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PSYCHOSOCIAL HEALTH OUTCOMES FOR FAMILY CAREGIVERS FOLLOWING THE FIRST YEAR OF BEREAVEMENT

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Abstract

We examine psychosocial outcomes following the first year of bereavement, for 51 family caregivers, including both spouses and offspring. Researchers assessed caregivers during palliative care and again during the second year of bereavement, for social functioning, depression, and distress. For all family caregivers, only depression scores declined significantly between T1 and T2 ($p < 0.05$). Caregiver relationship and gender did not make a difference in recovery. Results demonstrate that poor psychosocial health outcomes exist beyond the first year of bereavement. Early identification of these caregivers is necessary to provide mental health professionals the opportunity to intervene proactively.

Keywords

family caregivers; bereavement; longitudinal design; psychosocial outcomes

The cancer experience is life-altering, extending beyond the patient and impacting the entire family. Family members often take on the role of caretaking, handling the patient's practical and physical needs while also providing emotional support (Masterson, Schuler, & Kissane, 2013). Given these challenges, it is unsurprising that family caregivers report rates of distress and depression that match or exceed those of patients themselves (Taylor, Badr,

Fossella, Pisters, Gritz, & Schover, 2008; Hasson-Ohayon, Godzweig, Braun & Galinsky, 2010). Caregiving can be particularly taxing at the end of life. Caregivers grieve the pending loss of the patient, lose hope for his/her recovery, and may reach their limits in terms of care provision (Collins, Liken, King, & Kokinakis, 1993). For family members caring for a terminally ill patient, the high rate of psychological morbidity during care provision is particularly alarming as further stressors associated with bereavement are imminent.

For this reason, research efforts have been directed toward identifying the course and predictors of psychosocial morbidity in bereavement for families and caregivers of terminally ill patients (Tang, Chang, Chen, Wang, Shen, Li, & Liao, 2013; Chiu, Huang, Yin, Huang, Chien, & Cuang, 2010; Chentsova-Dutton, Shucter, Hutchin, Strause, Burns, Dunn, Miller, & Zisook, 2002; Ling, Chen, LI, Chang, Shen, & Tang, 2013). The relief and depletion models have been introduced to demonstrate the course by which family caregivers move through the stages of care and bereavement. Proponents of the relief model advocate that the death of the patient brings an end to the patient's suffering as well as an end to the burden of caregiving, and is therefore appraised as a relief to family caregivers (Li, 2005). The death provides caregivers with the opportunity to re-engage in their previous activities, which also help them to cope with the loss during bereavement. In contrast, the depletion model, argues that caregiving is a chronic stressor that depletes a person's social as well as personal resources. By the time the patient's death occurs, caregivers have already been depleted of their coping resources; therefore, at this time they are not equipped to combat a second stressor: the onset of bereavement. According to this model, the overwhelming strain resulting from the caregiving experience is expected to persist through bereavement, leaving the caregiving spouse vulnerable to negative bereavement outcomes (Li, 2005).

Research has demonstrated that family caregivers who are particularly distressed at the end of life are most often those who experience improved psychosocial health in bereavement, as overload predicts caregiver depression during active caregiving and relief during bereavement (Li, 2005). For example, following the death of their spouses, caregivers who previously had higher levels of depressive symptoms, worse health practices and higher strain, demonstrated improved health practices and no further increases in depression symptoms, anti-depressant medication use, or significant weight loss (Schulz et al., 2001). A number of studies have found complementary results in which, family caregivers experience increased depressive symptoms as their care recipients approach death, and in the immediate months following the death, and then report improvements across the first year of bereavement (Li, 2005; Chentsova-Dutton et al., 2002; Ling et al., 2013). For these caregivers who experience excessive strain, the death of their spouse represents a significant reduction in burden, rather than further weakening of their ability to cope, as hypothesized in the depletion model (Schulz et al., 2001).

Although research has supported the notion that the majority of family caregivers demonstrate improvements in psychosocial health across the first year of bereavement, a subset of caregivers demonstrate psychological morbidity that remains well beyond the one year anniversary. Risk factors for poor bereavement outcomes in family caregivers include, lack of social support, high patient distress, heavy burden, high rate of schedule disruptions,

health deterioration, sense of family abandonment, low caregiver esteem, female gender, dysfunctional family relations, lack of religious belief, history of mood-comorbidity, and spouse relationship to the patient (Tang et al., 2013; Chiu et al., 2010; Kissane, McKenzie, McKenzie, Forbes, O'Neill, & Bloch, 2003).

