Long-Term Caregiving: What Happens When It Ends?

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Data from a longitudinal study were used to examine what happens to caregivers in the years after their cognitively impaired spouse dies. Comparisons of 42 current caregivers, 49 former caregivers, and 52 noncaregivers over a 4-year period showed that former caregivers did not improve on several measures of psychological well-being. Although former caregivers experienced decreases in stress and negative affect, their scores on depression, loneliness, and positive affect did not rebound to levels comparable to noncaregivers and, in fact, remained similar to those of current caregivers up to 3 years after caregiving had ceased. The most consistent predictors of postcaregiving outcomes were social support and intrusive-avoidant thinking about caregiving. The data suggest that some consequences of long-term caregiving may be long-term as well. The needs of former spousal caregivers warrant greater attention both in research and in practice.

Caring for a relative with Alzheimer’s disease or other progressive dementing illness can be extremely stressful. In addition to watching a loved one gradually lose cognitive abilities, caregivers must cope with the loved one’s difficult behavioral problems and ultimately must assist with his or her basic care needs. The course of the disease is unpredictable and uncontrollable but often lengthy, with survival time after onset ranging from 8 to over 20 years (Butler & Lewis, 1982). For those caring for a close family member or spouse, caregiving is also accompanied by the gradual loss of an important relationship. Caregivers have described a kind of living bereavement as they watch the gradual loss of their family member (Light & Lebowitz, 1989). Both caring for a loved one with a dementing illness and experiencing the loss of a loved one can be severe psychosocial stressors, and such stressors have been related to the development of depression (Diagnostic and Statistical Manual of Mental Disorders, 4th ed.; DSM-IV; American Psychiatric Association, 1994). Studies of caregiving represent a natural experiment of the mental health consequences of extreme, chronic stress, allowing researchers to examine not only mental health outcomes, such as depression, but also the correlates of those outcomes.

Exposing mental health among caregivers, researchers have found higher scores on depression scales and higher rates of depressive disorders (see review in Schulz, O’Brian, Bookwala, & Fleissner, 1995). Dura, Stukenberg, and Kiecolt-Glaser (1990) found that caregivers had higher rates of syndromal depression despite no differences in lifetime history or family history of psychopathology. Thus, caregiving for a demented family member appears to be linked to the onset of depression even in individuals with no evidence of vulnerability.

Although researchers have studied the negative consequences of long-term caregiving for the past several decades, they have only recently questioned what happens to caregivers after the death of their loved one. Do caregivers improve in psychological health to precaregiving levels, or do they remain affected by their caregiving experiences and the slow, difficult loss of their family member? Does their vulnerability to depressive symptoms continue or remit? How do caregivers fare after long-term family caregiving ends and their lives without caregiving responsibilities resume?

We know little about how involvement in family caregiving affects caregivers’ response to a family member’s death (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995). Bass and Bowman (1990) were among the first to highlight competing hypotheses about the relationship between caregiving and bereavement. They hypothesized that, on the one hand, caregivers may experience positive outcomes following the death of their family member because of their relief from the burden of daily caregiving. They pointed out, however, that just the opposite may occur. It is possible that the long-term stress of caregiving may wear down caregivers’ resources, making it more difficult for them to cope with the loss of their loved one and resulting in further negative outcomes.

Schulz, Newsom, Fleissner, DeCamp, and Nieboer (1997) reviewed the available literature and found little evidence for the hypothesis that caregiving leaves the person depleted and disadvantaged in coping with the loss of their family member. They suggested that caregivers do not experience long-term difficulty in adjusting to the death of their family member. They reported that
although some studies have found short-lived (less than 1 year) increases in negative affect among caregivers following the death of their family member, there was also strong evidence that caregivers experienced positive outcomes, such as feelings of relief from caregiver burden and increased quality of life.

In contrast, Bodnar and Kiecolt-Glaser (1994) found that bereaved caregivers continued to exhibit elevated levels of depressive symptomatology and continued to experience higher rates of syndromal depression than noncaregivers for an average of almost 20 months after the death of their family member. These rates of depression did not differ from their group of caregivers who were continuing to care for a family member with a dementing illness. Similarly, Mullan (1992) reported that former caregivers’ level of depression was the same 1 year after the death of their family member as when they were in the midst of caregiving. Collins, Stommel, Wang, and Given (1994) found that although female caregivers experienced a decrease in depression following their relative’s death, male caregivers actually experienced an increase in depression for an average of 22 months after their relative’s death.

There are a number of methodological problems in the available literature, such as a lack of consistency in the timing of follow-up interviews (Schulz et al., 1997). In addition, most studies are limited to only one postdeath follow-up interview, typically within the first year after the death of the demented family member. Using data from a multiwave study of persons caring for a family member with a dementing illness, Mullan (1992) examined changes in well-being between the first and second annual interview of persons whose demented family member had died during the months between the two interviews. The time since loss ranged from 0.36 to 12.1 months. Examining changes in depression as a function of the time since the family member’s death, Mullan reported a curvilinear relationship. Caregivers appeared to experience an increase in depression immediately after the death of their family member, followed by a decrease in depression to below baseline levels at 6 months, followed again at 1-year follow-up to levels of depression similar to those during active caregiving.

In one of only a few studies to explore longer term (3 years postloss) changes following a demented family member’s death, Aneshensel et al. (1995) analyzed data from this same study using additional follow-up interviews. They reported that depression decreased slightly between the first (predeath) and second (initial postdeath) interview and then remained stable between the second and third follow-up interview. They reported large and significant changes in role overload between the predeath interview and subsequent interviews. Anger decreased sharply during the year postloss, and this improvement remained throughout the follow-up period. The authors concluded that family caregivers were functioning as well or better than they were while caring for their family member, with the greatest change observed in their feeling less overwhelmed by the demands of their lives. Finally, Skaff, Pearlin, and Mullan (1996) reported that these former caregivers experienced an increase in their sense of mastery in the years following the death of their demented family member, providing further support for improved psychological functioning after the cessation of caregiving.

