

The experience of providing end-of-life care to a relative with advanced dementia: An integrative literature review

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ABSTRACT

The number of people with dementia is growing at an alarming rate. An abundance of research over the past two decades has examined the complex aspects of caring for a relative with dementia. However, far less research has been conducted specific to the experiences of family caregivers providing end-of-life care, which is perplexing, as dementia is a terminal illness. This article presents what is known and highlights the gaps in the literature relevant to the experiences of family caregivers of persons with dementia at the end of life. A thorough search of the Cumulative Index to Nursing and Allied Health Literature (CINAHL) and PubMed databases from 1960 to 2011 was conducted. Ten studies were identified that specifically addressed the experience of family caregivers providing end-of-life care to a relative with advanced dementia. Common themes of these studies included: 1) the experience of grief, 2) guilt and burden with decision making, 3) how symptoms of depression may or may not be resolved with death of the care receiver, 4) how caregivers respond to the end-stage of dementia, and 5) expressed needs of family caregivers. It is evident from this literature review that much remains to be done to conceptualize the experience of end-of-life caregiving in dementia.

KEYWORDS: Dementia, Family caregiving, End of life, Literature review

INTRODUCTION

As the baby boomer population ages, and with no known cure for dementia, the number of people with this disease is expected to grow at an alarming rate worldwide (Alzheimer's Disease International, 2009). Dementia is a chronic disease of the brain resulting in a deterioration of thinking ability and memory to the degree that it interferes with one's ability to work or participate in social activities or relationships with others (Diamond, 2006; Feldman et al., 2008). The progressive nature of dementia can lead to an inability to make judgments, behavioral changes (e.g., agitation, aggression, or depression), changes in personality, and decreased functional ability. Persons with advanced dementia require

full-time care and assistance in activities of daily living (Herrmann & Gauthier, 2008). Given the disease trajectory, family caregivers to persons with dementia may have unique needs and experiences compared with other types of family caregivers (Hebert & Schulz, 2006; Gill et al., 2010; Lynn, 2001).

An abundance of research over the past two decades has examined the various and complex aspects of caring for a relative with dementia. The vast majority of this research has been conducted in relation to the burdensome or stressful nature of caregiving, including the effectiveness of interventions to alleviate these negative outcomes (Peacock & Forbes, 2003). This previous work often focuses on the earlier phases of the caregiving journey with dementia. Far less research has been conducted on the experiences of family caregivers providing end-of-life care, which is perplexing given dementia is a terminal illness (Mitchell et al., 2009; Gill et al., 2010). Much more needs to be done to add clarity and provide

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understanding within the end-of-life context, particularly for those who care for a relative or loved one with dementia (Allen et al., 2003; Sanders & Swails, 2009).

By presenting the current and relevant literature, this article encapsulates what is known, and highlights the gaps in current knowledge in the experiences of family caregivers of persons with dementia at the end of life. This is important, as no such review of this body of knowledge was located. The article is divided into three parts: the search strategies employed, presentation of the narrative synthesis of the included studies, and a discussion of the gaps identified in the literature and implications for future research.

METHOD

A thorough search of recent literature between the years 1960 and 2011 was undertaken using Cumulative Index to Nursing and Allied Health Literature (CINAHL) and PubMed databases. The search terms used in various combinations included: caregiving, family caregivers, dementia, end-of-life, palliative, experience, grief, and strain. Simply using the key words caregiving and dementia resulted in >550 studies; very few studies addressed the end-of-life care experience. An additional specific search was conducted using the search terms dementia, family caregivers, and end-of-life for studies conducted qualitatively (in order to identify experience-based studies); none were identified in either database. Hand searching pertinent journals and reference lists of caregiving articles was also undertaken.

To be included in this integrative review articles must have: 1) been available in English, 2) focused on the experience of end-of-life care to persons with advanced dementia, 3) included only the perspective of family or informal caregivers, and 4) employed either a quantitative, qualitative, or mixed methods approach. Studies with family caregivers to persons with non-dementia terminal illnesses, with a focus on the needs and experience of the person with advanced dementia alone, or that considered the view of formal care providers, were not included. In all, 10 publications were retrieved that examined the end-of-life care experience for family caregivers to persons with advanced dementia. These 10 studies formed the core of this integrative literature review. Data was extracted from each article pertaining to purpose, sample characteristics, study design, results, and implications of the research. Constant comparison was the overarching approach used to organize the data into themes that represent the findings of the included studies (Whittemore & Knaff, 2005).

RESULTS

Of the 10 studies retrieved, 4 reported on the same sample; they are part of the Resources for Enhancing Alzheimer's Caregiver Health (REACH) study (see Wisniewski et al., 2003). Half of the studies used a quantitative methodology ($n = 5$): two studies used mixed methods, one conducted naturalistic inquiry, one undertook a thematic analysis, and one used an ethnomethodology. Of the 10 studies, 1 was conducted in Australia, 1 in the United Kingdom, and the remaining 8 in the United States. Sample sizes range from 14 to 254 participants, with all participants being recruited from either an existing program or the long-term care home where their family member lived. Common themes of these studies were: 1) the experience of grief ($n = 5$), 2) guilt and burden with decision-making ($n = 1$), 3) how symptoms of depression may or may not be resolved with death of the care receiver ($n = 4$), 4) how caregivers respond to the end stage of dementia ($n = 2$), and 5) expressed needs of family caregivers ($n = 2$). These outcome themes guide the discussion of the end-of-life care experience for family caregivers to persons with dementia. A table summarizing these 10 dementia caregiver specific end-of-life care experience studies is provided in the Appendix.

