Published in final edited form as:

Am J Geriatr Psychiatry. 2019 April ; 27(4): 408–416. doi:10.1016/j.jagp.2018.10.018.

Feeling Relieved after the Death of a Family Member with Dementia: Associations with Post-Bereavement Adjustment

Sarah T. Stahl, PhD¹ and Richard Schulz, PhD^{1,2}

¹Department of Psychiatry, University of Pittsburgh School of Medicine, Pittsburgh, PA.

²University Center for Social and Urban Research, University of Pittsburgh, Pittsburgh, PA.

Abstract

Introduction: After an extended period of caregiving, the death of a family member with dementia can provide a sense of relief to individuals because caregiving has ended and their loved one is no longer suffering. Little is known about pre-death factors associated with feeling relieved after the death of a family member with dementia. This study examined: (1) pre-death factors associated with caregiver relief; and (2) whether caregiver relief is associated with post-bereavement adjustment, namely complicated grief and depression symptoms.

Methods: Participants were bereaved caregivers (CG) aged 28 – 90 years old, drawn from the Resources for Enhancing Alzheimer's Caregiver Health study (REACH, N = 223) and the Family Caregiver Transition Support study (FaCTS, N=89). In each sample, demographics were assessed at baseline and CG relief was assessed at the first follow-up assessment post death. Each study administered a similar bereavement battery to CGs following the death of their care recipients (CR).

Results: CGs of late-stage dementia patients (FaCTS) reported more relief compared to CGs of early- to mid-stage dementia patients (REACH). CGs were more likely to experience relief if they were prepared for their CR's death and if they perceived their CR's death to be a relief for the CR. A multivariate regression model showed that greater CG relief was associated with less complicated grief post-bereavement. CG relief was not significantly associated with depression symptoms.

Conclusions: We show prospectively that the caregiving experience impacts feelings of relief and that feeling relieved facilitates post-bereavement adjustment by lessening symptoms of complicated grief.

Keywords

aging; dementia caregiving; grief; relief model of bereavement

Address correspondence to: Sarah T. Stahl, PhD, Department of Psychiatry, University of Pittsburgh, 3811 O'Hara Street, Pittsburgh, PA 15213. **Twitter:** @SarahTStahl sarah.stahl@pitt.edu.

Conflicts of Interest

Drs. Stahl and Schulz have nothing to disclose

Publisher's Disclaimer: This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final citable form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

INTRODUCTION

Many family caregivers (CGs) show resilience in adapting to the death of a loved one for whom they were providing care ¹. In the first year following the death of a care recipient (CR), psychiatric symptoms like complicated grief and depression typically improve and return to normal levels. Possible mechanisms for this effect include having greater time to prepare for the CR's death, the end to the suffering of the CR, and relief from the burdens associated with caregiving. Existing research linking CG psychiatric symptoms to features of the caregiving experience typically focus on the level of preparedness or exposure to CR suffering ²⁻⁴. In this report, we focus attention on the feelings of relief as a key contributing factor to CG's psychological wellbeing post-bereavement.

The relief model of bereavement ⁵ proposes that relief is common when it is precipitated by heavy caregiving as the burdens associated with providing care are now alleviated. Caregivers experience less strain and can return to pre-caregiving roles. The end of heavy caregiving also frees psychological resources that allow CGs to better adjust to CR's death. Many aging services that offer support material to bereaved individuals (e.g., hospice foundations, AARP) report that positive feelings of relief are a normal, yet sometimes uncomfortable emotion following the death of a loved one.⁶ An important implication of the relief model is that feeling relieved should improve the long-term psychological wellbeing of bereaved individuals. However, this has never been studied before.

Feelings of relief may be particularly pronounced in dementia CGs ⁷. Compared with other types of CGs, dementia CGs spend more time delivering care, experience more strain while delivering care, and experience more psychiatric symptomatology pre-bereavement ^{8,9}. The challenges with dementia caregiving can become more extreme as the CR nears death. Feeling relieved after the CR's death may play a critical role in CG's psychiatric health because dementia caregiving is often overwhelming and exhausting.

