

University of Washington

Caregiver Stress Scale (UW-CSS) ©

Users Guide

Version 1.0 – English

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UNIVERSITY OF WASHINGTON CAREGIVER STRESS SCALE (UWCSS) ©

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Copyright Statement and Users' Agreement

The University of Washington Caregiver Stress Scale (UW-CSS) is the intellectual property of the University of Washington and is copyrighted. The contents of the UW-CSS were developed under an investigator initiated research agreement with Zogenix, Inc. Zogenix researchers involved in the study include Arnold R. Gammaitoni, Carey R. Aron, and Bradley S. Galer (Zogenix, Medical Affairs, 5858 Horton Street, Suite 455, Emeryville, CA 94608).

Permission to use the UW-CSS must be requested prior to use or publication from uwcorr@uw.edu.

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Please cite the UW-Caregiver Stress Scale user guide and short forms as follows:

University of Washington Caregiver Stress Scale (UW-CSS) Version 1 Users Guide. 2017.

<https://uwcorr.washington.edu/measures/uw-css-userguide.pdf>. Accessed on [insert date].

Terms of Use for UW-CSS

The University of Washington Caregiver Stress Scale instruments are **free of charge** for non-commercial use. Examples of non-commercial use include administration of surveys in clinical practices for purposes of monitoring patients or administration for research purposes. Presentation or publication of results using UW-CSS instruments should include a statement that indicates which instrument (including version number) was used and a reference to the UW-CSS user guide or website (<https://uwcorr.washington.edu/measures/uw-css-userguide.pdf>).

Permission to use the UW-CSS instruments does not grant permission to modify the wording or layout of items, to distribute to others in any form, or to translate items into any other language. Permission to modify, distribute, or translate must be requested in writing from the study principal investigator, Dagmar Amtmann, PhD at uwcorr@uw.edu.

Questions about the UW-CSS Instruments

If you have questions about the UW-CSS instruments or their use in clinical care or research, please contact the University of Washington Center on Outcomes Research in Rehabilitation (UWCORR).

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Overview of the UW-CSS

The University of Washington Caregiver Stress Scale (UW-CSS) is an Item Response Theory (IRT) based instrument intended for measuring caregiver stress in adults taking care of children under 18 years old. The UW-CSS is a publicly available, psychometrically sound item bank for measuring caregiver stress that can be administered by computerized adaptive testing or short forms (on paper or computer).

Caregiver Stress: Construct and definitions

The UW-CSS measures the stress experienced by caregivers of children under 18 years old age due to taking care of children. The questions were developed with participation of researchers and clinicians with expertise in pediatric neurology, as well as parents of children with severe epilepsy. The scale was developed to address all areas of stress important to caregivers of children with severe epilepsy, with an intention to make the scale universally applicable to caregivers of healthy children as well as children with any health conditions. The questions were also tested with caregivers of children with two other clinical conditions, Down syndrome and muscular dystrophy, as well as with a community sample of caregivers.

For the purposes of the UW-CSS a **caregiver** is defined as:

A person (most often a family member or legal guardian) who coordinates and provides most of the unpaid day-to-day care for, and is responsible for the raising, the health, and the well-being of a child or recipient of care. The UW-CSS is not intended to assess the stress of professional caregivers (e.g., nurses or nurse assistants), even if they are providing more hours of care than family caregivers.

For the purpose of the UW-CSS a **care recipient** is defined as: *A person or persons under 18 years of age who is/are receiving care. The care recipient might be a typically developing child or youth, or a person or persons with some form of chronic condition or disability that causes difficulties in completing the tasks of daily living.*

Caregiver Stress is defined as:

The caregiver's perception of the challenging physical, social, and emotional impact of caregiving on the caregiver's life. It includes the caregiver's perception of the effects of caregiving on the financial resources, time resources, health of the caregivers, work, and relationships.

These definitions guided the development of items across ten subdomains of caregiver stress including: (1) time to take care of one's own physical health, (2) sleep quality, (3) fatigue, (4) emotional health, (5) sense of confidence in/self-efficacy for caregiving, (6) relationship with spouse/significant other, (7) relationship(s) with other children, (8) relationship(s) with friends, (9) work hours/employment, and (10) family finances.

Development Sample:

The UW-CSS was developed in a sample of adults (18 years or older) living in the United States who were caring for a child under 18 years of age with either epileptic encephalopathies, Down syndrome, muscular dystrophy or no specific health care needs. The UW-CSS was developed in English, and has not yet been translated into other languages, but the translations into Italian, German, French and Spanish are under way. It was developed to be applicable to primary caregivers of children either with or without specific healthcare needs.

