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Pre-loss grief experiences of adults when someone important to them is at end-of-life: A qualitative systematic review

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ABSTRACT

Pre-loss grief can be experienced by relatives before impending death; however, limited understanding exists about the impact of pre-loss grief on bereavement. This systematic review aimed to synthesize qualitative research evidence reporting adults' experiences of pre-loss grief within cancer care. Thirteen studies were selected, and three key themes identified. Findings indicate that relatives transitioned through lived experiences during end-stage cancer, and that meanings attached to these experiences influenced how they experienced pre-loss grief. Limited formal support was identified to navigate these experiences; however, context was seen as important, and skilled healthcare practitioners and physical environment were key to facilitating preparedness.



Introduction

Cancer is an ongoing public health issue that resulted in approximately ten million deaths worldwide during 2020 (World Health Organization, 2021). With early detection and treatment, many cancers are curable (WHO, 2021). Other cancers are often non-curative and end-of-life care may be offered. Advances in diagnostic and therapeutic capabilities mean that the period between poor prognosis and death can be long (Lage & Crombet, 2011).

Although the terms anticipatory, pre-loss, and pre-death grief have been used interchangeably to describe grief symptoms in relatives or caregivers during the end-of-life phase (Lindauer & Harvath, 2014), there is also debate about how these concepts may differ. Lindauer and Harvath (2014) suggested that anticipatory grief can occur between 6 and 18 months before death, whereas in pre-death/pre-loss grief the time span is more likely to be over the entire course of the terminal illness. By contrast, Nielsen et al. (2016) speculated that the term pre-loss grief simply indicates the presence of grief symptoms, whereas anticipatory grief might involve anticipation of bereavement outcomes. More recently, Nielsen et al. (2017) defined

pre-loss grief as “grief reaction due to multiple losses during end-of-life caregiving” (Nielsen et al., 2017, p. 2048). Such grief can be experienced by patients and others including family members, close friends or family carers, and has been associated with negative psychological outcomes, and complicated grief (Holm et al., 2019; Nielsen et al., 2017). Responses to impending loss can result in grief, depression, guilt, and functional impairment in daily life (Nielsen et al., 2017).

There is a requirement for healthcare practitioners to be attentive to pre-loss grief reactions in family carers (Moon, 2016), and for tailored interventions to support pre-loss grief (Nielsen et al., 2017). Yet most research exploring the concept of pre-loss grief has centered on its measurement (Holm et al., 2019), the identification of risk factors (Burke et al., 2015), or on specific diagnoses such as dementia (Cheung et al., 2018). Although vast differences have been identified in disease trajectories between non-curative illnesses including cancer and dementia (Krikorian et al., 2020), there is still limited research focusing on the experience of pre-loss grief for cancer patients (Hottensen, 2010) and their family carers (Coelho & Barbosa, 2017). Furthermore, a scarcity of quality

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Table 1. Eligibility criteria.

Inclusion	Exclusion
<i>Phenomena of Interest:</i> Adults' experiences of anticipatory or pre-loss grief, coping mechanisms and support needs, when an adult who is important to them is at end-of-life from advanced/terminal cancer.	Conditions other than cancer, such as dementia, HIV/AIDS.
<i>Types of participants:</i> Adults from any sociodemographic background and ethnicity, who are important to someone at end-of-life from cancer.	Individuals <18 years old.
<i>Type of setting:</i> Studies conducted in any country were eligible but need to be in English.	Studies not published in the English language.
<i>Timeframe:</i> Studies published between 1 January 2000 and 31 October 2020.	Studies published prior to 2000.
<i>Types of outcome measures:</i> The phenomena of interest are the experiences and perspectives of relatives.	Studies that adopted quantitative research designs.

research in this area has been highlighted (Patinadan et al., 2020). This is an important gap to address, given reports indicating that pre-loss grief among relatives of someone with a terminal illness have been identified as an area of concern (Åberg et al., 2004), and also that when pre-loss grief needs are met, individuals are less likely to experience negative bereavement outcomes (Vergo et al., 2017).

Given the suggestion that the experience of pre-loss grief is multi-dimensional (Nielsen et al., 2017), a systematic review of qualitative studies may provide insight into the reality and meanings attributed to pre-loss grief by those who are experiencing it. This is important to increase awareness amongst clinicians and to inform current and future support services within cancer care. Consequently, our review aims to identify, appraise, and synthesize available qualitative evidence on adults who are experiencing pre-loss grief when someone important to them has a non-curative cancer prognosis. The research question is: "What do we currently know about the pre-loss grief experiences, coping strategies, and holistic support needs of adults when someone important to them is at end of life?"

The focus of this review is on adults when someone important to them is at end of life. Throughout, the terms carer/caregiver or relative will be used interchangeably when referring to adults, as these terms are often used to describe close relatives or friends who provide practical or emotional support for someone who is unable to do this themselves due to illness, frailty, or disability (NHS England, 2018). The term patient is used to describe someone important to them.

Materials and methods

Design

A systematic review of qualitative evidence was undertaken in accordance with Joanna Briggs Institute (JBI)

methodology (Lockwood et al., 2015). Reporting of the review findings were guided by The Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) framework (Tong et al., 2012; see [Supplementary File 1](#)).

Search strategy

Electronic searches were undertaken in Ovid MEDLINE, PsycINFO, CINAHL and EMBASE, on 17 October 2020. The search was limited to English language, and a timeframe of the year 2000–2020 was applied. MeSH terms and key words were used with Boolean logic and operators. [Supplementary File 2](#) provides the complete search strategy for one database. Google Scholar and reference lists of relevant studies were searched to identify research not indexed in the electronic databases. Screening was undertaken by two reviewers (AF, FH) and moderated by a third reviewer (JRH).

