

THE PITTSBURGH REGIONAL CAREGIVERS SURVEY
BREAKOUTS BY CAREGIVER RACE

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Notes

All entries are column percentages.

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

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

CR = care recipient; CG = caregiver

Sample sizes:

Non-Hispanic White n = 812

Non-Hispanic Black n = 152

Other n = 44

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?

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	49	60	46
No	51	40	55

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	98	98	93
No	2	2	7

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	63	66	61
No	37	34	39

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:

	Non-Hispanic White	Non-Hispanic Black	Other
Your mother or mother-in-law	42	43	41
Your father or father-in-law	14	7	9
Your wife / partner	7	3	5
Your husband / partner	16	11	9
Your daughter or daughter-in-law	1	1	2
Your son or son-in-law	1	0	0
Some other relative	13	25	18
A non-relative	8	9	16

QCS2. Is the person you care for:

	Non-Hispanic White	Non-Hispanic Black	Other
Male	37	32	32
Female	63	68	68

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

	Non-Hispanic White	Non-Hispanic Black	Other
50 – 64	13	28	30
65 – 74	16	22	32
75 – 84	27	18	21
85 +	43	32	18

QCS5. Where does [he/she] live?

	Non-Hispanic White	Non-Hispanic Black	Other
In your household → QCS9	44	40	41
Within 20 minutes of your home	41	49	43
Between 20 minutes and an hour from your home	11	11	7
One to two hours from your home	2	0	0
More than two hours away	2	0	9

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

	Non-Hispanic White	Non-Hispanic Black	Other
His or her own home	70	73	73
Someone else's home → QCS9	9	8	12
An independent living or retirement community	11	17	8
In an assisted living facility where some care may be provided → QCS9	10	3	8
Somewhere else	1	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?

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	68	74	48
No	32	26	52

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

	Non-Hispanic White	Non-Hispanic Black	Other
Short-term physical condition	12	13	18
Long-term physical condition	77	82	75
Emotional or mental health problem	20	14	21
Developmental or intellectual disorder or mental retardation	5	3	2
Behavioral issue	8	7	5
Memory problem	43	42	34
None of the above	5	5	2

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	24	24	19
No	76	77	81

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

QCS11. a heart attack or myocardial infarction?

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	22	28	26
No	79	72	74

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	34	29	33
No	66	71	67

QCS13. high blood pressure or hypertension?

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	63	80	72
No	37	20	28

QCS14. arthritis?

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	65	65	70
No	35	35	30

QCS15. osteoporosis or thinning of the bones?

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	38	25	25
No	62	75	75

QCS16. diabetes?

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	26	37	32
No	74	63	68

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	23	21	35
No	77	80	65

QCS18. cancer?

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	29	20	34
No	72	81	66

QCS18a. a stroke?

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	20	33	16
No	80	67	84

QCS19. serious difficulty seeing?

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	29	32	21
No	71	68	80

QCS20. serious difficulty hearing?

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	40	26	23
No	60	74	77

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

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	88	82	86
No	13	18	14

QCS22B. a hearing aid?

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	21	7	9
No	79	93	91

QCS22C. a cane?

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	40	50	49
No	60	50	51

QCS22D. a walker?

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	44	43	36
No	56	57	64

QCS22E. a wheelchair?

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	36	25	16
No	64	75	84

QCS22F. a scooter?

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	7	11	5
No	93	89	96

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	33	33	46
No	67	67	55

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	19	24	33
No	81	76	67

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.

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	6	5	2
No	94	95	98

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?

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	82	75	73
No → next section	18	25	27

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

	Non-Hispanic White	Non-Hispanic Black	Other
A railing or ramp	62	66	75
Grab bars in the bathroom	76	80	78
A seat for the shower or tub	71	71	75
An emergency call system	42	54	34
Other	34	33	31

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?

	Non-Hispanic White	Non-Hispanic Black	Other
Every day	52	47	26
Most days	14	18	37
Some days	20	21	19
Rarely	6	5	7
Never → QCA2	6	7	7
Does not do, but not because of poor health and functioning → QCA2	2	2	5

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]?

	Non-Hispanic White	Non-Hispanic Black	Other
Every day	41	39	18
Most days	16	22	32
Some days	30	28	34
Rarely	8	6	5
Never	5	5	11

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*)

	Non-Hispanic White	Non-Hispanic Black	Other
Yes, another unpaid family member / friend	51	56	55
Yes, a paid helper	25	19	13
No	35	34	37

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?

