INFLUENCES AND SUPPORTIVE INTERVENTIONS EXPERIENCED DURING PALLIATIVE CAREGIVING THAT IMPACT FAMILY CAREGIVERS’ BEREAVEMENT: A SCOPING REVIEW

by

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Abstract

The purpose of this scoping review was to examine the influences and supportive interventions in the caregiving experience that impact family caregivers’ (FCG) grief and loss journey in bereavement. Searches were conducted in CINAHL, MEDLINE, EMBASE and PsycINFO using four sets of search terms: 1) “grie*” or “bereav*”; 2) “palliative or terminal or end of life or life limiting”; 3) “caregiv*”; and 4) “support*”. Research studies published in English between 2010 and 2015, which provided evidence regarding influences during caregiving that impact the FCG’s experiences of grief and loss in bereavement were identified. A total of 21 articles were selected for inclusion. Studies were grouped into five major categories of influence: caregiver, caregiving circumstances, relational and health system. Evidence indicated the FCGs who find caregiving stressful and experience common mental health problems are at significant risk of experiencing difficulties in bereavement. Several factors may contribute to a stressful caregiving experience and subsequent FCG distress. These are: an increased experience of burden; coping strategies; barriers to the FCG’s ability to effectively provide care; and negative experiences with the death of the ill person. Implications for nursing practice include the importance of assessment for common mental health problems, burden from the perspective of the FCG, expectations of care and the importance of timely information and a thorough exploration of the FCGs’ desires/expectations around death. The results from this scoping review support a need for research focused on the development, implementation, and testing of supportive interventions offered during caregiving that have a positive impact on bereavement.

Keywords: grie*, bereav*, palliative, terminal, end of life, life limiting, caregiv*, support*
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Introduction

The health care system is reliant on family caregivers (FCG) and the need for FCGs will only grow. The Canadian population over the age of 65 is steadily growing and is projected to reach up to 28% of the total population by the year 2063 (Statistics Canada, 2014). Due to their age, this segment of the population will experience more chronic disease leading to advanced or life limiting illness (Canadian Cancer Agency, 2013). This demographic shift and associated increase in illness has been accompanied by a restructuring of the health care system (Motiwalla, Flood, Coyte & Laporte, 2005). The downsizing of hospitals and “insidious erosion of community care and public health systems” has moved more care into the home (Duncan & Ruetter, 2006, p. 242). As a consequence of both these influences, more family members have been required to step in to the role of care provider (Canadian Institute of Health Research [CIHR], 2014; Denton, Zeytinoglu, Davies, & Lian, 2002; Duncan & Reutter, 2006). There has also been a movement towards people choosing to die at home, which can only be fulfilled with the help of FCGs (CIHR, 2014; Duncan & Reutter, 2006; Kinosheta et al., 2014; Robinson, & Bottorff, 2013, World Health Organization [WHO], 2011).

The FCG role is associated with significant physical, psychological and social pressures that can make providing care challenging and can compromise the health of the FCG (Chentsova-Dutton et al., 2002; Holtslander & Duggleby, 2009; Thomas, Hudson, Trauer, Remedios & Clarke 2014). Further, it is well established that the impact of caregiving does not end when caregiving is over; it extends into and influences grief and bereavement (Francis, Kypriotakis, O'Toole, Bowman, & Rose, 2013; Ling et al., 2013; Stajduhar, Martin, & Cairns, 2010).
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Better understanding of the connection between experiences during caregiving and the subsequent experiences during grief and bereavement is needed in order to more effectively support the FCG and minimize the long-term consequences of providing palliative care in the home. The purpose of this scoping review was to identify influences during caregiving that have an impact on the caregiver's experiences of grief and loss in bereavement. The ultimate aim was to enhance evidence-informed practice through the identification of influences during caregiving that are amenable to intervention so that support to the FCG can be optimized and their experience of grief and loss in bereavement is eased.

Family Caregiving in Canada

The increase in the aging population and their wish to receive care at home has led to an increase in the number of FCGs present in Canada (Sanders, Ott, Kelber & Noonan, 2008). According to Statistics Canada (2013), the person who is most likely to provide care is a spouse. Elderly caregivers are a particularly vulnerable group and often provide complex palliative care while experiencing their own physical and mental health challenges (Chentsova-Dutton et al., 2002; Holtslander & Duggleby, 2009).

There is increasing recognition that FCGs experience physical, mental, emotional, and financial consequences related to caregiving (American Institute of Retired Persons, 2011; Stroebe et al., 2010). FCGs need to be acknowledged and supported for the significant role they play in providing care for aging family members as this helps them to continue successfully in the role (Hudson & Payne, 2011). Additionally, the need for the FCG to receive their own care alongside the palliative individual has been well established (Hudson et al., 2010).
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FCGs experience profound grief and loss both while they are caregiving and in bereavement (Agnew, Manktelow, & Donaghy, 2008). Influences during caregiving that have an impact on the FCG experience of grief and loss have been identified (Agnew, Manktelow, Taylor, & Jones, 2010). For instance, lack of support for the FCG can be devastating and can negatively impact his or her grief and bereavement journey (Montgomery & Campbell, 2012). According to Genevro, Marshal & Miller (2004), little however is known about how to provide effective support for the FCG, particularly grief and bereavement support (WHO, 2013). Many palliative care models explicitly identify that palliative care for the FCG should extend into the bereavement period (Allen, Haley, Small, Schonwetter, & McMilan, 2013; Canadian Home Care Association, 2015).

Based on the understanding that experiences during caregiving have an impact on later grief and loss in bereavement, the assumption underlying this scoping review was that bereavement support could begin during caregiving. The purpose of the scholarly project was to address the following questions: 1. What are the influences in the caregiving experience that impact FCGs’ grief and loss journey in bereavement? and 2. What do FCGs find supportive during caregiving that may positively influence their grief and loss journey in bereavement? To address these questions, a scoping review was conducted with the aim of informing community care nursing practice.

Clarification of Terms

Loss is “the failure to keep or to continue to have something and the experience of having something taken from you or destroyed” (Loss, 2015). Bereavement is a particular kind of loss and has been defined as “the loss of a loved one through death” (Genevro et al., 2004, p. 494). This indicates that the bereavement period begins when death occurs.
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Grief has been defined as “deep sadness caused especially by someone's death: a cause of deep sadness” (Grief, 2015). Grieve, the verb, is defined as “to feel or show grief or sadness” (Grieve, 2015). Thus grief is a response to loss and can be experienced during caregiving and in bereavement. This very simply describes grief, and while everyone experiences grief in bereavement, it is unique to each individual and how it impacts them physically, emotionally and socially (Agnew et al., 2008).

Grief has been traditionally conceptualized as a linear process of steps, as defined by Elizabeth Kubler-Ross: that move through denial, bargaining, anger, depression and then to acceptance (Maciejewski, Zhang, Block & Prigerson, 2007). This view of grief has become highly contested and other theories have emerged. There are now several ways to look at grief, for example, as: a series of tasks, a dual process of moving between loss orientation and reorientation, or as the work of relocating the grief in one’s life (Doka, 2006, p. 210).