The goal of this study is to (a) prospectively assess pre-death factors associated with CG relief; and to (b) examine its relation to post-bereavement adjustment, namely depression symptoms and complicated grief, a psychiatric disorder characterized by persistent and disruptive yearning, and longing for the deceased.¹⁰ We examine CG relief in two different study samples that together represent a continuum in the dementia caregiving trajectory. One sample of CGs was providing caring for CRs with mild- to moderate dementia; the other sample of CGs was providing care for CRs with late-stage dementia who were institutionalized and closer to death. We predicted greater relief in CGs who were providing care for CRs with late-stage dementia. We also predicted that feeling relieved (in both samples) would be associated with less complicated grief and fewer depression symptoms. We also explored the role of and CR functional status and preparedness for death as possible predictors of CG relief.

METHODS

Study design overview

This paper is based on secondary analyses of data collected from two randomized controlled trials (RCT) designed to enhance family caregiving: the Resources for Enhancing Alzheimer's Caregiver Health study (REACH, 1995–2001) and the Family Caregiver Transition Support – Nursing Home study (FaCTS, 2007–2012).

REACH was a multi-side RCT of multiple different interventions for family caregivers of persons with Alzheimer's disease at the mild or moderate level of impairment¹¹. The interventions implemented across the six sites included: individual Information and support strategies, group support and family systems therapy, psychoeducational and skill-based training approaches, home-based environmental interventions, and enhanced technology support systems. Baseline and follow-up data, as well as introductory information and the codebook, were downloaded from the National Archive of Computerized Data on Aging. More detailed information about sample characteristics and interventions is available elsewhere¹².

The FaCTS RCT assessed the effects of a psycho-education intervention on CG adjustment to having their CR placed in a long-term care facility.¹³ In the intervention condition, CGs received a multicomponent intervention designed to target three areas of need: knowledge and procedures of nursing homes, advanced care planning, and emotional well-being. In the information-only control condition, family CGs received treatment as usual with the addition of written documents on where to find information in the areas of need identified for the active treatment intervention. A detailed description of the intervention and intervention outcomes can be found in Schulz et al., 2014.

In both RCTs, interventions were delivered over a 6-month period. CG follow-up assessments were carried out 6-, 12-, and 18-months after the baseline assessment. Both studies administered a similar bereavement battery to CGs following the death of their CR. For this study, we used the last available measurement point prior to death and the first available measurement point after death. For example, if a care recipient died at 16 months after the baseline assessment, we would use the 12-month data as the pre-death assessment and 18 month data as the post-death assessment. Group assignment to either treatment or control condition was used as control variable in all analyses using post-treatment follow-up data.

Participants and procedure

CGs were self-identified as the individual providing the most instrumental and emotional support to the CR. A total of 1222 caregiver-care recipient dyads were recruited for participation in REACH (Wisniewski et al., 2003). Two hundred sixty-five CRs died during the course of the REACH trial; bereavement data were available for 223 CGs. Thirty-eight percent of CRs died in a hospital; 30% died at home; 26% in a nursing home. Deaths were distributed evenly across waves (number of deaths between baseline and 6-month follow-up = 77 (35%); 6 – 12 month follow-up = 63 (28%); 12 – 18 month follow-up = 83 (37%).

In FaCTS, a total of 217 caregiver–care recipient dyads were randomized for participation. Eighty-Nine CRs died during the course of the FaCTS trial; bereavement data were available for 85 CGs. All CRs died in a nursing home. Deaths occurred earlier in FACTs, but this is expected given that CRs were more physically and cognitively impaired (number of deaths between baseline and 6-month follow-up = 50 (59%); 6 – 12 month follow-up = 19 (22%); 12 – 18 month follow-up = 16 (19%). The focus of this report are the 223 CGs of early- to mid-stage dementia patients (REACH) and 85 CGs of late-stage dementia patients (FaCTS).

Measures

Our primary goal in this study was to examine correlates and predictors of CG relief, complicated grief, and depression symptoms, which were treated as outcomes in multivariate models. Both outcomes and predictors are described below.

Caregiver relief.

A single item was used to measure CG relief at the first measurement point post-death. CGs were asked, “To what extent was CR’s death a relief to you?” Response options were “not at all,” “somewhat,” and “very much.”

Complicated grief.

The Inventory of Complicated Grief was administered at each measurement point post-death. For each statement (e.g., “I feel I cannot accept the death of my spouse”), CGs were asked to report whether they currently felt this way on a scale from 0 (never) to 4 (always). The 32-item version was administered in REACH; the revised 19-item version was administered in FaCTS. Scores range from 0 through 79 (or 128 on the 32-item scale) with higher scores indicating pathological grief, such as anger disbelief, and hallucinations. Scores of ≥ 25 (on the revised 19-item scale) have been recommended as cutoffs for designating individuals at high risk for clinical care. Cronbach’s α was 0.94 in REACH and 0.91 in FaCTS.

