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## An Examination and Proposed Definitions of Family Members' Grief Prior to the Death of Individuals with a Life-limiting Illness: A Systematic Review

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### Abstract

**Background:** Research has extensively examined family members' grief prior to the death of an individual with a life-limiting illness but several inconsistencies in its conceptualization of related constructs, yet significant conceptualization issues exist.

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#### Declarations

#### Authorship:

J.S. was responsible for the planning, design, conduct, and reporting of the work. J.S. K.R. and W.L. were responsible for significant edits to the manuscript and conceptually proposing the definitions in this systematic review. C.F. and T.C. helped with building the tables and figures. K.G. performed the search in all databases and uploaded the studies into Covidence. J.S. K.R. E.M. C.F. T.C. M.R. M.W. performed the study selection and data extraction. J.S. K.R. E.M. C.F. T.C. M.R. M.W. were involved in the data analysis and synthesis process. All authors contributed and agreed to the final manuscript.

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**Aim:** This study aimed to identify and characterize studies published on family members grief before the death of an individual with a life-limiting illness, and propose definitions based on past studies in order to initiate conceptual clarity.

**Design:** A mixed-method systematic review utilized six databases and was last conducted July 10, 2021. The search strategy was developed using Medical Subject Headings. This study was prospectively registered on PROSPERO (CRD42020166254).

**Results:** 134 full-text articles met inclusion criteria. This review revealed across studies a wide variation in terminology, conceptualization, and characterization of grief before the death. More than 18 terms and 30 definitions have been used. In many cases, the same term (e.g., anticipatory grief) was defined differently across studies.

**Conclusions:** We found grief occurring before the death of a person with a life-limiting illness, which we termed pre-death grief, is comprised of two distinct constructs: anticipatory grief and illness-related grief. Anticipatory grief is future-oriented and is characterized by separation distress and worry about a future without the person with the life-limiting illness being physically present. Illness-related grief is present-oriented and is characterized by grief over current and ongoing losses experienced during the illness trajectory. These definitions provide the field with uniform constructs to advance the study of grief before the death of an individual with a life-limiting illness.

### Keywords

Palliative care; Grief; Family; Caregivers; Terminally ill

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Most deaths worldwide are attributed to a chronic or life-limiting illness<sup>1</sup>. In response to continued improvements in medicine, including advancements in early detection of medical conditions, the length of time between diagnosis and death has increased. While the increase in life expectancy for individuals living with a life-limiting illness may have notable benefits, there are also negative consequences for the patient<sup>2, 3</sup> and their family members<sup>4, 5</sup>. For example, increasing data trends indicate that family members are likely to experience some level of grief before the person with a life-limiting illness dies<sup>6, 7</sup>. The extent to which a family member experiences grief prior to a death occurring has been found to predict long-term functioning in bereavement, including developing depression<sup>8</sup> or prolonged grief disorder<sup>9, 10</sup>. However, our current understanding of grief experiences in family members prior to the death is hampered by the lack of a universal definition, the use of multiple terms, and inconsistent operationalization of constructs. By gaining a comprehensive understanding of the literature examining grief in family members before the death, researchers will be better equipped to understand what constitutes normative and non-normative experiences of grief before the death, and to identify key intervention targets that may decrease family members' risk for and experience of debilitating psychological symptoms both in the short- and long-term. Therefore, the current systematic review aimed to identify and characterize the studies published on grief before a death for family members<sup>5</sup> and propose definitions grounded in extant research for the types of grief that can occur before a death.

There has been an abundant amount of research examining family members' grief prior to the death of an individual with a life-limiting illness. The earliest documented definition of this form of grief came from Lindemann<sup>11</sup>, who described it as a grief process that begins when family members are provided advance warning of a patient's impending death. In her work on this topic, Rando then<sup>12</sup> defined it as a "reaction to the impending loss of a terminally ill loved one and to all other past and present losses related to the illness, in addition to the mourning and all other psychosocial processes stimulated by these losses" (p. 24). The most prominent and well-known term to describe this experience is anticipatory grief, but a recent review of articles examining anticipatory grief found ten different definitions used within studies<sup>13</sup>. In this review, Coelho and Barbosa<sup>13</sup> concluded that, when examining grief before the death, there are conceptualization issues, thereby limiting the ability to make comparisons of findings across studies. This is problematic for many reasons, as it hinders the potential advancement of the field in differentiating typical grief from more impairing grief before the death.

Further complicating the picture is the sheer number of terms used to describe grief before death; a concept analysis by Lindauer and Harvath<sup>14</sup> found that there were more than 20 terms other than anticipatory grief used in the literature between 2000 and 2013. The authors compared three terms found to be the most utilized in the literature: anticipatory grief, pre-death grief, and chronic sorrow.<sup>14</sup> They noted that one conceptual difference between anticipatory grief, pre-death grief, and chronic sorrow was the likely amount of time the person with life-limiting illness had left to live. While this effort to distinguish terms is useful, further clarity is needed for several reasons. First, determining a patient's prognosis is notoriously challenging<sup>15</sup>, and so defining grief before death based on prognosis would be correspondingly difficult. This concept analysis set important groundwork for the current review by identifying 20 different terms (see Appendix A) to examine grief before the death, but they only compared the three most used terms to exclusively provide a definition for pre-death grief.

Given these limitations and an increase in studies since 2014<sup>7</sup>, there is a need for an updated and systematic understanding of the full body of literature that comprehensively examines terms used to describe family members' grief before the death of an individual with a life-limiting illness. Thus, the present systematic review was undertaken to increase conceptual clarity on this grief experience and develop a consistent definition. To advance the field and allow for direct comparison between studies, a consistent definition is crucial. Additionally, the use of a uniform definition could provide clearer benchmarks of what constitutes debilitating grief before a death in order to appropriately develop and tailor interventions.

## Methods

This systemic review aimed to (1) identify and characterize the studies published on family member grief before a death of an individual with life-limiting illness, and (2) propose a definition for such grief that has conceptual clarity and precision and is grounded in past research.

## Systematic Review Design

This mixed-method systematic review and protocol were prospectively registered on PROSPERO on January 1, 2020 (Registration Number: CRD42020166254). This study used a phenomenological approach in which we integrated findings of primary quantitative and qualitative studies to build a network of related concepts that together provide a comprehensive understanding of grief before the death of a person with a life-limiting illness.

## Search Strategy and Data Sources

Procedures were conducted and reported according to Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines<sup>16</sup>. Six databases were selected: PubMed (via National Library of Medicine's [PubMed.gov](https://pubmed.ncbi.nlm.nih.gov/)), Embase (via Elsevier's [Embase.com](https://www.embase.com/)), Cochrane Central Register of Controlled Trials / Cochrane CENTRAL (via Wiley's Cochrane Library), PsycINFO (via Ovid), Web of Science Core Collection (via Clarivate Analytics), and Cumulative Index to Nursing and Allied Health Literature (CINAHL) (via EBSCO). Concepts were combined with the Boolean AND operator, and the Cochrane Handbook filter was used to exclude animal-only studies<sup>17</sup>. A second research informationist performed a Peer Review of Electronic Search Strategies (PRESS), and edits were implemented<sup>18</sup>. For a complete strategy, see the accompanying PubMed search displayed in Appendix B. The six databases were comprehensively searched on February 24, 2020. The first author (JS) later conducted two updates (April 1, 2021; July 10, 2021) and searched the six databases to identify if any new articles should be added to the review that were published after February 24, 2020. Results were entered as Research Information System files (i.e., standardized tag format) in Covidence, a web-based software platform for systematic review development<sup>19</sup>.

## Selection Strategy

Studies were considered eligible for inclusion if they evaluated family members' or friend's grief related to an individual currently living with a life-limiting illness. Studies that evaluated grief after the death had occurred or did not explicitly measure or refer to grief or examined grief related to non-life limiting illness (e.g., diabetes) were excluded.

## Screening Process

After duplicates were removed, abstracts were reviewed by two independent reviewers for initial eligibility. Articles were considered for full-text review if both reviewers agreed they met inclusion criteria. When there was disagreement between two reviewers, discrepancies were discussed with the first and second authors. All studies that met criteria for full-text evaluation were then independently reviewed by two reviewers and disagreements between reviewers were discussed with the first and second author. A standardized template was developed to extract pre-specified information from the final set of included articles. For each article, a reviewer completed the coding template to extract the pre-determined information from each article.

## Data Synthesis and Analysis

After studies were selected, they were individually entered by the authors into an Excel table for data extraction. Authors were instructed to indicate title, authors, whether the study was qualitative, quantitative, or mixed methods, design of the study, whether prospective or retrospective, purpose of the study, sample details (mean age, gender, race/ethnicity, relationship to patient/deceased, disease status), key qualitative and quantitative findings, term used to describe grief (e.g., anticipatory grief), and implications related to defining the term. The first author (JS) organized the studies by the grief term used and conducted a thematic synthesis of the definitions used within the terms. To interpret the results, a thematic synthesis was performed. The synthesis began with 'line-by-line' coding of the included articles (n=132), which were put into categories (i.e., term used; definition used; measure used). These were then aggregated by term used.

## Results

A total of 9,568 records were reviewed. A final set of 132 full-text articles underwent qualitative synthesis (see Figure 1 for PRISMA). Two studies<sup>7,20</sup> were added from the review of the databases on April 1, 2021 and another on July 10, 2021. Therefore, 134 full-text articles underwent thematic synthesis (see Figure 1).

The studies were predominantly quantitative (N=77; 57.46%). Thirty-three (23.88%) were qualitative and 24 (17.91%) used mixed methods. Most of the studies were prospective (N=110; 82.09%). Twenty (14.93%) were retrospective and four (3.00%) included both prospective and retrospective analyses.

Participants in these studies primarily endorsed their family member was diagnosed with dementia (N=51; 38.1%) or cancer (N=39; 29.1%) broadly. When examining the prognosis of the individual with the life-limiting illness, most studies stated that they had "late-stage dementia" or "advanced cancer." For the studies that provided the relationship to the person with the life-limiting illness, 58.0% were adult children, 28.1% were spouses/partners, and 13.9% were other relatives/friends (e.g., parents).

There were 18 different terms used to describe grief in family members of individuals who have a life-limiting illness. The terms used were anticipatory grief (N=34), pre-death grief (N=18), grief (N=12), pre-loss grief (N=6), caregiver grief (N=5), grief in caregivers (N=4), and anticipatory mourning (N=4). Nineteen studies used multiple terms throughout a single article. There were also 10 other terms that were each used only once in separate studies. Due to the large number of articles in this systematic review, we limited our in-text analysis to articles where the term (e.g., pre-death grief) was used in more than one article. Therefore, we did not analyze these 10 studies. However, they are described in Table 1. Also, there were two studies that described grief in family members of individuals who have a life-limiting illness but did not use a specific term to describe their experience.

In addition to varied terms used to characterize grief in family members of individuals with life-limiting illness, studies used 19 different scales to measure grief. The most prominent

were the Marwit-Meuser-Caregiver Grief Inventory (n=28), the Anticipatory Grief Scale (n=18), and the Prolonged Grief-12 (n=13).

### Anticipatory Grief

There were 54 studies identified that used anticipatory grief to describe family members' grief while a person with a life-limiting illness was alive. However, the definitions used for anticipatory grief differed drastically (see Table 1), and many studies used the term anticipatory grief but failed to define it. For example, one study<sup>21</sup> stated that anticipatory grief includes emotions associated with the fear of losing their significant other, whereas another study<sup>22</sup> stated anticipatory grief is a profound emotional response to impending, irreversible loss that is experienced by a family member. Overall, the first definition is related to worry about life without the person with the life limiting illness (e.g., what am I going to do when they pass away). However, the other study<sup>22</sup> appears to define anticipatory grief as a feeling of loss following diagnosis of the life limiting illness (e.g., I feel I have already lost the person). Nine studies<sup>23-31</sup> used Rando's<sup>12</sup> definition of anticipatory grief and two<sup>32,33</sup> used Lindemann's<sup>11</sup> definition of anticipatory grief. Ten studies<sup>34-43</sup> used the term anticipatory grief, but did not define it beyond using a measure conceptualized as measuring anticipatory grief. Finally, there was one study<sup>44</sup> that defined anticipatory grief as being an emotional response that is specific to a dementia (i.e., "a specific feeling of pre-death grief in response to compound serial losses in the dementia process;" p. 1).

Of the studies that used anticipatory grief, 16 were qualitative. The remaining 38 quantitative studies used a variety of measures, with five studies using author-generated questions that had not been psychometrically validated<sup>21,22,28,45,46</sup>. The studies using anticipatory grief were mostly conducted with family members of patients with dementia (N=17) or cancer (N=15). Lastly, of the studies that used the term anticipatory grief, the Anticipatory Grief Scale was the most used measure (14 studies; <sup>25,29,36,41,45,47-53</sup>). The Marwit-Meuser-Caregiver Grief Inventory<sup>26,27,54-58</sup> and Marwit-Meuser-Caregiver Grief Inventory- Short Form<sup>24,35,40,44</sup> was used in 11 studies.

### Pre-death grief

There were 18 studies identified that used pre-death grief to describe grief experienced by family members of a person with a life-limiting illness. Almost all 18 studies differed in their definitions of pre-death grief. For example, Rankin and colleagues<sup>59</sup> defined pre-death grief as grief experienced by family members prior to the death of the patient in response to losses that accompany the diagnosis of a family member, whereas Mulligan<sup>60</sup> defined pre-death grief as yearning for the family member to be healthy again and feeling shocked about the person's illness. One study<sup>61</sup> used Lindemann's definition<sup>11</sup>. Another study<sup>62</sup> framed grief as a spectrum, which they termed "triple grief" (i.e., grieving the loss of the patients' personhood, the family's experience of loss at the time of hospice admission, and the loss when the person dies). Two studies<sup>20,63,64</sup> used the term pre-death grief but did not define it.

Most studies that used pre-death grief were quantitative (N=16) and the remainder were qualitative (N=2). The studies that used the term pre-death grief were mostly with family

members of dementia (N=12) and cancer patients (N=3). The remaining studies included family members of individuals with other types of life-limiting illnesses, a mixed sample, or did not specify the illness. Of the 15 quantitative studies, most studies used the Marwit-Meuser-Caregiver Grief Inventory (n=4; <sup>65–68,68</sup>, the Marwit-Meuser-Caregiver Grief Inventory- Short Form (n=4; <sup>60,69–71</sup>), or the Prolonged Grief-12 (n=4; <sup>20,60,62,63</sup>). Two of the studies used multiple measures <sup>60,63</sup>.

## Grief

Twelve studies used the term, grief, to describe family members' grief while a person with a life-limiting illness was still alive. Five <sup>72–76</sup> of these studies did not provide a definition of the term. The six studies that used grief differed in their definition of the construct. One study <sup>77</sup> defined grief as the reaction to the perceived loss following the diagnosis of a life-limiting illness. However, another study <sup>77</sup> defined it as a “multifaceted caregiver response” (p. 198) to death and losses of all kinds associated with the illness, including grief related to “social” death and intellectual deterioration of a person with some form of dementia.

Most of the studies that used the term, grief, to describe the experience of grief before the death used mixed methods (N=7). Four were quantitative, and one qualitative. Studies were predominantly conducted with family members of cancer (N=5) and dementia (N=4) patients. Two of the studies used the Marwit-Meuser-Caregiver Grief Inventory <sup>72,79</sup> and three used the Marwit-Meuser-Caregiver Grief Inventory- Short Form <sup>73,77,80</sup>.

