Background

       Caregiving for an ill or disabled spouse is common and frequently entails substantial physical, emotional, or financial burdens. Of the estimated 6 million caregivers for disabled older (65+) persons in the U.S., nearly 25% are caring for their spouse[1]. While providing care for a family member has many potential benefits, prior research demonstrates that caregiving demands threaten the health of caregivers by decreasing healthful behaviors like exercise[2], increasing risk of cardiovascular disease onset[3, 4] and all-cause mortality[5]. Most commonly, caregiving increases strain[6-14], stress and burden [12, 15-19] and depression[12-14, 18, 20-23].

       Many studies have helped characterize people who provide care in the U.S. Caregivers tend to have significantly different health characteristics than non-caregivers: for example, caregivers are more likely to smoke, exercise less, go to fewer doctors' appointments, have more trouble managing medication adherence[24, 25]. Many studies have described the characteristics of existing caregivers, though there are gaps in our understanding of which of those characteristic *predicts* a spouse becoming a caregiver. While caregivers surely provide care due to their love for and familial bind for their family member[26-29], few studies have examined predictors of spousal caregiving. In particular, we know little about to what extent a spouse's health influences them to provide care for an ill-spouse.

       To date, we have learned a great deal about caregiving and depression. Caregiving is associated with increased depressive symptoms[11, 19, 30]. However, few of these associations have been tested for known moderating effects in a nationally representative sample. For example, there is evidence to suggest that the perceived burden associated with caregiving varies by race[32-34]. Moreover, caregivers of persons with dementia often have a variety of worse health outcomes than people who provide non-dementia related care[20, 35].

       While the literature on caregivers and investigating associations between caregiving activities and depression is vast, there are many gaps in this extant research. For example, we still know little about which characteristics of the caregiver predict them discontinuing care. This has been studied to some extent among people providing care for parents[36], but not among spousal caregivers. While we know the care quality of care suffers when the caregiver is depressed, compared to a non-depressed caregiver[31], we don't know if and to what extent depression specifically predicts whether spousal caregivers stop providing care.

       In this paper, we address three distinct, but related research questions to disentangle the temporal and causal ordering between spousal caregiving and depression. First, does depression predict onset or initial caregiving? We hypothesize that baseline depression will not be associated with providing care, because caregiving needs for a spouse are often done in spite of physical and other limitations by the caregiver. Second, we examine if caregiving predicts onset of depression; we posit caregiving will be positively associated with risk of depression onset. Third, does depression predict ending care? We hypothesize that depression will be the

negatively associated with caregiving and thus will be positively associated with stopping providing care.

Theoretical focus

Depression is a common outcome considered with respect to caregiving, in part because it is inherently connected to the stress and strain associated with caregiving for an ill or disabled loved one[34]. Accordingly, we model the onset of depression with lagged values of potential time-varying covariates that might be coping strategies and other responses to this stress. Furthermore, as Knight and colleagues have illustrated[34], the stress and coping process for caregivers varies by culture. Though our dataset is rich, there are no questions about specific cultural identification in HRS. Thus, we include stratified analyses of the onset of depression by race. Lastly, much of the caregiving literature is rooted in psychology, from which many of additional theories of caregiving burden and roles emerge[22, 37-41] that have informed the field and our work.

Methods

Study Population

HRS is a longitudinal survey of a national sample of US adults aged 50+ years and their spouses. This study was restricted to HRS participants born 1900 to 1947 and interviewed in 2000, which was the earliest year when caregiving assessments were consistently worded and asked with respect to spouses. Of 11,280 age-eligible, married respondents interviewed in 2000, we excluded 1,142 (10.12%) due to reporting depression before 2000 and 42 (0.37%) due to missing information on risk factors, leaving 10,097 individuals contributing time to the primary analyses.

Spousal Caregiving

Spousal caregiving demand was calculated in each biennial interview wave (2000 – 2006), based on the care recipient's report regarding assistance with activities of daily living (ADLs; including help with getting across a room, dressing, bathing, eating, getting in and out of bed, and using the toilet) and instrumental activities of daily living (IADLs; prepare meals, shop for groceries, make telephone calls, take medications). We dichotomized the hours of care to < 14 and ≥14 hours of care per week as our primary exposure classification (hereafter referred to as "high caregiving").

Assessment of Depression

Depressive symptoms were assessed using a modified, 8-item version of the Centers for Epidemiologic Studies-Depression (CES-D) scale. Our outcome variable is a dichotomized variable of whether the respondent reported 3 or more symptoms. Others have found that 3 or more symptoms of this scale had a high sensitivity and specificity with the CIDI-SF, a scale used for clinical diagnoses of depression[42].

