BRFSS Statistical Brief: Caregiver Optional Module

2015–2018

BRFSS™
Behavioral Risk Factor Surveillance System

Centers for Disease Control and Prevention
National Center for Chronic Disease Prevention and Health Promotion

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BRFSS™
Behavioral Risk Factor Surveillance System

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Alzheimer's Disease and Healthy Aging Program
National Center for Chronic Disease Prevention and Health Promotion
Centers for Disease Control and Prevention

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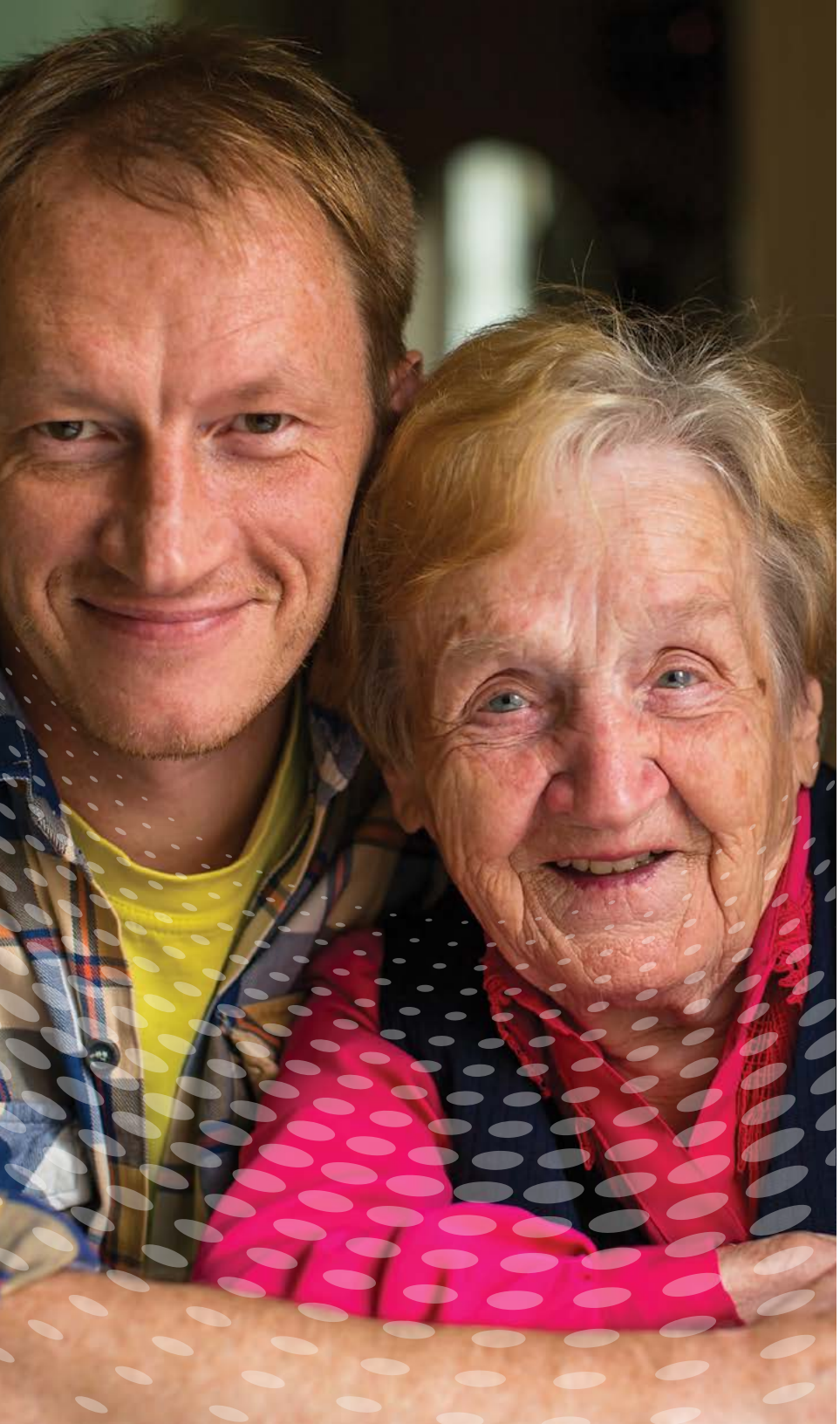


Objective

The purpose of this document is to provide guidance for BRFSS coordinators and researchers who would like to conduct analyses of the data collected through the 2015–2018 BRFSS Caregiver Optional Module and provide basic computer code for analyzing the data. The goal is to enable consistency in analytic methods and results reported.