	Non-Hispanic White	Non-Hispanic Black	Other
Every day	43	34	30
Most days	20	24	25
Some days	23	27	30
Rarely	7	10	9
Never → QCA3	5	3	5
Does not do, but not because of poor health and functioning → QCA3	2	2	2

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]?

	Non-Hispanic White	Non-Hispanic Black	Other
Every day	26	21	22
Most days	21	26	24
Some days	36	34	39
Rarely	10	10	10
Never	8	9	5

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes, another unpaid family member / friend	53	56	44
Yes, a paid helper	8	6	5
No	43	41	54

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	58	58	46
No → QCA4	39	41	55
Does not do, but not because of poor health and functioning → QCA4	3	1	0

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	76	75	90
No	25	25	10

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes, another unpaid family member / friend	33	36	55
Yes, a paid helper	11	8	10
No	58	56	40

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	69	62	50
No → QCA5	27	35	50
Does not do, but not because of poor health and functioning → QCA5	4	3	0

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	79	80	73
No	21	20	27

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes, another unpaid family member / friend	41	40	41
Yes, a paid helper	1	1	5
No	58	60	55

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?

	Non-Hispanic White	Non-Hispanic Black	Other
Every day	10	8	10
Most days	4	4	7
Some days	6	10	7
Rarely	10	10	14
Never → QCA6	70	69	62

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

	Non-Hispanic White	Non-Hispanic Black	Other
Every day	26	22	19
Most days	13	15	6
Some days	24	35	25
Rarely	25	17	25
Never	12	11	25

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes, another unpaid family member / friend	43	39	31
Yes, a paid helper	17	11	0
No	47	52	69

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

	Non-Hispanic White	Non-Hispanic Black	Other
Every day	24	30	5
Most days	10	11	8
Some days	11	10	30
Rarely	10	10	15
Never → QCA7	46	39	43

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

	Non-Hispanic White	Non-Hispanic Black	Other
Every day	20	32	0
Most days	11	18	17
Some days	22	21	30
Rarely	17	12	22
Never	29	17	30

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes, another unpaid family member / friend	34	38	44
Yes, a paid helper	32	21	9
No	42	46	48

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

	Non-Hispanic White	Non-Hispanic Black	Other
Every day	23	20	22
Most days	7	16	0
Some days	14	16	20
Rarely	13	12	20
Never → QCA8	42	36	39

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

	Non-Hispanic White	Non-Hispanic Black	Other
Every day	22	22	16
Most days	15	20	0
Some days	30	31	48
Rarely	23	17	24
Never	12	10	12

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes, another unpaid family member / friend	40	42	32
Yes, a paid helper	26	20	4
No	43	48	68

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

	Non-Hispanic White	Non-Hispanic Black	Other
Every day	17	12	10
Most days	3	6	5
Some days	5	12	5
Rarely	10	8	13
Never → QCA9	65	61	68

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

	Non-Hispanic White	Non-Hispanic Black	Other
Every day	30	27	15
Most days	10	20	8
Some days	21	25	23
Rarely	22	18	39
Never	17	11	15

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes, another unpaid family member / friend	46	45	54
Yes, a paid helper	32	29	8
No	35	41	46

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

	Non-Hispanic White	Non-Hispanic Black	Other
Every day	17	12	5
Most days	2	10	5
Some days	8	10	15
Rarely	13	14	20
Never → QCA10	60	53	56

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

	Non-Hispanic White	Non-Hispanic Black	Other
Every day	22	15	17
Most days	8	20	0
Some days	25	20	11
Rarely	28	35	50
Never	16	10	22

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes, another unpaid family member / friend	45	49	44
Yes, a paid helper	24	26	0
No	42	38	56

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

	Non-Hispanic White	Non-Hispanic Black	Other
Every day	17	14	12
Most days	4	7	5
Some days	12	14	12
Rarely	16	20	17
Never → QCA11	50	45	55

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

	Non-Hispanic White	Non-Hispanic Black	Other
Every day	21	17	16
Most days	11	12	21
Some days	33	28	32
Rarely	27	33	32
Never	8	9	0

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes, another unpaid family member / friend	54	48	58
Yes, a paid helper	23	12	0
No	35	43	42

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

	Non-Hispanic White	Non-Hispanic Black	Other
Every day	24	26	17
Most days	10	16	17
Some days	21	15	10
Rarely	12	16	21
Never → skip logic prior to QCA12A	33	27	36

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

	Non-Hispanic White	Non-Hispanic Black	Other
Every day	21	22	7
Most days	15	23	26
Some days	40	28	30
Rarely	18	18	33
Never	7	8	4

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes, another unpaid family member / friend	59	60	56
Yes, a paid helper	16	13	0
No	33	36	44

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?

