THE PITTSBURGH REGIONAL CAREGIVERS SURVEY

BREAKOUTS BY CAREGIVER ANNUAL HOUSEHOLD INCOME

Contents (click to jump to section)

Notes	1
Types of Caregiving	2
Caregiving Situation / Context	3
Care Activities	9
Aspects of Caregiving	25
Support Environment	29
Participation	33
Health	36
Health Literacy and Numeracy	42
Employment and Caregiving	44
Demographics	48
Information / Services / Policy	51
Health Insurance and Income	54

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:

Less than $$20,000 \quad n = 144$

20,000 to 49,999 n = 280

\$50,000 to \$99,999 n = 290

100,000 or more n = 143

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?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	56	58	46	41
No	44	42	54	59

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

	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Yes	94	98	99	97
No	6	2	1	4

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	66	69	63	55
No	34	31	37	46

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:

, and the second	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Your mother or mother-in-law	43	35	41	58
Your father or father-in-law	11	10	15	18
Your wife / partner	4	6	9	5
Your husband / partner	6	24	15	5
Your daughter or daughter-in-law	1	0	1	1
Your son or son-in-law	1	1	0	1
Some other relative	19	17	13	8
A non-relative	16	7	6	4

QCS2. Is the person you care for:

•	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Male	31	45	35	25
Female	69	55	66	75

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
50 - 64	23	19	16	4
65 - 74	23	20	15	20
75 - 84	18	25	30	26
85 +	36	36	39	50

QCS5. Where does [he/she] live?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
In your household → QCS9	50	57	40	23
Within 20 minutes of your home	40	35	48	46
Between 20 minutes and an hour from	9	8	10	20
your home				
One to two hours from your home	0	1	1	4
More than two hours away	1	0	0	8

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
His or her own home	74	71	71	69
Someone else's home → QCS9	7	14	10	5
An independent living or retirement community	13	8	10	16
In an assisted living facility where some care may be provided → QCS9	7	6	8	11
Somewhere else	0	1	1	0

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

QCS7. Does [he/she] live alone?

	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Yes	74	69	68	66
No	26	31	32	34

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

,	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Short-term physical condition	13	11	12	14
Long-term physical condition	82	80	77	73
Emotional or mental health problem	25	21	17	18
Developmental or intellectual disorder or mental retardation	8	4	5	6
Behavioral issue	8	6	8	8
Memory problem	44	41	42	44
None of the above	3	4	4	8

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	23	25	21	29
No	77	75	79	71

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

QCS11. a heart attack or myocardial infarction?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	29	23	21	19
No	71	77	79	81

QCS12. any other heart disease includ	ing angina or co		
Less than	\$20,000 -	\$50,000 -	\$100,000 or

	Less man	\$20,000 -	\$30,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	27	33	38	32
No	73	67	62	68

QCS13. high blood pressure or hypertension?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
_	\$20,000	\$49,999	\$99,999	More
Yes	64	69	65	61
No	36	32	35	39

QCS14. arthritis?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	70	69	62	60
No	30	31	38	40

QCS15. osteoporosis or thinning of the bones?

1	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Yes	40	31	34	43
No	60	69	66	57

QCS16. diabetes?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
_	\$20,000	\$49,999	\$99,999	More
Yes	31	27	27	23
No	69	73	73	78

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	27	25	23	21
No	73	75	77	79

QCS18. cancer?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	24	28	26	31
No	76	72	74	69

QCS18a.	a	stro	ke?
---------	---	------	-----

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	24	24	24	16
No	76	76	77	84

QCS19. serious difficulty seeing?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	37	27	28	20
No	63	73	72	80

QCS20. serious difficulty hearing?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	41	37	35	31
No	59	63	65	69

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

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	83	87	86	87
No	17	13	15	13

QCS22B. a hearing aid?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	13	17	20	21
No	88	83	80	79

QCS22C. a cane?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	44	43	43	38
No	56	57	57	62

QCS22D. a walker?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	41	43	41	48
No	59	57	59	52

QCS22E. a wheelchair?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	35	30	36	34
No	65	70	64	66

QCS22F. a scooter?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	6	9	9	6
No	94	91	91	94

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	35	32	35	33
No	65	68	65	67

QCS22H. special items to help with dressing, such as button hooks or clothes that are designed to get on and off easily?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	30	17	21	22
No	70	83	79	78

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.

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	5	7	6	4
No	95	94	95	96

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?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	76	80	80	85
No \rightarrow next section	24	20	20	15

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
A railing or ramp	67	61	65	61
Grab bars in the bathroom	77	74	76	81
A seat for the shower or tub	71	70	70	71
An emergency call system	42	38	43	52
Other	25	30	36	37

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?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
_	\$20,000	\$49,999	\$99,999	More
Every day	53	55	48	41
Most days	16	18	15	13
Some days	19	17	21	22
Rarely	5	5	6	9
Never \rightarrow QCA2	4	3	7	12
Does not do, but not because of poor health and functioning \rightarrow QCA2	3	2	2	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]?

