THE PITTSBURGH REGIONAL CAREGIVERS SURVEY

BREAKOUTS BY NUMBER OF HOURS OF CAREGIVING PER WEEK

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Notes

All entries are column percentages.

Percentages for single response items may not add to 100 due to rounding.

Some items allowed for multiple responses. For these items, percentages add to more than 100.

CR = care recipient; CG = caregiver

Sample sizes:

8 or less	n = 416
9 to 19	n = 254
20 to 39	n = 157
40 or more	n = 170

Missing data (i.e., "don't know" and "refused") are not presented.

TYPES OF CAREGIVING

SCRNPC. Do you currently help with PERSONAL CARE TASKS, such as bathing, dressing, grooming, eating, moving from bed to chair, or going to the toilet?

0,	U	8 or fewer	9 – 19	20 - 39	40 or more
		hours per week	hours per week	hours per week	hours per week
Yes		27	51	76	82
No		73	49	24	18

SCRNHT. Do you currently help with HOUSEHOLD TASKS, such as shopping, managing personal finances, arranging for outside services, or providing transportation?

	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	97	99	95	99
No	3	1	5	1

SCRNMNT. Do you currently help with MEDICAL OR NURSING TASKS, such as managing medications, changing dressing on wounds, or monitoring equipment like oxygen tanks?

-	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	42	68	80	93
No	58	32	20	7

Respondents were required to say YES to at least one of the three questions above to qualify. These tables present the responses of the 1,008 respondents who qualified.

CAREGIVING SITUATION / CONTEXT

QCS1. What is your relationship to the person you help with their personal care, routine household needs and/or medical/nursing tasks? Are you taking care of:

8 2	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Your mother or mother-in-law	42	44	45	37
Your father or father-in-law	14	15	10	7
Your wife / partner	5	5	3	12
Your husband / partner	9	13	17	28
Your daughter or daughter-in-law	1	1	0	2
Your son or son-in-law	1	0	0	1
Some other relative	16	14	17	11
A non-relative	11	8	10	3

QCS2. Is the person you care for:

-	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Male	32	36	34	44
Female	68	64	66	57

QCS4. How old is [he / she]? Your best estimate is fine. (Results categorized for display.)

	8 or fewer	9 – 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
50 - 64	16	14	21	14
65 - 74	18	15	19	20
75 - 84	25	28	22	26
85 +	42	43	38	40

QCS5. Where does [he/she] live?

CS5. Where does [he/she] live?				
	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
In your household \rightarrow QCS9	26	42	44	85
Within 20 minutes of your home	53	49	42	12
Between 20 minutes and an hour from your home	16	7	13	3
One to two hours from your home	2	2	0	0
More than two hours away	3	1	1	1

	mane [mer sme] m			
	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
His or her own home	69	71	69	96
Someone else's home \rightarrow QCS9	8	8	15	0
An independent living or retirement community	13	12	11	0
In an assisted living facility where some care may be provided \rightarrow QCS9	10	9	3	4
Somewhere else	1	0	1	0

QCS6. Which of the following best describes where [he/she] lives?

Note: Persons providing care to a CR in a nursing home were not eligible for the survey.

QCS7. Does [he/she] live alone?

	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	69	68	68	48
No	31	32	32	52

QCS9. Does [he/she] need care because of a... (multiple responses allowed therefore percentages add to more than 100)

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Short-term physical condition	11	16	10	10
Long-term physical condition	73	76	87	84
Emotional or mental health problem	17	18	30	17
Developmental or intellectual disorder or mental retardation	4	6	5	5
Behavioral issue	6	8	10	8
Memory problem	34	43	52	55
None of the above	9	3	1	0

QCS10. Does [he/she] suffer from Alzheimer's disease or other types of dementia?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	19	21	32	34
No	82	79	68	67

Has a doctor ever told [him / her] that [he / she] had...

	8 or fewer	9 - 19	20 - 39	40 or more		
	hours per week	hours per week	hours per week	hours per week		
Yes	18	25	29	25		
No	82	75	72	75		

QCS11. a heart attack or myocardial infarction?

QCS12. any other heart disease including angina or congestive heart failure?

·	8 or fewer	9-19	20-39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	29	35	38	38
No	71	65	63	63

QCS13. high blood pressure or hypertension?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	63	65	70	67
No	37	35	30	33

QCS14. arthritis?

S14. arthritis?				
	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	62	68	62	70
No	38	32	38	30

QCS15. osteoporosis or thinning of the bones?

*	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	35	38	34	35
No	65	62	66	65

QCS16. diabetes?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	25	27	31	33
No	75	73	69	67

QCS17. lung disease, such as emphysema, asthma, or chronic bronchitis?

C	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	23	21	24	27
No	77	79	76	73

ncer?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	29	31	23	25
No	71	69	77	75

QCS18a. a stroke?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	15	21	32	32
No	85	79	68	68

QCS19. serious difficulty seeing?

`	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	24	33	30	32
No	76	67	70	68

QCS20. serious difficulty hearing?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	36	39	30	42
No	64	61	70	58

In the last month has [he / she] used...

QCS22A. glasses or other vision aids such as a magnifying glass?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	87	90	82	82
No	13	10	19	18

QCS22B. a hearing aid?

S22B. a hearing aid?					
	8 or fewer	9 - 19	20 - 39	40 or more	
	hours per week	hours per week	hours per week	hours per week	
Yes	17	22	15	18	
No	83	78	85	82	

QCS22C. a cane?

S22C. a cane?				
	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	43	46	39	38
No	57	54	62	62

QCS22D.	a walker?
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	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	40	44	48	49
No	61	56	52	51

QCS22E. a wheelchair?

SZZE. a wheelchair?					
	8 or fewer	9 - 19	20 - 39	40 or more	
	hours per week	hours per week	hours per week	hours per week	
Yes	22	35	41	52	
No	78	65	59	48	

QCS22F. a scooter?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	8	8	5	9
No	93	92	95	91

QCS22G. a reacher or grabber to pick things up more easily?

	8 or fewer	9 – 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	35	32	33	34
No	65	69	67	67

QCS22H. special items to help with dressing, such as button hooks or clothes that are designed to get on and off easily? 8 or fewer 9 - 19 20 - 39 40 or more

	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	19	21	25	20
No	81	79	75	80

QCS22I. adaptive utensils to help to eat or cut food? IF NEEDED: Adapted utensils include things like easy-to-grip silverware, knives that rock, and plates with high sides.

	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	4	4	6	10
No	96	96	94	90

QCS23. Does the CR's residence have features to make it easier for older adults such as a railing or a ramp, grab bars in the bathroom, a seat for the shower or tub, or an emergency call system?

	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	79	82	80	84
No \rightarrow next section	21	19	20	16

CS24. Which of these readines does the CR s residence have. (<i>multiple responses accepted</i>)					
	8 or fewer	9 - 19	20 - 39	40 or more	
	hours per week	hours per week	hours per week	hours per week	
A railing or ramp	60	61	74	64	
Grab bars in the bathroom	75	77	80	80	
A seat for the shower or tub	70	68	71	80	
An emergency call system	45	48	39	36	
Other	30	36	33	39	
Other	50	50	33	39	

QCS24. Which of these features does the CR's residence have? (multiple responses accepted)

CARE ACTIVITIES

Caregivers of **persons living in assisted living** were not asked QCA1 through QCA4B if they indicated they did not help the care recipient with household tasks (household tasks screener question SCRNHT).

QCA1PRE. Next we have a few questions about CR's needs for assistance and ways you may have helped CR in the last month because of [his/her] health and functioning. Let's start with chores you may do around CR's home. This includes laundry, cleaning, or making hot meals.

QCA1. In the last month, how often did [he/she] need help with laundry, cleaning, or making hot meals due to poor health and functioning?

-	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Every day	29	49	65	89
Most days	15	21	21	5
Some days	30	21	11	2
Rarely	12	3	1	0
Never \rightarrow QCA2	12	4	1	1
Does not do, but not because of poor health and functioning \rightarrow QCA2	3	2	1	3

QCA1A. In the last month, how often did you help CR with laundry, cleaning, or making hot meals or do these chores for [him/her]?

	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Every day	15	36	48	88
Most days	12	24	30	8
Some days	44	34	21	4
Rarely	17	4	0	0
Never	13	2	1	1

QCA1B. Does anyone else help CR with laundry, cleaning, or making hot meals or do these chores for [him/her]? (*Unpaid and paid could be both be selected therefore percentages may add to more than 100*)

	8 or fewer	9-19	20-39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes, another unpaid family member / friend	56	54	54	42
Yes, a paid helper	27	23	18	24
No	30	34	35	42

1 8	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Every day	24	41	52	73
Most days	23	23	23	11
Some days	32	23	19	11
Rarely	12	8	2	1
Never \rightarrow QCA3	8	4	2	2
Does not do, but not because of poor health and functioning \rightarrow QCA3	2	2	3	2

QCA2. In the last month, how often did [he/she] need help with shopping for groceries or personal items due to poor health and functioning?

QCA2A. In the last month, how often did you shop with CR for groceries or personal items or do [his/her] shopping for [him/her]?