The spousal relationship has often been viewed as a relationship in which caregivers experience the most significant distress both while providing care, during, and after the patient's death. Recent studies examining the impact of the relationship between the caregiver and patient on psychosocial functioning have yielded mixed findings. Some research reported that spouses had significantly higher levels of depression in bereavement than adult offspring (Ling et al., 2013), but other research reported no significant differences across any of the assessed psychosocial domains between adult offspring and spousal caregivers (Chentsova-Dutton et al., 2002). Li (2005) suggested that the impact of caregiving was felt more strongly by spouse caregivers, as spouses demonstrated a significantly greater decline in depressive symptoms during bereavement than daughter caregivers.

Despite the insight that these findings provide, these results date back nearly a decade and may not capture experiences specific to the cohort of adult offspring providing care in today's climate. In past years, concern has been directed toward the growing population of the generation known as "Sandwich Generation." Recent statistics have shown that nearly 10 million Americans are considered to be a part of the "Sandwich Generation," aged 35–60 years, with over 25% of American families simultaneously providing child and elder care (Taylor, Parker, Patten, & Motel, 2013). The majority of adult offspring caregivers are members of the challenged group, who struggle to balance the role of caregiver in addition to the demands of caring for children, maintaining employment, and controlling finances. As demands of members of the "Sandwich Generation" continue to increase, adult offspring may be at higher risk for overload and caregiver burden. Further research directed at this subset of caregivers is warranted to adequately assess unmet needs as well as the prevalence of caregiver burden that is indicative of this role as well as to providing end of life care.

In addition to relational differences, gender differences have been widely researched in this context. Previous research has suggested that gender differences do exist between women and men both during care provision and bereavement (Navaie-Waliser et al., 2002; Matthews, 2003; Hagedoorn, Sanderman, Buunk, & Wobbes, 2002). Women caregivers are more anxious, fearful of a recurrence, uncertain about the future and worried about diagnostic tests than men caregivers (Matthews, 2003). Women caregivers also execute more intensive and complex caregiving tasks than men, and in turn report more difficulty providing care, perceived stress surrounding the role, and unmet needs (Navaie-Waliser et al., 2002; Kim, Baker, Spillers, 2007). In accordance with the relief model, due to the high distress that women caregivers experience at the end of life, we would expect women caregivers to show improvements in bereavement; yet, female gender continues to be cited as a risk factor for complicated grief (Chiu, 2010).

Bereavement-related depression can lead to adverse bereavement outcomes such as somatic distress; sleep disorders; social dysfunction; feelings of hopelessness, guilt, and worthlessness; suicidal ideation or suicide; and overall poor quality of life for bereaved

caregivers (Stroebe, Schut, & Stroebe, 2007; Zisook & Shear, 2009). During the first year, it is typical for the bereaved person's social support networks to mobilize in an attempt to offset feelings of sadness and loneliness. However, at the end of the first year, as these support networks begin to dissipate, it is particularly important to identify and attend to enduring psychosocial health issues that still remain. For this reason, the lack of longitudinal research on family caregivers extending beyond the first year of bereavement is problematic. It is of the utmost importance to understand not only the risk factors for poor psychosocial health outcomes for family caregivers, but to identify those caregivers who are particularly at risk for experiencing enduring issues following the first year of bereavement.

In secondary analyses of data from a larger randomized controlled trial (RCT), we examine psychosocial health outcomes of family caregivers whose loved one was in palliative care, following the first year of bereavement. We examined their depression, distress, and social functioning, as well the roles of relationship and gender in determining their adjustment during caregiving and following the first year of bereavement. Due to the immense stress that caregiving places on family members, we expected bereavement to serve as a relief for caregivers and to induce improved social functioning and reduced depression and distress in the second year of bereavement. Furthermore, we hypothesize that the relief model will be supported by adult offspring and women caregivers in particular due to the risk for overload and caregiver burden.

