BRFSS 2015-2017: EXPLORING THE BURDEN OF CARING FOR OTHERS

by

Teresa A. Vannoy, B.S, M.S., J.D.

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Committee Members:

 Debarun Majumdar, Chair

 Christopher Johnson

 Rebecca Deason

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ABSTRACT

Recognizing the growing public health need for informal care, the U.S. Centers for Disease Control & Prevention (CDC) commissioned an expert panel to develop a "caregiver module" for the Behavioral Risk Factor Surveillance System (BRFSS), the CDC's annual health survey. The new module was piloted in 2005 (U.S. CDC 2007), and in the decade since, the BRFSS survey has been an important resource for understanding the impact of the burden of caring for others on the health and well-being of those providing informal care in the United States.

However, the core survey has not included "caregiving" questions since the significant redesign of the BRFSS random selection process in 2011. In 2015, CDC released an updated Caregiver Module and by 2017 forty-five states had included care partner questions in one or more annual surveys. As states typically survey a subset of participants when implementing optional modules, the state-level data sets are relatively small, limiting analysis. Pooling available data and combining that data with the demographic and health data from the core survey provides an important new opportunity to test if the burden of care is influenced more strongly by the underlying reason for care or by the amount and duration of care, or whether all are instrumental in influencing or predicting burden. The purpose of this research was to test how these care characteristics and sociodemographic factors influence care burden as little comparative research exists. A self-reported measure of general health was used as the dependent variable to represent

care partner burden. These data suggest that providing care for 40 or more hours per week and over longer periods of time are significant factors and are more strongly associated with care partner poor health than sociodemographic factors such as age. These findings provide additional insight into this national public health challenge.

I. INTRODUCTION

Researchers interested in quantitative analysis and public health issues often look to national and state level data from the annual Behavioral Risk Factor Surveillance System (BRFSS), the largest ongoing health survey system in the world (U.S. CDC 2014). While the primary survey sponsor is the U.S. Centers for Disease Control and Prevention (CDC), much of the execution is performed at the state level. All core modules and questions are standardized, but each state selects which optional modules and state-specific questions to ask every year. Originally only landline phone numbers were part of the random selection protocol. Recognizing the limitation of that approach, the CDC added mobile phone numbers in 2011, and new survey baseline data were established as a result (U.S. CDC 2013). Questions about providing informal care to others have not been included as a national core survey topic since 2011.

Following a 2015 redesign of the optional "Caregiver Module," a total of 44 states included this optional module in their 2015, 2016, or 2017 surveys (U.S. CDC 2018a). With 44 states reporting data, we now have a significant pool of data that has yet to be analyzed and which could contribute to an improved understanding of the burden of providing care and related public health issues.   This research provides a first look at this pooled data for testing and comparison of several significant burden factors including the underlying reasons for care, the amount of care provided each week, the duration of care, the age of the person providing care, and other sociodemographic variables shown to be significant in research to date. The results will help focus and refine public health strategy to make interventions more targeted and effective and improve public health.

II. LITERATURE REVIEW

The Challenge and Value of Providing Care

The most recent published BRFSS studies analyzing the national size of the care partner population estimate that about 25%, or one in four, of the adult population provides care to others of all ages (Anderson et al. 2013; Trivedi et al. 2014). However, these studies were based on data collected before the new 2011 survey baseline was established. Regardless, the population percentage of adults providing care to others is expected to grow significantly given U.S. demographic trends (Talley and Crews 2007). These demographic trends include the overall rapid aging of the population (Kaye 2013), increases in the numbers of children and adults with disabilities (Brosco et al. 2013; Freedman, Wolf, and Spillman 2016; Gubata et al. 2014), and increases in life expectancy for those with significant disabilities (Coppus 2013). People of all ages with chronic diseases or serious injuries are living longer due to advances in medical care, nutrition, and technological improvements (Coppus 2013; Talley and Crews 2007).

While women continue to live longer than men, these later years are now less likely to be healthy ones (Freedman et al. 2016) as the U.S. has fallen significantly behind other wealthy nations when it comes to healthy aging (Murray et al. 2018). We can expect the U.S. to fall still further in global health rankings unless issues such as obesity, tobacco and opioid use, nutrition, and access to medical care are effectively addressed (Carter 2013; Crimmins 2015; Murray et al. 2018).

Putting additional pressure on informal caregiving is the historical reduction in U.S. fertility rates, leading to smaller average family size and fewer family members to share caregiving responsibilities (Redfoot, Lynn, and Houser 2013). The 2010 ratio of 7

potential care partners for every person over age 80 is projected to drop to 4-to-1 in 2030 and 3-to-1 by the year 2050 (Redfoot et al. 2013).

The U.S. is not alone; the challenges of rapid population aging and declining birth rates are being felt to an even greater degree in countries in Asia and Europe including Japan, South Korea, China, Spain, Italy, and Germany (Pew Research Center 2014), making the challenges of providing informal care a topic of global concern. Recognizing these challenges, the World Health Organization (2005) prioritized developing long-term care systems as one of the key components in an effective global public health care framework.

A recently published study analyzing the 2015 and 2016 BRFSS data calculated the economic contributions that informal care partners make in caring for people living with dementia and cognitive impairments (Rabarison et al. 2018). This study found that the approximate 3.2 million dementia care partners provided over 4.1 billion hours of care with an economic value of $41.5 billion per year in the U.S. alone (Rabarison et al. 2018). While focused on only one significant underlying reason for care, this study provides important perspective and validation of the economic value care partners provide.

Factors Impacting Care Partner Burden

Major Factors

Many studies in the U.S. and in other countries have described how care partners are negatively impacted by their care responsibilities including their physical and mental health and their emotional, physical, and financial well-being. Common findings included increases in disability or chronic conditions, poor overall health, and depression or poorer mental health (Brehaut et al. 2009; Dassel and Carr 2016; Do et al. 2015; Griffin et al.

2017b; Liu et al. 2015; Neugaard et al. 2008; Tanji et al. 2013; Trudeau-Hern and Daneshpour 2012). Additionally, heavily burdened care providers may be more prone to injury (Hayes et al. 2009), frailty (Dassel and Carr 2016), hospitalization, and death (Kuzuya et al. 2011).

However, emotional well-being can be positively influenced by the experience of providing care (Fauth et al. 2012). Spiritualism or religiosity (Heo 2014; Rabinowitz et al. 2009; Rabinowitz et al. 2010; Yoon et al. 2018), relationship quality (Hooker et al. 2015), social networks (Vaingankar et al. 2012), resilience (Weisser, Bristowe, and Jackson 2015), and mindfulness (Weisman de Mamani et al. 2018) may mitigate the burden of caring for others by reducing depressive symptoms caused by feelings of guilt or responsibility (Erlingsson, Magnusson, and Hanson 2012), ambivalence (Losada et al. 2018; Weisser et al. 2015), lack of choice (Schulz et al. 2012), and denial (Kogan, Dumas, and Cohen 2013).

