

## REVIEW

# Grief in family carers of people living with dementia: A systematic review

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## ABSTRACT

**Objectives:** Grief research in family carers of people with dementia has increased. We aimed to report the prevalence of pre-death and post-death grief and to synthesize associated factors and the relationship between pre-death factors and post-death grief and services used to manage grief.

**Design:** (Prospero protocol: CRD42020165071) We systematically reviewed literature from PsycINFO, MEDLINE, CINAHL, and ASSIA until April 2020. Effectiveness of intervention data and studies not written in English were excluded; qualitative studies were additionally excluded during study selection. Study quality was assessed using the Mixed Methods Appraisal Tool. Evidence was narratively summarized.

**Participants:** Family non-paid carers of somebody with any dementia type.

**Measurements:** Validated measures of pre-death and/or post-death grief.

**Results:** We included quantitative data from 55 studies (44 rated as high quality). Most included solely spouse or adult child carers. Forty-one studies reported pre-death grief, 12 post-death grief, and 6 service use; eight were longitudinal. 17% met the Prolonged Grief Disorder criteria pre-death ( $n = 1$ ) and 6–26% ( $n = 4$ ) of participants met the Complicated Grief criteria post-death. Being a spouse, less educated, caring for somebody with advanced dementia, and greater burden and depression were associated with higher pre-death grief. Lower education level and depression were predictive of higher post-death grief. Pre-death factors found to influence post-death grief were grief and depression. Limited service use evidence was reported.

**Conclusion:** Awareness of characteristics which increase the likelihood of higher grief can help identify those in need of support. Future research should focus on what supports or services are beneficial to grief experiences.

**Keywords:** Dementia, Carers, Grieving, Palliative Care

## Background

Dementia is the leading cause of death in the UK and the seventh commonest cause globally (World Health Organization, 2017). More than 80 billion hours of care a year are provided annually by informal carers. Dementia caregiving can have significant emotional implications for family carers, and the experience of grief while the person with dementia is still alive, known as pre-death grief (Blandin and

Pepin, 2017; Lindauer and Harvath, 2014), is particularly common.

As knowledge about pre-death grief in the context of dementia caring has increased in the literature, terms used to reflect this experience have also evolved moving from the concept of “anticipatory grief” to pre-death grief, which can also be referred to as “dementia grief.” There are many overlaps between anticipatory grief and pre-death grief; however, pre-death grief relates to losses experienced rather than anticipated and is thought to better encompass the important facets of pre-death grief for this population (Blandin and Pepin, 2017). Pre-death grief has been defined as “the emotional and physical response to the perceived losses in a valued care recipient. Family caregivers experience a variety

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of emotions (e.g. sorrow, anger, yearning and acceptance) that can wax and wane . . . from diagnosis to the end of life” (Lindauer and Harvath, 2014). Pre-death grief can occur due to the lengthy and uncertain dementia trajectory and can be triggered by losses associated with dementia such as compromised communication and changes in relationship quality and carer freedom (Lindauer and Harvath, 2014).

Bereavement and grief are a normal part of life; however, for a minority of people grief can interfere with everyday life and involve long-term severe reactions to the loss that impact on functioning. Researchers and clinicians have been attempting to differentiate between normative bereavement and pathological or disordered grief since the 1990s. A debate has ensued involving competing theoretical conceptualizations, diagnostic criteria, and psychometric measurement. The first diagnostic criteria for a bereavement related disorder were termed pathological grief (Horowitz *et al.*, 1993) which was then updated to Complicated Grief (CG) (Horowitz *et al.*, 1997). Different terminology has been used over time, but the terms CG and Prolonged Grief Disorder (PGD) have been most commonly used. Higher levels of grief prior to death are associated with PGD or CG after death (Chan *et al.*, 2013; Romero *et al.*, 2014). PGD is characterized by symptoms such as longing for and preoccupation with the deceased, emotional distress, and significant functional impairment for at least 6 months after the loss (Killikelly and Maercker, 2018). CG, while a very similar concept to PGD, is characterized by intense grief that lasts longer than would be expected according to social norms and impairment in daily functioning.

PGD has been associated with poor physical health, suicidality, reduced quality of life, and functional impairment (Boelen and Smid, 2017). Although distinct from other mental health disorders, PGD can co-occur with depression, post-traumatic stress disorder, and anxiety (Boelen and Smid, 2017). While pre-death grief is not PGD, the intensity and duration of pre-death grief experienced by some may be consistent with definitions of PGD, and therefore research has begun to explore this using adapted versions of PGD measures (Pasconi *et al.*, 2015; Moore *et al.*, 2017)

In response to advancing research evidence, grief disorders have been included in two diagnostic classification systems. The DSM-5 introduced Persistent Complex Bereavement Disorder under the conditions for further study, which is a combination of PGD and CG criteria, while the International Classification of Disease 11<sup>th</sup> revision (ICD-11) introduced PGD as a disorder based largely on the

PGD criteria proposed by Prigerson *et al.* (2009). For the purpose of this paper, post-death grief will be reported using the terminology used in the original studies, that is, CG or prolonged grief.

The most recent systematic review that synthesizes the prevalence and associated factors of pre-death, post-death, and prolonged/CG was published in 2013 (Chan *et al.*, 2013). The review included 31 studies, many of which were of poor quality, and included only 1 study reporting the prevalence of PGD. Studies exploring the relationship between pre- and post-death grief were also limited within this review. They found that moderate to severe stage of dementia predicted pre-death grief, while being a spousal carer and being depressed were the biggest predictors of both normal post-death grief and prolonged grief post-death. Poor quality evidence suggested that between 47% and 71% experienced pre-death grief, and around 20% experienced CG. Since this review of studies published until 2009, research has further explored the experience of grief. This, in turn, adding to our understanding of the prevalence and predictors of grief.

We do not know how many carers need support either before or after the death of the person with dementia. Current grief services tend to target those who have experienced a recent death. The current bereavement model in the UK suggests that most people manage with support from family and friends, and without the need for professional intervention. However, it is unclear whether this model meets the needs of carers of people living with dementia (National Institute for Clinical Excellence, 2004). While the prevalence of CG is estimated between 10 and 20% (Lobb *et al.*, 2010), one in three carers of people living with dementia was found to access bereavement services (Bergman *et al.*, 2011) suggesting a higher proportion of carers seek professional support than the bereavement model indicates. It is also less known if carers of people living with dementia seek services for pre-death grief, although a recent study of current carers found that 30% had accessed formal counseling (Moore *et al.*, 2020).

In light of the newer definitions regarding pre-death grief, CG and PGD, and the wealth of research exploring these experiences, we aimed to update and extend the review by Chan (2013). We aimed to seek answers to the following review questions:

In family carers of people living with dementia:

1. What is the prevalence of pre-death and prolonged/CG and when does it become a clinical disorder?
2. What are the factors associated with pre-death and prolonged/CG?

3. In longitudinal studies, what is the relationship between pre-death factors and post-death prolonged/CG?
4. What services do carers use to manage grief?

This review does not examine effectiveness of grief interventions as this was addressed in a recent review (Wilson *et al.*, 2017).

## Methods

The review protocol CRD42020165071 was registered on PROSPERO international prospective register of systematic reviews and followed PRISMA guidelines (Moher *et al.*, 2009).

We initially planned to include qualitative studies and gray literature; however, due to the large volume of literature available we decided to limit our inclusion criteria to quantitative studies during full-text review.

## Inclusion criteria

- Type of studies: All quantitative studies or quantitative data from mixed methods studies. Studies were not excluded based on quality.
- Topic: Grief prevalence, relationship between pre- and post-death grief, factors associated with grief and services used to manage grief.
- Participants: Family or friend non-paid carers (aged 18 or over) of people with dementia.
- Setting: Participants were providing care or support for somebody living with any type and severity of dementia in the community or in long-term care facilities. Bereaved carers were also included.

## Exclusion criteria

- Effectiveness of intervention data
- Studies not written in English
- Paid/professional carers
- Qualitative data (excluded at full-text review)
- Gray literature (excluded at full-text review).

## Search strategy

We searched PsycINFO, MEDLINE, CINAHL, and ASSIA to April 2020. The search strategy was refined through test searches using medical subject headings and free-text terms. The search included keywords and terms associated with dementia, grief and family carers as shown in Supplementary File 1.

## Selection of studies

Abstracts of identified citations were independently screened by two reviewers (either SC and KM, or

SC and NK) to ensure consistency when applying the inclusion criteria. Interrater reliability of full-text selection was calculated using Cohen's kappa (K) and ranged from moderate (93.3% agreement) to nearly perfect (97.8% agreement) between the author combinations (Landis and Koch, 1977). Full texts of citations were checked for eligibility by two reviewers, and any discrepancies resolved through discussion with all three reviewers.

## Data extraction

Characteristics of the studies were extracted by SC into a table developed for this review. Extracted data included country of origin, study design, details of grief measurement tools used, participant characteristics, and results such as relationship between factors associated with and prevalence of pre- and post-death grief, and services used by carers to manage grief. Two authors (KM, NK) independently checked 20% of data extraction.

## Quality assessment

The Mixed Methods Appraisal Tool (MMAT) 2018 revised version with improved content validity was used to assess the quality of included studies (Hong *et al.*, 2018). The MMAT appraises and describes the quality for three methodological domains: mixed, qualitative, and quantitative (subdivided into three sub-domains: randomized controlled, non-randomized, and descriptive). Authors are advised to present how studies meet the quality criterion appropriate to their study type. All studies were assessed using the tool, and 20% were checked by a second author (KM, NK, EW) with any discrepancies discussed and resolved.

## Data analysis

The Cochrane framework for summarizing study characteristics and synthesizing data was implemented. At protocol stage, questions were defined, and planned analyses proposed; evidence for Q1 was synthesized based on the measure of grief and the cut-off scores used in studies. Q2 was addressed by summarizing associations with grief and exploring subgroup differences such as differences in carer and the person living with dementia characteristics and experience of grief such as gender, ethnicity, age, relationship to the person living with dementia, and dementia severity. Longitudinal evidence for Q3 was summarized to describe the impact of carer and care-related factors assessed before the death of the person living with dementia on post-death grief. Services used to manage grief were described to address question Q4.

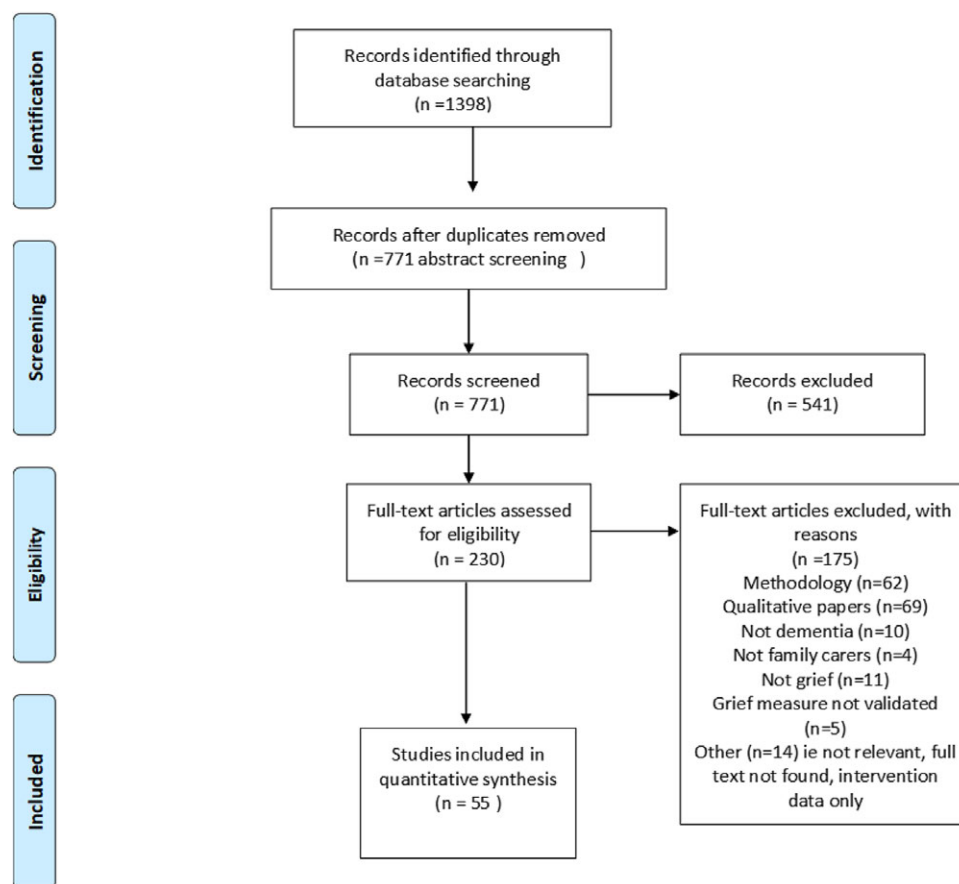


Figure 1. PRISMA diagram.

