

THE PITTSBURGH REGIONAL CAREGIVERS SURVEY

BREAKOUTS BY CAREGIVER-CARE RECIPIENT GENDER COMBINATION

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:

Female CG / Female CR n = 456

Female CG / Male CR n = 294

Male CG / Female CR n = 192

Male CG / Male CR n = 66

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?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	52	54	44	39
No	48	46	56	61

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	98	98	97	99
No	2	2	3	2

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	62	75	54	52
No	38	26	46	49

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:

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Your mother or mother-in-law	70	1	51	0
Your father or father-in-law	0	27	1	65
Your wife / partner	0	1	28	2
Your husband / partner	0	51	1	3
Your daughter or daughter-in-law	1	1	0	0
Your son or son-in-law	0	1	1	2
Some other relative	18	13	8	21
A non-relative	10	5	11	8

QCS2. Is the person you care for:

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Male	0	100	0	100
Female	100	0	100	0

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
50 – 64	15	19	15	17
65 – 74	11	28	20	11
75 – 84	26	27	24	24
85 +	49	26	41	49

QCS5. Where does [he/she] live?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
In your household → QCS9	28	65	51	33
Within 20 minutes of your home	54	27	37	58
Between 20 minutes and an hour from your home	14	7	12	6
One to two hours from your home	2	2	0	0
More than two hours away	2	0	2	3

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
His or her own home	69	73	74	73
Someone else's home → QCS9	8	9	10	11
An independent living or retirement community	14	7	8	9
In an assisted living facility where some care may be provided → QCS9	9	9	8	7
Somewhere else	0	3	0	0

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

QCS7. Does [he/she] live alone?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	71	63	73	47
No	29	37	27	53

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Short-term physical condition	12	12	15	6
Long-term physical condition	75	80	79	80
Emotional or mental health problem	19	19	19	20
Developmental or intellectual disorder or mental retardation	6	4	4	5
Behavioral issue	6	11	5	9
Memory problem	43	45	39	38
None of the above	6	2	5	9

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	28	22	19	20
No	73	78	81	80

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

QCS11. a heart attack or myocardial infarction?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	22	29	15	22
No	78	71	85	78

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	35	37	21	35
No	65	63	79	65

QCS13. high blood pressure or hypertension?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	68	69	61	49
No	32	31	39	51

QCS14. arthritis?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	73	63	59	40
No	27	37	41	60

QCS15. osteoporosis or thinning of the bones?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	52	13	39	14
No	48	87	61	86

QCS16. diabetes?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	28	36	18	17
No	72	64	82	83

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	25	26	18	17
No	75	74	83	83

QCS18. cancer?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	23	32	27	35
No	77	68	73	65

QCS18a. a stroke?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	21	27	18	21
No	79	73	82	79

QCS19. serious difficulty seeing?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	33	27	26	19
No	67	73	74	82

QCS20. serious difficulty hearing?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	35	41	32	46
No	65	59	68	54

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

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	88	84	86	83
No	12	16	14	17

QCS22B. a hearing aid?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	19	18	12	29
No	81	82	88	71

QCS22C. a cane?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	42	41	44	44
No	58	59	56	56

QCS22D. a walker?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	49	33	45	52
No	51	67	56	49

QCS22E. a wheelchair?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	35	32	33	32
No	65	68	68	68

QCS22F. a scooter?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	6	10	8	8
No	95	90	92	92

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	36	32	34	24
No	64	68	66	76

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	24	18	17	20
No	76	82	83	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.

