



THE USE OF PSYCHOTHERAPY AS AN EFFECTIVE TREATMENT FOR GRIEF AND
LOSS FOR PERSONS DIAGNOSED WITH DEMENTIA AND THEIR CAREGIVER: A
SYSTEMATIC REVIEW OF THE LITERATURE

A Thesis submitted by

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For the award of

Master of Science (Research)

2018

Abstract

The effects of dementia can be overwhelming not only for those diagnosed with dementia, but also their caregivers. Psychotherapy may be one way that can help the dyad better cope with this life-changing diagnosis, however whether psychotherapy is effective remains unclear. A systematic literature review was conducted to identify effective psychotherapeutic interventions to ameliorate the effects of grief and loss experienced by the dyad of the person experiencing dementia and their caregiver.

During the screening process a total of 1020 records were identified via searching University of Southern Queensland databases using the field “abstract”. After removing 354 duplicate records a total of 666 remained. Further screening by the researcher and a research assistant resulted in 30 articles being short-listed for full text review using title and abstract. On completion of this procedure it was found that no literature met the inclusion criteria specifically aimed to explore psychotherapy as an effective treatment for grief and loss experienced by the dyad of persons with dementia and their caregiver.

In collaboration with the researcher’s supervisors, a revised inclusion criteria was developed that moved from treatment aimed at the dyad to include research where either the caregiver, or the person with dementia, individually was a recipient of psychotherapeutic intervention. The 666 articles were re-screened and a total of eight articles were short-listed for full-text review. Four of the eight articles were discarded due to not meeting the inclusion criteria. On review it was found that the four articles included for review and synthesis focused on grief and loss experienced by the caregiver. No literature was identified relating to persons with dementia receiving psychotherapeutic intervention to ameliorate the effects of grief and loss.

Within the four articles reviewed and synthesised three interventions were identified as being used. These interventions included: (1) telephone-based cognitive behavioural therapy,

(2) coaching, and (3) the five component “Easing the Way” interventions (MacCourt, McLennan, Somers & Krawczyk, 2017; Meichsner, Schinkothe, & Wilz., 2016; Meichsner & Wilz., 2016; Ott, Kelber, & Blaylock, 2010). These interventions were found to be potentially beneficial in ameliorating the experience of grief and loss on the part of the caregiver. With further research these findings may be useful in its implications in supporting the dyad of caregivers and persons with dementia by guiding the future direction of psychotherapeutic intervention.

Certification of Thesis

This Thesis is entirely the work of Karen T. Breedon except where otherwise acknowledged.

The work is original and has not previously been submitted for any other award, except where acknowledged.

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Student and supervisors' signatures of endorsement are held at the University.

Acknowledgments

Firstly, I would like to thank my supervisors, Associate Professor Andrea Lamont-Mills and Dr Leander Mitchell for their patience and support in writing this thesis. Without your expectations, your knowledge and your expertise I have no doubt in my mind that I would not have been able to complete this degree. I would also like to thank my university lecturers and professors, Gerry Tehan, Annissa O'Shae and Jessica Marrington who, without realising it, have instilled within me a belief that I have the ability to complete the academic journey that I commenced many years ago. Special mention goes to Ron Houison for acting as my Research Assistant, and Duncan Lowes, Jessica Harrison and Matthew Williams for taking the time read or proofread my work. Your attention to detail and willingness to help were appreciated. Thank you also to the Australian Commonwealth Government under the Research Training Program (RTP) Fees Offset scheme for funding this research project.

Secondly, and most importantly I would like to thank my family. My husband Matt and two children, Chloe and Jordan, who have provided me with unwavering love and acceptance with regard to my university studies. To my parents, Bobbie and Glen, and my sister, Wendy, you have always been a pillar of support. Little did we realise when I first commenced this degree how special it would be to have the knowledge about a disorder that my father would be diagnosed with mid-thesis. This knowledge, while difficult to comprehend at times, has only highlighted the importance of my thesis topic.

Finally, I thank my friends, many of whom I have neglected and declined catch-ups due to this research. Your words of encouragement always seemed timely. The words "you've got this" are so simple, yet you will never understand how important they were to me. I look forward to repaying the favour as we continue our journey together through life.

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Chapter 1 - Introduction

In 2016, it was estimated that 354,000 Australians were living with dementia (Australian Institute of Health and Welfare [AIHW], 2016). By the year 2050, it is projected that this figure will rise to approximately 900,000 (AIHW, 2016). Dementia has a global prevalence of 44.4 million with this number predicted to increase to 80 million by the year 2040 (Alzheimer's Disease International, 2016; Ferri et al., 2005). Those above the age of 65 are at greatest risk of dementia, with risk predicted to double every 6.7 years (World Health Organisation [WHO], 2017). In light of the predicted increase in the prevalence of dementia, which commonly results in an increased need for care, it is important that effective interventions be identified to pre-empt and potentially decrease individual, familial and societal burden. In 2013, dementia's impacts on the mind and body resulted in the disease being the second leading cause of death within Australia's overall population (AIHW, 2016).

Dementia has been defined as a syndrome characterised by the abnormal deterioration of cognitive function (Sanders, Ott, Kelber, & Noonan, 2008). While dementia more commonly affects the elderly, people below the age of 65 can experience younger onset dementia (Alzheimer's Australia, 2017; Kuruppu & Matthews, 2013). Persons with dementia broadly range in age and present with different types of dementia. As a result, while many of the symptoms experienced are similar, the experience of dementia varies between individuals depending on the specific symptoms experienced and the degree of severity.

Broadly, dementia results from damage to the brain from an injury or medical condition, such as stroke, with the onset of disease primarily or secondarily affecting the brain (Bryden, 2002; Nicholson, 2013; WHO, 2017). The most frequently diagnosed forms of dementia are Alzheimer's disease, vascular dementia (formerly multi-infarct or post-stroke dementia), and dementia with Lewy bodies. Other types of dementia include frontotemporal, alcohol-related, mixed type, Down syndrome and Alzheimer's disease, HIV associated

dementia, Parkinson's disease dementia, Creutzfeldt-Jakob disease, and normal pressure hydrocephalus.

For the majority of dementia types, the onset is progressive and can be characterised by the loss of memory, agitation, aphasia and intellectual impairment affecting one's ability to problem solve, self-care and undertake essential daily-living activities (Downing et al., 2013; Spalding & Khalsa, 2010). Life expectancy post-diagnosis is dependent on the age of the person with dementia and type of dementia diagnosed (Zanetti, Solerte, & Cantoni, 2009). The progressive loss associated with symptoms of dementia can pose vast challenges, both physically and psychologically (Ott et al., 2010), for not only the person diagnosed, but family members and friends struggling to cope with the effects of the diagnosis.

1.1. Symptoms and Impact of Dementia

Symptoms of dementia vary, although they commonly include a decline in memory and capacity to communicate and reason (Alzheimer's Association, 2017; Wilson et al., 2017). Dementia affects thought, orientation, language, judgement and the ability to comprehend, calculate, and retain information (Gillick, 1999; Wilson et al., 2017). A range of adverse emotional effects may occur including, but not limited to: anger, fear, shock, self-stigmatisation, depression, and suicidal ideation (Gibson, 2010; Husband, 1999, 2000; Pearce, Clare, & Pristrang, 2002; Pratt & Wilkinson, 2003; Rohde, Peskine, & Raskind, 1995; Woods, 2001; Young, 2002). Further effects include lowered self-esteem, reduced social status, cognitive degeneration and changes in roles between family members, friends, including within their current workplace as well as loss of memory (Doka, 2004; Nicholson, 2013). Deterioration of memories may affect the ability to function effectively in a workplace or home, further exacerbating feelings of loss of independence (Doka, 2004).

It has been further noted that a common effect of cognitive impairment is a decline in

socially acceptable behaviour, motivation, and emotional control (Mendez et al., 2013). As dementia progresses, persons with dementia lose the ability to carry out activities of daily living and essential self-care (Tran, Bédard, Dubois, Weaver, & Molloy, 2013) such as “toileting, feeding, dressing, grooming, walking, and bathing” (Miyamoto, Tachimori, & Ito, 2010, p. 247). These losses occur over time and, as autonomy decreases, dependency by the persons with dementia on their caregiver increases (Andrieu et al., 2007).

The loss of ability to care for one’s self may lead to compromised quality of life for both the person with dementia, experiencing the loss first-hand, and the person that is tasked with caring for them (Andrieu et al., 2007). Such caregiver tasks may include managing difficult behavioural symptoms including aggressiveness, difficulties with sleep and tendencies to wander. Psychological symptoms such as anxiety, hallucinations, delusions and paranoid thoughts may emerge as well as issues with nutrition, skin, swallowing and incontinence (Cerejeira, Lagarto, & Mukaetova-Ladinska, 2012; Geldmacher & Kerwin, 2013; Ott et al., 2010). The loss of independence on the part of the person with dementia, and increase in burden on the caregiver, may impact the dyad’s ability to continue their previously adopted social roles, hence further impacting the psychological welfare of both the person with dementia and their caregiver (Andrieu et al., 2007).

The impact of the symptoms of dementia are not just confined to the person who has been diagnosed. The impact is also felt by carers providing formal care in a paid employee role, such as in an aged care facility, as well as the less formal caregiver role, where care is provided by family members or friends. The experience of caregiving for a person with dementia has been described as frustrating, distressing and difficult on the part of the caregivers (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999). Dupuis (1997) described one of the most difficult experiences for family caregivers to be witnessing the progressive loss of their loved one, both physically and psychologically.

1.2. Loss

Loss is defined by Miller and Omarzu (1998) as pertaining to one being deprived of something, or suggesting that a person or something in one's life is no longer available. Further, this loss is considered to be a product of an event that is negatively perceived and resulting in long-term effects to one's relationships, social situations, or cognitions. In research conducted by Aminzadeh, Byszewski, Molnar, and Eisner (2007) it was found that both the person with dementia and their caregiver experienced multiple losses post-diagnosis including: control, independence, self-esteem, capability, lifestyle, social standing, friendships and other forms of relationships, and most importantly, loss of identity. Loss for the dyad has the potential to be overwhelming (Doka, 2004).

