

## **Chapter 3**

# **The Need for Outreach and Case Management**

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# The Need for Outreach and Case Management

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## INTRODUCTION

People with dementia and their caregivers cannot be linked to services or sources of funding for services that do not exist, and as noted throughout this report, existing services and finding for services for people with dementia are inadequate (9,831 ).<sup>1</sup> Even when services and funding are available, however, some patients and caregivers do not use them. As discussed in chapter 2, one important reason why they do not use services is that they do not know about the services. To increase people's knowledge about services and sources of funding for services, an effective linking system must include public education and information and referral (see ch. 2).

The analysis in this chapter indicates that some people with dementia and some caregivers need assistance that goes beyond public education and information and referral if they are to be linked to appropriate services. The types of individuals who are likely to need such additional assistance include:

- individuals with dementia who live alone and have no family member or other informal (unpaid) caregiver to help them;
- individuals with dementia who have an involved family member or other informal caregiver who is aware of services but reluctant to use them even though the services are needed; and
- individuals with dementia who have an involved family member or other informal caregiver who is aware of services but unable to arrange them.

From the analysis in this chapter, OTA concludes that in order to serve these types of individuals effectively, a linking system must include outreach and case management in addition to public education and information and referral. *Outreach in this context* is defined by OTA as any active method of identifying individuals who need services but are unlikely to respond to a public education program or to contact an information and referral source on their own. *Case management in this context* is defined as a process that includes the five core functions shown in table 3-1.

The first section of this chapter presents the available data on the use of services by people with dementia and their caregivers. The data show that many of these individuals do not use services. Some of them do not use services because the services do not exist or are too costly or because they are not aware of the services. Data from several studies indicate, however, that some people with dementia and their caregivers do not use services even when the services are available and affordable and they know about the services. As discussed in the second section of the chapter, some people with dementia and some caregivers have characteristics, feelings, and perceptions that make them either unable to arrange services themselves or reluctant to ask for or accept services. To a great extent, these patient and caregiver characteristics, feelings, and perceptions explain why outreach and case management are essential components of an effective linking system.

Many of the same characteristics, feelings, and perceptions that interfere with the use of services by some people with dementia and by some caregivers also complicate the case management process with these individuals, making it difficult for a case manager to assess their needs and plan, arrange, and monitor services for them. The third section of the chapter discusses what is special about case management for people with dementia and draws implications for the skills and training needs of case managers who work with people with dementia and their caregivers.

Many questions about the case management component of a linking system for people with dementia remain to be answered, including whether, in general, families should be regarded by a linking system as “co-case managers” or “co-clients;” whether counseling should be part of the case management component of a linking system; and how many people with dementia and their caregivers need or should receive case management. These and other unresolved questions pertaining to case management for people with dementia are discussed at the end of this chapter. The answers to these questions have implications for the design and operation of the case management component of a

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<sup>1</sup>See table 1-2 in ch. 1 for a list of the services that may be needed for people with dementia.

Table 3-1-The Five Core Functions of Case Management

- 
1. Assessing a client's needs
  2. Developing a plan of care
  3. Arranging and coordinating services
  4. Monitoring and evaluating the services that are delivered
  5. Reassessing the client's situation as the need arises
- 

SOURCE: Office of Technology Assessment, 1990.

linking system and for the skills and training needs of case managers employed by the system.

This chapter relies heavily on the findings of two OTA contract reports. One OTA contract report describes a respite care demonstration project for families of people with dementia conducted by Duke University and identifies factors that interfered with the timely use of respite services by some families (291). The second OTA contract report describes an exploratory study conducted for OTA in 1988 that examined: 1) what case managers in five Pennsylvania area agencies on aging (AAAs) perceived to be the unique aspects and difficulties of working with people with dementia and their families; and 2) how family caregivers perceived the process by which the AAA case managers arranged services for them (934). The Duke respite care demonstration project and the study conducted for OTA in Pennsylvania are described later in this chapter as their findings are presented.<sup>2</sup>

## THE LIMITED USE OF SERVICES

Available data from 11 small-scale studies described below indicate that although the majority of people with dementia use physicians' services, only a minority of them use in-home and other community services. Several large-scale national studies, such as the 1982 and 1984 National Long-Term Care Surveys, also include information about subjects' use of services, but it is difficult to determine with any certainty which subjects in the surveys have dementia (468). Thus, it is not possible to develop valid figures on service use by people with dementia from those studies. For that reason, OTA's conclusions about service use are based on the 11 small-scale studies that focus exclusively on service use by people with dementia.

The source of the study sample, the severity of the subjects' dementia, and the time period and specific services covered by the 11 studies vary; hence, their

findings are not directly comparable. Moreover, the use of some services—mental health services, legal services, benefits counseling, and certain other services needed by some people with dementia—was not considered in any of these studies. Nevertheless, the findings suggest that many noninstitutionalized people with dementia do not use any paid in-home or community services other than physicians' services.

1. A 1985 survey of 597 caregivers of noninstitutionalized individuals with dementia in 16 States found that only one-fourth of the caregivers had ever used any paid in-home or community services (117).
2. A 1987 survey of 100 caregivers of noninstitutionalized individuals with dementia in Connecticut found that 14 percent of these individuals were receiving services from community agencies, an additional 12 percent were receiving services from "privately hired help," and 3 percent were receiving services from both sources. The results of a companion survey of 531 Connecticut health care and social service agencies suggest that only 13 percent of all noninstitutionalized individuals with moderate or severe dementia in the State were receiving any services from such agencies in 1987 (479).
3. A 1983 study of 501 family caregivers of individuals with dementia in North Carolina found that 43 percent of the caregivers had used a paid helper (usually a maid or sitter) to care for the patient (242,243,291). Fewer than one-fifth of the caregivers had used any other in-home or community services for the individual with dementia: of these, 19 percent had used in-home nursing services, 12 percent had used adult day care, and 13 percent had used homemaker or chore services. Followup interviews with the same caregivers a year later found that only one-fourth of the caregivers had used any paid services other than physicians' visits for the person with dementia in the intervening year. The average duration of the demented individuals' illness in this study was 5 years (range: 6 months to 30 years), and most services were used in the final year before the patient died or was placed in a nursing home.

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<sup>2</sup>The two contract reports are available from the National Technical Information Service in Springfield, VA (see app. A.)

4. A study of 101 people with dementia seen at an outpatient dementia clinic in Minnesota between 1982 and 1984 found that 48 of them had *severe* dementia at the time of their initial clinic visit; by the time of the last followup (2 to 4 years after their initial visit), 31 percent of these 48 patients had died; 40 percent had been put in a nursing home; and 29 percent were still living at home (411). Of those who were still at home, 79 percent, or 23 percent of the original sample, were using either adult day care or in-home nursing services. The same study found that 53 of the 101 people seen at the outpatient dementia clinic between 1982 and 1984 had mild dementia at the time of their initial visit; by the time of their last followup (2 to 4 years after their initial visit), about half of these 53 patients had died (9 percent) or been put in a nursing home (41 percent), and half were still living at home. Of those still at home, 32 percent, or 13 percent of the original sample, were using either adult day care or in-home nursing services.
5. A 1986 survey conducted for OTA of 569 family caregivers of people with dementia found that 11 percent of the caregivers were using paid companion or home health aide services at the time of the survey, and 21 percent had used them in the past but were not using them at the time of the survey (926). Eight percent of the caregivers were using visiting nurse services at the time of the survey, and 17 percent had used them in the past. Four percent were using adult day care services, and 6 percent had used them in the past. Three percent were using respite care services, and 5 percent had used them in the past.
6. A study of 117 individuals with dementia who were assessed from March to July 1987 by the Alzheimer's Project of Kennebec Valley, Maine, found that 11 percent of these individuals were using respite/adult day care, 11 percent were using homemaker services; 4 percent were using "hired help"; 4 percent were using a personal care attendant; and 3 percent were using a nurse assistant (223).
7. An analysis of data on 453 individuals with dementia seen at California's six Alzheimer's Disease Diagnostic and Treatment Centers in 1987 found that two-thirds of these patients had used physicians' services in the previous 6 months (227). Only 10 percent or fewer of the patients had used home health aide, homemaker/chore, or adult day services in that period.
8. A study of 213 family caregivers of individuals with dementia in Michigan found that while 63 percent of the patients had used physicians' services in the previous 3 months, fewer than one-third had used home health aide services (30 percent), visiting nurse services (18 percent), adult day services (14 percent), housekeeping services (8 percent), or respite care services (7 percent) (774). Moreover, many of the caregivers who had used a service had used it very few times. The researchers compared service use by people with dementia from this study and service use by people with stroke and other diagnoses (e.g., cardiovascular and renal diseases) from other studies and found that although the people with stroke and other diagnoses were only slightly more impaired than the people with dementia in terms of activities of daily living (ADLs) and instrumental activities of daily living (IADLs), the people with stroke and other diagnoses used in-home and community services two to three times more frequently (255).
9. A 1983-84 study that compared the amount of care received by 20 elderly people who had moderate to severe dementia and 20 elderly people who had moderate to severe physical impairments found that, on average, the people with dementia received less than half the amount of paid services received by the people with physical impairments (7.5 hours per week v. 16 hours per week of paid services, respectively) (71).
10. In a 3-year respite care demonstration project conducted by Duke University in North Carolina, families of people with dementia were offered two types of respite care: in-home respite or overnight care of the patient in a nursing home (291). Although the respite care was provided regardless of a family's ability to pay, only a small percentage of the families eligible for the respite services used them. Furthermore, many of the families in this study waited until just prior to the patient's death or placement in a nursing home to use respite services: about half of the people with dementia who received respite services died or were placed in a nursing home within 8 months of first receiving the services, and half of those individuals died or were placed

in a nursing home within 30 days of first receiving the services.<sup>3</sup>

11. In a 1-year respite care demonstration project conducted by the Philadelphia Geriatric Center, over 300 families of people with dementia were offered three types of respite care: 1) in-home respite care, 2) adult day care, and 3) overnight nursing home care. About half of these families used the respite services offered—35 percent used in-home respite care, 2 percent used adult day care, 7 percent used overnight nursing home care, and 8 percent used more than one type of respite care. Most of the families who used respite services used very few hours: during the year, only about one-third of the families who used in-home respite care used more than 100 hours of this type of care; families who used adult day care used an average of only 10 days of such care, and families who used overnight nursing home care used an average of only 11 nights of such care (88,448).

