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Preparedness for Death and Adjustment to Bereavement among Caregivers of Recently Placed Nursing Home Residents

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Abstract

Background: Preparedness for death as a predictor of post-bereavement adjustment has not been studied prospectively. Little is known about pre-death factors associated with feeling prepared prior to the death of a loved one.

Objective: Our aim was to prospectively assess the role of preparedness for death as a predictor of post-bereavement adjustment in informal caregivers (CGs) who experienced the death of their loved one and to identify predictors and correlates of complicated grief, depression, and preparedness for death among informal CGs.

Methods: We conducted a prospective, longitudinal study using data collected for a randomized trial testing the efficacy of an intervention for CGs of recently placed care recipients (CRs). Subjects were 217 informal CGs of care recipients recently placed in nursing homes, and they were followed for 18 months. CGs were assessed in person by certified interviewers at 6-month intervals. Eighty-nine CGs experienced the death of their loved one in the course of the study. Measurements used included preparedness for death, advance care planning (ACP), complicated grief, depression, and sociodemographic characteristics.

Results: CGs who reported feeling more prepared for the death experienced lower levels of complicated grief post-bereavement. A multivariate ordinal logistic regression model showed that spouses as opposed to adult child CGs were less prepared for the death, depressed CGs were less prepared, and patients who engaged in ACP had CGs who felt more prepared. CR overt expressions about wanting to die was also related to higher levels of preparedness in the CG.

Conclusions: We show prospectively that preparedness for death facilitates post-bereavement adjustment and identify factors associated with preparedness. ACP can be an effective means for preparing informal CGs for the death of their CRs.

Introduction

The common expression, ''forewarned is forearmed,'' is based on the belief that knowing about something beforehand enables one to prepare for it and, therefore, mitigate or diminish the effects of a negative event. This idea has been championed by bereavement researchers who have repeatedly shown that being prepared for the death of a loved one is associated with better post-bereavement adjustment.[1–5] For example, Barry and colleagues[2] found that perceptions of lack of preparedness for death was associated with complicated grief at follow-up, suggesting that feelings of lack of preparedness may be a risk factor for developing psychiatric morbidity. Similarly, Hebert et al.[1] found that caregivers (CGs) of patients with dementia who reported that they were not prepared for the death had significantly higher depression, anxiety, and complicated grief symptoms after death, and Hauksdottir and coworkers[3] found that among older widowers a low degree of preparedness increased the risk of having repeated painful memories and a heightened startle response. An important implication of these findings is that facilitators of preparedness should improve the long-term psychological well-being of bereaved individuals. To the extent that preparedness is associated with factors such as advance care planning (ACP), it may also have implications for the quality and quantity of care delivered to patients.

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Existing research on preparedness represents an important first step in pursuing a longer-term agenda of better preparing individuals for the death of a loved one. Inasmuch as most of the nearly 2.5 million deaths annually in the United States are the result of chronic disease, better preparation for death will likely reap benefits for surviving family members as well as patients. An important next step in moving this field forward will be to: (a) assess the effects of preparedness prospectively; and (b) identify the behavioral, contextual, and psychological predictors of preparedness.

One of the major shortcomings of existing studies of preparedness for death is that none are prospective. That is, they do not assess preparedness before the death occurred; instead, respondents are asked to recollect how prepared they felt after their loved one died. This raises obvious questions about the reliability of recall as well as concerns about post-bereavement adjustment influencing reports about preparedness. Individuals who do well after the death of a loved one may be more likely to conclude they must have been prepared for the death. In addition, the correlates or predictors of preparedness when collected after death may be different than the pre-death correlates of preparedness. The latter point is important because if our goal is to learn how to better prepare individuals for the death of a loved one, we will need to know how prepared they felt prior to death and which pre-death factors are associated with feeling prepared.