Method

Participants

Initially, 487 caregivers were enrolled in the RCT. Of these, 143 were randomized to the control condition (consisting of assessments only, and no therapy). Data from 52 of 143 possible family caregivers randomized to the RCT's control condition were included in the present study. Only partner and offspring caregivers were included; parents, friends, and caregivers of other relations were excluded ($n = 36$). For analysis purposes, caregivers who did not report data from both the T1 and T2 data collection time points were excluded ($n = 43$). In the larger RCT, if the patient outlived his/her prognosis, surviving throughout the average duration of the therapy phase, follow up (T2) assessments were administered at the end of this duration as opposed to being timed by the date of the patient's death. These cases ($n = 13$) were excluded from the current sample. 51 caregivers who had experienced a loss > 13 or more months prior to the final data collection time point (T2) were included. The range of time since loss at T2 was between 13 and 27 months, the average time since loss was 16 months.

Of the 51 family caregivers (29 women, 22 men) included in the current study, 30 (59%) were offspring and 21 (41%) were spouses. Sociodemographic, disease, caregiving, and family relationship information is provided in Table 1. Ages ranged from 13 to 78 years ($M = 44.1$, $SD = 16.5$). The age range for spouses was 42 to 78 years ($M = 58.8$, $SD = 10.6$) and for offspring was 13 to 52 years ($M = 33.8$, $SD = 11.2$). In the spouse group, 9 participants were men and 12 were women. The offspring group was comprised of 14 men/boys and 16 women/girls. The sample was primarily Caucasian (86.3%), in addition to Hispanic (7.8%), African American (3.9%), and Asian (2%). The patients receiving care

were diagnosed with a variety of cancers, with primary diagnoses including gastro-intestinal, melanoma, and lung.

Materials

Social Adjustment Scale (SAS; Weissman & Bothwell, 1976) is 45 questions in seven subscales, each assessing psychosocial functioning in the following domains: work outside the home, housework, social and leisure activities, extended family, marital, parental, and family unit. On a 5 item Likert scale ranging from 5 = *All of the time* to 1 = *Not at all* participants report how often they have experienced the following events, feelings, etc. in the past 2 weeks Sample items include, *‘Over the past 2 week have you...Been ashamed at how you have been doing your work?; Been able to talk openly about your feelings with relatives?’* With some items reverse scored, SAS total scores range from 45 (optimal adjustment) to 225 (poor adjustment). The SAS has demonstrated excellent reliability at 0.72 (Weissman & Bothwell, 1976).

Brief Symptom Inventory (BSI; Derogatis, 2000) is a reduced version of the Hopkins Symptom Checklist-90, which yields global ratings of psychological morbidity (Derogatis, 2000). The BSI has 3 sub-scales measuring somatic symptoms, depressive symptoms, and anxiety symptoms. Participants report how much a problem bothered them over the past 7 days (0 = *Not at all* to 4 = *Extremely*), total scores range from 0 to 72, with higher scores indicating higher distress. Sample items include, *‘faintness or dizziness, feeling hopeless about the future, and feeling tense or keyed up.’* The BSI has demonstrated reliability with alpha coefficients ranging from 0.68 to 0.91, in addition to convergent and predictive validity (Derogatis, 2000).

Beck Depression Inventory II (BDI-II; Beck, Steer, & Brown, 1996) is 21 items rated on a scale from 0 to 3. The cognitive items of the Beck Depression Inventory (BDI-II) constitute its short form, which correlates with the full version, yet eliminates somatic symptoms that may be misleading when administering the measure to the medically ill (Beck, Steer, & Brown, 1996). Respondents describe the way they have been feeling during the past week. Scores from the BDI-II range from 0 (minimal depression) to 63 (high depression), scores result in clinical categories of depression ranging from minimal depression (score of 13 or less) to severe depression (score of 29 or greater). The BDI-II has been shown to be reliable and valid in its 40 years of psychometric evaluation with an alpha coefficient of 0.91. This measure was also administered at all study time points.

Procedure

The study is a secondary analysis of data from a larger National Cancer Institute funded RCT involving family therapy. The RCT’s primary aim was to determine the optimal dosage of a family-focused grief therapy intervention for distressed families and patients, identified using the Family Relationships Index (Moos & Moos, 1986). Family members participated in the study from the time of consent (during palliative care) to approximately 13 months after the patient’s death. For participants under the age of 18, the minor’s assent was obtained, while his or her legal guardian provided informed consent. Due the unpredictable

nature of death, some families participated in the study for a longer period of time than others; the shortest participation was 13 months and the longest was 29 months.

