

# **The Wide Circle of Caregiving**

*Key Findings from a National Survey: Long-Term Care from the Caregiver's Perspective*

The Henry J. Kaiser Family Foundation  
Harvard School of Public Health  
United Hospital Fund of New York  
Visiting Nurse Service of New York

June 2002

## **Survey of Long-Term Care from the Caregivers' Perspective**

More than twelve million Americans require some kind of long-term care. Long-term care refers to a broad range of personal, social, and medical services required by people with chronic illnesses and disabilities. The large majority of persons needing long-term care services are living in their own homes or the home of a family member and are able to do so because of the millions of informal and unpaid caregivers that help them – some for periods of months, others for years. Approximately 1.5 million individuals have more substantial needs and are in nursing homes.

Recognizing the value of informal caregivers in this country's long-term care system, the Family Caregiver Support Act was implemented in 2001 — a federal initiative designed to expand services and assistance specifically for family caregivers. It includes funding for state and community-based support programs, as well as research dollars for innovations in long-term care services. Earlier proposals also included financial relief for certain primary caregivers in the form of tax credits. Even though caregiver tax credits had been proposed by both the current and past administration, as well as Members of Congress, direct financial relief has not progressed into legislation. However, broad recognition of the economic value of caregiving exists, as well as the dollars caregiving saves in our Medicaid and Medicare programs.

Research to date on America's unpaid caregivers has focused, for the most part, on primary caregivers -- relatives or friends who are the first person a disabled or elderly person depends on for help. However, in many situations, other family members and friends need to become involved in order to meet all of a person's day-to-day needs. Studies that focus only on primary caregivers under-represent all those who provide important, but perhaps less intensive, services. The definition of caregiver was purposefully broadened for this survey (see definition below). Rather than target a subgroup of caregivers, for example, those caring for persons recently hospitalized, the survey searched for all caregivers. By using a population-based survey method and randomly selecting households to screen for adults who are caring or have cared for someone in the past year, a broader perspective on the scope of caregiving is examined.

## **Caregiver Defined**

The definition of caregiver was broadened in this survey because it often takes more than one person to meet the needs of a family member or friend. The study included not only primary caregivers, but the extended group of caregivers as well.

Caregivers were defined as anybody who in the course of the previous year provided unpaid help, or arranged for help, to a relative or friend with an illness or disability that leaves them unable to do some things for themselves, or who needs assistance because they are simply getting older. This kind of help could be with household chores, finances, or with personal or medical needs. The person who needs help may live in his or her own home, in the caregiver's home, or in another place such as a nursing home.

The purpose of the Survey of Long-Term Care from the Caregiver's Perspective was to examine the experiences of a broad range of informal caregivers in the United States and to answer the following key questions:

- Who is providing informal and unpaid care? Why have they become involved in this person's care? What is their relationship to the person they help?
  
- What kinds of services and tasks are these caregivers performing?
  
- What kinds of paid assistance do caregivers arrange for and manage? Do caregivers have unmet needs for assistance?
  
- What are the rewards and challenges (both personal and financial) experienced by caregivers?

These questions organize the figures and accompanying information that follow in this chart pack summarizing the main findings from the national survey.

## Methods

The Survey of Long-Term Care from the Caregiver's Perspective was a nationally representative survey directed by Dr. Karen Donelan of the Harvard School of Public Health with the National Opinion Research Center (NORC) in collaboration with researchers from the Henry J. Kaiser Family Foundation, the Visiting Nurse Service of New York, and the United Hospital Fund of New York.

The telephone survey was conducted from May through July 1998 by NORC interviewers in either English or Spanish as necessary. An equal probability of selection method was used to sample households in the continental United States for the data presented here. A random respondent was then selected from each household contacted. Respondents were first screened to determine eligibility for the longer interview. Of 4,874 respondents, 1,404 informal caregivers were identified and agreed to participate in the full interview. The response rate for eligible caregivers was 83%. The margin of error on estimates in the national sample of caregivers is +/-3 percentage points.

Survey questions included information about the demographic characteristics of both the caregiver and care recipient, the kind of help the caregiver was providing, reasons for the informal caregiving arrangement, and the challenges and rewards of caregiving.

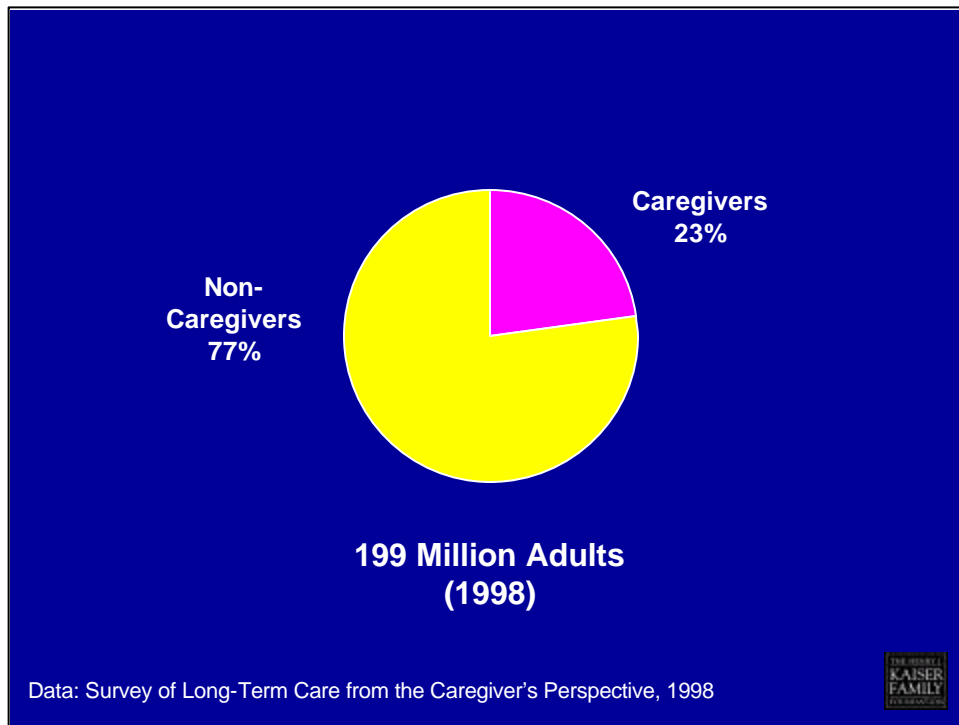
*Who is providing informal care?*



# Nearly One Out of Four Adults is an Informal Caregiver

Informal caregiving is common in America. Nearly one out of every four – over 45 million adults in 1998 -- provided or arranged help for a family member or friend some time in the year before.

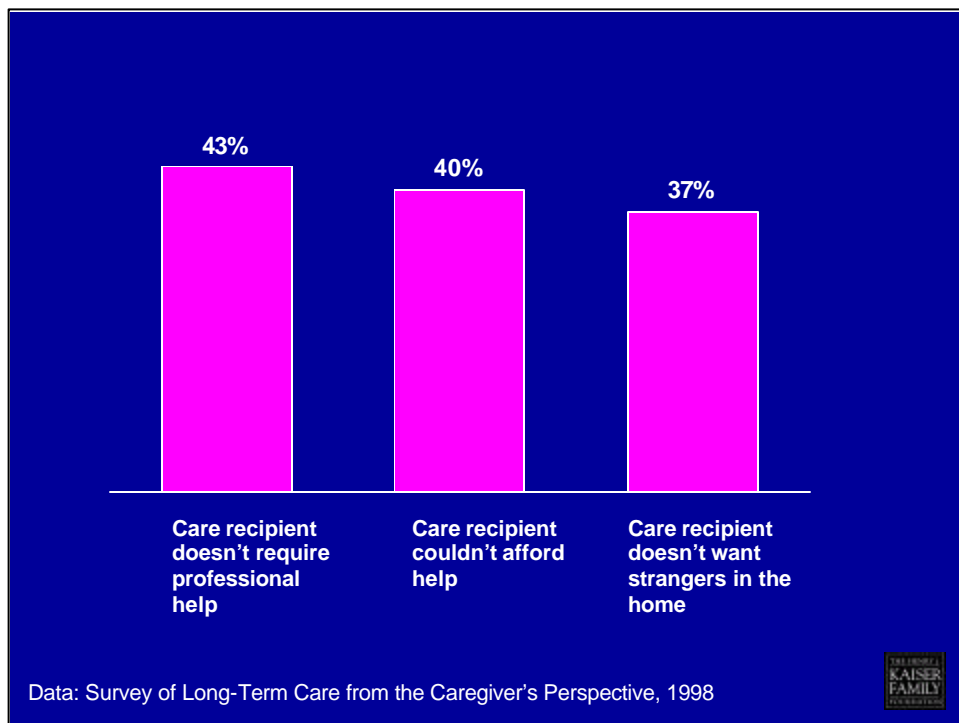
16% of all adults were providing care at the time of the survey, while an additional 7% said they had been caregivers in the past year but were not caring for that person now.



