Original Articles and Reviews

Reducing Dementia Grief Through Psychosocial Interventions

A Systematic Review

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Abstract: This review assessed the existing dementia grief interventions for caregivers of persons with dementia (PwD) prior to physical death from September 2016 to September 2021. Electronic databases Web of Science (SSCI), PsycArticles, Psychology and Behavioral Sciences Collection, PsycINFO, PSYNDEX Literature with PSYNDEX Tests, and MEDLINE were searched. Fifty-five publications meeting predetermined criteria were screened of which 12 were included in this review. Included interventions were multifaceted and the intervention format was heterogeneous. There has been a vast increase in dementia grief interventions in the last 5 years implying that the concept has been recognized as a valid and important construct to describe the caregiver experience. Implementation research should be undertaken to explore how well the concept of dementia grief is known and recognized and how elements of the interventions are used in everyday mental health care.

Keywords: anticipatory grief, dementia, family caregivers, grief interventions

Caregivers of persons with dementia (PwD) experience intense feelings of loss prior to the physical death of the care recipient (Lindauer & Harvath, 2014). The losses carers experience are described as cyclical and build up in impact as the disease progresses (Blandin & Pepin, 2017). They are called "compounded serial losses" (Blandin & Pepin, 2017, p. 69). The decline of retentiveness and memory are mourned as well as changes in personality, lost and forgotten family history, or identity (Blandin & Pepin, 2017). This grieving experience encompasses feelings of ambiguity, disenfranchised grief, loss of companionship, freedom, and control, as well as anger and guilt, but also psychosocial reorganization and coping (Blandin & Pepin, 2017; Doka, 2008; Large & Slinger, 2015; Marwit & Meuser, 2005; Sanders et al., 2008). Lindauer and Harvath (2014) list four factors contributing to dementia grief, namely the PwD's psychological death, which is different from physical death, the course of the disease which can be uncertain and protracted, impaired communication among PwD and their caregivers as well as relationship changes. Thus, Dehpour and Koffman (2023) describe dementia grief as "a distinctive type of grief, whereby the dependent or loved one is still physically 'present' but emotionally disconnected from the caregiver" (p. 110). Dementia grief is correlated with caregiver burden and depression, yet it is a unique concept (Liew et al., 2020). It encompasses caregivers' reactions to the irreversible deterioration during the disease trajectory that goes along with dementia (Lindauer & Harvath, 2014).

Dementia grief's occurrence is estimated to lie between 47% and 71% (Chan et al., 2013) and reaches the highest levels when dementia progresses to moderate and severe stages (Adams & Sanders, 2004; Blandin & Pepin, 2017). In general, grief can occur for everyone at all levels of the disease trajectory, yet spouses often show different grieving patterns than other family caregivers (Cheung et al., 2018; Johansson et al., 2013; Romero et al., 2014). Grief expressions are heightened at key transitional points such as the point of diagnosis, nursing home transition, or physical death (Andersson et al., 2019; Crawford et al., 2015; Gibson et al., 2019; Høgsnes et al., 2014; McCormack et al., 2017). The end-of-life experience is another transitive period for caregivers with a risk for elevated dementia grief. Preparedness for death and social support helps in processing dementia grief (Moore et al., 2017, 2020).

Grief itself is viewed as a normal emotional experience that comes along with a significant loss (Chan et al., 2013). Caregivers of patients with other incurable illnesses

https://doi.org/10.1027/1016-9040/a000501

such as terminal cancer suffer losses before the patient's physical death; therefore, some of them also show patterns of anticipatory grief (Coelho et al., 2018). A study comparing pre-loss grief in dementia and cancer patients found comparable levels of it within the two family member groups, but dementia carers were significantly more likely to meet adapted criteria for prolonged grief disorder (Singer et al., 2022). What distinguishes dementia grief from the anticipatory grief elicited by most other terminal medical conditions is the reduced opportunity to experience relationship resolution between the informal carers and the PwD as well as share feelings about the compounded serial losses and impending death (Blandin & Pepin, 2017; Lindauer & Harvath, 2014). This is due to the care recipients' emerging cognitive impairment, language deficits, and inability to recognize changes in their behavior or emotions which can occur early on and as the disease progresses (Blandin & Pepin, 2017). In addition, caregivers often do not know the length of the disease and the life expectancy which makes the caring experience ambiguous (Lindauer & Harvath, 2014). When exploring differences in dementia grief manifestation in caregivers of persons with Alzheimer's Dementia (AD) versus Mild Cognitive Impairment (MCI), Garand and colleagues (2012) found that AD caregivers reported significantly more grief than MCI caregivers. With regards to the content of dementia grief, MCI caregivers expressed "missing the person" (Garand et al., 2012, p. 159) while AD caregivers expressed more problems with daily functioning.

20–30% of dementia carers experience complicated grief after the physical death of the PwD (Blandin & Pepin, 2017; Holland et al., 2009). Carers who have higher levels of dementia grief prior to the death of the PwD are at increased risk of developing complicated grief after physical death (Romero et al., 2014). Contrary to the theory of anticipatory processing (Boerner & Schulz, 2009), dementia grief does not decrease post-loss grief but instead makes it more likely. With the inclusion of Prolonged Grief Disorder into ICD 11 (World Health Organization, 2019), dementia grief's predictive value for post-loss adjustment in family caregivers becomes more diagnostically and clinically important.