Grief and Loss

A common theme of four of the studies was the exploration of the experience of grief and loss as they relate to dementia caregiving at the end of life. The multiplicity of losses, before and after death of the care receiver, has been acknowledged as characteristic of caregiving in dementia because of the progressive nature of the disease and how it psychologically steals away the care recipient (Kuhn, 2001; Allen et al., 2003). Grief and loss are discussed in the caregiving literature in various ways; for example, how grief is experienced along the overall caregiving journey, as anticipatory grief with a focus on after-death grief, or in terms of consequences that may resolve or lessen grief.

Grief Experienced Over the Caregiving Journey

Meuser and Marwit (2001) undertook a mixed-methods exploratory study to define a model of caregiver grief along the journey with dementia. The qualitative portion of the study used 16 focus groups with semistructured interview guides. Participants were grouped according to relationship to the care receiver (either spouse or adult child) and by stage of dementia (using the *Clinical Dementia Rating Interview*, see Meuser & Marwit, 2001). This included two focus groups made up of adult child or spousal

caregivers of a person who had already died of dementia. Much of the findings are based on the responses from the caregivers engaged in actively providing care.

Results highlight how stage of disease and relationship to the care receiver may influence the experience of grief and how losses are perceived by family caregivers; for example, the changing demands of care as a result of the increasing dependence of the care receiver impact how grief is experienced. When grief was measured with respect to the stage of dementia (using the *Anticipatory Grief Scale* and *Many Faces of Grief Questionnaire*, see Meuser & Marwit, 2001), adult children seemed to experience the highest levels of grief in the middle stage of dementia, whereas spouses' grief continued to rise in a linear fashion as dementia progressed. In particular, during the third and severest stage of dementia, adult children spoke of their grief as being additive across time to this stage, whereas spouses expressed grief as feelings of sadness and bitterness. The anticipated death of the care receiver for adult children was viewed as loss that was now finalized, associated with expressions of helplessness and the feeling that nothing more can be done; spouses on the other hand expected new manifestations of grief to come. Therefore, it appeared that, perhaps, the experience of grief was influenced by both stage of dementia and relationship to the care receiver. These valuable insights were the common themes shared within and among focus groups.

Meuser and Marwit (2001) further discuss other findings on the relationship between care receivers and active caregivers. In the last stage of the disease, for example, adult children changed their focus to longing and increased empathy for their parent, and feelings of emptiness; spouses, on the other hand, moved to feelings of guilt and regret, and struggling to live as a single person when still married to another. These qualitative findings suggest there is more to the caregiving journey than experiencing grief. In fact, Meuser and Marwit state that at times quantitative and qualitative findings were not mutually supportive in their study. Qualitative findings suggest complex issues at play in the caregiving experience that cannot be explained by quantitative data alone.

Furthermore, Meuser and Marwit (2001) suggest that the perspectives of the experience of bereaved caregivers "differ in meaningful ways from the experiences reported by those actively caregiving" (p. 666). However, they did not elaborate on those differences and did not present data to support this statement. This is unfortunate, as a discussion of responses from these caregivers may have lent a different perspective that could have added to

understanding the grief experience across all stages of dementia, up to and including the death of the care receiver. Instead, the responses reported on from these two groups describe the perceived effects of anticipatory grief post-death. These findings are discussed subsequently in the review. It is important to point out that Meuser and Marwit used a cross-sectional design (rather than a longitudinal approach) and specifically sought common experiences shared within and across focus groups in order to develop a grief inventory. The unique lived experiences of family caregivers' grief and loss were not the focus of their study.

Anticipatory Grief

Research has shown that family caregivers may immediately experience loss and grief with a diagnosis of dementia; therefore, grieving for the care receiver may begin well before end of life or death occurs (Morgan & Laing, 1991; Lindgren et al., 1999; Kuhn, 2001). Kuhn regards anticipatory grief as a normal response in caregiving, given the number of losses associated with dementia. The experience of anticipatory grief may vary, depending upon the disease of the care recipient. For example, persons with cancer and their caregivers may be able to work through feelings of loss together during the earlier phases of the illness, but the cognitive decline in persons with dementia means that this opportunity for joint grieving is unlikely to be available for family caregivers.

Meuser and Marwit (2001) proposed that experiencing anticipatory grief may potentially reduce the amount of grief experienced once the care receiver with dementia dies. The quantitative findings that grief scores diminish as dementia progresses support their proposition. The qualitative findings, on the other hand, suggest something far more complex. The qualitative findings based on the responses in two focus groups of family caregivers whose relative with dementia was already deceased focus on the effects of anticipatory grief. Meuser and Marwit found varied responses among these bereaved family caregivers that did not support their initial hypothesis; for example, anticipatory grief did not lessen after-death grief as shared by family caregivers in the long term, and not at all in some cases. Further research in this area is warranted. Anticipatory grief and its relation to the many losses over the caregiving journey with dementia may have implications for how family caregivers experience end-of-life care. It may be beneficial to understand what is transpiring within the end-of-life context from the perspective of family caregivers themselves.