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	35	42	29
No	65	58	71

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?

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	71	77	67
No	29	23	33

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?

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	74	67	65
No	27	33	35

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

	Non-Hispanic White	Non-Hispanic Black	Other
Every day	12	9	14
Most days	16	16	25
Some days	38	34	21
Rarely	17	13	14
Never	17	29	27

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]?

	Non-Hispanic White	Non-Hispanic Black	Other
Every day	1	5	5
Most days	2	7	0
Some days	3	9	0
Rarely	4	7	9
Never	61	51	57
Do not use	29	21	30

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 SCRNMENT).

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?

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	61	63	60
No	39	37	41

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	46	49	48
No	54	51	52

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

	Non-Hispanic White	Non-Hispanic Black	Other
Orally (by mouth as pills, capsules, liquid)	99	97	100
Insulin injection	12	16	10
Other injection	6	6	5
Infusion pump	1	1	0
Inhaler	12	12	25
Suppository	3	4	10
Medication patch	5	7	0
Spray	3	7	10
Eye/Ear drops	17	21	15
Other	8	4	5

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	6	9	0
No	94	91	100

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	10	6	5
No	90	94	95

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	27	31	36
No	73	69	64

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	27	31	36
No	73	69	64

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	20	20	19
No	81	81	81

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	28	35	29
No	72	65	71

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	28	22	36
No	72	78	64

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	47	50	45
No	54	50	55

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?

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	39	42	26
No	61	58	74

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	51	45	67
No	49	55	33

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	4	3	4
No	96	97	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)?

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	45	56	41
No	55	44	59

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	18	16	19
No	82	84	81

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)?

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	8	11	4
No	92	89	96

(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.

	Non-Hispanic White	Non-Hispanic Black	Other
1. Not at all difficult	53	64	56
2.	22	13	15
3.	15	11	18
4.	6	11	3
5. Very difficult	4	2	8

QCA17. Did anyone prepare you to do these tasks?

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	26	23	18
No → QCA21	74	77	82

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

	Non-Hispanic White	Non-Hispanic Black	Other
Hospital nurse	23	23	0
Hospital doctor	6	7	0
Primary care doctor	15	7	29
Nurse in doctor's office or outpatient setting	11	17	14
Home care nurse	25	27	14
Social worker/geriatric care manager	2	7	0
Physical or occupational therapist	19	13	14
Pharmacist	5	13	0
Medical supply technician	9	7	0
Friend or neighbor	8	3	0
You learned on your own	30	10	14
Other	41	57	57

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

	Non-Hispanic White	Non-Hispanic Black	Other
Very well	81	69	86
Somewhat well	18	24	14
Not well	1	7	0

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

	Non-Hispanic White	Non-Hispanic Black	Other
None → QCA24PRE	46	38	32
One time	22	18	16
2 times	14	22	23
3 or more times	18	22	30

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...

	Non-Hispanic White	Non-Hispanic Black	Other
Yes, all the time	57	66	50
Only some of the time	24	21	33
No, and you should have been	5	3	10
No, but you did not need to be	14	10	7

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]?

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	74	70	63
No	19	23	30
Not applicable	7	7	7

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

	Non-Hispanic White	Non-Hispanic Black	Other
Very well	52	67	46
Somewhat well	37	25	39
Not well	11	8	14

QCA24PRE. Now think about the last YEAR.

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	66	65	55
No	34	35	46

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	67	65	56
No	33	36	44

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	85	84	84
No	15	16	16

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.]

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	25	30	30
No	75	70	71

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.]

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	40	34	34
No	61	66	66

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?

	Non-Hispanic White	Non-Hispanic Black	Other
8 hours or less per week	42	41	46
9 to 19 hours per week	27	19	22
20 to 39 hours per week	15	18	20
40 or more hours per week	16	22	12

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.

	Non-Hispanic White	Non-Hispanic Black	Other
Regular schedule	55	47	32
Varied	45	53	68

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

	Non-Hispanic White	Non-Hispanic Black	Other
3 months or less	6	3	7
4 to 12 months	12	8	5
1 - 2 years	18	24	25
3 - 5 years	29	28	27
More than 5 years	35	38	36

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

	Non-Hispanic White	Non-Hispanic Black	Other
Increased in the past month	36	35	39
Been about the same in the past month	57	51	43
Decreased in the past month	8	14	18

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?