Financial resources significantly affect the perceived burden of providing care as access to more resources lessens the perceived burden (Griffin et al. 2017b; Hong and Harrington 2016). One three-state BRFSS study found that care partners with the most significant financial burden were younger, poorer, and less healthy overall (Kusano et al. 2011). Financial difficulties seriously affect the mental health of those providing care (Nam 2016) and can spillover to other family members (Wittenberg and Prosser 2013).

While one study suggests that the quality of care is not impacted (Hazzan et al. 2016), other research suggests that care quality is impacted by high levels of care partner burden (Yuda and Lee 2016). High care partner burden may also increase risk of care recipient abuse (Orfila et al. 2018) and predict care recipient mortality (Lwi et al. 2017).

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Underlying Influences

The underlying reason for care may influence the intensity of care partner burden. Dementia care partners have reported high burden levels and have provided more intense care for longer periods (Bouldin and Andresen 2012; DeFries et al. 2009; Richardson et al. 2013) compared to care partners of older adults without dementia, however two studies suggest that care partners can learn to cope (Armstrong et al. 2018; Yoon et al. 2018). Similarly, cancer care partners have reported high burden levels when providing care to a spouse and improved health after the spouse's death (Trudeau-Hern and Daneshpour 2012). While stroke and cardiovascular disease (Hayes et al. 2009; Mochari-Greenberger and Mosca 2012; Saunders 2009), motor neuron disease (Weisser et al. 2015), Parkinson's Disease (Olsson et al. 2016), traumatic brain injury (Griffin et al. 2017a; Griffin et al. 2017b; Kreutzer et al. 2009; Saban 2016), disabled children (Brehaut et al. 2009; Brehaut et al. 2011; Wozencroft, Waller, and Kiernozek 2017), and disabled adults (Williamson and Perkins 2014) have also been studied, no U.S. research to date has been found measuring the comparative burden based on these different underlying reasons for care.

Globally there is also a paucity of research in comparing diverse underlying reasons for care and care partner burden. Most comparative studies to date have considered similar or related conditions such as diseases causing dementia (Küçükgüçlü et al. 2017; Lima-Silva et al. 2015; Liu et al. 2017; Millenaar et al. 2016; Uflacker et al. 2016) and mental illness (Kazhungil et al. 2016; Oza, Parikh, and Vankar 2017; Sinha et al. 2017). Only one study was found comparing the burden for three diverse conditions; this U.K. study compared care partner burden for cancer, dementia, and acquired brain

injuries, finding that care partners of those with acquired brain injuries reported the highest burden (Harding et al. 2015).

Not surprisingly, the degree of perceived burden increases with the number of hours of care provided (Doebler et al. 2017; Kim et al. 2018; Masanet and La Parra 2011; Tseliou et al. 2017). This has been found to be true across generations, and to be more significant in predicting burden than differences in sociodemographic variables (Kim et al. 2018).

Sociodemographic Factors

Throughout the life course people change family and social roles, and adults often have multiple concurrent roles including child, spouse, parent, employee, and care partner. Researchers have also considered the impact of these multiple roles on care partner burden. While multiple roles often lead to increased burden, researchers have also identified potentially positive mitigating factors such as marriage, employment, and income on the health of those who provide care (Barnett 2013; Barnett 2015; Chen et al. 2017; Do, Cohen, and Brown 2014; Doebler et al. 2017; Duxbury, Higgins, and Smart 2011; Glavin and Peters 2015; Hansen and Slagsvold 2015; Kim et al. 2018).

Existing research provides significant insight into key demographic factors that influence the burden of caring for others. These include age, race, gender, ethnicity, cultural norms, and location of care.

While advanced age tends to track with poorer overall health, significant health differences have been found at both ends of the age spectrum. Younger care partners of older adults have been found to have worse physical and mental health than their older counterparts (Neugaard et al. 2008), may engage in more risky health behaviors (Reeves,

Bacon, and Fredman 2012), and have a significantly higher mortality rate (Tseliou et al. 2017) than their peers.   However, older care partners of grandchildren perceive a significant negative impact on their health (Peterson 2017), which may be mitigated by social support (Hayslip, Blumenthal, and Garner 2015).

Age and race have been found to be important factors also. Single older adult care partners for a grandchild experience more health problems, demonstrate poorer health behaviors, and are disproportionately African American (Whitley, Fuller-Thomson, and Brennenstuhl 2015). Differences in coping strategies, response to interventions, the influence of religiosity, and health behaviors are also factors that have been shown to vary significantly by race (Chaney et al. 2015; Graham-Phillips et al. 2016; McGuire et al. 2008; Rabinowitz et al. 2010; Reeves et al. 2012; Tung et al. 2017). For example, African Americans are more likely to use avoidance coping behaviors than whites (Chaney et al. 2015), and Latinas benefit more from religiosity than whites (Rabinowitz et al. 2010).

Gender is a frequent focus for researchers. Caregiving throughout the world is highly gendered as women perform a significant majority of caregiving responsibilities, but respond to the experience differently than men (Alpass et al. 2013; Bédard et al. 2005; Chukwuorji, Amazue, and Ekeh 2017; Cuthbert et al. 2017; del Río Lozano et al. 2017; Gibbons et al. 2014; Glavin and Peters 2015; Masanet and La Parra 2011; McGuire et al. 2016; Ussher and Perz 2010; Yasuko et al. 2015). While studies suggest that women may perceive more burden, are more troubled by difficult behaviors in the care recipient, and have more difficulty in dealing with loneliness than men (Bédard et al. 2005; Chukwuorji et al. 2017; del Río Lozano et al. 2017; Gibbons et al. 2014), the findings are not always

consistent and differing gender role expectations and cultural differences may influence

specific findings (Srinivasagopalan 2015).

Ethnicity and cultural norms are also important to consider, including generational

differences that exist in immigrant populations (Browne et al. 2014; Do et al. 2014; Evans

et al. 2009; Grady and Rosenbaum 2015; McGuire et al. 2010; Miyawaki 2015; Piña-

Watson, Llamas, and Stevens 2015; Wilcox et al. 2000). Minority and indigenous peoples

often are economically disadvantaged and have less access to education and quality health

care, potentially making these care partners more vulnerable to health problems

(Hokanson et al. 2018).

Lastly, the geographic location of care – both the geographic proximity of the care

partner to the care recipient and the remoteness of where the care takes place – have been

found to be significant in determining the overall care burden and the impact on care

partner health (Doebler et al. 2017; Duxbury et al. 2011). In these two studies, living with

the care recipient and living in a remote area resulted in higher perceived burden which

may be due to fewer community respite services or lack of social support resources.

However, one recently published study using BRFSS 2011-2013 data from 10 states found

that rural care partners were less likely to report difficulty in providing care even though

they faced increased financial barriers compared to urban care partners (Bouldin et al.

