Universidade de Lisboa
Faculdade de Medicina de Lisboa

CONCEPTUALIZATION AND ASSESSMENT OF FAMILY CAREGIVERS` ANTICIPATORY GRIEF IN PALLIATIVE CARE

Manuela Alexandra de Moura Coelho

Orientadores: Prof. Doutor António José Feliciano Barbosa
Prof. Doutora Maria Luísa Torres Queiroz de Barros

Tese especialmente elaborada para obtenção do grau de Doutor em Ciências e Tecnologias da Saúde, especialidade de Cuidados Paliativos

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List of Abbreviations and Acronyms

AG	Anticipatory Grief
AGS	Anticipatory Grief Scale
BIS	Behavior Inhibition System
BSI	Brief symptom Inventory
CA	Cluster Analysis
CG	Complicated Grief
CGS	Caregiver Grief Scale
EFA	Exploratory Factor Analysis
FC	Family Caregiver
FcAG-CI	Family Caregiver Anticipatory Grief - Clinical Interview
ICD-11	International Classification of Diseases - 11th Revision
KMO	Kaiser-Meyer-Olkin Measure
MCA	Multiple Correspondence Analysis
MM-CGI	Marwit-Meuser Caregiver Grief Inventory
PG-12	Prolonged Grief Disorder Questionnaire – Pre-death Version
PG-13	Prolonged Grief Disorder Questionnaire
PGD	Prolonged Grief Disorder
PC	Palliative Care
PDG	Post-death Grief
WHO	World Health Organization

Abstract

Introduction

In cancer end-of-life trajectory, the family caregiver (FC) faces the patient´s successive functional losses and the perspective of imminent death, thus giving rise to a grief response that precedes the actual loss. Despite being emotionally painful, the experience of Anticipatory Grief (AG) was thought to be protective against the impact of sudden death. The AG concept is particularly useful in palliative care, as it allows for preventive intervention, by preparing FC for the terminally ill patient´s inevitable death. However, due to the lack of conceptual clarity, contradictory empirical results have been found, challenging the previous idea that AG was associated with stress reduction afterwards. Instead, it was proposed that the cumulative effect of the caregiver's distress exacerbates the grief reaction, thus predicting worse adjustment to loss. Recent research conceived pre-death grief manifestations as part of a continuum of grief symptoms that, in some cases, tends to persist over time, leading to Prolonged Grief Disorder (PGD). Although this perspective meets the purpose of early detection of those individuals at risk of developing PGD, on the other hand it fails to capture the multidimensionality and specificity of the AG concept. Overall, the AG phenomenology has been little explored in cancer FC, so there are not yet known its specific characteristics, nor the dynamics underlying individual differences in emotional response to this experience. Besides, the existing assessment instruments are self-reported, so they cannot grasp the implicit meanings that FC attribute to their experience. For clinical purposes, it is important to develop empirically based criteria that guide health professionals in a comprehensive evaluation of FC´s support needs. Accordingly, this research aims to contribute to a more comprehensive view and measurement of palliative care cancer family caregiver´s grief experience by analysing the trajectory of grief symptoms, their determinants and multidimensionality of anticipatory grief concept. As general objectives, we established: (a) To describe the trajectory of PGD symptoms and their determinants in a sample of the Portuguese sample of cancer FC followed in palliative care; (b) To contribute to the conceptualization and operationalization of the family caregiver anticipatory grief phenomenology by developing a clinical assessment instrument to measure individual differences in anticipatory grieving process.

Methods

This research project encompasses a literature review, followed by a series of multilevel studies, employing quantitative, qualitative and mixed method approaches. First, a literature review was conducted for gaining perspective on this problematic and capture the main domains of the AG concept. Then, a survey instrument design, including two longitudinal studies, addressed the first main objective (Empirical studies I and V). Data was collected from a convenience sample of cancer FC accompanied in a palliative care (PC) out-patient consultation. At the beginning of accompaniment (T1), the participants were evaluated through self-reported measures on the following variables: demographics, perception of illness, involvement in caregiving, caregiver burden, coping mechanisms, quality of the relationship, mental health symptoms and pre-death prolonged grief symptoms. During bereavement (T2, 6 - 12 months after the patient´s death), participants were contacted by phone to evaluate PGD symptoms. The initial phase of collection and analysis of results (Empirical study I, n= 94) consisted in the validation of the PG-12, a brief self-report diagnostic tool adapted from the Prolonged Grief Disorder Questionnaire to evaluate the presence of pre-death PGD. In a second phase, this sample was enlarged to perform a multivariate analysis of PGD predictors, both pre and post-death (Empirical study V, n= 156 at T1; n= 87 at T2). The other part of this research, corresponding to the second main objective, relied in qualitative and mixed method analysis. Two original cross-sectional and one longitudinal study were conducted using sub-samples of participants selected from the previous works. Data from interviews were submitted to thematic analysis (Empirical study II, n= 26) and then cross tab analysis with self-reported results for identifying patterns of AG according to the pre-death manifestations intensity (Empirical study III, n= 72). In this analysis, we used a combined inductive and deductive analysis, applying concepts from attachment theory to classify the FC´s response patterns. Findings from the qualitative studies were refined and operationalized into structured criteria, giving rise to a new assessment tool for evaluating individual differences in dealing with AG experience.

Results

Results showed that PG-12 is a valid and reliable unidimensional diagnostic tool, with predictive value for post-death PGD symptoms. In a sample of cancer FC in palliative care, up to 38.6% presented PGD symptomatology, with tendency to decrease during bereavement, although in many cases, severe manifestations persisted for longer. These findings provide evidence for both the perspectives of stress reduction and cumulative stress, which turned out to be complementary in explaining the diversity of the caregivers' grief manifestations evolution. In addition to intrapersonal (e.g., coping mechanisms) and relational factors (e.g., proximity of the relationship with the patient at the time of illness), the psychological distress and burden related to end-of-life caregiving contributed significantly to explain PLP variations, suggesting that FC´s grief manifestations cannot be decontextualized from the experience of end-of-life caregiving. Accordingly, two main dimensions emerged from qualitative data: (i) *traumatic distress* of witnessing the significant other´s life-threatening conditions, (ii) *relational distress,* inherent to the end-of-life caregiving relationship and future separation. Each theme includes several categories, conceived as different challenges that require a constant effort of emotional regulation. AG was therefore defined as the FC´s response to the perceived menace to the other´s life and subsequent anticipation of loss, in the context of an end-of-life caregiving relationship. Individual differences were classified according to self-reported pre-death grief intensity, resulting in the configuration of anticipatory grieving patterns, described qualitatively in the light of attachment theory: (i) *avoidant* (ii) *adjusted*, (iii) *intense*, and (iv) *traumatic.* Indicators were operationalized into evaluation criteria, constituting a new manualized instrument – the Family Caregivers´ Anticipatory Grief Clinical Interview (FcAG-CI). In this preliminary phase of validation, it has shown acceptable values of validity and reliability. The dimensionality of AG construct was confirmed, as well as the latent structure with four groups. Individual differences were found to be predictive of pre-death mental health outcomes. This association was not found with bereavement adjustment, which suggests that despite the continuity of PGD symptoms, the experience of AG is qualitatively different from post-death grief. However, it is also possible that this result is due to differences in the quantitative and qualitative assessment modalities and/or limitations of the study in terms of the follow-up sample size.

Conclusion

This research project contributes to the literature in several ways. First, by providing a comprehensive and parsimonious definition of AG, we contribute to a more precise and self-differentiated understanding of this phenomenon. Second, by integrating qualitative data from semi-structured in-depth interviews with theoretical concepts, we developed a conceptual model for explaining individual differences in AG. Third, on operationalizing empirically based assessment criteria, we created a new manualized instrument to guide clinical evaluation and distinguish anticipatory grieving patterns. Fourth, by collecting prospective data, we contribute to the description of the determinants and outcomes of this experience in long term. Specifically in the Portuguese reality, where the investigation is still scarce, it is important to generate valid empirical data that inform about the actual impact of end-of-life caregiving. In sum, results from this research contribute to a more coherent and elaborated understanding of AG, with clear clinical implications in terms of measurement, intervention and education of health professionals towards a more sensitive and effective response to family caregivers´ needs.

Keywords: Anticipatory Grief, Family Caregivers, Palliative Care, Clinical Assessment, Prolonged Grief Disorder

Resumo

Introdução

Durante a trajetória de fim-de-vida do doente oncológico, os cuidadores familiares (CF) lidam com sucessivas perdas funcionais do doente e perspetiva de morte iminente, dando origem a uma resposta de luto que antecede a perda real do doente. Apesar de emocionalmente dolorosa, esta experiência, reconhecida como Luto Antecipatório (LA), foi considerada protetora em relação ao impacto da morte súbita. O conceito de LA é particularmente útil em cuidados paliativos, uma vez que permite uma intervenção preventiva, preparando o CF para a morte inevitável do doente terminal. No entanto, devido à falta de clareza conceptual, têm sido encontrados resultados empíricos contraditórios, pondo em causa a anterior ideia de que o LA está associado à subsequente redução do stress. Em oposição, foi proposto que o efeito cumulativo do distress do cuidador exacerba a reação de luto, predizendo assim pior adaptação à perda. A investigação recente concebe as manifestações de luto pré-morte como parte de um continuum de sintomas de luto, que em alguns casos tendem a persistir no tempo, provocando Perturbação de Luto Prolongado (PLP). Embora esta perspetiva sirva o propósito de deteção precoce dos indivíduos em risco de desenvolver PLP, por outro lado falha na apreensão da multidimensionalidade e especificidade do conceito de LA. Em geral, a fenomenologia do LA tem sido pouco explorada nos CF de doentes oncológicos, por isso, não são ainda conhecidas as suas características específicas, bem como a dinâmica subjacente às diferenças individuais na resposta emocional a esta experiência. Além disso, os instrumentos de avaliação existentes são de auto-relato, por isso não conseguem captar os significados implícitos que os próprios cuidadores atribuem à sua experiência. Para fins clínicos, é importante desenvolver critérios baseados em dados empíricos que orientem os profissionais de saúde numa avaliação mais abrangente das necessidades de suporte dos CF. Assim, esta investigação pretende contribuir para uma compreensão e avaliação mais aprofundada da experiência de luto dos cuidadores familiares de doentes oncológicos em cuidados paliativos (CP), analisando a trajetória dos sintomas de luto, seus determinantes e multidimensionalidade do conceito de luto antecipatório. Como objetivos gerais, estabelecemos: (a) descrever a trajetória de sintomas de PLP e seus determinantes numa amostra da população portuguesa de CF de doentes oncológicos em CP; (b) contribuir para

a conceptualização e operacionalização da fenomenologia do luto antecipatório do cuidador familiar através da criação de um instrumento de avaliação clínica.

Método

Este projeto de investigação inclui uma revisão da literatura seguida de uma série de estudos empregando abordagens metodológicas quantitativas, qualitativas e mistas. Inicialmente, foi realizada uma revisão da literatura para obter uma melhor compreensão sobre a problemática e identificar os principais domínios do conceito. A seguir, procedemos à colheita de dados em formato de questionário, em dois estudos longitudinais, que dão resposta ao primeiro objetivo (Estudos empíricos I e V). Os dados foram colhidos de uma amostra de conveniência de CF de doentes oncológicos acompanhados numa consulta externa de CP. No início do acompanhamento (T1), os participantes foram avaliados através de escalas de auto-relato, nas seguintes variáveis: características demográficas, perceção da doença, envolvimento no cuidar, sobrecarga do cuidador, mecanismos de coping, qualidade da relação, sintomas de saúde mental e luto pré-morte. Na fase de luto (T2, 6 - 12 meses após a morte), os participantes foram contactados por telefone para avaliar os sintomas de PLP. A fase inicial de colheita e análise dos resultados (Estudo empírico I, n= 94) consistiu na validação do PG-12, um instrumento de diagnóstico de auto-relato adaptado do Questionário de Perturbação de Luto Prolongado para avaliar a presença de sintomas de PLP na fase de pré-morte. Posteriormente, esta amostra foi ampliada para realizar a análise multivariada dos preditores de PLP, na fase pré e pós-morte (Estudo empírico V, n= 156 no T1; n= 87, no T2). A outra parte desta investigação, correspondente ao segundo objetivo geral, baseou-se no método de análise qualitativa e mista. Foram realizados dois estudos transversais e um estudo longitudinal com sub-amostras dos participantes selecionados para os trabalhos anteriores. Os dados de entrevistas foram sujeitos a análise temática (Estudo empírico II, n= 26) e depois cruzados com os resultados do instrumento de auto-relato para identificar padrões de LA de acordo com a intensidade das manifestações de luto pré-morte (Estudo empírico III, n=72). Nesta análise, usámos um método combinado de análise indutiva e dedutiva, aplicando conceitos da teoria da vinculação para classificar os padrões de resposta dos CF. Os resultados dos estudos qualitativos foram refinados e operacionalizados em critérios, dando origem a um novo instrumento de avaliação para avaliar as diferenças individuais na gestão da experiência de LA.

Resultados

Os resultados demonstram que o PG-12 é um instrumento de diagnóstico válido e fiável de natureza unidimensional, com valor preditivo dos sintomas de PLP pós-morte. Na amostra global de CF de doentes oncológicos em cuidados paliativos, 38.6% apresentaram sintomatologia de PLP, com tendência a decrescer durante o período de luto pós-morte, embora em muitos casos as manifestações severas de luto persistam por muito tempo. Estes resultados suportam ambas as perspetivas de redução do stress e stress cumulativo, que se tornam complementares na explicação da diversidade das manifestações de luto dos cuidadores. Para além dos fatores pessoais (ex., mecanismos de coping) e os fatores relacionais (ex., proximidade da relação com o doente no momento da doença), o stress psicológico e a sobrecarga relacionada com o cuidar em fim-de-vida contribuíram significativamente para explicar a variância da PLP na fase pré-morte, o que sugere que as manifestações de luto do FC não podem ser descontextualizadas da experiência de prestação de cuidados em fim-de-vida. Em conformidade, dos dados qualitativos emergiram duas dimensões principais: (i) *distress traumático*, relacionado com o facto de presenciarem as condições ameaçadoras de vida do outro significativo; (ii) *distress relacional*, inerente à relação de cuidar em fim-de-vida e futura separação. Cada um dos temas inclui várias categorias, concebidas como diferentes desafios que requerem um constante esforço de regulação emocional. O LA foi então definido como a resposta do familiar face à ameaça percebida à vida do outro e consequente antecipação da perda, no contexto da relação de cuidar em fim-de-vida. As diferenças individuais foram classificadas de acordo com a intensidade das manifestações de luto auto-reportadas, resultando na configuração de diferentes padrões, descritos qualitativamente à luz da teoria da vinculação: (i) *evitante*; (ii) *ajustado*; (iii) intenso e (iv) traumático. Os indicadores foram operacionalizados em critérios de avaliação, constituindo um novo instrumento manualizado – a Entrevista Clínica do Luto Antecipatório dos Cuidadores Familiares (EC-LACf). Nesta fase preliminar de validação, este instrumento revelou valores aceitáveis de validade e fiabilidade. A dimensionalidade do conceito de LA foi confirmada, assim como a

estrutura latente de quatro grupos. As diferenças individuais revelaram ser preditivas dos resultados de saúde mental na fase pré-morte. Esta associação não foi demonstrada em relação à adaptação ao luto pós-morte, o que sugere que, apesar da continuidade dos sintomas de PLP, a experiência de LA é qualitativamente diferente. No entanto, também é possível que este resultado se deva a diferenças nas modalidades de avaliação quantitativa e qualitativa e/ou a limitações do estudo em termos da dimensão da amostra no follow-up.

Conclusão

Esta investigação contribui para a literatura das seguintes formas. Primeiro, ao gerar uma definição abrangente e parcimoniosa de LA, estamos a contribuir para uma compreensão mais precisa e diferenciada deste fenómeno. Segundo, ao integrar dados qualitativos das entrevistas com conceitos teóricos, desenvolvemos um modelo conceptual explicativo das diferenças individuais no LA. Terceiro, ao operacionalizar critérios de avaliação empiricamente baseados, criámos um novo instrumento manualizado para guiar a avaliação clínica e distinguir os padrões de LA. Quarto, ao recolher dados prospetivos, contribuímos para a descrição dos determinantes e consequências desta experiência a longo prazo. Especificamente na realidade portuguesa, onde a investigação ainda é escassa, é importante gerar dados empíricos válidos que informem acerca do real impacto do cuidar em fim-de-vida. Em suma, os resultados desta investigação contribuem para uma compreensão mais coerente e elaborada do LA, com claras implicações em termos de avaliação, intervenção e educação dos profissionais de saúde para uma resposta mais sensível e eficaz às necessidades dos cuidadores familiares.

Palavras-Chave: Luto Antecipatório, Cuidadores Familiares, Cuidados Paliativos, Avaliação Clínica, Perturbação de Luto Prolongado

Introduction

In addition to the demands inherent to the end-of-life caregiving, family members are confronted with successive losses that culminate in the death of the patient. Studies carried out with family caregivers (FC) in palliative care (PC) stressed that, for a large number of people, the experience of end-of-life caregiving encompasses intense grief reactions and emotional distress that compromise adjustment to the disease and bereavement[1] (Hudson, Thomas, Trauer, Remedios & Clarke, 2011; Thomas, Hudson, Trauer, Remedios, C., & Clarke, D. 2014). Deleterious effects of distress associated to end-of-life caregiving were observed in both FC´s physical and mental health (Schulz & Sherwood, 2008; Krikorian, Limonero & Maté, 2012; Garrido, Balboni, Maciejewski, Bao & Prigerson, 2015; Tan, Molassiotis, Lloyd-Williams & Yorke, 2018), as well as the patient´s well-being (Northouse, Katapodi, Schafenacker & Weiss, 2012).

According to World Health Organization (2002), family support is considered a pillar of palliative care´s philosophy, inseparable from the professional assistance provided to the patient. Guidelines for psychosocial and bereavement support of FCs in PC recommend that families should be assessed in their needs and involved in end-of-life care discussions in order to prepare them for the proximity of death (Hudson et al., 2012). Palliative care provides a window of opportunity to assess and intervene in face of expected death (Agnew, Manktelow, Taylor & Jones, 2010). Therefore, it is essential to identify those FCs most vulnerable and to implement intervention measures that minimize the negative outcomes of the FC´s distress. In this context, it seems reasonable to assume that facilitating FC´s Anticipatory Grief (AG) constitutes an opportunity for primary prevention and potentially facilitator of bereavement.

The concept of AG has been widely used in PC setting as it promotes a vision of continuity in the grief process and a preventive attitude in intervention with the multiple losses of FCs. In spite of this, the concept has been involved in large controversy concerning the validity and utility of the term. Reasons for contradictory empirical results were attributed to the lack of conceptual clarity. The most common AG definition continues to be Rando´s

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[1] Grief is defined as the involuntary reaction to a loss (physical or symbolic), primarily associated to emotions, though it also includes the somatic, cognitive, behavioral and spiritual realms. Bereavement is the state of having loss a significant other (Worden, 1982; Rando, 1995; 2000).

(1986a), which states that it is a phenomenon encompassing the mourning, coping, and planning of one's life in response to an impending loss as well as past, present and future losses. However, given the wide scope of this definition, a variable understanding of AG persists, leading to methodological bias in evaluating this experience (Reynolds & Botha, 2006). For example, some studies (Carr, House, Wortman, Nesse & Kessler, 2001; Valdimarsdóttir, Helgason, Fürst, Adolfsson & Steineck, 2004) evaluated AG as equivalent to forewarning death (time of awareness that the disease is fatal until the patient dies), ignoring that this is an individual and dynamic process that does not depend on time.

Recently, most studies evaluate pre-death symptoms using an instrument (PG-12) that relies in criteria of the Prolonged Grief Disorder (PGD) diagnostic (Prigerson et al., 2009). Criteria for PGD include separation anxiety, pervasive preoccupation and intense emotional pain, along with functional and social impairment. According to a systematic review of literature (Nielsen, Neergaard, Jensen & Guldin, 2016), empirical results show a continuum of manifestations between pre and post-death, thus failing to demonstrate the AG protective role in bereavement adjustment. Instead, AG has been considered a risk factor for developing Prolonged Grief Disorder. However, as stated by the authors, little is known about the underlying mechanisms of the concept and the multiple losses during caregiving.

Besides, most research on caregiver´s grief has been developed in dementia FC, which is characterized by a slow and gradual evolutionary end-of-life trajectory (Marwit & Meuser, 2005). On the contrary, the cancer trajectory is often considered more acute and death is a more expected endpoint (Teno, Weitzen, Fennell & Mor, 2001). Thus, it is reasonable to assume that cancer FCs have a distinct AG experience. For example, Sanderson et al. (2013) stated that dealing with terminal cancer exposes the caregiver to very shocking images, which can be registered as traumatic memories, resulting in intense feelings of powerlessness that, in some cases, persist beyond the patient´s death.

Given the existing gaps in literature on this topic, the current research proposes to develop a comprehensive view about caregiver´s grief by analysing the trajectory of grief symptoms, their determinants and the conceptualization of AG concept. Results will lead to the creation of a new AG instrument, designed specifically to cancer FC in palliative care, to clinically evaluate individual differences in managing the multiple challenges posed by this experience.

Reasons for conducting this research project derive mainly from my clinical practice, as a psychologist in palliative care. In the daily contact with the families of the terminally ill patients, I became aware of the multiple dilemmas and challenges they are dealing with when providing care to the terminally ill: they must protect the significant other, while managing their own overwhelming feelings of fear, loss and impotence. This made me aware of the specificity of this grief process and the need to adjust communication to the individual´s particular needs. Some people are receptive to talking openly about the subject of death and loss and clearly benefit of that; others experience great anxiety and ambivalence, or completely refuse this possibility, so they require a more cautious approach to this painful subject. Thus, in line with empirical research (Nielsen et al., 2016), we hypothesized that the way one regulates emotionally in face of the multiple challenges posed by the circumstances of terminality has a central role in the AG experience.

From the integrative perspective of emotional regulation, the response to events is organized by emotions (Siegel, 1999, 2001, 2015). They provide the meaning and the motivational direction by connecting mental processes and memories of past experience through neurophysiological circuits, thus integrating the distinct parts of the nervous system functions. Emotional regulation is associated to the quality of early dyadic interaction, recognized as secure attachment. It allows a flexible and adjusted response to the internal and external stimuli. On the contrary, emotional dysregulation is characterized by maladaptive strategies of emotion hyperactivation or deactivation; they are associated to insecure attachment styles and symptoms of affective disturbance (Marganska, Gallagher & Miranda, 2013). There is growing evidence of emotional regulation difficulties in grief complications (Gupta & Bonanno, 2011; Bonanno, 2013). However, little is known about how FC emotionally regulate themselves in face of the real threat of separation in the context of a caregiving relationship. Thus, it is important to evaluate FC's individual differences in dealing with multiple challenges posed by AG and how they are related with grief symptomatology, pre and post-loss.

The current study was developed in Palliative Care Unit of Centro Hospitalar Universitário Lisboa Norte. It is an hospital-based palliative care service that provides support to hospitalized and ambulatory patients with advanced progressive diseases, over 18 years of age. Most patients are at home, being cared by FC, with brief periods of hospitalization for symptom control. Referral for palliative care are mostly advanced cancer patients and the average follow-up time is about one month. The usual treatment comprises a first medical consultation (doctor and nurse), where patients and their families are assessed on their needs and, depending on that, introduced to the other members of the team, including the psychologist. According to the principles of palliative care, both the patient and the family members are supported by the multidisciplinary team, in a regular basis, either in face-to-face consultations (weekly or fortnightly), or by telephone contact.

The present dissertation is organized in four chapters, herein succinctly described.

Chapter I | Conceptual and theoretical framework constitutes an overview of relevant literature on the theme, including both empirical and theoretical work. The first part of the conceptual framework introduces the object of the study. In the second part of this chapter, we present the theoretical framework in which we rely to guide the research.

Chapter II| Objectives and Method integrates the problem statement, description of the objectives, study procedures, methodological options and ethics. The research is presented as a whole, although each of the articles presents an independent study, with its own methods.

Chapter III | Integrative Review and Empirical Studies includes one integrative review and five original empirical studies presented in the format of scientific papers. Presentation of the studies correspond to the chronological and sequential development of the studies.

Chapter IV | General Discussion offers a brief summary and discussion of the main results from empirical studies and a critical review of the methodological strengths and limitations of the study. Finally, clinical contributions of these results are discussed in order to inform future research and clinical practice in providing support to FC in PC.

Attached to this dissertation, we present the facsimiles of published articles and the Manual of the Clinical Interview of Family Caregiver Anticipatory Grief (FcAG- CI).

CHAPTER I

Conceptual and Theoretical Framework

1. FAMILY CAREGIVER´S GRIEF

1.1. Caregiving and Mental Health

With the ageing of population and increasing life expectancy, the global prevalence of chronic diseases is enlarging considerably (Mathers & Loncar, 2006). Most people face a long period of progressive illness and disability before death, requiring long-term care. To become sustainable, the health systems are being restructured, with a tendency to reduce length of stay in hospital and transfer care to home, thus relying in family members for informal caregiving. Family caregiver (FC) definition includes any family member, friend, or partner who maintains a significant relationship with the patient and provides some kind of care (Hudson & Payne, 2009). As opposed to formal caregivers, they are involved in care without prior preparation and receive no remuneration from this activity.

A recent international study carried out with 19 European countries (n= 32 894) showed that prevalence rates of informal caregiving varied between European countries, from 20% to 44%. Intensive caregiving (i.e. those who provide informal care for at least 11 hours a week) ranged from 4% to 11% (Verbakel, 2018). Another study carried out in the United States (Wolff, Spillman, Freedman & Kasper, 2016) referred that there are about 14.7 million caregivers who provide care to 7.7 million elderly patients. The family members most involved in caregiving were mainly adult daughters who cohabited with the patient and spouses.

As the disease progresses, FC are engaged in increasingly complex tasks, including functional aid, such as hygiene, mobilization and feeding, emotional support to the patient, symptom control through medication administration, disease management and decision-making regarding treatments. However, these tasks are often performed in overlap with other roles (Martz & Morse, 2016), with considerable impact on the daily routines of family members (Brazil, Bédard, Willison & Hode, 2003). Given the great involvement in the tasks of caring and the proximity of the relationship with the patient, this population becomes particularly vulnerable to high levels of distress and health problems (Raschick & Ingersoll-Dayton, 2004; Vitaliano, Young & Zhang, 2004).

In a sample of caregivers of cancer patients, 30% of the participants met criteria for a psychiatric disorder, namely panic disorder (8%), major depression (4.5%), posttraumatic stress disorder (4.5%), and generalized anxiety disorder (3.5%) (Vanderwerker, Laff, Lottick, McColl & Prigerson, 2005). In other studies evaluating the FC´s mental health, values of depression ranged from 12 to 67% (Grunfeld et al., 2004; Hauser & Kramer 2004; Rhee et al., 2008) and anxiety between 30 and 50% (Grunfeld et al., 2004). There are authors who suggest that FC`s levels of depression and anxiety even exceed those of the patients (Braun, Mikulincer, Rydall, Walsh, & Rodin, 2007; McLean, Walton, Matthew, & Jones, 2011). Studies carried out specifically in palliative care identified depression values ranging from 16 to 23% (Hudson, Thomas, Trauer, Remedios & Clarke, 2011; Nielsen et al., 2017[a]). According to the meta-analysis of Pinquart & Sörensen (2007), health problems are more related to the depressive symptoms of the caregiver than to the objective stressors.

1.2. Perspectives on Caregiver´s Grief

Two competing hypotheses were initially formulated to explain the course of bereavement after caregiving (Bass & Bowman, 1990). The *perspective of stress reduction,* posing that death represents an interruption of the caregiver's burden and simultaneously the end of the patient's suffering, thus eliciting a sense of relief that contributes to the decrease of symptomatology after the loss. On the contrary, the *cumulative stress perspective* argues that the combination of caregiver exhaustion and the subsequent death of the patient translates into the depletion of the individual's coping abilities, causing greater difficulties in bereavement.

The first perspective is supported by the evidence that, in spite of physical and emotional vulnerability of caregivers at the time of death, most FC can reasonably adapt and recover to previous levels of functioning. In fact, several studies reported improvement in mental health from pre to post-loss period. A prospective analysis of grief manifestations in a sample of caregivers of hospice patients showed that the depressive symptomatology persists two months after the loss, but decreases significantly after one year (Chentsova-Dutton et al., 2002). Similar results were found by Shultz et al., (2003) and Grant et al., (2002) in dementia caregivers.

However, there is also evidence that, in some cases, FC´s debilitating symptoms are predictive of long-term morbidity, corroborating the second hypothesis. It explains that some groups, with higher caregiver burden, report increased risk of adaptation post-loss, including symptoms of mental disorders and grief complications (Beery et al. 1997; Kapari, Addington-Hall, Hotopf, 2010; Ferrario, Cardillo, Vicario, Balzarini & Zotti, 2004, Lai et al., 2014). This is, for example, the case of the spouses, especially the older women (Gilbar & Ben-Zur, 2002). A possible explanation is that this group is prone to high levels of involvement and intensity of care, particularly when the caregiver and the patient live alone and maintain an emotional distressing relationship (Nijboer, Triemstra, Tempelaar, Sanderman & van den Bos, 1999). Holtslander & Mcmillan (2011) showed that, associated with the severity of grief, symptoms of depression reached clinically significant values in 34% of the relatives, three months after the loss. Grant et al. (2002) found manifestations of depression and physiological changes 12 months after the loss. Robinson-Whelen et al. (2001) observed that the differences in relation to the control group, composed of non-caregivers, persisted for 3 years after death.

A third hypothesis states that the *anticipatory grief* process would intensify caregiving experience, but alleviate or reduce distress after the death (Schulz, Boerner & Hebert, 2008). This perspective assumes that when death is predictable, it allows a preparatory psychological and practical adjustment process that results in better post-loss outcomes. However, most research on caregiving bereavement has been carried out in dementia FC, which has a very particular end-of-life trajectory, marked by a long course of gradual and progressive functional and cognitive decline, which can contribute to this adjustment process (Marwit & Meuser, 2005). Compared to dementia, the cancer trajectory is often considered more acute and death is a more expected endpoint, thus suggesting that cancer FCs may have a different AG experience.

1.3. Anticipatory Grief: Origins and Current Conceptual Discussion

From the diagnosis of a life-threatening disease through the progressive physical and mental deterioration during the patient´s advancing illness, relatives are confronted with several losses, including the inevitable death. This experience has been termed anticipatory grief (AG), based on the assumption that the threat of death or separation will itself initiate a grief reaction. As originally conceived by Lindemann (1944), AG is a “safeguard against the impact of a sudden death notice” (p. 200) that facilitates adjustment to bereavement.

Since then, AG concept received great attention from clinicians and researchers. Particularly in palliative care, it has been seen as a part of the grief trajectory continuum, providing a potential opportunity to preventively intervene with each successive loss, thereby minimizing preventable complications of post-loss grief (Moon, 2016). However, research has found contradictory results concerning its beneficial effect in post-loss, generating controversy about the validity and the usefulness of this concept. Inconsistencies in the literature have been attributed to the lack of a precise and operational definition, along with methodological weaknesses of the studies (Fulton Madden & Minichiello, 1996; Fulton, 2003; Reynolds & Botha, 2006).

Early studies focused on the experience of terminally ill children and the process of anticipation of death by their mothers (Bozeman, Orbach & Sutherland, 1955; Natterson & Knudson, 1960; Friedman, 1963, 1967; Binger et al., 1969). AG was defined according to the length of the disease and the awareness of death. This process of adjustment was described throughout stages, from denial to acceptance of death. Then, it was considered that AG was a subjective experience, difficult to measure, and whose effects could be beneficial or harmful. In subsequent research (Clayton, Halikas, Maurice, & Robins, 1973; Ball, 1977; Carey, 1980) carried out with diverse populations, it was assumed that the issues related to the anticipation of loss referred generically to AG and that this process had a beneficial effect in adaptation to bereavement. Although there was no evidence for this phenomenon, a linear view of anticipatory grief was created as a continuous and irreversible process, analogous to the adjustment subsequent to death.

Aldrich (1974) was the first to clearly distinguish the two phenomena, stressing that AG consists of any grief before death. The author argued that the AG dynamic has many similar aspects to the post-death grief (PDG), but there are also some significant differences between them. One of them concerns their course and ending: unlike the PDG, which decreases over time and can be extended indefinitely, the AG tends to increase as the anticipated loss becomes imminent, determining its ending.

Rando (1986a) also made a major contribution to the development of the concept. The author states that, although distinct from bereavement, this process that precedes the death of a significant one is still grief. Yet, she recognizes the inadequacy of the term, since "anticipatory" suggests that the person is grieving just the anticipation of losses, ignoring the past and current losses. Likewise, “grief” implies some detachment towards the person who is dying, when, on the contrary, this period is marked by the hope that the patient continues to live and the desire to keep her/him in the future. The acceptance and reconciliation do not exist in anticipatory grief because the irreversible separation did not happen yet, but some of the losses caused by the terminally ill may have already been resolved.

Acknowledging the complexity of the phenomenon, Rando (1986a) proposes a multidimensional concept encompassing the anticipatory grief of the patient and family. In her definition, this experience involves the processes of mourning, coping, interaction, planning and psychosocial reorganization stimulated by an awareness of inevitable death of a significant other, as well as recognition of the losses incurred in the past, present and future. She adds that for this experience to be therapeutic, it is necessary to strike a delicate balance of mutually conflicting requirements, which implies that the person can simultaneously hold, let go and remain close to the loved one (pp. 24).

According to Fulton et al., (1996), Rando’s definition contributes to perpetuate the confusion around the term, for three reasons. First, the author believes that this is a semantic issue, instead of recognizing the conceptual difficulties. Second, she continues to designate this experience as anticipatory grief, although recognizing that this is an inappropriate term. Thirdly, using the word grief in the definition of anticipatory grief, puts into question its operationalization.

In a critical review of the literature, Sweeting & Gilhooly (1990) have reached the following conclusions:

- Despite the obvious emotional changes that result from the awareness of a terminal illness, there is not enough empirical support to claim that this is a similar phenomenon to the conventional grief;
- Studies that focused on the experience of parents of terminally ill children are consistent because they describe the same process;

- Later studies, in addition to differing in the definition, show great variability in research methodology concerning population (parents, widowers, children), number of interviews and analysis method, which explains the inconsistency of the results;
- AG is a subjective phenomenon that does not depend on the length of illness, nor is it directly related to the awareness of terminal disease;
- The physical and emotional damages caused by terminal illness may overcome the positive effect of AG in the subsequent adaptation process;
- The relationship between AG and subsequent death adjustment should be assessed according to individual differences.

A recent systematic analysis (Nielsen et al., 2016) defines grief during caregiving as a complex experience that involves the relationship with the patient, the changes resulting from the multiple loss related to the impending death, and the caregiver's coping with this situation. Results suggested that contrary to what was previously thought, AG serves no protective function in adjustment to loss. Instead, it was considered a risk factor, since high grief symptomatology prior to death was associated with low preparedness for the loss, and additional problems in bereavement, such as prolonged grief disorder and post-loss depression. Authors also stated that most research refers only to the presence of grief symptoms, resulting in an increased tendency to the use of terminology “pre-death grief”.

However, in a conceptual analysis about “pre-death grief” (Lindauer & Harvath, 2014), it was emphasized that this term concerns specifically to the intermittent and ambiguous losses along the illness course, typical of the dementia grief. Instead, AG is defined by the reaction to the irrevocable losses associated with the terminal phase of disease, thus implying the anticipation of impending death. In spite of these conceptual differences, these two terms are generally used interchangeably.

1.4. Anticipatory Grief Assessment

Developments in AG concept reflect the different assessment measures that have been used to evaluate the construct. Previous assessment tools tried to capture the multidimensionality of AG, covering practical, emotional, social, and relational issues. In spite of the common focus on the caregiver's feelings toward illness and the risk of losing the relative, they lack congruity in thematic content (Nielsen, 2016). These instruments are generally extensive and focus on dementia FC population. Yet, recently, modified and shorter versions of these tools were developed and adapted to other populations, namely cancer and palliative care FC. Other scales were recently created, focusing on more specific aspects of anticipatory grief. In particular, PG-12 has been widely used to assess the symptoms of pre-death grief. However, according to a review about bereavement risk assessment measures, in spite of the majority having acceptable psychometric properties, feasibility for palliative care is questionable due to its specific circumstances (Sealey, Breen, O´Connor, Aoun, 2015). The instrument's characteristics are described below.

Anticipatory Grief Scale (AGS). Created by Theut, Jordan, Ross and Deutsch (1991). This instrument consists of 27 items measuring anticipatory grief on a Likert scale, ranging from 1 (strongly disagree) to 5 (strongly agree). Higher scores in this questionnaire indicate higher levels of anticipatory grief. The items were constructed based in a combination of clinical experience and other instruments measuring grief. It was originally developed to be used in dementia FC, although the wording can be changed and used in other contexts. In spite of being internationally used, the original AGS still lacks validity, and it is used as a unidimensional scale. A modified version of this instrument was recently developed by Holm, Alvariza, Furst, Ohlen & Arestedt (2019), in a sample of FC in palliative care (AG-13). It includes 13 items and presents two factors: Behavioral reactions and Emotional reactions, both showing excellent Cronbach's alpha coefficient (.83 and .84, respectively). Factors are only moderately correlated, suggesting that they measure two separate, but related constructs.

Meuser and Marwit Caregiver Grief Inventory (MM-CGI). Developed by Marwit & Meuser, (2005) specifically for dementia FC. The original scale is composed of 50 items and three subscales, all with high internal consistency: (1) Personal sacrifice and burden (18 items, measuring losses experienced as a result from caregiving; Cronbach's alpha: .93); (2) Heartfelt Sadness and longing (15 items measuring intrapersonal emotional reactions in response to caregiving; Cronbach's alpha: .90); (3) Worry and Felt Isolation (17 items measuring the feelings of losing connections with, and support from others; Cronbach's alpha: .91). A short-form of this instrument, also validated for dementia FC, includes 18 items, with six items per factor. Another version of this instrument was adapted and validated for cancer FC (Marwit, Chibnall, Dougherty, Jenkins & Shawgo, 2008), also showing high internal consistency (Cronbach's alpha range from .90 for Worry and Felt Isolation; 0.94 for Heartfelt Sadness and longing, 0.95 for Personal sacrifice and burden, and 0.96 for total scale).

Prolonged Grief Disorder Questionnaire – Pre-death Version (PG-12). Diagnostic tool adapted from (PG-13) to measure pre-death grief. It is based on the diagnostic criteria of prolonged grief disorder (PGD) (Prigerson *et al*., 2009). This instrument is composed of 11 items (5-point Likert scale) and one dichotomous response. Researchers studying caregiver grief have employed the PG-12 as a reliable tool for early identification of those at risk of developing post-loss PGD. Separation anxiety is identified as a key criterion, along with other emotional, cognitive and social symptoms, such as shock, trouble accepting the illness, confusion in life, numbness and significant reduction in social and occupational functioning.

Caregiver Grief Scale (CGS). Instrument created by Meichsner, Schinköthe & Wilz (2015) for dementia caregiver grief. It gathers items adapted from other grief instruments and new items that were developed from statements made by caregivers themselves. The CGS comprises 11 items (5-point Likert scale), assessing 4 significant aspects of caregiver grief: emotional pain (experience of grief and other painful emotions); relational loss (losses related to the relationship which are central to the caregiver's grief); absolute loss (death and the anticipation of the future without the person), and acceptance of loss (acceptance of dementia and of open expression of grief). The last aspect takes into account that caregivers often avoid expressing or even feeling grief while the care recipient is still alive, thus recognizing the experience of disenfranchised grief. A high internal consistency and reliability was found for the total scale (Cronbach's α = .89).

1.5. Caregiver´s Prolonged Grief Disorder Symptoms

Prolonged Grief Disorder (PGD), also known as complicated grief (CG), is a condition of intense grief manifestations that persists more than six months after the loss, associated with significant social and occupation impairment. The diagnosis of "Prolonged Grief Disorder" was recently accepted as a mental disorder in ICD-11 (WHO, 2018) with the following criteria:

A) Persistent and pervasive longing for the deceased;

B) Persistent and pervasive preoccupation with the deceased and intense emotional pain, which includes the following manifestations:

- Sadness, guilt, anger, denial, blame
- Difficulty accepting death
- Feeling one has lost a part of one´s self
- Inability to experience positive mood
- Emotional numbness
- Difficulty in engaging with social and other activities

c) Persisted for an abnormally long period of time (more than 6 months at a minimum): following the loss, clearly exceeding expected social, cultural or religious norms for the individual’s culture and context. Grief reactions that have persisted for longer periods that are within a normative period of grieving given the person’s cultural and religious context are viewed as normal bereavement responses and are not assigned a diagnosis.

- The disturbance causes significant impairment in personal, family, social, educational, occupational or other important areas of functioning.

Incidence of PGD in bereaved caregivers range between 6% to 40% (Ghesquiere, Haidar & Shear, 2011; Guldin, Vedsted & Zachariae, Olesen & Jensen, 2012; Tsai et al., 2016), comparing to 2.4% in the general population (Fujisawa et al., 2010). This suggest that the FC population face unique risks for developing grief complications due to the circumstances of caregiving.

In the phase prior to death, PGD symptoms ranges from 12.5%, in a Danish nationwide sample of cancer FC (n=2865; Nielsen et al, 2017a), 15% in palliative care FC (n= 381; Hudson et al., 2011), and 38.5% in caregivers of patients in vegetative states (n=52;

Bastianelli, Gius, & Cipolletta, 2016). A recent nationwide prospective study reported that levels of grief and depressive symptoms were higher preloss than in bereavement, suggesting that the caregiver distress exacerbates grief manifestations. It was also found that severe preloss grief symptoms are predictive of post-loss prolonged grief disorder (Nielsen et al., 2017b).

1.6. Factors Influencing Caregiver´s Grief Response

Below, we analyse aspects that affect the caregiver´s grief outcome, both pre and post-loss. First, circumstantial aspects related to the caregiving context will be presented, referring specifically to caregiver burden, forewarning and preparation to death. In addition to definition of terms, empirical results are displayed demonstrating the association of the referred variables with the grief manifestations or mental health outcomes. Then, interpersonal and intrapersonal aspects are discussed, highlighting individual differences in AG phenomenology and their influence in the bereavement course.

1.6.1. Circumstantial factors

1.6.1.1. Caregiver burden

Difficult circumstances of caring, such as caregiver burden, were associated to higher pre-death symptoms (Nielsen et al., 2017). Caregiver burden is considered “a multidimensional biopsychosocial reaction resulting from an imbalance of care demands relative to caregivers’ personal time, social roles, physical and emotional states, financial resources, and formal care resources given the other multiple roles they fulfil” (Given et al., 2001, p.5). Besides the practical and logistic dimensions inherent to caregiving, the burden also manifests through physical and mental health effects (Stenberg, Ruland & Miaskowski, 2010), as well as economic costs to the family (Rabow, Hauser & Adams, 2004). The high levels of caregiver burden in FC of cancer patients are widely documented (Chappell & Reid, 2004; Given, Wyatt, Given, Gift & Sherwood, 2004; Sharpe, Buttow, Smith, Mcconnell & Clarke, 2004; Schubart, Kinzie & Farace, 2008).

However, as stressed by Beery et al., (1997), the perception of overload is a subjective response to the act of caring, so it is not directly related to the amount of tasks. In PC, the caregiver burden is particularly associated with the acute exacerbation of symptoms and high levels of depression (Grov, Fosså, Sørebø, & Dahl, 2006; O'Hara et al., 2010). There is also evidence that, compared to the curative treatment phase, FCs in PC have lower quality of life and poorer health (Weitzner, McMillan & Jacobsen, 1999) as a reflection of the deterioration of the patient´s general state . In face of proximity of death, the spouses are the group that shows the highest level of burden (Doorenbos et al., 2007).

Generally, studies suggest that caregivers of terminally ill spouses who had higher levels of burden pre-loss present heightened risk of grief complications, pre and post-death (Beery et al., 1997; Schulz, Boerner, Shear, Zhang & Gitlin, 2006; Lobb et al., 2010; Neilsen, 2017b; Große, Treml & Kersting, 2018). However, it was also found that high subjective caregiving burden was associated with better adjustment in bereavement, corresponding to a response of relief from the demanding end-of-life caregiving tasks (Tsai et al., 2016).

1.6.1.2. Forewarning and preparation to death

Forewarning death is often evaluated according to the family´s time since awareness that the disease is fatal until the patient dies. The empirical results on the impact of this variable are inconsistent. For example, Butler et al., (2005) showed that the anticipation of death during illness induces symptoms of trauma only prior to death; but there is no evidence of its influence in the post-death symptoms. Byrne & Raphael (1994, 1997) studied prospectively the population of elderly male widows 6 weeks, 6 and 13 months after the loss. The results indicated that anticipating death does not contributed to anxiety, and predicted the intensity of grief only 6 weeks after the loss. Similarly, Marshall, Catanzaro & Lamb (1997) research with two groups of students revealed that the group that anticipated death had fewer symptoms and greater acceptance of death compared with those who reported having suffered an unanticipated death, which corresponds to a death awareness of less than a week. However, when controlling for age, the relation between the death anticipation and subsequent adjustment disappears, suggesting that this effect only occurs in the young population.

On the contrary, Valdimarsdóttir, Helgason, Fürst, Adolfsson & Steineck (2004) found that widows who reported 24 hours of awareness of death or less described this event as a shock and had twice the risk of anxiety two to four years after their husband's death, compared with those who had six months of awareness. A year or more of death awareness is associated with more risks: exhaustion and remorse related with the wish of the patient's death. According to these data, optimal time awareness is three to six months before death. An equivalent study of Carr, House, Wortman, Nesse & Kessler (2001) with the population of elderly widowers confirmed that prolonged anticipation of death was associated with high anxiety at 6 and 18 months of grief. Sudden death, where there is no prior notice, was predictive of more intrusive thoughts, but less anxiety. However, anticipating death had no influence on depression, anger, shock or general expressions of grief at 6 or 18 months after the death.

According to O'Bryant (1995), people who anticipated death were also those who provided care to the patient and had a greater awareness of their suffering. A positive but moderate relationship between the prediction of death and the discussion of issues relating to survivors´ future conditions was also found. The author attributes this result to the difficulty in talking about material matters with the spouses in the imminence of their death, though it is important for the survivors’ future. However, those who anticipated death and discussed financial matters obtained higher values in the positive affect scale.

The time of caregiving also influences, in an inverse way, the pre-death grief, since the intensity of the manifestations tends to decrease after a long period of care provision. In spouses of cancer patients, there is evidence that less time providing care and less patient´s functional losses are associated with higher levels of PGD (Burton et al., 2008). Based on these results, the authors suggested that the factor that most protects the family from experiencing intense grief reactions is the possibility to prepare for the loss resulting from the perception of growing dependence of the patient and the provision of continuing care in daily living tasks. In a longitudinal study, Barry, Kasl & Prigerson (2002) also detected an association between perceived lack of preparation for death and the incidence of complicated grief at four and nine months. This correlation is also significant for depression, but only at 9 months; there is no relationship with the manifestations of Post-traumatic stress disorder at 4 months.

When properly informed and involved in end-of-life decisions, the person is more likely to feel prepared for death (Apatira et al., 2008; Hebert, Schulz, Copeland & Arnold (2009). However, each family member has his or her own understanding of what it is to be prepared for death: for some, it means making decisions about early directives of will, for others it involves finding spiritual peace. In addition to the prognostic aspects, this preparation should include the discussion of end-of-life care and emotional and spiritual needs, conflict management, the expression of feelings of loss and discussion of spiritual concerns (Hebert, Prigerson, Schulz & Arnold, 2006).

Accordingly, Steinhauser et al., (2001) stated that the preparation for death is a multidimensional concept that implies: (1) Medical aspects: to know the signs and symptoms that are expected in the terminal phase; (2) Psychosocial aspects: being in relation with family and friends and expressing emotions and feelings of mourning; (3) Spiritual aspects: discuss the meaning of death and pray or perform religious rituals; (4) Practical aspects: planning the funeral. McLeod-Sordjan (2016) concluded that the preparation for death implies awareness and acceptance of the end of life, consolidated in a plan on end-of-life care. The greater preparation for death has been consistently associated with higher quality and more dignity of death (Steinhauser et al., 2001, Proulx & Jacelon 2004; Lokker, van Zuylen, Veerbeek, van der Rijt & van der Heide, 2012)

In its emotional component, preparation for death requires the acceptance of the end of the relationship as it was previously known, a process that is usually called "letting go." This term was defined by Lowey (2008) as a change of thought that implies the recognition and awareness of the inevitability of the death of the significant other, allowing the natural progression of events without making an attempt to prolong life. As a result, a person may experience death as an integral part of the life cycle without guilt or remorse over decisions that have been made. Thus, according to the same author, this process simultaneously involves some sense of liberation from the emotional constraints usually experienced in the phase prior to that consciousness. In the same way, the person can also release the patient and experience peace, allowing the integration of loss and personal growth. This process can begin in the final phase of the patient's life or only after death, during the bereavement period.

1.6.2. Relational factors

1.6.2.1. Kinship

Being a spouse and living with the care recipient were associated with high intensity of grief (Liew, 2016). Studies with the population of spouses (Costello, 1999; Saldinger & Cain, 2006; Gunnarsson & Ohlen, 2006, Sutherland, 2009) referred to the loss of intimacy and common objectives, as well as the loss of a friend, a confidant and a sexual partner. As spouses live in the same household, sharing daily responsibilities and experiences, marital relationship is usually highly intimate and interdepend, resulting in greater difficulty in adjusting to the partner´s illness and death. However, it was also found that spouses and adult-daughters who care for their terminally ill cancer mothers did not differ on levels of grief and despair 90 days after the patient´s death. The impact of this experience was particularly high for those daughters who live with their mother, suggesting that the grief response is related to the amount and nature of interaction within a shared household (Bernard & Guarnaccia, 2002).

Ziemba and Lynch-Sauer (2005) also stressed the aspects affecting the daughter’s grief. One of them relates to the reversal of roles during caregiving, because instead of receiving the parents´ support, they must provide it, now. Furthermore, there is a change in power dynamics between parents and daughters, since the latter are now taking the responsibility for decision making. However, there are cases where parents tend to infantilize daughters, so they feel they are experiencing a return to childhood. Consequently, the provision of care is often experienced with a mixture of anger and guilt. Moreover, the identification with the parent generates fears related to their own age, with the loss of health and lineage. Chapman and Pepler (1998) supported the idea that adult children express more anger than spouses.

1.6.2.2. Quality of relationship

Caregivers who describe better relation with the patient experience less burden and less negative impact in health (Yates, Tennstedt & Chang, 1999; Francis et al., 2010). One of the most influential aspects in the quality of the relationship is communication. In a meta-analysis of the couple's relationship in the disease situation, it was shown that better communication between couples – which includes talking about the relationship, discussing constructively about problems and the habit of exposing one's feelings – is associated with a more positive experience in caregiving and has a protective effect on the psychological distress of both, FC and patient (Li & Loke, 2013).

The quality of the previous relationship also influences the caregiving experience. A study carried out with dementia patients (Steadman, Tremont & Davis, 2007) noted that those who were less satisfied with the previous relationship tended to react more negatively to the disruptive behaviours of the patient and to present higher values of caregiver burden. In these cases, communication is also more restricted. Compared with the previous relationship, most caregivers reported that the current relationship had deteriorated, especially at the level of communication. Inhibitions to the open expression of feelings, caused by the asymmetry in the process of anticipating death, affect the intimacy of the relationship. In spite of this, many of these spouses reported that they felt closer to the patient than in the past (de Vugt et al., 2003). Those who felt more affective deprivation experienced more resentment related to the lack of equity between give-and-take in the caregiver relationship and referred less satisfaction with the quality of the relationship (Kuijer, Buunk & Ybema, 2001). In another study, perceived lack of equity was associated with depressive symptoms (Ybema, Kuijer, Buunk, DeJong & Sanderman, 2001).

Consistent with these results, Reblin et al. (2015) stressed that most of the couple's relationships in advanced disease are marked by some ambivalence. In the context of a caregiving relationship, ambivalence is defined as the simultaneous experience of positive and negative feelings about the care recipient. Those who find themselves more exhausted tend to attribute more negative feelings to their spouse (Reblin et al., 2015). In another study conducted with the Alzheimer's patient caregiver population, ambivalence was found to be higher when family members dealt with disturbing behaviours. Ambivalent feelings were related to more experience of guilt, which contributed to the manifestation of depressive symptoms (Losada et al., 2018). Likewise, ambivalent relationship with the patient was found to be correlated with grief complications (Dumont, Dumont & Mongeau, 2008).

The relational dependency was also associated to increased difficulties in adjusting to loss. Burke et al., (2015) stated that those family members who were struggling most with AG reported great tendency to rely heavily on the person they were about to lose. Circumstances of terminal illness may contribute to the intensification of relationship. Especially the spouses are exclusively focused in the survival of the patient, and often forget the previous characteristics of that person. But the proximity of a spouse´s death also induces the surviving in a life review, searching for what they had in common and the meaning of relationship. They review the way their spouses contributed to the family and how they influenced the life of their elements (Sutherland, 2009). Usually, caregivers like to remember the relative´s characteristics previous to the disease, showing photos and talking about the person he/she once was. Many spouses experience the anticipation of death as a rich time of great sharing, sincere respect and love (Swensen & Fuller, 1992; Gunnarsson & Ohlen, 2006; Sutherland, 2009; Clukey, 2007). Others retrospectively regret having missed the opportunity to achieve more closeness in the relationship (Saldinger & Cain, 2005). Preoccupation for not spending enough time with the patient was associated to grief complications post-death (Aoyama et al., 2018).

1.6.3. Intrapersonal factors

1.6.3.1. Demographic differences in stress and coping styles

Findings regarding gender differences suggest that women have higher values of despair, anger, loss of control, somatization and death anxiety and use more emotional coping strategies (Chapman & Pepler, 1998). On the other hand, men show more denial (Fleming, 1998). However, another study (Carr, House, Wortman, Nesse & Kessler, 2001) indicates that men who anticipate the death of the spouse express more longing for the deceased, associated with greater proximity and social isolation; by contrast, in women, expressions of longing are more intense in case of sudden death. Concerning age differences, Liu & Lai (2006) evidenced that older caregivers had higher values in the anticipatory grief scale. However, young people use more emotional coping strategies compared to older, and so they are more prone to despair, anger, hostility and lack of control (Chapman & Pepler, 1998).

1.6.3.2. Dispositional factors and emotional states

A nationwide study stated that pre-death depressive symptoms were associated to severe pre-loss grief symptoms, and were the key risk factor for maladjustment in bereavement, contributing to PGD and depressive symptoms post-loss (Nielsen et al., 2017a, 2017b). However, as stated by Francis, Kypriotakis, O´Toole, Bowman & Rose (2015), the risk of depression in bereavement is mediated by the severity of grief and it is little dependent from contextual factors of caregiving. Other aspects associated to problematic responses pre and post-death are the higher levels of neuroticism[2] and insecure avoidant attachment style[3] (Burke et al., 2015). Specifically, the attachment dimension "preoccupation with relationships" was considered a good predictor of prolonged grief risk (Lai et al., 2014).

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[2] Tendency to worry excessively

[3] Characterized by less comfort in close relationships and difficulty with intimacy

2. THEORETICAL FRAMEWORK

The pioneering work of Freud (1917), in "Mourning and Melancholia", drew attention to the intrapsychic dynamic of the grief work, stating that the bereaved must go through a painful process, expressing the sadness of the loss, and gradually emotionally detaching from the object of loss ("dechatesis") in order to reinvest the psychic energy in new relationships. This view influenced the literature on grief during decades, leading to the idea that the grief process develops through phases, stages, or normative and universal tasks (Lindemann, 1944; Kübler-Ross, 1969; Worden, 1982; Rando, 1986b; Sanders, 1989; Parkes, 1996).

However, the diversity of grief manifestations and their different trajectories of evolution (Zisook, Devaul & Click, 1982; Bonanno & Kaltman, 2001; Bonanno et al., 2002) challenged the assumption of a predictable and linear trajectory toward recovery and conducted to the perspective that grief is mainly individual and transformative. Most people who face major losses struggle with great distress during long time, displaying wide diversity of responses (Wortman & Silver, 1989), but instead of restoring the previous psychological, they experiment internal and relational changes.

Bowlby´s Attachment Theory (1969/1988) provides a useful framework for understanding individual differences in responses to loss. Following, we review the foundations and principles of this theory and present some of the empirical findings, as well as its application in contemporary bereavement conceptual models. Then, we introduce Emotion Regulation theory, referring results that elucidate about its role in adjustment to loss. Finally, the Integrative Neurobiological Model offers a comprehensive view of how those two theories articulate to explain individual differences in modulating emotional response to stress.

2.1. Attachment Theory

Bowlby (1969/1988) stated that the human being is endowed with an innate attachment system that motivates the subject to seek proximity, protection and comfort with the significant other in situations of threat. Hence, attachment fulfils a dual function: to guarantee survival and to regulate the individual's level of anxiety. This theory was largely based on observing the behavior of children who were separated from their parents in residential day care centers. Their reactions to the separation and subsequent reunion with the primary caregiver lead the authors to conclude about the universal need for contact and the importance of quality care for the child's safety.

The functioning of the attachment system varies depending on the mental representations formed throughout development based on the responsiveness of primary caregivers. During the first phase of life, child safety depends largely on the closeness and sensitivity of caregivers to meet their needs. If the caregiver is available, affectionate and consistent, the child learns that others are trustworthy. As a result, he/she can explore the world and develop social interactions, feeling safe and comfortable knowing that the caregiver is available if needed. If, on the contrary, the caregiver is unavailable, insensitive, rejecting or unpredictable, the child realizes that he/she cannot count on him/her for comfort and support, thus creating a negative representation of interaction with the other (Ainsworth, 1978). Over time, repeated experiences with primary attachment figures are internalized, forming a knowledge structure called by Bowlby (1973) as internal models. They will shape expectations, attitudes and beliefs about future relationships, influencing how one relates to others throughout the life cycle. Internal models are composed of dichotomous representations, positive or negative, of the other (whether or not it is reliable and available) and the self (whether or not one deserves the love and support of the other).

Beyond the influence of developmental aspects, research has been highlighting the role of emotional regulation as a mediator of attachment behavior in response to distress and loss events (Mikulincer, Shaver & Pereg, 2003; Mikulincer & Shaver, 2018). The person is considered secure when he/she has a positive representation of oneself and the other, which makes him/her comfortable with intimacy and autonomy. In stressful situations, this person is willing to activate the attachment system for protection and comfort, although still remaining confident in their ability to manage their own negative emotions and those of others. This constructive way of thinking, feeling, and acting is associated with resilience and positive affective states (Caldwell & Shaver, 2012).

However, when negative representations of oneself or the other were created, forms of secondary regulation are developed to compensate for attachment insecurity (as opposed to the primary one, which is the direct search for support). Such strategies may be used to reinforce or inhibit proximity seeking behaviours, which correspond, respectively, to the hyperactivation and deactivation of the attachment system (Cassidy & Kobak, 1988). Secondary regulation strategies involve a variety of cognitive, affective and behavioral mechanisms that exacerbate, obstruct or suppress the activation and expression of emotions (Mikulincer, Shaver & Pereg, 2003; Mikulincer & Shaver, 2008).

Hyperactivation of the attachment system is equivalent to the protest behavior (Bowlby, 1982) and includes cognitive and behavioral efforts to grasp, control, and coerce the other. These behaviours are characteristic of highly anxious attachments, specifically the insecure-preoccupied style. Given their insecurity about the other's love, these people are generally very dependent on protection (Shaver & Mikulincer, 2002) and tend to be hypersensitive to signs of possible rejection or abandonment (Collins & Feeney, 2000). Therefore, they have an extreme need to ensure contact with the significant other and to restore their sense of belonging. When faced with stressors that threaten the relationship, these individuals tend to increase the requests for support. However, due to their negative representation of the other, they tend to distrust or devalue possible support responses, thus creating a cycle of frustration that leads to a state of dissatisfaction and depression (Shaver, Schachner & Mikulincer, 2005).

On the contrary, hipoactivation of the attachment system implies the inhibition of the natural predisposition to seek proximity in the other, as well as the suppression of any threats that may activate the need for protection. These people, designated by Bowlby (1982) as compulsively self-sufficient, correspond to the insecure-avoidant style. They experience discomfort in proximity and intimacy, so they tend to be autonomous and distant in the relationship with others and fight for control. The pattern of highly-avoidant attachment, referred as avoidant-dismissed, corresponds, in Bartholomew's (1990) perspective, to a complex strategy of attachment needs’ denial. These individuals tend to devalue the importance of attachment and to shift attention to performance as a way of passively avoiding closeness in the relationship.

However, as stated by Bartholomew (1990), avoidance may also be related to fear of intimacy. This distinction gave rise to the fourth attachment style - avoidant-preoccupied style. These people desire social contact and intimacy, but they experience great mistrust and fear of rejection. To prevent the possibility of being rejected, they actively avoid social situations and intimate relationships in which they feel vulnerable.

The fifth attachment style corresponds to the disorganized behavior. According to Cassidy & Mohr (2001), these persons could not organize a coherent attachment behavior, since the protection figure is simultaneously the agent of threat. In consequence, they have a propensity to engage in competitive and incompatible approach-avoidance processes, which makes them particularly vulnerable to stressful situations. Disorganized attachment style has been consistently associated to more stress management difficulties, more dissociative behaviours, and a high risk of lifelong externalization problems (Van Ijzendoorn et al, 1999).

Attachment´s theory has been widely validated as a useful model to organize observations concerning relationship, emotional regulation, caregiving and loss (e.g., Shaver & Brennan, 1992; Cassidy, 1994; Diehl et al., 1998; Brennan & Shaver, 1998; Feeney & Collins, 2001; Diamond & Hicks, 2005; Kim & Carver, 2007; Stroebe, Schut & Boerner, 2010; Karreman & Vingerhoet, 2012; Maccallum & Bryant, 2013; Lai et al., 2014; Schenck et al., 2015; Braun et al., 2016). However, some of the theoretical assumptions have been reformulated based on empirical evidence.

One of the most important aspects refers to the deterministic view underlying the idea that the experience of early relationship with parents is decisive in the adult attachment pattern. This position was initially supported by the results of retrospective studies that were based on participants' reports of their childhood attachment experience (e.g., Collins & Read, 1990). Subsequently, longitudinal studies prospectively verified the influence of maternal care quality on long-term attachment (Sroufe, 2005; Dinero, Conger, Shaver, Widaman, & Larsen-Rife, 2008; Fraley, Roisman, Booth-LaForce, Owen & Holland, 2013; Salo, Jokela, Lehtimäki & Keltikangas-Järvinen, 2011). A meta-analysis confirmed the stability in the pattern of attachment from childhood to adulthood, but points out that the effect is moderate, suggesting some permeability of the attachment system to adult relationship experiences (Fraley, 2002).

This means that although residues of the parenting pattern are found in future relationships, people develop specific attachment styles adapted to different relational contexts (Fraley, Vicary, Brumbaugh & Roisman 2011). For example, someone who has a negative representation of parents may still develop a safe and satisfying romantic relationship or, on the contrary, if they have had a safe parenting may experience insecurity in the context of romantic relationships. According to Fraley & Roisman (2019), this does not necessarily imply a change in the pattern of attachment, but rather an adaptation of the internal schemas, which become more or less active depending on the relational context.

2.1.1. Attachment in Loss

Bowlby (1973, 1980) originally described grief as a sequence of normative reactions in face of the separation from an attachment figure. They include an initial phase of protest, in which one tries to recover the missing person. It is followed by despair and depression, finally leading to the emotional detachment. Nevertheless, his most relevant contribute lies in the perspective that the way people grieve is partly influenced by their attachment story. Specifically, Bowlby (1980) stated that individuals who are anxious-ambivalent attached would be more likely to show prolonged or chronic grief manifestations, whereas those who avoid or deny relational needs would be prone to express few overt signs of grief. Later, attachment implications in bereavement have been widely studied, giving rise to a theoretical framework on individual differences in adult response to loss (Wayment & Vierthaler, 2002; Fraley & Bonanno, 2004; Shear et al., 2007; Wijngaards-de Meij et al., 2007; Kho, Kane, Priddis & Hudson, 2015; Yu, He, Xu, Wang & Prigerson, 2016).

Literature shows that securely attached people tend to show a decrease in grief manifestations over time (Fraley & Bonanno, 2004; Levi-Belz & Lev-Ari, 2019). On the contrary, those with an insecure-preoccupied attachment style present heightened distress in response to loss, including more anxiety, feelings of rejection and self-blame (Mayseless, Danieli & Sharabany, 1996; Wayment & Vierthaler, 2002; Fraley & Bonanno, 2004; Field & Sundin, 2001; Jerga, Shaver & Wikinson, 2011). In respect to insecure-avoidant people, results are more controversial. When exposed to relational stressors, they tend to become disconnected at the emotional, cognitive and behavioral levels and react with less emotional reactivity to separation and loss (Mayseless et al., 1996). A study that assessed the mediating effect of attachment-related thoughts (Kho et al., 2015) suggests that this group of individuals show less refusal in accepting loss, which is reflected in fewer manifestations of longing for the deceased. These results corroborate the assumption that avoidant individuals tend to minimize attachment-related thoughts, thus experiencing less emotional distress in reaction to loss. However, as suggested by a study conducted with widowers (Mancini, Robinaugh, Shear & Bonanno, 2009), the avoidant style is only predictive of less complicated grief symptoms when the person has experienced a high quality marital relationship, otherwise this protective effect is not true. This can be explained by their difficulty in dealing with relational aspects. Maccallum & Bryant (2018) argue that this group of individuals is particularly prone to present other grief complications, such as depression, due to their tendency to inhibit the search for social support and create new relationships.

Finally, those with a disorganized attachment present lapses in reasoning, involving disbelief that the other is dead and intrusive thoughts that indicate a failure to integrate the loss (Field, 2006; Thomson, 2010). Reactions of traumatic distress to loss include surprise, confusion and deep impotence (Sanderson, Lobb, Mowll, Butow, Mcgowan & Price, 2013). Besides, they present signs of increased sympathetic nervous system such as recurrent dreams, tachycardia, disruption of sleep and appetite (Hagemann, Waldstein, & Thayer, 2003).

Stroebe, Schut & Boerner (2010) described the links between attachment styles and contemporary grief models. For example, in understanding the impact of *Continuing bonds* (Klass, Silverman & Nickman, 1996), they referred that persons with secure attachment styles are able to retain attachment to the deceased person and to use a continued connection to get comfort and guidance, based in positive working models. Finally, they relocate the lost relationship, and maintain an internal source of security. The insecure-anxious individuals are prone to hyperactivity because they worry about the other´s love for them, so they persistently cling and long for the deceased, as a way to maintain the bond and regain physical contact. Consequently, they fail to relocate the lost relationship and adjust to the new reality. On the contrary, avoidant people are unable to maintain symbolic bonds with the deceased. Oscillation between hyper and deactivating tendencies results in no clear strategy concerning continuing (clinging to) or relinquishing (detaching from) their bond with the deceased loved one.

Stroebe and Schut's (1999) *Dual Process Model* posited that adjustment to loss requires oscillation between loss-oriented coping, in which the person is directly focused in the lost relationship (remembering the deceased), and restauration-oriented coping, focused on secondary stressors that derive from bereavement (e.g., the change in identity from husband to widower). As stated by the authors (Stroebe, Schut & Boerner, 2010), a person with a secure attachment style would oscillate easily between these two dimensions, and even though intense grief reaction may be expected, this flexible coping style facilitates the progressive adaption to the new reality. The insecure-anxious pattern is predominantly focused in loss-oriented coping, leading to chronic grief manifestations. On the other hand, the insecure-dismissing is prone to restauration-oriented coping, which may evolve to absent or inhibit grief. Therefore, the process of transforming the relationship to the deceased involves elements of both disengagement and continuing connection, as well as the confrontation and avoidance of emotion.

Integrating the role of trauma and avoidance in Attachment theory, Shear et al., (2007) developed a model that stipulates that the death of an attachment figure represents a moment of disruption in the person´s inner world and in the relationships with others. It justifies the high distress response associated to the acute grief, as well as the difficulty in exploring the external reality. In most cases, manifestations of acute grief dissolve as attachment schemes are reviewed and separation is integrated into long-term memory. However, in other situations, this transition process is blocked by maladaptive regulation mechanisms, such as the avoidance of memories of death, which prevent the integration of the event of loss, leading to the maintenance and exacerbation of grief symptoms.

2.2. Emotion Regulation Theory

Although there is a considerable disagreement about the concept of emotion, some consensus was achieved in recent decades about its dynamic and functional nature. Frijda's theory (1987, 1989) gave an important contribution to the development of this perspective by describing emotion as a multifaceted process that results from the assessment of a stimulus and determining the tendency to a response. According to this author, emotions result from an assessment, that is, from a process of attribution of emotional meanings which links an event to the subject's self-reported experience. They consequently influence affect (perception of being pleasant or unpleasant), body activation and subject's behavioral response. One of the important implications of this conceptualization is that emotions have both intrapersonal and interpersonal regulatory consequences (Campos, Campos & Barret, 1989).

Emotion regulation is a recent concept that has attracted increasing interest in research. Emotional regulation integrates deliberate stress response processes, similar to those measured in self-reported coping scales, as well as the more spontaneous or automatic processes - defence mechanisms - that are unlikely to be accessible to consciousness, and therefore cannot easily be captured by self-reporting tools (Bonanno & Kaltman, 2000). This is also the position of Gross (1998), who stipulates that the processes of regulation of emotions can be automatic or controlled, conscious or unconscious. However, unlike coping and defense mechanisms, which have the sole purpose of reducing tension, emotional regulation aims to increase, maintain, or diminish negative and positive emotions. Another distinctive characteristic of emotional regulation concerns the expressive and physiological aspects of emotions (Gross, 1999).

Gross (1998) defines emotion regulation as "the process by which individuals influence the emotions they have, when they have them, and how they experience and express those emotions" (275). On the other hand, Thompson (1994) refers to emotion regulation as "the intrinsic and extrinsic process responsible for monitoring, evaluating and modifying emotional reactions, especially in aspects of intensity and temporality, to achieve the goals". This definition contemplates several important characteristics of the process of emotion regulation: (1) mechanisms of hyperactivation, inhibition and maintenance of emotions; (2) self-regulation and hetero-regulation, through various external influences that interfere in the process of regulating emotions; (3) interference in the emotion, the latency of the response, its intensity, limits, persistence and lability; (4) functionality, taking into account the objectives of the subject in the specific circumstances.

According to the definition of Garnefski, Kraaij and Spinhoven (2001), emotion regulation can be understood as the wide range of biological, social, behavioral and cognitive processes, the latter of a conscious or unconscious nature. At the physiological level, emotions are regulated, for example, by increasing heart rate and breathing activity. At the emotional level, through the search for emotional and instrumental support. On the behavioral level, strategies such as crying, screaming, hyperactivity or isolation are used. Finally, at the cognitive level, there are unconscious processes, such as selective attention, memory distortion, negation, and projection; on the other hand, conscious cognitive processes include rumination, catastrophic thinking and blame.

2.2.1. Emotion Regulation in Loss

Bonanno and collaborators (e.g., Bonanno, Keltner, Holen & Horowitz, 1995; Bonanno & Keltner; 1997) emphasized the expressive dimension of emotions in adaptation to loss. For example, in a longitudinal study (Bonanno and Keltner, 1997), the facial expressions of a group of widowers were registered while describing their previous relationship with the deceased spouse. Facial expressions were coded and compared prospectively with the severity of grief at 6, 14, and 25 months after the loss. The results revealed that open expression of negative emotions (anger, fear and rejection) was clearly correlated with grief severity and perceived poor health. Based on these data, the authors conclude that, contrary to what was postulated by the theory of *grief work*, emotional grief expression is not adaptive in all subjects, so there is some benefit in the reduced experience and expression of negative emotions, since it facilitates stress response.