In contrast to these longitudinal analyses, Wells and Kendig (1997) analyzed cross-sectional data from a large survey of approximately 600 community residing older adults. They were able to categorize and compare persons who were (a) married and not caregiving for their spouse, (b) married and the primary caregiver for their spouse, (c) recently widowed and the former caregiver for their spouse, and (d) recently widowed and not formerly caregiving for their spouse. Wells and Kendig reported that former caregivers fared reasonably well relative to widowed persons who had not been caregivers prior to their spouse’s death, and they suggested that having forewarning of a spouse’s death, as well as sufficient time to prepare for it, resulted in better adjustment following the loss of a spouse. However, former spousal caregivers described life as being less meaningful, manageable, and comprehensible than those who had never been caregivers. This apparent “loss of faith in the order and purpose of life” (Wells & Kendig, 1997, p. 672) persisted for years after the death of their spouse.

It is hard to reconcile these somewhat contradictory findings. We do not yet fully understand what happens to long-term caregivers when their caregiving role comes to an end. It is important to know what happens, not just immediately after the family member’s death, but in the years following the impaired family member’s death. Researchers need to more closely examine whether individuals who have spent years caring for a family member are able to recover from their caregiving experience and return to estimated baseline (i.e., pre caregiving) levels of functioning. We also need to explore how long it takes for caregivers to return to their estimated baseline and what variables predict that recovery.

A number of variables have been examined as predictors of outcomes following bereavement, including age, education, relationship to the deceased family member, forewarning of death, difficulties or dissatisfaction with caregiving, social support received during caregiving, and social support during bereavement (Schulz et al., 1997). Schulz et al. (1997) also argued that adjustment may be more difficult the longer the person had been providing care, the greater the amount of care provided, and the more stressful the caregiving, because of a depletion over time in stress-buffering resources. According to Schulz et al.’s (1997) review, however, the variable that has most consistently predicted post bereavement outcomes is social support, particularly support received from family and friends during the caregiving period. In addition to social support, Bodnar and Kiecolt-Glaser (1994) found that intrusive and ruminative thoughts about caregiving were significantly related to depression among former caregivers for, on average, almost 20 months following the death of their spouse.

In Bodnar and Kiecolt-Glaser’s (1994) study, data from an ongoing longitudinal research project were used to examine caregiver depression after bereavement. Their study consisted of a cross-sectional comparison between noncaregivers, continuing caregivers, and former caregivers who had lost their family member some time in the previous 3 years. The average time since the family member’s death was 19.80 months, but there was a great deal of variability in time since death (SD = 11.49). In contrast, the analysis of data from our project allows us to follow former caregivers over time, examining them at multiple time points after the loss of their care recipient. The data reported in our study consist of three assessments on each former caregiver after the loss of their spouse. Thus all former caregivers were followed for 2–3 years after the loss of their impaired spouse, which resulted in a longer average period of time since their family member’s death (28.24 months, SD = 4.20, range = 19–39 months).

Our study also differs from the previous one (Bodnar & Kiecolt-Glaser, 1994) in that only spousal caregivers are included in the
analyses; Bodnar and Kiecolt-Glaser’s (1994) work included individuals caring for a parent as well as those caring for a spouse. This is an important distinction also between this study and the previous longitudinal studies (Aneshensel et al., 1995; Mullan, 1992; Skaff et al., 1996). The consequences of caregiving can be different depending on the relationship of the family caregiver to the care recipient. In general, the negative effects following a care recipient’s death have been greater among persons who had been caring for a spouse than among those who had been caring for a parent (Schulz et al., 1997).

Our study examines the psychological well-being of spousal caregivers following the death of their cognitively impaired spouse. Using individuals who were enrolled in a longitudinal study on the effects of caregiving stress on health, we assessed caregivers prior to the death of their spouse and we followed their progress over a period of up to 3 years after their spouse’s death. Although the longitudinal nature of the data is a strength of the study, it also limited the selection of variables to those that were present across all 4 consecutive years on a relatively large number of participants. As a result, analysis of depression was limited to the short form of the Beck Depression Inventory (BDI–SF; Beck & Beck, 1972).

A strong feature of this data is the availability of comparison groups. Former caregivers were contrasted with a group of caregivers who continued to provide care throughout the study period as well as a group of noncaring control participants. Analyses evaluated whether former caregivers showed improvements over time in psychological well-being compared with caregivers who continued to provide care; analyses also examined whether the psychological well-being of former caregivers began to resemble that of a sample of peers who had not been engaged in caregiving activities.

This longitudinal data offered a rare opportunity to study the long-term impact of an extreme stressor on depression and other measures of psychological well-being. The data also allowed us to explore possible predictors of psychological well-being among spousal caregivers following their husband or wife’s death, enabling us to examine factors suggested in the literature to blunt or exacerbate negative outcomes, such as depression.

Method

Sample Recruitment and Data Collection

Participants were enrolled in a longitudinal study on the effects of caregiving stress on psychological health, physical health, and immune function. Approximately half of the participants in the longitudinal study were caring for a spouse with a progressive dementing illness at the time they enrolled; half were noncaring, community-residing adults. Noncaring participants were recruited through local newspapers, senior citizens’ organizations, church groups, and university publications. Caregivers were recruited through these same sources as well as through local diagnostic clinics, neurologists’ referrals, local caregiver support programs, and Alzheimer’s Association newsletters. Because the project did not maintain long-term follow-up of nonspousal caregivers, the data presented in this article consist of spousal caregivers’ data only. All caregivers were providing at least 5 hr of care per week to their spouse when they joined the study. Some were caring for their spouse at home; others were caring for a spouse who resided in a nursing home. Data were not grouped according to patient residence because previous studies failed to find a relationship between caregiver well-being and patient residence (Dura, Stukenberg, & Kiecolt-Glaser, 1990; Kiecolt-Glaser, Dura, Speicher, Trask, & Glaser, 1991).