After-Death Grief

The grief experience of family caregivers specifically after death of the care receiver with dementia has been explored in a sample taken from a randomized control trial of the REACH study (Schulz et al., 2006). The primary measure of grief in the REACH study was based on the *Inventory of Complicated Grief* (see, Schulz et al., 2006). Schulz and colleagues suggest that a minority (20% of their sample) of family caregivers continue to experience *complicated grief* after the death of their relative. Those caregivers already experiencing high levels of depression and strain while caring for a cognitively impaired relative were predisposed to suffer complicated after-death grief. Schulz and colleagues' findings demonstrate a connection between the experiences of depression, strain, and grief and how they may impact the end-of-life experience.

Similar to Meuser and Marwit (2001), Schulz and colleagues (2006) recommend supportive interventions earlier in the caregiving journey as a means to lessen the development of complicated grief after the death of a relative with dementia. Although grieving may be a normal response to the loss of a family member, complicated grief is not. Perhaps family caregivers at risk of developing complicated grief could be identified prior to the end-of-life phase and offered supportive interventions. The REACH was a prospective study conducted over 18 months, which also had the benefit of following participants after death of the care receiver. The findings of all the REACH studies included in the review are based on the bereaved participants' experiences. Of note, however, is that multiple post-death assessments were not available for the entire sample. Furthermore, predominantly reporting only quantitative results may be a limitation, as subjective experiences that participants might have shared were not explored.

Positive Experiences and the Impact on Grieving

Another article related to the REACH study explored how positive aspects of family caregiving may have impacted caregivers' adaptation to the death of their family member with dementia (e.g., Boerner et al., 2004). Boerner and colleagues found that the more family caregivers experienced benefits from their caregiving, the more grief they experienced with the death of the care receiver. The spousal caregivers in Boerner and colleagues' study seemed to experience more benefits from their caregiving role, suggesting a closer relationship. This resulted in experiencing a greater intensity of grief when the spousal care receiver finally died. Therefore, positive aspects may aid a family caregiver during active caring but do not carry over into bereavement. In

the REACH study, caregiver benefit was measured by 11 items phrased as statements; responses were rated on a five point Likert scale in order to measure positive aspects of caregiving. Perhaps the experience of grief as related to the benefits from caregiving is more complex than their quantitative study suggests.

Treloar and colleagues (2009) undertook an exploratory retrospective (mixed-methods) study to look at a community-based palliative and end-of-life care service for persons with advanced dementia. Detailed interviews using semistructured questions were conducted with family caregivers to identify major factors that made at-home care possible. Their findings suggested that the ability to fulfill caregiving at home, up to and including death, was viewed as rewarding and positive; so much so that it alleviated post-death grief. All of the participants in Treloar and colleagues' study stated they were glad to provide care at home and would do it all again. However, the small sample size ($n = 14$) and lack of detailed or thorough discussion of the resulting themes in this study call for caution with these findings.

Burden and Guilt

Burden as a consequence of family caregiving is a common theme in the caregiving literature. Care for a relative with dementia is an all-consuming, demanding role that can take a toll on family caregivers over time (Ory et al., 2000). The predominance of burden as a theme in the literature may also, in part, be a result of researchers initially studying family caregiving for persons with dementia from a stress/adaptation paradigm (Farran, 1997). Feelings of guilt may manifest for a number of reasons over the caregiving journey. For example, family caregivers may feel guilty about their inability to do more in providing care for their relative or being relieved when the care receiver finally dies (Meuser & Marwit, 2001; Schulz et al., 2003). Although guilt and burden are commonly studied in earlier parts of the caregiving journey, only a single study was retrieved for the review that explored these experiences during the end-of-life phase.

In a descriptive qualitative study, Forbes and colleagues (2000) explored how family caregivers make end-of-life decisions for care of their relative with dementia in long-term care. Reports of feelings of burden and guilt by family caregivers were a major outcome of the study. Despite the focus on decision making, this study demonstrated the lingering experience of burden and guilt from earlier in the caregiving journey that can flow into end-of-life care. There also appeared to be little relief for the caregiver from long-term care placement of the care receiver.

Family caregivers in the study found it difficult to make end-of-life decisions, coupled with being unfamiliar with the dying trajectory. This uncertainty may have negative impacts on decisions for care, and suggests the need for emotional and informational support for family caregivers during the end-of-life phase. It may be important to consider whether or not guilt and burden figure in the experiences of family caregivers providing care in other settings (i.e., hospital or home).

This study used focus groups rather than individual interviews to explore how family caregivers make decisions for end-of-life care. Nonetheless, exploring the family caregiver's perspective with a dying relative in long-term care is of benefit given that the focus of much of the research with this population to date is limited to the experience of grief and loss. What other experiences might family caregivers to persons with dementia share when not limited to a semistructured or structured research format?

