

Original Article

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# Psychological morbidity in family caregivers of people living with terminal cancer: Prevalence and predictors

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## Abstract

**Objective.** The issues surrounding a patient's terminal phase of cancer and the imminent death of the individual represent a major family crisis affecting all its members. The goal of this study was to assess the prevalence of psychological morbidity in family caregivers of persons with terminal cancer in terms of psychological distress, depression, anxiety, somatization, and complicated anticipatory grief, and to determine which factors may influence these responses.

**Method.** One hundred and twelve family caregivers of individuals with terminal cancer completed an assessment protocol comprising the Brief Symptom Inventory (depression, anxiety, somatization, and a computed score for global distress), the Marwit-Meuser Caregiver Grief Inventory - Short Form (anticipatory grief), the Family Inventory of Needs (importance and satisfaction of needs), and the Systemic Clinical Outcome Routine Evaluation -15 (family functioning). Prevalence of psychological morbidity was determined through descriptive and frequency statistics. Predictors of psychological morbidity were ascertained through structural equation modelling methods.

**Result.** Regarding the prevalence of psychological morbidity in family caregivers, 66.1% reported high levels of distress, 68.8% showed high risk of depression, 72.3% showed high risk of anxiety, 50.9% reported high levels of somatization, and 25.9% showed high risk of complicated anticipatory grief. It was found that the predictors of age, gender, relationship to the family member with terminal cancer, the caregiving role played (i.e., primary vs. non-primary), the satisfaction of needs by healthcare professionals, and family functioning play an important role in terms of one's risk of developing psychological morbidity.

**Significance of results.** This study revealed an alarming prevalence of psychological morbidity in family caregivers of individuals living with terminal cancer, making it crucial to move forward from a patient-centered approach to a family-centrad approach to reduce the risk of family maladjustment when facing the imminent death of a family member and to prevent postdeath unadjusted responses.

## Introduction

Cancer is presently viewed as a modern epidemic (Simões, 2014) and one of the leading causes of death worldwide (World Health Organization, 2015); it is the second leading cause of death in both Portugal (Instituto Nacional de Estatística, 2015) and the United States (Siegel et al., 2016).

Cancer affects not only the patient but also encompasses the entire family system and its elements (Rolland, 2005). The patient suffering from cancer and his or her family members are interdependent, with each individual having a significant effect upon another (Northouse, 2012). Healthcare professionals should afford special consideration to the manner in which a family responds to cancer and, when necessary, families should benefit from formal support. Rait (2015) suggests that traditional patient-centered care would benefit if replaced with family-centered care.

The terminal phase of cancer is particularly demanding on the family system. The imminent death of a family member is the most difficult crisis a family must confront and adjust to; as such, it is considered a “powerful nodal event that shakes the foundation of family life” (Walsh & McGoldrick, 2004, p 8). Families are forced to begin a major reorganization of the system (e.g., realignment of relationships, redistribution of roles and functions), simultaneously situational and anticipatory (Relvas, 1989), while grieving for the dying and assessing parallel losses (Walsh & McGoldrick, 2004).

Facing such a crisis within the system, family members, and particularly family caregivers, may experience difficulties in functionally adjusting to terminal cancer and its demands.

Despite the positive outcomes (e.g., personal growth) related to caring for a terminally ill person (Kang et al., 2013), family caregivers may show increased levels of psychological morbidity, such as depression (Fasse et al., 2015; Govina et al., 2015), anxiety (Perez-Ordóñez et al., 2016; Rumpold et al., 2016), heightened burden (Govina et al., 2015; Rha et al., 2015), and complicated anticipatory grief responses (Tomarken et al., 2008). Family caregivers tend to report lower levels of quality of life (Morishita & Kamibepu, 2014) and are at higher risk for developing or exacerbating physical health disorders (e.g., constipation, hypertension) (Haley et al., 2001), followed by an increased risk of mortality (Schulz & Sherwood, 2008).

