Preloss Spirituality Predicts Postloss Distress of Bereaved Cancer Caregivers

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Published online: 24 July 2018

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Abstract

Background Although spirituality has been identified as a psychological resource relevant to coping with caregiving stress, little is known about the differential roles of spirituality's facets in bereaved caregivers' adjustment.

Purpose This study examined this question with regard to bereavement-specific and general distress in cancer caregivers.

Methods Cancer caregivers provided data at 2 years after their relative's diagnosis when all the patients were alive (Time 1, preloss) and 3 years later, after the patient had died (Time 2, postloss: $N = 128$). Demographics and three facets of spirituality (meaning, peace, and faith) were measured at Time 1. Psychological distress and time since the death were measured at Time 2.

Results Younger age, less education, and being a spousal caregiver of the patient related to greater bereavement-specific and general distress ($t_s \geq 2.02$, $p_s < .05$, partial $\eta^2 \geq .15$). Above and beyond these demographic factors, two preloss spirituality facets related to postloss distress. Specifically, a greater sense of inner peace at preloss was prospectively associated with less bereavement-specific distress (both intrusive thoughts and hyperarousal, $t_s \geq 2.24$, $p_s < .05$, partial $\eta^2 \geq .41$). Greater reliance on faith at preloss was also prospectively associated with lower intrusive thoughts ($t = 2.24$, $p < .05$, partial $\eta^2 = .34$).

Conclusion Findings highlight the importance of preloss sense of peace as a predictor of psychological distress during bereavement. Programs and interventions might be designed to help caregivers find inner peace while caregiving, in an effort to augment their

resiliency against psychological distress when facing the loss of the patient.

Keywords Spirituality • Bereavement • Caregiving • Psychological distress • Longitudinal study

Introduction

Cancer is the second leading cause of death in the USA [1]. Although the overall 5-year survival rate has improved to 67% [2], a large number of family members (i.e., those of the 33% remaining patients) will still become bereaved over this time period. Bereavement imposes many challenges on family members, particularly those who have been involved in providing care to the patients: ~43.5 million adults (17.6%) in the USA have provided unpaid care to their family members [3]. A significant number of family caregivers experience debilitating psychological symptoms after the loss. The symptoms take two general forms [4, 5]. One is bereavement-specific distress, a set of emotional, cognitive, and behavioral symptoms that pertain directly to the loss and the grief experience. The second is general distress, which encompasses more global symptoms such as depression and anxiety.

Both types of psychological distress are common among family members during the first year after the loss. In previous studies, 19%–24% of bereaved family members reported symptoms of bereavement-specific distress, such as difficulty accepting the death, avoidance of reminders of the loss, or heightened physiological reaction when reminded of the loss [4, 6]; 11%–50% of bereaved family members reported elevated levels of general distress, such as depression, sadness, loss of interest, fatigue [4, 7, 8], anxiety, and inability to relax [9]. Both of these suggest the advisability of further screening for potential mental disorders.

Though they often co-occur, these two types of distress are sometimes associated with qualitatively distinct clusters of symptoms that define different facets of grief

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reactions [10], and their trajectories have been shown to diverge after the initial peak during the first year postloss. Specifically, symptoms of bereavement-specific distress tend to remain elevated for several years after the loss [11–13], whereas general distress often subsides by the end of the first year postloss [11]. Bereavement-specific distress, independent of general distress, has been shown to predict a decline in mental and physical functioning, lower self-esteem, and more sleep disturbances [14–16]. Findings suggest that time since the loss might have different effects in the different types of distress: a linear pattern for bereavement-specific distress and a curvilinear pattern for general distress. Thus, this study aimed to examine the changes in general and bereavement-specific distress over time several years since the loss, using a prospective, longitudinal study design.

Predictors of Bereavement-Specific and General Distress

Identifying predictors for each of these two types of psychological distress is an important first step to develop interventions designed to alleviate different symptoms of distress in bereaved caregivers. As posited in theoretical models of coping [17, 18], many psychosocial factors act as either resilience or risk factors for distress. Several demographic characteristics of caregivers—younger age, female gender, less education, and spousal relationship to the deceased—have all been related to greater bereavement-specific distress [4, 6, 8, 9, 19–21] and, to a lesser extent, general distress [9].

