

THE PITTSBURGH REGIONAL CAREGIVERS SURVEY
BREAKOUTS BY CARE RECIPIENT AGE

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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:

50 to 64 n = 161

65 to 79 n = 303

80 to 89 n = 333

90 and older n = 211

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?

	50 – 64	65 – 79	80 – 89	90 and older
Yes	50	51	48	54
No	50	50	52	46

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	99	98	98	96
No	1	2	2	4

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	64	64	64	62
No	36	36	36	38

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:

	50 – 64	65 – 79	80 – 89	90 and older
Your mother or mother-in-law	17	31	52	59
Your father or father-in-law	4	9	17	17
Your wife / partner	12	10	3	1
Your husband / partner	21	28	9	2
Your daughter or daughter-in-law	3	0	1	1
Your son or son-in-law	2	0	1	0
Some other relative	29	13	11	12
A non-relative	12	9	7	9

QCS2. Is the person you care for:

	50 – 64	65 – 79	80 – 89	90 and older
Male	42	47	29	26
Female	58	54	71	74

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

	50 – 64	65 – 79	80 – 89	90 and older
50 – 64	100	0	0	0
65 – 74	0	59	0	0
75 – 84	0	41	41	0
85 +	0	0	60	100

QCS5. Where does [he/she] live?

	50 – 64	65 – 79	80 – 89	90 and older
In your household → QCS9	55	56	35	30
Within 20 minutes of your home	34	32	51	52
Between 20 minutes and an hour from your home	8	9	12	14
One to two hours from your home	0	1	1	2
More than two hours away	3	1	2	2

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

	50 – 64	65 – 79	80 – 89	90 and older
His or her own home	69	83	70	62
Someone else's home → QCS9	17	5	6	12
An independent living or retirement community	7	8	13	16
In an assisted living facility where some care may be provided → QCS9	4	5	11	12
Somewhere else	3	0	1	0

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

QCS7. Does [he/she] live alone?

	50 – 64	65 – 79	80 – 89	90 and older
Yes	61	61	71	73
No	39	39	29	27

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

	50 – 64	65 – 79	80 – 89	90 and older
Short-term physical condition	12	13	11	11
Long-term physical condition	78	81	77	74
Emotional or mental health problem	29	22	17	11
Developmental or intellectual disorder or mental retardation	11	4	3	3
Behavioral issue	9	8	8	6
Memory problem	29	37	49	50
None of the above	1	2	6	9

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	7	16	34	31
No	93	84	66	69

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

QCS11. a heart attack or myocardial infarction?

	50 – 64	65 – 79	80 – 89	90 and older
Yes	16	28	22	22
No	84	73	78	78

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	23	29	37	41
No	77	71	63	59

QCS13. high blood pressure or hypertension?

	50 – 64	65 – 79	80 – 89	90 and older
Yes	63	66	69	62
No	37	34	31	38

QCS14. arthritis?

	50 – 64	65 – 79	80 – 89	90 and older
Yes	46	69	68	70
No	54	31	32	30

QCS15. osteoporosis or thinning of the bones?

	50 – 64	65 – 79	80 – 89	90 and older
Yes	20	27	42	50
No	80	73	58	50

QCS16. diabetes?

	50 – 64	65 – 79	80 – 89	90 and older
Yes	24	41	24	17
No	76	59	76	83

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	23	32	21	15
No	77	68	79	85

QCS18. cancer?

	50 – 64	65 – 79	80 – 89	90 and older
Yes	26	26	29	29
No	74	74	71	71

QCS18a. a stroke?

	50 – 64	65 – 79	80 – 89	90 and older
Yes	18	23	23	23
No	82	77	77	77

QCS19. serious difficulty seeing?

	50 – 64	65 – 79	80 – 89	90 and older
Yes	23	24	29	40
No	78	76	71	60

QCS20. serious difficulty hearing?

	50 – 64	65 – 79	80 – 89	90 and older
Yes	16	24	46	59
No	84	76	55	41

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

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	86	85	88	86
No	14	15	12	14

QCS22B. a hearing aid?

	50 – 64	65 – 79	80 – 89	90 and older
Yes	4	11	23	31
No	96	89	77	69

QCS22C. a cane?

	50 – 64	65 – 79	80 – 89	90 and older
Yes	40	39	47	40
No	60	61	53	60

QCS22D. a walker?

	50 – 64	65 – 79	80 – 89	90 and older
Yes	26	36	48	63
No	75	64	52	37

QCS22E. a wheelchair?

	50 – 64	65 – 79	80 – 89	90 and older
Yes	31	34	30	40
No	69	66	70	60

QCS22F. a scooter?

	50 – 64	65 – 79	80 – 89	90 and older
Yes	6	13	6	4
No	94	87	94	96

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	37	40	34	23
No	63	61	66	78

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	23	21	21	17
No	77	79	79	83

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.

	50 – 64	65 – 79	80 – 89	90 and older
Yes	6	8	3	5
No	94	92	97	95

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?

	50 – 64	65 – 79	80 – 89	90 and older
Yes	65	79	84	89
No → next section	35	22	16	11

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

	50 – 64	65 – 79	80 – 89	90 and older
A railing or ramp	70	63	67	54
Grab bars in the bathroom	71	72	78	85
A seat for the shower or tub	61	74	73	72
An emergency call system	30	37	46	54
Other	20	38	34	36

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?