Just over half of the calibration sample (400 out of 722 total) included primary caregivers of children with either epileptic encephalopathies, Down syndrome, or muscular dystrophy. However, scores were centered in a community based sample of caregivers (n=241) of children (i.e., the community based sample was chosen to be typical of caregivers in the community, without any consideration for the health of the children they were caring for).

As a result **UW-CSS score of 50 with a standard deviation of 10 represents the mean in a community based sample** with the following characteristics:

- Half the sample had income below and half above the median US income from 2014.
- Approximately one-third (35%) of the sample had non-white race, matching the US Census of adults from 2015.
- At least 36% had less than or equal to a high school education, which matches the Child Trends analysis of the Current Population Survey.
- One third of the children of the caregivers were in each of the three age groups (0-5 years, 6-11 years, 12-17 years), matching the distribution of estimated children from the US Census from 2010-2014.
- The number of male caregivers was 25% of the sample.

		Characteristics of Caregiver Sample Used for Centering CSS Scores (N=241)
Caregiver Stress Scale Score		50.0 (SD: 10)
Average Number of Children		1.9
Child Age Group		
	0-5 years	33%
	6-11 years	33%
	12-17 years	33%
Caregiver Gender		
	Male	25%
	Female	75%
Median Household Income		\$53,657
Non-White Race		35%
High School Education or Less		36%
Child Health Condition		
	None listed	60%
	1 Health Condition	18%
	2 Health Conditions	11%
	3+ Health Conditions	11%
Most Commonly Listed Health Conditions		
	ADD/Hyperactivity/Behavioral	16%
	Allergies/Sinus Trouble	14%
	Asthma	14%
	Speech Problems	8%

Focus groups and cognitive interviews were conducted in the process of developing the item bank to ensure that the instrument is both person-centered and clinically meaningful. The item bank was calibrated using IRT, and item parameters for all items are available upon request.

Additional information about the focus groups and definition development can be found in this publication: Jensen MP, Liljenquist KS, Bocell F, Gammaitoni AR, Aron CR, Galer BS, Amtmann D. Life impact of caregiving for severe childhood epilepsy: Results of expert panels and caregiver focus groups. *Epilepsy Behav.* 2017 Sep;74:135-143. doi: 10.1016/j.yebeh.2017.06.012.

Instructions for Using the UW Caregiver Stress Scale

Choosing a UW-CSS instrument and mode of administration:

Below you will find the full 19 item bank along with a 10-item short form. For lowest respondent burden and most reliable score, use computerized adaptive testing (CAT) if it is available. To learn more about CAT and why it is recommended, visit the Health Measures CAT website (<http://www.healthmeasures.net/resource-center/measurement-science/computer-adaptive-tests-cats>). If CAT is not available use the 10-item short form.

A participant or patient version is available on the website as a standalone PDF (<https://uwcrr.washington.edu/measures/uw-css-sf10.pdf>). Investigator versions with individual item scoring indicated are available below. It is best practice **not to administer the version that shows scoring to the participants**. The full bank, that is all 19 items, is provided below for informational purposes, as it is not necessary to administer all items in the item bank. **The full item bank is intended for CAT** which uses an algorithm to select items based on responses to previous items. If interested in administering the full bank a scoring table is provided below. Please note that several items in the item bank are not applicable to people who are either not working or do not have a spouse/partner. Therefore these items cannot be scored for some people and IRT scoring is best if these items are to be used.

The 10-item short form can be administered electronically (by computer or tablet) or on paper. The short form requires less than five minutes to administer and is recommended for use in situations where administration of CAT is not possible. The correlation between scores on the 10-item short form and on the full bank is 0.98.

Scoring

The UW-CSS short form is scored by summing the responses to the first 8 individual items and transforming the summary score to an IRT-based T-score using the conversion table provided. **The summary score should not be used for any purposes**. All reliability and validation information relates to the IRT based T-scores. Raw scores/codes for each item range from 1 to 5 as indicated in the investigator/clinician versions below. Only complete responses with no missing data can be scored using the provided conversion scoring table. However,

information on scoring with missing data is also provided under “Scoring with Missing Data” below. Detailed instructions for scoring the short form are outlined below.