·	Less than \$20,000	\$20,000 – \$49,999	\$50,000 - \$99,999	\$100,000 or More
Every day	49	53	32	21
Most days	19	17	20	13
Some days	25	26	32	41
Rarely	6	3	10	11
Never	1	2	6	13

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)

	Less than \$20,000	\$20,000 – \$49,999	\$50,000 - \$99,999	\$100,000 or More
Yes, another unpaid family member / friend	52	44	52	67
Yes, a paid helper	18	15	26	39
No	37	46	32	16

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?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
_	\$20,000	\$49,999	\$99,999	More
Every day	43	44	42	34
Most days	21	21	23	18
Some days	23	22	22	28
Rarely	8	8	7	10
Never \rightarrow QCA3	3	4	5	7
Does not do, but not because of poor	2	3	2	4
health and functioning \rightarrow QCA3				

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]?

mer Jamepping re	. [
	Less than	\$20,000 -	\$50,000 -	\$100,000 or
_	\$20,000	\$49,999	\$99,999	More
Every day	28	29	25	13
Most days	23	25	25	15
Some days	31	34	32	46
Rarely	11	6	11	15
Never	8	5	7	11

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

	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Yes, another unpaid family member / friend	56	44	55	66
Yes, a paid helper	7	5	6	14
No	42	53	41	30

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
_	\$20,000	\$49,999	\$99,999	More
Yes	53	58	57	60
No → QCA4	44	41	41	37
Does not do, but not because of poor health and functioning → QCA4	4	1	2	4

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	68	89	76	57
No	32	11	24	43

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

•	Less than \$20,000	\$20,000 – \$49,999	\$50,000 - \$99,999	\$100,000 or More
Yes, another unpaid family member / friend	40	24	34	51
Yes, a paid helper	9	7	10	21
No	51	70	57	32

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

	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Yes	67	64	66	74
No → QCA5	30	33	29	22
Does not do, but not because of poor health and functioning → QCA5	3	4	6	4

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	72	85	81	68
No	28	15	19	32

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

,	Less than \$20,000	\$20,000 – \$49,999	\$50,000 - \$99,999	\$100,000 or More
Yes, another unpaid family member / friend	41	28	41	58
Yes, a paid helper	5	1	1	1
No	55	71	58	43

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?

	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Every day	11	10	8	10
Most days	5	5	3	4
Some days	9	7	4	6
Rarely	9	9	13	9
Never \rightarrow QCA6	65	69	72	71

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Every day	31	26	19	21
Most days	18	16	12	5
Some days	29	28	19	33
Rarely	14	17	39	23
Never	8	13	12	18

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

	Less than \$20,000	\$20,000 – \$49,999	\$50,000 - \$99,999	\$100,000 or More
Yes, another unpaid family member / friend	39	34	45	59
Yes, a paid helper	8	14	13	28
No	53	61	50	23

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

C	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Every day	24	26	21	21
Most days	12	8	11	11
Some days	15	13	8	13
Rarely	9	9	10	11
Never \rightarrow QCA7	40	44	50	44

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Every day	24	30	15	8
Most days	15	12	15	15
Some days	24	25	20	23
Rarely	19	15	20	11
Never	20	18	30	43

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

	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Yes, another unpaid family member / friend	38	27	39	47
Yes, a paid helper	25	21	33	41
No	42	57	38	23

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

-	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Every day	23	22	21	26
Most days	11	9	8	6
Some days	14	15	16	15
Rarely	13	13	13	11
Never \rightarrow QCA8	38	40	42	42

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Every day	27	26	19	14
Most days	19	18	14	10
Some days	28	29	31	35
Rarely	17	21	25	22
Never	9	8	11	18

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

,	Less than \$20,000	\$20,000 – \$49,999	\$50,000 - \$99,999	\$100,000 or More
Yes, another unpaid family member / friend	43	27	46	56
Yes, a paid helper	21	19	26	35
No	44	60	40	26

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

mening.				
-	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Every day	17	17	16	17
Most days	6	3	3	3
Some days	9	8	5	5
Rarely	7	10	12	10
Never → QCA9	61	63	64	65

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Every day	32	33	26	22
Most days	20	13	7	9
Some days	19	26	20	24
Rarely	19	21	25	13
Never	11	8	22	31

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

	Less than \$20,000	\$20,000 – \$49,999	\$50,000 - \$99,999	\$100,000 or More
Yes, another unpaid family member / friend	48	33	54	64
Yes, a paid helper	30	23	30	44
No	37	53	31	11

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

J	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Every day	14	13	16	21
Most days	8	4	2	1
Some days	11	12	7	4
Rarely	11	14	17	9
Never \rightarrow QCA10	56	57	58	65

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

	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Every day	19	18	22	22
Most days	16	13	9	0
Some days	24	26	18	35
Rarely	29	33	32	22
Never	11	10	20	22

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

,	Less than \$20,000	\$20,000 – \$49,999	\$50,000 - \$99,999	\$100,000 or More
Yes, another unpaid family member / friend	55	36	49	54
Yes, a paid helper	21	16	25	35
No	34	56	37	30

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

100110111111111111111111111111111111111				
-	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Every day	19	17	16	18
Most days	6	4	5	2
Some days	17	14	9	15
Rarely	16	20	18	13
Never → QCA11	42	46	53	53

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

-	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Every day	24	20	19	20
Most days	10	12	10	11
Some days	34	34	32	36
Rarely	24	31	29	25
Never	7	3	11	8