As noted earlier, these 11 studies are not directly comparable because of differences in the time period and services covered, the source of the study sample, and the severity of the subjects' dementia. Nevertheless, the following general conclusions can be drawn from the studies' findings:

- only about one-fourth to one-half of all noninstitutionalized people with dementia use any paid in-home or community services other than physicians' services;
- among those noninstitutionalized people with dementia who do use services, many use very few services or use them infrequently;
- many noninstitutionalized people with dementia who do use services use them very late in the course of their disease; and
- on average, noninstitutionalized people with dementia use fewer paid services than noninstitutionalized people with physical impairments.

The percentage of people with dementia who use nursing homes in the course of their dementing illness is not known. The 1986 survey of 569 family caregivers conducted for OTA (study #5 above) found that half of the individuals with dementia

being cared for had been in a nursing home at some time in the course of their illness, including 36 percent who were in a nursing home at the time of the survey and 15 percent who had been in a nursing home previously but were not at the time of the survey (926). The five other studies cited above that included nursing home residents found that as few as 3 percent to as many as 33 percent of the individuals in their samples were in nursing homes (223,227, 242,479,774).<sup>4</sup> The wide range in these figures reflects differences in the source of the sample and the time frame of the studies and differences in Medicaid regulations, bed supply, and other factors that affect the number of people with dementia in nursing homes in different States.

The 1985 National Nursing Home Survey found that 620,000 nursing home residents—47 percent of all elderly nursing home residents—had senile dementia or chronic organic brain syndrome (846). That survey also found that 830,000 nursing home residents—63 percent of all elderly nursing home residents—were so disoriented or memory-impaired that their performance of the activities of daily living, mobility, and other tasks was impaired nearly every day. Using these figures from the National Nursing Home Survey and OTA's estimates of the prevalence of dementia nationwide,<sup>5</sup> one could estimate that from 9 to 33 percent of Americans with dementia are in nursing homes at any one time. The wide range in that estimate reflects uncertainty about the percentage of nursing home residents with dementia (e.g., 47 to 63 percent) and uncertainty about the prevalence of dementia.

### **PERSONAL FACTORS THAT MAY INTERFERE WITH INDIVIDUALS' ABILITY OR WILLINGNESS TO USE SERVICES**

There are many reasons why some people with dementia and some caregivers do not use services. As discussed in chapter 2, researchers performing a study for OTA in Cuyahoga County, Ohio, asked 26 caregivers of people with dementia to give their opinions about why people do not use services (186).<sup>6</sup> The reasons most frequently identified by

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<sup>3</sup>See box 3-A for further discussion of the Duke University Respite Care Demonstration Project.

<sup>4</sup>The specific estimates by study were 3 percent (223,227,774); 28 percent (242); and 33 percent (479).

<sup>5</sup>In 1987, OTA estimated that 1.5 million Americans had severe dementia, and 1 to 5 million had mild or moderate dementia (831).

<sup>6</sup>For more information on the study conducted for OTA in Cuyahoga County, OH, see app. A.

these caregivers were people's lack of knowledge about services and people's inability to afford services. In addition, many of the caregivers said that certain characteristics, feelings, and perceptions are barriers to service use for people in general and were reasons they did not use services themselves. The reasons these caregivers identified are listed in table 3-2.

Researchers in the study conducted for OTA in Cuyahoga County, Ohio, also asked 24 representatives of community agencies that provide services for people with dementia to identify barriers that kept people with dementia and their caregivers from using services (186). As noted in chapter 2, all 24 agency representatives said that their clients' lack of knowledge about available services was often or occasionally a barrier to the use of services, and most (87 percent) of them said that their clients' lack of financial resources to pay for services was often or occasionally a barrier. In addition, many of the agency representatives said that the following personal characteristics, feelings, and perceptions were often or occasionally barriers to service use:

- clients' desire to remain independent of the formal care system (identified by 91 percent of the agency representatives);
- clients' lack of recognition that they need formal services (identified by 96 percent of the agency representatives);
- clients' inability to arrange services once they know the services are available (identified by 88 percent of the agency representatives);

- clients' feeling that the recommended service was not needed (identified by 84 percent of the agency representatives);
- clients' feeling uncomfortable about using recommended services (identified by 76 percent of the agency representatives);
- clients' unwillingness to pay for services even though they are judged to have adequate financial resources (identified by 58 percent of the agency representatives); and
- clients' feeling that others will disapprove of their use of services (identified by 41 percent of the agency representatives) (186).

In the analysis that follows, OTA identifies the personal factors—i.e., characteristics, feelings, and perceptions—that may interfere with the ability or willingness of some individuals with dementia or their caregivers to use available services. A later section of the chapter discusses the implications of these patient and caregiver characteristics, feelings, and perceptions for an effective linking system.

### *Personal Factors Related to Individuals With Dementia*

Most studies and commentaries about people's characteristics, feelings, and perceptions that may limit their use of services pertain to family caregivers. Relatively little has been written about characteristics, feelings, and perceptions of individuals with dementia that may limit their use of services. At least 20 percent of people with dementia live alone, however, and up to half of these individuals have no family member or other informal caregiver to help them (see ch. 1). Such

Table 3-2--Caregivers' Opinions About People's Characteristics, Feelings, and Perceptions That Are Barriers to the Use of Services, Cuyahoga County, Ohio, 1988 (N = 26)

| Possible barriers to the use of services  | How often is it true for people in general? | Is there a reason you did not use the services? |
|---|---|---|
|   | usually<br>(in percent)                     | Yes<br>(in percent)                             |
| People know what services are available but don't know how to make arrangements to use them . . . . . | 42  | 50  |
| People don't think they need the services recommended to them . . . . .                               | 38  | 50  |
| People don't use the services because they do not want to lose their independence . . . . .           | 38  | 19  |
| People don't recognize the fact that they need services. . . . .                                      | 33  | 42  |
| Using services makes people feel uncomfortable . . . . .  | 27  | 31  |
| People are afraid others will not approve if they use services. . . . .                               | 19  | 19  |
| People have money but are not willing to pay for services. . . . .                                    | 12  | 8   |

SOURCE: S. Eckert and K. Smyth, "Methods of Locating and Arranging Health and Long-Term Care Services for Persons With Dementia," contract report prepared for the Office of Technology Assessment, U.S. Congress, Washington, DC, 1988.

individuals make decisions about services for themselves—either explicitly or implicitly—unless a case manager, service provider, or other health care or social service professional makes the decisions for them,

OTA's analysis of characteristics, feelings, and perceptions of individuals with dementia that may interfere with their ability or willingness to use available services is based primarily on two sources:

- . case managers' responses to an exploratory study conducted for OTA in five Pennsylvania AAAs (934); and
- . OTA's informal discussions with case managers, health care and social service professionals, and others, including members of the advisory panel for this study.

All of the case managers and other professionals just mentioned emphasized that many of their clients with dementia live alone and have no one to help them with decisions about services. They noted that clients who live alone with no one to help them are generally more isolated and more resistant to using services than people with dementia who have an informal caregiver to assist them.

Individuals with dementia vary greatly with respect to their cognitive and self-care abilities, emotional and behavioral characteristics, and other characteristics (e.g., age, ethnicity, socioeconomic status, and coexisting physical conditions) that are largely unrelated to their dementia. As an individual's dementing illness progresses, some of these characteristics change in ways that affect the individual's attitudes about services. It is important to point out, therefore, that although some people with dementia have the characteristics, feelings, and perceptions discussed below, not all people with dementia have them. Furthermore, people with dementia who have them at one time do not necessarily have them at another.

1. Some people with dementia do not know that they need services.

Because of lack of judgment, other cognitive deficits associated with dementia, or denial, some people with dementia are not aware of their own limitations. Consequently, they may not know they need services (487,934).