Depression.

The Center for Epidemiologic Studies Depression (CES-D) Scale was used to assess depression in CGs. Using the previous week as a reference, respondents rated each item on a scale from 0 (experienced rarely or none of the time) to 3 (experienced most or all of the time). The 20-item version was administered in REACH; the 10-item version was administered in FaCTS. Scores range from 0 through 60 (or 30 on the 10-item scale), with higher scores indicating increased presence of depressive symptoms; a score of 16 or higher (equivalent to 8 or higher on the 10-item scale) is widely interpreted as being at risk for clinical depression. Cronbach’s α was 0.76 in REACH and 0.87 in FaCTS.

Correlates and predictors of CG relief

Sociodemographic characteristics included CG age, sex, race/ethnicity, years of education, and CGs relationship to CR (spouse, adult child, other family member).

Caregiving characteristics included (1) preparedness for death, (2) CR functional status, and (3) CR relief. Preparedness for death was measured retrospectively in REACH and

prospectively in FaCTS, using a single item. In REACH, CGs were asked, “To what extent were you prepared for CRs death?” In FaCTS, CGs were asked, “If your loved one were to die soon, how prepared would you be for his/her death?” Response options for both items were “not at all,” “somewhat,” and “very much.” CR’s functional status was used as a proxy for heavy or strained caregiving. CR functional status was measured prospectively in each sample by administering an Activities of Daily Living (ADL) scale (6-item scale in REACH; 7-item scale in FaCTS); the scale asked CGs to indicate whether the CR needed help with each ADL. Finally, CR relief was used as a proxy for exposure to suffering. This was measured at the first measurement point post-death and with a single item that asked, “To what extent do you feel that CR’s death was a relief for him/her?”

Statistical Analyses

We first present descriptive statistics characterizing each sample’s participants. Next, ordinal regression was performed using a generalized linear model to predict CG relief. This is followed by multivariate regression models predicting post-bereavement complicated grief and depression at the first available measurement point after CRs death. We report the Nagelkerke R-square (or pseudo-R-square) effect size measure for ordinal regression and R-square effect size measure for linear regression and used well-known standards for interpreting the effects (0.02 is considered small, 0.13 is medium, and > 0.25 is large).¹⁴ In all analyses, we control for group assignment (intervention or control) to control for possible intervention effects. We also control for the number of days between CR’s date of death and the date of CGs first bereavement assessment to control for time since loss. All analyses were performed using SPSS, version 24.0, statistical software for windows.

RESULTS

Demographic characteristics of sample

Descriptive statistics for each sample are presented in Table 1. CGs were predominately White women whose mean age was 63 years ($SD=12$ years). CGs relationship to CRs varied between the two samples: REACH CGs were primarily spouses while FaCTS CGs were primarily adult children. In terms of CR functional status, REACH CGs were providing care approximately 13 hours per day while FaCTS CGs were providing care for highly impaired CRs with limitations in 6 of 7 ADLs. CG relief varied between the two samples. FaCTS CGs were more likely to report feeling “very much” relieved after their CRs death compared to REACH CGs. Mean values on the CES-D scale (16 on the 20-item scale in REACH; 8 on the 10-item scale in FaCTS) indicated that CGs were moderately depressed after the death of their CR; 42% (FaCTS) and 46% (REACH) of CGs were above the threshold for being at risk for clinical depression. Mean values on the inventory of complicated grief scale (80 on the 32-item scale in REACH; 14 on the 19-item scale in FaCTS) indicated a mild level of pathological or complicated grief.

Correlates of caregiver relief

Table 2 show the multivariate ordinal regression models that examined CG relief. The models included demographic variables and caregiving variables thought to be related to CG relief: preparedness for CRs death, CRs functional disability (strained caregiving), and the

perception that CRs death was a relief to him/her (perceived suffering of CR). In REACH, greater preparedness for CRs death and the perception that CRs death was a relief for him/her were significantly associated with CG relief. Younger age was also a significant correlate of CG relief. All other demographic main effects including age, sex, race, and education did not reach significance.

In FaCTS, results similarly indicate that greater preparedness for CRs death and the perception that CRs death was a relief for him/her were both significantly associated with greater feelings of relief post-death. Younger age, being male, and being African American were all significant correlates of CG relief. All other main effects including education, CG relationship, and CR functional disability, did not reach significance. The effect sizes in both RCTs were large (REACH $R^2 = .27$; FaCTS $R^2 = .38$).