The goal of this study is to address these shortcomings by assessing preparedness prior to death, examining its relation to post-bereavement adjustment, and collecting contextual, psychological, and behavioral data linked to preparedness prior to death. We studied 217 CGs of recently institutionalized care recipients (CRs) with high levels of disability and a high probability of dying in the near future. CGs were involved in caregiving prior to and after institutionalization and, therefore, had detailed knowledge of patient status. CGs and patients were followed for 18 months, during which 89 patients died. Demographic characteristics including age, gender, race, education, and relationship to the CR were examined as possible correlates of preparedness. CGss were also asked whether they anticipated the death of the CR/resident within the next 6 months and whether they had engaged in ACP. CG depression data were collected both before and after death of the patient, and the Complicated Grief Scale was administered after death. We predicted that level of pre-death preparedness would be negatively associated with post-death complicated grief and depression. We also predicted that anticipating the death of a loved one may be a precondition to preparedness and, therefore, we predicted an association between these variables. We also explored the role of CR functional status and symptoms as possible predictors of preparedness.

Methods

Study design overview

This paper is based on secondary analysis of data collected for a randomized trial assessing the effects of a psychoeducational intervention on CG adjustment to having their CR placed in a long-term care facility. The study design was a two-group, randomized, controlled trial comparing an active intervention condition with an information-only control condition. Family CGs were randomly assigned to one of two conditions: (1) in the active intervention condition, family CGs of recently placed CRs received a multicomponent intervention designed to target three areas of need: knowledge and procedures of nursing homes, ACP, emotional well-being; and (2) in the information-only control condition, family CGs of recently placed CRs 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. The intervention was delivered during a 6-month period following baseline assessment and randomization. CG follow-up assessments were carried out 6, 12, and 18 months after the baseline assessment. A detailed description of the intervention and intervention outcomes are found in Schulz et al.[6] We control for group assignment in our analysis of post-baseline data to control for possible intervention effects.

This study was approved by the Institutional Review Board of the University of Pittsburgh. A Data Safety Monitoring Board met at regular intervals throughout the study to monitor adverse events (e.g., high depression scores, severe CG medical problems/events) potentially associated with study participation.

Eligibility criteria, recruitment, and retention

The CG was self-identified as the individual providing the most instrumental and emotional support to the CR prior to placement. Dyads (CG and CRs) were eligible for entry if the CG: (1) was a family member/partner (e.g., spouse, child, or fictive kin); (2) was 21 years of age or older; (3) provided a minimum of 3 months of in-home care prior to institutionalization; (4) spoke English; and (5) planned to live in the area for at least 6 months. The CR had to: (1) be 50 years of age or older; (2) have been permanently placed in a long-term care facility within the last 120 days; and (3) be impaired in at least three of seven activities of daily living (ADLs). Dyads were excluded if the CR was enrolled in a hospice program at the time of recruitment.

Participants were recruited from 16 long-term care facilities in Western Pennsylvania with the help of clinical social workers and nurses at participating facilities. After obtaining family CG consent, CRs deemed competent to provide informed consent were approached to sign the CR consent form, which permitted access to nursing home medical records pertaining to the participating CR. For CRs who were unable to give informed consent, their legal surrogate (usually the family CG) was asked to give consent in their stead. If the family CG was willing to participate, and the competent CR was unwilling, the family CG was still eligible to be in the study, although CR information could not be used in this case.

A total of 317 dyads were screened. Of these, 52 were ineligible and 48 withheld consent, leaving 217 who completed the baseline assessment and were subsequently randomized to either control ($n = 108$) or intervention ($n = 109$) conditions; 204 CGs completed the 6-month assessment, 191 completed the 12-month assessment, and 190 completed the 18-month assessment. Retention did not vary by group assignment. A total of 89 CRs died in the course of the study (48 in the control condition and 41 in the intervention condition); these CGs continued to be followed after the death of their CR using an abbreviated assessment (see Schulz et al.[6] for a detailed description of attrition), which omitted survey items

that were no longer relevant because the CR had died (e.g., caregiver burden, CR disability status).

Measures

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

Depression. The 10-item version of the Center for Epidemiologic Studies Depression (CES-D) Scale[7,8] 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). Scores range from 0 through 30, with higher scores indicating increased presence of depressive symptoms; a score of 8 or higher (equivalent to 16 or higher on the 20-item scale) is widely interpreted as being at risk for clinical depression.[8,9] Cronbach's α at baseline was 0.87.