Associations were tabulated and a narrative summary was provided of evidence from studies which met at least four out of five of the MMAT quality criteria. Associations were discussed within the narrative summary if there were at least three studies reporting a factor for pre-death grief, while all factors were discussed for post-death grief as there were fewer included studies. Where associations were reported, factors were discussed within domains which were identified from the evidence: demographic carer factors; psychosocial characteristics; person living with dementia and care-related factors; and bereavement factors.

## Results

We identified 771 unique citations after removing 134 duplicates, of which 230 met our inclusion criteria for full-text review. Fifty-five quantitative and mixed methods studies were included. Only quantitative data were included from mixed methods studies as demonstrated in the PRISMA diagram (Moher *et al.*, 2009) (Figure 1).

## Sample size and characteristics

The majority of studies were conducted in the USA ( $n = 33$ ), seven in Europe, six in Singapore, three in Hong Kong, three in Canada, and one study each in Australia, Puerto Rico, and South Korea. Studies mainly consisted of spouse or adult child carers. Thirty-four studies reported dementia severity of the care recipient; 13 studies included moderate to severe dementia, 3 reported moderate, 3 reported advanced, and 10 included mild, moderate, and severe dementia. Forty studies reported pre-death grief, 11 post-death grief, 3 both pre- and post-death grief, and 6 service use. Eight of the 55 studies included longitudinal data. Pre-death grief was measured using the Marwit Meuser Caregiver Grief Inventory (MMCGI) ( $n = 11$ ), the MMCGI-Short Form (SF) ( $n = 14$ ), the PGD Scale pre loss (PG-12) ( $n = 1$ ), or the Inventory of PGD Scale short form pre-loss ( $n = 1$ ). Disordered post-death grief was measured using the Inventory of Complicated Grief ( $n = 8$ ) and the PGD Scale (PG-12) ( $n = 1$ ), while normal post-death grief was reported using the Texas Revised Inventory of Grief ( $n = 3$ ) (Table 1).

**Table 1.** Key findings

STUDY AND COUNTRY	DESIGN	PLWD			GRIEF SCORE/PREVALENCE OF GRIEF	REVIEW CONTRIBUTION MMAT
		(1) SAMPLE SIZE (2) SETTING (3) SAMPLE CHARACTERISTICS (GENDER, RELATIONSHIP TYPE)	(1) DEMENTIA TYPE (2) SEVERITY (3) RESIDENCE	(1) GRIEF MEASURE (2) TIME POINT		
Boerner 2004, USA	Prospective multi-site study: REACH <sup>a</sup>	(1) 217 bereaved FC (2) REACH <sup>a</sup> . (3) 84% female, 50% spouse, 50% other	(1) AD (2) MMSE M = 10.9, (SD = 7.2) moderate to severe impairment (3) Lived with FC	(1) TRIG (2) Post-death, average 15 weeks post-death	Post loss grief M = 3.2 (SD 0.8)	Q1 *****
Cheng 2019, Hong Kong	Cross-sectional survey	(1) 173 FC (2) Recruited via psychogeriatric clinics and from a master list of dyads with approximately 50 in each of the stages (3) 84% female, spouse 32%, adult children 59%, 9% other	(1) AD (2) 36% mild, 35% moderate, 29% severe (3) 64% living with FC	(1) CGS (2) Pre-death	<i>Total M by relationship:</i> Spouse = 27.56 (SD 8.26) Adult child = 29.73 (SD 9.10) <i>Total M by dementia severity:</i> Mild: 25.79 (SD 8.09) Moderate = 30.10 (SD 8.32) High = 31.96 (SD 9.16) M = 57.7 (SD 14.8)	Q1, Q2 *****
Cheung 2018, Hong Kong	Cross-sectional study using quota-sampling	(1) 108 FC (2) Recruited from 4 centers providing community elderly services (3) 79% female, 50% adult child, 50% spouse	(1) NR (2) Earlier stage = 67.6%. Later stage = 32.4% (FAST) (3) Community	(1) MMCGI (Cantonese translation) (2) Pre-death	Lower than cut-off 70, same as normative sample	Q1, Q2 *****
Epstein-Lublow 2012, USA	Cross-sectional exploratory cohort study	(1) 85 FC (2) Recruited via an inpatient geriatric psychiatry unit associated with a free-standing psychiatric hospital and outpatient (3) Whole sample: 65% female, 40% spouse	(1) NR (2) NR (3) 41 hospitalized, 44 outpatient	(1) The Inventory of Traumatic Grief; pre-loss version (2) Pre loss	Outpatient: M = 17.0 (SD 10.9) Hospitalized: M = 23.5 (SD 13.7) Both below cut-off of 25	Q1, Q2 *****
Hebert 2006, USA	Prospective multi-site study: REACH <sup>a</sup>	(1) 222 bereaved FC (2) REACH <sup>a</sup> . (3) 84% female, 50% spouse, 50% other	(1) AD (2) MMSE 10.9 (SD 7.2) moderate to severe impairment (3) Lived with FC	(1) ICG (2) Post-death	NR	Q2 *****
Hebert 2007, USA	Prospective multi-site study: REACH <sup>a</sup>	(1) 225 bereaved FC (2) REACH <sup>a</sup> (3) 84% female. Relationship; NR	(1) NR (2) NR (3) Lived with FC	(1) ICG (2) Post-death (median 15 weeks)	M = 18.4 (SD 12.8) Below cut-off of 25	Q1, Q3 *****



Table 1. Continued

STUDY AND COUNTRY	DESIGN	(1) SAMPLE SIZE (2) SETTING (3) SAMPLE CHARACTERISTICS (GENDER, RELATIONSHIP TYPE)	PLWD	(1) GRIEF MEASURE (2) TIME POINT	GRIEF SCORE/PREVALENCE OF GRIEF	REVIEW CONTRIBUTION MMAT	
			(1) DEMENTIA TYPE (2) SEVERITY (3) RESIDENCE				
Holland 2009, USA	Prospective multi-site study: REACH <sup>a</sup>	(1) 224 bereaved FC (2) REACH <sup>a</sup> (3) 84% female, 50% spouse, 50% adult child	(1) AD (2) NR (3) Lived with FC at recruitment	(1) ICG, TRIG (2) Post-death, M = 253 days after death	ICG M = 17.5 (SD 12.1) (below cut-off) TRIG M = 40.7 (SD 10.9)	Q1, Q2, Q3	*****
Liew 2017, Singapore	Cross-sectional cohort	(1) Same sample Liew 2019, 394 FC but excluded n = 9 (2) Recruited via dementia services of the two tertiary hospitals serving North East Singapore (3) Sample split; completed in Chinese language N = 103, English N = 291; overall sample; 60%, female, 86% adult child, 14% spouse	(1) NR (2) Overall sample mild n = 16%, moderate = 41%, severe 42% (3) Community	(1) MMCGI MMCGI-SF as part of full length (n103 Chinese language version) (2) Pre-death	MMCGI: Chinese language M = 144.1 (SD 28.0) English language M = 140.5 (SD 35.6) MMCGI-SF: Chinese language M = 51.9 (SD 10.6) and English language M = 51.5 (SD 13.5) All below cut-off for high grief	Q1	*****
Liew 2018, Singapore	Cross-sectional cohort, validation study	(1) 394 FC (2) Recruited via dementia services of the only two tertiary hospitals serving the North-Eastern population of Singapore. (88% response rate) (3) Sample split: derivation sample developed scale n = 179, validation sample tested n = 215. Total sample: 60% female, 86% adult child, 14% spouse	(1) NR (2) Total sample: Mild to moderate (57.1%) Severe (42.9%) (3) Community	(1) MMCGI MMCGI-BF (validated in this study) (2) Pre-death	Total sample MMCGI M = 141.4 (SD 33.8) lower than cut-off for high grief MMCGI BF validation sample (n = 215) M = 17.6 (SD 4.6) lower than cut-off of 21	Q1	*****
Liew 2019b, Singapore	Cross-sectional cohort study	(1) 403 (2) Recruited via dementia services of the only two tertiary hospitals serving the North-Eastern population of Singapore (3) Sample split: derivation sample n = 300, validation sample n = 103. Derivation sample gender: 60% female. Relationship: 88% adult child, 12% spouse. Validation sample; 59% male 82% adult child, 18% spouse.	(1) NR (2) Derivation: Mild 16%, Moderate 42%, Severe 42% Validation: Mild 13%, Moderate 40%, Severe 47% (3) Community	(1) MMCGI (2) Pre-death	Derivation sample (n = 300). M = 140.0 (SD 35.4). 18% high carer grief MMCGI > 175. 37% male Validation sample (n = 103). M = 44.1 (SD 28.0) 10.7% high grief	Q1, Q2	*****

**Table 1.** Continued

STUDY AND COUNTRY	DESIGN	(1) SAMPLE SIZE (2) SETTING (3) SAMPLE CHARACTERISTICS (GENDER, RELATIONSHIP TYPE)	PLWD	(1) GRIEF MEASURE (2) TIME POINT	GRIEF SCORE/PREVALENCE OF GRIEF	REVIEW CONTRIBUTION MMAT	
			(1) DEMENTIA TYPE (2) SEVERITY (3) RESIDENCE				
Liew 2019a, Singapore	Cross-sectional cohort, validation of tool	(1) 394 FC (2) Recruited via dementia services of the only two tertiary hospitals serving North East Singapore. (88% response rate). (3) Total sample: 60% female, 86% adult child, 14% spouse	(1) NR (2) Mild to moderate 57.1%, Severe 42.9% (3) Community	(1) MMCGI (2) Pre-death	Reported in Liew 2018	Q1	*****
McLennon 2014, USA	Mixed methods	(1) 19 FC (2) Purposively selected to replicate sample used in the development of original instruments. Recruited via community agencies, adult-day care facilities, and grass-roots level methods (3) 84% female, 84% adult children, 16% spouse. African-American, primary carer	(1) AD (2) Mild 26%, Moderate 26%, Severe 47% (3) NR	(1) MMCGI-SF (2) Pre-death	M = 54.1 (SD 16.3) range = 26–86 PSB: M = 19.8 (SD 6.6) range = 7–30 HSF: M = 19.8 (SD 5.9) range 6–30 WFI: M = 14.4 (SD 5.5) range 7–28 All below cut-offs and normative sample	Q1	*****
Meichsner 2016, Germany	RCT, development of measure	(1) 229 FCs (2) Larger study via nationwide recruitment; newspapers and cooperating institutions (clinics, practices, home support services), television and radio, project homepage (3) 79% female, 59% spouse, 40% adult child	(1) AD 44% Vascular 10% FTD 6% Other/unknown 40% (2) NR (3) Living with FC	(1) CGS (2) Pre-death	M = 3.005 SD = 0.71 Emotional Pain M = 2.996 (SD 0.89) Relational Loss M = 3.777 (SD 1.20) Absolute Loss M = 1.982 (SD = 0.91) Acceptance of Loss M = 2.846 (SD = 0.68)	Q1, Q2	*****
Nam 2015, South Korea	Prospective multi-site study: REACH <sup>a</sup>	(1) 221 bereaved FC (2) REACH <sup>a</sup> . (3) 84% female, 50% spouse, 50% adult child	(1) AD (2) NR (3) Lived with FC at time points post-recruitment	(1) ICG (2) Post-death, 3 death	26% persistently high grief, 74% low grief (M = NR)	Q1, Q2	*****
Ott 2007, USA	Cross-sectional survey	(1) 201 (2) Recruited via support groups and memory loss clinics (3) 81% female, 45% spouse, 55% adult child	(1) AD (2) Mild/mod 27%, Mod/severe 46%, Severe 26% (3) 48% home, 52% out of home	(1) MMCGI-SF (2) Pre-death	Overall M NR All subscale Ms below cut-offs for risk of high grief 22% risk of high grief on at least one subscale, reported in Sanders <i>et al</i> 2008	Q1, Q2	*****

