



Characteristics And Well-Being Of Informal Caregivers: Results From A Nationally-Representative US Survey

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Abstract

Given ongoing concerns about high levels of burden reported among some informal caregivers, the goal of this study was to characterize their socio-demographics, health, and well-being. Using cross-sectional data from a large nationally representative survey in the United States (N=438,712) we identified adults who provided informal care to friends or family members with a health problem, long-term illness, or disability. Descriptive statistics and propensity matching were used to characterize caregivers and compare their health and social support to socio-demographically-similar adults who were not caregivers. Logistic regression models examined associations between caregiving and respondents' mental health, general health, perceived social support, and sleep problems. A total of 111,156 (25.3%) participants reported being caregivers, most of whom reported good mental health (90%) good general health (83%), and adequate social support (77%). After adjusting for respondents' gender, caregivers reported worse mental health than non-caregivers (odds ratio (OR)=1.35, 95% confidence interval (CI)=1.31–1.39 for >15 days poor mental health in the past month) but better general health (OR=0.96, 95%CI=0.94–0.98 for fair or poor health). Men caregivers reported somewhat worse overall health than non-caregivers (OR=1.09, 95%CI=1.05–1.13) whereas women reported better overall health.

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Abstract

Objectives

Given ongoing concerns about high levels of burden reported among some informal caregivers, the goal of this study was to characterize their socio-demographics, health, and well-being.

Methods

Using cross-sectional data from a large nationally representative survey in the United States ($N = 438,712$) we identified adults who provided informal care to friends or family members with a health problem, long-term illness, or disability. Descriptive statistics and propensity matching were used to characterize caregivers and compare their health and social support to socio-demographically-similar adults who were not caregivers. Logistic regression models examined associations between caregiving and respondents' mental health, general health, perceived social support, and sleep problems.

Results

A total of 111,156 (25.3%) participants reported being caregivers, most of whom reported good mental health (90%) good general health (83%), and adequate social support (77%). After adjusting for respondents' gender, caregivers reported worse mental health than non-caregivers (odds ratio (OR) = 1.35, 95% confidence interval (CI) = 1.31–1.39 for >15 days poor mental health in the past month) but better general health (OR = 0.96, 95%CI = 0.94–0.98 for fair or poor health). Men caregivers reported somewhat worse overall health than non-caregivers (OR = 1.09, 95%CI = 1.05–1.13) whereas women reported better overall health.

Discussion

Although reporting good overall well-being, caregivers remain vulnerable for worse outcomes than non-caregivers. Caregiving is associated with poor mental health, and may have additional impacts on the physical health of caregiving men.

Keywords [Caregiver](#), [survey](#), [informal caregiving](#)

Introduction

There is evidence from a large number of countries and clinical populations that caregiving is costly and requires balancing competing priorities such as work, childcare, and personal healthcare needs.^{1–6} Whereas caregiving has been shown to improve patient outcomes,^{7–9} the consequence of caregiving for caregivers themselves remains debated. A landmark study showed that caregivers of people with multiple chronic conditions were at an increased risk of strain, depression, stress, and even death,¹⁰ leading to the widely accepted maxim that caregiving is detrimental to well-being.¹¹ Evidence also suggests that caregivers are more likely than their peers to delay preventive health activities and to report inadequate rest and sleep.^{10,12–14} However, some studies suggest that caregivers have better health outcomes than non-caregivers,

do not report increased depressive symptoms or social isolation, and even experience rewards.¹⁵⁻¹⁸

Across the globe, the majority of caregivers are women although men make up about one-third of informal caregivers.¹⁹ Differences in caregiving experience and the health effects of caregiving by gender have been investigated and reported for decades, often with an emphasis on mental health outcomes and burden. For example, Allen reported that male spousal caregivers assisted with less intense activities (more instrumental activities of daily living (IADLs) than activities of daily living (ADLs)) for fewer hours per week and had others who help in providing care compared to female spousal caregivers.²⁰ Across cultures and countries, women caregivers report higher burden than men caregivers.^{14,21-24} Because many of these studies involve small samples or subpopulations of caregivers, they provide an incomplete and unclear vision of the effect of caregiving on health. Yet, understanding the impact of caregiving on caregiver well-being is essential as health systems seek to rely more heavily on informal support to care for an increasingly aging population with complex medical problem.

