

EMPIRICAL RESEARCH QUANTITATIVE OPEN ACCESS

# Caregiving Satisfaction, Psychological Distress and Caregiver Burden in Family Caregivers of Dependent Older People: A Longitudinal Study

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## ABSTRACT

**Background and Objectives:** Although a substantial amount of research has focused on negative aspects of caregiving, less research has been conducted investigating positive aspects of providing informal care. The aim of this study was to investigate the longitudinal association between caregiving satisfaction and psychological distress in informal carers of dependent older people, and whether this relationship is mediated by caregiver burden.

**Research Design and Methods:** Prospective longitudinal study with a probabilistic sample of 332 caregivers of older relatives, with data collected at baseline and at 1-year follow-up. We measured caregiving satisfaction, psychological distress, subjective caregiver burden and several covariates (caregivers' sex, age and objective caregiver burden). Data were analysed using generalised estimation equations with multiple imputation. The STROBE checklist was used to support the writing of this document.

**Results:** After controlling for covariates, caregiving satisfaction was significantly negatively associated with lower levels of subjective caregiver burden ( $B = -0.17$ , 95% CI:  $-0.23$ ,  $-0.11$ ) and emotional distress ( $B = -0.23$ , 95% CI:  $-0.36$ ,  $-0.11$ ). When subjective burden was included in the model, the relationship between caregiving satisfaction and psychological distress was no longer significant ( $B = -0.11$ , 95% CI:  $-0.23$ ,  $0.02$ ), whereas the association between subjective burden and psychological distress remained ( $B = 0.75$ , 95% CI:  $0.57$ ,  $0.92$ ). The Sobel test confirmed these results ( $p < 0.001$ ), indicating that subjective caregiver burden mediates the relationship between caregiving satisfaction and psychological distress (complete mediation) over time.

**Discussion and Implications:** Caregiving satisfaction exerts a longitudinal protective effect on carers' psychological distress via subjective burden. Our findings indicate that interventions aimed at strengthening caregiving satisfaction may play a significant role in maintaining positive mental health outcomes for informal caregivers.

## 1 | Background and Objectives

Family members are now the main support of care for many dependent older people worldwide (Organisation for Economic Co-operation and Development 2021), with provision of care

offered usually over several years (Eurostat 2020). A significant body of empirical work has shown that caring for a dependent older person can be a source of significant psychological distress for informal caregivers (Jansen et al. 2018; Loh et al. 2017; Sallim et al. 2015).

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## Summary

- A better understanding of the effect of positive aspects of care on the emotional health of caregivers of older care dependents would help improve our knowledge of caregiver distress and design future preventative interventions.
- Our findings show that caregiving satisfaction exerts a longitudinal protective effect on carers' psychological distress via subjective caregiver burden.
- These results indicate that interventions aimed at strengthening caregiving satisfaction may play a significant role in maintaining positive mental health outcomes for informal caregivers.

Although much of informal care can be stressful, studies have consistently shown that family carers can also experience positive and rewarding outcomes as part of their caregiving role (Quinn and Toms 2019). Positive contributions of caregiving have been conceptualised in four main areas (Yu, Cheng, and Wang 2018) which includes (1) a sense of achievement, and personal satisfaction, (2) personal fulfilment and purpose in life, (3) feelings of reciprocity in a dyadic relationship and (4) increased family cohesion and functionality. Experiencing caregiving satisfaction, defined as the perception of rewards and gains associated with caregiving, has been found to act as a significant buffer against carers' psychological distress (Del-Pino-Casado, Palomino-Moral, and Frias-Osuna 2015; Lawton et al. 1991; Lopez, Lopez-Arrieta, and Crespo 2005). For example, studies have shown that carers of older dependent relatives reporting high levels of caregiving satisfaction are less likely to experience high levels of subjective caregiver burden (Park et al. 2018).

