

Collaborating Center for Questionnaire Design and Evaluation Research

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Cognitive Interview Evaluation of Questions on Caregiving

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INTRODUCTION

This report summarizes findings from an evaluation of survey questions on caregiving intended for inclusion in the National Center for Health Statistics' (NCHS) 2025 National Health and Nutrition Examination Survey (NHANES),¹ and for revisions to be made to the Centers for Disease Control and Prevention's (CDC) 2024 Behavioral Risk Factor Surveillance System (BRFSS)² optional caregiving module (often adopted by states and territories).

The study was conducted by staff in NCHS' Collaborating Center for Questionnaire Design and Evaluation Research (CCQDER) in collaboration with the CDC's National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP).

During the summer of 2023, 29 English-speaking adult respondents took part in one-on-one cognitive interviews, conducted remotely using video conferencing software, over two rounds. This report includes a high-level description of overarching findings, as well as a summary of the findings related to the performance of each question evaluated.

BACKGROUND

Caregiving is an important and cross-cutting public health issue given its population-level burden, known health impacts, and related disparities. In 2015, an estimated 17.7 million people in the U.S. were informal caregivers for family members and friends and the need for informal caregivers will likely increase as the population continues to age.³ In addition, informal caregiving tends to be more common among certain minority populations.⁴ While

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¹ NHANES is a major program of the National Center for Health Statistics (NCHS). [NHANES - National Health and Nutrition Examination Survey Homepage \(cdc.gov\)](#)

² [CDC - BRFSS](#)

³ Committee on Family Caregiving for Older Adults; Board on Health Care Services. Health and Medicine Division; National Academies of Sciences, Engineering, and Medicine. Families caring for an aging America. Schulz R, Eden J, eds. Washington, DC: National Academies Press (US); 2016. <https://www.ncbi.nlm.nih.gov/books/NBK396401/>

⁴ Alliance for Caregiving; AARP Public Policy Institute. Caregiving in the US: 2015 report. Washington, DC: National Alliance for Caregiving; AARP Public Policy Institute; 2015. https://www.caregiving.org/wp-content/uploads/2020/05/2015_CaregivingintheUS_Final-Report-June-4_WEB.pdf



caregiving can have many benefits, such as closer relationships and providing a sense of purpose, it can also place an emotional and physical strain on caregivers, leading to higher rates of depression, lower quality of life, stress, possibly chronic conditions, and poorer overall health.^{5,6} Several national public health efforts and policy initiatives have identified caregiving as a public health priority in the U.S.^{7,8} Further insights into the associated health impacts of caregiving on psychological, social, or physical measures could assist in developing effective public health and clinical interventions to support caregivers and reduce the negative impacts of caregiving.⁹ National surveys of the population may be the only mechanism for gathering data on the extent and nature of caregiving provided in an informal voluntary setting. Therefore, during the summer of 2023 a set of questions intended for use on such surveys were evaluated by CCQDER using cognitive interviews.

METHODS

Cognitive interviewing

This survey question evaluation utilized a one-on-one cognitive interviewing methodology. During the interviews, the survey questions under investigation were administered and cognitive interviewing techniques applied in order to make an assessment of the mental processes that respondents went through when answering the survey questions, within the context of their individual life circumstances (Miller, 2011).¹⁰ Using this method, researchers are able to explore construct validity and identify any difficulties respondents encounter in understanding and answering survey questions (Miller, 2016).¹¹ Ultimately, the findings from the cognitive interviews help in determining whether questions may be prone to measurement error when administered in a survey.

Study sample and respondent recruitment

For this study, a small-scale, purposive sample of respondents was selected for interview. With a purposive, non-random sample, the characteristics of the individual are used as the basis for sample selection. A purposive sample does not aim to produce a statistically representative sample or draw statistical inference. With a purposive non-random sample, the characteristics of the individual are used as the basis for sample selection, most often chosen to reflect the population under investigation.

CCQDER's Operations staff recruited and screened respondents. Respondents were recruited from advertisements emailed to members of CCQDER's respondent database, placed on websites such as Reddit and Craigslist, or posted on targeted listservs or on social media. Respondents were also recruited by word-of-mouth. CCQDER Operations staff reached out to people who expressed an interest in taking part, administered a set of screening questions, and scheduled appointments with those who fulfilled the screening criteria.

Screening criteria included age, gender, race/ethnicity, employment status, and the respondent's relationship to the person to whom they provided care (care recipient). Most of the respondents were female and were primarily 30-

⁵ Schulz R, Sherwood PR. Physical and mental health effects of family caregiving. *Am J Nurs* 2008;108(Suppl):23–7, quiz 27. <https://doi.org/10.1097/01.NAJ.0000336406.45248.4c>

⁶ Alliance for Caregiving; AARP Public Policy Institute. Caregiving in the US: 2015 report. Washington, DC: National Alliance for Caregiving; AARP Public Policy Institute; 2015. https://www.caregiving.org/wp-content/uploads/2020/05/2015_CaregivingintheUS_Final-Report-June-4_WEB.pdf

⁷ [Caregiving as a Public Health Issue \(cdc.gov\)](https://www.cdc.gov/healthyaging/healthy-brain/healthy-brain-initiative/). Accessed 8/21/2023.

⁸ [Caregiver Module | BRFSS FAQs | Healthy Brain Initiative | Surveillance | Alzheimer's Disease and Healthy Aging | CDC](https://www.cdc.gov/healthyaging/healthy-brain/healthy-brain-initiative/). Accessed 8/21/2023.

⁹ Miyawaki CE, Bouldin ED, Taylor CA, McGuire LC. Baby boomers as caregivers: results from the Behavioral Risk Factor Surveillance System in 44 states, the District of Columbia, and Puerto Rico, 2015–2017. *Prev Chronic Dis* 2020;17:E80. <https://doi.org/10.5888/pcd17.200010>

¹⁰ Miller, K. (2011). Cognitive interviewing. In J. Madans, K. Miller, A. Maitland & G. Willis (Eds.), *Question evaluation methods*. (1st ed.) Hoboken, NJ: Wiley.

¹¹ Miller, K. (2014). Introduction. In K. Miller, S. Willson, V. Chepp & J.L. Padilla (Eds.), *Cognitive interviewing methodology*. Hoboken, NJ: Wiley.

49 years of age, which is reflective of the caregiving population¹². However, the sample also included respondents in other age groups and male respondents. More people said they were working than were not working. Although most respondents provided care to a family member, a few provided care to a friend. Just under half provided care to a parent, stepparent, or parent-in-law, while others provided care to a grandparent, sibling, spouse, child, or other relative. One respondent said that he was paid by the state to provide care, but that he also considered the care recipient to be a friend. Most respondents provided care to adults. Three respondents cared for their minor child.¹³

Table 1 shows the overall achieved sample distribution by key demographic and relationship characteristics of respondents

Table 1: Respondent Demographics

Demographics	Number of respondents (N=29)
Age group in years	
18-29	2
30-49	19
50-64	5
65 or over	3
Gender	
Female	20
Male	9
Highest education level	
High School Diploma/GED or less	10
2- or 4-year college degree	13
Graduate degree	6
Race/Ethnicity	
Non-Hispanic	27
Black or African American	10
Native Hawaiian or Other Pacific Islander	1
White	14
Multiple Race Groups	2
Hispanic	2
Employed	
Yes*	20
No	9
Relationship to the care recipient	
Parent, stepparent, or parent-in-law	15
Grandparent, step grandparent or grandparent-in-law	3
Spouse or partner	2
Child or stepchild	3
Sibling, stepsibling, or sibling-in-law	2
Other relative	2
Friend or non-relative	2

*Includes part-time and full-time employment

¹² Alliance for Caregiving; AARP Public Policy Institute. Caregiving in the US: 2015 report. Washington, DC: National Alliance for Caregiving; AARP Public Policy Institute; 2015. https://www.caregiving.org/wp-content/uploads/2020/05/2015_CaregivingintheUS_Final-Report-June-4_WEB.pdf

¹³ Care recipients who were minor children living with a disability.

In addition to the demographic and relationship characteristics described in Table 1, screening criteria also included the type of caregiving provided. It was important for the testing of the questions on caregiving that the sample included a varied mix of respondents providing different kinds of help or assistance to a family member or friend, under different circumstances. Those additional characteristics of the sample are described next.

Some respondents were sole caregivers, while some shared the responsibility (for example with siblings) or were secondary caregivers (providing *'respite'* or *'back-up'* care, as respondents described it). Respondents who said that they provided care for more than one person also cared for a sister, a boyfriend's father, a friend's sister, parents, in-laws, children with disabilities, and neighbors. Some respondents lived with the person they cared for; others did not. Some provided constant care all day every day; others provided care for a few hours per week.

Some care recipients were relatively independent while others required the constant presence of a caregiver. One care recipient lived in a group facility, although the caregiver had legal guardianship and provided oversight, so there was also administrative work for the caregiver to perform. Most care recipients were aged 65 or over (range from 65 to 93). The youngest care recipients were teenagers. The care recipients presented with a range of different health problems or disabilities, some with multiple health problems or disabilities.

Respondents who took part in the study were located in different states across the United States, including the following: California, Florida, Illinois, Indiana, Louisiana, Maine, Maryland, Massachusetts, New Jersey, New York, South Carolina, Texas, Virginia, Washington, and the District of Columbia.

Data collection

This study received OMB and CDC Human Subjects review and approval. Each respondent took part in a cognitive interview lasting no more than one hour and received a \$50 e-gift card for participating. All interviews were conducted on a voluntary basis during the summer of 2023. The questions were tested iteratively over two rounds following a test-modification-retest approach (OMB, 2016).¹⁴ Each round of testing comprised a separate sample of respondents. In total 29 cognitive interviews were conducted, 14 Round 1 interviews and 15 Round 2 interviews. During a one-month pause in data collection following Round 1, a few amendments were made to the wording of questions 4,5,6,13,18,19 and 21. Where there are significant changes to the wording of either the question text or the response categories, the answer frequencies for each round are shown separately. Otherwise, the frequencies are shown combined for both rounds. Additionally, the order of Questions 1 and 2 was switched between rounds. Discussion of these changes is included in the question-by-question summaries below.

The interviews were conducted remotely via Zoom for government, to comply with the CDC's requirements to use an authorized and secure video conferencing platform through which to conduct the interviews. Consent forms were emailed in advance and verbal consent was sought prior to taking part in the interview. The approach to cognitive interviewing used by CCQDER staff is interpretivist. It focuses on how respondents' own life experiences inform their answers to survey questions. As such, staff rely on non-scripted, verbal probing to illuminate the respondent's circumstances and inform how and why they answered the question the way they did (Cibelli Hibben & de Jong, 2020).¹⁵ A mix of retrospective, after first administering the survey questions, and concurrent probing was used - whichever was most appropriate for the person being interviewed.

Regarding the question administration, the questions were first read out loud to the respondent by the interviewer. 'Don't know' and 'refusal' codes were available for interviewers to use if respondents answered spontaneously in this way. Consistent with the way the questions are asked by quantitative survey interviewers in the field, these response choices were not read to the cognitive interview respondent as part of the question administration.

¹⁴ [Statistical Policy Directive No. 2 Addendum: Standards and Guidelines for Cognitive Interviews \(whitehouse.gov\)](https://www.whitehouse.gov/policy-directory/statistical-policy-directive-no-2-addendum-standards-and-guidelines-for-cognitive-interviews/)

¹⁵ Cibelli Hibben, K.L. & de Jong, J. (2020). Cognitive Interviewing. *Guidelines for Best Practice in Cross-Cultural Surveys*. Ann Arbor, MI: Survey Research Center, Institute for Social Research, University of Michigan. Retrieved from <https://ccsg.isr.umich.edu/chapters/pretesting/cognitive-interviewing/>

Although reminded at the start of the interview that respondents did not have to answer any question they did not want to answer, no respondent refused any question that was asked.