	50 – 64	65 – 79	80 – 89	90 and older
Every day	39	53	51	53
Most days	27	14	12	15
Some days	21	19	22	18
Rarely	4	6	6	8
Never → QCA2	5	6	7	5
Does not do, but not because of poor health and functioning → QCA2	4	3	2	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]?

	50 – 64	65 – 79	80 – 89	90 and older
Every day	40	47	36	37
Most days	23	18	16	15
Some days	27	28	33	29
Rarely	7	6	8	11
Never	3	2	8	8

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*)

	50 – 64	65 – 79	80 – 89	90 and older
Yes, another unpaid family member / friend	43	47	57	60
Yes, a paid helper	14	17	28	34
No	52	43	28	19

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?

	50 – 64	65 – 79	80 – 89	90 and older
Every day	33	40	41	48
Most days	28	21	20	18
Some days	28	24	22	23
Rarely	8	7	9	7
Never → QCA3	4	5	6	4
Does not do, but not because of poor health and functioning → QCA3	1	4	2	1

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]?

	50 – 64	65 – 79	80 – 89	90 and older
Every day	27	26	24	24
Most days	26	22	22	20
Some days	30	38	36	35
Rarely	9	9	10	12
Never	9	5	9	10

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes, another unpaid family member / friend	41	48	58	61
Yes, a paid helper	6	7	8	10
No	55	48	38	35

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	48	50	63	68
No → QCA4	50	47	35	30
Does not do, but not because of poor health and functioning → QCA4	3	3	2	2

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	80	78	75	73
No	20	22	26	27

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes, another unpaid family member / friend	20	30	35	45
Yes, a paid helper	3	10	10	15
No	78	61	55	44

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	56	57	74	77
No → QCA5	38	39	22	20
Does not do, but not because of poor health and functioning → QCA5	6	3	4	2

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	88	82	77	72
No	12	18	23	28

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes, another unpaid family member / friend	22	32	47	49
Yes, a paid helper	0	1	1	4
No	78	68	52	48

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?

	50 – 64	65 – 79	80 – 89	90 and older
Every day	6	7	12	12
Most days	3	4	4	6
Some days	8	6	6	6
Rarely	14	10	7	12
Never → QCA6	69	72	71	63

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

	50 – 64	65 – 79	80 – 89	90 and older
Every day	14	27	30	24
Most days	18	7	11	18
Some days	27	23	30	24
Rarely	25	30	15	27
Never	16	13	14	7

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes, another unpaid family member / friend	25	31	51	54
Yes, a paid helper	10	15	15	20
No	67	60	40	37

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

	50 – 64	65 – 79	80 – 89	90 and older
Every day	14	23	23	34
Most days	12	8	10	11
Some days	10	14	10	13
Rarely	16	10	11	6
Never → QCA7	48	45	47	37

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

	50 – 64	65 – 79	80 – 89	90 and older
Every day	26	22	19	20
Most days	16	14	12	10
Some days	18	24	26	18
Rarely	27	17	13	14
Never	13	24	30	37

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes, another unpaid family member / friend	28	32	38	40
Yes, a paid helper	17	27	28	42
No	61	47	39	29

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

	50 – 64	65 – 79	80 – 89	90 and older
Every day	14	23	22	29
Most days	12	7	6	10
Some days	15	15	17	11
Rarely	19	13	11	12
Never → QCA8	41	42	43	37

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

	50 – 64	65 – 79	80 – 89	90 and older
Every day	17	27	22	17
Most days	24	11	10	21
Some days	25	29	35	32
Rarely	23	24	19	21
Never	11	10	14	10

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes, another unpaid family member / friend	27	35	44	50
Yes, a paid helper	18	20	25	33
No	62	52	41	29

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

	50 – 64	65 – 79	80 – 89	90 and older
Every day	13	15	13	25
Most days	4	3	3	5
Some days	7	7	5	7
Rarely	7	10	14	7
Never → QCA9	69	66	65	58

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

	50 – 64	65 – 79	80 – 89	90 and older
Every day	26	34	27	27
Most days	19	6	6	20
Some days	21	20	20	26
Rarely	17	24	31	12
Never	17	17	16	14

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes, another unpaid family member / friend	28	39	50	61
Yes, a paid helper	30	28	26	42
No	55	45	35	18

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

	50 – 64	65 – 79	80 – 89	90 and older
Every day	12	17	12	24
Most days	6	4	3	3
Some days	10	9	8	7
Rarely	16	16	13	8
Never → QCA10	57	55	64	58

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

	50 – 64	65 – 79	80 – 89	90 and older
Every day	16	22	20	23
Most days	15	8	6	16
Some days	25	20	25	26
Rarely	29	36	35	17
Never	15	14	15	19

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes, another unpaid family member / friend	37	37	48	66
Yes, a paid helper	19	21	20	33
No	56	51	39	19

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

	50 – 64	65 – 79	80 – 89	90 and older
Every day	11	18	12	26
Most days	8	4	4	5
Some days	12	17	12	8
Rarely	21	15	17	17
Never → QCA11	48	46	55	45

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

	50 – 64	65 – 79	80 – 89	90 and older
Every day	18	25	16	20
Most days	17	9	8	16
Some days	26	34	36	30
Rarely	31	25	33	27
Never	9	8	7	7

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes, another unpaid family member / friend	46	45	56	67
Yes, a paid helper	10	18	20	31
No	50	43	33	22

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

	50 – 64	65 – 79	80 – 89	90 and older
Every day	20	22	24	31
Most days	10	11	12	12
Some days	22	17	20	19
Rarely	16	13	14	12
Never → skip logic prior to QCA12A	33	37	30	27

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

	50 – 64	65 – 79	80 – 89	90 and older
Every day	22	21	19	20
Most days	14	17	16	19
Some days	32	36	41	38
Rarely	19	21	19	15
Never	12	5	6	8

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes, another unpaid family member / friend	46	56	60	69
Yes, a paid helper	13	14	15	17
No	47	36	32	25

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?