In the context of a diagnosis that evokes existential issues related to death and dying [22], spirituality has also emerged as an important resource through which individuals can cope with the challenges brought forth by the diagnosis [23–25]. Spirituality, which refers to a search for peace, wholeness, or harmony with a higher power, and a sense of meaning and purpose in life [26], has been studied mainly with cancer patients rather than their family members. Among cancer patients, findings on higher levels of overall spirituality being associated with better mental health have been inconsistent [27–30], suggesting that the association might be more nuanced, requiring investigation into subfacets of spirituality. For example, meaning (the ability to experience a sense of meaning in life) and peace (feeling of inner peace) facets of spirituality have been related to better mental health, whereas the faith facet of spirituality (a sense of connectedness with a higher power) related to poorer mental health [31]. Meaning and peace facets also differentially related to health outcomes among a large diverse sample of cancer survivors. The meaning facet score was more strongly associated with physical health outcomes, whereas the peace facet score was more strongly associated with mental health outcomes [28]. Statistically, a three-factor solution (meaning, peace,

and faith) fit the data better in that study [28] than a two-factor model (meaning/peace and faith) [28, 31, 32]. These findings suggest the desirability of treating spirituality as a tri-part construct and examining the parts separately.

Among these three facets of spirituality, its religious component, faith, has received the most attention in studies of caregivers' adjustment to bereavement [33]. Although findings have been mixed [33–35], some suggest that faith represents a positive resource during bereavement [34]. Most evidence of this relationship stems from cross-sectional studies [34]. However, a few prospective studies that examined the religiosity/faith facet alone have found that preloss faith was associated either with lower levels of both types of distress [6, 36, 37] or with lower bereavement-specific distress in particular [38]. Other studies have found the opposite effect [31].

Other studies that examined different aspects of spirituality have found that meaning is an important aspect of effective management of general psychological distress [39] in both bereaved caregivers [39–41] and cancer survivors [31, 33]. In one prospective study, mothers who reported finding meaning in life through the caregiving experience reported lower distress as they navigated bereavement, further indicating that cognitively processing the impact of a stressful experience can be a protective factor against future distress [42]. Peace has also been related to better psychological well-being among cancer survivors [31] and their family caregivers [25], contributing independently of meaning and faith.

Research is needed to determine the prospective influence of these facets of spirituality before the loss on distress during bereavement, considering that most evidence to date comes from cross-sectional studies. Thus, this study examined the role of three facets of spirituality—meaning, peace, and faith—assessed at preloss in prospectively predicting two types of distress among bereaved caregivers. We hypothesized that the meaning and peace facets of spirituality would be more robustly related to both general and bereavement-specific distress than the faith facet, above and beyond the associations of demographic risk and resource factors with the distress measures.

Methods

Participants

Family caregivers participated in the American Cancer Society's National Quality of Life Survey for Caregivers [43, 44], which was designed to investigate the impact of cancer on caregivers' quality of life. Patients nominated adult family members or family-like individuals who provided consistent assistance to them, hereafter termed caregivers. Patients were diagnosed with 1 of the

10 most common cancers and were identified through state cancer registries [45]. Eligibility criteria for caregivers were (a) being 18 or older, (b) being able to speak and read English, and (c) residing in the USA.

At initial assessment (Time 1), 1,635 family caregivers completed the survey. Their patients had been diagnosed with cancer an average of 2.1 years ($SD = 0.5$ years) at that time. At the follow-up that took place 5 years post-diagnosis (Time 2), 179 caregivers were identified as bereaved. Of those, 128 provided complete data for study variables and constitute this study sample. Caregivers who provided complete data did not differ from those with incomplete data ($ps > .20$), with one exception. Completers were more likely to report lower levels of intrusive thoughts about the loss than incompleters ($p < .04$).

