

Chapter 4
The Family

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The Family*

Families provide most of the care of the impaired elderly and act as the advocates for persons with dementia (1)30,65). They are appealing for relief from the burdens of patient care (1,74). Their appeals coincide with efforts to control public health care expenditures, including determining how much financial responsibility families should assume for the care of the elderly ill. Caregiving families are also receiving attention, as recent studies begin to show that the characteristics of a family are as important as those of the person with dementia in determining which individuals will be institutionalized (16).

This chapter examines the impact of dementing diseases on caregiving families and discusses

● "this chapter is a contract report by Nancy Mace, consultant in gerontology, Towson, MD

the potential effect of policy options. The first section asks:

- Who provides how much of what kinds of care and services to individuals with dementia?
- What is the impact of the disease on the family?
- Are the burdens caused by dementia unique to the condition or similar to those created by other long-term chronic illnesses?
- How will changing patterns of family life affect the availability of caregivers in the future?

The second section focuses on helping families and considers whether the family can be assisted to provide more care at a savings to the taxpayer. The last section examines six options available to the Federal Government to assist or support families.

A PROFILE OF FAMILY CARE

Who provides How Much and What Kind of Care in Which Families?

Extent of Care

Studies of the dependent or frail elderly show that family caregivers provide 80 to 90 percent of the care of these individuals (10). Even though the United States is a mobile society, most elderly persons live near at least one family member and see that person frequently (66). Families do not abandon the ill to institutions; they avoid placing their relatives in nursing homes as long as possible, often at great cost to themselves. Indeed, many nursing home placements are not only appropriate, but should have been made sooner (51).

Studies that focus on caregivers of persons with dementia confirm that families also provide the majority of care. The Secretary's Task Force on Alzheimer's Disease reported that most people with dementing illnesses are cared for by their families for the majority of their illness (77). The tasks of caring for a person with dementia are

constant. A significant number of caregivers of dementia victims spend more than 40 hours a week in direct personal care (54). In fact, a popular book refers to caregiving as "the 36-hour day" (44).

At the same time, persons with dementia are overrepresented in nursing homes (8). Many are placed there after having exhausted those caring for them:

In the overwhelming majority of cases, nursing home placement occurs only after responsible family caregivers have endured prolonged, unrelenting strain (often for years), and no longer have the capacity to continue their caregiving efforts (12).

Others have outlived their caregivers. Individuals who have no children or whose spouse becomes ill or dies are much more likely than those with families to be in nursing homes (8,45).

To learn more about family caregivers and how they obtain help, OTA surveyed 2,900 persons on the Alzheimer's Disease and Related Disorders

Association (ADRDA) mailing list. (See ref. 82; the study is referred to in this chapter as the OTA study.) Table 4-1 indicates the living arrangements of those with dementia identified in this study. Although 39 percent were currently living with a family caregiver, 50 percent had lived with relatives at some point in their illness. (This figure does not include those living in their own home and cared for by a spouse.) Thus, over the long course of a dementing illness, many people will be at home for part of their illness and in a nursing home or similar residential setting for part of the time.

Care providers Within Families

One definition of the family is:

that group of individuals [who] are related by blood or marriage. . . . The family may include those persons somewhat distantly related by blood or marriage, such as cousins of various degrees or in-laws, all of whom may be perceived as family members. Further, for any one person the family network is not static. It may expand to include even more distant relatives as a need arises for information, services, or help from these relatives (66).

A "family caregiver" may include individuals unrelated by blood or marriage but sharing in a relationship of intimacy and support. "Family" does not necessarily refer to persons sharing a household or living nearby—it may include someone living at great distance who is in close communication.

Within the white middle-class family, one individual usually assumes most of the tasks of car-

ing (51). Studies show that when the disabled individual is married, the caregiver will most often be the spouse (one-third to one-half of all caregivers—most of whom are women); when there is no available spouse, adult daughters or daughters-in-law assume the role. (One-quarter to one-third of the caregivers are adult children.) The remainder are other family members or unrelated persons. In the absence of immediate family members, often a sibling or the adult child of a sibling will assume primary responsibility for the patient (18,26,83). Even friends and neighbors occasionally act as primary caregivers (68). The patterns of family caregiving may be different for other socioeconomic or cultural groups (33,37,42).

Little is known about the ways in which other family members—whether living nearby or far away—help the primary caregiver, although it is clear that they do help (.59,71). Anecdotal information reveals that many family members who live further away also are actively involved in care plans.

More women than men are primary caregivers. This is in part because of women's traditional roles and in part because wives tend to be younger than their husbands. (Men are closely involved in care, but often their tasks and investments of time are different.) Nevertheless, many husbands and sons are providing around-the-clock intensive personal care.

Most caregivers are middle-aged. The 1982 Long-Term Care Survey found that the average age of caregivers was 57 years, with one-quarter aged 65-74, and 10 percent aged 75 or over (69). They are persons with numerous responsibilities, which may include the care of other dependent elderly, children, grandchildren, and spouses. Thus the difficulties they experience by helping a relative with dementia may affect many lives. Caregivers are often employed, and they often are beginning to experience chronic illnesses associated with their own aging (10). The Long-Term Care Study found that one-third of caregivers rated their health as fair or poor (69). Spouse caregivers are often as old as or older than the ill person and may have chronic illnesses of their own. They may be unable to meet the physical demands of caregiving. One program found that caregivers

Table 4-1.—Where The Person With Dementia Lives

Where the person with dementia lives:	Total respondents
With primary caregiver (if other than you) or with you.	39%
In a nursing home.	33%
Patient now deceased	17%
Alone	4%
In a foster, personal care, or boarding home	3%
In a Veterans Administration home or hospital.	1%
With someone else	1%
Not applicable	1%

NOTE Percentages rounded to nearest whole number

SOURCE Yankelovich, Skelly, & White, Inc., "Caregivers of Patients With Dementia," contract report prepared for the Office of Technology Assessment, U S Congress, 1986

using home respite care were much older than the average recipients of all programs (56).

Although this profile encompasses the majority of caregivers, the diversity among caregivers is striking (34). A few elderly parents are caring for middle-aged sons and daughters with a dementing illness and a significant number of younger spouses are caring for both a young victim and young children. More information about how families provide care is needed if successful services for them are to be developed. The diversity among caregivers indicates that no one service will serve all families.

Kinds of Care

Families provide a wide range of care: from giving advice and acting as a confidant, to providing financial help and total personal care. Family care is highly flexible. Unlike formal support services, families provide care at night, over weekends, and on demand. The care they give is individualized to meet the idiosyncratic needs of the person with dementia (23).

The care provided changes as the illness progresses. Early in the course of the disease, families must make decisions for the individual and take over shopping, meal preparation, banking,

and legal and financial responsibilities (44). Later, families must assume responsibility for personal tasks such as dressing, bathing, and eating. Because the individual is usually ambulatory but has impaired judgment, round-the-clock supervision is necessary. Many persons with dementia are awake and active at night—the OTA study found that 17 percent were out of bed most nights—and therefore their caregivers must also be awake. After a time, caregivers must assist persons with dementia to walk (or must lift those who become bedfast)—8 percent of the individuals in the OTA study were living with family and were bedfast. Many must help these persons use the toilet; others manage complete incontinence (14 percent of the persons in the OTA study were incontinent and were living with family caregivers).

For most of the illness, persons with dementia appear unaware of their need for help and may respond to assistance with anger or resistance. They may accuse a caregiver of stealing from them or trying to harm them. Many patients are unable to express any appreciation for their care. They may fail to recognize a spouse or child, or may exhibit bizarre behaviors that complicate the tasks of personal care. Families report a long list of difficult and upsetting behaviors (see table 4-2). In addition, the tasks of caring remind the caregiver

Table 4-2.—Patient's Behavior Problems Cited by Families

Behavior	Number of families reporting	Families reporting the behavior	Families reporting the behavior and citing it as a problem
		No. (%)	No. (%)
Memory disturbance	55	55 (100)	51 (93)
Catastrophic reactions	52	45 (87)	40 (89)
Demanding/critical behavior	52	37 (71)	27 (73)
Night waking	54	37 (69)	22 (59)
Hiding things	51	35 (69)	25 (71)
Communication difficulties	50	34 (68)	25 (74)
Suspiciousness	52	33 (63)	26 (79)
Making accusations	53	32 (60)	26 (81)
Needing help at mealtimes	55	33 (60)	18 (55)
Daytime wandering	51	30 (59)	21 (70)
Bathing	51	27 (53)	20 (74)
Delusions	49	23 (47)	19 (83)
Physical violence	51	24 (47)	22 (92)
Incontinence	53	21 (40)	18 (86)
Cooking	54	18 (33)	8 (44)
Hitting	50	16 (32)	13 (81)
Driving	55	11 (20)	8 (73)
Smoking	53	6 (11)	4 (67)
Inappropriate sexual behavior	51	1 (2)	0 (0)

SOURCE: Adapted from P.V.Rabins, N.L. Mace, and J.T.Rabins, "The Impact of Dementia on the Family," *Journal of the American Medical Association* 248:334, 1982.

of the deterioration of a loved one. The experience of ongoing grief was described by one family member as “the funeral that never ends” (29).

Even after someone has been placed in a nursing home, families continue to visit, assist staff, wash and mend clothing, dress the person, take him or her for walks, pay bills, handle money, and, finally, continue to give love and affection (18). For many caregivers, the year following placement in a nursing home may be as stressful as the years of caregiving (27).

Many families cover all the expenses of a relative placed in a home: half the total cost of nursing home care is borne by patients and their families (4). That figure does not include extras such as laundry, haircuts, toiletries, and sometimes medication.

Families That provide Care

Because there is no known racial or socioeconomic variation in the prevalence of Alzheimer's disease (47), the families that provide care are believed to represent all groups. Racial and socioeconomic differences have been found by clinical practice and in voluntary organizations, but these may reflect variations in knowledge of the disease, access to services, and ways of obtaining help rather than real variations in prevalence.

Little is known about patterns of elder care among minority groups. In States where the demand for nursing home beds exceeds the supply, facilities are able to selectively exclude “undesirable” patients—those who are receiving Medicaid, for example, or those who are difficult to care for (72). Since individuals with dementing illnesses are perceived by nursing home staff as difficult to care for, and since minorities are overrepresented among the poor, these persons are least likely to find a nursing home (38).