Data analysis and reporting

Analysis of cognitive interviewing data follows a systematic process of synthesis and reduction from interview to report (Miller et al., 2014).¹⁶ With consent, all interviews were video and audio¹⁷ recorded. Interviewers created summary notes about the way in which respondents interpreted and responded to the survey questions from the recordings, evidenced by verbatim statements made by respondents during the interview and observation of non-verbal behaviors. Where this report refers to verbatim statements, the respondent's accounts are italicized. The summary notes were organized by question and entered into CCQDER's Q-Notes software.¹⁸ Respondent confidentiality was maintained throughout the analytical process.

As mentioned, an interpretivist approach to cognitive interviewing assumes that respondents understand and process survey questions based on their own personal experience. Findings reported incorporate information elicited through probing the respondent narrative, which helps the analyst to identify the basis on which the survey question is answered, and the construct captured (Chepp & Gray, 2014).¹⁹ Furthermore, recognizing that respondents with different backgrounds and life experiences may interpret the questions differently, this study's approach to analysis is consistent with the socio-cultural approach to question evaluation as described by Miller and Willis (2016),²⁰ which is specifically focused on addressing comparability across sub-groups throughout the analysis process. Where appropriate, sub-group comparability is reported.

FINDINGS

Overarching findings

This section provides findings on overarching phenomena that affected question interpretation and response across questions in the question set. These highlighted phenomena relate to aspects of a caregiver's context, including the type of care they provided and the strategies they employed to balance caregiving with their other daily needs. The fact that caregiver experiences varied so widely highlighted the challenges of writing questions for the community of caregivers at large.

Type of caregiving provided: The amount and type of care provided varied depending on the age of the respondent, the respondent's relationship with the care recipient, the type of health problem or disability of the care recipient, and whether co-caregivers assisted the respondent. The amount of care or assistance provided by respondents ranged from those who provided occasional 'back-up' or respite care, a few hours per week, to those who took care of their friend or relative every day, seven days per week. Respondents who provided care infrequently sometimes had difficulty remembering whether less salient care events, such as taking a relative to a doctor's appointment one-time, had taken place within the 30-day reference period.

The types of care or assistance provided included help with everyday tasks such as, grocery shopping, preparing meals, cleaning the home, home maintenance tasks and yard work, running errands (to include picking up prescriptions, medication management, nursing care e.g., tube feedings), help with personal care such as bathing, help with managing finances, dealing with health insurance companies and legal matters, as well as assisting with the use of technology to help manage everyday tasks such as paying bills. Many caregivers were also involved in medical appointments and discussions with doctors and, in a few cases, were responsible for making medical

¹⁶ Miller, K., Willson, S., Chepp, V. & Ryan, J.M. (2014). Analysis. In K. Miller, S. Willson, V. Chepp & J.L. Padilla (Eds.), *Cognitive interviewing methodology*. Hoboken, NJ: Wiley.

¹⁷ One interview was audio recorded but not video recorded because the respondent's camera was not working at the time of the interview.

¹⁸ More information about Q-Notes is available at: <https://www.cdc.gov/nchs/ccqder/products/qnotes.htm>

¹⁹ Chepp, V. & Gray, C. (2014). Foundations and New Directions. In K. Miller, S. Willson, V. Chepp & J.L. Padilla (Eds.), *Cognitive interviewing methodology*. Hoboken, NJ: Wiley.

²⁰ Miller, K., & Willis, G. (2016). Cognitive models of answering processes. In C. Wolf D. Joye, & T. W. Smith *The SAGE Handbook of survey Methodology* (pp. 210-217). SAGE Publications Ltd, <https://dx.doi.org/10.4135/9781473957893.n15>

treatment decisions on behalf of the care recipient. Caregivers also provided emotional support and companionship to the care recipient, which was seen of equal importance.

Caregivers simultaneously working from home: Some caregivers were self-employed or worked from home remotely on a permanent basis, which meant that they were able to be flexible in work and more reactive to care recipients' needs. However, some tried to do both at the same time: *"I'm able to work from home more so that helps. So sometimes I can sneak out and do a quick food shop for my house and make sure we have what we need. And then I can get back before somebody calls or I have a zoom meeting."* This type of multitasking appeared to have caused additional stress for the respondents who were not able to work as many hours as they wanted or who felt 'on-call' and less able to take care of themselves.

Living arrangements: As detailed above in the section discussing the study sample, some respondents lived with the care recipient, while others did not. However, more nuanced living and caregiving arrangements became apparent through discussion. In one case, the care recipient, the respondent's father, lived eight months of the year with the respondent and four months of the year with a friend in another state. This respondent said that caring for her father was 'taxing' because, *"it's staying up all night with him, because every 15 minutes he would get out of bed."* The rotation of care helped her because, *"it gives you a break."* Additionally, one respondent cared for her brother who lived in a group facility. Despite the fact that he received 24-hour care at the facility, this respondent felt 'on-call' all of the time: *"I always have to have my phone with me, I always have to be there - as a caregiver you always have to be there for him."*

Assistive devices and monitors: Some respondents used assistive devices, namely video/audio cameras, to augment their care, by helping monitor the wellbeing of the care recipient when they could not be in attendance. Representing a different use of assistive devices, one respondent mentioned the use of an Artificial Intelligence (AI) program by the care recipient, which meant that he no longer needed to help her write letters, as he had done in the past.

Defining 'regular' care: Respondents considered 'regular' to mean something that occurred with predictable frequency. What that entailed varied from person to person. Some considered 'regular' to mean a set number of days per week, whereas others only focused on whether something was expected to occur, however infrequently. For example, one respondent explained,

"Well, regular care can be every day, but it can also mean every week or every month. It depends on what you're talking about. Like the psychiatrist appointments are once a month. I would consider that regular care because you are regularly doing that every month ... giving medicine, making sure they shower, cook for them, clean for them. All of that is regular care too."

QUESTION BY QUESTION REVIEW

This section describes the findings for each question evaluated. The question wording shown is that used for Round 2 interviewing²¹, except for Question 21 where the wording and findings for both versions are provided. Any changes made to the questions prior to Round 2 are described along with any impact on the question performance. A frequency distribution table is also shown indicating how respondents answered each question. These tables may give some indication of scale in relation to the qualitative sample of cognitive interview respondents; however, the distribution of the question-level responses may be different when compared to a random sample of the target population. Where a question was read, but a definitive answer not provided by the respondent, these cases are shown in the frequency table as 'No response provided.' Where a question not administered by the interviewer because of time constraints during the interview, these cases are also shown in the frequency table as 'Not asked.' Throughout, interviewers verified, to the extent possible, that reported activities had taken place within the specified reference period.

²¹ See Appendix 1 for Round 2 questionnaire

It should be noted that during Round 1 interviewing Question 2 was asked before Question 1. This was because respondents’ own definition of ‘caregiver’ was of particular interest. There was concern that the more detailed definition of caregiving, along with the reference period, provided in Question 1, might influence the answers provided to Question 2 about whether respondents considered themselves to be a caregiver. During Round 2 the questions were asked in the order presented below so that the questions could be tested as they were proposed to be administered in a quantitative survey.

Question 1

Q1. 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
- 3) Caregiving recipient died in past 30 days
- 4) Don’t know
- 5) Refused

Frequency distribution (N=29)

Response option	Count
Yes	27
No	2
Don’t know	0
Refused	0

Changes to question order between rounds

In Round 1 cognitive interviewing, Question 1 was asked after Question 2 such that the more detailed definition and reference period provided in Question 1, did not influence respondents’ own definition of the term ‘caregiver’ when answering Question 2.

Findings

Since caregiving had been the basis for screening in respondents to the study, unsurprisingly, most respondents answered ‘Yes’ to this question. Of interest however, during Round 1 when this question was asked after Question 2, two respondents answered ‘No,’ even though they had both said that they considered themselves a caregiver to a friend or family member. One respondent appeared to mishear the question thinking it was asking her about any previous or ‘past’ experiences of caregiving and answered, *“No, this is the first time that I have had anyone close to me that I have had to take care of.”* The other respondent answered ‘No’ because her usually live-in care recipient was staying with a family friend for a few months in another state, and therefore she had not provided in-person care within the past 30 days. This was despite the fact that she continued to provide care and assistance in the way of almost daily phone calls to the care recipient, as well as organizing his out of state medical treatment. During probing she said,

“I didn’t even think about how much I actually speak to him about his meds and that kind of thing. Because actual caregiving is so taxing. The physicality of it is more what I was thinking of in terms of this interview.”

Definitions

The terms ‘health problem’ and ‘disability,’ used in the question stem, helped respondents to focus on the caregiving they provided for people with a medical diagnosis. Both terms are required as some respondents mentioned that they were distinctly different.

Respondents' definition of a friend varied somewhat. One respondent was caring for a long-term friend who had had a bad accident, while another had become friends with the care recipient after initially carrying out some paid work for her. When asked Question 1, a few respondents included neighbors for whom they provided care.²²

Respondents considered 'regular' to mean something that occurred with predictable frequency. They described providing care on a daily, weekly or monthly basis. For example, a respondent said, "*Whenever she needs me I'm there,*" but described providing assistance, on average, about three times per week. However, depending on the need and the type of care, this could vary:

"Well, regular care can be every day, but it can also mean every week or every month. It depends on what you're talking about. Like the psychiatrist appointments are once a month. I would consider that regular care because you are regularly doing that every month."

One respondent only counted his time providing regular care from the time he had moved in with his parent and the intensity of the care he provided had changed. He considered himself "*on-call*" day and night. When asked by the interviewer if he thought that he had provided regular care prior to moving in with his parent he said, "*It was regular in that it was [calls] multiple times a day, but it wasn't for hours at a time though. It was periodic throughout the day.*" Nevertheless, the amount of caregiving could vary each week depending on need, the availability of other co-caregivers or, in the case of a paid respondent, if the care recipient was on a trip.

During probing respondents described providing help with: managing medications; ordering and picking up prescriptions; making doctor's appointments and taking the care recipient to those appointments if they were in-person, or helping them to receive a telehealth appointment; doing the grocery shopping; preparing meals; taking care of household chores and yard work; paying bills or supporting the care recipient with their use of technology when they needed to pay bills on line; dealing with health insurance or legal matters. In addition, respondents took the care recipient on outings, watched television with them, or listened to them in-person or on the phone, and generally provided emotional support and companionship.

"Basic home caregiving. Helping him take his medications, helping clean the house, driving him to the doctor's, scheduling things with the doctors, cooking, and all that."

"I mean I go to his house every day. I take him to the doctor. I make sure he takes his medicine. I go with him to doctor's appointments. I make sure he has food, I cook sometimes, I clean, I provide emotional support."

"...even if it's a cup of tea, or cup of coffee, hot meal, little things or clean the toilet....if the toilet's clean, it's going to make them feel good."

"Just assisting her with anything is caring for her."

Ultimately the care recipient was seen as being dependent on the caregiver for some or all aspects of their lives. For example, in some cases respondents described care recipients as previously living independently, and they commented on the degree of dependency or independence, in particular when comparing multiple care recipients: "*...but she is more independent, I don't have to assist her with hygiene.*"

Question 2

Q2. Do you consider yourself a caregiver for a friend or family member?

- 1) Yes
- 2) No [end of interview]
- 3) Caregiving recipient died in past 30 days [end of interview]
- 4) Don't know [end of interview]

²² In addition to the main care recipient – see commentary to Question 4.

5) Refused [end of interview]

Frequency distribution (N=29)

Response option	Count
Yes	29
No	0
Don't know	0
Refused	0

Changes to question order between rounds

In Round 1 cognitive interviewing, Question 2 was asked before Question 1 such that the more detailed definition and reference period provided in Question 1 did not influence respondents' own definition of the term 'caregiver' when answering Question 2.

Findings

All 29 respondents said that they considered themselves a 'caregiver' to at least one friend or family member. Some were the sole or primary caregiver, while others were co-caregivers, or referred to themselves as a "back-up" or "respite" caregiver. In some cases, the care recipients only required care in certain aspects of their lives, whereas others required help in all aspects. A few respondents found it difficult to disentangle their role as a child, spouse or parent, from their role as a caregiver. They provided a 'Yes' response because other people had referred to them in that way:

"I never thought of myself as her caregiver, but everybody else describes me as her caregiver."