Often, the loss is not acknowledged by health professionals, the peer group, or society (Doka, 2008) which can lead to a lack of adequate social support (Doka, 2008). Dementia grief has short- and long-term effects on other mental health outcomes. A longitudinal cohort study with a 2.5-year follow-up aimed to differentiate the effects of dementia grief and caregiver burden on caregiver depression (Liew et al., 2019). Higher caregiver grief combined with increasing burden led to a steep rise in depressive symptoms. Thus, even a low burden would lead to depressive symptoms if dementia grief were high. After 2.5 years, dementia grief significantly impacted depression. Furthermore, dementia grief had a direct effect on depression after 2.5 years.

Given dementia grief's impact on other mental health outcomes, interventions have been developed to manage or reduce grief reactions, for example *Easing the way* intervention (Ott et al., 2010). A systematic review by Cheng and colleagues (2020) investigated the effectiveness of evidence-based nonpharmacological interventions for family caregivers of PwD. Cognitive-Behavioral Therapy (CBT) programs, psycho-educative group formats, family therapy, mindfulness-based interventions, and new technology formats have a positive impact on burden and caregiver distress. Within these, only a few studies have been conducted to assess how therapeutic or educative interventions can influence the outcome of grief before the physical death of the PwD (Cheng et al., 2020). Since dementia grief overlaps with but is still distinct from burden or distress, research to address this specific construct is needed. This is in line with the findings of Wilson and colleagues (2017): Wilson and colleagues (2017) systematically reviewed interventions targeted to reduce grief pre- and post-death for carers of PwD. Only three valid studies were found, of which two targeted dementia grief and one targeted post-death grief, concluding this scarce evidence.

Aims and Objective

The objective of this review was to examine whether new interventions to assist caregivers in managing dementia grief have been developed and implemented since the results of Wilson and colleagues' review (Wilson et al., 2017). Therefore, the search commenced after Wilson's review end search date. The search was targeted solely at pre-loss grief interventions. For this review, we used Blandin and Pepin's (2017) term *dementia grief* which describes a caregiver's anticipatory grief experience resulting in the PwD's perceived losses before physical death. In particular, the review question was: What psychosocial interventions for family carers of PwD exist since September 2016 and how effective are they in reducing dementia grief?

Methods

Reporting adhered to the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) statement (Moher et al., 2009). A protocol was registered with the PROSPERO database (CRD42021268998).

Table 1. Keywords used in search

Category	Search words
Dementia	dementia OR vascular dementia OR mixed dementia OR Lewy Body OR frontal lobe OR Alzheimer
Carer	carer OR spouse OR family caregivers OR caregiver
Phenomena of interest	caregiving grief OR anticipatory grief OR complicated grief OR prolonged grief OR chronic grief OR maladaptive grief OR predeath grief OR pre-loss grief OR disenfranchised grief OR ambiguous grief
Interventions	blended model OR Caregiver Grief Intervention Model OR Dementia Caregiver Grief Model OR Easing the Way OR model of grief care OR intervention OR program, person-centered care, support group OR counseling OR self-help group OR Instrumental Activities of Daily Living OR case management OR social support
Study type	Quantitative OR quantitative study OR randomized controlled trial OR non-randomized controlled trial OR experimental OR quasi-experimental OR observational study OR case-control OR cohort OR descriptive OR case series OR cross-sectional

Search Strategy

The scientific databases Web of Science (SSCI), PsycArticles, Psychology and Behavioral Sciences Collection, PsycINFO, PSYNDEX Literature with PSYNDEX Tests via EBSCO Host, and MEDLINE via PubMed were searched. The main Boolean Search Operators were used as well as medical subject headings. In reference to Wilson and colleagues (2017), the main content categories used were dementia-related terms, caregiver-related terms, pre-death dementia grief-related terms, and intervention-related terms. These four main categories of interest were connected using and-relations. Within a category, or-relations were used. Disenfranchised grief is a MeSH term. Based on the research question, terms referring to post-death experiences were excluded. The search period commenced on September 9th, 2016. This date was chosen as a continuation of the systematic review by Wilson and colleagues (2017). The search ended on September 14th, 2021. Initial keywords are presented in Table 1.

Selection Criteria

Studies about young onset dementia and dementia grief were excluded, as the disease trajectory differs significantly. Systematic reviews or meta-analyses were excluded, too. Inclusion criteria are presented in Table 2.

Study Selection and Data Extraction

The records identified through databases (n = 66) and hand-search (n = 6) were entered into *Rayyan* (Ouzzani et al., 2016), a free online tool for systematic reviews. Titles and abstracts were screened independently by two reviewers (LR and KS) to identify inclusion in the full article review. A full-text review of potentially eligible studies was carried out by LR and discussed with KS. A further reviewer (JH) helped resolve potential disagreements on including or excluding articles.

