

THE PITTSBURGH REGIONAL CAREGIVERS SURVEY

TOPLINE RESULTS

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Notes

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.

Most questions offered responses of “don’t know” and “refused.” These responses only appear in the tables when selected by one or more respondents.

CR = care recipient; CG = caregiver

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?

	N	%
Yes	507	50
No	501	50

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

	N	%
Yes	983	98
No	25	3

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

	N	%
Yes	639	63
No	369	37

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:

	N	%
Your mother or mother-in-law	421	42
Your father or father-in-law	125	12
Your wife / partner	60	6
Your husband / partner	154	15
Your daughter or daughter-in-law	8	1
Your son or son-in-law	5	1
Some other relative	148	15
A non-relative	87	9

QCS2. Is the person you care for:

	N	%
Male	360	36
Female	648	64

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

	N	%
50 – 64	161	16
65 – 74	180	18
75 – 84	258	26
85 +	409	41

QCS5. Where does [he/she] live?

	N	%
In your household → QCS9	438	44
Within 20 minutes of your home	430	43
Between 20 minutes and an hour from your home	111	11
One to two hours from your home	12	1
More than two hours away	17	2

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

	N	%
His or her own home	403	71
Someone else's home → QCS9	49	9
An independent living or retirement community	66	12
In an assisted living facility where some care may be provided → QCS9	49	9
Somewhere else	3	1

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

QCS7. Does [he/she] live alone?

	N	%
Yes	318	68
No	151	32
Don't know	1	0
Refused	2	0

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

	N	%
Short-term physical condition	121	12
Long-term physical condition	783	78
Emotional or mental health problem	192	19
Developmental or intellectual disorder or mental retardation	49	5
Behavioral issue	74	7
Memory problem	427	42
None of the above	46	5
Don't know	4	0

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

	N	%
Yes	234	23
No	752	75
Don't know	22	2

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

QCS11. a heart attack or myocardial infarction?

	N	%
Yes	222	22
No	755	75
Don't know	30	3
Refused	1	0

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

	N	%
Yes	323	32
No	654	65
Don't know	30	3
Refused	1	0

QCS13. high blood pressure or hypertension?

	N	%
Yes	641	64
No	337	33
Don't know	29	3
Refused	1	0

QCS14. arthritis?

	N	%
Yes	641	64
No	342	34
Don't know	24	2
Refused	1	0

QCS15. osteoporosis or thinning of the bones?

	N	%
Yes	335	33
No	615	61
Don't know	57	6
Refused	1	0

QCS16. diabetes?

	N	%
Yes	278	28
No	722	72
Don't know	7	1
Refused	1	0

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

	N	%
Yes	234	23
No	762	76
Don't know	11	1
Refused	1	0

QCS18. cancer?

	N	%
Yes	274	27
No	725	72
Don't know	8	1
Refused	1	0

QCS18a. a stroke?

	N	%
Yes	219	22
No	772	77
Don't know	16	2
Refused	1	0

QCS19. serious difficulty seeing?

	N	%
Yes	288	29
No	712	71
Don't know	7	1
Refused	1	0

QCS20. serious difficulty hearing?

	N	%
Yes	370	37
No	630	63
Don't know	7	1
Refused	1	0

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

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

	N	%
Yes	867	86
No	137	14
Don't know	4	0

QCS22B. a hearing aid?

	N	%
Yes	183	18
No	825	82

QCS22C. a cane?

	N	%
Yes	423	42
No	580	58
Don't know	5	1

QCS22D. a walker?

	N	%
Yes	441	44
No	565	56
Don't know	2	0

QCS22E. a wheelchair?

	N	%
Yes	337	33
No	669	66
Don't know	2	0

QCS22F. a scooter?

	N	%
Yes	76	8
No	929	92
Don't know	3	0

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

	N	%
Yes	337	33
No	662	66
Don't know	9	1

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

	N	%
Yes	204	20
No	790	78
Don't know	14	1

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.

	N	%
Yes	55	6
No	951	94
Don't know	2	0

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?

	N	%
Yes	811	81
No → next section	197	20

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

	N	%
A railing or ramp	513	63
Grab bars in the bathroom	624	77
A seat for the shower or tub	579	71
An emergency call system	350	43
Other	273	34
Don't know	1	0

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?