# Why is the Caregiver Helping?

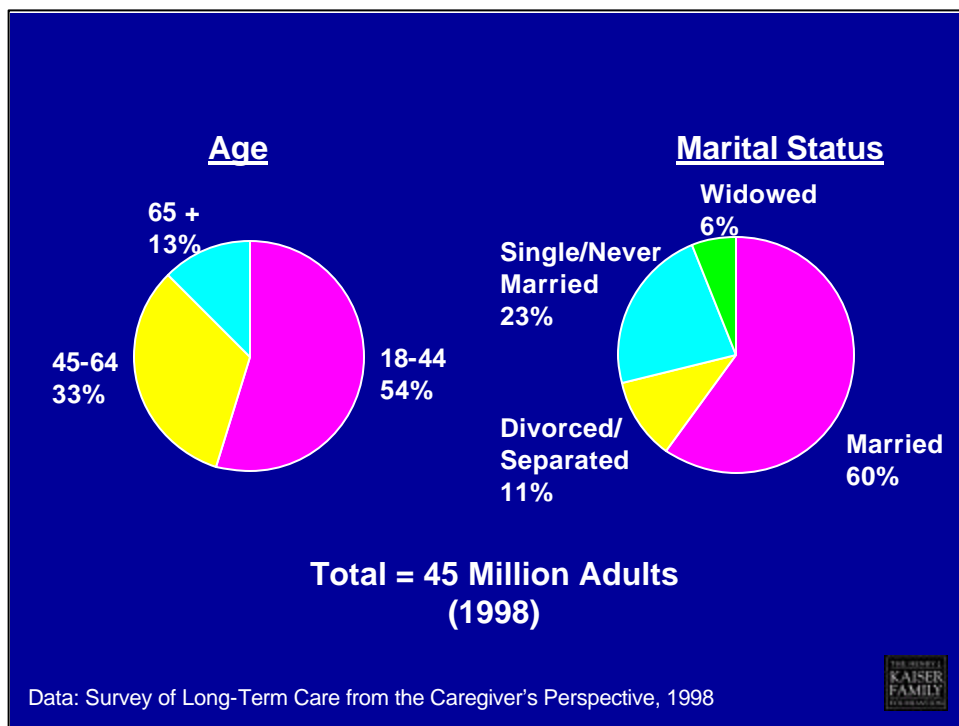
Informal caregiving fills in the gaps in long-term care. Often the kind of care a person needs does not require skilled nursing care, but is more personal in nature. Over forty percent say the reason they are helping is because professional help was not required. And over a third (37%) say that the person who needs help didn't want to have strangers in their home.

However 40% of caregivers report that the reason they are helping their family member or friend is because that person could not afford to pay for outside assistance.



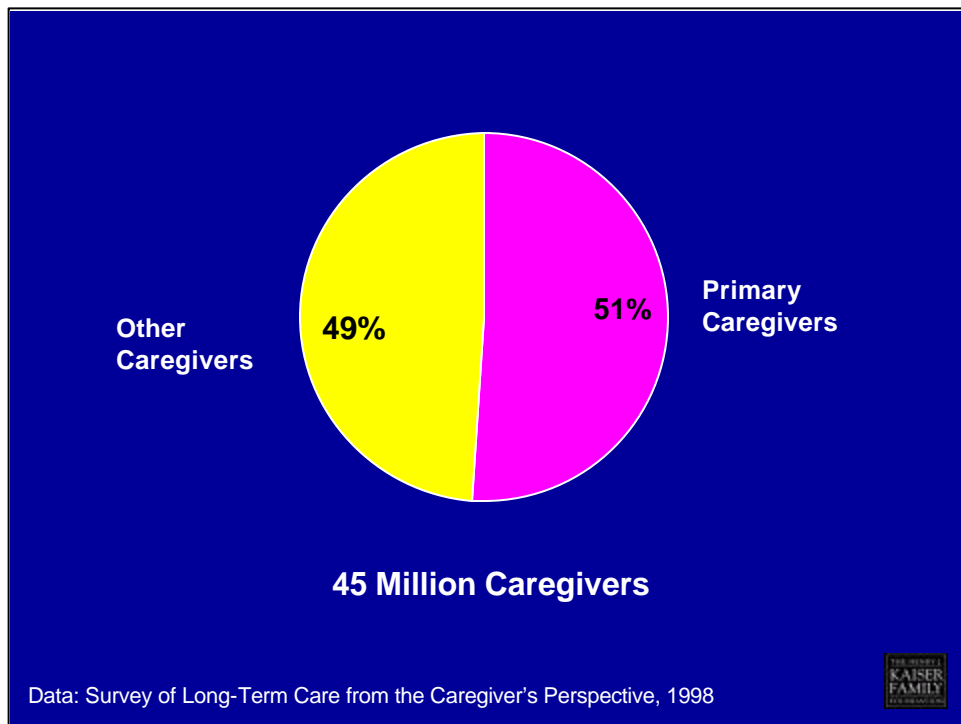
# Profile of Caregivers

The majority of caregivers are married (60%) and over half of caregivers are under age 45 — still in the child-raising years, many of whom have children living at home.



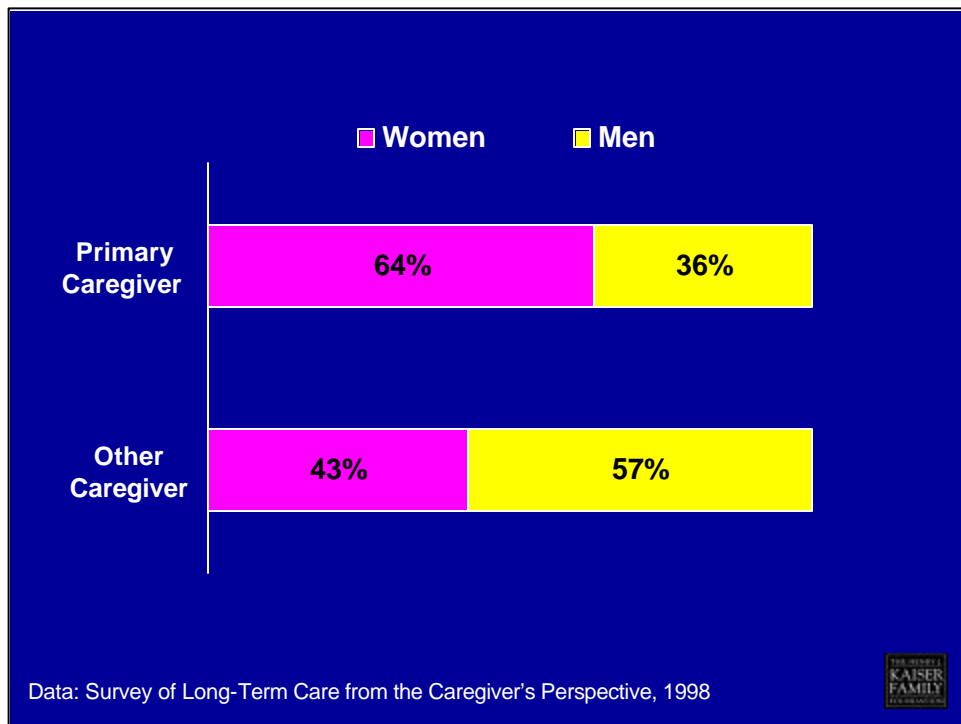
## Distribution of Caregivers, Primary vs. Other

Roughly half of all caregivers are primary caregivers – those who report they provide most of the care for the person who needs help.



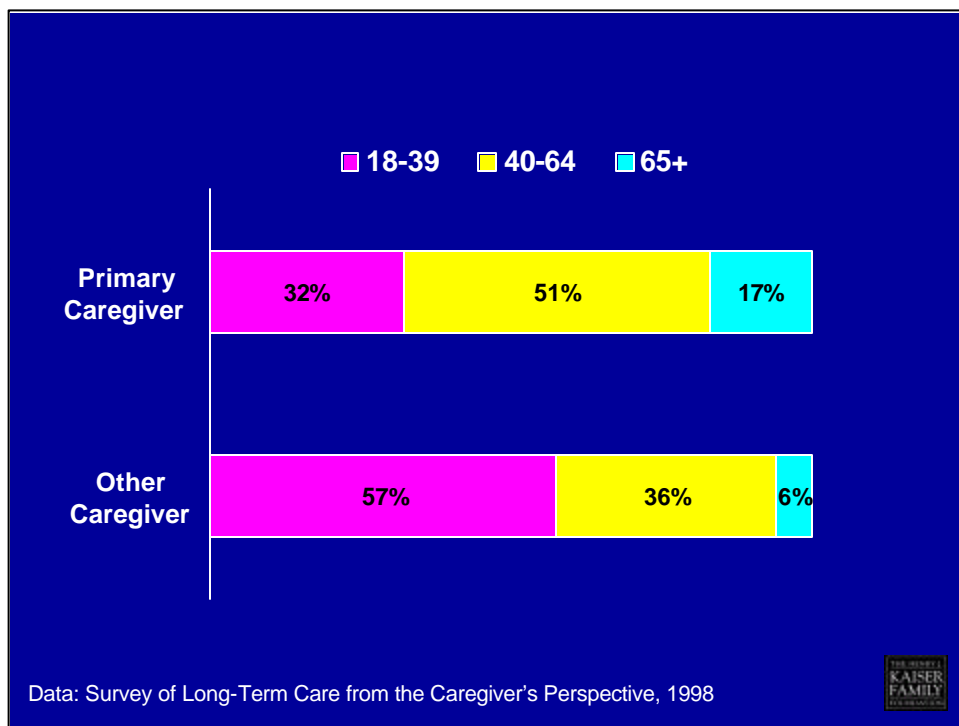
# Gender of Caregivers, Primary vs. Other

Nearly two-thirds of primary caregivers are women, while men are more likely to be other (secondary) caregivers.