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

,	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Yes, another unpaid family member / friend	52	44	60	72
Yes, a paid helper	16	15	20	33
No	39	49	33	13

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

8	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Every day	22	25	23	23
Most days	16	13	10	11
Some days	18	18	19	26
Rarely	16	11	13	11
Never → skip logic prior to QCA12A	28	34	35	29

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Every day	20	26	21	10
Most days	28	16	14	15
Some days	28	35	35	53
Rarely	19	15	23	15
Never	6	8	8	8

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

	Less than \$20,000	\$20,000 – \$49,999	\$50,000 - \$99,999	\$100,000 or More
Yes, another unpaid family member / friend	57	51	59	77
Yes, a paid helper	11	12	15	23
No	38	42	32	16

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?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	39	41	36	33
No	61	59	64	67

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?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	75	72	71	72
No	25	28	29	28

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?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	66	73	69	84
No	34	30	31	16

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Every day	10	14	13	7
Most days	20	21	13	11
Some days	19	35	39	49
Rarely	19	12	20	16
Never	32	18	15	17

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]?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Every day	4	2	1	1
Most days	6	3	1	1
Some days	7	5	1	3
Rarely	10	3	5	3
Never	49	60	61	64
Do not use	25	26	32	29

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.

QCA15A. In the last month, did you ever help CR keep track of [his/her] medications?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	55	66	62	54
No	45	34	38	46

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	44	55	44	34
No	56	46	56	66

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

_	Less than	\$20,000 -	\$50,000 -	\$100,000 or
_	\$20,000	\$49,999	\$99,999	More
Orally (by mouth as pills, capsules,	98	98	100	06
liquid)	98	98	100	96
Insulin injection	16	14	9	4
Other injection	5	3	8	2
Infusion pump	0	1	1	0
Inhaler	10	22	6	9
Suppository	5	3	2	2
Medication patch	7	4	7	9
Spray	3	5	2	4
Eye/Ear drops	16	18	11	18
Other	5	11	3	18

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	9	8	6	1
No	92	92	94	99

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	11	9	9	8
No	89	91	92	92

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	33	36	24	23
No	67	64	76	77

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	35	30	26	17
No	65	70	74	83

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

-	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Yes	22	24	17	14
No	78	76	83	86

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

-	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	36	32	26	21
No	65	68	74	79

QCA15H. [In the last month, did you ever help CR] with skin care related to wounds or sores?

·	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Yes	30	31	26	23
No	70	69	74	77

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	48	47	47	47
No	52	53	53	53

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?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	43	40	40	37
No	57	60	60	63

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	54	57	42	51
No	46	43	58	49

QCA15L. [In the last month, did you ever] administer test kits (bladder infection test, for example)?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	3	5	4	3
No	97	95	96	97

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)?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	54	46	48	49
No	46	54	52	51

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

	Less than \$20,000	\$20,000 – \$49,999	\$50,000 - \$99,999	\$100,000 or More
Yes	15	19	19	12
No	85	81	82	89

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)?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	4	7	10	12
No	96	93	90	89

(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.

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
_	\$20,000	\$49,999	\$99,999	More
 Not at all difficult 	52	54	57	60
2.	15	22	20	17
3.	19	15	14	12
4.	10	7	6	5
5. Very difficult	4	2	4	5

QCA17. Did anyone prepare you to do these tasks?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	22	26	29	22
No → QCA21	78	75	71	78

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Hospital nurse	21	23	27	20
Hospital doctor	0	8	8	4
Primary care doctor	7	13	21	8
Nurse in doctor's office or outpatient setting	14	11	15	8
Home care nurse	21	26	22	24
Social worker/geriatric care manager	0	3	4	4
Physical or occupational therapist	11	21	18	16
Pharmacist	0	7	8	4
Medical supply technician	0	8	11	4
Friend or neighbor	4	7	7	8
You learned on your own	11	31	33	16
Other	68	44	33	44

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Very well	82	77	81	80
Somewhat well	18	23	15	16
Not well	0	0	4	4

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
None \rightarrow QCA24PRE	43	47	43	45
One time	20	14	26	21
2 times	19	16	15	15
3 or more times	18	23	16	19

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...

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes, all the time	48	67	58	55
Only some of the time	25	22	22	30
No, and you should have been	10	4	6	5
No, but you did not need to be	18	8	14	10

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]?

Ç ,	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Yes	62	85	73	72
No	32	13	19	19
Not applicable	6	2	8	9

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

	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Very well	55	59	49	49
Somewhat well	28	33	39	41
Not well	16	8	12	10

QCA24PRE. Now think about the last YEAR.

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	54	69	68	65
No	46	31	32	35

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	55	70	68	67
No	45	30	32	33

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	72	90	89	80
No	28	10	11	20

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.]

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	25	31	25	23
No	75	69	75	78

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.]

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	31	40	40	40
No	69	60	60	60

QCA25. About how many hours per week on average do you help this person with personal care, routine household needs and/or medical/nursing tasks?

	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
8 hours or less per week	31	29	48	60
9 to 19 hours per week	24	29	27	23
20 to 39 hours per week	23	19	13	11
40 or more hours per week	22	23	13	6

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.