Feelings of satisfaction associated with caregiving are generally predictive of lower levels of symptoms of anxiety and depression (Lee and Li 2022; Quinn and Toms 2019). Despite however several studies reporting that positive aspects of caregiving are protective of negative mental health outcomes for carers, most studies to date remain largely cross-sectional (Cheng 2023; Quinn and Toms 2019). As a result, we have limited knowledge of how caregiving satisfaction influences carer outcomes over time (Quinn and Toms 2019), and whether these relationships are mediated by caregiver burden.

### 1.1 | Theories of Positive Aspects of Informal Care

The protective effect of caregiving satisfaction on caregivers' well-being can be theoretically explained by theories of stress proliferation (Lazarus and Folkman 1984). These argue that caregiving satisfaction can positively influence the assessment of caregiving stressors, thereby reducing carer distress, and positively influence mental health. Positive feelings may also sustain more effective coping skills (Robertson et al. 2007), which could lead to positive appraisal of the caregiving experience (Robertson et al. 2007).

The first theoretical model conceptualising the relationship between positive aspects of care and caregiver outcomes was

proposed by Lawton et al. (Kramer 1997; Lawton et al. 1991). In this model, positive effects (emotional well-being) and negative effects (psychological distress) of care are represented in two paths that occur simultaneously but are partially independent. Positive effects are motivated by positive aspects, whereas negative aspects are motivated by subjective caregiver burden. This theoretical approach however has received little empirical support in the literature (Del-Pino-Casado, Palomino-Moral, and Frias-Osuna 2015) given that positive aspects of care are generally associated with lower levels of subjective burden, and carer distress (Lee and Li 2022; Pinquart and Sorensen 2003; Quinn and Toms 2019).

Since theoretical models of stress proliferation (Lazarus and Folkman 1984; Pearlin et al. 1990) have not included positive aspects of caregiving, examining the role of positive aspects of caregiving and whether it can be an important coping resource for carers remains a key research objective (Folkman 2008). Studies that have analysed the mediating or moderating role of positive aspects of caregiving have consistently shown that positive gains related to caregiving are cross-sectionally associated with lower levels of subjective caregiver burden (Lee and Li 2022; Quinn and Toms 2019) (Del-Pino-Casado et al. 2021; Del-Pino-Casado et al. 2019a). An important limitation however is that most studies to date have used primarily cross-sectional descriptive designs (Lee and Li 2022). Therefore, an important aim of our study was to analyse whether subjective caregiver burden mediates the longitudinal relationship between positive aspects of caregiving and levels of anxiety and depression in carers.

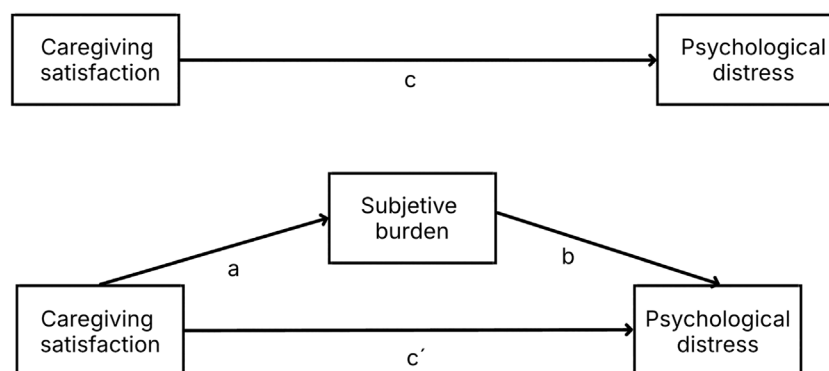
### 1.2 | The Present Study

To our knowledge, there are currently very few studies that have examined longitudinally whether caregiver burden mediates the relationship between positive aspects of caregiving and carer mental health outcomes (Palacio Gonzalez, Roman-Calderón, and Limonero 2021). Therefore, the purpose of our study was to analyse the longitudinal association between positive aspects of caregiving and psychological distress in caregivers of older dependent relatives and examine the possible mediating effect of subjective caregiver burden in this relationship.

