Published in final edited form as:

Am J Health Promot. 2012 ; 27(2): 84–89. doi:10.4278/ajhp.110606-QUAN-241.

Caregiver Burden and Nonachievement of Healthy Lifestyle Behaviors Among Family Caregivers of Cardiovascular Disease Patients

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Abstract

Purpose—To determine whether caregiver burdens are associated with lifestyle behaviors 1 year following the hospitalization of a family member with cardiovascular disease (CVD).

Design—Prospective follow-up study of National Heart Lung and Blood Institute sponsored Family Intervention Trial for Heart Health participants.

Setting—Hospital-based recruitment/baseline visit with 1-year follow-up.

Subjects—Family members of hospitalized CVD patients (N = 423; 67% female; 36% racial/ethnic minority; mean age 49 years).

Measures—Systematic evaluation at 1 year to determine heart-healthy diet (defined as <10% kcal from saturated fat; Block 98 Food Frequency Questionnaire) and physical activity (defined as 4 d/wk; Behavioral Risk Factor Surveillance System Survey) behaviors and caregiver burdens (five domains: employment, financial, physical, social, and time; Caregiver Strain Questionnaire).

Analysis—Logistic regression adjusted for covariates.

Results—Heart-healthy diet was less frequent among caregivers citing feeling overwhelmed (odds ratio [OR] = .50; 95% confidence interval [CI] = .26–.97), sleep disturbance (OR = .51; 95% CI = .27–.96), financial strain (OR = .41; 95% CI = .20–.86), upsetting behavior (OR = .48; 95% CI = .25–.92), and/or time demands (OR = .47; 95% CI = .26–.85) as burdens. Physical activity was less frequent among caregivers reporting financial strain (OR = .32; 95% CI = .13–.81) or upsetting patient behavior (OR = .33; 95% CI = .15–.76) as burdens. The most commonly cited caregiver burdens included changes in personal plans (39%), time demands (38%), and sleep disturbance (30%).

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Manuscript format: research; Research purpose: modeling/relationship testing; Study design: nonexperimental; Outcome measure: behavioral; Setting: clinical/healthcare; Health focus: stress management; Strategy: education; Target population: adults; Target population circumstances: education/income level

Conclusion—Caregiver burdens were associated with nonachievement of heart-healthy diet and physical activity behaviors among family caregivers 1 year after patient discharge. When developing heart-health promotion interventions, caregiver burden should be considered as a possible barrier to prevention among family members of CVD patients.

Keywords

Stress; Family; Caregiver; Lifestyle; Health Promotion; Prevention; Cardiovascular Disease; Prevention Research

Purpose

Patients hospitalized with acute cardiovascular disease (CVD) (e.g., myocardial infarction or coronary revascularization), often require assistance with health-related tasks, such as daily activities, doctor visits, and/or medication, after discharge.¹ It is estimated that more than one-half of hospitalized CVD patients plan to have an informal caregiver, such as a spouse or other family member, assist them.¹

Caregiver burden is a term used to describe the weight or load carried by caregivers as a result of adopting the caregiver role.^{2,3} Informal caregiving for patients with chronic illness has been associated with increased care-giver burden.⁴ As many as 3 out of 10 caregivers in the United States consider their caregiving to be emotionally stressful.⁵ Research conducted among caregivers for elderly and dementia patients has shown caregiver burden to be inversely associated with health promoting lifestyle behaviors, such as regular exercise, good nutrition, and routine medical follow-up for themselves.^{6–9} Less is known about the link between caregiver burden and achievement of healthy lifestyle behaviors among informal caregivers for CVD patients.¹⁰ However, being a caregiver has been associated with increased CVD risk.^{5,11,12}

Family members of CVD patients may be at increased risk of CVD themselves, in part because of genetic and/or lifestyle habits shared with the patient.¹³ Achievement of evidence-based lifestyle practices (i.e., diet and physical activity) is a key step in primary CVD prevention in this population. Evaluation of the association between caregiver burden and achievement of healthy lifestyle among family members who provide informal caregiving to CVD patients is important, because a link would implicate caregiver burden as a potential mediator of CVD risk in families. The purpose of this study was to examine the prevalence of caregiver burden, and the association between caregiver burden and achievement of heart-healthy diet and physical activity practices, among family members who provide caregiving to CVD patients.

