RIDING OUT THE STORM: A GROUNDED THEORY STUDY OF DEMENTIA CAREGIVER GRIEF AND BEREAVEMENT FOLLOWING FAMILY MEMBER DEATH IN LONG-TERM CARE SETTINGS

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ABSTRACT

Title of Dissertation: Riding Out the Storm: A Grounded Theory Study of Grief and Bereavement in Dementia Caregivers Following Family Member Death in Long-Term Care Settings

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Purpose: The purpose of this study is to explore the grief/bereavement process of Alzheimer's Disease and Related Dementias (ADRD) caregivers following death of a family member in long-term care (LTC) and develop a theoretical model of this phenomenon based upon in-depth individual interviews. There is limited evidence examining ADRD caregiver grief and bereavement following family member death in LTC settings. Grounded Theory methodology has not been utilized to explore this phenomenon.

Background: ADRD is estimated to be the 6th leading cause of death in the United States. Most individuals with ADRD die in LTC settings, where grief and bereavement support to surviving family members is virtually non-existent. Twenty-percent of these caregivers experience prolonged and/or exaggerated grief reactions that may impair their physical/mental health.

Method: A Grounded Theory design was used in this study. Participants were caregivers of a family member with ADRD who died in a LTC setting, recruited via Internet-based websites and caregiver forums. The interview guide explored recall of end-of-life grief and bereavement and the impact of LTC placement. Audio-taped individual interviews were conducted via Internet-based video-conferencing or telephone. Interviews were transcribed verbatim and entered into DeDoose© (qualitative data management software). Grounded theory methods were used to analyze data, formulate theoretical assumptions, and develop a theoretical model. Constant comparative analysis was used to interpret the findings and determine data saturation. Rigor was ensured through peer debriefing, audit trails, and expert reviews of the proposed model.

Results: Participants included adult children/grandchildren (*n*=16) and spouse (*n*=1) ranging in age from 30 to 77 years (M=56.94, SD=5.36). The mean time between death and the interview was 2.98 years (SD=2.22). The emerging model identified is comprised of 3 interdependent components of bereavement (behavioral, cognitive, and emotional). The following factors related to LTC placement were identified as facilitators or barriers to caregiver grief/bereavement: relationships/support with staff, death rituals, end-of-life care (hospice, end-of-life suffering), frequent deaths of other LTC residents, staffing-shortages, and length of time in LTC.

Conclusions: Findings from this study can be used to develop bereavement interventions for ADRD caregivers whose family members die in LTC.

DEDICATION

This dissertation is dedicated to my mother Agnes Thompson Merluzzo, who died in a long-term care facility after living with Alzheimer's disease for 6 years. My mother moved through the course of her illness with grace, love, and pride. I had the privilege of loving the person she was prior to her diagnosis as well as the individual she became as a result of her advancing dementia. Throughout her life, my mother continued to teach me important lessons. Without her love and belief in me, this research would not have been possible. May she rest in eternal peace.

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TABLE OF CONTENTS

CONTENT PAGE

3. APPENDICES

B. Manuscript #2

C. Manuscript #3

LIST OF TABLES

LIST OF FIGURES

Introduction

Purpose

The purpose of this study is to explore the grief and bereavement process that Alzheimer's Disease or a Related Dementias (ADRD) caregivers experience after their family members die in long-term care (LTC) and to develop a theoretical model of this phenomenon generated from the data obtained through individual interviews. Subsequent studies will continue to modify and adapt this proposed theory. For the purpose of this study, grief is defined as the emotional reactions that occur following the death of a family member. (Stroebe, Hansson, Schut, & Stroebe, 2008). Bereavement is defined as the process that individuals live through after the death of someone significant and during which grief is experienced and expressed. For the purpose of this dissertation research, we will apply these definitions of grief and bereavement to ADRD caregivers who lost family members with ADRD to death in long-term care. (Stroebe et al., 2008).

Background

ADRD Caregiver Grief and Bereavement

ADRD are estimated to be the 6th leading cause of death in the United States (Alzheimer's Association, 2017). In 2017, family members provided 83% of the care needed by individuals with ADRD (Alzheimer's Association, 2017). ADRD caregivers report increased emotional stress, depression, greater risk for suicide, decreased immune response, and worsening existing health conditions compared to non-ADRD caregivers (Adams & Sanders, 2004; Holland, Currier, & Gallagher-Thompson, 2009). It is estimated that approximately 40% of ADRD caregivers report depressive symptoms compared to 5-17% of non-ADRD caregivers (Alzheimer's Association, 2016). Prior to the death of their family members, ADRD caregivers on average have provided care for longer periods of time than caregivers of older adults with other health problems (Adams & Sanders, 2004).

ADRD caregivers experience a phenomenon referred to as "chronic grief" because they experience a variety of losses over a prolonged period of time, which are associated with their family member's advancing dementia (Boss, 2011). Following the death their family member, surviving ADRD caregivers experience a period of bereavement. ADRD caregivers may enter into the bereavement period with a reduced ability to cope as a result of their prolonged caregiving demands and chronic grief experiences. The bereavement process varies among individuals and may be accompanied by a variety of emotional, physical, and behavioral symptoms that can impact a person's ability to function (Strada, 2009). Although grief during bereavement is most often experienced as a natural process without lasting physical and emotional health impacts, for some caregivers, the death of a family member with ADRD is associated with increased risk for both physical and emotional health impairments as well as mortality (Givens, Prigerson, Kiely, Shaffer, & Mitchell, 2011). Approximately 20% of bereaved ADRD caregivers experience grief reactions that are considered prolonged and exacerbated, a syndrome referred to as complicated grief (Schulz et al., 2003; Shuter, Beattie, & Edwards, 2014).

The vast majority of individuals with ADRD will require LTC placement as their dementia progresses and an overwhelming number of these individuals will reside in LTC settings at the time of their death (Alzheimer's Association, 2016; Mitchell, Teno, Miller, & Mor, 2005). There is very little evidence examining the grief and bereavement experiences of ADRD caregivers whose family members die in LTC settings. The limited evidence available suggests that LTC placement impacts ADRD caregiver bereavement (Givens et al., 2011) and that the relationships between ADRD caregivers and LTC staff have an influence on the bereavement experiences of ADRD caregivers (Shuter et al., 2014). In particular, the evidence suggests that LTC staff play a pivotal role in shaping the final memories that ADRD caregivers have of their family members and that conflicts between LTC staff and ADRD caregivers may result in increased emotional upset and trauma that remain with some ADRD caregivers well past their family members' death (Shuter et al., 2014).

The Use of the Internet in ADRD Caregiver Research

Fifty-nine percent of ADRD caregivers use the Internet to obtain health-related information and support (Kim, 2015). Given the wide-spread use among ADRD caregivers, the Internet may offer innovative strategies for participant recruitment and data collection in ADRD caregiving research (Oates, 2015; Tolstikova & Chartier, 2010). The evidence suggests that the majority of ADRD caregiver studies that utilize the Internet for participant recruitment do so by purchasing paid advertising with on-line social networks and websites with varying degrees of success (Akard, Wray, & Gilmer, 2015; Leach, Ziaian, Francis, & Agnew, 2016). The Internet may allow for alternative approaches to data collection with ADRD caregivers by reducing travel time and expenses (Hamilton, 2014, Oates, 2015, Sullivan, 2012). While the evidence on using the Internet in ADRD caregiver research is convincing, we identified only one study that utilized the Internet for recruitment of ADRD caregivers, which had limited success

(O'Dwyer & Moyle, 2014). No studies were identified utilizing the Internet for both participant recruitment and data collection with ADRD caregivers.

Methods

Grounded Theory

Since there was no literature specifically identifying the grief and bereavement process that ADRD caregivers experience following their family members' death in LTC settings, Grounded Theory was determined to be an appropriate methodological approach for this research study. The intent of Grounded Theory is to generate and validate a theory based upon the narratives of those individuals who experience a similar phenomenon (Charmaz, 2006). Grounded Theory consists of "systematic yet flexible guidelines for collecting and analyzing qualitative data to construct theories 'grounded' in the data (Charmaz, 2006, pg 2). Grounded Theory has three basic tenets. The first basic tenet is that people who share common experiences often apply similar meaning to the experience and elicit similar behaviors (Drauker, 2015). The second basic tenet is that individuals who share common experiences share a similar psychosocial problem that is not necessarily articulated (Draucker, 2015). The third basic tenet is that this fundamental problem (in our case ADRD grief and bereavement following family member death in LTC) is resolved by way of a psychosocial process (Draucker, 2015).

Steps for conducting a Grounded Theory study according to Charmaz (2006) are flexible guidelines and begin with the researcher exploring a general research phenomenon. The first step in Grounded Theory is exposure to the phenomenon of study. The primary investigator was introduced to the phenomenon of ADRD caregiver grief and bereavement following family member death in LTC settings through her clinical practice as well as personal experience. The second step in Grounded Theory is data collection, which is done through interviews with individuals who share a similar experience. Grounded Theory methods include concurrent data collection and data analysis. At the conclusion of each interview, the researcher analyzes the data and this analysis guides future inquiry, a technique identified as constant comparative analysis (Charmaz, 2006).

Data Coding and Analysis in Grounded Theory

As data is analyzed, it is coded in 4 distinct phases (Charmaz, 2006). Coding is defined as categorizing segments of data with a short name that summarizes the content of the narrative (Charmaz, 2006). Phase one coding is called initial coding. In initial coding, every line of each interview transcript is coded by the researcher using gerunds in order to directly link the emerging theory to the data. The second phase of coding is called focused coding (Charmaz, 2006). According to Charmaz (2006), focused codes are used to identify the most significant and/or commonly occurring initial codes within and among the interview transcripts. These codes are the beginning categories that will define the concepts of the phenomenon. The third phase of coding is called axial coding. In axial coding, the researcher begins to link categories and sub-categories. It is during axial coding that the researcher begins to move beyond descriptive thinking toward conceptual analysis (Charmaz, 2006). The fourth and final phase of coding is called theoretical coding. In theoretical coding, relationships between and among the categories are identified. During theoretical coding, a metaphor is used to describe the psychosocial problem common among the participants. Data is collected and analyzed concurrently until no new theoretical insights are made and no new theoretical categories are identified, which is identified as data saturation (Charmaz, 2006).

Memo Writing in Grounded Theory

Memo writing is a critical component in Grounded Theory. The researcher uses memos to record thoughts, questions, observations, new ideas and insights throughout the research process. The researcher records memos using informal language for their future use as an analytic tool to assist with theoretical formulation (Charmaz, 2006).

Theory Validation and Rigor in Grounded Theory

Grounded Theory is both theory generating and theory validating and as such it utilizes several mechanisms to ensure rigor. Members of the research team participate in peer debriefing at regular intervals during a Grounded Theory study to ensure credibility. The primary researcher also maintains a memo-driven audit trail, which provides a record of all methodological and analytic decisions made during the study and further ensures credibility in Grounded Theory (Draucker, 2015). Following data saturation, the researcher may perform a limited number of additional interviews, which are transcribed verbatim but unanalyzed until the theoretical model has been identified. The researcher then reviews the final interview transcripts to ensure proper theoretical "fit". A selected number of participants then evaluate the proposed model to ensure that the phenomenon under investigation is understood by the researcher, which ensures resonance (Charmaz, 2006). In addition, clinical experts may also be asked to evaluate the proposed model to determine its' usefulness in practice (Charmaz, 2006).

Relationships among Dissertation Manuscripts

Manuscript One

In order to understand the state of the evidence regarding the process that ADRD caregivers experience following the death of their family members in LTC settings, an integrative review of the literature was conducted (see Appendix A, Manuscript #1, Arruda & Paun, 2016). The review identified 19 studies (15 quantitative, 3 qualitative, and 1 integrative review) that examined ADRD caregiver grief and bereavement. Only 2 of the 19 studies examined ADRD caregivers whose family members died in LTC settings. The majority of studies (*n*=13) had mixed samples of ADRD caregivers (spouses, adult-children, and/or other family members). The evidence suggested that bereaved ADRD caregivers whose family members died in LTC settings suffered higher levels of impaired emotional health compared to bereaved ADRD caregivers whose family members died outside of LTC settings (Arruda & Paun, 2016).

The integrative review revealed 5 critical gaps in the evidence: 1) lack of ethnic and gender diversity among ADRD caregivers studied; 2) limited use of reliable/valid instruments designed to objectively measure ADRD caregiver grief and bereavement; 3) no substantial evidence examining ADRD caregiver grief and bereavement following family member death in LTC settings; 4) limited grief and bereavement interventions for ADRD caregivers; and 5) no evidence of grief and bereavement interventions for bereaved ADRD caregivers whose family members die in LTC settings (Arruda & Paun, 2016). The integrative review informed the pilot study by identify the critical gap in the evidence that little was known about the phenomenon of ADRD caregiver grief and bereavement following family member death in LTC.

Manuscript Two

Following the integrative review, a pilot study was conducted as part of the Advanced Clinical Research Practicum (ACRP) to determine the feasibility of exploring the issues of ADRD caregiver bereavement following family member death in LTC setting utilizing the Internet for both participant recruitment and data collection (See Appendix B, Manuscript #2, Arruda, Paun, & Hamilton, 2017). The principal investigator proposed the use of Internet-based strategies because the evidence suggested that ADRD caregivers were already frequently utilizing the Internet and its use could improve efficiency and reduce the overall costs (Arruda, Paun, & Hamilton, 2017). The pilot study aimed to explore the feasibility of: 1) using the Internet to recruit ADRD caregivers for a research study; and 2) using Internet-based video conferencing (via personal computers, tablets, or Smartphones) to conduct in-depth individual interviews with bereaved ADRD caregivers. In addition to these two aims, the qualitative narratives obtained through individual interviews were used to inform the dissertation study. Inclusion criteria for the pilot study included: (a) former caregiver over the age of 21 years (b) family member (as defined by the participant) died with ADRD; (c) family member resided in a LTC setting at the time of their death; and (d) caregivers had the necessary equipment (personal computer, tablet, Smartphone, or telephone) and internet-based video conferencing capability (including video camera) if applicable, and e) an available private setting for the interview. These inclusion criteria were selected to allow for the analysis of various types of caregiver experiences using an individualized approach for data collection. Exclusion criteria for the pilot study were (a) caregivers whose family members died while receiving formal hospice services, (b) caregivers whose family members were diagnosed with early or young-onset ADRD. These exclusion criteria were created to eliminate any confounding effects hospice enrollment or young-onset ADRD would have on the grief and bereavement process.

The researcher evaluated the feasibility of using the Internet to recruit ADRD family caregivers based upon her ability to reach a goal of recruiting 10 eligible participants within a three-month time period, which was achieved. In addition, 10 individuals who did not meet the eligibility for the pilot study agreed to participate in the dissertation study, which was an unexpected finding. The final sample included 10 former unpaid ADRD caregivers whose family members died in LTC and did not receive hospice services at end-of-life. Of these 10 participants, half (*n*=5) agreed to utilize Internet-based video-conferencing (Skype© and Facetime©) for their interviews. Participants included adult-children (*n*=7), adult-grandchildren (*n*=2), and one spouse ranging in age from 30-77 years (M=55, SD=13.70). Family members resided in LTC for an average of 2.98 years prior to their death (Arruda, Paun, & Hamilton, 2017). These findings suggested that was feasible to utilize Internet-based strategies to recruit ADRD caregivers for a research study. The principal investigator determined that it was also cost effective to use Internet-based participant recruitment, as she incurred no financial cost to the study utilizing these strategies.

The researcher determined the feasibility of using Internet-based video conferencing for data collection based on: 1) an analysis of participant responses to the post-interview survey; and 2) a review of the interview transcripts themselves targeting statements related to ease of technology use. Post-interview, a brief, five-item survey was e-mailed to all study participants to gain insight into why they selected their chosen interview method. All five participants who chose Internet-based video-conferencing reported that they liked this interview method “very much” in the post-interview surveys. Participants who utilized video-conferencing also reported that this method provided a “personal connection with the interviewer”, a “personal conversation yet in the privacy of my own home”, and that they were “happy to see the face of the interviewer”. Of the five participants who selected telephone-based interviews, two individuals stated that they “didn’t know how to use video-conferencing” and three others stated that they were “somewhat likely” to participate in a future research study utilizing Internet-based video conferencing as a data collection tool (Arruda et al., 2017).

Interview transcripts from this study were transcribed verbatim and entered into DeDoose©, a qualitative data management software program. Data collection and analysis occurred concurrently. Line by line coding was performed on the data. Subsequent coding identified data categories and recurring major themes. Six major themes of ADRD grief and bereavement following family members’ death in long-term care settings were identified: 1) communications; 2) conflicts; 3) death rituals; 4) end-of-life issues; 5) support mechanisms; and 6) reactions to death. Both conflicts with LTC staff and barriers around receiving hospice services were commonly reported by the participants, which caused emotional upset during the interviews. The researcher noted no differences in the quality, quantity, or identified themes between the interviews conducted by Internet-based video-conferencing versus those conducted by telephone. The ACRP pilot study directly informed the dissertation study by identifying the major themes associated with ADRD caregiver grief and bereavement following family member death in LTC and by confirming the feasibility of utilizing the Internet for participant recruitment and data collection.

