Del-Pino-Casado R, López-Martínez C, Frías Osuna A, Orgeta V. The relationship between perceived social support and psychological distress in carers of older relatives: A longitudinal cross-lagged analysis. J Affect Disord. 2022. Jan 15; 297:401-6.

DOI: https://doi.org/10.1016/j.jad.2021.10.075

Title:

The relationship between perceived social support and psychological distress in carers of older relatives: A longitudinal cross-lagged analysis.

Running head:

Social support and psychological distress in carers.

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Declarations of interest:

None.

Abstract

Background and objectives: Although a large body of research has examined the relationship between social support and psychological health of family carers of frail older people, the exact nature and direction of this relationship is not well understood with most research to date being cross-sectional. This longitudinal study explored the relationship between perceived social support and psychological distress in carers of older relatives.

Methods: We used data from two longitudinal cohorts which included a total of 332 family carers of frail older people. We used cross-lagged panel analysis to investigate the longitudinal association between perceived social support and carer psychological distress controlling for a number of covariates over time.

Results: Fully-adjusted Generalised Estimating Equations (GEE) and cross-lagged models indicated that higher social support was significantly associated with lower carer psychological distress over time (regression coefficient [B] = -0.178, standard error [SE] = 0.028), with levels of perceived social support exerting an effect on psychological distress rather than vice versa ($\beta = 0.03$, $p = 0.32$).

Limitations: All observations were based on self-report data, and there may be other variables that may explain the results that we did not account for.

Discussion and implications: Our study finds that the directionality of the relationship appears to be from perceived social support to carer psychological distress suggesting that social support directly affects carer psychological health but not vice versa. This finding has important implications for the provision of social support interventions for carers of frail older people at risk of experiencing psychological distress.

Keywords: social support; psychological distress; caregiving; older people; longitudinal design.

Introduction

Providing care to dependent older people is becoming increasingly common due to increasing life expectancy and age-related morbidity and disability worldwide (United Nations, 2019). Given the greater emphasis on noninstitutional care it is now widely acknowledged that this informal care is primarily provided by family carers (Organisation for Economic Co-operation and Development, 2019). Despite the role of caregiving being a rewarding experience for many carers, providing full-time care to a dependent older relative can be very stressful, increasing risk of carer psychiatric morbidity and distress (Geng et al., 2018; Sallim et al., 2015; Zhu and Jiang, 2018). Several studies estimate that prevalence rates of anxiety and depression for family carers of people surviving cancer are as high as 46.6% and 42.3% respectively (Geng et al., 2018), with similarly high rates for carers of people living with dementia (43.6% for anxiety, and 33.9% for depression; (Sallim et al., 2015) and carers of stroke survivors (Zhu and Jiang, 2018); 21.4% for anxiety and 40.2 for depression).

Identifying which factors predispose family carers to increased risk of psychiatric distress and which factors may be protective is important for the development of preventative mental health strategies for the growing numbers of family carers worldwide. Despite the large evidence base of risk factors associated with increased psychiatric distress in family carers (Geng et al., 2018; Watson et al., 2019), evidence on potential protective factors remains small, limiting our knowledge of the key determinants of maintaining carer resilience over time (Lopez-Martinez et al., 2020).

It is well established that social support and social relationships influence positively individuals' physical and psychological health (Uchino, 2006; Wang et al., 2018). Current theoretical models of caregiving identify social support as a potentially important modifiable factor of caregiver well-being (Pearlin et al., 1990). In line with these models, social support has been conceptualised as an important resource that may buffer the effects of caregiver strain on carers' psychological health (del-Pino-Casado et al., 2018). Social support has been defined as "the existence or availability of people on whom individuals can rely upon" (Sarason et al., 1983), classified as encompassing both *structural* and *functional* dimensions. Structural dimensions of social support comprise the size, composition and complexity of an individuals' social network (Thompson et al., 1993; Vrabec, 1997), whereas functional dimensions refer to the types of assistance accessible to individuals (given or available), classified as emotional, instrumental and informational (Chang et al., 2001).

