

FAMILY

Caregiver characteristics

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Quick Facts...

Informal caregivers are individuals who provide unpaid assistance to elderly loved ones.

Informal caregivers tend to be female, about 57 years of age, and live in the same household as the care recipient.

Between 30 percent to 55 percent of informal caregivers of loved ones are employed.

Approximately one-third of the caregiving population have incomes in the poor or near poor category.

The majority of older adults in America are in relatively good health and live independently.

What is an "Informal caregiver"?

Informal caregivers are individuals who provide unpaid assistance to elderly loved ones. Examples of caregivers are described below:

- Mrs. G., age 62 and a resident of Rifle, Colorado, found herself torn between two telephone calls, both from Glenwood Springs. In one she heard about her 83-year-old father who had fallen and was feeling sick. In the other, she heard her daughter's tired voice pleading for help because her two small children were sick.
- Pat, a Denver trial lawyer, and Jackie, a teacher in Littleton, are two unmarried sisters who live with and share responsibility for their 79-year-old widowed mother who is blind and paralyzed by a stroke.
- Last year, Mildred, 63, took a leave of absence from her job at a hospital in Pueblo to care for her terminally ill husband, who died shortly thereafter. A month later, her severely impaired 88-year-old mother moved in, and Mildred has never returned to work.
- Mrs. T. lives on a farm in northeastern Colorado. She cares for her 78-year-old father, a stroke victim, in her home. She has four live-in helpers: her husband, two teenage daughters, and her mother. Two sisters and a brother live in Sterling and also share responsibilities.
- Mr. M., an 86-year-old retiree, killed his wife of 55 years and then committed suicide. He had been caring for his wife since she was stricken with Alzheimer's Disease eight years before and apparently could no longer cope with the pressure.

Differences Among Caregivers

These cases highlight the fact that there is a great deal of variety in the characteristics of the estimated 5 to 7 million individuals caring for loved ones in a family setting. However, there are distinctions among family caregivers and between caregivers and the larger population.

In general, informal (family) caregivers tend to be female and live in the same household as the care recipient. When compared to the total population of caregivers and no-caregivers, caregivers are less likely to be employed, more likely to be poor (or living near the poverty level), and more likely to report fair or poor health.

Characteristics of Caregivers

Gender

National estimates confirm the findings of numerous studies of informal caregivers: caregiving is primarily a female responsibility. (See Figure 1.)

- Approximately 72 percent of caregivers of loved ones who are functionally impaired are female.
- Daughters constitute 29 percent. Sons make up only 8 percent of caregivers, and husbands account for 13 percent of the caregiver population.
- The remainder is composed of daughters-in-law, grandchildren, siblings, other relatives, friends and other unpaid helpers.

Age

The average age of the informal caregiver population is 57. However, one-quarter is 65 to 74, and another 10 percent is 75 or older. Husbands are by far the oldest caregivers, with 42 percent of them 75 or older. These estimates suggest that the informal care system is composed, in large part, of the “young-old” caring for the “old-old.” (See Figure 2.)

Marital status

In 1991, 77 percent of older men were married and 41 percent of older women were married. Forty eight percent of all older woman were widows compared to 15 percent of older men. Divorced older adults represented 5 percent (1.5 million) of all older people in 1991. (See Figure 3.)

Employment

Employment status is particularly important, not only as a source of income, but because it represents a major competing demand for the attention and energies of the caregiver. Estimates from various studies indicate that between 30 percent and 55 percent of informal caregivers assisting elderly loved ones are employed. Two out of every five daughters and a little over one-half of sons are in the labor force. (See Figure 4.)

Economic status

Approximately one-third of the caregiving population have incomes in the “poor” or “near poor” category. This is particularly true for wives caring for husbands. Compared to their age peers in the general population, male and female caregivers are more likely to report adjusted incomes below the poverty line.

Health status

One-third of the informal caregiver population reports that their current health status is “fair” or “poor.” This percentage represents a much higher proportion than the general population. While it is impossible to draw causal conclusions from these data, one may speculate that the cumulative stress of caregiving can deteriorate the health of a caregiver.