Other characteristics of the caregiving situation also influence the decision to place an individual in a nursing home (16). Spouses who depend on the patient pension or who cannot afford a nursing home have little choice except to care for the person at home. These economic realities may operate in concert with strong cultural values of the importance of caring for family.

Many patients do not have family members available who can provide care. An estimated 7 million older people have no family, have families that are not nearby, or have family relationships that have long been impaired (8). As many as half the people living in unlicensed (and therefore uncounted) boarding homes, hotel rooms, “foster homes” and single-room occupancy hotels have dementing illnesses (8). These individuals also are less likely to have family members who could care for them or oversee the quality of the care they are given. Thus, a significant group of persons with dementia are at risk of exploitation, abuse, or neglect because they have no relatives to speak for them.

What Effect Does Caring for a Dementia Patient Have on the Family?

Reports from families of dementia victims are filled with accounts of the severe pressures created by these illnesses (30). The Secretary's Task Force on Alzheimer's Disease stated that:

... the extremely debilitating and chronic nature of Alzheimer's disease places a tremendous financial and social burden on family caregivers (77).

One observer found that:

... persons with dementing disorders contribute to the community burden disproportionately. This demonstrates . . . that the observations in clinical settings represent only the tip of an iceberg of unknown shape and size (68).

Several studies have sought to measure and describe the impact on families. Researchers unanimously report enormous and prolonged demands. Caring for a person who has a dementia often has an adverse effect on:

- the caregiver's physical and mental health (28,61),
- the caregiver's participation in recreation and social activities (62),
- the family living arrangements (26),
- the caregiver's employment status (73), and
- the caregiver's financial security (73).

Some of these and other studies have sought to identify the aspects of care that influence a care-

giver's feelings of burden. They have found that the burden a caregiver experiences may be influenced by the person's relationship (husband, wife, son, daughter) to the person with dementia (26), by whether caregiver and patient share a residence (10), and by the emotional support the caregiver receives from other members of the family (84). Symptoms of mental impairment, disruptive or 'acting out' behaviors, extent of need for personal care, and the number of disruptive behaviors all increase the caregiver's stress (59). There is no direct relationship between stress and a family's decision to use a nursing home, although stress may be a factor (see below).

Further study is needed to answer several questions:

- To what extent do the problems families face—poverty, the presence of children who need care, the demands of jobs, divorce, crowded living arrangements, unhappy family relationships, loss of a caregiver's income—interact with and compound their burden?
- In what ways is the burden of caring for a person with primarily mental or behavioral symptoms different from caring for a person with a physical disability?
- Why do a few families not report distress?
- Why do some persons with dementia not exhibit the disturbed behaviors commonly reported?
- Do some families have better resources that allow them to manage? If so, what are they—money; health; coping strategies such as religious faith, humor, cognitive restructuring skills?
- Does the duration of the illness affect feelings of burden?
- What are the special needs or problems of rural, minority, or socioeconomically disadvantaged families?

There are significant weaknesses in the design of some of the studies to date. For instance, most have examined white middle-class families. Little is known about the effects of caregiving on rural, minority, and impoverished families.

Physical and Mental Health

Because dementia is most prevalent late in life, caregivers are often elderly spouses or adult sons

and daughters who are themselves entering early old age, with their own age-related health problems (10). One report noted that three-fourths of the adult sons and daughters of dependent elderly entering the Philadelphia Geriatric Center were in their fifties or sixties (8).

Caregivers report that the tasks of caring have a deleterious effect on their health (61). One-third of the caregivers in a national study of people caring for the frail or disabled elderly rated their own general health as fair or poor (69). They report illnesses resulting from exhaustion and stress, as well as injuries resulting from the physical tasks of caregiving (17). When caregivers are compared with groups of similar individuals who are not caring for an ill relative, those living with an ill person tended to have poorer health. Men with ill wives are more likely than an aged-matched control to die prematurely of stress-related diseases (26). The OTA study found that 12 percent of the caregivers who were living with the person with dementia reported becoming physically ill or being injured as a result of caring for the person. That is a significant hazard, especially for wife caregivers who are smaller than a husband who has dementia.

Studies report high levels of depression among caregivers (25,40,60,62,81). These studies also find that many caregivers feel angry and guilty and are grieving. They report increased levels of family conflict. People caring for someone with dementia have three times as many stress symptoms as people of the same age who are not caregivers, and they report lower life satisfaction. Caregivers used more psychotropic drugs (sleeping medications, tranquilizers, and antidepressants) and more alcohol than comparison groups (28). Women who have given up a job to care for a parent experience poorer physical and mental health than other women (10). In the OTA study, 35 percent of caregivers who were living with the patient reported becoming very stressed and 11 percent of the primary caregivers sought the help of a counselor or psychiatrist.

Participation in Recreation and Social Activity

Closely related to mental health is the time caregivers spend in recreation and social activity and

their feelings of satisfaction from leisure activities. Often the tasks of giving care fill their days, allowing no time for recreation (62). The patient's bizarre behaviors and need for constant supervision further limit opportunities for social activity. Caregivers lose friends and give up hobbies. They become isolated by the need to provide full-time caregiving.

Yet a caregiver's need for social contact is underscored by studies showing that his or her feeling of burden is related to the amount of support given by others. Caregivers who felt well supported by friends and family had fewer feelings of burden than those who did not feel supported by others (7,84). One study reported that support from others had a greater effect on caregiver's feelings of burden than did any other factor, including patient behavior and level of cognition (84).

Living Arrangements

Neither elderly individuals nor their adult children prefer living in three-generation households. Instead, where possible, at least one adult child lives near the parents (65). However, the situation may be different for the families of persons with dementia. Unlike many other chronically ill persons who can be left alone for brief periods of time, individuals with dementia need constant supervision. Therefore, the family may have no choice but to share a household in order to watch the person day and night. Data tend to support this hypothesis: The greatly or extremely impaired are more likely to be in shared households (65). And shared households have been linked with the symptoms common to dementia (63). The OTA study found only 4 percent of persons with dementia living alone. The 1982 National Long-Term Care Survey found that almost three-quarters of caregivers in a nationally representative sample of people helping frail and/or disabled persons lived with the care recipient (69).

Sharing a household with the impaired elderly may lead to increased family conflict, poorer caregiver health, and greater caregiver stress (10,26). Shared households more often include children of the caregiver. The demands of a behaviorally disturbed elder and the needs of children may interact to increase the caregiver's stress.

Employment Status

Twenty-eight percent of the nonworking women in one study had quit their jobs in order to care for an aging parent, and an equal percentage of working women were considering doing so. (10). The women who had left employment had parents who were older. They more often shared their household with a parent, and the parents more often were cognitively impaired (i.e., had symptoms of dementia and scored lower on a standard mental status test). Caring for a parent had resulted in a greater deterioration in these women's physical and mental health, and their families had lower incomes.

The OTA study found that there was an employed person in 14 percent of households and that in 12 percent someone, almost always the primary caregiver, had stopped working in order to care for the person with dementia. The Travelers Insurance Co. conducted a study of employees at its Hartford, CT, headquarters and found that 28 percent of the full-time employees spent an average of 10.2 hours a week caring for an aged relative, while 8 percent devoted 35 hours a week to care (49). Those who quit work are only part of a much larger group. The 1982 National Long-Term Care Survey found that:

... among the one million caregivers who had been employed sometime during the caregiver's experience, one-fifth cut back on hours, 29.4 percent rearranged their schedules, and 18.6 percent took time off without pay to fulfill caregiver obligations (69).

Another study (52) found that higher percentages of the adult-child caregivers with children in the household were employed either part-time or full-time, particularly when the caregiver was divorced or separated. It is likely that the costs of child rearing necessitate the employment of many middle-aged women in three-generation households. Despite their multiple roles as spouse, parent, and primary caregiver, half these women were also in the labor force. In the summer of 1986, the Family Survival Project conducted a study of employed caregivers of persons with dementia. Preliminary data from that study indicate that many caregivers are leaving employment to provide care (24).

Financial Impact

The Maryland Report on Alzheimer's Disease and Related Disorders states that:

... the financial burdens of dementing disorders can be particularly devastating . . . the caregiver is faced with the prospect of wearing himself or herself out or spending large amounts of money for home nursing aides or nursing home placement (30).

The financial burdens include loss of the ill person's salary; denial of his or her disability or retirement income; loss of the caregiver's salary; the costs of home or respite care (which are generally not covered by insurance, Medicare, or Medicaid); and the costs of nursing home care (also rarely covered by insurance or Medicare). The 1982 National Long-Term Care Survey found that almost one-third of caregivers had incomes within the poor or near poor category (69).

Many families lose the salary of the person with dementia. Although the disease is more common among people who are likely to be retired, it strikes many people during their peak earning years. The percent of individuals who lose a job due to a dementia is not known and can only be inferred from epidemiologic data. The OTA study found that 11 percent of the persons with dementia had applied for Old Age and Survivors' Disability Insurance (OASDI) and 7 percent had applied for disability pension from an employer, one indicator of employment status at the time of the onset of the illness. In addition, many women with dementia had been homemakers at the onset of their illness (18). Since someone else must assume house-keeping tasks or a homemaker must be hired, that loss must also be considered in economic terms.

The onset of the disease is gradual and insidious, often going unnoticed or misunderstood. Therefore there may be a substantial number of individuals who leave employment or are asked to take an early retirement because of inadequate job performance. Some people have lost a job, only to try several more jobs unsuccessfully before the dementing illness is discovered (18).

Researchers and disability examiners both report a long litany of problems caregivers face in obtaining disability and retirement benefits on be-

half of an ill person (18,21). Some individuals have been fired because the disease was not recognized; others quit their jobs before a diagnosis had been made. Thus, an unknown number of persons with dementia may sometimes be denied disability or retirement benefits. In addition, some families, already exhausted by caregiving, have had to make repeated appeals to obtain benefits (18).

people with a dementing illness are often unable to learn a new, less difficult skill, and therefore may be totally disabled early in the illness. An Institute of Gerontology study mentioned one man who "was reduced from supervisor to work crew, then to janitor" but who was unable to function successfully at any level (18). Farm and unskilled laborers may be disabled as completely and quickly as persons with technical or professional skills. The same study described a farmer who:

... would take hours to do simple chores. He wouldn't be able to find farms where he was contracted to haul cattle and other livestock. He didn't know what to do when he got there. He needed help getting to the stockyard and doing routine things when he got there.