As dementia progresses, the decrease in the ability of the person with dementia to experience loss at an emotional level may be reflected in a change of behaviour, such as becoming agitated or restless (Doka, 2004; Spalding, & Khalsa, 2010). Doka (2004) states that damaged memory links may result in the loss of past memories, including that of family members, partners or friends, which can affect interpersonal relationships. The damage of memory links may cause the person with dementia to forget a person who has played a dominant role in their life (Doka, 2004), resulting in distress for both the person diagnosed and those surrounding them. Loss that is gradual and progressive, such as that associated with dementia, can be characterised by feelings of helplessness and a struggle to maintain quality of life (Dupuis, 2002). These difficulties arise due to the lack of social recognition of losses experienced due to the person still being alive (Boss, 2011). Such losses may be described as ambiguous and can be experienced on both the part of the person with dementia, as well as their caregiver.

Boss (1999) conceptualised ambiguous loss in two different ways. In one, loved ones

can experience ambiguous loss when the person is physically absent, yet psychologically present. An example of this would be when it is unknown whether a missing loved one at war is dead or alive. Secondly, ambiguous loss may refer to when a loved one experiences the loss of a person psychologically, despite this person being physically present. The latter form of ambiguous loss may be used to describe the loss experienced by the caregiver of a person with dementia. With respect to dementia, ambiguous loss is described as the caregiver witnessing the progressive loss of their loved one's cognition and psychological presence, while remaining physically alive (Boss, Caron, & Horbal, 1988; Dupuis, 2002). The person with dementia also experiences ambiguous loss as, while they are physically present, loss of identity occurs in many forms such as sense of self and role in the community (Boss & Couden, 2002; Roos, 2013). As degeneration progresses, the interpersonal roles of the dyad change. This transition in roles may cause distress, particularly to the caregivers of persons with dementia (Dupuis, 2002).

Research by Dupuis (2002) indicated that the emotional distress experienced by persons with dementia, and their caregiver, is the result of ambiguous loss. Dupuis suggested that the dyad experiencing ambiguous loss were, both frequently and simultaneously, undergoing a prolonged process of grieving. Three phases of ambiguous loss were proposed by Dupuis which are: (a) anticipation of the loss to be experienced, (b) experiencing the gradual progression of loss psychologically, and (c) acknowledgment of the loss sustained. During phase two it has been identified that interventions for the dyad may be particularly useful due to the distress they may be experiencing at this point (Dupuis, 2002). Dupuis notes all family members are significantly and negatively affected when a loved one is diagnosed with dementia and points out that there is limited research in the area of ambiguous loss and dementia. Ambiguous loss has been identified as a leading stressor affecting the caregiver (Boss et al., 1988).

1.3. Grief

As well as ambiguous loss, the experience of grief is a common reaction to the death of a person's psychological presence (Doka & Aber, 1989). Due to the gradual psychological degeneration, the experience of grief commences prior to the physical passing of the person with dementia and continues throughout the progression of the disorder. It has been found that the majority of the grief experienced by the caregiver occurs while the person with dementia is still alive (Dupuis, 2002).

Grief, as defined by Rando (2000), is a person's psychological response, or experience, (Bryant & Peck, 2009) to a significant loss. Kubler-Ross (1969) details the classic stages of grief as being: (1) denial and isolation, (2) anger, (3) bargaining (4) depression, and (5) acceptance. In terms of persons experiencing dementia, and their caregivers however, the process is considered to be less clear (Bryant & Peck, 2009). This is due to the gradual progression of dementia being incongruent with the classic onset of death as posed in the well-defined stages of Kubler-Ross (Bryant & Peck). A term posed to explain the particular type of grief experienced by caregivers is "anticipatory grief".

Anticipatory grief has been defined by Holley and Mast (2010) as the experience of grief in the situation that a loved one is physically present but, due to the diagnosis of a terminal illness, their loss is anticipated in the future. Rando (1988) noted that, when anticipatory grief is experienced, it appears to be related to losses associated with the illness, rather than the anticipation of death. It is further noted by Bryant and Peck (2009) that challenges experienced by persons experiencing anticipatory grief involve the caregiver knowing whether to grieve for their loved one when they are unable to continue to perform a particular function, as opposed to their physical death.

The reaction of grief, by a person experiencing loss, is characterised by symptoms such as the yearning and longing for a person, feelings of bitterness or anger relating to death, emotional numbness or detachment, shock or feeling stunned by the loss, diminished sense of self, mistrust of others and an inability or avoidance of accepting the loss (Prigerson et al., 1996, 1997; Prigerson & Maciejewski, 2005-2006). Both the person with dementia and their caregiver (Blandin & Pepin, 2017) may experience grief as a result of a dementia diagnosis.

Bowlby's (1982) Attachment Theory refers to ties formed between children and their caregivers and includes the desire of a person to remain in close proximity to a figure for security, particularly during times of distress (Burton, Weston, & Kowalski, 2012). Sanders et al. (2008) draw on Bowlby's theory of attachment to explain the psychological response of the dementia dyad. They state that the weakening of attachment and bonds may result in the experience of grief and loss. The stronger the attachment prior to decline, the stronger the feelings of grief and loss will be (Lieberman & Fisher, 2001). As dementia progresses, and the bonds of attachment decrease, caregivers will find coping with caring for the person with dementia more challenging (Jones, 1995). This can be attributed to the vacillating emotional states of persons with dementia when presented with loss and change associated with the progression of the disease (Blandin & Pepin, 2017). Meishsner, Schinköthe, and Wilz (2016) state, in accordance with Bowlby's Attachment Theory, that the breakdown of attachment bonds may result in meaningful relationships breaking down, resulting in the experience of grief.

Gilliland and Fleming (1998) found an association between the duration of an illness and the complication of the grieving process. That is, the longer the duration of the illness the more complicated the grief experienced. It was further found that feelings of anger, emotional instability and grief were all experienced at high intensities (Gilliland & Fleming, 1998). As the duration of life expectancy, after onset of dementia, is between 5 and 9.3 years

(Wolfson et al., 2001) anticipatory grief may be experienced by caregivers of persons with dementia.

Grief experienced over long periods of time can progress unnoticed by professionals and other existing supports (Sanders, Marwit, Meuser, & Harrington, 2007). The grief experienced by caregivers has been associated with caregiver burden, stress and depression that occurs prior to the passing of the person that they are caring for (Adams & Sanders, 2004; Blandin & Pepin, 2017; Joling et al., 2012; Meuser & Marwit, 2001; Ott et al., 2010; Pinquart & Sörenson, 2004). Caregiver grief can also continue after the person with dementia has passed (Sanders et al., 2007) and can be considered chronic when prolonged (Latham & Prigerson, 2004; Schulz & Beach, 1999). The continuation of grief can increase the risk of suicidality and negative psychological effects such as depression and chronic grief (Latham & Prigerson, 2004; Sanders & Sharpe, 2004; Schulz & Beach, 1999). Therefore, psychotherapeutic interventions may be beneficial in reducing the adverse effects associated with a dementia diagnosis, for both the caregiver and the person diagnosed with dementia.

1.4. Psychotherapeutic Intervention

Presently, awareness and understanding of dementia remains low (Alzheimer's Australia, 2017; Cations, Radisic, Crotty, & Laver, 2018; Glynn, Shelley & Lawlor, 2017) leading to barriers in obtaining much needed support and practical assistance, not only in terms of the person being diagnosed, but also in obtaining essential early intervention care (Bradford, Kunik, Schulz, Williams, & Singh, 2009). Traditionally, care of those with dementia has been predominantly via pharmacological treatment (Gibson, 2010), however, currently there is no medical treatment that will cure or cease the progression of dementia (Alzheimer's Association, 2016; Staedtler & Nunez, 2015). Medications currently available

to those experiencing dementia provide only temporary symptomatic relief and may increase one's life expectancy (Alzheimer's Association, 2016; Staedtler & Nunez, 2015).

Laver, Dyer, Whitehead, Clemson and Crotty (2016) and Boden (2002) have indicated that by combining pharmacological treatment and non-pharmaceutical dyadic interventions, including psychosocial therapeutic interventions and exercise, the negative impacts of dementia may decrease. This would provide the person diagnosed with dementia with their best future prospects. Further, this combination may assist in providing the person with dementia the opportunity to be involved in important decision making surrounding their future care, transport, living arrangements, finances and allowing for early access to support (Alzheimer's Association, 2017). Consideration of the unavoidable future deterioration of a person living with dementia is particularly important given the progressiveness of the disorder.

Miller and Reynolds (2007) note that in the later stages of dementia, implementing psychotherapy as a treatment for persons diagnosed may be difficult. They argue this is due to the person with dementia's limited recollection ability and decline of insight. However, in the early stages of onset, persons experiencing mild to moderate dementia often demonstrate an awareness of the memory loss and other negative cognitive changes (Aminzadeh, Byszewski, Molnar, & Eisner, 2007; Jones, 1995). During this onset period, persons with dementia hold the psychological capacity to report on their experiences and situations (Adams, 2006; Menne, & Whitlach, 2007; Witlatch, Feinberg, & Tucke, 2005). When implemented at early onset, psychotherapy may ensure a more positive trajectory of life by leading to increased independence (Smith & Beattie, 2001) and quality of life for persons experiencing minimal impairment, as well as having a positive flow on effect to their caregiver (Miller & Reynolds, 2007).

The positive outcomes of implementing psychotherapy at an early stage may decrease the severity of other negative effects of diagnosis (Aminzadeh et al., 2007) and increase the caregiver's ability to cope with loss and psychologically prepare them for the loss of the person with dementia (Kasl-Godley, 2003). Farias, Harrell, Neumann, and Houtz (2003) state that a therapist's understanding of the decline in ability to function is important. Further, Aminzadeh et al. (2007) and Yates (1999) state that a greater awareness of dementia in public and professional communities would assist to dispel the perception that persons diagnosed with dementia may not have the cognitive capacity to be receptive to therapy or psychotherapeutic intervention.

Research undertaken to date has found that the occurrence of grief and loss within the dyad is high (see Adams & Sanders, 2004; Joling et al., 2012; Meuser & Marwit, 2001; Ott et al., 2010; Pinquart & Sörenson, 2004). Despite this, literature to date has not been synthesised to identify effective interventions to assist in this area.

1.5. Research Question and Objective

The aim of this research was to conduct a systematic review of the literature on grief and loss and psychotherapy as it pertains to the dyad of the person with dementia and their caregiver. The research question was to identify psychotherapeutic interventions that are effective in ameliorating the effects of grief and loss experienced by adults experiencing dementia, prior to entering an aged care facility, and assist their caregivers as a dyad to cope with the experience of grief and loss. The grief and loss experienced by the dyad is a direct result of dementia diagnosis.

