

Role of family caregivers' self-perceived preparedness for the death of the cancer patient in long-term adjustment to bereavement

Youngmee Kim^{1,2*}, Charles S. Carver^{1,2}, David Spiegel³, Hannah-Rose Mitchell¹ and Rachel S. Cannady⁴

¹University of Miami, Coral Gables, FL, USA

²Center for Advanced Study in the Behavioral Sciences, Stanford University, Stanford, CA, USA

³Stanford University School of Medicine, Stanford, CA, USA

⁴American Cancer Society, Atlanta, GA, USA

*Correspondence to:

Department of Psychology,
University of Miami, 5665 Ponce
de Leon Blvd., Coral Gables, FL
33146, USA.
E-mail: ykim@miami.edu

Abstract

Background: A substantial number of family caregivers go through bereavement because of cancer, but little is known about the bereaved caregivers' long-term adjustment. This study aimed to document levels of bereavement outcomes (prolonged grief symptoms, intense emotional reaction to the loss, depressive symptoms, and life satisfaction) among family cancer caregivers 3–5 years post-loss and to investigate how self-rated preparedness for the patient's death predicted those bereavement outcomes.

Methods: Family members participated in a nationwide survey for cancer caregivers 2 years after the relative's diagnosis (T1). Of those, 109 were identified as bereaved by 5 years post-diagnosis (T2). Of those, 88 continued to participate at 8-year follow-up (T3) and provided valid data for the study variables. Caregivers' distress risk factors were measured at T1, satisfaction with palliative care and preparedness for the death of the patient at T2, and time since death of the patient at T2 or T3.

Results: Substantial numbers of family members (18% to 48%) displayed heightened levels of bereavement-related psychological distress years after the loss. Hierarchical general linear modeling revealed that perceived preparedness for the death of the patient concurrently and prospectively predicted better adjustment to bereavement, independent of contributions of other factors studied.

Conclusions: Findings underscore the high prevalence of long-lasting bereavement-related distress among family cancer caregivers and the role of preparedness for the relative's death in the level of that distress. Findings suggest that psychosocial programs among caregivers focus on not only caregiving skills *per se* but also preparedness for the death of the patient.

Copyright © 2015 John Wiley & Sons, Ltd.

Received: 27 June 2015

Revised: 30 October 2015

Accepted: 10 November 2015

Approximately 1.6 million people are diagnosed with cancer, and more than 570,000 die from cancer each year in the USA [1]. Although the 5-year survival rate has improved for all cancers combined, from 50% in 1974 to 66% in 2010 [1], cancer remains the second leading cause of death in the USA. This results in a substantial number of families going through end-of-life caregiving and bereavement processes because of cancer.

Adjustment outcomes to bereavement from cancer

Family members who are bereaved have shown clinical levels of psychological distress and a lack of meaning in life [2,3]. For example, during the 6 months after the death of their relative from cancer, 6% to 25% of bereaved caregivers have been found to meet the criteria for prolonged grief symptoms/disorder [4,5]; 7% to 40% met criteria for post-traumatic stress disorder [6,7]; and 7% to 42% reported moderate to severe levels of depression symptoms [8,9]. In addition, during the 6 months after the loss,

about 40% reported having difficulty establishing a new worldview [10] and reported lower levels of satisfaction with life compared with non-bereaved demographically similar individuals [11,12]. Grounded on these findings, this study investigated prolonged grief symptoms, post-traumatic stress disorder-like grief symptoms, depressive symptoms, and life satisfaction as primary outcomes.

Predictors of bereavement outcomes among cancer caregivers

A number of theories suggest factors that might predict differences in the extent of these adverse reactions to bereavement (e.g., [3,13–15]). The most widely known caregivers' characteristics that are related to poorer adjustment to bereavement include younger age and female gender [4,16,17], greater psychological distress [14,18], and lower spirituality (lack of meaning and purpose in life) [4,16] prior to the bereavement. Another group of factors relates to the nature of initial caregiving experiences.

Greater caregiving burden, from both perceived caregiving stress [19] and the severity of the cancer [20], has been related to poorer bereavement outcomes.

A third group of characteristics is more specific to end of life. Caregivers who report that healthcare professionals managed the patients' pain and physical ailments well, provided clear information about the patients' prognosis, and were available for the family caregivers prior to the death of the patient have reported better adjustment during end-of-life care and bereavement [21,22]. Despite the fact that death from cancer is statistically common, family members often encounter the death as an unexpected event. Caregivers who reported they were relatively unprepared have shown poor bereavement outcomes up to 12 months after the death, in both elevated depressive symptoms and bereavement-specific distress, such as prolonged grief symptoms [10,22].

Long-term bereavement outcomes among cancer caregivers

In the bereavement literature in general, approximately 10% to 15% of bereaved individuals have been found to display chronic levels of distress and depression for years after the loss, while others recover gradually over a period of 1–2 years after the loss [23]. The modal response to bereavement, however, seems to be acute reactions (about 6 months after the loss) and a return to and maintenance of levels of psychological functioning comparable with that of persons who did not experience the loss [23]. In a longitudinal study of bereaved cancer caregivers, by 18 months post-death, levels of prolonged grief symptoms fell significantly (from 40% at 6 months post-loss to 27% at 18 months post-loss), but symptoms of depression and anxiety remained elevated [24]. Further validation of these findings with family cancer caregivers and investigation of the longer-term bereavement outcomes and their predictors are desirable, as the number of families bereaved because of cancer is substantial and rising.

