and 3) analyse if an approach profile of coping would be protective a year later.

2. Methods

2.1. Design, setting, sample, and procedures

This study used a longitudinal design with one year follow-up. The sample included primary carers of older people living in the Spanish region of Alto Guadalquivir (46,560 inhabitants), in Andalusia. The sampling frame was established by the census of primary carers of older relatives of each health care centre from the Guadalquivir Health District (1,182 caregivers). The characteristics of our sample are very similar to the typical profile of family carers in Spain (IMSERSO-CIS, 2004), supporting the external validity of our study. Caregivers were eligible to participate if: (1) they were primary carers of (2) a dependent relative (needing help in at least one domain of basic activities of daily living, both basic and instrumental) aged 65 years or over. Primary carer was defined as any person who assumed primary responsibility for care and provided the greatest amount of care (Del-Pino-Casado et al., 2015).

Random, stratified sampling was carried out with proportional affixation by the population centre. First, a sample size of 200 study units was estimated. This sample size allowed us: a) to detect a correlation coefficient of at least 0.174 with a power of 80% at a significance level of 5%, b) to detect, with a power of 80%, an r^2 of at least 3% attributable to one independent variable adjusted by three independent variables with an r^2 of 20%, using and F-Test with a significance level of 5%, as Cohen (1988) recommended in a multiple linear regression model. Sample size calculations were computed using PASS 11 (NCSS, Kaysville, Utah, USA) and were chosen in order to reach a balance between the detection of an effect size as small as possible and the maximum sample size affordable. Then, a number of sample elements was assigned to each site according to its population, followed by systematic random sampling from the clinical records at each centre.

2.2. Procedure

All participants provided informed consent. Data were collected via individual interviews, carried out between 2013 and 2015. After intake at Time 1 (T1), the same interview was repeated at Time 2 (T2; 1 year after the initial interview). A pilot study was carried out (n = 20) in order to assess suitability of methods and instruments. The Research Ethics Committee of the province of Córdoba approved the study.

2.3. Statistical Methods

Measures

Socio-demographic variables. We collected data on age and sex of carers, living status, relationship to care recipient, and duration of care (years of caring). Care recipient data included age, sex and cause of dependence (presence of cognitive and/or physical impairment, stroke, cancer or other illness).

Coping strategies. Carers reported use of coping strategies using the abbreviated validated Spanish version (Crespo and Cruzado, 1997) of the COPE Questionnaire (Brief-COPE Inventory; (Carver, 1997). The COPE is a 28-item questionnaire classifying coping into 14 subscales (2 items per subscale; range: 2 to 8; proactive coping, planning, positive reframing, acceptance, humour, religion, using emotional and instrumental support, self-distraction, denial, venting, substance use, behavioural disengagement, and self-blame). Internal consistency (Cronbach’s alpha) ranged from 0.51 (self-blame) to 0.98 (substance use). Examples of items, for example of the substance use subscale, are “I've been using alcohol or other drugs to make myself feel better" and "I've been using alcohol or other drugs to help me get through it".

Coping strategies were used as quantitative variables (scores of the subscales) in all analyses except for objective 1 (frequency of coping strategies) where they were analysed as dichotomous variables (No = 2, Yes = 3 – 8).

Approach coping profile. To investigate objective 2, we created a new variable, approach coping, with the following categories: 1) yes: high proactive coping, high planning, high positive reframing and high acceptance and 2) no: low scores on one or more of these subscales. We considered a coping strategy as high in frequency when its score was over the median.

Dependent variable. Psychological distress was measured using the Goldberg Test (Goldberg et al., 1988), which has two subscales; one for anxiety and one for depression. Each subscale is comprised of 9 questions with higher scores indicating higher distress. We used the Spanish version of the scale, which has good psychometric properties (sensitivity of 83.1%, specificity of 81.8%; (Montón et al., 1993). Internal consistency in this sample was high (Cronbach's alpha = 0.91).

