



*ANTICIPATORY GRIEF EXPERIENCES OF ADULTS  
WHEN SOMEONE IMPORTANT TO THEM HAS A  
NON-CURATIVE CANCER PROGNOSIS: QUALITA-  
TIVE SYSTEMATIC REVIEW*

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Ulster University  
Institute of Nursing and Health Sciences Research  
Jordanstown Campus  
Shore Road, Newtownabbey  
Co Antrim, BT37 0QB

**Research Team**

Dr. Anne Fee, Researcher (Email: [a.fee@ulster.ac.uk](mailto:a.fee@ulster.ac.uk))

Jeff Hanna, Researcher (Email: [hanna-j25@ulster.ac.uk](mailto:hanna-j25@ulster.ac.uk))

Dr. Felicity Hasson, Researcher (Email: [f.hasson@ulster.ac.uk](mailto:f.hasson@ulster.ac.uk))

## TABLE OF CONTENTS

ACKNOWLEDGEMENTS	4
EXECUTIVE SUMMARY	5
INTRODUCTION	8
The research context	11
METHODOLOGY	13
Information sources	13
Eligibility criteria	13
Study selection and data extraction	15
Quality assessment	16
Synthesis of results	16
FINDINGS	18
Description of studies	18
Study characteristics	20
Data extraction	21
Quality assessment	35
Results of thematic synthesis	38
Theme 1: The experience of anticipatory grief	38
Theme 2: Impact of anticipatory grief	41
Theme 3: Support needs for the difficult road towards end of life	43
CONCLUSIONS & RECOMMENDATIONS	48
Strengths and limitations	50
Recommendations	50
REFERENCES	53
Appendix 1: ENTREQ Checklist	62
Appendix 2: Sample database search	65

Appendix 3: Quality appraisal checklists	66
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## LIST OF TABLES AND FIGURES

### Tables

Table 1: Eligibility criteria	14
Table 2: Quality banding	16
Table 3: Study characteristics	22
Table 4: Outcome of quality assessment	37
Table 5: Themes and sub-themes	38

### Figures

Figure 1: PRISMA 2009 FLOW DIAGRAM	19
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## EXECUTIVE SUMMARY

*Background:* Anticipatory grief is the grief reaction encompassing past, present and future losses experienced before a death. It is a time-based unique phenomenon, experienced by the patient and relative. Whilst recognised as a valid phenomenon within end of life, it has been subject to much debate regarding its conceptualisation and impact. A dearth of research on this topic exists with those diagnosed with cancer or their caregivers, despite being identified as an area of concern. To address this gap, Cruse Bereavement Care NI and Macmillan Cancer Support are working in partnership to explore, develop and test pre-bereavement support for people living with cancer. This synthesis of the literature represents the initial step to enable a better understanding of the evidence reporting the experiences of relatives, from which to guide future practice.

*Aim:* To synthesise evidence relating to anticipatory grief experiences, coping strategies, and holistic support needs of adults when someone important to them has a non-curative cancer prognosis.

*Design & Methods:* A systematic search of academic databases (Ovid MEDLINE, PsycINFO, CINAHL and Embase) and grey literature sources from 2000-2020 was undertaken. From 914 publications identified, 14 were retained. All selected papers originated outside the United Kingdom, predominately reporting on a female perspective, with only six of these having been published in the last five years.

*Findings:* Three key themes were reported. **Theme 1: The experience of anticipatory grief.**

This was reported to be a unique experience centered on the recognition and reaction to countless losses and the unpredictability of the journey ahead. Witnessing the physical and psychosocial loss of the patient due to the advancement of the disease had implications on role, relationship and self-identify of the relative. This was compounded by limited social contact resulting in relatives feeling invisible in the journey with their needs often left unvoiced and unrecognised. Co-existing with loss was the experience of uncertainty. Ambiguity surrounding the disease trajectory, intensified by a lack of clear communication from some health and social care practitioners made it difficult for families to anticipate and plan for what may come next. **Theme 2: Impact of anticipatory grief:**

Anticipatory grief had a profound impact on relatives physically and psychologically. Physical reactions included appetite and digestive changes, and muscle tension; whilst psychologically an onslaught of emotions was reported. Such reactions often co-existed with relatives adopting the main caregiving role, which potentially led to burden and exhaustion.

**Theme 3: Support needs for the difficult road towards end of life:** No study reported on the existence of clinical psychological interventions to support anticipatory grief. Informally, relatives reported they adopted various emotional, psychological and/or social processes as a way of coping. All the studies included in this review recommended the need for caregivers to access emotional and practical support surrounding the experience of

anticipatory grief. Underpinning this was the need for clear and consistent communication and technical support provided by health and social care practitioners.

*Conclusion & Recommendations:* Key findings from this review suggest that anticipatory grief centers on recognising and adapting to multiple losses, throughout an experience of uncertainty that impacts on relatives physically, psychologically and emotionally. Whilst formalised and informalised support is currently available in specialist palliative care settings and services, it is much less likely to be available in other settings (such as acute care or nursing homes), where most patients and relatives will access care and support. Several recommendations stem from this review:

- Provision of holistic support for anticipatory grief for the relative at a cognitive, emotional, behavioural, financial and social level.
- Health and social care practitioner practice to recognise anticipatory grief as part of routine care.
- There is a necessity to better understand the current provision of pre-loss support models to inform how such support can be delivered to best facilitate those pre death across generic settings and services.
- There is a clear need for further research to aid our understanding surrounding the concept of anticipatory grief, and caregiver preparedness for death.

## INTRODUCTION

Cancer is a major public health issue resulting in over 18 million new cases and 10 million deaths annually (World Health Organisation (WHO, 2018). With early detection and treatment many cancers are often curable (WHO, 2020). Others 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). When there is a forewarning of loss, anticipatory grief may occur (Fulton et al., 1986).

Anticipatory grief is the reaction that occurs in anticipation and growing expectancy/realisation of the impending loss of a loved one (Casarett et al., 2001) and can be experienced by patients and loved ones such as a spouse or partner, relatives, parents, siblings, close friends or caregivers. Although anticipatory grief has been recognised as a valid phenomenon within end-of-life contexts (Patinadan et al., 2020), it has also been the subject of debate over the past decade with various definitions and conceptualisations (Coelho et al., 2020).

Lindeman (1944) was among the first to acknowledge the existence of anticipatory grief, describing it as a situation when relatives experience *'all the phases of grief'* during the pre-bereavement period; theorising that anticipatory grief was a reaction to the threat of death rather, than death itself. In 1986, Rando, developed a multidimensional definition, encompassing loss related to the past, present and future. More recently anticipatory grief has been defined as *'pre-loss grief'*, suggesting that these concepts were defined as *'grief reaction due to multiple losses during end of life caregiving'* (Neilson et al., 2017, p. 2048).

Anticipatory grief differs in form and duration from post-death grief (Kehl, 2005). Post-death grief is the expression of psychological, cognitive, physical and behavioural response to a loss, which is indefinite. Anticipatory grief is time-based, related to the period preceding death (Fan, 2020). While experiences of pre- and post-lost grief share similarities, there are some experiences unique to the pre-loss period. For example, anticipatory grief has been associated with separation anxiety, heightened concern for the ill person, existential aloneness, rehearsal of the loved one's end of life and death, ongoing attempts to adjust to changing circumstances, anger, irritability, sadness, feelings of loss and decreased ability to function as usual (Rando, 1988; Cincotta, 2004; National Cancer Institute, 2018). Anticipatory grief can also result in depressive symptoms, emotional stress, cognitive dysfunction, loneliness, carer burden, and social withdrawal (Johanasson et al., 2012; Materson et al., 2015; Neilson et al., 2017). Although anticipatory grief has been recognised as an experience unique to the individual, some have asserted that it can be influenced by caregiver characteristics such as being female (Garand et al., 2012), or less educated schooling (Mystakidou et al., 2008). It has also been reported that a higher level of anticipatory grief may be associated with metastases in adults with advanced cancer (Mystakidou et al., 2008).

The focus of this review is on '*adults*' when '*someone important to them*' has a non-curative cancer prognosis. Throughout, the terms '*carer/caregiver*'; or '*relative*' will be used interchangeably when referring to '*adults*'. The term '*carers*' and '*caregivers*' 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 (National Health Service England, 2018; Social Care Institute for Excellence, 2013). In this review, it is recognised that close relatives or friends may only assume the caregiver role within the end-stage phase of the non-curative prognosis. The term '*patient*' will be used to describe '*someone important to them*'. Also, the term '*non-curative cancer prognosis*'

is a trajectory leading to end of life where death is anticipated (Reed & Corner, 2015). This included cancers that are advanced, progressive, terminal, palliative and incurable.