2018).

Theoretical Frameworks

Both the life course theory and stress process framework are helpful in

conceptualizing how caregiving affects care partners' health and well-being. Central to

life course theory are the concepts of natural life transitions (marriage, retirement, death of

a spouse), typical timing and sequencing of life events (marriage and parenthood), linked lives (relationships with others), role sets and expectations (family and employment), the influence of societal institutions and significant historical events (education, economic downturns, war), and aspects of human agency, or the control individuals exert over their lives that in turn influences their life course trajectories (Dannefer 2013). The life course framework is helpful in identifying common patterns, understanding how the past connects with and influences the present, and how these patterns can change across generations or "cohorts" (Pearlin 2010) and affect health and well-being.

Life course theory is less helpful in understanding differences within cohort groups. As stress process theory primarily focuses on reasons for differences, this theory is complementary to life course theory and can provide insight into variations that exist within defined cohort groups. Stress process theory is concerned with the reasons behind hierarchical social status differences which influence health and well-being. Many demographic variables including gender, race, education, and income are important to consider in addition to variables such as access to health care. Of course, the key framework concept is "stressors," a broad term encompassing events, behaviors, and sets of circumstances that can pose difficulties and hardships throughout life and lead to "stress proliferation." An example of stress proliferation is when care responsibilities impact employment responsibilities with negative workplace consequences for the care partner, and these stressors can accumulate over time and lead to chronic challenges with serious health and mortality implications (Fali, Vallet, and Sauce 2018; Pearlin 2010). Stressors may be objective or subjective in nature and may be considered primary (more directly impactful) or secondary (Kim et al. 2018).

Another important contribution of the stress process framework is the identification of mitigating factors or protective barriers to stress which help individuals adapt successfully. These mitigating factors include social support, coping skills, religiosity or spirituality, education, personal habits such as exercise, and psychosocial traits such as self-esteem (Pearlin 2010; Singh and Gupta 2018; Yoon et al. 2018), making this theory especially helpful in conceptualizing and integrating the different components of stress (Barnett 2015).

Mixed evidence in the degree of care partner burden over time led to the development of two stress process theory sub models: the "Wear and Tear" and "Adaptation" models (Swinkels et al. 2018). The Wear and Tear model suggests that over time stressors become more chronic and health suffers, while the Adaptation model suggests that over time the care partner adapts to care responsibilities and the impact on care partner burden and heath is reduced (Swinkels et al. 2018).

Gaps in the Literature

Many of the studies looking at care partner burden are based on convenience samples, so testing hypotheses using high quality quantitative data sets are important to verify research results. However, I could find only two published studies that use BRFSS data to analyze care partner data beyond the state level after the 2011 methodology change. The first study focused on the economic value provided by care partners of people with dementia (Rabarison et al. 2018), and the second study used 2011-2013 BRFSS data from 10 states to assess differences between rural and urban caregivers. In 2015, after the revised caregiver module was released, 45 states chose to include this topic

in either the 2015, 2016, or 2017 BRFSS (with some states participating in multiple years), demonstrating the high level of interest in the topic.

Pooling this care partner data allowed for testing and comparison of several significant influencers of burden. These factors include the underlying reason for care, the amount of care and duration of care provided, the age of the care partner, and key sociodemographic variables, such as education, income, and gender. This research should provide additional understanding about this growing public health challenge facing our nation.

III. DATA AND METHODOLOGY

The focus of this research will be on the BRFSS population that was currently providing regular care to a relative or friend. Based on the literature review, the burden experienced by this group is multi-faceted and factors to consider include physical and mental health, financial resources, the underlying reason for care, the amount and duration of care provided, the relationship to the care recipient, the age of the care partner and number of life roles, the location of care, care partner education and religiosity, and diverse well-being factors.

Research questions to be answered include:

- Are the most significant factors influencing care partner burden the amount of care provided per week and the length of time care has been provided?

- Or, is the underlying reason for care a more significant factor in determining care partner burden?

- To what degree do sociodemographic variables influence care partner burden?

As the physical and mental health impacts of providing care are well documented (Brehaut et al. 2009; Dassel and Carr 2016; Do et al. 2015; Griffin et al. 2017b; Liu et al. 2015; Neugaard et al. 2008; Tanji et al. 2013; Trudeau-Hern and Daneshpour 2012), care partner burden for purposes of this study will be assessed using the self-reported general health of respondent care partners.

Hypotheses

H1: The length of time that care has been provided will significantly influence care partner health.

H2: The number of care hours per week will significantly influence care partner health.

H3: The underlying reason for care will significantly influence care partner health.

Data

Table 1 is a summary of the states and other localities that implemented the Caregiver Module in 2015, 2016, or 2017 with the corresponding dataset version noted as 0, v1, v2, or v3 as determined by BRFSS. Each data set represents a different proportion of the population sampled, as states may choose to use optional modules in every version of the state's questionnaire or only in one or more subsamples. Version 0 means that the state treated the module as common and surveyed all respondents. Versions 1, 2, and 3 for a given year include different subsets of the state's sample population (U.S. CDC 2018b). Participant data were extracted from each of the eleven data sets and combined into one data set before analyses. The five states that did not participate in any of the three years are Delaware, Massachusetts, New Hampshire, Vermont, and Washington. However, six states participated in multiple years. Data from North Carolina was not included in the BRFSS 2017 files as care-related questions were optional state questions and that data was not available at the time of this analysis. The pooled data were not being analyzed at the state level, so no case weightings were calculated or assigned. A total of 362,260 cases with 67,610 care partners were analyzed for the three-year period: 160,958 cases from 2015 data, 134,701 cases from 2016, and 66,601 cases from 2017. Respondents were designated a care partner if they responded "Yes" to the question "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?" and were included in this analysis.

In addition to specific questions about caregiving in the optional module, the core survey offers health-related variables including a respondent self-rating of overall health

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and a section on chronic health diseases. Well-being variables include access to health care and lifestyle factors such as alcohol and tobacco use. To maximize the sample size, only variables common to all three years were used. To further explore the relationships between independent variables, a subset of care partners who provide care for 40 or more hours per week for 5 years or more were designated as "Heavy Burden Care Partners" and analyzed separately.

Before analysis, variables were recoded to eliminate missing responses and to accommodate changes in the response options that existed between the annual surveys. For example, the 2016 and 2017 questionnaires included two additional responses in the question about the main reason for care. To maximize sample size, the 2016 and 2017 responses were recoded to match the responses available in the 2015 survey. The questions and possible responses for the 2015 Caregiver Module are attached in the Appendix.

Dependent Variable

The dependent variable that assessed care partner burden was overall general health. General health is a five-category self-reported ordinal measure and was question 1.1 in the BRFSS core section for each year. The values for this question were Excellent (1), Very Good (2), Good (3), Fair (4), and Poor (5) with higher values indicating poorer health. This variable was treated as continuous in the multivariate regression analysis.