1 11 0	8 or fewer	9-19 20-39		40 or more
	hours per week	hours per week	hours per week	hours per week
Every day	11	27	27	50
Most days	16	23	33	23
Some days	44	39	30	18
Rarely	18	8	1	4
Never	11	3	9	5

QCA2B. Does anyone else help CR with shopping for groceries or personal items? (*Unpaid and paid could be both be selected*)

	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes, another unpaid family member / friend	60	52	57	36
Yes, a paid helper	9	6	6	8
No	35	47	39	60

QCA3. In the last month, did CR need help with ordering medicines due to poor health and functioning?

	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	44	59	66	82
No \rightarrow QCA4	54	39	33	15
Does not do, but not because of poor health and functioning \rightarrow QCA4	3	2	2	3

QCA3A. In the last month, did you ever help CR order [his/her] prescribed medicines or order these for [him/her]?

-	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	62	79	77	91
No	38	22	23	9

	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes, another unpaid family member / friend	46	30	41	19
Yes, a paid helper	17	8	7	7
No	40	62	52	76

QCA3B. Does anyone else help CR with ordering medicines? (Unpaid and paid could be both be selected)

QCA4. In the last month, did CR need help with handling bills or banking due to poor health and functioning?

-	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	57	67	74	85
No \rightarrow QCA5	39	30	25	10
Does not do, but not because of poor health and functioning \rightarrow QCA5	4	4	1	5

QCA4A. In the last month, did you ever help CR with handling bills or banking or do this for [him/her]?

	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	72	82	78	86
No	28	18	22	14

QCA4B. Does anyone else help CR with handling bills or banking? (Unpaid and paid could be both be selected)

	8 or fewer	9 – 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes, another unpaid family member / friend	53	34	44	26
Yes, a paid helper	0	2	1	2
No	47	65	55	72

Caregivers of **persons living in assisted living** were not asked QCA5 through QCA12C if they indicated they did not help the care recipient with personal care (personal care screener question SCRNPC).

QCA5PRE. Now, a few questions about personal care.

QCA5. In the last month, how often did CR need help with eating due to poor health and functioning?

	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Every day	4	8	16	21
Most days	2	7	5	5
Some days	5	6	10	8
Rarely	8	12	13	11
Never \rightarrow QCA6	81	68	56	55

QCA5A. In the last month, how often did you help [him/her] with eating?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Every day	7	15	29	47
Most days	4	11	27	11
Some days	34	34	18	17
Rarely	33	25	19	18
Never	22	14	7	7

QCA5B. Does anyone else help [him/her] with eating? (Unpaid and paid could be both be selected)

	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes, another unpaid family member / friend	47	47	49	26
Yes, a paid helper	15	11	12	24
No	41	49	44	61

QCA6. In the last month, how often did CR need help with showering or bathing due to poor health and functioning?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Every day	10	24	30	51
Most days	6	8	21	12
Some days	9	15	14	12
Rarely	12	9	8	10
Never \rightarrow QCA7	63	45	27	15

	8 or fewer	9–19 ¹¹	20-39	40 or more
	hours per week	hours per week	hours per week	hours per week
Every day	4	17	21	43
Most days	7	12	19	15
Some days	19	27	27	19
Rarely	19	14	14	16
Never	51	30	20	8

QCA6A. In the last month, how often did you help [him/her] with showering or bathing?

QCA6B. Does anyone else help [him/her] with showering or bathing? (Unpaid and paid could be both be selected)

, ,	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes, another unpaid family member / friend	39	41	42	21
Yes, a paid helper	34	30	24	29
No	33	39	41	56

QCA7. In the last month, how often did CR need help with dressing or grooming due to poor health and functioning?

-	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Every day	10	18	34	51
Most days	6	7	16	9
Some days	13	19	14	13
Rarely	13	15	14	11
Never \rightarrow QCA8	59	41	22	16

QCA7A. In the last month, how often did you help CR with dressing or grooming?

	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Every day	6	10	22	50
Most days	7	14	22	18
Some days	31	38	35	19
Rarely	31	27	16	11
Never	25	10	5	2

QCA7B. Does anyone else help [him/her] with dressing or grooming? (Unpaid and paid could be both be selected)

	8 or fewer hours per week	9 – 19 hours per week	20 – 39 hours per week	40 or more hours per week
Yes, another unpaid family member / friend	48	41	45	26
Yes, a paid helper	24	24	22	26
No	37	45	44	55

	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Every day	5	13	26	38
Most days	2	4	6	3
Some days	3	9	8	8
Rarely	9	9	12	11
Never \rightarrow QCA9	81	65	48	40

QCA8. In the last month, how often CR need help with using the toilet due to poor health and functioning?

QCA8A. In the last month, how often did you help CR with using the toilet?

	8 or fewer	9–19 ¹	20-39	40 or more
	hours per week	hours per week	hours per week	hours per week
Every day	8	15	26	58
Most days	7	12	15	12
Some days	15	30	30	13
Rarely	30	23	25	13
Never	40	20	5	4

QCA8B. Does anyone else help [him/her] with using the toilet? (Unpaid and paid could be be	oth be
selected)	

	8 or fewer hours per week	9 – 19 hours per week	20 – 39 hours per week	40 or more hours per week
Yes, another unpaid family member / friend	55	52	52	31
Yes, a paid helper	34	31	26	32
No	25	34	36	47

QCA9. In the last month, how often did CR need help getting in and out of bed due to poor health and functioning?

C C	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Every day	8	15	21	33
Most days	2	4	6	5
Some days	7	10	13	6
Rarely	10	14	17	16
Never \rightarrow QCA10	74	57	43	40

QCA9A. In the last month, how often did you help CR get in and out of bed?

	8 or fewer	9 – 19	20-39	40 or more
	hours per week	hours per week	hours per week	hours per week
Every day	4	14	14	51
Most days	4	10	16	11
Some days	23	26	33	14
Rarely	36	31	34	20
Never	33	19	5	5

QCA9B. Does anyone else help [him/her] get in and out of bed? (Unpaid and paid could be both be selected)

	8 or fewer hours per week	9 – 19 hours per week	20 – 39 hours per week	40 or more hours per week
Yes, another unpaid family member / friend	54	49	49	33
Yes, a paid helper	26	22	23	22
No	29	42	42	53

QCA10. In the last month, how often did CR need help getting around [his/her] home due to poor health and functioning?

C	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Every day	6	13	26	39
Most days	4	6	7	4
Some days	11	16	14	10
Rarely	18	18	16	13
Never \rightarrow QCA11	61	47	38	34

QCA10A. In the last month, how often did you help CR get around [his/her] home?

	8 or fewer	9–19	20-39	40 or more
	hours per week	hours per week	hours per week	hours per week
Every day	2	13	23	51
Most days	7	12	20	12
Some days	32	41	37	19
Rarely	43	29	19	16
Never	16	5	2	3

QCA10B. Does anyone else help [him/her] get around [his/her] home? (Unpaid and paid could be both be selected)

	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes, another unpaid family member / friend	62	54	56	40
Yes, a paid helper	20	18	19	25
No	30	40	35	43

-	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Every day	13	23	34	44
Most days	9	16	14	8
Some days	22	20	18	14
Rarely	16	13	8	12
Never \rightarrow skip logic prior to QCA12A	40	28	26	23

QCA11. In the last month, how often did CR need help leaving [his/her] home to go outside due to poor health and functioning?

QCA11A. In the last month, how often did you help CR leave [his/her] home to go outside?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Every day	7	17	23	47
Most days	10	21	25	15
Some days	44	42	33	24
Rarely	28	14	13	12
Never	11	6	6	2

QCA11B. Does anyone else help [him/her] leave [his/her] home to go outside? (Unpaid and paid could
be both be selected)

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes, another unpaid family member / friend	65	57	59	50
Yes, a paid helper	13	15	16	17
No	28	37	34	41

Skip logic: QCA12A, *QCA12B*, and *QCA12C* were asked if CG responded he / she ever provided care on QCA5A, *QCA6A*, *QCA7A*, *QCA8A*, *QCA9A*, *QCA10A*, or *QCA11A* (i.e., response of every day, most days, some days, or rarely on one or more of these items)

QCA12A. In the last month when you helped CR with personal care, did you ever lift [him/her] from a seated or lying position?

	8 or fewer	9-19 20-39		40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	21	40	46	50
No	79	60	54	50

QCA12B. [In the last month when you helped CR with personal care,] did you ever let [him/her] lean on you or support [his/her] weight?

· · ·	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	68	71	77	75
No	32	29	23	25

QCA12C. [In the last month when you helped CR with personal care,] did you ever hold [him/her] steady while [he/she] walked or stood?

	8 or fewer	9-19 20-39		40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	67	78	70	76
No	33	22	30	24

QCA13. In the last month, how often did you drive CR places?

	8 or fewer	9-19 20-39		40 or more
	hours per week	hours per week	hours per week	hours per week
Every day	5	13	10	30
Most days	11	20	24	16
Some days	42	39	31	24
Rarely	20	15	15	11
Never	22	13	20	19

QCA14. In the last month, how often did you go with CR in a van, shuttle or cab, or take public transportation -- the bus, subway, train, or light rail – with [him/her]?

