

Research article

Factors related to caregiving for individuals with spinal cord injury compared to caregiving for individuals with other neurologic conditions

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Context/objective: To compare outcomes among caregivers of adults with spinal cord injuries (SCIs) to caregivers of adults with other neurological conditions, and determine if caregiving for SCI is associated with poor health status and chronic conditions.

Design: Secondary data analysis of 2009/2010 Behavioral Risk Factor Surveillance System survey.

Participants: Informal caregivers of adults with neurological conditions.

Outcome measures: Sociodemographics, caregiving factors (e.g. role, emotional support, life satisfaction), lifestyle behaviors, chronic conditions, and health status.

Results: Demographics and lifestyle behaviors did not differ in caregivers of adults with SCI vs. caregivers of adults with other neurological conditions (except younger age of SCI caregivers). Greater proportions of caregivers of adults with SCI had coronary heart disease (CHD) (12% vs. 6%, $P = 0.06$) and were obese (43% vs. 28%, $P = 0.03$). Frequent physical distress was reported by 20% of caregivers of persons with SCI (vs. 12% of other caregivers, $P = 0.09$), but mental health did not differ between caregiver groups. A greater proportion of caregivers of adults with SCI experienced insufficient sleep (47% vs. 30%, $P = 0.008$) and more days without enough sleep (13 vs. 9 days, $P = 0.008$). Odds of being younger, caregiver of a spouse, having CHD, and being obese were associated with being a caregiver of an adult with SCI.

Conclusion: Caregivers of adults with SCI report similar mental health status, but more poor sleep, and have increased odds of CHD and obesity. Interventions to address physical distress, improve sleep, and address CHD and obesity are needed in this cohort.

Keywords: Caregiving, Spinal cord injury, Sleep, Coronary heart disease, Obesity

Introduction

Nearly 20% of caregivers in the US report that their health has gotten worse as a result of caregiving.¹ High levels of psychological² and physical morbidity^{3,4}

and mortality⁵ have been reported for caregivers of persons with chronic illnesses and disabilities. Being in an informal caregiving role has been associated with negative outcomes such as depression, caregiver burden, and poor health-related quality of life in informal caregivers of a wide range of cohorts (i.e. traumatic brain injury (TBI),⁶ dementia,⁷ stroke,^{8,9} multiple sclerosis (MS)¹⁰). Recent literature has highlighted several

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variables related to negative outcomes in the informal caregiving role, e.g. degree of disability of the care recipient,¹¹ amount of time spent providing care,⁷ and mental health status of the caregiver, as being tied to caregiver outcomes.

A study of caregivers of Veterans whose illness, injury, or condition is related to their military service showed that 68% indicated a high level of emotional stress related to caregiving and 40% indicated that their caregiving responsibility causes them a high degree of physical strain.¹² Providing more hours of care, greater impairment in activities of daily living (ADL) and instrumental ADL in the care recipient, as well as living with and being the spouse of the care recipient, have been tied to greater caregiver burden in caregivers of individuals with dementia.⁷ Providing care to an individual with a disability such as a spinal cord injury (SCI) has been linked with increased anxiety (88%), depression (60%), and sleep deprivation (77%).¹² Furthermore, behaviors such as exercise, healthy eating habits, and attending regular medical and dental appointments on schedule decline for about 6 in 10 caregivers.¹² Individuals with SCI require continuous support more than twice as often as do aging persons in the general population and require personal care assistance up to 7 times more often.¹³ Gerhart *et al.*¹⁴ found that 22% of individuals with SCI reported that the need for physical assistance from caregivers increased with age. In a study of persons with SCI and their spouses, caregiving spouses reported significantly more physical stress, emotional stress, anger and resentment, depressive affect, and somatic depression than spouses who were not caregivers.¹⁵ Schulz *et al.*¹⁶ reported high levels of depression and burden in caregivers of persons with SCI.

