BRIEF REPORT

Healthcare Coverage and Utilization Among Caregivers in the United States: Findings From the 2015 Behavioral Risk Factor Surveillance System

Jamie L. Tingey, Jeremiah Lum, Whitney Morean, Rebecca Franklin, and Jacob A. Bentley
Seattle Pacific University

Purpose/Objective: Caregivers are vital to our health care system and its sustainability, yet extensive literature has recognized caregivers’ vulnerabilities for experiencing financial, physical, and emotional difficulties—compromising the sustainability of their services. The risks associated with being a caregiver are not well-defined and warrant further exploration to guide national health initiatives underway. This brief report sought to identify risks that may be associated with the wide-ranging secondary effects of being a caregiver. Specifically, health care coverage and utilization were compared between caregivers and noncaregivers in a large national sample. Method: A cross-sectional study design was used with data from the 2015 Behavioral Risk Factor Surveillance System. Risk ratio analyses were conducted to assess how many times more likely unpaid adult caregivers were for experiencing specific risks related to health care access, relative to noncaregivers. Results: Caregivers (n = 24,034; 64.5% female; 69.6% preretirement age) were more at risk for lacking health care coverage and underutilizing needed health care service due to cost, when compared to noncaregivers (n = 84,412; 57.3% female; 61.8% preretirement age). Caregivers were also at an increased risk for lifetime diagnosis of a depressive disorder and activity limitations due to a health challenge. Conclusions: Our findings highlight the need for the development of low-cost and accessible clinical services available to caregivers. Rehabilitation psychology can offer unique and instrumental contributions for addressing this growing population’s health care needs by informing disability-focused public health agendas and incorporating caregivers into rehabilitation programs for care recipients.

Impact and Implications
Caregivers provide valuable services that benefit individuals with disabilities and society as a whole; however, despite identification as a population of interest in current public health initiatives in the United States, few studies have examined factors that influence health care access and utilization among caregivers at the population level. This study contributes to the literature by providing preliminary analysis of epidemiological data, specifically examining for potential differences between caregivers and noncaregivers with regard to health care coverage and financial barriers to health service utilization. The findings indicate that caregivers may be at a greater risk for lacking health care coverage and not accessing needed health care services due to costs—both of which have been shown to be determinants of adverse health outcomes.

Keywords: caregiver, health risk, rehabilitation, public health, surveillance

Introduction

“There are four kinds of people in the world: those who have been caregivers; those who currently are caregivers; those who will be caregivers; and those who will need caregivers” (Carter, 1997). This quote from Rosalynn Carter, former first lady of the United States, encapsulates the population-level significance of caregiving in the United States. In recognition of its public health relevance, national initiatives are underway to develop appropriate strategies and policies for the promotion of caregiver wellness (e.g., Healthy People, 2020; Office of Disease Prevention and Health Promotion [ODPHP], 2016a, 2016b). Rehabilitation psychology, with its foundation in a person-centered and multisystemic perspective (Dunn, Ehde, & Wegener, 2016), appears uniquely positioned to both promote caregiver well-being in clinical settings and influence disability-related public health initiatives (Bentley & Wegener, 2019).

This article was published Online First January 23, 2020.
Jamie L. Tingey, Jeremiah Lum, Whitney Morean, Rebecca Franklin, and Jacob A. Bentley, Department of Clinical Psychology, Seattle Pacific University.

Correspondence concerning this article should be addressed to Jacob A. Bentley, PhD, Department of Clinical Psychology, Seattle Pacific University, 3307 Third Avenue West, Suite 107, Seattle, WA 98119. E-mail: bentley@spu.edu
Caregiving: Benefits and Costs

**Benefit: Economic value.** In the United States, an estimated 43.5 million adults provided caregiving services in a single year (National Alliance for Caregiving and AARP, 2015). Approximately 80% of adults in need of care at home rely exclusively on unpaid help (ILC-SCSHE Taskforce, 2007). Informal caregiving also provides tremendous economic value to society. A recent study estimated that replacing informal care services in the United States would cost between $221 and $642 billion, when utilizing the federal minimum wage and average hourly wage rate of home health aide in 2011 and 2012 (Chari, Engberg, Ray, & Mehrrota, 2015). Furthermore, replacement costs are expected to rise alongside increases in minimum wage (Soenarie, 2015) and the demand for services among the growing older adult population (Redfoot, Feinberg, & Houser, 2013).