Complicated grief. For those CGs whose CR died in the course of the study, the Complicated Grief Scale[10] was administered at each measurement point post-death. For each of the 19 statements (e.g., ''I feel I cannot accept the death of…''), CGs were asked to report whether they currently felt this way: never (0), rarely (1), sometimes (2), often (3), or always (4) (possible range: 0–76, high values indicating high levels of complicated grief). Scores of ≥ 25 have been recommended as cutoffs for designating individuals with complicated grief.[11] Cronbach's α at baseline was 0.91.

Preparedness for death. A single item based on previous studies of preparedness was used to measure this construct.[1–3,5] Respondents 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.'' Sociodemographic characteristics included age and gender of CG and CR, race and education of the CG, and relationship of the CG to the CR.

We also administered a six-item scale from the measurement toolkit developed by Teno and colleagues[12] to assess the extent to which the CG/CR were engaged in ACP (see Table 1 for questions). Responses to the six questions with yes-no response options were summed yielding a score of 0 to 6.

To assess CR's functional status, we administered a seven-item ADL scale, asking the CG to indicate whether or not the CR needed help with each ADL.[13–15] We also asked CGs several questions assessing the presence or absence of patient symptoms and behaviors, including pain, anxiety, sadness, trouble breathing, and expressing feelings about wanting to die.

Statistical analysis

We first present descriptive statistics characterizing the study participants and their responses to ACP questions and questions about the CG's expectations and preparedness for the CR's death. Next, we test a multivariate ordinal logistic regression model predicting the CG's preparedness for death, and this is followed by multivariate regression models predicting post-bereavement complicated grief and depression at the first available measurement point after the death, typically within 6 months.

Results

Demographic characteristics of sample

Descriptive statistics for the sample are presented in Table 2. CGs were predominantly white women caring for highly impaired CRs with limitations in six of seven ADLs. CG depressive symptoms were high with a mean of 9.5 on the 10-item CES-D Scale, indicating that CGs were above the threshold for being at risk for clinical depression. CGs were highly engaged with their CRs, with the majority visiting the CR at least once a day (49.3%) or at least once a week (47.5%), and 59.9% provided physical care to the CR on a regular basis when they visited. Mean values on the Complicated Grief Scale were 14.4 on the first observation post-death, and 13 of 81 (16%) had scores of ≥ 25, which is considered the syndromal level of complicated grief.

Responses to preparedness and ACP questions are summarized in Tables 3 and 1, respectively. Baseline expectations about CR death varied as a function of whether or not the CR ultimately died. Compared with CGs whose CR did not die within 18 months, CGs in the CR deceased group were more likely to report that they expected their loved one to die in the next 6 months (36.8% versus 22.0%), and they were

Table 1. Caregiver Responses to Advance Care Planning Questions, Baseline Data

Question	*% Yes responses*
Has your relative been involved in making any advance care planning decisions, alone or with your help? ($n=217$)	79.3
Has your relative appointed anyone to act as his/her health care surrogate, to make health care decisions for your relative in the event he/she cannot make such decisions his/herself? Sometimes the health care surrogate is called a health care agent, or a proxy decision maker. ($n=215$)	87.4
Has your relative identified a substitute health care surrogate, in the event that the primary surrogate is unable to act in that capacity? ($n=205$)	63.9
Does your relative have a living will that indicates which medical interventions (i.e., cardiac resuscitation, artificial feeding/hydration, blood transfusions, etc.) he/she does and does not want in the event of serious end-of-life illness? ($n=215$)	69.3
Have you discussed a DNR order with your relative's physician? ($n=215$)	65.1
Is your relative's doctor aware of his/her decisions concerning end-of-life care? ($n=180$)	72.2

DNR, do not resuscitate.