The impact of grief is deep and far-reaching. Wright & Bell (2009) spoke to the nature of grief when they wrote, “grief remains, not with the same intensity of deep unrelenting sorrow, but with aspects of memory, joy, love, connection, celebration and yes, even pain” (p. 309). It is now recognized that there is no timetable for grief; it lessens over the years but people may still experience a “swell of grief” at times (Doka, 2006). This speaks to the changing yet pervasive nature of grief and loss. The word “journey” has been used in this paper as a descriptor for the FCGs' experience of grief and loss in bereavement, as it captures the ongoing process of movement in and through grief.

In the literature, two grief-related terms tend to be used interchangeably:
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prolonged grief and complicated grief. Prolonged grief has been identified as “a deviation from the normal (societal and cultural) grief experience in either time course, intensity, or both, entailing a chronic and more intense emotional experience or an inhibited response, which either lacks the usual symptoms or in which onset of symptoms is delayed” (Aoun, Connors, Priddis, Breen, & Colyer, 2011, p. 844). Complicated grief has been defined as “an over or unusual expression of grief or even inability to interact with and manage the external world after a loss. Complicated grief can also be defined as a cluster of experiences that includes separation distress, post-traumatic stress, and an inability to cope with the loss of a loved one” (Chiu et al., 2010, p. 1322). For the purposes of this paper, prolonged grief will be used because it is the most current term in the literature (Smith, Kalus, Russell, & Skinner, 2009; Thomas et al., 2014).

Method

A scoping review was conducted to answer the following questions: 1. What are the influences in the caregiving experience that impact FCGs’ grief and loss journey in bereavement? 2. What do FCGs find supportive during caregiving that may positively influence their grief and loss journey in bereavement? This scoping review followed the six step process described by Arksey and O’Malley (2005). Scoping reviews provide a preliminary look at the size and scope of the available research; however, they do not assess the quality of research that is reviewed. The search was conducted in the databases CINAHL, MEDLINE, EMBASE and PsycINFO. Controlled vocabulary was consulted with subject headings and they were found to be similar to search terms. To use both search terms and subject headings would have been redundant so it was decided to use search terms only. Relevant research articles were identified using four sets of search
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terms: 1) “grief*” or “bereav*”; 2) “palliative or terminal or end of life or life limiting”; 3) “caregiv*”; and 4) “support*”. These search terms were combined with “and” for the final combination, which yielded 970 articles for screening.

Exclusion criteria included articles on pediatric palliative care and dementia caregiving. Articles with a focus on pediatric palliative care were excluded because the focus of this scoping review was on caregivers for adults who are palliative. Articles focused on caregiving for those with dementia were excluded due to the potential length of caregiving and unique circumstances that dementia caregiving entails (Grant et al., 2002). Limits were set to English language articles and articles containing an abstract. Once the search was completed, duplicate articles were removed. Next, articles not pertaining to the topic were excluded by a title review. Then an abstract review was completed and 71 articles were retained. Articles published before 2010 were excluded to limit the number of articles to a manageable number. Conference reviews and articles that were not accessible were also excluded. A reference list review of all selected articles was completed to determine if significant publications were missed. This resulted in the addition of two articles. A Google Scholar search with chosen search terms and a 2015 publishing date was completed to update the search to include articles from 2015. This resulted in four more articles, with a final total of 21 articles for inclusion in this scoping literature review (Figure 1). A data extraction table was developed with the following categories: (a) citation, (b) purpose, (c) method, (d) sample, and (e) key findings (Appendix).
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Figure 1

Articles Retrieved for Screening = 970

Duplicates Removed, Articles without Abstracts Removed, Articles not in English Removed
(440) n= 530

Title Search: Excluded: Pediatric & Dementia Care, Non-research Articles
(241) n=289

Abstract Review:
Excluded articles that did not address focus of scoping review
(219) n= 70

Excluded Articles before 2010
(44) n=26

Excluded Conference Abstract
(9) n=17

Article Unavailable
(2) n=15

Reference List Review
(+2) n=17

Google Scholar search for 2015 To update review
(+4) n=21

Articles selected for Inclusion in Study
n=21
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Results

The studies included in this review were conducted in Australia (3), Canada (1), Japan (2), Portugal (1), Taiwan (2), United Kingdom (1), United States (5) and Sweden (1), and used both qualitative (n = 4) and quantitative (n = 17) methods of inquiry. Analysis of findings resulted in five categories of influences in caregiving that have an impact on grief and loss in bereavement: family caregiver, caregiving circumstance, ill person, relational, and health system. Supportive interventions in caregiving that have an impact on grief and loss in bereavement were identified.

Influences During Palliative Caregiving that Impact Bereavement

Family caregiver.

Attributes of family caregivers that have been found to impact bereavement were gender, age, race, education, personal beliefs, mental health, approach to coping, physical health and type of relationship; however, the evidence was inconsistent. A number of demographic and personal attributes of caregivers have been linked to difficulty in bereavement. Female gender has been identified as a risk factor that predisposes caregivers to risk of prolonged grief and was linked to poor coping in bereavement (Chiu et al., 2010; McNamara & Rosenwax, 2013). Other studies found that a younger caregiver age was associated with poor coping in bereavement and was inversely related to depressive symptoms in bereavement (Ling et al., 2013; McNamara & Rosenwax, 2010). Conversely, another study indicated that age had no impact on experiences of prolonged grief (Thomas et al., 2014). Race has been shown to be influential on bereavement as well; however the evidence was limited. For example, being African American was shown to directly influence depressed mood in bereavement (Francis et al.,
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2015). In addition, two studies found that lower levels of education were associated with increased symptoms of depression, feelings of grief and prolonged grief (Allen et al., 2013; Thomas et al., 2014).

Personal beliefs and place of death have also been shown to impact the FCGs’ experience of grief and bereavement. Beliefs about having achieved a ‘peaceful death’ were associated with decreased regret in bereavement (Akiyama, Numata & Mikami, 2010). Whereas, beliefs about having experienced a bad death were linked to increased anger in bereavement and were associated with higher scoring for common mental disorders (Akiyama et al., 2010; DiGiacomo et al., 2013). It was interesting to note that the quality of the ill person’s death, as determined by the nurse, was not found to be related to bereavement outcomes for the FCG (Kapari, Addington-Hall, & Hotopf, 2010). To add to this picture, if death was not in the caregivers’ preferred place, the FCG was significantly more likely to have poor health in bereavement (McNamara & Rosenwax, 2010). These results suggest that place of death may influence the FCGs’ evaluation of whether death was viewed as good or bad and that nurses’ assessment may not accurately represent the FCG perspective. Further, this highlights the importance of subjective rather than objective assessment.

The FCGs’ lack of acceptance of the terminal diagnosis, minimization of their emotional response, use of internal active coping and absence of religious beliefs were linked to difficulties in bereavement. A qualitative study examining sixteen FCGs’ experiences during caregiving and in bereavement found that rejection of the terminal illness diagnosis and coping by minimizing emotional responses during caregiving was associated with prolonged grief (Aoun et al., 2011). This was supported by results from a
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quantitative prospective cohort study which found the use of internal active coping during caregiving was associated with worse mental health outcomes in bereavement (Kapari et al., 2010). Finally, the absence of religious beliefs was shown to be a risk factor that predisposed caregivers to prolonged grief. However, it is important to note there may be a cultural component to this outcome as this study was conducted in Taiwan (Chiu et al., 2010).