LR extracted most data, and SP checked for completeness by examining random samples. We used an individualized data extraction form to extract data and summarize information (see Electronic Supplementary Material, ESM 1). The developed data extraction form was based on examples from the *Joanna Briggs Institute Reviewer's Manual* (Aromataris & Munn, 2017). For each study, we documented the authors, the country of study execution, study design, sample size (total and split in the control group and intervention group if applicable) and characteristics, recruitment strategies, inclusion and exclusion criteria, format (duration and the number of sessions if applicable), the dementia grief assessment used, the outcome, the contents of the intervention, the entity delivering the intervention and the level of evidence.

Quality Assessment

A standardized rating scale was used to assess the quality of evidence: Level 1 (systematic reviews), Level 2 (randomized controlled trials), Level 3 (quasi-experimental studies), Level 4 (non-experimental studies), Level 5 (single qualitative/quantitative studies), and Level 6 (expert opinions). Systematic reviews or meta-analyses were not included in this search, so the evidence in the result section starts at level 2.

Results

The study selection flowchart is shown in Figure 1.

Study Characteristics

Of the total 12 studies included, eight had a quantitative design, two had a mixed method design and two were qualitative studies. The two qualitative studies each were a secondary analysis based on two randomized controlled design intervention studies (Meichsner & Wilz, 2018; Wilz et al., 2011). One study was conducted in Spain, one

Table 2. Inclusion criteria presented according to the PICOS model

PICOS model	Description of inclusion criteria
Participants	All adult family or friend carers (≥ 18 years) of older persons with dementia. All types and severity stages of dementia. The person living with dementia could be living at home or residing in the community or facilities such as nursing homes. Family carers could not be bereaved. The support carers offered was not limited to a minimum hours or family status. Besides spouses, husbands, adult children or sibling carers, friends, and neighbors were included if the carers were unpaid and not professional.
Interventions	All psychosocial interventions targeting dementia grief offered by health professionals (e.g., but not limited to counselors, nurses, social workers, geriatric professionals, and psychological psychotherapists) within community health services or social care facilities to facilitate adaption to the disease trajectory.
Comparisons	Caregivers of people with other chronic or lethal illnesses such as cancer, or Parkinson disease, in situations of palliative nature or studies concerning other mental health outcomes such as caregiver burden or depression.
Outcome	Dementia grief in family caregivers measured with validated instruments.
Study design	Quantitative, qualitative, and mixed-method studies with experimental and epidemiological study designs.

in Great Britain, two in Canada, and four in Germany and the USA, respectively. Sample sizes varied across the studies, ranging from $n = 2$ to $n = 273$. Three studies had ≥ 200 participants. Regarding the inclusion and exclusion of participants based on the presence of mental or physical illness and treatment as well as the recruitment strategies, the included studies varied in their approach (see recruitment strategies and inclusion and exclusion in ESM 1).

Included interventions were multifaceted and the intervention format was heterogeneous including individual or group settings with face-to-face, telephone, and/or online execution (see format, duration, and number of sessions in ESM 1).

Content-wise, the psychosocial interventions incorporated – amongst others – cognitive behavioral strategies such as exposure, cognitive restructuring, mood management, social skills training, and self-care strategies (for a complete description see content in ESM 1). The interventions were delivered by licensed social workers, clinical counselors, psychologists, psychotherapists, dementia care researchers with clinical experience, and the authors themselves.

Nine studies used a validated assessment instrument to collect measures of dementia grief, and two used survey questions designed uniquely for the study purpose. For the two secondary analysis qualitative studies, grief assessment was not applicable, but they were based on a randomized controlled trial (RCT) and within that, a validated assessment instrument was used.

Table 3 shows the assessment instruments used to measure dementia grief and a short description.

Study Outcomes

The following results are subdivided based on the studies' level of evidence and provide an in-depth analysis of the intervention outcome of dementia grief.

Level 2 Evidence Randomized Controlled Trials

Two randomized controlled trials were conducted in Germany (Meichsner, Theurer, et al., 2019; Meichsner & Wilz, 2018).

In the telephone-based cognitive behavioral program *Tele.TAnDem*, dementia carers received twelve 50 min of individual psychotherapy sessions an intervention with ten modules, of which one module emphasized pre-death grief (Meichsner & Wilz, 2018). As a result, pre-death grief decreased for the intervention but not the control group after 6 months. This effect remained after controlling for the care situation and sociodemographic variables. Caregivers still caring at home showed a stronger decline in pre-death grief after post-intervention measures. Gender was not associated with increased grief symptoms (Meichsner & Wilz, 2018). The adaptation of the intervention was delivered online and consisted of ten modules and three assessments: baseline, 8 weeks after baseline, and 5 months after baseline (Meichsner, Theurer, et al., 2019). While participants showed high rates of satisfaction and acceptance of the treatment, there was no treatment effect on the overall measures of dementia grief at time 1 or time 2. One of the subscales, absolute loss, showed lower levels in the intervention group compared to postintervention 8 weeks after but not at follow-up 5 months after the postintervention assessment.