	N	%
Every day	503	50
Most days	157	16
Some days	197	20
Rarely	61	6
Never → QCA2	61	6
Does not do, but not because of poor health and functioning → QCA2	23	2
Don't know → QCA2	6	1

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]?

	N	%
Every day	366	40
Most days	158	17
Some days	273	30
Rarely	71	8
Never	50	5

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*)

	N	%
Yes, another unpaid family member / friend	478	52
Yes, a paid helper	217	24
No	317	35

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?

	N	%
Every day	409	41
Most days	209	21
Some days	238	24
Rarely	78	8
Never → QCA3	48	5
Does not do, but not because of poor health and functioning → QCA3	23	2
Don't know → QCA3	2	0
Refused → QCA3	1	0

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]?

	N	%
Every day	232	25
Most days	205	22
Some days	332	36
Rarely	93	10
Never	72	8

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

	N	%
Yes, another unpaid family member / friend	494	53
Yes, a paid helper	70	8
No	403	43
Don't know	2	0

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

	N	%
Yes	578	57
No → QCA4	402	40
Does not do, but not because of poor health and functioning → QCA4	25	3
Don't know → QCA4	3	0

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

	N	%
Yes	439	76
No	139	24

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

	N	%
Yes, another unpaid family member / friend	197	34
Yes, a paid helper	59	10
No	329	57
Don't know	3	1

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

	N	%
Yes	674	67
No → QCA5	295	29
Does not do, but not because of poor health and functioning → QCA5	38	4
Refused → QCA5	1	0

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

	N	%
Yes	530	79
No	144	21

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

	N	%
Yes, another unpaid family member / friend	273	41
Yes, a paid helper	9	1
No	394	59
Don't know	1	0

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?

	N	%
Every day	95	10
Most days	41	4
Some days	61	6
Rarely	100	10
Never → QCA6	674	69
Don't know → QCA6	5	1

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

	N	%
Every day	74	25
Most days	38	13
Some days	77	26
Rarely	71	24
Never	37	13

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

	N	%
Yes, another unpaid family member / friend	124	42
Yes, a paid helper	46	16
No	146	49
Don't know	3	1

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

	N	%
Every day	229	24
Most days	95	10
Some days	114	12
Rarely	97	10
Never → QCA7	427	44
Don't know → QCA7	14	1

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

	N	%
Every day	113	21
Most days	68	13
Some days	120	22
Rarely	88	16
Never	146	27

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

	N	%
Yes, another unpaid family member / friend	188	35
Yes, a paid helper	156	29
No	228	43
Don't know	2	0

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

	N	%
Every day	220	23
Most days	81	8
Some days	143	15
Rarely	128	13
Never → QCA8	398	41
Don't know → QCA8	6	1

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

	N	%
Every day	123	22
Most days	85	15
Some days	175	31
Rarely	124	22
Never	64	11
Don't know	1	0

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

	N	%
Yes, another unpaid family member / friend	227	40
Yes, a paid helper	137	24
No	259	45
Don't know	3	1

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

	N	%
Every day	155	16
Most days	33	3
Some days	60	6
Rarely	94	10
Never → QCA9	616	63
Don't know → QCA9	18	2

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

	N	%
Every day	99	29
Most days	39	11
Some days	74	22
Rarely	76	22
Never	54	16

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

	N	%
Yes, another unpaid family member / friend	158	46
Yes, a paid helper	105	31
No	124	36
Don't know	3	1

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

	N	%
Every day	154	16
Most days	35	4
Some days	81	8
Rarely	129	13
Never → QCA10	569	58
Don't know → QCA10	8	1

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

	N	%
Every day	82	21
Most days	40	10
Some days	94	24
Rarely	121	30
Never	62	16

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

	N	%
Yes, another unpaid family member / friend	183	46
Yes, a paid helper	92	23
No	166	42
Don't know	3	1

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

	N	%
Every day	162	17
Most days	46	5
Some days	122	13
Rarely	164	17
Never → QCA11	477	49
Don't know → QCA11	5	1

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

	N	%
Every day	99	20
Most days	58	12
Some days	159	32
Rarely	141	29
Never	37	8

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

	N	%
Yes, another unpaid family member / friend	264	53
Yes, a paid helper	99	20
No	181	37
Don't know	3	1

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

	N	%
Every day	235	24
Most days	110	11
Some days	187	19
Rarely	130	13
Never → skip logic prior to QCA12A	309	32
Don't know → skip logic prior to QCA12A	5	1

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

	N	%
Every day	134	20
Most days	108	16
Some days	248	38
Rarely	123	19
Never	48	7
Refused	1	0

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

	N	%
Yes, another unpaid family member / friend	388	59
Yes, a paid helper	97	15
No	225	34
Don't know	1	0

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?