2. People with dementia are unlikely to know about potentially helpful services.

Because of loss of memory and diminished ability to learn new information, many people with dementia cannot remember or learn about potentially beneficial services (934). People with dementia who live alone and have no informal caregiver are both physically and emotionally isolated. Even if they are cognitively able to learn about services, such individuals may not receive the necessary information.

3. Many people with dementia are not able to arrange services for themselves.

Because of cognitive deficits associated with dementia, people with dementia are unlikely to be able to remember or find the names and telephone numbers of service providers. They may not understand or remember what they are told about eligibility requirements, cost, reimbursement, and other factors. They may not be able to give service providers information the providers need to initiate services. Some people with dementia cannot communicate clearly with providers. Some forget what they are trying to do before the service arrangements are complete.

4. Some people with dementia do not want anyone to know about their cognitive and other deficits and may isolate themselves and refuse services for that reason.

At least in the early stages of dementing diseases, some people with dementia are ashamed of their memory loss and other impairments associated with dementia and try to conceal those impairments from other people to avoid embarrassment (535). Some people try to conceal their cognitive and other impairments because they are afraid that if the impairments are recognized, other people will try to take control of their lives (456). Anecdotal evidence indicates that some people with dementia isolate themselves completely, because they are afraid that if anyone finds out how poorly they are managing, they will be placed in a nursing home.

5. Some people with dementia are afraid of being exploited by service providers and may not use services for that reason.

Because of their memory impairment and lack of judgment, people with dementia are easily exploited by anyone who interacts with them (40,286). Many people with dementia have been, or fear they will be, exploited by service providers, especially nonprofessional in-home workers (934). For that reason, they may be reluctant to use services.





Photo credit: Bill Adams

**Some people with dementia who live alone and have no relative or friend to help them refuse services because they are afraid of being exploited by service providers or afraid that if anyone finds out how poorly they are managing, they will be placed in a nursing home.**

In addition, research indicates that one-fourth to one-half of people with Alzheimer's disease are paranoid. Beliefs that other people are stealing their possessions or planning to harm them are common (295,429,525,728,787). Realistic fears about exploitation may exacerbate an individual's paranoia, thus increasing his or her reluctance to use services.

6. Some people with dementia have realistic or unrealistic concerns about money that make them reluctant to use services.

People with dementia who live alone and have no relative or friend to help them may have both realistic and unrealistic concerns about money that make them reluctant to use services. On average, elderly people who live alone have less income than elderly people who live with someone else (687,838). Realistically, therefore, these individuals may not be able to afford services.

Some people with dementia whose memory for events in the distant past is better than their memory for events in the present may compare current prices with prices they remember from long ago and refuse to pay even very reasonable amounts for services because they think they are being overcharged. If no one else is legally empowered to spend the individual's money (e.g., through guardianship, conservatorship, or a durable power of attorney), a person

with dementia can effectively refuse services by refusing to pay for them (181).

### ***Personal Factors Related to Informal Caregivers***

Many studies and commentaries identify characteristics, feelings, and perceptions of family members and other informal caregivers that may interfere with the caregivers' ability or willingness to use available services. The analysis that follows draws on those studies and commentaries.

Not all informal caregivers of people with dementia have the characteristics, feelings, or perceptions that are discussed in this section. Nor are caregivers' feelings and perceptions necessarily consistent, clearly defined, or differentiated. Moreover, caregivers' feelings and perceptions change over time. If and when caregivers have the following characteristics, feelings, or perceptions, however, they are likely to be reluctant to use services.

1. Some caregivers do not regard the individual with dementia as being sick or having a disease and therefore do not perceive a need for services.

Some caregivers do not acknowledge a patient's confusion and unusual behavior (if any). Some ascribe the person's symptoms to normal aging. Others believe the symptoms are under the person's control-saying, for example, "If she paid attention, she wouldn't be so forgetful," or "He just does that to annoy me" (88). The fluctuating nature of cognitive and other deficits associated with dementing diseases and the lack of overt physical signs of many of the diseases make it easy for caregivers not to acknowledge that an individual has a dementing disease, especially in the early stages of the disease (286,643,936).

If a caregiver does not acknowledge that the person with dementia is sick or has a disease, the caregiver is unlikely to perceive a need for services. Ironically, some caregivers seem to resist using services because doing so would require them to admit to themselves that their relative has a dementing disease and may not recover (936).

2. Some caregivers believe that the family is morally obligated to provide all needed services for a person with dementia and that it is wrong to turn to agencies or outsiders for help.

Probably most people believe that families are to some degree morally obligated to take care of their members. Family caregivers of people with dementia frequently express this sense of obligation. Some feel that they must take care of their spouse, parent, or other relative with dementia to repay that person for taking care of them in the past. Spouse caregivers sometimes regard caregiving as a fulfillment of their marriage vows or other solemn pacts they made with their spouse. Adult children may have promised their parents to take care of them in old age (291,514,669). Whatever the source of their sense of obligation, violating it can cause intense and prolonged feelings of guilt (514,670,933). These feelings probably arise most often when family members place the patient in a nursing home, but some caregivers also feel guilty about leaving the patient at home with a home health aide or homemaker or at an adult day center (514). The fact that in caring for a person with dementia, there are few required skills that family caregivers do not have (or believe they have) makes some caregivers feel even more guilty about using services that they could—at least in theory—provide themselves.

Because of different societal expectations about the appropriate roles of men and women, women are more likely than men to feel obligated to provide all the patient's care themselves (85,669,936). Likewise, certain ethnic and social groups are more likely than others to believe that families—and sometimes specific family members—are obligated to provide all the patient's care themselves and that it is wrong to use paid services (330).

One might expect that family caregivers who have had a difficult relationship with the patient in the past or who feel angry or frustrated about aspects of the caregiving situation would feel less obligated to provide all the patient's care themselves, but research and anecdotal evidence indicate that the opposite is often true. Some of these caregivers feel guilty about their negative emotions and consequently redouble their efforts to provide all the person's care themselves (88,96,137,272,535,936).

3. Some caregivers do not feel burdened by caregiving tasks that seem extremely burdensome to other people. Caregivers who do not feel burdened are unlikely to perceive a need for services.

Caregiver burden has been defined and studied in terms of: 1) patient characteristics and behaviors that create demands on the caregiver; 2) the caregiver's subjective experience of those demands; and 3) the objective impact of caregiving on the physical and mental health, social participation, and financial status of the caregiver (932). Research has found a surprising lack of correlation between patient characteristics and behaviors that create demands on the caregivers and the caregiver's subjective experience of those demands (244,643,668,938). Some caregivers' subjective experience of burden is lower than might be expected given the objectively difficult caregiving situations they face (241,937). Moreover, many families have positive feelings about caregiving and pride in their ability to manage difficult caregiving situations (125,242,448,514,555,643).

To note the positive feelings of some caregivers and the lack of correlation between patient characteristics and behaviors and caregivers' subjective feelings of burden is not to suggest that caregivers of people with dementia are not burdened. In fact, research indicates that caregivers of people with dementia experience more subjective feelings of burden and more negative consequences of caregiving (e.g., increased use of alcohol and psychotropic drugs and reduced participation in social activities) than caregivers of other elderly people or other comparison groups (71,242,291,296,411,415,610,612). The intent here is simply to emphasize the diversity of caregivers' subjective experience of the demands of caregiving.

Many factors mediate between patient characteristics and behaviors that create demands on a caregiver and the caregiver's subjective experience of burden and explain some of the lack of correlation between them. These factors include the age and sex of the caregiver; the caregiver's relationship with the patient; whether the caregiver is employed; and whether the caregiver lives with the patient. Duke University's studies indicate, for example, that male (primarily spouse) caregivers of people with dementia experience less subjective burden than female caregivers (291). Although older spouse caregivers are generally more objectively burdened, younger adult child caregivers experience more subjective burden (291). Employed caregivers generally experience less subjective burden than unemployed caregivers (86,198,242), but caregivers who quit work or reduce their hours because of caregiving

responsibilities experience more subjective burden than other caregivers (86).

Caregivers' appraisals of patient characteristics and behaviors affect whether they experience the characteristics and behaviors as burdensome (297, 487, 533, 649, 938). Anecdotal evidence suggests, for example, that caregivers who view a patient's confusion and unusual behaviors as a direct consequence of a disease are generally less bothered by them than caregivers who view the same problems as in the patient's control. Caregivers' use of certain coping mechanisms, such as seeking information, problem solving and emphasizing positive feelings is associated with less subjective experience of burden (295, 487, 610, 649, 938). Lastly, the amount of social support provided by relatives, friends, and voluntary associations seems to be associated with the caregiver's subjective experience of burden (242, 297, 487, 610, 749, 936, 937), although some studies suggest that it is the caregivers' perception of social support, rather than the actual amount of support received, that correlates with their subjective experience of burden (291).

Three general hypotheses have been proposed about how family caregivers' subjective experience of burden changes over time (293). The 'wear-and-tear hypothesis' suggests that the longer the period of caregiving, the greater the caregiver's subjective experience of burden. The "adaptation hypothesis" suggests that caregiving initially involves new demands for which the caregiver is unprepared, but that as time passes, the caregiver develops ways of meeting the demands and is less burdened. The "trait hypothesis" suggests that caregivers' experience of burden remains the same despite changes in the patient's condition and the passage of time.