**Cost: Psychological and physical health.** Despite the economic benefits for society and valuable assistance provided to care recipients, caregivers are vulnerable to experiencing their own financial, physical, and emotional challenges (Givens, Mazzacappa, Heeren, Yaffe, & Fredman, 2014; Giozman, 2004). Demands of caregiving are extensive and often lead to role strain (Burns, Archbold, Stewart, & Shelton, 1993), as caregivers struggle to manage competing priorities (e.g., occupational tasks, family responsibilities; Liu et al., 2014, 2017). Role strain can lead to “caregiver burden,” which is described as “the extent to which caregivers perceive that caregiving has had an adverse effect on their emotional, social, financial, physical, and spiritual functioning” (Zarit, Todd, & Zarit, 1986, p. 261). Sustained burden can lead caregivers to experience a depletion of physical, mental, and emotional resources in relation to caring for another person (i.e., “caregiver burnout”; Almberg, Grafstöm, & Winblad, 1997; Mursch, 1982; Pinquart & Sörensens, 2007). Adverse outcomes, including depressive symptoms and lower health-related quality of life, have been associated with caregiver burnout (Takai et al., 2009; Wan-Fei et al., 2017). Moreover, psychological distress (e.g., depression, burnout) in caregivers has been found to be associated with elevated rates of premature health decline and mortality (Fredman et al., 2008; Shaffer, Kim, Carver, & Cannady, 2017).

An Often-Overlooked Population

Health-related challenges among caregivers are often overlooked. This oversight has led caregivers to be referred to as ‘the hidden patient’ (Fengler & Goodrich, 1979; Sambasivam et al., 2019), denoting the importance of evaluating and promoting caregiver health (Brown, Potter, & Foster, 1990). Unfortunately, the majority of research examining health factors associated with caregiver well-being has been based on small convenience samples or has specific diagnostic or age groups (Chappell & Dujela, 2008; Givens et al., 2014; Van Houtven, Ramsey, Hornbrook, Atienza, & van Ryn, 2010). To our knowledge, only two studies have utilized large national samples. Both studies found caregivers to be significantly more likely to report fair or poor health when compared to noncaregivers, by use of prevalence estimates and odds ratio analyses (Anderson et al., 2013; Neugaaard, Andresen, McKune, & Jamoom, 2008). Still, these findings remain equivocal, as no risks were investigated to infer etiology of health status disparities, such as barriers to accessing health care.

Access to Health Care Among Caregivers

Health care access has been defined in various ways over the years (Ansari, 2007; Frenk, 1992; Haggerty et al., 2007; Levesque, Harris, & Russell, 2013; Penchansky & Thomas, 1981). Here, we adopt a definition where access exists at the interface between potential users and health care resources and is further influenced by characteristics of those who supply and utilize the services (Levesque et al., 2013). Access to health care has been recognized in the Healthy People, 2020 initiative to be particularly impactful on individuals’ psychological and physical health status (ODPHP, 2016a). Prior research has demonstrated health care access to reduce morbidity and mortality among individuals with chronic conditions (e.g., cardiovascular disease, depression; McWilliams, 2009). Important facilitators to access (e.g., affordability of services, insurance coverage) have been shown to improve care and, consequently, to be associated with better health outcomes (Institute of Medicine, 2002). Unfortunately, barriers to accessing health care and lack of health care coverage are common (ODPHP, 2016a). Provided that such barriers can threaten individuals’ health status (Andrulis, 1998; Caldwell, 2008), coupled with our understanding for the health disparities that exist in the caregiver population, examining barriers to health care access among caregivers appears timely and relevant.

**Financial barriers.** Compared to noncaregivers, caregivers appear to be at an increased risk for financial distress (Kusano et al., 2011; Van Houtven et al., 2010). Various potential contributing factors have been identified, including reduced participation in formal employment (Cloutier et al., 2016; Wu et al., 2005). Yet, even when participating in the workforce, caregivers tend to experience financial disadvantages (Heitmueller & Inglis, 2007). One study suggested this may be related to the need for flexible arrangements to accommodate caretaking responsibilities, which could result in reduced earning potential and fewer promotion opportunities (Chari et al., 2015). Out-of-pocket expenses for caretaking responsibilities have also been noted as a considerable loss to caregivers’ annual income (Caldwell, 2008; Collins & Swartz, 2011). Moreover, working-age adults (aged 18 to 64) have been found to predominantly provide informal caregiving, and this might present a heightened economic burden in terms of opportunity costs related to establishing or advancing one’s career (Chari et al., 2015). Regardless of etiology, financial constraints appear to act as a significant barrier to accessing health care.