## Pre-Loss Grief

There were six studies identified that used pre-loss grief to describe family members' grief while a person with a life-limiting illness was still alive <sup>7–9,81–83</sup>. There were two studies <sup>7,81</sup> that defined pre-loss grief, whereas the remaining four studies <sup>8,9,82,83</sup> did not define the construct. Hudson and colleagues <sup>81</sup> defined pre-loss grief as follows: “Grief is a process involving some elements of ‘loss,’ which starts before the bereavement and can be onerous” (p.523). Singer and colleagues <sup>7</sup> similarly used pre-loss grief as more of an umbrella term, defining it as either family members' grief related to the impending loss of their loved one and/or the loss of components of the relationship with the loved one that existed pre-diagnosis.

All studies that used pre-loss grief were quantitative. Most of the pre-loss grief studies included a mixed sample with respect to illness type. Only one study <sup>8</sup> focused on a single specific illness (i.e., family members of individuals with a dementia). All the studies used the Prolonged Grief-12 to measure pre-loss grief.

## Caregiver Grief

There were five studies identified that used the term, caregiver grief, to describe family members' grief while a person with a life-limiting illness is still alive. Three of the articles were led by the same first author and described caregiver grief as anticipation of future losses related to physical death of a person with dementia <sup>84–86</sup>. Marwit and Meuser <sup>87</sup> discussed caregiver grief as a stage-determined, internally consistent construct that is

measurable but did not provide an explicit definition. Guerrero<sup>88</sup> defined caregiver grief as feelings of grief, including sadness, longing, worry, felt isolation, personal sacrifice, and burden prior to the death of the care recipient.

Most of the studies that used caregiver grief were quantitative studies (n=4), and one used mixed methods. The studies using the term caregiver grief were predominately conducted with family members of dementia patients and one study included family members of individuals with frontotemporal lobar degeneration. All five studies used some form of the Marwit-Meuser-Caregiver Grief Inventory.

### **Anticipatory Mourning**

There were four studies that used the term, anticipatory mourning, to describe family members' grief while a person with a life-limiting illness is still alive. Each of the four studies differed in their definition. One study<sup>89</sup> used Rando's<sup>12</sup> definition. Clukey<sup>90</sup> described anticipatory mourning as a set of dynamic processes involving emotional and cognitive transitions made in response to an expected loss. Angela-Cole<sup>91</sup> defined anticipatory mourning as uncertainty surrounding the amount of time a person with a life-limiting illness has left, which creates a heightened grieving experience before the person dies. Bielek and colleagues<sup>92</sup> defined anticipatory mourning as the act of mourning when facing a loss, whether it is sudden or prolonged. All the studies using anticipatory mourning were qualitative. Two studies<sup>91,92</sup> recruited participants whose family members had "terminal cancer" and two included family members of individuals with any "terminal illness."

### **Grief in Caregivers**

Four studies used the term, grief in caregivers, to describe family member's grief while a person with a life-limiting illness is still alive. Two studies<sup>93,94</sup> offered definitions of grief in caregivers, whereas two studies did not define the construct<sup>95,96</sup>. Ott and colleagues (2007)<sup>93</sup> used Rando's<sup>12</sup> definition. Li and colleagues<sup>94</sup> defined grief in caregivers as various physical and emotional reactions due to the various losses associated with dementia.

Three of the four studies were quantitative, and the other study used a mixed design. Three of the studies enrolled family members of dementia patients, and one study enrolled family members who had an acquired brain injury. One of the studies used the Marwit-Meuser-Caregiver Grief Inventory<sup>95</sup>, and three used the Marwit-Meuser-Caregiver Grief Inventory-Short Form<sup>93,93,94</sup>

### **Multiple Terms Used**

There were 19 studies that used multiple terms (e.g., anticipatory grief and pre-loss grief) within a single article to describe family members' grief experiences. In all cases, each of the terms were used interchangeably with the same definition applied. For example, Carter and colleagues<sup>97</sup> used pre-death grief, caregiver grief, and grief interchangeably. This study applied the same definition for each of these terms. All three constructs were characterized as involving personal sacrifice and burden, worry and feelings of isolation,



and heartfelt sadness and longing, which are key subscales in the Marwit-Meuser-Caregiver Grief Inventory.

## Discussion

This systematic review on grief experienced by family members prior to an individual's death to life-limiting illness revealed wide variation in the terminology used and characterization of such grief across studies. More than 18 terms and more than 30 definitions have been used to describe this form of grief. Further, in many cases, even when certain terms were frequently used (e.g., anticipatory grief, pre-death grief), the same term was often defined differently across studies. For example, one study<sup>49</sup> defined anticipatory grief as the process associated with grieving the eventual loss of a family member in advance of their inevitable death, whereas another study<sup>98</sup> defined anticipatory grief as a series of losses based on a loved one's progression of cognitive and physical decline. As is evident in this example, these definitions differ drastically, which limits the reliability and validity of the construct and, in turn, constrains the utility of the term anticipatory grief. Similar conceptual issues were found with and across other terms. Several studies (N=24; 17.9%) did not define the construct at all nor provide a citation for a past study that defined the construct. The net result is that the current conceptualization of a family member's grief experience prior to death lacks conceptual clarity and a precise, consistently applied definition.

### Conceptual Problems with the Construct and Measures Used

The lack of consensus in defining the construct of grief before a death occurs across studies presents problems for comparing study findings, in advancing research, and in providing appropriate clinical care to grieving families. The most frequently used definitions were those of Lindemann's<sup>11</sup> and Rando's<sup>12</sup>, yet less than 15% of the studies used one of these two definitions. Other studies either used their own definition, which differed drastically across studies using the same terms, or did not define the construct being examined. A recent systematic review<sup>99</sup> examining pre-loss grief with cancer patients stated that their results (i.e., higher pre-loss grief results in worse post-loss adjustment) were limited by an inconsistent operationalization of pre-loss grief. Clear and consistent definitions are necessary for other researchers to replicate findings and increase our understanding of theoretical constructs<sup>100</sup>. Further, Drost<sup>101</sup> found using multiple definitions to define the same construct can diminish reliability, as well as internal and external validity. Therefore, providing a universal definition of a construct can lead to an advancement of the field, allowing multiple researchers to examine the same construct and compare studies. For example, Holley's<sup>49</sup> study and Pote and colleagues'<sup>57</sup> investigation, which both used the term anticipatory grief, could not be appropriately compared because their definitions varied. The lack of uniformity of the definitions, coupled with studies not defining the construct, further increases the difficulty of comparing research findings and, importantly, limits the clinical utility of the constructs.

It was beyond the scope of this systematic review to examine the psychometric properties of individual instruments and homegrown questions used to measure grief in family members

of individuals with a life-limiting illness; however, examination of the connection between the definitions used and the measures used is salient to the focus of the paper. There were numerous instruments used to measure grief before death, which is not uncommon or specific to the grief literature. However, the articles that were identified in this systematic review differed drastically in their definition of the construct of grief before a death, despite often using the same scale. For example, Guererro<sup>88</sup> used the Marwit-Meuser-Caregiver Grief Inventory and defined the construct as sadness, longing, worry, felt isolation, personal sacrifice, and burden, whereas York and colleagues<sup>58</sup> also used the Marwit-Meuser-Caregiver Grief Inventory and defined the construct as grief related to anticipation of the forthcoming loss of a family member. Not only were different definitions used in studies using the same scales, but the same scale was used across terms, such as use of the Marwit-Meuser-Caregiver Grief Inventory to measure more than 6 different constructs. Thus, it is unclear whether the terms and the measures in fact reflect separate, distinct constructs or a single grief phenomenon.

### Limitations

Findings from this systematic review should be considered in the context of some limitations. First, this systematic review only focused on articles that were published in English or for which translations were available. It should be noted that 14 studies during the initial review were excluded for which translation could not be found. Second, this review only included studies that examined grief in family members of individuals with life-limiting illnesses and not other chronic medical (e.g., diabetes) or mental (e.g., schizophrenia) illnesses over which family members may grieve. Third, this study was limited in that it only examined published research articles and thus may have missed studies that were started during the pandemic that examined COVID-19 and grief before the loss. Finally, we did not include conference abstracts, which could limit the studies identified.

### Proposed Definitions

In synthesizing the results of this study, two overarching conceptualizations of grief occurring before the person with a life-limiting illness has died emerged: grief around the anticipated death of the person and grief associated with losses that occur throughout the illness trajectory. In light of the differences between definitions noted in this systematic review and the overlaps between constructs, we have attempted to provide clarity in the following proposed definitions. Under the umbrella category that we propose be termed *pre-death grief*, we propose two separate constructs: *anticipatory grief* and *illness-related grief*. Anticipatory grief is *future-oriented* and defined as a family members' grief experience while the person with the life-limiting illness is alive but that is focused on feared or anticipated losses that will occur after the person's death. Anticipatory grief includes worry about a future without the person with the life-limiting illness being physically present and feeling sad about future losses related to the deceased person. Many studies defined the construct of grief prior to a loss as the anticipation of future losses related to the physical death of a person (e.g.,<sup>23,24,26-28</sup>). Using our proposed definition, these studies would be measuring anticipatory grief.

Illness-related grief is, on the other hand, *present*-oriented. More specifically, illness-related grief includes grief related to current or ongoing losses experienced during the illness trajectory, such as loss of roles or loss of physical functioning. Some studies (e.g., <sup>7,60</sup>) provided a definition of grief before a death that would fit under illness-related grief when they defined the construct as longing and yearning for the family member to be as they were before the illness. We would expand on this definition and state that illness-related grief is the experience of grief before the death of a family member that relates to the numerous, multiplicative losses that can be incurred when a family member has a life-limiting illness. For example, a person might experience intense feelings of emotional pain, sorrow, or pangs of grief related to the family member's functional impairment and wish they were able to do what they used to be able to do.

Consistent use of these two constructs as we have defined them could provide the field with uniformity, facilitating advancement of the study of pre-death grief. Importantly, the definitions identified through this systematic review would not be able to differentiate if a person has anticipatory grief, illness-related grief, or both anticipatory grief and illness-related grief. While anticipatory grief and illness-related grief, may be distinguished, they may both be experienced by family members. Future research can further examine methods of measuring these distinct constructs in order to more effectively identify family members in need of support for pre-death grief and to establish intervention targets relevant to the type of grief they are experiencing.

Despite grief before the death of an individual with life-limiting illness being studied for more than 80 years with more than 130 studies identified, this systematic review provides evidence that there is no consistent definition of this construct and identifies numerous related limitations within the current body of literature that examines grief before death. These limitations appear to be hindering the advancement of the grief field. This study is novel as it provides the field with consistent terms: pre-death grief, anticipatory grief, and illness-related grief, as described above, which will facilitate clinical research to 1) replicating results, 2) better differentiating normative pre-death grief from impairing pre-death grief, 3) identifying of risk and protective factors for developing impairing pre-death grief, as well as the extent to which pre-death grief may be a risk factor for negative bereavement outcomes such as prolonged grief disorder, 4) developing and testing interventions to reduce distressing and impairing pre-death grief, and 5) understanding if there are differences in presentation of pre-death grief depending on the patient's illness (e.g., cancer; dementia). In a future report, we will also examine the psychometric properties of the scales identified in this systematic review to continue refining the field's conceptualization grief before death and to ultimately offer guidance on which measures may be most clinically useful. Additionally, future work should aim to examine pre-death grief from an interdisciplinary perspective by identifying possible biological, neuropsychological, and developmental influences in order to create more interdisciplinary interventions to mitigate pre-death grief. More specifically, due to the interdisciplinary nature of the work examining pre-death grief, a greater understanding of the neurobiological underpinnings of pre-death grief in family members is warranted and if these underpinnings differ depending on the patient's illness,

Such work has the potential to improve family-centered, bereavement-conscious, palliative care for family members of individuals with life-limiting illness before and after bereavement. A central component of palliative care is attending to the needs of family members through bereavement, but palliative care clinicians are understandably fulfilling many roles that hinder their ability to do so. In the context of the COVID-19 pandemic, palliative care professionals are spread thinner<sup>156, 157</sup>. Having a greater understanding of the manifestations of pre-death grief, as well as ways to briefly assess for pre-death grief and provide targeted intervention could better equip palliative care clinicians to provide care to those most in need. Further, intervening to assuage pre-death grief can place family members in a better position to cope with the challenges of bereavement and reduce their risk for bereavement-related mental health challenges<sup>158</sup>.

It would be neglectful to not mention the relationship between pre-death grief and family members' experiences during the COVID-19 pandemic. At this time, there are no empirical studies that have examined COVID-19 and pre-death grief, but several commentaries and reviews have discussed the implications of COVID-19 on pre-death grief. First, one commentary<sup>159</sup>, which used the term pre-loss grief, highlights that families face novel challenges when the person with COVID-19 becomes critically ill, including physical separation due to fear of COVID-19 being spread and the lack of preparedness for the death, which has been shown to increase pre-death grief and prolonged grief disorder. Another commentary<sup>160</sup> focused on the role of front-line workers who are uniquely positioned to provide critically needed psychosocial support to bereaved family members, yet who are also experiencing unprecedented levels of burnout. This speaks to the need for brief assessment and interdisciplinary intervention approaches that not only provide bereavement-conscious care to families but also seek to reduce systemic barriers to providing care. Also, palliative care clinicians could be involved earlier in the illness trajectory to help reduce pre-death grief in the family member. Therefore, palliative care doctors should be trained on assessing pre-death grief in family members of individuals with COVID-19. This systematic review and proposed definitions provide the ability to differentiate normative pre-death grief from impairing levels of grief and identify risk factors for developing pre-death grief in family members of individuals with life-limiting illness. This will hopefully result in an increase in targeted interventions for family members who have pre-death grief as well as the provision of support to reduce poor bereavement outcomes.

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### **Data management and sharing:**

All relevant data are within the manuscript. Any other data are available upon request from the corresponding author.