Caregiver relief and adjustment to bereavement

Table 3 show the linear regression models that tested the relationship between CG relief and complicated grief and depression symptoms at the first available observation post-death. Models predicting complicated grief showed that CG relief was associated with complicated grief in both samples. The effect size was large in FaCTS ($R^2 = 0.30$); and medium in REACH ($R^2 = 0.18$). CGs who experienced more relief post death had lower levels of complicated grief. Less education and being the spouse of the CR, were significantly associated with greater levels of complicated grief in REACH CGs. Models predicting depression symptoms showed that CG relief was not a significant correlate of CES-D scores. CRs functional disability and being the spouse of the CR were significantly associated with a greater frequency of depression symptoms in FaCTS CGs.

Exploratory analysis

The relief model of bereavement⁵ states that feeling relieved after the death of a CR may also allow CGs to re-establish neglected activities such as engagement in leisure and social activities. Both RCTs allowed us to explore this hypothesis. In FaCTS, we re-ran our linear regression model using the Pittsburgh Enjoyable Activities Test (PEAT) as our outcome measure. The PEAT measures the frequency of engagement in ten pleasurable activities: sports; quiet time by yourself; attending clubs, church, or fellowships; hobbies; going out for meals with friends/relatives; visiting family and friends; doing other fun things with people; taking vacations out of town; being in parks and other outdoor settings; and „unwinding’ at the end of the day. CG relief was significantly associated with greater engagement in leisure activities post-bereavement ($\beta = .337$, $t = 2.598$, $p < .05$; $R^2 = .20$). No other main effects emerged significant (data not shown). In REACH, seven of these items were assessed and used as our outcome variable in a linear regression model. CG relief was not significantly associated with leisure activities ($\beta = .003$, $t = 0.038$, $p = .970$; $R^2 = .11$).

DISCUSSION

Existing research on feeling relieved after the death of a CR is scarce. Our goal in this study was to assess feelings of relief in two different samples of dementia CGs, identify pre-death predictors of CG relief, and assess its association with post-death adjustment.

We report three main findings. First, the level of relief was relatively high in our sample of CGs who were providing care to family members with late-stage dementia (FaCTS) compared to CGs of family members with mild to moderate dementia (REACH). This might be expected given the demands associated with end-of-life care and the extreme impairment of CRs with late-stage dementia. Many of these CGs continued to provide care after institutionalized placement which poses unique challenges to the intensity and types of care provided prior to death¹⁵.

Second, greater preparedness for CR's death and CR suffering prior to death were associated with CG relief post-death. CR suffering was the strongest predictor of relief in CGs of mid-stage dementia patients (REACH) while preparedness was the strongest predictor of relief in late-stage dementia patients (FaCTS). It seems likely that FaCTS CGs would be more prepared because their CRs were in the late stages of AD with very high levels of impairment requiring institutionalization. Demographic factors also played a role in FaCTS. Individuals who are younger, those who are men, and those who are African Americans were also more likely to exhibit greater feelings of relief after the CRs death. There are several possible explanations for these findings. Younger individuals have more competing demands (work and child care) compared to older individuals and may therefore feel more relief when caregiving ends.¹⁶ Younger individuals are more likely to be adult children as opposed to spouses and therefore are less attached than spouses. To the extent that feelings of relief are driven by the cessation of the pragmatic challenges of caregiving as opposed to sadness about the death of a love one, we would expect less attached individuals to report greater relief. Men may report greater relief than women because they have lower self-efficacy and feel less confident about their ability to handle the chronic demands and challenges associated with late-stage dementia caregiving.^{17,18} Compared to White CGs, Black CGs provide more care to CRs with memory and behavior problems yet are more likely to report positive aspects of caregiving and greater engagement in leisure, social, and religious activities which may contribute to why they experience positive feelings of relief.¹⁹ Support systems of Black CGs may be more effective in legitimizing feelings of relief.