It was originally suggested that the experience/ recognition of anticipatory grief would improve bereavement outcomes (Lindemann, 1944) by facilitating post-death mourning (Fulton & Fulton 1971; Goldberg, 1973; Rando, 1986; Schulz et al., 2008). Pre-loss grief has been reported to have a positive impact, as it is thought to provide time to adjust to the reality of loss, say goodbye, create opportunities to spend quality time together, and for family members to learn skills necessary for the post-death period (Johansson & Grimby, 2011). Furthermore, it has been suggested that pre-loss grief may have an adaptive role in post-death bereavement (Moon, 2016), with little impact on post-loss grief (Hottenson et al., 2010). Other research indicates that pre-loss grief is associated with negative pathological outcomes pre- and post-bereavement (Cheung et al., 2018; Holly & Mast, 2009; Sander & Adams, 2005; Thomas et al., 2013), resulting in complicated grief and post-loss depression (Nielsen et al., 2017a&b).

Research exploring the concept of anticipatory grief has predominately centered on diagnoses such as dementia (Blandin & Pepin, 2017; Cheung et al., 2018; Liew, 2016; Sikes & Hall, 2017; Wilson et al., 2017). However, dementia grief is a specific type of anticipatory grief involving serial (cognitive, social, physical) losses across the disease trajectory (Blandin & Pepin, 2017; Lindauer et al., 2014). Krikorian et al. (2020) noted vast differences in the disease trajectories between a number of non-curative illnesses (including dementia and cancer). Although some studies have focused on the experience of anticipatory grief for cancer patients (Coelho et al., 2020) and their family caregivers (Bouchal et al., 2015; Coelho & Barbosa, 2017), there is still a scarcity of research in this area (Patinadan et al., 2020). This is an important gap to address, given reports indicating

that anticipatory grief among relatives of someone with a terminal illness have been identified as an area of concern (Åberg et al., 2004; Gilbar & Ben-Zur, 2002); and also that when anticipatory grief needs are met, individuals are less likely to experience negative bereavement outcomes (Vergo et al., 2017).

A review of current qualitative evidence is necessary in order to inform appropriate current and future support services for adults experiencing anticipatory grief within cancer care. Consequently, this review aims to identify, appraise and synthesise available qualitative evidence on adults who are experiencing anticipatory grief when someone important to them has a non-curative cancer prognosis. The research question is: *'What do we currently know about the anticipatory grief experiences, coping strategies, and holistic support needs of adults when someone important to them has a non-curative cancer prognosis?'*

### *The research context*

According to the World Health Organisation (WHO 2004; 2007) a central tenant of palliative care is the provision of support throughout the illness and following bereavement. This is replicated in several international and national strategies (Department of Health, 2008; National Institute for Clinical Excellence, 2004; 2011; National Consensus Project for Quality Palliative Care, 2009). Regionally this ethos is reflected in several strategic drivers such as Health and Social Care Services Strategy for Bereavement Care (Department of Health, Social Services and Public Safety, (DHSSPS 2009); Living Matters Dying Matters (DHSSPS 2010); Transforming your Palliative & End of Life Care Programme (DHSSPS, 2012) and the Regulation and Quality Improvement Authority Review (RQIA, 2016) which emphasise bereavement as a key part of palliative and end of life care. Such drivers are further underpinned by the establishment of the Health and Social Care Bereavement Network and the Regional Palliative Care Programme (RPCP) - `Palliative Care

in Partnership'. However, variation in quality and provision of bereavement care has been highlighted internationally (Breen et al., 2014) nationally (Arthur et al., 2010) and regionally (GAIN & RQIA, 2016), with emphasis placed on grief experienced after death, not in the pre-loss period.

Living with pre-loss at any time is hard, however at the time of writing this report, the world is facing an unprecedented challenge of the coronavirus pandemic. It has heightened uncertainty and transformed life as we know it, leading to experiences of isolation, restricted movement and limited contact with friends and family. This is a particularly vulnerable time for those who are caring for an adult with non-curative cancer prognosis. Given the uncertainty, anticipatory grief may intensify, which is compounded by the changes facing bereavement support services that have had to cease face to face interventions and adapted delivery of services to telephone or online support.

In Northern Ireland two leading organisations, Cruse Bereavement Care NI and Macmillan Cancer Support have joined forces, establishing The Macmillan Cruse Project. This collaboration aims to improve bereavement support for people affected by cancer through enabling Cruse staff to build capacity and engage with local communities to ensure meaningful and timely access to support. Further, the project aims to understand and raise awareness of information and support which effectively aids individuals before and throughout bereavement. This synthesis of the literature represents the initial step to enable a better understanding of the evidence reporting the experiences of relatives, from which to guide future practice.

## METHODOLOGY

A systematic review was undertaken in accordance with Joanna Briggs Institute (JBI) methodology for systematic reviews of qualitative evidence (Lockwood et al., 2015). The review team are health and social care experts with research and teaching experience in palliative care and bereavement support. Prior to commencement of this review the Cochrane Library, Joanne Briggs Institute (JBI) and CINAHL databases were searched by the second author [JH] to identify if a previous systematic review on this specific topic existed (21<sup>st</sup> April 2020). 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 Appendix 1).

### **Information sources**

Pre-planned searches were undertaken in four electronic databases (Ovid MEDLINE, PsycINFO, CINAHL and Embase) on 24<sup>th</sup> May 2020. The search strategy was developed by the first author [AF] alongside an experienced subject librarian. The search strategy was deployed by the first author [AF], with a time frame of the year 2000 to 2020. MeSH terms and key words were used with Boolean logic and operators. A complete search strategy for one database is included in Appendix 2. Google Scholar and reference lists of relevant papers were searched to identify research not indexed in the electronic databases.

### **Eligibility criteria**

The review considered studies that focused on qualitative data of any research design and analysis (see Table 1). Studies that adopted mixed-methods design that col-

lected, analysed and reported qualitative data were also included. However, mixed methods studies that analysed the data using quantitative approaches were excluded. Unpublished studies and other texts such as reports, expert opinion papers, clinical guidelines and reviews were excluded from the review.

Table 1: Eligibility criteria

Inclusion	Exclusion
<i>Phenomena of Interest:</i> Adults experiences of anticipatory grief, coping mechanisms and support needs when an adult who is important to them has a non-curative cancer prognosis.	Whose population is concerned with loved ones of people with conditions other than cancer such as dementia, HIV/AIDS.
<i>Types of participants:</i> Adults (male or female), aged 18 years or older from any sociodemographic background and ethnicities who are important to someone with a non-curative cancer prognosis.	Any participant under the age of 18 years.

<p><i>Type of setting:</i> Studies from any geographical setting globally and from any setting where they have reported adult's experiences of anticipatory grief, coping mechanisms and support needs when an adult who is important to them has a non-curative cancer prognosis. Studies conducted in any country will be included however only those published in English will be included.</p>	<p>Non-English.</p>
<p><i>Timeframe:</i> Studies published in the English language between 1<sup>st</sup> Jan 2000 and 24<sup>th</sup> May 2020.</p>	<p>Studies prior to the year 2000.</p>
<p><i>Types of outcome measures:</i> The phenomena of interest in this review are the experiences and perspectives of relatives.</p>	<p>Studies that adopted quantitative research designs.</p>

## Study selection and data extraction

Selection criteria was applied independently by two reviewers [AF, FH]. Titles and abstracts were screened, and full text of potentially relevant studies assessed for relevance. Discussion amongst all authors ensured that consensus was reached for inclusion of the final studies.

Data was extracted by two reviewers [AF, FH] using a form developed in line with review aims and research questions (Lockwood et al., 2017). Data extracted included:

name of the first author, year of publication, geographical location, study population, sample size, sampling procedures, study design, and the findings of interest relevant to the review questions.

This process was piloted on five studies by AF and FH in order to assess the integrity of the assessment process. After extraction, data were exported to NVivo v.12 qualitative data management software for management and refinement. Two authors [AF, FH] independently reviewed the information extracted from the data. The third reviewer [JH] was consulted on any differences in opinion concerning data extraction.

### **Quality assessment**

Risk of bias was assessed at study level as part of the quality assessment process. The appraisal was guided by the JBI-QARI framework (Lockwood et al., 2017). Two authors [AF, FH] applied the framework. A review level narrative summary and table matrix displaying the risk of bias based on an aggregate score for each study was reported. Studies were not excluded based on the quality assessment, rather to gauge the relative contribution of each study to the overall synthesis. Studies received a quality banding as either high, medium or low. Details of the quality banding are reported in Table 2.

Table 2: Quality banding

Quality banding	JBI-QARI Tool aggregate score	Definition
High	Over 7	A study with a rigour and robust scientific approach which meets most JBI benchmarks.