Forbes and colleagues (2000) also indicated the presence of feelings of ambivalence as family caregivers approached the death of their relative. Ambivalence manifests at the end of life when death occurs with feelings of sadness and possibly regret, while there is also relief at letting go of the care receiver and the suffering the care receiver has endured. Ambivalent feelings can be distressing to family caregivers. Other studies note that family caregivers express relief with the death of the care receiver, while having other conflicting feelings (e.g., Schulz et al., 2003). However, studies may not necessarily name those feelings as being ambivalent. It may be of value to further explore if ambivalent feelings figure prominently in the end-of-life experiences of family caregivers to persons with dementia.

Depression

Caregivers of persons with dementia have been found to have higher levels of depression than caregivers of persons who are cognitively intact (Neundorfer et al., 2001; Canadian Institute for Health Information, 2010). Depression as an outcome of providing care to a relative with dementia and ways to alleviate it are the focus of much of the family caregiving research (Peacock & Forbes, 2003). Not surprisingly, assessment of depressive symptoms is the focus of several ($n = 4$) studies included in the present review.

In an earlier article of the REACH study, Schulz and colleagues (2003) discovered that family caregivers to persons with dementia experienced high levels of depressive symptoms (as measured by the *Center for Epidemiologic Studies Depression Scale*, see Schulz et al., 2003) while providing end-of-life

care to their relative. More than half of the caregivers in their study admitted their relative to long-term care prior to death. Despite the potential relief from 24 hour care that institutionalization provides, those whose relatives with dementia died in long-term care did not have the same relief from depression as those caregivers who provided end-of-life care at home. Is it possible that the benefit of seeing caregiving through to the end-of-life at home provided relief from depressive symptoms? Or might there have been societal pressures at play here? For example, the healthcare system may impose expectations on family caregivers to maintain their relatives at home, and when this is not the case, perhaps caregivers feel a sense of failure.

Other findings from the REACH study revealed that increased levels of depression may lead to complicated grief after the death of a relative with dementia (Schulz et al., 2006). The REACH study revealed that caregivers who were unprepared for the death of their relative, despite experiencing grief all throughout their caregiving, were more depressed than those caregivers who reported being prepared for the death (Hebert et al., 2006). Boerner and colleagues' (2004) examination of the REACH study data indicated that the benefits of caregiving had little to do with influencing depressive symptoms after death of the care receiver. There appeared to be a connection (causal or otherwise) between grief and depression and how this impacted the end-of-life experience for family caregivers that warrants further investigation.

Bodnar and Kiecolt-Glaser (1994) measured levels of depression after death of a relative with dementia. In this study, depressive symptomology was assessed using the *Hamilton Depression Rating Scale* (see Bodnar & Kiecolt-Glaser, 1994). Their quantitative longitudinal study revealed that family caregivers continued to exhibit higher rates of depression compared with a non-caregiving control group for up to 3 years after death of the care receiver. This contrasts with Schulz and colleagues (2003) who found that depressive symptoms declined in the first 13 weeks after the death of the care receiver and continued to decline up to 65 weeks post-death. Both studies indicated that long-term care placement of the care receiver did not appear to bring relief from depressive symptoms. These findings are similar to those of Forbes and colleagues (2000) who also noted the lack of relief for family caregivers with long-term care placement of the care receiver at the end of life. Perhaps there are added challenges with long-term care placement that family caregivers in the community do not face.

Further, Bodnar and Kiecolt-Glaser (1994) found that other lingering effects from the negative outcomes of caregiving (e.g., social isolation) do not

seem to resolve even up to 3 years post death. Experiences or measures of grief were not completed nor was place of death indicated for comparison in this study; this is unfortunate, as it may have revealed further insights into the relationship between depression and grief. The main implication of this study is that family caregivers also require support after the caregiving journey ends. The structured quantitative approaches of Bodnar and Kiecolt-Glaser and the REACH study (Schulz et al., 2003; Boerner et al., 2004; Hebert et al., 2006; Schultz et al., 2006) may have limited the exploration of complex experiences that may not be entirely amenable to quantification. Unfortunately, the unique and subjective experience is neglected. The collection of data from the same sample over multiple points of time is a strength of both the REACH and Bodnar and Kiecolt-Glaser studies nonetheless.

Response to the End Stage

Sanders and colleagues (2009) used ethnomethodology to study the response of family caregivers to the end stage of their relatives' dementia. They report on a sample of 27 active family caregivers from a larger project that focused on hospice care for persons with end-stage dementia. The transcripts of four semistructured interviews with each participant were analyzed and coded to reveal themes that related to how the caregivers responded to their relative's end stage. Themes were organized into four distinct caregiver portraits: 1) *disengaged* caregivers, 2) *questioning* caregivers, 3) *all-consumed* caregivers, 4) *reconciled* caregivers. These portraits were based on how caregivers constructed their experiences. For example, disengaged and reconciled caregivers were ready for their relatives' death, but for different reasons; disengaged caregivers may have been covering up for difficult past relationships, whereas reconciled caregivers found closure to a close relationship with the care receiver. Questioning and all-consumed caregivers were very involved in the care of their relatives and this came at a price. Similar to those studied by Meuser and Marwit (2001), these caregivers experienced more burden, anxiety, and grief as the care receiver approached death. A strength of this study was continued contact and multiple interviews with participants over a 10 month period. However, the sample is limited to caregivers who were accessing hospice care and were of European American descent.