	50 – 64	65 – 79	80 – 89	90 and older
Yes	34	36	38	34
No	66	64	62	66

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?

	50 – 64	65 – 79	80 – 89	90 and older
Yes	72	70	74	70
No	28	30	26	31

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?

	50 – 64	65 – 79	80 – 89	90 and older
Yes	61	66	78	81
No	39	34	22	19

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

	50 – 64	65 – 79	80 – 89	90 and older
Every day	15	14	11	8
Most days	22	18	15	11
Some days	26	34	43	38
Rarely	12	14	17	22
Never	26	20	15	20

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]?

	50 – 64	65 – 79	80 – 89	90 and older
Every day	3	2	2	1
Most days	6	2	1	2
Some days	5	4	3	2
Rarely	8	4	5	5
Never	55	58	61	62
Do not use	24	29	29	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?

	50 – 64	65 – 79	80 – 89	90 and older
Yes	59	56	66	64
No	41	45	34	36

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	44	43	47	52
No	56	57	53	48

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

	50 – 64	65 – 79	80 – 89	90 and older
Orally (by mouth as pills, capsules, liquid)	99	97	99	99
Insulin injection	9	20	11	7
Other injection	9	7	5	3
Infusion pump	1	0	1	0
Inhaler	17	14	13	9
Suppository	6	2	3	3
Medication patch	7	5	4	6
Spray	3	5	6	1
Eye/Ear drops	13	14	22	17
Other	4	9	9	6

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	7	8	6	5
No	93	92	94	95

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	5	11	9	9
No	95	89	91	91

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	30	30	27	25
No	70	71	73	76

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	30	36	24	21
No	70	65	77	79

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	17	18	18	26
No	83	82	82	75

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	34	30	27	28
No	66	70	73	72

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	26	30	25	30
No	74	70	76	70

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	33	46	49	57
No	67	54	51	43

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?

	50 – 64	65 – 79	80 – 89	90 and older
Yes	30	35	39	53
No	70	66	61	47

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	46	56	47	53
No	54	44	53	47

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	4	4	4	3
No	96	96	96	97

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	49	49	39	55
No	52	52	61	45

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	18	21	13	19
No	82	79	87	81

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)?

	50 – 64	65 – 79	80 – 89	90 and older
Yes	6	7	10	10
No	94	93	90	90

(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.

	50 – 64	65 – 79	80 – 89	90 and older
1. Not at all difficult	55	58	52	54
2.	17	17	24	19
3.	14	14	14	17
4.	9	7	7	5
5. Very difficult	5	3	3	5

QCA17. Did anyone prepare you to do these tasks?

	50 – 64	65 – 79	80 – 89	90 and older
Yes	23	25	25	27
No → QCA21	77	75	75	74

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

	50 – 64	65 – 79	80 – 89	90 and older
Hospital nurse	29	24	17	25
Hospital doctor	16	5	4	5
Primary care doctor	13	9	23	11
Nurse in doctor's office or outpatient setting	10	6	21	9
Home care nurse	23	26	24	25
Social worker/geriatric care manager	3	2	6	0
Physical or occupational therapist	16	12	27	14
Pharmacist	7	2	11	5
Medical supply technician	7	8	11	5
Friend or neighbor	0	8	6	14
You learned on your own	26	24	31	23
Other	45	46	41	46

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

	50 – 64	65 – 79	80 – 89	90 and older
Very well	74	85	80	74
Somewhat well	26	12	17	26
Not well	0	3	3	0

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

	50 – 64	65 – 79	80 – 89	90 and older
None → QCA24PRE	43	44	43	48
One time	19	20	23	22
2 times	14	17	16	14
3 or more times	25	20	18	16

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...

	50 – 64	65 – 79	80 – 89	90 and older
Yes, all the time	57	56	59	60
Only some of the time	20	29	23	23
No, and you should have been	7	3	8	2
No, but you did not need to be	17	12	11	16

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]?

	50 – 64	65 – 79	80 – 89	90 and older
Yes	59	71	78	77
No	34	23	17	13
Not applicable	8	6	6	10

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

	50 – 64	65 – 79	80 – 89	90 and older
Very well	52	56	53	56
Somewhat well	33	33	41	31
Not well	15	11	7	13

QCA24PRE. Now think about the last YEAR.

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	62	61	67	72
No	39	39	33	28

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	60	65	67	71
No	40	35	33	29

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	85	85	85	84
No	15	15	15	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.]

	50 – 64	65 – 79	80 – 89	90 and older
Yes	29	31	25	20
No	71	69	75	80

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.]

	50 – 64	65 – 79	80 – 89	90 and older
Yes	36	36	41	39
No	64	64	59	61

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?

	50 – 64	65 – 79	80 – 89	90 and older
8 hours or less per week	42	40	45	39
9 to 19 hours per week	23	23	27	29
20 to 39 hours per week	21	16	16	13
40 or more hours per week	15	21	13	19

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.