Functional components of social support which represent the particular purposes and functions of interpersonal relationships, can be measured in two ways: perceived availability of support (perceived support) and received support (Gottlieb and Bergen, 2010; Uchino et al., 2012). Perceived support refers to the subjective perception of support available when it is needed, and the appraisal of its adequacy and/or quality, whereas received support refers to support actually received such as the specific helping and frequency of transactions provided by others (del-Pino-Casado et al., 2018).

In line with the *social causation model*, social support is an antecedent of well-being, therefore its lack or limited availability is viewed as being causal to psychological distress (Kaniasty and Norris, 2008). Indeed, several studies to date have shown that high levels of anxiety and depressive symptoms in family carers of dependent older people are associated with lower levels of social support (Garcia-Torres et al., 2020; Jeong and An, 2017). Regarding the importance of perceived versus received social support, most evidence to date shows that levels of perceived and not received social support, are the most important contributor of carers' emotional health (del-Pino-Casado et al., 2018). Thus, specific domains of social support available to carers may differentially influence their psychological health.

Despite however the increasing research interest on the protective effect of social support on carers' well-being the majority of studies conducted to date have examined the effects of social support cross-sectionally with very few longitudinal studies in the literature (Garcia-Torres et al., 2020). The use of longitudinal designs is very important in terms of understanding the influence of social support on carer well-being, and how social support and carer psychological distress influence each other over time (Sconfienza et al., 2019). Novel methods therefore of analysing longitudinal data are key in terms of testing complex models of directionality of social support and carer psychological health and for understanding the directionality between these variables.

The primary aim of this study was to analyze longitudinally the relationship between perceived social support and carer psychological distress in two Spannish probability-based representative samples of carers of dependent older people. A secondary aim was to test whether reciprocal relationships exist between carer psychological distress and social support and examine the cause-and-effect relationship between the two variables using cross-lagged panel analysis.

Methods

Design, setting and sample

This study is a secondary analysis of two longitudinal prospective cohort studies with a one year follow-up described in detail elsewhere (del-Pino-Casado et al., 2019; Lopez-Martinez et al., 2020). Both studies recruited primary carers of older relatives living in the Spanish Health Districts of Alto Guadalquivir (46,560 inhabitants; province of Córdoba) (del-Pino-Casado et al., 2019) and Jaén-Nordeste (175,000 inhabitants; province of Jaén) (Lopez-Martinez et al., 2020), in Andalusia. The sampling frame in both studies was established by the census of primary carers of older relatives of each health care centre (1,182 carers in the study of 2019 and 4,545 in the study of 2020). The final sample was selected by random sampling from the census of family carers of older dependants (4,545 caregivers). The combined sample therefore consisted of family carers of dependent older relatives recruited in two Andalusian Health Districts (in Córdoba and Jaén, Spain), from a population of 221,560 inhabitants distributed in both urban and rural population centres. Eligible participants were: 1) aged 18 or over, 2) being the main carer (having primary responsibility for the care provided) to a relative aged 65 years or over who was dependent in at least one activity of daily living (basic or instrumental), and 3) providing daily care. The sampling method in both of the studies was systematic random sampling, stratified by population nucleus (proportional affixation), with a total sample of 332 family carers providing data.

Measurements

Demographic characteristics assessed included age and sex of the family carer and care recipent, kinship status, co-residence, duration of caregiving and cause of dependency of the care recipient.

Perceived social support (independent variable) was measured by the Duke-UNK Functional Social Support Questionnaire (FSSQ) (Broadhead et al., 1988), comprising of 11 items rated using a Likert-type scale ranging from 1 to 5 (total range: 11–55), validated in Spanish (De la Revilla et al. (1991); Cronbach’s α coefficient: 0.81). The Cronbach’s α in this study was 0.84.

Psychological distress (dependent variable) was assessed using the Goldberg Anxiety and Depression Scale (GADS) (Goldberg et al., 1988; Montón et al., 1993), comprised of two subscales measuring both symptoms of anxiety and depression respectively. Each scale contains 9 items, with dichotomous responses (yes / no), and a total score ranging from 0-18. Cronbach’s α in the present study was 0.88.

Control variables

Based on previous research and theory (Cooper et al., 2007; Del-Pino-Casado et al., 2021; Li and Loke, 2013), we included levels of subjective caregiver burden, care recipient needs (functional capacity, cognitive impairment and behavioural problems) and sex as control variables.