Similar to the concept of questioning and all-consumed caregivers in Sanders and colleagues' (2009) study, Treloar and colleagues (2009) also identified that caregivers could be very determined in order to be able to provide care at home, so much so that

they would compromise their own physical health. Many of the participants avoided hospitalization of their relatives during the end stage of dementia; those that did hospitalize their relatives only did so because of a sudden change in health status. These non-long-term care setting studies revealed that family caregivers had a deep commitment to care through to death. How do family caregivers with their relatives in long-term care view their commitment to provide end-of-life caregiving?

Expressed Needs of Family Caregivers

Given the complex needs of persons with dementia at the end of life, it is inevitable that family caregivers will engage the health system to assist with the dying of their relatives. One study explored what it was like for family caregivers to live through the end stage of dementia (Shanley et al., 2011). Using semistructured interviews ($n = 15$) this qualitative investigation revealed that family caregivers desired a connection to formal care providers during the final stage of their relatives' dementia. This was because family caregivers often felt alone and relied on formal care providers to help with decision making and provide psychosocial support. Shanley and colleagues suggested that formal care providers respect and acknowledge the capacity of family caregivers by making genuine connections with them and their relatives with advanced dementia. This is further supported by Treloar and colleagues' (2009) study, which found family caregivers relied heavily on a wide range of formal care providers, and desired regular and continued contact and support from them. It is clear however, that these necessary services do not respond as well they should to the needs of family caregivers providing end-of-life care at home.

Other needs of family caregivers identified in Treloar and colleagues' (2009) study involved appropriate equipment (e.g., electric lifts, commodes, incontinence pads). Participants required assistance from formal care providers to determine what equipment was available and necessary. Having access to appropriate equipment was vital to being able to provide quality end-of-life care, and as a result family caregivers had a more positive and rewarding caregiving experience.

In summary, it may be difficult to disentangle what is occurring at the end of life for family caregivers based on the limited studies cited here. The vast majority of the studies were based on the researchers' assumptions about the end-of-life experience for family caregivers to persons with dementia (e.g., using semistructured interview guides). The control required of quantitative approaches (e.g., distance between the researcher and participant or

quantification of variables) may limit understanding of a phenomenon. It is often those unique and subjective elements in qualitative research that have the potential to reveal deeper understanding. Narrowing the focus of qualitative approaches to one concept (e.g., the experience of grief) may not allow participants to share other experiences that are important to them. Moreover, all the retrieved studies recruited participants from existing programs or long-term care homes. Family caregivers not accessing formal or support services may have differing experiences; these individuals also warrant attention, although they may be harder to locate.

Limitations of this review may be found in the conduct of the included studies. Although thorough search strategies were used, there may be literature that was not accessed and included. The diversity, both in methods and outcomes, of the included studies made it complicated to compare and contrast findings.

DISCUSSION

Although the studies retrieved for this review provide valuable insights, the differing methodologies and narrow focus of the studies prove challenging to synthesizing the overall end-of-life caregiving experience; too many gaps continue to exist that limit our understanding. What is known from the above-referenced studies is that many caregivers find the end-of-life experience difficult and burdensome. Some caregivers may experience positive outcomes from providing end-of-life care in their own home; however, these positive outcomes may or may not carry over into bereavement. There appears to be lingering guilt, burden, grief and depression for many family caregivers that is not resolved with either long-term care placement of the care receiver or the care receiver's death. Because of the high needs of care receivers with advanced dementia, long-term care placement is likely; long-term care homes must begin to address how to support family caregivers to provide meaningful end-of-life care. Furthermore, a number of studies (e.g., Meuser & Marwit, 2001; Boerner et al., 2004) identified that the end-of-life care experience varies and is affected by the relationship with the care receiver (e.g., noting differences between spouses and adult children).

There is also an indication that family caregivers lack knowledge regarding the death/dying trajectory as, for example, in being unprepared or shocked at the inevitable death of the care receiver (e.g., Forbes et al., 2000; Schulz et al., 2003; Hebert et al., 2006; Shanley et al., 2011). Formal care providers need to be cognizant of this lack of understanding and support family caregivers accordingly. More importantly,

this support needs to extend after the care receiver's death. Clearly, some of the included studies highlight that family caregivers desire support before and after death of their relatives with dementia (e.g., Forbes et al., 2000; Treloar et al., 2009; Shanley et al., 2011); the challenge remains to identify how best to support family caregivers all through the journey with dementia, up to and including the end of life. Adequate and cohesive support of family caregivers will ultimately lead to better end-of-life outcomes for their relatives with advanced dementia.

The review of knowledge regarding family caregiving to persons with dementia reveals a lack of published research focusing on the personal experience of end-of-life care. Specific gaps in the literature as identified in the abovementioned review include explorations of: 1) the potential differences in end-of-life experience based on place of death, 2) the positive and negative aspects of providing end-of-life care within the context of dementia, 3) the impact the gender or the sociocultural beliefs of the caregiver might have on the end-of-life care experience, 4) the roles family caregivers undertake and how that may affect their experience with end-of-life care, 5) how ambivalent feelings may or may not influence the end-of-life care experience, 6) how family caregivers can be supported as they provide end-of-life care, and 7) which past experiences have an impact on the end-of-life care experience. Evidently a great deal remains to be done to conceptualize the experience of end-of-life caregiving in dementia. The foundation for such studies: an exploration in which caregivers express their experiences and identify their needs as they care for family members with dementia at the end of life.