Living arrangements

The majority of older adults in America are in relatively good health and live independently. At any given point in time, 46 percent of those age 65 or older live with a spouse, and 20 percent live with adult children or other relatives. About 30 percent live alone. Only 5 percent of the population aged 65 or older lives in institutional settings (e.g. nursing homes).

The elderly prefer to live separate from their adult children, near near but not with their adult children. This phenomenon is referred to as “intimacy at a distance.”

Although the figures above describe living arrangements for a cross-section of the older population at one point in time, they are not accurate estimates of the number and proportion of older adults who

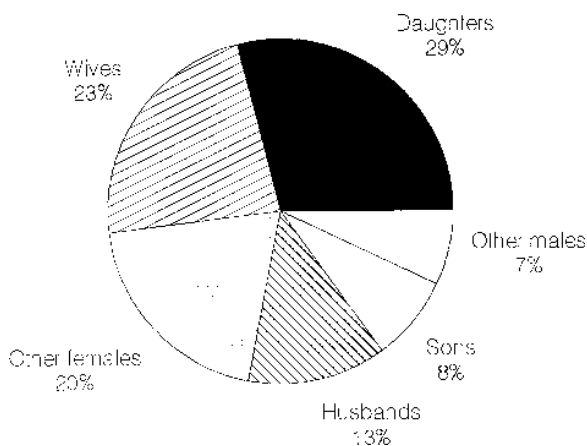


Figure 1: Distribution of caregivers by relationship to care recipient. Caregiver population includes primary and secondary caregivers.

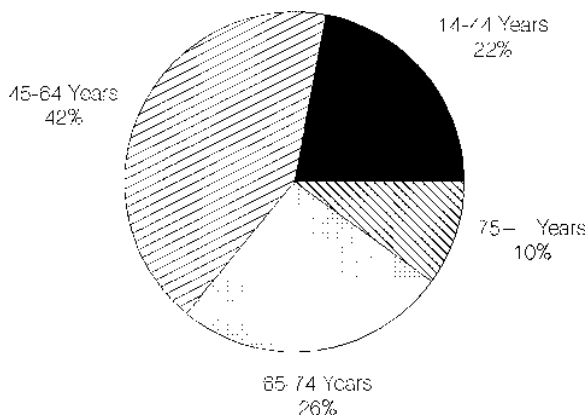


Figure 2: Distribution of caregivers by age. (Mean age is 57.3 years.)

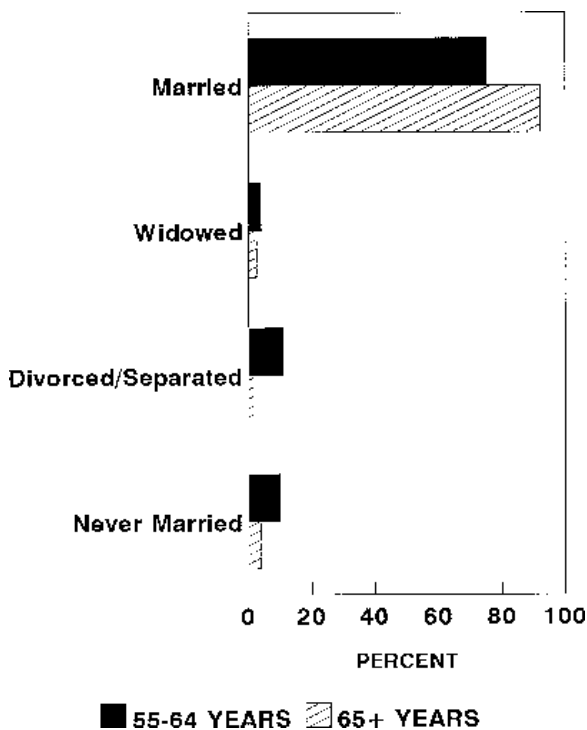


Figure 3: Marital status of male caregivers by age group.

eventually end up living with the caregiver. In fact, these data probably underestimate both the number and percentage of all people 65 and over who at some time in the course of their lives are cared for in the home of the caregiver.

National estimates of people caring for very impaired older individuals indicate that a shared living arrangement is the prevalent pattern when the elderly loved one is functionally dependent. Close to 75 percent of all caregivers live with the care recipient. Sixty-one percent of both caregiving daughters and sons report sharing households with an aged parent.