Manuscript Three

For dissertation purposes, a Grounded Theory study was conducted to address the important gap in the evidence by further exploring the grief and bereavement process that ADRD caregivers experience following their family members' death in LTC using the Internet for participant recruitment and data collection This study further aimed to develop a theoretical model of this phenomenon generated from the data obtained from in-depth individual interviews (See Appendix C, Manuscript #3, Sassatelli, Paun, Hamilton, 2017). Grounded Theory was selected for this study as it allowed for the emergence of a theoretical model of ADRD grief and bereavement based upon the lived experiences of former family ADRD caregivers. The dissertation study focused on answering the following research question, "What is the process that ADRD caregivers undergo following the death of their family members' in LTC settings?" For the purpose of this study, grief was defined as the emotional reactions caregivers experienced following the death of a family member with ADRD (Stroebe et al., 2008). Bereavement was defined as the process that ADRD caregivers live through after the death of their family member and during which grief is experienced and expressed. Inclusion criteria for this study were (a) former caregivers over age of 21 years, (b) family member died with ADRD with or without hospice; (c) family member resided in a LTC setting at the time of their death; (d) caregivers had the necessary equipment (personal computer, tablet, Smartphone, or telephone) and internet-based video conferencing capability (including video camera) if applicable, and (e) caregivers had an available private setting for the interview. These inclusion criteria were developed to allow for the analysis of a wide variety of caregiver experiences as well as the impact (if any) that receiving hospice utilization had on ADRD caregiver grief and bereavement in LTC settings. The exclusion criteria remained the same as in the pilot study with the exception of the removal of hospice utilization. Individuals who were ineligible for the pilot study and expressed interest in the dissertation study were contacted via individual emails by the researcher to confirm their continued interest in the study.

The data obtained from the pilot study interviews (*n*=10) provided the initial data for the dissertation study. Seven additional participants were recruited for the dissertation study from the list of individuals who were not eligible for the pilot study but did meet the inclusion criteria for the dissertation study. The final sample included former ADRD caregivers whose family members died in LTC settings with (*n*=7) and without (*n*=10) hospice services (Sassatelli et al., 201). The final sample included adult-children (*n*= 14), adult-grand-children (*n*= 2), and one spouse. Participants were all Caucasian and resided in the United States (*n*=16) and Canada (*n*=1). The vast majority of participants were female (*n*=16) and ranged in age from 30-77 years of age (M=56.94, SD=10.74). Care recipients ranged in age from 80-97 years (M=89.81, SD=5.36) and had resided in LTC for an average of 2.98 years (SD= 2.22) prior to their deaths. Prior to LTC placement, participants had provided care for an average of 5.63 years (SD= 3.77). Informed consent and privacy notices were obtained from all participants.

Interviews were transcribed verbatim. Data collection and analysis occurred concurrently based upon Grounded Theory methodology (Charmaz, 2006). Charmaz's (2006). A five-item interview guide was utilized, which explored ADRD caregiver recall of grief and bereavement beginning at end-of-life as well as any impact that either LTC placement or hospice utilization had on this phenomenon. Audio-taped individual interviews were conducted via Internet-based video conferencing or telephone. Transcribed interviews were entered into DeDoose© (qualitative data management software).

Grounded Theory methods were used to analyze data, formulate theoretical assumptions, and develop a theoretical model. Constant comparative analysis was used to interpret the findings and determine data saturation. (Sassatelli et al., 2017). After 15 interviews, data saturation was achieved. The final 2 interviews were transcribed but were left unanalyzed until the proposed theoretical model was identified. The proposed theory revealed that ADRD caregivers experience a grief and bereavement process following family member death that is categorized into 3 major components (behavioral, cognitive, and emotional) that are non-linear and interrelated. All 3 of these components have internal and external sub-components. The following factors related to LTC placement were identified as facilitators or barriers to caregiver grief/bereavement: relationships/support with staff, death rituals, end-of-life care (hospice, end-of-life suffering), frequent deaths of other LTC residents, staffing-shortages, and length of time in LTC (Sassatelli et al., 2017).

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Discussion

Synthesis of Findings

"The grief and bereavement process that ADRD caregivers experience following family member death in LTC settings is very complex because it is a phenomenon that is impacted by a combination of personal, social, and cultural influences" (Sassatelli, Paun, & Hamilton, 2017, p 23). Results of the dissertation study identified that this was a non-linear phenomenon, as bereaved ADRD caregivers attempt to process their losses and rebuild their lives while resolving behavioral, cognitive, and emotional components of their grief and bereavement simultaneously (Sassatelli et al., 2017).

The Integrative Review

As a whole, the integrative review revealed that very little is known about ADRD caregiver grief and bereavement following family member death in LTC. The pilot study was developed considering the following findings from the integrative review; 1) ADRD caregivers whose family members died in LTC settings had increased post-death psychosocial symptoms compared with other ADRD caregivers whose family members died in a home setting; 2) a variety of end-of-life issues impacted ADRD caregiver grief and bereavement; 3) ADRD caregivers who witnessed end-of life suffering or those that experienced conflict with LTC staff reported increased emotional upset after death; 4) a sub-set of ADRD caregivers were unprepared for the death of their family member despite years in LTC, which resulted in increased incidences of post-death depression and anxiety for the caregivers; 5) significant barriers existed for some caregivers regarding the receipt of hospice services for their family members with ADRD who reside in LTC settings; and 6) there was virtually no grief or bereavement support for surviving ADRD caregivers whose family members die in LTC settings (Arruda & Paun, 2016).

The Pilot Study

Results of the pilot study identified 6 themes (communications, conflicts, death rituals, end-of-life issues, support, and reactions to death) that were reoccurring in the grief and bereavement process experienced by ADRD caregivers whose family members died in LTC settings. Unanswered questions remained, however as it was unclear from the pilot study what factors (if any) were facilitators or barriers to the process of ADRD caregiver grief and bereavement. The pilot study informed the dissertation study by providing the baseline themes that were common among all participants' grief and bereavement experiences, however the relationships among the 6 themes was not yet identified.

The Dissertation Study

The dissertation study included a re-analysis of data from the initial ten transcripts together with data from the additional seven interviews conducted with ADRD caregivers whose family members had hospice services prior to death. These data supported the emerging model and identified sub-components of the major themes. The principal investigator identified linkages between the themes utilizing Charmaz's 4-step coding methodology. Constant comparative analysis was utilized until data saturation was achieved. Consistent with other research, findings from this study support the assumption that troublesome end-of-life issues as well as conflicts with LTC staff played a critical role in the grief and bereavement of surviving caregivers (Albinsson & Strang, 2003; Kiely et al., 2010; Shuter, Beattie, & Edwards, 2014). We noted no other theoretical model that identified the inter-relationships between behavioral, cognitive, and emotional factors that accompany ADRD grief and bereavement. A surprising finding from the dissertation study was that none of the participants recruited after the completion of the pilot study (*n*=7) elected to use Internet-based video-conferencing for their interviews. The principal investigator noted that the mean age of the caregivers in the pilot study was 55.1 years (SD=13.70) versus 60 years (SD=3.69) among the final seven participants. These results may indicate that utilizing the Internet for data collection is more feasible when interviewing younger ADRD caregivers.

Milestones in ADRD Caregiver Grief and Bereavement in Long-Term Care

Riding out the Storm

The dissertation study results suggest that ADRD caregiver grief and bereavement occurs over time and has lasting impact on surviving family members. Along with the proposed theoretical model, the principal investigator created a metaphorical representation of the process based on several important milestones that occurred during the process of ADRD caregiver grief and bereavement following family death in LTC settings, as described by the interviewed family caregivers. These milestones have been metaphorically named "Riding out the Storm".

The Hurricane Watch

The first milestone of ADRD caregiver grief and bereavement occurs during the prolonged course of caregiving as these caregivers experience grief that became chronic due to their family members' worsening dementia. We refer to this stage as the "Hurricane Watch" due to the fact that caregivers know that the storm (advancing dementia and death) is coming and they can do nothing to prevent the inevitable.

> "I felt so alone in following through with the responsibility for and care of the mother as her dementia worsened… With the exception of my sister who was in it with me, no one else understood what a huge responsibility it was and how overwhelming it was [because we knew what was coming]. I carry that feeling of aloneness with regard to my mother's care with me still. I realize now that even though my sister was there and sharing the burden and responsibility with me, I still felt so alone … We were experiencing it separately yet together." **Daughter, age 57, without hospice**

The Hurricane Warning

As the end-of-life draws closer, ADRD caregivers whose family members die in LTC experience a second milestone, which we identify as the "Hurricane Warning". During the "Hurricane Warning", ADRD caregivers attempt to plan and prepare for the inevitable loss of their family members in LTC. This is a very unpredictable time filled with swirling energy as caregivers search for meaning, ask questions, and observe for signs that death is approaching and that the storm is coming soon.

> "You do have this loneliness because you grieve before the person actually passes. I did a lot of praying … I prayed that God would take her. And in a way towards the end, I was mad at God because he wasn't listening to me … You want to put her out of her pain and everything else and I asked God 'Why does she have to go through this? Why do I have to go through this?'" **Daughter, age 59, with hospice**

The Storm Makes Landfall

Caregivers experience the third milestone of ADRD grief and bereavement as the death of their family member becomes imminent, a phase we call "The Storm Makes Landfall". During this milestone, caregivers seek to support end-of-life needs and attempt to resolve both internal and external conflicts by entering into a period, where protection from the elements is required for themselves and their family members. Failure to seek shelter results in increased devastation from the storm.

> "I carried a lot of grief and guilt with me over that last night … because of the pain and suffering … I was feeling like I was a failure because I couldn't make

> them understand that this was not OK … And to this day in my mind, I keep thinking that there must have been another way." **Daughter, age 57, without hospice**

The Aftermath of the Storm

Once death occurs, ADRD caregivers whose family members die in LTC experience the final milestone of grief and bereavement. We call this milestone "The Aftermath of The Storm" as caregivers begin to rebuild their lives and note that although moving on is difficult, it is necessary for their future survival.

> "I often thought through this time about the life stages of a butterfly. The dark, dried up chrysalis is the stage right before the butterfly emerges perfect and beautiful and it flies off into the sun. When my husband took his last breath, I sort of pictured that he emerged from the chrysalis and he left it behind on the bed and he was perfect and he was healed from his severely disabled body and he flew off into the sunshine of God's eternal home. He is not a butterfly but the symbolism of that butterfly flying out and the little chrysalis that is left is pretty useless and dried up. His body at the time he died had very little resemblance to what he really was earlier in life. … And now I look back and I realize you can't turn back the clock but you can wind it up again. After he died, I knew I needed to re-invent my life. It wasn't going to ever be the same again but it didn't need to be a black hole either." **Participant Four**

Strengths and Limitation

Strengths of this study include the utilization of Grounded Theory methodology. Grounded Theory methods allowed for an examination of the complex phenomenon of ADRD caregiver grief and bereavement from the lived experiences of the caregivers themselves. Through a systematic yet flexible process, Grounded Theory methods also allowed for both the generation and validation of our proposed theory. This study established rigor through the use of peer debriefing, audit trails, and expert reviews of the proposed model.

Limitations of this study include the small homogenous sample of ADRD caregivers studied. Despite our recruitment efforts, we were unable to advance the evidence beyond the study of Caucasian and predominantly female caregivers. Therefore, we are unable to generalize our findings to a broader population of ADRD caregivers whose family members die in LTC settings. Another limitation of this study is that our recruitment occurred via the Internet. For this reason, the experiences of the caregivers studied may not reflect those of caregivers who did not utilize the Internet to obtain health information or social support.

Clinical and Research Implications

Understanding the grief and bereavement process that ADRD caregivers experience following the death of their family members in LTC can assist health care providers in developing and delivering grief and bereavement interventions for these caregivers. The knowledge gained from this study further suggests that there are a variety of ways that grief and bereavement support to ADRD caregivers whose family members die in LTC could be improved (i.e. eliminating end-of-life suffering, reducing conflicts with LTC staff/physicians, improving access to hospice) and that by doing so, some of the negative emotional ailments experienced by these caregivers may be ameliorated. Future research should also aim to uncover more information surrounding the barriers to hospice utilization by individuals with ADRD who reside in LTC settings.

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Appendix A

Manuscript 1

Dementia Caregiver Grief and Bereavement: an Integrative Review

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Dementia Caregiver Grief and Bereavement: An Integrative Review

Elizabeth H. Arruda[1] and Olimpia Paun[1]

Abstract

Alzheimer's disease and related dementias make up the fifth leading cause of death for individuals of 65 years of age and older in the United States. Seventy percent of these individuals will die in long-term care settings. The aim of this integrative review was to examine and synthesize the evidence on grief and bereavement in Alzheimer's disease and related dementias caregivers. This review identified five critical gaps in the existing evidence: (a) a lack of ethnic and gender diversity among caregivers studied, (b) limited use of valid instruments to study dementia caregiver grief and bereavement, (c) no substantive research examining dementia caregiver grief and bereavement for caregivers whose family members die in long-term care, (d) a lack of evidence examining the effect of hospice services on dementia caregiver grief and bereavement, and (e) a lack of grief and bereavement interventions for dementia caregivers whose family members die in long-term care.

Keywords

dementia, caregiver, grief, bereavement

Alzheimer's disease and related dementias (ADRD) make up the fifth leading cause of death in the United States (Alzheimer's Association, 2016). Research suggests an increased trend in providing end-of-life care to persons with

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ADRD in either long-term care (LTC) settings or at home rather than in hospital settings (Alzheimer's Association, 2016; Mitchell, Teno, Miller, & Mor, 2005). Seventy percent of those diagnosed with ADRD will die in LTC settings, where grief and bereavement support for surviving family members is severely limited (Givens, Prigerson, Kiely, Shaffer, & Mitchell, 2011; Mitchell et al., 2005). The impact of grief and bereavement on the more than 15 million family members who provide extensive physical, emotional, and financial support to persons with ADRD has yet to be fully explored.

Grief and Bereavement in ADRD Caregivers

The terms *grief* and *bereavement* are often used interchangeably and are not always clearly defined in the literature (Zisook & Shear, 2009). Grief is a normal emotional reaction in response to actual or perceived losses such as those associated with aging, reduced physical abilities, financial insecurity, unemployment, and other tangible and intangible losses that are meaningful to an individual (Boss, 1999; Zisook & Shear, 2009). According to Stroebe, Hansson, Schut, and Stroebe (2008), grief encompasses physical (shortness of breath, palpitations, and pain), emotional (yearning, sorrow, anger), and cognitive (impaired memory and difficulty concentrating) symptoms. For the purposes of this review, we defined grief as a reaction to loss that occurs following the death of a loved one (Stroebe et al., 2008), and we defined bereavement as a term used to objectively describe the fact of having lost someone due to death (Zisook & Shear, 2009).

Although grief is an expected emotional reaction to loss, in the context of ADRD caregiving, grief is a unique experience in that for ADRD caregivers, grieving begins well before the actual death occurs and continues through the progressive disease course in response to prolonged losses (care recipients' personhood, relationship bonds, living life as planned before ADRD was diagnosed; Boss, 1999; Givens et al., 2011; Lindgren, Connelly, & Gaspar, 1999; Ott, Sanders, & Kelber, 2007; Ross & Dagley, 2009; Sanders & Adams, 2005). For these reasons, ADRD caregivers' grief is considered "chronic grief" (Boss, 1999; Noyes et al., 2010; Ott, Reynolds, Schlidt, & Noonan, 2006; Ross & Dagley, 2009; Sanders & Corley, 2003).

Many individuals with ADRD require LTC placement prior to their death. Following LTC placement, ADRD family caregivers retain their caregiver roles, as they continue to visit frequently and advocate for their family members, a process that at times may result in conflict with LTC staff (Chan, Livingston, Jones, & Sampson, 2013; Gaugler, Pot, & Zarit, 2007; Hennings, Froggatt, & Payne, 2013). LTC placement has an impact on ADRD caregiver chronic grief as it heightens guilt, resentment, loneliness, unresolved problems between the caregiver and the care recipient, and conflict with other family members over the placement decision (Chan et al., 2013; Gaugler et al., 2007; Givens et al., 2011; Marwit & Meuser, 2002; Paun et al., 2015).

Following the death of persons with ADRD, surviving family members experience a period of bereavement. According to Strada (2009), the grief experienced during bereavement varies among individuals and may be accompanied by a variety of emotional, physical, and behavioral symptoms that can affect a person's ability to function. Although grief during bereavement is most often experienced as a natural process without lasting physical and emotional health impacts, for some ADRD caregivers, the death of a family member is associated with increased risk for both physical and emotional health impairments as well as mortality (Givens et al., 2011). Approximately 20% of bereaved ADRD caregivers experience grief reactions that are considered prolonged and exacerbated, a syndrome referred to as complicated grief (Holland, Currier, & Gallagher-Thompson, 2009; Prigerson et al., 1995; Schulz, Boerner, Shear, Zhang, & Gitlin, 2006).