Subjective burden was measured by the Caregiver Strain Index (CSI) (Robinson, 1983), validated in the Spanish population by López Alonso and Moral Serrano (2005). The CSI includes 13 dichotomous questions (True / False), with scores ranging from 0-13 points. We observed a Cronbach's alpha of 0.78 in the present study.

Functional capacity was assessed using the Barthel Index (Mahoney and Barthel, 1965), validated in Spanish by Baztán et al. (1993). This questionnaire assesses the degree of independence for basic activities of daily living (range of scores: 0 – 20), with higher scores indicative of higher independence. Cronbach's alpha was 0.89.

Cognitive impairment was assessed using the Pfeiffer Test (Pfeiffer, 1975), which has strong validity in the Spanish population (Martínez de la Iglesia et al. (2001). The Cronbach's alpha was 0.85.

Behavioural problems were assessed using the Neuropsychiatric Inventory (Cummings et al., 1994), validated in Spanish by Vilalta-Franch et al. (1999). In the present study, Cronbach's alpha was 0.82.

Procedure

In both studies data collection was carried out by qualified research assistants. Prior to data collection extensive piloting took place to ensure adherence to the research protocol and minimise missing data. Initial contact with the participants was made through family nurses informing them of the study and its voluntary nature. All interviews took place at the home of the care recipient and all participants gave informed consent prior to taking part in the study. The Research Ethics Committee of the province of Jaén (reference number: 2706201306), and the Research Ethics Committee of the province of Córdoba (reference number: 2809201201) approved the studies.

Data analysis

Central tendency and dispersion measures for quantitative variables and percentages for qualitative variables were used in the descriptive analysis. For the bivariate analyses, we used the Student's t-test and the chi-square test to compare participants who remained in the study and those who dropped out at T2.

The longitudinal effect of social support on carer psychological distress was analysed using Generalised Estimating Equations (GEE), including several control variables. Based on previous research we hypothesised that social support and psychological distress have a reciprocal relationship (del-Pino-Casado et al., 2018), and augmented our longitudinal analysis with a cross-lagged path analysis. Cross-lagged models allow the examination of both auto-regressive and reciprocal relationships between two variables over time controlling for auto-regression (Kearney, 2017; Selig and Little, 2012). Such models have been used widely by several studies to analyse reciprocal relationships between risk factors and psychological distress in the general population (Brown et al., 2020; Piasecki et al., 2017; Sifaki et al., 2020). One of the requirements of the cross-lagged panel is that all important predictors are included in the model (Kearney, 2017; Selig and Little, 2012); thus, our model included the cross-lagged relationships between social support and psychological distress, together with several control variables (caregiver sex and age, care recipient needs, co-residence and subjective caregiver burden). In order to evaluate the fit of the model, we used the following measures and optimal ranges (Hooper et al., 2008; Hu and Bentler, 1999): 1) X^2/degree of freedom (df) values below 2, 2) RMSEA values below 0.08, 3) SRMR values below 0.08, and 4) CFI values above 0.95.

Regarding missing data, 258 carers (78%) completed data at T2. There were no statistically significant differences between participants who completed the study versus those that dropped out, except for carers of people living with cognitive impairment which were more likely to drop out of the study (see Results section for figures). In order to account for any biases related to missing data we used multiple imputation methods generating five sets of data (Rubin, 1987). For the GEE analysis, we used the automatic option in SPSS to generate the sets of data. This option chooses the best method of imputation based on the data analysed. The GEE analysis was performed from the combined results of the five data sets. For the cross-lagged analysis, we used Bayesian imputation, in order to take into account sample uncertainty, and the procedures described by Arbuckle (2011), computing coefficients and p-values from the five data sets.

A significance level of 5% was used for all statistical tests. Analyses were carried out with the statistical package of IBM SPSS Statistics, version 24.0 (IBM Corp, Armonk, NY, USA), and AMOS 18 (used to perform the path analysis).