Background

The demand for and burden on caregivers is projected to increase.[1,2] Caregivers must maintain their own health in order to provide appropriate care for others.[3] Therefore, understanding the activities of and effects of caregiving on health and function is an important goal for public health.[1]

Healthy People has included objectives related to caregivers for the past two cycles. In Healthy People 2020, multiple objectives target caregivers and could be addressed through increased surveillance (Appendix A).[4]

> **Disability and Health:** Objective DH-2.2 Increase the number of state and DC health departments that conduct health surveillance of caregivers for people with disabilities.
>
> **Disability and Health:** Objective DH-2.3 Increase the number of State and the District of Columbia health departments that have at least one health promotion program aimed at improving the health and well-being of caregivers of people with disabilities
>
> **Disability and Health:** Objective DH-2.7 (Developmental) Increase the number of Tribes that have at least one health promotion program aimed at improving the health and well-being of caregivers of people with disabilities
>
> **Dementia including Alzheimer's disease:** Objective DIA-1 Increase the proportion of persons with diagnosed Alzheimer's disease and other dementias, or their caregiver, who are aware of the diagnosis
>
> **Older Adults:** Objective OA-9 (Developmental) Reduce the proportion of unpaid caregivers of older adults who report an unmet need for caregiver support services

The Alzheimer's Disease and Healthy Aging Program's report, *The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2018-2023*, recommends implementing the BRFSS Caregiver Module (objective M-1).[5]

Caregiver Module History

In 2009, the BRFSS questionnaire included the question, "People may provide regular care or assistance to a friend or family member who has a health problem, long-term illness, or disability. During the past month, did you provide any such care or assistance to a friend or family member?" The caregiver screening question was asked to all respondents (age 18 and older). A descriptive report using these data was published in 2013.[6] Although it is important to be able to estimate the prevalence of caregiving and to identify caregivers, research demonstrates that the details of caregiving such as the type of care provided, the frequency of care, and the duration of care all relate to caregiver burden and well-being.[7-9] The Caregiver Module was developed to capture information about caregivers' activities and experiences to allow for a more in-depth assessment of caregiver status and health. Three rounds of cognitive testing on the module were performed to help ensure that the questions would be easy to understand and answer. The Caregiving Module was used by 24 states in 2015, 21 states in 2016, 12 states in 2017, and 5 states in 2018. The module was modified in 2016 to include 'Old age/infirmity/frailty' as a response option to the question "What is the main health problem, long-term illness, or disability that the person you care for has?" Users will need to consider the additional response item when combining several years of data.

Analytic Code

The 2018 Caregiver Module includes a screening question that is asked of all BRFSS respondents to identify caregivers. People who say "yes" to the caregiver screening question are considered caregivers and are asked 7 additional questions about their caregiving experience. People who say "no" or "don't know/not sure" to the caregiver screening question or who refuse to answer it are asked a follow-up question about anticipated caregiving in the next two years. Variable names used to create recoded variables are the CDC assigned variable names for each question. The sections below describe each item and include sample Stata and SAS code to analyze the data. All "don't know/not sure" and "refused" responses are set to missing. Respondents with missing responses are excluded from the denominator; however, there may be circumstances when these responses may be appropriate to include in the denominator. The full text of the 2018 Caregiver Module appears in Appendix B. Older versions of the module can be found on the BRFSS website.

Caregiver Status

The Caregiver Module begins with the following screening question to identify caregivers. It differs slightly from the original screening question used on the 2009 BRFSS core:

1. People may provide regular care or assistance to a friend or family member who has a health problem or disability. 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
VARIABLE NAME: CAREGIV1

The code below creates variables to classify respondents who say "yes" to the screening question as caregivers and respondents who say "no" or report that the care recipient died in the past 30 days as non-caregivers. All other respondents are coded as missing and are excluded from denominators.

Note that respondents whose care recipient died in the past 30 days are not asked any subsequent module questions and also are not asked the expected future caregiving question.

Caregiver Status

Software	Analytic Code
STATA	recode caregiv1 (1=1) (2=0) (7=.) (8=0) (9=.), gen(cg_current)

SAS	if caregiv1=1 then caregiv1_rc = 1;
	if caregiv1 in (2,8) then caregiv1_rc=2;
	if caregiv1 IN (7,9) then caregiv_rc =.;

The remaining questions are asked only of respondents who were classified as caregivers in the screening question (i.e., caregiv1=1).