Potential comparison participants who reported any recent caregiving activities were excluded from the study. Participants in the control group who assumed care responsibilities during the course of the study were dropped. Married control participants who experienced the loss of a spouse during the course of the study were not dropped. Rather, they were retained in the control sample. The occurrence of both such events, however, was relatively rare. Over the 4-year period that we examined attrition, no control participants were dropped because of caregiving responsibilities and only one control participant experienced the loss of a spouse. This bereaved control participant was retained in the control group.

Data Alignment

Participants in the study completed a series of interviews and self-report measures annually. For our analyses, we used data from former caregivers beginning with the year prior to their spouses’ death and continuing through the three testing cycles after their spouse’s death. Thus, we were able to examine caregivers for 2–3 years after the loss of their spouse, with a total of four times of testing for all former caregivers. Because participants were assessed annually, the first postbereavement interview could have occurred anywhere from less than 1 month to up to 12 months after the care recipient’s death. As a result, our focus is on well-being in the years following caregiving, not the immediate reaction to bereavement. We similarly examined continuing caregivers and controls annually over a 4-year period. For continuing caregivers and controls, we used data from the third data collection cycle and the three consecutive annual interviews that followed.

Sample Characteristics

Our sample consisted of 49 former caregivers, 42 continuing caregivers, and 52 noncaring control participants. Most (64%) were women, and most (68%) had completed at least some college coursework. Consistent with the demographics of the area, the majority (89%) were White. The three groups did not differ significantly in gender, $\chi^2(2, N = 142) = 0.48, p > .78$; race, $\chi^2(2, N = 144) = 0.51, p > .77$; or educational level, $\chi^2(8, N = 142) = 11.90, p > .15$. The two caregiver groups, however, were somewhat older than the noncaring control group, $F(2, 139) = 4.22, p < .05$. The average age of the former caregivers, continuing caregivers, and controls was 70.8 ($SD = 10.1$), 71.0 ($SD = 7.5$), and 66.4 ($SD = 8.9$), respectively.

Naturally, there were group differences in marital status. Current caregivers were married at all four times of testing; all former caregivers became widowed between the first and second time of testing. At the time of entry into the study, 40 of the noncaring controls were married, 8 were widowed, and 4 were divorced. Marital status among the control participants was stable across the 4-year period included in these analyses with the exception of 1 married control participant who became widowed between the second and the third time of testing.

Participant Attrition

Attrition rates were low for all three groups of participants in the project (i.e., controls, former caregivers, and continuing caregivers). Examining attrition over a representative 4-year period of the project, we found that

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1 Whereas previous articles based on data from this project have reported syndromal depression using the Structured Clinical Interview for DSM-III-R Disorders, nonpatient version (SCID–NP, Spitzer, Williams, Endicott, & Gibbon, 1987), this assessment instrument was discontinued midway through the study; thus, we were not able to analyze data from the SCID–NP for this article.
the average attrition rate for former caregivers (range = 2-10%), continuing caregivers (range = 3-8%), and controls (range = 2-7%) was 5%. During the 4-year period examined, reasons for attrition included serious illness (an exclusion criterion because of the immunocompetent condition of the study), death, living or moving too far away, and participant-initiated decision to drop. During the 4-year period, the distribution of reasons for participant attrition did not differ significantly for the three groups, $\chi^2(4, N = 35) = 2.74$, $p > .05$.

Within each group (i.e., controls, former caregivers, and continuing caregivers), participants who did not continue were compared with continuing study participants on age, gender, race, education, level of depressive symptoms (averaged over 4 years for the study participants and the last known level for attrition participants), and length of caregiving (for former and continuing caregivers). Analyses confirmed a lack of selective attrition bias with the exception of some differences in age, which were not unexpected because of the illness exclusion criteria of the study. Among controls and continuing caregivers, the attrition participants were significantly older than those continuing to participate in the study, $t(66) = 3.26$, $p = .002$, and $t(45) = 2.79$, $p = .008$, respectively. Among former caregivers, there were no significant differences between the attrition and continuing participants.

Data Analysis

Repeated measures analysis of variance (ANOVA) was conducted for each of five measures of psychological well-being to examine the effects of group (former caregivers, continuing caregivers, noncaregivers), time (four assessments), and Group $\times$ Time interactions. These analyses allowed us to examine whether the three groups were significantly different from one another when collapsed across all times of testing, whether participants changed over time on these measures, and most important, whether the three groups changed in different ways during the 4-year period. If caregivers experience relief and enhanced quality of life after the death of their spouse, they would be expected to demonstrate greater improvements in psychological well-being over the years compared with continuing caregivers and controls. Measures of psychological well-being were depression, loneliness, positive and negative affect, and perceived stress.

Similarly, years after caregiving has ended, when no longer facing the daily challenges of caring for an impaired spouse, former caregivers would be expected to more closely resemble noncaregiving controls than continuing caregivers. Post hoc pairwise comparisons allowed us to examine mean differences on the various measures at the final time of testing to see whether former caregivers differed significantly from current caregivers and noncaregiving controls. This allowed us to determine whether former caregivers reported greater psychological health and well-being compared with continuing caregivers or whether they remained significantly disadvantaged relative to noncaregiving controls 2-3 years after their caregiving ended. Given the age difference between the caregiver and control groups, we repeated these analyses using age as a covariate. Results were unchanged; thus, only the initial analyses will be reported here.