Level 3 Evidence Quasi-Experimental Studies

Three quasi-experimental studies (Bravo-Benítez et al., 2021; Hicken et al., 2017; MacCourt et al., 2017) were conducted.

In Spain, an on-site delivery group intervention led to a decrease in dementia grief in the intervention, but not in the control group in the CGS grief subscales of Emotional Pain and Absolute Loss (Bravo-Benítez et al., 2021). Thus grief-related emotions were significantly

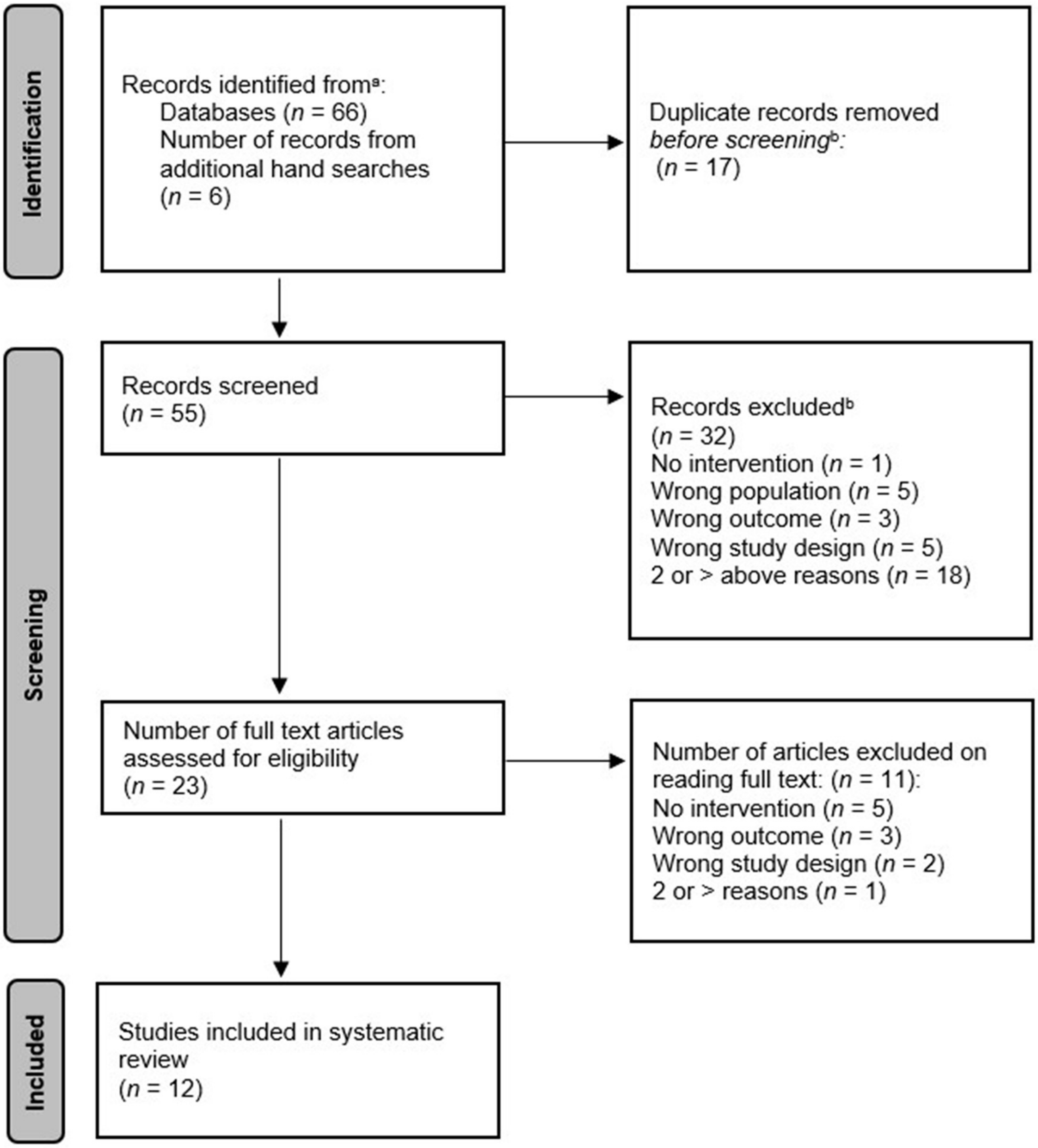

Figure 1. Flowchart displaying study selection according to PRISMA. [a]n = 26 Web of Science (SSCI); n = 6 PsycArticles, Psychology and Behavioral Sciences Collection, PsycINFO, PSYNDEX Literature with PSYNDEX Tests via EBSCO Host; n = 36 MEDLINE via PubMed. [b]Exact duplicates deletion in the web search by EBSCO Host, deleted duplicates by Rayyan tool which was double checked by LR.

dependent on whether participants received the intervention or did not.