There was consistent evidence across seven studies that the FCGs’ pre-death mental health was a strong predictor of bereavement mental health (Kapari et al., 2010; Thomas et al., 2014; Wright et al., 2010). The presence of common mental disorders pre-death (i.e., depression, anxiety, psychosocial distress) was linked to increased depression, anxiety, prolonged grief and decreased grief resolution among bereaved FCGs (Allen et al., 2013; Chiu et al., 2010; Kapari et al., 2010; Ling et al., 2013; Thomas et al., 2013; Winterling et al., 2010).

Physical health problems, such as disability, and the physical toll of caregiving continue into bereavement and contribute to difficulties with grief (Francis et al., 2015; Stajduhar et al., 2010). More specifically, the presence of FCG chronic illness has been associated with depressive symptoms in bereavement independent of gender, age, education and financial status (Ling et al., 2013). These findings indicate that the FCGs’ baseline physical health are risk factors for difficulties in bereavement.

There was conflicting evidence regarding the link between relationship to the ill person and difficulties in bereavement. Two studies found that spousal relationship was associated with increased depression and prolonged grief (Thomas et al., 2014; Ling et al., 2013). In contrast, Masterson et al. (2015) found that all FCGs (spousal and
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	offspring) experienced a decrease in depression in bereavement independent of age, relationship to patient, gender and months to loss. To further complicate the picture, an insecure pattern of relationship and a dependency relationship have been associated with prolonged grief (Coelho, Delalibera & Barbosa, 2015). This conflicting evidence further highlights the complexity of influences on the FCG’ bereavement.

In summary, a panoply of caregiver related influences have been identified as potentially placing a caregiver at risk of difficulties in bereavement. There was consistent evidence that when the FCG experiences mental and/or physical health problems concurrently with providing care, associated difficulties in bereavement are present. Particular coping strategies that buffer the emotional impact of the caregiving situation on the FCG may put them at risk of prolonged grief. Also, the FCGs’ beliefs about whether there was a good or bad death were linked to difficulties with grief in bereavement. Specifically, when place of death did not align with the FCGs’ preferred place of death, this was problematic. Older FCG age has consistently been shown to be a protective influence and to ease the grief and bereavement experience of the FCG. There was conflicting evidence about the influence of FCG gender and relationship with the dying person on subsequent grief and bereavement.

Caregiving circumstance.

Although the evidence is complex and not entirely consistent, aspects of the caregiving circumstance such as burden and duration of care, negative experience of providing care, living with the ill person, employment of the caregiver and missing the death have been shown to impact caregiver’s experience in bereavement, Some influences seem to reduce risk of difficulty in bereavement. For example, longer duration
of caring for the ill person was a protective factor according to Chiu et al. (2010). Additionally, providing direct care, higher burden of care and negative caregiving experience (subjective caregiving burden) have been associated with decreased regret, depression, and depressive symptoms in bereavement (Akiyama et al., 2010; Francis et al., 2015; Ling et al., 2013). However, in a descriptive longitudinal study of 186 FCGs, Ling and colleagues (2013) found that objective caregiving demands alone had no effect on depressive symptoms in bereavement. These somewhat contradictory findings suggest that it is important to distinguish between subjective and objective assessments of burden of care because they may have different influences on bereavement. Additional concerns about identifying depression in bereavement have been highlighted by Francis, Kypriotakis, O’Toole, Bowmand and Rose (2015), who found that depressed mood in bereavement was primarily predicted by grief rather than aspects of the caregiving circumstance. These researchers assert “the inappropriateness of equating grief and depression based purely on symptoms and the necessity of including context as a key factor in identification” (p. 373). To further complicate the picture, Ando, Ninosaka, Okamura and Ishi (2015) found that higher burden of care was related to complicated grief in bereavement.

There were a number of influences related to the circumstance of caregiving, such as living with the ill person, concurrent employment, missing the death and negative circumstances of the death that have been associated with increased difficulty in bereavement. For example, when there was a lack of other caregivers, this was associated with prolonged grief (Allen et al., 2013). Living with the ill person was associated with both increased grief and prolonged grief (Frances et al., 2015; Thomas et al., 2014);
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while, employment during caregiving was associated with heightened grief in bereavement (Francis et al., 2015). Our understanding of this influence is supported by a secondary analysis of qualitative data from focus groups that explored FCG coping in end-of-life cancer care and their perspectives on what made their grief difficult (Stajduhar et al., 2010). These researchers found that employment influenced caregivers’ ability to achieve balance in caregiving and that when this occurred, participants reported increased guilt and regret in bereavement. Guilt and increased regret during bereavement was also related to missing a death. Similarly, negative circumstance of death resulted in persistent self-blame according to DiGiacomo, Lewis, Nolan, Phillips and Davidson (2013).

In summary, much of the evidence was inconsistent in relation to the caregiving circumstances that influence grief and bereavement. However, like what was found in relation to caregiver influences, negative experiences with the death, including missing the death, as well as lack of other caregivers and living with the ill person were associated with heightened grief and difficulties in bereavement. However, this picture becomes complicated when taking into account the evidence that suggests that providing direct care, higher caregiver burden and negative caregiving experiences may be associated with a more positive grief and bereavement experience.

Ill Person.

Influences related to the ill person have been shown to have an impact on FCGs’ bereavement but, again, the evidence was complex and not consistent. FCGs for younger ill persons experienced increased depression in bereavement and prolonged grief when compared to caregivers for older ill persons (Allen et al., 2013; Thomas et al., 2014).

Perceived deterioration and disfigurement of the ill person as well as decreased
physical, emotional, and spiritual quality of life (QOL) for the ill person were associated with higher grief and prolonged grief for the FCG (Coelho et al., 2015; Francis et al., 2015). In contrast, a longitudinal follow up study found that the ill person’s level of function made no difference to prolonged grief symptom scores of the FCG (Thomas et al., 2015). In addition, Winterling et al. (2010) found that ill persons’ psychological distress had no relationship to spousal FCGs’ psychological distress or grief resolution. These conflicting findings highlight the difficulty of interpreting influences related to changes in the ill person. Time spent managing ill person’s behaviors was linked to increased grief in bereavement for the FCG (Francis et al., 2015).

As has been noted in previous sections, there are death related factors linked to the ill person that influence the FCG’s bereavement. Expectedness of death was a positive influence if the cause was not cancer. In other words, if a death was expected, it had a positive influence on grief and depression unless the cause was cancer. Death from cancer was associated with higher levels of grief and depression whether it was expected or unexpected (Caserta, Utz & Lund, 2013).

In summary, the evidence suggests that younger age of the ill person and their deterioration may negatively influence the FCG’s grief and bereavement but the latter was not consistently supported. As in the previous two categories, circumstances around the death have been identified as influencing bereavement. In this instance the influence of expectedness of death has been identified as well as the influence of a diagnosis of cancer.

Relational.

The relational environment of the family and social circle has been shown to
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Impact caregivers during caregiving and this continues into bereavement. Poor family environment and unresolved family crises resulted in an increase in prolonged grief symptoms and prolonged grief disorder (Coelho et al., 2015; Thomas et al., 2014). This was supported by qualitative research where participants reported that family disagreements as well as lack of friend and family support led to anger and feeling unappreciated in bereavement (Stajduhar et al., 2010). Having a dual caregiving role within the family (e.g., caring for the palliative person and a handicapped member and/or teenagers) also led to increased anger, poor coping and difficult grief in bereavement (Stajduhar et al., 2010). As well, when medical or prognostic information was withheld from the ill person, this was associated with family conflict that extended into bereavement and was accompanied by feelings of guilt and anger for caregivers (Stajduhar et al., 2010).