	N	%
Yes	285	36
No	503	64
Don't know	2	0

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?

	N	%
Yes	563	71
No	224	28
Don't know	3	0

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?

	N	%
Yes	568	72
No	220	28
Don't know	2	0

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

	N	%
Every day	119	12
Most days	162	16
Some days	368	37
Rarely	165	16
Never	194	19

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

	N	%
Every day	18	2
Most days	25	3
Some days	36	4
Rarely	49	5
Never	598	59
Do not use	282	28

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?

	N	%
Yes	595	61
No	377	39
Don't know	1	0

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

	N	%
Yes	450	46
No	520	54

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

	N	%
Orally (by mouth as pills, capsules, liquid)	443	98
Insulin injection	56	12
Other injection	25	6
Infusion pump	3	1
Inhaler	58	13
Suppository	14	3
Medication patch	23	5
Spray	18	4
Eye/Ear drops	77	17
Other	34	8

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

	N	%
Yes	63	7
No	910	94

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

	N	%
Yes	88	9
No	885	91

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

	N	%
Yes	271	28
No	700	72
Don't know	1	0
Refused	1	0

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

	N	%
Yes	269	28
No	703	72
Don't know	1	0

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

	N	%
Yes	189	19
No	783	81
Don't know	1	0

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

	N	%
Yes	285	29
No	687	71
Don't know	1	0

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

	N	%
Yes	269	28
No	704	72

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

	N	%
Yes	456	47
No	515	53
Don't know	1	0
Refused	1	0

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?

	N	%
Yes	250	39
No	389	61

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

	N	%
Yes	324	51
No	315	49

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

	N	%
Yes	24	4
No	615	96

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)

	N	%
Yes	298	47
No	341	53

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

	N	%
Yes	111	17
No	527	83
Don't know	1	0

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)

	N	%
Yes	54	9
No	585	92

(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.

	N	%
1. Not at all difficult	463	54
2.	169	20
3.	125	15
4.	58	7
5. Very difficult	33	4
Don't know	4	1
Refused	1	0

QCA17. Did anyone prepare you to do these tasks?

	N	%
Yes	212	25
No → QCA21	639	75
Don't know → QCA21	2	0

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

	N	%
Hospital nurse	48	23
Hospital doctor	13	6
Primary care doctor	31	15
Nurse in doctor's office or outpatient setting	26	12
Home care nurse	52	25
Social worker/geriatric care manager	6	3
Physical or occupational therapist	38	18
Pharmacist	13	6
Medical supply technician	17	8
Friend or neighbor	15	7
You learned on your own	56	26
Other	93	44

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

	N	%
Very well	166	78
Somewhat well	39	18
Not well	4	2
Don't know	2	1
Refused	1	1

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

	N	%
None → QCA24PRE	442	44
One time	212	21
2 times	156	16
3 or more times	192	19
Don't know → QCA24PRE	6	1

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...

	N	%
Yes, all the time	322	58
Only some of the time	135	24
No, and you should have been	28	5
No, but you did not need to be	73	13
Don't know	2	0

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]?

	N	%
Yes	403	72
No	115	21
Not applicable	39	7
Don't know	3	1

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

	N	%
Very well	272	52
Somewhat well	177	34
Not well	53	10
Don't know	13	3
Refused	6	1

QCA24PRE. Now think about the last YEAR.

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

	N	%
Yes	657	65
No	349	35
Don't know	2	0

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

	N	%
Yes	667	66
No	340	34
Don't know	1	0

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

	N	%
Yes	855	85
No	151	15
Don't know	2	0

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.]

	N	%
Yes	264	26
No	742	74
Don't know	2	0

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.]

	N	%
Yes	387	38
No	621	62

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?

	N	%
8 hours or less per week	416	41
9 to 19 hours per week	254	25
20 to 39 hours per week	157	16
40 or more hours per week	170	17
Don't know	10	1
Refused	1	0

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.