Recent literature has suggested that caregivers of persons with SCI may have to make unique adaptations to their lifestyle due to providing care for complications specifically tied to SCI, such as bladder and breathing problems and pressure ulcer management.¹⁷ The number of such complications experienced by the care recipient is associated with amount of support provided by the caregiver in the area of ADLs, a strong predictor of caregiver outcomes such as burden.¹⁸ Caregivers of individuals with SCI may be affected by the caregiving role differently than caregivers of persons with other neurologic conditions (e.g. TBI) because of differences in type of impairment experienced by individuals with these conditions.¹⁹

The unique challenges of caring for an individual with SCI coupled with the often physical demands of the caregiving role may place caregivers of individuals with

SCI at increased risk for negative outcomes,¹⁶ such as decreased life satisfaction, poor lifestyle behaviors, more prevalent chronic conditions, and poor health status.^{20,21} However, literature comparing outcomes among this caregiver cohort to caregivers of individuals who may have similar care needs (i.e. care recipients with other neurologic conditions such as TBI, stroke, and MS) is lacking. MS, stroke, TBI, Parkinson's disease (PD), and Alzheimer's, along with SCI, are collectively identified as common neurological disorders which have high rates of associated burden, morbidity, and mortality.²² This study aims to understand unique characteristics and factors associated with caregiving for individuals with SCI compared to caregiving of individuals with one of the aforementioned neurologic conditions, in order to identify outcomes that can be targeted to facilitate optimal health and quality of life for both caregivers and care recipients.

Methods

Design

Secondary data from the national 2009/2010 Behavioral Risk Factor Surveillance System (BRFSS) survey available from the Centers for Disease Control and Prevention (CDC). The study was approved by the Institutional Review Board at Edward Hines Jr. VA Hospital.

Participants

Informal caregivers who participated in the 2009 or 2010 BRFSS survey. Specifically, we compared outcomes among caregivers of adults with SCI to caregivers of adults with several common neurological disorders that were identified by multiple experts and organizations as neurological conditions that represent a substantial component of the global burden of neurological disorders,²³ to assess if providing care for an individual with SCI created different caregiving concerns. Our comparison group included caregivers of adults with other neurological conditions, including dementia, MS, TBI, PD, and stroke.

Data source

The CDC collects BRFSS survey data on non-institutionalized US adults annually. Surveys are fielded by telephone in the 50 states, the District of Columbia, and US territories (Guam, Puerto Rico, and the Virgin Islands). The national 2009/2010 CDC population-based BRFSS publicly available database was used to download CDC BRFSS data. The national BRFSS database recently added a module on caregiving, in addition, a novel feature includes the ability to obtain data on the

major care-condition of the recipient for which care is being provided.

Variables

Caregiver details were assessed, including: *Caregiver status* was determined by a 'yes' response to the question asking: During the past month, did you provide care or assistance to a friend or family member?

Sociodemographics included age, sex, race/ethnicity, marital status, education level, employment status, and income. *Unhealthy lifestyle behaviors* were measured by tobacco use, alcohol misuse, and exercise non-participation.

Caregiving factors included relationship to care recipient, length of time as caregiver, number of hours per week care is provided, area the care recipient needs most help, and the greatest difficulty faced as a caregiver (financial burden, no time for self, no time for family, interferes with work, creates stress, creates or aggravates health problems, etc.). We also examined *perceived emotional support*, assessed by a Likert scale asking how often do you get the social and emotional support you need? and *life satisfaction*, assessed by a Likert scale asking, in general, how satisfied are you with your life?