Table 1. Continued

STUDY AND COUNTRY	DESIGN	(1) SAMPLE SIZE (2) SETTING (3) SAMPLE CHARACTERISTICS (GENDER, RELATIONSHIP TYPE)	PLWD	(1) GRIEF MEASURE (2) TIME POINT	GRIEF SCORE/PREVALENCE OF GRIEF	REVIEW CONTRIBUTION MMAT	
			(1) DEMENTIA TYPE (2) SEVERITY (3) RESIDENCE				
Romero 2013, USA	Longitudinal cross-sectional (continuation of Ott 2007)	(1) 66 bereaved FC (2) Recruited via support groups and memory loss clinics. (3) 88% female, 56% adult child, 44% spouse	(1) AD (2) NR (3) NR	(1) MMCGI-SF, ICG-R (2) Pre-death, post-death-average 13 months since death	Pre-death: MMCGI M: 53.4 (SD 12.9) range 30–88. 14% (n = 9) scored above cut-off point of 70 Post-death: ICG-R M = 18.70 (SD 5.80) range 7–38 6% (n = 4) scored above cut-off point 30	Q1, Q2,	*****
Ross 2009, USA	Cross-sectional cohort	(1) 176 FC (dementia n = 138, cancer n = 38) (2) Recruited from central Alabama, central/western Georgia, and north/eastern Indiana (3) Dementia sample: 54% male, 62% adult child, 31% spouse, 7% other	(1) NR (2) NR (3) NR	(1) MMCGI-SF, The Loss Inventory (2) Pre-death	MMCGI Total M = 62.2 (SD 11.1) PSB: M = 20.6 (SD 4.2), HSL: M = 21.3 (SD 3.9), WFI = M = 20.3 (SD 4.5) Below cut-offs. Total, HSL and WFI higher than normative sample Loss inventory: Total M = 97.9 (SD 25.4) (validation study) M = 75.24 (SD 23.87)	Q1 Q2	*****
Schulz 2006, USA	Prospective multi-site study: REACH <sup>a</sup>	(1) 217 bereaved FC (2) REACH <sup>a</sup> . (3) 84% female, 50% spouse, 50% other	(1) AD (2) MMSE M = 10.3, (SD = 7.2) moderate to severe impairment (3) Lived with FC at recruitment	(1) ICG (2) Post-death	CG ≥ 30: N = 43 (19.8%)	Q1, Q2, Q3	*****
Stahl 2018, USA	Secondary analysis of 2 RCTs	(1) 308 bereaved FC (2) 223 from REACH <sup>a</sup> , 89 from FaCTS and 16 long-term care facilities in Western Pennsylvania (3) REACH <sup>a</sup> : 85% female, 50% spouse, 43% adult child, 7% other FaCTS: 62% female, 29% spouse, 52% adult child, 19% other	(1) REACH <sup>a</sup> : AD. FaCTS: NR (2) REACH <sup>a</sup> : Early/mid stage. FaCTS: Late stage (3) REACH <sup>a</sup> : 38% died in hospital, 30% died at home, 26% NH. FaCTS died in NH	(1) REACH <sup>a</sup> : ICG-32 item version in FaCTS: ICG-19 item (2) Post-death, both 107 days post-death	REACH <sup>a</sup> = 79.7 (SD 22.7) FaCTS = 14.3 (SD 10.9) Below 32 cut-off Both indicate mild levels of CG	Q1, Q2, Q3	*****



**Table 1. Continued**

STUDY AND COUNTRY	DESIGN	(1) SAMPLE SIZE (2) SETTING (3) SAMPLE CHARACTERISTICS (GENDER, RELATIONSHIP TYPE)	PLWD	(1) GRIEF MEASURE (2) TIME POINT	GRIEF SCORE/PREVALENCE OF GRIEF	REVIEW CONTRIBUTION MMAT
			(1) DEMENTIA TYPE (2) SEVERITY (3) RESIDENCE			
Adams 2004, USA	Mixed methods, cross-sectional	(1) 99 FC (same as Sanders <i>et al</i> 2005) (2) Randomly selected from community AA database (3) 70% female, 50% adult child, 35% spouse, 15% other	(1) AD = 71% other disease = 22% unknown = 7% (2) Early 25%, middle 41%, late 34% (3) 57% home, 22% NH, 16% assisted living, 5% other	(1) MMCGI (2) Pre-death	Overall sample NR By dementia stage: Total Grief early stage (n = 23) M = 149.83 (SD 33.7) middle stage (n = 43) M = 148.23 (SD 27.1) late stage (n = 29) M = 169.93 (SD 28.3). All under cut-off = 175 Late stage dementia “at-risk” for problematic grief reactions, higher than normative sample on total and all subscales M = 37.3, (SD 12.8), range = 19–86 (measured “never” as 1 instead of 0)	Q1, Q2 ****
Bergman 2011, USA	Prospective multi-site study: REACH <sup>a</sup>	(1) 224 bereaved FC (2) REACH <sup>a</sup> . (3) NR	(1) AD (2) NR (3) Lived with FC	(1) ICG (2) Post-death (average 3.3 months)	M = 4.37, (SD 3.45)	Q1, Q2, Q3, Q4 ****
Bindoff 1997, Australia		(1) 33/72 dementia FC (2) Recruited via ADARDS, media discussions, agency newsletters, support groups, and day care centers (3) 72% female; 51% spouse, 30% adult child, other 18%	(1) NR (2) NR (3) NR	(1) 6 item grief scale (2) Pre-death		Q1 ****
Chan 2017, Hong Kong	Cohort quantitative	(1) 120 FC (2) Recruited from two community-based day care centers and a memory clinic (3) 67% female, 67% adult children, 25% spouse, 8% other	(1) NR (2) FAST 6.8 (SD 2.81) (3) 57% living with FC	(1) MMCGI-SF (Chinese translation) (2) Pre-death	Total M = 48.78 (SD 13.83) PSB M = 17.13 (SD 5.42) HSL M = 16.49 (SD 5.15) WFI M = 15.16 (SD 4.70) Lower than cut-offs and, normative sample	Q1, Q2 ****
Chan 2019, Singapore	Cohort study	(1) 394 FC (2) Recruited by dementia services (outpatient memory clinic, inpatient geriatric psychiatry wards) of the only two tertiary hospitals serving the North-Eastern population of Singapore (3) 60% female, 86% adult children, 14% spouse	(1) NR (2) Mild to moderate 57.1%, severe 42.9% (3) 67% living with FC	(1) MMCGI (2) Pre-death	Total score M = 141.4 (SD 33.8), PSB M = 51.5 (SD 13.2) for PSB, HSL M = 74.8 (SD 19.3) WFI M = 15.2 (SD 4.0) for FI High scores > 175 (n = 65) 16%, Low scores < 175 (n = 329) 84%	Q1, Q3 ****

Table 1. Continued

STUDY AND COUNTRY	DESIGN	(1) SAMPLE SIZE (2) SETTING (3) SAMPLE CHARACTERISTICS (GENDER, RELATIONSHIP TYPE)	PLWD	(1) GRIEF MEASURE	GRIEF SCORE/PREVALENCE OF GRIEF	REVIEW CONTRIBUTION MMAT	
			(1) DEMENTIA TYPE (2) SEVERITY (3) RESIDENCE	(2) TIME POINT			
Crespo 2013, Spain	Cross-sectional survey	(1) 50 bereaved FC (2) Recruited from different Family Associations in Spain. (3) 88% female, 68% adult children 32% spouse. Primary carer	(1) NR (2) NR (3) NR	(1) TRIG present (2) Post-death (66% at least 1 year post-death)	Mean = 47.76 (SD 11.57) No clinical cut-off. Higher scores indicate lower grief. Lower grief than Spanish validation data of bereaved people for different death causes ( $t = -2.45$ , $df = 45$ , $p = 0.05$ , $d = -0.40$ )	Q1, Q4	****
Givens 2011, USA	Prospective cohort study	(1) 123 bereaved FC (2) Recruited through NHs (3) 61% female, 70% adult child, 7% spouse, 23% other	(1) NR (2) Died with advanced dementia (3) NH	(1) Modified PGD-12 pre loss (2) Pre-death, post-death 2 and 7 months	Pre-loss: (N = 122) m: 14.84 (SD 4.79) Post-loss: 2 month (N = 106) m: 15.86 (SD 5.19); 7 months (N = 123) m: 15.62 (SD 5.50) Low rate met full criteria for PGD (Stats NR)	Q1, Q2	****
Holley 2009, USA	Cross-sectional cohort	(1) 80 FC (2) Recruited from support groups, nursing homes, adverts, community physicians (3) 74% female, 26% spouse, 61% adult child, 12% other	(1) NR (2) Mean 5.36 (SD 0.96) (mid stage dementia on the FAST) (3) NR	(1) MMCGI, AGS (2) Pre-death	Reported in Holley 2010	Q1, Q2	****
Kiely et al. 2008, USA	Cross-sectional cohort study	(1) 315 carers (2) Recruited through NH (3) 63% female; 70% adult child; 10% spouse; 20% other	(1) NR (2) Severe functional disability (3) NH	(1) Modified PGD-12 pre loss version (10/12 items) (2) Pre-death	M = 15.0 (SD 5.6) (range: 10–49) Prevalence NR	Q1, Q2	****
Liew 2015, Singapore	Cross-sectional cohort study	(1) 72 FC (2) Recruited via consecutive sampling at a psychogeriatric clinic was conducted from July to November 2014 (3) 59% female, 93% adult child, 7% spouse	(1) NR (2) Mild 7% Moderate 39% Severe 54% (3) Community	(1) MMCGI (2) Pre-death	MMCGI total M = 148.6 (SD 31.5) higher than normative sample PSB: M = 56.3 (SD 13.1) Higher than normative sample HSL: M = 46.1 (SD 10.4) Lower than normative WFI: M = 46.2 (SD 10.3) Higher than normative NS difference to normative sample	Q1, Q2	****