Control variables. Subjective burden was measured using the validated Spanish version (López Alonso and Moral Serrano, 2005) of the Caregiver Strain Index (Robinson, 1983), which includes 13 statements about caring answered by yes or no. Cronbach's alpha was 0.78. Objective burden was measured using the Dedication to Care Scale (Escala de Dedicación al Cuidado –DeCuida-; Spanish; Del-Pino-Casado et al., 2015) and the Pfeiffer Test (Pfeiffer, 1975). The Dedication to Care Scale (Del-Pino-Casado et al., 2015) measures intensity of care and comprises 10 items corresponding to the 10 items of the Barthel Index (Mahoney and Barthel, 1965). Intensity of care was computed for each item by multiplying dependency level by frequency of care (from 0 = never to 5 = always), obtaining a total score for each need (range, 0–100; scores directly proportional to intensity of care). Cronbach's alpha was 0.86. The Pfeiffer Test (Pfeiffer, 1975) comprised 10 items and measured level of cognitive impairment in the care recipient (range 0-10; higher scores indicating higher levels of impairment). We used the Spanish validated version with Cronbach's alpha $\alpha = 0.94$ (Martínez de la Iglesia et al., 2001; sensitivity 85.7%; specificity 97.3%).

Data analysis

Descriptive analyses were carried out for calculating frequencies, measures of central tendency, dispersion, and corresponding confidence intervals (CIs). Bivariate analysis was carried out using the Pearson correlation coefficient r (objective 2) and the student t Test (objective 3). We estimated risk differences from the standardized mean difference (SMD) by first calculating the odds ratio and then computing a risk difference (based on formulas proposed by the Cochrane Collaboration; (Higgins and Green, 2008).

Multivariate analysis regressing distress on independent and control variables was performed using panel data analysis to compute individual effects and periods (objective 2). First, we used a pooled ordinary least square model (POLS) adding the following independent variables to the model: coping strategies (proactive coping, planning, positive reframing, acceptance, humour, religion, using emotional and instrumental support, self-distraction, denial, venting, substance use, behavioural disengagement, and self-blame) and control variables (subjective burden, intensity of care and cognitive impairment). The formal equation of the model was: $Y_{it} = \alpha + \beta X_{it} + u_{it,}$ where X_{it} is a set of independent variables (coping strategies and control variables) and $u_{it,}$ is the error term of the model. In order to analyse the impact of changes of the independent variables on changes in the dependent variable, a fixed-effects model was used (Burger et al., 2017). Because the control variables were time invariant, we dropped these from the fixed-effects model. The formal equation of this model was: $Y_{it} = \alpha + \beta X_{it} + u_{it,} + v_{i,}$ where X_{it} is the set of independent variables (coping strategies), $u_{it,}$ is the random error term of the model and v_i the fixed error term of the model, which is considered constant for each individual. For analyses of objective 3, a multiple linear regression was performed with distress at T2 regressed on approach coping profile and control variables (intensity of care, cognitive impairment and subjective burden at T1).

All statistical analyses were carried out using SPSS 19.0 for Windows, except for the calculation of the CIs for which EpiDat (version 3.1) was used. Level of statistical significance was set at 5%.

3. Results

3.1. Description of the sample

Carers had a mean age of 58.5 years (SD = 12.9), 88% were women, 58.5% were daughters, and 83.0% lived with the care recipient. Average duration of care at time of entry into the study was 6.8 years (SD = 5.3). Care recipients had a mean age of 82.0 years (SD = 9.7). Causes of dependence was physical disability (mobility or physical incapacity; 45.5%), followed by cognitive impairment (dementia or mild cognitive impairment; 31.0%), stroke (16.5%) and cancer (7%.0) (see Table 1 for socio-demographic characteristics of the sample). Twenty three carers were not re-interviewed (11.5%) because the care recipient had died. There were no statistically significant differences between those completing both interviews and those completing only the first interview on any variables tested (see Table 2).

3.2. Objective 1: frequency of coping strategies

Descriptive data of coping strategies are presented in Table 3. The frequency of coping strategies ranged from 10 to 99%. The most frequently used coping strategies were acceptance and use of emotional support, whereas behavioural disengagement and humour were the least used.

3.3. Objective 2: Longitudinal association of coping strategies with psychological distress

In the bivariate analysis, carer psychological distress at T2 was significantly negatively associated with the following baseline coping strategies: proactive coping ($r = -0.24$; $p = 0.001$), positive reframing ($r = -0.41$; $p< 0.001$), acceptance ($r = -0.16$; $p = 0.03$), emotional support ($r = -0.25$; $p = 0.001$) and self-distraction ($r = -0.22$; $p = 0.004$). Baseline denial ($r = 0.27$; $p < 0.001$), substance use coping ($r = 0.32$;

$p < 0.001$) and self-blame ($r = 0.20$; $p = 0.008$) were significantly positively associated with carer distress at T2 (see Table 4).