	N	%
Regular schedule	528	52
Varied	478	47
Don't know	1	0
Refused	1	0

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

	N	%
3 months or less	59	6
4 to 12 months	108	11
1 - 2 years	194	19
3 - 5 years	285	28
More than 5 years	361	36
Don't know	1	0

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

	N	%
Increased in the past month	360	36
Been about the same in the past month	555	55
Decreased in the past month	92	10
Don't know	1	0

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?

	N	%
Will increase	321	32
Will be about the same	581	58
Will decrease	82	9
Don't know	24	2

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

	N	%
Yes	452	45
No	540	54
Don't know	16	2

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

	N	%
Very worried	51	5
Somewhat worried	118	12
Only a little	286	28
Not at all	551	55
Don't know	1	0
Refused	1	0

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".)

	N	%
1 CR has not been suffering physically	132	13
2	94	9
3	141	14
4	93	9
5	143	14
6	87	9
7	114	11
8	94	9
9	44	4
10 CR has been suffering terribly	57	6
Don't know	9	1

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".)

	N	%
1 CR has not been suffering physically	129	13
2	94	9
3	109	11
4	70	7
5	148	15
6	96	10
7	97	10
8	120	12
9	54	5
10 CR has been suffering terribly	74	7
Don't know	17	2

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]?

	N	%
A lot	705	70
Some	234	23
A little	53	5
Not at all	12	1
Don't know	4	0

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

	N	%
A lot	187	19
Some	259	26
A little	291	29
Not at all	271	27

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

	N	%
A lot	787	78
Some	117	12
A little	57	6
Not at all	25	3
Don't know	22	2

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

	N	%
A lot	200	20
Some	309	31
A little	330	33
Not at all	168	17
Don't know	1	1

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...

	N	%
Gotten much better	170	17
Gotten somewhat better	204	20
Stayed about the same	475	47
Gotten somewhat worse	124	12
Gotten much worse	28	3
Don't know	6	1
Refused	1	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.

	N	%
Very much	378	38
Somewhat	371	37
Not so much	249	25
Don't know	8	1
Refused	2	0

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

	N	%
Very much	475	47
Somewhat	364	36
Not so much	159	16
Don't know	9	1
Refused	1	0

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

	N	%
Very much	476	47
Somewhat	355	35
Not so much	172	17
Don't know	4	0
Refused	1	0

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

	N	%
Very much	785	78
Somewhat	189	19
Not so much	32	3
Don't know	2	0

QAC6A. Is helping CR financially difficult for you?

	N	%
Yes	224	22
No	776	77
Don't know	7	1
Refused	1	0

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

	N	%
Yes	602	60
No	394	39
Don't know	10	1
Refused	2	0

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

	N	%
Yes	291	29
No	716	71
Refused	1	0

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*)

	N	%
1. A little difficult	25	11
2.	24	11
3.	69	31
4.	55	25
5. Very difficult	51	23

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

	N	%
1. A little difficult	71	12
2.	104	17
3.	170	28
4.	137	23
5. Very difficult	120	20

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

	N	%
1. A little difficult	27	9
2.	52	18
3.	104	36
4.	67	23
5. Very difficult	41	14

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

	N	%
Very much	66	7
Somewhat	169	18
Not so much	541	59
Not applicable.	143	16
Don’t know	2	0

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.

	N	%
Very much	319	32
Somewhat	301	30
Not so much	386	38
Don’t know	2	0

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

	N	%
Very much	237	24
Somewhat	340	34
Not so much	431	43

QAC9C. You don’t have time for yourself.

	N	%
Very much	264	26
Somewhat	335	33
Not so much	408	41
Don’t know	1	0

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

	N	%
Very much	111	11
Somewhat	276	27
Not so much	618	61
Don't know	3	0

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?

	N	%
Yes	901	89
No	105	10
Don't know	1	0
Refused	1	0

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?

	N	%
Yes	526	52
No	480	48
Don't know	1	0
Refused	1	0

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

	N	%
Yes	671	67
No	333	33
Don't know	2	0
Refused	2	0

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

	N	%
Yes	59	6
No	949	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?

	N	%
Yes	196	19
No	811	81
Don't know	1	0

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

	N	%
Yes	98	10
No	910	90

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

	N	%
Yes	173	17
No	830	82
Don't know	5	1

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)*

	N	%
Yes	188	19
No	816	81
Don't know	2	0

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?

