Restorative activities among bereaved caregivers of nursing home patients

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Abstract

This prospective study examined predictors and correlates of restorative activities in recently bereaved caregivers and their relation to post-bereavement adjustment, namely complicated grief. Participants included 89 caregivers (CGs) age 32–87 (*M* age - 63 years) whose care recipients recently died in a long-term care facility (*M* time since loss = 107 days). Our findings show that being prepared prior to death enables CGs the opportunity to engage in restorative activities post death. Restorative activities partially mediated the relationship between preparedness prior to death and complicated grief, but this association was attenuated in multivariable models. It is possible that being prepared prior to death allows CGs to engage in restorative activities post-death, which in turn decreases complicated grief. More research is needed in diverse populations of CGs to determine how restorative activities may impact post-bereavement adjustment.

Keywords

Restoration; Health behaviors; Bereavement; Complicated grief; Adjustment

Experiencing the death of a loved one is traditionally viewed as a highly stressful event.[1] Bereavement is associated with an intense period of suffering and elevated rates of chronic disease including hypertension, cardiovascular disease, depression, and anxiety.[2] Bereavement also increases mortality risk, particularly among surviving spouses.[3,4] A more recent perspective posits that stressful events like bereavement serve as a stimulus for post-traumatic growth for bereaved caregivers.[5] From this perspective, the death of a loved one results in the removal of stressors (caregiving strain, suffering of a loved one) and provides a sense of relief to caregivers, who are spared further emotional, physical, and financial challenges that are associated with providing care to a physically declining care recipient. These individuals not only successfully cope with the loss of a loved one, but are more likely to report positive symptoms after bereavement including personal growth and resilience.[5-8]

To understand the health outcomes of bereavement, most researchers use the stress-and-coping model as a basic guide.[9,10] In this model, an individual's response to a stressful event

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is the interaction between the individual's interpretation of the situation (bereavement) and the individual's available resources (personal, social, and cultural). Adjustment to the loss of a loved one can take months or even years and is highly variable between individuals.[2] Lazarus and colleagues have proposed that restorative activities may facilitate adjustment post stress because these activities help 'restore' the body back to a neutral state. Restorative activities are defined broadly as pleasurable activities that serve as 'breathers' from routine demands and responsibilities.[11] These might include hobbies, spending time in nature, and unwinding at the end of the day. Restoration occurs as a result of positive social interactions and/or increased positive emotion. Studies show that a greater frequency of engagement in restorative activities is associated with psychological and physical wellbeing.[12]

In the context of bereavement after caregiving, restorative activities may facilitate adjustment by allowing individuals the opportunity to make meaning of the loss.'[5] Studies show that when bereaved individuals can find meaning and assimilate to the loss, they are less likely to experience abnormal grief reactions.[13] Restorative activities may also facilitate re-integration into daily activities that characterized a person's life prior to taking on the caregiving role, and to adapting to life without their loved one. However, research has primarily focused on exercise behaviors among bereaved older adults.[14,15] Exercise behaviors are somewhat different than restorative activities in that exercise behaviors are bodily movements that increase breathing and heart rate and tend to be defined in terms of cardiovascular benefits. Some individuals may find exercise behaviors to be restorative. However, existing research shows that bereaved older adults tend to decrease their participation in physical exercise following the death of a spouse.[15] Restorative activities may be more feasible or therapeutic compared to exercise activities given mobility limitations of the elderly.

One of the major shortcomings of existing studies of restorative activities is that they do not specifically examine engagement in bereaved caregivers. Studies of physical activity and exercise behaviors have been conducted during the transition to bereavement,[15,16] but these studies do not comprehensively examine other activities that may help 'restore' the body back to a neutral state after a stressful event. Using Lazarus and colleague's conceptual model, restorative activities should facilitate adjustment post stress. After the death of a loved one, little is known about restorative activities relation to indicators of post-bereavement adjustment (positive or negative). This study examines complicated grief as an indicator of post-bereavement adjustment. Complicated grief represents an abnormal process of adjusting to the loss of a loved one.[17] While only a subset of caregivers (10-15%) are diagnosed with complicated grief disorder,[18] many individuals may report specific symptoms of complicated grief, particularly during the first few months after a loss. If practitioners' goal is to promote a healthy adaptation to bereavement, information is needed about restorative activities in bereaved caregivers' and the factors that predict engagement in them.