These findings are supported by the results of a previous study (Bonanno, Keltner, Holen & Horowitz, 1995), in which emotional avoidance, operationalized as a dissociative verbal-autonomic response pattern (reduced emotional experience associated with high cardiovascular reactivity) has shown adaptive value in grief. The same subjects describing the relationship with the deceased spouse were subject to physiological autonomic reactivity assessment and completed self-report emotion scales. These measurements were compared with grief severity and physical symptoms at 6 and 14 months of grief. Results showed that participants with this dissociative pattern reported minimal grief symptoms over 14 months. In addition, somatic symptom levels considered elevated at 6 months had already decreased significantly at 14 months.

Analysing individual differences in grief adaptation, Coifman, Bonanno and Eshkol (2007) concluded that individuals considered resilient in the face of significant loss are those who are most apt to cope with the affective complexity of situations. In other words, resilience implies the ability to experience positive and negative affect relatively independently. In grief, this means that one frees oneself from the negative emotions generated by a situation that evoked memories of loss to the experience and expression of other emotions, flexibly, as the context changes. In another study (Gupta & Bonanno, 2011), the participants were enrolled to perform a task of expressive flexibility, in which they were asked to amplify or suppress their expressions or to behave normally in the face of evocative images. Results showed that individuals with complicated grief symptomatology were less flexible to manifest and suppress their emotional expressions compared to non-bereaved bereaved subjects.

In sum, these findings suggest that resilience to loss does not depend on a particular way of coping, but rather on the subject's flexibility to use different responses and regulate distress emotions. Additionally, authors advocate the positive outcome of using avoidance mechanisms, such as distraction and dissociation through laughter and positive emotions.

2.3. Anxiety and Emotional Dysregulation Theory

The fear response has as normative function in facilitating the detection of a threat and preparing the organism to respond effectively in situations of danger. However, the relationship between the stimulus intensity and the activation level is not linear. There are people who, by being particularly sensitive to signs of threat, tend to experience exaggerated fear responses. Sensitivity to threat is a learned tendency to pay preferential attention to risk and to overestimate danger signs (Britton et al., 2011). It manifests in a state of constant concern and hypervigilance (Thompsom, Schlehofer & Bovin, 2006), accompanied by intense fear and high physiological reactivity (alarm reaction) towards threatening stimuli (Yancey, Venables & Patrick, 2016). It has been, therefore, consistently associated with the etiology and maintenance of anxiety (Bar-Haim, Lamy, Pergamin, Bakermans-Kranenburg & Van Ijzendoorn, 2007; Craske et al., 2009; Cisler & Koster, 2010; Britton et al., 2011; Pergamin-Hight et al., 2015).

Through the analysis of underlying cognitive mechanisms, it has been found that increased sensitivity to threat is generated by seemingly contradictory automatic processes, such as the difficulty in diverting attention from the potentially threatening stimulus and the attention avoidance, which consists in the propensity to divert attention to opposing stimuli (Cisler & Koster, 2010). These mechanisms underlie the vigilance-avoidance process (Mogg, Bradley, Miles & Dixon, 2004), whereby anxious individuals show preferential attention to threat and then avoid it (Weierich, Treat & Hollingworth, 2008).

Avoidance is defined as an instrumental response that modifies emotional states, thoughts and body sensations that are considered aversive or threatening (Schlund Hudgins, Magee & Dymond, 2013). When perceived threat is effectively avoided, the person experiences relief, which is interpreted as a sign of fear reduction, security and hope, thus reinforcing the avoidance learning (Carver, 2009). In the long term, the avoidance reaction becomes a habit of defence. McNaughton and Gray (2000) distinguish two types of defensive behaviour: the first type corresponds to an active avoidance inherent to fear (i.e., escape or flight behaviour), which is reactive to a current or imminent threatening stimulus; the second type constitutes a passive and distant defence (i.e., paralysing behaviour). This passive defensive behaviour has been attributed to the Behaviour Inhibition System (BIS; Gray, 1982). By being particularly sensitive to signs of conflict and uncertainty, it interrupts behaviour in order to facilitate the processing and response to these stimuli. Thus, instead of activating the behaviour towards escape, the person remains in an attitude of careful approach and risk assessment, where the components of rumination and concern for the future (which are characteristic of the state of anxiety) are emphasized.

This perspective is in line with the learned fear theory, which has been recovered through a progressive understanding of the neuronal mechanisms that underlie it (LeDoux, Moscarello, Sears & Campese, 2017). The results of the studies using functional neuroimaging reveal that sensitivity to threat and consequent defence reaction correspond to the amygdala automatic activity. However, according to LeDoux & Pine (2016), it is important to distinguish between the neural circuits that underlie the two types of response to threat: the first circuit corresponds to the limbic system, it is centralized in the amygdala, detects the sensorial stimuli and responds with physiological and behavioural activation (i.e, emotion of fear), generating automatic defence responses. On the other hand, physiological and behavioural signals contribute to the emergence of the subjective and conscious state of fear (i.e., feeling of fear) thus activating another circuit involving structures at cortical level that are responsible for consciousness.

Compared to healthy individuals, the anxious persons demonstrate an exaggerated activation of the amygdala (Etkin & Wager, 2007; Monk et al., 2008; Brühl et al., 2011). Besides, they present less involvement of the cortical structures, namely the prefrontal cortex, which, in healthy subjects, exerts a regulating function on the activity of the amygdala (Blair et al., 2012). The hyper-reactivity of the limbic circuit causes wear on the top-down system, making it impossible to access the prefrontal cortex. Considering that the capacity for self-regulation is based on limited resources (Baumeister & Heatherton, 1996), it is naturally prone to fatigue and dysregulation, especially when the person is involved in successive events that require self-control effort. This process of depletion of cognitive resources makes people less capable of managing emotional states in situations of threat (Holmes et al., 2014).

Consistently with these results, the theory of emotional deregulation (Mennin, Turk, Heimberg, & Carmin, 2004) postulates that anxious individuals experience more intense emotional states in any situation, particularly in negative situations. They tend, therefore, to express their emotions more often, especially the unpleasant ones. However, due to poor understanding of their emotional states, they have difficulty in identifying and describing emotions, as well as recognizing their useful information. Emotional overload generates great discomfort, which leads them to develop negative attitudes towards emotions (e.g., perception that emotions are threatening). They become fearful and hypersensitive to signs of internal threat, especially to anxiety-related sensations. This disposition is recognized as sensitivity to anxiety (Watt, Stewart & Cox, 1998). Consequently, they develop maladaptive mechanisms to deal with the emotions, that include minimizing, exercising super control or expressing emotions in an inappropriate way. Because it is ineffective, this attempt to deal with emotions lead to a negative effect, giving rise to a dysfunctional cycle that maintains the state of emotional deregulation (Mennin et al., 2004).

The individual disposition to deal with threat varies according to the mental representations of attachment. Research findings from Ein-Dor, MiKulincer and Shaver (2011) indicate that in threat situations, individuals with a preoccupied attachment style have internal schemes that emphasize the sense of vulnerability, dependence, and emotional instability. These schemes organize behaviour so that they become faster in detecting and responding to potential sources of threat, more willing to alert others to imminent danger and to maintain proximity for support and protection. In addition, they have more sensitivity to interpersonal problems, exacerbating their negative consequences. On the contrary, avoidant individuals are more likely to respond with escape or fight schemes, which are organized around the sense of strength, independence, and emotional suppression. They are therefore more reluctant to search for others in times of distress. This tendency leads them to postpone conversations about relational aspects and fail to coordinate efforts to solve problems.

2.3.1. Uncertainty of illness

Circumstances of end-of-life caregiving include several unexpected and threatening events. This experience is commonly referred as uncertainty of illness (Shilling, Starkings, Jenkins & Fallowfield, 2017; Strauss, Kitt-Lewis & Amory, 2019). The literature consistently associates uncertainty with reactions of emotional distress and anxiety (Neville, 2003; Mitchell & Courtney, 2004), although it was also related, albeit less frequently, to responses of hope and resilience (Morse & Penrod, 1999; Wong, Liamputtong, Koch & Rawson, 2017).

Several theoretical models were developed on this issue. One of the most prominent perspectives stems from Lazarus and Folkman´s (1984) cognitive theory of coping with stress. The authors conceived uncertainty as a state of confusion created by a situation where there is insufficient information or the stimuli are ambiguous, thus leading to conflicting wills, values, or goals, or the inability to decide at all what to do. According to this framework, uncertainty hinders the anticipatory coping process, as the strategies for dealing with the occurrence of the event are not compatible with those required for its non-occurrence. For example, one cannot simultaneously prepare for a functional loss while maintaining the hope that this function will be restored. Another consequence is the mental confusion generated by the impossibility of predicting whether or not the event will occur and when. Unable to choose an orientation, the person does not see a solution to the problem, which causes fear, excessive worry, rumination and anxiety.

Of course, the more imminent the threat, the greater is the stress reaction. Hence, the person remains in a state of constant alertness during the period of anticipation. But, according to the authors, this time of anticipation can also have the opposite effect: when the event is delayed, the individual has time to think, cry, avoid the problem, or mobilize resources to regain control, thereby reducing the level of anxiety associated with threat perception. On the contrary, when the event persists – as in chronic and recurrent situations –, after a habitual shock phase, there may be habituation processes, i.e. a reduction in the physiological and behavioral stress response (activation) that occurs with the repetition. Crisis are susceptible of being anticipated, given the likelihood of recurrence of the event, but the main uncertainty factor is the perception of one´s own coping resources to deal with the situation.

However, Lazarus and Folkman´s (1984) admit that ambiguous conditions, susceptible of more than one interpretation, allow for the influence of the individual's perception, determined by personal dispositions such as personality traits, beliefs and expectations. This is shown by empirical data indicating that the level of optimism appears to be negatively associated with uncertainty, which stresses the tendency of optimistic people to expect more favourable outcomes from events in ambiguous situations, such as chronic disease (Gold-Spink, Sher & Theodox, 2000). In contrast, individuals with neuroticism and high intolerance to uncertainty, when faced with a highly ambiguous situation such as chronic disease, tend to respond with excessive concern (Kurita et al., 2013), avoidance and passive coping (Buhr & Dugas, 2002; Reich et al., 2006).

Clearly influenced by the previous framework, Mishel (1988) conceives uncertainty as a cognitive state that reflects the inability to attribute meaning to disease-related events and predict their outcomes due to insufficient information. Under normal conditions, people interpret disease-related stimuli and create a framework of meanings that allow them to recognize and classify their signals in order to make them familiar and predictable. Uncertainty occurs as a result of difficulties in processing and integrating information, either because of the stimulus characteristics – the more inconsistent, new and vague the symptoms, the more difficult to predict –, or the cognitive failures of the subject.

Similarly, the lack of congruence between what was expected and the disease events raises doubts concerning to the predictability and stability of the events. This happens when, for example, expectations of cure are lowered by the recurrence of the disease or if treatment does not produce the intended effect. However, from this perspective, uncertainty is not necessarily threatening because, due to the lack of structure, facts can be interpreted according to one's expectations and reformulated in any direction, giving space to mobilize coping strategies that promote adaptation to the disease. Thus, it can be viewed as a threat or an opportunity, depending on how one interprets events.

Although this theory is widely documented, some limitations are acknowledged (Merle, 1995). One is that it focuses uncertainty only on information failures, when it is only one of its multiple causes (McCormick, 2002). Moreover, the relationship between the level of information and the degree of uncertainty is not linear. The view that people are intrinsically motivated to reduce perspective uncertainty has been challenged by information management theory (Brashers, Goldsmith & Hsieh, 2002), which states that people can avoid information to maintain the current state of knowledge, especially when it may cause discomfort or dissonance. From this perspective, health-related uncertainty is not necessarily a tension that must be eliminated, but rather as an expression of autonomy in managing information, objectives and expectations, depending on the person's circumstances and needs.

Another limitation concerns the definition of uncertainty as a neutral cognitive state, regardless of their emotional outcomes. This position is refuted by the evidence that the experience of uncertainty mainly reflects the emotional activation related to the perception of threat, as postulated by contemporary models of uncertainty (Carleton, 2016). However, perhaps the most contested aspect of Mishel's (1989) theory is that it confines uncertainty to disease events (symptoms, diagnosis and prognosis), when empirical studies support the idea that this experience has a pervasive effect on other aspects. For example, qualitative studies carried out with dementia caregivers (Unson et al., 2015; Hurt, Cleanthous & Newman, 2017) reported that this population is affected by several sources of stress and uncertainty. Besides the aspects of diagnosis and medical treatment, they referred uncertainty about if they were doing everything to manage the situation, insecurity on availability of support and various concerns about the impact of this situation on their health and financial life.

Miceli and Castelfranchi's (2005) conceptual model places intolerance to uncertainty as a core aspect of anxiety, an idea that has been corroborated by recent research data (Shihata et al., 2017). This conceptual model states that the need to resolve uncertainty involves taking control in two aspects: pragmatic control, which means having control over events to shape them to one's own goals; and epistemic control, related to the ability to predict what will happen, in particular whether or not the goals will materialize. In order to maintain control, the person keeps a future-oriented thinking and becomes hypervigilant about the possible threats. This causes a state of anxiety, conceived as the anticipation of an undefined threat, including the consequent uncertainty and expectation.

However, unable to find a specific object (as opposed to fear, which is reactive to a concrete damage), the anxious person shifts attention to something more controllable and definite. This is the origin of pessimistic thinking: it is better to anticipate a failure than to live in uncertainty and waiting. On the other hand, it is important to create the illusion of control through various active avoidance strategies. For example, one may focus on details, which eventually become rituals or preventive compulsions; may attempt a forward escape to reduce the waiting time; or develop a hypothetical-analytical form of reasoning that requires a thorough analysis of the situation, characterized by the “What if…?” style of thinking and a state of hypervigilance oriented toward possible threats. Through a process of selective attention, one “exaggerates” the threat and remains busy with very specific details that divert one's attention from the real threat. Therefore, albeit being preoccupied, it does not necessarily mean that the individual is waiting for the event to occur (even if it is considered probable), or that one has developed strategies to deal with the threat. There is evidence that anxious individuals, when compared to depressed, are more likely to anticipate negative outcomes but not lower positive expectations (MacLeod & Byrne, 1996). Therefore, while paying close attention to the threat, their objective will always be to prevent the negative outcome and maintaining the hope that the best will happen.

Therefore, it is also common that, no matter how great the obstacles are, the anxious people have an optimistic answer: "everything is in control." This statement presupposes the belief that one can deal with all possible threats, but is generally based on a poor assessment of circumstances. It is distinct from a positive view of coping, where one considers the “worst case scenario”, but remains confident that will survive. In any case, all of these responses are strategies used to avoid suffering related to the anticipation of the threat and to maintain some stability and congruence in the internal world, i.e. to exercise pragmatic and epistemic control. But, according to Miceli and Castelfranchi's (2005), people may be willing to give up some hope of pragmatic control in favour of the need to predict negative events and thus preserve epistemic control. This is especially true when the event is inevitable and the main uncertainty is whether or not the person will be able to deal with the threat. In other cases, to avoid deep disappointment at the impossibility of achieving one's goals, the most likely answer will be to ignore the potentially threatening information.

Carleton's (2016) conceptualization differs from the previous ones by framing the concepts of uncertainty in contemporary models of emotions and attachment, as well as in neurobiological research. It begins by establishing, in accordance with other authors, that the unknown is one of the main sources of fear and that this aspect is common to intolerance to uncertainty, which is defined as an individual's willingness to emit an aversive response to the perception of insufficient or inappropriate information. By understanding this characteristic as an affective trait, the author distinguishes it from the circumstances and emphasizes the aspects of attachment and temperament. Given the influence that the quality of the primary caregiver’s presence has on how a person responds to separation and the unknown, individuals with a secure attachment style are expected to be more tolerant to uncertainty, as compared to the insecure ones. This hypothesis was demonstrated by Wright et al (2016), by establishing a positive relationship between the level of anxiety and avoidance in attachment and the intolerance to uncertainty and worry.

By establishing that there is a predisposition to react with aversion to situations considered unknown or uncertain, Carleton (2016) also considers the role of the Behavior Inhibition System (BIS), responsible for risk assessment, increased vigilance and physiological activation. The parallel between the BIS system and neurobiological structures facilitates the understanding of the relationship between uncertainty, fear, anxiety and habituation: when the sensory system identifies novelty, they quickly stimulate the amygdala, which reacts with physiological activation corresponding to the fear reaction. This reaction can become persistent if it is reinforced by the threat perception. Otherwise, it is likely to trigger a habituation process, as advocated by Lazarus & Folkman (1984). However, due to a pattern of poor habituation, individuals with threat sensitivity tend to maintain high levels of activation, while in others this response is extinguished (Campbell et al., 2014).

2.4. Integrative Neurobiological Model of Attachment and Emotion Regulation

The central aspect of affect and emotion regulation has been emphasized by neurobiology, whose more recent developments have contributed to revolutionize attachment theory, by transforming it into a regulation theory where brain development plays a key role in emotion processing, stress modulation and self-regulation (Schore & Schore, 2008). In accord with this position, Siegel (1999; 2001; 2015) posits that the relations established from an early stage of life shape the structural development of the brain through activation of neuronal circuits – mental states – whose features will determine the subsequent evaluations and activation processes. This feedback mechanism is a form of self-reinforcement which ensures the consistency of the individual's emotional response patterns as well as the continuity of attachment experiences. An internal organization is created, which allows individuals to attribute meaning to their world experience and relationship with others. The self-organization of mental states is determined by the brain ability to modulate the flow of information and the level of activation (energy) associated with it, i.e., the process of emotional regulation.

A key concept in the process of emotional regulation is the one of "tolerance window", also introduced by Siegel (1999). According to the author, levels of emotional activation can only be processed when within the tolerance limits of the individual, otherwise they become disruptive to functioning. Some people are aware of a wide variety of pleasant or unpleasant emotions and feel comfortable with them. This makes them able to tolerate a high amplitude of emotional activation while they keep thinking, acting and feeling in a balanced and effective way. On the contrary, for other people, the level of tolerance of some emotions (e.g. fear or sadness) can be very low. Usually, in such cases, emotional states only become conscious when levels of intensity are already close to limits, therefore they produce a disorganizing effect.

Above the upper limit of the tolerance window, emotional activation corresponds to an excessive activity of the sympathetic nervous system, manifested through energy consuming processes, among them the increased heart and respiratory rate, accompanied by a sensation of head strain. At the other extreme, excessive activation of the parasympathetic nervous system leads to energy-conserving processes, manifested by decreasing heart and respiratory rate as well as a sense of numbness or a feeling of being turned off. The person may also alternate between these two states, giving rise to an internal sensation of explosion and high tension, translated into a state of explosive anger. Under these circumstances, upper cognitive functions of self-reflection (metacognition) and abstract thinking are blocked, so its functioning becomes only reflexive and not adapted to the environment. It corresponds, therefore, to a state of emotional dysregulation.

Tolerance levels may vary according to constitutional (temperament) and learned aspects, based on the subject's previous and current experience. For example, anxious people may experience more discomfort in new contexts, but their level of distress tolerance increases when they feel safe and accepted in their own social context. Adverse physiological conditions, such as tiredness, may also restrict tolerance, thus making the person more susceptible to angry outbursts. The recovery from this state of hyperactivation implies a reinstatement of the cortical circuit and the reflexive awareness, after the emotional state flood, which again depends on the individual's constitution, their personal history and current context. Some emotional states may be more or less easy to recover, depending on the disruptive effect of activation. For some people, the extreme difficulty in recovering from unpleasant emotional states leads them to avoid all situations that could activate strong emotions, constantly attempting to maintain the internal balance. Hence, this defensive effort becomes an integral part of their personality, influencing the way they relate to reality and others. However, the avoidance cycle only tends to extend the state of intolerance and emotional dysregulation, precisely because of the lack of opportunity to experience the recovery process, which gradually helps to make the limits flexible and broaden the tolerance window.

As capacity to recover from emotional activation states increases, the person receives more information about their functioning and develops the ability to assess and differentiate emotions. They also become more able to elaborate emotional states, finding similarities and differences, establishing connections, and recognizing patterns of relationship between feelings, emotions, thoughts, and behaviours. Representations of emotional states are subject of reflection, thus becoming conscious. Consciousness introduces the possibility of considering alternatives and thinking about the results of action, thus playing a key role in making attention flexible and regulating emotions. When emotions become conscious, they allow the individual to establish an intention of action and to mobilize behaviours with adaptive value in pursuit of that objective. In addition, consciousness introduces metacognition, which allows the individual to understand the influence that emotion exerts on perception and thought.

Therefore, achieving self-regulation depends on a sensitive and responsive communication to own and other’s emotional states. This capacity contributes to the development of a coherent and collaborative discourse that characterises people with secure attachment style. Siegel (1999) explains that achieving this state of the self’s coherence is the result of integration of the neural systems through dynamic networks that connect the vertical, dorso-ventral and lateral circuits. Its anatomical and functional articulation allows the integration of the self’s sensorimotor information into a complex space-time map, which constitutes the autobiographical memory. The right hemisphere involvement is responsible for capturing experiences and the left hemisphere for encoding them, in a process that integrates past, present and future experience. If people develop maladaptive forms of emotional regulation, due to constitutional characteristics, traumatic experiences and unsafe attachment styles, their capacity of resilience and flexibility will be compromised, especially in situations that could threaten the individual's psychological integrity. Anxiety states, for example, result from a state of emotional dysregulation that is characterized by excessive sensitivity to the environment, especially to situations of threat. In summary, these conceptual models contribute to a better understanding of the emotional response to particularly stressful circumstances, such as dealing with a life-threatening illness of a significant other. Higher sensibility to threat and low tolerance to uncertainty have been associated with increased levels of anxiety, which in turn, prevent the mobilization of personal and social resources. Hence, in spite of anticipating the threat, these individuals are prone to engage in avoidance mechanisms that protects them from the emotional overload, but simultaneously hinders the effective preparation. Recent developments in attachment theory play a key role in explaining dispositional tendencies to self-regulate in face of emotional distress.

CHAPTER II

Aims and Methods

1. PROBLEM STATEMENT AND OBJECTIVES OF RESEARCH

1.1. Problem Statement

According to palliative care guidelines (Hudson et al., 2012), the psychosocial support to the family members entails a comprehensive assessment of individual risk for poor psychological health and prolonged grief disorder. It is also recommended that discussions around preparedness for death are responsive to the individual needs, so health professionals should be trained in gradually approaching this sensitive subject without causing psychological harm to the person. In addition to the brief screening of the risk of prolonged grief disorder, this clinical evaluation implies that the professional is highly attentive to the FC´s emotional cues in order to understand how they emotionally regulate in face of imminent death. However, literature is still limited in explaining how caregivers deal with experience of anticipated loss.

Probably due to the complexity of the AG concept, contradictory results were obtained concerning its role in caregiver´s adjustment to loss. Specifically in FC of cancer patients, whose end-of-life trajectory is marked by a pronounced functional decline, this phenomenon have been understudied, thus little is known about its specific characteristics and variability of caregiver´s responses. Existing studies carried out in palliative care have focused predominantly in measuring risk factors for poor bereavement outcome, overlooking the adaptive efforts of FC in managing the multiple challenges posed by end-of-life caregiving circumstances. They are grounded in the perspective of a grief symptomatology continuum, thus failing to acknowledge the specificity and multidimensionality of the AG experience. In general, the assessment tools also reflect this lack of specificity of AG dimensions. Besides, being self-reported, they cannot capture implicit meanings that are not always accessible to consciousness.

It is therefore necessary to systematize knowledge in this area and to develop more empirical evidence, both through quantitative data on the evolution of grief symptomatology and predisposing factors, and qualitative exploration of the meanings and needs of caregivers from their own perspectives. This is particularly relevant because they provide valuable insights of key components and the dynamic complexity of this experience. Thus, it will be possible to operationalize the concept and contribute to a more comprehensive view of this phenomenon. Particularly in Portugal, where research on this topic is practically non-existent, it is important to develop research to inform the national palliative care strategy plans about the mental health impact of end-of-life caregiving and the specific needs of this population.

1.2. Research Aim, Questions and Objectives

Overall, this research aims to contribute to a more comprehensive view and measurement of palliative care cancer caregiver´s grief experience by analysing the trajectory of grief symptoms and the determinants and multidimensionality of anticipatory grief concept. This research project was guided by the following questions: “How does the FC´s grief evolves from pre to post-death phase?”, “What are the personal, circumstantial and relational aspects determining PGD manifestations?”, “What characterizes the family caregiver´s anticipatory grief experience?” and “How do family caregivers differ in managing the anticipatory grieving experience?”. To address these questions, we established two general objectives, operationalized in a set of specific objectives:

1. To describe the trajectory of Prolonged Grief Disorder symptoms and their determinants in a Portuguese sample of cancer family caregivers followed in palliative care;
    - 1.1. To adapt and validate for Portuguese population the pre-death PGD instrument;
    - 1.2. To estimate FC´s mental health outcomes and trajectory of PGD symptoms;
    - 1.3. To identify the determinants – including the personal, circumstantial and relational aspects – of PGD symptoms;
2. To contribute to the conceptualization and operationalization of family caregiver anticipatory grief phenomenology by developing a clinical assessment instrument to measure individual differences in anticipatory grieving process;
    - 2.1. To describe the FC AG phenomenology by identifying its nuclear characteristics and dynamics;

2.2. To characterize FC AG patterns in their relation with self-report prolonged grief intensity;

2.3. To operationalize the multidimensional AG concept in a clinical assessment instrument to measure the typology of FC AG response.

2. RESEARCH DESIGN AND METHODS

This research is part of a larger project which aimed to identify mediators and biopsychosocial and economic consequences of caregivers' grief. Research objectives were accomplished through a set of studies implemented as follows. We first conducted a literature review for gaining perspective on the problematic and identify the main content domains of the AG construct. Results from this review contributed to the outlining of the research project, which includes two distinct parts, corresponding to the two main objectives. One quantitative survey instrument design, including two original studies, addresses the first main objective. Next, a qualitative and mixed method study was conducted to fulfil the second objective, involving a series of three original studies. Below, we introduce the specific objectives and a brief description of each study for an overview of the current research project design. Table 1 displays a summary of the objectives, method and design of the studies.

In the integrative literature review (Literature review I), twenty-nine articles were selected (1990-2015), referring mostly to cancer FC end-of-life experience. Findings from this study suggest that this is a multidimensional and dynamic process. Among all the characteristics, the anticipation of death and relational losses were highlighted as the distinctive aspects of this experience. It was also noticed that in the western culture prevails an avoidant attitude toward death, which adds ambivalence to this experience. Thus, for most FC, the AG is highly distressful, so we cannot assume that because death was anticipated, they are more prepared to the loss. Afterwards, a scoping review was conducted[4], focusing the last advances in research on AG (2015-2017). Specifically, we

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[4] This papper was carried out at request of the journal Current Opinion of Palliative and Supportive Care, so it was not included in this research project; however, as it provides relevant data, it is presented attached to this dissertation.

discussed aspects of phenomenology in different FC groups, as well as the developments in evaluation and intervention in FC grief (Literature review II).

Table 1: Objectives, method and design of research studies

Study	Objective	Design
Literature Review	a) To synthetize research in order to develop further knowledge about the family experience of AG during a patient's end-of-life; b) To identify the main characteristics of FC AG	Integrative review
Empirical Study I	a) To translate, adapt and contribute to the Portuguese validation of PG-12, examining its construct validity and reliability; b) To determine the prevalence of PGD in a population of oncologic patients' FC assisted in palliative care; c) To identify the psychosocial factors that contribute to pre-death PGD (sociodemographic characteristics, perception of illness and intensity of care, coping and caregiver burden);	Longitudinal Quantitative
Empirical Study II	a) To identify the core characteristics of AG b) To describe the specific adaptive challenges posed by AG in the context of end-of-life caregiving	Qualitative
Empirical Study III	a) To describe individual differences in FC AG experience b) To identify AG patterns, based on the attachment framework	Cross-sectional Mixed-method
Empirical Study IV	a) To develop a valid, reliable and sensitive assessment instrument to clinically assess different AG response patterns in advanced cancer FC	Longitudinal Mixed-method
Empirical Study V	a) To measure the prolonged grief symptoms evolution between pre and post-death period b) To examine the path through which the caregiver context influences prolonged grief manifestations.	Longitudinal Quantitative

The first empirical study (Empirical study I) aimed to adapt and validate a reliable measure to evaluate PGD symptoms prior to death - PG-12. The instrument has shown to be reliable, with high internal consistency and monofactorial structure and predictive of post-loss PGD symptoms. In this sample (n= 94), 33% met the criteria for Pre-death PGD. Levels of caregiver burden are significant in 85.9%, depression symptomatology is present in 67.4% and anxiety in 62%. Pre-death grief influences Burden, Depression and

Anxiety although these are independent symptoms clusters. The perception of the patient´s poor physical condition and more involvement in care were associated to higher pre-death grief manifestations. Concerning coping mechanisms, acceptance and positive reinterpretation demonstrated to be protective, while denial was correlated to higher pre-death symptomatology.

Posteriorly, semi-structured in-depth interviews were carried out (Empirical study II) to continue exploring AG nuclear characteristics and describe its dynamics. From the thematic analysis of preliminary interviews (n=26) emerged the main categories of AG, formulated as emotional challenges. The categories were created based on a mixed analysis method, combining an inductive and deductive analysis and integrating the nuclear characteristics found in the literature review with those resulting from empirical data. Two main dimensions were identified: traumatic distress caused by witnessing of the other´s suffering and degradation; and separation distress, induced by loss anticipation and current relational losses. Characteristics of AG were described as challenges that the FC has to deal with to endure this distressful experience, requiring a constant effort of emotional regulation. These findings resulted in a conceptual model to explain the dynamics of AG in the context of cancer end-of-life caregiving.

Another cross-sectional study (Empirical Study III) aimed to characterize the anticipatory grieving patterns according to the self-report pre-death grief intensity. By performing a cross-case analysis, configurations of categories and sub-categories within groups were identified. Participants (n=72) were aggregated according to self-report scores of pre-death grief symptoms, ranging from low to extreme distress (using PG-12 Quartile values as cut-off points). From this exploratory analysis, emerged four different anticipatory grieving patterns: Avoidant, Adjusted, Intense and Traumatic. Specific characteristics of each anticipatory grieving pattern reflect individual dispositional tendencies to regulate emotions, as suggested by attachment theory. Since this is an exploratory study, we chose to capture the subjective perception of the subjects, instead of using a standardized instrument to evaluate these variables.

Findings from the previous qualitative studies yielded the assessment criteria for developing the clinical instrument of AG (Empirical Study IV). This instrument, designated as Family Caregiver Anticipatory Grief Clinical Interview (FcAG-CI), is composed by eight dimensions, evaluated in a nine-point Likert scale, from low to extremely high distress. In this preliminary study of validation (n=72), the psychometric characteristics of this instrument were tested through a series of analyses. FcAG-CI revealed convergent and concurrent validity with self-report pre-death PGD symptoms and divergent validity with the Zarit burden interview. Two main factors emerged (Traumatic and Relational distress) each one composed by four items. Four groups were obtained and related to mental health outcomes to verify criteria validity. FcAG-CI also showed reasonable internal consistency and excellent inter-rater reliability of the scales, based in the rating guidelines provided.

The last study (Empirical work V) was an extension of the first empirical work[5]. It aimed to prospectively evaluate the PGD manifestations and explore the complex pattern of influences between caregiving related factors and bereavement outcome. Participants in the first assessment moment (n=156) presented higher PGD values at pre-death (38.6%) comparatively to bereavement (33.7%). From those who meet the PGD criteria at pre-death, most also quoted positively at post-death (n= 26, 61.9%). Psychological distress and caregiver burden were highly correlated with pre-death grief, which in turn plays a critical role in mediating the link between psychological distress and bereavement outcome. On the contrary, long-term consequences of caregiver burden were not confirmed. Proximity in the relationship was predictive of the grief manifestations, both pre and post-death.

In line with the post-modern approach, which favours a multi-layered understanding of social reality (Hesse-Biber, 2010), a series of mixed methods studies were carried out, employing both quantitative (Empirical studies I and V) and qualitative approach (Empirical studies II and III). Integration occurred by transforming qualitative data into rates that were subsequently compared with quantitative survey data (Empirical study IV). This multi-method analysis was performed with different sets of data (see Fig. 1):

- Quantitative data, collected in a sample of FC, evaluated prospectively in two moments: before death (T1) and in post-loss period, six to 12 months after death (T2), using self-report instruments (Empirical studies I, III, IV and V).

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[5] Although addressing the first objective, this study was the last to be conducted, due to the length of time taken to collect longitudinal data.

- Qualitative cross-sectional data, collected from in-depth semi-structured interviews conducted before death, with a sub-sample of FC selected from the previous sample (Empirical studies II, III and IV).

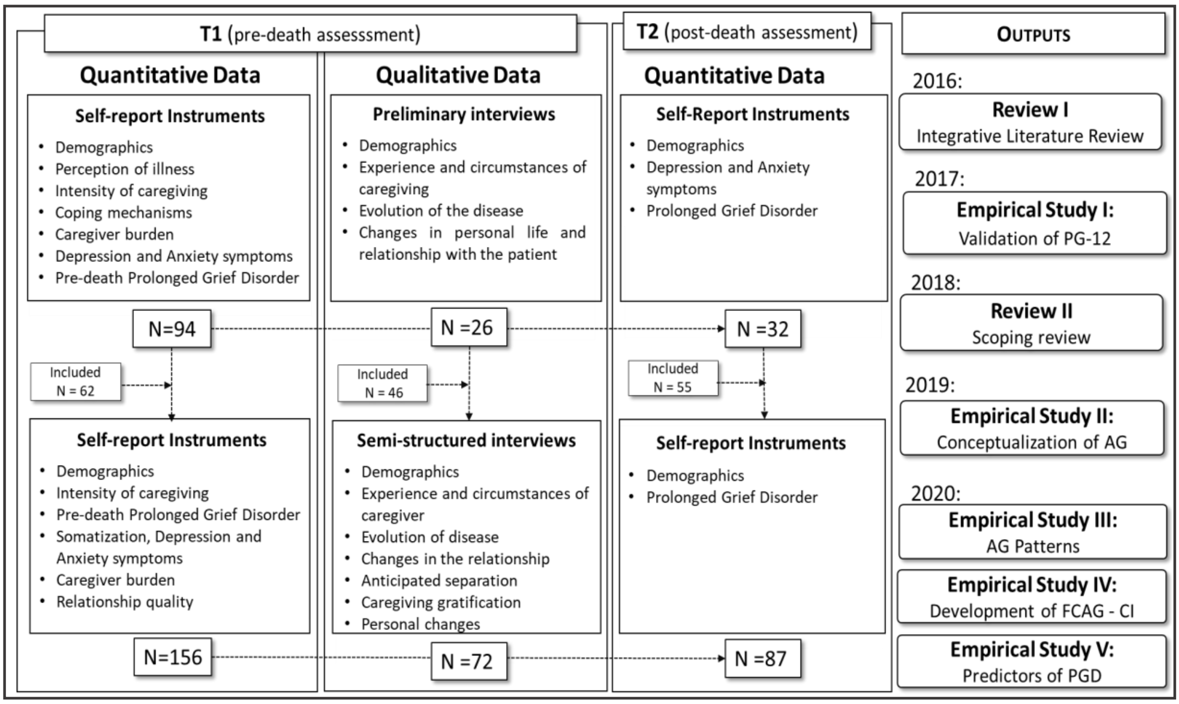

Fig. 1: Study design and outputs

2.1. Data Collection and Sampling Procedures

For ethical reasons, some measures have been taken to avoid the burden of the participants in a period of such great vulnerability. We made an effort to integrate research procedures into the usual palliative care treatment and adjusted the collection of data to the most opportune moment for the participant. For example, in times of patient´s symptomatic decompensation or family´s emotional crisis, we chose not to request their participation in the study. This meant delaying the collaboration and, in some cases, losing the possibility of including the FC in the study, thus explaining the small size of the samples. We also ensured that the questionnaires were as brief as possible and strictly those needed to evaluate the study variables. In addition, to facilitate the completion of the questionnaires, several response modalities were allowed: face-to-face, with the support of the researcher; at home, in paper format, online or by telephone.

Due to constrains in systematically accessing all FC followed in PC, a convenience sample was used. The researcher who collected the data is also the resident psychologist of the PC team, so we had preferential contact with the clinical population, i.e., those people who presented some degree of psychological distress.

2.2. Quantitative data

Quantitative data was collected by self-report instruments, evaluating: (i) *intrapersonal, circumstantial and relational factors*, including socio-demographics, perception of illness, involvement in caregiving, caregiver burden, coping mechanisms and quality of relationship; ii) *mental health and bereavement outcomes*, namely PGD criteria pre and post-loss; symptoms of depression, anxiety and somatization.

Selection of self-report scales was first conducted by a panel of six experts in grief. Preference was given to those instruments: (i) validated for Portuguese FC population; (ii) short and easily applicable, to avoid the burden of participants; (iii) frequently used in other studies to allow comparison of results. When appropriated standardized scales were not found, we created structured questions. This is the case, for example, of specific variables related to the involvement in caregiving and relationship quality. The entire assessment protocol was then subjected to a pre-test, conducted with 10 FCs. It included a cognitive interview, in which participants were asked about the adequacy and comprehensibility of items. According to participants' suggestions, some items were reformulated.

We also created a tool for assessing the Quality of Relationship (QRQ). Items for this instrument were generated based in literature review and clinical experience of panel´s elements. A set of 16 items was initially formulated to assess aspects of proximity, conflict, dependency and ambivalence in the relationship with the relative. This scale differs from others because it focuses the changes that occurred in the relationship. QRQ was then tested for factorial structure and internal consistency (n=152), proving to be a reliable instrument for assessing the quality of the relationship. The self-report instruments and psychometric characteristics are displayed in Table 2.

The original protocol assessment included an attachment scale – Relationship Questionnaire: Clinical Version (RQ-CV; Holmes & Lyons-Ruth, 2006). This instrument consists of five affirmations that classify the attachment styles, rated on a Likert type scale ranging from 1 (disagree strongly) to 7 (agree strongly). However, at pre-test, this scale was considered difficult to respond due to the complex structure of the sentences. Other attachment scales (e.g., Experiences in Close Relationships) were also excluded because they were extensive and focused exclusively in couple relationship. Besides, considering the real separation, by the death of the patient, the habitual descriptors of conventional attachment scales were not considerate appropriated (e.g., “I worry a fair amount about losing my partner.”, “I do not often worry about being abandoned.”) .

Bearing in mind that the specific attachment to the deceased differs significantly from global attachment style and that relationship quality has a determining influence on the severity of the grief response (Smigelsky, Bottomely, Relyea & Neimeyer, 2019), we opted for evaluating quantitatively only the relationship quality. Attachment will be analysed qualitatively, as described below.

2.2. Qualitative data

To collect qualitative data, individual interviews were conducted by the main researcher, in a face-to-face situation. After some exploratory unstructured interviews to identify the relevant themes, we developed a script for a semi-structured in-depth interview to obtain detailed information about the AG experience in the FC´s own perspective. The structure of the interview includes a first general topic (i.e., How has been your experience as caregiver?”), followed by other questions referring to the changes in the relationship and perception of illness evolution. All the interview topics need to be addressed, but not in a rigid way, which means that the interviewer doesn´t have to follow a pre-formatted order of questions, rather they should be asked in a way that develops the conversation. This empathic approach favours the relationship and enhances the possibility of gathering rich and authentic information about sensitive subjects (e.g., death proximity).

A qualitative thematic analysis was conducted in order to capture recurrent patterns (themes) and implicit meanings, using a mixed inductive (i.e., derived from the data or "bottom up") and deductive generated coding (i.e., theoretical based constructs or "top-down"). This analysis (n=26) resulted in the identification of the main characteristics of AG. Details on analysis method and results are described in Empirical Study II. Posteriorly, this sample was enlarged (n=72) to describe the individual differences in the AG process (Empirical Study III).

In the top-down analysis, we relied on the attachment theory to characterize manifestations of AG according to the attachment styles. However, we kept the coding system open to categories that emerged from the data precisely to capture other specific aspects of this experience, which have not yet been explored in attachment theory. The configuration of categories and subcategories within each group allowed us to create evaluation criteria in order to convert qualitative data into numerical values, thus giving rise to FcAG-CI. The description of the instrument development and coding system is presented in the Empirical Study IV and in the Manual attached to this dissertation.

Table 2: Self-report instruments used in empirical studies

Instruments	Description	Empirical Studies		
		I	IV	V
Intrapersonal, circumstantial and relational factors				
Socio-demographics	Gender (female; male); Age; Marital status (single, married or partnership, divorced, widow); Kinship (partner, adult children, parent, sibling, other); Scholarship; Cohabitation (yes/no question)	√	√	√
Perception of illness	Three structured questions, answered on a Likert scale from 1 (very bad/nothing) to 5 (very good/totally): *“At this moment, how do you see the health status of your relative?”*; *“Were you expecting this diagnosis?”*; *“Were you expecting the illness to evolve this way?”*	√		
Involvement in caregiving	Two structured questions: *“How long have you been caring for your relative?”*, evaluated answered on a Likert scale from 1 (less than three months) to 5 (more than two years); *“During the last week, how much time, in average, did you spend caring for your relative?*”, answered on a Likert scale from 1 (less than two hours) to 5 (more than 16 hours);	√		√
Zarit Burden Interview (ZBI)	Questionnaire developed by Zarit & Zarit (1987) to evaluate the caregiver burden – higher values correspond to more burden. Composed of 22 items, answered on a Likert scale from 0 (Nothing) to 4 (Extremely). Multifactorial structure, with five dimensions: (1) Loss of control; (2) Sacrifice; (3) Dependence; (4) Fear/Anguish; (5) Self-criticism. In Portuguese version (PV), internal consistency values range between .760 and .806. Value 22 was used as the cutting-off point. Adapted and validated to Portuguese FC population in CP by Ferreira et al. (2010).	√		√
Brief Cope	Questionnaire developed by Carver (1997) to evaluate coping strategies. Composed of 28 items, answered on a Likert scale from 1 (“I have not been doing this at all") to 4 ("I have been doing this a lot"). Multifactorial structure, with 14 dimensions: (1) Active Coping; (2) Planning; (3) Positive reframing; (4) Acceptance; (5) Humour; (6) Religion; (7) Using Emotional support; (8) Using Instrumental support; (9) Self-distraction; (10) Denial; (11) Venting; (12) Substance use; (13) Behavioural disengagement; (14) Self-blame. Adapted and validated to Portuguese population by Ribeiro & Rodrigues (2004). In P.V., internal consistency values range between .55 and .84.	√		
Quality of Relationship Questionnaire (QRQ)	Questionnaire developed by the authors to evaluate the quality of relationship with the patient at the illness. Composed of 8 items, answered on a Likert scale from 1 (Nothing) to 5 (Very much). Multifactorial structure with two dimensions: (1) Proximity, and (2) Conflict. Internal consistency values range between .854 and .868.			√

Mental health and bereavement outcomes				
BSI Subscales: Depression, Anxiety, Somatization	Developed by Derogatis & Melisaratos (1983) to evaluate symptoms of depression, anxiety and somatization. Composed of 19 items, answered on a Likert scale from 0 (never) to 4 (very often). Higher scores correspond to more severe symptoms. Adapted and validated to Portuguese population by Canavarro (1999).	√	√	√
Prolonged Grief Questionnaire (PG-13)	Questionnaire developed by Prigerson et al. (2008) for evaluation of PGD Criteria. Composed by 13 items, 11 evaluated by a Likert scale from 1 (almost never) to 5 (always), and two Yes/No questions. Monofactorial structure (α = 0.932) Criteria for diagnosing PGD: (1) Loss event; (2) Separation anxiety at least daily; (3) Duration criterion of 6 months; (4) Five cognitive and emotional symptoms at least daily; (5) dysfunctional criterion. Global score is obtained by calculating the sum of 11 items Likert-type items. Higher score corresponds to more intense grief manifestations. Adapted and validated for Portuguese FC population in CP by Delalibera, Coelho & Barbosa (2010).	√	√	√

Notes: P.V.: Portuguese version

Content analysis was carried out by the principal investigator because, by having direct contact with the respondents, she is the element who is in better position to interpret data consistently with the participant´s view and access implicit meanings that are not perceptible though the verbal content transcription (Levitt, 2015). To ensure trustworthiness of qualitative analysis, the following strategies were used, as recommended by Shenton (2004):

- Regular debriefing meetings were held with two consultants, who read some interviews randomly and discussed the coding system until a consensus was reached;
- Although a convenience sample was collected, we intentionally selected the participants who best represented or had knowledge of the research topic to ensure the richness and representativeness of data;
- The wide diversity of informants allows that individual viewpoints and experiences can be verified against others for scrutiny;
- People voluntarily agreed to participate in this study and were genuinely interested in giving honest information about their experience;
- Continuous redefinition of categories for addressing all the cases;
- The saturation point of the sample was defined when new interviews no longer added new data to the analysis;
- The researcher´s qualifications and experience in palliative care and grief therapy allowed the personal reflexivity on the data, namely in elaborating their clinical and theoretical implications.

Together, these strategies contributed to the trustworthiness and rigor of the qualitative research of this project.

CHAPTER III

Research Studies

1. LITERATURE REVIEW

FAMILY ANTICIPATORY GRIEF: AN INTEGRATIVE LITERATURE REVIEW

Alexandra Coelho & António Barbosa

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Abstract

Despite all the investment in research, uncertainty persists in Anticipatory Grief literature, concerning its nuclear characteristics and definition. This review aimed to synthetize recent research in order to develop further knowledge about the family experience of Anticipatory Grief during a patient's end-of-life. An integrative review was performed using standard methods of analysis and synthesis. The electronic databases Medline, Web of Knowledge, EBSCO and relevant journals were systematically searched since 1990 to October, 2015. Twenty-nine articles were selected, the majority with samples composed of caregivers of oncologic terminally ill patients. From systematic comparison of data referring to family end-of-life experience emerged ten themes, which correspond to AG nuclear characteristics: anticipation of death, emotional distress, intrapsychic and interpersonal protection, exclusive focus on the patient care, hope, ambivalence, personal losses, relational losses, end-of-life relational tasks and transition. For the majority of family caregivers in occidental society, Anticipatory Grief is a highly stressful and ambivalent experience due to anticipation of death and relational losses, while the patient is physically present and needed of care, so family must be functional and inhibit grief expressions. The present study contributes to a deeper conceptualization of this term and to a more sensitive clinical practice.

Key Words: Anticipatory Grief; Family Caregivers; Palliative Care; Cancer; Integrative Review; End-of-life Experience

Background

Family lives an extremely disturbing experience simultaneously to patients´ end of life trajectory, not only because of the physical and emotional stress inherent to care providing, but also due to feelings of loss and separation caused by advanced disease and imminent death (Waldrop, Kramer, Skretny, Milch & Finn, 2005; Given et al., 2004; Sales, 2003). However, this experience is considered a necessary and significant part of the adaptation process to loss (Hebert, Dang & Schulz, 2006; Hebert, Schulz, Copeland & Arnold, 2009).

After Lindemann (1944), the term Anticipatory Grief (AG) was applied to express in advance when the loss is a threat or inevitable, referring to any grief experienced by the patient or the survivor, before the death (Aldrich, 1974). Recognizing the complexity of this concept, Rando (1986) developed a multidimensional definition, encompassing the losses incurred in the past, present and future. Probably due to the large scope of this issue, it gave rise to a broad discussion (Fulton, Madden & Minichelo, 1996; Fulton, 2003; Reynolds & Botha, 2006). According to Fulton et al., (1996) it was assumed that when there is forewarning of loss, AG is likely to occur, and the two terms have been used interchangeably. Thus, a linear view of anticipatory grief was created as a continuous and irreversible process, analogous to the adjustment subsequent to death.

A previous review described AG as a subjective phenomenon that does not depend on the length of illness, nor is it directly related to the awareness of terminal disease (Sweeting & Gilhooly, 1980). Another review focused on the AG of family caregivers of patients with dementia found that characteristics of AG in this population are: anticipating, ambiguity, frustration and guilt (Chan, Livingston, Jones & Sampson, 2013) In a comparative study between caregivers of dementia and cancer patients, the latest demonstrated to fell closer to the ill relative, more preoccupation with thoughts about the illness and more symptomatology (Johansson, Sundh, Wijk & Grimby, 2012). These results suggest that different illness trajectories may influence AG experience.

Family caregivers are a key component in Palliative care, and AG issues are deemed of particular concern. Therefore, it is necessary to synthesize the existing data concerning AG in end-of-life and palliative care setting, mostly comprised by families of cancer patients.

Aim

This review aimed to synthetize research in order to develop further knowledge about the family experience of AG during a patient's end-of-life. This work was guided by the following research question: "What are the nuclear characteristics of family AG in end-of-life and palliative care setting?"

Method

The integrative review employs strict analysis and synthesis procedures (Table 1) by encoding and systematic comparison of data in order to identify patterns and relationships and to reach a deeper level of conceptualization (Whittemore & Knafl, 2005).

Table 1: Data analysis used in Integrative Review

Data reduction	The data extracted from primary sources are coded and categorized according a classification system that facilitates systematic comparison of the theme (deductive process), remaining open to other themes not yet captured within classification system (inductive process).
Data display	Disposition of themes in conceptual maps around the variables;
Data comparison	Identifying patterns and relationships between topics to identify contrasts, similarities and intervening factors;
Conclusion	Description of evidenced patterns, themes and relationships, conflicting results and confounding aspects in order to create a new conceptualization of the phenomenon.
Verification	Verify findings of this analysis process with primary sources for accuracy.

Adapted from Whittemore and Knafl, 2005.

The search methods were electronic databases, including Medline, Ebsco and Web of Knowlegde (1990 - October, 2015) with the following primary descriptors: anticipatory grief, anticipatory mourning, grief pre-death, anticipated death, combined with the terms: caregiver, family, relatives. Simultaneously, a manual search was carried out in relevant journals in palliative care and bereavement (Palliative Medicine, American

Journal of Hospice and Palliative Care, Death Studies, Omega – Journal of Death and Dying, Psycho-Oncology). As inclusion criteria, we considered the studies: 1) published in English, Portuguese and Spanish; 2) focused on the family grief experience during patient´s end of life; 3) population of adult family and patients; 4) context of advanced disease and end-of-life. We excluded the studies: 1) whose population is composed of caregivers of people with dementia and HIV/AIDS; 2) not published in scientific journals, opinion articles, review of theoretical concepts or book reviewing. The quality assessment of studies was carried out according to specific criteria of suitability for many types of research, methodological rigour and relevance of the results (Table 2). All studies were carefully read, analysed for their quality and summarized in tables (Table 3). The data extracted from each study were coded and grouped into themes according to similarities and differences. The themes were then synthesized into the nuclear characteristics of the experience, contributing to a new conceptualization of this phenomena.

Results

Characteristics of the Studies

The literature search in the databases resulted in 910 articles. Additionally, 13 articles were included by manual search. Based on the titles and abstracts reading, 35 articles were selected; after full text assessment, 29 articles meet the criteria previously defined. Details of the studies identification and selection process are shown in the PRISMA flow chart (Figure 1).

Twenty studies used qualitative methodology and eight were quantitative; one was mixed. Five quantitative studies used longitudinal design. Study quality was considered reasonable. Samples were mostly composed of caregivers of cancer terminally ill patients. The majority of studies stem from North America and Europe.

Through the data systematic comparison, ten major themes around family experience during a patient’s end-of-life were identified, which correspond to AG nuclear characteristics.

Figure 1. PRISMA Flowchart of the literature search process

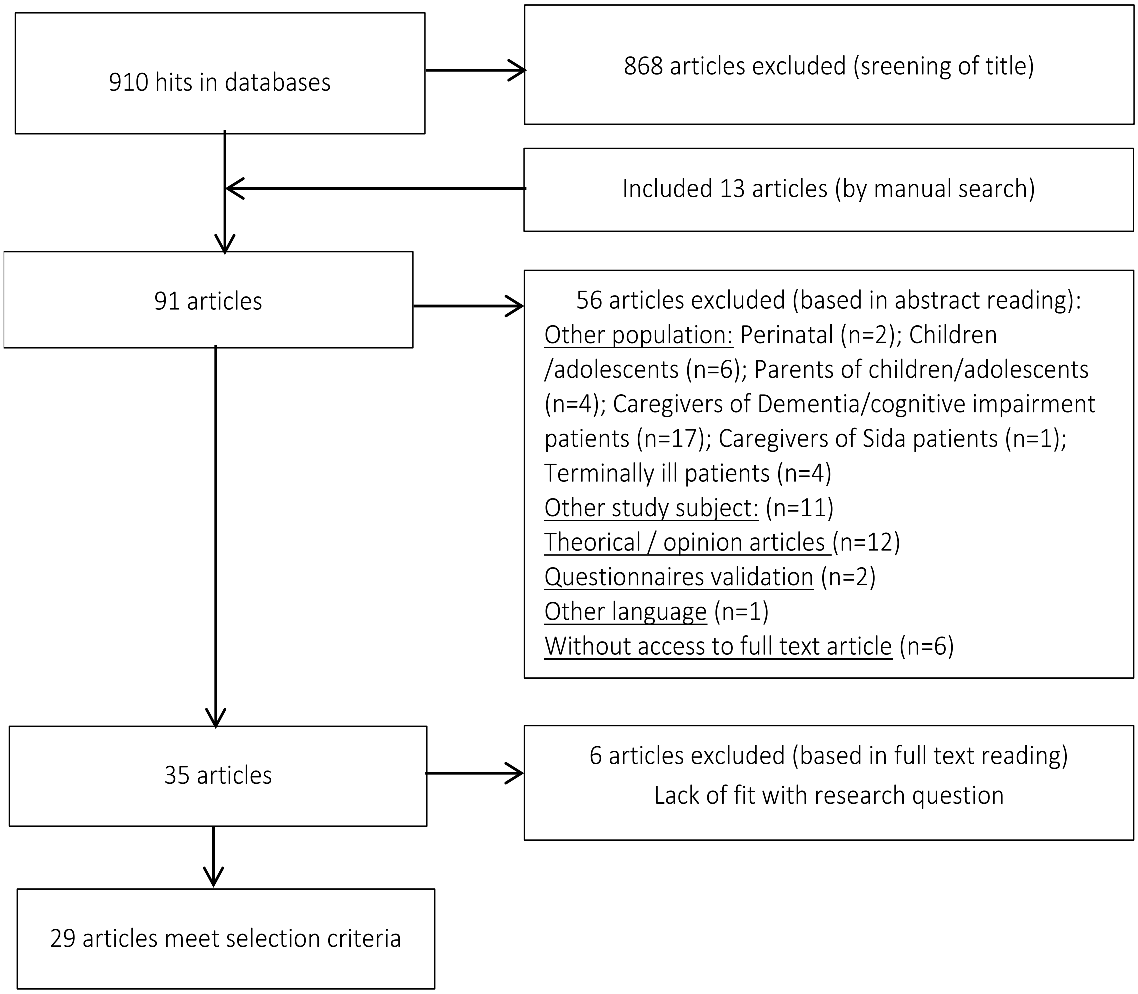

Table 2. Quality of studies assessment criteria

Quantitative Studies Checklist STROBE (adapt.)	Qualitative Studies Critical Appraisal Skills Programme (CASP)
1. Are the objectives and hypotheses well framed and defined?	1. Are the research objectives clearly defined?
2. Is the study design explained and correctly described?	2. Is the qualitative methodology appropriate?
3. Are the criteria and methods of selection of participants well described?	3. Is the study design appropriate to the objectives of the study?
4. Are the variables defined, as well as the instruments of measure?	4. Is the recruitment strategy appropriate to the objectives of the study?
5. Is data collection described, explaining all the moments and methods of application of instruments, allowing the replicability of the study?	5. Was data collected properly according to the objectives of the study?
6. Is data analysis appropriate and a detailed description of the statistical analyses and content done?	6. Is the relationship between the researcher and participants adequately considered?
7. Are the sociodemographic characteristics of participants descripted in detail, including an indication of the numbers and reasons for non-participation?	7. Were ethical considerations taken into account?
8. Is data presented on all studied variables, indicating, where applicable, the statistical degree of confidence?	8. Is data analysis sufficiently rigorous?
9. Are the results summarized giving answers to the objectives and hypotheses of the study and are they interpreted based on theory and previous studies?	9. Are the results clearly described?
10. Are the limitations of the study presented taking into account the possible biases and the possible generalization of the results discussed?	10. Is the research relevant?

Each item is scored in 3-point scale: 2 (well described), 1 (poorly described), 0 (absent or not described), in a total of 20 points.

Table 3: Studies describing family experience of a terminally ill patient

Author, year, country	Objectives	Participants	Design and Methods	Relevant findings	Study Quality
Clukey (2008), USA	To explore the retrospective perceptions of the anticipatory mourning experience of caregivers who had not received hospice services	Bereaved family caregivers (N=9)	Qualitative Retrospective Interviews	Anticipatory grief processes: realization; caretaking; presence; finding meaning; and transitioning	13
Clukey (2007), USA	To explore the anticipatory grief experience	Bereaved family caregivers, in hospice (N=22)	Qualitative Phenomenological Retrospective In-depth interviews	Themes: Being present Being in anticipatory grief: be informed, intuitive knowing, awareness is not preparation, death ends this state	15
Gunnarsson & Öhlen (2006) Sweden	To understand the meaning(s) of spouses' grief before the patient's death	Widows whose spouses died in palliative home care (N= 12)	Qualitative Phenomenological Retrospective In-depth interviews	Themes: Realizing that the partner would soon die, Changed relationship, Fear-inducing feelings, Focusing on doing the utmost for the partner Trying to live as usual, Time slipping away while also standing still.	18

Byrne & Raphael (1997), Australia	To investigate the psychological symptoms experienced by the recently widowed men	Widowed men with more than 65 years old (N= 57) Control group: married men N= 21)	Quantitative Longitudinal Double cohort Three assessment moments: 6 weeks, 6 and 13 months after death	Widowers reported more anxiety and general psychological distress, but no more depression or loneliness than matched married men over the 13 months post bereavement. Anxiety was correlated with intensity of grief but not with duration of wife´s final illness or expectedness of wife´s death.	16
Barry et al. (2002), USA	To evaluate the association between bereaved persons' perceptions of the death and preparedness for the death and psychiatric disorders.	Bereaved family members (N=122)	Quantitative Longitudinal Observational Two evaluation moments: 4 and 9 months after death; Inventory of Complicated Grief-Revised; Clinical Interview DSM-IV	Perception of the death as more violent was associated with major depressive disorder at baseline. Perception of lack of preparedness for the death was associated with complicated grief at baseline and at follow-up.	17
Carr et al. (2001) USA	To examined if older adults' psychological adjustment to widowhood varies based on whether the death was sudden or anticipated and if these effects are mediated by death context characteristics	Widowers (N= 210)	Quantitative Longitudinal Four assessment moments: 6, 18, 42 months Items to evaluate depression, anxiety, psychological reactions to grief, warning time prior death, and death context.	Forewarning did not affect depression, anger, shock, or overall grief 6 or 18 months after the loss. Prolonged forewarning was associated with elevated anxiety both 6 and 18 months after the death. Sudden spousal death elevated survivors' intrusive thoughts at the 6-month follow-up only.	19

Valdimarsdóttir et al. (2004) Sweden	To investigate the predictors and long-term consequences of awareness time of impending death	Widows of patients with cancer (N= 379)	Quantitative, Retrospective Observational Questionnaire of Awareness time, determinants and consequences State-trait Anxiety Inventory Center Epidemiological Studies' measure of depression	During a man's terminal cancer illness, the wife's awareness time varies considerably and is influenced by information and psychological support from caregivers. A short awareness time may result in an additional and avoidable psychological trauma.	16
Marshall et al. (1998), USA	To study the effect of anticipatory grief in post-death adjustment	Students (551) Two independent groups: anticipated loss (N=114) unanticipated death (N=437)	Quantitative, Cross-sectional Case-control Items to assess: Grief symptoms, Level of resolution of the death Perceived benefits associated with anticipating the death; religious affiliation; quality of the relationship; time since death; social support; previous losses	The anticipation group reported better post-death adjustment than the comparison group in grief-related symptoms, acceptance of the death, and perceived helpfulness and harmfulness of anticipation. Within the anticipation group, length of anticipation appeared to have little relationship to post-death adjustment.	18
Penrod et al., (2011), USA	To explore nature, course and duration of caregiving trajectories	Familiy caregivers in grief (N = 46)	Qualitative, Retrospective, Case study Interviews	Common theme: Search for normality. Death anticipation changes end-of-life experience.	10

Saldinger and Cain (2006) USA	To explore the extent to which spouses take advantage of their partner's terminal illness for accommodation to impending death	Widows of cancer patients (N= 30)	Qualitative Retrospective, Interviews	Emphasis is placed on the strains of terminal illness that outweigh the benefits of anticipatory grief, and often preclude the undertaking of anticipatory tasks.	14
Costello (1999), England	To examine the nature of the spouses' experiences in relation to anticipatory grief	Bereaved partners (N=12)	Qualitative Retrospective In-depth interviews	Anticipatory grief has a cumulative, rather than a specific influence on the spouse's bereavement. This experience allows the adaptation to the loss to begin prior to their partner's death	12
Wong & Chan (2007), China	To describe the experiences of family members of terminally ill patients during the end of life in palliative care	Bereaved family members, in palliative care (N=20)	Qualitative Phenomenological Retrospective In-depth interviews	Themes: Grief reactions Committed to care Being with the patient at the last moment	15
Beng et al. (2013) Malaysia	To explore the experiences of suffering in palliative care informal caregivers	Informal caregivers who were taking care of the adult palliative care (N=15)	Qualitative, Cross-sectional Semi-structured interview	Themes: Emphatic suffering Anticipatory grief (perceived impeding death and absence of the patient)	16
Costello and Hargreaves (1998) England	To compare anticipatory grief with conventional grief	Daughter of an oncologic patient (N=1)	Qualitative, Study case	Themes: Anticipatory grief Difficult decisions at end of life Support in the moment of death	3

Spichiger (2009), Switzerland	To explore terminally ill patients' and their caregivers experiences of being in hospital	Family caregivers of cancer patients (N=10) hospitalized general hospital	Qualitative, Cross-sectional, In-depth interviews	Themes: Personal suffering Sense of (not) being integrated in hospital Importance of caring for the patient Consequences of caring for the terminal patient	12
Ziemba and Lynch-Sauer (2005), USA	To study emotional reactions of daughters to multiple losses related to caring care of parents	Bereaved daughters who care for the elderly parents (N=8)	Qualitative Retrospective Semi-structured interviews	Actual and anticipatory losses: Loss of the parent Loss of one's own youth	8
Pereira and Dias (2007) Brasil	To explore the grief process of terminal illness, in hospital	Family caregivers (N=5)	Qualitative, Cross-sectional Phenomenological In-depth interviews	Terminal illness causes intense suffer, anguish, and ambivalent feelings, between guilt and hope. Feeling support helps the caregiver keeping care for the patient.	13
Plakas et al., (2009), Greece	To explore the experiences of patients' families in intensive care units	Family caregivers of patients with multiple diagnosis (N=25)	Qualitative Grounded Theory Interviews	Themes: Intense Emotions Vigilant Attendance Negative emotions are caused by death anticipation, conceptualized as anticipatory grief	17

Butler et al., (2005), USA	To examine pre and post-loss levels of posttraumatic stress symptoms in partners of breast cancer patients, and the relationship of these symptoms to past, current, and anticipatory stressors	Partners of breast cancer (N = 33)	Quantitative Longitudinal Prospective Impact of Event Scale (IES) Anticipation of Loss Inventory	34% experienced clinically significant symptom levels prior to the patients' deaths. Prior to loss, partners' symptoms were positively associated with their current level of perceived stress and anticipated impact of the loss.	15
Pusa et al., (2012), Sweden	To illuminate the meanings of relatives' live experience from diagnosis through and after the death	Relatives of cancer patients in grief (N = 11)	Qualitative retrospective Phenomenological hermeneutic method In-deph interviews	Themes: Being unbalanced Being unbalanced Being transitional Being cared for Moving forward	15
Sutherland (2009), Canada	To explore the meaning of being in transition to end-of-life care among female partners	Female spouses of cancer patients (N=25)	Qualitative Cross-sectional phenomenological. In-depth interviews	Themes: Meaning of Our Lives Dying with Cancer Glimpses of the Future	13
Chapman and Pepler (1998), Canada	To examine the relationships among general coping style, hope, and anticipatory grief	Family members of oncologic patients (N= 61);	Quantitative, Cross-sectional Exploratory Non-death Version – Grief Experience Inventory; Lalowiec Coping Scale; Herth Hope Index	Family members experienced individual anticipatory grief patterns. Death anxiety is preponderant. Emotive coping contributed significant variation in anger/hostility, whereas lack of hope accounted for variation in social isolation.	18
Spichiger (2008), Switzerland	To explore terminally ill patients' and their caregivers experiences of being in hospital	Family caregivers and patients (N=10)	Qualitative, Cross-sectional In-depth interviews	Unique life of the persons who deal with terminal illness Experience of being in hospital Commitment and care of family caregivers	12

Fleming (1999) Canada	To compare the degree of similarity between the grief experienced by spouses of terminally-ill patients prior to (anticipatory grief) and following the death (conventional grief).	Spouses of terminally ill in palliative care (N=30); Spouses of chronically ill (N=31); Spouses of healthy individuals (N=32)	Mixed Longitudinal, correlational, with 2 control groups Two assessment moments: before death; six weeks after death Grief Experience Inventory	These two phenomena are statistically similar with regard to the majority of subscales on the Grief Experience Inventory. Furthermore, when compared with conventional grief, anticipatory grief was unexpectedly associated with higher intensities of anger, loss of emotional control, and atypical grief responses.	16
Hegge (1991), USA	To study the effects of anticipatory grief in caregiving before and after the death	Widows who care for terminally ill patients with multiple diagnosis (N= 26)	Qualitative Cross-sectional Retrospective Interviews	Most frequent problems are the solitude, social isolation, disruption of eating and sleeping pat- terns and independent decision. Caregivers' health improved when those responsibilities were over.	6
Beery et al. (1997), USA	Examined the effects of changes in role function, caregiving tasks, caregiver burden and gratification on symptoms of depression and traumatic grief	Spouses of terminal ill patients with multiple diagnosis (N= 70)	Quantitative Longitudinal Correlational Four assessment moments: before death, 3, 6 and 13 months after; Inventory of Traumatic Grief (ITG Pre-death version) Hamilton Rating Scale for Depression (HRSD)	Level of caregiver burden was associated with the respondent's level of depression and traumatic grief. Changes in role function were associated with the caregiver's level of depression, but not with the caregiver's level of traumatic grief. The fewer tasks performed for the spouse, the greater severity of depressive symptoms.	15

Anngela-Cole and Busch (2011) Hawaii	To compare how family caregivers from a variety of ethnocultural groups emotionally respond to their caregiving role	Family caregivers of oncologic patients admitted in hospice (N=20)	Qualitative, Cross-sectional Phenomenological Phocus group	Different cultural role expectations, coping mechanisms for dealing with stress and grief, and expression of emotion	10
Duke (1998) England	To study the anticipatory grief experience during terminal illness and after the death	Widowers who care for patients in palliative care (N=4)	Qualitative Phenomenological hermeneutic In-depth interviews	Themes: Being with the spouse: being a career and a comforter; in suspense; Being bereaved: experiencing and gathering memories; being alone; cared and comforted; in a turmoil; At the time of interview: being with other as giving and receiving; integrating memories and experiences and balanced	17
Kerr et al., (1994) USA	To explore how meanings of adult daughters attached to their parent´s death influence the duration of their grief	Adult daughters (N=67) who lost a parent	Qualitative Retrospective Semi-structured interviews	How respondents experienced a parent´s death – including their guilt, regrets, anticipatory grief, shifts in other family relationships and changes in their lifestyle – influenced the duration of their grief.	6

Anticipation of death

Anticipation of death refers to the perception of threat to the life of someone close as a result of an advanced and irreversible disease. In qualitative studies, this concept is described as the recognition of the proximity of death (Clukey, 2008) being informed or having intuitive feeling of knowing (Clukey, 2007) and notice that the patient is dying (Gunnarsson & Öhlén, 2006). Quantitative studies evaluate this variable as equivalent to the degree of predictability and preparation for death (Byrne & Raphael, 1997; Barry, Kasl & Prigerson, 2002) or by the period of time the death was expected (Carr, House, Wortman, Nesse & Kessler, 2001; Valdimarsdóttir et al., 2004; Marshall, Catanzaro & Lamb, 1997).

Anticipation of death represents a transition moment in the onset of AG process (Clukey, 2008; Gunnarsson, Öhlén, 2006; Penrod, Hupcey, Baney & Loe, 2011) although it may fluctuate due to uncertainty and hope (Saldinger & Cain, 2005). Some people refuse to deal with the situation of the terminally illness, and although family caregivers accompany the increasing deterioration of the patient, they remain unbelieving about the diagnosis and never quit investing in the recovery of patients (Costello, 1999; Wong & Chan, 2007; Beng et al., 2013). Others recognize the severity of the diagnosis and need to predict how long the patient is going to live, planning and anticipating the death in order to cope with the unpredictability of the path of the disease (Beng et al., 2013; Costello & Hargreaves, 1998; Spichiger, 2008) although often at a cognitive level, only Saldinger & Cain, 2005). This means that not always the cognitive recognition of the proximity of death translates into emotional awareness – the person may recognize the family death cognitively, and still maintain the fantasy that it can be avoidable. Similarly, emotional awareness does not lead to acceptance of death – those who can gradually deal with its proximity, experience resignation and suffering (Beng et al., 2013; Spichiger, 2008). The anticipated perception of death means a threat of loss and therefore represents a main cause of distress during the illness (Saldinger & Cain, 2005).

Emotional distress

Anticipation of death introduces disruption at several levels: family members feel that their reality is continually affected by new and disturbing events and the whole world shakes (Gunnarsson & Öhlén, 2006; Spichiger, 2008) that the relationship with the patient changes, as well as family structure (Clukey, 2008), and soon his whole life will inevitably change (Costello, 1999). This awareness is usually accompanied by intense emotional reactions. Some families report that this perception is accompanied by a physical sensation, like a punch in the stomach (Clukey, 2007), which illustrates the sense of shock and surprise often reported by relatives (Gunnarsson & Öhlén, 2006; Costello, 1999; Wong & Chan, 2007; Beng et al., 2013).

Terminality, although expected, is generally regarded as too sudden (Saldinger & Cain, 2005; Beng et al., 2013). Faced with the imminent loss, people react with separation anxiety (Ziemba & Lynch-Sauer, 2005; Saldinger & Cain, 2005; Plakas, Cant & Taket, 2009) and concerns about the future (Clukey, 2007; Gunnarsson & Öhlén, 2006; Beng et al., 2013; Pereira & Dias, 2007; Butler et al., 2005). This state of fear persistent is referred as ruminative anxiety (Saldinger & Cain, 2005; Beng et al., 2013). Several motives were mentioned: uncertainty about the evolution of the disease (Saldinger & Cain, 2005; Costello, 1999; Sutherland, 2009) and their ability to meet the requests that will arise, particularly in emergency situations (Gunnarsson & Öhlén, 2006; Saldinger & Cain, 2005; Bemg et al., 2013); fear of the patient suffering, that s/he has a painful death (Gunnarsson & Öhlén, 2006); fear of their own reaction to the death (Clukey, 2007) and of this happens at any moment (Beng et al., 2013). According to Gunnarsson and Ohlen (2006), when fear dominates there is no space for the grieving process.

Caregivers ruminate about feelings of sadness, for losing a loved one and for the patient suffering (Clukey, 2007; Beng et al., 2013; Spichiger, 2009). Living in the proximity of the patient suffering, caregivers experience feelings of helplessness (Gunnarsson & Öhlén, 2006; Beng et al., 2013; Pusa, Persson & Sundin, 2012) and compassion fatigue (Costello, 1999; Beng et al., 2013). Therefore, they experience more or less deep feelings of depression, manifested by sadness and apathy (Costello, 1999; Pereira & Dias, 2017). Caregiver also manifest intense feelings of anger directed to the disease (Clukey, 2007) or to the sick person, because of the sense of abandonment (Hegge, 1991). Hostility may also be projected to the health professionals, due to conflicts in decision making, or to other relatives, related to the perception that they are free of the burden of caring (Costello & Hargreaves, 1998; Hegge, 1991) or by neglecting the patient (Pereira & Day, 2007). Some people question God, "Why?" (Hegge, 1991; Beng et al, 2013). In other cases, anger is directed to themselves, as a sense of frustration (Pusa et al., 2012) or guilt by the uncertainty of having taken the right decisions (Gunnarsson & Öhlén, 2006) or by the failure to prevent death (Wong & Chang, 2007).