**Table 1.** Continued

STUDY AND COUNTRY	DESIGN	(1) SAMPLE SIZE (2) SETTING (3) SAMPLE CHARACTERISTICS (GENDER, RELATIONSHIP TYPE)	PLWD	(1) GRIEF MEASURE (2) TIME POINT	GRIEF SCORE/PREVALENCE OF GRIEF	REVIEW CONTRIBUTION MMAT
			(1) DEMENTIA TYPE (2) SEVERITY (3) RESIDENCE			
Loos 1997, Canada	Mixed methods cross-sectional cohort	(1) 67 FC (2) Recruited via HCPs, community agencies, and media (3) 56% spouse, 21% adult child, 19% other	(1) 81% AD	(1) N/A (2) Pre-death	N/A	Q4 ****
MacCourt 2017, Canada	Controlled study of mixed methods design	(1) 200 FC (2) Recruited via local media and AA (3) Intervention (n = 123), control (n = 77). Whole sample: 79% female, 62% spouse, 23% adult child. 5% other	(1) AD or dementia (2) NR (3) NR	(1) MMCGI (2) Pre-death; pre- and post-intervention/control	Grief baseline: spouse M = 161.76 adult child M = 154.58 Below cut-off ≥ 175, higher than normative sample	Q1, Q2 ****
Marwit 2002, USA	Cross-sectional cohort developing scale	(1) 166 FC (2) Recruited via Memory and Aging Project, AA and Alzheimer list. 81% response rate (3) 81% female, 50% Spouse, 50% adult child	(1) AD 86% (2) CDR mean: 1.84 (SD 0.90) (3) 7% Assisted living, 28% NH, 64% other	(1) MMCGI (2) Pre-death	Total M = 144.01 (SD 31.57) PSB n = 154 M = 54.34 (SD 14.06) HSF: n = 151 M = 48.15 (SD 11.08) WFI: n = 159 M = 40.60 (SD 11.95) (scores provide “normative data” for the scale. MMCGI Scores in the average range (1 SD either side of M)	Q1, Q2 ****
Meichsner 2018, Germany	RCT	(1) 273 FCs (2) Part of larger study via nationwide recruitment, for example, newspapers and cooperating institutions (3) 81% female, 59% spouse, 38% adult child (may be overlap in sample Meichsner 2016)	(1) AD: 45%, vascular: 11%, FTD: 5% (2) Mild 3% Moderate 39% severe 38% very severe 20% (3) NR	(1) CGS (8/11 items included) (2) Pre-death	Intervention baseline n = 139 mean 3.732 (SD 0.848) range = 1.5–5 Control baseline n = 134 mean = 3.666 (SD 0.804) range = 1–5	Q1, Q2 ****

Table 1. Continued

STUDY AND COUNTRY	DESIGN	(1) SAMPLE SIZE (2) SETTING (3) SAMPLE CHARACTERISTICS (GENDER, RELATIONSHIP TYPE)	PLWD (1) DEMENTIA TYPE (2) SEVERITY (3) RESIDENCE	(1) GRIEF MEASURE (2) TIME POINT	GRIEF SCORE/PREVALENCE OF GRIEF	REVIEW CONTRIBUTION MMAT	
Moore 2017, UK	Longitudinal mixed methods cohort study	(1) 35 FC (2) Recruited across London identified by GP or care home manager. 52% response rate 12 FC were bereaved during the study (3) 69% female, 68% adult child, 20% spouse, 11% other	(1) NR (2) Advanced dementia (3) 17% living at home, 83% living in care home with nursing	(1) ICG (short form pre-loss) (2) Pre-death (baseline) f/u monthly until death. Post-death; 7 months post-death	Whole sample: Baseline median = 27 (IQR 22–37) final ax median = 24 (IQR 18–33) Score of 32 indicates high grief. 38% at study entry: 35% Non-bereaved carers at final pre-death ax 27% Bereaved carers at final pre-death ax and 22% 7 months post-death	Q1	****
Ott 2010, USA	Pilot study of RCT	(1) 20 FC (2) Recruited via community agencies, parish nurses, AA support groups sponsored, and adult care centers (3) 75% female, 100% spouse	(1)NR (2) Moderate to severe (3) 100% Living with FC at recruitment, 60% living with FC 3 months post-intervention	(1) MMCGI-SF (2) Pre-death; baseline, post intervention 5 months f/u, 8 months f/u	Grief at baseline for all (n = 20) M=56.68 (SD 11.28) CR Living at Home (n = 12) Baseline M = 51.8 (SD 10.26) Month 5 M = 47.7 (SD 10.18) Month 8 M = 46.8 (SD 10.47) CR Moved out of Home (n = 8) Baseline M=62.8 (SD 8.60) Month 5 M=57.9 (SD 10.50) Month 8 M=62.5 (SD 12.31) All Ms below cut-off	Q1, Q4	****
Park 2019, USA	Cross-sectional survey	(1) 606 FC (2) Recruited via LBDA, dementia organizations. (3) 89% female, 57% spouse, 38% adult child	(1) AD 12.9% PDD 12.4% DLB 74.8% (2) NR (3) NR	(1) MMCGI-SF (2) Pre-death	AD M = 58.7 (SD 14.8) range 23–87 PDD M = 59.6 (SD 13.1) range 5–83 DLB M = 61.5 (SD 13.1) range 26–90 All below cut-off of 70. DLB higher than normative sample	Q1, Q2	****
Passoni 2015, Italy	Cross-sectional cohort	(1) 90 primary FC (2) Recruited at the Alzheimer Evaluation Unit (3) 67% female, 58% spouse, 37% adult child, 5% other	(1) NR (2) MMSE M: 19.56 SD: 6.52 (3) Community	(1) PG-12 Italian translation (2) Pre-death	Prevalence of PGD: n = 15 (16.7%) As continuous variable, score range from 0 to 1 range (min: 0.03; max: 0.94), M = 0.532 (SD 0.25) FC with PGD M = 0.864 (SD 0.05); FC without PGD M = 0.465 (SD 0.21)	Q1, Q2	****

**Table 1.** Continued

STUDY AND COUNTRY	DESIGN	(1) SAMPLE SIZE	PLWD	(1) GRIEF	GRIEF SCORE/PREVALENCE OF GRIEF	REVIEW CONTRIBUTION MMAT	
		(2) SETTING	(1) DEMENTIA TYPE	MEASURE			
		(3) SAMPLE CHARACTERISTICS (GENDER, RELATIONSHIP TYPE)	(2) SEVERITY (3) RESIDENCE	(2) TIME POINT			
Sanders <i>et al</i> 2005, USA	Cross-sectional cohort	(1) 69 FC (2) Affiliated with a chapter of AA (3) 70% female, 50% adult child, 35% spouse, 15% other	(1) AD or other (2) NR (3) 57% at home, 22% NH, 16% assisted living, 5% other	(1) MMCGI (2) Pre-death	M = 155 (SD 30.5) higher than normative sample, 10% scored high total grief	Q1, Q2	****
Sanders <i>et al</i> 2008, USA	Mixed methods cross-sectional	(1) 201 FC (from Ott 2007 study) (2) Recruited via memory clinics, AA support groups, dementia networks (3) 86% female, 52% spouse, 48% adult child	(1) AD (2) Moderate/severe (3) 55% lived at home, 45% in LTC	(1) MMCGI-SF (2) Pre-death	Cut-offs determined by normative sample: N = 44 high grief on at least one subscale 77% scored high ( $\geq 24$ ) on the HSL scale, 59% PSB ( $\geq 25$ ), 39.8% on WFI ( $\geq 25$ )	Q1, Q2	****
Strong 2013, USA	Cross-sectional cohort	(1) 80 FC (2) Recruited via advertisements, support groups, nursing homes, community physicians (3) 73% female. Relationship; NR	(1) NR (2) Mild, moderate and severe (3) NR	(1) MMCGI (2) Pre-death	NR	Q2	****
Supiano 2017, USA	Mixed methods RCT	(1) 16 FCs (2) Control group recruited by larger study via grief and bereavement programs, AA, senior centers, LTC facilities and University of Utah (3) 87.5% female, 69% spouse, 25% adult child. Positive ICG-r score	(1) NR (2) NR (3) NR	(1) ICG-r (2) Post-death	100% had CG ( $>30$ ) Pre-intervention $m = 32.33$	Q1	****
Walker 1996, USA (same sample as Ponder 1997, Walker 1997)	Cross-sectional cohort	(1) 100 FC (2) Recruited from chapters of ADRDA and other community organizations (3) 83% female, 31% spouse, 69% adult child. Minimum 20 hours p/w care provided	(1) NR (2) Part A of the Memory and Behavior Problems Checklist: mean: 66.65 out of a possible 155 (3) Community	(1) NDRGEI (2) Pre-death	Reported above in Ponder 1997	Q2	****



Table 1. Continued

STUDY AND COUNTRY	DESIGN	(1) SAMPLE SIZE (2) SETTING (3) SAMPLE CHARACTERISTICS (GENDER, RELATIONSHIP TYPE)	PLWD (1) DEMENTIA TYPE (2) SEVERITY (3) RESIDENCE	(1) GRIEF MEASURE (2) TIME POINT	GRIEF SCORE/PREVALENCE OF GRIEF	REVIEW CONTRIBUTION MMAT	
Walker 1997, USA,	Cross-sectional cohort	(1) 100 FC (2) Recruited from chapters of ADRDA and other community organizations (3) 83% female, 31% spouse, 69% adult child. Minimum 20 hours p/w of care provided	(1) NR (2) Part A of the Memory and Behavior Pro- blems Checklist: mean: 66.65 out of a possible 155 (3) Community	(1) SGL, NDRGEI (2) Pre-death	Reported above in Ponder 1997	Q2, Q4	****
Warchol- Biedermann 2014, Poland	Cross-sectional cohort validation study	(1) 151 FC (2) Recruited online; advert, and Day Care and Rehabilitation Center for AD Patients in Poznan (3) 63% women, 55% spouse, 43% adult child, 2% other	(1) AD (2) severe: 46% moderate: 52%, mild: 2% (3) Community	(1) MMCGI (Polish translation) (2) Pre-death	M: 156.9; (SD 22.2) range: 106- 198 Mean is below cut-off $\geq 175$	Q1, Q2	****
Alvelo 2018, Puerto Rico	Cross-sectional valida- tion study	(1) 100 FC (2) Recruited via referrals/atten- dance at Dementia Workshop (3) 82% female, 47% spouse, 44% adult child, 9% other	(1) AD and other dementias (2) NR (3) 70% living with FC	(1) MMCGI-SF Spanish translation (2) Pre-death	M = 66.6, (SD 14.14) range: 23- 90. Below cut-off score of 70	Q1, Q2	***
Duggleby 2018, Canada	Mixed-methods single- arm repeated mea- sures feasibility	(1) 37 FC (2) Recruited via previous study involvement, advertisement, AA (3) 65% female, 30% spouse, 60% adult child, 10% other. Internet/ email using	(1) NR (2) NR; months in 24-h care mean: 37 (SD 22.5) (3) LTC	(1) NDRGEI (2) Pre-death; baseline, 1 month f/u, 2 month f/u	Total baseline: M = 55.2 (SD 21.1) 1 month f/u: M = 50.9 (SD 21.0) 2 month f/u M = 50.2 (SD 21.9) Higher scores indicate higher grief	Q1	***
Garand, 2012, USA	Cross-sectional cohort	(1) 30 FC dementia, 43 MCI (2) Recruited via ADRC patient and family caregiver registry as part of wider study. 66% response rate (3) AD FC: 90% female, 63% spouse. Primary carer	(1) AD (2) MMSE; M: 29.30 (SD 1.34) (3) Living with FC	(1) AGS (2) Pre-death	AD: M = 78.17 (SD 14.85). Range 40-114 Higher than mean reported by original study (Marwit 2002)	Q1	***
Holley 2010 (same sample as Holley 2009), USA	Cross-sectional cohort	(1) 80 FC (2) Recruited from support groups, nursing homes, adverts, com- munity physicians (3) 74% female, 26% spouse, 61% adult child, 12% other	(1) NR (2) Mean 5.36 (SD 0.96) (mid stage dementia on the FAST) (3) NR	(3) MMCGI, AGS (4) Pre-death	MMCGI total sample: M = 144.13 (SD 36.84). Adult children n = 49 M = 142.02 (SD 38.52) Spouses n = 21 M = 145.48 (SD 30.94). AGS not reported All under cut-off scores, spouses higher than normative sample	Q1, Q2	***