## 2 | Research Design and Methods

### 2.1 | Design

Our study was a secondary analysis of two longitudinal prospective studies with 1-year follow-up reported in detail here (Del-Pino-Casado et al. 2019b; Lopez-Martinez et al. 2021). Our study population was 5727 primary caregivers of dependent older people residing in two health districts with both urban and rural centres, in the provinces of Jaén and Córdoba (Andalusia, Spain). Eligibility criteria were: (1) being a primary caregiver (a person with primary responsibility of care for the care recipient), (2) aged 18 years or over and (3) providing daily unpaid care to a family member aged  $\geq 65$  years, who is dependent in at least one activity of daily living (basic or instrumental). Both studies used systematic random sampling stratified by population



**FIGURE 1** | Paths for the mediation analysis.

nucleus (proportional allocation), reporting on an initial sample of 332 family caregivers and a final sample of 258 completing the follow-up.

This final sample size allows us to identify differences of at least 0.2 units in the rate of change of the coefficients, with a power of 85% and a significance level of 5%.

## 2.2 | Procedure

All participants were contacted by telephone and gave informed consent after receiving information about the study. Data were collected through individual interviews at baseline (T1) and at 1-year follow-up (T2). Prior to the main study, a pilot study was conducted with 20 participants to evaluate and modify the interview protocol as appropriate. The Research Ethics Committees of the province of Jaén (reference number: 2706201306) and Córdoba (reference number: 2809201201) approved the studies.

## 2.3 | Measurement

### 2.3.1 | Dependent Variable: Psychological Distress

We used the Goldberg Anxiety and Depression Scale (GADS) (Goldberg et al. 1988) to measure carer psychological distress. The GADS comprises of two separate subscales of anxiety and depression, each containing nine dichotomous items (yes/no), with scores ranging from 0 to 18. The scale has good internal and external validity in Spanish (Montón Franco et al. 1993), with higher scores indicating more severe symptoms. Cronbach's alpha in our study was 0.88.

### 2.3.2 | Independent Variable: Caregiving Satisfaction

Positive aspects of caregiving were measured using the caregiving satisfaction subscale of the Caregiving Appraisal Scale of Lawton et al. (1989), with scores ranging from 6 to 30 points, with higher scores indicative of higher satisfaction. This instrument has shown good psychometric properties and has been adapted and validated in Spanish (Del-Pino-Casado, Palomino-Moral, and Frias-Osuna 2015). Cronbach's alpha in this study was 0.86.

### 2.3.3 | Mediating Variable: Subjective Caregiver Burden

Subjective caregiver burden was assessed using the Caregiver Strain Index (Robinson 1983), containing a total of 13 questions with dichotomous answers. Scores range from 0 to 13, with scores 7 or higher indicative of high levels of subjective caregiver burden. The scale has shown strong validity in the Spanish population (López Alonso and Moral Serrano 2005). In this study, Cronbach's alpha was 0.77.

### 2.3.4 | Covariates

Sex (male/female), caregiver age and objective caregiver burden were considered as covariates. Objective burden was measured by: functional capacity in the care recipient (Barthel Index-BI), presence of cognitive impairment (Pfeiffer test) and behavioural and psychological symptoms (Cummings' Neuropsychiatric Inventory -NPI). The BI (Mahoney and Barthel 1965) is a 10-item scale used widely to measure levels of dependency in activities of daily living. Scores range from 0 to 100 with degree of dependency being inversely proportional to the test score. The BI has been validated in Spanish by Baztán et al. (1993) with adequate psychometric properties. Cronbach's alpha for this study was 0.89. The Pfeiffer Test (Pfeiffer 1975) comprises of 10 items measuring levels of cognitive impairment in the care recipient (range of scores 0-10; higher scores indicating higher levels of impairment). We used the Spanish validated version (Martínez de la Iglesia et al. 2001), with Cronbach's alpha 0.85. The NPI (Cummings et al. 1994) evaluates frequency and severity of behavioural and psychological symptoms that may be bothersome to the caregiver. Scores range from 0 to 120 with higher scores indicative of higher presence of symptoms. It has been validated in Spanish by Vilalta-Franch et al. (1999) with adequate psychometric data. Cronbach's alpha for our study was 0.82.