Some predictors are commonly identified in the literature as negatively influencing outcomes of caring for a terminally ill family member. Female (Given et al., 2004; Morgan et al., 2016; Valeberg & Grov, 2013) and older individuals (Marwit & Meuser, 2002), spouses (Fasse et al., 2015; Götze et al., 2014; Rumpold et al., 2016), adult children (Given et al., 2004), and individuals with a history of psychiatric disorders (Tomarken et al., 2008) are more likely to develop some kind of psychological morbidity. Furthermore, concurrent stressful life events (Tomarken et al., 2008), financial burden (Götze et al., 2014; Tomarken et al., 2008), and perceived low social support (Götze et al., 2014; Tomarken et al., 2008) may predict family caregivers' maladjustment. Finally, with respect to the patient's characteristics, younger patients (Tang et al., 2013), the patient's physical decline (Valeberg & Grov, 2013), and patient's psychological maladjustment (Götze et al., 2014) seem to increase family caregivers' psychological morbidity.

Research on caregivers has focused more on the role of the family's primary caregivers (Given, 2004), leaving the impact of terminal cancer on other family members who may not be exclusively responsible for the care of the person with cancer inadequately represented in the literature. Therefore, describing the impact of terminal cancer on family caregivers, both primary and nonprimary, together with identifying which factors may be associated with how they experience psychological morbidity, are essential steps in designing interventions that might prevent or reduce psychopathological symptoms in family caregivers of people with terminal cancer. The purpose of this study was thus twofold: (1) to determine the prevalence of psychological morbidity with regard to psychological distress, depression, anxiety, somatization, and complicated anticipatory grief (high to severe grief levels) in family caregivers of people living with terminal cancer and (2) to describe which factors may be related to an unadjusted emotional response.

## Method

### Data collection and procedures

Data were collected from January 2014 to March 2016 at two hospice palliative care units from an oncology hospital and a general hospital and through a specialist home-based palliative care team from a general hospital. For inclusion in the study, participants fulfilled the following prerequisites: (1) a family member of a person with terminal cancer providing some level of care to his/her relative; (2) aged 18 years or older; and (3) able to understand the study, read, and complete the scales. Permission to conduct this study was received from the institutional review boards and ethic committees of each medical institution; all participants provided written informed consent.

The sample collection procedures differed depending on the context of care: hospice palliative care units or home-based palliative care. In hospice palliative care units, family caregivers, either closely accompanying their relatives in the unit or regularly visiting them, were invited by a healthcare professional (e.g., nurse) to participate in this study. If the family caregiver agreed to participate, he or she was then taken to a private room where the interviewer clarified the goals of the study. Upon obtaining written consent, participants completed a self-administered protocol, with the interviewer available nearby for any queries.

In home-based palliative care, family caregivers receiving support from the home professional care team were contacted by telephone by a healthcare professional (e.g., nurse) to participate in the study. If the family caregiver agreed to participate, the interviewer administered the protocol in similar fashion to the hospice context at the person's home.

In both cases, the assessment protocol lasted approximately 30 minutes.

## Measurements

### Family caregivers' demographics and patients' medical information

A sociodemographic and complementary data questionnaire was used to collect general information related to: (1) demographics, (2) family, (3) patient care, (4) social support, (5) psychological/spiritual support, and (6) patient medical data.

### Psychological distress, depression, anxiety, and somatization

Participants responded to anxiety, depression, and somatization subscales of the Portuguese version of the Brief Symptom Inventory (BSI) (Canavaro, 1999). To achieve the goals of this study, we also computed one global severity index (GSI), summing up the items proposed in a short version of the BSI (Derogatis, 2001) to obtain a measure of individual's global distress. T scores were used as indicative of caseness: subjects were considered as clinical cases or noncases according to the general rule for caseness suggested by Derogatis (2001):  $T \geq 63$  in GSI or in at least two subscales. The Portuguese version of BSI shows good psychometric properties (Canavaro, 1999). For this study, the following Cronbach's  $\alpha$  results were obtained: "somatization,"  $\alpha = 0.81$ ; "depression,"  $\alpha = 0.81$ ; "anxiety,"  $\alpha = 0.84$ ; and GSI (sum of the selected items),  $\alpha = 0.91$ .