"It's a word tell the truth, that has just started being used... I never thought that I was one... It's very unpersonal when you use that word 'caregiver' because people get paid to be just that, a caregiver, but not with love...I feel like I'm a good wife before I am anything else."

"Everything that he needs to do I basically do for him or help him, and that includes helping with school, medication, driving him to the doctor...bathing. Just everything. I mean I just coordinate it all. But I guess that's just being a good parent."

Although the amount of time spent caregiving varied (see commentary to Question 13), respondents' definition of 'caregiver' was similar. In addition to more practical or physical support with day-to-day living activities that the care recipient could not do for themselves, respondents also described the emotional support and companionship they provided to the care recipient, using those terms even before hearing the later question about that specific type of support (Question 12).

"Providing logistical, financial or physical help to someone to maintain their daily lifestyle."

"To help them to live their normal life and helping them to do things they are not able to do any more."

"Being a caregiver means taking care of someone who most likely couldn't take care of themselves alone. And I would say that is the condition my dad has developed. He couldn't take care of himself."

"It's definitely caregiving, but it's a lot more than what you might expect somebody to think of as far as like...cleaning up their bed...I think sometimes people think that's the only type of caregiving."

"It doesn't always mean physical care, but some aspect of their life requires assistance."

Some thought of their caregiving role as being 'on call' or 'on hand' whenever they were needed, for any task that was required:

“I’m around. It’s not like I’m waiting for a call, but I’m not surprised if I get a call.”

“I guess it’s not as much as someone else might think. Some other people think it’s a 24/7 thing, this person can’t do anything for themselves. I’m not quite at that point. But I feel I do things she really wouldn’t be able to do normally on her own. It’s not every single thing, but I’m there for the necessary parts that she can’t do.”

Even if respondents had not viewed themselves as a ‘caregiver’ when they first started providing help or assistance, there came a point in time when the regularity of the help or assistance provided changed their perception: *“Yeah I do at this point identify as a caregiver because I do help on a consistent basis and the kind of tasks that I help with.”*

Nevertheless, the term ‘caregiver’ was seen by some as a more formal term, applied to someone whose paid job it is to provide caregiving services. One respondent thought that the term more specifically suggested the type of care one might receive in a nursing facility or elder care home:

“The term caretaker to me always resembles later in life kind of thing...Like at some point my father will have a caretaker when he goes to a nursing facility or something. Caretaker’s always felt very much more about later in life.”

Respondents made a reasonably clear distinction between different types of caregiving provided. For example, they distinguished between ‘in-person’ and ‘remote’ caregiving. The latter being where respondents were unable to be with the care recipient but were still providing or facilitating support via the internet or through phone calls to service providers and to the care recipient themselves: *“Sometimes I am the caregiver and sometimes I am the facilitator of the caregiving and finding someone to help when I can’t.”* One respondent made a clear distinction between what he referred to as a “medical caregiver” for his mother who had a medical diagnosis for her health problem, versus a “helping hand” caregiver for a friend who had lost his driving license due to an undiagnosed health problem but also needed support with transportation.

In Round 2, there was some possible evidence from the way in which respondent’s described caregiving, that their definition of caregiving, to include regular help or assistance, had been influenced by the wording of Question 1, which included the phrase “did you provide care or assistance.” For example, one respondent said, *“My role as a caregiver is to provide assistance, unpaid of course, but ongoing as well.”*

Question 3

Q3. How many people with a health care problem or disability did you provide care for in the past 30 days?

- 1) 1
- 2) 2
- 3) 3
- 4) 4 or more
- 5) Don’t know
- 6) Refused

Frequency distribution (N=29)

Response option	Count
1	19
2	9
3	1
4 or more	0
Don’t know	0

Refused	0
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Findings

All 29 respondents provided care for at least one person, and in some cases up to three different people. In general, respondents reported all of the people with a health problem or disability for whom they had provided ‘regular’ care in the past 30 days, to include family members, friends and neighbors. However, while a few counted caring for an elderly parent due to ‘old age, infirmity or frailty;’ others did not. For example, one respondent, who considered himself a caregiver to his grandfather who had had a stroke, did not count his two grandmothers whom he also helped with errands, such as grocery shopping or collecting prescriptions. This was because the grandmothers did not have a specific health problem. Another respondent did not include her father because he did not have a specific health problem (nor a need for assistance in the past 30 days.)

Question 4

Q4. (Thinking about that person / For the next few questions, please only think about the person you care for the most). What is their relationship to you? For example, is this person your parent or your child.

- 1) Parent, stepparent, or parent-in-law
- 2) Grandparent, step grandparent or grandparent-in-law
- 3) Spouse or partner
- 4) Child or stepchild
- 5) Grandchild or step grandchild
- 6) Sibling, stepsibling, or sibling-in-law
- 7) Other relative
- 8) Friend or non-relative
- 9) Don’t know
- 10) Refused

Frequency distribution (N=29)

Response option	Count
Parent, stepparent, or parent-in-law	15
Grandparent, step grandparent or grandparent-in-law	3
Spouse or partner	2
Child or stepchild	3
Grandchild or step grandchild	0
Sibling, stepsibling, or sibling-in-law	2
Other relative	2
Friend or non-relative	2
Don’t know	0
Refused	0

Changes made between rounds

For Round 2 the wording of the question stem was changed to reflect the response provided to Question 3. If respondents answered more than one, in response to Question 3, they were asked to only think about the person they cared for the most. For simplification, and for gender neutrality, the examples given in the question stem

were changed from ‘...is this person your mother or daughter or father or son?’ to ‘...is this person your parent or your child?’

Findings

All 29 respondents were asked this question. Most provided care to a parent (one respondent cared for a stepparent; one for a parent-in-law) or other family member (grandparent (3), minor child (3), spouse (2), sibling (2), and great-aunt (1)). Finally, two respondents provided care to a friend or other non-relative.

Respondents were able to identify their relationship to the care recipient, often answering the question before the response options were read out by the interviewer. However, in one instance a respondent changed her answer after hearing the response options. This was in the case of a respondent providing care for her boyfriend’s mother. Because she had been in a relationship with her boyfriend for a long time she thought of, and referred to, his mother as her mother-in-law: “*So that would be my boyfriend’s mother, my mother in-law.*” After hearing the response options, she determined that she should select item 8 (non-relative).

For some, the examples provided in the question stem impacted the way in which they initially answered. For example, during Round 1 administration, a few respondents answered ‘mother’ or ‘father,’ rather than ‘parent,’ after hearing the examples used in Round 1. During Round 2, a respondent answered ‘No’ to the question after hearing the examples – the person she cared for was her great aunt and not her parent or child (the examples used in Round 2).

When respondents cared for more than one person, they had to decide who they cared for the most. Although other factors were considered, such as the respondent’s relationship to the care recipient, the level of responsibility they felt towards the care recipient, the severity of the care recipient’s health problem or disability, and how demanding the care recipient was, in all cases the final determination was based on the amount of time spent caring for the person. For example, when considering her mother or her neighbor for whom she also provided care, a respondent answered, “*My mom...I spend the most time with her and if two people needed me at the same time I would have to be with my mom.*” Another respondent selected her sister rather than her mother because she said, between the two, her sister was the most dependent on others. The respondent was her sister’s legal guardian, and she spent more time caring for her sister than for her mother.

Question 5

Q5. How old is that person?

- 1) Under 18 years of age
- 2) Aged 18-44 years
- 3) Aged 45-64 years
- 4) Aged 65-79 years
- 5) Aged 80 years or older
- 6) Don’t know
- 7) Refused

Frequency distribution (N=29)

Response option (Round 1)	Count (Round 1)	Response option (Round 2)	Count (Round 2)
Under 18 years of age	0	Under 18 years of age	3
Aged 18-44 years	1	Aged 18-44 years	0
Aged 45-64 years	1	Aged 45-64 years	3
Aged 65 years or older	12	Aged 65-79 years	4

		Aged 80 years or older	5
Don't know	0	Don't know	0
Refused	0	Refused	0

Changes made between rounds

Following Round 1 interviewing, an additional age-group was added to distinguish between care provided for those aged 65-79 and the oldest old aged 80 or more.

Findings

In general, respondents were confident that they knew the age of their care recipient and either gave the exact age without waiting to hear the response groups, or selected the correct response group – verified, as far as is possible, by the interviewer on probing. As a husband pointed out to the interviewer, *“If you forget your wife's birthday, you're dead.”* In one case a child was confident about the care recipient's age, but based on discussion about his role in WWII, the care recipient may have been older than described. A few respondents with slightly more distant relationships, such as a sibling, stepparent or parent-in-law, knew the birth date of the care recipient and calculated their age from that date. One sibling knew the age-gap between her and her brother and made the calculation from on her own current age.

Question 6

Q6. What is the main health problem or disability that the person you care for has?

- 1) Alzheimer's disease, dementia or other cognitive impairment [[skip to question 8](#)]
- 2) Heart disease, hypertension, or stroke
- 3) Cancer
- 4) Diabetes
- 5) Injuries including broken bones or traumatic brain injury
- 6) Mental illness such as depression, anxiety, or schizophrenia
- 7) Developmental disorders such as autism, Down syndrome, or spina bifida
- 8) Respiratory conditions such as asthma, emphysema, or chronic obstructive pulmonary disease (COPD)
- 9) Arthritis/rheumatism
- 10) Hearing or vision loss
- 11) Movement disorders such as Parkinson's, spinal cord injury, or multiple sclerosis
- 12) Old age, infirmity, or frailty
- 13) Other
- 14) Don't know
- 15) Refused

Frequency distribution (N=29)

Response option	Count
Alzheimer's disease, dementia or other cognitive impairment	8
Heart disease, hypertension, or stroke	2
Cancer	0
Diabetes	0
Injuries including broken bones or traumatic brain injury	3
Mental illness such as depression, anxiety, or schizophrenia	0
Developmental disorders such as autism, Down syndrome, or spina bifida	4
Respiratory conditions such as asthma, emphysema, or chronic obstructive pulmonary disease (COPD)	2

Arthritis/rheumatism	1
Hearing or vision loss	1
Movement disorders such as Parkinson’s, spinal cord injury, or multiple sclerosis	2
Old age, infirmity, or frailty	1
Other	3
Don’t know	1
Refused	0
No response provided	1

Changes made between rounds

Following Round 1 the abbreviation ‘COPD’ was added to response item 8. This was because it was thought that some people may be more familiar with the abbreviation than the full term. During Round 1 interviewing, a respondent answered “COPD” before hearing the response categories and explained, “To be honest I couldn’t think what the whole COPD stands for.”

Findings

All 29 respondents were routed to this question. For the purposes of the cognitive interview, respondents were asked to provide an answer before hearing the list of possible response options. Some answers were based on a medical diagnosis of the condition; others on the impact of the condition, either on the care recipient’s life or that of the caregiver. For example, one respondent selected response item 10, ‘Hearing or vision loss,’ based on the main effect of her husband’s stroke that had impacted her, rather than perhaps selecting item 2 which includes ‘stroke.’

Many care recipients had multiple health problems or disabilities. When answering this question respondents had to decide on the main health problem or disability of the care recipient. A few were related conditions: “Advance Parkinson’s disease I think is the main one and dementia’s a sub of that.”

Ultimately the decision as to which was the main health problem or disability was determined according to which had the greatest impact on the care recipient’s life or which had the greatest impact on the caregiver: “I mean another way to ask it is ‘what is the main health problem that led you to care for this individual.’” Often, this was the health problem that could not be controlled with medication and was getting worse. For example, one respondent selected a lung disease diagnosis over long term anxiety because it “...requires the most amount of attention, treatment, and management... The anxiety you could say was in check for now.” Another respondent explained, “That’s why I picked autism because it’s just all day it affects his life in all different ways.” Another chose Alzheimer’s over other health problems because it’s “...always there, the others come up from time to time. It’s intermittent but the Alzheimer’s is chronic.” Another chose dementia over stroke and movement issues because the stroke had not impacted the care recipient’s ability to work or to make “executive decisions.” This respondent also thought that the movement issues were likely associated with the dementia because they occurred after the dementia diagnosis. One other respondent selected ‘heart disease’ over other health problems because she said, you can’t live without a heart, and the diabetes and hypertension were under control with medication and diet.