In the POLS regression model (Table 5, first column), positive reframing ($B = -0.81$, $p < 0.001$), substance use ($B = 0.49$, $p < 0.001$) and subjective burden ($B = 0.45$, $p < 0.001$) were significantly related to distress. The fixed-effects model (FE) confirmed these results (Table 5, second column), showing significant relationships with distress and positive reframing ($B = -0.79$, $p < 0.001$), substance use ($B = 0.57$, $p < 0.001$), self-distraction ($B = -0.46$, $p = 0.034$) and use of denial ($B = 0.57$, $p = 0.049$).

3.4. Objective 3: Approach coping profile and psychological distress

Carers with an approach coping profile at baseline experienced significantly less distress at 12-month follow-up compared to those scoring low on approach oriented coping ($M = 5.38$; SD = 5.40 vs. $M = 8.07$; SD = 6.39, $p < 0.001$; SMD = -0.45). A SMD of -0.45 corresponds to an OR of 0.44 (CIs) and a risk difference of 0.19. Thus, the change of a non-approach coping profile to approach oriented coping could lead to a reduction of 19 points in the probability of experiencing psychological distress a year later.

After controlling for intensity of care, cognitive impairment and subjective burden through multiple linear regression, the relationship between an approach coping profile at baseline and psychological distress at T2 remained statistically significant ($\beta = -0.21$, $p = 0.003$; Table 6). When approach coping profile was included in the model after the control variables, the r^2 of the model increased by five points (from 15 to 20%).

4. Discussion

The objective of this study was to analyse longitudinally the association of coping strategies with caregivers' distress using panel data analysis, which allows capturing the longitudinal structure of the data (Söderbom et al., 2014). In line with stress process models of caregiving, we found that specific coping styles are potentially effective buffers of distressing psychological symptoms over time. An important strength of our study is that we were able to demonstrate this by using probabilistic sampling, and therefore have been able to limit selection bias. In comparison to previous studies we controlled for several confounders in the relationship between coping strategies and carer distress.

4.1. Coping and psychological distress

Our analyses showed that positive reframing was a significant predictor of carer distress 1 year later. These findings match those of several studies (Garcia-Alberca et al., 2012b; Lu et al., 2017; Roche et al., 2015) showing that generally use of active coping strategies oriented towards problem solving and regulating affect such as positive reframing (Cooper et al., 2008a) modify the negative impact of carer distress. We found that the most frequently used coping strategies by carers were acceptance and accessing emotional support. Our finding that almost all carers reported using acceptance as a coping strategy suggests that this form of coping may be a natural reaction or adaptive response to caregiving, at least for carers in this region.

Our study expands current evidence regarding the protective effect of active/approach coping and carers' psychological health (Pérez-Ordóñez et al., 2016; Pérez-Sánchez et al., 2014; Roche et al., 2015). Our findings show that an approach coping profile characterised by high proactive coping, planning, positive reframing and acceptance may protect from distress and assist carers in appraising the caregiving situation as less stressful, which may in turn be protective of their psychological health. This finding reinforces the view that encouraging and supporting carers to engage in active coping will protect them from experiencing high levels of distress in line with clinical effectiveness data of interventions supporting carers (Cheng et al., 2014; Livingston et al., 2013; Losada et al., 2015).

In line with our hypotheses use of passive and dysfunctional coping strategies such as denial and substance use predicted higher levels of distress 1 year later (Cooper et al., 2008b; Garcia-Alberca et al., 2012b; Lambert et al., 2012; Pérez-Ordóñez et al., 2016). Substance use coping and denial may interfere with the use or effectiveness of adaptive coping strategies. For example, avoiding and denial focused coping may prevent carers from identifying helpful coping strategies, which over time may maintain or worsen distress. Our findings therefore add to current evidence that passive coping may be an important risk factor for psychological morbidity and may be a marker signalling carer distress in clinical practice.

Unexpectedly, we found that self-distraction, classified as a dysfunctional coping response (Carver, 1997), was negatively related to carer distress. Our findings are similar to those of Leon-Campos (León-Campos et al., 2018), whereby use of self-distraction was significantly negatively related to depressive symptoms in carers of people with dementia, and may therefore have a protective effect by assisting carers to cope with high levels of distress.

