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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.

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 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,

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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 well-being; 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. Eighty-nine CRs died during the course of the study (48 in the control and 41 in the intervention condition); their CGs continued to be followed-up 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