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	4	8	4	6
No	96	92	96	94

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?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	81	78	83	80
No → next section	19	22	17	20

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
A railing or ramp	62	67	62	57
Grab bars in the bathroom	82	71	72	85
A seat for the shower or tub	74	73	64	70
An emergency call system	50	28	48	43
Other	35	37	30	21

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?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Every day	48	60	44	37
Most days	14	14	18	29
Some days	22	12	25	22
Rarely	8	5	5	2
Never → QCA2	7	4	7	8
Does not do, but not because of poor health and functioning → QCA2	1	4	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]?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Every day	32	59	36	17
Most days	17	16	19	24
Some days	35	18	31	45
Rarely	10	5	6	5
Never	7	2	8	9

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*)

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes, another unpaid family member / friend	62	35	48	71
Yes, a paid helper	27	18	24	24
No	24	53	37	21

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?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Every day	41	43	38	38
Most days	21	17	25	26
Some days	27	20	23	18
Rarely	8	8	8	5
Never → QCA3	3	7	4	11
Does not do, but not because of poor health and functioning → QCA3	1	4	2	3

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]?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Every day	22	34	22	18
Most days	19	25	24	21
Some days	39	31	34	39
Rarely	13	5	11	7
Never	8	5	8	16

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes, another unpaid family member / friend	61	36	53	70
Yes, a paid helper	10	5	6	7
No	35	60	44	28

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	57	67	45	59
No → QCA4	41	29	54	41
Does not do, but not because of poor health and functioning → QCA4	2	4	2	0

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	72	86	66	69
No	28	14	34	31

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes, another unpaid family member / friend	38	20	44	59
Yes, a paid helper	15	6	7	5
No	49	74	52	36

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	71	66	60	65
No → QCA5	27	27	35	35
Does not do, but not because of poor health and functioning → QCA5	2	7	5	0

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	76	89	75	67
No	25	11	25	33

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes, another unpaid family member / friend	44	26	48	58
Yes, a paid helper	2	1	2	0
No	55	73	50	42

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?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Every day	11	10	8	8
Most days	3	6	5	3
Some days	7	6	4	11
Rarely	9	11	11	11
Never → QCA6	70	67	72	67

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Every day	22	33	21	14
Most days	12	12	15	14
Some days	32	19	25	19
Rarely	22	23	29	29
Never	12	13	10	24

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes, another unpaid family member / friend	44	31	39	81
Yes, a paid helper	19	11	17	10
No	45	62	50	14

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Every day	28	21	18	20
Most days	9	12	12	5
Some days	12	14	9	9
Rarely	11	10	8	13
Never → QCA7	40	44	52	53

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Every day	20	29	15	10
Most days	13	13	9	13
Some days	26	22	11	27
Rarely	17	15	17	13
Never	24	20	48	37

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes, another unpaid family member / friend	39	21	48	43
Yes, a paid helper	31	25	29	33
No	36	60	33	37

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Every day	23	25	23	14
Most days	8	11	6	6
Some days	14	15	16	20
Rarely	14	14	9	11
Never → QCA8	41	36	46	48

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Every day	19	27	21	9
Most days	16	16	9	15
Some days	31	30	31	33
Rarely	24	21	17	21
Never	11	5	21	21

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes, another unpaid family member / friend	47	22	48	61
Yes, a paid helper	30	17	22	21
No	34	66	41	30

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Every day	18	16	15	10
Most days	4	3	3	3
Some days	6	6	7	5
Rarely	9	11	12	8
Never → QCA9	64	64	63	74

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Every day	27	35	27	25
Most days	13	9	10	13
Some days	26	21	13	19
Rarely	21	27	19	19
Never	13	9	30	25

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes, another unpaid family member / friend	51	27	58	75
Yes, a paid helper	41	21	24	19
No	26	59	30	19

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Every day	18	14	16	13
Most days	3	5	3	2
Some days	6	11	9	9
Rarely	12	15	14	13
Never → QCA10	61	55	58	64

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Every day	18	22	28	9
Most days	13	9	7	4
Some days	23	24	22	30
Rarely	32	31	25	30
Never	14	14	18	26

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes, another unpaid family member / friend	57	28	46	57
Yes, a paid helper	34	13	17	17
No	26	63	45	30

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Every day	19	14	17	13
Most days	6	2	6	2
Some days	10	18	11	13
Rarely	16	18	19	16
Never → QCA11	50	48	47	58

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Every day	18	22	24	15
Most days	13	12	10	7
Some days	31	36	29	37
Rarely	29	29	26	30
Never	10	2	10	11

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes, another unpaid family member / friend	62	35	57	70
Yes, a paid helper	27	14	17	11
No	26	55	36	26