	Non-Hispanic White	Non-Hispanic Black	Other
Will increase	31	38	48
Will be about the same	61	53	41
Will decrease	8	9	11

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	45	52	41
No	55	48	59

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

	Non-Hispanic White	Non-Hispanic Black	Other
Very worried	6	3	2
Somewhat worried	12	10	18
Only a little	30	19	27
Not at all	53	68	52

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".)

	Non-Hispanic White	Non-Hispanic Black	Other
1 CR has not been suffering physically	12	18	11
2	9	13	11
3	15	14	5
4	10	7	11
5	14	15	11
6	8	7	23
7	12	10	14
8	10	5	5
9	5	4	2
10 CR has been suffering terribly	6	5	7

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".)

	Non-Hispanic White	Non-Hispanic Black	Other
1 CR has not been suffering physically	12	22	9
2	10	9	12
3	11	13	9
4	8	7	0
5	15	16	12
6	10	10	12
7	9	12	9
8	13	7	16
9	6	3	12
10 CR has been suffering terribly	8	3	9

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]?

	Non-Hispanic White	Non-Hispanic Black	Other
A lot	68	83	75
Some	25	14	18
A little	6	3	7
Not at all	2	0	0

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

	Non-Hispanic White	Non-Hispanic Black	Other
A lot	18	20	27
Some	26	26	27
A little	29	26	32
Not at all	27	28	14

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

	Non-Hispanic White	Non-Hispanic Black	Other
A lot	79	87	73
Some	12	9	20
A little	6	3	7
Not at all	3	2	0

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

	Non-Hispanic White	Non-Hispanic Black	Other
A lot	20	21	23
Some	32	26	14
A little	33	30	42
Not at all	15	22	21

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...

	Non-Hispanic White	Non-Hispanic Black	Other
Gotten much better	14	31	24
Gotten somewhat better	21	18	21
Stayed about the same	48	43	45
Gotten somewhat worse	14	7	10
Gotten much worse	4	0	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.

	Non-Hispanic White	Non-Hispanic Black	Other
Very much	35	51	50
Somewhat	39	33	25
Not so much	27	17	25

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

	Non-Hispanic White	Non-Hispanic Black	Other
Very much	44	65	52
Somewhat	39	24	27
Not so much	17	11	21

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

	Non-Hispanic White	Non-Hispanic Black	Other
Very much	45	61	55
Somewhat	37	29	30
Not so much	19	10	16

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

	Non-Hispanic White	Non-Hispanic Black	Other
Very much	77	84	77
Somewhat	20	14	18
Not so much	3	2	5

QAC6A. Is helping CR financially difficult for you?

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	22	18	39
No	78	82	61

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	63	48	55
No	37	52	46

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	30	24	27
No	70	76	73

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)

	Non-Hispanic White	Non-Hispanic Black	Other
1. A little difficult	10	19	12
2.	12	4	6
3.	32	30	24
4.	23	26	41
5. Very difficult	23	22	18

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

	Non-Hispanic White	Non-Hispanic Black	Other
1. A little difficult	10	23	8
2.	17	21	21
3.	29	26	21
4.	24	15	21
5. Very difficult	20	15	29

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

	Non-Hispanic White	Non-Hispanic Black	Other
1. A little difficult	8	19	8
2.	19	14	8
3.	39	22	17
4.	23	31	8
5. Very difficult	12	14	58

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

	Non-Hispanic White	Non-Hispanic Black	Other
Very much	9	6	13
Somewhat	21	26	19
Not so much	70	68	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.

	Non-Hispanic White	Non-Hispanic Black	Other
Very much	32	27	36
Somewhat	31	27	25
Not so much	37	46	39

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

	Non-Hispanic White	Non-Hispanic Black	Other
Very much	25	15	27
Somewhat	34	34	34
Not so much	41	51	39

QAC9C. You don't have time for yourself.

	Non-Hispanic White	Non-Hispanic Black	Other
Very much	28	16	30
Somewhat	34	30	36
Not so much	38	54	34

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

	Non-Hispanic White	Non-Hispanic Black	Other
Very much	11	9	14
Somewhat	28	23	34
Not so much	61	68	52

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?

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	89	93	88
No	11	7	12

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?