The study reported here aimed (a) to document levels of bereavement outcomes among family cancer caregivers 3 to 5 years post-loss and (b) to cross-sectionally examine and prospectively predict family caregivers' bereavement outcomes (in this study, prolonged grief symptoms, intensive emotional reaction to the loss, depressive symptoms, and life satisfaction) from the variables identified as key predictors by several bereavement theories and empirical studies. We hypothesized adverse effects of several preexisting risk factors: greater psychological distress and caregiving burden and lower spirituality prior to the death of the patient, younger age, and female gender. We also predicted that lower satisfaction with palliative care and lower level of self-reported preparedness for the death of the patient would be associated with greater bereavement-related outcomes. We hypothesized further

that satisfaction with palliative care and preparedness for death would have stronger association with bereavement-specific distress than with general distress (depressive symptoms and lower satisfaction with life).

Methods

Participants

The National Quality of Life Survey for Caregivers [25] was designed to longitudinally assess the impact of cancer on the quality of life of family members and close friends who were caring for cancer survivors. Caregivers were nominated by the cancer patients for whom they provided care. The patients were identified using multiple state cancer registries as diagnosed with one of the 10 most common cancers [mean age=60.3 years (SD=13.4); 48% female; 92.5% non-Hispanic White; and diagnosed with localized (22.2%), regional (37.3%), or distant (35.4%) cancer; see [26] for more information]. Caregivers were adult family or family-like individuals who provided consistent help during a patient's cancer experience. Eligibility criteria for the caregiver study also included being (a) 18 years and older, (b) able to speak/read English or Spanish, and (c) residing in the USA.

At caregivers' initial assessment (T1: $N=1634$), patients were on average 2.2 years (SD=0.6 years) post-diagnosis. Follow-up data collection [27] at 5 years (T2) and 8 years post-diagnosis (T3) [28] included a survey designed for caregivers whose index patient had passed away by T2 or T3. A total of 159 caregivers were identified as bereaved at T2, and 137 of them provided valid data for study variables at both T1 and T2. Caregivers who provided complete information for the study variables at both T1 and T2 did not differ from those with incomplete data ($ps > 0.19$), with two exceptions. Those with incomplete data, compared with those with complete data, were more likely to be male and had been more recently bereaved at T2 ($ps < 0.03$).

At the second follow-up at 8 years post-diagnosis (T3), 88 of the 137 who were bereaved and provided valid data at T2 continued participation in the study and provided valid data for study variables. Compared with caregivers who provided complete data at both T2 and T3, those who did not provide complete data at T3 did not differ in study variables at T2 ($ps > 0.07$). Characteristics of caregivers with complete information are reported in Table 1.

Procedure

This study was conducted in compliance with the regulations of the Emory University Institutional Review Board. A packet containing an introductory letter, T2 main survey (MS), self-addressed stamped envelope, and a \$10 gift card as an incentive was mailed to the sample of nominated family caregivers who completed T1. The T2 MS

Table 1. Characteristics of the sample and variables

	M	SD	Scale range		
Demographics at T1					
Age	55.99	12.50	24–83 (actual range)		
Gender (female)	82.5%				
Education (>high school)	68.4%				
Income (>\$40,000)	56.2%				
Spouse	57.7%				
Caregiver pre-bereavement risk factors at T1					
Distress (POMS-SF)	3.41	4.81	–4 to 20		
Spirituality	2.78	0.87	1–4		
Caregiving stress	1.89	0.73	1–4		
Cancer severity	0.37	0.29	0–1		
Satisfaction with end-of-life care at T2					
Patient pain	3.84	0.86	1–5		
Patient physical symptoms	3.89	0.96	1–5		
Information	3.92	0.89	1–5		
Access	4.11	0.82	1–5		
Preparedness at T2	3.00	1.24	1–5		
Time since death (years) at T2 (N = 119)	2.87	1.01	0.55–4.96 (actual range)		
Time since death (years) at T3 (N = 86)	4.43	1.32	1.13–6.84 (actual range)		
Bereavement outcomes					
ICG at T2	17.09	12.69	0–76	Clinical cutoff >25	% ¹ 24.1
ICG at T3 (N = 88)	16.74	11.06	0–76	>25	18.2
TRIG at T2	40.20	10.79	13–65	>37	61.3
TRIG at T3 (N = 88)	38.32	10.77	13–65	>37	47.7
CES-D at T2	13.85	11.16	0–60	≥16	36.5
CES-D at T3 (N = 88)	7.85	5.84	0–30	≥8	44.3
Life satisfaction at T2	4.44	1.47	1–7		
Life satisfaction at T3 (N = 88)	4.43	1.32	1–7		

N = 137, otherwise noted.

T1, 2 years post-diagnosis of the relative; T2, 5 years post-diagnosis of the relative; T3, 8 years post-diagnosis of the relative; ICG, Inventory of Complicated Grief; TRIG, Texas Revised Inventory of Grief; CES-D, Center for Epidemiologic Studies Depression Index; SWLS, Satisfaction with Life Scale.

¹Proportion of sample who met the cutoff criteria.

included an item to identify bereaved caregivers. Caregivers who responded ‘no’ to the question ‘Is [patient’s name] alive?’ were instructed to stop completing the MS and return it to receive the bereaved caregiver survey at T2. Those who were identified as a bereaved at T2 received the bereaved caregiver survey at T3. Returning the completed survey served as evidence of informed consent to participate. Two cycles of mailing and telephone follow-up calls were made during an 8-week data collection period corresponding to each time point.