### Anticipatory grief

The Marwit-Meuser Caregiver Grief Inventory – Short Version (MM-CGI-SF) was used to measure the anticipatory grief experience. Its 18 items are based on a 5-point Likert scale. The MM-CGI-SF allows for a "total grief level" and three subscale scores: "personal sacrifice burden," "heartfelt sadness and longing," and "worry and felt isolation" (Marwit & Meuser, 2005). For the purpose of this study, only the total grief level was considered. Total scores above the 75th percentile (high levels of grief) and 90th percentile (severe levels of grief) were considered to represent the at-risk level for a complicated anticipatory grief response. The MM-CGI-SF shows good psychometric properties for both the original (Marwit & Meuser, 2005) and Portuguese (Areia et al., 2016 b) versions. For this study, a Cronbach's  $\alpha = 0.86$  was obtained for the entire scale.

### Unmet needs

The Family Inventory of Needs (FIN) is a questionnaire designed to measure the importance of caregiving-related needs of families with advanced cancer patients and the extent to which these needs are

met by healthcare professionals (Kristjanson et al., 1995). It includes 20 items rated on two subscales: FIN-importance and FIN-fulfillment. FIN-importance measures the importance of each need on a scale that ranges from 1 (not important) to 5 (extremely important). On the subscale FIN-fulfillment, respondents indicate whether those needs rated as being important (2 or more) were met, partly met, or not met (Fridriksdottir et al., 2006). FIN proved to be a reliable tool in both the original (Kristjanson et al., 1995; Fridriksdottir et al., 2006) and Portuguese (Areia et al., 2016 a) versions. For the purpose of this study, only the total number of unmet needs, obtained from the FIN-fulfillment, was used. The FIN-fulfillment items showed a Cronbach's  $\alpha = 0.92$  for this study.

### Family functioning

The Systemic Clinical Outcome Routine Evaluation-15 (SCORE-15) is a measure of family functioning comprising 15 items and based on a 5-point Likert scale. Items are organized into three dimensions—"family strengths," "family difficulties," and "family communication"—and a total score. Both the original (Stratton et al., 2010) and Portuguese versions of SCORE-15 (Vilaça et al., 2015) have been shown to be valid and reliable tools. For the purpose of this study, only the total score was used. In this case, the higher the total score, the poorer the family functioning. For this study, a Cronbach's  $\alpha = 0.86$  for the SCORE-15 total score was obtained.

### Statistical analyses

Statistical analyses were performed using IBM SPSS Statistics and AMOS, version 22. Descriptive and frequency statistics were calculated to provide information about participants' characteristics and the patient's clinical information and to determine the prevalence of severe psychological morbidity. With regard to the BSI-18, a comparison with the Portuguese community norms (Canavarró et al., 2017) was also conducted through the calculation of the difference effect size, Glass's delta ( $\Delta$ ).

To determine the predictors of psychological morbidity, the structural equation modelling method was applied. Simple linear regression and uni- and multivariate multiple regression models were tested through the maximum likelihood estimation. More specifically, analyses were conducted to understand the influence of demographic characteristics (age, sex, education), relationship to the family member suffering from cancer, type of patient care (caregiving role, time spent in caregiving per day, care setting), unmet needs by healthcare professionals (i.e., number of important unmet needs), and family functioning with respect to the experience of psychological morbidity. These predictors were chosen for inclusion in the study following consultation of previous international literature.

For each tested model, violations of assumptions were assessed beforehand. Mahalanobis distance was used to detect the presence of outliers. The normality of variables was evaluated through uni- and multivariate skewness and kurtosis. Variance inflation factors were used to detect multicollinearity. Any violation of assumptions was identified in the tested models.

