



# The Evercare® Survey of The Economic Downturn and its Impact on Family Caregiving

**Report of Findings**

*April 28, 2009*



## Background

In the past year, the U.S. has experienced an economic recession and upheavals in the financial and mortgage markets that have had widespread impact on the financial well-being of millions of Americans. Evercare by UnitedHealthcare and the National Alliance for Caregiving (the Alliance), felt that it was important to take a look at this current economic downturn and its impact on the nation's 44 million family caregivers. This invaluable group in our society represents a \$375 billion annual economic value to the U.S. Family caregivers are the backbone of our health care system by providing long-term care in the home to those with chronic illness or disabilities<sup>1</sup>.



A previous study conducted by Evercare and the National Alliance for Caregiving, was the first in-depth look at the personal out-of-pocket costs for caregivers. ***Family Caregivers – What They Spend, What They Sacrifice***, published in November 2007, found that more than half of caregivers who were caring for someone 50 years or older, were spending on average more than 10 percent of their annual income – an average of \$5,531 per year. That study also found that 34 percent of caregivers had used some of their savings to cover caregiving costs.

With the current economic situation having tremendous impact on all Americans, Evercare and the Alliance felt it was imperative to look at some specific implications of how this economic downturn was affecting family caregivers and their loved ones. This survey acknowledges that family caregivers are especially vulnerable in these uncertain economic times as they struggle to maintain their own financial stability as well as continue to provide quality care to their loved one.

<sup>1</sup> *Valuing the Invaluable, The Economic Value of Family Caregiving* (November, 2008) – AARP

## About the Publishers

### Evercare

Evercare® is one of the nation's largest care coordination programs for people who have long-term or advance illness, are older or have disabilities. Founded in 1987, Evercare today serves members nationwide through Medicare, Medicaid and private-pay health plans, programs and services – from health plans for people in community and skilled nursing settings, to caregiver support and hospice care. Evercare offerings are designed to enhance health and independence, and in the complex world of health care, making getting care easier.

Evercare is part of Ovations, a division of UnitedHealth Group (NYSE:UNH) dedicated to the health care needs of Americans over age 50.

Evercare  
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Minnetonka, MN 55343  
AboutEvercare.com

### National Alliance for Caregiving

Established in 1996, the National Alliance for Caregiving is a non-profit coalition of more than 40 national organizations that focuses 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. They also work to strengthen state and local caregiving coalitions as well as create international caregiving alliances. 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  
4720 Montgomery Lane, Suite 205  
Bethesda, MD 20814  
www.caregiving.org

Evercare and the National Alliance for Caregiving deeply appreciate the work of Lisa Weber and Linda Naiditch of Mathew Greenwald & Associates in heading the survey work.

## Methodology

The main goal of the survey was to learn how caregivers and their recipients are affected by the economic downturn, with specific exploration of impacts on:

- Caregivers and their job situation
- Care-related spending by family caregivers
- Living situation of family caregivers and their care recipients
- Emotional impact on caregivers
- The quality and quantity of care experienced by the care recipient

The National Alliance for Caregiving and Evercare worked with Mathew Greenwald & Associates, a leading market research firm, to implement the survey. The research was fielded through a telephone omnibus survey from February 25 to March 19, 2009. All respondents were asked whether they had been a caregiver for an adult in the past 12 months:

*In the last 12 months, have you provided unpaid care to a sick, frail, or disabled relative or friend 18 years or older to help them take care of themselves? Unpaid care may include help with personal needs or household chores. It might be managing a person's finances, arranging for outside services, or visiting regularly to see how they are doing. This person need not live with you.*

In addition, to qualify as a caregiver, respondents had to report having helped their care recipient with at least one Activity of Daily Living (ADL) or Instrumental Activity of Daily Living (IADL) (See Appendix A for the full questionnaire). Qualified caregivers were then asked additional questions.

The omnibus survey was fielded by ICR. The survey uses a stratified, single-stage random-digit-dialing (RDD) sample of telephone households. Quotas were set so that half the interviews were with men and half with women. The data were weighted and balanced to provide nationally representative and projectable estimates of the adult population 18 years of age and older by key demographics such as age, sex, region and education.

A total of 3,505 respondents went through the screening questions, and as a result, 1,005 caregivers were identified. Based on weighted data, the incidence of caregiving was 30.7%.

