

Evercare® Study of
Caregivers in Decline

A Close-up Look at the Health Risks of Caring for a Loved One



Report of Findings
September 2006



Evercare®
Study of Caregivers in Decline
Findings from a National Survey

September 2006

Evercare
in collaboration with
National Alliance for Caregiving

Evercare

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National Alliance for Caregiving

Established in 1996, the National Alliance for Caregiving is a non-profit coalition of more than 40 national organizations that focus on issues of family caregiving across the life span. The Alliance was created to conduct research, do policy analysis, develop national programs and increase public awareness of family caregiving issues. Recognizing that family caregivers make important societal and financial contributions toward maintaining the well-being of those for whom they care, the Alliance's mission is to be the objective national resource on family caregiving with the goal of improving the quality of life for families and care recipients.

National Alliance for Caregiving
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The sponsors thank Linda Naiditch and Priya Vasan of Mathew Greenwald and Associates, Inc. for conducting the study.

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Section 1
Introduction

Background

In 2004, the National Alliance for Caregiving and AARP conducted a national caregiver survey of adult caregivers in the U.S. Results showed that over 44 million Americans age 18 or older, or an estimated 21% of the adult population, provide care for an adult family member or friend age 18 or older. In this study, caregivers were asked two questions about their health, identical to CDC self-reported health questions. In the population as a whole, 9% of people report their health as only fair or poor. Yet, 17% of all caregivers in the national study reported their health as fair or poor, with 35% of those doing the most intense caregiving saying they have fair or poor health. In addition, 34% of those with only fair or poor health said that caregiving had made their health worse.

Method

This report presents the results of quantitative and qualitative research conducted by Mathew Greenwald & Associates on behalf of Evercare and the National Alliance for Caregiving to better understand the needs of caregivers who are in fair or poor health and who say their health has declined as a result of providing care for a loved one. In addition, this research sought to identify the specific wellness and prevention areas in which caregivers need help, as well as programs and services that would help caregivers attain better health.

The following topics are covered in this report:

- Degree of deterioration of health
- Effect of health on ability to provide care
- Choice in caregiving responsibility
- Aspects of health that have worsened
- Amount of time spent caregiving and ADLs assisted with
- Types of self-care affected by caregiving
- Doctors' awareness of caregiving role and suggestions made
- How preventative care and doctors' visits are affected by caregiving
- Receptiveness to services and programs for caregivers

Online Study

All of the quantitative findings presented in this report come from an online survey, conducted from July 21 to July 28, 2006, with 528 caregivers in fair or poor health who indicated that taking care of a friend or relative has made their health worse. These individuals qualified as caregivers because they indicate that they provided unpaid care to a relative or friend 18 years or older in the last 12 months. Caregivers who participated in the study were from Greenfield Online's panel of non-professional caretakers.

Assuming the panel sample is equivalent to a random sample of the targeted caregivers, the margin of error for the quantitative findings at the 95% confidence level is approximately plus or minus 4.3 percentage points. Sub-groups will have larger margins of error, depending on the size and sample of the groups.

Qualitative Research

Findings from 12 in-depth telephone interviews and four small discussion groups are described in this report to give insight into the meaning of the online study findings.

All results from this qualitative research is distinguished in the text by shaded boxes such as this one. In addition, all of the quotations from caregivers appearing in the report come from the in-depth interviews or discussions.

These interviews and groups involved caregivers in fair/poor and declining health like those in the online study. The interviews were held from November 30, 2005 to January 13, 2006. Two discussion groups were held in Alexandria, Virginia on January 11, 2006, and two were held in Baltimore, Maryland on January 12, 2006. All interviews and discussions were audiotaped.



Section 2
Key Findings

The caregivers who were surveyed find themselves in a downward spiral of health that worsens as a result of giving care, and now their overall health status is fair to poor. Fifteen percent of them say their health has gotten *a lot* worse because of providing care, and four in ten say it has gotten *moderately* worse (44%). The remaining 41% say their health is a *little* worse as a result of their caregiving.

These caregivers' health situation is more than just a problem for themselves. Fully half say their decline in health has also affected their ability to provide care (53%).

Despite their health problems, caregiving responsibilities do not subside for these caregivers. In fact, they report spending an average of 41 hours each week giving care. Half of them have intensive caregiving responsibilities, performing three or more activities of daily living (ADLs) for their care recipients (53%). ADLs are personal care, such as bathing, dressing, feeding, etc. A quarter perform one or two ADLs (28%), while 18% do not help with any. The latter group provides assistance with everyday activities like fixing meals, doing housework, and transporting their loved one to the doctor.

Not surprisingly, the degree of deterioration in caregivers' health increases in relation to the amount of time they spend caregiving and the intensity of their caregiving. In particular, the caregivers who spend 40 hours or more weekly attending to their loved one are more than twice as likely as those spending fewer than 20 hours per week to say their health became *a lot* worse as a result of caregiving (23% vs. 9%). Similarly, caregivers who perform three or more ADLs are almost twice as likely as those who are not performing any to say their health is *a lot* worse (19% vs. 10%).

Three-quarters of these caregivers in declining health feel they did not have a choice of whether or not to take on their caregiving responsibility (75%).

The most common aspects of their health that have worsened as a result of caregiving are as follows:

- Energy and sleep (87%)
- Stress and/or panic attacks (70%)
- Pain, aching (60%)
- Depression (52%)
- Headaches (41%)
- Weight gain/loss (38%)

When caregivers talk about their worsened health, stress seems to be the most pervasive health problem in their lives. They say they are under constant worry about their care recipient's well-being and whether more can be done to help them. When caregivers' responsibilities and concerns are taken in the context of the responsibilities they have for their own lives, including work and family, they are completely overwhelmed. Caregivers believe that the stress takes physical form as some of the other health problems that they report, including increased blood pressure, heart attack scares, arthritis flare-ups, acid reflux, headaches, and other conditions.

Those who spend 20 or more hours weekly giving care are more likely than others to report loss of sleep, loss of appetite, increased pain, and worsened headaches.

Nearly all of these caregivers in decline suffer from depression (91%), including 60% who say their depression is *moderate* or *severe*. Eight in ten of those who are depressed say caregiving made their depression worse (81%).

Some say the depression stems from the sadness of seeing a loved one in ill health, stress in their own life, feelings of being overwhelmed, and a lack of sleep.

Caregiving has an impact on various aspects of caregivers' overall well-being. Nine in ten say they now worry more or feel more stress (90%), and seven in ten spend less time with family and friends (69%). Those who feel they did not have a choice in becoming a caregiver are particularly likely to experience these changes. Those who perform three or more ADLs are especially likely to spend less time with family and friends.

Half report taking more medications as a result of providing care (51%) and 10% report more frequently misusing alcohol or prescription drugs.

Even though one might hope that these caregivers in fair/poor and declining health could be focusing on ways to improve their health situation, their own health behavior is negatively affected by caregiving. Specifically, eight in ten say their sleeping is worse than before they were caregivers (82%), and six in ten say their eating habits are worse (63%) or their exercising has gotten worse (58%).

Moreover, half of caregivers now do at least one basic preventative care practice less often than they used to (52%). The practices that caregivers most commonly put off are getting their teeth cleaned at the dentist (33%), having a periodic vision test (29%), or getting a routine medical exam (26%).

Caregivers' self-care suffers because they lack the time and energy to prepare proper meals or to exercise. Their sleep may be interrupted several times a night by their care recipient, and they cannot tally a sufficient number of hours a night to stay rested.

The dropping off of these self-care habits and preventative health care practices is more prevalent among caregivers whose health condition is *moderately* or *a lot* worse than it is among those whose health is only *little* worse as a result of caregiving. The worsening of basic sleeping, eating, and exercise habits is also more common among caregivers who spend more time giving care or who are in more intense caregiving situations (in terms of ADLs).

Perhaps most worrisome is the finding that seven

in ten of these caregivers in decline say they have not gone to the doctor as often as they should since they began providing care (72%). The top reasons caregivers give for not going to the doctor is that caregivers put their family's needs over their own (67% say this is a *major* reason) or their care recipient's needs over their own (57%). Perhaps relatedly, 51% say a *major* reason they do not go to the doctor as often as they should is because they have no time to take care of themselves, given their other responsibilities. Nearly half say they are simply too tired (49% *major* reason).

They do not keep up their medical care because of lack of time and energy, or the difficulty of finding back-up caregivers for the time they take to attend to themselves. A few cite financial reasons for cutting back on medical care.

A large majority of these caregivers say a doctor is aware of their caregiving role (82% overall), with 64% saying one of their own doctors is aware and 74% saying their care recipient's doctors are aware.