Given the similar health effects of caregiver burden across cultures and countries, we were interested in conducting a national study of caregiving with a focus on caregiver outcomes. We used nationally representative data collected by the Behavioral Risk Factor Surveillance System (BRFSS) in the United States to achieve three aims: (1) to characterize the well-being of US caregivers; (2) to compare well-being between caregivers and non-caregivers; and (3) to explore the differential burden of caregiving as experienced by caregivers who are men versus women.

Methods

BRFSS is a collaborative project between Centers for Disease Control and Prevention and US states and territories with the objective to collect uniform, nationally-representative data on preventative health practices, chronic diseases, injuries, and infectious diseases found in the adult population (www.brfss.gov). BRFSS data are collected from a random-digit dialed telephone survey of the non-institutionalized U.S. civilian population aged ≥ 18 years. All respondents are asked a core set of questions. In addition, states can select from optional BRFSS modules each year, such as the Caregiver Module. The VA Puget Sound Institutional Review Board (IRB) approved this study.

Identifying caregivers and matched non-caregivers

Between 2009 and 2010, all BRFSS respondents were asked, “People may provide regular care or assistance to a friend or family member who has a health problem, long-term illness, or disability. During the past month, did you provide any such care or assistance to a friend or family member?” Participants who responded either “yes” or “no” were included in this study ($N = 438,712$). Those who responded “yes” were classified as “caregivers.” We used propensity score matching^{25,26} to identify a group of non-caregivers who were similar to caregivers, since people may be non-caregivers for a variety of reasons (e.g. disability). Propensity scores are used to balance potential confounding variables in observational studies by combining information about multiple covariates into a single score and then using that score to stratify, adjust, weight, or match exposed and unexposed individuals (here, caregivers and non-caregivers). Propensity

score matching technique used was based on a greedy 5→1 digit match, where propensity scores were defined to be the probability that an individual person will be a caregiver, given a set of covariates. Based on existing literature and available data,^{27,28} we identified factors that were available in the BRFSS dataset that we believed could potentially be associated with the likelihood of being (or not being) a caregiver including: respondents' age, race, ethnicity, marital status, number of children, education, employment, income, veteran status, and number of adults (men vs. women) living in the household. We also matched on factors considered relevant to caregiver health and well-being, including immunizations within the previous year, exercise, tobacco use, self-identified physical disability, obesity status (defined as being overweight, obese, or neither); number of telephones in the household; cell phone usage; healthcare access; and survey characteristics, including year and language in which questionnaire was administered. Because we were interested in the potentially different association between caregiving and the various health outcomes by gender, we did not include gender in the propensity score models. Using logistic regression, we used these variables to predict the probability of being a caregiver. Using the predicted probabilities from this model, we matched caregivers to compare respondents based on the propensity scores. After propensity matching, 642 caregivers had incomplete matches and were excluded. Therefore, the matched data set included 110,514 caregivers and an equal number of non-caregivers. These groups did not differ on the covariates included in the propensity models, indicating a good match.

To evaluate the role of caregiver specific attributes, we included a subsample of BRFSS participants who completed the optional Caregiver Module in 2009 and 2010. This module was administered in Illinois, Louisiana, and Washington, DC (2009) and Connecticut and New Hampshire (2010) to participants who indicated they were caregivers ($N = 5188$). This module assessed various aspects of caregiving. The following variables were treated as predictors in multivariate regression analyses:

1. *Hours spent caregiving*: Caregivers were asked, "In an average week, how many hours do you provide care for [care recipient] because of his/her health problem, long-term illness, or disability?" Responses were categorized hours spent caregiving into 0–8 h, 9–19 h, 20–39 h, and ≥ 40 per week.
2. *Level of need*: Caregivers were asked, "In which one of the following areas does the person you care for most need your help?" Responses were combined into ADLs (taking care of self, i.e. eating, dressing, or bathing), IADLs assistance (taking care of residence, i.e. cleaning, managing finances, preparing meals, or transportation outside of the home), and other (i.e. communicating with others, learning/remembering, seeing/hearing, moving around within the home, getting along with people, relieving/decreasing anxiety or depression, or something else).
3. *Relationship with care recipient*: Caregivers were asked, "What is [care recipient's] relationship to you?" Answers were grouped into parent/parent-in-law, spouse, other family member, and non-family member.
4. *Duration of caregiving*: Caregivers were asked, "For how long have you provided care for the [care recipient]?" Responses were collapsed into five categories: 0–3 months, 4–12 months, 13–24 months, 25–60 months, and >60 months.
5. *Major health problem of care recipient*: Caregivers were asked, "What has a doctor said is the major health problem, long-term illness, or disability that the person you care for

has?” Categories captured chronic health conditions that are prevalent and the focus of past caregiving research: neurological conditions (Alzheimer's disease, dementia, Parkinson's disease, stroke, multiple sclerosis, spinal cord injury, traumatic brain injury); cancer; diabetes; cardiovascular conditions; and “other” such as developmental disabilities, sensory impairments, and arthritis.