Caregivers' subjective experience of burden has been shown to predict service use (291). Caregivers who do not feel burdened are unlikely to perceive a need for services even if their caregiving situations seem burdensome to others.

4. Caregivers who have devoted themselves to the care of the patient, often for years, sometimes find it difficult to "give up" and use paid services.

Caring for a person with dementia is an objectively difficult task that takes caregivers away from other interests, activities, and relationships. To function in this role for a prolonged period, care-

givers may have to commit themselves to it single-mindedly, not allowing themselves to question what they are doing or to focus on the negative aspects of caregiving. In this state of mind, they may regard the use of services as "giving up" and resist it for that reason.

The feeling that using paid services constitutes "giving up" often occurs in the context of nursing home placement (96). One 76-year-old woman who placed her husband, who had Alzheimer's disease, in a nursing home described that feeling as 'the trauma of finally having to accept the fact that you cannot care for him any longer' (670). Some family caregivers also regard the use of in-home and community-based services as "giving up," sometimes because they regard the use of these services as the first step toward nursing home placement (88, 186).

5. Some caregivers are reluctant to use services because they fear the disapproval of relatives or friends.

Family caregivers who have come to accept the need for services still may not use services because they fear criticism from others. This often occurs when one family member, particularly the spouse or an adult child, has provided all the patient's care. Other relatives and friends who have been uninformed may not be aware of changes in the patient's cognitive ability and behavior or of the difficulty of caring for the person. The primary caregiver may not have told them about the problem, or they may not have been willing or able to acknowledge it. In either case, they do not understand the need for services and may criticize the primary caregiver for shirking his or her obligation to the patient by using paid services. Such criticism, or even the anticipation of it, compounds the caregiver's guilt feelings and discourages him or her from using services (514, 936).

6. Some caregivers are too overwhelmed with various feelings to think clearly about how services might benefit them or the patient.

Alzheimer's disease and other diseases that cause dementia create devastating losses for the patient and patient family. Every account of these diseases by the spouses and adult children of patients conveys the sadness and trauma for the family of witnessing the deterioration of their relative with dementia and losing meaningful aspects of their relationship with the person. In addition, problems associated with

caregiving often cause feelings of frustration and anger. Changing roles and responsibilities within a family due to the incapacity of one family member cause feelings of anxiety and resentment. Some caregivers feel ashamed of their negative emotions, guilty for not doing more for the patient, and depressed about their own lives and the caregiving situation. Some are so overwhelmed by these feelings that they cannot think clearly about how to solve their problems (39,88,129,137,201,535,610,916,936).

Many caregivers become physically and emotionally isolated from other people because of their caregiving responsibilities. Because of that isolation, they may assume that they are the only ones who have negative feelings. Family counseling and family support groups often help caregivers understand that other caregivers have similar feelings (88,137,256,272,933,936). For some caregivers, that understanding is the first step in coming to terms with their own feelings so that they can begin to think clearly about their caregiving problems and consider possible solutions, including the use of services.

7. Some caregivers do not use services because they are unable to arrange the services.

Eighty-eight percent of the agency representatives and 73 percent of informal caregivers interviewed in Cuyahoga County, Ohio, said that people's lack of knowledge about how to arrange services is a barrier to their use of services for people with dementia. One half of the caregivers said that not knowing how to arrange services was a reason why they did not use services (186).

The complexity and fragmentation of services in many communities makes it difficult for anyone to arrange services (see ch. 2). If a person with dementia has physical or other problems in addition to dementia and so requires services from several different providers, the task of arranging and coordinating the needed services can be extremely difficult. Because of the constant demands of caring for "Person with dementia, some caregivers have neither the time nor the energy to arrange services. Language and cultural differences limit some caregivers' ability to arrange services. In families in which the person with dementia was the "organizer" or "arranger" prior to his or her illness, the family member who has become the caregiver may have no experience in these roles.

Some people with dementia have a primary caregiver, who provides most of their care, and other relatives and friends who provide occasional assistance. These "secondary caregivers" sometimes help to arrange services. In 1986, 57 percent of family members who were first-time callers to a California agency that provides information about services for brain-impaired adults were not the primary caregivers (199). Likewise, a study of 25 families of persons with Alzheimer's disease who had a secondary caregiver found that the secondary caregiver sometimes helped by arranging appointments and handling legal and financial matters, in addition to providing respite for the primary caregiver (749). Anecdotal evidence suggests that because secondary caregivers often help to arrange services, people with dementia who have a secondary caregiver are more likely than other people with dementia to receive formal services (483).

8. Some caregivers do not use services because they do not believe the services will help.

Family members and other informal caregivers usually focus on the needs of the patient. Some caregivers fear, often with good reason, that the patient will be upset by any new service provider or new service setting, or that the patient will feel abandoned. Moreover, caregivers often are skeptical about service providers' capability to care for their relative with dementia and fearful that the patient may be abused or neglected. As a result, some caregivers conclude that services will not benefit the patient (88,117,291,670,936).

Caregivers who consider their own needs still may conclude that services will not help because the patient may be more agitated and difficult for them to take care of afterwards than he or she otherwise would have been. For some caregivers, services such as adult day care that require the caregiver to dress the patient and take him or her to another setting are more trouble than they are worth. Lastly, some caregivers anticipate, sometimes correctly, that they will not be able to enjoy the time away from their caregiving responsibilities because of guilt about leaving the patient with strangers and worry about the quality of care he or she is receiving. Caregivers who have a bad experience with one service or service provider for any of these reasons often are reluctant to try again (88,186,291,533,936).

9. Some caregivers do not use services because they are embarrassed about the patient's behavior.

Because of the stigma associated with mental illness in our society, families of people with dementia often are embarrassed by patient behaviors, such as hallucinations, delusions, and agitation, that suggest the patient is mentally ill. Families of people with dementia who are verbally or physically aggressive also may be embarrassed by these behaviors (72,291,533,936). Some caregivers try to conceal the behaviors from other people in order to protect themselves and the person with dementia from potential embarrassment. They may choose not to use services for this reason.

10. Some caregivers do not use services because they do not want service providers in their home.

Some caregivers are reluctant to use in-home services because of the loss of privacy and control that using such services may entail (450). One caregiver may not want a "bossy" homemaker or home health aide in his or her home. Another caregiver may not want to "share the kitchen" with an in-home service provider. Still another caregiver may be afraid that the service provider will notice that the caregiver has a substance abuse problem or some other problem that the caregiver would prefer to conceal.

11. Some caregivers feel uncomfortable about making decisions for the patient, including decisions about the use of services.

Informal caregivers may be reluctant to assume authority for decisions for the patient (39,669). One study that compared the caregiving styles of husbands and wives of people with dementia (533) found that husbands generally were more comfortable than the wives about assuming control of decisions for their cognitively impaired spouse. The wives worried about their husbands' reactions to the decisions they made and to their assumption of decisionmaking authority. Anecdotal evidence suggests that some adult children of people with dementia also are troubled by taking over decision-making authority for their cognitively impaired parent.

Because of one or more of the characteristics, feelings, or perceptions discussed in this section, some caregivers never use paid services for their

relative with dementia. Other caregivers eventually use services, but not until long after the time when an objective observer would have said they needed help.

The results of the Duke University Respite Care Demonstration Project, mentioned earlier in this chapter and described in box 3-A, emphasize the extent of some family caregivers' reluctance to use services and the tendency of some family caregivers to put off using services for as long as they can, even when the services are available, affordable, and specifically designed to respond to the caregivers' needs and preferences (291). Some of the features of the Duke Respite Care Demonstration Project that were at least partially successful overcoming caregivers' reluctance to use services are described in box 3-A.

The objectives of respite services are to prevent or reduce caregiver burden, to increase the effectiveness and quality of caregiving, and to prolong caregivers' ability to provide home care for their impaired relatives. These goals cannot be met if caregivers delay using services until just before the person with dementia dies or is put into a nursing home. Thus, a major conclusion of the Duke Respite Care Demonstration Project, in the opinion of its directors, was that ways must be found to encourage caregivers to use services on a timely basis (291).

One of the stated reasons why caregivers who were eligible for respite services in the Duke project did not use them or waited so long to use them was the cost of the services. Interestingly, however, their primary concern was not about current costs but about future *costs* (291). Caregivers participating in the project were charged for the respite services on the basis of self-perceived ability to pay—i.e., they were told the hourly cost for the services, asked what portion of the hourly rate they could pay, and charged that amount. Subsidies were available for up to \$40 a week for 20 families per site. Overall, the caregivers paid only 20 percent of the cost of the services, and many families received totally subsidized care. Some caregivers wanted more respite services than they received but felt they could not afford the cost of services above the \$40 per week cap on subsidies. These caregivers had no idea how long care would be needed for their relative with dementia, and many of the older spouse caregivers knew that they would have to spend most of their assets before Medicaid would pay for nursing home

***Box 3-A—Findings From the Duke University Respite Care Demonstration Project  
Regarding Family Caregivers' Reluctance To Use Services***

From 1985 through 1987, Duke University conducted a respite care demonstration project in four counties in North Carolina. In earlier Duke studies, family caregivers of people with dementia had said they needed respite services to provide temporary relief from the constant care and supervision of their relative with dementia. The caregivers had said they wanted in-home respite services provided by individuals who were knowledgeable about the care of people with dementia. They wanted services that would be inexpensive or subsidized and that would be available at night and on weekends, as well as on weekdays.