10-Item Short Form: These instructions are only valid if there are complete responses with no missing data on items 1-8. **Items 9 and 10 are for informational purposes only and do not contribute to the raw summary score.** **Step 1:** The **first 8** items on the short form are summed using the values provided for each response available in the clinician/researcher version of the form. This will give a summary score that ranges from 8 to 40. This is **not** a score that can be used for clinical or analytical purposes. **Step 2:** Using the Summary Score to T-score Conversion Table, use the summary score to look up the IRT-based T-score in the column labeled “T-score” in the conversion table (page 7 below). For example, a person with a summary score of 18 would have a T-score of 45.6. This T-score is your final score you will use for all analyses.

Scoring with Missing Data: The 10-item short form scoring table should only be used when all responses are completed for all of the first 8 items. For missing responses on any of the first 8 items use IRT software if possible. If IRT software is not available, the short form score can be approximated if a person skips up to two questions. If more than 2 of the 8 items are missing, a score cannot be generated without IRT software. **Step 1:** For respondents with missing data, first check how many items were answered and confirm that at least 6 items of the 8 items were answered before proceeding. **Step 2:** Next, sum the response scores from the items that were answered. Multiply this sum by 8 (i.e. the number of items used in scoring the short form). **Step 3:** Next divide by the number of items that were answered (this will be either 6 or 7). If the result is a fraction, round up to the nearest whole number. This will give a pro-rated summary score that ranges from 8 to 40. This is **not** a score that can be used for clinical or analytical purposes. **Step 4:** Finally, using the Summary Score to T-score Conversion Table (page 7), translate the pro-rated summary score into a T-score for the respondent just as you would for any person who did not have missing responses.

Again, the formula is:

$$\frac{\text{(Raw sum x 8)}}{\text{(Number of items actually answered)}} = \text{Pro-rated summary score (round up to nearest whole number)}$$

For example, if a respondent answered 6 of 8 questions and answered all items with the second lowest response option (2), you would sum all responses (12), multiply by the number of items in the short form (8) and divide by the number of items that were answered (6). Here: $(12 \times 8) / 6 = 16$. If the result is a fraction, round up to the nearest whole number; the pro-rated summary score of 16 is translated to a T-score of 43.0. This T-score is your final score you will use for all analyses.

Interpreting UW-CSS Scores

The UW-CSS T-score is a standardized score with a mean of 50 and a standard deviation (SD) of 10. A higher T-score represents a higher level of caregiver burden. T-scores are comparable across all UW-CSS instruments. This means that a score obtained by a respondent using the 10-item short form may be compared directly to a score obtained by a respondent using the full bank or a CAT administration of the scale with the understanding that the score based on CAT is more reliable (i.e., accurate) than the score based on the short form. T-scores of 50 represent the mean score of the community based sample described on page 4 above. Based on a normal distribution of UW-CSS T-scores, 50% of caregivers in the community have a T-score of 50 or higher (see Figure 1 below). A respondent that receives a T-score of 60 has reported a level of caregiver burden approximately 1 standard deviation above the mean of other caregivers and their caregiver burden level is higher than 84% of individuals in the community based centering sample.