## APPENDIX

### Appendix

#### Appendix A.

Terms for Pre-death grief found in the literature, 2000– 2013 in Lindauer & Harvath (2014) study

Anticipatory grief	Latent grief
Anticipating grief	Sorrow
Living grief	Anticipatory mourning
Masked grief	Bereavement
Mourning	Caregiver grief
Ongoing mourning	Chronic grief
Pre-bereavement grief	Chronic grief reaction
Pre-death grief	Chronic sorrow
Pre-loss grief	Disenfranchised grief
Preparatory grief	Grief

#### Appendix B: Database Search Strategies

##### 1. PubMed (via National Library of Medicine's [PubMed.gov](https://pubmed.ncbi.nlm.nih.gov/))

(“Caregivers” [Mesh] OR “Family” [Mesh:NoExp] OR “Adult Children” [Mesh] OR “Family Relations” [Mesh] OR “Grandparents” [Mesh] OR “Nuclear Family” [Mesh] OR “Friends” [Mesh] OR caregiver [TIAB] OR “care giver” [TIAB] OR caregivers [TIAB] OR “care givers” [TIAB] OR caretaker [TIAB] OR “care taker” [TIAB] OR caretakers [TIAB] OR “care takers” [TIAB] OR caregiving [TIAB] OR “care giving” [TIAB] OR caretaking [TIAB] OR “care taking” [TIAB] OR carer [TIAB] OR carers [TIAB] OR family [TIAB] OR families [TIAB] OR relative [TIAB] OR relatives [TIAB] OR spouse [TIAB] OR spouses [TIAB] OR wife [TIAB] OR wives [TIAB] OR husband [TIAB] OR husbands [TIAB] OR fiancée [TIAB] OR fiancées [TIAB] OR fiancé [TIAB] OR fiancés [TIAB] OR “domestic partner” [TIAB] OR “domestic partners” [TIAB] OR girlfriend [TIAB] OR girlfriends [TIAB] OR boyfriend [TIAB] OR boyfriends [TIAB] OR daughter [TIAB] OR daughters [TIAB] OR son [TIAB] OR sons [TIAB] OR child [TIAB] OR children [TIAB] OR offspring [TIAB] OR parent [TIAB] OR parents [TIAB] OR stepparent [TIAB] OR “step-parent” [TIAB] OR stepparents [TIAB] OR “step-parents” [TIAB] OR mother [TIAB] OR mothers [TIAB] OR father [TIAB] OR fathers [TIAB] OR sister [TIAB] OR sisters [TIAB] OR brother [TIAB] OR brothers [TIAB] OR sibling [TIAB] OR siblings [TIAB] OR aunt [TIAB] OR aunts [TIAB] OR uncle [TIAB] OR uncles [TIAB] OR niece [TIAB] OR nieces [TIAB] OR nephew [TIAB] OR nephews [TIAB] OR cousin [TIAB] OR cousins [TIAB] OR grandparent [TIAB] OR grandparents [TIAB] OR grandmother [TIAB] OR grandmothers [TIAB] OR grandfather [TIAB] OR grandfathers [TIAB] OR friend [TIAB] OR friends [TIAB] OR companion [TIAB] OR companions [TIAB] OR acquaintance [TIAB] OR acquaintances [TIAB] OR friendship [TIAB] OR friendships [TIAB]) AND (((“Bereavement” [Mesh] OR grief [TIAB] OR

grieve [TIAB] OR grieves [TIAB] OR grieving [TIAB] OR bereavement [TIAB] OR bereaved [TIAB] OR sorrow [TIAB] OR sorrowful [TIAB] OR mourning [TIAB] OR mourn [TIAB] OR mourns [TIAB] OR mournful [TIAB]) AND (“Catastrophic Illness” [Mesh] OR “Critical Illness” [Mesh] OR “Terminal Care” [Mesh:NoExp] OR “Terminally Ill” [Mesh] OR “Hospice Care” [Mesh] OR “Palliative Care” [Mesh] OR “catastrophic illness” [TIAB] OR “catastrophic illnesses” [TIAB] OR “catastrophic disease” [TIAB] OR “catastrophic diseases” [TIAB] OR “prolonged illness” [TIAB] OR “prolonged illnesses” [TIAB] OR “prolonged disease” [TIAB] OR “prolonged diseases” [TIAB] OR “critical illness” [TIAB] OR “critical illnesses” [TIAB] OR “critical disease” [TIAB] OR “critical diseases” [TIAB] OR “critically ill” [TIAB] OR “life-limiting condition” [TIAB] OR “life-limiting conditions” [TIAB] OR “life-limiting illness” [TIAB] OR “life-limiting illnesses” [TIAB] OR “life-limiting disease” [TIAB] OR “life-limiting diseases” [TIAB] OR “life-threatening health condition” [TIAB] OR “life-threatening health conditions” [TIAB] OR “life-threatening condition” [TIAB] OR “life-threatening conditions” [TIAB] OR “life-threatening illness” [TIAB] OR “life-threatening illnesses” [TIAB] OR “life-threatening disease” [TIAB] OR “life-threatening diseases” [TIAB] OR “advanced medical illness” [TIAB] OR “advanced medical illnesses” [TIAB] OR “advanced illness” [TIAB] OR “advanced illnesses” [TIAB] OR “advanced disease” [TIAB] OR “advanced diseases” [TIAB] OR “terminal care” [TIAB] OR “terminal illness” [TIAB] OR “terminal illnesses” [TIAB] OR “terminal disease” [TIAB] OR “terminal diseases” [TIAB] OR “terminally ill” [TIAB] OR “terminal stage” [TIAB] OR “terminal stages” [TIAB] OR “fatal illness” [TIAB] OR “fatal illnesses” [TIAB] OR “fatal disease” [TIAB] OR “fatal diseases” [TIAB] OR “pre-loss” [TIAB] OR preloss [TIAB] OR “pre-death” [TIAB] OR predeath [TIAB] OR “end of life” [TIAB] OR “hospice care” [TIAB] OR “bereavement care” [TIAB] OR “palliative care” [TIAB] OR “supportive care” [TIAB])) OR (“pre-bereavement” [TIAB] OR prebereavement [TIAB] OR “caregiver grief” [TIAB] OR “caregiver bereavement” [TIAB] OR “caregiver distress” [TIAB] OR “carer distress” [TIAB] OR “anticipatory grief” [TIAB] OR “anticipatory bereavement” [TIAB] OR “anticipatory mourning” [TIAB] OR “pre-death grief” [TIAB] OR “predeath grief” [TIAB] OR “pre-loss grief” [TIAB] OR “preloss grief” [TIAB] OR “preparatory grief” [TIAB])) NOT (“Animals” [Mesh] NOT “Humans” [Mesh])

## 2. Embase (via Elsevier’s [Embase.com](#))

(‘caregiver’/exp OR ‘relative’/exp OR ‘family’/de OR ‘adopted child’/exp OR ‘adult child’/exp OR ‘aunt’/exp OR ‘cousin’/exp OR ‘extended family’/exp OR ‘family health’/exp OR ‘family life’/exp OR ‘family relation’/exp OR ‘family service’/exp OR ‘foster child’/exp OR ‘grandchild’/exp OR ‘grandparent’/exp OR ‘great-grandparent’/exp OR ‘nephew’/exp OR ‘niece’/exp OR ‘nuclear family’/exp OR ‘parenthood’/exp OR ‘stepfamily’/exp OR ‘uncle’/exp OR ‘friend’/exp OR caregiver:ab,ti OR ‘care giver’:ab,ti OR caregivers:ab,ti OR ‘care givers’:ab,ti OR caretaker:ab,ti OR ‘care taker’:ab,ti OR caretakers:ab,ti OR ‘care takers’:ab,ti OR caregiving:ab,ti OR ‘care giving’:ab,ti OR caretaking:ab,ti OR ‘care taking’:ab,ti OR carer:ab,ti OR carers:ab,ti OR family:ab,ti OR families:ab,ti OR relative:ab,ti OR relatives:ab,ti OR spouse:ab,ti OR spouses:ab,ti OR wife:ab,ti OR wives:ab,ti OR husband:ab,ti OR husbands:ab,ti OR fiancée:ab,ti OR fiancées:ab,ti OR fiancé:ab,ti OR fiancés:ab,ti OR ‘domestic partner’:ab,ti OR

'domestic partners':ab,ti OR girlfriend:ab,ti OR girlfriends:ab,ti OR boyfriend:ab,ti OR boyfriends:ab,ti OR daughter:ab,ti OR daughters:ab,ti OR son:ab,ti OR sons:ab,ti OR child:ab,ti OR children:ab,ti OR offspring:ab,ti OR parent:ab,ti OR parents:ab,ti OR stepparent:ab,ti OR 'step-parent':ab,ti OR stepparents:ab,ti OR 'step-parents':ab,ti OR mother:ab,ti OR mothers:ab,ti OR father:ab,ti OR fathers:ab,ti OR sister:ab,ti OR sisters:ab,ti OR brother:ab,ti OR brothers:ab,ti OR sibling:ab,ti OR siblings:ab,ti OR aunt:ab,ti OR aunts:ab,ti OR uncle:ab,ti OR uncles:ab,ti OR niece:ab,ti OR nieces:ab,ti OR nephew:ab,ti OR nephews:ab,ti OR cousin:ab,ti OR cousins:ab,ti OR grandparent:ab,ti OR grandparents:ab,ti OR grandmother:ab,ti OR grandmothers:ab,ti OR grandfather:ab,ti OR grandfathers:ab,ti OR friend:ab,ti OR friends:ab,ti OR companion:ab,ti OR companions:ab,ti OR acquaintance:ab,ti OR acquaintances:ab,ti OR friendship:ab,ti OR friendships:ab,ti) AND (((('bereavement'/exp OR 'grief'/exp OR grief:ab,ti OR grieve:ab,ti OR grieves:ab,ti OR grieving:ab,ti OR bereavement:ab,ti OR bereaved:ab,ti OR sorrow:ab,ti OR sorrowful:ab,ti OR mourning:ab,ti OR mourn:ab,ti OR mourns:ab,ti OR mournful:ab,ti) AND ('terminal disease'/exp OR 'critical illness'/exp OR 'terminal care'/de OR 'terminally ill patient'/exp OR 'hospice care'/exp OR 'palliative therapy'/exp OR 'catastrophic illness':ab,ti OR 'catastrophic illnesses':ab,ti OR 'catastrophic disease':ab,ti OR 'catastrophic diseases':ab,ti OR 'prolonged illness':ab,ti OR 'prolonged illnesses':ab,ti OR 'prolonged disease':ab,ti OR 'prolonged diseases':ab,ti OR 'critical illness':ab,ti OR 'critical illnesses':ab,ti OR 'critical disease':ab,ti OR 'critical diseases':ab,ti OR 'critically ill':ab,ti OR 'life-limiting condition':ab,ti OR 'life-limiting conditions':ab,ti OR 'life-limiting illness':ab,ti OR 'life-limiting illnesses':ab,ti OR 'life-limiting disease':ab,ti OR 'life-limiting diseases':ab,ti OR 'life-threatening health condition':ab,ti OR 'life-threatening health conditions':ab,ti OR 'life-threatening condition':ab,ti OR 'life-threatening conditions':ab,ti OR 'life-threatening illness':ab,ti OR 'life-threatening illnesses':ab,ti OR 'life-threatening disease':ab,ti OR 'life-threatening diseases':ab,ti OR 'advanced medical illness':ab,ti OR 'advanced medical illnesses':ab,ti OR 'advanced illness':ab,ti OR 'advanced illnesses':ab,ti OR 'advanced disease':ab,ti OR 'advanced diseases':ab,ti OR 'terminal care':ab,ti OR 'terminal illness':ab,ti OR 'terminal illnesses':ab,ti OR 'terminal disease':ab,ti OR 'terminal diseases':ab,ti OR 'terminally ill':ab,ti OR 'terminal stage':ab,ti OR 'terminal stages':ab,ti OR 'fatal illness':ab,ti OR 'fatal illnesses':ab,ti OR 'fatal disease':ab,ti OR 'fatal diseases':ab,ti OR 'pre-loss':ab,ti OR preloss:ab,ti OR 'pre-death':ab,ti OR predeath:ab,ti OR 'end of life':ab,ti OR 'hospice care':ab,ti OR 'bereavement care':ab,ti OR 'palliative care':ab,ti OR 'supportive care':ab,ti)) OR ('pre-bereavement':ab,ti OR prebereavement:ab,ti OR 'caregiver grief':ab,ti OR 'caregiver bereavement':ab,ti OR 'caregiver distress':ab,ti OR 'carer distress':ab,ti OR 'anticipatory grief':ab,ti OR 'anticipatory bereavement':ab,ti OR 'anticipatory mourning':ab,ti OR 'pre-death grief':ab,ti OR 'predeath grief':ab,ti OR 'pre-loss grief':ab,ti OR 'preloss grief':ab,ti OR 'preparatory grief':ab,ti)) NOT (('animal'/exp OR 'nonhuman'/exp) NOT 'human'/exp)

### 3. Cochrane Central Register of Controlled Trials / Cochrane CENTRAL (via Wiley's Cochrane Library)

#1) MeSH descriptor: [Caregivers] explode all trees

#2) MeSH descriptor: [Family] this term only

- #3) MeSH descriptor: [Adult Children] explode all trees
- #4) MeSH descriptor: [Family Relations] explode all trees
- #5) MeSH descriptor: [Grandparents] explode all trees
- #6) MeSH descriptor: [Nuclear Family] explode all trees
- #7) MeSH descriptor: [Friends] explode all trees
- #8) caregiver:ab,ti OR “care giver”:ab,ti OR caregivers:ab,ti OR “care givers”:ab,ti OR caretaker:ab,ti OR “care taker”:ab,ti OR caretakers:ab,ti OR “care takers”:ab,ti OR caregiving:ab,ti OR “care giving”:ab,ti OR caretaking:ab,ti OR “care taking”:ab,ti OR carer:ab,ti OR carers:ab,ti OR family:ab,ti OR families:ab,ti OR relative:ab,ti OR relatives:ab,ti OR spouse:ab,ti OR spouses:ab,ti OR wife:ab,ti OR wives:ab,ti OR husband:ab,ti OR husbands:ab,ti OR fiancée:ab,ti OR fiancées:ab,ti OR fiancé:ab,ti OR fiancés:ab,ti OR “domestic partner”:ab,ti OR “domestic partners”:ab,ti OR girlfriend:ab,ti OR girlfriends:ab,ti OR boyfriend:ab,ti OR boyfriends:ab,ti OR daughter:ab,ti OR daughters:ab,ti OR son:ab,ti OR sons:ab,ti OR child:ab,ti OR children:ab,ti OR offspring:ab,ti OR parent:ab,ti OR parents:ab,ti OR stepparent:ab,ti OR “step-parent”:ab,ti OR stepparents:ab,ti OR “step-parents”:ab,ti OR mother:ab,ti OR mothers:ab,ti OR father:ab,ti OR fathers:ab,ti OR sister:ab,ti OR sisters:ab,ti OR brother:ab,ti OR brothers:ab,ti OR sibling:ab,ti OR siblings:ab,ti OR aunt:ab,ti OR aunts:ab,ti OR uncle:ab,ti OR uncles:ab,ti OR niece:ab,ti OR nieces:ab,ti OR nephew:ab,ti OR nephews:ab,ti OR cousin:ab,ti OR cousins:ab,ti OR grandparent:ab,ti OR grandparents:ab,ti OR grandmother:ab,ti OR grandmothers:ab,ti OR grandfather:ab,ti OR grandfathers:ab,ti OR friend:ab,ti OR friends:ab,ti OR companion:ab,ti OR companions:ab,ti OR acquaintance:ab,ti OR acquaintances:ab,ti OR friendship:ab,ti OR friendships:ab,ti
- #9) #1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8
- #10) MeSH descriptor: [Bereavement] explode all trees
- #11) grief:ab,ti OR grieve:ab,ti OR grieves:ab,ti OR grieving:ab,ti OR bereavement:ab,ti OR bereaved:ab,ti OR sorrow:ab,ti OR sorrowful:ab,ti OR mourning:ab,ti OR mourn:ab,ti OR mourns:ab,ti OR mournful:ab,ti
- #12) #10 OR #11
- #13) MeSH descriptor: [Catastrophic Illness] explode all trees
- #14) MeSH descriptor: [Critical Illness] explode all trees
- #15) MeSH descriptor: [Terminal Care] this term only
- #16) MeSH descriptor: [Terminally Ill] explode all trees
- #17) MeSH descriptor: [Hospice Care] explode all trees