As indicated earlier, a significant number of family members give up jobs to care for the patient. Families with lower incomes are more likely to experience the loss of a caregiver's salary (10). Table 4-3, taken from the OTA study, shows the amount of salary lost by those who quit a job to care for a person with dementia. These data agree with reports that low-income women are more likely than higher-income women to quit a job to care for an aged parent (10). Families face the financial burdens of care that extend over many years. Insurance or Medicare usually covers the

Table 4-3.—Amount of Salary Lost by Family Members Who Quit a Job to Care for a Person with Dementia

Approximate amount of salary lost	Total respondents
Less than \$4,999	23%
\$5,000 to \$9,999	17%
\$10,000 to \$14,999	12%
\$15,000 to \$19,999	18%
More than \$20,000	11%
Did not answer	20%

NOTE: Percentages rounded to nearest whole number.

SOURCE: Yankelovich, Skelly, & White, Inc., "Caregivers of Patients With Dementia," contract report prepared for the Office of Technology Assessment, U.S. Congress, 1986.

costs of diagnosis and physician care, but that represents only part of the total. The financial burden on family caregivers has been widely documented (18,30,75).

In addition to the loss of income, individuals with dementia often give away, hide, or spend money needed for their long-term care.

Half the total costs of nursing home care are borne by residents and families (4). Most respite and home care programs, when available, depend on client fees or private sources (30). The care of persons with dementia in such programs usually does not qualify as medical (skilled nursing) care and therefore is not reimbursed by Medicare; nor is it tax deductible. Day care programs that focus on service to people with dementia report less use of Medicaid than programs that serve other frail elderly, and almost no use of Medicare (46).

The OTA study found that no respondents had been reimbursed by either Medicaid or Medicare for a visiting nurse or day care program. Many families in the OTA survey (11 to 31 percent by program) did not use *available* services because they were too expensive. Families caring for a person with dementia also pay for renovations to make their home safe for the resident and for over-the-counter medications, diapers, special diets, and supportive devices, many of which are not covered by Medicare.

Although the ill person's own income and assets appear to be used first, 29 percent of the respondents report that a spouse was contributing to the cost of care, and one in five report that children and other relatives contribute to the cost of care (see table 4-4). One family in four reports that all the patient's savings had already been spent on care (table 4-5) and half expected that all or most of the patient savings would eventually be spent (table 4-6). Those who had been ill longer were more likely to have expended their savings.

The financial impact on family varies. Half report that there has been no impact thus far or that they had been able to handle extra expenses fairly easily. However, 22 percent report not being able to make ends meet or having to cut back sharply on expenses (table 4-7). Nearly 20 percent

of families had spent all or at least half the family's savings on care; another 21 percent had spent less than half (table 4-8).

Spouse caregivers are more likely to be impoverished than other family members. One-third of families report that the person with dementia relies on the spouse for support, and 15 percent report that very little of the couple's income was left for the well spouse (table 4-9). That agrees with the finding of another study that spouse caregivers are disproportionately impoverished (26).

Between one-fourth and one-third of families surveyed in the OTA study reported that they were facing the early stages of the relative's illness when financial drains are not so great as when he or she is in a nursing home. When families were surveyed by another study 2 years later, more reported a serious financial impact (26). Thus more families in the OTA sample can be expected to become impoverished or experience a significant impact of the cost of care in coming years. Programs that provide assistance and see families after they have provided care for many years report higher percentages who are severely affected by the burdens of care. A Massachusetts study found that two-thirds of individuals and one-third of couples aged 66 and older would spend themselves into poverty within 13 weeks if stricken by a chronic illness that required long-term care (74). Clearly, not only does the impact fall most heavily on spouses, but it is also heaviest when the person must be cared for in an institution.

Because persons on the ADRDA mailing list cannot be assumed to be representative of all persons caring for someone with a dementing illness, the findings of the OTA study must be regarded as preliminary. Furthermore, many of the caregivers who responded to the survey did not answer the questions about expenses, making these findings on costs much less reliable (see table 4-9). For these reasons, it is likely that the data in these tables underreport the financial impact on families.

The OTA study also asked families what sources of funds helped support the person with dementia or pay for the person's care and what percent of care was provided by each source (see table 4-4). Of all families surveyed, 70 percent report

Table 4-4.—Sources of Income Used To Support Person With Dementia^a

Source	Percent of total respondents reporting this source ^b	Mean contribution
Patient's Social Security	700/0	38%
Patient's own savings, income from assets	530/0	46 ^c /10
Other retirement/pension income of patient	32%	34%
Patient's spouse	30%	11%
Medicare	29%	19%
Medicaid	15%	9%
Patient's children	15%	240/0
SSI (Supplemental Security Income)	6%	37%
Veterans Administration	5%	67%
OASDI or other disability payment	4%	23%
Contributions from other relatives	4%	13%
Other	4%	37%

^aMost families report having more than One Source Of income

^bDoes not indicate percent of contribution by source

^cRespondents were asked what percent of the person's overall support was from each source. These responses were summed to obtain a mean

SOURCE: Yankelovich, Skelly, & White, Inc., "Caregivers of Patients With Dementia," contract report prepared for the Office of Technology Assessment. U S Congress, 1986

Table 4-5.—Amount of Patient's Savings Spent on Care Since Becoming Ill

How much of patient's savings spent	Total respondents (%) ^a
All or most	23%
A large amount (at least half)	16%
Some but less than half	28%
None	14%
Patient had no savings	9%
Did not answer	12%

^aPercent based on total sample

NOTE: Percentages rounded to nearest whole number.

SOURCE: Yankelovich, Skelly, & White, Inc., "Caregivers of Patients With Dementia," contract report prepared for the Office of Technology Assessment, U S Congress, 1986

Table 4-6.—Proportion of Patient's income/Savings Expected to Eventually Go for Care

How much expected to go for care	Total respondents (%) ^a
All or most	51%
At least half	15%
Less than half	8%
None	7%
Did not answer	20%

^aPercent based on total sample

NOTE: Percentages rounded to nearest whole number.

SOURCE: Yankelovich, Skelly, & White, Inc., "Caregivers of Patients With Dementia," contract report prepared for the Office of Technology Assessment, U S Congress, 1986.

that the patient's social security is a source of income. Among those who receive social security, it accounts for an average of 38 percent of their income. On the other hand, Veterans Administration funds account for an average of 67 per-

cent of a person's income, but only 5 percent of individuals rely on VA funds. Few patients rely on financial help from their children, but those who do report that an average of one-fourth of the ill-person's income comes from the children.

Thus, families do make major contributions to care and are able and willing to share in the cost of care. At the same time, government funding sources are an essential resource. Not all families rely on sources such as Medicaid for patient care, but financial demands increase with the progression of the disease. The burden of care can quickly exhaust the resources of persons with dementia and impoverish their families, especially those most vulnerable—spouses, female heads of household, and minorities (see ch. 12)—and ultimately have a significant effect on the resources of many families.

Families have charged that Medicaid and Medicare standards contain biases and restrictions that mitigate against persons with dementia, against women caregivers, and against home care as opposed to nursing home care (13,18,30,51,70).

Except for physician care and medications, most persons with a dementing illness do not need the medically oriented care Medicare/Medicaid call "skilled" until late in their illnesses. The care they need is termed "custodial" by Medicare and Medicaid; it does not qualify them for Medicare coverage in nursing homes, or for home health care.

Table 4-7.—Financial Impact on Family Paying for Patient's Care

Which statement best describes the financial impact on your family?	Total respondents
We have had to cut back sharply on expenses and still can't make ends meet.	5.7 %/0
We have had to cut back sharply on expenses but have been able to make ends meet	16.20/o
We have had to do without some things but are getting by.	7.5%
We have been able to pick up the extra expenses fairly easily	14.5 %/0
So far there has been no impact; we have not had to contribute to the patient's support.	34.5 %/0
Did not answer	28.00/o

^aMore than one response was allowed.

SOURCE: Yankelovich, Skelly, & White, Inc., "Caregivers of Patients With Dementia," contract report prepared for the Office of Technology Assessment, U.S. Congress, 1986.

Table 4-8.—Proportion of Family Savings Spent for Patient Care

Portion of family savings	Total respondents
All or most	90/0
More than half	10 %/0
Less than half	21 %/0
None	47 %/0
No answer	140/0

NOTE: Percentages rounded to nearest whole number.

SOURCE: Yankelovich, Skelly, & White, Inc., "Caregivers of Patients With Dementia," contract report prepared for the Office of Technology Assessment, U.S. Congress, 1986.

Table 4.9.—Proportion of Income/Savings Left for Patient's Spouse After Paying for Care

Proportion of income/savings left	Total respondents
All or most	17 %/0
About half.	190/0
Some but very little	15 %/0
Patient has no living spouse.	70/0
Did not answer	43 %/0

NOTE: Percentages rounded to nearest whole number.

SOURCE: Yankelovich, Skelly, & White, Inc., "Caregivers of Patients With Dementia," contract report prepared for the Office of Technology Assessment, U.S. Congress, 1986.

In some States it means that the care of persons with dementia in nursing homes is reimbursed at lower rates by Medicaid. Families and professionals have argued that considerable skill is needed to care for these persons successfully (30) and "custodial" rates are too low to provide the care needed by people with dementia.

Certain groups are especially vulnerable to the financial biases of some government programs. Although the financial well-being of the elderly in general has improved, aged female heads of households remain impoverished (79). It is these women who are most likely to give up a job to provide care for a person with dementia (11) and

who can least afford to lose income. Women are much more likely than men to receive no retirement pension or only Supplemental Security Income (SSI)—\$325/month—because many older women did not work outside the home or worked only as domestics (18). Women are more likely than men to be widowed and therefore to have lost the pension on which they depended. Daughters caring for an aged parent in a household without a male wage-earner and retired couples on a fixed income also report high levels of financial burden.

The Maryland State Office on Aging found that Medicaid policy is inadvertently biased against wives (13). Since many women in the older cohorts of the elderly were never employed, they depend on their husband's retirement income, almost all of which must be paid for his nursing home care if he is to qualify for Medicaid. The wife then becomes eligible for SSI, at a much lower standard of living, often after she has devoted years to her husband's care. In contrast, when a wife with no income of her own is institutionalized, 23 States do not require the husband who continues living in the community to spend his pension on her care. He can continue to live at his previous standard of living (see ch. 11).