Moderate	Between 5 and 7	A study with some flaws but not seriously undermining the quality and scientific value of the research conducted.
Low	Under 5	A study with flaws and poor scientific value.

(Source : Evans et al., 2019)

## Synthesis of results

A thematic synthesis approach was adopted (Thomas & Harden, 2008). Thematic synthesis involves three main steps: (1) the coding of text, (2) the development of descriptive themes, and (3) the generation of analytical themes. The first author [AF] coded the findings from the extraction form using NVivo v.12. Following line by line coding, the first author [AF] inductively coded data to identify descriptive themes that merged (categories and concepts based on the research question). Descriptive themes were further defined and refined, and then clustered to generate analytical themes. Descriptive and analytical themes were discussed and checked for reliability through continuous peer review within the research team.

## FINDINGS

### **Description of studies**

In total, 914 articles were identified from the database and grey literature search and exported to RefWorks Reference Management system. Duplicates (n=299) were removed and the remaining 615 papers were screened by title and abstract. From this, 567 studies were excluded at this stage as they did not meet the inclusion criteria. Forty-eight were fully read and screened by full text, of these fourteen met inclusion criteria (Figure 1).

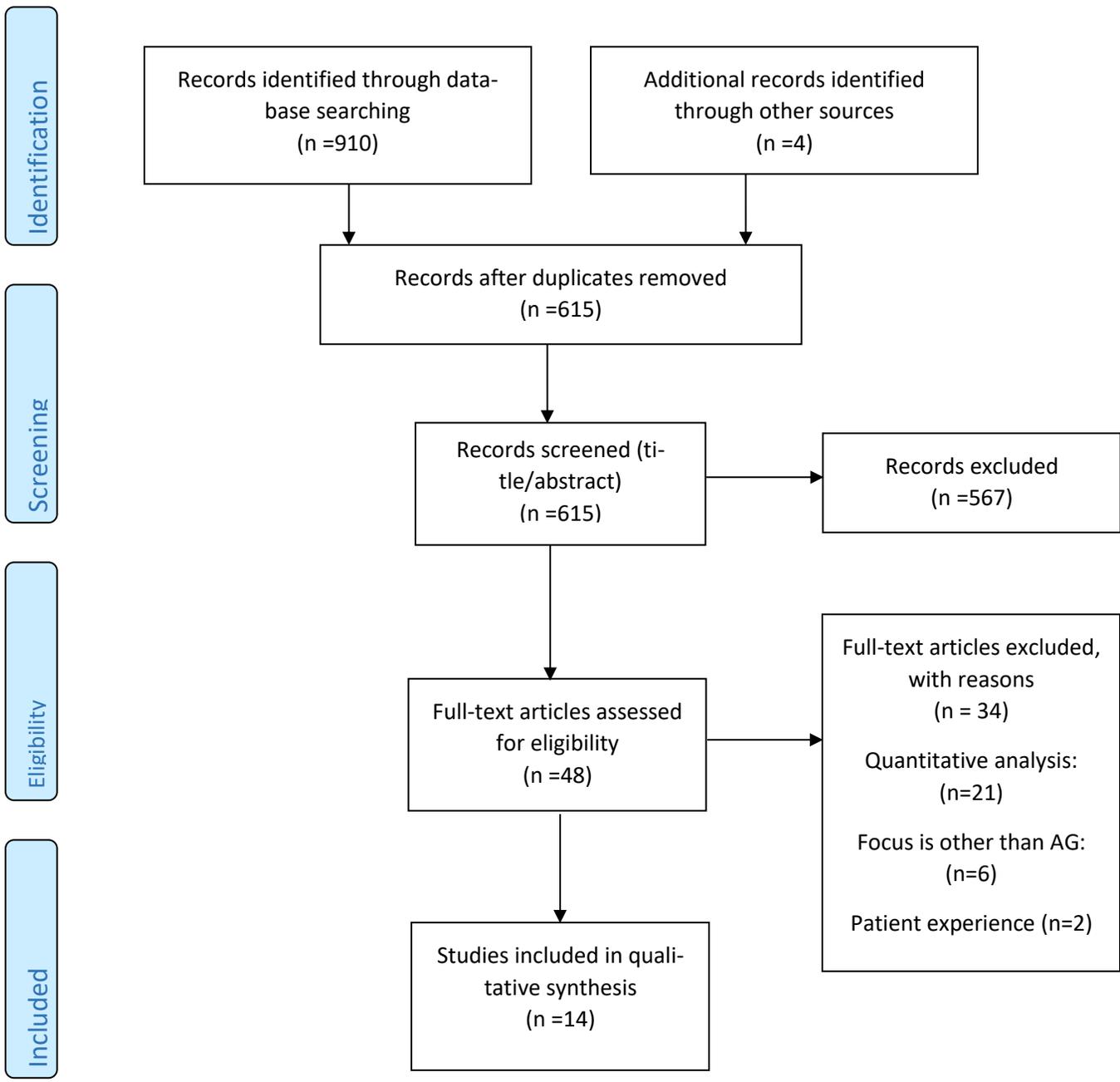


Figure 1: PRISMA 2009 Flow Diagram

## Study characteristics

Characteristics of selected articles are summarised in Table 3. Studies originated from the United States of America (Anngela-Cole & Busch 2011; Cagle & Kovacs, 2011; Clukey, 2007; Herbert et al., 2009; Waldrop, 2007; Werner-Lin et al., 2020); Canada (Bouchal et al., 2015; Dumont et al., 2008); Portugal (Coelho & Barbosa, 2017; Coelho et al., 2020); Sweden (Pusa et al., 2012; Sand & Strang, 2006); Australia (Breen et al., 2018), and Japan (Toyama & Honda, 2016).

Study methods included focus group interviews (Anngela-Cole & Busch, 2011; Werner-Lin et al., 2020); one-to-one semi-structured interviews (Bouchal et al., 2015; Breen et al., 2018; Clukey, 2007; Coelho et al., 2020; Dumont et al., 2008; Herbert et al., 2009; Pusa et al., 2012; Sand & Strang, 2006; Toyama & Honda, 2016; Waldrop, 2007), narrative responses (Cagle & Kovacs, 2011); and a literature review (Coelho & Barbosa, 2017).

Total participants in interviews (either one-to-one or focus groups) were 242; narrative responses to survey were 69; and one study undertook 66 interviews with 45 families (individually or dyad) (Werner-Lin et al., 2020). Study samples comprised spouses: (n=167); adult children (n=21); siblings (n=22); parents (n=52); other/unspecified (n=55). Of the eleven studies that recorded gender, it was reported that 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; Herbert et al., 2009; Pusa et al., 2012; Sand & Strang, 2006; Toyama & Honda, 2016).

All studies were exploratory and descriptive, and five studies employed a phenomenological design (Anngela-Cole & Busch, 2011; Bouchal et al., 2015; Clukey, 2007; Pusa et al., 2012; Waldrop, 2007). Most data were collected pre-death (Anngela-Cole & Busch, 2011; Breen et al., 2018; Cagle & Kovacs, 2011; Coelho et al., 2020; Herbert et al., 2009;

Sand & Strang, 2006; Toyama & Honda, 2016; Werner-Lin et al., 2020). Others collected data post-death (Bouchal et al., 2015; Clukey, 2007; Dumont et al., 2008; Pusa et al., 2012). In two studies, data were collected at two time points, once before and once after death. These were interviews (Waldrop, 2007); and survey responses (Cagle & Kovacs, 2011).

## **Data extraction**

Table 3 shows the articles included with key data extracted (study characteristics).

Table 3: Study characteristics

Author/ publication year/location	Study aim	Study de- sign/method	Study population/ sample size	Sampling procedure	Findings relevant to the research question
Anngela-Cole & Busch (2011)  USA	Investiga- tion into stress, an- ticipatory mourning, and cultural practices among family care- givers from independ- ent and in- ter-depend- ent cultural groups.	Qualitative, phe- nomenological ap- proach focus group interviews (N=8). Thematic analysis was adopted.	A group of culturally diverse (Chinese, Eu- ropean American, Japanese, Native Ha- waiian) family care- givers, caring for older adults with can- cer (n=56).  Female (n=51), male (n=5). Mean age: 57.9	A conven- ience sam- ple of fam- ily caregiv- ers from peer-led caregiver support groups.	<b>Experience:</b> Culturally based differences existed in how caregivers experi- enced and coped with anticipatory mourning. <b>Coping:</b> All experienced similar stressors, yet vari- ations existed in how they perceived stress and how they coped with anticipatory mourn- ing. <b>Support needs:</b> All care- givers from all ethnic groups had strong feel- ings about their experi- ences of caregiving and anticipatory grief yet, the perceptions and attribu- tions of their feelings varied. The provision of culturally sensitive sup- port was suggested as beneficial.