Health conditions/diseases assessed included diabetes, myocardial infarction, coronary heart disease (CHD), stroke, asthma (ever), cancer (ever), and obesity. Participants were asked if they were ever told by a healthcare professional that they had the condition. Health status included measures of *general health* (excellent, very good, good, fair, poor), *physical unhealthy days*, *frequent physical distress* (≥ 14 days in prior month), *mental unhealthy days*, *frequent mental distress* (≥ 14 days in prior month), *impaired sleep days*, and *frequent insufficient sleep* (≥ 14 days in prior month). The cut-off score of ' ≥ 14 days in prior month' has been defined in the literature as appropriate for the indication of frequent mental distress,²⁴ frequent physical distress,²⁵ and frequent insufficient sleep.²⁶

Details about the care recipient that were available included care recipient: age, sex, and major health condition for which care is needed (SCI, MS, TBI, PD, stroke, dementia) (neurological disorders identified by the World Health Organization as public health challenges).²³

Analyses

Bivariate analyses, χ^2 tests for categorical variables and *t* tests for continuous variables, were conducted to describe characteristics and outcomes among caregivers of persons with SCI (relative to other care recipient

conditions), bivariate comparisons of study variables were made for caregivers of persons with SCI vs. caregivers of adults with other neurological conditions/disorders overall.

A multivariate logistic regression model was used to generate odds ratios (ORs) and 95% confidence intervals (CIs) to identify variables independently associated with being a caregiver of an individual with SCI. The dependent variable (caregivers of adults with SCI) was dichotomous, taking the value of 1 for being a caregiver of an individual with SCI and 0 for not caregiving for an individual with SCI, but for an individual with another neurological condition. Several variables were considered for inclusion in the model as independent variables; these included caregiver demographics and other characteristics, lifestyle factors, chronic conditions, general health, mental/physical health, and sleep. Collinearity was assessed for variables for inclusion in the model, in order to attain the model with the best fit (based on the likelihood ratio test). The model with the best fit, based on inclusion of variables documented in the literature as important associations, statistical significance in bivariate analyses, and guided by the -2 log likelihood, was used. The Hosmer and Lemeshow Goodness-of-Fit test was calculated to examine model fit. To determine significance, an alpha level of 0.05 was used. Statistical analyses were performed using SAS 9.2 (SAS Institute Inc, Cary, NC, USA).

Results

The 2009 and 2010 national BRFSS yielded data for 5956 caregiver and care recipient adult dyads. Among those, 1127 were caregivers of adults with neurological conditions (SCI, MS, TBI, PD, stroke, and dementia). The sample was composed of caregivers of persons with neurological conditions for whom complete data were available ($n = 1067$: SCI = 51, other neurological conditions = 1016).

Caregiver demographics and lifestyle behaviors

Comparisons of sociodemographic characteristics of caregivers of adults with SCI vs. caregivers of adults with other neurological conditions combined showed no overall differences in sex, race/ethnicity, marital status, education, employment status, or annual household income. However, SCI caregivers were younger than other caregivers (53 vs. 57 years, $P = 0.05$). There were no significant differences in lifestyle behaviors (current smoker, chronic drinker, binge drinker, non-participation in physical activity/exercise) between caregivers of persons with SCI and other caregivers combined (Table 1).

Table 1 Sociodemographic characteristics and health behaviors of caregivers of adults with neurological conditions (n = 1067)*

(% unless otherwise indicated)	SCI (n = 51)	ALL (n = 1016)	P value
<i>Caregiver sociodemographics</i>			
Age (years) mean, median (range)	53.02, 54.00 (21.00–83.00)	56.90, 57.00 (19.00–94.00)	0.05
S.D.	14.62	13.48	
Sex (female)	68.63	72.24	0.57
Race/ethnicity [†]			0.76
White	76.47	80.06	
Black/African American	13.73	13.89	
Other race/ethnicity [‡]	5.88	3.57	
Hispanic/Latino	3.92	2.48	
Marital status			0.57
Married or member of unmarried couple	60.78	62.27	
Never married	17.65	11.53	
Divorced/separated	11.76	15.27	
Widowed	9.80	10.94	
Highest grade completed			0.82
Some college/technical school or college graduate (1–4 years or more)	72.55	69.00	
High school graduate (grade 12 or equivalent)	21.57	25.59	
Less than high school graduate (grades 1–11)	5.88	5.41	
Employment status			0.67
Currently employed/self-employed	58.82	54.79	
Retired	19.61	25.17	
Other [§]	21.57	20.04	
Annual household income			0.2986
≥ \$50 000 [¶]	42.55	50.32	
<i>Caregiver lifestyle factors/risk behaviors</i>			
Did not participate in physical activity in past month	23.53	21.18	0.69
Smoking status ^{**}			0.71
Never	58.82	53.74	
Past	23.53	28.64	
Current	17.65	17.62	
Chronic drinker ^{††}	1.96	5.02	0.48
Binge drinker ^{‡‡}	5.88	10.24	0.55