Given the importance of depression as an outcome variable, we attempted to examine more closely whether there were group differences in clinically significant depression. Using a cutoff score of 5, as recommended by Scogin, Beutler, Corblish, and Hamblin (1988) for screening for depression among older adults, we classified participants as depressed or not depressed. The percentage of participants classified as depressed and nondepressed was then compared across groups. In addition, the number of participants reporting mild, moderate, and severe depression was also examined separately for the three groups.

Finally, we examined some of the variables discussed in the literature as possible predictors of postbereavement outcome by exploring whether they predicted psychological well-being among former caregivers 2-3 years after the loss of their spouse. Using data on the 49 former caregivers, we first examined the relation between psychological well-being and demographic variables (age, gender, and education). We then examined the relation between psychological well-being at Time 4 (i.e., at the third testing cycle after their spouse’s death) and characteristics of the caregiving experience (length of caregiving career, hours per week spent caregiving, and caregiving difficulties), ruminative thoughts about caregiving, and social support, assessed both during caregiving and years later. Selecting variables on the basis of the zero-order correlations and controlling for initial scores on the health and well-being measures, we examined the extent to which these variables predicted outcomes years after caregiving had ceased.

Measures

Psychological Health and Well-Being

Depression. The BDI-SF was used to assess depressive symptomatology; participants endorsed the statements that best described how they had been feeling in the past week. The 13-item measure includes statements graded in symptom severity for each item, and it provides information on the severity of affective and cognitive depressive symptoms. The BDI-SF correlates highly with the total score of the 21-item BDI ($r = .96$) and with clinician’s ratings of depression ($r = .61$; Beck & Beck, 1972; Beck, Steer, & Garbin, 1988). BDI-SF scores in the range 0–4 demonstrate no or minimal depression, scores of 5–7 demonstrate mild depression, scores of 8–15 demonstrate moderate depression, and scores greater than 15 demonstrate severe depression (Beck & Beck, 1972). A review of the 25-year history of the BDI indicated that the short form has good internal consistency (Beck et al., 1988), and Cronbach’s alpha, averaged over four annual administrations, (for the BDI-SF in the current study was .79 (range = .76–.82). The validity of the short form has also been demonstrated in several studies. Using a sample of older adults receiving outpatient treatment for depression and older adult nondepressed controls, Scogin et al. (1988) found acceptable internal reliability, Spearman–Brown split half = .84, coefficient $\alpha = .90$. In terms of criterion group validity, depressed and nondepressed groups significantly differed, $t(116) = 10.58$, $p < .01$, for the BDI-SF; in their sample, a cutoff score of 5 on the BDI–SF differentiated depressed and nondepressed older adults with adequate sensitivity (97%) and specificity (77%). This cutoff score has since been used as a threshold for clinically relevant depressive symptoms in other studies (see, e.g., Kissane et al., 1996).

Loneliness. Participants’ self-reported loneliness was measured using a modified version of the New York University Loneliness Scale (NYUL; Rubenstein & Shaver, 1982). The shortened version of the NYUL used in this study included three items that assessed how often participants felt lonely, how lonely they felt, and how lonely they thought they were compared with other people their own age. Because of the focus on current perceptions of loneliness, items that had a trait orientation (e.g., “I am a lonely person”) were excluded. Scores on this abbreviated measure range from 3 to 18, with higher scores indicating a greater sense of loneliness. Cronbach’s alpha, averaged over four annual administrations, for the NYUL in the current study was .86 (range = .85–.86).

Affect. The Positive and Negative Affect Schedule (Watson, Clark, & Tellegen, 1988) was used to measure two independent dimensions of emotional experience, positive affect and negative affect. Participants rated the extent to which they experienced each of the 20 mood states in the past week using a 5-point scale. Possible scores range from 10 to 50 for each of the scales. The positive affect scale reflects alertness, energy, and enthusiasm; the negative affect scale reflects a variety of aversive states, including anger, guilt, and nervousness. The scales are internally consistent and have demonstrated excellent convergent and discriminant validity (Watson et al., 1988). Cronbach’s alpha, averaged over four annual administrations, for the positive and negative affect scales in the current study was .88 (range = .87–.89) and .87 (range = .85–.89), respectively.

Stress. The 10-item Perceived Stress Scale (PSS; Cohen, Kamarck, & Mermelstein, 1983) was used to measure the extent to which participants perceived their recent life circumstances as stressful (i.e., unpredictable, uncontrollable, and overloading). Participants rated each of the 10 statements on a 5-point scale (0 = never to 4 = very often) with scores ranging
from 0 to 40. The scale is internally consistent and has demonstrated moderate correlations with other measures of appraised stress (Cohen & Williamson, 1988). Cronbach’s alpha, averaged over four annual administrations, for the PSS in the current study was .88 (range = .88–.90).

Possible Predictors of Former Caregivers’ Well-Being

Characteristics of the caregiving experience. The number of months the caregiver had been providing care for their impaired spouse and the number of hours per week that the caregiver had been providing care at the last annual assessment prior to their spouse’s death were used as measures of the intensity of the caregiver experience. The Memory and Behavior Problem Checklist (MBPC; Zarit & Zarit, 1982) was used to assess some of the difficulties faced in caregiving. This measure assesses 30 problems that demented patients may experience in memory and behavior as well as caregivers’ reaction to those problems. The MBPC includes problems that are often most distressing to caregivers such as incontinence, wandering, destroying property, inability to communicate, and inability to recognize familiar people. For our analyses, we used the combined score from this measure, which considers both the frequency of behavioral problems (0 = never to 4 = daily) as well as the extent to which the caregiver is upset by those problems (0 = not at all to 4 = extremely). The score used in our analyses was the sum of the cross products (frequency × reaction). Studies have reported the MBPC frequency scores to be highly correlated with level of dementia (Dura, Bornstein, & Kiecolt-Glaser, 1990) and with behavioral logs of Alzheimer’s disease patients’ behaviors over a 48-hr period (O’Leary, Haley, & Paul, 1993). Studies have found that the cross products score, used in our analyses, is a better predictor of caregiver burden than is level of impairment or frequency of memory and behavior problems alone (Zarit, Todd, & Zarit, 1986).