Outcome measures

Mental health

Participants were asked, “Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good?” Consistent with self-report measures of mental health,²⁹ we defined poor mental health as having bad mental health days for most of the months (>15 days).

General health

Participants were asked, “Would you say that in general your health is: excellent, very good, good, fair, or poor?” Those who rated their health as “excellent,” “very good,” or “good” were compared to those responding “fair” or “poor” health status.

Perceived social and emotional support

All participants were asked, “How often do you get the social and emotional support you need?” Those who responded “usually” or “always” were classified as receiving “adequate emotional support” and were compared to those responding “sometimes,” “rarely” or “never” (“inadequate emotional support”).

Sleep hygiene

Sleep hygiene was assessed in a subset of participants ($N = 43,222$) from seven states (CT, GA, HI, IL, LA, MN, and WY). These participants were asked, “On average, how many hours of sleep do you get in a 24-hour period?” Based on the recommendations of the National Sleep Foundation, respondents were classified as receiving adequate sleep (7–9 h per night) or not. Participants were also asked “During the past 30 days, for about how many days did you find yourself unintentionally falling asleep during the day?” Responses were categorized into 0 or ≥ 1 days.

Data analyses

Using descriptive statistics, we characterized the sociodemographic characteristics and well-being of caregivers. Our next aim was to compare the national sample of caregivers to a propensity matched group of non-caregivers to determine whether caregiving was associated with the outcomes. To accomplish this, logistic regression analyses were conducted with caregiver status as the predictor of interest. Gender was used as a covariate. Gender-stratified logistic regression analyses were conducted to determine the differences in the relationship

between caregiving and each outcome among male versus female caregivers, and to examine the interaction between gender and caregiver status.

We conducted a secondary set of logistic regression analysis among caregivers who responded to the Caregiver Module to assess whether specific attributes of caregiving were associated with mental health, general health, and perceived support. Given the small sample that received both the Sleep Module and the Caregiver Module outcomes related to sleep were not addressed in these analyses. All predictors (hours spent caregiving, level of need, relationship, duration of caregiving, and major health problem) were introduced in one model. Covariates included caregiver age, gender, race/ethnicity, and marital status. Gender stratified analyses were also conducted for each outcome.

BRFSS-recommended weights were used in all analyses. Statistical analyses were performed using STATA version 11.2 (StataCorp, College Station, TX) and SAS version 9.2 (SAS Institute Inc., Cary, NC).

Results

Of the 438,712 participants included in the 2009–2010 BRFSS, 111,156 self-identified as caregivers. On average, caregivers were 55 years old, female (56.7%), had a significant other (65.7%) and had at least some college education (63.2%; [Table 1](#)). Caregivers frequently reported chronic health problems, including diabetes (10.3%), myocardial infarction (7.8%), cancer (10.1%), or asthma (16.1%; data not shown). A greater proportion of caregivers than non-caregivers were women, more caregivers were out of work for at least a year, and more caregivers were White and Hispanic race. Although many of the demographic differences between caregivers and non-caregivers were statistically significant, the absolute differences were small.

Table 1. Caregiver and non-caregiver characteristics from the full sample.