It was expected that evidence-based interventions would be identified that have been found to be effective in helping the dyad cope with the grief and loss associated with a dementia diagnosis. By identifying psychotherapeutic interventions that are effective in

alleviating the grief and loss experienced by people with dementia, and their caregivers, it is hoped that this will result in an improved standard of living by ameliorating these on both members of the dyad. It was also expected that this identification would help the dyad and health care team make better informed choices regarding psychotherapeutic interventions.

Chapter 2 – Method

This systematic literature review was undertaken using the Joanna Briggs Institute (JBI) Systematic Review approach as its framework (Aromataris & Munn, 2017). In the following chapter the methodology undertaken to systematically review the literature will be presented.

2.1. Search Strategy

The initial step in the systematic review process was to design an *a priori* systematic review protocol as per the JBI Reviewers' Manual (Aromataris & Munn, 2017). The protocol included: (1) the title of the systematic review, (2) the research question, (3) background to the study, (4) the search strategy, (5) inclusion and exclusion criteria, (6) how studies would be selected, (7) what critical appraisal approach would be used, (8) how the data would be extracted, and (9) data synthesis. A panel of experts assessed the protocol and gave feedback on the search strategy and inclusion and exclusion criteria that was incorporated into the protocol that was used for the review.

A three-phase search strategy was used to systematically search and locate relevant literature within selected electronic databases. Phase one consisted of the identification of appropriate key search words and electronic databases. This became the basis of the search strategy that was presented in the protocol. Phase two involved searching relevant electronic databases and phase three involved a review of the reference lists from the selected studies.

In phase one keywords were identified in collaboration with a research librarian, to ensure that the relevant literature that met the inclusion criteria was captured. The following keywords were considered appropriate to the research question: (dementia OR alzheimer*) AND (grief OR loss) AND (carer? OR caregiver?) AND (psychotherapy OR treatment OR intervention). These keywords were chosen specifically to optimise the balance of

sensitivity-specificity while maintaining the aim of capturing all relevant literature during the search. The electronic databases included in the search were deemed to best acquire the relevant literature were: EBSCOhost MegaFile Ultimate Academic Search Complete, E-Journals, PsycARTICLES Psychology, Behavioural Sciences Collection, PsychINFO; PubMed, Science Direct. Grey literature, in the form of dissertations and theses, were also searched using the databases ERIC and ProQuest Dissertations and Theses A&I.

In phase two, database searching was conducted independently by both the researcher and a research assistant. Any disagreement between the researcher and research assistant was resolved through consensus. The aforementioned keywords were searched across all databases using the field “Abstract”. A total of 1020 records was located across all databases and imported to EndNote X8.1 (Thomson Reuters, 2018) for further examination. Results for each of the databases were as follows: EBSCOhost MegaFile Ultimate Academic Search Complete (91), E-Journals (143), PsycARTICLES Psychology (2), Behavioural Sciences Collection (24), PsychINFO (176); PubMed (486) and Science Direct (42), ERIC (10) and ProQuest Dissertations and Theses A&I (46).

2.2. Screening Phase, Inclusion and Exclusion Criteria

A search for duplicates was run via EndNote X8.1 (Thomson Reuters, 2018), leading to removal of 354 records. A total of 666 records remained for screening using the inclusion and exclusion criteria in Table 1. The title and abstract of these articles were examined independently by both the researcher and research assistant and 30 articles were short-listed for further review. The full text of the short-listed literature was reviewed in accordance with the criteria listed in Table 1. Any disagreement between the researcher and research assistant was resolved through discussion until arrival of consensus.

Table 1

Summary of Inclusion and Exclusion Criteria

	Included	Excluded
Study Characteristics		
Participants	Persons diagnosed with dementia, including younger onset dementia.	
	Persons with dementia are to be at an early stage in the progression of dementia so that they have the cognitive capacity to be receptive to psychotherapeutic interventions.	Persons with dementia who are at an advanced stage in the progression of dementia and do not have the cognitive capacity to be receptive to psychotherapeutic interventions.
	Persons with dementia are considered to be at an early stage if they are living at home, capable of performing acts of daily living, and have not transited	Persons diagnosed with dementia who have transited to residential aged care (or similar formalised care outside of the home). Persons with dementia incapable of

	Included	Excluded
	to residential care outside of their home.	performing acts of daily living.
	Caregivers, being those providing informal unpaid assistance to persons with dementia, such as a family member or friend.	Carers, being a paid employee or volunteer of an organisation providing assistance to those experiencing dementia.
Interventions	Psychotherapeutic interventions aimed to improve the psychological wellbeing of the participants of any type and duration.	Non-psychotherapeutic interventions.
Comparisons	All studies	Not applicable.
Outcomes	Studies that met the relevant inclusion criteria and demonstrated effectiveness, or non-effectiveness, in	Not applicable.

	Included	Excluded
	improving the quality of life by ameliorating the effects of grief and loss for the dyad of the person diagnosed with dementia and their caregiver.	
Studies	Studies with psychotherapeutic interventions that focus on the dyad of persons diagnosed with dementia and/or their caregivers experiencing grief and loss. These interventions are to be undertaken with both the person with dementia, and their caregiver, undertaking therapy together.	Focus not related to grief and loss: behaviour (e.g., wandering, incontinence)
Age	Adults	Under 18

	Included	Excluded
Publication Characteristics		
Literature age	From the year 1980 to the present date. Preliminary searches indicated that awareness of dementia and research commenced after this date.	Prior to 1980.
Literature type	Peer-reviewed academic journal articles published in a scientific journal, grey literature to include dissertations and theses.	Book reviews, newspaper articles, government and educational documentation, books and book chapters.
Language criteria of literature	Only literature published in English were to be included in the review due to the limitation in accessing services to translate articles into English.	Not applicable.

2.3. Selection of studies

No articles met the stipulated inclusion criteria to identify research exploring psychotherapy as an effective treatment for grief and loss experienced by the dyad of persons with dementia and their caregiver. In collaboration with the researcher's supervisors, it was decided that the researcher would re-screen the records identified in the aforementioned search. The re-screening focused on psychotherapy for grief and loss for either the person with dementia, or their caregiver. That is, the outcome criteria of therapy being with the dyad was removed in the inclusion process and replaced with therapy with either the caregiver or the person with dementia. Thus, inclusion and exclusion criteria were applied as per the first search, with the exception that participants were either the caregiver or person diagnosed with dementia rather than the participants being the dyad.

The 666 records were re-screened by the researcher using the amended inclusion criteria. The title and abstract of these articles were examined by the researcher and 83 articles were short-listed for further review. Of these 83, eight articles were short-listed for full-text review. No grey literature was located for inclusion in the review. The full text of the short-listed literature was examined by the researcher to ensure inclusion criteria were met and, if not, they were discarded.

In total, four of the short-listed eight articles selected for review were discarded due to not meeting the selection criteria. Reference lists of the four remaining articles were reviewed by the researcher for further literature appropriate for inclusion. As a result of this, one further article was identified for full-text review and was discarded as it did not meet the inclusion criteria. Four articles were considered appropriate for inclusion in the review.

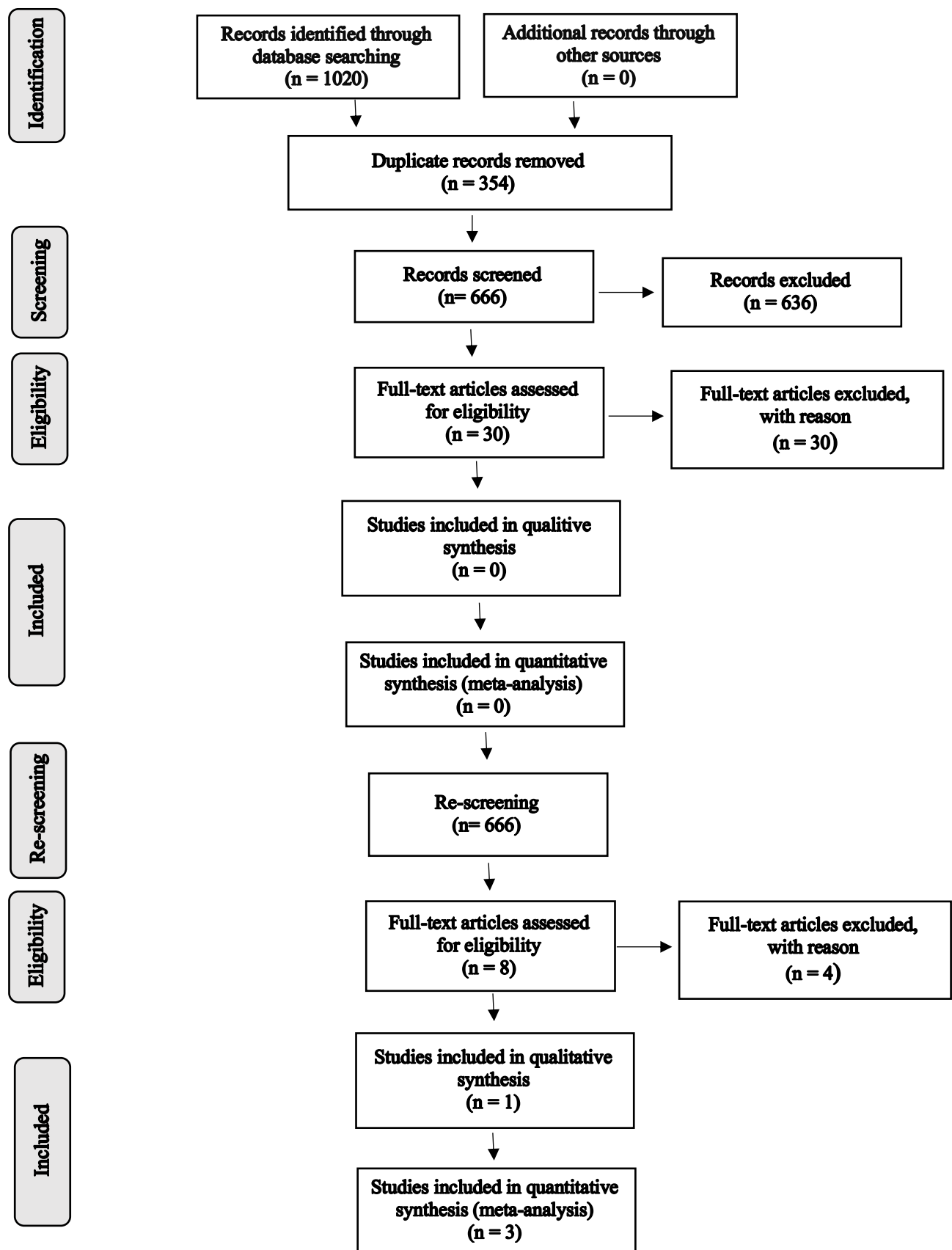


Figure 1. Flow diagram indicating the search procedure

2.4. Data Extraction, Quality Appraisal and Data Synthesis

Critical appraisal was conducted by the researcher to determine the quality of a study's methodology and the extent that bias had been controlled throughout the research design, conduct and analysis. The JBI Critical Appraisal tools: Checklist for Randomised Control Trials, Checklist for Qualitative Research and Checklist for Quasi-Experimental Studies were used as the quality appraisal in this study. These checklists are located at Appendix A.

