

# Burden and anticipatory grief in caregivers of family members with Alzheimer's disease and other dementias

## Original Article

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### Abstract

**Objectives.** This study aimed to analyze the different factors that intervene in the task of caring for relatives of people with Alzheimer's and other dementias. A first objective focused on assessing the relation between burden and anticipatory grief, considering the possibility of social support and the risk of psychopathology. A second objective aimed to examine whether caregiver burden modulates the relationships between anticipatory grief and psychopathology. A cross-sectional design was employed.

**Methods.** The sample consists of 129 participants who care for a family member with Alzheimer's and other dementias. A protocol based on a battery of tests has been applied and a mediation analysis was carried out.

**Results.** The results show a positive relationship between burden and anticipatory grief. Social support could have an indirect relationship with anticipatory grief, based on its effect on the level of psychopathology and caregiver burden. Finally, a modulation model reflects that the relationship between anticipatory grief and psychopathology is strong, the latter having a greater effect as a result variable than as a risk variable. However, it seems that the relationship between grief and psychopathology is better explained directly than not through the modulating effect of the caregiver burden.

**Significance of results.** The results obtained encourage us to think that an approach focused on intervening in the anticipatory grief may be an opportunity to reduce or buffer other caregiving outcomes, especially those related to the perception of caregiver burden and psychopathology.

### Introduction

The task of caring remains an essentially family task, falling on 1 or 2 people, mainly spouses or children, and a very high percentage of whom are female (Janssen et al. 2017). Conceptually, the process of Alzheimer's disease is always unidirectional, that is, losses will always occur in the person's consolidated cognitive-behavioral performance and with a relatively generalizable pattern of decline by areas. However, for the caregiver, the ability and skills with which to face the situation and continue to find positive or healthy aspects in the relationship will largely determine the prognosis of their grief in the future (Nielsen et al. 2017).

The challenge for health-care professionals is to find instruments that help to assess the process from a psychological perspective, as well as to know the key points in the intervention to facilitate the adaptive process of family members, especially for the following aspects of the care task: the caregiver's burden, the risk of psychopathology, and the anticipatory grief process.

### Anticipatory grief

Anticipatory grief (Lindemann 1944; Rando 2000) is the term used to refer to the particular moment described as the emotional response to the potential threat of the death of a loved one or oneself. The question that has guided the studies has not usually been whether anticipatory grief exists, but if it is psychologically useful when mitigating post-mortem grief.

In this sense, it is not the case that when the person dies a part of the grieving process has already been completed but rather that anticipating a death allows the individual, over time, to understand the loss as a natural process during which he/she can deploy coping mechanisms to make it less painful, resolve pending issues, and say goodbye to the family member (Rando 1984). This implies a broad look at the phenomenon of anticipatory grief,

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assessing the set of variables that are related to it and that can have important implications in the care process, including both the skills and possible effects of the caregiver as well as the affectation of the person cared for, even the relationship between them (Rando 2000).

### Caregiver burden

Zarit et al. (1986) defined the burden as the psychological impact that caregivers perceive caring for a relative has on their emotional or physical health, their social life, and financial situation. In this sense, it is possible to determine different dimensions that comprise the caregiver's burden (Ankri et al. 2005): caregiver's perception about the changes in his/her life, perception about his/her relationship with the family member, as well as assessment of his/her own competence to care.

### Relationship models between different factors

The available research allows us to affirm that caring for a person with dementia is different from any other care task. Greater stress, higher prevalence of depressive disorders, greater social limitation, and more demands for change in their daily lives are identified in caregivers of relatives with dementia, even compared to caring for individuals with other diseases (Lindeza et al. 2020; Mueller et al. 2022). Among the sources of stress that affect the caregiver, 2 large groups are identified: (1) those produced by the disease itself and (2) the stressors produced by the characteristics of the caregiver and contextual variables. Here the psychological profile of the caregiver and the available support (social and professional) exert an important influence on stress assessment and coping (George et al. 2020; Lindeza et al. 2020; Seeher et al. 2013). In addition, the changes and losses are multiple and cumulative, occurring unequally in some areas than in others, and at different times (first psychological loss, and then physical loss of the person) as manifested in the experience of anticipatory grief (Rando 2000). That is why caring for people with Alzheimer's and other dementias has come to be described as a chronic stressor that significantly affects the lives of caregivers, producing emotional distress that remains relatively stable over the years (Vitaliano et al. 2003), and from which a natural adjustment or adaptation to the care situation does not seem to be observed (Knight and Losada 2011).

Despite all the above, the task of caring is not necessarily considered a source of stress. In fact, it has been shown that caregivers seem to experience both negative and positive emotions when it comes to caring (Kramer 1997). Some of the benefits highlighted by caregivers are self-satisfaction, self-esteem, learning, competence and mastery of situations, improvement in the relationship with the person they care for, etc. (National Opinion Research Center (NORC) 2014).