A multisite intervention for caregivers of US veterans with dementia in rural and urban areas showed a significant decrease in dementia grief for telehealth users, especially in the MMC-GI-SF subscale Worry and Felt Isolation, and an increase in dementia grief for phone users in the group that was not comfortable using internet service (Hicken et al., 2017). Intervention via phone seemed to either increase dementia grief or did not change it, but never showed a decrease whereas, in the internet group or the non-Internet group using telehealth devices via phone line, there were significant decreases in dementia grief.

In Canada, a coaching grief intervention delivered by counselors was evaluated by MacCourt and colleagues (2017). Intervention group members showed less grief compared to the control group. Grieving at baseline assessment and having no university education predicted a decrease in dementia grief at time 2 assessment. Dementia grief in spouses decreased significantly in the intervention group but was still higher than for adult caregiving children.

Table 3. Dementia grief assessment instruments

Assessment instrument	Description of assessment instrument
CGS = The Caregiver Grief Scale	The CGS (Meichsner et al., 2016b) was developed in Germany and comprises 11 items. All items can be rated on a 5-point Likert-type scale where 1 = *strongly disagree* and 5 = *strongly agree*. There are 4 subscales, namely Emotional Pain (EP) with Cronbach's α = .81, Relational Loss (RL) with Cronbach's α = .89, Absolute Loss (AL) with Cronbach's α = .82, and Acceptance of Loss (AoL) with Cronbach's α = .67. The construct validity coefficients proved good construct validity. An English version is planned to be validated to use the scale in international contexts.
NDRGEI = Non-Death Revised Grief Experience Inventory	The NDRGEI (Lev et al., 1993) is a scale measuring the grief experiences of persons anticipating a loss through four domains: (a) existential concerns, (b) depression, (c) tension and guilt, and (d) physical distress. The NDRGEI is a reliable tool (Cronbach's α = .93) and consists of 22 items scored on a 6-point Likert scale from *slightly disagree* to *strongly agree*, where higher scores are indicative of lower grief responses.
MM-CGI = Marwit and Meuser Caregiver Grief Inventory	The MM-CGI (Marwit & Meuser, 2005) and its short form MMCGI-SF are the most used scales in the original research reviewed in this paper. The long-form MMCGI consists of 50 items on a 5-point Likert scale. Total scores range from 50 to 250 with higher scores indicating higher levels of grief. Factor analysis revealed 3 subfactors, namely personal sacrifice burden (PSB, with Cronbach's α = .93), Heartfelt Sadness and Longing (HSL with Cronbach's α = .90), Worry and Felt Isolation (WFI, with Cronbach's α = .91). An overall total score of >175 classifies as high grief and for subscale scores, 70, 25, 25, and 24 classifies as high grief (Marwit & Meuser, 2005).
MM-CGI-SF = Marwit and Meuser Caregiver Grief Inventory – Short Form	The short form MM-CGI-SF (Marwit & Meuser, 2005) comprises 18 items. It showed strong internal consistency reliability concerning the subscores, as well as convergence and discriminant validity, thus leading to the author's assumption that the short scale was as good as the long form.
ICG-r pre-loss = Inventory of Complicated Grief Short Form Pre-Loss version	The ICG-r pre-loss is based on the Inventory of Complicated Grief (ICG; Prigerson et al., 1995). It is comprised of 16 items with a range from 16 to 80. Caregivers are asked to reflect on their grief in the last month. The higher the score, the higher the grief. The wording was switched from "since death" to "since diagnosis" for the pre-loss version. To date, there are no established clinical cut-off values. A score of $\geq$ 32 indicates that on average, all 16 grief items were reported at least once a month. The original ICG has adequate properties. To our knowledge, there is no known test of psychometric qualities of the ICG-r pre-loss.
p-BGQ = pre-loss Brief Grief Questionnaire	The p-BGQ (Shear & Essock, 2002) is a 5-item self-report or interview instrument for screening complicated grief which was modified for pre-loss grief. Each item can be scored from 0 to 2 (0 = *not at all*, 1 = *somewhat*, 2 = *a lot*).

Level 4 Evidence Non-Experimental Studies

Five non-experimental studies (Duggleby et al., 2018; Jain et al., 2019; Paun & Cothran, 2019; Shear & Essock, 2002; Supiano et al., 2021) were conducted.

A web-based intervention with information and interactive activities called "My tools for care" decreased dementia grief for carers whose PwD were transferred to a long-time care facility (Duggleby et al., 2018). The caregivers of the repeated measures feasibility study were able to use a self-administered web-based interactive site for 2 months.

Jain and colleagues (2019) could show that mindfulness was negatively correlated with dementia grief in self-reports at baseline measurement. In nine caregivers, a decrease in grief symptoms was measured from baseline to assessment 2. Grief stimuli used in this study elicited brain activation in regions that are commonly identified as regions activated with bereavement grief. On a neural level, the authors suggest that these activation patterns could be used to assess how well the treatment response is in caregivers.

A study in Great Britain evaluated the usefulness and acceptability of animation in dementia grief (Shear & Essock, 2002). The quantitative result suggested 94% of carers found the animation relevant. Qualitative analysis revealed the helpfulness for understanding grief and pointed to newer carers as targets of the animation.