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Every day	27	21	23	23
Most days	13	10	10	8
Some days	20	17	21	23
Rarely	12	12	19	17
Never → skip logic prior to QCA12A	29	40	27	28

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Every day	16	29	22	13
Most days	20	13	15	11
Some days	40	35	33	44
Rarely	16	22	22	17
Never	8	2	8	15

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes, another unpaid family member / friend	67	42	58	63
Yes, a paid helper	19	11	12	9
No	23	50	38	35

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?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	33	35	46	36
No	68	65	54	64

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?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	75	65	75	64
No	25	35	26	36

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?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	75	64	77	77
No	25	36	23	23

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Every day	8	18	13	11
Most days	16	18	15	14
Some days	38	34	37	33
Rarely	17	13	17	24
Never	22	16	19	18

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]?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Every day	0	2	4	3
Most days	2	3	2	2
Some days	5	4	1	2
Rarely	6	4	3	3
Never	58	57	65	64
Do not use	28	30	26	27

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?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	59	76	50	44
No	41	24	50	56

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	44	60	38	30
No	56	40	63	70

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Orally (by mouth as pills, capsules, liquid)	98	99	97	100
Insulin injection	12	16	6	11
Other injection	5	7	6	0
Infusion pump	1	1	0	0
Inhaler	14	14	12	0
Suppository	5	2	3	0
Medication patch	5	3	12	5
Spray	3	5	6	0
Eye/Ear drops	18	19	13	5
Other	8	7	7	5

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	5	11	4	3
No	95	89	96	97

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	9	13	4	8
No	91	88	96	92

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	28	31	28	16
No	72	69	72	84

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	25	38	19	25
No	75	62	82	75

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	20	23	15	13
No	80	77	85	87

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	30	35	22	22
No	71	65	78	78

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	25	38	20	21
No	75	62	80	79

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	48	42	52	47
No	52	58	48	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?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	46	36	35	18
No	54	64	65	82

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	49	54	49	47
No	51	46	51	53

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	5	4	0	0
No	95	96	100	100

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)?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	51	43	46	35
No	49	58	54	65

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	16	17	21	21
No	84	83	79	79

QCA150. [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)?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	7	10	9	9
No	93	90	91	91

(If YES to any of QCA15A – QCA150, 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.

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
1. Not at all difficult	56	50	58	61
2.	21	20	15	27
3.	15	16	16	6
4.	6	10	6	4
5. Very difficult	3	5	4	2

QCA17. Did anyone prepare you to do these tasks?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	26	29	16	25
No → QCA21	75	71	84	76

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Hospital nurse	9	38	17	42
Hospital doctor	2	13	0	8
Primary care doctor	18	13	13	8
Nurse in doctor's office or outpatient setting	10	15	17	0
Home care nurse	22	29	25	17
Social worker/geriatric care manager	1	4	4	8
Physical or occupational therapist	15	20	25	17
Pharmacist	5	8	4	8
Medical supply technician	6	10	13	0
Friend or neighbor	7	8	8	0
You learned on your own	29	26	21	17
Other	53	34	46	33

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Very well	78	83	83	64
Somewhat well	20	15	17	36
Not well	2	3	0	0

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
None → QCA24PRE	46	39	48	46
One time	20	24	23	14
2 times	15	19	12	14
3 or more times	20	18	18	27

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...

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes, all the time	53	67	57	47
Only some of the time	23	24	26	28
No, and you should have been	6	4	6	0
No, but you did not need to be	18	5	11	25

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]?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	65	81	73	78
No	25	16	19	17
Not applicable	10	2	8	6

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Very well	54	54	52	64
Somewhat well	34	37	37	24
Not well	12	8	11	12

QCA24PRE. Now think about the last YEAR.

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	67	79	45	50
No	33	21	55	50

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	66	80	49	53
No	34	20	51	47

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	84	90	81	82
No	16	10	19	18

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.]

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	24	38	19	14
No	76	62	81	86

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.]