Table 2. Baseline Characteristics of Study Participants

Characteristics	*All* (n = *217*)	*Bereaved* (n = *89*)	*Nonbereaved* (n = *128*)	P *Value*[a]
CG age, mean (SD)	61.8 (10.78)	62.6 (11.29)	61.2 (10.42)	0.365
CR age, mean (SD)	82.8 (9.23)	84.1 (8.78)	82.0 (9.47)	0.092
CG gender				
Women, No. (%)	163 (75.1)	60 (67.4)	103 (80.5)	0.029
Men, No. (%)	54 (24.9)	29 (32.6)	25 (19.5)	
CR gender				
Women, No. (%)	136 (62.7)	53 (59.6)	83 (64.8)	0.428
Men, No. (%)	81 (37.3)	36 (40.4)	45 (35.2)	
CG race				
Non African American, No. (%)	195 (89.9)	78 (87.6)	117 (91.4)	0.366
African American, No. (%)	22 (10.1)	11 (12.4)	11 (8.6)	
CG education				
High school or less, No. (%)	64 (29.5)	30 (33.7)	34 (26.6)	.256
More than high school, No. (%)	153 (70.5)	59 (66.3)	94 (73.4)	
CG relationship to CR				
Spouse, No. (%)	57 (26.3)	25 (28.1)	32 (25.0)	0.209
Adult child, No. (%)	119 (54.8)	43 (48.3)	76 (59.4)	
Other, No. (%)	41 (18.9)	21 (23.6)	20 (15.6)	
CG depression score,[b] mean (SD)	9.5 (7.26)	9.0 (7.15)	9.9 (7.34)	0.380
CR ADL difficulties,[c] Mean (SD)	5.8 (1.88)	6.0 (1.88)	5.7 (1.87)	0.252

[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]Depression scores are based upon the Center for Epidemiologic Studies Depression Scale (range, 0–30; higher scores indicate more reported depression).
[c]Any reported problems with seven ADLs are counted and summed (range, 0–7; higher scores indicate more ADL problems).
ADL, activities of daily living; CG, caregiver; CR, care recipient; SD, standard deviation.

more likely to have discussions with the nursing staff about the possibility of the CR dying (14.6% versus 1.6%). There were no differences between the two groups in terms of CG preparedness for death, with >90% of both groups reporting that they were ''somewhat'' or ''very prepared.'' Responses to the ACP questions suggested moderate to high levels of CG/CR participation (see Table 1).

A multivariate ordinal logistic regression model was run to identify predictors of preparedness using baseline values for the entire sample (see Table 4). The model included sociodemographic variables and two indicators thought to be important for preparedness: ACP and the expectation that the CR would die within the next 6 months. Among sociodemographic indicators, the only statistically significant effect was found for the CG relationship variable. Spouses of the CR were less prepared for the death than adult children ($p < 0.001$) or others ($p < 0.001$). CGs with higher depression scores were also less prepared ($p < 0.01$). ACP was significantly associated with preparedness ($p < 0.002$). We also explored the association between preparedness and CG perceived patient symptoms such as pain, anxiety, sadness, trouble breathing, and expressing feelings about wanting to

Table 3. Caregiver Expectations of and Preparedness for Death of the Care Recipient

	% yes responses	
Question	*CR not deceased* (n = *128*)	*CR deceased* (n = *89*)
Do you anticipate that your loved one is likely to pass away during the next 6 months? ($n = 127$; $n = 87$)	22.0	36.8
Has the nursing home staff discussed with you the possibility of your loved one dying in the next 6 months? ($n = 128$; $n = 89$)	1.6	14.6
Has the nursing home staff discussed with you steps you should take to prepare for your loved one's death? ($n = 128$; $n = 89$)	4.7	9.0
If your loved one were to die soon, how prepared would you be for his/her death? ($n = 128$; $n = 88$)		
Not at all	7.0	8.0
Somewhat	39.8	43.2
Very	53.1	48.9

Baseline data stratified by CR status at end of study.
CG, caregiver; CR, care recipient.