Intrusive and avoidant thoughts. The Impact of Events Scale (Horowitz, Wilner, & Alvarez, 1979) was used to assess the extent to which former caregivers ruminate about their former caregiving experiences in the years after caregiving has ended. This 15-item scale was designed to measure intrusive and avoidant thinking following the termination of a specific stressful event. It has been widely used in studies of community disasters and individual traumas (Dougall, Craig, & Baum, 1999). In this study, it was used to measure former caregivers’ attempts to suppress thoughts about caregiving (avoidant thinking) as well as the extent to which they experience unintended thoughts about caregiving (intrusive thinking). For each of the 15 items, former caregivers indicated how often (0 = not at all to 3 = often) they had experienced each of the 15 items in the past 7 days. Scores on the eight-item Avoidance subscale range from 0 to 24; scores on the seven-item Intrusion subscale range from 0 to 21. An example of an avoidance item is “I stayed away from reminders of caregiving”; an example of an intrusion item is “I thought about my caregiving years when I didn’t mean to.” Cronbach’s alpha, averaged over four annual administrations (former caregivers only), for the Avoidance and Intrusion subscales in the current study was .79 (range = .71–.85) and .85 (range = .77–.90), respectively.

Social support. Perceived social support was measured using a six-item version of the Interpersonal Support Evaluation List (ISEL; Cohen, Merckelstein, Kamarck, & Hoherman, 1985). Participants rated each of the six statements (1 = definitely false to 4 = definitely true). Although Newsom and Schulz (1996) described that two items each from the tangible, belonging, and appraisal support factors of the original ISEL were selected to create the six-item scale, the summary score of the six-item scale has been reported to have reasonable internal consistency among middle-aged and older adults (Williamson, 2000; Williamson & Schulz, 1992). The summary score correlated as expected with other measures and was reported to significantly predict depressive symptomatology among older adults attending outpatient clinics at a university medical center after controlling for objective and subjective health indicators (Williamson & Schulz, 1992). Cronbach’s alpha, averaged over four annual administrations (former caregivers only), for the ISEL in the current study was .79 (range = .62–.87).

Results

Comparing Changes in Outcome Variables Over Time Among Former Caregivers, Current Caregivers, and Controls

We calculated the correlations among the five outcome variables across the four times of testing. The correlations between the five outcome measures within any given year ranged from .28 to .71, with a mean of .55. (See Table 1 for the correlations among the five outcome variables at Time 1 and Time 4.) Although these correlations were moderately strong, they were not strong enough to justify aggregating the five variables into a single composite. Therefore, a repeated measures ANOVA was conducted separately for each of the outcome variables of interest (depression, loneliness, positive and negative affect, and perceived stress).

For depression, results revealed overall group and time effects, $F(2, 141) = 14.237, p = .001, \hat{\omega}^2 = .099$, and $F(3, 423) = 4.869, p = .002, \hat{\omega}^2 = .005$, respectively, but no significant interaction of Group × Time, $F(6, 423) = 1.694, p = .121, \hat{\omega}^2 = .002$. Although both caregiver groups demonstrated a slight decrease in depression over time, post hoc comparisons showed that the two caregiver groups remained significantly different from the non-caregiving controls even at Time 4 ($\bar{y}_{\text{former}} - \bar{y}_{\text{control}} = 2.180, p = .001$ and $\bar{y}_{\text{current}} - \bar{y}_{\text{control}} = 2.080, p = .001$). As can be seen in Figure 1, the two caregiver groups did not differ significantly from one another, even at the fourth assessment which occurred up to 3 years after the former caregivers’ caretaking responsibilities had ended ($\bar{y}_{\text{former}} - \bar{y}_{\text{current}} = 0.100, p = .984$).

Our analysis of loneliness revealed a significant group, $F(2, 127) = 18.370, p = .001, \hat{\omega}^2 = .128$, and time, $F(3, 381) = 8.266, p = .001, \hat{\omega}^2 = .011$, effect as well as a significant effect for the Group × Time interaction, $F(6, 381) = 3.502, p = .002, \hat{\omega}^2 = .007$. An examination of this data revealed that on average the two caregiver groups both experienced a decrease in loneliness over the 4-year period whereas the non-caregiving controls remain fairly stable on this variable (see Figure 2). Post hoc comparisons again, however, revealed that although the two caregiver groups did not differ significantly from one another ($\bar{y}_{\text{former}} - \bar{y}_{\text{control}} = 0.2845, p = .890$), they both tended to report greater loneliness than the noncaregiving controls at Time 4 ($\bar{y}_{\text{former}} - \bar{y}_{\text{control}} = 1.657, p = .015, \hat{\omega}^2 = .015, \bar{y}_{\text{current}} - \bar{y}_{\text{control}} = 1.372, p = .047$).

In the analysis of positive affect (Figure 3), results revealed no significant overall time effect, $F(3, 411) = 1.675, p = .172, \hat{\omega}^2 = .001$, but a significant overall group effect, $F(2, 137) = 7.161, p = .001, \hat{\omega}^2 = .045$, and a significant Group × Time interaction, $F(6, 411) = 3.013, p = .007, \hat{\omega}^2 = .006$. Although on average the former caregivers experienced an increase in positive affect during the year after their impaired spouse’s death, post hoc analyses again revealed that they tended to be more similar to the continuing caregiver group ($\bar{y}_{\text{former}} - \bar{y}_{\text{current}} = 1.452, p = .576$) than they were to the non-caregiving control group ($\bar{y}_{\text{former}} - \bar{y}_{\text{control}} = -3.326, p = .045$) at Time 4.