	N	%
Yes	429	43
No	578	57
Don't know	1	0

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?

	N	%
Yes	438	44
No	567	56
Don't know	2	0
Refused	1	0

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

	N	%
Yes	212	21
No	794	79
Don't know	1	0
Refused	1	0

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?

	N	%
One	152	23
Two	181	27
Three or more	333	50
Don't know	3	0
Refused	2	0

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

	N	%
Caregiver's Brother(s)	178	27
CG's Sister(s)	257	39
CG's husband	129	19
CG's wife	52	8
CG's other relative(s) / in-law(s)	360	54
CG's friend(s)	82	12
Other	161	24
Refused	1	0

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

	N	%
Live(s) with you	262	39
Within twenty minutes of your home	428	64
Between twenty minutes and an hour from your home	169	25
One to two hours from your home	39	6
Two to four hours away	27	4
More than four hours away	73	11

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

	N	%
We complement each other – we each help CR with different tasks.	185	28
We help with the same things but we divide the help over time.	109	16
We share some tasks, and others we do separately	344	52
Don't know	25	4
Refused	3	1

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?

	N	%
Respondent is the primary caregiver	370	56
Someone else is the primary caregiver	199	30
Care is equally shared	94	14
Don't know	3	1

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

	N	%
To a great extent	14	2
To a moderate extent	56	8
Only a little	193	29
Not at all	402	60
Refused	1	0

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

	N	%
Very satisfied	448	67
Moderately satisfied	166	25
Moderately dissatisfied	34	5
Very dissatisfied	15	2
Don't know	2	0
Refused	1	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?

	N	%
Yes	853	85
No	152	15
Don't know → QPP4	2	0
Refused → QPP4	1	0

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]?

	N	%
Yes	307	31
No	697	69
Refused	1	0

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

	N	%
Very important	527	52
Somewhat important	332	33
Not so important	141	14
Don't know	5	1

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

	N	%
Yes	607	60
No	399	40
Refused → QPP7	2	0

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

	N	%
Yes	129	13
No	876	87
Don't know	1	0

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

	N	%
Very important	465	46
Somewhat important	237	24
Not so important	304	30

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.]

	N	%
Yes	483	48
No	524	52
Refused → QPP10	1	0

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.]

	N	%
Yes	206	21
No	800	79
Refused	1	0

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.]

	N	%
Very important	308	31
Somewhat important	312	31
Not so important	387	38

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.

	N	%
Yes	842	84
No	166	17

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.]

	N	%
Yes	248	25
No	758	75
Don't know	2	0

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.]

	N	%
Very important	481	48
Somewhat important	377	37
Not so important	149	15
Don't know	1	0

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

	N	%
Yes	365	36
No	643	64

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

	N	%
Yes	158	16
No	848	84
Don't know	2	0

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.

	N	%
Yes	412	41
No	595	59
Don't know → next section	1	0

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

	N	%
Yes	78	8
No	929	92

HEALTH

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

	N	%
Excellent	155	15
Very good	313	31
Good	313	31
Fair	189	19
Poor	36	4
Don't know	1	0
Refused	1	0

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

	N	%
Yes	70	7
No	935	93
Don't know	1	0
Refused	2	0

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

	N	%
Yes	90	9
No	915	91
Don't know	1	0
Refused	2	0

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

	N	%
Yes	413	41
No	592	59
Don't know	2	0
Refused	1	0

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

	N	%
Yes	480	48
No	525	52
Don't know	1	0
Refused	2	0

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

	N	%
Yes	197	20
No	804	80
Don't know	6	1
Refused	1	0

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

	N	%
Yes	146	15
No	858	85
Don't know	3	0
Refused	1	0

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

	N	%
Yes	159	16
No	845	84
Don't know	2	0
Refused	2	0

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

	N	%
Yes	140	14
No	867	86
Refused	1	0

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

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

	N	%
Yes	623	62
No	384	38
Refused	1	0

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

	N	%
Yes	171	17
No	836	83
Refused	1	0

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

	N	%
Yes	307	31
No	700	69
Refused	1	0

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

	N	%
Yes	395	39
No	612	61
Refused	1	0

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

	N	%
Yes	522	52
No	483	48
Don't know	2	0
Refused	1	0

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

	N	%
Every night	93	9
Most nights	149	15
Some nights	330	33
Rarely	263	26
Never	172	17
Refused	1	0