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	36	48	32	33
No	64	52	68	67

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?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
8 hours or less per week	42	33	48	56
9 to 19 hours per week	27	26	22	27
20 to 39 hours per week	17	17	15	8
40 or more hours per week	15	24	16	9

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.

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Regular schedule	52	57	51	39
Varied	48	43	49	61

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
3 months or less	5	5	7	11
4 to 12 months	11	11	10	9
1 - 2 years	20	20	19	14
3 - 5 years	30	25	25	42
More than 5 years	34	39	39	25

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Increased in the past month	39	35	31	33
Been about the same in the past month	53	54	58	64
Decreased in the past month	8	11	11	3

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?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Will increase	35	29	32	30
Will be about the same	58	62	56	61
Will decrease	7	9	12	9

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	45	40	47	70
No	55	60	53	30

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Very worried	5	7	5	3
Somewhat worried	13	10	13	9
Only a little	25	28	34	35
Not at all	58	55	48	53

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 suffering physically 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".)

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
1 CR has not been suffering physically	14	11	15	17
2	10	9	9	11
3	13	13	18	13
4	10	9	7	17
5	15	16	14	5
6	9	9	8	8
7	11	12	13	11
8	9	9	11	9
9	4	6	3	6
10 CR has been suffering terribly	6	7	3	3

QCA32. Now, please rate the degree to which you think CR has been suffering psychologically or emotionally 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".)

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
1 CR has not been suffering physically	13	13	14	11
2	11	6	10	12
3	11	9	14	17
4	8	5	5	15
5	14	18	13	9
6	10	10	10	3
7	9	11	12	9
8	13	13	9	12
9	5	6	6	5
10 CR has been suffering terribly	7	9	7	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]?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
A lot	67	69	79	71
Some	25	25	17	24
A little	6	6	3	3
Not at all	1	1	1	2

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
A lot	19	19	19	11
Some	24	29	26	21
A little	28	29	28	35
Not at all	28	23	27	33

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
A lot	78	75	88	87
Some	13	15	6	8
A little	7	6	4	2
Not at all	2	4	1	3

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
A lot	21	21	19	11
Some	29	35	29	27
A little	33	32	31	38
Not at all	17	12	21	24

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...

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Gotten much better	20	15	16	11
Gotten somewhat better	18	20	24	24
Stayed about the same	48	43	51	55
Gotten somewhat worse	12	18	6	11
Gotten much worse	2	5	4	0

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.

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Very much	36	42	38	32
Somewhat	38	34	39	44
Not so much	26	24	23	24

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Very much	48	56	40	32
Somewhat	34	31	46	52
Not so much	19	14	13	17

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Very much	48	47	51	36
Somewhat	34	34	36	47
Not so much	18	19	14	17

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Very much	81	80	74	62
Somewhat	16	17	22	32
Not so much	3	3	4	6

QAC6A. Is helping CR financially difficult for you?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	20	32	16	14
No	80	68	84	86

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	64	66	48	46
No	36	34	52	54

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	27	40	21	14
No	73	60	79	86

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*)

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
1. A little difficult	13	6	17	22
2.	12	7	13	22
3.	28	31	37	44
4.	25	30	10	11
5. Very difficult	22	26	23	0

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
1. A little difficult	11	10	18	10
2.	17	15	20	30
3.	30	25	28	33
4.	24	24	17	17
5. Very difficult	18	25	18	10

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
1. A little difficult	11	6	12	22
2.	17	16	29	0
3.	40	33	27	44
4.	22	25	20	33
5. Very difficult	11	20	12	0

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Very much	10	6	11	4
Somewhat	25	20	16	28
Not so much	65	75	74	68

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.

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Very much	34	35	26	20
Somewhat	28	36	26	33
Not so much	39	30	48	47

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Very much	25	25	18	24
Somewhat	37	38	23	26
Not so much	38	37	59	50

QAC9C. You don't have time for yourself.