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	51	58	50
No	49	42	50

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	67	68	58
No	33	33	42

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	6	5	5
No	94	95	96

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	20	18	14
No	80	82	86

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	10	11	11
No	91	90	89

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	16	21	21
No	84	79	80

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)*

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	19	21	16
No	82	80	84

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?

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	43	45	25
No	57	55	75

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?

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	44	41	41
No	56	59	59

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	23	12	21
No	77	88	80

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?

	Non-Hispanic White	Non-Hispanic Black	Other
One	23	23	29
Two	28	29	13
Three or more	50	49	58

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

	Non-Hispanic White	Non-Hispanic Black	Other
Caregiver's Brother(s)	27	29	21
CG's Sister(s)	38	45	33
CG's husband	21	11	13
CG's wife	9	2	8
CG's other relative(s) / in-law(s)	55	53	50
CG's friend(s)	11	19	13
Other	24	22	33

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

	Non-Hispanic White	Non-Hispanic Black	Other
Live(s) with you	42	26	29
Within twenty minutes of your home	65	66	46
Between twenty minutes and an hour from your home	25	30	17
One to two hours from your home	6	6	4
Two to four hours away	4	1	8
More than four hours away	12	7	17

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

	Non-Hispanic White	Non-Hispanic Black	Other
We complement each other – we each help CR with different tasks.	30	23	35
We help with the same things but we divide the help over time.	17	19	17
We share some tasks, and others we do separately	53	58	48

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?

	Non-Hispanic White	Non-Hispanic Black	Other
Respondent is the primary caregiver	55	57	64
Someone else is the primary caregiver	31	25	36
Care is equally shared	14	18	0

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

	Non-Hispanic White	Non-Hispanic Black	Other
To a great extent	2	4	0
To a moderate extent	8	9	8
Only a little	30	23	33
Not at all	60	64	58

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

	Non-Hispanic White	Non-Hispanic Black	Other
Very satisfied	68	67	63
Moderately satisfied	24	30	29
Moderately dissatisfied	6	3	4
Very dissatisfied	3	0	4

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?

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	85	88	81
No	16	12	19

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]?

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	33	19	28
No	67	81	72

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

	Non-Hispanic White	Non-Hispanic Black	Other
Very important	55	40	51
Somewhat important	32	37	44
Not so important	13	23	5

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	59	65	61
No	41	35	40

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	13	13	14
No	87	87	86

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

	Non-Hispanic White	Non-Hispanic Black	Other
Very important	44	60	42
Somewhat important	23	26	21
Not so important	33	14	37

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.]

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	48	48	54
No	52	52	47

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.]

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	22	15	16
No	78	86	84

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.]

	Non-Hispanic White	Non-Hispanic Black	Other
Very important	30	32	37
Somewhat important	31	32	23
Not so important	39	37	40

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.

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	84	85	80
No	17	15	21

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.]

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	27	13	23
No	73	87	77

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.]

	Non-Hispanic White	Non-Hispanic Black	Other
Very important	49	40	43
Somewhat important	37	40	39
Not so important	14	20	18

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	35	41	46
No	65	59	55

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	17	11	14
No	83	90	86

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.

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	39	49	48
No	61	51	52

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	8	7	9
No	92	93	91

HEALTH

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

	Non-Hispanic White	Non-Hispanic Black	Other
Excellent	16	10	16
Very good	33	22	21
Good	31	36	23
Fair	16	28	33
Poor	3	4	7

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	7	6	10
No	93	94	91

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	10	5	12
No	91	95	88

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	39	53	44
No	61	47	56

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	48	46	42
No	52	54	58

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	21	14	21
No	79	86	79

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	14	19	16
No	86	82	84

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	15	19	21
No	85	81	79

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	14	9	23
No	86	91	77

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

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	62	61	56
No	38	39	44

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	17	18	16
No	83	82	84

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	31	28	37
No	69	72	63

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	39	38	42
No	61	63	58

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	53	47	58
No	48	53	42

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

	Non-Hispanic White	Non-Hispanic Black	Other
Every night	10	5	9
Most nights	14	15	26
Some nights	34	28	30
Rarely	26	32	14
Never	16	22	21

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

	Non-Hispanic White	Non-Hispanic Black	Other
Every night	3	0	2
Most nights	5	4	9
Some nights	19	16	23
Rarely	25	19	14
Never	48	61	52

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:

	Non-Hispanic White	Non-Hispanic Black	Other
< 18.5 (underweight)	1	1	0
18.5 – 24.9 (normal)	28	22	31
25.0 – 29.9 (overweight)	38	29	31
30.0 – 34.9 (moderately obese)	22	26	19
35.0 – 39.9 (severely obese)	6	12	10
40.0 + (very severely obese)	5	10	10

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	29	34	44
No → QHE25A	71	66	56

QHE24a. Were you trying to lose weight?