Lack of social support during caregiving has been found to negatively impact bereavement experience. Decreased social support can predispose the FCG to increased feelings of grief and prolonged grief (Allen et al., 2013; Chiu et al., 2010). This was supported by Ling et al. (2013), who found that caregivers with increased social support experienced decreased levels of depression in bereavement. However, in contrast, in a prospective cohort study with 100 family caregivers, Kapari et al. (2010) found no relationship between family relations and levels of social support and bereavement outcomes. They note that this was an unusual finding and query whether their sample might have been biased towards high functioning, balanced families. In summary, lack of supportive relational connections experienced during caregiving can lead to many difficulties including: increased prolonged grief symptoms, prolonged grief, anger,
feeling unappreciated, and poor coping.

**Health System.**

Various touch points within the health care system including practical supports, communication, and place of death have been shown to have a lasting impact on the caregiver. However, there was conflicting evidence regarding the influence of sufficient practical supports in the home during caregiving on the FCGs’ bereavement. Unmet expectations regarding health services, lack of integration of services, and lack of attention to personalized services were found to be related to poor physical health, anger and negative impressions beyond death for the FCG (McNamara & Rosenwax, 2010; Stajduhar et al., 2010). Whereas, fulfilled expectations regarding home medical services were associated with decreased regret in bereavement (Akiyama et al., 2010). However, in contrast, Kapari et al. (2010) found the opposite; that unmet needs for practical support and higher discrepancy between actual and ideal support were related to more positive bereavement outcomes.

Poor communication between health care providers, caregivers and ill persons can lead to difficulties in bereavement. A longitudinal, qualitative study designed to explore the transition to widowhood found that inadequate information from health care providers, missed communication opportunities, and perceived negative interaction with health care providers during caregiving led to guilt, anger, increased distress and difficulties for caregivers in bereavement (DiGiacomo et al., 2013). This was supported by Stajduhar et al. (2010) who found that lack of acknowledgement by health care professionals and inattentive health care professionals at critical points during caregiving led to anger and bitterness that did not resolve in bereavement. Whereas, access to
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accurate and timely information helped caregivers deal with grief in bereavement (Stajduhar et al., 2010).

Place of death was found to be a significant influence on FCGs’ grief and bereavement. Wright et al. (2010) conducted a prospective, longitudinal, multi-site study of 342 patients with advanced cancer and their caregivers. These researchers found that place of death was significantly related to the development of psychiatric illness in bereaved caregivers. Further, an intensive care unit death or a hospital death, even when adjusted for previous psychiatric illness of the FCG, was linked to a higher incidence of psychiatric illness, increased risk of developing post-traumatic stress disorder and increased odds of meeting criteria for prolonged grief for bereaved caregivers.

In summary, health system factors such as the provision of practical support that meets the FCGs’ needs and effective, supportive communication during caregiving have the potential to influence both caregiving and bereavement. However, the evidence was contradictory. A number of factors related to the FCG’s experience with the death of their ill person have been identified to be important influences on bereavement and place of death adds to that picture.

Supportive Interventions That Impact Caregivers During Bereavement

Limited results for interventions that positively influence bereavement were found. A single study by Dionne-Odom et al. (2015) found that early initiation of palliative care decreased the FCGs’ depression and decreased stress burden in bereavement. Two studies focused on individual level therapeutic interventions. Fegg et al. (2013) and Kögler et al. (2015), reporting on a single study, found that Existential Behavioral Therapy and mindfulness training show potential for supporting positive
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bereavement outcomes (trends shown in relation to more positive affect, decreased depression, increased quality of life and increased satisfaction with life over time). There was also some evidence that the effect of Existential Behavioral Therapy was moderated by mindfulness (Kögler et al., 2015) and that the mindfulness component may be the effective element of the therapy. However, findings from this study should be viewed with caution because the majority of the sample were bereaved when the intervention occurred. The second therapeutic intervention found was dignity therapy (Bentley, O’Connor, Breen & Kane, 2014). Dignity therapy (i.e., the creation of a legacy document) with FCGs and ill persons showed some benefit to the caregiver in bereavement as it brought them comfort (Bentley et al., 2014). In conclusion, there are few studies on interventions offered during caregiving that help ease family caregivers’ grief and loss in bereavement.

**Limitations**

This review did not focus on diversity issues in relation to FCGs’ gender and culture, which may have an influence on bereavement. Given the wide variety of methods represented in the sample and lack of evaluation of the quality of the research, interpretation of contradictory results was difficult.

**Discussion**

FCGs who find caregiving stressful and experience common mental health problems such as increased anxiety and depression are at significant risk of experiencing difficulties in bereavement including prolonged grief (Allen et al., 2013; Chiu et al., 2010; Kapari et al., 2010; Ling et al., 2013; Thomas et al., 2014; Winterling et al., 2010; Wright et al., 2010). The evidence suggests several factors may contribute to a stressful
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caregiving experience and subsequent FCG distress: an increased experience of burden; coping strategies; barriers to the FCG’s ability to effectively provide care; and negative experiences with the death of the ill person.

Increased Experience of Burden

There are several influences that could contribute to FCGs’ heightened sense of burden and negative bereavement outcomes. Objective caregiving burden has not been shown to relate to bereavement outcomes (Kapari et al., 2010; Ling et al., 2013), which suggests that the FCG’s perspective on burden is the most important and that subjective assessment is key. Influences that seem related to caregiving burden include: living with the ill person, caring alone, family conflict, dual caregiving, lack of social support, time spent managing ill person behaviors, caring impact on schedule and unmet expectations, or needs for instrumental, emotional and informational support from paid providers (Allen et al., 2013, Chiu et al., 2010; Choelho et al., 2015; Francis et al., 2015; McNamara & Rosenwax, 2010; Stajduhar et al., 2010; Thomas et al., 2014). Statistics Canada (2012) indicate that spouses spend 14 or more hours a week providing care and on average provide the most number of care hours a week when compared to other caregivers. With high number of caring hours per week, the caring impact on the FCG’s schedule may be burdensome and the evidence has linked this to long-term risks such as increased guilt, regret and prolonged grief for the FCG (Ando et al., 2015; Stajduhar et al., 2010; Thomas et al., 2014).

However, there are contradictory findings regarding the influence of high burden of care on bereavement outcomes. Some studies have found high burden related to negative bereavement outcomes (Ando et al., 2015; McNamara & Rosenwax, 2010;
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Stajduhar et al., 2010) while others have found high burden related to positive bereavement outcomes (Kapari et al., 2010). Kapari et al. (2010) note that high burden and positive bereavement outcomes is contrary to most of the research in the area. The researchers link this finding to high reported discrepancy between actual and ideal levels of support during caregiving, which they suggest indicated that it was a very difficult situation. They postulate that in this circumstance, when the ill person dies and difficult caregiving ends, FCGs may experience relief and an easier bereavement. This is commonly referred to as the ‘relief theory’ (Li, 2005); however, Li notes that even though relief is felt by the FCG, they still experience grief. On balance, the evidence supports nurses’ need for heightened awareness of caregivers’ subjective sense of burden, as well as the influences of living with the ill person, caring alone, family conflict, dual caregiving, lack of social support, time spent managing ill person behaviors, caring impact on schedule and unmet expectations or needs for instrumental, emotional and informational support from paid providers.