#18) MeSH descriptor: [Palliative Care] explode all trees

#19) “catastrophic illness”:ab,ti OR “catastrophic illnesses”:ab,ti OR “catastrophic disease”:ab,ti OR “catastrophic diseases”:ab,ti OR “prolonged illness”:ab,ti OR “prolonged illnesses”:ab,ti OR “prolonged disease”:ab,ti OR “prolonged diseases”:ab,ti OR “critical illness”:ab,ti OR “critical illnesses”:ab,ti OR “critical disease”:ab,ti OR “critical diseases”:ab,ti OR “critically ill”:ab,ti OR “life limiting condition”:ab,ti OR “life limiting conditions”:ab,ti OR “life limiting illness”:ab,ti OR “life limiting illnesses”:ab,ti OR “life limiting disease”:ab,ti OR “life limiting diseases”:ab,ti OR “life threatening health condition”:ab,ti OR “life threatening health conditions”:ab,ti OR “life threatening condition”:ab,ti OR “life threatening conditions”:ab,ti OR “life threatening illness”:ab,ti OR “life threatening illnesses”:ab,ti OR “life threatening disease”:ab,ti OR “life threatening diseases”:ab,ti OR “advanced medical illness”:ab,ti OR “advanced medical illnesses”:ab,ti OR “advanced illness”:ab,ti OR “advanced illnesses”:ab,ti OR “advanced disease”:ab,ti OR “advanced diseases”:ab,ti OR “terminal care”:ab,ti OR “terminal illness”:ab,ti OR “terminal illnesses”:ab,ti OR “terminal disease”:ab,ti OR “terminal diseases”:ab,ti OR “terminally ill”:ab,ti OR “terminal stage”:ab,ti OR “terminal stages”:ab,ti OR “fatal illness”:ab,ti OR “fatal illnesses”:ab,ti OR “fatal disease”:ab,ti OR “fatal diseases”:ab,ti OR “pre-loss”:ab,ti OR preloss:ab,ti OR “pre-death”:ab,ti OR predeath:ab,ti OR “end of life”:ab,ti OR “hospice care”:ab,ti OR “bereavement care”:ab,ti OR “palliative care”:ab,ti OR “supportive care”:ab,ti

#20) #13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19

#21) #12 AND #20

#22) “pre-bereavement”:ab,ti OR prebereavement:ab,ti OR “caregiver grief”:ab,ti OR “caregiver bereavement”:ab,ti OR “caregiver distress”:ab,ti OR “carer distress”:ab,ti OR “anticipatory grief”:ab,ti OR “anticipatory bereavement”:ab,ti OR “anticipatory mourning”:ab,ti OR “pre death grief”:ab,ti OR “predeath grief”:ab,ti OR “pre loss grief”:ab,ti OR “preloss grief”:ab,ti OR “preparatory grief”:ab,ti

#23) #21 OR #22

#24) #9 AND #23

#25) MeSH descriptor: [Animals] explode all trees

#26) MeSH descriptor: [Humans] explode all trees

#27) #25 NOT #26

#28) #24 NOT #27

#### 4. PsycINFO (via Ovid)

(exp caregivers/ or family/ or exp biological family/ or exp extended family/ or exp family members/ or exp family relations/ or exp family structure/ or exp nuclear family/ or exp stepfamily/ or exp friendship/ or caregiver.ti,ab. or “care giver”.ti,ab. or caregivers.ti,ab.

or “care givers”.ti,ab. or caretaker.ti,ab. or “care taker”.ti,ab. or caretakers.ti,ab. or “care takers”.ti,ab. or caregiving.ti,ab. or “care giving”.ti,ab. or caretaking.ti,ab. or “care taking”.ti,ab. or carer.ti,ab. or carers.ti,ab. or family.ti,ab. or families.ti,ab. or relative.ti,ab. or relatives.ti,ab. or spouse.ti,ab. or spouses.ti,ab. or wife.ti,ab. or wives.ti,ab. or husband.ti,ab. or husbands.ti,ab. or fiancée.ti,ab. or fiancées.ti,ab. or fiancé.ti,ab. or fiancés.ti,ab. or “domestic partner”.ti,ab. or “domestic partners”.ti,ab. or girlfriend.ti,ab. or girlfriends.ti,ab. or boyfriend.ti,ab. or boyfriends.ti,ab. or daughter.ti,ab. or daughters.ti,ab. or son.ti,ab. or sons.ti,ab. or child.ti,ab. or children.ti,ab. or offspring.ti,ab. or parent.ti,ab. or parents.ti,ab. or stepparent.ti,ab. or “step-parent”.ti,ab. or stepparents.ti,ab. or “step-parents”.ti,ab. or mother.ti,ab. or mothers.ti,ab. or father.ti,ab. or fathers.ti,ab. or sister.ti,ab. or sisters.ti,ab. or brother.ti,ab. or brothers.ti,ab. or sibling.ti,ab. or siblings.ti,ab. or aunt.ti,ab. or aunts.ti,ab. or uncle.ti,ab. or uncles.ti,ab. or niece.ti,ab. or nieces.ti,ab. or nephew.ti,ab. or nephews.ti,ab. or cousin.ti,ab. or cousins.ti,ab. or grandparent.ti,ab. or grandparents.ti,ab. or grandmother.ti,ab. or grandmothers.ti,ab. or grandfather.ti,ab. or grandfathers.ti,ab. or friend.ti,ab. or friends.ti,ab. or companion.ti,ab. or companions.ti,ab. or acquaintance.ti,ab. or acquaintances.ti,ab. or friendship.ti,ab. or friendships.ti,ab.) **and** ((exp bereavement/ or grief.ti,ab. or grieve.ti,ab. or grieves.ti,ab. or grieving.ti,ab. or bereavement.ti,ab. or bereaved.ti,ab. or sorrow.ti,ab. or sorrowful.ti,ab. or mourning.ti,ab. or mourn.ti,ab. or mourns.ti,ab. or mournful.ti,ab.) and (exp terminally ill patients/ or exp hospice/ or palliative care/ or ‘catastrophic illness’.ti,ab. or ‘catastrophic illnesses’.ti,ab. or ‘catastrophic disease’.ti,ab. or ‘catastrophic diseases’.ti,ab. or ‘prolonged illness’.ti,ab. or ‘prolonged illnesses’.ti,ab. or ‘prolonged disease’.ti,ab. or ‘prolonged diseases’.ti,ab. or ‘critical illness’.ti,ab. or ‘critical illnesses’.ti,ab. or ‘critical disease’.ti,ab. or ‘critical diseases’.ti,ab. or ‘critically ill’.ti,ab. or ‘life-limiting condition’.ti,ab. or ‘life-limiting conditions’.ti,ab. or ‘life-limiting illness’.ti,ab. or ‘life-limiting illnesses’.ti,ab. or ‘life-limiting disease’.ti,ab. or ‘life-limiting diseases’.ti,ab. or ‘life-threatening health condition’.ti,ab. or ‘life-threatening health conditions’.ti,ab. or ‘life-threatening condition’.ti,ab. or ‘life-threatening conditions’.ti,ab. or ‘life-threatening illness’.ti,ab. or ‘life-threatening illnesses’.ti,ab. or ‘life-threatening disease’.ti,ab. or ‘life-threatening diseases’.ti,ab. or ‘advanced medical illness’.ti,ab. or ‘advanced medical illnesses’.ti,ab. or ‘advanced illness’.ti,ab. or ‘advanced illnesses’.ti,ab. or ‘advanced disease’.ti,ab. or ‘advanced diseases’.ti,ab. or ‘terminal care’.ti,ab. or ‘terminal illness’.ti,ab. or ‘terminal illnesses’.ti,ab. or ‘terminal disease’.ti,ab. or ‘terminal diseases’.ti,ab. or ‘terminally ill’.ti,ab. or ‘terminal stage’.ti,ab. or ‘terminal stages’.ti,ab. or ‘fatal illness’.ti,ab. or ‘fatal illnesses’.ti,ab. or ‘fatal disease’.ti,ab. or ‘fatal diseases’.ti,ab. or ‘pre-loss’.ti,ab. or preloss.ti,ab. or ‘pre-death’.ti,ab. or predeath.ti,ab. or ‘end of life’.ti,ab. or ‘hospice care’.ti,ab. or ‘bereavement care’.ti,ab. or ‘palliative care’.ti,ab. or ‘supportive care’.ti,ab.)) or (‘pre-bereavement’.ti,ab. or prebereavement.ti,ab. or ‘caregiver grief’.ti,ab. or ‘caregiver bereavement’.ti,ab. or ‘caregiver distress’.ti,ab. or ‘carer distress’.ti,ab. or ‘anticipatory grief’.ti,ab. or ‘anticipatory bereavement’.ti,ab. or ‘anticipatory mourning’.ti,ab. or ‘pre-death grief’.ti,ab. or ‘predeath grief’.ti,ab. or ‘pre-loss grief’.ti,ab. or ‘preloss grief’.ti,ab. or ‘preparatory grief’.ti,ab.))

## 5. Web of Science Core Collection (via Clarivate Analytics)

TS=(caregiver OR “care giver” OR caregivers OR “care givers” OR caretaker OR “care taker” OR caretakers OR “care takers” OR caregiving OR “care giving” OR caretaking

OR “care taking” OR carer OR carers OR family OR families OR relative OR relatives OR spouse OR spouses OR wife OR wives OR husband OR husbands OR fiancée OR fiancées OR fiancé OR fiancés OR “domestic partner” OR “domestic partners” OR girlfriend OR girlfriends OR boyfriend OR boyfriends OR daughter OR daughters OR son OR sons OR child OR children OR offspring OR parent OR parents OR stepparent OR “step-parent” OR stepparents OR “step-parents” OR mother OR mothers OR father OR fathers OR sister OR sisters OR brother OR brothers OR sibling OR siblings OR aunt OR aunts OR uncle OR uncles OR niece OR nieces OR nephew OR nephews OR cousin OR cousins OR grandparent OR grandparents OR grandmother OR grandmothers OR grandfather OR grandfathers OR friend OR friends OR companion OR companions OR acquaintance OR acquaintances OR friendship OR friendships) AND ((TS=(grief OR grieve OR grieves OR grieving OR bereavement OR bereaved OR sorrow OR sorrowful OR mourning OR mourn OR mourns OR mournful) AND TS=(“catastrophic illness” OR “catastrophic illnesses” OR “catastrophic disease” OR “catastrophic diseases” OR “prolonged illness” OR “prolonged illnesses” OR “prolonged disease” OR “prolonged diseases” OR “critical illness” OR “critical illnesses” OR “critical disease” OR “critical diseases” OR “critically ill” OR “life-limiting condition” OR “life-limiting conditions” OR “life-limiting illness” OR “life-limiting illnesses” OR “life-limiting disease” OR “life-limiting diseases” OR “life-threatening health condition” OR “life-threatening health conditions” OR “life-threatening condition” OR “life-threatening conditions” OR “life-threatening illness” OR “life-threatening illnesses” OR “life-threatening disease” OR “life-threatening diseases” OR “advanced medical illness” OR “advanced medical illnesses” OR “advanced illness” OR “advanced illnesses” OR “advanced disease” OR “advanced diseases” OR “terminal care” OR “terminal illness” OR “terminal illnesses” OR “terminal disease” OR “terminal diseases” OR “terminally ill” OR “terminal stage” OR “terminal stages” OR “fatal illness” OR “fatal illnesses” OR “fatal disease” OR “fatal diseases” OR “pre-loss” OR preloss OR “pre-death” OR predeath OR “end of life” OR “hospice care” OR “bereavement care” OR “palliative care” OR “supportive care”)) OR TS=(“pre-bereavement” OR prebereavement OR “caregiver grief” OR “caregiver bereavement” OR “caregiver distress” OR “carer distress” OR “anticipatory grief” OR “anticipatory bereavement” OR “anticipatory mourning” OR “pre-death grief” OR “predeath grief” OR “pre-loss grief” OR “preloss grief” OR “preparatory grief”))

## 6. Cumulative Index to Nursing and Allied Health Literature (CINAHL) (via EBSCO)

((MH “Caregivers+”) OR (MH “Family”) OR (MH “Adult Children+”) OR (MH “Extended Family+”) OR (MH “Family Characteristics”) OR (MH “Parenthood+”) OR (MH “Stepfamilies+”) OR (MH “Family Functioning+”) OR (MH “Family Relations+”) OR (MH “Nuclear Family+”) OR (MH “Friendship+”) OR TI(caregiver OR “care giver” OR caregivers OR “care givers” OR caretaker OR “care taker” OR caretakers OR “care takers” OR caregiving OR “care giving” OR caretaking OR “care taking” OR carer OR carers OR family OR families OR relative OR relatives OR spouse OR spouses OR wife OR wives OR husband OR husbands OR fiancée OR fiancées OR fiancé OR fiancés OR “domestic partner” OR “domestic partners” OR girlfriend OR girlfriends OR boyfriend OR boyfriends OR daughter OR daughters OR son OR sons OR child OR children OR offspring OR parent OR parents OR stepparent OR “step-parent” OR stepparents OR “step-parents” OR mother

OR mothers OR father OR fathers OR sister OR sisters OR brother OR brothers OR sibling OR siblings OR aunt OR aunts OR uncle OR uncles OR niece OR nieces OR nephew OR nephews OR cousin OR cousins OR grandparent OR grandparents OR grandmother OR grandmothers OR grandfather OR grandfathers OR friend OR friends OR companion OR companions OR acquaintance OR acquaintances OR friendship OR friendships) OR AB(caregiver OR “care giver” OR caregivers OR “care givers” OR caretaker OR “care taker” OR caretakers OR “care takers” OR caregiving OR “care giving” OR caretaking OR “care taking” OR carer OR carers OR family OR families OR relative OR relatives OR spouse OR spouses OR wife OR wives OR husband OR husbands OR fiancée OR fiancées OR fiancé OR fiancés OR “domestic partner” OR “domestic partners” OR girlfriend OR girlfriends OR boyfriend OR boyfriends OR daughter OR daughters OR son OR sons OR child OR children OR offspring OR parent OR parents OR stepparent OR “step-parent” OR stepparents OR “step-parents” OR mother OR mothers OR father OR fathers OR sister OR sisters OR brother OR brothers OR sibling OR siblings OR aunt OR aunts OR uncle OR uncles OR niece OR nieces OR nephew OR nephews OR cousin OR cousins OR grandparent OR grandparents OR grandmother OR grandmothers OR grandfather OR grandfathers OR friend OR friends OR companion OR companions OR acquaintance OR acquaintances OR friendship OR friendships) AND (((MH “Bereavement+”) OR TI(grief OR grieve OR grieves OR grieving OR bereavement OR bereaved OR sorrow OR sorrowful OR mourning OR mourn OR mourns OR mournful) OR AB(grief OR grieve OR grieves OR grieving OR bereavement OR bereaved OR sorrow OR sorrowful OR mourning OR mourn OR mourns OR mournful)) AND ((MH “Catastrophic Illness+”) OR (MH “Critical Illness+”) OR (MH “Terminal Care”) OR (MH “Terminally Ill Patients+”) OR (MH “Hospice Care+”) OR (MH “Palliative Care+”) OR TI(“catastrophic illness” OR “catastrophic illnesses” OR “catastrophic disease” OR “catastrophic diseases” OR “prolonged illness” OR “prolonged illnesses” OR “prolonged disease” OR “prolonged diseases” OR “critical illness” OR “critical illnesses” OR “critical disease” OR “critical diseases” OR “critically ill” OR “life-limiting condition” OR “life-limiting conditions” OR “life-limiting illness” OR “life-limiting illnesses” OR “life-limiting disease” OR “life-limiting diseases” OR “life-threatening health condition” OR “life-threatening health conditions” OR “life-threatening condition” OR “life-threatening conditions” OR “life-threatening illness” OR “life-threatening illnesses” OR “life-threatening disease” OR “life-threatening diseases” OR “advanced medical illness” OR “advanced medical illnesses” OR “advanced illness” OR “advanced illnesses” OR “advanced disease” OR “advanced diseases” OR “terminal care” OR “terminal illness” OR “terminal illnesses” OR “terminal disease” OR “terminal diseases” OR “terminally ill” OR “terminal stage” OR “terminal stages” OR “fatal illness” OR “fatal illnesses” OR “fatal disease” OR “fatal diseases” OR “pre-loss” OR preloss OR “pre-death” OR predeath OR “end of life” OR “hospice care” OR “bereavement care” OR “palliative care” OR “supportive care”) OR AB(“catastrophic illness” OR “catastrophic illnesses” OR “catastrophic disease” OR “catastrophic diseases” OR “prolonged illness” OR “prolonged illnesses” OR “prolonged disease” OR “prolonged diseases” OR “critical illness” OR “critical illnesses” OR “critical disease” OR “critical diseases” OR “critically ill” OR “life-limiting condition” OR “life-limiting conditions” OR “life-limiting illness” OR “life-limiting illnesses” OR “life-limiting disease” OR “life-limiting diseases” OR “life-threatening health condition” OR “life-threatening health