4.2. Limitations

Our study can not rule out reverse causality, therefore our results remain limited. For example, it is possible that carers with symptoms of psychological distress are more likely to report using more dysfunctional coping and less active coping rather than vice versa. We were not able to collect any information on carers' income, or control for previous psychiatric history, which may have biased our findings. Although our sample is representative of carers in Spain our results do not generalise to all caregiving populations given that ethnicity and culture influence carers' appraisals of distress and coping behaviours (Napoles et al., 2010). We were not able to examine effects of multimorbidity, which is highly prevalent in frail older people, and future research should address this limitation. We used a brief measure of substance use coping, therefore our findings may underestimate or overestimate the association between substance use coping and distress, indicating that replication of our results is necessary.

4.3. Conclusions

Despite limitations, our findings show that positive reframing may be protective for carers' psychological heath and an approach coping profile characterised by high proactive coping, planning, positive reframing and acceptance could be protective long-term. Early detection of carers at risk of experiencing distress may benefit from assessing coping strategies such as denial and substance use coping. Our results suggest that interventions that focus on positive reframing and assisting carers in decreasing dysfunctional coping may be useful therapeutic targets mitigating carer psychological morbidity.

5. References

Batt-Leiba, M.I., Hills, G.A., Johnsons, P.M., Bloch, E., 1998. Implications of coping strategies for spousal caregivers of elders with dementia Topics in Geriatric Rehabilitation 14, 54-62.

Brüderl, J., Ludwig, V., 2015. Fixed-effects panel regression, In: Best, H., Wolf, C. (Eds.), The Sage handbook of regression analysis and causal inference. Sage, London, pp. 327-357.

Burger, R., Posel, D., von Fintel, M., 2017. The relationship between negative household events and depressive symptoms: Evidence from South African longitudinal data J Affect Disord 218, 170-175.

Carver, C.S., 1997. You want to measure coping but your protocol's too long: consider the brief COPE Int. J. Behav. Med. 4, 92-100.

Cohen, J., 1988. Statistical power analysis for the behavioral sciences. Lawrence Erlbaum Associates, Hillsdale, NJ.

Cooper, C., Katona, C., Livingston, G., 2008a. Validity and reliability of the brief COPE in carers of people with dementia: the LASER-AD Study. J. Nerv. Ment. Dis. 196, 838-843.

Cooper, C., Katona, C., Orrell, M., Livingston, G., 2008b. Coping strategies, anxiety and depression in caregivers of people with Alzheimer's disease. Int. J. Geriatr. Psychiatry 23, 929-936.

Cooper, C., Selwood, A., Blanchard, M., Walker, Z., Blizard, R., Livingston, G., 2010. The determinants of family carers' abusive behaviour to people with dementia: Results of the CARD study. J Affect Disord 121, 136-142.

Crespo, M., Cruzado, J., 1997. La evaluación del afrontamiento: adaptación española del cuestionario COPE con una muestra de estudiantes universitarios [The assessment of coping: Spanish adaptation of the COPE questionnaire in a sample of college students]. Análisis y Modificación de Conducta 23, 797-830.

Cheng, S.T., Lau, R.W., Mak, E.P., Ng, N.S., Lam, L.C., 2014. Benefit-finding intervention for Alzheimer caregivers: conceptual framework, implementation issues, and preliminary efficacy Gerontologist 54, 1049-1058.

Del-Pino-Casado, R., Frias-Osuna, A., Palomino-Moral, P.A., 2011. Subjective burden and cultural motives for caregiving in informal caregivers of older people J. Nurs. Scholarsh. 43, 282-291.

Del-Pino-Casado, R., Palomino-Moral, P.A., Frias-Osuna, A., 2015. The Association of Satisfaction and Perceived Burden With Anxiety and Depression in Primary Caregivers of Dependent Elderly Relatives Res. Nurs. Health 38, 384-391.

Garcia-Alberca, J.M., Cruz, B., Lara, J.P., Garrido, V., Gris, E., Lara, A., Castilla, C., 2012a. Disengagement coping partially mediates the relationship between caregiver burden and anxiety and depression in caregivers of people with Alzheimer's disease. Results from the MALAGA-AD study J Affect Disord 136, 848-856.

