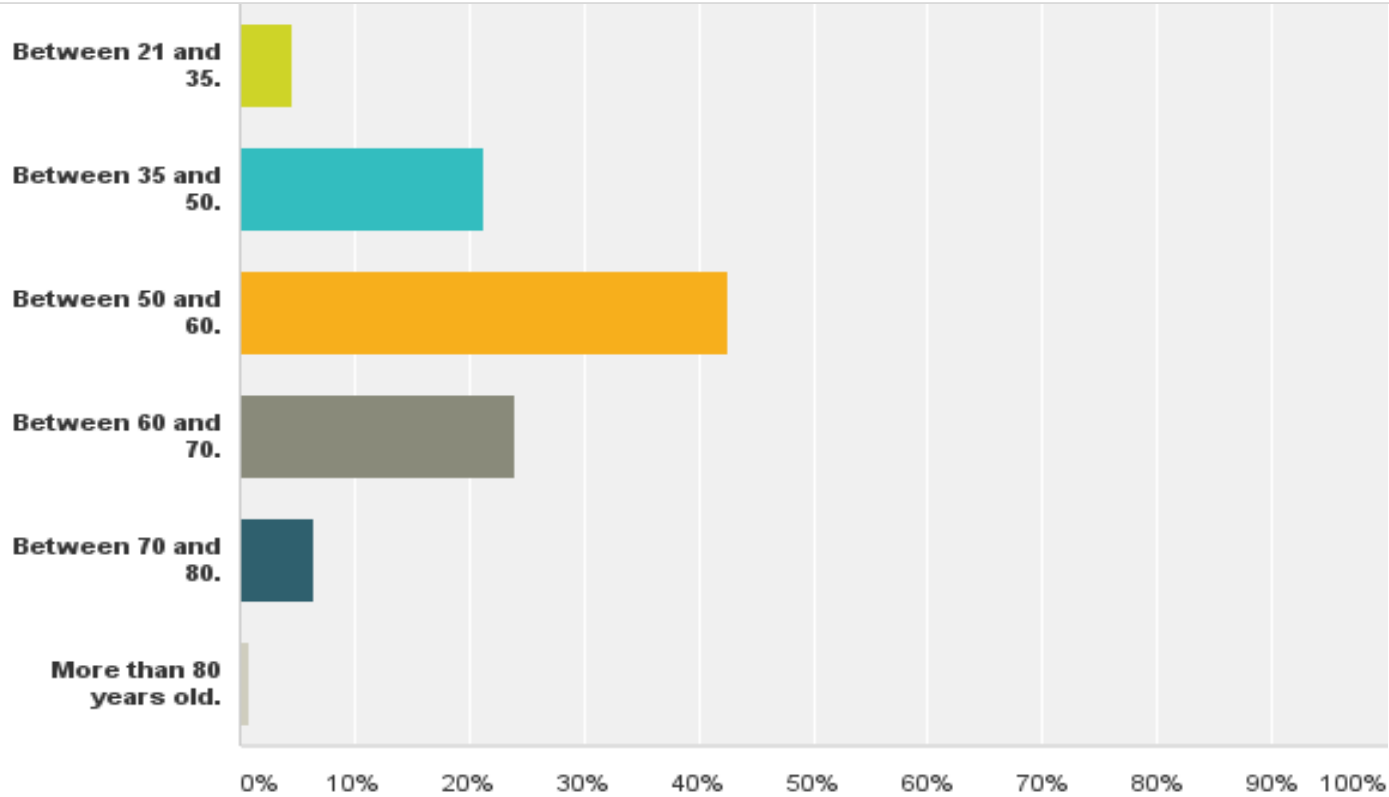


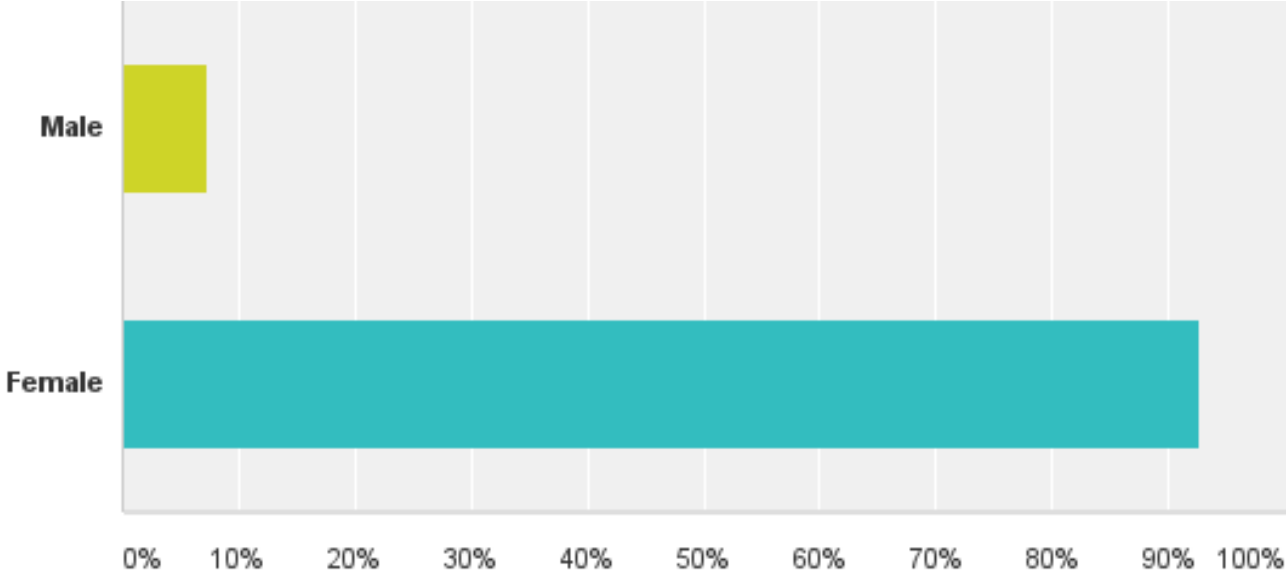
2014 Annual Family Caregiver Survey Results

Denise M. Brown
CareGiving.com

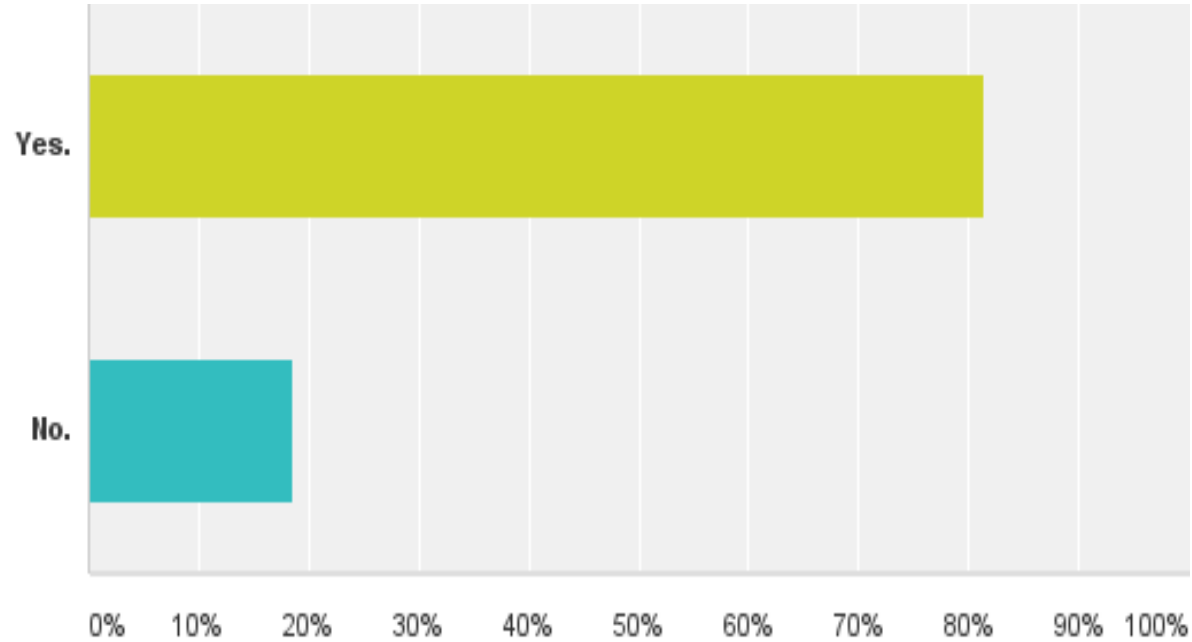
Q1: How old are you?



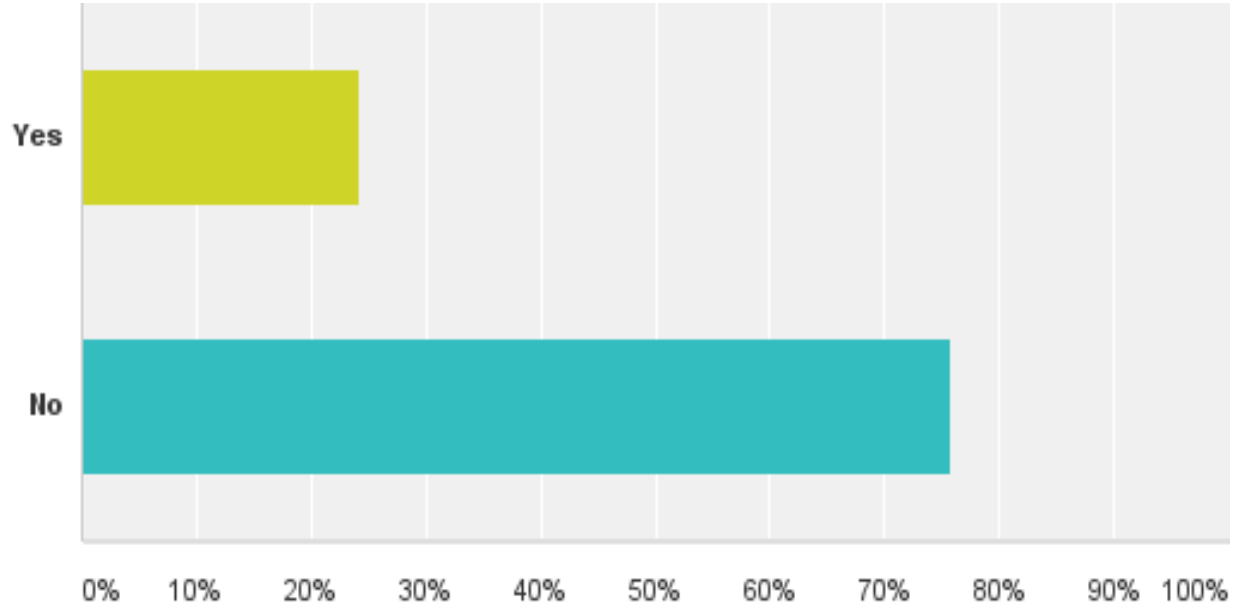
Q2: Your gender:



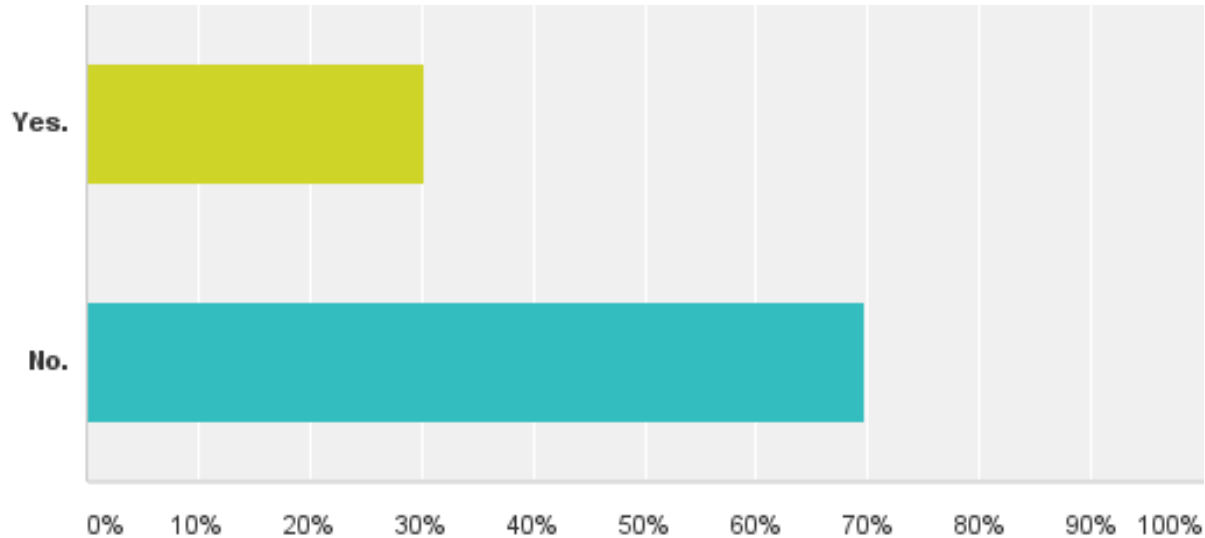
Q3: Are you married or in a committed relationship?



Q4: Do you have children still living at home?



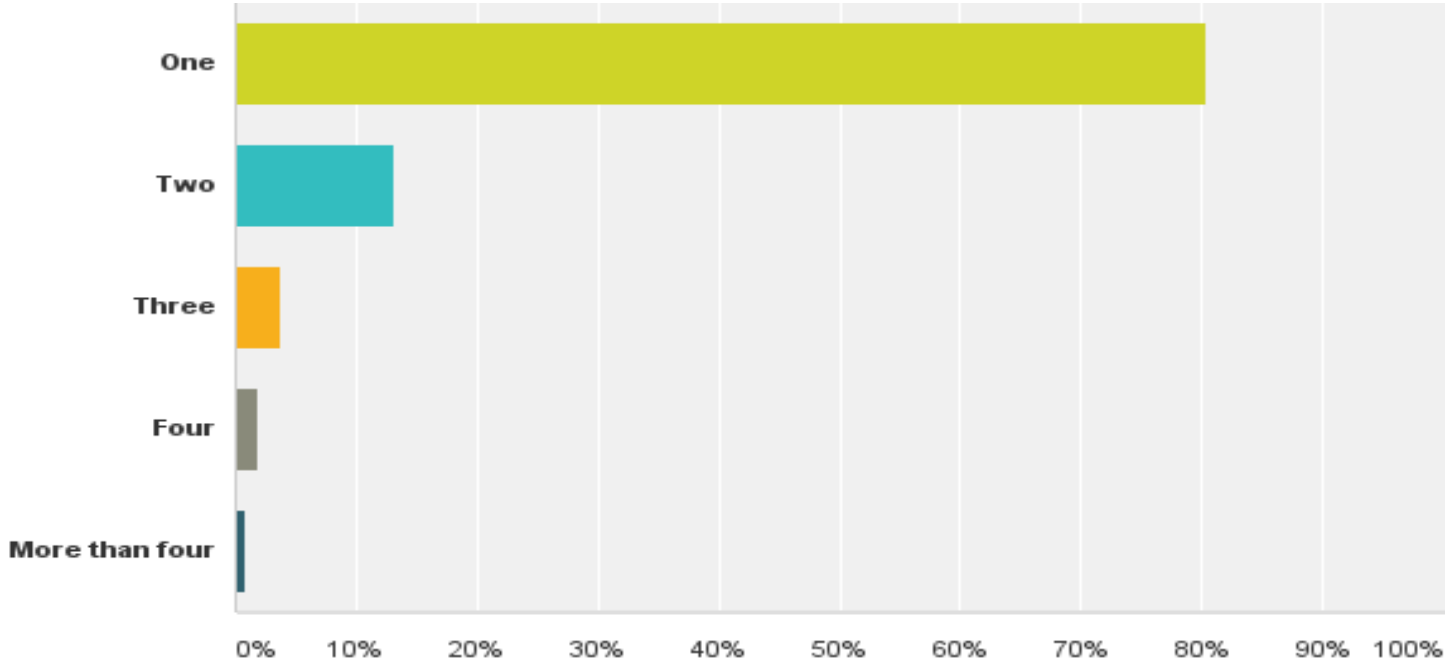
Q5: Do you adequately take care of your physical, emotional, dental and medical needs?



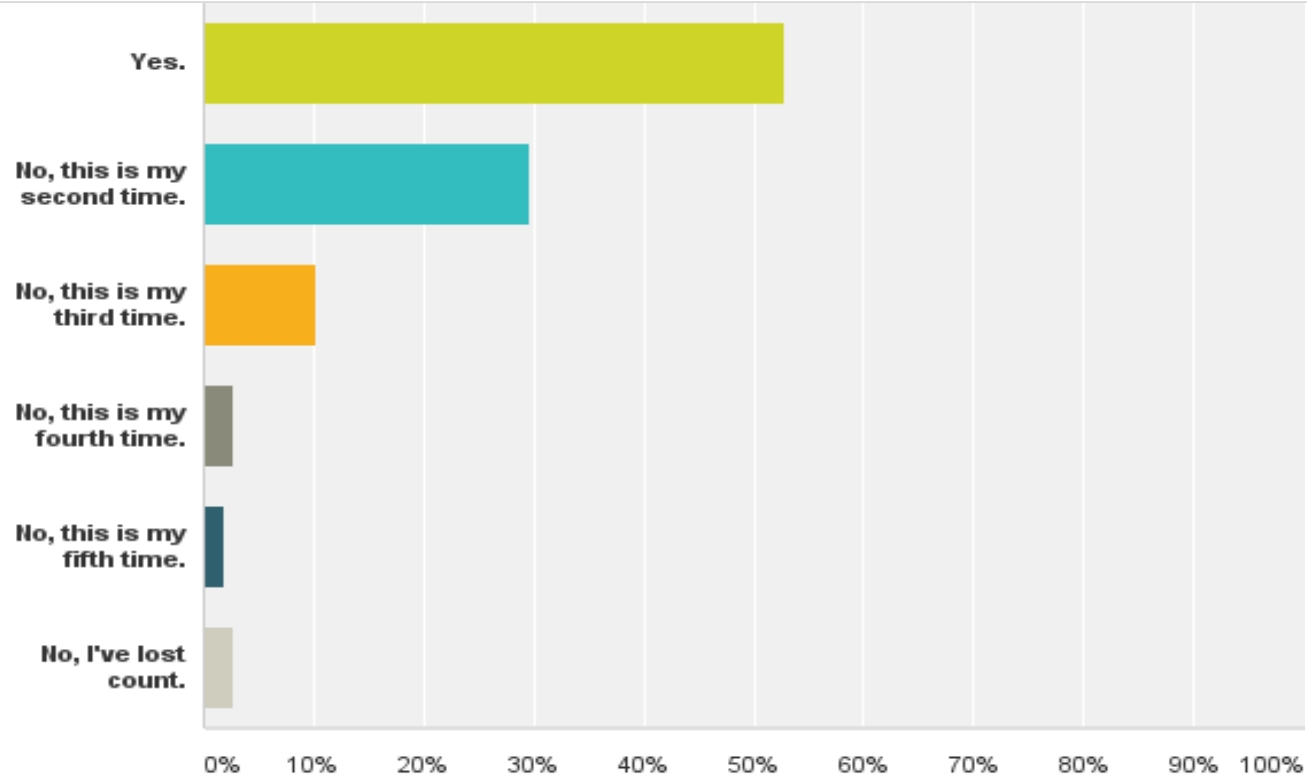
Q6: If you answered "No" to the above question, why not?

Answer Choices	Responses	
I just don't have the energy.	41.33%	31
Somethings gotta give--and that's what gives.	56.00%	42
I do not have health insurance.	20.00%	15
I don't have the back-up in place to leave my career.	25.33%	19
It's not important.	5.33%	4
Other (please specify)	14.67%	11
Total Respondents: 75		

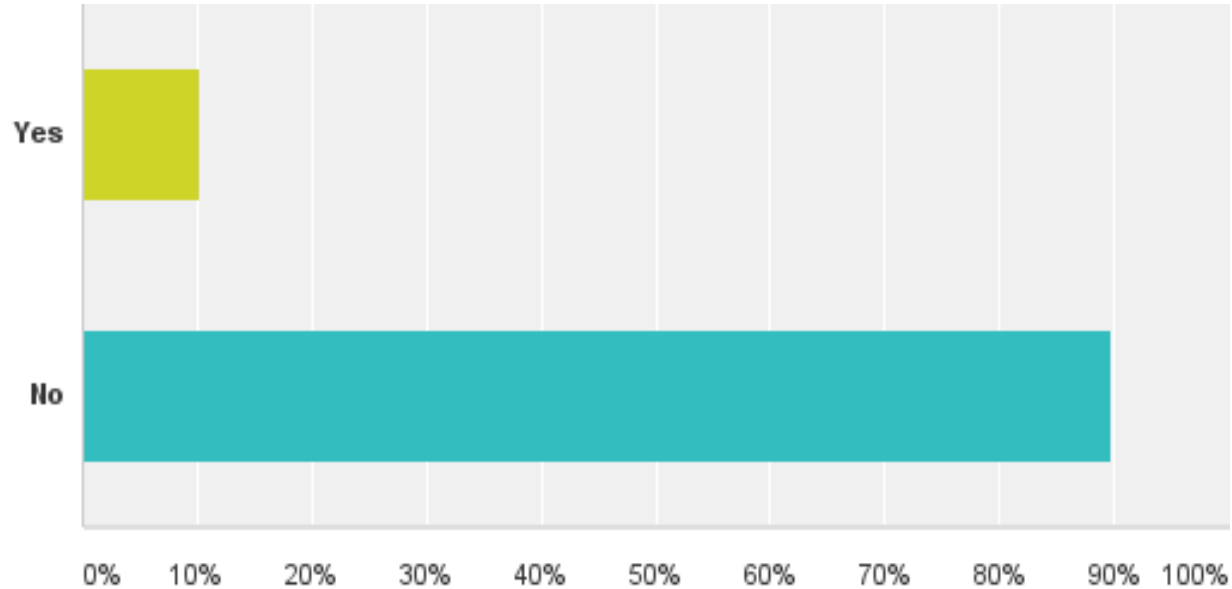
Q7: For how many family members or friends are you caring?



Q8: Is this your first time caring for a family member or friend?



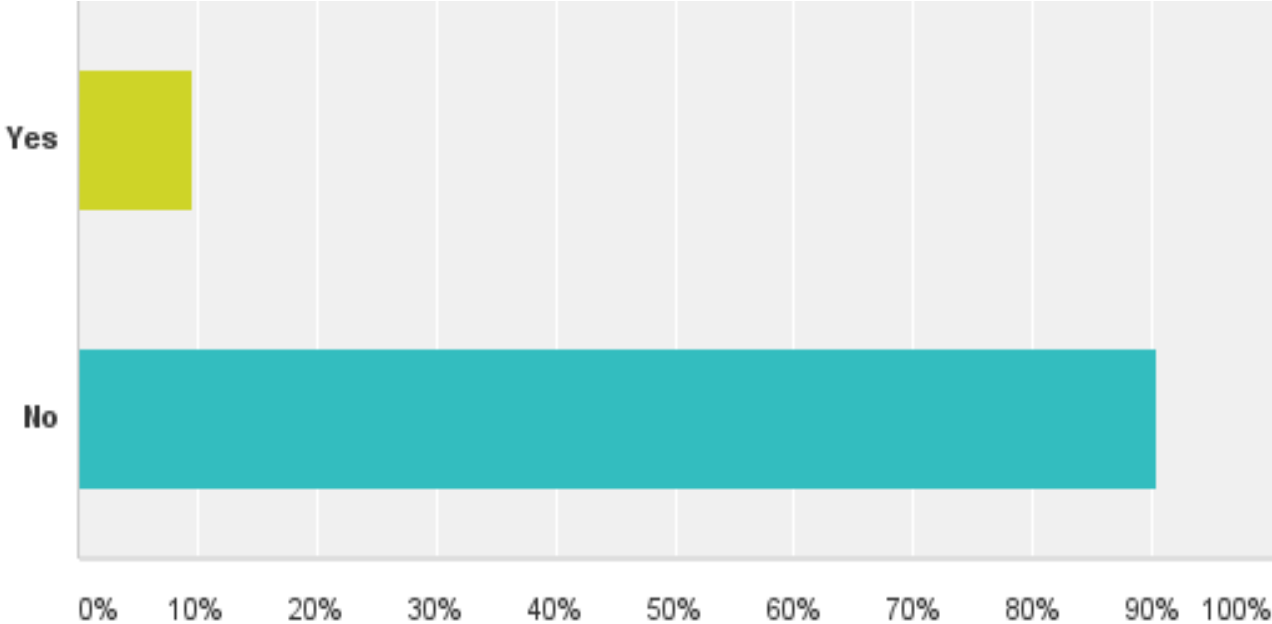
Q9: If you care for more than one, are you caring for a married couple?



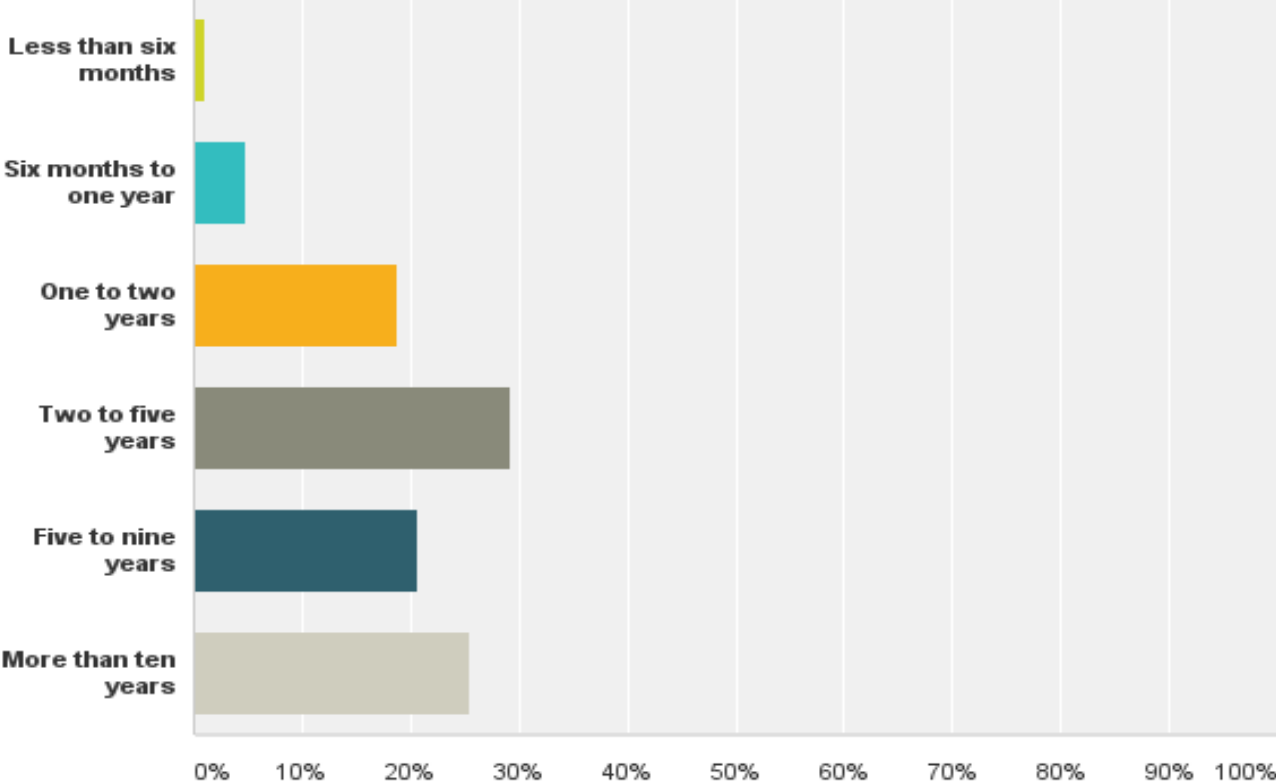
Q10: How old is your caree?

Answer Choices	Responses	
Under 10.	2.83%	3
Under 20.	0.00%	0
Under 30.	3.77%	4
Between 30 and 45.	6.60%	7
Between 45 and 60.	17.92%	19
Between 60 and 70.	20.75%	22
Between 70 and 80.	31.13%	33
Between 80 and 90.	22.64%	24
More than 90 years old.	12.26%	13
Total Respondents: 106		

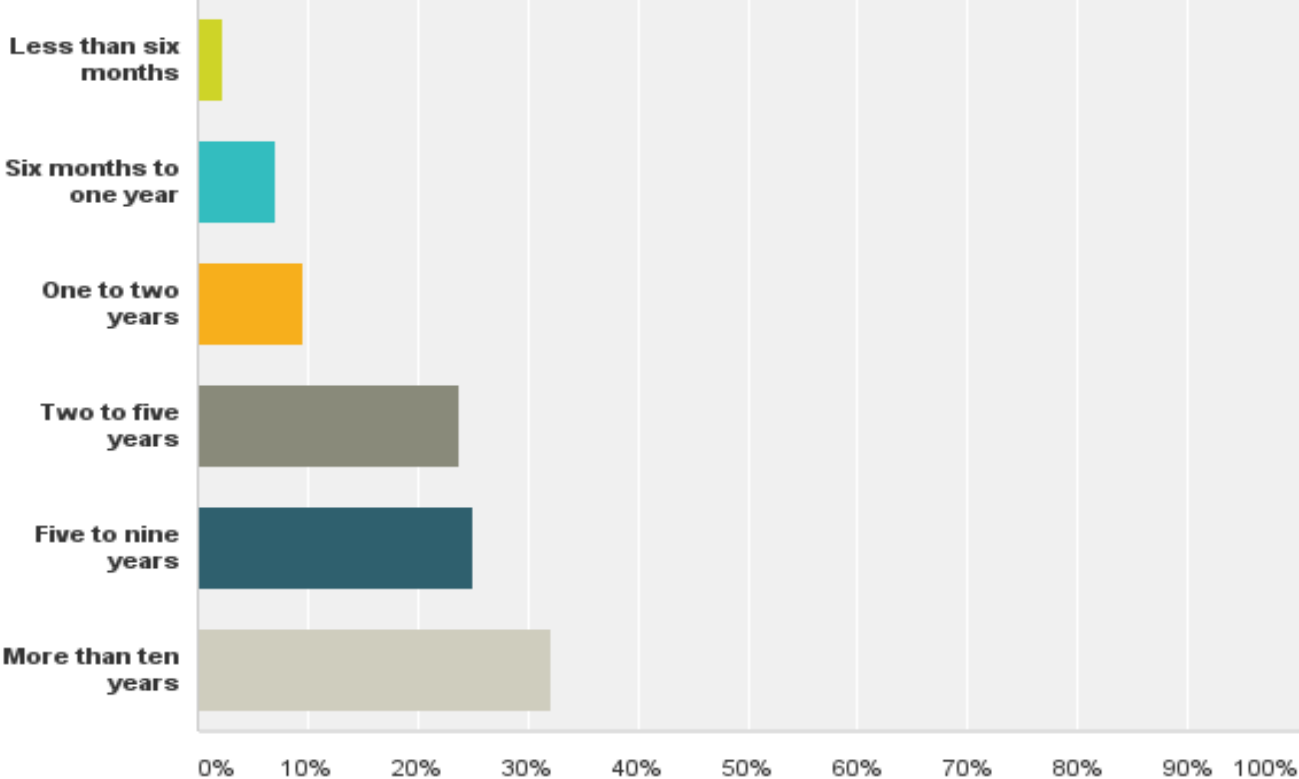
Q11: Do you receive reimbursement for providing care?



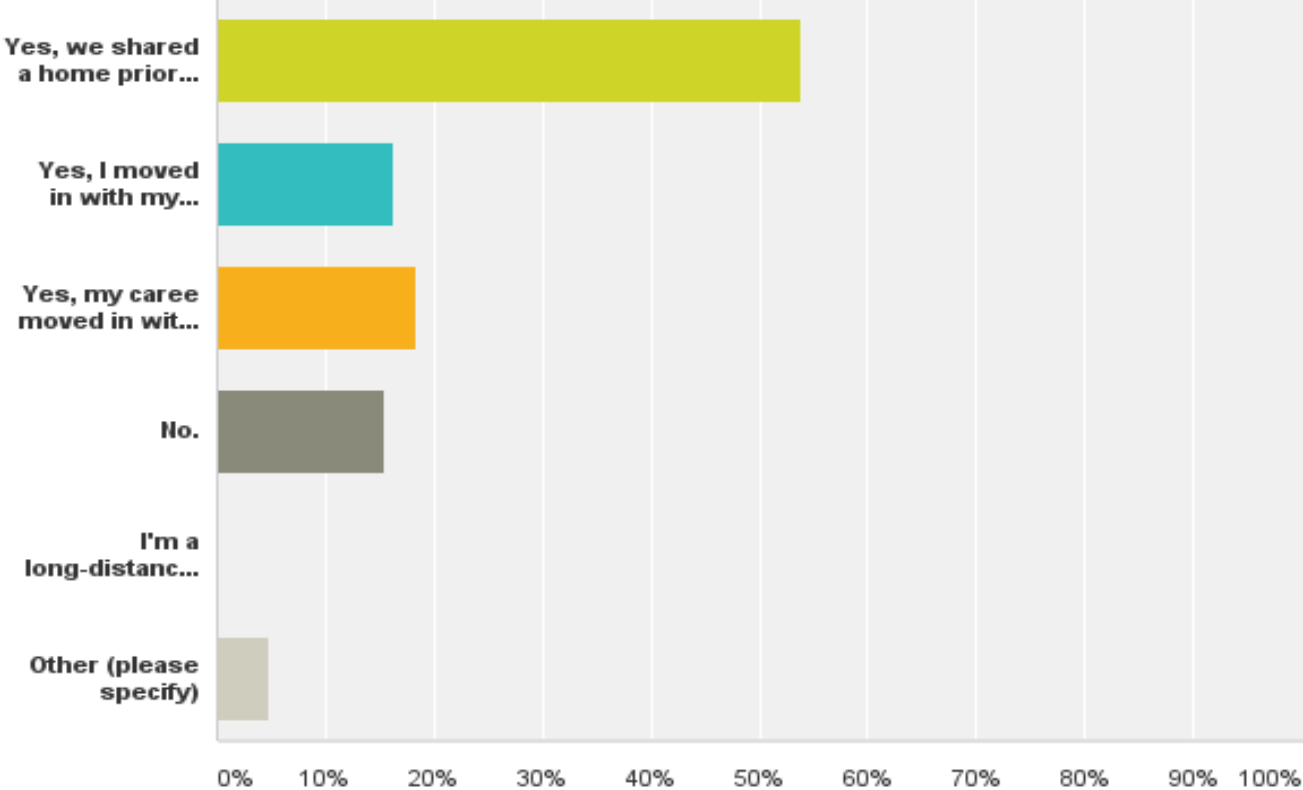
Q12: How long have you been a family caregiver?



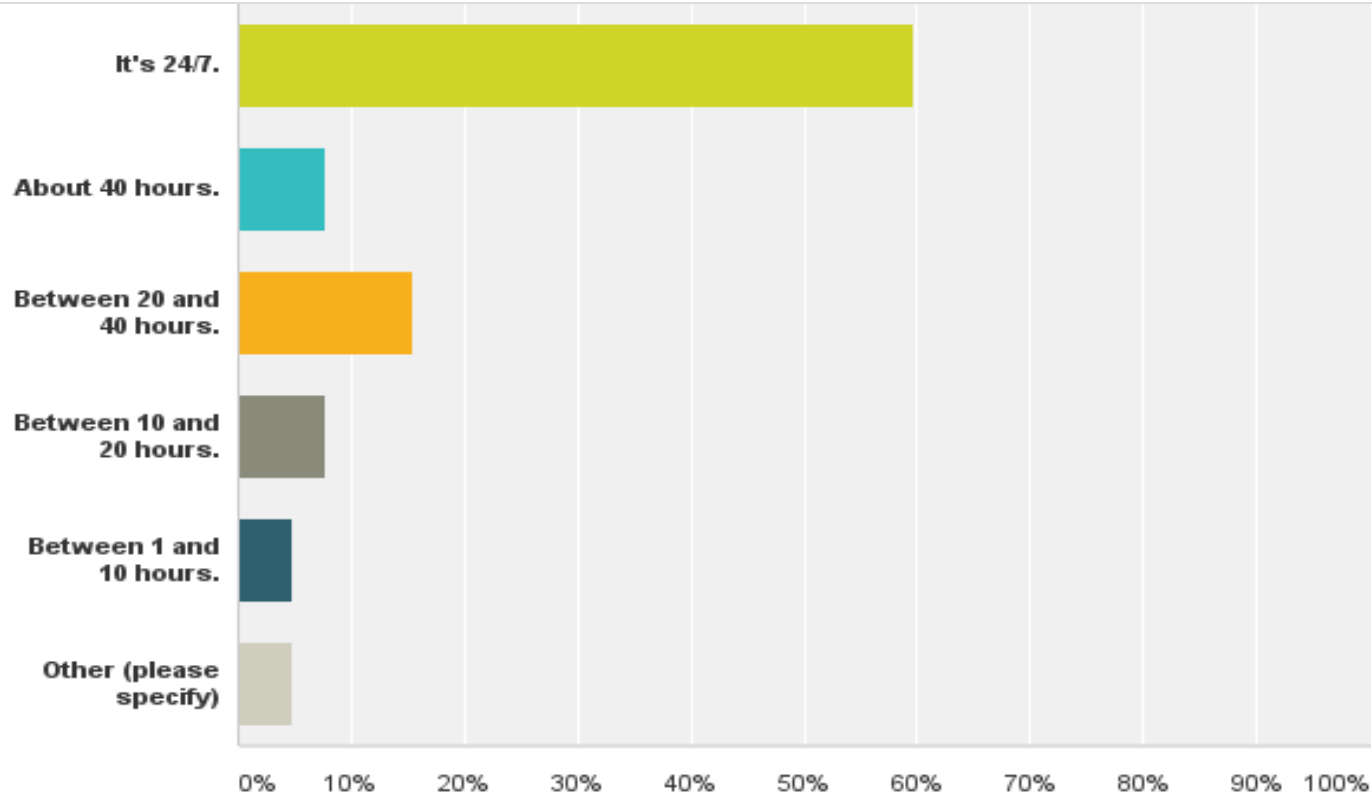
Q13: How much longer do you expect to be a family caregiver?



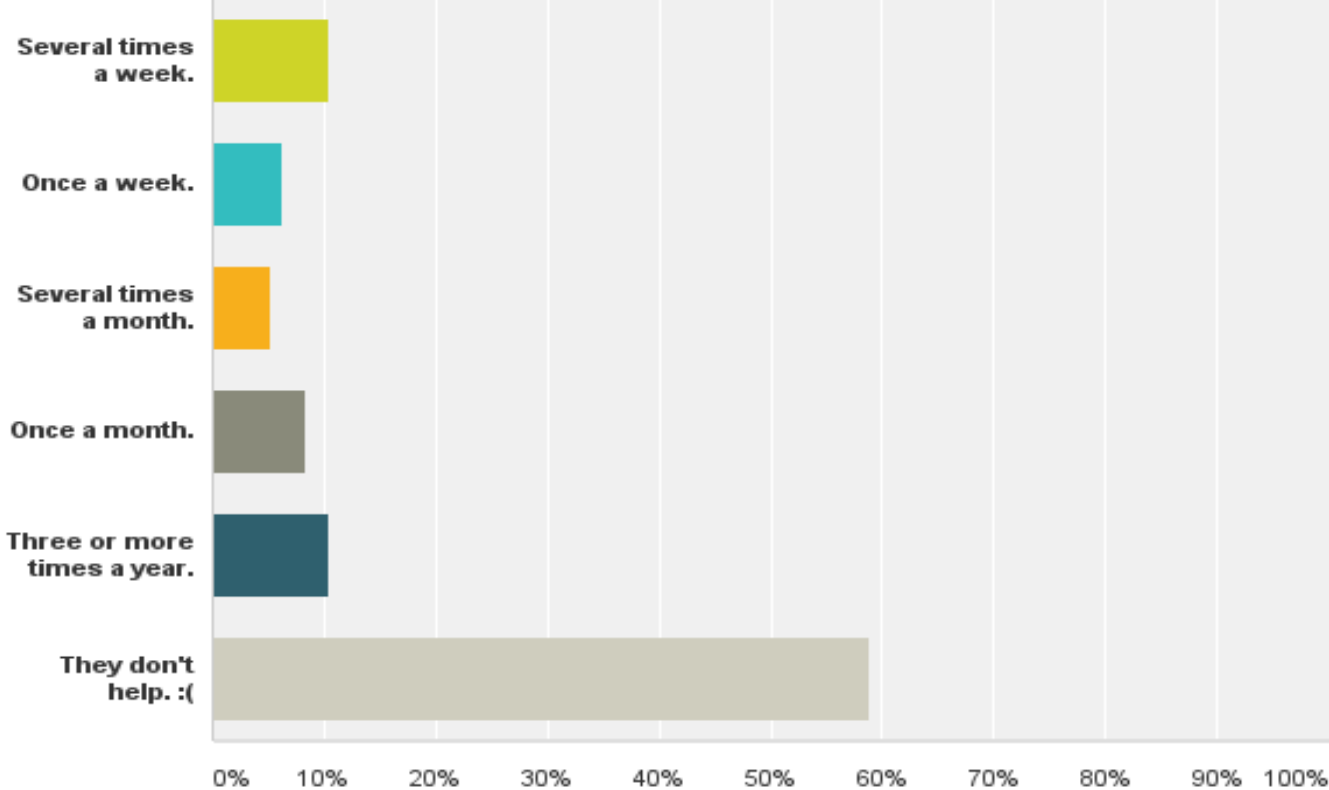
Q14: Do you and your caree live together?



Q15: How many hours per week do you provide care?



Q16: How often do other family members help you?



Q17: If other relatives do not help, why not?

Answer Choices	Responses
They live out-of-town.	45.88% 39
I am the only one (i.e., you are the only adult child or only healthy relative).	11.76% 10
I've asked, but they refuse.	28.24% 24
Other (please specify)	37.65% 32
Total Respondents: 85	

Why don't they help?

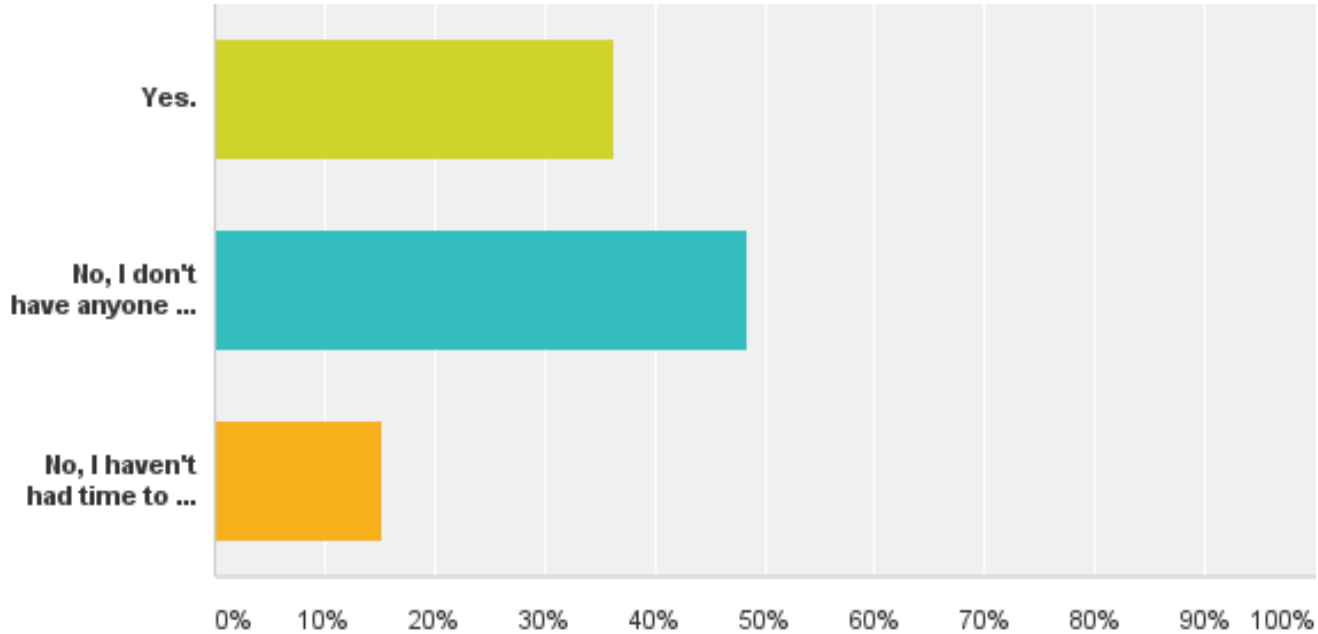
They are busy with their own lives

As soon as he was out of the woods, they disappeared

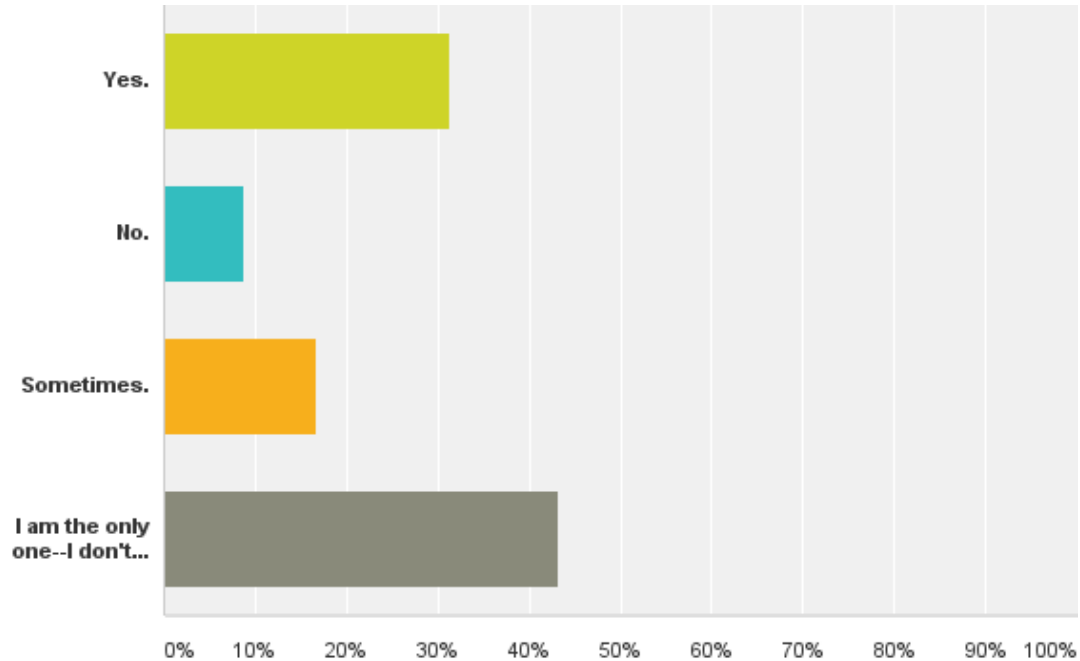
They don't realize his illness is getting worse.

Too hard to coordinate w/ their schedules/Would feel guilty/Not sure what to ask for help with

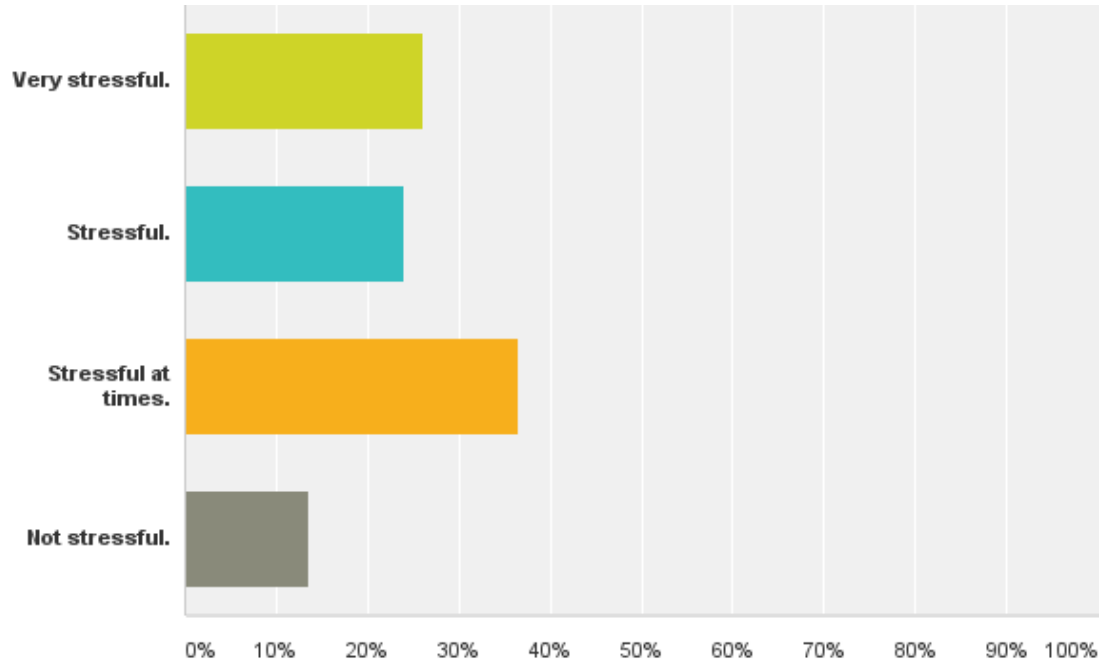
Q18: Have you trained a back-up who can provide care in case you can't?



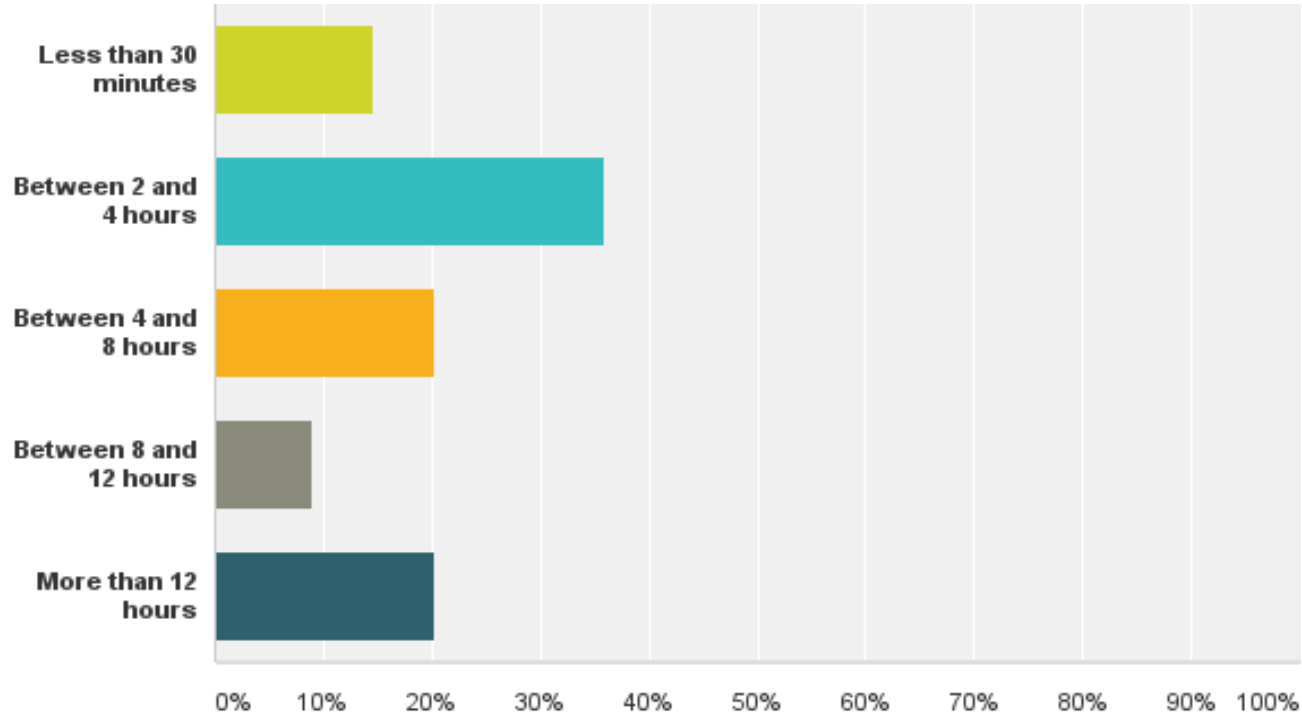
Q19: Are you and your family all in agreement about your caree's treatment plan and care budget?



Q20: Please indicate your stress level in dealing with other family members about caregiving.



Q21: How much time each week do you have for yourself?



Q22: What's the worst question others ask you about your caregiving situation?

Answer Choices	Responses	
Why don't you find a nursing home for your caree?	18.09%	17
Are you taking care of yourself?	20.21%	19
How much longer can you possibly manage?	6.38%	6
Why don't you just get some help?	12.77%	12
Why is this so stressful for you?	8.51%	8
Why are you so angry?	8.51%	8
Why are you so sad?	1.06%	1
Why are you so serious?	3.19%	3
Other (please specify)	21.28%	20
Total		94

What's the worst question?

Have you thought about things you'd like to do in life after she dies?

Seems like she's holding you back. (Yes, someone actually told me this!)

They aren't bad, but just don't understand..why don't you work..I DO work, they should come and do this...I do get sad, and down sometimes, and tired. They say to get some help, but right now I don't feel I need it, so far, and he doesn't like strangers in the house, and I'm not too trustful either

I don't know how you handle all of that by your self, how much longer are you going o do this??

How are you REALLY doing? (as if I must be lying)

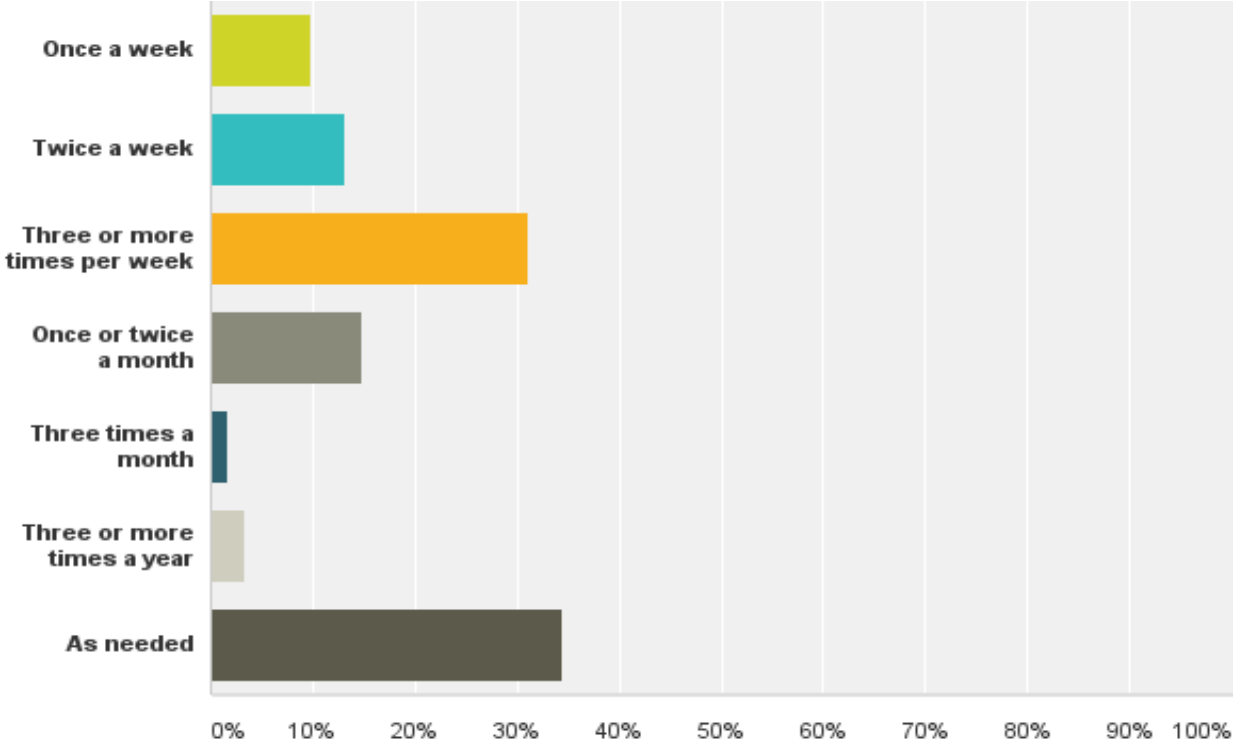
Q23: When was/is the hardest time for you?

Answer Choices	Responses	
When my caree was first diagnosed.	13.27%	13
When I first started helping and family/friends disappeared.	11.22%	11
When I first tried to find help for myself and my caree.	5.10%	5
When I hadn't taken a break in awhile and I was exhausted.	35.71%	35
Now because my caree is declining so quickly.	12.24%	12
Other (please specify)	22.45%	22
Total		98

Q24: Which services do you use in your community? Select as many as you use.

Answer Options	Response Percent
Area Agency on Aging	14.8%
Caregiver conferences, seminars or workshops	12.5%
Home health agencies	28.4%
Respite care so you can get a break	11.4%
Support groups	11.4%
My caree refuses to use any services.	18.2%

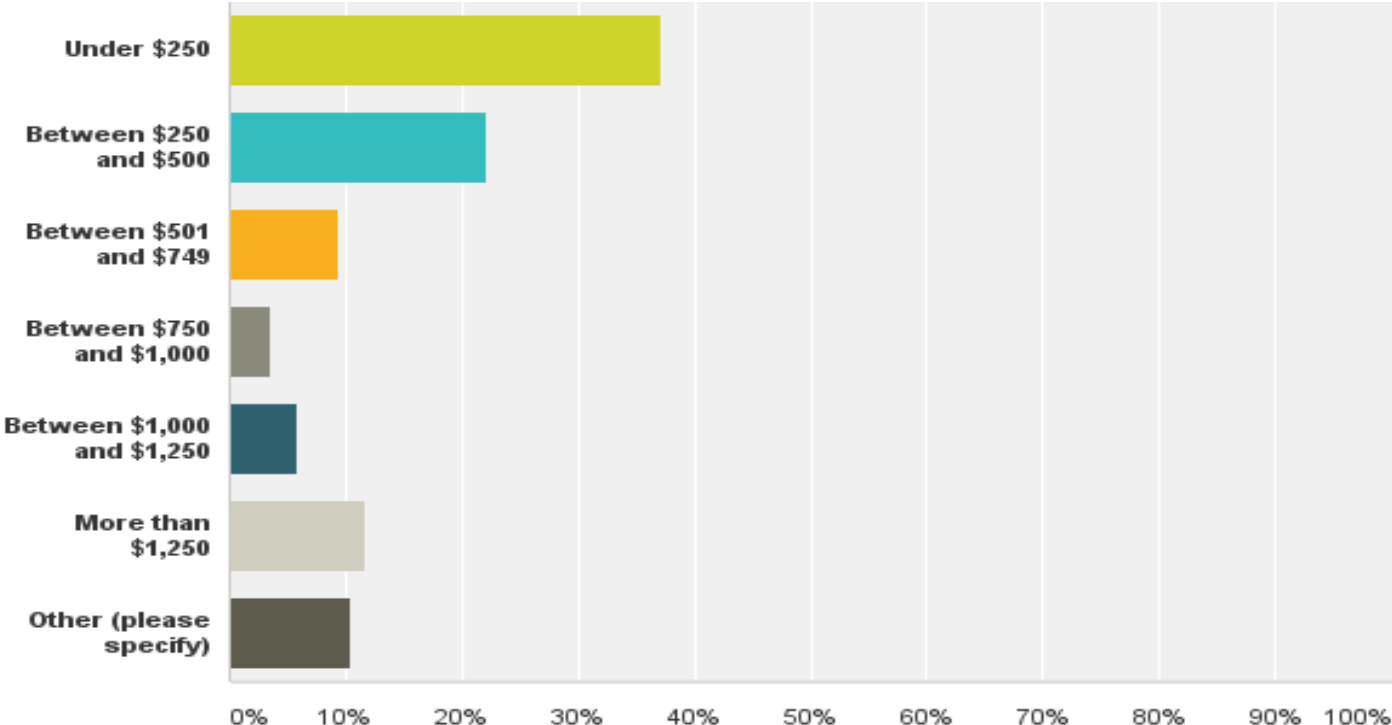
Q25: How often do you use these services?



Q26: How are these services paid?

Answer Choices	Responses	
Medicare	40.00%	24
My caree's long-term care insurance	3.33%	2
My caree's workman's compensation insurance	0.00%	0
My caree's disability insurance	1.67%	1
Medicaid	16.67%	10
My caree pays	26.67%	16
I pay	33.33%	20
A combination of the above	21.67%	13
Total Respondents: 60		

Q27: Overall, how much do you and/or your caree spend on all health care services per month?



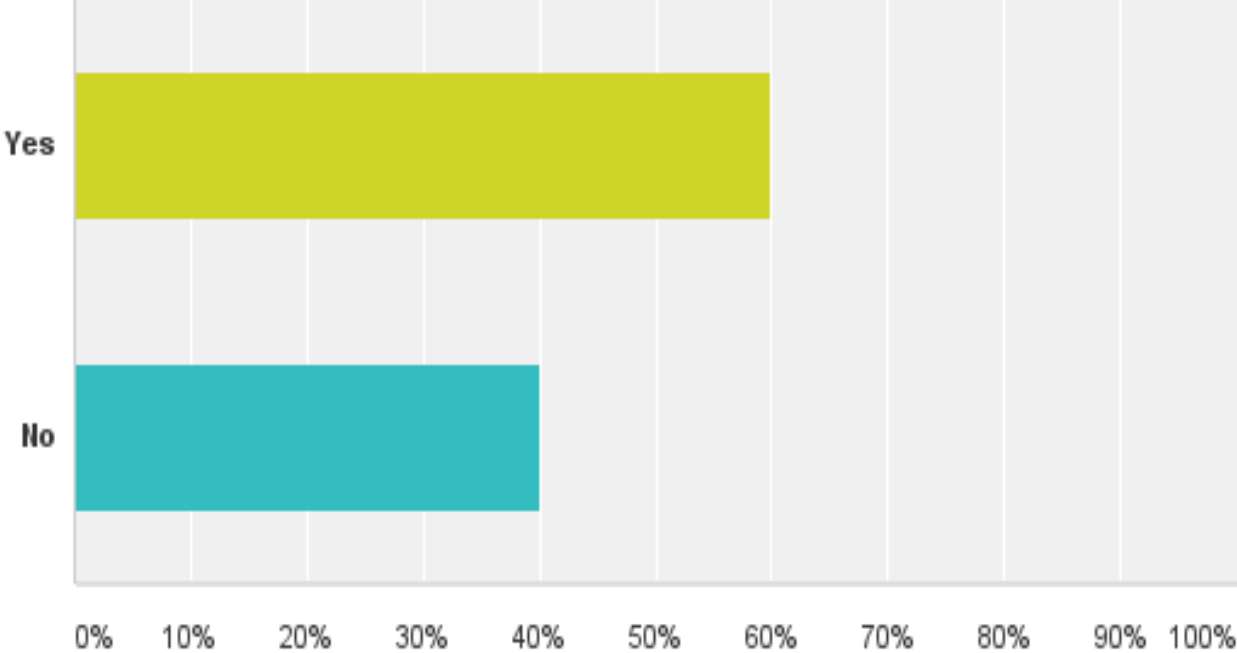
Q28: What's the greatest expense related to providing care?

Answer Choices	Responses
Health care professionals, such as physicians	8.99% 8
Housing, such as assisted living and nursing homes	4.49% 4
Community services, such as adult day centers, Meals on Wheels, transportation	2.25% 2
Home care services, such as companion sitters, home health aides, visiting nurses	19.10% 17
Home medical equipment, such as wheelchair, walker, bathroom grab bars	7.87% 7
Medications	29.21% 26
Ancillaries, such as disposable briefs and other supplies	10.11% 9
Other (please specify)	17.98% 16
Total	89

Q29: How did you hear about the services that you use?

Answer Choices	Responses
Community agency or organization	14.29% 11
Friend or family member	15.58% 12
Support group	3.90% 3
Newspaper ad	2.60% 2
Website	12.99% 10
Physician	9.09% 7
Healthcare professional	22.08% 17
Minister, priest or rabbi	0.00% 0
Other (please specify)	19.48% 15
Total	77

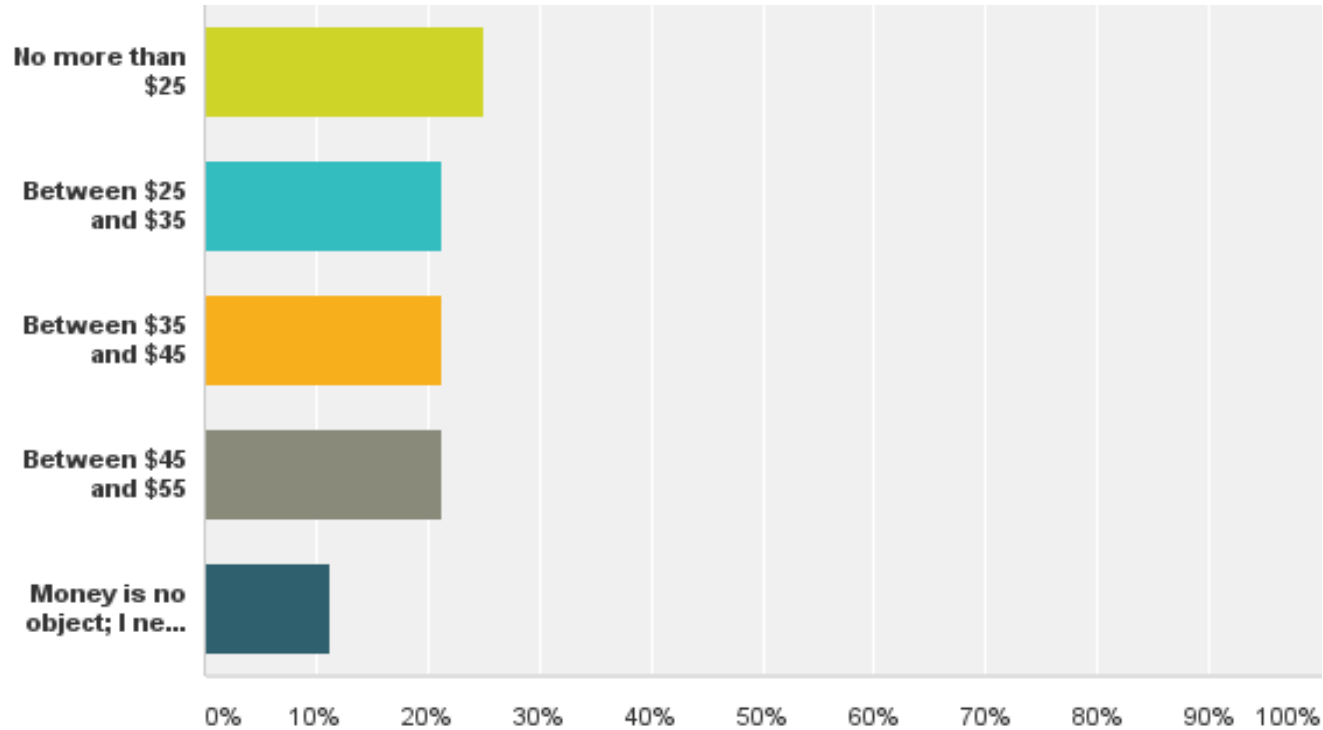
Q30: Are you happy with the services in your area?



Q31: Which services would you like to see more of?

Caregiver conferences, seminars or workshops	44.3%	35
Coaching or counseling services	29.1%	23
Financial aid for family caregivers	46.8%	37
Respite care so you can get a break	41.8%	33
Support groups	43.0%	34

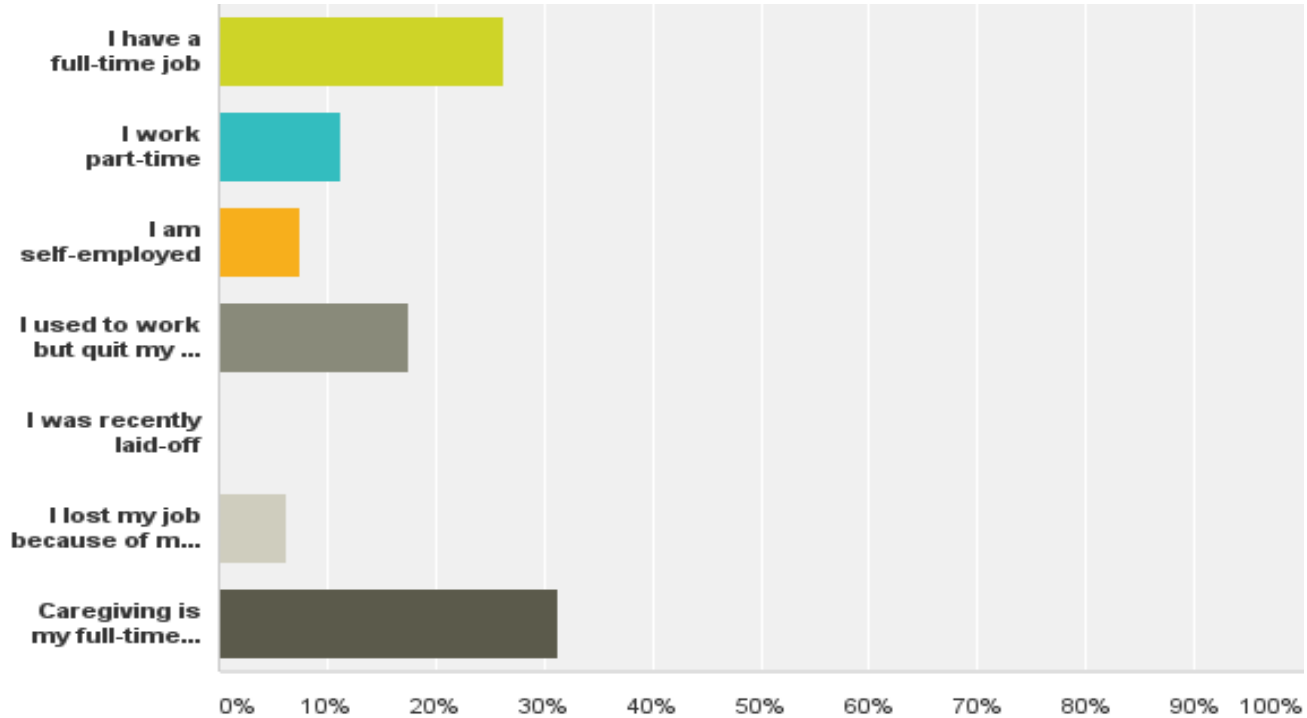
Q32: How much will you pay for a home care worker to stay with your caree so you can leave for three hours?



Q33: How do you use the Internet to help you?

Answer Choices	Responses
For support	64.84% 59
To learn about my caree's illness or disease	62.64% 57
To find services in my community	43.96% 40
To learn how to care for my caree	37.36% 34
To take a break from caregiving	56.04% 51
Other (please specify)	5.49% 5
Total Respondents: 91	

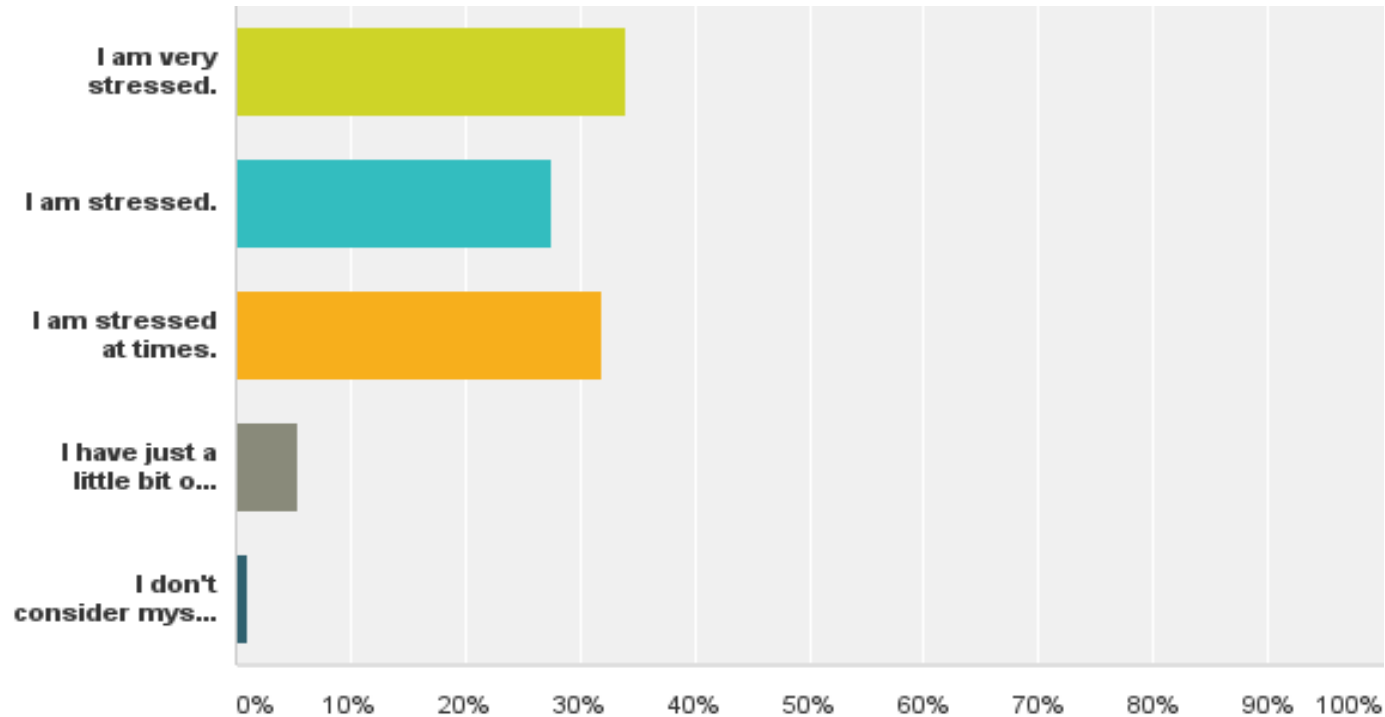
Q34: Do you also work?



Q35: What is the most difficult part of caregiving?

Answer Options	Response Percent	Response Count
Finding the patience that's needed	51.1%	47
Finding time to socialize with family and friends	45.7%	42
Getting a break	50.0%	46
Getting a good night's sleep	56.5%	52
The loneliness and isolation	59.8%	55
Managing my emotions (guilt, anger, grief)	65.2%	60

Q36: Please indicate your stress level when it comes to your caregiving role.



Q37: What's most stressful for you?

Answer Choices	Responses
Communicating with my family about caregiving.	6.52% 6
The day-to-day grind.	27.17% 25
Getting along with my caree.	7.61% 7
Knowing what to do, how to do and when to do.	7.61% 7
Making decisions on behalf of my caree.	3.26% 3
Managing my difficult emotions (anger, guilt, resentment).	25.00% 23
Trying to coordinate care.	9.78% 9
Other (please specify)	13.04% 12
Total	92

Q38: Who has been most helpful to you in your caregiving role?

Answer Choices	Responses
Adult day care staff	6.82% 6
Community organization or agency	3.41% 3
Family member and friends	35.23% 31
The Internet (please tell us which sites help you in the question below)	22.73% 20
Home health agency staff	18.18% 16
Hospital staff, such as discharge planner or social worker	5.68% 5
Nursing home staff	1.14% 1
Physician	12.50% 11
My priest, minister or rabbi	3.41% 3
Support group	17.05% 15
Other (please specify)	38.64% 34
Total Respondents: 88	

What has been your most difficult decision so far?

“buying a car. Seriously, I know this doesn't sound caregiving related, but it is because I am now the primary decision maker. EVERY decision falls on me, especially as my husband's answer to questions involving a choice is, "I don't know."

There are little things, like do I listen to this doctor, or that doctor? Do I take a chance and take him out today, or will something happen?

“All of the hospital decisions. It was just terrifying.”

“Knowing what to say the first time my father said, 'In case I don't make it...' just before a surgery.”

“Deciding which bills to pay.”

“Having to ask my employer to work part time from home due to the cost involved with hiring a full time caregiver while I was at work.”

“should I stay or should I leave?”

What's the best thing you've done for yourself?

bought a new car to take our road trips in

Taking music lessons once a week

built an in-ground pool

I took a weekend went to the ocean by myself. Spent one night alone and got a good night's sleep and walked the beach. Even then I got grief--people commented that I must have been going away with a secret lover!

Feeling that it is not nuts to be a care giver that thrives on his appreciation of all I do. To love him as I did before he got sick

Sticking to my guns with hard decisions I've had to make even though I've been told by my carees (for a short while) that they hated me & my decisions. (Even tho it broke my heart.)

If you could make any changes in your community to help family caregivers, what changes would they be?

Make options available to caregivers for respite care. Our area has very little to assist the caregivers.

Taking a bit of the isolation away...making sure local help is available and affordable
have an adult day care closer to my home

Support services for caregivers, health, education, housing etc.

Medicare-funded respite care. It is significantly cheaper to keep mom at home than to put her in a long-term facility, so they should provide more help in the home?

Have visiting caregivers "sit" with difficult carees.

Support group time that meshes with my work schedule

During your time as a family caregiver, what changes have you seen that have made caregiving easier or harder?

Lack of cooperation among medical practitioners

Our council on the aging has closed. They were a great resource for a lot of people.

One thing that has made things so much harder is all of the specialists that you have to see. We can't go to our PCP anymore to get toe nails trimmed, have to set an appointment with a different dr at a different location. We used to be able to go to our PCP for everything now we are running all over town for appointments. This has made it very hard on both caree and caregiver. (Sorry, this is not a community issue but a Medicare one)

My grandfather is homebound but they discontinued his meals on wheels because I was his caregiver. They knew I was his caregiver since 2010 but cut this service in 2013. This increases the feelings of isolation for the caree and the caregiver.

What advice would you give to a new family caregiver?

Be kind to yourself. You are doing the best you can.

Pace yourself. You're in this for the long-haul, so be sure to take time out for yourself.

Don't neglect you. And learn to take mini breaks throughout the day when things get a little crazy.

ask questions and ask this question -- can you tell me anything else I should know...

because you don't know what you should be asking often, until it's too late. You will feel guilty at times, that is NORMAL.

Get plugged in with someone, somewhere, where you can talk about the realities of what it is like to care for someone. People who are not going through this can empathize and mean well, but they can't really ever understand the conflicting needs/emotions, etc. as well as someone who is also caring for a loved one.

Never turn down the offer of help.

How do you manage your feelings of being isolated and lonely?

I don't really. I figure it's just the way it is - get over it! But now I am comfortable in my "caregiver's cave" and lack the desire to get out. I try to do at least 2 races per month.

Try not to dwell on it. I go online and read other people's experiences with it, and get tips on how to deal with it. I try to have at least one thing planned every month that I can look forward to.

this is the worst part

I am very good at wearing a mask when I am around people that I know don't really want to know how I am doing. I talk to my husband a lot and share at my support group meeting.

I swallow them for the most part.

What advice would you give to a health care professional who helps family caregivers?

I never knew they did. They only ever ask me to help them with their job.

LISTEN. Share information. Give resources and directions in written form.

They should just listen be compassionate, get to know the real person in the caregiver and caree before making suggestions.

Never say, we understand. They only people who fully understand are the ones in the situation. Just say things such as what can I do to support you? what do you feel you need?

Just tell me what is normal for a 96 year old. Don't focus on unfixable problems.

What advice would you give to a health care professional who helps family caregivers?

They have all been nice, except I think 2 out of 3 cardiologists/surgeons are pompous jerks. (but one is nice)

Give it to them straight. Let them know the worst and best of situation from the beginning. No false hopes or maybes.

LISTEN to me!!!!!!!!!!!!!!! Don't brush me off.

Be real. Don't beat about the bush. Be direct. It saves so much time and angst.

What has been your greatest lesson learned as a result of your caregiving experience?

Don't argue. Don't engage in disagreements. I don't have to win.

Just to let it go!

Live moment to moment. Looking into the future makes it overwhelming.

I can't make everything better.

If I begin our day with a good attitude then my mother-in-law has a good attitude also. The classic "If mama ain't happy then no one's happy." If my attitude is good then it is much easier to tackle the not so fun tasks that come up through the day.

What has been your greatest lesson learned as a result of your caregiving experience?

I am stronger and more compassionate than I ever thought but after 12 years I've had enough!

What people say and what they do are two different things, and you cannot understand a person until you walk in their shoes

To speak up and to trust my judgment over some healthcare providers. They don't always know what they are talking about. Get another opinion.

I now know there are many people doing this. this is much more isolating than I expected.

I AM AMAZING!!

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