## 2.4 | Statistical Analysis

Measures of central tendency and dispersion were calculated for quantitative variables and percentages for qualitative variables. Differences in means (Mann-Whitney *U* test) were used to compare participants who remained in the study versus those that were lost. To explore the relationship between caregiver satisfaction, subjective caregiver burden and psychological distress,

we used multivariate analysis and specifically generalised estimation equations (GEE), adjusting for covariates (sex, caregiver age and objective caregiver burden).

We used Baron and Kenny (1986) to define mediation (Figure 1): (1) variations in levels of the independent variable significantly account for variations in the presumed mediator (path a), (2) variations in the mediator significantly account for variations in the dependent variable (path b), and (3) the effect of a significant relationship between independent and dependent variable (path c) is reduced by adding the mediator to the model (path c'), showing full mediation (no direct effect) when the effect is no longer significant. To analyse the mediating effects of subjective caregiver burden, we used the Sobel test (Sobel 1982) from the regression coefficients provided by the covariate-adjusted GEE analyses.

To correct for possible selection bias due to losses we used the multiple imputation method, generating five data sets (Rubin 1987) using the automatic option of the Statistical Package for Social Sciences (SPSS). GEE analyses were calculated by SPSS via combining the results of the five data sets (weighted mean by standard error). All analyses were performed using SPSS software, version 24.0 (IBM Corp.).

### 3 | Results

#### 3.1 | Description of the Sample

Table 1 shows descriptive statistics of the sample. Mean age was 56.3 years for caregivers and 85.2 years for care recipients, with 80% of caregivers and 75.8% of care recipients being women. Most frequent kinship relationship was being the daughter/son of the care recipient (74.2%). The most frequent cause of dependency was frailty (76.5%), followed by cognitive impairment (11.4%) and cancer (7.6%). Table 2 presents measures of central tendency and dispersion for the main study variables at baseline (T1) and 1-year follow-up (T2). All variables remained stable throughout the follow-up. Table 3 shows differences between study variables in participants who remained in the study versus those that were lost; analyses showed no statistically significant differences in any of the study variables between the two groups except for (1) cognitive impairment; with those dropping out of the study experiencing more severe symptoms, and (2) behavioural and psychological symptoms; with those dropping out having more symptoms.

#### 3.2 | Correlations Between Main Variables

Table 4 shows correlations between main study variables. Distress at T2 correlated with subjective caregiver burden at T2, caregiving satisfaction at T1, caregiver sex, caregiver age and objective burden at T1 (functional capacity, cognitive impairment and behavioural and psychological symptoms). Subjective caregiver burden at T2 correlated with caregiving satisfaction at T1 and objective caregiver burden at T1 (functional capacity, cognitive impairment and behavioural and psychological symptoms).

**TABLE 1** | Sample characteristics.

Variable	M	SD <sup>a</sup> /SE <sup>b</sup>	N	%
Caregiver age	56.27	11.75 <sup>a</sup>		
Caregiver's sex				
Female			114	86.40
Male			18	13.6
Kinship				
Daughter/son			98	74.2
Husband			17	12.9
Daughter-in-law/ son-in-law			6	4.5
Other			11	8.3
Age of care-recipient	85.20	6.20 <sup>a</sup>		
Co-residence				
Yes			92	69.7
No			40	30.3
Length of care (years)	9.2	0.26 <sup>b</sup>		
Employment status				
Employed			20	15.2
Not employed			112	84.8
Sex of care-recipient				
Female			100	75.8
Male			32	24.2
Cause of dependency				
Frail older people			101	76.5
Cognitive impairment			15	11.4
Cancer			10	7.6
Other			6	4.5

Abbreviations: M, mean; N, number of people in each category and % percentage in each category; SD, standard deviation; SE, standard error of the mean.  
Note: <sup>a</sup>, standard deviation; <sup>b</sup>, standard error.