Relationship to Care Recipient

The Caregiver Module asks the caregiver to describe the person for whom they provide care. This question may be recoded to set "don't know/not sure" and "refused" responses to missing as well as code to create comparison groups such as distinguishing spousal/partner from non-spousal/partner caregivers or family caregivers from non-family caregivers.

2. What is his/her relationship to you? For example is he/she your (mother/daughter or father/son)?

1—Mother
2—Father
3—Mother-in-law
4—Father-in-law
5—Child
6—Husband
7—Wife
8—Live-in partner
9—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
VARIABLE NAME: CRGVREL2

Relationship to Care Recipient

Software	Analytic Code
STATA	recode crgvrel2 (77/99=.), gen(cg_relationship) recode crgvrel2 (1/5=0) (6/8=1) (9/15=0) (77/99=.), gen(cg_spousepartner) recode crgvrel2 (1/14=1) (15=0) (77/99=.), gen(cg_family)

SAS	crgvlel2_rc= crgvrel2;
	if 77<= crgvrel2 <=99 then crgvrel2_rc=.;
	
	if 1<= crgvrel2 <=5 then cg_spousepartner_=2;
	if 6 <= crgvrel2 <=8 then cg_spousepartner =1;
	if 9 <= crgvrel2 <=15 then cg_spousepartner =2;
	if 77<= crgvrel2 <=99 then cg_spousepartner =.;
	
	if 1<= crgvrel2 <=14 then cg_family=1; *Family Member/Relative;
	if crgvrel2 =15 then cg_family=2; * Non-Family Member/Non-Relative;
	if 77<= crgvrel2 <=99 then cg_family =.

Length of Care

Caregivers are asked how long they have provided care to the care recipient. Analysts could use the categories provided or collapse categories to identify people who have recently become caregivers (e.g., in the past 6 months) or long-term caregivers (e.g., more than 5 years).

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
VARIABLE NAME: CRGVLNG1

Length of Care

Software	Analytic Code
STATA	recode crgvlng1 (7/9=.), gen(cg_duration) recode crgvlng1 (1/2=1) (3/5=0) (7/9=.), gen(cg_recent) recode crgvlng1 (1/4=0) (5=1) (7/9=.), gen(cg_longterm)

SAS	crgvlng1_rc= crgvlng1;
	if 7<= crgvlng1<=9 then crgvlng1_rc=.;
	if 1 <= crgvlng1<=2 then cg_recent=1; *< 6 months;
	if 3<= crgvlng1<=5 then cg_recent=2; * 6 months or more;
	if 7<= crgvlng1<=9 then cg_recent=.;
	if 1 <= crgvlng1<=4 then cg_longterm=2; * < 5 years;
	if crgvlng1=5 then cg_longterm=1; *> 5 years;
	if 7<= crgvlng1<=9 then cg_longterm=.;

Time Spent Providing Care

Response options for time spent providing care each week are based on a standard work schedule. Researchers may be interested in reporting whether caregiving represents the equivalent of a part-time job (20-39 hours per week) or a full-time job (40 hours or more per week).

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 per week
7—Don't know/Not sure
9—Refused
VARIABLE NAME: CRGVHRS1

Time Spent Providing Care

Software	Analytic Code
STATA	recode crgvhrs1 (7/9=.), gen(cg_time) recode crgvhrs1 (1/2=0) (3/4=1) (7/9=.), gen(cg_parttime) recode crgvhrs1 (1/3=0) (4=1) (7/9=.), gen(cg_fulltime)

SAS	crgvhrs1_rc= crgvhrs1;
	if 7<= crgvhrs1<=9 then crgvhrs1_rc=.;
	
	if 1<=crgvhrs1<=2 then cg_parttime=1; * < 20 hours;
	if 3 <= crgvhrs1 <=4 then cg_parttime=2; * 20 or more hours;
	if 7<=crgvhrs1<=9 then cg_parttime=.;
	
	if 1<= crgvhrs1<=3 then cg_fulltime=1; * < 40 hours;
	if crgvhrs1=4 then cg_fulltime=2; * 40 or more hours;
	if 7<= crgvhrs11<=9 then cg_fulltime=.;

Care Recipient Major Health Problem

Caregivers are asked to report the care recipient's major health condition or disability that necessitates care. The list of response options can be grouped into categories by type of health condition. For example, code distinguishing caregivers of people with dementia or other cognitive impairment disorders from other types of caregivers is shown below.

