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Research Article

Preparedness for Death: How Caregivers of Elders With Dementia Define and Perceive its Value

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Abstract

Purpose: The purpose of this study is to ascertain how bereaved caregivers of a family member who died from a dementia-related diagnosis (a) define preparedness and (b) perceive its value.
Design and Methods: Purposive criterion sampling was employed to identify 30 bereaved caregivers of family members aged 65 and older who died with a dementia-related diagnosis. In-depth, qualitative interviews were conducted over a 12-month period, and qualitative content analysis was used to analyze the data.
Results: Only one third (n = 10) of caregivers interviewed were prepared for the death, and the majority who were prepared were enrolled in hospice. Five primary themes revealed ways that caregivers define various domains of preparedness: (i) *accepting reality*; (ii) *knowing death is near*; (iii) *getting your "house in order"*; (iv) *saying "what you need to say"*; and (v) *giving "permission" to die*. The majority (87%) believed that it is important for caregivers to be prepared, and the value of preparedness was exemplified in five domains reflecting the *benefits of being prepared*.
Implications: The results support further attention to the development and testing of interventions to address the unmet needs of caregivers of family members with dementia to help prepare them for the death in a variety of contexts.

Keywords: Death and dying, Alzheimer's, Dementia at end of life

More than 15 million unpaid caregivers are providing care for a person diagnosed with dementia in the United States (Alzheimer's Association, 2015). Alzheimer's disease, the sixth leading cause of death among older adults (Heron, Hoyert, Xu, Scott, & Tejada-Vera, 2008), accounts for 60%–80% of all dementias (Alzheimer's Association, 2015). Persons with advanced chronic progressive dementia require 24-hour care, experience numerous health-related complications due to swallowing disorders, immobility, and malnutrition, and are at increased risk for developing pneumonia, the most common cause of dementia-related death (Ganguli & Rodriguez, 1999).

The dying process and the death of individuals with dementia may be particularly difficult for family caregivers due to ambiguity concerning the process of dying and the timing of death. The ambiguous dying syndrome refers to "the collection of medical and social uncertainties" that may be present when the term "dying" applies only to those who are expected to die within days or weeks (Bern-Klug, 2004, p. 55). The ambiguous dying syndrome suggests that this lack of knowledge of impending death impedes quality end-of-life care and leaves caregivers unprepared for the death in a variety of ways. Although the ambiguous dying syndrome may be applicable to many advanced chronic diseases, the changes in cognitive functioning, personality, and communication impairments associated with dementia and the need for 24-hour care pose additional and enduring challenges to family caregivers. More than a third of bereaved caregivers of individuals with dementia report being unprepared for the death (Schulz et al., 2003) leaving them at increased risk for depression, anxiety, and complicated grief (Barry, Kasl, & Prigerson, 2002; Hebert, Dang, & Schulz, 2006).

Individuals with advanced dementia often receive life prolonging treatments similar to those without a terminal illness. Aggressive treatments for individuals dying from a dementia-related diagnosis have been shown to cause discomfort and have ineffectual results (Fabiszewski, Volicer, & Volicer, 1990); yet these treatments continue to be used (Di Giulio et al., 2008; Evers, Purohit, Perl, Khan, & Marin, 2002). As one example, 25% of patients with dementia in the nursing home die with a feeding tube as compared with only 5% of those dying with cancer (Mitchell, Kiely, & Hamel, 2004).

Although hospice utilization has steadily increased among patients with diagnoses other than cancer, hospice remains underutilized among those with advanced dementia (McCarty & Volicer, 2009), and those with dementia in nursing homes as compared with community settings (Mitchell, Morris, Park, & Fries, 2004). Fewer than half of community-dwelling elders with dementia seen in primary geriatric care clinics received hospice care in the last weeks of life (Shega, Hougham, Stocking, Cox-Hayley, & Sachs, 2008). Barriers to hospice utilization among those with dementia include prognostication challenges, misperceptions by family members of the dying process, regulatory barriers, and reimbursement issues (Shega & Tozer, 2009). In turn, this excludes family caregivers from the psychosocial and spiritual support that may assist in preparing them for the death which the hospice care team provides (Luchins, Hanrahan, & Murphy, 1997).