1	8 or fewer	9-19	20-39	40 or more
	hours per week	hours per week	hours per week	hours per week
Every day	1	1	1	7
Most days	1	2	4	5
Some days	3	5	4	4
Rarely	4	4	8	4
Never	66	59	52	49
Do not use	25	29	31	31

Caregivers of **persons living in assisted living** were not asked QCA15A through QCA19 if they indicated they did not help the care recipient with medical / nursing task care (medical / nursing tasks screener question SCRNMNT).

QCA15PRE. The next few questions are about help related to CR's health care.

	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	43	66	71	87
No	57	34	30	13

QCA15A1. In the last month, did you ever actually give CR [his/her] medications?

	8 or fewer	9 - 19	20-39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	25	48	62	79
No	75	53	38	21

ATJAZ. The are mese and s administered. (<i>multiple responses could be selected</i>)						
8 or fewer $9 - 19$ $20 - 39$						
hours per week	hours per week	hours per week	hours per week			
97	99	99	99			
9	12	11	17			
5	2	6	9			
1	1	1	0			
16	10	11	14			
3	3	3	3			
4	5	6	5			
4	3	2	7			
20	9	15	24			
3	8	9	8			
	8 or fewer hours per week 97 9 5 1 16 3 4 4 20	$\begin{array}{c c c c c c c c c c c c c c c c c c c $	$\begin{array}{c c c c c c c c c c c c c c c c c c c $			

QCA15A2. How are these drugs administered? (multiple responses could be selected)

QCA15B. [In the last month, did you ever help CR] take shots or injections?

-	8 or fewer	9 – 19	20-39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	2	7	8	15
No	98	93	92	85

QCA15C. [In the last month, did you ever help CR] manage medical tasks like ostomy care, IVs, or testing blood?

C	8 or fewer	9-19 20-39		40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	5	9	12	17
No	95	91	89	83

QCA15D. [In the last month, did you ever help CR] with exercises [he/she] was supposed to do?

-	8 or fewer	9 - 19 20 - 39		40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	12	29	48	45
No	88	71	52	55

QCA15E. [In the last month, did you ever help CR] with a special diet?

Ľ	8 or fewer	9 – 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	17	31	40	36
No	83	69	61	64

15F. [In the las	teeth or dentures.			
	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	8	15	31	44
No	92	85	69	56

QCA15F. [In the last month, did you ever help CR] care for [his/her] teeth or dentures?

QCA15G. [In the last month, did you ever help CR] care for [his/her] feet, like clipping nails?

	8 or fewer	9 – 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	13	33	37	55
No	87	67	63	45

QCA15H. [In the last month, did you ever help CR] with skin care related to wounds or sores? 8 or fewer $\begin{vmatrix} 9-19 \\ 20-39 \end{vmatrix}$ 40 or more

	8 or fewer	9 – 19	20 - 39	40 or more	
	hours per week	hours per week	hours per week	hours per week	
Yes	15	29	34	48	
No	85	71	66	52	

QCA15I. [In the last month, did you ever help CR] with assistive devices for mobility like canes or walkers?

	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	37	50	55	59
No	63	50	46	41

Caregivers were only asked QCA15J through QCA19 if they indicated they did help the care recipient with medical / nursing task care (medical / nursing task screener question SCRNMNT).

You indicated at the beginning of the survey that you perform some medical/nursing tasks. Many different tasks are considered medical/nursing tasks even though they are done at home. Some require equipment; others do not. Which of the following additional medical tasks do you perform?

QCA15J. [In the last month, did you ever] use incontinence equipment like catheters, supplies like adult diapers, or administer enemas?

-	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	23	37	48	53
No	77	63	52	47

QCA15K. [In the last month, did you ever] use meters/monitors (e.g., thermometer, glucometer, stethoscope, weight scales, blood pressure monitors, oxygen saturation monitors)?

	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	39	54	52	60
No	61	46	48	40

QCA15L. [In the last month, did you ever] administer test kits (bladder infection test, for example)? 8 or fewer 9-19 20-39 40 or more

	8 or fewer	9 – 19	20 - 39	40 or more	
	hours per week	hours per week	hours per week	hours per week	
Yes	2	2	4	8	
No	98	98	96	92	

QCA15M. [In the last month, did you ever] operate durable medical equipment (hospital beds, lifts, wheelchairs, scooters, toilet or bath chairs, geri-chairs, for example)?

eremans, secorers, remer or our enums, gen enums, for enumpre).						
8 or fewer		9-19	20 - 39	40 or more		
	hours per week	hours per week	hours per week	hours per week		
Yes	31	48	52	60		
No	69	52	48	40		

QCA15N. [In the last month, did you ever] operate mechanical ventilators, oxygen, tube feeding equipment, or home dialysis equipment?

-	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	11	16	18	25
No	89	84	83	75

QCA15O. [In the last month, did you ever] use telehealth equipment (cameras, sensors, phone lines to collect medical data in the home and transmit it to doctor or nurse)?

	8 or fewer	9 - 19	20 - 39	40 or more	
	hours per week	hours per week	hours per week	hours per week	
Yes	7	6	10	13	
No	93	94	91	87	

(If YES to any of QCA15A – QCA15O, ask QCA16 – QCA19; otherwise skip to QCA21)

QCA16. How difficult is it for you to do the medical and nursing tasks that are required to help CR? Please answer by choosing a number between 1 and 5, where 1 means not at all difficult and 5 means very difficult.

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
1. Not at all difficult	60	58	45	49
2.	21	21	20	17
3.	11	11	23	19
4.	4	6	11	10
5. Very difficult	3	4	2	6

QCA17. Did anyone prepare you to do these tasks?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	22	26	26	30
No \rightarrow QCA21	78	74	75	70

QCA18. Who prepared you to do the medical and nursing tasks needed to help CR? (multiple responses could be selected)

,	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Hospital nurse	29	16	15	28
Hospital doctor	9	2	8	6
Primary care doctor	9	18	5	26
Nurse in doctor's office or outpatient setting	17	11	10	10
Home care nurse	17	30	26	28
Social worker/geriatric care manager	3	5	3	0
Physical or occupational therapist	8	18	21	30
Pharmacist	6	11	5	2
Medical supply technician	6	7	5	14
Friend or neighbor	6	11	10	2
You learned on your own	24	23	31	30
Other	52	40	49	34

CA19. How well do you leef that person prepared you to take on these medical and hursing t					
	8 or fewer	9-19	20 - 39	40 or more	
	hours per week	hours per week	hours per week	hours per week	
Very well	83	82	64	84	
Somewhat well	14	14	36	16	
Not well	3	4	0	0	

QCA19. How well do you feel that person prepared you to take on these medical and nursing tasks?

QCA21. During that last 12 months, how many times has [he/she] been hospitalized overnight?

e	8 or fewer	9 – 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
None \rightarrow QCA24PRE	46	44	39	44
One time	24	21	15	22
2 times	13	15	22	17
3 or more times	17	20	25	18

QCA22. When [he/she] was in the hospital, were you included by health care workers, like nurses, doctors, or social workers, in discussions about CR's care? Would you say...

, , , ,	8 or fewer	9 – 19	20-39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes, all the time	49	58	63	73
Only some of the time	26	27	25	16
No, and you should have been	5	6	4	6
No, but you did not need to be	21	9	8	5

QCA23. Before CR left the hospital or was discharged, did you receive clear instructions about any medical or nursing tasks you would need to perform for [him/her]?

C	8 or fewer	9 – 19	20-39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	62	77	80	80
No	24	21	15	18
Not applicable	13	2	5	2

QCA23b. How prepared did you feel to take on any medical and nursing tasks after CRs hospitalization?

	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Very well	50	52	52	67
Somewhat well	38	35	39	26
Not well	12	13	9	7

QCA24PRE. Now think about the last YEAR.

QCA24A. In the last year, did you ever make appointments for CR with a medical provider?

	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	53	72	66	85
No	47	28	34	15

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	55	72	70	81
No	45	28	30	19

QCA24B. [In the last year, did you ever] speak to or email CR's medical provider about [his/her] care?

QCA24B1. [In the last year, did you ever] go with the CR to appointments with a medical provider?

	8 or fewer	9 – 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	78	90	87	93
No	22	10	13	7

QCA24C. [In the last year, did you ever] help [him/her] change or add a health insurance or prescription drug plan? [IF NEEDED: For example, changed or helped [him/her] change a Medicare supplemental plan or prescription drug plan, or helped [him/her] decide to join or leave a managed care plan.]

	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	20	33	23	35
No	80	67	77	65

QCA24D. [In the last year, did you ever] handle any other health insurance matters related to [his/her] medical care? [IF NEEDED: This includes contacting Medicare or another insurer to find out what is covered, comparing plans or providers, finding out about bills, or filing a claim.]