Measures

Distress risk factors at T1

Caregivers’ self-reported age and gender were assessed at T1. Four other measures were assessed as personal pre-bereavement risk characteristics at T1, which have been known to be associated with post-bereavement distress. First, individual differences in pre-bereavement distress were measured by the 30-item Profile of Mood States-Short Form [29], using a 5-point response format

(0 = *not at all*, 4 = *extremely*). A distress score was calculated by subtracting the vigor subscale score from the sum of other subscale scores of anger, anxiety, confusion, depression, and fatigue. Higher scores reflected great levels of psychological distress. This scale had good internal consistency in the present study ($\alpha = 0.74$).

A second measure assessed the extent to which the caregivers reported finding peace and meaning, and relying on faith (i.e., spirituality) when dealing with the patients’ cancer at T1, using the 12-item Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being [30], using a 5-point response format (0 = *not at all*, 4 = *very much*). The mean of the 12 items represented the overall levels of spirituality, with lower scores reflecting lower spirituality. This scale had good internal consistency in our study sample ($\alpha = 0.92$).

Two measures served to capture caregiving burden at T1. The extent to which caregivers felt overwhelmed by tasks and responsibilities was assessed by the 4-item stress overload subscale of the Pearlin Stress Scale [31], using a 4-point response format (1 = *not at all*, 4 = *completely*).

Higher mean scores reflect greater stress from providing care to the cancer patient. This scale had good internal consistency in the present study ($\alpha=0.86$).

A severity index of the care recipients' cancer was created for each patient based on the mortality rate calculated by type and stage of cancer and the time since diagnosis [1,32]. This index, ranging from 0 to 1, served as an indicator of the patient's cancer severity that is comparable across the 10 most common cancers and different stages of cancer at the time of diagnosis. Higher scores reflect a more fatal cancer diagnosis and therefore greater caregiving strain.

Satisfaction with end-of-life care services

The degree to which caregivers were satisfied with the end-of-life care for the patient provided by healthcare professionals prior to the death of the patient was assessed using the 18-item FAMCARE [33] at T2. The FAMCARE includes four aspects of end-of-life care: *managing patients' pain* (three items), *managing patients' physical symptoms* (six items), *providing information* about the patient's prognosis and care coordination to the family members (six items), and being *accessible* for the family members (three items), using a 5-point Likert-style response format (1=*very dissatisfied*, 3=*undecided*, 5=*very satisfied*). Higher scores represented greater levels of satisfaction with the service provided. The subscales had good internal consistency in this sample ($\alpha=0.71$, 0.94, 0.91, and 0.79 for pain, physical symptoms, information, and access subscales, respectively).

Preparedness for the death of the patient

The extent to which the caregivers reported that the family was *prepared* for the death at T2 was assessed by two items, 'I was prepared for his/her death' and 'My family was prepared for his/her death' [34], using a 5-point response format (1=*strongly disagree*, 5=*strongly agree*). Higher mean scores indicated a greater sense of having felt prepared for the death of the patient. This measure had good internal consistency in our sample ($\alpha=0.92$).

Bereavement outcomes

Four indicators served as the family caregivers' adjustment to the loss at T2 and at T3. The first was prolonged grief symptoms, the degree to which the caregivers reported functionally debilitating intrusive thoughts about and yearning for the deceased, resentment, and lack of acceptance of the death, during the past 4 weeks. This was measured by the 19-item Inventory of Complicated Grief (ICG) [35], using a 5-point response format (0=*never*, 4=*always*). Higher sum scores of the ICG represented greater levels of complicated and prolonged grief. This scale had good internal consistency in this study ($\alpha=0.93$ at T2; 0.92 at T3). A score greater than 25 on

the ICG is considered indicating clinical levels of complicated prolonged grief [35].

Second, the degree to which bereaved caregivers reported intense emotional reactions to the loss presently was assessed by the 13-item Present Emotion of Grief subscale of the Texas Revised Inventory of Grief (TRIG) [36], using a 5-point response format (1=*completely false*, 5=*completely true*). Higher sum scores of the TRIG represented greater levels of intense grief that tend to resolve with the passage of time. This scale had good internal consistency in the present study ($\alpha=0.90$ at T2 and T3). A score greater than 37 on the TRIG is considered indicating clinical levels of intense grief [36]. Both the ICG and the TRIG are considered as measuring bereavement-specific distress.

Third, the overall level of depressive symptoms experienced during the past 4 weeks was measured using the 20-item Center for Epidemiologic Studies Depression scale (CES-D) [37] at T2 and the 10-item CES-D [38] at T3, using a 4-point response format (0=*rarely or none of the time*, 3=*most or all of the time*). Higher sum scores represented greater depressive symptoms. This scale had good internal consistency in the present study ($\alpha=0.93$ at T2; 0.90 at T3). A score greater than 16 on the 20-item CES-D and a score greater than 8 on the 10-item CES-D are considered to indicate clinical levels of depressive symptoms [37,38].

Fourth, the degree to which caregivers were in general satisfied with their lives during the past 4 weeks was measured by the 5-item Satisfaction With Life Scale (SWLS) [39], using a 7-point scale (1=*strongly disagree*, 7=*strongly agree*). Lower average scores represent less satisfaction with life. This scale had good internal consistency in the present study ($\alpha=0.92$ at T2; 0.89 at T3). Both the CES-D and the SWLS are considered as indicators of general distress.