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

	N	%
Every night	26	3
Most nights	49	5
Some nights	188	19
Rarely	236	23
Never	508	50
Don't know	1	0

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:

	N	%
< 18.5 (underweight)	8	1
18.5 – 24.9 (normal)	265	26
25.0 – 29.9 (overweight)	355	35
30.0 – 34.9 (moderately obese)	219	22
35.0 – 39.9 (severely obese)	72	7
40.0 + (very severely obese)	60	6
Missing	29	3

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

	N	%
Yes	302	30
No → QHE25A	704	70
Don't know → QHE25A	1	0
Refused → QHE25A	1	0

QHE24a. Were you trying to lose weight?

	N	%
Yes	205	68
No	96	32
Don't know	1	0

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

	N	%
Every day	153	15
Most days	461	46
Some days	297	30
Rarely	88	9
Never	8	1
Refused	1	0

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

	N	%
Every day	123	12
Most days	388	39
Some days	331	33
Rarely	136	14
Never	25	3
Don't know	3	0
Refused	2	0

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

	N	%
Every day	159	16
Most days	325	32
Some days	317	31
Rarely	163	16
Never	39	4
Don't know	3	0
Refused	2	0

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

	N	%
Every day	26	3
Most days	56	6
Some days	217	22
Rarely	316	31
Never	391	39
Refused	2	0

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

	N	%
Every day	26	3
Most days	74	7
Some days	207	21
Rarely	284	28
Never	415	41
Refused	2	0

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

	N	%
Every day	36	4
Most days	87	9
Some days	475	47
Rarely	346	34
Never	61	6
Don't know	1	0
Refused	2	0

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

	N	%
Not at all	552	55
Several days	317	31
More than half the days	80	8
Nearly every day	46	5
Don't know	11	1
Refused	2	0

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

	N	%
Not at all	567	56
Several days	319	32
More than half the days	73	7
Nearly every day	38	4
Don't know	8	1
Refused	3	0

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

	N	%
Not at all	410	41
Several days	436	43
More than half the days	83	8
Nearly every day	69	7
Don't know	8	1
Refused	2	0

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

	N	%
Not at all	504	50
Several days	310	31
More than half the days	84	8
Nearly every day	98	10
Don't know	9	1
Refused	3	0

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?

	N	%
Not at all	30	3
A little bit	42	4
Somewhat	90	9
Quite a bit	282	28
Extremely	562	56
Don't know	1	0
Refused	1	0

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?

	N	%
Never	682	68
Rarely	234	23
Sometimes	80	8
Often	7	1
Always	4	0
Don't know	1	0

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

	N	%
Never	654	65
Rarely	249	25
Sometimes	91	9
Often	7	1
Always	7	1

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)?

	N	%
Correct	673	67
Incorrect	333	33
Refused	2	0

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*)

	N	%
Correct	824	82
Incorrect	180	18
Refused	4	0

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*)

	N	%
Correct	766	76
Incorrect	238	24
Refused	4	0

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.

	N	%
Yes → QEC4	472	47
No	223	22
Retired / don't work anymore → QEC16	312	31
Refused	1	0

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

	N	%
Yes → QEC4	16	7
No	154	69
Retired / don't work anymore → QEC16	53	24
Refused	1	0

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

	N	%
Yes, looking for a job → QEC16	23	15
Yes, on layoff → QEC16	8	5
No → QEC16	113	73
Retired / don't work anymore → QEC16	10	7
Refused → QEC16	1	1

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

	N	%
Yes	106	22
No	382	78

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

	N	%
20 or fewer	105	22
21 – 39	92	19
40 or more	286	59
Don't know	4	1
Refused	1	0

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?

	N	%
Yes	289	59
No	196	40
Don't know	3	1

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

	N	%
Daytime	395	81
Some other schedule	91	19
Don't know	2	0

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?

	N	%
Yes	208	44
No → QEC12	264	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.

	N	%
Yes	71	32
No	152	68
Don't know	1	0

QEC9B. You were sick.

	N	%
Yes	90	40
No	133	59
Don't know	1	0

QEC9C. You took time off to help CR.

	N	%
Yes	100	45
No	124	55

QEC9D. Other family members were sick.