Methods

Design

This was a 1-year nonexperimental prospective analysis of data provided by participants in the Family Intervention Trial for Heart Health (FIT Heart), a randomized controlled trial that enrolled family members of CVD patients admitted to New York-Presbyterian Hospital/Columbia University Medical Center, between January 2005 and June 2007 and collected 1-

year follow up data from January 2006 to June 2008.¹⁴ Primary outcome analyses of the FIT Heart randomized controlled trial showed that a screening and educational intervention for family members of CVD patients, provided at the time the patient is hospitalized, was effective at improving risk factors and lifestyle 1 year later.^{14,15}

Sample

All FIT Heart participants who completed baseline and 1-year follow-up, including assessment of caregiver status, were included in this analysis ($n = 423$; 85%). Participants were English- and/or Spanish-speaking adults (67% female; mean age 48.7 ± 13.5 years) who had a family member admitted to the hospital with CVD. A family member was defined as a blood relative or spouse or other individual (e.g., adopted son/daughter) who was living with the CVD patient or who had cohabitated with him/her for a minimum of 1 year within the previous 5, or for 10 or more years in the past. The majority of participants (78%) were formally educated beyond the high school level. More than one-third (36%) were racial/ethnic minorities, of whom more than one-half were born outside of the United States.¹⁶ Exclusion criteria were established as CVD, diabetes, active liver disease, chronic kidney disease, life expectancy fewer than 5 years, current or planned pregnancy, prescription of a diet non-compatible with National Heart Lung and Blood Institute Therapeutic Lifestyle Changes diet recommendations,¹⁷ or participation in a clinical study within 3 months of randomization. All subjects completed written informed consent and Health Insurance Portability and Accountability Act procedures prior to study participation. The study was approved by the Institutional Review Board of Columbia University Medical Center.

Measures

Caregiving and Caregiver Burden—Caregiving was assessed by self-report using a standardized survey question at 1-year follow-up. Participants were asked, “To what extent were you involved in the posthospitalization care (such as assistance with daily activities, doctor visits, and/or medication) for the family member who was hospitalized at New-York-Presbyterian Hospital when you enrolled in the FIT Heart study?” Participants selected from the following answers: (1) I was the primary caregiver, (2) I cared for the patient most of the time, (3) I cared for the patient some of the time, (4) I cared for the patient occasionally, (5) I was not involved in posthospitalization care for the patient, or (6) unsure/no answer/not applicable (e.g., patient deceased during hospitalization). For this study, those who selected answer number 1 or answer number 2 were considered frequent caregivers and a primary focus of analysis.

Caregiver burden was evaluated using the Caregiver Strain Questionnaire at 1 year.¹⁸ The questionnaire consists of a list of 13 items (“burdens”) that people providing care to adults have encountered in relation to their caregiver roles and responsibilities, such as time demands, disturbance in sleep, and physical strain. There are one or more items in the questionnaire for each of the following major burden domains: employment, financial, physical, social, and time.¹⁹ Participants endorsed each of the 13 burdens as yes or no. Yes responses were summed to calculate Caregiver Strain Index scores (range 0–13).¹⁸ Positive response to seven or more burdens indicates a greater level of stress.¹⁸ The Caregiver Strain

Index has demonstrated internal consistency among items ($\alpha = .86$) and has been validated in heart patients against measures of perceptions of the caretaking relationship by caregivers and emotional health of caregivers.¹⁸

Lifestyle Factors—The diet endpoint of interest was percentage of kilocalories from saturated fat. Participant diet was assessed using the Block 98 Food Frequency Questionnaire (FFQ). The Block 98 FFQ has been validated in diverse populations,^{20–24} and is designed to estimate usual intake of a wide array of nutrients, including saturated fat.²⁵ Individual portion size is asked for each food, and participants are provided with pictures to enhance accuracy of quantification.²⁵ The Block 98 FFQ has been demonstrated to have high reliability ($r = .72$), and validity against 24-hour recall data ($r = .41$) for the measurement of dietary saturated fat.²⁰ *Heart-healthy diet* for CVD primary prevention was defined as consuming fewer than 10% of daily calories from saturated fat.²⁶ Percentage of daily calories from saturated fat was determined using nutrient and calorie estimates yielded through processing of the Block 98 FFQ (NutritionQuest, Berkeley, California) and calculated using the equation $([g \text{ saturated fat}/d]/[9 \text{ cal/g}])(\text{cal}/d)$.