Statistical analyses

Means, standard deviations, and ranges of study variables are reported in Table 1. The proportions of the study participants who met the clinical cutoffs of the scales we used are also reported in Table 1. We began by examining bereavement outcomes at T2. General linear modeling (GLM) was used to examine the contribution of each variable to the four bereavement outcomes studied simultaneously while adjusting inflated type I error by multiple comparisons. The GLM (also called multivariate analysis of variance) approach is appropriate to examine outcomes that are highly correlated with each other yet might have different predictors [40]. Predictor variables were entered into the GLM in groups. First, caregivers' distress risk factors, such as age, gender, psychological distress, spirituality, perceived caregiving stress, and patient's cancer severity, that were measured at T1 (block 1) were entered

into the equation predicting bereavement outcomes at T2. Second, the four aspects of satisfaction with end-of-life care and preparedness for the death of the patient assessed at T2 (block 2) were added to the equation, in order to examine the unique effect of satisfaction with care and preparedness on bereavement outcomes, controlling for the effects of factors examined in block 1.

A separate GLM was used to predict bereavement outcomes at T3. Specifically, the four indicators of bereavement outcomes at T3 were simultaneously predicted by caregivers' distress risk factors at T1 (block 1), and satisfaction with end-of-life care and preparedness for the death of the patient measured at T2 (block 2). Significance levels were set at $p < 0.05$. All tests were two sided.

Results

Bereavement-specific and general distress levels

As shown in Table 1, caregivers who participated in this study were overall middle-aged, more female, relatively educated and affluent, and most often spouse to the deceased. While the caregivers were providing care to the patient around the time of cancer diagnosis and treatment (T1), they reported mild levels of caregiving stress. Their care recipient had mild to moderately severe type and stage of cancer. Caregivers reported elevated levels of distress at that time (around 2 years after their relative's initial cancer diagnosis), on average being higher than the US norm [29] ($p < 0.001$). On the other hand, their spirituality levels were comparable with those found in cancer patients [30]. Caregivers reported neutral to slightly favorable levels of satisfaction with the end-of-life care provided prior to the death of the patient, and the levels of satisfaction across the four aspects of the end-of-life care services were highly correlated with each other ($0.70 < r < 0.92$, $ps < 0.001$). Caregivers also reported on average that they were moderately prepared for the impending death of the patient.

Caregivers who were bereaved at the first follow-up (T2) had been bereaved an average of almost 3 years; the average bereavement at the second follow-up (T3) was approximately 5 years. Approximately one-fourth of the bereaved caregivers at T2 and one-fifth at T3 had prolonged grief symptoms that were greater than 25 on the ICG, implying clinically meaningful levels of prolonged grief. In addition, about two-thirds of the caregivers at T2 and half at T3 had intense emotional reactions to the loss that were greater than 37 on the TRIG, which is a clinical cutoff for intense grief. Approximately one-third at T2 had 20-item CES-D scores of 16 or above, and close to half of the caregivers had 10-item CES-D scores of 8 or above at T3, the usual criterion for moderate depression. The percentages of bereaved caregivers who met the criteria for prolonged grief symptoms ($\chi^2 = 1.10$, $p = 0.29$) and

intense emotional reactions to the loss ($\chi^2 = 4.01$, $p = 0.045$) fell from T2 to T3, but the percent meeting criteria for elevated depressive symptoms tended to rise from T2 to T3 ($\chi^2 = 1.37$, $p = 0.24$). Despite this, however, bereaved caregivers at both T2 and T3 reported satisfaction with life at a level that was comparable with that of elderly caregivers [41].

Predicting bereavement outcomes at 5 years post-diagnosis

Next, we examined associations of concurrently reported satisfaction with care and preparedness for the death of the patient with bereavement outcomes at 5 years post-diagnosis (T2) simultaneously. The bereavement outcomes were significantly correlated with each other ($0.461 < r < 0.811$, $ps < 0.001$). As shown in Table 2, caregivers' distress risk factors measured at T1 were entered into the equation first (Block 1). Younger and more distressed caregivers at T1 reported greater levels of prolonged grief symptoms, more intense emotional reaction to the loss, greater depressive symptoms (not significant with age), and lower levels of satisfaction with life, after the loss. Caregivers who had higher spirituality scores at T1, on the other hand, reported lower levels of prolonged grief and depressive symptoms (marginal), and greater levels of satisfaction with life, after the loss. Caregivers whose patient had a less fatal kind of cancer reported less intense emotional reaction to the loss and greater satisfaction with life at T2.

Among the variables entered at block 2 (controlling for effects of factors entered in block 1), the degree to which caregivers were satisfied with the healthcare professional managing their patient's physical ailments during the end-of-life care phase was significantly associated with lower levels of prolonged grief and depressive symptoms after the loss. Caregivers who perceived they were prepared for the death of the patient reported less prolonged grief symptoms, intense emotional reaction to the loss, and depressive symptoms.

Predicting bereavement outcomes at 8 years post-diagnosis

Next, we predicted bereavement outcomes 3 years later (T3) prospectively from measures assessed at T1 and T2. The four bereavement outcomes were once again significantly correlated with each other ($0.371 < r < 0.781$, $ps < 0.001$). As shown in Table 3, age and distress at T1 remained significant predictors of bereavement outcomes at T3 other than life satisfaction. Caregiving stress assessed at T1 emerged to predict less prolonged grief symptoms and intense emotional reaction to the loss at T3, about 5 years post-loss for the most of participants.