**Table 1. Continued**

STUDY AND COUNTRY	DESIGN	(1) SAMPLE SIZE	PLWD	(1) GRIEF MEASURE	GRIEF SCORE/PREVALENCE OF GRIEF	REVIEW CONTRIBUTION MMAT	
		(2) SETTING	(1) DEMENTIA TYPE	(2) TIME POINT			
		(3) SAMPLE CHARACTERISTICS (GENDER, RELATIONSHIP TYPE)	(2) SEVERITY (3) RESIDENCE				
Jain 2019, USA		(1) 23 FC (2) Recruited via flyers, newsletters, advertisements, and presentations at local support groups for a pilot feasibility trial of guided imagery and mindfulness vs. relaxation (3) 91% female, 30% spouse, 70% adult child. Elevated depressive symptoms, primary carer	(1) NR (2) NR (3) 65% living with FC	(1) MMCGI-SF (2) Pre-death	M = 58.1(SD 11.7) Below cut-off 70, higher than normative sample	Q1	***
Johannson 2013, Sweden	Cross-sectional cohort	(1) 53 FC (2) 3 Swedish cities (3) Gender NR. 38% spouse, 55% adult children, 6% other	(1) AD 49% Vascular 21%, other 30% (2) NR (3) NH/dementia unit	(1) AGS (2) Pre-death	NR, item by item analysis only	Q1	***
Kobiske 2019, USA	Cross-sectional online survey, correlational	(1) 104 FC (2) Recruited via AA, Department of aging and disability, University Alzheimer's disease center, Alzheimer's network (3) 65% female, 100% partner	(1) Young onset dementia (2) NR (3) NR	(1) MMCGI-SF (2) Pre-death	M = 3.54 (SD 0.78) range 18–90	Q1	***
Marwit 2005, USA		(1) 292 FC (2) 96 from original MMCGI development sample who participated in a second administration, 114 who responded to an on-line administration of the 50-item scale, and 82 who took the 50-item scale as part of an independent study (2) 76%, 42% spouse, 51% adult child, 6% unknown	(1) 77% AD (2) Mild 32% Moderate 35% Severe 32% (1) NR	(1) MMCGI-SF (2) Pre-death	Total M = 57 (SD 12.9) HSL M = 20.2 (SD 5) PSB M = 20.2 (SD 5.3) WFI M = 16.6 (SD 5.2) Provides normative data for MMCGI-SF	Q1	***

Table 1. Continued

STUDY AND COUNTRY	DESIGN	(1) SAMPLE SIZE	PLWD	(1) GRIEF MEASURE	GRIEF SCORE/PREVALENCE OF GRIEF	REVIEW CONTRIBUTION MMAT
		(2) SETTING	(1) DEMENTIA TYPE	(2) TIME POINT		
		(3) SAMPLE CHARACTERISTICS (GENDER, RELATIONSHIP TYPE)	(2) SEVERITY (3) RESIDENCE			
Meuser 2001, USA	Exploratory mixed methods cohort, focus groups	(1) 87 FC (2) Recruited via Memory and Aging Project, AA, Alzheimer list, community volunteers (3) 77% female. 48% Spouse (71% current, 29% former), 52% Adult child (78% current, 22% former)	(1) AD 87%, vascular 6%, other 6% (2) Mild, moderate, severe (3) NR	(1) AGS (minus 3 items), MFG (2) Current and former carers	AGS M = 61, (SD 13) Many faces of grief: M = 142, (SD 52)	Q1 ***
Ponder 1997, USA	Cross-sectional cohort study	(1) 100 FC (same as Walker 1994, 1996) (2) Recruited from chapters of ADRDA and other community organizations. (3) 83% female, 31% spouse, 69% adult child. Minimum 20 hours p/w of care provided	(1) NR (2) Part A of the Memory and Behavior Problems Checklist: mean: 66.65/155 (3) Community	(1) SGI, NDRGEI (2) Pre-death	Intensity (GEI) M = 4.91 (SD 4.13) range = 0–16. NS difference to normative sample SGI Denial M = 14.54 (SD 4.0) range = 7–26 SGI Overinvolvement M = 16.03 (SD 3.7) range = 7–25 SGI Anger M = 13.05 (SD 3.9) range = 6–24 SGI Guilt M = 14.62 (SD 3.78) range = 6–27 SGI Acceptance M = 22.92 (SD 2.9) range = 16–30	Q1 ***
Pote 2018, USA	Cross-sectional cohort	(1) 90 FC (2) Recruited via American AA, Family Caregiver Alliance and caregivers.org (3) 73% female; 100% spouse	(1) AD = 60%, vascular = 14.4% other = 25.6% (2) NR (3) NR	(1) MMCGI-SF (2) Pre-death	NR	Q2 ***

AA, Alzheimer's Association; AD, Alzheimer's Disease; NH, Nursing home; MMCGI-SF, Marwit Mesuer Caregiver Grief Inventory-Short Form; FC, Family Carer; MMCGI BF, Marwit Meuser Caregiver Grief Inventory Brief Form; AGS, Anticipatory Grief Scale; PDG, pre-death grief; PS, perceived stress; ADRDA, Alzheimer's Disease and Related Disorders Association; LBDA, Lewy Body Dementia Association; PDD, Parkinson's disease with dementia; DLB, Dementia with Lewy Bodies; GI, Grief Intensity; RMBPC, Revised Memory and Behavior Problem Checklist; PE, Parameter estimate; REACH, Resources for Enhancing Alzheimer's Caregiver Health; FaCTs, Family Caregiver Transition Support; CDR, Clinical Dementia Rating; CG, complicated grief; NDRGEL, Non-Death Revised Grief Experience Inventory; SGI, Stage of Grief Inventory; CGS, Caregiver Grief Scale; MFG, Many Faces of Grief; TRIG Texas Revised Inventory of Grief.

<sup>a</sup>REACH (1996–2000 at six sites in the USA (Boston, MA; Birmingham, AL; Memphis, TN; Miami, FL; Philadelphia, PA; and Palo Alto, CA) Recruited through media, memory clinics, primary care clinics, and social services. Outreach efforts to the community at all sites included radio, television, targeted newsletters, public service announcements, and community presentations.

## Quality appraisal

As only quantitative data were included from mixed methods studies, the appropriate quantitative section was completed. Similarly, for RCT studies, as only data reporting grief prevalence or associated factors were included, either the non-randomized quantitative study or quantitative descriptive study component of the MMAT was more appropriate to complete than the RCT component. For the purpose of this review, a high-quality study was determined by studies meeting four or five of the MMAT criteria. Of the six studies where the quantitative descriptive component of the MMAT was completed, five studies were rated high quality. No studies met the criteria related to the sample being representative of the target population. Of the 49 studies assessed using the non-randomized quantitative study component, 16 studies met all the criteria, 23 studies met four of the five criteria, and 10 met 3/5. Twenty-five studies did not meet the criteria regarding representativeness of sample, 4 studies did not use appropriate measures to assess grief, and 12 studies did not control for confounders. Two studies did not have complete data (Table 2).

### Q1. What is the prevalence of pre-death and prolonged/CG and when does it become a clinical disorder?

**Pre-death grief:** Four studies (Chan Wei Xin *et al.*, 2019; Liew and Yap, 2018; Sanders and Adams, 2005; Ott *et al.*, 2007) reported the prevalence of pre-death grief data; 10–18% of participants were reported to be at risk of high grief based on the MMCGI or MMCGI-SF cut-off criteria of scores being one standard deviation above the mean (Marwit and Meuser, 2002). One study reported 16.7% met the criteria for PGD as assessed using the PG-12 before death (Passoni *et al.*, 2015); Givens (2011) used 11 items of the PG-12 and reported a low rate of participants met the criteria for PGD. Moore *et al.* (2017) reported 38% had a high occurrence of symptoms as assessed by the ICG short-form pre-loss version. See Supplementary File 2 for detailed prevalence data.

**Complicated grief:** 20–26% of participants were reported to meet the criteria of CG as assessed by the 19 item ICG (Schulz *et al.*, 2006; Nam, 2015). Two studies used revised versions of the ICG; Moore *et al.* (2017) reported 22% met the criteria of CG using a 16 item version, and Romero *et al.* (2013) reported 6% of participants met the criteria using a 15 item version.

**Prolonged grief:** Givens *et al.* (2011) reported a low rate of participants met the criteria for PGD as assessed using 11/12 item PG-12 (see Supplementary File 2)

### Q2. What factors associated with pre-death and prolonged/CG?

Pre-death and post-death associations are shown in Table 3.

#### PRE-DEATH ASSOCIATIONS (N = 31)

**Carer demographic factors Relationship type:** The evidence indicates being a spousal carer is associated with higher pre-death grief than adult children or other relationship types with 10/16 studies reporting significant findings. Two studies found interaction effects: Cheung *et al.* (2018) found spouses caring for someone in later stages had the highest grief, and Ott *et al.* (2007) found being a spouse was only associated with higher grief when the carer did not live with the person living with dementia.

**Lower education** was found to be associated with higher grief in most of the studies which explored education (Liew, 2015; Liew *et al.*, 2019a; Passoni *et al.*, 2015; Kiely *et al.*, 2008). However, one study (MacCourt *et al.* 2017) reported contradicting findings that not having a university education predicted lower grief and Marwit and Meuser (2002) found no association.

**Gender** was not found to be associated with grief (Kiely *et al.*, 2008; Passoni *et al.*, 2015; Sanders and Adams, 2005; Warchol-Biedermann *et al.*, 2014; Liew, 2015; Meichsner *et al.*, 2016; Meichsner and Wilz, 2018; Sanders *et al.*, 2008; Liew *et al.*, 2019b) with the only significant association reported by Passoni *et al.* (2015) who found being female was significantly associated with higher grief when gender was the only predictor.

**Ethnicity:** The included studies reported mixed evidence for the impact of ethnicity on grief. Ross and Dagley (2009) in a US-based study found African-Americans reported higher grief than white carers. Similarly, two Singapore-based studies found being of Malay ethnicity was associated with higher grief than Chinese/Indian/Eurasian/other ethnicities (Liew, 2015; Liew *et al.*, 2019b). However, two US studies with a majority of white sample found no association with ethnicity (Kiely *et al.*, 2008; Sanders and Adams, 2005).

**Age:** Carer age was not independently associated with total grief scores, with only one study reporting an association between older carer age and grief when age was combined into a demographic variable with education and caring time (Passoni *et al.*, 2015).

**Care-related features Living situation:** Evidence was mixed regarding living situation of the person living with dementia and grief. Caring for someone who was hospitalized (Epstein-Lubow *et al.*, 2012), living

**Table 2.** MMAT results

QUANTITATIVE NON-RANDOMIZED STUDY (N = 49) <i>Studies involving some statistical comparison of data</i>		QUANTITATIVE DESCRIPTIVE STUDY (N = 6) <i>Studies reporting descriptive/prevalence data</i>	
CRITERIA	STUDIES MEETING CRITERIA	CRITERIA	STUDIES MEETING CRITERIA
Are participants representative of target population	25 (51%)	Is the sample strategy relevant	6 (100%)
Are measurements appropriate	46 (94%)	Is the sample representative	0
Are there complete outcome data (80%)	47 (96%)	Are measurements appropriate	6 (100%)
Are confounders accounted for	37 (75%)	Is the risk of nonresponse bias low	5 (83%)
Did the exposure occur as intended	49 (100%)	Is the statistical analysis appropriate	6 (100%)
Number of criteria met by studies	5/5 criteria (n = 19) 4/5 criteria (n = 20) 3/5 criteria (n = 9) 2/5 criteria (n = 1)	Number of criteria met by studies	4/5 criteria (n = 5) 3/5 criteria (n = 1)

with the person before institutionalization (Kiely *et al.*, 2008), and currently living with the person (Liew *et al.*, 2019b; Meichsner *et al.*, 2016; Meichsner and Wilz, 2018) were found to be associated with higher grief. Whereas no associations were found between grief and living with the person in two studies (Cheng *et al.*, 2019; Warchol-Biedermann *et al.*, 2014) or whether the person lived at home or in residential settings and grief (Sanders and Adams, 2005; Sanders *et al.*, 2008).