Procedure

This study was conducted in compliance with the regulations of the Emory University Institutional Review Board. Caregivers at Time 1 received a packet containing an introductory letter, the survey, a self-addressed stamped envelope, and a \$10 gift card as incentive. At Time 2, the caregivers received a similar packet with the Time 2 Main Survey. The Time 2 Main Survey identified bereaved caregivers through the following question: “Is {patient’s name} alive?” Caregivers who answered “no” to that question were asked to return the Main Survey and subsequently received the Bereaved Caregiver Survey.

Measures

Demographics

Age, gender, education, income, and relationship to the care recipient were self-reported at Time 1.

Spirituality

Individual differences in spiritual adjustment with regard to the cancer in the family were measured at Time 1 by the 12-item Functional Assessment of Chronic Illness Therapy–Spiritual Well-being Scale [31, 32], on a 5-point Likert scale (0 = *not at all*, 4 = *very much*). This scale contains three facets of spirituality: *meaning* (four items; e.g., “I feel a sense of purpose in my life”), *peace* (four items; e.g., “I feel peaceful”), and *faith* (four items; e.g., “His/Her illness has strengthened my faith”). Items were slightly reworded to reflect the patient’s illness rather than one’s own illness, for which the scale had originally been designed. Item scores were summed within each subscale. Higher scores of the subscales reflect greater levels of meaning and purpose in life, a greater sense of inner peace, and higher spiritual and religious

faith, respectively. The three subscales have been previously validated among populations of cancer survivors [31] and cancer caregivers [46, 47] and had good internal consistency in our sample ($0.82 < \alpha < 0.91$).

Time since death

The date of the patient’s death was obtained by asking bereaved caregivers at Time 2: “When did [patient’s name] pass away?” Time since death was then calculated in reference to the date at which the caregivers completed the Bereaved Caregiver survey. The curvilinear time term was calculated by squaring time since death.

Bereavement-specific distress

Caregivers’ psychological distress pertaining to the loss was measured at Time 2 using the 22-item Impact of Event Scale–Revised (IES-R) [48], with the traumatic event identified as the patient’s death. Using a 5-point Likert scale (0 = *not at all*, 4 = *extremely*), caregivers indicated the extent to which they experienced *avoidance* (eight items; e.g., “I stayed away from reminders about his/her death”), *intrusive thoughts* (eight items; e.g., “Pictures about his/her death popped into my mind”), and *hyperarousal* (six items; e.g., “I was jumpy and easily startled”) with respect to the death of the patient. Three subscale scores were calculated by averaging scores within each subscale. Higher scores reflect greater avoidance of cancer-related reminders, more frequent intrusive thoughts, and higher hyperarousal, respectively. The three subscale scores of the IES-R had good internal consistency in our sample ($.79 < \alpha < .86$).

General distress

Caregivers’ general distress was measured with the 30-item Profile of Mood States–Short Form at Time 2 [49]. They were asked to rate 30 adjectives describing current feelings and moods on a 5-point Likert scale (0 = *not at all*, 4 = *extremely*). An overall composite score of mood disturbance was calculated by summing the scores of the tension, depression, confusion, anger, and fatigue subscales and subtracting the vigor subscale score. A higher composite score reflects greater overall mood disturbance and general distress. The general distress composite score demonstrated good psychometric properties in prior samples of older adults [49] and had good internal consistency in our study ($\alpha = .86$).

Analysis Plan

Descriptive statistics (means, standard deviation, and range) of study variables were computed. Outcome variables were evaluated to ensure they met assumptions of normality. Data that violated the normal distribution

assumption were to be log transformed, but no such violations were observed. Simple associations among study variables were tested using Pearson correlations for continuous variables and Spearman rank order correlations for categorical variables. Multivariate hierarchical general linear models were used to predict bereavement-specific and general distress simultaneously. In the first step, covariates (i.e., demographics and time since death) were entered into the model. The three facets of spirituality were entered in the second step. Analyses were conducted using SPSS version 24.0. Statistical significance was set at $p < .05$.