SCI, spinal cord injury. ALL: Other neurological conditions (Multiple Sclerosis, Traumatic Brain Injury, Parkinson's Disease, Stroke, Dementia).

*Item response was 91% or greater for all items.

[†]All respondents who reported they are of Hispanic or Latin ethnic origin are coded as Hispanic. All others reported they were of said race, and not of Hispanic origin.

[‡]Other race/ethnicity includes Asian, American Indian/Alaska Native, Native Hawaiian /Pacific Islander, or 'other.'

[§]Other includes out of work for more or less than 1 year, unable to work, homemaker, and student.

[¶]All respondents who reported having an annual household income of \$50 000–<\$75 000 or \$75 000+ are coded as greater than \$50 000. Those who reported having an annual household income of <\$10 000, \$10 000–<\$15 000, \$15 000–<\$20 000, \$20 000–<\$25 000, \$25 000–<\$35 000, or \$35 000–<\$50 000 comprise the reference group, less than \$50 000.

^{**}Current smoking % (defined as having smoked at least 100 cigarettes in one's lifetime and now smoking on at least 'some days.' Former/past smoking was defined as having smoked at least 100 cigarettes in one's lifetime but not currently smoking. Never smoking was defined as not having smoked at least 100 cigarettes in one's lifetime.

^{††}Chronic drinkers defined as adult men having more than two drinks per day and adult women having more than one drink per day.

^{‡‡}Binge drinkers defined as males having five or more drinks on one occasion, females having four or more drinks on one occasion.

Source: Connecticut, District of Columbia, Illinois, Louisiana, and New Hampshire participated in the CDC BRFSS 2009/2010 optional caregiver modules.

Caregiving-related factors

Relationship/role

The relationship between the caregiver and the person receiving care significantly differed for caregivers of persons with SCI vs. other caregivers ($P < 0.001$). More caregivers of persons with SCI were caring for spouses (24%) than other caregiver groups combined (14%) ($P < 0.001$). Fewer caregivers of persons with SCI were caring for a parent/parent-in-law (29%) than were caregivers of other groups combined (51%)

($P < 0.001$). Greatest difficulties faced as a caregiver differed for SCI caregivers vs. other caregivers; fewer reported stress (24% vs. 29%), and more reported financial burden (18% vs. 6%). Caregivers of individuals with SCI reported a wide range of time spent providing care, with the lowest reported amount of time being 1 hour per week and the highest being 168 hours per week (the equivalent of about 24 hours per day). The variability in time spent providing care was also large, with a mean of approximately 34 hours

Table 2 Caregiving relationship/role factors, emotional support, and life satisfaction of caregivers of adults with neurological conditions (n = 1067)*

