

Measuring caregiving exposure

Caregiving exposure can be measured by (1) asking subjects whether they engage in caregiving-related activities such as helping a family member with activities of daily living (without using the word caregiving), and (2) asking if they self-identify as caregivers. In both versions of exposure items, follow-up questions should be asked to capture further information about the experience such as the disability of the care recipient and hours per week spent caregiving.

Approach #1. If you are sampling from a general population and want to identify anyone who is engaging in caregiving, we suggest the following two questions. If the answer yes to a and b, they would typically be considered a caregiver as they are assisting others with activities of daily living.

In the past month, have you had the primary responsibility for assisting 1 or more relatives or friends with any of the following tasks because they need help in response to a cognitive, emotional or physical condition?

Activities of daily living, such as bathing, dressing, eating, walking across a room?

0= No

1= Yes

2. Instrumental activities of daily living, such as preparing meals, medical or therapeutic treatments, handling finances?

0 = No

1 = Yes

Approach #2. A second way to identify caregivers is to define it for people and ask them to self-identify. This method is more direct, though it may miss people who do not identify as being caregivers despite helping others with activities of daily living. We suggest using this approach if you are interested in recruiting a select group of potentially high-stress caregivers.

1) Family caregiving means caregiving for a loved one with a condition (mental, cognitive, or physical). This means providing daily help beyond what is typically involved in caring for healthy children or healthy older adults. Are you the primary caregiver for someone who needs daily and significant assistance due to a disability, illness or a condition (even if it doesn't have a clear diagnosis)?

0=No

1= Yes

If yes, subject is coded as a caregiver.

Items to capture details of stress exposure.

Who is the family member or close friend you are caregiving for?

Options: Spouse/ partner, sibling, parent, son or daughter, son or daughter-in-law, grandparent, grandchild, another relative: please specify: friend/ companion, roommate. I am a paid caregiver. I am employed as a caregiver to take care of someone who needs my daily assistance.

2. What is the primary illness that requires this person to need your care?

Options: Cancer, diabetes, heart disease, other chronic illness, physical disability or injury, mental disability or impairment, dementia, brain-related injury (e.g. tumor, stroke, traumatic brain injury), mental or psychiatric illness, or other.

Note: For participants who check any of the following boxes: mental disability or impairment, dementia, brain-related injury, the 24-item Revised Memory and Behavior Checklist (Teri et al., 1992) can be used to assess the severity of patient symptoms. See the link here: <http://www.apa.org/pi/about/publications/caregivers/practice-settings/assessment/tools/memory-behavior.aspx>

3. For how long have you been caregiving?

Years ____ Months ____ (e.g. 1 year, 3 months. Note to programmer: 0 is an acceptable answer for a number of years)

4. Do you live with your care recipient?

Yes/ No

5. What is your employment status (outside of caregiving)?

Employed full-time

Employed part-time

Full-time student

Part-time student

Unemployed

Retired

6. Did you have to leave your paid job, cut down on your hours, or drop out of school due to your caregiving responsibilities?

Yes/No

7. In addition to your role as caregiver, how many hours per week do you work at a paid job or attend school? If you do not have a job or go to school, please write 0.

___text box where they can write numbers

8. How many hours per week do you spend caring for your care recipient? We know this may be difficult to estimate, just give your best guess.

___text box where they can write numbers

9. Has caregiving for your_____affected your ability to care for yourself? For example, have you missed appointments with health care providers, have you stopped flossing, exercising, eating hot meals, and/or doing something you enjoyed that you used to do before you became a caregiver?

Yes/No

Caregiving can also be physically demanding, as the caregiver role can include helping the care recipient with daily dressing, bathing, walking, etc. To capture the physical burden of caregiving, the Caregiver Burden Inventory physical burden subscale can be used (Novak & Guest, 1989).

Vulnerability factors

How distressed a caregiver is by the demands of the caregiving role is influenced by many factors, including contextual, demographic, biological, psychological, and social components. The lack of group differences in health outcomes between caregivers and controls in some studies may be because not all caregivers are vulnerable to the potential negative effects of caregiving.

Vulnerabilities are characteristics that interact with stress exposures and place someone at greater risk of being overwhelmed or distressed by the demands of caregiving, and thus at risk of poorer outcomes. Researchers have identified demographic, biological, personality, and contextual factors

that place caregivers at greater risk of health decline. These factors can not be fully described in this brief summary, though those examining the impact of caregiving on health need to think carefully about measuring moderators and including them in analytic plans. Some of these vulnerability factors are co-morbidities of the caregiver such as metabolic syndrome, care recipient disease type and severity, and gender (Dyck, Short, & Vitaliano, 1999; Fredman, Cauley, et al., 2010; Fredman, Doros, Cauley, Hillier, & Hochberg, 2010).