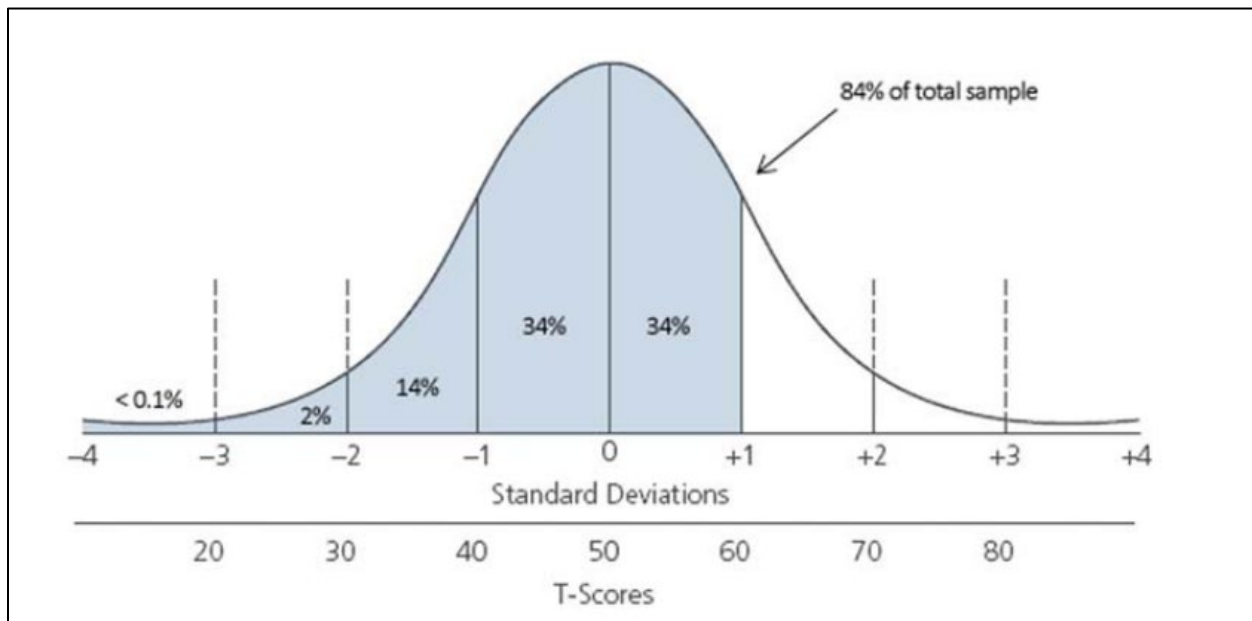


Figure 1 – A UW-CSS T-score of 60 indicates that approximately 84 percent of persons in the community sample reported lower caregiver burden, as reflected by the shaded area.

Summary Score to T-score Conversion Table

10 Item Short Form V.1.0 – UW-CSS Summary Score to T-score Conversion

Summary Score	T-score	SD of T-score
8	27.5	4.9
9	30.7	4.2
10	33.2	3.9
11	35.2	3.6
12	37.0	3.5
13	38.6	3.4
14	40.2	3.3
15	41.6	3.2
16	43.0	3.2
17	44.3	3.1
18	45.6	3.1
19	46.8	3.1
20	48.0	3.0
21	49.2	3.0
22	50.4	3.0
23	51.5	3.0
24	52.7	3.0
25	53.9	2.9
26	55.0	2.9
27	56.2	2.9
28	57.3	2.9
29	58.5	2.9
30	59.7	3.0
31	60.9	3.0
32	62.2	3.0
33	63.5	3.0
34	64.9	3.1
35	66.3	3.2
36	68.0	3.4
37	69.8	3.6
38	71.9	3.8
39	74.4	4.2
40	77.8	4.9

19 Item Full Bank V.1.0 – UW-CSS Summary Score to T-score Conversion

Summary Score	T-score	SD of T-score
19	23.1	4.4
20	25.9	3.8
21	27.9	3.4
22	29.5	3.2
23	30.9	3.0
24	32.1	2.8
25	33.2	2.7
26	34.2	2.6
27	35.1	2.5
28	35.9	2.4
29	36.7	2.3
30	37.5	2.3
31	38.2	2.2
32	39.0	2.2
33	39.7	2.2
34	40.3	2.1
35	41.0	2.1
36	41.6	2.1
37	42.2	2.1
38	42.9	2.1
39	43.5	2.1
40	44.1	2.1
41	44.7	2.1
42	45.3	2.1
43	45.8	2.1
44	46.4	2.1
45	47.0	2.1
46	47.6	2.1
47	48.1	2.1
48	48.7	2.1
49	49.2	2.0
50	49.8	2.0

Summary Score	T-score	SD of T-score
51	50.4	2.0
52	50.9	2.0
53	51.4	2.0
54	52.0	2.0
55	52.5	2.0
56	53.1	2.0
57	53.6	2.0
58	54.1	2.0
59	54.7	2.0
60	55.2	2.0
61	55.7	2.0
62	56.3	2.0
63	56.8	2.0
64	57.3	2.0
65	57.9	2.0
66	58.4	2.0
67	59.0	2.0
68	59.5	2.0
69	60.0	2.0
70	60.6	2.0
71	61.1	2.0
72	61.7	2.0
73	62.3	2.0
74	62.8	2.0
75	63.4	2.0
76	64.0	2.0
77	64.6	2.1
78	65.2	2.1
79	65.8	2.1
80	66.4	2.1
81	67.1	2.1
82	67.8	2.2

Summary Score	T-score	SD of T-score
83	68.5	2.2
84	69.2	2.3
85	70.0	2.3
86	70.8	2.4
87	71.6	2.5
88	72.6	2.6
89	73.6	2.7
90	74.7	2.9
91	76.0	3.1
92	77.4	3.3
93	79.1	3.6
94	81.2	4.0
95	84.0	4.6