Coping Strategies

There is evidence that coping strategies that support the ‘doing’ of caregiving may place the FCG at risk of negative bereavement outcomes. These coping strategies include denying the terminal diagnosis, minimizing emotional response to the situation, and using active coping strategies and problem solving rather than emotional strategies (Aoun, et al., 2011; Kapari et al., 2010). These coping strategies can lead to long-term consequences including prolonged grief and poorer mental health outcomes (Aoun et al., 2011; Kapari et al., 2010). The above coping strategies enable the FCG to provide care while buffering their own emotions (Aoun et al., 2011). Furthermore, coping by denying
the terminal diagnosis can be so strong that it follows the FCG into bereavement (Stajduhar et al., 2010). The risk here is that FCGs may be unprepared for death and the onslaught of emotions in bereavement.

Kapari et al. (2010) highlight the ramifications of high levels of active coping. Active coping is defined as the FCGs’ need to take immediate action to make the situation better. They posit that high levels of active coping indicate a difficult caregiving experience, which requires the FCG to deal with the immediate practical elements of care and shelve the uncontrollable emotional aspects of care. This is supported by Stajduhar et al. (2010) who found that active coping can lead to negligence in attending to the emotions associated with caregiving, which can lead to poorer mental health outcomes in bereavement. The evidence supports the idea that the balance of active and emotional coping strategies in caregiving is an important area for assessment. But this is inherently difficult because an actively coping caregiver may ‘look’ like he or she is doing well. For example, they may be effectively coping with physical problems as they arise and efficiently completing tasks.

**Barriers to Providing Care**

FCGs need to be good caregivers and need to provide excellent care (Robinson, Pesut & Bottrorff, 2012). When FCGs are not successful in providing what they view to be excellent care, they may be at risk for difficulty in bereavement (Topf et al., 2013). The identified influences that may impede FCGs’ ability to be successful caregivers include: their own physical and mental health problems including disability and chronic illness, employment outside the home while providing care, dual caregiving, and problematic communication with paid providers including lack of necessary information.
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(DiGiacomo et al., 2013; Francis et al., 2013; Stajduhar et al., 2010). These influences have been linked to feelings of guilt, anger and regret long into bereavement (DiGiacomo et al., 2013; Francis et al., 2013; Stajduhar et al., 2010). One way to make sense of these findings is to conceptualize the influences as barriers to FCGs being able to see themselves as good caregivers and having done their best for the ill person. Influences such as FCG disability and chronic illness make it difficult to physically provide the care. Mental health problems make it challenging to be emotionally present and to cope with the demands of caregiving. Having to divide one’s time between caregiving and employment or caregiving for multiple family members may make it hard to provide the level and kind of care that the FCG desires. The final barrier is problematic communication; not having the right or enough information for decision-making makes it very difficult for the FCG to provide timely and appropriate care (Robinson et al., 2012). It is clear that these influences have long-term consequences for bereavement. These findings extend those of Robinson et al. (2012) by establishing a link between difficulties providing excellent care and bereavement outcomes.

**Negative Death Experience**

Finally, there is consistent evidence that when FCGs have negative experiences with the death of their ill person, they are at significant risk during bereavement. The factors that have been identified include: the FCG’s beliefs about whether the death was ‘good’ or ‘bad,’ missing the death, unexpected death, death due to cancer, place of death that was not in alignment with the FCG’s preferred place and death in hospital or intensive care unit (Akiyama et al., 2010; Caserta et al., 2013; DiGiacomo et al., 2013; Kapari et al., 2010; McNamara & Rosenwax, 2013; Stajduhar et al., 2010; Wright et al.,
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2010). Kapari et al. (2010) found the nurse’s assessment of quality of death was unlinked to FCG outcomes. This is supported by Topf et al. (2013) who suggest that beliefs about a ‘good’ or ‘bad’ death from the FCG perspective may be quite different than the health care professional perspective. Missing the death and unexpected death are also considered negative experiences and are related to poor health, persistent self-blame and increased grief, depression and loneliness in bereavement (Caserta et al., 2013; DiGiacomo et al., 2013; Stajduhar et al., 2010). Death in hospital or intensive care unit is not likely the FCG’s preferred place as more people are choosing to die at home (CIHR, 2014). Topf et al. (2013) also suggest that when FCGs want to support a death at home and this is not accomplished, the FCG experiences despair and prolonged grief.

In summary, influences that contribute to high burden of care, coping strategies that buffer or set aside emotional coping, barriers that impede FCGs’ ability to provide excellent care, and negative experiences around the death of the ill person place the FCG at risk of difficulties in bereavement. These all have implications for practice, which will be discussed below.

Implications for Practice

The findings have several implications for practice, primarily in the area of assessment. These include assessing for common mental health problems, assessing burden from the perspective of the FCG, assessing expectations for care, providing timely information and exploring expectations around death. The evidence indicates there are long-term consequences present when these areas are not addressed. Therefore, there are weighty implications for community care nurses’ practice.
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There is consistent evidence linking baseline mental health problems such as anxiety and depression to difficulties in bereavement, which begs the question, should FCG’s be screened? A screening practice would give the nurse concrete assessment data on who would benefit most from increased supports during the caregiving phase to ease their bereavement and brief, valid and reliable instruments are available.

Assessing the burden of care from the perspective of the FCG was shown to give a true picture of burden experienced by FCGs (Kapari et al., 2010; Ling et al., 2013). As the nurse hears the FCG burden experience, they will be able to better determine which FCG would benefit most from further support and what kind of support to offer. Furthermore, predominant reliance on active coping (the ‘doing’ of caregiving) is a red flag to the nurse to do further assessment (Stajduhar et al., 2010). Nurses need to pay special attention to sole caregiving, family conflict, and lack of social and emotional support.

Further implications for community care nurses’ practice includes assessment of expectations of care. This encompasses what the FCG views as essential elements of their own caregiving along with the barriers they are experiencing. In addition, determining expectations for emotional, instrumental, and informational support from providers is essential. This exploration is where the nurse may try and align expectations of care with expressed burden of care and creatively seek solutions and supports for the FCG.

Maintaining clear, effective communication between the community care nurse and FCG is a crucial practice. Finally, it is of utmost importance for community care nurses to assess and work with FCGs around their desires and expectations around death.
Little is known about what interventions during caregiving have a positive influence on bereavement. It may be possible that enhanced assessment leads to more individualized care that benefits FCGs in bereavement. The one intervention that was found that may address many of the identified influences because of its comprehensive and inter-professional approach is early initiation of palliative care.