Inclusion and exclusion criteria

Studies were eligible for inclusion if they met eligibility criteria ([Table 1](#)). Studies using a mixed-methods design that collected, analyzed, and reported qualitative data were also included. Unpublished studies and other texts such as reports, expert opinion papers, and clinical guidelines were excluded from the review.

Data extraction and quality assessment

Data on the characteristics of included studies were extracted using a form developed in line with review aims (Lockwood et al., 2015). This included the name of the first author, year of publication, geographical location, study population, sample size, study design, and the findings of interest relevant to the review questions ([Table 2](#)). Data extraction was undertaken

Table 2. Characteristics of included studies.

Author/publication year/location	Study aim	Study design/method	Study population/ sample size	Quality appraisal score	Findings relevant to the research question
Anngele-Cole and Busch (2011) USA	Investigation into stress, anticipatory mourning, and cultural practices among family carers from independent and inter-dependent cultural groups.	Qualitative, phenomenological approach focus group interviews ($N = 8$). Thematic analysis was adopted.	Convenience sample of family carers from peer-led carer support groups ($N = 56$). Female ($n = 51$), male ($n = 5$). Mean age 57.9	6/10	Experience: Culturally based differences existed in how carers experienced and coped with anticipatory mourning. Coping: All experienced similar stressors, yet variations existed in how they perceived stress, and how they coped with anticipatory mourning. Support needs: Carers from all ethnic groups had strong feelings about their experiences of caregiving and anticipatory grief, yet the perceptions and attributions of their feelings varied. The provision of culturally sensitive support was suggested as beneficial. Experience: Family members experienced a complex process of <i>holding on and letting go</i> which was central to the anticipatory grief experience. Coping: Carer preparedness involved cognitive, emotional, and social processes. Experience: Themes: "Here and Now," and "Negotiating the Here/After." The unpredictable trajectory of the illness and feeling consumed by the care complicated preparations for the death. Coping: Carers were cognitively prepared, some were behaviorally prepared, but emotional preparedness was challenging. Support: Services should not assume that all family carers are well-prepared for the death. Carers would likely benefit from the assessment and promotion of their death preparedness. Support: Sources of support for pre-death preparedness were identified as: (a) informational (communication, information, and education); (b) hospice staff and volunteers; (c) family, friends, and
Bouchal et al. (2015) Canada	To explore the retrospective experiences of anticipatory grief of families who have lost a loved one from cancer.	Qualitative, hermeneutic phenomenological approach, in-depth interviews with individuals representing the family.	Purposeful sample. Families who lost a loved one to cancer. Spouses ($N = 8$). Female ($n = 2$); male ($n = 6$). Age range 55–81	9/10	Experience: Family members experienced a complex process of <i>holding on and letting go</i> which was central to the anticipatory grief experience. Coping: Carer preparedness involved cognitive, emotional, and social processes. Experience: Themes: "Here and Now," and "Negotiating the Here/After." The unpredictable trajectory of the illness and feeling consumed by the care complicated preparations for the death. Coping: Carers were cognitively prepared, some were behaviorally prepared, but emotional preparedness was challenging. Support: Services should not assume that all family carers are well-prepared for the death. Carers would likely benefit from the assessment and promotion of their death preparedness. Support: Sources of support for pre-death preparedness were identified as: (a) informational (communication, information, and education); (b) hospice staff and volunteers; (c) family, friends, and
Breen et al. (2018) Australia	To explore family carers' preparation for death	Semi-structured interviews using grounded theory analysis. Informed by social constructionism.	Purposeful sample. Family carers in receipt of palliative care ($N = 16$). Spouses ($n = 10$), adult child ($n = 5$), friend ($n = 1$). Female ($n = 12$), male ($n = 4$) Age range: 45–77 (mean age 64.4)	9/10	Experience: Family members experienced a complex process of <i>holding on and letting go</i> which was central to the anticipatory grief experience. Coping: Carer preparedness involved cognitive, emotional, and social processes. Experience: Themes: "Here and Now," and "Negotiating the Here/After." The unpredictable trajectory of the illness and feeling consumed by the care complicated preparations for the death. Coping: Carers were cognitively prepared, some were behaviorally prepared, but emotional preparedness was challenging. Support: Services should not assume that all family carers are well-prepared for the death. Carers would likely benefit from the assessment and promotion of their death preparedness. Support: Sources of support for pre-death preparedness were identified as: (a) informational (communication, information, and education); (b) hospice staff and volunteers; (c) family, friends, and
Cagle and Kovacs (2011) USA	To examine perceptions of preparedness and support of informal carers of hospice oncology patients.	Narrative response to pre-death and post-death questionnaires. Thematic content analysis using the constant-comparison method.	Purposeful sample. Informal carers of hospice oncology patients ($n = 69$). Spouse ($n = 22$); parent ($n = 22$), sibling ($n = 10$), other ($n = 14$), missing ($n = 1$)	4/10	Experience: Family members experienced a complex process of <i>holding on and letting go</i> which was central to the anticipatory grief experience. Coping: Carer preparedness involved cognitive, emotional, and social processes. Experience: Themes: "Here and Now," and "Negotiating the Here/After." The unpredictable trajectory of the illness and feeling consumed by the care complicated preparations for the death. Coping: Carers were cognitively prepared, some were behaviorally prepared, but emotional preparedness was challenging. Support: Services should not assume that all family carers are well-prepared for the death. Carers would likely benefit from the assessment and promotion of their death preparedness. Support: Sources of support for pre-death preparedness were identified as: (a) informational (communication, information, and education); (b) hospice staff and volunteers; (c) family, friends, and

(Continued)

Table 2. Continued.