Results

Description of the sample and study variables

The total sample consisted of 332 carers (Table 1), of whom 87.3% were female, and 64.8% were children of the care recipient. The average age was 57.6 years (standard deviation [SD] = 12.5). Seventy-seven percent of the sample lived in the same household as the person being cared for (Table 1). Care recipients were mainly women (71.4%), with a mean age of 83.3 years (SD = 8.7) and were mostly frail older people (57.8%) or people living with cognitive impairment/dementia (23.2%) (Table 1).

Means and SDs of study variables are presented in Table 2. Mean psychological distress and social support at T1 were 6.82 (out of 18; SD = 5.6) and 37.0 (out of 55; SD = 8.6) respectively, with levels of social support remaining relatively stable during follow up (Table 2).

There were no statistically significant differences between participants who completed the study versus those that dropped out, except for carers of people living with cognitive impairment which were more likely to drop out of the study (see Table 3).

Effect of social support on carer psychological distress

The findings of the GEE analysis are shown in Table 4. After controlling for subjective caregiver burden, care recipient needs, co-residence, and caregiver sex and age, higher levels of social support were significantly associated to lower levels of carer psychological distress over time (regression coefficient [B] = -0.178, standard error [SE] = 0.028); carer psychological distress increased by 1.78 points (9.9%) for every decrease of social support by 10 points (18.2%). Caregiver sex (female; B = 2.737, SE = 0.612), and levels of subjective caregiver burden (B = 0.707, SE = 0.083) were significantly associated with psychological distress. Specifically, female carers reported higher distress compared to males, and experiencing higher burden was associated with higher distress over time. Care recipient functional capacity (B = -0.129, SE = 0.056), predicted carer distress, with carers looking after someone with high levels of functional dependency more likely to report higher distress over time.

Our cross-lagged analysis (see Figure 1) showed a significant cross effect of social support at T1 on psychological distress at T2 (standardized regression coefficient [β] = -0.14, p = 0.01), but not a significant cross effect of psychological distress at T1 on social support at T2 (β = 0.03, p = 0.32), indicating that social support affects carer psychological distress but not vice versa. We found auto-regressive effects (from T1 to T2) for both social support (β = 0.79, p < 0.001) and psychological distress (β = 0.59, p < 0.001), suggesting that, for each variable, scores at T1 predict scores at T2. Fit indices of the cross-lagged model showed an overall goodness of fit for the model: $X^2/df = 1.52$, RMSEA = 0.04 (95% confidence interval = 0.009 – 0.070; p = 0.676), SRMR = 0.02 and CFI = 0.99, which was adjusted for subjective caregiver burden, care recipient needs, co-residence, and caregiver sex and age.

Discussion

Our study is one of the few large-scale population-based longitudinal studies in the area of social support and carer psychological distress of family carers of frail older people. To our knowledge, this is the first longitudinal study examining how levels of perceived social support by carers operate over time and the direction of the relationship between perceived social support and carer psychological distress. We found that, after controlling for caregiver sex, care-recipient needs and levels of subjective caregiver burden experienced by carers, higher perceived social support was significantly associated with lower psychological distress over time. An important contribution of our study is the finding that perceived social support impacts carer psychological distress over time but not vice versa, providing therefore evidence for a unidirectional association. Our results indicative of a specific effect of perceived social support on carer psychological distress is an important and original finding as it suggests that increasing levels of perceived support mitigates carer distress over time.

We were able to test the bidirectional relationship between social support and carer distress via a large-scale representative sample of family carers of frail older people utilising a prospective design. Overall, our results are largely consistent with longitudinal studies of social support and psychological distress in family caregivers (Butow et al., 2014; Reblin et al., 2018). The findings of our GEE analyses for example, showed that carer female gender, subjective caregiver burden and functional capacity of the care-recipient were important predictors of psychological distress, supporting results of several studies (Cooper et al., 2007; Del-Pino-Casado et al., 2021; Li and Loke, 2013). However, our data have additionally contributed important new evidence on the longitudinal effect of domain-specific social support on carer psychological distress. A further important strength of our study was the observation that the positive longitudinal effect of perceived social support on carer psychological distress over time was observed over and above the effect of changes in levels of subjective caregiver burden and level of dependency of the care recipient. The relationship therefore between perceived social support and carer psychological distress is independent of perceived burden, and functional capacity of the care-recipient.