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APPENDIX. SUMMARY TABLE OF DEMENTIA CAREGIVER SPECIFIC END-OF-LIFE CARE STUDIES

Author	Purpose	Sample	Design	Results	Implications
Bodnar & Kiecolt-Glaser, 1994 USA	To examine differences in levels of depression among caregivers with more time to adjust to the death of the care receiver than those recently bereaved.	$N = 254$; $n = 98$ continuing caregivers (72% female, mean age 59 years), $n = 49$ bereaved caregivers (69% female, mean age 63 years), $n = 107$ controls (79% female, mean age 63 years). Recruited through a variety of sources.	Longitudinal study (4 years) with structured interviews and measures completed yearly. Eight different instruments administered to participants.	Compared with controls, caregivers continue to show higher rates of depression and anxiety for as long as 3 years after bereavement. Relationships and social activities did not improve following bereavement. Time since bereavement did not hold any significant differences between caregivers. No differences in depressive scores detected between spousal and adult child caregivers.	Family caregivers require support even after death of the care receiver because of the rates of depression and continued rumination about the former caregiver role.
Boerner et al., 2004 USA	To examine how the positive aspects of caregiving affect adaptation to bereavement among older adults who cared for a family member with dementia.	$n = 217$ bereaved family caregivers (from $N = 1222$), 84% female; mean age 65 years; 50% spouses, 50% children and other relatives; mean time of caregiving 3 years. Care receivers mean age 81 years; 46% female; moderately to severely impaired; place of death: 32% home, 40% hospital, 27% long-term care (LTC). All recruited from the Resources for Enhancing Alzheimer's Caregiver Health (REACH) study.	Prospective survey study part of the REACH study. As many as 6 different standardized survey instruments with structured questions in interviews conducted at baseline, and 6, 12, and 18 months follow-up. Positive aspects were assessed with 11 items, phrased as statements (developed for the REACH).	Caregiving benefit was positively linked to grief and less correlated to depression. Caregivers who reported poorer health, more pre-death depressive symptoms, more caregiving benefit pre-death, as well as less time between death and the post-death assessment were likely to show more depressive symptoms within a year following death of the care receiver. Those who were spouses were more likely to report higher levels of grief after the loss.	The positive aspects within active caring may not carry over into bereavement. Caregiver benefit may be in relation to having a close relationship (e.g., spouse, in this study) to the care receiver; therefore, with death, the loss may feel greater than by those with a less close relationship. Depressive symptoms may be related to negative mental health, whereas grief is related to feelings of loss; therefore, grief and depression may be represented by different facets of bereavement. Both the negative and positive aspects of caregiving should be assessed.

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APPENDIX. *Continued*

Author	Purpose	Sample	Design	Results	Implications
Forbes et al., 2000 USA	To describe families' decision-making processes, both cognitive and affective, regarding end-of-life treatments for nursing home residents with moderately severe to very severe dementia.	N = 28 family caregivers; 64% female; mean age 66 years. Care receivers mean age 84 years; length of time since loss of decision-making capacity: mean 4 years. Recruited from four LTC facilities that utilize advanced directives for residents.	Descriptive, qualitative study, using naturalistic inquiry. Focus groups (n = 4) using open-ended questions (e.g., "With regard to your family member, what does quality at the end of life mean to you?"); data analyzed with content analysis.	Five decision-making themes: 1) <i>Emotional effect</i> (revealed the emotional burdens of decision making with underlying guilt stemming from LTC placement; burden and sense of responsibility were unresolved with LTC placement, caregiving continued in LTC; pain from multiple losses; hesitant to make end-of-life decisions); 2) <i>Insult-to-life stories</i> (present reality of care receiver not consistent with the life story family members had envisioned, personhood shattered; caregivers' own life story changed); 3) <i>Two faces of death</i> (death seen as a tragedy and/or a blessing, accepted versus forbidden, acknowledged versus unacknowledged; resulted in difficulties making decisions and caregivers wanting other's help); 4) <i>End-of-life treatments</i> (value quality of life, preserve dignity, promote comfort, ensure good care, and have peace of mind regarding decisions); and 5) <i>Unrecognized dying trajectory</i> (caregivers unable to conceptualize the dying process, and therefore made decisions with limited knowledge; desired a natural death; lack of communication with one person/consistent provider a barrier).	Family caregivers' decision-making can be compared to traveling on a long, unwelcomed journey. Facing the death of the care receiver was filled with intense emotional pain and conflict. Caregivers' own peace of mind was the most significant outcome of the journey after death of the care receiver. Even though all of the care receivers were in the moderately severe to severe stages of dementia caregivers did not view death as part of the experience. This study provides an illustration of the unrecognized trajectory of dying.