Conclusion

Evidence to date suggests a lack of knowledge regarding optimal support for palliative FCGs to reduce negative experience in bereavement. To begin to address the paucity of research, a scoping review was completed with the goal of identifying the influences during caregiving that have an impact on bereavement as well as supportive interventions. The factors influencing caregiving experiences are complex and interrelated. We now know FCG experiences during caregiving have long term consequences in bereavement such as mental health problems, anger, guilt and prolonged grief. Primary implications for practice are a heightened awareness of factors that place FCGs at risk for difficulties in bereavement. This awareness also provides focus for nursing assessment and development of individualized plans of care. Clearly, more research is needed to better understand the complex influences during caregiving, their interactions and how to best support FCG’s. As well, additional clarification of contradictory findings around these complex influences is needed. Furthermore, the results from this scoping review are a clear call for future research to develop and test comprehensive assessment tools as well as supportive interventions that can be offered during caregiving with the aim of easing bereavement. A systematic review of literature where the quality of the research is evaluated is likely the best place to start.
References


Canadian Home Care Association (2015). The caregivers voice: Consultations with family caregivers. Retrieved from Canadian Hospice Palliative Care Association
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website: http://www.hpcintegration.ca/media/56359

/Consultation%20Report_English%20web.pdf


doi:10.2190/VYN8-6NKY-RKUM-L0XW
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Transitioning from caregiving to widowhood. *Journal of Pain and Symptom Management*, 46(6), 817-825. doi:10.1016/j.jpainsymman.2013.01.005


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INFLUENCES AND SUPPORTIVE INTERVENTIONS EXPERIENCED DURING PALLIATIVE FAMILY CAREGIVING

Death Studies, 32 (6), 495-523. doi:10.1080/07481180802138845


Winterling, J., Wasteson, E., Arving, C., Johansson, B., Glimelius, B., & Nordin, K.
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## Appendix

### Data Table

<table>
<thead>
<tr>
<th>Author &amp; Title</th>
<th>Purpose</th>
<th>Method</th>
<th>Sample</th>
<th>Key Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Akiyama, A., Numata, K., &amp; Mikami, H. (2010). Importance of end-of-life support to minimize caregiver's regret during bereavement of the elderly for better subsequent adaptation to bereavement. <em>Archives of Gerontology and Geriatrics, 50</em>(2), 175-178. doi:10.1016/j.archger.2009.03.006</td>
<td>Examines whether the quality of end-of-life home medical care affected caregiver's psychological recovery from bereavement</td>
<td>Retrospective Survey: Mailed anonymous, self administered questionnaire. Measures: Depression symptoms; 15 Item Geriatric Depression Scale [15-GDS] and Quality End-of-life Medical Care assessed using 7 sub-scales.</td>
<td>Sample $n=326$ bereaved family member (caregivers) Respondents: 147 Gender Female:110 Male:37 Relationship to Patient Spouse:54 Child:57 Child in Law:27</td>
<td>-Providing direct care during caregiving decreased regret in bereavement. -Patients' peaceful death, providing direct care by the caregiver and fulfilled home medical care service system were variables that significantly decreased measures of regret during bereavement. -Suggests that end-of-life support to minimize caregiver regret during bereavement was crucial for better subsequent adaptation to bereavement.</td>
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<tr>
<td>Allen, J. Y., Haley, W. E., Small, B. J., Schonewetter, R. S., &amp; McMillan, S. C. (2013). Bereavement among hospice caregivers of cancer patients one year</td>
<td>Investigated risk factors that may predict psychological distress, which could aid hospice</td>
<td>Analysis of bereaved caregiver sub-sample from larger randomized control trial. Measures: Demographics: Patient</td>
<td>Sample $n=188$ Participants Caregivers 74% female 26% male</td>
<td>-Fewer years of caregiver education, less patient impairment (Palliative Performance Scale), and more caregiver symptoms of depression at baseline were significantly associated with more symptoms of depression one year following loss. -Younger patient age, fewer years of</td>
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</table>
| Ando, M., Ninosaka, Y., Okamura, K., & Ishi, Y. (2015). | Examines the relationships between difficulties with care and complicated grief. | Mail questionnaire: Measures: Family Difficulty Scale (FDS), the Inventory of Complicated Grief (ICG) | Sample
\(n=45\) Bereaved family member
Gender
Female: 38
Male: 7
Relationship with Patient who died
Spouse: 35
Other: 10 | - Increased burden of care is associated with complicated grief. |

| following loss: Predictors of grief, complicated grief, and symptoms of depression. *Journal of Palliative Medicine, 16*(7), 745-751. doi:10.1089/jpm.2012.0450 | bereavement departments in targeting bereavement services. | impairment (Palliative Performance Scale & Memorial Symptom Assessment Scale): Caregiver psychological well being (Center for Epidemiological Studies Depression [CES-D] & Texas Revised Inventory of Grief [TRIG] & Inventory of Complicated Grief [ICG] measures); Caregiver resources (Satisfaction with Social Support & availability of caregiving support) | caregiver education, greater number of baseline symptoms of depression, and less social support satisfaction at baseline were significantly associated with greater (i.e., higher) present feelings of grief.  
- Younger patient age, fewer years of caregiver education, greater number of symptoms of depression at baseline, lack of other caregivers, and less satisfaction with social support were significantly associated with higher complicated grief at 12-month follow-up.  
- Lower social support satisfaction was associated with worse grief and complicated grief. |
| **Palliative Care**, 32(2), 173-177.  
doi:10.1177/1049909113514626 |
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<tr>
<td>Explores the experiences of MND family carers, both during their time as carers and following bereavement</td>
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<td>Semi-structured interview schedule, demographic questionnaire, and a measure of prolonged grief (Prolonged Grief Tool-13[PG-13])</td>
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<td>Sample</td>
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<td>n=16 family carers between one and four years after the death of their spouse from MND.</td>
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<td>Gender</td>
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<td>Female: 13</td>
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<td>Male: 3</td>
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<td>-Coping strategies for managing chronic illness included rejection of terminal nature of illness and minimizing emotional response (&quot;shutting off&quot;).</td>
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<td>-Suggests that the strength of this coping strategy follows FCG into bereavement.</td>
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<tr>
<td>-Suggests that these coping strategies are related to prolonged grief.</td>
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</table>