× 1 0	8 or fewer	9 – 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	28	45	40	51
No	72	55	60	49

QCA25b. Thinking about all of the ways you helped CR in the last month, did you help on a regular basis or did it vary? By regular schedule, we mean the same days or times every week.

	8 or fewer	9 – 19	20-39	40 or more
	hours per week	hours per week	hours per week	hours per week
Regular schedule	37	52	62	82
Varied	63	48	38	18

QCA26. For how long have you been helping this person with personal care routine household needs and/or medical/nursing tasks?

C	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
3 months or less	7	5	6	5
4 to 12 months	11	11	14	7
1 - 2 years	21	20	19	14
3 - 5 years	28	31	26	28
More than 5 years	34	33	34	47

	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Increased in the past month	26	38	46	47
Been about the same in the past month	63	55	44	48
Decreased in the past month	12	7	10	5

QCA27. Over the past month, has the amount you helped CR increased, decreased, or been about the same as before?

QCA28. Thinking ahead to next few months, do you think the amount you will help CR will increase, decrease, or be about the same as the past month?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per	hours per	hours per	hours per
	week	week	week	week
Will increase	28	31	42	41
Will be about the same	66	61	49	50
Will decrease	7	8	9	10

QCA29. Do you feel you had a choice in taking on this responsibility for caring for CR?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	49	46	41	41
No	51	54	59	59

QCA30. In general, how worried are you about making a mistake or error, or unintentionally hurting CR while caring for him / her?

e	8 or fewer	9-19	20 - 39	40 or more	
	hours per week	hours per week	hours per week	hours per week	
Very worried	3	6	7	8	
Somewhat worried	10	13	13	14	
Only a little	28	30	27	27	
Not at all	59	51	53	51	

Illness, disability, and life circumstances may cause some people to suffer either physically or psychologically.

QCA31. I'd like to ask you to the degree to w	vhicł	n you th	ink CF	R ha	s been	suffe	ring	physic	ally	during the
past month on a scale from 1 to 10 where 1 ec	quals	"CR h	as not l	been	n suffer	ing p	hysi	cally,"	and	10 equals
"CR has been suffering terribly".)			1		10					

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
1 CR has not been suffering physically	15	10	7	21
2	11	7	9	11
3	16	12	16	12
4	9	11	10	8
5	14	17	14	11
6	8	10	9	9
7	11	13	11	11
8	10	9	12	7
9	3	7	6	4
10 CR has been suffering terribly	5	6	6	7

QCA32. Now, please rate the degree to which you think CR has been <u>suffering psychogically or</u> <u>emotionally</u> during the past month on a scale from 1 to 10 where 1 equals "CR has not been suffering psychologically / emotionally," and 10 equals "CR has been suffering terribly".)

	8 or fewer	9 – 19	20-39	40 or more
	hours per week	hours per week	hours per week	hours per week
1 CR has not been suffering physically	15	9	9	19
2	10	7	8	13
3	12	12	8	9
4	9	9	5	2
5	14	18	17	11
6	10	10	12	7
7	10	10	10	8
8	10	11	18	15
9	4	8	5	5
10 CR has been suffering terribly	7	6	7	11

ASPECTS OF CAREGIVING

QAC1PRE. Now we have a few questions about your relationship with CR.

AC1. How much do you enjoy being with [him/her]?						
	8 or fewer		20 - 39	40 or more		
	hours per week	hours per week	hours per week	hours per week		
A lot	71	71	67	71		
Some	22	23	26	24		
A little	6	4	6	4		
Not at all	1	2	1	1		

QAC1. How much do you enjoy being with [him/her]?

QAC2. How much does [he	e/she] argue with	you?
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	8 or fewer	9 – 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
A lot	14	17	31	20
Some	23	24	29	30
A little	30	30	22	31
Not at all	33	29	19	19

QAC3. How much does CR appreciate what you do for [him/her]?

	8 or fewer	9 – 19	20 - 39	40 or more	
	hours per week	hours per week	hours per week	hours per week	
A lot	84	79	75	78	
Some	10	13	14	11	
A little	4	6	8	8	
Not at all	2	2	3	4	

QAC4. How often does [he/she] get on your nerves?

	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
A lot	18	15	24	29
Some	29	33	34	28
A little	34	33	29	32
Not at all	20	19	13	10

QAC4b. How would you say the quality of your relationship with CR has changed, if at all, since you began helping him/her? Would you say your relationship has...

1 0	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Gotten much better	15	23	15	18
Gotten somewhat better	24	19	16	20
Stayed about the same	52	41	51	41
Gotten somewhat worse	8	15	16	16
Gotten much worse	2	2	3	6

QAC5PRE. Next we have a few questions about your experience helping CR. For each statement I read, please tell me whether this describes your situation very much, somewhat, or not so much.

QAC5A. Helping [him/her] has made you more confident about your abilities.				
	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Very much	31	38	41	52
Somewhat	37	43	34	33
Not so much	32	20	26	16

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QAC5B. Helping [him/her] has taught you to deal with difficult situations.

1 01	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Very much	38	55	49	58
Somewhat	42	35	31	30
Not so much	19	10	19	12

QAC5C. Helping CR has brought you closer to [him/her].

1 8	8 or fewer	9 – 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Very much	44	54	39	55
Somewhat	39	29	43	30
Not so much	17	17	18	15

QAC5D. Helping CR gives you satisfaction that [he/she] is well cared for.

	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Very much	72	80	81	88
Somewhat	23	18	17	11
Not so much	5	3	1	1

QAC6A. Is helping CR financially difficult for you?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	14	21	33	33
No	86	79	67	68

QAC6B. Is helping [him/her] emotionally difficult for you?

	8 or fewer	9 – 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	50	65	68	71
No	50	35	32	29

QAC6C. Is helping [him/her] physically difficult for you?

	8 or fewer	9 – 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	20	32	34	40
No	80	68	66	60

QAC7A. Please tell me how difficult helping is by picking a number from 1 to 5. The number 5 means very difficult and the number 1 means a little difficult. How financially difficult is helping CR? (Asked if "yes" to QAC6A)

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
1. A little difficult	16	11	10	9
2.	18	13	6	4
3.	25	30	42	29
4.	25	34	19	20
5. Very difficult	18	11	23	38

QAC7B. How emotionally difficult is helping [him/her]? (Asked if "yes" to QAC6B)

	8 or fewer	9 - 19	20 - 39	40 or more	
	hours per week	hours per week	hours per week	hours per week	
1. A little difficult	13	9	9	16	
2.	23	18	15	8	
3.	28	32	29	22	
4.	19	27	23	24	
5. Very difficult	17	14	24	30	

QAC7C. How physically difficult is helping [him/her]? (Asked if "yes" to QAC6C)

1 5 5	8 or fewer	9 – 19	20-39	40 or more
	hours per week	hours per week	hours per week	hours per week
1. A little difficult	12	11	8	4
2.	30	17	13	9
3.	35	42	40	27
4.	17	22	23	34
5. Very difficult	6	7	17	27

QAC8. In general, how much has your family disagreed over the details of [his/her] care? (Asked if CR was related to CG)

	8 or fewer $9-19$		20 - 39	40 or more	
	hours per week	hours per week	hours per week	hours per week	
Very much	8	7	13	10	
Somewhat	20	20	23	26	
Not so much	72	73	64	64	

QAC9PRE. Please listen to a few more statements and answer whether this describes your situation very much, somewhat, or not so much.

AC9A. You are exhausted when you go to bed at night.						
	8 or fewer	9 - 19	20 - 39	40 or more		
	hours per week	hours per week	hours per week	hours per week		
Very much	19	32	47	47		
Somewhat	28	32	27	33		
Not so much	53	35	26	20		

QAC9A. You are exhausted when you go to bed at night.

QAC9B. You have more things to do than you can handle.

	8 or fewer	9 – 19	20 - 39	40 or more	
	hours per week	hours per week	hours per week	hours per week	
Very much	16	22	34	33	
Somewhat	31	43	32	30	
Not so much	53	34	34	37	

QAC9C. You don't have time for yourself.

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Very much	16	27	35	41
Somewhat	29	38	40	32
Not so much	55	35	24	27

QAC9D. As soon as you get a routine going, CR's needs change.

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Very much	7	11	17	18
Somewhat	23	30	31	32
Not so much	70	59	53	50

SUPPORT ENVIRONMENT

QSE1PRE. The next questions are about support you may be getting.

QSE1. Do you have friends or family that you talk to about important things in your life?						
	8 or fewer	9 – 19	20 - 39	40 or more		
	hours per week	hours per week	hours per week	hours per week		
Yes	92	89	88	85		
No	8	11	12	15		

QSE2. Do you have friends or family that help you with your daily activities, such as running errands, or helping you with things around the house?

1 07	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	55	50	52	49
No	45	50	48	52

QSE3. Do you have friends or family that help you care for CR?

J	8 or fewer	9 – 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	74	65	63	57
No	26	35	37	44

QSE4. In the last year, have you gone to a support group for people who give care?

	8 or fewer	9 – 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	3	7	6	12
No	97	93	94	88

QSE4a. In the last year, have you used any service that took care of CR so that you could take some time away from helping?