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Very much	29	29	20	15
Somewhat	31	40	29	29
Not so much	40	31	51	56

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Very much	13	10	8	11
Somewhat	27	33	23	21
Not so much	60	57	69	68

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?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	91	92	82	89
No	9	9	18	11

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?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	59	44	46	64
No	42	56	54	36

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	74	53	64	83
No	26	47	36	17

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	6	8	4	6
No	94	93	96	94

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?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	23	17	17	15
No	77	83	83	85

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	9	13	5	9
No	91	87	95	91

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	20	15	15	17
No	80	85	85	83

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)*

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	20	21	15	11
No	80	79	85	89

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?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	42	44	46	36
No	59	57	54	64

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?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	40	48	47	38
No	60	52	53	62

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	22	21	24	8
No	78	79	76	92

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?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
One	26	21	17	22
Two	28	28	26	22
Three or more	46	51	57	56

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Caregiver's Brother(s)	24	30	27	33
CG's Sister(s)	41	34	33	49
CG's husband	29	18	2	0
CG's wife	0	0	28	31
CG's other relative(s) / in-law(s)	46	68	62	46
CG's friend(s)	14	13	12	4
Other	25	24	23	22

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Live(s) with you	42	34	37	46
Within twenty minutes of your home	56	80	66	73
Between twenty minutes and an hour from your home	28	20	29	16
One to two hours from your home	7	4	4	6
Two to four hours away	3	6	2	11
More than four hours away	10	8	15	15

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
We complement each other – we each help CR with different tasks.	31	26	27	30
We help with the same things but we divide the help over time.	15	14	22	24
We share some tasks, and others we do separately	54	60	51	46

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?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Respondent is the primary caregiver	54	70	50	40
Someone else is the primary caregiver	28	22	37	47
Care is equally shared	18	8	13	13

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
To a great extent	2	2	2	2
To a moderate extent	10	7	8	4
Only a little	30	24	34	29
Not at all	58	68	57	66

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Very satisfied	66	69	70	67
Moderately satisfied	25	25	23	32
Moderately dissatisfied	5	5	6	2
Very dissatisfied	3	1	2	0

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?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	86	84	80	92
No	14	16	20	8

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]?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	30	36	27	18
No	70	64	73	82

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Very important	55	55	43	53
Somewhat important	33	31	36	32
Not so important	11	14	21	15

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	64	61	50	59
No	36	39	50	41

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	11	20	10	6
No	89	81	90	94

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Very important	47	54	35	39
Somewhat important	26	21	23	23
Not so important	27	25	43	38

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.]

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	53	44	45	42
No	47	56	56	58

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.]

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	21	25	17	9
No	79	75	83	91

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.]

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Very important	33	30	28	24
Somewhat important	33	31	26	36
Not so important	34	40	47	39

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.

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	88	76	84	91
No	13	25	16	9

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.]

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	23	30	23	15
No	77	70	77	85

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.]

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Very important	53	44	42	46
Somewhat important	37	38	36	44
Not so important	10	18	22	11

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	38	32	39	36
No	62	68	62	64

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	14	23	10	12
No	86	77	90	88

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.

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	44	46	26	38
No	56	54	75	62

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	7	11	6	6
No	93	89	94	94

HEALTH

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Excellent	17	12	17	18
Very good	36	26	27	36
Good	28	36	33	29
Fair	18	22	19	12
Poor	2	4	5	5

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	4	6	12	17
No	96	94	88	83

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	5	9	14	18
No	95	91	86	82

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	36	44	49	41
No	64	56	51	59

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	47	57	41	35
No	53	44	59	65

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	19	31	9	8
No	81	69	92	92

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	14	14	17	11
No	86	86	83	89

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	16	18	14	8
No	84	82	86	92

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	11	17	19	11
No	90	83	81	89

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

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	61	69	60	41
No	39	31	40	59

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	15	21	20	8
No	86	79	80	92

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	30	36	26	26
No	70	64	74	74

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	38	50	31	26
No	63	50	69	74

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	52	62	43	33
No	48	38	57	67

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Every night	9	11	8	11
Most nights	15	15	15	12
Some nights	31	38	30	29
Rarely	27	22	26	33
Never	18	14	21	15