| Bentley, B., O'Connor, M., Breen, L. J., & Kane, R. (2014). Feasibility, acceptability and potential effectiveness of dignity therapy for family carers of people |
| Assess' the feasibility, acceptability, and potential effectiveness of |
| Cross-sectional study utilizing a one-group pre-test post-test design |
| Outcomes measured caregiver burden, anxiety, depression, |
| Sample |
| n=18 family carers of people diagnosed with MND |
| Gender: |
| MND family carers saw benefits to themselves after bereavement, in that it brought comfort to the FCG. |
$n=325$  
$n = 112$ participants  
spouses died of cancer  
$n = 213$ participants  
spouses died of other causes  
Expected, cancer  
$n = 89$  
Not expected, cancer  
$n = 23$  
Expected, non-cancer  
$n = 95$  
Not expected, non-cancer  
| | | -Those who lost spouse due to cancer were more depressed and experienced higher levels of grief than those who lost spouse due to other causes  
-Those who’s lost spouses’ due to causes other than cancer experienced lower grief and depression  
-Those whose partners died unexpectedly and those who’s partners died from cancer had similar high levels of grief and depression over time.  
-Those whose spouses'/partners’ deaths were expected and due to a cause other than cancer experienced the lowest levels of loneliness (gender, age, and length of marriage did not affect this finding). |
<table>
<thead>
<tr>
<th>Reference</th>
<th>Study Design</th>
<th>Sample Description</th>
<th>Key Findings</th>
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<tbody>
<tr>
<td>Chiu, Y., Huang, C., Yin, S., Huang, Y., Chien, C., &amp; Chuang, H. (2010). Determinants of complicated grief in caregivers who cared for terminal cancer patients. <em>Supportive Care in Cancer: Official Journal of the Multinational Association of Supportive Care in Cancer, 18</em>(10), 1321-1327. doi:10.1007/s00520-009-0756-6</td>
<td>To evaluate factors which influence complicated grief among caregivers who cared for patients who died of cancer in Taiwan. Prospective study telephone interview with caregiver after their love one died (average 8.9 months after death)</td>
<td>Sample ( n=668 ) Caregivers Gender 263-male 405-female 386-Caregivers of patients who lived in hospice ward 282-Caregivers who received shared care only</td>
<td>- Females predisposed to complicated grief. - Education level is not statistically significant for impacting complicated grief. - Spouse and parent-child relationships were predisposed to complicated grief. - Absence of religious belief predisposed one to complicated grief. - Unavailability of family support predisposed one to complicated grief. - Mood co-morbidity predisposed one to complicated grief.</td>
</tr>
<tr>
<td>Coelho, A. M., Delalibera, M. A., &amp; Barbosa, A. (2015). Palliative care caregivers’ grief mediators a prospective study. <em>American Journal of Hospice</em></td>
<td>To identify the mediators of complicated grief. Prospective study Grief mediators were prospectively evaluated using a list of risk factors during the predeath and bereavement period (6 months) Convenience Sample ( n=64 ) Gender Male ( n=11 ) Female ( n=53 )</td>
<td></td>
<td>- Statistically associated with Prolonged Grief Disorder (PGD) are: insecure pattern of relationship, the dependency relationship, the unresolved family crisis, and the perceived deterioration and disfigurement of the patient.</td>
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<tr>
<td>Reference</td>
<td>Participants</td>
<td>Findings</td>
<td>Comments</td>
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<tr>
<td>DiGiacomo, M., Lewis, J., Nolan, M. T., Phillips, J., &amp; Davidson, P. M. (2013). Transitioning from caregiving to widowhood. <em>Journal of Pain and Symptom Management, 46</em>(6), 817-825. doi:10.1016/j.jpainsymman.2013.01.005</td>
<td>To explore older women’s experiences of spousal caregiving at the end of life and the ways in which this experience impacts on the transition to widowhood.</td>
<td>Longitudinal, in-depth, semi-structured interviews were conducted with older women three times over a one-year period after the death of their husbands.</td>
<td>Sample $n=21$ women - Perceived negative interaction with health care professional led to difficult transition to widowhood. - A link suggested between missed communication opportunities with health care professionals and increased guilt and anger in bereavement. - Suggested a link between perceptions of poor quality of death and increased level of patient suffering and increased anger in bereavement for the caregiver. - Suggested a link between perceived negative circumstances of death and persisting self blame and sorrow. - Suggested a link between health care professionals giving inadequate information and increased distress in bereavement.</td>
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<tr>
<td>Dionne-Odom, J. N., Azuero, A., I.yons, K. D., Hull, J. G.,</td>
<td>To determine the effect of</td>
<td>Randomized Control Trial</td>
<td>Sample $n=122$ caregivers - CGs in the early compared with delayed group experienced lower depression and lower stress burden and trended toward higher</td>
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*and Palliative Medicine, Published online before print.*
doi:10.1177/1049909114565660
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<tr>
<td>early versus delayed initiation of a palliative care intervention for family caregivers of patients with advanced cancer.</td>
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<td>Three structured weekly telephone coaching sessions, monthly follow-up, and a bereavement call either early after enrollment or 3 months later.</td>
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<td>QOL.</td>
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<td>-CG support at the time of advanced-cancer diagnosis may be the essential ingredient to achieving positive outcomes.</td>
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<tr>
<td>To test the effectiveness of Existential Behavioural Therapy (EBT) on mental stress and quality of life (QOL) of informal</td>
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<tr>
<td>Randomized Control Trial</td>
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<td>Parallel-group design (with equal randomisation 1:1).</td>
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<td>Five assessments (baseline, pretreatment, post-treatment and follow-ups after 3 and 12</td>
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<tr>
<td>Sample</td>
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<tr>
<td>$n=160$</td>
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<tr>
<td>$n=81$(EBT)Group</td>
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<td>$n=79$ Control Group</td>
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<td>-EBT showed a less negative trending towards more positive affect.</td>
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<td>-EBT had medium effects on depression and Quality of Life-Numeric Rating Scale (QOL-NRS).</td>
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<tr>
<td>-EBT had small effects on World Health Organization Quality of Life-BREF and Satisfaction with Life Scale (SWLS).</td>
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<tr>
<td>-Results must be interpreted with caution as</td>
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<td>Reference</td>
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- Grief was the main predictor of depressed mood and mediated almost all other effects. 
- Being African American and caregiver burden directly influenced depressed mood in bereavement. 
- Important note on context of Grief: “While grief may trigger depression, the dissimilar connection to context means that the two emotional states should not be equated based purely on similarity of expression”. |
| Kapari, M., Addington-Hall, J., & Hotopf, M. (2010). Risk factors for common mental | Aimed to establish links between symptoms | Prospective cohort study following carers of patients receiving palliative care from the point shortly after | Sample $n=100$ | - Caret health during the caregiving experience was predictive of their mental health at three and six months after death. 
- Caregivers who had reported more symp- |
disorder in caregiving and bereavement. *Journal of Pain and Symptom Management, 40*(6), 844-856. doi:10.1016/j.jpainsymman.2010.03.014

<table>
<thead>
<tr>
<th>Kögler, M., Brandstätter, M., Borasio, G. D.,</th>
<th>To investigate the</th>
<th>Randomized-controlled Existential Behavioral Therapy</th>
<th>Sample $n = 130$</th>
<th>The EBT effects were partly mediated by mindfulness.</th>
<th>Dispositional mindfulness may predict</th>
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<tbody>
<tr>
<td>the patient was referred to a hospice to six months after the death of the patient.</td>
<td>symptoms of CMD at baseline were likely to do the same at six months after the death of their loved one.</td>
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<td>-Carers who had reported high levels of active coping mechanisms during their caregiving experience had worse mental health outcomes during their bereavement.</td>
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<td>-Carers whose practical support needs were not met while caring for their loved one had better mental health outcomes in bereavement.</td>
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<td>-Carers whose patients had undergone a “better death” had more symptoms of CMD at six months after death.</td>
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<td>-Carers who had experienced more symptoms of CMD while caring for their loved one had poorer bereavement outcomes.</td>
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<td>-Carers who had reported a higher discrepancy between their actual and ideal levels of practical support while caring for their loved one had better bereavement outcomes.</td>
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<tr>
<th>Relationship between mindfulness, mental distress, and psychological well-being in informal caregivers, and to evaluate if the effects of the intervention were mediated by mindfulness</th>
<th>(EBT) trial Evaluation at pre- and post-intervention, and a 3- and 12-months follow-up.</th>
<th>EBT Control Group = 73</th>
<th>adaption and well being in all FCGs. This finding must be interpreted with caution as only a small amount of sample was in the caregiving stage.</th>
</tr>
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<tbody>
<tr>
<td>Included: - Cognitive and Affective Mindfulness Scale-Revised (CAMS-R), - Five Facets of Mindfulness - Brief Symptom Inventory, - SWLS - WHOQOL-BREF</td>
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Ling, S., Chen, M., Li, C., Chang, W., Shen, W. C., & Tang, S. T. (2013). Trajectory and influencing factors of depressive symptoms in family caregivers before and after the To explore the occurrence of depressive symptoms and factors that affect | Descriptive, longitudinal study. | Sample | - Caregivers’ depressive symptoms peaked at one month and decreased significantly during the first 13 months after the patient’s death.
- Bereaved caregivers experienced a lower level of depressive symptoms if they had cared for older patients, reported a higher level of subjective caregiving burden during |
| | | n = 186 primary family caregivers. (Convenience Sample) | | |