The goal of this study was to address these shortcomings and identify predictors and correlates of restorative activities in recently bereaved caregivers and to examine its relation to post-bereavement adjustment, namely complicated grief. Demographic characteristics (including age, gender, race, education, and relationship to the care recipient) caregiver

physical health, caregiver preparedness prior to death, and care recipient functional status were examined as possible predictors and correlates of restorative activities post death. It was hypothesized that feeling prepared prior to death would be associated with greater engagement in restorative activities post death. Caregivers who feel more prepared for their loved one's death also experience lower levels of complicated grief post bereavement.[19] It was hypothesized that restorative activities mediates this relationship, in that being prepared prior to death facilitates engagement in restorative activities post death which in turn reduces complicated grief.

Methods

Participants and procedure

A prospective, longitudinal study was conducted using data from a randomized controlled trial assessing the effects of a psychoeducational intervention on caregiver (CG) adjustment to having their care recipient (CR) placed in a long-term care facility.[20] Family CGS were randomized to one of two conditions: a multicomponent intervention designed to target: 1) knowledge of nursing home practices; 2) advanced care planning; and 3) emotional wellbeing; or an information-only control. The intervention was delivered over a 6-month period. CG follow-up assessments were carried out 6, 12, and 18 months after the baseline assessment. A detailed description of the intervention and outcomes can be found in Schulz et al. (2014). We control for group assignment in all analysis reported in this paper.

Participants were recruited from long-term care facilities in Western Pennsylvania. CGs were self-identified as the individual providing the most support (instrumental and emotional) to the CR for at leave 3 months prior to institutionalization. CGs were eligible if they were a family member or partner (spouse, child, fictive kin); and at least 21 years of age. CRs were eligible if they were at least 50 years of age; institutionalized within the last 120 days; and impaired in at least three of seven activities of daily living. A total of 217 dyads (CG and CRs) completed the baseline assessment and were randomized to either control or intervention conditions. Eightynine CRs died during the course of the study (48 in the control and 41 in the intervention condition); their CGs continued to be followedup after the death using an abbreviated assessment. These 89 CGs are the focus of this report.

Measures

Sociodemographic characteristics included CG age, gender, race/ethnicity, and years of education. CGs' physical health was assessed by asked whether CGs currently had (or were ever told by a doctor that they had) the following health problems: arthritis, high blood pressure, heart condition, chronic lung disease, diabetes, stroke, stomach problems, kidney problems, cirrhosis, cancer, vision/ hearing problems, and 'other' physical health problems. Response options were 1 (yes) and 0 (no); the possible range is 0–12 with higher scores indicating more physical health problems. CR's functional status was assessed by administering a 7-item Activities of Daily Living (ADL) scale and asked the CG to indicate whether the CR needed help with each ADL.[21]

Pre-death assessments

Preparedness for death—A single item was used to measure preparedness for death. CGs were asked, "If your loved one were to die soon, how prepared would you be for his/her death?" Response options were "not at all," "somewhat," and "very much." Previous studies have examined preparedness for death using a single-item indicator.[22,23] This question has been tested extensively for wording and has strong face validity.[22,24] In analyses that use post death outcomes, group assignment is used as a control variable.

Depression—The 10-item Center for Epidemiological Studies Depression Scale (CES-D) was used to assess the frequency of depressive symptoms in CGs.[25,26] For each item, responses ranged from 0 (experienced rarely or none of the time) to 3 (experienced most of the time); the possible range is 0–30 with higher scores indicating a greater frequency of depressive symptoms within the last week. A score of 8 or higher is associated with an increased risk of clinical depression.[25] Cronbach's α at baseline was 0.82.

Post-death assessments

Restorative activities—The Pittsburgh enjoyable activities test (PEAT)[12] was used to measure engagement in restorative activities. The PEAT assesses 10 pleasurable activities in which adults engage in voluntarily to induce positive emotions and reduce stress. Items asked about sports; quite 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. Respondents rated each item on a scale from 0 (never) to 4 (everyday). Scores range from 0 through 40 with higher scores indicating greater frequency of engagement in restorative activities. Restorative activities was collected before and after CRs' death. There was no significant change in CGs' engagement in restorative activities from pre- to post-death (M change = 0.54, SD = 5.38, p = 0.35). Therefore, restorative activities collected at the closest interview post-death was the main outcome in our regression analysis. Cronbach's α was 0.71.

Complicated grief—The 19-item inventory of complicated grief (ICG) was used to measure maladaptive symptoms of loss.[27] For each item, CGs were asked if they felt that way "never," "rarely," "sometimes," "often," or "always." The possible range is 0–76 with higher scoring indicating high levels of complicated grief. A score of 25 or higher is associated with prolonged grief disorder. Cronbach's α was 0.91.