A few respondents changed their mind as to the coding of the care recipient’s health problem or disability after hearing the response option list. For example, one respondent initially said ‘Alzheimer’s’ basing her answer on the medical diagnosis, but changed to ‘Other,’ “Severe vertigo” after hearing the list of response options. This was, she said, because it was the vertigo that had the greatest impact on her mother’s well-being, due to the large number of falls, and the fact that the medical profession could not seem to get the vertigo under control:

“I think the Vertigo that they can’t get under control is actually causing her to fall. Which has been the biggest source of problems in the last year and a half is her falling. So, I’m going to say that. Even though it doesn’t sound like it’s the most serious, it’s been the most serious for her.”

Once the list of response options was revealed, some respondents selected an answer that may be different from that which might be coded by a quantitative survey field interviewer. For example, before hearing the response categories a respondent determined that “mobility issues” due to arthritis, was the main health issue, over a multitude of other issues, including prostate cancer. This was because she said the cancer was controllable, but there was nothing that could be done about the arthritis. This respondent selected item 12 ‘Old age, infirmity, or frailty.’ However, another respondent, also reporting mobility issues or rather “immobility,” which she said “came with age” chose the ‘Other’ category over item 12 “...because she is very aware, she doesn’t have dementia or anything like that. It’s just immobility because the medications take care of the other things.”

The examples provided alongside some of the response options were important for some to be able to code the main health problem. A respondent selected item 7 ‘Developmental disorders’ because she said her sibling’s disability was closely related to Down syndrome. The examples also indicated to some that a category they were initially intending to select should not be used. For example, the terms ‘Alzheimer’s’ and ‘Dementia’ used in response item 1, suggested to one respondent, who initially thought about selecting that category because of the use of the term ‘cognitive impairment,’ that the cognitive impairment should be post-developmental and quite serious: “Not that much. There is a cognitive decline, but I would not put it in the category of Alzheimer’s or dementia yet.” Similarly, a respondent who initially selected item 11 because of the term ‘Movement disorders,’ changed her mind after hearing the examples of Parkinson’s, spinal cord injury, or multiple sclerosis: “No, not with those examples, No.” Instead, this respondent selected item 12: “Because he can’t barely move. He is worried he is going to fall. He has dizzy spells. He has no strength. So, I thought of frailty and movement in the same way.”

One respondent said that he had never heard of the term ‘spina bifida’ used as an example in item 7.

In a few cases the respondent was not aware of the care recipient’s medical information or did not understand the medical classification or the disability. They reported on the basis of what they had been told by the care recipient. For example, one respondent was not present when his stepmom was diagnosed and does not go her into the actual doctor’s appointments. He knows that she suffers from COPD because, “That is what she has told me.” A respondent who was paid to provide care knew the medical term for the care recipient’s disability but did not realize that her disability, cerebral palsy, could be classified as a developmental disorder. This respondent answered on the basis of the cause of the disability, as he had been told by the care recipient, and selected item 5 ‘traumatic brain injury,’ rather than item 7 ‘developmental disorders.’

One respondent selected item 1 as she suspected that her mother had dementia due to her forgetfulness. On probing she confirmed that her mother had not received an official medical diagnosis.

Three respondents selected the ‘Other’ category to code health problems associated with “severe vertigo,” “immobility,” and “chronic back pain.”

One respondent answered ‘Don’t know’ because she was unable to determine the main health problem or disability:

“Um, it’s more than one and I don’t know which one is the main because they are all, like two of them...Bipolar 1 and autism...It says ‘the main’ I mean, ...I consider both of those ‘the main’ because they are equally disabling...I’m doing the same for both of them, if that makes sense.”

The interviewer did not obtain a response from one respondent who talked about her father’s health problems as a consequence of his HIV/AIDS. HIV/AIDS was not listed specifically and in this case would likely have been coded in the ‘Other’ category.

Question 7

Q7. Does the person you care for also have Alzheimer’s disease, dementia or other cognitive impairment?

- 1) Yes
- 2) No
- 3) Don’t know
- 4) Refused

Frequency distribution (N=21)

Response option	Count
Yes	8
No	11
Don’t know	0
Refused	0
No response provided	0
Not asked by interviewer	2

Findings

When Alzheimer’s disease or dementia was reported as being the care recipient’s main health problem in answer to Question 6, respondents were routed past Question 7.

Question 7 was successful in that it picked-up those care recipients with dementia where the dementia was diagnosed but considered secondary to the main health problem reported in answer to Question 6. Sometimes the dementia was said to be a “*side effect*” of the main health problem. This was the case for two respondents reporting Parkinson’s disease in answer to Question 6, and a respondent reporting HIV/AIDS.

Where the care recipient was experiencing diagnosed mild cognitive impairment, the respondent selected ‘yes’ to this question. For example, one respondent said that the care recipient had been diagnosed with “*minor cognitive impairment*” which could be directly related to Post-Traumatic Stress Disorder. However, in answer to Question 7, respondents did not report undiagnosed less severe cognitive decline that they associated with old age: “*There is memory issue there that’s to be expected but it’s not to the point where it’s a hindrance or disabling at all.*” (One respondent reported undiagnosed dementia they associated with old age in answer to question 6 and therefore was not asked question 7.)

Question 7 did pick up where a developmental disorder had been reported as the main health problem or disability in answer to Question 6, but where the respondent said that the child also experienced cognitive impairment: “*They said, ‘moderate to severe’ and that’s in addition to the Bipolar and the Autism.*” However, as mentioned in the commentary to Question 6, another respondent did not include cognitive impairment associated with a developmental disorder because she said the terms ‘Alzheimer’s’ and ‘dementia’ implied that the impairment would be post-developmental.

One respondent answered ‘Yes’ to Question 7 because he said his mother’s epilepsy was classified as a cognitive impairment:

“Yes, to cognitive impairment...Sometimes they classify it as cognitive and sometimes they classify it as neurological...you can pick and choose what you attach it to...the Alzheimer’s and dementia is a brain thing and that’s pretty much what the epilepsy, is a brain thing.”

Question 8

Q8. In the past 30 days, did you provide care for this person by helping with nursing or medical tasks such as injections, wound care, or tube feedings?

- 1) Yes
- 2) No
- 3) Don't know
- 4) Refused

Frequency distribution (N=29)

Response option	Count
Yes	9
No	20
Don't know	0
Refused	0

Findings

All 29 respondents interviewed provided an answer to this question. Nine answered 'Yes.' Those who answered 'Yes' reported providing help with medication management and wound care, one respondent took blood pressure readings, one provided help with tube feeding, and one facilitated nursing or medical tasks by taking the care recipient to medical appointments.

When answering this question respondents applied different interpretations of 'nursing or medical tasks.' The term 'nursing' implied to some that a formal medical qualification was required, or that specialized training would be required: *"They [nursing or medical tasks] would be more invasive and almost like you have to have a medical background or some knowledge in how to do the procedure."* A respondent, who cared for her son with a disability, answered 'Yes' because if her son had a seizure that went on too long, then she would have to administer what she referred to as *"emergency medication."*

Some included medication management in their definition of medical tasks which involved making sure that the care recipient took the correct medications at the correct time each day. For one respondent who answered 'Yes' to this question, medication management was the only 'medical' help they said they provided, *"Nothing like that [referring to the examples provided in the question stem], but I do his medication, so medication only."* However, other caregivers did not include medication management. A respondent who focused on the examples provided answered 'No' explaining, *"Helping with medication, but you left it out."* Likewise, another respondent said, *"I administer meds but that's not like tube feeding or injections, so I would guess 'No' to that answer."*

Although respondents tended to focus on the examples provided in the question stem, they applied different definitions. To some, the examples used led them to think that the question was asking about more serious medical support provided. As one respondent commented, *"That person would really have a hard time if you need tube feeding. That's pretty high-end stuff."*

One respondent answered 'Yes' because they took the blood pressure of the care recipient, whereas another who answered 'No' said that the question implied, *"Something more than taking blood pressure."*

The definition of 'wound care' varied. One respondent included teaching her sister to apply cream to a rash, and answered 'Yes' to this question, another who answered 'No' said *"If he has a cut I put on Neosporin."* One respondent, who answered 'No,' explained that the family provide care to prevent the need for wound care, in this

case bed sores, by using medicated powders and making sure that they did not allow the care recipient to remain in one position for a long period of time.

A few respondents were uncertain about whether to include one-time medical aid, interpreting the question as asking about ‘regular’ nursing or medical care. For example, one respondent said that within the past 30 days he had provided wound care after his care recipient had fallen, but he answered ‘No’ to the question because he said, *“That was more like one-time medical aid. The things you mentioned seemed like it was more, um, almost like you think of say, almost like in a nursing home...changing the tubes...it’s not that.”*

One respondent answered ‘Yes’ on the basis that he was the facilitator: *“I would say ‘yes,’ I mean I didn’t do it but I would take her to where it gets done. Which is the reason why I would say ‘yes.’”*

When answering this question there was evidence that respondents had taken on board the reference period of ‘past 30 days.’ *“No none of that...well, not in the last 30 days.”* (Interviewers also verified that the activities reported had taken place within the specified reference period of the past 30 days.)

Question 9

Q9. In the past 30 days, did you provide care for this person by managing personal care such as bathing, getting to the bathroom, or helping to eat?

- 1) Yes
- 2) No
- 3) Don’t know
- 4) Refused

Frequency distribution (N=29)

Response option	Count
Yes	16
No	13
Don’t know	0
Refused	0

Findings

When considering whether they helped the care recipient with personal care tasks, respondents focused on the examples of personal care provided in the question stem, although a few also talked about helping the care recipient to get dressed.

Interpretations of the examples provided varied. Respondents answered ‘Yes’ when they physically helped the respondent to wash themselves in the bath tub or shower, *“...if there are certain areas that she has trouble reaching because she has limited mobility.”* Respondents also included washing the care recipient with a washcloth, or *“hospital provided cleaning cloths,”* when the care recipient was unable to use a bathtub or shower. However, inconsistency in reporting occurred where the care recipient only required help getting the bath or shower ready for use, rather than needing help with actually washing themselves. Sometimes respondents included this type of help with bathing; sometimes they did not. A respondent who answered ‘Yes’ explained that she had to supervise her son to make sure that he washed himself properly. Another respondent helped her husband by *“setting the shower.”* One respondent answered ‘Yes’ purely on the basis that she helped her father to get in and out of the tub (her father could wash himself). This respondent queried whether that counted as help with bathing. On the other hand, a respondent answered ‘No’ on a similar basis: *“He needs help with showering,*

he can shower himself, but I would get it ready.” Another respondent answered ‘No’ but explained that the care recipient “...forgets how to set up the water heater – every single day. So that’s one thing. I do it for him.”

In general, the phrase ‘getting to the bathroom’ was clear to respondents who were able to describe how they provided assistance. Additionally, one respondent explained that he had to make sure his daughter flushed after herself and washed her hands - so he had to “*check all the steps.*” Another described helping his father to find the restroom when they were out in public – although he never had to help him at home. In one case, a respondent who answered ‘Yes’ said that the care recipient used adult incontinence underwear and therefore no longer needed help with getting to the bathroom: “*She stopped using the bathroom this year, she is using disposables. So that is a big change.*” Sometimes this respondent helped with changing the incontinence underwear.