The results of our analyses with negative affect (Figure 4) and perceived stress (Figure 5) were strikingly similar. Results revealed a significant overall (a) group, $F(2, 137) = 5.104, p = .007$, and treatment.
Table 1
Correlations Among Time 1 and Time 4 Outcome Variables for the Three Groups
Combined (N = 143)

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Note. Correlations of .22 or greater absolute value are significant at the .01 level. Correlations of .28 or greater absolute value are significant at the .001 level. BDI = Beck Depression Inventory; Pos = positive; Neg = negative; PSS = Perceived Stress Scale; NYUL = New York University Loneliness Scale.

\( \omega^2 = .030 \), for negative affect, and \( F(2, 129) = 4.592, p = .012 \), \( \omega^2 = .031 \), for perceived stress; (b) time, \( F(3, 411) = 6.319, p = .001 \), \( \omega^2 = .008 \) for negative affect, and \( F(3, 387) = 9.588, p = .001 \), \( \omega^2 = .012 \), for perceived stress; and (c) Group × Time effect, \( F(6, 411) = 6.035, p = .001 \), \( \omega^2 = .016 \) for negative affect, and \( F(6, 387) = 7.672, p = .001 \), \( \omega^2 = .019 \), for perceived stress. On average, former caregivers reported less stress and less negative affect in the year immediately following their spouse’s death, and this improvement was generally maintained throughout the remaining assessments. At the fourth testing, post hoc analyses revealed no significant differences between former caregivers and controls on either of these variables (\( \bar{y}_{\text{former}} - \bar{y}_{\text{control}} = 1.877, p = .165 \), for negative affect and \( \bar{y}_{\text{former}} - \bar{y}_{\text{control}} = 0.722, p = .851 \), for perceived stress). On average, continuing caregivers demonstrated a gradual decrease in negative affect and stress over time, resulting in nonsignificant differences with controls at Time 4 as well (\( \bar{y}_{\text{current}} - \bar{y}_{\text{control}} = 0.757, p = .755 \), for negative affect and \( \bar{y}_{\text{current}} - \bar{y}_{\text{control}} = 0.601, p = .885 \), for perceived stress). Although the decrease in mean negative affect and stress among former caregivers is understandable in light of reduced burden and strain from caregiving, the corresponding decrease observed among continuing caregivers was unexpected.

Comparing Levels of Depression Among Former Caregivers, Current Caregivers, and Controls

Using the cutoff score of 5 on the BDI–SF suggested by Scogin et al. (1988), we found no significant difference between the two caregiver groups with respect to frequency of those exceeding the cutoff at any of the four times of testing, Time 1, \( \chi^2(1, N = 91) = 0.15, p = .70 \); Time 2, \( \chi^2(1, N = 91) = 0.42, p = .51 \); Time 3, \( \chi^2(1, N = 91) = 1.85, p = .17 \); Time 4, \( \chi^2(1, N = 91) = 0.04, p = .84 \). In

Figure 1. Mean Beck Depression Inventory scores over four times of testing for former caregivers, current caregivers, and controls.
LONG-TERM CAREGIVING

Figure 2. Mean New York University Loneliness Scale scores over 4 times of testing for former caregivers, current caregivers, and controls.

In contrast, former caregivers differed significantly from controls at all four times of testing. Time 1, $\chi^2(1, N = 101) = 9.66, p < .01$; Time 2, $\chi^2(1, N = 101) = 4.58, p < .05$; Time 3, $\chi^2(1, N = 101) = 5.49, p < .05$; Time 4, $\chi^2(1, N = 101) = 8.14, p < .01$, with a significantly higher frequency of former caregivers than controls exceeding the cutoff. As can be seen in Table 2, 15–23% of the control participants exceeded the depression screening cutoff, with 2–6% scoring in the moderate to severe range. In contrast, 41–53% of the former caregivers exceeded the cutoff for depression, with 14–18% scoring in the moderate to severe range, and 43–57% of the current caregivers exceeded the cutoff for depression, with 9–21% scoring in the moderate to severe range.

Examining Possible Predictors of Former Caregivers' Time 4 Outcomes

Next using data from the 49 former caregivers only, we examined the relation between former caregivers' Time 4 outcomes and possible predictors suggested in the literature (Table 3). Although there was a strong trend toward more positive affect among former caregiving wives compared with former caregiving husbands, $r(45) = -2.00, p = .052$, demographic variables (age, education, and gender) were not significantly related to any of the outcomes examined. Characteristics of the caregiving experience were also, with one exception, nonsignificantly related to Time 4 outcomes. The one exception was a significant negative correlation between length of caregiving career and positive affect. In contrast, avoidant and intrusive thoughts at Time 4 were significantly correlated with most of the Time 4 measures of psychological health and well-being. The correlations between Time 4 social support and all of the Time 4 outcome measures were moderate in size (absolute range = .22–.36), and correlations between Time 4 outcomes and social support at Time 1 were generally smaller (absolute range = .15–.23).