<p>Bouchal et al. (2015)</p> <p>Canada</p>	<p>To explore the retrospective experiences of anticipatory grief of families who have lost a loved one from cancer.</p>	<p>Qualitative, hermeneutic phenomenological approach, in-depth interviews with individuals representing the family.</p>	<p>Families who lost a loved one to cancer. Spouses, (n=8).</p> <p>Female (n=2); male (n=6).</p> <p>Age range: 55-81</p>	<p>Purposive approach to sampling was used.</p>	<p><b>Experience:</b> Family members experienced a complex process of <i>holding on and letting go</i> which was central to the anticipatory grief experience.</p> <p><b>Coping:</b> Caregiver preparedness involves cognitive, emotional, and social processes.</p> <p><b>Support:</b> Findings did not report any support mechanisms.</p>
<p>Breen et al. (2018)</p> <p>Australia</p>	<p>To explore family caregivers' preparation for death</p>	<p>Semi-structured interviews, grounded theory analysis. informed by social constructionism.</p>	<p>Family caregivers in receipt of palliative care (n=16). Spouse (n=10), adult child (n=5), friend (n=1).</p> <p>Female (n=12), male (n=4)</p> <p>Age range: 45-77 (mean age= 64.4)</p>	<p>A purposive sample of caregivers were invited to participate in the study by a third party (nurses from palliative care services).</p>	<p><b>Experience: Themes:</b> '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.</p> <p><b>Coping:</b> Caregivers were cognitively prepared, some were behaviourally prepared, but emotional</p>

					preparedness was challenging. <b>Support:</b> Services should not assume that all family caregivers are well-prepared for the death. Caregivers would likely benefit from the assessment and promotion of their death preparedness.
Cagle & Kovacs (2011)  USA	Examined the perceptions of preparedness and support of informal caregivers of hospice oncology patients.	Narrative response to pre-death and post-death questionnaires. Thematic content analysis using the constant-comparison method.	Informal caregivers of hospice oncology patients (n=69). Spouse (n=22); parent (n=22), sibling (n=10), other n=14, missing (n=1), of hospice oncology patients (n=69).  Female (n=50), male (n=8), missing (n=1).	Purposeful sample, identified by hospice social workers.	<b>Support:</b> 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 neighbours; (d) resources—specific services and equipment; and (e) faith and spirituality.
Clukey (2007)  USA	To explore the anticipatory grief experience.	Phenomenological approach using semi-structured interviews.	Recently bereaved who had received the services of a home care hospice (n=22).	Purposive sample from a list generated from the	<b>Experience:</b> Being in a state of anticipatory grief was defined as: a state of transition usually initi-

			<p>Spouses (n=9), uncle (n=1), parents (n=11), grandparent (n=1).</p> <p>Female (n=18), male (n=4). Age range: 22-79 (mean = 53).</p>	<p>records of a local hospice provider.</p>	<p>ated by either the diagnosis of a terminal illness or the prognosis from a physician that no further medical intervention will cure the dying person.</p> <p><b>Coping:</b> Components of coping included: finalizing of the connection with the loved one through touch, saying goodbye, being present, resolving issues, or sharing experiences. Other elements were making preparations (for example funeral arrangements) and maintaining hope.</p> <p><b>Support:</b> Hospice services were essential. Delivery of medical equipment and medications eased the burden of the caregivers, or financial relief provided by hospice supplying medications was appreciated. Other ways of being</p>
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					supportive included being available 24 hours a day by phone.
Coelho & Barbosa (2017)  Portugal	To synthesize research to develop knowledge about the family experience of anticipatory grief during a patient's end of life.	Integrative literature review undertaken according to Whittemore and Knafl (2005) guidelines and guided by PRISMA flowchart.  Thematic analysis employed.	Three empirical databases searched (Medline, EBSCO, and Web of Knowledge) from 1990-October 2015).	Eligibility criteria: (1) Published in English, Portuguese, and Spanish; (2) focused on the family grief experience during patient's end of life; (3) population of adult family and patients; and (4) context of advanced disease and end of life.	<b>Experience:</b> Ten themes identified: Anticipation of death – represents a key focus of anticipatory grief occurring, relates to a perception of death and threat of loss which is a fluctuating process. <b>Coping:</b> strategies differ in studies, from acceptance to denial. The acceptance can fluctuate cognitively and emotionally. Emotional distress: Intrapsychic and interpersonal protection: Hope; Exclusive focus on the patient care; Personal issues: Relational losses: Ambivalence: End of life relational tasks: Transition <i>Summary:</i> anticipation of the patient's loss and transition to a different reality, in the absence of

					the significant other. Ambivalence between two key dimensions of realisation that death will occur and impact on personal and relational losses whilst balancing a mode of protection of reality sustaining hope and caring for the ill person.
Coelho et al. (2020)  Portugal	To explore the experience of family caregivers of patients with terminal cancer to identify the core characteristics and the specific adaptive challenges related to AG in the context of	Qualitative design utilising in-semi-structured interviews. Analysed using thematic analysis (Braun & Clarke 2006).	Family caregivers 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 55.5).	Sampled using purposive sampling.	<b>Experience:</b> <i>Themes:</i> 1) Traumatic distress: uncertainty of illness; image of degradation; vicarious suffering: caregiver impotence and: life disruption. 2) Separation distress: Anticipation of death; relational losses; separation anxiety; sense of protection and; affective deprivation. <b>Coping:</b> 3) Emotional regulation and dysregulation (Self-regulation efforts; Symptoms of disorganisation).

	end-of-life caregiving.				
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 three conceptual frameworks (a) Dumont et al. (2000), pertains to psychological and emotional burden experienced by family caregivers during palliative care (b) Richard Schulz (1990) on the concept of caregiving, which is more specific to the context of palliative care and (c) Worden (2002) on grief determinants, were used to orient comprehension of family caregivers' experience.	Family caregivers of adults with cancer (n=18). Spouses (n=12), parent or friend (n=6). Age range: 33-75.  18 participants took part, most were female, most were of Roman Catholic faith and one was an atheist.	Purposive sample.	<b>Experience:</b> Six principal dimensions were reported: a) characteristics of the family caregiver. (b) patient characteristics. (c) symptoms of the illness. (d) the relational context. (e) social and professional support; (f) circumstances surrounding the death, this relates to the moment of the death and the level of preparedness for death.
Herbert et al. (2009)	To determine the factors that	Qualitative design employing focus groups (n=2) and	Family caregivers of adults (n=33). Active	Purposeful sample.	<b>Experience: Themes:</b> 1) Life experiences: The duration of the caregiving

USA	family caregivers 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.	ethnographic interviews.	<p>caregivers (n=27), bereaved (n=7).</p> <p>Spouse (n=7), child (n=12) and other (n=14).</p> <p>Female (n=27), male (n=6).</p> <p>Age range: 50-59.</p>	<p>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 HCPS 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 because of the illness and death; (d) Religious/ spiritual referred to existential concerns and issues of meaning.</p> <p><b>Support:</b> 3) Communication: A key to prepare caregivers was the need</p>
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					for clear, consistent and reliable information between all parties (HCP, patient and caregiver). 4) Preparedness: The degree to which a caregiver is ready for death, has cognitive, affective and behavioural dimensions.
Pusa et al. (2012)  Sweden	To illuminate the meanings of significant other's lived experiences of their situation from diagnosis through and after the death of a family member because of inoperable lung cancer.	Qualitative design using an interpreted phenomenological hermeneutic approach using interviews.	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).		<b>Experience: Themes:</b> 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 life, gaining strength and changing perspective.
Sand & Strang (2006) Sweden	To explore the experience of existential isolation experienced in associated with an incurable disease, the origins of these feelings and their interaction.	Qualitative design using semi-structured interviews with open ended questions.	Next-of-kin (n=20). Spouses (n=12), children/parents/siblings (n=8)  Age range: 21-92 (mean 63).	Purposive sampling with data collected using maximum variation sampling technique.	<b>Experience: Themes:</b> 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 realisation that the patient and the caregiver went their separate ways.
Toyama & Honda (2016) Tokyo	To explore and clarify how talking to family	Qualitative design using an intervention study targeting family caregivers.	Two family caregivers, Case A: the patient's daughter, aged in her 20s who was a		<b>Experience: Themes</b> 1) Talking about their obsession with their expected role in the family.