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 or other Cognitive Impairment Disorders
6—Developmental Disabilities such as Autism, Down's Syndrome, and Spina Bifida
7—Diabetes
8—Heart Disease, Hypertension, Stroke
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—Injuries, including broken bones
14—Old age/infirmity/frailty
15—Other
77—Don't know/Not sure
99—Refused
VARIABLE NAME: CRGVPRB2

Care Recipient Major Health Problem

Software	Analytic Code
STATA	recode crgvprb2 (77/99=.), gen(cg_recipcond) recode crgvprb2 (1/4=0) (5=1) (6/15=0) (77/99=.), gen(cg_dementia)

SAS	if 1<= crgvprb2<=4 then cg_dementia=2; * Non-Dementia or other Cognitive Impairments;
	if crgvprb2=5 then cg_dementia=1; * Dementia or other Cognitive Impairment Disorders;
	if 6<= crgvprb2<=15 then cg_dementia=2; * Non-Dementia or other Cognitive Impairments;
	if 77<= crgvprb2<=99 then cg_dementia=.;

Types of Assistance

As with all surveillance systems, it is not possible to collect all the details of respondents' experiences. However, the Caregiver Module captures two commonly reported types of assistance: personal care activities (6) and household tasks (7). The code below recodes "don't know/not sure" and "refused" responses to missing.

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
VARIABLE NAME: CRGVPERS

Types of Assistance (Personal Care Activities)

Software	Analytic Code
STATA	recode crgvpers (1=1) (2=0) (7/9=.), gen(cg_personalcare)

SAS	if crgvpers =1 then crgvpers _rc=1;
	if crgvpers =2 then crgvpers _rc=2;
	if 7<= crgvpers <=9 then crgvpers _rc=.;

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?