Results

Characteristics of the Sample and Variables

Participants' demographic characteristics and descriptive statistics of study variables are presented in Table 1. Participants were middle aged, predominantly women, more likely to be educated ($\geq$ college education), relatively affluent ($\geq$ \$40,000), and spouse to the care recipient. They reported moderate to high levels of spirituality about 2 years after their relative's cancer diagnosis, levels that were lower than those of cancer survivors assessed in other research an average of 2 years [50] or 10 years postdiagnosis [28, 31]. At Time 2, caregivers had been

Table 1 Descriptives of study variables

	Mean (SD) or frequency	Scale range
Demographics at Time 1		
Age	58.85 (13.15)	28–87
Gender (female)	79.7%	–
Education (<high school)	32.8%	–
Ethnicity (non-Hispanic White)	94.5%	–
Income (<\$40,000)	30.5%	–
Relationship to the deceased (spouse)	59.4%	–
Spirituality at Time 1		
Meaning	3.19 (0.79)	0–4
Peace	2.41 (1.06)	0–4
Faith	2.59 (1.24)	0–4
Time since death at Time 2 (years)	2.84 (1.04)	0.49–4.96
Bereavement-specific distress at Time 2		
Avoidance	0.62 (0.54)	0–4
Intrusive thoughts	1.07 (0.68)	0–4
Hyperarousal	0.60 (0.62)	0–4
General distress at Time 2	3.10 (4.20)	–4 to 20

$N = 128$; Time 1: 2 years after the patient's diagnosis, Time 2: 5 years after the patient's diagnosis. The actual ranges of responses were reported for age and time since death.

bereaved an average of 2.8 years. Thirteen percent of bereaved caregivers met criteria for post-traumatic stress disorder -like bereavement symptoms assessed by the total score of the IES-R (≥ 33) [51]. Bereaved caregivers in the sample reported significantly less avoidance than a sample of nonbereaved cancer caregivers [52] ($t = 2.75$, $p < .01$) and comparable levels of intrusive thoughts and hyperarousal ($ps > .33$).

Correlations Among Study Variables

Correlations among study variables are presented in Table 2. All three facets of spirituality were significantly correlated with each other at Time 1, and all psychological distress outcomes were positively correlated with each other at Time 2. All three facets of spirituality were also correlated with both bereavement-specific and general distress outcomes.

Predictors of Bereavement-Specific and General Distress

This study aimed to determine the relation of facets of preloss spirituality with bereavement-specific and general distress. Results from the multivariate general linear modeling analysis are shown in Table 3. Among covariates, younger caregivers reported greater both bereavement-specific and general distress. Less education was a consistent predictor of higher levels of both bereavement-specific and general distress. Lower income was associated with greater general distress. Spousal caregivers were more likely to experience greater intrusive thoughts and general distress ~3 years post loss. Gender and time since death (both linear and curvilinear effects) did not significantly predict any outcome.

Above and beyond demographics and time since death, spirituality (three facets) accounted for additional 11.1%–16.5% variances in outcomes. Specifically, reports of greater inner peace while providing care to the patient (preloss) uniquely predicted lower levels of intrusive thoughts and hyperarousal, and (marginally) general distress after the loss of the patient, providing partial support for our hypothesis. Reports of faith at preloss independently predicted lower levels of intrusive thoughts and marginally predicted lower levels of hyperarousal and general distress, providing again partial support for our hypothesis. Reports of meaning did not uniquely predict any distress outcome, failing to support our hypothesis.

Discussion

This study examined the differential impact of three facets of preloss spirituality on two forms of psychological

Table 2 Correlation coefficients among study variables

	2	3	4	5	6	7	8	9	10	11	12	13	14
1 Age	-.08	.08	.18*	.34***	.14	.15	.11	-.03	-.02	.00	-.08	-.08	-.28***
2 Gender	–	.06	.00	-.22*	.07	.04	.06	.04	.04	-.06	-.01	-.09	-.04
3 Education		–	.22**	.04	-.11	-.15	-.11	.00	.00	.13	.21*	.14	.20*
4 Income			–	-.01	-.16	-.11	.01	.06	.06	.05	.15	.16	.17*
5 Spouse				–	-.10	-.14	-.07	-.08	-.08	.09	.11	.15	.07
6 Meaning					–	.72***	.54***	-.11	-.12	-.29***	-.28**	-.37***	-.46***
7 Peace						–	.59***	-.15	-.14	-.32***	-.39***	-.44***	-.48***
8 Faith							–	-.04	-.04	-.28**	-.36***	-.39***	-.40***
9 Time (L)								–	.98***	-.08	-.08	-.13	.01
10 Time (C)									–	-.08	-.06	-.13	-.01
11 Avoidance										–	.70***	.69***	.45***
12 Intrusive thoughts											–	.80***	.54***
13 Hyperarousal												–	.71***
14 Mood disturbance													–

Pearson product-moment correlation coefficient (r) is reported except for categorical variables (i.e., age, female, spouse, education), for which we used Spearman rank order correlation (ρ).