(% unless otherwise indicated)	SCI (n = 51)	ALL (n = 1016)	P value
<i>Caregiving relationship/role factors</i>			
Caring for ...			<0.001
Caregiver's parent/parent-in-law	29.41	50.59	
Caregiver's spouse	23.53	13.78	
Caregiver's non-relative	19.61	14.17	
Caregiver's other relative [†]	15.69	18.90	
Caregiver's adult child	11.76	2.56	
Caregiver's spouse (ref: all other)	23.53	13.78	0.05
Length of care provided (years) mean, median (range)	3.52, 1.50 (1.00–25.00)	4.92, 3.00 (1.00–99.00)	0.05
S.D.	4.70	7.97	
Hours of care provided per week mean, median (range)	34.16, 20.00 (1.00–168.00)	24.63, 8.00 (1.00–168.00)	0.11
S.D.	44.08	37.82	
Area care recipient needs most help			0.06
ADLs: eating, dressing, or bathing	34.04	31.22	
IADLs: cleaning, managing money, or preparing meals	27.66	28.20	
Transportation outside the home	14.89	16.58	
Emotional support (relieving anxiety or depression)	14.89	5.27	
Moving around within the home	4.26	5.17	
Other [‡]	4.26	13.56	
Greatest difficulty faced as a caregiver			0.03
No difficulty	41.18	35.57	
Creates stress	23.53	28.56	
Creates financial burden	17.65	5.91	
Does not leave enough time for self	7.84	10.52	
Misc (affects family relationships, interferes with work, other difficulty)	5.88	11.62	
Does not leave enough time for family	1.96	4.81	
Creates or aggravates health problems	1.96	3.01	
No difficulty (ref: any difficulty)	41.18	35.57	0.42
Care recipient experienced changes in thinking/remembering during the past year	42.86	77.49	<0.001
<i>Receive needed emotional and social support</i>			
Always	47.06	46.39	0.56
Usually	31.37	30.86	
Sometimes	9.80	15.83	
Rarely	7.84	4.06	
Never	3.92	2.87	
Always (ref: all other)	47.06	46.39	0.93
<i>General satisfaction with life</i>			
Very satisfied	38.00	45.17	0.61
Satisfied	58.00	49.01	
Dissatisfied	4.00	5.03	
Very dissatisfied	0.00	0.79	
Very satisfied (ref: all other)	38.00	45.17	0.32
Satisfied (ref: dissatisfied)	96.00	95.30	0.59

*Item response for all items 92% or better.

[†]Care recipient was a sibling, grandparent, grandchild, or other relative.

[‡]Care recipient needs most help in learning/remembering, communicating with others, seeing or hearing, getting along with others or 'something else'.

Source: Connecticut, District of Columbia, Illinois, Louisiana, and New Hampshire participated in the CDC BRFSS 2009/2010 optional caregiver modules.

ADL, activities of daily living; IADL instrumental activities of daily living.

per week, but a median of 20 hours (SD = 44.08 hours). Caregivers of persons with SCI reported providing care for fewer years, on average, than other caregiver groups combined (3.52 vs. 4.92, P = 0.05). For over one-third of all individuals with neurologic conditions, the majority of care was needed in the area of ADLs (Table 2).

Emotional support; satisfaction with life

There were no differences in SCI caregivers and other caregivers in perceived receipt of needed social and emotional support or general satisfaction with life. Nearly half (47%) of caregivers of adults with SCI reported always receiving needed emotional support and 38% indicated being 'very satisfied' with life (Table 2).

Care recipient characteristics

Care recipients with SCI were younger, on average, than the other care recipient groups overall (60 vs. 77 years, $P < 0.001$). Overall, a greater proportion of care recipients with SCI vs. other care recipients were male (53% vs. 37%, $P = 0.03$) (Table 2).

Chronic conditions

Greater proportions of caregivers of persons with SCI vs. caregivers of adults with other neurological conditions combined had CHD (12% vs. 6%, $P = 0.06$, marginal), and were obese (43% vs. 28%, $P = 0.03$). The proportion of caregivers who ever had cancer was

lower in SCI caregivers vs. other caregivers overall (7% vs. 17%, $P = 0.09$) although not statistically significant (Table 3).