Author/publication year/location	Study aim	Study design/method	Study population/ sample size	Quality appraisal score	Findings relevant to the research question
Clukey, (2007) USA	To explore the anticipatory grief experience.	Phenomenological approach using semi-structured interviews.	Female ($n = 50$), male ($n = 18$), missing ($n = 1$). Purposeful sample. Recently bereaved who had received the services of a home care hospice ($N = 22$). Spouses ($n = 9$), uncle ($n = 1$), parents ($n = 11$), grandparent ($n = 1$). Female ($n = 18$), male ($n = 4$). Age range: 22-79 (mean age 53).	6/10	neighbors; (d) resources-specific services and equipment; and (e) faith and spirituality. Experience: Being in a state of anticipatory grief was defined as: a 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. Coping: Components of coping included: finalizing of the connection with the loved one through touch, saying goodbye, resolving issues, or sharing experiences. Other elements were preparing (for example funeral arrangements) and maintaining hope. Support: Hospice services were essential. Delivery of medical equipment and medications eased the burden of the carers, or financial relief provided by hospice supplying medications was appreciated. Other ways of being supportive included being available 24 h a day by phone. Experience: Themes: (1) Traumatic distress; uncertainty of illness; image of degradation; carer impotence; life disruption. (2) Separation distress: anticipation of death; relational losses; separation anxiety; sense of protection; and affective deprivation. Coping: Emotional regulation and dysregulation (self-regulation efforts; symptoms of disorganization). Experience: Six principal dimensions were reported: a. Characteristics of the family carer b. Patient characteristics c. Symptoms of the illness d. The relational context e. Social and professional support
Coelho et al. (2020) Portugal	To explore the experience of family carers of patients with terminal cancer to identify the core characteristics and the specific adaptive challenges related to AG in the context of end-of-life caregiving.	Qualitative design utilizing in-semi-structured interviews. Analyzed using thematic analysis.	Purposeful sample. Family carers of adult cancer patients ($N = 26$). Adult children ($n = 14$), spouses ($n = 10$), parent ($n = 1$), aunt ($n = 1$). Female ($n = 23$), male ($n = 3$). Age range: 27-78 (mean age 55.5).	7/10	
Dumont et al. (2008) Canada	To identify the main elements constitutive of the experience of providing care and assistance to a patient with terminal cancer that influence the grieving process.	Semi-structured interviews. Qualitative design guided by a three conceptual frameworks.	Purposeful sample. Family carers of adults with cancer ($N = 18$). Spouses ($n = 12$), parent or friend ($n = 6$). Age range: 33-75.	7/10	

<p>Hebert et al. (2009) USA</p>	<p>To determine the factors that family carers believe are important to preparing for death and bereavement, determine the relationship between them, and develop a conceptual model of preparedness that can help guide clinical practice and future research.</p>	<p>Qualitative design employing focus groups ($n = 2$), and ethnographic interviews ($N = 33$).</p>	<p>Purposeful sample. Family carers of adults ($N = 33$). Active carers ($n = 27$), bereaved carers ($n = 6$). Spouse ($n = 7$), child ($n = 12$) and other ($n = 14$). Female ($n = 27$), male ($n = 6$). Age range 50–59.</p>	<p>7/10</p>	<p>f. Circumstances surrounding the death, this relates to the moment of death and the level of preparedness for death. Experience: (1) Life experiences: The duration of the caregiving experience influenced the level of preparedness of the participants and opportunity to talk about advanced care plans. (2) Uncertainty—concurrent theme in relation to: (a) medical—reflected in the need for information from healthcare practitioners relating to diagnosis, prognosis, and clinical course. (b) practical uncertainty—related to a range of tasks such as completing will, managing patient finances and estate planning. (c) psychosocial—reflected concerns about altered family dynamics and relationships as a consequence of the illness and death. (d) religious/ spiritual referred to existential concerns and issues of meaning.</p>
<p>Pusa et al. (2012) Sweden</p>	<p>To illuminate the meanings of significant other's lived experiences of their situation from diagnosis through and after the death of a family member as a consequence of inoperable lung cancer.</p>	<p>Qualitative design using an interpreted phenomenological hermeneutic approach using interviews.</p>	<p>Significant others ($N = 11$) Partner ($n = 7$); child ($n = 3$); other ($n = 1$). Female ($n = 9$), male ($n = 2$). Age range 35–79 (mean age 57.9).</p>	<p>8/10</p>	<p>Support: Communication: A key to prepare carers was the need for clear, consistent, and reliable information between all parties (healthcare practitioner, patient, and carer). Preparedness: The degree to which a carer is ready for death, has cognitive, affective, and behavioral dimensions. Experience: Themes: (1) Being unbalanced—this is further divided into feeling distressed and experiencing ambivalence. (2) Being transitional—this is further divided into being responsible, feeling secluded and struggling for good care. (3) Being cared for—this is further divided into feeling safe and being pleased with patient care, related to feelings of satisfaction concerning healthcare and medical service. (4) Moving forward—this is further divided into adjusting in everyday</p>

(Continued)

Table 2. Continued.