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	66	70	84
No	34	30	16

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

	Non-Hispanic White	Non-Hispanic Black	Other
Every day	13	20	33
Most days	46	43	44
Some days	30	31	16
Rarely	9	6	7
Never	1	0	0

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

	Non-Hispanic White	Non-Hispanic Black	Other
Every day	10	23	23
Most days	39	41	35
Some days	34	29	26
Rarely	15	7	16
Never	3	0	0

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

	Non-Hispanic White	Non-Hispanic Black	Other
Every day	13	28	30
Most days	33	29	33
Some days	32	33	23
Rarely	18	8	14
Never	4	2	0

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

	Non-Hispanic White	Non-Hispanic Black	Other
Every day	3	2	5
Most days	6	6	5
Some days	21	25	16
Rarely	31	34	35
Never	40	34	40

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

	Non-Hispanic White	Non-Hispanic Black	Other
Every day	3	2	0
Most days	7	11	2
Some days	21	17	28
Rarely	29	22	30
Never	40	48	40

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

	Non-Hispanic White	Non-Hispanic Black	Other
Every day	4	1	7
Most days	10	5	2
Some days	49	42	43
Rarely	33	43	38
Never	5	10	10

HE26a. Over the last month, how often have you had little interest or pleasure doing things?

	Non-Hispanic White	Non-Hispanic Black	Other
Not at all	55	59	58
Several days	32	30	33
More than half the days	8	8	5
Nearly every day	5	3	5

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

	Non-Hispanic White	Non-Hispanic Black	Other
Not at all	55	69	57
Several days	33	26	31
More than half the days	8	3	7
Nearly every day	4	3	5

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

	Non-Hispanic White	Non-Hispanic Black	Other
Not at all	38	55	54
Several days	45	39	28
More than half the days	10	4	7
Nearly every day	8	2	12

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

	Non-Hispanic White	Non-Hispanic Black	Other
Not at all	48	63	54
Several days	34	22	16
More than half the days	9	9	5
Nearly every day	10	6	26

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?

	Non-Hispanic White	Non-Hispanic Black	Other
Not at all	3	5	2
A little bit	4	7	5
Somewhat	9	9	11
Quite a bit	29	25	27
Extremely	56	55	55

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?

	Non-Hispanic White	Non-Hispanic Black	Other
Never	68	69	66
Rarely	24	19	25
Sometimes	7	12	7
Often	1	0	0
Always	0	0	2

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

	Non-Hispanic White	Non-Hispanic Black	Other
Never	65	61	73
Rarely	25	24	16
Sometimes	8	15	11
Often	1	0	0
Always	1	1	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)?

	Non-Hispanic White	Non-Hispanic Black	Other
Correct	69	54	73
Incorrect	31	46	27

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*)

	Non-Hispanic White	Non-Hispanic Black	Other
Correct	85	65	81
Incorrect	15	36	19

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*)

	Non-Hispanic White	Non-Hispanic Black	Other
Correct	80	61	70
Incorrect	21	39	30

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.

	Non-Hispanic White	Non-Hispanic Black	Other
Yes → QEC4	45	55	49
No	22	22	28
Retired / don't work anymore → QEC16	33	24	23

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes → QEC4	8	3	8
No	67	76	83
Retired / don't work anymore → QEC16	25	21	8

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes, looking for a job → QEC16	12	20	40
Yes, on layoff → QEC16	5	4	10
No → QEC16	77	68	50
Retired / don't work anymore → QEC16	7	8	0

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	20	30	27
No	80	70	73

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

	Non-Hispanic White	Non-Hispanic Black	Other
20 or fewer	19	35	27
21 – 39	19	19	14
40 or more	62	46	59

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?

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	60	60	50
No	40	40	50

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

	Non-Hispanic White	Non-Hispanic Black	Other
Daytime	82	80	68
Some other schedule	18	21	32

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?

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	45	35	57
No → QEC12	55	65	43

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.

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	32	30	42
No	69	70	58

QEC9B. You were sick.

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	39	50	33
No	61	50	67

QEC9C. You took time off to help CR.