Third, and as predicted, CG relief was strongly associated with complicated grief demonstrating that CG relief may be a protective factor against significant distress and impairment in CGs of both mid- and late-stage dementia patients. The effect sizes were larger in FaCTS than REACH. This finding supports the relief model of bereavement by showing that positive feelings of relief may ease the bereavement process and allow better adjustment to the CRs death, particularly among late-stage dementia caregivers. Contrary to our prediction, CG relief was not related to depression. Although we would expect relief and depression to be moderately negatively correlated, the mechanism underlying these feelings are possibly different. Feelings of depression are more likely to be driven by sadness over losing a close loved one while feeling of relief may be driven by the cessation of suffering in the care recipient and in the pragmatics of providing care to the CR. While symptoms of depression and complicated grief tend to co-occur in the bereavement period, they are distinct disorders with varying pre-disposing factors.¹ They are also treated in different ways. The only significant predictor of depression was the functional status of CRs in FaCTS (who were highly impaired and closer to death). If we assume that functional status

is correlated with caregiver strain, this finding is consistent with other studies showing that caregiver strain prior to death places dementia CGs at high risk for depression.^{20,21}

From a clinical perspective, these findings suggest 3 potential targets for interventions: (1) strategies to increase preparedness prior to death; (2) reassuring individuals that feelings of relief after a loved one's death are common and warranted following their role as a family caregiver; and (3) cognitive strategies to reappraise bereavement by thinking about its positive aspects. First, developing interventions that address preparedness require health care providers to develop trusting relationships with caregivers and provide reliable information to them so that caregivers have time to process the information and complete necessary end-of-life tasks^{3,22}. Several studies show that quality communication from health care providers improves the psychological wellbeing of bereaved survivors.²³ Second, bereavement support is an essential component of hospice care. Hospice social workers often provide ongoing support for bereaved family members via telephone conversations over a period of approximately 12 months²⁴. Regular discussions about feelings of relief as a normative reaction may help comfort caregivers and promote post-bereavement adjustment. Third, acceptance-based interventions could help caregivers manage their thoughts to think about the positive aspects of bereavement (e.g., "My loved one would want me to live my life;" "I am less stressed now and can focus on myself," "I now have time to enjoy the activities that I used to do before I was a caregiver").

These findings must be interpreted in light of several limitations, including the number of statistical tests that were performed, resulting in an increased risk for Type 1 error. Another limitation is that our measure of CG relief is based on a single item. While this single item has face validity, reliable assessment tools for this construct need to be developed and used in future studies on relief. Another limitation is that we used two variables as proxy indicators for caregiver strain and care recipient suffering. Although we would expect caregiver strain to be correlated with our measure of CR's functional status, and CR suffering to be correlated with our measure of CR relief, our data do not allow us to test these associations directly. The post-death assessment was relatively soon after the CR's death (approximately 100 days); highlighting that our sample of CGs were newly bereaved. A longer follow-up would allow insight into the long-term effects of relief on psychological wellbeing. Finally, generalizability is limited by multiple factors, including the patient care-recipient population studied, and the fact that caregivers volunteered for and participated in an intervention study.

Our goal in this paper was to show how feelings of relief may facilitate post-bereavement adjustment. This construct provides new insights into mechanisms linking the caregiving experience to bereaved family members' psychological wellbeing. Encouraging feelings of relief in dementia caregivers could decrease symptoms of complicated grief, which may help them better adapt to the death of their family member.

Acknowledgments

Funding sources:

This work was supported in part by Grants from the National Institute on Aging (AG13305), the National Institute of Mental Health (MH103467), and the National Institute of Nursing Research (NR009573, NR 13269).

Abbreviations:

CG	caregiver
CR	care recipient

References

- Schulz R, Hebert R, Boerner K. Bereavement after caregiving. *Geriatrics*. 2008;63(1):20–22. <http://www.ncbi.nlm.nih.gov/pubmed/18257616>. Accessed June 8, 2018.
- Hebert RS, Prigerson HG, Schulz R, Arnold RM. Preparing Caregivers for the Death of a Loved One: A Theoretical Framework and Suggestions for Future Research. *J Palliat Med*. 2006;9(5):1164–1171. doi:10.1089/jpm.2006.9.1164. [PubMed: 17040154]
- Schulz R, Boerner K, Klinger J, Rosen J. Preparedness for Death and Adjustment to Bereavement among Caregivers of Recently Placed Nursing Home Residents. *J Palliat Med*. 2015;18(2):127–133. doi:10.1089/jpm.2014.0309. [PubMed: 25469737]
- Schulz R, Savla J, Czaja SJ, Monin J. The role of compassion, suffering, and intrusive thoughts in dementia caregiver depression. *Aging Ment Health*. 6 2016:1–8. doi: 10.1080/13607863.2016.1191057. [PubMed: 26516791]
- Bernard LL, Guarnaccia CA. Two Models of Caregiver Strain and Bereavement Adjustment: A Comparison of Hu ... Heal (San Fr. 2003;43(6):808–816.
- Jacobs BJ. Feeling Relief (and Guilt) at Caregiving's End. <https://www.aarp.org/caregiving/life-balance/info-2017/relief-guilt-caregiving-ends.html>. Accessed August 9, 2018.
- Schulz R, Mendelsohn AB, Haley WE, et al. End-of-Life Care and the Effects of Bereavement on Family Caregivers of Persons with Dementia. *N Engl J Med*. 2003;349(20):1936–1942. doi: 10.1056/NEJMsa035373. [PubMed: 14614169]
- Wolff JL, Spillman BC, Freedman VA, Kasper JD. A National Profile of Family and Unpaid Caregivers Who Assist Older Adults With Health Care Activities. *JAMA Intern Med*. 2016;176(3):372. doi:10.1001/jamainternmed.2015.7664. [PubMed: 26882031]
- Ory MG, Hoffman RR, Yee JL, Tennstedt S, Schulz R. Prevalence and impact of caregiving: a detailed comparison between dementia and nondementia caregivers. *Gerontologist*. 1999;39(2):177–185. <http://www.ncbi.nlm.nih.gov/pubmed/10224714>. Accessed June 13, 2018. [PubMed: 10224714]
- Shear MK, Simon N, Wall M, et al. Complicated grief and related bereavement issues for DSM-5. *Depress Anxiety*. 2011;28(2):103–117. doi:10.1002/da.20780. [PubMed: 21284063]
- Schulz R, Burgio L, Burns R, et al. Resources for Enhancing Alzheimer's Caregiver Health (REACH): overview, site-specific outcomes, and future directions. *Gerontologist*. 2003;43(4):514–520. <http://www.ncbi.nlm.nih.gov/pubmed/12937330>. Accessed June 6, 2018. [PubMed: 12937330]
- Wisniewski SR, Belle SH, Coon DW, et al. The Resources for Enhancing Alzheimer's Caregiver Health (REACH): project design and baseline characteristics. *Psychol Aging*. 2003;18(3):375–384. doi:10.1037/0882-7974.18.3.375. [PubMed: 14518801]
- Schulz R, Rosen J, Klinger J, et al. Effects of a Psychosocial Intervention on Caregivers of Recently Placed Nursing Home Residents: A Randomized Controlled Trial. *Psychiatry Interpers Biol Process*. 2014;37(4):347–367. doi:doi:10.1080/07317115.2014.907594.
- Bakeman R Recommended effect size statistics for repeated measures designs. *Behav Res Methods*. 2005;37(3):379–384. doi:10.3758/BF03192707. [PubMed: 16405133]
- Crawford K, Digby R, Bloomer M, Tan H, Williams A. Transitioning from caregiver to visitor in a long-term care facility: the experience of caregivers of people with dementia. *Aging Ment Health*. 2015;19(8):739–746. doi:10.1080/13607863.2014.962008. [PubMed: 25266371]

16. Wiemers EE, Bianchi SM. Competing Demands from Aging Parents and Adult Children in Two Cohorts of American Women. *Popul Dev Rev.* 2015;41(1):127–146. doi:10.1111/j.1728-4457.2015.00029.x. [PubMed: 26594071]
17. Hagedoorn M, Sanderman R, Buunk BP, Wobbles T. Failing in spousal caregiving: The “identity-relevant stress” hypothesis to explain sex differences in caregiver distress. *Br J Health Psychol.* 2002;7(4):481–494. doi:10.1348/135910702320645435. [PubMed: 12614498]
18. Monin JK, Schulz R. Interpersonal Effects of Suffering in Older Adult Caregiving Relationships. *Psychol Aging.* 2009;24(3):681–695. doi:10.1037/a0016355. [PubMed: 19739924]
19. Williams IC. Emotional health of black and white dementia caregivers: a contextual examination. *J Gerontol B Psychol Sci Soc Sci.* 2005;60(6):P287–P295. <http://www.ncbi.nlm.nih.gov/pubmed/16260702>. Accessed August 21, 2018. [PubMed: 16260702]
20. Beach SR, Schulz R, Yee JL, Jackson S. Negative and positive health effects of caring for a disabled spouse: longitudinal findings from the caregiver health effects study. *Psychol Aging.* 2000;15(2):259–271. <http://www.ncbi.nlm.nih.gov/pubmed/10879581>. Accessed June 20, 2018. [PubMed: 10879581]
21. Blanco V, Rohde P, Vázquez FL, Torres Á. Identification of caregivers at greatest risk of major depression in two prevention studies. *Psychother Res.* 2014;24(5):578–593. doi:10.1080/10503307.2013.847989. [PubMed: 24274260]
22. Hebert RS, Schulz R, Copeland VC, Arnold RM. Preparing Family Caregivers for Death and Bereavement. Insights from Caregivers of Terminally Ill Patients. *J Pain Symptom Manage.* 2009;37(1):3–12. doi:10.1016/j.jpainsymman.2007.12.010. [PubMed: 18538977]
23. Wright AA, Zhang B, Ray A, et al. Associations Between End-of-Life Discussions, Patient Mental Health, Medical Care Near Death, and Caregiver Bereavement Adjustment. *JAMA.* 2008;300(14):1665. doi:10.1001/jama.300.14.1665. [PubMed: 18840840]
24. Barry CL, Carlson MDA, Thompson JW, et al. Caring for grieving family members: results from a national hospice survey. *Med Care.* 2012;50(7):578–584. doi:10.1097/MLR.0b013e318248661d. [PubMed: 22310561]