Controlling for these factors, caregivers' satisfaction with management of their patients' pain at T2 was significantly associated with greater satisfaction with life at T3,

Table 2. General linear modeling predicting bereavement outcomes at 5 years post-diagnosis (T2)

	Bereavement outcomes at T2															
	ICG				TRIG				CES-D				SWLS			
	B	t	p	η^2	B	t	p	η^2	B	t	p	η^2	B	t	p	η^2
Block 1: distress risk factors at T1																
Age	-0.16	-2.03	0.05	0.03	-0.01	-2.13	0.04	0.03	-0.10	-1.54	0.13	0.02	0.02	2.71	0.01	0.05
Gender	-4.44	-1.76	0.08	0.02	0.10	0.60	0.55	0.00	-0.75	-0.35	0.73	0.00	0.36	-1.25	0.21	0.01
Distress	0.84	2.49	0.01	0.05	0.05	2.37	0.02	0.04	0.89	3.09	0.01	0.07	-0.11	-2.80	0.01	0.06
Spirituality	-3.41	-2.24	0.03	0.04	-0.17	-1.67	0.10	0.02	-2.32	-1.79	0.08	0.02	0.35	2.00	0.05	0.03
Caregiving stress	-1.77	-1.01	0.31	0.01	-0.22	-1.83	0.07	0.03	0.13	0.09	0.93	0.00	0.21	1.04	0.30	0.01
Pt cancer severity	-4.54	-1.38	0.17	0.01	-0.56	-2.50	0.01	0.05	-3.44	-1.22	0.23	0.01	0.77	2.05	0.04	0.03
	$R^2 = 0.265$				$R^2 = 0.212$				$R^2 = 0.304$				$R^2 = 0.290$			
Block 2: satisfaction with end-of-life care and preparedness at T2																
Pt pain	0.70	0.40	0.69	0.00	0.11	0.92	0.36	0.01	-0.16	-0.11	0.91	0.00	-0.21	-1.02	0.31	0.01
Pt physical symptoms	-6.16	-2.25	0.03	0.04	-0.34	-1.84	0.07	0.03	-7.27	-3.18	0.01	0.08	0.12	0.39	0.70	0.00
Information	2.89	1.16	0.25	0.01	-0.03	-0.18	0.86	0.00	3.41	1.64	0.10	0.02	0.06	0.22	0.83	0.00
Access	2.56	1.09	0.28	0.00	0.24	1.52	0.13	0.02	2.74	1.41	0.16	0.02	0.17	0.61	0.54	0.00
Preparedness	-2.43	-2.91	0.01	0.06	-0.15	-2.73	0.01	0.06	-1.83	-2.63	0.01	0.05	0.18	1.82	0.07	0.03
	$\Delta R^2 = 0.079$				$\Delta R^2 = 0.087$				$\Delta R^2 = 0.107$				$\Delta R^2 = 0.040$			

N = 137. Time since death was referenced at T2. Gender = 1 for female, 0 for male.

ICG, Inventory of Complicated Grief; TRIG, Texas Revised Inventory of Grief; CES-D, Center for Epidemiologic Studies Depression Index; SWLS, Satisfaction with Life Scale; Pt, patient.

approximately 3 years after T2. Satisfaction with the patients' physical ailments at T2 remained to predict less intense emotional reaction to the loss and depressive symptoms at T3. Satisfaction with healthcare providers being available for them reported, unexpectedly, greater levels of prolonged grief symptoms, intense emotional reaction to the loss, and depressive symptoms years after the loss. Finally, caregivers who perceived themselves and their family members as being prepared for the death of the patient reported lower levels of prolonged grief symptoms and intensive emotional reactions to the loss years after the loss.

Discussion

Long-term adjustment outcomes of bereavement to cancer

Our bereaved caregivers reported substantial difficulty with bereavement 3–5 years after the loss. Such heightened levels of both bereavement-specific distress—prolonged grief symptoms and intense emotional reaction to the loss—and of general distress—depressive symptoms—have commonly been found among those bereaved less than 6 months [5,9]. However, our study is the first to document bereavement outcomes of family caregivers 3 to 5 years after the death of cancer patients. It is noteworthy that both bereavement-specific and general distress remained quite high at both 3 and 5 years after the loss and the prevalence of bereaved caregivers who met the criteria, indicating clinical levels of both bereavement-specific and general distress was strikingly high at both times.

The prevalence of caregivers who met the criteria for heightened bereavement-specific distress tended to decline, whereas that of general distress tended to increase between 3 and 5 years post-loss, which is directionally consistent with that found by Guldin *et al.* [24]. This suggests the utility of examining profiles of these two correlated types of distress separately in future research. Our findings suggest that mental health professionals should be cognizant of the long-lasting impact of the loss to cancer on the surviving family. Findings also suggest that bereavement support programs should be delivered to family caregivers beyond the acute phase of the bereavement and that those programs should target not only prolonged grief symptoms and intense emotional reactions to the loss but also general depressive symptoms.

Correlates and predictors of long-term adjustment outcomes of bereavement to cancer

We examined several characteristics known to be predictors of adjustment to bereavement months after the loss, looking now for their role in adjustment years later. Unsurprisingly, greater levels of pre-bereavement distress predicted greater levels of prolonged grief symptoms, intense emotional reaction to the loss, and depressive symptoms at both 3 and 5 years after the loss. Higher levels of pre-bereavement spirituality, on the other hand, predicted better bereavement outcomes only at 3 years post-loss. These findings support the notion that some persons are more vulnerable than others to the adverse effects of stress [42,43], including loss of a family member to cancer.