Researchers mailed questionnaire packets to all participants at two time points. Time point 1 (T1) was upon the participant's study enrollment, while a loved one was receiving palliative care and time point 2 (T2) occurred approximately 13 months after the patient's. Questionnaire packets included items and measures collecting demographic information, and self-report measures assessing levels of depression, social adjustment, and psychological distress. All study measures and procedures were approved by the Institutional Review Board.

Results

All analyses utilized generalized estimating equations (GEEs) to estimate associations with psychosocial health. Observations were nested by family and individual to control for potential intraclass correlations. Descriptive statistics for outcome variables explored are presented in Table 2, and results from GEE analyses are presented in Table 3.

In an initial analytic step, we examined changes in social functioning, distress symptoms, and depression between time 1 and time 2, nesting observations by family and by individual. Time (pre- vs. post-loss) was significantly associated with depression ($\beta = -2.6$, $\chi^2(1, N = 100) = 7.8$, $p = .005$), and BDI score means decreased from pre- ($M = 12.0$, $SD = 7.4$) to post-loss ($M = 9.4$, $SD = 8.9$). This association was still significant when age, relationship to the patient, gender, and months since loss at T2 were included as covariates in the model. Time relative to the patient's death was not significantly associated with SAS or BSI scores.

In the second analytic step, we examined differences in change over time between spouses and offspring. Interestingly, offspring reported fewer distress symptoms from T1 to T2 (T1: $M = 12.6$, $SD = 10.5$ versus T2: $M = 9.5$, $SD = 10.4$, respectively), whereas partners reported more symptoms (T1: $M = 8.1$, $SD = 7.7$ versus T2: $M = 11.7$, $SD = 11.9$, respectively). However, this association did not reach significance ($\beta = 6.6$, $p = .08$). In contrast, offspring demonstrated worsening social functioning (T1: $M = 93.7$, $SE = 3.3$; T2: $M = 96.5$, $SE = 4.3$) while partners' social functioning improved (T1: $M = 100.8$, $SE = 4.4$; T2: $M = 90.3$, $SE = 5.1$). Neither of these associations was significant.

In the final analytic step, we examined whether gender relates to psychosocial health following the first year of bereavement, which included looking at offspring and spouses separately. Overall, women expressed an increase in distress symptoms (T1: $M = 11.2$, $SD = 10.3$; T2: $M = 8.1$, $SD = 6.6$), while men experienced a decrease (T1: $M = 105.7$, $SD = 21.3$; T2: $M = 95.1$, $SD = 24.0$). However, these results, as well as all the time x gender interactions were not significantly associated with psychosocial health for any of the assessed domains.

Discussion

Family caregivers face unique and, at times, overwhelming challenges during palliative care and through bereavement, resulting in high levels of self-reported distress. The present

family caregivers reported significantly fewer depressive symptoms following the first year of bereavement than during caregiving. This result supports previous research that has identified a trajectory where depressive symptoms peak during end-of-life care and immediately following the death, but then decline during the first 13 months of bereavement (Chentsova-Dutton et al., 2002; Ling et al., 2013). Furthermore, our finding contributes to the current body of literature by demonstrating that caregiver depressive symptoms continue to decline beyond the first 13 months of bereavement and into the second year. We hypothesized that a uniform improvement in the psychosocial sphere would be witnessed post-loss, in accordance with the relief model. However, although family caregivers reported significantly fewer depressive symptoms, their social functioning and overall distress were not significantly improved at the post-loss time point.

Other research has suggested that gender differences for caregiving partners may exist during care provision as well as in bereavement (Navaie-Waliser et al., 2002; Matthews, 2003; Hagedoorn, Sanderman, Buunk, & Wobbes, 2002). Previous literature has hypothesized that bereaved men, more so than bereaved women, may struggle to engage in social activities and to find an outlet for emotional expression that rivals what their spouses provided (Strobe et al., 2001). Our findings do not support this notion.

Changes in depressive symptoms from pre- to post- loss were not significantly different between offspring and spousal caregivers; both offspring and spouses showed improvements from end of life care through the second year of bereavement. Surprisingly, the decline of depressive symptoms was not accompanied by a significant decline in distress or improvements in social functioning. Clinically, it is not uncommon to encounter a bereaved caregiver who is experiencing relief in one domain, yet prolonged sadness in another. It is possible that even as the acute pain of loss eases, there may be an enduring legacy of familial dysfunction that interferes with reorganizing one's social connections, both within and outside the family, after a key member is gone. These findings highlight the complicated nature of the grief experience and support a need for a further investigation with a larger sample size to develop an integrated view of grief that encompasses these contradictory manifestations.