Garcia-Alberca, J.M., Cruz, B., Lara, J.P., Garrido, V., Lara, A., Gris, E., 2012b. Anxiety and depression are associated with coping strategies in caregivers of Alzheimer's disease patients: results from the MALAGA-AD study Int. Psychogeriatr. 24, 1325-1334.

Goldberg, D., Bridges, K., Duncan-Jones, P., Grayson, D., 1988. Detecting anxiety and depression in general medical settings Br. Med. J. 297, 897-899.

Goode, K.T., Haley, W.E., Roth, D.L., Ford, G.R., 1998. Predicting longitudinal changes in caregiver physical and mental health: a stress process model Health Psychol. 17, 190-198.

Higgins, J., Green, S., 2008. Cochrane handbook for systematic reviews of interventions, version 5.0.1. Wiley Online Library, Chichester.

Huang, M.F., Huang, W.H., Su, Y.C., Hou, S.Y., Chen, H.M., Yeh, Y.C., Chen, C.S., 2015. Coping Strategy and Caregiver Burden Among Caregivers of Patients With Dementia Am. J. Alzheimers Dis. Other Demen. 30, 694-698.

IMSERSO-CIS, 2004. Encuesta de condiciones de vida de los mayores, 2004. Estudio 4597 [Survey of living conditions of the elderly. Study 4597]. IMSERSO-CIS, Madrid.

Khalaila, R., Cohen, M., 2016. Emotional suppression, caregiving burden, mastery, coping strategies and mental health in spousal caregivers Aging Ment Health 20, 908-917.

Lambert, S.D., Girgis, A., Lecathelinais, C., Stacey, F., 2012. Walking a mile in their shoes: anxiety and depression among partners and caregivers of cancer survivors at 6 and 12 months post-diagnosis Support. Care Cancer 21, 75-85.

León-Campos, M.O., Slachevsky Chonchol, A., Miranda-Castillo, C., 2018. Afrontamiento, apoyo social y depresión en cuidadores informales y su relación con necesidades no cubiertas de personas con demencia Ansiedad y Estrés.

Li, R., Cooper, C., Bradley, J., Shulman, A., Livingston, G., 2012. Coping strategies and psychological morbidity in family carers of people with dementia: A systematic review and meta-analysis J Affect Disord 39, 1-11.

Litman, J.A., 2006. The COPE inventory: Dimensionality and relationships with approach-and avoidance-motives and positive and negative traits Pers. Individ. Dif. 41, 273-284.

Livingston, G., Barber, J., Rapaport, P., Knapp, M., Griffin, M., King, D., Livingston, D., Mummery, C., Walker, Z., Hoe, J., Sampson, E.L., Cooper, C., 2013. Clinical effectiveness of a manual based coping strategy programme (START, STrAtegies for RelaTives) in promoting the mental health of carers of family members with dementia: pragmatic randomised controlled trial BMJ 347, f6276.

Loh, A.Z., Tan, J.S., Zhang, M.W., Ho, R.C., 2017. The Global Prevalence of Anxiety and Depressive Symptoms Among Caregivers of Stroke Survivors J. Am. Med. Dir. Assoc. 18, 111-116.

López Alonso, S.R., Moral Serrano, M.S., 2005. Validación del Índice de Esfuerzo del Cuidador en la población española [Validation of the Caregiver Strain Index in a Spanish population]. Enferm Comunitaria (Gran) 1, 12-17.

Losada, A., Marquez-Gonzalez, M., Romero-Moreno, R., Mausbach, B.T., Lopez, J., Fernandez-Fernandez, V., Nogales-Gonzalez, C., 2015. Cognitive-behavioral therapy (CBT) versus acceptance and commitment therapy (ACT) for dementia family caregivers with significant depressive symptoms: Results of a randomized clinical trial J. Consult. Clin. Psychol. 83, 760-772.

Lu, N., Liu, J., Wang, F., Lou, V.W., 2017. Caring for disabled older adults with musculoskeletal conditions: A transactional model of caregiver burden, coping strategies, and depressive symptoms Arch. Gerontol. Geriatr. 69, 1-7.

Mahoney, F., Barthel, D., 1965. Functional evaluation: The Barthel Index Md. State Med. J. 14, 61-65.

Martínez de la Iglesia, J., Duenas Herrero, R., Onis Vilches, M.C., Aguado Taberne, C., Albert Colomer, C., Luque Luque, R., 2001. Adaptación y validación al castellano del cuestionario de Pfeiffer (SPMSQ) para detectar la existencia de deterioro cognitivo en personas mayores de 65 años [Spanish validation of the Pfeiffer test (SPMSQ) for assessing cognitive impairment in older people]. Med Clin (Barc) 117, 129-134.