Having demonstrated the complexity of the factors related to the prolonged care of persons with Alzheimer's disease and other dementias, several authors have designed explanatory models including the variables of anticipatory grief and caregiver burden among others, in order to better explain the positive and negative consequences of care (Conde-Sala et al. 2010; Goode et al. 1998; Haley et al. 1987; Kim et al. 2012; Liew et al. 2019; Noonan and Tennstedt 1997; Pearlin et al. 1990; Pushkar et al. 1995; Seeher et al. 2013; Zarit et al. 1986). The results point to the importance of multifactorial examination of the components of anticipatory grief and caregiver burden, taking a comprehensive approach to help caregivers. Furthermore, recent bibliography

(Holley 2009; Liew et al. 2019) points to a possible relationship between anticipatory grief and caregiver burden that may be relevant both in the caregiving experience (Holley 2009; Liew et al. 2019) and in the risk of distress and psychopathology in the caregiver (Liew et al. 2019). These findings suggest that anticipatory grief is a central component in understanding caregiver burden. In Alzheimer's disease, the cognitive impairment, the progressive dependency, and the uncertainty of the duration of the process have a notable impact on this variable and its direct influence on the appearance of symptoms of anticipatory grief (Rando 2000).

### Purpose of the present study

The number of factors theoretically associated with the task of care in general, and particularly with anticipatory grief, is enormous. An approach that contemplates a multivariable constellation of associated factors is required, but among them, the relationship between anticipatory grief and caregiver burden emerges as important. Thus, the purpose of the present study is to assess the relationship between burden and anticipatory grief in caregivers of family members with Alzheimer's disease and other dementias, contributing to increase the available findings on this relationship of influence.

However, we also suggest that variables such as social support from family, friends, and/or community modulate the intensity of the variables that influence anticipatory grief (Seeher et al. 2013). Likewise, it is expected that the existence of psychopathology in the caregiver hinders the acceptance of loss and increases the elements of burden, sadness, and isolation. In this sense, a mediation analysis may better represent the possible relationship between anticipatory grief and caregiver burden regarding psychopathological risk.

With this objective, the present study allows to know the influence of the different variables involved in the caregiving task and specifically in the variable anticipatory grief, establishing the impact between them through statistical estimates. Thus, it is possible to determine an order of interrelation of the variables, estimating those variables that have a greater impact in relation to those that have less intensity. All the above should guide possible prevention and/or support interventions for caregivers.

## Method

### Participants

The sample consists of a total of 129 participants who care for a family member with Alzheimer's and other dementias, 67.8% of whom are women and 32.2% are men, aged between 32 and 85 years ( $M = 62.09$ ,  $SD = 10.89$ ).

Participants were chosen based on their relationship with an association of family members and/or day care units for people with Alzheimer's and other dementias. The participating associations are located in neighborhoods of low, medium, and high socioeconomic status, and located mainly in urban areas from Catalonia (Spain). The associations focus their function to cover the needs of caregivers of family members with Alzheimer's or other dementias in situations of lack of social resources and information about the disease. With this objective, they provide assistance to both patients and caregivers.

We excluded from the study all those participants with some cognitive or language comprehension difficulty that was determined to reduce the validity of the answers. In the same way, those

participants who could be particularly emotionally affected were excluded, as it was considered that responding to the battery of tests may seriously affect their state of mind. Based on these exclusion criteria, only 2 people were excluded from the initial sample (1.5%) because they themselves decided not to participate when reading the questionnaire. One of them was due to a recent loss and the other because she did not seem able to continue for emotional reasons.

## Measures

### Sociodemographics

For the purpose of this study, an ad hoc demographic information sheet was administered. It asks about age, gender, educational level and employment status, family structure, marital status and family relationship with the relative, diagnosis, characteristics of the care experience and possible consequences derived from it.

### Anticipatory grief

The MM Caregiver Grief Inventory (MM-CGI) (Marwit and Meuser 2002) is a 50-item inventory designed to measure the grief experience of family members who are caregivers of people living with a diagnosis of neurodegenerative dementia. The inventory provides information on 3 factors (personal sacrifice burden, feelings of sadness and nostalgia, and worry and isolation) as well as a total grief score. The MM-CGI is an evaluation measure that has shown good psychometric properties, both in reliability and in validity, with high scores in internal consistency ( $\alpha = 0.90$  and  $0.96$ ) (Marwit and Meuser 2002). The translation into Spanish of the MM-CGI has been carried out specifically for this study, with the consent of the authors. The questionnaire was translated into Spanish by psychologists, and the backtranslation was carried out by a native British English speaker (percentage of agreement between the items: 100%). The estimation of reliability index in this Spanish version was  $\alpha = 0.85$ .

### Caregiver burden

The caregiver burden was assessed using both the Zarit Burden Interview and the Caregiver Strain Index (CSI). The first, adapted to Spanish (Martín *et al.* 1996), consists of 22 items related to the feelings of the caregiver when caring for another person. The questionnaire presents values of internal consistency of 0.91 and a test–retest reliability of 0.86 (Martín *et al.* 1996). With regard to the CSI (Robinson 1983), it is a self-report measure composed of 13 items which assess the degree of overexertion of caregivers as well as fatigue in the role of caregiver. At the psychometric level, the Spanish version presents an adequate measure of internal consistency (0.81) (López and Moral 2005).