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	Caregiver N = 111,156	Non-caregiver N = 327,556	p-value
Age, M (SD)	55.0 (14.8)	56.10 (17.1)	<.001
Male, N (%)	36,119 (43.3)	130,053 (50.4)	<.001
Marital status, N (%)			<.001
Significant other	69,474 (65.7)	186,500 (63.6)	
Divorced or separated	17,924 (11.7)	50,887 (8.3)	
Never married or widowed	23,352 (22.3)	88,958 (25.9)	
Race, N (%)			<.001
White	86,903 (68.2)	258,829 (67.7)	
Black	9,953 (11.6)	24,454 (9.5)	
Hispanic	6,749 (12.7)	23,096 (15.2)	
Other	6,354 (6.5)	17,709 (6.7)	
Veteran, N (%)	12,857 (10.7)	45,707 (11.4)	<.001
Employment, N (%)			<.001
Employed	58,563 (57.1)	161,548 (57.4)	
Out of work > 1 y	3,290 (4.1)	7,216 (2.9)	
Out of work for < 1 y	4,200 (5.5)	10,702 (5.3)	
Homemaker	8,707 (7.9)	24,524 (7.7)	
Student	1,599 (4.2)	5,279 (5.1)	
Retired	27,859 (15.6)	94,855 (16.1)	
Unable to work	6,673 (5.5)	22,523 (5.3)	
Education, N (%)			<.001
≤High school	39,658 (36.6)	131,977 (39.3)	
Some college/technical school	32,838 (28.9)	84,363 (25.7)	
College graduate	38,491 (34.3)	110,479 (34.8)	
Income, N (%)			<.001
≤\$15,000	9,812 (8.6)	33,627 (9.4)	
>\$15,000 to <\$50,000	45,178 (38.0)	126,592 (34.9)	
≥\$50,000	43,055 (41.8)	122,756 (42.9)	

[Table 2](#) shows the sociodemographic distribution in the propensity matched sample. The caregiver and non-caregiver groups did not differ, indicating a good match.

Table 2. Caregiver and non-caregiver characteristics from the propensity matched sample.

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	Caregiver N = 110,514	Non-caregiver N = 110,514	p-value
Age, M (SD)	55.03 (14.8)	55.1 (14.9)	NS
Male, N (%)	36,033 (32.6)	35,996 (32.6)	NS
Marital status, N(%)			NS
Significant other	69,080 (62.6)	69,120 (62.6)	
Divorced or separated	17,798 (16.1)	17,751 (16.1)	
Never married or widowed	23,291 (21.1)	23,300 (21.1)	
Race, N (%)			NS
White	86,553 (78.3)	86,506 (78.3)	
Black	9,823 (8.9)	9,754 (8.8)	
Hispanic	6,705 (6.1)	6,728 (6.1)	
Other	6,281 (5.7)	6,378 (5.8)	
Veteran, N (%)	12,824 (11.6)	12,864 (11.6)	NS
Employment, N (%)			NS
Employed	58,237 (52.7)	57,929 (52.4)	
Out of work > 1 y	3,216 (2.9)	3,161 (2.9)	
Out of work < 1 y	4,148 (3.8)	4,155 (3.8)	
Homemaker	8,648 (7.8)	8,667 (7.8)	
Student	1,590 (1.4)	1,597 (1.5)	
Retired	27,781 (25.1)	27,894 (25.2)	
Unable to work	6,645 (6.0)	6,866 (6.2)	
Education, N (%)			NS
≤High school	39,454 (35.7)	39,566 (35.8)	
Some college/technical school	32,581 (29.5)	32,512 (29.4)	
College graduate	38,330 (34.7)	38,278 (34.6)	
Income, N (%)			NS
≤\$15,000	9,742 (8.8)	9,864 (8.9)	
>\$15,000 to <\$50,000	44,830 (40.6)	44,910 (40.6)	
≥\$50,000	42,974 (38.9)	42,856 (38.8)	

Most caregivers from the national sample (89.5%) reported ≤15 days per month of poor mental health (80% reported fewer than 6 days) and that their overall health was excellent (17.4%), very good (32.4%), or good (31.3%). Most caregivers reported that they received the necessary emotional and social support always (45.5%) or usually (31.1%). Among caregivers for whom sleep was assessed, 56.6% received the recommended amount of sleep and 59.4% did not fall asleep unintentionally. Descriptive analyses of the gender-specific differences between caregivers and non-caregivers are provided in [Table 3](#).

Table 3. Descriptive statistics for outcomes among caregivers overall and by gender, Behavioral Risk Factor Surveillance System, 2009–2010.

Table 3. Descriptive statistics for outcomes among caregivers overall and by gender, Behavioral Risk Factor Surveillance System, 2009–2010.