	N	%
Yes	46	21
No	177	79
Don't know	1	0

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

	N	%
Yes	82	37
No	142	63

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?

	N	%
One	50	50
Two	22	22
Three or more	26	26
Don't know	2	2

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?

	N	%
Yes	124	25
No →QEC14	363	74
Refused →QEC14	1	0

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.

	N	%
1 A little harder	17	14
2	13	11
3	24	19
4	17	14
5	20	16
6	10	8
7	8	7
8	11	9
10 A lot harder	4	3

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

	N	%
Yes	374	77
No	106	22
Don't know	7	1
Refused	1	0

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

	N	%
Telecommuting or working from home	151	31
Programs like information, referrals, counseling, or an employee assistance program, to help caregivers like yourself	173	36
Paid leave, where you could take paid time off from work for several weeks to care for a family member	164	34
Paid sick days	263	54
None of the above	135	28
Don't know	4	1
Refused	1	0

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

	N	%
Went in late, left early, or took time off during the day to provide care	427	42
Took a leave of absence	124	12
Went from working full-time to part-time, or cut back your hours	146	15
Turned down a promotion	36	4
Lost any of your job benefits	45	5
Gave up working entirely	133	13
Retired early	126	13
Received a warning about your performance or attendance at work	38	4
None of the above	435	43
Don't know	2	0
Refused	3	0

DEMOGRAPHICS

QDE1. INTERVIEWER: RECORD PERSON'S SEX

	N	%
Male	258	26
Female	750	74

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

	N	%
44 or under	116	12
45 – 54	188	19
55 – 64	386	38
65 or older	316	31
Refused	2	0

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

	N	%
Married	591	59
Living with a partner in a marital-like relationship	49	5
Divorced or separated	135	13
Widowed	50	5
Single/never married	182	18
Refused	1	0

QDE4. Are you of Hispanic or Latino descent?

	N	%
Yes	15	2
No	990	98
Refused	3	0

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

	N	%
Caucasian/White	829	82
Asian/Pacific Islander	6	1
American Indian or Alaskan Native	13	1
Black or African-American	162	16
None of the above	7	1
Don't know	1	0
Refused	4	0

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

	N	%
Eighth grade or less	2	0
Some high school	11	1
High school graduate or GED	194	19
Some college, no degree	205	20
Associate's degree, occupational	71	7
Associate's degree, academic	58	6
Bachelor's degree	263	26
Master's degree	153	15
Professional degree	24	2
Doctoral degree	23	2
Don't know	3	0
Refused	1	0

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

	N	%
Live alone → QDE11PRE	147	15
Live in a household with family or others	851	84
Have some other living arrangements	9	1
Refused → QDE11PRE	1	0

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

	N	%
One	40	5
Two	558	65
Three	190	22
Four	60	7
Five	11	1
Six	1	0

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

	N	%
Zero	691	80
One	86	10
Two	53	6
Three	19	2
Four	6	1
Five	3	0
Six	1	0
Don't know	1	0

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

	N	%
Your spouse / partner	651	76
Your child(ren)	279	32
Your grandchild(ren)	39	5
Your parent(s)	156	18
Other relatives of yours	87	10
Non-relatives	28	3
Don't know	2	0
Refused	2	0

QDE11PRE. And now just a couple questions about CR.

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

	N	%
Eighth grade or less	55	6
Some high school	66	7
High school graduate or GED	446	44
Some college, no degree	79	8
Associate's degree, occupational	64	6
Associate's degree, academic	30	3
Bachelor's degree	128	13
Master's degree	53	5
Professional degree	17	2
Doctoral degree	23	2
Don't know	46	5
Refused	1	0

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

	N	%
Yes	5	1
No	1003	100

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

	N	%
Caucasian/White	833	83
Asian/Pacific Islander	6	1
American Indian or Alaskan Native	12	1
Black or African-American	164	16
None of the above	5	1
Refused	3	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?

	N	%
Yes	371	37
No	627	62
Don't know	10	1

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?

	N	%
Yes	182	18
No	819	81
Don't know	7	1

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.

	N	%
1. Not at all difficult	729	72
2	121	12
3	77	8
4	26	3
5. Very difficult	34	3
Don't know	20	2
Refused	1	0

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.