Preparedness has been challenging to define and conceptualize. It is referenced as the psychological forewarning (Cagle & Kovacs, 2011; Hebert, Dang, et al., 2006) and perception of readiness for death (Barry et al., 2002; Hebert, Prigerson, Schulz, Arnold, 2006) that may entail cognitive, affective, and behavioral dimensions (Hebert, Schulz, Copeland, & Arnold, 2008). A mixed-method study with professionals, patients, and family members revealed several attributes of the patient's preparedness for death: (a) naming someone to make decisions; (b) knowing what to expect about one's physical condition; (c) having financial affairs in order; (d) having treatment preferences in writing; and (e) knowing that one's physician is comfortable talking about death and dying (Steinhauser et al., 2001). A recent concept analysis suggests that death preparedness of a patient "involves a transition of facilitated communication with a healthcare provider that leads to awareness and/or acceptance of end of life, as evidenced by an implementation of a plan," that must include six key attributes: communication between patient and care providers that delivers prognosis and explores attitudes regarding end-of-life decision; acceptance; awareness; transition in death attitudes and participation in decisions and a care plan (McLeod-Sordjan, 2014, p. 1008).

Although research on the concept of preparedness for death in recent years has received increased attention, very few prior studies on preparedness for death investigated the experience of caregivers to persons with dementia (Hebert, Dang, et al., 2006). Recent studies of caregivers of persons with dementia have contributed to our understanding of lived experience of providing end-of-life care (Peacock, Duggleby, & Koop, 2014), the experiences and needs of family carers of persons with end-stage dementia (Shanley, Russell, Middleton, & Simpson-Young, 2011), grief and personal growth experiences (Ott, Sanders, & Kelber, 2007), and the impact of anticipatory grief on caregiver burden (Holley & Mast, 2009). Shanley and colleagues (2011) reported that caregivers of persons with end-stage dementia have expressed "a need for information about the dying process to be more available to them and for them to be better prepared for the death of their loved one" (p. 334), yet we know virtually nothing about what preparedness for death means to caregivers of elders with dementia. In order to engage in preparedness, individuals must perceive the benefits of doing so (McLeod-Sordjan, 2014) and professionals must understand the dimensions of preparedness that are important to caregivers to develop and test appropriate interventions. The purpose of this study is to ascertain how bereaved caregivers of a family member who died from a dementia-related diagnosis (a) define preparedness and (b) perceive its value.

Design and Methods

A qualitative descriptive approach was employed to describe how caregivers define preparedness and its perceived value. This approach "is the method of choice when straight descriptions of phenomena are desired" (Sandelowski, 2000, p. 339) and is often employed to answer questions of practical significance. Although not free from interpretation, this approach seeks to describe phenomenon in everyday language, making as few inferences as possible during analysis (Sandelowski, 2000).

Sampling and Recruitment

A purposive criterion sampling strategy was employed to include individuals who had a family member die from a dementia-related death (Miles & Huberman, 1994). As the Alzheimer's Association was the main organization for recruitment, the study announcement was published in two Midwest region Alzheimer's Association newsletters and program services staff at the two chapters who work directly with caregivers assisted in recruitment. Prior to recruitment, Institutional Review Board (IRB) approval was obtained through an Education and Social/Behavioral Science IRB. Additionally, the proposal was reviewed by the Medical and Scientific Advisory Committee (MSAC), which reviews all proposed research to be conducted with the Alzheimer's Association-Greater Michigan Chapter (GMC). At the time of the interview, the purpose of the study was reviewed and consent was obtained.

Data Collection

Thirty in-depth, one-time qualitative interviews were conducted by the primary investigator over a 12-month period with bereaved caregivers of family members aged 65 and older who died with dementia within 6 to 18 months of the interview, with an average of 9 months from time of death. This time frame allowed a minimum of 6 months to process the death, but not so much time to make recall difficult. Interviews averaged 80 minutes in length (range = 60–120 minutes). Twenty-four interviews took place in caregivers' homes and six transpired over the phone due to distance. All interviews were audio taped and transcribed verbatim by the principal investigator; transcripts ranged from 20 to 71 pages. Opening questions that were conversational in nature, open-ended, and focused on the two central research questions were considered in developing the interview guide. The first explored defining the concept of preparedness. How would you define preparedness for death? What does it mean? What does it look like? What are the various ways family members might be prepared? The second sought to understand the perceived value of preparedness with questions asked both indirectly, elicited through the invitation to talk about and share what they experienced at the end of life, and directly. What was happening in the weeks prior to and leading up to the death? What was it like for you? To what extent did you feel prepared for your family member's death? How important do you think it is for a family member to be prepared for the death of a loved one? What difference does it make? How does it help or possibly hurt?