In this review, data were extracted from each of the selected studies using the JBI standardised data extraction tool: JBI Data Extraction Form for Experimental/Observational Studies. A copy of this form is located at Appendix B. The data extracted included details such as the publication, study design, participants, interventions, comparators, outcomes and results. Extraction of data was undertaken independently by the researcher. Data synthesis was performed by the researcher to evaluate the effectiveness of the interventions upon either the person with dementia or the caregivers experiencing grief and loss as a result of the diagnosis.

Chapter 3 – Results

3.1 Data Synthesis

The following four journal articles were eligible for inclusion in the review: MacCourt et al., (2017), Meichsner et al., (2016), Meichsner and Wilz (2016) and Ott et al., (2010). All four studies focussed upon the effects of grief and loss experienced by the caregiver. No research was identified that focused on the person with dementia.

These four studies comprised data that were collected from a total of 449 participants with sample sizes ranging from 20 to 273 ($M = 112.25$, $SD = 116.54$). The age of the participants ranged from between 45 to 87 years. Approximately 81% were female and 19% were male. Participants were recruited in a number of different ways, including by local media, cooperating institutions, primary care physicians and support groups sponsored by the Alzheimer's Association, adult care centres and referrals from the Alzheimer's Society of British Columbia. The studies were conducted in, and data collected from, Canada, Germany and the United States of America. The psychotherapeutic interventions administered included coaching, telephone-based cognitive behavioural therapy, and a five-component intervention pilot study. Study designs included mixed-methods, qualitative research, randomised-control trial, and single-group repeated measures. Outcomes that were measured included coping, resilience, levels of grief, depression, anxiety, positive states of mind, self-efficacy and quality of life.

Table 2 overviews the four articles in alphabetical order. The overview comprises the articles' authors, year and location of publication, the study design, the focus of the study, measures used, key findings and limitations of the study. Analysis of the four articles are located beneath Table 2.

Table 2

Synopsis of the four articles

Authors/Year/ Location	Study Design	Focus of Study	Sample	Measures	Key Findings	Limitations
MacCourt, McLennan, Somers, and Krawczyk, (2017), Canada	Mixed methods design (only quantitative results were reported in the article)	Caregivers To determine the effectiveness of a coaching intervention with caregivers of persons with dementia by increasing caregivers' coping and resilience, as well as decreasing levels of grief	There were 200 participants including 123 participants in the intervention group and 77 participants in the control group. Age ($M = 64.4$) 79% female 21% male	Data were collected for both pre-intervention (Time 1) and post- intervention (Time 2) for both the intervention and control groups. Data were collected using the following instruments: <ul style="list-style-type: none">• <i>The Demographic and Caregiving Characteristics Questionnaire</i> (McGee & Tuokko, 2005)• <i>The Caregiver Grief Inventory</i> (Marwit & Meuser, 2002)• <i>The Empowerment Questionnaire</i> (Man, 1998 adapted by McGee & Tuokko, 2005)	<ul style="list-style-type: none">• At Time 1 no significant difference in grief was noted between the intervention group and the control group. At Time 2, scores indicated that the intervention groups exhibited less grief when compared to the control group.• Grief scores declined from Time 1 to Time 2 for participants in the control group and the intervention group. A declination in grief scores indicated a	<ul style="list-style-type: none">• Group outcomes may have been affected by the skills and expertise of the presenter delivering the intervention. This was particularly in terms of the presenter's experience with, and exposure to, dementia care grief and whether they could adapt their coaching skills to be appropriate to each individual. These outcomes may have been reflected in grief levels either increasing or decreasing.• Participants volunteered to participate in the coaching intervention

Authors/Year/ Location	Study Design	Focus of Study	Sample	Measures	Key Findings	Limitations
				<ul style="list-style-type: none"> • <i>The Brief COPE</i> (Carver, 1997) in a shorter form • <i>The Resilience Scale</i> (Wagnild & Young, 1993) <p>Five methods of delivery included:</p> <ul style="list-style-type: none"> • Individual (face-to-face); • Individual (telephone); • Group (face-to-face); • Group (telephone); and • Group (online). <p>Multivariate analysis were conducted to explore relationships between:</p> <ul style="list-style-type: none"> • Participant outcomes; • Participant characteristics; and 	declination in grief experienced.	<p>possibly leading to self-selection bias and a possible over-representation of help-seeking caregivers.</p> <ul style="list-style-type: none"> • Data were not gathered on the participant's socio-economic status, nor their ethnicity. Participants consisted predominantly of Caucasians, with average to above average income backgrounds. This lack of diversity may impact generalisability to the greater population.

Authors/Year/ Location	Study Design	Focus of Study	Sample	Measures	Key Findings	Limitations
				<ul style="list-style-type: none"> Methods of delivering intervention. <p>Subscales on the four instruments were collapsed.</p>		
Meichsner, Schinköthe, and Wilz (2016), Germany	Qualitative Research Design	<p>Caregivers</p> <p>The aim of the study was to provide an understanding of issues explored by therapists, as well as intervention strategies used to support caregivers experiencing grief and loss, using cognitive behavioural therapy-based intervention.</p> <p>Examination of a telephone-</p>	<p>The sample initially consisted of 229 caregivers who were allocated into three groups: intervention, treated control group, or untreated group.</p> <p>Only the intervention group ($n = 129$) sessions were considered for analysis and the transcripts from this group were scrutinised to determine</p>	<p>Qualitative content analysis using a category system consisting of four categories to represent grief intervention strategies:</p> <ul style="list-style-type: none"> Recognition and acceptance of loss and change; Normalisation of grief; Redefinition of the relationship; and Addressing future losses. <p>These categories were assigned to sequences during the coding process of therapy sessions that</p>	<ul style="list-style-type: none"> Grief interventions were more likely to occur in earlier stages of therapy The intervention strategies coded as “recognition and acceptance of loss and change”, “addressing future losses”, “normalisation of grief” and “redefining of the relationship” were most frequently used The strategy of “recognition and acceptance of loss and change” was used most frequently 	<ul style="list-style-type: none"> Only techniques that directly applied to grief and loss were transcribed, leading to possible omission of strategies indirectly related to grief and loss. Telephone therapeutic interventions do not allow for non-verbal communication and assessment by the therapist. These factors may impact the overall assessment and intervention provided if non-verbal cues are missed.

Authors/Year/ Location	Study Design	Focus of Study	Sample	Measures	Key Findings	Limitations
		based cognitive behavioural therapy intervention to support caregivers experiencing grief.	<p>whether their sessions addressed grief and loss.</p> <p>Only sessions (61) that addressed grief and loss were included in the analysis.</p> <p>Of the intervention group 33 caregivers (26.19 % of intervention group) received grief intervention treatment.</p> <p>Age: 45-87 ($M = 62.97$, $SD = 10.46$)</p> <p>Female: 90.9% ($n = 30$)</p> <p>Male: 9.1%</p>	<p>included grief interventions.</p> <p>The deductive approach was used to determine the appropriate categories and additional strategies were also added using the inductive approach (additional strategies added after observing and reasoning were undertaken during the research process).</p> <p>Qualitative content analysis (Mayring, 2004) is described as a “systematic theory and rule-based analysis of communication” due to the allowance for structure and differentiating between intervention strategies.</p>	<p>in 41 of 61 sessions (47.31%)</p> <ul style="list-style-type: none"> • The strategy “addressing future losses” was used in 21 of 61 sessions (22.58%) • The strategy of “normalisation of grief” was used in 13 of 61 sessions (13.98%) • The strategy of “redefinition of the relationship” was used in 9 of the 61 sessions (9.68%) • Results of the qualitative content analysis identified intervention strategies that could be used by therapists to support caregivers experiencing grief, resulting from the person they are 	

Authors/Year/ Location	Study Design	Focus of Study	Sample	Measures	Key Findings	Limitations
			(<i>n</i> = 3)		caring for experiencing dementia.	
Meichsner, and Wilz, (2016), Germany	Randomised control trial	<p>Caregivers of persons with dementia residing at home, prior to transiting to an in-care facility.</p> <p>The aim of this study was to evaluate the effectiveness of a manualised telephone-based cognitive behavioural therapy intervention on pre-death grief of caregivers of persons with dementia.</p>	<p>There were 273 caregiver participants</p> <p>Age: 23-91 (<i>M</i> = 64.20, <i>SD</i> = 11.04)</p> <p>Female: 80.6% Male: 19.4%</p> <p>Baseline participants: Control group (<i>n</i> = 134) Telephone intervention group (<i>n</i> = 139).</p> <p>Post-intervention assessment (6 months):</p>	<p>Assessment was conducted at:</p> <ul style="list-style-type: none"> • Baseline; • 6 months post-intervention; and • 6 months follow up. <p>The questionnaire used to assess coping with pre-death grief was the Caregiver Grief Scale (CGS; Meichsner et al., 2016a)</p> <p>The intervention group received twelve, 50 minute therapy sessions over a period of six months.</p> <p>The control group were in receipt of written literature on dementia, caregiving and given 40 euros for participating.</p>	<ul style="list-style-type: none"> • The use of problem actualisation (Grawe, 2004) by therapists, to address loss and loss-related emotion, resulted in changed caregiver behaviour and acceptance of change and painful emotions. It also resulted in a reduction in grief experienced by the caregiver. • At six months post-intervention results indicated caregivers were experiencing a reduction in grief experienced by “working through the grieving process” Meichsner 	<ul style="list-style-type: none"> • The intensity of the intervention sessions and the implementation by the therapists of the interventions were not controlled across all participants, allowing for inconsistencies. Further implications may include the possibility of the intensity of therapy sessions affecting the effectiveness of the therapy being administered to the participants • Focus was on caregivers of persons with dementia residing at home, prior to entering an in-care facility, rather than being generalised across the person’s life

Authors/Year/ Location	Study Design	Focus of Study	Sample	Measures	Key Findings	Limitations
			<p>Control group ($n = 104$)</p> <p>Telephone intervention group ($n = 108$)</p> <p>Follow up (6 months post-intervention):</p> <p>Control group: ($n = 89$)</p> <p>Telephone intervention group: ($n = 97$)</p>		<p>& Wilz, 2016, p. 223).</p> <ul style="list-style-type: none"> At 6 months post-intervention the intervention group caregivers appeared to have come to terms with their grief more effectively than those in the control group. Home-caregivers were found to be experiencing lower levels of grief, in the post-intervention group, than those whose caregiving recipient had transitioned to an in-care facility. Results indicated that scores for pre-death grief were significantly influenced when the relationship between 	<p>span. As persons with dementia are likely to enter an in-care facility as dementia severity increases this may affect generalisability to the population of persons with dementia.</p> <ul style="list-style-type: none"> Telephone therapeutic interventions do not allow for non-verbal communication and assessment by the therapist and may impact the overall assessment and intervention provided if non-verbal cues are missed.