Efforts to encourage alternatives to nursing home care can also result in inadvertent discrimination. Programs that fund in-home care often require clients to meet criteria for skilled nursing care. That requirement is to ensure that home care replaces institutional care and does not become an add-on service. Persons with dementia, excluded by the skilled-nursing language, are thereby unable to use these programs until they are too severely ill to be managed at home,

In some States, Medicaid considers room and board provided by a caregiving family to be part of the applicant income. That effectively makes the income of persons living with family members higher than that of comparable persons living alone or in a nursing home. Family caregivers complain that this method of calculation is inequitable since persons with dementia cannot live alone.

Families report being given incorrect or conflicting information when they have applied for Medicaid. Such problems produce further stress, and may have resulted in the unnecessary impoverishment of caregivers. The extent of this problem is difficult to document, although complaints are common (14).

Medicaid law is convoluted and difficult to understand. It is a mix of Federal and State statutes and varies from State to State (14). The minutes of the Governor's Task Force on Alzheimer's Disease in Maryland reveal that even experts disagreed on their interpretations of that State's Medicaid law (30). Anecdotal reports tell of different Medicaid offices within a State giving different information, nursing home staff giving incorrect information about eligibility, families being required to pay private rates for nursing home care after being incorrectly told that the patient was not eligible for Medicaid, and families being required to make a donation to nursing homes or to sign agreements to pay at private rates.

The OTA study found that of the 164 families who had applied for Medicaid, 38 percent had encountered problems; 22 percent could not get a clear explanation of the eligibility rules, and almost 9 percent said they were treated rudely.

Of those who applied for Medicaid, 38 percent were told by the Medicaid office that the spouse must provide support, although 23 States do not hold spouses responsible for long-term care. ADRDA chapters report numerous spouses who were required to support a patient in nursing homes, often for many years, even in States in which spouses are not responsible for support after the first month (2,3).

Among families who sought to place relatives in a nursing home, the OTA study found that 12

percent were told they must make a donation to the home—a practice that violates Federal policy in homes accepting Federal funds. One-third were asked to sign agreements to pay privately. (Eleven different attorneys general in States with Federal support have issued opinions holding that Federal law makes it a felony to require a person who is Medicaid-eligible to agree to pay privately) (15).

Varying Impact on Spouses, Adult Children, and Young Children

Although studies have shown that men and women, adult children, and spouses experience burden in different ways, the research has covered only a narrow socioeconomic subgroup. Differences between economic or racial groups may be greater than those between the sexes or by relationship. Much more significant than these differences is the number of caregivers of all types who are significantly distressed. Nevertheless, if supportive services are to be targeted effectively, the differences among caregivers must be better understood.

Little is known about the number of children living with or near a person with dementia or about the impact of these diseases on children. Younger persons with dementia often still have young children or adolescents at home. Many individuals live in three-generation families, where grandchildren grow up in the presence of a person with dementia; a national survey of caregivers of the frail or disabled elderly found that one-quarter of the caregiving sons and daughters had children in the household (69).

One commentator has stated, "problems and role changes experienced by one family member affect every other family member and each person in the family feels the repercussions" (9). Thus even children not living with the ill person may experience the effects of their parent's burden.

The 36-Hour Day (44), a guide for families of persons with dementia, identifies some of the common problems encountered when children or adolescents share a home with a person with dementia. When the child's parent is the primary caregiver, parenting roles may be diminished by the demands on the exhausted caregiver. Caregivers often cannot leave a person with dementia

in another room for even a few minutes, so finding time to talk alone with a worried child can be difficult. Family activities may cease because no sitter can be found for the ill person; family meals and sleep may be disrupted by disturbed behavior during the years a child is growing up. Many caregivers are also employed—often of necessity—adding to the burdens of both caregiver and child (52).

Disoriented and distressed people with dementia may punish a child unjustly, or may berate an adolescent for being a “hippie,” “lazy” or “a thief.” They may yell or curse. Their behavior may make a child too embarrassed to bring friends home. Because the person cannot control his or her behavior or learn not to act that way, children may have no choice but to put up with it—and with little support from their exhausted and depressed parent.

The number of children touched by a dementing illness maybe quite high. The OTA study found that 6 percent of persons with dementia currently living in a family household shared the home with children. Many more children may have shared a household with a person with dementia at some point. The Travelers Insurance Co. surveyed its employees who were caring for an elder family member and found “(that 52 percent of those giving care were adults between the ages of 41 and 55, many of whom were attempting to satisfy the needs not only of elderly parents but also those of their own children” (49). A study of schoolchildren found that 25 percent had an elderly family member who was not mentally alert and that these children had more negative attitudes toward aging than other young people did (67).

Although many schools now offer courses in family life, many have little or no material about abnormal aging. The Maryland Report on Alzheimer's Disease and Related Disorders, for example, found no material in the Maryland school curriculum about abnormal aging (30). In 1986 Maryland (HB173) and Virginia (HJR105) introduced legislation to correct that lack. It is the current generation of schoolchildren who will have to assume responsibility for vast numbers of the elderly with dementing illnesses.

Varying Impact on Different Socioeconomic Groups

As indicated, little information exists on the effect of dementing diseases on minority populations or on different socioeconomic groups. Studies of the minority aged indicate that the burden of a dementing illness may be experienced differently by different socioeconomic groups. Two general theories are postulated: that minority groups have stronger family ties and are more willing to keep their aged at home; or that the combined burdens of minority status, poverty, and age exacerbate the problems faced by these families.

Minority groups tend to have lower incomes and more single women as heads of household. As mentioned earlier, both factors point to higher levels of caregiver stress. Such multiple disadvantages probably compound the struggle these families face. Blacks and Hispanics are underrepresented in nursing homes (42), which implies that informal caregivers are providing extensive amounts of care. It may also reflect the shorter life expectancy of blacks and significant inequalities in access to resources.

Burdens Related to Public Policy or Access to Services

Families report that there are few services to assist them in caring for a person with a dementing illness, that the services that do exist will not accept persons with dementia, or that staff members of these services are not trained in the special care of persons with dementia (70).

The OTA survey of ADRDA members asked several questions about use of services. Table 4-10 shows caregiver's subjective assessment of health care for persons with a dementing illness. High proportions reported dissatisfaction with the service, a position consistent with the concerns expressed publicly and through ADRDA.

The responses in tables 4-11 and 4-12 show that these persons made considerable use of physicians (although this sample cannot be assumed to be representative). Many respondents reported that professional caregivers were not knowledgeable

Table 4-10.—Assessment of Health Care Professional's Role in Caring for Patients With Alzheimer's or Another Dementing Illness

What is your reaction to these statements?	Strongly agree	Agree	Disagree	Strongly disagree	Not sure/ not applicable	No answer
The assistance I've received from health care professionals— in caring for an individual with Alzheimer's disease—has been excellent.	8	29	23	12	19	9
In my experience, most health care professionals know little about managing patients who have Alzheimer's disease	21	36	20	2	13	9
From what I have seen, a patient who is ill with dementia receives worse care from health professionals than patients who are ill with something else	15	24	30	4	20	7
I have found it difficult to find satisfactory paid professionals to assist in caring for an Alzheimer's patient at home	25	26	8	1	29	11
I really don't know where to go to get help in caring for an Alzheimer's patient at home	20	28	21	3	17	11
In my view, the existing nursing homes where Alzheimer's patients might live are inadequate in the care they provide	20	30	20	4	19	8

NOTE: Percentages rounded to nearest whole number.

SOURCE: Yankelovich, Skelly, & White, Inc., "Caregivers of Patients With Dementia," contract report prepared for the Office of Technology Assessment, U.S. Congress, 1986.

Table 4-11.—Number of Physicians Seen by Patient To Diagnose or Treat the Dementia

Number of physicians seen	Total respondents
1	18%
2 to 3	46%
More than 3	20%
Don't know/no answer	17%

NOTE: Percentages rounded to nearest whole number.

SOURCE: Yankelovich, Skelly, & White, Inc., "Caregivers of Patients With Dementia," contract report prepared for the Office of Technology Assessment, U.S. Congress, 1986.

Table 4-12.—Frequency of Patient Visits to a Physician Who Treats Patients With Dementia

Frequency	Total respondents
At least once a month	25%
Several times a year	19%
Only occasionally	27%
Never	16%
No answer	12%

NOTE: Percentages rounded to nearest whole number.

SOURCE: Yankelovich, Skelly, & White, Inc., "Caregivers of Patients With Dementia," contract report prepared for the Office of Technology Assessment, U.S. Congress, 1986.

about care of patients with dementia, or that they had trouble finding a physician to care adequately for the patient (tables 4-13 and 4-14). While these figures represent a serious knowledge gap, equal

Table 4.13.—Amount of Trouble Finding a Doctor To Care Adequately for Patient With Dementia

How much trouble had	Total respondents
A great deal of trouble	17%
A moderate amount	25%
Only a little	16%
None at all	30%
No answer	12%

NOTE: Percentages rounded to nearest whole number.

SOURCE: Yankelovich, Skelly, & White, Inc., "Caregivers of Patients With Dementia," contract report prepared for the Office of Technology Assessment, U.S. Congress, 1986.

Table 4-14.—Level of Satisfaction With Care Patient Currently Receives From Doctor(s)

How satisfied are You?	Total responses
Very satisfied	25%
Moderately satisfied	33%
Only somewhat satisfied	21%
Not satisfied at all	9%
No answer	12%

NOTE: Percentages rounded to nearest whole number.

SOURCE: Yankelovich, Skelly, & White, Inc., "Caregivers of Patients With Dementia," contract report prepared for the Office of Technology Assessment, U.S. Congress, 1986.

numbers of respondents who used a family doctor for care reported satisfaction with physician expertise (table 4-15). These findings may be an indication that some sectors are responding to the

Table 4-15.—Caregiver Rating of Family Doctor's Knowledge of Care of Persons With Dementia

Doctor's rating	Total respondents
Very knowledgeable	17%
Somewhat knowledgeable	53%
Not knowledgeable	16%
Don't know/no answer	14%

^aAmong caregivers reporting that the patient sees a family doctor; base is 88 percent of those surveyed.

NOTE: Percentages rounded to nearest whole number.

SOURCE: Yankelovich, Skelly, & White, Inc., "Caregivers of Patients With Dementia," contract report prepared for the Office of Technology Assessment, U.S. Congress, 19SS.

demand for improved care of these individuals. However, the group surveyed may be better able to locate services than others who do not receive ADRDA newsletters and information. The informed family physician plays an important role in maintaining patient function (31) (see ch. 2). Pathologists (who conduct autopsies), ophthalmologists, podiatrists, and dentists who are knowledgeable about the care of confused persons are also important to families.