#### 3.3 | Mediation Analysis

First, we checked Baron and Kenny's criteria (1986): (1) higher levels of caregiving satisfaction were significantly associated with lower subjective caregiver burden ( $B = -0.17$ , 95% CI:  $-0.23$ ,  $-0.11$ ; Figure 2, path a), after controlling for caregivers' sex, age and objective burden; (2) caregiving satisfaction was also significantly negatively associated with carer emotional distress (coefficient [ $B$ ] =  $-0.23$ , 95% confidence interval [CI]:  $-0.36$ ,  $-0.11$ ; Figure 2, path c) after controlling for covariates; (3) when subjective caregiver burden however was included in the model (Table 5), the relationship between caregiving satisfaction and



**TABLE 2** | Description of study variables.

Variable	Time	M	CI
Caregiving satisfaction	1	26.7	25.5–27.0
	2	26.8	25.8–27.2
Psychological distress	1	6.8	6.1–7.5
	2	6.5	5.7–7.2
Subjective caregiver burden	1	4.9	4.4–5.2
	2	5.1	4.7–5.5
Care-recipient functional capacity	1	6.5	5.9–7.1
	2	6.1	5.4–6.8
Care-recipient cognitive impairment	1	4.3	3.9–4.8
	2	4.6	4.2–5.1
Care-recipient behavioural and psychological symptoms	1	8.8	7.4–10.3
	2	8.0	6.3–9.7

Abbreviations: CI, confidence interval; M, mean.

**TABLE 3** | Differences (means; M) between participants who completed the study versus those that dropped out.

Variables	Remaining (N=258)	Dropping out (N=74)	<i>p</i> *
Psychological distress	6.83	6.87	0.752
Caregiving satisfaction	26.70	26.61	0.231
Subjective caregiver burden	4.62	5.28	0.253
Care-recipient functional capacity	6.75	5.58	0.090
Care-recipient cognitive impairment	4.07	5.35	0.010
Care recipient behavioural and psychological symptoms	8.34	10.49	0.003

\*Mann–Whitney *U* test.

psychological distress was no longer statistically significant ( $B = -0.11$ , 95% CI:  $-0.23, 0.02$ ; Figure 2, path c', Table 5), with the association between subjective caregiver burden and psychological distress remaining significant ( $B = 0.75$ , 95% CI:  $0.57, 0.92$ ; Figure 2, path b).

The Sobel test showed that the above results were significant ( $p < 0.001$ ), indicative of a mediating effect of subjective caregiver burden on the relationship between caregiving satisfaction and psychological distress (Figure 2). Because the *B* coefficient of the relationship between caregiving satisfaction

and psychological distress was no longer significant when the mediator was included in the model; mediation was complete; this indicates no direct effect between levels of caregiving satisfaction and carer psychological distress. The indirect effect of caregiving satisfaction and psychological distress via subjective caregiver burden was  $B = -0.17 \times 0.75 = -0.13$ .

#### 4 | Discussion and Implications

To our knowledge, this is the first prospective cohort study investigating the longitudinal association between caregiving satisfaction and carer psychological distress, controlling for the effects of caregiver burden. Our study adds to the limited body of evidence linking caregiving satisfaction with carer well-being over time. An important contribution of our study is that we have been able to longitudinally assess the mediating effect of subjective caregiver burden on the relationship between caregiving satisfaction and carer psychological distress. As predicted by stress process theories of caregiving (Pearlin et al. 1990), we found that caregiver burden plays an important role in mediating the relationship between caregiver satisfaction and carer distress over time. Our results were consistent with a full mediation effect indicating that caregiver burden experienced by carers is a key mediation mechanism that links caregiving satisfaction to psychological distress. An important strength of our study is that we have been able to demonstrate this mediating effect using a probabilistic sample and controlling for several confounding variables such as caregivers' sex, age and experience of objective burden.