The Duke Respite Care Demonstration Project was designed to respond to these caregiver preferences. Respite care was provided by nursing assistants who volunteered for the project and were trained by Duke University staff to care for people with dementia. The respite services were available weekdays, nights, and weekends. To be eligible for the services, an individual with dementia had to live in one of the four counties served by the project and had to have a memory impairment severe enough so that he or she could not stay alone safely.

Over the 3-year period of the demonstration project, 100 families received respite services. Families used services for an average of 8 months and received an average of 8 hours of respite care per week. Although more than 95 percent of the families who used the services reported that they were helpful, only a small portion of the families who were potentially eligible for the services used them. Moreover, 50 percent of the individuals with dementia who received respite services through the project died or were placed in a nursing home within 8 months of entry into the project, and half of those died or were placed in a nursing home within 30 days of entry into the project. Some families used the respite services as a stopgap measure while they waited for a nursing home bed for the patient. Indeed some families waited so long to ask for help that a hospice model of care would have been more appropriate for the patient than the companion-type respite services provided by the demonstration project.

Several features of the demonstration project were at least partially successful in addressing caregivers' concerns about the use of services. The training provided for the respite workers reassured caregivers that the respite workers could care for people with dementia effectively. The training was unique in that it was open to anyone, and prospective client families were encouraged to attend. This open training offered families a preview of the workers and their skills and created a sense of trust between the workers and the families.

The flexibility of the respite services that were offered and the workers' responsiveness to the needs of both the patients and their families also helped to overcome some caregivers' reluctance to use respite services. Respite workers performed housekeeping, meal preparation, personal care, and other functions. They also took patients and their caregivers to the doctor or beauty shop and provided companionship for the caregiver as well as the patient. Because the demonstration project considered the family unit as the client, caregivers were accepted as legitimate recipients of care.

The nurses who supervised the respite workers and functioned as case managers for the patients and families were another strength of the Duke project. During their monthly visits to monitor the respite services, the nurse supervisor/case managers provided a variety of services for the patients and caregivers, including screening caregivers for high blood pressure and other health problems, reviewing and revising the patient plan of care, and providing individualized teaching and counseling. As caregivers developed a trusting relationship with a nurse supervisor/case manager, they became more open to referrals, and many increased their use of other community services,

The willingness of the nurse supervisor/case managers **to accommodate** patients' and caregivers' preferences with respect to respite workers also helped to overcome caregivers' reluctance to use services. Although all the respite workers had similar training, some patients and families had strong positive or negative responses to certain workers. Sometimes it was the worker's gender, age, beliefs, race, or appearance that prompted these strong reactions. When the nurse supervisor/case managers assigned respite workers in accordance with patients' and caregivers' preferences, the patients and caregivers were more comfortable with the services. Some caregivers fear that accepting any outside help means relinquishing family control to strangers. Having the nurse supervisor/case managers acknowledge their preferences with respect to respite workers reassured caregivers that they were still in control.

The dependability and continuity of respite services were important to caregivers in the Duke study. Caregivers came to cherish their time off, and tardiness or absence of the worker was disappointing. For some caregivers, it was easier not to plan on time off than to plan the time and be disappointed. Continuity of respite workers was also critical to caregivers' acceptance of services. With too much turnover of assigned respite workers, some families lost adaptive energy and stopped using the services.

One important finding of the Duke demonstration project was that many caregivers of individuals with dementia can accept respite services more easily if the services are presented as being for the patient rather than the caregiver. At the beginning of the project, the respite services were promoted as providing relief for caregivers. It quickly became apparent that many caregivers were reluctant to spend money for relief for themselves when faced with the deterioration of a family member. When the initial approach was changed, and the respite services were presented in terms of their potential benefits for patients, caregivers responded more enthusiastically.

Many of the family caregivers in the Duke project considered the use of services more acceptable if the services were connected to the health care system rather than to the social service system. Social services seemed to have a 'charity stigma' that was troublesome to some caregivers. Moreover, some caregivers who believed that their relative was 'sick' seemed to prefer that recommendations about services be made by a physician rather than a social worker.

In 1988, Duke University began another 3-year demonstration project to test an intervention intended to facilitate the timely use of all kinds of services for people with dementia. This new project is based in a health care setting (an outpatient memory disorders clinic) because of the previous project's findings that caregivers prefer health-related services. Clinic physicians refer caregivers to social workers who are knowledgeable about services for people with dementia. The social workers then develop an individualized service plan with the caregiver and facilitate and monitor the plan over an 18-month period.

SOURCE: L.P. Gwyther, "Barriers to the Appropriate Use of Community-Based Services by Families of Persons With Dementia," contract report prepared for the Office of Technology Assessment, U.S. Congress, Washington, DC, June 1988.

care. Given these concerns about future costs, many of the caregivers felt they could not afford even \$10 a week for respite services.

### ***Implications for an Effective System To Link People With Dementia to Services***

The characteristics, feelings, and perceptions discussed in the preceding sections stop some people with dementia and some caregivers from using services. Some of these individuals probably do not need the services, but others do. For example, some caregivers who say that they do not need services or that they do not need services "yet" actually do need services for their own well-being and for the well-being and safety of the patient (88,514). It is unclear whether or to what extent caregivers should be encouraged to use services the caregivers say they do not want or need. On the one hand, encouraging people who say they do not want services to use them seems absurd when there are not enough services to meet the needs of people who are asking for them. On the other hand, some commentators have noted that it is often the most isolated and objectively burdened caregivers who say they do not want or need services (88,291,418,688). Likewise, some people with dementia who refuse services, or

are unaware that they need services, or are unable to arrange services are very confused, afraid, and perhaps in physical danger because of their dementia.

Everyone has a different opinion about who needs services, but there is little question that some people with dementia and some caregivers who do not use services for any of the reasons discussed in the preceding sections do in fact need services. Improved public education and information and referral programs might make it possible for some of these individuals to contact service providers on their own, but some patients and families still would not be willing or able to do so. For this reason, OTA concludes that in addition to public education and information and referral, outreach and case management are essential components of an effective system to link people with dementia and their caregivers to services.

### **The Need for Outreach**

Outreach is defined in this OTA report as any active, individualized method of identifying people who need services but are unlikely to respond to public education programs or to contact an informa-

tion and referral source on their own.<sup>7</sup> Outreach may be needed for people with dementia who live alone and have no relative or friend to help them; these individuals are particularly unlikely to request services on their own. Outreach also maybe needed for overburdened caregivers who are not connected to a community agency or individual health care or social service provider. It is not clear how many patients or caregivers are included in these categories. It is clear, however, that the best possible public education and information and referral programs would not be effective in linking many of these individuals to services.

Outreach to identify people with dementia who are in need of services can take any of several forms. One way to conduct outreach is to screen individuals at places like senior centers and senior nutrition sites. Another way is to have health care and social service professionals and other service providers who interact with elderly people and their families identify people with dementia who may need services.

Although the two methods of outreach just mentioned would reach some people with dementia and their caregivers, neither approach would reach isolated patients and caregivers who do not go to senior centers' or senior nutrition sites and who do not interact with health care and social service professionals or other service providers. A third method of outreach is to send paid or volunteer workers out specifically to look for potential clients (97). Although this method has been successful in reaching people with various kinds of service needs who would not have been reached otherwise, the method requires a major commitment of resources by the sponsoring agency and is therefore difficult to sustain for long periods of time.

An outreach method that can be sustained over time and is likely to reach isolated people with dementia and isolated caregivers is a "gatekeeper program" that makes use of the observations of individuals such as mail carriers and utility meter readers who come into contact with many individuals in the course of their regular daily activities. The gatekeeper programs that have been implemented in

Spokane, Washington, several rural counties in Iowa, and in other jurisdictions offer models for outreach that closely match the needs of isolated people with dementia and their caregivers (97, 148,456,688)<sup>8</sup>. The Spokane program recruits mail carriers, utility meter readers, and other individuals who interact with many people in the course of their regular activities and trains them to identify isolated elderly people who may need assistance and to notify a central agency. In addition to mail carriers and utility meter readers, gatekeepers may include apartment managers, police, pharmacists, grocers, delivery persons, and others. To become gatekeepers, these individuals do not have to become case workers or counselors; they do have to be trained to notice signs that an elderly person is confused, ill, or otherwise at risk. When a gatekeeper identifies an individual who seems to be at risk, the gatekeeper phones a central agency. The central agency takes responsibility for contacting the person and assessing his or her need for assistance.

#### The Need for Case Management

The term case management is used in a wide range of contexts, and its precise meaning is often unclear. Many commentators agree, however, that case management includes the five functions shown in table 3-1—namely, assessing a client's needs, developing a plan of care, arranging and coordinating services, monitoring and evaluating the services delivered, and reassessing the client's situation as the need arises (22,43,59,110,271,382,572,574,58 1, 657,757,769,891,902). As defined by OTA in this report, case management is a process that includes these five functions.