End-of-Life (EOL) Care for Persons With ADRD

Despite great advancements in providing end-of-life care, individuals dying with ADRD often receive sub-optimal treatment (Sachs, Shega, & Cox-Hayley, 2004). The risk of dying with unmanaged high levels of pain is increased for individuals with ADRD (Kiely, Givens, Shaffer, Teno, & Mitchell, 2010; Sachs et al., 2004). In addition, it has been estimated that as many as 44% of nursing home residents with ADRD die with feeding tubes in place despite evidence suggesting little benefit (Sachs et al., 2004). The evidence also suggests that individuals with ADRD often receive inadequate end-of-life care as a direct result of the under-utilization of hospice services (Sachs et al., 2004). Individuals with ADRD in the United States are less likely to receive hospice for three primary reasons: (a) physicians' difficulty in determining that an individual with ADRD has less than 6 months to live; (b) physicians, clinicians, and family members may not perceive dementia as a terminal illness; and (c) barriers in health care services reimbursement (McCarty & Volicer, 2009; Sachs et al., 2004).

In 1996, Medicare expanded the hospice eligibility guidelines to include individuals dying with ADRD. Hospice care is designed to provide comfort and reduce suffering for terminally ill individuals and their families (Irwin et al., 2013). Following death, hospice care also provides grief and bereavement support to surviving family members (Kuebler, Davis, & Moore, 2005). Despite the availability of hospice, health care providers are less likely to refer their patients with ADRD to hospice services, thus rendering their EOL care sub-optimal (Kiely et al., 2010; McLaughlin, Brazil, & Carter, 2015). Although overall hospice usage is rising, only a small percentage of LTC residents with ADRD receive hospice care (Kiely et al., 2010; Sachs et al., 2004).

The most significant barrier to referring individuals with ADRD to hospice services is attributed to the physicians' difficulty in determining that the individual has less than 6 months to live (McCarty & Volicer, 2009). As of yet, the current prognostic markers for a 6-month life expectancy for individuals with ADRD (functional dependency, recurrent hospital admissions, and greater than a 10% body weight loss) have not been found to be accurate predictors for this population (Sachs et al., 2004). In addition, individuals with ADRD do not follow any predictable course of illness and instead appear to experience multiple acute illnesses (most often infections) and subsequent delirium as death approaches (Sachs et al., 2004).

Another primary reason for the under-utilization of hospice services for individuals with ADRD is due to the fact that physicians, clinicians, and families may not perceive ADRD as a terminal illness (Kiely et al., 2010; McCarty & Volicer, 2009; McLaughlin et al., 2015). Despite the fact that dementia in and of itself often results in apraxia, dysphagia, and reduced mobility, many physicians, clinicians, and families do not to see its direct correlation as an independent cause of death (Sachs et al., 2004).

In addition, current economic barriers within the Unites States health care system often make receiving hospice services in LTC settings more difficult (Kiely et al., 2010; Sachs et al., 2004). One primary economic barrier faced by LTC residents who receive hospice benefits is that Medicare may discontinue their hospice authorization if they are hospitalized for an acute illness (Sachs et al., 2004).

Despite the challenges of providing hospice services to individuals with ADRD, there appear to be benefits for the patient and surviving family. Kiely et al. (2010) found that individuals with ADRD that obtain hospice services in LTC are more likely to receive scheduled opiods for successful pain management along with increased treatments for dyspnea and that these individuals are less likely to have an un-met need during the last 7 days of their life.

Purpose

The purpose of this integrative review was to examine and synthesize the evidence on grief and bereavement in ADRD caregivers following the death of their care recipients. The research question was as follows:

> **Research Question 1:** What do we know about the phenomenon of grief and bereavement in ADRD family caregivers following care recipient's death?

Method

Design and Sample

We searched several databases, including MEDLINE, Cumulative Index to Nursing and Allied Health Literature Complete (CINAHL), Scopus, and PsycINFO in two phases. In the first phase, we used the key words "dementia," "caregiver," and "grief" along with the MeSH (medical subject headings) terms of "dementia" and "grief." In the second phase, we substituted the keyword "grief" with "bereavement," which resulted in three additional publications. Reference lists of included studies were also examined. In addition, we consulted with the reference librarian at the parent institution to ensure that publications had been identified with accuracy.

Inclusion criteria for this integrative review were (a) articles were peer-reviewed; (b) published in English between 1994 and 2014; (c) available in full-text; and (d) included family caregivers of individuals diagnosed with ADRD who died either at home, in the hospital, or in LTC (nursing home or assisted living), (e) with or without hospice services. We excluded studies that examined (a) care-recipient grief, (b) professional caregiver grief or bereavement, (c) exclusively ADRD family caregiver pre-death grief, and (d) post-death grief in non-ADRD caregivers.

The initial search identified 179 publications, 38 of which were duplicate titles. Eight additional publications were reviewed as a result of hand searches for a total of 149 publications. The 149 unique titles were then read to determine if they met inclusion criteria. Based on the title review, 62 publications did not meet the inclusion criteria, with the majority of these (n = 32) being excluded because they did not examine post-death grief and bereavement. We reviewed the abstracts of the remaining 87 publications. Fifty-six of these abstracts were excluded because they did not meet the inclusion criteria; the majority either did not measure post-death grief and bereavement or they examined only pre-death ADRD caregiver grief. We conducted full-text retrieval for the remaining 31 publications, which were then read to assess their fit with the inclusion criteria. Twelve publications were excluded because they examined only pre-death ADRD caregiver grief (n = 6) or they did not examine death of individuals with ADRD (n = 6). The remaining 19 publications were included in the final review. Figure 1 illustrates our search and retrieval process.

Data Extraction

The studies in this integrative review were abstracted and examined by selected variables using a data collection tool adapted from Buchholz, Wilbur, Ingram, and Fogg (2013). For each study, we documented the first author,

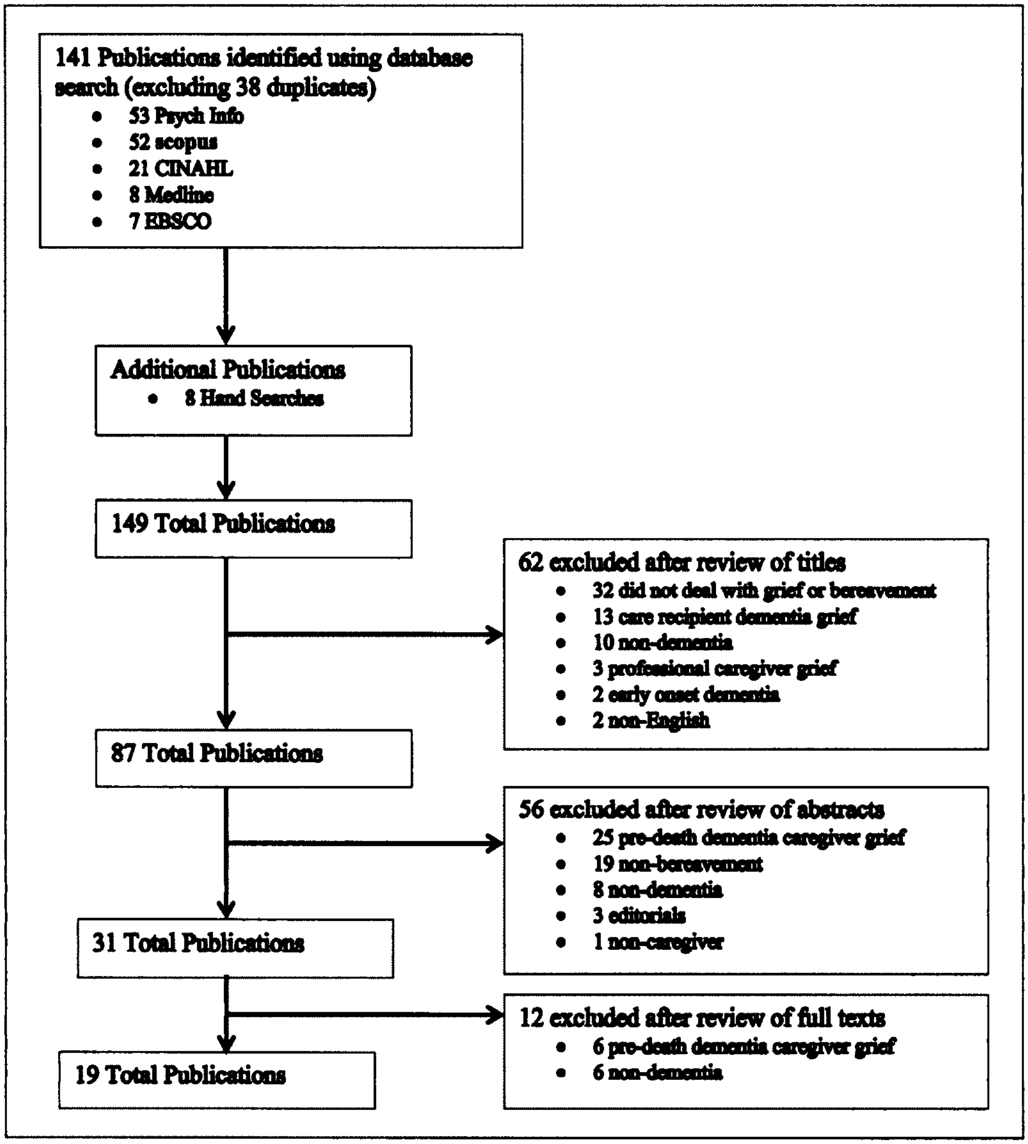

Figure 1. Flow chart of search and retrieval process and results.
Note. CINAHL = Cumulative Index to Nursing and Allied Health Literature.

year of publication, country, study design, participant demographics, ADRD care recipient residence at time of death, instruments utilized, the outcome measures, results, and level of evidence (see Table 1). Each study was reviewed 3 times by the primary investigator to ensure all relevant data were captured. We assessed the quality of the evidence using a standardized rating scale modified by Boltz, Capezuti, Fulmer, and Zwicker (2012). This scale has six levels: Level 1 (systematic reviews), Level 2 (randomized controlled trials), Level 3 (quasi-experimental studies), Level 4 (non-experimental studies), Level 5 (single qualitative/quantitative studies), and Level 6 (expert

Table 1. Summary of Articles Included in the Integrated Review.

Author (Year), Country	Design and Duration	Demographics and Residence at Time of Death	Instruments	Outcome Measures	Results	Level of Evidence
Albinsson and Strang (2003), Sweden	Qualitative design Pre and post-death. Time since death not disclosed.	Total Sample ($N = 20$). Spouse ($n = 4$), adult children ($n = 12$), and other ($n = 4$). Assisted living ($n = 15$), in home ($n = 4$), and LTC ($n = 1$)	Semi-structured individual interview guide	NA	Anticipatory grief was common. Thoughts about impending death influenced (positively and negatively) by previous death experiences. LTC staff failed to discuss end-of-life issues with family.	5
Almberg, Grafstrom, and Winblad (2000), Sweden	Qualitative design Pre and post-death. Time since death less than 6 months.	Total sample ($N = 30$). Spouses ($n = 7$), adult children ($n = 16$), and other ($n = 7$). LTC and in-home. Number of subjects in each category not disclosed.	Semi-structured individual interview guide	NA	Post-death experiences influenced by pre-death experiences. Being with CR at time of death offered "closeness," Death came as a shock and then relief even if it was expected. Fifty percent felt death brought relief. Social isolation was common post-death. Religiosity provided social support and mitigated feelings of loss.	5
Aneshensel, Botticello, and Yamamoto-Mitani (2004), USA	Longitudinal prospective cohort study. Pre and post-death. Time since death up to 5 years.	Total sample ($N = 291$). Spouses, adult children, and other. LTC ($n = 155$) and in-home ($n = 136$).	Modified Hopkins Symptom Checklist	Depressive symptoms	Post-death, about 1 in 5 CGs experience improved emotional well-being over time. CGs with lower pre-death levels of depression have lower levels of depression post-death. Emotionally distressed caregivers pre-death have high depression post-death.	4
Bergman, Haley, and Small (2011), USA	RCT. Secondary analysis of REACH Study. Pre and post-death. Time since death less than 6 months.	Total sample ($N = 224$). Spouses, adult children, and other. Intervention (68%) and control (36.2%). In-home only	CES-D, STAI, ICG Bereavement Services Questionnaire	Bereavement service utilization	Slightly less than 1/5 of CGs utilized bereavement services. CGs with higher post-death depression, anxiety, and those with complicated grief reactions had higher utilization of bereavement services.	5

(continued)

Table 1. (continued)

Author (Year), Country	Design and Duration	Demographics and Residence at Time of Death	Instruments	Outcome Measures	Results	Level of Evidence
Bodnar and Kiecolt-Glaser (1994), USA	Longitudinal design Pre and post-death. Time since death 19.8 months.	Spouses and adult children (N = 254). Continuing (n = 98), bereaved (n = 49), and controls (n = 107). Year 1: LTC (23.4%), in-home (76.6%) Year 4: LTC (61.2%), in-home (38.8%)	Hamilton Depression Rating Scale, Perceived Stress Scale, Social Support Interview, Impact of Events Scale, Blessed Dementia Scale	Depressive symptoms, social support	Bereaved CGs have increased depression and anxiety for up to 3 years following CR death. CGs who ruminated about their loss were more likely to be depressed, socially isolated, and have higher levels of stress. Social support and engagement in social activities did not improve after CR death.	3
Boerner, Schulz, and Horowitz (2004), USA	Secondary analysis REACH Study. Prospective cohort study. Post-death. Time since death less than 3 months.	Bereaved CGs spouses, adult children, and other (n = 224) In-home only	CES-D, TRIG, Caregiver Benefit Assessment Scale, Caregiver Burden Scale	Post-death depressive symptoms, post-death grief	Pre-loss caregiving benefit associated with higher post-loss depression and grief. CGs with stronger pre-death relationship with CR had higher levels of grief post-death. Effects of REACH intervention on grief and bereavement not directly measured.	4
Chan, Livingston, Jones, and Sampson (2013), United Kingdom	Systematic review (n = 31) Pre and post-death. Time since death varied.	17 quantitative, 11 qualitative, and 3 mixed-methods studies from 1992 to 2009. Anticipatory grief (n = 20) and bereavement (n = 11). In-home (n = 27), LTC (n = 3), and hospice (n = 1).	NA	NA	Grief in ADRD caregivers may be normal or prolonged and begins prior to death. Complicated post-death grief reactions occur in 20% of ADRD CGs. No studies were identified that examined ADRD bereavement after CR death in LTC.	1

(continued)

Table 1. (continued)

Author (Year), Country	Design and Duration	Demographics and Residence at Time of Death	Instruments	Outcome Measures	Results	Level of Evidence
Givens, Prigerson, Kiely, Shaffer, and Mitchell (2011), USA	Prospective cohort study. Part of CASCADE study. Pre and post-death.	Spouses, adult children, and other (n = 123) LTC only	Modified PGD-12, CAD-EOLD	Pre-loss grief, post-loss grief	CG depression increased post-loss. 43.9% experienced pre-occupation with thoughts of the resident's death. 47.2% experienced longing or yearning at a frequency of sometimes, often or always. Living with CR prior to LTC placement and higher pre-loss grief correlated with higher post-loss grief. Grief for ADRD CGs whose CR die in LTC is prolonged and begins prior to death.	4
Haley et al. (2008), USA	RCT. Part of NYUCI Study. Post-death	Spouses (n = 254), LTC and in-home. Number of subjects in each category not disclosed.	GDS	Depressive symptoms	Post-death depressive symptoms for both control and treatment were reduced from pre-death levels. Treatment had lower depressive symptoms before and after death than control. Post-death depression higher for 1 year in CGs who were placed in LTC. Religiosity was not associated with preparedness for death.	2
Hebert, Dang, and Schulz (2006), USA	Prospective cohort study Post-death. Time since death up to 2 years.	Spouses (n = 112) and other (n = 110; N = 222) LTC and in home	Preparedness for Death Scale, CES-D, ICG, STAI, Religiosity Scale	Preparedness for death	Unprepared caregivers had more depression, anxiety, and complicated grief symptoms. Black caregivers were less prepared for death. Preparedness was not associated with CG burden, location of death, or religiosity. Preparedness was associated with ethnicity, education, income, CR pain, and pre-loss CG depression.	4

(continued)

Table 1. (continued)

Author (Year), Country	Design and Duration	Demographics and Residence at Time of Death	Instruments	Outcome Measures	Results	Level of Evidence
Holland, Currier, and Gallagher-Thompson (2009), USA	Secondary analysis of REACH Study. Longitudinal design Pre and post-death. Time since death up to 18 months.	Bereaved spouses and adult children (n = 224) LTC and in home	CES-D, TRIG, ICG	Complicated grief, normal grief, and depressive symptoms	Intervention group reported significantly fewer symptoms of normal grief than the control. Post-death depression for the intervention group was non-significant.	4
Irwin et al. (2013), USA	Pilot exploratory study. Post-death. Time since death average 7.3 months.	Spouses (n = 32), in home, hospice (n = 10) vs. non-hospice (n = 22) In-home only with and without hospice.	HAM-D, HAM-A, Ways of Coping Instrument, Global Sleep Quality Score, Pittsburgh Sleep Quality Index	Depressive symptoms, anxiety, coping, overall health outcomes, resting blood pressure, resting heart rate, hemodynamic reaction to stress (blood pressure and heart rate)	CGs who utilized hospice had less post-death depression and anxiety. No group differences were found in physical health outcomes, coping strategies, or sleep quality.	5
Murphy, Hanrahan, and Luchins (1997), USA	Prospective cohort study, LTC with and without hospice Post-death only. Time since death not disclosed.	LTC facilities located in the lower peninsula of Michigan (n = 111). LTC only	Caregiver Support Questionnaire	Bereavement service provision	Support included sympathy cards (55%) and attendance at the funeral (45%). 99% did not provide material on bereavement. None sent information on bereavement support groups, 98% neither visited the family post-death, made phone calls, nor provided written communication (bereavement newsletter) to the families after death.	5