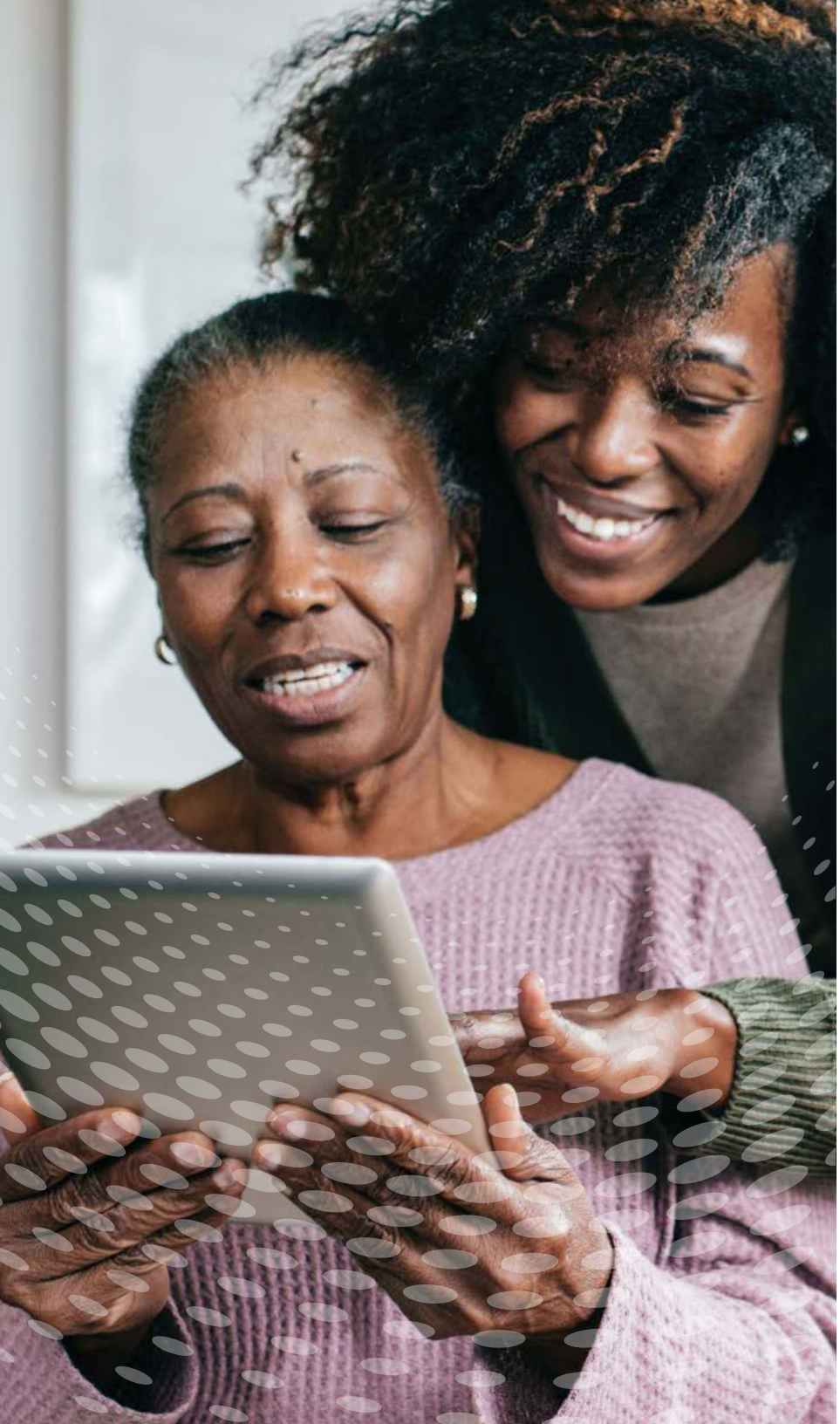
1—Yes
2—No

7—Don't know/Not sure
9—Refused
VARIABLE NAME: CRGVHOUS

Types of Assistance (Household Tasks)

Software	Analytic Code
STATA	recode crgvhous (1=1) (2=0) (7/9=.), gen(cg_householdtasks)

SAS	if crgvhous =1 then crgvhous _rc=1;
	if crgvhous =2 then crgvhous _rc=2;
	if 7<= crgvhous <=9 then crgvhous _rc=.;



Types of Assistance (continued)

Researchers might use these two questions together (6. crgvpers and 7. crgvhous) to create a categorical variable for type(s) of care provided: neither personal care nor household tasks, household tasks only, personal care only, or both personal care and household tasks.

**Note: responses for don't know/not sure and refused for either crgvpers or crgvhous are set to missing using this code.*

Types of Assistance (Combined)

Software	Analytic Code
STATA	gen cg_assistancecat=. replace cg_assistancecat=0 if crgvpers==2 & crgvhous==2 replace cg_assistancecat=1 if crgvpers==2 & crgvhous==1 replace cg_assistancecat=2 if crgvpers==1 & crgvhous==2 replace cg_assistancecat=3 if crgvpers==1 & crgvhous==1

SAS	if crgvpers=2 and crgvhous =2 then cg_assistancecat=4;
	* Provided other types of care;
	if crgvpers=2 and crgvhous =1 then cg_assistancecat=1;
	* Household tasks only;
	if crgvpers=1 and crgvhous =2 then cg_assistancecat=2;
	* Personal Care only;
	if crgvpers=1 and crgvhous =1 then cg_assistancecat=3;
	* Both Personal and Household Tasks;

Support Service Needs

Assessing caregivers' unmet needs for support services may be helpful in local or state-level planning activities. The next question asks about the service needed most and should not be used to identify services that are unneeded by caregivers. It does not indicate whether caregivers are currently receiving services. In some cases, it may be useful to distinguish caregivers with any unmet needs for support services from caregivers who do not have unmet needs.