Outcome	All caregivers	Male caregivers	Female caregivers
Mental health, N (%)			
≤15 bad days	98,696 (89.5)	32,715 (91.2)	65,981 (88.26)
>15 bad days	10,867 (10.5)	2,947 (8.8)	7,920 (11.74)
General health, N (%)			
Excellent/very good/good	90,208 (83.2)	29,085 (83.3)	61,123 (83.0)
Fair/poor	20,410 (16.8)	6,854 (16.7)	13,556 (17.0)
Emotional support, N (%)			
Usually/always	82,436 (76.7)	26,107 (74.68)	56,329 (78.2)
Sometimes/rarely/never	23,776 (23.3)	8,088 (25.32)	15,688 (21.8)
Sleep hours per night, N (%) ^a			
7–9 h	6,009 (56.6)	1,830 (54.8)	4,179 (57.7)
<7 or >9 h	4,020 (43.5)	1,282 (45.2)	2,738 (42.3)
Unintentionally falling asleep, ^a N (%)			
No	6,191 (59.4)	1,826 (56.1)	4,365 (61.6)
Yes	3,785 (40.6)	1,266 (43.9)	2,519 (38.4)

^aSleep module administered to a subset of participants (n = 43,222) in 7 states.

In logistic regression models controlling for gender (Table 4), caregivers were more likely to report >15 days of poor mental health than non-caregivers (odds ratio (OR) = 1.35, 95% confidence interval (CI) = 1.31–1.39) and receiving inadequate emotional support (sometimes/rarely/never; OR = 1.09, 95%CI = 1.07–1.12), but less likely than non-caregivers to report fair or poor health (OR = 0.96, 95% CI = 0.94–0.98). Caregivers were less likely than non-caregivers to receive the recommended amount of sleep (OR = 0.89, 95% CI = 0.84–0.94) and more likely to fall asleep unintentionally during the day (OR = 1.10, 95%CI = 1.04–1.17).

Table 4. Logistic regression models of propensity score-matched adult caregivers and non-caregivers on physical, mental, and sleep health outcomes, Behavioral Risk Factor Surveillance System, 2009–2010.

Table 4. Logistic regression models of propensity score-matched adult caregivers and non-caregivers on physical, mental, and sleep health outcomes, Behavioral Risk Factor Surveillance System, 2009–2010.

Outcome	Caregivers vs. non-caregivers, AOR (95%CI)	Male caregivers vs. male non-caregivers, AOR (95%CI)	Female caregivers vs. female non-caregivers, AOR (95%CI)
>15 days of poor mental health in the past 30 days	1.35*** (1.31–1.39)	1.31*** (1.27–1.36)	1.46*** (1.38–1.54)
“Fair/poor” general health	0.96* (0.94–0.98)	1.09** (1.05–1.13)	0.91** (0.88–0.93)
“Sometimes, rarely or never” receiving the emotional support needed	1.09** (1.07–1.11)	1.09** (1.06–1.12)	1.09** (1.05–1.13)
7–9 h of sleep/day	0.89** (0.84–0.94)	0.81** (0.73–0.89)	0.88** (0.82–0.95)
Unintentionally falling asleep during the day ≥ 1 in the past 30 days	1.10** (1.04–1.17)	1.18** (1.07–1.3)	1.05 (0.98–1.13)

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

Male caregivers were 30% more likely to experience >15 days of poor mental health than male non-caregivers (OR = 1.31, 95% CI = 1.27–1.36), whereas female caregivers were nearly 50% more likely to experience >15 poor mental health days compared to female non-caregivers (OR = 1.46, 95% CI = 1.38–1.59). Female caregivers had better general health since they were less likely to report fair or poor general health (OR = 0.91, 95% CI = 0.88–0.93). However, male caregivers were more likely to report worse health than non-caregiving men (OR = 1.09, 95% CI = 1.05–1.13). Both men and women caregivers reported difficulty obtaining the emotional support that they needed (OR = 1.09, 95% CI = 1.06–1.12 for men; OR = 1.09, 95% CI = 1.05–1.13 for women) and were less likely to get adequate sleep compared to non-caregivers (OR = 0.81, 95% CI = 0.73–0.89 for men; OR = 0.88, 95% CI = 0.82–0.95 for women). Men caregivers, but not women, were more likely to unintentionally fall asleep compared to non-caregivers (OR = 1.18, 95% CI = 1.07–1.30).