The OTA report found that 64 percent of persons with dementia have been hospitalized at least overnight since becoming ill with dementia, but of these, only 41 percent of caregivers felt hospital care had been good. Twenty-six percent reported receiving fair care, and 21 percent said care was poor. Nineteen percent of families felt that the patient had been discharged from the hospital prematurely.

The Family Survival Project in San Francisco, CA, points out that families often report a need for legal and financial advice and counseling. Families need help with wills, insurance, and property disposition (56). Lawyers and financial advisors received criticism for their lack of knowledge about the illness. OTA found that 60 percent of families had consulted a lawyer to obtain power of attorney or guardianship, but only 27 percent of them felt that the attorney was informed about the disease. Thirty-eight percent of families sought professional financial advice, with 29 percent of these reporting they found a knowledgeable consultant.

Family members may work hard to get a confused person to visit a physician or lawyer. When that professional fails to offer appropriate help,

families may be unable to persuade the confused person to visit a second professional.

Caregivers gave nursing homes mixed marks. Fifty-four percent of families had applied for admission to a nursing home at some time; 30.5 percent of the patients had been in more than one home. Ten percent of these patients had been asked to leave a nursing home, usually due to their behavior. That response by nursing homes places great burdens on the caregiver who must find another resource for a hard-to-place and often severely ill individual. Such requests are often made suddenly; families have only a few days to find a new facility or arrange for care at home.

Of those families using nursing homes, 18 percent say the care the patient received was excellent; 37 percent reported it to be good; 27 percent say care was "average"; and 16 percent said care was poor or very poor. Families who had placed a patient in a nursing home in the preceding year experienced greater stress than families who were providing care at home (33).

Caregivers report a great need for services (ch. 6 discusses the availability and use of supportive services). Sixty-four percent of caregivers said that having the services of a paid companion in the home for a few hours a week to give the caregiver a rest is essential. However, more than 40 percent of the families ranked all services except domiciliary care as "essential/most important." The rank order may be of less significance than the families' overall need for a range of services.

Many respondents reported that services were not available, but a surprising number were unsure about availability. Although that uncertainty may reflect a need for case management (see discussion of issue 3, "Issues and Options" section, below), it may also indicate absence of services. Almost half of caregivers report that visiting nurses or paid companions were available, but fewer than one in four thought that overnight respite, adult day care, or domiciliary care was available. Many reported that available services were too expensive (see table 7-4, ch. 7).

In summary, the minimal availability of services, the difficulty in locating services, cost, and the absence of informed professionals can add sig-

nificantly to the burdens experienced by caregivers.

For some family members, providing information about resources is not sufficient. Family members may be so demoralized that they are unable to negotiate the bureaucracy in search of help. The OTA study revealed that half of families ranked “help in locating people or organizations that provide care for the patient” as “most important” and 47 percent of families ranked “assistance in applying for Medicare, OASDI, etc.,” as “most important” (see table 4-16).

Day care, home care, and other programs report large amounts of staff time spent helping families find other needed resources or giving short-term, problem-oriented counseling even though their funding sources do not provide for such assistance. Typically, a day care program may offer the following services to one caregiver over a period of about 2 years: referral to a support group, referral to a dentist who cares for people with dementia, advice on behavior management, assistance in better coordinating the help of other family members, referral to a lawyer, referral to a private home health aide, short-term counsel-

ing, and, finally, help in selecting a nursing home. Thus, the current fragmented nature of the service providing system compounds the caregiver’s burden.

The Impact Over Time

For many caregivers the tasks of care may extend over 10 years or more (85). In this way dementing illnesses differ from many others. During such a long period, many changes may occur in the caregiver’s own status-employment, marriage, personal health, and children—that can affect that person’s ability to provide care. The nature of the illness and the demands it makes also change over time. The burden on families shifts but does not necessarily increase (86). Some families report that it is easier to care for a bedfast patient than for an agitated and wandering one. Others find that the physical effort of providing total personal care is more difficult.

Such factors affect the family’s continued ability to care at home. (Some of the hypotheses regarding the family’s ability to care over time are discussed later.) Little is known, however, about the impact such prolonged caregiving has on the

Table 4.16.—Assessment of Importance of Certain Services To Be Provided to Patients With Dementia, Regardless of Cost and Current Availability

How important is it that these services be provided?	Essential, very/most important %	Very important %	Important %	Not important %	SO No answer %
A paid companion who can come to the home a few hours each week to give caregivers a rest	64	19	7	3	7
Assistance in locating people or organizations that provide care for the patient	50	26	12	3	9
Assistance in applying for Medicaid, OASDI, SSI, etc.	47	20	15	5	12
Paid companion—overnight care	48	23	13	7	9
A home health aide—a person paid to provide personal care for a patient, such as bathing, dressing, or feeding in the home.	46	27	13	6	8
Support groups of others who are caring for persons with dementia	45	26	14	5	10
Nursing home care—special nursing home programs only for persons with dementia.	43	22	17	8	11
Respite care—temporary round-the-clock care in a nursing home or hospital to care for the patient while the caregiver is away or takes some rest	43	25	16	7	9
A visiting nurse—a registered nurse paid to provide nursing care to the patient at home	36	23	19	19	9
Adult day care—a group program that provides out-of-the-home activity and supervision during the day	36	22	19	12	11
Domiciliary or boarding care—a living arrangement that provides residential care but not nursing care either in another family’s home or in a group home	21	15	24	26	14

NOTE: Percentages rounded to nearest whole number.

SOURCE: Office of Technology Assessment, 1987.

family members themselves. Nor is there adequate information on how easily people return to normal social activities, employment, and good health at the end of their work as caregivers.

Are the Burdens Caused by Dementia Unique to the Condition?

In 1985, Secretary of Health and Human Services Margaret Heckler stated that:

... the pattern of care for persons with Alzheimer's disease is not unlike the long-term care required for many other adults with multiple numbers of chronic physical and mental impairments (78).

In contrast, one expert claimed that those with dementia are more likely to be institutionalized because:

... senile dementia is the most socially disruptive ailment of all, placing a particularly severe burden on families (8).

The position of the Department of Health and Human Services (DHHS) was based on studies that showed that functional ability, how much a person can do for him- or herself, is a better measure than a diagnosis for determining the amount of care the individual will need. (One person with a diagnosis of cancer may be able to dress, eat, and bathe while another person with the same diagnosis might need total care.)

For several reasons, it is difficult to carry that assumption to dementia. DHHS relied on findings that applied to the costs of institutional care, not to the burdens of families, which might be quite different. And, as discussed in chapter 7, the care needs of persons with impaired thinking may be quite different from those with a physical handicap. Studies such as the Resource Utilization Group Survey based their findings on measurements made in traditional nursing homes (22), where the physical care model might be inappropriately applied to people who have dementia.

Many believe that caregiving is made more difficult by the unique characteristics of a dementing illness that affect the relationship between the caregiver and the care receiver, impede communication, cause a lack of cooperation or apprecia-

tion for care, require constant supervision, and lead to bizarre behaviors. Since dementia is characterized by changes in behavior, it may be more appropriate to compare the problems of caring for a person with dementia to those of caring for a person with mental retardation, brain damage, or mental illnesses.

Greater caregiver stress has been noted in those who care for persons with more personal care dependencies, more symptoms of mental impairment, and more disruptive or "acting out" behaviors (19,41)52,59). Of these, one study found disruptive behavior to be most stressful for families (59),

Caregivers of persons with a dementing illness have been compared with those who care for equally impaired, nondemented elderly:

Caring for the physically disabled versus the mentally disabled are unique situations The mean number of hours spent providing care was remarkably similar, . . . but the personal stress and negative feelings were significantly higher for the dementia group . . . and caregivers of dementia victims were more likely to be considering placement (7).

How will Changing Patterns of Family Life Affect the Availability of Caregivers in the Future?

Increasing Numbers of the Very Old

The oldest age groups are among the fastest growing segments of the population. It is these groups that are most at risk of developing a dementia (12). They are also more vulnerable to multiple health problems, increasing the amount of care they may need, and reducing the likelihood that family members can provide it. The very old are more often widowed or have a spouse too frail or ill to care for a person with dementia (8). Their children are entering old age themselves. One study found that 40 percent of those admitted to a nursing home had an adult son or daughter over 60, and that half the applications for admission to a nursing home were precipitated by the death or severe illness of the spouse or adult child (8). Thus age makes this cohort both more vulner-

able to dementia and less likely to have caregivers available.

As more people live into old age, four-generation families become more common. From the point of view of the younger potential care provider, the family tree is exceedingly top heavy (9). Over time, an individual caregiver may provide care to several dependent family members: an in-law, a parent, and a spouse. In addition, the declining birth rate reduces the ratio between potential caregivers and the elderly. Other changes—including the increasing number of women working outside the home, rising divorce rates, mobility, and smaller families—also contribute to the number of persons without available caregivers.

Return of Women to the Work Force

The number of working women has quadrupled in the past 50 years, with women between the ages of 45 and 64 accounting for the largest increase in the labor force (80). It is women in this age group who are most likely to be called on to provide care for a parent or spouse with a dementing disease. Although women of all ages agree that care of a frail elderly relative becomes the responsibility of daughters, the majority also feel that a woman should not adjust her work schedule to care for aging parents (10).

Women face conflicting demands on their time—work, parents, children, an aging spouse—a conflict that has been called the “woman in the middle” (9). Often women in older cohorts give up time for rest or recreation for themselves. Some point out that there is a limit to the amount these women can do (9). Others argue that the “baby boom” women have entered the labor force and are raising children, with fathers assuming a more active role in child care (51). Currently working women are more willing than those of previous generations to purchase child care while they work, and they may follow the same pattern in care of their parents, with sons assuming increasing responsibility for aging parents and with families becoming more willing to purchase care for elderly family members. Single women heads of households and low-income women, however, have fewer options for sharing or purchasing care (52).

Increasing Numbers of Single Persons Living Alone

The number of single-person households is increasing (76). These individuals lack the most common source of caregivers should they become impaired—other members of a household. Since individuals with dementia generally need a person living in the home to provide supervision, the growing number of persons living alone is of particular concern. The OTA study found that 4 percent of persons with a dementing illness were living by themselves. That figure is probably a significant underestimate because the sample was taken from those who had taken action to join ADRDA—unlikely in the case of an individual with dementia living alone.

The insidious onset of Alzheimer’s disease is often overlooked in persons who continue to live by themselves although significantly impaired. They are at risk of accidents, robbery, and severe personal neglect, and they pose dilemmas for social agencies who are asked to assist them.