Physical activity was assessed at 1 year using standardized questions adapted from the validated Behavioral Risk Factor Surveillance System (BRFSS) survey.²⁷ BRFSS questions have been shown to have good reliability to measure moderate to vigorous intensity physical activity ($\kappa = .35$ – $.53$ and $\kappa = .80$ – $.86$, respectively) as well as validity against accelerometer measurements ($\kappa = .31$ and $\kappa = .17$, respectively).²⁸ Participants were asked, “At least once a week, do you engage in any regular physical activity (brisk walking, jogging, bicycling, etc.) long enough to work up a sweat?” and, if yes, “How many days per week do you engage in physical activity that works up a sweat?” Results were recorded as number of days per week. *Heart-healthy physical activity* was defined as engaging in physical activity on most (≥ 4) days of the week.

Demographics, education level, and other characteristics were obtained from participants at baseline and 1 year by standardized questionnaire. All study forms were available in both English and Spanish and research staff were bilingual English/Spanish-speaking.

Analysis

Data were double entered and ranges and distributions were evaluated for outliers. Participants with extreme caloric intake values (defined as <500 or >3500 kcal/d in women and <800 or >4000 kcal/d in men based on published guidelines²⁹) were excluded from analysis ($n = 16$). Participant characteristics are presented using means for continuous variables and proportions for categorical variables. Caregiver status, caregiver burdens, and diet and physical activity behaviors are presented using proportions.

Categorical associations between baseline characteristics and caregiver status at 1-year follow-up, and between each caregiver burden (yes versus no), elevated Caregiver Strain Index (≥ 7 versus <7), and diet and physical activity at 1-year follow-up are evaluated by χ^2 analysis. Logistic regression was used to assess potential confounding of the association between caregiver burden and diet and physical activity by caregiver age, gender, race/ethnicity, education level, and assignment to the intervention arm in the FIT Heart

randomized controlled trial. All analyses were performed using SAS statistical software (version 9.1, 2002–2003, SAS Institute, Cary, North Carolina). Significance was set at $p < .05$.

Results

Characteristics of study participants are summarized in Table 1. One year after discharge of the CVD patient, fewer than one-half of patient family members were consuming <10% of daily calories from saturated fat and fewer than one in three were participating in physical activity 4 or more days per week.

Most patient family members reported that they provided caregiving for the CVD patient during the year following hospital discharge (Table 2). Approximately 48% cared for the patient most of the time, or considered themselves to be the primary patient caregiver.

Frequencies of caregiver burdens and elevated Caregiver Strain Index score among family members who were primary/most of the time caregivers for the hospitalized CVD patient are presented in Table 3. Changes in personal plans and time demands were the most commonly reported burdens. Additionally, sleep disturbance, emotional adjustments, and family adjustments were burdens reported by almost one-third of caregivers. The mean Caregiver Strain Index score was 3.5 (± 3.7).

Univariate associations between caregiver burdens, elevated Caregiver Strain Index, and lifestyle for CVD prevention 1 year after CVD patient discharge among primary/most of the time caregivers ($n = 205$) are shown in Table 4. Caregivers who reported feeling overwhelmed, financial strain, time demands, sleep disturbance, and/or upsetting patient behavior as caregiver burdens were significantly less likely to consume <10% of daily calories from saturated fat compared to caregivers who did not report these burdens at 1 year. Caregivers who reported financial strain and/or upsetting patient behavior were significantly less likely to participate in moderate or greater intensity physical activity most days of the week or more compared to caregivers who did not report these burdens at 1 year. These associations retained both magnitude and significance after adjustment for assignment to the FIT Heart intervention arm, age, gender, race/ethnicity, and education level.

The link between caregiver burdens and lifestyle habits was observed to a lesser degree among family members who cared for the CVD patient only some of the time or occasionally; within this subgroup, feeling overwhelmed and sleep disturbance were significantly associated with not consuming a diet with <10% of calories from saturated fat at 1 year (odds ratio [OR] = .24, 95% confidence interval [CI] = .08–.75 and OR = .20, 95% CI = .04–.96, respectively).

Discussion

In this study of family members of hospitalized CVD patients, most participants identified themselves as caregivers. Time demands and sleep disturbance were two of the most common caregiver burdens reported. These burdens and others, as well as an elevated Caregiver Strain Index score, were significantly and independently associated with lower

odds of consuming a diet with <10% of daily calories from saturated fat at 1-year follow-up. Financial strain and upsetting patient behavior were two burdens linked to lower odds of exercising most days of the week at 1-year follow-up.