Finally, we used hierarchical multiple regression analyses to examine the ability of these variables to predict former caregivers' Time 4 outcomes, after partialling the effect of Time 1 outcome measures. In conducting these analyses, we examined the incremental variance explained when measures that were significantly correlated with outcomes (i.e., all significant zero-order correlations previously noted) were included in the analysis. None of the variables examined here accounted for significant variance in Time 4 depression or perceived stress above and beyond that accounted for by scores at Time 1. Intrusive and avoidant thinking together accounted for a small but significant proportion of the variance in Time 4 negative affect after partialling Time 1 negative affect, $\Delta R^2 = .092, F(2, 41) = 3.411, p = .043$. The duration of the caregiving career and Time 4 social support accounted for a significant amount of variance in positive affect above and beyond that accounted for by Time 1 positive affect, $\Delta R^2 = .104, F(2, 32) = 3.496, p = .042$. Time 4 social support and intrusive thinking together accounted for significant variance in Time 4 loneliness after partialling Time 1 loneliness, $\Delta R^2 = .184, F(2, 31) = 5.082, p = .012$.

Discussion

Several researchers, noting that family caregivers fail to report a worsening state after the death of their care-recipient, have concluded that caregivers generally adapt well following the loss of their family member. Others have reported that senior caregivers experience improved psychological well-being following the loss of their demented family member, such as decreased overload (Mullan, 1992), increased mastery (Mullan, 1992; Skaff et al.,

3Because all of the self-report measures administered in the study are presumably contaminated to some extent by negative affect, hierarchical multiple regression analyses were repeated where possible (loneliness and positive affect) to determine if the predictors accounted for significant variance above and beyond that accounted for by Time 1 score and negative affect. In neither analysis did the results change; thus it does not appear that negative affect accounts for the influence of the predictor variables on Time 4 outcomes.
1996), decreased anger (Aneshensel et al., 1995), and increased agreeableness (Gold, Reis, Markiewicz, & Andres, 1995). Data from this study present a more mixed picture of outcomes following the cessation of spousal caregiving.

Results of this study reveal that former spousal caregivers on average experienced decreases in perceived stress and negative affect in the years following the cessation of caregiving. On these variables, former caregivers looked no different than noncaregiving control participants after their years of caregiving had ended. In contrast, less change was observed over time on other key measures of psychological well-being (depression, positive affect, and loneliness). On these variables, former caregivers did not, on average, return to levels comparable to those of noncaregivers within 3 years after caregiving had ceased. In fact, former spousal caregivers tended to resemble current, active caregivers on these measures. Although spousal caregivers did not get worse on key measures of psychological well-being following the death of their spouse, our study suggests that they also did not get much better.
It may be that the effects of long-term caregiving for a spouse with a slow, progressive, dementing illness can have long-lasting psychological consequences that continue well beyond the caregiving years.

Especially striking is the finding that depressive symptoms exceeding a cutoff score for clinical significance were present in 40% or more of the former caregivers at each annual assessment over the 3-year period following the death of their spouse. The level of depressive symptoms was typically mild to moderate, exceeding a threshold for clinical relevance (Kissane et al., 1996; Scogin et al., 1988) but likely not meeting criteria for a clinical diagnosis of depression. The significantly greater proportion of continuing and former caregivers reporting subthreshold depressive symptoms relative to controls suggests that the vulnerability to depression previously associated with the chronic stress and social loss of caregiving for a spouse with dementia (Dura, Stuckenberg, & Kiecolt-Glaser, 1990) may persist well beyond the death of the care recipient.

This chronic elevation of depressive symptoms could have important public health consequences in that significant psychosocial and functional impairment has been associated with subthreshold depression in older adults (Hays et al., 2000; Olsson et al., 1996; Penninx et al., 1998). In fact, subthreshold depression ongoing from several months to several years has predicted persistent limitations in functioning and well-being, and it has even increased rates of stroke (Beekman et al., 1995; Hays et al., 1995; Penninx et al., 1999; Simonsick, Wallace, Blazer, & Berkman, 1995). The degree of impairment that has been associated with subthreshold depressive symptoms makes clear the importance of determining what factors maintain these symptoms and what methods may effectively eradicate them before negative psychosocial and physical health outcomes occur.

In our study, the variables most predictive of psychological health and well-being for former caregivers 2–3 years after the loss of their spouse were continued intrusive and avoidant thoughts about caregiving and social support. In contrast to the results of previous studies, current social support was more strongly related to postcaring outcomes than was support received during the caregiving years. Other characteristics of the caregiving experience (duration of caregiving, hours per day spent caregiving, and caregiving difficulties) were generally unrelated to longer term
Table 3
Pearson Product-Moment Correlations Between Time 4 Outcomes and Possible Predictors
Among Former Caregivers (n = 49)

<table>
<thead>
<tr>
<th>Possible predictor</th>
<th>BDI-SF</th>
<th>Negative affect</th>
<th>Positive affect</th>
<th>PSS</th>
<th>NYUL</th>
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<td>-.22</td>
<td>-.20</td>
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<td>-.08</td>
<td>-.42**</td>
<td>.18</td>
<td>.09</td>
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<td>.12</td>
<td>-.02</td>
<td>-.02</td>
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<td>.16</td>
<td>.15</td>
<td>.19</td>
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<tr>
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<td></td>
</tr>
<tr>
<td>Avoidant thoughts at Time 4</td>
<td>.31*</td>
<td>.42**</td>
<td>.08</td>
<td>.38**</td>
<td>.18</td>
</tr>
<tr>
<td>Intrusive thoughts at Time 4</td>
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<td>.51***</td>
<td>.02</td>
<td>.44***</td>
<td>.30*</td>
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<td>.15</td>
<td>-.21</td>
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<tr>
<td>Support at Time 4</td>
<td>-.28</td>
<td>-.22</td>
<td>.33*</td>
<td>-.28</td>
<td>-.36*</td>
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</table>

Note. BDI-SF = Beck Depression Inventory, short form; PSS = Perceived Stress Scale; NYUL = New York University Loneliness Scale.