$N = 128$; Gender = 1 for female, 0 for male; Education = 1 for high school or less than high school, 0 for higher than high school; Income = 1 for less than \$40,000 annual income/household, 0 for more than \$40,000 annual income/household; Spouse = 1 for spouse or partner in a marriage-like relationship, 0 for other relationships; Time (L) = Time since death—Linear; Time (C) = Time since death—Curvilinear.

* $p < .05$, ** $p < .01$, *** $p < .001$.

distress reported by cancer caregivers during bereavement. Although all three facets of spirituality were significantly correlated with all aspects of distress in univariate analyses, multiple regression analyses revealed that only one facet made a unique prediction beyond the predictive power shared by the three facets.

Specifically, caregivers with a greater sense of inner peace during active caregiving later reported lower levels of intrusive thoughts and hyperarousal associated with the loss. These results are consistent with the previous findings of significant associations between inner peace and better mental health among cancer survivors [31]. However, the findings now extend this link to bereaved caregivers, highlighting the role of inner peace prior to the loss as a resilience factor shielding against bereavement impediment. Findings also extend prior cross-sectional studies [25, 31] by suggesting a protective role of peace against psychological distress years after the loss. At a conceptual level, the unique relationship between peace and psychological adjustment shown in the multivariate analysis further supports the necessity to assess this facet of spirituality separately from meaning and faith [31]. The sense of peace could be used as an indicator to detect at-risk caregivers for experiencing greater overall difficulties adjusting to the loss.

The faith facet of spirituality predicted psychological distress in a pattern similar to that of peace, though more

weakly. This finding sheds light on previously reported mixed findings about the role of faith in psychological well-being [33, 35, 53], suggesting that the religious organizational aspect of spirituality may help individuals to cope better with uncontrollable adversity, such as a death in the family. In contrast, meaning, which has widely been considered to be a construct highly similar to peace, and which made significant contribution to adjustment outcomes in previous studies, did not independently predict bereavement distress in the current study. This inconsistent finding may be attributable to the fact that the majority of existing findings reported concurrent associations of meaning with adjustment outcomes. Ability to find meaning after the loss (as opposed to preloss meaning, which we assessed) might be a better predictor of uncontrollable thoughts of the deceased (a subcomponent of the bereavement-specific distress) or the loss experience in general. This needs to be investigated in future studies.

It is noteworthy that bereavement-specific distress, which was assessed an average 3 years after the death of the patients, was high—indeed, at a level that has commonly been found among those bereaved for less than 6 months [54, 55]. Our findings suggest that mental health professionals should be cognizant of the enduring impact of the loss to cancer on the surviving family. Findings also suggest that bereavement support

Table 3 Hierarchical general linear model predicting psychological distress at Time 2