(continued)

Table 1. (continued)

Author (Year), Country	Design and Duration	Demographics and Residence at Time of Death	Instruments	Outcome Measures	Results	Level of Evidence
Owen, Goode, and Haley (2001), USA	Prospective cohort study Pre and post-death. Time since death within 4 months.	Spouses, adult children, and other (*n* = 63) LTC (*n* = 24.2%), hospital (30%), and in home (42.4%).	Caregiver Bereavement Questionnaire	Adaption to death of care recipient, use of support services after death, life sustaining decision making at time of death	African American less likely to withhold treatment at the time of death (72.3% Caucasian and 29.4% African American), less likely to have their CR die in LTC (29.8% Caucasian and 5.9% African American), and reported less acceptance of their CR's death and greater perceived loss than Caucasian CGs. African Americans were less likely to view death as a relief.	5
Robinson-Whelen, Tada, MacCallum, McGuire, and Kiecolt-Glaser (2001)	Longitudinal design. Secondary analysis of REACH Study Pre and post-death. Time since death varied from 1 month up to 1 year.	Spouses (*n* = 143), non-caregivers (*n* = 52), bereaved caregivers (*n* = 49), and current caregivers (*n* = 42). LTC and in home.	BDI, University Loneliness Scale, Positive and Negative Affect Scale, Perceived Stress Scale, Interpersonal Support Evaluation List	Stress, negative affect, depressive symptoms, loneliness, positive affect	Bereaved CG depression, loneliness, and positive affect did not rebound to levels comparable with non-caregivers and remained similar to those of current caregivers up to 3 years after death. Predictors of post-caregiving outcomes were social support and intrusive-avoidant thinking about caregiving. Current levels of social support were more strongly r/t post-caregiving outcomes than was support received during the CG years. The longer the duration of spousal caregiving, the less likely CGs were to endorse positive emotions 2-3 years after death. Did not measure in-home vs. LTC bereavement outcomes. Those who received REACH intervention had less complicated grief.	4

(continued)

Table 1. (continued)

Author (Year), Country	Design and Duration	Demographics and Residence at Time of Death	Instruments	Outcome Measures	Results	Level of Evidence
Schulz, Boerner, Shear, Zhang, and Gitlin (2006), USA	Secondary analysis of REACH Study. Longitudinal design. Pre and post-death. Time since death 6, 12, and 18 months	Spouses, adult children and other (n = 217). LTC and in home.	ICG, Spielberger State-Trait Personality Inventor, Revised Memory and Behavior Problem Checklist, Positive Aspects of Caring Scale.	Complicated grief	20% of AD CGs experienced complicated grief along with high levels of depressive symptoms post-death. Complicated grief was positively correlated with decreased education and lower income. Pre- and post-loss depression was + correlated with complicated grief. Complicated grief also + associated with caring for younger CRs. Effects of REACH intervention on grief and bereavement not directly measured.	4
Schulz, Burgio, et al. (2003), USA	Reach RCT Pre and post-death. Time since death varied (median 15 weeks)	Spouses, adult children, and other (n = 217). Hospital (40.5%), in-home (32.2%), and LTC (27.3%).	CES-D, Revised Memory, and Behavior Problems Checklist.	Caregiver response to death (relief, depressive symptoms)	CG had clinically significant depressive symptoms within first 3 months post-death, and within 1 year, the depression levels were substantially lower than levels reported during caregiving. CGs who placed in LTC did not show recovery from depressive symptoms. 72% of CGs reported that death was a relief to them and 90% reported death was a relief to the CR. Effects of REACH intervention on grief and bereavement not directly measured.	2

(continued)

Table 1. (continued)

Author (Year), Country	*Design and Duration*	*Demographics and Residence at Time of Death*	Instruments	Outcome Measures	Results	Level of Evidence
Shuter, Beattie, and Edwards (2014), Australia	Qualitative design Pre and post-death. Time since death within 12 months.	Spouses and adult children (n = 13). LTC (n = 9), in-home (n = 3), and hospital (n = 1)	Semi-structured individual interview guide	NA	Three key areas emerged: (a) caregiver/CR characteristics, (b) CG role appraisal (grief, experiences of health care personnel, EOL issues, and events surrounding the death event), and (c) the interaction between caregiver/CR. End-of-life was a time when negative vs. positive experiences with professional care providers had the greatest impact. Professional EOL care in LTC settings was inconsistent.	5
Tweedy and Guarnaccia (2007), USA	Retrospective cohort study. Secondary analysis of Health and Retirement Study. Longitudinal Study. Post-death. Time since death varied.	Spouses (n = 87) In-home only	CES-D	Depressive symptoms	Spousal caregivers have increased depression after death (wives reported a greater increase and slower resolution). Together gender and time elapsed since death accounted for 11% of the change in depression levels in surviving spouses.	5

Note. LTC = long-term care; REACH = Resources for Enhancing Alzheimer's Caregiver Health; CES-D = Centers for Epidemiologic Studies Depression Scale; STAI = State-Trait Anxiety Inventory; ICG = Inventory for Complicated Grief; TRIG = Texas Revised Inventory of Grief; ADRD = Alzheimer's disease and related dementias; CASCADE = choices, attitudes, and strategies for care of advanced dementia at the end-of-life; PGD = Prolonged Grief Disorder; CAD-EOLD = Comfort Assessment in Dying With Dementia Scale; NYU = New York University; NYUCI = NYU Caregiver Intervention; GDS = Geriatric Depression Scale; HAM-D = Hamilton Depression Scale; HAM-A = Hamilton Anxiety Scale; BDI = Beck Depression Inventory; EOL = end-of-life; CR = care recipient; CG = caregiver; RCT = randomized controlled study; AD = Alzheimer's Disease; r/t = related to.

opinions). We assessed secondary data analyses based on the methods utilized in the published manuscript rather than those implemented in the primary study, which resulted in either a Level 4 or Level 5 ranking.

Results

Study Origin and Design

Of the total 19 studies, the majority were conducted in the United States (n = 15) and four were conducted in Sweden (n = 2), the United Kingdom (n = 1), and in Australia (n = 1), respectively (Table 1). There were 15 quantitative studies (Aneshensel, Botticello, & Yamamoto-Mitani, 2004; Bergman, Haley, & Small, 2011; Bodnar & Kiecolt-Glaser, 1994; Boerner, Schulz, & Horowitz, 2004; Givens et al., 2011; Haley et al., 2008; Hebert, Dang, & Schulz, 2006; Holland et al., 2009; Irwin et al., 2013; Murphy, Hanrahan, & Luchins, 1997; Owen, Goode, & Haley, 2001; Robinson-Whelen, Tada, MacCallum, McGuire, & Kiecolt-Glaser, 2001; Schulz et al., 2006; Schulz, Mendelsohn, et al., 2003; Tweedy & Guarnaccia, 2007), three qualitative studies (Albinsson & Strang, 2003; Almberg, Grafstrom, & Winblad, 2000; Shuter, Beattie, & Edwards, 2014), and one systematic review (Chan et al., 2013) in the final analysis (Table 1). Two studies were secondary analysis based on randomized controlled studies (Haley et al., 2008; Schulz, Mendelsohn, et al., 2003). The systematic review conducted by Chan et al. (2013) included 31 publications (20 pre-death grief and 11 post-death grief) published between 1950 and 2010. Overall, the quality of the evidence reviewed was limited.

Sample Size and Socio-Demographics

Sample sizes varied across the studies, ranging from 13 (Shuter et al., 2014) to 291 (Aneshensel et al., 2004) ADRD caregivers who were predominantly Caucasian and female. The studies included in this review examined ADRD caregivers who had a variety of relationships to their family members. The majority of the studies (n = 13) included mixed samples of ADRD caregivers (spouses, adult children, and/or other family members; Albinsson & Strang, 2003; Almberg et al., 2000; Aneshensel et al., 2004; Bergman et al., 2011; Bodnar & Kiecolt-Glaser, 1994; Boerner et al., 2004; Givens et al., 2011; Hebert et al., 2006; Holland et al., 2009; Owen et al., 2001; Schulz et al., 2006; Schulz, Mendelsohn, et al., 2003; Shuter et al., 2014). Four studies recruited exclusively spousal caregivers (Haley et al., 2008; Irwin et al., 2013; Robinson-Whelen et al., 2001; Tweedy & Guarnaccia, 2007). No studies were identified that exclusively examined ADRD post-death grief and bereavement in adult-child caregivers.

The majority of the studies ($n = 12$) recruited only participants who were providing care in the home at the start of the study (Aneshensel et al., 2004; Bergman et al., 2011; Bodnar & Kiecolt-Glaser, 1994; Boerner et al., 2004; Haley et al., 2008; Hebert et al., 2006; Holland et al., 2009; Irwin et al., 2013; Owen et al., 2001; Schulz et al., 2006; Schulz, Mendelsohn, et al., 2003; Tweedy & Guarnaccia, 2007). Of the 12 studies that recruited only in-home caregivers, 10 had a percentage of caregivers that placed their family members in LTC during the course of the project (Aneshensel et al., 2004; Bergman et al., 2011; Bodnar & Kiecolt-Glaser, 1994; Boerner et al., 2004; Haley et al., 2008; Hebert et al., 2006; Holland et al., 2009; Owen et al., 2001; Schulz et al., 2006; Schulz, Mendelsohn, et al., 2003). Four other studies recruited participants who were either providing care in the home or in LTC at the beginning of the study (Albinsson & Strang, 2003; Almberg et al., 2000; Robinson-Whelen et al., 2001; Shuter et al., 2014). Only two studies exclusively recruited participants from LTC (Givens et al., 2011; Murphy et al., 1997). In the 11 post-death studies reviewed by Chan et al. (2013), there were mixed samples of caregivers who were providing care to their family members both in the home and in LTC settings.

Eight studies directly measured post-death grief and bereavement using standardized instruments (Bergman et al., 2011; Boerner et al., 2004; Givens et al., 2011; Hebert et al., 2006; Holland et al., 2009; Owen et al., 2001; Schulz et al., 2006). The grief and bereavement instruments used among these studies included the Caregiver Bereavement Questionnaire (Owen et al., 2001), the Inventory for Complicated Grief (Bergman et al., 2011; Hebert et al., 2006; Schulz et al., 2006), the Modified Prolonged Grief Disorder Scale (Givens et al., 2011), and the Texas Revised Inventory of Grief (Boerner et al., 2004; Holland et al., 2009).

Factors Influencing ADRD Caregiver Grief Following Care Recipient's Death

Our review found that the post-death grief and bereavement experiences of ADRD caregivers were influenced by a variety of factors such as gender, relationship status with the care recipient, mental and physical health, religiosity, race, location of family member death, and the circumstances that surround the final days of the family member's life (Albinsson & Strang, 2003; Almberg et al., 2000; Bodnar & Kiecolt-Glaser, 1994; Boerner et al., 2004; Givens et al., 2011; Chan et al., 2013; Haley et al., 2008; Hebert et al., 2006; Murphy et al., 1997; Owen et al., 2001; Robinson-Whelen et al., 2001; Schulz, Mendelsohn, et al., 2003; Shuter et al., 2014). Surprisingly, the impact of religiosity on post-death grief has not yet been fully explored. The limited data available suggest that religiosity provides a greater sense of social support (Bergman et al., 2011) and relief (Almberg et al., 2000) but did not assist bereaved ADRD caregivers in their preparation for death (Hebert et al., 2006).

Based on the limited number of studies that included minority samples, the evidence suggests that African American ADRD caregivers have unique challenges as their care recipients approach end-of-life in that they are less prepared for the family member's death, less likely to place their family member in LTC, less likely to decide to withhold treatment at the time of death, and are less likely to view the death of their family member as a relief compared with their Caucasian counterparts (Hebert et al., 2006; Owen et al., 2001). The evidence suggests that bereaved caregivers who are either unprepared for death, exhausted from caregiving, or report that death is "not at all" a relief are more likely to experience worse mental health outcomes (Almberg et al., 2000; Hebert et al., 2006; Owen et al., 2001).

The evidence from this integrative review further suggests that the relationship between the caregiver and the care-recipient plays an important role in how the death is viewed and in the post-death grief and bereavement outcomes. Caregivers who reported stronger pre-death relationships with their family members reported higher levels of grief after death (Boerner et al., 2004). The post-death grief and bereavement outcomes for surviving ADRD spouses are particularly concerning. Some evidence suggests that spouses experienced decreased depressive symptoms following care recipient's death, and this decrease was more pronounced for those spouses who did not place their family member in LTC (Haley et al., 2008). Other evidence suggests that bereaved spouses remained depressed, lonely, and with negative affect for up to 3 years following the death of their family member whether their family member died in the home or in LTC (Robinson-Whelen et al., 2001). In addition, bereaved adult–child ADRD caregivers were found to be less prepared for death, have higher levels of anger, and increased guilt compared with spousal caregivers (Chan et al., 2013).

Negative Grief and Bereavement Outcomes

In the studies reviewed, ADRD caregiver mental health was the most frequently measured outcome of grief and bereavement. Among the most prevalent negative mental health outcomes were depressive symptoms, anxiety, guilt, longing, social isolation, and loneliness; all were found to interfere with the ability of some ADRD caregivers to move forward following the death of their family members (Almberg et al., 2000; Aneshensel et al., 2004; Bodnar & Kiecolt-Glaser, 1994; Chan et al., 2013; Givens et al., 2011; Haley et al., 2008; Hebert et al., 2006; Irwin et al., 2013; Robinson-Whelen et al., 2001; Schulz et al., 2006; Schulz, Mendelsohn, et al., 2003).

One study suggested that ADRD caregivers may experience higher levels of negative mental health outcomes following the death of their family members (Almberg et al., 2000). Bereaved ADRD caregivers were found to experience higher levels of negative mental health outcomes compared with other chronic illness caregivers due to (a) the reduced ability of the caregiver and care recipient to communicate with one another in the final stages of illness, (b) the increased length of time spent in the caregiving role by ADRD caregivers, (c) higher levels of perceived caregiver burden by ADRD caregivers, (d) the presence of significant and prolonged predeath grief resulting from ongoing losses as dementia worsens, (e) the frequent need for LTC placement, and (f) the reduced likelihood of individuals with ADRD to receive hospice services prior to their death (Albinsson & Strang, 2003; Almberg et al., 2000; Chan et al., 2013; Givens et al., 2011; Irwin et al., 2013).

A significant degree of evidence indicated that bereaved ADRD caregivers that experience depressive symptoms (Aneshensel et al., 2004; Bodnar & Kiecolt-Glaser, 1994; Chan et al., 2013; Givens et al., 2011; Haley et al., 2008; Hebert et al., 2006; Irwin et al., 2013; Robinson-Whelen et al., 2001; Schulz et al., 2006; Schulz, Mendelsohn, et al., 2003) are also immunologically compromised with heightened stress responses and worsened chronic health conditions (Bodnar & Kiecolt-Glaser, 1994; Irwin et al., 2013). Post-family member death, depressive symptoms were found to be higher among men, spousal ADRD caregivers, those with perceived poor health, and in those caregivers who experienced depressive symptoms during active caregiving (Aneshensel et al., 2004; Boerner et al., 2004; Robinson-Whelen et al., 2001; Tweedy & Guarnaccia, 2007). Bereaved ADRD caregivers whose family members received hospice care prior to their death were found to experience decreased depressive symptoms (Irwin et al., 2013). Depressive symptoms were found to resolve at a slower rate for ADRD caregivers whose family members did not receive hospice and died in LTC (Haley et al., 2008; Schulz, Mendelsohn, et al., 2003).

The evidence suggests that bereaved ADRD caregivers whose family members died in LTC and those community-based caregivers who ruminated (either before or after death) about their caregiving experiences suffered increased post-death psychosocial symptoms that included yearning, longing, loneliness, greater stress, higher levels of guilt, and social isolation (Albinsson & Strang, 2003; Almberg et al., 2000; Aneshensel et al., 2004; Bodnar & Kiecolt-Glaser, 1994; Givens et al., 2011; Hebert et al., 2006; Robinson-Whelen et al., 2001; Schulz, Mendelsohn, et al., 2003).

Positive Grief and Bereavement Outcomes

The studies reviewed also identified a limited number of positive outcomes in the context of ADRD caregiver bereavement. The most frequently reported positive bereavement outcomes included relief, decreased perceived stress levels, and positive affect (Almberg et al., 2000; Chan et al., 2013; Owen et al., 2001; Robinson-Whelen et al., 2001). One study indicated that 3 years following family member death, bereaved wives experienced positive affect more frequently than bereaved husband caregivers (Robinson-Whelen et al., 2001). Some caregivers reported relief both for themselves and their care recipient when death finally occurred (Albinsson & Strang, 2003; Almberg et al., 2000; Chan et al., 2013). Greater relief was reported among caregivers who identified positive aspects of their caregiving roles when reflecting back on their experiences post-death (Almberg et al., 2000; Chan et al., 2013). These positive post-death experiences were found to assist some caregivers with expressing gratitude to their family members who passed (Albinsson & Strang, 2003; Almberg et al., 2000).