	<p>caregivers of patients with end-of-life illness using the narrative approach influences the process of anticipatory grief.</p>		<p>nurse and in Case B the caregiver was the patient's wife, in her 50s, who was a cancer survivor.</p>	<p>An expectation for the daughter (as a nurse) to adopt the caregiver 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 encouraged her father's anticipatory grief. The patient's wife recognised that she had to force herself to fulfil the caregiver's role and recognised problems acting as her husband's substitute. This led her to feel she was not sufficiently fulfilling either role.</p> <p>3) Facing the patient departing for death as a family member. Both recognised that the roles expected of them were not their true roles and began to prepare for the coming less and end of</p>
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					<p>life care while feeling conflicted over this realization.</p> <p>4) Grieving in anticipation of less from the viewpoint of a family member. Over time they did not feel trapped but anticipated and grieved for the loss.</p>
<p>Waldrop (2007) USA</p>	<p>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?</p>	<p>Exploratory descriptive phenomenological study. Qualitative (interviews) and quantitative methods used</p>	<p>Family caregivers (n=30) who were caring for a relative or friend with terminal illness.</p> <p>Females (daughters, daughters-in-law, wives, grand-daughter and a friend) (n=23); males (husbands and sons) (n=7).</p>	<p>Purposeful sample.</p>	<p><b>Experience:</b> 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</p>

					family cohesion; increased or decreased social support.
Werner- Lin et al. (2020)  USA	Study aimed to evaluate the psychological, social and behavioural impact of Li-Fraumeni Syndrome (LFS), and to refine evidence-based counselling strategies.	Semi-structured interviews (n=66), using modified grounded theory and interpretive description.	Families (n=45) completed 66 interviews. Family members (n=117) were aged 13-81 years, with 19 parent-child groups, 26 partner dyads, 11 sibling groups, and 10 mixed groups.	Purposeful sample.	<b>Experience:</b> 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 LFS which compromised mourning.

## **Quality assessment**

All fourteen studies were assessed for methodological quality (see Table 4 and Appendix 3 for checklists). Eleven studies scored above '7' (Sand & Strang, 2006; Waldrop, 2007; Dumont et al., 2008; Herbert et al., 2009; Pusa et al., 2012; Bouchal et al., 2015; Toyama & Honda, 2016; Coelho & Barbosa, 2017; Breen et al., 2018; Coelho et al., 2020; Werner-Lin et al., 2020). Two studies scored between 5 and 7 (Clukey, 2007; Anngela-Cole & Busch, 2011), and one study scored below 5 (Cagle & Kovacs, 2011).

Table 4: Outcome of quality assessment

Quality banding	JBI-QARI Aggregate score	Definition	Score
High N=11	Over 7	A study with a rigorous and robust scientific approach which meets most JBI benchmark	Bouchal et al. 2015; Coelho et al. 2020; Dumont et al. 2008; Herbert et al. 2009; Pusa et al. 2012; Sand & Strang 2006; Toyama & Honda 2016; Waldrop 2007; Werner-Lin et al. 2020; Coelho & Barbosa 2017; Breen et al. 2018
Moderate N=2	Between 5 and 7	A study with some flaws but not seriously undermined the quality and scientific value of the research conducted	Anngela-Cole & Busch 2011; Clukey 2007
Low N=1	Under 5	A study with flaws and poor scientific value	Cagle & Kovacs 2011

## Results of thematic synthesis

The analysis of the articles gave rise to three main themes and several sub-themes (see table 5 below).

Table 5: Themes and sub-themes

Themes:	The experience of anticipatory grief	Impact of anticipatory grief	Support and spiritual needs for the difficult road towards end of life
Subthemes:	<i>Living with loss</i>	<i>Physical and emotional onslaught</i>	<i>Coping strategies</i>
	<i>Living with uncertainty</i>	<i>Emotional strain</i>	<i>Meeting the holistic support needs of relatives during end-stage care.</i>

### Theme 1: The experience of anticipatory grief

Research supports the notion that the way a person experiences and expresses grief varies, influenced by diversity among individuals, families, networks, and socio-cultural factors (Strobe et al., 2007). Findings in this review about the experience of anticipatory grief are centered on the recognition and reaction to loss, and the unpredictability of the journey ahead, rather than emphasising the death of the patient.

#### *1. Living with loss*

Findings in selected studies revealed that the impending loss of a loved one led to a recognition of countless losses, related to the past, present and future. In this situation, both the patient and the relative observed, felt and lived with physical and psychosocial

loss. In advance of death, witnessing and being part of the loss of the patient's abilities, dreams, independence and future was mixed with relatives' own loss for their future, stability, security, freedom, and personal or family identity (Coelho & Barbosa, 2017). When the patient was alive, relatives reported how the dying patient was not the same person as before and felt loss regarding issues such as '*intimacy and reciprocity in the relationship*' and '*loss of everyday protection*' (Sand & Strang, 2006). Similarly, Pusa et al. (2012) reported how significant others experienced feelings of loss of intimacy with their dying spouse. Alongside this, it was suggested that the patient and caregiver often felt isolated (Coelho et al., 2020) as their friends and family members may not have acknowledged their distress as a result of declining health, and the reality that the patient was dying.

It was reported that relatives experienced relational losses when they had greater involvement in managing tasks that had previously been undertaken by the patient, such as keeping records, managing medication or day-to-day household activities. Study findings indicated that relatives often felt emotionally overwhelmed in taking on these tasks in addition to their own daily activities. It was suggested that undertaking these new tasks and assuming new roles created uncertainty among the family and had ramifications for the functioning and dynamics of the wider family. Moreover, engagement in a caregiver role was suggested to create a loss of self for relatives, as the focus was on the patient which was compounded by limited social contact with others (Pusa et al., 2012). Some reported to feeling trapped within this role (Toyama & Honda, 2016), with many reporting that their lives and other responsibilities took second place (Pusa et al., 2012). Yet they rarely expressed their needs in the presence of the patient or to a healthcare practitioner, therefore leaving them feeling exhausted (Coelho et al., 2020), and that their needs were invisible and often unrecognised (Pusa et al. 2012). This appeared to be compounded when relatives experienced expressions of compassion that '*felt fake and un-genuine*' from healthcare practitioners (Pusa et al., 2012). Subsequently, this impacted on the relative's

sense of attachment to the patient and potentially resulted in feelings of resentment towards the patient needing care, wider family for not assisting, and health practitioners for not recognising their needs (Coelho & Barbosa, 2017; Coelho et al., 2020).

## *2. Living with uncertainty*

Co-existing with loss was the experience of uncertainty and unpredictability, which were reported throughout the pre-death period. There was ambiguity around the disease trajectory in the face of approaching death, and Herbert et al., (2009) found that vague or ambiguous communication could make preparation for death more difficult for relatives. It was suggested that a lack of clear communication from healthcare practitioners contributed to uncertainty and remained '*one of the most neglected aspects of end-of-life care*'; specifically, regarding the prognosis, psychosocial prognosis and clinical course. This was echoed by Pusa et al. (2012), as participants in this study often experienced a struggle for good care from medical services. It was perceived that healthcare practitioners should provide unambiguous communication surrounding the prognosis, making it clear that no further medical intervention would cure the patient (Clukey, 2007; Herbert et al., 2009). Some authors believed this would signify the realisation of impending death for the patient and family (Clukey, 2007; Herbert et al., 2009).

The period between prognosis and the active dying phase was referred to by Breen et al., (2018) as unpredictable. A common perception was that this period offered a time for preparation, the completion of unfinished business, and the chance to say goodbye (Bouchal et al., 2015; Clukey, 2007; Herbert et al., 2009; Toyama & Honda, 2016). However, this was not always practiced in families (Breen et al., 2018; Coelho & Barbosa, 2017; Coelho et al., 2020). Evidence suggested that during this time relatives found it difficult to anticipate what might come next, and the time and circumstances of death (Coelho et al., 2020; Pusa et al., 2012). The art of living in the midst of death, was referred to in the

literature as “*holding on while letting go*” for relatives (Bouchal et al., 2015). The beginning of this paradoxical position was at initial terminal prognosis, when relatives strived to cope with the prognosis, while doing everything possible for the patient and the gradual realisation that death was inevitable (Bouchal et al., 2015). This was followed by other transition points such as leaving home for the hospice or letting go of the physical body when the patient stopped eating or communicating. During these transition points, relatives potentially found themselves in a state of shock regarding the present and future, resulting in them becoming hyper-vigilant to the condition of the patient (Coelho et al., 2020). Often relatives oscillated between ‘*hope*’ (regarding patient’s time and quality of death) and ‘*fear*’ (of the unknown, or of what the future may hold) in a period that was marked by tension (Breen et al., 2018).

## Theme 2: Impact of anticipatory grief

Anticipatory grief was reported to have a profound impact on relatives physically and psychologically (Clukey, 2007; Pusa et al., 2012; Werner-Lin et al., 2020). The transition of being ill to dying involved the realisation that death was likely.