•	•	C	8 or fewer	9 - 19	20 - 39	40 or more
			hours per week	hours per week	hours per week	hours per week
Yes			17	21	21	24
No			83	79	79	77

OSE5.	In the last v	ear. have voi	a received any	training to he	lp you take care of CR?

	5	8 or fewer	9-19	20 - 39	40 or more
		hours per week	hours per week	hours per week	hours per week
Yes		7	13	10	11
No		93	87	90	89

QSE6. In the last year, have you found financial help for CR, including helping [him/her] apply for Medicaid?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	17	16	20	19
No	83	84	80	81

QSE7. Have you ever looked for [A support group for people who provide care] or [A service to care for CR so you could take time away] or [Training to help you care for CR] or [Information about how to get financial help for CR]? (Asked regarding items the respondent did not say YES to)

-	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	14	17	23	29
No	86	83	77	71

QSE8. In the last year, have you helped [him/her] to get devices to get around more easily, such as a cane, walker, wheelchair, or scooter?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	30	48	55	55
No	70	52	45	45

QSE9. In the last year, have you [made your home safer] [helped CR make [his/her] home safer] by adding features such as a railing or a ramp, grab bars in the bathroom, a seat for the shower or tub, or an emergency call system?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	34	44	53	58
No	66	56	47	42

QSE10. In the last year, have you helped [him/her] find a paid helper to do household chores or personal care?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	16	26	18	29
No	84	74	82	71

Shared Caregiving (Questions QSE11 through QSE16 were asked if the respondent indicated that he/she has family or friends to help care for CR in QSE3)

You mentioned that you have other family or friends that help you care for CR. I'd now like to ask a few questions about that.

E11. First, how many other family and friends help you care for CR?							
8 or fewer		9-19	20 - 39	40 or more			
	hours per week	hours per week	hours per week	hours per week			
One	21	27	27	19			
Two	28	22	25	36			
Three or more	51	52	49	45			

09	SE11.	First.	how	manv	other	family	v and	friends	help	you care	e for	CR?
										J		

QSE11A. Who is that (are they)? (multiple responses accepted)

		8 or fewer	9-19	20 - 39	40 or more
		hours per week	hours per week	hours per week	hours per week
(Caregiver's Brother(s)	27	31	24	22
(CG's Sister(s)	39	38	38	39
(CG's husband	21	18	20	18
(CG's wife	10	8	9	0
(CG's other relative(s) / in-law(s)	51	56	58	57
(CG's friend(s)	11	15	12	13
(Other	27	22	21	22

QSE12. Which of the following best describes where this/these additional helper(s) live(s)? (multiple *responses accepted*)

-	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Live(s) with you	39	37	48	33
Within twenty minutes of your home	63	65	65	67
Between twenty minutes and an hour	27	25	24	22
from your home	21	23	27	
One to two hours from your home	6	7	7	4
Two to four hours away	4	5	2	3
More than four hours away	13	11	5	10

OSE13.	Which of the following best describ	es how you divide the	tasks of caring for CR?
· ·	8	<u> </u>	. 8

C	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
We complement each other – we each help CR with different tasks.	35	30	16	21
We help with the same things but we divide the help over time.	15	17	23	20
We share some tasks, and others we do separately	50	53	61	59

QSE14. Would you say that you or someone else is the "primary caregiver," or the person that provides MOST of the help for your CR?

1	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Respondent is the primary caregiver	42	63	61	80
Someone else is the primary caregiver	42	25	25	6
Care is equally shared	16	12	14	14

QSE15. To what extent would you say that you and the other caregiver(s) experience confilict or disagreement over coordinating care for the CR?

0	8 or fewer	9-19	20 - 39	40 or more
	hours per	hours per week	hours per week	hours per week
	week			
To a great extent	2	2	3	1
To a moderate extent	6	7	11	15
Only a little	33	27	24	27
Not at all	59	63	62	57

QSE16. Overall, how satisfied or dissatisifed are you with the care coordination between you and your family / friends?

-	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Very satisfied	70	68	59	67
Moderately satisfied	23	26	29	27
Moderately dissatisfied	5	4	9	5
Very dissatisfied	2	2	3	1

PARTICIPATION

QPP1PRE. Now let's talk about other activities you may have done in the last month.

QPP1. In the last month, did you ever visit in person with friends or family NOT living with you, either at your home or theirs?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	88	87	83	77
No	12	13	17	24

QPP2. In the last month, did helping CR ever keep you from doing this [visiting in person with friends or family NOT living with you]?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	19	30	43	49
No	81	71	57	51

QPP3. How important is it to you to visit in person with friends or family NOT living with you?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Very important	57	51	53	46
Somewhat important	32	34	35	31
Not so important	11	15	12	23

QPP4. In the last month, did you ever attend religious services?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	63	61	55	58
No	37	39	45	42

QPP5. In the last month, did helping CR ever keep you from doing this [attending religious services]?

	8 or fewer	9 – 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	5	11	21	27
No	95	89	79	73

QPP6. How important is it to you to attend religious services?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Very important	48	47	38	49
Somewhat important	20	23	34	23
Not so important	32	30	29	28

QPP7. In the last month, [besides religious services,] did you ever participate in club meetings or group activities? [IF NEEDED: These could be any ongoing group activity including dinner or bridge clubs, neighborhood or political organizations, knitting or regular exercise groups.]

ghoomood of pointed ofgamzations, kintling of regular excitese groups.]					
	8 or fewer	9-19	20 - 39	40 or more	
	hours per week	hours per week	hours per week	hours per week	
Yes	55	47	44	37	
No	45	53	56	64	

QPP8. In the last month, did helping CR ever keep you from doing this [participating in club meetings or group activities [other than religious services]]? [IF NEEDED: These could be any ongoing group activity including dinner or bridge clubs, neighborhood or political organizations, knitting or regular exercise groups.]

	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	12	17	32	37
No	88	83	68	63

QPP9. How important is it to you to participate in club meetings or group activities [other than religious services]? [IF NEEDED: These could be any ongoing group activity including dinner or bridge clubs, neighborhood or political organizations, knitting or regular exercise groups.]

	0		0 10		10
		8 or fewer	9 – 19	20 - 39	40 or more
		hours per week	hours per week	hours per week	hours per week
Very important		36	27	24	28
Somewhat important		28	34	41	25
Not so important		35	39	35	47

QPP10. In the last month, [besides for club or group activities,] did you ever go out for enjoyment? This includes things like going out to dinner, a movie, to gamble, or to hear music or see a play.

C	C	8 or fewer	9-19	20 - 39	40 or more
		hours per week	hours per week	hours per week	hours per week
Yes		91	85	80	68
No		9	15	20	32

QPP11. In the last month, did helping CR ever keep you from doing this [going out for enjoyment]? [IF NEEDED: This includes things like going out to dinner, a movie, to gamble, or to hear music or see a play.]

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	14	20	37	46
No	86	80	63	54

QPP12. How important is it to you to go out for enjoyment? [IF NEEDED: This includes things like going out to dinner, a movie, to gamble, or to hear music or see a play.]

e ,	, 0	8 or fewer	9 – 19	20 - 39	40 or more
		hours per week	<i>y</i> 1 <i>y</i>	hours per week	hours per week
Very important		53	48	42	41
Somewhat important		36	38	43	38
Not so important		12	14	15	21

QPP13. In the l	ast month, o	did you ever	do volunteer work?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	41	39	27	32
No	59	61	73	68

QPP14. In the last month, did helping CR ever keep you from doing this [volunteer work]?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	7	15	24	31
No	93	85	76	69

QPP15. In the last month, [besides as a job or volunteer work,] did you ever provide care to or look after a child or adult who cannot care for themselves? We mean someone besides CR.

	8 or fewer	9 – 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	42	39	43	39
No	58	61	57	61

QPP16. In the last month, did helping CR ever keep you from doing this [caring for a child or other adult]?

	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	4	7	12	15
No	96	93	88	85

HEALTH

	o of fewer	9 - 19	20 - 39	40 01 11010
	hours per week	hours per week	hours per week	hours per week
Excellent	17	19	12	9
Very good	34	32	31	26
Good	29	28	33	36
Fair	17	17	20	25
Poor	3	4	5	3

QHE2. Has a doctor ever told you that you had a heart attack or myocardial infarction?

	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	6	7	9	8
No	94	93	91	92

QHE3. Has a doctor ever told you that you had any other heart disease including angina or congestive heart failure?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	8	7	10	13
No	93	93	90	87

QHE4. [Has a doctor ever told you that you had] high blood pressure or hypertension?

	8 or fewer	9 – 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	39	40	39	49
No	61	60	61	51

QHE5. [Has a doctor ever told you that you had] arthritis?

-	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	43	45	44	64
No	57	55	56	36

QHE6. [Has a doctor	ever told you that	at you had] ostee	porosis or thinn	ing of the bones?
				1

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	16	20	19	28
No	84	80	81	72

QHE7. [Has a doctor ever told you that you had] diabetes?