Over sixty percent of the respondents were providing personal care or ADLs—bathing, dressing, feeding, toileting, dealing with incontinence, and/or transferring from bed to wheelchair or wheelchair to bath. All of the remaining caregivers were providing at least one Instrumental Activity of Daily Living, such as cooking, housecleaning, handling finances, transportation to doctor appointments, overseeing medications, etc.

## Summary of Key Findings

The survey found that the economic downturn has affected family caregivers in some significant ways including their current work situation, their use of savings or additional debt to cover caregiving expenses, their living situation with regards to their care recipient and the impact to the caregiver's health, in terms of stress.

When it comes to the workplace, the financial burden of caregiving coupled with economic realities are causing caregivers either to be more reluctant to take time away from work for caregiving or to take on additional work to cover caregiving costs.

- Fifty percent of working<sup>2</sup> caregivers said they were less comfortable taking time off from work to provide care.
- One in three working caregivers reported they were having to work more hours or get an additional job.
- Forty-three percent of working caregivers have had their work hours or pay cut.
- One in six (15%) says that the downturn has caused them to lose their job or be laid off.

In terms of caregiving costs, 13 percent say the economic downturn has caused them to spend more on caregiving expenses. Of these, more than half of these caregivers are struggling with just basic needs and are putting their own financial futures at risk.

- Six out of ten caregivers who reported increasing their caregiving spending also reported having difficulty paying for their own basic necessities.
- Sixty-three percent are saving less for retirement.
- Almost half of these caregivers who are spending more on caregiving expenses (47%) reported using all or most of their savings and 43 percent are borrowing money or increasing their credit card debt as a result of the downturn.

- Those caregivers providing more intense personal care seem to be at greater financial risk.

In the 2004 study, *Caregiving in the U.S.* (NAC/AARP), 24 percent of caregivers reported living with their care recipient.

In this Evercare/NAC 2009 *Survey of the Economic Downturn and its Impact on Family Caregiving*:

- Just in the past 12 months, 21% of caregivers report moving into the same household with their loved one.



When it comes to stress and caregiving, previous studies, including *Caregivers in Decline* (Evercare/NAC, 2006), reported stress as one of the key reasons caregivers felt their own health was at risk. In this 2009 survey, stress surfaces again due to the coupled economic pressure of providing care.

- Half of the caregivers reported the economic downturn has increased their stress about being able to continue caring for their loved one.

Some good news: the survey found that while caregivers are burdened financially, the quality of care they provide has not diminished.

- Seventy-six percent of caregivers indicated the quality of care their loved one receives has not decreased.

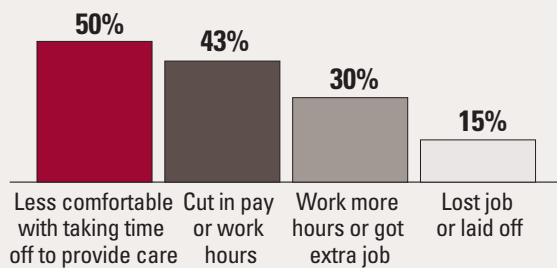
<sup>2</sup> Working caregivers are defined as having worked at some point while providing care in the past 12 months.

## Detailed Findings

### Impact of Economic Downturn on Caregivers and Their Job Situation

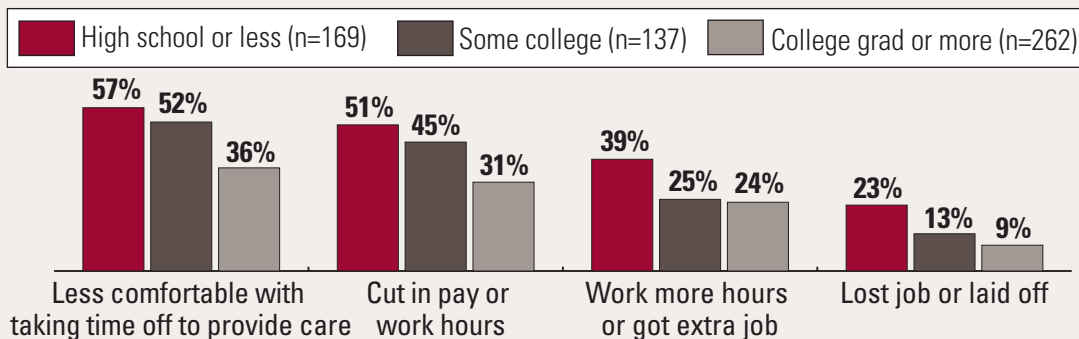
About six in ten caregivers (64%) were employed at some point in the last 12 months while caring for their relative or friend. The economic downturn has affected these working caregivers in a number of ways, the most common being that they are less comfortable with taking time off from work to care for their relative or friend (50%).

**FIGURE 1: Impact of Economic Downturn on Caregivers' Job Situation**  
(Caregivers who had been employed while caregiving, n=571)



Four in ten have experienced a cut in their pay or work hours because of the economic downturn (43%), and three in ten say the downturn has caused them to work more hours or to get an additional job (30%). About one in six says the downturn has caused them to lose their job or be laid off (15%).

**FIGURE 2: Impact on Caregivers' Job Situation by Educational Status**  
(Caregivers who had been employed while caregiving)

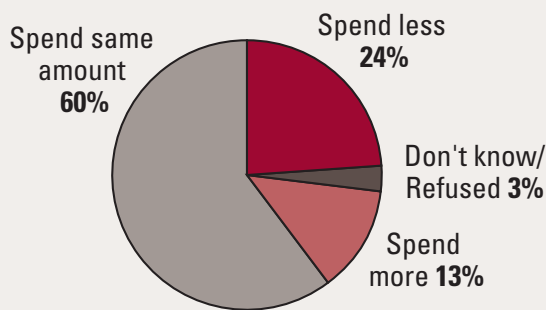


- Working caregivers ages 18 to 44 are more likely than those age 45 and over to feel uncomfortable taking off time from work to provide care as a result of the economic situation (59% vs. 36%). They are also more apt to work additional hours because of it (35% vs. 22%).
- The 61 percent of caregivers who are in more intensive caregiving situations—that is, they help their care recipient with at least one Activity of Daily Living (ADL) which can include: bathing, incontinence, dressing, feeding and getting out of beds and chairs—are more likely than non-ADL performing caregivers to say the economic downturn has caused two of these job-related impacts:
  - Feeling less comfortable taking time off to provide care (56% vs. 41%)
  - Working more hours or getting an additional job (35% vs. 23%)
- Discomfort with taking time off for caregiving is more prevalent in the Northeast region (63%) than in other geographic areas of the country (46%).
- Caregivers with lower educational levels are more vulnerable to these job-related impacts of the economic downturn.

## Financial Impact of Economic Downturn

One in eight caregivers reports that, because of the economic downturn, they are spending more money caring for their relative or friend (13%). However, one in four have cut back on spending (24%).

**FIGURE 3: Change in Care-Related Spending Due to Economic Downturn**  
(All caregivers, n=1,005)

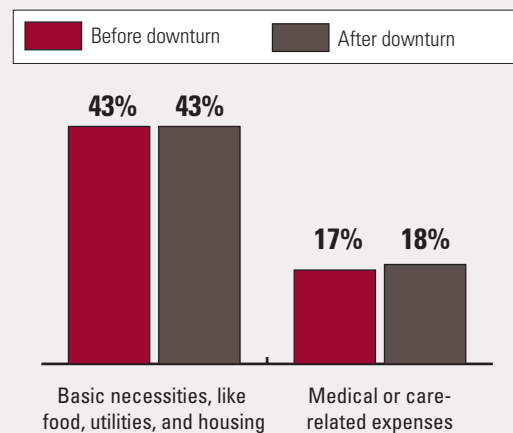


- The likelihood of cutting back on caregiving expenses is higher among younger caregivers. One in three 18- to 34-year old caregivers has cut back (33%), and this proportion falls steadily as age rises until it reaches 11% of caregivers who are 65 or older.
- Hispanic caregivers are more likely to say they cut back on care expenses (35%) than are non-Hispanic Whites (19%).
- Caregivers in households with less than \$75,000 in income are more than twice as likely as higher income households to report a change in spending. Specifically, 17% say they now spend more and 29% have cut back, whereas among those with \$75,000 in income, only 6% increased their spending and only 13% cut back.

The economic downturn does not seem to have significantly affected the *types* of care recipient expenses that caregivers help pay for. Four in ten caregivers report that they helped pay for their relative's or friend's basic necessities before the economic downturn, the same as the proportion that report helping with this currently, post-downturn (43% each).

Prior to the downturn, 17% helped pay for medical or care-related expenses; again, a similar percentage pay for these expenses now, post-downturn (18%).

**FIGURE 4: Percentage of Caregivers Who Help Pay for Recipient's Needs**  
(All caregivers, n=1,005)



There are some groups of caregivers, however, that show marked changes in the types of expenses they contribute to financially.

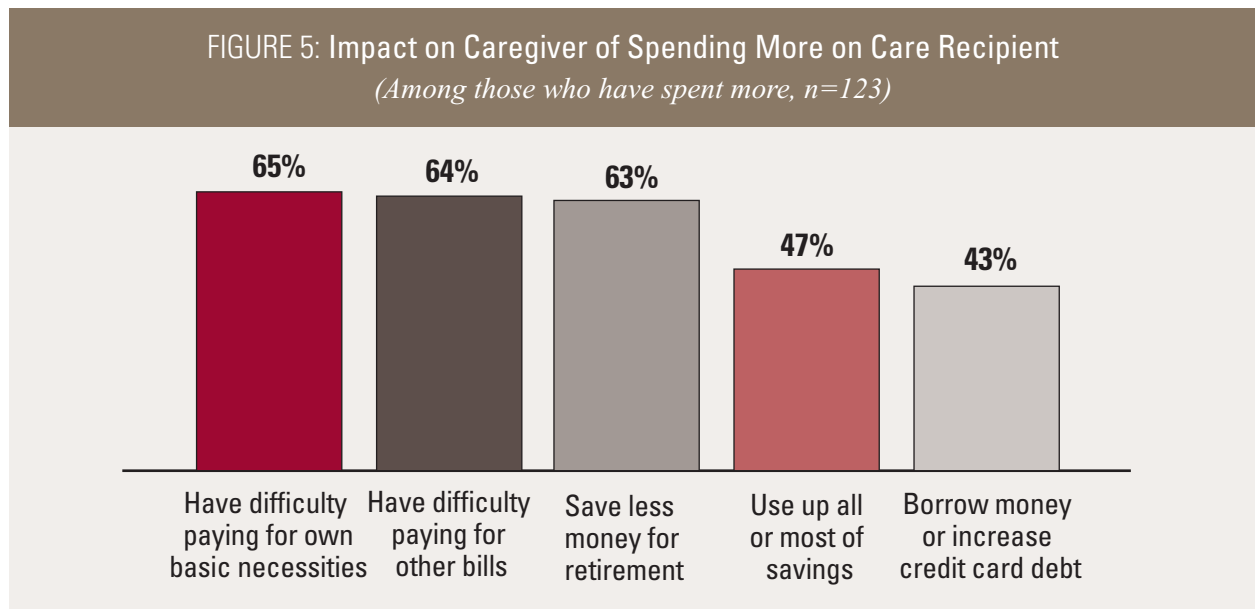
- Among caregivers with household incomes of less than \$25,000, a smaller share now contribute to their relative's or friend's basic necessities (57% prior to the downturn vs. 44% now).
- The proportion of caregivers with no more than a high school degree who contribute to their care recipient's basic needs has also declined, from 51% prior to the downturn to 41% now.

Among the caregivers who say the downturn caused them to spend *more* on care for their relative or friend, there has been an increase in the share contributing to their relative’s or friend’s basic necessities, from 64% prior to the downturn to 77% now.

The caregivers who increased their care-related spending have seen effects in their own personal finances. Specifically, six in ten caregivers who are spending more on care for their loved one as a result of the downturn say this increase has caused them to have difficulty paying for their own basic necessities (65%), have difficulty paying their other bills (64%), or save less for retirement (63%).

Nearly half report the increase in caregiving spending has caused them to use up all or most of their savings (47%), and 43% say they borrowed money or increased their credit card debt as a result.

- Caregivers who are in more intensive caregiving situations—that is, they help with ADLs—seem to be at greater risk for adverse financial impacts. They are more likely to say increased caregiving expenses caused them to save less for retirement (75% vs. 36% of non-ADL performing caregivers) and to use up their savings (57% vs. 26%).
- Caregivers who are not currently employed are more likely than currently employed caregivers to report that their increase in caregiving-related spending resulted in difficulty paying for basic necessities (80% vs. 49%) for other bills (78% vs. 51%).



## Impact of Economic Downturn on Living Situations of Caregiver and Recipient

The economy has had some impact on caregivers and their care recipients with regard to their living situations. One in five caregivers say they and their care recipient have moved in together in the past 12 months because of the economy (21%).

One in ten (10%) has been unable to place their care recipient into a nursing home or assisted living facility as they had planned, and 9% have had trouble selling their care recipient's home as planned.

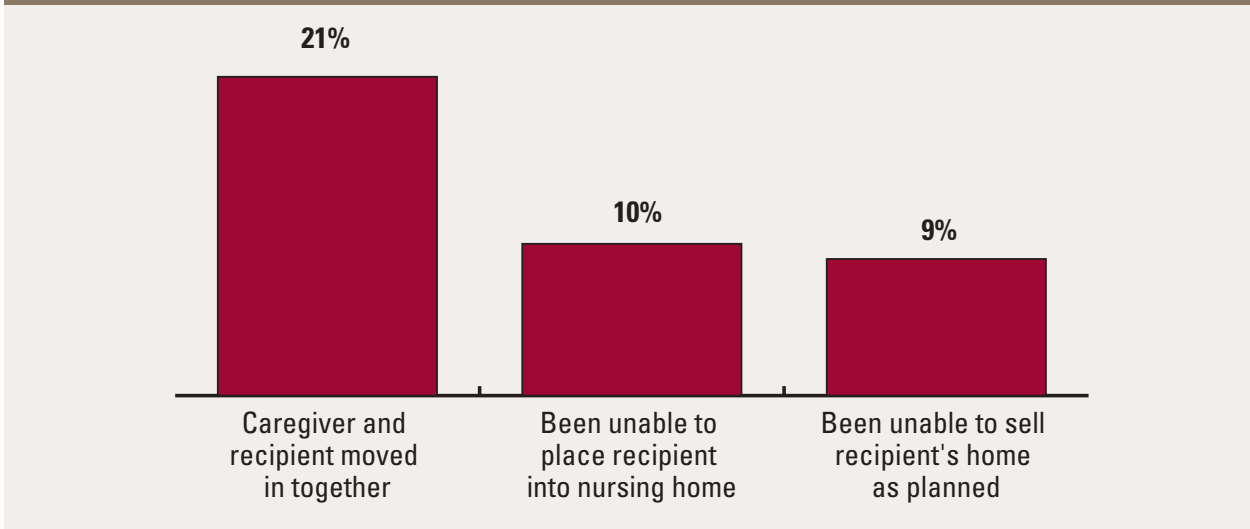
- Again, intensive caregivers are more likely to report having experienced each of these events as a result of the economic downturn. Specifically, caregivers who perform ADLs are more likely than those who do not perform ADLs to have:
  - Started co-residing with their care recipient (28% vs. 9%)

- Had trouble placing their relative or friend in a facility as planned (14% vs. 4%)
- Been unable to sell their recipient's home as planned (12% vs. 6%)

Of course, one might presume that caregivers who are doing more intense (ADL) caregiving are more likely to have care recipients who are sicker and more frail and thus, are more likely to need the support of living with the caregiver or even moving to assisted living or a nursing home.

- Those caregivers with household incomes under \$50,000 are twice as likely as those with higher incomes to have moved in with their recipient (27% vs. 14%).
- Caregivers living in metropolitan areas are more likely than non-metro dwelling caregivers to have started living together with their care recipient (22% vs. 13%) and to have had trouble placing their care recipient into a facility as planned (11% vs. 4%).

**FIGURE 6: Impact of Economic Downturn on Care Recipient's Living Situation**  
*(All caregivers, n=1,005)*



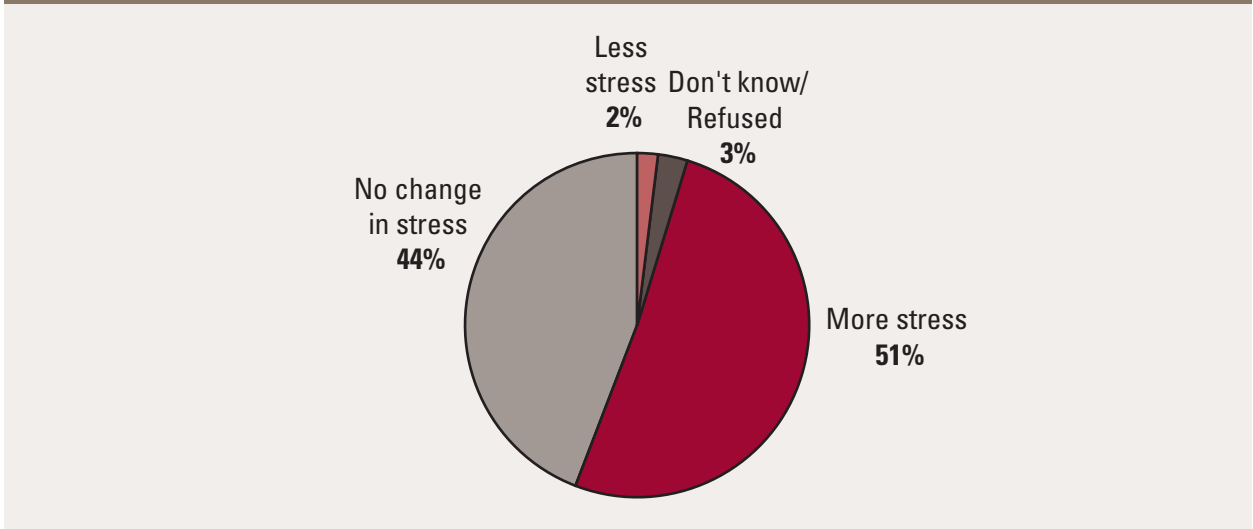


### Emotional Impact of Economic Downturn

Half of all caregivers say the economic downturn has increased the amount of stress they feel about being able to care for their relative or friend (51%). As we know from *Caregivers in Decline*, stress can lead to impacts on the caregiver's own health.

- Caregivers under the age of 65 are much more likely to feel added stress as a result of the downturn (54% vs. 31% of older caregivers).

FIGURE 7: Change in Stress Felt About Caregiving Due to Economic Downturn  
(All caregivers, n=1,005)



## Impact of Economic Downturn on Quality and Quantity of Care

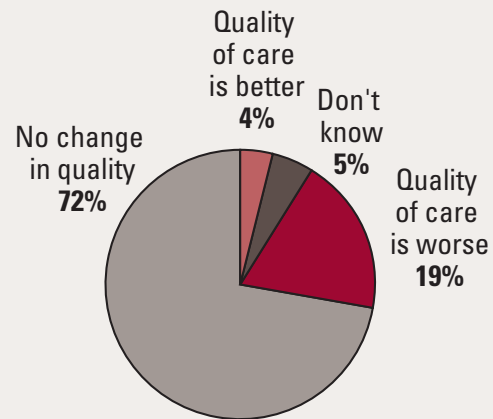
Fortunately, most caregivers report that the economic downturn has not had any negative impact on the quality of care that their friend or relative is receiving (76% same or better). However, one in five reports that the downturn is responsible for a decline in the quality of their loved one's care (19%).

- The decline in the quality of care seen by some appears to be partly driven by financial circumstances. The lowest income caregivers—those in households with less than \$25,000 in income—are twice as likely as those in households with \$75,000 or more in income to report a worsening of the quality of care (27% vs. 14%).



FIGURE 8: Change in Quality of Care Due to Economic Downturn

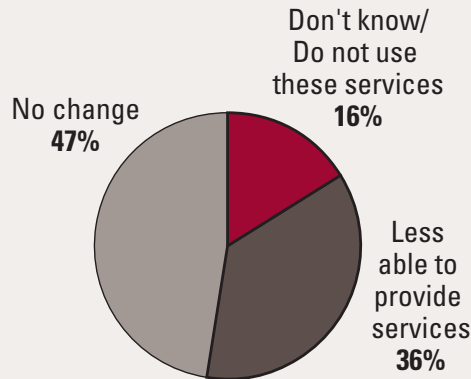
(All caregivers, n=1,005)



- Hispanic caregivers are more likely to feel their care recipient's quality of care has suffered as a result of the economic downturn (37%), relative to non-Hispanics—both whites (14%) and African-Americans (15%).
- Caregivers who perform ADLs are also more likely to report a decline in the quality of their loved one's care (23% vs. 12% of non-ADL performing caregivers).

There is some evidence that the economic downturn has affected the broader context in which caregivers and care recipients function. One in three caregivers (36%) reports they have found that government agencies or non-profit groups are less able to provide services or outside help to their relative or friend because of the economic downturn. Nearly half have not experienced such capacity problems (47%), while 16% are unsure.

**FIGURE 9: Change in Government and Non-Profit Agencies' Ability to Provide Services Due to Economic Downturn**  
(All caregivers, n=1,005)



- Again, intensive caregivers are more likely to report these capacity problems (42% vs. 28% of non-ADL performing caregivers).

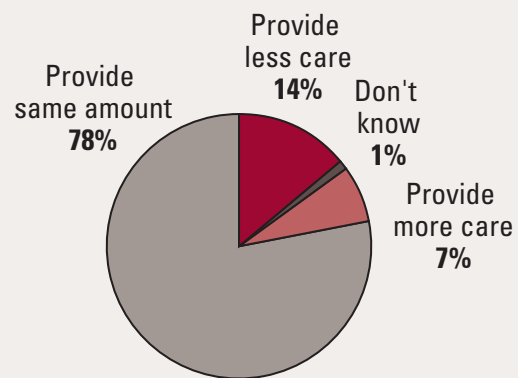
One in four caregivers reports that services or outside help for their care recipient have been cut back as a result of the economic downturn (27%). This may be related to organizational budgets and resources, but it may also be related to caregivers' and care recipients' ability to pay for services they want.

- A larger share of ADL-performing caregivers have experienced actual cutbacks in services compared to caregivers in less intensive situations (32% vs. 18%).

- Those caregivers with household incomes under \$50,000 are more likely to say that services or outside help for their relative or friend have been cut back (35% vs. 19% of higher-income caregivers).

While three-quarters of caregivers (78%) say that the amount of care they give has not changed, one in seven caregivers acknowledge they spend less time providing care as a result of the economic situation (14%). However, 7% say they provide more care.

**FIGURE 10: Change in Amount of Care Provided Due to Economic Downturn**  
(All caregivers, n=1,005)



- Caregivers in intensive situations are more apt than those not helping with ADLs to have stepped up the amount of care (9% vs. 3%).

## Respondent Profile

The demographic profile of caregivers who participated in the study is as follows.

<i>Percentage of Caregivers (n=1,005)</i>		<i>Percentage of Caregivers (n=1,005)</i>	
<b>Gender</b>		<b>Metropolitan Status</b>	
Female	54%	Metro	83%
Male	46	Non-Metro	17
<b>Performs ADLs and IADLs</b>		<b>Head of Household Status</b>	
Performs ADLs	61%	Yes	83%
Performs IADLs only	39	No	17
<b>Home Ownership</b>		<b>Children in Household</b>	
Own	77%	Yes	38%
Rent	22	No	60
Don't know/Refused	1	Don't know/Refused	1
<b>Respondent Age</b>		<b>Household Size</b>	
18 – 34	31%	Lives alone	11%
35 – 44	17	Two people	26
45 – 54	23	Three people	19
55 – 64	16	Four people	23
65 plus	11	Five or more	20
<i>Average Age</i>	<i>44.6 years</i>	Don't know/Refused	1
<b>Marital Status</b>		<b>Employment Status</b>	
Married	51%	Employed full-time	45%
Single	24	Employed part-time	14
Divorced	9	Retired	14
Single, living with a partner	7	Temporarily unemployed	13
Widowed	5	Student	5
Separated	3	Homemaker	5
Don't know/Refused	1	Disabled	5
<b>Education</b>		<b>Household Income</b>	
Less than High School	12%	Under \$25,000	23%
High School graduate	28	\$25,000 – \$49,999	22
Some college	32	\$50,000 – \$74,999	14
College graduate or more	25	\$75,000 or more	25
Technical school/other	2	Don't know/Refused	16
Don't know/Refused	<0.5		
<b>Race/Ethnicity</b>		<b>Geographic Region</b>	
White non-Hispanic	66%	Northeast	18%
Black non-Hispanic	13	North Central	24
Hispanic	16	South	34
Other	3	West	24
Don't know/Refused	2		

## Appendix A: Questionnaire

1. In the last 12 months, have you provided unpaid care to a sick, frail, or disabled relative or friend 18 years or older to help them take care of themselves? Unpaid care may include help with personal needs or household chores. It might be managing a person’s finances, arranging for outside services, or visiting regularly to see how they are doing. This person need not live with you.

**[IF R. ASKS “DOES GIVING MONEY COUNT?,” ASK:** Aside from giving money, do you provide any other type of unpaid care to help them take care of themselves, such as help with personal needs, household chores, arranging for outside services, or other things?**]**  
**[IF NOTHING OTHER THAN MONEY, CODE “NO”]**

Yes . . . . . 1  
 No . . . . . 2 **[NOT CAREGIVER – SKIP OUT]**  
**(VOL) Don’t know/Refused . . . . . 3 [NOT CAREGIVER – SKIP OUT]**

2. Please tell me if you have provided help to your relative or friend with any of the following tasks. Have you helped him or her: get in and out of beds or chairs; get dressed; get to and from the toilet; bathe or shower; deal with incontinence or diapers; or by feeding them?

**[IF NEEDED:** Have you helped your relative or friend with any of these tasks?**]**

Yes . . . . . 1 **[SKIP TO Q4]**  
 No . . . . . 2  
**(VOL) Don’t know/Refused . . . . . 3**

3. Have you provided help to your relative or friend with any of these tasks: giving medicines, pills, or injections; managing finances; grocery shopping; housework; preparing meals; transportation; or arranging or supervising services from an agency?

**[IF NEEDED:** Have you helped your relative or friend with any of these tasks?**]**

Yes . . . . . 1  
 No . . . . . 2 **[TERMINATE]**  
**(VOL) Don’t know/Refused . . . . . 3 [TERMINATE]**

4. Were you employed at any time during the last 12 months while you were caring for your relative or friend?

Yes . . . . . 1  
 No . . . . . 2 **[SKIP TO Q6]**  
**(VOL) Don’t know/Refused . . . . . 3 [SKIP TO Q6]**

5. **[IF EMPLOYED (Q4=1), ASK]:** How—if at all—has the economic downturn over the past 12 months affected your job situation? Has the economic downturn caused... **[RANDOMIZE & READ LIST]?**

		Yes	No	(VOL) DK/REF
a.	A cut in your pay or work hours?	1	2	3
b.	You to lose your job or be laid off?	1	2	3
c.	You to be less comfortable with taking time off from work to care for your relative or friend?	1	2	3
d.	You to work more hours or get an additional job?	1	2	3

6. Has the economic downturn over the past 12 months caused any change in the... **[RANDOMIZE & READ LIST WITH STEM EACH TIME. IF YES, IMMEDIATELY FOLLOW WITH Q7]?**

7. **[IF YES (Q6=1), ASK]:** Because of the economic downturn... **[READ ITEM]?**

<i>Q6: Changed?</i>					<i>Q7: How?</i>				
		Yes	No	(VOL) DK/REF			More/ Better	Less/ Worse	(VOL) DK/REF
a.	Amount of money you spend on caring for your relative or friend?	1	2	3	a.	Are you spending more or less money on their care?	1	2	3
b.	Amount of care that you provide to your friend or relative?	1	2	3	b.	Are you providing more or less care?	1	2	3
c.	Overall quality of care that your friend or relative gets from the people who care for him or her?	1	2	3	c.	Has the quality of their care gotten better or worse?	1	2	3
d.	Amount of stress you feel about being able to care for your loved one?	1	2	3	d.	Are you feeling more or less stress about caring for him	1	2	3

8. **[IF GONE UP (Q7a=1), ASK]:** You said that because of the economic downturn, you are spending more money caring for your relative or friend.

Has spending more on his or her care caused you to... **[READ LIST IN ORDER WITH THIS STEM EACH TIME]?**

		Yes	No	(VOL) DK/REF
a.	Use up all or most of your savings?	1	2	3
b.	Save less money for your retirement?	1	2	3
c.	Borrow money or increase your credit card debt?	1	2	3
d.	Have difficulty paying for your own basic necessities, like food, utilities, or	1	2	3
e.	Have difficulty paying for your other bills?	1	2	3

**9. Because of the economic downturn over the past 12 months, have... [RANDOMIZE & READ LIST]?**

		Yes	No	(VOL) DK/REF
a.	You and the friend or relative you're caring for moved in together?	1	2	3
b.	Services or outside help for your relative or friend been cut back?	1	2	3
c.	You been unable to sell your relative or friend's home as you had planned?	1	2	3
d.	You been unable to place your relative or friend into a nursing home or assisted living facility as you had planned?	1	2	3

**10a. Before the economic downturn, did you help pay for your relative or friend's... [READ LIST IN ORDER]?**

**10b. Do you now help pay for your relative or friend's... [READ LIST IN ORDER]?**

		<i>Q10a: Helped before</i>			<i>Q10b: Help now</i>		
		Yes	No	(VOL) DK/REF	Yes	No	(VOL) DK/REF
a.	Basic necessities, like food, utilities, and housing?	1	2	3	1	2	3
b.	Medical or care-related expenses, like in-home help?	1	2	3	1	2	3

**11. Because of the economic downturn in the past 12 months, have you found that government agencies or non-profit groups are less able to provide services or outside help to care for your relative or friend?**

*Yes* .....1

*No* .....2

**(VOL)** *Do not use these kinds of help or services* .....3

**(VOL)** *Don't know/Refused* .....4

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