Intrapsychic and interpersonal protection

Many families protect themselves from this painful reality by triggering intrapsychic protection mechanisms. Repression of feelings and numbness allow them to anticipate and plan practical aspects without being overwhelmed by emotional burden (Clukey, 2008; Saldinger & Cain, 2005). There is also a tendency to rationalize (Pereira & Dias, 2005) or to be distracted with the structured routines imposed by caregiving responsibilities (Costello, 1999; Penrod et al., 2011; Costello, 199). Others develop a religious belief that everything is decided by God, so they pray and seek protection in a transcendental entity (Beg et al., 2013).

Some people cry alone, as a way to relieve tension, but this expression may be seen as a sign of weakness (Pereira & Dias, 2007), so it tends to be suppressed, for interpersonal protection, because the whole family is under stress. (Saldinger & Cain, 2006; Beng et al, 2013). To avoid the emotional burden of the patient (Costello, 1999; Pereira & Dias, 2007) the caregiver escapes from talking about death or even referring the word death in conversations (Gunnarsson & Öhlén, 2006; Costello, 1999; Spichiger, 2009; Duke, 1998). Instead, they continue to talk about common projects for the future (Costello, 1999).

Family keep the communication closed for several reasons: bringing together the aspects of anticipating death would be an emotionally painful conversation which they feel unable to have (Gunnarsson & Öhlén, 2006; Wong & Chan, 2007); an open discussion can symbolically confirm the reality of an impending separation, so the family choose to share common hopes only (Saldinger & Cain, 2006; Duke, 1998); besides, forewarning death is felt as a disloyalty to the patient. Another argument is the explicit message from the patient that s/he does not want to address the experience of anticipating death. However, in most cases, the closed communication is an unconscious reflection of the survivor’s desire to avoid the proximity of death of the significant other. Even this may compromise the intimacy of the relationship, they do it with the conviction that they are providing a good death to the patient (Saldinger & Cain, 2006; Costello & Hargreaves, 1998).

Hope

The presence of the patient allows hope and accentuates the sense of responsibility of the caregiver, who is willing to sacrifice everything to keep the patient alive; ultimately, this guarantees that the relative continues, absorbing all their attention and becoming the sole focus of thoughts, feelings and actions (Beng et al., 2013).

Chapman and Pepler (1998) stress that there is an inverse relationship between hope and signs of AG. However, hope remains in the entire end-of-life trajectory, though it changes along this process. Initially, the family hopes that everything returns to normal, that the patient's suffering ceases and life will no longer be the chaos that it is now; hopes that the patient continues to fight and stays healthy; that s/he remains independent and experiences more moments of joy; that s/he lives longer if the family is happy and remains a positive environment (Beng et al., 2013); that the patient shows everyone they are wrong and will be able to recover (Castello, 1998). Some families reported that sustained hope of recovery is not to create false expectations – it is, rather, a way of supporting the current situation, even though death is the most likely outcome (Clukey, 2007; Sutherland, 2009). Others lose hope before the signs of death: when the patient stops eating, talking and responding (Beng et al., 2013). But gradually, the family´s hope starts to focus on other aspects: that the patient dies peacefully (Gunnarsson & Öhlén, 2006) or that s/he feels they played their role of caregivers well, achieving relief from suffering. Hope also focuses on aspects of the relationship – that the patient becomes aware of how important s/he is and how s/he was loved by them; that s/he knows how his/her presence will be missed and, at the time of death, s/he heard the words of affection and reassurance (Clukey, 2007).

Exclusive focus on the patient care

There is a compulsion to help, due to the perception of the patient's suffering, which is experienced both as a duty and a will (Gunnarsson & Öhlen, 2006; Spichiger, 2009; Beng, 2013). Facing end-of-life, family value more the time spent with the patient, and they want to learn how to care (Wong & Chang, 2007; Clukey, 2008; Wong & Chang, 2007). This task is assumed with the purpose of being present (Clukey, 2007, 2008) and to compensate for the weaknesses of the illness, relieving the suffering (Pusa et al., 2012; Spichiger, 2008). But it is also as way to mitigate their own sense of powerlessness (Pusa et al., 2012), by feeling that they did their best and they are a good family (Pereira & Dias, 2007). The assistance to the patient may imply providing support only in some activities or remaining constantly beside the patient, ensuring comfort, companionship and emotional support (Clukey, 2008; Beng et al., 2013; Spichiger, 2009). Many families claim the need to be physically present to ensure the touch and communication with the patient, and that all his/her wishes are met (Clukey, 2007; Spichiger, 2009).

Personal Losses

Although the motivations to care bring them a strength that many of the relatives were unaware of (Gunnarsson & Öhlen, 2006), it is inevitable that the family is affected by the increasing caregiver burden, especially by work overload (Clukey, 2007, 2008; Gunnarsson & Öhlen, 2006; Beng et al., 2013; Hegge, 1991) and sleep deprivation (Gunnarsson & Öhlen, 2006; Beng et al., 2013) due to permanent hypervigilance 8Pereira & dias, 2007). However, the perception of burden is a subjective response to the act of caring, so it is not directly related to the amount of tasks in the provision of patient care. In fact, the amount of tasks is inversely correlated to the level of depression, which means that the family benefit from some sort of routine and structure in care (Beery et al., 1997).

Restrictions on personal autonomy of the family are another consequence of the exclusive focus on the patient. The caregivers´ need to adapt their life to the demands of presence and caring (Clukey, 2007) results in the limited sense of freedom and suppression of personal needs (Clukey, 2008; Gunnarsson & Öhlen, 2006; Wong & Chan, 2009; Beng et al., 2013; Spichiger, 2008, 2009). Therefore, caregivers refer to this period as a time of waiting, during which they only survive, without space or interest for their previous activities or social contacts, with the feeling that the world has become monotonous and restricted, and the future was postponed indefinitely (Clukey, 2008;

Gunnarsson & Öhlen, 2006; Wong & Chan, 2009; Beng et al., 2013; Spichiger, 2008, 2009; Anngela-Cole & Busch, 2011).

Relational losses

But before confronting the real loss of the patient, the family realize the relational losses resulting from physical and emotional degradation. The feeling of absence starts at the moment that family is forced to play the role of the patient (Beng et al., 2013). Assuming the tasks that the patient used to perform confronts caregivers with the patient´s current disability (Saldinger & Cain, 2006; Costello, 1999) making them more aware of the proximity of death. Gradually, they recognize that he/she is not the same person and feel the absence, although the patient is still alive. The family especially feel the loss of intimacy and reciprocity in the relationship (Beng et al., 2013; Pusa et al., 2012). Here begins a deep sense of loneliness (Gunnarsson & Öhlen, 2006; Saldinger & Cain, 2006; Beng et al., 2013; Chapman & Pepler, 1998) which is even more intense when the patient stops talking and responding, setting the end of the relationship (Saldinger & Cain, 2006; Beng et al., 2013; Pusa et al., 2012).

Ambivalence

Thinking about death while the person is still present raises several dilemmas that cause intense ambivalence: caregivers should keep their ability to function in a combative way against the disease and simultaneously handle the tasks of end-of-life (Saldinger & Cain, 2006; Pusa et al., 2012) it is also expected to take care to preserve the dignity of the sick person and, at the same time, grieve the loss of his/her personality (Sutherland, 2009) relatives must respect the autonomy of the patient, while questioning the patient's ability to decide what is best for the situation (Pusa et al., 2012); one has to choose between the sense of loyalty to the patient, keeping exclusive devotion to him/her or, at the other hand, to seek support in order to ease the burden, in spite of the guilt that it carries (Costello, 1999; Pusa et al., 2012). The caregiver must also face the decision regarding the place of death: although hospitalization may represent a relief from overload, they worry about maintaining contact and fear that a sudden worsening prevents them from seeing the patient. All these conflict situations cause stress to the caregiver, since they add blame for not being certain about the right decision (Gunnarsson & Öhlen, 2006). The exception is the coexistence of feelings of joy and sadness, emerging from the positive aspects of care at end-of-life, mainly related to the presence and the ability to communicate with the patient (Pusa et al., 2012).

End of life relational tasks

In most cases, the increased physical proximity inherent to caregiving also corresponds to an emotional closeness (Pusa et al., 2012). Some families experience remorse for not having spent more time with the patient in the past; therefore, they reinforce the dedication and feel the need to intensify the relationship with the person who is dying (Clukey, 2007) completing end-of-life relational tasks such as reviewing life events, talking and sharing with the patient significant experiences ((Clukey, 2007, 2008; Gunnarsson & Öhlen, 2006) and solving previous problems (Clukey, 2007; Gunnarsson & Öhlen, 2006; Kerr, Ross & Cowles, 1994).

This is also the moment the family perspectives the future absence of the patient. Some have great difficulty to foresee the future; others anticipate loneliness, sadness and emptiness in later life. Some of them worry for not knowing what to do, since they were accustomed to share decisions with the patient. They are grieving the loss of a common future, plans that have been established and the expectation of been cared by the patient in the future. In the case of spouses, they do not imagine to get out of home because of loneliness, but also do not think of rebuilding a new family and intend to visit the cemetery every day (Beng et al., 2013; Spichiger, 2008).

Often, it is the patient who conveys information and instructs the survivor about tasks that he/she has never realized (Gunnarsson & Öhlen, 2006). The patient may also leave the legacy and express desires, including in relation to the funeral or economic aspects (Duke, 1998). These manifestations are valued and the family strives to meet them (Clukey, 2007).

Still, they all maintain some degree of avoidance to protect themselves from the emotional pain of these moments of farewell (Duke, 1998). In some cases, planning the practical things is the only task that family members can carry out, and yet these plans are performed in hypothetical thinking: "If it happens ...". For others, the symbolic meaning of planning the practical aspects is enough to prevent them from realizing these end-of-life plans. Saldinger and Cain (2005) note that it is the exclusive focus on caring for the patient and the denial of impending death that allow the caregiver to continue to function. But, often the caregiver burden is impeditive of anticipating death and realizing the end-of-life relational tasks. Therefore, the authors reiterate their position that, for many people, the anticipation of death is more a stress factor than an opportunity.

Transition

After an emotional intense period of care, many people perceive that death has ended the patients suffering and their own burden, and feel relieved (Clukey, 2007; Costello, 1999; Wong & Chan, 2007). Even those that continued to believe in possibility of patient´s healing are able, at death, to abdicate the role of caregiver and let him go (Costello & Hargreaves, 1998). Some can actually say goodbye to the patient before death (.[17,18] However, for other family members, the sense of tranquillity and the intention to continue is not present. Some people reported that the pain of grief has never before been as intense as at the time of death (Clukey, 2007), and that despite the relief they feel, it does not lessen the pain of loss ((Clukey, 2007; Costello, 1999).

Results Summary

Based in the preceding analysis, conceptual definition of AG was synthetized as follows: family distressing process of anticipation the patient´s loss and transition to a different reality, in the absence of the significant other, characterized by ambivalence between two main dimensions: one the one hand, the recognition of death proximity due to current personal and relational losses; on the other hand, the mutual protection from this painful reality and sustaining hope in order to keep functioning and caring for the ill person.

Discussion of Results

This integrative review intended to reach a deeper level of conceptualization of AG by identifying the nuclear characteristics of the phenomenon and contributing to its definition. Since the concept of AG is operationally vague, it is essential to use the qualitative methodology, from which categories of analysis empirically based emerge, illuminating the subjective experiences and the meanings attributed by the participants themselves, rather than exclusively using the standardized instruments that mainly reflect the researcher's framework.

From systematic comparison of data referring to family end-of-life experience emerged ten themes, which correspond to the AG nuclear characteristics. These results lead to a conceptual definition that encompasses the mutual relationships between nuclear characteristics and highlights the multidimensional and dynamic nature of this process.

Despite of reservations concerning AG concept, we consider it reflects the anticipation of death, which is probably the aspect that better distinguishes AG from other forms of grief process, namely the "bereavement", where the loss has already occurred, and "indefinite loss", characterized by the experiences of carers outside of the terminal stage, where the future loss of the patient remains uncertain (Oslon, 2014). Yet, AG is not restricted to anticipation of death. As suggested by Fulton et al., (2003) forewarning of loss cannot be equivalent to AG. Indeed, this may have been a confounding factor, responsible for contradictory data referring the subject. AG process is strongly influenced by socio-cultural representations of death and dying that states an attitude of avoidance toward this reality (Lehto & Stein, 2009). In modern occidental society, family members tend to protect each other from the emotional distress related to the pain of loss. This leads to ambivalence, another nuclear characteristic of this process. Aldrich (1974) stated that ambivalent feelings are harder to solve while the patient is still alive and particularly vulnerable, so the denial is more likely to persist during the anticipation period.

Finally, this conceptualization of AG introduces personal and relational losses to reflect the disruption this experience represents in caregiver´s life. This aspect is equivalent to past, present and future losses in Rando´s definition (1986). However, instead of focusing in course of time, we emphasize relational losses as the specific characteristic of AG: the loss of the relationship with the significant other, while s/he is physically present.

Limitations

Although most samples were composed mostly by family of cancer patients, there is some heterogeneity that can influence dispersion of reactions. Caution is also warrant concerning retrospective studies on AG experience. Another restriction is related to the cultural context of these studies, so it does not allow generalization of this conceptualization. Lastly, because of focus of this review, selected studies were mainly centered in internal experience of family caregiver anticipatory grief, so the systemic issues related to family relationship were not included, which could potentially add clarity to the findings around interpersonal aspects of this phenomenon.

Conclusions

This literature review serves the purpose of clarifying the conceptual issues about AG. Selected population was the family caregivers in context of advanced disease and end-of-life, most of them with oncologic disease in occidental culture. Findings were grouped in ten themes, which correspond to AG nuclear characteristics. Analysis of results confirms that this is multidimensional and dynamic process. The heuristic value of this concept concerns to its clinical implications, considering that a better understanding of this phenomena will promote a more sensitive intervention. Particular attention should be paid to increase awareness about ambivalent feelings, normalizing these reactions in order to reduce caregiver´s guilt and to promote family communication.

Future research should also focus on studying relation AG mediators and its influence in bereavement. Another topic of interest refers to the relationship between AG experience and decision making regarding end-of-life care.

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2. EMPIRICAL STUDY I

PORTUGUESE VALIDATION OF PROLONGED GRIEF DISORDER QUESTIONNAIRE - PRE-DEATH (PG-12): PSYCHOMETRIC PROPERTIES AND CORRELATES

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PORTUGUESE VALIDATION OF PROLONGED GRIEF DISORDER QUESTIONNAIRE - PRE-DEATH (PG-12): PSYCHOMETRIC PROPERTIES AND CORRELATES

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Abstract

Objectives: This study aimed to contribute to the Portuguese validation of Prolonged Grief Disorder Questionnaire - Pre-death (PG-12), examining its psychometric properties, including factorial, discriminant and predictive validity. The Pre-death Prolonged Grief Disorder (PGD) prevalence and its psychosocial correlates were also analysed. Method: PG-12 was assessed in a sample of family caregivers (FC) of oncologic patients in palliative care. Factorial and discriminant validity of PG-12 were evaluated by confirmatory factor analysis (CFA). Pre-death Prolonged Grief Disorder (PGD) prevalence was calculated and correlated with sociodemographic characteristics, perception of illness, intensity of care, coping and caregiver burden. Prospective data was used to assess predictive validity. Results: The sample was composed of 94 FC, mostly female (78.8%) and daughters (61.3%) with mean age of 52.02 (SD= 12.87). PG-12 have shown to be reliable, with high internal consistency, monofactorial structure and independent from Depression, Anxiety and Burden, although Pre-death grief influences these symptoms. In this sample, 33% met criteria for Pre-death PGD. Circumstances and coping mechanisms are also correlated with Pre-death Grief. PG-12 revealed to be predictive of post-death outcome. Significance of Results: PG-12 can be a useful screening tool for early identification of FC at risk of maladjustment to loss.

Keywords: Pre-death Grief, Prolonged Grief Disorder, Confirmatory factor analysis, Discriminatory validity, Predictive validity

Introduction

Caregiving in the context of a seriously illness represents a great demand for the family members. In addition to the strain that stems from the caregiving role, family is exposed to the patient´s deterioration and to multiple losses (Bevans & Sterberg, 2012; Li et al., 2013; Adelman et al., 2014; Revenson et al., 2016). Family caregivers (FC) experience personal losses due to restrictions of autonomy and suppression of their own needs, as well as relational losses, such as deprivation of intimacy and reciprocity with the patient, causing intense feelings of grief while the relative is still physically present (Coelho & Barbosa, 2016). Grief during caregiving has been operationalized as Anticipatory Grief (Lindemann, 1944/1994; Rando, 1986b, 1988), but recent research uses predominantly the terms “pre-death” or “pre-loss grief”, because it merely indicates the presence of grief symptoms before the patient´s death (Nielsen et al., 2016).

Research on caregivers´ grief has been using PGD-12 as a valid screening tool for assessing pre-death grief. PG-12 consists in a minor adaptation of Prolonged Grief Disorder Questionnaire (PG-13) created to assess grief experience related to illness, rather than the death of the person (Prigerson et al., 2008). As a diagnostic instrument of Prolonged Grief Disorder (PGD), requires the following criteria: 1) event: respondent is experiencing the severe illness or the loss of a significant other; 2) separation distress: characterized by manifestations of longing and yearning; 3) emotional cognitive and behavioural symptoms: include avoidance of remainders, diminished sense of self, feeling stunned or shocked for the patient´s illness, trouble accepting it, bitterness, numbness and sense of meaningless, 4) impaired social and occupational functioning. In PG-13, there is an additional temporal criterion that requires six months of persistent grief symptoms after the loss of the family member (Prigerson et al., 2009).

Symptomatology associated to PGD is distinguishable from manifestations of normal grief (Boelen & van den Bout, 2008; Dillen et al., 2008) and only the former are associated with significant impairment (Latham & Prigerson, 2004; Simon et al., 2007; Marques et al., 2013). PGD symptoms, trajectory and risk factors differ from other psychiatric conditions, both in bereaved (Ogrodniczuk et al., 2003; Boelen, & van den Bout, 2005) and caregivers (Kiely et al., 2008; Chiambretto et al., 2010; Guarnerio et al., 2012).

Most studies using PG-12 to investigate pre-death grief were carried out with the population of FC of patients in vegetative state. Guarnerio et al., (2012) assessed 40 caregivers of patients in vegetative state or minimally conscious state and observed that, although significant correlations emerged among symptom domains of PGD, depression and Post-Traumatic Stress disorder, in a categorical perspective, no relevant association was found, so they should be considered independent nosological entities. Chiambretto et al., (2010) also distinguished caregivers' grief from depression: in a sample of 45 family members of patients in a vegetative state, 20% met criteria only for PGD, and the total prevalence was 35,5%. In a similar sample, PGD prevalence value reached 38.5%, and it did not change during time, suggesting this is a stable condition, unlike other caregiver´s distress indicators (Bastianelli et al., 2014).

Data concerning FC of patients in vegetative state suggest that the young age of the family member and the patient is associated to higher risk of PGD (Chiambretto et al., 2010). Other studies using PG-12, also in a sample of caregivers of patients with disorders of consciousness, assessed caregivers' coping strategies associated to pre-loss grief. Acceptance demonstrated to be highly protective of PGD, while Denial and Self-blame were associated with an increased presence of PGD (de la Morena & Cruzado, 2013). In Cipolletta et al., (2013), the group of highly stressed caregivers, including those with PGD, used more Avoidance strategies.

Kiely et al., (2008) evaluated 315 health care proxies of nursing home residents with advanced dementia. Results corroborated that pre-death grief symptoms were associated with, but distinct from those of depression. Separation distress was the most frequent grief symptom. Higher values of pre-death grief were registered in those individuals whose primary language was not English, who lived with a resident before institutionalization, had more depressive symptoms, were less satisfied with care, and when the resident relative was younger.

A comparative study between PG-12 and other self-reported measure of pre-death grief, designed specifically for use with dementia caregivers, the Marwit-Meuser Caregiver Grief Inventory-Short Form (MM-CGI; Marwit & Meuser, 2005), verified that both of these measures can be used reliably with these caregivers. It also proved the convergent validity of each measure. A significantly smaller proportion of the caregivers met diagnostic criteria for PGD with the PG-12 (7%) comparing to the prevalence obtained by MM-CGI (27%), which has a less rigorous criterion of scoring (Mulligan, 2011).

In palliative care, PG-12 was applied to 301 FC, and 15% of the participants met the PGD criteria. Caregivers who had a probable anxiety and/or depressive disorder also reported higher levels of pre-loss grief than caregivers without these disorders. Lack of family support, greater dependency and greater impact of caregiving in health were related to pre-loss grief (Hudson et al., 2011). Prospective data ascertained that PG symptoms at pre-death were a strong predictor of both PGD symptoms at six and 13 months post-death, which demonstrates the predictive value of PG-12 of bereavement outcome, in accordance with Thomas et al., 2014).

Previous studies have provided evidence for the discriminant validity of this measure. PG-12 has also good internal consistency, with values of Cronbach alpha of 0.88 in a sample of 45 FC of patients in vegetative state (Chiambretto et al., 2008), .87 in a sample of 202 dementia FC (Mulligan, 2011) and .78 in a sample of 39 cancer FC (Prigerson, 2008). Studies also are consistent concerning the mono-factorial structure of the scale (Chiambretto et al., 2008; Mulligan, 2011). Other versions of this instrument varying in length from 4 to 19 items have been used with caregiver samples (Tomarken et al., 2008; Prigerson et al., 2003; van Doorn et al.,1998; Beery et al., 1997) and patients (Jacobsen et al., 2010).

The early detection of PGD avoids pathologization of pre-death grief normal manifestations and promotes the recognition of those caregivers who might present greater vulnerability in posterior adjustment to loss. The aims of this study are: a) traduce, adapt and contribute to Portuguese validation of PG-12, examining its confirmatory factor validation, reliability, discriminant and predictive validity; b) determine the prevalence of PGD in a population of oncologic patients FC assisted in palliative care; c) identify the psychosocial factors that contribute to pre-death PGD (sociodemographic characteristics, perception of illness and intensity of care, coping and caregiver burden).

Methods

Participants

The sample, selected by convenience, was composed of FC of cancer patients followed in Palliative Care Unit of the Hospital of Santa Maria, Lisbon, Portugal. As family caregivers, we considered 'family members, friends and other people who have significant non-professional or unpaid relationships with a patient'. The exclusion criteria were: individuals under the age of 18 years; with cognitive impairment or physical/mental disorder that hamper the ability to respond to the instruments; who did not speak Portuguese. Participants were informed about the purpose of the study and an informed consent was requested.

Instruments

PG-12 is a 12-item, self-report questionnaire for the diagnosis of PGD pre-loss. Respondents are asked to rate on a 5-point Likert scale (''1'': almost never; ''5'': always) how often they experience distressing grief symptoms. PGD requires the following criteria: score of four or five on either in items 1 or 2, indicating that separating distress is present at least daily; a score of four or five on at least five of items 3 to 11, indicating that cognitive, emotional, and behavioural symptoms are present daily or quite a bit and overwhelmingly. The last item is dichotomic; the respondents have to answer "Yes" to meet the Impairment criterion. Examples of items are: "In the past month, how often have you had intense feelings of emotional pain, sorrow, or pangs of grief related to (patient's) illness?", "Do you feel that life is unfulfilling, empty, or meaningless since (patient's) illness?".

PG-13 is a 13-item self-report questionnaire for the diagnosis of PGD post-loss. It is equivalent to PG-12, but includes one more item, also dichotomic, in which respondents have to answer "Yes" to meet the temporal criteria. This instrument was validated for Portuguese population by Delalibera, Coelho & Barbosa (2011). The internal consistency was considered very good (α=.932).

Depression and anxiety symptoms were evaluated by the subscales of depression (6 items) and anxiety (6 items) of Psychopathological Symptom Inventory (BSI; Derogatis, &

Melisaratos, 1983), validated for the Portuguese population by Canavarro (1999). Items are rated on a 5-point Likert scale (0: almost never; 4: always). According to Portuguese normative values, the cut-off point to Depression sub-scale is 0.89 and to Anxiety is 0.94.

Caregiver burden was assessed by the Zarit Burden Interview validated for the Portuguese population by Ferreira et al. (2010). The scale contains 22 items with scores ranging from 0 (never) to 4 (always). According to Portuguese normative values, cut-off point is 17.

Coping mechanisms were evaluated by Brief Cope (Carver, 1997), in Portuguese adaptation of Ribeiro & Rodrigues (2004). It is composed by 28 items, ranging from "I have not been doing this at all" to "I have been doing this a lot", scored from 1 to 4. The scores were averaged in pairs to produce 14 coping dimensions.

A questionnaire was used for sociodemographic characterization. Data concerning perception of illness and intensity of care (length and amount of hours of daily caregiving) were evaluated through structured questions in a 5 point likert scale. Examples of items are: “Were you expecting this diagnosis?” (1: not at all; 5: totally), “How much time do you daily spend caring for your relative?” (1: less than 2 hours, 5: more than sixteen hours).

Procedure

The process of translating, adaptation and validation of PG-12 to Portuguese population occurred according the phases stipulated by Beaton, Bombardier, Guillemin, & Ferraz (2000). Initially, we asked for the author´s authorization to perform this study. Then, two independent translations to Portuguese were made by bilingual translators. Translations were based in PG-13 portuguese validation. A consensual synthesis of these versions was conducted. Then, it was translated back into the original language by an independent translator to make sure that the translated version was reflecting the same item content as the original versions. The committee of psychologists reviewed all the translations and reached a consensus, in order guarantee semantic, idiomatic, experiential and conceptual equivalence. Then, the final version was subjected to a pre-test with 10 FC to verify the items comprehensibility and check difficulties in the interpretation of the questions. Based on the respondents´ comments, some adaptations were made and the final version of PG-12 was concluded.

FC assisted in palliative care during March 2104 to June 2016 were contacted and invited to collaborate in this study. Those who agreed to participate responded to PG-12, depression and anxiety sub-scales and demographic questionnaire. They could choose to fill in the questionnaires on paper (presently, take home and return by hand or by mail) or electronically (through an online questionnaire). A second assessment moment was conducted in order to verify the predictive validity of PG-12. We contacted the participants, at least 6 months after the patient´s death, to apply PG-13 and sub-scales of depression, anxiety and somatization Those who agreed to participate answered the questionnaires by phone, mail or electronically. Individuals who manifested the need of psychological support were referred to Bereavement Consultation.

The present study was approved by the Ethics Committee of Hospital de Santa Maria (reference No. 344/14).

Data Analysis

Descriptive data was analysed using the SPSS (Statistical Package for Social Sciences) version 22.0 and factorial validity of the PG-12 was evaluated by confirmatory factor analysis (CFA) with Amos (Analysis of Moment Structures).

Descriptive statistic (frequency and percentage) was used for sociodemographic characterization of the sample. Means and standard deviation of each item were calculated. The psychometric sensitivity of the PG-12 was evaluated through the measures of central tendency and form, and the normality of the variables through the asymmetry coefficients (*sk*) and kurtosis (*ku*) and the respective standard error (*s.e.*). The *sk* values are considered suitable when less than 3 and when *ku* is less than 7 (Maroco, 2010). In this analysis, item 12 was excluded since it is a dichotomic variable.

Several fit indices were selected in order to test which CFA model best represents the present dataset: root-mean-squared error of approximation (*RMSEA*), which is a measure of the average of the residual variance and covariance; comparative fit index (*CFI*), chi-square, and change in chi-square, given the change in degrees of freedom between models. According to Maroco (2010) ratios model adequacy are considered satisfactory when *RMSEA* value is less 0.10, change in chi-square less than 3 and CFI index is higher than 0.90. *CFA* was also used to test the divergent validity between PG-12 and depression and anxiety BSI subscales. We also assessed the influence of PG-12 in BSI items using regression values.

Internal consistency was assessed by Cronbach's alpha (α). This index is used to measure the internal consistency of a scale, or to assess the magnitude of the items of apparatus are correlated to each other. Usually, alpha values between 0.80 and 0.90 are preferred (Streiner, 2003).

Predictive validity was tested with correlations and simple linear regression between PG-12 and the follow-up variables: PG-13 and depression, anxiety and somatization BSI subscales.

Results

Descriptive Analysis

Sample was composed of 94 FC of oncologic patients. As described in Table 1, the majority was female (78.8%), daughter (61.3%) of the patient, married (79.9%), with mean age of 52.02 (SD= 12.87), who completed high school or graduation (57.9%).

In this sample, 33% met criteria for Pre-death PGD. Mean value of PG-12 was considered moderate (M = 34.35; S.D = 9.53; Amplitude: 13 - 56). According to the instruments´ cut-off points, levels of caregiver burden are significant in 85.9, depression symptomatology is present in 67.4% and anxiety in 62%.

Table 1. Sociodemographic characteristics

	Participants (N= 94)
Age Mean (S.D)	52.02 (DP= 18.87)
Amplitude	18 - 79
Gender N (%)	
Male	20 (21.3)
Female	74 (78.8)
Marital status N (%)	
Single	13 (13.8)
Married	75 (79.9)
Widow	1 (1,1)
Divorced	5 (5.3)
Scholarity N (%)	
Elementary school	8 (8.4)
6º Grade	5 (5.3)
9º Grade	13 (13.8)
12º Grade	27 (27.7)
Technological school	7 (7.4)
Graduation	25 (26.6)
Master	4 (4.3)
Kinship N (%)	
Spouse	30 (31.9)
Offspring	57 (60.6)
Parent	2 (2.1)
Sibling	1 (1.1)
Other	3 (3.3)

Confirmatory Factor Validation and Internal Consistency Reliability. The normality of the sample was confirmed by the values of assimetry (*sk*) and kurtosis (*ku*). The highest mean values were obtained in the two first items, corresponding to daily frequency of separation distress symptoms (Table 2).

Unidimensional model of PG-12 was tested. Goodness of fit revealed poor quality of this original model in most indexes, except in X^2/df. As shown in Figure 1, model was modified by correlating the error of items 1 and 2, 2 and 4 and 9 and 10, and this adjusted model had a significant improvement of fit indexes (x^2 (3) = 51.726; $p < 0.05$] (table 3).

Itens of PG-12 present a high internal consistency (Alpha de Cronbach = 0.846), and none of the items affects negatively the consistency of the scale (Table 4).

Table 2. Amplitude, mean and sensibility of PG-12 items

Variável	min	max	mean	*s.d.*	*sk*	*s.e.*	*ku*	*s.e.*
1	2.000	5.000	4.626	.724	-1.975	.253	3.246	.500
2	1.000	5.000	4.285	1.088	-1.441	.253	1.031	.500
3	1.000	5.000	1.932	1.498	1.258	.255	-.116	.506
4	1.000	5.000	3.370	1.562	-.349	.255	-1.434	.506
5	1.000	5.000	2.244	1.357	.649	.249	-1.010	.493
6	1.000	5.000	3.351	1.419	-.555	.249	-1,072	.493
7	1.000	5.000	1.670	1.176	1.644	.249	1.444	.493
8	1.000	5.000	3.872	1.184	-1.216	.249	.755	.493
9	1.000	5.000	3.000	1.451	-.086	.249	-1.354	.493
10	1.000	5.000	3.223	1.228	-.368	.249	-.851	.493
11	1.000	5.000	2.712	1.411	.222	.249	-1.336	.493

Table 3. Fit indexes of models

Indexes	Initial Model	Adjusted Model
χ^2/df	2.330	1.545
CFI	0.748	0.919
TLI	0.637	0.876
RMSEA	0.127	0.070
PCFI	0.518	0.601
MECVI	2.578	2.035

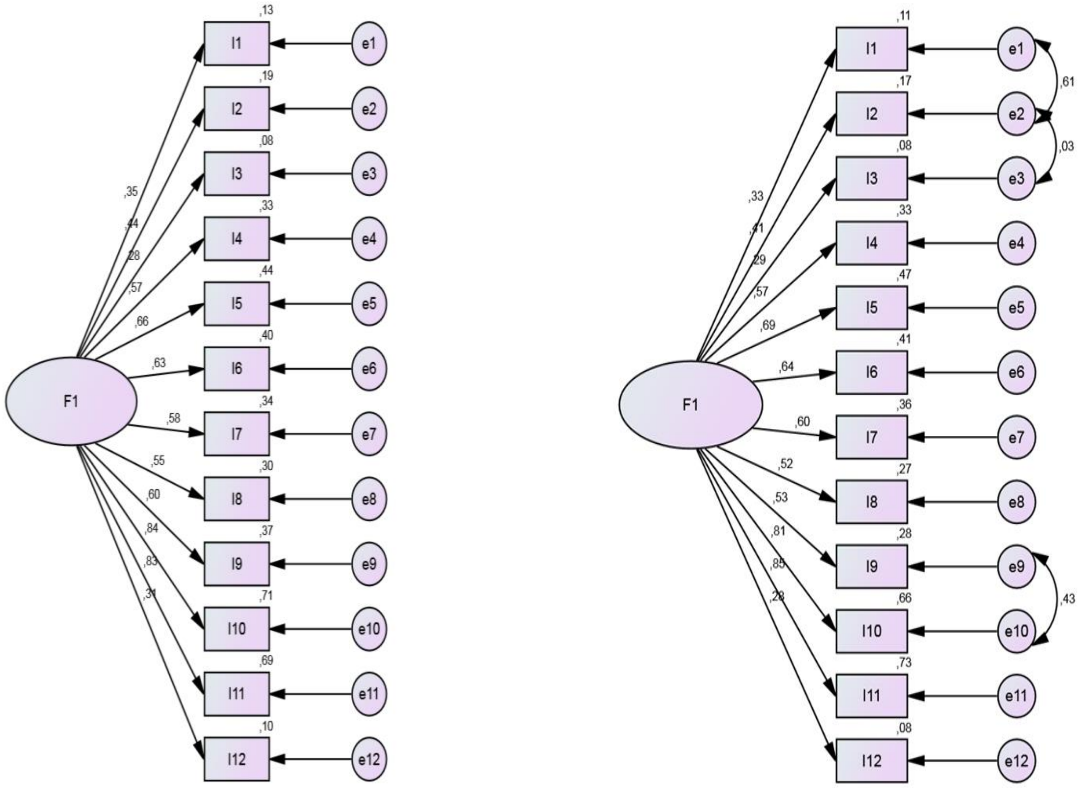
Divergent Validity. A confirmatory factor validation was conducted to evaluate if PG-12 is conceptually distinct from Depression and Anxiety. As shown in Figure 2, first, a one-factor model was tested, but it does not fit the data (x^2 = 1.80; TLI= .746; CFI = 0.800; *RMSEA* = 0.092; *PCFI* = 0.629). A three factor model obtained satisfactory indexes ($X^{2/}$df = 1.545; TLI= .822; CFI = 0.919; RMSEA = 0.77; PCFI = 0.674), confirming that these constructs are distinct (Fig. 2).We also tested the influence of PG-12 in BSI subscales by Standardized Regression Weights and the results inform that pre-death grief is predictive of Depression and Anxiety (Table 5)

Predictive Validity. To verify the predictive validity of the instrument, PG-12 data was correlated with the results obtained in a sub-sample of CF (n = 32), evaluated at least six months after the patient´s death with PG-13, depression and anxiety BSI subscales.

Correlation values were statically significant, positive and moderate with PG-13 (R= .62), Depression (R= .559) and Anxiety (R= .45).

A Simple Linear Regression was also calculated to evaluate the explained variance of PG-12 relating to the variables assessed at follow-up period. The explained variance is 36.3% (Adjusted R Square = .363) for post-death prolonged grief, 30% (Adjusted R Square= .300) for Depression and 17.9% (Adjusted R Square= .179) for Anxiety.

Fig.1. Confirmatory factor validity of PG-12



Initial Model

Adjusted Model

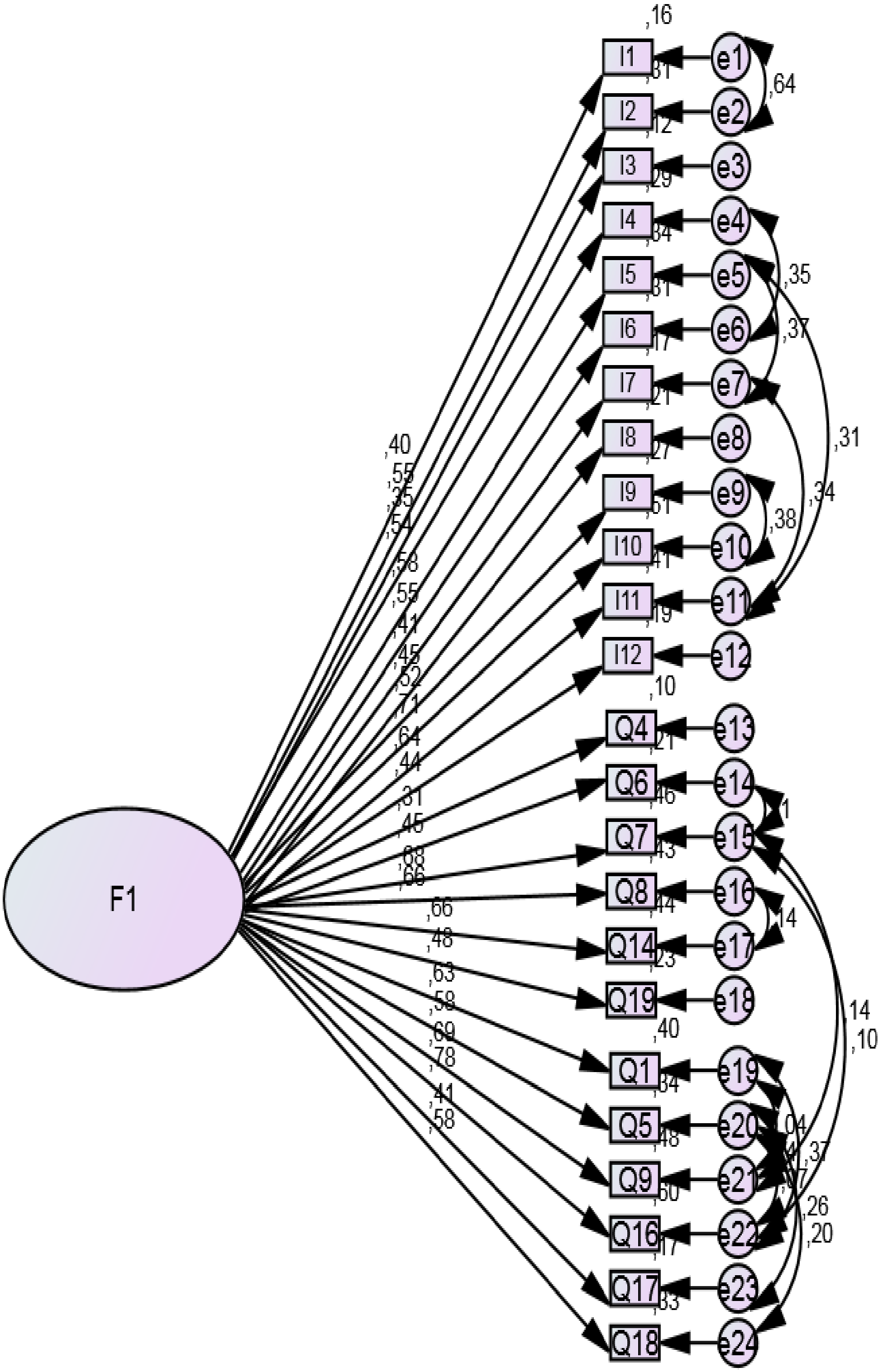
Table 4. Reliability of PG-12

	Item	Item-total correlation	Cronbach´s Alpha if item deleted
1	longing or yearning for patient	.475	.840
2	intense feelings of emotional pain. sorrow. or pangs of grief related to patient´s illness	.494	.836
3	tried to avoid reminders that the patient is ill	.257	.856
4	stunned. shocked. or dazed by patient´s illness	.635	.824
5	confusion about your role in life or a diminished sense of self	.549	.831
6	trouble accepting patient's illness	.616	.826
7	hard for you to trust others	.475	.837
8	bitter over patient's illness	.537	.832
9	feel that moving on (e.g.. making new friends. pursuing new interests) would be difficult	.441	.841
10	emotionally numb since patient's illness	.757	.816
11	feel that life is unfulfilling. empty. or meaningless since patient's illness	.749	.814
12	significant reduction in social. occupational. or other important areas of functioning	.250	.849

Correlates of PG-12. Intensity of grief manifestations did not vary much according to sociodemographic characteristics, with exception of gender: female presented significantly higher values than male (t (80) = 1.941; *p*= .05). PG-12 is positively and moderately associated with caregiver burden (*r* = .442, *p* < .01). Using a Simple Linear regression, PG-12 explained 18.5% (Adjusted R Square = .185) of burden variance, evaluated by Zarit scale.

Fig. 2. Divergent Validity of PG-12

One Factor Model



Three factor model

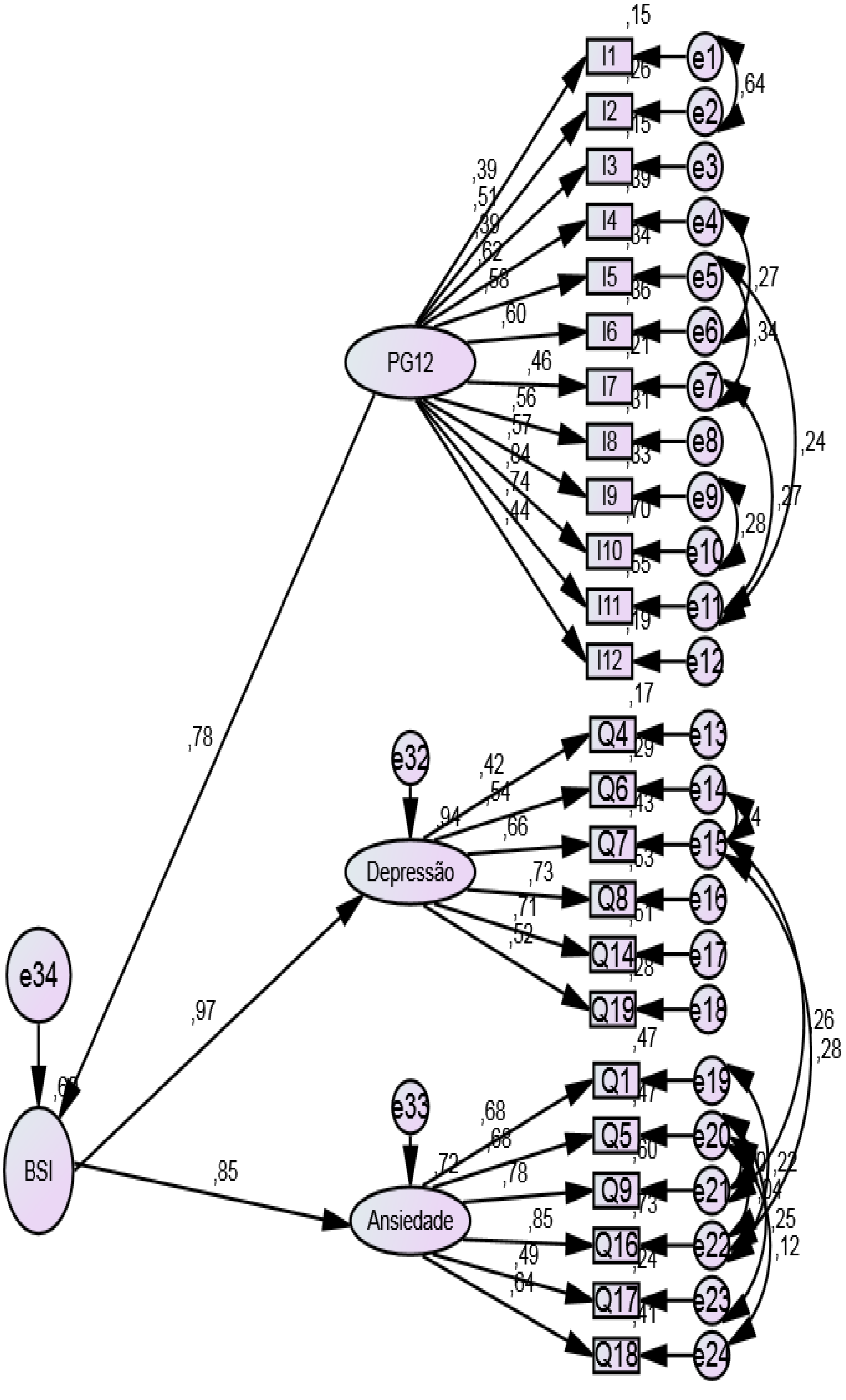


Table 5. Regression Weights of PG-12 and BSI subscales

PG-12 Items	Regression Weights
1. Longing or yearning for patient	.393
2. Intense feelings of emotional pain, sorrow or pangs of grief related to patient´s illness	.511
3. Tried to avoid reminders that the patient is ill	.392
4. Stunned, shocked, or dazed by patient´s illness	.622
5. Confusion about your role in life or a diminished sense of self	.583
6. Trouble accepting patient's illness	.604
7. Hard for you to trust others	.457
8. Bitter over patient's illness	.561
9. Feel that moving on (e.g.. Making new friends. Pursuing new interests) would be difficult	.573
10. Emotionally numb since patient's illness	.835
11. Feel that life is unfulfilling, empty, or meaningless since patient's illness	.742
12. Significant reduction in social, occupational or other important areas of functioning	.441
BSI sub-scale Depression items	
9. Thoughts about ending your life	.417
16. Feeling lonely	.541
17. Feeling blue	.656
18. Feeling no interest in things	.729
35. Feeling hopeless about the future	.714
50. Feelings of worthlessness	.525
BSI sub-scale Anxiety items	
1. Nervousness or shakiness inside	.682
12. Suddenly scared for no reason	.682
19. Feeling fearful	.775
38. Feeling tense or keyed up	.855
45. Spells of terror or panic	.489
45. Feeling so restless you couldn't sit still	.637

Acceptance and Positive reinterpretation coping mechanism are negatively associated to PG-12 (*r* = -.427; *p* < .05; r = -.421, *p* < .05, respectively), while Denial was positively associated (*r* = .402; *p* < .05). Concerning circumstances of illness, those CF who assessed the physical condition of the patient as bad or very bad presented higher intensity of pre-death grief (*t* (77) = -.199; *p* = .05), as well as those who were not expecting the diagnosis (*t* (78) = -2.15; *p* = .03). Denial is negatively correlated with the degree the disease was expected for the CF (*r* = -448). The length of caring did not affect grief manifestations (t (78) = .556; *p* = n.s.), but the amount of hours of daily care was associated with more intense grief manifestations (*t* (78) = 3.12; *p* = .003).

Discussion

This Portuguese validation study of PG-12, carried out with FC of oncologic patients in palliative care, confirmed the high internal consistency of this instrument (Alpha de Cronbach = 0.846), as in other populations (Chiambretto, 2008; Prigerson, 2008; Mulligan, 2011). It was not necessary to remove any item to improve the consistency of the scale.

According to previous studies (Chiambretto et al., 2008; Mulligan, 2011), Confirmatory Factor Analysis evidenced its mono-factorial structure. Since the initial model did not obtained satisfactory indexes, it was necessary to readjust the model. Covariance between items 1 and 2 may reflect the fact that both items assess to the separation distress. Items 2 and 4 include multiple feelings, which may induce confusion in respondents. Items 9 and 10 refer to numbness and the lack interest, so they may be related.

As evidenced by other authors (Guarnerio et al., 2012; Chiambreto et al., (2010), Pre-death Grief proved to be distinct from Depression, as well as Anxiety, although it may influence these symptoms. Another independent but correlate construct is Caregiver Burden. This result is consistent with a previous study in dementia caregivers (Holley & Mast, 2009). Although Prolonged Grief Disorder prevalence (33%) is a much less common than caregiver burden (85.9), depression symptomatology (67,4%) and anxiety (62%), PG-12 proved to be predictive of Post-death Prolonged Grief, Depression and Anxiety, thus constituting a reliable and sensitive assessment tool to the early identification of those CF at risk of maladjustment to loss.

Prevalence rates of Pre-death PGD is higher than in other Palliative FC, and near of the percentage verified in FC of patients in vegetative state (38,5% in Bastianelli et al., 2014). This result may be explained by the patients´ advanced state of disease, due to the late referral to palliative care and eventually by the convenience nature of the sample, which means that the participants who agreed to participate in this study were probably those who felt more affected by the experience of the relative´s terminal illness.

Among grief manifestations, separation distress reaches the highest intensity levels. This symptom has been identified as a highly prevalent among patients with Complicated Grief and is associated with greater symptom severity post-death (Gesi et al., 2016). Another qualitative study (Saldinger & Cain, 2005) draw attention to its centrality also in Pre-death Grief. Taking into account the imminent physical separation and the relational losses that characterize this experience, separation anxiety may be considered a nuclear dimension of Pre-death Grief, but this hypothesis requires further research.

Coping mechanisms have shown to be predictive of pre-death PGD, in line with previous studies (de la Morena & Cruzado, 2013; Cipolletta et al., 2013). Acceptance and Positive Reinterpretation demonstrated to be protective of pre-death grief. As Carver et al. (1989) noted, these mechanisms are most adaptive in situations where the stressor is unchangeable, requiring accommodation. Although this concept is controversial, denial was defined as “the refusal to believe that the stressor exists or of trying to act as though the stressor is not real” (Carver et al., 1989; pp. 270). According to the results of Yale Bereavement Study, a longitudinal cohort study (Maciejewski et al., 2007), a high degree of acceptance is the norm in the natural deaths, contrasting with deaths caused by traumatic causes, where higher levels of disbelief and lower levels of acceptance are observed. In this FC population, Denial was associated to more intense grief manifestations. In fact, Denial was associated with the perception of not being expecting the diagnosis, and those CF who were not expecting, obtained higher score in PG-12. Simultaneously, the perception of the patient´s poor physical condition and more involvement in care also contributed to more Pre-death Grief manifestations. These results may contribute to a better understanding of the traumatic experience of CF. As suggested by Sanderson et al. (2013), the recurrent exposition to distressing sights related to the significant others´ vulnerability and dying process may trigger some degree of traumatization.

This study has limitations related to the reduced sample size and its convenience nature, which requires some caution in the generalization of the results, particularly regarding the predictive validity, which was calculated with a sub-sample. Findings refer primarily to middle-aged daughters, so other family caregivers and contrast with widows and widowers should be examined. Further research should also investigate the underlying mechanisms of Pre-death Grief, in order to address the specific intervention needs to a better adjustment during caregiving and bereavement.

Conclusion

This study contributes with psychometric testing of PG-12, a Pre-death Grief scale that evaluates Criteria for PGD, involving pre and post-loss assessments with a sample of oncologic patients´ FC in palliative care. This instrument have shown to be reliable, with high internal consistency, monofactorial structure and predictive of post-death PGD, Depression and Anxiety. PG-12 can be easy applied and a useful screening tool for early identification of those FC at risk of maladjustment to loss.

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3. EMPIRICAL STUDY II

CAREGIVERS´ ANTICIPATORY GRIEF: A CONCEPTUAL FRAMEWORK FOR UNDERSTANDING ITS MULTIPLE CHALLENGES

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CAREGIVERS´ ANTICIPATORY GRIEF: A CONCEPTUAL FRAMEWORK FOR UNDERSTANDING ITS MULTIPLE CHALLENGES

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Abstract

End-of-life trajectory of cancer patients in palliative care (PC) is characterized by a precipitous functional decline, eliciting in family caregivers (FC) the experience of anticipatory grief (AG). Although widely recognized, AG lacks conceptual clarification. The present study aims to explore qualitatively the experience of the terminally cancer FC, in order to identify the core characteristics and the specific adaptive challenges posed by AG in the context of end-of-life caregiving. Data were collected through in-depth semi-structured interviews, carried out with a clinical sample of 26 cancer FC in PC. Findings from thematic analysis suggest that AG experience is characterized by the traumatic distress of being exposed to threatening-life conditions and, simultaneously, the separation distress induced by loss anticipation and current relational losses. Ambivalence elicited by competing tasks (i.e., dealing with death while protecting the other´s life) challenges the FC to a permanent emotional regulation effort. Results contribute to the conceptualization of AG and may inform intervention programs about the main challenges the FC are dealing with in adjusting to loss during end-of-life caregiving.

Keywords: Caregivers; Palliative care; grief; Life-threatening; qualitative thematic analysis; Portugal

Introduction

With the aging of population, the chronic disease care has been transferred to the outpatient treatment, involving the family in caregiving tasks that become more complex and demanding as the illness progresses (Weitzner, Haley & Chen, 2000; Aoun, Kristjanson, Currow & Hudson, 2005). The family caregiver (FC) definition includes any family member, friend, or partner who maintains a significant relationship with the patient and provides some kind of care (Hudson & Payne, 2009). Given the large involvement in caring tasks and the affective proximity to the patient, this population is vulnerable to high levels of distress during caregiving and bereavement (Raschick & Ingersoll-Dayton, 2004; Waldrop, 2007). Distress is commonly defined as prolonged internal suffering that can range from self-focused processing of negative emotions and stressors, to highly intensely aversive and prolonged processing of emotional states (Brosschot, Verkuil & Thayer, 2018). Besides stressors directly related to caregiving and their impact in their personal life (e.g., sleep deprivation), FC have to manage expectations and emotions associated with fear of losing the significant other, a phenomenon designated by Anticipatory Grief (AG) (Wittenberg et al., 2012).

Caregiver AG stems from the expectation of the relative´s death, giving rise to a wide range of manifestations that are socially and culturally associated with the grief response for the loss of a significant other (National Cancer Institute, 2011). Although widely used in research and clinical practice, this concept has been involved in great controversy due to contradictory results concerning its adaptive role in bereavement outcome. Inconsistencies are attributed mainly to the conceptual uncertainty and to methodological errors in the evaluation of the construct (Fulton, Madden & Minichelo, 1996; Fulton, 2003; Reynolds and Botha, 2006). Based on a review of empirical studies, Nielsen, Neergaard, Jensen, Bro and Guldin (2016) stated that it is a complex risk factor of prolonged grief disorder, connected with caregiver's perceived losses during caregiving, their relation with the patient, the caregiver's attachment style, coping mechanisms and emotion regulation. This definition recognizes the multidimensionality of the phenomenon, but further research is needed regarding its underlying mechanisms.

In a previous scoping review (Coelho, de Brito & Barbosa, 2018), we concluded that the anticipation of death, at the terminal phase of illness, may be the distinctive aspect of AG in the pre-death grief manifestation continuum that encompasses several progressive functional and relational losses. Other aspects, such as separation anxiety and avoidance, were also highlighted as nuclear characteristics of AG. However, most literature is focused in the dementia FC (e.g., Shuter, Beattie & Edwards, 2014; Liew, 2016; Blandin & Pepin, 2017; Sikes & Hall, 2017). Comparing to dementia, the dying trajectory of the cancer patients is characterized by a more abrupt functional decline (Teno, Wittzen, Fennel & Mor, 2001), which may influence the FC experience. For example, Sanderson et al. (2013) stated that dealing with a terminal cancer illness exposes the caregiver to very shocking images, which can be registered as traumatic memories, resulting in powerless feelings. Therefore, we intend to explore qualitatively the experience of the terminally cancer FC, in order to identify the core characteristics and the specific adaptive challenges posed by AG in the context of end-of-life caregiving.

Methods

Participants Selection and Study Procedures

Relatives of adult cancer patients accompanied by an outpatient palliative care service were approached by the resident psychologist (the first author) at the first consultation (from October 2015 to October 2016), and invited to participate in a larger study, involving quantitative and qualitative data. Inclusion criteria were: a) being an adult caregiver (over 18 years old) and b) being directly involved in the patient care. Those who agreed to participate in an interview gave their informed consent and were recruited to the present study. They were mostly people with high psychological distress related to the advanced illness, who simultaneously accepted the psychology consultation, so we consider that this is a clinical sample.

The interviews took place in the palliative care unit and were scheduled according to the availability of the participant. They were conducted by a trained psychologist with experience in clinical practice and research interviewing with the bereaved population. For ethical reasons, and taking into account the sensitive nature of the theme, the interviews were conducted individually, with full respect to the subjects' emotional state, specific concerns and personal rhythm. The interviews were transcribed verbatim in Portuguese. This research was approved by the Ethical Committee of the Hospital.

Data Collection

Data were collected through in-depth semi-structured interviews over a period of 12 months. Interviews average duration was 60 min (range: 35 – 120 min). The interview script included the following main topics: (1) perceived experience and circumstances of caregiving (e.g., "How has been your experience as caregiver of your relative?", "What, in your opinion, has been more difficult?", "How do you handle it?"); (2) perceived evolution of the disease (e.g., "How do you see the current state of your family member's illness?", "What do you think might happen next?"); (3) perceived changes in the caregiver's personal life and in the relationship with the patient (e.g., "How has this illness changed your life?", "What changes do you notice in the relationship with your relative?"). Initial answers were probed for more details (e.g., "Can you tell me more about this?", "Could you give me an example?"). Particularly difficult issues, such as the proximity of death, were not directly questioned unless they were introduced by the participant. In these cases, the interviewer asked the emotional impact of this experience ("How do you feel about the death of your relative?").

Data analysis

The analysis of interviews was conducted by one coder and two consultants[6]. According to Levitt (2015) suggestions, the interviewer is the researcher with a closer connection to the data and able to recognize other meanings absent when only transcripts are used, thus allowing an analysis highly consistent with the participants´ experiences. A qualitative thematic analysis was conducted in order to capture recurrent patterns (themes) and implicit meanings, using a mixed inductive (i.e., derived from the data) and deductive generated coding (i.e., theoretical based constructs). Process was guided by Braun & Clarke (2006) guidelines, which includes the following six steps: (1) familiarizing with data: repeated reading of the interviews, searching for meanings and noting initial

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[6] The coder was the first author and the consultants were the fourth and the fifth

ideas; (2) generating an initial coding: systematically coding interesting features of the data (semantic content or latent); (3) searching for themes: gathering codes into a hierarchical category system, and then potential themes, a higher level concept; (4) reviewing themes: checking the coherence of the pattern at the level of the coded data extracts and then in the entire data set; (5) defining and naming themes: identifying the specificity of each theme; (6) producing the report: beyond description, this implies interpretation of data making and argument in relation to the research question. Data saturation was achieved when new data was no longer attained. To establish validity, the coder and the two consultants analysed the data openly, discussed and resolved inconsistencies. The qualitative data analysis was assisted by the computer software NVIVO 12.

Results

Participant´s Characterization

The sample was composed of 26 participants, mostly female (n = 23), aged 27-78 (Median: 55.5), the majority adult child (n= 14), and spouses (n=10); the remaining were a parent and an aunt. Education degree was 4-years (n= 1), 6-years (n=4), 9 years (n=5), secondary (9) and graduation (6). Over half the people (n=14) cohabited with the patient at the time of the interview.

Findings

During thematic analysis, references were coded and organized in three main themes: (1) *Traumatic distress,* (2) *Separation distress,* and (3) *Emotional regulation and dysregulation*. A summary of the main themes and categories along with frequency of cases is displayed in Table 1. Subcategories frequency is presented in brackets throughout the findings section. Following, themes are described in terms of commonalities and variances, Commonalities include the circumstances and/or manifestations described by most participants. Variations represent the range of individual responses to stress. Participant´s quotes are used to illustrate the meaning attributed by the FC. However, some results emerged through implicit meanings and thus are difficult to capture by a single reference.

Table 1: Main categories and cases frequency

Themes and categories		Freq. (n= 26)
Traumatic distress	Uncertainty of illness	21
	Image of degradation	20
	Caregiving impotence	24
	Vicarious suffering	18
	Life disruption	25
Separation distress	Death anticipation	22
	Relational losses	16
	Separation anxiety	6
	Sense of protection	23
	Affective deprivation	17
Emotional regulation and dysregulation	Regulation efforts	22
	Symptoms of disorganization	21

Traumatic distress

Uncertainty of Illness. Most FC (21/26) emphasized the difficulty in dealing with uncertainty of illness related to the unpredictability and ambiguity of events, either the onset of illness, the course of symptoms or their cause: "*It is a pain that suddenly appears, coming from nothing...*". They were frequently invaded by doubts and generalized preoccupation with the uncertainty of the future: *"The future, which is uncertain. The unknown."*. In response to uncertainty, several participants (11) showed an attitude of hypervigilance to the illness signs, manly after crisis episodes: "*Every day in the morning I saw his eyes to see if they were yellow again*.". Especially when the cancer diagnosis was particularly sudden and unexpected (2), it caused a general sense of insecurity and hopelessness. On the contrary, for others (10) uncertainty allowed to postpone the threat and keep hoping for a small recovery or prolongation of life: *"We do not know what will happen next… he has always recovered, after coming to the hospital. I´m always holding on to this hope"*.

Image of degradation. The majority of FC (20) mentioned the patient's progressive decline, referring to their extreme thinness and frailty, loss of autonomy and cognitive impairments: "*I feel like my husband is disappearing*."; "*Things are not well ... she is losing her abilities and becoming a child*.". All these losses contribute to create an image of degradation that contrasts with the previous representation of the ill person. In spite of being informed about the illness progression, this confrontation with the extreme fragility causes strangeness and insecurity: *"(...) because everything is happening... strange things... no matter how much we read and know... I do not feel prepared for these situations."*. Indeed, in some cases (6), it provoked a shock reaction, described as traumatic: "*So fragile, a person who was so strong (cries)! So strong! (...) It´s very traumatic!*". This reaction was generally triggered by the fact that the decline is very pronounced and sudden: *"What strikes me the most is the degradation of the person, so fast, from one day to another"*.

Vicarious Suffering. Most FCs (18) identified manifestations of patient´s suffering and were able to empathize with the other´s emotional state. But the continuous exposure to the other´s suffering also causes them psychological distress, which sometimes (6) becomes overwhelming, particularly in cases of identification and emotional contagion: *"The worst thing is... my great terror is to see the state of my father, the suffering of my father, to imagine what my father thinks..."*. But there were also participants (3) for whom continuous exposure to the other´s suffering gave rise to a state of habituation and desensitisation: *"My neighbour said that she could not see it, she was really upset. My sister-in-law was also crying a lot... but not me... I know it was painful for me, but I've seen it so many times..."*.

Caregiver impotence. As the disease progresses, the patient's suffering becomes more difficult to manage, leading most FC (24) to experience feelings of impotence, either in preventing the other´s suffering or keep the disease from progressing. Some (12) focused in external causes, such as professional faults or lack of social-support. Other participants (4) complained about the patient's refusal behavior in collaborating with caregiving. But limitations were also perceived as failure in helping the patient (16): "*I feel incapable. I cannot get him to react*". In an attempt to compensate these limitations, some participants invested obstinately in caregiving. They avoid asking for help and try to be always present and available to the patient, thus becoming more vulnerable to exhaustion. On the contrary, for another group of FC (7), feelings of impotence facilitates the awareness of caregiving difficulties and their need for help. Besides, by recognizing their inability to control the course of the disease, they tend to focus on providing comfort to the patient, in order not to feel so helpless before the inexorable advance of the disease.

Life disruption. FC felt that their own life was invaded by the illness and indefinitely interrupted. For example, most participants gave up work, leisure time and other pleasurable activities: "*Now it's just my mother, home, and job. This is my life. Because I do not have time.*" They claim that the care provision is a gruelling schedule, depriving them of all strength and vitality: "*Having to pass this energy, we run out of strength...*". Pressure to care and excessive demands are associated to a generalized sense of physical and/or emotional exhaustion (18): "*It's all happening at the same time. I'm getting tired, very tired*". In particular, sleep deprivation contributes greatly to this sense of resource depletion, converting emotional exhaustion into physical fatigue. FC reported that they feel invaded and that their life is suspended. Besides, caregiving also affects family and social relations, contributing to the isolation of the caregiver. For example, one participant stated that, because of care provision, she has neglected her marital relationship. But these personal restrictions also led FC to recognize the need to request and accept support (8): *"I had to ask them for help, otherwise I would not bear all this".*

Separation distress

Anticipation of death. The possibility of death was mostly (22) addressed in an implicit way, by recognizing the irreversibility of disease. But there were also FC (6) who described situations of imminent death and constant threat of losing their relative: "*I was really disoriented! I thought: and if he dies here, what do I do?*"; *"It's a fear... I'm afraid he'll die, I´m always seeing if he's still breathing."*. Of those who spoke about proximity of death (11), almost half (5) stated they were not prepared for it. But FC (5) also expressed the desire to hastened death: *"I swear, I'll never have the courage to say this to anyone else, but I just wanted my dad to die fast, not realizing what was happening"*. Consequently, death was lived with great ambivalence: although it represents the definitive separation from the loved one, it is the only way to terminate the other´s suffering, as well as their own distress: *“Sometimes I think: this is not forever. And then I think: but I´m talking about the life of a person I love. If this is not forever, it's because I´m going to lose that person.”.*

Relational losses. Several FC perceived changes in the relationship that affected their sense of attachment to the ill relative, eliciting feelings of grief and longing. The majority (8) referred the loss of dialogue and presence: “*I feel alone, now that I do not have anyone to talk to... to [patient´s name], I cannot tell anything...;*”, “*I miss his company*”. Others mentioned they were losing protection (3), especially when there is a reversal of roles, as in the case of father-daughter relationship: *“Now, I have to be the one to help him. The strong man, to whom I have so often asked for help: ´Daddy, help me, something happened in my life`. Now I cannot do it anymore.”*. They also expressed sorrow for the past life (4) and for future they will not share with the patient (3).

Separation anxiety. A few FC (6) openly showed signs of distress related to with anticipated separation. However, most participants show great preoccupation that something bad happens to the patient when they are not present. This feeling contributes to maintain the relationship, despite the changes it had undergone. But it can be also an impediment to the subject's sense of security and autonomy, which reflects in the fear of being alone (3): *“It scares me because I do not like being alone. I never liked it... just thinking that one day I'll be alone and I do not have anyone to take care of me... it scares me”*. Others (2) cannot even think of their family member's future absence and immediately deviate from the subject.

Sense of protection. *M*ost FC (22) expressed the desire to help by meeting the other´s needs. Responsibility for caregiving involves making decisions for the well-being of the patient, giving rise to moral dilemmas (15). For example, FC have to decide about whether to ask for another medical opinion, invest in more treatments, and the best place of care. Retrospectively, these doubts are subject of rumination: *“At the time, it seemed that this was the solution (...) But now, I do not know... as things are getting worse, it comes back to memory if it was the best decision.”*. The excessive responsibility for the other gives rise to overprotective attitudes. In some cases (3), participants impose their decision in an authoritarian way, sometimes infantilizing the patient. Overprotection may also be the source of closed communication (16). FC inhibited the expression of emotions and avoid talking about illness and death to prevent the significant other from suffering (3): *“I am always afraid that they give her the news as they gave me. In the appointments, I always say: ´Oh, beware, she does not know anything...´”*.

Affective deprivation. Many FC (17) did not feel retributed for their efforts, so they experimented a great sense of affective deprivation by the disproportion between what they give and receive. This uncovers the FC´s relational needs, leading them to review previous failures in the relationship (14): *“My husband was a very selfish person. He only thought about himself and did not give me the affection I needed.”* FC also expected that, at this stage, there would be more contact and affection, and when it is not accomplished, they feel frustrated (2): *“I would like that, at the end of life, she would think: ´I'm here for a short time, I'm going to dedicate myself to others´. But this is not happening. She is still angry and complaining with me.*” Others (3) continued longing for the idealized relationship: *“I wish she would look at me, and we could both create that bond, only for a moment. I just wanted to feel it* (cries).” On the contrary, some participants (4) reported that now the patient shows more caring and concern than ever.

Emotional regulation and dysregulation

Self-regulation efforts. Several caregivers (14) shared the belief that, by inhibiting their feelings, they were protecting each other from emotional distress. Hence, they tend to cover up the painful aspects of their experience: *“I'd rather shut up so I would not hurt anyone.”*. But many of them (10) are aware of the need to set boundaries and find some way to compensate for the emotional and physical burnout of caring. In an effort to self-regulate, some (5) try to distract themselves with work. Others (2) seek relief by walking in contact with nature, by practicing meditation, or by connecting with God. There are also those who used cognitive strategies to self-reassurance (4): *“I'm going to get hurt, with scars, but life goes on (...) I am strong, I will survive.”*. Finally, some seek help in family and friends for distraction and instrumental aid (3), but rarely for emotional support because they are convinced that the others are not available for sharing painful feelings.

Symptoms of disorganization. The AG experience elicits some degree of emotional dysregulation (21). Manifestations include mood instability, impatience and irritability, anxiety, anguish and panic and other signs of acute stress. Physical signs (8) were: appetite and digestive changes, tachycardia and muscle tension. Cognitive manifestations (12) comprise intrusive and ruminative thoughts, recurrent dreams, dissociative experiences and disorganization of speech. The devastating impact of the other´s illness also reflects in feelings of abandonment and helplessness, loss of faith and purpose in life (3), leading one participant to suicidal ideation. Some of these individuals felt unable to manage their emotional state, conducting to fear of losing control: "*I am afraid, I don't want to fall…*". Social and occupational difficulties was shown by disorganization of habits, generalized distrust on others and isolation for self-protection.

The main themes and categories were organized in a conceptual map that shows the dynamic relationship between the concepts (Fig.1).

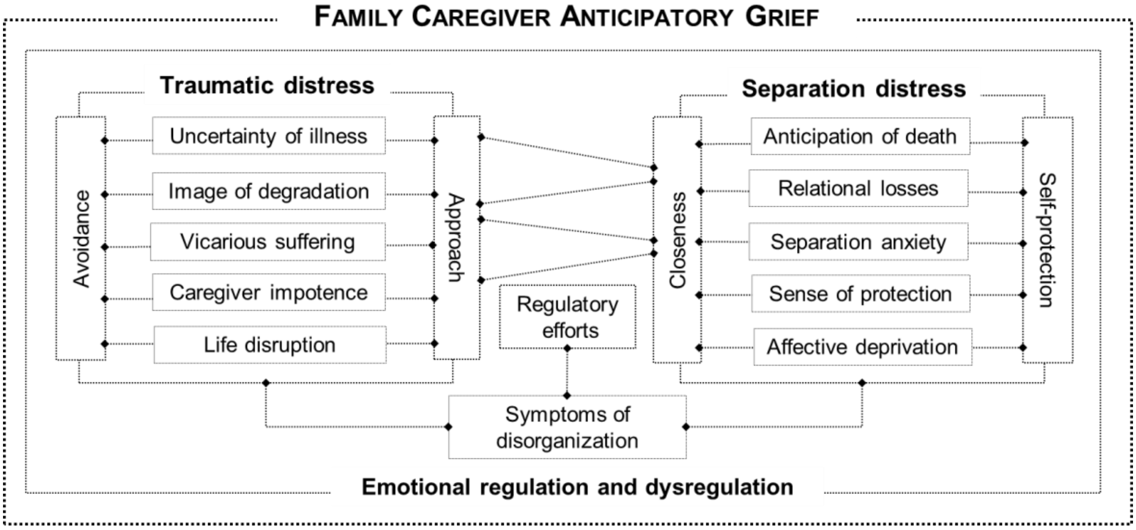

Fig. 1: Conceptual map configuring the FC AG core characteristics and their relationships

Discussion

This study aimed to contribute to the conceptualization of AG by analysing qualitatively the testimony of a clinical sample of cancer FC in PC. Findings suggest that this phenomenon involves several core characteristics that were grouped in two main dimensions. First, *Traumatic distress*, related to the continuous exposure to life-threatening conditions resulting in a generalized sense of lack of control over the illness circumstances and one´s own life. Second, *Separation distress*, elicited by the perceived menace to the relationship, stemming from the current relational losses and unavoidable future separation. A third dimension, *Emotional regulation and dysregulation*, is not a specific attribute of AG process, but, as evidenced in other studies (Fernández-Alcántara et al., 2016; Camacho, Pérez-Nieto & Gordillo, 2018), it has a central role as moderator effect of grief experience.