	8 or fewer	9 – 19	20-39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	13	14	14	19
No	87	86	86	81

QHE8. [Has a doctor ever told you that you had] lung disease, such as emphysema, asthma, or chronic bronchitis?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	14	16	17	21
No	87	84	83	79

QHE9. [Has a doctor ever told you that you had] cancer?

-	8 or fewer	9 – 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	13	15	11	17
No	87	85	89	83

QHE10PRE. Now I have a few questions about health problems.

QHE10. In the last month, have you be	een bothered by	pain?
8 or fewer	9 – 19	20 - 39

	8 or fewer	9 – 19	20 – 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	61	58	62	69
No	40	42	38	31

QHE12. In the last month, did you have any breathing problems, including shortness of breath or difficulty breathing?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	14	15	20	22
No	86	85	80	78

QHE14. In the last month, did you have limited strength or movement in your shoulders, arms, or hands?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	25	28	35	42
No	75	72	65	58

QHE16. In the last month, did you have limited strength in your hips, legs, knees, or feet?

	8 or fewer	9 - 19	$20 - 39^{-1}$	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	36	37	40	47
No	64	63	60	53

	8 or fewer	9 – 19	20-39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	46	51	62	58
No	54	49	38	42

QHE18. In the last month, did you have low energy or were you easily exhausted?

QHE20. In the last month, on nights when you woke up before you wanted to, how often did you have trouble falling back asleep?

C	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Every night	7	10	9	14
Most nights	14	11	19	19
Some nights	32	35	36	29
Rarely	29	27	21	22
Never	18	17	15	17

QHE21. In the last month, how often did helping CR cause your sleep to be interrupted?

	8 or fewer	9-19	20-39	40 or more
	hours per week	hours per week	hours per week	hours per week
Every night	1	1	2	10
Most nights	2	5	7	10
Some nights	11	19	27	31
Rarely	20	30	24	22
Never	68	45	40	27

QHE23a. How tall are you? (see BMI below) QHE23b. How tall are you? (see BMI below) QHE22. How much do you currently weigh? (see BMI below)

BMI categories:

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
< 18.5 (underweight)	1	1	1	1
18.5 – 24.9 (normal)	25	27	31	28
25.0 - 29.9 (overweight)	38	39	29	36
30.0 - 34.9 (moderately obese)	25	21	21	19
35.0 - 39.9 (severely obese)	6	8	11	7
40.0 + (very severely obese)	6	4	7	10

QHE24. Have you lost 10 or more pounds in the last 12 months?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	29	28	33	34
No → QHE25A	71	72	68	67

QHE24a. Were you trying to lose weight?

	5	8 or fewer	9 – 19	20 - 39	40 or more
		hours per week	hours per week	hours per week	hours per week
Yes		74	73	63	55
No		26	27	37	45

QHE25a. Thinking about the last month, how often did you feel cheerful?

6	8 or fewer	9 – 19	20-39	40 or more
	hours per week	hours per week	hours per week	hours per week
Every day	17	14	11	15
Most days	49	48	42	38
Some days	27	26	36	34
Rarely	6	11	11	12
Never	1	2	1	1

QHE25b. Thinking about the last month, how often did you feel calm and peaceful?

	8 or fewer	9 – 19	20-39	40 or more
	hours per week	hours per week	hours per week	hours per week
Every day	15	9	9	13
Most days	42	41	34	33
Some days	32	34	36	30
Rarely	10	15	18	17
Never	1	2	3	7

QHE25c. [Thinking about the last month,] how often did you feel full of life?

L	$\boldsymbol{\omega}$		/ _	2	
		8 or fewer	9 - 19	20 - 39	40 or more
		hours per week	hours per week	hours per week	hours per week
Every day		18	15	10	17
Most days		36	37	27	24
Some days		32	27	38	30
Rarely		12	16	23	21
Never		2	5	2	8

QHE25d. [Thinking about the last month,] how often did you feel bored?

- L	0	. /]		
	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Every day	2	3	2	4
Most days	5	7	5	7
Some days	19	19	26	25
Rarely	36	28	34	24
Never	37	43	34	41

1223e. [1 minking about the last month,] now often did you leef lonery?					
8 or fewer		9 - 19	20 - 39	40 or more	
	hours per week	hours per week	hours per week	hours per week	
Every day	1	2	5	5	
Most days	5	9	7	11	
Some days	18	16	26	28	
Rarely	31	29	28	20	
Never	45	44	34	35	

QHE25e. [Thinking about the last month,] how often did you feel lonely?

QHE25f. [Thinking about the last month,] how often did you feel upset?

	8 or fewer	9 – 19	20-39	40 or more
	hours per week	hours per week	hours per week	hours per week
Every day	3	2	4	7
Most days	8	10	6	12
Some days	42	47	58	50
Rarely	41	34	26	28
Never	7	8	6	3

QHE26a. Over the last month, how often have you had little interest or pleasure doing things?

	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Not at all	59	56	50	51
Several days	34	30	35	28
More than half the days	5	8	9	14
Nearly every day	2	6	6	8

OHE26b. [Over the last month, how often have you] felt down, de	epressed, or hopeless?
---	------------------------

-	8 or fewer	9 – 19	20-39	40 or more
	hours per week	hours per week	hours per week	hours per week
Not at all	62	61	48	48
Several days	31	28	42	32
More than half the days	5	6	6	14
Nearly every day	2	5	4	7

QHE26c. [Over the last month, how often have you] felt nervous, anxious, or on edge?						
	8 or fewer	9 - 19	20 - 39	40 or more		
	hours per week	hours per week	hours per week	hours per week		
Not at all	44	38	36	44		
Several days	45	48	46	34		
More than half the days	8	7	11	10		
Nearly every day	4	8	7	12		

E26d. [Over the last month, how often have you] been unable to stop or control worrying?						
	8 or fewer	9 - 19	20 - 39	40 or more		
	hours per week	hours per week	hours per week	hours per week		
Not at all	57	51	45	43		
Several days	28	31	35	32		
More than half the days	7	9	10	10		
Nearly every day	7	10	10	15		

QHE26d. [Over the last month, how often have you] been unable to stop or control worrying?

HEALTH LITERACY AND NUMERACY

QLN1PRE. The next few questions are about your abilities and skills in understanding medical information when you have a health problem.

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Not at all	3	2	2	5
A little bit	4	4	3	6
Somewhat	8	9	7	12
Quite a bit	31	25	33	22
Extremely	54	61	55	55

QLN1. How confident are you filling out medical forms by yourself?

QLN2. How often do you need to have someone help you when you read instructions, pamphlets, or other written material from a doctor or pharmacy?

	8 or fewer	9 – 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Never	69	70	68	62
Rarely	23	22	24	25
Sometimes	8	8	5	12
Often	1	0	3	0
Always	0	0	1	1

QLN3. How often do you have problems learning about a medical condition because of difficulty understanding written information?

C	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Never	66	67	65	61
Rarely	26	22	27	24
Sometimes	7	10	8	13
Often	1	0	0	1
Always	0	0	1	2

QLN4PRE. As a caregiver, you might be asked to help CR understand medical information like test results, diagnoses, or the likelihood of side effects of various medications. This can sometimes involve working with and understanding numbers. The next few questions are designed to measure your ability to work with numbers. Many people have trouble with some of these questions, so don't worry if you find any of them difficult. Just do the best you can.

QLN4. Which of the following numbers represents the biggest risk of getting a disease (1 in 100; 1 in 1,000; or 1 in 10)?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Correct	69	72	62	59
Incorrect	31	28	38	41

QLN5. If the chance of getting a disease is 10%, how many people out of 1000 would be expected to get the disease? (*open-ended question; responses categorized for presentation*)

	8 or fewer	9 – 19	20-39	40 or more
	hours per week	hours per week	hours per week	hours per week
Correct	83	84	85	75
Incorrect	17	16	15	25

QLN6. If the chance of getting a disease is 20 out of 100, this would be the same as having a what percent chance of getting the disease? (*open-ended question*; responses categorized for presentation)

0 0	8 or fewer	9-19	20-39	40 or more
	hours per week	hours per week	hours per week	hours per week
Correct	80	75	76	71
Incorrect	20	25	24	29

EMPLOYMENT AND CAREGIVING

QEC1PRE. Now I'd like to ask you some questions about work and jobs you may have had.

QEC1. Did you do any work for pay in the last week? By the last week, I mean the last full week beginning on a Sunday and ending on a Saturday.

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
$Yes \rightarrow QEC4$	53	51	45	29
No	19	21	26	28
Retired / don't work anymore \rightarrow QEC16	28	28	29	43

QEC2. Do you have a job from which you were absent last week because of illness, vacation, or some other reason?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes \rightarrow QEC4	6	19	2	0
No	68	57	83	70
Retired / don't work anymore \rightarrow QEC16	25	24	15	30

QEC3. In the last week, were you looking for a job or were you on layoff from a job?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes, looking for a job \rightarrow QEC16	9	10	27	18
Yes, on layoff \rightarrow QEC16	6	0	6	9
No \rightarrow QEC16	76	84	62	70
Retired / don't work anymore \rightarrow QEC16	9	7	6	3

QEC4. Last week, did you have more than one job, including part-time, evening, or weekend work?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	22	21	21	24
No	78	79	79	76

QEC5. How many total hours per week do you usually work? (*open-ended question; categorized for display*)

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
20 or fewer	20	23	19	29
21 – 39	18	20	24	16
40 or more	62	57	57	55

QEC6. [On your main job do / Do] you have flexible work hours that allow you to vary or make changes in the time you begin and end work?