	Bereavement-specific distress						General distress					
	Avoidance			Intrusive thoughts			Hyperarousal			Mood disturbance		
	<i>B</i>	<i>t</i>	<i>p.η</i> ²	<i>B</i>	<i>t</i>	<i>p.η</i> ²	<i>B</i>	<i>t</i>	<i>p.η</i> ²	<i>B</i>	<i>t</i>	<i>p.η</i> ²
Block 1. demographic characteristics	$R^2 = .038$			$R^2 = .119$			$R^2 = .125$			$R^2 = .227$		
Age	−0.02	−0.42	.001	−0.01	−2.15*	.037	−0.01	−2.06*	.034	−0.13	−4.66***	.153
Gender (female)	−0.07	−0.57	.003	−0.01	−0.07	.000	−0.07	−0.51	.002	−0.69	−0.80	.005
Education (≤high school)	0.18	1.70 [†]	.024	0.27	2.13*	.036	0.26	2.23*	.040	1.63	2.21*	.039
Income (<\$40,000)	0.03	0.25	.001	0.22	1.66	.022	0.22	1.88 [†]	.029	2.12	2.78**	.061
Spouse	0.06	0.53	.002	0.26	2.02*	.033	0.20	1.73 [†]	.024	1.60	2.13*	.036
Time since death (linear)	0.03	0.14	.000	−0.36	−1.33	.015	−0.01	−0.04	.000	2.10	−2.15*	.015
Time since death (curvilinear)	−0.01	−0.31	.001	0.06	1.17	.011	−0.01	−0.26	.001	−0.38	−1.35	.015
Block 2. spirituality	$\Delta R^2 = .111$			$\Delta R^2 = .127$			$\Delta R^2 = .165$			$\Delta R^2 = .159$		
Meaning	−0.08	−0.90	.007	0.09	0.88	.007	−0.03	−0.30	.001	−0.76	−1.30	.014
Peace	−0.10	−1.48	.018	−0.19	−2.27*	.042	−0.16	−2.24*	.041	−0.77	−1.69 [†]	.024
Faith	−0.04	−0.89	.007	−0.12	−2.04*	.034	−0.09	−1.81 [†]	.027	−0.54	−1.72 [†]	.025

$N = 128$; $p.\eta^2$ = partial eta squared; Gender = 1 for female, 0 for male; Education = 1 for high school or less than high school, 0 for higher than high school; Income = 1 for less than \$40,000 annual income/household, 0 for more than \$40,000 annual income/household; Spouse = 1 for spouse or partner in a marriage-like relationship, 0 for other relationships.

[†] $p < .09$, * $p < .05$, ** $p < .01$, *** $p < .001$.

programs should be made available to family caregivers beyond the acute phase of the bereavement.

Limitations should be noted in these findings. First, the sample was homogeneous with regard to ethnicity (mainly Caucasians) and was predominantly more educated and relatively affluent; thus, generalizability might be limited. The study should be replicated with ethnic minorities [56, 57]. Second, all variables were self-reported, which might be subject to a social desirability bias. Objective measurement of psychological distress (e.g., a structured clinical interview) and investigation into psychosocial and biobehavioral mechanisms linking different facets of spirituality to various aspects of adjustment to bereavement are warranted. The role of additional psychosocial and behavioral factors independent of preloss spirituality, such as general levels of anxiety and depression, social support, and healthy lifestyle behaviors, in adjustment to bereavement should also be examined with a larger sample.

Despite limitations, this study contributes to the literature on spirituality and cancer bereavement. The findings highlight the importance of operationalizing spirituality as a multidimensional construct and guide identifying at-risk caregivers for elevated and prolonged postloss distress [58]. Family caregivers

would benefit from preloss programs and interventions designed to assist them in finding inner peace during the cancer experience in the family. Such programs may beneficially cultivate resilience against additional adversities throughout survivorship and bereavement for caregivers.

Acknowledgment 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) to the last author. The authors extend their appreciation to all the families who participated in this investigation. The last author dedicates this research to the memory of Heekyoung Kim and Keun Meeso Kim.

Authors' Statement of Conflict of Interest and Adherence to Ethical Standards Amanda Ting, Aurelie Lucette, Charles Carver, Rachel Cannady, and Youngmee Kim declare that they have no conflict of interest. None of the authors have financial conflict of interest to disclose.

Ethical Approval All procedures, including the informed consent process, were conducted in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000.

Compliance with Ethical Standards

Authors' Contributions Amanda Ting was involved in conceptualization, data analysis, and writing (drafting and revision). Aurelie Lucette was involved in conceptualization, writing (drafting and revision), and editing. Charles Carver was involved in conceptualization, revision and editing, and manuscript supervision. Rachel Cannady was involved in editing and data collection and management. Youngmee Kim was involved in conceptualization, investigation process, resource provision, data management, data analysis, writing (drafting and revision), manuscript supervision, and funding acquisition.

Informed Consent Returning the completed survey served as informed consent to participate.

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