Respondents queried the definition of ‘helping to eat,’ explaining that they may prepare meal plans, buy food, prepare food, and cut the food up/mash the food, but the care recipient then was capable of feeding themselves. Respondents were not always sure whether to count these actions as ‘helping to eat.’ Some did and some did not. As a respondent, who eventually determined a ‘No’ response said,

“I do hesitate a little bit with that one. ‘Helping to eat’ ‘cause it sounds a little bit like spoon feeding the person...I don’t do that. But I have helped with meal prep. So, I’m kind of on the fence there, like, should I say ‘Yes’ to that or not? It’s not entirely clear to me what I should do there.”

A respondent, who answered ‘No,’ said, “*Probably not, the way the question is intended. I mean, I cook for her, but I wouldn’t consider that ‘helping to eat.’*” Another described taking food to her father’s home, preparing meals and cutting up his food into small pieces so that he didn’t choke. She also described having to remind him to chew if he is distracted. She also answered ‘No’. However, a respondent answered ‘Yes’ on a similar basis: “*Mmm, helping to eat, so I would say ‘Yes’... Buy the food, make the food and cut the food up and all ‘cause, eh, because of her condition.*” Another, who answered ‘Yes,’ described meal planning and grocery shopping. The one person who was a paid care giver for a friend answered ‘Yes’ to this question, purely on the basis that he did some grocery shopping on behalf of the care recipient. Just one respondent, who answered ‘Yes,’ described actually helping the care recipient to transfer the food from the plate to her mouth. Due to Parkinson’s disease, the aforementioned care recipient “*...does not do well with a fork so sometimes you have to do the hand over hand with her so she has the sensation of feeding herself, rather than someone else feeding her.*”

Respondents described how the need for personal care support could vary “*some good days, some bad days.*” In fact, in some cases, the need for help with personal care was infrequent, and respondents could not always remember if the help they had provided was within the 30- day reference period.

Of note: a respondent may only help with one type of personal care task, while other co-caregivers help with other personal care tasks. Depending on the relationship or gender of the respondent, they may not have helped with bathing for example. As one female respondent explained that her brothers helped with bathing her father because, “*He don’t let me help him that way.*”

Question 10

Q10. In the past 30 days, did you provide care for this person by managing household tasks such as help with transportation, shopping, or managing money?

- 1) Yes
- 2) No
- 3) Don’t know
- 4) Refused

Frequency distribution (N=29)

Response option	Count
Yes	26
No	3
Don't know	0
Refused	0

Findings

Most respondents answered ‘Yes’ to this question. They answered ‘Yes’ even if they shared tasks with other co-caregivers, or they were not the primary care giver. For example, one respondent who cared for a non-relative said that the primary care giver (a blood relative) managed the finances, but she would pick up groceries when needed. About caring for her mother, another respondent said,

“My dad is still here, but he works full time, so he’s not able to help out as much [with caregiving] but he takes care of a lot of the financial aspects of it. I mean I’ll buy things to help out, but I’m not the one managing money.”

Household tasks may also have been shared with the care recipient themselves:

“Well, she manages her own money. But, I do all the shopping...”

“Sometimes I’ll go for her or sometimes she stays in the car. She does go with me sometimes, but I do a lot of the lifting of the stuff, moving it to the car, and stuff like that.”

Respondents focused on the tasks presented as examples in the question stem. In general, the examples mentioned resonated with respondents who provided or organized transportation to appointments, helped with or did the grocery shopping, and helped with or did the money management (ranging from paying bills to trustee of finances). Those who did not live with the care recipient were more likely to mention help with cleaning the home (during probing at Questions 1 and 2), but they focused on the examples provided when responding to this question. Similarly, many respondents had previously mentioned cooking and preparing meals, but did not mention this spontaneously in response to this question (possibly because that discussion may have already taken place as part of the cognitive interviewing process when answering the previous question about helping to eat). A few respondents also mentioned doing laundry. A few said that they carried out a lot of administrative and organizational tasks.

With respect to help with transportation, respondents included driving the care recipient to medical appointments, to the grocery store or to hair appointments, as well as to take part in leisure activities, such as going for a walk or to lunch *“providing the companionship I mentioned earlier.”* Those caring for people with Alzheimer’s or dementia also said that they did not leave the care recipient alone: *“She comes with me. I try not to leave her alone. I basically drive. Not just the car, but pretty much everything we do.”*

With respect to shopping respondents mainly mentioned grocery shopping, although a few also included clothes shopping, as well as ordering items online.

A few queried what they should count as ‘managing money.’ For example, one respondent answered ‘Yes,’ but explained that his care recipient gives him the money to go grocery shopping, but because she is not *“tech-savvy”* they pay the household bills together online. He answered, *“Yes, but not the money. I mean I guess maybe the money. The money is always tricky.”* One respondent, who was paid for caregiving, included in his definition of managing money help with *“investment stocks and crypto”* that his care recipient had wanted to convert. Managing money also included checking accounts to make sure that social security payments had been received for example, as well as checking accounts to make sure the care recipient had not been taken advantage of financially:

“Yes, I’m still not sure how they got her credit card number. She was getting calls at night from some scammers that were trying to sell her computer protection software or something. And, the charges started appearing on her credit card. And, we would have to call the bank and get it reversed, then another charge would show up.”

Two of the three respondents caring for a minor child answered, ‘Yes’ to this question because, of course, they do all of the driving, shopping and money management: *“It’s just me, but I can’t give him much money otherwise he turns around and blows it. So I’m trying to teach him to save money and stuff like that but it doesn’t go too well.”* One said that the question did not apply to him because his daughter was a child, and answered ‘No.’

In total, only three respondents answered ‘No’ to this question.

- As mentioned, one respondent did not think that this question applied to him as his minor child did not have her own household to manage: *“Yeah the only thing I really help her with in that area is like putting some stuff away in her room.”*
- One respondent did not live with the care recipient and the tasks used as examples in the question stem were conducted by her co-caregivers who did live with the care recipient: *“No, that’s what my brothers do because they live there, they get the bills, and they do the shopping on the weekend.”*
- One respondent answered ‘No’ because her brother lived in a care home and all household tasks, including money management, were carried out by the home.

Question 11

Q11. In the past 30 days, did you provide care for this person by coordinating their care such as scheduling appointments, dealing with insurance, or filling out paperwork?

- 1) Yes
- 2) No
- 3) Don’t know
- 4) Refused

Frequency distribution (N=29)

Response option	Count
Yes	23
No	5
Don’t know	1
Refused	0

Findings

Most respondents answered ‘Yes’ to this question, although the degree to which they were involved in helping with scheduling, dealing with insurance, and helping with paperwork, varied. Respondents focused on the examples provided in the question stem:

“Yes, all of those things”

“Oh yes, definitely. All that.”

“I do all of it. Scheduling, talking with the insurance company to make sure she is getting all of the benefits that she’s entitled to. I schedule the doctor’s appointments. The go-betweens – she has several different doctors that are in different places.”

“The ones you listed, no. I mean, I take her to doctors’ appointments, and I’ll be part of that appointment and maybe ask a question she didn’t think of, but based on the examples you said, none of those though.”

Respondents who answered ‘Yes’ described, in particular, scheduling and managing medical appointments: *“She’d have the same appointment written in three different places – different dates.”* This included helping to set up telehealth appointments and downloading the required software. Respondents also described ordering medication refills, and dealing directly with health insurance companies and government health care agencies, i.e. Medicare and Medicaid:

“Dealing with insurance and filling out paperwork...Talk to people, clarify situations. Why bills weren’t being paid - why she was being billed while she had insurance, et cetera et cetera.”

“Yes, I deal with [the insurance company] quite often. And I’ve learned a lot about Medicare. So, I’m the point of contact for that.”

A few respondents mentioned helping the care recipient to understand the paperwork they received. A few mentioned sitting with the care recipient when doing paperwork so that the care recipient felt involved. A few respondents, who had power of attorney or were the care recipient’s legal guardian, even mentioned that dealing with paperwork was the task they did the most.

Respondents answered ‘Yes’ even if they were the secondary care giver and only sometimes helped with coordinating care, which they had done within the past 30 days. For example, a respondent who cared for a grandparent talked about taking him for an appointment at social services, but that it was the caregivers’ s mother who did most of the paperwork.

One respondent also answered ‘Yes’ to this question because she coordinated care for someone who lived in a group home where many of the other tasks asked about in previous questions were carried out by the home: *“Yes, I had to fill out paperwork. And, we had an IHP²³ meeting, I had to be at the IHP meeting. We had a conference phone call.”*

All three respondents who cared for their child answered ‘Yes’ to this question. They dealt with all required paperwork and managed their child’s schedule.

‘No’ responses were given when support for these tasks was provided occasionally but not within the past 30 days: *“Not lately no.”* Although respondents who provided occasional support in this way had to think carefully about whether it had occurred within the reference period. A ‘No’ response was also provided in cases where the care recipient was capable of coordinating their own care. For example, where care was provided in relation to the recipient’s mobility issues. A ‘No’ response was also provided when a co-caregiver provided this kind of support, not the respondent: *“I would say ‘No’ because my boyfriend does all of that.”*

There was one possible case of response error where a respondent answered ‘Yes’ but the issue she referred to, in relation health coverage, occurred more than 30 days ago. She answered about the time she had discovered that her father was no longer covered by his state health insurance. This fact had had a significant financial impact stood out in her memory: *“I did that, that’s when I knew they cut him off from one thing.”*

One ‘Don’t know’ response came from a respondent who was unsure whether helping her grandmother with technology would be included in the survey definition of ‘coordinating care,’ and she wondered if that might have been counted in the previous question as a household task:

²³ Individualized Health Plan (IHP)

“Um, I will say that I’ve been helping with printing stuff out. She’s been trying to do some stuff with the mortgage and stuff like that. So, I’ll help her with the technology...I don’t know if that goes into that [meaning this question]...I don’t know if that would go under the ‘normal tasks’ thing. I mean, you said paperwork, so that’s what made me think of it.”

Question 12

Q12. In the past 30 days, did you provide care for this person through mental health support, emotional support, or companionship?

- 1) Yes
- 2) No
- 3) Don’t know
- 4) Refused

Frequency distribution (N=29)

Response option	Count
Yes	28
No	1
Don’t know	0
Refused	0

Findings

All but one respondent answered ‘Yes’ to this question. Most considered emotional support and companionship to be a key role for a caregiver. For example, a respondent said, *“I think it’s actually the biggest way that we help.”* Another said, *“I don’t want no person feeling negative...who in their right mind would let a friend or family member think that they had no hope, and they can’t go on, and just not say nothing. I do it.”* Furthermore, one respondent said that he could not imagine that anyone would say ‘No.’ *“Asking that question is equivalent to someone cutting their leg open and asking if you would put a towel on it to stop the bleeding. If you said ‘no’ you’re crazy.”*

However, one respondent did select ‘No’ thinking that the care recipient, her father, did not need any emotional support that was *“anything out of the ordinary.”* Additionally, she considered ‘mental health’ support to refer to support from a professional, which her father did not need, and ‘companionship’ to refer specifically to romantic companionship.

Support provided

Respondents said that they provided one or a combination of the different types of support mentioned in the question stem (mental health support, emotional support, companionship). While some respondents felt that the three types of support *“kind of runs together,”* others noted subtle differences in meaning. For example, some respondents viewed emotional support as being different from companionship and involved talking to the care recipient about their feelings: *“So you can provide companionship without asking someone how they are feeling.”*

According to some respondents, ‘mental health support’ was something that a professionally trained person would provide. They felt that type of support was different from providing emotional support or companionship, which they associated with caregiving. As one respondent remarked, mental health support is something that *“should be left in the hands of professionals, emotional support is more associated with caregiving.”*

Some respondents noted the importance of keeping care recipients feeling engaged with their family, engaged with life, feeling positive, and keeping their minds active. As one respondent said, *“Sometimes she is feeling*

down [...] *Because, she is still aware and everything – and we didn't want her to get depressed.*” Likewise, another respondent said, *“It's important that he hears about that family and what we're doing. He wants to talk about my mother, and all of that keeps him motivated and going.”*

Of note: One respondent who answered ‘Yes’ to this question had selected ‘No’ to all prior questions about other types of care provided (such as personal care tasks, household tasks, et cetera), as the caregiving duties for the care recipient were shared among others.