### Psychopathology

Two measuring instruments were administered to assess the presence of psychological symptoms. The Symptom Checklist-90-Revised (SCL-90-R) (Derogatis 1977; Derogatis *et al.* 1973) is a self-report to assess the degree of current psychological. The reliability is very acceptable, with internal consistency coefficients of the 9 primary dimensions and the Global Severity Index (GSI) ranging between 0.77 and 0.90, depending on the scale and study (De Las Cuevas *et al.* 1991; Derogatis 1977; Derogatis *et al.* 1973). The Spanish version of the inventory used in this study was developed by Casullo (1999/2004). Another measuring instrument used was the Depression, Anxiety and Stress Scale (DASS-21) (Lovibond

and Lovibond 1995). It is a short form (21 items), for self-reported assessment of depression, anxiety and stress in the last week. The Spanish version was adapted by Daza *et al.* (2002). The reliability, evaluated through Cronbach's  $\alpha$ , has also been shown to be acceptable for the 3 scales (0.81, 0.73, and 0.81, respectively) (Lovibond and Lovibond 1995).

### Self-esteem

The Rosenberg Self-Esteem Scale (Rosenberg 1965) is a self-report questionnaire to explore personal self-esteem. The scale has been translated and validated into Spanish (Echeburúa 1995). The internal consistency is between 0.76 and 0.87, with a total reliability of 0.80.

### Social support

The Multidimensional Scale of Perceived Social Support (Zimet *et al.* 1988) is a 12-item scale that assesses the perceived support in 3 areas: family, friendships, and other significant persons. This scale has shown good reliability and validity, obtaining  $\alpha$  coefficient between 0.84 and 0.92 in several samples in the U.S. (Zimet *et al.* 1990). The version of the scale adapted to Spanish (Landeta and Calvete 2002), obtained a Cronbach's  $\alpha$  coefficient of 0.89.

### Procedure

First, contact was made with the coordinators of different associations and day care units for people with Alzheimer's and other dementias and their families to inform them of the purpose of the study. Those associative effects that could be adequately interpreted in the sense provided by the theoretical framework and that, in turn, were consistent with the clinical and social situation of the participating families, were selected. All the entities decided to participate in the investigation, providing their verbal consent. Subsequently, the associations informed the caregivers about the existence of the study and indicated the day on which the information and data collection session would take place. So, the initial contact with the sample was made by the association to maintain the confidentiality and anonymity of the participants. On the indicated days, sessions were held to inform those caregivers interested in participating in the study. The purpose and objectives of the research were explained, and the voluntary participation of the people (write consent) was requested based on their responses to a battery of tests. They were informed of the confidential nature of the data as well as the possibility of abandoning the study if it caused them a high level of discomfort. The battery of questionnaires was administered in a single session and collectively, carried out by 2 expert and trained psychologists. The questions that were presented were answered and more information was offered to the doubts about certain items. Data collection lasted around half a year.

### Data analysis

The statistical analysis of the data was carried out using the statistical package IBM *SPSS Statistics* version 23 for those analyses in which the usual inferential techniques based on parametric or nonparametric reference distributions have been used. In the usual contrasts, techniques based on Student's *t*, Snedecor's *F* (with equal variances), and estimates of Pearson's correlations for linear bivariate distributions and Spearman's for nonlinear ones have been used.

**Table 1.** Sociodemographic characteristics (Pérez-González et al. 2021)

		<i>n</i>	%
Gender	Male	38	32.2
	Female	80	67.8
Marital status	Single	8	6.7
	Married	99	82.5
	Separated	1	0.8
	Divorced	9	7.5
	Widower	3	2.5
Educational level	None	5	4.2
	Primary	33	28.0
	Secondary	45	38.1
	University students	35	29.7
Employment situation	Active worker	43	36.1
	House chores	26	21.8
	Retired	49	41.2
	Unemployed	1	0.8
Where the person with dementia lives	With caregiver	61	51.7
	Without caregiver	9	7.6
	At home assisted	8	6.8
	In residence	38	32.2
	Others	2	1.7
Type of dementia	Alzheimer	84	65.1
	Other dementias	23	17.8
Years since diagnosis	0–5	57	55.9
	6–10	31	30.4
	11–15	6	5.9
	16–20	6	5.9
	More than 20	2	2.0
Main caregiver	Yes	82	70.7
	No	34	29.3
Caregiver's relationship	Spouse	39	32.8
	Child	73	61.3
	Grandchild	1	0.8
	Sibling	2	1.7
	Other: niece, nephew	4	3.4
Weekdays dedicated to caring	0	2	1.6
	1	2	1.6
	1.5	1	0.8
	2	5	3.9
	3	11	8.5

(Continued)

**Table 1.** (Continued.)

		<i>n</i>	%
	4	11	8.5
	5	6	4.7
	5.5	1	0.8
	6	6	4.7
	7	71	55.0
	Alternating days	1	0.8
	Alternating weeks	1	0.8
Other care responsibilities	Yes	39	33.1
	No	79	66.9
How many people care for the person with dementia?	0	16	16.7
	1	51	53.1
	2	15	15.6
	3	8	8.3
	4	5	5.2
	6	1	1.0
One caregiver is a professional caregiver	Yes	33	30.0
	No	77	70.0
You combine care hours with hours of rest	Yes	83	79.0
	No	22	21.0
Guilt if you are not caring	Yes	49	44.1
	No	61	55.0
Loss of independence	Yes	85	72.6
	No	32	27.4
Fatigue	Yes	84	73.0
	No	31	27.0
Do you often feel like quitting?	Yes	18	16.7
	No	90	83.3
Do you think that a residence would be better if it was possible?	Yes	46	45.1
	No	56	54.9
Do you often think that there is no one better than you to care for the person with dementia?	Yes	63	54.3
	No	53	45.7
Do you think that, if you are not present, unexpected negative things can happen?	Yes	49	42.6
	No	66	57.4
Household income per month	Up to 1000 EUR	77	59.9
	From 1001 to 2000 EUR	37	28.7
	More than 2000 EUR	15	11.4