	50 – 64	65 – 79	80 – 89	90 and older
Regular schedule	48	51	53	57
Varied	52	49	47	43

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

	50 – 64	65 – 79	80 – 89	90 and older
3 months or less	9	7	6	2
4 to 12 months	11	13	8	12
1 - 2 years	17	20	21	17
3 - 5 years	29	26	31	28
More than 5 years	35	35	34	41

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

	50 – 64	65 – 79	80 – 89	90 and older
Increased in the past month	36	32	39	37
Been about the same in the past month	49	58	53	59
Decreased in the past month	15	10	9	5

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?

	50 – 64	65 – 79	80 – 89	90 and older
Will increase	28	29	36	37
Will be about the same	62	58	59	59
Will decrease	10	13	5	5

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	46	42	47	48
No	54	58	53	52

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

	50 – 64	65 – 79	80 – 89	90 and older
Very worried	5	7	4	4
Somewhat worried	14	11	12	11
Only a little	21	27	32	32
Not at all	61	56	52	53

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

QCA31. I'd like to ask you to the degree to which you think CR has been suffering physically during the past month on a scale from 1 to 10 where 1 equals "CR has not been suffering physically," and 10 equals "CR has been suffering terribly".)

	50 – 64	65 – 79	80 – 89	90 and older
1 CR has not been suffering physically	15	10	13	17
2	5	8	10	15
3	13	11	16	17
4	6	8	10	13
5	11	14	16	14
6	11	11	9	5
7	10	17	10	7
8	13	9	9	9
9	6	5	4	3
10 CR has been suffering terribly	11	7	5	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”.)

	50 – 64	65 – 79	80 – 89	90 and older
1 CR has not been suffering physically	18	10	14	13
2	6	8	9	14
3	7	10	10	16
4	4	4	9	10
5	14	16	15	13
6	9	11	9	8
7	12	11	8	9
8	13	12	14	8
9	6	6	6	4
10 CR has been suffering terribly	11	10	6	3

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]?

	50 – 64	65 – 79	80 – 89	90 and older
A lot	73	69	69	71
Some	21	22	25	24
A little	4	7	5	4
Not at all	1	2	1	1

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

	50 – 64	65 – 79	80 – 89	90 and older
A lot	23	20	19	12
Some	27	29	22	26
A little	29	27	29	32
Not at all	22	24	30	30

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

	50 – 64	65 – 79	80 – 89	90 and older
A lot	82	78	79	82
Some	11	13	13	9
A little	4	6	6	7
Not at all	3	3	3	2

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

	50 – 64	65 – 79	80 – 89	90 and older
A lot	25	24	18	13
Some	27	32	28	36
A little	29	32	36	33
Not at all	19	13	18	19

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

	50 – 64	65 – 79	80 – 89	90 and older
Gotten much better	19	16	16	19
Gotten somewhat better	23	18	21	21
Stayed about the same	43	48	49	47
Gotten somewhat worse	14	14	11	12
Gotten much worse	2	4	3	1

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

QAC5A. Helping [him/her] has made you more confident about your abilities.

	50 – 64	65 – 79	80 – 89	90 and older
Very much	42	41	33	38
Somewhat	30	33	42	41
Not so much	28	26	25	21

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

	50 – 64	65 – 79	80 – 89	90 and older
Very much	49	52	44	46
Somewhat	33	36	38	39
Not so much	18	13	18	15

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

	50 – 64	65 – 79	80 – 89	90 and older
Very much	49	49	44	50
Somewhat	35	30	37	41
Not so much	16	21	19	10

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

	50 – 64	65 – 79	80 – 89	90 and older
Very much	76	75	80	81
Somewhat	19	21	18	17
Not so much	5	4	2	3

QAC6A. Is helping CR financially difficult for you?

	50 – 64	65 – 79	80 – 89	90 and older
Yes	29	24	21	18
No	71	76	79	82

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	55	59	63	64
No	46	41	38	36

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	32	33	26	25
No	68	67	74	75

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*)

	50 – 64	65 – 79	80 – 89	90 and older
1. A little difficult	7	9	15	16
2.	7	11	15	8
3.	28	31	30	34
4.	30	24	20	26
5. Very difficult	28	25	20	16

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

	50 – 64	65 – 79	80 – 89	90 and older
1. A little difficult	9	12	10	15
2.	24	12	15	24
3.	28	25	31	29
4.	20	25	26	17
5. Very difficult	19	26	18	16

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

	50 – 64	65 – 79	80 – 89	90 and older
1. A little difficult	8	7	12	11
2.	18	17	24	9
3.	31	32	36	47
4.	28	24	20	23
5. Very difficult	16	20	9	9

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

	50 – 64	65 – 79	80 – 89	90 and older
Very much	13	9	8	6
Somewhat	18	16	25	26
Not so much	69	75	67	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.

	50 – 64	65 – 79	80 – 89	90 and older
Very much	29	33	32	30
Somewhat	32	32	28	28
Not so much	39	35	39	41

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

	50 – 64	65 – 79	80 – 89	90 and older
Very much	26	22	23	24
Somewhat	34	34	34	32
Not so much	41	43	43	44

QAC9C. You don't have time for yourself.

	50 – 64	65 – 79	80 – 89	90 and older
Very much	27	29	26	22
Somewhat	35	31	32	37
Not so much	37	41	42	40

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

	50 – 64	65 – 79	80 – 89	90 and older
Very much	9	12	11	11
Somewhat	26	27	27	30
Not so much	65	62	61	58

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?