	Less than	\$20,000 -	\$50,000 -	\$100,000 or	
	\$20,000	\$49,999	\$99,999	More	
Regular schedule	58	56	52	40	
Varied	42	44	48	60	

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

-	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
3 months or less	8	4	6	6
4 to 12 months	9	9	10	20
1 - 2 years	23	21	19	19
3 - 5 years	29	26	29	31
More than 5 years	32	40	37	25

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

	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Increased in the past month	41	39	31	32
Been about the same in the past month	49	55	60	54
Decreased in the past month	11	6	9	15

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?

	Less than \$20,000	\$20,000 – \$49,999	\$50,000 - \$99,999	\$100,000 or More
Will increase	39	32	32	29
Will be about the same	53	60	60	64
Will decrease	9	9	9	7

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

•	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	51	45	42	46
No	49	55	58	55

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

3	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Very worried	6	5	4	7
Somewhat worried	13	11	12	13
Only a little	18	31	27	36
Not at all	63	53	58	43

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 which you think CR has been <u>suffering physically</u> during the past month on a scale from 1 to 10 where 1 equals "CR has not been suffering physically," and 10 equals "CR has been suffering terribly".)

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
1 CR has not been suffering physically	14	10	16	13
2	10	10	8	8
3	10	15	17	16
4	8	9	8	11
5	14	16	13	14
6	7	9	9	10
7	12	11	11	13
8	15	8	9	8
9	4	7	4	5
10 CR has been suffering terribly	7	7	6	3

QCA32. Now, please rate the degree to which you think CR has been <u>suffering psychogically or 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".)

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
1 CR has not been suffering physically	11	13	14	11
2	14	10	9	7
3	8	10	12	18
4	4	7	7	9
5	14	18	18	6
6	9	11	8	9
7	10	9	9	11
8	12	10	12	17
9	7	5	5	7
10 CR has been suffering terribly	11	9	6	6

ASPECTS OF CAREGIVING

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

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

	J	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
A lot		73	71	71	61
Some		20	23	24	30
A little		5	6	5	7
Not at all		2	1	1	2

QAC2. How much does [he/she] argue with you?

	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
A lot	26	23	15	13
Some	26	27	27	26
A little	25	29	31	25
Not at all	22	21	27	36

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
A lot	76	83	78	82
Some	15	9	15	10
A little	6	5	6	6
Not at all	4	4	1	2

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

	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
A lot	22	23	16	20
Some	25	30	35	28
A little	39	32	31	34
Not at all	14	14	19	19

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...

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Gotten much better	25	19	15	10
Gotten somewhat better	22	20	18	28
Stayed about the same	42	47	49	48
Gotten somewhat worse	9	11	13	14
Gotten much worse	2	3	5	1

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.

1 01	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Very much	38	46	31	25
Somewhat	38	37	42	38
Not so much	24	17	27	37

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
_	\$20,000	\$49,999	\$99,999	More
Very much	55	50	46	41
Somewhat	25	37	39	42
Not so much	21	12	16	18

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Very much	54	50	45	36
Somewhat	34	34	36	39
Not so much	13	16	19	25

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

1 6 6	Less than \$20,000	\$20,000 – \$49,999	\$50,000 - \$99,999	\$100,000 or More
Very much	76	82	76	69
Somewhat	20	14	21	28
Not so much	4	4	3	4

QAC6A. Is helping CR financially difficult for you?

	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Yes	29	27	21	15
No	72	73	79	85

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	55	62	57	67
No	45	38	43	33

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
_	\$20,000	\$49,999	\$99,999	More
Yes	35	30	28	19
No	65	70	72	81

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)

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
1. A little difficult	7	9	15	19
2.	5	15	10	19
3.	34	25	34	38
4.	20	28	22	19
Very difficult	34	23	19	5

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

·	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
1. A little difficult	15	18	7	5
2.	11	18	21	17
3.	24	23	32	24
4.	25	21	23	28
5. Very difficult	24	21	18	25

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

erening un	initiality is morphing	8 [need by yes to g	211000)
	Less than	\$20,000 -	\$50,000 -	\$100,000 or
_	\$20,000	\$49,999	\$99,999	More
1. A little difficult	14	12	7	7
2.	12	12	27	26
3.	28	32	39	52
4.	28	27	18	11
5. Very difficult	20	18	9	4

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Very much	11	10	7	8
Somewhat	24	19	24	18
Not so much	65	71	69	74

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

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Very much	32	33	31	31
Somewhat	27	32	29	28
Not so much	41	35	40	41

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
_	\$20,000	\$49,999	\$99,999	More
Very much	24	25	24	20
Somewhat	24	30	38	39
Not so much	51	45	38	41

QAC9C. You don't have time for yourself.

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Very much	25	29	29	24
Somewhat	27	36	30	34
Not so much	49	35	41	43

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

, ,	Less than \$20,000	\$20,000 – \$49,999	\$50,000 - \$99,999	\$100,000 or More
Very much	13	12	11	10
Somewhat	16	28	31	25
Not so much	71	60	58	65

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?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	83	89	93	97
No	17	12	7	3

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?

	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Yes	48	47	56	64
No	52	53	44	36

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

·	Less than \$20,000	\$20,000 – \$49,999	\$50,000 - \$99,999	\$100,000 or More
Yes	59	60	70	84
No	41	40	30	16

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

·	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	6	8	6	4
No	94	92	95	96

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?