Independent Variables

To test Hypotheses 1 through 3, independent variables were selected from the caregiver module (See Appendix). The length of time that care has been provided is question 3 in the caregiver module. The question is "For how long have you provided

care for that person? Would you say . . ." and the responses are less than 30 days (1), 1 month to less than 6 months (2), 6 months to less than 2 years (3), 2 years to less than 5 years (4), and more than 5 years (5). The number of care hours per week is question 4 in the module and asks "In an average week, how many hours do you provide care or assistance? Would you say. . ."   and the responses are up to 8 hours per week (1), 9 to 19 hours per week (2), 20 to 39 hours per week (3), and 40 hours or more (4).

The main care reason is a nominal variable and the question asked is: "What is the main health problem, long-term illness, or disability that the person you care for has?" Care reason includes 12 specific reasons for care and one "Other" category and is question 5 in the caregiver module. The 12 specific conditions are arthritis/rheumatism (1), asthma (2), cancer (3), chronic respiratory conditions such as emphysema or COPD (4), dementia and other cognitive impairment disorders (5), developmental disabilities such as autism, Down's Syndrome, and spina bifida (6), diabetes (7), heart disease, hypertension (8), HIV (9), mental illnesses, such as anxiety, depression or schizophrenia (10), other organ failure or diseases such as kidney or liver problems (11), and substance abuse or addiction disorders (12).

To test sociodemographic influences, a number of variables were used from the BRFSS core demographics questionnaire section. For purposes of analysis, the ordinal variables of household income and age were treated as continuous. Household income has eight categories: less than $10,000 (1), less than $15,000 (2), less than $20,000 (3), less than $25,000 (4), less than $35,000 (5), less than $50,000 (6), less than $75,000 (7), $75,000 or more (8). Age in years data were reported by BRFSS in 13 age ranges: Age 18 – 24 (1), Age 25 – 29 (2), Age 30 – 34 (3), Age 35 – 39 (4), Age 40 – 44 (5), Age 45 – 49

(6), Age 50 – 54 (7), Age 55 – 59 (8), Age 60 – 64 (9), Age 65 – 69 (10), Age 70 – 74

(11), Age 75 – 79 (12), and Age 80 or Older (13).

Dichotomous variables included gender, and nominal variables included race and

ethnicity and partnership status. In this analysis Females were designated "0" and Males

were designated "1." Eight race and ethnicity groups were included in the univariate

analysis: White (1), Black/African American (2), American Indian or Alaska Native (3),

Asian (4), Native Hawaiian or Pacific Islander (5), Other (6), Multiracial (7), and Hispanic

(8). Due to low representation, American Indian or Alaska Native, Asian, Native

Hawaiian or Pacific Islander, and Other are included as "Other" in the multivariate

analysis and the values for each are White (1), Black/African American (2), Other (3),

Multiracial (4), and Hispanic (5). Partnership status was divided between those

respondents who had never married (1), and those that were currently partnered, married,

or had ever been married including those widowed, separated, or divorced (2).

Analytical Strategy

The data analysis was performed using SPSS version 24. I performed three types

of analyses. First, univariate analysis was be conducted to describe the sample of current

care partners and its subset Heavy Burden Care Partners. Bivariate analysis was then

performed to assess the relationship between dependent and independent variables. The

main statistical analyses are chi-square tests of association due to the number of

categorical variables in the data set. Dummy variables were created for nominal and

categorical variables to further test significant relationships using multivariate analysis.

Table 1. Participation Summary: BRFSS Caregiver Module 2015-2017

Data Set	2015			2016				2017			
	0	v1	v2	0	v1	v2	v3	0	v1	v2	v3
State											
Alabama, AL	●										
Alaska, AK								●			
Arizona, AZ						●					
Arkansas, AR				●							
California, CA						●					
Colorado, CO							●				
Connecticut, CT						●					
Delaware, DE											
District of Columbia, DC				●							
Florida, FL			●								
Georgia, GA				●							
Hawaii, HI	●							●			
Idaho, ID	●										
Illinois, IL	●										
Indiana, IN	●										
Iowa, IA	●										
Kansas, KS									●		
Kentucky, KY	●										
Louisiana, LA	●										
Maine, ME		●									
Maryland, MD		●									●
Massachusetts, MA											
Michigan, MI									●		
Minnesota, MN				●							
Mississippi, MS	●										
Missouri, MO				●							
Montana, MT				●							
Nebraska, NE		●									
Nevada, NV				●							
New Hampshire, NH											
New Jersey, NJ	●			●					●		
New Mexico, NM								●			
New York, NY			●				●			●	
North Carolina, NC								●*			
North Dakota, ND				●							
Ohio, OH					●						

Data Set	2015			2016				2017			
	0	v1	v2	0	v1	v2	v3	0	v1	v2	v3
State											
Oklahoma, OK										●	
Oregon, OR	●			●				●			
Pennsylvania, PA	●										
Puerto Rico, PR				●							
Rhode Island, RI								●			
South Carolina, SC	●										
South Dakota, SD				●							
Tennessee, TN	●			●							
Texas, TX						●					
Utah, UT			●		●					●	
Vermont, VT											
Virginia, VA	●										
Washington, WA											
West Virginia, WV	●										
Wisconsin, WI	●										
Wyoming, WY	●										

Notes: States in boldface did not participate in any of the three years. The 5 states are Delaware, Massachusetts, New Hampshire, Vermont, and Washington.

* North Carolina added two questions to the Caregiving Module; all caregiving questions were then considered state specific and not included in the BRFSS files on the CDC website. North Carolina's 2017 data had not been made publicly available as of September 15, 2018 and has not been included in this analysis.

Source: Compiled from the BRFSS website, https://www.cdc.gov/brfss/

IV. RESULTS AND ANALYSIS

Univariate Analysis

Table 2 summarizes general health, care characteristics, and key sociodemographic characteristics of all care partners and Heavy Burden Care Partners, a subset of care partners who reported providing care for 40 or more hours per week for five or more years.

While 19.8% of all care partners report having fair or poor health, 29.2% of Heavy Burden Care Partners report general health as fair or poor. Excluding "other", the most common major care reason for all care partners is dementia and other cognitive impairments at 10.1%, followed by cancer at 8.1%. For Heavy Burden Care Partners, developmental disabilities are the most frequently identified major care reason representing 15.6% of cases, and dementia and other cognitive impairments is second at 10.1%. This difference in major reason of care is not surprising as 59.1% of people being cared for with developmental disabilities were identified as either children or grandchildren who typically require more care over longer periods of time.

In regard to how long care has been provided, care partners are evenly split with 50% providing care for less than 2 years, and 50% providing care for more than 2 years. The largest group were care partners providing 5 or more years of care representing 29.7% of the total. The most common average number of care hours per week was up to 8 hours with 59.2%, followed by 40 or more hours at 18.3%.