<p>Hebert et al., 2006 USA</p>	<p>To determine the relationship between preparedness for the death and mental health in bereaved caregivers of persons with dementia and explore predictors of preparedness.</p>	<p>$n = 222$ bereaved family caregivers (from $N = 1222$), 84% female; mean age 63 years; 50% spouses; 50% adult children and other relatives. Care receiver mean age 82 years; place of death: home 32%, hospital 41%, LTC 27%. All recruited from the REACH study.</p>	<p>Prospective survey study part of the REACH study. Standardized survey instruments with structured questions in interviews conducted at baseline, and 6, 12, and 18 months follow-up.</p>	<p>Twenty-three percent of caregivers were “not at all” prepared for the care receiver’s death; those caregivers had the worst mental health (i.e., were more depressed, experienced complicated grief, and had anxiety symptoms). African American caregivers, those with less education, those with less income, or those with more depressive symptoms were more likely to perceive themselves as “not at all” prepared for the death. Amount of pain care receiver was in prior to death was positively associated with preparedness.</p>	<p>Perhaps asking about preparedness for death may serve as a screen for psychiatric morbidity. Family caregivers who have less education, have less income, are more depressed, or are African American may be more in need of supportive interventions (authors suggest these caregivers are at risk for not receiving quality end-of-life care).</p>
<p>Meuser & Marwit, 2001 USA</p>	<p>To define a model of caregiver grief to aid in clinical interventions and further research.</p>	<p>$N = 87$ family caregivers; $n = 45$ adult children (93% female, mean age 52 years), $n = 42$ spouses (60% female, mean age 72 years). Care receivers: 67% female. Recruited from Alzheimer’s Association, other memory/dementia services and by word of mouth.</p>	<p>Qualitative -quantitative exploratory design using focus groups (16 in total) and survey data. Focus groups divided according to relationship to and stage of dementia of the care receiver. Four instruments utilized.</p>	<p>In early stages of caregiving, adult children exhibit more denial than spouses, and are more likely to focus loss as being about themselves, whereas spouses are open and accepting about impending burdens and loss of their partner. Middle stage adult child caregivers experience anger and frustration, grief is at its highest; in contrast spouses increase in empathy and have little anger. Late stage caregiving is marked by LTC placement: adult child caregivers express relief and are able to reflect on their experience and feel the loss of the care receiver, whereas spouse caregivers experience high amounts of grief and sometimes anger and frustration with loss of the relationship. Post-death groups’ findings relate to anticipatory grief; it has an ameliorating affect on post-death grief, but not over the long run.</p>	<p>It appears that adult child caregivers express grief in a curvilinear fashion, as it peaks in the middle stage of caregiving, whereas spouses express grief in a linear fashion, increasing as dementia progresses. Anticipatory grief is real grief and may be equal to the intensity of death-related grief.</p>

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APPENDIX. Continued

Author	Purpose	Sample	Design	Results	Implications
Sanders et al., 2009 USA	To investigate how family caregivers respond to the end stages of dementia with assistance of hospice. Part of a larger study focusing on hospice care for people with end-stage dementia.	$n = 27$ family caregivers using hospice care; 74% female; age ranged from 38 to 88 years; 15% spouses, 81% adult children, and 1 grandchild. 70% of care receivers lived in LTC, 22% in assisted living, and 7% at home with caregiver. Recruited from two hospice programs.	Exploratory qualitative study using ethnomethodology. Up to 4 semistructured interviews were conducted with each participant, starting after care receiver was admitted to hospice, then every 8–10 weeks while care receiver remained in hospice. Transcripts and notes were analyzed and coded in a constant comparative process. Chart reviews also conducted.	Four caregiver portraits emerged 1) <i>disengaged caregivers</i> (physical and/or emotional distance between caregiver and care receiver), 2) <i>questioning caregivers</i> (asked many questions and struggled to understand dementia and changes in the care receiver), 3) <i>all-consumed caregivers</i> (preoccupied with every aspect of care and the impact of this on their lives), and 4) <i>reconciled caregivers</i> (accepting and prepared for care receivers' dying and death).	These 4 portraits provide an important foundation for determining how caregivers construct their situation and ways to support them during end-of-life care. This study highlights that healthcare professionals cannot assume that caregivers of persons with dementia will feel relief or will be able to reconcile their emotions with the death of the care receiver.
Schulz et al., 2003 USA	To describe the caregiving experience of family caregivers who provided in-home care to persons with dementia during the year before the care receiver's death and to characterize the nature of caregivers' responses to bereavement.	$n = 217$ bereaved family caregivers (from $N = 1222$), 84% female; mean age 65 years; 50% spouses, 50% children and other relatives; mean time of caregiving 3 years. Care receivers mean age 81 years; 46% female; moderately to severely impaired; place of death: 32% home, 40% hospital, 27% LTC. All recruited from the REACH study.	Prospective survey study, part of the REACH study. Standardized survey instruments with structured questions in interviews conducted at baseline, and 6, 12, and 18 months follow-up. Data used from assessments done before or closest to the care receiver's death and assessments done after the death.	Approximately 60% of the caregivers reported feeling as if they were on duty 24 hours/day. As many as 18% left employment to caregive; 46% used formal services, and 56% used informal help. Over 90% believed death was a relief to the care receiver, 72% felt it was a relief to them; 69% stated they were prepared for the death. More than 62% stated they thought the care receiver was in pain at the time of their death. More than 21% used bereavement services after the care receiver's death. Scores on depression scale spiked at time of death and decreased to less than pre-death scores by 1 year anniversary ($n = 53$); almost one third had scores indicating risk of clinical depression. The $n = 180$ caregivers who institutionalized the care receiver had higher depression score than bereaved caregivers who cared for their family member at home. Among all caregivers, depression scores after the care receiver's death declined in the first 13 weeks and continued to decline to 65 weeks.	Family caregivers are intensely involved in providing end-of-life care. Caregivers demonstrate resilience in adapting to the death of the care receiver. Those who institutionalized the care receiver did not show the same relief from depressive symptoms. It is possible that in the end stage, caregivers grieve the loss of the care receiver before actual death.