Author/publication year/location	Study aim	Study design/method	Study population/ sample size	Quality appraisal score	Findings relevant to the research question
Sand and Strang (2006) Sweden	To explore the experience of existential isolation experienced in association with an incurable disease, the origins of these feelings and their interaction.	Qualitative design using semi-structured interviews with open ended questions.	Purposeful sample. Next-of-kin ($N = 20$). Spouses ($n = 12$), children/parents/siblings ($n = 8$) Female ($n = 12$), male ($n = 8$) Age range: 21–92 (mean age 63).	9/10	life, gaining strength, and changing perspective. Experience: Themes: (1) Changes: reduced protection; changed life conditions; altered everyday circumstances; emotional changes and pathological changes of the patient's body. (2) Circumstances—not enough time; ignored; inability to communicate; without information; suffering; separate ways; and the next of kin's experiences of responsibility. (3) Separate ways—as the disease progressed and hope for long survival lessened there was a realization that the patient and the carer went their separate ways. Experience: Themes: (1) Talking about their expected role in the family. An expectation for the daughter (as a nurse) to adopt the carer role. (2) Responding to expectations within the family in a way that does not fit with the present self. The daughter was conflicted about providing care and also encouraged her father's anticipatory grief. The patient's wife recognized that she had to force herself to fulfill the carer's role and recognized problems acting as her husband's substitute. This led her to feel she was not sufficiently fulfilling either role. (3) Facing the patient departing for death as a family member. Both recognized that the roles expected of them were not their true roles and began to prepare for the coming less and end-of-life care while feeling conflicted over this realization. (4) Grieving in anticipation of less from the viewpoint of a family member. Over time they did not
Toyama and Honda (2016) Japan	To explore and clarify how talking to family carers of patients with end-of-life illness using the narrative approach influences the process of anticipatory grief.	Qualitative design using an intervention study targeting family carers.	Two family carers, Case A: the patient's daughter, aged in her 20's who was a nurse. Case B: the carer was the patient's wife, in her 50's and a cancer survivor.	8/10	

Waldrop (2007) USA	The study aim was to answer two questions: (1) What is the nature of caregiver grief in terminal illness. (2) How do the features of caregiver grief change after death?	Exploratory descriptive phenomenological study. Qualitative (interviews) and quantitative methods used.	Purposeful sample. Family carers ($n = 30$) who were caring for a relative or friend with terminal illness. Females (daughters, daughters-in-law, wives, grand-daughter, and a friend; $n = 23$); males (husbands and sons; $n = 7$).	8/10	feel trapped but anticipated and grieved for the loss. Experience: (1) Physical symptoms of grief involved sleep disruption, exacerbation of chronic problems such as blood pressure or back pain; physically burdensome tasks such as housework. (2) Psychological and emotional well-being including sadness and tears; anger (at providers and family) and attempts to gain control over grief. (3) Social functioning: increased or decreased family cohesion; increased or decreased social support.
Werner-Lin et al. (2020) USA	To evaluate the psychological, social, and behavioral impact of Li-Fraumeni Syndrome (LFS), and to refine evidence-based counseling strategies.	Semi-structured interviews ($n = 66$), using modified grounded theory and interpretive description.	Purposeful sample. Families ($n = 45$) completed 66 interviews. Family members ($n = 117$) were aged 13-81 years. Parent-child groups ($n = 19$), partner dyads ($n = 26$), sibling groups ($n = 11$), mixed groups ($n = 10$).	8/10	Experience: Families reported high burden on roles and resources and limited guidance to prepare for or achieve resolution with grief. Anticipatory loss, the experience of bereavement prior to an expected change, distinguishes hereditary cancer risk from a sporadic diagnosis. Such grief is often incomplete in impact or meaning, subjected to rapid or profound change as conditions worsen, and poorly understood. In this study losses were compounded by profound uncertainty, a chronic feature of Li-Fraumeni Syndrome which compromised mourning.

independently by two authors (AF, FH). Any disagreement was resolved by discussion and referral to a third reviewer (JRH).

Studies were appraised for quality by two reviewers (AF, FH) and guided by the JBI-QARI framework (Lockwood et al., 2015). A review level narrative summary and table matrix displaying the risk of bias based on an aggregate score for each study was developed. Studies received a quality banding as either high, medium, or low; however, no studies were excluded based solely on quality assessment. Quality appraisal scores are shown in Table 2.

Data synthesis

A thematic synthesis was adopted (Thomas & Harden, 2008) as a suitable approach for synthesizing the findings of multiple qualitative studies (Evans et al., 2019). For data extraction, findings related to the experience, coping and support were extracted from selected articles. Only data and quotes from primary studies were extracted and used to inform the analysis.

Thematic synthesis involved the coding of text, the development of descriptive themes, and the generation of analytical themes. Following line by line coding, authors (AF, FH) inductively coded data by identifying categories and concepts based on the research question, which resulted in descriptive themes. Next, these themes were further defined and refined, and clustered to generate analytical themes and sub themes. Descriptive, analytical, and sub-themes were discussed and checked for reliability through continuous peer review within the research team [AF, JRH, FH]. NVivo v.12 (NVivo, 2013) was used to manage data.

Results

A total of 914 articles were identified from the searches and exported to RefWorks Reference Management system, of which 299 were removed due to duplication. The remaining 615 papers were screened by title and abstract and 567 were excluded as they did not meet the inclusion criteria (Figure 1).

Characteristics of the included studies

Six studies originated from the United States (Anngela-Cole & Busch, 2011; Cagle & Kovacs, 2011; Clukey, 2007; Hebert et al., 2009; Waldrop, 2007; Werner-Lin et al., 2020), two from Canada (Bouchal

et al., 2015; Dumont et al., 2008), and two from Sweden (Pusa et al., 2012; Sand & Strang, 2006). There was one study each from Portugal (Coelho et al., 2020), Australia (Breen et al., 2018) and Japan (Toyama & Honda, 2016). Study foci were spouses ($n=167$), adult children ($n=21$), siblings ($n=22$), parents ($n=52$), other/unspecified relationships ($n=55$). Of the 12 studies that reported gender, the majority of the sample were female (Anngela-Cole & Busch, 2011; Bouchal et al., 2015; Breen et al., 2018; Cagle & Kovacs, 2011; Clukey, 2007; Coelho et al., 2020; Dumont et al., 2008; Hebert et al., 2009; Pusa et al., 2012; Sand & Strang, 2006; Toyama & Honda, 2016; Waldrop, 2007). Research approaches used were phenomenology (Anngela-Cole & Busch, 2011; Bouchal et al., 2015; Clukey, 2007; Pusa et al., 2012; Sand & Strang, 2006; Waldrop, 2007), grounded theory (Breen et al., 2018; Werner-Lin et al., 2020), narrative (Cagle & Kovacs, 2011; Toyama & Honda, 2016), ethnography (Hebert et al., 2009), thematic analysis (Coelho et al., 2020), and content analysis (Dumont et al., 2008).