The age range curve is similar for all care partners and Heavy Burden Care Partners with the Heavy Burden Care Partner curve having a slightly higher proportion of

caregivers in midlife and fewer under age 30 (-3.2%).   The mean indicates that the

average age for care partners is between 53 and 54 years for both groups.

Care partners, especially Heavy Burden Care Partners are predominantly women;

63.7% of all care partners and 70.0% of Heavy Burden Care Partners are female. Heavy

Burden Care Partners are less likely to have never been married (13.4%) compared to all

care partners (14.1%) and are more likely to be a member of a racial or ethnic minority;

28.6% of Heavy Burden Care Partners are minorities compared to 22.8% of all care

partners.

Heavy Burden Care Partners also have less household income; while 37.7% of all

care partners have total income of less than $35,000 per year, a majority, 51.8%, of Heavy

Burden Care Partners have income under $35,000.

Additional data presented in the following sections, not included in Table 2, are

also helpful in understanding care partner burden and health differences between non-care

partners, all care partners, and Heavy Burden Care Partners. Financial challenges can be

seen in the number of care partners reporting that cost is a barrier to getting health care for

themselves; 13.5% of all care partners and 17.7% of Heavy Burden Care Partners reported

they could not afford health care in the last year as compared to 8.8% of non-care partners.

BRFSS questions about specific diagnoses provide additional insight into the

health challenges faced by care partners. Diagnosed depressive disorders were more

common. The percentage of all care partners diagnosed with depressive disorders was

24.1%, and for Heavy Burden Care Partners 29.5%, while the reported rate for non-care

partners was 17.4%. Heavy Burden Care Partners also reported increased rates of stroke

(5.5%), cancer (11.1%), COPD (12.5%), and diabetes (18.1%) than did all care partners

who reported the following rates: stroke 4.1%, cancer 10.4%, COPD 9.4%, and diabetes 13.6%.

Care partners also reported increased rates of obesity and smoking. The percentage of all care partners considered obese, defined as a body mass index of 30 or more, is 33.8%, and for Heavy Burden Care Partners is 40.6%, compared to 29.8% for non-care partners. The percentage of all care partners that smoke daily is 12.9%, and for Heavy Burden Care Partners 17.5%, compared to 9.6% of non-care partners.

Table 2. Comparison for All Care Partners and Heavy Burden Care Partners, BRFSS 2015-2017

Characteristics	All Care Partners		Heavy Burden Care Partners*	
	n	%	n	%
General Health				
Excellent	10,087	15.0	636	11.5
Very Good	21,829	32.4	1,359	24.6
Good	22,172	32.9	1,927	34.8
Fair	10,018	14.8	1,145	20.7
Poor	3,357	5.0	468	8.5
Major Care Reason				
Arthritis or Rheumatism	3,378	5.3	180	3.4
Asthma	341	0.5	47	0.9
Cancer	5,196	8.1	185	3.4
Chronic Respiratory Disease	2,433	3.8	164	3.1
Dementia or Cognitive Impairment	6,482	10.1	542	10.1
Developmental Disabilities	2,369	3.7	836	15.6
Diabetes	3,448	5.4	302	5.6
Heart Disease or Hypertension	4,895	7.6	373	6.9
HIV	115	0.2	10	0.2
Mental Illness	2,864	4.5	403	7.5
Other Organ Failure[a]	1,549	2.4	112	2.1
Substance Abuse or Addiction	264	0.4	13	0.2
Other	30,739	48.0	2,201	41.0
Length of Time Care Provided				
Less than 30 days	12,813	19.3		
1 month to 6 months	8,325	12.5		
6 months to less than 2 years	12,110	18.2		
2 years to less than 5 years	13,480	20.3		
5+ years	19,728	29.7	5,554	100.0
Care Hours in Average Week				
Up to 8 hours per week	37,522	59.2		
9 to 19 hours per week	8,063	12.7		
20 to 39 hours per week	6,164	9.7		
40+ hours per week	11,600	18.3	5554	100.0
Age				
Mean (SD)	7.77	(3.101)	7.87	(2.913)
Age 18 - 24	2,731	4.1	93	1.7
Age 25 - 29	2,307	3.4	141	2.6
Age 30 - 34	2,849	4.3	237	4.3
Age 35 - 39	3,457	5.2	339	6.2

Characteristics	All Care Partners		Heavy Burden Care Partners*	
	n	%	n	%
Age 40 - 44	3,864	5.8	390	7.1
Age 45 - 49	5,119	7.7	495	9.0
Age 50 - 54	7,397	11.1	635	11.5
Age 55 - 59	8,944	13.4	720	13.1
Age 60 - 64	9,159	13.7	734	13.3
Age 65 - 69	8,116	12.1	644	11.7
Age 70 - 74	5,731	8.6	462	8.4
Age 75 - 79	3,647	5.5	338	6.1
Age 80 or Older	3,556	5.3	271	4.9
Gender				
Female	43,042	63.7	3940	70.9
Male	24,556	36.3	1614	29.1
Partner Status				
Never Married	9,500	14.1	743	13.4
Ever Married/Partnered	57,715	85.9	4789	86.2
Race & Ethnicity[b]				
White	51,326	77.2	3902	71.4
Black	6,211	9.3	593	10.9
American Indian or Alaska Native	1,281	1.9	146	2.7
Asian	1,186	1.8	97	1.8
Native Hawaiian or Pacific Islander	184	0.3	20	0.4
Other	289	0.4	22	0.4
Multiracial	1,899	2.9	205	3.8
Hispanic	4,143	6.2	478	8.7
Household Income				
Mean (SD)	5.83	(2.107)	5.16	(2.207)
Less than $10,000	2,589	4.5	358	7.5
$10,000 to $14,999	2,921	5.0	334	7.0
$15,000 to $19,999	4,379	7.5	542	11.3
$20,000 to $24,999	5,459	9.4	625	13.0
$25,000 to $34,999	6,513	11.2	625	13.0
$35,000 to $49,999	8,711	15.0	680	14.2
$50,000 to $74,999	9,855	17.0	689	14.3
$75,000 or more	17,610	30.3	949	19.8

Notes: Maximum sample size for care partners is 67,610, and for Heavy Burden Care Partners, 5,554. These data sets include 44 states, the District of Columbia, and Puerto Rico.

* Heavy Burden Care Partners provided 40 or more hours of care per week for 5 or more years.

[a]Other Organ Failure excludes Heart Failure

[b]Due to low representation, American Indian or Alaska Native, Asian, Native Hawaiian or Pacific Islander, and Other are included as "Other" in subsequent analyses.

Source: Compiled from 2015 – 2017 data available from https://www.cdc.gov/brfss/

Bivariate Analysis

Next, bivariate analysis was used to test the relationships of care-related

independent variables to general health, the dependent variable representing care partner

burden. Table 3 summarizes the results of this Chi-Square analysis.