Health status (mental health, physical health, insufficient sleep)

There were no statistically significant differences in self-reported general health status of SCI caregivers vs. other caregivers combined. However, slightly more caregivers of persons with SCI reported fair/poor health (27%) than caregivers of persons with other neurological conditions (17%) ($P = 0.06$). Frequent mental distress (≥ 14 days per month that mental health was not good) was

Table 3 Health conditions and health status of caregivers of adults with neurological conditions (n = 1067)*

(% unless otherwise indicated)	SCI (n = 51)	ALL (n = 1016)	P value
Health conditions/disease (%)			
Obese [†]	43.14	27.85	0.03
Myocardial infarction	12.00	6.22	0.11
Asthma (ever)	11.76	12.70	0.85
Diabetes	11.76	9.45	0.58
Coronary heart disease	11.76	5.51	0.06
Cancer (ever) [‡]	6.98	16.79	0.09
Stroke	3.92	3.44	0.86
Health status			
General health			0.06
Excellent	27.45	18.75	
Very good	19.61	37.10	
Good	25.49	27.18	
Fair	21.57	13.00	
Poor	5.88	3.97	
Physical health			
Days physical health not good in past month mean, median (range), S.D.	5.75, 0.00 (0.00–30.00)	3.76, 0.00 (0.00–30.00)	0.16
Frequent physical distress (≥ 14 days in past month that physical health was not good) [§]	19.61	11.61	0.09
Mental health			
Days mental health not good in past month mean, median (range), S.D.	5.16, 0.00 (0.00–30.00)	4.07, 0.00 (0.00–30.00)	0.37
Frequent mental distress (≥ 14 days in past month that mental health was not good) [¶]	17.65	12.60	0.29
Sleep characteristics			
Days not enough sleep in past month mean, median (range), S.D.	12.84, 10.00 (0.00–30.00)	8.89, 4.00 (0.00–30.00)	0.008
Frequent insufficient sleep (≥ 14 days in past month that did not get enough sleep) ^{**}	47.06	29.55	0.008

*Item response for all items 81% or better

[†]Respondents classified as overweight based on body mass index ($25.00 \leq \text{BMI} < 30.00$) and obese based on body mass index ($30.00 \leq \text{BMI}$)

[‡]Smaller sample because 2010 survey included as CORE question (whereas 2009 was optional module)

[§]Frequent physical distress was defined on the basis of participants' response to the question, 'Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?' A response of ≥ 14 days in the past 30 indicates frequent physical distress.

[¶]Frequent mental distress was defined on the basis of participants' response to the question, '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?' A response of ≥ 14 days in the past 30 indicates frequent mental distress.

^{**}Frequent insufficient sleep was defined on the basis of participants' response to the question, 'During the past 30 days, for about how many days have you felt you did not get enough rest or sleep?' A response of ≥ 14 days of insufficient sleep in past 30 indicates frequent insufficient sleep. Source: Wheaton et al. BMC Public Health 2011, 11:295.

Source: Connecticut, District of Columbia, Illinois, Louisiana, and New Hampshire participated in the CDC BRFSS 2009/2010 optional caregiver modules.

Table 4 Variables associated with being the primary informal caregiver of an adult with SCI (n = 1067)*

	Odds ratio	95% Wald confidence limits		Standard error	P value
<i>Caregiver characteristics/lifestyle factors</i>					
Caregiver age	0.96	0.94	0.99	0.01	0.002
Caregiver for spouse [†]	2.99	1.39	6.48	0.39	0.005
Current smoker [‡]	0.89	0.41	1.91	0.39	0.76
<i>Chronic conditions and mental/physical health[§]</i>					
Diabetes	1.02	0.40	2.58	0.47	0.97
Coronary heart disease	2.77	1.04	7.40	0.50	0.04
Stroke	1.12	0.24	5.21	0.78	0.88
Asthma	0.74	0.30	1.82	0.46	0.51
Obesity	1.79	0.99	3.25	0.30	0.05
Frequent mental distress [¶]	1.15	0.52	2.54	0.40	0.73
Frequent physical distress ^{**}	1.70	0.78	3.71	0.40	0.18

*Likelihood ratio: $\chi^2(10) = 22.76$, $P = 0.0117$; Hosmer and Lemeshow Goodness-of-Fit Test: HL 5.2405, $P = 0.7316$.