## Results

### Subjects

One hundred and twelve family caregivers for persons living with terminal cancer completed the assessment protocol. The majority of participants were women ( $n = 92$ ; 82.1%) with a mean age of

44.45 years ( $SD = 15.32$ ) and educational level at less than a university degree ( $n = 71$ ; 63.4%). Concerning the familial relationship to the person with terminal cancer, 42 participants (37.5%) were adult children and 22 (19.6%) were spouses. As for the caregiver role, 52 participants (46.4%) perceived themselves as primary caregivers and 60 (53.6%) as nonprimary caregivers. The majority of individuals with terminal cancer were receiving outpatient care ( $n = 62$ ; 55.4%) and were diagnosed with either gastrointestinal cancer ( $n = 27$ ; 24.5%), respiratory cancer ( $n = 23$ ; 20.9%), or other solid tumors ( $n = 23$ ; 20.9%). Last, one-half of the patients with cancer had received their diagnosis less than a year before the study ( $n = 56$ ; 50.0%). Table 1 presents a summary of the sociodemographic data and clinical information.

### Prevalence of psychological morbidity

According to the rule for caseness (Derogatis, 2001), a considerable proportion of participants was found to present clinically

**Table 1.** Sample characteristics,  $N = 112$

	n	%
Sex		
Male	20	17.9
Female	92	82.1
Age	44.45 (15.32)*	
Education		
Less than university degree	71	63.4
University degree	41	36.6
Relationship to patient		
Spouse	22	19.6
Adult child	42	37.5
Other	48	42.9
Caregiving role		
Primary caregiver	52	46.4
Nonprimary caregiver	60	53.6
Care site		
Outpatient	62	55.4
Inpatient	50	44.6
Primary diagnosis (patient)		
Breast	10	9.1
Central nervous system	13	11.8
Gastrointestinal	27	24.5
Genitourinary	7	6.4
Head and neck	3	2.7
Respiratory	23	20.9
Other solid tumors	23	20.9
Other not solid tumors	4	3.6
Time since diagnosis (patient)		
$\leq 1$ year	56	50.0
$> 1$ year	56	50.0

\*Mean (SD).

significant psychological morbidity. Specifically, (1) 66.1% of family caregivers reported high levels of distress (mean = 6.34;  $SD = 14.38$ ), (2) 68.8% showed high risk of depression disorder (mean = 9.67;  $SD = 5.58$ ), (3) 72.3% showed high risk of anxiety disorder (mean = 10.10;  $SD = 5.82$ ), and (4) 50.9% of the sample reported high levels of somatization (mean = 6.57;  $SD = 5.18$ ).

Observed results were higher than the community national average (Canavaro et al., 2017). Indeed, when comparing with the national average, large size effects were obtained for distress (Glass'  $\Delta = 0.96$ ), depression (Glass'  $\Delta = 1.01$ ), and anxiety (Glass'  $\Delta = 0.89$ ). The effect size for somatization was medium (Glass'  $\Delta = 0.56$ ).

Regarding the anticipatory grief level measured by the MM-CGI-SF, the obtained mean score was 56.16 ( $SD = 12.61$ ) and 25.9% of participants reported high (16.1%) to severe level of grief (9.8%).

### Predictors of psychological morbidity

Multivariate multiple regression models were established with the endogenous variables depression, anxiety, and somatization, considering that the dependent variables errors are correlated

( $r_{e1(\text{depression}).re2(\text{anxiety})} = 0.76-0.79$ ;  $r_{e1(\text{depression}).re3(\text{somatization})} = 0.47-0.54$ ;  $r_{e2(\text{anxiety}).re3(\text{somatization})} = 0.62-0.74$ ). Linear and univariate multiple regression models were established considering the endogenous variables distress and anticipatory grief independently.

Models were defined with regard to the following exogenous variables: age, sex and education (models 1, 2, and 3); being a spouse and being an adult child (models 4, 5, and 6); caregiving role, hours of care per day, care setting (models 7, 8, and 9); number of unmet needs by healthcare professionals (models 10, 11, and 12); and family functioning (models 13, 14, and 15).

Results of linear and multivariate multiple regression analysis and simple regression analysis are detailed in Table 2.

Sex revealed to be a statistically significant predictor of psychological morbidity. In particular, women show higher levels of depression ( $\beta_{\text{depression.sex}} = -0.25$ ,  $p < 0.01$ ), anxiety ( $\beta_{\text{anxiety.sex}} = -0.25$ ,  $p < 0.01$ ), somatization ( $\beta_{\text{somatization.sex}} = -0.27$ ,  $p < 0.01$ ), and distress ( $\beta_{\text{distress.sex}} = -0.29$ ,  $p < 0.01$ ).