Table 4. Multivariate Ordinal Regression for CG Preparedness for CR Death ($N=216$[a]), Baseline Data

Variables	*Coefficient (SE)*		P *Value*	*95% confidence interval*	
				Lower bound	*Upper bound*
CG age	0.03	(0.02)	0.080	0.00	0.06
CG is male	−0.21	(0.34)	0.536	−0.88	0.46
CG CES-D Scale score	−0.05	(0.02)	0.010	−0.09	−0.01
ACP index[b]	0.27	(0.09)	0.002	0.10	0.45
CG anticipation of CR death in next 6 months	0.58	(0.35)	0.097	0.10	1.25
CR expresses feelings about wanting to die	0.67	(0.34)	0.045	0.02	1.33
CG is African American[c]	−0.70	(0.48)	0.144	−1.65	0.24
CG completed more than high school[d]	−0.22	(0.33)	0.519	−0.87	0.44
CG is adult child of CR[e]	1.80	(0.44)	<0.001	0.94	2.67
CG is not spouse or child of CR[e] (other relationship)	1.87	(0.51)	<0.001	0.86	2.87
CR ADL difficulties[f]	−0.16	(0.08)	0.063	−0.32	0.01

[a]One observation lost due to missing outcome data.
[b]ACP index is the sum of ''yes'' responses to six items assessing ACP (range 0–6).
[c]Reference group is non African American.
[d]Reference group is high school or less.
[e]Reference group is spouse CG.
[f]Number of ADLs with which CR has difficulty (range: 0–7).
ACP, advance care planning; ADL, activities of daily living; CES-D, Center for Epidemiologic Studies Depression; CG, caregiver; CR, care recipient; SE, standard error.

die. Only the latter item was significantly associated with preparedness in the multivariate model ($p=0.045$). We replicated this model using only CGs whose CR later died and found the same statistically significant effects with one exception: the p value for ''CR expresses feelings about wanting to die'' was no longer statistically significant.

Models predicting level of complicated grief at the first available observation post-death showed that only preparedness for death assessed at baseline ($p=0.038$) and CES-D Scale ($p<0.001$) were significantly associated with complicated grief (see Table 5). CGs who felt more prepared had lower levels of complicated grief, and this effect remained statistically significant ($p=0.04$) even after controlling for ACP in this multivariate model. In follow-up analysis, we also tested the mediation hypothesis that ACP is mediated through increased preparedness to reduce complicated grief, but this was not supported. Regression models predicting post-bereavement depression showed that higher levels of CR functional disability ($p=0.012$) and higher levels of CG baseline depression ($p<0.001$) are significant predictors of post-death depression.

Discussion

Existing research on preparedness for death is based exclusively on retrospective accounts of preparedness. Our goal in this study was to assess preparedness for death prior to death, identify pre-death predictors of preparedness, and assess its association with post-death adjustment.

Several important findings emerged from this study. First, the level of reported preparedness for death in this population of caregivers of recently institutionalized older persons was relatively high, with >90% of respondents reporting that they were either ''somewhat'' or ''very'' prepared for the death. This may be expected given the high levels of functional disability of the residents and the fact that their health status required permanent nursing home placement. Spouses reported feeling less prepared than adult children or others, suggesting that their closeness to or dependency on the CR made it more difficult to feel prepared for the death. CGs who were more depressed also felt less prepared. Note that depression levels were relatively high among these CGs; this is consistent with other studies showing that there is little relief associated with institutionalizing the CR.[16]

Contrary to our prediction, anticipating death within 6 months was only marginally related to preparedness; however, this may be due to the short time frame of this question. CGs

Table 5. Multivariate Regression for Complicated Grief after CR Death (N = 80)[a]

Variables	*Coefficient (SE)*		P *Value*
Intercept	9.33	(13.98)	
CG age	0.17	(0.15)	0.269
CG is male	0.10	(2.50)	0.968
CG completed more than high school[b]	−1.07	(2.77)	0.701
CG is adult child of CR[c]	4.33	(3.90)	0.271
CG is not spouse or child of CR[c] (other relationship)	0.30	(4.43)	0.947
CG is African American[d]	3.46	(3.40)	0.312
CG CES-D Scale score	0.70	(0.19)	0.001
Intervention group	1.74	(2.32)	0.457
CR ADL difficulties[e]	−0.25	(0.65)	0.708
CG preparedness for CR death	−4.75	(2.24)	0.038
Time in days between CR death and CG assessment	−0.01	0.02	0.678