•	•	Less than \$20,000	\$20,000 – \$49,999	\$50,000 - \$99,999	\$100,000 or More
Yes		13	16	20	29
No		87	84	80	71

QSE5. In the last year, have you received any training to help you take care of CR?

·	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Yes	11	12	7	9
No	89	88	93	91

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

	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Yes	22	16	18	18
No	78	84	82	82

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)

-	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	14	22	20	17
No	86	78	80	83

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?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	48	44	42	41
No	52	56	58	59

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?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	42	46	44	49
No	58	54	56	51

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	14	19	23	28
No	86	81	77	72

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.

QSE11. First, how many other family and friends help you care for CR?

	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
	\$20,000	\$ 17,777	. ,	TVIOLE
One	33	27	20	17
Two	27	25	30	28
Three or more	41	48	51	56

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

	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Caregiver's Brother(s)	31	29	21	35
CG's Sister(s)	41	36	40	43
CG's husband	5	13	25	27
CG's wife	0	4	13	13
CG's other relative(s) / in-law(s)	48	58	57	47
CG's friend(s)	12	15	11	8
Other	24	23	22	25

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
_	\$20,000	\$49,999	\$99,999	More
Live(s) with you	37	32	46	42
Within twenty minutes of your home	55	68	66	59
Between twenty minutes and an hour	31	24	23	24
from your home	31	24	23	24
One to two hours from your home	5	5	5	11
Two to four hours away	4	4	4	5
More than four hours away	6	5	12	23

QSE13. Which of the following best describes how you divide the tasks of caring for CR?

3	Less than \$20,000	\$20,000 – \$49,999	\$50,000 - \$99,999	\$100,000 or More
We complement each other – we each help CR with different tasks.	25	28	29	34
We help with the same things but we divide the help over time.	18	17	20	16
We share some tasks, and others we do separately	57	55	50	50

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?

	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Respondent is the primary caregiver	60	64	56	42
Someone else is the primary caregiver	29	24	28	44
Care is equally shared	11	13	16	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?

	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
To a great extent	4	2	2	3
To a moderate extent	11	9	8	8
Only a little	24	23	34	33
Not at all	61	66	57	56

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

	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Very satisfied	59	71	70	61
Moderately satisfied	34	20	24	31
Moderately dissatisfied	6	7	4	5
Very dissatisfied	1	2	2	3

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?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	79	83	89	88
No	21	18	11	12

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]?

	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Yes	28	29	34	29
No	72	71	66	71

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

1	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Very important	43	51	55	63
Somewhat important	35	32	35	30
Not so important	23	16	10	7

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	49	59	60	75
No	51	41	40	25

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or	
	\$20,000	\$49,999	\$99,999	More	
Yes	13	15	12	11	
No	87	85	88	89	

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Very important	39	48	46	45
Somewhat important	24	23	23	27
Not so important	37	30	30	29

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.]

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	40	41	50	59
No	60	59	50	41

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.]

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	22	21	20	20
No	79	79	80	80

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.]

1	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Very important	30	25	35	30
Somewhat important	26	31	29	41
Not so important	44	44	36	29

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.

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	71	79	88	94
No	29	21	12	6

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.]

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	24	24	27	22
No	76	76	73	78

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.]

0	, 0	,				
		Less than	\$20,000 -	\$50,000 -	\$100,000 or	
		\$20,000	\$49,999	\$99,999	More	
Very important		35	42	59	57	
Somewhat important		42	39	28	41	
Not so important		23	19	13	3	

QPP13. In the last month, did you ever do volunteer work?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	26	28	40	49
No	74	72	60	51

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	13	21	12	13
No	87	79	88	87

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.

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	40	43	40	44
No	60	58	60	56

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

	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Yes	9	8	6	11
No	91	92	94	89

HEALTH

QHE1. Would you say that in general, your health is excellent, very good, good, fair, or poor?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Excellent	9	12	18	22
Very good	20	22	39	41
Good	31	39	26	27
Fair	31	24	15	11
Poor	10	3	2	0

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	4	9	7	6
No	96	91	93	94

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
_	\$20,000	\$49,999	\$99,999	More
Yes	8	13	6	8
No	92	88	94	92

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

_	Less than \$20.000	\$20,000 – \$49,999	\$50,000 - \$99,999	\$100,000 or More
Yes	43	44	41	35
No	57	56	59	66

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	51	56	44	32
No	49	44	56	69

QHE6. [Has a doctor ever told you that you had] osteoporosis or thinning of the bones?

