

A Report from The Robert Wood Johnson Foundation  
National Strategic Indicator Surveys

# A Portrait of Informal Caregivers *in* America, 2001



THE  
ROBERT WOOD  
JOHNSON  
FOUNDATION®

**FACCT**  
FOUNDATION FOR ACCOUNTABILITY

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# Acknowledgements

This Portrait of Informal Caregivers in America is one of three data portraits produced in 2002 by The Robert Wood Johnson Foundation as part of its National Strategic Indicators Project. Other volumes in the series address the experience of individuals with chronic disease and teens in today's health system.

Many different people and organizations have been involved in the framing and construction of this Portrait of Informal Caregivers in America. Jim Knickman and John Fiorillo at the Foundation provided the initial conceptualization as well as continuing oversight to the project. Christina Bethell and David Lansky at FACCT executed the design, administration, analysis, and reporting of the surveys.

The surveys themselves reflect the contributions of many investigators over the past decade. Researchers, clinical scholars, and survey methodologists have developed superb tools for measuring the experiences of caregivers. We particularly acknowledge those individuals and organizations that have been key sources of survey items and measures. These include items and measures developed by Joan Teno, MD, Brown University, JoAnne Lynn, PhD, Rand Center to Improve the Care of the Dying, the California Healthcare Foundation, the Centers for Disease Control and Prevention, the Diabetes Patient Outcomes Study (Greenfield, et al.), Harris Interactive, and the Outcomes Measures for Health Education project at Stanford University (Lorig, et al.). We also offer special appreciation and heartfelt thanks to the individuals who participated in the survey.



# Introduction: A Portrait of Informal Caregivers in America

## INTRODUCTION

Millions of hours of help and support are provided daily by family members and friends to individuals who are either temporarily or permanently unable to function independently. We call this help “caregiving,” and it encompasses a range of activities from administering medications to providing comfort and affection. The work is unpaid and largely ignored in our calculations of the costs of health care and long-term care in America.

Caregivers\* are a population in demand as America ages and the incidence of chronic disease increases. Estimates are that 52 million people serve as caregivers.<sup>1</sup> Two decades ago, families started to talk publicly about the emotional, physical, and financial hardships of caregiving, which we coined “caregiver burden.” Largely by disease or disorder, we became aware of how hard it was to provide care day in and day out and never receive a break or support. *The 36-Hour Day*<sup>2</sup> was an introduction for many policymakers to the incredible stress placed on caregivers of individuals with Alzheimer’s disease. The epidemic of HIV/AIDS shed a similar light on providing care for younger adults, not always by a family member but often by a partner.

This chart book explores the experiences of 1,005 caregivers of the chronically ill surveyed on-line in May 2001. The Robert Wood Johnson Foundation, in collaboration with FACCT—The Foundation for Accountability, conducted this survey to learn more about what caregivers are feeling about providing care and what they need from the health care and social services systems.

We address five questions in this report:

1. What roles do caregivers play?
2. What are the experiences of caregivers?
3. How responsive is the health system to caregivers?

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\* Throughout this document the term ‘caregivers’ refers to ‘informal caregivers’.

<sup>1</sup> Health and Human Services (June, 1998). *Informal Caregiving: Compassion in Action*. Department of Health and Human Services, Washington, DC. Based on data from the National Survey of Families and Households (NSFH).

<sup>2</sup> Mace, N., Rabins, P. *The 36 Hour Day*. Baltimore: Johns Hopkins Press, 1981.

4. How easy is it for caregivers to get help?
5. Are caregivers prepared for the future?

We hope the answers contained in this chartbook will stimulate discussions and actions on how we can better support caregivers. The use of online surveys is an early step in a long-term strategy to provide rapidly available, relevant information to inform program planning and evaluation and policy decision-making. We acknowledge that many older caregivers do not use the Internet, and thus this survey may not be generalizable to all caregivers. But the data offer a compelling portrait of the experiences of a growing number of Americans. Most of all, the chartbook provides a view into a world many of us will know in our lifetime.

The “Fast Facts” on the following pages provide a quick overview of what survey respondents told us. Each of these findings is explored in greater depth in the main body of the chartbook.



## ***Fast Facts***

- What caregivers provide most (83%) is emotional support to the care recipient. Almost half (47%) of caregivers feel it is “very” or “extremely difficult” for the care recipient to tolerate the emotional problems and symptoms he or she experiences.
- More than half (55%) of all caregivers feel isolated. Feelings of isolation increase with duration of caregiving.
- Fifty percent of all caregivers feel that the burden of caregiving is “frequently” or “sometimes” too much to handle.
- Almost one in five (22%) have been told by a health professional in the last 12 months that they have depression, nearly twice the rate in the general population.
- Less than half (43%) of all caregivers feel involved in health care decisions for the care recipient.
- Less than half (48%) of caregivers feel the health care provider is “helpful” or “very helpful” in making clear the specific goals for treatment, helping the caregiver understand what needs to be done in the care recipient’s treatment, and keeping the caregiver motivated on things that need to be done in the course of treatment.
- Caregivers have the most difficult time getting counseling for the care recipient. Money remains the largest barrier to getting help. Lack of insurance or fear of spending money was cited by 30% of the caregivers for not getting a service.
- Overall 39% of caregivers report needing respite care within the past 12 months; only half of that number say they received it.
- Less than half of care recipients have completed a living will (45%) or a durable power of attorney (49%).



# Prologue: Who are America's Caregivers?

## PROLOGUE

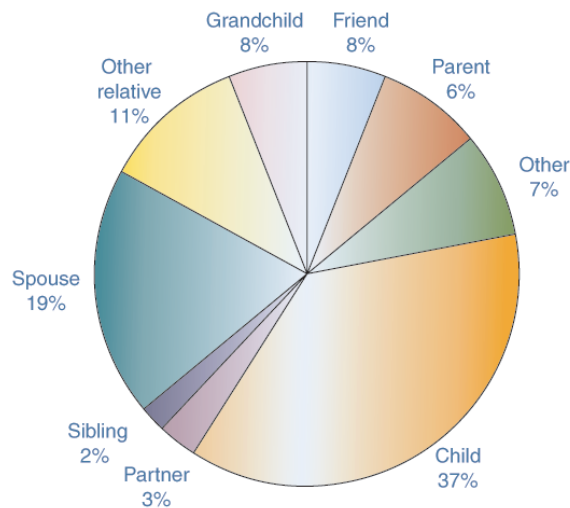
We are everyone. We are husbands and wives, children, parents and partners. We are friends, cousins, and brothers and sisters. The people we care for are frequently old and have congestive heart failure, Alzheimer's or Parkinson's disease. We also care for severely disabled children and young adults with traumatic injury. Some of us are HIV/AIDS caregivers, and others are tending to children or adults with cancer.

We juggle our time and squeeze caregiving into the hours between waking up, working and falling asleep. Numbers of us still have children living at home, earning an identity as members of the sandwich generation.

We frequently become caregivers by default. We are the child living closest to an elder parent or the only one with sufficient time to help a sibling or friend. We learn about caregiving on-the-job. Few experiences prepare us for the burdens and rewards of caring for someone else.

**Chart 1: America's caregivers**

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## PROFILE OF SURVEY RESPONDENTS

The wide demographic differences among respondents to this survey reflect the universality of caregiving. We do not become caregivers because we reach a certain age or have a certain income. On average, we are middle-aged, female, married and caring for an individual 65 years and older. Our profile reflects national statistics, which estimate that the average age of caregivers caring for someone aged 20 or more is 43 years.<sup>3</sup> Our children are grown, and most of us have attended or graduated from college. We speak from experience; a majority of us have been caregiving for more than 12 months. And, many of us are balancing our caregiving responsibilities with a job. More than half of us are either employed or self-employed.

| <b>Table 1: Demographics of Caregivers</b> |                    |     |
|--|--------------------|-----|
|  | <b>Sample size</b> |     |
| <b>Age</b>                                 |                    |     |
| 18-24 years                                | 88                 | 9%  |
| 25-44 years                                | 306                | 31% |
| 45-64 years                                | 475                | 47% |
| 65 years+                                  | 133                | 13% |
| <b>Gender</b>                              |                    |     |
| Female                                     | 683                | 68% |
| Male                                       | 322                | 32% |
| <b>Marital status</b>                      |                    |     |
| Married                                    | 541                | 54% |
| Single                                     | 198                | 20% |
| Divorced                                   | 152                | 15% |
| Separated                                  | 17                 | 2%  |
| Widowed                                    | 36                 | 3%  |
| Living with partner                        | 60                 | 6%  |
| <b>Children living in household</b>        |                    |     |
| 0  | 733                | 73% |
| 1  | 148                | 15% |
| 2  | 73                 | 7%  |
| 3 or more                                  | 51                 | 5%  |
| <b>Education</b>                           |                    |     |
| High school graduate or less               | 301                | 30% |
| Some college or associate degree           | 378                | 38% |
| College graduate                           | 146                | 14% |
| Some graduate school or graduate degree    | 179                | 18% |
| <b>Length of caregiving</b>                |                    |     |
| Less than 3 months                         | 99                 | 10% |
| 3 –12 months                               | 169                | 17% |
| > 12 months                                | 736                | 73% |

<sup>3</sup> Cohen, D., Luchins, D., Eisdorfer, C., Paveza, G., Ashford, J., Gorelick, P., Hirschman, R., Freels, S., Levy, P., Semia, T., and Shaw, H. (1990). Caring for Relatives With Alzheimer's Disease: The Mental Health Risks to Spouses, Adult Children, and Other Family Caregivers. *Behavior, Health and Aging*, Vol. 1, No. 3, pp. 171-182.

| <b>Table 1: Demographics of Caregivers</b> |                    |     |
|--|--------------------|-----|
|  | <b>Sample size</b> |     |
| <b>Employment status</b>                   |                    |     |
| Employed full-time                         | 379                | 38% |
| Employed part-time                         | 89                 | 9%  |
| Self-employed                              | 87                 | 9%  |
| Not employed                               | 236                | 23% |
| Retired                                    | 214                | 21% |

| <b>Table 2: Demographics of Care Recipients</b> |                    |     |
|---|--------------------|-----|
|   | <b>Sample Size</b> |     |
| <b>Diagnosis</b>                                |                    |     |
| Major organ disease                             | 149                | 15% |
| Cancer  | 98                 | 10% |
| Injury/accident                                 | 37                 | 4%  |
| Dementia/frailty                                | 338                | 33% |
| Other   | 382                | 38% |
| <b>Age</b>                                      |                    |     |
| 0-17 years                                      | 44                 | 4%  |
| 18-34 years                                     | 47                 | 5%  |
| 35-49 years                                     | 115                | 11% |
| 50-64 years                                     | 215                | 22% |
| 65-79 years                                     | 289                | 29% |
| 80+ years                                       | 290                | 29% |
| <b>Gender</b>                                   |                    |     |
| Female  | 623                | 62% |
| Male  | 379                | 38% |
| <b>Income</b>                                   |                    |     |
| < \$15,000                                      | 121                | 12% |
| \$15,000 - \$24,000                             | 155                | 15% |
| \$25,000 - \$49,000                             | 312                | 31% |
| \$50,000 - \$75,000                             | 139                | 14% |
| > \$75,000                                      | 99                 | 10% |
| Declined to answer                              | 178                | 18% |

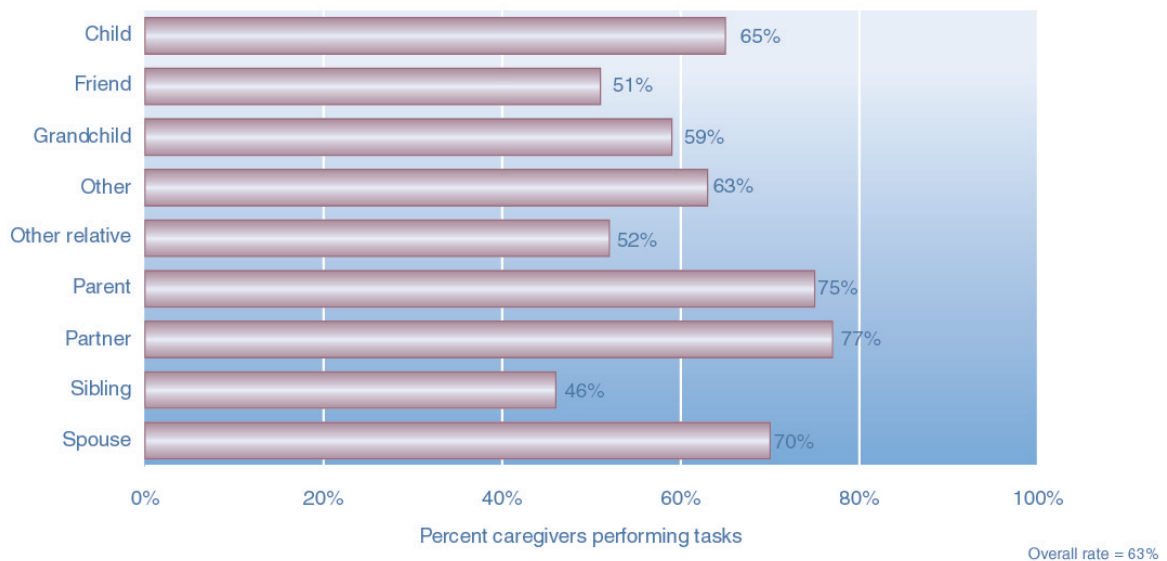


# What Roles do Caregivers Play?

## 1.1 HELP WITH DAILY LIVING – NUMBER OF TASKS

In defining our role as caregiver, we list the tangible things we do to help the care recipient function, often on a daily basis. These are what professionals call “activities of daily living” (ADLs). They are the physical tasks—bathing, dressing, toileting, transferring, and eating—required to live independently. We also help with the “instrumental activities of daily living” (IADLs). These are tasks related to management— transportation, cooking, and housework. Most caregivers (63%) help the care recipient with four or more ADLs or IADLs. Partners, parents and spouses offer the most assistance, although children—daughters and sons—are of growing importance.