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	49	23	39
No	51	77	62

QEC9D. Other family members were sick.

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	22	10	23
No	78	90	77

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	36	37	46
No	64	63	54

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?

	Non-Hispanic White	Non-Hispanic Black	Other
One	50	71	40
Two	24	0	20
Three or more	26	29	40

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?

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	28	10	36
No → QEC14	72	91	64

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.

	Non-Hispanic White	Non-Hispanic Black	Other
1 A little harder	14	25	0
2	12	0	0
3	20	0	25
4	10	38	38
5	18	13	0
6	8	0	13
7	7	0	0
8	7	13	25
10 A lot harder	3	13	0

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	81	69	57
No	19	31	43

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

	Non-Hispanic White	Non-Hispanic Black	Other
Telecommuting or working from home	32	27	32
Programs like information, referrals, counseling, or an employee assistance program, to help caregivers like yourself	35	38	41
Paid leave, where you could take paid time off from work for several weeks to care for a family member	32	42	27
Paid sick days	53	56	55
None of the above	29	26	18

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

	Non-Hispanic White	Non-Hispanic Black	Other
Went in late, left early, or took time off during the day to provide care	45	34	32
Took a leave of absence	12	11	16
Went from working full-time to part-time, or cut back your hours	15	14	14
Turned down a promotion	4	1	7
Lost any of your job benefits	4	5	5
Gave up working entirely	13	15	11
Retired early	13	15	5
Received a warning about your performance or attendance at work	4	3	5
None of the above	42	48	46

DEMOGRAPHICS

QDE1. INTERVIEWER: RECORD PERSON'S SEX

	Non-Hispanic White	Non-Hispanic Black	Other
Male	27	18	32
Female	73	82	68

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

	Non-Hispanic White	Non-Hispanic Black	Other
44 or under	10	18	28
45 – 54	17	22	33
55 – 64	39	42	19
65 or older	34	18	21

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

	Non-Hispanic White	Non-Hispanic Black	Other
Married	64	34	42
Living with a partner in a marital-like relationship	4	9	12
Divorced or separated	12	22	14
Widowed	5	7	5
Single/never married	15	30	28

QDE4. Are you of Hispanic or Latino descent?

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	0	0	37
No	100	100	63

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

	Non-Hispanic White	Non-Hispanic Black	Other
Caucasian/White	100	0	39
Asian/Pacific Islander	0	0	14
American Indian or Alaskan Native	0	0	30
Black or African-American	0	100	23
None of the above	0	0	16

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

	Non-Hispanic White	Non-Hispanic Black	Other
Eighth grade or less	0	1	0
Some high school	1	2	2
High school graduate or GED	18	26	14
Some college, no degree	19	28	28
Associate's degree, occupational	6	11	5
Associate's degree, academic	5	9	9
Bachelor's degree	29	15	16
Master's degree	17	6	14
Professional degree	2	1	9
Doctoral degree	2	2	2

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

	Non-Hispanic White	Non-Hispanic Black	Other
Live alone → QDE11PRE	14	19	12
Live in a household with family or others	85	80	88
Have some other living arrangements	1	1	0

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

	Non-Hispanic White	Non-Hispanic Black	Other
One	4	9	8
Two	66	56	74
Three	22	24	16
Four	7	7	3
Five	1	4	0
Six	0	0	0

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

	Non-Hispanic White	Non-Hispanic Black	Other
Zero	84	62	74
One	8	16	18
Two	6	10	5
Three	1	7	3
Four	0	3	0
Five	0	1	0
Six	0	1	0

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

	Non-Hispanic White	Non-Hispanic Black	Other
Your spouse / partner	80	55	63
Your child(ren)	31	42	32
Your grandchild(ren)	2	20	5
Your parent(s)	18	18	24
Other relatives of yours	8	23	5
Non-relatives	3	2	8

QDE11PRE. And now just a couple questions about CR.

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

	Non-Hispanic White	Non-Hispanic Black	Other
Eighth grade or less	5	7	9
Some high school	7	9	5
High school graduate or GED	48	43	33
Some college, no degree	7	11	14
Associate's degree, occupational	6	7	12
Associate's degree, academic	2	7	2
Bachelor's degree	14	12	7
Master's degree	5	4	12
Professional degree	2	0	5
Doctoral degree	3	0	2

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	0	0	11
No	100	100	89

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

	Non-Hispanic White	Non-Hispanic Black	Other
Caucasian/White	99	3	50
Asian/Pacific Islander	0	0	9
American Indian or Alaskan Native	0	3	14
Black or African-American	0	98	27
None of the above	0	1	9

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?