**Utilization of services.** Health service utilization (i.e., the quantification of the use of services for the purpose of promoting health and well-being; Carrasquillo, 2013) is a useful measure when investigating access. However, empirical findings remain equivocal regarding health service utilization among caregivers (Buyck et al., 2011; Musich, Wang, Kraemer, Hawkins, & Wicker, 2017). Several of these studies assessed utilization for acute services but not for routine or preventative care. The need to address this gap has been identified and encouraged (Bakas et al., 2014; Lorig, Ritter, Laurent, & Yank, 2019; Musich et al., 2017), yet there remains a paucity of studies. Even with the acknowledged financial difficulties associated with caregiving, little research has examined if cost influences caregivers’ utilization of health services. The research that has examined this relationship has indicated that a significant portion of caregivers postpone or delay needed medical care due to financial costs (Caldwell, 2008; Yun et
al., 2005). Further examination that considers financial barriers as a risk factor for accessing health care appears warranted.

**Health care coverage.** Considered in tandem with caregivers’ financial challenges and difficulties in maintaining full-time employment (Chari et al., 2015), health care coverage emerges as a salient determinant for accessing health care (Centers for Disease Control and Prevention [CDC], 2014b; McWilliams, 2009). Lacking financial resources and employment benefits, such as health care coverage, may limit caregivers’ access to health care. An early study showed rationing of health care coverage within families with a member experiencing disability, where caregivers were more likely to forgo their own care (Altman, Cooper, & Cunningham, 1999). Caregivers have been found more likely than non-caregivers to lack health insurance coverage, putting them at a greater risk for access limitations (Ho, Collins, Davis, & Doty, 2005). One recent study research on health care utilization among caregivers required that participants be insured as eligibility criteria, limiting the ability to address questions concerning possible discrepancies in health care coverage based on caregiver status. To our knowledge, no recent studies have examined health care coverage and access among caregivers at the population level.

**Present Study**

Caregivers, by virtue of the wide-ranging services they provide, represent an understudied and potentially vulnerable population. Efforts to promote caregivers’ health have gained attention in recent years, including a national public health initiative with objectives set for improving caregivers’ health and well-being by increasing health promotion programs (i.e., Healthy People, 2020 initiative; ODPHP, 2016a, 2016b). However, an insufficient understanding of specific health risks experienced by caregivers adds dimensions of complexity for effective implementation of such programs. Given the value that caregivers provide to care recipients and society at large, it is important to direct attention to attain a population-level view of health care access and health outcomes in this group. The purpose of this study is to compare specific indicators of health care access between caregivers and non-caregivers in a large national sample, specifically group-level differences in financial barriers to utilizing needed health services and health care coverage status. Based on the literature that suggests potential barriers to health care access among caregivers, we hypothesized that caregivers would be at an increased risk for both lacking health care coverage and not utilizing needed health services due to financial costs. Additionally, based on the literature outlined above, we hypothesized that caregivers would be at increased risk related to overall health indicators relative to non-caregivers.

**Method**

**Data and Sample**

The Institutional Review Board at Seattle Pacific University exempted and approved the study in accordance with institutional policies and procedures related to the use of de-identified archival databases. Adults aged 18 and older (N = 108,668) were recruited through a nationwide survey conducted annually by the Centers for Disease Control and Prevention (CDC, 2014b; Gentry et al., 1985; Remington et al., 1988). Table 1 contains sample demographic characteristics.

**Measures**

**Behavioral Risk Factor Surveillance System (BRFSS).** The 2015 BRFSS (CDC, 2014a) served as the data source for this study. Initiated in 1984, the BRFSS is an annual national household phone survey conducted in all states and territories. Data from the BRFSS are maintained by the CDC and available to the public. In the BRFSS sampling methodology, the noninstitutionalized adult population (aged 18 and older) in the United States is surveyed using random digit-dialed telephone interviews. Beginning in 2011, changes to the BRFSS weighting methodology went into effect in order to address underlying statistical assumptions (for more information, see https://www.cdc.gov/brfss/annual_data/2015/pdf/weighting-the-data_webpage_content.pdf). The BRFSS survey contains Core Sections with items used by all states and territories to query demographics, health conditions, health-related perceptions, and behaviors (e.g., alcohol consumption, tobacco use, fruit and vegetable consumption).