EOL Issues

A range of end-of-life factors was found to have significant impact on ADRD caregiver grief and bereavement. ADRD caregivers reported feelings of connectedness and comfort if they were present at the time of their family member's death (Almberg et al., 2000; Chan et al., 2013). In contrast, other ADRD caregivers reported increased emotional upset following death if their family members had diminished dignity, increased pain, and no quality of life prior to their deaths (Albinsson & Strang, 2003; Almberg et al., 2000; Shuter et al., 2014). Lack of preparedness for family member death also affected ADRD caregiver grief and bereavement and for some caregivers, death came as a shock despite the long course of illness (Almberg et al., 2000; Chan et al., 2013). ADRD caregivers who were emotionally unprepared for the death of their family member were found to have higher levels of post-death depression and anxiety (Chan et al., 2013; Haley et al., 2008; Hebert et al., 2006; Schulz, Mendelsohn, et al., 2003). One study reported that lack of preparedness for death was higher in caregivers that had lower incomes, were African American, and those with less education (Hebert et al., 2006). Another study noted that ADRD caregivers whose family members died in LTC also reported increased post-death emotional upset if their family members had expressed a wish to die in their final days or if they had negative experiences with LTC staff before death occurred (Albinsson & Strang, 2003).

ADRD Caregiver Interventions

A limited number of pre-death community-based interventions were shown to improve ADRD caregiver post-death grief and bereavement outcomes. Seven of the studies reviewed were secondary analyses that used samples from two separate multi-component pre-death ADRD caregiver interventions focusing on caregivers' emotional health while their family members with dementia were still alive (Bergman et al., 2011; Boerner et al., 2004; Holland et al., 2009; Haley et al., 2008; Schulz et al., 2006; Schulz, Mendelsohn, et al., 2003; Robinson-Whelen et al., 2001). Both the Resources for Enhancing Alzheimer's Caregiver Health (REACH; Schulz, Burgio, et al., 2003) and the New York University (NYU) Caregiver Intervention Project (Mittelman, Roth, Haley, & Zarit, 2004) used the stress process model to develop their interventions (Lazarus & Folkman, 1984). The overall objectives of both the REACH and NYU Caregiver Interventions were to enhance the positive aspects of ADRD caregiving, while reducing its negative aspects (Mittelman et al., 2004; Schulz, Mendelsohn, et al., 2003). Overall, caregivers who participated in pre-death interventions had more favorable post-death emotional health outcomes, including lower levels of grief and depressive symptoms (Haley et al., 2008; Holland et al., 2009; Robinson-Whelen et al., 2001). We were unable to identify a single intervention based on a caregiver grief model specifically designed to improve the emotional health of ADRD caregivers post-death. Moreover, we found no intervention to address caregiver grief and bereavement after their family members's death in LTC.

Grief and Bereavement Support

The support provided to bereaved ADRD caregivers is severely limited. Bereaved ADRD caregivers may receive formal support (health care providers support groups and targeted interventions) and/or informal support (friends, family, spiritual communities, and acquaintances; Bergman et al., 2011). The evidence suggests that bereaved ADRD caregivers often experience emotional upset, loneliness, and in some cases, social isolation for up to 18 months after their family members' death due to a lack of support (Almberg et al., 2000; Bodnar & Kiecolt-Glaser, 1994; Burton, Haley, & Small, 2006; Chan et al., 2013). The evidence further suggests that when ADRD caregivers do receive affective support both before and after their family members' death, this support mediates negative bereavement outcomes such as depressive symptoms, anxiety, and guilt (Almberg et al., 2000; Bodnar & Kiecolt-Glaser, 1994; Chan et al., 2013; Robinson-Whelen et al., 2001). One study reported that the formal bereavement services provided by hospice enrollment reduced post-death depression and anxiety for surviving ADRD spousal caregivers (Irwin et al., 2013).

Formal support was found to be virtually non-existent for those caregivers whose family members died in LTC (Givens et al., 2011; Murphy et al., 1997). The evidence suggests that the grief and bereavement support offered to ADRD caregivers whose family members die in LTC is often limited to sympathy cards written by a member of the admission staff (55%) and visitation at funeral services (44%; Murphy et al.,1997). In addition, it was reported that 99% of the facilities surveyed ($N = 111$) did not provide bereaved ADRD caregivers with any written information about grief or bereavement support and 76% were unable to provide referrals to ADRD caregivers when grief and bereavement interventions were deemed necessary (Murphy et al., 1997). We were unable to identify another study since Murphy et al. (1997) that re-examined the grief and bereavement support provided by LTC facilities to surviving ADRD family members.

Discussion

The evidence from our review supports the findings of the review by Chan et al. (2013) and reveals that little is known about the phenomenon of ADRD caregiver grief and bereavement. Although we included six studies that were also reviewed by Chan et al. (2013; Almberg et al., 2000; Boerner et al., 2004; Hebert et al., 2006; Holland et al., 2009; Owen et al., 2001; Schulz et al., 2006), this integrative review contributes to the evidence by synthesizing the findings of 12 additional ADRD caregiver post-death grief and bereavement studies (Albinsson & Strang, 2003; Aneshensel et al., 2004; Bergman, Haley & Small, 2011; Bodnar & Kiecolt-Glaser, 1994; Givens et al., 2011; Haley et al., 2008; Irwin et al., 2013; Murphy et al., 1997; Robinson-Whelen et al., 2001; Schulz, Mendelsohn, et al., 2003; Shuter et al., 2014; Tweedy & Guarnaccia, 2007).

The evidence is consistent across many studies that the grief and bereavement of ADRD caregivers is unique and often problematic when compared with the experiences of other chronic disease caregivers because of the prolonged caregiving demands, the progressive course of illness, the reduced likelihood of receiving hospice services, and the eventual need for LTC placement prior to death (Albinsson & Strang, 2003; Almberg et al., 2000; Bergman et al., 2011; Bodnar & Kiecolt-Glaser, 1994; Chan et al., 2013; Givens et al., 2011; Owen et al., 2001; Robinson-Whelen et al., 2001; Schulz et al., 2006). Our review further points out that after their care recipients' death, ADRD caregivers' grief is problematic because it is often associated with a variety of physical and emotional health factors that include chronic health conditions, immunological compromise, depressive symptoms, increased stress, shock, anxiety, guilt, longing, and loneliness (Albinsson & Strang, 2003; Almberg et al., 2000; Bodnar & Kiecolt-Glaser, 1994; Chan et al., 2013; Givens et al., 2011; Haley et al., 2008; Hebert et al., 2006; Irwin et al., 2013; Owen et al., 2001; Robinson-Whelen et al., 2001;Schulz et al., 2006; Schulz, Mendelsohn, et al., 2003). The evidence suggests these physical and emotional health effects may remain with bereaved ADRD caregivers for up to 3 years following the death of their family member (Bodnar & Kiecolt-Glaser, 1994).

The evidence also suggests that relationship status of the caregiver plays a role in ADRD caregiver post-death grief and bereavement (Albinsson & Strang, 2003; Chan et al., 2013). Due these differences, the use of mixed samples may not adequately capture the unique differences in post-death grief and bereavement across specific relationship categories. Particular focus should be placed on examining the grief and bereavement experiences of adult–child ADRD caregivers as the evidence is lacking for this population.

Our review demonstrates that the phenomenon of ADRD caregiver grief and bereavement is superficially understood. Although numerous gaps in the evidence have been identified in this integrative review, we identified five critical gaps in the existing evidence that we believe must be urgently addressed: (a) a lack of ethnic and gender diversity among ADRD caregivers studied, (b) limited use of valid instruments to measure ADRD caregiver grief and bereavement, (c) no substantive research examining ADRD caregiver grief and bereavement for caregivers whose family members die in LTC, (d) a lack of evidence examining the effect of hospice services on ADRD caregiver grief and bereavement, and (e) no evidence of a grief and bereavement intervention designed for ADRD caregivers whose family members died in LTC.

The first gap in the research that we identified is the lack of ethnic and gender diversity in the studies reviewed. The lack of ethnic diversity in grief and bereavement research is of particular concern because Hispanics and African Americans are 1½ to 2 times more likely to be diagnosed with ADRD than Caucasians, respectively (Alzheimer's Association, 2015). In addition, nearly 20% of ADRD caregivers are either African American (10%) or Hispanic (8%), who provide care more frequently and for longer durations than their Caucasians counterparts, and report higher levels of stress associated with caregiving (Alzheimer's Association, 2015). It is very likely that variables such as disparities in health care, socioeconomic status, and lifestyle and mistrust in the health care establishment that contribute to the increased prevalence of ADRD among Hispanics and African Americans

(Alzheimer's Association, 2015) also limit the ability/willingness of minority caregivers to participate in ADRD research activities. We also found limited gender diversity among these studies, despite the fact that one third of all ADRD caregivers are male (Alzheimer's Association, 2015). According to Chan et al. (2013), the lack of male participants in ADRD caregiver grief and bereavement research is likely attributed to the fact that males may be less willing to acknowledge and talk about their grief experiences. Future ADRD caregiver grief and bereavement research should focus on improving sample representativeness.

The second gap in the evidence that we identified is the limited use of valid instruments to measure the multiple components of ADRD caregiver post-death grief and bereavement. Of the 19 studies included in our review, only seven studies used instruments to measure post-death grief and bereavement in ADRD caregivers (Bergman et al., 2011; Boerner et al., 2004; Givens et al., 2011; Hebert et al., 2006; Holland et al., 2009; Owen et al., 2001; Schulz et al., 2006). Among these studies, the two most commonly used instruments for post-death grief were the Inventory of Complicated Grief (consistency = .94, reliability = .80; Prigerson et al., 1995) and the Texas Revised Inventory of Grief (consistency = .77, reliability = .81; Faschingbauer, 1981). We were unable to identify a tool specifically designed to measure ADRD post-death grief and bereavement among any of the studies reviewed. The lack of valid instruments limits our ability to make comparisons across studies and weakens the overall strength of the evidence.

The third gap in the research that we identified is the lack of evidence examining the grief and bereavement experiences of ADRD caregivers whose family members died in LTC. The limited evidence available suggests that LTC placement affects ADRD caregiver grief and bereavement (Givens et al., 2011; Haley et al., 2008; Schulz, Mendelsohn, et al., 2003) and that the relationships between ADRD caregivers and LTC staff has an influence on the grief and bereavement experiences of ADRD caregivers (Shuter et al., 2014). In addition, the evidence suggests that LTC staff play a pivotal role in shaping the final memories that ADRD caregivers have of their family members and that conflicts between LTC staff and ADRD caregivers may result in increased emotional upset and trauma that remain with some ADRD caregivers well past care recipient's death (Shuter et al., 2014). Our review expands on the work of Chan et al. (2013), who reported that LTC placement had an impact on pre-death grief but did not examine the impact that LTC placement had on post-death grief and bereavement in ADRD family caregivers. In addition, our review identified the critical lack of support provided to bereaved ADRD caregivers whose family members die in LTC by including Murphy et al. (1997), a study absent from the Chan et al. (2013) review.

The lack of research examining ADRD caregiver grief and bereavement following death in LTC was an unexpected finding given the overwhelming number of individuals who die from ADRD in LTC settings. Of the 19 studies that met inclusion criteria for this review, only six studies examined the impact that LTC placement had on ADRD caregiver grief and bereavement (Givens et al., 2011; Haley et al., 2008; Murphy et al., 1997; Owen et al., 2001; Schulz, Mendelsohn, et al., 2003; Shuter et al., 2014), and only two of these studies specifically targeted ADRD caregivers whose family members died in LTC (Givens et al., 2011; Murphy et al., 1997).

The fourth gap in the research that we identified is a lack of evidence examining the effect of hospice services on ADRD caregiver grief and bereavement, particularly for those caregivers whose family members' die in LTC. In addition, this integrative review revealed critical public policy issues that we believe should be addressed by further examining the factors that contribute to the under-utilization of hospice services for individuals with ADRD, which results in reduced support to surviving caregivers.

The fifth gap in the research that we identified is the complete absence of interventions specifically designed to improve post-death outcomes for bereaved ADRD caregivers whose family members die in LTC. We believe that the primary factors limiting the utilization of formal ADRD caregiver grief and bereavement support are attributed to the lack of interventions available, the failure to identify ADRD as a terminal illness, and reduced hospice referrals for individuals with ADRD by LTC facilities.

The five research gaps we identified expand on the findings of Chan et al. (2013), who reported that higher levels of evidence are needed from a broader population of caregivers to fully understand the complex process of ADRD caregiver grief and bereavement. Despite the evidence from the additional 12 studies not included in Chan et al. (2013), there is still very little known about the phenomenon of ADRD caregiver grief and bereavement and there are a limited number of interventions available to facilitate the physical and emotional health of this growing and vulnerable population.

This integrative review has several limitations. Articles that were not written in English as well as those that were not available in full-text format were excluded from this analysis, which may have resulted in the omission of some meaningful evidence.

ADRD caregiver grief and bereavement is a complex phenomenon that is influenced by a variety of personal, familial, environmental, and cultural factors. Much of the evidence concerning ADRD caregiver grief and bereavement is based on examining the post-death experiences of ADRD caregivers whose family members die at home, yet 70% of those with ADRD die in LTC settings, where grief and bereavement support for their family members is virtually inexistent (Alzheimer's Association, 2014; Givens et al., 2011; Murphy et al., 1997).

To address the five research gaps that we identified, future ADRD grief and bereavement investigation should focus on recruiting male, and both African American and Hispanic caregivers. Researchers should examine the current level of support that is being provided to surviving ADRD caregivers whose family members die in LTC, as we found no study that explored this important aspect since the 1997 study conducted by Murphy et al. Focus should be placed on developing interventions that would increase the utilization of hospice for individuals with ADRD as well as examining the impact that hospice use has on surviving ADRD caregivers' grief and bereavement, particularly for those individuals residing in LTC. ADRD caregivers whose family members die in LTC recover more slowly and will likely require targeted post-death grief and bereavement interventions to regain and maintain their physical and emotional health (Haley et al., 2008; Schulz, Mendelsohn, et al., 2003). Future research should also include the development and validation of standardized instruments that measure the key factors that affect grief and bereavement in ADRD caregivers, such as preparedness for death, end-of-life conflicts, and social isolation. Finally, future research should focus on the development of targeted grief and bereavement interventions aimed at supporting the emotional and physical health of ADRD caregivers following the death of their family members.

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Appendix B

Manuscript #2

Using the Internet for Recruitment and Qualitative Data Collection in Alzheimer's Disease and Related Dementia Caregivers: a Pilot Feasibility Study

Using the Internet for Recruitment and Qualitative Data Collection in Alzheimer's Disease and Related Dementia Caregivers: a Pilot Feasibility Study

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Abstract

Aims: To determine the feasibility of: 1) using the Internet to recruit Alzheimer's Disease and Related Dementia (ADRD) caregivers for a qualitative study; and 2) using Internet-based video conferencing to conduct in-depth individual interviews.

Background: Increasingly, healthcare researchers are using the Internet to identify and recruit subjects through paid advertising with on-line social networks and websites because its use has been shown to offer a cost effective and efficient alternative compared to traditional recruitment methods (Akard, Wray, & Gilmer, 2015). Although evidence suggests that ADRD caregivers are already well accustomed to using the Internet for personal and health-related reasons (Kim, 2015), the feasibility of using the Internet for recruitment and in-depth interviewing of ADRD caregivers is yet to be determined.

Data sources: The findings of a qualitative feasibility study utilizing the Internet for both subject recruitment and data collection are discussed. We compared survey data on the use of on-line video conferencing versus telephone to conduct in-depth personal interviews with bereaved ADRD caregivers.

Implications for research/practice: The Internet offers ADRD caregiving researchers opportunities for alternative, efficient, and cost-effective approaches to subject recruitment and data collection. This study contributes to the growing body of evidence examining the use of Internet-based technology in qualitative nursing research.

Conclusion: Utilizing the Internet for research recruitment and data collection with ADRD caregivers is feasible and cost-effective. Technical difficulties commonly reported as barriers to using Internet-based video-conferencing can be reduced and/or eliminated with proper planning and basic participant training.

Keywords: dementia caregivers, Skype©, FaceTime©, Internet-based research methods, qualitative methodology

Using the Internet for Recruitment and Qualitative Interviewing of Alzheimer's Disease and Related Dementia Caregivers: a Pilot Feasibility Study

The Internet offers promising opportunities for healthcare researchers because its use has the potential to enhance subject identification, increase recruitment and enrollment, reduce costs, and to support interviewing and data collection (Oates, 2015; Tolstikova & Chartier, 2010). Evidence suggests that the Internet may be suitable for those conducting research with Alzheimer's Disease and Related Dementia (ADRD) caregivers because more than half of these caregivers in the United States already have access to and use the Internet for health-related reasons (Kim, 2015).

Background

Internet-based Subject Identification and Recruitment

Increasingly, researchers are using the Internet to identify and recruit subjects through paid advertising with on-line social networks and websites (Akard, Wray, & Gilmer, 2015; Leach, Ziaian, Francis, & Agnew, 2016). Of the available social networking sites, Facebook© advertising is being used more frequently than other social networking sites for subject recruitment (Heywood et al., 2015; Thornton et al., 2016)). Other social networking sites such as Google©, My Space©, Instagram©, Tumblr©, Twitter©, and targeted Internet-based forums are also being utilized for recruitment (Leach et al., 2016; Maloni, Przeworski, & Damato, 2013; O'Dwyer & Moyle, 2014; Ramo, Hall, & Prochaska, 2010; Mishra et al., 2014).