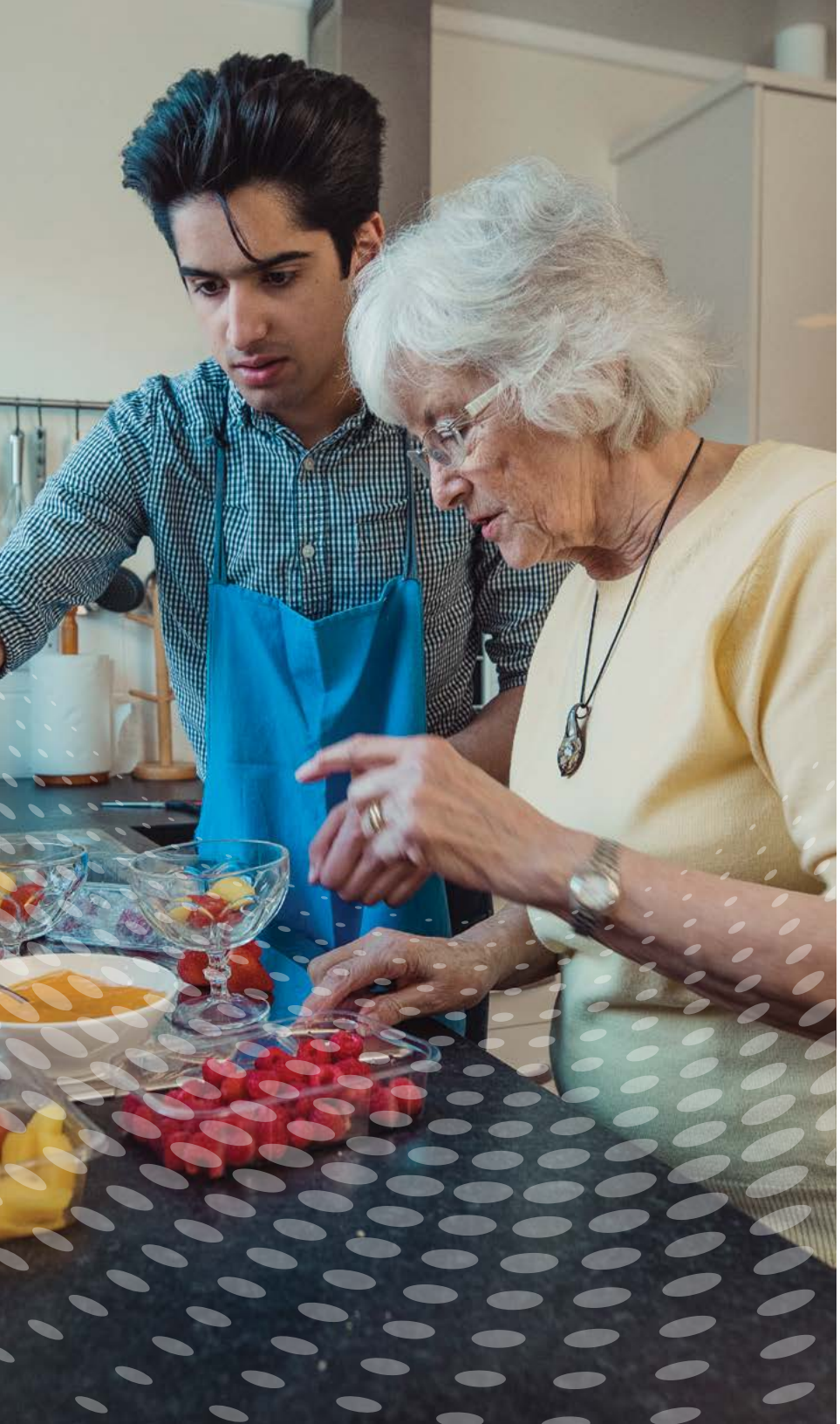
8. Of the following support services, which one do you MOST need, that you are not currently getting?

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
VARIABLE NAME: CRGVMST3

Support Service Needs

Software	Analytic Code
STATA	recode crgvmst3 (7/9=.), gen(cg_servicemostneed) recode crgvmst3 (1/5=1) (6=0) (7/9=.), gen(cg_anyserviceneed)

SAS	crgvmst3_rc=crgvmst3;
	if 7<=crgvmst3=9 then crgvmst3_rc=.;
	if 1 <= crgvmst3<=5 then cg_anyserviceneed=1;
	if crgvmst3=6 then cg_anyserviceneed=2;
	if 7<=crgvmst3=9 then cg_anyserviceneed=.;



Expected Future Caregiving

Respondents who are not current caregivers (who say "No" to Question 1) or who do not answer the caregiving screening question (Question 1), are asked a follow-up question about anticipated caregiving within the next two years. This question may be useful for communities, public health agencies, and other organizations involved in planning programs and services to estimate future demands of caregiving.

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
VARIABLE NAME: CRGVEXPT

Expected Future Caregiving

Software	Analytic Code
STATA	recode crgvexpt (1=1) (2=0) (7/9=.), gen(cg_future)
SAS	crgvexpt_rc=crgvexpt; if 7<=crgvexpt<=9 then crgvexpt_rc = .;

References

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10. Garand L, Dew MA, Eazor LR, DeKosky ST, Reynolds CF. Caregiving burden and psychiatric morbidity in spouses of persons with mild cognitive impairment. International Journal of Geriatric Psychiatry 2005;20:512-522.