	50 – 64	65 – 79	80 – 89	90 and older
Yes	86	88	92	92
No	14	12	9	9

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?

	50 – 64	65 – 79	80 – 89	90 and older
Yes	47	50	52	61
No	53	50	48	39

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	52	63	71	79
No	48	38	30	21

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	5	7	5	6
No	95	93	95	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?

	50 – 64	65 – 79	80 – 89	90 and older
Yes	11	17	22	26
No	89	83	78	74

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	9	12	10	7
No	91	88	90	93

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	25	15	16	16
No	75	85	84	84

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)*

	50 – 64	65 – 79	80 – 89	90 and older
Yes	17	17	19	22
No	83	83	81	78

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?

	50 – 64	65 – 79	80 – 89	90 and older
Yes	36	43	45	43
No	64	57	55	57

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?

	50 – 64	65 – 79	80 – 89	90 and older
Yes	31	47	48	43
No	69	54	52	57

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	12	19	23	29
No	88	82	77	71

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

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

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

	50 – 64	65 – 79	80 – 89	90 and older
One	35	26	16	24
Two	27	26	28	27
Three or more	38	48	56	49

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

	50 – 64	65 – 79	80 – 89	90 and older
Caregiver’s Brother(s)	15	23	30	32
CG’s Sister(s)	24	28	47	46
CG’s husband	21	13	24	20
CG’s wife	3	6	8	12
CG’s other relative(s) / in-law(s)	57	61	55	44
CG’s friend(s)	17	14	10	11
Other	27	25	24	21

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

	50 – 64	65 – 79	80 – 89	90 and older
Live(s) with you	46	36	41	37
Within twenty minutes of your home	58	63	68	64
Between twenty minutes and an hour from your home	20	22	29	27
One to two hours from your home	6	5	5	7
Two to four hours away	3	3	5	5
More than four hours away	3	10	13	13

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

	50 – 64	65 – 79	80 – 89	90 and older
We complement each other – we each help CR with different tasks.	21	31	33	26
We help with the same things but we divide the help over time.	13	19	16	19
We share some tasks, and others we do separately	65	51	52	55

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?

	50 – 64	65 – 79	80 – 89	90 and older
Respondent is the primary caregiver	66	58	54	51
Someone else is the primary caregiver	26	28	34	29
Care is equally shared	8	14	13	20

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

	50 – 64	65 – 79	80 – 89	90 and older
To a great extent	1	3	2	2
To a moderate extent	5	7	10	10
Only a little	25	29	31	29
Not at all	69	61	58	59

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

	50 – 64	65 – 79	80 – 89	90 and older
Very satisfied	78	62	68	68
Moderately satisfied	16	30	26	23
Moderately dissatisfied	4	6	4	7
Very dissatisfied	3	2	2	3

PARTICIPATION

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

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	85	83	88	83
No	15	17	12	17

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]?

	50 – 64	65 – 79	80 – 89	90 and older
Yes	24	29	33	33
No	76	71	67	67

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

	50 – 64	65 – 79	80 – 89	90 and older
Very important	53	50	55	54
Somewhat important	29	35	35	31
Not so important	18	16	10	15

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	54	56	65	65
No	46	44	35	35

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	16	14	11	12
No	84	86	89	88

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

	50 – 64	65 – 79	80 – 89	90 and older
Very important	41	44	50	47
Somewhat important	21	27	21	26
Not so important	38	29	29	28

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	39	49	49	53
No	62	52	51	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.]

	50 – 64	65 – 79	80 – 89	90 and older
Yes	15	21	20	25
No	85	79	80	75

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.]

	50 – 64	65 – 79	80 – 89	90 and older
Very important	24	32	28	38
Somewhat important	29	28	35	30
Not so important	47	40	37	32

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.

	50 – 64	65 – 79	80 – 89	90 and older
Yes	81	82	87	84
No	19	19	14	16

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.]

	50 – 64	65 – 79	80 – 89	90 and older
Yes	20	27	22	30
No	80	73	78	71

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.]

	50 – 64	65 – 79	80 – 89	90 and older
Very important	44	48	50	47
Somewhat important	36	35	38	40
Not so important	19	17	11	13

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	37	35	37	36
No	63	65	63	64

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	13	17	16	16
No	88	83	84	84

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.

	50 – 64	65 – 79	80 – 89	90 and older
Yes	40	44	40	39
No	60	56	60	61

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	4	10	7	8
No	96	90	93	92

HEALTH

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

	50 – 64	65 – 79	80 – 89	90 and older
Excellent	15	15	16	16
Very good	24	29	34	35
Good	33	30	31	32
Fair	24	22	16	15
Poor	4	4	4	3

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	7	9	6	6
No	93	91	94	94

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	8	9	10	8
No	92	91	90	92

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	41	42	39	43
No	59	58	61	57

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	46	53	45	46
No	54	47	55	54

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	16	23	17	23
No	84	77	83	77

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	16	13	15	15
No	84	87	85	85

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	25	20	11	11
No	75	80	89	90

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	12	14	15	15
No	88	86	86	85

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

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	61	65	62	59
No	39	35	38	41

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	27	20	14	10
No	73	81	86	90

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	29	35	28	29
No	71	65	72	71

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	37	42	38	39
No	63	58	62	61

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	53	52	52	51
No	47	48	48	50

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

	50 – 64	65 – 79	80 – 89	90 and older
Every night	9	9	10	8
Most nights	17	17	12	14
Some nights	29	32	36	31
Rarely	27	23	26	30
Never	19	19	15	17