Prior research about prevalence of caregiver burdens among family caregivers for CVD patients is limited; however, it has been examined among coronary artery bypass graft (CABG) patients.³⁰ Similar to our findings, Halm and colleagues³⁰ found that family caregivers of CABG patients ranked providing emotional support, managing patient behavior, and additional household tasks as the most difficult burdens. More data are available on prevalence of caregiver burdens among family caregivers for physically dependent and/or mentally impaired elderly patients. Commonly cited caregiver burdens in this population also include burdens related to demands/restrictions on one's personal time and emotional adjustments related to caregiving.⁶ Caregiver burden prevalence data from the present investigation are consistent with this previous research, with time demands and emotional adjustments ranked as frequent caregiver burdens.

Few studies have directly evaluated the link between caregiver burden and lifestyle habits among CVD patient caregivers.³¹ Qualitative research conducted among caregivers for stroke survivors showed that most caregivers experience at least one lifestyle change.³² The link between caregiver burden and health promotion has been studied more extensively among caregivers for elderly and/or dementia patients. Overall, research conducted in this population shows that caregivers practice fewer health promoting self-care behaviors compared to noncaregivers,³³ and perceived caregiver burden is negatively correlated with self-rated physical health, self-care, and health promoting self care behaviors.^{7,8,33} This is consistent with results from the present study linking increased caregiver strain with higher saturated fat intake.

Past work also suggests that caregivers for the elderly and/or mentally impaired who report higher objective caregiver burdens (e.g., "less time" for oneself, "less money available") participate in less exercise and caregivers with higher subjective caregiver burdens (e.g., it is "painful to watch carerecipient age") have poorer nutrition.⁶ These results corroborate results from the present study, which linked objective burdens such as financial strain to lower physical activity levels and subjective burdens such as upsetting patient behavior to poorer diet 1 year after CVD patient discharge.

In a nationally representative random-digit-dial survey of caregiving recently completed in the United States, it was shown that greater than one in three households have an informal caregiver providing assistance to a patient, and that CVD is a top health issue addressed by caregivers (following old age, Alzheimer's, cancer, and mental illness).⁵ Recent research completed by our study team documents that more than half of patients hospitalized with CVD plan to have a nonpaid caregiver after discharge from the hospital and that almost all nonpaid caregivers are family members.¹ Results from this study are in line with these national and inpatient data, indicating that a majority of family members surveyed provide some level of caregiving to the CVD patient, with approximately half providing primary caregiving or caring for the patient most of the time.

Prior work has documented an association between family caregiver strain and increased estimated risk for stroke,^{5,12} coronary heart disease,¹¹ and overall mortality.³⁴ This study is one of the first to link caregiver burdens to measured health promoting lifestyle behaviors in CVD patient family caregivers.¹⁰ Adherence to nationally recommended prevention activities (such as heart-healthy diet and regular physical activity) is known to have beneficial impact on CVD risk factors such as serum lipids, body mass index, and blood pressure.¹⁷ Improved adherence to prevention activities, especially in atrisk populations, could prevent a high proportion of CVD events that are expected to occur among adults in the United States.³⁵ Identifying the role that caregiver burdens and lifestyle may play in the pathway between caregiving and CVD morbidity and mortality is a key step in developing health promotion interventions targeted to reduce risk among CVD patient family caregivers.

A strength of this study was inclusion of an ethnically diverse primary prevention population (including 36% racial/ethnic minorities and 67% females). This allowed us to examine caregiving burden in the context of a population at increased CVD risk and allowed for adjustment for common confounders such as gender, age, race/ethnicity, and education level. Heterogeneity of the sample with respect to age, race/ethnicity, and gender may increase generalizability of results to CVD patient caregivers in other acute settings. The data may not generalize to other settings or to noncaregiver populations. Caregiver burden and lifestyle behaviors were based on self-report, which is subject to recall bias; however, the use of standardized questionnaires and uniformly trained research staff reduces the likelihood of differential bias. Other relevant health behaviors (e.g., cigarette smoking, stress management) not assessed in this study may be important to assess in future studies of caregiving and health.

This research provides new information about the link between caregiver burdens and achievement of heart-healthy lifestyle habits among family members of CVD patients. Caregiver burdens were significantly associated with poorer diet and physical activity habits 1 year after patient discharge, suggesting suboptimal lifestyle habits could be a potential mechanism through which caregiver burden could increase CVD risk in caregivers. Caregivers may benefit from targeted interventions designed to cope with or lessen burdens, but this needs to be formally tested in future studies. When developing health promotion interventions to improve adherence to lifestyle recommendations, caregiver burden should be considered as a possible barrier to primary prevention among family members of CVD patients.

Acknowledgments

This work was supported by the National Heart, Lung, and Blood Institute (grant number RO1 HL075101); a National Institutes of Health Research Career Award (grant number K24 HL076346); a National Institutes of Health T32 Training Grant (grant number HL007343); and the National Institutes of Health–Funded Clinical and Translational Science Award at Columbia University. Trial Registration: clinicaltrials.gov Identifier: NCT00728637.