From the BRFSS Core Sections, we used two Yes/No items to examine health care access and utilization respectively: (a) “Do you have any kind of health care coverage, including healthcare coverage, prepaid plans such as HMOs, or government plans such as Medicare, or Indian Health Service?” and (b) “Was there a time in the past 12 months when you needed to see a doctor but could not because of cost?” To evaluate for potential health concerns experienced by caregivers, we also analyzed responses on the following Yes/No questions from the Core Sections: (a) “Are you limited in any way in any activities because of physical, mental, or emotional problems?” and (b) “Ever told you have a depressive disorder, including depression, major depression, dysthymia, or minor depression?” Additionally, we dichotomized responses to an item on overall health status (e.g., “Would you say that in general your health is . . . ?”) to examine caregivers’ relative risk for fair-to-poor perceived health.

**BRFSS Caregiver Module.** The BRFSS includes optional modules on specific topics of potential interest to individual states. The 2015 version of the BRFSS supported 25 optional modules on such topics as arthritis management, cognitive decline, and social context. Individual states are permitted to develop and add questions to their BRFSS questionnaires. A question about caregiver status was first added to the BRFSS core in 2009. An optional 10-item caregiver module was included from 2008 to 2012 in order to capture a broad spectrum of caregiving, ranging from full-time caregivers to those who provide care for only a few hours per week. From 2013 to 2014, an expert panel revised, piloted, and tested an update to the module. As a result, the optional caregiver module was reduced to eight items for the 2015 BRFSS. See Table 2 for module questions, response options, and sample frequencies. The revised 8-item module was subsequently adopted by 24 states. Six states elected to use alternate versions of the caregiver module; these states were excluded from our analyses. Given that the caregiver module was expanded into its current form in 2014, no psychometric properties are presently available.
Table 1
Characteristics of Caregivers and Noncaregivers From the 2015 BRFSS

<table>
<thead>
<tr>
<th>Demographic factor</th>
<th>Caregiver (n = 24,034) (%)</th>
<th>Noncaregiver (n = 84,412) (%)</th>
<th>Total (N = 108,668) (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18–64</td>
<td>16,734 (69.6)</td>
<td>52,195 (61.8)</td>
<td>68,929 (63.4)</td>
</tr>
<tr>
<td>≥65</td>
<td>7,113 (29.6)</td>
<td>31,474 (37.3)</td>
<td>38,587 (35.5)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>8,539 (35.5)</td>
<td>36,025 (42.7)</td>
<td>44,564 (41.0)</td>
</tr>
<tr>
<td>Female</td>
<td>15,495 (64.5)</td>
<td>48,387 (57.3)</td>
<td>63,882 (58.8)</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>18,351 (76.4)</td>
<td>64,924 (76.9)</td>
<td>83,275 (76.6)</td>
</tr>
<tr>
<td>Black</td>
<td>3,129 (13.0)</td>
<td>9,422 (11.2)</td>
<td>12,551 (11.5)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>665 (2.8)</td>
<td>3,121 (3.7)</td>
<td>3,786 (3.5)</td>
</tr>
<tr>
<td>Multiracial/other/Non-Hispanic</td>
<td>1,541 (6.4)</td>
<td>6,945 (8.2)</td>
<td>8,486 (7.8)</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>13,850 (57.6)</td>
<td>43,506 (51.5)</td>
<td>57,356 (52.8)</td>
</tr>
<tr>
<td>Divorced</td>
<td>3,296 (13.7)</td>
<td>11,595 (13.7)</td>
<td>14,891 (13.7)</td>
</tr>
<tr>
<td>Single</td>
<td>6,773 (28.2)</td>
<td>28,918 (34.3)</td>
<td>35,691 (32.8)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did not graduate high school</td>
<td>1,604 (6.7)</td>
<td>7,183 (8.5)</td>
<td>8,787 (8.1)</td>
</tr>
<tr>
<td>High school diploma or GED</td>
<td>7,019 (29.2)</td>
<td>25,553 (30.3)</td>
<td>32,572 (30.0)</td>
</tr>
<tr>
<td>Some college</td>
<td>7,338 (30.5)</td>
<td>22,474 (26.6)</td>
<td>29,812 (27.4)</td>
</tr>
<tr>
<td>College graduate</td>
<td>8,019 (33.4)</td>
<td>28,964 (34.3)</td>
<td>36,983 (34.0)</td>
</tr>
<tr>
<td>Employment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>11,571 (48.1)</td>
<td>39,434 (46.8)</td>
<td>51,005 (46.9)</td>
</tr>
<tr>
<td>Unemployed/retired</td>
<td>12,341 (51.3)</td>
<td>44,524 (52.8)</td>
<td>56,865 (52.3)</td>
</tr>
<tr>
<td>Income</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;$10k</td>
<td>987 (4.1)</td>
<td>3,705 (4.4)</td>
<td>4,692 (4.3)</td>
</tr>
<tr>
<td>$10k–$35k</td>
<td>7,122 (29.7)</td>
<td>23,496 (27.8)</td>
<td>30,618 (28.2)</td>
</tr>
<tr>
<td>$35k–$70k</td>
<td>6,432 (26.8)</td>
<td>21,373 (25.3)</td>
<td>27,805 (25.6)</td>
</tr>
<tr>
<td>≥$75k</td>
<td>5,706 (23.7)</td>
<td>21,563 (25.5)</td>
<td>27,269 (25.1)</td>
</tr>
</tbody>
</table>