Table 3. Chi-Square Analysis – Care Reason, Hours Per Week, Length of Time, and General Health, BRFSS 2015-2017

	General Health					
	Excellent	Very Good	Good	Fair	Poor	n
All Care Partners						
Care Reason						
Dementia*** $\chi^2 = 40.407$	15.5%	34.5%	32.7%	13.4%	3.9%	6,472
Non-Dementia	14.8%	32.2%	32.8%	15.1%	5.1%	57,474
Care Hours Per Week *** $\chi2 = 921.887$						
Up to 8 Hours	16.6%	35.0%	31.5%	12.9%	4.0%	37,463
9 – 19 Hours	14.1%	32.7%	33.7%	14.6%	4.9%	8,048
20 – 39 Hours	12.8%	29.9%	35.7%	16.2%	5.4%	6,153
40+ Hours	11.9%	26.5%	34.5%	19.8%	7.3%	11,568
Length of Time Care Provided *** $\chi2 = 323.516$						
Less than 30 days	16.8%	34.4%	31.8%	13.3%	3.7%	12,787
1 month to 6 months	15.7%	33.5%	32.6%	14.1%	4.1%	8,315
More than 6 months less than 2 years	15.4%	32.9%	32.7%	14.4%	4.6%	12,086
2 years to less than 5 years	14.6%	32.6%	33.2%	14.8%	6.4%	13,456
5 years or more	13.5%	30.2%	33.4%	16.4%	4.9%	19,673

* p<.05, ** p<.01, *** p<.001
Source: Compiled from 2015 – 2017 BRFSS data available from https://www.cdc.gov/brfss/

Excluding "Other", dementia and other cognitive impairments represented the

largest number of cases, so this major care reason was included to test care reason as an

independent variable. The other independent variables tested are average number of care

hours provided per week and the length of time care has been provided. All independent

variables were significant at the α=.001 level.

For dementia and other cognitive impairments 17.3% of care partners reported fair or poor health. For all other care reason categories fair or poor health was reported by 20.2% of care partners. In average care hours provided per week, the percentage of care partners reporting fair or poor health was 16.9% for up to 8 hours, 19.5% for 9 to 19 hours, 21.5% for 20 to 39 hours, and 27.1% for 40 or more hours. For length of time care has been provided, the percentage of care partners reporting fair or poor health was 17.0% for less than 30 days, 18.2% for 1 month to 6 months, 19.0% for more than 6 months and less than 2 years, 21.4% for 2 years but less than 5 years, and 21.3% for 5 years or more.

These results suggest that providing care for people with dementia and cognitive impairments are associated with care partner health but not poorer health. However, as hours per week of care and length of time care provided increases, poorer health becomes more likely.

Multivariate Analysis

Lastly, multivariate analysis was performed to assess the effects of independent variables on care partner general health after controlling for sociodemographic variables. Two models were created with the first assessing care-related independent variables (Model 1), and the second model adding the sociodemographic variables of age, gender, household income, and race and ethnicity (Model 2). Multivariate results can be impacted by collinearity when independent variables are highly correlated with each other. As the number of care hours per week and the length of time care was provided are both time-based variables, I performed collinearity testing on all independent variables included in Model 2. The Variance Inflation Factor (VIF) values ranged from 1.012 to 1.108. As

these values were substantially less than 10, all independent variables were retained. Care partner models are summarized in Tables 4 and 5.

Model 1, the first care partner regression model, included three care characteristics variables. The first care characteristic variable is the average number of care hours provided per week and the reference category is providing up to 8 hours of care. Controlling for other variables, the category of 9 to 19 hours of care provided per week has a positive coefficient and the mean of health is .101 units greater than the mean for providing care up to eight hours per week. The category of 20 to 39 hours per week has a positive coefficient and the mean of health is .179 units greater than the mean for providing care for up to eight hours per week. The final category, 40 or more hours per week, has a positive coefficient and the mean of health is .289 units greater than the mean for providing care for up to eight hours per week. These results suggest that as the number of care hours per week increases, health gets poorer.

The second care variable is length of time care has been provided and the reference category is 0 to 30 days. Controlling for other variables, the mean for the category of 1 month to less than 6 months is not significantly different than the mean for 0 to 30 days. The category of 6 months to less than 2 years has a positive coefficient and the mean of health is .041 units greater than the mean for providing care for 0 to 30 days. The category of providing care for 2 years to less than five years has a positive coefficient and the mean of health is .059 units greater than the mean for providing care for 0 to 30 days. The final category, five or more years, has a positive coefficient and the mean of health is .117 units greater than the mean for providing care for 0 to 30 days. These results suggest

that as the length of time care provided increases beyond 6 months, health status becomes

poorer.

The third care characteristic variable is dementia or other cognitive impairments as

the main reason for care. The reference categories are all reasons other than dementia and

other cognitive impairments. Controlling for other variables, dementia and other cognitive

impairments had a negative coefficient and the mean was -.103 units less than the mean

for other reasons for care. This result suggests that dementia and other cognitive

impairments as a reason for care does not increase poorer health status.

Table 4. Model 1 Regression: Care Characteristics and General Health – All Care Partners

Model 1	Unstandardized Coefficients		Standardized Coefficients	95.0% Confidence Interval for B	
	B	SE	Beta	Lower Bound	Upper Bound
9 to 19 hours per week***	0.101	0.013	0.032	0.075	0.127
20 to 39 hours per week***	0.179	0.015	0.050	0.150	0.208
40+ hours per week***	0.289	0.012	0.106	0.266	0.312
1 month to less than 6 months	0.014	0.016	0.004	-0.017	0.045
6 months to less than 2 years**	0.041	0.014	0.015	0.013	0.069
2 years to less than 5 years***	0.059	0.014	0.023	0.032	0.087
5+ years***	0.117	0.013	0.051	0.092	0.143
Dementia or Cognitive Impairment***	-0.103	0.014	-0.030	-0.131	-0.075

Note: The reference category for care hours provided per week is less than 8 hours per week; the reference category for length of time care is provided is less than 30 days, and the reference categories for care reason are all major care reasons other than dementia and other cognitive impairments.
* p<.05, ** p<.01, *** p<.001
n=59,990
Source: Compiled from 2015 – 2017 BRFSS data available from https://www.cdc.gov/brfss/

In Model 2, sociodemographic variables were added to the care characteristics in

Model 1. In the second model, the care variables of average hours of care provided per

week, duration of care, and major care reason retained both their significance and

direction.