Paun and colleagues modified their *Chronic Grief Management Intervention* (CGMI; Paun et al., 2015) into a video-group-based pilot intervention (CGMI-V; Paun & Cothran, 2019). A description of CGMI and its evaluation can be found elsewhere (Chan et al., 2013; Paun & Farran, 2011) and was evaluated in Wilson and colleagues' review (2017). The CGMI-V was accepted by all five of the participants (Paun & Cothran, 2019).

Another pilot intervention study (Supiano et al., 2021) assessed dementia grief prior to the intervention (n = 25) and at the end of the study (n = 22). The scores showed a decrease in dementia grief for intervention participants after the intervention that were below the threshold for complicated grief.

Level 5 Evidence Qualitative Studies

Two qualitative studies (Meichsner, Köhler, et al., 2019; Meichsner et al., 2016a) were conducted in Germany.

Sequences from 61 therapy sessions of 33 caregivers from an RCT (Wilz et al., 2011) were analyzed (Meichsner et al., 2016a). Grief interventions addressing acceptance of loss and change, overcoming avoidance of associated painful emotions via CBT techniques, and Acceptance and Commitment Therapy (ACT) (Hayes et al., 2006) techniques proved to be promising. Thus, cognitive reframing, acceptance of emotions, and third-wave approaches of CBT such as ACT are suitable for grieving caregivers. This is supported by another qualitative study by this research group. Three CBT sessions with grief-focused content within another RCT (Meichsner & Wilz, 2018) were analyzed for two participants (Meichsner, Köhler, et al., 2019). Therapy intervention strategies addressing grief and losses, tolerating difficult feelings and individual adaptation in line with the dementia grief model (Blandin & Pepin, 2017) proved to be helpful. Caregivers reported heightened skills to successfully deal with losses and painful emotions.

In addition to dementia grief, the effect of the interventions on other mental health constructs was measured in seven of the twelve included studies (for a complete list of all other outcome variables and the effects of the interventions on these variables see Table 4).

Discussion

The goal of this present systematic review was to examine the existing interventions addressing dementia grief from September 2016 to September 2021. In total, 12 studies were found in a 5-year search period. This shows a tremendous increase in interventions tailored at dementia grief compared to Wilson and colleagues' review (2017) finding where in a 21-year (1995 until September 2016) search period, only three studies for pre- and post-bereavement interventions were found of which only two tailored anticipatory grief (Wilson et al., 2017). The reviewed dementia grief interventions in the present paper comprised psychoeducation elements, cognitive and emotional therapeutic strategies based on CBT, acceptance-based, and mindfulness-based strategies. The above interventions showed statistically significant small to moderate effects on dementia grief. This is in line with the findings of Pinquart and Sörensen (2006) for caregiver interventions targeting other outcomes such as depression or caregiver burden. The interventions also had significant effects on other variables such as burden, depression or empowerment, and resilience (for a complete list, see Table 4). These results suggest that by aiming to reduce dementia grief through suitable interventions, other mental health-related variables improve, too. Also, almost all studies used valid instruments to measure dementia grief. Compared to the intervention studies in Wilson's review (Wilson et al., 2017), some studies accommodated the need for distance delivery mode. For instance, an intervention program for rural caregivers (Hicken et al., 2017) was developed to make support more accessible. Also, a self-administered web-based program (Duggleby et al., 2018) allowed caregivers to make use of certain elements of the interventions in their own time. Therapeutic tools could be accessed more flexibly and were tailored to caregivers' unique needs in the time-consuming and challenging caregiving role. Various interventions are offered not only face-to-face but also purely virtual (e.g., Meichsner, Theurer, et al., 2019) or mixed face-to-face/virtual intervention formats (MacCourt et al., 2017; Paun & Cothran, 2019). Furthermore, grief experiences were assessed on a neural level with new insights into brain activation of grief experiences (Jain et al., 2019). Also, the concept of mindfulness (Jain et al., 2019) was not included in any of the studies in Wilsons' review.

In their review, Wilson and colleagues (2017) recommended adding dementia grief assessment times post-intervention and after physical death of the PwD to determine the sustainability of outcomes, conducting longitudinal studies to better identify altering caregivers' needs, developing interventions in the earlier stages of the disease, and testing the impact of individual elements of the interventions' components. Some of the recommendations were implemented in the included studies of this review. In terms of post-intervention assessment, the longest intervention was 6 months long (Meichsner & Wilz, 2018) and the longest follow-up of grief scores was measured at 6 months (Meichsner & Wilz, 2018). Joling and colleagues (2020) found that the median dementia disease trajectory from diagnosis to death is 5.0 years. With the ongoing experience of multiple losses, support needs to change. Therefore, it is advisable to test dementia grief interventions over a longer period.