Individuals with dementia who are likely to need case management include those who live alone and have no relative or friend to help them and those whose relatives live too far away to monitor their care or reevaluate their needs on a regular basis. Case management is also likely to be needed by some individuals with dementia who have an informal caregiver, including those whose caregivers are unable to define their service needs, reluctant to use needed services, or unable to arrange services for any reason. Because of the complexity and fragmen-

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<sup>7</sup>Some agencies and commentators use the term outreach in a sense that is different from the sense in which it is used by OTA in this report. They use it to refer to programs or services that an agency provides outside the agency. Some of these programs and services—e.g., lectures given by agency staff members to senior citizens, caregiver support, and other community groups—me effective in reaching some people with dementia and their caregivers but are unlikely to reach isolated, confused patients or isolated caregivers. In the context of OTA's model in this report, such programs and services are considered public education.

<sup>8</sup>The gatekeeper program in Spokane, WA, is described further in box 8-C in ch. 8.



tation of services in many communities, individuals with dementia who need several different services are likely to need case management to arrange and coordinate the services of multiple providers. It is not clear how many people with dementia or how many caregivers are included in these categories.

Despite the general agreement about the five case management functions listed earlier, there are many unresolved definitional and practice issues with respect to case management. First, some commentators include other functions-e. g., case finding, screening, patient and family education, and counseling-in their definitions of case management.<sup>9</sup> Second, the implementation of each of the case management functions varies, depending on factors such as the goals and training of the case manager, the number of clients the case manager has, the type of the agency for which the case manager works (if any) and the other functions of that agency, and the extent to which the agency or independent case manager provides services in addition to providing case management. The same factors also influence the relative importance case managers place on different functions. Depending on these factors, for example, one case manager may focus primarily on arranging and coordinating services, spending most of her or his time making arrangements for specific services and less time on assessing the client needs and developing a plan of care. Another case manager may focus more on the assessment and care planning functions, spending most of her or his time talking with patients or caregivers about the problems they are facing and what services, if any, would be helpful.

A third unresolved issue is the relationship between case management as an administrative process and case management as a clinical process. In agencies that allocate services and funding for services, case managers are frequently responsible for "administrative" tasks such as determining people's eligibility for services, authorizing services and funding for services, and monitoring the provision of services. When case managers are responsible for these administrative tasks, the five case management functions shown in table 3-1 are modified to include the tasks. Thus, for example, the function of assessing a client's needs is modified to



Photo credit: Bill Adams

**A method of outreach that closely matches the needs of isolated people with dementia is a "gatekeeper" program that relies on mail carriers and others who have daily interactions with many people to identify elderly people in need of assistance.**

include administrative procedures for determining a client's eligibility for services. The functions of developing a plan of care and of arranging and coordinating services are modified to include administrative procedures for selecting service providers and authorizing benefits. The functions of monitoring the services delivered and of reevaluating the client's needs are modified to include procedures to recertify the client's eligibility for services and to account for the services and funds that are used.

In some agencies that allocate services and funding for services, case management seems to be primarily a series of administrative tasks intended to allocate benefits in accordance with agency or program regulations. In other agencies, case management seems to be primarily a 'clinical' process in which the case manager functions more as a professional helper, counselor, and client advocate than as an administrator of benefits. If it were possible to make a clear distinction between case

<sup>9</sup>In the context of the model for a linking system described in this report, OTA considers those activities that are usually involved in case finding and screening to be part of the public education, information and referral, and outreach components of the system and the assessment function of the case management component of the system. Patient and family education are considered services that maybe needed for people with dementia (see table 1-2 in ch.1). The question of whether counseling should be part of the case management component of a linking system is discussed later in this chapter.

management as an administrative process and case management as a clinical process and call one case management and the other something else, it would be easier for everyone to understand and communicate clearly about case management. In reality, however, that distinction does not hold up. Many case managers who administer benefits for their agencies perceive themselves as professional helpers, counselors, and advocates and perform the five core functions in much the same way as case managers who do not administer benefits.

In a study by the University of Washington, 127 case managers in agencies that allocate services and funding for services in Oregon and Washington State were asked to rate the importance of 11 possible goals of case management (47). All these case managers' jobs involved administrative tasks related to allocating services and funding for services, but the goals they identified as most important had to do with helping and advocacy. Table 3-3 lists the goals of case management in order of their average ranking by case managers in Oregon and Washington. In the view of these case managers, at least, the administrative and clinical aspects of case management are intertwined.

In addition to these definitional and practice issues with respect to case management, there are many other unanswered questions about case management in a system to link people with dementia to services. These questions are discussed in a later section of this chapter.

## WHAT IS SPECIAL ABOUT CASE MANAGEMENT FOR PEOPLE WITH DEMENTIA?

Except for anecdotes and case histories, very little has been written specifically about case management for people with dementia. OTA is not aware of studies specifically designed to compare case management for people with dementia and case management for nondemented people. Many research and demonstration projects that involve case management have included subjects with dementia, but with a few exceptions, the findings of those research and demonstration projects have not been analyzed for demented v. nondemented subjects.

Table 3-3-Ranking of Certain Goals of Case Management by Case Managers in Oregon and Washington State

| Rank | Goals  |
|------|--|
| 1    | To assure that services given are appropriate for the needs of a particular client.                                  |
| 2    | To facilitate the development of a broader array of noninstitutional services.                                       |
| 3    | To follow clients to guarantee the continued appropriateness of services.  |
| 4    | To improve client access to the continuum of long-term care services.  |
| 5    | To target individuals most at risk of nursing home placement in order to prevent inappropriate institutionalization. |
| 6    | To support the client's caregivers.  |
| 7    | To serve as bridges between institutional and community-based care systems.  |
| 8    | To promote quality and efficiency in the delivery of long-term care services.  |
| 9    | To enhance the coordination of long-term care service delivery.  |
| 10   | To prevent inappropriate use of hospital inpatient services.   |
| 11   | To contain costs by controlling client access to services, especially high Cost services.                            |

SOURCE: C.D. Austin, E.F. Borgatta, E.A. Roberts, et al., *Improving Access for Elders: The Role of Case Management: Final Report* (Seattle, WA: University of Washington, January 1987).

Some aspects of case management are undoubtedly similar for demented and nondemented people, but it is easy to imagine ways in which the characteristics and care needs of people with dementia might change the case management process, make it more difficult, and/or limit its effectiveness. The process of assessing an individual's needs may be more difficult in the case of individuals with dementia, e.g., because such individuals often are not a good source of information. The process of planning care maybe more complicated for individuals with dementia because of the fact that some demented individuals are unable to participate in decisions about services.<sup>10</sup> The process of arranging services may differ for people with dementia because such people (unlike many nondemented elderly people) often are not able to assist with the arrangements. It also may be more difficult to find services for people with dementia or to select an appropriate service provider. Since people with dementia are often unaware that they need help, they may be more likely than people without dementia to refuse needed services. Lastly, the process of monitoring and evaluating services may be more difficult

<sup>10</sup>The problems involved in determining the decisionmaking capacity of individuals with dementia and making decisions about services for people with dementia who are not capable of making decisions for themselves are discussed in ch. 4.

if the individual receiving the services is too confused to report problems with the services.

To explore the question of what is different or special about case management for people with dementia, OTA contracted for an exploratory study that involved interviews with case managers in five Pennsylvania AAAs and family caregivers, most of whom had interacted with the AAA case managers (934). The results of the study are discussed in the following section.

### ***Findings From an Exploratory Study of Case Management for People With Dementia***

***In 1988***, a study was conducted for OTA in Pennsylvania to learn about:

- case managers' views regarding the unique aspects and difficulties of working with people with dementia and their families, and
- family caregivers' views regarding the process by which case managers arrange services for their relative with dementia (934).<sup>11</sup>

The study was done in four counties in central Pennsylvania and involved in-depth interviews with 15 staff members from five AAAs and 46 family caregivers of people with dementia, most of whom had received some services through one of the AAAs (934). The 15 AAA staff members who were interviewed for this OTA study included the case management supervisor and two other staff members selected by the supervisor at each AAA; the staff members selected by the supervisors included eight case managers and two case aides. All 15 AAA staff members are referred to as 'case managers' in the following discussion.

The AAAs in Pennsylvania provide some services directly or through contracts with other agencies. Elderly people who come to an AAA in need of services are generally evaluated by a case manager, who may then arrange the services for them. If they are not eligible for the AAA's services or if they need services the AAA does not provide, the case manager refers them to other agencies.

Case managers in Pennsylvania's AAAs do not necessarily perform all five case management functions for all their clients, and the AAA case managers interviewed for this OTA study interacted with some of their clients only briefly to determine eligibility or refer them to other agencies. In that sense, they were not always providing case management. Moreover, some of the family caregivers the case managers interacted with may not have needed case management. The observations of the case managers and the family caregivers are instructive, however, with respect to the question of what is special about working with and arranging services for people with dementia.