Matson, N., 1994. Coping, caring and stress: a study of stroke carers and carers of older confused people Br. J. Clin. Psychol. 33 (Pt 3), 333-344.

Montón, C., Pérez-Echevarría, M.J., Campos, R., García Campayo, J., Lobo, A., 1993. Escalas de ansiedad y depresión de Goldberg: una guía de entrevista eficaz para la detección del malestar psíquico [Golberg's Anxiety and depression scales: An effective interview guide for the detection of psychological distress]. Aten. Primaria 12, 345-349.

Napoles, A.M., Chadiha, L., Eversley, R., Moreno-John, G., 2010. Reviews: developing culturally sensitive dementia caregiver interventions: are we there yet? Am. J. Alzheimers Dis. Other Demen. 25, 389-406.

OECD, 2013. Health at a Glance 2013. OECD indicators. OECD Publishing, Paris.

Pearlin, L.I., Mullan, J.T., Semple, S.J., Skaff, M.M., 1990. Caregiving and the stress process: An overview of concepts and their measures. Gerontologist 30, 583-594.

Pérez-Ordóñez, F., Frías-Osuna, A., Romero-Rodriguez, Y., Del-Pino-Casado, R., 2016. Coping strategies and anxiety in caregivers of palliative cancer patients Eur. J. Cancer Care (Engl). 25, 600-607.

Pérez-Sánchez, I.N., Rascón-Gasca, M.L., Villafana-Tello, J.J., 2014. Coping and emotional discomfort in primary caregivers of cancer patients Rev. Invest. Clin. 66, 495-504.

Pfeiffer, E., 1975. A short portable mental status questionnaire for the assessment of organic brain deficit in elderly patients. J. Am. Geriatr. Soc. 23, 433-441.

Pinquart, M., Sorensen, S., 2003. Associations of stressors and uplifts of caregiving with caregiver burden and depressive mood: a meta-analysis J. Gerontol. B Psychol. Sci. Soc. Sci. 58, P112-128.

Powers, D.V., Gallagher-Thompson, D., Kraemer, H.C., 2002. Coping and depression in Alzheimer's caregivers: longitudinal evidence of stability. The journals of gerontology. Series B: Psychological sciences and social sciences 57, P205-211.

Prince, M., Ali, G.-C., Guerchet, M., Prina, A.M., Albanese, E., Wu, Y.-T., 2016. Recent global trends in the prevalence and incidence of dementia, and survival with dementia Alzheimers Res. Ther. 8, 23.

Robinson, B.C., 1983. Validation of a Caregiver Strain Index J. Gerontol. 38, 344-348.

Roche, D.L., Croot, K., MacCann, C., Cramer, B., Diehl-Schmid, J., 2015. The Role of Coping Strategies in Psychological Outcomes for Frontotemporal Dementia Caregivers J. Geriatr. Psychiatry Neurol. 28, 218-228.

Romero-Moreno, R., Marquez-Gonzalez, M., Mausbach, B.T., Losada, A., 2012. Variables modulating depression in dementia caregivers: a longitudinal study Int. Psychogeriatr. 24, 1316-1324.

Romswinkel, E.V., Konig, H.H., Hajek, A., 2018. The role of optimism in the relationship between job stress and depressive symptoms. Longitudinal findings from the German Ageing Survey J Affect Disord 241, 249-255.

Sallim, A.B., Sayampanathan, A.A., Cuttilan, A., Chun-Man Ho, R., 2015. Prevalence of Mental Health Disorders Among Caregivers of Patients With Alzheimer Disease J. Am. Med. Dir. Assoc. 16, 1034-1041.

Shaw, W.S., Patterson, T.L., Semple, S.J., Grant, I., Yu, E.S., Zhang, M., He, Y.Y., Wu, W.Y., 1997. A cross-cultural validation of coping strategies and their associations with caregiving distress. Gerontologist 37, 490-504.

Söderbom, M., Teal, F., Eberhardt, M., Quinn, S., Zeitlin, A., 2014. Empirical development economics. Routledge, New York.