Statistical analyses

Descriptive statistics characterizing the 89 bereaved caregivers are presented first. For the first research question, a multivariate linear regression model was tested using sociodemographic variables and pre-death factors as predictors of CGs engagement in restorative activities at the first available measurement point after CR's death, typically within 6 months. For the second research question a univariate regression model was tested to establish whether restorative activities mediate the preparedness - complicated grief relationship using steps recommended by Baron and Kenny.[28] Based on these steps, (1) the causal variable (preparedness) should be correlated with both the outcome (complicated

grief) and the mediator (restorative activities); and (2) the mediator (restorative activities) should be correlated with the outcome (complicated grief). Full mediation exists if preparedness no longer predicts complicated grief, after controlling for the mediator (restorative activities). This analysis is re-run by testing a multivariate model while adjusting for known correlates of complicated grief (e.g., demographics, and CG depression). Analyses were performed with SPSS, version 24.0.

Results

Descriptive statistics for the sample are presented in Table 1. Bereaved CGs were predominately White women approximately 63 years of age. Forty-eight percent of CGs were adult children; the remaining CGs were spouses (28%) and other familymembers (23%). CGs were caring for highly impaired CRs with limitations in 6 out of 7 ADLs. Half of CGs reported feeling 'very much' prepared for their CR's death; 44% reported feeling 'a little' prepared, and 5% reported feeling 'not at all' prepared. Mean values on the CES-D scale were 8.6, indicating the CGs were mildly depressed. After CRs' death, follow-up data were available for 85 out of 89 CGs. Mean values on the inventory of complicated grief scale were 14.4, and 16% had scores greater than 25, indicating a syndromal level of abnormal or prolonged grief. CG engagement in restorative activities was of moderate frequency with a mean score of 23 (range = 0–40) indicating CGs engaged in a several activities during the past week.Table 2 shows CG responses to the restorative activity items; more than half of CGs reported hobbies and visiting family and friends at least once a week, and most (88%) reported "unwinding" at the end of the day at least once a week.

Table 3 shows the multivariate linear regression model that examined pre-death predictors of CG restorative activities after death. The model included sociodemographic characteristics, CG physical health, CG preparedness for CR death, and CR functional status. The only statistically significant effect was found for preparedness. CGs who were more prepared for the death of their CR engaged in a greater frequency of restorative activities post death ($p <$. 05). Given the diversity of CGs in this sample (spousal, adult child, and 'other' relationships), we wanted to compare adult child CGs to spousal CGs only, in terms of engagement in restorative activities. Therefore, in a follow-up analysis of 68 (out of 89) CGs, CGs relationship to CR was explored. Adult child CGs (n = 43) were more likely to engage in restorative activities than spousal CGs (n = 25) (β = .27; $p < .05$).

Table 4 shows the multivariate analysis that tested whether increased preparedness prior to death is mediated through restorative activities to reduce complicated grief post death. In univariate analyses, the standardized regression coefficient between preparedness and restorative activities was statistically significant (β = 0.22, p = .039), as was the standardized regression coefficient between restorative activities and complicated grief (β=−0.31, p =. 001). The relationship between preparedness and complicated grief (β=−0.32) was reduced when restorative activities was added to our model (β=−0.25) but was still significant $(p =$. 015), indicating partial mediation. To control for potential confounders of complicated grief, the model was re-run to include CG demographics, pre-death variables, and study characteristics. CG preparedness and CG depression were the only significant predictors of complicated grief. Adding restorative activities to the model attenuated the effect of

preparedness on complicated grief, but this effect was not statistically significant. The relation between restorative activities and complicated grief was also not statistically significant. The multivariate model accounted for a modest proportion of variance in complicated grief (31%).

Discussion

This study sought to identify predictors and correlates of restorative activities in recently bereaved caregivers and to examine its relation to post-bereavement adjustment, namely complicated grief, using a stress-and-coping theoretical framework. Two main findings emerged. First, being prepared prior to CR's death was associated with a greater frequency of engagement in restorative activities post death. This finding is consistent with other studies showing the value of being prepared for the death of a loved one.[23,29,30] There are several possible mechanisms through which preparedness prior to death leads to greater engagement in restorative activities post death. Being prepared often means that decisions about end-of-life care and funeral arrangements have been made, which may allow CGs to 'function' and engage in variety of activities post death.[31] It is also possible that being prepared helps CGs to be less traumatized by CRs' death thereby allowing individuals the ability to engage in restorative activities post death. This is in line with current literature on posttraumatic growth and the positive aspects of dealing with stressful events. Posttraumatic growth is defined as the positive psychological change that occurs after experiencing a highly stressful event.[32–35] Posttraumatic growth can manifest in many ways (e.g., increased sense of strength, change in priorities),[32] one of which may be engagement in restorative activities because these are activities that individuals find personally meaningful.