Qualitative Content Analysis

The analytic team was comprised of the principal investigator and two experienced qualitative academic researchers. Conventional content analysis, the method of choice in qualitative descriptive studies (Sandelowski, 2000), is commonly used to describe and understand a phenomenon (Hsieh & Shannon, 2005). In order to focus the analysis, data were organized by interview questions and all responses were reviewed for uniformity and variation (Miles & Huberman, 1994). Qualitative content analysis procedures summarized by Hsieh and Shannon (2005) were followed. Transcripts were read multiple times "…to achieve immersion and obtain a sense of the whole" (Hsieh & Shannon, 2005, p. 1279) and read verbatim to search for and identify key concepts, deriving initial codes (e.g., financial planning, making funeral/burial arrangements). Next, overarching labels for codes were identified and, as the initial coding schema emerged, the codes were sorted into categories based on common associations. In keeping with the qualitative descriptive approach, exact words were highlighted from the data that encapsulated significant ideas or concepts that were grounded in the central research questions (e.g., in vivo codes using exact words of "getting your house in order" and "say what you need to say" were used to describe the definition of preparedness for death). Categories were formed and organized into meaningful clusters, combining similar themes (e.g., financial planning and making funeral arrangements were clustered into the "getting your house in order" category to describe preparedness for death). Ultimately essential themes (e.g., benefits of being prepared), categories (e.g., eases transitions to), and subcategories when appropriate (e.g., bereavement) relevant to the two primary research questions were identified. With the goal of clearly reporting the data and enhancing trustworthiness, all data were entered into NVIVO software for organization and storage of the coding structure, allowing for easy access to text illustrations for each code, category, and subcategory. Finally, the relationship among the categories and subcategories was determined (Hsieh & Shannon, 2005).

Ensuring Analytic Rigor

Several strategies were employed to ensure analytic rigor. First, peer debriefing with two experienced qualitative researchers was performed. This process entailed review of codes, memos, and excerpts of text/data to ensure that they descriptively reflected the participants' words and experiences. Second, member checking, a process that includes "returning periodically to the field to ensure that one is on the right track" (Padgett, 1998, p. 100), was conducted. Permission to make follow-up calls for the purpose of member checking was included in the informed consent. All respondents agreed to follow-up telephone calls for possible member checking of analysis. In total, member checking was carried out with four caregivers who were provided a written description of the themes generated from the content analysis of their interview transcript before reviewing the content over the phone. Given that all four caregivers confirmed that findings were consistent with their experience and offered no modifications, a decision was made to discontinue member checking. Third, with the goal to conduct research that has credibility, attention was given to leaving an audit trail (i.e., memoing, and interview transcripts) (Padgett, 1998). Finally, a research journal of personal thoughts, feelings, and ideas was maintained by the primary investigator throughout the study to facilitate reflexivity.

Results

As shown in Table 1, caregivers were predominantly women (89%), spousal caregivers (60%), who had been providing care from 2 to 12 years, with an average of 6.6 years. Of the adult children, all but one were adult daughters. Caregivers ranged in age from 45 to 88 years, the vast majority were White (93%), and all had at least a high school diploma. Most of the care recipients died at home (44%) or in a nursing center (40%), and the majority were enrolled in hospice (67%).