### 1. *Physical and emotional onslaught*

Physically, Coelho et al., (2020) asserted that the signs of anticipatory grief included ‘*appetite and digestive changes; tachycardia; and muscle tension*’; and Clukey (2007) described the sensation of realising that death was inevitable as similar to ‘*being punched*’ for relatives. Other studies reported on the emotional impact of anticipatory grief (Waldrop, 2007; Bouchal et al., 2015; Breen et al., 2018; Coelho et al., 2020). For example, it was described as a period of ‘*traumatic distress*’ (Coelho et al., 2020); ‘*a great number of stressful emotions*’ (Pusa et al., 2012); ‘*intense*’ psychological and emotional responses’ (Waldrop, 2012); ‘*anguish and panic*’ (Coelho et al., 2020; Toyama & Honda, 2016). Some significant

others in Pusa et al. (2012) reported that they expressed anger towards the disease, other relatives, or God (Coelho & Barbosa, 2017).

Sand and Strang (2006) highlighted how next-of-kin could experience '*existential loneliness*' manifesting in strong feelings of '*sorrow, fear and desolation*', upon realising that after the person died, they would be on their own. Also, Breen et al., (2018) found that due to the 'all-consuming' nature of caregiving in the pre-death phase, feelings of loneliness were 'palpable' after the patient had died. Additionally, Coelho and Barbosa (2017) referred to relatives '*deep sense of loneliness*' resulting from the loss of intimacy and relationship reciprocity when the patient's illness symptoms led to changes in personality, such as loss of communication.

## *2. Emotional strain*

Management of the experience and control of emotional reactions resulted in emotional strain. Coelho et al., (2020) described emotions involved in the anticipatory grief experience as: '*mood instability, impatience and instability....as well as other signs of acute stress*'. It was suggested that when this co-existed with relative's caregiving responsibilities such as providing practical and emotional support to the patient, it could potentially result in a sense of being overwhelmed or impotent (Coelho et al., 2020). Findings in other studies also suggested that the demands and responsibilities of caregiving throughout the non-curative trajectory were exhausting and overwhelming (Waldrop, 2007; Clukey, 2007; Pusa et al., 2012; Breen et al., 2018). Waldrop (2007) further explained that carers were often overwhelmed because they had to face the impending death of a loved one while simultaneously feeling '*on-edge and responsible*'.

It was reported that the active dying phase was also compounded by relatives' feelings of inhibition at expressing their true feelings about the impending death, as it

conflicted with their responsibility to protect the patient's life and welfare (Pusa et al., 2012; Coelho et al., 2020). Findings of some studies indicated that relatives were conflicted between feeling devoted to the patient and seeking support for their own distress, and feelings of burden which sometimes resulted in guilt (Costello, 1999; Coelho & Barbosa, 2017; Pusa et al., 2012). Breen et al., (2018) found that guilt could also be the result of relatives looking forward to when caregiving ended, or to the period after the patient had died, and were concerned that if they moved on '*too quickly*' they may be negatively judged by others.

### Theme 3: Support and spiritual needs for the difficult road towards end of life

Review findings suggested that anticipatory grief could lead to negative physical and psychological outcomes for relatives. Alongside this, all the studies in this review recognised the need for support. There was some evidence of a need for informal strategies (Waldrop 2007; Dumont et al., 2008; Pusa et al., 2012; Bouchal et al., 2015; Coelho & Barbosa, 2017; Coelho et al., 2020), whereas others made recommendations for future support initiatives (Dumont et al., 2008; Herbert et al., 2009; Pusa et al., 2012; Toyama & Honda, 2016; Breen et al., 2018; Coelho et al., 2020; Werner-Lin et al., 2020).

#### *1. Coping strategies*

As a coping strategy, relatives adapted physically and psychologically to continual losses. This adaptation was influenced by factors such as personal characteristics of the relative and patient, illness symptoms, social and professional support; and the relational context (Dumont et al., 2008). Bouchal et al., (2015) described how relatives often assumed a new role as caregiver, which quickly became intense and exhausting. They adopted various emotional, psychological and, or social processes as a way of coping with this transition and making sense of the evolving situation during the end-of-life stage.

These included avoidance strategies, whereby some relatives coped by periodically avoiding discussion surrounding the impending death due to the emotional strain of this conversation (Waldrop, 2007; Pusa et al., 2012; Coelho et al., 2020). Similarly, Coelho et al. (2020) described carer 'self-regulation' through inhibiting their feelings as a way to protect each other from emotional distress. Coelho and Barbosa (2017) noted that *'repression of feelings and numbness allow them to anticipate and plan practical aspects without being overwhelmed by emotional burden. There is also a tendency to rationalize.'* Other strategies included relaxation and exercise, venting emotions to gain strength to carry on (Pusa et al., 2012) and adopting positive affirmation strategies of self-assurance such as *'I am strong; I will survive'* (Coelho et al., 2020). Cognitive strategies such as reading, journaling, and reflection were highlighted as ways to enable relatives to become aware of the process of anticipatory grief and help in the transition of accepting the illness as a terminal event (Bouchal et al., 2015). It is unclear if these strategies were adopted in line with advice from healthcare practitioners; or the relative's personal coping mechanisms.

The existence of a faith community or spiritual support were often noted, alongside a belief in a higher power, a connection with God, and prayers, as helpful coping strategies (Dumont et al., 2008; Anngela-Cole & Busch, 2011; Cagle & Kovacs, 2011; Pusa et al., 2012; Coelho et al., 2020). Coelho and Barbosa (2017) found that some relatives coped by turning to, or developing, spiritual beliefs to help them adapt and cope with their situation; leading some to believe that everything was decided by God, and out of their control. Breen et al., (2018) suggested that next-of-kin were often *'consoled by their beliefs'* towards the end of life; buffering the effects of loss and reinforcing hope for reunion with their loved one in the afterlife.

Whilst death was inevitable, many relatives were drawn to nurture hope as a coping

mechanism. This was perceived to be hope for recovery or hope that the patient's suffering would lessen or end (Clukey, 2007; Coelho & Barbosa, 2017). The maintenance of hope was important, as some relatives believed that they had the primary responsibility to instill hope in the patient throughout the end-of-life experience (Breen et al., 2018). Despite the realities of the progressive degenerative process of the illness, the maintenance of hope was often seen to be a measure of their success as a carer (Clukey, 2007). It was suggested that as the patient's health deteriorated towards end of life, hope was shifted from a desire for full recovery to a peaceful death (Coelho & Barbosa, 2017).

## *2. Meeting the holistic support needs of relatives during end-stage care*

None of the studies reported on the existence of clinical psychological interventions to support anticipatory grief, yet recommended the need to access emotional and practical support for caregivers (Dumont et al., 2008; Herbert et al., 2009; Toyama & Honda, 2016; Coelho et al., 2020); caregivers and patients (Cagle & Kovacs, 2011); and families (Pusa et al., 2012; Werner-Lin et al., 2020).

Review findings highlighted several aspects of support needed by relatives throughout the end-stage phase. Specifically, a need for clear information surrounding the non-curative cancer prognosis, as well as support to help with the pragmatic (i.e. having funeral arrangements in place) and informational components (i.e. medical aspects of providing end-of-life care) (Herbert et al., 2009). One study also reported that healthcare practitioners should provide technical support to enable caregivers to fulfill their caregiving role, and how to manage emotions throughout the end-of-life journey (Toyama & Honda, 2016). Alongside this, some authors referred to the concept of 'preparedness' surrounding the impending death (Herbert et al., 2009; Cagle & Kovacs, 2011; Bouchal et al., 2015; Coelho & Barbosa, 2017; Breen et al., 2018). 'Preparedness' was defined by Herbert et al. (2009) as *'the degree to which a caregiver is ready for the death'*. Herbert et al.,

(2009) asserted that components of preparedness before death comprised cognitive (understanding that death was imminent), behavioural (beginning funeral arrangements) and affective (emotional). Herbert et al., (2009) emphasised that support for affective (emotional) preparedness was most important for relatives. Although some relatives in Herbert et al.'s (2009) study met the cognitive and, or behavioural aspects of preparedness, few were perceived as emotionally prepared. Thus, Herbert et al., (2009) cautioned against palliative care services assuming that just because relatives knew that death was imminent, that they were well-prepared emotionally. Authors concluded that clear and consistent communication was key in enabling the promotion of all aspects of preparedness. It was perceived that healthcare practitioners needed to provide information and communicate in a way that was sensitive to relatives' emotional needs in order to facilitate emotional preparedness and to complete important caregiving tasks (Herbert et al., 2009). Similarly, Cagle and Kovacs (2011) emphasised the need for the provision of clear communication from healthcare practitioners for relatives about the disease process and prognosis, along with information around care needs, and expectations of them as carers.