[†]Reference group, non-spouse, includes caring for parent/parent-in-law, adult child, other relative (sibling, grandparent, grandchild, other), and non-relative.

[‡]Reference group includes past smoker or never smoked.

[§]Reference groups for chronic conditions and mental/physical distress was 'not present.'

[¶]Mental distress is defined as ≥ 14 days in prior month that mental health was not good.

**Physical distress is defined as ≥ 14 days in prior month that physical health was not good.

experienced by 18% of caregivers of persons with SCI vs. 13% of other caregivers ($P = 0.29$). Frequent physical distress (≥ 14 days per month that physical health was not good) was experienced by 20% of caregivers of persons with SCI vs. 12% of other caregivers ($P = 0.09$).

A greater proportion of caregivers of adults with SCI experienced frequent insufficient sleep than caregivers of adults with other neurological conditions overall (47% vs. 30%, $P = 0.008$). In fact, caregivers of adults with SCI experienced an average of 13 days in the prior month without enough sleep vs. 9 days for other caregivers ($P = 0.008$) (Table 3).

Multivariate regression model

Covariates in the final multivariate regression model (Table 4) included caregiver age, relationship with recipient, smoking status, diabetes, CHD, stroke, asthma, obesity, frequent mental distress, and frequent physical distress. The Hosmer and Lemeshow Goodness-of-Fit statistic of 5.2405 has 8 degrees of freedom and is non-significant ($P = 0.7316$), demonstrating that the model does not lack fit. The regression model showed several variables to be significantly associated with being a caregiver of an adult with SCI relative to caregivers of adults with other neurological conditions. Caregivers of adults with SCI were younger (OR = 0.96, 95% CI 0.94–0.99, $P = 0.002$) and more likely to be providing care to a spouse (OR = 2.99, 95% CI 1.39–6.48, $P = 0.005$). The odds of having CHD (OR = 2.77, 95% CI 1.04–7.40, $P = 0.04$) and being obese (OR = 1.79, 95% CI 1.00–3.25, $P = 0.05$) were higher in caregivers of adults with SCI.

Discussion

Our study is the first of its kind to evaluate outcomes among caregivers of adults with SCI and to make comparisons with caregivers of adults with other neurological conditions using nationally representative BRFSS data. Our findings reveal that caregivers of adults with SCI are younger than other caregivers, but are similar across all other sociodemographics and risk factors. We found that caregivers of adults with SCI report similar mental health status; however, they appear to have more frequent insufficient sleep, and higher odds of CHD and obesity compared to caregivers of individuals with other neurological conditions.

The quality of patient-caregiver relationships has great effect on the physical and mental health of both individuals to the point where a change in functioning of one individual can affect the functioning of the other.²⁷ The current literature suggests that caregivers of individuals with SCI are likely to suffer from several negative mental health outcomes such as depression, anxiety, burden, and stress.^{18,20,28–30} Similarly, poor outcomes have been reported among caregivers of other neurological injury groups that have many physical needs and/or mobility limitations, such as TBI.³¹ Our findings suggest that in terms of mental health status, perceived social/emotional support, and satisfaction with life, caregivers of persons with SCI are similar to other caregivers of neurological disorders.

Because there were high standard deviations, we looked at medians along with the means and found a much smaller median value for time spent providing

care. The range reported by our sample was slightly lower than recently reported estimates of time spent providing informal care to persons with SCI (about 80 hours per week, on average); however, the large corresponding standard deviation²⁰ suggests that high variability of time spent providing informal care is not uncommon within this cohort.

Providing informal care may make it difficult for caregivers to balance other aspects of their lives.³² In fact, research has reported that caregivers commonly suffer from sleep problems.³³ However, much sleep research has been focused primarily on the sleep of caregivers of persons with cancer^{34–38} and dementia/Alzheimer's disease.^{33,39–41} Additionally, it has been shown that short self-reported sleep duration is independently associated with a modest increased risk of coronary events⁴² and CHD death.⁴³ Moreover, short sleep duration combined with sleep disturbances increases the risk of CHD.⁴⁴ Given that caregivers of individuals with SCI often provide care for complications that arise as a direct consequence of injury (e.g. bowel and bladder management, pressure ulcer management),¹⁷ caregiving tasks that may arise frequently throughout both day and nighttime hours, our findings that caregivers of individuals with SCI experience more frequent insufficient sleep than caregivers of individuals with other neurologic conditions were not entirely surprising.