[a]Nine observations lost due to missing data on outcome or main predictor (CG preparedness for CR death). Predictors are baseline values; outcome is first observation post-death.
[b]Reference group is high school or less.
[c]Reference group is spouse CG.
[d]Reference group is non African American.
[e]Number of ADLs with which CR has difficulty (range, 0–7).
ADL, activities of daily living; CES-D, Center for Epidemiologic Studies Depression; CG, caregiver; CR, care recipient.

knew that death was likely to occur at some point in the future, but not necessarily within the next 6 months. Finally, CGs who reported that the CR ''expressed feelings about wanting to die'' also reported higher levels of preparedness. This is a new finding that highlights the CR's role in stimulating thoughts about and preparation for death. Expressing a desire to die may reflect high levels of suffering in the CR, which motivates the CG to engage in ACP to reduce the suffering of the CR.

Second, and as predicted, ACP was strongly associated with preparedness even after controlling for sociodemographic characteristics and baseline depression levels. It seems logical that ACP should enhance feelings of preparedness. Although unlikely, we cannot rule out the possibility that feelings of preparedness facilitate ACP because the two measures were collected at the same time prior to death.

Third, CGs who reported feeling more prepared for the death experienced lower levels of complicated grief post-bereavement, demonstrating that preparedness protects against survivor distress. This extends the findings of Barry et al.[2] by showing that pre-bereavement preparedness, as opposed to retrospective accounts of preparedness, also facilitates post-bereavement adjustment.

Even though ACP enhanced CG preparedness, the impact of ACP on survivor distress was not mediated through preparedness; nor was there a direct relationship between ACP and complicated grief. Supplementary analyses, assessing the relation between ACP and patient symptoms as a proxy for quality of death (i.e., CG perceived patient pain, anxiety, or sadness; trouble breathing; expressing feelings about wanting to die) among CGs who experienced the death of the CR yielded no statistically significant relationships. These findings conflict with others showing that ACP improves the quality of end-of-life care as measured by metrics reflecting less aggressive patient care (e.g., lower ventilator use, resuscitation, hospital or intensive care unit admission, and higher hospice enrollment)[17–19]and findings that less aggressive care is associated with fewer depressive symptoms and higher quality of life post-bereavement.[19] Because our proxy metrics for quality of care (caregiver perceived patient symptoms) are different than those typically reported in the literature it is difficult to reconcile these differences. Moreover, none of the existing studies focus exclusively on patient populations in nursing homes as ours does, which may also contribute to the lack of comparable findings. Clearly, more research is needed to explore these differences.

Our findings show that among CGs whose CR dies, $< 15\%$ of nursing home staff have conversations with CGs about the probable death of the CR or ways in which the CG might prepare for this. This is consistent with other studies showing that that communication about death and dying with health care providers remains one of the most neglected aspects of end-of-life care.[5,20,21] This is unfortunate, as many studies have demonstrated links between quality communication and improved psychological well-being of the survivor.[5,19]

One of the limitations of this study is that our measure of preparedness is based on a single item. Based on a series of qualitative studies, Hebert and colleagues[5] proposed that preparedness has emotional (e.g., being at peace with prospect of death), pragmatic (e.g., having funeral arrangements planned), and informational (e.g., medical aspects of end of life) components. Reliable multidimensional assessment tools for measuring preparedness need to be developed and used in future studies of this topic. Such studies would help us to understand the relative importance of different domains of preparation and would enable clinical interventions specifically targeting those aspects of preparation that are most important to CG coping with end of life and death of the CR. Another limitation of this study is the unique population recruited for the study. We focused on CGs who recently placed their CRs in a nursing home, limiting the generalizability of our findings. Nevertheless, these data underscore the importance of preparation as a means for successfully coping with the death of a loved one.

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Author Disclosure Statement

No competing financial interests exist.

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