Highlights

- The purpose of this study is to examine pre-death factors associated with caregiver relief and whether caregiver relief is associated with post-bereavement adjustment, namely complicated grief and depression symptoms.
- Feelings of relief were relatively high among caregivers of family members with late-stage dementia compared to caregivers of family members with mild-to-moderate dementia. Greater preparedness for death and care recipient suffering prior to death were associated with caregiver relief post-death. Caregiver relief was associated with fewer symptoms of complicated grief post-death.
- These findings demonstrate that caregiver relief protects against significant distress and impairment in caregivers of both mid- and late-stage dementia patients.

Table 1.

Characteristics of Bereaved Caregivers

Characteristic	REACH (N=223)	FaCTS (N=89)	<i>p</i> -value ^a
	M (SD) or n (%)	M (SD) or n (%)	
Age, years	63.7 (13.4)	62.6 (11.3)	0.501
Sex, male	34 (15.2)	27 (31.8)	<.001
Race, African American	76 (34.1)	12 (14.1)	<.001
Education, some college or more	107 (48.0)	59 (69.4)	<.01
CG relationship to CR			<.01
Spouse	110 (49.5)	25 (29.4)	
Adult Child	96 (43.2)	44 (51.8)	
Other	16 (7.2)	16 (18.8)	
CG preparedness for CR death			<.001
Not at all	69 (31.1)	4 (4.8)	
A little	93 (41.9)	37 (44.6)	
Very much	60 (27.0)	42 (50.6)	
CR ADL difficulties ^b	4.5 (1.7)	6 (1.9)	-
<u>Post death</u>			
CR death was a relief to CG			<.001
Not at all	62 (28.8)	17 (20.2)	
Somewhat	95 (43.2)	38 (45.2)	
Very much	63 (28.3)	29 (34.5)	
CG depression ^c	16.1 (14.0)	7.8 (6.3)	-
CG complicated grief ^d	79.7 (22.7)	14.3 (10.9)	-
Time since CR's death, days	107.3 (70.8)	107.2 (59.0)	0.838

Notes.

^a *p*-values are based on two group comparisons: Pearson χ^2 test for categorical outcomes (presented by number [%]) and one-way analysis of variance (ANOVA) tests for continuous outcomes (presented by mean and SD)

^b 7-item ADL scale in FaCTS; 6-item ADL scale in REACH

^c 10 item CES-D in FaCTS; 20-item CES-D in REACH

^d 19-item ICG in FaCTS; 32 item ICG in REACH

CG = caregiver; CR = care recipient; ADL = activities of daily living.

Table 2.