Synthesis

Thematic analysis of reported data resulted in 14 descriptive themes reflecting groupings of similarities and differences in initial codes (Thomas & Harden, 2008), and aligned with the main tenants of the research question. On further analysis, the descriptive themes were collapsed into three overarching themes—making sense of pre-loss grief, pre-loss grief processes, and the impact of context on meaning and process of pre-loss grief (Table 3).

Making sense of pre-loss grief

Making sense of pre-loss grief comprised four descriptive themes: recognition of transition, planning for the future, living in uncertainty, and multiple losses. The theme describes how participants in the primary studies attempted to make sense of this complex and uncertain period in their lives through recognizing loss and transitions and making plans for their future.

Pusa et al. (2012) described the nature of lived experiences of relatives of end-stage lung cancer patients. Participants in this study described changes that occurred in their lives in line with the illness trajectory and often as a result of the patient's increased need for help. One such change was their transition into the role of carer. Although this was viewed by some as limiting their life, it was also important for relatives to feel that they had done their very best for

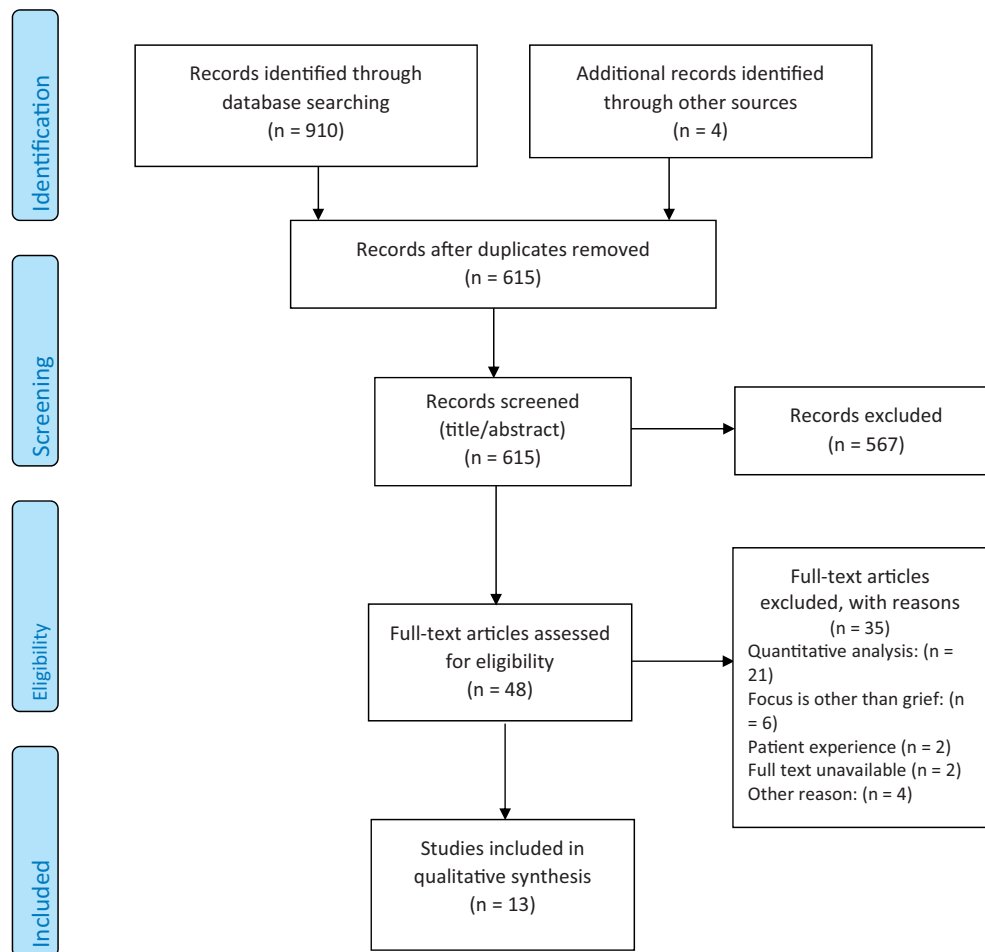


Figure 1. PRISMA 2009 flow diagram.

their loved one: “It has been so important to me that... that I’ve done everything I could. I am not ashamed, because I did what I could. And it has been really important not having to proceed with a bad conscience” (Pusa et al., 2012, p. 37).

Similarly, other studies reported that relatives attempted to make sense of their experiences whilst in the pre-loss phase (Bouchal et al., 2015; Clukey, 2007; Toyama & Honda, 2016). A common perception from relatives was that the period between receiving the poor prognosis and the active dying phase offered a time for planning for the future, such as managing the patient’s financial matters, and a chance for them (patients and relatives) to make the most of their remaining time together (Bouchal et al., 2015; Clukey, 2007; Hebert et al., 2009; Toyama & Honda, 2016). During the pre-loss phase relatives perceived the patient as not the same person as before (Pusa et al., 2012), and the patient’s loss of independence often resulted in distress for relatives. For these relatives, overwhelming feelings of loss of the patient as they knew them, consumed their lives, and often defined their pre-loss grief experience (Clukey, 2007; Pusa

et al., 2012; Werner-Lin et al., 2020). Such loss was reported to be compounded by uncertainty (Werner-Lin et al., 2020). However, other authors associated uncertainty with distress (Coelho et al., 2020), or altered family dynamics (Hebert et al., 2009). Participants in one study described how uncertainty allowed them to foster hope: “We do not know what will happen next. He has always recovered after coming to the hospital. I’m always holding on to this hope” (Coelho et al., 2020, p. 695).