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

	50 – 64	65 – 79	80 – 89	90 and older
Every night	3	3	2	2
Most nights	6	4	5	6
Some nights	16	23	17	17
Rarely	29	20	24	23
Never	46	50	52	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:

	50 – 64	65 – 79	80 – 89	90 and older
< 18.5 (underweight)	1	1	1	1
18.5 – 24.9 (normal)	23	20	31	34
25.0 – 29.9 (overweight)	29	39	36	38
30.0 – 34.9 (moderately obese)	26	22	22	22
35.0 – 39.9 (severely obese)	15	10	5	2
40.0 + (very severely obese)	8	9	5	3

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	37	33	27	25
No → QHE25A	63	67	73	75

QHE24a. Were you trying to lose weight?

	50 – 64	65 – 79	80 – 89	90 and older
Yes	67	67	77	58
No	33	33	23	42

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

	50 – 64	65 – 79	80 – 89	90 and older
Every day	17	18	16	9
Most days	47	43	44	52
Some days	25	29	33	29
Rarely	10	11	6	10
Never	1	1	1	0

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

	50 – 64	65 – 79	80 – 89	90 and older
Every day	15	12	13	10
Most days	34	41	37	43
Some days	35	27	37	34
Rarely	14	17	12	11
Never	3	3	2	2

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

	50 – 64	65 – 79	80 – 89	90 and older
Every day	18	17	16	13
Most days	34	32	31	34
Some days	26	28	37	33
Rarely	17	20	13	16
Never	4	4	4	4

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

	50 – 64	65 – 79	80 – 89	90 and older
Every day	6	3	2	1
Most days	7	7	4	5
Some days	22	22	22	21
Rarely	30	30	31	35
Never	35	39	41	39

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

	50 – 64	65 – 79	80 – 89	90 and older
Every day	3	3	3	1
Most days	7	9	5	9
Some days	22	18	23	20
Rarely	24	28	28	33
Never	44	43	42	37

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

	50 – 64	65 – 79	80 – 89	90 and older
Every day	5	3	3	3
Most days	9	11	7	7
Some days	45	47	48	48
Rarely	32	31	37	37
Never	9	7	5	5

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

	50 – 64	65 – 79	80 – 89	90 and older
Not at all	57	52	56	59
Several days	28	31	34	34
More than half the days	8	11	8	5
Nearly every day	8	6	3	3

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

	50 – 64	65 – 79	80 – 89	90 and older
Not at all	57	57	55	59
Several days	30	29	35	33
More than half the days	6	9	7	5
Nearly every day	6	4	3	3

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

	50 – 64	65 – 79	80 – 89	90 and older
Not at all	42	40	39	45
Several days	45	41	47	42
More than half the days	6	10	9	8
Nearly every day	8	10	5	5

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

	50 – 64	65 – 79	80 – 89	90 and older
Not at all	56	49	50	50
Several days	27	31	33	32
More than half the days	6	7	10	10
Nearly every day	11	13	7	8

HEALTH LITERACY AND NUMERACY

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

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

	50 – 64	65 – 79	80 – 89	90 and older
Not at all	3	3	3	3
A little bit	4	3	3	7
Somewhat	11	9	9	7
Quite a bit	27	26	28	32
Extremely	54	59	57	52

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?

	50 – 64	65 – 79	80 – 89	90 and older
Never	64	66	72	67
Rarely	27	25	20	23
Sometimes	9	7	7	10
Often	1	1	1	1
Always	0	1	1	0

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

	50 – 64	65 – 79	80 – 89	90 and older
Never	66	66	66	61
Rarely	24	25	23	28
Sometimes	9	7	11	10
Often	1	1	1	1
Always	0	2	0	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)?

	50 – 64	65 – 79	80 – 89	90 and older
Correct	78	63	67	64
Incorrect	23	37	33	36

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*)

	50 – 64	65 – 79	80 – 89	90 and older
Correct	82	78	86	83
Incorrect	18	22	15	17

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*)

	50 – 64	65 – 79	80 – 89	90 and older
Correct	71	75	78	80
Incorrect	29	26	22	21

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.

	50 – 64	65 – 79	80 – 89	90 and older
Yes → QEC4	50	45	52	38
No	27	21	20	25
Retired / don't work anymore → QEC16	23	35	28	37

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes → QEC4	9	8	8	4
No	72	63	74	68
Retired / don't work anymore → QEC16	19	29	19	28

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes, looking for a job → QEC16	19	13	8	22
Yes, on layoff → QEC16	7	8	2	6
No → QEC16	71	74	85	58
Retired / don't work anymore → QEC16	3	5	4	14

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	19	25	21	22
No	81	75	79	78

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

	50 – 64	65 – 79	80 – 89	90 and older
20 or fewer	20	23	22	21
21 – 39	15	18	24	15
40 or more	65	59	55	64

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?

	50 – 64	65 – 79	80 – 89	90 and older
Yes	51	63	60	63
No	49	37	40	37

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

	50 – 64	65 – 79	80 – 89	90 and older
Daytime	71	78	84	93
Some other schedule	29	22	16	7

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?

	50 – 64	65 – 79	80 – 89	90 and older
Yes	49	40	47	38
No → QEC12	51	60	53	62

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.

	50 – 64	65 – 79	80 – 89	90 and older
Yes	26	40	29	33
No	74	60	71	67

QEC9B. You were sick.