Table 1. Characteristics of Study Participants

Caregivers (*N* = 30)	
Relationship to patient, *n* (%)	
Spouse/significant other/life partner	18 (60)
Adult child (daughter/son)	12 (40)
Age (years)	
Female caregivers	65
Male caregivers	75
Gender, *n* (%)	
Female	24 (80)
Male	6 (20
Ethnicity, *n* (%)	
White	28 (93)
Black	2 (7)
Education, *n* (%)	
High school graduate	14 (46.7)
Some college	4 (13.3)
College graduate	8 (26.7)
Graduate degree	4 (13.3)
Duration of caregiving in years (range)	2–12
Location of care recipient at death, *n* (%)	
Home	13 (44)
Hospital	4 (13)
Skilled or rehab nursing center	12 (40)
In-patient hospice	1 (3)
Enrolled in hospice, *n* (%)	21 (67)

Perceptions of Preparedness

Caregivers emphasized that preparedness for death is a "very individual thing" that may vary by one's beliefs, relationship with the person with dementia, and life experiences. Of the 30 participants, only 10 stated that they were prepared for the death; 13 stated they were not prepared; 4 reported "yes and no"; 2 stated "I don't think so"; and 1 didn't know. Nine of the 10 who were prepared for death and all of those who indicated "yes and no" were enrolled in hospice. Only 5 of the 13 caregivers who were not prepared for death received hospice care and 3 of the 5 who received hospice care were enrolled for less than 1 week. Interestingly, 13 caregivers stressed that to some extent one "can never fully be prepared" for the death. A 53-year-old woman who provided care for her mother stated, "…coming to terms with reality and knowing that it's going to happen in itself is good…But, I don't think you ever can fully prepare for it." Although more than one third of caregivers felt that one can never be fully prepared for the death of a loved one, they went on to define what preparedness means to them.

Eight caregivers described the extreme stress they suffered due to being unprepared for the physical and emotional aspects of caring for their family member with dementia at end of life and their death. They reported "crying all the time," "vomiting every morning," and described the experience at end of life as "devastating" and "a nightmare." A woman who provided care to her husband shared: "I was vomiting every morning because of the stress [crying], it's a dreaded…horrid disease." Caregivers described horrible images of the person with dementia's last hours/days that for some were "seared in [their] brain." Another caregiver, a 62-year-old woman who cared for her mother with dementia, recalled witnessing "deep depression" in people who are not prepared for a death:

> …I think it's very important [being prepared for death]. I really do…I see very serious kind of effects…going overboard, going into deep, dark depression...an unwillingness to accept the fact that someone is gone.

Of these caregivers who reported extreme stress who received hospice care, all but two of them had only recently enrolled; within hours to days of death. Three of them had endured traumatic experiences through myriad nursing home and/or hospital admissions. One participant had been referred to hospice, but due to it being a holiday weekend they had to wait until Monday, and the person with dementia died before they could sign up. A 50-year-old man who cared for his mother (age 67 at time of death) who was diagnosed with Alzheimer's disease shared how having hospice services for only 5 days did not allow him to benefit from the supportive services that hospice admission discussed. One caregiver, traumatized by the treatment during her mother's several hospitalizations, finally hired a professional advocate who referred her to hospice just 5 days before her mother's death.

Defining Preparedness

The first research question sought to understand how family caregivers defined preparedness. Five primary themes revealed ways that caregivers define various domains of preparedness. The first two, (i) *accepting reality* and (ii) *knowing death is near*, reflect cognitive, emotional, and/or intuitive awareness of approaching death perceived as central to being prepared for death. The other three (iii) *getting your "house in order"*; (iv) *saying "what you need to say"*; and (v) *giving "permission" to die* reflect instrumental dimensions of preparedness, that to some extent may depend on this growing awareness. Each of these will be described in the following subsections.

Accepting Reality

Caregivers discussed the aspect of preparedness as accepting the truth of persistent physical deterioration and "accepting the fact" that "death is imminent." Thirteen caregivers described "accepting reality" as germane to defining preparedness. A 62-year-old woman who had cared for her mother defined preparedness for death as an acknowledgment of its inevitability.

> … it would have to be acknowledging that it's going to happen…it was very hard [crying], but once I knew that it was going to happen…there's almost like a calmness…

Similarly, a 71-year-old woman who provided care to her husband for 10 years defined her experience with preparedness as acknowledgment of the inevitability of death: “Well, I think to me it probably means accepting the fact that the person isn’t going to be there anymore.”