Pre-loss grief processes

The theme of pre-loss grief processes comprised eight descriptive themes: a spectrum of intense emotions, physical and cognitive strategies to alleviate stress, faith-based strategies, managing unpredictability, holding on while letting go, dimensions of preparedness, avoidance strategies, and altered family dynamics. This theme encompasses psychological and physical processes described by relatives during the pre-loss phase and how they were experienced and managed. Studies reported that in the pre-loss phase, relatives experienced a range of emotions such as traumatic

Table 3. Overview of analytical and descriptive themes.

Analytical themes	Descriptive themes	Studies
Making sense of loss	Living in uncertainty	Hebert et al., 2009; Coelho et al., 2020; Werner-Lin et al., 2020; Pusa et al., 2012; Sand & Strang, 2006.
	Planning for the future	Breen et al., 2018; Pusa et al., 2012; Werner-Lin et al., 2020; Sand & Strang, 2006; Clukey, 2007; Bouchal et al., 2015; Hebert et al., 2009; Toyama & Honda, 2016
	Recognition of transitions	Breen et al., 2018; Clukey, 2007; Bouchal et al., 2015; Pusa et al., 2012; Toyama & Honda, 2016.
	Multiple losses	Clukey, 2007; Pusa et al., 2012; Werner-Lin et al., 2020; Coelho et al., 2020; Toyama & Honda, 2016; Sand & Strang, 2006; Hebert et al., 2009.
Pre-loss grief processes	Faith based strategies	Anngela-Cole & Busch, 2011; Breen et al., 2018; Cagle & Kovacs, 2011; Coelho et al., 2020; Dumont et al., 2008; Hebert et al., 2009.
	Altered family dynamics	Hebert et al., 2009; Toyama & Honda, 2016; Sand & Strang, 2006; Waldrop, 2007.
	A spectrum of intense emotions	Breen et al., 2018; Coelho et al., 2020; Pusa et al., 2012; Waldrop, 2007; Toyama & Honda, 2016; Werner-Lin et al., 2020; Anngela-Cole & Busch, 2011; Dumont et al., 2008.
	Managing unpredictability	Coelho et al., 2020; Breen et al., 2018; Clukey, 2007; Hebert et al., 2009; Sand & Strang, 2006; Werner-Lin et al., 2020.
	Dimensions of preparedness	Bouchal et al., 2015; Breen et al., 2018; Dumont et al., 2008; Hebert et al., 2009; Toyama & Honda, 2016; Sand & Strang, 2006; Cagle & Kovacs, 2011.
	Holding on while letting go	Bouchal et al., 2015; Breen et al., 2018; Clukey, 2007; Hebert et al., 2009
	Avoidance strategies	Coelho et al., 2020; Pusa et al., 2012; Waldrop, 2007; Anngela-Cole & Busch, 2011
Impact of context on meaning and process of pre-loss grief	Physical and cognitive strategies to alleviate stress	Pusa et al., 2012; Bouchal et al., 2015; Clukey, 2007; Waldrop, 2007; Anngela-Cole & Busch, 2011.
	Emotional support as essential for carer well-being	Breen et al., 2018; Cagle & Kovacs, 2011; Pusa et al., 2012; Waldrop, 2007; Anngela-Cole & Busch, 2011; Dumont et al., 2008
	Influence of healthcare practitioners on the experience of pre-loss grief	Clukey, 2007; Pusa et al., 2012; Toyama & Honda, 2016; Waldrop, 2007; Cagle & Kovacs, 2011; Hebert et al., 2009; Sand & Strang, 2006; Werner-Lin et al., 2020; Dumont et al., 2008
	Effective communication	Breen et al., 2018; Cagle & Kovacs, 2011; Hebert et al., 2009; Pusa et al., 2012; Sand & Strang, 2006; Dumont et al., 2008
	Contextual factors	Cagle & Kovacs, 2011; Pusa et al., 2012; Dumont et al., 2008; Bouchal et al., 2015; Clukey, 2007

distress (Coelho et al., 2020); stressful emotions (Pusa et al., 2012), intense psychological and emotional responses (Waldrop, 2007), mood instability, impatience, and acute stress (Coelho et al., 2020). Often such intense experiences impacted on family dynamics or social functioning (Hebert et al., 2009; Sand & Strang, 2006; Toyama & Honda, 2016; Waldrop, 2007). To manage emotional strain some study participants adopted strategies such as avoiding conversations about the impending death as this was perceived as too emotionally demanding (Coelho et al., 2020; Pusa et al., 2012; Waldrop, 2007). Physical strategies that were perceived to be important for relatives during the end-of-life period included relaxation or exercise such as getting out for a walk (Pusa et al., 2012) and cognitive strategies included engagement in activities such as reading and journaling (Bouchal et al., 2015). Six studies reported dependance on preexisting religious and spiritual beliefs (Anngela-Cole & Busch, 2011; Breen et al., 2018; Cagle & Kovacs, 2011; Coelho et al., 2020; Dumont et al., 2008; Hebert et al.,

2009). One study found that, although relatives experienced traumatic distress and life disruption, they oscillated between these feelings and a process of emotional regulation whereby they inhibited intense feelings to minimize emotional distress (Coelho et al., 2020).

It was suggested that a sense of “holding on whilst letting go” was central to the pre-loss grief experience as it signified relatives’ desire to hold on to the patient whilst acknowledging that death was unavoidable. This sense was heightened for relatives during times of physical transition, such as leaving home for hospice (Bouchal et al., 2015).