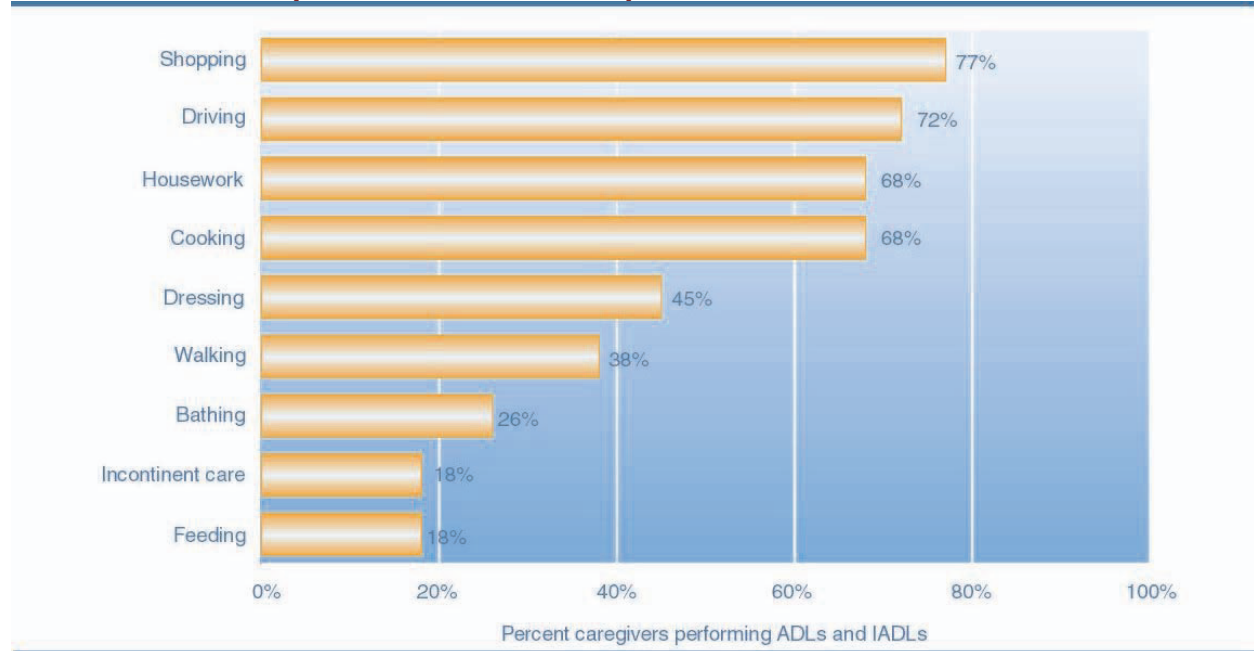
**Chart 2: Caregivers performing four or more tasks**



## 1.2 THE ADLS AND IADLS PROVIDED BY CAREGIVERS

We help most often with transportation and shopping. Just under 20% of caregivers provide help with feeding or incontinent care; females more often than males. The burden of these latter tasks, which are so time intensive and intimate, is a major reason for placing a care recipient into a long-term care facility. In this survey more male caregivers report cooking and doing housework for the care recipient than females.

**Chart 3: Activities performed for the recipient**





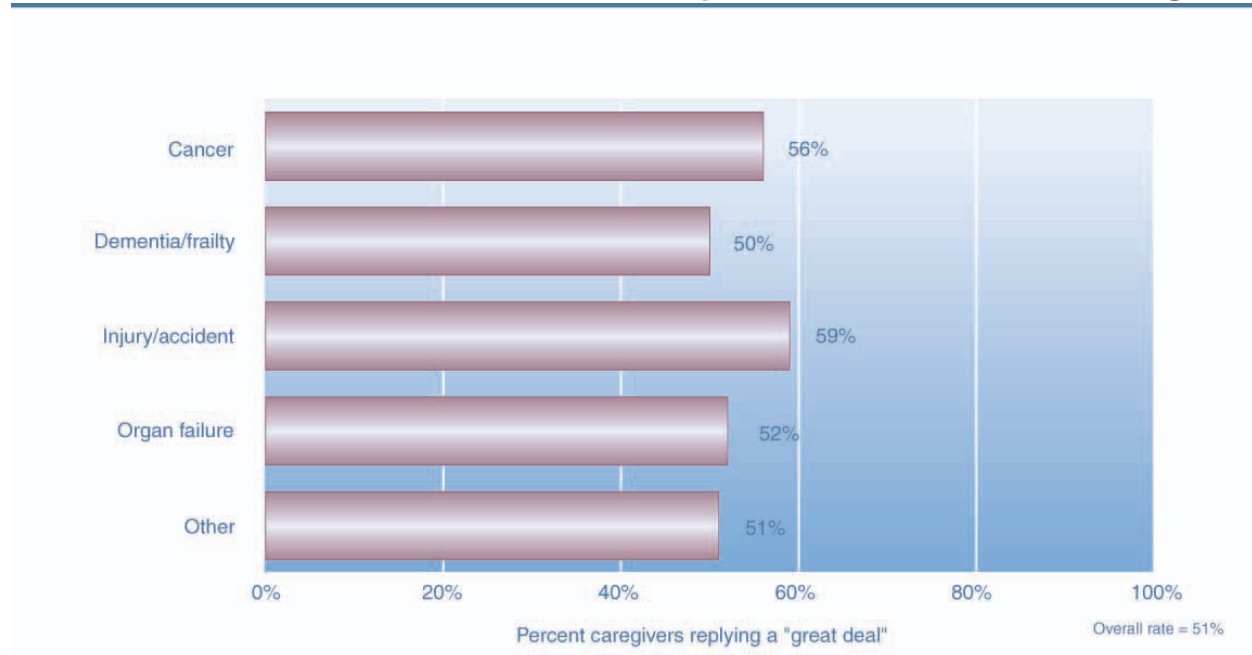
### 1.3 MANAGING MEDICAL CARE

About half of us (51%) report spending a “great deal” of time and effort trying to make sure the medical needs of the care recipient are being met by doctors or other health care providers. In addition to coordinating appointments and managing medication, we often play a larger role as the care recipient’s spokesperson in interacting with the health care team.

Caregivers (60%) often must coordinate the medical care with more than one health care provider. Seventy-five percent also say they are responsible for getting drug prescriptions filled, and of this number, 34% say they had some problem in getting prescriptions filled.

The time and effort required to make sure a recipient’s medical needs are being met vary according to the recipient’s diagnosis. Caregivers of individuals with a traumatic injury (59%) report spending the most time and effort, perhaps reflecting the need to coordinate rehabilitative care.

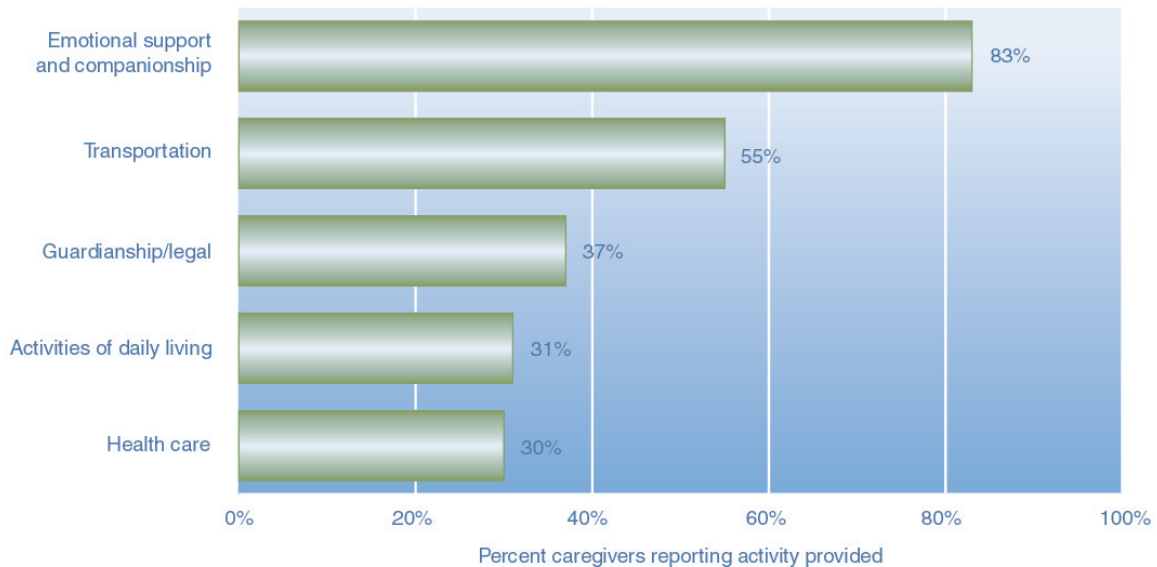
**Chart 4: Time and effort to make sure the recipient’s medical needs are being met**



## 1.4 EMOTIONAL SUPPORT

Caregiving is not a solitary experience. We are helping another person who is dependent upon us. Some care recipients are in pain; others are emotionally distraught over losing their independence and ability to function. Beyond the physical help of shopping, transportation, etc., we provide the intangibles of caregiving—friendship, hope, love, reassurance, and security. Eighty-three percent of us report that our major task is giving emotional support and companionship. More than anything else, this defines our role as caregiver.

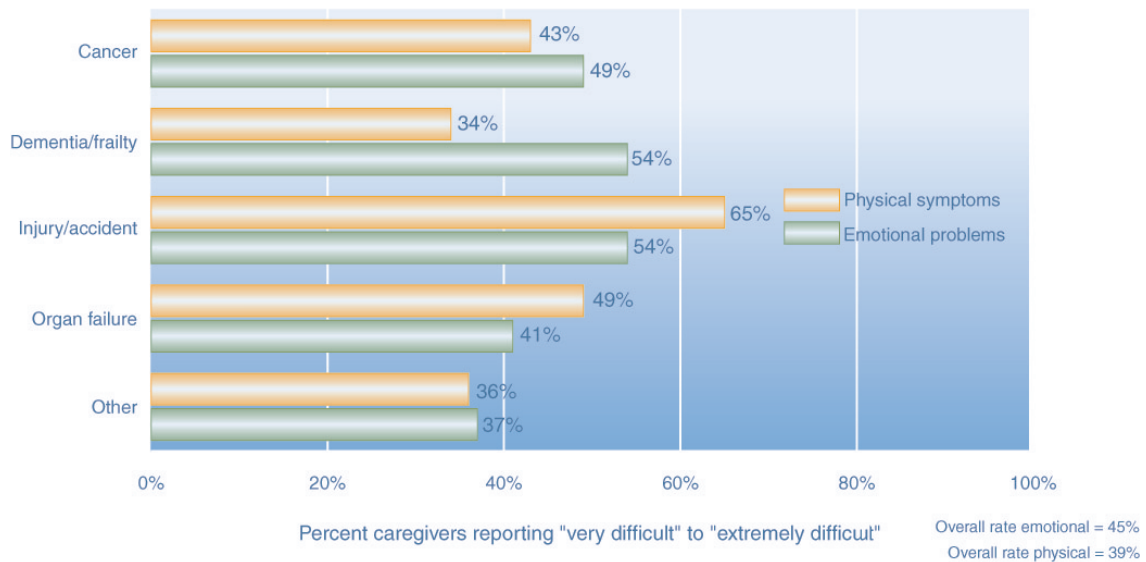
**Chart 5: Caregiving activities most often provided to the recipient**



## 1.5 DEALING WITH PHYSICAL AND EMOTIONAL SUFFERING

As caregivers, we are acutely aware of the physical suffering or emotional anguish brought on by a debilitating injury or illness. Forty-five percent of caregivers say the care recipient experiences “very” or “extremely difficult” emotional symptoms, and 39% of caregivers say the care recipient has a “very” or “extremely difficult” time tolerating physical problems. Not surprisingly the degree of difficulty varies according to the recipient’s diagnosis. Individuals with traumatic injury have the hardest time coping with physical symptoms (65%) but also experience frequent emotional problems (54%). Individuals with dementia experience frequent emotional problems (54%) but much fewer problems coping with physical symptoms (34%).

**Chart 6: Difficulty of recipient in tolerating experiences**



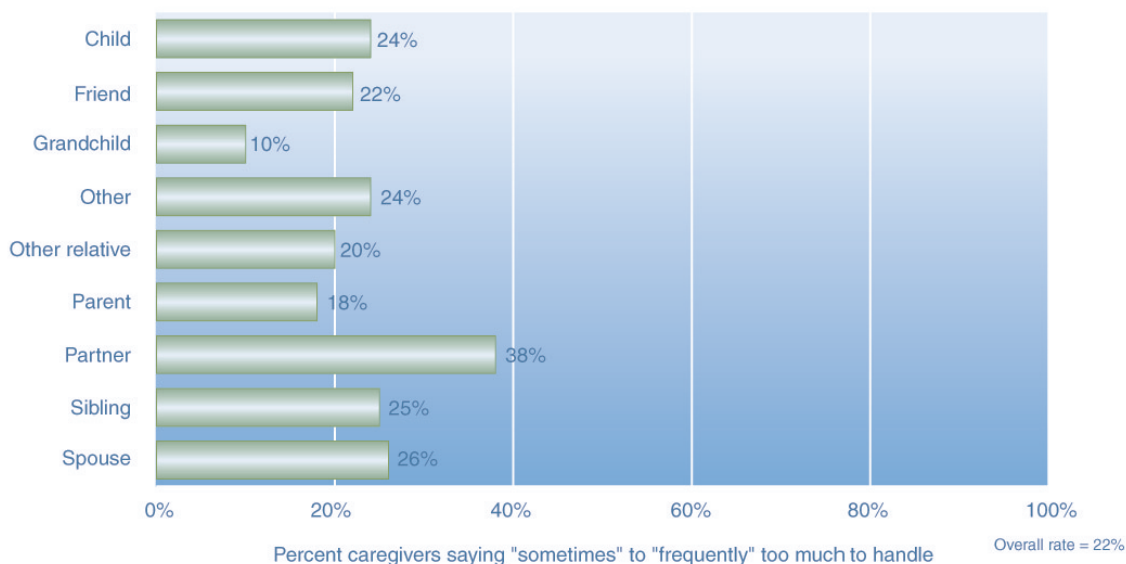


# What are the Experiences of Caregivers?

## 2.1 FEELINGS OF ISOLATION

Social contact is important to our sense of well-being. We may not be able to leave the care recipient or have any time left in the day as we struggle to balance work, family and caregiving. We admit we feel isolated. Nearly one in four caregivers (22%) say that their feelings of isolation are “sometimes” or “frequently” too much to handle. An additional 23% regard their feelings of isolation as “moderate, but tolerable.” Caregiving partners and spouses feel the most isolated; grandchildren the least.

**Chart 7: Caregivers reporting feelings of isolation**

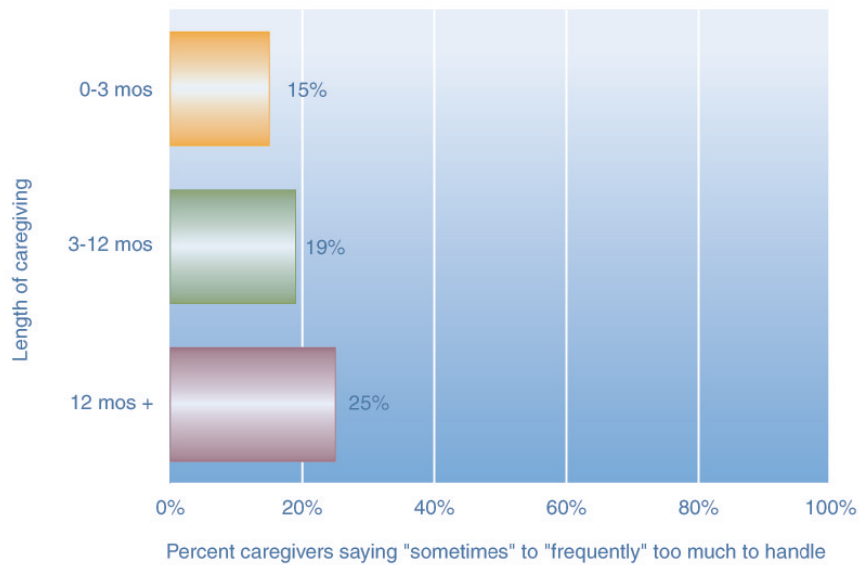


## 2.2 FEELINGS OF ISOLATION AND LENGTH OF CAREGIVING

As the months pass, our feelings of isolation increase. The demands of caregiving often shut out other social activities and narrow our social network and community ties. Under three months, 15% of us report feeling isolated. After 12 months, this percentage increases to 25%, one in four of us.

**Chart 8: Caregivers reporting feelings of isolation**

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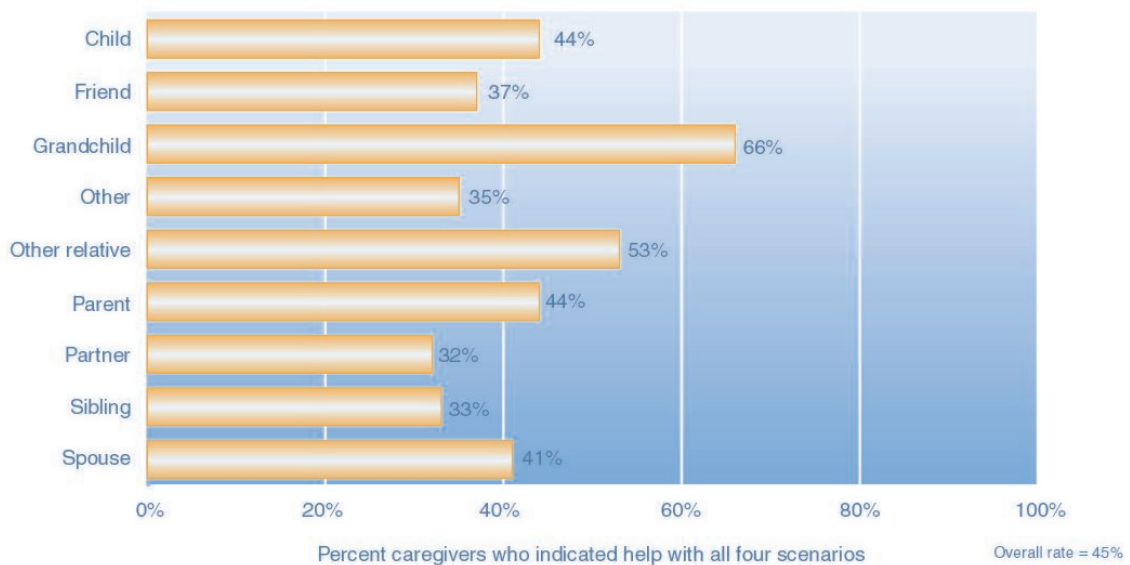


## 2.3 SOCIAL SUPPORT

Decreased social contact may erode our confidence in getting help when we face an unexpected or stressful life event. “Social support” is our ability to get materials, services, and information from families and friends. A high percentage of caregivers feel they cannot count on family or friends to help with everyday chores (33%), housekeeping (38%), or moving (27%). When asked about getting help in an emergency, they are more often able to identify someone: only 9% feel they would have trouble finding someone to come and get them if they were stranded 10 miles from home.

Social support is widely recognized as an important determinant of health. Less than half (45%) of the caregivers in this survey as compared to 55% of the general population feel they can count on a high level of social support from friends or family, i.e, they indicate they would be supported in all four ways mentioned above. Grandchildren and other relatives feel the most supported. Partners and siblings feel the least supported.

**Chart 9: Caregiver social support**



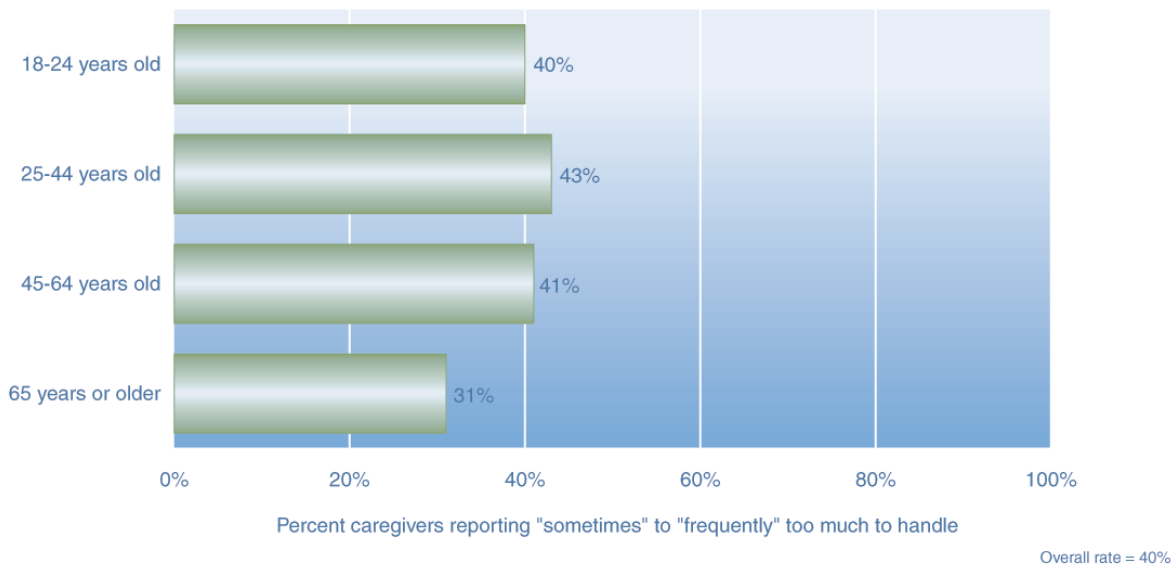
## 2.4 CAREGIVER STRESS: EMOTIONS

Caregiving poses multiple challenges to our own physical, mental and financial sense of well-being. Many of us feel overwhelmed by the emotional demands of caregiving. In this study older caregivers (31%) report less emotional stress than caregivers in other age groups. This may reflect less competing demands on the older caregiver such as children in the home, employment or school.

The degree of stress experienced by the caregiver varies by the care recipient's diagnosis. Caregivers providing care to an individual with traumatic injury (54%) experience the most emotional stress, followed by those who provide care to individuals with cancer (43%).

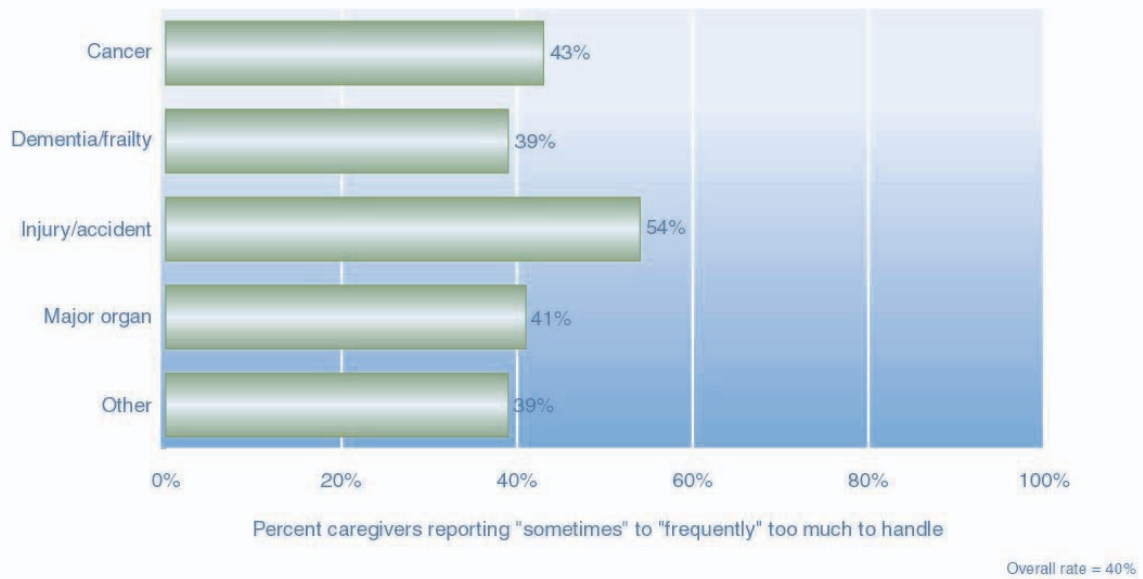
Our relationship with the care recipient may be another source of emotional stress. Partners (65%) and siblings (50%) feel the most emotional stress, followed by children who are caring for a parent (43%) and spouses (40%). Other relatives (29%) and friends (33%) feel the least emotional stress.

**Chart 10: Emotional stress and age of caregiver**

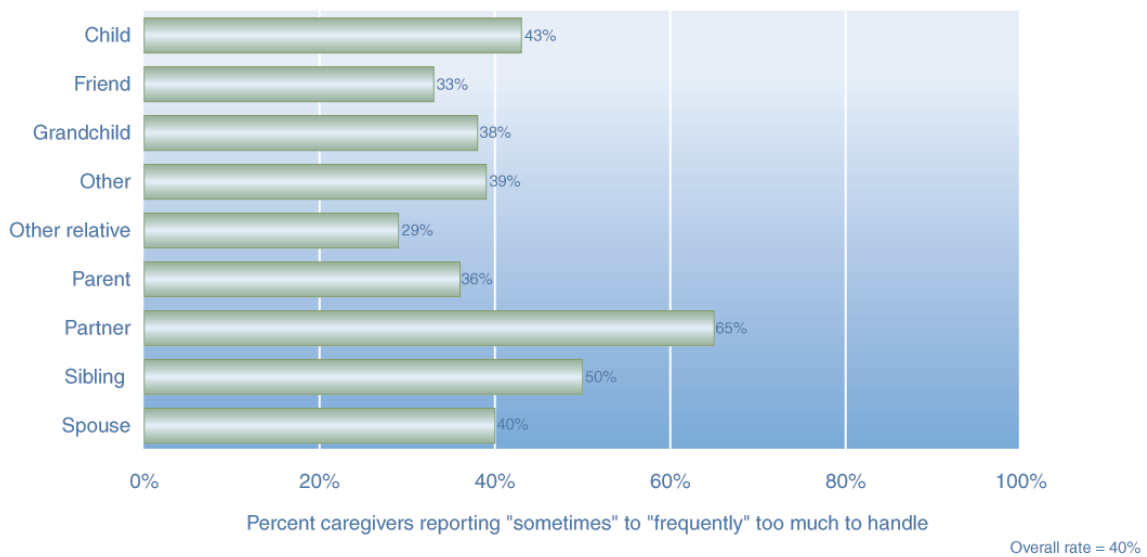




**Chart 11: Emotional stress and diagnosis of care recipient**



**Chart 12: Emotional stress and relationship to care recipient**

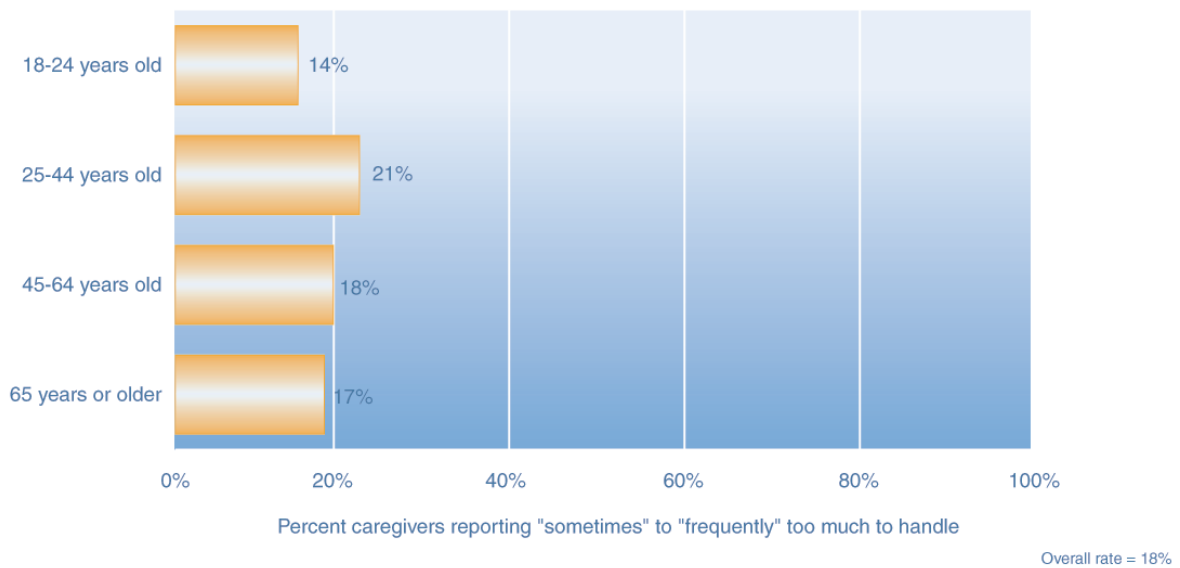


## 2.5 CAREGIVER STRESS: PHYSICAL

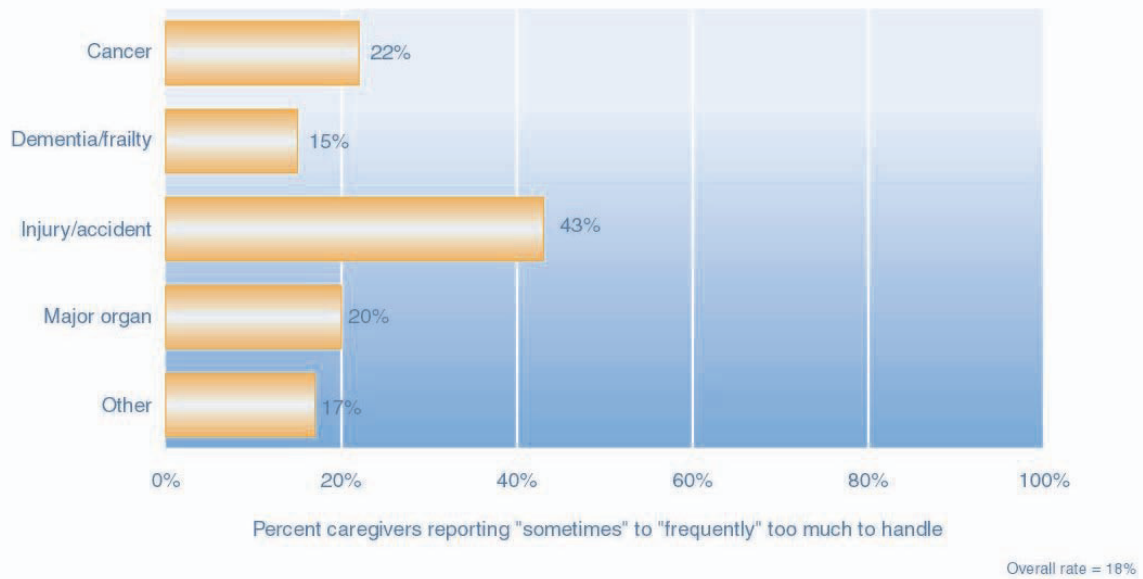
Fewer of us (18%) report that the physical demands of caregiving are too much to handle. The youngest caregivers (14%) report less strain than the other age groups.

Partners (32%) report the most physical stress. By far, caregivers caring for someone with a traumatic illness (43%) report the most physical strain while caregivers caring for someone with dementia (15%) report the least.

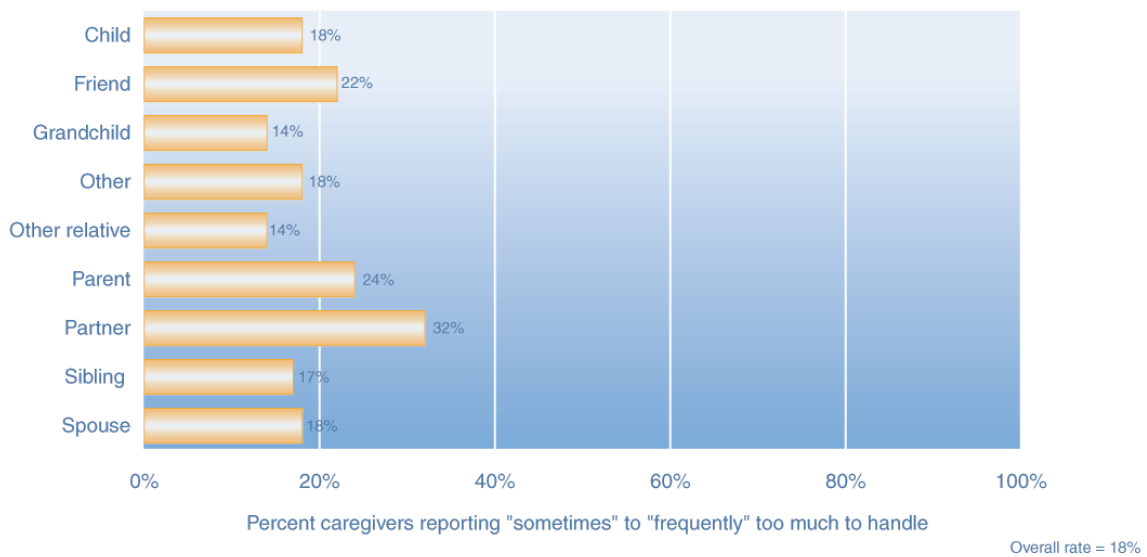
**Chart 13: Physical strain and caregiver age**



**Chart 14: Physical strain and diagnosis of care recipient**



**Chart 15: Physical strain and relationship to care recipient**

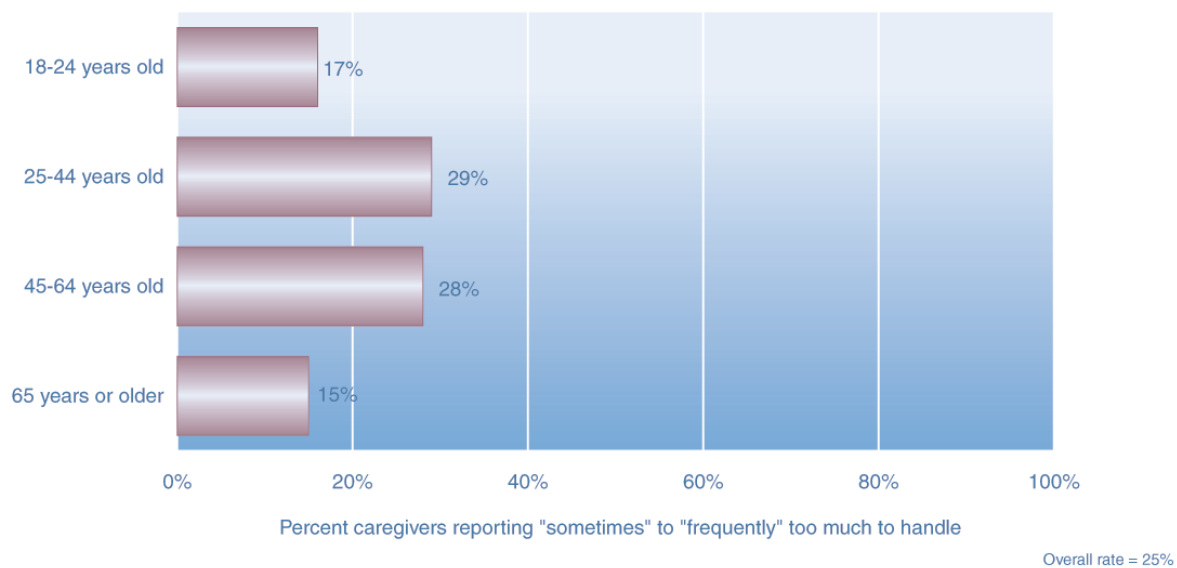


## 2.6 CAREGIVER STRESS: FINANCIAL

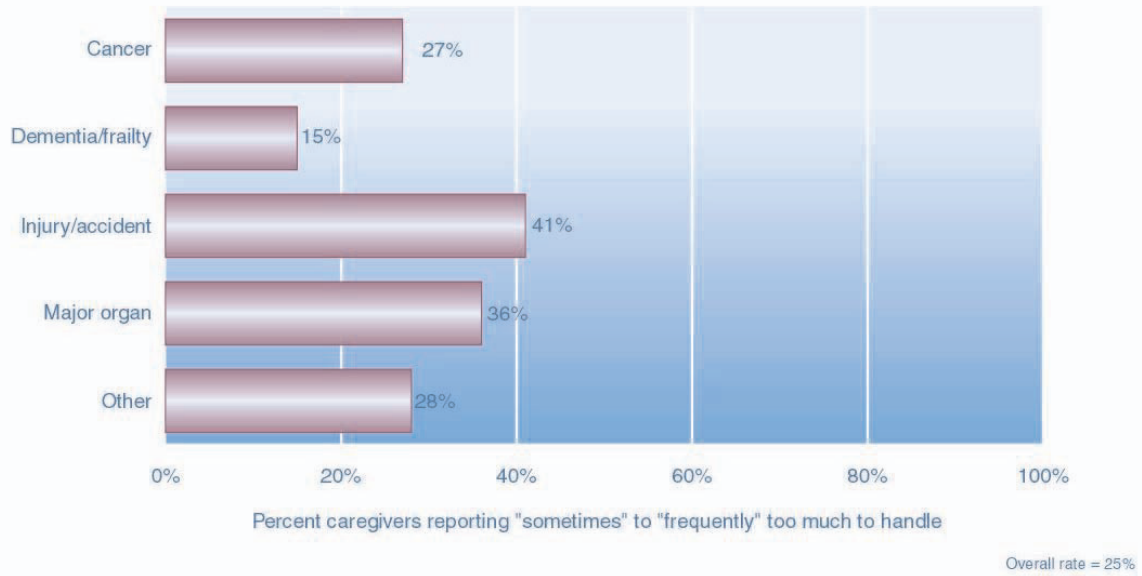
Financial concerns that accompany caregiving frequently overwhelm us. Thirty-eight percent of us report that the financial hardship of caring is “sometimes” to “frequently” too much to handle. Some of us manage the care recipient’s finances, which may be limited. It is not uncommon for families to provide financial support. Other times, we worry about the future and whether we can afford long-term care or to continue support as a child grows up. This financial stress is aggravated if we have to cut back on work hours or quit work to provide care.

All ages feel financial stress but the oldest caregivers (15%) feel the least. This may reflect not having children in the home or having to worry about employment. Caregivers of individuals with dementia or frailty (15%) report the least financial stress. Costs of care may be less for this population while the individual is still in the home than for other diagnoses. Individuals dealing with traumatic injury (41%) may have higher out-of-pocket costs in terms of co-pays and deductibles because of the cost of treatment. Partners (56%) feel the most financial stress, followed by parents (44%).

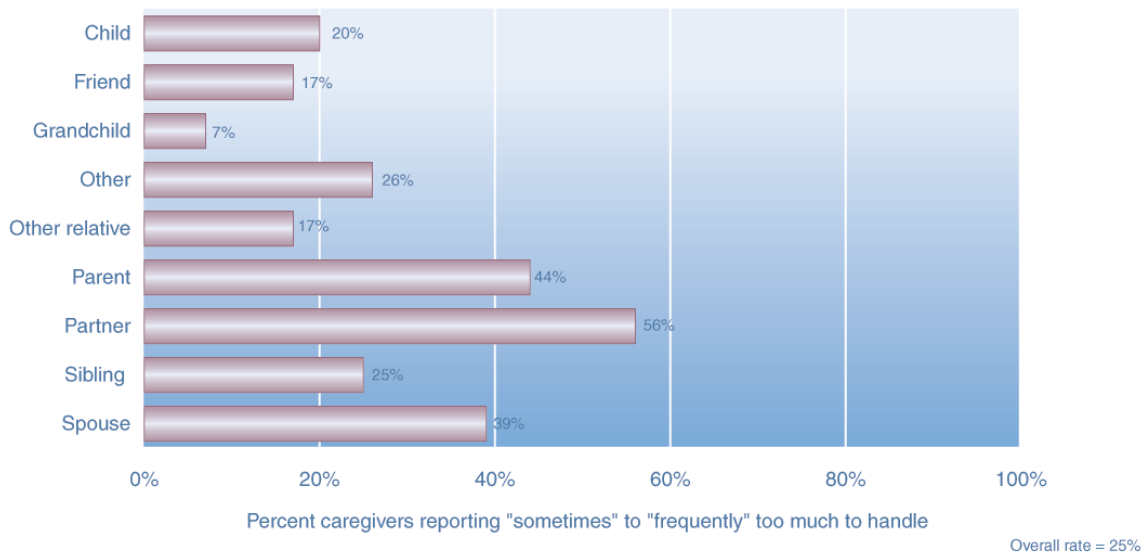
**Chart 16: Financial hardship and age of caregiver**



**Chart 17: Financial hardship and diagnosis of care recipient**



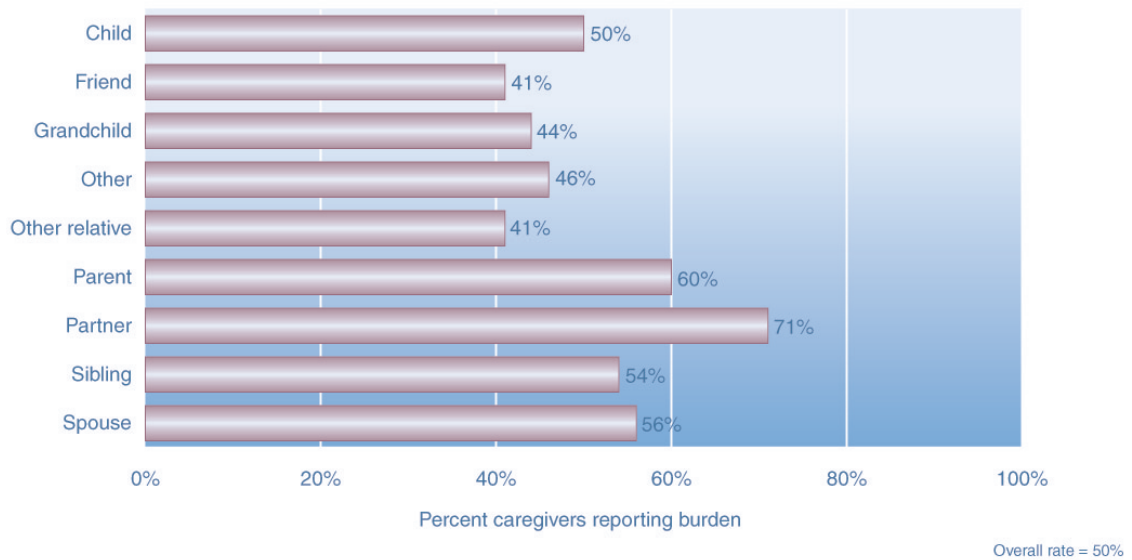
**Chart 18: Financial hardship and relationship to care recipient**



## 2.7 CAREGIVER BURDEN

The combination of physical, emotional and financial stresses plus the feelings of isolation stretch our ability to cope. Professionals call this “caregiver burden” and define it as the strain caused by the physical, psychological, emotional, social, and financial stressors associated with the caregiving.<sup>4</sup> Caregiver burden has been the subject of much research and is linked to caregiver illness and early long-term care placement of the care recipient.<sup>5</sup> One half of the caregivers in this survey (50%) experience caregiver burden. Partners (71%), parents (60%), and spouses (56%) experience the most burden; other relatives (41%) and friends (41%) the least.

**Chart 19: Caregiver burden**



<sup>4</sup> Stuckey JC, Neundorfer MM, Smyth KA. Burden or well-being: the same coin or related currency? *Gerontologist* 1996;36(5):686-93

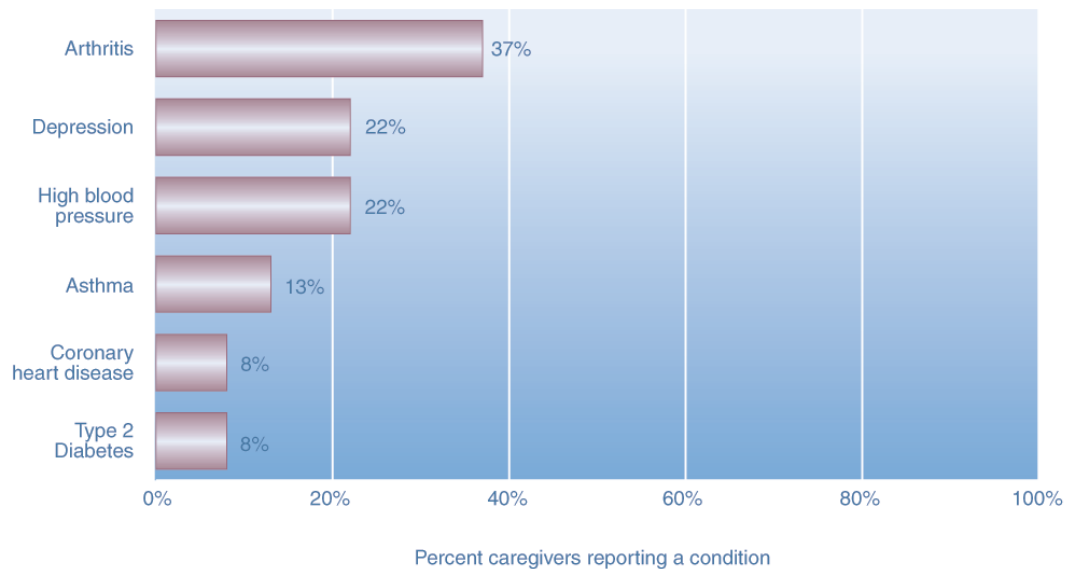
<sup>5</sup> Newman SJ, Struyk R, Wright P, Rice M. Overwhelming odds: caregiving and the risk of institutionalization. *J Gerontol Soc Sci.* 1990;45:S173-S183.

## 2.8 CAREGIVER HEALTH

We suffer from an array of chronic diseases, particularly arthritis. The incidence of chronic disease may be due to our own aging, but other health symptoms likely reflect the stresses of caregiving. Almost one in five of us (22%) has been told by a health professional in the last 12 months that we have depression, nearly twice the rate of the general population.

On average, we report eight days each month when our physical health is not good and eight days when our mental health is not good, as compared to five and one half days of poor physical health and four and one half days of poor mental health for the general adult population.

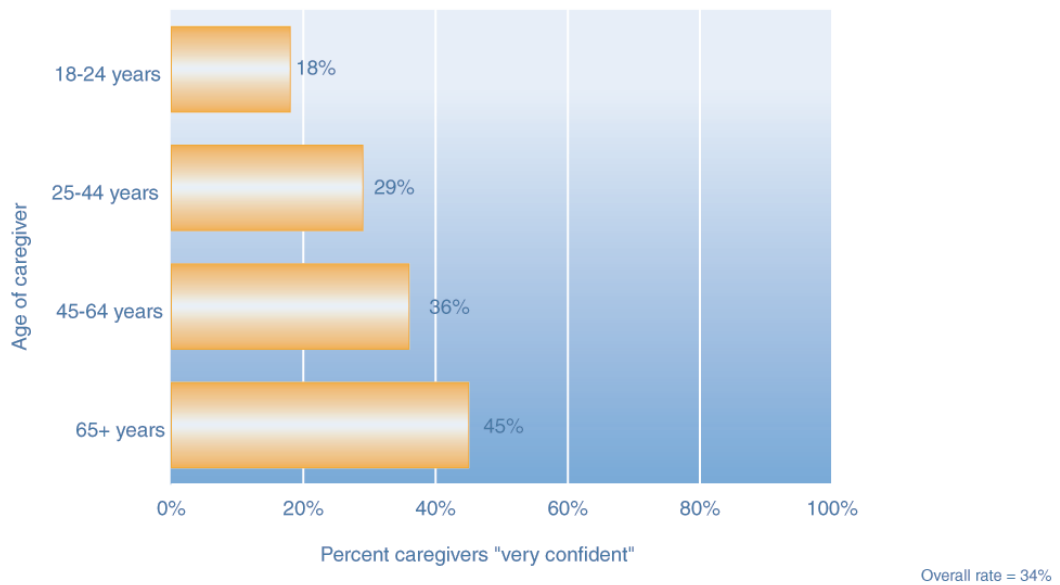
**Chart 20: Caregiver told by doctor of health condition**



## 2.9 CAREGIVER CONFIDENCE IN TAKING CARE OF OWN GENERAL HEALTH

Although we are caring for another individual, only one third of us (34%) are “very confident” about taking care of our own general health. We vary in how well we know what to do when taking medications, deciding when to see a physician for our health care, and eating right. We are least confident in knowing when to see a physician. The older we are, the more confident we are. This is true for the general adult population as well.

**Chart 21: Confidence in ability to take care of one’s health by age of caregiver**



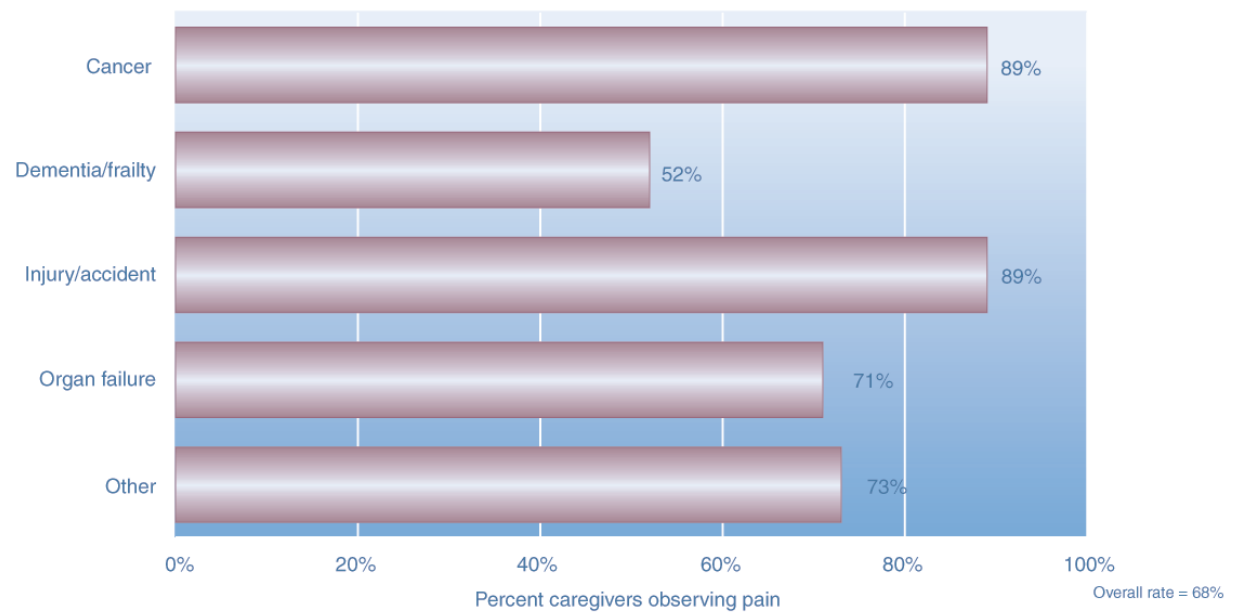


# How Responsive is the Health System?

## 3.1 CARE RECIPIENTS IN PAIN

Part of the physical suffering of care recipients is the experience of pain. Two thirds of caregivers (68%) report they have observed the care recipient in pain. Caregivers taking care of individuals with cancer (89%) or traumatic injury (89%) report observing the most pain, and those caring for an individual with dementia (52%) observe the least. Among caregivers reporting they had observed pain, 27% feel the pain bothered or distressed the recipient “very much,” and 36% “quite a bit.”

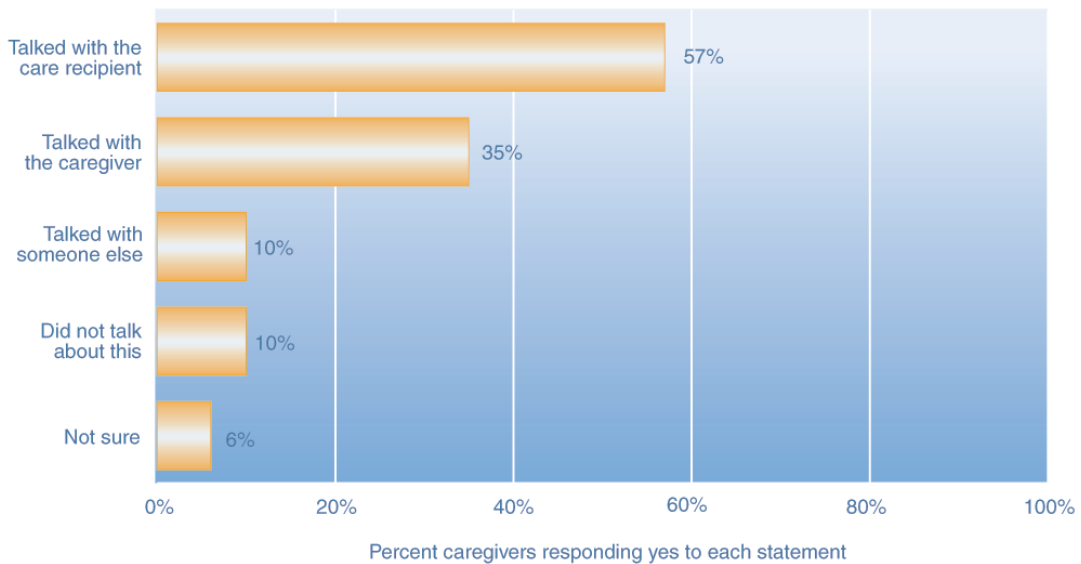
**Chart 22: Observed recipient in pain**



### 3.2 COMMUNICATION ABOUT PAIN MANAGEMENT

The need for better pain management among the chronically ill has been noted for more than a decade. Among caregivers who observed pain, 84% report that the doctors communicated with the patient, the caregiver or someone else about how any pain was to be treated. Doctors most often talked with the care recipient (57%), followed by the caregiver (35%).

**Chart 23: Doctor communication about how pain will be treated**

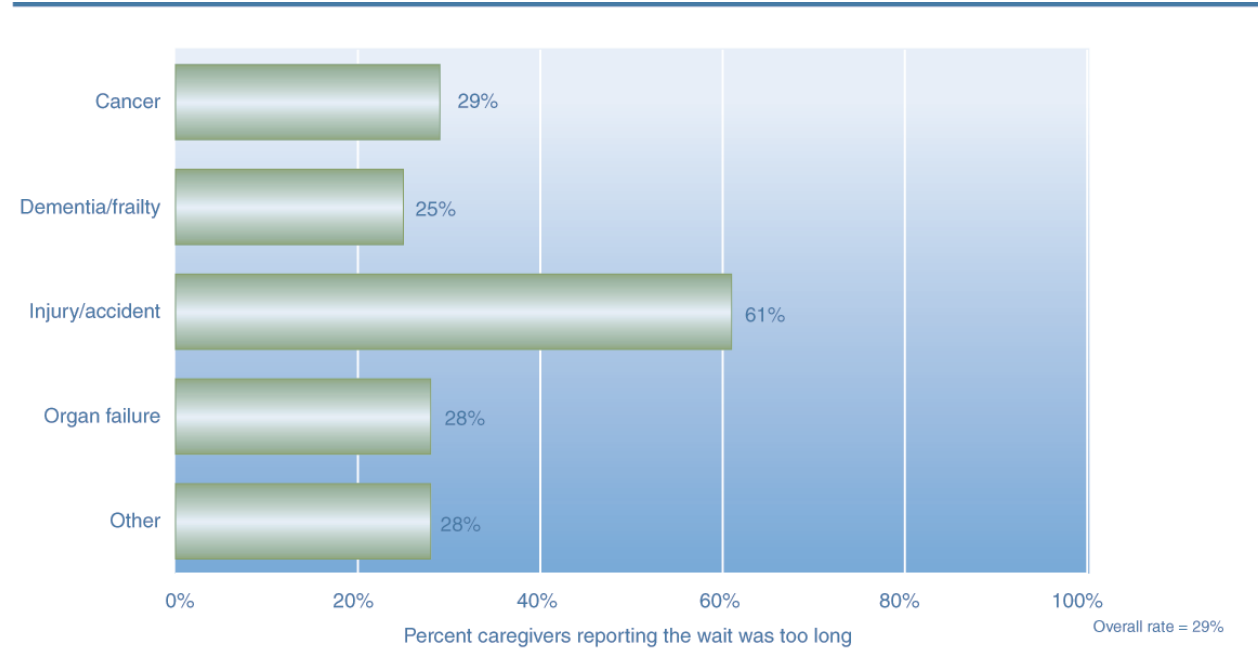


### 3.3 APPROPRIATE LEVEL OF INTERVENTION

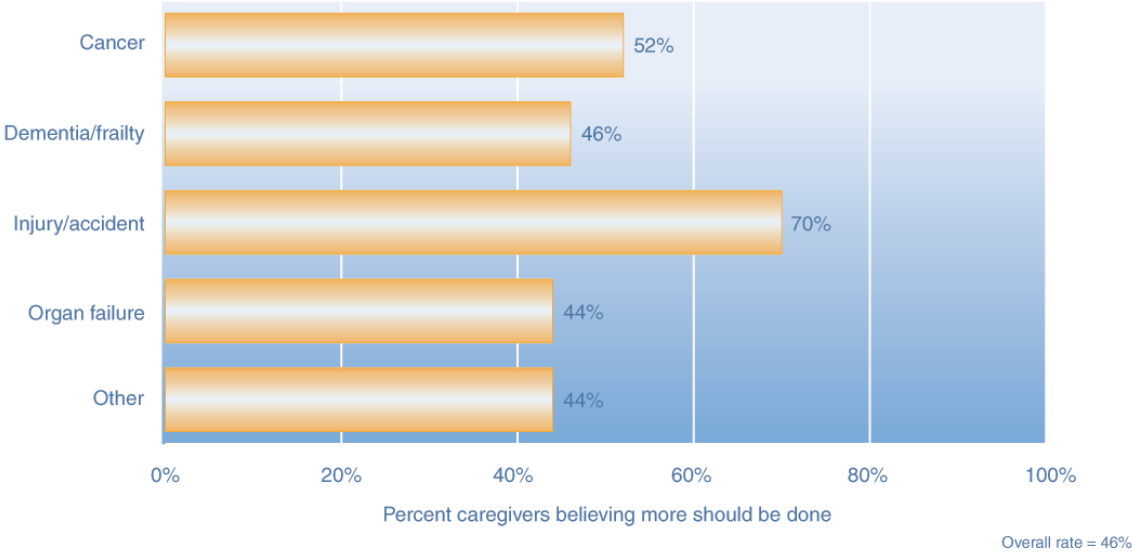
Our expectations of what should be done to keep the care recipient comfortable do not always get met. Nearly one third of us (29%) who observed pain feel that the care recipient had to wait too long to get pain medication. Caregivers of individuals with traumatic injuries report this most often (61%).

Aside from pain management, many caregivers (46%) feel that more could be done medically to keep the care recipient comfortable. Caregivers of individuals with traumatic injuries (70%) are most likely to report this expectation.

**Chart 24: Waited too long for medication**



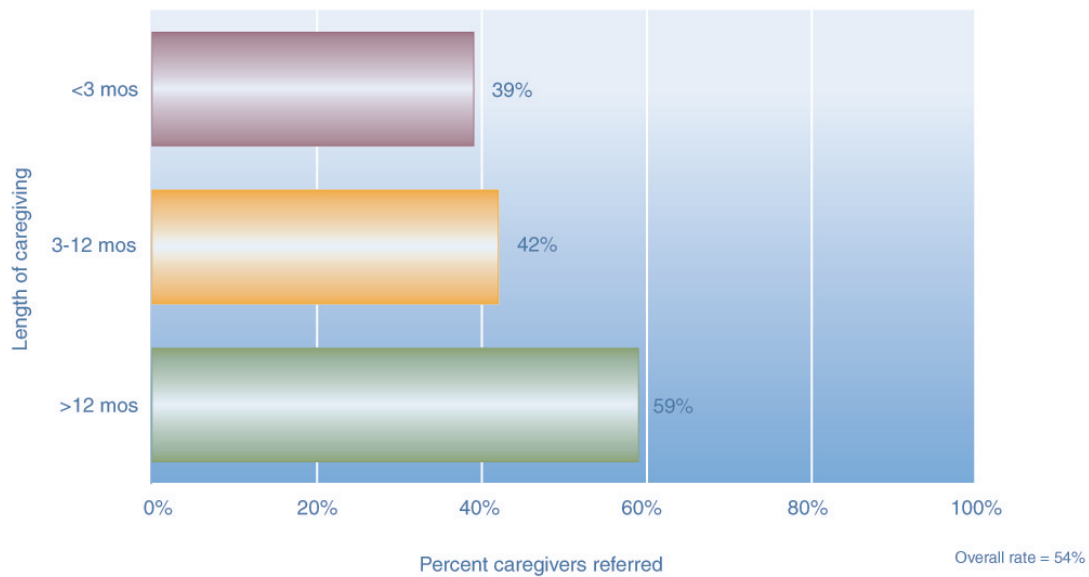
**Chart 25: Belief that more should be done to make the recipient comfortable**



### 3.4 SUPPORT FOR CAREGIVERS OF INDIVIDUALS WITH DEMENTIA

We receive no formal training to become caregivers, and few of us are aware at the start of caregiving of any support services to help us. For many, the physician’s office is the first and sometimes only contact outside of our friends and families. In communities across the country, support groups and advocacy organizations have worked hard to publicize the needs of caregivers of individuals with dementia to the medical community and to encourage physicians to direct the caregiver to support services. In a subset of this survey, these caregivers were asked about referrals by physicians to support services. More than half (54%) of physicians provide referrals. The longer the time as a caregiver, the more likely it is for the physician to refer the caregiver to support services.

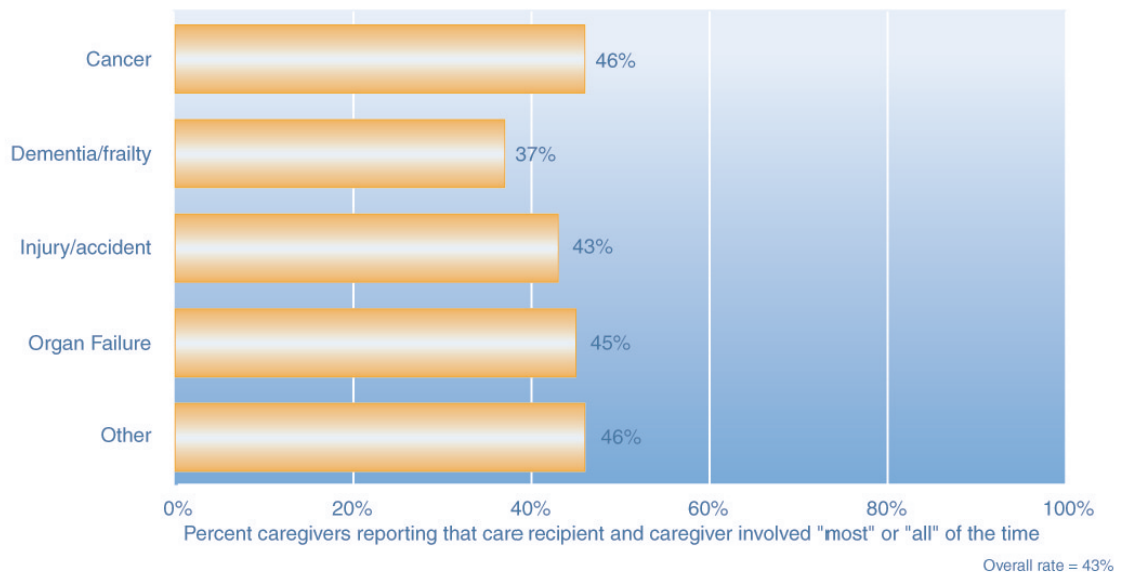
**Chart 26: Referral to services**



### 3.5 CAREGIVER INVOLVEMENT IN DECISION-MAKING

Less than half of us (43%) say we and/or the care recipient (if able) were involved “most” or “all of the time” in decisions about the care recipient’s health care. This composite measure combined answers on four types of involvement including being provided with choices and taking the caregiver and care recipient’s preferences into account when making treatment decisions. Caregivers of individuals who suffer from dementia or frailty (37%) report the least involvement in decision-making. This may reflect the gradual decline in cognitive status of the care recipient and the health care provider’s uncertainty about when to include the caregiver in discussions.

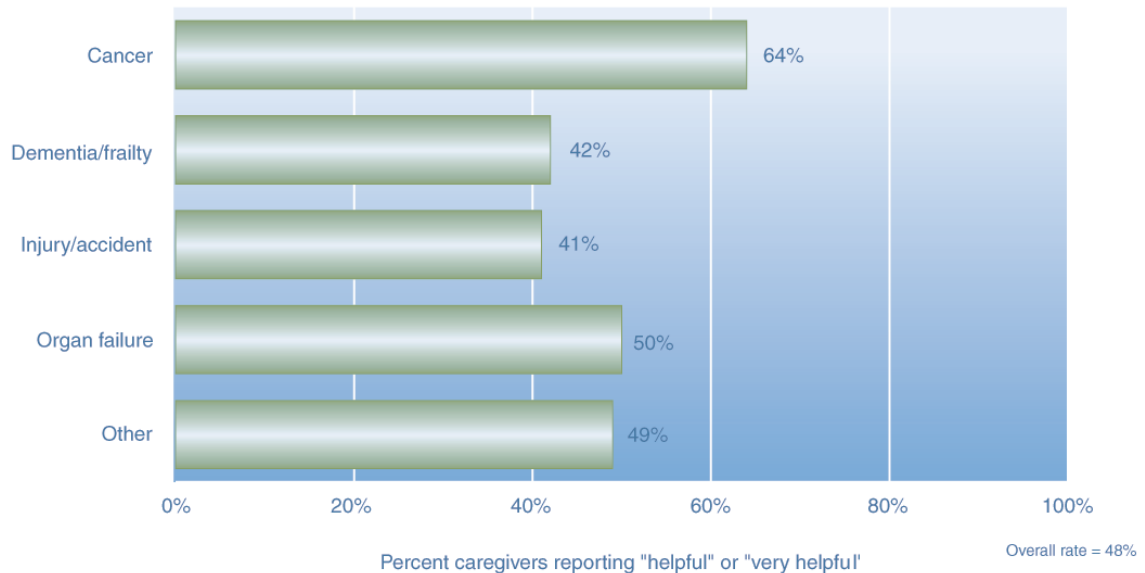
**Chart 27: Involved in decision-making**



### 3.6 HELP IN UNDERSTANDING AND MANAGING MEDICAL CARE

As caregivers, we often must manage the treatment provided to the care recipient. We look to the health care team to guide us in doing this task. About half of us (48%) feel the care recipient's health care provider makes clear the specific goals for treatment, helps us understand what needs to be done in the care recipient's treatment, and keeps us motivated on things that need to be done in the course of treatment. Sixty-four percent of caregivers of individuals with cancer say their providers were "helpful" or "very helpful" as compared to 41% of caregivers of individuals with a traumatic injury or accident. This may be because many oncology practices and medical centers offer cancer support services.

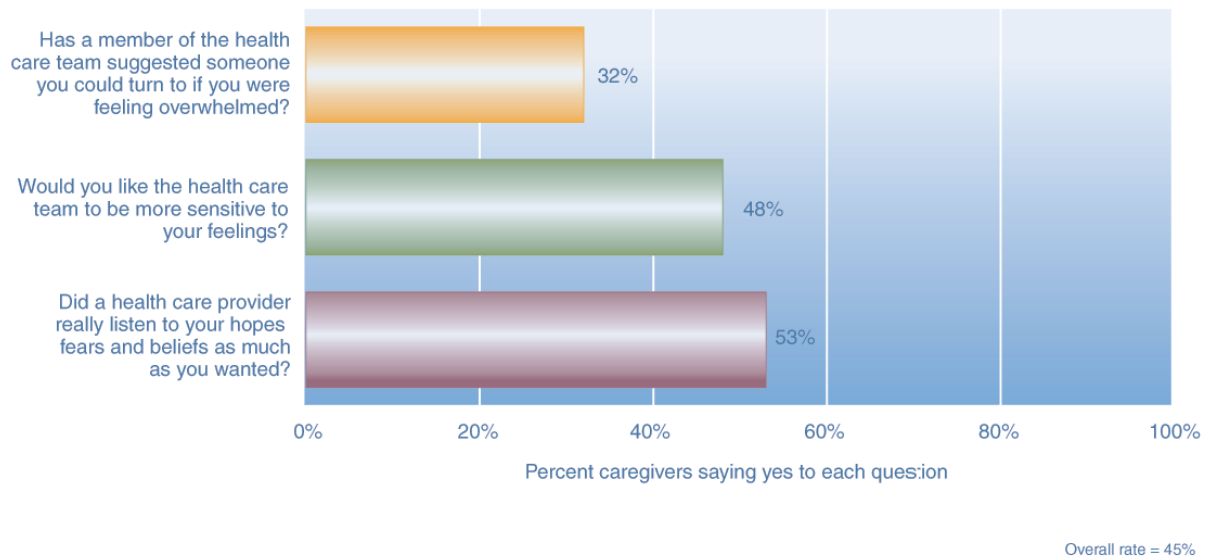
**Chart 28: Helpfulness of the doctor**



### 3.7 PROVIDER COMMUNICATION AND CAREGIVER SUPPORT

Medical education curricula encourage health care providers to show concern for the caregiver and regularly assess for caregiver burden.<sup>6,7</sup> Slightly less than half of caregivers (45%) in this survey feel supported by health care providers in their role as caregivers as measured by the three questions below.

**Chart 29: Provider communication and support**



<sup>6</sup> Council on Scientific Affairs, American Medical Association. Physicians and family caregivers: a model for partnership. *JAMA*. 1993;269:1282-1284.

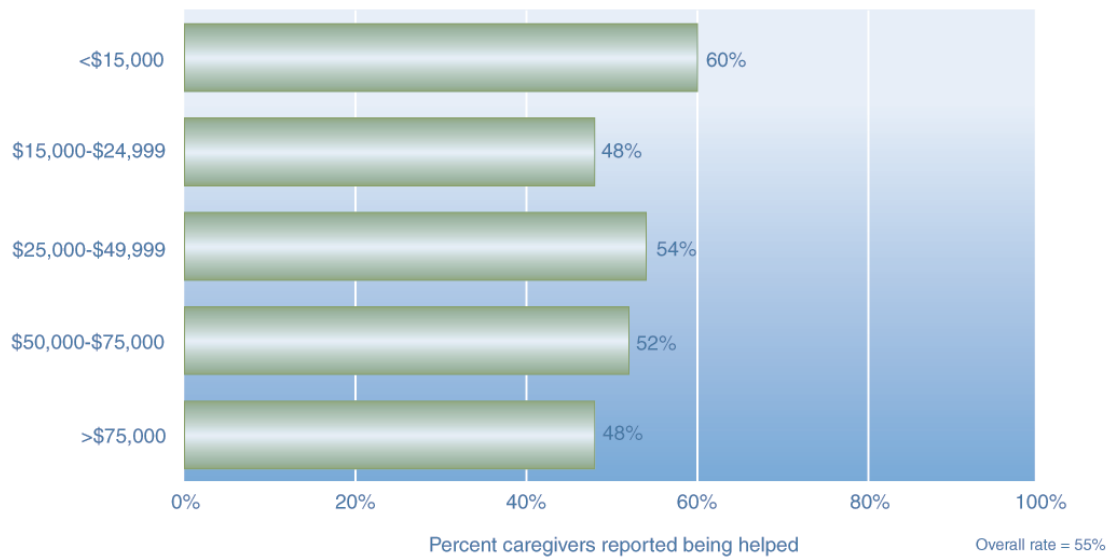
<sup>7</sup> Kasuya RT, Polgar-Bailey P, Takeuchi R. Caregiver burden and burnout: a guide for primary care physicians. *Postgrad Med* 2000;108(7):119-123.



### 3.8 COORDINATING CARE

Fifty-five percent of us report that we have had help from someone at the health plan, doctor's office or the hospital in coordinating care for the care recipient. Care recipients with the lowest income (less than \$15,000 annually) report receiving the most coordination. This may be because of wider availability of case management services for low-income families.

**Chart 30: Help with coordination of care**



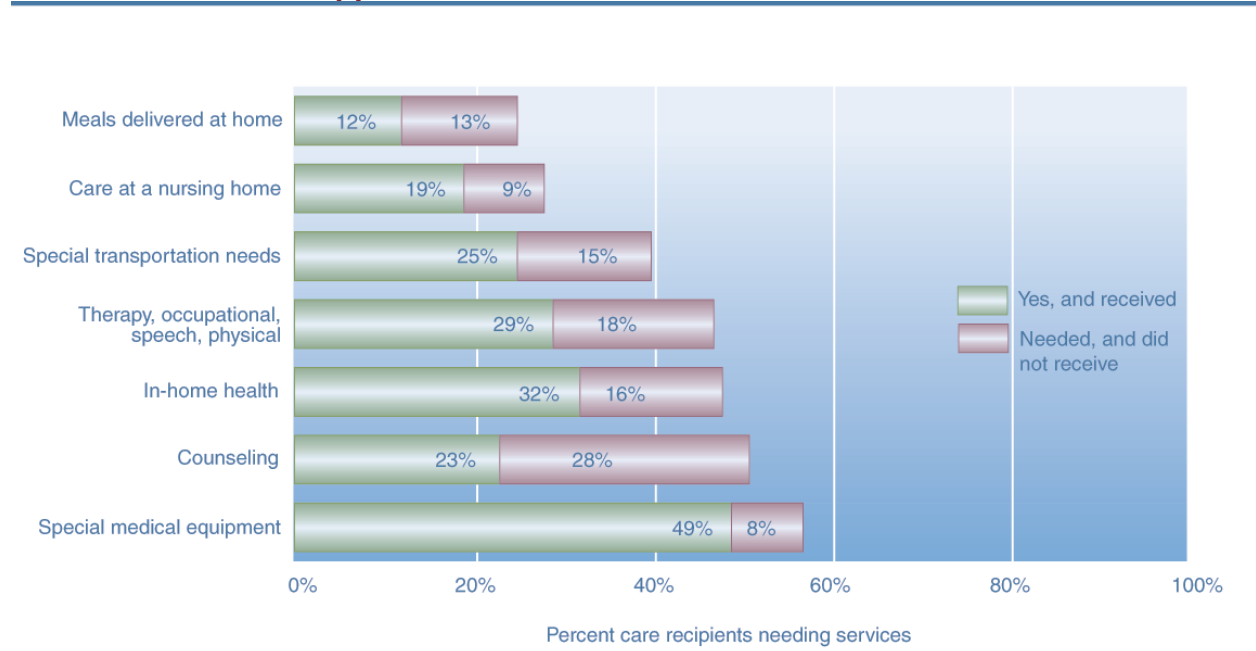


# How Easy is it for Caregivers to Get Help?

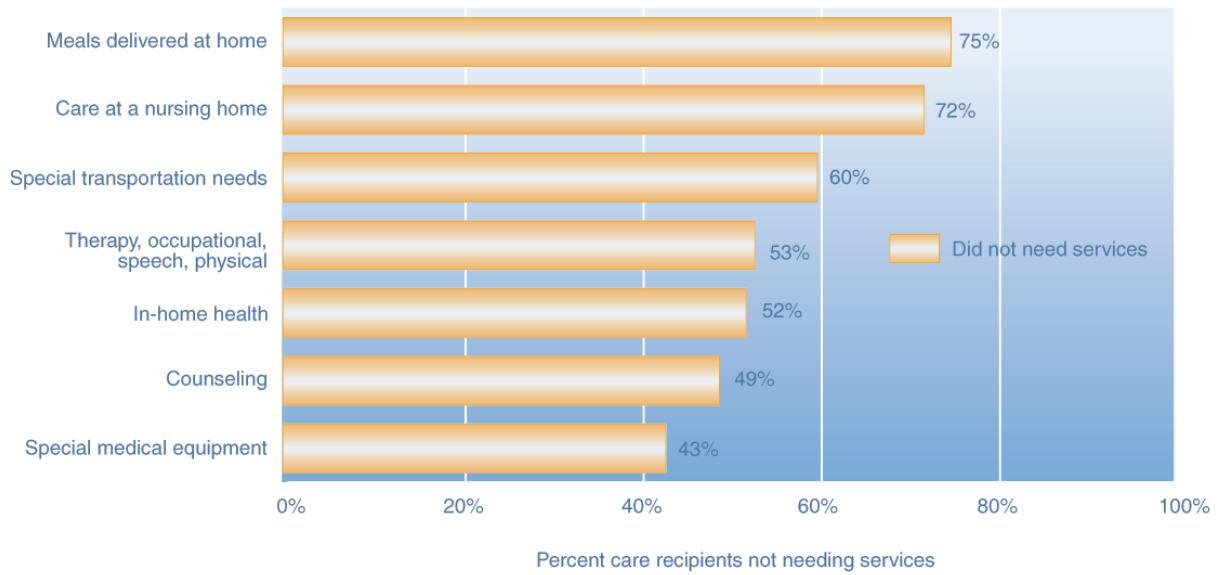
## 4.1 GETTING NEEDED SERVICES OR EQUIPMENT

Depending on the particular situation, care recipients have varying needs for formal support services. Caregivers report the most needed service within a 12-month period is special medical equipment (57%). A high percentage of caregivers who report that special medical equipment was needed say it was received. The next most needed services are counseling for the care recipient and in-home health care. Many caregivers reported that they could not get counseling for the care recipient or in-home health care, suggesting a high unmet need for these services. Three quarters or 75% of caregivers say the care recipient did not need meals delivered at home within the same 12-month period.

**Chart 31: Need for supportive services**



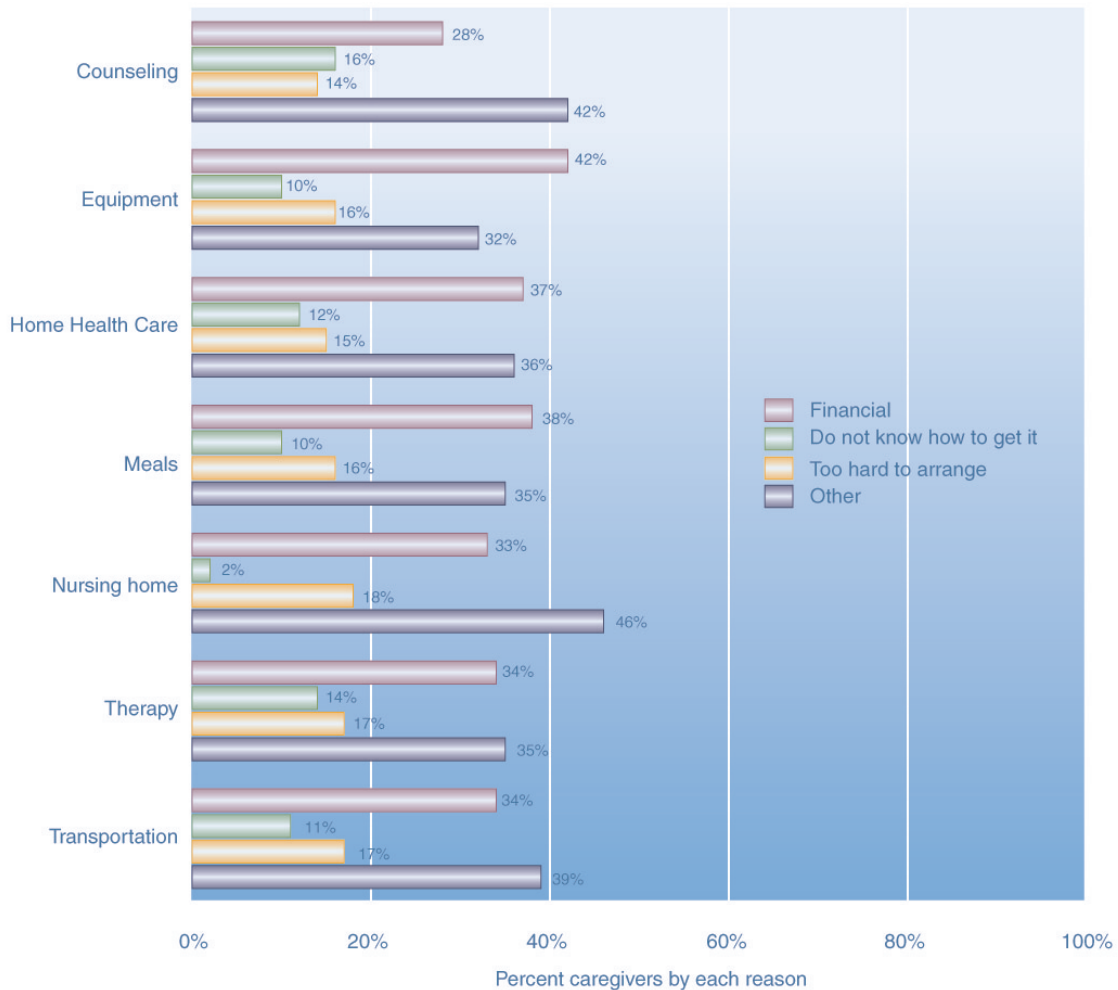
**Chart 32: Care recipients not needing supportive services**



## 4.2 BARRIERS TO SERVICES OR EQUIPMENT

Finances frequently prevent care recipients from getting the services they need. The major barrier to getting needed services according to caregivers is that most are not covered by insurance, and that they need to save money “for when things really get bad.” The second largest barrier is the “hassle factor” - not being able to get off work, not being able to arrange transportation, not having services available at the time of need, and not having help in coordination. A third barrier is the lack of knowledge of how to get the service. Most caregivers know how to get nursing home care but fewer are familiar with how to arrange for counseling or rehabilitative therapy.

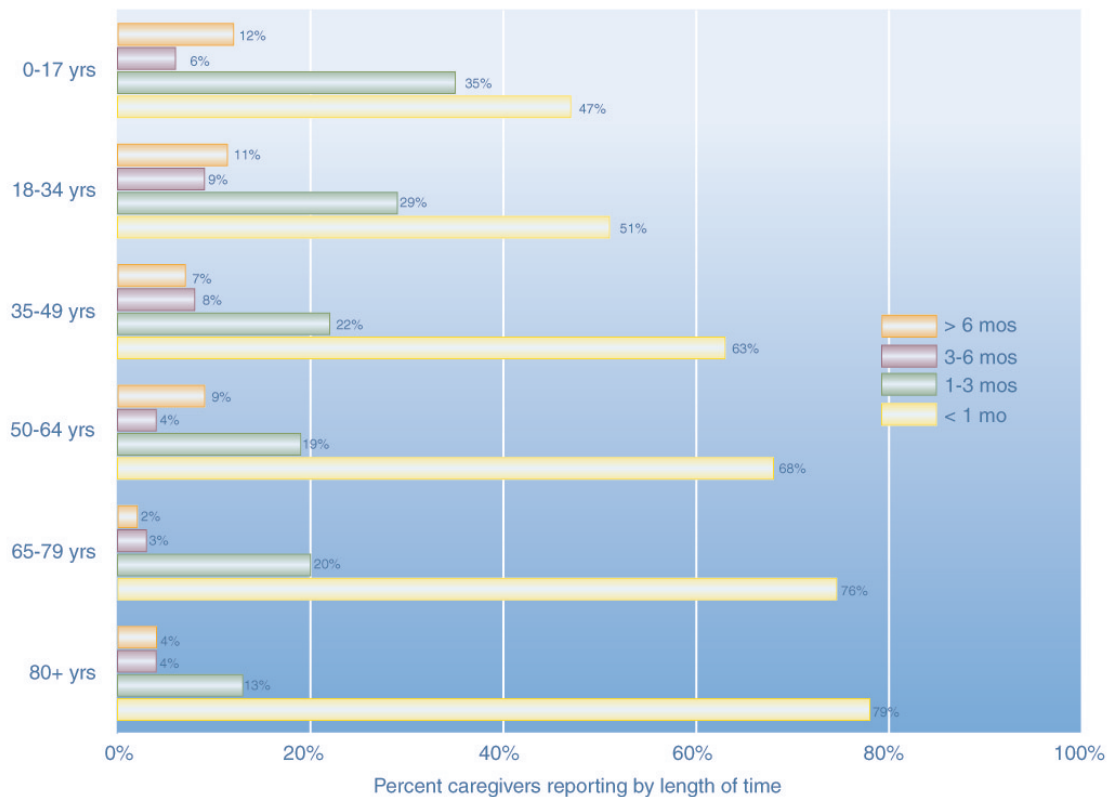
**Chart 33: Main reasons for not receiving services**



### 4.3 WAITING TIME FOR SERVICES OR EQUIPMENT

Most services are received within one month. Wait time is longer for services for the non-elderly, suggesting a more robust service system for seniors. Twelve percent of caregivers of children wait longer than six months for services they report they needed in the past 12 months.

**Chart 34: Length of waiting time for services by recipient's age**

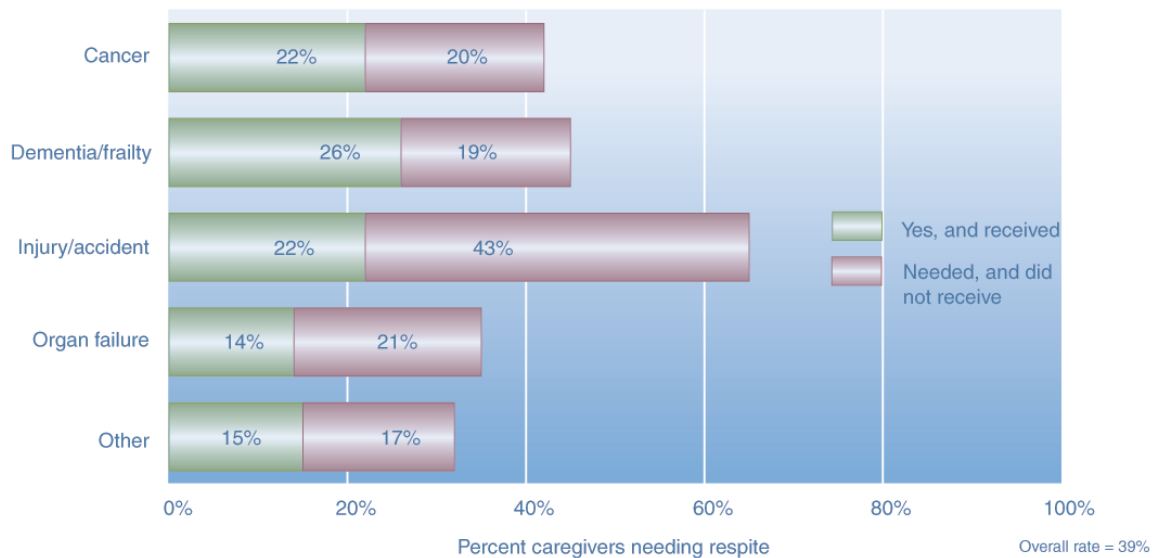


## 4.4 GETTING RESPITE CARE

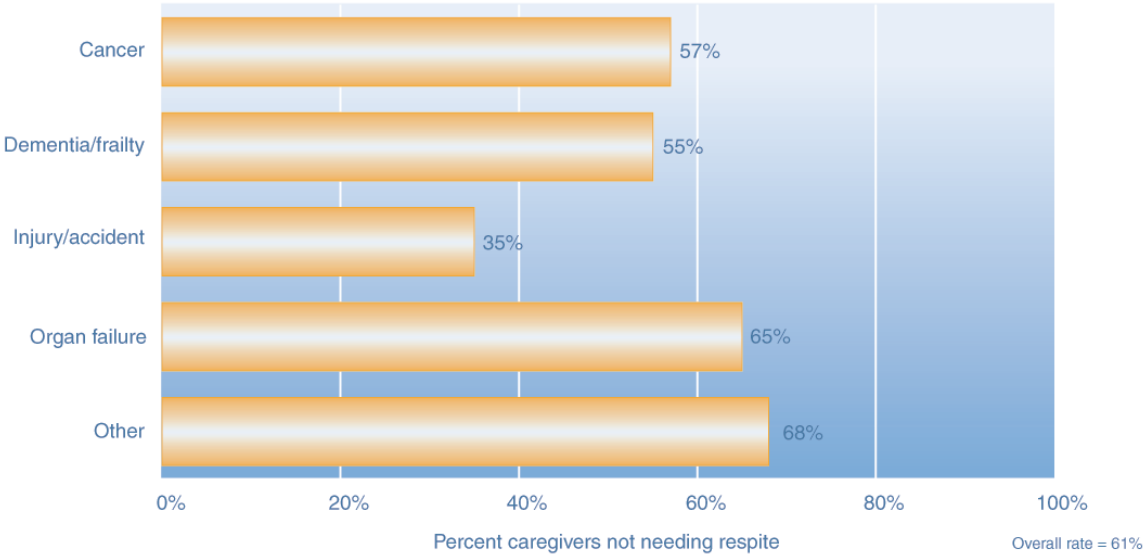
Respite care - a break from caregiving - is a relatively new service, offered in the home or through adult daycare. Overall about 39% of caregivers report needing respite care within the past 12 months; about half (19%) say they received it. Caregivers of individuals with traumatic injury (65%) report they had the most need for respite care, but only 22% report they got it.

A continual challenge for respite care programs, particularly those offering services for individuals with dementia, is getting caregivers to understand their need to take a break. Many feel guilty about leaving their loved ones in the care of a non-family member. In this study, 55% of these caregivers say they did not need respite care.

**Chart 35: Caregivers needing and receiving respite**



**Chart 36: Did not need respite care**

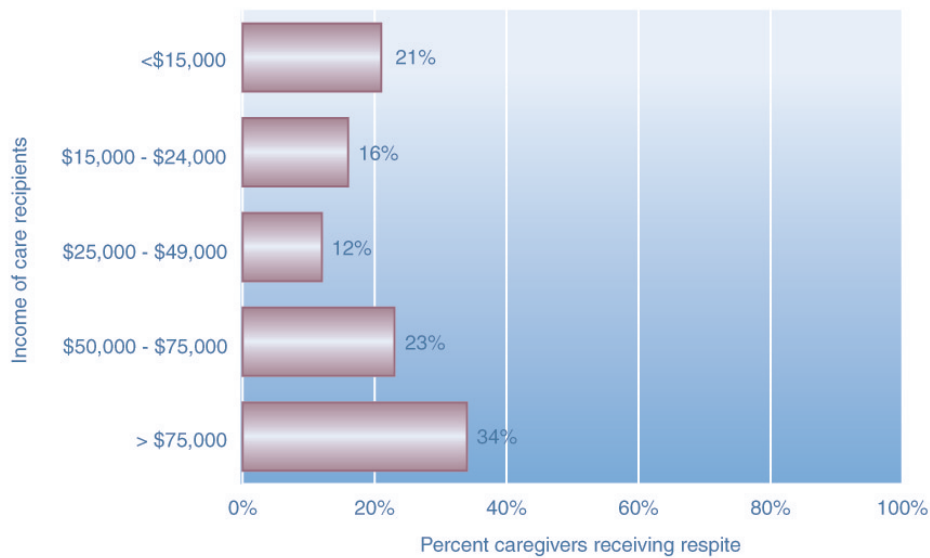




## 4.5 ACCESSIBILITY OF RESPITE CARE

Respite care is usually not reimbursed by Medicare, Medicaid or private insurance. Some communities have organized volunteer in-home respite or adult day care or offer services on a sliding fee scale. Caregivers of care recipients with the highest incomes (34%) made more use of respite care than others, suggesting that cost is a significant barrier.

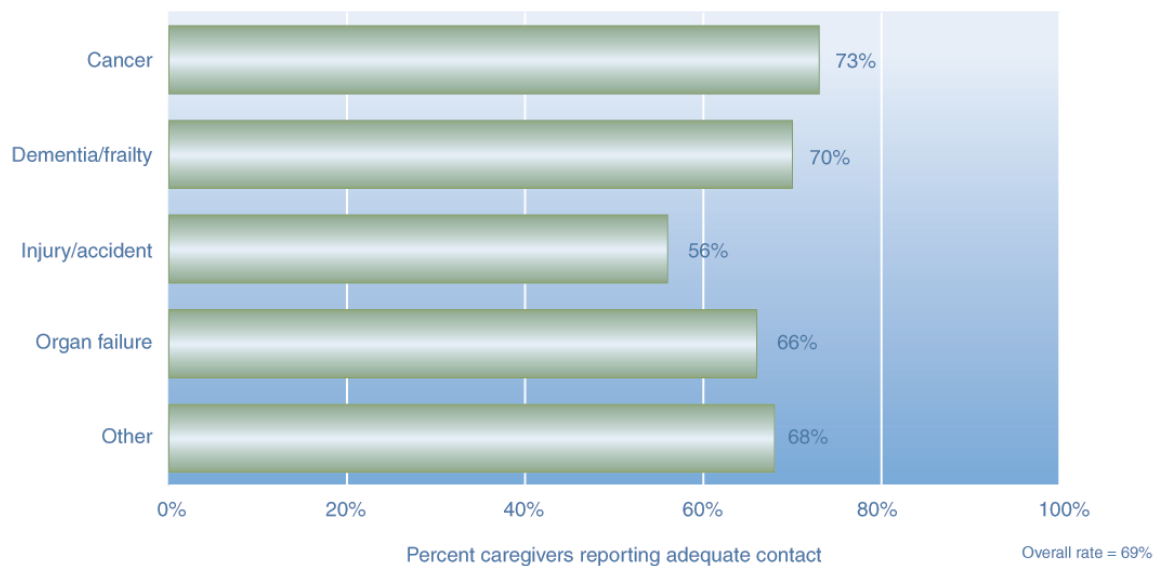
**Chart 37: Use of respite and income**



## 4.6 CONTACT WITH THE CLERGY

The religious community is an important source of support for caregivers and care recipients. Faith has been found to be an important factor in relieving caregiver stress and in comforting the care recipient. Overall, caregivers are satisfied with the support the recipients receive from the religious community. More than two thirds (69%) believe that the care recipient has as much contact with a priest, rabbi, minister or other religious person as he or she wants.

**Chart 38: Care recipient has adequate contact**

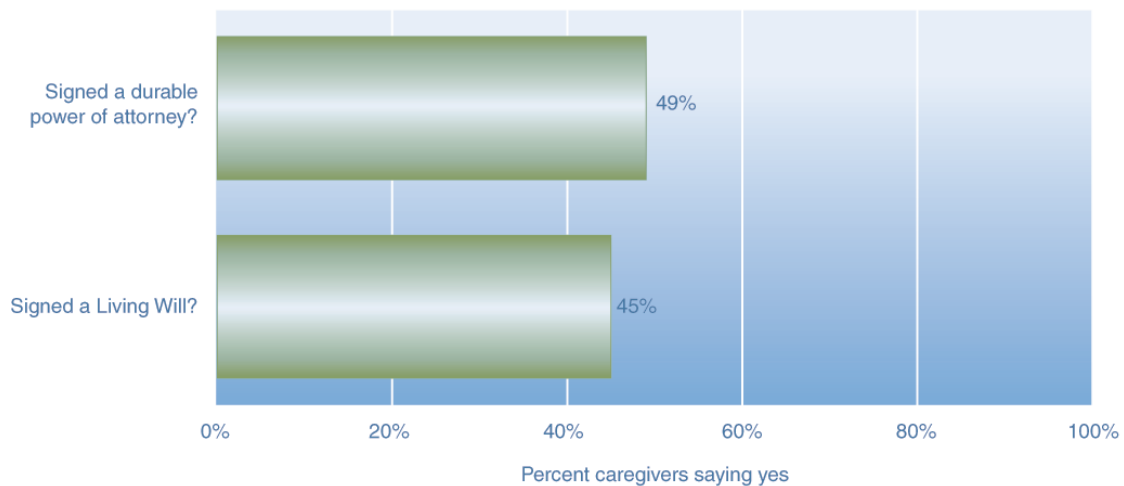


# Are Caregivers Prepared for the Future?

## 5.1 ADVANCED PREPARATIONS

We and our care recipients are likely to face difficult decisions in the near future. Planning for the future ideally should involve discussions about advanced directives and long-term care. Most caregivers report that the necessary legal steps have not been taken that will make future treatment decisions easier. Only half of care recipients completed legal documents necessary to assure that any of their wishes are carried out.

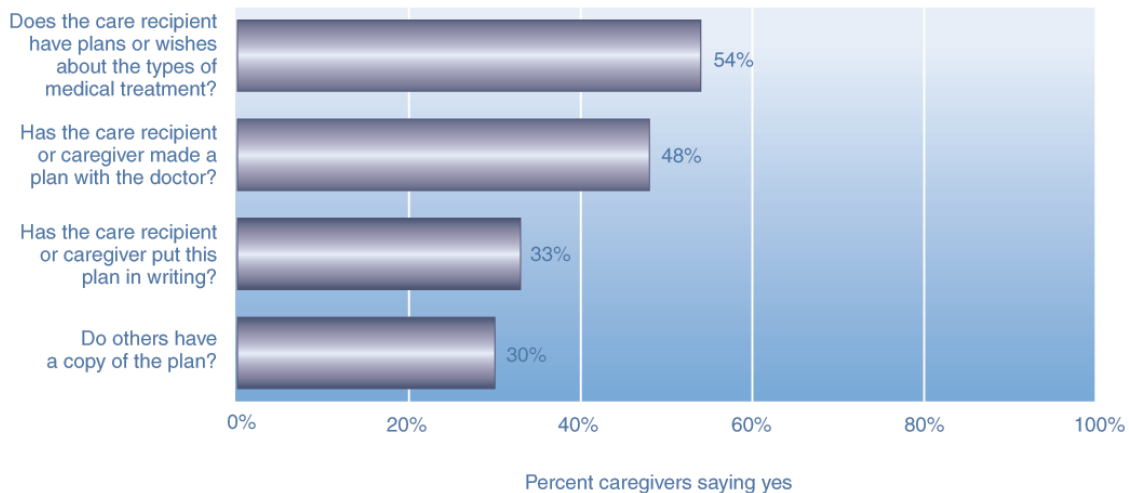
**Chart 39: Has the care recipient . . .**



## 5.2 CARE RECIPIENT'S PREFERENCES

Despite our closeness to the care recipient, just slightly more than half of us (54%) know the care recipient's wishes about the type of medical treatment wanted as the illness progresses. We are unprepared for future decision making, and for some the time for discussion about the future is too late. Only 47% of caregivers or care recipients have talked to the doctor about these wishes or plans, fewer have put this plan in writing (33%), and even fewer have shared this plan with others involved in the caregiving process, e.g., families or hospice workers. Caregivers of individuals who are frail or suffer from dementia (55%) are least likely to report that they know the care recipient's wishes.

**Chart 40: As illness progresses . . .**



# Conclusion: A Portrait of Informal Caregivers in America

## CONCLUSION

- Caregivers are a population at-risk. Many caregivers are depressed, and they feel isolated and burdened. Their physical and mental health is worse than the general adult population, and their health status shows classic symptoms of stress. If they burnout, both their loved one and society suffers.
- Caregiving is a long-term commitment, which consumes more and more time and requires considerable personal investment. Caregivers remind us in this survey that they give comfort and solace to individuals who are in a great deal of emotional or physical pain. This giving takes its toll. Many caregivers are juggling multiple responsibilities – family, work – while caring for an ill or impaired individual.
- Caregivers need help but support services are neither consistent, organized, accessible or affordable.
- Many health care providers do not adequately recognize the role of caregivers or include them in health care decisions about the medical management of the care recipient. Caregivers feel helpless as they believe more could be done.
- Caregivers lack the tools, living will or advanced directives, which would make significant care decisions easier.
- This survey reflects the lives of real people. Measuring and reporting on their experiences are essential to learning how to support these loving, intimate relationships with more accessible and affordable support services, more involvement and recognition from the health care community, and more respite.



# About The Survey

## BACKGROUND

The caregivers survey is part of The Robert Wood Johnson Foundation National Strategic Indicators Project. This project was designed to address two broad objectives:

1. To provide RWJF with a snapshot of health and healthcare today
2. To establish baseline indicators of health system performance in major topical areas in which the Foundation operates.

The project sought to develop a stable hierarchy of measures to guide program planning and evaluation. The National Strategic Indicators Project uses established survey research items and scales, groups them into computed performance measures that represent understandable concepts of interest to the public, and aggregates those measures into broad concepts that address policy goals for the health system.

Information was collected for a total of eleven on-line populations (N=9400):

- Teenagers (age 13-17)
- A random sample of all adults, age 18 and over
- Adult populations for each of the following chronic conditions: Arthritis, Asthma, Coronary Artery Disease, Depression, Type 2 Diabetes, Hypertension
- Parents of Children with Asthma
- Caregivers of people who recently passed away
- Caregivers of people with Alzheimer's or other serious chronic conditions

The on-line sample was drawn from approximately one million individuals recruited to participate in an on-line survey panel (70% recruited via on-line sources, and 30% using random digit-dialing and mailed requests).

The on-line panel was stratified into groups according to age, gender, and education, based on U.S. Current Population Survey distributions (2000). Random samples were sequentially drawn

from the one million person sample frame for purposes of survey administration. E-mail invitations and reminders were sent 3000 at a time until target sample sizes were completed. Each invitation included a link to the online survey and a unique 5-digit access code that ensured that only one survey was taken from an individual computer, and that each invited participant only took the survey once. Only those respondents who completed at least 80% of the survey items were considered in the analyses.

## **SURVEY RESPONDENTS**

- A total of 110,574 invitations to participate in the chronic condition and caregiver population surveys were sent out. Based on information from the research firm contracted to collect the data, approximately 2.5% (n=2764) of the email addresses were not valid, resulting in a base rate of 107,810 invitations. A total of 19,434 responded to the invitation (18.0%) and 17,879 completed the survey (16.7%). Table 1 provides a breakdown of individual samples. Of those who responded to the invitation, 11,432 did not qualify for any condition (10.6%).
- In order to have a dataset that is more reflective of the general US population, several datasets were weighted by age and sex within that condition using estimates from the 1998 National Health Interview Survey. The sample of caregiver parents to children with asthma was also weighted by race of the child, in addition to age and sex. The samples of caregivers to terminally ill and chronically ill patients were not weighted as no nationally-representative standard data for such caregivers could be found.



**Table 1: Response Rates for Each Chronic and Caregiver Survey 2001**

| Survey  | Qualified | Started | Completed<br>(80% of all<br>questions) | Incidence<br>Rate<br>(Qualified/<br>Baseline) | Completion<br>Rate<br>(Completed/<br>Started) |
|---|-----------|---------|--|---|---|
| <i>Baseline: 110,574 invitations sent - estimated 2.5% non-functional emails (n=2764) = <b>107, 810 invitations</b></i> |           |         |  |   |   |
| <u>Chronic conditions:</u>  |           |         |  |   |   |
| • Arthritis   | 2823      | 712     | 425                                    | 2.6%  | 59.7%   |
| • Asthma  | 2571      | 579     | 443                                    | 2.4%  | 76.5%   |
| • Cardiovascular<br>Disease   | 1555      | 525     | 421                                    | 1.4%  | 80.2%   |
| • Depression  | 4270      | 1477    | 1217                                   | 4.0%  | 82.4%   |
| • Adult diabetes  | 1764      | 1127    | 1048                                   | 1.6%  | 93.0%   |
| • Hypertension  | 4524      | 694     | 459                                    | 4.2%  | 66.1%   |
| <u>Caregivers:</u>  |           |         |  |   |   |
| • Chronically ill   | 2928      | 1174    | 1005                                   | 2.7%  | 85.6%   |
| • End of Life Care  | 2603      | 1218    | 999                                    | 2.4%  | 82.0%   |
| • Pediatric<br>Asthma   | 1015      | 496     | 430                                    | .9%   | 86.7%   |
| • NONE  | 11,432    | Na      | na                                     | 10.6%   | na  |

## MEASURES

All measures were selected such that they were:

- stable over time and between surveys
- scientifically credible (items used were borrowed, or derived from such reputable sources as HEDIS, CAHPS, BRFS)
- comparable between this particular sample and sources of benchmark data to check the external validity of the sample

Measures were re-coded to create proportions along a 0-100 continuum for ease of reporting and to standardize all scores for comparability. Measures with multiple items were combined in one of three ways:

1. A mean score was computed and a cut-off point assigned, so that people who fell above the cut-off were assigned a score of '100'.
2. A certain number of positive responses were required, for example 3 out of 4, in order to qualify for a score of '100'.
3. Responses across all items had to be positive to score 100.

In addition, responses of "I don't know" or "Refuse to answer" were counted as missing data.

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