Knowing Death Is Near

Eight caregivers discussed an inner “knowing” that death is coming as central to their definition of preparedness. Some described it as a “sixth-sense” and an intuitive process. A 50-year-old daughter of a woman with cardiovascular dementia, described how she “could feel it” coming.

> I knew her life was, I could feel it. When that time was coming….I kind of had this sixth-sense that she wasn’t going to be here that much longer... I just didn’t know when it was going to happen, but I could feel that...You can tell…I knew.

An 85-year-old caregiver for her husband with Lewy-body dementia also described her intuitive sense that death was near, a feeling that is based on her deep understanding of her husband after over six decades of marriage.

> I knew that last month…that any day. I didn’t want to leave this house. I didn’t want to walk out of the living room into the bedroom because I thought his death was that close... I wanted to be with him when it happened…. when you’ve spent sixty-three years with somebody you almost read their mind. I could tell when I woke up in the morning and walked into the living room.

Getting Your “House in Order.”

Twelve caregivers discussed getting your “house in order” as a core concept in defining preparedness. This represents having financial, legal, medical, and insurance planning and completed documents in place, and funeral/burial arrangements made prior to death. A 69-year-old wife summed up this theme in detail.

> …one is to get your house in order in terms of write a will, have a patient advocate appointed, have it easy for if you can’t make financial decisions for somebody to step in without having to go to court…having a conversation with your patient advocate about what you’d want vis-à-vis end of life decisions . . .Tell your family whether you want to be cremated or buried…where do you want to be buried? …What do you want done with your ashes… and some preferences for your funeral…. the lessons that they are going to read… and you want hymns that you like…

A 75-year-old husband caregiver highlighted the need to have a “plan in place” and avoid last minute decisions at end of life:

> Being prepared…for legal, estate, religion, family, and funeral arrangements…there should be a plan in place… and a consensus and agreement with the family... the worst possible moment is not the time to think about these things.

“Saying What You Need to Say.”

Five participants reported “saying what you need to say” as part of their definition of preparing for death. This theme represents the opportunity to “say goodbye,” to acknowledge accomplished goals (e.g., “you got to stay at home to the end like you wanted”), to honor the accomplishments of the care receiver, to express appreciation for the shared life and relationship among family members, to give thanks, and to express one’s undying love. A 47-year-old woman who cared for her mother with vascular dementia shared how regardless of her mother’s capacity to understand, her preparedness was aided by the process of communicating her thoughts and feelings to her.

> Say what you need to say even though you don’t think they understand…I definitely… talked to her and that was important to me…I think that should be done when anyone loses a loved one...I don’t know what she understood...I still said what needed to be said.

A 53-year-old daughter of a woman with Alzheimer’s disease highlighted the opportunity to say things “you don’t go around all the time saying,” and how this was meaningful to her preparedness.

> You want to be able to say “goodbye” and …whatever you want to tell them…I think that’s important to say. I’m just glad that I got to...because, you know what?... you don’t go around all the time saying…what a good dad you are, what a good mom you are… how thankful…

Giving “Permission” to Die

The fifth central theme highlighted caregivers’ need to give “permission” for their family member to die. They discussed “letting them go” and granting permission as “lifting the weight of the world off [their] shoulders.” Two respondents discussed this concept in defining preparedness. One spouse shared how giving permission for her husband to die helped her prepare for his death:

> … if I had not gotten to the place where I could give him permission…that’s something that I don’t think I could live with…It helped me. It was like I had the weight of the world lifted off my shoulders when I finally got to the place where I could tell him, “You have my permission to go whenever you feel like it.”

Additionally, a 76-year-old woman who cared for her husband with Alzheimer’s disease recounted how giving him permission to die helped her prepare for his death.

> … I said to him one day…”I don’t want you to die, because I don’t want to live by myself. I don’t want to

> be alone, but if you think dying is better than living like this, then go ahead. I'll be okay."

Value of Preparedness to Caregivers

To avoid making assumptions regarding the value of preparedness for caregivers, study participants were asked how important it is to be prepared and what difference it makes if they are prepared or not. Of the 30 respondents, 26 reported that it is important to be prepared; 2 suggested that "it depends"; 1 stated that "it didn't make a difference"; and 1 did not voice an opinion. The value of preparedness was best represented by the primary theme of the *Benefits of Being Prepared*.