Older individuals are at higher risk of developing complicated anticipatory grief responses ( $\beta_{\text{grief.age}} = 0.24$ ,  $p = 0.01$ ). This is also true when the family member is a spouse ( $\beta_{\text{grief.spouse}} = 0.30$ ,  $p < 0.01$ ) or a primary caregiver ( $\beta_{\text{grief.caregiving role}} = -0.34$ ,  $p < 0.01$ ).

**Table 2.** Standardized regression coefficients ( $\beta$ ) and determination (adjusted  $R^2$ ) for each tested model

Factors	Psychological morbidity				
	Depression	Anxiety	Somatization	Distress	Grief
Demographic	Model 1*			Model 2 <sup>†</sup>	Model 3 <sup>†</sup>
	Adjusted $R^2 = 0.07$	Adjusted $R^2 = 0.12$	Adjusted $R^2 = 0.09$	Adjusted $R^2 = 0.09$	Adjusted $R^2 = 0.08$
Age	0.08	-0.17	0.15	0.02	0.24 <sup>†</sup>
Sex	-0.25 <sup>§</sup>	-0.25 <sup>§</sup>	-0.27 <sup>§</sup>	-0.29 <sup>§</sup>	-0.14
Education	-0.05	-0.10	-0.06	-0.08	0.06
Relationship	Model 4 <sup>§</sup>			Model 5 <sup>b</sup>	Model 6 <sup>b</sup>
	Adjusted $R^2 = 0.03$	Adjusted $R^2 = 0.02$	Adjusted $R^2 = 0.00$	Adjusted $R^2 = 0.02$	Adjusted $R^2 = 0.08$
Spouse	0.18	-0.02	-0.04	0.04	0.30 <sup>§</sup>
Adult child	0.07	0.13	0.02	0.08	0.16
Patient care	Model 7*			Model 8 <sup>†</sup>	Model 9 <sup>†</sup>
	Adjusted $R^2 = 0.11$	Adjusted $R^2 = 0.06$	Adjusted $R^2 = 0.02$	Adjusted $R^2 = 0.07$	Adjusted $R^2 = 0.18$
Caregiving role	-0.10	-0.07	0.03	-0.05	-0.34 <sup>§</sup>
Hours of care	0.20	0.11	0.17	0.18	0.13
Care site	0.14	0.18	0.01	0.12	0.04
Needs	Model 10*			Model 11 <sup>  </sup>	Model 12 <sup>  </sup>
	Adjusted $R^2 = 0.09$	Adjusted $R^2 = 0.10$	Adjusted $R^2 = 0.00$	Adjusted $R^2 = 0.06$	Adjusted $R^2 = 0.05$
Unmet needs	0.30 <sup>§</sup>	0.32 <sup>¶</sup>	-0.01	0.24 <sup>†</sup>	0.21 <sup>†</sup>
Family	Model 13 <sup>a</sup>			Model 14 <sup>c</sup>	Model 15 <sup>c</sup>
	Adjusted $R^2 = 0.12$	Adjusted $R^2 = 0.08$	Adjusted $R^2 = 0.03$	Adjusted $R^2 = 0.10$	Adjusted $R^2 = 0.11$
Family functioning**	0.35 <sup>¶</sup>	0.29 <sup>§</sup>	0.16	0.31 <sup>¶</sup>	0.34 <sup>¶</sup>

\*Multivariate multiple regression model.

<sup>†</sup>Univariate multiple regression model.

<sup>‡</sup> $p < 0.05$ .

<sup>§</sup> $p < 0.01$ .

<sup>||</sup>Simple linear regression model.

<sup>¶</sup> $p < 0.001$ .

\*\*A higher score represents a poorer family functioning.