**Duration of care** was not found to be associated with grief (Liew, 2015; Cheng *et al.*, 2019; Liew *et al.*, 2019b; Sanders and Adams, 2005; Kiely *et al.*, 2008; Meichsner *et al.*, 2016; Passoni *et al.*, 2015).

**Primary carer:** Being the primary carer was mainly found to be associated with higher grief (Liew *et al.*, 2019b; Liew *et al.*, 2019a; Chan *et al.*, 2017).

**Amount of care provided:** The studies report mixed evidence for an association between providing daily care or amount of time spent providing care and grief. Liew *et al.* (2019b) found providing daily care was associated with higher grief and Kiely *et al.* (2008) found an association with providing a minimum of 7 hours of care a week. However, no association was found between perceived amount of care provided and grief (Liew, 2015; Marwit and Meuser, 2002).

*Carer health and psychosocial factors* **Depression and burden:** Greater depression (Kiely *et al.*, 2008; Walker and Pomeroy, 1996; Ott *et al.*, 2007; Strong and Mast, 2013; Passoni *et al.*, 2015; Marwit and Meuser, 2002; Romero *et al.*, 2013; Liew, 2015;

Chan *et al.*, 2017; Meichsner *et al.*, 2016; Sanders and Adams, 2005; Chan Wei Xin *et al.*, 2019; Cheng *et al.*, 2019) and higher levels of burden (Liew, 2015; Cheng *et al.*, 2019; Cheung *et al.*, 2018; Holley and Mast, 2009; Passoni *et al.*, 2015; Chan Wei Xin *et al.*, 2019) were associated with higher grief.

**Coping styles:** Dysfunctional coping was found to be positively associated with grief (Romero *et al.*, 2013; Ott *et al.*, 2010). Additionally, Ott *et al.* (2007) found greater use of coping by emotional venting was associated with grief when the person lived at home, and coping by planning and self-blame were positively associated with grief when the person did not.

**Social support:** Elements of social support appear to have a positive impact on grief. Negative associations were found between grief and perceived social support (Chan *et al.*, 2017; Marwit and Meuser, 2002; Romero *et al.*, 2013) and an association was found between greater satisfaction with social relationships and lower grief (Meichsner *et al.*, 2016). Support was reported to buffer the effect of grief and mediate the negative relationship between grief and psychological well-being in a study by Park *et al.* (2019). Social network size was not found to be associated with grief (Cheng *et al.*, 2019).

**Carer health problems:** The studies report mixed evidence as to whether greater health problems were associated with higher grief; two found significant positive associations (Walker and Pomeroy, 1997) and two reported no association (Cheng *et al.*, 2019; Kiely *et al.*, 2008) while Sanders and Adams (2005) reported an association for the MMCIGI sub-scale HSL only.



**Table 3.** Q2 Associations with pre-death and post-death grief

		PRE-DEATH GRIEF				POST-DEATH GRIEF			
		ASSOCIATION FOUND		NO ASSOCIATION FOUND		ASSOCIATION FOUND		NO ASSOCIATION FOUND	
SUB-DOMAIN		ADJUSTED ANALYSIS	NON-ADJUSTED ANALYSIS	ADJUSTED ANALYSIS	NON-ADJUSTED ANALYSIS	ADJUSTED ANALYSIS	NON-ADJUSTED ANALYSIS	ADJUSTED ANALYSIS	NON-ADJUSTED ANALYSIS
Carer demographics	Spouse carer	Liew 2015 M	Liew 2019b H	Adams 2004	Sanders 2008	Holland 2009 H	Givens 2011 H	Stahl 2018 <sup>f</sup>	Schulz 2006
		Liew 2019b H	Cheung 2018 H		Passoni 2015	Stahl 2018 M <sup>e</sup>		Givens 2011	Nam 2015
		Liew 2019a M	Romero 2013 M	Ott 2007 <sup>a</sup>	Kiely 2008	Romero 2013 M		Schulz 2006	
		Cheung 2018 H	MacCourt 2017 M		Warchol-Biedermann 2014				
		Meichsner 2016 H	Chan 2017 H		Sanders 2005				
		Meichsner 2018 H	Chan 2019						
		Ott 2007 <sup>b</sup> M	<i>Johannson 2013 M</i>						
	Lower education	Liew 2019a M	Liew 2019b M	Liew 2019b	Marwitt 2002	Holland 2009 M	Nam 2015 M	Stahl 2018 <sup>f</sup>	Givens 2011
		Liew 2015 M	Liew 2015 M	Passoni 2015 H		Stahl 2018 M <sup>e</sup>	Bergman 2011 M		Schulz 2006 M
			Kiely 2008 M	-MacCourt 2017 M					
	Gender: Female		Passoni 2015 H	Meichsner 2016	Liew 2019b Sanders 2008			Stahl 2018 <sup>ef</sup>	Bergman 2011
				Meichsner 2018	Liew 2015 Kiely 2008			Schulz 2006	Holland 2009
				Passoni 2015	Warchol-Biedermann 2014				Givens 2011
					Sanders 2005				Schulz 2006
					<i>Pote 2018</i>				
	Ethnicity	Liew 2015 M	Liew 2019b M		Liew 2015	Holland 2009 M		Stahl 2018	Bergman 2011
		Ross 2009 M			Kiely 2008			Schulz 2006	Givens 2011
					Sanders 2005				Schulz 2006
					<i>Pote 2018</i>				

**Table 3. Continued**

SUB-DOMAIN	PRE-DEATH GRIEF				POST-DEATH GRIEF			
	ASSOCIATION FOUND		NO ASSOCIATION FOUND		ASSOCIATION FOUND		NO ASSOCIATION FOUND	
	ADJUSTED ANALYSIS	NON-ADJUSTED ANALYSIS	ADJUSTED ANALYSIS	NON-ADJUSTED ANALYSIS	ADJUSTED ANALYSIS	NON-ADJUSTED ANALYSIS	ADJUSTED ANALYSIS	NON-ADJUSTED ANALYSIS
Younger age	Strong 2013 M <sup>c</sup>	-Liew 2019b M	Liew 2019b	Marwitt 2002 Liew 2015 Passoni 2015 Kiely 2008 Warchol-Biedermann 2014 Sanders 2005 <i>Pote 2018</i> 2019 Kiely 2008	Holland 2009 H Stahl 2018 H <sup>e</sup>	Nam 2015 Schulz 2006	Stahl 2018 <sup>f</sup> Schulz 2006	Bergman 2011 Givens 2011
Greater health problems		Meichsner 2016 H Walker 1997 M Sanders 2005 M <sup>c</sup>		Ott 2007 <sup>ab</sup> Liew 2015 Liew 2015 Kiely 2008				
Marital status: Married		Liew 2019b M Kiely 2008 M						
Not employed		Liew 2019b M						
Primary language not English		Kiely 2008 H						
Greater economic hardship				<i>Pote 2018</i>		Schulz 2006 M	Schulz 2006	Nam 2015
Marriage length				<i>Pote 2018</i>				
Care related features	Living situation	Epstein-Lublow 2012 M Meichsner 2016 M Meichsner 2018 M Kiely 2008 M Ott 2007 <sup>ab</sup> M-H	Epstein-Lublow 2012 M Kiely 2008 H Liew 2019b M	Liew 2019b Sanders 2008 Cheng 2019 Warchol-Biedermann 2014 Sanders 2005				

**Table 3.** Continued

SUB-DOMAIN	PRE-DEATH GRIEF				POST-DEATH GRIEF			
	ASSOCIATION FOUND		NO ASSOCIATION FOUND		ASSOCIATION FOUND		NO ASSOCIATION FOUND	
	ADJUSTED ANALYSIS	NON-ADJUSTED ANALYSIS	ADJUSTED ANALYSIS	NON-ADJUSTED ANALYSIS	ADJUSTED ANALYSIS	NON-ADJUSTED ANALYSIS	ADJUSTED ANALYSIS	NON-ADJUSTED ANALYSIS
Duration of care			Meichsner 2016	Liew 2019b Cheng 2019 Liew 2015 Passoni 2015 Kiely 2008 Sanders 2005 Jain 2019				
Providing daily care/ higher amount of care	Liew 2019b M	Liew 2019b M Kiely 2008 H	Ott 2007 <sup>ab</sup> Kiely 2008 Holley 2010	Marwit 2002 Liew 2015 Holley 2010 Jain 2019 Liew 2015				
Primary carer	Liew 2019a M	Liew 2019b M Chan 2017M Walker 1997 M <sup>c</sup>						
Expectation to insti- tutionalize								
Less satisfaction with care	Kiely 2008 M	Kiely 2008 H						
Greater perceived deterioration		Passoni 2015 M						
Less close relation- ship than cancer carers		Johannson 2013 M						
Dr Discussed Advanced Directives		Kiely 2008 M						
Communication/ preparation <sup>c</sup>				Kiely 2008				
Move to care home				Ott 2010				
Supported with care				Pote 2018				
Supporting children				Pote 2018				
Change in work circumstances				Warchol-Bieder- mann 2014				
% of free time devoted to care				Warchol-Bieder- mann 2014				
Changes to marital status				Warchol-Bieder- mann 2014				
Distance lived				Marwitt 2002				

**Table 3.** Continued

		PRE-DEATH GRIEF				POST-DEATH GRIEF			
		ASSOCIATION FOUND		NO ASSOCIATION FOUND		ASSOCIATION FOUND		NO ASSOCIATION FOUND	
SUB-DOMAIN		ADJUSTED ANALYSIS	NON-ADJUSTED ANALYSIS	ADJUSTED ANALYSIS	NON-ADJUSTED ANALYSIS	ADJUSTED ANALYSIS	NON-ADJUSTED ANALYSIS	ADJUSTED ANALYSIS	NON-ADJUSTED ANALYSIS
Psychosocial factors	Greater depression	Ott 2007 <sup>a</sup> M <sup>b</sup> H Strong 2013 <sup>c</sup> M Walker 1996 H Kiely 2008 H	Marwit 2002 M Meichsner 2016 H Romero 2013 H Liew 2015 H Chan 2017 H Passoni 2015 H Sanders 2005 H <sup>c</sup> Chan 2019 H Cheng 2019 H <i>Alvelo 2018 H</i> <i>Park 2019 H</i> <i>Jain 2019 H</i>	Passoni 2015	Strong 2013	Schulz 2006 H	Bergman 2011 H Givens 2011 H Schulz 2006 H	Givens 2011	
	Social support	<i>Kobiske 2019 M</i> <i>Park 2019 H</i>	Marwitt 2002 M Meichsner 2016 H Romero 2013 M Chan 2017 H <i>Alvelo 2018 H</i>	Ott 2007 <sup>ab</sup>	Cheng 2019		Nam 2015 M <sup>h</sup> H <sup>g</sup> Bergman 2011 H <sup>i</sup> M <sup>k</sup>		Nam 2015 <sup>ij</sup>
	Greater burden		Cheung 2018 H Cheng 2019 H Liew 2015 H Passoni 2015 M Holley 2009 H Chan 2019						
	Lower well-being		Cheung 2018 H Marwit 2002 M <i>Duggleby H</i>						
	Greater anxiety	Passoni 2015 M	Meichsner 2016 H				Bergman 2011 H Schulz 2006 M	Schulz 2006	
	Type of coping style	Ott 2007 <sup>ab</sup> M	Romero 2013 H Ott 2010 M						
	Greater positive state of mind	Ott 2007 <sup>a</sup> H	Romero 2013 H	Ott 2007 <sup>b</sup>					
	Greater Strain		Marwit 2002 M Chan 2017 H <i>Alvelo 2019 H</i>						