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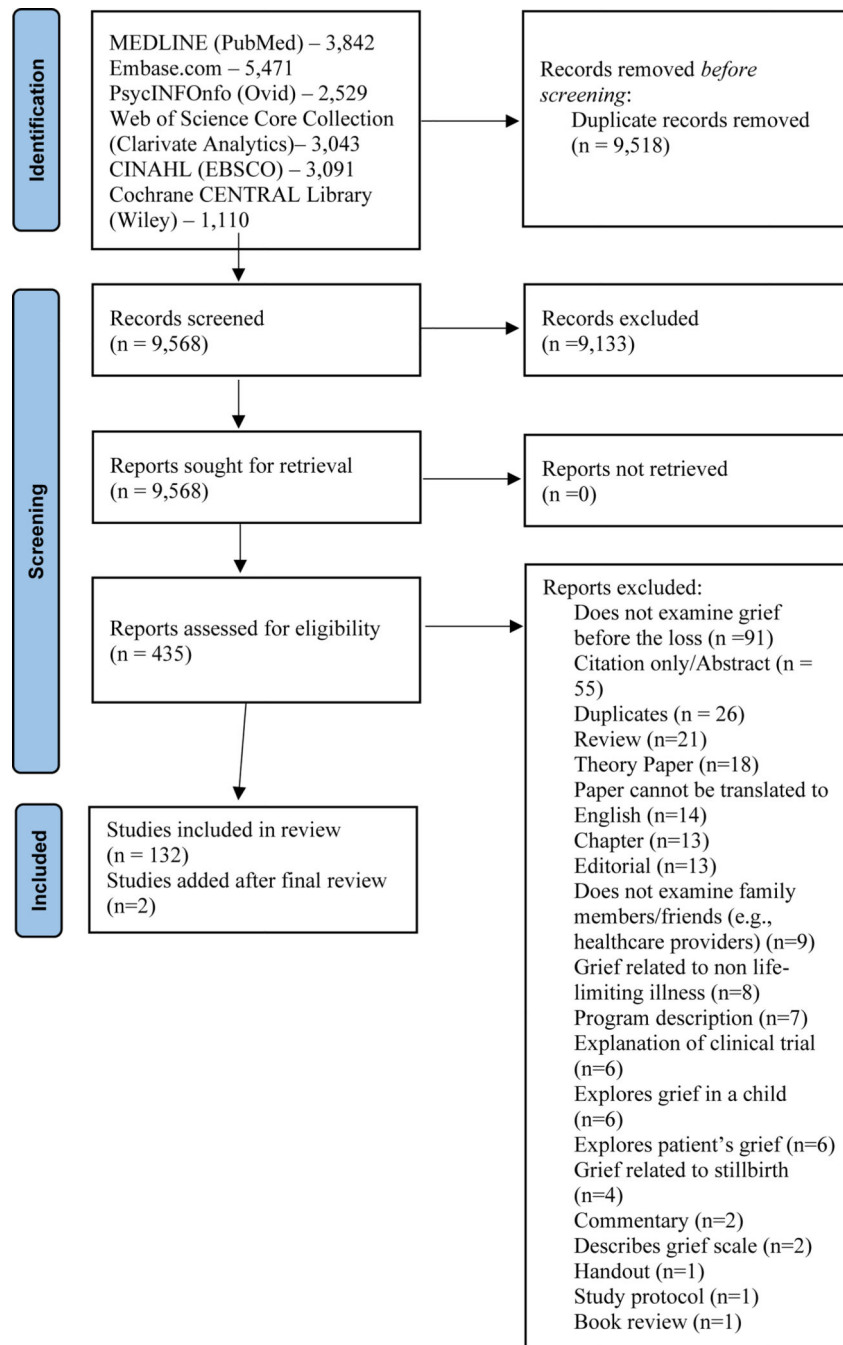
### Key Statements

#### What is already known about the topic?

- Current evidence suggests that grief before the death in family members of individuals with a life-limiting illness is a robust predictor of prolonged grief disorder.
- Significant conceptualization issues exist when defining and measuring grief before the death.

#### What this paper adds

- This systematic review of the literature on grief experienced by family members prior to an individual's death to life-limiting illness revealed wide variation in the terminology used and characterization of such grief across studies (e.g., more than 18 terms and more than 30 definitions have been used to describe this form of grief).
- In many cases, even when certain terms were frequently used (e.g., *anticipatory grief*, *pre-death grief*), the same term was often defined differently across studies.
- In synthesizing the results of this study, we propose the overarching term is *pre-death grief*, with the two separate constructs under *pre-death grief*: *anticipatory grief* and *illness-related grief*.



**Figure 1.**  
PRISMA Flow Diagram

**Table 1.** Articles Examining Family Members' Grief Prior to the Death of Individuals with a Life-limiting Illness

Author et al. (Year)	Methods	Field	Purpose of Study	Illness Context	Sample characteristics	AG/Pre-loss measure or Qualitative interview questions	Term used	Definition of pre-grief term
Adams & Sanders (2004) [71]	Mixed	Neurology	Examine the self-reported losses, grief reactions, and depressive symptoms among caregivers of persons with Alzheimer's disease or other progressive dementia	AD, other known disease, not known disease	n = 99 M = 59.07 (14.55) f: 69; m: 30	Qual interview guide	Grief	Not defined
Al-Gamal et al. (2009) [103]	Quant	Oncology	Develop a modified version of MM-CGI for the assessment of AG among Jordanian parents of children with cancer (the MM-CGI Childhood Cancer)	Cancer	n = 140 Mmothers = 34.4 (6.93), Mfathers = 39.5(8.62) Fnewly: 57; mnewly: 13; f6-12:42; m6-12: 28	MM-CGI-CC	AG	AG is the process of mourning, coping, interaction, planning and psychological reorganization that are stimulated and are in response to the impending loss of a loved one and the recognition of associated losses in the past, present and future
Albinsson & Strang (2003) [34]	Qual	Neurology	Examine issues relevant to family members caring for patients with dementia	Dementia	n = 20 M = not provided, Age range = 44-80 f: 12; m: 8	Qual interview guide	AG	Not defined
Aungela-Cole et al. (2011) [91]	Qual	Oncology	Investigate stress, AM, and cultural-practices among family caregivers different cultural groups	Terminal cancer	n = 56 M = 57.9, SD = not provided f: 51; m: 5	Qual interview guide	AM	AM is time-limited: the uncertainty surrounding the amount of time a loved one has left often creates a more concentrated and heightened grieving and experience pre-death, as opposed to post-death
Areia et al. (2019) [35]	Quant	Oncology	Assess the prevalence of psychological morbidity in family caregivers of persons with terminal cancer	Terminal cancer	n = 112 M = 44.45 (15.32) f: 92; m: 20	MM-CG-SF	AG	Not defined
Benefield et al. [45]	Quant	Nursing	Examine AG experienced by parents when they are informed their critically ill infant must be transferred to a center for special care	Critically ill newborns	n = 202 (101 mother-father pairs) Mmaternal = 25, Mpaternal = not reported f: 50%; m: 50%	Measure designed by authors, name not mentioned, included 7 key items from the	AG	AG as the reaction felt before the actual loss of a loved object assumed a different meaning in this context, since the actual loss never occurred;



Author et al. (Year)	Methods	Field	Purpose of Study	Illness Context	Sample characteristics	AG/Pre-loss measure or Qualitative interview questions	Term used	Definition of pre-grief term
Benfield (1976) <sup>104</sup>	Quant	Nursing	Compare the AG responses of mothers and fathers neonatal ICU experiences over time	Neonatal ICU recipients	n = 70 (35 couples) Mmaternal = 28.6, SD = not provided, Mpaternal = 30, SD = not provided f: 35; m: 35	study of Kennell, which were considered to represent a measure of AG expressed after transfer of their baby.	AG	instead defined by these seven items: feelings of sadness, loss of appetite, inability to sleep, increased irritability, preoccupation thinking about the baby, thinking one had done something to cause the baby's problem (guilt), and feelings of anger
Beng et al. (2013) <sup>105</sup>	Qual	Nursing	Explore the experiences of informal caregivers of patients in Malaysian palliative care	Palliative care recipients	n = 15 M = not provided f: 10; m: 5	Semi-structured questions	AG	Grief reaction that occurs before an impending loss
Bielek (2008) <sup>92</sup>	Qual	Oncology	Understand the lived experience of parents who have lost a child to cancer	Cancer, mostly leukemia or lymphoma	n = 8 (4 couples) M = not provided w: 4, m: 4	Qual interview guide	AM	The act of mourning when facing a loss whether it is sudden or prolonged
Bonanno et al. (2002) <sup>106</sup>	Quant	Psychology	Examine whether bereaved individuals exhibit different patterns of distress following the loss of a spouse	Unspecified	n = 205 M = 72, SD = not provided f: 87.8%; m: 12.2%	16 items derived from the Bereavement Index, the Present Feelings About Loss Scale and the TRIG.	Chronic grief	Not defined
Bouchal et al. (2015) <sup>107</sup>	Qual	Oncology	Explore the retrospective experiences of AG in eight families of people with cancer	Cancer	n = 8 M = not provided	Qual interview guide	AG, AM	Grief is a reaction to separation, and in the case of AG, it is a reaction to the threat of death rather than death itself
Breen et al. (2019) [59]	Quant	Palliative Medicine	Examine PDG as a predictor for outcomes among bereaved caregivers and non-caregivers	Mixed, mostly cancer (check this)	ncaregivers = 38, nmismatchedcomparison = 32 M = not reported fcaregivers: 68.4%; mcaregivers: 26.3%;	HGRC; PG-12	PDG	Not defined

Author et al. (Year)	Methods	Field	Purpose of Study	Illness Context	Sample characteristics	AG/Pre-loss measure or Qualitative interview questions	Term used	Definition of pre-grief term
Broom et al. (2019) <sup>108</sup>	Qual	Oncology	Explore caregiving as a social practice that occurs across dying and bereavement	Cancer	missingcaregivers: 5.3%; fcomparison: 68.8%; mcomparison: 31.3%; missingcomparison: 0%  n = 15 M = not provided, Age range = 40–80 w: 10; m: 5	Qual interview guide	None	Not defined
Burke et al. (2015) <sup>36</sup>	Quant	Palliative Medicine	Explore risk factors for AG in a sample of family members preparing for the death of their veteran family member	Varied, mostly cancer (check this)	n = 57 M = 56.11 (12.97) f: 42; m: 15	AGS- with "dementia" replaced to "life-threatening illness"	AG	The process associated with grieving the loss of loved ones in advance of their inevitable death
Burke et al. (2019) <sup>109</sup>	Quant	Palliative Medicine	Examine the grieving experience of survivors of veterans and to determine risk factors for PLG distress	Palliative care recipients	n = 35 M = 58.64 (13.25) f: 27; m: 13	AGS- with "dementia" replaced to "life-threatening illness"	AG	Not defined
Butler et al. (2005) <sup>110</sup>	Quant	Oncology	Explore associations between residual, current, and anticipatory stressors in partners of women with metastatic breast cancer, pre and post-loss	Recurrent breast cancer	n = 50 M = 56.5 (11.3) f: 1; m: 49	Anticipation of Loss Inventory	AG, Anticipated loss	Partners' feelings about the possible impact of losing their wife/partner
Carr et al. (2001) <sup>111</sup>	Quant	Psychology	Examine if older adults' psychological adjustment to spousal death varies based on the death context	Unspecified	n = 210 Mfemales = 69.43 (6.99), Mmales = 73.46 (5.92) f: 151; m: 59	Bereavement Index; Present Feelings about Loss; TRIG	Grief during the pre death period	Not defined
Carter et al. (2012) <sup>97</sup>	Mixed	Neurology	Examine caregiver grief in Parkinson's disease across the three domains of the MM-CGI Short Form	Parkinson's disease	n = 74 M = 69.2 (8.2) f: 28%; m: 72%	MM-CGI; What would you say is the biggest barrier you have faced as a caregiver?	PDG, CG	PDG is defined by the MM-CGI: personal sacrifice and burden (i.e., losses of time, freedom, sleep, health), worry and felt isolation (i.e., loss of personal connection to others and worries about the future) and heartfelt sadness and longing (i.e., emotional response to loss of relationship)

Author et al. (Year)	Methods	Field	Purpose of Study	Illness Context	Sample characteristics	AG/Pre-loss measure or Qualitative interview questions	Term used	Definition of pre-grief term
Chan et al. (2017) <sup>73</sup>	Quant	Neurology	Validate the C-MMCGI-SF among Hong Kong Chinese caregivers of people with dementia	Dementia	n = 120 M = 55.46 (14.89) f: 80; m: 40	C-MM-CGI	Grief	The authors discuss diverging opinions for AG in caregivers of PWD: some use AG, the the anticipation of the impending death of family members while others suggest that the grief experienced by these caregivers should include broader physical and emotional reactions in response to various losses
Chan et al. (2019) <sup>112</sup>	Quant	Neurology	Evaluate the validity and utility of MM-CGI dimensions in a multiethnic Asian population	Dementia	n = 394 M = 53 (10.7) f: 236; m: 158	C-MM-CGI	PDG, CG	Emotive responses as caregivers mourn for the psychological and physical changes in PWD; grief comprise factors unique to caring for PWD (i.e., communication challenges, asynchronous loss, and an ambiguous disease trajectory leading to worry and uncertainty about the future)
Chapman & Pepler (1998) <sup>113</sup>	Quant	Oncology	Examine the relationships among AG in family members of people with terminal cancer	Terminal cancer	n = 61 M = 48 (18.3) f: 37; m: 24	NDGEI	AG	AG is grief occurring before death
Cheng et al. (2019) <sup>114</sup>	Quant	Neurology	Validate CGQ assessing two dimensions of PDG	AD	n = 173 f: 73%; m: 27%	CGQ	PDG	Sense of loss, such as the eroded personal qualities of the care recipients and the loss of intimacy and companionship, across all stages of dementia
Chentsova-Dutton et al. (2002) <sup>115</sup>	Quant	Palliative Medicine	Compare the emotional adjustment and grief intensity of bereaved spouses and adult children caregivers' pre-loss throughout one-year post-loss	Terminal chronic illness and hospice care recipients	ncaregivers = 48, ncontrols = 36 Mcaregivers = 63, SD = not provided, Mcontrols = 56, SD = not provided fcaregivers: 83%; mcaregivers: 17%; fcontrols: 75%; mcontrols: 25%	TRIG	None	Not defined