More than half of the caregivers who say a doctor is aware of their role say that a doctor has given them suggestions about how to take better care of their health.

What services would help these caregivers? Of the several services described to them, they would be most likely to use a service in which they could call an expert about the stress they feel and other caregiving issues (63% *very/somewhat* likely to use).

Six in ten of these caregivers in declining health would also be likely to use a mobile health service that gives them health services in their neighborhood (63%).

Caregivers say a mobile health service would save them the time of traveling to the doctor's office, and they may be able to use the service without having to schedule back-up care for their care recipient. Caregivers would like it if the service could fill their prescriptions also. Caregivers say that they would be more likely to do their routine care if they could quickly visit a mobile van.

More than half would be at least *somewhat* likely

to talk to someone who could tell them about caregiving products that might save them time and energy (55%).

Caregivers also recognize that they could save time, reduce stress, and possibly avoid injury or problems if a consultant helped them identify products that would ease their caregiving efforts (e.g., products that make bathing easier, a medical alert system, something to carry several oxygen tanks on a wheelchair).

Half of caregivers in declining health would like to talk to someone who could help them identify tasks that other family members/friends could be doing for them and teach them how to gain that cooperation (51%).

Caregivers often have family members or friends who could help them but do not. Caregivers are reluctant to ask for help and they make false assumptions that certain people are unable to help. Some caregivers also do much more for their care recipients or their families than they need to. They would benefit greatly from someone who could help them identify people who can give them support or respite, break through their preconceived notions about who can help, and phrase the requests to be as effective as possible. Any additional help from others would give them more time to address their health needs.

Half would like to be able to call a nurse to stay with their care recipient while they go to the doctor themselves (50%).

Almost as many would be at least *somewhat* likely to use a service where someone calls them to check up on their health, remind them to set doctors' appointments, and to encourage them toward their own personal health goals (47%).

Caregivers say that they would care more about themselves if someone conveyed that they care about them. They say if a "health coach" elicited personal commitment from them to do a particular health behavior, they would be more likely to follow through. Even simple reminders about their medical appointments or to eat right may help them keep their own health as a priority.

Nearly half indicate they would be *somewhat* or

very likely to use a service where someone teaches them how to do certain caregiving tasks (45%).

Four in ten indicate they would be likely to use a transportation service (40%).

Key Elements for Programs Supporting Caregiver Health

Qualitative research indicates that programs have a chance to improve caregivers' health if they do at least one of the following:

- Save caregivers' time
- Relieve them from caregiving responsibilities for any period of time
- Reduce their level of stress
- Make them feel cared about, valued

The existence of caregiver support services is not sufficient to ensure they are used. Caregivers need to be made aware of their existence through concerted communications efforts. Caregivers may also need encouragement to initially try whatever services are offered. Further, the programs need to be affordable.



Section 3
Detailed Findings

Caregiver Health Decline

Most of these caregivers' health has gotten at least moderately worse. Half believe their health decline has affected their ability to provide care.

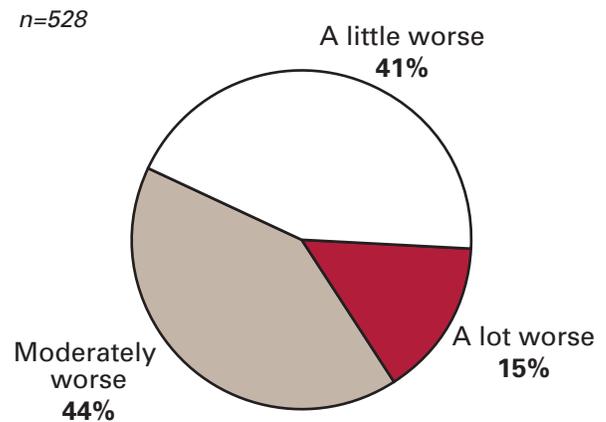
Of the caregivers surveyed — all in fair/poor health and having seen a decline in their health as a result of caregiving — 15% say their health has gotten *a lot* worse because of providing care, and four in ten say it has gotten *moderately* worse (44%). Another 41% say it has become *a little* worse.

- The degree of deterioration in caregivers' health increases in relation to the amount of time they spend caregiving. It also increases with the intensity of the caregiving in terms of the number of activities of daily living (ADLs) they perform. In particular, nearly one-quarter of the caregivers who spend 40 hours or more weekly attending to their loved one say their health became *a lot* worse (23%) as a result of providing care, compared to 9% of those who spend fewer than 20 hours a week caregiving. Similarly, the degree of health decline is greater for caregivers who help with three or more ADLs (19% *a lot* worse vs. 10% who are not involved in ADLs).
- Caregivers with severe depression are much more likely than those with slight or moderate depression to say that their health has gotten *a lot* worse (37% vs. 11%).

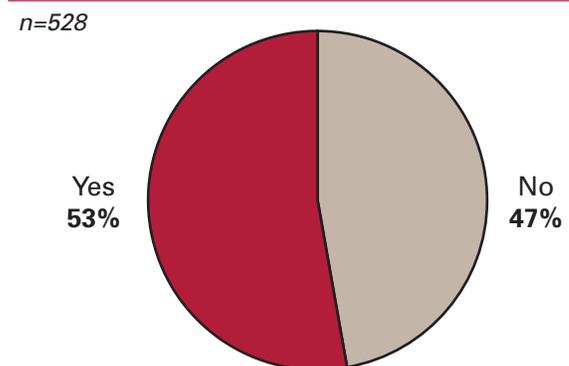
Half of these caregivers feel the worsening of their health has affected their ability to provide care (53%).

- The greater the effect caregiving has had on their health, the more likely caregivers are to say that their worsened health has affected their ability to provide care. Specifically, four in ten of those whose health is *a little* worse say their ability to provide care has been affected (40%), compared to 58% who had a *moderate* decline, and 73% of those whose health is *a lot* worse.

How much worse has your health gotten as a result of providing care?



Has the worsening of your health affected your ability to provide care?



Hours of Care Per Week

Nearly four in ten caregivers who are in declining health provide at least 40 hours of care per week.

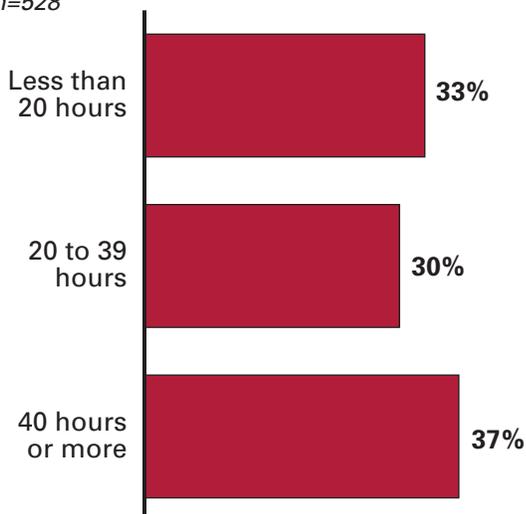
Close to four in ten caregivers with declining health (37%) spend 40 hours or more weekly providing care. Another three in ten care for someone between 20 and 39 hours per week (30%), and the remaining third spend less than 20 hours per week caregiving.

On average, the caregivers surveyed report spending 41 hours each week providing care.

- The amount of time spent caregiving rises with the number of ADLs the caregiver performs. Those who assist with three or more ADLs spend an average of 51 hours each week giving care, compared to 34 hours for those who do one or two ADLs, and 26 hours for those who do not perform any.
- The caregivers who say their health is *a little* worse than before caregiving spend the fewest hours per week on average (35). Those seeing a *moderate* deterioration in their health spend 42 hours per week on average, and those experiencing the greatest drop in their health status spend 58 hours, on average.

About how many hours do you spend in an average week providing care?

n=528



ADL Assistance

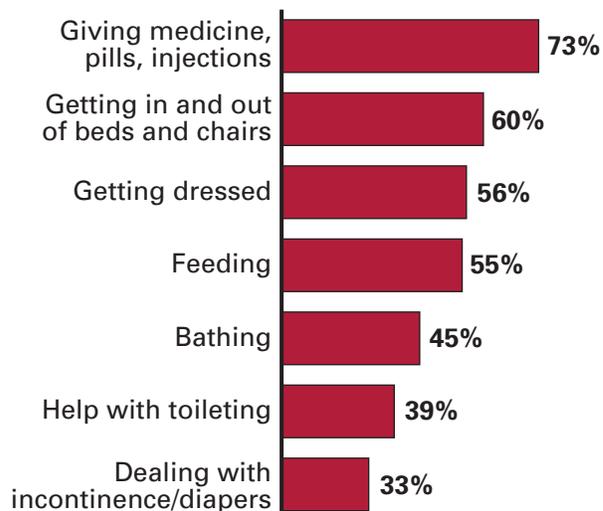
At least half provide assistance with three or more ADLs.*

Seven in ten of the caregivers with declining health help their loved one with medicines (73%). Over half help with getting in and out of bed or chairs (60%), dressing (56%), or feeding (55%). Roughly four in ten provide help with bathing (45%) or toileting (39%), and one-third assist with incontinence or diapers (33%).

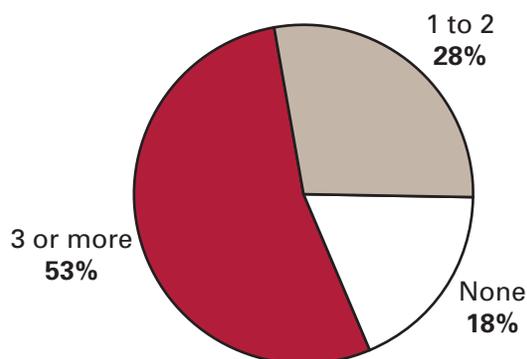
More than half of caregivers report helping with three or more ADLs* (53%).

Which of the following kinds of help, if any, have you provided?

n=528



Number of ADLs Performed*



* Activities of Daily Living, including all the tasks in the graphic except giving medicines.

No Choice

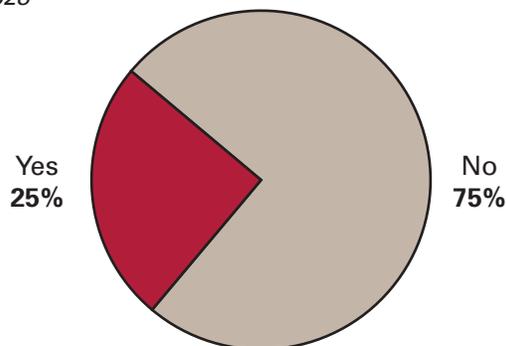
The large majority believe they had no choice in taking on their caregiving responsibility.

Three-fourths of caregivers whose health has worsened as a result of providing care believe they did not have a choice of whether or not to take care of their relative or friend.

- Those in the 35 to 44 age group are the most likely to feel they had no choice in taking on the caregiving responsibility (85%), more so than those who are younger (65%) or those who are older (75%).
- Caregivers who are in *poor* health are more likely to feel they had a choice than those in *fair* health are (33% vs. 21%).

Do you feel you had a choice in taking on this responsibility for caring for your relative or friend?

n=528



Caregiver Health Decline Symptoms

The most common aspects of caregivers' health that worsen from caregiving: **fatigue, stress, pain, and depression.**

Caregivers who say their health has worsened as a result of providing care report lack of sleep and energy most often as the aspect of their health that has worsened as a result of caregiving (87%). Another seven in ten indicate that they feel more stress (70%) than before they became caregivers, including some who say they have more panic attacks than before (24%). Six in ten report they now feel more aches or pain (60%), and half say that they are more depressed than before they became caregivers (52%).

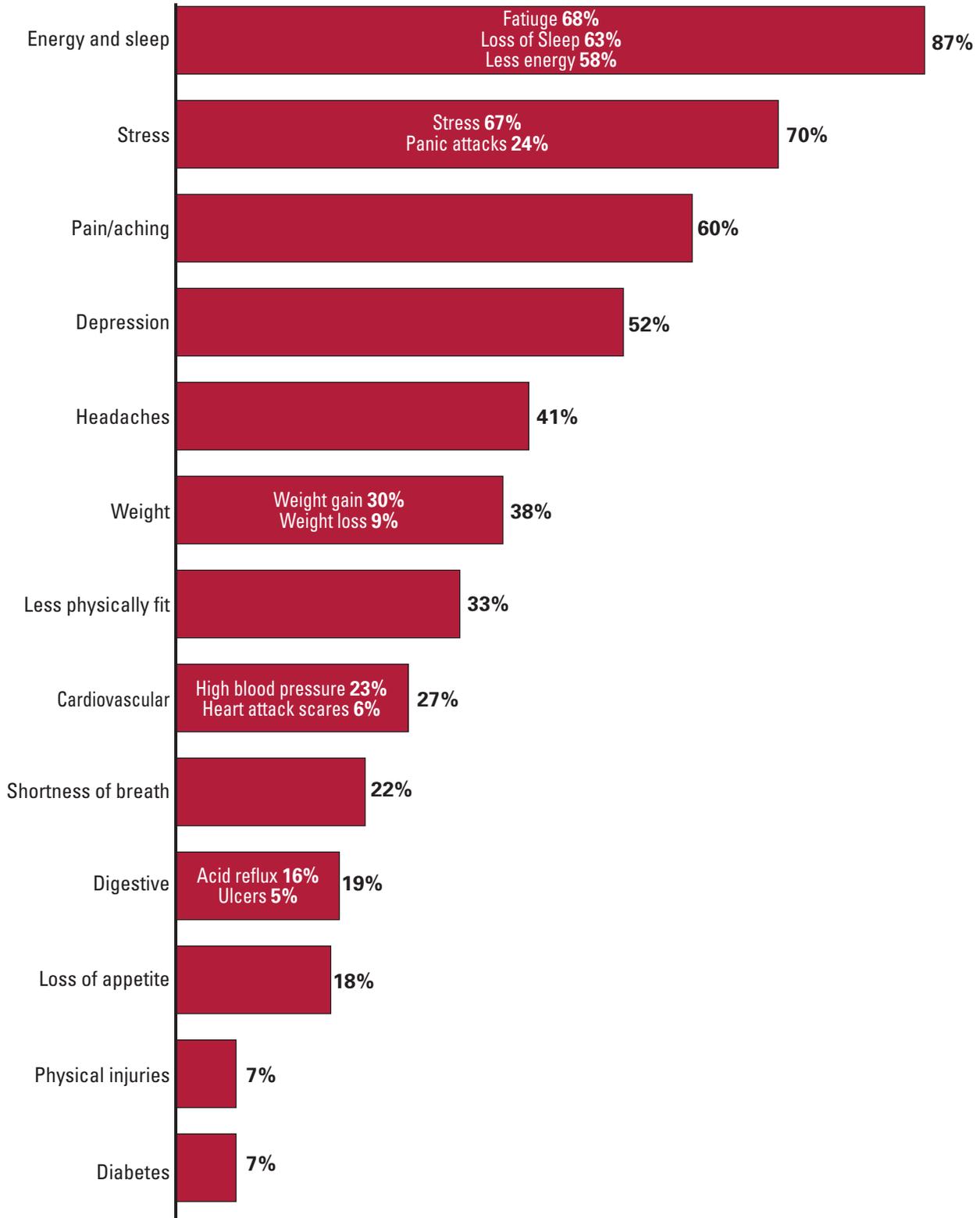
Other common aspects of health that worsened include headaches (41%), weight (38%), physical fitness (33%), high blood pressure or heart attack scares (27%), shortness of breath (22%), digestive problems (19%), and loss of appetite (18%).

- For almost every one of the specific types of conditions, caregivers who report the steepest overall declines in health are more likely to note that the particular condition worsened. The main exception is that lack of energy and sleep is an equal opportunity problem, worsening just as often for caregivers who had modest declines in overall health status as those who had more severe declines.
- Fatigue is a condition that worsens more for caregivers ages 35 or older than for younger caregivers (70% vs. 57%). As one might expect, worsened high blood pressure is more prevalent among those 55 or older (33% vs. 18% of those who are younger). Caregivers who are at least 45 years of age are less likely, however, to say their panic attacks have worsened (19% vs. 32%) or their headaches have (33% vs. 55%).
- Those who spend 20 hours or more caregiving are more likely than others to report loss of sleep, loss of appetite, increased pain, and worsened headaches. Performance of ADLs is also associated with sleep loss, pain, and headaches. Moreover, those who help with three or more ADLs are most likely to mention loss of appetite, being less physically fit, aches and pain and shortness of breath.

Caregiver Health Decline Symptoms (continued)

In what way did your health become worse as a result of giving care?

n=528



Stress

Stress is the symptom that stands out most day to day, and it may be causing some other health problems.

When caregivers explain in what way their health has worsened as a result of caregiving, stress stands out the most to them. They feel they are under constant stress from the caregiving workload, the ongoing worry about their loved ones' health conditions, and the concern about whether they are doing their caregiving job well. They describe the stress as extremely fatiguing and generally wearing on their well-being.

It keeps me under stress because of the worrying if there's something I could do to make her more comfortable. Just constantly having to do something, between the working and trying to do stuff at home, and it seems like there's no time for time out... Stress pulls you down both mentally and physically.

In turn, the stress emerges in varied physical forms. Many caregivers say the stress raised their blood pressure—to the point of a heart attack scare in some cases. For other caregivers, the stress created arthritis flare-ups, acid reflux, panic attacks, an increase in smoking, or TMJ (temporomandibular joint disorder).

If I'm stressed all the time, it [my blood pressure] would jump really high, to the point one time they told me if I didn't calm down, I'd have a stroke... I had to be on three medications instead of one medication.

I also have TMJ, the dental thing where my jaw locks, and that's stress. That's nerves.

The stress affected me a great deal, just not feeling well, being depressed, and crying a lot... They had to put me on medication for blood pressure... I never had that before. Then, for a couple of months, I couldn't stop vomiting, they said I had reflux... I never had it in life before and I haven't had it since... A couple times, just from the stress I thought I was having a heart attack. I had to go to the hospital.

Some health problems are actually caused by caregiving responsibilities, as when caregivers suffer injury from tasks such as lifting and transferring. Some caregivers who should be particularly careful because of their own health issues—a serious back problem or a prolapsed uterus, for example—find it difficult to avoid the tasks that they should.

My wife, she's in decent health, but things are happening to her like her shoulders, from pulling on her mom, are really sore, and she can't do a full rotation of her arm. One of her thumbs is hurting so bad she can't rotate it properly.

Because she is heavy, me picking her up and moving her, because she was bedridden, that caused me to start having back problems. I had actually thrown my back out.

My back is getting... [affected], I'm doing things I'm not supposed to be doing—laundry, cooking, cleaning, and helping my mom up when she needs help. It's making it [my back problem] progress a lot faster, and I end up taking more pain pills to counteract the pain.

Depression

Nearly all of these caregivers experience depression.

Nearly all caregivers whose health is declining as a result of providing care have some level of depression (91%). Six in ten report that their depression is *moderate* or *severe* (60% combined), while three in ten say their depression is *slight* (30%).

The depression appears to stem from the sadness of seeing a loved one suffer and from being overwhelmed with the responsibilities of caregiving.

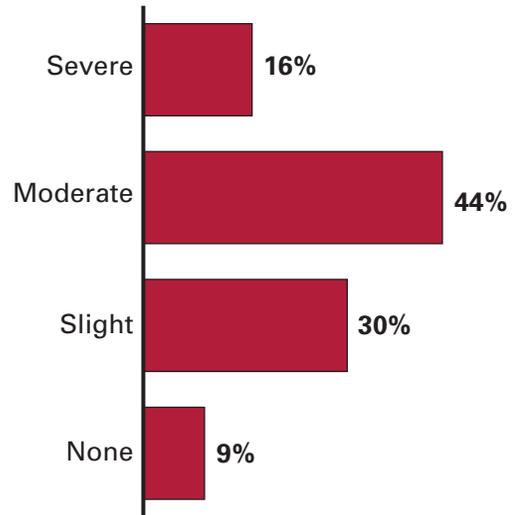
- The likelihood of having severe depression increases in relation to the intensity of caregiving. Only 8% of those providing less than 20 hours of care per week report *severe* depression, compared to 23% of those spending at least 40 hours a week giving care. Since the amount of time caregiving increases with performance of ADLs, *severe* depression is also more prevalent among caregivers who help with three or more of these tasks.
- Caregivers who are age 55 or older are half as likely as others to report a *severe* depression (10% vs. 19%).

Of those who report having depression, 81% say caregiving has made their depression worse.

- As one would expect, those who feel they had no choice in taking on the responsibility of caregiving are more likely than those who felt they had a choice to say their depression has become worse (84% vs. 70%).
- Caregivers who assist with three or more ADLs are more likely to say caregiving made their depression worse (86% vs. 75% who assist with fewer or no ADLs).

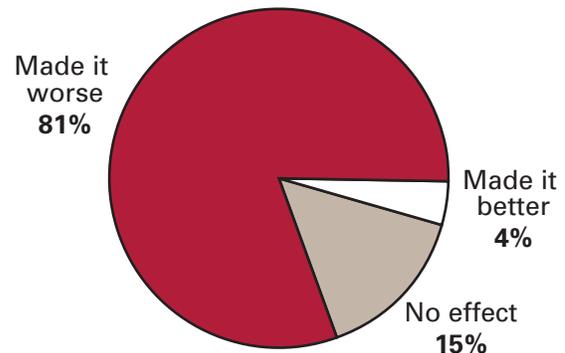
To what degree, if at all, do you have depression now?

n=528



How did caregiving affect your depression?

Those with severe to slight depression
n=479



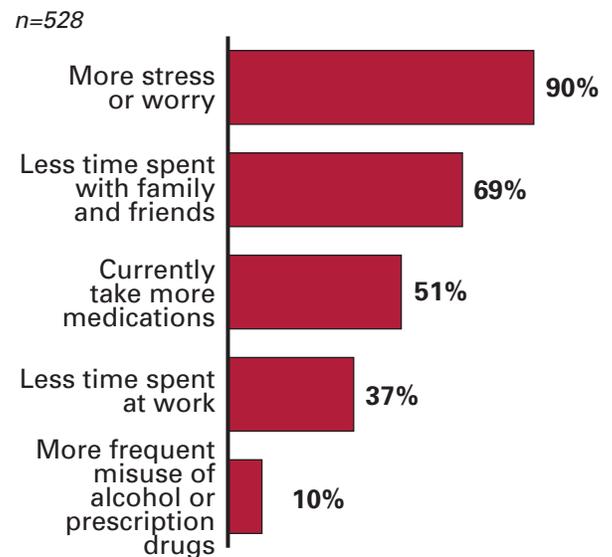
Less Time with Family/Friends

Stress/worry and less time with family and friends are prevalent.

Caregiving has an impact on various aspects of overall well-being. Nine in ten caregivers in declining health experience an increase in stress or worry as a result of providing care (90%). Nearly seven in ten are spending less time with family and friends (69%), and half say they are currently taking more medication than they did prior to becoming a caregiver (51%). Close to four in ten are spending less time at work (37%). Even one in ten admit to misusing prescription drugs or alcohol more often (10%).

- Those who feel they had no choice in taking on the responsibility of caregiving are more likely than those who felt they had a choice to say they have more stress or worry (92% vs. 83%) and spend less time with family and friends (73% vs. 58%).
- As the time spent caregiving increases, the more likely a caregiver is to report spending less time at work and an increase in the number or amount of medication.
- Caregivers who help with three or more ADLs are more inclined than those who assist with fewer ADLs to say they spend less time with friends and family (76%) and at work (45%).
- It is more common for caregivers under the age of 45 to say they misuse prescription drugs or alcohol (15% vs. 7% of older caregivers), but the older caregivers are more likely to say they increased the number or amounts of medications they take (42% vs. 56%).
- Those ages 35 to 54 express a greater likelihood of having more stress or worry since they started caregiving (95%) than their older (84%) or younger counterparts (85%). One might not expect this since the youngest caregivers (under age 35) appear to have even greater commitments outside of caregiving—they are most likely to have children at home and most likely to work full time.

How have the following aspects of your life changed, if at all, as a result of providing care?



Doctors' Advice

Only half say doctors gave them advice on taking care of their health.

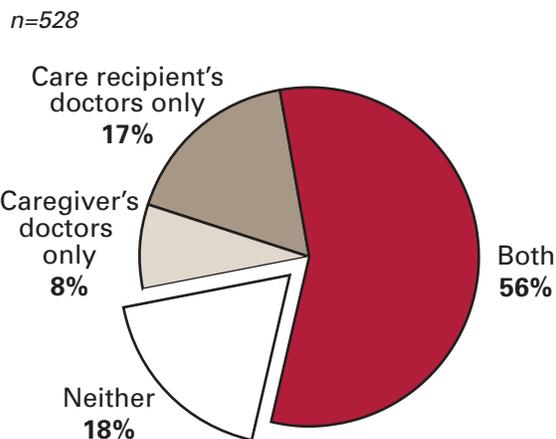
More than eight in ten of these caregivers say their own doctors or their care recipient's doctors are aware of their caregiving role (82%). A larger share of caregivers say that their care recipient's doctors are aware of their role (74%) than say their own doctors are (64%).

- As the amount of time spent caregiving increases, the more likely both types of doctors are to be aware of the caregiver's role. The same holds true for those helping with three or more ADLs compared to those who help with fewer or none.

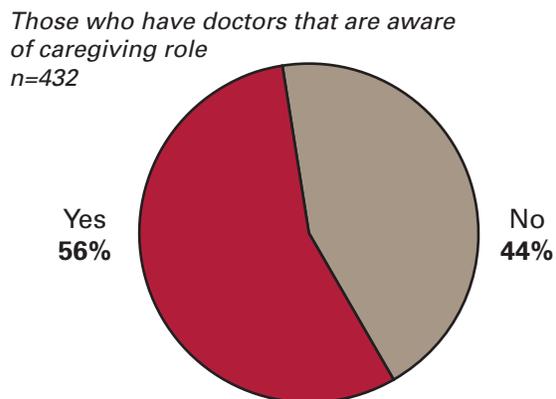
Among caregivers who say one or more doctors is aware of their caregiving role, over half say the doctors have made suggestions on how they can take better care of their health (56%). Four in ten, however, say the doctors have not given them such recommendations (44%).

- Caregivers who say their condition has gotten *a lot* worse (69%) since they began caregiving are more likely to say they have received suggestions from a doctor than those who say their health has worsened only *a little* (52%) or *moderately* (56%).
- Those who believe they had a choice in taking on the caregiving responsibility are more likely to have received suggestions about better taking care of their own health than those who say they had no choice (67% vs. 53%).

Are any of your doctors/the doctors of the person you provide care for aware of your caregiving role?



Have any of your doctors/the doctors of the person you provide care for made suggestions about how to better take care of your personal health?



Physicians' involvement ranges from simply urging the caregiver to take care of him/herself to actively arranging for supportive services.

One example of the type of suggestions that doctors offer to caregivers is simply to urge them to try to take care of themselves.

He told me to do exercise and relaxation. He didn't tell me to join Weight Watchers, but he said Weight Watchers would be a good thing. I did lose some pounds there, which helped bring my cholesterol down.

They always ask, "And how are you doing?" because they know what has been going on. I just tell them, "Okay." He'll say, "Are you taking care of your health?" They're very concerned, and they check up on me.

Some physicians suggest that caregivers take time away from their care recipient or consider placing him/her in a nursing home.

My doctor...wanted me to get more rest than I was getting. Since he was her doctor, he knew what she was doing. He was a great help to me in that he would explain each step of this disease...He also wanted me to get some time away from Ellen, some time either with my wife or by myself. He told me that many times.

She [the doctor] wanted me to go to caregivers meetings. She warned me that I had to take care of myself. She suggested that I think about placing my mother since it was a strain on me. She helped me talk to an organization on aging, and with her help I was able to get help for my mother. They sent a home health aide out to bathe her. That would give me a two-hour break twice a day. She talked to me about nutrition. She even gave me some medicine to relax me enough so I could get some sleep. She also talked about me about getting professional help for myself, a therapist.

On occasion, physicians help caregivers obtain part-time nurses aide services or other caregiving supports. One physician changed the type of catheter the care recipient had in order to alleviate the need for the caregiver to change it every four hours.

When I got sick, I told my doctor about it [the catheter issue]...And I said, "How am I ever going to take care of my husband and do this [catheter] every four hours if I go through chemo?" He right away called my husband's doctor, and they decided between them that it would be better for both of us if they put in a permanent catheter.

My father's doctors tell me more like that. They tell me, and they actually tell him too...it's time to take the load off of your daughter and son-in-law. It's taking too hard of a toll on us.

Sleep, Exercise, Eating Habits

Sleep, exercise and eating habits are worse than before caregiving.

When asked how their most basic types of self-care—sleeping, eating, and exercise—have been affected by caregiving, sleeping habits are most likely to have been negatively affected. Eight in ten of the caregivers in declining health say their sleep is worse than before (82%).

Some caregivers say their sleep is interrupted several times a night and they just do not tally the total number of hours of sleep that they need. Others say they are kept awake by the stress of their responsibility, and some feel a hesitance to sleep deeply in case their loved one calls for help. The sleep deprivation takes a particular toll over a long period of time.

When she first could not get up on her own...you would go to bed and two or three hours later she is asking to get up for half an hour, 45 minutes. That was a period that was really frustrating for us. Now she still calls out some at night... but it is not as bad. But, still you've had five years of interrupted rest.

About six in ten acknowledge that their eating habits (63%) and exercising (58%) are worse than before.

Caregivers say they have less time and energy to cook proper meals for themselves, or they eat whatever is easy, such as packaged foods, junk foods, and fast foods. Some, feeling depressed, lose their appetite, or contrastingly, binge or eat what they know is not healthy for them.

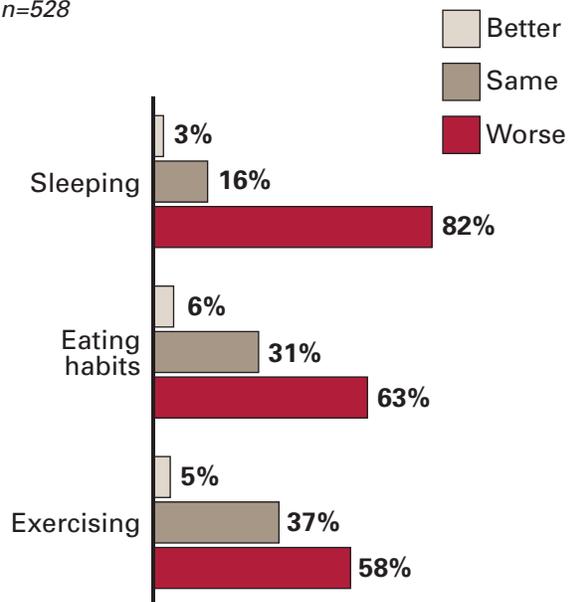
With sleep problems so common, it is not surprising that those who used to exercise fairly regularly have less energy to keep up their prior exercise routine. Others say they do not exercise because their caregiving and home responsibilities take up all of their time. A few feel that they cannot leave their loved one alone at all.

I used to walk every day, about three miles. That was my exercise. [Then, as a caregiver], when I did have a little time, I was so tired, I was trying to get a little rest for myself.

I have horses; we used to ride... [I don't ride anymore because] the minute I walk out the front door, mama's gonna call me.

Are the following types of self-care better, the same or worse than before you started caregiving?

n=528



Drop-off in self-care correlates with a greater degree of health decline.

- Those whose health condition is *moderately* or *a lot* worse as a result of providing care are much more likely than those whose health is only *a little* worse to say their exercising, eating, and sleeping habits are not as good as they were prior to caregiving.
- These self-care habits are more commonly worse among those who provide care for more than 20 hours weekly than among those who spend less time caregiving. Those who help with three or more ADLs are also more likely than those who do not help with any ADLs to say each of these habits has become worse.
- Negatively affected eating habits are more common for caregivers under age 45 than for older caregivers (74% vs. 56%). Those who work full-time are also more apt than others to say their eating habits are worse than before (73% vs. 53% for part-timers and 62% for those who are retired or not employed).

Preventative Care

Half have slipped on at least one preventative care activity.

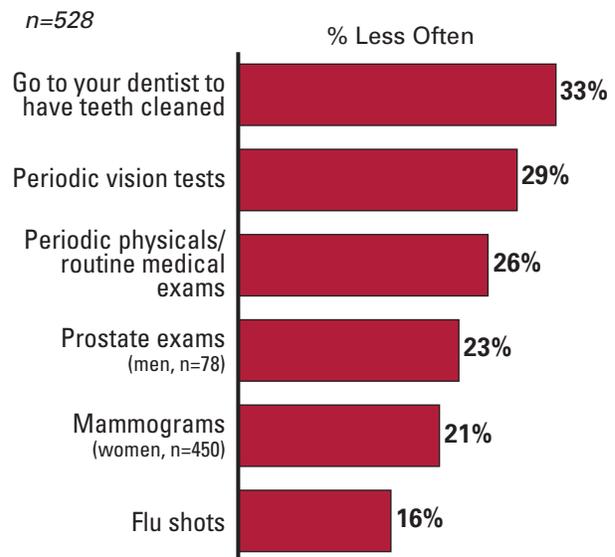
Half of caregivers with declining health say they engage in at least one of the various preventative health measures examined in the survey less often than they did before they began providing care (52%).

The most common preventative health measures to be neglected are having one's teeth cleaned by the dentist and having periodic vision tests; 33% and 29%, respectively, do these less often than before they were caregivers. One-quarter have a physical exam less frequently (26%).

More than one in five men are not as up to date with their prostate exams as they used to be (23%), and a similar proportion of women have mammograms less often (21%). Sixteen percent get flu shots less often since becoming a caregiver.

- Those whose health has worsened at least *moderately* are more likely than those with only a *little* decline in health to report doing each of these health care activities less often than before, with the exception of prostate exams for men.
- Caregivers who feel they did not have a choice in taking on their caregiving responsibility are more likely than others to do at least one of the activities less often, particularly teeth cleanings with their dentist (35% vs. 26%) and routine medical exams (29% vs. 17%).
- Caregivers ages 55 and older are most likely to keep up with their vision tests (20% have them less often vs. 33% of caregivers under age 55). They are also most likely to continue their flu shots on the same frequency as before (11% get them less often vs. 22% of caregivers under age 45).

How often do you do each of the following compared to before you began providing care?



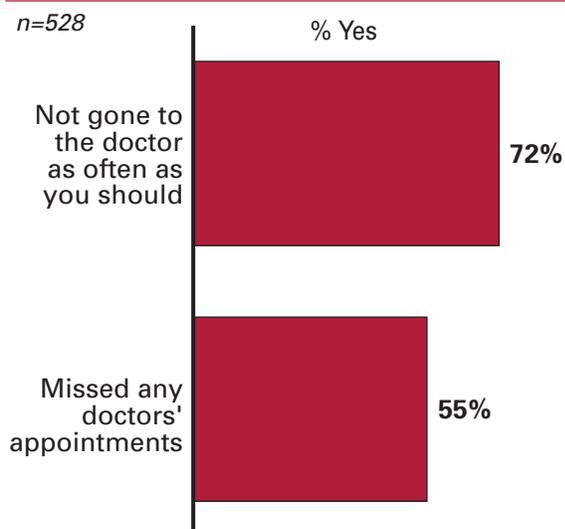
Seven in ten of these caregivers do not go to the doctor as often as they should.

Even though all of the surveyed caregivers are in fair/poor health and have seen a worsening of their health since becoming a caregiver, seven in ten acknowledge they have not gone to the doctor as often as they should (72%), and more than half have missed doctors' appointments (55%).

- These impacts rise in relation to the time and intensity of the caregiving responsibility. Specifically, a larger share of caregivers who spend 20 or more hours a week giving care have missed appointments (61%) than caregivers who spend less time in their caretaking role (42%). Correspondingly, those who are involved in three or more ADLs are more likely to have missed appointments (66% vs. 42% of those helping with two or fewer ADLs). They are also more likely to have not gone to the doctor when they felt a need (77% vs. 61% of those who do not help with any ADLs).

- Perhaps demonstrating a sense of depression, caregivers who feel they had no choice in taking on their caregiving responsibility are also more likely than their counterparts to report that they have not gone to the doctor when they felt the need (75% vs. 61%).
- Ironically, the caregivers whose health has declined the worst since caregiving (*moderately* or *a lot* worse) are more likely than those whose health has only gotten *a little* worse to have missed doctors' appointments (63% vs. 42%) or to have not gone to the doctor when they felt the need (78% vs. 63%).
- Older caregivers, age 55 or over, are less likely than younger ones to have missed doctors' appointments (44% vs. 59%).

At any point since you have been providing care, have you...



I had a hernia—they said from lifting her—and I needed to get surgery and I had to postpone the surgery...until I was able to could get some help. I postponed that surgery for about four months.

I haven't had my thyroid tested for three years. I take Synthroid. I've had a refillable prescription...I used to get my thyroid levels checked every six months.

I was in the process, when I took over taking care of mother, of having my teeth worked on and having them fixed, and I had to quit doing that so I've lost three of them.

The top reasons caregivers do not go to the doctor when they should: putting family needs and their care recipient’s needs ahead of their own.

The top two reasons caregivers say they do not go to the doctor as often as they should is that they put their family’s needs or their care recipient’s needs over their own. (67% and 57% cite these as *major* reasons, respectively.) Along these lines, half say they have no time to take care of themselves, given their other responsibilities (51% *major* reason).

Nearly half consider fatigue a *major* reason (49%) they do not go to the doctor as often as they should.

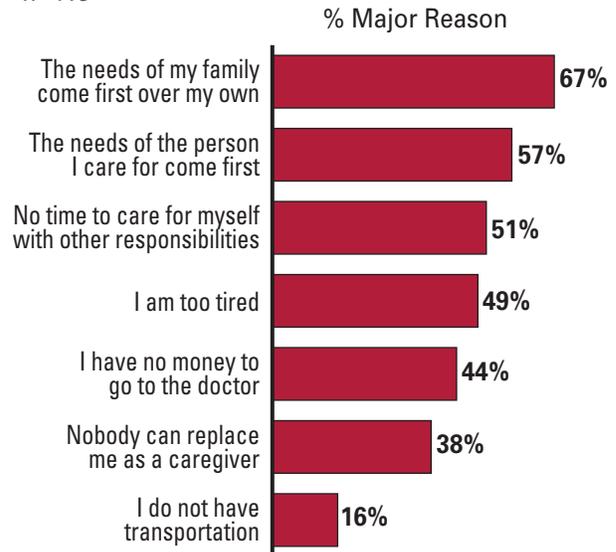
Money is a *major* issue for 44%, and transportation is a *major* barrier for 16% of these caregivers.

Nearly four in ten feel there is no one who can replace them as a caregiver (38%) .

- Those who provide more intensive care — three or more ADLs or 20 or more hours — are most likely to report the needs of their care recipient coming first, lack of time with all their responsibilities, and lack of anyone to replace them as *major* reasons for not going to the doctor as often as needed.
- Those who feel they had no choice in taking on their caregiving responsibility and those whose health decline was at least *moderate* are also more likely to report the same three reasons.
- As caregivers get older, they are less likely to consider each of these a major reason for not going to the doctor, with one exception— similar proportions of all age groups of caregivers say the needs of their care recipient come first.

To what extent is each of the following a reason you are not going to the doctor as often as you should?

Those who missed doctors’ appointments or have not gone to the doctor when they felt the need
n=415



Caregivers explain some of the reasons they do not always go to the doctor when they should.

The Care Recipients' Needs Come First

They're pushing for back surgery, and I keep putting it off. I just can't do it. You're talking probably six months of rehab. I'd have to put my mom in a rest home.

We try to take care of our health, but sometimes if there's a problem with her, you don't feel like you can go do what you need to do until her problem is straightened up.

I think it was hard for me to take time to get sick when I got cancer because I was so busy taking care of my husband...Their cares come before your cares. You have to get up and do it regardless of whether you're sick. If you're vomiting you just quit and...do something else to take care of a need they have.

Lack of Time

I've never had a mammogram. I'm supposed to. I'm 42. I actually am carrying a prescription from my doctor that has been in my purse for about six months. I just haven't had the time to do it.

I'm overdue for [a vision appointment]. It's been over two years...I just don't want to make the appointment and go because we're always running and doing something. It's just one of the things you just put off.

There were times when I felt like I needed a physical, and I had bad knees and aches and pains. But I just didn't take the time to do it.

Financial Reasons

It became a financial thing...I had to get a second mortgage on my house. I had to pay for her medications which were very expensive. I know I didn't go to the doctor as much because I chose to give her medication and pay for her doctor's stuff more than for my stuff.

The last one [mammogram] was seven years ago...Before, I had a different job and I had insurance. I don't now.

No One Can Replace the Caregiver

I would go to my appointments, but that would be about every three months when I could get someone to stay with her. Sometimes I cancelled because I couldn't get anyone. [I was supposed to go] every month.

You know how they tell you go for a sleep disorder, you have to spend the night. I scheduled it maybe four times, rescheduled and rescheduled and rescheduled, because I couldn't find someone to stay with my mommy, and my husband said, "I'm not going to do it," and my son said, "I'm not changing diapers."

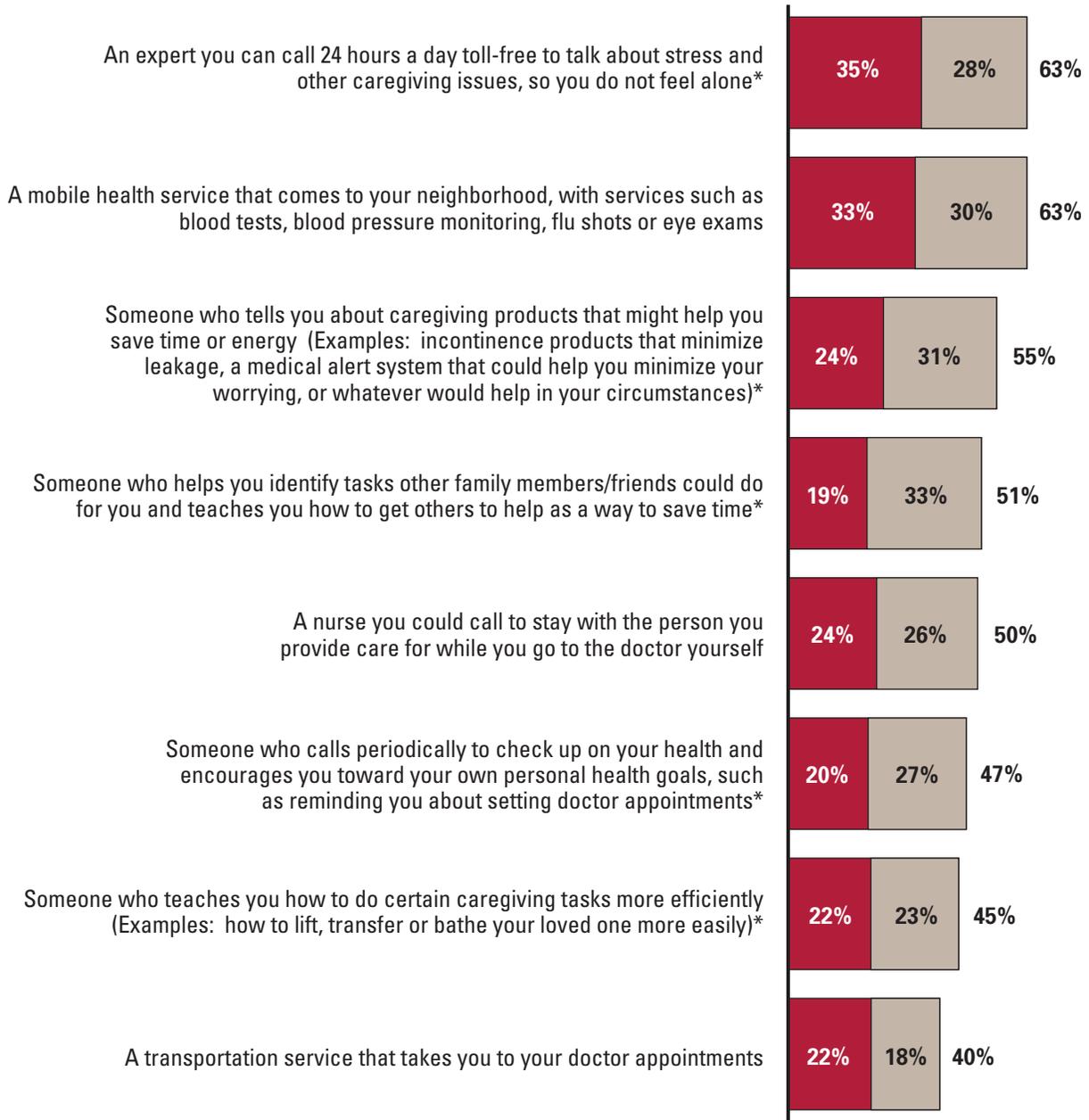
Caregiver Solutions

Caregivers are receptive to services that offer support for health goals, caregiving expertise, or time savings.

How likely would you be to use each of the following types of assistance?

n=528

Very likely Somewhat likely



* Caregivers were asked to assume that there would be minimal, if any, costs for these services.

Six in ten would call an expert about stress and other caregiving issues or use a mobile health service.

What services would help caregivers who are in fair/poor health and whose health has been negatively impacted as a result of providing care? Of the services described to them, these caregivers indicate they would be most likely to use two services:

- 1) a service in which they could call an expert — toll free and 24 hours a day — about stress and other caregiving issues so they do not feel alone (63% *very* or *somewhat* likely to call), or
- 2) a mobile health service that would enable them to get health services in their neighborhood, such as blood tests, blood pressure monitoring, flu shots or eye exams (63%).

Roughly half say they would be at least *somewhat* likely to talk to someone about time- and energy-saving products (55%), talk to someone about how to get family members and friends to help more with caregiving (51%), or to have a nurse stay with their care recipient, so they could go to the doctor to take care of themselves (50%).

Almost as many would be likely to use a service where someone calls them to check up on their health, to remind them to set doctors' appointments and to encourage them toward their own health goals (47%) or a service where they are taught how to do caregiving tasks more efficiently (45%). Fewer, four in ten, would be likely to use a transportation service that would take them to their doctor appointments (40%).

- For each of the services, interest is more common among those who assist with three or more ADLs.
- Those whose health has gotten *moderately* or *a lot* worse show a much greater likelihood than those with a *slight* decline in health of calling the expert about stress and caregiving (70% vs. 54%), having someone call them to encourage their own health progress (53% vs. 38%), or using a transportation service (44% vs. 34%) or mobile health service (66% vs. 58%).

- Caregivers who spend 40 hours or more per week giving care show significantly higher interest than others in having someone help them identify tasks that other family members or friends could do and to teach them how to get others to help (59% vs. 47% of those who spend fewer hours).
- Larger shares of caregivers in *poor* health say they are *very* likely to use the mobile health service (40% vs. 30%), a nurse to stay with their care recipient (31% vs. 22%), and a transport service (31% vs. 18%) than do caregivers who are in *fair* health.
- Similarly, those who have received suggestions from doctors to take better care of their own health are more apt than those who have not received suggestions to say they are *very* likely to use the mobile health service (39% vs. 29%), a nurse to stay with their care recipient (30% vs. 20%), and a transport service (28% vs. 15%).
- Caregivers who feel they had a choice in taking on the responsibility of providing care are more likely than those who feel they had no choice to use a transportation service (*very/somewhat* likely: 51% vs. 37%).

Mobile health services are seen as a time-saver.

Expert on Call*

Having an expert on call for help handling a difficult situation makes a caregiver feel less “alone.”

I know the Alzheimer's Association has a 24/7 hotline, and I think there was one night—it was 2:00 in the morning—and my father had done some behavioral thing. I didn't know how to deal with it, and there was somebody there to talk to... That just made me feel like I wasn't completely alone with it.

* The qualitative research did not examine this type of service directly, although one participant recounted an experience with a similar service.

Mobile Health Services

Caregivers who would like a mobile health service say it would save them time and make it easier for their medical care to fit into their schedule. A mobile health vehicle in their neighborhood would save them the time of traveling to and from their doctors, and they believe they would wait less time than they do at their doctors' offices. If the service is very close to their home, they may not even need to arrange for someone to care for the care recipient in their absence.

That would be a wonderful thing. Even the travel time to get ready to go somewhere, that adds up to a lot of time. And if you had something that was actually coming to you, it wouldn't take up nearly so much of your time, and it would encourage people; you would be more likely to do it.

Scheduling is an important consideration for a mobile health service. For working caregivers, the service would have to be available after work or on weekends. Some caregivers feel they cannot schedule anything, so the service would have to arrive at regular, predictable times that would allow the caregiver to "pop in" if he or she had the flexibility to do so on a given day.

Caregivers who are interested in mobile health services envision that the service could include flu shots, blood tests for diabetes or other conditions, blood pressure monitoring, eye exams, mammograms, general check-ups, lab work and prescription services for them or their care recipients. Some say it would be nice if the service specialized in the needs of caregivers or if it offered mental health counseling.

Caregivers realize that specialized products could help save them time and energy and minimize stress.

Resource Person on Time- and Energy-Saving Products and Services

Caregivers who like this type of service see it as a way to reduce the physical and mental stress they feel. It would save them the time they take to research different types of products to buy. Further, if they find the right products, it would help reduce the amount of physical effort it takes to do certain caregiving tasks. Some have already experienced the "Aha!" of finding an appropriate caregiving product, while others lament the lack of one. One caregiver suggests that this consulting service could also help her spend money more wisely.

I think anything that can help you solve a problem and make your life easier, you go, "Woo!"... Sometimes you don't even know to ask the question, like you have no idea it could be better... And if you can save time, like with bed and bath products, anything that could save time would be a big help.

I would love that... I'd like for someone to help me how to better handle wheelchairs... they don't have anything to put oxygen bags on. My mother is on two liters, so if you want to take her out, you take that one and you've got to run back to the car to get more. So there's got to be a gadget [where you can put four oxygen bags on]... I am stressed before I get to it. So if they can come up with something to make it easier... then I feel better... because stress is a downer. So if I relieve the stress, it keeps me up... I would start buying outfits for myself. I might even go out and get me a new boyfriend!

I'd be interested in the products because we are having some issues already with incontinence. And when you go to the store they just show the most expensive thing they can find... It would help me to know what things we actually needed and didn't need. Why waste your money?

Helping caregivers get more support from friends and family has great potential to relieve their burden.

Service Helping Caregivers Identify and Obtain Help from Others

One of the main reasons caregivers do more than they need to is that they are reluctant to ask others for help for fear of overburdening others. Some caregivers have had requests for help turned down, but many have not directly asked others to help because they think family members should proactively offer to help. Second, some caregivers unwittingly make false assumptions about why particular people cannot help. Third, many caregivers shy away from making hard decisions about tasks that they can shed entirely. Sometimes caregivers say that if they did not fulfill a particular request of their care recipient, they would feel guilty or they would see themselves as an inadequate caregiver.

The result of all of these factors is that many caregivers shoulder more responsibility than they have to, given the other family members and friends who could potentially help them and given what is truly necessary to be a good caregiver. Examples of such situations for people who are already stretched to their limits include:

- A caregiver who does the grocery shopping for her mother, even though her siblings are willing to, because her mother complains if someone else takes her
- A caregiver who does laundry for children ages 11 and older
- A caregiver who styles the hair and manicures the fingers of her mother who has dementia
- A caregiver who home schools her children
- A caregiver who takes care of 12 chickens, a rooster, a rabbit, two dogs and two cats
- Several caregivers who do not ask their adult children who still live at home to help them

A number of caregivers recognize they would be better off if family members helped more with the caregiving, and they respond positively to the idea of a consultant who would work with them on obtaining this. They acknowledge that a consultant could help them word any request for help, so that it would be effective and could work in conjunction with family members to increase the likelihood that caregiving responsibilities would be shared more widely.

It would also give me a chance to maybe learn how to approach my family members in a different way...and if they can help do things, then maybe I will have time to go to the gym or whatever it is that I want to do to help improve my health.

If they could offer a service that would teach me how to delegate more, I'm sure my siblings would respond...If they taught me how to realize that some things are on the A list and some things are on the Z list, prioritizing, that would be a God-sent type of service...You wouldn't be running around like a chicken with your head cut off.

Having an objective consultant advocating that caregivers try to share their responsibilities seems to make some caregivers feel like they have permission to do so. In other words, a consultant could help a caregiver establish boundaries.

Nurse Who Stays with Care Recipient While Caregiver Goes to Doctor

Caregivers believe this nursing service would positively impact their health in two ways. First, it would relieve them of their caregiving responsibilities long enough for them to take care of the medical appointments that many would otherwise neglect. Second, it would reduce the stress they feel when leaving their care recipient. They believe a nursing service would be able to competently handle any needs that may arise with the care recipient. Any reduction of stress could alleviate their stress-related physical symptoms.

That would be a blessing. I'd just feel more at ease. At least I'd know when I came home everything would be the same, it's not going to be that she fell or needed me for something and I wasn't here.

Checking up on caregivers' health by phone makes them care more about themselves.

Service That Checks Up on Caregivers' Health by Phone

Caregivers say that simple encouragement and reminders from a "health coach" may help them make and follow through on their medical appointments or take steps to eat better or exercise. They explain that just having someone care about them would make them care about themselves more. Accordingly, it is important to them that the health coach be a person who is caring, someone with whom they feel they could talk. Another reason a health advocate would be effective is because such a person would elicit a personal commitment from the caregiver to take action; some caregivers say they would follow through on whatever they said they would do. Caregivers say to be credible in this role, a person would need to be a nurse or someone else who has broad knowledge about health.

It would help, because they're focusing on you, the caregiver. It would validate you...It would be like friendly nudging to take care of yourself and to make your doctor appointments, because when you're caregiving, you're not focusing on yourself at all.

When I go to the doctor, you are in there and out...So I think if somebody could just call me, and if they really cared about me, that would help me better myself. Just to hear somebody push me and I think they care, that would help.

Of note, some caregivers say a health coach would not make a difference, because no matter how much they are encouraged to take care of themselves better, they still do not have the time or the money to do so.

Training on caregiving tasks makes caregivers feel more confident, and that reduces their stress.

Help Learning How to Do Caregiving Tasks More Efficiently

Caregivers say that learning techniques for caregiving tasks makes them feel more confident and reduces the stress they feel. They also recognize that learning how to do physical tasks properly could help them avoid injury. Any efficiencies and time savings would be a bonus that would give them some rest or free time they need.

[It would help] if she was able to tell me...how I could lift my sister and teaching me to bend my knees, because I'm going with minimal knowledge based on 10, 20 minutes instructions I got from the hospital. So it would make you assured that you are doing the right thing for yourself. I don't want to hurt my back, and I don't want to harm my knees. I would appreciate it very much.

When my mother was alive I had some people come in and teach me how to care for her; different things, whether it was preventing bed sores—and she had a couple of those she developed—and then when she couldn't swallow I had to crush up her pills and mix with food. They would tell me how to [do] things... We would be more self assured. We'd know what we're doing, and it would make us feel not nervous, take that little bit of strain off.

Transport Service

Qualitative research participants generally felt they would not be helped by a service that could transport them to medical appointments. They say they already have transportation—whether they drive themselves or whether family members take them. A few add that a transport service would not alleviate the need to find someone to take care of their care recipient in their absence. Further, some caregivers are skeptical that any transport service would be dependable or easy to work with.

Programs that help caregivers' health: save time, offer time off, reduce stress, show caring.

Characteristics of Programs That Help Caregivers Achieve Better Health

In summary, the types of programs that caregivers believe will help them achieve better health all do at least one of the following:

- **Save them time.** Time savings allow them time to exercise, to eat better, to go to the doctor, or simply to rest—all critical to their well being.
- **Relieve them from caregiving responsibilities for any period of time.** This relief clearly gives caregivers “extra” time to look after themselves, but it also gives them a temporary break from the worry and responsibility they shoulder. Nearly all caregivers wish for a significant amount of respite.
- **Reduce their level of stress.** Of course, gaining time and receiving respite can reduce caregiver stress, but so can programs that increase caregivers' confidence in their caregiving or help them make difficult decisions about caregiving. A reduction in stress would lead to a decline in the stress-related physical problems that caregivers endure, from high blood pressure to acid reflux.
- **Make them feel cared about, valued.** Caregivers are so used to caring about other people and have so little time and energy to take care of themselves that they would be responsive to someone who cares about their well being. Such a caring person could influence them to take better care of themselves or possibly give them the confidence to make tough decisions about what they do as caregivers.

With any service designed to support caregivers' health, however, the cost is a consideration for caregivers. Many are already on limited incomes, and some pitch in toward their care recipient's medical and living expenses. They are most likely to use services that are free or that cost the equivalent of a medical insurance co-payment.

Further, it seems the existence of caregiver support services is not sufficient to ensure they are used. First, many caregivers do not know that help exists and some feel too helpless to envision that they could be helped. Second, caregivers could clearly arrange some of the services they would like—such as nutritional counseling to improve their eating habits—by simply opening up the phone book, and some even have partial coverage through medical insurance, yet they do not. The services would have to be promoted and caregivers would need to be encouraged to try them. Without such encouragement and without an understanding of how they may be helped by a service, many caregivers would be reluctant to make the effort to carve the time needed to seek them out.



Section 4
Respondent Profile

Demographics

Eighty-five percent of the caregivers who responded to this survey are female, and about one in seven (15%) is male.

These caregivers are 47 years of age, on average, similar to the national caregiver average age of 46. Seven in ten are under the age of 55, including 17% under the age of 35, 20% who are 35 to 44, and 32% ages 45 to 54.

Most do not have a child under age 18 living in their household (65%).

Nearly two-thirds of respondents are not currently working—23% are retired and 41% are not employed. One-quarter are employed full-time (23%), and 13% are employed part-time.

Over seven in ten report their health as fair (73%). More than one-quarter say their health is poor (27%).

Over seven in ten have household incomes of under \$50,000 (71%), with 37% who have incomes of between \$25,000 and \$50,000. Less than one in five say they earn between \$50,000 and \$75,000 (17%). Only 11% report a household income of \$75,000 or more.

	<i>Total</i> <i>n=528</i>
Gender	
Female	85%
Male	15%
Age	
Under 25	4%
25 to 34	13%
35 to 44	20%
45 to 54	32%
55 to 64	25%
65 or older	5%
Average Age	47 years
Children Under 18 in Household	
Yes	35%
No	65%
Employment Status	
Employed full-time	23%
Employed part-time	13%
Retired	23%
Not employed	41%
Health Status	
Fair	73%
Poor	27%
Income* <i>(n=357)</i>	
Less than \$25,000	34%
\$25,000 to less than \$50,000	37%
\$50,000 to less than \$75,000	17%
\$75,000 to \$99,999	5%
\$100,000 or more	6%

* Based on respondents who disclosed their income.



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