Table 3. General linear modeling predicting bereavement outcomes at 8 years post-diagnosis (T3)

	Bereavement outcomes at T3															
	ICG				TRIG				CES-D				SWLS			
	B	t	p	η^2	B	t	p	η^2	B	t	p	η^2	B	t	p	η^2
Block 1: distress risk factors at T1																
Age	0.19	2.25	0.03	0.06	0.01	1.10	0.28	0.02	0.09	2.17	0.03	0.06	0.00	0.38	0.71	0.00
Gender	-2.07	-0.81	0.42	0.01	0.23	1.14	0.26	0.02	0.03	0.03	0.98	0.00	0.31	0.89	0.38	0.01
Distress	1.10	3.25	0.01	0.17	0.08	2.97	0.01	0.10	0.58	3.39	0.01	0.12	-0.06	-1.32	0.19	0.02
Spirituality	-3.09	-1.96	0.05	0.05	-0.18	-1.39	0.17	0.02	-1.45	-1.82	0.07	0.04	-0.23	1.07	0.29	0.01
Caregiving stress	-4.04	-2.27	0.03	0.06	-0.44	-3.06	0.01	0.10	-0.32	-0.35	0.73	0.00	-0.20	-0.84	0.40	0.01
Pt cancer severity	-3.13	-0.94	0.35	0.01	-0.33	-1.24	0.22	0.02	0.21	0.12	0.90	0.00	0.13	0.30	0.77	0.00
	$R^2 = 0.364$				$R^2 = 0.273$				$R^2 = 0.420$				$R^2 = 0.198$			
Block 2: satisfaction with end-of-life care and preparedness at T2																
Pt pain	-0.90	-0.50	0.62	0.00	-0.10	-0.66	0.51	0.01	0.22	0.24	0.81	0.00	0.68	2.83	0.01	0.10
Pt physical symptoms	-3.61	-1.29	0.20	0.02	-0.45	-2.00	0.05	0.05	-2.91	-2.04	0.05	0.05	-0.33	-0.89	0.38	0.01
Information	-0.70	-0.28	0.78	0.00	0.23	1.12	0.27	0.02	-0.15	-0.12	0.91	0.00	0.30	0.89	0.38	0.01
Access	5.80	2.34	0.02	0.07	0.40	2.00	0.05	0.05	2.90	2.30	0.02	0.07	-0.24	-0.72	0.48	0.01
Preparedness	-1.83	-2.13	0.04	0.06	-0.14	-1.95	0.05	0.05	-0.50	-1.15	0.25	0.02	0.11	0.96	0.34	0.01
	$\Delta R^2 = 0.075$				$\Delta R^2 = 0.082$				$\Delta R^2 = 0.059$				$\Delta R^2 = 0.119$			

N = 88. Time since death was referenced at T2. Gender = 1 for female, 0 for male.

ICG, Inventory of Complicated Grief; TRIG, Texas Revised Inventory of Grief; CES-D, Center for Epidemiologic Studies Depression Index; SWLS, Satisfaction with Life Scale; Pt, patient.

The findings also suggest that palliative care programs should target caregivers who were displaying elevated levels of psychological distress and difficulties with finding meaning, while providing cancer care. The programs should provide coping skills training [44] to help manage distress both then and when they would face the further stressful event of the death of the patient. Such programs may become even more effective in reducing bereavement difficulties by incorporating a spirituality or meaning-based component, as this has been associated with lower levels of bereavement-specific distress and higher levels of life satisfaction in our study and other bereavement studies [45].

Beyond these individual characteristics, satisfaction with palliative care, consistent with existing findings that quality of palliative care provided to the patients [21,22], particularly for managing physical functioning, also played a significant role in surviving family members' adjustment to the loss. On the other hand, the perception that palliative care professionals were accessible was unexpectedly related to greater depressive symptoms years after the loss. This association might be attributable to patients' poorer physical functioning and caregivers' own heightened psychological distress, creating greater needs for having the medical professionals available. Palliative care professionals may have sensed the needs of more depressed caregivers and made themselves more available for that reason. These potential contributing factors, however, had been accounted for in our modeling, suggesting that the target association was significant beyond the effects of patients' illness severity, caregivers' psychological distress, and other individual and caregiving characteristics we studied. Further information about the circumstances

in which family members needed palliative care professionals and whether family members actually sought out them would help clarify how the perceived availability of healthcare professionals during the end-of-life care phase links to better or worse bereavement outcomes of the family members years after the death of the patient.

Another variable shown to be important in bereavement outcomes here was the degree to which family members reported being prepared for the death of the patient. Prepared family caregivers displayed less severe bereavement-specific symptoms, such as prolonged grief symptoms and intensive emotional reactions to the death for an average of 5 years after the death. These associations were significant after accounting for caregivers' other individual and caregiving characteristics as well as their perceptions of quality care given to the patient during the end-of-life care period. This finding highlights the critical need for cancer survivorship and palliative care programs to pay close attention to family caregivers, not only for improving their caregiving skills and competency and enhancing their well-being while they are actively providing care to the patients but also to help them to be prepared for inevitable death of the patient. Family members will benefit from such integrative caregivership programs during various phases of their patients' illness and after the loss.