Second, restorative activities partially mediated the association between preparedness and complicated grief, but this effect was attenuated when demographic characteristics and pre-death variables were included in the model. This suggests that the relationship between preparedness and complicated grief may be driven by a combination of variables that includes lower levels of depression and greater engagement in restorative activities. Restoration is marked by greater feelings of calmness, vigor, and positive affect[12]; therefore, it is possible that restorative activities have a stronger effect on other indicators of post-bereavement adjustment such as posttraumatic growth and/or resilience.

These findings have several implications for professionals who work with family CGs before and after CRs death. First, the support provided to family CGs should include conversations about CGs daily routine and ways in which they could schedule time for restorative activities throughout the week, along with strategies to track engagement in restorative activities from pre- to post-bereavement. Tracking strategies could include paper-and-pencil self-monitoring methods or inexpensive objective monitoring devices. Second, bereavement support groups could specifically target restorative activities by including sessions on how to relax or 'unwind' at the end of the day, social events that include family and friends, and opportunities to visit parks or other outdoor settings. It is possible that bereaved CGs with small social networks may need extra support (from practitioners and/or bereaved CGs) and opportunities to engage in restorative activities. This possibility suggests that clinicians and scientists should not only view restorative activities as activities in which CGs engage alone,

but together with others as an opportunity for social engagement. Finally, it is important to provide ongoing motivation and reward for CG engagement in restorative activities. This could be in the form of motivational health coaching, verbal encouragement, and goal setting via ongoing telephone follow-ups.

This study had several limitations. First, this study is based on a sample CGs caring for an institutionalized older adult. The bereavement experience for these CGs may be less intense than they would be for in-home CGs because of the reduced contact with the CR and the fact that death is more likely to be expected for these severely impaired CRs. As a result, this population of CGs may be more prepared for the death than in-home CGs and the effects of restorative activities on bereavement adjustment may be attenuated. Second, the measure of preparedness was based on a single item. Preparedness is a multidimensional construct with emotional, pragmatic, and informational components.[30] Future research would benefit from understanding the relative impact of each component on CG wellbeing. Third, there might be other activities that CGs find restorative that were not included in the restorative activities measure. Fourth, the post-bereavement interview was conducted in a relatively short amount of time after CR's death (approximately 3 months). It is possible that CGs initial grief reactions were quite variable and may not be indicative of clinically significant grief symptoms.[36] Our small sample was not conducive to conducting subgroup analyses and comparing adult child CGs to spousal CGs. It is possible that restorative activities' effect on complicated grief may vary according to CGs relationship to CRs. Given that older spouses tend to withdraw from preventive behaviors such as healthy eating and sleeping after the death of their spouse,[15] restorative activities may be more (or less) beneficial to older spouses compared to adult child CG in terms of promoting post-bereavement adjustment. This report provides early evidence that adult child CGs were more likely to engage in restorative activities than spousal CGs. However, this potential relation should be replicated in larger, more diverse samples of CGs.

This study highlights the need to consider restorative activities in bereaved CGs, as these activities may serve as targets for future bereavement interventions. Our findings show that being prepared enables CGs the opportunity to engage in pleasurable activities post death. However, more research is needed in diverse populations of CGs to determine how restorative activities may impact psychological adjustment. Future research should consider assessing adjustment across several domains including physiological health and posttraumatic growth as they may provide a more complete understanding of adjustment.

Acknowledgments

Abbreviations:

CG	caregiver
CR	care recipient

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Table 1

Characteristics of Bereaved Caregivers (N = 89).

Descriptive variable	Value
CG Age, mean (SD)	62.6(11.3)
CG is Male, n (%)	29(32.6)
CG is African American, n (%)	11 (12.4)
CC completed less than high school, n (%)	30 (33.7)
CG relationship to CR, n (%)	
Spouse	25(28.1)
Adult child	43 (48.3)
Other	21 (23.6)
Pre death	
CG physical health, mean (SD)[b]	2.5 (1.6)
CG depression, CES-D score, mean (SD)	9.0(7.15)
CR ADL difficulties, mean (SD)[c]	6.0 (1.88)
CG preparedness for CR death, n (%)	
Not at all	4 (4.8)
A little	37 (44.6)
Very much	42 (50.6)
Post death (n = 85)[a]	
CG restorative activities, PEAT score, mean (SD)	23.0 (6.6)
CG complicated grief, ICG score, mean (SD)	14.32(10.87)
Time in days since CR death, mean (SD)	107.22 (58.98)

CG = caregiver; CR = care recipient; CES-D = Center for Epidemiologic Studies - Depression Scale; PEAT = Pittsburgh Enjoyable Activities Test (range = 0–40); ICG = Inventory of Complicated Grief (range = 0–76).