2	U	8 or fewer	9-19	20 - 39	40 or more
		hours per week	hours per week	hours per week	hours per week
Yes		60	60	51	66
No		40	40	49	34

QEC7. [On your main job do / Do] you usually work a daytime schedule or some other schedule?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Daytime	84	78	85	78
Some other schedule	17	23	16	22

If response to QEC2 was yes, skip to QEC9A

QEC8. Now thinking back over the last month, were you ever absent from work for any reason?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	43	47	44	40
No \rightarrow QEC12	57	53	56	60

QEC9A. I will read a few reasons people miss work. For each one, please say "yes" if this was a reason you missed work over the last month, and say "no" if you did not miss work for this reason.

You were on vacation.

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	38	30	13	40
No	62	70	88	60

QEC9B. You were sick.

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	36	40	53	40
No	64	60	47	60

QEC9C. You took time off to help CR.

	8 or fewer 9 – 19		20 - 39	40 or more	
	hours per week	hours per week	hours per week	hours per week	
Yes	36	47	59	60	
No	64	54	41	40	

QEC9D. Other family members were sick.

	8 or fewer	9-19	20 - 39	40 or more	
	hours per week	hours per week	hours per week	hours per week	
Yes	20	24	10	25	
No	80	76	90	75	

QEC9E. You took personal time for other reasons. [IF NEEDED: For example, a school visit for a child, looking for a job, taking classes.]

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	44	32	31	25
No	56	68	69	75

If response to QEC9C was yes, ask QEC10; otherwise, skip to QEC12

QEC10. You said one of the reasons you were absent from work last month was because you were helping CR. About how many days of work did you miss last month to do this?

C	8 or fewer	9 – 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
One	63	47	37	50
Two	23	25	16	25
Three or more	14	28	47	25

QEC12. We are interested in whether helping CR affects you at work. In the last month, did helping [him/her] make it harder for you to get your work done?

	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	19	27	34	40
No →QEC14	81	73	66	60

QEC13. Please tell me how much helping CR affected you at work by picking a number from 1 to 10. The number 10 means helping [him/her] made your work a lot harder and the number 1 means helping [him/her] made your work a little harder.

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
1 A little harder	19	16	0	15
2	17	8	13	0
3	21	21	21	10
4	14	11	17	15
5	5	24	17	25
6	7	8	8	10
7	10	3	4	10
8	7	5	17	10
10 A lot harder	0	5	4	5

QEC14. [On your main job does / Does] your supervisor know that you are caring for C							
	8 or fewer	9-19	20 - 39	40 or more			
	hours per week	hours per week	hours per week	hours per week			
Yes	72	82	80	92			
No	28	19	20	8			

QEC14. [On your main job does / Does] your supervisor know that you are caring for CR?

QEC15. For employees in your position, which of the following does your employer offer? (*multiple responses accepted*)

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Telecommuting or working from home	36	29	25	26
Programs like information, referrals, counseling, or an employee assistance program, to help caregivers like yourself	41	39	24	20
Paid leave, where you could take paid time off from work for several weeks to care for a family member	36	35	30	26
Paid sick days	57	52	58	40
None of the above	22	32	27	42

QEC16. As a result of caregiving, did you e	ver ex	xperienc	e any	of the fol	lowing	g thin	gs at v	vork?	(multiple
responses accepted)			I	0 10	1				

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Went in late, left early, or took time off during the day to provide care	40	50	39	41
Took a leave of absence	8	17	14	17
Went from working full-time to part-time, or cut back your hours	11	19	13	19
Turned down a promotion	2	5	4	5
Lost any of your job benefits	3	4	5	8
Gave up working entirely	7	13	16	28
Retired early	10	12	10	24
Received a warning about your performance or attendance at work	3	5	3	4
None of the above	51	35	40	38

DEMOGRAPHICS

	8 or fewer	9 - 19	20 - 39	40 or more			
	hours per week	hours per week	hours per week	hours per week			
Male	31	23	21	21			
Female	69	77	79	79			

QDE1. INTERVIEWER: RECORD PERSON'S SEX

QDE2. What is your age now? (*categorized for display*)

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
44 or under	13	9	17	8
45 - 54	19	21	22	12
55 - 64	41	41	33	36
65 or older	27	29	29	45

QDE3. What is your current marital status? Are you:

8 or fewer	9-19	20 - 39	40 or more
hours per week	hours per week	hours per week	hours per week
64	54	51	60
4	5	3	8
10	16	19	14
6	4	3	5
16	21	24	14
	hours per week 64 4 10 6	$\begin{array}{c c c c c c c c c c c c c c c c c c c $	$\begin{array}{c c c c c c c c c c c c c c c c c c c $

QDE4. Are you of Hispanic or Latino descent?

· ·	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	2	1	3	1
No	98	99	98	99

QDE5. How would you describe your race or ethnicity? (multiple responses accepted)

	8 or fewer	9-19	20-39	40 or more
	hours per	hours per	hours per	hours per
	week	week	week	week
Caucasian/White	83	86	78	78
Asian/Pacific Islander	1	0	1	0
American Indian or Alaskan Native	1	1	1	2
Black or African-American	16	12	18	21
None of the above	1	0	2	0

	8 or fewer	9 – 19	20 - 39	40 or more
	hours per	hours per	hours per	hours per
	week	week	week	week
Eighth grade or less	0	0	0	0
Some high school	1	0	2	2
High school graduate or GED	16	17	20	28
Some college, no degree	20	22	23	17
Associate's degree, occupational	6	6	8	11
Associate's degree, academic	6	6	8	5
Bachelor's degree	28	29	20	25
Master's degree	18	15	16	8
Professional degree	2	2	2	5
Doctoral degree	3	3	1	1

QDE6. What is the highest level of education you have completed?

QDE7. What are your current living arrangements? Do you ...

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Live alone \rightarrow QDE11PRE	17	16	19	4
Live in a household with family or others	82	83	81	94
Have some other living arrangements	1	1	1	2

QDE8. Including you, how many adults, age 18 and older, currently live in your household?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per we	eek hours per week	hours per week	hours per week
One	5	5	6	3
Two	65	64	67	63
Three	21	22	20	26
Four	7	8	6	7
Five	2	1	1	2
Six	0	1	0	0

QDE9. How many children under age 18 currently live in your household?

						
-	8 or fewer	9 – 19	20 - 39	40 or more		
	hours per week	hours per week	hours per week	hours per week		
Zero	76	81	78	89		
One	12	8	16	4		
Two	8	7	5	4		
Three	4	2	1	1		
Four	0	1	0	2		
Five	1	1	0	0		
Six	0	0	1	0		

JETU. What is the relationship	of cach of these	people to you?	(muniple responses accepted)		
	8 or fewer	9 – 19	20 - 39	40 or more	
	hours per week	hours per week	hours per week	hours per week	
Your spouse / partner	84	71	67	71	
Your child(ren)	39	32	31	23	
Your grandchild(ren)	4	4	5	7	
Your parent(s)	8	20	24	32	
Other relatives of yours	8	13	9	13	
Non-relatives	4	4	2	2	

QDE10. What is the relationship of each of these people to you? (multiple responses accepted)

QDE11PRE. And now just a couple questions about CR.

QDE11.	What is the highest le	evel of education	[he/she]	completed?

8	L 1	1 ¹		
	8 or fewer	9 – 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Eighth grade or less	5	6	7	7
Some high school	7	5	8	7
High school graduate or GED	46	47	43	48
Some college, no degree	9	7	9	7
Associate's degree, occupational	6	8	7	6
Associate's degree, academic	3	3	1	6
Bachelor's degree	14	14	14	12
Master's degree	6	6	6	5
Professional degree	2	1	3	2
Doctoral degree	2	3	2	2

QDE12. Is [he/she] of Hispanic or Latino descent?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	1	0	1	0
No	100	100	99	100

QDE13. How would you describe [his/her] race or ethnicity? (multiple responses accepted)

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per	hours per	hours per	hours per
	week	week	week	week
Caucasian/White	83	86	80	79
Asian/Pacific Islander	1	0	1	0
American Indian or Alaskan Native	1	0	2	2
Black or African-American	16	13	19	21
None of the above	1	0	1	0

INFORMATION / SERVICES / POLICY

QIN1. In your experience as a caregiver, have you ever had a doctor, nurse, or social worker ask you about what you need to help care for CR?

at 11 mat joa meet	in what you need to help cure for ere.					
	8 or fewer	9 - 19	20 - 39	40 or more		
	hours per week	hours per week	hours per week	hours per week		
Yes	27	42	39	56		
No	74	59	61	44		

QIN2. In your experience as a caregiver, have you ever had a doctor, nurse, or social worker ask you what you need to take care of yourself?