A major limitation in this study is the limited number of follow-up assessments. While the pre- and post- loss study design is beneficial and represents a strength of this project, the lack of additional assessments over the first year of bereavement prevents us from investigating at which points along this trajectory bereaved family members encounter difficulties and are able to make adaptive adjustments. However, our study does illustrate an understudied time point, the period of time at which the first year of bereavement concludes. Many changes occur in a bereaved family member's life as the first anniversary of the patient's death passes; this study highlights the experience of family members during this time and identifies the psychosocial health issues that still remain for the bereaved. A second limitation is the label of "family caregiver." This sample was composed of both offspring and partners of the patient, identified by the patient as family members involved in his/her care. Although these family members performed some degree of caregiving duties, it is unclear which participants were "primary caregivers" and which were "supplemental caregivers." It is possible that within these families, a friend, sibling, or formal caregiver

provided the majority of care. In future studies, it is of paramount importance to ask the patient to identify the primary caregiver. This study design will ensure that the caregiver most at risk of psychological morbidity will be the target of the research or intervention. Finally, although our sample of 51 participants is considerably large for research with this population, future studies with larger sample sizes could be extremely beneficial. A larger sample would enable analyses to more effectively control for relevant covariates. Although our results were not affected by the inclusion of age, time since death at T2, relationship to the patient, and gender in the models run, we only report results for models with no covariates because of concerns about the over inclusion of predictor variables given the number of observations we obtained.

Our findings illustrate the difficulties that family caregivers encounter when caring for an ill loved one and the adjustments that are made throughout bereavement. Rather than supporting the existing relief and depletion models, our results suggest the need to integrate these models to better depict the true path through which family caregivers travel through the illness experience. The results demonstrate the need for further longitudinal research across this continuum to explore the specific mechanisms of the caregiving experience that result in depression, poor social adjustment, and caregiver burden beyond the first year of bereavement. It is imperative to identify the problematic pieces of the caregiving experience that may be responsible for negative bereavement outcomes, particularly in family members who report extreme distress prior to the loss of the patient. The identification of these factors could provide clinicians with the ability to proactively foster healing during caregiving as opposed to resorting to reactive methods during bereavement.

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Table 1.

Demographic Information (N=51)

Demographic Variable	M (SD) / n (%)
<i>Age (average in years)</i>	44.1 (16.5)
Relationship	
Offspring	30 (58.8%)
Partners	21 (41.2%)
Race	
Caucasian	44 (86.3%)
Hispanic	4 (7.8%)
African American	2 (3.9%)
Asian	1 (2%)
Gender	
Male	22 (43.1%)
Female	29 (56.9%)
Patient's Cancer Type	
Gastrointestinal	30 (58.8%)
Lung	4 (7.8%)
Melanoma	2 (3.9%)
Brain	1 (2%)
Other Type	14 (27.5%)

Table 2.

Descriptive statistics for measures of psychosocial health during caregiving and after the first year of bereavement, broken down by gender and relationship to patient (N=51)

Caregiver Group	SAS Score ^a (Social Functioning)		BDI Score ^a (Depression)		BSI Score (Distress)	
	Pre-Death M (SD)	Post-Death M (SD)	Pre-Death M (SD)	Post-Death M (SD)	Pre-Death M (SD)	Post-Death M (SD)
All Caregivers	101.9 (20.5)	99.0 (24.8)	12.0 (7.4)	9.4 (8.9)	10.8 (9.6)	10.4 (11.0)
Spouses (n=21)	105.7 (21.3)	95.1 (24.0)	13.1 (8.9)	10.4 (10.3)	8.1 (7.7)	11.7 (11.9)
Offspring (n=30)	99.1 (19.8)	101.9 (25.3)	11.2 (6.2)	8.6 (7.8)	12.6 (10.5)	9.5 (10.4)
Males (n=22)	99.6 (22.9)	92.6 (19.1)	10.6 (8.1)	7.4 (6.7)	11.2 (10.3)	8.1 (6.6)
Females (n=29)	103.7 (18.6)	104.1 (27.7)	13.1 (6.8)	10.9 (10.2)	10.4 (9.2)	12.2 (13.2)

^a = 1 participant's responses are missing.