[a] Measured at the closest interview after CR death.

[b] Number of chronic health conditions (range: 0–12).

[c] Number of ADLs with which CD has difficulty (range: 0–7).

Table 2

CG Responses to Restorative Activity Items after CR Death (N = 85).

Restorative activity	Never n(%)	Less than once a Month n(%)	At least once a month n(%)	At least once a week n(%)	Every day n(%)
Item, n (%)					
Sports	24 (28.2)	4 (4.7)	9 (10.6)	39 (45.9)	9 (10.1)
Quiet time by yourself	16 (18.8)	3 (3.5)	10 (11.8)	31 (36.5)	25 (29.4)
Attending club/church/fellowship	28 (32.9)	3 (3.4)	14 (16.5)	39 (45.9)	1 (1.2)
Hobbies	24 (28.2)	3 (3.5)	8 (9.4)	34 (40.0)	16 (18.8)
Going out for meals with friends and relatives	7 (8.2)	3 (3.5)	32 (37.6)	38 (44.7)	5 (5.9)
Visiting family and friends	8 (9.4)	5 (5.9)	22 (25.9)	42 (49.4)	8 (9.4)
Doing other fun things with people	15 (17.6)	4 (4.7)	25 (29.4)	39 (45.9)	2 (2.4)
Taking vacations out of town	56 (65.9)	10 (11.8)	15 (17.6)	3 (3.5)	1 (1.2)
Being in parks and other outdoor settings	37 (43.5)	5 (5.9)	11 (12.9)	23 (27.1)	9 (10.6)
"Unwinding" at the end of the day	5 (5.9)	0 (0.0)	2 (2.4)	13 (15.3)	65 (76.5)

Table 3

Multivariate Regression for Restorative Activities after CR Death (N = 85).

Pre-death variables	B	SE (B)	β	t-test	*p*-value
CG age	−0.05	0.07	−0.08	−0.61	0.543
CG is male	−1.57	1.59	−0.11	−0.98	0.329
CG is African American[a]	−1.76	2.21	−0.10	−0.79	0.430
CG completed more than high school	−1.55	1.79	−0.11	−0.87	0.388
CG is spouse/adult child of CR[b]	1.66	2.04	0.10	0.82	0.417
CG physical health[c]	−0.44	0.48	−0.11	−0.93	0.356
CG preparedness for CR death	3.21	1.34	0.29	2.40	0.019
CR ADL difficulties[d]	0.49	0.41	0.14	1.19	0.237
Intervention group	−0.44	1.51	−0.03	−0.29	0.774

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

[a]Reference group in non-African American.

[b]Reference group is other CG.

[c]Total number of chronic health conditions (range: 0–7).

[d]Number of ADLs with which CD has difficulty (range: 0–7).

Table 4

Multivariate Regression Model for Complicated Grief (N = 85).

Variables	B	SE (B)	β	t-stat	p-value	R²
CG Demographics						
Age	0.10	0.10	0.10	0.96	0.34	
Male	−0.53	2.39	−0.02	−0.22	0.83	
African American	1.52	3.13	0.05	0.48	0.63	
Pre-death						
CG depression score (CES-D)	0.67	0.17	0.41	3.84	0.00	
CG preparedness for CR death	−3.95	1.95	−0.21	−2.02	0.04	
Study Characteristics						
Intervention group	1.51	2.25	0.07	0.69	0.51	
Time in days since CR's death	−0.02	0.02	−0.10	−0.96	0.34	
Step 1, F (7, 72) = 3.97,p <.01						0.28
CG Demographics						
Age	0.08	0.10	0.09	0.80	0.424	
Male	−0.65	2.36	−0.03	−0.27	0.786	
African American	1.14	3.10	0.04	0.37	0.714	
Pre-death						
CG depression score (CES-D)	0.57	0.18	0.35	3.13	0.002	
CG preparedness for CR death	−3.52	1.95	−0.19	−1.81	0.075	
Study Characteristics						
Intervention group	1.36	2.22	0.06	0.61	0.543	
Time in days since CR's death	−0.02	0.02	−0.08	−0.84	0.406	
Post-death						
CG restorative activities	−0.30	0.18	−0.18	−1.69	0.090	
Step 2, F (8, 71) = 3.93,p <.01						0.31

CG = caregiver, CR = care recipient, CES-D = Center for Epidemiologic Studies - Depression Scale.