The samples of case managers and family caregivers who were interviewed were both samples of convenience, not representative groups, and thus allow for a preliminary (rather than a definitive) inquiry into questions about working with and arranging services for people with dementia. The case managers did not know which family caregivers were interviewed for the study. When they spoke about families of people with dementia, they were reflecting on their entire caseload, and their comments do not refer specifically to families that were interviewed.

### ***Perceptions of the Case Managers***

The interviews with the case managers were based on a questionnaire designed to elicit information about the types and adequacy of services provided for people with dementia and problems case managers confront in working with and arranging services for people with dementia and their families<sup>12</sup> (934). Although discussions with the case managers inevitably turned to the limited availability of needed services, the primary focus of the interviews was the linking process.

***The Types and Adequacy of Services Provided for People With Dementia.--Most*** of the case managers said that *some* of the needs of people with dementia are being met (934). They indicated a need for more respite services and more in-home personal care. Another problem noted in some counties was the insufficient availability of nursing homes and board and care facilities able to manage patients with

<sup>11</sup>A complete report of the OTA-commissioned study in Pennsylvania is available from the National Technical Information Service in Springfield, VA (see app. A).

<sup>12</sup>To ensure that the case managers had a uniform set about what was meant by dementia, they were told that the researchers were interested in their "memory-impaired" clients. "Memory-impaired" was defined as having a diagnosis of Alzheimer's disease or dementia and/or significant functional impairment due to cognitive deficits.

disruptive behavior. A third problem noted by some of the case managers was transportation. They said that although people with dementia often need transportation—e. g., to a doctor's appointment—the existing transportation services are not appropriate for them because no escort is provided, and the patient could get lost, forget why he or she was out, or encounter other difficulties.

Even with existing resource constraints, some case managers showed considerable ingenuity and persistence in stretching limited resources to the maximum (934). One case manager commented:

There's a huge gap between what is needed to maintain someone in the community and when they need nursing home care. We patch and bandaids, and people see it as a lifeline and are glad for it (934).

***Unique Aspects and Difficulties of Working With People With Dementia and Their Families***—Several general themes emerged in case managers' comments about working with people with dementia and their families (934). First, the case managers unanimously agreed that working with people with dementia and their families takes more time and effort than working with other clients. Second, the case managers indicated a need for more flexibility in their jobs to work effectively with dementia clients. They said they need to be able to take the person to a service program for the first time, to be present when an aide first comes into the home, and to take clients to the doctor, drug store, or other places. These kinds of assistance may be needed even for clients with a supportive family, since the family is not always available.

***Problems in Working With People With Dementia Who Live Alone***—The case managers said that many people with dementia who are served by the AAAs live alone and have no family or other caregiver to help them (934). They noted several ways in which working with these patients is difficult. One problem is getting the patient to recognize his or her need for help and to accept services. They also pointed out that assessment is difficult if a reliable informant is not available at the initial assessment. One said:

You have to call other people if the pieces of the dementia patient's story don't fit. You have to put a puzzle together. Call a daughter. Find out who else is involved. To determine eligibility, you have to hunt for papers. Finding information takes time (934).

The case managers said that people with dementia usually cannot make arrangements for services themselves or remember arrangements that are made for them. One case manager noted:

When they need SSI or other benefits or services, they can't do it for themselves. They couldn't handle the phone calls or remember the details (934).

Case managers said that people with dementia who live alone are often fearful and suspicious. One said that she calls clients with dementia before a service provider is scheduled to arrive: "I make them aware someone else is coming to provide the service, and it's not me who will be coming out. A lot of them are skeptical and have been taken advantage of (934).

Another case manager described how she works with a confused client who lives alone and has no family:

To get in to see her, I told her I was from the senior center, not the agency. That seemed to help establish trust at first. She doesn't really know who I am or where I come from, but she thinks I'm a godsend. We go from problem to problem with her. I take care of one need, and then wait for a new problem to arise (934).

A third case manager told about a case of hers that illustrates the difficulty of working with someone who cannot report his or her problems (934). The client lived alone in a senior housing facility. Her personal hygiene was sometimes a problem, but the case manager did not think to check her feet. One day, a home health nurse visited the client for other reasons and found the woman's toenails had curled around and were growing into the bottom of her feet. The case manager had taken her to the doctor a week earlier, but the doctor did not check her feet either. A nurse comes to the senior housing facility once a week but stays in her office, waiting for people to come to her. As the case manager noted, confused residents cannot remember when the nurse is there and often fail to report problems, as happened in this instance.

Some case managers were clearly more comfortable than others working with dementia patients who live alone, and they seemed to do it well (934). They would find an entree, establish a relationship and give the client reminders rather than expecting him/her to remember. The case managers who appeared successful with this task also tended to

view it as a challenge in which they would somehow piece together a service program from the patchwork of available services. Sometimes this task involved bending procedures a little, and it always involved spending more time with the person than with other clients.

***Problems in Working With Families of People With Dementia***—The case managers said that families of people with dementia often wait until a crisis to seek help (934). At that point, the family may be too desperate to wait for services, or the available services may be insufficient to meet the patient's and family's needs. One case manager said:

A lot of times, the family has burned out before we get the referral. They want us to do everything. They want someone to come stay with the patient, help with bathing, or do the finances. Families don't give us the time to work out all these things, though we could do it (934).

The case managers cited many of the same reasons discussed earlier in this chapter as to why families wait until a crisis to seek help, e.g., families believe they should "care for their own," they do not want to leave their relative with strangers, and they feel guilty about using services (934). The case managers also said that some families are deterred from seeking help because the patient denies needing help or resists when it is provided.

Although most of the case managers noted families' reluctance to seek help, two case managers reported that families of people with dementia were more eager than the families of other elderly clients to use services (934). One case manager said:

Families are anxious, stressed, overwhelmed, scared. They will seek out help more readily than families of physically disabled (934).

According to the case managers, the amount of stress experienced by families of people with dementia contributes to the difficulty of helping them (934). This problem is exacerbated, of course, when families wait until they are at the end of their rope to seek help.

Some case managers distinguished between families who are already involved with the patient and families who are drawn in reluctantly (934). In their view, reluctant families become involved only when the situation has gotten so serious it cannot be

ignored, or when they are told to get involved by someone else, such as the patient's doctor, neighbors, or the AAA. Often they are particularly reluctant to get involved if doing so would require managing the patients' finances or placing the patient in a nursing home. The case managers said reluctant families are difficult to work with because they often do not follow through on treatment plans.

Several case managers commented on some families' fear that agencies will take control of the patient (934). One said, "There is a fear of agencies, that they may pull the elder out of the home." Another said, "They fear I will take over, and I won't." This issue of control arose again strongly in the interviews with families.

Some case managers raised another issue that was difficult for them in working with families of people with dementia—that the families persisted in providing care at home beyond what the case manager or physician felt was appropriate (934). Four case managers referred to families' refusal of nursing home placement in these circumstances as 'denial' and saw their role as breaking down the family's denial and arranging nursing home placement. They put more emphasis on that activity than on arranging services for home care. OTA's contractors concluded that these case managers were doing what they felt was in the patient's and family's best interest. The case managers felt that some families were coping with intolerable caregiving situations and that too few services could be provided to support continued caregiving at home.

Other case managers saw their role as doing what they could to support home care (934). They provided information about and assisted with nursing home placement, but they wanted families to make the decision about placement, except in cases of clear danger to the patient.

### Perceptions of the Family Caregivers

The 46 family caregivers interviewed for the study in Pennsylvania included some caregivers who were identified by the AAA case managers and some who were recruited independently (934). The primary sources of the independent sample were support groups, an adult day program, and other sources. Despite these sources, it turned out that all but two of the caregivers had been in contact with

and received at least minimal assistance from an AAA.<sup>13</sup>

All the caregivers were contacted by an interviewer who explained the study and arranged an interview (934). Interviews were conducted in the family's home or the patient's home if they lived separately. There were very few refusals.

The mean age of the patients whose caregivers were interviewed was 77 years (934). Thirty-six of the patients were living at home; 9 were living in a nursing home or board and care home; and 1 had just died. All but four of the patients had a diagnosis of Alzheimer's disease or another dementing disease, and in those four cases, the patient's history and functioning were consistent with dementia.

The mean age of the 46 caregivers was 55. Eighteen of the caregivers were spouses of the patient; 20 were daughters or daughters-in-law, and 8 were other relatives (934). Duration of caregiving averaged 4 1/2 years, with a range of 3 months to 14 years. Nineteen of the 46 caregivers (41 percent) said they had someone they could count on as backup caregiver, whereas 27 (59 percent) said they did not have a backup caregiver.

**Sources of Information About Services—**The caregivers said they most often learned about formal services from the AAA, physicians, and other family members (934). When asked whom they would turn to for more information, caregivers noted the AAA most frequently. Many caregivers said the patient's doctor did not refer them for case management or for home care. Most physician referrals apparently were for nursing home care.

Overall, about half the family caregivers said they had received enough information about services, and half said they had not. Forty-one caregivers (89 percent) said it would be extremely or very helpful to have a central source of information about services.