	50 – 64	65 – 79	80 – 89	90 and older
Yes	33	43	41	42
No	67	57	59	58

QEC9C. You took time off to help CR.

	50 – 64	65 – 79	80 – 89	90 and older
Yes	41	27	59	46
No	59	73	41	55

QEC9D. Other family members were sick.

	50 – 64	65 – 79	80 – 89	90 and older
Yes	14	20	24	21
No	86	80	76	79

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	43	35	33	39
No	57	65	67	61

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?

	50 – 64	65 – 79	80 – 89	90 and older
One	44	56	47	67
Two	17	13	31	13
Three or more	39	31	22	20

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?

	50 – 64	65 – 79	80 – 89	90 and older
Yes	19	24	30	24
No → QEC14	81	76	70	76

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.

	50 – 64	65 – 79	80 – 89	90 and older
1 A little harder	19	6	15	20
2	6	12	13	5
3	13	27	22	5
4	0	9	17	25
5	13	15	17	20
6	13	12	7	0
7	6	9	2	15
8	25	9	6	5
10 A lot harder	6	3	2	5

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	73	73	82	83
No	27	27	18	17

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

	50 – 64	65 – 79	80 – 89	90 and older
Telecommuting or working from home	26	29	34	33
Programs like information, referrals, counseling, or an employee assistance program, to help caregivers like yourself	32	36	41	27
Paid leave, where you could take paid time off from work for several weeks to care for a family member	35	35	35	28
Paid sick days	51	57	54	52
None of the above	31	26	26	33

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

	50 – 64	65 – 79	80 – 89	90 and older
Went in late, left early, or took time off during the day to provide care	42	39	47	40
Took a leave of absence	17	10	11	14
Went from working full-time to part-time, or cut back your hours	20	15	13	13
Turned down a promotion	4	4	3	5
Lost any of your job benefits	5	4	4	5
Gave up working entirely	14	14	13	12
Retired early	14	13	8	18
Received a warning about your performance or attendance at work	6	5	3	1
None of the above	41	43	44	43

DEMOGRAPHICS

QDE1. INTERVIEWER: RECORD PERSON'S SEX

	50 – 64	65 – 79	80 – 89	90 and older
Male	24	25	24	29
Female	76	75	76	71

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

	50 – 64	65 – 79	80 – 89	90 and older
44 or under	29	12	6	6
45 – 54	12	28	20	10
55 – 64	40	20	50	45
65 or older	19	40	24	40

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

	50 – 64	65 – 79	80 – 89	90 and older
Married	51	63	63	52
Living with a partner in a marital-like relationship	11	6	2	3
Divorced or separated	8	13	15	17
Widowed	4	4	4	9
Single/never married	26	15	16	20

QDE4. Are you of Hispanic or Latino descent?

	50 – 64	65 – 79	80 – 89	90 and older
Yes	2	3	0	1
No	98	97	100	100

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

	50 – 64	65 – 79	80 – 89	90 and older
Caucasian/White	68	82	87	87
Asian/Pacific Islander	1	1	1	0
American Indian or Alaskan Native	3	1	1	1
Black or African-American	28	17	12	13
None of the above	1	1	1	1

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

	50 – 64	65 – 79	80 – 89	90 and older
Eighth grade or less	1	0	0	0
Some high school	1	1	2	1
High school graduate or GED	20	23	16	19
Some college, no degree	31	20	19	16
Associate's degree, occupational	10	8	5	6
Associate's degree, academic	6	6	5	6
Bachelor's degree	22	23	30	28
Master's degree	7	15	16	22
Professional degree	2	3	3	1
Doctoral degree	0	3	3	2

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

	50 – 64	65 – 79	80 – 89	90 and older
Live alone → QDE11PRE	9	13	14	22
Live in a household with family or others	90	86	86	77
Have some other living arrangements	1	1	1	1

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

	50 – 64	65 – 79	80 – 89	90 and older
One	7	5	4	4
Two	67	65	64	66
Three	18	22	22	25
Four	8	6	9	4
Five	0	2	1	2
Six	0	0	0	0

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

	50 – 64	65 – 79	80 – 89	90 and older
Zero	73	78	81	90
One	13	9	13	4
Two	7	8	4	6
Three	3	4	1	1
Four	1	1	0	0
Five	1	0	0	0
Six	1	0	0	0

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

	50 – 64	65 – 79	80 – 89	90 and older
Your spouse / partner	71	80	76	72
Your child(ren)	40	32	33	26
Your grandchild(ren)	6	5	4	4
Your parent(s)	12	12	22	27
Other relatives of yours	13	11	7	11
Non-relatives	5	3	3	2

QDE11PRE. And now just a couple questions about CR.

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

	50 – 64	65 – 79	80 – 89	90 and older
Eighth grade or less	3	4	6	11
Some high school	5	7	8	7
High school graduate or GED	35	44	50	54
Some college, no degree	19	6	6	7
Associate's degree, occupational	14	7	5	3
Associate's degree, academic	5	5	2	2
Bachelor's degree	14	15	13	11
Master's degree	5	7	6	4
Professional degree	1	3	2	1
Doctoral degree	1	3	3	2

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	2	1	0	0
No	98	99	100	100

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

	50 – 64	65 – 79	80 – 89	90 and older
Caucasian/White	70	81	87	87
Asian/Pacific Islander	0	1	1	0
American Indian or Alaskan Native	2	2	0	1
Black or African-American	29	17	11	13
None of the above	1	1	0	1

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?