-	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Yes	17	21	22	12
No	83	79	79	88

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	20	19	14	6
No	80	81	87	94

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	24	17	15	12
No	76	84	86	88

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

	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Yes	12	13	16	11
No	88	88	84	90

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

QHE10. In the last month, have you been bothered by pain?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	67	68	62	48
No	33	33	38	52

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

,	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	26	21	13	8
No	74	79	87	92

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	35	37	28	15
No	65	63	72	85

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

	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Yes	51	46	36	26
No	49	54	65	74

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or	
	\$20,000	\$49,999	\$99,999	More	
Yes	58	57	49	41	
No	42	43	51	59	

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	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
	Ψ20,000		Ψ,,,,,,,	-
Every night	13	10	8	7
Most nights	22	14	16	11
Some nights	29	35	31	36
Rarely	16	27	28	26
Never	20	15	17	20

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Every night	4	2	3	1
Most nights	6	7	4	5
Some nights	19	20	16	21
Rarely	24	25	24	19
Never	49	47	54	54

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:

	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
< 18.5 (underweight)	1	1	1	0
18.5 – 24.9 (normal)	35	23	25	29
25.0 – 29.9 (overweight)	25	39	38	43
30.0 - 34.9 (moderately obese)	22	20	24	19
35.0 - 39.9 (severely obese)	9	10	6	5
40.0 + (very severely obese)	10	8	5	4

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	38	34	26	24
No → QHE25A	62	66	74	76

QHE24a. Were you trying to lose weight?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
_	\$20,000	\$49,999	\$99,999	More
Yes	60	66	72	85
No	40	34	28	15

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

5	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Every day	16	14	14	19
Most days	33	43	50	48
Some days	35	31	26	29
Rarely	12	11	10	4
Never	4	1	0	0

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

	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Every day	10	13	11	15
Most days	40	36	42	36
Some days	27	33	32	36
Rarely	18	14	14	12
Never	6	4	1	1

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

	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Every day	17	13	16	20
Most days	24	34	35	37
Some days	31	30	31	30
Rarely	17	19	17	13
Never	10	4	2	1

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
_	\$20,000	\$49,999	\$99,999	More
Every day	6	4	0	1
Most days	8	6	5	4
Some days	31	22	20	15
Rarely	26	32	33	34
Never	29	36	41	47

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Every day	6	3	1	1
Most days	13	10	5	4
Some days	20	24	19	15
Rarely	26	26	30	30
Never	35	36	45	50

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

	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Every day	5	5	3	1
Most days	12	10	8	8
Some days	46	43	50	49
Rarely	33	35	32	38
Never	5	8	7	4

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Not at all	42	53	59	69
Several days	38	30	32	25
More than half the days	8	12	6	5
Nearly every day	12	5	2	1

QHE26b. [Over the last month, how often have you] felt down, depressed, or hopeless?

,	Less than \$20,000	\$20,000 – \$49,999	\$50,000 - \$99,999	\$100,000 or More
Not at all	48	52	62	62
Several days	33	33	31	34
More than half the days	10	10	6	3
Nearly every day	10	5	1	1

QHE26c. [Over the last month, how often have you] felt nervous, anxious, or on edge?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Not at all	39	41	43	38
Several days	40	41	45	50
More than half the days	9	9	8	8
Nearly every day	12	9	5	5

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Not at all	52	44	51	59
Several days	25	33	33	25
More than half the days	9	9	8	8
Nearly every day	14	13	8	8

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.

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Not at all	5	4	2	1
A little bit	4	4	5	4
Somewhat	15	10	6	8
Quite a bit	24	32	28	24
Extremely	52	51	59	64

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?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Never	64	63	71	76
Rarely	22	26	23	18
Sometimes	13	10	5	6
Often	1	0	0	1
Always	1	0	0	0

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Never	62	59	69	73
Rarely	22	29	25	20
Sometimes	15	10	6	7
Often	0	1	0	0
Always	1	1	0	0

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)?

ŕ	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Correct	62	62	70	78
Incorrect	38	38	30	22

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)

. 1	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Correct	72	81	86	92
Incorrect	28	19	14	8

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)

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Correct	65	71	80	90
Incorrect	35	29	20	11

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.

	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Yes → QEC4 No	25 36	44 20	59 15	65 21
Retired / don't work anymore → QEC16	39	36	26	14

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

	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Yes → QEC4	4	7	9	10
No	89	64	55	67
Retired / don't work anymore → QEC16	8	29	36	23

OEC3. In the last week, were you looking for a job or were you on layoff from a job?

ss. In the last week, were you recking for a joe or were you on layers from a joe.					
	Less than	\$20,000 -	\$50,000 -	\$100,000 or	
	\$20,000	\$49,999	\$99,999	More	
Yes, looking for a job \rightarrow QEC16	28	8	8	0	
Yes, on layoff \rightarrow QEC16	4	6	8	0	
No → QEC16	67	83	75	85	
Retired / don't work anymore →	0	2	o	15	
QEC16	U	3	0	13	

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	37	29	18	15
No	63	71	82	85

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
20 or fewer	41	23	16	19
21 - 39	27	20	21	12
40 or more	32	57	63	70

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?

·	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Yes	63	60	55	72
No	37	40	45	28

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Daytime	58	75	87	88
Some other schedule	42	25	13	12

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?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	25	38	50	44
No → QEC12	75	62	50	56

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.

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	0	30	30	41
No	100	70	70	59

QEC9B. You were sick.

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	64	46	34	39
No	36	54	66	61

QEC9C. You took time off to help CR.

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	18	44	47	50
No	82	56	53	50

QEC9D. Other family members were sick.

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	9	22	18	27
No	91	78	82	73

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	18	46	39	27
No	82	54	61	73

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?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
One	50	41	51	43
Two	0	23	32	19
Three or more	50	36	17	38

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?