Doka (2008) reports that anticipatory grief may not be openly acknowledged by families themselves, and therefore there is limited recognition that relatives have a right to grieve or claim sympathy or support. This can be compounded by a lack of social validation for the grieving relative and an absence of rituals, such as a funeral (as in post-death bereavement). It was highlighted that a continuum of support from the point of terminal prognosis through to post-death is needed by relatives, in order to minimise the risk of post-death grief complications (Breen et al., 2018).

The key support offered to relatives stemmed from healthcare practitioners, however this was context and time specific. Healthcare practitioners 'being present' for relatives, to offer security, guidance on the illness trajectory, information, or someone to talk

to was highlighted as significant in the period before death (Waldrop, 2007; Clukey, 2007; Pusa et al., 2012; Toyama & Honda, 2016). Specifically, Waldrop (2007) stressed the importance of regular supportive and therapeutic contact between healthcare practitioners and relatives during end-stage cancer care, which authors suggested could assist in 'normalising' grief. In contrast, Pusa et al. (2012) described how *'significant others experienced a lack of support including insufficient understanding from care professionals'*, resulting in feelings of being over-loaded, uninformed, invisible and isolated. Pusa et al. (2012) asserted that this was potentially due to a heightened focus on the patient, with both relatives and healthcare practitioners during end-stage cancer care.

Environments were also identified as being either supportive or unsupportive. Some perceived the hospice environment as a positive, relational space which was viewed as 'home' (Bouchal et al., 2015; Breen et al., 2018); whereas Pusa et al., (2012) described *'unaesthetic healthcare environments'* as being a barrier to support.

The provision of practical and emotional support that met the needs of relatives during end-of-life care was described as decreasing *'anxiety and distress in family caregivers and positively orienting their bereavement'*, contributing to *'positive repercussions on adjustment to bereavement'* (Dumont et al., 2008); and increasing *'the sense of wellbeing, providing feelings of safety and confidence'*. Thus, some evidence in the review showed how the provision of appropriate support during the end-stage period promoted adjustment and coping and enabled relatives to *'endure the altered situation of the illness period'* (Pusa et al., 2012).

## CONCLUSIONS & RECOMMENDATIONS

This review reports on the anticipatory grief experiences, coping mechanisms and support provided for adults when someone important to them has a non-curative cancer diagnosis. The timing of anticipatory grief is commonly associated with receiving a non-curative diagnosis which confirms no cure, and that death is inevitable.

Our review process entailed an analysis and synthesis of the published literature over the last twenty years (2000-2020). From a total of 914 papers found, fourteen met the inclusion criteria, with only six of these having been published in the last five years. This suggests that anticipatory grief, focusing on the family members experience with a non-curative cancer diagnosis, is an emerging area requiring further attention. None of the selected articles originated in the United Kingdom, and findings are predominantly from a female perspective, which indicates a gap in empirical evidence in this area.

In summary, the key findings from this review suggest that anticipatory grief centers on recognising and adapting to multiple losses, throughout an experience of uncertainty, that impacts on relatives physically, psychologically and emotionally. Whilst formalized and informalised support is currently available in specialist palliative care settings and services, 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. Formalised and informal support is currently available in specialist palliative care settings and services: while this forms the core role of some professions, all members of the specialist multi-disciplinary team play a role. However, this focus is much less likely within generic acute and community services where most patients and relatives will access care and support. However, without the widespread availability of support, many relatives may be left to navigate this distressing experience on their own. Unlike post-death grief, there is limited social recognition that the patient or relative have the right to grieve or claim social sympathy or

support. There is a need to raise awareness about grief that is experienced pre-loss, and to develop targeted interventions to meet support needs.

The implications of anticipatory grief outlined in this review are not new and have been acknowledged in other research within cancer literature (Hottenson et al., 2010, Neilson et al., 2016; Neilson et al., 2017; Coelho et al., 2018). However previous research has indicated that a lack of support for anticipatory grief can result in negative carer bereavement outcomes (Burke et al., 2015). Thus, consideration of appropriate and meaningful interventions to support a grieving process are important in order to facilitate the end-of-life transition and reduce the risk of post-loss complications within palliative cancer care (Shore et al., 2016; Patinadan et al., 2020). However, a previous systematic review of studies of support interventions for addressing anticipatory grief and its components reported similar findings to the current review and suggested that none of them addressed anticipatory grief directly (Patinadan et al., 2020).

Reasons for the lack of support directly targeting anticipatory grief are unclear. However, Neilson et al. (2017) indicated that severe pre-loss grief among caregivers may be overlooked within palliative cancer care and highlighted a potential lack of support in this area. It could be argued that a lack of support is related to misunderstandings surrounding the concept of anticipatory grief (Moon, 2016). Neilson et al., (2016) argued that within end-stage palliative care grief and preparedness were two different concepts, which not only needed to be measured separately, but also targeted separately for support, as it was the concept of preparedness that needed to be measured and supported as opposed to grief.

## **Strengths and limitations**

This review offers an initial synthesis of qualitative literature on the anticipatory grief experiences from the caregiver and relative's perspective. Strengths of the review include the use of a comprehensive search strategy using explicit pre-defined eligibility criteria, which enhanced rigour. The application of a validated assessment tool (JBI-QARI framework) ensured methodological quality of the included papers, and the use of a recognised reporting framework (ENTREQ) added to transparency in reporting findings. However, several review limitations are also noted. Limiting the search to papers published in English potentially limits the scope of the review and may have resulted in some eligible papers published in other languages being missed. Given that the current review did not consider other influencing factors on relative's experience of anticipatory grief (such as sociodemographic factors), this remains an area for future research.

## **Recommendations**

Several recommendations have been made

**Provision of holistic support for anticipatory grief:** Pre-loss grief requires holistic preparedness and planning for the relative at a cognitive, emotional, behavioural, spiritual, financial and social level. Although a multi-factored response to support the relative is recommended, an initial need exists to raise awareness of the existence of anticipatory grief amongst families who are caring for a loved one who has a non-curative cancer prognosis during the end-stage phase. Relatives, especially those who are assuming a caring role, may be unprepared for intense and overwhelming emotions that they experience during the end-of-life experience. Education about the grief process and preparing families for death and dying are important in order to minimise the risk of post-death grief complications (Breen et al., 2018).

**Health and social care practitioner practice:** Whilst anticipatory grief is a unique experience for everyone, the wellbeing of adults who are caring for a loved one who has a non-curative cancer prognosis needs to be acknowledged as part of routine care. Findings of this review suggest that although relatives may be cognitively or behaviourally prepared for death, they may not be emotionally prepared (Herbert et al., 2009; Bouchal et al., 2015; Breen et al., 2018). It would be important to raise awareness of this amongst health and social care practitioners, and to ensure that this is addressed through regular and routine emotional support for families during the end-stage phase across all settings, not just in specialist sites or services. This could be facilitated by health and social care professionals enabling choice through advance care plans and for caregivers and wider family network to be offered the choice to be supported and be prepared in their grief.

**Models of good practice:** This review highlights the negative impact of anticipatory grief on people and the need to ameliorate these effects. However, the evidence for how best to support people is limited. There is a necessity to better understand the current provision of pre-loss support models to inform how such support can be delivered to best facilitate those pre death across generic settings and services. An essential attribute of such models is the delivery of empathic client focused communication strategies to be embedded within the delivery to ensure services are aligned and best outcomes are attained.

**Further Research:** Findings of the current review have highlighted experiences of profound loss and uncertainty, together with intense emotional strain among adults who are caring for a loved one with a non-curative cancer prognosis, in the pre-death period. There is a clear need for further research to aid our understanding surrounding the concept of anticipatory grief, and caregiver preparedness for death. Further research may

lead to a better understanding of these concepts, enabling health and social care practitioners to adequately assess caregiver/relative's support needs during the end-stage phase and allow for more targeted support.