Author et al. (Year)	Methods	Field	Purpose of Study	Illness Context	Sample characteristics	AG/Pre-loss measure or Qualitative interview questions	Term used	Definition of pre-grief term
Cheung et al. (2018) <sup>44</sup>	Quant	Neurology	Compare AG levels between spousal and adult children caregivers' of people at earlier or later stages of dementia; to explore the associations with AG	Dementia	n = 108 M = 62.9 (12.6) f: 85; m: 23	MM-CG-SF	AG	PDG is a feeling in response to compound serial losses in the dementia process
Clayton et al. (1973) <sup>46</sup>	Quant	Psychology Palliative Medicine	Examine the symptoms of bereavement during the terminal illness of the spouses of widows and widowers	Terminal illness	n = 81 M = 61, SD = not provided	Were provided symptoms (e.g., depressed mood; crying) but no scale identified	AG	The reaction seen in people (usually primary relative) coping with the expected death of someone close
Clukey (1997) <sup>116</sup>	Qual	Palliative Medicine Nursing	Retrospectively explore the AG experience of caregivers of family members with terminal illness	Cancer, heart disease, chronic obstructive pulmonary disease, Hepatitis C	n=22 M = 53, SD = not provided f: 18; m: 4	Qual interview guide	AG	State of transition usually initiated by either the diagnosis of a terminal illness or the prognosis from a physician that no further medical intervention will cure the dying person.
Clukey (2003) <sup>90</sup>	Qual		Retrospectively explore AM for family members who had not used hospice or had minimal hospice services	Cancer, stroke, old age (check old age)	n = 9 M = 52.2, SD = not provided, Age range = 36–68 f: 7; m: 2	Qual interview guide	AM	AM is a dynamic set of processes that involve emotional and cognitive transitions made in response to an expected loss
Clukey (2008) <sup>116</sup>	Qual	Palliative Medicine; Nursing	Explore the retrospective perceptions of the AM experience of caregivers who had not received hospice services	Dying patients who did not receive hospice care (check this)	n = 9 M = not provided, Age range = 36–68	Qual interview guide	AG, AM	AM involves a dynamic set of processes that include emotional and cognitive transitions made in response to an expected loss
Coelho et al., (2016) <sup>74</sup>	Quant	Palliative Medicine	Identify the mediators of CG in caregivers	Cancer, cardiovascular disease	n = 64 M = 58.2, SD = not provided f: 82.8%; m: 17.2%	Modified Bereavement Risk Questionnaire	Grief	Not defined
Coelho et al. (2017) <sup>13</sup>	Quant	Oncology	Validate a Portuguese version of the PG-12	Cancer	n = 94 M = 52.02 (12.87) f: 78.8%; m: 21.3	PG-12	AG, PDG, PLG	Personal losses (i.e., restrictions of autonomy and suppression of their own needs), relational losses (i.e., deprivation of intimacy and reciprocity with the patient) causing intense feelings of grief

Author et al. (Year)	Methods	Field	Purpose of Study	Illness Context	Sample characteristics	AG/Pre-loss measure or Qualitative interview questions	Term used	Definition of pre-grief term
								while the relative is still physically present
Coelho et al. (2019) <sup>21</sup>	Qual	Oncology	Qualitatively explore the experience of family caregivers of patients with terminal cancer related to AG in the context of EOL caregiving	Cancer	n = 26 M = not provided, Age Range = 27-78 f: 23, m: 3	Qual interview guide	AG	AG is expectations and emotions associated with the fear of losing their significant other
Coelho et al. (2021) <sup>20</sup>	Quant	Oncology	Examine the evolution of PGD symptoms and the predictive role of the caregiving-related factors in the FCs' grieving trajectory from pre- to post-death	Cancer	n=156 M=51.78 (13.29) f: 127; m: 29	PG-12	PDG	Not defined
Collins et al. (1993) <sup>23</sup>	Qual	Neurology	Describe family caregiver experiences of loss and grief pre and post-death of PWD	AD, other progressive dementia	ntotal = 350, npostbereaved = 87 M = 66 (11) f: 79%; m: 21%	Open-ended questions	AG	AG is a psychological response initiated by a person's growing awareness of the impending loss of a loved one and the associated losses in the past, present, and future
Collins et al. (2016) <sup>37</sup>	Qual	Palliative Medicine	Explore the experiences of parents who are providing care for a child with a life-limiting condition in Australia	Life-limiting condition	n = 14 M = 40, SD = not provided f: 12; m: 2	Semi-structured interviews	AG	Not defined
D'antonio (2014) <sup>117</sup>	Quant	Oncology	Examine AG and AM, comparing the terms and examining both terms within the case study	Cancer	n = 1 M = 72, SD = N/A f: 0, m: 1	AGS	AG	Mourning is a process whereby one tries to cope with loss and the ensuing grief
DeCaporale et al. (2013) <sup>24</sup>	Quant	Palliative Medicine	Examine grief reactions in current spousal and adult-children caregivers and in-home respite utilization over 3 months	Cognitive and physical conditions	n = 72 M = 69.8, SD = not provided f: 20.1%; m: 79.9%	MM-CGI-SF-Heartfelt Sadness and Longing Subscale	AG	AG is the process of mourning, coping, interaction, planning and psychological reorganization that occurs as a result of the impending loss of a loved one
Dempsey et al. (2020) <sup>118</sup>	Qual	Neurology	Explore the experience of carers who provide EOL care for a person	Late stage dementia	n = 23 M = not provided f: 70%; m: 30%	Qual interview guide	Dementia grief	An experience of questioning the self and their own sanity, struggle to care and burden of care

Author et al. (Year)	Methods	Field	Purpose of Study	Illness Context	Sample characteristics	AG/Pre-loss measure or Qualitative interview questions	Term used	Definition of pre-grief term
			with late-stage dementia at home					
Dighe et al. (2008) <sup>38</sup>	Qual	Oncology	Identify concerns of parents with advanced, incurable cancers, and to elicit their attitudes toward revealing the diagnosis and prognosis to the sick child	Advance cancer	n = 31 M = not provided	Qual interview guide	AG	Not defined
Dillon (2016) <sup>34</sup>	Quant	Neurology	Examine how adult-child caregivers for parents with dementia experience depression and AG	Dementia	n = 3 M = 55.16, SD = not provided f: 42; m: 8	MM-CGI	AG	AG can be defined as the experience of grief prior to the physical death of a person
Dionne-Odom et al. (2016) <sup>119</sup>	Quant	Oncology	Test the effect of palliative care telehealth support on bereaved family caregivers	Cancer	n = 44 M = 61.6 (10.1) f: 37; m: 7	PG-12	Grief	Pathological grief over the past-month measured pre-death
Duggleby et al. (2013) <sup>120</sup>	Mixed	Oncology	Evaluate the Living with Hope Program in rural women caregivers of persons with advanced cancer	Cancer	n = 36 M = 59 (11.6) f: 36; m: 0	NRGEI: Questions were part of the Living with Hope Program in the form of a hope directed journaling activity entitled "Stories of the Present"	Grief, Loss	Grief that is not associated with the death of a person (e.g., existential concerns, depression, tension and guilt, physical distress)
Duke (1998) <sup>39</sup>	Qual	Palliative Medicine	Explore AG through a Heideggerian phenomenological approach	Terminal malignant disease (cancer? check)	n = 4 M = not provided	Qual interview guide	AG	Not defined
Elliott & Dale (2007) <sup>121</sup>	Qual	Oncology	Illustrate the impact of AG on people with learning disabilities through three case studies	Cancer	n = 3 M = not provided	Questions unspecified	AG	Provides an overview of various definitions in literature; the emotional experience a person might have prior to losing someone of significance to him or her
Evans (2009) <sup>122</sup>	Qual	Oncology	Explore the experience of AG and cancer among individuals living with cancer, their primary	Cancer	n = 22 M = not provided	Qual interview guide	AG	AG is a profound emotional response to impending, irreversible loss, which may be experienced by both dying

Author et al. (Year)	Methods	Field	Purpose of Study	Illness Context	Sample characteristics	AG/Pre-loss measure or Qualitative interview questions	Term used	Definition of pre-grief term
			caregivers, and their families					people and their loved ones
Ford et al. (2013) <sup>123</sup>	Mixed	Neurology	Examine the lived experience of three wives caring for husbands with dementia	Dementia	n = 3 M = not provided f: 3; m: 0	Qual interview guide	Psychosocial death	Irreversible mental deterioration, unlike physical death that is not a terminal event
Fowler et al. (2013) <sup>25</sup>	Quant	Neurology	Measure involvement in medical decision making and if AG is associated with problem-solving in family caregivers of older adults with cognitive impairment	Dementia	n = 73 M = 64.9 (11.28) f: 78.1%; m: 21.9%	AGS	AG	AG is the process of experiencing the phases of normal bereavement in advance of the loss of a loved one
Francis et al. (2015) <sup>124</sup>	Mixed	Oncology	Explore the medical perspective of the social perspective of grief and depression	Cancer	n = 199 M = 54.8, SD = not provided f: 81.4%; m: 18.6%	BEQ	Grief	A normative emotional response to loss; extreme sadness appropriate to the situation
Frank (2008) <sup>125</sup>	Mixed	Neurology	Explore links between AG for family caregivers of PWD	Dementia	n = 415 M = 60.5, SD = not provided	MM-CGI	AG, AM	AG comprises past, present, and future losses; AM is "leaving without saying goodbye," where the person is still psychologically present although physically absent. In the second form, the person remains physically present but psychologically absent (i.e., "the goodbye without leaving")
Fronzaglia (2009) <sup>55</sup>	Quant	Neurology	Examine the relationship between AG and satisfaction with life in rural Alzheimer's caregivers	AD	n = 74 M = 65.49, SD = not provided f: 73.6%; m: 26.4%	MM-CGI	AG	Grief that occurs in recognition of the fact that the person is going to die
Garand et al. (2012) <sup>126</sup>	Quant	Neurology	Examine differences of AG between family caregivers of persons with a new diagnosis of mild cognitive impairment and associations with AG	MCI, AD	n = 73 M = 64.88 (11.27) f: 57; m: 16	AGS	AG	AG refers to the process of experiencing the phases of normal bereavement in advance of the loss of a significant person
Giannone-Tyler (2016) <sup>32</sup>	Qual	Oncology	Understand the lived experiences of elderly	Cancer	n = 4 M = not provided, Age	Qual interview guide	PDG	The grief process that a person experiences before a loss actually occurs

Author et al. (Year)	Methods	Field	Purpose of Study	Illness Context	Sample characteristics	AG/Pre-loss measure or Qualitative interview questions	Term used	Definition of pre-grief term
			women grieving the death of their husbands		range = 67–78 f: 4; m: 0			giving advance warning of impending death and helping to mitigate grief reactions once death has occurred
Gilliland & Fleming (1998) <sup>127</sup>	Quant	Palliative Medicine; Nursing; Oncology; Neurology	Assess the influence of a number of factors on AG and conventional grief reactions	Terminal illness unspecified (check this)	n = 93 Mpalliative = 62, Mchronicare = 68.58, Mcontrol = 55.29 wpalliative: 63.3%; mpalliative: 36.7%; wchronic: 53.3%; mchronic: 46.7%	Grief Experience Inventory	AG	Grief before the loss of someone with a chronic illness
Givens et al. (2011) <sup>8</sup>	Quant	Neurology	Describe pre-loss and post-loss grief symptoms among family members of nursing home residents with advanced dementia, and to identify predictors of post-loss grief	Dementia	n = 123 M = 59.6 (10.6) f: 75; m: 48	PG-12	PLG	Not defined
Glick et al. (2018) <sup>48</sup>	Quant	Nursing; Psychology	Evaluate AG in the ICU setting	Unspecified	n = 50 M = 55.5 SD = not provided f: 72%; m: 28%	AGS	AG	AG is the experience of grief before the death of a mourned individual
Guerrero (2012) <sup>88</sup>	Quant	Neurology	Investigate the relationship between frontal systems behavioral functioning and the experience of grief and burden on spousal caregivers of persons with frontotemporal lobar degeneration	Frontotemporal lobar degeneration	n = 76 M = not provided w: 91.2%; m: 8.8%	MMCGI-SF	CG	Grief prior to death of the care recipient; caregiver grief is comprised of sadness and longing, worry and felt isolation, and personal sacrifice and burden
Gunnarsson & Ohlen (2006) <sup>128</sup>	Qual	Oncology	Retrospectively explore meaning(s) of spouses' grief before their partners' death after being admitted to a palliative home care team	Advanced cancer	n = 12 M = not provided w: 75%; m: 25%	Qual interview guide	AG	Grief before the loss
Hampe (1975) <sup>129</sup>	Qual	Nursing	Examine if spouses caring for their terminally ill partners can recognize their own needs and nurses who help them	Terminal illness unspecified	n = 27 M = not provided f: 42.7%; m: 57.3%	Qual interview guide	AG, Grief	AG is before the actual loss of a valued mate; dependent upon the spouse's awareness of the impending loss



Author et al. (Year)	Methods	Field	Purpose of Study	Illness Context	Sample characteristics	AG/Pre-loss measure or Qualitative interview questions	Term used	Definition of pre-grief term
Hicken et al. (2017) <sup>40</sup>	Mixed	Neurology	Test the efficacy of the “Supporting Caregivers of Rural Veterans Electronically” program	Check this	n = 229 M = 70.16, SD = not provided f: 92.6%; m: 7.4%	MM-CGI-SF	AG	Not defined
Higgs et al. (2016) <sup>33</sup>	Qual	Nursing; Palliative Medicine	Examine parents’ perspectives of having a child with Spinal Muscular Atrophy type 1, from diagnosis to bereavement	Spinal muscular atrophy	n=13 M = not provided f: 7; m: 6	Questions unspecified	AG	Grief experienced in anticipation of a loss that has yet to occur
Hill et al. (1988) <sup>130</sup>	Quant	Psychology	Examine the role of anticipatory bereavement in the adjustment to widowhood in older women	Unspecified, patients had died within the last 2–4 weeks	n = 95 M = 66.5, SD = not provided f: 95; m: 0	TRIG	Anticipatory bereavement	Grief reaction before the actual death
Hinton (1994) <sup>75</sup>	Mixed	Oncology	Evaluate the circumstances of location of death and quality of life in both relatives and patients	Terminal cancer	n = 77 M = 60 (14) w: 34; m: 43	No grief measure reported	Grief	Not defined
Hisamatsu et al. (2020) <sup>131</sup>	Qual	Oncology	Follow spouses of patients with palliative chemotherapy discontinuation until bereavement in Japan	Cancer	n = 13 M = not reported w: 1; m: 1	Qual interview guide	AG	AG of the family caregivers may be a highly stressful experience; their experiences during the patient’s battle with cancer affect them even after bereavement and have the potential to facilitate appropriate grief work
Holley & Mast (2009) <sup>132</sup>	Quant	Neurology	Understand which aspects of the caregiving situation may lead to greater levels of AG	Dementia	n = 80 M = 60.53 (12.66) w: 73.8%; m: 26.2%	MM-CGI	AG	AG is a multifaceted concept that encompasses emotional reactions to the impending loss of a loved one and associated losses in the past, present, and future
Holley & Mast (2010) <sup>26</sup>	Quant	Neurology	Investigate AG in dementia caregivers; examine correlates of caregiver grief; and relationship between AG and caregiver burden	Dementia	n = 80 M = 60.53 (12.36) f: 59; m: 21	AGS; MM-CGI	AG	AG is the psychological experience occurring from the point of recognition and acceptance of the impending death until the time of death
Holm et al. (2019) <sup>64</sup>	Quant	Palliative Medicine	Evaluate the psychometric properties of AGS in a sample	Palliative care recipients	n = 270 M = 61.0(14) w: 184; m: 86	AGS	AG	Grief, which is the psychological physiological response to a