Emotional regulation refers to the individual´s efforts to manage the experience and expression of emotions in order to achieve one´s personal goals (Gross and Thompson, 2007). On the opposite, emotional dysregulation reflects difficulties in modulating emotions, either by underregulation (insufficient control) or misregulation (ineffective control) (Tice & Bratlavsky, 2000). It reflects, for example, in emotional ambivalence, i.e. conflict about whether to express feelings that may also lead to ambivalent feelings (Gohm & Clore, 2000). As suggested by data, the FC´s tendency to inhibit their feelings contributes to the emotional ambivalence and disorganization symptoms. However, we argue that this conflict arises from the very circumstances of end-of-life caregiving. In other words, the FC is required to deal with the threat of death and separation, while protecting the patient´s life and welfare. Balancing these apparently competing positions constitutes, in our view, the major dilemma the FC has to deal with, from which many other adaptive challenges derive.

The perspective of grief as an oscillatory process is well documented in literature. This idea has hallmarks of the Dual Process Model of coping with bereavement (Schut, 1999), which establishes a regulatory coping process of oscillation between approach and restoration positions. Specifically, in AG phenomena, Rando (1986) described a delicate balance between mutually conflicting demands of simultaneously holding onto and letting go the patient. Recently, Breen, Aoun, O'Connor, Howting & Halkett, (2018) also drew attention to this vacillation process, emphasising that FC either focus on circumstances of illness and caregiving (here) or the preparation for the future (after). In line with these perspectives, we articulated the circumstances and relational aspects, stating that AG oscillation process occurs both between and within two different levels: managing the perceived menace to the other´s life and to the relationship. As a result, we propose a conceptual model that identifies the AG core characteristics and configures them as adaptive challenges that require constant balance between two competing positions.

Traumatic distress: Managing the threat to the other´s life

Caregiving in life-threatening conditions expose FC to several unexpected and threatening events, causing traumatic distress. In accordance to Roth & Cohen (1986), we understand that FC´s responses to perceived menace to the other´s life correspond to the dynamic organization of defensive behavior facing an inevitable threat, involving an *approach* and *avoidance* pattern. *Avoidance* orientation protects the individual from anxiety-arousing stimuli and their consequences. *Approach* orientation, on the other hand, allow for appropriate action by noticing the threat stimuli and making it more controllable.

One of the aspects that threatens the individual's sense of security is the *uncertainty of illness,* caused by the unpredictability of events and consequent lack of control over the illness circumstances (Shilling, Starkings, Jenkins & Fallowfield, 2017; Strauss, Kitt-Lewis & Amory, 2019). This generalized sense of insecurity may develop to a permanent state of hypervigilance and startle reaction (Brosschot et al., 2018). Yet, similar to other studies (Janze and Henriksson, 2016; Wong et al., 2017), we found that uncertainty is also related to hope, by enabling to postpone threat. Hence, in face of uncertainty, the FC is challenged to balance vigilance to the illness signs while holding on to hope.

As the illness progresses, major changes in behavior and great body deterioration may lead the FC to feel that they no longer recognize the terminally ill relative (Dumont, Dumont & Mongeau, 2008). This experience, evoked by the patient's functional decline was designated by *image of degradation*. The sharp contrast with the previous representation provokes reactions of shock and strangeness, thus constituting one of the main factors of impact on the psychological wellbeing of the caregiver (Schumacher, Dodd and Paul, 1993) Besides, many of these functional losses are ambiguous, since the changes are fluctuating and unclear (van Wijngaarden et al., 2018). Consequently, FC is challenged to review the previous image of the patient, integrating fragility while trying to preserve the inner representation.

Witnessing the other´s degradation and inherent suffering, evokes in FC an experience of *vicarious suffering.* It corresponds to the affective empathy, defined as sharing or feeling another person´s emotional state (i.e., "feeling what another person feels") which is associated, by excess or by fault, to increased emotional distress (Jutten, Margriet & Sitskoorn, 2019). The state of compassion fatigue is characterized by physical, psychological, and social exhaustion that reduces the ability and interest to endure suffering and care for the other (Lynch & Lobo, 2012). To balance the emotional costs of empathy, FC is challenged to differentiate from the patient's emotional and physical state, while remaining sensitive to the other´s suffering.

Being exposed to the other´s suffering without being able to prevent it gives rise to *caregiver impotence*. It reflects in expressions of intense powerlessness and frustration (Sanderson et al., 2013). Difficulties may be attributed to external factors (i.e., lack of support), or internalized (i.e. personal faults). The latter seems to have a more devastating effect in the sense of self-efficacy of the caregiver. Notably, the caregiver impotence also led FC to reformulate expectations and recognize their inability to reverse the situation and impede death from happening. Thus, the challenge consists in balancing the acknowledgment of limits of caregiving while maintaining some sense of control.

As a result of exclusive dedication to the terminally ill patient, FC experimented personal constraints, creating a sense of *life disruption*. When the demands are excessive and the resources become depleted (e.g., deprivation of pleasurable moments), it gives rise to a state of emotional and physical exhaustion, with several implications in FC´s physical and mental health (Sharpe, Buttow, Smith, Mcconnell & Clarke, 2005; Schubart, Kinzie & Farace, 2008). Although some FC avoid to recognize the devastating impact of caregiving to prevent the patient from feeling a burden, it also challenges FC to recognize their limits and to mobilize resources.

Separation distress: Managing the threat to the relationship

As a consequence of the functional decline of the patient and the disruption of life, the FC experiences changes in the sense of connectedness with the patient that threatens the security of attachment and/or reactive previous relational failures. In addition, the proximity of death represents the last and most important threat, leading the FC to anticipate the inevitable loss. As a way of regulating the risk in relationship, FC are prone to seek proximity or to withdraw from the other for self-protection against feelings of rejection and loss (Murray, Holmes & Collins, 2006). Shifts in motivation for seeking or avoiding contact seems to be related to the ambivalent feelings, which are prevalent in close relationships at end-of-life (Reblin et al., 2016). In fact, several aspects are likely to generate ambivalence in this relational context.

First, the *anticipation of death,* defined as the awareness of proximity of other´s death. Besides being an ancestral fear, biologically sustained and responsible for the survival response, individuals are imbued of implicit and explicit emotional representations, influenced by sociocultural attitudes and beliefs that contribute to death anxiety (Panksepp, 1998). Thus, although recognizing the irreversibility of illness, many participants could not mention the proximity of death. But death was also anticipated as a way of escaping from suffering and burden of caregiving. Hence, the FC is challenged to assume the inevitability of death, in spite of not wanting the separation.

Another aspect that creates ambivalence is the experience of grieving the loss of relationship while the significant other is still physically present. Accordingly to other studies (Pusa et al., 2012; Beng et al., 2013), we found that the feeling of loss exists even before the patient's death. *Relational losses* include, for example, missing the patient´s company and protection, their previous life together and the unlived future. This contributes to a sense of being disconnected with the patient, which is perceived as a sign of distance and rupture in the relationship. So, in order to keep investing affectively in the significant other, the FC is challenged to relinquish some aspects of the relationship, in spite of their wish to preserve or even strengthen the connection with the patient.

As a consequence of disruption in contact, both patient and FC experience intense solitude. Loneliness was found to be correlated with anxiety in caregivers of terminal stage of cancer disease (Soylu, Ozaslan, Karaca & Oszkan, 2016). S*eparation anxiety* is manifested mainly by the FC´s reluctance in moving away from the patient. There are two main reasons for that: first, because they are afraid that something bad will happen to them in their absence, so they have to be present to ensure the patient´s safety; second, because they are aware that they do not have much more time near the ill relative, so they want to enjoy all the time they have together. Thus, the challenge consists in valuing the other´s presence while maintaining one´s autonomy.

The need to ensure the patient´s safety corresponds to the *sense of protection*. As noted by Martz & Morse (2017), FC are prone to feel guilty in the transition to end-of-life care, so they mitigate this felling by being present and ensuring that the patient is peaceful. It traduces in an attitude of “protective buffering” (Langer, Rudd & Syrjala, 2007) from all the sources of distress, inclusively from their own feelings, leading to chronic emotional inhibition and avoidance of painful subjects related to illness and death. The challenge lies in balancing between protecting the other and attending to one´s own needs.

Due to lack of reciprocity in the caregiver relationship, the FC is prone to experience *affective deprivation*. Besides, it uncovers the previous relational failures and the loss of expectation of affection, thus contributing to a generalized sense of dissatisfaction that adds ambivalence to the relationship. As noted by Harding and Higginson (2001) the caregiver ambivalence reflects in difficulties in taking decisions toward their unmet needs. Thus, in order to preserve the relationship, FC are reluctant in addressing pending issues, although they experiment relational needs that ought to be expressed.

Conceptualization of Family Caregiver Anticipatory Grief

A clear and comprehensive definition of AG is been difficult to achieve mainly due to the multidimensionality and complexity of this experience. However, based on results, we propose that FC AG is defined as the family response to the perceived menace to the other´s life and subsequent anticipation of loss, in the context of end-of-life caregiving relationship.

Clinical Implications

For most FC, in spite of emotionally intense, this is part of the adjustment process to advanced illness. It is important to keep in mind that under conditions of an ongoing, real threat, the emergency reactions, including avoidance and hyperarousal, can be understood as natural, protective and adaptive responses (Diamond et al., 2013). However, due to the accumulative effect of incidents, some people may feel that the circumstances are unbearable, resulting in a sense of overwhelming distress and symptoms of emotional disorganization. It corresponds to a failure in enduring, that is, the innate capacity of getting through a life crisis (Morse & Penrod, 1999). Psychological intervention programs directed to this population should identify the main challenges the FC is struggling with, in order to promote the clarification of dilemmas and develop specific strategies for supporting emotional regulation and preventing symptoms of emotional disorganization.

Limitations and Future Research

There are some limitations in this study. First, recruitment was conducted by the resident psychologist of the palliative care team, which means that the people who agreed to participate in the study were those who were open to psychological consultation, which is mainly a clinical population. So, we probably did not captured the experience of those who consider themselves more adjusted to the situation. Second, the characteristics of the sample, especially the high academic level, are not representative of the general population of caregivers. Future research is needed to investigate the role of emotional regulation in explaining the individual differences in dealing with AG challenges and their impact in the subsequent bereavement. Likewise, it would be important to verify the relationship between each of AG dimensions in preparedness to death and subsequent adjustment to the loss. This analysis should be extended to the non-clinical population, in order to identify patterns of adjustment and their deviations. Finally, we suggest that mixed-method research is used to verify and develop the results obtained in this study.

Conclusions

Taking together, these findings provide an in-depth description of FC AG core characteristics that go beyond the mere identification of grief symptoms, contributing to expand comprehension about its multidimensional and dynamic nature. For most participants, this is considered a very disturbing experience, requiring great emotional regulation effort to manage both the threatening circumstances of end-of-life caregiving and the anticipated loss. By inhibiting their own feelings of distress to protect the significant other, FC are generating ambivalent feelings that hinders the readjustment of the relationship. But the balance between these two positions (i.e. anticipating loss while protecting the other) also challenges the FC to adjust to the reality of imminent loss. Results may inform clinicians in creating intervention programs focused on the identification and management of these specific challenges posed by the AG in the context of end-of-life caregiving.

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4. EMPIRICAL STUDY III

FAMILY CAREGIVERS´ ANTICIPATORY GRIEVING PATTERNS: A QUALITATIVE CLINICAL ANALYSIS

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Abstract

This study aims to qualitatively describe individual differences in AG of cancer family caregivers (FC), in order to identify grieving patterns based on the attachment framework. A clinical sample of cancer FC (n=72) was interviewed to capture subjective experience in dealing with terminal illness. A mixed top-down thematic coding, followed by cross-case analysis was used to identify configurations of categories and sub-categories within groups. Participants were grouped according to self-report scores of pre-death grief symptoms, using PG-12. Four different anticipatory grieving patterns emerged: a) Avoidant; b) Adjusted; c) Intense and d) Traumatic. Specific characteristics are described, along with suggestions for psychological intervention.

Keywords: Anticipatory grief; family caregivers; attachment theory; qualitative research; cross-case analysis

Introduction

Anticipatory Grief (AG) refers to the perceived threat to the significant other´s life (instead of definitive loss), along with the successive functional and relational losses resulting from the advanced disease (Coelho, de Brito, & Barbosa, 2018). Generally, AG occurs in the context of a demanding caregiving relationship, which makes family caregivers (FC) particularly vulnerable to high levels of distress (Dumont, Dumont, & Mongeau, 2008). Bowlby's attachment theory (Bowlby, 1988) offers a valid and comprehensive rationale for understanding individual differences in response to distress of loss and caregiving.

Attachment and Loss

The securely attached person is willing to activate the attachment system for protection and comfort in stressful situations, although still remaining confident in their ability to manage their own negative emotions and those of others. When facing loss, the secure person is able to remain attached to the deceased and integrate the lost relationship, converting it into a sense of internal security (Stroebe, Schut e Boerner, 2010). Thus, secure attached people tend to show a decrease in grief manifestations over time (Fraley & Bonanno, 2004; Levi-Belz & Lev-Ari, 2018).

On the contrary, the highly anxious attachments, designated as insecure-preoccupied, are characterized by the exaggerated need for closeness and dependence, along with the fear of rejection (Collins & Feeney, 2000). However, due to their negative representation of the other, they tend to distrust or devalue possible support responses, thus creating a cycle of frustration that leads to a state of dissatisfaction and depression (Shaver, Schachner & Mikulincer, 2005). Therefore, insecure-preoccupied individuals are prone to intense yearning and distress in response to loss, conducting to prolonged grief disorders (Jerga, Shaver & Wikinson, 2011).

The avoidant attachment is defined by independence, distance from others, and discomfort with closeness. The pattern of highly-avoidant attachment, referred as avoidant-dismissed, tend to devalue the importance of attachment and to shift attention to performance as a way of passively avoiding closeness in the relationship

(Bartholomew, 1990). When exposed to relational stressors, they become disconnected at the emotional, cognitive and behavioral levels and so they tend to react with less emotional reactivity to separation and loss (Kho et al., 2015). However, as stated by Bartholomew (1990), avoidance may also be related to fear of intimacy. This distinction gave rise to the fourth attachment style, the avoidant-preoccupied style. To prevent the possibility of being rejected, they actively avoid social situations and intimate relationships in which they feel vulnerable.

The fifth attachment style corresponds to the disorganized behavior. According to Cassidy & Mohr (2001), these persons could not organize a coherent attachment behavior, since the protection figure is simultaneously the agent of threat. In bereavement, the person with a disorganized state of mind presents lapses in reasoning, involving disbelief that the other is dead and intrusive thoughts that indicates a failure to integrate the loss (Thomson, 2010). Reactions of traumatic distress to loss include surprise, confusion and deep impotence (Sanderson, Lobb, Mowll, Butow, Mcgowan & Price, 2013). Besides, they present signs of increased sympathetic nervous system such as recurrent dreams, tachycardia, disruption of sleep and appetite (Hagemann, Waldstein, & Thayer, 2003).

Attachment and Caregiving

Individuals learn to provide care based on the model they constructed from their own attachment experiences. Several studies (e.g., Feeney & Collins, 2001; Gillath, Shaver & Mikulincer, 2005) showed consistent differences in caregiving patterns depending on the attachment style. A secure attachment allows people to focus on the other´s needs, thus manifesting an attitude of greater sensitivity, availability and compassion in the provision of care, comparing to those with an insecure attachment (Gillath et al., 2005). Those with an avoidant attachment pattern are less sensitive to the patient's signs of suffering and provide less emotional and instrumental support, especially in times of greater need (when they perceive more suffering in the other). They divert attention and move away from others, especially when they perceive vulnerability and suffering (Feeney & Collins, 2001).

On the contrary, anxiously attached caregivers show an extreme need to maintain closeness to the significant other. Generally, they are hyper vigilant and over-involved in caregiving, especially when they perceive that the others are in need of help. They are also prone to reactivate personal concerns and ruminate about them, maintaining an excessive focus on the other´s and on their own distress, thus feeling overwhelmed with suffering. Additionally, although focused on the other, the difficulty in differentiating themselves from the other (Mikulincer & Horesh, 1999) may be an impediment to empathy.

The Present Study

There is a gap in the literature regarding the influence of attachment in pre-death grief manifestations. In the current study, we aim to describe individual differences and identify AG patterns, based on the attachment framework. Instead of using standardized scales, we opted for a qualitative study that allows us to capture the meanings attributed by the subject, based on the contents and structure of the narrative.

Methods

Sampling and Study Procedures

Participants were relatives of cancer patients followed in an outpatient palliative care consultation. Those who fulfilled the inclusion criteria (older than 18 years and being directly involved in the patient care) were invited to participate in the study by the PC team's resident psychologist. Qualitative and quantitative data were collected through in-depth semi-structured interviews and a self-report questionnaire. The interview script included the following main topics: a) perceived experience and circumstances of caregiving; b) perceived evolution of the disease; d) perceived changes in the caregiver's personal life and in the relationship with the patient. Interviews averaged 60 min (range: 35 – 120 min).

We used the PG-12, a self-report screening tool, for assessing pre-death grief (P.V.: Coelho, Silva & Barbosa, 2017). PG-12 was adapted from the Prolonged Grief Disorder

Questionnaire (PG-13; Prigerson et al., 2008), to assess the grief experience related to the illness, rather than the death of the person.

Data analysis

The analysis was conducted by the interviewer, who had privileged access to the implicit contents of the interview for having had direct contact with the participants (Levitt, 2015). Coding was afterwards validated with two consultants for discussing and resolving inconsistencies. Transcribed interviews were subjected to a qualitative thematic analysis, using a mixed coding, that is, some codes derived directly from data and others were theoretical based constructs. Analysis was carried out according to Braun & Clarke (2006) guidelines. The qualitative data analysis was assisted by the software NVIVO 12.

Categories that emerged from thematic analysis were then compared in cross-case analysis. This approach involved two basic steps: a) rank the cases in groups according to the severity of pre-death grief manifestations b) compare the relative prevalence of particular categories of each dimension among cases in each group. Participants were divided according to their PG-12 score, constituting four different groups. Quartiles were used as cut-off points to divide the four groups. Values ranged between 18 and 50; differentiation was computed at quartile 25 (score 29), 50 (score 35) and 75 (score 42), corresponding to increasing severity levels of pre-death grief symptomatology (low, moderate, high and severe). In order to perform the analysis, coding matrices were constructed to cross-case reference each pattern of AG with the qualitative descriptors of AG experience.

Results

Demographics

The sample was composed of 72 participants, mostly female (n = 63; 87.5%), aged 27-78. Regarding kinship, majority were adult children (n= 37; 51.5%) and spouses (n=24; 33.3%). Most participants were graduated (n=18; 25%) or completed secondary education (n= 14; 19.4%); fourteen participants (19.4%) were less than six years of education. Over half the persons (n= 39; 54.2%) cohabited with the patient at the time of the interview.

Findings

Three main themes emerged from the content analysis: a) *Traumatic distress*, defined as the emotional response to the threat that results from the repeated exposure to the patient's deterioration and suffering, as well as the perceived lack of control and impotence over the illness circumstances; b) *Separation distress*, corresponding to the perceived threat to the relationship in face of the inevitable separation and current relational losses; c) *Emotional regulation and dysregulation* processes that moderate the experience and expression of emotions. Each one of these themes is composed of several categories and subcategories.

For this study, cross-case analysis was used to identify configurations of categories and subcategories within groups, corresponding to AG patterns. Based on the score of self-reported pre-death grief manifestations, participants were divided in four groups, corresponding to low, moderate, high and extreme levels of distress, which were labelled as Avoidant (n=16), Adjusted (n=17), Intense (n=19) and Traumatic (n=20) grieving patterns. Table 1 displays the distribution of cases within each group by themes, categories and subcategories resulting from thematic analysis. A comparative explanation of these groups will be presented with exemplificative quotes, identified by gender, age and kinship, between straight parentheses.

Table 1: Distribution of cases within groups by themes, categories and subcategories

	Avoidant Grief (n= 16)	**Adjusted Grief** (n=14)	**Intense Grief** (n=21)	**Traumatic Grief** (n=21)
Themes, categories and subcategories	**N %**	**N %**	**N %**	**N %**
Traumatic Distress	15 (93.75%)	14 (100%)	21 (100%)	21 (100%)
Uncertainty of illness	**14 (87.5%)**	11 (78.57%)	13 (61.90%)	14 (66.66%)
Anticipation and attention to illness signs	5 (31.25%)	**7 (50%)**	9 (42.85%)	8 (39.09%)
Sudden and unpredictable events	**12 (75%)**	9 (64.28%)	8 (38.09%)	13 (61.90%)
Oscillation between hope and disillusion	6 (37.5%)	3 (21.42%)	6 (28.57%)	**8 (39.09%)**
Image of degradation	11 (68.75%)	**11 (78.57%)**	15 (71.42%)	15 (71.42%)
Physical and mental losses	7 (43.75%)	**10 (71.42%)**	12 (51.14%)	13 (61.90%)
Preservation of the other´s image	0 (0%)	**3 (21.42%)**	2 (9.52%)	3 (14.28%)
Strangeness in face of fragility	5 (31.25%)	5 (35.71%)	5 (23.81%)	**9 (42.86%)**
Vicarious suffering	9 (56.25%)	8 (57.14%)	**17 (80.95%)**	13 (61.90%)
Physical and emotional suffering	7 (43.75%)	7 (50%)	**15 (71.42%)**	9 (42.86%)
Identification and projection	1 (6.25%)	1 (7.14%)	**7 (33.33%)**	4 (19.05%)
Intolerance to the patient´s suffering	3 (18.75%)	3 (21.42%)	**6 (28.57%)**	5 (23.81%)
Impotence of caregiver	9 (56.25%)	**11 (78.57%)**	13 (61.90%)	16 (76.19%)
Difficulties in end-of-life care	7 (43.75%)	**10 (71.43%)**	12 (57.14%)	**15 (71.43%)**
Perception of limits in caregiving	6 (37.5%)	**7 (50%)**	8 (39.09%)	9 (42.86%)
Obstinacy in caregiving	1 (6.25%)	0 (0%)	1 (4.76%)	**4 (19.05%)**
Disruption of life	7 (43.75%)	11 (78.57%)	**18 (85.71%)**	**18 (85.71%)**
Exclusive dedication	2 (12.5%)	7 (50%)	9 (42.86%)	**11 (52.38%)**
Secondary losses	3 (18.75%)	0 (0%)	**6 (57.14%)**	3 (14.28%)
Physical and emotional exhaustion	3 (18.75%)	**9 (64.28%)**	12 (57.14%)	11 (52.38%)
Separation Distress	16 (100%)	12 (85.71%)	19 (90.47%)	20 (95.24%)
Death anticipation	**11 (68.75%)**	5 (23.81%)	9 (42.86%)	9 (42.86%)
Proximity of death	**11 (68.75%)**	4 (28.57%)	6 (28.57%)	7 (33.33%)
Lack of emotional preparation	0 (0%)	2 (14.28%)	5 (23.80%)	**6 (28.57%)**
Ambivalence toward death	**6 (37.5%)**	2 (14.28%)	3 (14.28%)	3 (14.28%)
Sense of protection	9 (56.25%)	11 (78.57%)	14 (66.67%)	**17 (80.95%)**
Preoccupation and hypervigilance in care	3 (18.75%)	**5 (35.71%)**	6 (28.57%)	6 (28.57%)
Dilemmas in managing caregiving	5 (35.71%)	7 (50%)	7 (33.33%)	**12 (57.14%)**
Overprotection	7 (43.75%)	5 (35.71%)	8 (38.09%)	**14 (66.67%)**
Relational losses	7 (43.75%)	**7 (50%)**	7 (33.33%)	10 (47.61%)
Loss of the relationship and presence	1 (6.25%)	5 (35.71%)	**5 (23.81%)**	4 (19.04%)
Longing for the past and non-lived future	4 (25%)	**5 (35.71%)**	2 (9.52%)	5 (23.81%)
Loss of protection	2 (12.5%)	2 (14.28%)	3 (14.28%)	**6 (28.57%)**
Separation anxiety	1 (6.25%)	1 (7.14%)	**5 (23.81%)**	5 **(23.81%)**
Reluctance to current separation	0 (0%)	0 (0%)	**2 (9.52%)**	**3 (14.29%)**
Afraid to be alone	1 (6.25%)	1 (7.14%)	3 (14.28%)	**5 (23.81%)**
Ambivalence toward separation	0 (0%)	0 (0%)	**1 (4.71%)**	**1 (4.71%)**

Affective deprivation	6 (37.5%)	**7 (50%)**	10 (47.71%)	9 (42.86%)
Relational needs	4 (25%)	4 (28.57%)	7 **(33.33%)**	7 **(33.33%)**
Relational failures	3 (18.75%)	7 (33.33%)	9 (42.86%)	8 (38.10%)
Loss of expectation of affect	3 (18.75%)	**4 (28.57%)**	4 (19.05%)	5 (23.81%)
Emotional regulation and dysregulation	12 (75%)	13 (92.85%)	20 (95.24%)	18 (85.71%)
Self-regulation efforts	12 (75%)	9 (64.28%)	**16 (76.19%)**	12 (57.14%)
Avoidance and emotional inhibition	9 (64.28%)	6 (42.86%)	**14 (66.66%)**	11 (52.38%)
Positive reinterpretation and endurance	**12 (75%)**	8 (57.14%)	7 (33.33%)	6 (28.57%)
Support seeking	3 (18.75%)	**4 (28.57%)**	5 (23.81%)	**6 (28.57%)**
Symptoms of disorganization	9 (56.25%)	11 (78.57%)	**18 (85.71%)**	17 (80.95%)
Physical, emotional and cognitive symptoms	9 (56.25%)	10 (71.42%)	**17 (80.95%)**	16 (76.19%)
Social and occupational disruption	2 (12.5%)	1 (7.14%)	4 (19.05%)	**5 (23.81%)**
Cumulative effect of multiple trauma	4 (25%)	3 (21.42%)	4 (19.05%)	**8 (39.09%)**

Notes: Categories are not mutually exclusive, thus the total of each category does not correspond to the sum of the subcategories. The percentages were calculated in relation to the total number of subjects in each group. The bold values correspond to the highest percentage value between groups.

Avoidant grieving pattern

Participants who self-reported low severity pre-death symptoms were particularly sensitive to the uncertainty of illness (87.5%). Most of them referred they were surprised by its unpredictable and sudden evolution (75%). However, despite showing reactions of shock in face of unexpected events, they were able to normalize and get accustomed the day-to-day events:

> *"It all went very quickly, I never expected it to be so fast. Although I already knew how it was because we accompanied a family member also with cancer. But we're never prepared."* [M, 45, son].
>
> *"I am already used to it. I try not to think about it, but I know it´s reality"* [F, 44, spouse].

Comparing to other groups, they were less prone to mention the patient´s image degradation (68.75%) and the other´s suffering (56.25%). They also referred less feelings of impotence (56.25%), as well as disruption of life (43.75%) related to caregiving. Their main difficulty in providing care is to manage the patient's behavior, especially in moments of crisis:

> *"He seems to be afraid to come to the hospital. But next time, if anything happens, I won't say anything. I'll call the ambulance and we'll come to the hospital" [F, 44, spouse].*

The avoidant participants made several references to the proximity and inevitability of death (68.75%). This event seems to be rationalized and perceived as a way of escaping from suffering; yet, it still elicits ambivalent feelings (37.5%) because although they desire the end of this painful situation, they feel guilty for anticipating death. Nevertheless, the most disturbing aspect for some of these FCs is the waiting time and the unpredictability of death.

> *"I know she's going to die. Sometimes I even get surprised by thinking this way, but for me, it was easier if she died suddenly than to be going through all this."* [F, 62, sister].
>
> *"Sometimes it is better for the person to go suddenly, than to be suffering... and not knowing if it´s going to happen today or tomorrow."* [M, 52, son].

In spite of showing less preoccupation and hypervigilance in caregiving (18.75%), they are especially concerned in assuring the patient´ security, which in some cases, includes assuming overprotective attitudes (43.75%). These participants are particularly focused in preventing the patient´s emotional burden by avoiding discussing the subject of disease or death and hindering the patient from knowing the severity of the diagnosis. Some of them even expressed the will to protect the patient from others (health professionals or family members) who are seen as potential inducers of distress. This motivation reflects their own relational need to be protected from further distress.

> *"When my mother goes to the doctor, I am always afraid that they give her the news as they gave to me. I'm always there and I say, "Ah, beware, she doesn´t know..." [F., 45, daughter].*
>
> *"She is surrounded by cancers, always calling her to give her bad news, and she keeps on thinking about it." [F, 56, daughter].*

Comparatively with others groups, these FCs do not get so involved in care provision, thus explaining the lowest value in disruption of life (43.75%) and exhaustion (18.75%). Likewise, they did not express feelings of loss or separation anxiety. Only one participant acknowledged feelings of loss caused by changes in the relationship, although some (25%) regretted that the patient had no opportunity to live more pleasant moments in the future. Most of them used avoidance mechanisms (64.28%), such as distraction, suppression of thoughts and focusing in practical aspects of caregiving. Nevertheless, they were also able to reinterpret positively the events and adapt themselves to difficult situations (75%).

> *"I've got defense mechanisms to protect myself. I got used to accepting the facts as they are and to focus in positive objectives"* [F, 62, sister].
>
> *"What does not kill us, make us stronger"* [F, 62, spouse].

These self-regulatory efforts seem to be effective in reducing the adverse impact of events, considering that this is the group that reports the lowest level of emotional disorganization symptoms (56.25%). Still, they referred intrusive and ruminative thoughts about illness and death. They were also prone to feel irritated and angry, as well as to experience physical symptoms of anxiety (e.g., tachycardia, chest pressure, difficulty in breathing, muscle tension, stomach aches).

> *"I fall asleep and get up thinking about it. It's all registered in the head... things come to mind..."* [M, 56, son].
>
> *"I begin to feel a ball here (points to stomach and throat) it seems to me that they are suffocating me. And some days ago, I started to feel stomach aches."* [F, 45, daughter].

In spite of generally devaluating their relational needs, some of them referred affective deprivation (37.5%) caused by previous relational failures or current lack of recognition from the patient.

> *I do not know if he recognizes my effort, he never said that. From his mouth, I have never heard a thank you. But I already know him. He's proud, he'll never say that.*" [F, 61, spouse].

Adjusted grieving pattern

Participants with moderate levels of pre-death symptoms also made reference to the uncertainty of the illness (64.28%). In response to unpredictability of events, they keep vigilant and anticipate future events (50%). Many of them predicted the worsening of the disease, in light of the illness signs.

> "*The situation will worsen. That's what we're waiting for.*" [F, 64, daughter].

> *"Earlier, this year, she began to have pain and then and then the tests confirmed that the disease was evolving*." [F, 54, daughter].

They are also particularly sensitive to the degradation of the patient´s image, which is perceptible through the detailed description of gradual changes in the patient´s physical and mental capacity (71.42%). Yet, some of these participants tried to preserve the patient´s previous image (21.42%), by evoking their representation of the relative before the illness and setting small targets for recovery. Simultaneously, they assumed their impotence in caregiving (78.57%), frequently using expressions such as *"I feel impotent"* and "*I can do nothing more*" to describe difficulties (71.43%) and limitations in reverting the patient´s clinical condition (50%). These FC also recognized the disruptive impact of caregiving due to time-restrictions. But the major causes of exhaustion are the patient's difficult behavior, the lack of support and the continuous overload.

> *"It is very tiring because she is a very absorbent person and has a difficult temperament."* [F, 57, daughter].
>
> *"I can´t bear with all this alone. I´ve been caring for my father for two years, and now it´s my mother."* [F, 50, daughter].

In spite of the caregiving difficulties, they manifested the will to be present because they are preoccupied with the patient´s well-being and vigilant in caregiving (35.71%).

> *"I do not want to keep him in suffering, either. But as long as he is minimally well, I will accompany him. Against death, there is nothing to be done. But it's important for me to know that I'm there for him now."* [F, 46, daughter].

They also seek support from others, mainly in practical aspects. For instance, when realizing that the death was near, a FC took the initiative of asking for help in preparing for it.

> *"If I do not talk to anyone, the time comes and I will not be able to do anything! So I phoned my friends and said, ´You have to ask the mortuary agency what to do.´ And then they said: ´There's nothing to do. Call us and we'll figure it all out.´*. [F, 61, aunt].

Although conscious of the irreversibility of the disease, few people mentioned the proximity of death (23.81%); instead, they recognized the loss of the relationship and truncated projects (35.71%) and showed sadness for it. They also readjusted expectations and focused in providing comfort and well-being to the patient.

> *"He is no longer the father I´ve used to know"* [F, 22, daughter].
>
> *"I thought they were going to enjoy this phase for longer. It's a very abrupt cut. I wish they would enjoy their house. If I could, I would give him part of me. But we cannot do anything, I just have to wait. Giving him the pills and trying to make sure he's all right."* [F, 46, daughter].

When the previous relationship with the patient was distant, they assumed their unmet relational needs as well as sadness for the loss of affective expectations (28.57%). In fact, comparing to the other groups, these FC were those who reported less avoidance and emotional inhibition (42.86%). They seem to be aware of their emotional states and their limits, so they tried to establish boundaries in the caregiving relationship and acknowledged the benefit of maintaining other activities, in addition to caregiving role. They also can understand the other's limits, as well, and appreciate small manifestations of affect.

> *"There was a time when I began to feel depressed. And I would stand there... so I said: this cannot be, this will not work."* [F, 61, aunt].
>
> *"While my father was affectionate and kissed us, she was always a bit colder, but it does not mean she does not like us, because, there are people like this. But it's funny that the second time she went to the S.O. she said to me: I really like you." [F, 56, daughter].*

Intense grieving pattern

The participants who presented high scores in PG-12 showed a tendency to be hyper vigilant and preoccupied with future difficulties (57.14%). This is expressed in the following statements:

> "*If I feel my husband moving in bed, or any little thing, I wake up."* [F, 50, spouse];
>
> *"This is going to be harder and harder. So far, he has not fallen. If he starts falling, it will be very difficult because I do not have the strength to lift him"* [F, 66, spouse].

However, this does not necessarily mean that they are more aware of the threat posed by the life-threatening disease. They avoid talking about the progression of the disease, and make few references to the uncertainty evoked by the unpredictable circumstances (38.09%). However, they are visibly overwhelmed by the vicarious suffering (80.95%) because they have a tendency to identify themselves with the significant other and project their own thoughts and feelings of distress (33.33%).

> *"The worst (trembling voice) is to see her becoming aware of what is happening to her. Despite being prostrated, she feels, she knows, she must be thinking: "What am I still doing here? Please help me."* [F, 29, daughter].

Absorbed by their own distress, they sometimes become intolerant to the other´s suffering and fail to empathize with the patient´s needs. For instance, several participants viewed the patient´s prostration as a sign of withdrawal and abandonment:

> "*She is giving up living*" [F, 28, daughter].
>
> "*My husband is giving up fighting.*" [F, 66, spouse].

Hence, they anticipated their relative´s death with intense suffering, feeling constantly under the threat of losing the significant other. They frequently manifested anger about the injustice of patient's suffering, and blamed themselves or the others for the failures in the patient's care. As a way of compensating the significant other, FCs expressed the desire to be always present, including at the moment of the patient's death, evidencing high separation distress (23.81%). Some of these FCs remained focused on recovery, although they have limited hope and their self-efficacy is reduced. They were reluctant in accepting help because they believe that nobody else will be able to care adequately for their relative, and they do not want to displease the patient. Besides, they cannot divert their attention from caregiving:

> *"Wherever I am, I cannot enjoy what I am doing because I am always thinking: how is he? I should go home early... so it's not worth going out, it's not worth it."* [F, 66, spouse].

In the relationship with the patient, these FC frequently suppress their emotions (66.66%), because they need to highlight the positive aspects and erase old resentments. In fact, although they often feel they have been deprived of affection (47.71%), they are greatly influenced by the need to strengthen the relationship with the patient. For instance, one FC described that previous anger has now evolved to feelings of pity. Another showed indulgence and rationalized the patient's abusive behavior:

> "*It's always like this with families that have ill people: those who are closest are the ones who put up with everything*." [F, 78, mother].

These regulation efforts seems to be ineffective in preventing emotional disorganization, since they clearly show signs of high physical, emotional and cognitive disturbance (80.95%). Many referred a state of anguish and panic, accompanied by tachycardia and digestive problems. One person reported habits disruption, associated to periods of dissociation and compulsion to eat. They also manifested social disruption, caused by general distrust of others:

> *"Friendships are sometimes for convenience, so there are things I do not have to share and they do not have to know about my life because people will talk to others. And that's why I'm very reserved"* [F, 27, daughter].

Traumatic grieving pattern

The participants who scored higher in PG-12 combined great disruptive effect of caregiving (85.71%) and severe symptoms of emotional disorganization. The cumulative effect of multiple previous traumas (39.09%) probably contribute to this situation. For instance, one FC reported the experience of a previous loss that had elicited strong feelings of impotence:

> "*My son died, and I could not do anything. He died in front of me, in his room.*" [F, 69, spouse].

Additionally, they reported concurrent stressors, including having other ill or dependent relatives and economic difficulties. Many of these participants showed failures in self-care, namely difficulty in maintaining an eating and sleeping routine, generalized dissatisfaction with life and, in some cases, suicidal ideation:

> "*Yes, I've already thought about ending my life. And I'm afraid... because everything stopped making sense. Why is this life like this?"* [M, 64, spouse].

They felt as if they were losing a part of themselves, which translates in a sense of deep loneliness and abandonment. The expression of sadness was associated with intense crying and their speech was often disorganized, with lapses and interruptions. They made self-devaluating comments, and generally, they avoided social contact, although many of them recognized that they greatly needed the presence of others to self-regulate their emotions:

> *"I am very dependent of this friend, because I need to talk to her continuously (...) It does not necessarily have to be about my father, but since I am not able to distract by myself…"* [F, 36, adult child].

Some of these persons felt little acknowledged and gratified by the ill relative (38.10%), which reflects in unmet relational needs (33.33%), such as being protected, valued, accepted and respected. However, they resigned themselves, often paralyzed by the fear of losing the patient and being alone. Some dreaded the patient's behavior, which was sometimes unpredictable and threatening:

> *"He always said he would kill himself. Before he was ill, he said that one day, if he knew that he had a bad disease, he would kill himself. Then, he began to say: "One day, I'll take the wheelchair out, a car passes and takes me."* [F, 69, spouse].

These participants also shared the perception that the disease had evolved in a sudden and unexpected way, but they keep hoping for some recovery, which leads to successive disillusions (39.09%). They described episodes of crisis and imminent death with intense terror. When confronted with the patient's functional losses, they were very impressed by the marked deterioration. A daughter described how she was trying to preserve her father´s previous protective image:

> *"I need to feel that he is the same father from years ago. Not as he is now (trembling voice). He's a strong (strong voice) parent, because he has always been a very dynamic father, a father with a voice at home. And that's how I want to keep seeing him."* [F, 55, daughter].

In some cases, the generalized preoccupation with the patient's suffering leads them to overprotecting the patient (66.67%). Others feel desperate and often become intolerant to the other´s complaints (23.81%). Many participants emotionally restrained themselves to protect the patient from their own distress, but this eventually reverted to ambivalent feelings about caregiving. For example, a FC assumed that her motivation to provide care was a mix of sacrifice, duty and resignation:

> “*We have to give up on ourselves for their benefit. They need us now, and we have a duty to help. It's complicated, but I'm not complaining.*” [F, 56, daughter].

Ambivalent feelings also occur in relation to the patient's death: at the same time they longed for the end of the suffering, they felt guilty for anticipating the patient's death. For instance, a participant said:

> *“I swear, I will never have the courage to say this to anyone else, but I just want my father to die fast, without realizing it, because when I put myself in his shoes, I say: this is not bearable! This is the worst that anyone can go through.”* [F, 36, daughter].

Others feared their own reaction to death, stating that they can never really be prepared to lose their significant other. For most, the loss is imminent, so they are often invaded by great death anxiety, which in some cases translates into panic attacks and fear of their own death.

Discussion

The purpose of this study was to gain a better understanding of cancer FC response variability, in order to identify the specific features of anticipatory grieving patterns. A cross-case analysis was performed according to self-reported severity of pre-death grief manifestations. Consistent with previous findings (Nicholls, Hulbert-Williams & Bramwell, 2014), we found that individual differences in FC adjustment process reflect characteristics of attachment styles. Based on the self-reported AG distress level, measured by PG-12, we classified the four groups as avoidant, adjusted, intense and traumatic anticipatory grieving patterns, corresponding to avoidant, secure, preoccupied and disorganized attachment styles, respectively.

Participants with *adjusted grief* are particularly sensitive to changes in the patient´s image, recognizing their impotence to reverse the illness. In the caregiver relationship, they acknowledge the uncertainty of the future and talk about the multiple doubts that arise from caregiving, while responding with compassionate care (Shaver, Mikulincer, Sahdra & Gross, 2016). They were also able to adjust the vigilance level and support to the other´s needs. These observations are congruent with a previous study (Simpson, Rholes, Oriña and Grich, 2002), whose findings suggest that the caregiving system of more secure persons are triggered automatically by the expressed needs of the significant other. Besides, the safety provided by secure internal models (Bowlby, 1988; Feeney, 2004), allows them to question their decisions as caregivers, as well as the unsatisfactory aspects of the relationship with the patient, without compromising their sense of self-efficacy and intention to care. Hence, rather than absence of distress, these people are characterized by the ability to be in contact with feelings of sadness and anger, and speak openly of their difficulties, revealing self-awareness and tolerance to internal emotional states. Such reactions suggest tolerance to uncertainty, which is typical of secure attached individuals, as opposed to insecure attachment (Wright et al., 2017). Besides, their willingness to accept help from others and to recognize positive exchanges in the relationship with the patient contributes to balance their sense of deprivation, promoting adjustment to the successive losses and to the patient´s future absence.

On the contrary, the *avoidant grief* group developed ways of habituation and rationalization that seem to be effective in deactivating the sense of threat posed by the terminal illness. This makes them less likely to detect the signs of illness progression, justifying the shock reaction to the crisis episodes. Considering these anxious reactions, we can assume that this group corresponds to the avoidant-preoccupied attachment style, instead of avoidant-dismissing. The lack of motivation to caregiving of the dismissing people (Kim Carver, Deci & Kasser, 2008) explains why they are less likely to be found in the caregiver population. Avoidant-preoccupied attachment caretakers, on the contrary, are very concerned about the significant other, but they use avoidant attentional style as a way of deactivating painful emotions. In other words, they divert attention from the threatening stimulus as a strategy of emotional regulation (Dewitte Koster, De Houwer & Buysse, 2007). Consequently, they do not value the losses or the other´s suffering; instead, they are focused on their difficulty in managing the patient's behavior. This finding is in line with evidence that avoidant individuals report less compassion and react to the significant other´s negative emotions with distance and anger (Monin, Xu, Mitchell, Buurman & Riffin, 2018). They are sometimes restrictive and controllers in the management of care, as a way of protecting themselves and the other from further complications. Similarly to other studies (e.g., Vogel & Wei, 2005), we verified that the avoidant people are prone to deny distress and avoid asking for help. Therefore, they feel trapped in this situation and make great efforts for self-control, which translates into somatic symptoms and difficulties in adjusting to the current changes in relationship.

The *intense grief* group presents a heightened vigilance in dealing with threat, a hyper activating strategy characteristic of anxious attachment style (Fraley et al., 2006). However, by ruminating about their own and the other's suffering, they were also diverting attention from the illness signs. Recent results concerning the central role of uncertainty in anxiety corroborate these findings (Shihata et al., 2017). This experience activates their fear of losing the significant other, causing overwhelming distress that leads them to seek more closeness, often through exclusive dedication and great reluctance in separating from the patient. However, the difficulties in differentiating themselves from the other compromise their emphatic response (Mikulincer & Horesh, 1999). Nevertheless, in revising the relationship with the patient, they suppress their negative feelings toward the significant other, which may be explained by their need to be valued (Gentzler & Kerns, 2006). For the same reason, they have difficulty in establishing limits in the relationship with the patient, so despite feeling impotent, they continue taking care obstinately, becoming vulnerable to high levels of disorganization symptoms.

Finally, *traumatic grief* is distinguished by persistent and pervasive feelings of shock and helplessness and other post-traumatic reactions, translating the disorganization of the attachment system (Mikulincer, Shaver & Solomon, 2015). For these people, the anticipation of loss has a devastating impact on all levels of experience, leaving the person in a deep state of solitude and abandonment, which elicits intense feelings of despair, fear and hostility. As demonstrated by Paetzold, Rholes and Kohn (2015), the experience of relationships of the disorganized adult include a conflict between aggressiveness and withdrawal, resulting from feelings of anger and fear directed toward the attachment figure. Accordingly, we found that many of these FC expressed great resentment at the patient's relational failures, but at the same time they feared him, so they avoided talking about their feelings. They were also confused about the other´s image of degradation, as if it threatens their sense of security. Hostility manifests through an authoritarian and intrusive behavior in the provision of care or intolerance to the patient complaints. As a result, they experienced great ambivalence toward the other´s death, since the separation is at the same time desired and feared.

Clinical Implications

Results from this study may inform clinicians about qualitative criteria in assessing FC individual differences, in order to diagnose distinctive anticipatory grieving patterns and develop individualized intervention programs focused in the FC AG. Following are some general guidelines for clinical intervention directed for each grieving pattern, based on the results of this study. Those who present an adjusted grief pattern clearly need to be heard and validated in their feelings of loss and uncertainty. Their capacity for self-regulation needs to be recognized, to increase their sense of confidence in dealing with difficulties. The avoidant grief pattern person would benefit from being validated in their need to protect themselves. However, it is also important to raise their awareness about the costs of diverting attention and trying to control their feelings, not only for their physical health but also for their relationship with significant others. The intervention with the intense AG group should value their caregiving efforts, but it also requires strategies to increase their ability to differentiate themselves from others (in their feelings, thoughts, behaviours and sensations) and to develop self-regulation resources to decrease the intensity of distress and promote their autonomy in relation to the patient. Finally, the traumatic grief group should be protected from the devastating impact of end-of-life caregiving and learn more effective ways of communicating their relational needs in order to preserve themselves from destructive relationships.

Limitations and future research

We identified some limitations in this study. First, participants were selected from a clinical population, which is not representative of general caregiver population. Second, the small size of each group may compromise the extrapolation of results. Third, we may be over-simplifying, since individual variability does not correspond exclusively to these four patterns, nor the characteristics combine perfectly in all the individuals that constitute the same group. However, this is a first attempt to find clinical criteria to better assess and intervene in AG individual differences. Future research is needed to verify if these AG patterns correspond effectively to the person's attachment styles, by triangulating these data with self-reported attachment measures. It would also be important to investigate the evolution of these grieving patterns in the post-death bereavement period to verify if these manifestations persist over time. Finally, it is necessary to develop studies that evaluate the effectiveness of the intervention measures suggested for each of the anticipatory grieving patterns.

Conclusions

The way the FC reacts depends on their dispositional tendency to regulate emotions and the current relational context of caregiving. To identify individual differences in FC response, self-reported AG distress was used to classify participants in four different groups, ranging from low to severe pre-death grief manifestations. From cross-case analysis, the main characteristics of each group emerged, classified as anticipatory grieving patterns, namely: a) Avoidant, b) Adjusted, c) Intense and d) Traumatic, corresponding, according to theoretical and empirical previous findings, to Avoidant, Secure, Preoccupied and Disorganized attachment, respectively. This integrative framework aims to improve the understanding of individual differences in order to offer a more adequate therapeutic response to the needs of FC in palliative care.

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5. EMPIRICAL STUDY IV

FAMILY CAREGIVER´S ANTICIPATORY GRIEF - CLINICAL INTERVIEW (FCAG-CI): PSYCHOMETRIC CHARACTERISTICS AND SCORING PATTERN

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Abstract

The current study describes the development and the preliminary validation of the Family Caregiver Anticipatory Grief Clinical Interview (FcAG-CI), which evaluates Anticipatory Grief (AG) response patterns of cancer family caregivers. Semi-structured interviews were carried in a sample of family caregivers in palliative care ($n = 72$, mostly women, adult children or spouses, mean age of 52.37) and coded according to the rating guidelines. FcAG-CI, composed of eight domains, shows convergent and concurrent validity with self-reported pre-death Prolonged Grief Disorder symptoms, as well as divergent validity with the Zarit Burden Interview. Tests for reliability suggest that it has reasonable consistency (Cronbach´s $\alpha = .750$) and very good inter-rater reliability. Two factors were identified, corresponding to the two major sources of distress: Traumatic and Relational aspects of end-of-life caregiving. This instrument allows the categorization of respondents in four different profiles (Avoidant, Adjusted, Traumatic and Intense AG), with clear implications for clinical practice.

Keywords: Anticipatory grief, family caregivers, semi-structured interview, palliative care, end-of-life

Introduction

As indicated in the palliative care (PC) clinical practice guidelines, support to family caregivers (FC) should be ensured as a continuum during advanced disease and bereavement (Hudson et al., 2012). Identifying the people who most need and stand to benefit from support is, therefore, an essential part of this preventive intervention. Compared to the general population and other carers, the FC of cancer patients are particularly prone to higher psychological morbidity, poor quality of life and general health (Grande, Rowland, van den Berg & Hanratty, 2018; Kim & Given, 2008; Wallace, Oliver, Demiris, Washington & Smith, 2018).

The experience of a threat to the other´s life along with multiple losses resulting from advanced disease (i.e., perceived limitations of patient´s physical and mental abilities) leads FC to experience anticipatory grief (AG) (Coelho & Barbosa, 2016). In a nationwide population of cancer FC, 15% showed severe grief symptoms, which were associated with high caregiver burden and depressive symptoms, pre and post-death. High grief intensity was also correlated to low preparedness for the impending death, low communication about death and "too much" prognostic information (Nielsen et al., 2017). As suggested by the authors, this reflects the inability of the health professionals to identify and meet the real needs of caregivers in grief, especially in cases where the person is emotionally dysregulated.

AG is a complex and multidimensional construct (Cheng, Ma & Lam, 2019; Marwit & Meuser, 2005; Rando, 1986; Siegel & Weinstein, 1983). Some of the existing self-report instruments also reflect this complex, multidimensional view of the AG experience, but as noted by Cheng et al., (2019), dimensions still lack clarity and specificity. For example, a popular AG scale (Meuser and Marwit Caregiver Grief Inventory; Meuser & Marwitt, 2005) includes burden as an attribute of grief, which constitutes a confounding factor because AG and burden are two different concepts.

In spite of the new developments in anticipatory grief assessment tools (for review, see Coelho, de Brito & Barbosa, 2018), these instruments - all self-reported - are usually used for research purposes. In clinical practice, they are more likely to be used as a complementary tool to the clinical interview, the preferred means to collect information and establish contact with the FC. Thus, clinicians would benefit from an assessment instrument that guides them in collecting in-depth information about the way FC deal with the multiple emotional challenges posed by AG. The current study intends to develop a valid, reliable and sensitive assessment instrument to clinically assess different AG response patterns in advanced cancer FC.

Method

Sampling and Study Procedures

Participants were Portuguese FC of adult cancer patients followed in an outpatient PC consultation of a general hospital, in urban context. The inclusion criteria were being: a) adult family member (older than 18 years old); b) able to speak, read and write in Portuguese, c) involved in caregiving. The PC team's resident psychologist presented the study at the first consultation. Those who agreed to participate in the study gave their oral informed consent.

Interviews were scheduled according to the patient´s convenience and carried out in the hospital. FC were told that the purpose of the interview was to understand how they managed the emotional impact of the cancer disease. The semi-structured interview, lasting about one hour, were then conducted by a psychologist with experience in clinical practice and research interviewing with the bereaved population. For this study, all the interviews were audiotaped and rated by the first author. Additionally, a subset of randomly selected interviews (n = 30; 41.67%), were rated by a second trained clinical psychologist.

Self-report scales were subsequently filled at home, either online or on paper, and in the latter case, delivered at the next palliative care appointment. In the first assessment, we evaluated pre-death Prolonged Grief Disorder (PGD) symptoms, caregiver burden, depression, anxiety, and somatization. After six months after the death of the family member, participants were contacted by phone to assess PGD symptoms (follow-up). We used as rationale for defining the follow-up period the temporal criterial of six months, according to Prigerson et al., (2009). Participants were informed that they could interrupt their participation in the study at any time and whenever high emotional distress was detected, a referral for psychological consultation was suggested.

Instruments

Rationale and Development of FcAG-CI

The Family Caregivers´ Anticipatory Grief Clinical Interview (FcAG-CI) is an assessment tool based on a semi-structured interview administered individually to the FC. Being of conversational nature, the interview favours the therapeutic relationship and the contact with the participant´s internal experience, in a progressive and careful manner. This sensitive approach is especially important for three reasons. The first one is for ethical motives. Since FC are already in a state of such great vulnerability, direct questions about death and dying (that might be intrusive), for which they may not be prepared, should be avoided. The second motive is the instrument's reliability. Some grief manifestations may be observed, but not always accessible to introspection, so they cannot be captured through a self-report instrument. Especially when confronted with an emotionally demanding task that evokes painful memories (such as talking about the previous relationship or evoking grief feelings), it is natural for people to respond defensively, reducing their level of awareness and dissociating (Van der Hart, Nijenhuis, Steele & Brown, 2004). Thus, to access this level of implicit meanings, it is necessary to conduct a conversational interview, in which the interviewer is both the facilitator of the narrative, requesting details and examples, and the agent who decodes and interprets signs and symptoms, integrates contradictions and discrepancies throughout the narrative, and establishes a relation between phenomena, in the light of an analysis system sufficiently flexible to allow individual variability (Nordgaard, Sass & Parnas, 2013). The third motive is for practical reasons: a clinical interview is more user-friendly for clinicians and prevents overloading participants with written questionnaires.

This clinical interview was developed through a three-step process, as follows: a) determining content domains, b) definition of evaluation criteria and c) testing psychometric properties (Clark & Watson, 1995). The content domains were determined by the literature review on the topic (edited out for blind review), which allowed us to clarify the nature and range of the AG construct. It also allowed us to identify problems with the existing measures that justify the development of this new comprehensive measure. Additionally, we conducted a pilot qualitative study, with 26 preliminary interviews carried out with FC in a PC setting, in order to enrich and develop what was previously found about the concept (edited out for blind review). Data from the literature review and the qualitative study were systematically refined into critical domains of the AG experience and then operationalized evaluation criteria. Finally, a panel of researchers and practitioners with expertise in this field reviewed the selected domains and evaluation criteria, thus conferring content validity to the instrument.

Construct and criterion validity were tested by comparing FcAG-CI with gold-standard criteria (PGD criteria) and health outcomes measures (depression, anxiety, somatization, and caregiver burden), evaluated by self-report instruments.

FcAG-CI Protocol and Coding System

The interview protocol is composed of 15 questions, followed by probes introduced in a non-directive and flexible way, respecting the participant´s interests and concerns, their conversation rhythm and natural interruptions. The interviewer begins by requesting information about the family structure and then invites the person to talk about their experience as a caregiver, their perception of the illness evolution, changes in the relationship with the patient, dealing with anticipated separation, caregiving gratification and personal changes in reaction to this experience. Examples of questions are: “Would you say [family member's name] is very different from what he/she was previously? In what aspects?”. In this case, we start by asking a closed question to give the participant the opportunity to answer that there are no major changes, rather than asking directly what differences are noted in the familiar. In evaluating the participant's response, the interviewer should consider verbal and non-verbal communication, as well as the characteristics of the discourse (e.g., repetitions, hesitations, length of response).

The FcAG-CI quotation grid was initially composed of nine domains. Table 1 provides definition of domains and a brief description of the evaluation criteria, according to the classification level. Each domain is rated on a scale of nine points, corresponding to an increasing degree of distress, in which the value one corresponds to a Absent and nine to an extreme of distress. The zero value is assigned when the dimension is not-evaluable, because of the lack of clarity of the answer or because no specific question has been asked. The quotation is guided by qualitative descriptors: Absent (1), reduced (3), moderate (5), high (7) and extreme (9). The remaining values apply when the content of the response seems to correspond better to an intermediate point between two descriptors because it brings together elements of both and cannot be classified by only one. A detailed characterization of the FcAG-CI protocol and coding system is available at: www.figshare.com.

Table 1: FcAG-CI domains and evaluation criteria

1. Uncertainty of illness
Perceived threat related to the unpredictability, complexity and ambiguity inherent to the advanced disease and its disruptive impact on other areas of life. *Abs*: no sense of threat, minimal vigilance, preserved security and hope *Red*: distant threat, reduced vigilance to preserve security and hope *Mod*: possible threat, anticipation and vigilance to preserve security, adjusted hope *High*: near threat, hypervigilance, generalized insecurity and unstable hope *Extr*: constant threat, disruption of security and hope, hypervigilance and escape
2. Vicarious suffering
Sensitivity and empathic response to the physical and emotional suffering of the ill person. *Abs*: no signs of suffering, lack of empathy towards the other´s feelings *Red*: some signs of suffering but relativizes or devalues the other´s feelings *Mod*: signs of suffering and empathy towards the other´s feelings *High*: intense suffering, cannot differentiate from the other´s feelings *Extr*: intolerable suffering, withdrawal from the other´s feelings
3. Image of degradation
Perceived physical or mental losses resulting from the disease, with impact on the representation of the patient. *Abs*: does not identify losses, no changes in the patient´s representation *Red*: few losses, with little emotional impact on the patient´s representation *Mod*: some losses and fragility, with adaptation of the patient´s representation *High*: many losses and great fragility, degradation of the patient's representation *Extr*: complete deterioration, shock caused by major changes in the patient´s representation

4. Anticipation of death

Awareness of terminality and threat to the significant other’s life as a result of an advanced and irreversible disease.

Abs: not aware of the possibility of death, clearly not informed about terminality
Red: irreversibility of the disease without mentioning the possibility of death
Mod: inevitability of death, feelings of loss, no signs of death anxiety
High: near death, does not feel emotionally prepared, signs of death anxiety
Extr: imminent death, intense death anxiety, intrusion and avoidance of thoughts about death

5. Separation anxiety

Concern with the separation and with the other´s future absence.

Abs: no concern about separation and with the other´s absence
Red: reduced concern about separation and with other´s absence
Mod: some concern with separation, ability to anticipate the other´s absence
High: great concern about separation, difficulty in imaging the other´s absence
Extr: extreme concern about separation, ambivalence toward the other´s absence

6. Relational losses

Changes in the relationship that affect the sense of attachment to the patient

Abs: no changes in the relationship
Red: few changes in the relationship, focused on the positive aspects
Mod: some changes related with communication failures and lack of reciprocity
High: great changes related with failures in the sense of belonging and protection
Extr: loss of expectation of affection, longing for the idealized relationship

7. Sense of protection

Predisposition to respond to the patient's needs and prevent the other from experiencing physical and/or emotional suffering.

Abs: no response to the patient's needs, lack of involvement and motivation to care
Red: limited response to the patient's needs, external motivation to care
Mod: sensitive response to the patient's needs, empathic and affective care
High: persistent preoccupation with the other´s needs, over involvement in caregiving
Extr: compulsive response and intrusive attitudes in managing caregiving

8. Impotence of caregiver

Recognition of limits in caregiving and failure in protecting the patient from suffering and dying.

Abs: no sense of impotence, illusion of control and high sense of efficacy
Red: difficulties are attributed to external causes, do not affect self-efficacy
Mod: aware of difficulties and limits of caregiving, self-efficacy in managing distress
High: serious difficulties in caregiving, helplessness and inability to manage distress
Extr: illness evolution is perceived as a personal failure, causing intense guilt/revolt

9. Personal restrictions
Perceived restrictions in personal, social and occupational life caused by caregiving demands. *Abs:* no personal restrictions, free of caregiving demands, preservation of normal routine *Red*: few personal restrictions, scarce involvement in caregiving, devaluation of its impact *Mod*: some personal restrictions, involvement in caregiving with capacity to establish limits *High*: major personal restrictions, great involvement in caregiving, devaluation of sacrifice *Extr*: total restriction of personal life, intense pressure and feeling of being invaded

Abs - Absent: 0-1; Red - Reduced: 2-3; Mod - Moderate: 4-5; High - High: 6-7; Extr - Extreme: 8-9

Self-report Instruments

Prolonged Grief Disorder Questionnaire (Prigerson et al., 2009). Used as a diagnostic instrument for Prolonged Grief Disorder (PGD), considering the following clinical criteria: separation distress; cognitive, emotional, and behavioural symptoms; social and functional impairment. The pre-death version (PG-12) was designed to assess grief experience related to illness. It is composed of 12 questions, rated n a 5 point Likert scale, ranging from 1 (almost never) to 5 (always), except the last item, which is dichotomous (e.g., “In the past month, how often have you had intense feelings of emotional pain, sorrow, or pangs of grief related to (patient’s) illness?”). In the Portuguese validation (Coelho, Silva & Barbosa, 2017), this instrument has demonstrated a unifactorial structure with high internal consistency (α = 0.846). PG-13 is focused on the post-death grief and it includes one more item, also dichotomous, in which respondents are questioned if the grief symptoms persist for longer than 6 months (temporal criteria). This instrument was validated for the Portuguese population by Delalibera, Coelho & Barbosa (2011). The internal consistency was considered excellent (α = .932).

Depression, Anxiety and Somatization BSI subscales of Psychopathological Symptom Inventory (BSI; Derogatis & Melisaratos, 1983). The subscales used consist of 18 statements evaluating symptoms of depression (e.g., feeling blue, lack of interest in things), anxiety (e.g., feeling tense, fearful) and somatization (e.g., feeling weak, nausea). Responses are evaluated in a Likert scale, ranging from 0 (never) to 4 (always). This measure was validated for the Portuguese population (Canavarro,1999), showing acceptable to excellent internal consistency (sub-scales between α = 0.67 and α = 0.92). We used the recommended cut-off points of 1.051 for depression, 0.940 for anxiety, and 1.004 for somatization.

Zarit Burden Interview. This instrument, developed by Zarit, Reever, Bach-Peterson (1980), evaluates the feelings of stress related to the caregiving role. It contains 22 items (e.g., "Patient asks for more help than he/she needs"), with scores ranging from 0 (never) to 4 (always). The Portuguese validation (Ferreira et al., 2010) obtained high internal consistency (α = 0.88). The cut-off point for the total score is 21.

Data analysis

Analysis included a descriptive summary statistics characterizing the sample. Next, the factorability of the nine domains was examined using exploratory factor analysis (EFA). A ratio of 5 participants per variable was applied (e.g., Cattell, 1978). We checked the main assumptions of EFA with data being screened for outliers and normal distribution. Domains correlation was evaluated using Bartlett's test of sphericity and the Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy. KMO values higher than .70 were considered acceptable. Considering factor extraction, three factor retention methods were applied: 1) parallel analysis with factors being retained when EFA eigenvalues are higher than those based on the randomisation of datasets derived from the study dataset (Hayton, Allen, & Scarpello, 2004); followed by 2) the Kaiser criterion suggesting factors with eigenvalues above 1 should be retained; and 3) the visual scree plot with factors being retained before the "elbow". Afterward, assuming factors multidimensionality an oblique rotation (direct oblimin) was applied. Finally, domain factor representativeness was evaluated through factor loadings on communalities.

In the next step, we carried out Multiple Correspondence Analysis (MCA), complemented with Cluster Analysis (CA). MCA is used to detect and represent underlying structures in a nominal categorical data set. This procedure evaluates the interconnections between qualitative data and works as an exploratory multivariate strategy procedure providing a low-dimensional space, where for each variable, and given categories, a specific score is calculated leading to the graphical representation of the data (Di Franco, 2016). Thus, it allows us to identify similarities between participant's ratings in FcAG-CI scale and mental health outcomes (i.e., symptoms of pre-death PGD, depression, anxiety, somatization and caregiver burden). For this analysis, the nine-point scale was recoded into a categorical variable, corresponding to: Absent to Reduced (1-3), Moderate (4-5), High (6-7) and Extreme (8-9). The remaining variables were introduced as binary data, using the cut-off points ("presence/absence of symptoms"). Dimensions to be retained should have inertia scores higher than 0.2 (Johnson & Wichern, 1998), yet Gifi (1996) determines the need to establish a parsimonious solution stating data interpretation is highly improved when only two dimensions are chosen to graphically represent the data.

CA is an explorative analysis that identifies homogeneous groups of cases based in the distribution of FcAG-CI dimension's scores. In this study, we adopted a two-step method, where the hierarchical method is followed by an iterative partitioning cluster analysis (Aldenderfer & Blashfield, 1984). The mean values of the two factors entered to derive clusters. A fixed number of clusters was defined, according to results of MCA and previous qualitative analysis of data. Clusters profiles were classified according to FcAG-CI descriptive statistics (mean, standard deviation and Z-values). Further characterization included estimating differences in demographics and health outcomes. Considering the small groups size, we used non-parametric tests. Chi-Square test was used when analysing dichotomous or categorical variables and Kruskal-Wallis H test when comparing continuous variables (McKight & Najab, 2010).

Then, Cronbach's alpha coefficients were used to assess the internal consistency of the instrument. Values higher than .70 suggested good levels of internal consistency (Nunnaly & Bernstein, 1994). The inter-rater reliability was evaluated using the intraclass correlation coefficient (Won, 1981). Convergent and divergent validity was assessed using Pearson correlations of FcAG-CI total score with PG-12 and Zarit Burden Interview. For the former, we expect that the FcAG-CI total score correlates with PG-12 score since it is a measure of pre-death grief; the latter should be demonstrated by a low or no correlation with Zarit, as it evaluates a different construct. Concurrent validity was estimated using pre-death PGD as the dependent variable in a binary logistic regression. For this analysis, the categorical variable was converted into dummy variables. The predictive validity was also tested with binary regression, using post-death PGD as the dependent variable.

Analyses were performed using IBM SPSS software (v.25, SPSS Inc. Chicago, IL) and the following R packages (R Core Team, 2019): *psych* (Revelle, 2018) for parallel analysis and *FactoMineR* (Le, Josse, & Husson, 2008), *ggplot2* (Wickham, 2016) and *factoextra* (Kassambara, & Mundt, 2017) for multidimensional scaling.

Results

Descriptives

The sample was composed of 72 FC of patients in PC. Demographics are displayed in Table 2. At the baseline, the sample was constituted mostly by female (n = 63), married or cohabiting (n = 50), with mean age of 52.37 (SD = 13.33). Twenty-five percent had a university degree (n = 18). Concerning kinship, most were adult children (n = 37) or spouses (n = 24) of the patient. More than half (n = 38) lived with the patient at the time of the interview and the household mean was 2.66 persons (SD = .92). At follow-up, 50 participants responded. The average time since the loss of the family member was 8.67 months (SD = 2.30, range: 6-12).

In this sample, 45.8% met the criteria for pre-death PGD, 54.2% reported symptoms of depression, 41.7% symptoms of anxiety, and 22.2% symptoms of somatization. Most participants presented moderate to severe burden (75%). Post-death PGD criteria were met by 30.6% participants.

Descriptives of FcAG-CI are presented in Table 3. Uncertainty of illness presents the highest mean value, while Separation anxiety has the lowest. For most domains, response amplitude was between 2 and 9.

Table 2: Sample´s demographics

	T1 (n= 72)	T2 (n= 50)
Age		
Mean (S.D.)	52.22 (13.29)	53.34 (13.13)
Amplitude	21 - 78	21-78
Gender n (%)		
Female	63 (87.5)	44 (88)
Male	9 (12.5)	6 (12)
Kinship n (%)		
Spouse	24 (33.3)	19 (38)
Adult child	37 (51.4)	25 (50)
Parent	1 (1.4)	1 (2)
Sibling	4 (5.6)	2 (4)
Grandchild	1 (1.4)	1 (2)
Other	5 (6.9)	2 (4)
Marital status n (%)		
Single	6 (12.7)	6 (12)
Married / Cohabiting	50 (69.4)	17 (34)
Divorced	12 (16.7)	7 (14)
Widow	1 (1.4)	20 (40)
Education		
4 years	4 (5.6)	3 (6)
6 years	10 (13.9)	5 (10)
9 years	14 (19.4)	11 (22)
Secondary school	16 (22.2)	10 (20)
Technological school	6 (8.3)	6 (12)
University degree	18 (25.0)	13 (26)
Master	4 (5.6)	2 (4)
Household size		
Mean (S.D.)	2.66 (.92)	
Amplitude	1-5	

Construct validity

Visual analysis of the detrended normal Q-Q plots showed all observed values clustering around 0. Plotted points did not exceed one deviation from the normal distribution. The boxplot for Personal Restrictions revealed three moderate outliers. However, due to the small number of extreme values (less than 5%), all data points were maintained in the following analyses. For the EFA with direct oblimin rotation, reasonable factorability was suggested (X^2 (36) = 166.011, p < .001; KMO = .72) with the three extraction methods suggesting two factors to be retained. Both factors explained 54% of the total variance. Factor loadings and communalities are displayed in Table 4. The first factor comprised four variables: Uncertainty of Illness, Image of degradation, Vicarious suffering and Caregiver impotence. This factor was labelled Traumatic distress, as it refers to the disruptive impact of life-threatening conditions in the context of advanced illness. The second factor included another 4 variables: Anticipation of death, Relational Losses, Separation Anxiety and Sense of Protection. This factor was labelled Relational distress, referring to the difficulties in managing the relationship in face of imminent death. Item 9 related to personal restrictions due to the caregiving role presented a factor loading lower than the cut-off value of .40 (Stewart, Barnes, Cote, Cudeck, & Malthouse, 2001). This item also presented the lowest communality value (h^2 = .15). To that end, item 9 was excluded from the analysis. The correlation between factors was small (.27). Results for the subsequent EFA without item 9 were similar also showing reasonable factorability (X^2 (28) = 156.149, *p* < .001; KMO = .72). A total explained variance of 59% was achieved. Correlation between factors was around .26.

Table 3: Descriptives of FcAG-CI domains

	Mean (*SD*)	Range	ICC
Uncertainty of illness	6.47 (1.69)	3-9	6.07 - 6.85
Vicarious suffering	5.29 (1.95)	2-9	4.85 - 5.75
Image of degradation	6.00 (2.07)	2-9	5.53 - 6.44
Anticipation of death	5.11 (1.98)	2-9	4.60 - 5.54
Separation anxiety	4.34 (2.13)	1-9	3.83 - 4.87
Personal Restrictions	6.60 (1.98)	1-9	6.11 - 7.03
Relational losses	4.50 (2.38)	1-9	3.97 - 5.06
Sense of protection	5.43 (1.90)	2-9	4.97 - 5.88
Impotence of caregiver	4.76 (1.92)	1-8	4.31 - 5.19

p<.05; ** p<.01*

Table 4: Factor loading and communalities

Item	Factor 1	Factor 2	Communalities
Uncertainty of illness	**,799**	,199	,678
Vicarious suffering	**,520**	,091	,278
Image of degradation	**,715**	-,091	,519
Impotence of caregiver	**,536**	,286	,369
Anticipation of death	,393	**,542**	,448
Separation anxiety	,030	**,823**	,678
Relational losses	,083	**,659**	,442
Sense of protection	,074	**,528**	,284
Personal restrictions	,322	,053	,107

Results from MCA suggested the retention of the first two dimensions, which contributed the most to explain the data structure. Particularly, dimension 1 had an eigenvalue of 0.38 and an explained inertia of 12.7%, while dimension 2 presented an eigenvalue of 0.36 with an explained inertia of 11.9%, both yielding a total explained variance of 24.5%. Discrimination measures, describing the variable variance associated to each dimension ranged from .52 to .23 for dimension 1, with the variable Death Anticipation being the most discriminant and Image Degradation the least discriminant. For dimension 2 discrimination measures ranged from .49 to .23 with the most discriminant variable being Sense of Protection and the least discriminant Death Anticipation. The joint plot of category points revealed a clear differentiation between four different groups corresponding to low, moderate, high and severe AG manifestations (Fig.1).