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	37	41	30
No	63	59	70

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?

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	17	24	18
No	83	76	82

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.

	Non-Hispanic White	Non-Hispanic Black	Other
1. Not at all difficult	75	72	67
2	12	15	14
3	8	7	12
4	3	2	0
5. Very difficult	3	4	7

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.

	Non-Hispanic White	Non-Hispanic Black	Other
1. Not at all difficult	69	74	69
2	13	10	10
3	9	11	12
4	5	3	5
5. Very difficult	5	3	5

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.

	Non-Hispanic White	Non-Hispanic Black	Other
1. Not at all difficult	36	59	34
2	9	5	14
3	12	9	11
4	8	5	2
5. Very difficult	9	4	18
Not applicable	26	18	21

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.

	Non-Hispanic White	Non-Hispanic Black	Other
1. Not at all difficult	30	47	34
2	9	9	14
3	11	8	5
4	7	3	7
5. Very difficult	14	12	14
Not applicable	29	22	27

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.

	Non-Hispanic White	Non-Hispanic Black	Other
1. Not at all difficult	25	42	27
2	9	5	2
3	14	12	7
4	9	11	11
5. Very difficult	15	11	23
Not applicable	29	20	30

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*)

	Non-Hispanic White	Non-Hispanic Black	Other
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	83	87	82
Requiring hospitals to keep you informed about major decisions, like transferring or discharging CR	86	88	82
Requiring hospitals or facilities to instruct or demonstrate any medical or nursing tasks you might need to do	86	90	86
Having respite services available, where someone would take care of CR to give you a break	71	71	68
Requiring a doctor, nurse, or social worker ask you about what you need to help care for CR	78	85	77
Requiring a doctor, nurse, or social worker ask you about what you need to take care of yourself	62	72	64
None of the above	6	3	5

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.

	Non-Hispanic White	Non-Hispanic Black	Other
An income tax credit to caregivers, to help offset the cost of care	37	24	29
A partially paid leave of absence from work for caregivers who are employed	19	14	24
A program where caregivers could be paid for at least some of the hours they provide care	45	62	48

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?

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	41	43	41
No → QHI3	59	57	60

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	69	63	59
No	31	38	41

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	8	32	21
No	92	68	79

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.

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	79	59	71
No	21	41	29

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?

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	3	3	5
No	97	97	95

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

	Non-Hispanic White	Non-Hispanic Black	Other
Medicare	79	64	61
Medicaid	14	34	34
Private Health Insurance	59	45	39
Tricare/CHAMPVA	3	3	7

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	82	50	58
No	18	50	42

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	98	85	95
No	2	15	5

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	81	49	55
No	19	51	45

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	21	7	18
No	79	93	82

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	77	39	68
No	23	61	32

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	40	12	15
No	60	88	85

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?

	Non-Hispanic White	Non-Hispanic Black	Other
0 – less than \$10,000	6	14	11
\$10,000 to less than \$20,000	7	24	11
\$20,000 to less than \$30,000	10	9	14
\$30,000 to less than \$40,000	12	14	17
\$40,000 to less than \$50,000	10	11	11
\$50,000 to less than \$60,000	10	8	9
\$60,000 to less than \$70,000	8	9	9
\$70,000 to less than \$80,000	7	4	0
\$80,000 to less than \$90,000	6	2	0
\$90,000 to less than \$100,000	6	0	0
\$100,000 to less than \$110,000	5	2	9
\$110,000 to less than \$120,000	2	1	3
\$120,000 to less than \$130,000	2	0	0
\$130,000 to less than \$140,000	0	0	0
\$140,000 to less than \$150,000	2	0	3
More than \$150,000	8	3	3

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	39	37	54
No	61	63	47

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?

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	22	21	19
No	78	79	81

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	15	9	5
No	85	91	95

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?

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	30	20	23
No	71	80	77

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.

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	21	17	23
No	79	83	77

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	11	5	7
No	89	95	93

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,]

	Non-Hispanic White	Non-Hispanic Black	Other
More than \$1,000 → QHI6	45	29	50
Less than \$1,000 → QHI7	55	71	50

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

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	65	40	67
No	35	60	33

(skip to next section)

QHI17. Was it less than \$500?

	Non-Hispanic White	Non-Hispanic Black	Other
Yes	71	78	92
No	30	22	8