Authors/Year/ Location	Study Design	Focus of Study	Sample	Measures	Key Findings	Limitations
					the caregiver and the person with dementia was being assessed. It was found that spouses experienced more pre-death grief than children.	
Ott, Kelber, and Blaylock, (2010), United States of America	Single-group, repeated measures design	Caregivers To determine the effectiveness of the five component “Easing the Way” intervention pilot manual. Exploration of changes in caregiver grief as a result of the implementation of the intervention	There were 20 spouse caregiver participants. Age: 56-85 ($M = 77.7$, $SD = 7.8$) Female: 75% Male: 25%	An adaption of <i>The Caregiver Questionnaire</i> (Mittelman et al., 2003) Grief: Marwit and Meuser’s (2005) <i>Caregiver Grief Inventory Short Form</i> (MMCGI-SF) <i>Depression and anxiety: 20 item Centre for Epidemiologic Studies Depression Scale</i> (CES-D) (Radloff, 1977) and <i>20 item State-Trait Anxiety Inventory</i> (STAI) (Spielberger, 1983) <i>Positive States of Mind: Positive States of Mind</i>	<ul style="list-style-type: none"> Results indicated that grief declined significantly when comparing assessment at baseline to assessment at completion of the intervention. During the course of the intervention 8 of the 20 caregivers were found to no longer be living with their spouses after three months. Analysis indicated that grief scores remained stable for the remaining 12 	<ul style="list-style-type: none"> The lack of a control group does not allow for comparison of results to determine whether the intervention had an effect on the participants levels of grief in the intervention group. The intervention was carried out by the principal investigator of the study, possibly leading to researcher bias given that they had primary interest in the study and its results.

Authors/Year/ Location	Study Design	Focus of Study	Sample	Measures	Key Findings	Limitations
		was also a focus.		<p>(Horowitz, Adler, & Kegeles, 1988)</p> <p><i>Self-Efficacy: The General Self-Efficacy Scale</i> (Schwartz & Jerusalem, 1995)</p> <p><i>Coping Strategies: The Brief Cope</i> (BC) (Carver, 1997)</p> <p><i>Program Acceptability: Interview</i></p> <p>The participants were assessed at:</p> <ul style="list-style-type: none"> • Baseline; • Post-intervention; and • Follow up (8 months post-intervention). 	<p>participants at three month follow up.</p> <p>For the 8 caregivers whose spouses were either living in-care or who had passed away it was found that their grief scores had returned to baseline.</p> <ul style="list-style-type: none"> • Significant results indicated that baseline dysfunctional coping and grief were correlated. As grief increased a decrease was noted in positive state of mind. • A correlation was not found between the amount of intervention delivered and grief experienced. 	<ul style="list-style-type: none"> • Participants volunteered to participate in the coaching intervention possibly leading to self-selection bias and a possible over-representation of help-seeking caregivers. • There was a lack of ethnic diversity in the spousal caregivers. Prior research has indicated that different ethnic backgrounds may experience caregiving differently (Hayley et al., 2004). • Due to the study being a pilot study there was only a small sample of 20 participants included in the study.

Authors/Year/ Location	Study Design	Focus of Study	Sample	Measures	Key Findings	Limitations
					<ul style="list-style-type: none"> There was no significant difference noted between participants receiving in-person sessions or telephone sessions. 	

3.1.1 MacCourt, McLennan, Somers and Krawczyk (2017)

Data were analysed using paired *t* tests to determine the relationship between pre-intervention (Time 1) and post-intervention (Time 2) for participant outcomes using a control and intervention group to examine and compare the effectiveness of five forms of coaching intervention on grief, sense of empowerment, coping and resilience. Multivariate analyses were conducted to determine the relationship between the levels of grief experienced by participants. The subscales were collapsed for the four instruments used in this study and total scores for each outcome measure were calculated at Time 1 and Time 2 for each participant. Higher scores for grief represented higher levels of grief experienced by participants.

A chi-square analysis was used to compare the control ($n = 77$) and intervention group ($n = 123$) caregiver characteristics. The researchers' results found that there were significant differences in education between groups, $X^2(4, N = 200) = 13.69, p = .008$, indicating that the control group were of a higher education level. Further, it was found that the control group consisted of more caregivers caring for their spouses than the intervention group participants $X^2(4, N = 200) = 10.29, p = .036$. Overall, however, it was found that across characteristics including employment status, gender of care recipient, mean caregiver age, gender of caregiver and months of caregiving, few differences were found between the control and intervention groups and as such, the groups were considered homogenous.

The overall scores were used to measure the differences in outcomes between the control and intervention groups using an independent *t* test. At Time 1 there were no significant differences between the control and intervention group for grief ($p = .987$). Outcome scores were analysed using a paired *t* test to examine differences between Time 1 and Time 2 for both control and intervention groups and found significant differences within the intervention group for grief at Time

2, $t(195) = 2.09$, $p = .038$; no significant differences when assessing the control group between Time 1 and Time 2 ($p = .074$); and significant differences when assessing the intervention group between Time 1 and Time 2, $t(119) = 5.28$, $p < .001$, with grief scores declining indicating that their level of grief experienced declined during intervention.

For the overall impact of the intervention, an ANCOVA was used to determine if the intervention was affected by the mode of delivery. A significant main effect result was found for the intervention group, ($F(181, 1) = 16.35$, $p = .003$) indicating that less grief was experienced at Time 2 than Time 1. Grief scores at Time 1 ($p < .001$) and lack of university education ($p = .047$) also predicted less grief at Time 2.

3.1.2 Meichsner, Schinköthe and Wilz (2016)

Results were analysed and coded using ATLAS.ti software (2012). These results were obtained from the construction of a category system to code the qualitative content obtained from participants in the study. Using the deductive system, grief interventions and dementia caregiving grief were reviewed from literature and strategies for intervention were recommended to be used as categories. Using the inductive approach, further strategies were added from transcripts and rules for coding and anchor items were also added to the category system. The category systems used for grief intervention strategies were coded as follows: “recognition and acceptance of loss and change”, “addressing future losses”, “normalisation of grief” and “redefining of the relationship”. It was found that these grief interventions assisted in the acceptance of loss and emotional processing in caregiver’s self-report.

The strategy of “recognition and acceptance of loss and change” was used most frequently in 44 of 61 grief intervention sessions (47.31%). Loss of communication, intimacy and change of rituals were addressed in this category, as well as future plans for retirement that were no longer

valid. During this intervention strategy, psychoeducation was used to provide the caregivers with the insight that loss was part of dementia, and link caregiver emotions such as anger, grief, and guilt to the identified losses. The anchor item for this category was:

“Because of this disease, he has changed so much; he is not the man you married, the man he used to be, anymore. In reality, you have already had to say goodbye to your husband, even though he is still alive” (Meichsner et al., 2016, p.235).

The coding rule for this category was:

The therapist concretises and explores what has changed due to the disease and which losses (primary or secondary) the caregiver has experienced. The therapist asks the caregiver to name and describe associated emotions from specific situations. Also focuses on feelings of guilt (Meichsner et al., 2016, p.235).

An example of an exchange between therapist and caregiver, in receipt of psychoeducation provided on loss was:

“Therapist: There is a difference between someone who has a partner, but that partner is not capable of being a real partner anymore, and someone who does not have a partner at all and who can get used to the situation. You are married, you have a partner. But still he cannot offer you what that healthy man could offer.”, “Caregiver: Yes.”, “Therapist: And that is sad, that is what is sad about dementia. Sometimes, it is easier to accept it when somebody dies, but this disease is so difficult to bear because the person is still here but also gone” (Meichsner et al., 2016, p.236).

The strategy of “addressing future losses” was found to be addressed in 21 of the 61 grief intervention sessions (22.58%). During the sessions addressing future losses, therapists assisted in addressing feelings of anticipation relating to future loss of the person with dementia. This was addressed by the focus being placed on achieving acceptance of the loss that was forthcoming, which

was avoided by many caregivers. Resources were identified and provided to caregivers to enable future coping. The anchor item for this category was: “You said, you hope you don’t have to go as far as putting your husband in a nursing home... How do you cope with the fact that your husband is suffering from a terminal disease?” (Meichsner et al., 2016, p.235). The coding rule for this category was “The therapist focusses on anticipatory grief, painful future decisions associated with grief, and plans for the future, which can include the time after the care recipient has died” (Meichsner et al., 2016, p.235). An example of an exchange between therapist and caregiver, identifying resources for coping with anticipated losses included:

“Therapist: Saying goodbye is a difficult topic that we don’t like to think about. But it could be helpful to think about it before it is imminent, although you don’t know exactly what is coming, to think about what you would need for it to be a good goodbye. Something you would like to have done together or what you would like to have said. Just as a preparation to feel - I don’t know if you could call it that – “ready”. I think it is helpful to prepare for these difficult moments by thinking them through” (Meichsner et al., 2016, p.237).