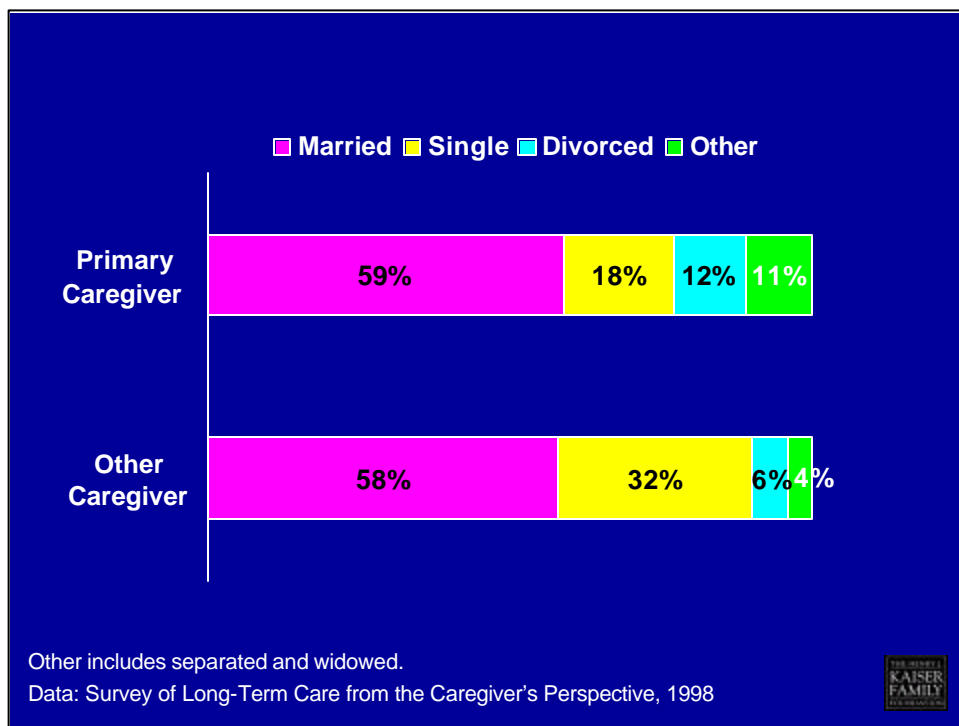
# Age of Caregivers, Primary vs. Other

Primary caregivers are older than other caregivers. Two-thirds are middle-aged or elderly, while over half (57%) of other caregivers are under age 40.



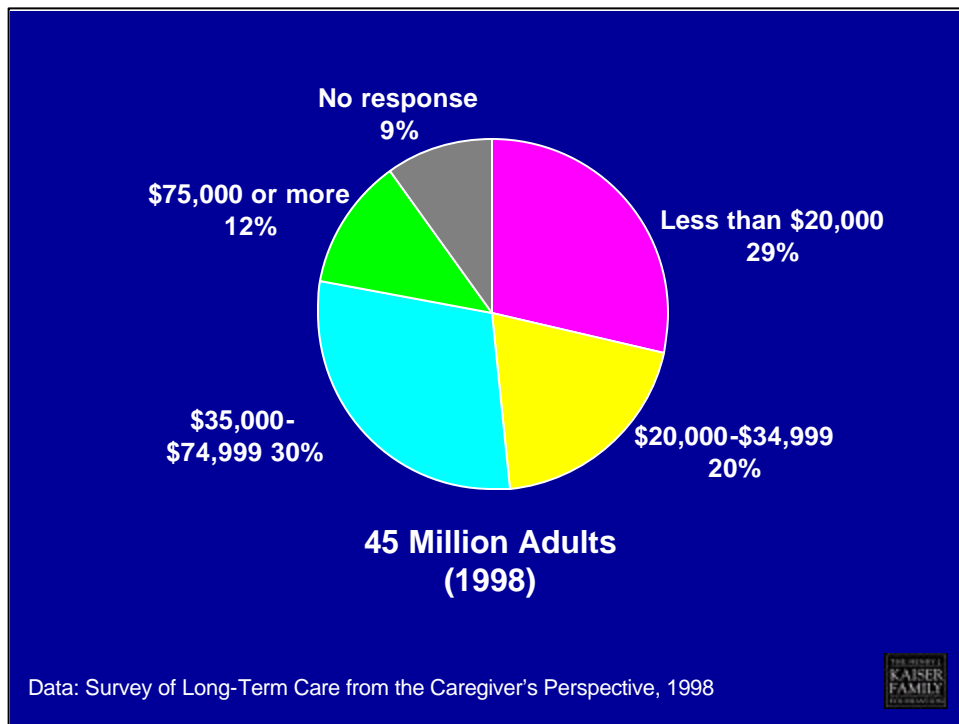
# Marital Status of Caregivers, Primary vs. Other

The majority of both primary and other caregivers are married, however secondary caregivers are more likely never to have been married.



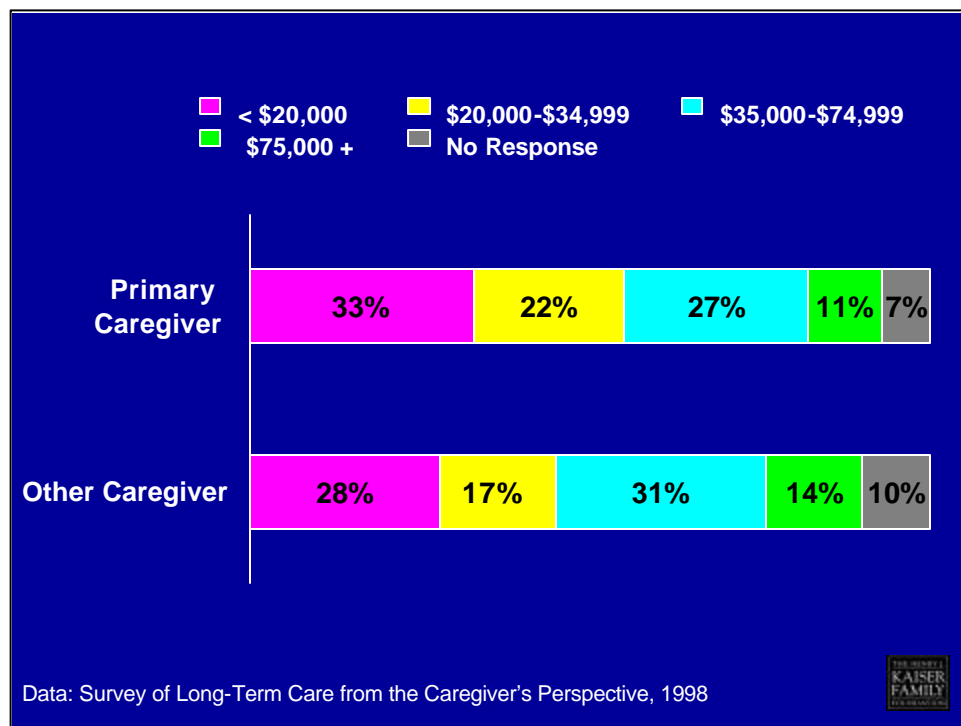
# Family Incomes of Caregivers

Caregivers often are not financially able to help the person they are caring for. More than a quarter of them have family incomes less than \$20,000. Nearly half (49%) have incomes under \$35,000.



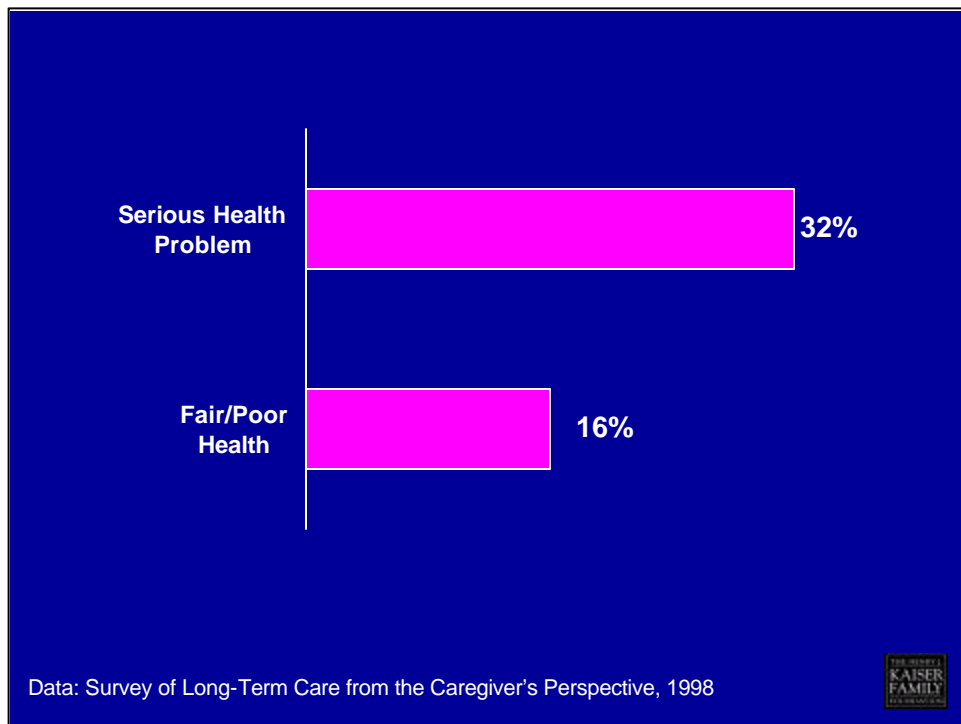
# Family Incomes of Caregivers, Primary vs. Other

Primary caregivers are more likely to be from low-income families. One-third have annual incomes less than \$20,000 compared to 28% of other caregivers.



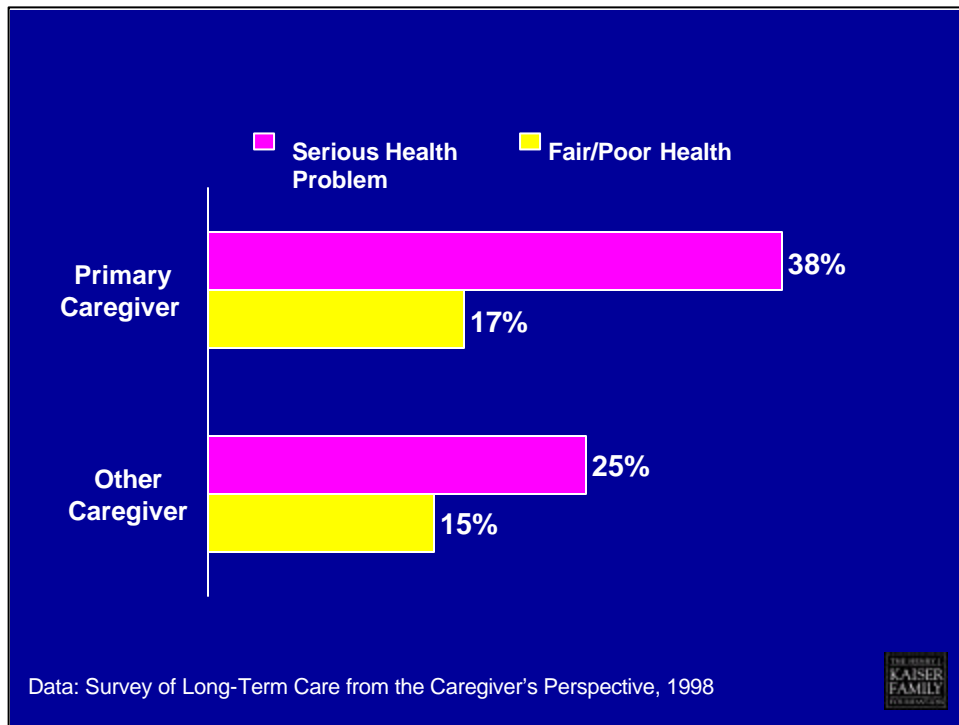
# Health Status of Caregivers

Caregivers often are not in good health. Almost a third have a serious health problem themselves and one in six describe their health as only fair or poor.



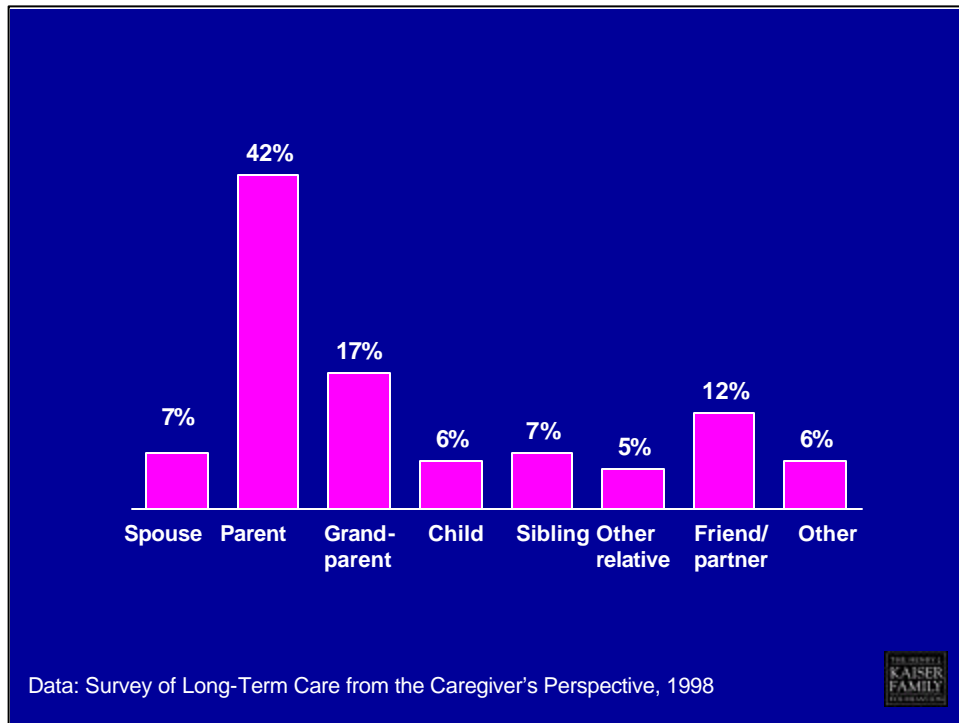
## Health Status of Caregivers, Primary vs. Other

Primary caregivers, who are generally older than secondary caregivers, are also far more likely to have a serious health problem themselves.



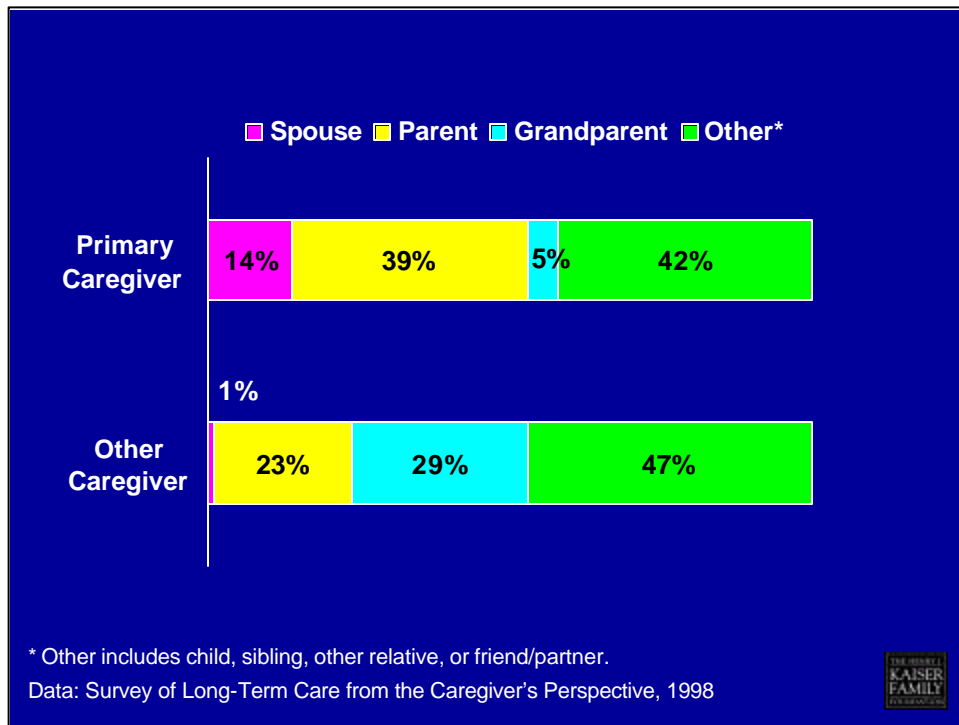
## Majority of Caregivers are Caring for a Member of the Immediate Family

Two-thirds of caregivers are helping either their parents, grandparents, or a spouse. However, caregiving does extend outside the family for 18% of caregivers who are caring for persons other than relatives.



## Relationship of Care Recipient, Primary vs. Other Caregivers

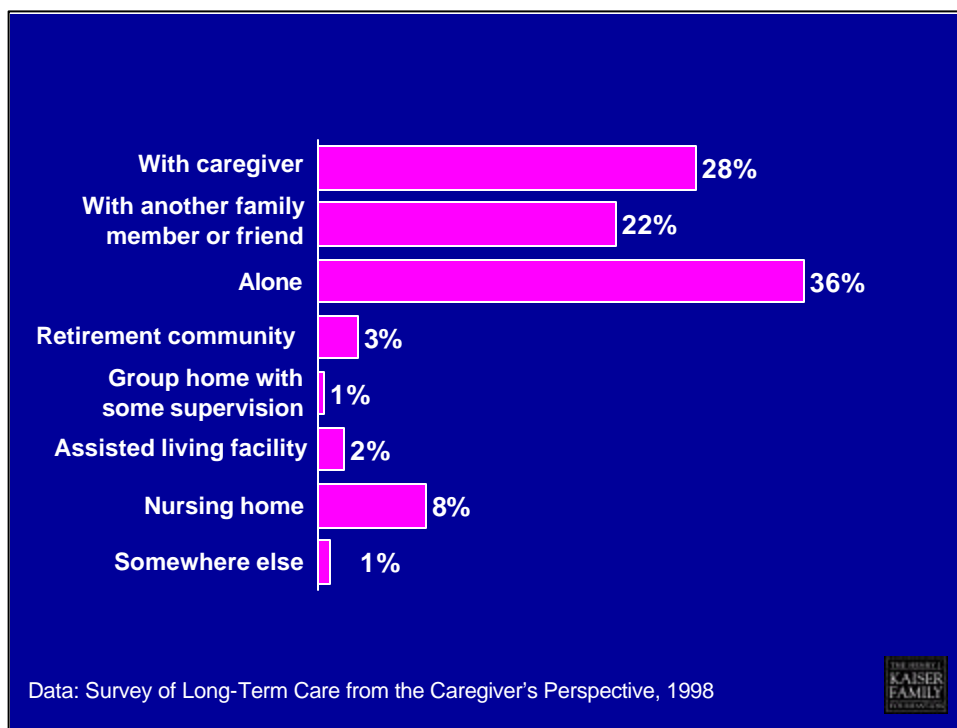
Primary caregivers are more likely to be caring for their spouse or parent (53%) compared to other caregivers (24%) who are more likely to be caring for a grandparent or someone else.



## Where Do Recipients of Care Live?

Many of the policy proposals to financially assist caregivers have focused on those who are living with the person they are helping, which is a small share of all caregivers. Only 28% of persons receiving informal help live with their caregiver.

A quarter of caregivers who live with the person they are caring for (26%) do not describe themselves as the primary caregiver. And 40% of caregivers who do not live with the person they are caring for consider themselves the primary caregiver (data not shown).

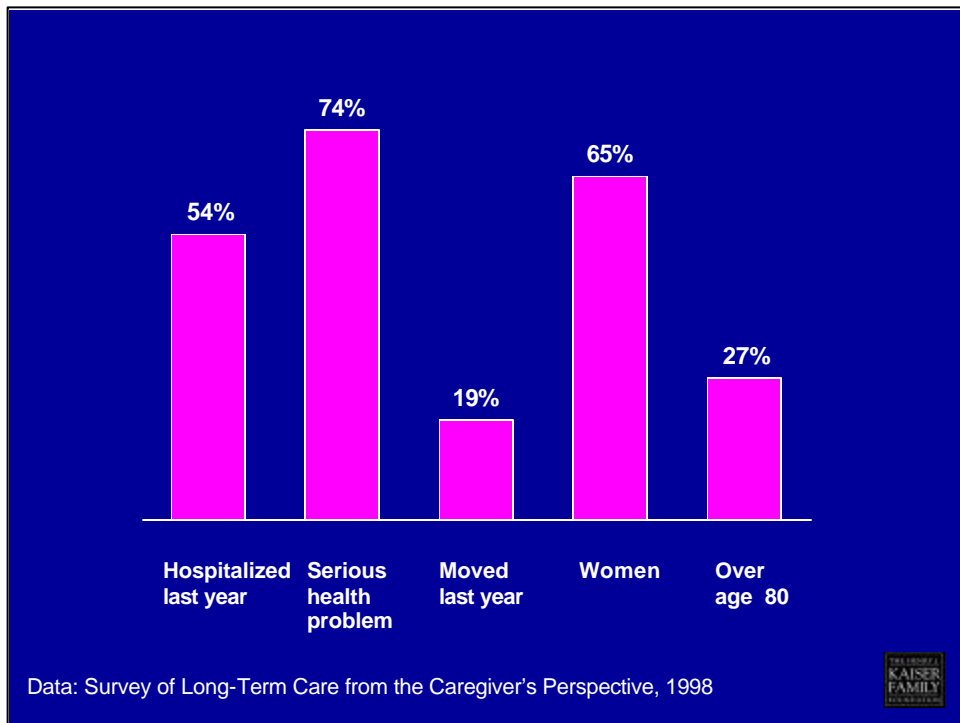


# Characteristics of Recipients of Care

Most people who need help with their every day activities or managing their health needs have serious health problems and the majority have required hospital care in the past year.

One in five care recipients have changed their residence in the past year, most often because of a change in their health status.

The majority of care recipients are women, who typically live longer than men.



*What kinds of help are informal caregivers providing?*

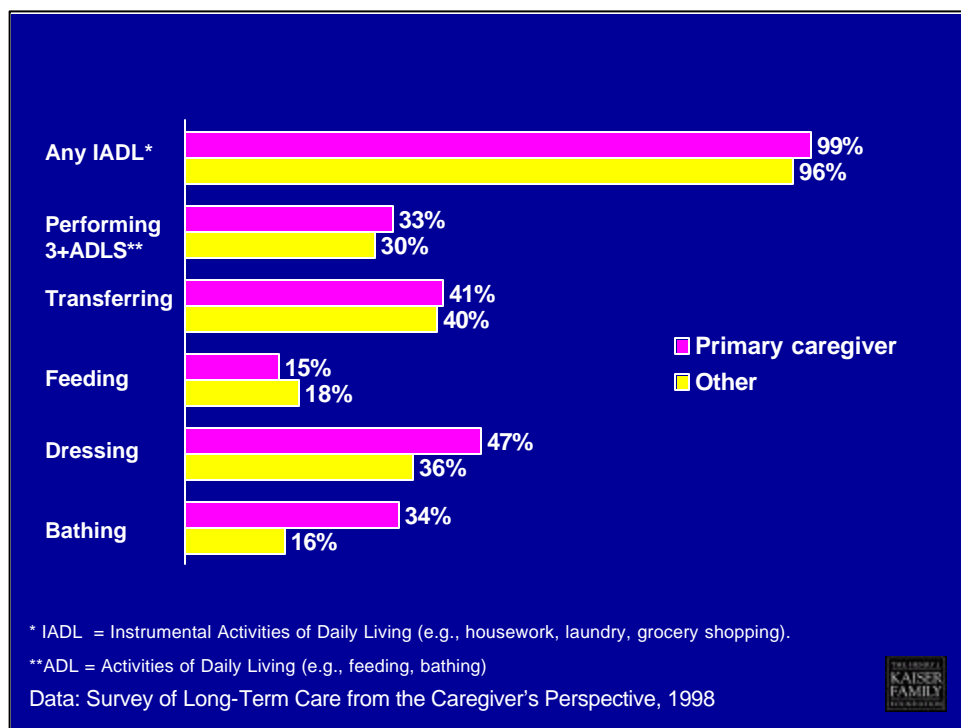


## Caregivers Help with Many Activities

Almost all caregivers are supporting their family member or friend by helping with “instrumental activities of daily living” or IADLs – services that include meal-making, managing bills and insurance forms, shopping, housework, and transportation for example.

A good share of caregivers however are also helping with more personal needs, such as bathing and dressing. Nearly a third of caregivers are helping with at least three “activities of daily living” or ADLs – which besides bathing and dressing include feeding, toileting, and assistance with walking and transferring. Recent policy proposals containing financial assistance for caregivers have required the caregiver to provide help with three or more ADLs in order to be eligible for benefits.

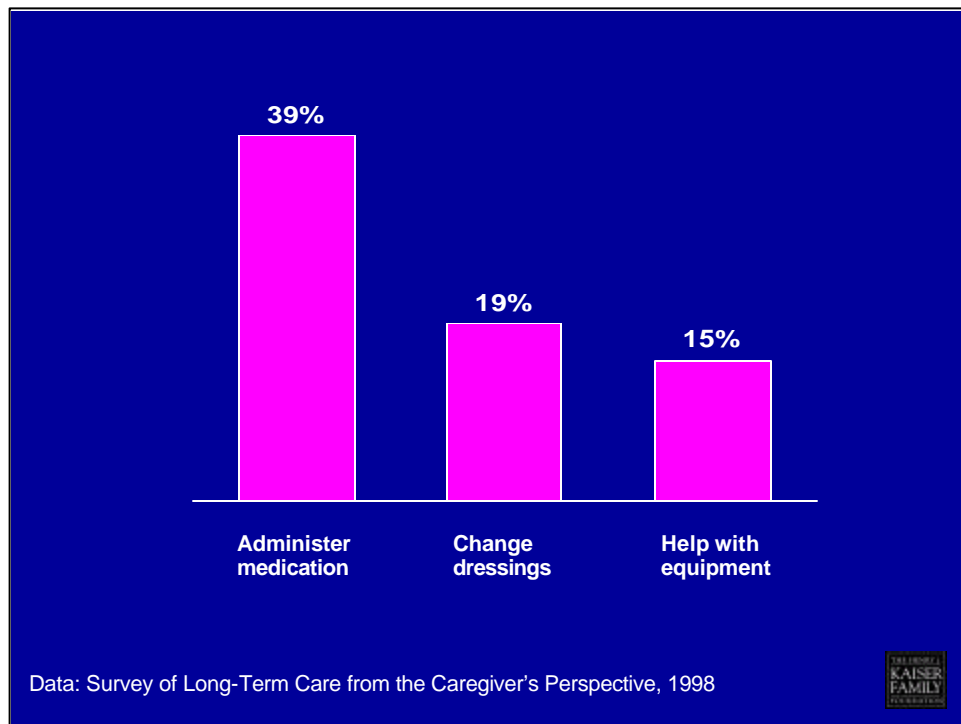
Primary caregivers’ services are similar to other caregivers except they are more likely to help with dressing and bathing.



## Caregivers Provide Help with Medical Tasks

Changes in hospital financing, including the growth in managed care contracting, have contributed to shorter hospitalizations. What was once supported by additional days in the hospital or home visits by registered nurses is now handled by the patient themselves or often caregivers.

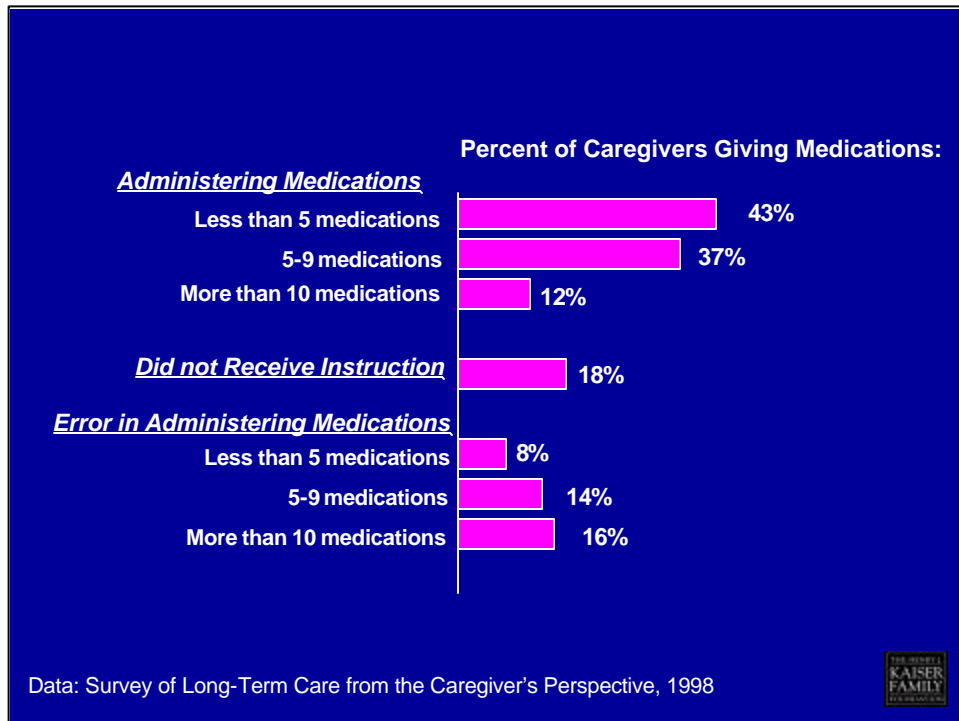
One fifth of all caregivers helped with dressing changes in the past year and nearly 40% were administering medications.



# Many Caregivers Help with Multiple Medications

More than a third (39%) of all caregivers are helping to give medications. Among these caregivers almost half (49%) are administering 5 or more medications. One in six caregivers are helping give medications other than oral medications – including injections.

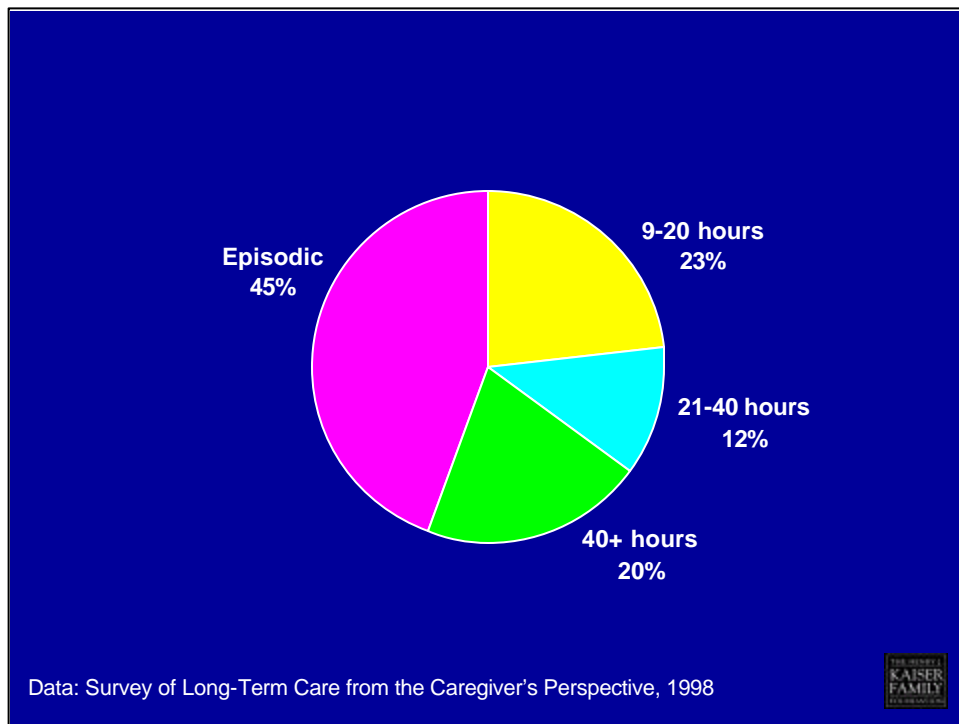
The opportunity to make mistakes increases with the amount and complexity of prescribed drugs– 18% of caregivers who are helping to give medications report they have received no specific instructions about how to do so.



# Hours Spent Providing Care, Per Week

A large share of caregivers (45%) provide only episodic care, meaning eight hours or less a week, but a third provide more than 20 hours of help each week.

For one in five caregivers, the responsibilities are at least equal to a full-time job.




# Caregiver Intensity Level

The work involved in caregiving is a function of both the tasks involved as well as the number of hours required. For example, while helping with activities of daily living (ADLs) can be more difficult than helping with instrumental activities of daily living (IADLs), it probably is more of a burden to provide help with two IADLs for 21 hours in a week (level 3) than helping with one ADL for just 7 hours each week (level 2).

<u>Activity</u>	<u>Hours per Week</u>
• <b>Level 1</b>	
– 0-1 IADL	<21 hrs.
– 2+ IADLs	<9 hrs.
• <b>Level 2</b>	
– 0-1 IADL	21-40 hrs.
– 2+ IADLs	9-20 hrs.
– 1 ADL	<9 hrs.
• <b>Level 3</b>	
– 0-1 IADL	41+ hrs.
– 2+ IADLs	21-40 hrs.
– 1 ADL	9-20 hrs.
– 2+ ADLs	<9 hrs.
• <b>Level 4</b>	
– 2+ IADLs	41+ hrs.
– 1 ADL	21-40 hrs.
– 2+ ADLs	9-40 hrs.
• <b>Level 5</b>	
– 2+ ADLs	41+ hrs.

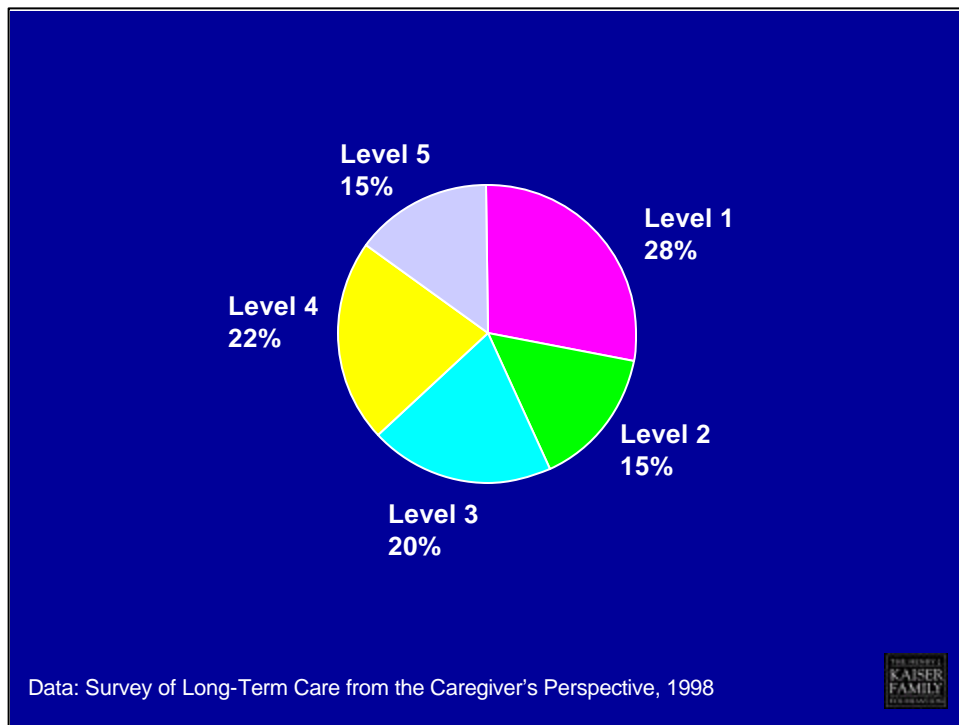
Data: National Alliance for Caregiving and the American Association of Retired Persons, 1997



# Level of Caregiver Intensity Level

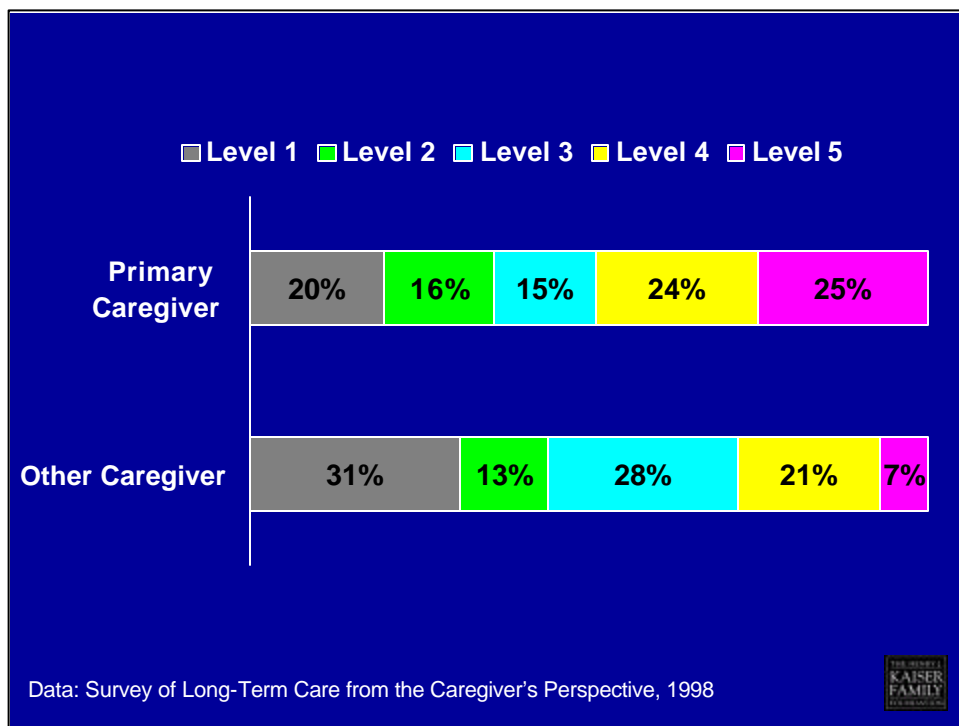
More than one-third (37%) of all caregivers are providing the highest levels of caregiving, levels 4 and 5 -- where helping long hours and with more personal kinds of care (ADLs) is common.

Many caregiver policy proposals have required the caregiver to be helping with three or more ADLs in order to qualify for benefits and the amount of time or help with IADLs (instrumental activities of daily living, such as shopping, housework, and errands) is not factored into the eligibility requirements. Over a third (35%) of caregivers classified as providing high intensity care in this study (levels 4 and 5) would not qualify under the three-plus ADL threshold for eligibility (data not shown).



## Level of Caregiver Intensity, Primary vs. Other

Primary caregivers provide a higher than average amount and type of care. Half (49%) are providing level 4 or 5 care – meaning at least nine hours a week with ADL help **or** full-time help (41+ hours) with a minimum of 2 IADLs. Most secondary caregivers provide less intensive care, yet 28% of these caregivers are also providing level 4 or 5 care.



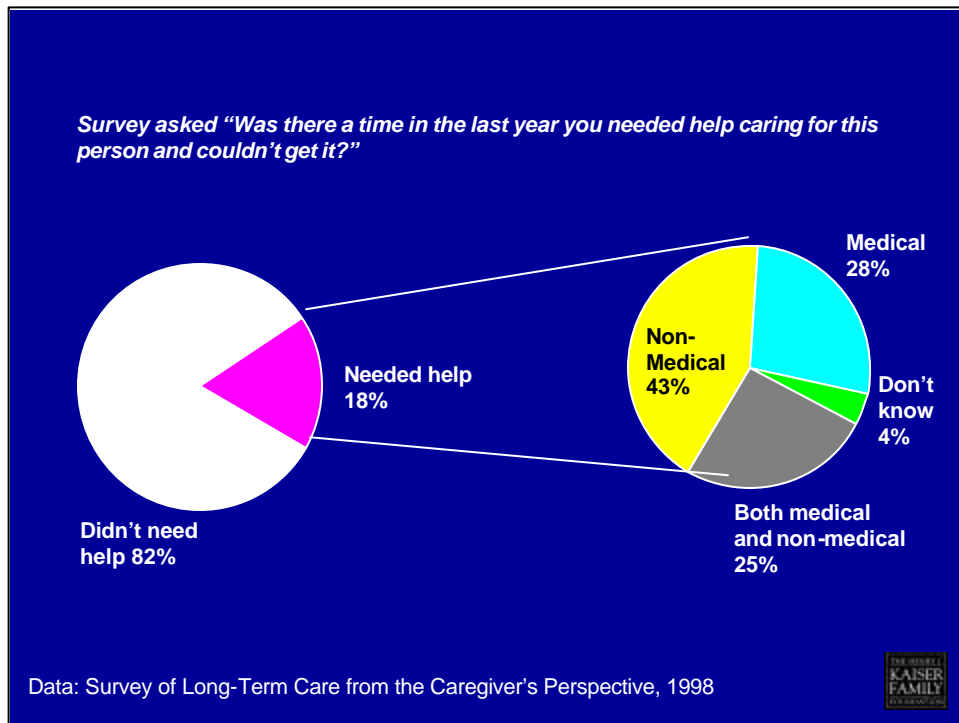
*Are there unmet needs for help?*



# Caregivers Perceptions of Unmet Need for Help

Informal caregivers are managing well, but about one in five (18%) say that there was a time in the past year when they needed help caring for the person but could not get it.

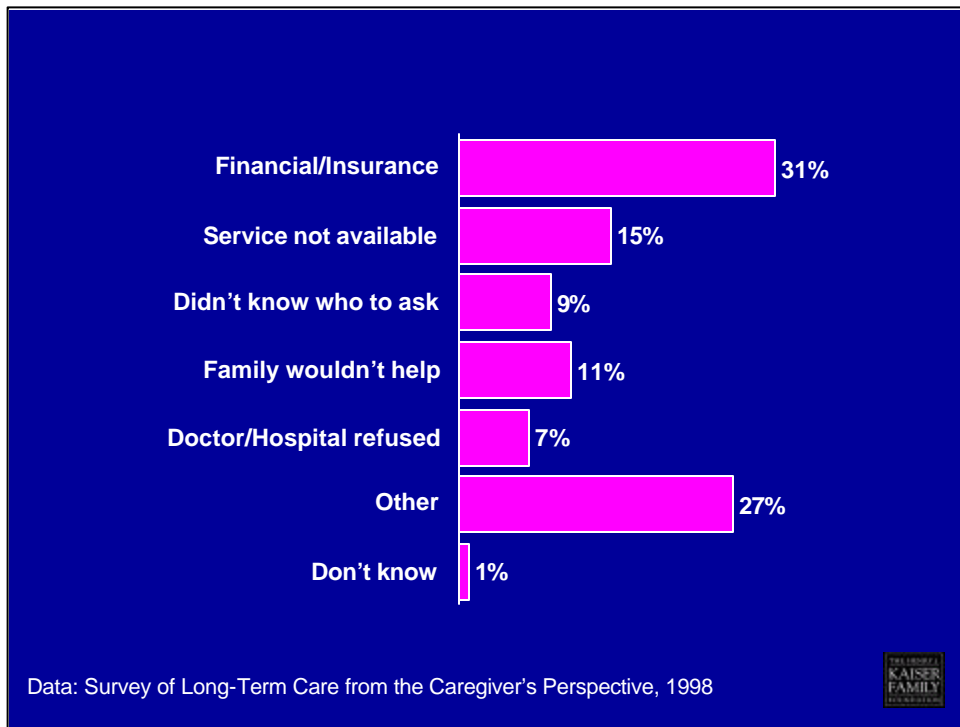
Among those caregivers who needed more help providing care in the past year, more needed help with services that were not medical in nature (68%). However slightly over half needed, but could not get, help providing medical services.



# Reasons for Unmet Need

Almost a third of caregivers who reported that they needed help caring for a person but could not get it, said that financial concerns, including the fact that insurance was not available or did not cover the particular service, was the reason they were not able to get the help they could have used.

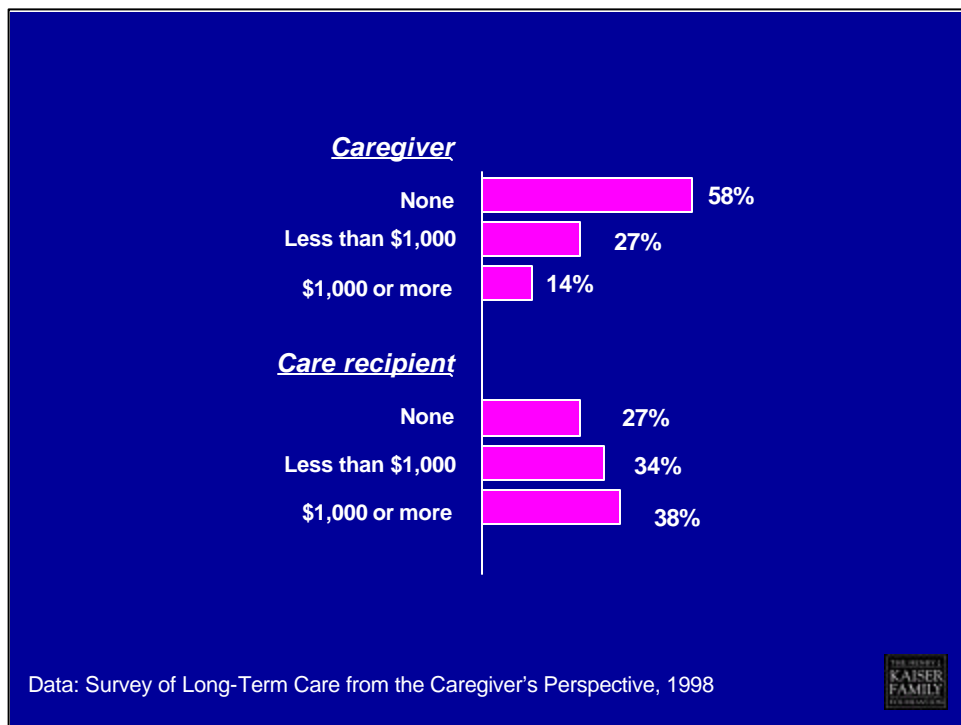
Just as many (31%) reported what could be considered deficiencies in the home care system – 15% said the services were not available in their area, another 9% did not know who to ask for help, and 7% said that they had actually been refused help by doctors or hospitals.



# Out-of-Pocket Costs

Most caregivers and care recipients actually spend less than \$1,000 out-of-pocket each year and the majority of caregivers report having no expenses in caring for their family member or friend.

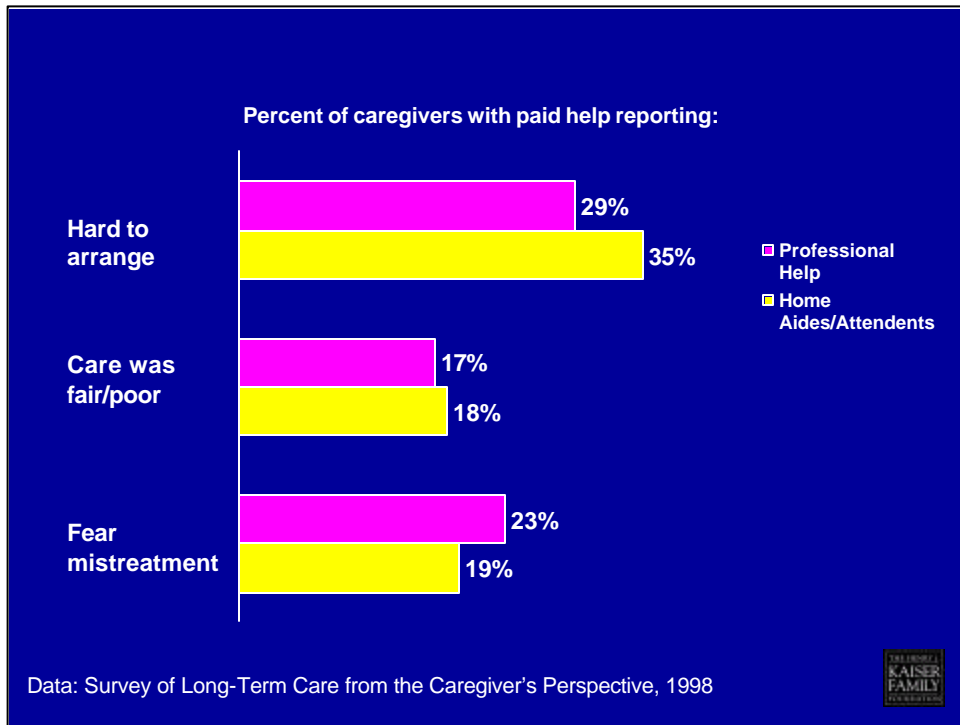
However, a third (38%) of care recipients incur \$1,000 or more in out-of-pocket expenses in the course of a year. Just 14% of caregivers spent more than \$1,000 of their own funds to meet their relative's or friend's needs.



# Barriers to Paid Assistance

A small minority of caregivers were assisted by paid caregivers. Only 9% said they had help from home care aides or nursing assistants and 17% had help from visiting nurses. Part of the reason for this may be the difficulty in finding good home care services. Among those who had home care aides, 35% reported they had been hard to arrange and 29% of those with paid professional help (i.e., visiting nurses) found them hard to arrange.

The majority of caregivers felt the paid care they did manage was excellent, very good, or at least good, however about 18% felt the services were only fair or even poor. In addition, about one in five of these informal caregivers actually fear that their family member or friend may be mistreated by the paid help.



*What are the rewards and challenges for caregivers?*

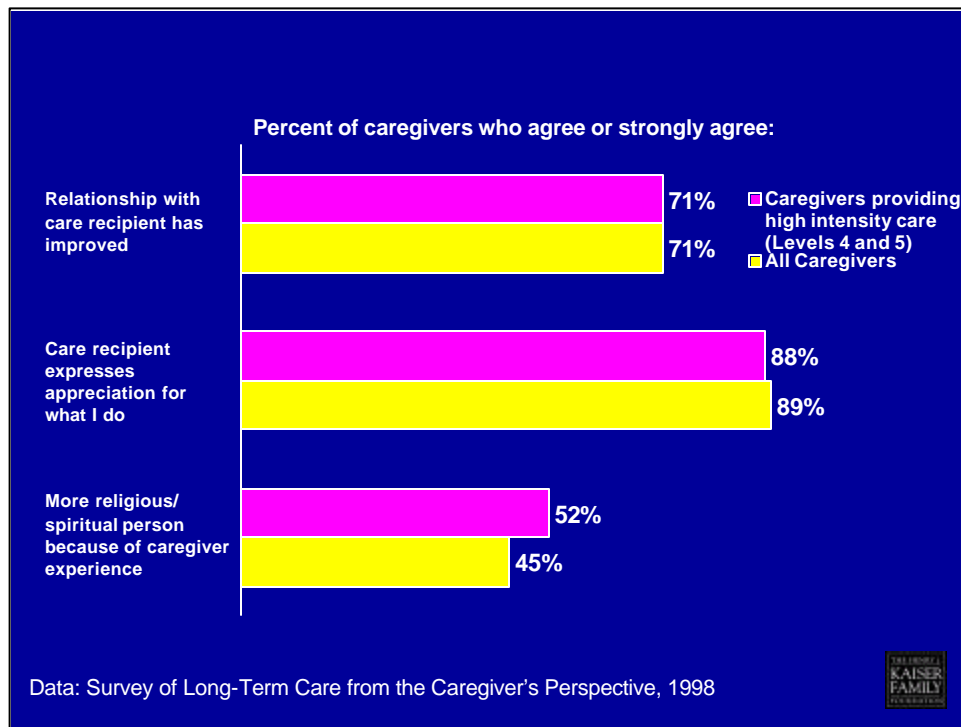


# Being a Caregiver Can be Rewarding

Caregiving can be a positive experience for many. Interpersonal relationships with the person needing care improved for 71% of all caregivers, even for those who were providing the highest amounts of help.

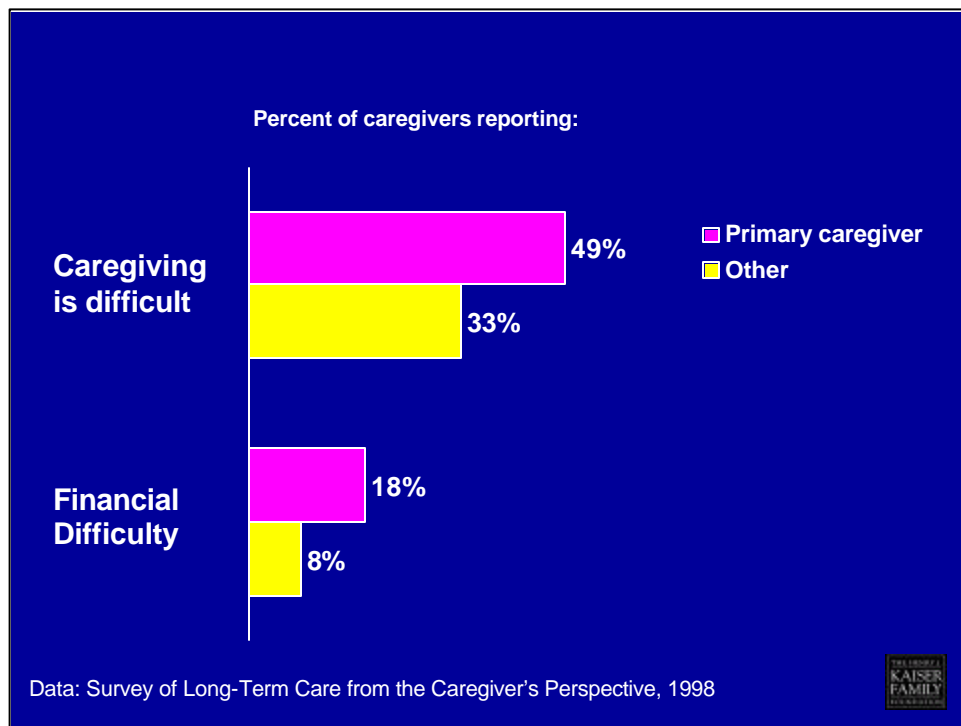
Care recipients let their caregivers know that their help is appreciated, with nearly 90% of all caregivers saying they have been told their help is valued.

For many, the altruism of caregiving has made them a more religious or spiritual person.



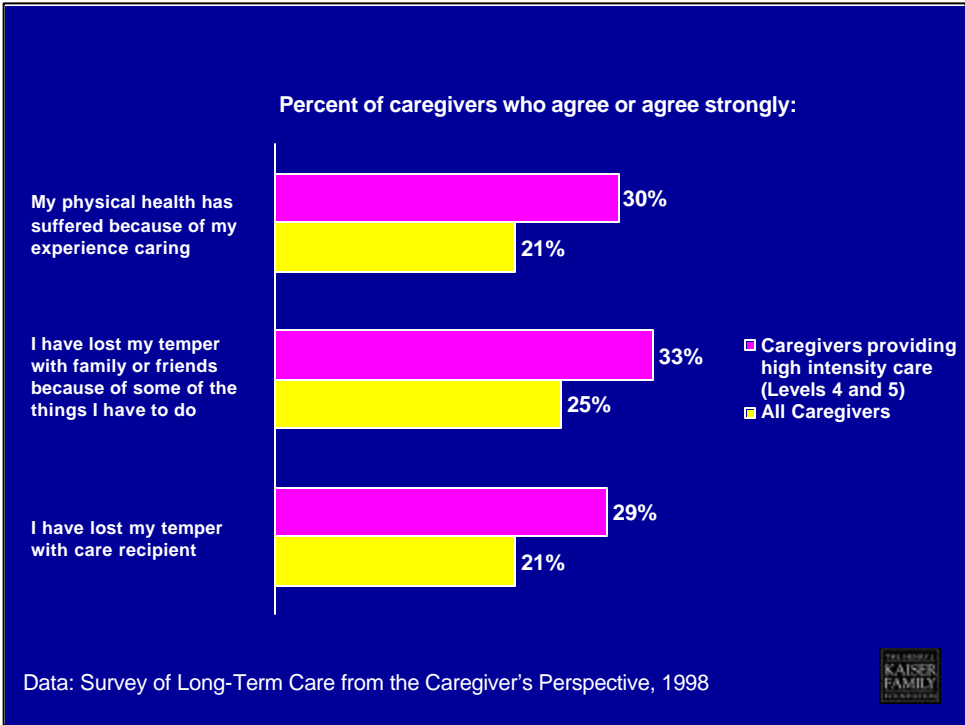
# Amount Reporting Difficulty, Primary vs. Other Caregiver

Caregiving brings personal challenges as well. While the majority of caregivers describe their responsibilities as not difficult, this varies depending on whether a person is the primary caregiver or not, and how much care the relative or friend requires. Almost half of primary caregivers say that providing help is difficult or very difficult, compared to a third of other caregivers. Primary caregivers are also more likely than other caregivers to agree or strongly agree that their help has created financial difficulties for them.



# Many Caregivers Face Challenges

For some caregivers the experience is stressful, particularly for those who are helping with a great deal of care. Thirty percent of level 4 and 5 caregivers report their own health has suffered because of the stress of caregiving. And a similar share say they have lost their temper with their own family, friends, and the care recipient.



## Some Caregivers Face Difficult Choices

Caregiving creates trade-offs for many. The hours given to help another can take a toll on personal and family time and can also take time away from a job.

Perhaps the greatest tension is between the demands of the caregiver's own family and the time needed to help the relative or friend -- 30% of all caregivers agree or strongly agree that this is an issue for them. Forty percent of caregivers in the "sandwich generation" (those who have children living at home and are also caring for a parent) say that they are torn between the two demands for their time and energy.

About one in six of all caregivers says they are torn between their job and caring for a relative or friend, while nearly a quarter of level 4 and 5 caregivers are dealing with this issue.

When caregiving involves financial support it can create problems for the caregiver's own family budget. One in five caregivers providing high intensity care reports their caregiving responsibilities created a financial problem for their own family.