The King's Fund, 2012. The care of frail older people with complex needs: time for a revolution. The King’s Fund, London.

van der Lee, J., Bakker, T.J., Duivenvoorden, H.J., Droes, R.M., 2014. Multivariate models of subjective caregiver burden in dementia; a systematic review Ageing Res Rev.

Vedhara, K., Shanks, N., Anderson, S., Lightman, S., 2000. The role of stressors and psychosocial variables in the stress process: a study of chronic caregiver stress Psychosom. Med. 62, 374-385.

Vedhara, K., Shanks, N., Wilcock, G., Lightman, S.L., 2001. Correlates and predictors of self-reported psychological and physical morbidity in chronic caregiver stress J. Health Psychol. 6, 101.

Wright, L.K., 1994. AD spousal caregivers. Longitudinal changes in health, depression, and coping J. Gerontol. Nurs. 20, 33-48.

Zarit, S.H., Reever, K.E., Bach-Peterson, J., 1980. Relatives of the impaired elderly: Correlates of feelings of burden Gerontologist 20, 649-654.

Table 1

Baseline socio-demographic characteristics of the sample

			Caregiver			
		M	*SD*	N	%	95% CI
Age		58.5	12.9	200	58.5	56.7; 60.3
Duration of care (years)		6.8	5.3	200	72.9	63.9; 81.8
Sex	Female			176	88.0	83.2; 92.7
	Male			24	12.0	7.2; 16.7
Kinship	Daughter/son			117	58.5	51.4; 65.5
	Daughter/son in law			12	6.0	2.4; 9.5
	Spouse			52	26.0	19.6; 32.3
	Others			19	9.5	5.1; 13.8
Co-residence	No			34	17.0	11.5; 22.4
	Yes			166	83.0	77.5; 88.4
			Care recipient			
		M	*SD*	N	%	95% CI
Sex	Female			137	68.5	61.8; 75.2
	Male			63	31.5	24.8; 38.2
Cause of dependence	Cognitive impairment (dementia or mild cognitive impairment)			62	31.0	24.3; 37.6
	Physical disability			91	45.5	38.3; 52.6
	Stroke			33	16.5	11.1; 21.8
	Cancer			14	7.0	3.2; 10.7

Table 2

Differences on main study variables between completers (n= 177) and non-completers (n= 23)

	Complete Follow up	No Complete Follow up	Value of p (1)
Proactive coping (mean; range: 2-8)	3.70	4.03	0.344
Planning (mean; range: 2-8)	3.96	3.45	0.295
Positive reframing (mean; range: 2-8)	4.30	4.50	0.564
Acceptance (mean; range: 2-8)	6.61	6.55	0.950
Humor (mean; range: 2-8)	2.26	2.29	0.941
Religion (mean; range: 2-8)	3.52	4.29	0.085
Using emotional support (mean; range: 2-8)	4.91	5.09	0.585
Using instrumental support (mean; range: 2-8)	3.70	3.71	0.913
Self-distraction (mean; range: 2-8)	5.17	4.67	0.090
Denial (mean; range: 2-8)	2.48	2.59	0.595
Venting (mean; range: 2-8)	4.13	3.81	0.462
Substance use (mean; range: 2-8)	2.96	3.56	0.181
Behavioural disengagement (mean; range: 2-8)	2.07	2.00	0.416
Self-blame (mean; range: 2-8)	2.70	2.47	0.647
Female (%)	82.6	88.7	0.491
Intensity of care (mean; range: 0-100)	47.0	47.5	0.840
Cognitive impairment (mean; range: 0-10)	4.12	5.39	0.084
Subjetive burden (mean; range: 0-13)	4.70	4.40	0.680

Notes: (1) Mann-Whitney’s test except for % female (Fisher test).

Table 3

Descriptive data of coping strategies (reported by frequency of use)

	Range	*M*	*SD*	Frequency
Acceptance	2–8	6.56	1.227	99.0%
Using emotional support	2–8	5.07	1.502	93.5%
Self-distraction	2–8	4.73	1.268	90.5%
Positive reframing	2–8	4.48	1.719	80.5%
Using instrumental support	2–8	3.70	1.243	80.5%
Proactive coping	2–8	4.00	1.434	79.5 %
Planning	2–8	3.69	1.387	76.5%
Venting	2–8	3.85	1.625	66.5%
Religion	2–8	4.20	2.025	66.0%
Substance use	2–8	3.50	2.233	35.0%
Denial	2–8	2.58	1.044	32.0%
Self-blame	2–6	2.50	0.919	29.0%
Humour	2–7	2.29	0.854	13.5%
Behavioural disengagement	2–7	2.07	0.460	10.0%