The strategy of “normalisation of grief” was used in 13 of 61 of the grief intervention sessions (13.98%). During the sessions addressing normalisation of grief, therapists provided education on both accepting emotions and encouraged expressions. They further provided explanations that grief is normal and that acknowledgment of grief is beneficial for one’s mental health. Self-care was also encouraged. The anchor item for this category was “I think it is normal to be sad once in a while. I think it is quite important.” “Well, because... you worry you could become depressed if you allow yourself to grieve, be sad...” (Meichsner et al., 2016, p.235). The coding rule for this category was:

The therapist explains that grief is a normal reaction to a family member's dementia that caregivers should allow themselves to grieve, and that grief does not cause mental health problems. Can also be directed at grief or expressions of grief (e.g., crying) experienced during the therapy session (Meichsner et al., 2016, p.235).

An example of framing grief as a normal reaction, validation of its expression was:

“Therapist: This sadness you are feeling is absolutely normal and it is important to allow yourself to grieve. These negative emotions are absolutely normal; they are a kind of signal... - they mean that you had a wonderful time with your husband and it is very important to give them space and to admit them for a moment, okay? Caregiver: Yes, I am admitting them” (Meichsner et al., 2016, p.237).

The strategy of “redefinition of the relationship” was used in 9 of the 61 of the grief intervention sessions (9.68%). During these sessions, therapists addressed caregiver's lack of insight into the change of roles that they were experiencing during their time of caregiving. Exploration into the way in which the roles of the caregiver and the person with dementia had changed, as well as focus on redefinition of the relationship, was undertaken. The anchor item for this category was “You are not husband and wife anymore. Maybe you are mother and child, but more likely caregiver and care recipient, right?” (Meichsner et al., 2016, p.235). The coding rule for this category was “The therapist focuses on anticipatory grief, painful future decisions associated with grief, and plans for future, which can include the time after the care recipient died” (Meichsner et al., 2016, p.235). An example of redefinition includes:

“Therapist: Anyway, your relationship has changed; it is not like it used to be anymore. That is painful; you are not husband and wife anymore. Maybe you are caregiver and care recipient now, aren't you? ... “Caregiver: Well, you know what I

think sometimes? It would be better if I could define us as caregiver and patient”
(Meichsner et al., 2016, p.237).

Results from the analysis of sequences, from a larger study (Wilz, Schinköthe & Soellner, 2011), relevant to the research question were found to be supportive of the concept that grief experienced by dementia caregivers is multifaceted and it was anticipated that the strategies used to address “recognition and acceptance of loss and change”, “addressing future losses”, “normalisation of grief” and “redefining of the relationship” may be used for future therapy to alleviate symptoms of grief and loss.

3.1.3 Meichsner and Wilz (2016)

Data were analysed using the latent state model and latent change model across time and study groups. This method was used to determine measurement invariance and to test for changes in pre-death grief. The pre-death grief scores were as follows for the intervention group: baseline ($n = 139$, $M = 3.73$, $SD = 0.85$); post-intervention ($n = 108$, $M = 3.42$, $SD = 0.91$); and follow up ($n = 97$, $M = 3.32$, $SD = 0.94$). The pre-death grief scores were as follows for the control group: baseline ($n = 134$, $M = 3.67$, $SD = 0.80$); post-intervention ($n = 104$, $M = 3.50$, $SD = 0.93$), and at follow up ($n = 89$, $M = 3.61$, $SD = 0.89$).

Results for the latent change model, including study group as a predictor of change, indicated that pre-death grief from baseline to post-intervention were not significant for the study group ($\beta = -.13$, $p = .124$), however, results identified that the study group caused change between baseline and follow-up ($\beta = -.26$, $p = .003$, $d = -0.36$). It was found that a score for the intervention group declined in strength for pre-death grief in the intervention group when compared to the control group. Standardised regression coefficients in the latent change models were as follows: from

baseline to post-intervention ($\beta = -.13$, $SE = 0.085$) and from baseline to follow up ($\beta = -.26$, $SE = 0.09$), indicating a significant interaction between baseline to follow up.

Results for the latent change model, including study group and care situation, found that after controlling for differences in care, the study group impacted significantly on pre-death grief change from baseline to follow up ($\beta = -.92$, $p < .001$, $d = -0.43$). The situation with care during post-intervention assessment indicated significant influence on pre-death grief change from baseline to post-intervention ($\beta = -.18$, $p = .008$, $d = -0.32$), indicating that caregivers caring for persons with dementia at home showed stronger decline in pre-death grief. Other predictors did not pose significant influence (all $p > .05$).

Results for the latent change model, including study group, care situation and sociodemographic variables found that after controlling predictors, the study group influence on pre-death grief change remained significant between baseline and follow-up ($\beta = -.91$, $p = .004$, $d = -0.35$). Further, the study group influenced change between baseline and post-intervention significantly ($\beta = -.70$, $p = .042$, $d = -0.25$).

After controlling for predictors, it was found that participants who were still home caregivers, at the time of post-intervention assessment, retained the reduction in pre-death grief from baseline to post intervention with results remaining significant ($\beta = .20$, $p = .001$, $d = -0.40$). Caregiver relationship to person with dementia had an influence on the baseline of pre-death grief values ($\beta = .21$, $p = .001$, $d = -0.399$), however, gender did not have an influence on the pre-death grief baseline value ($\beta = .13$, $p = .057$), indicating that being a spousal caregiver predicted higher levels of pre-death group. There was no significance found with the influence of all other predictors (all $p > .05$).

3.1.4 Ott, Kelber and Blaylock (2010)

Data were analysed using paired *t*-tests and repeated measures analysis of variance (ANOVAs). Paired *t* tests were used to compare the means of grief of participants ($N = 20$) from baseline ($M = 56.68$, $SD = 11.28$) to completion of the intervention ($M = 51.91$, $SD = 11.10$) and showed significant changes with grief having decreased ($t = 2.41$, $p = 0.026$, $d = -0.04$), indicating positive change.

Data were further analysed using repeated-measures ANOVAs to analyse whether the caregiver living at home ($n = 12$) with the person with dementia affected the levels of grief experienced, compared to participants that during the study experienced their caregiving recipients entering an aged care facility ($n = 8$). For the 12 participants that continued in-home care, scores were recorded at baseline ($M = 51.8$, $SD = 10.26$), month 5 ($M = 47.7$, $SD = 10.18$) and month 8 ($M = 46.8$, $SD = 10.47$). Grief scores remained stable at the three-month follow up assessment. For the 8 caregivers whose spouses had either moved into an in-care facility, or who had passed away, it was found that their grief scores returned to baseline. It was noted by the researchers that, due to the small sample sizes, some of the measures lacked statistical significance. They further stated that, despite this, the trends and effect sizes remained noteworthy.

Data were analysed to compare grief and positive states of mind as well as grief and strategies for coping using paired *t* tests from baseline to completion of the intervention. Results indicated positive change when comparing grief and positive states of mind ($t = 3.04$, $p < .001$, Cohen's $d = .79$). Strategies for coping by caregivers when comparing levels of grief were found to be varied among the caregivers. At initial intake, it was found that the majority of caregivers used a problem-focussed coping style ($t = 2.90$, $p < .001$, $d = 0.49$), rather than an emotion-focussed style (t

= 3.81, $p < .001$, $d = 0.42$), followed by dysfunctional coping ($t = 2.00$, $p = .035$, $d = -0.37$).

Results indicated that dysfunctional coping and grief were significantly correlated ($r = 0.62$, $p = .004$). As dysfunctional coping increased, grief also increased.

Finally, it was found that there was no significant correlation between the amount of intervention delivered and the amount of grief experienced. There was also no significant difference in the amount of grief experienced between participant's receiving face to face support as opposed to telephone intervention.

Chapter 4 – Discussion

The aim of this research was to locate and conduct a systematic review of the literature on psychotherapeutic interventions for persons with dementia, and their caregivers, experiencing grief and loss. The grief and loss experienced by the dyad is a direct result of dementia diagnosis. A further purpose of this research was to identify psychotherapeutic interventions that were effective in ameliorating the effects of grief and loss experienced by both persons experiencing dementia, and their caregivers as a dyad, and assist them to cope with the experience of grief and loss.

It was expected that evidence-based interventions would be identified that have been found to have been effective in helping the dyad cope with the grief and loss associated with a dementia diagnosis. The expected outcomes were that by identifying psychotherapeutic interventions that are effective in alleviating grief and loss experienced by people with dementia, and their caregivers, that this would result in increased levels of coping and an improved standard of living by ameliorating the effects of grief and loss on both members of the dyad. It was also expected that this identification would help both the dyad and their health care team make better informed choices regarding psychotherapeutic interventions.

4.1 Key Findings

The systematic literature review was conducted by the researcher and a research assistant using a number of standard databases. In the initial search 666 journal articles were located for screening. The key findings of this systematic literature review were that there had been no research undertaken to explore effective psychological interventions specifically for the dyad of persons with dementia and their caregivers experiencing grief and loss. Further, there had been no research focussing on grief and loss experienced by the person with dementia. Limited research focussing on the grief and loss experienced by caregivers were located. Due to the projected increase in future persons living

with dementia, and the severity of the psychological implications of such a diagnosis, the lack of literature warrants attention. The researcher undertook to locate literature that met all other inclusion criteria, excluding the inclusion criteria stating that participants must be dyadic.

The 666 articles were re-screened and four studies were selected for final review. No literature was located that explored the effectiveness of psychotherapeutic interventions on the person with dementia experiencing grief and loss. Research was located that explored effective psychotherapeutic interventions to reduce the grief and loss experienced by the caregiver using three different types of intervention. The results of all three interventions: (1) telephone-based cognitive behavioural therapy, (2) coaching, and (3) the five component “Easing the Way” interventions (MacCourt et al., 2017; Meichsner et al., 2016; Meichsner & Wilz., 2016; Ott et al., 2010) were found to be potentially beneficial in reducing the experience of grief and loss on the part of the caregiver.