A higher number of unmet needs was related to higher scores in terms of depression ( $\beta_{\text{depression.unmet needs}} = 0.09, p = 0.01$ ), anxiety ( $\beta_{\text{anxiety.unmet needs}} = 0.13, p < 0.001$ ), distress ( $\beta_{\text{distress.unmet needs}} = 0.24, p = 0.01$ ), and anticipatory grief ( $\beta_{\text{grief.unmet needs}} = 0.21, p = 0.05$ ). Finally, family functioning revealed to be a strong predictor of psychological morbidity. In particular, lower family functioning was related to higher levels of depression ( $\beta_{\text{depression.family functioning}} = 0.35, p < 0.001$ ), anxiety ( $\beta_{\text{anxiety.family functioning}} = 0.29, p = 0.002$ ), distress ( $\beta_{\text{distress.family functioning}} = 0.31, p < 0.001$ ), and anticipatory grief ( $\beta_{\text{grief.family functioning}} = 0.34, p < 0.001$ ). Figure 1 depicts these findings.

### Discussion

The aim of the present study was to examine the prevalence and predictors of psychological morbidity of family caregivers of individuals living with terminal cancer. Specifically, the prevalence of high levels of depression, anxiety, somatization, psychological distress, and complicated anticipatory grief was analyzed. Demographic data, care-related factors, unmet needs, and family functioning were also investigated as potential predictors of psychological morbidity.

#### Prevalence of psychological morbidity

Findings from this study showed a high prevalence of psychological morbidity in family caregivers of individuals with terminal cancer receiving palliative care. It is noteworthy that more than half of the participants reported a positive risk for psychological distress, depression, anxiety, and somatization, showing significantly higher levels than the community national average (Canavarró et al., 2017). Additionally, more than one-quarter of the participants reported a positive risk for complicated anticipatory grief. These prevalence rates of psychological morbidity are somewhat alarming and intensify the sense of urgency, as stated by Rait (2015), for expanding patient-centered care more in the direction of family-centered care. Undoubtedly, these results

corroborate the idea that cancer is a “we-disease” (Kayser et al., 2007) and family members are cosufferers alongside cancer patients (Northouse, 2012), showing heightened levels of psychological morbidity.

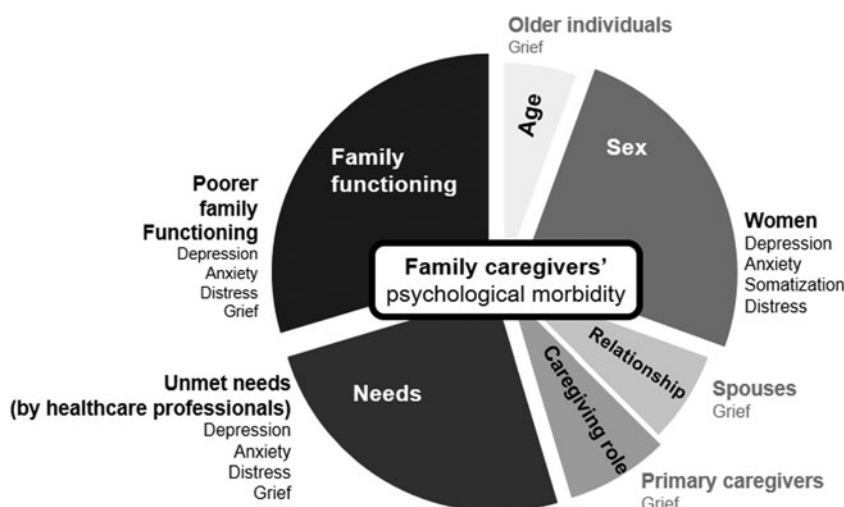
#### Factors associated with psychological morbidity

As for the predictors, it was found that older individuals, women, spouses, primary caregivers, important unmet needs by healthcare professionals, and poor family functioning may influence the presence of some form of psychological morbidity.

Some predictors were expected, such as age and sex. Indeed, the literature frequently points out that older individuals (Marwit & Meuser, 2002) and women (Burridge et al., 2009; Morgan et al., 2016) are more likely to develop mood-related complications when facing an imminent death of a family member.