The missing data were managed via pairwise; therefore, the degrees of freedom have small variations. To estimate indirect and total effects between the variables, a mediation analysis was carried out

based on structural equation modeling (SEM), through the maximum likelihood estimation process and supported by MPlus v.8. Mediation models have been shown to be sensitive for studying the decomposition of correlations in cases in which the effect to be estimated is the possibility of an intervening variable, not in the estimation of the effects of effect-modifying variables. In the contrasts that have been identified as statistically significant, the values of the effect size and power have been incorporated.

**Results**

**Caregiver profile and care task**

As Table 1 shows, more than 70% of participants were primary caregivers of relatives with Alzheimer’s disease. The relationship with the relative was mostly that of children who care for their parents (61.3%) and that of spouses (32.8%). More than half of these caregivers (55%) are taking care of this family member 7days a week. And 33.1% also have other care responsibilities. On the other hand, only 30% have professional help with their care task.

**Variables that influence anticipatory grief**

In relation to the measure of anticipatory grief, Table 2 shows the correlation values obtained between the unobservable factors of sadness, burden, and isolation. In this regard, highly significant effects ( $p < 0.01$ ) can be observed with effect sizes greater than 0.35. The correlation between the burden factor and the total scale ( $r = 0.903, p < 0.001; r^2 = 0.815$ ) would indicate that, for this sample, this factor is a determining factor in obtaining a total score.

Likewise, Table 3 shows the scores obtained from the total sample in relation to each of the variables related to anticipatory grief, such as measures of psychopathology, burden, self-esteem, and social support.

First, the detailed results of anticipatory grief evaluated using the MM-CGI show that most cases present scores within the range considered normal for the burden (57.9%), sadness (51.5%), and isolation (62.7%) dimensions, and the total score for the scale (59.8%) also falls into this range. However, it should be noted that a considerable percentage of the sample, approximately a quarter, has high scores in all of the dimensions. At the symptoms level, the answers provided for the DASS-21 scale place most of the sample in a normal range of depressive symptoms (71.3%), anxiety (76.1%), and stress (73.0%). In the same way, the responses provided for the SCL-90-R indicate that most of the sample (93.0% and 93.5%) have a normal range of symptoms in the global index of positive symptoms and the total SCL-90-R score, respectively. Regarding caregiver burden and strain, the scores of the CSI show

**Table 2.** Matrix of correlations between the latent factors of the Anticipatory Grief scale

	Burden	Sadness	Isolation	Total
Burden	1			
Sadness	0.648	1		
Isolation	0.667	0.596	1	
Total	0.903*	0.856	0.828	1

Note: \* $p < 0.01$ .

**Table 3.** Categorical scales description

			n	%
MM-CGI	Burden	Low (18–40)	13	13.7
		Average (41–68)	55	57.9
		High (69–85)	27	28.4
	Sadness	Low (15–37)	22	22.2
		Average (38–59)	51	51.5
		High (60–75)	26	26.3
	Isolation	Low (18–28)	10	9.8
		Average (29–52)	64	62.7
		High (53–72)	28	27.5
Total	Low (58–112)	11	13.4	
	Average (113–175)	49	59.8	
	High (176–231)	22	26.8	
CSI	Total	No overexertion ( $\geq 6$ )	80	62.0
		Overexertion ( $\leq 7$ )	49	38.0
Social Support	Family	Low (1–2.9)	14	11.7
		Average (3–5)	28	23.3
		High (5.1–7)	78	65.0
	Friends	Low (1–2.9)	19	15.8
		Average (3–5)	34	28.3
		High (5.1–7)	67	55.8
	Significant others	Low (1–2.9)	14	11.7
		Average (3–5)	26	21.7
		High (5.1–7)	80	66.7
	Total	Low (1–2.9)	11	9.3
		Average (3–5)	33	28.0
		High (5.1–7)	74	62.7
DASS-21	Depression	Normal (0–9)	82	71.3
		Mild (10–13)	9	7.8
		Moderate (14–20)	14	12.2
		Severe (21–27)	4	3.5
		Extremely severe ( $\geq 28$ )	6	5.2
	Anxiety	Normal (0–7)	89	76.1
		Mild (8–9)	5	4.3
		Moderate (10–14)	8	6.8
		Severe (15–19)	6	5.1
		Extremely severe ( $\geq 20$ )	9	7.7
	Stress	Normal (0–14)	84	73.0
		Mild (15–18)	11	9.6
Moderate (19–25)		7	6.1	

(Continued)

Table 3. (Continued.)