Schulz et al., 2006 USA	To better understand why some caregivers manifest clinical levels of complicated grief post-death.	n = 217 bereaved family caregivers (from N = 1222), 84% female; mean age 65 years; 50% spouses, 50% children and other relatives; mean time of caregiving 3 years. Care receivers mean age 81 years; 46% female; moderately to severely impaired; place of death: 32% home, 40% hospital, 27% LTC. All recruited from the REACH study.	Prospective survey study part of the REACH study. Standardized survey instruments with structured questions in interviews conducted at baseline, and 6, 12, and 18 months follow-up.	Twenty percent of participants exhibited clinical levels of complicated grief. These participants were those with less education, lower incomes, higher levels of pre- and post-death depression scores, higher levels of pre- and post-death anxiety, or reported higher levels of caregiver burden pre-death or had more positive aspects of caregiving pre-death. No sociodemographic variables were associated with complicated grief. Findings suggest that complicated grief increases during the first 15 weeks post-death, then decreases in the subsequent 6-12 months.	Data suggest that reducing caregiver burden, treating depression prior to the death of the care receiver and providing supportive interventions may assist the caregiver to better manage consequences of death. Those family caregivers who experience positive aspects in their caregiving may be more attached to the care receiver and may value their caregiving role more; therefore, they may not be able to deal as well with the death of the care receiver (discussed further in Boerner et al., 2004). Interventions should be targeted to those who are at risk for complicated grief.
Shanley et al., 2011 Australia	To focus on the needs and experiences of family caregivers to persons with end-stage dementia.	n = 15 bereaved family caregivers; 53% female; 10 spouses and 5 adult children; average of spouses 64 years, children 48 years; mean time of caregiving 5 years. All but one care receiver died in hospital or long-term care setting. Recruited through the newsletter of Alzheimer's Australia.	Exploratory qualitative study; semistructured in-depth interviews analyzed with thematic analysis. Broad topic areas included: history of caregiving experience during the last year of care receiver's life and post-death; understandings of quality of life and care during the end of life; challenges encountered; sources of support; needs of caregiver; and aspects of formal care.	Themes from the data specific to end-stage dementia: 1) getting support, 2) having to trust others with care, 3) managing the loneliness of being a carer, 4) witnessing a loved one fade away, 5) anticipating and experiencing death, and 6) re-establishing life after the funeral. Expressed needs were identified through specific questions; instrumental needs were physical help with dressing the care receiver or acquiring respite; psychosocial needs: were to have empathetic understanding from family/friends and formal care providers, continue an intimate relationship to care receiver, and receive advocacy from formal care providers.	Most important outcome is in regard to the need for understanding and connection from family/friends and formal care providers. Formal care providers need to be empathetic and support caregivers with decision making and encourage them to provide as much care as the caregiver wishes.

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APPENDIX. *Continued*

Author	Purpose	Sample	Design	Results	Implications
Treloar et al., 2009 United Kingdom	To explore and identify the key factors that support caregivers of persons with advanced dementia to provide palliative and end-of-life care at home.	<i>n</i> =14 bereaved caregivers; 50% female; mean age 68.1 years; 71% spouses, 29% children. Care receivers 57% female; mean age 80.6 years; all had a diagnosis of dementia; 57% died at home, 43% in hospital. Recruited through the Hope for Home study.	Mixed methods, with qualitative semistructured questionnaire and descriptive statistics gathered. Unclear how interviews were analyzed.	Key themes identified: 1) bereavement (caring at home helped with bereavement), 2) essential caregiver characteristics (caregivers are determined and will risk own health to provide care at home), 3) required resources (irregularity with formal care providers, but also indispensable; need for equipment), 4) funding and financial control (costs were lower than care in a nursing home; control payment to formal care providers), 5) feeding (care receivers often did not eat well and caregivers had to be creative in what was offered); 6) medication (antipsychotics and antidepressants used the most at end of life; few used narcotics), 7) availability of support services (perceived blockages to care and unavailability of help), 8) end-of-life care and place of death (hospital was to be avoided), and 9) overall evaluation (caregivers would gladly do it again).	Managing advanced dementia at home, up to and including death, is feasible and can be associated with good outcomes. End-of-life caregiving at home may provide an opportunity to finish the journey with dementia positively and alleviate grief. Managing palliative and end-of-life care at home requires specialized expertise and formal support to family caregivers; such care may be cost effective.