In terms of the effectiveness of individual elements of the interventions, Meichsner and her research team found acceptance-based intervention strategies helpful for the family carers in their two qualitative studies (Meichsner, Köhler, et al., 2019; Meichsner et al., 2016a). The strategies used by the study therapists matched the three dynamic mechanisms "acknowledging loss, tolerate difficult feelings and adaptation" suggested by Blandin and Pepin (2017). Thus, it can be inferred that acceptance-based therapy elements with a focus on dealing with losses seem helpful. The effectiveness of these third-wave elements of CBT (Hayes et al., 2006) yet must be tested in larger caregiver samples since the qualitative case studies had very few participants. Furthermore, CBT techniques such as psychoeducation, overcoming dysfunctional cognitions, de-pathologizing grief, and talking about anger, sadness, or pain were used by the study therapists and elicited a positive response. They can be seen as pivotal components of dementia grief interventions (Meichsner, Köhler, et al., 2019).

Table 4. Other outcome variables and effects of the interventions on these variables

Study	Outcome variables	Effects
Bravo-Benítez et al., 2021	Caregiver overload, resilience, acceptance and action, positive aspects of caregiving, posttraumatic growth, perceived health	Significant decrease in burden, overload, and experiential avoidance; a significant increase in resilience, post-traumatic growth, and quality of life
Duggleby et al., 2018	Hope, general self-efficacy, health-related quality of life	Significant increase in hope
Hicken et al., 2017	Burden, depression, family conflict, desire to institutionalize the patient	No significant effects
Jain et al., 2019	Depression	Depression symptoms at baseline of moderate severity; at follow-up, decrease in depression
MacCourt et al., 2017	Coping, sense of empowerment, resilience	Significant improvement in coping, empowerment, and resilience in the intervention group
Meichsner, Theurer, et al., 2019	Depression, burden, utilization of psychosocial resources, emotional wellbeing	Significant increase in well-being and use of psychosocial resources at end of intervention but not at follow-up
Supiano et al., 2021	Preparedness for the death of the family member, self-reported health status, anxiety, depression, stressful life events, meaning-making	Significant improvement in preparedness and in meaning-making (sense of peace and a reduction of loneliness)

Concerning developing interventions in the earlier stages of the disease, the care recipients' stage was not always reported in the 12 included studies of this review and if so, there were no treatment distinctions made within the intervention based on the progression of the disease. The care situation was considered in some studies, as it is known that placement into long-term care often increases the grief experience. The group video intervention (Paun & Cothran, 2019) addressed caregivers whose family members resided in long-term care and was rated as very helpful. Yet, the small sample size does not permit us to draw larger conclusions for the general caregiver population with PwD in long-term care. Meichsner and Wilz (2018) reported lower levels of dementia grief after the intervention for caregivers with care recipients at home compared to care recipients at care facilities.

Aside from Wilson and colleagues' (2017) recommendations, it should be noted that MacCourt and colleagues (2017) found a significant dementia grief decrease in spouses which was nevertheless still higher than for adult caregiving children. This latter finding is in line with previous research showing that spousal caregivers show higher grief levels than adult children (Chan et al., 2013). Thus, spousal caregivers should be the target group to consider when developing dementia grief interventions.

Furthermore, it should be noted that all the included intervention studies were undertaken in Western countries. Until 2010, dementia grief had not been extensively studied by caregivers outside of the United States (Chan et al., 2013). Since then, more studies have shown distinctive cross-cultural features of dementia grief and its construct validity (Liew, 2016; Liew et al., 2018) and differences within subpopulations of carers (Lindauer et al., 2016). Yet, none of these studies incorporated any intervention targeting dementia grief. Further research should be focused on the application of interventions in different cultural settings or subpopulations since caring for a family member with PwD in more collectivistic-oriented communities presents unique challenges that might have to be accounted for when developing suitable interventions for caregivers.

Another aspect that demands further research attention is the transferability of the intervention effects to caregivers of patients with other severe, terminal illnesses or degenerative disorders. As stated in the introduction, there are unique aspects to the grief experience in informal dementia caregivers such as the type and frequency of losses, reduced opportunity for conflict or relationship resolution, and impaired communication about the dying process (Blandin & Pepin, 2017; Lindauer & Harvath, 2014). Thus, future research should examine whether the components of the dementia grief interventions discussed in this review can be applied to other forms of disenfranchised grief and other populations of carers or whether they must be modified.

Limitations of Included Studies

This paragraph summarizes the limitations of the included studies as noted by the authors of the included studies and the team of this review. Three reviewed dementia grief interventions were pilot studies with few participants (Jain et al., 2019; Paun & Cothran, 2019; Supiano et al., 2021) or qualitative studies with limited explanatory power in terms of generalizability to a larger caregiver population (Meichsner, Köhler, et al., 2019; Meichsner et al., 2016a). The video group intervention developed for carers after the care recipients resided in long-term care (Paun & Cothran, 2019) did not use a valid measurement of dementia grief. In several studies, there was a lack of ethnic diversity (Duggleby et al., 2018; MacCourt et al., 2017) and a lack of a control group (Duggleby et al., 2018; Hicken et al., 2017;

Jain et al., 2019; Supiano et al., 2021). Also, there was a lack of gender diversity. Females represented the majority of caregivers with over 75% in 11 of the 12 studies (Bravo-Benítez et al., 2021; Hicken et al., 2017; Jain et al., 2019; MacCourt et al., 2017; Meichsner, Köhler, et al., 2019; Meichsner, Theurer, et al., 2019; Meichsner & Wilz, 2018; Meichsner et al., 2016a; Paun & Cothran, 2019; Scher et al., 2022; Supiano et al., 2021). Only Duggleby and colleagues (2018) had a ratio of 65% female to 35% male caregivers.