Appendix A: Healthy People 2020 Objectives Related to Caregivers

DH-2.2 Increase the number of State and the District of Columbia health departments that conduct health surveillance of caregivers for people with disabilities

DH-2.3 Increase the number of State and the District of Columbia health departments that have at least one health promotion program aimed at improving the health and well-being of caregivers of people with disabilities

DH-2.7 (Developmental) Increase the number of Tribes that have at least one health promotion program aimed at improving the health and well-being of caregivers of people with disabilities

DIA-1 Increase the proportion of persons with diagnosed Alzheimer's disease and other dementias, or their caregiver, who are aware of the diagnosis

OA-9 (Developmental) Reduce the proportion of unpaid caregivers of older adults who report an unmet need for caregiver support services

Appendix B: BRFSS 2018 Caregiver Module

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?

INTERVIEWER INSTRUCTIONS: If caregiving recipient has died in the past 30 days, say "I'm so sorry to hear of your loss." and code 8.

1—Yes
2—No—[Go to Question 9]
7—Don't know/Not sure—[Go to Question 9]
8—Caregiving recipient died in past 30 days—[Go to next module]
9—Refused—[Go to Question 9]

2. What is his or her relationship to you? For example is he or she your (mother or daughter or father or son)?—

INTERVIEWER NOTE: If more than one person, say: "Please refer to the person to —whom you are giving the most care."

01—Mother
02—Father
03—Mother-in-law
04—Father-in-law
05—Child
06—Husband
07—Wife
08—Live in 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
16—Unmarried partner
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?

IF NECESSARY: Please tell me which one of these conditions would you say is the major problem?

[DO NOT READ: RECORD ONE RESPONSE]

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, Stroke
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—Injuries, including broken bones
14—Old age/infirmity/frailty
15—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?

[INTERVIEWER NOTE: IF RESPONDENT ASKS WHAT RESPITE CARE IS]: Respite care means short-term or long-term breaks for people who provide care.

[READ OPTIONS 1 – 6]

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

[DO NOT READ]

7—Don't Know /Not Sure
9—Refused

[If Q1 = 1 or 8, GO TO NEXT MODULE]

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

Selected Scientific Publications

Barnhart, W. R., Ellsworth, D. W., Robinson, A. C., Myers, J. V., Andridge, R. R., & Havercamp, S. M. (2020). Caregiving in the shadows: National analysis of health outcomes and intensity and duration of care among those who care for people with mental illness and for people with developmental disabilities. *Disability and Health Journal*, 13(1), 100837. doi: 10.1016/j.dhjo.2019.100837