Seven studies referred to the concept of preparedness for the impending death (Bouchal et al., 2015; Breen et al., 2018; Cagle & Kovacs, 2011; Hebert et al., 2009; Pusa et al., 2012; Sand & Strang, 2006; Toyama & Honda, 2016). Preparedness was defined by one author as “the degree to which a caregiver is ready for the death” (Hebert et al., 2009, p. 8). Components of preparedness before the death

comprised informational (having clear information surrounding the patient's poor prognosis and declining health); cognitive (an awareness that death was the inevitable outcome); behavioral (understanding their loved one's funeral wishes or having their personal matters organized such as having a will); and affective (spending quality time with their loved one before the death; Hebert et al., 2009). It was suggested that these four dimensions may have different relative weights; that is, for some carers, information was primarily needed; whereas for others, being comforted in the immediate pre-loss period was key. Breen et al. (2018) concurred with these assertions and added that the "multidimensional nature of preparedness is overlooked" (Breen et al., 2018, p. 1478) and further suggested that some relatives were cognitively and behaviorally prepared, emotional preparedness was challenging, as described by one participant: "You know it's happening but you can't prepare for it; you don't want it to happen. I'm not prepared for her not to be here, to never see her again. I'm not prepared for that" (ID14; Breen et al., 2018, p. 1476).

Impact of context on meaning and process of pre-loss grief

The third theme impact of context on meaning and process of pre-loss grief comprised four descriptive themes: specific contextual factors, influence of healthcare practitioners, effective communication, and emotional support as essential for carer well-being. This theme reflected how the experience of pre-loss grief may have been impacted by contextual factors. Findings from a Canadian study revealed that for some relatives, during the pre-death phase their experience was one of "personal growth and valorization" (Dumont et al., 2008, p. 1051), while for others it was "experienced as disruptive and as having exerted a rather negative influence on the grieving process" (Dumont et al., 2008, p. 1056). Whether relatives in this study experienced the former or latter was potentially influenced by contextual factors such as characteristics of both the patient and their relative, illness symptoms, relationship between the relative and patient or other family members, and support and circumstances surrounding death. Authors concluded that ultimately these contextual factors could not only influence the pre-death experience but also bereavement outcomes (Dumont et al., 2008).

Nine studies showed that the input from healthcare practitioners could potentially influence the pre-loss grief processes. For example, some relatives found it helpful when healthcare practitioners provided clear

information on the reality of the poor prognosis, guidance surrounding how the illness would unfold at the end, or someone to talk to (Cagle & Kovacs, 2011; Clukey, 2007; Hebert et al., 2009; Pusa et al., 2012; Toyama & Honda, 2016; Waldrop, 2007). One study emphasized that regular supportive and therapeutic contact between healthcare practitioners and relatives during end-stage cancer care could assist in normalizing pre- and post-loss grief (Waldrop, 2007). Similarly, findings from another study showed that emotional preparedness would be better facilitated if healthcare practitioners provided prognostic information in a way that was sensitive to relatives' emotional needs (Hebert et al., 2009). Others, however, reported a lack of supportive care from healthcare practitioners, and it was suggested by relatives that healthcare practitioners' focus was on the patient's needs and not the carer's needs (Clukey, 2007; Pusa et al., 2012; Toyama & Honda, 2016; Waldrop, 2007). Pusa et al. (2012) described how insufficient understanding from healthcare practitioners resulted in feelings of being overloaded, uninformed, invisible and isolated. A lack of clear communication from healthcare practitioners surrounding the patient's poor prognosis and declining health was perceived to contribute to relatives' feelings of uncertainty and reported by relatives as "one of the most neglected aspects of end-of-life care" (Hebert et al., 2009, p. 9).

The physical environment in which palliative care was provided was also seen as impacting on pre-loss grief. For example, a participant described the hospice environment as:

An amazing place. The people, the people who worked there, the aides, I thought were amazing in the way they handled people physically and emotionally ... they could read where pain was in a person's face and that sort of thing ... (Bouchal et al., 2015, p. 55)

Similarly, delivery of medical equipment and medications was found to ease relatives' burden, or the financial relief provided by hospice supplying medications was appreciated. Other ways of being supportive included being available 24 h a day by telephone (Clukey, 2007).

Discussion

This qualitative systematic review and thematic synthesis has provided insight into the pre-loss experiences among relatives of palliative cancer patients. Findings described how relatives transitioned through lived experiences during end-stage cancer, and that

the meanings they attached to these experiences influenced how they experienced pre-loss grief.

Assessment of methodological quality of the studies showed that ten of the selected studies scored in the high range (above a score of 7), and the remaining studies scored in the medium ($n=2$) or low ($n=1$) range. Whilst this outcome signifies a robust scientific approach in the majority of selected studies, flaws and methodological weaknesses were noted across all selected studies reflecting a need for greater rigor (especially in the three studies that had moderate or low scores).

Although several studies in the current review viewed the concept of preparedness as central to the pre-loss grieving process (Bouchal et al., 2015; Breen et al., 2018; Hebert et al., 2009), others reported it to be only one element of pre-loss experience (Coelho et al., 2020; Dumont et al., 2008; Pusa et al., 2012). A systematic review of caregiver studies during end-of-life caregiving, found that low preparedness for death was associated with post-loss complicated grief, depression and anxiety, irrespective of the patients illness (Nielsen et al., 2016). A more recent American qualitative study about preparedness of cancer and dementia caregivers ($N=40$), highlighted that preparedness was an important aspect of pre-loss grief due to its association with Prolonged Grief Disorder (Singer & Papa, 2021). Findings indicated that preparedness for loss could be enhanced by reducing uncertainty before the loss (present uncertainty) and after the loss (future uncertainty). According to study authors, some of these findings provided new insights into preparedness such as the identification of relationship quality between the patient and the relative as being an important factor.