Multivariate Ordinal Regression Model for CG Relief after CR death

Variables	REACH Sample (N=211) ^a							FaCTs Sample (N=82) ^b						
	Coefficient	SE (B)	Wald	df	p-value	Lower bound	Upper bound	Coefficient	SE (B)	Wald	df	p-value	Lower bound	Upper bound
<u>Demographics</u>														
CG age	−0.033	0.014	5.611	1	0.018	−0.061	−0.006	−0.081	0.032	6.628	1	0.010	−0.143	−0.019
CG is male	0.185	0.280	0.238	1	0.626	−0.559	0.930	1.275	0.529	5.812	1	0.016	0.238	2.312
CG is African American	.356	0.309	1.321	1	0.250	−0.251	0.962	1.599	0.742	4.647	1	0.031	0.145	3.052
CG completed more than HS	−0.051	0.284	0.032	1	0.858	−0.607	0.505	0.872	0.575	2.302	1	0.129	−0.254	1.999
CG is spouse of CR [^]	−0.750	0.376	3.971	1	0.046	−1.488	−0.012	−0.846	0.719	1.384	1	0.239	−2.254	0.563
Nature of the caregiving experience														
CG prepared for CR death	0.701	0.190	13.641	1	<0.001	0.329	1.073	1.592	0.490	10.580	1	0.001	0.633	2.552
CR functional status	−0.091	0.082	1.219	1	0.270	−0.252	0.070	0.220	0.128	2.958	1	0.085	−0.031	0.471
CRs death was a relief for him/her	1.290	0.274	22.207	1	<0.001	0.753	1.826	0.852	0.421	4.099	1	0.043	0.027	1.677
<u>Study characteristics</u>														
Intervention group	−0.636	0.327	3.781	1	0.052	−1.277	0.005	0.294	0.471	0.391	1	0.532	−0.629	1.217
Time in days since CR death	0.001	0.002	0.347	1	0.556	−0.003	0.005	−0.004	0.004	1.041	1	0.308	−0.012	0.004

Notes. **Boldface** highlights statistically significant results.

[^] reference group is adult child/other CG

^a $\chi^2 = 55.705$, $p < .001$, $df = 10$; 12 observations lost to missing data on outcomes or predictors.

^b $\chi^2 = 30.639$, $p < .01$, $df = 10$; 7 observations lost due to missing data on outcomes or predictors.

CG = caregiver; CR = care recipient.

Table 3.

Multivariate Regression Model for Post-bereavement Adjustment after CR Death

Variables	REACH sample						FaCTs sample					
	Depression (n=201) ^a			Complicated grief (n=203) ^b			Depression (n=82) ^c			Complicated grief (n=80) ^d		
	β	t	p-value	β	t	p-value	β	t	p-value	β	t	p-value
CG demographics												
CG age	-0.317	-2.863	0.005	-0.317	-3.527	0.001	-0.182	-1.208	0.231	-0.167	-1.104	0.273
CG is male	0.069	0.836	0.405	-0.113	-1.715	0.088	0.014	0.131	0.896	-0.077	-0.700	0.486
CG is African American	-0.141	-1.671	0.097	-0.009	-0.123	0.902	-0.185	-1.590	0.116	-0.117	-0.996	0.323
CG completed more than HS	-0.172	-2.071	0.040	-0.169	-2.547	0.012	0.014	0.120	0.905	-0.106	-0.906	0.368
CG is spouse of CR [^]	0.128	1.149	0.253	0.313	3.546	<0.001	0.441	2.927	0.005	0.180	1.199	0.235
<u>Nature of the caregiving experience</u>												
CG prepared for CR death	0.040	0.464	0.643	-0.147	-2.167	0.031	-0.046	-0.361	0.719	-0.110	-0.855	0.396
CR functional status	0.066	0.808	0.420	0.023	0.352	0.725	-0.271	-2.417	0.018	0.066	0.576	0.567
CRs death was a relief for him/her	-0.021	-0.250	0.803	0.017	0.244	0.807	-0.198	-1.778	0.080	-0.072	-0.638	0.526
CRs death was a relief to CG	-0.078	-0.878	0.382	-0.291	-4.072	<0.001	-0.192	-1.569	0.121	-0.449	-3.689	<0.001
<u>Study characteristics</u>												
Intervention group	0.083	1.001	0.319	0.050	0.772	0.441	-0.031	-0.292	0.771	0.046	0.432	0.667
Time in days since CR death	0.002	0.027	0.979	0.095	1.474	0.142	-0.159	-1.503	0.137	-0.144	-1.351	0.181

Notes. **Boldface** highlights statistically significant results.

[^] reference group is adult child/other CG

^a $F(11, 189) = 3.333, p < .001; R^2 = .162$

^b $F(11, 191) = 5.225, p < .001; R^2 = .231$

^c $F(11, 70) = 2.563, p = .009; R^2 = .287$

^d $F(11, 68) = 2.615, p = .008; R^2 = .297$

CG = caregiver; CR = care recipient.