**Table 3.** Continued

SUB-DOMAIN	PRE-DEATH GRIEF				POST-DEATH GRIEF				
	ASSOCIATION FOUND		NO ASSOCIATION FOUND		ASSOCIATION FOUND		NO ASSOCIATION FOUND		
	ADJUSTED ANALYSIS	NON-ADJUSTED ANALYSIS	ADJUSTED ANALYSIS	NON-ADJUSTED ANALYSIS	ADJUSTED ANALYSIS	NON-ADJUSTED ANALYSIS	ADJUSTED ANALYSIS	NON-ADJUSTED ANALYSIS	
Person living with dementia features	Declining satisfaction with life		Walker 1997 H <i>Pote 2018 H</i>						
	Greater stress		<i>Kobiske 2019 H</i>						
	Greater distress		Walker 1997 M						
	Greater attachment		<i>Pote 2018 H</i>						
	Lower perceived closeness		<i>Johannson 2013 M</i> <i>Pote 2018 H</i>						
	Positive aspects of care						Chan 2019		
	Greater dementia severity	Liew 2019b M Liew 2019a H Adams 2004 M <sup>c</sup>	Liew 2019b M Marwit 2002 M Sanders 2008 M Warchol-Biedermann 2014 H Chan 2019 <i>Ponder 1997 H</i>	Meichsner 2016 Ott 2007 <sup>ab</sup> <i>Holley 2010</i>	Strong 2013 Chan 2017 Passoni 2015 <i>Holley 2010</i>				
	Greater behavioural problems/NPS	Liew 2019b M Liew 2019a H	Liew 2019b H Cheng 2019 H Sanders 2005 H <sup>c</sup>	<i>Holley 2010</i>	<i>Holley 2010</i>				
	Younger age	Liew 2019a M Kiely 2008 H	Kiely 2008 H		Liew 2019b Liew 2015 Passoni 2015				
	Less duration of dementia		<i>Meuser 2001 H</i>	Meichsner 2016	Liew 2019b Marwitt 2002 Liew 2015				
	Greater ADL/IADL impairments		Cheng 2019 M	<i>Holley 2010</i>	<i>Holley 2010</i>				
	Gender: Female				Liew 2019b Liew 2015 Kiely 2008	Schulz 2006 M		Schulz 2006	
	Age at diagnosis				Liew 2019b Liew 2015				
Dementia type				<i>Pote 2018</i> <i>Park 2019</i>					



**Table 3.** Continued

SUB-DOMAIN	PRE-DEATH GRIEF				POST-DEATH GRIEF			
	ASSOCIATION FOUND		NO ASSOCIATION FOUND		ASSOCIATION FOUND		NO ASSOCIATION FOUND	
	ADJUSTED ANALYSIS	NON-ADJUSTED ANALYSIS	ADJUSTED ANALYSIS	NON-ADJUSTED ANALYSIS	ADJUSTED ANALYSIS	NON-ADJUSTED ANALYSIS	ADJUSTED ANALYSIS	NON-ADJUSTED ANALYSIS
			Kiely 2008					
Bereavement factors	In special care unit, length of stay						Schulz 2006	Schulz 2006
	Education							Schulz 2006
	Ethnicity					Hebert 2006 M	Nam 2015 H	Stahl 2018 <sup>f</sup>
	Carer unprepared for death					Stahl 2018 H <sup>c</sup>		
	Lower levels of carer relief					Stahl 2018 H <sup>ef</sup>	Nam 2015 M	
	Less time since death					Holland 2009 M Schulz 2006 H	Schulz 2006 M	Stahl 2018 <sup>ef</sup> Romero 2013
	Greater anti-depressant use					Schulz 2006 M	Schulz 2006	
	Greater anxiolytics use					Schulz 2006 M	Schulz 2006	

M = Moderate statistical strength  $p < 0.5$ ; H = High statistical strength  $p < 0.01$ , *low quality study*.

<sup>a</sup>FC living with CR, <sup>b</sup>FC not living with CR, <sup>c</sup>significant for at least one grief subscale, <sup>d</sup>in one of two studies reported, <sup>e</sup>REACH sample, <sup>f</sup>FaCTS sample, <sup>g</sup>negative interactions, <sup>h</sup>social activities, <sup>i</sup>satisfaction with social support, <sup>j</sup>social support, <sup>k</sup>social network.

*Person living with dementia related factors* **Dementia severity:** Mixed findings were reported for the impact of dementia severity and grief. Eleven studies explored severity, and associations between greater dementia severity and higher grief were found in seven (Adams and Sanders, 2004; Liew *et al.*, 2019b; Liew *et al.*, 2019a; Marwit and Meuser, 2002; Sanders *et al.*, 2008; Warchol-Biedermann *et al.*, 2014; Chan Wei Xin *et al.*, 2019). One study (Chan *et al.*, 2017) found dementia severity was only associated with grief for spouse carers and four studies found no association (Meichsner *et al.*, 2016; Ott *et al.*, 2007; Passoni *et al.*, 2015; Strong and Mast, 2013)

**Behavioral problems/neuropsychiatric symptoms:** There was some indication that behavioral problems or neuropsychiatric symptoms were associated with higher grief; severe behavioral problems (Liew *et al.*, 2019a; Liew *et al.*, 2019b) and disruptive behaviors and psychotic symptoms (Cheng *et al.*, 2019) were associated with higher grief.

**Age of person living with dementia:** Evidence was mixed regarding younger age of the person living with dementia and carer grief.

**Duration of dementia** was not found to be significantly associated with grief (Liew, 2015; Liew *et al.*, 2019b; Marwit and Meuser, 2002; Meichsner *et al.*, 2016).

**Gender of person living with dementia** was also not associated with grief (Kiely *et al.*, 2008; Liew, 2015; Liew *et al.*, 2019b).

#### ASSOCIATIONS WITH CG/PGD (N = 6)

*Carer demographic and care-related factors* There was no association between carer gender and CG. Less education was mainly found to be associated with higher CG. Ethnicity was explored in five studies, with the evidence suggesting no association with grief. There was mixed evidence regarding whether being a spouse carer was associated with higher CG than adult children or other relationship types.

*Carer health and psychosocial factors post loss* **Post-death social support:** Surprisingly, Nam (2015) found participants with higher grief were more likely to participate in social activities and less likely to pursue negative interactions. Social support and satisfaction with support were not significant. Bergman *et al.* (2011) found satisfaction with support was strongly negatively associated with grief, and having less people in their social network was moderately associated with higher grief.

**Post-death depression:** Higher post-loss depression was associated with higher CG in all studies (Schulz *et al.*, 2006; Bergman *et al.*, 2011; Givens *et al.*, 2011).

*Bereavement factors* Mixed findings were reported regarding an association between time since death and grief. Schulz *et al.* (2006) and Holland *et al.* (2009) reported strong evidence that grief improved over time, while Stahl and Schulz (2018) and Romero *et al.* (2013) did not find associations. Retrospective reporting of being unprepared for the death (Hebert *et al.*, 2007; Nam, 2015; Stahl and Schulz, 2018) and lower levels of relief (Stahl and Schulz, 2018; Nam, 2015) were associated with higher grief.

#### Q3. In longitudinal studies, what is the relationship between pre-death factors and post-death prolonged/CG?

Associations from six longitudinal studies relating to this research question are shown in Table 4.

##### PRE-LOSS CARER FACTORS

Two studies explored pre-death grief (Givens *et al.*, 2011; Romero *et al.*, 2013) and both report strong evidence of an association between high pre-death and high post-death grief even when accounting for confounders. Romero *et al.* (2013) reported 34% of post-death grief was accounted for by pre-death grief. The evidence indicates pre-loss depression is associated with CG post-death, with all studies finding associations between higher depression and higher grief (Holland *et al.*, 2009; Bergman *et al.*, 2011; Givens *et al.*, 2011; Romero *et al.*, 2013; Schulz *et al.*, 2006; Boerner *et al.*, 2004).

Of the three studies (Givens *et al.*, 2011; Bergman *et al.*, 2011; Hebert *et al.*, 2007) which explored elements of religiosity, a significant negative association was only found between religious attendance and grief (Hebert *et al.*, 2007).

Two studies measured social support before and after the death. Romero *et al.* (2013) found no association between grief and social support. Hebert *et al.* (2007) found an increase in social integration from pre-loss to post-loss was associated with fewer grief symptoms. An increase in satisfaction with support pre- and post-death was not associated with grief.

Amount of care provided, believing the person had at least 6 months to live, and carer's understanding of the complications of dementia were explored in one study, and no associations with grief were found (Givens *et al.*, 2011).

##### PRE-LOSS PERSON LIVING WITH DEMENTIA FACTORS

Schulz *et al.* (2006) found that younger age, greater dementia severity, and a higher dependence in activities of daily living (ADLs) were all significant independent predictors of higher grief. When demographic and bereavement confounders were

**Table 4.** Q3 Associations between pre-death factors and post-death grief in longitudinal studies

		LONGITUDINAL STUDIES N = 6			
		ASSOCIATION FOUND		NO ASSOCIATION FOUND	
DOMAIN	SUB-DOMAIN	ADJUSTED ANALYSIS	NON-ADJUSTED ANALYSIS	ADJUSTED ANALYSIS	NON-ADJUSTED ANALYSIS
Carer related factors	Amount of care provided				Givens 2011
	Understood complications of dementia				Givens 2011
	Visited 4+ hours a week				Givens 2011
	Believed person living with dementia had 6 months to live				Givens 2011
	Living with the person before NH admission	Givens 2011 M	Givens 2011 H		
	Higher pre-death grief	Givens 2011 H Romero 2013 H	Romero 2013 H		
	Higher pre-death depression	Holland 2009 H Schulz 2006 M Romero 2013 H	Schulz 2006 H Romero 2013 H Givens 2011 H	Givens 2011	
	Pre-death anti-depressant use			Schulz 2006	Schulz 2006
	Greater pre-death anxiety		Schulz 2006 M	Schulz 2006	
	Greater pre-death burden	Schulz 2006 M	Schulz 2006 H		
	Pre-death anxiolytics use			Schulz 2006	Schulz 2006
	Pre-death positive aspects	Schulz 2006 H	Schulz 2006 M		
	Pre-death less positive state of mind			Romero 2013	
	Pre-death social support	Hebert 2007 H <sup>c</sup> M <sup>e</sup>		Romero 2013 Hebert 2007 <sup>d</sup>	
	Lower pre-death religious attendance	Hebert 2007 M			
	Pre-death prayer			Hebert 2007	
	Pre-death religiosity			Hebert 2007	Bergman 2011 Givens 2011
Greater pre-death dysfunctional coping		Romero 2013 H	Romero 2013		
Person living with dementia factors	Younger age at diagnosis		Schulz 2006 M Givens 2011 H	Schulz 2006 Givens 2011	
	Greater dementia severity		Schulz 2006 M	Stahl 2018 <sup>ab</sup>	Givens 2011
	Greater ADL/IADL impairments	Schulz 2006 M	Schulz 2006 M		
	Duration of dementia				Givens 2011
	Living in special care unit				Givens 2011
	Hospitalization before death		Givens 2011 H	Givens 2011	
	Hospice referral				Givens 2011
	Acute event				Givens 2011
Comfort				Givens 2011	

M = Moderate statistical strength  $p < 0.5$ , H = High statistical strength  $p < 0.01$ .