Note. BRFSS = Behavioral Risk Factor Surveillance System.

Analytic Plan

The current study assessed for differences based on caregiver status using risk ratio (RR) analyses, which were performed in SPSS 25 (IBM Corp., 2017). RR provides an index of risk by dividing the incidence of an outcome in a specified reference group (e.g., caregivers) by the incidence in a comparison group (e.g., noncaregivers), thereby yielding a ratio of risk between the two groups (Viera, 2008). Since RR provided an opportunity to analyze how many more times likely our outcomes of interest (e.g., not having health care coverage) occurred for caregivers versus noncaregivers, we chose to utilize this approach as opposed to other statistical options. A cross-tabulation table was created with outcome variables (e.g., having health care coverage) coded dichotomously (No = 0 and Yes = 1), and caregiver status was categorized into two separate groups (i.e., caregiver and noncaregiver). The dichotomous groupings provide a basis for calculating the ratio between the two incidence proportions. Due to the large sample size, we set the threshold for statistically significant differences between caregivers and noncaregivers at p < .001. Statistical significance for RR was evaluated based on 95% confidence intervals (95% CI). This approach is consistent with recommendations for analytic techniques that utilize incidence rates to appropriately demonstrate relative measures of effect (Tripepi, Jager, Dekker, Wanner, & Zoccali, 2007; Viera, 2008). In RR analyses, a value of 1.00 indicates equivalent risk between groups. As a result, the RR is not statistically significant if the CI includes the value 1.00.

Results

Frequencies of responses to the BRFSS Caregiver Module questions can be found in Table 2. Figure 1 provides a graphical depiction of the RR analyses. The cumulative incidence of lacking health care coverage within caregivers was 8.3% (e.g., the number of caregivers without health coverage divided by the total number of caregivers in the sample). As hypothesized, caregivers were at a statistically significant risk for lacking health care coverage, relative to noncaregiver (RR = 1.26, 95% CI [1.20, 1.32]). Incidence of lacking health coverage was 26% higher among those engaged in regular caregiving responsibilities. Caregivers also exhibited a 59% increased risk for reduced access to needed health care services due to cost when compared to their noncaregiver counterparts (RR = 1.59, 95% CI [1.53, 1.65]). Approximately 15% of caregivers reported cost as a barrier to accessing needed health care services. More than 20% of caregivers reported unmet need for at least one support service.