Our finding that low levels of perceived social support seem to directly foster higher levels of psychological distress in carers highlights the importance of social support as a key variable in moderating the negative impact on carers' psychological health. For example, our findings suggest that family carers who perceive their levels of social support as adequate or positive (Cohen et al., 2000; Cohen and Wills, 1985), will be more likely to view the caregiving situation as less stressful, which may potentially positively affect outcomes for the care recipient.

Perceived informal social support provided to family carers may therefore be an important target for future interventions and commissioning these types of interventions more widely to serve a largely underrepresented group.

Our data provide further support for the use of GEE in caregiving research to analyse longitudinal datasets in order to overcome important methodological limitations, such as controlling for within-effect variability, and allowing the testing of reciprocal models of directionality for carer outcomes. Such analyses in future studies are very important to ensure that treatments are better targeted for family carers and for understanding mechanisms of action of interventions. Future studies should investigate which types of perceived social support are most valuable to family carers in order to inform the development of interventions that are easily accessible and clinically effective. Such studies should additionally investigate which mechanisms may drive the association of perceived social support and carer psychological distress and how these could potentially differ across different groups of family caregivers.

To conclude, our findings have important clinical implications for caregiving intervention research, showing that enhancing levels of perceived social support in carers is associated with decreased psychological distress over time. Our results showing that high levels of perceived social support accessible to carers have a long-term beneficial effect for carers' well-being support calls for the wider availability of these types of interventions.

Limitations

There are several limitations to our study. Despite the use of a longitudinal design all observations were based on self-report data, and there may be other variables that may explain the results that we did not account for, such as personality characteristics, which correlate with both social support and carer psychological distress. Levels of social support were quite stable over time in the current sample which limits the generalisability of our findings and how applicable they may be throughout the caregiving journey. In addition, we observed a lower rate of response for carers looking after people living with cognitive impairment which may have biased our findings. Carers of people living with cognitive impairment may typically have smaller social networks which could place them more vulnerable to social isolation compared to those looking after relatives that do not experience cognitive decline. Nevertheless, our use of multiple imputations in handling missing data, has allowed us to address this issue. Although this study is a secondary study based on two separate samples, both samples were based on large-scale probability-based studies with similar populations and sampling procedures so the risk of bias comparisons between samples is low. However, despite these similarities, the interpretation of the main variables of interest may differ between cohorts (i.e. the meaning of social support and distress may change over time or geography).

Conclusions

Overall our results offer important new insights into the relationship between perceived social support and carer psychological health over time. Furthermore, our findings have important clinical implications suggesting that interventions that aim to increase levels of perceived social support for carers may be protective over time indicating that access to such interventions should be a priority for the growing numbers of family carers worldwide.

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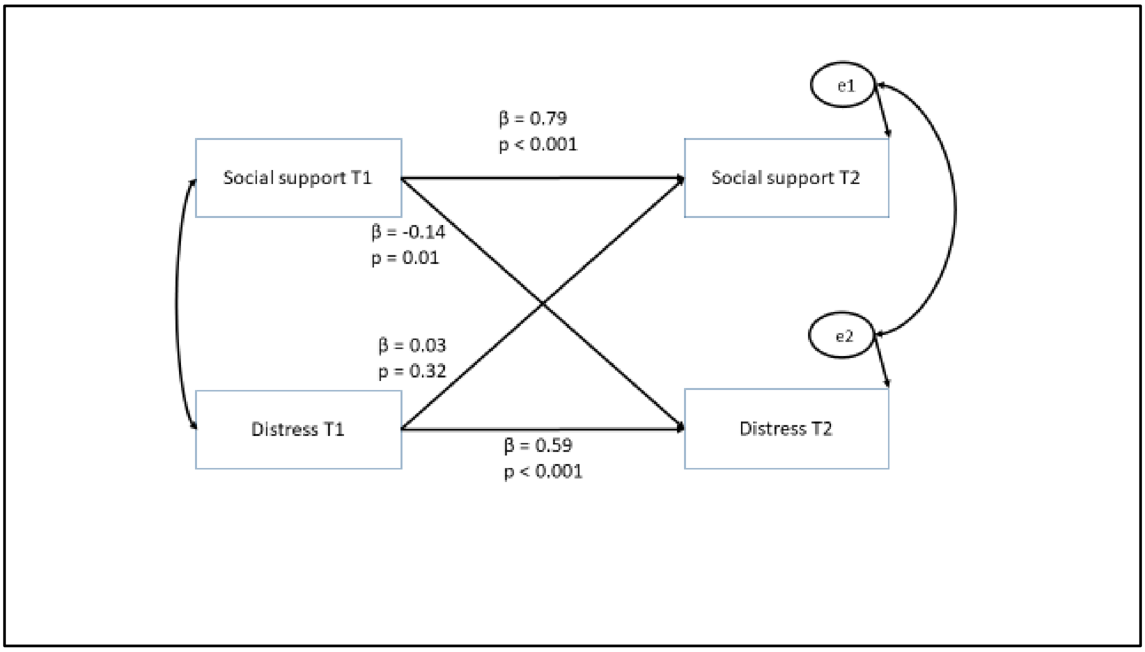
Figure 1 Cross-lagged model for social support and carer psychological distress.



