

## Health of Caregivers in Rhode Island

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Approximately 44 million adults in the United States serve as a caregiver for a family member or friend.<sup>1</sup> Caregiving duties generally consist of assisting with activities of daily living, household tasks, and providing medical care.<sup>2</sup> Prior research has found caregiving was associated with stress, depression, worsening physical health, substance use, and lack of preventative care.<sup>3,4,5,6</sup> With the increasing age structure of the population, the demand for caregivers is expected to increase in upcoming years. The state of Rhode Island has one of the oldest populations in the nation, and thus the burden of caregivers may be of particular concern. The purpose of this analysis was to measure the burden of caregiving in RI and to assess health indicators associated with caregiving.

### METHODS

Data were from the 2017 RI Behavioral Risk Factor Surveillance System (RIBRFSS). The RIBRFSS is a telephone survey of non-institutionalized adults  $\geq 18$  years that is administered by the RI Department of Health (RIDOH) with support from the Centers for Disease Control and Prevention (CDC) and is used to measure risk behaviors and health. Data obtained from the survey sample are weighted to obtain statewide population estimates.

Caregiving was measured with the question: "Did you provide regular care or assistance to a friend or family member who has a health problem or disability in the last 30 days?" Those who answered "yes" were defined as caregivers and were asked a series of follow-up questions about the caregiving recipient and the duration and nature of the care given. Those who are not currently caregivers were asked if they anticipate they will become one within the next two years.

Descriptive analyses were conducted to measure the prevalence and details of caregiving and the demographic characteristics and health of caregivers in the state. Logistic regression analyses adjusting for age, sex, race/ethnicity, education level, and relationship status were conducted to examine the association between caregiving and health indicators. Health indicators of interest included fair/poor general health (measured from: "Would you say that in general your health is – Excellent, Good, Fair, or Poor?"); chronic disease diagnosis (diabetes, myocardial infarction, angina/coronary artery disease, stroke, cancer, asthma, COPD, arthritis/gout/lupus/fibromyalgia, or kidney disease); history of depression; frequent mental distress (FMD;  $\geq 14$  days in the last 30 days where mental health was not good); inadequate social support (response of sometimes/rarely/never to "How often do you get the social and emotional support you need – Always, Usually,

Sometimes, Rarely, or Never?"); binge drinking ( $\geq 4$  drinks for females or  $\geq 5$  drinks for males, in one sitting in the last 30 days); current cigarette smoking; and current marijuana use.

### RESULTS

Overall, 22.1% of RI adults – an estimated 159,477 individuals – reported serving as a caregiver for a family member or friend in the last 30 days. Of those not currently providing care, 14%, or an additional 71,973 adults, anticipate they will become one within the next two years. The average age of caregivers in RI is 51 years and they are most likely to be female (59%) and white (82%; **Table 1**). About half (56%) of caregivers are employed and 65% have greater than a high school level of education.

Details about caregiving recipients and the workload of caregivers are displayed in **Table 2**. The most common individual caregivers provided care for was their parent or their partner's parent (39%), followed by their partner (14%), a friend (13%), and a child or grandchild (12%). The most common conditions that necessitated the care were old age (12%), cognitive impairment (9%), and cancer (8%). Most caregivers (79%) help with managing household tasks (e.g., chores) and about half (53%) help with personal care (e.g., bathing). Length of time providing care varied with about a third (34%) serving as a caregiver for  $\geq 5$  years and about 19% serving as a caregiver for less than 30 days.