Question 13

Q13. In the past 30 days, on average, how many hours did you provide regular care or assistance? Would you say...

- 1) Up to 19 hours per week
- 2) 20 to 39 hours per week
- 3) 40 hours or more per week
- 4) Don't know
- 5) Refused

Frequency distribution (N=29)

Response option	Count
Up to 19 hours per week	8
20 to 39 hours per week	9
40 or more hours per week	10
Don't know	0
Refused	0
No response provided	2
Not asked	0

Changes made between rounds

During Round 1, two caregivers gave no response due to their difficulty calculating hours ‘on average.’ One felt she could not separate her general household duties from her caregiving duties, all of which amounted to a fulltime job. She simply said, *“Wow.”* Another could not average the two segments of the year where she was either providing hands-on, constant caregiving or providing remote caregiving. To be consistent with the prior questions and to help respondents focus their responses, the introductory phrase for this question was changed from “In an average week...” to “In the past 30 days, on average...”

Findings

While some Round 2 respondents still noted they had difficulties selecting a response due to their fluctuating hours, all respondents in Round 2 provided answers specific to the prior 30 days. For example, one respondent said his duties used to be ‘40 hours or more per week’ but in the past 30 days were down to ‘29-39 hours per week,’ and he answered as such. He explained, *“When I moved in it was definitely more than 40 hours per week. And when he started taking all his meds, he started calming down.”*

Respondents tended to count only their hands-on time with the care recipient. The other kinds of caregiving work that those respondents did, including shopping, time spent driving to errands, making phone calls, or even looking after the care recipient overnight, were often undercounted or not counted at all. For example, one respondent who answered ‘Up to 19 hours per week’ said, *“Most days I work remotely parttime, so I'll take my laptop over and try to do things there. Usually she's calm, she can watch TV, sleeping for hours.”* Another respondent who answered ‘20 to 39 hours per week’ and who did not consider her hours spent overnight on-call explained, *“I*

usually get there around 11 [AM] or so, and then her sister will leave and then I'll stay for several days. Then her sister comes back." One notable exception to the tendency for respondents to only consider hands-on caregiving was a respondent who was the legal guardian for her brother with Down's Syndrome who lived in a developmental center. She counted her hours on the phone with his case manager, medical care team, and time visiting the center.

Live-in, full-time caretakers tended to fully account for their full-time work – 40 hours or more. One respondent estimated she provided about 70 hours of care per week. She said, "It sounds really high, but if you are living with the person and they're not really going out, and they're hanging out at the house, and I'm working at the house then I'm with him a lot."

Some respondents short-handed their estimate based on 'fulltime' versus 'parttime' job efforts. As one said, "I know what a part-time job feels like, and I know it's not quite 20 hours."

For those without a clear daily or weekly schedule, calculating hours took guesswork and averaging. For example, one respondent who answered 'Up to 19 hours per week' said, "Just like – the little things. Cleaning up, cooking, doing laundry, walking the dog. Those everyday things that add up, I guess."

Question 14

Q14. How long have you provided regular care to this person? Would you say...

- 1) Less than 30 days
- 2) 1 month to less than 2 years
- 3) 2 years to less than 5 years
- 4) 5 years or more
- 5) Don't know
- 6) Refused

Frequency distribution (N=29)

Response option	Count
Less than 30 days	2
1 month to less than 2 years	7
2 years to less than 5 years	10
5 years or more	9
Don't know	0
Refused	0
Not asked	1

Findings

Respondents generally viewed this question as asking about when they started providing 'regular care' to the care recipient, though what initiated and constituted that 'regular care' varied. Some respondents calculated the start of 'regular care' from a specific event, like when they moved in with the care recipient, when a diagnosis occurred, or when they took over duties from a prior caregiver, even if they had provided some care before that point. For example, one respondent thought about when she moved back in with her mother and said, "I guess it helps with that 'regular' word, because I've helped my mom for a while [...] It was when I moved back in and consistently helped her, and the tasks I'm helping her with."

Some used references outside of their caregiving tasks to help anchor the timeframe. For example, one respondent anchored her caregiving from when she started her job, and others thought about increases in care that

happened during the early stages of the Covid-19 pandemic. As one respondent whose duties began during the pandemic said, “*You can’t have old people going outside that’s what they were saying.*”

Parents of minors with disabilities tended to consider different types of salient reference periods than other caregivers. For example, one parent said the following: “*For some reason since birth she has clung to me.*” Another said, “*I would say it started at age 3 because he used to sleepwalk. So, I used to be up all night because he used to literally sleepwalk right out the door.*” Similarly, one person who was the guardian of her brother with Down Syndrome thought about when she began helping her brother as a young child. She said, “*Since I was a child [...] I grew up with it, that’s my norm. It’s my norm since I was age 2.*”

For those whose duties and caregiver roles have gradually evolved over time, the question was a bit more nuanced than for those who calculated their start from a clear-cut event. For example, one respondent said, “*More than five years, but five years ago it was not on a daily basis. It was with Covid, I’d say in 2020 is when she started to need daily health [...] She kind of stayed, weaker, loss of interest, general ability to leave [the house] started to decrease.*” Another respondent who was unsure how to calculate the start of her ‘regular’ care thought about the fact that she is still getting used to her new role that has gradually emerged. She explained, “*...like I’m in discovery mode with it.*”

Of note: In one case, this question captured a different aspect of the respondent’s experience providing ‘regular care’ than that of Question 1 (‘During the past 30 days, did you provide regular care or assistance to a friend or family member who has a health problem or disability?’). The respondent had answered ‘No’ to Question 1 because her father temporarily had been staying with a friend in another state over the past month. While she provided care remotely on a daily basis, talking to him on the phone and arranging his medical care, she initially considered her intensive, hands-on care that she does when he is with her in-person. For this question, she answered ‘2 years to less than 5 years’ because that is when he moved into her house.

Question 15

Q15. Does this person receive any additional unpaid or paid care besides routine medical care?

- 1) Yes
- 2) No
- 3) Don’t know
- 4) Refused

Frequency distribution (N=29)

Response option	Count
Yes	6
No	19
Don’t know	3
Refused	0
Not asked by interviewer	1

Findings

Consideration and response to this question depended on not only care services the care recipient used, but also the core caregiver arrangement for the care recipient. Those respondents who shared the caregiving duties among family members answered based on whether the care recipient received other care in addition to the core group of caregivers. They did not answer based on other, regular family member assistance when considering this question. For example, a respondent who shared caregiving among nine siblings answered ‘No’ and said, “*No. Just us the*

kids take care of him. We don't wanna get paid for it." When thinking about 'additional' care besides the core caregiver group, respondents did consider services such as day programs, paid aides, and volunteer visitors.

Those who were sole caregivers, sometimes contemplated other family members here as possibilities, but ultimately did not count occasional family help. As one respondent who answered 'No' said, *"I'm the one that consistently helps her, and I have some people that come in here and there, but is that 'unpaid care?'"*

Three people did not know how to answer the question. Two of the three people with a 'Don't know' response were respondents who shared their caregiving duties among family. They were not sure how to account for the other core caregivers. As one respondent said, *"Unpaid would be all the work we are doing as a family. And paid care, that's someone coming in, is that what that question is asking?"* The third person who gave a 'Don't know' response also shared caregiving duties with the care recipient's sister. She was uncertain how to answer because she expected the care recipient, her close friend, to recover completely from her recent injury. She said, *"I don't know how to answer that. Because it's not permanent. It'll probably be another three months if all goes well. It's a temporary thing."*

A few respondents considered out-of-scope interpretations. They thought the question was either asking whether the care recipient had other types of medical insurance, or if the care recipient was receiving more care than was typical for someone that age.

Response error

Two respondents misheard the question, and in one case, that resulted in response error. She thought the question was asking if the respondent receive routine medical care and answered 'Yes' despite the fact that he did not receive additional care apart from his routine medical care.

Question 16

Q16. Do you get paid to provide care for this person?

- 1) Yes
- 2) No [go to question 18]
- 3) Don't know [go to question 18]
- 4) Refused [go to question 18]

Frequency distribution (N=29)

Response option	Count
Yes	3
No	25
Don't know	0
Refused	0
Not asked by interviewer	1

Findings

Respondents generally considered being 'paid' to refer to receiving income directly from any source for their caregiving work. Most did not consider rent-free living or reimbursed medical or nutritional supplies to be payment.

While many respondents lived in the care recipient's house without paying rent, most did not count free housing as payment for providing care. For example, one respondent who answered 'No' said, *"I guess in a way I'm getting compensation – I guess technically I am living here and not paying to live here – rent."* One respondent who answered 'Yes', however, did consider his rent-free living arrangement and help with other finances as

payment. He said, “*Well I mean I don’t necessarily get paid a stipend or anything but I do get considerations for what I do like not having to pay rent [...] and they do help me out with some of my finances ...I would count that as a payment of sort.*”

A few respondents who answered ‘No’ discussed the fact that the care recipient received social security payments due to their disability. In those cases, the respondents were not using the money themselves, rather, the money was either paying for other care services directly or being saved for future use by the care recipient.

The three respondents who answered ‘Yes’ to this question comprised distinct perspectives on payment for their caregiving work. One respondent, as discussed above, considered his compensation to be living rent-free and receiving other financial help. Another respondent worked as a paid caregiver, and he had only become friends with the care recipient after he had been hired by her. And finally, the third respondent who said she was paid received payment from the state to care for her 92-year-old mother. However, the question was particularly sensitive for her. She initially answered ‘No’ and only later amended her answer to be ‘Yes’ in a statement sent to the interviewer the following day. She explained, “*...along with the guilt, emotional turmoil of caring for a family member, long-term, I did not want to disclose that I was getting paid to help support this effort [...] the question brought emotions of ‘how can [she] accept money for something that you as a daughter should be able to do.’*” This respondent’s statement highlights the sensitivity of asking some respondents about their compensation for caring for their loved one, something they feel should be their duty as a family member. Indeed, some respondents who answered ‘No’ said that they were providing care “*out of love*” and not for payment, as if payment might lessen the work they do. For example, one respondent had heard he could be compensated and said, “*seemed crazy to me, I don’t care about no dollars.*”

Question 17

Q17. What is the main source from which you are paid?

- 1) I am paid by the person I care for or their family directly.
- 2) I am paid through a state or community agency like an Area Agency on Aging
- 3) I am paid through a health care system like the VA
- 4) I am paid through an insurance provider like Medicaid or a private insurance plan
- 5) Other
- 6) Don’t know
- 7) Refused

Frequency distribution (N=3)

Response option	Count
I am paid by the person I care for or their family directly	1
I am paid through a state or community agency like an Area Agency on Aging	1
I am paid through a health care system like the VA	0
I am paid through an insurance provider like Medicaid or a private insurance plan	0
Other	
Don’t know	0
Refused	0
Not asked by interviewer	1

Findings

This question is intended for all those who answered ‘Yes’ to Question 16 (‘Do you get paid to provide care for this person?’). Two respondents were routed to and asked this question. Another respondent answered ‘Yes’ to

Question 16 after the interview was complete as an amendment, so she was not asked Question 17 by the interviewer.

One respondent who worked as a paid caregiver asked for response items two and three to be repeated to him, and he ultimately selected item two (I am paid through a state or community agency like an Area Agency on Aging). The care recipient set up his payment by the state, though she had originally paid him directly. The other respondent to this question selected item one, ‘I am paid by the person I care for or their family directly,’ because he considered living rent-free and receiving help with some of his other finances as payment.

Questions 18 and 18a

Q18. Which of the following services or supports, if any, do you use to help you care for this person? (Select one or more).