High Divorce Rates and Changing Patterns of Remarriage and Cohabitation

The current frequency of divorce and remarriage can be expected to have an impact on the number of caregivers available to persons with dementia. Single adults often have multiple responsibilities for children, employment, and homemaking and may have little time for the added demands of caring for the elderly. Divorced women frequently have lower incomes and are thus less able to purchase care. In fact, many such women depend on their parents, if they are healthy, to provide both financial help and child care.

Remarried families have complex and varied loyalties and feelings of obligation that complicate plans for coordinated patient care. The number of unmarried couples living together is also increasing and these people may have different concepts of responsibility for “in-law” care (9).

Increasing Mobility of Families

One study found that most elderly persons have at least one child living near them, and that child’s

proximity has been stable for over 20 years (66). But often only one child assumes responsibility for the majority of parental care because siblings live out of town. The role of these more distant adult children in caregiving is unknown. However, it is known that caregivers who feel well supported by their families feel less burdened by care. This feeling of support maybe more important to the caregiver than even the severity of patient behaviors (85). Isolated caregivers thus maybe additionally burdened by the limited support of other family members imposed by geographic distance.

Changing Attitudes About Family Responsibility

Some commentators believe that the spouses of persons with dementia demonstrate exceptional

loyalty to the ill partner, remaining in the marriage and providing care for many years (36). Whether future cohorts of caregiving spouses will display a similar loyalty is not known. Most of the present group of elderly Americans are in first marriages of long duration at the time of the onset of the disease. In addition, this cohort entered marriage with a commitment to a lifelong relationship. Future cohorts with marriages of shorter duration or different commitments may show different patterns.

HELPING FAMILIES

A major concern for those who shape policy for persons with dementia and their families is identifying services that will assist caregivers and at the same time control government costs. Respite care has been identified as a key element in helping families and has been proposed as a means of reducing costs by enabling families to continue to care at home rather than turn to more costly nursing home care. Respite care is any formal program that cares for the person with dementia on a part-time basis so that the caregiver can rest, remain employed, seek medical care, etc. Respite programs include in-home companion care, in-home personal care, adult day care, and short-term stays in a nursing home, hospital, or boarding home.

A Duke University survey of families (26) and the OTA survey (see table 4-16) both found that families preferred care in the home to other forms of respite. The OTA study also found that families called several options for respite care “urgently needed.” That finding, rather than the ranking of those options, may be the most significant: A family’s choice of services may change as the patient’s disease progresses and the family’s ability to provide care changes.

The Family Survival Project has described the characteristics of respite it has found to be workable. This description points out that respite is intended to be temporary, is not to replace other services, and describes what works with family caregivers.

- Respite services work best when the family (and, if possible, the patient) works with the service provider to structure the care plan. Before a program is set up, the ages and traditional values of both the disabled person and the caregiver (and others in the home) should be considered, as should the home environment and the relationship between the patient/disabled person and the caregiver. The patient’s functional level and behavioral status should be assessed in conjunction with the caregiver’s health status and needs for relief.
- Any amount of respite seems to work for those who accept it as an option. Ten hours a week of home care, 1 day a week in day care centers, an occasional weekend, 2 weeks in a foster home—all achieve some degree of relief and help to postpone or avoid institutional placement and family breakdown.

- **In cases where the patient or caregiver faces a deteriorating situation**, usually because of failing health, respite must be seen as a temporary solution. It is not a substitute for the family but for a much needed community-based and coordinated long-term care program.
- As many community resources as possible should be utilized in designing and providing a respite service. What works in a respite program will depend on what supports it in the community: volunteer programs, day care centers, nursing homes, companion programs, etc.
- Training of family members in physical patient care, behavioral problem management (particularly for persons with dementing illness or mental disability), financial management, and stress reduction all enhance the potential for success of respite. At the same time, self-care training for disabled persons will increase opportunities for independence. Respite is, after all, temporary and time controlled and should be offered together with other caregiving education.
- All situations will not be served by respite care. Many family members do not seem to give up their care role easily, even when 24-hour care exceeds 10 to 20 years. For some caregivers, the concept of respite is simply an unknown and, once the new term is explained, they seek the service readily. Others fear that one small vacation will disrupt their ability to continue as they did before. Some fear that once the patient is out of the home for even a short period, the door to permanent institutional placement will be opened. As in home health care, strangers in the home present problems to some families. Many patients are too ill or disabled (given the declining health of the caregiver) to be cared for at home, and respite will help only in a short-term, limited way. Appropriateness of respite must be considered for each situation (58).

Will Improving Supports for Caregivers Ease the Burdens on Families?

Although the burden families experience is well established, and some things are known about the

groups most at risk (28), the relationship between providing respite or support and reducing family burdens may not be straightforward. For example, increased respite will not alleviate the grief that adds to the caregiver's experience of burden. Also, the level of either distress or burden may not correlate with family use of nursing homes. Families may choose to keep a person at home despite their burden, or because a satisfactory nursing home may not be available. There may be no relationship between burden and placement, or the relationship may be a complex one, invoking behavioral symptoms, prior relationship, the needs of the family, and access to suitable care.

Two conflicting theories about family needs sometimes influence policy. The '(wear and tear' theory holds that families are fragile and unstable, and that unless they are assisted they will become exhausted, overburdened, unable to provide adequate care to the frail elderly, and impaired as a family unit (subject, for example, to divorce, delinquency, substance abuse, chronic illnesses of caregivers, or suicide). The "adaptation" theory, on the other hand, assumes that families have a great capacity for change and therefore will adjust to the demands of care, through sharing of tasks, purchase of care, personal growth, and so on.

Neither theory has been proven. Either can be argued effectively on the basis of existing data. Equally significant is the fact that either can be intuitively accepted, based on one's knowledge of families. Thus they both influence public thinking about the kinds of services and government assistance families need,

Although researchers disagree about the kinds of care needed and the nature of the burden experienced, no one claims that most families are *not* burdened. Evidence of increased substance abuse and indications of poor mental health support the position that at least some families are vulnerable to the pressures of care.

The fact that the majority of caregivers continue to provide care for years and to juggle the many demands of caregiving, employment, and the needs of other family members does not entirely support the hypothesis of adaptation, for it does not reveal the damage done by concealed stress.

One study found that husbands who provided care complained less about the burden of care but tended to die prematurely (26).

The most reasonable assumption is that both theories are correct. Some families adapt successfully to the demands of caregiving for at least part of a relative's illness, and others show symptoms of distress (26). In fact, a family may adapt successfully for part of the illness but experience problems during other periods. One study found that caregivers were more stressed in the year following nursing home placement than were those caring for a patient at home (26) but bereaved caregivers experienced increased well being. This indicates that relief from caregiving does not necessarily bring relief from the emotional burden of care.

Research has identified some ways in which family burden or distress can be alleviated (32,35,64). Counseling and support groups decrease caregivers' feelings of loneliness and of being misunderstood. They also help caregivers better adapt to the demands of caregiving. Families and respite care staff both report that respite from caregiving plays a vital role in reducing family stress and burden. Families are enthusiastic in their praise of respite programs and many report that a program "saved my life" or "kept me sane." Family concern over the urgent need for respite has led ADRDA chapters to set up successful grassroots programs (see ch. 7). However these elements may not influence the family decision to place a person in a nursing home (86).

A controlled, prospective study (funded by the American Association of Retired Persons and the Andrus Foundation and carried out at Duke University-George and Gwyther, principal investigators) is looking at the effects of home care on the family, the patient, and the provider. Such studies will identify the kinds of services that help families most or predict which services are most urgently needed.

Will Respite Care Reduce Use of Costly Nursing Homes at a Savings to the Taxpayer?

Families clearly need respite. The role of respite in reducing the use of nursing homes and

the cost to the taxpayer of institutionalizing, however, is not so clear. In fact, when respite postpones placement, it may also result in the admission of sicker persons, resulting in a more costly case mix. There are several other reasons why provision of respite may not influence cost of institutionalization to the taxpayer.

- Patients without caregiving families will continue to need institutional care,
- Persons with serious multiple illness—including cognitive impairment—will need more care than respite can provide.
- Families may choose to keep ill persons at home despite the burden caused.
- Nursing homes may not be available to some persons.
- Studies that report that respite postpones placement may not have measured what families would actually do in the absence of respite.
- Families now receiving few services may be more willing to use respite than nursing home care.

Half the residents of nursing homes have no family, and those who do have fewer caregivers, or have caregivers who are ill or have sensory impairments (12). The death or serious illness of a caregiver clearly predicts placement (45). Thus more than half the residents of nursing homes have no one to care for them at home. Savings to taxpayers from enabling a family to keep a patient at home longer cannot be calculated on the basis of institutional costs, but only on that fraction of the institutional costs expended on patients with available families. Since the sizes of the oldest cohorts are growing rapidly and since these people are the most vulnerable both to developing a dementia and to loss of caregivers, the need for institutional care for patients without families can be expected to grow.

Many people in nursing homes have multiple illnesses, including dementia or delirium, and need more care than respite can give. The severity of illness, not the presence of dementia or the family's need for respite is the cause of nursing home placement.

In addition, families who do not have close bonds to the person with dementia or who are poorly

equipped to provide care can be expected to turn to nursing homes. This group includes families in which the caregiver is not a close relative, the caregiver is seriously or chronically ill, there is a long history of family discord, the caregiver is psychiatrically or intellectually impaired, or the patients' needs are not met because the family is so disorganized. There may be no financial incentive that will make ill-equipped or unavailable kin provide care (5 I).

Conversely, are there incentives that would encourage more families to keep patients at home longer? One study found that 42 percent of patients who had caregivers lived with that caregiver until the patient died (26). The OTA study found that 74 percent of families felt that a person with a severe dementia should be in a nursing home, but only 45 percent had placed a family member and 48 percent felt that nursing homes did not provide high-quality care. Thus many families never use placement.

Some families chose to keep patients at home, despite the burden; or place loved ones too late rather than too early. Dedication to the ill person and barriers to nursing home use combine to keep people at home. Testimony from the Maryland Governor's Task Force on Alzheimer's Disease and handwritten comments attached to the OTA survey questionnaires included many reports of a frail or exhausted caregiver continuing to care at home for a person who needed skilled nursing care. Respondents indicated that the cost of the nursing home would impoverish both the caregiver and the ill person.