Results of caregivers who responded to the optional caregiver module

Caregivers spent an average of 18.9 h/week on caregiving activities (i.e. 2.7 h/day), with a median of 7 h of caregiving per week; 18.6% spent >40 h per week providing care. The length of caregiving was distributed as follows: 0–3 months (24%), 4–12 months (20%), 1–2 years (12.3%), 2–5 years (20.4%), and ≥5 years (21.5%). The largest group of care recipients was parents/parents-in-law (42%), the most care was provided for IADLs (55.2%), and largest health problem group was neurological problems (19.4%).

Accounting for caregiver characteristics, men caregivers were more likely to report poor mental health than women caregivers (OR = 0.60, 95% CI = 0.39–0.92). Women providing care for 20–39 h/week were twice as likely to experience poor mental health compared to women who provided care <8 h/week (OR = 2.04, 95% CI = 1.13–3.69). For men, the duration of caregiving was more salient. Men providing care for 1–2 years were significantly more likely to experience poor mental health compared to those who provided care for <3 months, although the results may not have been stable given the small sample size (OR = 6.21, 95% CI = 1.69–22.86). Divorced/separated caregivers were more likely to experience poor mental health compared to those who were married regardless of whether they were male (OR = 3.31, 95% CI = 1.45–7.56) or female (OR = 2.56, 95% CI = 1.49–4.41).

There was no significant difference in general health status between men and women when adjusting for caregiving and other demographic characteristics (OR = 0.81, 95% CI = 0.58–1.13). Compared to men who provided care for <3 months, poor general health was more likely among men who provided care for 4–12 months (OR = 2.67, 95% CI = 1.15–6.18) and 1–2 years (OR = 2.25, 95% CI = 1.03–4.92). On the other hand, women who provided care for 4–12 months were less likely to experience poor general health compared to those who had provided care for <3 months (OR = 0.50, 95% CI = 0.29–0.86). Women who provided care for 20–39 h were more likely to report poor general health compared to those providing care for less than 8 hours (OR = 2.44, 95% CI = 1.44–4.12). Finally, taking care of other relatives led to poorer general health compared to taking care of one's own or spouse's parents (OR = 1.75, 95% CI = 1.11–2.75).

The care recipient's major health condition influenced the caregiver's emotional support, with caregivers of people with diabetes (OR = 2.74, 95% CI = 1.49–5.06), cardiovascular conditions

(OR = 2.52, 95%CI = 1.35–4.70), and other conditions (OR = 1.71, 95%CI = 1.07–2.75) being more likely to report inadequate emotional support than caregivers of people with cancer. There was no difference in the reported emotional support between caregivers of people with a neurological condition and caregivers of people with cancer (OR = 1.55, 95%CI = 0.92–2.61). Men were more likely than women to report inadequate emotional support (OR = 1.50, 95%CI = 1.11–2.01). In gender stratified analyses, women reported inadequate emotional support if they cared for diabetic patients (OR = 3.2, 95% CI = 1.53–6.68) or other problems (OR = 1.8, 95%CI = 1.01–3.23) when compared to caring for cancer patients. No differences were found among men.

Discussion

In this nationally representative sample of US adults, we found that the majority of caregivers experienced ≤ 15 poor mental health days; most caregivers reported good general health; and most caregivers received necessary emotional and social support. Approximately 60% caregivers had adequate sleep duration, which is similar to national estimates reported by the National Sleep Foundation.³⁰ Overall, caregivers appear to be doing well. However, compared to non-caregivers, caregivers were more likely to poor mental health, low social support, and inadequate sleep which can lead to poor quality of life among caregivers.^{31,32} Poor mental health and sleep hygiene have been shown to reduce quality of life, increase the risk of developing chronic conditions,^{33,34} and this might be compounded by poor social support.³⁵ Therefore, being a caregiver may remain an independent risk factor for downstream health effects.

We found that general health was similar among caregivers and non-caregivers. This is inconsistent with a recent study of caregivers in the UK of >44 million people (5 million caregivers), which found poorer general health among caregivers compared to non-caregivers.³⁶ One possible explanation is the discrepancy in caregiver definition. In the UK study, the caregiver screening question asked for the number of hours of care provided per week. By their definition, the prevalence of caregiving was 12.3%, about half the prevalence reported among adults on the BRFSS. By contrast, BRFSS captures more individuals who provide sporadic care.³⁷ BRFSS caregivers also represent a broader range of caregiving experience. A standardized definition of caregiving will help us compare results of such large scale studies in the future.