Notwithstanding, results regarding the caregiving role and the relationship to the person with terminal cancer were slightly surprising. It was expected that being a primary caregiver and/or a partner would predict greater psychological morbidity. Indeed, it is well established in the literature that primary caregivers and spouses are at higher risk of developing severe mood complications, such as depression and anxiety (Fasse et al., 2015; Given, 2004; Gotze, 2014). The current results showed that primary caregivers and nonprimary caregivers share a similar risk of developing psychological morbidity, in terms of distress, depression, anxiety, and somatization. The caregiving role and relationship to the person with terminal cancer significantly influenced the levels of grief only. This indicates that primary caregivers and partners (20 of 22 spouses in this study considered themselves primary caregivers) are more likely to develop complicated anticipatory grief responses.

We believe that these results may be explained by an increased awareness of the relative’s approaching death and levels of suffering, as well as by the multiple present losses (e.g., loss of freedom) that primary caregivers/spouses may experience as a result of their



**Note**  
The number of influenced outcomes and  $\beta$  values obtained in the models were taken into account in the creation of the figure, specifically determining the size of each portion of the circle.

**Fig. 1.** Summary of the findings on the predictors of psychological morbidity of family caregivers of people with terminal cancer.

caregiving tasks. As found by Janze and Henriksson (2014), family primary caregivers/spouses are more likely to become increasingly aware of death because they continually experience first-hand the extent to which their relative's condition is deteriorating. They may also anticipate and imagine the physical deterioration and death of their family member by picturing a variety of scenarios. Although primary caregivers struggle to focus on the present and on responding to practical challenges related to caregiving, it is unavoidable that death is always either in the background or at the forefront (Janze & Henriksson, 2014), which may explain an increased anticipatory grief response. Additionally, as stated previously, predeath grief is not only focused on future losses (e.g., the patient's death), but also on present and past losses. Becoming a primary caregiver of a terminally ill person is considered a complex transition process that implies a wide range of changes in identity, roles, relationships, abilities, and patterns of behaviors (Schumacher & Meleis, 1994) over a short period; thus, primary caregivers may be more exposed to several losses. As such, primary caregivers/spouses may not only grieve the imminent death of their family member but also the present changes in the relationship with their relative, roles, social involvement (isolation), personal projects, and pursuits and so on, which explains a higher risk of complicated anticipatory grief responses. Likewise, present caregiving demands are related to higher levels of loss appraisal (Oberst et al., 1989) and, as is well-known, the terminal phase of cancer is particularly demanding on primary caregivers.

Confronting the challenging task before them, primary caregivers tend to postpone their emotional responses by withholding their own feelings and needs. They usually take on the role of being the "strong one" and thus focus on the present by assigning priority to the needs of their ill loved-ones and addressing whatever practical demands and caregiving tasks that may arise (Janze & Henriksson, 2014). Although it is unknown whether this response has a positive or negative outcome in the middle and long term (Janze & Henriksson, 2014), we believe that this may explain the study results that indicate, contrary to what was previously expected, that being a primary caregiver/spouse does not have a direct effect on distress, depression, anxiety, and somatization. There is also some evidence that being a primary caregiver may bring positive consequences (e.g., Kang et al., 2013). Indeed, despite the well-known challenges of caring for a terminally ill individual, the caregiving experience may simultaneously serve as a wake-up call about life, heightening and/or altering the sense of priorities, changing one's life patterns of and reorienting life goals and hopes (Walsh, 2003). Thus, further research should thoroughly examine whether these positive effects can explain the similar levels of distress, depression, anxiety, and somatization obtained by both primary caregivers and nonprimary caregivers in our study.

The results of this study support the importance of attending not only to family primary caregivers, but also to family nonprimary caregivers because both seem to show a similar probability for developing psychological morbidity.

Additionally, our results show that unmet needs seem to be a strong predictor of psychological morbidity in family caregivers of people with terminal cancer. Similar results were reported by Fridriksdottir et al. (2011) and Buzgová et al. (2016), who found associations between perceived unmet needs, psychological morbidity (anxiety), and lower quality of life. As briefly mentioned earlier, families commonly prioritize a relative's wishes and needs above their own, deemphasizing their own needs

(Milne & Quinn, 2009). This may partially preclude an adequate fulfilment of these needs by healthcare professionals. In addition, there is still a gap in palliative care settings in adequate care for families of terminally ill people (Milne & Quinn, 2009). Healthcare professionals still tend to focus on the patient and to dedicate little time to addressing family members' difficulties, also being reluctant to openly attend to these matters in the cancer patient's presence (Grande et al., 2009). Nevertheless, adequate patient-family support must overcome these difficulties, and families should be encouraged to identify their own needs, and in so doing, better fulfill them, as unmet needs seem to have worrying negative outcomes for family members (Milne & Quinn, 2009).