The first care characteristic variable is the average number of care hours provided per week and the reference category is providing up to 8 hours of care per week. Controlling for other variables, the category of 9 to 19 hours of care provided per week has a positive coefficient and the mean of health is .063 units greater than the mean for providing care up to eight hours per week. The category of 20 to 39 hours per week has a positive coefficient and the mean of health is .086 units greater than the mean for providing care for up to eight hours per week. The final category, 40 or more hours per week, has a positive coefficient and the mean of health is .136 units greater than the mean for providing care for up to eight hours. These results suggest that as the number of care hours per week increases, the probability of poorer health also increases even when controlling for sociodemographic differences.

The second care variable is length of time care has been provided and the reference category is 0 to 30 days. Controlling for other variables, the category of 1 month to less than 6 months has a positive coefficient and does not differ significantly from the mean of providing care for 0 to 30 days. The category of 6 months to less than 2 years has a positive coefficient and the mean of health is .037 units greater than the mean for providing care for 0 to 30 days. The category of providing care for 2 years to less than five years has a positive coefficient and the mean of health is .050 units greater than the mean for providing care for 0 to 30 days. The final category, five or more years, has a positive coefficient and the mean of health is .093 units greater than the mean for providing care for 0 to 30 days. These results suggest that as the length of time care provided increases beyond 6 months, the probability of poorer health also increases even when controlling for sociodemographic differences.

The third care characteristic variable is dementia and other cognitive impairments as the main reason for care. The reference categories are reasons other than dementia and other cognitive impairments. Controlling for other variables, dementia and other cognitive impairments had a negative coefficient and the mean was -.070 units less than the mean for other reasons for care. This result suggests that dementia and other cognitive impairments as a reason for care does not increase poorer health status even when considering sociodemographic differences.

Sociodemographic variables included age, gender, annual household income, and race and ethnicity. Age was treated as a continuous variable and has a positive slope. For each additional year, health increases by .032 units controlling for other variables which means that health is perceived as poorer. Gender is a dichotomous variable and male gender has a mean level .096 greater than the mean for females controlling for other variables. This implies that males perceive a poorer health status than females in this data set. Household income was treated as a continuous variable and has a negative slope. For every unit increase in household income, health decreased by .161 units controlling for other variables, implying that health status was perceived as better as income increased. The reference category for race and ethnicity was white. Controlling for other variables, the category of black or African American has a positive coefficient and the mean of health is .102 units greater than the mean for whites. The category of other race has a positive coefficient and the mean of health is .133 units greater than the mean for whites. The category of multiracial has a positive coefficient and the mean of health is .156 units greater than the mean for whites. The final category, Hispanic, has a positive coefficient and the mean of health is .101 units greater than the mean for whites. From a

sociodemographic perspective being older, male, lower income, and minority are associated with poorer perceived health status.

Results supported both H1 and H2 – both the average number of care hours provided per week and the duration of care provided by care partners were significantly associated with care partner health when controlled for sociodemographic variables. More hours per week and longer durations of time were both associated with poorer health. These results also provided limited support for H3. The one major care reason tested, dementia and other cognitive impairments, was significant and negatively associated with care partner health, suggesting that this major care reason is not associated with perceived poorer health and leaves open the question of the effect of other major care reasons on health.

BRFSS use complex sampling methods to collect data and provides individual case weightings for each data set version. In addition to testing the cases unweighted, I also weighted the cases and performed the same Model 1 and 2 multivariate analysis. Weighting the data did not change the findings. The same data patterns were present in both analyses.

Table 5. Model 2 Regression: Care Characteristics and General Health – All Care Partners with Sociodemographic Control Variables

Model 2	Unstandardized Coefficients		Standardized Coefficients	95.0% Confidence Interval for B	
	B	SE	Beta	Lower Bound	Upper Bound
9 to 19 hours per week***	0.063	0.013	0.020	0.037	0.090
20 to 39 hours per week***	0.086	0.015	0.024	0.056	0.116
40+ hours per week***	0.136	0.012	0.050	0.112	0.160
1 month to less than 6 months	0.010	0.016	0.003	-0.021	0.041
6 months to less than 2 years*	0.037	0.014	0.014	0.008	0.065
2 years to less than 5 years***	0.050	0.014	0.019	0.022	0.078
5+ years***	0.093	0.013	0.040	0.067	0.119
Dementia and Cognitive Impairments**	-0.070	0.015	-0.020	-0.099	-0.042
Age***	0.032	0.001	0.091	0.029	0.035
Male Gender***	0.096	0.009	0.044	0.078	0.113
Annual Household Income***	-0.161	0.002	-0.320	-0.166	-0.157
Black/African American***	0.102	0.016	0.028	0.072	0.133
Other***	0.133	0.021	0.026	0.091	0.175
Multiracial***	0.156	0.026	0.025	0.105	0.207
Hispanic***	0.101	0.018	0.023	0.065	0.137

Note: The reference category for care hours provided per week is less than 8 hours per week; the reference category for length of time care is provided is less than 30 days, and the reference categories for care reason are all major care reasons other than dementia and other cognitive impairments.
* $p<.05$, ** $p<.01$, *** $p\leq.001$
n=51,641
Source: Compiled from 2015 – 2017 BRFSS data available from https://www.cdc.gov/brfss/

V. DISCUSSION AND CONCLUSION

This research provides a first look at 2015-2017 pooled BRFSS data for testing and comparison of multiple care partner burden factors. This study found that as the number of care hours provided per week and the length of time care provided increased, care partners' perception of poorer health also increased. These findings support the "Wear and Tear" model suggested by stress process theorists (Swinkels et al. 2018).

Prior studies suggesting that the reason for care influences burden found limited support in this study and may be due to the research design or limitations in the dataset, as 48% of care reasons were designated "Other." The major care reason tested, dementia and other cognitive impairments, had a negative association with poor perceived health. This result could reflect the success that organizations such as the Alzheimer's Association have achieved in supporting and educating care partners or may be due to care recipients in this data set having milder cognitive impairments, for example. This result could be interpreted as support for the "Adaptive" stress process model (Swinkels et al. 2018) and is consistent with other research findings suggesting that dementia care partners can cope with increased care demands (Armstrong et al. 2018; Yoon et al. 2018), however, more research is required to confirm this interpretation.

Age, while significantly associated with changes in health, had a weaker positive association than did gender. Notably, in this study male care partners beginning at age 50 reported higher levels of fair or poor health than did female care partners in the same age range suggesting that gender should continue to be an important research focus.

The results of this study are consistent with other studies which have found that care partners are at increased risk of disability, poor health, and depression (Brehaut et al.

2009; Dassel and Carr 2016; Do et al. 2015; Griffin et al. 2017b; Liu et al. 2015; Neugaard et al. 2008; Tanji et al. 2013; Trudeau-Hern and Daneshpour 2012). Findings of increased financial burden (Griffin et al. 2017b; Hong and Harrington 2016) are also supported by this research and is most evident in the Heavy Burden Care Partners, who reported lower household income and higher rates of cost being a barrier to receiving health care.