Limitations and future directions

Besides the limitations of the study described earlier, other domains of adjustment to bereavement, such as benefit finding/post-traumatic growth, spirituality, physical health, and their attitude and practice in healthy lifestyle behaviors, need to be investigated, as they have important implications

in examining how and whether the cancer death compromises the surviving family members' health. Another limitation is that the sample was of relatively high education and income, and primarily Caucasian. Although the sample is moderately large and collected nationwide and prospectively across a substantial period of time, it will also be important to replicate these findings with ethnic minorities, and individuals of lower socioeconomic status. Other individual and caregiving characteristics, such as personality, coping styles, caregiving duration, specific types of care provided, and care network, need also to be investigated in future studies. Developing and validating a measure assessing the degree to which family caregivers are medically, cognitively, and affectively prepared for the impending death of the patient [22] and prospectively testing the effects of preparedness in bereaved family members' long-term adjustment are also important next steps.

Conclusion

Our findings are relevant to survivorship, palliative care, and bereavement research and clinical practice for family cancer caregivers. Importantly, better medical care of the dying patient and emotional preparation of their caregivers both seem to improve bereavement outcomes. The nature of the period of dying, both medically and emotionally, influences long-term psychological outcomes. The results highlight the need for provision of good palliative care

and also bereavement services beyond the acute phase of grief to surviving family members, particularly distressed caregivers. Findings also suggest programs for cancer caregivers during survivorship and end-of-life care phases must incorporate ways in which the family caregivers prepared for the death of the patient in addition to psychoeducational and symptom management training. Family members will benefit from such integrative programs not only while they are providing cancer care but also years after the death of the patient by enhancing their psychological adjustment across the caregivership trajectories.

Conflict of interest

None of the authors have financial conflict of interest to disclose.

Acknowledgements

The authors extend their appreciation to all the families who participated in this investigation and to Richard Schulz for his valuable comments to an earlier draft of this paper. The first author dedicates this research to the memory of Heekyoung Kim and Jagun Meeso. This study was funded by the American Cancer Society National Home Office, intramural research. Writing of this manuscript was supported by American Cancer Society Research Scholar Grants (121909-RSG-12-042-01-CPPB) and the Sylvester Comprehensive Cancer Center, University of Miami, FL, to the first author.

References

- Howlander N, Noone AM, Krapcho M, *et al.* (eds). SEER Cancer Statistics Review, 1975–2009 (vintage 2009 populations). National Cancer Institute. Bethesda, MD. (Available from: http://seer.cancer.gov/csr/1975_2009_pops09/) based on November 2011 SEER data submission, posted to the SEER web site, April 2014.
- Kim Y, Carver CS, Schulz R, Lucette A, Cannady RS. Finding benefit in bereavement among family cancer caregivers. *J Palliat Med* 2013;**16**:1040–1047.
- Schulz R, Hebert R, Boerner K. Bereavement after caregiving. *Geriatrics* 2008;**63**:20–22.
- Chiu YW, Huang CT, Yin SM, Huang YC, Chien CH, Chuang HY. Determinants of complicated grief in caregivers who cared for terminal cancer patients. *Support Care Cancer* 2010;**18**:1321–1327.
- Tomarken A, Roth A, Holland J, *et al.* Examining the role of trauma, personality, and meaning in young prolonged grievers. *Psycho-Oncology* 2012;**21**:771–777.
- Elklit A, Reinholt N, Nielsen LH, Blum A, Lasgaard M. Posttraumatic stress disorder among bereaved relatives of cancer patients. *J Psycho-Oncology* 2010;**28**:399–412.
- Kristensen TE, Elklit A, Karstoft KI. Posttraumatic stress disorder after bereavement: early psychological sequelae of losing a close relative due to terminal cancer. *J Loss Trauma* 2012;**17**:508–521.
- Goodenough B, Drew D, Higgins S, Trethewie S. Bereavement outcomes for parents who lose a child to cancer: are place of death and sex of parent associated with differences in psychological functioning? *Psycho-Oncology* 2004;**13**:779–791.
- Jalmsell L, Kreicbergs U, Onelöv E, Steineck G, Henter J. Anxiety is contagious—symptoms of anxiety in the terminally ill child affect long-term psychological well-being in bereaved parents. *Pediatr Blood Cancer* 2010;**54**:751–757.
- Alam R, Barrera M, D'Agostino N, Nicholas DB, Schneiderman G. Bereavement experiences of mothers and fathers over time after the death of a child due to cancer. *Death Stud* 2012;**36**:1–22.
- Feigelman W, Jordan JR, Gorman BS. How they died, time since loss, and bereavement outcomes. *OMEGA: J Death Dying* 2008;**58**:251–273.
- Haley WE, LaMonde LA, Han B, Burton AM, Schonwetter R. Predictors of depression and life satisfaction among spousal caregivers in hospice: application of a stress process model. *J Palliat Med* 2003;**6**:215–224.
- Lazarus RS, Folkman S. *Stress, Appraisal, and Coping*. Springer Publishing, Inc.: New York, 1984.
- Stroebe M, Folkman S, Hansson RO, Schut H. The prediction of bereavement outcome: development of an integrative risk factor framework. *Soc Sci Med* 2006;**63**:2440–2451.
- Stroebe M, Schut H. The dual process model of coping with bereavement: rationale and description. *Death Stud* 1999;**23**:197–224.
- Kang J, Shin D, Choi J, *et al.* Factors associated with positive consequences of serving as a family caregiver for a terminal cancer patient. *Psycho-Oncology* 2013;**22**:564–571.
- Bernard L, Guarnaccia CA. Two models of caregiver strain and bereavement adjustment: a comparison of husband and daughter caregivers of breast cancer hospice patients. *Gerontologist* 2003;**43**:808–816.
- Aneshensel CS, Botticello AL, Yamamoto-Mitani N. When caregiving ends: the course of depressive symptoms after bereavement. *J Health Soc Behav* 2004;**45**:422–440.
- Wright AA, Keating NL, Balboni TA, Matulonis UA, Block SD, Prigerson HG. Place of death: correlations with quality of life of patients with cancer and predictors of bereaved caregivers' mental health. *J Clin Oncol* 2010;**28**:4457–4464.
- Given BA, Given CW, Kozachik S. Family support in advanced cancer. *CA: Canc J Clinician* 2001;**51**:213–231.
- Aoun S, Bird S, Kristjanson LJ, Currow D. Reliability testing of the FAMCARE-2 scale: measuring family carer satisfaction with palliative care. *Palliat Med* 2010;**24**:674–681.