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Every night	1	4	4	3
Most nights	5	6	5	3
Some nights	18	24	15	9
Rarely	22	26	22	26
Never	54	40	55	59

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:

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
< 18.5 (underweight)	1	1	1	0
18.5 – 24.9 (normal)	31	26	22	24
25.0 – 29.9 (overweight)	31	34	46	53
30.0 – 34.9 (moderately obese)	24	22	22	15
35.0 – 39.9 (severely obese)	6	10	7	5
40.0 + (very severely obese)	7	7	3	3

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	30	32	27	29
No → QHE25A	70	68	73	71

QHE24a. Were you trying to lose weight?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	74	64	62	68
No	27	36	39	32

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Every day	14	15	19	17
Most days	51	43	41	38
Some days	27	32	30	35
Rarely	9	9	8	9
Never	0	1	1	2

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Every day	12	9	17	15
Most days	39	38	38	39
Some days	33	36	31	30
Rarely	14	14	12	14
Never	2	3	2	2

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Every day	17	11	19	17
Most days	34	30	35	27
Some days	31	32	30	38
Rarely	15	22	12	15
Never	3	4	5	3

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Every day	2	3	4	3
Most days	5	6	8	3
Some days	19	24	20	35
Rarely	30	29	39	29
Never	44	39	29	30

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Every day	2	3	3	2
Most days	6	10	7	8
Some days	19	22	22	20
Rarely	29	29	26	26
Never	43	37	41	46

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Every day	3	5	5	0
Most days	8	10	7	11
Some days	47	54	42	32
Rarely	36	27	38	47
Never	6	4	8	11

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Not at all	61	48	55	54
Several days	28	35	35	35
More than half the days	7	12	6	6
Nearly every day	4	6	5	5

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Not at all	60	50	56	69
Several days	31	35	33	25
More than half the days	6	10	7	2
Nearly every day	3	6	4	5

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Not at all	44	33	46	46
Several days	43	47	40	49
More than half the days	6	13	9	2
Nearly every day	8	7	6	5

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Not at all	52	40	62	54
Several days	30	38	25	31
More than half the days	8	10	5	12
Nearly every day	10	12	8	3

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?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Not at all	2	1	5	9
A little bit	4	5	5	3
Somewhat	8	9	12	6
Quite a bit	27	30	30	23
Extremely	59	55	48	59

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?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Never	72	63	64	71
Rarely	21	27	25	20
Sometimes	7	9	10	6
Often	0	1	1	2
Always	0	0	1	2

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Never	71	59	59	67
Rarely	21	29	28	26
Sometimes	8	10	10	8
Often	0	1	1	0
Always	0	0	2	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)?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Correct	68	64	69	68
Incorrect	32	37	31	32

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*)

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Correct	82	78	86	86
Incorrect	18	22	14	14

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*)

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Correct	75	72	83	85
Incorrect	25	28	17	15

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.

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes → QEC4	52	37	48	56
No	24	21	18	24
Retired / don't work anymore → QEC16	24	43	34	20

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes → QEC4	6	7	11	6
No	74	67	60	63
Retired / don't work anymore → QEC16	20	26	29	31

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes, looking for a job → QEC16	15	5	24	40
Yes, on layoff → QEC16	5	5	10	0
No → QEC16	68	90	67	60
Retired / don't work anymore → QEC16	12	0	0	0

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	22	24	18	24
No	78	76	82	76

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
20 or fewer	24	26	17	8
21 – 39	20	20	20	11
40 or more	57	55	63	82

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?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	59	59	56	71
No	41	41	44	29

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Daytime	82	80	82	79
Some other schedule	18	20	18	21

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?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	47	42	45	30
No → QEC12	53	58	55	70

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.

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	38	25	21	42
No	62	76	80	58

QEC9B. You were sick.

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	40	49	36	25
No	60	51	64	75

QEC9C. You took time off to help CR.

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	47	45	40	42
No	53	55	60	58

QEC9D. Other family members were sick.

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	22	22	11	33
No	78	78	89	67

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	34	41	40	33
No	66	59	60	67

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?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
One	53	41	56	60
Two	23	14	28	40
Three or more	25	46	17	0

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?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	28	30	18	18
No →QEC14	72	70	82	82

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.

