

What Matters Most – Attitudes Toward Dementia

Date Created: Wednesday, April 20, 2022

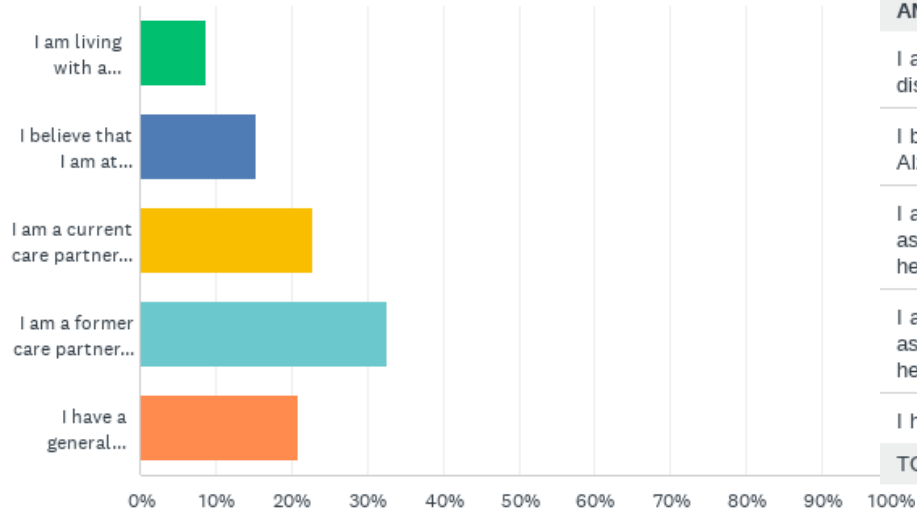
Complete Responses: 682

A-LIST n=559

Partner list n=123

Q1: Please select the category that best describes you:

Answered: 682 Skipped: 0



ANSWER CHOICES	RESPONSES
I am living with a diagnosis of Mild Cognitive Impairment (MCI), Alzheimer's disease (AD), or another dementia	8.65% 59
I believe that I am at significant risk for Mild Cognitive Impairment (MCI), Alzheimer's disease (AD), or another dementia	15.25% 104
I am a current care partner (to a relative, friend or neighbor) who provides unpaid assistance to a person, with Alzheimer's (AD) or another dementia, who requires help with activities of daily living	22.73% 155
I am a former care partner (to a relative, friend or neighbor) who provided unpaid assistance to a person, with Alzheimer's (AD) or another dementia, who required help with activities of daily living	32.55% 222
I have a general interest in brain health	20.82% 142
TOTAL	682

N=682

- 74% female
- 62% over age 65; 32% age 51-65
- 14% non-Caucasian
- While 83% have at least some college, only 31% disclose HH income > \$100K

Summary of findings

Diagnosed individuals

- Broad range in time since diagnosis (31% last 5 years, 41% 1-5 years, 29% > 5 years)
- Relatively modest stigma among diagnosed individuals; mainly related to feeling left out of things, seeing people are uncomfortable with them, and embarrassment about illness and physical limitations

Care partners

- Caregivers exhibit more types of stigma than other respondent types
- Caregivers note reduction in social contacts (for them and the care recipient)
- They note that the diagnosed person is treated differently by family, HCPs, and other individuals
- They believe that the diagnosis will/did affect the person's function as a spouse, parent, grandparent
- Over half of respondents (55%) feel some guilt

Summary of findings

Those not directly affected by AD (“At risk”/”Brain health”)

- Those without any connection to someone with dementia have positive feelings about the diagnosed individual and working with them
- Only 9% of respondents were ‘afraid’ of individuals with dementia but 46% would avoid an agitated person
- Those without any connection to someone with dementia note that familiarity is key but feel somewhat frustrated about knowing how to help them
- This group can largely imagine caring for someone with dementia and admire their coping skills

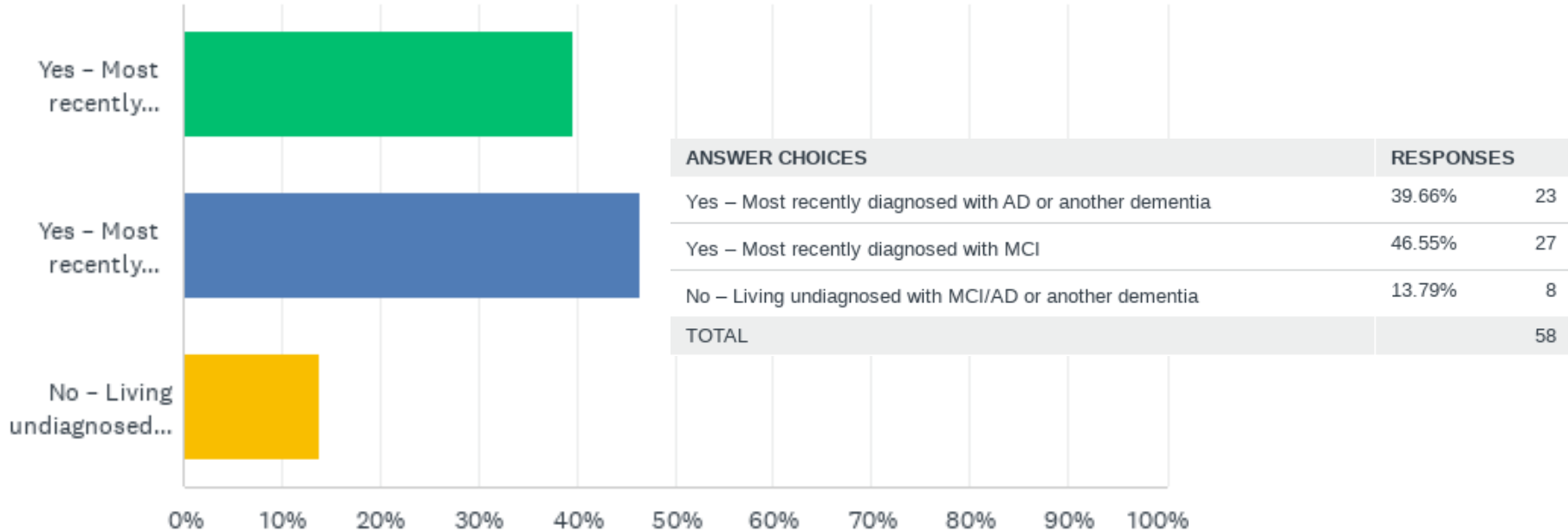
Differences among diverse groups?

- The sample was too small to test for between group differences by ethnicity/race

Diagnosed individuals

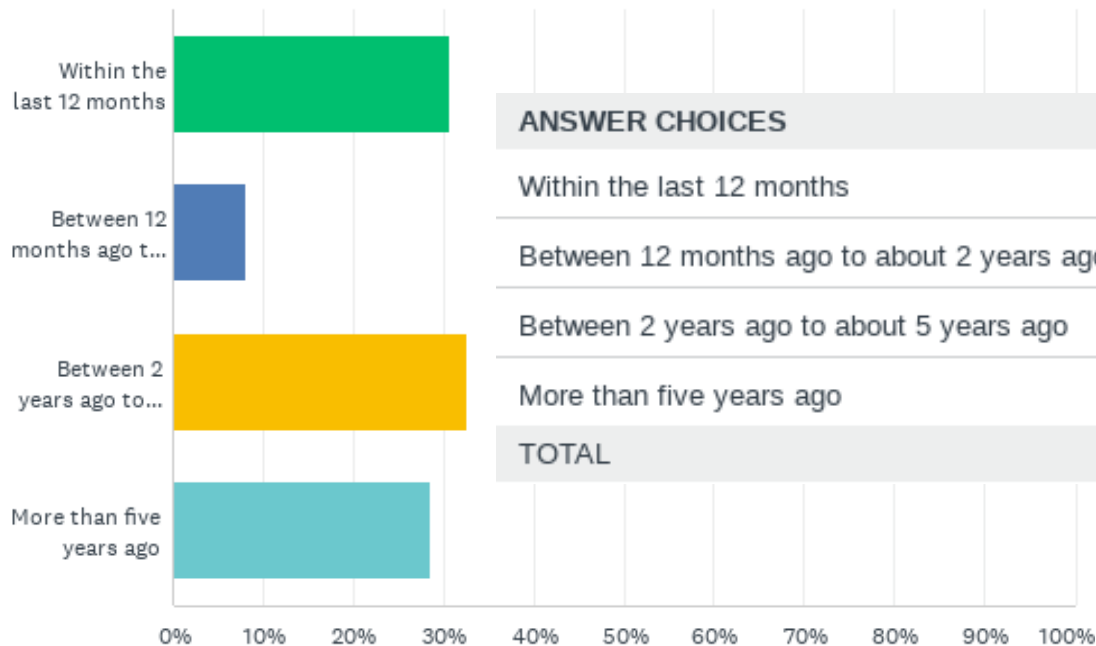
Q2: Have you been diagnosed with MCI, AD or another dementia?

Answered: 58 Skipped: 624 in total, skipped 1 with MCI, AD, or another dementia



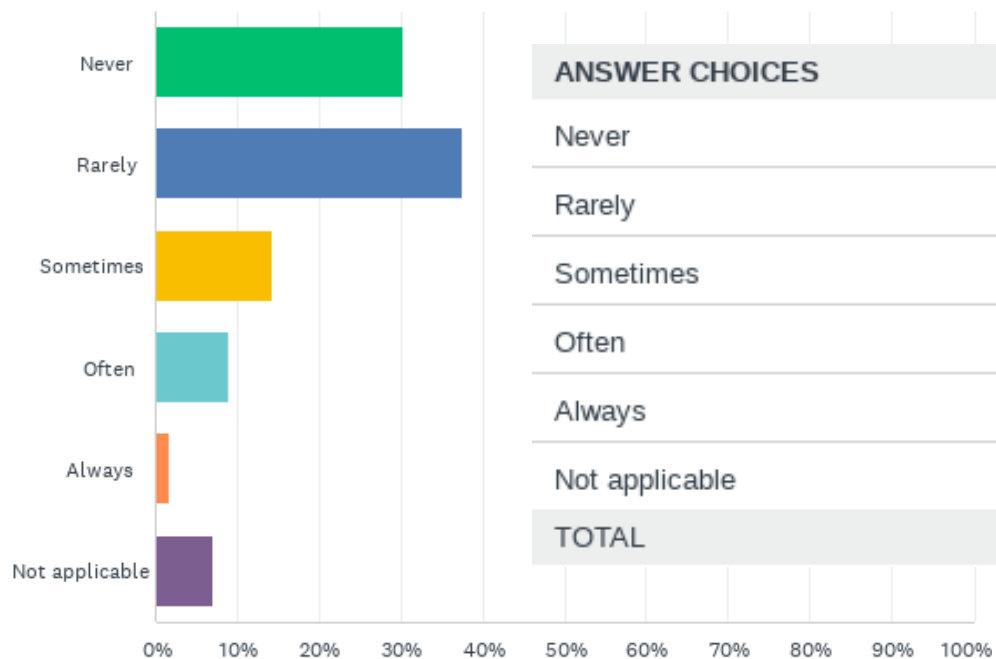
Q3: When was your most recent diagnosis made?

Answered: 49 Skipped: 633, skipped 1 with MCI, AD, or another dementia and a diagnosis



Q4: Because of my illness, some people avoid me:

Answered: 56 Skipped: 626, skipped 3 with MCI, AD or another dementia



ANSWER CHOICES

Never

RESPONSES

30.36%

17

Rarely

37.50%

21

Sometimes

14.29%

8

Often

8.93%

5

Always

1.79%

1

Not applicable

7.14%

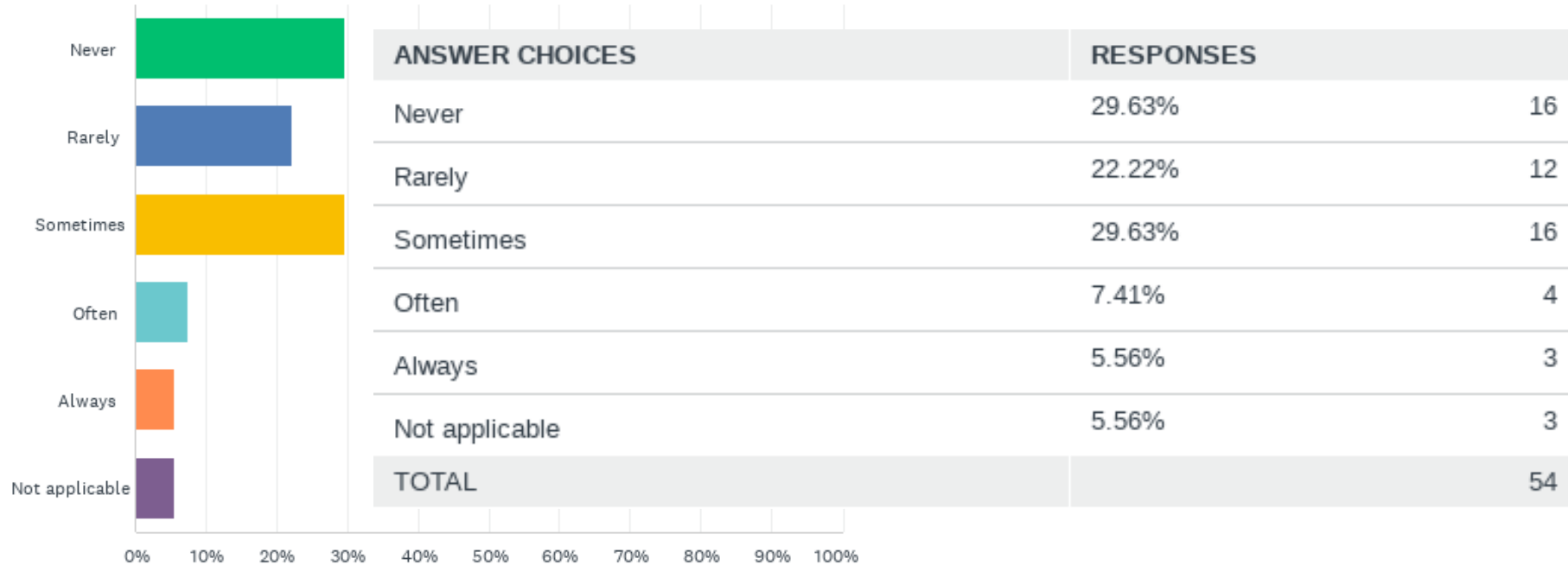
4

TOTAL

56

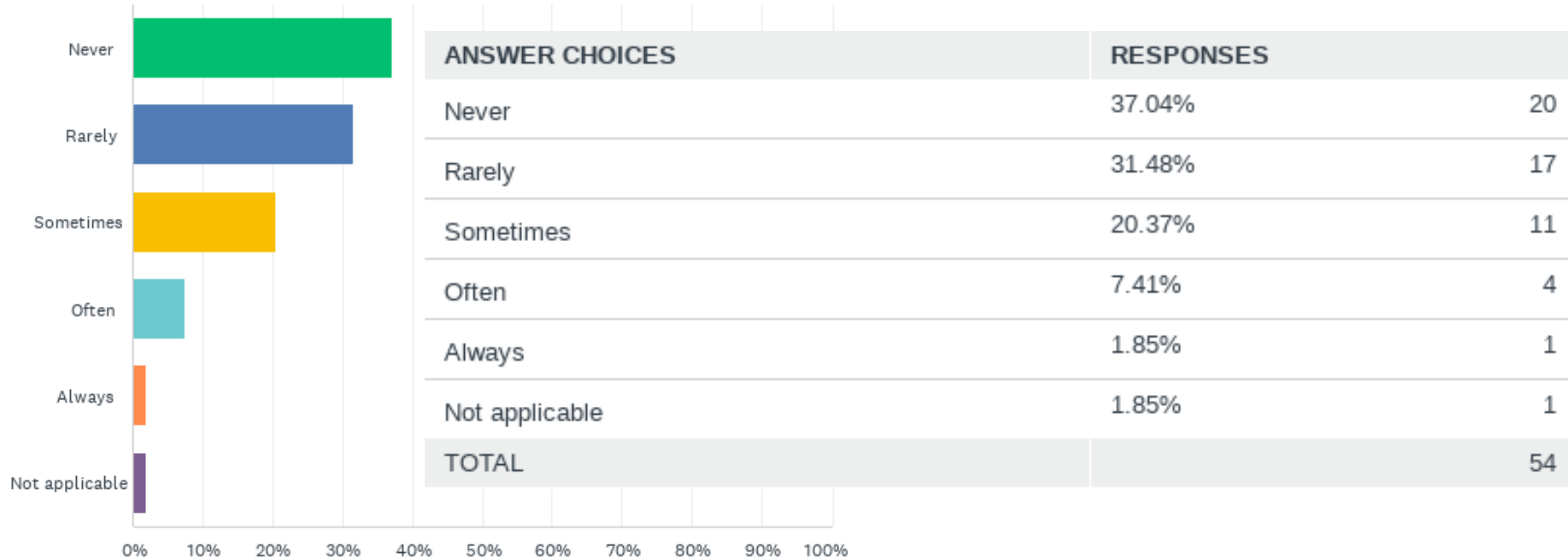
Q5: Because of my illness, I feel left out of things:

Answered: 54 Skipped: 628 skipped 5 with MCI, AD or another dementia



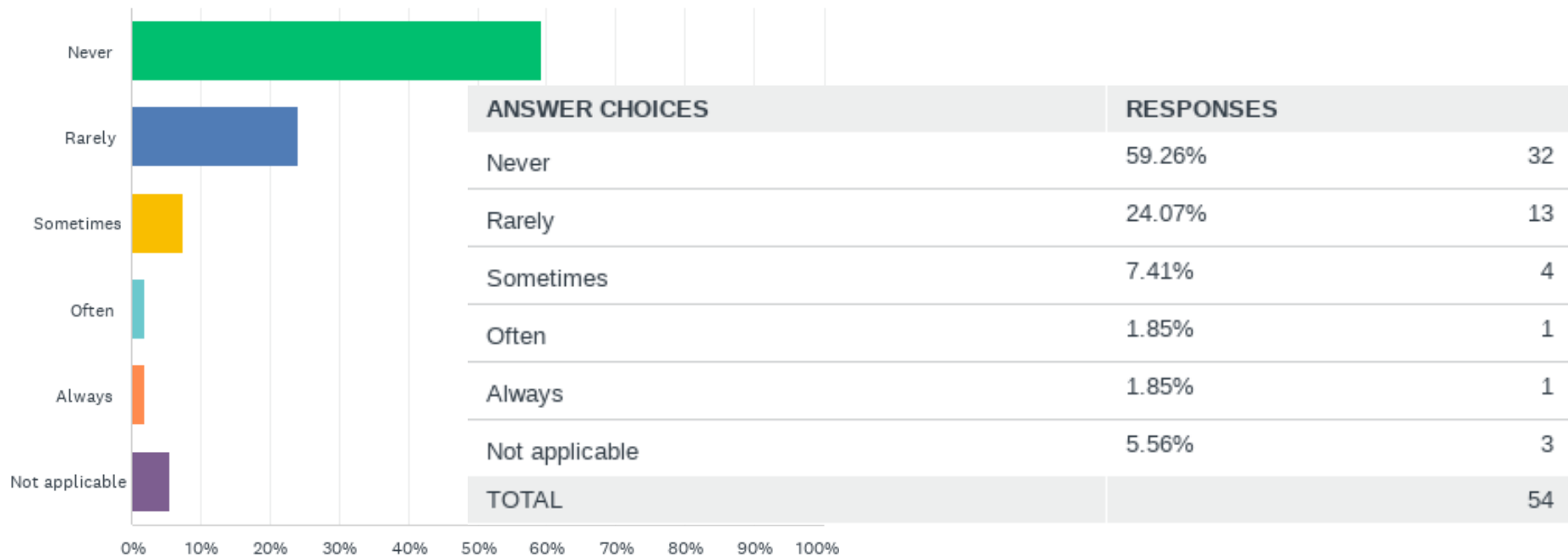
Q6: Because of my illness, some people seem uncomfortable with me:

Answered: 54 Skipped: 628 skipped 5 with MCI, AD or another dementia



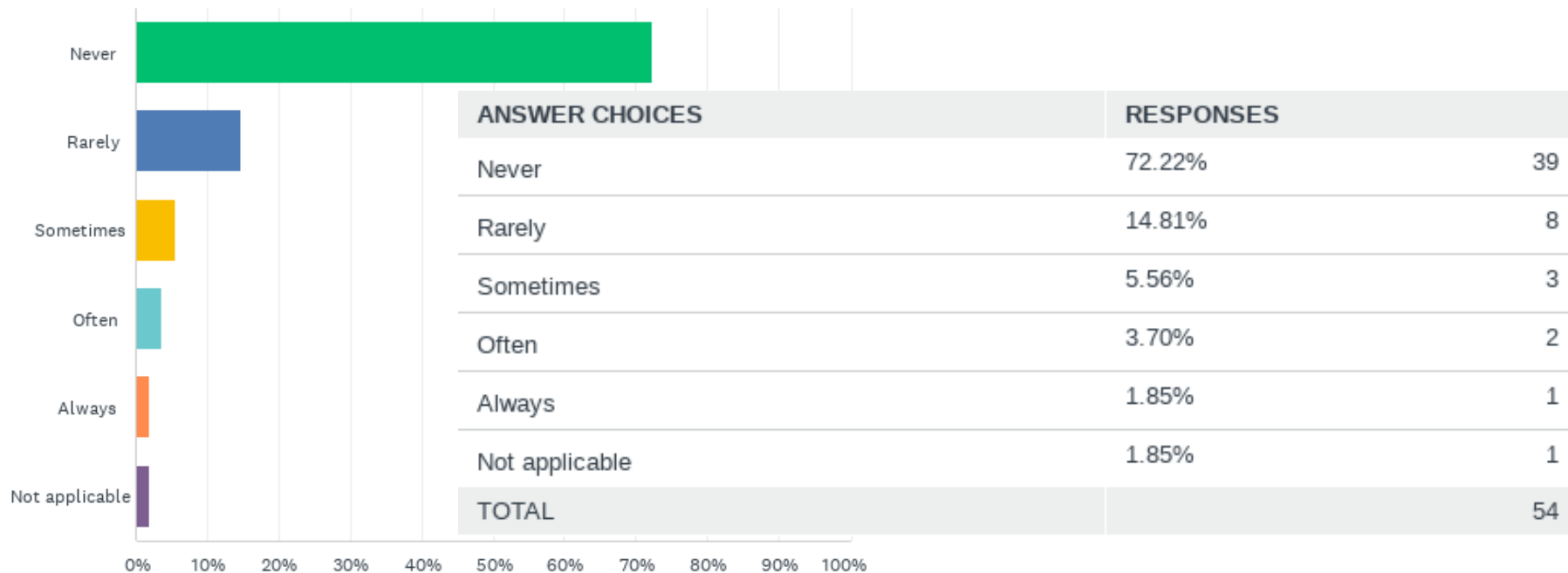
Q7: Because of my illness, people are unkind to me:

Answered: 54 Skipped: 628 skipped 5 with MCI, AD or another dementia



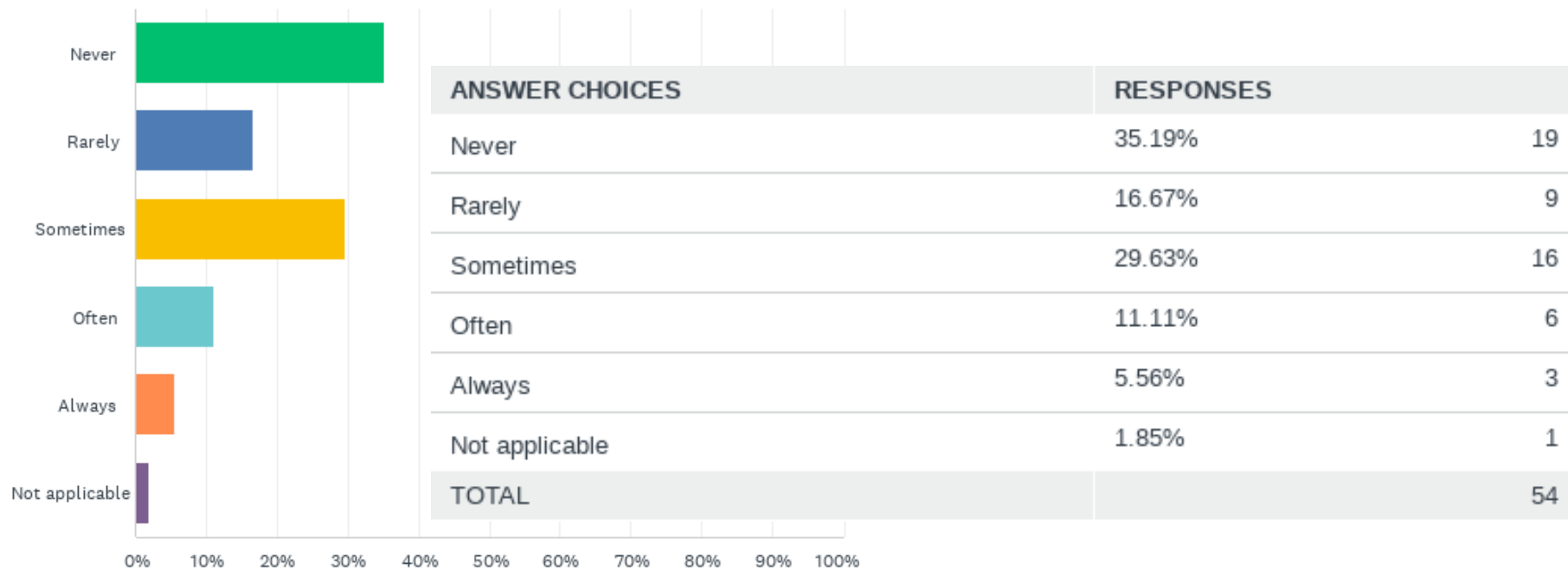
Q8: Because of my illness, people avoid looking at me:

Answered: 54 Skipped: 628 skipped 5 with MCI, AD or another dementia



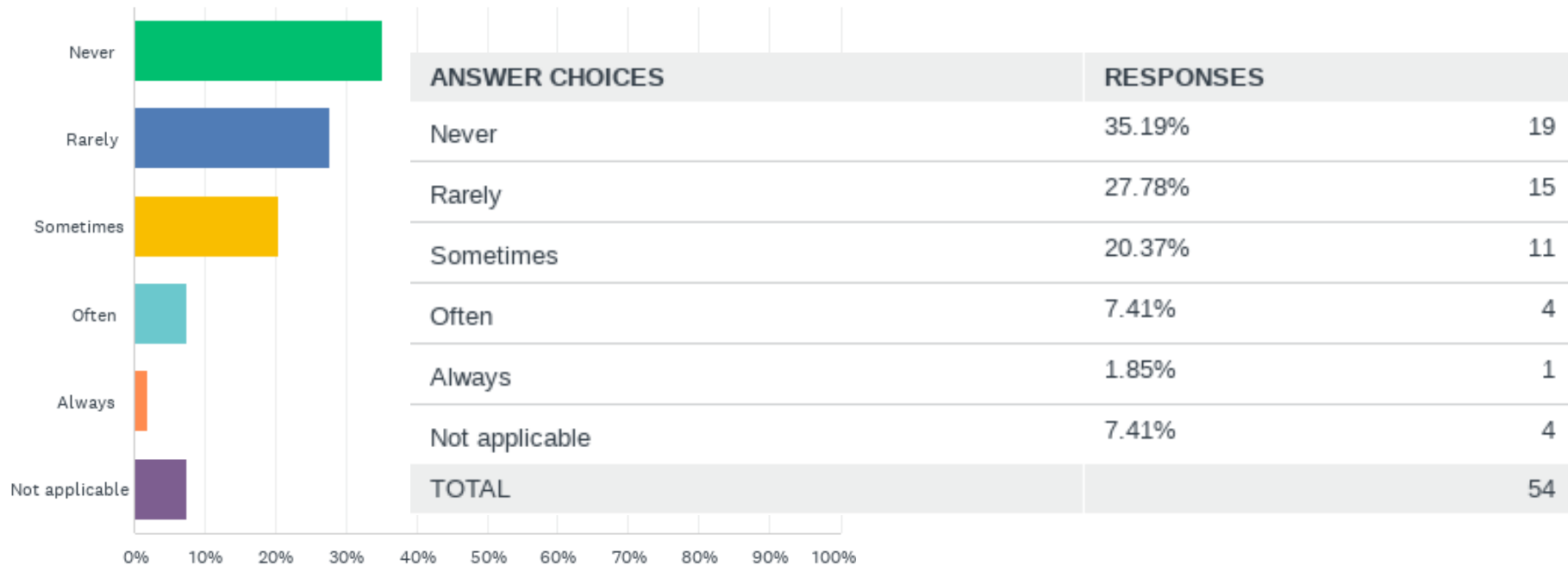
Q9: I feel embarrassed about my illness:

Answered: 54 Skipped: 628 skipped 5 with MCI, AD or another dementia



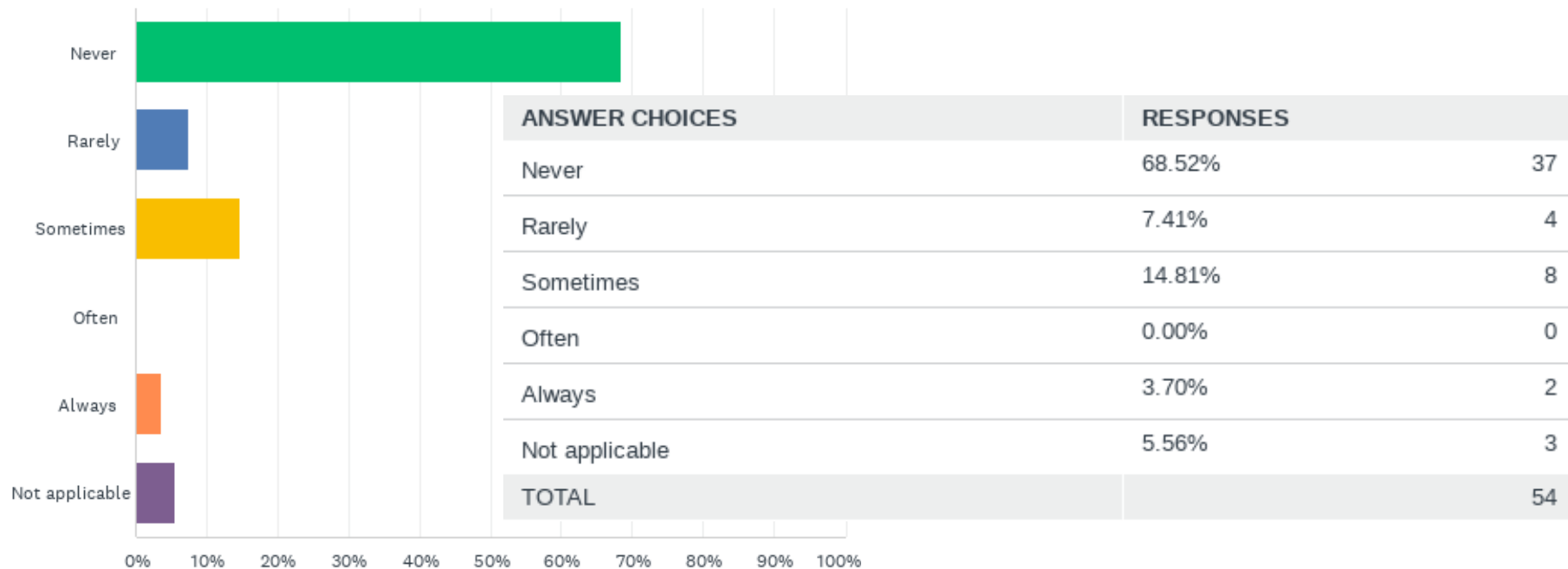
Q10: I feel embarrassed because of my physical limitations:

Answered: 54 Skipped: 628 skipped 5 with MCI, AD or another dementia



Q11: Some people act as though it is my fault I have this illness:

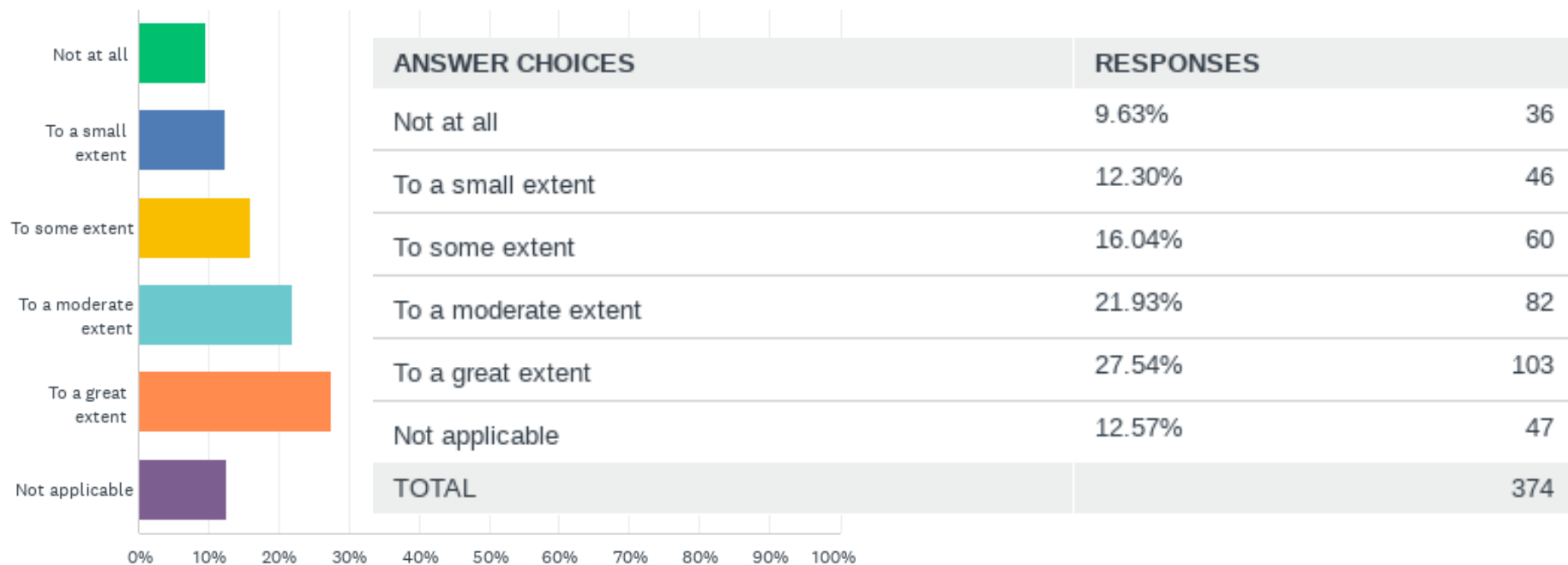
Answered: 54 Skipped: 628 skipped 5 with MCI, AD or another dementia



Current and former caregivers

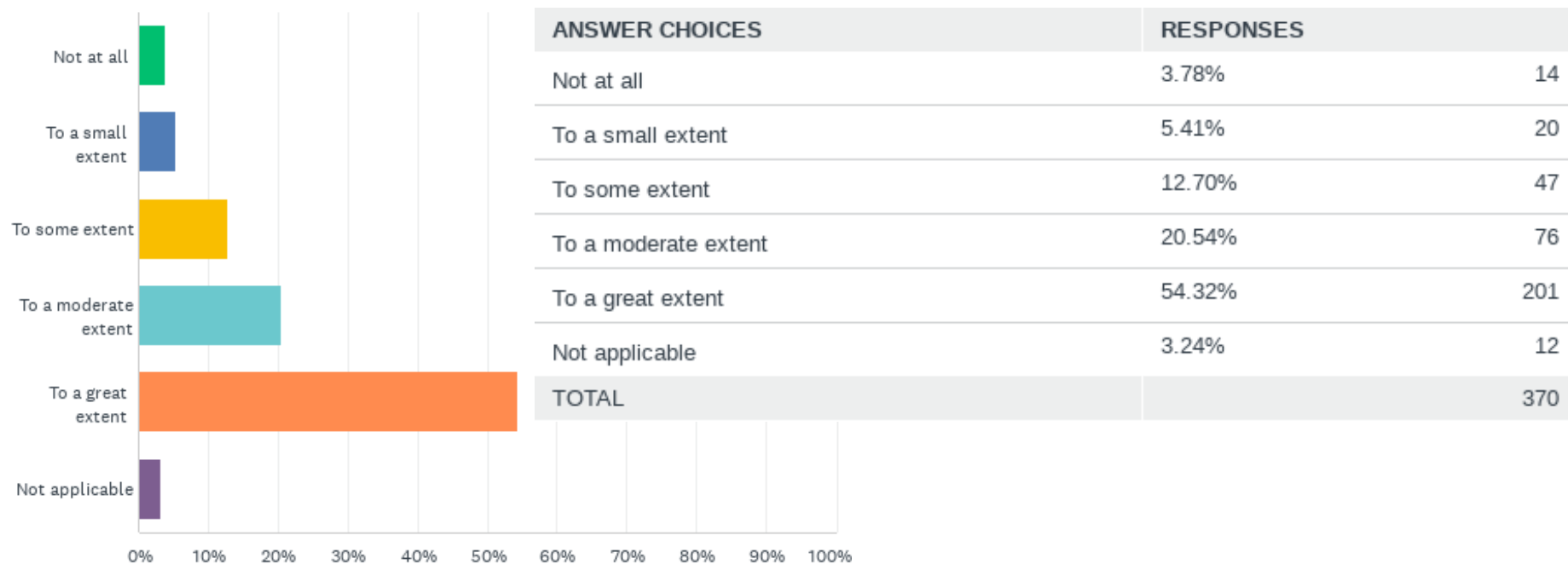
Q12: To what extent do/did you experience a reduction in your social contacts after the diagnosis?

Answered: 374 Skipped: 308, skipped 3 current/former caregivers



Q13: To what extent do/did you experience a reduction in the person's social contacts after the diagnosis?

Answered: 370 Skipped: 312, skipped 7 current/former caregivers



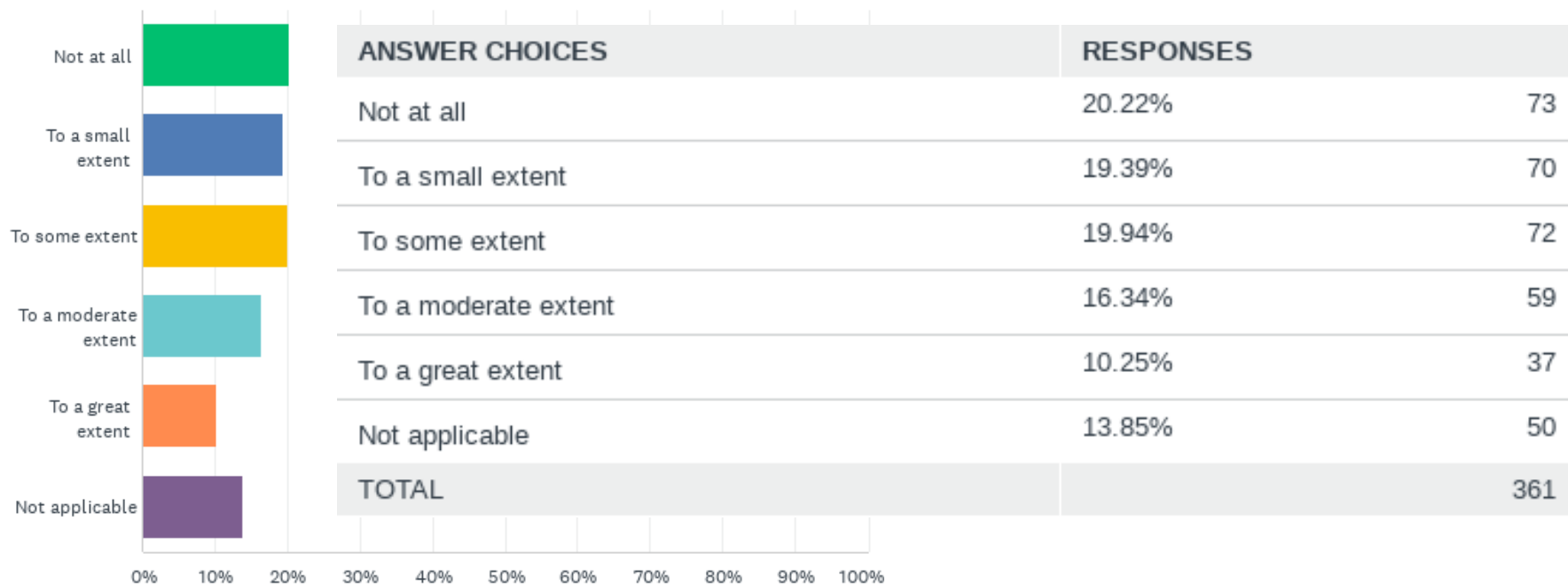
Q14: To what extent do/did you feel that you are treated differently by family members since the diagnosis?

Answered: 368 Skipped: 314, skipped 9 current/former caregivers



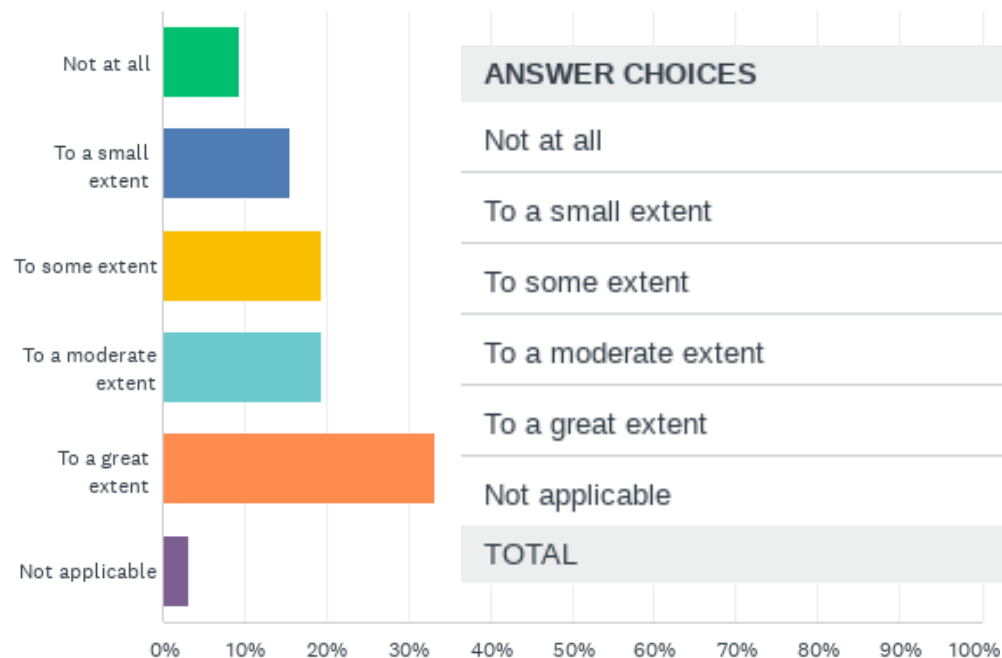
Q15: To what extent do/did you feel that you are treated differently by other persons since the diagnosis?

Answered: 361 Skipped: 321, skipped 17 current/former caregivers



Q16: To what extent do/did you feel that the person is treated differently by family members since the diagnosis?

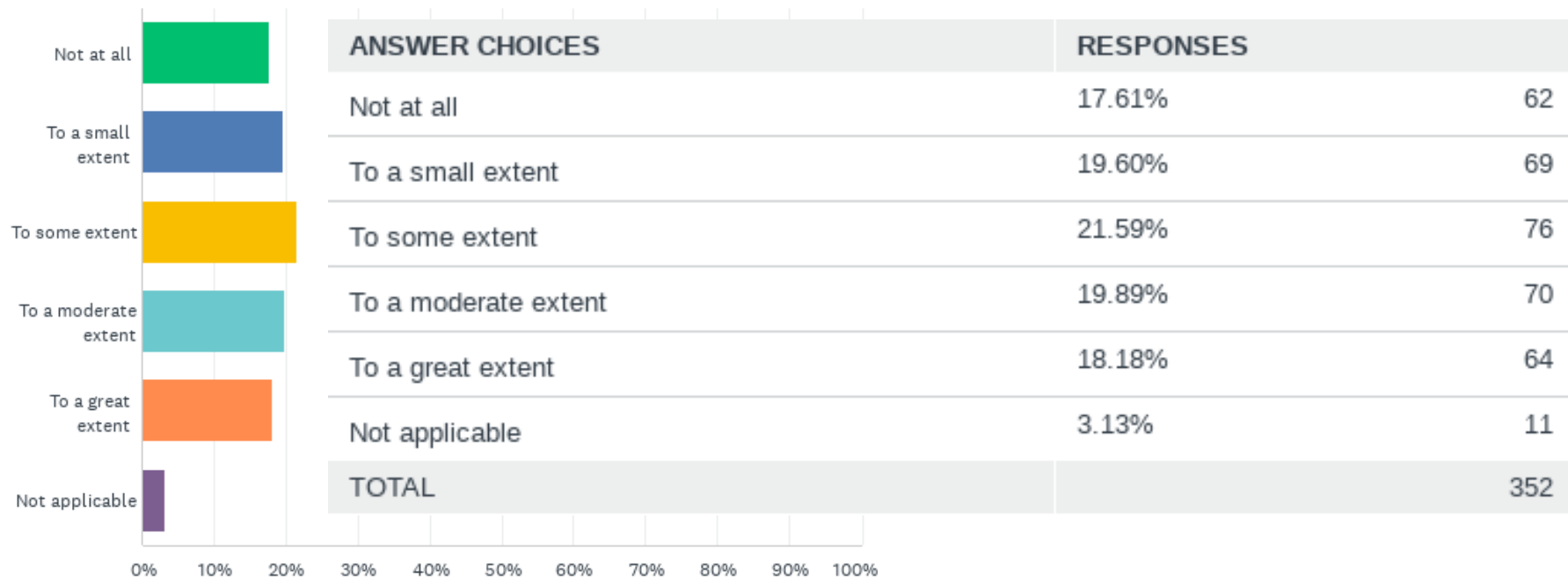
Answered: 355 Skipped: 327, skipped 23 current/former caregivers



ANSWER CHOICES	RESPONSES
Not at all	9.30% 33
To a small extent	15.49% 55
To some extent	19.44% 69
To a moderate extent	19.44% 69
To a great extent	33.24% 118
Not applicable	3.10% 11
TOTAL	355

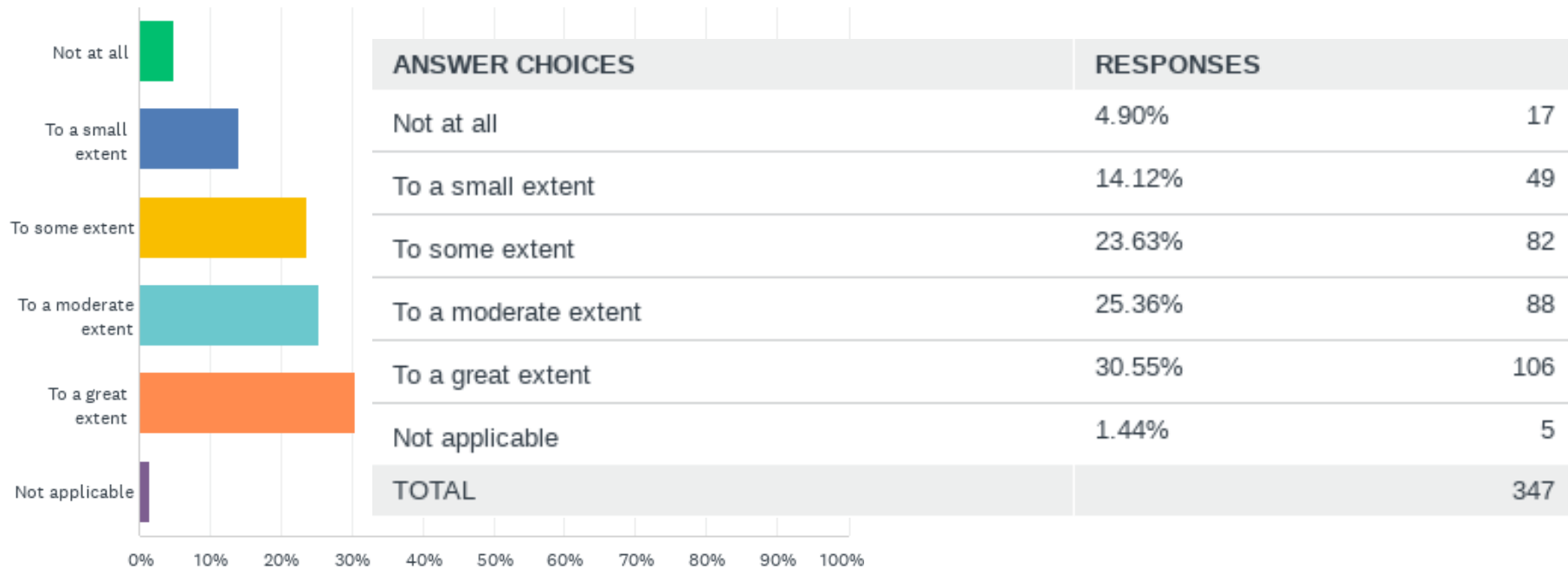
Q17: To what extent do/did you feel that the person is treated differently by health professionals since the diagnosis?

Answered: 352 Skipped: 330, skipped 26 current/former caregivers



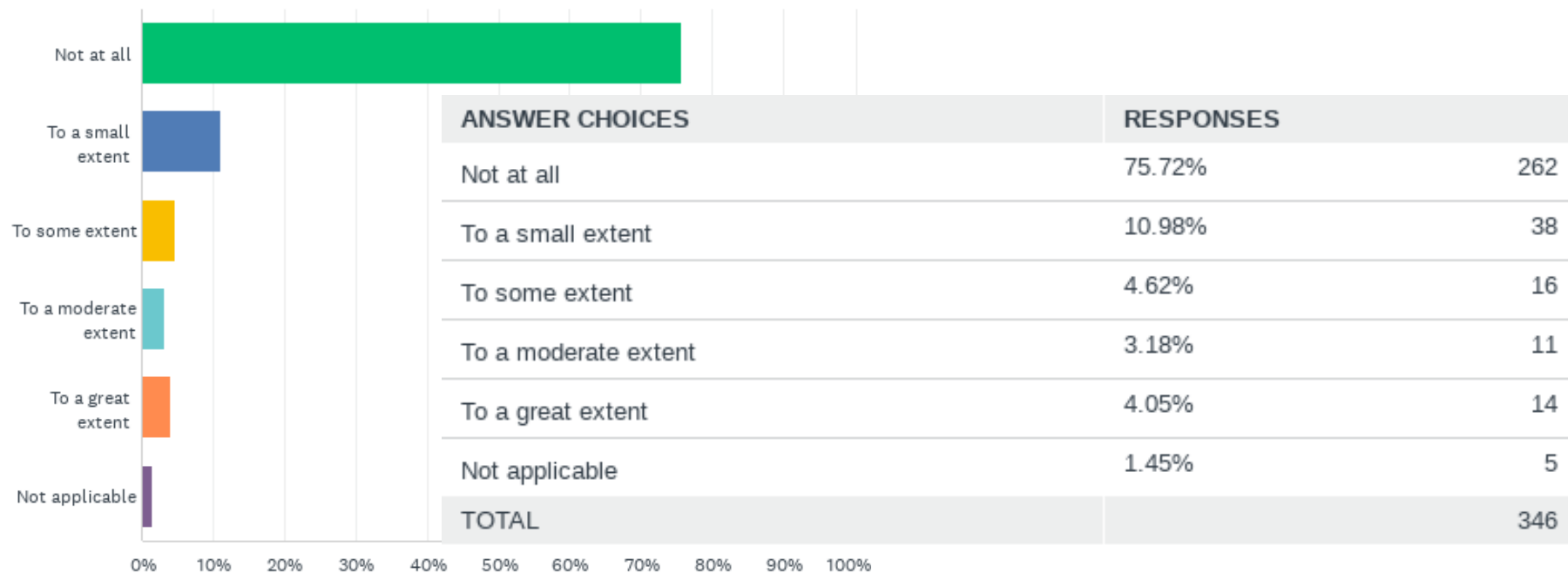
Q18: To what extent do/did you feel that the person is treated differently by other persons since the diagnosis?

Answered: 347 Skipped: 335, skipped 31 current/former caregivers



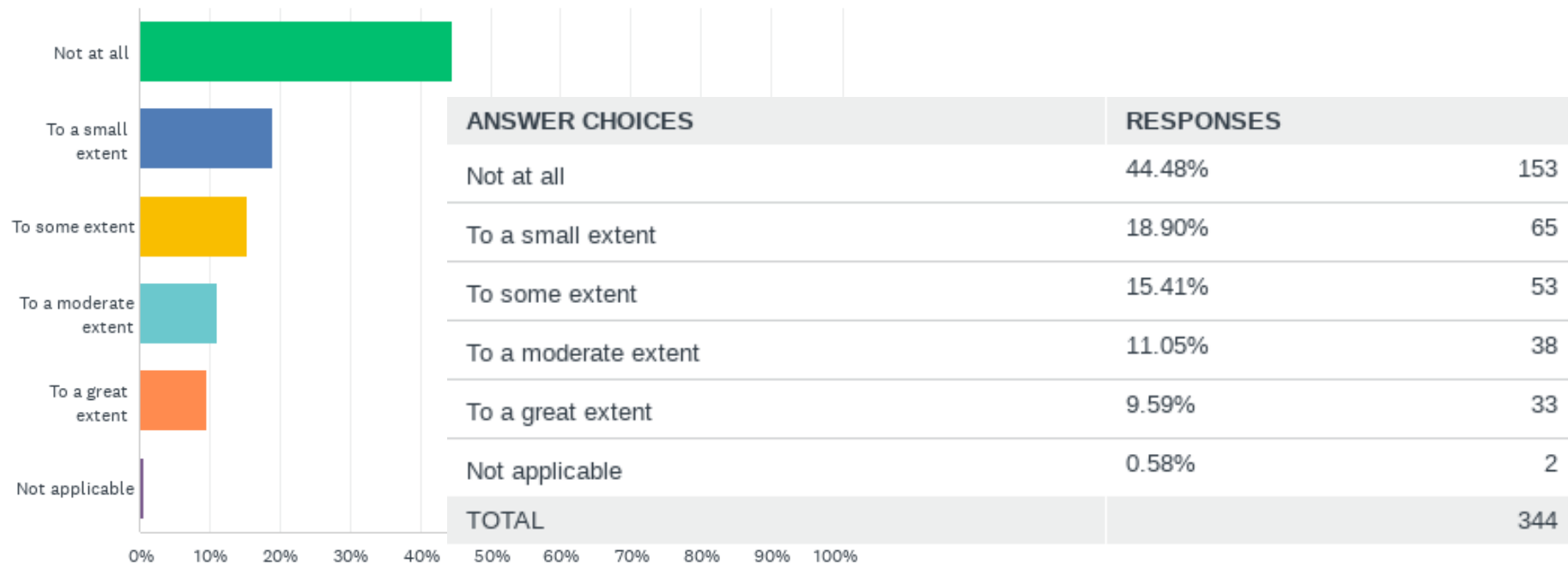
Q19: To what extent do/did you fear that other people will blame you for the person's situation?

Answered: 346 Skipped: 336, skipped 32 current/former caregivers



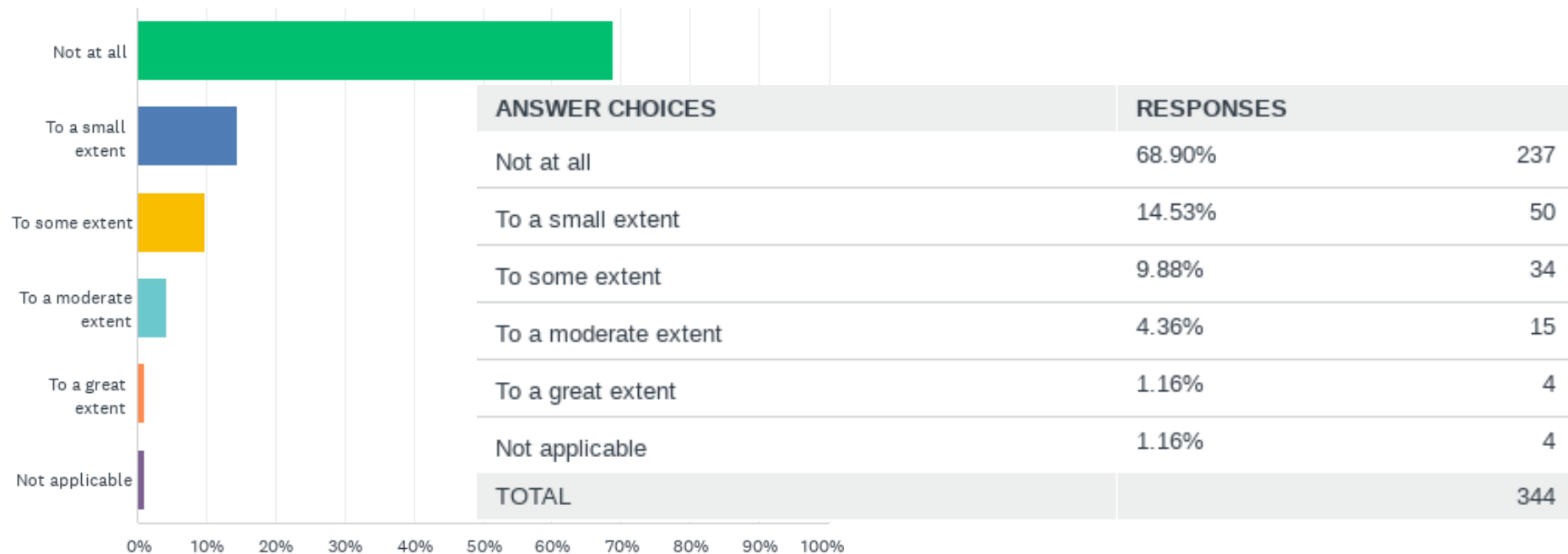
Q20: To what extent do/did you feel guilty about the person's situation?

Answered: 344 Skipped: 338, skipped 34 current/former caregivers



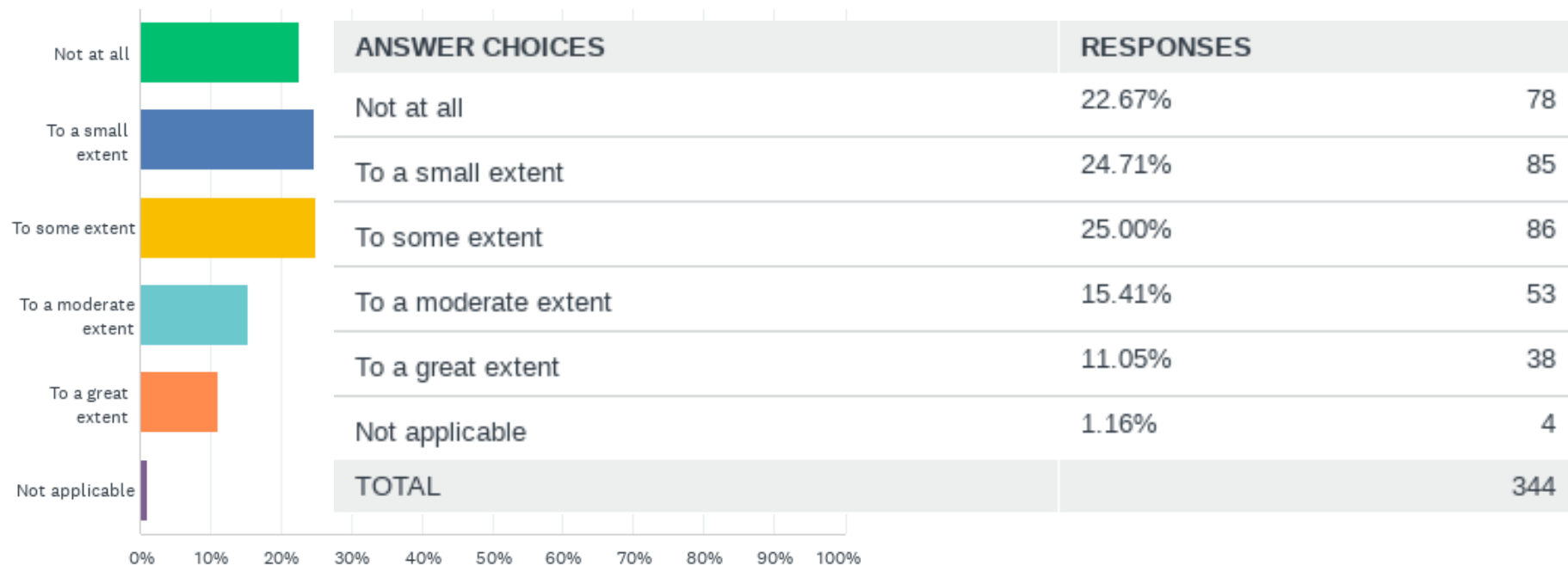
Q21: To what extent do/did you try to hide the person with Alzheimer's disease or another dementia?

Answered: 344 Skipped: 338, skipped 34 current/former caregivers



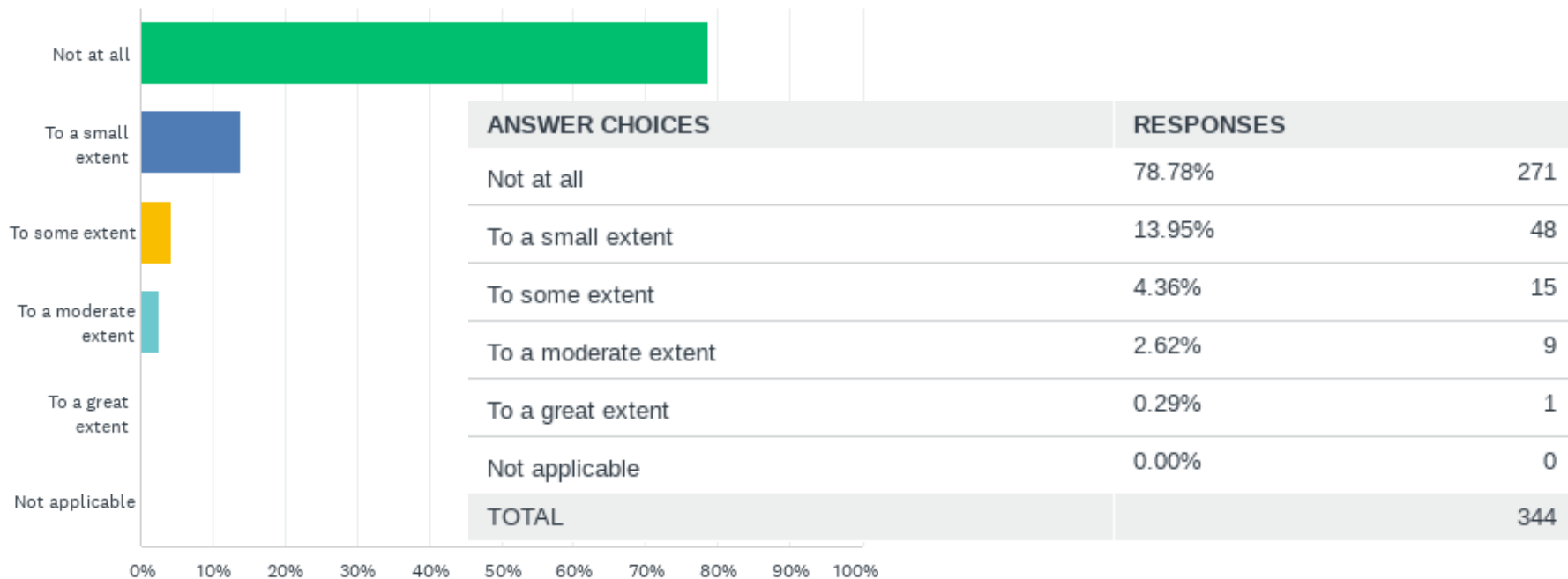
Q22: To what extent are/were you afraid of taking the person with Alzheimer's disease or another dementia outside the home?

Answered: 344 Skipped: 338, skipped 34 current/former caregivers



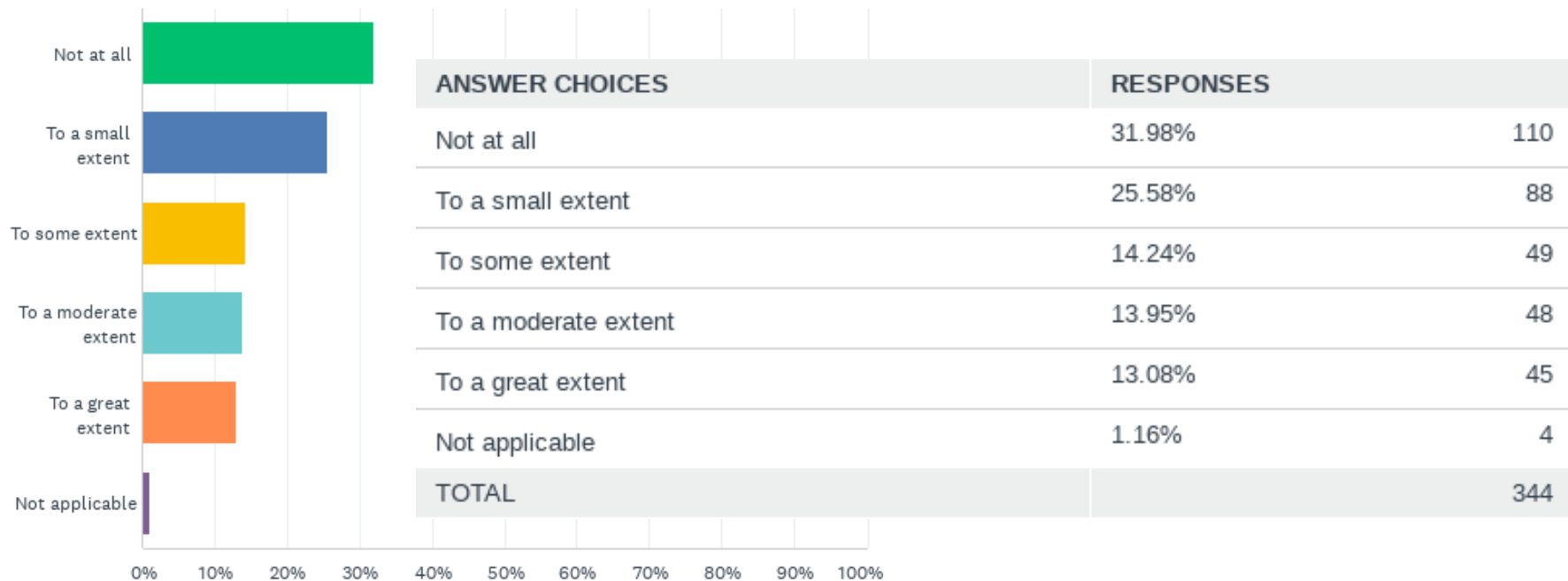
Q23: To what extent are/were you ashamed of the person with Alzheimer's disease or another dementia?

Answered: 344 Skipped: 338, skipped 34 current/former caregivers



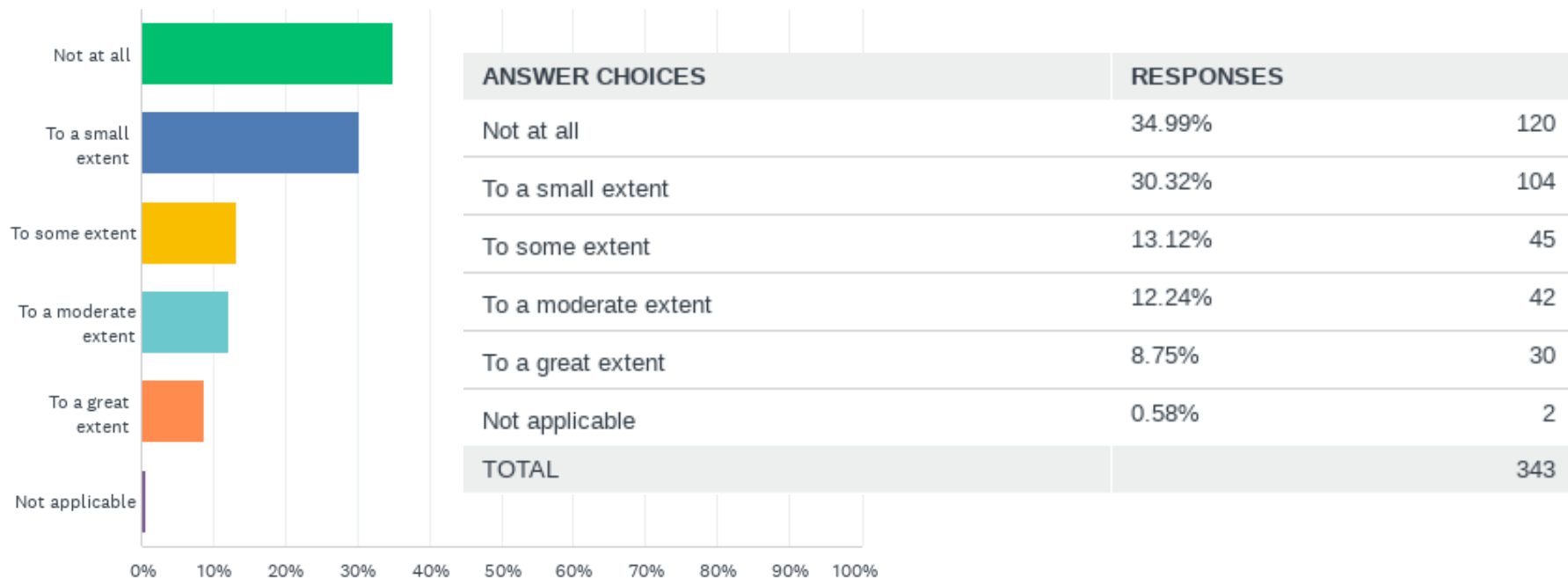
Q24: To what extent do/did you feel that there are enough services for people with Alzheimer's disease or another dementia?

Answered: 344 Skipped: 338, skipped 34 current/former caregivers



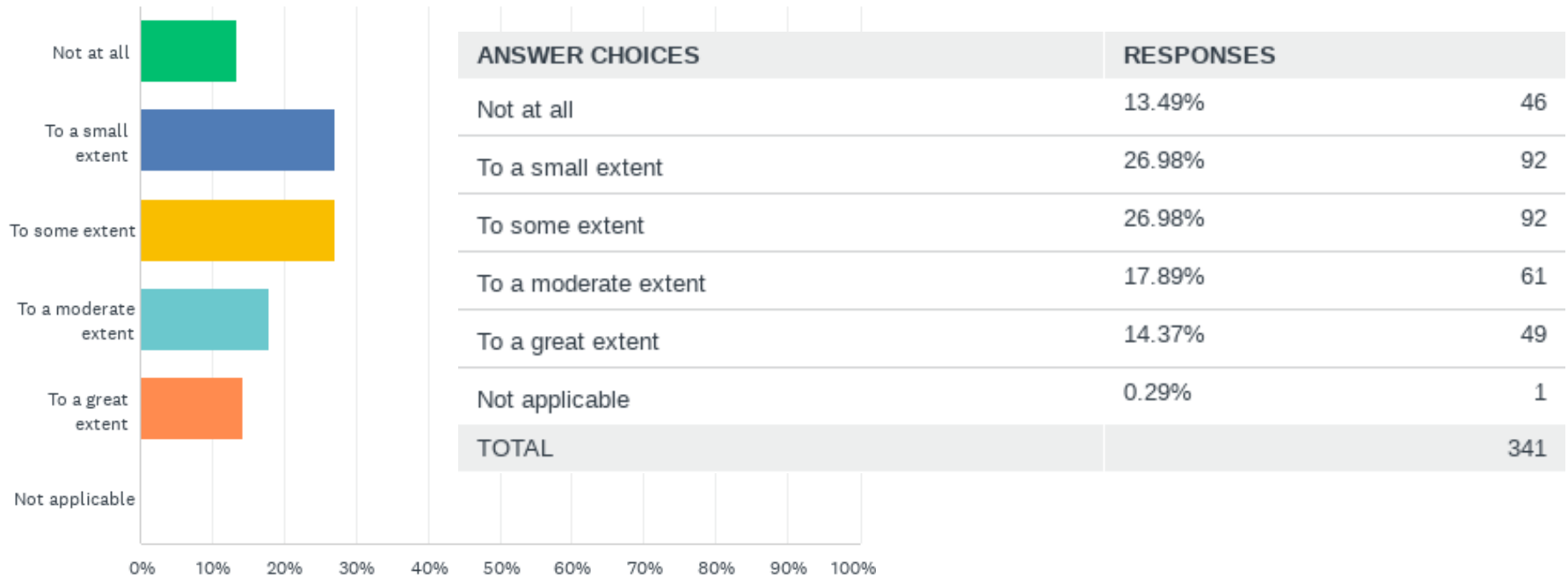
Q25: To what extent do/did you feel that there are enough services for caregivers of persons with Alzheimer's disease or another dementia?

Answered: 343 Skipped: 339, skipped 35 current/former caregivers



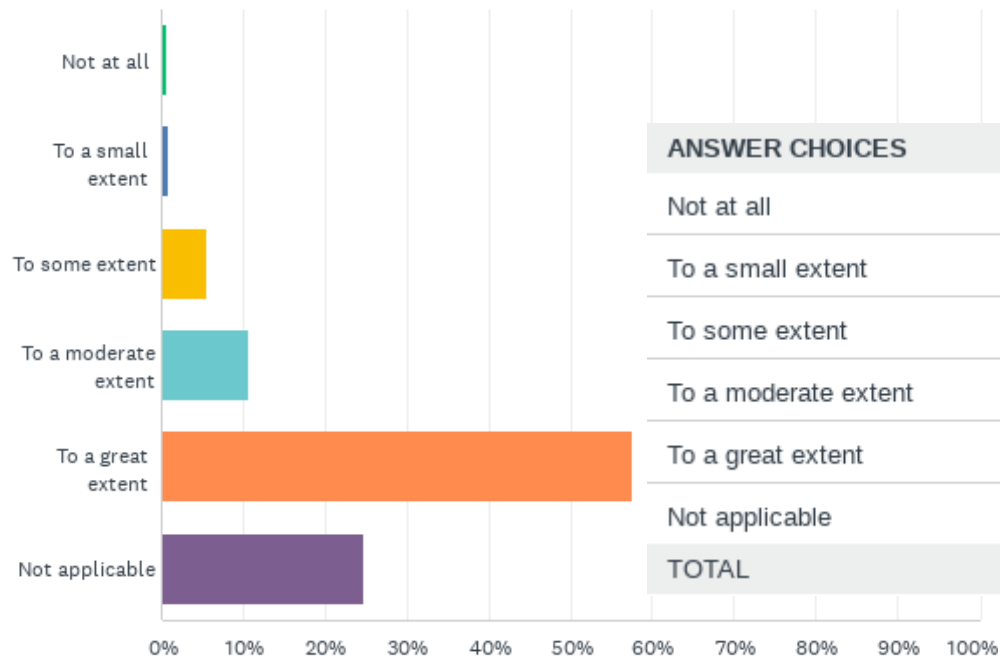
Q26: To what extent do/did you feel that there are enough sources of information for persons with Alzheimer's disease or another dementia and their caregivers?

Answered: 341 Skipped: 341, skipped 37 current/former caregivers



Q27: To what extent do/did you think that the diagnosis will/did affect the person functioning as a spouse?

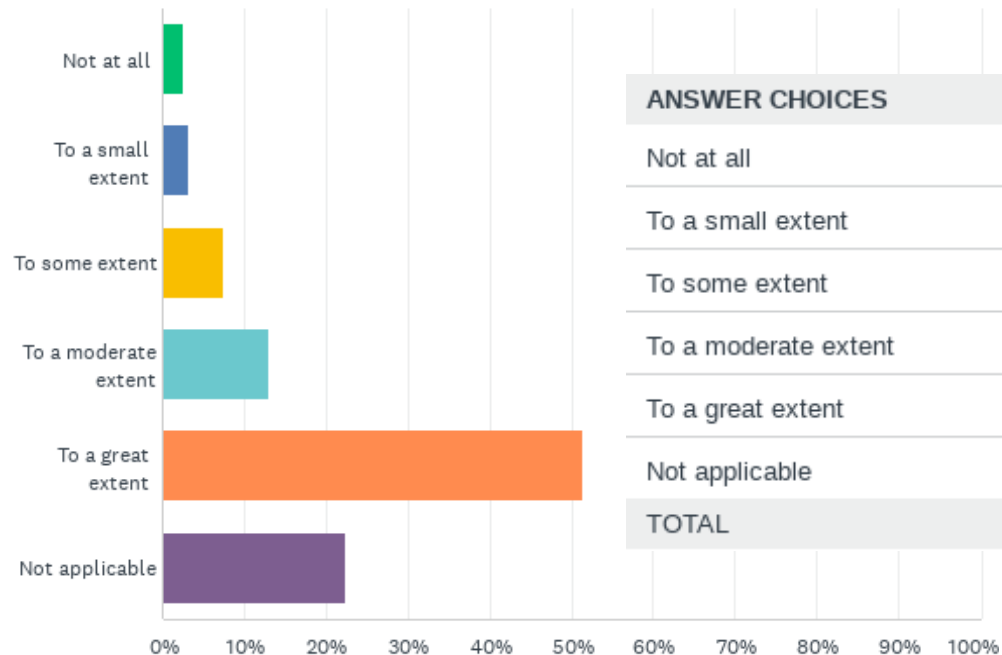
Answered: 339 Skipped: 343, skipped 39 current/former caregivers



ANSWER CHOICES	RESPONSES
Not at all	0.59% 2
To a small extent	0.88% 3
To some extent	5.60% 19
To a moderate extent	10.62% 36
To a great extent	57.52% 195
Not applicable	24.78% 84
TOTAL	339

Q28: To what extent do/did you think that the diagnosis will/did affect the person(s) functioning as a parent?

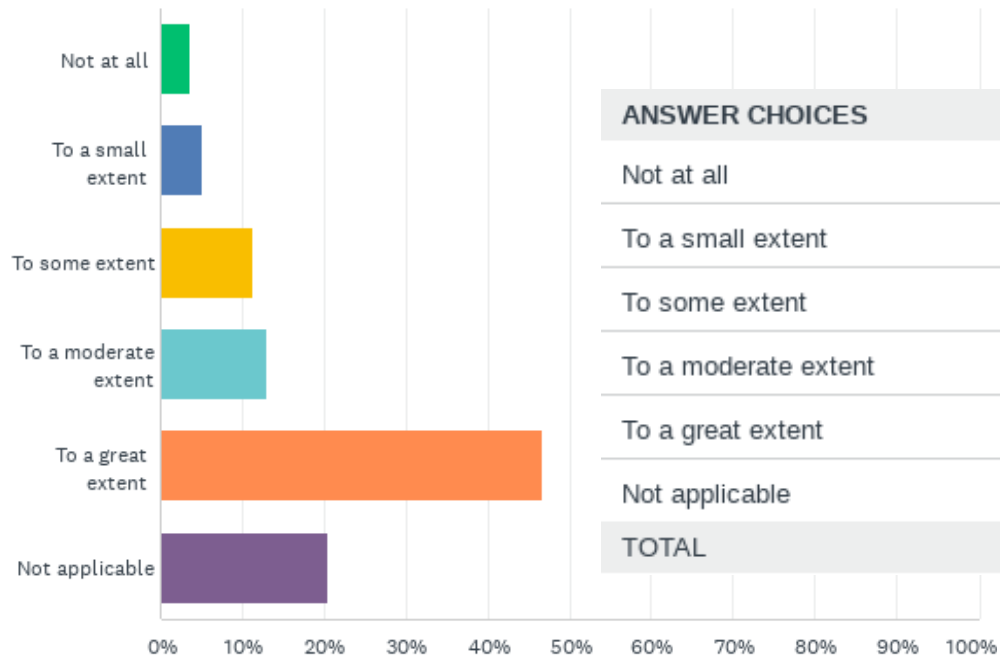
Answered: 339 Skipped: 343, skipped 39 current/former caregivers



ANSWER CHOICES	RESPONSES
Not at all	2.65% 9
To a small extent	3.24% 11
To some extent	7.37% 25
To a moderate extent	12.98% 44
To a great extent	51.33% 174
Not applicable	22.42% 76
TOTAL	339

Q29: To what extent do/did you think that the diagnosis will/did affect the person(s) functioning as a grandparent?

Answered: 338 Skipped: 344, skipped 40 current/former caregivers

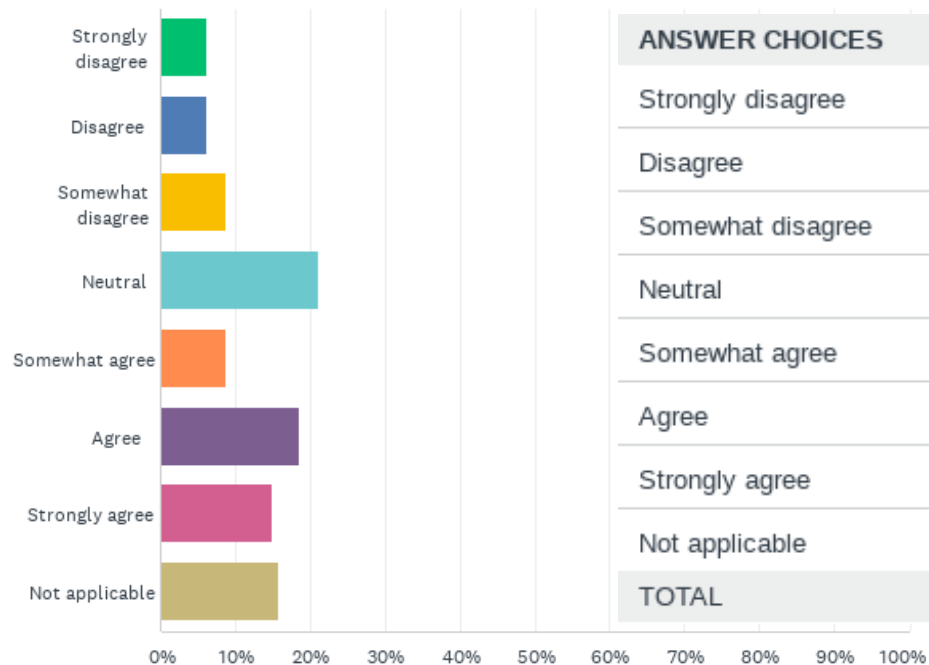


ANSWER CHOICES	RESPONSES
Not at all	3.55% 12
To a small extent	5.03% 17
To some extent	11.24% 38
To a moderate extent	13.02% 44
To a great extent	46.75% 158
Not applicable	20.41% 69
TOTAL	338

Interested in brain health/at risk (not diagnosed or caregiver)

Q30: It is rewarding to work with people with dementia:

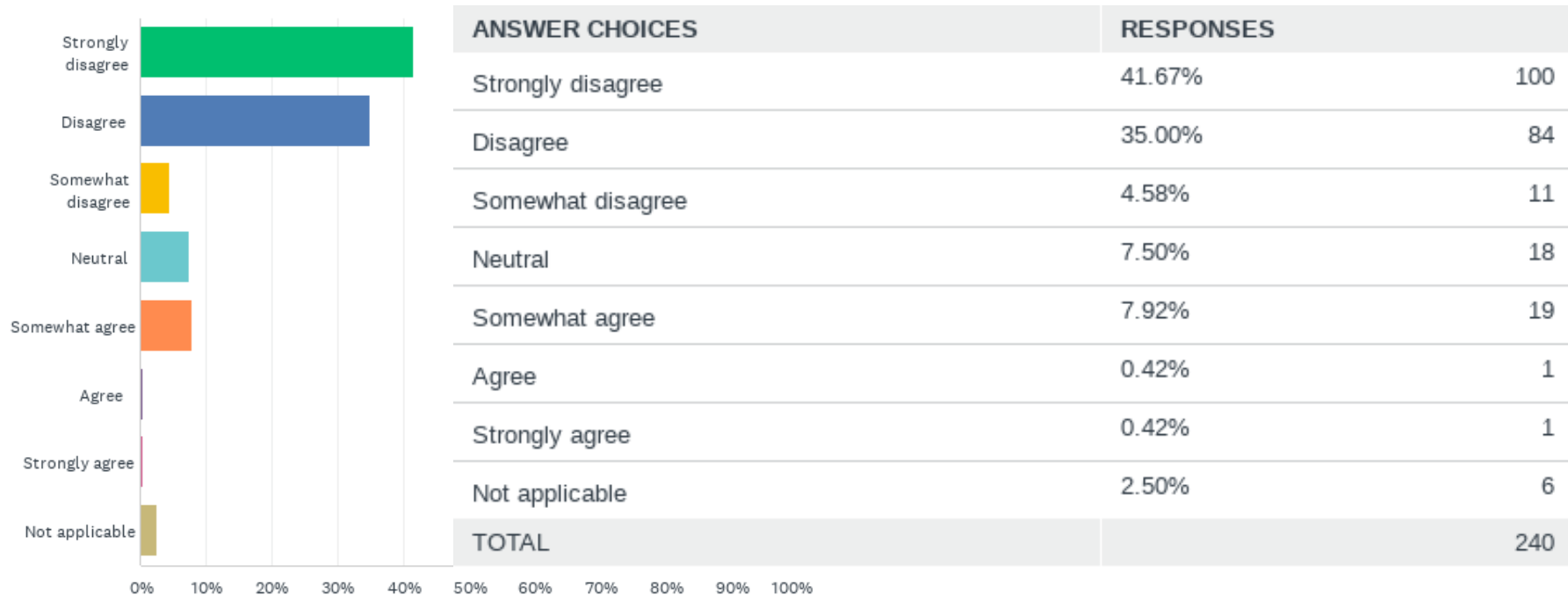
Answered: 242 Skipped: 440, skipped 4 interested in brain health/at risk



ANSWER CHOICES	RESPONSES
Strongly disagree	6.20% 15
Disagree	6.20% 15
Somewhat disagree	8.68% 21
Neutral	21.07% 51
Somewhat agree	8.68% 21
Agree	18.60% 45
Strongly agree	14.88% 36
Not applicable	15.70% 38
TOTAL	242

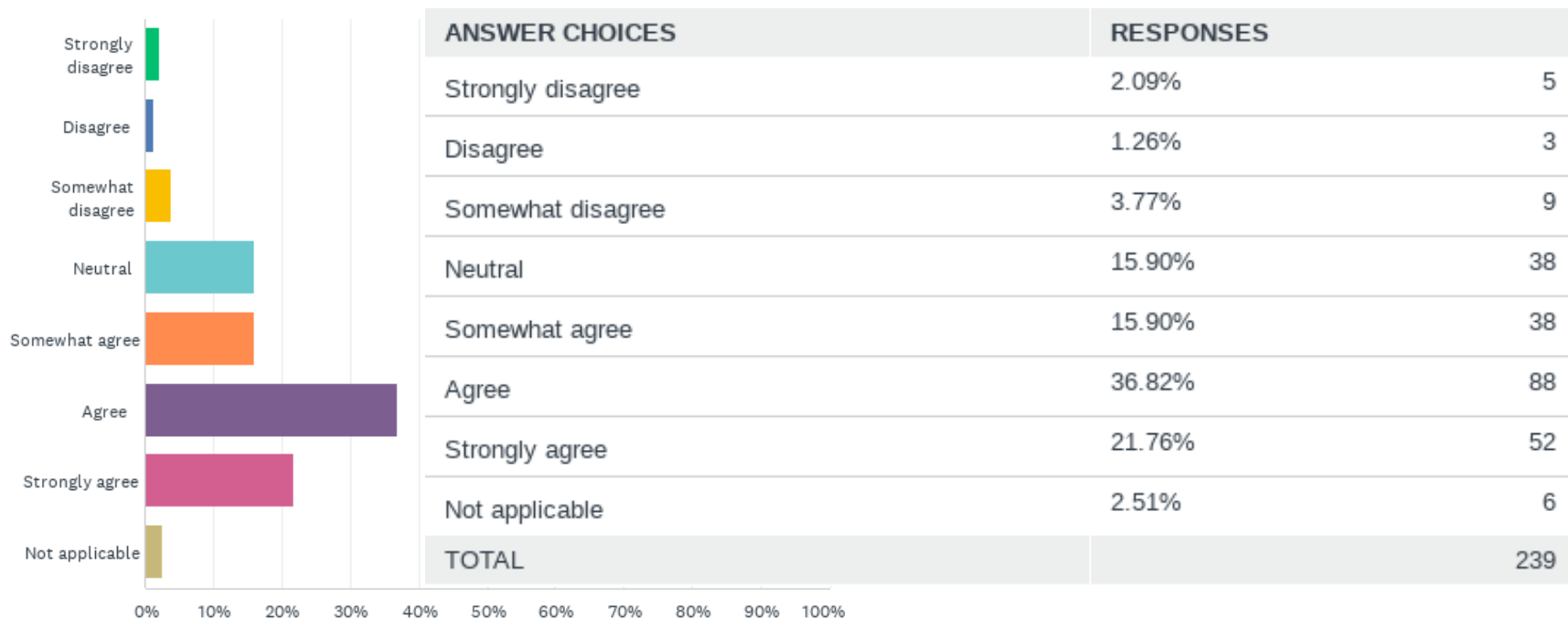
Q31: I am afraid of people with dementia:

Answered: 240 Skipped: 442, skipped 6 interested in brain health/at risk



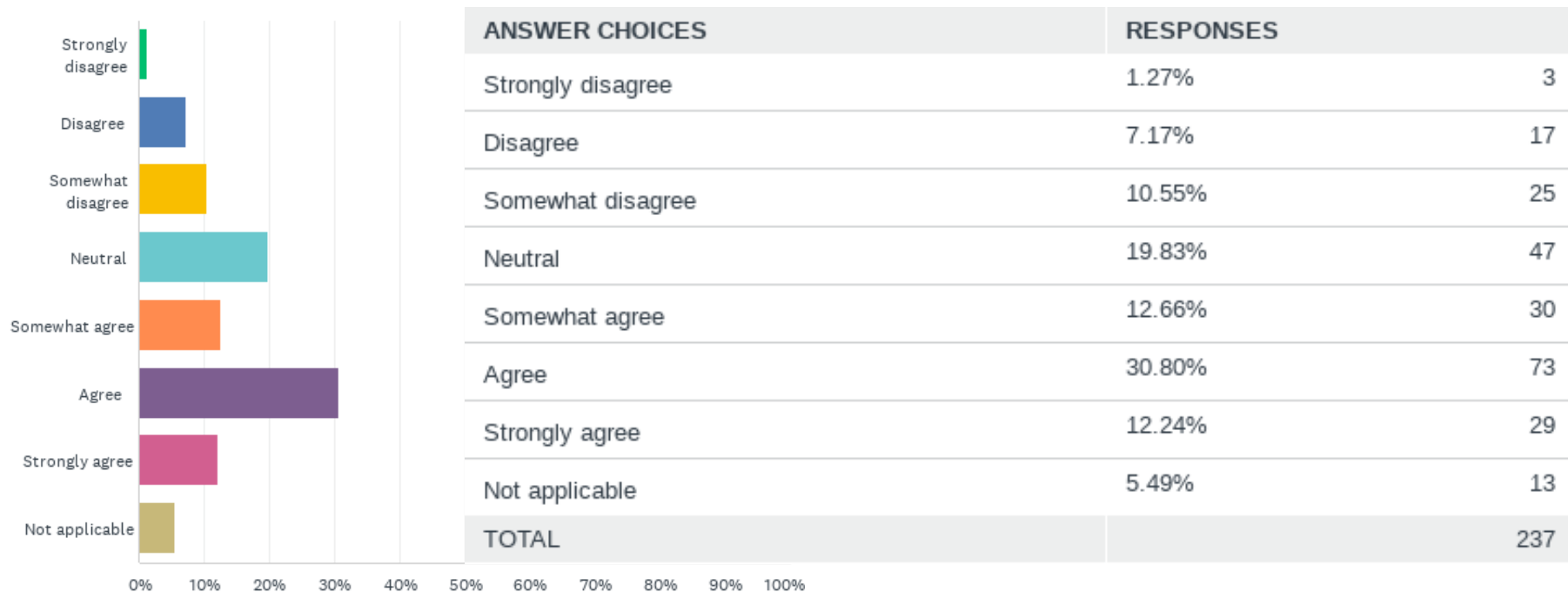
Q32: People with dementia can be creative:

Answered: 239 Skipped: 443, skipped 7 interested in brain health/at risk



Q33: I feel confident around people with dementia:

Answered: 237 Skipped: 445, skipped 9 interested in brain health/at risk



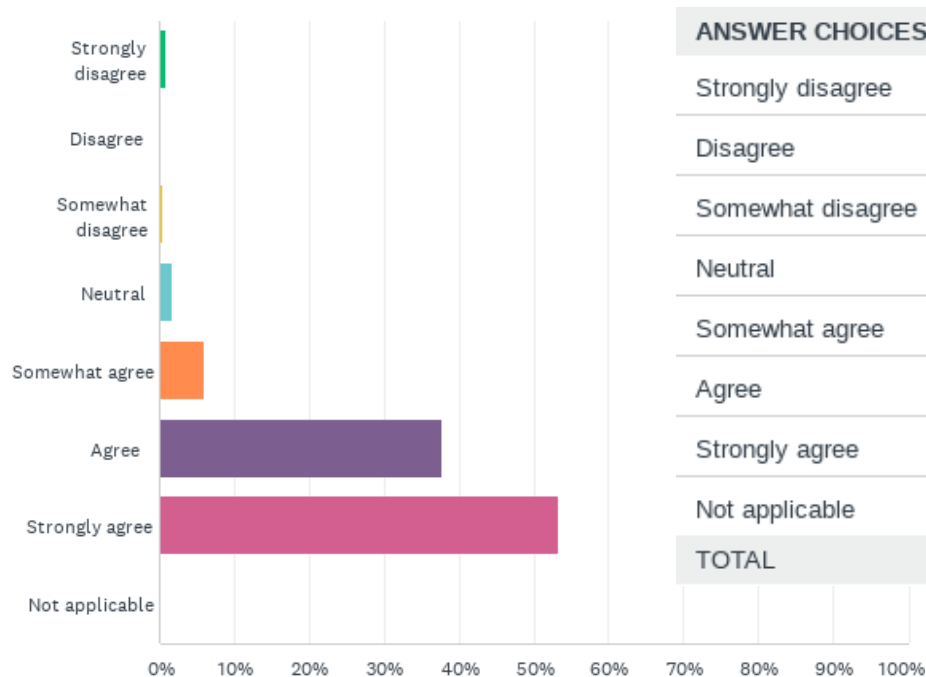
Q34: I feel comfortable around people with dementia:

Answered: 234 Skipped: 448, skipped 12 interested in brain health/at risk



Q35: Every person with dementia has different needs:

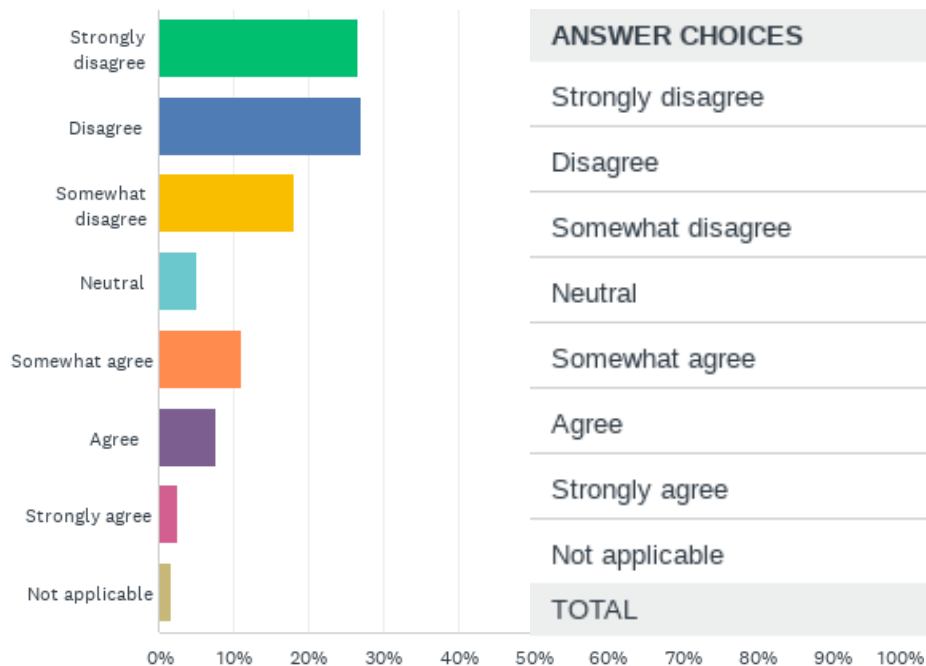
Answered: 233 Skipped: 449, skipped 13 interested in brain health/at risk



ANSWER CHOICES	RESPONSES
Strongly disagree	0.86% 2
Disagree	0.00% 0
Somewhat disagree	0.43% 1
Neutral	1.72% 4
Somewhat agree	6.01% 14
Agree	37.77% 88
Strongly agree	53.22% 124
Not applicable	0.00% 0
TOTAL	233

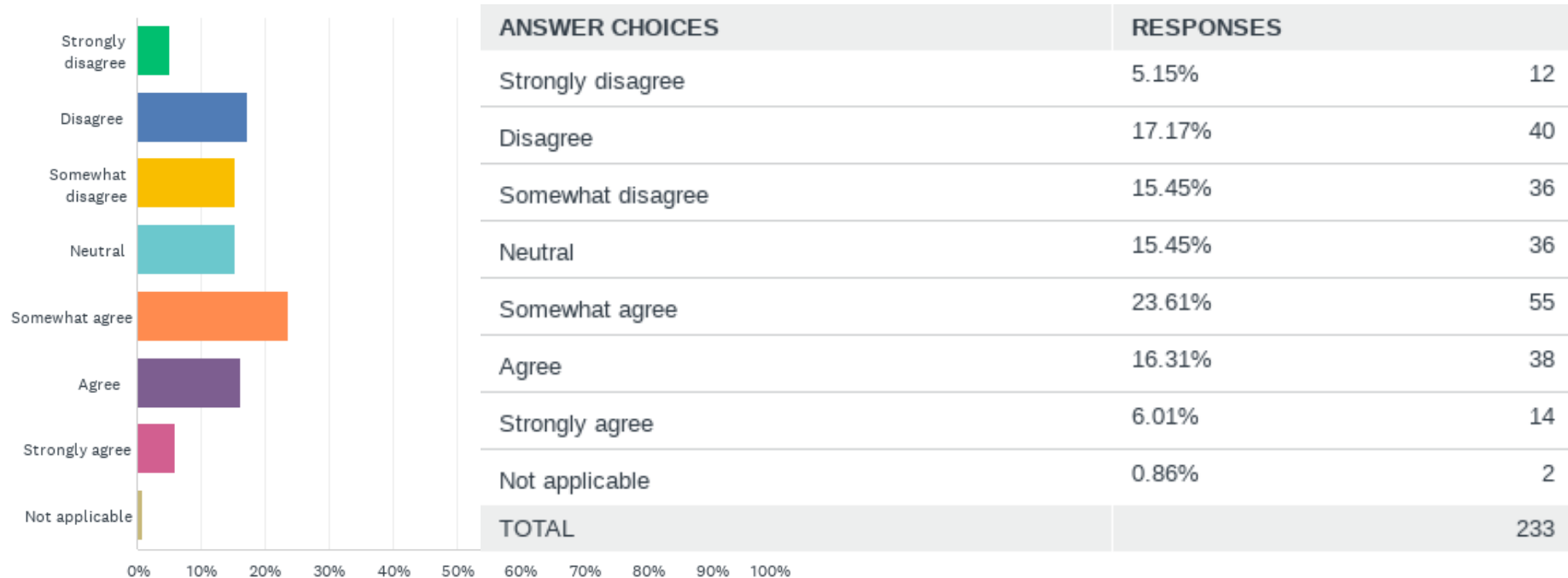
Q36: I am not very familiar with dementia:

Answered: 233 Skipped: 449 , skipped 13 interested in brain health/at risk



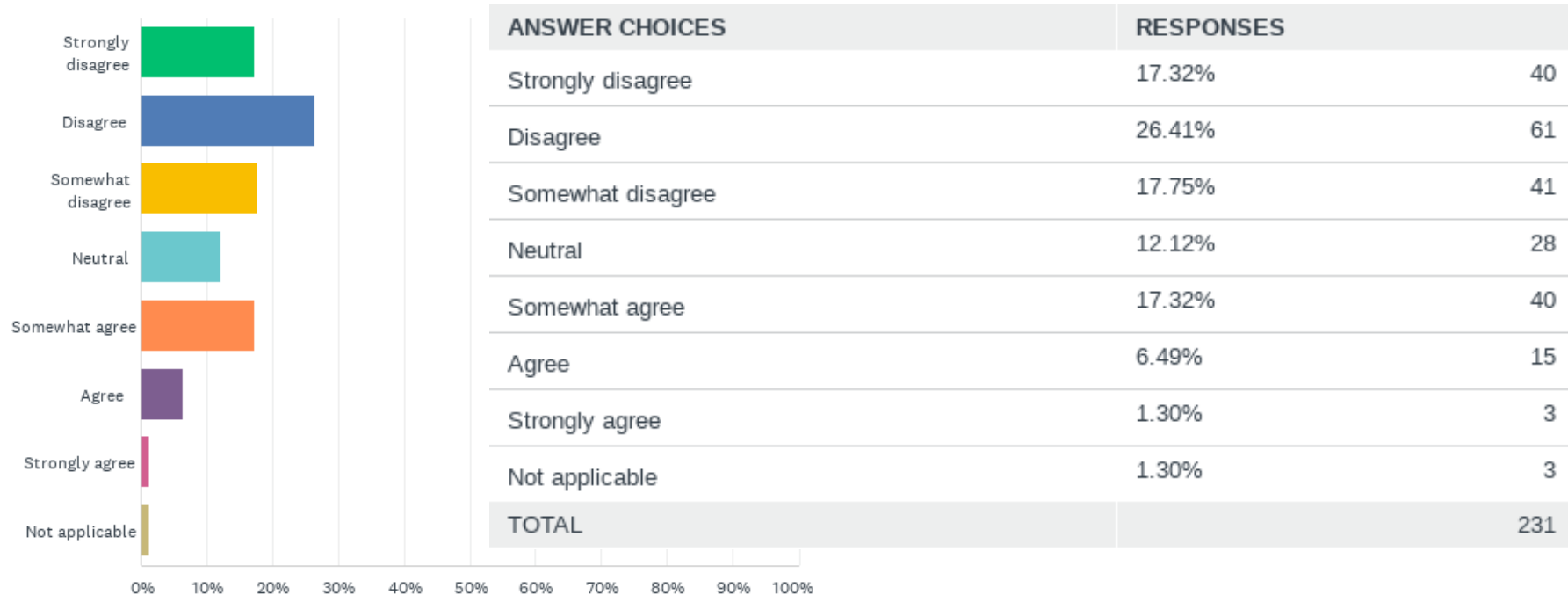
Q37: I would avoid an agitated person with dementia:

Answered: 233 Skipped: 449, skipped 13 interested in brain health/at risk



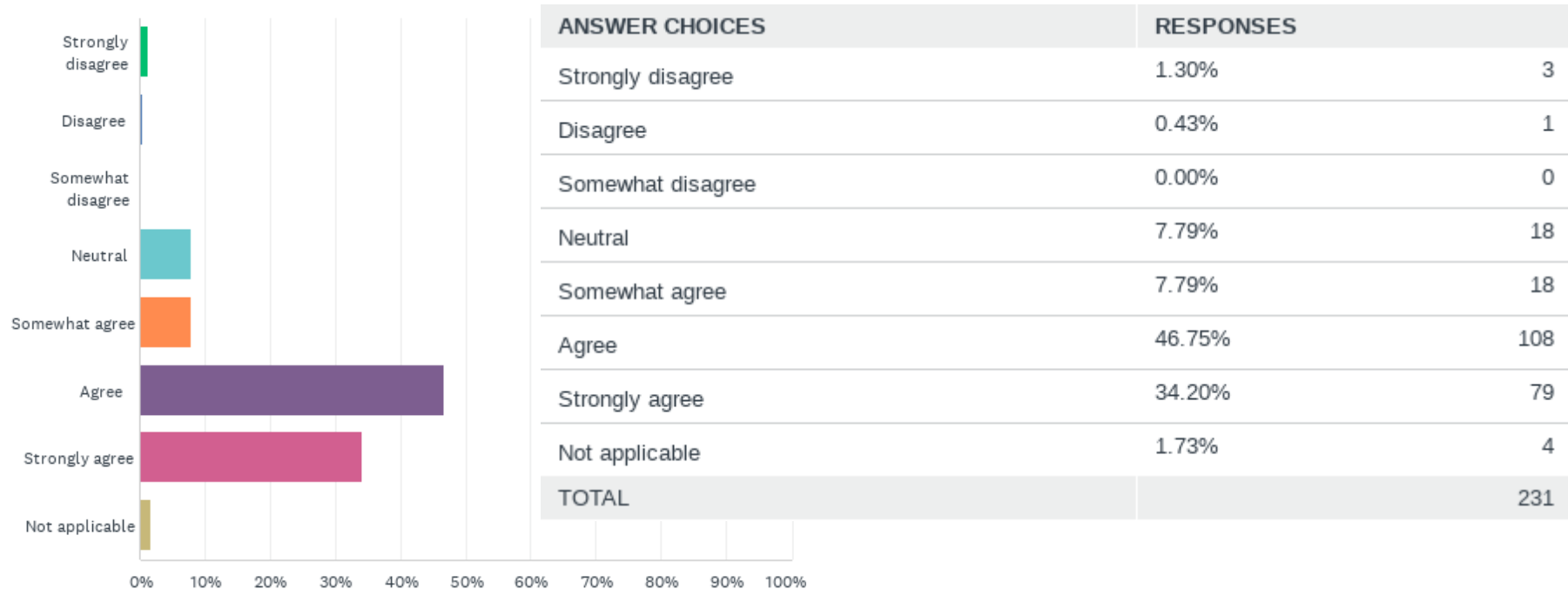
Q38: I am uncomfortable being around people with dementia:

Answered: 231 Skipped: 451, skipped 15 interested in brain health/at risk



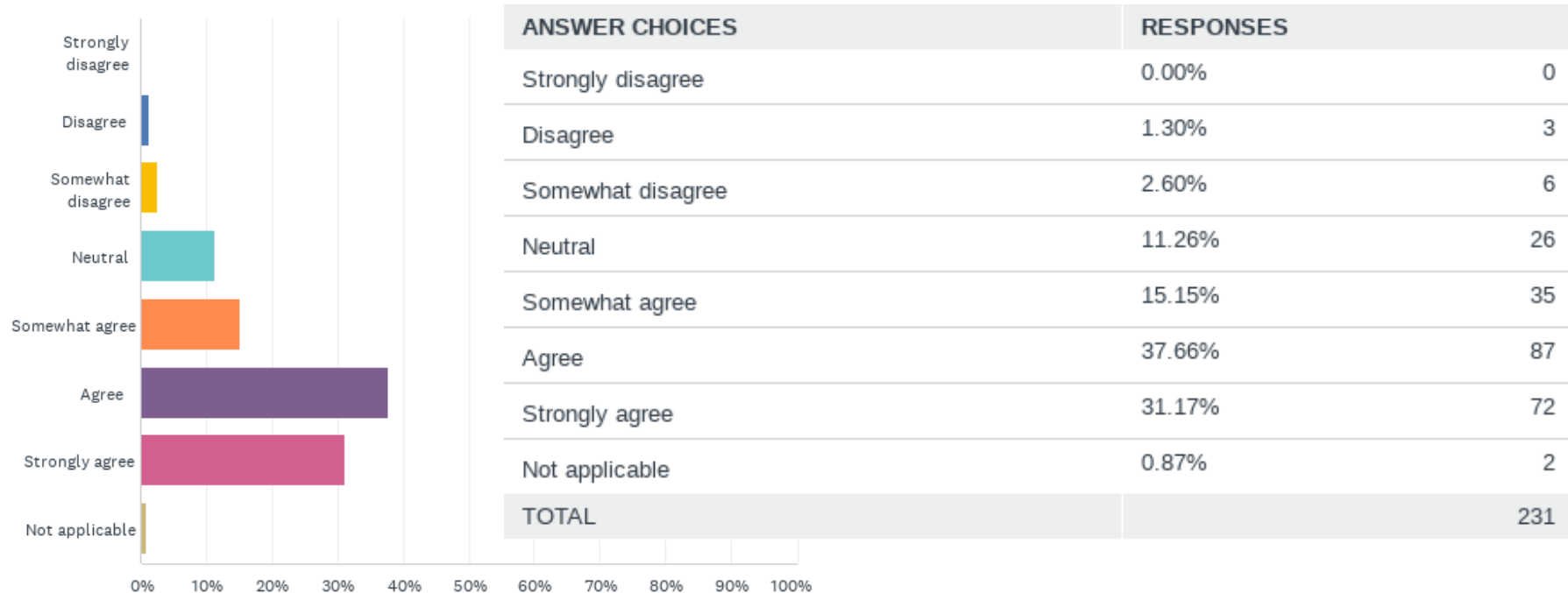
Q39: People with dementia like familiar things nearby:

Answered: 231 Skipped: 451, skipped 15 interested in brain health/at risk



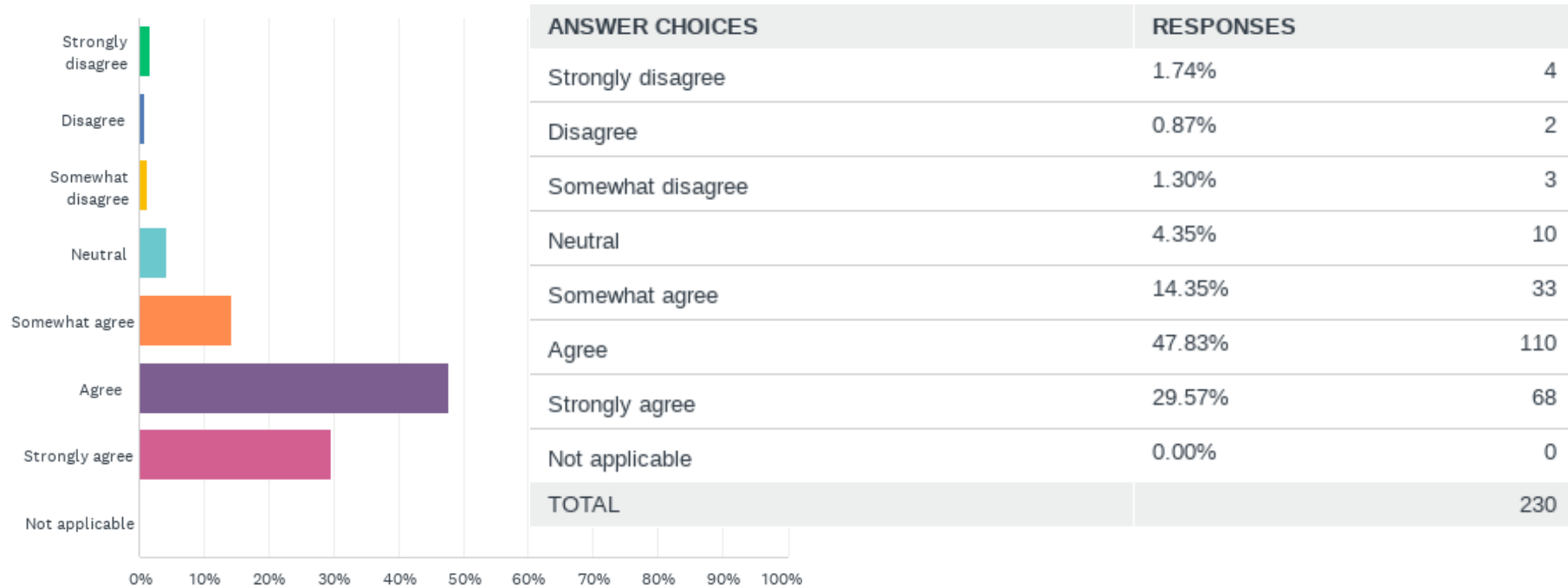
Q40: It is important to know the past history of people with dementia:

Answered: 231 Skipped: 451, skipped 15 interested in brain health/at risk



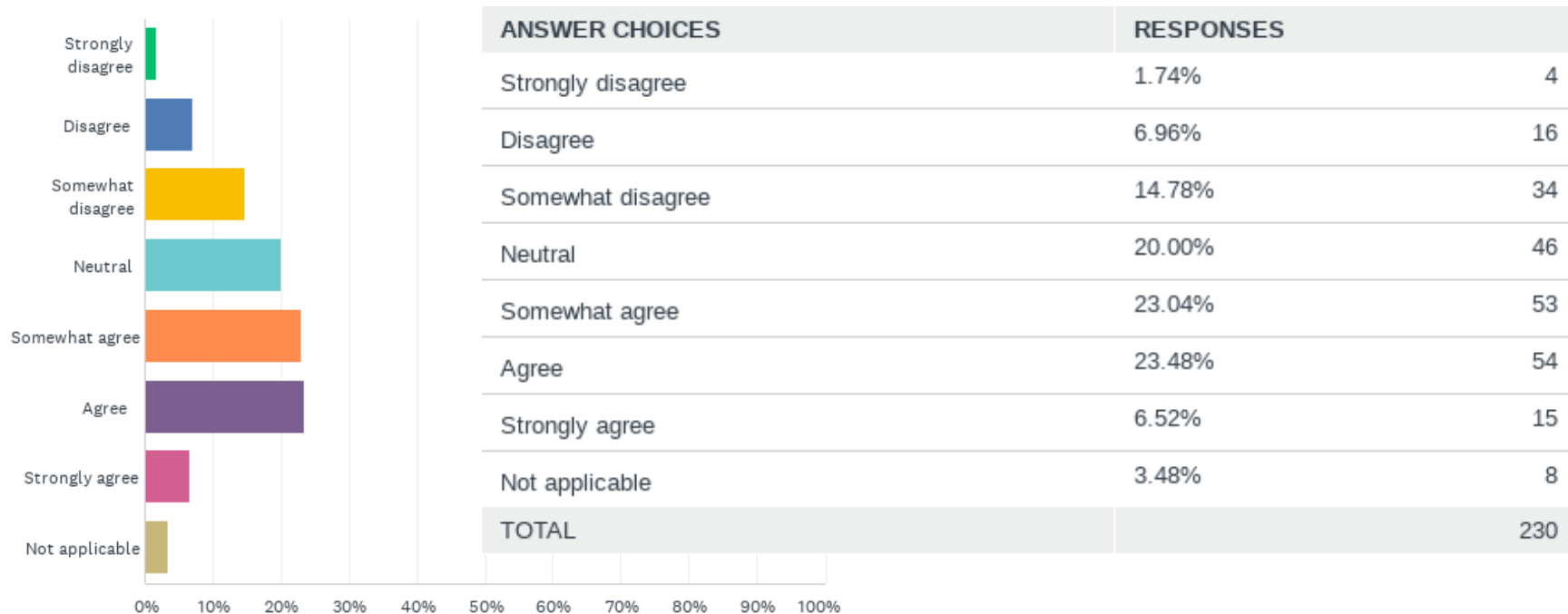
Q41: It is possible to enjoy interacting with people with dementia:

Answered: 230 Skipped: 452, skipped 16 interested in brain health/at risk



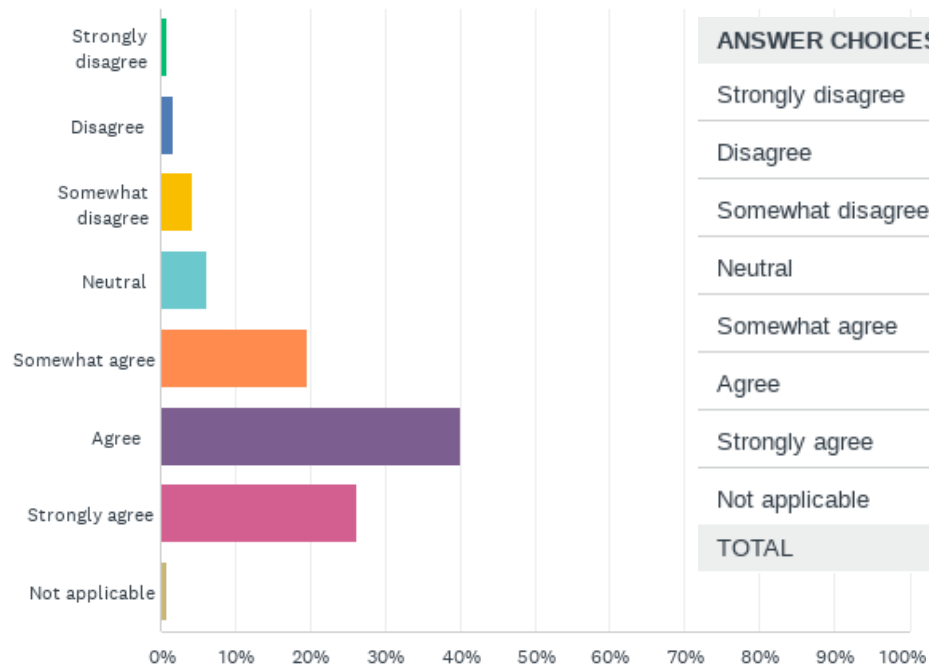
Q42: I feel relaxed around people with dementia:

Answered: 230 Skipped: 452, skipped 16 interested in brain health/at risk



Q43: People with dementia can enjoy life:

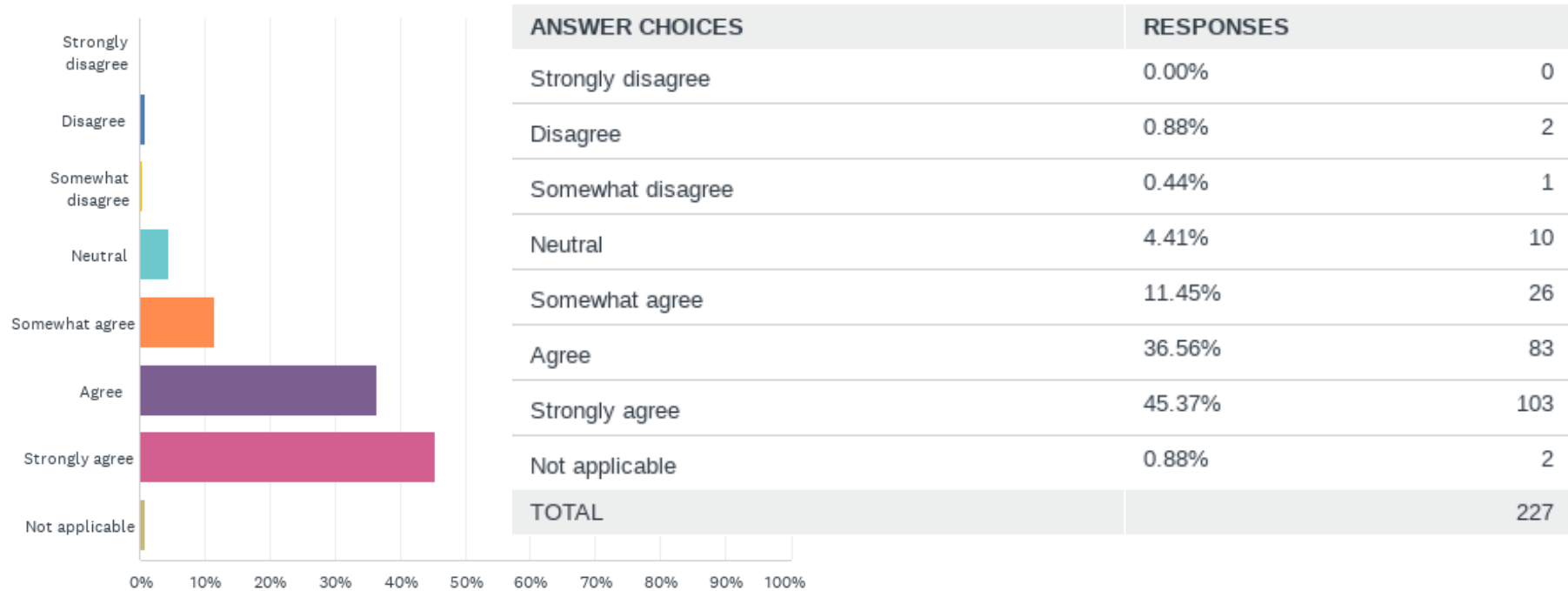
Answered: 229 Skipped: 453, skipped 17 interested in brain health/at risk



ANSWER CHOICES	RESPONSES
Strongly disagree	0.87% 2
Disagree	1.75% 4
Somewhat disagree	4.37% 10
Neutral	6.11% 14
Somewhat agree	19.65% 45
Agree	40.17% 92
Strongly agree	26.20% 60
Not applicable	0.87% 2
TOTAL	229

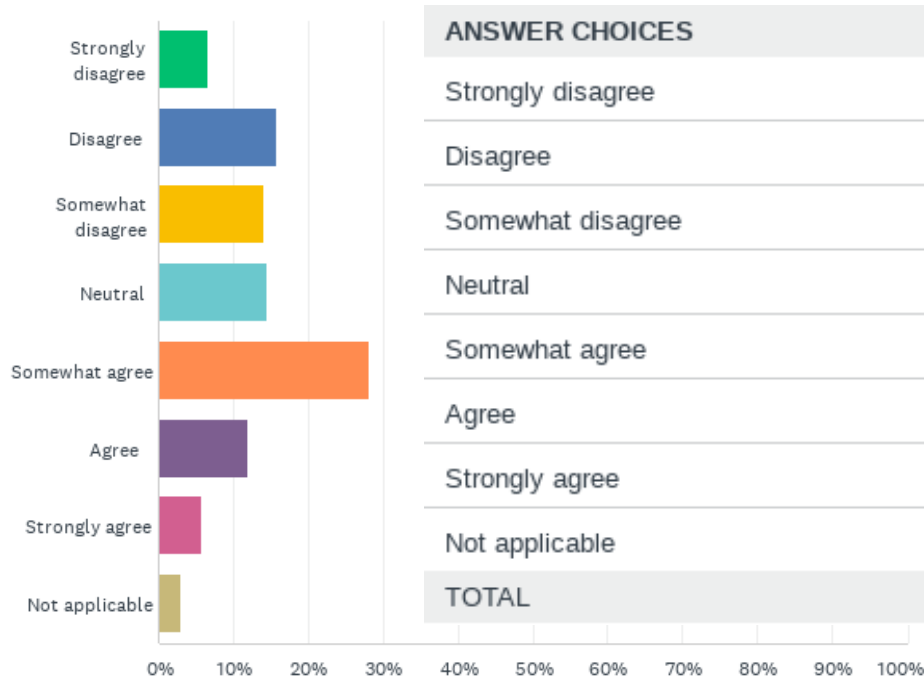
Q44: People with dementia can feel when others are kind to them:

Answered: 227 Skipped: 455, skipped 19 interested in brain health/at risk



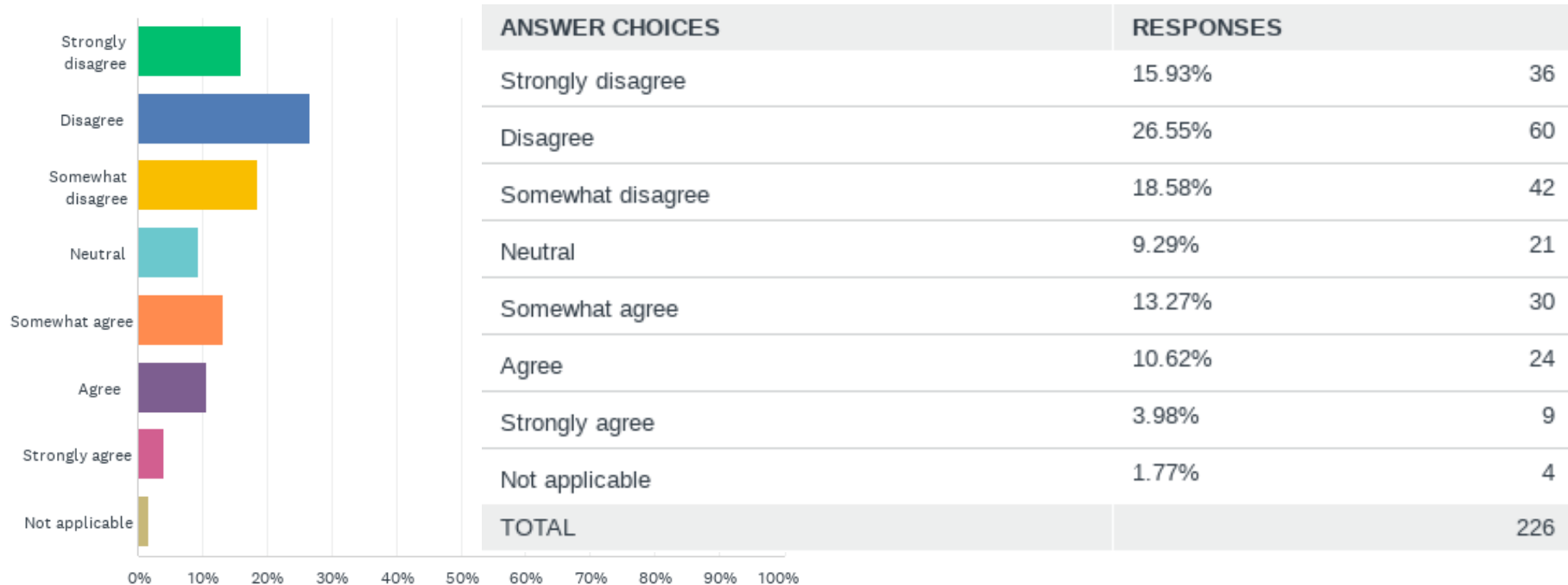
Q45: I feel frustrated because I do not know how to help people with dementia:

Answered: 227 Skipped: 455, skipped 19 interested in brain health/at risk



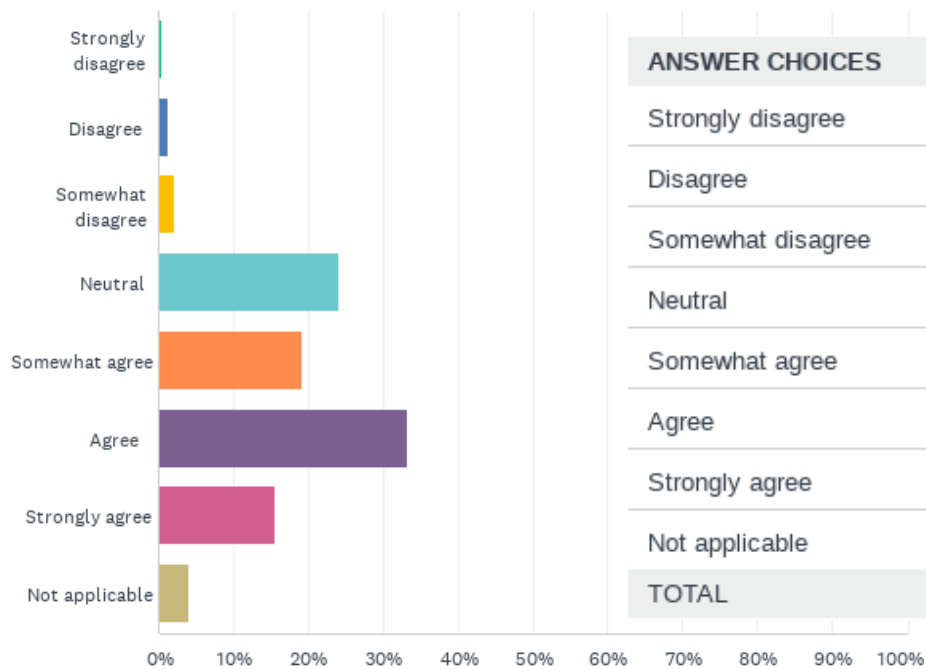
Q46: I cannot imagine caring for someone with dementia:

Answered: 226 Skipped: 456, skipped 20 interested in brain health/at risk



Q47: I admire the coping skills of people with dementia:

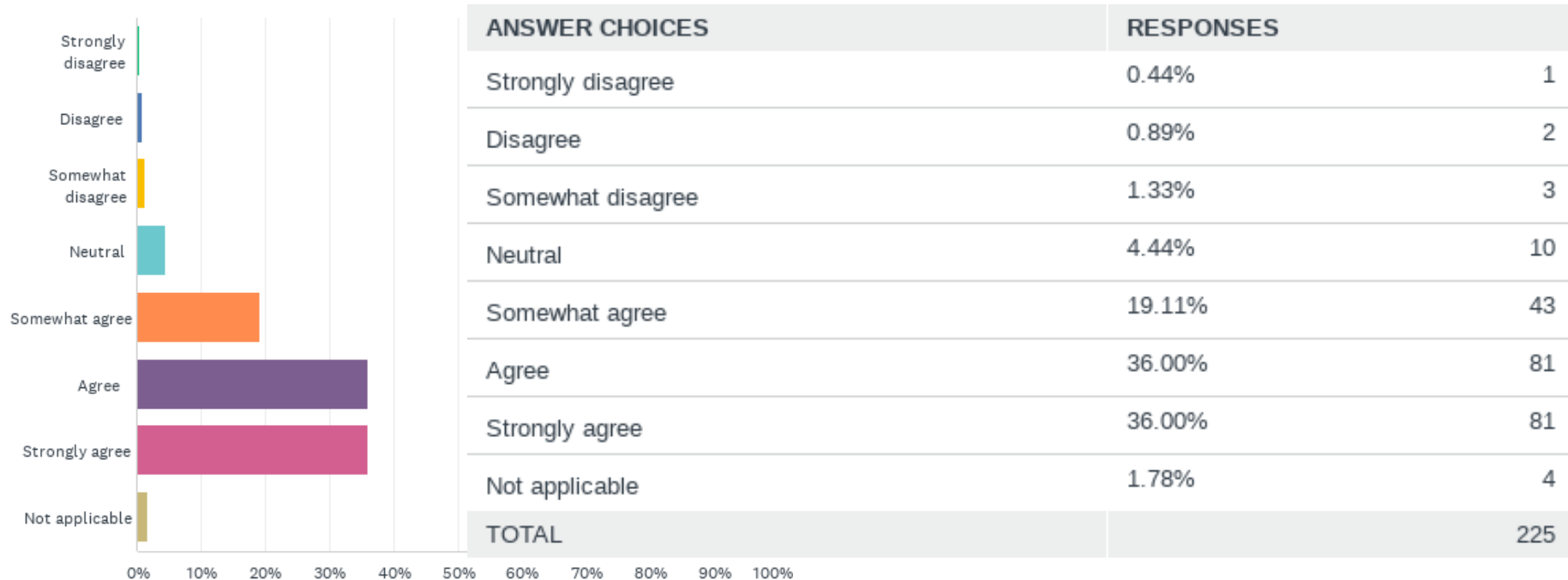
Answered: 225 Skipped: 457, skipped 21 interested in brain health/at risk



ANSWER CHOICES	RESPONSES
Strongly disagree	0.44% 1
Disagree	1.33% 3
Somewhat disagree	2.22% 5
Neutral	24.00% 54
Somewhat agree	19.11% 43
Agree	33.33% 75
Strongly agree	15.56% 35
Not applicable	4.00% 9
TOTAL	225

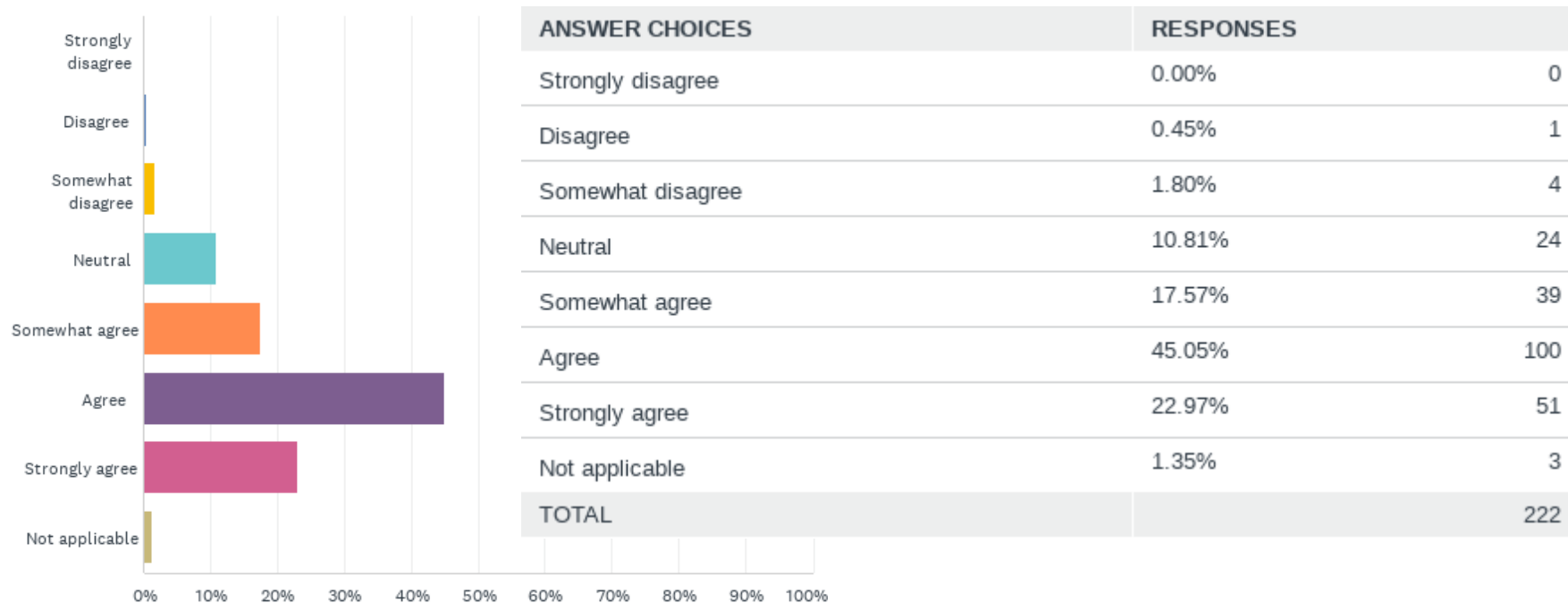
Q48: We can do a lot now to improve the lives of people with dementia:

Answered: 225 Skipped: 457, skipped 21 interested in brain health/at risk



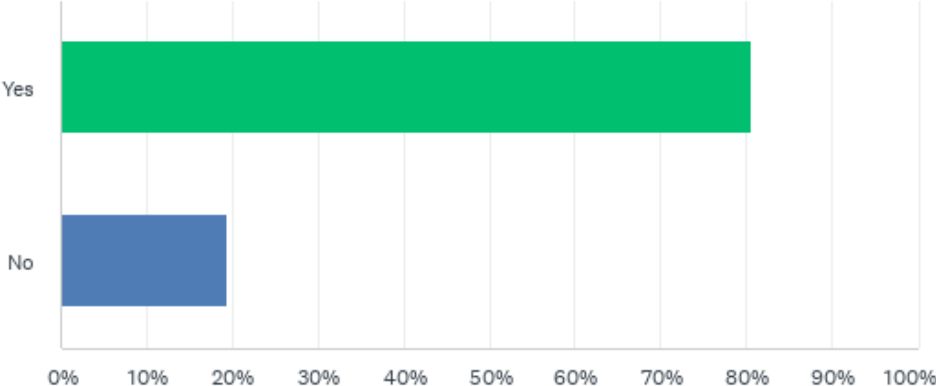
Q49: Difficult behaviors may be a form of communication for people with dementia:

Answered: 222 Skipped: 460, skipped 24 interested in brain health/at risk



Q50: Have you had experience with someone living with dementia?

Answered: 222 Skipped: 460, skipped 24 interested in brain health/at risk

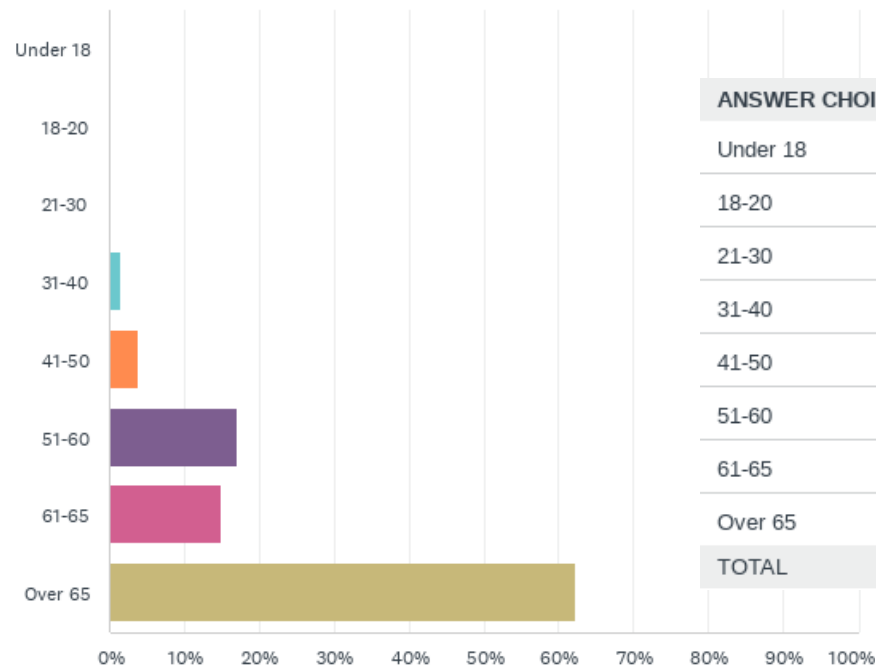


ANSWER CHOICES	RESPONSES	
Yes	80.63%	179
No	19.37%	43
TOTAL		222

Demographics across groups

Q51: What is your age?

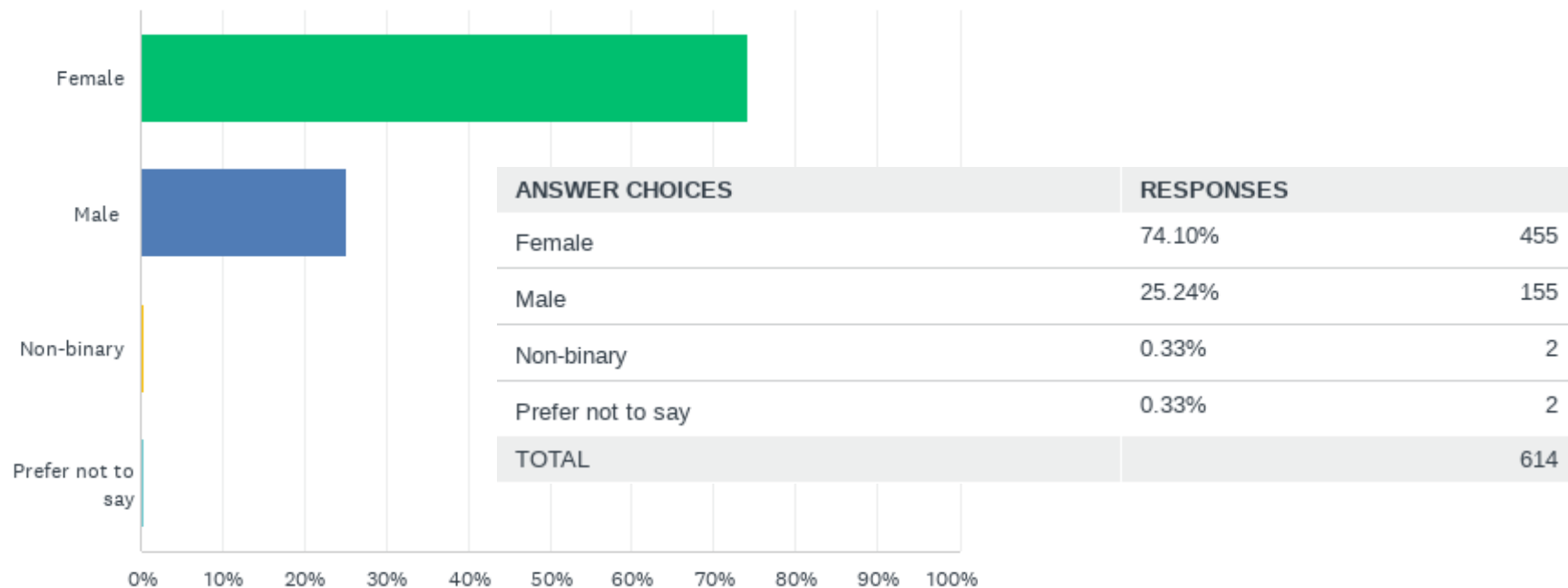
Answered: 614 Skipped: 68



ANSWER CHOICES	RESPONSES
Under 18	0.00% 0
18-20	0.16% 1
21-30	0.16% 1
31-40	1.47% 9
41-50	3.91% 24
51-60	17.10% 105
61-65	14.98% 92
Over 65	62.21% 382
TOTAL	614

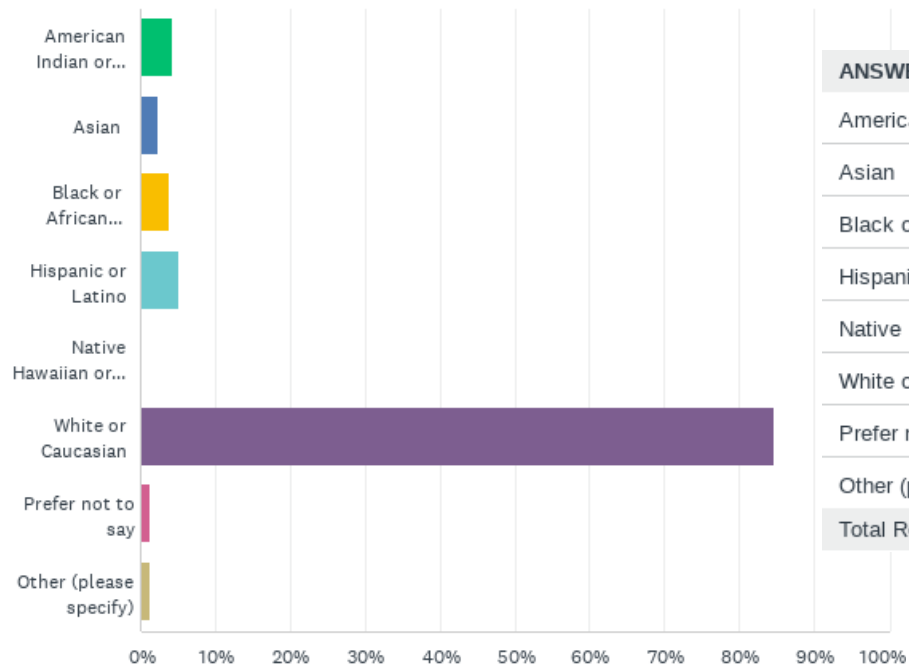
Q52: What is your gender?

Answered: 614 Skipped: 68



Q53: How would you describe your race or ethnicity? (check all that apply)

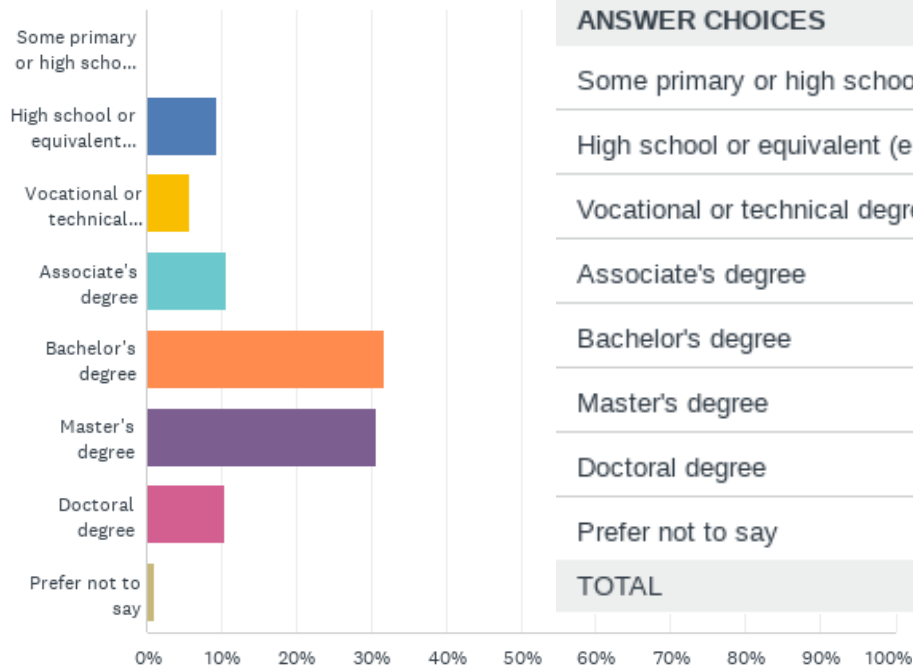
Answered: 614 Skipped: 68



ANSWER CHOICES	RESPONSES
American Indian or Alaska Native	4.23% 26
Asian	2.28% 14
Black or African American	3.91% 24
Hispanic or Latino	5.21% 32
Native Hawaiian or other Pacific Islander	0.16% 1
White or Caucasian	84.69% 520
Prefer not to say	1.30% 8
Other (please specify)	1.30% 8
Total Respondents: 614	

Q54: What is the highest level of education completed?

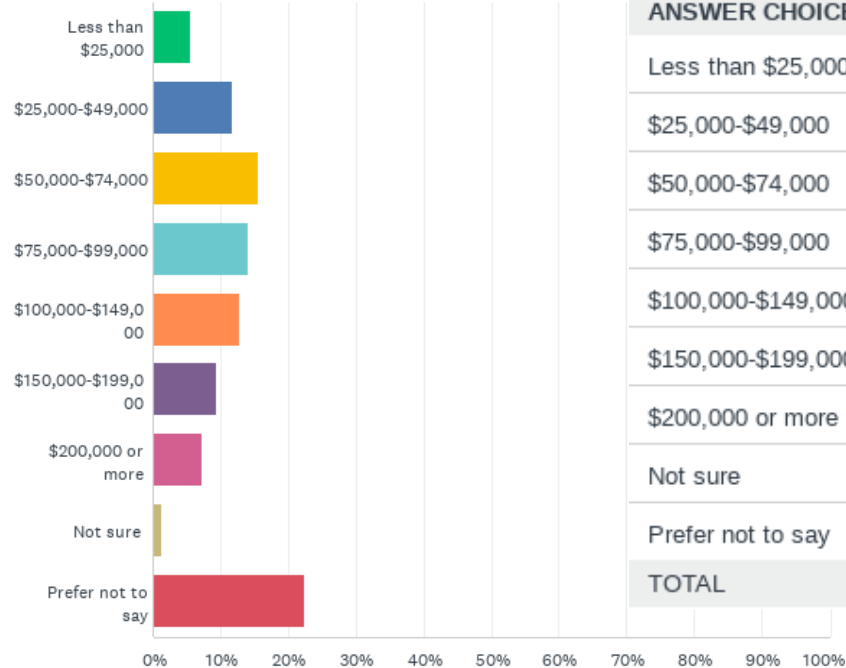
Answered: 614 Skipped: 68



ANSWER CHOICES	RESPONSES	
Some primary or high school	0.16%	1
High school or equivalent (e.g., GED)	9.45%	58
Vocational or technical degree	5.86%	36
Associate's degree	10.59%	65
Bachelor's degree	31.76%	195
Master's degree	30.78%	189
Doctoral degree	10.42%	64
Prefer not to say	0.98%	6
TOTAL		614

Q55: What was your total household income before tax and other deductions in 2021?

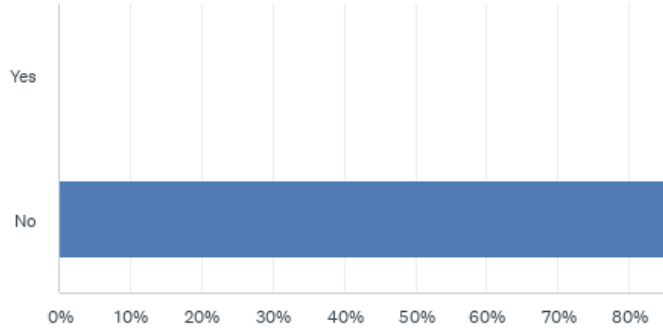
Answered: 614 Skipped: 68



ANSWER CHOICES	RESPONSES
Less than \$25,000	5.54% 34
\$25,000-\$49,000	11.73% 72
\$50,000-\$74,000	15.64% 96
\$75,000-\$99,000	14.17% 87
\$100,000-\$149,000	12.70% 78
\$150,000-\$199,000	9.45% 58
\$200,000 or more	7.17% 44
Not sure	1.30% 8
Prefer not to say	22.31% 137
TOTAL	614

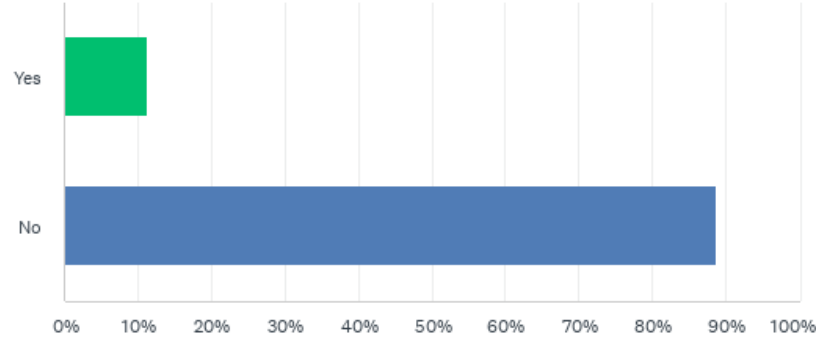
Q56: Are you an active member of the military?

Answered: 614 Skipped: 68



ANSWER CHOICES	RESPONSES
Yes	0.00% 0
No	100.00% 614
TOTAL	614

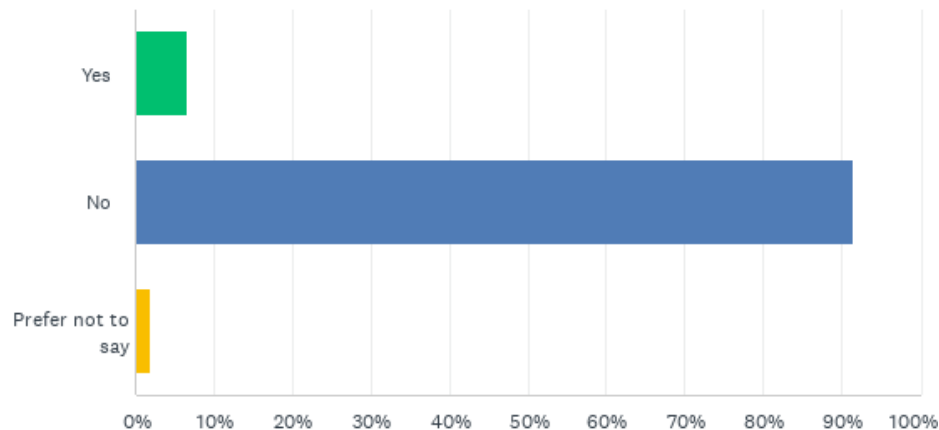
Answered: 614 Skipped: 68



ANSWER CHOICES	RESPONSES
Yes	11.40% 70
No	88.60% 544
TOTAL	614

Q58: Do you identify as a member of the Lesbian, Gay, bisexual, transgender (LGBT) community?

Answered: 614 Skipped: 68



ANSWER CHOICES	RESPONSES	
Yes	6.68%	41
No	91.37%	561
Prefer not to say	1.95%	12
TOTAL		614