The solution of 4 groups was then used in CA, revealing reasonable quality. Figure 2 show the graphical clusters profiles using Z scores means to represent dispersion of results around mean values in FcAG-CI factors and domains. Z-scores of ±.05 or greater were used as criteria to describe a group scored relatively “high” or “low”, compared to the sample mean. For descriptive statistic of each cluster, see Table 5. The first cluster (n = 15; 20.8%) is characterized by values below the average in both traumatic and relational distress. This group is labelled “Avoidant AG” because it reflects the use of avoidance mechanisms in dealing with the distress of advanced illness. Comparatively to other groups, these participants obtained low scores in pre-death PGD symptoms, as well as in the other mental health outcomes, with exception of burden, which is relatively high, particularly in the Fear and Anguish subscale.

Fig. 1: Multiple Correspondence Analysis

The second cluster (*n* = 22; 30.6%) is characterized by values close to average, although the traumatic distress is relatively below. This group, labelled “Adjusted AG” because it reflects the FC´s ability to respond emotionally to the current situation without experiencing high distress. As a result, they present slightly higher symptoms comparatively to the previous group. The third cluster (*n* = 21; 29.2%) is characterized by higher traumatic distress – especially in image of degradation and vicarious suffering – and less relational distress. This group show more severe symptoms of pre-death PGD, anxiety, somatization and burden. It is labelled “Traumatic AG” because these participants appear to respond mainly to the disruptive circumstances of the end-of-life care experience. Finally, the fourth cluster (*n* = 14; 19.4%) is characterized by very high relational distress and moderate to high traumatic distress, thus called “Intense AG”.

These participants show the highest mean value of pre-death PGD symptoms and high scores in the other mental health outcomes.

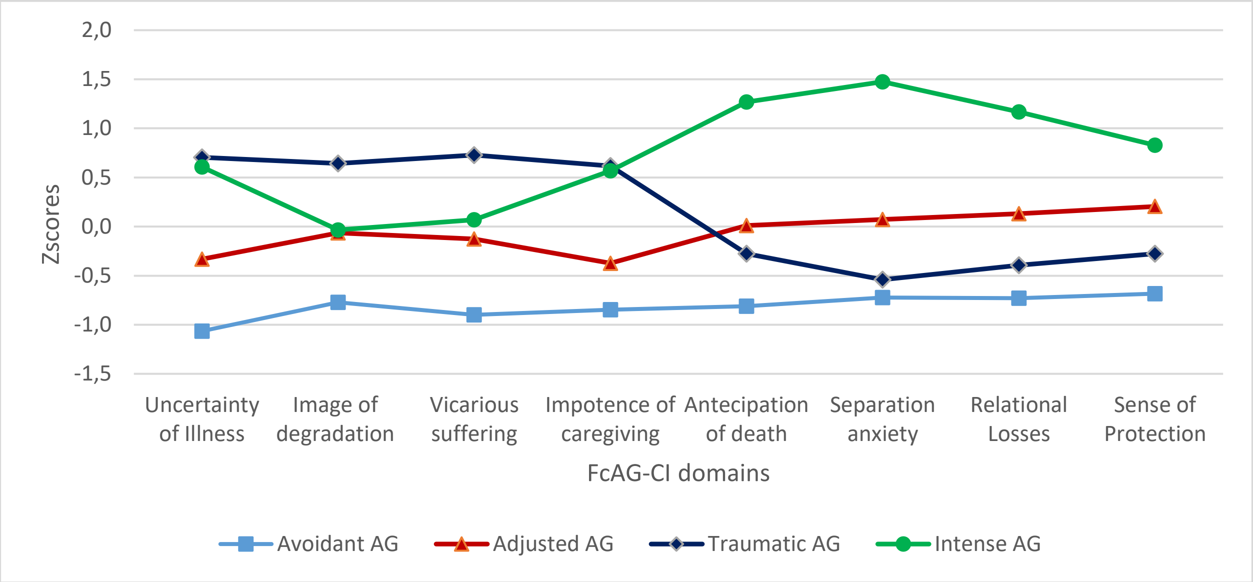

Fig.2: Distribution of FcAG-CI domains Zscores by clusters

Table 5: Descriptive statistics (frequencies, mean, standard deviation and Z-values) of clusters

	Avoidant AG (n= 15)		Adjusted AG (n= 22)		Traumatic AG (n= 21)		Intense AG (n= 14)	
	Mean ± SD	Z	Mean ± SD	Z	Mean ± SD	Z	Mean ± SD	Z
FcAGI domains								
Uncertainty of illness	4.66 ± 1.58	-1,06	5.90 ± 1.47	0,33	7.66 ± .85	0,70	7.50 ± .759	0,61
Image of degradation	4.40 ± 1.91	-,77	5.86 ± 1.64	-0,07	7.33 ± 1.79	0,64	5.92 ± 2.09	-0,03
Vicarious suffering	3.53 ± 1.40	-,90	5.04 ± 1.29	-0,13	6.71 ± 1.67	0,73	5.42 ± 2.17	0,07
Impotence of caregiver	3.13 ± 1.50	-,84	4.04 ± 1.21	-0,37	5.95 ± 1.65	0,62	5.85 ± 1.91	0,57
Anticipation of death	3.46 ± .63	-,81	5.09 ± 1.77	0,01	4.52 ± 1.66	-0,28	7.57 ± 1.15	1,27
Separation anxiety	2.80 ± 1.42	-,72	4.50 ± 1.30	0,07	3.19 ± 1.24	-0,54	7.50 ± 1.40	1,48
Relational losses	2.80 ± 2.21	-,73	4.77 ± 1.84	0,13	3.57 ± 1.71	-0,39	7.14 ± .94	1,17
Sense of protection	4.13 ± 1.99	-,68	5.81 ± 1.36	0,20	4.90 ± 1.97	-0,28	7.00 ± 1.03	0,83
FcAGI dimensions								
Traumatic Distress	3.93 ± .87	-1,19	5.21 ± .78	-0,29	6.91 ± .81	0,90	6.18 ± 1.31	0,38
Relational Distress	3.30 ± .80	-0,98	5.04 ± .56	0,14	4.48 ± 1.01	-0,50	7.30 ± .49	1,58

Except for somatization, mental health indictors differed across groups (Table 6). Specifically, in pre-death PGD symptoms, differences occurred between the first and third clusters (*p* = .002) and the first and the fourth clusters (*p* = .002). In anxiety, differences occurred between the first and the third clusters (*p* = .008). In caregiver burden, differences occurred between the second and the third clusters (*p* = .022). There were no statistically significant differences referring to demographics. Regarding the caregiver burden dimensions, statistically significant differences were found only for Fear and anguish and Self-criticism. In the former, the first cluster reached the highest values (p = .013); in the last, the third group scored higher.

Table 6: Comparison of clusters by mental health outcomes

	Avoidant AG (n = 15)	Adjusted AG (n = 22)	Traumatic AG (n = 21)	Intense AG (n = 14)	P value (95% ci)
			Mean ± SD		
Pre death PGD (Sum)	28,33 ± 6,61	33,68 ± 8,18	38,24 ± 6,26	39,36 ± 8,03	.001
BSI Subscales					
Depression	1,25 ± 0,79	1,78 ± 0,79	2,03 ± 0,91	1,99 ± 0,96	.050
Anxiety	1,05 ± 0,63	1,30 ±0,80	1,96 ± 0,73	1,90 ± 0,96	.003
Somatization	0,65 ± 0,67	0,74 ± 0,81	1,11 ± 0,63	0,76 ± 0,47	.093
Caregiver burden (Sum)	31,47 ± 17,30	27,05 ± 15,29	42,00 ± 12,58	34,43 ± 12,39	.034
Loss of control	1,68 ± 0,85	1,56 ± 0,81	2,23 ± 0,77	1,80 ± 0,84	.080
Sacrifice	1,06 ± 0,86	0,92 ± 0,70	1,55 ± 0,76	1,26 ± 0,65	.081
Patient´s dependency	1,80 ± 1,08	1,77 ± 1,00	2,42 ± 0,78	2,24 ± 0,59	.092
Fear and anguish	1,00 ± 0,75	0,48 ± 0,83	0,95 ± 0,67	0,50 ± 0,57	.013
Self-criticism	1,43 ± 0,82	1,27 ± 0,95	2,08 ± 0,99	1,68 ± 1,08	.039

[a] Significance value using Kruskal-Wallis Test

Association between FcAG-CI domains was tested using Pearson product-moment correlations. Values range from -.057 to .603 (Table 7). The final version of FcAG-CI mean was moderately correlated with PG-12 (*r* =. 368, *p* = .001), but not with Zarit Burden scale (*r* = .086, *p* = .510), thus confirming convergent and divergent validity. Traumatic distress was correlated with pre-death PGD (*r* = .342, *p* = .003) and Zarit (*r* = .254, *p* = .032), but the Relational distress was statistically correlated only with pre-death PGD (*r* = .253, *p* = .032).

Criterion Validity

The model composed by the four groups as covariates explained 28.9% of the variance results and predicted 72.2% of pre-death PGD outcome (Table 8). Comparatively to the first cluster, participants of the third cluster were 10.56% more likely to present PGD symptoms; the fourth cluster more 23.83%. These results show concurrent validity between FcAG-CI and pre-death PGD. For post-death PGD, this model only explained 7.3% of variance results, and none of the groups showed predictive value.

Table 7: Correlations between FcAG-CI domains

	1	2	3	4	5	6	7	8
1. Uncertainty of illness								
2. Vicarious suffering	.428**							
3. Image of degradation	.603**	.347**						
4. Anticipation of death	.421**	.232	.284*					
5. Separation anxiety	.244*	.016	-.057	.523**				
6. Relational losses	.176	.177	-.044	.314**	.548**			
7. Sense of protection	.205	.095	.018	.384**	.372**	.400**	.	
8. Impotence of caregiving	.431**	.386**	.275*	.299*	.274*	.259*	.140	
9. Personal Restrictions	.240*	.162	.237*	.087	-.006	.189	. 028	.252*

Table 8: Prediction of PGD pre and post-loss by FcAG-CI clusters

	Wald	df	p	Exp (B)	95%_CI
			Pre-death PGD		
Avoidant AG (n= 15)[a]					
Adjusted AG (n=22)	1.56	1	.211	3.03	.53 - 17.25
Traumatic AG (n= 21)	7.13	1	.008	10.56	1.87 - 59.56
Intense AG (n= 14)	10.4	1	.002	23.83	3.35 - 169.38
			Post-death PGD		
Avoidant AG (n = 7)[a]					
Adjusted AG (n = 14)	0,11	1	0,74	1,39	0,19 - 9.97
Traumatic AG (n = 18)	1,99	1	0,16	4,37	0,56 - 33.95
Intense AG (n = 11)	0,52	1	0,47	2,00	0,30 - 13-17

[a] Cluster 1 (Avoidant AG) was used as the reference category

Reliability

Reliability analysis of FcAG-CI, comprised by eight domains, indicated reasonable internal consistency (Cronbach´s Alpha = .750). Subscales composed of Factor 1, Traumatic distress and Factor 2, Relational distress, also presented acceptable values (.694 and .730 respectively). Item-total correlations were high for every domains. Interclass correlation coefficient (ICC) was used to assess the inter-rater reliability of the scales. Values ranged between .808 and .963, indicating excellent inter-rater reliability (Table 9).

Table 9. Interclass correlation coefficient

	ICC	p
Uncertainty of illness	.923	.000
Vicarious suffering	.911	.000
Image of degradation	.912	.000
Anticipation of death	.963	.000
Separation anxiety	.918	.000
Relational losses	.961	.000
Sense of protection	.903	.000
Impotence of caregiving	.808	.000

Discussion

In this study, we describe the development and the preliminary validation of the Family Caregiver Anticipatory Grief Clinical Interview (FcAG-CI), an instrument specifically oriented to cancer FC in palliative care that captures the way one emotionally experiences and deals with the multiple demands posed by the family member´s anticipatory grieving experience. Based on an in-depth semi-structured interview, it favours an interactive, flexible and cautious approach to sensitive aspects, such as death approximation and future separation. Besides, it allows a broader comprehension of the grieving experience than what would be captured by a focus on grief symptomatology alone. This position is backed by other authors, such as Mahat-Shamir, Neimeyer & Pitcho-Prelorentzos, (2019). Considering the clinical applicability of the instrument, there is some value in conducting an exploratory analysis of profiles that allow the categorization of respondents, which facilitates decision making in clinical practice.

Tests for reliability suggest that FcAG-CI, composed of eight domains, has reasonable consistency and very good inter-rater reliability, based in the rating guidelines provided. Using an exploratory factor analysis, two main factors were identified, each one composed of four variables. First, Traumatic Distress, referring to the disruptive impact of end-of-life caregiving circumstances, which includes: Uncertainty of illness, Image of degradation, Vicarious suffering and Impotence of caregiving. Second, Relational distress, referring to the difficulties in managing the caregiving relationship in face of imminent death. It includes Anticipation of death, Relational losses, Separation anxiety and Impotence of caregiving. These results are in line with previous research suggesting the multidimensionality of the AG construct (Cheng, Ma & Lam, 2019; Marwit & Meuser, 2005).

In addition, we are contributing to a more accurate definition of AG by excluding the item Personal restrictions, based on its low factor loading. This domain refers to the feeling of sacrifice and being deprived from other meaningful activities due to the caregiver's role, which is clearly a feature of burden (Lai et al., 2014). Also, the FcAG-CI total score is not correlated with the Zarit burden scale, thus demonstrating divergent validity. Only traumatic distress was weakly correlated with burden, which can be justified by the compassion fatigue of end-of-life caregiving, caused by the FC´s intense preoccupation and the absorbing of their relative’s pain and suffering (Lynch, 2018).

On the other hand, FcAG-CI was correlated with PG-12, confirming its convergent validity. However, the correlation between the two measures is moderate, indicating that they evaluate relatively different constructs. This finding is in line with a previous concept analysis (Lindauer & Harvath, 2014), which established that pre-death grief refers mainly to the loss of the patient´s personhood, while AG is a response to the awareness of impending death. Nevertheless, we have chosen to apply this instrument because it is the most frequently used in palliative care. Recently, a modified version of the Anticipatory Grief Scale (AG-13) was validated with a sample of FC in palliative care (Holm, Alvariza, Furst, Ohlen & Arestedt, 2019), so it would be interesting to use it in further validation studies of FcAG-CI. Yet another new scale, the Caregiver Grief Questionnaire (Cheng et al., 2019), although specifically designed for dementia FC, is also composed of two dimensions (Emotional Pain and Relational deprivation) similar to those of FcAG-CI. However, in the present study, instead of Emotional Pain, we chose the designation of “Traumatic distress” to allude to the disruptive impact of life-threatening conditions in the context of advanced illness. The sudden and unexpected circumstances of the cancer end-of-life trajectory are often associated with deep feelings of impotence (Sanderson, Lobb, Mowll, Butow, Mcgowan & Price, 2013). The second dimension includes, in addition to Relational deprivation, the anticipation of death and future separation, often involving increased efforts of protection and presence, which adds distress to the relationship, thus being generically addressed as Relational Distress. Although further research is needed, the results appear to be consistent, suggesting that AG is composed of these two core dimensions.

Exploration of FcAG-CI´s latent structure resulted in four AG profiles, illustrating the diversity of responses. Those participants who scored low in both dimensions were considered “Avoidant AG”, as they can reduce the emotional impact of the experience by withdrawing from the threatening situation. Therefore, they experience reduced levels of grief, depression, and anxiety symptoms. However, they present a higher burden, particularly in the Fear and Anguish subscale. This finding is in line with another study that associates caregiver burden to the use of avoidance-escaping coping style (Washington et al., 2018). The second cluster, called “Adjusted AG” showed moderate levels of distress related both with traumatic circumstances and relational aspects. It means that they are sensitive to the threat to the other´s life and to changes in the relationship, but they do not feel overwhelmed by the distress. As a result, they reported slightly higher symptoms comparatively to the previous group, but the caregiver burden is lower. The third cluster, labelled “Traumatic AG”, mainly reflects the high reactivity to the disruptive circumstances of end-of-life caregiving, particularly to the other´s degradation and suffering. These participants are more prone to present worse mental health outcomes, inclusively high levels of burden. As emphasized by Sanderson et al., (2013), having witnessed deathbed experiences trigger painful and intrusive memories, suggesting the presence of post-traumatic stress disorder. Finally, the fourth cluster, designated as “Intense AG”, is distinguished by the heightened values in the two dimensions, especially in the Relational distress. Within this dimension, Anticipation of death and Separation anxiety reached the highest values. As a result, they show severe mental health symptoms, but compared to the previous group, the burden is lowest.

In short, the mental health outcomes increase from the first to the fourth group, while the level of burden differs, being less present in the groups that show more sensitivity to relational aspects. We hypothesise that a greater affective involvement in the relationship leads people to devalue the burden inherent to caregiving, as FC tend to to focus on the positive aspects of this experience and wish to prolong the patient's life. On the contrary, those who devalue relational aspects are more likely to feel fatigued and express dissatisfaction related to the caregiver role. It is also worth noting that FcAG-IC profiles are predictive of pre-death PGD, thus confirming concurrent validity, but not post-death PGD. This finding suggests that AG, as evaluated by FcAGI, is qualitatively different from post-death grief, thereby challenging the perspective of continuity between pre and post-death grief manifestations (Nielsen et al., 2016).

However, it should be reinforced that, given the small sample size, these results are merely exploratory, thereby interpretations are limited and cannot be generalized. In particular, a larger follow-up sample is needed to verify the predictive value of FcAGI in bereavement outcome. In addition, the convenience nature of the sample makes it mostly clinical, since the most accessible and motivated people to participate in the study were probably also those who felt particularly affected by the experience. This, therefore, justifies the high rates of mental health symptoms, which may not be representative of the general FC population. Nevertheless, we consider that this selection biases can also be considered a strength of the study, as it provides insight into the emotional needs of the most vulnerable people, for whom the intervention is also more needed.

Besides, this study has clear clinical implications as it allows recognizing and adapting intervention measures to individual needs, according to AG profiles. Those with Avoidant Profile would benefit from a careful approach to avoid feeling overwhelmed with the demands of caregiving. When the level of traumatic aspects is high, we recommend an approach focused on emotional regulation skills. If, on the contrary, the relational aspects are prominent, it is important to develop ways of managing conflitual feelings toward the family member.

Conclusion

Results from this exploratory study suggest that FcAG-CI shows convergent and concurrent validity with self-reported pre-death PGD symptoms, as well as divergent validity with the Zarit Burden Interview. FcAG-CI also showed good reliability and reasonable internal consistency. Two factors were identified, corresponding to the two major sources of distress: Traumatic and Relational. AG profiles results are particularly promising in predicting mental health outcomes. However, the generalization of these results requires further validation studies of FcAG-IC.

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6. EMPIRICAL STUDY V

FAMILY CAREGIVER´S GRIEF AND POST LOSS ADJUSTMENT: A LONGITUDINAL COHORT STUDY

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Abstract

In this prospective cohort study carried out with advanced cancer family caregiver (FC), we aimed to explore the complex pattern of influences between caregiving related factors and its impact on grief manifestations evolution. Two main objectives were established: first, to measure the caregiver distress levels and prolonged grief symptoms evolution between pre and post-death period; second, to examine the path through which the caregiver context influences prolonged grief manifestations. Participants at pre-death evaluation (T1) were 156, mostly female, adult child or spouse, with mean age of 51.78 (S.D.= 13.29). At follow-up (T2), six months after the death (M=9.05, S.D. = 2.123, 6 - 12 months) 87 FC participated in the survey. Pre-death Prolonged Grief Disorder (PGD) (38.6%) were higher than in bereavement (33.7%). From those who meet the PGD criteria at pre-death, most also quoted positively at post-death (n= 26, 61.9%). Psychological distress and caregiver burden were highly correlated with pre-death grief, which in turn plays a critical role in mediating the link between psychological distress and bereavement outcome. Proximity in the relationship was predictive of the grief persistence. On the contrary, long-term consequences of caregiver burden were not confirmed.

Keywords: Family Caregivers, Palliative Care, Mediators, Prolonged Grief Disorder, Prospective study

Introduction

End-of-life caregiving encompasses great adaptive efforts and intense grief responses that extend beyond the death of the terminally ill, influencing posterior adjustment to bereavement (Boerner & Schulz, 2009). Two competing theoretical perspectives were previously formulated to explain the caregiver´s transition to bereavement (Bass & Bowman, 1990; Bernard & Guarnaccia, 2003). The *perspective of stress reduction* argues that the patient´s death represents a relief from the suffering and, simultaneously, ceases the physical and emotional demanding tasks of end-of-life caregiving, thus predicting better outcome. Alternatively, the *perspective of cumulative stress* postulates that the accumulation of distress depletes resources, therefore undermining the adjustment to loss.

Support for the first perspective derives from prospective data stressing that family caregiver´s (FC) grief is exacerbated by the intense end-of-life caregiving distress and then gradually declines, after the acute grief period (Chentsova et al., 2002; Ferrario, Cardillo, Vicario and Balzarini, 2004). However, there is also evidence that, for many FC, this pervasive effect remains over time, thus suggesting *the cumulative stress* effect. For instance, Breen, Aoun, O´Connor, Johnson and Howring, (2019) found that only 9-10 months after death the levels of grief, general health and quality of life were equalled to the non-caregiver comparison group. Studies using Prolonged Grief Disorder (PGD) criteria have consistently evidenced that high pre-death grief symptoms tend to persist for long term, predicting prolonged grief manifestations (Thomas Hudson, Trauer, Remedios & Clarke, 2014; Nielsen et al., 2017; Zordan et al., 2019).

Newly recognized as a mental health disorder (WHO, 2018), PGD includes intense longing and preoccupation with the deceased, along with the pervasive emotional pain that persists for an abnormally long period of time (more than 6 months at a minimum). Incidence of PGD in bereaved FC range between 6% to 40% (Ghesquiere, Haidar & Shear, 2011; Guldin, Vedsted & Zachariae, 2012; Tsai et al., 2015), comparatively to 2,4%, in the general population (Fujisawa et al., 2010), thus indicating that FC population face unique risks for developing grief complications due to the circumstances of caregiving.

Extensive research has been conducted emphasizing the deleterious effect of end-of-life caregiving distress, including symptoms of depression, anxiety and burden (Given et al., 2004; Ferrario et al., 2004; Tomarken et al., 2008). In particular, high levels of depressive symptoms in FC during end-of-life caregiving have consistently been associated to worst bereavement outcome (Stroebe, Schut & Stroebe, 2007; Schulz & Boerner, 2008; Lobb et al., 2010; Gesquiere et al., 2011; Kersting, Brahler, Glaesmer, Wagner, 2011; Tsai et al., 2016). Concerning caregiver burden, studies provide divergent results: some authors found no association (Kapari, Addington-Hall & Hotopf, 2013), whereas others reported that high burden is predictive of grief complications (Ferrario et al., 2004; Nielsen et al., 2017). Above all, literature has suggested that, more than the objective aspects of the role strain, the emotional burden seems to play a critical role in caregiver adjustment to loss (Große, Treml & Kersting, 2018).

However, response to caregiving distress is greatly influenced by the quality of the relationship with the patient (Kelly et al., 1999; Williams & McCorkle, 2011). Higher quality relationship was associated to lower burden (Francis, Worthington, Kypriotakis & Rose, 2010; Tough, Brinkhof, Siegrist & Fekete, 2017). On the contrary, great proximity and dependence from the partner were associated to more burden (Spaid, Barusch, 1994) and more difficulties in adjustment to loss (Rickerson et al., 2005; Pruchno, Catwright & Wilson-Genderson, 2009; Thomas et al., 2014). When the relationship is marked by conflicts and discord, adding ambivalence to the relationship, it results in increased burden and distress during caregiving (Reblin, 2016). Conflictual relationship has also been traditionally associated to grief complications (Parkes & Weiss, 1983; Stroebe & Stroebe, 1993), but this assumption was rejected with the argument that it may reflect a bias of bereaved retrospective memory (Bonanno et al., 2002).

In this prospective cohort study carried out with advanced cancer FC, we aimed to explore the complex pattern of influences between these caregiving related factors and its impact on grief manifestations evolution. Two main objectives were established: first, to measure the prolonged grief symptoms evolution between pre and post-death period; second, to examine the path through which the caregiver context influences prolonged grief manifestations.

Method

Instruments

The survey included the following self-report instruments:

Sociodemographic questionnaire, developed by the research team to evaluate demographic data (age, gender, scholarship, kinship);

Intensity of caregiving, composed by two items: “Cohabitation with the patient”, with an Yes (1) or No (0) response; “Number of daily hours spent, in average, caring for the patient, in the last week” rated in a 5 point scale: <2hrs = 1; 2-4hrs = 2; 4-8hs = 3; 8-16hs = 4; <16hrs= 5.

Prolonged Grief Disorder Questionnaire (Prigerson et al., 2009). Used as a diagnostic instrument for Prolonged Grief Disorder (PGD), considering the following clinical criteria: separation distress; cognitive, emotional, and behavioural symptoms; social and functional impairment. The pre-death version (PG-12) was designed to assess grief experience related to illness. It is composed of 12 questions, rated in a 5 point Likert scale, ranging from 1 (almost never) to 5 (always), except the last item, which is dichotomous. In the Portuguese validation (Coelho, Silva & Barbosa, 2017), this instrument has demonstrated a unifactorial structure with high internal consistency (α = 0.846). Examples of items are: “In the past month, how often have you had intense feelings of emotional pain, sorrow, or pangs of grief related to (patient’s) illness?”, “Do you feel that life is unfulfilling, empty, or meaningless since (patient’s) illness?”. PG-13, used at the follow-up, is focused on the post-loss grief and it includes one more item, also dichotomous, in which respondents are questioned if the grief symptoms persist for longer than 6 months (temporal criteria). This instrument was validated for the Portuguese population by Delalibera, Coelho & Barbosa (2011). The internal consistency was considered excellent (α = .932).

Depression, Anxiety and Somatization subscales of Psychopathological Symptom Inventory (BSI; Derogatis & Melisaratos, 1983). These subscales consist of 19 statements evaluating symptoms of psychological distress, including depression (feeling blue, lack of interest in things, loneliness, hopeless about future, worthlessness and suicidal thoughts), anxiety (feeling tense, nervousness, fearful, spells of panic, suddenly scared and restless) and somatization (feeling weak, nausea, numbness, faintness, trouble getting breath and pains in chest). Responses are evaluated in a Likert scale, ranging from 0 (never) to 4 (always). This measure was validated for the Portuguese population (Canavarro,1999), showing acceptable to excellent internal consistency (sub-scales between α = 0.67 and α = 0.92). We used the recommended cut-off points of 1.051 for depression, 0.940 for anxiety, and 1.004 for somatization. A score of psychological distress, also referred as Global severity Index, was computed by calculating the mean total score of the three subscales (Meijer, Vries & Bruggen, 2011).

Zarit Burden Interview. This instrument, developed by Zarit, Reever, Bach-Peterson (1980), evaluates the feelings of stress related to the caregiving role. It contains 22 items with scores ranging from 0 (never) to 4 (always). Items include: "Patient asks for more help than he/she needs", "Afraid of patient's future" and "Negative effect on other relationships". The Portuguese validation (Ferreira et al., 2010) obtained high internal consistency (α = 0.88). The cut-off point for the total score is 21.

Relationship Quality. Composed of 8 items, developed by researchers, to evaluate the current and previous quality of relationship with the patient. Items are evaluated by a Likert scale from 1 (Nothing) to 5 (Very much). Examples of questions are: "We use to talk about what we are feeling intimately", "I feel hurt by some things my family member tells me". Every item was rated both for current and previous relationship. It has a multifactorial structure with two dimensions: (1) Proximity, and (2) Conflict. Internal consistency values range between .854 and .868. In this study, we only used the questions referring to the current relationship.

Statistical Analysis

Descriptive and frequencies analysis were conducted to characterize the sample and establish prevalence of distress symptoms, burden and PGD symptoms. Difference in PGD rates were then analysed by Chi-square test. Demographics mean differences in caregiving distress indicators and grief manifestations were evaluated by Anova and t test. In this analysis, demographic variables were recoded (age: <40, 41 – 60, <61 years old; married status: yes/no; kinship: spouse/others; education: ≤9 years/>9 years;

cohabitation with the patient: yes/no). To establish relationship between caregiver distress, relationship quality and grief manifestations, Pearson´s correlations were computed. Prediction of pre-death PG manifestations was estimated by hierarchical regression. Values for independence (Durbin-Watson: 2.082-2.229) and multicollinearity (1.063 < VIF values < 1.402; .503 < tolerance values < .941) were considered acceptable. Analysis were performed using complete cases. Statistical analysis were performed using SPSS.

Results

Participants and demographics

Participants in the survey were 156. At bereavement, 87 responded to the questionnaires, corresponding to a response rate of 55.77%. Reasons for non-participation were: unable to contact, because they were discharged from palliative care and researchers were not informed of the patient´s death (n= 40; 25.6%); did not respond or were no longer interested in participating in the study (n= 24; 15,4%); the patient was still alive (n= 4; 2.6%); less than 6 months after death (n= 1; 0,6%).

Demographic information is displayed in Table 1. Participants in T1 were mostly female, married, adult child and with high education level, with mean age of 51.78 (S.D.= 13.29). At follow-up, the average length of time since death was 9.05 months (S.D. = 2.123, ranging from 6 to 12 months). Sample at T2 was equivalent in demographics.

Sampling and Procedures

Participants were recruited in an out-patient palliative care consultation of a general hospital. Eligible participants were family caregivers of cancer patients (i.e., relative or friend involved in the caregiving), older than 18 years old. Caregivers were excluded if they were illiterate or had a cognitive impairment. After explaining the aims of the study, those who gave their oral consent were invited to respond to the questionnaires, either presentially or at home. Modalities of response were on paper or by mail. When the questionnaires were completed at home on paper, they were requested at the next appointment. FC who completed the survey at pre-death phase (T1) were posteriorly contacted six months after the patient´s death, to complete the follow-up (T2). Participants were invited to respond presentially, by phone or mail. All the participants were advised to give feedback about the emotional impact of responding to the questionnaires, and if emotional distress was experienced, they were offered referral for psychology consultation. This study was approved by the hospital ethics committee.

Table 1: Demographics at T1 and T2

	T1 (n= 156)		T2 (n= 87)	
	n	*%*	*n*	*%*
Gender				
Female	127	81.4	73	83.9
Male	29	18.6	14	16.1
Marital status				
Single	21	13.5	9	10.3
Married	108	69.2	35	40.2
Cohabiting	9	5.8	5	5.7
Divorced	16	10.3	9	10.3
Widowed	2	1.3		26
Kinship				
Spouse/partner	50	32.1	30	34.5
Adult child	89	57.1	49	56.3
Parent	3	1.9	1	1.1
Sibling	5	3.2	3	3.4
Grandson	1	0.6	1	1.1
Son/daughter-in-law	1	0.6	1	1.1
Others	6	3.8	2	2.3
Education				
Able to read and write	1	0.6	1	1.1
4 years	11	7.1	4	4.6
6 years	15	9.6	7	8.0
9 years	24	15.4	14	16.1
Secondary school	38	24.4	21	24.1
Technological school	15	9.6	10	11.5
University degree	40	25.6	24	27.6
Master	8	5.1	4	4.6
Missing	3	1.9	2	2.2
Living with the patient				
Yes	89	57.1		
No	60	38.5		
Missing	7	4.5		
Age Mean (S.D)	51.77 (13.29)		52.89 (12.63)	
Amplitude	18 - 79		21-78	

PGD symptoms evolution

Pre-death PGD symptoms (38.6%) were higher than in bereavement (33.7%). This difference was statistically significant (X^2 = 28.51, p=.000). From those who meet the PGD criteria at pre-death, most also quoted positively at post-death (n= 26, 61.9%). Remission of symptoms occurred in 16 FC (38.1%) and only 3 (7%) new cases of PGD emerged at T2 that have not been diagnostic in pre-death phase.

Relationship between demographics, caregiver distress and grief symptoms

Analysis of mean differences in grief levels across demographics (table 2) showed that being a spouse and having lower education were associated with increased pre-death PG manifestations. There were no differences in demographics regarding bereavement outcome.

Table **2: Demographic mean differences in pre and post-death PG manifestations**

	Pre-death Grief			Post-death grief		
	Mean	S.D	*F, t, P*	Mean	S.D	F, t, P
Age						
<40	33.10	9.926	.174 ns	31.066	8.145	.596 ns
41 - 60	33.397	8.666		32.976	10.716	
> 61	36.404	9.793		34.374	10.046	
Married status						
No	33,776	9,037	-.883 ns	32,373	10,111	-.868 ns
Yes	35,289	9,560		34,286	9,940	
Kinship						
Spouse	37,102	9,986	2.792**	34,867	10,636	1.164 ns
Other	32,771	8,450		32,232	8,689	
Education						
≤9 years	36,471	8,860	2.242*	36,148	9,746	1.904 ns
> 9 years	33,000	9,131		31,780	9,934	
Cohabitation						
No	32,783	8,283	-1945 ns	30,946	9,809	-.178 ns
Yes	35,690	9,307		34,833	10,071	

* p< .05
** p< .01

Correlations between caregiving context variables and grief symptoms are displayed in table 3. Pre-death grief was highly correlated with psychological distress and caregiver burden. As for the post-death grief, high correlation values were found with psychological distress, but not with burden. Proximity was moderately associated with pre and post-death grief. On the other hand, conflict presents moderate correlation with caregiver burden and post-death grief, but not with pre-death grief manifestations.

Table 3. Correlations between grief manifestations, caregiver distress and relationship quality

	1	2	3	4	5
1. Pre-death grief					
2. Post-death grief	.568**				
3. Psychological distress	.643**	.511**			
4. Caregiver Burden	.447**	0.009	.397**		
5. Proximity	.377 **	.417**	.203*	-.175*	
6. Conflict	.143	.304**	.237**	.231*	-.033

* p< .05
** p< .01

Predictive effect of the caregiving related variables in grief symptoms

Hierarchical regression was used to explore the predictive effect of caregiving related factors in both pre and post-death. In these analysis, we excluded the factors that were not correlated with the dependent variables. For predicting pre-death grief (Table 4), being spouse entered in the first model, predicting 7.2% of variance. At model 2, the length of time spent in caregiving was not significative. The biggest predictor was the caregiving distress, including psychological distress and burden. They both explained 41.4% of the PG-12 variance ($R^2 = .495$; F(2-129)= 25.314, p= .000). At last, in the model 4, quality of relationship explained 12.23% of variance ($R^2 = .577$; F (2-127) = 24.726, p= .000). At the final model, the caregiver distress, burden and proximity showed to be a predictor of pre-death PG manifestations. Overall, this model explained 57.7% of the PG-12 score.

In predicting post-death grief (Table 5), psychological distress entered in the first model, predicting 28.2% of the variance (R2 = .282; F(1-78)= 30.675, p= .000). At model 2, pre-death grief concurred with 8.2% (R2 = .364; F(1-77)= 22.46, p= .000). The model 3, including relationship quality, contributed with 6.1% of the variance (R2 = .425; F(2-75)= 13.848, p= .000). At the final model, only pre-death grief and proximity have shown to be predictive of post-death PG manifestations. Together, these factors explained 42.5% of the PG-13 score variance.

Table 4. Predictors of pre-death PGD symptoms

	Model 1			Model 2			Model 3			Model 4		
	B	SE B	β	B	SE B	β	B	SE B	β	B	SE B	β
Demographics												
Kinship	3,476*	1,690	,178	2,686	1,814	,137	3,093*	1,356	,158	1,740	1,295	,089
Education	-3,091	1,655	-,161	-2,864	1,663	-,150	-,275	1,270	-,014	-1,108	1,186	-,058
Involvement in caregiving												
Time spent on caregiving [b]				2,002	1,687	,109	,246	1,279	,013	-1,068	1,235	-,058
Caregiver distress												
Psychological distress [c]							,117*	,045	,181	,192***	,044	,298
Caregiver burden [d]							1,158***	,143	,569	,956***	,141	,470
Quality relationship												
Proximity [e]										2,769***	,568	,320
Conflict [f]										-,387	,500	-,048
R^2		.072			.082			.495			.577	
Adjusted R^2		.058			.060			.476			.553	
ΔR^2		8.928			8.914			.553			6.145	

*** p<.001; ** p<.01; * p<.05

[a] Kinship: Spouse=1; Other= 0

[b] Education: ≤9 =0; >9 =1

[c] Time spent daily on caregiving in the last week <8hr = 0; > 8hr = 1

[d] Sum of mean values of BSI subscales of Depression, Anxiety and Somatization

[e] Total score of Zarit Burden scale

[f] Subscale Current Proximity, Relationship Quality Questionnaire

[g] Subscale Current Conflict, Relationship Quality Questionnaire

Table 5. Predictors of post-death PGD symptoms

	Model 1			Model 2			Model 3		
	B	SE B	β	B	SE B	β	B	SE B	β
Caregiver distress									
Psychological distress [c]	1.140***	.206	.531	.530	.275	.247	.456	.270	.213
Pre-death PG symptoms				.465**	.148	.403	.333	.151*	.289
Quality relationship									
Proximity [e]							2.185	.930*	.226
Conflict [f]							1.652	.882	.177
R^2		.282			.364			.425	
Adjusted R^2		.273			.348			.394	
ΔR^2		8.558			.8.108			7.813	

*** p<.001; ** p<.01; * p<.05

[a] Kinship: Spouse=1; Other= 0

[b] Education: ≤9 = 0; >9 = 1

[c] Time spent daily on caregiving in the last week <8hr = 0; > 8hr = 1

[d] Sum of mean values of BSI subscales of Depression, Anxiety and Somatization

[e] Total score of Zarit Burden scale

[f] Subscale Current Proximity, Relationship Quality Questionnaire

[g] Subscale Current Conflict, Relationship Quality Questionnai

Discussion

This longitudinal study examined the evolution of caregivers PGD symptoms and its association with caregiving related factors in a sample of cancer FC accompanied in a palliative care outpatient consultation. Consistently with other studies (Nielsen et al., 2017), levels of pre-death grief were higher than those presented during bereavement, although, more than 6 months after the patient´s death, 33.7% still meet criteria for PGD. However, findings from this study challenge the perspective of the long-term deleterious consequences of caregiver burden. Instead, findings suggest the pervasive effect of grieving feelings, starting prior to death, and enhanced by the proximity of the relationship in the caregiving context.

Results documented that the vast majority of FC who presented worst outcome at bereavement already met criteria for PGD previous to the patient´s death, thus supporting the evidence of the grief manifestations continuity over time (Nielsen et al., 2016; Thomas et al., 2014; Nielsen et al., 2017; Zordan et al., 2019; Holm, Årestedt, Öhlen, Alvariza, 2019). It is worthwhile to emphasize that comparatively to other studies carried out with FC in palliative care (e.g., Hudson Thomas, Trauer, Remedios & Clarke, 2011), this sample reports high levels of psychological distress, burden and PGD, both pre and post-death. However, these findings are consistent with previous studies in Portuguese population (Coelho, Delalibera, Barbosa & Lawlor, 2015; Areia, Fonseca, Major & Relvas, 2019), thus suggesting the influence of cultural aspects.

Although in general, demographics did not show predictive value, being a spouse and having poor education were associated to worst outcome in pre-death grief. These data are supported by the literature (Hudson et al., 2011; Liew, 2016; Kiely Prigerson, & Mitchell, 2008). Confirming that the objective aspects of burden do not influence the experience of caregiving, we found that the time spent in caregiving was not associated to worst outcome (Große et al., 2018). On the opposite, the influence of distress was notorious, especially during caregiving, where psychological distress and caregiver burden jointly contributed to explain 41.4% of PG-12 score variance. This reinforces that it is mostly the subjective impact of this experience that influences grief adjustment. The overlap between caregiver distress, burden and pre-death symptoms has also been noted by other authors (Thomas et al., 2014; Nielsen et al., 2017).

Psychological distress also contributed to explain post-death grief (Nielsen et al., 2017), but when controlling for pre-death grief in multivariate analysis, its effect decreased, suggesting the mediating effect of the later variable in the link between psychological distress and bereavement outcome. On the contrary, we did not find evidence for the influence of caregiver burden in post-death grief. This result may be explained by the fact that, while grieving for the lost person, FC is no longer feel affected by previous experience of exhaustion, although it has been felt as very severe in the caregiving phase.

As regards the relationship quality, only the proximity was correlated with grief manifestations during caregiving. Other studies (Spaid & Barusch, 1994; Thomas et al., 2014) also emphasized the difficulties of dependent caregivers in dealing with separation and death. Interestingly, during bereavement, conflicting feelings toward the patient was correlated to worst adaptation, although only the proximity revealed predictive value in multivariate analysis. This suggests that, during illness, the caregiver is exclusively focused in providing care, therefore, the relationship with the patient becomes closer, hindering the anticipation of loss. However, after the patient´s death, previous conflicting feelings become more salient, causing difficulties in adjusting to loss. Although, as characteristic of ambivalent relationships, the proximity continues to be the most important factor, contributing to the persistence of longing and yearning for the deceased. This observation is in line with previous theoretical formulations (e.g., Horowitz et al., 1983), but it requires further empirical validation.

In short, findings provide support for the *stress reduction perspective*, as levels of caregiving distress clearly decreases after the patient´s death, as demonstrated by the fact that caregiver burden no longer influences grief manifestations at bereavement outcome. Simultaneously, there is evidence that FC´s pre-death PG manifestations have a cumulative effect with psychological distress, contributing to the persistence of grief manifestations, as suggested by *cumulative stress perspective*. These findings indicate that those two apparently opposed perspectives are not mutually exclusive, as previously noted by other authors (Schulz, Boerner & Herbert, 2008; Große, Treml & Kersting, 2018).

Instead, they reflect the diversity of FC individual responses and the complex pattern of interactions of caregiving related factors, across time.

This research has limitations that should be considered before any definitive conclusions can be drawn. One potential bias may be related with the convenience sampling method. Participants were selected based on their accessibility and willingness to participate in the study, so it is possible that those subjects with more difficulties in adjusting to the end-of-life caregiving experience are overrepresented in this sample. This fact eventually contributes to explain the high rates of caregiver distress that were found in the sample. Another limitation refers to the reduced sample size due to missing values and low rates of response in the second assessment moment. This led us to reduce the number of variables in the study, mainly due to multivariate analysis, which requires a larger number of participants. As a result, we had no opportunity to control the effect of demographic variables. The predictive effect of other caregiving related variables potentially relevant for this analysis was not verified either (e.g., past relationship, coping mechanisms). Thus, further research is needed to explore the influence of these factors.

In spite of these limitations, results have important clinical implications, as they reinforce the high levels of caregiving distress and prolonged grief symptoms, which are likely to persist in long-term. As recommended by the international guidelines of palliative care, emphasis should be given to the early screening and intervention of FC who are most vulnerable to grief complications (Hudson et al., 2012). Moreover, a deeper understanding of the complex dynamic between underlying caregiving related factors may contribute to a more empathetic attitude on the part of health professionals. For example, although in clinical practice it is often assumed that the end of a conflicting and stressful caregiving relationship represents a relief to the caregiver, this may not be true due to the presence of intense and prolonged loss feelings.

Conclusion

Results from this prospective cohort study support the evidence that carer´s grief manifestations are heightened by the caregiver distress and current proximity with the patient. By clarifying the relationship between caregiving related variables and grief manifestations, both pre and post loss, these findings contribute to a better understanding of the path through which caregiving distress contributes to PG manifestations. Results showed that pre-death grief plays a critical role in mediating the link between psychological distress and bereavement outcome. On the contrary, long-term consequences of caregiver burden were not confirmed. A last remark to the post loss influence of conflicting feelings toward the patient, although proximity is the relational aspect that most influences the grief persistence. Further research is needed to confirm these findings and explore the role of other influencing factors in this complex and dynamic process of transition from caregiving to bereavement.

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CHAPTER IV

General Discuss

1. Summary of Results and General Discussion

In this section, we provide a summary of the main findings from the current investigation, followed by some methodological and conceptual considerations to clarify analysis and interpretation of results. Then, a general and integrative discussion of results is made in light of the objectives outlined. Finally, we reflect on the strengths and limitations of this research and elaborate on its clinical implications.

The current research aimed to contribute to a more comprehensive view and measurement of the caregiver´s grief experience by analysing the trajectory of grief symptoms, their determinants and multidimensionality of AG concept. Within the scope of the project, one literature review and five original empirical studies were carried out, encompassing both quantitative and qualitative methods. The **first main objective** of this research was to describe the trajectory of Prolonged Grief symptoms and their determinants in a Portuguese sample of family caregivers followed in palliative care. To address this objective, two original empirical studies were conducted (Empirical Study I and V). Overall, findings can be summarized as follows:

- Portuguese validation of PG-12 has shown that this unidimensional instrument is a valid and reliable tool for early screening of prolonged grief disorder;
- At pre-death period, up to 38.6% FC met the criteria for PGD; levels of caregiver burden were significant in 85.9%, depression symptomatology was present in 67.4% and anxiety in 62%;
- Pre-death PGD was heightened comparatively to values obtained in bereavement;
- Pre-death PGD symptoms were correlated with, but independent from Depression, Anxiety and Caregiver burden;
- Those FCs who were spouses and had low education level presented higher grief symptomatology at pre-death;
- The perceived severity of illness and more involvement in caregiving were associated with higher grief manifestations, although the latter did not show predictive effect of PG-12 score;
- Regarding coping mechanisms, denial contributed to the severity of pre-death grief symptoms; on the contrary, Acceptance and Positive Reinterpretation demonstrated to be protective of pre-death grief;

- Caregiver distress, including a global indicator of psychological distress (symptoms of depression, anxiety and somatization) and caregiver burden, were the strongest predictors of pre-death PG manifestations;
- At bereavement, psychological distress was associated with worst outcome, but this value decreased as we controlled for pre-death PG symptoms in multivariate analysis, indicating that the last variable is a mediator in the link between pre-death caregiver distress and post-death loss adjustment;
- The caregiver burden was not correlated with post-death PG manifestations, suggesting that its effect evanish after the patient´s death;
- Relational aspects, especially proximity with the patient during the illness period, were a predictor of both pre and post-death PG manifestations; conflict was also correlated with bereavement outcome, but its weight was lower.
- Together, these personal, circumstantial and relational factors combined to create a complex and dynamic pattern of interactions that influence caregiver´s grief evolution.

The **second general objective** was to contribute to the conceptualization and operationalization of the family caregiver anticipatory grief phenomenology by developing a clinical assessment instrument to measure individual differences in the anticipatory grieving process. Three empirical studies were conducted to assert this objective. The findings are summarized as follows:

- AG core characteristics were grouped in two main dimensions: Traumatic distress, referring to the continuous exposure to life-threatening conditions; and Separation distress, related to the perceived menace to the relationship;
- AG experience was described as an oscillatory process, involving a constant emotional regulation effort to manage the perceived menace to the other´s life and to the relationship;
- Response to these main challenges has shown to vary between two competing positions: in dealing with the traumatic distress, FC may avoid or approach the threaten stimulus; in managing separation distress, FC may seek proximity or withdraw from the other for self-protection;

- Variances in the response to these challenges configure anticipatory grieving patterns;
- Avoidant AG was characterized by deactivating the sense of threat posed by the terminal illness and by protecting themselves and the significant other from painful aspects;
- Adjusted AG was characterized by the capacity to speak openly about their difficulties and intimate feelings and ask for help;
- Intense AG presented heightened vigilance in dealing with threat and great reluctance in separating from the patient, causing intense separation anxiety;
- Traumatic AG showed persistent and pervasive feelings of shock and helplessness, as well as other post-traumatic stress reactions;
- Anticipatory grieving patterns reflected individual dispositional tendencies to regulate emotions, as suggested by attachment theory;
- Individual differences in managing the AG challenges were operationalized as assessment criteria, constituting a clinical tool for assessing the caregiver´s grief experience – the Family caregiver Anticipatory Grief - Clinical Interview (FcAG-CI);
- This instrument is based in a semi-structured interview, the clinician’s privileged means of gathering information and establishing relationship with the FC;
- Preliminary evaluation of FcAG-CI psychometric characteristics revealed this instrument to be reliable and valid; two main dimensions were identified: Traumatic and Relational distress (the latter is equivalent to Separation distress);
- Traumatic distress is significantly correlated with pre-death PG symptoms and caregiver burden, while Relational distress is associated only with pre-death PG symptoms;
- FcAG-CI dimensions were then clustered, resulting in four different AG profiles, which were described according to their rating in self-report scales (Prolonged Grief Questionnaire, Depression, Anxiety, Somatization and Caregiver burden);
- Avoidant AG scored low in both traumatic and relational distress, as well as in other symptoms´ scales, except for burden;

- Adjusted AG presented moderate levels in Traumatic and Relational distress, as well as in the symptoms´ scales, but comparatively to the previous group, the burden was lower;
- Traumatic AG reported high levels in Traumatic distress as well as in other symptoms scale, reflecting intense emotional reactivity to the disruptive circumstances of end-of-life caregiving;
- Intense AG is characterized both by heightened Traumatic and Relational distress, along with severe PGD manifestations and other mental health symptoms, with exception of caregiver burden, which was lowest comparatively with the previous group.

1.1. Methodological and Conceptual considerations in Operationalizing Anticipatory Grief

In order to conceptualize AG, we started by considering the literature on the topic (Literature Review). Most existing studies were qualitative and exploratory, reflecting the need to capture the experience through the meanings attributed by the caregivers themselves. These studies have the advantage of illustrating the complexity of the phenomenon by contextualizing it in the end-of-life caregiving setting, but they are generally based on a vague definition of AG, contributing to the lack of conceptual clarity around this subject. Notwithstanding the claims of several authors (e.g., Fulton, 2003) for more consistent approaches in defining AG, most studies are still based on Rando´s formulation, that clearly fails in capturing the construct multidimensionality in a precise and operational definition.

Another important strand of research arises from the quantitative self-report assessment of grief manifestations. Most AG instruments were developed for dementia caregivers (Theut et al., 1991; Marwit & Meuser, 2005). Although other versions for cancer caregivers have been posteriorly created (Marwit et al., 2008), we questioned whether their dimensions really reflect the AG experience (Literature Review, Empirical study IV). For example, the dimension *Personal sacrifice and burden*, as the name implies, refers mainly to the experience of caregiver burden, which is a distinct concept from pre-death grief, although they are both correlated (Empirical studies I, IV and V).

Alternatively, an adapted version of Prolonged Grief Questionnaire (PG-13) was created as an early screening tool of PG symptoms (Prigerson et al., 2008). This unidimensional instrument is based on the diagnosis criteria for PGD recently accepted by the International Classification of Diseases - 11th Revision (ICD-11, WHO, 2018). Given its predictive value of bereavement outcome, this instrument has been widely used in PC (e.g., Thomas et al., 2014). Therefore, our first empirical study aimed to adapt and validate PG-12 for the Portuguese population. This has proven to be a reliable instrument for early PGD diagnosis, independent from other mental health outcomes, such as depression and anxiety (Empirical study I). By comparing results from PG-12 with those reported in post-loss, assessed by PG-13, we were able to establish the course of prolonged grief symptoms and identify the predictors of bereavement outcome (Empirical study V), thus addressing the first main objective of this research.

Consistent with other studies (Thomas et al., 2014; Nielsen et al., 2017), we verified that FC who presented high symptomatology pre-death were also prone to worst bereavement outcome. These findings lead Nielsen et al., (2016) to conclude that, as opposed to what was previously assumed (Lindeman, 1944), pre-death grief manifestations were not protective of posterior adjustment. Instead, they suggested that AG constitutes a complex risk factor grounded in the relationship with the deceased and intrapersonal predisposition factors such as attachment style, coping and emotion regulation. The same authors emphasized that more research is needed to identify the underlying mechanisms of this process.

Hence, the conceptualization and assessment of caregivers' grief requires a more comprehensive approach that captures the multidimensionality of this experience. This constitute the rationale for developing a new instrument of AG, intended to be complementary to the self-reported evaluation of PGD symptoms. The definition of a multidimensional construct refers to “distinct but related dimensions treated as a single theoretical concept” (Edwards, 2001, p.144). It is used to provide a holistic representation of a complex phenomenon, combining different components (i.e., dimensions), which are, themselves, latent constructs. Each dimension concerns a specific content domain that can be subdivided in sets of second-order constructs (Polites, Roberts & Tatcher, 2012).

Systematic analysis of empirical results from the literature review enabled the identification of the various facets of the content domain (nuclear characteristics), candidates to be included as latent concepts. Nuclear characteristics were afterwards used as codes in thematic analysis, in conjunction with those derived from the data from in-depth semi-structured interviews (Empirical study III). The content and relationship between categories were revised and redistributed, resulting in successive changes in their configuration, as new data was included and bridges were made to theoretical concepts. This explains that new categories emerged and others had disappeared from one study to the next. For example, the content from the category initially designated as Emotional distress (Literature review) was disassembled and distributed across the various domains, since it is a transversal aspect. Criteria for distinguishing the main categories was the frequency of their occurrence in interviews, which lead us to conclude about its centrality in the AG experience. Concepts were aggregated in three main themes, each one composed by main categories and subcategories: (1) Traumatic distress; (2) Separation distress, and (3) Emotion regulation and dysregulation.

Next, to address variations in latent concepts, we performed a cross-case analysis, using a top-down analysis based in attachment theoretical-based constructs (Empirical study IV). This allowed us to create profiles, composed by different characteristics within each dimension. The concepts were then operationalized into evaluation criteria, constituting the quotation grid of the “Family Caregiver Anticipatory Grief – Clinical Interview” (FcAG-CI) which is, as the name implies, a clinical assessment tool, based in a semi-structured interview that evaluates how FC emotionally regulates themselves in face of the multiple challenges posed by the AG experience. Interviews were rated according to these criteria in a scale of 9 points, corresponding to increasing degree of emotional distress. Data were then compared with quantitative results from self-report instruments in order to test the psychometric characteristics of FcAG-CI. Segmentation of results by factorial analysis confirmed the existence of two dimensions, each one aggregating four domains.

The first dimension, *Traumatic distress,* includes the following categories: (1) Uncertainty of illness; (2) Vicarious suffering; (3) Image of degradation; (4) Caregiving impotence, and (5) Life disruption. This last category, previously designated as Personal Losses, was posteriorly relabelled as Personal Restrictions because we think it better captures the true meaning of this content domain. However, in study IV this domain was excluded, as it presented low factor loading. Given that this category was specifically related with caregiver burden, this result corroborates our position that this is a distinct construct, therefore it should not be included when measuring AG.

The second AG dimension refers to the separation distress – or relational distress as labelled posteriorly (Empirical study IV). We preferred the latter for being more general, including also the difficulties inherent to caregiving relationship. This dimension encompasses: (1) Anticipation of death; (2) Separation anxiety; (3) Relational losses; (4) Sense of protection and (5) Affective deprivation. The last category was omitted in Study IV since it was considered to be related with Relational losses, so it was included in the latter.

Below, we converge results from quantitative and qualitative studies to describe the trajectory and determinants of PGD and the multidimensional phenomenological structure of AG. Individual differences are analysed in their relationship with prolonged grief manifestations and other mental health outcomes.

1.2. Trajectory of Caregiver´s Prolonged Grief symptoms

Literature suggest that FC in PC is particularly vulnerable to intense grief manifestations (Zordan et al., 2019). In accordance, data from our study showed that cancer FC in palliative care presented high prevalence rates of PGD. Specifically in pre-death, values reached 38.6% (Empirical study V), broadly exceeding those from other international studies carried out with FC in PC. For example, Hudson et al., (2011) found that, prior to death, 14.9% of the sample met the criteria for PGD. At 6 months, Thomas et al. (2014) reported that only 6.7% had criteria of PGD, and this value increased at 12 months (11.3%).

In previous studies conducted with Portuguese samples, high levels of psychological distress were also found (Delalibera, Coelho, Presa, Barbosa & Leal, 2018), namely in comparison with the Brazilian FC in PC (Delalibera, Coelho, Frade, Barbosa & Leal, in press). Another study carried out with Portuguese FC reported that 25.9% showed high risk of grief complications (Areia, Fonseca, Major & Relvas, 2019). These findings lead us to consider the role of cultural aspects, such as the importance of family ties and religion, typical of Southern Europe countries (Meñaca et al., 2012).

As documented in other studies (Thomas et al, 2014; Nielsen et al., 2017b), we found that the presence of pre-death PGD symptomatology is associated to worst bereavement outcome. Most participants who presented persistent symptoms of grief more than six months after loss already reported intense grief manifestations prior to death (Empirical Study V). These findings provide support for the continuity of grief manifestations, in line with the perspective of cumulative stress. However, there is also evidence for stress reduction, as values decrease significantly from pre to post-death phase. In the prospective study, remission of symptoms occurred in 38.1% (n= 16) of the cases. This progressive reduction of grief manifestations is visible more than a year after the patient´s death. In a previous study conducted with a Portuguese sample (Coelho, Delalibera, Barbosa & Lawlor, 2015), 28.8% presented PGD criteria at 6 to 7 months after death, with a significant decrease (15.1%) after the first year of bereavement.

In short, results from the current study confirm that in spite of most caregivers being able to adapt reasonably in the long run, many of them continue to struggle with severe symptoms long after the loss. Those who report more difficulties in adjusting to the feelings of loss during advanced illness are more likely to present grief complications. Hence, data provides support for both the perspectives of *stress reduction* and *cumulative stress*, which turned out to be complementary in explaining the diversity of caregiver´s grief manifestations evolution. Therefore, it is important to identify the adverse aspects of caregiving context that are potentially modifiable through early intervention in PC, in order to prevent future grief complications.

1.3. Determinants of Prolonged Grief Disorder

As the disease progresses, FC in PC are in increased risk for burden and mental disturbance symptoms (Williams & Mccorklec, 2011) and these are predictive of FC´s grief severity (Tomarken et al., 2008; Hudson et al., 2011; Nielsen et al., 2017a). In accordance, we found (Empirical study I) that most participants reported clinically significant values in burden (85.9%), depression (67.4%) and anxiety symptomatology (62%). Severity of burden and mental disturbance were correlated with the intensity of pre-death grief symptoms. However, it is worth mentioning that, in comparison with PGD, symptoms of burden and mental disturbance are much more frequent, corroborating the idea that these are independent conditions.

The female gender was correlated with pre-death grief manifestations (Empirical study I). This finding is consistent with other studies (Hudson et al., 2011; Nielsen, 2017). As stated by Stroebe (1998) this reflects gender differences in coping with grief, specifically in expressiveness of emotions and emotional sharing. Women can access their emotions and express them more easily, while men find it easier to avoid feelings, by diverting attention to distracting activities and dealing with concurrent problems, rather than with the grief emotions. However, female caregivers are usually overrepresented in research samples, potentially introducing bias (Stroebe & Stroebe, 1993). Other characteristics, such as being spouse and having low level of education were also associated with heightened pre-death grief (Empirical study V), as documented previously (Hudson et al., 2011; Liew, 2016; Kiely, Prigerson, & Mitchell 2008).

Referring to the circumstances of caregiving, despite not being considered a significant predictor, the results show that the more hours spent in caregiving, the more severe the manifestations of grief (Empirical study I). This association have been reported in bereavement (McLean, Barbara & Higginson, 2016), but not in pre-death grief (Hudson, 2011). The time spent by FC in providing care to the cancer patient is considered an important component of the burden (Yabroff & Kim, 2009) because it implies the diminution of personal freedom and less engagement in fulfilling activities (Noyes et al., 2010). On the other hand, spending more time with the patient also eventually entails the perception of higher severity of illness, which we also found to be associated with higher PG-12 scores. This means that, as the FC realizes the irreversibility of illness, the grief is more intense. However, in accordance to Nielsen et al (2017a), “too much” prognostic information is associated to more intense pre-death manifestations, suggesting that these people are dealing with information that they are not prepared for.

On the opposite, denial was also found to be maladaptive. According to Ferrario et al., (2017), denial is a way of preserving oneself from something that the person is not yet ready to face. Thus, in the initial phase of illness, it has a positive effect in reducing depression and anxiety. However, denial is also correlated to low registration of threatening stimulus and anxious attachment (Jerome & Liss, 2005). So, when disease progresses, they claim that they were not expecting the diagnosis (Empirical study I), which contributes to a sense of lack of preparedness to the current situation and more intense pre-death symptoms. Hence, both excessive awareness of illness severity and denial seem to have a deleterious effect on adaptation to advanced disease. This is in conformity with the perspective that anxious individuals show preferential attention to threat and then avoid it (Weierich, Treat & Hollingworth, 2008).

On the opposite, acceptance and positive reframing demonstrated a protective effect of pre-death PGD symptoms. These conscious cognitive regulation processes were considered crucial in the management of threatening or stressful events by assisting individuals to manage, regulate, and control the emotions (Garnefski et al., 2001). Mancini & Bonanno (2009) argued that the experience of positive emotions, by reframing the aversive experience, along with the capacity to accept death and accommodate the reality of the loss into their worldviews, are the main precursors of resilience trajectory in grief. Consistently, greater levels of acceptance and positive reappraisal were also related to lower levels of excessive worry and anxiety (Zlomke & Khan, 2010).

Regarding the relational aspects, the high proximity with the patient during the illness was considered an important predictor of PG manifestations, both pre and post-death. This finding is in line with previous results suggesting that FC who struggle the most with grieving feelings are those who most relied in the person they were about to lose (Burke et al., 2015). The previous dependent relationship continues to hinder adaptation to loss during bereavement (Denckla, Mancini, Bornstein & Bonanno; Hudson et al., 2014; Coelho, Delalibera & Barbosa, 2016). Conflict was also correlated with post-death grief outcome suggesting that, during bereavement, FC are prone to review the previous relationship with the deceased, thus being affected by negative feelings. Conflictual relationship has been traditionally associated to grief complications (Parkes & Weiss, 1983; Stroebe & Stroebe, 1993), but this perspective was rejected with the argument that it reflects a bias of bereaved retrospective memory (Bonanno et al., 2002). Prospective data from the present study declines this argument, reaffirming the validity of that connection. Figure 1 presents a conceptual map integrating these research findings.

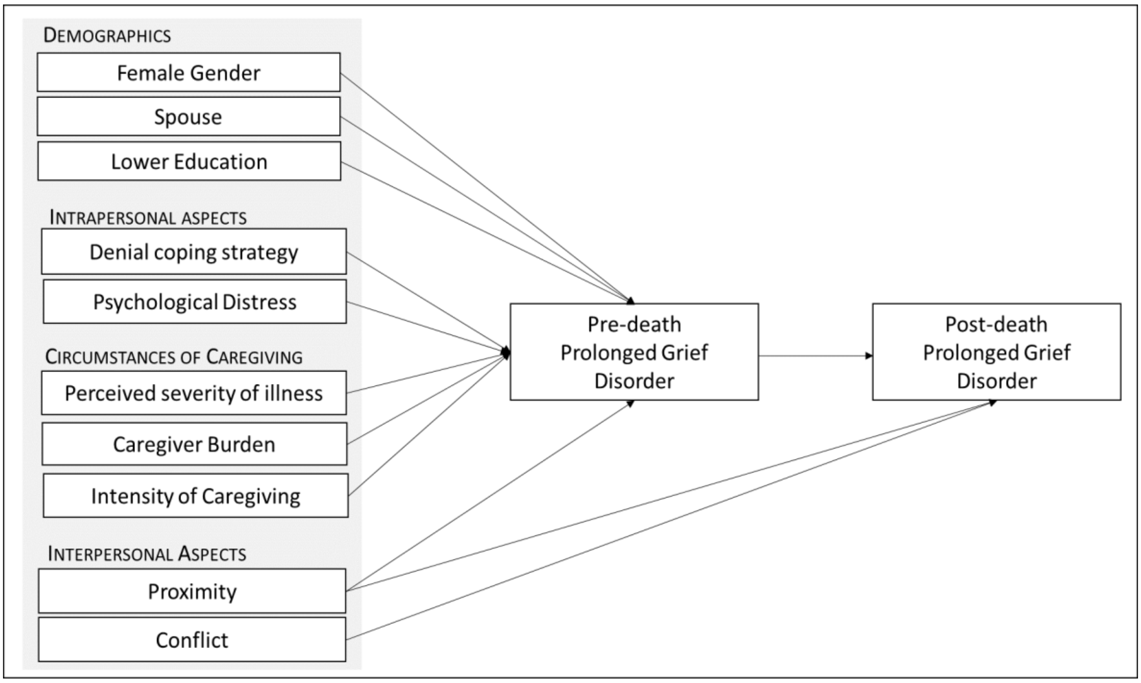

Fig. 1: Determinants of pre and post-death PGD

Results from these empirical studies document that despite the continuity of grief symptoms, the pre and post-death grief experiences reflect distinct aspects of caregiving experience. Qualitative and mixed method studies, discussed below, provide further insight about this topic.

1.4. Multidimensional phenomenological structure of Anticipatory Grief

Findings from the literature review stressed that AG is a complex and dynamic process characterized by ambivalent feelings resulting from two conflictual positions: FC need to hang out to hope in order to stay functional and protective in the relationship with the patient, while at the same time, they anticipate death and experience the loss of the relationship as it was known before. This view is in line with Rando´s perspective (1986), that the AG process is a delicate balance between mutually conflicting demands of simultaneously holding onto and letting go the patient.

As opposed to bereavement, where the death is a tangible reality and materialized in the physical absence of the significant other, in this case, the patient is alive and in need of care, so the caregiver lacks the legitimacy to mourn the loss. This formulation of the AG is compatible with the definition of disenfranchised grief, as originally conceived by Doka (1989, 1999). By failing to recognize the loss experience, the family members are deprived of the possibility of openly expressing their pain, and being recognized and supported in the devastating impact of this experience (Attig, 2004). The attitude of avoidance is reinforced by death-denial Western culture (Kellehear, 1984), which conveys the idea that the good death is neither consciously nor openly spoken. In fact, many of the family members interviewed in the present study did not explicitly address the subject of death, despite recognizing the terminal and irreversible condition of the disease (Empirical study II).

Although often veiled, *anticipation of death* assumes a central role in the AG process, as it dictates the beginning of AG, itself (Literature Review). However, this is not a linear process that evolves necessarily toward preparation to death. On the contrary, it is subject to an oscillatory process that occurs at both intra and interpersonal level, through a constant effort of emotional regulation. It involves two main different dimensions: first, Traumatic distress, related to the continuous exposure to life-threatening conditions; second, Relational distress, elicited by the perceived menace to the relationship (Empirical study II). These two dimensions are deemed to be interrelated because Traumatic distress captures the life-threatening condition that induces the experience of death anticipation and early loss underlying the Relation distress.

AG nuclear characteristics were described as emotional stimulus requiring balance between two conflictual positions. In managing threat to the other´s life, people may organize their defensive response in terms of two response patterns: approach, by noticing the threat stimuli and making it more controllable; or avoidance, which protects the individual from anxiety-arousing stimuli and their consequences (Roth & Cohen, 1986). In managing the distress in the relationship, FC may seek for closeness or withdraw from the other for self-protection against feelings of rejection and loss (Murray, Holmes & Collins, 2006). This conceptualization is clinically useful as it confers a function to the FC´s behavior rather than a mere description of a symptomatic reaction.

Based in previous considerations, we proposed a clear and parsimonious definition of AG which condenses these two dimensions and enables a more precise understanding of the construct. AG is then defined as the family response to the perceived menace to the other´s life and subsequent anticipation of loss, in the context of end-of-life caregiving relationship. This concept is distinct from that of pre-death PGD in three fundamental aspects: first, because it is two-dimensional, unlike the latter which is unidimensional; second, it focuses on the experience of death anticipation and early loss during end-of-life caregiving, as opposed to pre-death grief, which simply refers to the symptoms of PGD in phase preceding death; third, it is grounded in a dimensional approach, which allows for a ore fine-grained conceptualization and assessment of symptom profiles, on contrary to PGD, a categorical diagnosis based in the presence versus absence of symptoms.

In the following, we describe the two dimensions in more detail, both at the phenomenological level and in their relationship to PGD symptoms. Then, anticipatory grief profiles will be discussed, based in qualitative and mixed method analyses.

1.4.1. Traumatic distress

Most caregivers interviewed described very shocking and emotionally overwhelming situations related to the continuous exposure to actual life-threatening conditions. FC are confronted, for example, with the presence of complex and unexpected symptoms, major changes in behavior and great body deterioration (Koop & Strang, 2003; Dumont et al., 2008). Besides, the perspective about the future is undermined by the uncertainty of illness (Unson et al., 2015; Hurt, Cleanthous & Newman, 2017). The generalized sense of lack of control over the illness circumstances and one´s own life, along with intense feelings of anxiety, impotence and helplessness were designated as *traumatic distress*. Other authors have already mentioned the presence of traumatic aspects in end-of-life care experience, emphasizing the disruptive impact of persistently witnessing the patient´s suffering and degradation (Prigerson et al., 2003; Lynch & Lobo, 2012).

Results from study IV reported that the traumatic aspects were associated to higher pre-death grief manifestations and caregiver burden, which reinforces its disruptive impact on mental health symptoms during the caregiving period. However, traumatic distress did not predict long-term consequences. This may indicate that pre-death grief differs significantly from the experience of bereavement, which probably reflects other aspects than the experience of trauma prior to the loss. In line with this position, findings from Study V revealed that caregiver burden influences pre-death grief, but not post loss adjustment, suggesting that the adverse effects of caregiving tend to dissipate over time. These results contradict those reported by a previous qualitative study (Sanderson et al., 2013), in which symptoms of trauma persisted for more than six months after the patient´s death through intrusive memories. We speculate that this inconsistency may translate differences in the assessment method, as PG-13 does not capture the specific characteristics of caregiving experience. Another reason why we found no correlation may be due to the small sample size at follow-up. Further research is needed to clarify the effect of traumatic circumstances od caregiving in post loss outcome.

1.4.2. Relational distress

The progressive decline of the patient is, itself, a forewarning of death. Yet, the experience of death anticipation is quite ambivalent. As observed by other authors (e.g., Pusa, Persson & Sundin 2012), FC wish this situation to end quickly, but on the other hand, this represents the definitive separation from the significant other. In other words, death is simultaneously a relief from the suffering – the other´s and their own – and the most feared moment. As a result, carers are prone to feel guilty, so they mitigate this felling by being present, and exclusively focusing in the caregiving (Martz & Morse, 2016; Breen, Aoun, O'Connor, Howting & Halkett, 2018). Despite the physical proximity, there is a tendency to emotionally withdraw from contact and deal alone with the suffering (Langer, Rudd & Syrjala, 2007), thus accentuating the feelings of loss, solitude and lack of reciprocity (Read & Wuest, 2007; Pusa et al., 2012; Beng et al., 2013). In addition, the imbalance between what FC gives and takes in the relationship with the patient (Ybema et al., 2002) uncovers previous relational failures and increases ambivalent feelings to the caregiving relationship. Overall, these aspects contribute to the *Relational distress* inherent to the caregiving circumstances and imminent separation.

As referred in Empirical Study IV, FC who presented more Relational distress were also more likely to show intense pre-death PGD grief manifestations. On the contrary, Relational distress was not correlated to the post loss grief outcome. However, in line with other studies (e.g., Dumont et al., 2008), results from Empirical Study V suggested that the relationship quality in the caregiving context were predictive both of pre and post-death grief, so it would be reasonable to expect that the relational aspects influence the bereavement outcome. Once again, we think that methodological issues may have influenced this outcome. In addition to the small sample size, it is possible that some particular characteristics, rather than the relational distress as a whole, have a long-term effect. In particular, it is important to distinguish the way people regulate themselves emotionally in view of the different challenges posed by this AG dimension.

1.5. Anticipatory Grieving Patterns

Results from studies II, III and IV support that FC differ significantly in managing distress associated to AG. Individual differences were attributed to the FC attachment-based dispositional tendency to regulate emotions, along with variables of the caregiving context. In this analysis, we considered aspects arising from the qualitative analysis of interviews, such as the FC´s attention to the illness signs, their ability to tolerate the patient´s suffering and changes in previous image, reluctance to physical separation and relational needs. In study III, qualitative individual differences were classified according to the level of pre-death grief intensity and then set up in different anticipatory grieving patterns, conceptualized at light of attachment theory. Evidence for four pattern classification was confirmed in Study IV, by using statistical analysis to create profiles.