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
1 A little harder	16	6	12	29
2	9	9	12	29
3	16	30	18	0
4	16	15	0	14
5	18	15	18	0
6	8	6	12	14
7	6	3	12	14
8	8	9	18	0
10 A lot harder	3	6	0	0

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	79	84	72	71
No	21	16	28	29

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Telecommuting or working from home	31	26	30	47
Programs like information, referrals, counseling, or an employee assistance program, to help caregivers like yourself	40	39	21	32
Paid leave, where you could take paid time off from work for several weeks to care for a family member	36	38	26	29
Paid sick days	55	54	50	55
None of the above	26	30	31	24

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Went in late, left early, or took time off during the day to provide care	47	41	37	35
Took a leave of absence	13	16	9	5
Went from working full-time to part-time, or cut back your hours	14	18	12	11
Turned down a promotion	5	4	1	0
Lost any of your job benefits	5	6	3	3
Gave up working entirely	13	20	7	6
Retired early	9	18	13	9
Received a warning about your performance or attendance at work	4	4	3	6
None of the above	41	40	51	55

DEMOGRAPHICS

QDE1. INTERVIEWER: RECORD PERSON'S SEX

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Male	0	0	100	100
Female	100	100	0	0

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
44 or under	15	7	8	20
45 – 54	22	16	17	18
55 – 64	42	33	37	39
65 or older	21	45	37	23

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Married	52	71	61	44
Living with a partner in a marital- like relationship	4	6	2	12
Divorced or separated	14	12	12	17
Widowed	8	4	2	2
Single/never married	22	8	23	26

QDE4. Are you of Hispanic or Latino descent?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	2	1	2	0
No	98	99	98	100

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Caucasian/White	79	83	87	88
Asian/Pacific Islander	0	0	1	2
American Indian or Alaskan Native	1	2	1	0
Black or African-American	20	15	12	11
None of the above	0	1	1	0

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Eighth grade or less	0	0	1	0
Some high school	1	1	3	2
High school graduate or GED	18	25	15	17
Some college, no degree	20	21	23	17
Associate's degree, occupational	7	8	5	8
Associate's degree, academic	6	8	5	3
Bachelor's degree	28	20	28	39
Master's degree	17	12	18	11
Professional degree	2	3	2	2
Doctoral degree	2	2	2	3

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Live alone → QDE11PRE	15	11	18	15
Live in a household with family or others	84	88	81	83
Have some other living arrangements	1	1	1	2

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
One	5	4	6	2
Two	58	74	67	66
Three	28	15	19	20
Four	8	5	8	9
Five	1	2	1	4
Six	0	0	0	0

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Zero	74	85	89	79
One	14	7	6	13
Two	8	5	4	7
Three	3	2	1	2
Four	1	2	0	0
Five	1	0	0	0
Six	0	0	0	0

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Your spouse / partner	68	87	77	70
Your child(ren)	42	26	22	29
Your grandchild(ren)	5	6	3	0
Your parent(s)	24	7	21	27
Other relatives of yours	13	5	10	20
Non-relatives	3	2	5	7

QDE11PRE. And now just a couple questions about CR.

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Eighth grade or less	6	6	5	3
Some high school	8	7	5	3
High school graduate or GED	49	43	45	50
Some college, no degree	9	8	7	6
Associate's degree, occupational	6	6	8	9
Associate's degree, academic	3	3	4	0
Bachelor's degree	11	13	17	17
Master's degree	4	7	6	5
Professional degree	1	2	2	2
Doctoral degree	0	6	2	5

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	1	0	0	0
No	99	100	100	100

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Caucasian/White	80	83	87	86
Asian/Pacific Islander	0	1	1	2
American Indian or Alaskan Native	1	1	1	2
Black or African-American	19	15	13	11
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?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	34	48	30	35
No	66	52	70	65

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?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	15	27	13	17
No	85	73	87	83

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.

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
1. Not at all difficult	77	73	70	69
2	11	12	16	13
3	7	10	6	6
4	3	2	3	3
5. Very difficult	2	4	5	9

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.