Unfortunately, data from the BRFSS caregiver module is of limited usefulness in determining what services would be most helpful for care partners. The one question asked is "Of the following support services, which one do you most need, that you are not currently getting?" The possible responses include classes about giving care, help in accessing services, support groups, individual counseling, respite care (short term breaks from care partner responsibilities), or none of these support services. The resounding majority, 82.5%, say they do not need any of the five support services. Does that mean that care partners don't need or wouldn't benefit from additional support including perhaps more support from an existing resource? That seems unlikely given the challenges care partners face.

What seems more likely is that the BRFSS question does not ask about services that care partners would find helpful. For example, affordable day care for people of all ages with functional disabilities would allow care partners to consider part or full-time employment. Low-cost technology solutions, such as smart phone applications allowing for effective care monitoring, medication management, and communication between care partners, care recipients, and health care providers, might also be highly valued by care partners.

Contributions

The results of this study demonstrate the value of using BRFSS data to understand the main care characteristics that influence care partner burden. Further, pooling care-related data from multiple years has been shown to be valuable in analyzing the effects and relationships between overall health and well-being and the care partner role, and this value will only grow as more data becomes available over time.

Limitations

In addition to the usual limitations inherent in phone surveys, there are further limitations that should be noted. The dependent variable of general health may not reflect the full health and wellness impact of providing care over time. Also, health may be influenced by a number of factors not controlled for in this study such as education, employment status, genetics, access to health care, lifestyle habits, and social support.

Data for many care reasons and relationships is still sparse or not identifiable. For example, it is not possible to analyze burden associated with Traumatic Brain Injuries, a condition impacting veterans and their families at an increasing rate (Griffin et al. 2017a; Griffin et al. 2017b; Saban 2016).

Some states were not represented in this three-year data set while other states that participated in multiple years may be over represented. As health has been shown to vary across the U.S. (Adams 2017; Murray et al. 2018), this over and under representation may have influenced some of the results.

This survey is not a longitudinal study that captures changes in the same set of care partners over time. To assess change over time, this study identified Heavy Burden Care Partners who provide care for 40 or more hours per week for five or more years and

compared this group's health with all care partners. While this comparison provides useful insight, the results of a longitudinal study may differ.

Care recipient characteristics which may influence burden are not included in BRFSS and may be important in understanding care partner burden and its impact on care partner health. Similarly, this survey does not include spirituality or other individual traits in the care partner or care recipient that could influence care partner burden (Singh and Gupta 2018; Yoon et al. 2018).

Future Directions

The BRFSS consists of core questions that are asked every year of all respondents, rotating core questions that are asked every other year, optional modules which states can elect to use with all or a sub sample of participants, and state-added questions which could include questions from existing optional modules or other standalone questions (U.S. CDC 2018b). This study included only questions common to the three-year period 2015 to 2017, so no rotating core questions, questions from other optional modules, or new questions introduced since 2015 were analyzed. Each of these areas represents important research opportunities.

By leveraging data from the core rotating questions, either individually or in an index, researchers could explore relationships between care partnering, exercise, nutrition, sleep quality, health literacy, and health care usage.

Pooling data from states that included the caregiving module and one or more other optional modules could provide additional insight into other aspects of care partner burden. For example, identifying states that included both the caregiving module and the

emotional support and life satisfaction module, would allow analysis of variables related to emotional health and care partnering not possible in the data set used in this study.

New variables should also be explored in future studies. For example, the addition of a more refined metropolitan variable can be used to determine if rural care partners' health is impacted differently by providing care over time. Major care reason and its relationship with burden can be further explored with the addition of new care reasons that have been added since the 2015 survey. In particular, the new care reason of old age, frailty and infirmity, should be evaluated given the aging of our population (Redfoot et al. 2013).

However, even without expanding the data set additional value could be gained. Researchers could test life course theory by evaluating the impact of multiple roles that care partners must navigate including family, social, and employment roles. This research could contribute to understanding how services should be prioritized for maximum impact in reducing care partner burden.

Pooled BRFSS care partner data has the potential for providing increased understanding of this growing public health challenge and this study should be just one of many more to come.

APPENDIX SECTION

2015 BRFSS Optional Caregiver Module Questions and Possible Responses

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?
    1 Yes
    2 No
    7 Don't know/Not sure
    8 Caregiving recipient died in past 30 days
    9 Refused
2. What is his or her relationship to you?
    01 Mother
    02 Father
    03 Mother-in-law
    04 Father-in-law
    05 Child
    06 Husband
    07 Wife
    08 Same-sex partner
    09 Brother or brother-in-law
    10 Sister or sister-in-law
    11 Grandmother
    12 Grandfather
    13 Grandchild
    14 Other relative
    15 Non-relative/Family friend
    77 Don't know/Not sure
    99 Refused
3. For how long have you provided care for that person? Would you say
    1 Less than 30 days
    2 1 month to less than 6 months
    3 6 months to less than 2 years
    4 2 years to less than 5 years
    5 More than 5 years
    7 Don't Know/ Not Sure
    9 Refused
4. In an average week, how many hours do you provide care or assistance? Would you say…
    1 Up to 8 hours per week
    2 9 to 19 hours per week
    3 20 to 39 hours per week
    4 40 hours or more
    7 Don't know/Not sure
    9 Refused

5. What is the main health problem, long-term illness, or disability that the person you care for has?

1 Arthritis/Rheumatism
2 Asthma
3 Cancer
4 Chronic respiratory conditions such as Emphysema or COPD
5 Dementia and other Cognitive Impairment Disorders
6 Developmental Disabilities such as Autism, Down's Syndrome, and Spina Bifida
7 Diabetes
8 Heart Disease, Hypertension
9 Human Immunodeficiency Virus Infection (HIV)
10 Mental Illnesses, such as Anxiety, Depression, or Schizophrenia
11 Other organ failure or diseases such as kidney or liver problems
12 Substance Abuse or Addiction Disorders
13 Other
77 Don't know/Not sure
99 Refused

6. In the past 30 days, did you provide care for this person by managing personal care such as giving medications, feeding, dressing, or bathing?

1 Yes
2 No
7 Don't Know /Not Sure
9 Refused

7. In the past 30 days, did you provide care for this person by managing household tasks such as cleaning, managing money, or preparing meals?

1 Yes
2 No
7 Don't Know /Not Sure
9 Refused

8. Of the following support services, which one do you MOST need, that you are not currently getting?

1 Classes about giving care, such as giving medications
2 Help in getting access to services
3 Support groups
4 Individual counseling to help cope with giving care
5 Respite care
6 You don't need any of these support services
7 Don't Know /Not Sure
9 Refused

9. In the next 2 years, do you expect to provide care or assistance to a friend or family member who has a health problem or disability?

1 Yes
2 No
7 Don't know/Not sure
9 Refused

Source: Centers for Disease Control and Prevention (CDC).
https://www.cdc.gov/BRFSS/questionnaires/index.htm

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