Results clearly distinguish a first group, corresponding to the least symptomatic. This profile, labelled “Avoidant AG”, reported less intense pre-death grief, as well as values below average in both FcAG-CI dimensions, namely the traumatic and relational distress. Considering results from study III, people with low PG-12 scores were significantly less sensitive to the patient´s suffering and image deterioration, which can be explained by their tendency to divert attention from the threatening stimulus as a strategy of emotional regulation, as typically observed in insecure-avoidant attachment (Dewitte, Koster, de Houwer & Buysse, 2007). These FC were likely to express surprise and shock by the occurrence of sudden and unexpected events, but posteriorly to crisis episodes, they tend to normalise their routine, probably due to the habituation process, as described by other authors (Lazarus & Folkman, 1984; Campbell et al., 2014; Carleton, 2016). Besides, by rationalizing death they were able to talk openly about its inevitability and see it as a way to escape suffering. Although the use of avoidant mechanisms to deal with difficult situations is common in caregiving (Balbim et al., 2019), this feature is particularly salient in this group. Avoidant strategies were previously associated with less self-reported symptomatology (Coifman et al., 2007) and less refusal in accepting loss (Kho et al., 2015). The exception was for burden, which was considerably high. In fact, although generally less involved in caregiving, these FC referred severe difficulties in managing the patient´s behavior and less satisfaction in the caregiving relationship, which can lead to emotional exhaustion, as documented by Reblin et al. (2015).

A moderate level of self-reported PG symptoms corresponded to levels close to average in both dimensions of FcAG-CI. Hence, this group was assigned as *Adjusted AG,* corresponding to the secure attachment style. Most of them were able to anticipate illness evolution by remaining vigilant to the illness signs. This confirms the use of approach strategies to deal with the threat, instead of avoidance, as in the previous group. They were also more sensitive to the patient´s physical and mental losses, although they expressed the need to preserve the patient´s image. Other studies demonstrated that securely attached caregiver present greater sensitivity, availability and compassion (Gillath et al., 2005). Additionally, they were more prone to manifest open expressions of sadness related to relational losses, while appreciating small manifestations of affection on the part of the patient. Comparatively with the avoidant group, these participants scored slightly higher in pre-death grief and mental health symptoms, but lower in caregiver burden (Empirical study IV). These results may be explained by the fact that they were more aware of their feelings, and therefore, abler to manage the caregiving relationship in order to avoid burden.

The group of participants with high levels of PG-12 was labelled as *Intense AG* pattern, corresponding to the insecure-preoccupied attachment style. This profile was characterized by scores above average in both traumatic and relational distress.

Specifically, these participants were more sensitive to the patient´s physical and emotional suffering, but they were also more prone to identify themselves and project in the other´s emotional state, a phenomenon called emotional contagion (Hatfield, Cacioppo, Rapson, 1994; Hatfield, Rapson & Le, 2008). As a consequence, these participants showed more signs of intolerance to the patient´s suffering. It has been demonstrated that, due to their hyper-involvement in caregiving, the anxiously attached individuals presented more emotional distress associated to this experience (Kim, Kashy & Evans, 2007). They have also tendency to maintain hypervigilant, as a result of their high sensitivity to threat (Thompson, Schlehofer & Bovin, 2006) and low tolerance to uncertainty (Carleton, 2016; Shihata et al., 2017).

The classification of traumatic AG group seems to be less consistent. In Study III, we considered that those with extremely high scores in PG-12 corresponded to Traumatic AG. Qualitative analysis of these participants confirmed the presence of features that characterize disorganized attachment style. For example, they presented difficulties in dealing with sudden changes inherent to the advanced illness and the marked oscillation between hope and disillusion, as a reflection of their approach-avoidance processes (Cassidy & Mohr, 2001), which reflects high traumatic distress. Interviews also showed deep state of solitude and abandonment, as well as intense feelings of resentment at the patient's relational failures, suggesting high relational distress, which does not match with the Traumatic AG pattern, as defined in Study IV. Nevertheless, the presence of high caregiver burden clearly indicates the wearing of the relationship exhibited by this group. More research is needed to better describe this group of caregivers.

These findings suggest that caregivers are a heterogeneous population, presenting different levels of emotional reactivity to end-of-life caregiving circumstances, with clear repercussions in mental health outcomes. Hence, AG cannot be generally considered as a protective or risk factor as it has been conceptualized so far. Instead, we argue that the emphasis should be placed on how caregivers emotionally regulate themselves in the face of the multiple challenges posed by this experience. Individual differences seem to reflect dispositional characteristics of the attachment style. However, we cannot assume that they are reflected linearly in these particular circumstances. According to Fraley &

Roisman (2019), some attachment schemas may become more or less active, depending on the relational context.

The only existing study evaluating the effect of attachment in FC´s pre-death recognized that the “preoccupation with the relationships”, typical of anxiously attached individuals, was associated with more grief manifestations in FC (Lai et al., 2015). The authors recognized that this dimension may be exacerbated by the experience of grief, thus suggesting that the particular characteristics of this context may influence the way one experiences the relationship with the attachment figures, modifying the individual´s usual reaction pattern. Yet, as evidenced by qualitative data, manifestations are diverse: some are more concerned with controlling circumstances to avoid further emotional overload; others approach the patient affectionately to enjoy their little time together. There are also caregivers who worry so intensely that they become susceptible to emotional contagion; in the extreme, they may become intolerant and oscillate between approaching and withdrawing from the patient.

Each of these positions reflects different gradients of emotional activation, as postulated by Siegel's (1999) conceptualization of tolerance window. The first, typical of *avoidant* individuals, indicates discomfort with emotional stimuli and the consequent need to deactivate the attachment system. In this case, the level of emotional activation is below the lower limit of the tolerance window. The second position, typical of securely attached individuals, reflects awareness and ability to self-regulate, so the level of emotional activation is within the limits of the tolerance window. Therefore, it is considered *adjusted anticipatory grieving* pattern. The third reflects the tendency to hyper activate, therefore the emotional activation level is above the upper limit of the tolerance window. This pattern of emotional deregulation is typical of preoccupied style, here referred to as the *intense AG*. Finally, the fourth is likely to marked oscillation between hipo and hyperactivation, so it is also a pattern of emotional deregulation. Due to its high reactivity to the traumatic circumstances of end-of-life care, it corresponds to the pattern of traumatic AG. Figure 1 configures this conceptual map.

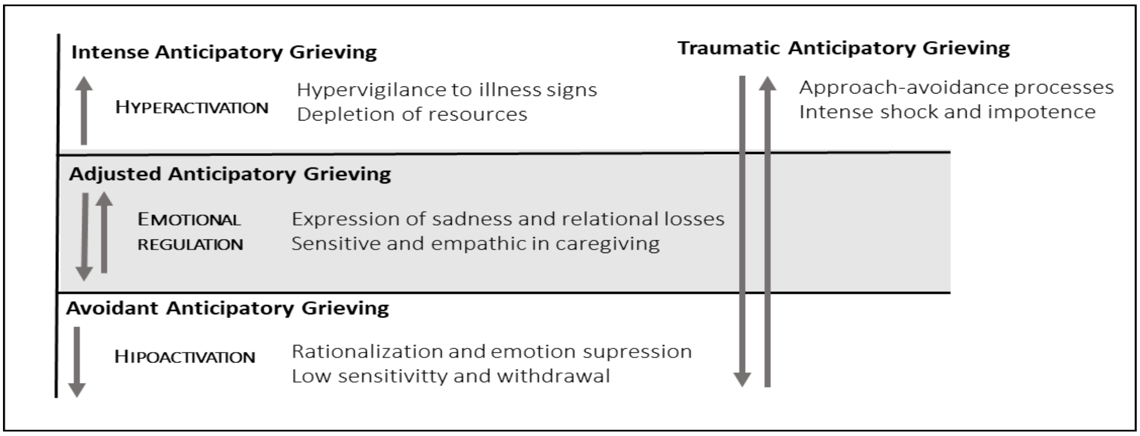

Fig. 2: Window of tolerance scheme representing AG patterns

A detailed analysis of the individual differences in each of the AG domains can be found in the FcAG-CI Manual attached to this dissertation.

2. Strengths, Limitations and Suggestions for Future Research

This research project contributes with empirical data to the conceptualization and assessment of FC AG. First, our empirical studies provided a more comprehensive view of the AG as a multidimensional construct, resulting in a more precise and self-differentiated definition. Second, we contribute with the development of a new manualized clinical instrument, as a complementary assessment tool to the self-report assessment of pre-death PG manifestations. This instrument ensued from the recognition of the need to guide clinical evaluation and therapeutic approaches according to FC´s individual differences in dealing with this highly sensitive subject. Based in a semi-structured interview, it allows access to the internal meanings of FC, thus capturing a more authentic view of the complexity and dynamics of this phenomenon.

As stated by Ratcliffe (2017), clarifying the phenomenology of grief is essential for understanding its distinctive structure. Therefore, in evaluating AG, we privileged qualitative methods, using a top-down thematic analysis, based in an integrative model of attachment and emotional regulation. These perspectives offer a comprehensive framework of this phenomenon, explaining individual differences in the way FC manage the threat to the significant other´s life. Although specifically attachment theory has been extensively studied in bereaved response, its application to pre-loss FC grief experience has been poorly explored. Only one study was found associating attachment to pre-death grief (Lai et al., 2015). Circumstances of end-of-life clearly constitute a challenge to the security of the relationship, so in this research we intended to understand how attachment and related caregiving behavior influence FC´s response. As far as we know, this is the first study integrating concepts from these different perspectives to develop theoretical knowledge about how FC emotionally manages, both intra and interpersonally, the significant other´s imminent death and separation.

Besides, by collecting prospective data, we described the trajectories of grief evolution and identified personal, circumstantial and relational factors associated with grief complications, both pre and post-death. Overall, insights from empirical studies challenged the idea that grief evolves as a continuous linear process influencing negatively the bereavement outcome. Instead, we elaborated about AG patterns distinct characteristics and their mental health outcomes. These results are particularly relevant for understanding the pathway through which end-of-life caregiving affects the carers' adjustment. Moreover, although only PGD is recognized as a form of complicated grief, our study suggests the existence of sub typologies, characterized by distinct phenomenology. Although grounded in a long tradition (Bowlby, 1980; Parkes & Weiss, 1983; Raphael, Middleton, Martinek, & Misso, 1993; Horowitz, Bonanno & Holen, 1993), this perspective still lacks validity (Stroebe et al., 2000). The present study contributes with empirical data for the differentiation of this multiple clinical syndromes.

However, this study also entails limitations. First, the non-probabilistic nature of the sampling (i.e., convenience sample) restricts its representativeness. Selection of participants was conditioned by the researchers´ accessibility and the participant´s willingness to participate in the study, so it is possible that those FC who were more distressed are overrepresented in this sample, thus explaining the heightened symptomatology. Particularly in the Study V, the selection of participants was biased, as we were simultaneously recruiting participants for the qualitative study, which implied accepting to be interviewed by the psychologist. Naturally, those FC who considered themselves adjusted to the current circumstances of illness were less prone to be enrolled in the study, so the sample became eminently clinical. Moreover, since one form of filling out the questionnaires was by mail, accession was mostly by the younger caregivers with higher education, which may not be representative of the general caregiver population. Nevertheless, high rates of response from daughters with a university degree were also found in other studies, both international and Portuguese (Hudson et al., 2011; Areia et al., 2018).

Second, the sample size is small, thus implying cautions in the interpretation of results. In spite of our effort to recruit more individuals, especially for the follow-up, several factors accounted for the low participation. The most important was the loss of contact with many FC after the patient transfer to a Palliative Care Unit outside the Hospital. Another reason was the reluctance of many family members to come to the hospital in the post-death phase in order to avoid painful memories related to end-of-life period. As a result, most participants responded by phone or via email, which impeded the realization of face-to-face interviews to collect more quantitative and qualitative data, as was initially planned. This precluded a more detailed analysis on the consequences of AG in the bereavement period.

Additionally, we emphasize that the association with attachment styles is merely exploratory, as the classification is based on theoretical concepts. Although it was our choice not to use any structured scale to evaluate attachment, we recognize that this may be a limitation in interpreting the results. The relationship between attachment, caregiving and AG is clearly an understudied subject, so further research is required to address this issue. However, conventional attachment scales are not sensitive to this specific context, so we suggest creating a specific self-report measure, complementary to the FcAG-CI, that specifically assesses anticipatory grieving responses according to attachment styles. Anecdotal data from interviews can be used to generate empirically based items reflecting the naturalistic experience of FC.

Additional studies are needed for further refinement of the pathways through which AG influences loss adjustment. For instance, it would be important to verify, with a larger sample, to what extent individual variations in management of each of the AG components influence response to loss in the pre and post-death stages. Another question that needs to be addressed is if patterns of reaction are stable across the time.

This requires the longitudinal evaluation of grief phenomenology identifying the presence of specific characteristics of each pattern in different moments. Finally, we suggest that cancer FC grief experience should be analysed in comparison with controls from other life-threatening diseases and sudden death.

3. Contributes to Clinical Practice

This research project encompasses some important contributes to the development of clinical practice. The first concerns the early risk assessment of caregivers. This research provides a reliable instrument for a more accurate and sensitive evaluation of individual vulnerability. Our clinical experience suggests that exposing family members to structured questionnaires with questions focused on death and grief at an early stage may have a counterproductive effect. On the one hand, it can induce avoidance responses, leading people to deny feelings of grief related to the anticipation of death; on the other hand, it can create false expectations of a correct way to respond to this situation, disrespecting the individuality of grief process. Hence, we argue that the approach should be built on a therapeutic relationship, through a conversational phenomenological-oriented interview that progressively deepens the topics potentially most painful. In this way, it will be possible to gather information that is not always consciously accessible to the interviewee and therefore cannot be captured by self-report scales. The codification of qualitative material through empirically based criteria provides an individual´s profile, identifying how one regulates emotionally in the several domains of this experience. Those with highest scores indicate the presence of intense psychological distress and therefore should be considered priority intervention aspects.

The second implication of this research concerns the delineation of an individual intervention programme. Based in the specific needs outlined by the clinical assessment, the key elements of the intervention programme are defined, although this process can be adapted to the unique profile of each subject. From a two-dimensional perspective of AG, there are some FCs who require an approach mainly focused in traumatic aspects of this experience, while others would benefit from an intervention focused on the relational distress caused by imminent death and physical separation. The former are usually most affected by the disruptive impact of end-of-life caregiving, so intervention should include psychoeducation about illness evolution, processing of painful memories and anxiety management techniques. The latter are generally more dependent and insecurely attached, so therapeutic intervention should favour the resolution of pending issues and the creation of memories that can contribute to a safer representation of the bond.

Finally, we consider that insights from this research provide a more comprehensive and empathic view of this experience, informing health professionals training in improving the quality of care. Ultimately, we expect to contribute to the education of the general population and the development of health policies, by drawing attention to the real impact of end-of-life caregiving and the neglected needs of family caregivers.

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ATTACHMENTS

ATTACHMENT 1

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Family Anticipatory Grief: An Integrative Literature Review

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Abstract

Despite all the investment in research, uncertainty persists in anticipatory grief (AG) literature, concerning its nuclear characteristics and definition. This review aimed to synthesize recent research in order to develop further knowledge about the family experience of AG during a patient's end of life. An integrative review was performed using standard methods of analysis and synthesis. The electronic databases Medline, Web of Knowledge, and EBSCO and relevant journals were systematically searched since 1990 to October 2015. Twenty-nine articles were selected, the majority with samples composed of caregivers of terminally ill patients with cancer. From systematic comparison of data referring to family end-of-life experience emerged 10 themes, which correspond to AG nuclear characteristics: anticipation of death, emotional distress, intrapsychic and interpersonal protection, exclusive focus on the patient care, hope, ambivalence, personal losses, relational losses, end-of-life relational tasks, and transition. For the majority of family caregivers in occidental society, AG is a highly stressful and ambivalent experience due to anticipation of death and relational losses, while the patient is physically present and needed of care, so family must be functional and inhibit grief expressions. The present study contributes to a deeper conceptualization of this term and to a more sensitive clinical practice.

Keywords

anticipatory grief, family caregivers, palliative care, cancer, integrative review, end-of-life experience

Background

Family lives an extremely disturbing experience simultaneously to patient's end-of-life trajectory, not only because of the physical and emotional stress inherent to care providing but also due to feelings of loss and separation caused by advanced disease and imminent death.[1-3] However, this experience is considered a necessary and significant part of the adaptation process to loss.[4,5]

After Lindemann,[6] the term anticipatory grief (AG) was applied to express in advance when the loss is a threat or inevitable, referring to any grief experienced by the patient or the survivor before death.[7] Recognizing the complexity of this concept, Rando[8] developed a multidimensional definition, encompassing the losses incurred in the past, present, and future. Probably due to the large scope of this issue, it gave rise to a broad discussion.[9-11] According to Fulton et al,[9] it was assumed that when there is forewarning of loss, AG is likely to occur, and the 2 terms have been used interchangeably. Thus, a linear view of AG was created as a continuous and irreversible process, analogous to the adjustment subsequent to death.

A previous review described AG as a subjective phenomenon that does not depend on the length of illness nor is it directly related to the awareness of terminal disease.[12] Another review focused on the AG of family caregivers of patients with dementia found that characteristics of AG in this population are anticipating, ambiguity, frustration, and guilt.[13] But, in a comparative study between caregivers of patients with dementia and cancer, the latest demonstrated to feel more closer to the ill relative, more preoccupation with thoughts about the illness, and more symptomatology.[14] These results suggest that different illness trajectories may influence AG experience.

Family caregivers are a key component in palliative care, and AG issues are deemed of particular concern. Therefore, it is necessary to synthesize the existing data concerning AG in end of life and palliative care setting, mostly comprised by families of patients with cancer.

Aim

This review aimed to synthesize research in order to develop further knowledge about the family experience of AG during a patient's end of life. This work was guided by the following

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Table 1. Data Analysis Used in Integrative Review.[a]

Data reduction	The data extracted from primary sources are coded and categorized according a classification system that facilitates systematic comparison of the theme (deductive process), remaining open to other themes not yet captured within classification system (inductive process)
Data display	Disposition of themes in conceptual maps around the variables
Data comparison	Identifying patterns and relationships between topics to identify contrasts, similarities, and intervening factors
Conclusion	Description of evidenced patterns, themes and relationships, conflicting results, and confounding aspects in order to create a new conceptualization of the phenomenon
Verification	Verify findings of this analysis process with primary sources for accuracy

[a] Adapted from Whittemore and Knafl.[15]

Table 2. Quality of Studies Assessment Criteria.[a]

Quantitative Studies Checklist STROBE (adapt.)	Qualitative Studies Critical Appraisal Skills Programme (CASP)
1. Are the objectives and hypotheses well framed and defined?	1. Are the research objectives clearly defined?
2. Is the study design explained and correctly described?	2. Is the qualitative methodology appropriate?
3. Are the criteria and methods of selection of participants well described?	3. Is the study design appropriate to the objectives of the study?
4. Are the variables defined, as well as the instruments of measure?	4. Is the recruitment strategy appropriate to the objectives of the study?
5. Are data collection described, explaining all the moments and methods of application of instruments, allowing the replicability of the study?	5. Were data collected properly according to the objectives of the study?
6. Is data analysis appropriate and a detailed description of the statistical analyses and content done?	6. Is the relationship between the researcher and participants adequately considered?
7. Are the sociodemographic characteristics of participants descripted in detail, including an indication of the numbers and reasons for nonparticipation?	7. Were ethical considerations taken into account?
8. Are data presented on all studied variables, indicating, where applicable, the statistical degree of confidence?	8. Is data analysis sufficiently rigorous?
9. Are the results summarized giving answers to the objectives and hypotheses of the study and are they interpreted based on theory and previous studies?	9. Are the results clearly described?
10. Are the limitations of the study presented taking into account the possible biases and the possible generalization of the results discussed?	10. Is the research relevant?

[a] Each item is scored in a 3-point scale: 2 (*well described*), 1 (*poorly described*), 0 (*absent or not described*), in a total of 20 points.

research question: "What are the nuclear characteristics of family AG in end of life and palliative care setting?"

Method

The integrative review employs strict analysis and synthesis procedures by encoding and systematic comparison of data in order to identify patterns and relationships and to reach a deeper level of conceptualization (Table 1).[15]

The search methods were electronic databases, including Medline, EBSCO, and Web of Knowledge (1990-October 2015) with the following primary descriptors: anticipatory grief, anticipatory mourning, grief pre-death, anticipated death, combined with the terms: caregiver, family, relatives. Simultaneously, a manual search was carried out in relevant journals in palliative care and bereavement (*Palliative Medicine*, *American Journal of Hospice and Palliative Care*, *Death Studies*, *OMEGA—Journal of Death and Dying*, *Psycho-Oncology*). As inclusion criteria, we considered the studies (1) published in English, Portuguese, and Spanish; (2) focused on the family grief experience during patient's end of life; (3) population of adult family and patients; and (4) context of advanced disease and end of life. We excluded the studies (1) whose population is composed of caregivers of people with dementia and HIV/AIDS and (2) not published in scientific journals, opinion articles, review of theoretical concepts, or book reviewing.

The quality assessment of studies was carried out according to specific criteria of suitability for many types of research, methodological rigor, and relevance of the results (Table 2). All studies were carefully read, analyzed for their quality, and summarized in tables (Table 3). The data extracted from each study were coded and grouped into themes according to similarities and differences. The themes were then synthesized into the nuclear characteristics of the experience, contributing to a new conceptualization of this phenomena.

Results

Characteristics of the Studies

The literature search in the databases resulted in 910 articles. Additionally, 13 articles were included by manual search. Based on the titles and abstracts reading, 35 articles were selected; after full-text assessment, 29 articles met the criteria

Table 3. Studies Describing Family Experience of a Terminally Ill Patient and Its Impact.

Author (year), country	Objectives	Participants	Design and Methods	Relevant Findings	Study quality
Clukey[16] (2008), United States	To explore the retrospective perceptions of the anticipatory mourning experience of caregivers who had not received hospice services	Bereaved family caregivers (N = 9)	Qualitative Retrospective Interviews	Anticipatory grief processes: realization, caretaking, presence, finding meaning, and transitioning	13
Clukey[17] (2007), United States	To explore the anticipatory grief experience	Bereaved family caregivers, in hospice (N = 22)	Qualitative Phenomenological Retrospective In-depth interviews	Themes: being present, being in anticipatory grief: be informed, intuitive knowing, awareness is not preparation, death ends this state	15
Gunnarsson and Öhlen[18] (2006), Sweden	To understand the meaning(s) of spouses' grief before the patient's death	Widows whose spouses died in palliative home care (N = 12)	Qualitative Phenomenological Retrospective In-depth interviews	Themes: realizing that the partner would soon die, changed relationship, fear-inducing feelings, focusing on doing the utmost for the partner, trying to live as usual, time slipping away while also standing still	18
Byrne and Raphael[19] (1997), Australia	To investigate the psychological symptoms experienced by the recently widowed men	Widowed men with more than 65 years old (N = 57); Control group: married men (N = 21)	Quantitative Longitudinal Double cohort Three assessment moments: 6 weeks, 6 months, and 13 months after death	Widowers reported more anxiety and general psychological distress but no more depression or loneliness than matched married men over the 13 months postbereavement. Anxiety was correlated with intensity of grief but not with duration of wife's final illness or expectedness of wife's death	16
Barry et al[20] (2002), United States	To evaluate the association between bereaved persons' perceptions of the death and preparedness for the death and psychiatric disorders	Bereaved family members (N = 122)	Quantitative Longitudinal Observational Two evaluation moments: 4 and 9 months after death; Inventory of Complicated Grief—Revised; Clinical Interview *DSM-IV*	Perception of death as more violent was associated with major depressive disorder at baseline. Perception of lack of preparedness for the death was associated with complicated grief at baseline and at follow-up	17
Carr et al[21] (2001), United Sates	To examined whether older adults' psychological adjustment to widowhood varies based on whether the death was sudden or anticipated and whether these effects are mediated by death context characteristics	Widowers (N = 210)	Quantitative Longitudinal Four assessment moments: 6, 18, 42 months. Items to evaluate: depression, anxiety, psychological reactions to grief, warning time prior death, and death context	Forewarning did not affect depression, anger, shock, or overall grief 6 or 18 months after the loss. Prolonged forewarning was associated with elevated anxiety both 6 and 18 months after the death. Sudden spousal death elevated survivors' intrusive thoughts at the 6-month follow-up only	19
Valdimarsdóttir et al[22] (2004), Sweden	To investigate the predictors and long-term consequences of awareness time of impending death	Widows of patients with cancer (N = 379)	Quantitative Retrospective Observational Questionnaire of Awareness time, determinants and consequences. State-trait Anxiety Inventory Center Epidemiological Studies' measure of depression	During a man's terminal cancer illness, the wife's awareness time varies considerably and is influenced by information and psychological support from caregivers. A short awareness time may result in an additional and avoidable psychological trauma	16

(continued)

Table 3. (continued)

Author (year), country	Objectives	Participants	Design and Methods	Relevant Findings	Study quality
Marshall et al[23] (1998), United States	To study the effect of anticipatory grief in postdeath adjustment	Students (551). Two independent groups: anticipated loss (n = 114), unanticipated death (n = 437)	Quantitative Cross-sectional Case control Items to assess: grief symptoms, level of resolution of the death, perceived benefits associated with anticipating the death, religious affiliation, quality of the relationship, time since death, social support, previous losses	The anticipation group reported better postdeath adjustment than the comparison group in grief-related symptoms, acceptance of the death, and perceived helpfulness and harmfulness of anticipation. Within the anticipation group, length of anticipation appeared to have little relationship with postdeath adjustment	18
Penrod et al[24] (2011), United States	To explore nature, course, and duration of caregiving trajectories	Family caregivers in grief (N = 46)	QualitativeRetrospective Case study Interviews	Common theme: search for normality. Death anticipation changes end-of-life experience	10
Saldinger and Cain[25] (2006), United States	To explore the extent to which spouses take advantage of their partner's terminal illness for accommodation to impending death	Widows of patients with cancer (N = 30)	Qualitative Retrospective Interviews	Emphasis is placed on the strains of terminal illness that outweigh the benefits of anticipatory grief and often preclude the undertaking of anticipatory tasks	14
Costello[26] (1999), England	To examine the nature of the spouses' experiences in relation to anticipatory grief	Bereaved partners (N = 12)	Qualitative Retrospective In-depth interviews	Anticipatory grief has a cumulative, rather than a specific, influence on the spouse's bereavement. This experience allows the adaptation to the loss to begin prior to their partner's death	12
Wong and Chan[27] (2007), China	To describe the experiences of family members of terminally ill patients during the end of life in palliative care	Bereaved family members in palliative care (N = 20)	Qualitative Phenomenological Retrospective In-depth interviews	Themes: grief reactions, committed to care, being with the patient at the last moment	15
Beng et al[28] (2013), Malaysia	To explore the experiences of suffering in palliative care informal caregivers	Informal caregivers who were taking care of the adult palliative care (N = 15)	Qualitative, cross-sectional, semistructured interview	Themes: emphatic suffering, anticipatory grief (perceived impeding death and absence of the patient)	16
Costello and Hargreaves[29] (1998), England	To compare anticipatory grief with conventional grief	Daughter of an patient with cancer (N = 1)	Qualitative study case	Themes: anticipatory grief, difficult decisions at end of life, support in the moment of death	3
Spichiger[30] (2009), Switzerland	To explore terminally ill patients' and their caregivers experiences of being in hospital	Family caregivers of patients with cancer (N = 10) hospitalized general hospital	Qualitative, cross-sectional, in-depth interviews	Themes: personal suffering, sense of (not) being integrated in hospital, importance of caring for the patient, consequences of caring for the terminally ill patient	12
Ziemba and Lynch-Sauer[31] (2005), United States	To study emotional reactions of daughters to multiple losses related to caring care of parents	Bereaved daughters who care for the elderly parents (N = 8)	Qualitative, retrospective, semi-structured interviews	Actual and anticipatory losses: loss of the parent, loss of one's own youth	8

(continued)

Table 3. (continued)

Author (year), country	Objectives	Participants	Design and Methods	Relevant Findings	Study quality
Pereira and Dias[32] (2007), Brazil	To explore the grief process of terminal illness in hospital	Family caregivers (N = 5)	Qualitative, cross-sectional, phenomenological, in-depth interviews	Terminal illness causes intense suffer, anguish, and ambivalent feelings between guilt and hope. Feeling support helps the caregiver keeping care for the patient	13
Plakas et al[33] (2009), Greece	To explore the experiences of patients' families in intensive care units	Family caregivers of patients with multiple diagnosis (N = 25)	Qualitative, grounded theory interviews	Themes: intense emotions, vigilant attendance, negative emotions are caused by death anticipation, conceptualized as anticipatory grief	17
Butler et al[34] (2005), United States	To examine pre- and postloss levels of posttraumatic stress symptoms in partners of patients with breast cancer and the relationship of these symptoms to past, current, and anticipatory stressors	Partners of breast cancer (N = 33)	Quantitative, longitudinal, prospective, Impact of Event Scale (IES), Anticipation of Loss Inventory	34% experienced clinically significant symptom levels prior to the patients' deaths. Prior to loss, partners' symptoms were positively associated with their current level of perceived stress and anticipated impact of the loss	15
Pusa et al[35] (2012), Sweden	To illuminate the meanings of relatives' live experience from diagnosis through and after death	Relatives of patients with cancer in grief (N = 11)	Qualitative retrospective phenomenological hermeneutic method; in-depth interviews	Themes: being unbalanced, being unbalanced, being transitional, being cared for, and moving forward	15
Sutherland[36] (2009), Canada	To explore the meaning of being in transition to end-of-life care among female partners	Female spouses of patients with cancer (N = 25)	Qualitative, Cross-sectional, phenomenological, in-depth interviews	Themes: meaning of our lives, dying with cancer, glimpses of the future	13
Chapman and Pepler[37] (1998), Canada	To examine the relationships among general coping style, hope, and anticipatory grief	Family members of patients with cancer (N = 61)	Quantitative, cross-sectional, exploratory, Nondeath Version—Grief Experience Inventory; Lalowiec Coping Scale; Herth Hope Index	Family members experienced individual anticipatory grief patterns. Death anxiety is preponderant. Emotive coping contributed significant variation in anger/hostility, whereas lack of hope accounted for variation in social isolation	18
Spichiger[38] (2008), Switzerland	To explore terminally ill patients' and their caregivers experiences of being in hospital	Family caregivers and patients (N = 10)	Qualitative, cross-sectional, in-depth interviews	Unique life of the persons who deal with terminal illness; experience of being in hospital; commitment and care of family caregivers	12
Gilliland and Fleming[39] (1999), Canada	To compare the degree of similarity between the grief experienced by spouses of terminally ill patients prior to (anticipatory grief) and following the death (conventional grief)	Spouses of terminally ill in palliative care (N = 30); spouses of chronically ill (N = 31); spouses of healthy individuals (N = 32)	Mixed, Longitudinal, correlational with 2 control groups. Two assessment moments: before death; 6 weeks after death; Grief Experience Inventory	These 2 phenomena are statistically similar with regard to the majority of subscales on the Grief Experience Inventory. Furthermore, when compared with conventional grief, anticipatory grief was unexpectedly associated with higher intensities of anger, loss of emotional control, and atypical grief responses	16
Hegge[40] (1991), United States	To study the effects of anticipatory grief in caregiving before and after the death	Widows who care for terminally ill patients with multiple diagnosis (N = 26)	Qualitative, cross-sectional, retrospective interviews	Most frequent problems are the solitude, social isolation, disruption of eating and sleeping patterns, and independent decision. Caregivers' health improved when those responsibilities were over	6

(continued)

Table 3. (continued)

Author (year), country	Objectives	Participants	Design and Methods	Relevant Findings	Study quality
Beery et al[41] (1997), United States	Examined the effects of changes in role function, caregiving tasks, caregiver burden, and gratification on symptoms of depression and traumatic grief	Spouses of terminal ill patients with multiple diagnosis (N = 70)	Quantitative, longitudinal, correlational. Four assessment moments: before death, 3, 6, and 13 months after; Inventory of Traumatic Grief (ITG Pre-death version); Hamilton Rating Scale for Depression (HRSD)	Level of caregiver burden was associated with the respondent's level of depression and traumatic grief. Changes in role function were associated with the caregiver's level of depression but not with the caregiver's level of traumatic grief. The fewer tasks performed for the spouse, the greater severity of depressive symptoms	15
Anngela-Cole and Busch[42] (2011), Hawaii	To compare how family caregivers from a variety of ethnocultural groups emotionally respond to their caregiving role	Family caregivers of patients with cancer admitted in hospice (N = 20)	Qualitative, Cross-sectional, Phenomenological focus group	Different cultural role expectations, coping mechanisms for dealing with stress and grief, and expression of emotion	10
Duke[43] (1998), England	To study the anticipatory grief experience during terminal illness and after the death	Widowers who care for patients in palliative care (N = 4)	Qualitative, Phenomenological, hermeneutic in-depth interviews	Themes: being with the spouse: being a career and a comforter, in suspense; being bereaved: experiencing and gathering memories; being alone; cared and comforted; in a turmoil; at the time of interview: being with other as giving and receiving; integrating memories and experiences and balanced	17
Kerr et al[44] (1994), United States	To explore how meanings of adult daughters attached to their parent's death influence the duration of their grief	Adult daughters (N = 67) who lost a parent	Qualitative, retrospective, semistructured interviews	How respondents experienced a parent's death—including their guilt, regrets, anticipatory grief, shifts in other family relationships, and changes in their lifestyle—influenced the duration of their grief	6

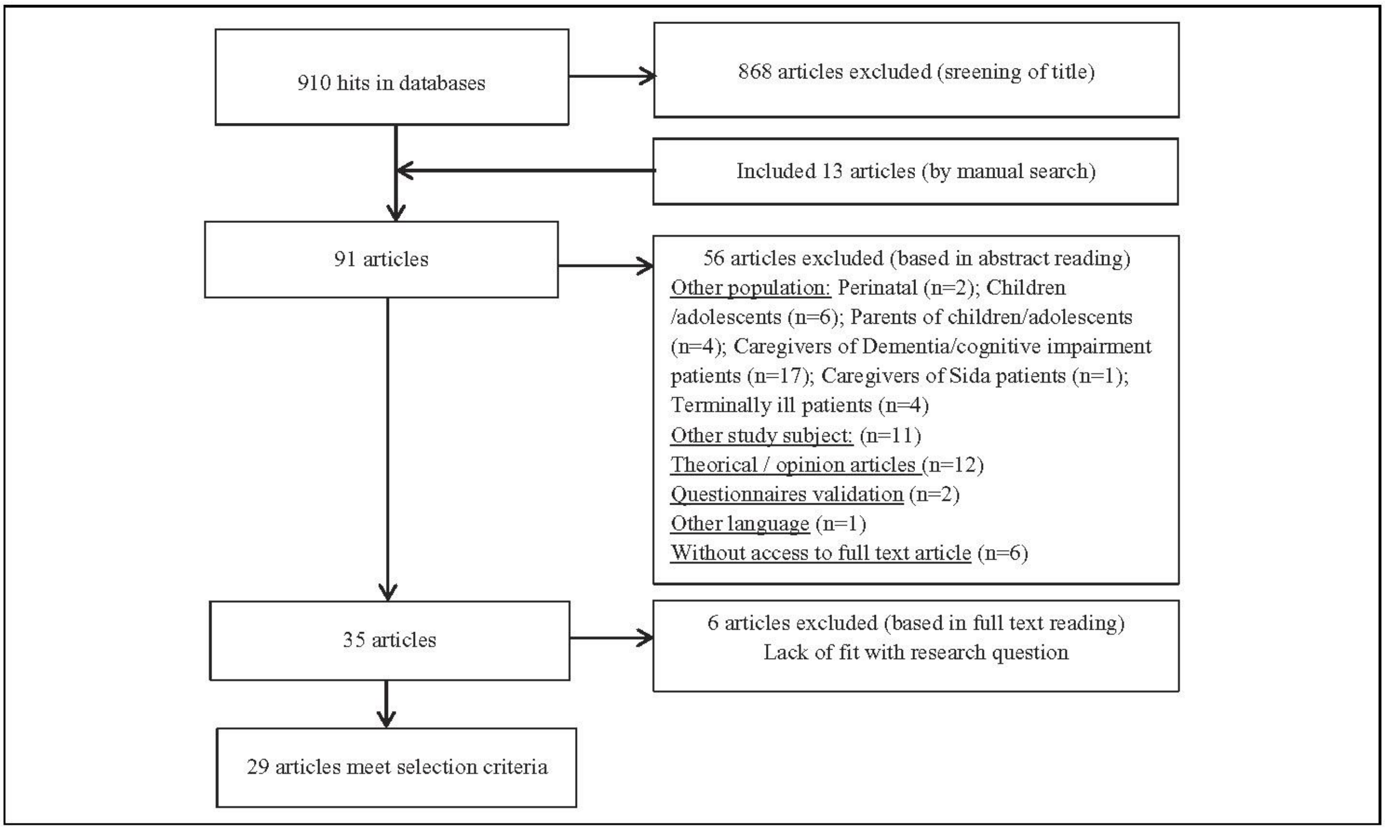

Figure 1. PRISMA flowchart of the literature search process.

previously defined. Details of the studies identification and selection process are shown in the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flowchart (Figure 1).

Twenty studies used qualitative methodology and 8 were quantitative; 1 was mixed. Five quantitative studies used longitudinal design. Study quality was considered reasonable. Samples were mostly composed of caregivers of terminally ill patients with cancer. The majority of studies stem from North America and Europe.

Through the data systematic comparison, 10 major themes around family experience during a patient's end of life were identified, which correspond to AG nuclear characteristics.

Anticipation of Death

Anticipation of death refers to the perception of threat to the life of someone close as a result of an advanced and irreversible disease. In qualitative studies, this concept is described as the recognition of the proximity of death,[16] being informed, or having intuitive feeling of knowing[17] and notice that the patient is dying.[18] Quantitative studies evaluate this variable as equivalent to the degree of predictability and preparation for death[19,20] or by the period of time the death was expected.[21-23]

Anticipation of death represents a transition moment in the onset of AG process,[16,18,24] although it may fluctuate due to uncertainty and hope.[25] Some people refuse to deal with the situation of the terminally illness, and although family caregivers accompany the increasing deterioration of the patient, they remain unbelieving about the diagnosis and never quit investing in the recovery of patients.[26-28] Others recognize the severity of the diagnosis and need to predict how long the patient is going to live, planning and anticipating the death in order to cope with the unpredictability of the path of the disease,[29,30] although often at a cognitive level, only.[25] This means that not always the cognitive recognition of the proximity of death translates into emotional awareness—the person may recognize the family death cognitively and still maintain the fantasy that it can be avoidable. Similarly, emotional awareness does not lead to acceptance of death—those who can gradually deal with its proximity experience resignation and suffering.[28,30] The anticipated perception of death means a threat of loss and therefore represents a main cause of distress during the illness.[25]

Emotional Distress

Anticipation of death introduces disruption at several levels: family members feel that their reality is continually affected by new and disturbing events and the whole world shakes[18,30] and that the relationship with the patient changes, as well as family structure,[16] and soon his whole life will inevitably change.[26] This awareness is usually accompanied by intense emotional reactions. Some families report that this perception is accompanied by a physical sensation, like a punch in the stomach,[17] which illustrates the sense of shock and surprise often reported by relatives.[18,26-28] Terminality, although expected, is generally regarded as too sudden.[25,28] Faced with the imminent loss, people react with separation anxiety[31,25,33] and concerns about the future.[17,18,28,32,34] This state of fear persistent is referred to as ruminative anxiety.[25,28] Several motives were mentioned: uncertainty about the evolution of the disease[25,26,36] and their ability to meet the requests that will arise, particularly in emergency situations;[18,25,28] fear of the patient suffering, that he or she has a painful death[18]; and fear of their own reaction to the death[17] and of this happens at any moment.[28] According to Gunnarsson and Ohlen,[18] when fear dominates, there is no space for the grieving process.

Caregivers also ruminate about feelings of sadness for losing a loved one and for the patient suffering.[17,28,38] Living in the proximity of the patient suffering, caregivers experience feelings of helplessness[18,28,35] and compassion fatigue.[26,28] Therefore, they experience more or less deep feelings of depression, manifested by sadness and apathy.[26,32]

Caregivers also manifest intense feelings of anger[16,32,35,39] directed to the disease or to the sick person because of the sense of abandonment.[40] The feelings of hostility may also be projected to the health professionals, or to other relatives,[29,40] by neglecting the patient.[32] Some people question God, "Why?".[28,38] In other cases, anger may be directed to themselves, expressed through the sense of frustration about their own performance.[35] The anger manifests also in form of guilt by the uncertainty of having taken the right decisions[18] or by the failure to prevent death.[27]

Intrapsychic and Interpersonal Protection

Many families protect themselves from this painful reality by triggering intrapsychic protection mechanisms. Repression of feelings and numbness allow them to anticipate and plan practical aspects without being overwhelmed by emotional burden.[16,25] There is also a tendency to rationalize[32] or to be distracted with the structured routines imposed by caregiving responsibilities.[18,24,26] Others develop a religious belief that everything is decided by God, so they pray and seek protection in a transcendental entity.[28]

Some people cry alone, as a way to relieve tension, but, this expression may be seen as a sign of weakness[32], so it tends to be suppressed, for interpersonal protection, because the whole family is under stress.[25,28] To avoid the emotional burden of the patient,[26,32] the caregiver escapes from talking about death or even referring the word death in conversations.[18,26,38,43] Instead, they continue to talk about common projects for the future[26]

Family keeps the communication closed for several reasons: bringing together the aspects of anticipating death would be an emotionally painful conversation which they feel unable to have[18,27]; an open discussion can symbolically confirm the reality of an impending separation, so the family choose to share common hopes only[25,43]; besides, forewarning death is felt as a disloyalty to the patient. Another argument is the explicit message from the patient that he or she does not want to address the experience of anticipating death. However, in most cases, the closed communication is an unconscious reflection of the survivor's desire to avoid the proximity of death of the significant other. Even this may compromise the intimacy of the relationship, they do it with the conviction that they are providing a good death to the patient.[25,29]

Hope

The presence of the patient allows hope and accentuates the sense of responsibility of the caregiver who is willing to sacrifice everything to keep the patient alive; ultimately, this guarantees that the relative continues absorbing all their attention and becoming the sole focus of thoughts, feelings, and actions.[28]

Chapman and Pepler[37] stress that there is an inverse relationship between hope and signs of AG. However, hope remains in the entire end-of-life trajectory, although it changes along this process. Initially, the family hopes that everything returns to normal and that the patient's suffering ceases and life will no longer be the chaos that it is now; hopes that the patient continues to fight and stays healthy; that he or she remains independent and experiences more moments of joy; that he or she lives longer if the family is happy and remains a positive environment[28]; and that the patient shows everyone they are wrong and will be able to recover.[26] Some families reported that sustained hope of recovery is not to create false expectations—it is, rather, a way of supporting the current situation, even though death is the most likely outcome.[17,36] Others lose hope before the signs of death: when the patient stops eating, talking, and responding.[28] But, gradually, the family's hope starts to focus on other aspects: that the patient dies peacefully[18] or that he or she feels they played their role of caregivers well, achieving relief from suffering. Hope also focuses on aspects of the relationship—that the patient becomes aware of how important he or she is and how he or she was loved by them and that he or she knows how his or her presence will be missed and, at the time of death, he or she heard the words of affection and reassurance.[17]

Exclusive Focus on the Patient Care

There is a compulsion to help, due to the perception of the patient's suffering, which is experienced both as a duty and as a will.[18,28,38] Facing end of life, family value more the time spent with the patient, and they want to learn how to care.[16,17,27] This task is assumed with the purpose of being present[16,17] and to compensate for the weaknesses of the illness, relieving the suffering.[35,38] But it is also as a way to mitigate their own sense of powerlessness[35] by feeling that they did their best and they are a good family.[32] The assistance to the patient may imply providing support only in some activities or remaining constantly beside the patient, ensuring comfort, companionship, and emotional support.[16,28,38] Many families claim the need to be physically present to ensure the touch and communication with the patient and that all his or her wishes are met.[17,38]

Personal Losses

Although the motivations to care bring them a strength that many of the relatives were unaware of,[18] it is inevitable that the family is affected by the increasing caregiver burden, especially by work overload[16-18,28,40] and sleep deprivation[18,28] due to permanent hypervigilance.[32] However, the perception of burden is a subjective response to the act of caring, so it is not directly related to the amount of tasks in the provision of patient care. In fact, the amount of tasks is inversely correlated with the level of depression, which means that the family benefits from some sort of routine and structure in care.[41]

Restrictions on personal autonomy of the family are another consequence of the exclusive focus on the patient. The caregivers' need to adapt their life to the demands of presence and caring[17] results in the limited sense of freedom and suppression of personal needs.[16,18,27,28,30,38] Therefore, caregivers refer to this period as a time of waiting, during which they only survive, without space or interest for their previous activities or social contacts, with the feeling that the world has become monotonous and restricted, and the future was postponed indefinitely.[16,18,28,30,38,42]

Relational Losses

But before confronting the real loss of the patient, the family realizes the relational losses resulting from physical and emotional degradation. The feeling of absence starts at the moment that family is forced to play the role of the patient.[28] Assuming the tasks that the patient used to perform confronts caregivers with the patient's current disability,[25,36] making them more aware of the proximity of death. Gradually, they recognize that he or she is not the same person and feel the absence, although the patient is still alive. The family especially feels the loss of intimacy and reciprocity in the relationship.[28,35] Here begins a deep sense of loneliness[18,25,28,37] which is even more intense when the patient stops talking and responding, setting the end of the relationship.[25,28,35]

Ambivalence

Thinking about death while the person is still present raises several dilemmas that cause intense ambivalence: caregivers should keep their ability to function in a combative way against the disease and simultaneously handle the tasks of end of life[25,35]; it is also expected to take care to preserve the dignity of the sick person and, at the same time, grieve the loss of his or her personality[36]; relatives must respect the autonomy of the patient while questioning the patient's ability to decide what is best for the situation[35]; one has to choose between the sense of loyalty to the patient, keeping exclusive devotion to him or her or, at the other hand, to seek support in order to ease the burden, in spite of the guilt that it carries.[26,35] The caregiver must also face the decision regarding the place of death: although hospitalization may represent a relief from overload, they worry about maintaining contact and fear that a sudden worsening prevents them from seeing the patient. All these conflict situations cause stress to the caregiver, since they add blame for not being certain about the right decision.[18] The exception is the coexistence of feelings of joy and sadness, emerging from the positive aspects of care at end of life, mainly related to the presence and the ability to communicate with the patient.[35]

End-of-Life Relational Tasks

In most cases, the increased physical proximity inherent to caregiving also corresponds to an emotional closeness.[35] Some families experience remorse for not having spent more time with the patient in the past; therefore, they reinforce the dedication and feel the need to intensify the relationship with the person who is dying,[17] completing end-of-life relational tasks such as reviewing life events, talking and sharing with the patient significant experiences,[16-18] and solving previous problems.[17,18,44]

This is also the moment the family perspectives the future absence of the patient. Some have great difficulty to foresee the future; others anticipate loneliness, sadness, and emptiness in later life. Some of them worry for not knowing what to do, since they were accustomed to share decisions with the patient. They are grieving the loss of a common future, plans that have been established, and the expectation of been cared by the patient in the future. In the case of spouses, they do not imagine to get out of home because of loneliness but also do not think of rebuilding a new family and intend to visit the cemetery every day.[28,30]

Often, it is the patient who conveys information and instructs the survivor about tasks that he or she has never realized.[18] The patient may also leave the legacy and express desires, including in relation to the funeral or economic aspects.[43] These manifestations are valued and the family strives to meet them.[17]

Still, they all maintain some degree of avoidance to protect themselves from the emotional pain of these moments of farewell.[43] In some cases, planning the practical things is the only task that family members can carry out, and yet these plans are performed in hypothetical thinking: "If it happens ...." For others, the symbolic meaning of planning the practical aspects is enough to prevent them from realizing these end-of-life plans. Saldinger and Cain[25] note that it is the exclusive focus on caring for the patient and the denial of impending death that allow the caregiver to continue to function. But, often the caregiver burden is impeditive of anticipating death and realizing the end-of-life relational tasks. Therefore, the authors reiterate their position that, for many people, the anticipation of death is more a stress factor than an opportunity.

Transition

After an emotional intense period of care, many people perceive that death has ended the patient's suffering and their own burden and feel relieved.[17,26,27] Even those who continued to believe in possibility of patient's healing are able, at death, to abdicate the role of caregiver and let him go.[29] Some can actually say goodbye to the patient before death.[17,18] However, for other family members, the sense of tranquillity and the intention to continue is not present. Some people reported that the pain of grief has never before been as intense as at the time of death[17] and that despite the relief they feel, it does not lessen the pain of loss.[17,26]

Results Summary

Based on the preceding analysis, conceptual definition of AG was synthesized as follows: family distressing process of anticipation the patient's loss and transition to a different reality, in the absence of the significant other, characterized by ambivalence between 2 main dimensions: on the one hand, the recognition of death proximity due to current personal and relational losses; on the other hand, the mutual protection from this painful reality and sustaining hope in order to keep functioning and caring for the ill person.

Discussion of Results

This integrative review intended to reach a deeper level of conceptualization of AG by identifying the nuclear characteristics of the phenomenon and contributing to its definition. Since the concept of AG is operationally vague, it is essential to use the qualitative methodology, from which categories of analysis empirically based emerge, illuminating the subjective experiences and the meanings attributed by the participants themselves, rather than exclusively using the standardized instruments that mainly reflect the researcher's framework.

From systematic comparison of data referring to family end-of-life experience emerged 10 themes, which correspond to the AG nuclear characteristics. These results lead to a conceptual definition that encompasses the mutual relationships between nuclear characteristics and highlights the multidimensional and dynamic nature of this process.

Despite of reservations concerning AG concept, we consider it reflects the anticipation of death, which is probably the aspect that better distinguishes AG from other forms of grief process, namely, the "bereavement," where the loss has already occurred and "indefinite loss," characterized by the experiences of carers outside of the terminal stage, where the future loss of the patient remains uncertain.[45] Yet, AG is not restricted to anticipation of death. As suggested by Fulton,[10] forewarning of loss cannot be equivalent to AG. Indeed, this may have been a confounding factor, responsible for contradictory data referring the patients. The AG process is strongly influenced by sociocultural representations of death and dying that states an attitude of avoidance toward this reality.[46] In modern occidental society, family members tend to protect each other from the emotional distress related to the pain of loss. This leads to ambivalence, another nuclear characteristic of this process. Aldrich[7] stated that ambivalent feelings are harder to solve while the patient is still alive and particularly vulnerable, so the denial is more likely to persist during the anticipation period.

Finally, this conceptualization of AG introduces personal and relational losses to reflect the disruption this experience represents in caregiver's life. This aspect is equivalent to past, present, and future losses in Rando's definition.[8] However, instead of focusing in course of time, we emphasize relational losses as the specific characteristic of AG: the loss of the relationship with the significant other, while he or she is physically present.

Limitations

Although most samples were composed mostly by family of patients with cancer, there is some heterogeneity that can influence dispersion of reactions. Caution is also warrant concerning retrospective studies on AG experience. Another restriction is related to the cultural context of these studies, so it does not allow generalization of this conceptualization. Finally, because of focus of this review, selected studies were mainly centered in internal experience of family caregiver AG, so the systemic issues related to family relationship were not included, which could potentially add clarity to the findings around interpersonal aspects of this phenomenon.

Conclusions

This literature review serves the purpose of clarifying the conceptual issues about AG. Selected population was the family caregivers in context of advanced disease and end of life, most of them with oncologic disease in occidental culture. Findings were grouped in 10 themes, which correspond to AG nuclear characteristics. Analysis of results confirms that this is multidimensional and a dynamic process. The heuristic value of this concept concerns to its clinical implications, considering that a better understanding of this phenomenon will promote a more sensitive intervention. Particular attention should be paid to increase awareness about ambivalent feelings, normalizing these reactions in order to reduce caregiver's guilt and to promote family communication.

Future research should also focus on studying relationship between AG mediators and its influence in bereavement. Another topic of interest refers to the relationship between AG experience and decision-making regarding end-of-life care.

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Portuguese validation of the Prolonged Grief Disorder Questionnaire–Predeath (PG–12): Psychometric properties and correlates

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ABSTRACT

Objective: This study aimed to contribute to the validation of the Portuguese version of the Prolonged Grief Disorder Questionnaire–Predeath (PG–12), examining its psychometric properties, including factorial, discriminant, and predictive validity. The prevalence of predeath prolonged grief disorder (PGD) and its psychosocial correlates were also analyzed.

Method: The PG–12 was assessed in a sample of family caregivers (FCs) of oncological patients in palliative care. The factorial and discriminant validity of the PG–12 were evaluated by confirmatory factor analysis. The prevalence of predeath PGD was calculated and correlated with sociodemographic characteristics, perception of illness, intensity of care, coping, and caregiver burden. Prospective data were used to assess predictive validity.

Results: The sample was composed of 94 FCs, mostly female (78.8%) and daughters (61.3%), with a mean age of 52.02 (*SD* = 12.87). The PG–12 has been shown to be reliable, to have high internal consistency, to be monofactorial in structure, and to be independent from depression, anxiety, and burden, although predeath grief influences these symptoms. In our sample, 33% met the criteria for predeath PGD. The circumstances and coping mechanisms are also correlated with predeath grief. The PG–12 has also been shown to be predictive of postdeath outcome.

Significance of results: The PG–12 can be a useful screening tool for early identification of risk for maladjustment to loss among family caregivers.

KEYWORDS: Predeath grief, Prolonged grief disorder, Confirmatory factor analysis, Discriminatory validity, Predictive validity

INTRODUCTION

Caregiving in the context of a serious illness represents a great demand on family members. In addition to the stresses and strain that stem from the role of caregiver, family members are exposed to a patient's deterioration and to multiple other losses (Bevans & Sterberg, 2012; Li et al., 2013; Adelman et al., 2014; Revenson et al., 2016). Family caregivers (FCs) experience personal losses due to restrictions of autonomy and suppression of their own needs, as well as relational losses, including deprivation of intimacy and reciprocity with the patient, causing intense feelings of grief while the relative is still physically present (Coelho & Barbosa, 2016). Grief during caregiving has been operationalized as "anticipatory grief" (Aldrich, 1974; Lindemann, 1944; Rando, 1986; 1988), but recent research predominantly utilizes the terms "predeath" or "preloss grief," because it merely indicates the presence of grief symptoms before a patient's death (Nielsen et al., 2016).

Researchers studying caregivers' grief have employed the PGD–12 as a valid screening tool for assessing predeath grief. It is basically an adaptation

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of the Prolonged Grief Disorder Questionnaire (PG–13) created to assess grief experiences associated with illness, rather than just to the death of a person (Prigerson et al., 2008). The PGD–12 is an instrument employed to diagnose prolonged grief disorder (PGD), which requires the following criteria: (1) the event—the respondent is experiencing the severe illness or the loss of a significant other; (2) separation distress—characterized by manifestations of longing and yearning; (3) emotional, cognitive, and behavioural symptoms—including avoidance of reminders, diminished sense of self, feeling stunned or shocked by the patient's illness, having trouble accepting it, and experiencing bitterness, numbness, and a sense of meaningless; and (4) impaired social and occupational functioning. With the PG–13, there is an additional temporal criterion that requires six months of persistent grief symptoms after the loss of the family member (Prigerson et al., 2009).

The symptomatology associated with PGD is distinguishable from manifestations of normal grief (Boelen & van den Bout, 2008; Dillen et al., 2008), and only the former is associated with significant impairment (Latham & Prigerson, 2004; Simon et al., 2007; Marques et al., 2013). The trajectory and risk factors of PGD symptoms differ from those of other psychiatric conditions, for both the bereaved (Ogrodniczuk et al., 2003; Boelen & van den Bout, 2008) and their caregivers (Kiely et al., 2008; Chiambretto et al., 2010; Guarnerio et al., 2012).

Most studies that have employed the PG–12 to investigate predeath grief have been carried out in populations of FCs whose patients are in a vegetative state. Guarnerio et al. (2012) assessed 40 caregivers of patients in a vegetative state or who were minimally conscious, and observed that, although significant correlations emerged among the symptom domains of PGD, depression, and posttraumatic stress disorder, from a categorical perspective, no relevant association was found, so that they should be considered as independent nosological entities. Chiambretto et al. (2010) also distinguished caregivers' grief from depression: in a sample of 45 family members of patients in a vegetative state, 20% met the criteria for PGD only and total prevalence was 35.5%. In a similar sample, the prevalence of PGD reached 38.5%, and it did not change over time, suggesting that this is a stable condition, unlike other caregiver distress indicators (Bastianelli et al., 2014).

The data concerning FCs of patients in a vegetative state suggest that young age family members and patients is associated with a higher risk of PGD (Chiambretto et al., 2010). Other studies using the PG–12 assessed caregivers' coping strategies associated with preloss grief in a sample of caregivers of patients with disorders of consciousness, and found that acceptance is highly protective of PGD, while denial and self-blame are associated with an increased incidence of PGD (de la Morena & Cruzado, 2013). Cipolletta et al. (2014) found that highly stressed caregivers, including those with PGD, more often employ avoidance strategies.

Kiely et al. (2008) evaluated 315 healthcare proxies of nursing home residents with advanced dementia. Their results corroborated the fact that predeath grief symptoms are associated with, but distinct from, those of depression. Separation distress was the most frequently cited grief symptom. Higher levels of predeath grief were registered in individuals whose primary language was not English, who lived with the resident before institutionalization, had more depressive symptoms, were less satisfied with their care, and were older than their resident relative.

A comparative study between the PG–12 and the Marwit–Meuser Caregiver Grief Inventory–Short Form (MM–CGI; Marwit & Meuser, 2005), another self-report measure of predeath grief, one designed specifically for use with dementia caregivers, verified that both of these measures can be utilized reliably with such caregivers. The study also verified the convergent validity of each measure. A significantly smaller proportion of caregivers met the diagnostic criteria for PGD: 7% with the PG–12 compared to 27% with the MM–CGI, which has less rigorous scoring criteria (Mulligan, 2011).

In the palliative care context, the PG–12 was administered to 301 FCs, 15% of whom met the criteria for PGD. Caregivers who had a probable anxiety and/or depressive disorder also reported higher levels of preloss grief than caregivers without signs of these disorders. Lack of family support, greater dependency, and greater impact of caregiving on health were found to be related to preloss grief (Hudson et al., 2011). Prospective data ascertained that PG symptoms at predeath constituted a strong predictor of PGD symptoms at both 6 and 13 months postdeath, which demonstrates the predictive value of the PG–12 in terms of bereavement outcomes, in accordance with the findings of Thomas et al. (2014).

Previous studies have provided evidence supporting the discriminant validity of the PG–12. It has also demonstrated good internal consistency, with values of Cronbach's α of 0.88 in a sample of 45 FCs of patients in a vegetative state (Chiambretto et al., 2008), 0.87 in a sample of 202 dementia FCs (Mulligan, 2011), and 0.78 in a sample of 39 cancer FCs (Prigerson & Maciejewski, 2008). Studies have also consistently shown the scale to be monofactorial in nature (Chiambretto et al., 2008; Mulligan, 2011). Other versions of the instrument varying in length from 4 to 19 items have been used in different samples of caregivers (Tomarken et al., 2008; Prigerson et al., 2003; van Doorn et al., 1998; Beery et al., 1997) and patients (Jacobsen et al., 2010).

Early detection of PGD avoids pathologization of normal manifestations of predeath grief and promotes recognition of those caregivers who might present greater vulnerability when adjusting to loss. The aims of our study were as follows: (1) to translate, adapt, and contribute to the Portuguese version of the PG–12, examining its confirmatory factor validation, reliability, and discriminant and predictive validity; (2) to determine the prevalence of PGD in a population of family caregivers for oncological patients in palliative care; and (3) to identify the psychosocial factors that contribute to predeath PGD (e.g., sociodemographic characteristics, perception of illness, intensity of care, coping, and caregiver burden).

METHODS

Participants

The sample, selected by convenience, was composed of FCs for cancer patients followed on the palliative care unit of the Santa Maria Hospital in Lisbon, Portugal. We considered "family caregivers" to include family members, friends, and others with a significant nonprofessional or unpaid relationships with the patient. Those who were excluded from the study were: (1) under the age of 18 years; (2) had cognitive impairment or a physical/mental disorder that hampered their ability to respond to the instruments; and (3) did not speak Portuguese. Participants were informed about the purpose of the study, and an informed consent was obtained from each.

Instruments

The PG–12 is a 12-item self-report questionnaire for the diagnosis of preloss PGD. Respondents are asked to rate on a 5-point Likert-type scale (1 = almost never, 5 = always) how often they have experienced distressing grief symptoms. A diagnosis of PGD requires the following: (1) a score of 4 or 5 on either item 1 or 2, indicating that separation distress is present at least daily; (2) a score of 4 or 5 on at least five of items 3–11, indicating that cognitive, emotional, and behavioural symptoms are present daily, quite often, or overwhelmingly so. The last item is dichotomous. Respondents must answer "yes" to meet the impairment criterion. Examples of items include: "In the past month, how often have you had intense feelings of emotional pain, sorrow, or pangs of grief related to [the patient's] illness?" and "Do you feel that life is unfulfilling, empty, or meaningless since [the patient's] illness?"

The PG–13 is a 13-item self-report questionnaire used to diagnose postloss PGD. It is equivalent to the PG–12, but it includes an additional item, also dichotomous, in which respondents have to answer "yes" to meet the timeframe criteria. This instrument was validated for a Portuguese population by Delalibera and colleagues (2011), and its internal consistency was considered to be very good ($\alpha = 0.932$).

Symptoms of depression and anxiety were evaluated by the depression (six items) and anxiety (six items) subscales of the Brief Psychopathological Symptom Inventory (BSI; Derogatis & Melisaratos, 1983), validated for a Portuguese population by Canavarro (1999). Items were rated on a 5-point Likert-type scale (0 = almost never, 4 = always). According to Portuguese normative values, the cutoff point for the depression subscale was set at 0.89 and for the anxiety subscale at 0.94.

Caregiver burden was assessed by the Zarit Burden Interview, which was validated for a Portuguese population by Ferreira et al. (2010). It contains 22 items, with scores ranging from 0 (never) to 4 (always). According to Portuguese normative values, its cutoff point was set at 17.

Coping mechanisms were evaluated by the Brief COPE (Carver, 1997), which was adapted for Portuguese by Ribeiro and Rodrigues (2004). It includes 28 items, ranging from "I have not been doing this at all" to "I have been doing this a lot," and it is scored from 1 to 4. Scores are averaged in pairs to produce 14 coping dimensions.

A questionnaire was employed to gather a sociodemographic characterization of the participants. Data concerning perception of illness and intensity of care (length and amount of hours of daily caregiving) were evaluated through structured questions on a 5-point Likert-type scale, for example: "Were you expecting this diagnosis?" (1 = not at all, 5 = totally); "How much time do you daily spend caring for your relative?" (1 = less than 2 hours, 5 = more than 16 hours).

Procedure

The process of translation, adaptation, and validation of the PG–12 in a Portuguese population occurred according to the phases stipulated by Beaton and coworkers (2000). We first asked the author for permission to perform the study. Two independent translations of the scale into Portuguese were then made by bilingual translators. The translations were based on the validated version of the PG–13. A consensual synthesis of these versions was then constructed. This was back-translated into the original language by an independent translator to make sure that the translated version reflected the same

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item content as the original. A committee of psychologists reviewed all the translations and reached a consensus, so as to guarantee semantic, idiomatic, experiential, and conceptual equivalence. The final version was then subjected to a pretest with 10 FCs to verify the comprehensibility of its items and to search for difficulties related to interpretation of questions. Some adjustments were made based on respondents' comments, and this resulted in the final version of the PG–12.

Family caregivers who had assisted with palliative care from March of 2104 to June of 2016 were contacted and invited to participate in our study. Those who agreed to participate responded to the PG–12, to the depression and anxiety subscales, and to a demographics questionnaire. They could choose to fill out the questionnaires on paper (immediately in the office, on the phone, take it home and return it by hand or mail) or electronically (via an online questionnaire). A second round of assessments was conducted in order to verify the predictive validity of the PG–12. We contacted the participants at least six months after the patient's death to administer the PG–13, as well as the depression, anxiety, and somatization subscales. Those who agreed to participate answered the questionnaires by phone, by mail, or electronically. Individuals who manifested a need for psychological support were referred for bereavement consultation.

Our study was approved by the ethics committee of the Santa Maria Hospital (reference No. 344/14).

Data Analysis

Descriptive data were analyzed using SPSS statistical software (v. 22.0), and the factorial validity of the PG–12 was evaluated by confirmatory factor analysis (CFA) with AMOS (Analysis of Moment Structures) software.

Descriptive statistics (frequency and percentages) were utilized for sociodemographic characterization of the sample. Means and standard deviations were calculated for each item. The psychometric sensitivity of the PG–12 was evaluated through the measures of central tendency and form, and the normality of variables through the asymmetry coefficients (*sk*), kurtosis (Kurt), and the respective standard error (*SE*). The values of *sk* are considered suitable when <3 and those of Kurt when <7 (Maroco, 2010). Item 12 was excluded from this analysis since it is variable.

Several fit indices were selected in order to test which CFA model best represented the present dataset: root-mean-squared error of approximation (*RMSEA*), which is a measure of the average of the residual variance and covariance; the comparative fit index (*CFI*), chi-square (χ^2), and change in chi-square ($\Delta\chi^2_{\mathrm{df}}$), given the change in degrees of freedom between models. According to Maroco (2010), the adequacy of a model ratio is considered satisfactory when $RMSEA < 0.10$, $\Delta\chi^2_{\mathrm{df}} < 3$, and $CFI > 0.90$. CFA was also employed to test divergent validity between the PG–12 and the BSI depression and anxiety subscales. We also assessed the influence of the PG–12 on BSI items using regression analysis.

Internal consistency was assessed via Cronbach's α. This index was employed to measure the internal consistency of a scale or to establish whether the magnitude of the items of an apparatus were correlated with each other. Values of alpha between 0.80 and 0.90 are generally preferred (Streiner, 2003).

Predictive validity was tested with correlations and simple linear regressions between the PG–12 and the follow-up variables: the PG–13, and the BSI depression, anxiety, and somatization subscales.

RESULTS

Descriptive Analysis

Our sample included 94 FCs of oncological patients. As shown in Table 1, most were female (78.8%), the daughter (61.3%) of the patient, and married (79.9%), with a mean age of 52.02 (*SD* = 12.87), who had completed high school (57.9%).

Table 1. *Sociodemographic characterization*

	Participants ($N = 94$)
Age, mean (*SD*)	52.02 (*DP* = 18.87)
Amplitude	18–79
Gender, *n* (%)	
Male	20 (21.3)
Female	74 (78.8)
Marital status, *n* (%)	
Single	13 (13.8)
Married	75 (79.9)
Widow	1 (1,1)
Divorced	5 (5.3)
Level of education, *n* (%)	
Elementary school	8 (8.4)
6th grade	5 (5.3)
9th grade	13 (13.8)
12th grade	27 (27.7)
Technical school	7 (7.4)
Graduation	25 (26.6)
Master's	4 (4.3)
Kinship, *n* (%)	
Spouse	30 (31.9)
Offspring	57 (60.6)
Parent	2 (2.1)
Sibling	1 (1.1)
Other	3 (3.3)

Table 2. *Amplitude, mean, and interpretability of PG–12 items*

Variable	min	max	mean	*SD*	*sk*	*SE*	Kurt	*SE*
1	2.000	5.000	4.626	0.724	−1.975	0.253	3.246	0.500
2	1.000	5.000	4.285	1.088	−1.441	0.253	1.031	0.500
3	1.000	5.000	1.932	1.498	1.258	0.255	−0.116	0.506
4	1.000	5.000	3.370	1.562	−0.349	0.255	−1.434	0.506
5	1.000	5.000	2.244	1.357	0.649	0.249	−1.010	0.493
6	1.000	5.000	3.351	1.419	−0.555	0.249	−1.072	0.493
7	1.000	5.000	1.670	1.176	1.644	0.249	1.444	0.493
8	1.000	5.000	3.872	1.184	−1.216	0.249	0.755	0.493
9	1.000	5.000	3.000	1.451	−0.086	0.249	−1.354	0.493
10	1.000	5.000	3.223	1.228	−0.368	0.249	−0.851	0.493
11	1.000	5.000	2.712	1.411	0.222	0.249	−1.336	0.493

Some 33% of participants met the criteria for predeath PGD. The mean values for the PG–12 were considered moderate ($M = 34.35, SD = 9.53$, amplitude = 13–56). According to the instrument's cutoff points, levels of caregiver burden were significant in 85.9%, depression symptomatology was present in 67.4%, and anxiety in 62%.

Confirmatory Factor Validation and Internal Consistency Reliability

The normality of the sample was confirmed by the values of asymmetry (*sk*) and kurtosis (Kurt). The highest mean values were obtained on the first two items, corresponding to daily frequency of the symptoms of separation distress (Table 2).

A unidimensional model of the PG–12 was then tested. Goodness of fit revealed poor quality of the original model for most indices, except for $\Delta\chi^2_{\text{df}}$. As depicted in Figure 1, the model was modified by correlating the error of items 1 and 2, 2 and 4, and 9 and 10, and this adjusted model had significantly improved fit indices ($\chi^2(3) = 51.726, p < 0.05$) (Table 3).

The items of the PG–12 demonstrated high internal consistency ($\alpha = 0.846$), and none of the items negatively affected the consistency of the entire scale (Table 4).

Divergent Validity

A confirmatory factor validation was conducted to evaluate whether the PG–12 is conceptually distinct from the depression and anxiety subscales. As shown in Figure 2, a one-factor model was first tested, but it did not fit the data ($\chi^2 = 1.80$, $TLI = 0.746$, $CFI = 0.800$, $RMSEA = 0.092$, parsimonious comparative fit index [$pCFI$] = 0.629). A three-factor model yielded satisfactory indices ($\Delta\chi^2_{\text{df}} = 1.545$, $TLI = 0.822$, $CFI = 0.919$, $RMSEA = 0.77$, $pCFI = 0.674$), confirming that these constructs are indeed distinct (Figure 2). We also tested the influence of the PG–12 on the BSI depression and anxiety subscales using standardized regression weights, and our results indicated that predeath grief is predictive of depression and anxiety (Table 5).

Predictive Validity

To verify the predictive validity of the PG–13, PG–12 data were correlated with the results obtained with the PG–13 and the BSI depression and anxiety subscales in a subsample of family caregivers ($n = 32$), evaluated at least six months after the patient's death. The obtained values were positive and moderate, and the correlations with the PG–13 ($R = 0.62$), depression ($R = 0.559$), and anxiety ($R = 0.45$) were statistically significant.

A simple linear regression was also calculated to evaluate the explained variance of the PG–12 related to the variables assessed at follow-up. The explained variance was 36.3% (adjusted R^2 [aR^2] = 0.363) for postdeath prolonged grief, 30% (a$R^2 = 0.300$) for depression, and 17.9% (a$R^2 = 0.179$) for anxiety.

Correlates of the PG–12

The intensity of manifestations of grief did not vary much according to sociodemographic characteristics, with the exception of gender: females presented significantly higher values than males ($t(80) = 1.941$, $p = 0.05$). The PG–12 was positively and moderately associated with caregiver burden ($r = 0.442$, $p < 0.01$). Using a simple linear regression, the PG–12 explained 18.5% (a$R^2 = 0.185$) of the burden variance, as evaluated by the Zarit Scale.