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
1. Not at all difficult	72	67	71	62
2	12	10	11	21
3	8	10	11	6
4	4	5	5	3
5. Very difficult	3	7	2	8

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.

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
1. Not at all difficult	41	35	38	49
2	8	8	11	17
3	13	10	12	5
4	8	7	6	6
5. Very difficult	8	11	7	8
Not applicable	23	30	25	15

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.

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
1. Not at all difficult	34	29	33	43
2	9	6	14	14
3	11	10	11	11
4	7	4	7	3
5. Very difficult	14	16	8	11
Not applicable	25	35	27	19

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.

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
1. Not at all difficult	28	25	28	38
2	8	6	8	15
3	14	10	17	9
4	11	10	8	5
5. Very difficult	16	16	11	11
Not applicable	24	33	28	23

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*)

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
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	84	88	79	76
Requiring hospitals to keep you informed about major decisions, like transferring or discharging CR	86	90	83	79
Requiring hospitals or facilities to instruct or demonstrate any medical or nursing tasks you might need to do	88	90	83	82
Having respite services available, where someone would take care of CR to give you a break	71	74	70	59
Requiring a doctor, nurse, or social worker ask you about what you need to help care for CR	79	83	73	74
Requiring a doctor, nurse, or social worker ask you about what you need to take care of yourself	63	72	58	47
None of the above	5	4	8	9

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.

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
An income tax credit to caregivers, to help offset the cost of care	28	37	43	40
A partially paid leave of absence from work for caregivers who are employed	20	18	15	15
A program where caregivers could be paid for at least some of the hours they provide care	52	45	42	45

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?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	31	56	45	39
No → QHI3	69	44	56	61

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	67	65	74	69
No	33	35	26	31

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	14	12	11	6
No	86	88	90	94

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.

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	77	75	73	80
No	23	25	27	20

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?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	2	3	6	2
No	98	97	94	99

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Medicare	79	75	71	76
Medicaid	18	14	22	20
Private Health Insurance	52	64	52	55
Tricare/CHAMPVA	2	7	2	8

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	75	81	73	71
No	25	19	27	29

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	96	97	95	94
No	4	3	5	6

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	76	71	80	70
No	24	29	20	30

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	18	17	25	13
No	82	83	75	88

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	75	66	70	70
No	25	34	30	30

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	37	26	40	47
No	63	74	60	53

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?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
0 – less than \$10,000	9	5	7	5
\$10,000 to less than \$20,000	11	10	8	9
\$20,000 to less than \$30,000	8	13	11	7
\$30,000 to less than \$40,000	9	19	11	14
\$40,000 to less than \$50,000	9	11	11	14
\$50,000 to less than \$60,000	11	9	9	5
\$60,000 to less than \$70,000	8	9	8	10
\$70,000 to less than \$80,000	6	6	6	3
\$80,000 to less than \$90,000	6	4	6	7
\$90,000 to less than \$100,000	5	5	4	9
\$100,000 to less than \$110,000	4	3	6	5
\$110,000 to less than \$120,000	2	1	2	0
\$120,000 to less than \$130,000	2	1	1	3
\$130,000 to less than \$140,000	0	1	0	0
\$140,000 to less than \$150,000	3	1	1	0
More than \$150,000	8	3	9	9

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?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	31	55	42	29
No	70	46	58	71

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?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	9	41	27	8
No	91	59	73	92

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	8	20	18	11
No	92	80	82	89

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?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	25	33	31	15
No	75	67	69	85

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.

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	18	24	22	14
No	82	76	78	86

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	10	11	11	2
No	90	89	89	99

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,]

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
More than \$1,000 → QHI6	31	58	44	18
Less than \$1,000 → QHI7	69	42	56	82

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

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	59	67	62	40
No	41	33	38	60

(skip to next section)

QHI17. Was it less than \$500?

	Female CG – Female CR	Female CG – Male CR	Male CG – Female CR	Male CG – Male CR
Yes	74	73	66	78
No	26	27	34	22