Table 4
Pearson's product moment correlation coefficients of study variables

	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18
1 Distress T2	-0.237**	-0.124	-0.410**	-0.163*	-0.091	0.016	-0.250**	-0.043	-0.216**	0.271**	0.016	0.320**	-0.066	0.200**	0.092	0.175*	0.398**
2 Proactive coping T1		0.606**	0.270**	0.247**	0.227**	0.182**	0.269**	0.323**	0.184**	-0.042	-0.104	-0.100	0.130	-0.052	-0.059	0.017	-0.102
3 Planning T1			-0.011	0.238**	0.433**	0.131	0.032	0.256**	0.051	0.028	0.004	-0.093	0.166*	0.067	-0.114	0.054	0.012
4 Positive reframing T1				0.459**	0.031	-0.012	0.382**	0.116	0.155*	-0.366**	-0.131	-0.208**	-0.033	-0.185**	0.100	-0.091	-0.128
5 Acceptance T1					0.114	0.101	0.126	0.108	0.154*	-0.367**	-0.044	-0.007	-0.011	-0.078	0.125	0.114	0.016
6 Humour T1						0.039	-0.028	0.251**	0.042	0.002	-0.005	-0.033	0.450**	0.192**	-0.134	0.006	-0.027
7 Religion T1							0.170*	0.185**	0.182**	0.080	-0.086	0.076	0.013	-0.038	-0.087	0.015	-0.116
8 Emotional support T1								0.361**	0.227**	-0.087	-0.080	-0.138	-0.232**	-0.357**	0.043	0.003	-0.236**
9 Instrumental support T1									0.133	-0.034	-0.107	-0.010	0.104	-0.059	0.044	0.119	-0.039
10 Self-distraction T1										-0.149*	-0.040	-0.090	-0.029	-0.119	-0.098	-0.057	-0.247**
11 Denial T1											0.037	0.103	0.057	0.147*	-0.052	0.010	0.172*
12 Venting T1												-0.047	0.067	0.219**	0.027	0.191*	0.174*
13 Substance use T1													0.061	0.310**	0.003	0.043	0.203**
14 Behavioural disengagement T1														0.244**	-0.075	-0.033	0.038
15 Self-blame T1															0.034	0.062	0.333**
16 Intensity of care T1																0.366**	0.470**
17 Cognitive impairment T1																	0.325**
18 Subjective burden T1																	

Notes: T1: baseline; T2: final assessment (at 12 months follow-up); ** p<0.01, * p<0.05 (two tails).

Table 5

Pooled Ordinary Least Squares (POLS) and fixed-effects (FE) regressions of distress on coping strategies

	POLS	FE
Proactive coping	-0.08	-0.18
Planning	-0.16	0.040
Positive reframing	-0.81***	-0.79***
Aceptance	-0.24	-0.05
Humour	-0.09	-0.42
Religion	-0.02	-0.12
Emotional support	-0.16	-0.32
Instrumental support	0.30	0.41
Self-distraction	-0.20	-0.46*
Denial	0.30	0.57*
Venting	0.07	0.21
Substance use	0.49***	0.57***
Behavioural disengangement	-1.10	-1.05
Blame	0.10	0.67
Intensity of care	-0.02	
Cognitive impairment	0.01	
Subjective burden	0.75***	
R^2	0.34	0.14

Note: The POLS model includes covariates (intensity of care, cognitive impairment and subjective burden), whereas the FE model does not include these covariates because they are time invariant.

Table 6
Multiple linear regression of distress at T2 on approach coping profile, intensity of care, cognitive impairment and subjective burden at T1

Predictor	β	p-value	Δ r^2
Step 1			0.15
Intensity of care	-0.12	0.129	
Cognitive impairment	0.06	0.420	
Subjective burden	0.42	< 0.001	
Step 2			0.05
Intensity of care	-0.13	0.113	
Cognitive impairment	0.07	0.331	
Subjective burden	0.39	< 0.001	
Approach coping profile	-0.21	0.003	
Total r^2			0.20

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Authors' contributions

Rafael del-Pino-Casado. Conceptualization, design, data extraction, analysis, writing, review and editing.

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