Acceptance and positive reinterpretation coping mechanisms were found to be negatively associated with the PG–12 ($r = -0.427$, $p < 0.05$; $r = -0.421$, $p < 0.05$, respectively), while denial was positively associated ($r = 0.402$, $p < 0.05$). Concerning the circumstances of the illness, those family caregivers who assessed the physical condition of the patient as bad or very bad exhibited a higher intensity of predeath grief ($t(77) = -0.199, p = 0.05$), as well as those who were not expecting the diagnosis ($t(78) = -2.15$,

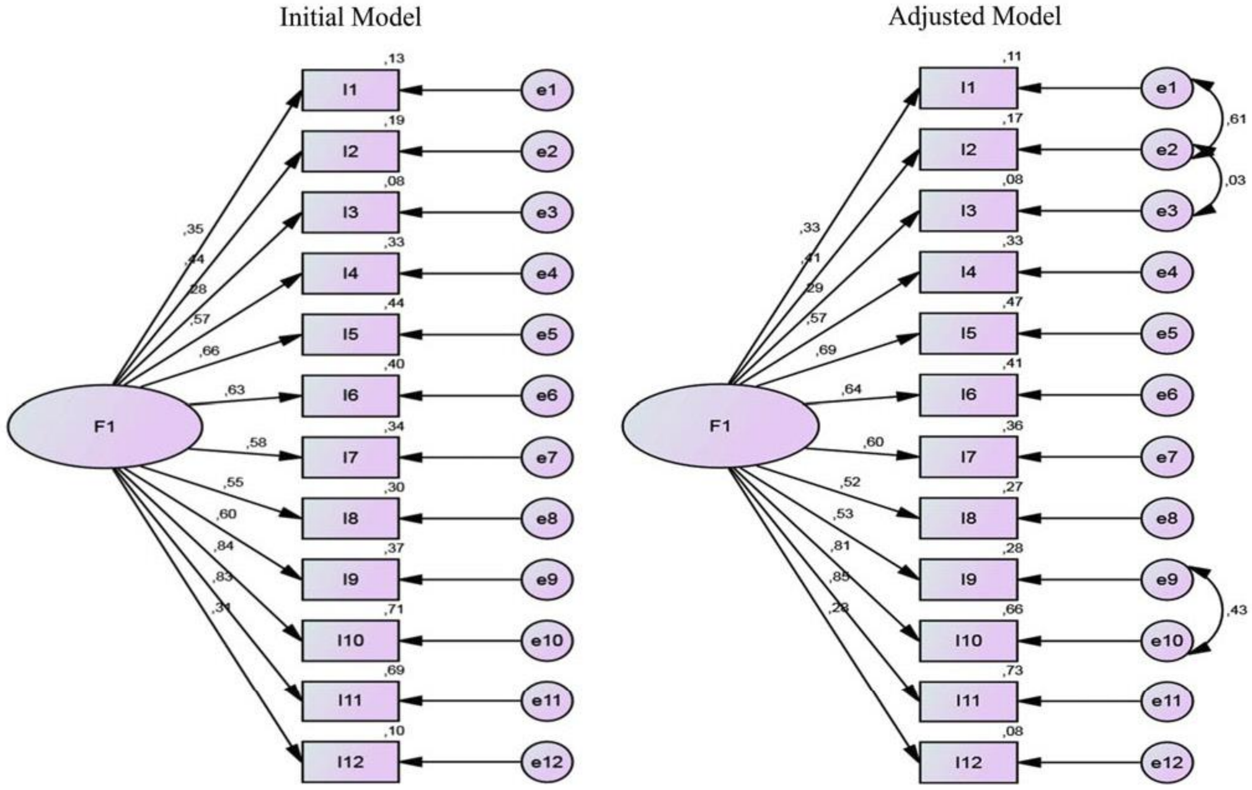

Fig. 1. Confirmatory factor validity of the PG−12.

Table 3. *Fit indices of models*

Indices	Initial model	Adjusted model
χ^2/df	2.330	1.545
CFI	0.748	0.919
TLI	0.637	0.876
RMSEA	0.127	0.070
pCFI	0.518	0.601
MECVI	2.578	2.035

MECVI = modified expected cross-validation index.

$p = 0.03$). Denial was negatively correlated with the degree to which the disease was expected by the caregiver ($r = -448$). The length of caring did not affect manifestations of grief ($t(78) = 0.556$, $p = \text{n.s.}$), but the amount of hours of daily care was associated with higher-intensity grief manifestations ($t(78) = 3.12, p = 0.003$).

DISCUSSION

This Portuguese validation study of the PG−12, carried out with FCs of oncological patients undergoing palliative care, confirmed the high internal consistency of this instrument ($\alpha = 0.846$), as has been accomplished in other populations (Chiambretto et al., 2008; Prigerson & Maciejewski, 2008; Mulligan, 2011). It was not necessary to remove any items to improve the scale's consistency.

According to previous studies (Chiambretto et al., 2008; Mulligan, 2011), CFA evidenced its monofactorial structure. Since the initial model did not yield satisfactory indices, it was necessary to readjust the model. The covariance between items 1 and 2 may reflect the fact that both items are correlated with separation distress. Items 2 and 4 include multiple feelings, which may induce confusion in respondents. Items 9 and 10 refer to numbness and a lack of interest, so they may be correlated.

As evidenced by other authors (e.g., Guarnerio et al., 2012; Chiambretto et al., 2010), predeath grief proved to be distinct from depression, as well as anxiety, though it may influence these symptoms. Another independent but correlated construct is "caregiver burden"). This result is consistent with a previous study among caregivers of patients with dementia (Holley & Mast, 2009). Although the prevalence of prolonged grief disorder (33%) is much less common than caregiver burden (85.9%), depression symptomatology (67,4%), and anxiety (62%), the PG−12 proved to be predictive of postdeath prolonged grief, depression, and anxiety, making it a

Table 4. *Reliability of the PG-12*

Item		Item–total correlation	Cronbach's α if item deleted
1	Longing or yearning for patient	0.475	0.840
2	Intense feelings of emotional pain. sorrow. or pangs of grief related to patient's illness	0.494	0.836
3	Tried to avoid reminders that the patient is ill	0.257	0.856
4	Stunned. shocked. or dazed by patient's illness	0.635	0.824
5	Confusion about role in life or a diminished sense of self	0.549	0.831
6	Trouble accepting patient's illness	0.616	0.826
7	Hard to trust others	0.475	0.837
8	Bitter over patient's illness	0.537	0.832
9	Feel that moving on (e.g., making new friends. pursuing new interests) would be difficult	0.441	0.841
10	Emotionally numb since patient's illness	0.757	0.816
11	Feel that life is unfulfilling, empty, or meaningless since patient's illness	0.749	0.814
12	Significant reduction in social, occupational, or other important areas of functioning	0.250	0.849

reliable and sensitive assessment tool for early identification of family caregivers at risk for maladjustment to loss.

The prevalence rate of predeath PGD is higher than in other palliative family caregivers, and close to the percentage verified in FCs of patients in a vegetative state (38.5% in Bastianelli et al., 2014). This result may be explained by the patients' advanced state of disease, their late referral to palliative care, and by the convenience nature of the sample, which means that those who agreed to participate in the study were probably those who felt more affected by the experience of their relative's terminal illness.

Among the manifestations of grief, separation distress reached the highest intensity levels. This

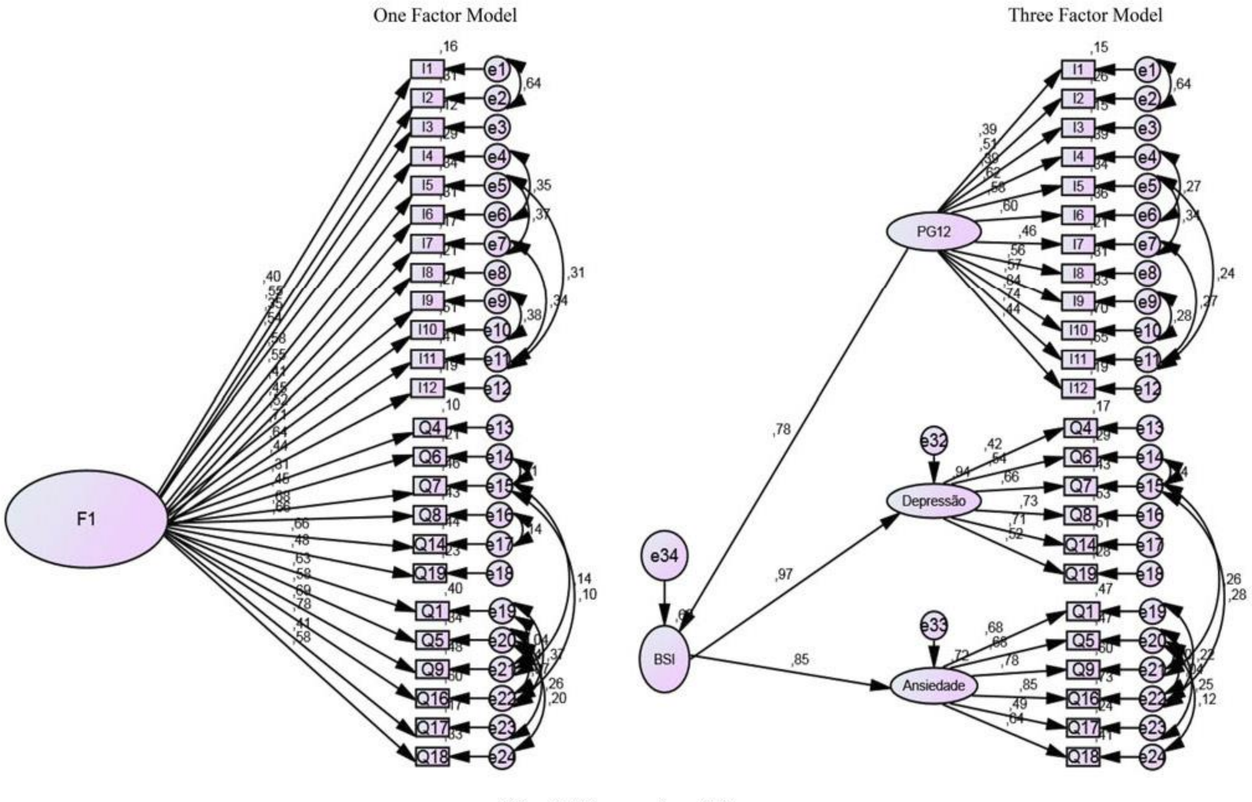

Fig. 2. Divergent validity.

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Table 5. *Regression weights of the PG–12 and the BSI subscales*

PG–12 items	Regression weights
1. Longing or yearning for patient	0.393
2. Intense feelings of emotional pain and sorrow or pangs of grief related to patient's illness	0.511
3. Tried to avoid reminders that the patient is ill	0.392
4. Stunned, shocked, or dazed by patient's illness	0.622
5. Confusion about role in life or diminished sense of self	0.583
6. Trouble accepting patient's illness	0.604
7. Hard to trust others	0.457
8. Bitter over patient's illness	0.561
9. Feel that moving on (e.g., making new friends, pursuing new interests) would be difficult	0.573
10. Emotionally numb since patient's illness	0.835
11. Feel that life is unfulfilling, empty, or meaningless since patient's illness	0.742
12. Significant reduction in social, occupational, or other important areas of functioning	0.441
BSI depression subscale items	
9. Thoughts about ending your life	0.417
16. Feeling lonely	0.541
17. Feeling blue	0.656
18. Feeling no interest in things	0.729
35. Feeling hopeless about the future	0.714
50. Feelings of worthlessness	0.525
BSI anxiety subscale items	
1. Nervousness or shakiness inside	0.682
12. Suddenly scared for no reason	0.682
19. Feeling fearful	0.775
38. Feeling tense or keyed up	0.855
45. Spells of terror or panic	0.489
45. Feeling so restless you couldn't sit still	0.637

symptom has been identified as highly prevalent among patients with complicated grief and to be associated with greater symptom severity postdeath (Gesi et al., 2016). Another qualitative study (Saldinger & Cain, 2005) drew attention to its centrality in predeath grief. Taking account of the imminent physical separation and the relational losses that characterize this experience, separation anxiety can be considered a pivotal dimension of predeath grief, but proving this hypothesis will necessitate further research.

Coping mechanisms were shown to be predictive of predeath PGD, in line with previous studies (de la Morena & Cruzado, 2013; Cipolletta et al., 2014). Acceptance and positive reinterpretation were demonstrated to be protective of predeath grief. As Carver et al. (1989) noted, these mechanisms are most adaptive in situations where the stressor is unchangeable, requiring accommodation. Although this concept is controversial, denial was defined as "the refusal to believe that the stressor exists or of trying to act as though the stressor is not real" (Carver et al., 1989, pp. 270). According to the results of the Yale Bereavement Study—a longitudinal cohort study (Maciejewski et al., 2007)—a high degree of acceptance is the norm in the case of natural death, in contrast to deaths that are traumatic in nature, where higher levels of disbelief and lower levels of acceptance are observed. In our family caregiver population, denial was associated with more intense manifestations of grief. In fact, denial was associated with the perception of not having expected the diagnosis, and those caregivers who did not expect it scored higher on the PG–12. At the same time, a perception of the patient's poor physical condition and greater FC involvement in care also contributed to more intense manifestations of predeath grief. These results may contribute to a better understanding of the traumatic experience of family caregivers. As suggested by Sanderson et al. (2013), recurrent exposure to the distressing sights related to a significant other's vulnerability and dying process is likely to trigger some degree of traumatization.

Our study has limitations related to its small sample size and its convenience nature, which requires some caution when generalizing our results, particularly with respect to its predictive validity, which was calculated in a subsample. Our findings primarily involve middle-aged daughters, so that other family caregivers and contrasts with widows and widowers should be examined. Further research should also investigate the underlying mechanisms of predeath grief in order to address the specific intervention needs for better adjustment during caregiving and bereavement.

CONCLUSIONS

This study provides psychometric testing of the PG–12, a predeath grief scale that evaluates the criteria for PGD, involving pre- and postloss assessments, with a sample of family caregivers for oncological patients in palliative care. The PG–12 has been shown to be reliable, to have a high level of internal consistency, to have a monofactorial structure, and to be predictive of postdeath PGD, depression, and anxiety. The instrument is easy to apply and has been shown to be a useful screening tool for early identification of family caregivers who are at risk for maladjustment to loss.

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CONFLICTS OF INTEREST

The authors hereby state that they have no conflicts of interest to declare.

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Family Caregivers' Anticipatory Grief: A Conceptual Framework for Understanding Its Multiple Challenges

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Abstract

The end-of-life trajectory of cancer patients in palliative care (PC) elicits an anticipatory grief (AG) process in family caregivers (FCs). Although widely recognized, AG lacks conceptual clarification. This study aims to qualitatively explore the experience of FCs of patients with terminal cancer to identify the core characteristics and the specific adaptive challenges related to AG in the context of end-of-life caregiving. Data were collected through in-depth semi-structured interviews conducted in a clinical sample of 26 FCs of cancer patients in PC. Findings from thematic analysis suggest that the AG experience is characterized by traumatic distress from being exposed to life-threatening conditions and the separation distress induced by loss anticipation and current relational losses, challenging the FCs to long-term emotional regulation effort demands. These results contribute to the conceptualization of AG and may inform intervention programs for the main challenges the FCs face when adjusting to loss during end-of-life caregiving.

Keywords

caregivers; palliative care; grief; life-threatening; qualitative thematic analysis; Portugal

Introduction

With the aging of the population, chronic disease care has been transferred to outpatient treatment, involving the family in caregiving tasks that become more complex and demanding as the illness progresses (Aoun, Kristjanson, Currow, & Hudson, 2005; Weitzner, Haley, & Chen, 2000). The family caregiver (FC) definition includes any family member, friend, or partner who maintains a significant relationship with the patient and provides some kind of care (Hudson & Payne, 2009). Given their high level of involvement in caring tasks and their affective proximity to the patient, this population is vulnerable to high levels of distress during caregiving and bereavement (Raschick & Ingersoll-Dayton, 2004; Waldrop, 2007). Distress is commonly defined as prolonged internal suffering that can range from self-focused processing of negative emotions and stressors to an intensely aversive and prolonged processing of emotional states (Brosschot, Verkuil, & Thayer, 2018). In addition to stressors directly related to caregiving and their impact on their personal life (e.g., sleep deprivation), FCs must manage expectations and emotions associated with the fear of losing their significant other, a phenomenon designated as anticipatory grief (AG) (Wittenberg-Lyles et al., 2012).

Caregiver AG stems from the expectations surrounding the relative's death, giving rise to a wide range of manifestations that are socially and culturally associated with grief in response to the loss of a significant other (National Cancer Institute, 2011). Although widely used in research and clinical practice, this concept has been very controversial due to contradictory results concerning its adaptive role in bereavement outcomes. Inconsistencies are attributed mainly to its conceptual uncertainty and to methodological errors in the evaluation of the construct (G. Fulton, Madden, & Minichiello, 1996; R. Fulton, 2003; Reynolds & Botha, 2006). Based on a review of empirical studies, Nielsen, Neergaard, Jensen, Bro, and Guldin (2016) stated that AG is a complex risk factor for prolonged grief disorders, in combination with the

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caregiver's perceived losses during caregiving, their relation to the patient, and the caregiver's attachment style, coping mechanisms, and emotion regulation. This definition recognizes the multidimensionality of the phenomenon, but further research is needed regarding its underlying mechanisms.

In a previous scoping review (Coelho, de Brito, & Barbosa, 2018), we concluded that the anticipation of death at the terminal phase of illness may be the distinctive aspect of AG that encompasses several progressive functional and relational losses in the pre-death grief manifestation continuum. Other aspects, such as separation anxiety and avoidance, were also highlighted as nuclear characteristics of AG. However, most literature is focused on the FCs of patients with dementia (e.g., Blandin & Pepin, 2017; Liew, 2016; Shuter, Beattie, & Edwards, 2014; Sikes & Hall, 2017). Compared with dementia patients, the death trajectory of cancer patients is characterized by a more abrupt functional decline (Teno, Witzen, Fennel & Mor, 2001), which may influence the FC experience. For example, Sanderson et al. (2013) stated that dealing with terminal cancer exposes the caregiver to very shocking images, which can be registered as traumatic memories, resulting in feelings of powerlessness. Therefore, we intend to qualitatively explore the experience of the FCs of patients with terminal cancer to identify the core characteristics and specific adaptive challenges posed by AG in the context of end-of-life caregiving.

Methods

Participant Selection and Study Procedures

Relatives of adult cancer patients accompanied by an outpatient palliative care service were approached by the resident psychologist (the first author) at the first consultation (from October 2015 to October 2016) and were invited to participate in a larger study, involving quantitative and qualitative data. Inclusion criteria were (a) being an adult caregiver (over 18 years old) and (b) being directly involved in the patient care. Those who agreed to participate in an interview gave their informed consent and were recruited to this study. Participants were mostly people with high levels of psychological distress related to the advanced illness, who simultaneously accepted a psychology consultation, so we consider that this is a clinical sample.

The interviews took place in the palliative care unit and were scheduled according to the availability of the participants; they were conducted by a trained psychologist with experience interviewing the bereaved population in clinical practice and for research purposes. For ethical reasons, taking into account the sensitive nature of the theme, the interviews were conducted individually, with full respect to the subjects' emotional state, specific concerns, and personal rhythm. The interviews were transcribed verbatim in Portuguese. This research was approved by the Ethical Committee of the Hospital.

Data Collection

Data were collected through in-depth semi-structured interviews over a period of 12 months. The average duration of interviews was 60 min (range: 35–120 min). The interview script included the following main topics: (a) perceived experience and circumstances of caregiving (e.g., "How has your experience been as a caregiver for your relative?," "What, in your opinion, has been the most difficult aspect?," and "How do you handle it?"); (b) perceived evolution of the disease (e.g., "How do you see the current state of your family member's illness?" and "What do you think might happen next?"); (c) perceived changes in the caregiver's personal life and in the relationship with the patient (e.g., "How has this illness changed your life?" and "What changes do you notice in your relationship with your relative?"). Initial answers were probed for more details (e.g., "Can you tell me more about this?" and "Could you give me an example?"). Particularly difficult issues, such as the proximity of death, were not directly questioned unless they were introduced by the participant. In these cases, the interviewer asked about the emotional impact of this experience (e.g., "How do you feel about the death of your relative?").

Data Analysis

Analysis of the interviews was conducted by one coder and two consultants.[1] According to suggestions from Levitt (2015), the interviewer is the researcher, who has a closer connection to the data and is able to recognize other meanings that may be hidden when only transcripts are used, thus allowing an analysis that is highly consistent with the participants' experiences. A qualitative thematic analysis was conducted to capture recurrent patterns (themes) and implicit meanings using mixed inductive (i.e., derived from the data) and deductive generated coding (i.e., theoretical-based constructs). The process was guided by guidelines from Braun and Clarke (2006) that include the following six steps: (a) familiarization with the data: repeated readings of the interviews, searching for meanings, and noting initial ideas; (b) generation of initial coding: systematically coding interesting features of the data (semantic or latent content); (c) searching for themes: gathering codes into a hierarchical category system and then looking for potential themes, a higher level concept; (d) reviewing themes: checking the coherence of the pattern at the level of the coded data extracts and, then, in the entire data set; (e) defining and naming the themes: identifying the specificity of each theme; and (f) producing the report: beyond description, this implies interpreting the data and making an argument in relation to the research question. Data saturation was achieved when new data were no longer attained. To establish validity, the coder and the two consultants analyzed the data openly and discussed and resolved inconsistencies. Qualitative data analysis was assisted by the computer software NVivo 12.

Results

Participant Characterization

The sample was composed of 26 participants, mostly female ($n = 23$), aged 27 to 78 (median: 55.5), and the majority were adult children ($n = 14$) or spouses ($n = 10$); the remaining participants were a parent and an aunt. The levels of education among the participants were 4 years ($n = 1$), 6 years ($n = 4$), 9 years ($n = 5$), secondary (9), and graduate (6). Over half of the participants ($n = 14$) cohabited with the patient at the time of the interview.

Findings

During thematic analysis, references were coded and organized into three main themes: (a) *Traumatic distress*, (b) *Separation distress*, and (c) *Emotional regulation and dysregulation*. A summary of the main themes and categories, along with the frequency of cases, is displayed in Table 1. Subcategory frequency is presented in brackets throughout the findings section. Next, themes are described in terms of commonalities and variances. Commonalities include the circumstances and/or manifestations described by most participants. Variances represent the range of individual responses to stress. Participant quotes are used to illustrate the meaning attributed by the FC. However, some results emerged through implicit meanings and, thus, are difficult to capture by a single reference.

Table 1. Main Categories and Cases Frequency.

Themes and Categories	Frequency ($n = 26$)
Traumatic distress	
Uncertainty of illness	21
Image of degradation	20
Caregiving impotence	24
Vicarious suffering	18
Life disruption	25
Separation distress	
Death anticipation	22
Relational losses	16
Separation anxiety	6
Sense of protection	23
Affective deprivation	17
Emotional regulation and dysregulation	
Regulation efforts	22
Symptoms of disorganization	21

Traumatic Distress

Uncertainty of illness. Most FCs (21/26) emphasized difficulty in dealing with the uncertainty of the illness, related to the unpredictability and ambiguity of events, in terms of the onset of illness, the course of symptoms, and their cause: "It is a pain that suddenly appears, coming from nothing . . ." FCs were frequently plagued by doubts and a generalized preoccupation with the uncertainty of the future: "The future, which is uncertain. The unknown." In response to uncertainty, several participants (11) showed an attitude of hypervigilance toward the illness signs, mainly after crisis episodes: "Every day, in the morning, I looked at his eyes to see if they were yellow again." When the cancer diagnosis was particularly sudden and unexpected (2), this especially caused a general sense of insecurity and hopelessness. In contrast, for others (10), uncertainty allowed them to postpone the threat and keep hoping for a small recovery or the prolongation of life: "We do not know what will happen next. He has always recovered after coming to the hospital. I'm always holding on to this hope."

Image of degradation. The majority of FCs (20) mentioned the patient's progressive decline, referring to their extreme thinness and frailty, loss of autonomy, and cognitive impairments: "I feel like my husband is disappearing."; "Things are not well . . . she is losing her abilities and becoming a child." All these losses contribute to the creation of an image of degradation that contrasts with the previous representation of the now ill person. Despite being informed about the illness progression, this confrontation with extreme fragility causes strangeness and insecurity: ". . . because everything is happening . . . strange things . . . no matter how much we read and know . . . I do not feel prepared for these situations . . ." Indeed, in some cases (6), it provoked a shock reaction, described as traumatic: "So fragile, a person who was so strong (cries)! So strong! . . . It's very traumatic!." This reaction was generally triggered by the fact that the decline is very pronounced and sudden: "What strikes me the most is the degradation of the person, so fast, from one day to the next."

Vicarious suffering. Most FCs (18) identified manifestations of patient suffering and were able to empathize with the other's emotional state. However, the continuous exposure to the other's suffering also caused the FCs psychological distress, which sometimes (6) became overwhelming, particularly in cases of identification and emotional contagion: "The worst thing is . . . my great terror is to see the state of my father, the suffering of my father, to imagine what my father thinks . . ." However, there were also participants (3) for whom continuous exposure to the other's suffering gave rise to a state of habituation and desensitization:

> My neighbour said that she could not see it; she was really upset. My sister-in-law was also crying a lot . . . but not me . . . I know it was painful for me, but I've seen it so many times . . .

Caregiver impotence. As the disease progressed, the patient's suffering became more difficult to manage, leading most FCs (24) to experience feelings of impotence, either in preventing the other's suffering or in keeping the disease from progressing. Some (12) focused on external causes, such as professional faults or a lack of social support. Other participants (4) complained about the patient's refusal behavior in cooperating with caregiving. However, limitations were also perceived as failure in helping the patient (16): "I feel incapable. I cannot get him to react." In an attempt to compensate for these limitations, some participants invested obstinately in caregiving. They avoided asking for help and tried to always be present and available for the patient, thus becoming more vulnerable to exhaustion. In contrast, for another group of FCs (7), feelings of impotence facilitated the awareness of caregiving difficulties and their need for help. In addition, by recognizing their inability to control the course of the disease, they tended to focus on providing comfort to the patient not to feel so helpless before the inexorable advance of the disease.

Life disruption. Many FCs felt that their own life had been invaded and indefinitely interrupted by the illness. For example, most participants gave up work, leisure time, and other pleasurable activities: "Now it's just my mother, home, and job. This is my life. Because I do not have time." They claimed that providing care was a grueling schedule, depriving them of all strength and vitality: "Having to give this energy, we run out of strength . . ." Pressure to provide care and excessive demands are associated with a generalized sense of physical and/or emotional exhaustion (18): "It's all happening at the same time. I'm getting tired, very tired." In particular, sleep deprivation substantially contributes to this sense of resource depletion, converting emotional exhaustion into physical fatigue. FCs reported that they feel invaded and that their life is suspended. In addition, caregiving also affects family and social relations, contributing to the isolation of the caregiver. For example, one participant stated that because she provides care, she has neglected her marital relationship. However, these personal restrictions also led FCs to recognize the need to request and accept support (8): "I had to ask them for help, otherwise I would not be able to bear all this."

Separation Distress

Anticipation of death. The possibility of death was mostly (22) addressed in an implicit way by recognizing the irreversibility of the disease. However, FCs (6) described situations of imminent death and the constant threat of losing their relative: "I was really disoriented! I thought: 'and if he dies here, what do I do?'" and "It's a fear . . . I'm afraid he'll die, I'm always seeing if he's still breathing . . ." Of those who spoke about the proximity of death (11), almost half (5) stated they were not prepared for it. However, FCs (5) also expressed a desire to hasten death: "I swear, I'll never have the courage to say this to anyone else, but I just wanted my dad to die fast, not realizing what was happening." Consequently, the possibility of death was felt with much ambivalence: Although it represented definitive separation from the loved one, it is the only way to terminate the other's suffering, as well as their own distress: "Sometimes I think: this is not forever. In addition, then I think: but I'm talking about the life of a person I love. If this is not forever, it's because I'm going to lose that person."

Relational losses. Several FCs perceived changes in the relationship that affected their sense of attachment to the ill relative, eliciting feelings of grief and longing. The majority (8) referred to the loss of dialogue and presence: "I feel alone, now that I do not have anyone to talk to . . . to [patient's name], I cannot tell anything . . ." and "I miss his company." Others mentioned they were losing protection (3), especially when there is a reversal of roles, as in the case of the father–daughter relationship: "Now, I have to be the one to help him. The strong man, to whom I have so often asked for help: 'Daddy, help me, something happened in my life'. Now I cannot do it anymore . . ." They also expressed sorrow for past life (4) and for the future that they will not share with the patient (3).

Separation anxiety. A few FCs (6) openly showed signs of distress related to anticipated separation. However, most participants were preoccupied by the idea that something bad would happen to the patient when they are not present. This feeling contributed to maintaining the relationship, despite the changes it had undergone. However, this feeling can also be an impediment to the subject's sense of security and autonomy, which was reflected in a fear of being alone (3): "It scares me because I do not like being alone. I never liked it . . . just thinking that one day I'll be alone, and I do not have anyone to take care of me . . . it scares me." Others (2) could not even think of their family member's future absence and immediately deviated from the subject.

Sense of protection. Most FCs (22) expressed a desire to help by meeting the other's needs. The responsibility that comes with caregiving involves making decisions for the well-being of the patient, which can give rise to moral dilemmas (15). For example, FCs must decide whether to ask for another medical opinion, whether to invest in more treatments, and which is the best place for care. Retrospectively, these doubts are subject to rumination: "At the time, it seemed that this was the solution . . . But now, I do not know . . . as things are getting worse, it comes back to my memory to wonder if it was the best decision." The excessive responsibility for the other gives rise to overprotective attitudes. In some cases (3), participants impose their decision in an authoritarian way, sometimes infantilizing the patient. Overprotection may also be the source of closed communication (16). FCs inhibited their expression of emotions and avoided talking about illness and death to prevent the significant other from suffering (3): "I am always afraid that they will give her the news as they gave me. In the appointments, I always say: 'Oh, beware, she does not know anything . . .'."

Affective deprivation. Many FCs (17) did not feel appreciated for their efforts, so they felt a great sense of affective deprivation due to the disparity between what they were giving and what they received. This uncovers the FC's relational needs, leading them to review previous failures in the relationship (14): "My husband was a very selfish person. He only thought about himself and did not give me the affection I needed." FCs also expected that, at this stage, there would be more contact and affection, and when it did not occur, they felt frustrated (2): "I would like that, at the end of life, she would think: 'I'm here for a short time, I'm going to dedicate myself to others.' But this is not happening. She is still angry and complaining with me." Others (3) continued longing for an idealized relationship: "I wish she would look at me, and we could both create that bond, only for a moment. I just wanted to feel it (cries)." In contrast, some participants (4) reported that now the patient showed more caring and concern than ever before.

Emotional Regulation and Dysregulation

Self-regulation efforts. Several caregivers (14) shared the belief that by inhibiting their feelings, they were protecting each other from emotional distress. Hence, they tended to cover up the painful aspects of their experience: "I'd rather shut up, so I would not hurt anyone." However, many of them (10) were aware of the need to set boundaries and find some way to compensate for the emotional and physical burnout of caring for their relative. In an effort to self-regulate, some participants (5) tried to distract themselves with work. Others (2) sought relief by walking in nature, by practising meditation, or by connecting with God. There were also those who used cognitive strategies of self-reassurance (4): "I'm going to get hurt, with scars, but life goes on . . . I am strong, I will survive." Finally, some sought help from family and friends for distraction and instrumental aid (3), but rarely for emotional support, because they were convinced that the others were not available for sharing painful feelings.

Symptoms of disorganization. The AG experience elicits some degree of emotional dysregulation (21). Manifestations include mood instability, impatience and irritability, anxiety, anguish and panic, as well as other signs of acute stress. Physical signs (8) included appetite and digestive changes, tachycardia, and muscle tension. Cognitive manifestations (12) comprise intrusive and ruminative thoughts, recurrent dreams, dissociative experiences, and disorganization of speech. The devastating impact of the other's illness was also reflected in feelings of abandonment, helplessness, and loss of faith and purpose in life (3), leading one participant to suicidal ideations. Some of these individuals felt unable to manage their emotional state and had a fear of losing control: "I am afraid, I don't want to fall . . ." Social and occupational difficulties manifested in a disorganization of habits, generalized distrust of others, and isolation for self-protection.

The main themes and categories were organized in a conceptual map that shows the dynamic relationship between the concepts (Figure 1).

Discussion

This exploratory descriptive study aimed to contribute to the conceptualization of AG by qualitatively analyzing the testimony of a clinical sample of cancer FCs of patients in PC. The findings suggest that this phenomenon involves several core characteristics that were grouped into two main dimensions. First, *traumatic distress* is related to continuous exposure to life-threatening conditions, resulting in a generalized sense of having a lack of control over illness circumstances and one's own life. Second, *separation distress*, elicited by the perceived threat to the relationship, stems from the current relational losses and unavoidable future separation. A third dimension, *emotional regulation and dysregulation*, is not a specific attribute of the AG process, but as evidenced in other studies (Camacho,

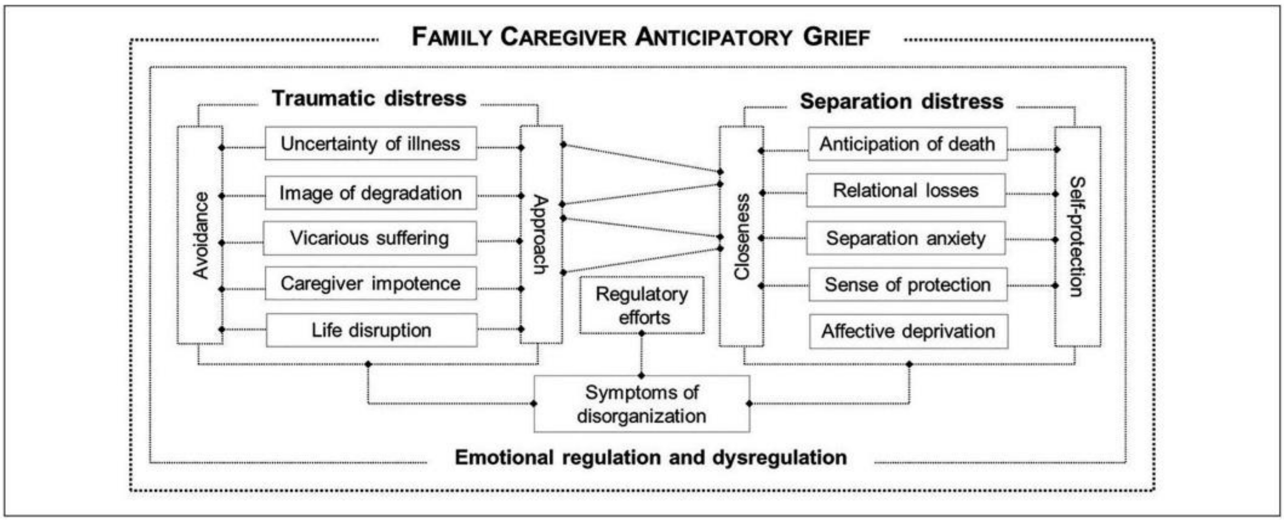

Figure 1. Conceptual map configuring the FC AG core characteristics and their relationships.
Note. FC = family caregiver; AG = anticipatory grief.

Pérez-Nieto, & Gordillo, 2018; Fernández-Alcántara et al., 2016), it has a central role as a moderator of grief.

Emotional regulation refers to an individual's efforts to manage the experience and one's expression of emotions to achieve one's personal goals (Gross & Thompson, 2007). In contrast, emotional dysregulation reflects difficulties in modulating emotions, either by underregulation (insufficient control) or misregulation (ineffective control) (Tice & Bratslavsky, 2000). Emotional dysregulation is reflected, for example, in emotional ambivalence, that is, conflict about whether to express feelings that may also lead to ambivalent feelings (Gohm & Clore, 2000). As suggested by the data, FCs' tendency to inhibit their feelings contributes to emotional ambivalence and disorganization symptoms. However, we argue that this conflict arises from the very circumstances of end-of-life caregiving. In other words, the FC is required to address the threat of death and separation while protecting the patient's life and welfare. Balancing these apparently competing positions constitutes, in our view, the major dilemma the FC has to deal with, from which many other adaptive challenges derive.

The perspective of grief as an oscillatory process is well documented in the literature. This idea has hallmarks of the dual process model of coping with bereavement (Schut, 1999), which establishes a regulatory coping process of oscillating between approach and restoration positions. Specifically, in AG phenomena, Rando (1986) described a delicate balance between mutually conflicting demands of simultaneously holding onto and letting go of the patient. Recently, Breen, Aoun, O'Connor, Howting, and Halkett (2018) also drew attention to this vacillation process, emphasizing that FCs either focus on circumstances of illness and caregiving (here) or preparation for the future (after). In line with these perspectives, we articulated the circumstances and relational aspects, stating that the AG oscillation process occurs both between and within two different levels: managing the perceived threat to the other's life and that to the relationship. As a result, we propose a conceptual model that identifies the AG core characteristics and configures them as adaptive challenges that require constant balance between two competing positions.

Traumatic Distress: Managing the Threat to the Other's Life

Caregiving in life-threatening conditions exposes FCs to several unexpected and threatening events, causing traumatic distress. In accordance with Roth and Cohen (1986), we understand that FC responses to perceived threats to the other's life correspond to the dynamic organization of defensive behaviors when facing an inevitable threat, involving an *approach* and *avoidance* pattern. An *avoidance* orientation protects the individual from anxiety-arousing stimuli and their consequences. An *approach* orientation, in contrast, allows for appropriate action by noticing the threat stimuli and making it more controllable.

One of the aspects that threatens the individual's sense of security is the *uncertainty of illness*, which is caused by the unpredictability of events and the consequent lack of control over illness circumstances (Shilling, Starkings, Jenkins, & Fallowfield, 2017; Strauss, Kitt-Lewis, & Amory, 2019). This generalized sense of insecurity may develop into a permanent state of hypervigilance and may lead to a heightened startle reaction (Brosschot et al., 2018). However, similar to other studies (Janze &

Henriksson, 2014; Wong, Liamputtong, Koch, & Rawson, 2017), we found that uncertainty is also related to hope in that it allows the threat to be postponed. Hence, in the face of uncertainty, the FC is challenged with balancing vigilance regarding the illness signs, while still holding on to hope.

As the illness progresses, major changes in behavior and extensive body deterioration may lead the FC to feel that they no longer recognize the terminally ill relative (Dumont, Dumont, & Mongeau, 2008). This experience, evoked by the patient's functional decline, was designated as *the image of degradation*. The sharp contrast with the previous representation of the relative provokes reactions of shock and strangeness and is, thus, a main factor that impacts the psychological well-being of the caregiver (Schumacher, Dodd, & Paul, 1993). In addition, many of these functional losses are ambiguous, because the changes fluctuate and are unclear (van Wijngaarden, van der Wedden, Henning, Komen, & The, 2018). Consequently, the FC is challenged to review the previous image of the patient, integrating fragility, while trying to preserve the inner representation.

Witnessing the other's degradation and inherent suffering evokes in the FC an experience of *vicarious suffering*; this feeling corresponds to affective empathy, defined as sharing or feeling another person's emotional state (i.e., "feeling what another person feels"), which is associated, by excess or by fault, to increased emotional distress (Jutten, Mark & Sitskoorn, 2019). The state of compassion fatigue is characterized by physical, psychological, and social exhaustion that reduces one's ability to and interest in enduring suffering and caring for the other (Lynch & Lobo, 2012). To balance the emotional costs of empathy, the FC is challenged to dissociate from the patient's emotional and physical state, while remaining sensitive to the other's suffering.

Being exposed to the other's suffering without being able to prevent it gives rise to *caregiver impotence*, which reflects a feeling of intense powerlessness and frustration (Sanderson et al., 2013). Difficulties may be attributed to external factors (i.e., lack of support) or internal factors (i.e., personal faults). The latter seems to have a more devastating effect on the caregiver's sense of self-efficacy. Notably, caregiver impotence also led FCs to reformulate expectations and recognize their inability to reverse the situation and stop death from happening. Thus, the challenge consists of balancing the acknowledgment of the limits of caregiving, while maintaining some sense of control.

As a result of their exclusive dedication to the terminally ill patient, FCs experimented with personal constraints, creating a sense of *life disruption*. When the demands become excessive and the resources become depleted (e.g., deprivation of pleasurable moments), this situation gives rise to a state of emotional and physical exhaustion, with several implications in the FC's physical and mental health (Schubart, Kinzie, & Farace, 2008; Sharpe, Butow, Smith, McConnell, & Clarke, 2005). Although some FCs avoid recognizing the devastating impact of caregiving to prevent the patient from feeling a burden, this mind-set also challenges the FC to recognize their limits and to mobilize resources.

Separation Distress: Managing the Threat to the Relationship

As a consequence of the functional decline of the patient and the disruption of life, the FC experiences changes in their sense of connectedness with to patient, which threatens the security of the attachment and/or reactivated thoughts of previous relational failures. In addition, the proximity of death represents the last and most important threat, leading the FC to anticipate the inevitable loss. As a way of regulating the risk to the relationship, FCs are prone to seek proximity or to withdraw from the other for self-protection against feelings of rejection and loss (Murray, Holmes, & Collins, 2006). Shifts in motivation for seeking or avoiding contact seem to be related to ambivalent feelings, which are prevalent in close relationships at the end-of-life caregiving (Reblin et al., 2016). In fact, several aspects are likely to generate ambivalence in this relational context.

First, the *anticipation of death*, defined as an awareness of the proximity of the other's death. In addition to being an ancestral fear that is biologically sustained and responsible for the survival response, individuals are imbued with implicit and explicit emotional representations that are influenced by sociocultural attitudes and beliefs, which contribute to death anxiety (Panksepp, 1998). Thus, despite recognizing the irreversibility of the illness, many participants could not mention the proximity of death. However, death was also anticipated as a way of escaping from suffering and the burden of caregiving. Hence, the FC is challenged to assume the inevitability of death, despite not wanting the separation.

Another aspect that creates ambivalence is grieving the loss of the relationship while the significant other is still physically present. According to other studies (Beng et al., 2013; Pusa, Persson, & Sundin, 2012), we found that the feeling of loss exists even before the patient's death. *Relational losses* include, for example, missing the patient's company and protection, their previous life together, and their unlived future. This contributes to a sense of being disconnected from the patient, which is perceived as a sign of distance and as a rupture in the relationship. Therefore, to keep affectively investing in the significant other, the FC is challenged to relinquish some aspects of the relationship, despite their wishes to preserve or even strengthen the connection with the patient.

As a consequence of this disruption in contact, both the patient and FC experience intense solitude. Loneliness was found to be correlated with anxiety in caregivers of patients in the terminal stage of cancer (Soylu, Ozaslan, Karaca, & Ozkan, 2016). S*eparation anxiety* is manifested mainly in the FC's reluctance to move away from the patient. There are two main reasons for that: First, because the FC is afraid that something bad will happen to the patient in their absence, they have to be present to ensure the patient's safety; and second, because they are aware that they do not have much more time to be near the ill relative, they want to enjoy all the time they have together. Thus, the challenge consists of valuing the other's presence, while maintaining one's autonomy.

The need to ensure the patient's safety corresponds to the *sense of protection*. As noted by Martz and Morse (2017), FCs are prone to feel guilty in the transition to end-of-life care, so they mitigate this feeling by being present and ensuring that the patient is peaceful. This feeling translates into an attitude of "protective buffering" (Langer, Rudd, & Syrjala, 2007) from all the sources of distress and internally from their own feelings, leading to chronic emotional inhibition and the avoidance of painful subjects related to illness and death. The challenge lies in balancing protecting the other and attending to one's own needs.

Due to a lack of reciprocity in the caregiver relationship, the FC is prone to experience *affective deprivation*. In addition, this feeling can uncover previous relational failures and the loss of expectations of affection, thus contributing to a generalized sense of dissatisfaction that adds ambivalence to the relationship. As noted by Harding and Higginson (2001), caregiver ambivalence reflects difficulties in making decisions toward their unmet needs. Thus, to preserve the relationship, FCs are reluctant to address pending issues, so they tend to suppress relational needs that should be expressed.

Conceptualization of AG in the FC

A clear and comprehensive definition of AG is difficult to achieve, mainly due to the multidimensionality and complexity of this experience. However, based on these results, we propose that FC AG is defined as the family response to the perceived threat to the other's life and the subsequent anticipation of loss in the context of the end-of-life caregiving relationship.

Clinical Implications

For most FCs, despite being emotionally intense, this feeling is part of the adjustment process of advanced illness. It is important to keep in mind that under conditions of an ongoing, real threat, emergency reactions, including avoidance and hyperarousal, can be understood as natural, protective, and adaptive responses (Diamond, Lipsitz, & Hoffman, 2013). However, due to the accumulative effect of incidents, some people may feel that the circumstances are unbearable, resulting in a sense of overwhelming distress and symptoms of emotional disorganization. These feelings correspond to a failure in enduring, that is, the innate capacity of getting through a life crisis (Morse & Penrod, 1999). Psychological intervention programs directed at this population should identify the main challenges the FC is struggling with to promote the clarification of dilemmas and to develop specific strategies for supporting emotional regulation and preventing symptoms of emotional disorganization.

Limitations and Future Research

There are some limitations to this study. First, recruitment was conducted by the resident psychologist of the palliative care team, which means that the people who agreed to participate in the study were those who were open to psychological consultation, which is mainly a clinical population. Therefore, we probably did not capture the experiences of those who consider themselves to be more adjusted to such situations. Second, the characteristics of the sample, especially the high academic level, are not representative of the general population of caregivers. Future research is needed to investigate the role of emotional regulation in explaining individual differences in dealing with AG challenges and their impact on subsequent bereavement. Likewise, it is important to verify the relationship between each of AG dimensions in preparedness for death and the subsequent adjustment to the loss. This analysis should be extended to the nonclinical population to identify patterns of adjustment and their deviations. Finally, we suggest that mixed-method research be used to verify and develop the results obtained in this study.

Conclusion

Taken together, findings from this exploratory study provide an in-depth description of FC AG core characteristics that go beyond the mere identification of grief symptoms, contributing to the expanded comprehension of grief's multidimensional and dynamic nature. For most participants, caring for a terminally ill relative is considered a very disturbing experience, requiring much emotional regulation effort to manage both the threatening circumstances of end-of-life caregiving and the anticipated loss. By inhibiting their own feelings of distress to protect the significant other, FCs are generating ambivalent feelings that hinder the readjustment of the relationship. However, the balance between these two positions (i.e., anticipating loss, while protecting the other) also challenges the FC to adjust to the reality of imminent loss. The results may inform clinicians in creating intervention programs focused on the identification and management of these specific challenges posed by AG in the context of end-of-life caregiving.

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Note

1. The coder was the first author, A.C., and the consultants were the fourth and the fifth, P.F. and A.B.

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Caregiver anticipatory grief: phenomenology, assessment and clinical interventions

Alexandra Coelho[a], *Maja de Brito*[b], *and António Barbosa*[c]

Purpose of review

This review aims to synthesize recent findings on anticipatory grief in caregivers, referring to its phenomenology, assessment and clinical interventions.

Recent findings

Recent literature illustrates the wide scope of the current use of the term anticipatory grief, reflecting caregivers' experiences in different end-of-life trajectories. The anticipation of death is the distinctive aspect of anticipatory grief in the predeath grief continuum, encompassing several progressive losses, past and future. Recently developed assessment instruments capture key aspects of this experience, such as separation anxiety, anticipation of death and future absence of the person, denial and relational losses. Recent findings on prevalence of clinically significant predeath symptoms in caregivers range from 12.5 to 38.5%. Beyond personal and relational factors, difficult circumstances of end-of-life care significantly interfere in adjustment to anticipatory grief. Useful therapeutic interventions were identified, such as validation of grief feelings, increased coping and self-care, anticipation of future losses and reframing roles. However, rigorous interventional studies are needed to create guidelines and the manualization of specific therapeutic approaches to caregiver anticipatory grief.

Summary

Findings suggest that anticipatory grief dynamics in different end-of-life trajectories should be recognized and adequately assessed. Clinical interventions considered useful to support anticipatory grief caregivers are presented, but further research is needed to verify effectiveness.

Keywords

anticipatory grief, assessment, caregiver grief, intervention, predeath grief

INTRODUCTION

From the time of diagnosis of a life-threatening disease, through the progressive physical and mental deterioration during the patient's advancing illness, relatives are confronted with several losses, including the inevitable death. These losses induce psychological distress, requiring great adaptive efforts by the caregiver. This experience has been termed anticipatory grief, based on the assumption that the threat of death or separation will itself initiate a grief reaction. As originally conceived by Lindemann in 1940 [1], anticipatory grief is a 'safeguard against the impact of a sudden death notice' (p. 200) that facilitates adjustment to bereavement. Since then, anticipatory grief concept received great attention from clinicians and researchers. Particularly in palliative care, it was seen as a part of the grief trajectory continuum, providing a potential opportunity to preemptively intervene with each successive loss, thereby minimizing preventable complications of postloss grief [2]. However, research has found contradictory results concerning its beneficial effect in postloss, generating controversy about the validity and the usefulness of this concept. Inconsistencies in the literature have been attributed to the lack of a precise and operational definition, along with methodological weaknesses of the studies [3–5]. This review aims to synthesize the recent research in anticipatory grief literature, contributing to the expansion of knowledge on its phenomenology, assessment and clinical interventions. We begin by presenting current perspectives

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KEY POINTS

- Anticipatory grief literature is mainly theoretical or uses qualitative data, focused on phenomenological aspects of this experience.
- End-of-life trajectories influence the grief experience, and specific characteristics can be found in different groups of caregivers, such as dementia or cancer caregivers.
- The anticipation of death, at the terminal phase of illness, may be the distinctive aspect of anticipatory grief in the predeath grief manifestation continuum that encompasses several progressive losses.
- Recent assessment tools focus on key dimensions of anticipatory grief dynamics, such as anticipation of death and of the future without the person, separation anxiety denial and relational losses.
- Clinical interventions addressing caregivers' anticipatory grief include disclosing adequate information on illness progression, supporting caregiving skills and self-help strategies, validating grief feelings, anticipating future losses, reframing roles and reformulating the relationship with the dying patient.

on the nature and assessment of anticipatory grief, followed by a review of supportive interventions for anticipatory grief. The scope of the present review is solely on the informal caregivers' perspectives on anticipatory grief, thus, excluding the patient's preparatory grief.

THE CURRENT CONCEPTUAL DISCUSSION

Literature on anticipatory grief is mainly theoretical or uses qualitative data to identify anticipatory grief manifestations, without a clear operationalization of the concept. The most common anticipatory grief definition continues to be Rando's [6], which states that it is a phenomenon encompassing the mourning, coping, and planning of one's life in response to an impending loss as well as past, present and future losses. However, given the wide scope of this definition, a variable understanding of anticipatory grief persists. It reflects an overlap between concepts that still persists in literature. We understand bereavement as the state of having loss a significant other [7]. Grief is seen as the involuntary reaction to a loss (physical or symbolic), primarily associated with emotions, though it also includes the somatic, cognitive, behavioral and spiritual realms [7,8]. Mourning is the active process of allowing and dealing with the pain of loss and adjusting to living life without the person who will die or who has died, and coping with the shock of bereavement and the emotions of grief [7]. This process is unique to each individual, in spite of being greatly influenced by the sociocultural norms. According to these definitions, it is expected that grief and mourning would be associated with different outcomes, as the latter implies some kind of integration and acceptance of the loss experience [9]. Yet, previous anticipatory grief literature does not clearly distinguishes these two processes, failing to recognize that grief may be avoided, disguised, denied or repressed, thereby preventing the grief work – that is, mourning process – to be carried out.

A recent systematic review [10▪▪] stated that grief during caregiving is a complex experience that involves the relationship with the patient, the changes resulting from the multiple loss situation of the impending death, and caregivers coping with this situation. However, the authors recognized that most research refers only to the presence of grief symptoms, resulting in an increased tendency to the use of terminology 'predeath grief' instead of the anticipatory grief, which presupposed a positive impact on bereavement outcome. Results from this review suggested that anticipatory grief served no protective function in adjustment to the *loss*; instead, it was considered a risk factor for bereavement as the symptomatology prior to death tended to persist postloss. Although providing care of a seriously ill, caregivers are exposed to great distress, which puts them in a particularly vulnerable position to develop grief complications, worsening caregiver outcome at bereavement According to the recent proposed diagnostic to International Classification of Diseases (ICD)-11, complicated grief, also known as prolonged grief, is characterized by intense yearning for the deceased and other persistent grief symptoms, accompanied by social and occupational impairment [11]. A nationwide prospective cohort study [12] found that 7.6% of the caregivers reported complicated grief and 12.1% reported depressive symptoms at 6 months postloss. The levels of grief and depressive symptoms were higher preloss than in bereavement, evidencing that the caregiver distress accentuate grief symptomatology. This effect is may be because of caregiver exhaustion, so the relationship between predeath grief and burden should be further examined.

A conceptual analysis of predeath grief [13] emphasized that this term relates specifically to the intermittent and ambiguous losses along the illness course, typical of the dementia grief. Instead, anticipatory grief is defined by reaction to the irrevocable losses associated with the terminal phase of disease, thus implying the anticipation of impeding death. This definition of anticipatory grief is congruent with the theoretical positions of Lindemann [1], Rando [6,14] and Fulton [4]. It is also supported by a literature review on patients with cancer [15••], in which anticipation of death was noted to be a core characteristic of anticipatory grief, representing the transition moment in the onset of the anticipatory grief process. However, anticipation of death may be confused with other concepts, such as forewarning and preparation for death, which are clearly distinct from anticipatory grief [7,15••]. It is, therefore, necessary to identify other underlying components of anticipatory grief, comparing recent findings from different illness trajectories and particular groups of caregivers.

DEMENTIA CAREGIVER GRIEF

Dementia has a gradual, often prolonged, dwindling; with death occurring after a long period of time. As a result of the disruptions in communication and impairments in awareness that occur even early in the disease, those with dementia are unable to access personal memories, leading the family members to feel that their loved one with dementia is not the same person, which can be very confusing. Along with profound changes in their relationship and expected future, relatives are unable to resolve issues, such as reconciliation of past conflicts, which can add ambiguity to the loss experience. In this prolonged, stepwise loss of the person while living, caregivers invariably experience a succession of losses that constitute a source of ongoing and unresolved distress [16••]. These losses are seldom validated during the caregiving journey [17], which renders this experience similar to Doka's [18] concept of disenfranchised grief. Experience of isolation because of the social misunderstanding of particular forms of grief expression is particularly noticed in overlooked groups, such as children and young people [19•], as well as other cultures, as demonstrated by a study carried out with a multi-ethnic Asian population [20].

CAREGIVER GRIEF IN CANCER

Compared with dementia, the cancer trajectory is often considered more acute and death is a more expected endpoint. Although expected, death is often experienced as too sudden. A review of 29 studies with a majority of cancer patients [15••] found that the experience of anticipating death disrupts the family's life and gives rise to intense emotional distress, especially separation anxiety. Nevertheless, this study also emphasized that, although the onset of anticipatory grief occurs with the anticipation of death, the awareness of the impeding loss may fluctuate because of uncertainty and hope. Influenced by the current death-avoidant sociocultural norms, caregivers avoid thinking and talking about this painful reality and sustain hope in order to keep functioning and caring for the ill person. So, despite maintaining the ability to communicate and having the opportunity to strengthen the relationship with the patient at the end-of-life, most caregivers keep a closed communication about death. It reflects the survivor's desire to avoid the proximity of death of the significant other and, simultaneously, the need to protect the dying loved one from emotional overload. This prevents caregivers from completing pending issues and facilitating other end-of-life tasks, such as conflict resolution, forgiveness of self and other, a sense of continuity and legacy, funeral and estate planning and from the potential of dyadic mutual comfort and shared mourning and acceptance. Thus, anticipatory grief manifestations are largely inhibited, which leads to 'self-disenfranchisement.' This dynamic results in intense ambivalent and contradictory feelings: on the one hand, caregivers experiment unpleasant emotions, while grieving for personal and relational losses; on the other hand, they need to maintain a protective attitude and a positive facade towards the dying patient. Further research is needed to reach consensus on key characteristics of cancer caregivers as predictors of distress and on interventions that may be helpful in anticipatory grief.

PARENTS OF CHILDREN AND YOUNG PEOPLE WITH A LIFE-THREATENING DISEASE

Parents of children and young people with a life-threatening disease are a particularly vulnerable group of caregivers. Their experience has been explored through qualitative studies [21•,22••], which highlight feelings of helplessness and impotence related to the multiple losses and frequent failures in their children's treatment. In some, the perspective of finitude led parents to reconfigure their meaning in life: they enhance the parent–child relationship, share decision-making and give the child more autonomy. In other cases, parents take more control and responsibility for the decisions about their child's life and death.

DEVELOPMENTS IN ANTICIPATORY GRIEF ASSESSMENT TOOLS

Previous anticipatory grief scales [23,24] tried to capture the multidimensionality of anticipatory grief, covering practical, emotional, social and relational issues. Although they share the common focus on the caregiver's feelings toward illness and the risk of losing the relative, these instruments lack congruity in thematic content [10■■] and do not capture certain features of anticipatory grief, such as the continuous and relational losses as well as avoidance of grief.

In order to overcome this gap, a new instrument named the Caregiver Grief Scale (CGS) [25■■] was created for dementia caregiver grief. It gathers items adapted from other grief instruments and new items that were developed from statements made by caregivers themselves. The CGS comprises 11 items (5-point Likert scale), assessing 4 significant aspects of caregiver grief: emotional pain (experience of grief and other painful emotions); relational loss (losses related to the relationship, which are central to the caregiver's grief); absolute loss (death and the anticipation of the future without the person), and acceptance of loss (acceptance of dementia and of open expression of grief). The last aspect takes into account that caregivers often avoid expressing or even feeling grief while the care recipient is still alive, thus recognizing the experience of disenfranchised grief. A high internal consistency and reliability was found for the total scale (Cronbach's $\alpha = .89$). It is worth noting that the aspects evaluated in this instrument coincide, to a large extent, with the characteristics identified as core features of anticipatory grief. Further studies on this scale are needed, as well as validation in other caregiver populations.

Another frequently used scale is PG-12, a diagnostic tool adapted from Prolonged Grief Disorder Questionnaire (PG-13) to measure predeath grief. It is based on the diagnostic criteria of prolonged grief disorder (PGD) [26]. It is composed of 12 items (5-point Likert scale) and one dichotomous response. Researchers studying caregiver grief have employed the PG-12 as a reliable tool for early identification of those at risk of developing postloss PGD. Separation anxiety is identified as a key criterion, along with other emotional, cognitive and social symptoms, such as shock, trouble accepting the illness, confusion in life, numbness and significant reduction in social and occupational functioning. Predeath grief proved to be distinct from depression and anxiety, though it may influence these symptoms [27]. However, this scale is based on the assumption that predeath and postdeath grief are phenomenologically comparable, so it fails to recognize the other distinct dynamics of anticipatory grief.

In addition to using standardized instruments, the literature recommends that anticipatory grief assessment includes a careful observation of the caregiver, elucidating concerns and feelings about the situation, as well as physical and cognitive symptoms, such as difficulties in concentration and problem solving. It is also important to look for avoidance of social interactions, being confined to the caregiver role, and to assess how the caregiver is dealing with the progressive losses, and to understand what coping mechanisms are being used. This evaluation allows for the identification of strengths and vulnerabilities and mobilization of resources to support extreme distress, poor functioning and limited coping [28].

PREVALENCE AND PREDICTORS OF ANTICIPATORY GRIEF

Recent studies using PG-12 reported that the prevalence of severe predeath symptoms ranges from 12.5%, in a Danish sample of caregivers ($n = 2865$) for those with cancer [29■■], to 33% in a similar population of Portuguese caregivers ($n = 94$) [27]. The value reached 38.5%, in caregivers of patients in vegetative states ($n = 52$) [30■]. Given the methodological differences in these studies, a comparative analysis between the prevalence data is not possible. We have not found any results referring to predeath PGD in dementia caregivers.

High predeath grief symptoms in Danish populations were associated with depressive symptoms, and with difficult circumstances of caring, such as caregiver exhaustion, lack of preparation to death, excessive prognostic information and low communication about death [29■■]. In a Portuguese sample of cancer caregivers [27], burden was also considered a risk factor, along with the perception that the cancer diagnosis was not expected and that the illness was a serious condition. Coping mechanisms such as acceptance and positive reinterpretation were considered protective, whereas denial was associated with higher grief symptoms. This evidence supports the position that whenever grief emotions are avoided, they cannot be processed, thus remaining high.

Another study evaluated German home-caregivers of a family member with dementia ($n = 229$) with CGS [25■■]. Results showed that being a spouse and living with the care recipient were associated with a higher intensity of grief, whereas caregiver's sex, time since diagnosis, duration of caregiving and severity of dementia were not associated with the intensity of grief. Asian caregivers evaluated by Marwit-Meuser Caregiver Grief Inventory (MM-CGI) were more prone to present higher predeath grief symptoms if they were spouses, had lower education and Malay ethnicity [20].

The Anticipatory Grief Scale was used to evaluate US adult family members ($n = 57$) who were anticipating the death of a terminally ill veteran in the palliative care unit (PCU). Several personal and interpersonal risk factors were identified, including: the relational dependency with the patient; insecure avoidant attachment style (less comfort in close relationships and difficulty with intimacy), spiritual distress insufficient social support, higher levels of neuroticism, lower levels of meaning making and lower educational level [31].

CLINICAL INTERVENTIONS IN ANTICIPATORY GRIEF

Research exploring professional support for caregivers reinforces the need for continuity of care through the grief trajectory [32], the use of humanistic care practices [33] and a family-centered approach [34]. However, few recent studies describe interventions oriented to help caregivers during their process of anticipatory grief.

Existing programs include psychoeducational interventions, which consist of sharing information about illness evolution and providing support to improve caregiving skills and self-care strategies. A recent study on this type of intervention piloted a support program for caregivers of rural veterans with dementia in USA, using technology-based services. The finding was that internet intervention was more helpful than phone in reducing isolation [35].

Psychotherapeutic approaches, including cognitive–behavioral therapy (CBT) and narrative therapy, have been used for caregiver anticipatory grief. CBT for dementia caregivers ($n = 33$) was evaluated through a randomized-controlled trial [36▪▪]. Content analysis of session transcripts showed that therapists used mainly techniques such as recognizing and naming experienced losses, expressing associated feelings and fostering acceptance of losses. Although caregivers were reluctant to talk about the future, addressing future losses was important to prepare them for death. Focussing on the redefinition of relationships allowed caregivers to deal with changes, accept help from others and adopt new roles. It also prevented emotional disengagement and led to more empathic caring toward the patient.

A study using the narrative approach [37] aimed to clarify how talking to family caregivers of patients at end-of-life influences the process of anticipatory grief. Extracts from conversations with the participants ($n = 2$) illustrating emotional transitions were selected and then consolidated to clarify their meaning. In this study, the narrative approach facilitated the caregiver's ability to recognize if they were trapped in their role, to release themselves from being trapped, to face their own emotions, and to cope with losses in their own way. By reframing their roles, facing their emotions and coping with loss, they were better able to prepare for the patient's death.

CONCLUSION

This review of the literature published in the last 2 years showed a shift of focus from the effect of anticipatory grief on bereavement to a better understanding of its phenomenology and the areas requiring validation, education, facilitation and intervention. Taking into account the wide scope of the definition and distinguishing between end-of-life trajectories help in understanding dimensions of this experience, as well as the risk factors for complicated grief, or prolonged grief disorder (PGD). The anticipation of death at the terminal phase of illness may be the distinctive aspect of anticipatory grief in the predeath grief manifestation continuum. Recent assessment tools focus on key dimensions of anticipatory grief dynamics, such as anticipation of death and a future without the person, separation anxiety, denial and relational losses. Risk assessment includes personal, relational and circumstantial factors. Personal factors include depressive symptoms, denial-coping mechanisms, insecure avoidant attachment style, neuroticism, spiritual distress, lower level of meaning making and lower educational level. Relational factors constitute being a spouse, cohabiting with the patient, relational dependency and insufficient social support. Difficult circumstances, such as caregiver exhaustion and lack of preparation to death, also contribute to high levels of anticipatory grief. Intervention studies demonstrated the feasibility of psychotherapeutic techniques focused on supporting caregivers, but further evaluation of their effectiveness is needed. Support of caregiving skills and self-help strategies, providing adequate information about illness progression, validation of grief feelings, reframing roles, anticipation of future losses and relationship reformulation can be helpful techniques specifically addressed to caregiver anticipatory grief. However, rigorous interventional studies are needed to evaluate the efficacy of these programs. In the future, those may be used as a base to create guidelines and manualization of therapeutic approaches focused on the caregiver anticipatory grief.

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Conflicts of interest

There are no conflicts of interest.

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ATTACHMENT 2

MANUAL

FAMILY CAREGIVER ANTICIPATORY GRIEF - CLINICAL INTERVIEW
(FCAG-CI)

MANUAL

FAMILY CAREGIVER ANTICIPATORY GRIEF - CLINICAL INTERVIEW (FcAG-CI)

Interview Script and Scoring System

Introduction

The Family Caregiver Anticipatory Grief Clinical Interview (FcAG-CI) is a semi-structured interview for clinical application that assesses how participants emotionally regulate and respond in face of the multiple challenges placed by the end-of-life caregiving. It is directed to the adult population of family caregivers[7] (FC) of adult patient with advanced cancer, regardless of the degree of kinship. Designed to be a hetero-evaluation instrument, it is supported by qualitative criteria that allows the interviewer to code the level of emotional activation related to each specific challenge. These criteria were developed based in the literature review and in qualitative studies carried out with FC in palliative care. The purpose is to contribute with a comprehensive analysis of individual differences in the anticipatory process, in order to guide intervention programs focused on the specific needs of the caregiver population.

The interview is composed by 15 questions, followed by probes, that are introduced in a non-directive and flexible way, respecting the participant´s areas interest and concern, their conversation rhythm and natural interruptions. It begins by requesting information about the family structure and then invites the person to talk about their experience as a caregiver, the perceived illness evolution and the relationship with the patient. The interview script presented below is only guiding, which means that is not necessary its full application or that the order of questions is respected. It is desirable, however, that all issues are addressed. It may happen that some contents are mentioned spontaneously, without needing to be directly questioned. On the contrary, others may remain hidden. In this case, it is important to discriminate whether it is a less salient aspect of the person's inner experience or if it is a topic avoided by emotional issues. All these discursive aspects, as well as the non-verbal behavior of the subject, are taken into account in the evaluation of the answers.

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[7] Includes any family member, friend, or partner who maintains a significant relationship with the patient and provides some kind of care (Hudson & Payne, 2009)

Interview script

I am going to ask you some questions about your experience as a family member and [patient's name]´s caregiver, and how this experience has affected you in various aspects of your life. This interview aims to get to know you and your family member better. The interview will take about 50 minutes, but you can stop it at any time if necessary.

1. Can you start by describing your family - who you live with, whether or not you currently live with [patient´s name], and for how long?
   - Are there other people close to you - who do not currently live with you - but who are an important part of your family?

- This question allow to know the structure of the family and aims to involve the family caregiver (FC) in the relationship. The quality of relationships should not be addressed. The goal is only to obtain some demographic information to briefly build the family genogram. No more than 3/4 minutes should be used for this question.

2. How has been your experience as caregiver of [patient´s name]?
   - What are your daily activities in patient care?
   - What changes did you noticed in your routine?
   - What other people are involved in caring for the patient?

- The aim is to capture the involvement in the care provision, the attitudes toward caring, impact of the events in the caregiver's schedule and the resources. It is important to identify the emotional quality of speech when the FC describes the changes in the routine and the activities they perform, as well as to understand how they articulate with the rest of the family.

3. When did you first notice that [patient´s name] was ill?
   - Were there signs of disease before the diagnosis?
   - How did you get to know the diagnosis?
   - Had you ever thought that [patient's name] could have this disease?

- Encourage the person to describe the episode of information transmission and its immediate reaction. Verify if the diagnosis was totally unexpected or if the person was aware of the illness signs. Be attentive to expressions that reflect manifestations of shock, disbelief, anxiety or trauma related to the diagnosis transmission. Evaluate the presence of avoidance mechanisms.

4. How would you describe the current health state of your relative?

- Would you say the illness has evolved gradually or in a sudden and unexpected way? What makes you think so?
- What is your hope, at this moment?
- What do you think will happen? How does it makes you feel?

- The aim is to capture the FC´s ability to anticipate the illness events or if there is a sensation of total uncertainty and lack of control. Evaluate if the person can adjust hope, depending on the events. This question may lead the person to anticipate death; in that case, explore the FC´s feelings.

5. Would you say [patient's name] is very different from what he/she was? In what aspects?
    - How is it for you, to see him/ so different from the person he was?
    - Do you think this has changed the way you used to see your relative? In what aspects?
    - How do you manage those losses?

- Verify the perceived changes in the patient´s functional and mental status. Attend to the emotional tone and expressions used in order to capture the image of degradation and its impact in the FC´s representation of the patient. Evaluate if it interferes with the capacity to adjust the care to the patient´s needs.

6. Would you say this is causing suffering to [patient´s name]?
    - What would you say is the main cause of suffering of the patient?
    - Do you consider some of this suffering could be avoided?
    - How is it for you to witness the suffering of [patient's name]?

- The aim is to assess FC´s vicarious suffering. Be attentive to expressions of empathy and compassion, as well as the mechanisms used to avoid being in contact with the other´s suffering. Verify if there is a change in the person´s response related to the prolonged exposure to suffering.

7. Have there been particularly difficult times in managing patient care?
    - Do you experience specific difficulties, for example, in managing symptoms or making decisions? Can you give me an example of that?
    - How do you handled that situation?
    - Would you say that your reaction is different compared to what it used to be?

- Ask for a specific episode and request a detailed description of the reaction. Identify the main area of difficulty: focused on patient suffering, care management, personal burden or other. Be sensitive to the emotional tone to assess specifically feelings of impotence. Inquire the resources the person uses to deal with the distressful episode and to what extent they were adjusted to the situation, as well as eventual changes in the FC response to the other´s distress.

8. Do you have an idea of what *[patient´s name]* **thinks about his/her illness?**

- **Have you had a chance to talk with** *[patient´s name]* **about that***?*
- (If yes) **How is it for you to talk about this with him/her?**
- **Would you like that these conversations were more frequently?**
- (If not) **Could you give me the reason why you do not talk about that with** [patient´s name]?
- **When do you think of having that conversation, what do you think it would happen?**

- This issue allows to understand the communication about the disease, the existence of interpersonal protection mechanisms and deepening attitudes towards caring. It introduces aspects of the quality of the relationship.

9. How would you describe your relationship with [patient´s name]**?**

- **Could you give me two or three words that best describe the actual relationship?**
- **You told me that your relationship is [descriptor]. Can you give me an example of that?**
- **How do you feel about that?**

- Verify if the example is congruent with the descriptor. Identify the associated emotional state and check whether it is adaptive or reflects a distortion (avoidance of feeling). Attend, in particular, to the aspects suggesting a dependent and/or ambivalent relationship and eventual pending issues related to an insecure attachment with the patient.

10. Did you noticed any changes in the relationship compared to what it was before?

- **Could you give me an example of that?**
- **What do you feel you have lost, since the** [patient's name] **is sick?**
- **How do you feel about those losses?**

- Ask for specific examples of changes in the relationship (e.g., what they used to do before that can no longer do now). Detect the relational losses and associated emotional expression.

11. How is it, for you, to be separated from [patient's name]**?**

- **How do you manage your time to be around your relative and keeping other activities?**
- **How do you feel when it cannot be you taking care of** [patient's name]**?**
- **How do you feel when you think your family member may not always be around you?**

- The aim is to evaluate the separation anxiety and the caregiver vigilance. Ask for specific moments when the FC has to be away from the patient and evaluate the emotional tone the person uses to describe its reaction. Future separation should be posed as a possibility, without reference to a real loss: it only serves to evaluate how the CF imagines living the absence of the relative.

12. Would you say that, despite these changes, there have been good times, since you are taking care of [patient's name]?
    - Do you feel that your relative recognizes everything you do for him?
    - How does that make you feel?
    - Is there anything you would like to say or hear from the patient about it?

- This question allows us to deepen the evaluation of the quality of the relationship and gives indications about the gratification that CF feels in the role of caregiver. It also captures eventual pending issues related to the FC´s difficulty in expressing its relational needs.

13. Besides this issue, is there anything else that is disturbing you?
    - Sometimes, this situation affects the relationship with other family members. Is that happening in your family?
    - This experience may remind you of other difficult situations in the past. Is that happening to you?
    - How do you feel when you remember that?

- It is important to identify eventual concurrent stressors, secondary losses or previous distressful experiences related to illness and death. Evaluate the current emotional impact of these events to assess if there is a cumulative effect of distress.

14. How has it been for you going through all this?
    - In what ways has this affected your life in general terms?
    - Has your health been affected? In what ways?
    - Did you noticed any change in your in your sleep or eating habits? And in your capacity to perform the daily activities?