			<i>n</i>	%
SCL-90-R	PST	Severe (26–33)	9	7.8
		Extremely severe ( $\geq 34$ )	4	3.5
	Total score	Normal ( $\leq 64$ )	120	93.0
		At risk (65–79)	9	7.0
		Normal ( $\leq 64$ )	72	93.5
		At risk (65–79)	3	3.9
	Severe ( $\geq 80$ )	2	2.6	
Rosemberg	Total	High self-esteem (normal; 30–40)	95	80.5
		Average self-esteem (to improve, 26–29)	14	11.9
		Low self-esteem (<25)	9	7.6
Zarit	Total	Little or no burden (0–20)	33	36.7
		Mild to moderate burden (21–40)	35	38.9
		Moderate to severe burden (41–60)	19	21.1
		Severe burden (61–88)	3	3.3

that 38.0% of the sample displays values corresponding to a level of overexertion. In the same way, responses to the Zarit questionnaire indicate that 38.9% would be at a level of mild to moderate burden, 21.1% at moderate to severe burden, and 3.3% at severe burden. On the other hand, self-esteem scores place most of the sample (80.5%) at a high level of self-esteem. Finally, the responses in the social support scale indicate high values of support from family (65.0%), friends (55.8%), and the person indicated in significant others (66.7%).

Additionally, the responses given by the participants for each of the scales have been assessed in relation to the responses for the rest of the scales. Table 4 presents these results.

For the measure of anticipatory grief (MM-CGI), there seems to be a positive relationship between this scale and the CSI, the symptom inventory SCL-90-R in all its total measures, the DASS-21 in its dimensions of depression and anxiety, as well as the Zarit questionnaire. In the same way, an inverse relationship is established between the Anticipatory Grief inventory and the Rosemberg scale.

Taking into account the results obtained in the correlation analysis, a decision was taken to explore more closely the relationship between psychopathology (SCL-90-R) and caregiver burden (Zarit) with the measure of anticipatory grief (MM-CGI).

### Effect of anticipatory grief in relation to caregiver burden

The results indicate that there is a positive relationship between both scales, so that it seems that the caregiver's burden increases when anticipatory grief increases (Burden:  $F = 10,397$ ,  $p < 0.001$ ,  $\eta^2 = 0.354$ ; Sadness:  $F = 4,282$ ,  $p = 0.042$ ,  $\eta^2 = 0.312$ ; Isolation:

$F = 13,733$ ,  $p < 0.001$ ,  $\eta^2 = 0.377$ ; Total:  $F = 6,982$ ,  $p < 0.001$ ,  $\eta^2 = 0.318$ ). Figure 1 show this effect.

### Effect of anticipatory grief in relation to psychopathology

The results show a positive relationship between the global index of positive symptoms (SCL-90-R PST) and the Sadness dimension of the anticipatory grief inventory ( $t = 2.071$ ;  $g.l. = 97$ ;  $p = 0.021$ ;  $d = 1.79$ ). Likewise, a positive relationship was found between the total SCL-90-R score and the Burden dimension of the MM-CGI ( $t = 2.004$ ,  $g.l. = 58$ ,  $p = 0.025$ ,  $d = 1.44$ ) (See Table 5).

### Effect of social support in relation to burden, psychopathology, and anticipatory grief

Regarding the measure of social support, no significant direct effects of their relationship with anticipatory grief have been found. However, there seems to be an inverse relationship between this scale and the DASS-21 scale in its depression dimension ( $r = -0.190$ ,  $p < 0.01$ ,  $r^2 = 0.04$ ), and the Zarit questionnaire ( $r = -0.311$ ,  $p < 0.05$ ,  $r^2 = 0.09$ ), which do have a significant direct effect on anticipatory grief. So, social support could have an indirect relationship with anticipatory grief based on its effect on the level of psychopathology and caregiver burden.

### Assessing the modulating role of caregiver burden between anticipatory grief and psychopathology

Considering the results obtained regarding anticipatory grief in relation to the caregiver's burden and psychopathology, a modulation model is proposed to explore the possible relationship between the 3 variables and the effect of grief and burden (together or separately) on the level of psychopathology. We examined only 1 model, analyzing the role of caregiver burden as a possible modulator between the anticipatory grief and psychopathology, in front the possible direct relation between anticipatory grief and psychopathology. In addition, we also explored the effect that social support could have as a fourth variable to consider. Thus, following the usual criteria for SEM, the model had a good global fit (CFI = 0.93, TLI = 0.94, RSMR = 0.03; good fit implies CFI and TLI > 0.90 and RSMR < 0.04) (Stone 2021).

As shown in Fig. 2, load analysis was performed for the 4 variables (anticipatory grief, caregiver burden, psychopathology, and social support), and each path was statistically significant. The results of the modulation model had shown that anticipatory grief had significant direct effects on psychopathology and that psychopathology in relation to anticipatory grief, has a greater effect as a result variable ( $\beta = 0.468$ ;  $p < 0.001$ ) than as a risk variable ( $\beta = 0.323$ ;  $p < 0.01$ ). Likewise, anticipatory grief had significant direct effects on caregiver burden ( $\beta = 0.297$ ;  $p < 0.01$ ) and indirect effects on psychopathology through caregiver burden ( $\beta = 0.268$ ;  $p < 0.01$ ). Based on the above, the results of the modulation model revealed that although anticipatory grief had significant indirect effects on psychopathology through caregiver burden (as modulator variable), the direct effect of anticipatory grief on psychopathology had higher and more significant. Regarding social support, the results showed that it would only act as a buffer through a direct relationship with psychopathology, while the caregiver's burden would be a risk in terms of the perception of social support.