| Masterson, M. P., Hurley, K. E., Zaider, T., Corner, G., Schuler, T., & | To examine psychosocial outcomes | Randomized Control Trial- secondary analysis of data from a larger National Cancer | Sample  
| n=51  
| 29-woman  
| 22-men | the patient’s dying process, and had greater social support.  
-Caregivers reported a higher level of depressive symptoms after bereavement if they had a higher level of depressive symptoms before the patient’s death, had poorer health, and were the patient’s spouse.  
-Level of depressive symptoms after the patient’s death was not impacted by caregivers’ gender, age, educational level, and financial status.  
-caregivers with chronic illness has higher depressive symptoms after patient death.  
-The older the patient, the less depressive symptoms their caregiver had, with each year increasing in the patient’s age, the caregiver’s depressive symptoms decreased.  
-If the primary family caregivers was the patient’s spouse, they had significantly higher CES-D scores then caregivers who were offspring or sibling.  
-For FCG (spouse/other family member) depression and the BDI decreased post patient’s death. Note: Age, relationship to the patient, gender, and months since loss did not
<table>
<thead>
<tr>
<th>Study</th>
<th>Design/Methodology</th>
<th>Sample Size</th>
<th>Results/Findings</th>
</tr>
</thead>
</table>
| McNamara, B., & Rosenwax, L. (2010). Which carers of family members at the end of life need more support from health services and why? *Social Science & Medicine*, 70(7), 1035-1041. doi:10.1016/j.socscimed.2009.11.029 | This study identifies which carers believed they did not get enough support from health services when caring for a terminally ill family member, what factors influenced perceptions of support, Population-based, cross-sectional study (semi-structured telephone interview) | Sample n=1110 69% - female 31% - male | - Carers were significantly more likely to have poor health if they perceived they did not get enough support from health services and the terminally ill family member did not die in their preferred place.  
- Carers’ were significantly likely to be not coping if they were in youngest age range (less than 60), female, had lost a spouse or partner, and the terminally ill had not died in the carers’ preferred place. |
| and whether inadequate support influenced the carer’s health following the death of a family member. |
|---|---|---|
| Stajduhar, K. I., Martin, W., & Cairns, M. (2010). What makes grief difficult? Perspectives from bereaved family caregivers and healthcare providers of advanced cancer patients. *Palliative & Supportive Care, 8*(3), 277-289. doi:10.1017/S1478951510000076 | To describe, from the perspectives of bereaved family caregivers, their perspectives on what made their grief difficult. | Secondary Analysis of Qualitative Data from five focus groups. Data was subjected to interpretive thematic analysis. | Sample n=33 - three focus groups with family caregivers (n=19) - two focus groups with health professionals (n=14) Gender 14-female 5-male | - Lack of acknowledgement of death by Health Care Professional lead to increased grief difficulties.  
- Withholding medical or prognostic information from the client can lead to feelings of guilt and anger in bereavement.  
- Access to accurate and timely information (help deal with caregiving) this helped deal with their grief.  
- Unmet expectations of services lead to anger in bereavement.  
- Lack of attention to personalized services lead to negative impressions that went beyond grief.  
- Inattentive Health Care Professionals at
| Thomas, K., Hudson, P., Trauer, T. | To ascertain whether | Longitudinal study, based on a previous sample $n=301$ | Critical points lead to bitterness that did not reduce in bereavement and anger in bereavement.  
- Government systems not working together lead to anger.  
- Health problems during caregiving made dealing with grief difficult due to continuing health problems.  
- The emotional and physical toll of caregiving impact bereavement as the emotional and physical toll continues.  
- Employment and caregiving balance leads to increased guilt and increased regret.  
- Missing death leads to increased guilt and increased regret.  
Dual caregiving role leads to increased anger, poor coping and difficult grief.  
- Lack of family and friend support leads to anger and feeling unappreciated.  
- Disagreements in families leads to bad feelings.  
- Living with the patient was significantly associated with Prolonged Grief (PG). |
### Table: Family Carers of Cancer Patients in Palliative Care

<table>
<thead>
<tr>
<th>Gender</th>
<th>Female</th>
<th>n=125</th>
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<tbody>
<tr>
<td>Male</td>
<td>n=37</td>
<td></td>
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<tr>
<td>Missing</td>
<td>n=1</td>
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</tbody>
</table>

- **Study of 301 Carers of Patients Receiving Palliative Care**
  - Completed T1 – T3
  - N=134

- **Symptom Scores**
  - Spouses reported higher PG symptom scores than careers of parents.
  - Age is negatively correlated with prolonged grief symptoms.
  - Lower level of education (not completed high school vs finishing high school) had higher prolonged grief scores.
  - Carers who had not completed high school had higher prolonged grief symptom scores than those who had not completed high school.
  - There were no differences in PG symptom scores found for carer gender, carer age, patient level of functioning, length of time spent caring, or previous caregiving experience.
  - Psychological distress factors at admission (T1) significantly predicted prolonged grief symptom scores at 13 months post death (T3).
  - Caring impact on schedule, being a spouse, poor family environment, and lower scores on optimism, were also weakly (but significantly) related to higher scores on T3.
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<tbody>
<tr>
<td>To explore whether psychological distress at diagnosis, the course of the illness, the spouses' experience of the care and of losing a loved one were related to distress and grief resolution after the patient had deceased</td>
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<td>Prospective study: Twenty-one spouses were followed prospectively from the patient's diagnosis of advanced gastrointestinal cancer to 6 months after the patient death. Spouses' experiences were measured with an interview, psychological distress with the Hospital Anxiety and Depression Scale and grief resolution with the Grief Resolution Index.</td>
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</tbody>
</table>
| Sample 
*n=*21  
Gender  
Female
*n=*15  
Male
*n=*6 |
| prolonged grief symptoms. -The spouses' anxiety at the time of diagnosis was positively correlated with anxiety in bereavement. -The spouses' anxiety at baseline was negatively correlated with grief resolution in bereavement. -Two additional factors were associated with higher levels of anxiety at follow-up; the patient having received anti-tumour treatment and the spouse having experienced stress as a caregiver. Note: Spousal FCG anxiety was not correlated with depression post death. Spousal FCGs depression was not correlated with psychological distress or grief resolution. Also, patients psychological distress had no relationship to spousal psychological distress or grief resolution. |

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<tbody>
<tr>
<td>To determine whether the place of death for patients with cancer is</td>
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<tr>
<td>Prospective, longitudinal, multisite psychiatric epidemiologic study of patients with advanced cancer and</td>
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</tbody>
</table>
| Sample 
*n=*342 dyads |
| -ICU deaths were associated with a heightened risk for posttraumatic stress disorder, compared with home hospice deaths. Even after adjustment for caregivers' preexisting psychiatric illnesses. -Hospital deaths were associated with a |
-Caregivers pre existing psychiatric comorbidities was a significant predictor of psychiatric illness in bereavement.
-Hospital deaths and ICU deaths (compared to home hospice deaths) are more associated with psychiatric illness during bereavement.
-Bereaved caregivers who’s loved one dies in ICU has a heightened risk of PTSD as opposed to place of death in home hospice.