Both men and women caregivers reported poor mental health but only men reported poorer general health compared to their non-caregiving peers. These findings are unexpected given that previous studies suggest women are more likely to provide intensive care management (e.g. assist with ADLs) and are less likely to participate in respite programs.¹⁹ Other researchers have speculated that the problem-focused coping strategies more common among men may protect them against caregiver stress.^{14,38,39} It is also possible that findings are influenced by care recipient factors such as level of need and health problems, which was not available on the full sample. Indeed, once we accounted for the type and amount of caregiving, men caregivers were no more likely than women caregivers to report fair or poor general health. Future studies should also explore mechanisms that may differentially influence gender-based experiences, such as problem-solving strategies.

Our results from a subsample of caregivers shed further light on gender differences. For women, more caregiving per week led to poorer mental health whereas for men, longer duration of being a caregiver led to poorer mental health. We found that the caregiving characteristics assessed, such as amount and duration of caregiving and the type of care provided, rarely influenced the mental health outcomes. General health was influenced by duration of being a caregiver for men; however, for women, it was influenced by duration, amount of caregiving per week, and relationship to care recipient. The type of illness affected outcomes for women, but not men. It is clear, then, that men and women are affected by caregiving in different ways, and that predictors of negative outcomes are not the same. Future research focused on examining gender differences in caregiving effects should further examine these associations.

Approaches that aim to capitalize on caregivers' impacts on adult patients' health (cf. [40,41](#)) have been largely developed and implemented among caregivers of people with specific health conditions, such as dementia or cancer. Our understanding of caregivers and their needs at the population level, across health conditions, and across variations in caregiving intensity is more limited. Our study addresses this deficit by providing epidemiological data on caregivers in the United States based on a large and nationally representative sample. Given that health care activities are increasingly being assigned to informal caregivers it is heartening to note that most caregivers appear to be able to bear this responsibility. This is in keeping with the literature showing that caregivers may experience uplifts and rewards from their caregiving responsibilities.[42](#) However, our study also emphasizes that being a caregiver may increase vulnerability to poor quality of life, and that the predictors of mental health, general health, and other outcomes are not the same.[27,43](#) Recognizing that caregivers experience both uplifts and decrements in well-being opens the door to policies intended to augment informal caregiving by providing additional resources and support to caregivers.

There are several important limitations of this study, mainly due to the population-based surveillance data source used. First, the study lacks complete information on the characteristics of care recipients, such as their level of disability. Because much of the caregiver research has taken place in disease specific clinical population,[44-46](#) it is unclear which illnesses require the most caregiver effort at the population level. Second, the Caregiver Module does not include a measure of burden, making it difficult to compare population-level caregiver burden with published studies from clinic-based samples. Third, this study is based on cross-sectional data so it is difficult to determine the temporal sequence. It is possible that people with limited social and emotional support become caregivers, as suggested by the high proportion of caregivers who report that they felt they did not have a choice in undertaking caregiving responsibilities.[47,48](#) Finally, the gender differences between caregivers may differ in the United States and in other countries. For example, a qualitative study of formal male caregivers in South Africa indicated that discomfort with men as caregivers may lead to increased stress.[49](#)

Despite these limitations, this study affirms some of the widely held assumptions regarding the negative health and quality of life effects of caregiving while challenging others. It also suggests different caregiving impacts based on caregiver gender. As posited by Talley and Crews, caregiving is an issue of public health importance and successful caregiving depends on the sound mental and physical health of the caregiver.[50](#) In order to support successful informal caregiving, additional research and ongoing surveillance are needed to fully understand the

caregiving experience and health impacts of caregiving for both men and women. Longitudinal studies that can document changes in measures of health, quality of life, and caregiving burden over time will be helpful in clarifying the directionality of the relationships identified in this study. Informal caregivers are rapidly becoming the single most important allies in healthcare; results of this study shed light on the characteristics and experiences of these individuals. Ultimately, understanding the multidimensionality of caregiver outcomes will provide important insights into how intervention programs can best be tailored to maximize informal caregivers' effectiveness while minimizing the burden associated with this role.

Authors' contributions

RB Trivedi conceptualized the study. K Beaver and E Eugenio performed all statistical analyses and contributed to revising the paper. S Zeliadt and E Eugenio constructed the propensity scores. K Nelson, AM Rosland, J Grimesey, ED Bouldin, and JD Piette advised on the analysis and revised the manuscript.

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