Benefits of Being Prepared

Fourteen caregivers described the benefits of being prepared for the death of a family member with dementia. The benefits of being prepared were represented in five subthemes.

"Eliminates the surprise."

Of those who identified benefits to being prepared, six reported how being prepared allowed them to avoid shock and surprise. By avoiding a shocking death, they were able to "say goodbye" and "deal with those last hours in a different way." An 84-year-old husband for his wife with Parkinson's related dementia told how being prepared for the death was beneficial in that "it takes away that surprise factor. It eliminates the surprise." A 65-year-old wife of a man with Alzheimer's disease, stated: "…if [spouse] had dropped dead of a heart attack instead, it would have been a lot harder for me at the moment of death, because I wasn't prepared."

"Takes off fear."

In this second subtheme of *Benefits of Being Prepared*, two caregivers described how preparedness for death lessens fear throughout the physical dying process. A 60-year-old registered nurse who cared for her husband with vascular dementia for 3 years stated: "And that's why I hope your study, your research shows that the more you know, the less fear you have." She further explains:

> It …takes off the fear…when things start to happen, 'cause you have to explain it to them…instead of do something you know when they start to…turn blue…

Makes it "easier to accept" death.

Three caregivers highlighted how being prepared makes it "easier to accept" a family member's impending death and in some cases makes the caregiver "stronger to get through it" as well as allowing them to provide a "calm presence" to the person with dementia. A 61-year-old daughter who provided care to her mother for 3 years, stated: "I think when you're prepared, it's easier to accept." A 69-year-old woman who cared for her husband with Alzheimer's disease for 4 years explained the following:

> I don't think it takes away the hurt. But it helps you deal with those last hours in a different way. It makes you stronger, I think, to do what you have to do to make the end of a person's life easy. If I hadn't been prepared, I would have been emotionally different, and I think it would have made [person with dementia] more anxious... I would go lie down on the bed, and a couple of times…I even took a little nap, but we took a little nap together. I would snuggle up to his back…I don't think I could have done that had I not been prepared…I brought a calm presence to him…That…made it easier for him...

Facilitates being present at end of life

Three of the caregivers described how being prepared for the death alerted them to be present with their family member at the time of death and to have a family "vigil" during the final days of life. A 65-year-old wife explained how being prepared permitted her and her family to be present during her husband's final days.

> I had such wonderful support from my family and his family…my friends…There was like 24/7 vigil…in his room until he died. And they brought in an extra mattress on the floor for us…coffee pots for us…there was somebody there with him…until he died.

Conversely, three caregivers reported how not being prepared resulted in substantial regret at not being present at the time of death. A 77-year-old wife caregiver of 3 years described how she had no understanding that her husband was dying, missed being present and having the ability to say "goodbye."

> My grandson…he stopped at the nursing home…my son said "Why don't you take [grandson] home a get him some lunch?" And I said "Okay," …I feel so bad now…I should have been there…saying goodbye to my husband and everything… [crying]…why didn't those people from the- they looked at me…when we were leaving…I didn't think…he was dying. I've never seen anybody die before…I just really didn't…we pretty much just…got in the house, and the phone rang…it was [son]. He said "Mom, he's gone" …"Uh, you're kidding, you're kidding!" I just… could not believe it.

A 50-year-old man who cared for his mother described how the facility staff gave him no indication that his mother was nearing death before he left town on business, and he experienced deep regret that he was not there when she died.

> … how good they can predict those things that happen I don't know, but I think if …they would have said to me, "this is really…this may be very quick," I wouldn't have went…I'm really upset that I wasn't there…

Eases transitions

Four caregivers highlighted the importance of preparedness for death as it eases the process after the death (i.e., funeral arrangements, family discord, notifying coworkers), and how being prepared benefits the family in terms of sharing caregiver tasks and facilitating consensus among family members regarding end-of-life decisions. Two categories were identified.

To bereavement

In this first category of *Eases transitions, a* 53-year-old woman who provided care to her mother at the end of life shared how being prepared eases the transition to bereavement.