	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	12	19	19	31
No	88	82	81	69

QIN2b. How difficult is it for you to communicate when necessary with healthcare professional such as doctors, nurses, social workers, pharmacists, and rehabilitation therapists about CR's needs for care? Please answer by using a number between 1 and 5, where 1 means not at all difficult and 5 means very difficult.

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
1. Not at all difficult	71	77	76	75
2	15	10	12	10
3	8	8	7	8
4	3	3	3	2
5. Very difficult	4	2	2	5

QIN2c. How difficult is it for you to communicate when necessary with healthcare professional such as doctors, nurses, social workers, pharmacists, and rehabilitation therapists about your own needs for information and support as a caregiver? Please answer by using a number between 1 and 5, where 1 means not at all difficult and 5 means very difficult.

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
1. Not at all difficult	73	68	67	70
2	14	13	10	9
3	8	9	13	10
4	4	6	8	2
5. Very difficult	2	5	3	9

QIN3. How difficult is it to locate and arrange for affordable community-based services in CR's local area that could help you care for CR, such as like delivered meals and transportation? Please answer by using a number between 1 and 5, where 1 means not at all difficult and 5 means very difficult.

8	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
1. Not at all difficult	41	38	37	41
2	11	9	8	7
3	10	14	14	8
4	7	7	8	8
5. Very difficult	6	10	7	14
Not applicable	26	22	26	24

QIN3a. How difficult is it to locate and arrange for affordable paid in-home personal care such as helping with bathing, dressing, and meals? Please answer by using a number between 1 and 5, where 1 means not at all difficult and 5 means very difficult.

	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
1. Not at all difficult	33	31	34	34
2	10	10	8	9
3	9	16	8	10
4	6	5	6	8
5. Very difficult	10	12	20	17
Not applicable	33	26	24	21

QIN3b. How difficult is it to locate and arrange for affordable community-based service providers that you can trust to provide good care for CR? Please answer by using a number between 1 and 5, where 1 means not at all difficult and 5 means very difficult.

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
1. Not at all difficult	27	29	24	31
2	11	8	6	2
3	12	15	12	15
4	10	9	12	8
5. Very difficult	9	14	23	22
Not applicable	31	26	23	23

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Requiring health care providers to include your name on CR's medical chart, so you are part of conversations or decisions about [his/her] care	81	88	85	84
Requiring hospitals to keep you informed about major decisions, like transferring or discharging CR	83	91	87	87
Requiring hospitals or facilities to instruct or demonstrate any medical or nursing tasks you might need to do	84	90	89	87
Having respite services available, where someone would take care of CR to give you a break	64	73	76	79
Requiring a doctor, nurse, or social worker ask you about what you need to help care for CR	75	83	82	80
Requiring a doctor, nurse, or social worker ask you about what you need to take care of yourself	56	69	70	69
None of the above	8	4	3	3

QIN4. Various organizations are thinking about ways to help caregivers like you. Which of the following do you think would be helpful to you? *(multiple responses accepted)*

QIN5. Next I'll read three ways that people are proposing to help caregivers financially. Please tell me which ONE you would find most helpful.

	8 or fewer hours per week	9 – 19 hours per week	20 – 39 hours per week	40 or more hours per week
An income tax credit to caregivers, to help offset the cost of care A partially paid leave of absence	38	30	27	37
from work for caregivers who are employed A program where caregivers could	24	19	13	9
be paid for at least some of the hours they provide care	38	51	60	54

HEALTH INSURANCE AND INCOME

QHI1pre. We have a few last questions.

QHI1. Are you currently covered by Medicare, a health insurance program for person 65 years and over and persons with disabilities?

-	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	36	39	43	56
No → QHI3	64	61	57	44

QHI2. Some people with Medicare also have a Medigap or Medicare Supplement plan. Do you have this type of health insurance coverage?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	66	77	55	69
No	34	23	46	31

QHI3. Medicaid is a state program for low-income persons or for persons on public assistance. Are you now covered by Medicaid?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	9	12	18	15
No	91	88	82	85

QHI4. Are you currently covered by a private health insurance plan? IF NEEDED: This may be a policy you [or your {spouse/partner}]have through a job, a labor union, or an association or organization you belong to. It may also be bought directly from an insurance agent or company.

0	5	8 or fewer	9-19	20-39	40 or more
		hours per week	hours per week	hours per week	hours per week
Yes		82	78	70	62
No		18	22	30	38

QHI5. TRICARE and CHAMPVA are health care programs for active duty and retired members of the uniformed Armed Forces, their families, and survivors. Are you now covered by either one of these programs?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	2	4	5	4
No	98	97	96	96

(multiple responses accepted)				
	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Medicare	75	77	74	78
Medicaid	15	17	24	21
Private Health Insurance	51	65	47	59
Tricare/CHAMPVA	3	5	1	5

QHI7C. What kind of health insurance does the CR have? (multiple responses accepted)

QHI8. Do you own your home? (select "yes" if owned with spouse/partner)

2	8 or fewer	9 – 19	20-39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	80	78	68	73
No	21	22	32	27

QHI9A. Do you [and your {spouse/partner}] have any checking accounts?

	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	99	95	95	92
No	1	5	5	8

QHI9B. Do you [and your {spouse/partner}] have any savings or money market accounts?

	•	-	8 or fewer	9-19	20 - 39	40 or more
			hours per week	hours per week	hours per week	hours per week
Yes			80	78	69	65
No			20	22	31	35

QHI9C. Do you [and your {spouse/partner}] have any certificates of deposit?

	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	21	18	17	17
No	79	82	83	83

QHI9D. Do you [and your {spouse/partner}] retirement plans such as IRAs, SEPs, 401K, or 403b plans? 8 or fewer $\begin{vmatrix} 9 - 19 \\ 20 - 39 \end{vmatrix}$ 40 or more

) 1)	20 57	
	hours per week	hours per week	hours per week	hours per week
Yes	78	74	62	59
No	22	26	38	41

QHI9E. Do you [and your {spouse/partner}] stocks or mutual funds that are not in retirement accounts?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	42	34	28	28
No	58	66	73	72

QHI10. Now thinking about the income that you [and your {spouse/partner}] have from [work and] all other sources, about how much was your [and your {spouse/partner's}] total income for the last year (in the last 12 months ending in December 2016) before taxes?

	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
0 - less than \$10,000	5	5	11	11
\$10,000 to less than \$20,000	8	10	13	11
\$20,000 to less than \$30,000	7	10	13	14
\$30,000 to less than \$40,000	9	14	15	17
\$40,000 to less than \$50,000	8	11	10	14
\$50,000 to less than \$60,000	11	9	10	8
\$60,000 to less than \$70,000	10	8	8	6
\$70,000 to less than \$80,000	7	7	3	5
\$80,000 to less than \$90,000	6	5	2	6
\$90,000 to less than \$100,000	6	7	4	1
\$100,000 to less than \$110,000	7	5	2	1
\$110,000 to less than \$120,000	2	1	2	1
\$120,000 to less than \$130,000	1	3	2	0
\$130,000 to less than \$140,000	0	1	0	0
\$140,000 to less than \$150,000	3	2	1	2
More than \$150,000	12	5	4	3

QHI14A. Family members often help each other out financially. In the last year have you used your own money to pay for CR's medications or medical care?

• • •	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	30	40	43	58
No	70	60	57	43

QHI14B. In the last year have you used your own mon	ney to pay for CR's Medicare premiums or
copayments or other insurance premiums and copayme	

•	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	14	20	24	38
No	86	80	76	62

QHI14C. In the last year have you used your own money to pay for mobility devices for CR such as walkers, canes, or wheelchairs?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	10	14	15	20
No	90	86	85	80

QHI14D. In the last year have you used your own money to pay for features that made CR's home safer such as a railing or a ramp, grab bars in the bathroom, a seat for the shower or tub, or an emergency call system?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	18	32	33	38
No	82	68	67	62

QHI14E. In the last year have you used your own money to pay for any other assistive devices for CR that make it easier or safer for [him/her] to do activities or do them on [his/her] own? This includes devices to help [him/her] see, hear, reach, hold things, or pick things up.

	8 or fewer	9-19	20-39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	13	22	21	34
No	87	78	80	66

QHI14f. In the last year have you used your own money to pay for a paid in-home helper for CR?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	3	10	12	24
No	97	90	88	76

If QHI14A through QHI14F are all no, don't know, or refused skip to next section.

QHI15. Altogether last year, would you say you paid more or less than \$1,000 for CR's [medications or medical care,]

icultations of medical care,				
	8 or fewer	9-19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
More than $1,000 \rightarrow \text{QHI6}$	32	42	37	62
Less than $1,000 \rightarrow \text{QHI7}$	68	58	63	38

OHI16.	Was	it more	than	\$2,000?
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	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	59	66	54	68
No	42	34	46	32
(1				

(skip to next section)

QHI17. Was it less than \$500?

	8 or fewer	9 - 19	20 - 39	40 or more
	hours per week	hours per week	hours per week	hours per week
Yes	67	78	72	73
No	31	22	28	27