**Table 4.** Correlations between total scales

	Anticipatory Grief	CSI	Social Support	SCL-90-R Total	SCL-90-R IGS	SCL-90-R PST	SCL-90-R PSDI	DASS-21 Depression	DASS-21 Anxiety	DASS-21 Stress	Rosem-berg	Zarit
Anticipatory Grief	1											
CSI	0.467**	1										
Social Support	-0.024	-0.131	1									
SCL-90-R Total	0.312*	0.337**	0.130	1								
SCL-90-R IGS	0.312*	0.337**	-0.130	1**	1							
SCL-90-R PST	0.275*	0.237*	-0.017	0.879**	0.879**	1						
SCL-90-R PSDI	0.498**	0.347**	-0.198	0.669**	0.669**	0.311**	1					
DASS-21 Depression	0.311**	0.054	-0.190*	0.612**	0.612**	0.343**	0.484**	1				
DASS-21 Anxiety	0.267*	0.220*	-0.150	0.489**	0.489**	0.335**	0.396**	0.665**	1			
DASS-21 Stress	-0.378	0.314	-0.108	0.715**	0.715**	0.515**	0.521**	0.697**	0.769**	1		
Rosemberg	-0.302**	-0.089	0.170	-0.504**	-0.504**	-0.281**	-0.338**	-0.378**	-0.209*	-0.315**	1	
Zarit	0.491**	0.682**	-0.311**	-0.544**	0.544**	0.457**	0.417**	0.432**	0.300**	0.434**	-0.183	1

\*\*p < 0.05; \*p < 0.01 Determination Coefficient (R<sup>2</sup>) ranging 0.075-0.772.

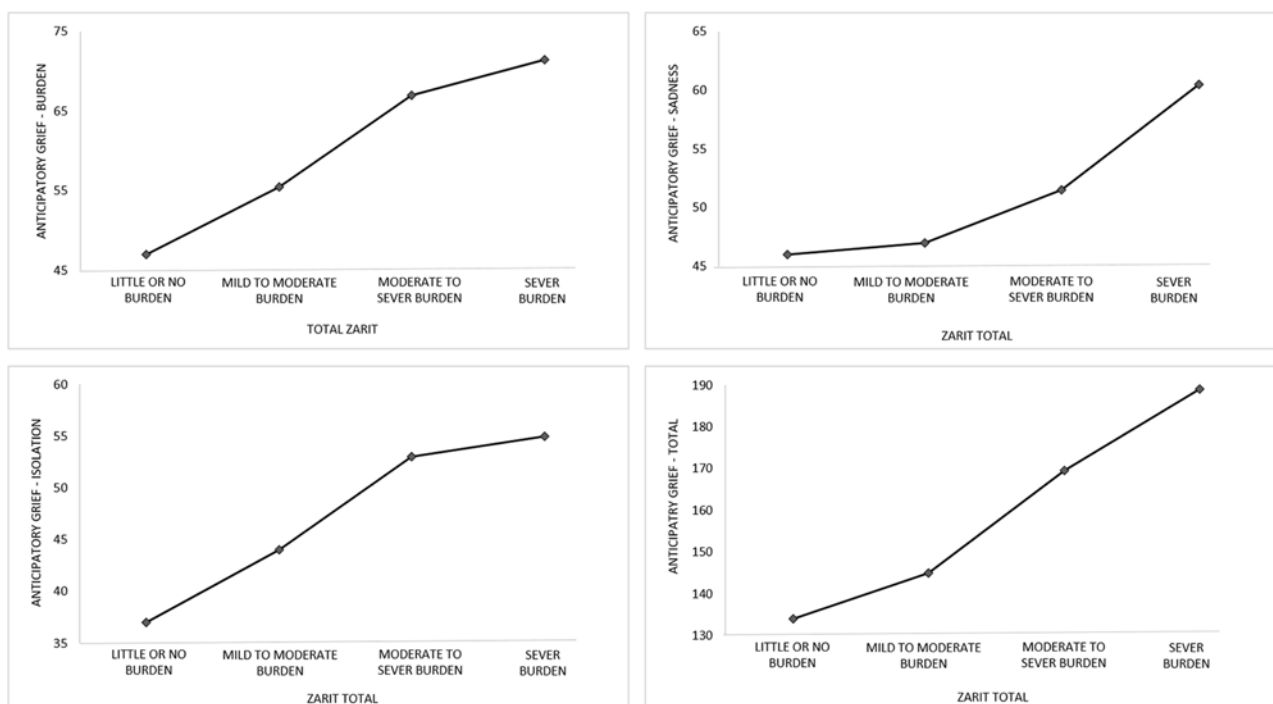


Figure 1. Effect of the burden (Zarit) on the measurement of the dimensions of the Anticipatory Grief MM Caregiver Inventor

Table 5. Relation between the Anticipatory Grief Inventory dimensions and the SCL-90-R Index (Positive Symptoms Global Index – PST, and the Total Score)