	N	%
1. Not at all difficult	675	67
2	116	12
3	87	9
4	45	5
5. Very difficult	42	4
Don't know	40	4
Refused	3	0

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.

	N	%
1. Not at all difficult	394	39
2	90	9
3	112	11
4	71	7
5. Very difficult	86	9
Not applicable	249	25
Refused	6	1

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.

	N	%
1. Not at all difficult	328	33
2	95	9
3	106	11
4	60	6
5. Very difficult	133	13
Not applicable	280	28
Refused	6	1

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.

	N	%
1. Not at all difficult	277	28
2	77	8
3	132	13
4	97	10
5. Very difficult	147	15
Not applicable	274	27
Refused	4	0

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*)

	N	%
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	845	84
Requiring hospitals to keep you informed about major decisions, like transferring or discharging CR	867	86
Requiring hospitals or facilities to instruct or demonstrate any medical or nursing tasks you might need to do	875	87
Having respite services available, where someone would take care of CR to give you a break	715	71
Requiring a doctor, nurse, or social worker ask you about what you need to help care for CR	793	79
Requiring a doctor, nurse, or social worker ask you about what you need to take care of yourself	644	64
None of the above	55	6
Don't know	7	1

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.

	N	%
An income tax credit to caregivers, to help offset the cost of care	325	32
A partially paid leave of absence from work for caregivers who are employed	171	17
A program where caregivers could be paid for at least some of the hours they provide care	450	45
Don't know	57	6
Refused	5	1

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?

	N	%
Yes	415	41
No → QHI3	590	59
Don't know → QHI3	3	0

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

	N	%
Yes	273	66
No	130	31
Don't know	12	3

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

	N	%
Yes	122	12
No	873	87
Don't know	13	1

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.

	N	%
Yes	756	75
No	241	24
Don't know	11	1

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?

	N	%
Yes	30	3
No	975	97
Don't know	3	0

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

	N	%
Medicare	767	76
Medicaid	180	18
Private Health Insurance	561	56
Tricare/CHAMPVA	35	4
Don't know	39	4

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

	N	%
Yes	765	76
No	239	24
Don't know	1	0
Refused	3	0

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

	N	%
Yes	959	95
No	40	4
Refused	9	1

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

	N	%
Yes	742	74
No	248	25
Refused	18	2

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

	N	%
Yes	180	18
No	776	77
Don't know	29	3
Refused	23	2

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

	N	%
Yes	703	70
No	285	28
Don't know	3	0
Refused	17	2

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

	N	%
Yes	338	34
No	632	63
Don't know	16	2
Refused	22	2

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?

	N	%
0 – less than \$10,000	60	6
\$10,000 to less than \$20,000	84	8
\$20,000 to less than \$30,000	84	8
\$30,000 to less than \$40,000	109	11
\$40,000 to less than \$50,000	87	9
\$50,000 to less than \$60,000	82	8
\$60,000 to less than \$70,000	72	7
\$70,000 to less than \$80,000	50	5
\$80,000 to less than \$90,000	44	4
\$90,000 to less than \$100,000	42	4
\$100,000 to less than \$110,000	37	4
\$110,000 to less than \$120,000	13	1
\$120,000 to less than \$130,000	15	2
\$130,000 to less than \$140,000	2	0
\$140,000 to less than \$150,000	17	2
More than \$150,000	59	6
Don't know	46	5
Refused	105	10

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?

	N	%
Yes	396	39
No	603	60
Don't know	4	0
Refused	5	1

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?

	N	%
Yes	213	21
No	783	78
Don't know	8	1
Refused	4	0

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

	N	%
Yes	137	14
No	866	86
Don't know	2	0
Refused	3	0

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?

	N	%
Yes	279	28
No	724	72
Don't know	1	0
Refused	4	0

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.

	N	%
Yes	203	20
No	800	79
Don't know	2	0
Refused	3	0

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

	N	%
Yes	98	10
No	905	90
Don't know	2	0
Refused	3	0

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 [SP]'s [medications or medical care,]

	N	%
More than \$1,000 → QHI6	241	42
Less than \$1,000 → QHI7	321	56
Don't know → next section	7	1

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

	N	%
Yes	144	60
No	84	35
Don't know	13	5

(skip to next section)

QHI17. Was it less than \$500?

	N	%
Yes	225	70
No	85	27
Don't know	11	3