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## Appendix 1: ENTREQ Checklist

ENTREQ checklist (Enhancing transparency in reporting the synthesis of qualitative research) \*

No. Item	Question/Description	Reported on Page Number:
1. Aim	State the research question the synthesis addresses.	p12
2 Synthesis	Identify the synthesis methodology or theoretical framework which underpins the synthesis and describe the rationale for choice of methodology (e.g. meta-ethnography, thematic synthesis, critical interpretive synthesis, grounded theory synthesis, realist synthesis, meta-aggregation, meta-study, framework synthesis).	p13
3. Approach to Searching	Indicate whether the search was pre-planned (comprehensive search strategies to seek all available studies) or iterative (to seek all available concepts until they theoretical saturation is achieved).	p13
4. Inclusion Criteria	Specify the inclusion/exclusion criteria (e.g. in terms of population, language, year limits, type of publication, study type).	Table 1 p14
5. Data Sources	Describe the information sources used (e.g. electronic databases: MEDLINE, EMBASE, CINAHL, PsycINFO), grey literature databases (digital theses, policy reports), relevant organisational websites, experts, information specialists, generic web searches (Google Scholar) hand searching, reference lists, and when the searches were conducted; provide the rationale for using the data sources.	p13

6. Electronic Search strategy	Describe the literature search (e.g. provide electronic search strategies with population terms, clinical or health topic terms, experiential or social phenomena related terms, filters for qualitative research, and search limits).	Appendix 2 p65
7. Study Screening Methods	Describe the process of study screening and sifting (e.g. title, abstract and full text review, number of independent reviewers who screened studies).	p15-16
8. Study Characteristics	Present the characteristics of the included studies (e.g. year of publication, country, population, number of participants, data collection, methodology, analysis, research questions).	Table 3 p22
9. Study Selection Results	Identify the number of studies screened and provide reasons for study exclusion (e.g. for comprehensive searching, provide numbers of studies screened and reasons for exclusion indicated in a figure/flowchart; for iterative searching describe reasons for study exclusion and inclusion based on modifications to the research question and/or contribution to theory development).	Figure 1 p19
10. Rationale for Appraisal	Describe the rationale and approach used to appraise the included studies or selected findings (e.g. assessment of conduct, validity and robustness), assessment of reporting (transparency), assessment of content and utility of the findings.	p16
11. Appraisal Items	State the tools, frameworks and criteria used to appraise the studies or selected findings (e.g. Existing tools: CASP, QARI, COREQ; reviewer developed tools; describe the domains assessed; research team, study design, data analysis and interpretations, reporting).	p16 Appendix 3 p66
12. Appraisal Process	Indicate whether the appraisal was conducted independently by more than one reviewer and if consensus was required.	p16-17

13. Appraisal Results	Present results of the quality assessment and indicate which articles, if any, were weighted/excluded based on the assessment and give the rationale.	Appendix 3 p66
14. Data Extraction	Indicate which sections of the primary studies were analysed and how the data were extracted from the primary studies (e.g. all text under the headings "results /conclusions" were extracted electronically and entered a computer software).	p21-22 Table 3
15. Software	State the computer software used, if any.	p18
16. Number of Reviewers	Identify who was involved in coding and analysis.	p16-17
17. Coding	Describe the process for coding of data (e.g. line by line coding to search for concepts).	p16-17
18. Study Comparison	Describe how were comparisons made within and across studies (e.g. subsequent studies were coded into pre-existing concepts, and new concepts were created when deemed necessary).	p16-17
19. Derivation of Themes	Explain whether the process of deriving the themes or constructs was inductive or deductive.	P16-17
20. Quotations	Provide quotations from the primary studies to illustrate themes/constructs and identify whether the quotations were participant quotations of the author's interpretation.	p38-47
21. Synthesis Output	Present rich, compelling and useful results that go beyond a summary of the primary studies (e.g. new interpretation, models of evidence, conceptual models, analytical framework, development of a new theory or construct).	p20-21

\* Reference: Tong A, Flemming K, McInnes E, Oliver SA, Craig J. Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. BMC Medical Research Methodology 2012, 12:181.

## Appendix 2: Sample database search

See below a complete search strategy for one database:

- 1) anticipatory grieving (MeSH)
- 2) anticipatory (grie\* or mourning or loss) OR preparatory grie\* OR pre-grief OR pre-bereavement OR "premature bereavement" OR pre-loss OR pre-death OR Preparedness OR Loneliness
- 3) 1 or 2
- 4) Palliative care (MeSH)
- 5) Terminal care (MeSH)
- 6) Hospice care (MeSH)
- 7) care (palliative OR terminal OR end-of life OR end of life OR eol OR hospice) OR "terminally ill" OR non-curative OR incurable OR dying OR death
- 8) 4 OR 5 Or 6 OR 7
- 9) 3 AND 8
- 10) Neoplasm (MeSH)
- 11) Cancer\* OR carcinoma\* OR neoplasm\* OR lymphoma\* OR leukaemia
- 12) 10 OR 11
- 13) Family (MeSH)
- 14) Caregivers (MeSH)
- 15) Relative\* OR partner OR spouse OR care-giver\* OR caregiver\* OR "care giver\*" OR carer\* OR wife OR husband OR "close friend" OR Spouse OR "significant other" OR "next of kin" OR Adult
- 16) 13 OR 14 OR 15
- 17) 12 AND 16
- 18) 9 AND 17
- 19) Young OR youth OR teenager OR babies OR children OR child
- 20) 18 NOT 19

Limits: English/ 2000 - 2020

### Appendix 3: Quality appraisal checklists

Table: JBI Critical Appraisal Checklist for Qualitative Research – Studies 1-7 (\*Y = Yes N=No U=Unclear)

<b>Critical appraisal questions</b>	An- ngela- Cole & Busch 2011	Bouc hal et al. 2015	Bree n et al. 201 8	Cagle & Ko- vacs 2011	Cluk ey 200 7	Co- lho et al. 2020	Dum ont et al.20 08
1. Is there congruity between the stated philosophical perspective and the research methodology?	Y*	Y	Y	U*	Y	U	U
2. Is there congruity between the research methodology and the research question or objectives?	Y	Y	Y	U	Y	Y	Y
3. Is there congruity between the research methodology and the methods used to collect data?	Y	Y	Y	U	Y	Y	Y
4. Is there congruity between the research methodology and the representation and analysis of data?	Y	Y	Y	U	Y	Y	Y
5. Is there congruity between the research methodology and the interpretation of results?	Y	Y	Y	U	U	Y	Y
6. Is there a statement locating the researcher culturally or theoretically?	N*	Y	Y	N	N	N	N
7. Is the influence of the researcher on the research, and vice-versa, addressed?	N	N	N	N	N	N	N

8. Are participants, and their voices, adequately represented?	N	Y	Y	Y	Y	Y	Y
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	U*	Y	Y	N	Y	Y	Y
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	Y	Y	Y	Y	U	Y	Y
<b>Total Score</b>	<b>6/10</b>	<b>9/10</b>	<b>9/10</b>	<b>2/10</b>	<b>6/10</b>	<b>7/10</b>	<b>7/10</b>

Table: (continued): JBI Critical Appraisal Checklist for Qualitative Research – studies 8-13

<b>Critical appraisal questions</b>	Herbert et al. 2009	Pusa et al. 2012	Sand & Strang 2006	Toyam a & Honda 2016	Wal-drop 2007	Werner-Lin et al. 2020
1. Is there congruity between the stated philosophical perspective and the research methodology?	U	Y	Y	Y	Y	Y
2. Is there congruity between the research methodology and the research question or objectives?	Y	Y	Y	Y	Y	Y
3. Is there congruity between the research methodology and the methods used to collect data?	Y	Y	Y	Y	Y	Y

4. Is there congruity between the research methodology and the representation and analysis of data?	Y	Y	Y	Y	Y	Y
5. Is there congruity between the research methodology and the interpretation of results?	y		Y	Y	Y	Y
6. Is there a statement locating the researcher culturally or theoretically?	N	N	Y	U	N	U
7. Is the influence of the researcher on the research, and vice- versa, addressed?	N	U	N	N	N	N
8. Are participants, and their voices, adequately represented?	Y	Y	Y	Y	Y	Y
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	Y	Y	Y	Y	Y	Y
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	Y	Y	Y	Y	Y	Y
<b>Total score</b>	<b>7/10</b>	<b>8/10</b>	<b>9/10</b>	<b>8/10</b>	<b>8/10</b>	<b>8/10</b>

\*Y = Yes    N=No    U=Unclear

*Table: JBI Critical Appraisal Checklist for Systematic Reviews and Research Syntheses – study 14*

<b>Critical appraisal questions</b>	Coelho & Barbosa 2017
1. Is the review question clearly and explicitly stated?	Y*
2. Were the inclusion criteria appropriate for the review question?	Y
3. Was the search strategy appropriate?	Y
4. Were the sources and resources used to search for studies adequate?	y
5. Were the criteria for appraising studies appropriate?	Y
6. Was critical appraisal conducted by two or more reviewers independently?	U*
7. Were there methods to minimize errors in data extraction?	U
8. Were the methods used to combine studies appropriate?	U
9. Was the likelihood of publication bias assessed?	U
10. Were recommendations for policy and/or practice supported by the reported data?	U
11. Were the specific directives for new research appropriate?	Y
Total Score	<b>6/11</b>

\*Y = Yes U=Unclear