Author et al. (Year)	Methods	Field	Purpose of Study	Illness Context	Sample characteristics	AG/Pre-loss measure or Qualitative interview questions	Term used	Definition of pre-grief term
			of family caregivers in palliative care					person's death, before said close person's death
Holm et al. (2019) <sup>61</sup>	Quant	Palliative Medicine	Investigate associations between PDG and post-death grief and potential moderators	Advanced illness	n = 128 M = 62 (13.2) f: 66.4%; m: 33.6%	AGS	PDG	Grief that might begin long before the actual death; in some cases already starts when they receive information about a diagnosis of incurable illness, while others continue to invest in the patient's recovery; grief before an expected death has been associated with characteristics similar to those often observed after the death: emotional distress, frustration, hope, and ambivalence; PDG also differs from post-death grief because it involves losing a person who is still physically present
Holm et al. (2019) <sup>133</sup>	Quant	Palliative Medicine	Investigate longitudinal variations in grief, symptoms of anxiety and depression, and self-rated health	Palliative care recipients, mostly cancer	n = 117 M = 62(13.1) w: 75; m: 42	AGS	PDG	Referred to as the experience before death
Hovland (2018) <sup>134</sup>	Qual	Neurology	Explore the EOL and PDG experiences for bereaved family caregivers of older adults with dementia	Dementia	n = 36 M = 64, SD = not provided f: 81%; m: 19%	Qual interview guide	PDG	A reaction to perceived losses throughout the caregiving process and in anticipation of the death
Hudson et al. (2011) <sup>81</sup>	Quant	Oncology	Examine the psychological and social profile of family caregivers on commencement of receiving palliative care services	Cancer, non-cancer	n = 301 M = 56.52 (13.89) f: 220; m: 79	PG-12	PLG	Grief is a process involving some elements of "loss," which starts before the bereavement and can be onerous
Jain et al. (2019) <sup>69</sup>	Quant	Neurology	Identify the clinical relationship between grief, depression and mindfulness and identify neural predictors of symptomatology and improvement	Dementia	n = 23 M = 60 (11) f: 21; m: 2	MM-CGI-SF	PDG	PDG are reactions that may occur prior to death when observing and caring for a loved one afflicted with a serious illness such as dementia

Author et al. (Year)	Methods	Field	Purpose of Study	Illness Context	Sample characteristics	AG/Pre-loss measure or Qualitative interview questions	Term used	Definition of pre-grief term
Johansson & Grimby (2012) <sup>50</sup>	Quant	Oncology	Explore the feelings and expressions of AG	Cancer	n = 49 M = 56.9 (17.4)	AGS	AG, Preparatory grief	AG is prolonged and occurs even before a person dies; compared to conventional grief, AG has been associated with higher intensities of anger, loss of emotional control, and atypical grief
Johansson et al. (2013) <sup>135</sup>	Mixed	Neurology/Oncology	Compare reactions on the AG scale of relatives of PWD with relatives of cancer patients	Dementia, cancer	n = 102 Mdementia = 62.3 (13.3), Mcancer = 56.9 (17.4) Fdementia: 53; mdementia: 53; fcancer: 49; mcancer: 49	AGS; Semi-structured questions	AG	AG, compared to grief after death, is associated with higher intensities of anger, loss of emotional control, and atypical grief; and despite the experience of AG, the grief after the death of a loved one is not likely to be lessened
Kiely et al. (2008) <sup>62</sup>	Quant	Neurology	Identify factors associated PDG symptoms among health care proxies of nursing home residents with advanced dementia	Dementia	n = 315 M = 59.9 (11.5) f: 63%; m: 27%	PG-12	PDG	PDG is the loss experienced by family members of dementia patients before their actual death; multiple losses, sometimes referred to as "triple grief": first they grieve loss of the patients' personhood before their actual bodily death, next experience loss at the time of nursing home admission, finally loss when the patient ultimately dies
Kilty et al. (2019) <sup>156</sup>	Qual	Neurology	Explore the experience of family caregivers of persons with young-onset dementia and use of support services	Dementia	n = 6 M = 55, SD = not provided f: 3; m: 3	Semi-structured interview; questions not reported	AG, Ambiguous loss	Loss that can occur when a family member remains physically present, but because of the dementia process, the caregiver experiences reduced connection and support from the person with dementia over time; a complex concept with grief experienced in anticipation of future loss of a loved one

Author et al. (Year)	Methods	Field	Purpose of Study	Illness Context	Sample characteristics	AG/Pre-loss measure or Qualitative interview questions	Term used	Definition of pre-grief term
Kobiske et al. (2019) <sup>70</sup>	Quant	Neurology	Examine the moderating effects on the relationship between PDG and perceived stress among young-onset dementia caregivers	Dementia	n = 104 M = 104 f: 68; m: 36	MM-CGI-SF	PDG	Losses experienced by a caregiver
Lai et al. (2017) <sup>137</sup>	Quant	Oncology	Investigate the course of psychological symptoms, emotional and social abilities in caregivers of terminally ill cancer patients from 1 month before loss to 14 months after	Cancer	n = 60 M = 75 (11) f: 43; m: 17	PG-12	AG	AG is a reaction that occurs in the caregiver before an impending loss; a psychological mechanism characterised by emotional stress, intense pre-occupation with the dying, longing for his/her former personality, loneliness, fearfulness, irritability, anger and social withdrawal
Lane (2007) <sup>51</sup>	Quant	Unspecified	Explore the potential predictors of AG	Unspecified	n = 70 M = 54.7 (12.7) f: 63; m: 7	AGS	AG	AG is any grief occurring prior to a loss, as distinguished from the grief that occurs at or after a loss
Li et al. (2019) <sup>94</sup>	Quant	Neurology	Evaluate the Mandarin version of the MM-CGI-SF; grief of family caregivers of patients with dementia; and predictors of grief	Dementia	n = 91 M = 52.19 (14.35) f: 65.9%; m: 34.1%	MM-CGI-SF	Grief in caregivers	Grief in dementia caregivers defined as "true grief," which can reflect the qualities and intensities of caregivers' grief after the dementia patient dies; includes various physical and emotional reactions due to various losses of the dementia patients
Liew (2016) <sup>65</sup>	Quant	Neurology	Explore the prevalence of pre-death grief in a multi-ethnic Asian population using the MM-CGI	Dementia	n = 72 M = 50.9 (11.6) f: 58.3%; m: 41.7%	MM-CGI	PDG	PDG is the emotional response as dementia family caregivers mourn for the psychologically absent patient and anticipate impending losses
Liew & Yap (2020) <sup>86</sup>	Quant	Neurology	Develop a briefer scale than the MM-CGI-SF, while still capturing the essence of caregiver grief	Dementia	n = 394 M = 53(10.7) f: 236; m: 158	MM-CGI; MM-CGI-SF	CG	The experience of grief and loss in dementia caregiving, characterized by multiple losses within the context of caregiving, including the anticipation

Author et al. (Year)	Methods	Field	Purpose of Study	Illness Context	Sample characteristics	AG/Pre-loss measure or Qualitative interview questions	Term used	Definition of pre-grief term
Liew et al. (2018) <sup>67</sup>	Quant	Neurology	Determine differences in the risk factors of PDG and caregiver burden	Dementia	n = 394 M = 55 (10.7) f: 256; m: 138	MM-CGI	PDG	of future losses related to physical death of the PWD and the ambiguous loss of the PWD who is physically present but increasingly disconnected from the caregiver  Emotional, cognitive, and behavioral responses to the multiple losses in caregiving; include ambiguous loss due to increasing disconnectedness from the PWD who is physically present but psychologically absent; and the anticipation of future losses relating to the physical death of the person
Liew et al. (2018) <sup>85</sup>	Quant	Neurology	Produce a Mandarin-Chinese version of MM-CGI and evaluate its psychometric properties	Dementia	n = 394 M = 53 (10.7) f: 236; m: 131	MM-CGI	PDG	PDG is the caregivers' responses to perceived losses in the pre-death context; anticipation of future loss related to the physical death of PWD; and the mourning of present loss related to the psychological death of PWD, whereby they are still physically present but emotionally disconnected
Liew et al. (2019) <sup>66</sup>	Quant	Neurology	Compare the effects of baseline grief and burden on caregiver depression at baseline and 2.5 years later	Dementia	n = 131 M = 55.1 (11.0) f: 58.3%; m: 41.7%	MM-CGI	CG	For caregivers of PWD, bereavement that is before the physical death; multiple losses within the context of caregiving, including the ambiguous loss of the person with dementia who is physically present but becomes increasingly disconnected from the caregiver
Liew et al. (2019) <sup>84</sup>	Quant	Neurology	Construct screening tool based on factors associated with caregiver	Dementia	n = 300 M = 52.1 (11) f: 60%; m: 40%	MM-CGI	CG	Loss and grief are experienced by caregivers of PWD; ambiguous loss of PWD even when

Author et al. (Year)	Methods	Field	Purpose of Study	Illness Context	Sample characteristics	AG/Pre-loss measure or Qualitative interview questions	Term used	Definition of pre-grief term
Lou et al. (2015) <sup>138</sup>	Qual	Oncology	Retrospectively explore maternal experiences of anticipatory loss of families of a child with advanced cancers	Brain cancer (previously tumor check this)	n = 10 M = 42, SD = not provided	Qual interview guide	Anticipated loss	Anticipated loss as the family's realization of the meaning of the disease and the process of facing the loss of their child in the future
MacCourt et al. (2017) <sup>95</sup>	Mixed	Neurology	Determine the effect of a grief management coaching intervention for caregivers of individuals with dementia	Dementia	n = 200 M = 64.4, SD = not provided f: 79%; m: 21%	MM-CGI	Grief in caregivers	Not defined
Marwit & Kaye (2006) <sup>96</sup>	Quant	Neurology	Investigate the properties of MM-CGI-SF for caregivers of patients with acquired brain injury	Brain injury	n = 28 M = 55.22 (14.25) f: 25; m: 5	MM-CGI-SF	Grief in caregivers	Not defined
Marwit & Meuser (2002) <sup>87</sup>	Mixed	Neurology	Develop an instrument for the assessment of grief in caregivers of persons with AD	Dementia	n = 166 Madtchild = 51.81 (8.05), Mspouse = 71.47 (8.93) fadtchild: 73; madtchild: 10; fspouse: 62; mspouse: 21	MM-CGI	CG	Complicated grief as divided into AG reactions and bereavement; pre- and post-death grief, are unique phenomena from each other and other psychiatric diagnoses
Marwit & Meuser (2005) <sup>139</sup>	Quant	Neurology	Derive a short-form of the existing MM-CGI and establish preliminary reliability and validity	Dementia	n = 292 M = not provided, f: 76.4%; m: 23.6%	AGS; MM-CGI-SF	PDG, CG	Grief before death
Marwit et al. (2008) <sup>68</sup>	Quant	Oncology	Examine the MM-CGI psychometric and validity properties in caregivers of persons with cancer	Cancer	n = 75 M = 52.8 (12.8) f: 69.3%; m: 30.7%	MM-CGI	PDG	Grief within the emotional reactions of 'pre-death' loss among caregivers of people with chronic/debilitating and life-threatening conditions, including dementia, where a series of cognitive, emotional, and social losses precede death; caregiver grief is considered a unique affect, similar to bereavement, discriminable from depression and anxiety, and associated negatively

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McLennan et al. (2014) <sup>140</sup>	Qual	Neurology	Understand African-American caregivers PDG experiences; to assess the validity of items on the MM-CGI-SF	Dementia	n = 19 M = 60 (13.5) f: 16, m: 3	MM-CGI-SF	PDG	with caregiver health, social relations, and post-death bereavement  PDG experienced by AD caregivers is similar to AG, grief in anticipation of death to come; feelings of loss and sadness experienced by caregivers as they watch the gradual deterioration of the personality and memory of their loved one into "dependent shadows of their former selves", also referred to as "psychosocial death."
McRae (2005) <sup>141</sup>	Qual	Neurology	Examine the phenomenological experience of daughters-in-law caring for a parent-in-law with dementia	Dementia	n = 11 M = 50, SD = not provided f: 11; m: 0	Qual interview guide	AG	The experience of current losses or the anticipation of loss and grief
Meichsner & Witz (2018) <sup>142</sup>	Quant	Neurology	Examine if a cognitive-behavioral intervention increases caregivers' coping with PDG	Dementia	n = 273 M = 64.20 (11.04) f: 80.6%; m: 19.4%	Caregiver Grief Scale	PDG	PDG is defined as the 'emotional and physical response to the perceived losses in a valued care recipient'
Meichsner et al. (2019) <sup>143</sup>	Qual	Neurology	Illustrate how dementia caregivers experience loss and PDG, and examine how therapists respond to this grief	Dementia	n = 273 M = not provided	Questions unspecified	PDG	Emotional and physical response to the perceived losses in a valued care recipient
Meuser & Marwit (2001) <sup>41</sup>	Mixed	Neurology	Develop a stage-sensitive, caregiver-specific model of grief for a measure of dementia caregiver grief	Dementia	n = 87 MAdultchild = 51.6 (9.6), M spouse = 71.8 (9) w: 20; m: 67	AGS; MFG	AG	Not defined
Mulligan (2011) <sup>60</sup>	Quant	Neurology	Identify areas of overlap and disjunction between the PG-12 and the MM-CGI-SF	Dementia	n = 202 M = 67.67 (11.52) f: 148; m: 54	MM-CGI-SF; PG-12	PDG	Symptoms include yearning for the family member to be healthy again and feeling shocked about the person's illness

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Nanni et al. (2014) <sup>144</sup>	Quant	Oncology	Examine the relationship between pre and post-loss criteria for CG and the validity of ICG for Italian caregivers	Cancer	n = 60 M = 60.3 (12.08) f: 75%; m: 25%	ICG-PL	Pre-loss caregiver grief	A syndrome characterized by emotional, behavioral and cognitive symptoms (e.g. yearning, searching, detachment, numbness, bitterness, emptiness, and lost sense of trust and control) named as: complicated grief, then traumatic grief, and, more recently, prolonged grief
Neyshabouri et al. (2018) <sup>56</sup>	Quant	Oncology	Compare AG of mothers of children diagnosed with cancer within the previous month to those diagnosed 6–12 months earlier	Cancer	n = 70 M1month = 32.27, M6–12month = 33.12 f: 100%; m: 0%	MM-CGI	AG	An active process of being sad that occur prior to actual loss
Nielsen et al. (2016) <sup>82</sup>	Quant	Psychology/Palliative Medicine	Describe PLG and other relevant outcomes in caregivers to terminally ill patients	Terminal illness	n = 3560 M = 61.2, SD = not provided f: 66.6%; m: 29.4%	PG-13	PLG	Not Defined
Nielsen et al. (2017) <sup>83</sup>	Quant	Oncology	Investigate whether severe preloss grief and depressive symptoms, caregiver burden, preparedness for death, communication about dying, and socioeconomic factors predict CG and postloss depressive symptoms	Cancer	n = 3635, 38% bereaved w/in 6mo, of these 88% completed T2 M = 62 f: 70%; m: 30%	PG-12	PLG	Not defined
Nielsen et al. (2017) <sup>9</sup>	Quant	Oncology	Explore associations between severe PLG symptoms in caregivers and modifiable factors	Cancer	n = 2865 M = 61, SD = not reported f: 69%; m: 31%	PG-12	AG, PLG	PLG and AG as grief symptoms in caregivers before death have been; can be described as a grief reaction due to multiple losses during end-of-life caregiving
Olson (2014) <sup>145</sup>	Qual	Oncology	Explore cancer carers' experiences of loss with Australian carers of a spouse with cancer	Cancer	n = 32 Age range = 30–89 f: 14; m: 18	Qual interview guide	AG, Indefinite loss	AG experienced at the end of a patient's life; AG occurs when the emotions related to loss arise a substantial time before the person stops breathing