Items from the Core Sections of the survey examined risk for health and mental health difficulties experienced by caregivers. Overall health status was rated as either fair or poor by 20.7% (n = 4,973) of caregivers, slightly higher than the prevalence observed among noncaregivers (e.g., 20.4%). However, this did not represent a statistically significant increased risk (RR = .99, 95% CI [.99, 1.00]). Twenty-four percent of caregivers (n = 5,819) reported ever being diagnosed with a depressive disorder by a health care provider. This contrasts with a lifetime prevalence of 17.8% among noncaregivers (n = 15,044) and represents a 36% increased
<table>
<thead>
<tr>
<th>Question</th>
<th>Response options</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
</table>
| Question 1. During the past 30 days, did you provide regular care or assistance to a friend or family member who has a health problem or disability? [Caregiver status] | Yes 24,034 5.4  
No 84,412  77.4  
Don’t know/not sure  217 .2  
Caregiving recipient died in past 30 days  222 .2  
Refused  110 .1 |
| Question 2. What is his or her relationship to you? For example is he or she your (mother or daughter or father or son)? | Mother 5,342 22.2  
Father 1,956 8.1  
Mother-in-law 967 4.0  
Father-in-law 365 1.5  
Child 2,078 8.6  
Husband 2,475 10.3  
Wife 1,709 7.1  
Same-sex partner 35 .1  
Brother or brother-in-law 833 3.5  
Sister or sister-in-law 1,156 4.8  
Grandmother 858 3.6  
Grandfather 290 1.2  
Grandchild 214 .9  
Other relative 1,735 7.2  
Non-relative/family friend 3,849 16.0  
Don’t know/not sure  43 .2  
Refused  115 .5 |
| Question 3. For how long have you provided care for that person? Would you say . . . | Less than 30 days  4,379 18.2  
1 month to less than 6 months  2,977 12.4  
6 months to less than 2 years  4,353 18.1  
2 years to less than 5 years  5,000 20.8  
More than 5 years  6,933 28.9  
Don’t know/not sure  293 1.2  
Refused  60 .3 |
| Question 4. In an average week, how many hours do you provide care or assistance? Would you say . . . | Up to 8 hours per week  13,103 54.7  
9 to 19 hours per week  2,927 12.2  
20 to 39 hours per week  2,265 9.5  
40 hours or more  4,243 17.7  
Don’t know/not sure  1,203 5.0  
Refused  202 .8 |
| Question 5. What is the main health problem, long-term illness, or disability that the person you care for has? | Arthritis/rheumatism  1,473 6.1  
Asthma  121 .5  
Cancer  1,910 8.0  
Chronic respiratory conditions such as: Emphysema or COPD  959 4.0  
Dementia and other cognitive impairment disorders  2,331 9.7  
Developmental disabilities such as: Autism, Down’s Syndrome, and Spina Bifida  796 3.3  
Diabetes  1,328 5.5  
Heart disease, hypertension  1,679 7.0  
Human immunodeficiency virus infection  37 .2  
Mental illnesses, such as: Anxiety, depression, or schizophrenia  915 3.8  
Other organ failure or diseases such as: Kidney or liver problems  571 2.4  
Substance abuse or addiction disorders  73 .3  
Other  10,620 44.4  
Don’t know/not sure  549 2.3  
Refused  570 2.4  
Yes  12,099 50.6  
No  11,657 48.8  
Don’t know/not sure  57 .2  
Refused  89 .4  
Yes  18,523 77.1  
No  5,218 22.9  
Don’t know/not sure  69 .3  
Refused  75 .3  
Classes about giving care, such as giving medications  319 1.3  
Help in getting access to services  1,985 8.3  
Support groups  639 2.7  
Individual counseling to help cope with giving care  461 1.9  
Respite care  643 2.7  
You don’t need any of these support services  19,047 79.3  
Don’t know/not sure  575 2.4  
Refused  153 .6 |
risk for caregivers ($RR = 1.36, 95\% CI [1.33, 1.39])]. Nearly 30% ($n = 7,071) of caregivers reported experiencing at least one activity limitation because of physical, mental, or emotional problems. This represented a 14\% increased risk for activity limitations as compared to noncaregivers ($RR = 1.14, 95\% CI [1.12, 1.17])).

**Discussion**

Using a large national sample, these preliminary analyses identify barriers to health care access as potential secondary effects associated with caregiving. Specifically, the study identified two potential contributing risk factors: Caregivers are at a greater risk for lacking health care coverage and not utilizing needed health care services due to costs. Both of these risks have been shown to be prominent barriers to health care access and, consequently, determinants of adverse health outcomes (Institute of Medicine, 2002; Sommers, 2017). Moreover, our analyses suggested caregiver status to be associated with reduced overall health status, activity limitations, and higher rates of lifetime depression. Taken together, these findings indicate significant health challenges and difficulties accessing needed services encountered by a subset of caregivers.