A systematic review conducted by Thornton et al. (2016), examined 110 unique publications that utilized Facebook© for recruitment (96.4% quantitative (*n*=106) and 3.6% (*n*= 4) qualitative) and found Facebook© to be a cost effective and efficient recruitment tool across a wide variety of topics, populations, methodologies, and settings (Thornton et al., 2016). However, the evidence is less conclusive when other Internet venues are being utilized for subject recruitment (Leach et al., 2016; O'Dwyer & Moyle, 2014).

Internet-based Data Collection

The Internet also offers qualitative researchers opportunities for alternative approaches to data collection. Internet-based data collection strategies include the use of video conferencing, chat room discussions, texts, blogs, virtual message boards, and emails (Hamilton, 2014; Leach et al., 2016; Oates, 2015; Sullivan, 2012; Weinmann, Thomas, Brilmayer, Heinrich, & Radon, 2012). Traditionally, qualitative interviews are conducted either in person or via the telephone (Hamilton, 2014; Oates, 2015; Weinmann, Thomas, Brilmayer, Heinrich, & Radon, 2012), however, both of these methods have limitations that Internet-based strategies may reduce (travel time and travel expenses). The use of the Internet for qualitative interviews may also expand the geographical reach of the research study. (Sullivan 2012).

Internet Use in ADRD Research

Although evidence suggests that approximately 59% of ADRD caregivers are already well accustomed to using the Internet as a regular means of obtaining health information and needed support (Kim, 2015), the feasibility of using the Internet for recruitment and data collection in dementia caregiver research is yet to be determined.

Although the evidence suggests that the majority of ADRD caregivers are already using the Internet (Kim, 2015), we identified only one study that utilized the Internet for recruitment in this population (O'Dwyer & Moyle, 2014). In this study, 49 ADRD caregivers were recruited over a 6-week period using a Google© Adwords campaign. Google© Adwords campaigns are paid advertisements that are configured based upon the results of the Google© search terms that potential subjects enter on their computer. Without disclosing specific recruitment targets, O'Dwyer & Moyle (2014) reported that the use of a Google© Adwords campaign was less successful than projected.

While some evidence suggests that ADRD caregivers are typically older (Grill & Galvin, 2014; O'Dwyer & Moyle, 2014), the latest reports indicate that nearly two-thirds of dementia caregivers are under the age of 65 (Alzheimer's Association, 2017), further supporting the likelihood that Internet-based research methods may be feasible in this population.

Description of the Study

This pilot study explored the feasibility of: 1) using the Internet to recruit ADRD caregivers for a research study; and 2) using Internet-based video conferencing (via personal computers, tablets, or Smartphones) to conduct in-depth individual interviews with bereaved ADRD caregivers.

A purposive sample of 10 bereaved ADRD caregivers were interviewed in this study. We included caregivers who met the following inclusion criteria: 1) a former family caregiver over the age of 21 years whose family member (as defined by the participant) died with ADRD; 2) family member resided in a long-term care (LTC) setting at the time of death; and 3) caregivers had the necessary equipment (personal computer, tablet, Smartphone, or telephone) and Internet-based video conferencing capability (including video camera) if applicable, and 4) caregivers had an available private setting for interviewing.

In 2015 after obtaining Internal Review Board (IRB) approval from the parent institution, we contacted 8 website/web forum administrators to obtain their consent for on-line subject recruitment for our study. Subjects interested in participating in this pilot study were encouraged to contact the PI via email. The PI conducted introductory telephone calls with interested individuals to screen for subject eligibility and to explain the study. Once eligibility was confirmed, informed consent was obtained. The PI evaluated recruitment efforts by collecting and analyzing the following data: 1) date of recruitment attempt; 2) website or forum utilized; 3) number of email responses received by the PI; 4) number of individuals willing to participate in the study; and 5) reason for exclusion or lack of participation; 6) preference for interview method.

The interviews were conducted using either Internet-based video-conferencing or the telephone, based on participant preference, the availability of high speed Internet access, and the accessibility and knowledge of using a computer, tablet, or Smartphone that supported video-conferencing. The PI scheduled and conducted test video-conferences for those participants that elected to use video-conferencing for their interviews to ensure that participants had the necessary equipment and technical proficiency to participate in an interview utilizing video-conferencing. During the test session, the PI evaluated and responded to any emerging technical difficulties. An interview guide that included 4 open-ended questions was utilized for all participants. Following the interviews, participants were asked to complete a brief email-survey concerning their use/non-use of the Internet for the interviews. Results of the surveys were tabulated and analyzed using descriptive statistics.

Table One: Interview Guide

Question	Content
One	What helped you determine the interview method you selected?
Two	What prevented you from choosing one of the other interview methods?
Three	If you chose Internet-based video conferencing as an interview method for this study, how did you like using it? (liked it very much, liked it somewhat, neutral, disliked it somewhat, did not like it at all)
Four	Did you experience any technical difficulties using Internet-based video conferencing or the telephone? If yes, what was the problem?
Five	How likely would you be to participate in another research study that utilized internet-based video-conferencing (very likely, somewhat likely, neutral, somewhat unlikely, not at all likely)? What were the strengths and/or limitations of this method?

Findings

Participants included 9 females and 1 male ranging in age from 30 to 77 years (M=55 years, SD=13.70 years). All caregivers were Caucasian and the majority (*n*=9) lived in the United States with one from Canada. Our sample included individuals who were the primary caregivers to parents (mothers *n*=5, fathers *n*=2), spouses (*n*=1), and grandparents (grandfather n=2). Caregivers reported time since care recipient death ranging from 67 days to 7.5 years (M=2.5 years, SD=2.35 years). Care recipients ranged in age from 81 to 97 years (M=91 years, SD=5.81 years) and were diagnoses with ADRD for an average of 9.3 years (range 1-20 years) at the time of their death. Care recipients resided in LTC for an average of 3.2 years (range 1 month-7.5 years) prior to their death.

We determined the feasibility of using the Internet to recruit ADRD family caregivers for our study based upon our ability to reach our goal of recruiting 10 eligible participants within a three-month time period. The first step in our on-line recruitment effort was to obtain approvals from the website/forum administrators to place a recruitment postings. We selected 5 websites/forums designed to provide support to caregivers whose family members suffered from a variety of illnesses. These 5 websites/forums had specific discussion groups for ADRD caregivers. Additionally, we selected 3 websites/forums designed to support only ADRD caregivers. Three out of eight website/forum administrators granted our request to place recruitment postings. Of the remaining 5 websites/forum administrators, two responded to us via email that they did not allow recruitment for research studies, two others blocked our email correspondence without offering a reply, and one did not respond. There were no identifiable differences between those sites which allowed on-line research recruitment as compared to those that did not.

We achieved full study recruitment in a three-month time period, which exceeded our expectations. Our initial recruitment postings (*n*=3) were placed in November 2015, which included a brief overview of the study, the eligibility criteria, and the contact information of the primary investigator. Within 60 days of our initial recruitment requests, we received 17 responses, 77% of which were a direct result of our Internet recruitment efforts from 2 of the 3 websites/forums. In December 2015, one website/forum administrator contacted us and offered to feature our study in their on-line news bulletin, in January 2016. This resulted in 3 additional responses from interested caregivers. In addition, we screened 2 individuals for eligibility as a result of word-of-mouth referrals. In total, we screened 22 individuals for eligibility from November 2015 to January 2016. Of these 22 individuals, 10 met inclusions criteria for the study and agreed to participate in the interviews. Of the 12 individuals who did not meet our eligibility criteria, ten persons agreed to participate in a future Internet-based study with ADRD caregivers, which was an unexpected finding.

We determined the feasibility of using Internet-based video conferencing for data collection based on: 1) an analysis of participant responses to the post-interview survey; and 2) a review of the interview transcripts themselves targeting statements related to ease of technology use. Post-interview, a brief, 5-item survey was e-mailed to all study participants to gain insight into why they selected their chosen interview method. All participants who opted to conduct their interview using video-conferencing (*n*=5) reported that they liked this interview method "very much". A portion of our participants specifically referred to the Internet as their "lifeline" .and stated that its use provided them immense support during their years of prolonged caregiving. Participants' comfort level in utilizing the Internet was stated as a primary factor contributing to their preference for video-conferencing in lieu of a telephonic interview. Of the 5 video-conferencing interviews, only one participant experienced a technical difficulty when her computer ran out of battery power mid-way through the interview. In this instance, the participant connected his/her computer to an electricity source and the interview was resumed within 5 minutes.

All participants who selected video-conferencing stated that it was "easy to use" and that they enjoyed participating in a video-conferencing interview "very much". The oldest caregiver in the study, (age 77) stated that she regularly used video-conferencing to communicate with her family. Participants who utilized video-conferencing also reported that this method provided a "personal connection with the interviewer", a "personal conversation yet in the privacy of my own home", and that they were "happy to see the face of the interviewer". Of the five participants who selected telephone-based interviews, two individuals stated that they "didn't know how to use video-conferencing" and three others stated that they were "somewhat likely" to participate in a future research study utilizing Internet-based video conferencing. In addition, we examined all ten interview transcripts for any potential differences in completeness and reflexivity of participant responses. Our analysis revealed that both the telephone and the Internet-based interviews provided equally rich data with similar themes.

Discussion

Our findings suggest that it is feasible to utilize the Internet for recruitment of ADRD caregivers in a research study. Using the recruitment strategies outlined in Leach et al (2016) and O'Dwey & Moyle (2014) allowed us to balance our exposure while reaching a broad population of caregivers. The evidence from our study expands upon the work of Leach et al. (2016) by utilizing targeted ADRD caregiver websites and forums. Based upon the findings of Leach et al. (2016), we posted our recruitment announcements only in those forums designed to support ADRD caregivers following the death of their family member. We further expanded upon the findings of O'Dwey & Moyle (2014) - who noted that their use of overly broad terms in their recruitment postings limited their response rate - by using the pre-determined key words of "grief, death, and loss" for inclusion in our recruitment announcement. We found no other study that utilized the Internet for both the recruitment of ADRD caregivers as well as the collection of qualitative in-depth individual interview data.

One unexpected finding was that we had a greater than anticipated number of caregivers respond (22 individuals) to our requests for enrollment in a short period of time. Recruitment in our study was completed in only 3 months, which is significantly faster than the average of 5.5 months reported by Thornton et al (2016). We attribute our recruitment success to the purposeful drafting of a targeted enrollment announcement as well as to the lack of competing studies examining the phenomenon of ADRD caregiver grief and bereavement.

Other unexpected findings were that we recruited for our entire study without incurring any advertising or printing expenses and that we received an unsolicited request to have our study featured in an ADRD caregiver newsletter at no cost. These results suggest that well planned, strategically placed ads on well targeted websites may yield cost-free recruitment of ADRD caregivers over short periods of time (Oates, 2015). Moreover, these findings indicate ADRD caregivers' desire to share their stories, thus contributing to the body of knowledge about their specific experiences.

Our findings also suggest that it is feasible to utilize the Internet to conduct in depth individual interviews with bereaved ADRD caregivers. Results of our study further imply that Internet-based video conferencing (via personal computers, tablets, or Smartphones) is a cost effective and efficient strategy that ADRD caregivers enjoy. Half of our participants (*n*=5) chose to utilize Internet-based video conferencing for their interviews suggesting that ADRD caregivers are willing to utilize technology for communications. Our findings were consistent with those of Oates (2015) in that there were no significant differences in caregiver age between those participants who selected Internet-based interview methods and those participants who selected telephonic interviews. Our study was also consistent with Hamilton (2014), who noted that Internet-based video conferencing allowed for visual examination of participant facial expressions during the interview. Several of our participants who chose video-conferencing became tearful when speaking of the loss of their family members, and as noted by Hamilton (2014), this interview component may not have been identified and/or acknowledged by the participants in a telephone interview.

Our study expanded upon the findings of Oates (2015) by working to reduce the technical difficulties experienced when utilizing Internet-based video conferencing to conduct qualitative research. While Oates (2015) had to discount 2 of her 27 interviews (7.4%) due to technical difficulties, we were able to utilize 100% of our interview data for content analysis. By conducting pre-interview video-conferences for those participants who chose Internet-based video conferencing to ensure that each participant had the technical abilities and equipment necessary for a successful interviewing, we eliminated the need to dedicate actual interview minutes to video-conferencing training/support, which was a weakness found in the Oates (2015) study. In addition, the Principal Investigator utilized a pre-interview check list that tested for possible technical malfunctions (tape recorder and computer battery life, external noise/distractions, Internet connectivity) that ensured a smooth interviewing process.

Implications for further research and Limitations

ADRD caregiving researchers should strongly consider incorporating Internet-based methods into future studies because many of these caregivers (regardless of their age) are already accustomed to using the Internet in their personal lives. With proper planning and basic participant training, our Internet-based research methods resulted in highly successful recruitment, reduced costs, improved efficiency, and enhanced researcher-participant rapport.

Our findings are limited to those participants who had already utilized the Internet for personal use. For this reason, the caregivers who participated in our study may have exhibited higher technical competence and may have been more willing to utilize video-conferencing than ADRD caregivers in general.

Conclusions

Utilizing the Internet for research recruitment and data collection (in-depth interviewing) with ADRD caregivers is feasible and cost-effective. We reduced recruitment time and incurred no cost to the study by utilizing Internet-based recruitment sources. In addition, we reduced technical difficulties commonly reported as barriers to using Internet-based video-conferencing with proper planning and basic participant training.

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Appendix C

Manuscript #3

Riding Out the Storm: A Grounded Theory Study of Dementia Caregiver Grief and Bereavement Following Family Member Death in Long-Term Care

Riding Out the Storm: A Grounded Theory Study of Dementia Caregiver Grief and Bereavement Following Family Member Death in Long-Term Care

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Abstract

In this study, we utilize Grounded Theory methods to explore the process of grief and bereavement that Alzheimer's Disease and Related Dementia caregivers experience following the death of their family members in long-term care settings. We interviewed 17 former caregivers utilizing Internet-based video-conferencing (Skype© and FaceTime©) as well as the telephone to develop a theoretical model of this phenomenon. Participants described their grief and bereavement experiences as being categorized by 3 interdependent major concepts (behavior, cognitive, and emotional). Relationships and support mechanisms tide the three major components. Long-term care placement and the use of hospice services were identified as factors impacting caregiver grief and bereavement. Findings from this study can be utilized to develop bereavement interventions for Alzheimer's Disease and Related Dementia caregivers whose family members die in long-term care.

Keywords

Alzheimer's Disease; dementia; caregivers; grief; bereavement; Internet-based research methods

Riding out the storm: A grounded theory study of dementia caregiver grief and bereavement following family member death in long-term care

Alzheimer's Disease and Related Dementias (ADRD) are estimated to be the 6th leading cause of death in the United States (Alzheimer's Association, 2017). The evidence suggests that there is an increasing trend to provide end-of-life care to individuals with ADRD in long-term care (LTC) settings, yet there is very little evidence examining the grief and bereavement experiences of the caregivers of these individuals. (Alzheimer's Association, 2016; (Mitchell, Teno, Miller, & Mor, 2005)). Up to twenty-percent of ADRD caregivers experience prolonged and/or exaggerated grief reactions that may impair their physical/mental health (Schulz et al., 2003; Shuter, Beattie, & Edwards, 2014).

Background and Significance

Prevalence and Mortality of ADRD

In 2017, 5.3 million Americans over the age of 65 years have been diagnosed with ADRD (Alzheimer's Association, 2017). By 2025, it is estimate that 7.1 million Americans will be diagnosed with ADRD (Alzheimer's Association, 2016). Currently, it is estimated that approximately 37% of all Americans diagnosed with ADRD are 85 years of age or older (Alzheimer's Association, 2016). The evidence suggests that individuals diagnosed with ADRD live for an average of four to eight additional years, yet some individuals live as long as 20 years following an ADRD diagnosis (Alzheimer's Association, 2016). Along with the increase in prevalence of ADRD, the mortality rates are also rising. In 2017, it is estimated that 700,000 Americans over age 65 had ADRD at the time of their death (Alzheimer's Association, 2017).

ADRD Caregiving Stress

In 2017, family members provided 83% of the care needed by individuals with ADRD (Alzheimer's Association, 2017). In 2016, more than 15 million Americans provided 18.2 billion hours of unpaid care to persons with ADRD valued at $230.1 billion, which represents on average 21.9 hours of caregiving each week (Alzheimer's Association, 2017). As dementia advances, the care required by ADRD family members also increases, which in turn can result in increased emotional stress, depression, greater risk for suicide, decreased immune response, and worsening existing health conditions for the caregivers (Adams & Sanders, 2004; Holland, Currier, & Gallagher-Thompson, 2009). Fifty-nine percent of ADRD caregivers report that the emotional stress of caregiving is high or very high (Givens, Prigerson, Kiely, Shaffer, & Mitchell, 2011). ADRD caregivers are also more likely to report physical health complications, which include worsening chronic conditions, reduced immune response, and sleep deprivation compared to non-ADRD caregivers (Alzheimer's Association, 2016). It is estimated that approximately 40% of ADRD caregivers report depressive symptoms compared to 5-17% of non-ADRD caregivers (Alzheimer's Association, 2016). The evidence suggests that 23% of ADRD caregivers are adult-children who are not only caring for an aging parent but also for children under the age of 18 (Alzheimer's Association, 2016). Prior to the death of their family members, ADRD caregivers on average have provided care for longer periods of time than caregivers of older adults with other health conditions (Alzheimer's Association, 2016).