The limitations of the coaching intervention by MacCourt and colleagues was – as stated by the authors – a potential self-selection bias because participants volunteered for the intervention. Also, the authors noted that combined clinician expertise in dementia, grieving, and coaching cannot be expected by every counselor (MacCourt et al., 2017). In the intervention study by Bravo-Benítez and colleagues (2021), there were only two assessment times (pre- and post-intervention) so nothing is known about long-term effects of the intervention. Only two studies had an RCT design and a stringent CBT-based therapeutic foundation (Meichsner, Theurer, et al., 2019; Meichsner & Wilz, 2018). Yet, there are limitations in those two RCTs, too. In the RCT telephone intervention *Tele.TAnDem* (Meichsner & Wilz, 2018), the authors noted that nonverbal information could have been lost via a telephone intervention. Within the ten-module intervention, therapists decided when grief-focused interventions took place; thus, it cannot be assumed that all participants received uniform grief-focused interventions. In the online RCT adaption of the intervention *Tele.TAnDem* (Meichsner, Theurer, et al., 2019), the authors stated the caregivers were self-selected and younger than the average caregiver in Germany. The sample size was not as big as in the telephone *Tele.TAnDem* intervention (Meichsner & Wilz, 2018). Interviewers knew which group the participants were in (Meichsner, Theurer, et al., 2019). Randomization was imperfect because of depression outcomes and resource utilization that differed between the intervention and the control waiting group at baseline. The authors (Scher et al., 2022) of the animation grief awareness intervention stated several limitations. The participants were drawn from another study and were interviewed 1–2 years ago during which demographic variables and grief experiences might have changed (Scher et al., 2022). Also, only primary carers were included which the authors see as critical to reaching other persons affected by dementia grief (Scher et al., 2022).

In general, sample size, the ratio of spouses to adult children, modes of delivery, persons carrying out the intervention, and assessment times were heterogenous, too so it is not possible to compare the interventions. Spousal caregivers show heightened dementia grief compared to adult children (e.g., Cheung et al. 2018), yet interventions did not accommodate this. More interventions with rigorous randomized and longitudinal designs and stringent use of empirically approved therapy methods should be conducted.

Limitations of This Review

This review has some limitations. First, we excluded studies about young onset dementia and dementia grief, as the disease trajectory differs significantly. This caregiver population's dementia grieving might evoke unique, yet important challenges that should be accounted for in future studies. Second, the results were reported by quality of evidence categories. It should be emphasized that other categorizations would also have been appropriate. For example, categorizing the included studies based on similar content or similar format might have provided additional perspectives. Third, the authors in our reviewed papers use different names for dementia grief such as pre-death grief, pre-loss grief, or caregiver grief. A more in-depth analysis of the different approaches to terminology can be found here (Lindauer & Harvath, 2014). For this review, we used Blandin and Pepin's (2017) term *dementia grief*. In our keywords searches (see Table 1) we used 10 different alike descriptions to prevent the exclusion of relevant studies. Yet, since there is not one definite term officially acknowledged in the research community, we potentially did not find studies that describe interventions for the concept of dementia grief but used a different term describing it.

Conclusion

In sum, the results show a vast increase in dementia grief interventions implying that the concept has been recognized as a valid and important construct to describe the caregiver experience. The interventions to date have proven to be effective in their entirety. Tests of single elements of the multicomponent interventions or comparative interventions to examine which contents are more successful than others are lacking. Also, it is unclear whether the available interventions are known by practicing healthcare providers. To date, the authors know of no study examining how many carers of PwD use therapeutic services such as self-help groups, psychotherapy, or counseling and how often grief is addressed during those therapeutic contacts. To use appropriate dementia grief interventions, potential healthcare professionals must recognize dementia grief first. Since the concept is relatively new and the grief experience often presents itself as disenfranchised (Doka, 2008), it might often be overlooked or confused with caregiver burden or stress. Training health care professionals via continuing medical education or clinical workshops about disenfranchised grief and dementia grief especially might increase its visibility in clinical practice. In sum, implementation research should be undertaken to explore how well the concept of dementia grief is known and recognized. Furthermore, on the intervention level, it should be examined how elements of the above-described grief interventions are used in everyday mental health care and how they are evaluated by health care providers.

Electronic Supplementary Material

The electronic supplementary materials are available with the online version of the article at https://doi.org/10.1027/1016-9040/a000501

ESM 1. Summarized information of the included intervention studies

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History

Received May 22, 2022
Revision received January 18, 2023
Accepted February 25, 2023
Published online May 22, 2023

Conflict of Interest

We have no conflicts of interest to disclose.

Publication Ethics

Reporting adhered to the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) statement (Moher et al., 2009). A protocol was registered with the PROSPERO database (CRD42021268998).

Funding

Open access publication enabled by the Siegen University Library.

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