Management of chronic health conditions and disability represents prominent challenges to health care delivery and, by extension, public health in the United States. Rehabilitation psychology’s underlying foundational principles, which inform research and practice on behalf of individuals with disabilities and their families (Dunn et al., 2016; Wright, 1983), has the potential to utilize epidemiologic data to inform disability-focused public health agendas (Bentley & Wegener, 2019). Our findings assist in these efforts by identifying health risks associated with the caregiver role in a large national sample that can be addressed and integrated into health policy development and disability and rehabilitation program planning to optimize quality of life for caregivers and, by extension, care recipients.

Considered within the context of the broader caregiver literature, our results highlight ongoing needs for the development of low-cost and accessible clinical services for caregivers. These services may have the most impact when initiated in the early stages following diagnosis or injury (e.g., at acute hospitalization of the potential care recipient), and graduated over time to meet the evolving needs of caregivers. With regard to early intervention, a recent randomized controlled trial (RCT) showed preliminary support for a five-session manualized self-management intervention for caregivers of individuals participating in acute traumatic brain injury (TBI) rehabilitation (Niemeyer, Kreutzer, Marwitz, & Sima, 2019). Results showed increases in emotional, instrumental, and professional support as well as brain injury knowledge among caregivers at posttreatment, when compared to baseline; however, these effects did not hold at 3-month follow-up. Another recent RCT showed adaptive coping outcomes at 6-month follow-up in response to participation in a telephone-based program that provided individualized education and mentored problem-solving for caregivers of individuals with TBI (Powell, Fraser, Brockway, Temkin, & Bell, 2016), providing one example of an approach to meeting ongoing caregiver needs in a more accessible format than the traditional in-person clinic visit. These findings are consistent with a systematic review that indicated that telehealth modalities may present viable pathways toward extending effective services to caregivers (Chi & Demiris, 2015). Such encouraging results argue for further implementation research and policies aimed at increasing access to services to improve health outcomes in the caregiver population.
 Limitations

The present study relied on BRFSS methods developed by the CDC, which did not include psychometrically validated instruments to measure our primary variables. Additionally, the analytic plan that was utilized (e.g., risk ratio analyses) required dichotomous outcomes, in which some responses were omitted in order to execute analyses (e.g., do not know, refused), and many variables that may hold relevance to our findings were not included in our analyses (e.g., frequency of utilizing services). However, given that the purpose of the present study was to identify the likelihood of these outcomes in the caregiver population, we believe this procedure was a viable method for assessing for group differences in the variables of interest.

The cross-sectional analyses present other limitations, including the nature of data, for which it restricts causal inferences. Likewise, the study only represents a snapshot in time and results do not allow us to observe any change or development of these risks. It should also be noted that results are not guaranteed to represent caregivers’ typical experiences in the domains we investigated. For example, proximate external factors (e.g., societal events) that occurred within the timeframe that data was collected may have influenced responses. Concerning survey research in general, the BRFSS response rate for 2015 was approximately 48%, and this rate varies by state (CDC, 2015). As such, we cannot attest that our results are free from bias.

Conclusion

The present study identifies specific risks associated with being a caregiver that may contribute to adverse health outcomes that prior studies have revealed (e.g., mood disorders, premature health decline). Our findings support the premise that initiatives to care-giver health should be included as a part of disability reduction strategies. For example, we found that caregivers are at a greater risk for not utilizing health care services due to cost. These findings argue for the development of community-based and cost-effective caregiver interventions. Self-management models provide a mechanism for extending services and increasing health access capacity for caregivers at risk for not accessing services due to perceived financial distress or as a result of being under- or uninsured (Ho et al., 2005; Niemeier et al., 2019; Powell et al., 2016). As a discipline, rehabilitation psychology is uniquely positioned to intervene in the dialectic between micro- and macro-level factors influencing the well-being of caregivers and individuals with disabilities alike (Bachani et al., 2018; Bentley, Bruyère, LeBlanc, & MacLachlan, 2016; Bentley & Wegener, 2019).

References


Received March 24, 2019
Revision received November 22, 2019
Accepted November 25, 2019