_	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	16	23	28	29
No →QEC14	84	77	72	71

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.

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
1 A little harder	17	7	12	14
2	0	14	12	11
3	17	17	18	25
4	0	7	10	21
5	0	24	18	11
6	50	0	8	11
7	0	7	8	4
8	17	17	10	0
10 A lot harder	0	7	2	4

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	71	81	80	72
No	29	19	20	28

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

_	Less than \$20,000	\$20,000 – \$49,999	\$50,000 - \$99,999	\$100,000 or More
Telecommuting or working from home	13	17	33	52
Programs like information, referrals, counseling, or an employee assistance program, to help caregivers like yourself	8	31	39	49
Paid leave, where you could take paid time off from work for several weeks to care for a family member	3	27	37	49
Paid sick days	18	49	59	65
None of the above	61	41	22	12

QEC16. As a result of caregiving, did you ever experience any of the following things at work? (multiple responses accepted)

	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Went in late, left early, or took time off during the day to provide care	31	40	52	51
Took a leave of absence	16	16	9	9
Went from working full-time to part-time, or cut back your hours	19	17	14	10
Turned down a promotion	6	4	4	2
Lost any of your job benefits	6	6	3	3
Gave up working entirely	22	19	8	6
Retired early	13	18	8	7
Received a warning about your performance or attendance at work	6	5	5	1
None of the above	48	41	39	41

DEMOGRAPHICS

QDE1. INTERVIEWER: RECORD PERSON'S SEX

	Less than \$20,000	\$20,000 – \$49,999	\$50,000 - \$99,999	\$100,000 or More
Male	23	27	26	30
Female	77	73	74	70

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

,	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
44 or under	21	14	9	10
45 - 54	21	11	20	32
55 - 64	38	37	38	39
65 or older	20	38	33	20

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

	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Married	12	49	73	90
Living with a partner in a marital- like relationship	6	6	3	2
Divorced or separated	29	16	9	4
Widowed	10	4	4	1
Single/never married	42	24	10	4

QDE4. Are you of Hispanic or Latino descent?

•	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	3	1	1	2
No	97	99	99	98

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

, ,	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Caucasian/White	63	81	90	93
Asian/Pacific Islander	1	1	0	1
American Indian or Alaskan Native	1	3	0	0
Black or African-American	34	18	10	5
None of the above	1	1	0	1

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

· ·	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Eighth grade or less	0	0	0	0
Some high school	3	2	0	0
High school graduate or GED	29	27	15	4
Some college, no degree	31	22	19	9
Associate's degree, occupational	5	8	8	4
Associate's degree, academic	7	7	5	4
Bachelor's degree	18	23	30	34
Master's degree	6	10	18	33
Professional degree	1	1	1	5
Doctoral degree	0	0	4	7

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

, ,	Less than \$20,000	\$20,000 – \$49,999	\$50,000 - \$99,999	\$100,000 or More
Live alone → QDE11PRE	30	14	12	6
Live in a household with family or others	69	85	87	94
Have some other living	1	1	0	0
arrangements				

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

Ec. moraamg j	20. morading jou, now many addres, ago 10 and order, carrenary nive in jour nous						
	Less than	\$20,000 -	\$50,000 -	\$100,000 or			
	\$20,000	\$49,999	\$99,999	More			
One	9	6	3	4			
Two	53	69	65	61			
Three	29	18	25	21			
Four	6	6	7	13			
Five	4	1	1	1			
Six	0	0	0	0			

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

J	Less than \$20,000	\$20,000 – \$49,999	\$50,000 - \$99,999	\$100,000 or More
Zero	76	83	80	69
One	10	10	10	15
Two	7	3	9	11
Three	5	2	1	5
Four	0	2	0	0
Five	1	0	0	1
Six	1	0	0	0

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

_	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Your spouse / partner	26	66	91	97
Your child(ren)	31	26	35	47
Your grandchild(ren)	10	6	4	1
Your parent(s)	47	22	11	10
Other relatives of yours	26	13	7	3
Non-relatives	10	3	2	2

QDE11PRE. And now just a couple questions about CR.

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

-	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Eighth grade or less	9	6	6	2
Some high school	9	8	7	4
High school graduate or GED	45	50	45	45
Some college, no degree	9	10	7	4
Associate's degree, occupational	6	8	6	7
Associate's degree, academic	2	2	5	4
Bachelor's degree	10	10	14	19
Master's degree	5	4	6	11
Professional degree	2	2	1	1
Doctoral degree	2	1	3	3

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	1	1	0	1
No	99	99	100	99

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

	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Caucasian/White	65	81	90	92
Asian/Pacific Islander	1	0	0	3
American Indian or Alaskan Native	4	2	0	0
Black or African-American	35	18	9	6
None of the above	0	1	0	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?

•	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	33	43	40	31
No	67	57	60	69

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?

	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Yes	22	25	15	9
No	79	75	85	91

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.

	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
1. Not at all difficult	72	72	76	70
2	12	14	12	9
3	4	7	7	16
4	3	4	2	2
Very difficult	10	4	2	2

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.

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
1. Not at all difficult	71	66	72	67
2	10	13	13	14
3	8	9	9	11
4	5	4	4	7
5. Very difficult	7	7	3	2

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.