While the methods used in three of the four interventions reviewed were dissimilar, similarities were found within the studies that may contribute to their significant findings. Such similarities include that all participants were caregivers of recipients currently living at home. Of further note was that the majority of participants (81%) were female which may be indicative of the gender being more receptive to acting in a help-seeking manner. In two of the three interventions (1) coaching, and (2) “Easing the Way” five component manual, increasing the level of caregiver coping was a focus for participants as a means to reduce the experience of grief. The remaining two studies used telephone-cognitive behavioural therapy with one exploring therapy using the categories of “recognition and acceptance of loss and change”, “addressing future losses”, “normalisation of grief” and “redefinition of the relationship” to reduce the experience of grief and loss. The other study focussed on problem actualisation (Grawe, 2004) using telephone-cognitive behavioural therapy to

assist with coping with grief and loss, and associated emotions as a result of the loss. All four studies provided positive results which may provide direction for future research to be undertaken.

4.2 Caregiver Grief and Loss

Caregivers of persons with dementia are faced with many caregiving tasks for their care recipient. The demands that are placed on caregivers are ever-increasing and may result in the risk of long term-mental health and physical health concerns as well as premature death (Hebert, Scherr, Bienias, Bennet, & Evans, 2003; Schulz et al., 2004). Due to the gradual losses over time caregivers may develop a chronic state of emotional grief and loss (Boss, 2011; Chan, Livingston, Jones, & Sampson, 2013). Research on caregivers experiencing mental illness has found that psychosocial interventions such as counselling, support groups and education (Sörenson, Pinquart, & Duberstein, 2002) are effective in reducing depression. Limited research has been undertaken on the whether these types of interventions are effective in reducing the caregiver experience of grief and loss.

4.2.1 Telephone-based cognitive behavioural therapy

Two of the four studies reviewed (Meichsner et al., 2016; Meichsner & Wilz, 2016) used telephone-based cognitive behavioural therapy as an intervention to support caregivers of persons with dementia experiencing grief and loss. Meichsner et al. explored strategies that could be used by therapists to support caregivers of persons with dementia experiencing grief and loss. They further explored how these interventions could be applied to support caregivers to prevent further adverse impacts of grief and loss.

Telephone-based interventions used cognitive behavioural therapy techniques to include psychoeducation, thought restructuring of thought dysfunction and balancing negative emotions with positive activities. Results were supportive of the concept that grief is multifaceted (Sanders &

Corley, 2003; Noyes et al., 2010; Sanders et al., 2008) and that the categories of “recognition and acceptance of loss and change”, “addressing future losses”, “normalisation of grief” and “redefinition of the relationship” were all representative of a different aspect of grief. The most commonly used strategy during the intervention process was “recognition and acceptance of loss and change” followed by “addressing future losses”, “normalisation of grief” and finally “redefinition of the relationship”. The frequency of these strategies was considered to be indicative of the most useful and effective form of intervention strategy for persons experiencing grief.

The category of “recognition and acceptance of loss and change” was used to address the relationship and loss of companionship between the dyad of caregiver and the person with dementia. It further addressed the loss of future shared plans and current status of life. Intervention strategies used by therapists included aiding participants to recognise grief and address the associated emotions towards caregiving and emotions felt in given situations surrounding caregiving. Education was provided surrounding emotion to caregivers for them to gain an understanding of why certain emotions were being experienced as well as the natural course of the disorder. This was due to misinformation being previously learnt in relation to the disorder, its cause and the care recipient’s changes in behaviour.

The category of “addressing future losses” was used to address the progressive losses experienced by the caregiver over the trajectory of the disorder, to include the person with dementia’s eventual death. Interventions in this category focussed upon loss that was yet to be experienced due to the progressive nature of the disorder. Emphasis was placed on the importance of discussing future loss so that caregivers were able to prepare for their care recipient’s death. This was due to prior research having found that caregivers that were unprepared for their care recipient’s death and were at an increased risk of complicated grief, depression and anxiety (Hebert, Dang, & Schulz, 2006).

The category of “normalisation of grief” was used to propose grief as being a normal stage of the caregiving process. Grief was framed as being preventative in future mental health and physical issues and not possessing negative consequences. During this phase of treatment therapists provided education about grief and worked with caregivers to restructure thoughts in relation to acceptance and allowance of grief and accepting negative emotions. Acceptance of emotion was considered a key strategy due to research indicating that avoiding negative emotions being related to depressive emotions (Spira et al., 2007).

The category of “redefinition of the relationship” addressed the loss of the relationship between the caregiver and the person with dementia that they were caring for. Therapists focussed upon assisting the caregivers to defining the new roles that they were tasked with. The majority of these relationship were changing from those of spouse or partner, child or friend to caregiver of a person requiring care as if they were a child. Therapists encouraged caregivers to accept the change of role rather than avoid it.

In the research conducted by Meichsner and Wilz (2016) the use of telephone-based cognitive behavioural therapy was also used to determine the effectiveness of the intervention to encourage caregiver acceptance of loss and change and decrease the experience of grief and loss. The intervention used problem actualisation (Grawe, 2004) to target the loss experienced by the caregiver, emotion experienced as a result of this loss, and to assist with coping of pre-death grief. Changes of behaviour were noted and acceptance of change and painful emotions were also found. It was noted at 6 weeks post-intervention that caregivers were working through their experience of grief. At 6 months post-intervention, until follow-up assessment, the caregivers in the intervention group were found to be processing their experience of grief better than the control group.

The findings from this study indicated that caregivers in receipt of telephone-based cognitive behavioural therapy were coping better with the experience of grief than those in the control group

who had received written literature on dementia and caregiving. It was further found that those living at home with the caregiving-recipient experienced lower levels of grief post-intervention than those who had transitioned to a long-term care facility. Prior research supports these findings wherein it was found that caregivers who remain caring for the care recipient at home experience less pre-death grief (Kiely, Prigerson, & Mitchell, 2008). This was thought to be attributed to the caregiver realising the magnitude of care that had been provided, as well as losses that are realised after transition to a long-term care facility has been actioned (Meichsner & Wilz, 2016; Rudd, Viney, Preston, 1999).

4.2.2. Coaching

In the study by MacCourt et al., (2017), coaching was used to decrease the levels of grief experienced, as well as increasing caregiver coping and resilience. Coaching has been described by Biswas-Diener (2010) as the use of a positive psychological intervention that is specific and goal oriented, focusing on positive aspects of a person and their strengths to enhance performance. Results indicated that coaching was effective equally across the five levels of method delivery which included: (1) individual (face-to-face), (2) individual (telephone), (3) group (face-to-face), (4) group (telephone), and (5) group (online). At pre-intervention (Time 1), it was found that the intervention group exhibited more grief than the control group. At post-intervention (Time 2), it was found that the intervention group were exhibiting less grief than the control group. Despite this, scores were not found to be significantly higher for the intervention group at Time 2 than that of the control group.

Caregivers who expressed higher levels of coping and reduced levels of grief at Time 1 experienced higher levels of improvement in all areas at Time 2 than other caregivers. A possible explanation for these results was posed that those presenting with higher levels of coping at Time 1

may have found the coaching more beneficial due to innate strengths such as resilience. During the period of intervention, it was found that the control group experienced an increase in grief and reduced ability to cope from Time 1 to Time 2. It was noted that this was possibly due to raised awareness of dementia and measures imposed during the period between Time 1 and Time 2. Results indicated that those who were caring for spouses experienced higher levels of grief than those who were not. An explanation was posed that higher levels of grief may be experienced in spousal caregiver relationships with their loved one due to the experience of a more intense bond than that of a parent-child bond (Meuser & Marwit, 2001).

4.2.3 “Easing the Way” five component manual

The final study explored the use of “Easing the Way” five component manual, via a pilot study to initiate change in caregiver grief, which was guided by the pre-death dementia caregiver grief model (Meuser, Marwit, & Sanders, 2004; Ott et al., 2010). The researchers’ pilot-tested this intervention to determine its effectiveness prior to conducting a randomised control trial. The model used subscales of heartfelt sadness and longing, worry and felt isolation, and personal sacrifice burden to address pre-death grief and loss.

Caregivers who participated in the study were found to have their experience of grief reduced when comparing baseline to post-intervention assessment. It was further found that the experience of grief was related to coping strategies used by caregivers. This experience of grief in turn influenced depression, stress and burden as well as emotional well-being of the participants. It was noted that these findings are consistent with the model proposed by Meuser et al., (2004).

Caregiver coping strategies were measured at baseline to determine the level individually possessed prior to intervention. Baseline dysfunctional coping, for instance alcohol and drug use, were associated with increased grief experienced. It was recommended that in the instance of poor

coping strategies are identified intervention should focus on increasing these skills (Cooper, Katona, Orrell, & Livingstone, 2008). This can be achieved by addressing dysfunctional thoughts using reframing and self-care. When these methods were adopted it was found that grief levels decreased.

Consistent with the findings of Meichsner et al. (2016) it was noted by Ott et al., (2010) that higher levels of grief are associated with caregivers that are unprepared for their care recipient's death. Consistent with Meichsner and Wilz (2016) were findings of that those living at home with the caregiving-recipient experienced lower levels of grief post-intervention than those who had transitioned to a long-term care facility. Prigerson (2003) states that this is due to the realisation of further losses which in turn increases the experience of grief. As grief levels increased, it was found that positive state of mind decreased. There was no correlation found between the amount of intervention received by participants and the grief that was experienced, nor was there any difference found between participants in receipt of face-to-face therapy or telephone sessions.

4.3 Limitations

The absence of literature relating to effective psychotherapeutic interventions to assist the dyad of adult persons experiencing dementia and their caregivers to cope with the experience of grief and loss resulting from a dementia diagnosis was the main limitation of this review. On speculation, the reason for omission in this area of important research may be due to challenges in practicalities. Such practicalities may include the awareness, or availability, of therapies available. Further, often the delay between the onset of dementia and diagnosis may prove challenging in caregivers' ability to seek out support. This is due to the progressive nature of dementia whereby the time that the caregiver seeks psychotherapeutic intervention their loved one may be too advanced to participate. A further consideration is that participants' involvement in the studies may have alleviated their experience of grief. In many studies on grief, isolation and feelings of loneliness have been shown

to exacerbate feelings of grief. Participants' interaction in studies therefore may have been a contributory factor to the improved results in the reviewed studies.

The literature located and reviewed in this study (MacCourt et al., 2017; Meichsner et al., 2016; Meichsner & Wilz., 2016; Ott et al., 2010) found support for psychotherapeutic interventions reducing caregiver grief and loss only. An absence of literature was found on interventions that explored the effectiveness in ameliorating the effects of grief and loss on the part of the person diagnosed with dementia. Further research to determine whether the interventions are effective in reducing the experience of grief and loss for the dyad is necessary.