Approximately one-quarter of caregivers do not live with the care recipient. Many of these caregivers face the special challenge of "long-distance" caregiving.

The Myth of Neglect

The myth

There is a common belief, even among caregivers, that families abandon their elderly loved ones and prematurely place them in nursing homes. With respect to adult children who care for aged parents, the general public believes that today's adult children do not provide the same dedicated care to their parents as was the case with previous generations.

The reality

All caregiving research conducted over the past 30 years indicates that this belief is a myth. Some findings from these studies include the following: family caregivers provide 80 percent of the in-home care of older people who suffer from chronic disabilities. About 10 percent of those living with family caregivers would require institutionalization if family members did not care for them. This would triple the number of older adults in nursing homes. In up to 25 percent of the applications to nursing homes, the decision to seek admission is the result of the death of a caregiver with poor health. Almost 30 percent of female caregivers (mostly daughters) quit their jobs or reduce their involvement in the labor force in order to care for elderly parents.

The irony of the myth of neglect is that, due to increased life expectancy, adult children nowadays provide more care and more difficult care to more parents over much longer periods of time than they did in previous generations.

Why do adult child caregivers believe in the myth of neglect? Possibly because at the heart of the myth is some truth. Members of all generations may have the expectation that the devotion and care given by the young parent to the infant and child should be reciprocated and the indebtedness repaid when the parent, having grown old, becomes dependent.

The truth that lies at the heart of the myth is that adult child caregivers (adults who care for their elderly parents) cannot and often do not provide the same total care to their elderly parents as those parents gave to them in their infancy and childhood. The roles of parent and child cannot be reversed in that sense.

Guilt

Belief in the myth of neglect exists because of the disparity between standards and expectation, and the unavoidable realities.

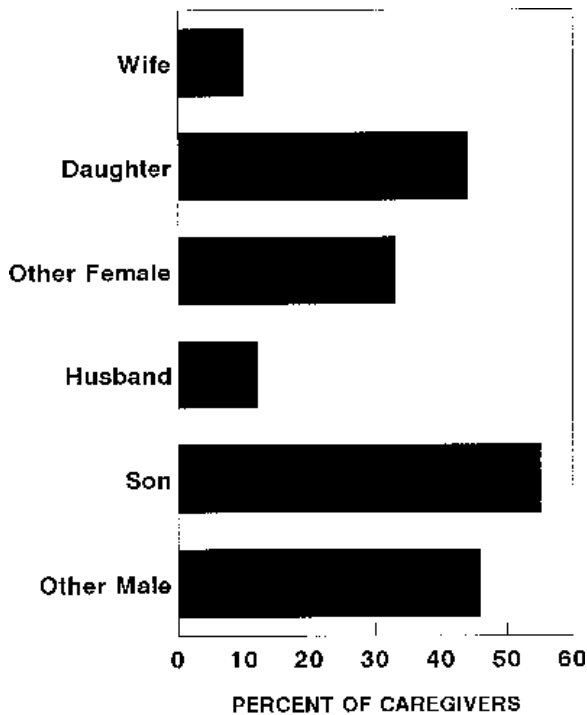


Figure 4: Percent of caregivers who are employed.

This leads to guilt. That may be why we hear over and over again from adult child caregivers, "I know I'm doing everything I can for my mother, but somehow I still feel guilty." The fantasy is that somehow one should do more. That may be one reason why so many adult child caregivers (especially daughters) are overwhelmed with guilt when a parent enters a nursing home. It is experienced as the total surrender of a parent to the care of others.

Guilt may also be a reason why many adult child caregivers assert that they and their own families do not neglect their elderly loved ones, but that other adult children nowadays generally neglect their aged parents more than was the case in previous generations. They need to defend against the guilt they feel and deny their own negative emotions (anger) by feeling that other caregivers do not behave as responsibly as they do.

Belief in the myth of parental neglect makes adult child caregivers feel even guiltier and contributes to the stress and strain they experience. Paradoxically, not only does the myth persist because the guilt persists, but the guilt persists because the myth persists.

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