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
1. Not at all difficult	48	42	39	31
2	7	8	10	10
3	8	11	13	16
4	5	8	7	9
Very difficult	8	10	7	9
Not applicable	24	21	24	25

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.

	Less than \$20,000	\$20,000 – \$49,999	\$50,000 - \$99,999	\$100,000 or More
1. Not at all difficult	41	35	33	28
2	8	6	10	13
3	9	8	13	16
4	2	6	6	10
5. Very difficult	14	17	13	10
Not applicable	26	29	25	23

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.

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
1. Not at all difficult	33	30	29	20
2	4	7	9	12
3	16	10	14	15
4	8	10	10	17
Very difficult	15	18	12	12
Not applicable	26	26	27	25

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)

1 3	Less than \$20,000	\$20,000 – \$49,999	\$50,000 - \$99,999	\$100,000 or More
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	76	85	86	87
Requiring hospitals to keep you informed about major decisions, like transferring or discharging CR	81	89	89	90
Requiring hospitals or facilities to instruct or demonstrate any medical or nursing tasks you might need to do	83	89	87	92
Having respite services available, where someone would take care of CR to give you a break	68	72	75	71
Requiring a doctor, nurse, or social worker ask you about what you need to help care for CR	76	82	80	79
Requiring a doctor, nurse, or social worker ask you about what you need to take care of yourself	60	69	68	56
None of the above	6	5	5	2

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.

	Less than \$20,000	\$20,000 – \$49,999	\$50,000 - \$99,999	\$100,000 or More
An income tax credit to caregivers, to help offset the cost of care	22	32	39	41
A partially paid leave of absence from work for caregivers who are employed	11	16	20	30
A program where caregivers could be paid for at least some of the hours they provide care	67	53	41	29

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?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	55	50	35	19
No → QHI3	45	51	65	81

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

	Less than \$20,000	\$20,000 – \$49,999	\$50,000 - \$99,999	\$100,000 or More
Yes	61	72	77	44
No	39	28	23	56

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

•	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	54	9	2	1
No	46	91	98	99

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.

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	35	72	91	93
No	65	28	9	7

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?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	2	5	3	1
No	98	95	97	99

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Medicare	67	79	78	85
Medicaid	31	21	13	11
Private Health Insurance	42	51	65	61
Tricare/CHAMPVA	4	4	3	2

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

	Less than \$20.000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Yes	36	72	90	92
No	64	28	10	8

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

J [Less than \$20,000	\$20,000 – \$49,999	\$50,000 - \$99,999	\$100,000 or More
Yes	82	98	100	100
No	18	3	0	0

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

•	-	Less than	\$20,000 -	\$50,000 -	\$100,000 or
		\$20,000	\$49,999	\$99,999	More
Yes		35	71	88	95
No		65	29	12	5

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	5	15	27	26
No	95	85	73	74

QHI9D. Do you [and your {spouse/partner}] retirement plans such as IRAs, SEPs, 401K, or 403b plans?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or	
	\$20,000	\$49,999	\$99,999	More	
Yes	19	66	88	98	
No	81	34	13	2	

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	5	24	38	74
No	95	76	62	26

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?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
_	\$20,000	\$49,999	\$99,999	More
0 - less than \$10,000	42	0	0	0
\$10,000 to less than \$20,000	58	0	0	0
\$20,000 to less than \$30,000	0	30	0	0
\$30,000 to less than \$40,000	0	39	0	0
\$40,000 to less than \$50,000	0	31	0	0
\$50,000 to less than \$60,000	0	0	28	0
\$60,000 to less than \$70,000	0	0	25	0
\$70,000 to less than \$80,000	0	0	17	0
\$80,000 to less than \$90,000	0	0	15	0
\$90,000 to less than \$100,000	0	0	0	0
\$100,000 to less than \$110,000	0	0	0	26
\$110,000 to less than \$120,000	0	0	0	9
\$120,000 to less than \$130,000	0	0	0	11
\$130,000 to less than \$140,000	0	0	0	1
\$140,000 to less than \$150,000	0	0	0	12
More than \$150,000	0	0	0	41

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?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or	
	\$20,000	\$49,999	\$99,999	More	
Yes	30	46	41	41	
No	70	54	59	59	

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	14	28	23	17
No	86	72	77	83

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	9	17	14	17
No	91	84	86	83

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?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	15	32	28	36
No	85	68	72	64

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.

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	15	22	21	25
No	85	78	79	75

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

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	6	9	11	15
No	94	91	89	85

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,]

,	Less than \$20,000	\$20,000 – \$49,999	\$50,000 - \$99,999	\$100,000 or More
More than $$1,000 \rightarrow QHI6$	22	44	45	46
Less than $1,000 \rightarrow QHI7$	78	56	55	54

QHI16. Was it more than \$2,000?

	Less than	\$20,000 -	\$50,000 -	\$100,000 or
	\$20,000	\$49,999	\$99,999	More
Yes	46	65	74	59
No	54	35	26	41

(skip to next section)

QHI17. Was it less than \$500?

	Less than \$20,000	\$20,000 - \$49,999	\$50,000 - \$99,999	\$100,000 or More
Yes	81	73	75	62
No	19	28	25	38