- 1) Out of home services for the care recipient
- 2) In home services for the care recipient
- 3) Caregiver support groups
- 4) Food and nutrition service for care recipient
- 5) Transportation services for care recipient
- 6) Financial planning for care recipient
- 7) Caregiving/caregiver skills-based training (e.g., The Savvy Caregiver)
- 8) Other
- 9) I don’t use any services or supports
- 10) Don’t know
- 11) Refused

Frequency distribution (N=29)

Response option*	Count
Out of home services for the care recipient	8
In home services for the care recipient	5
Caregiver support groups	5
Food and nutrition service for the care recipient	7
Transportation service for the care recipient	6
Financial planning for the care recipient	4
Caregiving/Caregiver skills-based training (e.g. The Savvy Caregiver)	1
Other	1
I don’t use any services or supports	7
Don’t know	0
Refused	0
No response provided	1

*Respondents could select multiple response items for this question

Changes made between rounds

Initially for Round 1, the question read as follows: “Various services or supports may be available to assist you in providing care. Which of the following services or supports do you currently use that is most important caring for this person?” Some respondents were unclear as to which services to include and how many. Some did not comprehend the question until the response options were read aloud, giving them more information about the

question's intended meaning. Following Round 1, the wording was simplified and clarified to remove the introductory sentence and to indicate that the respondents could select all response options that applied to them.

Findings

Following the question update, respondents were aware they could indicate all the services that applied to them. However, in both rounds, some were unsure what the response items meant, especially the first item: 'out of home services or supports.' Some included all doctors' visits that occurred outside the home, whereas others only included specialists or specialty care, such as physical therapy, behavioral therapy, or an adult day program.

Some respondents requested examples or asked for the question to be re-read several times. Additionally, comprehension tended to improve as the interviewers read aloud the response item choices, and then respondents began to infer meaning and consider their own examples from their caregiving work. For example, one respondent who asked for the question to be re-read multiple times said, "*Oh does EBT²⁴ count? Social services? ... Oh no like food stamps, general EBT. That's one thing we applied for when we went to social services.*"

Considerations of 'in-home services' included paid aides, case managers that came to the house, visiting nurses or physical therapists, and house cleaners.

Caregiver support groups, both virtual and in-person, were selected by most people who had participated in one. However, in one case, a respondent who used an online group did not include it in his answer, because he was not an active member.

When considering the food services care recipients use, respondents included services like EBT²⁵ and PEBT,²⁶ nutritionist consultations, and subsidized prepared meals or Ensure nutritional drinks.

Regarding transportation services, respondents included formal medical transport as well as service worker-provided transport.

One respondent who selected 'other' thought of her mother's tele-health appointments with her psychiatrist. Also, another respondent did not provide a response. She spoke about the special diet that her father required, but this information was simply given to her by her father's doctor.

Those who said that they did not use any services or supports either took care of all needs themselves within their caregiver network or the care recipient had no need of extensive services or supports.

Most respondents considered services they currently used. However, in some cases, respondents thought about prior services or services that were used at any point in their caregiving role. For example, one respondent thought about the one time that her brother, who was living in a developmental center, got a transportation service to visit their mother, who was in a nursing home. The respondent remarked, "*It was a special request, and it was really neat ... life is fleeting. You don't know what's going to happen one day to the next, so it was really special that that happened.*"

Out-of-scope

A few Round 2 respondents either considered all the tasks that they themselves do in their caregiving role, or they wondered if that was the correct way to interpret the question. For instance, one respondent, who was paid, asked the following: "*Do you mean...if she used a driver service or do you mean me being in service. Are you asking, are you the driver, or do you set that up, like how in detail do you mean?*" While he initially thought of the work he did as a caregiver, he ultimately answered based on other services the care recipient received such as transportation services and a house cleaner. However, another respondent answered based on all the tasks he does

²⁴ Electronic Benefit Transfer.

²⁵ Electronic Benefit Transfer, used to purchase food and other essential items.

²⁶ Pandemic-Electronic Benefit Transfer, used to purchase school lunches during the Covid-19 pandemic.

for his father as a caregiver. In that, when answering about financial planning services he said, “*I would say yes. When his pension arrives, I’m the one that usually does the planning.*”

Of note: For those respondents who were the caregiver for a child with a disability, certain services and supports were provided by schools. These supports were not included here by those respondents.

18a. Which one of the supports or services you use is the most important to help you care for this person? (Select one.)

- 1) Out of home services for the care recipient
- 2) In home services for the care recipient
- 3) Caregiver support groups
- 4) Food and nutrition service for care recipient
- 5) Transportation services for care recipient
- 6) Financial planning for care recipient
- 7) Caregiving/caregiver skills-based training (e.g., The Savvy Caregiver)
- 8) Other
- 9) Don’t know
- 10) Refused

Frequency distribution (N=8)

Response option	Count
Out of home services for the care recipient	3
In home services for the care recipient	1
Caregiver support groups	0
Food and nutrition service for the care recipient	0
Transportation service for the care recipient	2
Financial planning for the care recipient	1
Caregiving/Caregiver skills-based training (e.g. The Savvy Caregiver)	0
Other	0
Don’t know	0
Refused	0
Not asked by the interviewer	1

Findings

This question was asked of those in Round 2 who provided multiple answers to Question 18 (‘Which of the following services or supports, if any, do you use to help you care for this person?’). Eight respondents were routed to this question, though one person was not asked the question by the interviewer because the respondent had not understood Question 18.

Interviewers asked respondents to select only from the items mentioned in the previous multiple response question.

Because this question asks respondents to choose the most important service or support, some were forced to choose between supports for themselves (such as caregiver support groups) or supports for the care recipient (such as doctors and access to medications). When balancing these options, respondents chose to favor the service or support for the care recipient that was most important. However, this dilemma in response selection highlighted that the question itself covers both supports for caregiver and care recipient. As one respondent said the following to describe her thought process when selecting ‘Out of home services for the care recipient’:

“Honestly, I get more help myself from the caregiver support groups. But I feel like that first one you mentioned – the out of home care – that’s important as well because that includes his neurologist, his epileptologist, his psychiatrist, his therapy. So, I guess for him and his care, it would be the first one. But for me, it would be the caregiver support.”

Question 19

Q19. Do you have friends or family that help you out with your own needs?

- 1) Yes
- 2) No
- 3) Don’t know
- 4) Refused

Frequency distribution (N=29)

Response option	Count (Round 1) N=14	Count (Round 2) N=15
Yes	10	9
No	4	2
Don’t know	0	0
Refused	0	0
No response provided	0	3
Not asked	0	1

Round 1 Findings

During Round 1, the question read ‘Do you have friends or family that help you out?’ respondents primarily thought of this question as asking if anyone could help them in their caregiving duties to lighten their workload, providing relief care. As one respondent who answered ‘Yes’ said, *“If I had to make circles in terms of help, it’s me and my grandmother in one circle, it’s [name A] and [name B], my cousin, my aunt [name], and from a distance it’s my mom – because she can only do things virtually. She’s still heavily involved – she tries to.”*

Co-caregivers or those who regularly helped provide care for the care recipient were not considered by respondents consistently. As in, those with co-caregivers sometimes did not count those people as ‘friends and family’ that may or may not help, while others did.

In two Round 1 cases, respondents talked specifically about care they received in their home life, but only one of them included that type of help in her answer. Thinking about help her friends provide by caring for her son at home while she cared for her mother, one respondent answered ‘Yes’ and said, *“It allows me to go to my mother’s home as frequently as I do.”* On the other hand, another respondent answered ‘No’ explaining, *“No. My husband helps me a bit, but really more at home. He doesn’t really help with my dad, that’s just me.”*

Of note: A few respondents wondered ‘whose friend’ this question referred to: theirs or the person cared for. Also, there is a scale of help here – a tiny bit of help or a fair proportion of help all could be captured in a ‘Yes’ response.

Changes made between rounds

The intent of this question was to capture help provided to the caregiver themselves, rather than help provided by additional carers for the care recipient. Since question interpretation during Round 1 was inconsistent with regards to who was receiving help from friends or family, the interview team used an updated version of the question for

Round 2. The phrase, "...with your own needs" was added to help clarify the intent. The updates did improve performance with regards to question intent, but in some cases, respondents were confused by the updated question.

Round 2 Findings

In Round 2, after the updated language was added, respondents more often considered the personal help they receive such as emotional support, help with their own cooking and cleaning, handyman work around the house, or help with personal finances and bills. For example, one respondent who answered ‘Yes’ said, *“I would say my fiancée helps me because he is an ear...So, he can’t begin to understand what I’m dealing with, but he can just sympathize.”* Another said, *“Well because my parents will pay – I’m still a part of their health insurance and they pay for my schooling.”*

However, some Round 2 respondents still considered the question to be asking about whether they have relief care, someone to come lighten their caregiving workload by helping care for the care recipient. For instance, one respondent thought about her co-caregivers when she answered ‘Yes’ and said, *“Relief, when I can go home and take care of my own family.”*

Additionally, some respondents were confused by the new phrase, ‘with your own needs,’ resulting in non-response. As one respondent said, *“What kind of needs though ‘cause that’s a very broad question.”* Another respondent who was unable to provide a response thought that the question was asking if she herself had any health problems that required the help of a caregiver.

Question 20

Q20. Has being a caregiver created financial difficulty for you?

- 1) Yes
- 2) No
- 3) Don’t know
- 4) Refused

Frequency distribution (N=29)

Response option	Count
Yes	8
No	21
Don’t know	0
Refused	0

Findings

When thinking about this question, respondents considered not only financial effects from their caregiving work, but also, if that work creates a strain on their finances. Respondents answered based on whether they felt financial strain or limitation – and not if there were any general financial effects from their caregiving work. Aspects of household finances that respondents considered included their ability to work, and work the hours they want to, costs, such as gas, groceries, and medicines, and who pays for what, and whether or not they were able to meet financial planning goals for the future.

Those who answered ‘No’ were able to balance their finances, and in some cases, they utilized the savings or income from the person they cared for to help pay for those caregiving costs (groceries and gas, for instance). Also, respondents who answered ‘No’ either were able to keep working enough hours to get by or they did not need to work. For example, one respondent had reduced her hours, but her husband still worked full time. She

said, “I could work full-time and that would be nice, but we’re ok, so I’ll say ‘No.’” Similarly, another respondent spoke about the overall balance of his household budget. He said,

“I was working, and I stopped working to actually do this with her. And we found that it really didn’t affect much. At that time my wife got a raise, and then she started working nights – and the overtime [...] has kind of made up for me not working. So, we haven’t noticed it.”

Of interest, however, is that one respondent said that while she and her boyfriend did not need to pay rent caring for his mother, they were therefore not placed in financial difficulty, so she had answered ‘No.’ But, they also felt trapped in their situation, unable to move out.

Those who answered ‘Yes’ felt that the financial effects from caregiving constituted an actual strain, and in some cases the effect was long lasting. For example, some said that they had to reduce hours at work, which affected their income. Also, some spoke about the recent increase in prices due to inflation as an important factor when budgeting for things like groceries and gas. As one respondent explained, *“Gas was so expensive at one point, it was easier for me to walk and check on her. And some days I can’t work -even part time because I’m doing something else. So, I have to consider that as well.”* Additionally, a few respondents were limited in their ability to meet their financial or career goals. For example, one respondent explained, *“I gave up my career, college, and everything for this.”*

Question 21

Q21 (Version 1). Has being a caregiver provided you personal fulfillment, purpose, or satisfaction?

- 1) Yes
- 2) No
- 3) Don’t know
- 4) Refused

Frequency distribution (N=14)

Response option	Count
Yes	12
No	0
Don’t know	0
Refused	0
No response provided	1
Not asked	1

Findings

The question wording as shown above was administered in Round 1 only. All those who provided an answer to this question responded ‘Yes.’ One respondent ran out of time in the interview before being asked, and another was not able to provide a response.

Some respondents easily answered ‘Yes,’ speaking about the fulfillment they felt in doing their caregiving work and their ability to “give back.” As one respondent said,

“This is probably the most important thing I will ever do. I’m not going to have kids, I don’t have a family. I’m not going to invent anything or discover anything. This is the most important thing I’ll do. So, it gives me a sense of fulfillment.”