UW Caregiver Stress Scale © Investigator or Clinician Forms

Versions 1.0 – English

UW Caregiver Stress Scale 10-Item Short Form V. 1.0©
(Investigator/Clinician Version)

Information for Clinicians and Researchers:

It is common for people who are caregivers to experience feelings of stress or burden sometimes. The UW-CSS is a way to try to measure those feelings and to compare them to what other caregivers experience. High scores on the UW-CSS (> 55) suggest that the individual's level of stress or burden is higher than what other caregivers living in the community experience. A high score suggests that clinicians should speak with their patients about their particular concerns or level of stress related to their caregiving burdens. If the patient appears particularly distressed the clinician should consider referring them to a professional who can help them better cope with the burdens of caregiving or provide them resources for support.

UW Caregiver Stress Scale 10-Item Short Form V. 1.0©
(Investigator/Clinician Version)

Instructions: Please choose the response that best describes how you **usually** feel about caregiving. By **caregiving** we mean all aspects of taking care of a child or children under 18 years -- that is providing help and support (typically unpaid and typically by a parent or guardian) for their physical, psychological, or developmental needs. When choosing your answers consider how having a child or children you take care of affects all areas of your life.

		Not at All	A little bit	Some-what	Quite a bit	Very much	
1.	How much are your finances strained because of caregiving?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	
2.	How difficult is it for you to get a good night's sleep because of caregiving?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	
3.	How difficult is it to find time to spend with your friends because of caregiving?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	
4.	How much do you feel always "on call" because of caregiving?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	
5.	How difficult is it for you to take care of yourself because of caregiving?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	
6.	How difficult is it to do things you like to do because of caregiving?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	
		Never	Rarely	Some-times	Often	Always	
7.	On a typical day, how often do you feel overwhelmed by caregiving?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	
8.	How often do you feel socially isolated because of caregiving?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	
		N/A (I don't currently work)	Never	Rarely	Some-times	Often	Always
9.	How often do you need to miss work because of caregiving?	<input type="checkbox"/>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
		N/A (I don't have a partner)	Not at All	A little bit	Some-what	Quite a bit	Very much
10.	How much does caregiving strain your relationship with your partner?	<input type="checkbox"/>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

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Information for Clinicians and Researchers:

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UW Caregiver Stress Scale Item Bank V. 1.0©
(Investigator/Clinician Version)

Instructions: Please choose the response that best describes how you **usually** feel about caregiving. By **caregiving** we mean all aspects of taking care of a child or children under 18 years -- that is providing help and support (typically unpaid and typically by a parent or guardian) for their physical, psychological, or developmental needs. When choosing your answers consider how having a child or children you take care of affects all areas of your life.

	Not at All	A little bit	Some-what	Quite a bit	Very much
1. How much are your finances strained because of caregiving?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
2. How much does your own health suffer because of caregiving?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
3. How difficult is it for you to get a good night's sleep because of caregiving?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
4. How difficult is it for you to take care of your household because of caregiving?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
5. How difficult is it to find time to spend with your friends because of caregiving?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
6. How much do you feel always "on call" because of caregiving?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
7. How difficult is it for you to take care of yourself because of caregiving?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
8. How difficult is it to make plans because of caregiving?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
9. How difficult is it to do things you like to do because of caregiving?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
10. How difficult is it to do things that are important to you because of caregiving?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
11. How much does caregiving limit your work opportunities?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

	Never	Rarely	Some-times	Often	Always
12. On a typical day, how often do you feel overwhelmed by caregiving?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
13. How often do you feel socially isolated because of caregiving?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
14. How often do caregiving responsibilities make you feel physically exhausted?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
15. How often do caregiving responsibilities make you feel mentally exhausted?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
16. How often does caregiving make it difficult for you to take care of your health?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

	N/A (I don't currently work)	Never	Rarely	Some-times	Often	Always
17. How often do you need to miss work because of caregiving?	<input type="checkbox"/>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
	N/A (I don't have a partner)	Not at All	A little bit	Some-what	Quite a bit	Very much
18. How much does caregiving strain your relationship with your partner?	<input type="checkbox"/>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
	N/A (I don't have a partner)	Never	Rarely	Some-times	Often	Always
19. How often it is difficult to do things you enjoy with your partner because of caregiving?	<input type="checkbox"/>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

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