> …I think it helps from the standpoint that…you can function. I think…if you weren't prepared for it, everything else falls apart...the rest of your life…you can't focus, you can't cope, you can't…your mind is somewhere else.

To deal with postdeath responsibilities

In the second category to *Eases transitions*, another caregiver, who provided care for her mother, describes how stressful it would have been to make arrangements after the death if she were not prepared.

> …I thought…"God forbid," …I mean we knew this was going to happen to Dad. How do people handle this… that lose somebody SUDDENLY. And have no sense… this is going to happen. Those are decisions that you have to make… And, you can't say "Well, I really don't know. Let me think about it." There's no time to think about it...it's like you gotta do this, and you gotta do it now.

Discussion

To our knowledge, this is the first study to directly ask caregivers of persons with dementia to define what it means to be prepared for the death and share their perceptions of its potential value for caregivers of elders with dementia. Of the five themes inherent in the caregiver's definition of preparedness, *accepting reality* and *knowing death is near* reflect similarities with the attributes of death preparedness for the patient (i.e., *acceptance* and *awareness*) recently proposed by McLeod-Sordjan (2014). Bereaved spouses previously reported that accepting that the person was dying would have better prepared them for the death (Barry & Prigerson, 2002). Interestingly, some caregivers in the current study spoke about death awareness as an intuitive form of knowing. To our knowledge, this has not been previously reported in the literature and may have implications for the extent to which professionals will or will not be able to assist caregivers in incorporating this into their preparedness for death. However, we may do a better job of helping family members understand that Alzheimer's disease is a terminal illness. A recent study found that fewer than half of caregivers to institutionalized elders understand that progressive, irreversible forms of dementia are diseases that you can die from (Van der Steen, Onwuteaka-Philipsen, Knol, Ribbe, & Deliens, 2013), and yet the perception of dementia as a terminal disease was associated with higher comfort at the end of life.

Getting your house in order parallels aspects of preparedness previously identified as having financial affairs in order (Steinhauser et al., 2001), behavioral dimensions of preparedness defined by Hebert, Prigerson, Schulz, and Arnold (2009) and estate and funeral planning. Caregivers additionally talked about the importance of planning for legal, medical, and insurance considerations. *Saying what you need to say* also described caregiver's definition of preparation for death and referred to as a "component of completion"; an element of a good death (Steinhauser et al., 2001). Approximately one fifth of Barry and Prigerson's (2002) respondents reported that they could have been better prepared if they had had the opportunity to tell their loved one goodbye or other words of closing. Caregivers in the current study additionally spoke about the importance of acknowledging accomplishments, expressing appreciation, and giving thanks to the care receiver.

This study affirms the importance and value of preparedness to caregivers. Overwhelmingly, family caregivers affirmed that being prepared for the death of a family member was important to them (i.e., 87%). Interestingly, 43% of caregivers stated that one can never be fully prepared. These findings are congruent with other studies in which caregivers highlighted "…how hard it was to accept the reality that their loved one was actually dying, even if the person had been very ill for a long time" (Kehl, Kirchhoff, Kramer, & Hovland-Scafe, 2009, p. 144), and that death could still come as a shock even for caregivers who know that dementia is a terminal condition (Shanley et al., 2011). This may reflect the very unpredictable causes of death associated with comorbid or coexisting medical condition (Mitchell, 2015).

Caregivers identified several benefits of preparedness as well as the negative outcomes of being unprepared. Steinhauser and colleagues (2001) found that a lack of preparation for death impeded the experience of a "good death." The results of the current study build upon experiencing a "good death" and highlight how preparation may improve the caregiver's experience of the dying process, ease transitions to bereavement, making postdeath decisions and death-related responsibilities. These findings provide a glimpse into what is really important to these caregivers. Specifically, caregivers emphasized how having the opportunity to "accept [the] reality" of the death permitted them to make decisions and prepare emotionally for the death, thereby improving their bereavement experience. Although we did not ask specifically how the specific domains of preparedness were related to each of the benefits that they described, it is plausible that *accepting reality* and *knowing death is near* may actually contribute to the perceived benefits of *eliminating the surprise* and *taking off the fear.* Further, without preparedness, caregivers missed opportunities to say goodbye or to resolve "unfinished business." Congruent with the literature, the present study also found that being prepared for death offered benefits that included reducing caregiver fear and anxiety (Barry et al., 2002; Hebert, Dang, et al., 2006).