Analysis of health outcomes revealed poor mental health was common among caregivers with 30% reporting a history of depression, 22% suffering from FMD, and 33% reporting they do not get the social/emotional support they need (**Table 3**). Adjusted logistic regression analyses revealed that differences between the mental health of caregivers and non-caregivers remained significant even when controlling for demographic variables. Caregivers had more than twice the odds of FMD (Adjusted odds ratio [AOR]=2.14, 95% Confidence Interval [95% CI]=1.60-2.85) and were also significantly more likely to report history of depression, and that they do not usually get needed social/emotional support. Analysis of general health indicators found caregivers were more likely to report fair/poor overall health and have a chronic disease, but there were no differences between caregivers and non-caregivers in prevalence of obesity. Analysis of risk behaviors revealed caregivers were more likely than non-caregivers to smoke cigarettes and use marijuana, but less likely to have binge drunk in the last month. There were no differences between the two groups in exercise rates or health care utilization.

Additional analyses found associations between caregiving and negative mental health outcomes tended to increase with increasing time spent as a caregiver. For example, prevalence of FMD increased from 13% in non-caregivers to 17% in those who have been caregiving less than 6 months, to 24% among those who have been caregiving for 6 months or more. Those who have been caregiving for  $\geq 6$  months were also more likely to report inadequate social support (35%) when compared to those who have been caregiving for less than 6 months (26%).

**Table 1.** Demographic characteristics of caregivers and non-caregivers in Rhode Island, 2017

	% of caregivers	% of non-caregivers
<b>Sex*</b>		
Male	41.2%	48.4%
Female	58.8%	51.6%
<b>Age*</b>		
18 –29 years	14.8%	21.0%
30 –44 years	20.8%	23.6%
45 –64 years	43.4%	32.5%
65+ years	21.0%	22.9%
<b>Race/Ethnicity*</b>		
Non-Hispanic White	81.5%	74.9%
Non-Hispanic Black	4.4%	4.6%
Hispanic	9.2%	13.8%
Non-Hispanic other race	5.0%	6.7%
<b>Relationship status*</b>		
Married/partnered	56.7%	51.4%
Single/divorced/separated/ widowed	43.3%	48.6%
<b>Education*</b>		
Less than high school	12.9%	12.9%
High school graduate	22.4%	28.5%
Some college/College grad	64.8%	58.5%
<b>Income Level</b>		
<\$25,000	25.1%	25.4%
\$25,000-\$49,999	22.3%	21.9%
\$50,000-\$74,999	14.3%	15.1%
\$75,000+	38.3%	37.7%
<b>Employment status</b>		
Employed	56.3%	57.7%
Unemployed	5.7%	6.0%
Homemaker/Student/Retired	27.3%	28.0%
Unable to work	10.7%	8.2%

\*p<.05 indicates significant difference between caregivers and non-caregivers  
Source: 2017 RIBRFSS

## DISCUSSION

Data from the RIBRFSS revealed an estimated 159,477 Rhode Island adults are currently serving as caregivers for a family member or friend and nearly 72,000 who are not currently a caregiver anticipate becoming one within the next two years. Caregivers reported several poorer physical and mental health outcomes when compared to non-caregivers. This high burden, both in the prevalence of caregiving and the negative health effects associated with it, highlight the need to focus on the health of caregivers.

**Table 2.** Details of caregiving provided by RI caregivers

Relationship of caregiving recipient to caregiver	%
Parent/partner's parent	39.3%
Partner	14.1%
Non-relative/friend	12.8%
Child/grandchild	11.9%
Sibling/spouse's sibling	9.5%
Other relative	8.6%
Grandparent	3.8%
<b>Major health problem necessitating care</b>	
	%
Old age/infirmity/frailty	12.2%
Dementia/Cognitive impairment	8.8%
Cancer	8.0%
Heart disease/stroke/hypertension	6.1%
Mental illness	5.8%
<b>Length of time caregiver has been providing care</b>	
	%
<30 days	18.5%
1 –5 months	10.9%
6 months –2 years	16.8%
2 –4 years	19.8%
5+ years	34.0%
<b># hours per week caregiver provides care</b>	
	%
$\leq 8$ hours	61.0%
9 –19 hours	13.0%
20 –39 hours	8.6%
40+ hours	17.3%
<b>Types of care provided</b>	
	%
Managing household tasks	79.3%
Managing personal care	52.7%
<b>Support services needed most</b>	
	%
Classes about giving care/medications	2.2%
Help in getting access to services	8.2%
Support groups/individual counseling	5.5%
Respite care	2.3%
None of the above	81.9%