ADRD Caregiver Grief and Bereavement

While the terms grief and bereavement are often used interchangeably, they describe different components of loss. Grief is the term used to describe the normal emotional reaction that individuals have as the result of experiencing a significant loss in their lives (Stroebe, Hansson, Schut, & Stroebe, 2008). Once thought to occur only with the loss of a significant individual due to death, grief encompasses many different types of loss including loss of relationships, pets, jobs, or ideals (Stroebe et al., 2008). Physical symptoms associated with grief may include but are not limited to pain, digestive upset, muscle tension, body aches, and nausea. Emotional symptoms of grief may include sleep disturbances, eating problems, mood fluctuations, sadness, relief, anxiety, anger, and guilt (Stroebe et al., 2008). Bereavement is the process that individuals live through after the death of someone significant and during which grief is experienced and expressed. For the purpose of this study, we will apply these definitions of grief and bereavement to ADRD caregivers who lost family members with ADRD to death in long-term care. (Stroebe et al., 2008).

The grief that the ADRD caregivers experience is quantitatively and qualitatively distinct due to the prolonged and progressive course of illness, the failure to recognize dementia as a terminal illness, and the potential loss of care recipient personhood associated with the disease from the perspective of the caregivers (Givens, Prigerson, Kiely, Shaffer, & Mitchell, 2011; Ott, Sanders, & Kelber, 2007). Prior to the death of their family members, ADRD caregivers experience a phenomenon referred to as "chronic grief" because they experience a variety of losses, which are associated with their family member's advancing dementia for long periods of time (Boss, 2011). Following the death of persons with ADRD, surviving family members may enter into the bereavement period with a reduced ability to cope as a result of their prolonged caregiving demands and chronic grief experiences. Although grief and bereavement are most often experienced as a natural process without lasting physical and emotional health impacts, for some ADRD caregivers, grief and bereavement are associated with increased risk for both physical and emotional health impairments as well as mortality (Givens et al., 2011). Up to 20% of bereaved ADRD caregivers experience grief reactions that are considered prolonged and/or exacerbated, a syndrome referred to as complicated grief (Schulz et al., 2003; Shuter et al., 2014).

The Impact of LTC Placement on ADRD Caregiver Grief and Bereavement

The vast majority of individuals with ADRD will require LTC placement as their dementia progresses and an overwhelming number of these individuals will reside in LTC settings at the time of their death (Alzheimer's Association, 2016; Mitchell et al., 2005). There is very little evidence examining the grief and bereavement experiences of ADRD caregivers whose family members die in LTC settings. The evidence available suggests that LTC placement impacts ADRD caregiver grief and bereavement (Givens et al., 2011) and that the relationships between ADRD caregivers and LTC staff have an influence on the grief and bereavement experiences of ADRD caregivers (Shuter et al., 2014). In particular, the evidence suggests that LTC staff play a pivotal role in shaping the final memories that ADRD caregivers have of their family members and that conflicts between LTC staff and ADRD caregivers may result in increased emotional upset and trauma that remain with some ADRD caregivers well past their family members' death (Shuter et al., 2014).

Description of the Study

Our study aimed to address the existing gap in the state of the evidence by using a qualitative design to explore ADRD caregivers' process of grief and bereavement following their family members' death in LTC and to develop a theoretical model of this process.

Research Question: What is the grief and bereavement process that ADRD caregivers experience following the death of their family members in LTC settings?

Research Design

Grounded Theory was utilized for this study because there was no evidence identifying the grief and bereavement process that ADRD caregivers experience following their family members' death in LTC settings. The intent of Grounded Theory is to generate and validate a theory based upon the narratives of those individuals who experience a similar phenomenon (Charmaz, 2006). Grounded Theory consists of "systematic yet flexible guidelines for collecting and analyzing qualitative data to construct theories 'grounded' in the data themselves (Charmaz, 2006, p 2). The basic assumptions of Grounded Theory include: 1) the idea that people who share common experiences often apply similar meaning to the experience and elicit similar behaviors; 2) individuals who share a common experience share a similar psychosocial problem that they are attempting to resolve but may not articulate; and 3) this shared psychosocial problem is resolved through a psychosocial process (Draucker, 2015). This study offers a theoretical model of the grief and bereavement process that ADRD caregivers experience following the death of their family members' in LTC settings. Subsequent studies will continue to modify and adapt this proposed theory.

Methods

The first step in a Grounded Theory study is for the researcher to begin to explore a general research phenomenon. The primary investigator in this study was exposed to ADRD caregiver grief and bereavement through clinical practice as well as personal experience.

Participants and Recruitment

Participants in this study included former ADRD caregivers whose family members died in LTC settings. Inclusion criteria were: (a) former ADRD caregiver over age 21 years; (b) family member died with ADRD with or without hospice involvement at end-of-life; (c) family member died in a LTC setting; (d) caregivers possessed the necessary equipment (personal computer, tablet, Smartphone, or telephone) and internet-based video conferencing capability (including video camera) if applicable, and (e) caregivers had an available private setting for data collection.

Table One: Characteristics of Caregivers

ID	Caregiver/ family member	Caregiver age at time of interview (years)	Time elapsed since death of family member (years)	Interview type	Hospice use
1	D/M	53	0.20	Telephone	N
2	GD/GF	30	1.10	Skype	N
3	D/F	46	2.10	Telephone	N
4	FS/MS	77	4.20	FaceTime	N
5	D/M	57	2.00	FaceTime	N
6	GD/GF	41	0.36	Skype	N
7	D/M	56	7.50	Telephone	N
8	D/F	66	0.40	Telephone	N
9	D/M	57	2.00	FaceTime	N
10	S/M	68	5.20	Telephone	N
11	D/M	64	6.00	Telephone	Y
12	D/M	57	6.20	Telephone	Y
13	D/M	64	6.13	Face Time	Y
14	D/M	64	1.84	Telephone	Y

15	D/F	62	2.80	Telephone	Y
16	D/F	59	2.82	Telephone	Y
17	D/F	61	1.39	Telephone	Y
		M=89.91, SD=5.36	M=2.98 SD=2.22		

D=daughter, S=son, M=mother, F=father, GD=grand-daughter, GF=grandfather, FS=female spouse, MS=male spouse

ADRD caregivers were recruited from 3 Internet websites/forums after we received Institutional Review Board approval from the Rush University Office for Research Compliance (Arruda, Paun, & Hamilton, 2017). Individuals interested in participating in the study contacted the primary investigator (PI) via email. The PI conducted introductory telephone calls to screen potential participants for eligibility, to explain the study, and to answer any questions caregivers may have about the study. No incentives were utilized for participation in this study. From November 2015- January 2016, we recruited caregivers whose family members died in LTC settings without hospice services (*n*=10) (Arruda et al., 2017). From February 2017- June 2017, we recruited an additional 7 caregivers whose family members died in LTC settings and received hospice services provided by an agency independent of the LTC facility (Arruda et al., 2017). A 3-stage sampling plan was utilized for this study based upon established grounded-theory methods (Charmaz, 2006). The first stage of the sampling plan included obtaining a convenience sample of former ADRD caregivers whose family members died in LTC settings include (n= 5) in order to identify the scope and dimension of the problem of ADRD caregiver grief and bereavement (Draucker, 2015). The second stage of our sampling plan included the recruitment of a purposive sample of caregivers (n=5) which demonstrated characteristics consistent with the emerging theoretical model of ADRD grief and bereavement. The third stage of our sampling plan included theoretical sampling, (n= 7) where information-rich cases were analyzed that manifested the phenomenon of ADRD caregiver grief and bereavement intensely (Draucker, 2015). During theoretical sampling, we also analyzed cases that were unusual or atypical.

Our final sample included adult-children (*n*= 14), adult-grand-children (*n*= 2), and one spouse. Participants were all Caucasian and resided in the United States (*n*=16) and Canada (*n*=1). The vast majority of participants were female (*n*=16) and ranged in age from 30-77 years of age (M=56.94, SD=10.74). Care recipients ranged in age from 80-97 years (M=89.81, SD=5.36) and had resided in LTC for an average of 2.98 years (SD= 2.22) prior to their deaths. Prior to LTC placement, participants had provided care at home for an average of 5.63 years (SD= 3.77). There were no demographic differences between those caregivers whose family members received hospice services from an agency independent of the LTC facility (*n*=7) compared to those that did not receive hospice services at all (*n*=10).

Data Collection and Analysis

We obtained signed informed consent forms and Health Information Portability and Accountability (HIPPA) notices from all participants prior to data collection. The PI collected demographic information from all participants via telephone and maintained this de-identified data in a double-password protected electronic file. In total, the PI conducted 17 in-depth individual interviews based on an interview guide at dates and times convenient to the participants. Five interviews were conducted via Internet –based video conferencing and 12 were conducted via telephone based on participant preference. Interviews were audio-recorded and transcribed verbatim by the PI and stored in DeDoose© (a qualitative data management software platform). The interviews ranged in length from 26- 54 minutes (M=41.38, SD=9.20). The PI recorded field notes following each interview, which recorded visual data concerning body language and environmental factors for all interviews conducted by Internet-based video conferencing and voice tone and background noise for all telephone interviews. We noticed no evidence of differences in the quality or quantity of information shared by those interviewed by Internet-based video conferencing versus those interviewed via telephone.

Table Two: Interview Questions

Question	Content
One	Take me back to the final days of your family member's life. What happened? What were you thinking/feeling?
Two	Did you have the sense that death was imminent?
Three	As you look back on the death of your family member, what has helped or not helped you?
Four	What (if any) impact did the LTC staff play in your experience with this death?
Five	What advice would you give to professionals who are working with caregivers who have had a similar situation to yours?

Data collection and analysis were conducted concurrently in congruence with Grounded-Theory methodology (Charmaz, 2006). Using Charmaz (2006) as a methodological guide, data was coded in a 4-level format. Level 1 (initial coding) was conducted as the PI began data analysis by reading each of the transcripts in their entirety. In level 1 (initial coding), the transcripts were analyzed and coded line by line to identify common concepts within the phenomenon of ADRD caregiver grief and bereavement following family member death in LTC. Every line of each transcript was assigned an initial code, which represented the idea or experience expressed by the participant. Level 2 (focused coding) utilized constant comparison analysis to identify the most commonly reoccurring codes among and between the transcripts and continued throughout the data collection/data analysis. Level 3 (axial coding) was performed to identify relational propositions among the themes and concepts of the emerging model. During Level 3 coding, similar categories and themes were combined allowing our analysis to move beyond description of the phenomenon towards theoretical model formulation. Level 4 (theoretical coding) was conducted by the PI to further examine the theoretical themes and concepts and develop the theoretical model. Two senior members of the research team reviewed the data analysis throughout the study to confirm that appropriate theoretical assumptions had been made by the PI.

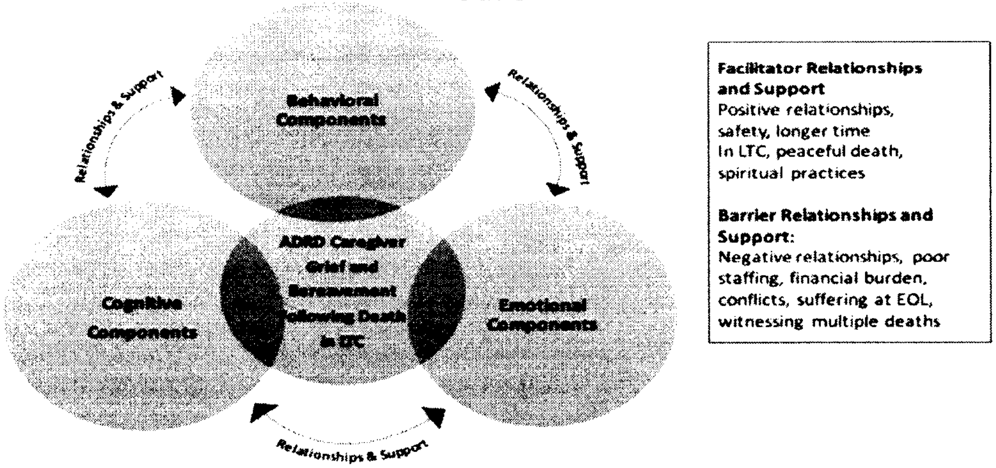
The PI continued data collection and analysis concurrently utilizing constant comparative analysis until data saturation was achieved, which occurred at the conclusion of the 15th interview. The PI conducted two additional interviews following data saturation. These interviews were transcribed but not analyzed until the final theoretical model was identified. After consensus was obtained among the research team on the theoretical model, the final two transcripts were analyzed to ensure model fit. Additionally, the final model along with the concepts, themes, and sub-themes were reviewed by a nurse researcher uninvolved in the study but who had extensive experience in grounded theory research to ensure clarity, consistency, and parsimony. A sub-sample (n=2) of the participants reviewed the final model to ensure credibility and confirmability and all agreed that our theoretical assumptions were valid and that the model appropriately represented their experiences. The PI maintained a memo-driven audit trail throughout the study, which documented her thoughts on data categorization, data consolidation, themes, questions, and decisions made concerning the emerging model.

Results

The analysis revealed the process of grief and bereavement that ADRD caregivers experience following the death of their family members in LTC settings. This process consists of three major components (behavioral, cognitive, and emotional) that were non-linear and interrelated. Relationships and support mechanisms united the three major components. Experiences around end-of-life care and LTC placement were identified as factors influencing the process of ADRD caregiver grief and bereavement.

Figure 1

Model of ADRD Caregiver Grief and Bereavement Following Family Member Death in Long-Term Care



Facilitator Relationships and Support
Positive relationships, safety, longer time In LTC, peaceful death, spiritual practices

Barrier Relationships and Support:
Negative relationships, poor staffing, financial burden, conflicts, suffering at EOL, witnessing multiple deaths

ADRD= Alzheimer's disease and other dementias
LTC= Long-term care

Behavioral Components of ADRD Grief and Bereavement

Behavioral components of ADRD grief and bereavement were defined as the physical activities undertaken and the verbal exchanges expressed by the caregivers. Behavioral components of ADRD caregiver grief and bereavement following family member death in LTC settings were multifaceted, as they included a number of sub-components which included: communication, conflicts, and death rituals.

Communication

Communication occurred within oneself and/or with LTC staff, family members, physicians, hospice staff, and friends. Communication was usually positive but for some participants it was negative. The negative or absent communication often resulted in emotional upset for the caregivers, which worsened their grief and bereavement and persisted for up to 2 years following family member death. Examples of negative communication included:

> "The Administrator never stopped in to say a word but yet, she joked around at the nurse's station in the hallway and my dad was dying in his bed ... That is just hurtful to the family and after 5 years and you know all of these people who are like family to you and then when you are grieving ... when you are going through the most heartbreaking time, they just weren't there. It felt horrible. It was painful." **Daughter, age 54, without hospice**
>
> "The LTC staff were not there for me ... nobody asked how we were doing and then after she died, it was like so matter of fact. [They said] what funeral home do you want? I was like OK ... is that it?" **Daughter, age 53, without hospice**
>
> "After my mother died, I started receiving form letters from hospice agency and that didn't really help. I am not a form letter person and I was very offended by them. I never had any personal phone call or interaction from hospice after she died and I thought that was horrible and then it dawned on me that they were compassionate and kind to the patient but to the family, they were just doing their job." **Daughter, age 64, with hospice**

Conflicts

Unresolved conflicts between the caregivers, family members, LTC staff/administrators and/or hospice staff resulted in significant emotional upset for the caregivers following their family members' death. Examples of unresolved conflicts predominantly centered around family discourse, dissatisfaction with care provided in the

LTC facility, unmet care recipient end-of-life needs, and the inability to receive hospice services from agencies independent of LTC facility.

> "My mother had a pacemaker and [at the end] her battery was going to timeout ... We had a big family meeting and my brother said, 'Oh, so you are going to murder her? You are going to kill her?'" **Daughter, age 57, without hospice**

> "We were robbed of a lot because we had to spend so much time taking care of her and fighting for her [at the LTC] and that is what I am so angry about. Going in and me having to do nursing care when I just wanted to be with my Mom is unforgivable ... I am angry. I am so angry about it and I stuff it inside most of the time." **Daughter, age 66, without hospice, professional nurse**

> "As it became more and more difficult for my mother to breath and she hadn't had any liquids or nourishment and she was dry and dehydrated, then it seemed uncomfortable for her. So for me, I was nervous for her because I really did not want her to suffer. I was also angry...angry at the nursing home because they were just ignorant. I think they failed her and they failed us." **Daughter, age 68, without hospice**

> "I asked for hospice but he wasn't eligible so I never asked again. The doctor finally prescribed it but they cut me off at the reception desk and I never got any further. My sister also tried to get hospice and her husband is a doctor. It didn't change anything. Finally, in the end and when he was dying, the LTC staff called hospice, and they were there but honestly it caused more problems ... It was more of an irritation for the LTC staff more than it was a help". **Daughter, age 59, with hospice**

> "We were denied hospice either two or three times and then I finally gave up trying to resolve this [conflict] and I said, '**I** will be hospice' ... so I was the hospice nurse and the daughter and that was hard." **Daughter, age 57, without hospice, professional nurse**

> "Well let me tell you, we were supposed to get hospice and it took like 4 days to get it all together... and she died in 3 [days]. It was very frustrating because when you need hospice, you **need** hospice." **Daughter, age 56, without hospice**

Death Rituals

Participants described a variety of death rituals that accompanied the loss of their family member, which typically assisted them with their grief and bereavement. These death rituals included writing eulogies, wearing black, going through the deceased's belongings, resolution of wills/probate, attending funerals and memorial services, sitting vigil with the family member at end-of-life, and visiting the cemetery. Participants regularly talked about a variety of death rituals that appeared specific to LTC settings which included: 1) being asked to remove the family member's belongings from the LTC setting too soon (sometimes within moments of the actual death); 2) the receipt of special supplies/linen to be used at end-of-life; and 3) the need to re-visit the LTC setting after family death to offer thanks for the care provided to the deceased.