Our finding that caregivers of persons with SCI experience significant insufficient sleep highlights the need for more research on the poor sleep of caregivers, with a special focus on caregivers of persons with SCI. Our findings highlight the need for efforts to understand the reasons for poor sleep in this caregiving population. For example, whether caregivers of adults with SCI are sleeping poorly due to similar reasons as caregivers of persons with other conditions (e.g. cancer, stroke), such as waking up regularly or experiencing sleep disturbances due to the care recipients' sleep patterns. Research shows that individuals with SCI, do in fact, suffer from dysfunctional sleep,² and general worry.^{45,46} It is also possible that poor sleep may be associated with reasons unique to SCI, such as needing to reposition the care recipient during the night to prevent pressure ulcers. Understanding concerns that may be specific to, or more problematic in, caregiving situations with SCI cohorts is needed.

The finding that caregivers of adults with SCI have increased odds of being obese should also be considered in the context of sleep. Several studies have shown that there is an increased risk of obesity among short sleepers in adults,⁴⁶ that short sleep duration is independently associated with weight gain,^{47,48} and that sleep plays a

pivotal role in vital biological pathways that affect obesity.^{49–51} In a recent study on caregivers of Veterans with chronic SCI it was found that the responsibilities associated with caring for someone with chronic SCI can increase fatigue and lower the caregiver's quality of life.⁵² Since lack of sleep has been associated with obesity and caregiving is associated with fatigue, caregivers of individuals with SCI would benefit from concerted efforts to get adequate rest and sleep. Caregivers of individuals with SCI may find great value in community and healthcare-based interventions geared toward improving sleep hygiene.

Additionally, our findings show that nearly a quarter of caregivers of persons with SCI did not exercise in the last month. Possible interventions that might benefit the health and well-being of caregivers of this cohort could include respite care for temporary cessation of caregiving duties^{53,54} a potential avenue through which these caregivers may be afforded the time to engage in physical activity and/or catch up on rest. Regular cardiovascular exercise is shown to improve sleep patterns in aging individuals, and may contribute to overall sleep improvements in caregivers as well.⁵⁴ Future research might consider the mediating and moderating relationships of insufficient sleep, physical distress, CHD, and obesity as seen in caregivers of persons with SCI. Research that tests the impact of interventions that include free time, respite care, and/or physical activity, among other activities, are needed to understand what has a meaningful impact on caregiver outcomes.

Limitations

These data are self-reported and are subject to recall bias. Participation in the CDC BRFSS 2009/2010 optional caregiver modules was limited to Connecticut, District of Columbia, Illinois, Louisiana, and New Hampshire, and the sample size of caregivers of adults with SCI was small, which may affect generalizability of findings. Use of publically available data from national surveys like the BRFSS survey are limited to standard items/responses that are included. Our sample sizes were too small to examine caregivers of individuals with each neurological condition with SCI separately, which is a research question that may warrant future study utilizing multiple years of data in order to obtain a larger sample for each caregiver group.

Conclusions

Caregivers of adults with SCI report having more frequent insufficient sleep, and have increased odds of having CHD and obesity. Interventions to improve

sleep may help to lower CHD and obesity in this caregiver group.

This paper reflects the authors' findings and conclusions and does not necessarily reflect the official position of the Department of Veterans Affairs.

Disclaimer statements

Contributors All authors listed have contributed sufficiently to the project to be included as authors, and all those who are qualified to be authors are listed in the author byline.

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Conflicts of interest None of the authors have a financial or other relationship that might signify a conflict of interest.

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