- Ask for specific physical and emotional symptoms related to the experience of caregiving. Evaluate the emotional tone and the disturbing effect on the FC´s functioning. Consider these aspects when quoting the intensity of the responses in the various dimensions of the scale.

15. To conclude, would you say that this experience has changed you in some way?

- **Do you feel that this experience has changed you and the way you relate to the others? In what aspects?**
- **Do you feel that this experience has changed the way you see life, your future, or the world in general?**
- **Would you say that despite all this, your life is still satisfying and meaningful?**

- This last question assesses changes caused by the current experience, either in the FC´s identity, interpersonal relationships and meanings system. It allows to understand if the person tends to show signs of post-traumatic growth or if, on the other hand, he/she is hopeless and cannot find a meaning or purpose for life in the current experience.

Coding system

The interview protocol is analysed through a coding system composed of eight dimensions, each with 10 items, corresponding to an increasing degree of distress, in which the value one corresponds to minimum and nine to extreme; the zero value is assigned when the dimension is non-evaluable, because of the lack of clarity of the answer or because no specific question has been asked. The quotation is oriented by qualitative descriptors that classify the levels: minimum (1), reduced (3), moderate (5), high (7) and extreme (9). The remaining values apply when the content of the response seems to correspond better to an intermediate point between two descriptors because it brings together elements of both and cannot be classified by only one.

It is also possible that, in some interviews, elements of the various descriptors are observable, taking into account the wide dispersion of responses of the subject. However, it is important that in the coding of the answers, these differences are integrated into a classification that seems more frequent and natural in the individual, in this specific context. If it is impossible at all to choose only one classification, the dimension should be considered as non-evaluable. The following describes each dimension and its evaluation criteria.

1) Uncertainty of the disease

It is defined as the perceived threat related to the unpredictability, complexity and ambiguity inherent to the disease and its disruptive impact on FC´s other areas of life. Low scores in this dimension reflect reduced perceived threat related to the evolution of events, without significant interference in the sense of predictability, security and hope in the future. High scores correspond to perceived imminent threat and maintained hypervigilance.

1- Minimum uncertainty of the illness

The participant perceives the current circumstances as non-threatening and does not feel affected in the sense of safety, predictability and hope for the future. There are no doubts and concerns related to the illness evolution and its management, so the vigilance to the illness signs is minimal. The impact of the disease on the various dimensions of a person's life is minimal, which means that the participant was not hampered in the daily routine and continues to carry out long-term projects.

3- Reduced uncertainty of the disease

The uncertainty associated with the instability of the illness is seen as an opportunity to maintain hope. In this case, the participant may react with some anxiety to sporadic crisis situations, but when these are overcome, the threat is postponed and there is hope of a favourable recovery. In these periods, the person feels reasonably safe and the level of vigilance for signs of illness is reduced, which makes it possible to normalize life, returning to the habitual routine. Although aware of the threat, the FC experiences some habituation to the normal circumstances of illness, and devaluate their emotional impact, thus reacting with reduced distress (e.g., "Other people are scared, but I am not, he's been through it so many times!"; "I'm always prepared, I say: it will happen this and that").

5- Moderate uncertainty of the disease

The participant is aware of the evolutionary signs of the disease and is able, based on past experience, to anticipate future events without being surprised by unexpected episodes (e.g., "There are things I'm used to, I already know... I know that more episodes of these will happen, that from now on he will have more infections, I know this will happen"). The FC realizes that the threat may be near; however, it is predictable, allowing him/her to adjust hope to the current situation and develop some tolerance for uncertainty (e.g., "I continue to make plans, but I may have to change them if the circumstances change."). Still, the sense of security may be moderately disturbed because he/she is aware of the complexity of the situation and that some situations may be out of control. Therefore, the participant maintains some level of vigilance with a slight level of anxiety that does not interfere significantly with the global functioning.

7- High uncertainty of the disease

The person is greatly affected by the impossibility of exerting control over the evolution of events and experiences a general insecurity that extends to other dimensions of his/her life, experiencing the cumulative effect of the various stressors. The uncertainty of the disease has a disruptive effect on the participant´s personal life, hindering the routine planning or the projects for the future. The participant may also present difficulties in managing hope because, on the one hand, they need to avoid the threat and believe in a favourable evolution of events, on the other hand he/she is hypersensitive to its signs and tends to anticipate negative events as a way of predicting the future and mitigate the feeling of uncertainty (eg, "I always hope that he will improve, but he may not improve…"; "The situation will worsen.”). The FC remains hypervigilant in a crisis period, although attention is often restricted to some particular aspects (e.g., preventing the patient from falling, or ensuring that medication is taken correctly) as a way to divert attention and avoid thinking about the threat of loss.

9 - Extreme uncertainty of the disease

The participant reports a sudden and completely unexpected evolution of the disease (e.g., "She was well and suddenly this news, and a disease like that!). There are symptoms whose pattern of occurrence cannot be understood or anticipated, as in breakthrough pain (e.g., "It's a sudden pain coming from nowhere") or in other refractory symptoms. Extreme uncertainty may also be related to shock episodes due to sudden transmission of the diagnosis or exposure to traumatic events (e.g., massive bleeding episode or seizures). These circumstances are accompanied by the loss of control and feelings of hopelessness, which in some cases results in the disruption of the beliefs system (e.g., questioning persistently the meaning of life and suffering, indignation at the succession of absurd events, questioning the existence of God). The person remains in a state of maintained hypervigilance, including alarm reactions, high anxiety and inability to relax. In some cases, these manifestations may be associated with panic attacks and/or dissociative episodes that keep the person relatively anesthetized.

0. Not Evaluable or Not Applicable

1. Minimum uncertainty of disease.
Little or no evidence of perceived threat; stable circumstances, predictability, security and hope are not affected; minimal vigilance to illness signs.

3. Reduced uncertainty of the disease.
Perceived distant threat related to unstable circumstances; maintains hope in the future with slight disruption of the sense of security; reduced vigilance to the illness signs.

5. Moderate uncertainty of the disease.
Perceived near threat related to predictable and anticipated disease circumstances; adequacy of hope and moderate disruption of personal security; moderate level of vigilance.

7. High uncertainty of the disease.
Perception of near threat related to unpredictable and complex disease conditions; generalized insecurity with disruptive effect on the various dimensions of life; periods of hypervigilance to the signs of the disease.

9. Extreme uncertainty voltage.
Perceived constant threat related to unpredictable and uncontrollable circumstances; total loss of hope and disruption of the assumptive world; hypervigilance maintained at illness signs.

2) Vicarious suffering

Defined as the caregiver's empathic response to the patient´s physical and emotional suffering. Low scores in this dimension correspond to reduced perception of suffering. High scores apply to situations in which there is perceived intense and intolerable suffering, associated with signs of compassion fatigue.

1 - Minimal vicarious suffering

The caregiver does not realize the patient´s suffering. It is described a state of physical and psychological well-being based on the absence of physical symptoms, without considering other possible sources of suffering (e.g., relational, existential, spiritual). Lack of sensitivity to possible changes in the patient's behavior, revealing difficulty in empathizing with the other´s emotional state.

3 - Reduced vicarious suffering

Although recognizing the existence of physical or mental symptoms generated by the disease, the participant seems to be absorbed by his/her own distress. The FC rarely identifies the patient´s feelings and manifests few gestures of sympathy and compassion. The personal distress related to the demands of caregiving prevails, which make the person self-focused and little permeable to the other´s suffering.

In other situations, given the need to maintain a positive view of events and to encourage the patient, the participant relativizes or denies the other´s suffering, which turns out to be effective in reducing their own distress, but causes failures in empathic response to the other (e.g., "He's fine, he's had some pain, but that's normal."). It may also occur that, because of mental limitations, the patient is unable to verbally transmit the suffering so that the caregiver cannot adequately value the experience of the other.

5 - Moderate vicarious suffering

The caregiver perceives some physical and/or emotional distress, but it is reasonably tolerated and understood in light of the current circumstances of the illness. This participant shows high sensivity and empathy, thereby is able identify the emotional states, putting himself/herself in the place of the other. The patient's behavior becomes comprehensible (e.g., "He becomes more upset when he has more pain."), and there is no tendency to overestimate or devalue the signs of suffering by interference of personal concerns. The ability to understand the other makes this caregiver more available and motivated to help. However, due to the reflexive capacity, the FC is also attentive to his/her own level of distress and able to regulate emotions. The involvement in caregiving is managed according to the real needs of the patient, adjusting availability without feeling overwhelmed by suffering. Although feelings of sadness and moderate distress related to the perceived suffering of the significant other may be present, there are no signs of physical and/or emotional fatigue.

7 - High vicarious suffering

The caregiver manifests intense distress reaction related to the patient's physical and/or emotional suffering. This empathic concern is clearly directed towards alleviating the other´s suffering and does not seem to translate intolerance or emotional divestment. In times of great need, the caregiver reinforces the investment in care and does not manifest intention to escape the situation. The participant may tend to dissociate from his own distress to support the patient, although later this is reflected in great physical and psychological exhaustion. Therefore, there are several complaints of physical fatigue and emotional vulnerability (e.g., intense crying and sadness, difficulty in relaxing) that leads them to focus on their own distress, reflecting in failures in the empathic response. The excessive focus on suffering and difficulties of differentiation from the significant other also gives rise to an experience of emotional contagion, which means the FC tends to identify himself/herself with the emotional state of the other, to mimic their reactions or to project their own needs into it (e.g., need to influence the patient with his or her own beliefs about death).

9 - Extreme vicarious suffering

Includes situations of prolonged exposure to very intense suffering, which can be manifested through evident pain behavior (e.g. crying, screaming, moaning and frowning facial expression), or other signs interpreted as such. These circumstances, coupled with the closeness of the relationship and strong susceptibility of self (generated by past experiences of adversity and temperamental factors), make the individual particularly permeable to the other´s suffering. As a result, the caregiver experiences a response of intense personal distress, with several signs of compassion fatigue, including disinvestment in caring. Despite being highly involved in the role of caregiver, the participant exhibits manifestations of intolerance and emotional disorganization in the face of recurrent complaints from the patient (e.g., "He's always moaning, I cannot hear him anymore!"). Self-focused responses lead to rumination about the disruptive impact of the other's suffering and to the expression of a desire for escape, which can be accomplished by avoiding contact with the patient (e.g., escape through work or distraction with other activities) and/or isolation.

Another manifestation that may be present is the state of apparent apathy or depersonalization in the face of suffering. In spite of being extremely sensitive to the intense suffering of the other, in the FC´s discourse the manifestations of sympathy and altruistic behavior directed at the other are almost nonexistent. Although fully committed in contributing to the patient's well-being, the FC´s empathy is greatly compromised by its own intense distress, which impairs the ability to understand the patient's emotional states and effectively respond to their needs. Therefore, the participant experiences difficulty in dealing with patients' behavior. On the other hand, there is a tendency to behave in an automated way, performing practical tasks without emotional involvement, which translates into depersonalization and instrumentalization of care. As a result, there is a combination of two opposing attitudes: on the one hand, the extreme concern about suffering and, on the other hand, the emotional withdrawal motivated by the strong intolerance to the other´s suffering. The person feels emotionally flooded and unable to self-regulate.

0. Not Evaluable or Not Applicable

1. Minimal vicarious suffering
Little or no evidence of perceived suffering; absence or omission of symptoms by the patient; insensitivity to the manifestations of suffering, without empathic capacity.

3. Reduced vicarious suffering
Perception of symptoms without appreciation of the associated suffering; self-focusing on one's own personal distress, with few demonstrations of empathy; tendency to relativize or deny the emotional impact of suffering.

5. Moderate vicarious suffering
Perceived physical and/or emotional suffering, reasonably tolerated, generates moderate personal distress and adequate investment in care, without signs of fatigue; empathic understanding with reflective ability.

7. High vicarious suffering
Perceived intense suffering, poorly tolerated, generates high personal distress and over-investment in care, with signs of physical and/or emotional fatigue; high empathic concern with little capacity for differentiation.

9. Extreme vicarious suffering

Perceived intense suffering, totally intolerable, generates extreme personal distress, with disinvestment in the care and physical and emotional exhaustion; extreme empathic concern with emotional withdrawal.

3) Image of degradation

Refers to the perception of the physical or mental losses resulting from the disease and their impact on the FC´s representation of the patient. Low scores in this dimension correspond to the perception of minor losses. High scores reflect an image of complete degradation of the patient.

1 – Minimal image of degradation

The caregiver does not perceive significant losses associated with the disease. The patient is described as maintaining their capacity of autonomy and functionality, with no visible changes regarding the pre-disease state. There is no need to adjust or redistribute family roles. The image of the patient is fully preserved.

3 - Reduced image degradation

The caregiver identifies some losses associated to the disease but there are no significant changes in the patient's representation. This may be related to disinvestment in the patient's previous image and/or long processes of deterioration, which create some desensitization to the degradation process. The first case refers to situations in which the patient's previous representation was devalued (e.g., stories of abandonment or affective neglect); in this context, impairment of functional capacity or physical changes have little meaning, either affectively or in practical terms. The second case refers to situations of slow and prolonged evolution in time, in which the caregiver creates habituation to successive losses, thus justifying the reduced emotional impact. In both situations, there may be some expression of commiseration for the degradation, loss of dignity and/or suffering that may cause the patient, but this does not have a significant emotional impact on FC. Instead, the participant is focused mainly on the fatigue related to the increasing demanding in caregiving, due to the patient´s limitations. As a result, he/she may experience some irritability in responding to the patient's difficult behavior, which is generally interpreted as lack of collaboration.

5 - Moderate image degradation

The caregiver demonstrates sensitivity to the patient's physical, mental, behavioral, and functional changes and recognizes their impact in practical and emotional terms. There are clear adaptation efforts to fit this new reality (e.g., "I see that he is very different, he does not have the strength that he had before "," I know that I cannot expect him to do what he did before "). However, the participant demonstrates tolerance and develops compensatory mechanisms to deal with capacity decline (e.g., "I had to adapt things at home"). Emotional impact of the loss reflects into the expression of feelings of sadness when describing the process of degradation of the patient. Possible behavioral changes are viewed as arising from the loss of mental faculties, so they do not have a disruptive impact on the relationship. The caregiver may feel the need to anticipate future losses in order to prepare and mobilize support resources, but the focus is to maintain the patient´s dignity, autonomy and comfort.

7 - High image degradation

The caregiver makes several references to the patient's current losses and fragility. This is visible through a very detailed account of the physical or psychological changes and their implications in terms of care management. When describing the difference of the patient's physical image from the pre-disease stage, it is emphasized the image of vulnerability, resulting from a progressive and gradual process of degradation. The FC is able to adapt procedures to the increasing degree of physical need and to manage with dexterity the care of the patient's body. However, the participant may be exclusively focused on the patient's comfort or physical rehabilitation (e.g., adjusting the space to facilitate movement and/or hygiene of the patient, insisting on physiotherapy treatments), as a way to avoid emotional contact with the reality of losses.

On the other side, the caregiver experiences high anxiety about changes in the patient's behavior (e.g., because he does not want to get out of bed, does not communicate, is not feeding or is more irritated). These behaviours are understood as an attitude of giving up or opposition, instead of being seen as a natural process of evolution of the disease. It should be noted that the attribution that caregivers make of this behavior is usually based in the relationship antecedents (e.g., patient´s authoritarian or conflicting behavior). This perspective on the patient´s behavior corresponds to the FC´s need to maintain the previous relationship with the patient, which denotes difficulty in the adequacy of the image to the current situation.

These people also tend to anticipate with great anxiety future mental ill limitations and/or total loss of autonomy (e.g., "If my husband starts to get insane... this will be very difficult for me to bear", "I do not want her to stay in bed, without autonomy, I did not like to see her like this."). They show particular concern about the impact the degradation may have on the patient, for causing additional suffering and loss of hope (e.g., "My greatest concern is that he doesn’t see himself degraded and lose hope"). This concern usually results from anticipating the difficulty in managing the other´s suffering or projecting one's own fear of degradation (e.g., "If I saw myself like this, I would rather die.").

9 - Extreme image degradation

The caregiver describes complete deterioration of the patient, associated with total dependence. Such an image generates feelings of deep strangeness, confusion and lack of preparation to deal with the current situation (e.g., "The way she is now makes me confused, I cannot deal with it, I cannot do it!"). This state of confusion cannot be attributed to a lack of information or to the uncertainty of the disease (e.g., "I feel strange things happening... no matter how much we read, I never feel ready for these things").

The impact of degradation is greater when the illness evolution is sudden and unexpected. Sometimes the loss of capacities occurs within a few hours/days, causing caregiver´s perplexity (e.g., "In the morning, we managed to get her to the bathroom, but at the evening, she could no longer go."). However, the main criterion for assigning the highest value on this scale is the shock reaction caused by the marked difference from the patient's previous image (e.g., "Just seeing her in that state! The person she was!") or by his state of complete physical deterioration (e.g,, "He is so thin that he even makes me impressed!"). This reaction is perceptible through the use of expressions of strong emotional intensity ("It was a very abrupt difference! It shocked me! It shocked me a lot!").

The inability to adequately represent the patient has negative consequences on the adjustment to the reality of the disease and on the role of caregiver. In some situations, the person expresses the need to retain the previous representation, which implies the fixation on an idealized image that has no correspondence in the current reality (e.g., "I want to continue to feel that he is my father from a few years ago, a strong father, not as he is now... "). As a consequence, the caregiver may be resistant to adequately care for the patient's current difficulties (e.g., to insist that he/she continues to drive in spite of no longer being able to do so). In the case of an adult child, they often feel uncomfortable with the reversal of roles and, especially, having to provide hygiene care. If this situation is perceived by the caregiver as very aversive, it can translate into reluctance to provide care (eg, "I cannot give him/her a shower, I cannot do the hygiene").

In other cases, the main difficulty is in dealing with the patient´s functional losses. Especially in situations where the patient was an autonomous and very active person who until recently assumed important responsibilities in family and/or in professional life, the contrast with the current image of fragility can be disconcerting for the caregiver. The need to readjust roles and take responsibility for the patient can be very disruptive, not only in terms of family dynamics, but also for the self-image of the family member. The caregiver may often feel unable and/or unavailable to compensate for patient failures (e.g., husband who feels incapable of taking on household chores or supporting the study of children because this role was played by the patient). The cumulative effect caused by this destabilization of the individual's sense of normality and quality of life can have a generalized effect, creating in the caregiver the feeling that everything around him, including his own person, is degrading as a reflex of what is happening to the patient.

0. *Not Evaluable or Not Applicable*

1. *Minimal perception of degradation*
Little or no evidence of losses related to the patient´s autonomy and functionality; the other´s image is fully-preserved.

3. *Reduced perception of degradation*
Perception of some losses, without significant changes in the patient's representation, due to disinvestment in the previous image or desensitization in the face of the cumulative effect of the losses.

5. Moderate perception of degradation
Perceived significant losses and some fragility; adaptation of patient´s image; understanding and tolerance towards the reduction of capacities and eventual behavioral changes.

7. High perception of degradation
Perception of various losses, great fragility and degradation of the patient's image; focus on the increasing need for care; high anxiety in managing behavioral changes and anticipating future losses or total loss of autonomy.

9. Extreme perception of degradation
Perception of total dependence and complete degradation of the patient's image; strangeness and shock caused by the contrast with previous representation, impairing the ability to care; generalized effect in various dimensions of the person's life.

4) Anticipation of death

Perception of terminality and threat to the other significant´s life as a result of an advanced and irreversible disease. Low scores in this dimension translate poor awareness of the possibility of death. High scores correspond to the perception of imminent death, lived with many signs of death anxiety.

1 - Minimum anticipation of death
It applies to situations where death is not anticipated because the person is clearly not informed and avoids interpreting the patient's degradation as a sign of terminality. Another possibility is that the patient shows clear signs of recovery, leading the FC to expect the reversion of disease. In the first case, people show evident lack of knowledge about the severity of the disease so they do not suspect that the patient dies in the short term. In the second case, attention is drawn to the aspects of recovery and the possibility of death is not mentioned.

3 - Reduced anticipation of death

This applies when the FC does not perceive death as an imminent or constant threat. There is an implicit idea that the disease is irreversible and there are obvious signs that the person is informed about the prognosis of the disease, but the subject of death is not addressed. This can happen when the caregiver is not significantly affected by the threat of the patient´s death. But it can also be attributed to one's own resistance in addressing the subject of death. In the first case, there are no manifestations of death anxiety related to the disappearance of the patient, although there may be emotional impact related to the illness process. In the second case, the person represses effectively the death anxiety and diverts attention to other less threatening aspects. In both cases, the subject of anticipation of death is not openly discussed, so the presence of specific fears related to the proximity of death or the impact it has on the caregiver's personal life are not perceptible. However, since it is clear from the content of the interview that the person is aware of the patient's terminality (e.g., recognizes evolution and severity and does not express expectation of recovery), it must be acknowledged that there is some awareness of the proximity of death.

5 - Moderate anticipation of death

The caregiver is informed about the prognosis of the disease, recognizes the inevitability of death, and does not intend to extend the patient's life. This subject is discussed openly, accompanied by the expression of sorrow and moderate emotional pain (commotion and crying, with no signs of emotional disorganization). On the other hand, the participant is concerned to ensure that the patient receives the best care; therefore, the attention is not focused on the fear of death, but on the dying process. The FC is interested in involving significant others in the preparations for the end-of-life and requests information on the resources available. Events are anticipated proactively as a way to prepare for eventual difficulties in the management of end-of-life care. These elements evidence that the person is cognitively and emotionally prepared for death; as a result, the level of anxiety related to the anticipation of this event decreases.

7 - High anticipation of death

The person is informed and realizes the physical and mental degradation of the patient. In spite of recognizing that death is a near, the FC does not feel emotionally prepared, especially because of the difficulty in letting go the significant other. Death anxiety manifests itself in the FC´s concern about their own reaction to the other´s death. It may also be reflected in an obstinate investment in caregiving, as a way of prolonging the other´s life and maintaining the illusion of control over death. The threat to the other´s life may also exacerbate concern about one's own mortality, as the participant realizes that the disappearance of the significant other means he/she will be alone and, therefore, more vulnerable to threats.

9 - Extreme anticipation of death

Death-related thoughts are very frequent in the interview, motivated, or not, by obvious signs of patient´s terminality. In the presence of these signs, the person expresses intense fear related to the possibility of, at any moment, face the death. Hence, they may remain hypervigilant (eg, "I wake at the night to make sure he is breathing"), which creates a state of great emotional tension. This fear is usually associated with specific reasons, such as being alone at the time of death, or that the patient dies with great suffering (e.g., dyspnea crisis). In other cases, it may be related to intolerance in the face of the impossibility of predicting the time of death (e.g., "It's today, it's tomorrow, you never know..."; "I'm afraid she´ll die suddenly."). People often relate this fear of death to previous experiences of loss, showing that they continue to influence the way individual thinks and feels in the current situation. When there are no signs of imminent death, anxiety may correspond to an intense reaction to the diagnosis of life-threatening illness.

In these cases, there is a marked oscillation between intrusion and avoidance of thoughts, memories and feelings related to the fear of death. Avoidance may involve more or less conscious strategies of refusing reality (e.g., refusing to talk or thinking about the possibility of death), suppression and distraction (e.g., avoiding the stimulus that reminds one that the patient will die, or watching TV for not to think about what is happening), dissociative states (e.g., periods when the person seems to be disconnected from reality) or compensatory behaviours that reflect the urgent need to guarantee immortality (e.g., procreation, institution affiliation or reinforcement of life beliefs after death). However, avoidance proves to be ineffective in dealing with fear of death, so it manifests itself through a state of generalized anxiety (constant worry, psychomotor agitation, etc.), phobias related to the fear of death (e.g. , fear of getting cancer) or other manifestations of anxiety (e.g., rituals or physical symptoms).

0. Not Evaluable or Not Applicable

1. Minimum anticipation of death
Little or no evidence of death anticipation; insufficient information or perception of a favourable evolution of the disease; threat of death is removed.

3. *Minimum anticipation of death*
Perception of the irreversibility of the disease, but death is not anticipated; without appreciation of threat related to the death of the patient or resistance in addressing the issue.

5. Moderate anticipation of death
Perception of the inevitability of death, with adequate cognitive and emotional preparation; reduced death anxiety, focus on feelings of loss and in the end-of-life caregiving.

7. High anticipation of death
Perception of terminality and cognitive recognition of the proximity of death, but emotionally unprepared; some signs of death anxiety and concern about one's own vulnerability to significant other's death.

9. Extreme anticipation of death
Perception of imminent or constant threat of death; intense death anxiety, oscillation between intrusion and avoidance of thoughts, memories and feelings related to the other´s or one´s own death.

5) Separation Anxiety

Separation anxiety is defined as the concern with separation and loss of the patient. Low scores refer to reduced concern regarding separation and loss of the patient. High scores translate into extreme concern, sense of abandonment and guilt.

1 - Minimum separation anxiety

The theme of the future separation is not mentioned, which may be related to the fact that the person does not anticipate death. Alternatively, death and separation may not constitute a significant threat, in cases of a distant relationship. In both cases, the participant does not express signs of anxiety and/or sadness related to their future absence.

3 - Reduced separation anxiety

These people feel the need to be vigilant to the patient, but show little concern about separation. They tolerate being apart and may even express the desire for some distance because of the need to rest and to have time for themselves. Although in some cases they express concern about future loss, this feeling is mainly associated with fear of the unknown, not necessarily because of the manifestation of sadness and loss related to the patient´s absence (e.g., "One day when he dies, God wants it to last a long time, but I do not know how it's going to be").

5 - Moderate separation anxiety

The participant expresses some concern and feelings of sadness related to the future separation and loss of the significant other, but does not to feel threatened by separation. There may be the need to be present and reinforce the expression of mutual affection in order to finish the relationship. However, the caregiver does not feel disturbed if the patient is no longer able to return the expression of affection because the loss of communication was anticipated and they were able to close any pending issues in a timely manner. The participant tolerates physical separation and demonstrates the capacity to continue autonomously in the patient's absence, anticipating the future without experiencing feelings of deep loneliness. Nevertheless, the FC admits that it will be difficult to adjust to this new reality.

7 - High separation anxiety

In this case, the anticipation of separation and loss causes great concern, given the need to ensure the affection and/or support of the patient. Participant convey the idea of close proximity to the patient (although they do not report specific episodes that demonstrate it) and express a need to preserve the relationship as it was before. Although avoiding thinking about this possibility, it can be shown intense feelings of loneliness and sadness related to the anticipation of the patient's absence. There is great difficulty in prospecting the future life in the absence of the patient (e.g., "I do not want to think about it!"). It can be expressed the desire to die simultaneously with the patient to avoid the pain of separation. Participant is also likely to express feelings of discomfort from being alone and show concern about being unable to care for themselves without the support of others. Therefore, FC is always present and may show some difficulty in tolerating physical separation from the patient (avoid leaving home not to leave the patient alone).

9 - Extreme separation anxiety

Extreme cases of separation anxiety include intense preoccupation and rumination about the possibility of separation, motivated by deep ambivalence and attachment disorganization. Ambivalence translates into the need to be always present and simultaneously in the desire to move away from the patient. Caregivers may, for example, be reluctant to get away from the patient or have urgency to return next to him/her for fear that something bad will happen to their relative in their absence. However, this makes them feel trapped and completely absorbed by the caregiving tasks, thus increasing the desire to escape, thus adding ambivalence to the relationship. Moreover, as the participant interprets separation as abandonment, he/she is prone to experience intense feelings of guilt, which leads them to reinforce their presence to compensate the patient. Additionally, FC shows extreme sensitivity to signs of rejection, so he/she tends to be submissive and dependent on the patient. There is difficulty in making decisions and taking responsibility, as well as disagreeing with the other for fear of losing support or approval. Ambivalence about the future absence is reflected in veiled desire for hastened death, accompanied by a deep sense of helplessness and a negative perspective of the future.

0. Not Evaluable or Not Applicable

1. *Minimum separation anxiety*

Little or no evidence of concern about separation and loss; does not anticipate future separation or demonstrates need for closeness.

3. *Reduced anxiety of separation*
Reduced concern about separation and loss, need for presence only by vigilance; the prospect of future absence of the patient does not generate feelings of loss.

5. *Moderate separation anxiety*
Some concern about separation and loss generates the need to strengthen affection and finalize the relationship; ability to anticipate the patient's future absence without experiencing feelings of helplessness and loneliness.

7. High separation anxiety
Great concern about the separation and loss generated by the need to maintain the affection and/or support of the other significant; intense feelings of loneliness and difficulty in imagining the future absence of the patient.

9*. Extreme Separation Anxiety*
Extreme concern about the separation and loss generated by deep ambivalence related to guilty feelings of abandonment or desire for hastened death of the patient; intense feelings of helplessness and generalized negative perspective of the future life.

6) Relational Losses

Defined as changes in the relationship that affect the sense of attachment to the patient. Low scores in this dimension refer to the perception of few or no changes in the relationship. High scores refer to feelings of intense loss related to permanent longing for the idealized relationship.

1 - Minimal relational losses

Attributed to reports where the changes in the relationship arising from the disease are little or nothing perceptible. This can happen in situations where the manifestations of the disease are not severe enough to modify the dynamics of the relationship. In these cases, the person reports that there has been a normalization of exchanges and does not manifest any feelings of loss. But the absence of feelings of loss may also be related to the fact that people do not value relational aspects, or be a sign of some affective distance in relation to the patient. In the first case, the caregiver is usually focused on other aspects of the disease or on secondary stressors, thus being unable to notice or valuing the existing changes in the relationship. The second case implies that the person experiences some emotional indifference in the face of eventual changes caused by the illness.

3 - Reduced relational losses

The participant feels that the disease does not involve significant relational losses; on the contrary, it helps to strengthen the relationship. These people tend to idealize the relationship, so they focus only on positive aspects, isolating or rationalizing the negative affects related to the frustration of relational needs (e.g., "When you love someone, you think this is another phase of life for be worth"). They do not mention, for example, the loss of reciprocity and intimacy in the relationship. Although they value the quality of the relationship, they are not sensitive to these aspects of the bond, which reflects some avoidance of contact.

5 - Moderate relational losses

It implies the presence of feelings of loss and sadness by the recognition of the changes in the relationship. Participant complains about the impossibility of maintaining the reciprocity and intimacy of the relationship due to the degree of dependence and/or communication failures. FC may also mention projects that did not materialize or the unlived future related to the prospect of seeing the patient happily (e.g., "I would like to feel that she had enjoyed life a little bit”). They often say that they would like to take the patient for a walk, to provide a holiday he/she had never had or to return the love they have previously received.

7 - High relational losses

The person reports strong feelings of loss generated by failures in the sense of belonging, acceptance or protection. FC perceive major changes in the relationship: the patient can no longer assume the role of main source of support and narcissistic investment, which is reflected in a deep relational and affective void. Generally, this situation occurs in relations of exclusivity and mutual dependence, where the presence of the other represents a guarantee of security and stability. When participants realize that they can no longer rely on this source of support, they express intense concern and disorientation and may resist relinquishing the previous relationship. Therefore, FC tend to idealize it, which is visible through descriptors that reveal some exaggeration (e.g., "He is the only person who cares about me", "Without him, I have no one, I am alone", "We did everything together, one did not walk without the other. It was a life of great complicity.")

In other cases, the relationship deteriorates as a result of the illness, causing intense sadness and regret for the loss of the previous relationship (e.g., I know my father adored me, he loves me, but now I'm thinking he's not proud of me anymore."; " We were very close, always hand in hand, now the relationship is different.") This feeling of loss can translate into longing and yearning for the lost relationship (e.g., "If my husband, as he was before, were here, he would not treat me like that"), or generalization to all dimensions of life (e.g., "I miss the life I had.").

9 - Extreme Relational Loss

Corresponds to situations in which the family member experiences a permanent desire for the idealized relationship and loss of expectation of affection. Generally, these people have a history of serious relational failures and view the patient's end-of-life as an opportunity to reconcile or approach. In fact, it is common to see some approximation at this stage, since the caregiver-patient relationship promotes feelings of vulnerability, protection and dependence. Many relatives report that, contrary to what was customary, since the patient is more fragile, the relationship is marked by more demonstrations of attention, exchange of affectionate words or physical contact between both. This creates the expectation that the relationship can evolve to greater approximation, as wished. When relational deprivation occurs in these cases, the family member experiences intense distress for feeling that is missing the opportunity of living the relationship they never had before.

However, for most people, despite some approximation, the serious difficulties of communication remain, as well as a strong imbalance in the relationship equity. Relatives feel that they are more caring and affectionate than they have ever received from the patient, which causes intense ambivalence in the relationship. Another aspect that adds ambivalence are the contradictory feelings elicited by the loss of expectation of affection: on the one hand, participants experiment frustration and revolt by affective deprivation (e.g., "I am very angry because I do not have a kinder mother"); on the other hand, a strong desire for closeness and longing for a connection that never existed (e.g., "I just needed her to look at me like as a mother and we could both create a connection.") However, this desire is not always consciously and openly expressed by the difficulty in assuming the state of great affective deprivation and emotional vulnerability to others.

0. *Not Evaluable or Not Applicable*

1. *Minimal relational losses*
Little or no evidence of relational losses; the relational dynamics were not affected by the disease; devaluation of relational aspects and/or emotional distance in relation to the patient.

3. Reduced relational losses
Relational losses related to illness are reduced; perception of rapprochement of the relationship; tendency to idealize the current relationship and devalue negative affects related to frustration of relational needs.

5. Moderate relational losses
Relational losses due to communication failures and lack of reciprocity in the relationship; sadness for not having accomplished projects or for the not lived future, related mainly to the desire of living happy moments in the company of the ill person.

7. High relational losses
Relational losses generated by failures in the sense of belonging, acceptance and/or protection, in the context of a dependent and exclusive relationship; idealization and yearning for the previous relationship, expressed through intense sadness.

9. Extreme Relational Loss
Feeling of intense loss generated by long history of relational deprivation; loss of expectation of affection and longing for the idealized relationship expressed through strong feelings of frustration, anger and/or anxiety.

7) Sense of protection

Predisposition to provide care to the patient and prevent him/her from experiencing physical and/or emotional suffering. Low scores in this dimension denote a limited response and restricted involvement in care. High scores mean that FC has a compulsive response and intrusive attitudes in managing patient care.

1 - Minimum sense of protection

Attributed to people who refuse or are unable to provide care to the patient. These people avoid contact with the patient's concerns and fragility, and although they may be aware the other's needs, they are very reluctant to dispense their attention and offer help. Participant often feel overwhelmed with their own worries, thus feeling less available to the other. By assuming a secondary role, he/she let the others assume the tasks of primary caregivers. On the other hand, the deactivation of the protection system may be motivated by the fact that the relative does not perceive the other´s needs. This happens in situations where the patient is stable and does not require special care. In other cases, the participant diverts attention and does not value any requests for support. In general, this person has no motivation to provide care, so in cases where there is social pressure to perform this position, they feel uncomfortable and assume defensive positions of flight or anger over others.

3 - Reduced sense of protection

This caregiver assumes responsibility for caring for the patient, but their affective involvement is restricted, and there is no sign of a genuine and compassionate sense of protection (no expressions of affection or any sense of gratification in care are present). Participant feels overload due to the over-responsibility for care and openly expresses the desire to escape this role. Thus, he/she tends to be exclusively functional, focusing attention only on the management of practical aspects (which may imply daily visits to the patient to administer the medication, maintain vigilance at critical times, provide food or support movement), but contact with the patient is as little as possible. The FC feels that the time spent with the patient is wasted, avoids communication about painful things, and rejects attempts to approach the ill relative.

5 - Moderate sense of protection

The caregiver perceives the patient's needs and experiences genuine interest in being present and contributing to the other´s well-being. The participant knows and respects the significant other's preferences, wishes and autonomy. Simultaneously, he/she encourages the patient to maintain abilities and is able to impose limits. In information management, the FC is sensitive to the needs of the patient and respects their will. There may be a tendency to experiment dilemmas in caregiving decisions related to balancing costs and benefits (e.g.., wondering if the patient should do more chemotherapy, deciding if the patient may stay at home or needs to be hospitalized). However, those difficulties in decision making are viewed as an inherent responsibility in careging and they are not associated with guilt or less self-efficacy. The FC has clearly integrated the social value of caring, which translates into the intrinsic motivation to provide help, as well as the ability to express love, respect and solidarity for the other. The participant regards care as an end in itself, which gives value and meaning to his/her life.

7 - High sense of protection

The participant is intensely concerned with responding to the patient´s needs, although very permeable to the moral duty of care (e.g., marital or filial obligation, obligation to return the care he/she received from the patient). There is a tendency to overprotect the patient and to avoid at all costs his suffering; however, as FC is extremely zealous of the other´s needs, feelings and wills, he/she often abdicates his/her own needs to respond to the patient's, in a passive and submissive way.

The caregiver tends to experience great uncertainties and dilemmas related to the decision making (e.g., persistent doubt about decisions that have been made because of the impact they may have on the patient; difficulty in addressing the issue of palliative care for fear of a reaction negative, reluctance to admit the patient because they feel that this can be seen as abandonment). These dilemmas are associated with great anxiety and fear of disillusioning the patient, so often the participant is blocked and unable to make the decision. Doubts can also be raised regarding the management of information about the illness: on the one hand, they need to protect themselves and the patient from the impact of information, on the other, they wonder what the patient thinks about this.

They feel the need to know the patient's thoughts and wish to be close to them, but they are inhibited mainly by the fear of causing them psychological suffering. FC feel unauthorized to express their feelings either because of his/her need to protect the patient or to follow the other´s desire not to address the issue of illness and death (in the caregiver-sick relationship or with others).

All his actions are driven by the goal of avoiding inflicting any harm on the significant other, and at the same time trying to compensate the patient for the suffering he is living. Hence, they tend to submit themselves to the other´s will and seldom contradict the patient. When sometimes they feel the need to assert themselves, they do it with difficulty and experience feelings of guilt, which they tend to rationalize by thinking they are doing the best for the patient (e.g., "I had to put a brave face for him to eat"). Although they may feel exhausted for caring for the patient, they avoid to transmit this feeling to prevent the patient from feeling a burden. Their goal is to think they are doing well, to avoid guilty feelings for making inappropriate decisions.

9 - Extreme sense of protection

It applies to people who understand that the patient is exclusively dependent on them and exhibit a pattern of compulsive response to the needs of the other, manifesting intrusive and overprotective attitudes in care management, which may imply disrespect for the patient's autonomy and will. An example of this is the caregiver who is permanently and exclusively involved, exercising dominating control, with a restrictive effect on the behavior of the other. In attempting to implement her care plan, he/she overrides the patient, making decisions that she considers to be for her benefit, in an authoritarian and/or paternalistic way (eg, "It has to be this way, I do what is best for her! "). The FC may tend to infantile or devalue the patient's will, even if the intention is to provide him/her with the best conditions. They do it from a strictly functional and practical point of view, without regard to emotional aspects.

This controlling attitude also manifests itself through the conspiracy of silence, which consists in attempting to conceal the clinical information to the patient, based on the conviction that this is protective, but without questioning its harmful consequences.

Generally, such a position results from the perception that the patient does not want to be informed about the severity of his condition, but the FC assumes the role of decision maker in a more or less authoritarian way. Underlying this attitude is the need to control and subjugate the patient (or other family members) as a sublimated expression of resentment feelings towards the patient and the role of caregiver (e.g., "He has always treated me badly, but now it´s me who is there to take care of him! "). However, the impossibility of controlling all aspects of care and, on the other hand, the frustration of their need to be valued, are reasons for great distress in caregiving. Therefore, along with the illusion of control, there may be intense feelings of dissatisfaction and anger related to the deprivation of one's own emotional needs.

0. Not Evaluable or Not Applicable

1. Minimal sense of protection
Little or no evidence of response to the patient's needs; self-protection and unwillingness to dedicate to the other; lack of perception or devaluing the other´s needs.

3. Reduced sense of protection
Limited response to patient needs, with restricted and/or uncaring involvement in care; minimum care, with little motivation for caregiving.

5. Moderate sense of protection
Sensitive response to the patient´s needs, empathic and affective care, with respect for the will and autonomy of the patient; ability to adjust attitudes and communication according to the needs of the other; intrinsic motivation for caregiving.

7. High sense of protection
Persistent preoccupation in responding to the patient´s needs, with attitudes of compensation and submission to the other´s wishes; caregiving dilemmas caused by the intention to protect the patient from all psychological suffering; need to feel that they are doing well in order to prevent feelings of guilt.

9. Extreme sense of protection
Compulsive response to the patient´s needs, overprotective and intrusive attitudes in the management of care, tending to infantile, devalue or overlap the patient's will; restrictive control as a means of ventilating resentment towards the patient and the role of caregiver.

8) Impotence of caregiving

Impotence refers to the sensing of failure to protect the patient. Low scores in this dimension apply to caregivers who do not show impotence or attribute caregiving difficulties to external factors. High scores are characteristic of the participants who assume the evolution of the disease with feelings of personal failure, guilt and/or intense revolt.

1 - Minimal impotence of caregiving

The minimum value on this scale is attributed to people who do not feel threatened by illness or caregiving conditions or, on the other hand, can minimize this sense of threat by covering up signs of disability and frustration. The first case corresponds to situations in which the disease remains stable and there are no symptoms of difficult management. It can also happen in the context of a distant relationship, marked by a great affective disinvestment, in which the person does not feel affected by the inability to protect the other.

3 - Reduced impotence of caregiving

People with reduced impotence manifest confidence in their ability to manage the disease process and are not confronted with feelings of frustration related to the limits of care. Generally, these caregivers do not question their ability to care because they perceive that they expend great effort and are providing every possible care to the patient. There is an effort to maintain the illusion of control through a positive reinterpretation of events and/or a denial of the threat. Thus, the participant can maintain self-efficacy in caring and feel rewarded for its efforts, which enhances the sense of confidence. Although the FC can admit some difficulties, especially in critical situations, he/she has a determined attitude in the management of care and mobilizing resources. Hence, there are no feelings of impotence due to failures in the protection of the patient.

However, they acknowledge that, due to external causes (e.g. previous patient´s negligence, lack of collaboration of other relatives or professionals´ failure), may have occurred some failures and difficulties in managing the illness. Their sense of impotence does not refer to the difficulty in controlling their symptoms, but above all, to the harmful role of these external agents. This is the case, for example, of the family member who is angry with the attitude of others, and therefore tends to project much of their frustration as a caregiver. In other cases, the greatest difficulty is managing the patient's behavior. When the other refuses to adhere to care or to collaborate, it can be frustrating for the caregiver who feels unable to carry out what he/she feels would be best for the patient. However, this sense of helplessness is not experienced with a sense of failure of protection, but rather as an obstacle that prevents it from realizing its intention.

In other situations, it is not possible to identify an external agent, but the distress of the situation ends up generating frustration and disinvestment in caring. In general, these caregivers show some resignation before the limits of care and do not experience feelings of helplessness in the face of the impossibility of reversing the patient's current situation (e.g., "I am very sorry but it is not in my hands"; "I cannot do more than what I did ").

5 - Moderate impotence of caregiving

The level of moderate impotence applies to people who demonstrate that they are aware of their inability to reverse the disease, but fell self-efficacy in managing care. They admit that there may have been faults in the process of diagnosis or treatment that will have contributed to the evolution of the disease, but show some resignation to the events and recognize their irreversibility, focusing on the current demands of care. They recognize the limits of care and assume their impotence to reverse the evolution of the disease without experiencing feelings of guilt or revolt. Instead, they express their sadness at confronting the limits - theirs, as caregiver, and those of the patient, for their inability to continue to resist disease -, which mobilizes them to letting go. As a result, they give up futile treatments and feel compensated for the fact that they can contribute to reducing the patient's discomfort.

They perceive that they are reasonably effective in managing the symptoms and do not experience feelings of helplessness or frustration related to the inability to control the patient's symptoms (e.g., "When he has pain, I have to give him that medicine. And then he can rest"). However, in crisis situations they may experience more difficulties and recognize that if care becomes too complex, they may not be able to continue to care and in that case, they will have to mobilize other resources. The realization that support is available and easily accessible is crucial to ensuring a sense of security and personal competence.

7 - High impotence of caregiving

It applies to a group of caregivers who manifest a strong feeling of impotence related to great difficulties in caregiving, motivated by the perception of low self-efficacy in controlling symptoms, in the management of the patient's feelings and behavior or in its capacity to manage the distress. These people develop an intense effort to counteract the evolution of symptoms, in the expectation of achieving the patient's complete physical and emotional well-being, or to obtain some prolongation of life (e.g., stimulating the patient to continue talking, eating or getting out of bed, hoping it will keep him alive).

This means that they maintain unrealistic expectations regarding the current disease and have difficulty recognizing the limits of care. It is hard for them to tolerate, for example, that it is not within their reach to recover the patient´s mood or their ability to communicate. Thus, given the inability to reverse the clinical picture and achieve the goals for which they proposed, they realize that they are no longer able to respond effectively to the needs of the patient (e.g., "I feel helpless. So far, I could handle this, but not now..."; "It's horrible, we cannot do anything "). They anticipate that, soon, this task will become more complicated and exhausting (e.g.," This will be more and more difficult. If he falls, this will be very difficult because I do not have the strength to grab him").

As a result, they may tend to ruminate over the impotence they feel in the face of disease progression. They are also prone to experience guilt or resentment stemming from failures in the process of diagnosis or treatment, but these feelings are not overtly expressed (e.g., "I know everyone does what is possible"). They are therefore overwhelmed by unpleasant feelings of frustration and helplessness that have difficulty managing internally and/or in relation to the patient. This leads them to fear for their own health and to question their ability to continue to care.

9 - Extreme impotence of caregiving

It corresponds to situations in which the caregiver experiences an intense personal failure related to the inability to prevent the progression of the disease and simultaneously maintains the illusion of control through a counterfactual ruminant thinking style. This means that the person refuses reality and continues to fantasize about alternatives to the current situation (eg, "If I had done... then this would not have happened"). These caregivers have difficulty admitting the personal limits of care, so the progressive deterioration of the patient is more easily attributed to a failure in their protective role than to external and unmanageable factors.

As a result, they blame themselves for not being able to anticipate and prevent the current situation. In other cases, there is a strong revolt, usually directed at health professionals or other family members, due to perceived neglect, abandonment or diagnostic failures. The revolt is also addressed to the patient when the person realizes that the significant other is giving up or has not had the appropriate attitudes to protect themselves against the disease. In either situation, there is the feeling of guilt (internalized or externalized) that stems from the belief that the current situation was preventable if it had anticipated future events and acted differently.

On the other hand, the illusion of control can be translated into the magical thought of omnipotence based on the conviction that it may still be possible to "save the life” of the ill relative. Often, this conviction results from past experience in which it was possible to reverse a serious illness or imminence of death. This happens, for example, when the caregiver has gone through a limit situation and has managed to recover, generating the expectation that this can be repeated. In other cases, the caregiver was capable of a "heroic" gesture that helped to avoid the death of the patient, leading him to believe that if he is present, he will have this opportunity again. However, this expectation of control also leaves room for an intense fear of failure. When they are finally confronted with the impossibility of control, they experience a feeling of utter helplessness and desperation (e.g., "Now there is no giving back.", "If it were up to me, she would already be cured. If I had that power!").

0. Not Evaluable or Not Applicable

1. Minimal impotence of caregiver

Little or no evidence of impotence feelings; not aware of or minimizes the threat of the disease; keeps the illusion of control and a high sense of self-efficacy in managing care.

3. Reduced impotence of caregiver

Some feeling of impotence related to external causes; does not experience lack of sense of protection or helplessness for not being able to reverse the disease, but mainly frustration because of the difficulty in controlling the situation.

5. Moderate impotence of caregiver

Feeling of impotence related to the recognition of the limits of care and perception of inability to reverse the disease; perception of self-efficacy in the management of symptoms and in one's ability to manage distress.

7. High impotence of caregiver

Strong feeling of impotence related to serious difficulties in caregiving, due to the expectation of reversion the clinical situation; perception of inability to respond to the needs of the patient and management of the distress itself; tendency to feelings of helplessness, but without open expression of guilt or revolt.

9. Extreme Impotence of caregiver

Intense feelings of personal failure, lived with guilt and/or revolt; difficulty in recognizing the limits of care; ruminative counterfactual thinking with a focus on healing and fantasy about alternatives to the current situation; perception that the evolution of the disease was preventable if events were anticipated.

ATTACHMENT 3

INFORMED CONSENT, QUESTIONNAIRES AND ASSESSMENT INSTRUMENTS

CONSENTIMENTO INFORMADO:

É fundamental para nós conhecer os aspetos que o/a estão a afetar neste período, de modo a criar um plano de intervenção que vá de encontro às suas necessidades.

Para isso, vou pedir a sua colaboração para a realização de uma entrevista que visa detetar os agentes que mais contribuem para a vulnerabilidade dos familiares, ou que, por outro lado, parecem facilitar a adaptação às atuais circunstâncias.

Esta entrevista insere-se num trabalho de investigação realizado no âmbito da Faculdade de Medicina da Universidade de Lisboa, em colaboração com a Equipa Intra-Hospitalar de Suporte em Cuidados paliativos

A sua participação será voluntária e a seleção dos participantes aleatória. A entrevista demorará cerca de 50 minutos, mas se considerar preferível, poderemos dividi-la em dois momentos. Poderá escolher interromper a entrevista em qualquer momento, sem que isso tenha nenhuma implicação.

Caso aceite participar, peço autorização para fazer a gravação audio dos dados da entrevista, apenas para garantir a fidelidade das informações em análise. A confidencialidade dos dados será garantida.

Fui informado sobre os objetivos da presente investigação e concordo voluntariamente em participar na realização da entrevista.

___________________________________	______________________________
(Participante)	(Entrevistador)

T1

DADOS SOCIODEMOGRÁFICOS

Sexo: F M

Data de Nascimento ___ / ___ / ___ Idade: _____

Nacionalidade: Portuguesa Estrangeira Indique: _________________________

Estado Civil:

Solteiro(a) Casado(a)/ União de facto Divorciado(a) Viúvo(a)

Parentesco:

Cônjuge/Companheiro(a) Filho/a Pai/Mãe Irmão/ã Sogro/a

Sobrinho/a Genro/nora Neto/a Tio/a Outro

Escolaridade:

Sabe ler e escrever 1º ciclo 2º ciclo 3º ciclo E. Secundário

E. tecnológico Licenciatura Mestrado Doutoramento

Cohabita com o doente? Sim ☐ Não

PERCEÇÃO DA DOENÇA

1. Neste momento, como vê o estado de saúde do seu familiar?
1. Muito mau
2. Mau
3. Razoável
4. Bom
5. Muito bom

2. Estava à espera deste diagnóstico?
1. Nada
2. Pouco
3. Moderadamente
4. Bastante
5. Totalmente

3. Esperava que a doença evoluísse desta maneira?
1. Nada
2. Pouco
3. Moderadamente
4. Bastante
5. Totalmente

ENVOLVIMENTO NOS CUIDADOS

1. Há quanto tempo está envolvido(a) nos cuidados ao doente?
1. Menos de 3 meses
2. Entre 3 e 6 meses
3. Entre 6 meses e um ano
4. Entre um a dois anos
5. Mais de 2 anos

2. Ao longo da última semana quanto tempo dedicou por dia, em média, a ajudar o doente?
1. Até 2h
2. Entre 2 e 4 h
3. Entre 4 e 8 h
4. Entre 8 e 16 h
5. Mais de 16 h

AVALIAÇÃO DA SOBRECARGA - ZARIT

INSTRUÇÕES: Em seguida, apresentamos uma lista de perguntas que refletem a forma como as pessoas por vezes se sentem quando tomam conta de outra pessoa. Depois de cada pergunta, indique com que frequência se sente dessa forma: nunca, raramente, por vezes, muito frequentemente ou quase sempre. Não existem respostas certas ou erradas.

1. Sente que o seu familiar pede mais ajuda do que a que ele precisa?
0. Nunca 1. Raramente 2. Por vezes 3. Muito frequentemente 4. Quase sempre

2. Sente que, por causa do tempo que dedica ao seu familiar, não tem tempo suficiente para si próprio/a?
0. Nunca 1. Raramente 2. Por vezes 3. Muito frequentemente 4. Quase sempre

3. Sente-se stressado/a por ter de tomar conta do seu familiar e de tentar cumprir outras responsabilidades familiares ou profissionais?
0. Nunca 1. Raramente 2. Por vezes 3. Muito frequentemente 4. Quase sempre

4. Sente-se envergonhado/a com o comportamento do seu familiar?
0. Nunca 1. Raramente 2. Por vezes 3. Muito frequentemente 4. Quase sempre

5. Sente-se zangado/a quando está com o seu familiar?
0. Nunca 1. Raramente 2. Por vezes 3. Muito frequentemente 4. Quase sempre

6. Sente que o seu familiar prejudica presentemente o seu relacionamento com outros elementos da família ou amigos?
0. Nunca 1. Raramente 2. Por vezes 3. Muito frequentemente 4. Quase sempre

7. Teme o que o futuro reserva ao seu familiar?
0. Nunca 1. Raramente 2. Por vezes 3. Muito frequentemente 4. Quase sempre

8. Sente que o seu familiar está dependente de si?
0. Nunca 1. Raramente 2. Por vezes 3. Muito frequentemente 4. Quase sempre

9. Sente-se nervoso/a quando está com o seu familiar?
0. Nunca 1. Raramente 2. Por vezes 3. Muito frequentemente 4. Quase sempre

10. Sente que a sua saúde foi prejudicada devido ao seu envolvimento com o seu familiar?
0. Nunca 1. Raramente 2. Por vezes 3. Muito frequentemente 4. Quase sempre

11. Sente que não dispõe de tanta privacidade como gostaria de ter por causa do seu familiar?
0. Nunca 1. Raramente 2. Por vezes 3. Muito frequentemente 4. Quase sempre

12. Sente que a sua vida social foi prejudicada por estar a tomar conta do seu familiar?
0. Nunca 1. Raramente 2. Por vezes 3. Muito frequentemente 4. Quase sempre

13. Sente-se desconfortável, ao receber visitas de amigos, por causa do seu familiar?
0. Nunca 1. Raramente 2. Por vezes 3. Muito frequentemente 4. Quase sempre

14. Sente que o seu familiar parece esperar que tome conta dele, como se você fosse a única pessoa de quem ele pode depender?
0. Nunca 1. Raramente 2. Por vezes 3. Muito frequentemente 4. Quase sempre

15. Sente que, para além das suas outras despesas, não tem dinheiro suficiente para cuidar do seu familiar?
0. Nunca 1. Raramente 2. Por vezes 3. Muito frequentemente 4. Quase sempre

16. Sente que não será capaz de tomar conta do seu familiar por muito mais tempo?
0. Nunca 1. Raramente 2. Por vezes 3. Muito frequentemente 4. Quase sempre

17. Sente que perdeu o controlo sobre a sua vida desde que o seu familiar adoeceu?
0. Nunca 1. Raramente 2. Por vezes 3. Muito frequentemente 4. Quase sempre

18. Gostaria de poder, simplesmente, entregar o seu familiar aos cuidados de outra pessoa?
0. Nunca 1. Raramente 2. Por vezes 3. Muito frequentemente 4. Quase sempre

19. Sente-se indeciso/a quanto ao que fazer em relação ao seu familiar?
0. Nunca 1. Raramente 2. Por vezes 3. Muito frequentemente 4. Quase sempre

20. Sente que deveria estar a fazer mais pelo seu familiar?
0. Nunca 1. Raramente 2. Por vezes 3. Muito frequentemente 4. Quase sempre

21. Sente que poderia fazer melhor ao tomar conta do seu familiar?
0. Nunca 1. Raramente 2. Por vezes 3. Muito frequentemente 4. Quase sempre

22. De um modo geral, até que ponto se sente sobrecarregado/a por tomar conta do seu familiar?
0. Nada 1. Um pouco 2. Moderadamente 3. Bastante 4. Extremamente

AVALIAÇÃO DAS ESTRATÉGIAS DE COPING – BRIEF COPE

Os itens que vai encontrar abaixo exprimem o modo como lida com o stress neste processo de adaptação à doença. Há muitas maneiras de lidar com o stress/situações de dificuldade e estes itens questionam o que tem feito para lidar com a doença do seu familiar. Obviamente, diferentes pessoas lidam com as situações de modo diferente, mas estamos interessados no modo como você tentou lidar com a situação. Queremos saber em que medida faz aquilo que o item diz ou com que frequência. Não responda com base no que lhe parece ser mais eficaz, mas apenas se o tem feito ou não. Tente classificar cada item individualmente. Assinale a opção que melhor se adequa a si.

1. Refugio-me noutras atividades para me abstrair da situação
1. Nunca faço isto 2. Faço isto por vezes 3. Em média faço isto 4. Faço quase sempre isto

2. Concentro os meus esforços para fazer alguma coisa que me permita enfrentar a situação
1. Nunca faço isto 2. Faço isto por vezes 3. Em média faço isto 4. Faço quase sempre isto

3. Tenho dito para mim próprio (a): “isto não é verdade”
1. Nunca faço isto 2. Faço isto por vezes 3. Em média faço isto 4. Faço quase sempre isto

4. Refugio-me no álcool ou noutras drogas (comprimidos, etc.) para me sentir melhor
1. Nunca faço isto 2. Faço isto por vezes 3. Em média faço isto 4. Faço quase sempre isto

5. Procuro apoio emocional de alguém (família, amigos)
1. Nunca faço isto 2. Faço isto por vezes 3. Em média faço isto 4. Faço quase sempre isto

6. Simplesmente desisto de tentar lidar com isto
1. Nunca faço isto 2. Faço isto por vezes 3. Em média faço isto 4. Faço quase sempre isto

7. Tomo medidas para tentar melhorar a minha situação
1. Nunca faço isto 2. Faço isto por vezes 3. Em média faço isto 4. Faço quase sempre isto

8. Recuso-me a acreditar que isto esteja a acontecer comigo
1. Nunca faço isto 2. Faço isto por vezes 3. Em média faço isto 4. Faço quase sempre isto

9. Fico aborrecido e expresso os meus sentimentos
1. Nunca faço isto 2. Faço isto por vezes 3. Em média faço isto 4. Faço quase sempre isto

10. Peço conselhos e ajuda a outras pessoas para enfrentar melhor a situação
1. Nunca faço isto 2. Faço isto por vezes 3. Em média faço isto 4. Faço quase sempre isto

11. Uso álcool ou outras drogas (comprimidos) para me ajudar a ultrapassar os problemas
1. Nunca faço isto 2. Faço isto por vezes 3. Em média faço isto 4. Faço quase sempre isto

12. Tento analisar a situação de maneira diferente, de forma a torná-la mais positiva
1. Nunca faço isto 2. Faço isto por vezes 3. Em média faço isto 4. Faço quase sempre isto

13. Faço críticas a mim próprio
1. Nunca faço isto 2. Faço isto por vezes 3. Em média faço isto 4. Faço quase sempre isto

14. Tento encontrar uma estratégia que me ajude no que tenho que fazer
1. Nunca faço isto 2. Faço isto por vezes 3. Em média faço isto 4. Faço quase sempre isto

15. Procuro o conforto e compreensão de alguém
1. Nunca faço isto 2. Faço isto por vezes 3. Em média faço isto 4. Faço quase sempre isto

16. Desisto de me esforçar para lidar com a situação
1. Nunca faço isto 2. Faço isto por vezes 3. Em média faço isto 4. Faço quase sempre isto

17. Procuro algo positivo em tudo o que está a acontecer
1. Nunca faço isto 2. Faço isto por vezes 3. Em média faço isto 4. Faço quase sempre isto

18. Enfrento a situação levando-a para a brincadeira
1. Nunca faço isto 2. Faço isto por vezes 3. Em média faço isto 4. Faço quase sempre isto

19. Faço outras coisas para pensar menos na situação, tal como ir ao cinema, ver TV, ler, sonhar ou ir às compras
1. Nunca faço isto 2. Faço isto por vezes 3. Em média faço isto 4. Faço quase sempre isto

20. Tento aceitar as coisas tal como estão a acontecer
1. Nunca faço isto 2. Faço isto por vezes 3. Em média faço isto 4. Faço quase sempre isto

21. Sinto e expresso os meus sentimentos de aborrecimento
1. Nunca faço isto 2. Faço isto por vezes 3. Em média faço isto 4. Faço quase sempre isto

22. Tento encontrar conforto na minha religião ou crença espiritual
1. Nunca faço isto 2. Faço isto por vezes 3. Em média faço isto 4. Faço quase sempre isto

23. Peço conselhos e ajuda a pessoas que passaram pelo mesmo
1. Nunca faço isto 2. Faço isto por vezes 3. Em média faço isto 4. Faço quase sempre isto

24. Tento aprender a viver com a situação
1. Nunca faço isto 2. Faço isto por vezes 3. Em média faço isto 4. Faço quase sempre isto

25. Penso muito sobre a melhor forma de lidar com a situação
1. Nunca faço isto 2. Faço isto por vezes 3. Em média faço isto 4. Faço quase sempre isto

26. Culpo-me pelo que está a acontecer
1. Nunca faço isto 2. Faço isto por vezes 3. Em média faço isto 4. Faço quase sempre isto

27. Rezo ou medito
1. Nunca faço isto 2. Faço isto por vezes 3. Em média faço isto 4. Faço quase sempre isto

28. Enfrento a situação com sentido de humor
1. Nunca faço isto 2. Faço isto por vezes 3. Em média faço isto 4. Faço quase sempre isto

AVALIAÇÃO DA QUALIDADE DA RELAÇÃO COM O DOENTE

1. Sente que a presença dele/a lhe traz conforto?
1. Nada 2. Pouco 3. Razoavelmente 4. Bastante 5. Muito

2. Sente que a presença dele/a o/a faz sentir-se seguro/a
1. Nada 2. Pouco 3. Razoavelmente 4. Bastante 5. Muito

3. A relação com o seu familiar é marcada por muitas discussões e conflitos?
1. Nada 2. Pouco 3. Razoavelmente 4. Bastante 5. Muito

4. Sente que gosta muito do seu familiar, apesar de estarem muitas vezes zangados?
1. Nada 2. Pouco 3. Razoavelmente 4. Bastante 5. Muito

5. A relação com o seu familiar o/a fá-lo sentir-se acarinhado/a ?
1. Nada 2. Pouco 3. Razoavelmente 4. Bastante 5. Muito

6. Precisa de estar perto dele/a para se sentir bem?
1. Nada 2. Pouco 3. Razoavelmente 4. Bastante 5. Muito

7. Sente que para viverem bem tem que fazer tudo à maneira do seu familiar?
1. Nada 2. Pouco 3. Razoavelmente 4. Bastante 5. Muito

8. Sente-se magoado/a com coisas que o seu familiar faz ou diz?
1. Nada 2. Pouco 3. Razoavelmente 4. Bastante 5. Muito

AVALIAÇÃO DOS SINTOMAS DE DEPRESSÃO, ANSIEDADE E SOMATIZAÇÃO - BSI

A seguir encontra-se uma lista de problemas ou sintomas que por vezes as pessoas apresentam. Assinale, num dos espaços à direita de cada sintoma, aquele que melhor descreve o GRAU EM QUE CADA PROBLEMA O INCOMODOU DURANTE A ÚLTIMA SEMANA. Para cada problema ou sintoma marque apenas um espaço com uma cruz. Não deixe nenhuma pergunta por responder.

1. Nervosismo ou tensão interior.
0. Nunca 1. Poucas vezes 2. Algumas vezes 3. Muitas vezes 4. Muitíssimas vezes

2. Desmaios ou tonturas.
0. Nunca 1. Poucas vezes 2. Algumas vezes 3. Muitas vezes 4. Muitíssimas vezes

3. Dores sobre o coração ou no peito.
0. Nunca 1. Poucas vezes 2. Algumas vezes 3. Muitas vezes 4. Muitíssimas vezes

4. Pensamentos de acabar com a vida.
0. Nunca 1. Poucas vezes 2. Algumas vezes 3. Muitas vezes 4. Muitíssimas vezes

5. Ter um medo súbito sem razão para isso.
0. Nunca 1. Poucas vezes 2. Algumas vezes 3. Muitas vezes 4. Muitíssimas vezes

6. Sentir-se sozinho.
0. Nunca 1. Poucas vezes 2. Algumas vezes 3. Muitas vezes 4. Muitíssimas vezes

7. Sentir-se triste.
0. Nunca 1. Poucas vezes 2. Algumas vezes 3. Muitas vezes 4. Muitíssimas vezes

8. Não ter interesse por nada.
0. Nunca 1. Poucas vezes 2. Algumas vezes 3. Muitas vezes 4. Muitíssimas vezes

9. Sentir-se atemorizado.
0. Nunca 1. Poucas vezes 2. Algumas vezes 3. Muitas vezes 4. Muitíssimas vezes

10. Vontade de vomitar ou mal-estar no estômago.
0. Nunca 1. Poucas vezes 2. Algumas vezes 3. Muitas vezes 4. Muitíssimas vezes

11. Sensação de que lhe falta o ar.
0. Nunca 1. Poucas vezes 2. Algumas vezes 3. Muitas vezes 4. Muitíssimas vezes

12. Calafrios ou afrontamentos.
0. Nunca 1. Poucas vezes 2. Algumas vezes 3. Muitas vezes 4. Muitíssimas vezes

13. Sensação de anestesia (encortiçamento ou formigueiro) no corpo.
0. Nunca 1. Poucas vezes 2. Algumas vezes 3. Muitas vezes 4. Muitíssimas vezes

14. Sentir-se sem esperança perante o futuro.
0. Nunca 1. Poucas vezes 2. Algumas vezes 3. Muitas vezes 4. Muitíssimas vezes

15. Falta de forças em partes do corpo.
0. Nunca 1. Poucas vezes 2. Algumas vezes 3. Muitas vezes 4. Muitíssimas vezes

16. Sentir-se em estado de tensão ou aflição.
0. Nunca 1. Poucas vezes 2. Algumas vezes 3. Muitas vezes 4. Muitíssimas vezes

17. Ter ataques de terror ou pânico.
0. Nunca 1. Poucas vezes 2. Algumas vezes 3. Muitas vezes 4. Muitíssimas vezes

18. Sentir-se tão desassossegado que não consegue manter-se sentado quieto.
0. Nunca 1. Poucas vezes 2. Algumas vezes 3. Muitas vezes 4. Muitíssimas vezes

19. Sentir que não tem valor.
0. Nunca 1. Poucas vezes 2. Algumas vezes 3. Muitas vezes 4. Muitíssimas vezes

AVALIAÇÃO DOS SINTOMAS DE LUTO PRÉ-MORTE - PG-12

Instruções. Assinale com um X a sua resposta em relação a cada item.

1. No último mês, quantas vezes sentiu saudade ou anseio de ver a/o seu familiar saudável?
1. Quase nunca
2. Pelo menos uma vez
3. Pelo menos uma vez por semana
4. Pelo menos uma vez por dia
5. Várias vezes por dia

2. No último mês, quantas vezes sentiu intensa dor emocional, tristeza/pesar ou episódios de tensão relacionados com a doença da/o seu familiar?
1. Quase nunca
2. Pelo menos uma vez
3. Pelo menos uma vez por semana
4. Pelo menos uma vez por dia
5. Várias vezes por dia

3. No último mês, quantas vezes tentou evitar contacto com tudo o que lhe faz lembrar que a/o seu familiar está doente?
1. Quase nunca
2. Pelo menos uma vez
3. Pelo menos uma vez por semana
4. Pelo menos uma vez por dia
5. Várias vezes por dia

4. No último mês, quantas vezes se sentiu estonteada/o, chocada/o ou confusa/o pela doença da/o seu familiar?
1. Quase nunca
2. Pelo menos uma vez
3. Pelo menos uma vez por semana
4. Pelo menos uma vez por dia
5. Várias vezes por dia

5. Sente-se confusa/o quanto ao seu papel na vida ou sente que não sabe tão bem quem é (i.e., sente que uma parte de si morreu)?
1. Não, de todo
2. Ligeiramente
3. Razoavelmente
4. Bastante
5. Extremamente

6. Tem tido dificuldade em aceitar a doença dela/e (doente)?
1. Não, de todo

2. Ligeiramente
3. Razoavelmente
4. Bastante
5. Extremamente

7. Tem tido dificuldade em confiar nos outros desde que ela/e (doente) ficou doente?
1. Não, de todo
2. Ligeiramente
3. Razoavelmente
4. Bastante
5. Extremamente

8. Sente amargura pela doença dela/e (doente)?
1. Não, de todo
2. Ligeiramente
3. Razoavelmente
4. Bastante
5. Extremamente

9. Sente que continuar com a sua vida (por exemplo, fazer novos amigos, ter novos interesses) seria difícil neste momento?
1. Não, de todo
2. Ligeiramente
3. Razoavelmente
4. Bastante
5. Extremamente

10. Sente-se emocionalmente entorpecida/o desde que ela/e (doente) ficou doente?
1. Não, de todo
2. Ligeiramente
3. Razoavelmente
4. Bastante
5. Extremamente

11. Sente que a sua vida é insatisfatória, vazia ou sem significado desde que ela/e (doente) ficou doente?
1. Não, de todo
2. Ligeiramente
3. Razoavelmente
4. Bastante
5. Extremamente

12. Sentiu uma redução significativa na sua vida social, profissional ou em outras áreas importantes (por exemplo, responsabilidades domésticas)?
0. Não 1. Sim

T2

AVALIAÇÃO DA PERTURBAÇÃO DE LUTO PROLONGADO - PG13

Instruções. Assinale com um X a sua resposta em relação a cada item.

1. No último mês, quantas vezes sentiu saudades e a ausência da pessoa que perdeu?
1. Quase nunca
2. Pelo menos uma vez
3. Pelo menos uma vez por semana
4. Pelo menos uma vez por dia
5. Várias vezes por dia

2. No último mês, quantas vezes sentiu intensa dor emocional, tristeza/pesar ou episódios de tensão relacionados com a relação perdida?
1. Quase nunca
2. Pelo menos uma vez
3. Pelo menos uma vez por semana
4. Pelo menos uma vez por dia
5. Várias vezes por dia

3. Relativamente às questões 1 e 2, teve essa experiência pelo menos diariamente, por um período de, pelo menos, 6 meses?
0. Não 1. Sim

4. No último mês, quantas vezes tentou evitar contacto com tudo o que lhe faz lembrar que a pessoa realmente faleceu?
1. Quase nunca
2. Pelo menos uma vez
3. Pelo menos uma vez por semana
4. Pelo menos uma vez por dia
5. Várias vezes por dia

5. No último mês, quantas vezes se sentiu estonteado, chocado/a ou confuso pela sua perda?
1. Quase nunca
2. Pelo menos uma vez
3. Pelo menos uma vez por semana
4. Pelo menos uma vez por dia
5. Várias vezes por dia

6. Sente-se confuso/a quanto ao seu papel na vida ou sente que não sabe quem é desde a sua perda (i.e., sente que uma parte de si morreu)?
1. Não, de todo
2. Ligeiramente
3. Razoavelmente

4. Bastante
5. Extremamente

7. Tem tido dificuldade em aceitar a perda?
1. Não, de todo
2. Ligeiramente
3. Razoavelmente
4. Bastante
5. Extremamente

8. Tem tido dificuldade em confiar nos outros desde a perda?
1. Não, de todo
2. Ligeiramente
3. Razoavelmente
4. Bastante
5. Extremamente

9. Sente amargura pela sua perda?
1. Não, de todo
2. Ligeiramente
3. Razoavelmente
4. Bastante
5. Extremamente

10. Sente ainda dificuldade em continuar com a sua vida (por exemplo, fazer novos amigos, ter novos interesses)?
1. Não, de todo
2. Ligeiramente
3. Razoavelmente
4. Bastante
5. Extremamente

11. Sente-se emocionalmente entorpecido desde a sua perda?
1. Não, de todo
2. Ligeiramente
3. Razoavelmente
4. Bastante
5. Extremamente

12. Sente que a sua vida é insatisfatória, vazia ou sem significado desde a sua perda?
1. Não, de todo
2. Ligeiramente
3. Razoavelmente
4. Bastante
5. Extremamente

13. Sentiu uma redução significativa na sua vida social, profissional ou em outras áreas importantes (por exemplo, responsabilidades domésticas)?
0. Não   1. Sim