One surprising finding was the frequency with which caregivers reflected upon what was referred to as a "hospitality cart". The hospitality cart was described by several participants as a small metal cart on which coffee, tea, and snacks were provided for the family who were sitting vigil. This hospitality cart elicited a wide variety of emotions by the participants.

> "The hospitality cart ... the cart itself it is a scary thing. I mean, it is a metaphor for death to put it plainly ... From time to time, we would see it in the hall and when you do [see it] you have compassion for the family because you know they are holding a vigil. But you know, when it is your time, you would like that cart too ... and if you don't get it, it is a slap in the face to the resident. It is like saying your family member doesn't matter." **Daughter, age 46, without hospice**

> "That night they had this courtesy cart that they brought in that was fully loaded down ... as if there was a whole family instead of it just being me ... I thought to myself that they wasted their time making a whole pot of coffee because it was just me." **Daughter, age 53, without hospice**

Another surprising finding was the frequency with which the participants reflected upon their memories of being around others' death often while visiting the LTC facility.

> "I saw death regularly. Some of the caregivers would talk about that fact that we would come in and people you would normally see were all of a sudden gone." **Daughter, age 64, with hospice**

> "A lot of residents passed away before my grandfather and we had to say goodbye to them and they had become … those men and women became part of our extended family. And so, we saw other deaths a lot. Over 5 years you are going to see other deaths and it is quite sad. It is very sad." **Granddaughter, age 26, without hospice**

The behavioral components of ADRD caregiver grief and bereavement (communications, conflicts, and death rituals) were experienced simultaneously and appeared to be impacted by the cognitive and emotional components.

Cognitive Components of ADRD Grief and Bereavement

The cognitive components of ADRD grief and bereavement were defined as those thoughts and observations experienced by the caregivers throughout their grief and bereavement. These cognitive components of ADRD caregiver grief and bereavement included "balancing acts", memories, observations, and questions.

Balancing Acts

We use the term "balancing acts" to identify situations where caregivers reflected on the variety of ways they had to balance their attention, love, and support. The most frequently reported "balancing acts" included examining the cycle of life and death and knowing that although life goes on it is never the same as before death. Younger caregivers seemed especially reflective of the "balancing acts" comparing life and death.

> "He didn't know who he was. He didn't know if he was in the house or where he was but he could tell me about growing up and when he was a kid. I had time with him that I wouldn't have had otherwise. Back then I thought 'God, why are you putting us through this' and then and I would think 'Oh, I wouldn't trade this time for anything in the world.'" **Daughter, age 59, with hospice**

> "Grief is like this beautiful kind of [thing]. Loss doesn't stay forever. I mean, it does but it doesn't because it is like you lose and then you gain … Life and death are always right there next to each other." **Granddaughter, age 30, without hospice**

Caregivers among all age groups and relationships reflected on the challenges of moving forward and rebuilding their life after the death of their family member.

> After he died, I knew I needed to re-invent my life. It wasn't going to ever be the same again but it didn't need to be a black hole either." **Spouse, age 77, without hospice**

Memories

The cognitive component of ADRD grief and bereavement also involved recalled memories, which were either previously openly communicated or kept private prior to our interviews. Caregivers frequently reflected upon the difficulty of celebrating the holidays after the death of their family members as well as their memories around the decision to place their family members in LTC.

> "I remember how hard all of the 'firsts' were. When a holiday came [and] we were all together ... it was more of a sad occasion than a celebration because I didn't know how to fill that missing link". **Granddaughter, age 41, without hospice**
>
> I was also remorseful because Mom started out staying with my husband and I. She lived here for 6 years before her dementia got to the point where I could not...I had to make a choice between taking care of her and my job and we were not financially in a place where I could leave my work. I wished that I had found a way to make that work and that I had kept her here longer. So I have a lot of remorse about that. I thought of this a lot after she passed away. **Daughter, 57 years old, without hospice**

Observations

Caregivers further reflected upon their personal observations how grief was "different" among surviving family members and how grieving the loss of this individual was "different" than their previous grief experiences. A common circumstance that brought emotional upset to the caregivers involved their observations of the level of care provided to other LTC residents.

> "Mother could no longer feed herself so one of us would be there for every evening meal to make sure that she was fed because we didn't trust that the Aides would either feed or would feed her in a way that would not be comfortable for her. Because we were there every night and we saw how they were with some of the residents, either shoveling the food in their mouths real fast or walking away without really understanding whether the resident was finished with their meal or not." **Daughter, age 57, without hospice**

Observing end of life suffering brought tremendous emotional upset to some caregivers, especially for those caregivers that were also employed as registered nurses (n=3) This was an especially negative experience for one adult-daughter registered nurse caregiver.

> "I remember speaking to the nurse because we couldn't get hospice and my mother was suffering. The doctor wouldn't give us the order for hospice or for pain medication that we needed ... It was just a baby dose ... and I said to the nurse, 'If you give me 10 mg of Morphine, I will give it myself'... and then after she died, I said to that nurse 'this was a really bad death' and then she said to me 'I've seen worse'... I remember bursting into tears on my way home ... I was ashamed to be a nurse." **Daughter, age 57, without hospice, professional nurse**

> "I carried a lot of grief and guilt with me over that last night ... because of the pain and suffering ... I was feeling like I was a failure because I couldn't make them understand that this was not OK ... And to this day, in my mind, I keep thinking that there must have been another way." **Daughter, age 57, without hospice, professional nurse**

Questions

A significant number of caregivers questioned their own mortality and their personal risk for developing ADRD. This concern for developing ADRD was expressed by all caregiver relationships (adult-children, adult-grandchildren, and spouse) and by both male and female caregivers. Some caregivers expressed an interest in quantifying their risk for developing ADRD while other caregivers did not want to identify the likelihood of being diagnosed with ADRD in the future. The one male caregiver in our study provided very strong views regarding his wishes should he develop ADRD in the future.

> "I don't want to be a burden to anybody (as I define a burden). Living without cognition is not a life as far as I am concerned … [If it happens to me] I want to tell my family to pull the plug." **Son, age 68, without hospice**

Several female caregivers also expressed concern over the possibility of their developing ADRD but they did not discuss specific actions they would want taken by their family members should a diagnosis of ADRD be given to them in the future.

> "I wonder a lot if it is inevitable that I will get it [ADRD] too." **Granddaughter, age 41, without hospice**
>
> "A lot of people feel because if one person in the family has ADRD does that mean that everybody is going to get ADRD? People said, 'Would you like to have a test to check out if you are going to get it?' I mean, would you want that test? I chose absolutely not because there is no cure." **Daughter, age 56, with hospice**

The cognitive components of ADRD caregiver grief and bereavement ("balancing acts", memories, observations and questions) were expressly intertwined with both the emotions expressed and behaviors elicited by the caregivers.

Emotional Components of ADRD Grief and Bereavement

The emotional components of ADRD caregiver grief and bereavement were defined as the emotions felt by the caregiver during their grief and bereavement. Some emotions were openly shared by the caregivers, while other emotions were kept private by the caregivers prior to our interviews. We categorized these emotional components as positive, negative, and mixed.

Positive Emotions

Positive emotions included finding peace, gratefulness, thankfulness, feeling blessed, and feeling loved. The most commonly reported positive emotion was relief.

> "I was praying practically every night that God would take her because it was sad to see her at 67 pounds and so upset. I could only imagine … It was a relief. You know, I was crying needless to say but it was also a relief that she was out of pain, and so was I." **Daughter, age 59, with hospice**

> "It was a gradual letting go and really, you know (to be very truthful) it was a relief. With him it was a relief act that he was finally able to let go because he just wasn't really having a good quality of life." **Daughter, age 55, with hospice**

Negative Emotions

The vast majority of emotions that were expressed by the caregivers were negative, and included among many, fear, anger, unwelcomed surprise, guilt, fatigue, exhaustion, depression, loneliness, abandoned, orphaned, ashamed, bitter, embarrassed, disappointed, frazzled, heartbroken, stressed, jealous, feeling like a failure, feeling lost, worried, vulnerable, and unprepared for death. Several caregivers of all ages and relationships appeared to be taken by surprise when their family member had died despite years of prolonged illness and the need for LTC placement.

> "His death, it came as a great surprise to me it really did and I think it was more because I thought **I** had more time, not that he had more time because he was living on borrowed time." **Granddaughter, age 41, without hospice**

Anger, remorse, and guilt were common negative emotions reported by many caregivers. These negative emotions remained with some caregivers for years following the death of their family member.

> "I was angry. My sister was really angry too. When I walked out of there [LTC], I thought to myself that I will never come in this place again because I am so angry and so bitter.' **Daughter, age 57, without hospice, professional nurse**

> "I was remorseful because we placed Mom in LTC … I wished that I could have taken her back home, especially when [the LTC] failed her with nursing care (which happened often). I thought a lot about that after she passed." **Daughter, age 57, without hospice**

> "I feel guilty because I was not more loving in a demonstrative way to my mother when she was dying." **Son, age 68, without hospice**

Mixed Emotions

Caregivers also reported mixed emotional responses that impacted their grief and bereavement.

> "What was I feeling? It bounced all the way from acceptance to 'No. I am not ready for this' to 'Yes I am ready' because this is not my Mom. This is just some old lady in a wheelchair." **Daughter, age 53, without hospice**

Although the average time between the caregiver interviews and the death of their family members was 2.9 years, recalling these emotions still often resulted in our female participants crying and then apologizing for "being emotional".

Relationships and Support

Our analysis suggests that relationships and support tie the 3 main components (behavioral, cognitive, and emotional) of ADRD grief and bereavement following family member death in LTC together. The elements that determined helpful versus unhelpful relationships and support varied among caregivers. Overall, helpful relationships and support assisted caregivers with their grief and bereavement. Unhelpful relationships and lack of support created difficulties for surviving ADRD caregivers during their grief and bereavement.

Relationships:

The relationships that impacted ADRD caregiver grief and bereavement took many forms. Some of these relationships were ongoing, others changed in some way as a result of prolonged caregiving and the need for LTC placement, many were lost due to death, and a few never developed. We categorized these ADRD caregiver relationships as either general relationships (friends, the family member with ADRD, other family members, God/a higher power, ADRD caregiver support groups) or specific LTC relationship (LTC staff, LTC administration, physicians, and hospice staff). On-going positive relationships with friends/family and with God provided support for a significant number of the caregivers.

> "The support of family and friend [has helped me]. There are 3 other women my age who are widows. We don't like that word, but that is what we are." **Spouse, age 77, without hospice**

> "I don't know what I would have done without my religion. It helped with the aloneness. I don't quote well from the Bible but it says 'You're never alone. I'll never leave you and I'll never forsake you" so that is what I keep telling myself." **Daughter, age 59, with hospice**

Helpful relationships with LTC staff was found to provide comfort for ADRD caregiver grief and bereavement.

> "We had great care staff and I knew most of them by name. You know, at the point at which you know you have really built relationships with the people at the nursing home, that helps too because they... I don't know. I feel like when you are a nurse, it is not just about caring for the patient. It is kind of about caring for the family too." **Granddaughter, age 30, without hospice**

Support:

Caregivers noted a variety of support mechanisms that assisted them with their grief and bereavement. Caregivers found support both within themselves and with/from others. The most common forms of support were received from social connection with others, which were in experienced both in-person and virtually through the Internet. Other forms of support came from creative outlets and hobbies (singing, painting, cooking, gardening, and reading).

> "I listen a lot to music that we liked ... and I read his love letters and I write letters to him ... Initially I wrote often but I go to my book now and I go 'Oh. I haven't written to you in about 3 months or more'... I guess that is probably a good sign, because I am learning to get along without him." **Spouse, age 77, without hospice**

> "Those people on the website were my lifeline. There was nobody near me. I'd never known anybody going through this." **Daughter, age 68, without hospice**

Unhelpful or missing relationships and support created emotional upset for caregivers during their grief and bereavement. Four caregivers reflected on support they had wished for but never received.

> "I didn't get a card. I didn't get anything from them [the LTC staff] ... When you are paying $8,500 a month, the least they [LTC staff] could do is show compassion, and don't call and say 'When are you gonna get her things out'. **Daughter, age 64 with hospice**
>
> "It was really shocking that friends that we thought were close, when we needed something... they just weren't able to do it. They didn't want to know what we going through." **Daughter, age 64, with hospice**
>
> "Grief is hard because people don't want to talk about it. You know friends and family are there at the time that [death] happens and then they think like a week later, that it is just going to go away." **Daughter, age 46, without hospice**
>
> "They [the nurses who came to the LTC setting from the hospice company] were standing there when I got to the nursing home but like I said, that didn't really feel like I had support ... The nurses from the hospice company didn't reach out to me at any time after her death. So like I said, hospice was good for her but I was not impressed for the caregiver." **Daughter, age 64, with hospice**

Discussion

The grief and bereavement experienced by ADRD caregivers following family member death in LTC is very complex because it is a phenomenon that is comprised of behavioral, cognitive, and emotional factors. Our findings show that ADRD caregivers whose family members die in LTC settings experience grief and bereavement with a reduced ability to cope as a result of their prolonged caregiving demands and chronic grief experiences. Consistent with previous studies (Boss, 1999; Givens et al., 2011; Zisook & Shear, 2009), the evidence from our study further supports the fact the grief and bereavement process these caregivers experience lingers for years following family member death in LTC settings.

The phenomenon of ADRD caregiver grief and bereavement is particularly multifaceted because it is a process both openly shared and kept private by the caregiver and is impacted further by both LTC placement and hospice utilization. Our results support previous research findings that identified a variety of barriers to obtaining hospice referrals for individuals with end-stage ADRD, which prevent and/or delay hospice utilization (Kiely, Givens, Shaffer, Teno, & Mitchell, 2010). Our study expanded on the findings of Kiely et al. (2010) by examining the impact that delayed or failed hospice utilization had on ADRD caregiver grief and bereavement. The evidence indicates that failure to obtain hospice services significantly impaired the caregivers' grief and bereavement process because these caregivers were more likely to witness their family members in pain and suffering at end-of-life. Relationships with LTC staff and administration played a critical role in ADRD caregiver grief and bereavement. Our findings supported previous research that identified that positive caregiver: LTC relationships assisted with ADRD caregiver grief and bereavement while negative caregiver/LTC relationships created emotional upset for ADRD caregivers during grief and bereavement (Albinsson & Strang, 2003; Shuter et al., 2014).

Based on our review, we believe ours to be the first study that formally explored the grief and bereavement process that ADRD caregivers experienced following family member death in LTC. This research fills a critical gap in the evidence by exploring a previously unknown phenomenon that impacts an estimated 70% of all ADRD caregivers. Our theoretical model depicts this complex, non-linear phenomenon parsimoniously, allowing for the integration and utilization of the model by the nursing discipline.

Our study revealed several unexpected findings. One unexpected finding was the lingering toll that failed hospice referral attempts had on the emotional health of surviving caregivers, which were particularly worrisome for one our participants who described herself as a registered nurse. Another unexpected finding was that even those caregivers whose family members died peacefully while receiving hospice services often felt a complete lack of grief and bereavement support from both the LTC facility and the external hospice providers following their family member's death. The impact of the "hospitality cart" on grieving ADRD caregivers was a final unexpected finding. We found no other study that uncovered the significance of this common nursing intervention. Some caregivers found receipt of the hospitality cart helpful and comforting while other caregivers found it to be unhelpful and frightening.

Limitations of this study include the small homogenous sample of ADRD caregivers studied. Despite our recruitment efforts, we were unable to advance the evidence beyond the study of Caucasian and predominantly adult-daughter caregivers. Therefore, we are unable to generalize our findings to a broader population of ADRD caregivers. Another limitation of this study is that our recruitment occurred via the Internet. For this reason, the experiences of the caregivers studied may not reflect those of caregivers who do not utilize the Internet to obtain health information or social support.

Future research should expand upon our findings by examining the phenomenon of ADRD caregiver grief and bereavement following family member death in LTC with a larger sub-set of the ADRD caregiver population. Future research should also aim to uncover more information surrounding the barriers to hospice utilization by individuals with ADRD who reside in LTC settings. Opportunities also exist to further explore this phenomenon with ADRD caregivers who are also employed as professional nurses, as this sub-set of our sample had higher levels of emotional upset during the interviews compared to non-nurses. Finally, the use of the "hospitality cart" should be examined as a possible grief and bereavement intervention for ADRD caregivers whose family members die in LTC.

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