An interesting finding of our study was that levels of caregiving satisfaction remained stable over time. Our results indicative of a possible protective effect of caregiving satisfaction on carer psychological distress are in line with prior studies (Del-Pino-Casado, Palomino-Moral, and Frias-Osuna 2015), highlighting the important contribution of positive aspects of caregiving (Lloyd, Patterson, and Muers 2016) in predicting carer outcomes over time.

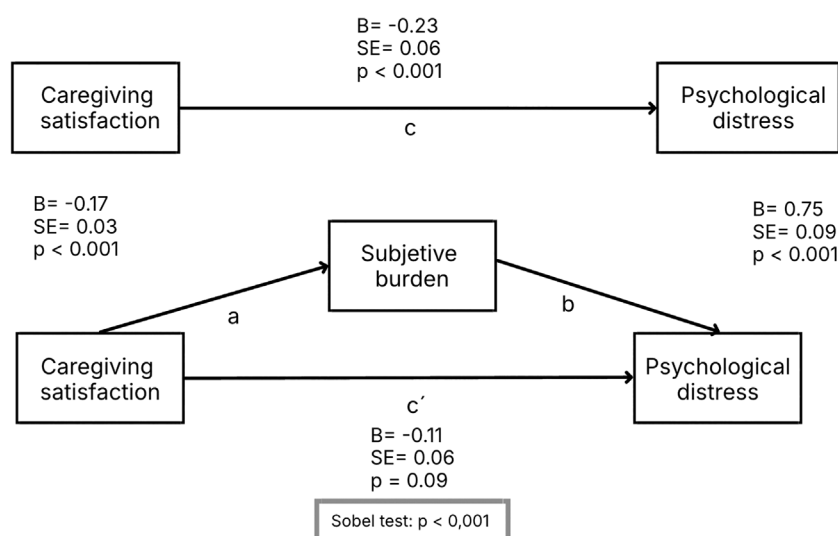
Subjective caregiver burden relates to the perceptions and evaluations that caregivers have of the caregiving situation (Zegwaard et al. 2011). In line with Lazarus and Folkman's theory of stress proliferation, this evaluation is related to how carers cognitively appraise the caregiving situation (Lazarus and Folkman 1984). In stressful situations, individuals carry out a cognitive assessment of the possible repercussions of the stressful situation and their ability to cope. When these evaluations are negative, subjective burden increases. As our results showed, an increase in caregiving satisfaction could make this cognitive assessment more positive and therefore decrease feelings of burden, reducing their effect on carers' levels of psychological distress. Our data therefore support the hypothesis that adequate satisfaction with care being provided may result in carers viewing caregiving more positive, which may in turn result in perceiving caregiving stressors as less threatening, thereby supporting carers' coping.

Our data have shown that caregiving satisfaction is an important outcome for carers and that interventions aimed at strengthening caregiving satisfaction, by improving carers' perception of

**TABLE 4** | Correlation matrix of main variables of the study (Spearman's correlations).

	1	2	3	4	5	6	7	8
1 Distress T2	1	0.458**	-0.129*	0.139*	-0.017	-0.124*	0.183**	0.249**
2 Subjective burden T2	0.458**	1	-0.193**	0.098	-0.005	-0.302**	0.347**	0.397**
3 Satisfaction T1	-0.129*	-0.193**	1	0.028	-0.109*	-0.020	-0.091	-0.127*
4 Caregiver sex (women)	0.139*	0.098	0.028	1	-0.038	-0.039	0.012	-0.023
5 Caregiver age	-0.017	-0.005	-0.109*	-0.038	1	-0.001	0.006	0.034
6 Care-recipient functional capacity T1	-0.124*	-0.302**	-0.020	-0.039	-0.001	1	-0.442**	-0.194**
7 Care-recipient cognitive impairment T1	0.183**	0.347**	-0.091	0.012	0.006	-0.442**	1	0.354**
8 Care-recipient behavioural and psychological symptoms T1	0.249**	0.397**	-0.127*	-0.023	0.034	-0.194**	0.354**	1

Abbreviations: T1, time 1; T2, time 2.