Finally, consistent with Melbourne Grief Studies (Kissane & Bloch, 2002), the results of our study confirmed that family functioning is related to individuals' psychological morbidity. Specifically, poorer family functioning may predict individuals' maladaptive responses to the approaching death of a family member (e.g., complicated anticipatory grief), whereas it is legitimate to expect that healthier family functioning may act as a buffer against the impact of terminal cancer on family caregivers.

Indeed, in a systemic perspective, family is considered an interactional system and so, the impact of a death, actual or in the near future, would have far-reaching effects for every member and all other relationships within a complex chain of influences that reverberates throughout the family network (Walsh & McGoldrick, 2004). Maladaptive relational processes within the family system constrain the full coping potential of the family as a whole, the patient, and all other family members (Zaider & Kissane, 2015), putting them at risk for developing psychological morbidity. Our results, therefore, emphasize the importance of developing and delivering relationship-focused interventions to strengthen the quality of family relationships and reduce the risk for psychological morbidity in people living with terminal cancer and their family caregivers (Zaider & Kissane, 2015) and also promote not only the family caregivers' personal growth (Walsh, 2003), but also the experience of positive consequences related to the caregiving of the terminally ill (Kang et al., 2013).

### **Strengths and Limitations**

Within the field of family studies and the contexts of oncology and palliative care, the major strengths of this study lie in how it scrutinized and examined the factors related to family caregivers' maladjustment, identifying a worrying prevalence of psychological individual morbidity strongly linked to family functioning and to inadequate family support.

The main weaknesses of our study may be found in its cross-sectional nature, the modest sample size, and its homogeneity (e.g., most participants were female). This study was also limited in that it did not consider certain other factors as influencing the presence of psychological morbidity. For example, it would have been interesting to investigate how a patient's characteristics, such as type of cancer, level of physical deterioration, and psychological adjustment, influence his or her relative's adjustment as well as to strictly underscore the interdependence of patient-family adjustment. In addition, other important care-related variables should have been addressed. Fatigue and related perceived burden emerge as crucial variables in palliative care settings (Peters et al., 2015) and, thus, it should have been addressed in depth to determine how much a heightened burden may contribute to family caregivers' maladjustment to an imminent death of their relatives.

### Research and clinical implications

The present study has implications for both research and clinical practice. In the area of research, this study points to the importance of more research focused on factors related to family caregivers' psychological morbidity. Additionally, a scrutinized study of family caregivers' responses in palliative care should investigate the mediator role of family functioning in family caregivers' adaptation to the terminal phase of a cancer.

As for this study's clinical implications, it provides some preliminary evidence that psychosocial interventions should be targeted first to older individuals, women, spouses, and primary caregivers. As is known, clinicians must move forward to a family-centered approach to address and better fulfill family caregivers' needs.

Given the alarming risk of psychological morbidity for family caregivers of people living with terminal cancer, it is hoped that this work will trigger future research in the field and raise awareness of the importance of better support for families that face the imminent death of a family member.

### Conclusions

Family caregivers of individuals with terminal cancer reported worrying levels of psychological morbidity, specifically a high prevalence of global distress, depression, anxiety, somatization, and complicated grief. Factors associated with family caregivers' psychopathological symptomatology (i.e., global distress, depression, and anxiety) accounted for sex, unmet needs by healthcare professionals and family functioning. Remarkably, all the predictors studied, with the exception of sex, revealed to have an influence on complicated anticipatory grief responses. Palliative care must ensure that whole family support and family-centered interventions adequately replace the traditional patient-, primary caregiver-interventions to consider the entire family as a unit of care.

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