*p < .05. **p < .01. ***p < .001.

outcomes, with the exception that length of caregiving was inversely correlated with positive affect. Thus, the longer a person had been caring for a spouse with dementia, the less likely they were to endorse positive emotions 2–3 years after the death of their spouse. This is consistent with the hypotheses that long-term caregiving can wear down caregivers’ resources, making it more difficult for them to adjust after their spouse’s death. It is important to note that this relationship was observed on only one of five measures of psychological health and well-being and, therefore, does not reflect a strong or consistent pattern in the data.

Baum and his colleagues (Baum, 1990; Baum, Cohen, & Hal, 1993) have described that distress persists in some individuals for years after a stressor has ended. In a number of studies on individuals exposed to a diverse range of stressors, Baum and his colleagues (Baum, 1990; Baum et al., 1993; Dougall et al., 1999) have found that persons who had more intrusive thoughts about a past stressor were more likely to experience continued distress. Thus, intrusive thoughts about a past stressor are one mechanism by which a past event can continue to influence a person well after the stressor has ended. In our study, the strongest and most consistent predictors of postcaregiving psychological well-being were continued intrusive thoughts about caregiving and continued efforts to avoid such thoughts. Intrusive thoughts about caregiving were related to depression, negative affect, loneliness, and perceived stress; efforts to avoid thinking about past caregiving were related to depression, negative affect, and perceived stress. It is important to note that, although intrusive thoughts may play a causal role in the maintenance of depression in the years postcaregiving, it is possible that depression causes intrusive thoughts or that the two are reciprocally related.

Although some have argued that the time to initiate interventions to improve postbereavement outcomes among caregivers is during the period of active caregiving (Bass, Bowman, & Noelker, 1991; Norris & Murrell, 1987), it is important that the needs of former spousal caregivers are not ignored. A recent survey of 121 nursing homes demonstrated that few grief and bereavement services were offered to families of patients who had died of end-stage Alzheimer’s disease (Murphy, Hanrahan, & Luchins, 1997). Offering services and support to long-term spousal caregivers following the death of their impaired spouse may prove to be beneficial for those continuing to report elevated depression and distress. Pennebaker and O’Heeren (1984) have suggested that ruminative thoughts, known to be associated with persistent depressive symptoms (Nolen-Hoeksema, Morrow, & Fredrickson, 1993), are more likely among those who have not had as many opportunities for self-disclosure. They found that individuals who had lost their spouse approximately 1 year previous were less likely to experience ruminative thoughts if they had discussed their spouse’s death with others. They also found that those who had not discussed their spouse’s death with friends and those who had more persistent thoughts about their spouse’s death were more likely to have experienced increased health problems since their spouse’s death.

Among those former caregivers at risk of long-term negative outcomes, postbereavement interventions have the potential to influence their physical as well as psychological health and well-being. Caregiver stress has been associated with poorer immune function (Kiecolt-Glaser et al., 1991), poorer vaccine response (Kiecolt-Glaser, Glaser, Gravenstein, Malarkey, & Sheridan, 1996), and slower wound healing (Kiecolt-Glaser, Marucha, Malarkey, Mercado, & Glaser, 1995). Moreover, bereaved caregivers continued to show evidence of dysregulated immune function an average of 2 years after their caregiving had ended (Esterling, Kiecolt-Glaser, Bodnar, & Glaser, 1994; Glaser, Kiecolt-Glaser, Malarkey, & Sheridan, 1998). It is unclear whether such immune dysregulation is reversible given more time following the care recipient’s death. It similarly remains to be seen whether a longer period of time would allow for greater psychological recovery among long-term spousal caregivers following the death of their spouse.

We have highlighted the role of stress in the development of depression in caregivers. We have also suggested that former caregivers’ continued thoughts about caregiving offers one explanation why some people fail to rebound after the cessation of caregiving. An alternative hypothesis, however, is that the loss of a lifelong partner is the critical factor both in the development and maintenance of poor outcomes. Unfortunately, we were not able to examine this alternative hypothesis because we
did not have a group of bereaved noncaregivers on which to make comparisons. It is certainly possible that the loss of a spouse contributes to or even accounts for the differences observed. However, a number of longitudinal studies of spousal bereavement have found that although depressive symptomatology is often elevated in the initial months postloss, depression declines thereafter and returns to baseline within 1 to 2 years postloss (Harlow, Goldberg, & Comstock, 1991; Levy, Derby, & Martinkowski, 1993; Rosenzweig, Priegson, Miller, & Reynolds, 1997; Stroebe, Stroebe, & Dommert, 1988; Thompson, Gallagher-Thompson, Futterman, Gilewski, & Peterson, 1991).

Comparing recently widowed and nonwidowed persons over time, Thompson et al. (1991) reported that although the widowed group scored higher on measures of depression and psychopathology at 2 months postloss the two groups were not significantly different at 12 months or at 30 months postloss. This is not to argue that the grieving process is complete within a year. Despite no differences in depression, the two groups did continue to show differences on measures of grief 30 months after the loss of their spouse. In a twin study examining response to widowhood, Lichtenstein, Gatz, Pedersen, Berg, and Mclean (1996) reported that although long-term (more than 5 years) widowed co-twins no longer reported greater depressive symptomatology than married co-twins, the widowed co-twins continued to report greater loneliness.

Although greater loneliness may reflect a natural consequence of losing one’s partner, the apparent failure of former caregivers in our study to return to estimated baseline scores on measures of depression and positive affect suggests that adjustment following a long period of caregiving for a spouse with a dementing illness may pose unique challenges. Data from our study suggest that although negative affect and perceived stress may decrease when individuals are no longer providing care for an impaired spouse, other critical measures of psychological health and well-being do not rebound as expected within 3 years after the cessation of caregiving.

References


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