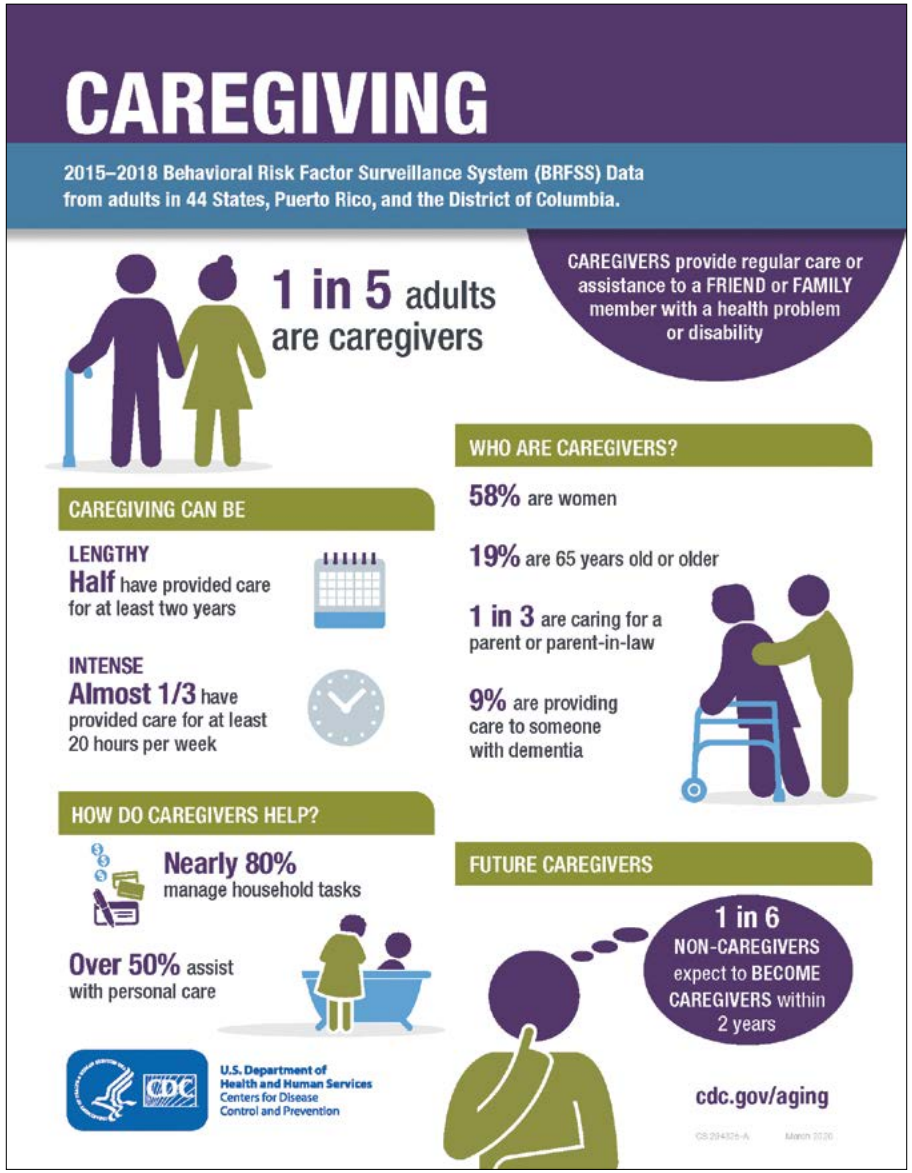
Boehmer, U., Clark, M. A., Lord, E. M., & Fredman, L. (2018). Caregiving Status and Health of Heterosexual, Sexual Minority, and Transgender Adults: Results From Select U.S. Regions in the Behavioral Risk Factor Surveillance System 2015 and 2016. *The Gerontologist*, 59(4), 760–769. doi: 10.1093/geront/gny109

Edwards, VJ, Bouldin ED, Taylor CA, Olivari BS, McGuire LC. Characteristics and Health Status of Informal Unpaid Caregivers—United States, 2015–2017 (2020). MMWR Morb Mortal Wkly Rep, 69(6).

Rabarison, K. M., Bouldin, E. D., Bish, C. L., Mcguire, L. C., Taylor, C. A., & Greenlund, K. J. (2018). The Economic Value of Informal Caregiving for Persons With Dementia: Results From 38 States, the District of Columbia, and Puerto Rico, 2015 and 2016 BRFSS. *American Journal of Public Health*, 108(10), 1370–1377. doi: 10.2105/ajph.2018.304573

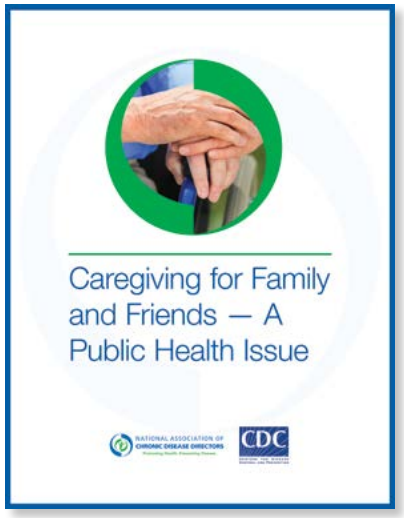
Tingey, J. L., Lum, J., Morean, W., Franklin, R., & Bentley, J. A. (2020). Healthcare coverage and utilization among caregivers in the United States: Findings from the 2015 Behavioral Risk Factor Surveillance System. Rehabilitation Psychology. doi: 10.1037/rep0000307

Data For Action: Selected Examples



Infographics

The 2015-2018 Caregiving infographic utilizes key BRFSS data from the Caregiving module. The infographics are available nationally, by state, and for several demographic groups, in both English and Spanish at https://www.cdc.gov/aging/data/index.html.



State of Aging and Health in America: Data Brief Series

The Caregiving Data Brief utilizes BRFSS data from the Caregiving module. The Caregiving brief includes the most recent and relevant Caregiving data available, including aging related conditions, the importance of brain health, and the management of chronic conditions to help identify needs and mitigate the future effects of a growing older population.

Full brief: https://www.cdc.gov/aging/publications/briefs.htm

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