Although previous research identified postdeath bereavement outcomes of being unprepared (Barry et al., 2002; Hebert, Prigerson, Schulz, & Arnold, 2006), this study provides insights about possible precipitants to these negative outcomes. More than a quarter of participants connected their stress to being unprepared. Caregivers emphasized how their experience would have been better if they had known what to expect and had accessed hospice care earlier. As found with many elders with advanced dementia, several of these caregivers had family members who bounced in an out of nursing homes or hospitals and had difficulties accessing hospice care. These findings are congruent with previous studies showing that individuals with dementia are less likely to access hospice services and if they do, enrollment is late and they are not able to fully benefit from the services available (McCarty & Volicer, 2009; Mitchell, Morris, et al., 2004; Shega et al., 2008; Shega & Tozer, 2009; Sloane, Zimmerman, Williams & Hanson, 2008).

Findings lend support to the conceptual model, put forth by Hudson (2003), for supporting family caregivers of those dying with cancer. In this model, preparedness is identified as a "favorable resolution" in that it decreases levels of depression for caregivers. This study supports and expands the dementia care practice at end-of-life guidelines put forth by the Alzheimer's Association (2007). Such practice includes the patient, caregiver, and family as central to the care planning at end of life. Health care professionals in long-term care and hospital settings need to provide psychosocial, spiritual, and physical care, pain and symptom management, education on supportive services, advocate for end-of-life discussions and advanced care planning, and refer patients with dementia for hospice and/or palliative care services (Alzheimer's Association, 2007). Although hospice utilization rates tend to be low for those with dementia (Shega et al., 2008), the majority of caregivers in this study (67%) were enrolled in hospice at the time of death. Ninety percent of those who reported feeling prepared were receiving hospice, in comparison with only 38% of those who were not prepared, the majority of whom had just recently enrolled. Caregivers enrolled in hospice tend to report greater satisfaction with care when compared with nonenrollees, and hospice enrollment is associated with dying at home and/or in one's preferred location (Shega et al., 2008). An important role of hospice providers is to help caregivers know what to expect regarding the dying process and death, which may support a number of the domains of preparedness for death (Goldberger, Mohl, & Thompson, 2009). By educating caregivers on the role of hospice in the long-term setting, the primary goals of hospice support, and the admission guidelines, health care professionals can guide caregivers toward an awareness of impending death and of supportive services to help improve preparedness. Such preparedness by the health care professionals can help the caregiver "understand, identify, practice and implement options and strategies they may use to better proceed through the experience" (Goldberger et al., 2009, p. 161).

Limitations and Recommendations for Future Research

There were several limitations to this study. Given the substantive nature of this study, interviews were conducted with bereaved caregivers retrospectively. Because they were not interviewed "in the moment," there is the possibility that their perspective and grief may have changed since the death occurred. A related limitation is that the current study entailed one data collection effort that did not allow for the investigation of how the experience of preparedness might unfold over time. Prospective studies following caregivers of patients with dementia through the end-of-life trajectory and into bereavement would provide insights into how preparation contributes to beneficial outcomes and enriches understanding. It is also important to note that another family member may have reported different experiences in preparing for the death of the same person. Although this study focused on the primary family caregiver, future research could benefit from focusing on understanding the experience of preparedness among multiple family members of persons with dementia. Another limitation is that the study took place in a relatively racially/ethnically homogenous community, where it was difficult to recruit a diverse sample. One study highlighted how African American caregivers of elders with dementia were inclined to focus on attributes of the individual with dementia that remain, rather than the losses experienced throughout the caregiving process (Lindauer, Harvath, Berry, & Wros, 2015), suggesting that definitions of preparedness may vary in this population. Because there is tremendous need for research with ethnic minority populations, future research should draw from more racially/ethnically diverse communities. Due to the large percentage of persons with dementia and caregivers who had hospice, future research could be done with a sample that did not access hospice services, as well as exploration of the experiences of caregiving in a variety of circumstances and settings, including non-hospice settings.

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