Limitations were noted in the researcher's conduct of the systematic literature review. Such limitations included the re-screening of records being conducted only by the researcher without the assistance of the research assistant possibly leading to selection bias of the literature. Data were also extracted by the researcher only which could have possibly resulted in the omission of relevant data. Despite these limitations, the absence of a research assistant is not uncommon during the process of systematic literature review. Other limitations included the lack of inclusion of non-english studies, book chapters and grey literature in the form of reports or conference proceedings which may have contained important research findings.

Differences in participant recruitment and samples across the four studies also presented limitations. Participant self-selection was used for two of the four studies (Ott et al. 2010; MacCourt et al., 2017), allowing the possibility of self-selection bias and the over-representation of help-seeking caregivers. It was further noted that in two of the studies, there was a lack of ethnic diversity (Ott et al., 2010; MacCourt et al., 2017) and socioeconomic diversity, which may affect the generalisability of these findings to a broader community of caregivers of persons with dementia. The types of psychotherapeutic interventions explored also presented limitations. In the studies

undertaken by Meichsner et al., (2016) and Meichsner and Wilz (2016) telephone-based therapeutic interventions were used. It can be noted that a limitation of telephone therapeutic interventions is that only verbal cues are able to be considered. This means that non-verbal cues such as body language and facial expressions are missed which may provide valuable insight into the participant's emotional state.

A third study was undertaken as a manualised five component "Easing the Way" intervention pilot study with a sample size of only 20 participants. The participants in this study consisted of spousal caregivers only, meaning that results of this study may not be applicable to caregivers other than spouses, such as children caregivers. This study also lacked the presence of a control group to control for extraneous variables (Ott et al., 2010). While results were significant, indicating that the intervention was found to ameliorate grief and loss on the part of the caregiver, further research is required to ensure that the results are able to be generalised beyond this sample.

The final study used the administration of a coaching intervention. Results of this research may have been dependent on the level of expertise and delivery of the presenter. A presenter with a high level of experience may induce greater results than one that has had little experience in presenting (MacCourt et al., 2017). The literature stated that the mixed-methods design was used for the research, however, only qualitative data were reported. The absence of these data is curious and leads to questions of its relevance and of the accuracy of the literature as a whole. This study also lacked the presence of a control group to control for variables which may have affected the group outcomes of the groups of the research undertaken.

4.4 Implications and Future Research

Despite a rigorous and systematic approach to reviewing the literature currently available, this review was unable to identify articles using psychotherapeutic interventions to reduce the experience

of grief and loss and increase coping in the dyad of a person with dementia and their caregiver. It can therefore be concluded that there has not been any published research undertaken to support the dyad to date. This finding is important, as it highlights an area of research that is yet to be explored. A plethora of research has been undertaken to highlight the detrimental effects of a dementia diagnosis, to include the experience of grief and loss. In such, research is essential in order to ensure that appropriate support services are provided to all during this distressing time. Therefore, to improve outcomes for people with dementia and their caregivers, future research should identify effective interventions to support both individuals dealing with a dementia diagnosis.

Research exploring the effects of telephone-based, cognitive behavioural intervention for dementia caregivers found that caregivers reported that the grief interventions implemented assisted in the acceptance of loss and allowed for processing of their emotions (Meichsner et al., 2016). It was also found that by focusing on accepting a new reality that this approach was congruent with grief counselling and bereavement therapy, including acceptance and commitment therapy. This allowed for acceptance of loss, change and negative and painful emotions that may otherwise be avoided (Kasl-Godley, 2003). Research indicated that caregivers of persons with dementia struggle with recognising that they experience grief, and further find it difficult to talk about. This understanding may assist therapists' decision making with areas to target, while being mindful that this avoidance can also be protective in certain cases. More research is required to understand and explore ways for therapists to identify grief and whether it is appropriate to discuss that grief during therapy.

Research by Meichsner & Wilz (2016), Maccourt et al., (2017) and Ott et al., (2010) highlighted the importance of future research being undertaken to explore the long-term effects of pre-death grief and whether pre-death grief interventions alleviate the experience of post death grief. A longitudinal designed study would be an appropriate approach to explore these questions.

Online and telephone-based coaching interventions (MacCourt et al., 2017) were found to be a way to increase support to caregivers finding it difficult to travel to therapeutic appointments. These methods of intervention are also cost-effective and allow for those in rural areas or with age or health-based issues to access therapeutic support. It was noted that, despite lack of contact being considered a limitation, participants' results improved regardless of whether the method of intervention accessed was by face-to-face therapists, or support via the phone. This indicates that these methods of intervention can meet the needs of caregivers who find treatment difficult to access due to their geographical location.

Ott et al., (2010) recommended that research in the future randomly allocate participants to treatment and control groups, and that ethnically-diverse populations need to be included as participants. They further stated that future studies required larger sample sizes to avoid questions of adequate power. The experience of those administering the interventions requires consideration and the inclusion of qualified health care practitioners with prior knowledge of grief, loss, dementia and community resources as participants is needed. The use of other interventions considered to be effective upon grief and loss, such as Interpersonal Therapy (Howarth, 2011), Focussed Family Grief therapy (Kissane & Bloch, 2002) and Complicated Grief Therapy (Howarth, 2011; Shear, Frank, Houck & Reynolds, 2005; Wetherell, 2012) is recommended in further exploring the effectiveness on the dyad of persons with dementia and their caregiver.

All four studies included for review indicated positive results in ameliorating the effects of grief and loss on the part of the caregiver. It can be noted that while some studies related to examining the effectiveness of the intervention used, others focussed on supporting the caregiver while caring for a person with dementia. Despite the differences, all four studies were attempting to improve outcomes for caregivers of persons with dementia.

4.5 Conclusion

For the majority of dementia types, the onset of the syndrome is progressive (MacCourt et al., 2017), leading to a long-term experience of a complex variety of symptoms and adverse effects, most of which cannot be treated or reversed. A common effect of dementia, experienced by both the person with dementia and their caregiver, is grief and loss due to the multitude of losses that are experienced. These losses are experienced both while the person is progressing through the stages of the disorder, as well as once they have passed (Alzheimer's Association, 2018; Doka & Aber, 1989). Due to the prolonged period that persons may experience bereavement in this context, it is imperative that interventions are identified to reduce the severity of the impact upon the dyad. This will subsequently improve the mental health and wellbeing of both members of the dyad.

The contributions of this review included the discovery of an absence of current research exploring psychotherapeutic interventions to support the dyad of a person with dementia and their caregiver experiencing grief and loss, possibly due to the complexities and challenges facing persons with dementia, and their caregivers on diagnosis. Research on caregivers of persons with dementia included telephone-based and online grief interventions, such as the use of cognitive behavioural therapy and coaching, that were effective in reducing the experience of grief and loss by the caregiver (Meichsner & Wilz, 2016; Meichsner et al., 2016; Ott et al., 2010). The manualised “Easing the Way” approach used by Ott et al., (2010) was also found to alleviate the experience of grief and loss, with significant results found from baseline to intervention. With further research, these findings may have implications by guiding future direction of psychotherapeutic intervention to support caregivers and their care recipients affected by dementia.

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Appendix A: Appraisal Instruments



JBI Critical Appraisal Checklist for Randomized Controlled Trials

Reviewer _____ Date _____

Author _____ Year _____ Record Number _____

	Yes	No	Unclear	NA
1. Was true randomization used for assignment of participants to treatment groups?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Was allocation to treatment groups concealed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Were treatment groups similar at the baseline?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Were participants blind to treatment assignment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Were those delivering treatment blind to treatment assignment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Were outcomes assessors blind to treatment assignment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Were treatment groups treated identically other than the intervention of interest?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Were participants analyzed in the groups to which they were randomized?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Were outcomes measured in the same way for treatment groups?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Were outcomes measured in a reliable way?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Was appropriate statistical analysis used?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Was the trial design appropriate, and any deviations from the standard RCT design (individual randomization, parallel groups) accounted for in the conduct and analysis of the trial?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Overall appraisal: Include ☐ Exclude ☐ Seek further info ☐

Comments (Including reason for exclusion)



JBI Critical Appraisal Checklist for Qualitative Research

Reviewer _____ Date _____

Author _____ Year _____ Record Number _____

	Yes	No	Unclear	Not applicable
14. Is there congruity between the stated philosophical perspective and the research methodology?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Is there congruity between the research methodology and the research question or objectives?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Is there congruity between the research methodology and the methods used to collect data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Is there congruity between the research methodology and the representation and analysis of data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Is there congruity between the research methodology and the interpretation of results?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Is there a statement locating the researcher culturally or theoretically?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. Is the influence of the researcher on the research, and vice-versa, addressed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. Are participants, and their voices, adequately represented?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Overall appraisal: Include ☐ Exclude ☐ Seek further info ☐

Comments (Including reason for exclusion)



JBI Critical Appraisal Checklist for Quasi-Experimental Studies (non-randomized experimental studies)

Reviewer _____ Date _____

Author _____ Year _____ Record Number _____

	Yes	No	Unclear	Not applicable
24. Is it clear in the study what is the 'cause' and what is the 'effect' (i.e. there is no confusion about which variable comes first)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. Were the participants included in any comparisons similar?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. Was there a control group?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. Were there multiple measurements of the outcome both pre and post the intervention/exposure?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analyzed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. Were the outcomes of participants included in any comparisons measured in the same way?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. Were outcomes measured in a reliable way?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. Was appropriate statistical analysis used?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Overall appraisal: Include ☐ Exclude ☐ Seek further info ☐

Comments (Including reason for exclusion)

Appendix B – Data Extraction Tool

JBI Data Extraction Form for Experimental/Observational Studies2

Reviewer _ _____ Date _____
 Author _____ Year _____
 Journal _____ Record Number _____

Study Method RCT ☐ Quasi-RCT ☐ Longitudinal ☐
 Retrospective ☐ Observational ☐ Other ☐
Participants

Setting _____
 Population _____
 Sample size _____

Intervention 1 _____ Intervention 2 _____ Intervention 3 _____

Interventions

Intervention 1: _____

Intervention 2: _____

Intervention 3: _____

Clinical outcome measures

Outcome Description	Scale/measure

--	--

Study results

Dichotomous data

Outcome	Intervention () number / total number	Intervention () number / total number

Continuous data

Outcome	Intervention () mean & SD (number)	Intervention () mean & SD (number)

Authors' conclusions:

Comments: