

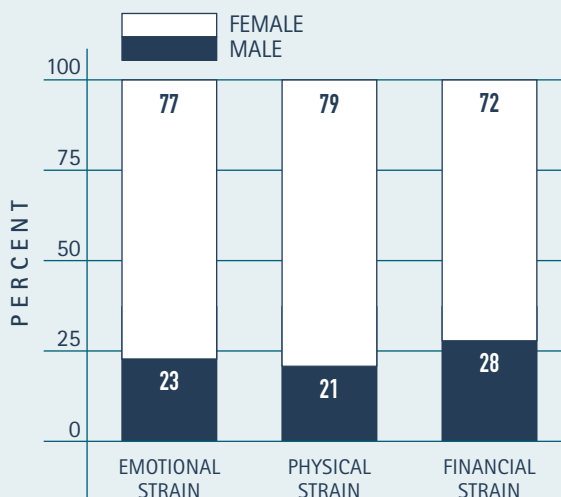
Center on an Aging Society
GEORGETOWN UNIVERSITY

How Do Family Caregivers Fare?

A Closer Look at Their Experiences

Caregiving is often life changing and consuming, leaving some caregivers exhausted and depressed. Some 15 percent of family caregivers report high levels of overall stress as a result of caring for an older family member or friend with long-term care needs.¹ Caring for a friend or relative, however, can also be a positive and rewarding experience. Many caregivers handle the stress well by turning to friends and family or prayer to help cope.

FIGURE 1
Gender Distribution of Primary Caregivers that Report Being “Very Strained” Emotionally, Physically, or Financially Due to Caregiving



NOTE: Data were missing for roughly 6 percent of caregivers for each of the three questions about caregiver strain. Caregivers with “missing” data were omitted from the calculation of the gender distributions.

SOURCE: Center on an Aging Society’s analysis of data from the Informal Caregiver Supplement (ICS) to the 1999 National Long Term Care Survey (NLTC).

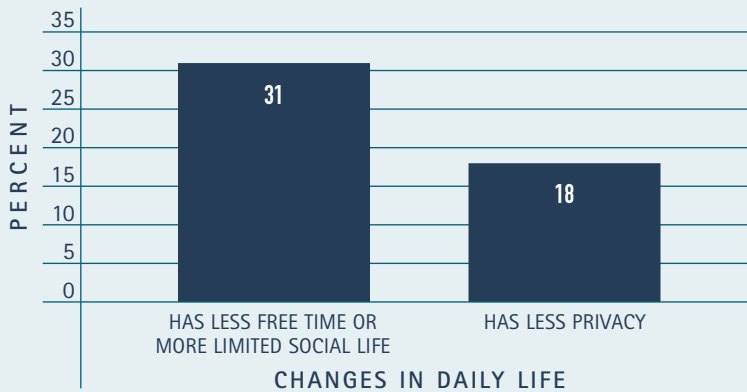
This *Profile* provides an overview of the physical, emotional, financial and social experiences of primary family caregivers. Primary family caregivers are people who take responsibility for coordinating and providing the majority of the care received by someone who needs long-term care. Long-term care is the need for assistance performing one or more Instrumental Activities of Daily Living (IADLs) such as doing housework, managing medication or finances, or transportation, and/or Activities of Daily Living (ADLs) such as eating, bathing, dressing, using the toilet, or moving about.

The majority of primary caregivers feeling stressed are women

The majority – 64 percent – of all primary family caregivers are women.² Roughly four out of five primary family caregiver who report that caregiving is stressful are women³, and roughly three-quarters of primary caregivers who report feeling ‘very strained’ physically, emo-

FIGURE 2

Proportion of Primary Caregivers Who Experience Changes in Daily Life



NOTE: Data were missing for 6 percent of primary caregivers.

SOURCE: Center on an Aging Society's analysis of data from the Informal Caregiver Supplement (ICS) to the 1999 National Long Term Care Survey (NLTC).

available to spend with other family members or friends, and limits the time available to participate in other social activities, hobbies, community activities, regular exercise, or vacations. Nearly a third – 31 percent – of caregivers report having less free time or a limited social life due to caregiving (See Figure 2).

Providing care to a family member with long-term care needs often necessitates the transfer of personal information about the care recipient or the care provided, or the acceptance of ‘strangers’ such as formal care providers into their home, resulting in a lack of privacy. Some 18 percent of caregivers feel that their privacy as been invaded (see Figure 2).

Some caregivers feel overwhelmed

Family caregivers often become caregivers with little or no preparation, support, or understanding about providing long-term care. The experience can be overwhelming. Over one-fifth – 22 percent – of caregivers are exhausted when they go to bed at night, and many feel that they cannot handle all of their caregiving responsibilities (see Figure 3). Some 13 percent of caregivers feel frustrated with the lack of progress made with the care recipient.

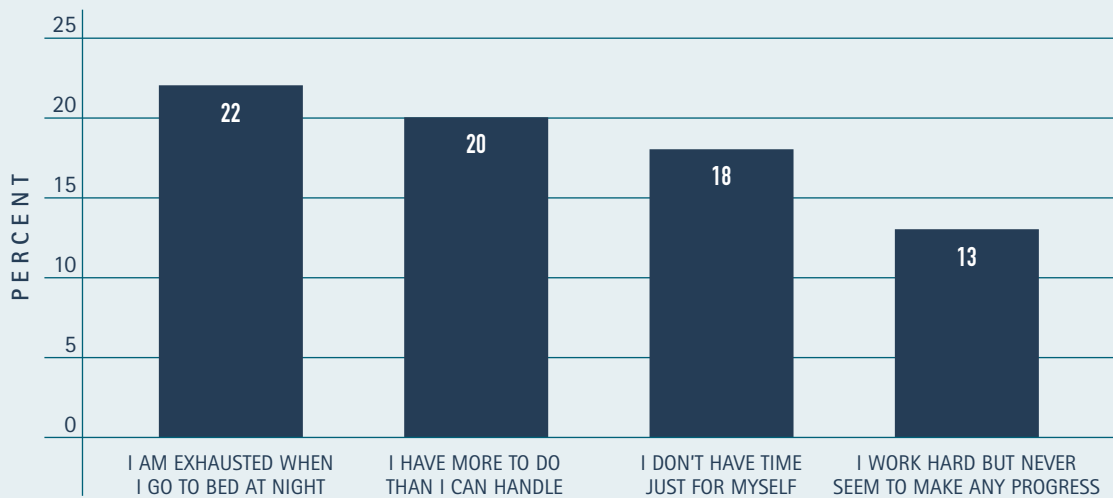
tionally, or financially as a result of providing care are female (See Figure 1).

Caregiving often changes daily life

Being a primary caregiver is time-consuming. Nearly one in five primary caregivers – 19 percent – report that their relative or friend requires constant attention.⁴ Caregiving often usurps the time

FIGURE 3

Proportion of Primary Caregivers Who Agree “Quite a Lot” or “Completely” With Each of the Statements About Their Caregiver Experiences

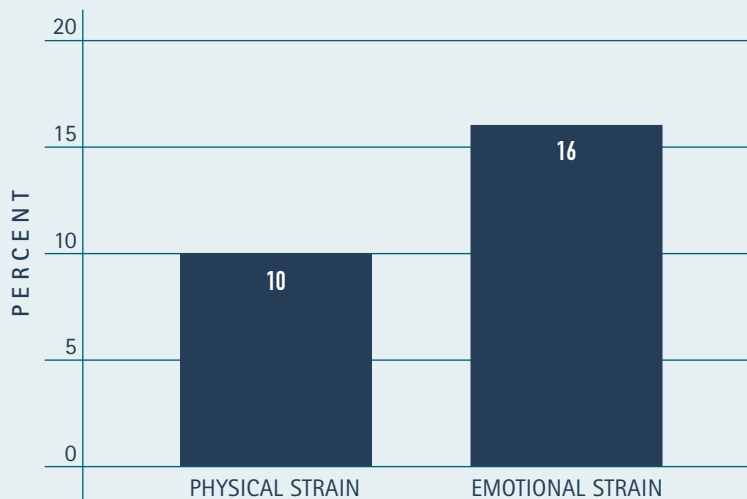


NOTE: Data were missing for 7 percent of primary caregivers.

SOURCE: Center on an Aging Society's analysis of data from the Informal Caregiver Supplement (ICS) to the 1999 National Long Term Care Survey (NLTC).

FIGURE 4

Proportion of Caregivers Who Report that Taking Care of the Care Recipient is Hard on Them Physically or Emotionally



NOTE: Data were missing for 6 percent of primary caregivers.

SOURCE: Center on an Aging Society's analysis of data from the Informal Caregiver Supplement (ICS) to the 1999 National Long Term Care Survey (NLTC).

Emotional strain is more common than physical strain among primary caregivers

The physical stress of caregiving, especially in relation to providing care for someone who is bedridden or wheelchair bound, can affect the physical health of the caregiver. One-tenth of primary caregivers report that they are physically strained (See Figure 4). Similarly, about one in ten caregivers – 11 percent – report that caregiving has caused their physical health to get worse.⁵ A decline in the physical capacity of caregivers affects their ability to continue providing care and increases the risk of their own frailty later in life.

The emotional strain of caregiving is somewhat more prevalent. Some 16 percent of caregivers feel emotionally strained (See Figure 4) and 26 percent say taking care of the care recipient is hard on them emotionally.⁶ Caregivers often report feeling frustrated, angry, drained, guilty, or helpless as a result of providing care. Caregiving can also result in feeling a loss of self identity, lower levels of self esteem, depression, constant worry, or feelings of uncertainty.

Caregivers generally cope well with their responsibilities

The majority of primary caregivers do not report feeling stressed. Although, many do engage in various activities to help them cope (see Table 1). Over one-third of caregivers turn to prayer or meditation. Nearly two out of five caregivers – 38 percent – report that they talk with family or friends when stressed. Relatively few caregivers report engaging in drinking or smoking explicitly to help them cope with their caregiving responsibilities.

TABLE 1

Proportion of Primary Caregivers that Engage in Various Coping Activities When Stressed

	CAREGIVERS (%)
Spend time alone	17
Eats	18
Takes medications	5
Drinks alcohol	2
Smokes	7
Prays/meditates	39
Talk to friends/family	38
Exercises or does a hobby	23
Watches TV	33
Reads	31
Gets professional help	2

NOTE: Proportions represent those who report engaging in an activity 'fairly to very often.' Data are missing for 10 percent of caregivers.

SOURCE: Center on an Aging Society's analysis of data from the Informal Caregiver Supplement (ICS) to the 1999 National Long Term Care Survey (NLTC).

Caregivers are somewhat wealthier than non-caregivers

Although Medicare, Medicaid and private insurance represent the majority of long-term care expenses, much of the financial burden associated with long-term care weighs heavily on the pockets of care recipients and their family. The majority of caregivers – 60 percent, however, do not feel that caregiving causes any financial hardship.⁷ One in ten caregivers reports that caregiving causes a fair amount of financial difficulties.

TABLE 2
Wealth and Income of Adult Children by Caregiving Status, 2000

	PRIMARY CAREGIVERS	NON-CAREGIVERS	NO LIVING PARENTS
WEALTH			
TOTAL ASSETS, Median (<i>excluding home equity</i>)	\$104,000	\$77,500	\$55,000
HOME EQUITY (<i>primary home</i>)			
Proportion with home equity	88%	86%	81%
Median	\$90,000	\$85,000	\$89,000
IRAs			
Proportion with IRAs	52%	49%	37%
Median value	\$50,000	\$60,000	\$50,000
INCOME			
ANNUAL HOUSEHOLD INCOME, Median	\$54,720	\$55,000	\$27,880
ANNUAL EARNINGS (<i>of respondent and spouse</i>)			
Proportion with earnings	79%	79%	38%
Median earnings	\$48,000	\$52,000	\$25,000
ANNUAL SOCIAL SECURITY BENEFITS			
Proportion receiving benefits	34%	31%	78%
Median benefits	\$11,796	\$11,500	\$11,940
ANNUAL PENSION INCOME			
Proportion receiving pension	29%	26%	46%
Median pension	\$14,400	\$12,024	\$9,000

SOURCE: Center on an Aging Society's analysis of data from the Health and Retirement Study (HRS), 2000.

Most primary caregivers, however, are not low-income and tend to have more wealth, on average, than non-caregivers (see Table 2). Low-income caregivers are more likely to experience financial burden as a result of providing long-term care to an older family member or friend than caregivers with higher incomes.

Caregiving can affect work, income and savings

Caregiving can interfere with work, causing the caregiver to take time off from work without pay, cut back on the number of hours worked per week, retire early, or leave the workforce entirely; all of which can affect a caregiver's income and financial resources. Some 17 percent of caregivers worked fewer hours, 16 percent have taken time off without pay, and 8 percent quit their jobs to provide care.⁸ In the long run, there could be considerable financial

consequences to caregivers who reduce their hours or retire early as a result of their caregiving responsibilities, especially lower income caregivers.

Chronic conditions are somewhat common among caregivers

Although the majority of caregivers are in good physical health, it is not uncommon for caregivers to also have chronic health conditions (see Table 3). Some of these conditions could interfere with the availability and ability of caregivers. For example, almost half – 46 percent – of caregivers suffer from arthritis, a chronic condition that can potentially cause severe physical limitations.

TABLE 3
Prevalence of Chronic Conditions among Adult Children Primary Caregivers

	PRIMARY CAREGIVERS (%)
Hypertension	39
Diabetes	11
Cancer (ever had)	8
Chronic Lung Disease	7
Heart Condition	14
Arthritis	46
Stroke	3

SOURCE: Center on an Aging Society's of data from the Health and Retirement Survey (HRS), 2000.

Caregiving can also be a rewarding experience

Although caregiving is a taxing experience, it also has positive and rewarding side-effects. For example, almost half – 47 percent – of caregivers strongly agree that they appreciate life more as a result of their caregiving experience.⁹ A similar proportion – 48 percent – report that caregiving has made them feel good about themselves. Other studies have suggested that caregiving has lead caregivers to feel useful or proud, or experience personal growth or an enhanced relationship with the care recipient and other family members.¹⁰

ABOUT THE PROFILES

This is the third in a set of *Data Profiles, Family Caregivers of Older Persons*. The series is supported by a grant from AARP and MatherLifeways. This *Profile* was written by Katherine Mack with assistance from Robert Friedland.

The Center on an Aging Society is a Washington-based non-partisan policy group located at Georgetown University's Health Policy Institute. The Center studies the impact of demographic changes on public and private institutions and on the economic and health security of families and people of all ages.

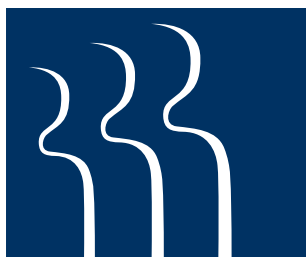
Conclusion

The stress associated with providing care can be detrimental to the health and well-being of both the caregiver and the care recipient putting the care recipient at risk today and putting the caregiver at risk when they are older and frailer. While caregivers tend to cope well with the stressors of providing care, easy and affordable access to information, education, and training about long-term care as well as technology, support groups, counseling, respite care and financial assistance are beneficial to the well-being of both the caregiver and the care recipient.



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ABOUT THE DATA

Unless otherwise noted, data in this *Profile* are from the 1999 National Long Term Care Survey (NLTC) and the 2000 Health and Retirement Study (HRS). The NLTC is sponsored by the U.S. Department of Health and Human Services and conducted by the Center for Demographic Studies at Duke University. The Informal Caregiver Supplement to the NLTC collects data on the experiences of the primary informal caregivers of the population age 65 and older living in the community and need help performing one or more Instrumental Activities of Daily Living (IADLs) and/or Activities of Daily Living (ADLs). The 2000 Health and Retirement Study (HRS) provides information about the economic, health, marital, and family status of the community-dwelling population age 51 or older. HRS is sponsored by the National Institute on Aging and conducted by the University of Michigan.

1. Center on an Aging Society's analysis of data from the Informal Caregiver Supplement (ICS) to the 1999 National Long Term Care Survey (NLTC). On a scale of 1 to 10, 10 being the highest level of stress, the term "high levels of overall stress" represents a rating of 6 or higher.
2. Mack, K., & Thompson, L. (2005). *A Decade of Informal Caregiving: Are today's caregivers different than informal caregivers a decade ago?* Data Profile (Washington, DC: Center on an Aging Society), <http://ihcrp.georgetown.edu/agingsociety/pub-html/caregiver1/caregiver1.html>.
3. Center on an Aging Society's analysis of data from the Informal Caregiver Supplement (ICS) to the 1999 National Long Term Care Survey (NLTC). On a scale of 1 to 10, 10 being the highest level of stress, the term "stressful" represents a rating of 6 or higher.
4. Center on an Aging Society's analysis of data from the Informal Caregiver Supplement (ICS) to the 1999 National Long Term Care Survey (NLTC).
5. Ibid.
6. Ibid.
7. Ibid.
8. Ibid.
9. Ibid.
10. Amirkhanyan, A.A., & Wolf, D.A. (2003). Caregiver Stress and Noncaregiver Stress: Exploring the Pathways of Psychiatric Morbidity. *The Gerontologist* 43(6):817-827.

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