Covariates

We consider 7 sets of covariates: socio-demographic (age, sex, race/ethnicity), socioeconomic status (SES), recipient cognitive status, health behaviors, comorbid conditions, self-reported health and disability measures, and social support. For the depression onset models, these were added to the models in groups, sequentially. We lagged reports of cognitive status, work status/income, health behaviors, comorbid conditions, and self-rated health, using the values of these covariates reported in 1998 as baseline and including them in the models as time-varying covariates. We consider all other covariates time-constant and use the covariates reported in 2000 as baseline.

Methods of Analysis

The first analysis phase was to estimate predictors of caregiving status using discrete-time hazard models. We estimated three models for predictors of caregiving to assess both existing and new caregiving during our study period. First, we estimated baseline (2000) prevalence of caregiving using the prior wave's covariates. Next, we estimated incident caregiving; that is, people who did not provide care at baseline but did provide care during a follow-up wave (between 2002-2008). Lastly, we estimated prevalent caregiving over our total study period (2000-2008), which included a lagged variable indicating whether the respondent provided care in the previous wave. This model mimics the inverse probability of treatment model described below.

In the second phase of our analysis, elevation in hazard of depression associated with high caregiving was estimated with discrete-time hazard models. Individuals contributed person-time to the models as long as they could have experienced the high caregiving exposure—that is, alive and married to their spouse from baseline—and had not yet reported a new onset depression. A respondent was censored from the analysis once she had high depressive symptoms. We adjusted for time-varying confounding by using inverse probability of treatment and survival weights[43-45]. Thus, we weighted each observation by the inverse of the probability that individual was alive at the exposure wave, times the inverse of the probability that individual (conditional on having survived) was in the sample at both exposure and outcome waves, times the inverse of the probability that the individual received the treatment he or she actually received. Stabilized weights were calculated using previously described protocols[43]. We also examined models stratified by caregiver's age, sex, race, education and recipient's cognitive status.

In the final stage of our analyses, we estimated a model that assesses whether depression predicted discontinuing caregiving. We consider discontinuing care as reporting providing no care (0 hours) and separately decreased care (reporting providing 1-13 hours of care) and use discrete-time hazard models to estimate these effects. Specifically, these models estimated, among caregivers at the exposure and prior wave, whether an exposure of depression predicted not providing care in the outcome wave. In other words, for someone providing care in both 1998 and 2000, whether their 2000 depression status predicted either 0 or 1-13 hours of care in

2002. Both of these models are weighted for the inverse probability of treatment (depression), inverse probability of selection, and sampling weights as described above.

Results

There were 2,582 incidents of depression during 59,064 person-years of follow-up. Among those eligible for the depression onset analysis, 8.4% of spouses provided some care and 2.9% were "exposed" to high caregiving over all person-years of follow-up.

We examined estimated of predictors of high caregiving. Current alcohol use and at least one reported limitation of instrumental activities of daily living were significantly associated with a *reduced* risk of baseline (Model 1), incident caregiving (Model 2), as well as any caregiving over our study period (Model 3). The care recipient having health insurance predicted a significant 17% reduced risk of providing care over our whole sample period, but not baseline or incident caregiving. The care recipient's reported limitations with instrumental/activities of daily living predicted *excess* risk of providing baseline, incident, and care at any time point. Age (HR=1.05; 95% CI: 1.04, 1.06) and interrupted sleep (HR=1.23; 95% CI: 1.03, 1.47) were significantly associated with excess risk of high caregiving in all models (Model 3 results reported). Current smoking predicted baseline (HR=1.31; 95% CI: 1.01, 1.70) and incident (HR=1.31; 95% CI: 1.01, 1.70) caregiving, but the confidence interval for predicting care across any time period included the null value (HR=1.29; 95% CI: 1.00, 1.67).

We examined crude and adjusted estimates of caregiving risk on depression. In the crude model, high caregiving was associated with more than a two-fold excess risk of depression (HR=2.18; 95% CI: 1.72, 2.74). Once adjusted for demographic, socioeconomic status (SES), recipient cognitive status, health behaviors, comorbid conditions, self-reported health and disability measures, and social support, high caregiving predicted excess risk for depression (HR=1.76; 95% CI: 1.38, 2.25). In models stratified by gender, race, and age, we found no significant differences between caregivers by these characteristics for risk of depression.

We also examined adjusted estimates of depression on discontinuing care among existing caregivers (n=696). In the crude model, depression was associated with a 55% excess risk of discontinuing high caregiving (HR=1.55; 95% CI: 1.08, 2.02) Once adjusted for demographic, socioeconomic status (SES), recipient cognitive status, health behaviors, comorbid conditions, self-reported health and disability measures, and social support, depression status predicted excess risk for discontinuing caregiving (HR=1.46; 95% CI: 1.00, 2.15), though the confidence interval included the null value.

References

1. Spector WD, Fleishman JA, Pezzin LE, Spillman BC. The characteristics of long-term care users. Rockville, MD.: Agency for Healthcare Research and Quality (AHRQ); 2001;Publication No. 00-0049. Available from: http://www.ahrq.gov/research/ltcusers/.

2. Harralson TL, Emig JC, Polansky M, Walker RE, Cruz JO, Garcia-Leeds C. Un corazon saludable: Factors influencing outcomes of an exercise program designed to impact cardiac and metabolic risks among urban latinas. *J Community Health*. 2007;32(6):401-412.

3. Lee S, Colditz GA, Berkman LF, Kawachi I. Caregiving and risk of coronary heart disease in U.S. women: A prospective study. *Am J Prev Med*. 2003;24(2):113-119.

4. Lee S, Colditz G, Berkman L, Kawachi I. Caregiving to children and grandchildren and risk of coronary heart disease in women. *Am J Public Health*. 2003;93(11):1939-1944.

5. Schulz R, Beach SR. Caregiving as a risk factor for mortality: The caregiver health effects study. *JAMA*. 1999;282(23):2215-2219.

6. Haley WE, Roth DL, Howard G, Safford MM. Caregiving strain and estimated risk for stroke and coronary heart disease among spouse caregivers: Differential effects by race and sex. *Stroke*. 2010;41(2):331-336.

7. Kim Y, Schulz R. Family caregivers' strains: Comparative analysis of cancer caregiving with dementia, diabetes, and frail elderly caregiving. *J Aging Health*. 2008;20(5):483-503.

8. Spaid WM, Brusch AS. Social support and caregiver strain: Types and sources of social contacts of elderly caregivers. *J Gerontol Social Work*. 1991;18:151-161.

9. Aggarwal B, Liao M, Christian A, Mosca L. Influence of caregiving on lifestyle and psychosocial risk factors among family members of patients hospitalized with cardiovascular disease. *J Gen Intern Med*. 2009;24(1):93-98.

10. Covinsky K, Newcomer R, Fox P, et al. Patient and caregiver characteristics associated with depression in caregivers of patients with dementia. *Journal of General Internal Medicine*. Springer New York; 2003;18(12):1006-1014.

11. Taylor DH, Kuchibhatla M, Østbye T, Plassman BL, Clipp EC. The effect of spousal caregiving and bereavement on depressive symptoms. *Aging & Mental Health*. 2008;12(1):100.

12. Clyburn LD, Stones MJ, Hadjistavropoulos T, Tuokko H. Predicting caregiver burden and depression in alzheimer's disease. *J Gerontol B Psychol Sci Soc Sci*. 2000;55:S2-13.

13. Schulz R, Visintainer P, Williamson GM. Psychiatric and physical morbidity effects of caregiving. *J Gerontol*. 1990;45(5):P181-91.

14. Schulz R, Williamson GM. A 2-year longitudinal study of depression among alzheimer's caregivers. *Psychol Aging*. 1991;6(4):569-578.

15. Rigby H, Gubitz G, Phillips S. A systematic review of caregiver burden following stroke. *International Journal of Stroke*. 2009;4(4):285-292.

16. Luttik ML, Jaarsma T, Veeger N, Tijssen J, Sanderman R, van Veldhuisen DJ. Caregiver burden in partners of heart failure patients; limited influence of disease severity. *Eur J Heart Fail*. 2007;9(6-7):695-701.

17. Pinto RA, Holanda MA, Medeiros MMC, Mota RMS, Pereira EDB. Assessment of the burden of caregiving for patients with chronic obstructive pulmonary disease. *Respir Med*. 2007;101(11):2402-2408.

18. Gallicchio L, Siddiqi N, Langenberg P, Baumgarten M. Gender differences in burden and depression among informal caregivers of demented elders in the community. *Int J Geriatr Psychiatry*. 2002;17:154-163.

19. Bookwala J, Schulz R. A comparison of primary stressors, secondary stressors, and depressive symptoms between elderly caregiving husbands and wives: The caregiver health effects study. *Psychol Aging*. 2000;15(4):607-616.

20. Mausbach BT, Patterson TL, Rabinowitz YG, Grant I, Schulz R. Depression and distress predict time to cardiovascular disease in dementia caregivers. *Health Psychology*. 2007;26(5):539-544.

21. Mausbach BT, Patterson TL, Grant I. Is depression in alzheimer's caregivers really due to activity restriction? A preliminary mediational test of the activity restriction model. *J Behav Ther Exp Psychiatry*. 2008;39(4):459-466.

22. Monin JK, Schulz R. Interpersonal effects of suffering in older adult caregiving relationships. *Psychol Aging*. 2009;24(3):681-695.

23. Tsai P, Jirovec M. The relationships between depression and other outcomes of chronic illness caregiving. *BMC Nursing*. 2005;4(1):3.

24. Schulz R, Newsom J, Mittelmark M, Burton L, Hirsch C, Jackson S. Health effects of caregiving: The caregiver health effects study: An ancillary study of the cardiovascular health study. *Ann Behav Med*. 1997;19(2):110-116.

25. Ory MG, Hoffman RR,3rd, Yee JL, Tennstedt S, Schulz R. Prevalence and impact of caregiving: A detailed comparison between dementia and nondementia caregivers. *Gerontologist*. 1999;39(2):177-185.

26. Cohen CA, Colantonio A, Vernich L. Positive aspects of caregiving: Rounding out the caregiver experience. *Int J Geriatr Psychiatry*. 2002;17(2):184-188.

27. Tarlow BJ, Wisniewski SR, Belle SH, Rubert M, Ory MG, Gallagher-Thompson D. Positive aspects of caregiving. *Research on Aging*. 2004;26(4):429-453.

28. Boerner K, Schulz R, Horowitz A. Positive aspects of caregiving and adaptation to bereavement. *Psychol Aging*. 2004;19(4):668-675.

29. Piercy KW. Theorizing about family caregiving: The role of responsibility. *Journal of Marriage and Family*. 1998;60(1):pp. 109-118.

30. Zanetti O, Frisoni GB, Bianchetti A, Tamanza G, Cigoli V, Trabucchi M. Depressive symptoms of alzheimer caregivers are mainly due to personal rather than patient factors. *Int J Geriatr Psychiatry*. 1998;13:358-367.

31. Covinsky KE, Newcomer R, Fox P, et al. Patient and caregiver characteristics associated with depression in caregivers of patients with dementia. *J Gen Intern Med*. 2003;18:1006-1014.

32. Janevic MR, M Connell C. Racial, ethnic, and cultural differences in the dementia caregiving experience. *The Gerontologist*. 2001;41(3):334-347.

33. Connell CM, Gibson GD. Racial, ethnic, and cultural differences in dementia caregiving: Review and analysis. *The Gerontologist*. 1997;37(3):355-364.

34. Knight BG, Sayegh P. Cultural values and caregiving: The updated sociocultural stress and coping model. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*. 2010;65B(1):5-13.

35. Schulz R, Martire LM. Family caregiving of persons with dementia: Prevalence, health effects, and support strategies. *Am J Geriatr Psychiatry*. 2004;12(3):240-249.

36. Coe NB, Van Houtven CH. Caring for mom and neglecting yourself? the health effects of caring for an elderly parent. *Health Econ*. 2009;18(9):991-1010.

37. Schulz R. Theoretical perspectives on caregiving. *Aging and Caregiving: Theory, Research, and Policy*. 1990.

38. Haug MR. Elderly patients, caregivers, and physicians: Theory and research on health care triads. *J Health Soc Behav*. 1994;35(1):pp. 1-12.

39. Pearlin LI, Mullan JT, Semple SJ, Skaff MM. Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist*. 1990;30(5):583-594.

40. Pearlin LI. Conceptual strategies for the study of caregiver stress. *Stress Effects on Family Caregivers of Alzheimer's Patients, Research and Interventions*. 1994.

41. Aneshensel CS, Pearlin LI, Mullan JT, Zarit SH, Whitatch CJ. Profiles in caregiving: The unexpected career. 1995.

42. Turvey CL, Wallace RB, Herzog R. A revised CES-D measure of depressive symptoms and a DSM-based measure of major depressive episodes in the elderly. *International Psychogeriatrics*. 1999;11(02):139.

43. Hernan MA, Brumback B, Robins JM. Marginal structural models to estimate the causal effect of zidovudine on the survival of HIV-positive men. *Epidemiology*. 2000;11(5):561-570.
44. Robins JM, Hernan MA, Brumback B. Marginal structural models and causal inference in epidemiology. *Epidemiology*. 2000;11(5):550-560.
45. Hernan MA, Brumback BA, Robins JM. Estimating the causal effect of zidovudine on CD4 count with a marginal structural model for repeated measures. *Stat Med*. 2002;21(12):1689-1709.