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SO WHAT? Implications for Health Promotion Practitioners and Researchers

What is already known on this topic?

Caregiver burden is a term used to describe the stress experienced by caregivers as a result of adopting the caregiver role. Past research has linked caregiver burden to increased cardiovascular disease risk; however, mechanisms through which increased risk is conferred are not yet established.

What does this article add?

This article provides evidence that suboptimal lifestyle habits may be one pathway through which caregiver burden increases cardiovascular disease risk among family members of cardiovascular disease patients, a population known to be at increased risk for cardiovascular disease themselves because of shared genes and/or lifestyle habits.

What are the implications for health promotion practice or research?

When developing health promotion interventions to improve adherence to lifestyle recommendations, caregiver burden should be considered as a possible barrier to prevention among family members of cardiovascular disease patients.

Table 1
Characteristics of Participants (N = 423)

Characteristic	No. (%)
Baseline demographic factors	
Age, y, mean (SD)	48.7 (13.5)
Female	284 (67)
Racial/ethnic minority	154 (36)
Education beyond high school	329 (78)
Diet and physical activity behaviors at 1 y	
Saturated fat <10% of cal/d	197 (48)
Physical activity 4 d/wk	118 (28)

Table 2
Frequency of Caregiving at 1 Year Among Participants in the Family Intervention Trial
for Heart Health (N = 423)

Frequency of Caregiving	No. (%) [*]
1. Cared for patient all of the time (primary caregiver)	157 (37)
2. Cared for patient most of the time	48 (11)
3. Cared for patient some of the time	75 (18)
4. Cared for patient occasionally	57 (13)
5. Not involved in posthospitalization care	81 (19)

^{*} n = 5 participants unsure/patient deceased.

Table 3
Caregiver Burdens at 1-Year Follow-up Among FIT Heart Primary/Most of the Time
CVD Patient Caregivers (n = 205)*

Caregiver Burdens	No. (%)
Changes in personal plans	80 (39)
Time demands	77 (38)
Disturbed sleep	62 (30)
Emotional adjustments	61 (30)
Family adjustments	61 (30)
Changes in patient from former self	57 (28)
Feeling overwhelmed	52 (25)
Work adjustments	52 (25)
Caregiving is confining	51 (25)
Upsetting patient behavior	51 (25)
Financial strain	41 (20)
Physical strain	35 (17)
Caregiving is inconvenient	30 (15)
Caregiver Strain Index 7	45 (22)

* FIT Heart indicates Family Intervention Trial for Heart Health; CVD, cardiovascular disease.

Table 4
Odds of Adherence to Lifestyle Goals at 1-Year Follow-up by Caregiver Burden Among
FIT Heart Primary/Most of the Time CVD Patient Caregivers (n = 205)*

Caregiver Burdens	OR (95% CI)	
	<10% kcal Saturated Fat/d	Physical Activity 4 d/wk
Changes in personal plans	0.73 (0.41–1.31)	1.38 (0.76–2.53)
Time demands	0.47 (0.26–0.85)	1.52 (0.83–2.78)
Disturbed sleep	0.51 (0.27–0.96)	1.11 (0.58–2.10)
Emotional adjustments	0.57 (0.30–1.06)	1.03 (0.54–1.96)
Family adjustments	0.54 (0.29–1.00)	0.92 (0.48–1.77)
Changes in patient from former self	0.73 (0.39–1.37)	0.58 (0.29–1.17)
Feeling overwhelmed	0.50 (0.26–0.97)	0.69 (0.34–1.40)
Work adjustments	0.53 (0.27–1.03)	0.78 (0.39–1.58)
Caregiving is confining	0.53 (0.27–1.03)	0.92 (0.46–1.84)
Upsetting patient behavior	0.48 (0.25–0.92)	0.33 (0.15–0.76)
Financial strain	0.41 (0.20–0.86)	0.32 (0.13–0.81)
Physical strain	0.71 (0.34–1.51)	0.51 (0.21–1.24)
Caregiving is inconvenient	0.60 (0.27–1.34)	1.37 (0.61–3.08)
Caregiver Strain Index 7	0.31 (0.15–0.64)	0.58 (0.27–1.25)

* Univariate associations assessed by χ^2 statistics. Bold type indicates significant results at $p < 0.05$. FIT Heart indicates Family Intervention Trial for Heart Health; CVD, cardiovascular disease.