Abbreviations: β: standardised regression coefficient, p: p-value, e1 and e2: latent errors.

Notes: model adjusted by subjective caregiver burden, care recipient needs, co-residence and caregiver sex and age. Paths of these variables do not appear in the model diagram for ease of presentation.

Table 1 Descriptive characteristics of the sample.

		n	**%**	$\bar{X}$	**SD**
Caregiver					
Age				57.6	12.5
Sex	Female	290	87.3		
	Male	42	12.7		
Kinship	Daughter/Son	215	64.8		
	Spouse	69	20.8		
	Others	48	14.5		
Co-residence	Yes	258	77.7		
	No	74	22.3		
Duration of caregiving (years)				7.3	6.6
Care recipient					
Age				83.3	8.7
Gender	Female	237	71.4		
	Male	95	28.6		
Cause of dependency	Frail older people	192	57.8		
	Cognitive impairment	77	23.2		
	Cancer	24	7.2		
	Stroke	37	11.1		
	Missing data	2	0.6		

Abbreviations: n: subgroup size, %: percentage, $\bar{X}$: mean, SD: standard deviation.

Table 2 Description of study variables.

Variable	**Time**	**M / n**	**SD / %**
Perceived social support	1	36.96	8.62
	2	36.81	8.53
Psychological distress	1	6.82	5.57
	2	6.47	5.84
Subjective caregiver burden	1	4.85	2.97
	2	5.11	3.16
Care-recipient functional capacity	1	6.49	5.51
	2	6.10	5.56
Care-recipient cognitive impairment	1	4.34	3.70
	2	4.63	3.48
Care recipient behavioural problems	1	8.83	12.77
	2	7.98	12.87

Table 3 Differences in main study variables between completers and non-completers.

Variables		Remaining (N= 258) (M or %)	Dropping out (N= 74) (M or %)	P-value
Distress		6.83	6.87	0.956[a]
Perceived social support		36.71	37.79	0.343[a]
Subjective caregiver burden		4.62	5.28	0.254[a]
Carer sex	Female	87.80	77.20	0.886[b]
	Male	12.20	12.80	
Care-recipient functional capacity		6.75	5.58	0.108[a]
Care-recipient cognitive impairment		4.07	5.35	0.017[a]
Care recipient behavioural problems		8.34	10.49	0.225[a]

Note: [a] Student’s test; [b] Chi-square

Table 4: Effects of social support on carer psychological distress controlling for several variables (Generalized estimating equations).

	B	SE	p-value
Social support	-0.178	0.028	<0.001
Subjective caregiver burden	0.707	0.083	<0.001
Caregiver gender (female)	2.737	0.612	<0.001
Caregiver age	-0.015	0.018	0.403
Care-recipient functional capacity	-0.129	0.056	0.023
Care-recipient cognitive impairment	0.100	0.103	0.302
Care-recipient behavioural problems	0.037	0.196	0.062
Co-residence	0.374	0.557	0.502

Abbreviations: B: regression coefficient, SE: standard error.