	50 – 64	65 – 79	80 – 89	90 and older
Yes	35	35	37	43
No	65	65	63	57

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?

	50 – 64	65 – 79	80 – 89	90 and older
Yes	17	18	18	20
No	83	82	82	81

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.

	50 – 64	65 – 79	80 – 89	90 and older
1. Not at all difficult	76	73	75	72
2	9	12	13	14
3	9	9	7	7
4	1	3	3	3
5. Very difficult	6	3	2	3

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.

	50 – 64	65 – 79	80 – 89	90 and older
1. Not at all difficult	73	69	71	68
2	6	12	13	15
3	7	9	10	9
4	6	5	3	6
5. Very difficult	8	5	3	4

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.

	50 – 64	65 – 79	80 – 89	90 and older
1. Not at all difficult	44	36	41	37
2	7	8	9	13
3	11	9	12	13
4	6	8	6	8
5. Very difficult	9	11	7	8
Not applicable	23	29	24	22

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.

	50 – 64	65 – 79	80 – 89	90 and older
1. Not at all difficult	34	32	33	32
2	6	8	10	13
3	9	8	14	11
4	4	6	6	7
5. Very difficult	15	15	12	11
Not applicable	33	31	25	25

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.

	50 – 64	65 – 79	80 – 89	90 and older
1. Not at all difficult	34	27	26	27
2	4	8	9	9
3	14	11	13	15
4	10	8	11	10
5. Very difficult	11	17	16	12
Not applicable	27	30	25	28

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*)

	50 – 64	65 – 79	80 – 89	90 and older
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	83	83	87
Requiring hospitals to keep you informed about major decisions, like transferring or discharging CR	80	86	89	87
Requiring hospitals or facilities to instruct or demonstrate any medical or nursing tasks you might need to do	83	87	87	90
Having respite services available, where someone would take care of CR to give you a break	63	70	72	76
Requiring a doctor, nurse, or social worker ask you about what you need to help care for CR	79	75	79	83
Requiring a doctor, nurse, or social worker ask you about what you need to take care of yourself	61	64	63	68
None of the above	6	6	6	3

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.

	50 – 64	65 – 79	80 – 89	90 and older
An income tax credit to caregivers, to help offset the cost of care	33	37	35	30
A partially paid leave of absence from work for caregivers who are employed	18	17	17	22
A program where caregivers could be paid for at least some of the hours they provide care	49	46	48	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?

	50 – 64	65 – 79	80 – 89	90 and older
Yes	32	50	36	45
No → QHI3	68	51	64	55

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	67	69	64	71
No	33	31	36	29

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	22	12	11	8
No	79	88	89	92

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.

	50 – 64	65 – 79	80 – 89	90 and older
Yes	68	72	82	78
No	32	28	18	22

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?

	50 – 64	65 – 79	80 – 89	90 and older
Yes	3	4	2	4
No	98	96	98	96

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

	50 – 64	65 – 79	80 – 89	90 and older
Medicare	48	79	84	81
Medicaid	31	17	16	12
Private Health Insurance	48	52	60	61
Tricare/CHAMPVA	1	6	4	1

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	65	74	81	80
No	35	27	19	20

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	93	96	97	96
No	7	4	3	4

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	62	72	82	79
No	38	28	18	21

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	9	18	22	24
No	91	83	78	76

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	58	66	78	79
No	42	34	22	21

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	22	33	39	41
No	78	67	61	60

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?

	50 – 64	65 – 79	80 – 89	90 and older
0 – less than \$10,000	11	7	7	5
\$10,000 to less than \$20,000	13	11	8	10
\$20,000 to less than \$30,000	16	8	9	10
\$30,000 to less than \$40,000	14	14	13	10
\$40,000 to less than \$50,000	9	12	8	13
\$50,000 to less than \$60,000	9	10	9	10
\$60,000 to less than \$70,000	9	8	8	9
\$70,000 to less than \$80,000	6	4	6	8
\$80,000 to less than \$90,000	4	4	5	9
\$90,000 to less than \$100,000	6	4	7	3
\$100,000 to less than \$110,000	2	6	4	3
\$110,000 to less than \$120,000	1	1	3	1
\$120,000 to less than \$130,000	1	2	1	3
\$130,000 to less than \$140,000	0	0	0	1
\$140,000 to less than \$150,000	0	3	2	2
More than \$150,000	1	7	10	6

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?

	50 – 64	65 – 79	80 – 89	90 and older
Yes	45	50	33	31
No	55	51	67	69

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?

	50 – 64	65 – 79	80 – 89	90 and older
Yes	31	32	14	10
No	69	68	86	90

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	14	19	13	8
No	86	81	87	92

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?

	50 – 64	65 – 79	80 – 89	90 and older
Yes	22	31	31	23
No	78	69	69	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.

	50 – 64	65 – 79	80 – 89	90 and older
Yes	22	21	19	20
No	78	79	81	80

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	6	10	11	11
No	94	90	89	89

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,]

	50 – 64	65 – 79	80 – 89	90 and older
More than \$1,000 → QHI6	46	53	38	30
Less than \$1,000 → QHI7	54	47	62	70

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

	50 – 64	65 – 79	80 – 89	90 and older
Yes	56	70	59	61
No	44	31	41	39

(skip to next section)

QHI17. Was it less than \$500?

	50 – 64	65 – 79	80 – 89	90 and older
Yes	82	72	70	71
No	18	28	30	29