Uncertainty leading to low preparedness for relatives during the pre-loss phase could have been addressed to some degree by specific supportive interventions such as effective communication from healthcare practitioners, as indicated by some studies in the current review (Breen et al., 2018; Cagle & Kovacs, 2011; Hebert et al., 2009; Pusa et al., 2012). However, findings of this review also suggest that these interventions were few (Clukey, 2007; Coelho et al., 2020; Pusa et al., 2012; Waldrop, 2007; Werner-Lin et al., 2020). This is consistent with a Canadian qualitative study which explored family support needs within the context of end-of-life cancer care (Nissim et al., 2017). Even though Nissim et al. (2017) found that carers needed support around decision-making, information about death and dying, and emotional distress, this support was limited, and carers

experienced fear and distress in the pre-loss phase. Similarly, Nielsen et al. (2017) hypothesized that severe pre-loss grief in carers was partially a result of an information mismatch between carers' perceptions of prognostic information, and the healthcare practitioners' lack of adaptation of prognostic information to an already stressful situation. On this basis, it was suggested that pre-loss information was individualized to a family's information preferences and coping style (Tarberg et al., 2019). Explanations surrounding a lack of support from healthcare practitioners directly targeting pre-loss grief are unclear. It may be suggested that healthcare practitioners find this an emotionally challenging aspect of their role and feel ill-equipped to deliver this care in practice (Tarberg et al., 2019), or that nursing staff can experience difficult emotions when providing end-stage cancer care (Dobrina et al., 2020). For example, an Italian qualitative study of nursing staff caring for end-stage cancer patients in a hospice setting, found that nurses often felt emotional burden when they were nursing patients with whom they felt close, or frustration if they couldn't relieve patient suffering which triggered the perception of being limited in their skills (Dobrina et al., 2020). Findings emphasized the importance of communication between healthcare practitioners, and structured psychological support for palliative care providers, in order to alleviate emotional burden and ease ethical dilemmas (Connolly et al., 2015).

Consistent with recent findings (Vasileiou et al., 2020), evidence from the current review suggests that other contextual factors including physical environment may have a key role to play in facilitating emotional preparedness. Hospices in the United Kingdom and Canada are usually independent facilities providing in-patient and community-based palliative care (Bainbridge et al., 2018). Authors in some included studies in the current review highlighted the essential role played by hospices in providing practical support (such as financial support and medication) and psychological support (Cagle & Kovacs, 2011; Clukey, 2007). One study in the current review found that hospice staff being present was akin to a skill involving active listening, concern, and empathy (Clukey, 2007); whilst another reported that hospice team members played a vital role in supporting patients during end-stage cancer care (Cagle & Kovacs, 2011). Other literature has shown that hospices address aspects of palliative care that families value (Bainbridge et al., 2018), whereas acute settings are inadequate for end-of-life care due to factors including lack of privacy. It has been reported that such

settings are not conducive to end-of-life conversations (Brereton et al., 2012).

Irrespective of the context and setting in which palliative care is provided, pre-loss and carer support both form part of the ethos for palliative care and their efforts are often indispensable to the healthcare system (Grande et al., 2009), therefore the need for tailored interventions to provide this support are important. Such interventions could facilitate end-of-life preparedness and transition, and may reduce the risk of post-loss complications within palliative cancer care (Patinadan et al., 2020).

It has been previously asserted that the impact of pre-loss grief on relatives may vary, depending on the type of illness and end-of-life trajectory (Singer et al., 2021). In their comparison of pre-loss grief between relatives of cancer and relatives of dementia patients, Singer et al. (2021) found that more relatives of advanced dementia patients reported clinically relevant symptoms of pre-loss grief than relatives of cancer patients. By contrast, others have identified similarities of pre-loss grief between caregivers of cancer and dementia patients (Johansson & Grimby, 2012), thus findings of the current review could potentially be relevant for other disease trajectories. However, given the dearth of literature in this area (Tremblay et al., 2021), further research is warranted.

Findings of the current review suggest that relatives need information about death and dying, and support for emotional distress. Healthcare practitioners who have appropriate skills and training, along with a conducive physical environment, such as a hospice setting, can contribute to relatives' preparedness when a loved one/family member is at end-of-life, through the provision of practical or psychological support (Cagle & Kovacs, 2011; Clukey, 2007). This is important given that formalized support is currently available in specialist palliative care settings and services (such as hospice); however, it is much less likely to be available in acute care and nursing home settings, where most patients and relatives will access care and support. Thus, future research about pre-loss grief within cancer care should focus on acute and nursing home settings.

Strengths of the review include the application of a validated assessment tool (JBI-QARI framework) to ensure methodological quality of the included studies, and the use of a recognized reporting framework (ENTREQ) which added transparency in reporting findings. However, some studies may have been missed as this review only included studies in the English language. The review was limited by an

overwhelmingly female sample; however, this may be because women are more likely to be family carers than men. Finally, low rates of minority participants is also a limitation of the review.

Our review contributes to current research about pre-loss grief, specifically around the concept of preparedness of relatives, and factors that can facilitate preparedness to support pre-loss grief. Findings indicate that relatives transitioned through lived experiences during end-stage cancer, and that meanings attached to these experiences influenced how they experienced pre-loss grief. Preparedness was found to be important in reducing uncertainty and stress, however preparedness could be influenced by context, such as the physical environment in which end-of-life care was provided. Participants in selected studies described a need for information about death and dying, and support for emotional distress, yet such support from healthcare practitioners was often limited. This suggests a need to raise awareness about preparedness and pre-loss grief among palliative care providers; and to increase recognition of the impact of end-of-life care among healthcare practitioners. This may enable healthcare practitioners to adequately assess carer/relative's support needs during the end-stage phase and allow for more targeted support within cancer care.

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