As stated, 48 percent of the respondents to the OTA survey felt that nursing homes provided unacceptably poor quality care. Families also resist nursing home care because they have much less control of their relatives' quality of life or type of care after placement, especially when Medicaid funds are used (33). Caregiver attitudes about the quality of care nursing homes provide has been found to be at least as important to placement as the ill person's physical and emotional health (20).

Nursing homes may not be available to some people. The General Accounting Office found that persons with dementia are less likely than other

individuals to be admitted to nursing homes and, if admitted, less likely to receive quality care (72). Cost saving ceilings on nursing home beds, imposed by some States, create a situation in which nursing home bed use is artificially low. Difficult dementia patients are less likely to be admitted than other patients.

While certain incentives such as tax credits might help a subgroup of affluent families, the commitment families show to continue providing care despite the stress it causes indicates that further incentives would have a limited impact on caregiving. In addition, there may be negative implications to incentives: Is it desirable to encourage an employed head of household to give up a job to provide more hours of care? Should incentives encourage a frail wife to continue to care for a violent husband? Should incentives encourage a caregiver who is abusing tranquilizers to continue providing care? How can a caregiving wife care for an ill husband much larger than she is? If the caregiver becomes ill from caregiving, both persons may need institutionalization—at a greater cost.

Discouraging nursing home use further may compromise patient care and family survival. Since families are already providing almost all care, the effect of further incentives may be limited by families' ability to do more. Virtually the only resources available to families are nursing homes and family support groups.

Furthermore, there may be many families needing extensive care that are not now using nursing homes due to bed shortages, cost, poor quality care, etc. These families may be more willing to use respite resources than existing nursing home services, especially if a plan for shared payment allows the family to remain partially in control of care and if such services are readily accessible, are individualized, and provide better care than families believe is available in nursing homes.

Will Providing Supports for Caregivers Cause Them To Do Less for the Recipient?

There has long been a debate over whether formal supports tend to supplant informal support (friends, family, or neighbors). Much of the evi-

dence, however, indicates that both formal and informal care, working together, would best serve persons with dementia. For example, the object of respite care is to provide care for some of the hours a family would otherwise cover. Replacement of family care is intended in this case, and should be expected. In other cases, caps on respite reimbursement stretch programs' limited resources. Such caps also control runaway costs. The Family Survival Project, which offers respite care, reports that 59 percent of families in the respite program supplemented cost out of pocket in 1984-85 (57). Counseling and family support groups offer caregivers improved caregiving skills, reassurance, and other assistance, supplementing informal services rather than supplanting them.

The current behavior of families supports the belief that they will continue to care for family members. Despite the fact that Medicaid encourages institutionalization over home care for some people, families have resisted use of nursing homes until they can no longer manage. Indeed, a common complaint in nursing homes is that some caregivers continue to spend many hours a week with patients and are not reestablishing their other social relationships.

Studies have shown that families do not decrease the care they provide when alternative services are available. Many of the services families provide are individualized and are offered at all hours and on weekends (23). The family "contribution" includes emergency assistance for short periods (28). In addition, important components of the family contribution include love, financial advice, and someone to talk to—things no formal support service is likely to supply. And given the magnitude of the need for supportive care resources, it is unlikely that a program large enough to supplant the family could be established. Some caregivers provide all care and refuse offers of assistance such as day care even when clearly overburdened. The thrust of public policy will be most effective if it aims to supplement, not supplant, family care.

Factors Leading a Family To Seek Nursing Home Placement

Research has sought to identify the factors that lead to placing someone in a nursing home. If re-

searchers could identify a specific behavior that is likely to trigger placement, better treatment of that symptom might result in fewer placements. Unfortunately no such factor has been identified. Incontinence, violence, extreme mood swings, and night wandering are suspected as precipitant of placement, but the data neither confirm nor refute this belief. Severity of physical disability as well as severity of mental impairment both add to caregiver stress (19,41,53,59) and perhaps to the decision to place a person in the nursing home. Rather than seeing specific problems (such as incontinence) as overwhelming, the experience of families is variable, with many factors, not just behavior, causing burden (86).

The characteristics of caregivers influence placement decisions at least as much as the characteristics of the person with dementia. A prospective study identified caregivers who are more likely to turn to nursing home care. They are often younger women, and more often the adult child of the ill person than the spouse. They report high levels of stress, used more psychotropic drugs in the year before placement, and had higher incomes (16). Caregivers who are isolated or have sensory impairments may also be more likely to use placement (33).

Studies That Examine the Relationship of Respite and Placement

Some studies have looked at patients already in nursing homes and asked questions about why they were admitted. For example, the New York State Respite Demonstration Project found that families receiving services were less inclined than before to place patients in nursing homes (48); another study reported that families found day-care postpones placement (55). These studies are subject to bias; the weakness of retrospective research is that there maybe a difference between what families think they would have done, and what they actually have done.

Several studies funded by the Health Care Financing Administration (HCFA) under so-called 2176 waivers have matched families receiving care with a control group who did not receive respite care (see ch. 11 for a discussion of 2176 waivers). These studies looked at the frail elderly in general, not just those with dementia. But to ensure

that the intervention was directed at persons who really were at risk of placement, the studies required that all persons in the experimental and control groups be eligible for Medicare's skilled nursing care (a medically oriented definition that excludes the kind of care needed by people in the middle stages of dementia). These studies did not find significant differences in placement rates between those using and not using respite care. One possible explanation is that the skilled care requirements meant that interventions were offered too late (i.e., when the patient already needed more care than the family could provide) and that if family stress is to be reduced, or placement postponed, the intervention must be made earlier. Also, selection for those requiring skilled care would exclude most people with dementia unless they also have other serious illnesses or are in the late phases of their dementia.

A study at Duke University found that families who used formal community services were more likely to turn to placement within a year (26). This finding supports the hypothesis that families who actually need nursing home care turn to respite when they are desperate, but are reluctant to think about nursing home care. The involvement of a professional may reassure families of their need for more help with care. Respite may be a temporary bridge—the Family Survival Project originally named its program “Bridges to Survival”—between total family care and institutionalization. Such abridge may be necessary for families and it needs to be provided before it is too late to help (33). It may be inappropriate to consider respite as a solution to the high public costs of nursing homes. Policies that place cost saving as the primary goal of respite care may be likely to fail.

The OTA survey asked families who had used respite care why they had stopped using it (see ch. 7). The most common reason was that the person had entered a nursing home. The other major reasons are that the service is too expensive, the patient died or became worse, or the caregivers found they did not need the service. These findings support the hypothesis that nursing home

care is a needed part of the continuum of care for many families, and that after a certain point other services do not prevent its use. (These data do *not* tell whether respite postponed nursing home placement.) The finding that many families in the survey did not feel the need for respite services does not indicate that these resources are not needed in general. Respite care is probably most needed in the middle phases of a dementing illness. Many respondents were caring for people who were too ill to use programs such as day care or who were too early in the course of their illness to need constant supervision. That finding may also explain the number of families who avoid using formal services.

Provision of family support may postpone placement, though studies have not yet confirmed that hypothesis. Recent studies do point to interventions that should be tested: providing additional emotional support to caregivers, using information to reduce difficulties in providing care, case management, assistance, equipment, or respite (16,20,50). Interventions to reduce disruptive and socially inappropriate behavior and to enable management of incontinence are also needed.

In summary, the reasons behind placement may lie with the characteristics of the family and its support system:

When physicians assess a patient's need for nursing home care, it is not enough to evaluate symptoms or to know how long the patient has been ill or functioning at the current level. The structure and characteristics of the caregiver support system are also important—and, in fact, are better predictors of institutional placement than patient characteristics (20).

The combined stress of multiple role demands, problems in caring for the patient, the caregivers' perception of burden, the absence of support or help, the lack of information about how to care for the patient, and high cost, poor quality, and limited capacity may all be factors in nursing home placement. The final straw may be less significant than the years of attrition that have finally exhausted the caregiver (12).

ISSUES AND OPTIONS

ISSUE 1: Should the Government Encourage Families To Assume Additional Responsibility for Their Relatives Who Have a Dementing Illness?

Option 1. *Make no change in the current division of responsibility for persons with dementia between government and families.*

Option 2. *Encourage greater family responsibility for persons with dementia.*

Option 3. *Assume a greater share of the task of caring for persons with dementia.*

Examples of the government shouldering more of the burden (option 3) include tax breaks to caregivers, allowing services on the basis of caregiver need as well as patient need, reimbursing respite programs, and correcting inequities in Medicaid laws.

Examples of encouraging increased family responsibility (option 2) include holding sons and daughters responsible for parent care in a nursing home, encouraging purchase of insurance coverage, reverse mortgage plans, etc. The complex issue of the responsibility of government and families is discussed in chapter 12. This chapter has pointed out some of the issues raised about families.

1. Families already provide the majority of care.
2. Families provide kinds of care that formal services cannot or do not provide,
3. Current policies create inequities in the financial burden imposed on families; for example, spouses, particularly women, are more likely to be impoverished by care than other family members.
4. Efforts to control government expenditures can result in inequitable access to services; persons who are dependent on Medicaid, have a dementia, and who have behavior problems are less likely to be admitted to nursing homes.
5. Current funding policy encourages use of nursing homes but does not support use of other services.
6. Respite care cannot be assumed to be a substitute for nursing home care, but is needed

by families to assist them in the burdens of care and to reduce caregiver exhaustion and burnout.

7. Families prefer to share the costs and burdens of care. The present system, however, requires families to impoverish themselves and to give up control and involvement in patient care in order to receive help with the cost of institutionalization.
8. Current funding is based on medical need for care. This approach excludes many patients and their families from appropriate assistance until late in their illness.
9. Families contribute about half the costs of **nursing home care** and most of the costs of **respite care**, as well as **large** amounts of in-kind services and room and board.

Efforts to obtain further contributions from families may be difficult and costly to enforce. Such steps could harm some caregivers and families (by leading to increased drug use, poor health, inattention to children, loss of employment) or push families to neglect the person with dementia.

If government assumes a greater role in caring for persons with dementia (option 3), it will probably cost more than the current government share of care (see ch. 12 for a more complete discussion).

ISSUE 2: Should the Government Include the Caregiver in the Definition of the Care Recipient?