Others, however, were more measured, saying that it is not their caregiving that gives them ‘purpose’ in life. Rather, they would do this for their loved one no matter how they felt. One respondent explained, *“I already had purpose in life, you know what I’m saying? And, that’s just to help another human being, serving my lord, and seek justice. That’s with or without [helping his grandfather]. I would do it all over again.”*

When speaking about why they answered the way they did, some respondents noted that their caregiving work is a way to keep the loved one at home and out of a nursing home or assisted living, and therefore it has inherent value: *“This way I know that he is taken care of and he is not in a nursing home or cared for by random people who may not really care about him.”*

Ultimately, the lack of scaled response options was challenging for some respondents. The respondent who was not able to provide a response said the following: *“I wish there was a gradient scale on which to say ‘No’ ‘Somewhat’. I’d say ‘Somewhat.’ We’ll say ‘A little.’”* A gradient would have allowed her to relate the conflict emotions and the burden that caregivers can feel. At the end of their interviews, many Round 1 respondents discussed the emotional toll and physical strain of caregiving, something they felt was not fully addressed with the question set from Round 1. As one respondent commented, *“Are you conscious of caring for yourself properly when caring for someone else whose needs are so critical...I forget to take my vitamins, I’m not as regular to care for myself and I’m elderly myself.”*

Of note: One respondent seemed to interpret the question as asking if he himself was successful as a caregiver, in an out-of-scope consideration.

Changes made between rounds

Due to the lack of response variation seen in Round 1, as well as the desire among respondents to provide a scaled response, the question was updated following Round 1 interviews. To account for variability in feeling across their duties and experience, the question was divided into two statements, each with a scale of response options. Results from those updated questions are provided below.

The updated Questions 21a and 21b constituted a significant change from the original question used in Round 1, and they served as an improved way to account for the complex mixture of feelings and stressors that respondents experienced in the course of their caregiving work. Indeed, unlike in Round 1, where respondents often shared additional concluding thoughts about the emotional and physical strain they experienced due to caregiving after the interview had concluded, in Round 2, respondents generally did not add additional thoughts at the end of the interview about the personal toll of caregiving. Instead, those types of comments emerged through the discussion of Questions 21a and 21b.

Q21 (Version 2). How much do you agree or disagree with the following statements?

a. Being a caregiver provides me personal fulfillment, purpose, or satisfaction.

- 1) Strongly agree
- 2) Somewhat agree
- 3) Somewhat disagree
- 4) Strongly disagree
- 5) Don’t know
- 6) Refused

Frequency distribution (N=15)

Response option	Count
Strongly agree	9
Somewhat agree	4
Somewhat disagree	0

Strongly disagree	1
Don't know	0
Refused	0
No response provided	1

Findings

Respondents considered the question to be asking about whether they felt positively about their caregiving work. The scaled response options allowed for respondents to express both their positive feelings about caregiving and their reservations. Those who selected ‘Strongly agree’ talked about their caregiving as important work. They spoke of the love they had for family members, the ability to give back to those who had provided for them in the past, and the fulfillment they felt in providing what the care recipient needed. One respondent who provided care to her grandmother said, *“I’m just glad I can offer some help to her, especially now that my grandpa is not here anymore.”* Similarly, those who answered, ‘Somewhat agree’ also described how glad they were to provide the care, but they were more measured. As one respondent said, *“I am happy I am able to help, but I would be happy if he never had this condition in the first place.”* This sentiment echoed what some respondent in Round 1 mentioned, supporting the scaled response as a way to provide more nuanced answers.

One respondent answered ‘Strongly disagree.’ She was under a great deal of stress caregiving for three people with mental illnesses in her family. She said, *“I think I would be more satisfied if I didn’t have to spend 24/7 caring for somebody. I don’t see it as fulfillment or satisfaction. I would rather not have to do it.”*

One respondent was not able to provide a response, explaining that it’s both *“a struggle”* and *“worth it”* to provide care for her father in the final stage of his life. She said, *“That’s hard. I agree. It is. It is a struggle...I agree that it can be a struggle, but I mean it’s worth it if it’s the one you care about. We just doing it right now. We’re just winging it.”*

b. Being a caregiver has worsened my physical, mental, or emotional health.

- 1) Strongly agree
- 2) Somewhat agree
- 3) Somewhat disagree
- 4) Strongly disagree
- 5) Don't know
- 6) Refused

Frequency distribution (N=15)

Response option	Count
Strongly agree	3
Somewhat agree	3
Somewhat disagree	2
Strongly disagree	6
Don't know	0
Refused	0
Not asked	1

Findings

When discussing this question, respondents considered whether they had been negatively impacted by their caregiving duties. Considerations included whether they felt occasional or chronic stress, whether they had

noticed changes in their own physical or mental state, and whether they needed to get professional help, such as counseling.

Those who selected ‘Strongly agree’ all had felt a significant impact from caregiving. Two had needed to get professional mental health support, and another had taken over caregiving after her sister had unexpectedly passed away, in part due to the toll of caregiving for their mother. Similarly, those who selected ‘Somewhat agree’ also all discussed their own mental health struggles that came about due to caregiving, either due to the diagnoses their loved one received or due to the caregiving work itself.

The two respondents who selected ‘Somewhat disagree’ both noted that sometimes the work can be “*stressful*,” but neither indicated that they had a serious, lasting impact from the stress. As one respondent said, “*It’s unrealistic not to think that it’s going to be stressful but at the same time has it made things worse for me mentally? ...No.*”

Those who selected ‘Strongly disagree’ felt positively about their caregiving work, and some even noted that it has benefited them personally. One respondent said, “*I’ve learned a lot of patience. It’s helped a lot. And, to help her, I have become more organized.*”

Appendix 1: Round 2 Questionnaire

Q1. 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
- 3) Caregiving recipient died in past 30 days
- 4) Don't know
- 5) Refused

Q2. Do you consider yourself a caregiver for a friend or family member?

- 1) Yes
- 2) No [end of interview]
- 3) Caregiving recipient died in past 30 days [end of interview]
- 4) Don't know [end of interview]
- 5) Refused [end of interview]

Q3. How many people with a health problem or disability did you provide care for in the past 30 days?

- 1) 1
- 2) 2
- 3) 3
- 4) 4 or more
- 5) Don't know
- 6) Refused

Ask If (Q3 = 1 / Q3=2-4)

Q4. (Thinking about that person / For the next few questions, please only think about the person you care for the most). What is their relationship to you? For example, is this person your parent or your child.

- 1) Parent, stepparent, or parent-in-law
- 2) Grandparent, step grandparent or grandparent-in-law
- 3) Spouse or partner
- 4) Child or stepchild
- 5) Grandchild or step grandchild
- 6) Sibling, stepsibling, or sibling-in-law
- 7) Other relative
- 8) Friend or non-relative
- 9) Don't know
- 10) Refused

Q5. How old is that person?

- 1) Under 18 years of age
- 2) Aged 18-44 years
- 3) Aged 45-64 years
- 4) Aged 65-79 years

- 5) Aged 80 years or older
- 6) Don't know
- 7) Refused

Q6. What is the main health problem or disability that the person you care for has?

- 1) Alzheimer's disease, dementia or other cognitive impairment [skip to question 8]
- 2) Heart disease, hypertension, or stroke
- 3) Cancer
- 4) Diabetes
- 5) Injuries including broken bones or traumatic brain injury
- 6) Mental illness such as depression, anxiety, or schizophrenia
- 7) Developmental disorders such as autism, Down syndrome, or spina bifida
- 8) Respiratory conditions such as asthma, emphysema, or chronic obstructive pulmonary disease (COPD)
- 9) Arthritis/rheumatism
- 10) Hearing or vision loss
- 11) Movement disorders such as Parkinson's, spinal cord injury, or multiple sclerosis
- 12) Old age, infirmity, or frailty
- 13) Other
- 14) Don't know
- 15) Refused

Q7. Does the person you care for also have Alzheimer's disease, dementia or other cognitive impairment?

- 1) Yes
- 2) No
- 3) Don't know
- 4) Refused

Q8. In the past 30 days, did you provide care for this person by helping with nursing or medical tasks such as injections, wound care, or tube feedings?

- 1) Yes
- 2) No
- 3) Don't know
- 4) Refused

Q9. In the past 30 days, did you provide care for this person by managing personal care such as bathing, getting to the bathroom, or helping to eat?

- 1) Yes
- 2) No
- 3) Don't know
- 4) Refused

Q10. In the past 30 days, did you provide care for this person by managing household tasks such as help with transportation, shopping, or managing money?

- 1) Yes
- 2) No
- 3) Don't know
- 4) Refused

Q11. In the past 30 days, did you provide care for this person by coordinating their care such as scheduling appointments, dealing with insurance, or filling out paperwork?

- 1) Yes
- 2) No
- 3) Don't know
- 4) Refused

Q12. In the past 30 days, did you provide care for this person through mental health support, emotional support, or companionship?

- 1) Yes
- 2) No
- 3) Don't know
- 4) Refused

Q13. In the past 30 days, on average, how many hours per week did you provide regular care or assistance? Would you say...

- 1) Up to 19 hours per week
- 2) 20 to 39 hours per week
- 3) 40 hours or more per week
- 4) Don't know
- 5) Refused

Q14. How long have you provided regular care to this person? Would you say...

- 1) Less than 30 days
- 2) 1 month to less than 2 years
- 3) 2 years to less than 5 years
- 4) 5 years or more
- 5) Don't know
- 6) Refused

Q15. Does this person receive any additional unpaid or paid care besides routine medical care?

- 1) Yes
- 2) No
- 3) Don't know
- 4) Refused

Q16. Do you get paid to provide care for this person?

- 1) Yes
- 2) No [go to question 18]
- 3) Don't know [go to question 18]
- 4) Refused [go to question 18]

Ask if Q16=Yes

Q17. What is the main source from which you are paid?

- 1) I am paid by the person I care for or their family directly.

- 2) I am paid through a state or community agency like an Area Agency on Aging
- 3) I am paid through a health care system like the VA
- 4) I am paid through an insurance provider like Medicaid or a private insurance plan
- 5) Other
- 6) Don't know
- 7) Refused

Q18. Which of the following services or supports, if any, do you use to help you care for this person? (Select one or more.)

- 1) Out of home services for the care recipient
- 2) In home services for the care recipient
- 3) Caregiver support groups
- 4) Food and nutrition service for care recipient
- 5) Transportation services for care recipient
- 6) Financial planning for care recipient
- 7) Caregiving/caregiver skills-based training (e.g., The Savvy Caregiver)
- 8) Other
- 9) I don't use any services or supports
- 10) Don't know
- 11) Refused

(Ask if Q18 = At least 2 of 1-9)

Q18a. Which one of the supports or services you use is the most important to help you care for this person? (Select one.)

If automated only those items selected at Q18 should be shown. Item 9 not required if automated.

- 1) Out of home services for the care recipient
- 2) In home services for the care recipient
- 3) Caregiver support groups
- 4) Food and nutrition service for care recipient
- 5) Transportation services for care recipient
- 6) Financial planning for care recipient
- 7) Caregiving/caregiver skills-based training (e.g., The Savvy Caregiver)
- 8) Other
- 9) I don't use any services or supports
- 10) Don't know
- 11) Refused

Q19. Do you have friends or family who help you with your own needs?

- 1) Yes
- 2) No
- 3) Don't know
- 4) Refused

Q20. Has being a caregiver created financial difficulty for you?

- 1) Yes
- 2) No

- 3) Don't know
- 4) Refused

Q21. How much do you agree or disagree with the following statements?

a. Being a caregiver provides me personal fulfillment, purpose, or satisfaction.

- 1) Strongly agree
- 2) Somewhat agree
- 3) Somewhat disagree
- 4) Strongly disagree
- 5) Don't know
- 6) Refused

b. Being a caregiver has worsened my physical, mental, or emotional health.

- 1) Strongly agree
- 2) Somewhat agree
- 3) Somewhat disagree
- 4) Strongly disagree
- 5) Don't know
- 6) Refused

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