\*Note: not all percentages are intended to add up to 100%, Source: 2017 RIBRFSS

**Table 3.** Health indicators among caregivers compared to non-caregivers

Health indicator	% of Caregivers	% of Non-Caregivers	Adjusted odds ratio [95% CI] Caregivers vs. non-caregivers
<b>Mental Health</b>			
Frequent mental distress*	21.5%	12.5%	<b>2.14 [1.60–2.85]</b>
Depression*	30.1%	22.0%	<b>1.61 [1.27–2.04]</b>
Do not usually get support*	32.7%	25.9%	<b>1.58 [1.25–2.00]</b>
<b>General Health</b>			
Fair/Poor health*	20.8%	16.3%	<b>1.59 [1.21–2.08]</b>
Have chronic disease*	57.6%	47.2%	<b>1.44 [1.14–1.82]</b>
Obese	32.0%	29.8%	1.10 [0.88–1.38]
<b>Health Risk Behaviors</b>			
Binge drink*	12.3%	18.5%	<b>0.69 [0.49–0.97]</b>
Smoke cigarettes*	16.3%	13.6%	<b>1.34 [1.00–1.81]</b>
Used marijuana*	12.8%	10.2%	<b>1.59 [1.11–2.29]</b>
Did not exercise	26.1%	26.9%	1.00 [0.79–1.26]
<b>Healthcare Utilization</b>			
Did not have annual checkup	15.7%	19.2%	0.89 [0.66–1.21]
Did not receive annual flu shot	50.1%	46.2%	0.94 [0.76–1.16]

Note: Percentages were obtained from descriptive analysis and AOR were obtained from adjusted logistic regression model. Each outcome was measured in a separate model, adjusting for age, race/ethnicity, sex, education level, and relationship status. AORs compare caregivers to non-caregivers.

\*Indicates statistically significant difference ( $p < .05$ ) between caregivers and non-caregivers in adjusted model

Source: 2017 RIBRFSS

The findings that caregivers have higher rates of depression, stress, and poorer health are supported by prior research.<sup>1,3-6</sup> Other studies have found caregiving was also associated with increased substance use and lack of preventative healthcare.<sup>3-5</sup> Prior research indicates caregivers often feel unprepared to provide the needed care and would like more information and help with caregiving topics.<sup>1,5,6</sup> Medical professionals who interact with caregivers should be aware of this burden and work to evaluate caregiver stress. Some resources to evaluate caregiver needs include a toolkit<sup>7</sup> and assessment measures<sup>8</sup> available from the Family Caregiver Alliance. Providers should be aware of organizations such as the Alzheimer's Association and AARP that have support groups and other information available for caregivers.

This study has several limitations. First, data were self-reported and thus, may be prone to recall bias. Additionally, it is possible some unmeasured confounders are responsible for the association between caregiving and poor health. For example, having a family member in poor health, aside from the caregiving aspect, may be a source of stress for respondents and responsible for some of the health problems.

However, a study conducted by AARP found that 22% of caregivers reported their health had gotten worse as a result of caregiving, further indicating caregiving itself may be harmful to health.<sup>1</sup>

Future research on caregivers in RI should focus on additional health measures and in identifying the best methods to help caregivers. The caregiver module is not routinely included on the RIBRFSS; however, including it in future years, would allow for analysis of items such as sleep, cancer screening, and life satisfaction that were not included on the 2017 survey. Having multiple years of caregiver data would also allow for subgroup analysis to see if health indicators varied based on age and sex of caregiver, length of time caregiving, health condition of caregiving recipient, etc.

The results of this study highlight the need to focus on caregiver health. Caregivers can experience high rates of mental distress and other health problems and their needs should not be overlooked.

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