\* $p < 0.05$ .\*\* $p < 0.01$ .**FIGURE 2** | Paths for the mediation analysis. All analyses are adjusted for covariates (caregivers' sex, age and objective caregiver burden).

how well they adapt to the caregiving role (sense of competence, personal fulfilment), may result in positive mental health outcomes long term. This is in line with evidence that interventions aimed at improving care skills, either directly (Cheng, Chair, and Chau 2018; McDonald et al. 2017) or through the improvement of sense of competence (Quinn et al. 2012) or coping (Porter et al. 2021), are associated with higher levels of caregiving satisfaction. Given our results indicative of a mediated effect of caregiver burden on the relationship between caregiving satisfaction and psychological distress, these interventions if offered more widely could potentially prevent or reduce both subjective caregiver burden and carer psychological distress.

#### 4.1 | Limitations

Despite the originality of our findings the present study has several limitations. First, we observed a significant number of losses at follow-up which may have influenced our results.

However, when comparing our main study variables between participants who remained in the study versus those that dropped out, the only statistically significant difference observed was severity of cognitive impairment in the care recipient. Although we did employ multiple imputation to correct for possible bias due to losses, it is likely that significant risk of bias remained. Other factors which were not measured in our study such as financial or social support received by carers, may have influenced our results. Future studies should examine how financial assistance and different types of social support may influence caregiver satisfaction over time. Despite the use of a longitudinal prospective design, our data and method of analysis used (GEE) does not allow us to control for reverse causality; so, it is likely that carers' psychological distress influenced levels of caregiving satisfaction not vice versa. Our study examined caregiver satisfaction in frail older people in general, which included people living with frailty, cancer or cognitive impairment. Although our sample is representative of frail older people, these groups have very different care

**TABLE 5** | Full regression model for psychological distress.

Variable	Coefficient (B)	Standard error	95% Confidence interval of B		p
			Lower limit	Upper limit	
Caregiving satisfaction	-0.105	0.0612	-0.225	0.015	0.086
Subjective burden	0.748	0.0895	0.572	0.923	<0.001
Caregiver sex (women)	2.448	0.6752	3.777	1.119	<0.001
Caregiver age	-0.003	0.0183	-0.039	0.033	0.882
Care-recipient functional capacity	0.114	0.0521	0.012	0.216	0.029
Care-recipient cognitive impairment	0.077	0.0853	-0.092	0.245	0.370
Care recipient behavioural and psychological symptoms	0.047	0.0211	0.005	0.089	0.027
Intercept	4.543	2.387	-0.147	-1.537	0.058

needs. This means our findings may not be informative across all these groups and differences may still exist which we have not been able to detect. Further studies are needed to examine how the specific demographic characteristics of these groups, and associated comorbidities may influence levels of caregiving satisfaction over time.

## 4.2 | Conclusions

Our results show that, in caregivers of older dependent relatives, caregiving satisfaction can have a protective effect on carers' psychological distress over time via the mediating effect of subjective caregiver burden. Interventions that strengthen caregiving satisfaction and reduce caregiver burden may prevent high levels of carer psychological distress over time. Future longitudinal studies that examine reverse causality in the relationship between caregiving satisfaction and psychological distress are important to better understand how to support and maintain carers' positive mental health.

### Acknowledgements

We are grateful for the participation of all the carers who took part in the study.

### Conflicts of Interest

The authors declare no conflicts of interest.

### Data Availability Statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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### **Supporting Information**

Additional supporting information can be found online in the Supporting Information section.