

# Transitions in Spousal Caregiving

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**Purpose:** This study describes transitions over 5 years among community-dwelling elderly spouses into and within caregiving roles and associated health outcomes. **Design and Methods:** Participants in the Caregiver Health Effects Study ( $n = 818$ ) were interviewed four times over 5 years with changes in their caregiving status described. Analyses of the effect on health outcomes of transitions were performed on those for whom four observations were available ( $n = 428$ ). **Results:** Only half (49.5%) of noncaregivers at baseline remained noncaregivers at 5-year follow-up. The remainder experienced one or more transitions, including moving into the caregiving role, their own or their spouse's death, or placement of their spouse in a long-term care facility. The trajectory of health outcomes associated with caregiving was generally downward. Those who transitioned to heavy caregiving had more symptoms of depression, and poorer self-reported health and health behaviors. **Implications:** Transitions into and within the caregiving role should be monitored for adverse health effects on the caregiver, with interventions tailored to the individual's location in the caregiving trajectory.

**Key Words:** *Depression, Self-mastery, Health risk behaviors*

The sheer numbers of individuals moving into old age, coupled with increased risk of functional impairment, has heightened public health interest

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in issues of caring for older persons with impairment and the disability it may cause. In 1994, 21.3% of older persons had functional impairments requiring need for assistance (Manton, Corder, & Stallard, 1999). However, the percentage who reported receiving long-term care was somewhat lower (16.7%), with the majority (11.8%) receiving care in the community. Of those receiving community care, 23.4% received this from spouses (Spector, Fleishman, Pezzin, & Spillman, 2000). Knowledge of the patterns of movement into caregiving and different levels of caregiving is of great importance in planning health and social support services for the spousal caregivers, as well as for the care recipients. In this study, we followed older married couples over 5 years (from 1993 through 1998), and report on their transitions into caregiving roles and the associated physical and mental health effects of these transitions.

The detrimental effects of spousal caregiving on physical and mental health and mortality of the caregiver have been documented in numerous cross-sectional (Schulz et al., 1997; Schulz, O'Brien, Bookwala, & Fleissner, 1995), prospective (Schulz & Beach, 1999), and longitudinal studies of short duration (Lawton, Moss, Hoffman, & Perkinson, 2000; Seltzer & Li, 2000). However, few studies have examined the health and mental health effects resulting from transition into caregiving and the effect of multiple years in a caregiving role. The Caregiver Health Effects Study (CHES) was designed to fill this gap by assessing the physical and psychiatric health effects of transitioning into the caregiving role among individuals who had no caregiving responsibilities at the time of recruitment, as well as documenting the long-term effects of continuing caregiving in a representative sample of approximately 800 spousal pairs. Earlier reports from CHES focused on the health and mental health outcomes associated with spousal caregiving. For example, those who reported strain associated with caring were shown to have elevated depressive symptoms (Schulz et al., 1997) and were at increased risk for mortality (Schulz & Beach, 1999). We have also reported findings regarding the impact of transitioning out of the caregiving role as a result

of the death of the care recipient (Schulz et al., 2001), but we have not examined the effects of taking on the caregiving role among individuals who had no caregiving responsibilities at the outset of the study, nor have we assessed the impact of moving to a more demanding level of caregiving.

Information from other studies about transitions into different caregiving states is limited. Seltzer and Li (2000) addressed the effect of moving from noncaregiving at baseline into caregiving at 3-year follow-up for wives and daughters. Among wives, they observed that 12% moved into a caregiving role over this period and 6% became bereaved. Both caregiving status and duration of caregiving were associated with declines in leisure activity and self-mastery and more depressive symptoms. Lawton and colleagues (2000) examined transitions in daughter caregiver careers, comparing veteran caregivers, caregiving entrants, and continuing noncaregivers. They found that caregiving entrants, compared with those in the other two groups, did not have significantly different changes in quality of life from baseline through 2 years of follow-up observations. They suggested that definitive support for the deleterious effect of transitioning into caregiving would require a prospective study of a representative sample of noncaregivers "following them until enough have entered caregiver status to afford comparison with those who had not entered the status." The study reported here was designed to meet these criteria.

This study had two goals. First, we wanted to characterize the nature of the caregiving transitions experienced by a large cohort of elderly married respondents. We followed 818 married men and women for 5 years with four measurement points and describe their movement into and out of caregiving roles. Second, we examined changes in mental and self-reported health status among individuals who transition into caregiving roles of varying intensity compared with those who remain noncaregivers. The outcomes of interest were symptoms of depression, self-reported health, preventive health behavior, and self-mastery, chosen because prior cross-sectional analyses have shown them to be strongly associated with caregiving status (Burton, Newsom, Schulz, Hirsch, & German, 1998; Schulz et al., 1997).

## Methods

The community-based population for CHES was drawn from the Cardiovascular Health Study (CHS), a prospective epidemiological study designed to investigate the incidence of and risk factors for coronary artery disease and stroke among persons age 65 and over. Persons eligible to participate in CHS were noninstitutionalized and expected to remain in the area for the next 3 years, were able

to give informed consent, and did not require a proxy. A total of 5,201 participants were recruited from four sites around the county: Forsyth County, North Carolina; Washington County, Maryland; Sacramento County, California; and, Pittsburgh (Allegheny County), Pennsylvania. Because minority representation was relatively low in the original cohort, an additional 687 African American participants were added to the CHS. Potential participants were identified from a random sample stratified by age group (65–74, 75–84, >85 years) from Medicare enrollment lists. Details of the study design and recruitment for the CHS have been published previously (Fried et al., 1991; Tell et al., 1993). At baseline, the mean age of the CHS population was 72.8; the proportion of females was 57%; Caucasian, 95%; high school graduates, 72%; and those that described their health as good, very good, or excellent, 76%. The goal of the CHES was to recruit approximately 400 caregivers and 400 controls matched for age and gender. All individuals in the CHS sample who shared a household and indicated that they were married and living with their spouse or living as married were eligible to be recruited into the caregiving study ( $N = 3,185$ ). A screening instrument was used to identify potential caregivers and noncaregiving spouses. Potential caregivers were defined as individuals whose spouses had difficulty with at least one activity of daily living (ADL) or instrumental activity of daily living (IADL) "because of physical or health problems or problems with confusion" ( $n = 619$  or 19% of married couples). A total of 548 individuals in the caregiving pool were consecutively approached to achieve the required sample size, yielding a refusal rate of 28%. The noncaregiving group was comprised of individuals whose spouses or partners did not have any difficulty with ADLs or IADLs from physical or health problems or problems with confusion ( $n = 2,566$ ). In selecting noncaregivers, we attempted to match the age and gender distribution of the caregivers. A total of 515 noncaregivers were approached with a refusal rate of 18%. A total of 819 individuals distributed evenly across the four recruitment sites were enrolled into the study. In the Results section, we describe the transitions of 818 respondents (one person was excluded because of missing data). Based on their status at the time of the baseline interview that occurred approximately 2 weeks after respondents were screened, 395 respondents were classified as potential caregivers and 424 as noncaregivers. (The caregiving status of a few individuals changed between screening and the baseline interview.) For the purposes of this analysis, we further classified potential caregivers into actual caregivers versus noncaregivers. This was achieved by asking potential caregivers whether or not they provided assistance for any of the ADL/IADL difficulties of their spouses. Thus, an additional 77 individuals were classified as noncaregivers at

baseline because they did not provide assistance to their spouses even though their spouse had one or more ADL/IADL difficulties, leaving a baseline caregiving sample of 317. Following enrollment, trained interviewers carried out structured interviews with caregivers and noncaregivers in their homes, collecting health and mental health data and documenting caregiving status. Enrollment and baseline interviews began in 1993. Interviews were carried out at 1 year intervals with the exception of a 2-year interval between the third and fourth measurement points brought about by a gap in funding of the continuation grant.

For the analysis of transitions and associated health outcomes, we selected those respondents who were available for baseline and all three follow-up observations ( $n = 428$ ), and placed them in three transition categories based on a retrospective determination of their movement to their most demanding caregiving state. Those who were heavy caregivers at baseline were excluded because they could not transition to a more demanding state of caregiving using our criteria. Also, few remained in the study for four observations primarily because of the high rate of death of either themselves or the care recipient. Outcomes associated with moving out of the caregiving role because of death have been previously reported by Schulz and colleagues (2001). Study subjects were classified into one of the following three groups: (1) noncaregivers if they remained in this state throughout the 5 years; (2) moderate caregivers if they transitioned from noncaregiving to providing IADL assistance, and this was the most demanding level of care they provided; and (3) as heavy caregivers if they transitioned into the provision of ADL assistance at any one of the three follow-up measurement points. This categorization resulted in three transition groups: remaining noncaregivers ( $n = 209$ ); moderate caregivers ( $n = 136$ ); and heavy caregivers ( $n = 83$ ). Reverse transitions, that is, moving from a more demanding to a less demanding state at some point, occurred infrequently ( $n = 7$ ) and were not adjusted for in the analysis. In summary, the numbers of study participants used for each part of the study were: 818, for descriptive information on participant status and transitions across all observation points; 428, for the outcomes analysis in which observations at four points were required; and 219, for a temporal change analysis that used pre- and posttransition outcome values for those who transitioned to a more demanding caregiving state. Those who were not available for four observations because of death, death of spouse, entry of spouse into a nursing home, moving away, or refusal to participate were compared with those who remained in the study. Although many of the baseline differences between these two groups were statistically reliable, the magnitude of the differences was small.

## Classification of Caregiving Status

For the current study of transitions, we used a functional definition of caregiving status without regard to the perception of strain. That is, a person was classified as a caregiver if he/she: (a) answered affirmatively to one or more of the following 12 questions: "Because of health or physical problems does your spouse have any difficulty or is he/she unable ..." to perform ADLs (eating, dressing, bathing, transferring, toileting, walking) or to perform IADLs (using the telephone, preparing meals, doing light or heavy housekeeping, shopping, or managing money); and (b) indicated that they provided help for one or more of these problems. Individuals were classified into one of three categories: noncaregiver (no help given), moderate caregiver (help given for one or more IADL, but no ADL help given), and heavy caregiver (help given for at least one ADL impairment). There was a strong association between the number of extra hours of help given to a spouse because of disability and the level of caregiving, thus validating the use of our functional definitions (Burton et al., 1998).

## Outcome Variables

Depressive symptoms were measured using the 10-item version of the Center for Epidemiologic Studies–Depression scale (Radloff, 1977). The 10-item version has been found to be highly correlated with the full 20-item version ( $r = .96$ ) and to have little or no loss in sensitivity, specificity, or internal reliability (Shrout & Yager, 1989). Participants respond on a 0–3 scale ("rarely or none of the time" to "most of the time") to statements such as "I felt depressed" or "I felt hopeful about the future" (reverse coded) using the preceding week as a time frame. The scores for the 10 items were summed to create a depressive symptoms score ( $\alpha$  at baseline = .79). Self-mastery, or a person's sense of control over life events, was operationalized using a scale developed and validated by Pearlin (Pearlin & Schooler, 1978). This is a seven-item scale in which the respondent is asked for his/her level of agreement with each of these statements: "There is really no way I can solve some of the problems I have," "Sometimes I feel that I am being pushed around in life," "I have little control over the things that happen to me," "I can do just about anything I really set my mind to do" (reverse coded), "I often feel helpless in dealing with the problems of life," "What happens to me in the future mostly depends on me (reverse coded)," and "There is little I can do to change many of the important things in my life." The five possible responses, ranging from "strongly agree" to "strongly disagree," were coded so that higher scores indicated more mastery. Alpha at baseline for the scale was .69.

The impact of transitions on general health was evaluated by observing changes in self-reported health and health risk behaviors. Self-reported health

was rated as excellent, very good, good, fair, or poor, with higher scores indicating worse health. Previous analysis using the CHS sample have shown that self-ratings of health are highly correlated with prevalent clinical disease and the number of prescription medications used by study participants (Schulz et al., 1994). Six health risk behaviors were assessed: not having enough time to get as much exercise as respondent would like; not getting enough rest; not getting enough rest when recuperating from illness; forgetting to take medications; trouble finding time to get to a physician if a health problem was suspected; and missing one or more physician appointments. These health risk behaviors have been shown in cross-sectional studies to be associated with poorer health outcomes (Burton et al., 1998; Schulz et al., 1997). Demographic variables included age, education, and income, all treated as continuous variables, and gender (male = 1) and race (non-White = 1) as dichotomous.

### Data Analytic Strategy

To accomplish the two main goals of the study (description of transitions and examining temporal changes in health outcomes among transition groups), two approaches to data analysis were followed. The first was descriptive, tracking study participants to show their caregiving status at the three subsequent observations. The entire sample was used for this analysis. The second approach was analysis of outcomes for the three transition groups based on 428 cases of the original study population for whom data from four observations were available. The primary analytic strategy used was a repeated-measures analysis of covariance (ANCOVA), with three levels of caregiver status (non-caregiver, moderate caregiver, and heavy caregiver) for the between-subjects factor and four time points for the within-subjects factor. The observed differences in the longitudinal patterns of health outcomes among the three transition groups were further validated by looking at outcome changes at the point of transition for moderate and heavy caregivers. For example, depression levels pre- and posttransition were compared for persons who moved to moderate caregiving versus those who moved to heavy caregiving. To analyze the differences between the caregiving transition groups on outcome variables at baseline, post-hoc simple effects were examined.

Factors that have been shown or could be expected to have an impact on the outcome variables, such as demographic characteristics, were controlled for in the analyses. These included age, education, income, gender, and race. In addition, self-reported health of the caregiver was controlled for in the analyses of depression, health risk behaviors, and self-mastery.

## Results

### Descriptive Analysis of Transitions

At baseline, there were 501 noncaregivers, 166 moderate caregivers, and 151 heavy caregivers. Their transitions from the original observation to the three remaining observation points are shown in Figures 1A–1C. In addition to showing caregiving transitions, we also indicate other transitions, including death of the care recipient, placement of the recipient into a long-term care facility, death of the respondent, and other (refusal, too ill to continue, could not contact). The most stable group was noncaregivers, with nearly half (49.5%) remaining in that category, and the balance moving to caregiving roles or death of care recipient or self at a fairly steady rate, detailed in the figure. Those who at first observation were moderate caregivers had the most varied changes, with only 18.7% remaining as moderate caregivers. Almost one-fourth had returned to a noncaregiving state at the second observation (22.3%), but only 13.3% remained noncaregivers by the final observation. A majority of those who were heavy caregivers at baseline transitioned out of caregiving because of their own or their spouses' death. Nearly a quarter (24%) moved temporarily to non- or moderate caregiving status at the second observation, and this proportion fell to 20% at the third observation and 11.3% at the fourth observation. Detailed movements for all study participants are tracked in Appendices A–C, which trace movement into and out of various states. Table 1 summarizes the status at the final observation based on their starting status.

**Outcomes Analysis.**—For the outcomes analysis, assignment to a transition group was based on transition to the most demanding caregiver state over the four observations. This allowed us to trace the effect over time on health outcomes associated with the most demanding state they entered. An ancillary analysis focused on pre- and posttransition scores. Of the 428 subjects for whom four observations were available and who had not been heavy caregivers at baseline, 209 were continuing non-caregivers, 136 made transits to moderate caregiving, and 83 made transits to heavy caregiving. Characteristics of the transition groups at baseline are shown in Table 2. Those who remained noncaregivers were younger on average than the moderate and heavy caregiver transition groups (78.2 years, 79.3 years, and 80.2 years, respectively;  $F = 6.34, p < .01$ ), and had a lower proportion with incomes less than \$25,000 (32%, 52%, and 61%, respectively;  $\chi^2 = 21.36, p < .001$ ).

Figures 2 through 5 show depressive symptoms, self-mastery, self-reported health, and health risk behavior scores at four observations based on the transition groups. Those who transitioned to heavy caregiving had more depressive symptoms on

average than either noncaregivers or those who transitioned to moderate caregiving ( $F = 6.88, p < .001$ ; Figure 2). Although the main effect for time was not significant, there was an interaction of transition category and time ( $F = 2.74, p < .05$ ), indicating that the increase in depressive symptoms over time was greater for those who transitioned into heavy caregivers than it was for moderate caregivers or noncaregivers. For self-mastery, continuous noncaregivers reported highest levels on average at all observations, followed by moderate and then heavy caregiver transition groups ( $F = 12.82, p < .001$ ; Figure 3). These differences among groups neither changed significantly over time nor interacted with time. For self-reported health, remaining noncaregivers reported, on average, better scores than those in the moderate or heavy caregiver transition category ( $F = 3.85, p < .05$ ; Figure 4). The main effect for time was not significant; however, there was a significant interaction effect indicating that the difference in general health between the transition groups increased over time ( $F = 2.14, p < .05$ ). For health risk behaviors, those who transitioned into heavy caregiving reported on average higher counts than those who remained noncaregivers or those who transitioned to moderate caregiving ( $F = 7.28, p < .001$ ; Figure 5). The significant interaction between transition group and time ( $F = 2.31, p < .05$ ) indicated that the differences between those who transitioned into heavy caregivers and the other two groups increased over time, with heavy caregivers having a sharp rise in the number of health risk behaviors between the second and third observations.

Because these transition findings were based on assignment to a group without regard to when the transition occurred, we examined the temporal effect on changes in caregiver outcomes more precisely by comparing the outcomes directly before and after transition. We performed repeated-measures ANCOVA using time of measurement (pre- and posttransition) as a within-subject factor and transition category as a between-subject factor. Only the two groups who transitioned (moderate caregivers and heavy caregivers) were included. The pattern of results was similar to the transition outcomes analysis reported previously. For depressive symptoms, there was a significant main effect for the transition category ( $F = 4.06, p < .05$ ), indicating that those who transitioned to heavy caregiving had, on average across the two time points, higher levels

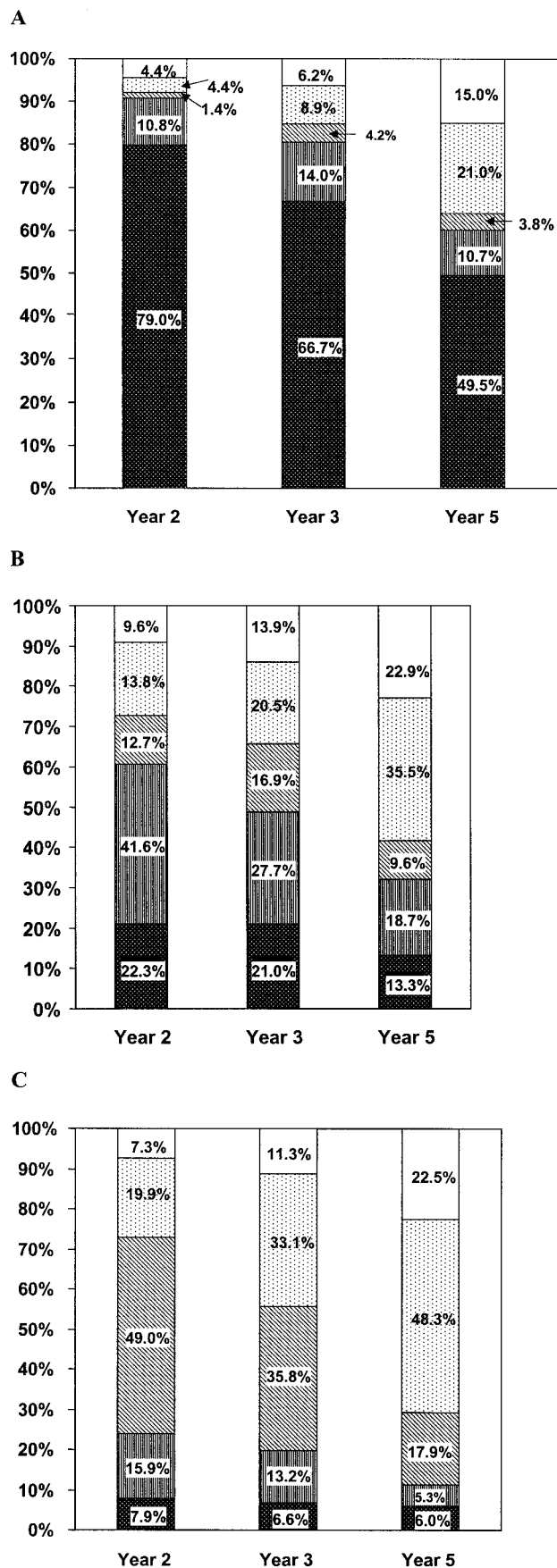


Figure 1. Transitions of those who began the study as A, noncaregivers ( $n = 501$ ); B, moderate caregivers ( $n = 166$ ); C, heavy caregivers ( $n = 151$ ). □ refused, too ill, could not be located, other; ▨ death of care recipient or caregiver, or nursing home placement of care recipient; ▩ heavy caregivers; ▪ moderate caregivers; ■ noncaregivers.

Table 1. Summary of Final Status at Year 5, by Caregiving Status at Baseline

Status at Final Observation	Noncaregivers at Baseline, % ( <i>n</i> = 501)	Moderate Caregivers at Baseline, % ( <i>n</i> = 166)	Heavy Caregivers at Baseline, % ( <i>n</i> = 151)
Noncaregiver	49.5	13.3	6.0
Moderate caregiver	10.8	18.7	5.3
Heavy caregiver	3.7	9.6	17.9
Care recipient died	10.2	21.7	25.8
Care recipient placed	1.8	6.0	11.9
Caregiver died	9.0	7.8	10.6
Other	15.0	22.9	22.5

of depressive symptoms than those who transitioned from noncaregiving to moderate caregiving. The main effect for time was also significant ( $F = 4.66, p < .05$ ), indicating that the average level of depressive symptoms across both transition groups was higher after the transition than before. There was no significant interaction of transition category and time. However, the simple effect tests of time within the transition category revealed expected patterns. There was a significant increase in depressive symptoms from pre- to posttransition for heavy caregivers (5.59 vs. 6.94,  $t = -3.02, p < .01$ ), but not for moderate caregivers (4.66 vs. 5.31,  $t = 1.73, ns$ ). The analysis of self-mastery revealed a main effect for caregiving transition category because those who transitioned to moderate caregiving had higher self-mastery scores across the two time points than those who transitioned to heavy caregiving (24.71 vs. 23.0,  $F = 10.90, p < .001$ ). There was no significant interaction or main effect for time.

The analysis of self-reported general health revealed no significant main effects, but a marginally significant interaction of transition category and time ( $F = 3.59, p = .06$ ). The post-hoc analysis of the simple effects of time within the transition category indicated that there was a significant pre- to posttransition decrease in quality of self-reported health for those who transitioned to heavy caregiving (2.63 vs. 2.98,  $t = 3.75, p < .001$ ), but not for

those who transitioned to moderate caregiving (2.7 vs. 2.81,  $t = 1.55, ns$ ). In terms of health risk behaviors, those who transitioned to heavy caregiving reported, on average, higher counts of health risk behaviors than those who transitioned from noncaregiving to moderate caregiving (.33 vs. .56,  $F = 5.46, p < .05$ ). The analysis also yielded a significant interaction between transition category and time ( $F = 11.2, p < .001$ ), indicating that the changes in health risk behaviors from pre- to posttransition measurement varied across the transition categories. The post-hoc examination of the simple effects revealed that there was a significant pre- to posttransition increase in health risk behaviors for heavy caregivers (.38 vs. .75,  $t = -3.84, p < .01$ ), but not for moderate caregivers (.35 vs. .30,  $t = .64, ns$ ).

Differences in physical and mental health measures among transition groups at baseline reveal some early associations that may be predictive of moving to a caregiving role even when controlling for demographic characteristics. The post-hoc simple effects tests revealed that baseline levels of health risk behaviors and self-mastery differed among the groups. Specifically, those who remained noncaregivers reported fewer health risk behaviors at baseline than either those who transitioned to moderate caregiving ( $t = -2.42, p < .05$ ) or heavy caregiving ( $t = -2.62, p < .01$ ; estimated marginal means from the repeated-measures ANCOVA, .24,

Table 2. Characteristics of Transition Groups<sup>a</sup> at Baseline

Characteristic	Remained Noncaregiver ( <i>N</i> = 209)	Became Moderate Caregiver ( <i>N</i> = 136)	Became Heavy Caregiver ( <i>N</i> = 83)
Age (mean)**	78.2	79.3	80.2
Male (%)	47	54	47
White (%)	93	85	90
Income < \$25,000 (%)***	32	52	61
Education ≤ 12 years (%)	41	47	53

<sup>a</sup>For the analysis of transitions and associated health outcomes we selected those respondents who were available for baseline and all three follow-up observations ( $n = 428$ ), and placed them in three transition categories based on a retrospective determination of their movement to their most demanding caregiving state. Those who were heavy caregivers at baseline were excluded because they could not transition to a more demanding state of caregiving using our criteria. Study subjects were placed into a transition group as: (1) noncaregivers if they remained in this state throughout; (2) moderate caregivers if they transitioned to giving instrumental activity of daily living assistance, and this was the most demanding level of care they provided; and (3) as heavy caregivers if they transitioned into the provision of activity of daily living assistance at any one of the three follow-up measurement points.

\*\* $p < .01$ ; \*\*\* $p < .001$ .

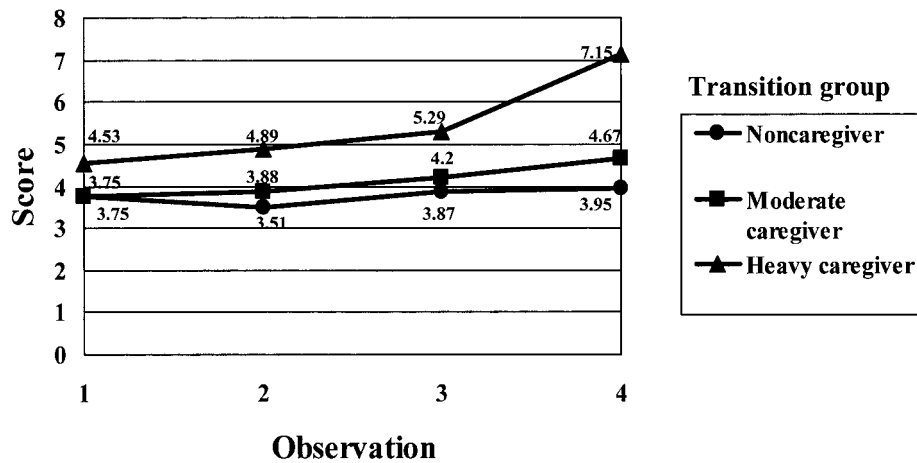


Figure 2. Depressive symptoms at four observations, by transition group. Repeated-measures analysis of covariance statistics. Main test for transition group,  $F = 6.88, p < .001$ . Main effects test for time not significant. Interaction of transition category and time,  $F = 2.74, p < .05$ . Control variables: age, education, gender, self-reported health, and income. Possible range of depressive symptoms 0–30. Higher scores indicate more symptoms of depression.

.47, and .54, respectively). The difference between the moderate and heavy caregivers was not significant. At baseline, self-mastery was significantly lower for those who would later transition to heavy caregiving, compared with both of those who transitioned to moderate caregiving ( $t = 2.24, p < .05$ ) and those who remained noncaregivers ( $t = 4.01, p < .001$ ; estimated marginal means 23.6, 25.0, and 25.9, respectively). Differences between the three transition groups at baseline for depression and general health were not significant.

## Discussion

We followed 818 older married couples (mean age 79.3 years) recruited from a large sample of community-dwelling older adults to characterize transitions into and out of the caregiving role over a 5-year period. Of the 501 individuals who were

noncaregivers at baseline, approximately 50% remained noncaregivers at the end of the 5-year period. Only 15% were caregivers, and the remainder experienced a wide range of outcomes, including death or nursing home placement of their spouse, their own death, or were lost to follow-up because of illness, refusal, or failure to locate. Among individuals who were caregivers at baseline ( $n = 317$ ), approximately one-fourth (25.8%) were still providing care 5 years later, whereas the remainder transitioned out of the caregiving role through their own deaths, their spouses' deaths, or placement of their spouses in a long-term care facility. The trajectory of health outcomes associated with caregiving was generally downward. Those who transitioned to heavy caregiving had more symptoms of depression, poorer self-reported health and health behaviors, and outcomes that became progressively worse over time. In addition, baseline scores on self-mastery and health risk behaviors were worse among

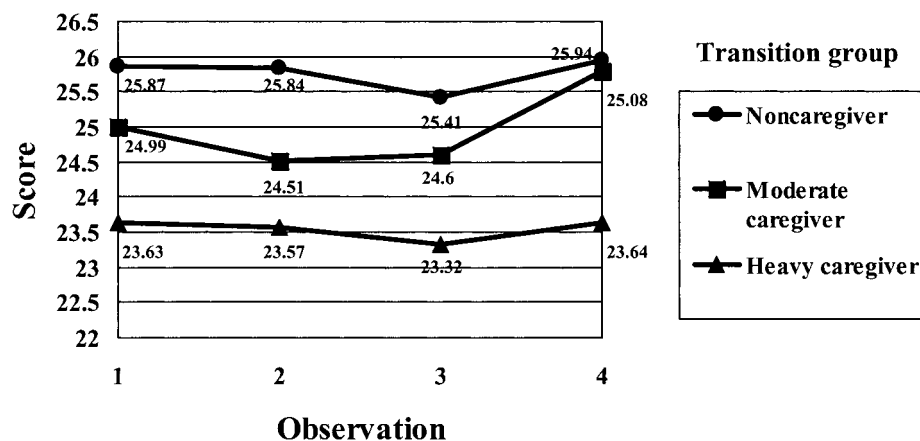


Figure 3. Self-mastery at four observations, by transition group. Repeated-measures analysis of covariance statistics. Main effects test for transition group,  $F = 12.82, p < .001$ . Main effects test for time not significant. Interaction of transition category not significant. Control variables were age, education, gender, self-reported health, and income. Possible range of self-mastery scores 0–35, with higher scores indicating greater self-mastery.

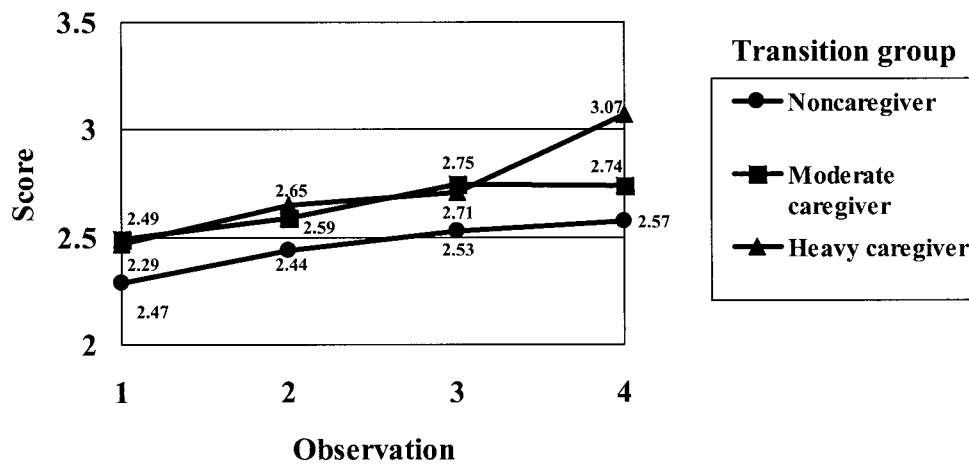


Figure 4. Self-reported health at four observations, by transition group. Repeated-measures analysis of covariance statistics. Main effects test for transition group,  $F = 3.85, p < .05$ . Main effects test for time not significant. Interaction of transition category and time,  $F = 2.14, p < .05$ . Control variables were age, education, gender, and income. Possible range for self-reported health 0–5, with higher scores indicating poorer health.

those who initially did not give care, but later became caregivers.

For those individuals who were providing care for their spouse in one or more IADL at the initial observation, approximately one-fourth returned to noncaregiving status over the next 2 years. However, by Year 5, the majority were either providing care for spouses with IADL or ADL impairment. For those who were heavy caregivers at the initial observation, few had positive outcomes. Nearly half experienced death of the spouse, placement of the spouse into a long-term care facility, or had died themselves. Nearly one-fourth had been lost from the study for other reasons, such as inability to contact, too ill to interview, or other reasons.

We coupled these observations with analyses of the outcomes associated with transitioning to a more demanding caregiving role. Our data confirmed

earlier findings that caregivers compared with non-caregivers have more depressive symptoms, poorer self-reported health (Schulz et al., 1997), and a greater number of health risk behaviors (Burton et al., 1998; Schulz et al., 1997). Given the four observations we had over 5 years, we were able to show what has been suspected but not previously documented—that these outcomes become worse over time. An additional new finding was the difference in self-mastery among the transition groups not only at follow-up observations, but present at the initial observation, prior to transition to a more demanding level of caregiving. Our finding that self-mastery did not change significantly over time is in contrast to earlier work among caregivers of Alzheimer’s disease patients who had sought help in coping with their role that showed fluctuations in self-mastery related to changes in the caregiving state

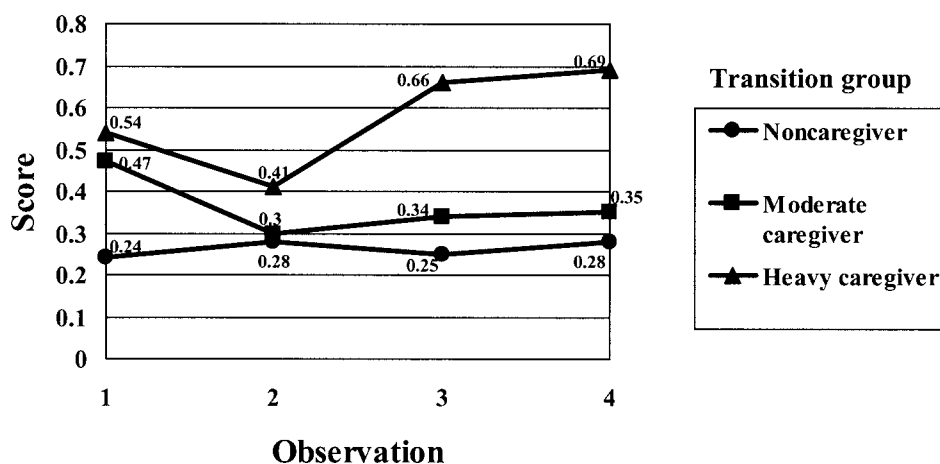


Figure 5. Health risk behaviors at four observations, by transition group. Repeated-measures analysis of covariance statistics. Main effects test for transition group,  $F = 7.28, p < .001$ . Main effects test for time not significant. Interaction of transition category and time,  $F = 2.31, p < .05$ . Control variables were age, education, gender, self-reported health, and income. Possible range of health risk behaviors was 0–6, with higher scores indicating more health risk behaviors.



(Skaff, Pearlin, & Mullen, 1996). The sample for our study differs from that of Skaff and Colleagues, in that our participants were recruited from the community without regard to dementia status and at various levels of caregiving.

The examination of sociodemographic characteristics and health and mental health measures at baseline of the three transition groups allowed us to identify factors that precede versus those that coincide with transition to a more demanding caregiving status. People at greater risk of becoming caregivers tend to be older, have lower income, have a lower sense of self-mastery, and have higher levels of health risk behaviors prior to the transition. The link between socioeconomic status and poor health is well established (Mechanic, 2000). Our findings suggest that such a link could extend to an increased risk of becoming a spousal caregiver. Further work needs to be done to determine if this finding holds up in other populations of caregivers and also to determine if the course of spousal caregiving is similar for both high and low socioeconomic groups and those with high or low mastery. A previously reported CHES finding may help explain the baseline differences in self-mastery and health behaviors. Bookwala and Schulz (1996) have shown that spousal pairs are similar in subjective well-being, which, in our study, may translate into physical and mental health effects, such as health risk behaviors, appraisal of one's health, or self-mastery. Thus, the spouse who becomes impaired in functions of daily living and becomes a care recipient is more likely to have a spouse (in this study, our respondent) with a predisposition for a dysfunction, evident in their lower baseline values.

In addition to baseline differences, we found that across-time patterns of health and mental health outcomes differ between noncaregivers and those who transition to moderate or heavy caregiving states. A closer examination of the interactions between the time factor and the transition category for health outcomes suggests that progressively declining health was associated with transition to a more demanding caregiving state. In terms of depressive symptoms, those who transitioned to heavy caregiving experienced the greatest decline. Similarly, the number of health risk behaviors increased significantly over the four observations for those who transitioned to heavy caregiving. A consistent pattern of change was observed for self-reported general health: of the four observations, those who transitioned to heavy caregiving reported a greater decline in general health than moderate caregivers or noncaregivers. Because of the correlational nature of the data, it is not possible to conclude that transitions to caregiving caused a decline in health. Our findings, however, highlight an important fact that transitioning to caregiving, and especially a transition toward caring for a spouse with ADL impairments (heavy caregivers), is asso-

ciated with declines in physical and mental health indicators in the caregiver over time.

For the outcomes analysis, we chose for interpretability to assign persons to one caregiving role, regardless of when a transition took place. We augmented this by exploring the temporal relationship between change in caregiving state and the outcomes by carrying out an analysis that looked explicitly at caregiver outcomes at the point of transition; for example, depression levels pre- and posttransition for persons who moved from non-caregiving to moderate caregiving or who moved to heavy caregiving. Findings were very similar to the main analysis in that transition to heavy caregiving was associated with more depression overall, lower self-mastery overall, larger pre- to posttransition drop in self-reported health, and larger pre- to posttransition increase in health risk behaviors.

A limitation to the longitudinal analysis is the attrition over the course of the study, mainly because of deaths or institutionalizations. The absence of these caregivers—who would be expected to have experienced the greatest amount of stress, caregiving duties, and poor outcomes associated with this stress—may have caused us to underestimate the effects of caregiving over time. By limiting the first set of outcome analyses to those for whom data were available at four times, we may in effect be presenting results for those with long caregiving careers. To address this concern, we carried out a second analysis of outcomes that used pre- and posttransition observations at the point at which a transition occurred regardless of longevity in the study. The results were very similar to the results of analyses of those who remained in the study longer.

Greater understanding of the spousal caregiver career over many years is important for planning for support services for both the caregiver and potentially for the impaired spouse who may be left without his/her primary informal support. The role of caregivers is receiving increasing attention by governments. States and local communities have a variety of programs to support caregivers, and the federal Family Caregiver Program of 2000 recognized the need to grant added resources to states to run programs that provide help to families to maintain their caregiver roles (Department of Health and Human Services, 2001). Although it is possible that future cohorts may rely less on spouses and more on other informal or formal supports for assistance with functional impairments, it is likely that spousal caregivers will continue to provide the majority of assistance. This underscores the need for greater understanding of the dynamics of transitions among spousal caregivers.

#### References

- Bookwala, J., & Schulz, R. (1996). Spousal similarity in subjective well-being: The Cardiovascular Health Study. *Psychology and Aging, 11*, 582–590.
- Burton, L. C., Newsom, J. T., Schulz, R., Hirsch, C. H., & German, P.

- (1998). Preventive health behaviors among spousal caregivers. *Preventive Medicine*, 26, 162–169.
- Fried, L. P., Borhani, N. O., Enright, P., Furberg, Co. O., Gardin, J. M., & Kronmal, R. A., et al., (1991). The cardiovascular health study: Design and rationale. *Annals of Epidemiology*, 1, 263–276.
- Lawton, M. P., Moss, M., Hoffman, C., & Perkinson, M. (2000). Two transitions in daughters' caregiving careers. *The Gerontologist*, 40, 437–448.
- Manton, K. G., Corder, L., & Stallard, E. (1999). Chronic disability trends in elderly United States populations: 1982–1994. *Proceedings of the National Academy of Sciences U.S.A.*, 94, 2593–2598.
- Mechanic, D. (2000). Rediscovering the social determinants of health. *Health Affairs*, 19, 269–276.
- Pearlin, L. I., & Schooler, C. (1978). The structure of coping. *Journal of Health and Social Behavior*, 19, 2–21.
- Radloff, L. S. (1977). The CES-D Scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement*, 1, 385–401.
- Schulz, R., & Beach, S. R. (1999). Caregiving as a risk factor for mortality: The Caregiver Health Effects Study. *Journal of the American Medical Association*, 282, 2215–2219.
- Schulz, R., Beach, S. R., Lind, B., Martire, L. M., Zdaniuk, B., Hirsch, C., et al. (2001). Involvement in caregiving and adjustment to death of a spouse: Findings from the Caregiver Health Effects Study. *Journal of the American Medical Association*, 285, 3123–3129.
- Schulz, R., Mittelmarm, M., Kronmal, R., Polak, J. F., Hirsch, C. H., German, P., et al. (1994). Predictors of perceived health status in elderly men and women. The Cardiovascular Health Study. *Journal of Aging Health*, 6, 419–447.
- Schulz, R., Newsom, J. T., Mittelmarm, M., Burton, L. C., Hirsch, C. H., & Jackson, S. (1997). Health effects of caregiving: The Caregiver Health Effects Study. *Annals of Behavioral Medicine*, 19, 110–116.
- Schulz, R., O'Brien, A. T., Bookwala, J., & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates, and causes. *The Gerontologist*, 35, 771–791.
- Seltzer, M. M., & Li, L. W. (2000). The dynamics of caregiving: Transitions during a three-year prospective study. *The Gerontologist*, 40, 165–178.
- Shrout, P. E., & Yager, T. J. (1989). Reliability and validity of screening scales: Effect of reducing scale length. *Journal of Clinical Epidemiology*, 42, 69–78.
- Skaff, M. M., Pearlin, L. I., & Mullan, J. T. (1996). Transitions in the caregiving career: Effects on sense of mastery. *Psychology of Aging*, 11, 247–257.
- Spector, W. D., Fleishman, J. A., Pezzin, L. E., & Spillman, B. C. (2000). *The characteristics of long-term care users* (AHRQ Publ. No. 00-0049). Washington, DC: Agency for Health Research and Quality.
- Tell, G. S., Fried, L. P., Hermanson, B., Nanolio, T. A., Newman, A. B., Borhani, N. O., et al. (1993). Recruitment of adults 65 years and older as participants in the Cardiovascular Health Study. *Annals of Epidemiology*, 3, 358–366.
- U.S. Department of Health and Human Services. (2001). HHS launches National Family Caregiver Program. Retrieved 2001 from <http://www.aoa.gov/pressroom/pr2001>

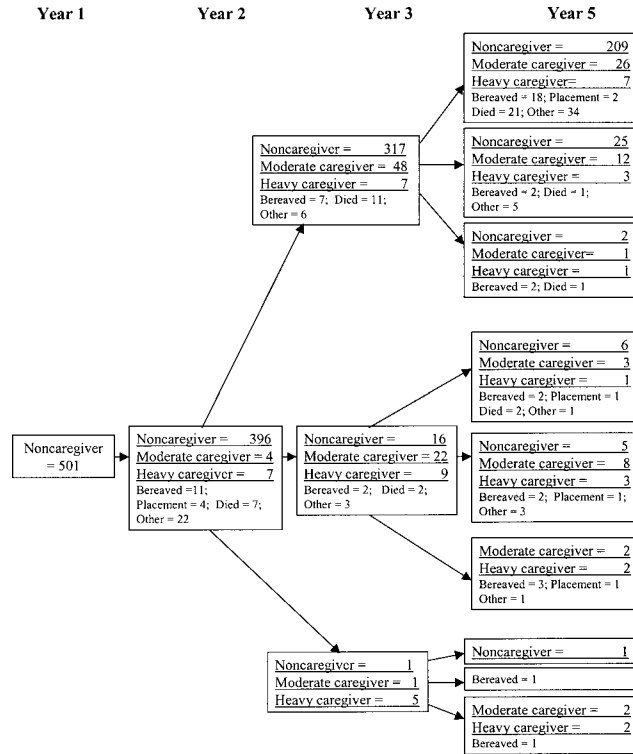
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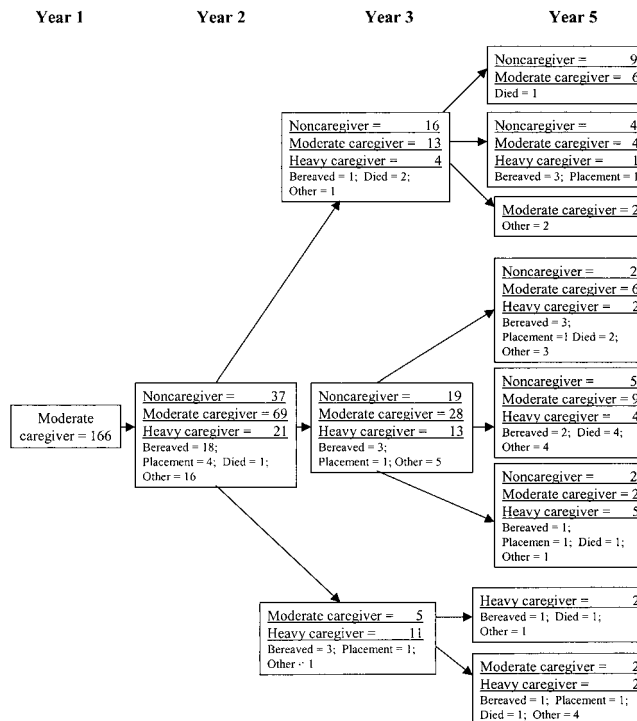
## Appendix A

### Transitions of Persons Who Entered Study as Noncaregiver



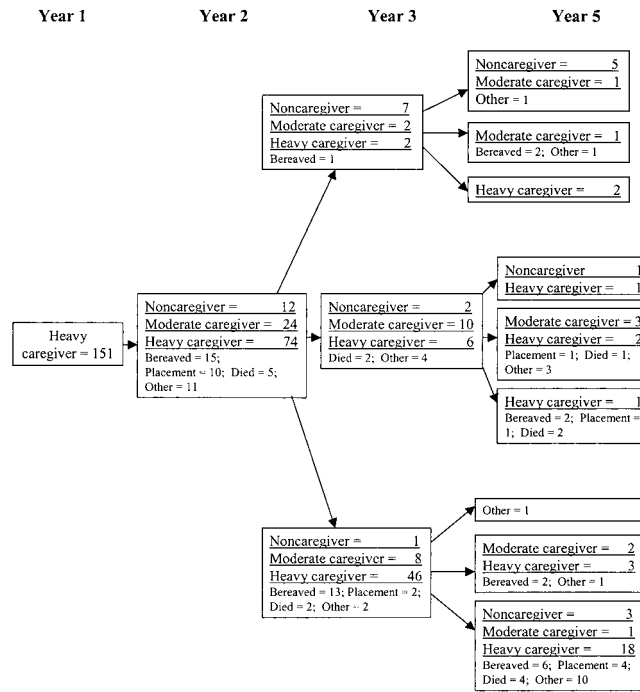
## Appendix B

### Transitions of Persons Who Entered Study as Moderate Caregivers



## Appendix C

### Transitions of Persons Who Entered Study as Heavy Caregivers



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