		Anticipatory Grief Inventory				
		Burden	Sadness	Isolation	Total	
SCL-90-R (PST)	Normal	$\bar{x}$	57.07	49.02	43.36	151.24
		s	16.05	14.02	11.39	35.16
	Risk level	$\bar{x}$	54	37.86	45.43	130.5
		s	19.45	8.43	10.11	27.56
		t	0.48	2.071	-0.467	1.407
		p	0.633	0.041	0.642	0.163
g.l.	93	97	100	79		
SCL-90-R (Total score)	Normal	$\bar{x}$	55.14	46.92	42.65	146.22
		s	13.73	12.59	11.02	31.72
	Risk level	$\bar{x}$	69.5	38	45.33	143
		s	15.69	16.82	12.66	42.42
		t	-2.004	1.183	-0.41	0.14
		p	0.05	0.241	0.683	0.889
g.l.	58	62	63	50		

Discussion

The present study incorporates a contingency relationship between burden and anticipatory grief, with the main purpose, of assisting the professionals in the guidance that they can provide early on when a family member is affected by a diagnosis of dementia

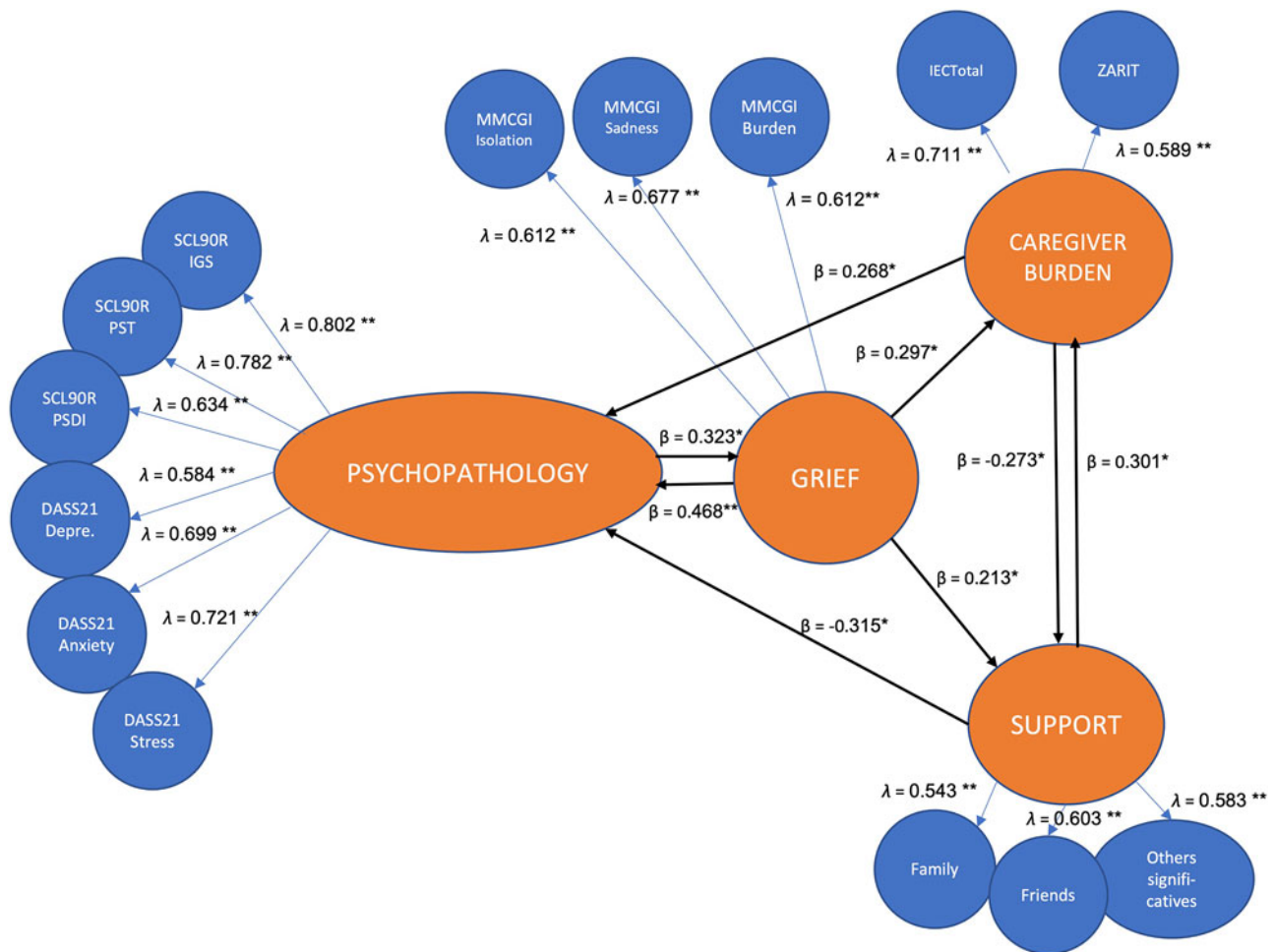
(Rando 2000). In this sense and for this sample, the burden factor is a determining factor in obtaining a total score of anticipatory grief. The influential variables in the burden symptoms are multiplied by the effect of the different variables studied, giving rise to what we call OVERBURDEN. Its translation into elements typified as ANTICIPATORY GRIEF will allow a guided approach during the disease process, especially in the initial and final phases, with the aim of improving the quality of care, with the lowest cost of health to the caregiver, as well as minimizing the symptoms of post-mortem grief.