Option 1. *Continue to consider eligibility for services based only on the needs of the patient.*

Option 2. *Modify existing programs to provide services that are more social and less narrowly medical in defining eligibility.*

Option 3. *Modify existing programs so that individuals with dementia are eligible for services geared to the caregiver.*

Option 4. *Develop new programs that provide both care for the patient and care aimed at giving respite to the caregiver.*

Current criteria for eligibility for most services is based on the needs of the ill person. However,

it is clear that caregivers of persons with dementia also need services to enable them to continue to provide care and to reduce the negative effects of burden. Option 1, maintaining current criteria for eligibility for services, will help to contain costs, but places severe and in some cases harmful burdens on families and includes inequities of access.

Providing services to other than ill persons (option 4) would require a major shift from current policy. It would also create difficult issues in determining which caregivers should be eligible for service. A compromise would be to broaden patient eligibility for social or psychosocial services (option 2). These are the kinds of services most often needed by persons with dementia and their families and include case management (or case coordination, or information and referral), adult day care, in-home respite care, and short-term respite care. Support for this approach comes from preliminary findings that both the individual and the caregiver benefit from psychosocial interventions (see ch. 7.)

option 3, modifying existing program so that individuals with dementia are eligible for services geared to the caregiver, would limit additional costs to those people who are now eligible for services. However, this option would exclude services to those families in which it is the caregiver's need for help, rather than the patient's need for service, that precipitates placement or caregiver morbidity. Since access to services is already limited for persons not needing skilled nursing care, this plan would restrict help for the caregiver except when the patient is severely ill. Many providers believe that if interventions are to be effective, they must be provided early enough to avoid caregiver burnout.

While option 4 would require a shift of policy, it has the major advantage of being flexible enough to allow the system to respond either to the needs of the patient or of the caregiver.

Options 2, 3, and 4 would probably increase costs. In most instances, they will not replace existing services, which are generally limited to the patient's need for skilled nursing care. In addition, an unknown number of persons in the community who are not now using funded services will use respite or home care services. The ex-

tent to which interventions aimed at the caregiver will postpone or prevent placement is not known. It is almost certain that additional services will reduce caregiver burden, may reduce caregiver morbidity, and may enable caregivers to remain productively employed.

ISSUE 3: Should the Government Assist in Coordination or Selection of Services

Option 1. Leave case management a State, local, or informal system.

Option 2. Link case coordination or case management to services it provides or funds.

Option 3. In place of case management or case coordination, require that programs using Federal funds establish and use efficient coordination with other existing programs.

Information about available service is a primary need for caregivers. The OTA survey found that many families need help finding services and negotiating the system to obtain needed services. Families also need information on a variety of topics: how and where to get help, what the implications of a diagnosis of dementia are, what the genetic risks are, what costs and burdens they will face and should plan for (39,43). Families and service providers report that existing services are fragmented and that families and patients cannot move easily from one to another.

Case management has been proposed as one method of assisting families. One accepted definition of case management describes functions in terms of long-term care:

The principal functions of case management in long-term care are the following: 1) screening and determining eligibility; 2) assessing the need for services and related needs; 3) care planning (developing a care plan); 4) requisitioning services; 5) implementing the service plan, coordinating service delivery and following up; and 6) reassessing, monitoring, and evaluating services periodically (6).

The lack of available information, services, and limited and uneven case management resources have been well documented. The existing services are not well coordinated in many areas. Those providing services frequently do not know about

or refer families to complementary resources. And there are major gaps in the range of services available. The need for better referral to services and coordination of services is clear; the solution is less clear.

Case management is rarely mentioned as a critical part of any respite program although many programs offer some form of case management despite the absence of funding for it. Many argue that case management is essential to efficient service delivery (33). OTA previously reviewed the effectiveness of cases management systems such as ACCESS, TRIAGE, and channeling (73). The effect of such programs on persons with dementia or their families is not known. However, families rarely seek and use as many services on their own as case managers would prescribe.

There may be great variations in the amount of case management a family will need. Some families may be so overwhelmed by the demands of care that they cannot seek help for themselves, even when given the necessary information. Individuals with dementia who have no family member to coordinate services are especially disadvantaged. Service providers often do not help such people obtain appropriate care. Other families may be capable of coordinating care if supplied with information, and many would prefer to do so rather than use the services of a stranger.

Case management can have several objectives, and they will affect its success. Case management helps persons with dementia and their families use available services. It may enable them to make financial plans for future care needs. It may also permit more efficient use of services. Case management may ensure that individuals are not placed prematurely. It can be used to guarantee that the least restrictive environment be available to those who have no family members to advocate for them. However, when case management is a required part of programs whose goal (or financial objective) is to prevent placement, it can cause further delays and suffering for caregivers already exhausted by care.

The effectiveness of case management is limited when important services are not available. While it can efficiently use services that are available,

case management does not address the related problem, lack of resources.

Case management, or case coordination, can have several kinds of beneficial indirect effects. Formal providers who are reluctant to accept a person with dementia are more likely to do so when they are assured that others are continuing to assist the patient and family. Case managers sometimes informally train providers in care in order to gain admission for a person with dementia. Thus case managers increase the community response. Families are often reluctant to use respite resources, even when their own health or the patient's well being is in jeopardy. Case managers report that an important part of their role is to gain the trust of caregivers and thus enable them to accept services. Case managers can work with a family to reduce conflict and enable family members to better support the caregiver. When little family support is available, the case manager may serve as a substitute, providing necessary encouragement and sympathy to the caregiver.

Because management has strengths and weaknesses, it will be needed by some families and not by others. Families clearly wish to remain in control of the patient care. Case management must be designed to assist when families are too overwhelmed to seek proper care for themselves or the patient but it must not usurp the family's role.

The existing system (option 1) does not provide needed information about services or ensure that additional case management services are available to those who need them. Option 2, including case coordination or case management in Federal programs, may improve access to services. It would also increase Federal costs, due to both the added service and the tendency of case management to increase the total number of services used. Further, case management must be designed so that it does not usurp family responsibility or create new problems. An effective and efficient method of delivering case management services must be identified.

Whether case management or case coordination is provided or not, more coordinated access to appropriate resources could be achieved by re-

quiring that programs using government funds establish effective liaisons with other nearby programs so that they all routinely inform caregivers of other services that might help them (option 3). Federal agency policies could be reviewed for their impact on “issues related to overlapping and conflicting responsibilities. Federal funds could be directed toward communities that have established interagency cooperation and have resolved issues of duplication of services.

ISSUE 4: Should the Government Provide Respite Services?

Option 1. Leave provision or purchase of respite care to the States, the private sector, and to families.

Option 2. Fund a limited number of model respite programs.

Option 3. Provide some or all respite care through direct provision of services, by paying for services, or by such things as tax credits.

Families urgently need low cost, readily available noninstitutional services. These services must not take control away from the family; they must be flexible and varied enough to meet the needs of different families and patients. They should be convenient and offer families options. Passage from one service to another must be smooth, and gaps in service must be eliminated. For at least some families, the caregiver’s physical and mental well-being may depend on respite programs. However, not all families use respite when it is available. There appear to be many reasons for this, including the quality and cost of the service, and caregiver’s reluctance to turn over even part of care. Families are concerned that their resources will be depleted and seek to postpone purchase of any care, even at reasonable cost, in order to conserve funds. If a continuum of services at known costs were available, families could project their long-term expenses and budget accordingly.

Providing such programs is unlikely to save money, however, either through preventing placement or sustaining the caregiver. And such a program would be costly. Meeting the need for nonin-

stitutional care for large numbers of persons with dementia is probably beyond the capabilities of at least some States (option 1), and programs such as block grants have repeatedly been shown to underserve this population. Many families are unable to purchase the services they need.

However, there is insufficient information about what kinds of services are needed, what services families will use, how much they can afford to pay for services, what care techniques are beneficial to patients and families, and what other barriers to service delivery exist for this group. This lack of information impedes planning a federally funded service package, although a few centers could provide information for later national implementation. Some models do exist: the Family Survival Project has been a notably successful program, and California has initiated studies that will generate answers to some of these questions. If the Federal Government were to support research into care delivery for persons with dementia (option 2), costs of open-ended programs would be avoided, data would be gathered to answer vital questions about services, and some families would benefit directly from the use of pilot programs.

ISSUE 5: Should the Government Make Access to Reimbursable Resources Easier; More Equitable, or Available Sooner?

Option 1. Leave access to Federal programs as is.

Option 2. Change accessibility, to, for example, Medicare and Medicaid.

Access to Medicare and Medicaid is discussed in chapters 11 and 12. Extensive modification of these programs could make problems of access even worse for some groups or could significantly increase costs. However, relatively minor changes in these two programs could greatly assist families (option 2). The government could establish a policy requiring all services using Federal funds to make clear and complete information about eligibility and the application process readily available to the public. There is considerable anecdotal information that information given to families is erroneous, or that families have difficulty getting this information. Easy access to such information would reduce the stress families experience in get-

ting help, would assist those families who are given erroneous information, and would encourage families to plan ahead for major health expenditures.

Medicare could expand the coverage for certain home care services to include preventive nursing care. Such visits are not now covered. For example, some clinicians report that many cases of incontinence can be reduced by medical and nursing interventions and by training the family. Nursing visits might therefore reduce incontinence, which is known to be a source of severe burden to caregivers. Severe agitation and hallucinations are also known to respond to medical interventions. Nurses trained in managing these symptoms could greatly reduce the burdens families face. Home visits by a nurse maybe preferable to physician office visits because assessment of the patient in the home allows an appraisal of the environmental factors that trigger behavior (see ch. 7).

These are but two examples of many possible. Further discussion of specific options is found in chapter 12. Further information about the care needs of people with dementia (ch. 7) and about respite programs will provide needed data for modifying these programs.

ISSUE 6: Should the Government Provide Family Support Groups or Information Centers for Caregivers?

Option 1. Provide information and support directly to families.

Option 2. Support the private sector in provision of these services.

It is clear that support groups and information are critical for families. The voluntary sector (primarily ADRDA) has been effective in establishing support groups and in disseminating information. However, their efforts have reached primarily the white middle classes. It maybe most efficient for government to encourage the endeavors of the private sector (option 2) and focus government skill on research to identify how to reach the hard-to-reach socioeconomic groups. Information dissemination efforts should include the considerable resources of the Federal agencies with relevant expertise, such as the National Institute on Aging, National Institute on Mental Health, Health Care Financing Administration, Administration on Aging, National Center for Health Services Research, and others. A Federal mechanism for centrally collecting relevant information would facilitate both government and private efforts.

In addition, families continue to have difficulty obtaining support and information from the professionals to whom they turn. The government's role in educating these professionals is discussed in chapter 9.

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