<sup>a</sup>REACH sample, <sup>b</sup>FaCTS sample, <sup>c</sup>negative interactions, <sup>d</sup>satisfaction with support, <sup>e</sup>social integration.

NH, nursing home; ADL, activities of daily living; IADL, instrumental activities of daily living.

controlled for, however, greater dementia severity and dependence in ADLs, and the person being female emerged as significant predictors of higher grief. However, Givens *et al.* (2011) and Stahl and Schulz (2018) both found dementia severity was not

associated with grief, with Givens *et al.* (2011) reporting younger age, having lived with the person prior to nursing home admission, and the person having been hospitalized in the last 90 days of life to be associated with higher grief.

#### Q4. What services do carers use to manage grief?

**Pre-death:** Walker and Pomeroy (1997) and Ott *et al.* (2010) reported support group attendance (36% and 35%, respectively). Ott *et al.* (2010) found nearly a third of participants used resources from dementia-related organization and 60% attended an adult care program. Loos and Bowd (1997) reported perceived helpfulness of services; family assistance was the most helpful (60%), followed by physicians (57%), friends (43%), Alzheimer's Society dementia charity (32%), support groups (22%), and nurses (22%). Kobiske *et al.* (2018) reported 56% of carers of someone living with young onset dementia had not received professional counseling.

**Post-death:** Bergman *et al.* (2011) reported 30% accessed at least one service (i.e. counseling, support group or psychotropic medication), 13% received either individual, family, or pastoral counseling, and 13% accessed a bereavement support group. Crespo *et al.* (2013) found 98% accessed professional help and 84% received support from non-formal sources. While only 16% accessed bereavement services, 38% reported a need to attend a bereavement-related service.

### Discussion

This review synthesizes quantitative data from an extensive and disparate body of international literature. We attempted to address four key research questions, however, the bulk of the evidence focused on determining associations with grief.

#### Q1. What is the prevalence of pre-death and prolonged/CG and when does it become a clinical disorder?

The most commonly used measure of grief was the MMCGI and MMCGI-SF. The majority of studies reported mean grief scores for the whole sample which does not indicate whether individual participants scored at risk of high grief. From the studies that did report individual risk, 10–18% scored above this normative cut-off score, which fits the statistics of the original study assessing grief using this measure (Marwit and Meuser, 2002). This suggests that a subsample of carers may need support at this stage. This is also likely to be at a time where grief is not recognized by society or family and friends and can lead to complex grief situations and feelings of isolation (Sanders *et al.*, 2007).

An important finding is that, despite an abundance of research into dementia carer grief, we are unable to determine the prevalence of carers experiencing high pre-death grief. This is reflective of pre-death grief being a described concept without

diagnostic criteria, and lack of a clinical tool to assess the experience. The MMCGI and MMCGI-SF allow comparisons with a normative sample score, which is statistically and not clinically driven. In the absence of a gold-standard screening tool, using this approach can identify carers who may be at risk of experiencing higher grief who are in need of further assessment, but may miss others in need of support but who score lower than the top 18%.

Indicators of disordered post-death grief are identified in the literature by the use of validated measures developed against a defined criteria; the ICG was most commonly used and determines indicators of pathological grief. The prevalence of CG ranged from 6 to 26% from four studies (although there is no validated cut-off score for the ICG-r). One study used a modified version of the PG-12 measure to assess PGD, and found a low rate of participants met the criteria. Subtle but key differences exist among the different criteria for PGD or CG and the algorithms applied to determine prevalence, and while PGD is a classified disorder in the ICD-11, there is not currently a validated tool which assesses all of the proposed criteria. Therefore, reported prevalence should be interpreted with caution and within the context of individual studies' criteria and assessment of grief (Lenferink *et al.*, 2019; Eisma *et al.*, 2020).

#### Q2. What factors are associated with pre-death and prolonged/CG?

Our findings build on the work of Chan 2013 and highlight that being a spouse carer, less educated, caring for somebody at a more severe stage of dementia, and higher levels of burden and depression are associated with greater pre-death grief. Studies exploring associations with post-death grief scores reported using the measures described above found that higher levels of pre-death grief and depression were predictive of higher post-death grief. Not being prepared for the death of the person and lower levels of carer education were also indicative of higher grief scores post-death. No studies conducted analysis to determine factors that were associated only with those who met the criteria for CG or PGD. There is mixed evidence for relationship type and post-death grief in comparison to pre-death grief, which may suggest that bereavement factors and other demographic or psychosocial variables have a stronger role post-death. Bereavement factors were less frequently explored in the reported studies, and it is unclear from the evidence whether time since death is associated with grief. Evidence for both pre-death and post-death grief suggests there is no relationship between carer gender and grief. Research in diverse samples is needed to

further understand the relationship between ethnicity and grief.

There is, however, a difficulty of determining which factors are most associated with grief, which lies within the complexity and interplay of different variables. Evidence is limited to the factors included in studies and the type of analyses carried out. Variations in associations could be in part attributed to study methodology and study participants, particularly as 12 studies did not meet the MMAT criteria for attempting to account for confounders. For example, in contrast to much of the evidence, Passoni *et al.* (2015) found relationship type had no direct impact on grief, and instead suggested the higher probability of spouses developing PGD can be attributed to sociodemographic or psychophysical features rather than being a spouse or adult child carer. Additionally, few studies explored how anxiety impacts on grief, but as evidence suggests carers do experience anxiety (Meichsner *et al.*, 2016; Passoni *et al.*, 2015; Bergman *et al.*, 2011; Schulz *et al.*, 2006) often at the level of a clinical disorder (Moore *et al.*, 2017), future studies should be including it as a potentially influencing factor, particularly exploring direction of causality and the role of predisposing factors such as personality type.

The different measures used to assess grief and associated variables can also make it difficult to interpret or generalize findings. This is particularly relevant where different elements of a concept are explored under a shared term. For example, various aspects of social support were measured ranging from one question determining network size to a 20-item scale designed to measure the extent to which the individual perceives their needs for support, information, and feedback are fulfilled. It is therefore unsurprising that there is mixed evidence about the impact of social support. However, there is indication that elements of social support have a positive impact on grief, and exploring the role of social support domains and grief will increase our knowledge on how to support carers with grief. A recent study exploring grief in family carers in palliative care found that while there were no differences in pre-death or post-death grief in relation to social support, social support moderated the relationship between them. This was significantly stronger for those with lower social support, suggesting that those with high pre-death grief and low social support were more likely to have high post-death grief (Axelsson *et al.*, 2020).

### **Q3. In longitudinal studies, what is the relationship between pre-death factors and post-death prolonged/CG?**

While only two studies (Givens *et al.*, 2011; Romero *et al.*, 2013) explored the relationship between

pre-death and post-death grief, they provide strong evidence that higher pre-death grief is associated with higher grief post-death. Higher pre-death depression was also associated with higher grief post-death. This highlights the importance of recognizing that carers may benefit from support with grief while they are still providing care. The need for grief support pre-death suggests that current grief and bereavement programs which target post-death grief may not be meeting the needs for this population. Further exploration of the role of social support and post-death grief is needed; Hebert *et al.* (2007) found an increase in social integration and having fewer negative social interactions were associated with lower post-death grief, while Nam (2015) found greater social activities were associated with higher grief. Nam (2015) interprets this finding within the context of the dual-process model, where social activities during bereavement may be indicative of a coping strategy.

### **Q4. What services do carers use to manage grief?**

Due to the little evidence on service use in the included studies, it is difficult to draw definitive conclusions to this question. Those that explored service use pre-death found that over a third of participants received counseling or attended a support group. An older study by Loos and Bowd (1997) found participants reported support from family as being the most helpful. Typically, grief services are offered post-death, with pre-death grief being less frequently screened for by services. Therefore, increasing awareness and understanding of pre-death grief could be a promising step in being able to support those experiencing it. A recent study exploring the usefulness and acceptability of an animation to raise awareness of grief found some benefits of recognizing and identifying experiences as grief in carers of people living with dementia (Scher *et al.*, 2021). Post-death service use was explored in just two studies where bereavement support groups and counseling were reported. Perhaps the most important finding was that self-reported need for bereavement services more than double the number of participants who used them (Crespo *et al.* 2013). Service evaluations may provide further insight into what services are being provided, who utilizes services, and the effectiveness of them.

#### STRENGTHS AND LIMITATIONS

We excluded non-English studies, qualitative studies and gray literature which may have meant we missed useful evidence. However, this study is able to provide an up-to-date reflection of what



demographic and psychosocial factors are important to the experience of grief. While the included studies were conducted in a range of countries, studies from lower middle-income countries are underrepresented. However, research from different cultures is emerging, and differences in grief experiences being reported; relationship type was not found to be significant for Polish carers, and the authors suggest this is reflective of three-generational living and emotional ties between adult children and their parents remaining strong (Warchol-Biedermann *et al.*, 2014). Similarly, Asian carers expressed more worry and felt isolation than the normative sample which was conducted in the USA (Liew, 2015). There were also very few longitudinal studies that explored grief over time or into bereavement, which would provide a richer understanding of the grief experience. In some studies by the same authors, it was difficult to determine if the same samples were being reported so there may be some over-reporting factors associated with grief (e.g. Liew and Yap (2018) and Liew *et al.* (2019a). The included studies were of high quality as determined by the MMAT, with 44/55 studies meeting at least 4 of the 5 quality criteria. However, 25 studies did not meet the criteria related to samples being representative as most cohort studies recruited from dementia-related clinical or information services rather than general population samples.

#### CLINICAL AND RESEARCH IMPLICATIONS

Tools such as the MMCGI may provide a useful screen to identify those at risk of high pre-grief, but awareness that certain demographic, psychosocial, and care recipient-related factors can influence the experience of grief will also be beneficial. While pre-death grief interventions are in their infancy, evidence from pilot studies indicates that interventions should be multifaceted and not increase carer burden due to the unique clinical presentation of pre-death grief in this population (Wilson *et al.*, 2017).

While there is a huge body of research reporting cross-sectional data on the factors associated with grief, a shift is needed toward research building on the evidence from the few promising intervention studies undertaken (Wilson *et al.*, 2017). For carers of people living with dementia living in care homes, a grief management intervention that involved group sessions with dementia education, communication skills, conflict management, and grief management skills demonstrated a reduction in the heartfelt sadness and longing subscale of the MMCGI (Paun *et al.*, 2015). Another intervention, aimed at carers caring for the person living at home, involved one to one counseling and reported promising grief-related benefits (Ott *et al.*, 2010). Future research should continue to build on these findings to identify what

individual components of grief interventions are most beneficial and who they are most beneficial for with regard to particular demographic and psychosocial factors. Utilizing standardized measures to assess grief and reporting those who are at risk of higher grief or who meet the criteria for Complicated or Prolonged Grief across the dementia caregiving trajectory will also further our understanding of who needs support and when.

#### Conclusion

This review builds on the previous findings of Chan *et al.* (2013) and synthesizes quantitative data exploring the grief experience of carers of people living with dementia. The findings indicate that particular demographic features and psychosocial characteristics play a role in grief for these family carers. Awareness of factors that increase the likelihood of experiencing higher levels of grief can help to identify those in need of support. Future research should consider the interplay of such factors and focus on potentially modifiable elements such as social support. There is limited evidence regarding service use and grief, and future research should also focus on what components of support or service provision are important for carers with regard to grief.

#### Conflict of interest

None.

#### Description of authors' roles

The review was designed and conducted by SC, KM, and NK. EW supported with the quality appraisal of studies, and ES contributed to the protocol. The manuscript was prepared by SC and critically reviewed and approved by all authors.

#### Acknowledgements

SC is part supported by Marie Curie, and NK is supported by Alzheimer's Society Junior Fellowship grant funding, AS-JF-17b-016.

#### Supplementary material

To view supplementary material for this article, please visit <https://doi.org/10.1017/S1041610221002787>

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