In relation to the previous point, the relationship between burden and anticipatory grief is confirmed in the main caregiver since the results show that the caregiver’s burden increases when anticipatory grief increases. Thus, as the manifestations of loss and anticipatory grief that occur during the dementia process increase, the greater is the perception of the caregiver’s burden in its 3 domains (Zarit et al. 1986): self-perception about the changes in one’s life (especially in early stages but also after some years of care); self-perception about the relationship with the relative (the more dependent and/or depressive psychological profiles have a more negative view of the changes in the relationship with person with Alzheimer’s disease); and self-assessment of the competency itself (although the responses to the Rosenberg scale remain at a high level of self-esteem, we cannot deduce that the assessment of competencies is harmonious with that perception).

In relation to the level of psychopathology, the results show that a higher risk of psychopathology favors greater probabilities of anticipatory grief, especially burden and sadness dimensions. However, in light of the results of the mediation analysis, it seems that for this sample of participants psychopathology has a greater effect as a result variable than as a risk variable. So, the results of the mediation analysis should be viewed in this regard.

On the other hand, regarding the modulation effect of the caregiver burden variable, the results show that although anticipatory





**Figure 2.** Model of modulation between anticipatory grief, psychopathology, caregiver burden and social support (Note:  $^{**}p < 0.001$ ;  $^*p < 0.01$ ).

grief had significant indirect effects on psychopathology through caregiver burden, the direct effect of anticipatory grief on psychopathology had higher and more significant.

Taking all the above into consideration, the results obtained show the need to attend and accompany the anticipatory grief of caregivers of people with dementia as the primary objective of intervention. Considering the results of the present study, and of other recent research (Holley 2009; Liew et al. 2019), the grief approach may be an opportunity to reduce or buffer other caregiving outcomes, especially those related to psychopathology and perception of caregiver burden. This approach, which is primarily focused on the intervention in anticipatory grief, in addition to being a more preventive perspective, can allow a better preparation of family members for the task of caring. It allows a better understanding of the changes in behavior of the person with dementia as well as the possible losses derived from the Alzheimer's process and, on the other hand, entails lower resistance than those generated by the approach aimed at directly reducing the caregiver burden. Knowing and preparing caregivers in all these aspects will make it possible to mobilize the available support resources and perhaps buffer the psychological (and psychopathological) impact that the care experience can have (George et al. 2020).

There is a wide range of supportive therapies to caregiver (Cheng and Zhang 2020), but the challenge for the future is to establish different phases in the process to improve adherence and

medium- and long-term effects. Generally speaking, the levels of self-perception and, consequently, self-assessment found in the questionnaire results were acceptable; however, in the records obtained through the individual clinical interviews, considerable fluctuations of these levels were observed depending on the particular stage in the disease process. This is also an aspect which can be helped by different psychological therapies. The issue is to identify any fluctuations in the mental state of the caregivers and relate them to objective events (behavior of the person with dementia), their subjective perception of them, their self-assessment and their view of the difficulties (coping). And then, to help to work through the losses in all their dimension, maintaining an adequate level of care and promoting the connection with the social support network of each person, as found in the results of the mediation analysis regarding the variables of caregiver burden, social support and the relationship between both. This intervention approach, as a whole, can provide a window of opportunity to improve caregiving outcomes (Liew et al. 2019). It is obvious that the intervention must and can improve the relationship between the demands of care and the needs of the caregiver, with the clear benefit of greater well-being for the caregiver, which will ultimately result in greater well-being for the person with dementia. In this sense, the grief-focused interventions appear to help caregivers cope with the multiple and progressive dementia-associated losses that occur in anticipatory grief (Gilsenan et al. 2022).

## Limitations

First, the size of the sample requires certain prudence in generalizing the results. Additionally, the cross-sectional approach used to obtain information prevents us from establishing causal relationships between variables. However, the present study can be used as a guide to better understand the relation between anticipatory grief, burden, and psychopathology in the main caregiver.

Another limitation to consider is that the variability in the date of diagnosis was wide, and it should be noted that the emotional swings of caregivers throughout the disease process make it difficult to measure these characteristics with self-report and cross-sectional questionnaires.

Furthermore, all the participants in the study were linked to specialized resources and/or family associations, which exclude people who do not have any support; this aspect could increase the percentage of severity in terms of anticipatory grief.

## Conclusions

According with the results obtained and in the context of a stress-coping model, it is possible that anticipatory grief may be a secondary stress factor that results from primary stressors such as cognitive decline, behavior problems and the growing need for physical assistance. Many caregivers report that the emotional work of caring is much more demanding than physical care tasks. In contrast to the painful life crisis that death represents, several authors (Gatto 2004; Lindemann 1944; Rando 1984) consider early grief as a necessary and healthy emotional process. In this sense, to establish guidelines for early intervention in grief that take into account aspects such as (1) the multiple losses and slow detachment, (2) the demands of the care task and the necessary individual and family reorganization that it entails, and (3) the sources of support available, seem to be, in view of the results, one of the keys to avoiding or at least minimizing the effects of a care task, especially in the perception of caregiver burden and psychopathology. With this objective, it seems necessary that future intervention programs can ensure a close collaborative relationship between the services, methodologically more homogeneous and rigorous, guaranteeing a recognized follow-up and assessment process.

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