Author et al. (Year)	Methods	Field	Purpose of Study	Illness Context	Sample characteristics	AG/Pre-loss measure or Qualitative interview questions	Term used	Definition of pre-grief term
Ott et al. (2007) <sup>93</sup>	Quant	Neurology	Describe the grief experience of spouses and adult children of individuals with Alzheimer's disease and related dementias	Dementia	n = 201 M = 64.07 (13.88) f: 80.6%; m: 19.4%	MM-CGI-SF	Grief in caregivers	Grief as the reaction to the perception of loss with normative symptoms including yearning, sadness, anger, guilt, regret, anxiety, loneliness, fatigue, shock, numbness, positive feelings, and a variety of physical symptoms that are unique to the individual
Ott et al. (2010) <sup>80</sup>	Quant	Neurology	Determine if the Easing the Way intervention is feasible for caregivers of spouses with dementia	Dementia	n = 23 M = 73.5, SD = not provided f: 75%; m: 25%	MMCGI-SF	Grief	Increased sadness and longing, worry and isolation, and personal sacrifice burden
Park et al. (2018) <sup>146</sup>	Quant	Neurology	Examine the relationships among burnout, depressive symptoms, social support, and psychological wellbeing in caregivers of PWD	Dementia	n = 606 M = 60.5 (10.6) f: 88.9%; m: 10.6%	MM-CGI	AG, CG	An emotional reaction to actual or perceived losses among caregivers marked by increased sadness and longing, worry and isolation, and personal burden; in caregivers, grief starts with early signs of dementia in the family member and continues through the stages of dementia; AG is defined as anticipation of the loss of a family member
Ponder & Pomeroy (1996) <sup>42</sup>	Quant	Neurology	Provide evidence of the intensity, nature and persistence of AG among caregivers of PWD	Dementia	n = 100 M = 56.6, SD = not provided f: 83 m: 17	GEI-Loss Despair Scale; Stage of Grief Inventory; self-developed scale	AG	Not defined
Pote (2017) <sup>98</sup>	Quant	Neurology	Understand the effect of perceived closeness and attachment styles of spousal caregivers of individuals with dementia	Dementia	n = 90 M = not reported f: 66; m: 24	MMCGI-SF	AG	AG is the process whereby individuals mourn the approaching death of a loved one, particularly through the physical and cognitive decline that plagues individuals who are at a terminal stage in life

Author et al. (Year)	Methods	Field	Purpose of Study	Illness Context	Sample characteristics	AG/Pre-loss measure or Qualitative interview questions	Term used	Definition of pre-grief term
Poie & Wright (2018) <sup>57</sup>	Quant	Neurology	Evaluate AG as a moderator for marriage and life satisfaction in spousal caregivers of dementia patients	Dementia	n = 90 M = 63, SD = not provided f: 66; m: 24	MM-CGI-SF	AG	AG is a process that many informal caregivers go through and involves a series of losses that stem from their loved one's progression of cognitive and physical decline
Prigerson et al. (2019) <sup>43</sup>	Mixed	Nursing; Psychology	Investigate effects of the EMPOWER intervention for surrogate decision-makers of critically ill ICU patients	Critically ill ICU patients	n = 60	FOLLOS; PG-12	AG	Not defined
Rankin (2011) <sup>59</sup>	Quant	Oncology	Examine how coping styles influence seeking social support for carers of persons with cancer	Cancer	n = 103 M = 49.57 (12.43) f: 68; m: 35	WOC	PDG	Grief experienced by caregivers prior to the death of the patient in response to the many losses that accompany the cancer diagnosis of a loved ones
Rider (1994) <sup>52</sup>	Quant	Psychology/Palliative Medicine	Examine the effects of ambiguity of loss and type of relationship on AG in family caregivers of chronically ill patients	Terminal illness	n = 53 M = 46.4, SD = not provided f: 86.8%; m: 13.2%	AGS-CIV; RAGC; TRIG-CIV1	AG	A multifaceted process occurring over time, involving physical, cognitive, emotional, behavioral, and social reactions or tasks in response to the death of a loved one; efforts at coping with and resolving the loss are part of this grief process; also called post-death grief
Riley et al. (2013) <sup>147</sup>	Quant	Neurology	Develop a measure on spousal carers' perception of their relationship as "continuous"	Dementia	nstudy1 = 51, nstudy2 = 84 Mstudy1 = 73 (7.6), Mstudy2 = 71.6 (7.8) fstudy1: 23, mstudy1: 28; fstudy2: 58, mstudy2: 26	Birmingham Relationship Continuity Measure	Relationship continuity, Negative emotions related to the relationship	Feelings of loss and negative emotions related to whether the spouse experiences the relationship as essentially changed and radically different relationship
Rini & Lorig (2007) <sup>89</sup>	Qual	Nursing; Palliative Medicine	Describe the role of AM in parents who recently experienced the death of a hospitalized child	Mixed cause of death (check this)	n = 11 M = not provided f: 9; m: 2	Qual interview guide	AM	AM is the process of emotional preparatory experience leading up to the time of death, formerly termed AG; AM describes not only the process of grief but other processes as well; AM encompasses

Author et al. (Year)	Methods	Field	Purpose of Study	Illness Context	Sample characteristics	AG/Pre-loss measure or Qualitative interview questions	Term used	Definition of pre-grief term
Romero et al. (2014) <sup>71</sup>	Quant	Neurology	Identify predictors of higher levels of grief in bereaved caregivers of persons with Alzheimer's prior to death	AD	n = 66 M = 64.3, SD = not provided f: 88%; m: 22%	MMCGI-SF	PDG	seven operations according to Rando (2001): grief and mourning, coping, interaction, psychosocial reorganization, planning, balancing of conflicting demands, and facilitation of an appropriate death
Ross & Dagle (2009) <sup>27</sup>	Quant	Neurology	Explore the reliability of the MM-CGI and AG as a multi-cultural phenomenon among caregivers of patients with dementia	Dementia and cardiac patients	n = 176 M = not provided f: 45.5%; m: 54.5%	MM-CGI-SF	AG	PDG results from losses in the quality of the original relationship, roles, well-being, intimacy, health status, social interaction, communication, and opportunities to resolve issues from the past
Saldinger & Cain (2004) <sup>148</sup>	Qual	Oncology	Explore the extent to which spouses take advantage of their partner's terminal illness for cognitive, emotional, practical, and interpersonal accommodation to impending death	Cancer	n = 30 M = not provided	Qual interview guide	AG	Grief process of individuals who are losing someone slowly, expectedly, and many times, in stages
Sanders et al. (2008) <sup>77</sup>	Mixed	Neurology	Describe the experience of spouses and adult children who are caregivers of persons with Alzheimer's disease and related dementias.	AD and dementia	n = 44 M = 65.18, SD = not provided f: 86%; m: 14%	MM-CGI-SF	Grief	Cognitive, emotional, practical, and interpersonal accommodation to impending death.
Singer et al. (2021) <sup>7</sup>	Quant	Neurology; Oncology	Examine changes in PLG among individuals whose family member has a life-limiting illness	Cancer; dementia	nbaseline = 138, n1month = 61 M = 62.81 (14.41) f: 70.8%; m: 29.2%	PG-12	PLG	The reaction to the perception of loss
								The impending loss of their loved one or the loss of their pre-diagnosis relationship or the loss of their pre-diagnosis relationship with the loved one (e.g., yearning for the individuals to be as they were before the illness)

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Stajduhar et al. (2010) <sup>76</sup>	Mixed	Oncology	Understand why some family caregivers cope better than others even under similar caregiving demands	Cancer	n = 14 Msample1 = 63; Age rangesample2 = 46–57 f: 73.7%; msample1: 26.3%; f: 92.9%; msample2: 7.1%	Questions unspecified	Grief	Not defined
Swensen et al. (1992) <sup>28</sup>	Mixed	Oncology	Examine the relationship between married couples when one of the spouses is dying of terminal illness	Various cancers, others unspecified, healthy controls	nexperimental = 114, ncontrol = 100 Mexperimental = 58.6, SD = not provided, Mcontrol = 58.4, SD = not provided	The Marriage Problems Scale; The Scale of Feelings and Behavior of Love	AG	In AG, spouses can move closer behaviorally or socially, while starting to move away intra-psychically
Theut et al. (1991) <sup>29</sup>	Quant	Neurology	Assess the validity and reliability of the AGS scale in documenting AG in carers of spouses of patients with dementia	Dementia	n = 27 M = 68.1, SD = not provided f: 100%; m: 0%	AGS	AG	The process of slowly experiencing the phases of normal post-death grief in the face of a potential loss of a significant person
Tomarken et al. (2006) <sup>149</sup>	Mixed	Oncology	Examine differences in caregiver age groups and potential risk factors for CG pre-death	Cancer	n = 248 M = 52 (13.67) f: 73%; m: 27%	Pre-ICG	Complicated grief pre-death	Complicated grief pre-loss is an AG reaction prior to death; unique phenomena from post-death grief with different psychiatric diagnoses
Toyama & Honda (2017) <sup>30</sup>	Qual	Oncology	Examine the influence of a narrative approach AG in family caregivers of patients with terminal illness	Terminal illness	n = 10 M = not provided f: 80%; m: 20%	Narrative approach	AG	The grief reaction that occurs in anticipation of an impending loss
van Doorn et al. (1998) <sup>150</sup>	Quant	Psychology Palliative Medicine	Test pre-loss effects of having a security-enhancing marriage on traumatic grief and depressive symptoms among caregivers of terminally ill spouses	Cancer, AD, stroke, heart-related problems, "other" serious illness	n = 59 M = 66.2 (9.1)	HRSD; ITG-pre-loss	Depressive symptoms, Traumatic grief	Certain symptoms of grief (e.g., yearning, searching, preoccupation with thoughts of the deceased, avoidance of reminders of the deceased) that predict impaired global functioning, such as poor sleep, sad mood, and low self-esteem at 18 months post-loss
Waldrop (2007) <sup>78</sup>	Mixed	Palliative Medicine	Explore grief during a terminal illness and after the care recipient's death	Patients in hospice care	n = 30 M = 64.1, SD = not provided f: 77%; m: 23%	TRIG; BSI	Grief	The multifaceted response to death and losses of all kinds, including emotional (i.e., affective), psychological (i.e.,

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Walker & Pomeroy <sup>151</sup>	Quant	Neurology	Measure levels of and distinguish AG and depression in caregivers of patients with dementia	Dementia	n = 100 M = 56.6, SD = not provided f: 83; m: 17	GEI-Loss Despair Scale	AG	cognitive and behavioral), social, and physical reactions  AG as the "funeral that never ends"; grieving for losses that have already occurred and are currently occurring (e.g., altered relationship or lifestyle; dreams for the future that will not be realized; loss of companionship, security, economic certainty)
Walker & Pomeroy(1996) <sup>152</sup>	Quant	Neurology	Examine AG and its impact on the current functioning of caregivers	AD and other dementias	n = 100 M = 56.6, SD = not provided f: 83%; m: 17%	Stage of Grief Inventory; Grief Experience Inventory	AG	AG for caregivers caring for persons with a chronic debilitating illness such as Alzheimer's disease and other dementias, grieve for losses that have already occurred and those that are occurring. Such losses may include a relationship and lifestyle that have been altered, dreams for the future that will never be realized, companionship, security, and economic certainty, in addition to the actual presence of the loved one.
Warchol-Biedermann et al. (2014) <sup>79</sup>	Mixed	Neurology	Evaluate the MM-CGI for Polish family caregivers and determinants of grief in carers of Alzheimer's disease patients	AD	n = 151 M = 58.9, SD = not provided f: 63%; m: 37%	MM-CGI	Grief	Psychological (emotional, cognitive, functional and behavioral responses) response to a loss such as a death
Welch (1982) <sup>155</sup>	Quant	Oncology	Investigate AG in family members of adult cancer patients	Cancer	n = 41 M = 44, SD = not provided f: 25; m: 16	12-item Faschingbauer's Texas Inventory of Grief.	AG, Unresolved grief	AG as cyclical periods of mental anguish and feelings of loss that begin at the time of initial diagnosis of a malignancy, in expectation of the deprivation of a significant relationship and social role through the expected death of a loved one.

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Wong & Chan (2007), <sup>154</sup>	Qual	Oncology	Understand the experiences of Chinese family members of terminally ill patients during the EOL	Cancer	nfcg = 19, nhealthcareprofessionals = 14 M = not provided, Age range = 18–60 f: 80%; m: 20%	Qual interview guide	Grief	Not defined
York (2017), <sup>58</sup>	Quant	Neurology	Assess AG and relationship status along with other outcomes	AD	n = 66 M = not provided	CSI; MMCGI; MSPSS	AG	A model that is comparable to grief, but it anticipates the forthcoming loss of a family member to previously experienced losses from an incurable disease
Zamanzadeh et al. (2013), <sup>53</sup>	Quant	Nursing; Palliative Medicine	Evaluate AG reactions among fathers with hospitalized premature infants	Unspecified	n = 120 M = 31.8, SD = not provided f: 0%; m: 100%	AGS-Farci	AG	A type of grief that happens before the actual loss
Zordan et al. (2019), <sup>155</sup>	Quant	Oncology	Prospectively evaluate the prevalence and long-term predictors of PGD in bereaved cancer caregivers	Cancer	nsample1 = 246, nsample2 = 55 Msample1 = 56.4 (13.93), Msample2 = 57.8 (12.40) fsample1: 175; msample1: 70; fsample2: 45; msample2: 10	PG-12	Preloss prolonged grief	Grief related to the illness rather than the death of the person being cared for (i.e., “avoiding reminders of the diagnosis/prognosis” rather than “avoiding reminders of the death”)

Note. Qual= Qualitative. Quant= Quantitative. AD=Alzheimer’s Disease. MM-CGI= Marwit-Meuser Caregiver Grief Inventory. AG=Anticipatory Grief. MM-CGI CC= Marwit-Meuser Caregiver Grief Inventory Childhood Cancer. AM=Anticipatory Mourning. MM-CGI-SF= Marwit-Meuser Caregiver Grief Inventory Short Version. ICU=Intensive Care Unit. M=Mean. SD=Standard Deviation. TRIG=The Texas Inventory of Grief. PDG=Pre-Death Grief. HGRG=Hogan Grief Scale. PG-12=Prolonged Grief. AGS=Anticipatory Grief Scale. PLG=Pre-loss grief. C-MMCGI-SF=Chinese Marwit-Meuser Caregiver Grief Inventory Short Version. PWD= psychological well-being. NDGEI=Non-death Version of the Grief Experience Inventory. CGQ=Caregiver Grief Questionnaire. EOL=End of Life. FC=Family caregivers. AGS=Anticipatory Grief Scale. BEQ=Bereavement Experience Questionnaire. MCI=Mild Cognitive Impairment. MFG=Many Faces of Grief Questionnaire. ICG=Inventory of Complicated Grief. ICG-PL=Pre-death Inventory of Complicated Grief. EMPOWER=Enhancing & Mobilizing the Potential for Wellness & Emotional Resilience. FOLLOS=Fears of Losing Loved Ones Scale. WOC=Ways of Coping Questionnaire. AGS-CIV=Anticipatory Grief Scale, Chronic Illness Version. TRIG-CIV1=Texas Revised Inventory of Grief Chronic Illness Version. RAGC=Rando Anticipatory Grief Checklist. BSI=Brief Symptom Inventory. CSI=Caregiver Strain Index. MSPSS=Multidimensional Scale of Perceived Social Support.