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**:3–12.
23. Bonanno GA, Boerner K, Wortman CB. Trajectories of grieving. In *Handbook of Bereavement Research and Practice: Advances in Theory and Intervention*, Stroebe MS, Hansson RO, Schut H, Storebe W (eds.), American Psychological Association: Washington, DC, 2008;287–307.
24. Guldin M, Vedsted P, Zachariae R, Olesen F, Jensen AB. Complicated grief and need for professional support in family caregivers of cancer patients in palliative care: a longitudinal cohort study. *Support Care Cancer* 2012;**20**:1679–1685.
25. Kim Y, Spillers RL. Quality of life of family caregivers at 2 years after a relative's cancer diagnosis. *Psycho-Oncology* 2010;**19**:431–440.
26. Smith T, Stein KD, Mehta CC, Kaw C, Kepner JL, Buskirk T, Stafford J, Baker F. The rationale, design, and implementation of the American Cancer Society's studies of cancer survivors. *Cancer* 2007;**109**:1–12.
27. Kim Y, Spillers RL, Hall DL. Quality of life of family caregivers 5 years after a relative's cancer diagnosis: follow-up of the National Quality of Life Survey for Caregivers. *Psycho-Oncology* 2012;**21**:273–281.
28. Kim Y, Shaffer KM, Carver CS, Cannady RS. Quality of life of family caregivers eight years after a relative's cancer diagnosis: follow-up of the National Quality of Life Survey for Caregivers. *Psycho-Oncology* 2016;**25**:266–274. DOI: 10.1002/pon.3843
29. McNair DM, Lorr M, Droppelman LF. *Manual for the Profile of Mood States (POMS), Revised*, EDITS/Educational and Industrial Testing Service: San Diego, CA, 1992.
30. Peterman AH, Fitchett G, Brady MJ, Hernandez L, Cella D. Measuring spiritual well-being in people with cancer: the functional assessment of chronic illness therapy—spiritual well-being scale (FACIT-Sp). *Ann Behav Med* 2002;**24**:49–58.
31. Pearlin LI, Mullan JT, Semple SJ, Skaff MM. Caregiving and the stress process: an overview of concepts and their measures. *Gerontologist* 1990;**30**:583–594.
32. Kim Y, Baker F, Spillers RL. Cancer caregivers' quality of life: effects of gender, relationship, and appraisal. *J Pain Symptom Manage* 2007;**34**:294–304.
33. Kristjanson LJ. Validity and reliability testing of the FAMCARE scale: measuring family satisfaction with advanced cancer care. *Soc Sci Med* 1993;**36**:693–701.
34. 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**:1936–1942.
35. Prigerson HG, Maciejewski PK, Reynolds CF III, et al. Inventory of complicated grief: a scale to measure maladaptive symptoms of loss. *Psychiatry Res* 1995;**59**:65–79.
36. Faschingbauer TR, Zisook S, DeVaul R. The Texas Revised Inventory of Grief. In *Biopsychosocial Aspects of Bereavement*, Zisook S (ed.), American Psychiatric Press, Inc.: Washington, DC, 1987;109–124.
37. Radloff LS. The CES-D scale: a self-report depression scale for research in the general population. *Appl Psychol Meas* 1977;**1**:385–401.
38. Andresen EM, Malmgren JA, Carter WB, Patrick DL. Screening for depression in well older adults: evaluation of a short form of the CES-D. *Am J Prev Med* 1994;**10**:77–84.
39. Diener E, Emmons RA, Larsen RJ, Griffin S. The satisfaction with life scale. *J Pers Assess* 1985;**49**:71–75.
40. Dobson AJ, Barnett AG. *An Introduction to Generalized Linear Models* (3rd ed.), Chapman & Hall/CRC: Boca Raton, FL, 2008.
41. Vitaliano PP, Russo J, Young HM, Becker J, Maiuro RD. The screen for caregiver burden. *Gerontologist* 1991;**31**:76–83.
42. Zisook S, Chentsova-Dutton Y, Shuchter SR. PTSD following bereavement. *Ann Clin Psychiatry* 1998;**10**:157–163.
43. Bernard LL, Guarnaccia CA. Two models of caregiver strain and bereavement adjustment: a comparison of husband and daughter caregivers of breast cancer hospice patients. *Gerontologist* 2003;**43**:808–816.
44. Nezu AM, Nezu CM, Felgoise SH, McClure KS, Houts PS. Project Genesis: assessing the efficacy of problem-solving therapy for distressed adult cancer patients. *J Consult Clin Psychol* 2003;**71**:1036–1048.
45. Breitbart W, Chochinov HM, Alici Y. End-of-life care. In *Clinical Psycho-Oncology: An International Perspective*, Grassi L, Riba M (eds.), Wiley-Blackwell: Oxford, UK., 2012;249–270.