**Use of and Satisfaction With Formal Services—**The caregivers reported using various kinds of services, including personal care (22 families), respite care (14 families), and adult day care, homemaker, legal and financial services, and home-delivered meals (11 families each) (934). They generally were satisfied with the services they were using. Almost unanimously, however, they said they

could use "a little more help." Sometimes, "a little more" was a global understatement of the desperation the caregivers felt, but in other cases, it meant that a little assistance—an occasional phone call or a couple of hours of respite a week—would go a long way.

Despite their general satisfaction with services, some caregivers complained about respite and personal care workers who did not show up or were poorly trained (934). Many of the caregivers also complained about the inflexibility of the service system. They were upset about not being able to schedule helpers at a convenient time or specify a particular worker. They complained about the lack of services on evenings and weekends and about services that excluded patients with behavioral or emotional problems or severe fictional impairments.

As a result of these difficulties, many caregivers were frustrated (934). Some dropped out of the service system altogether and used no services. A few hired home health aides privately. Others said they learned how to work with agencies to get what they wanted. One caregiver said that she had gone through three home health agencies and 10 nurses whom she thought were not adequate. She now has worked out an arrangement with a home health agency so they send only their better trained nurses.

The caregivers said that they could accept services more easily if the services were therapeutic, not just "babysitting (934)." Moreover, like the caregivers who received services from the Duke respite care demonstration project, many of these caregivers said they had difficulty accepting services if the focus is on their needs and that they could accept services more easily if the services are for the patient. Many of the caregivers did not see a connection between their own physical and psychological well-being and their ability to continue caring for the patient.

**Interactions With AAA Case Managers—**As mentioned earlier, all but 2 of the 46 family caregivers in this study had had at least some contact with an AAA (934). The caregivers' overall satisfaction with all these interactions was quite high. One caregiver, a 53-year-old woman who was caring for her mother-in-law with Alzheimer's disease, said:

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<sup>13</sup>This finding should not be interpreted as indicating that most families are in contact with an AAA or are receiving services from an AAA; the result is probably a function of the sampling method, since people who attend support groups or a day care program are likely to use other services (934).

The AAA is the best link for help with the elderly. We have been well pleased. We recommend them to anyone with an elder. They can link you up to all the help that is out there. They are concerned, they follow-up, and they do their homework (934).

Another caregiver, a 63-year-old woman who had taken care of her mother with Alzheimer's disease until the mother was placed in a nursing home, also was very pleased with AAA case management. The primary assistance she received was an assessment and help with nursing home placement. She said:

The AAA returned calls, the staff was compassionate and helpful. They gave us time. They didn't make us feel unimportant or an imposition (934).

Despite the caregivers' generally positive attitudes about AAA case management, they did note several problems (934). Caregivers complained about overly bureaucratic procedures, particularly when steps they considered unnecessary were required in order to arrange services. For example, one caregiver felt she received a "runaround" when scheduling respite services that were already authorized by the AAA case manager. She said she frost had to call the case manager, who then called the agency providing the services. In her view, this process led to additional slipups. She said she would have preferred to arrange the services herself. Other caregivers agreed. When asked, "If someone were available to arrange services, who would you prefer that person to be?" 12 caregivers (26 percent) said they would prefer to do it themselves; 29 (63 percent) said an agency should do it; 3 (7 percent) said both; and 2 (4 percent) named other alternatives.

One caregiver, a 33-year-old woman who had been caring for her mother-in-law for 14 years, said that the critical factor in case management is having someone to talk to (934). She said the AAA case manager had helped her by spending time with her, allowing her to talk out some of her frustrations, but that she would have preferred to arrange services herself.

Some of the caregivers understood the process by which AAA case managers authorized and arranged services, but most did not (934). Several said they did not know how they were identified to receive help in the first place. They said someone from the AAA "just showed up one day," or they received a letter saying they were eligible. One caregiver said he felt the AAA came in almost surreptitiously, without involving him. Some said they did not

understand how benefits were determined, but they did not want to ask because they were afraid of losing the services they were receiving.

The primary concern of caregivers was not case managers, however, or the positive or negative aspects of the case management process. For them, the bottom line was services (934). Several caregivers were angry at the AAA case manager or the AAA because of policies that denied them services they needed. OTA's contractors in Pennsylvania reported the following example:

One 49-year-old widow was taking care of both her 87-year-old mother with dementia and a severely disabled 29-year-old daughter. The mother was attending a day care program, which the caregiver liked. She also got some in-home help for her daughter. She used this help to care for both her mother and daughter but felt that doing so was unfair to the helper. Because of an AAA policy, she was not able to get any in-home help for her mother as long as the mother was in the day care program. She did not understand this policy and was very angry with the AAA (934).

An important aspect of satisfaction for caregivers was having a relationship with someone in the service system who would give them emotional support and help them navigate the system (934). For some caregivers, this person was the case manager; in many cases, however, it was someone else, e.g., the person who delivered meals to the home or the aide who provided personal care. To the caregivers, having an advocate in the system seemed to make the difference between getting what they needed or giving up. OTA's contractors noted that such a relationship seemed more important for less educated and less sophisticated caregivers.

### ***Implications for an Effective System To Link People With Dementia to Services***

The overriding consensus of the 15 case managers in the Pennsylvania AAAs was that working with and arranging services for people with dementia is more difficult and more time-consuming than working with and arranging services for their other clients (934). Many people with dementia deny their need for services and refine services. They cannot provide information or remember arrangements that have been made for them. Some are fearful and suspicious. Case managers need special skills to work with these patients. Problems that arise in working with families of people with dementia—particularly



*Photo credit: Alzheimer's Association and Rush-Presbyterian/St. Luke's Medical Center*

**Case managers need special skills to work effectively with people with dementia and their families.**

problems related to the tendency of families to hold back from seeking services until the situation is desperate—also may require special skills.

Judging from examples the AAA case managers gave, OTA's contractors concluded that some of the case managers dealt with people with dementia and their families in very skillful ways (934). The case managers had received no formal training for this ability, however. Given the difficulty of providing case management for some people with dementia and their families, it is reasonable to suggest that case managers need special training to work effectively with these patients and families.

The majority of the 46 family caregivers interviewed for the study in Pennsylvania were satisfied with the services they had received and with their contacts with the AAA case managers (934). Their primary concerns were that not enough help is available and that the quality of personal care and respite services is sometimes poor.

Another concern of the family caregivers was control (934). Caregivers want to have control over services, particularly in-home services. They want to have some say as to when services are provided and who provides them. A lot of resentment was directed at the AAAs for not allowing families to request a

particular nurse or aide. They also were angry when bureaucratic procedures resulted in services not being delivered. One-fourth said they would rather arrange services themselves than have a case manager act as an intermediary.

OTA does not know whether families of people with dementia are more likely than families of nondemented elderly people to want to retain control over services and how the services are provided. It is possible that families of people with dementia become more protective than families of nondemented people in response to the diminishing ability of the dementia patient to plan or advocate for himself or herself. In any event, a recognition of families' desire to have control over services should be built into the case management component of a system that links people with dementia to services.

One aspect of control is understanding the rules of the game—in this context, how eligibility is determined and services are authorized (934). Many of the family caregivers interviewed for the study in Pennsylvania were mystified about how the level of service was determined or why they received help at all. This lack of understanding undermines their sense of control. In the view of the advisory panel and contractors for this OTA assessment, an impor-



tant objective of case management with families of people with dementia is to help them understand the basis for decisions about services so as to increase their sense of control.

Finally, some case managers interviewed for the study regarded the more impaired dementia patients as needing institutionalization, regardless of the their families' wishes (934). They believed that the families could not continue to provide adequate care and that available services were not sufficient to supplement the families' efforts. Other case managers made extensive efforts to support home care, even when services were limited, if that was the preference of the family. These differences in approach were due to several factors, including how comfortable case managers were in working with people with dementia and the advice they received from "experts," including one geriatric assessment team that frequently urged nursing home placement.

In the interactions of health care and social service professionals, case managers, and families, the issue of when institutionalization should occur is often couched as a professional or even medical decision. Except in cases where there is abuse or neglect, however, the timing of institutionalization is probably more appropriately and realistically viewed as a question of individual values and perceptions. Some families are willing to make tremendous sacrifices to keep a relative at home, and, as discussed earlier, some apparently do not perceive objectively difficult caregiving situations as overwhelmingly burdensome. It is probably inappropriate for case managers to regard these enduring caregivers as neurotic or to label their feelings as "denial." That some caregivers have conflicted motives is obvious; they may also have sincere and profound beliefs about what they are doing. They often continue home care despite intense pressure to institutionalize from doctors, service providers, and other family members. If a case manager pushes family members to institutionalize their relative, they may withdraw from the service system completely and consequently receive no services (934).

It is the opinion of OTA's contractors and the advisory panel for this study that except in cases of abuse or neglect, case managers should inform family caregivers about all their options, including nursing home placement, and allow them to make the decision. The question of what constitutes sufficiently poor family care to trigger a decision to

institutionalize a dementia patient over the objections of his or her family requires further analysis.

## **UNRESOLVED QUESTIONS ABOUT CASE MANAGEMENT IN A SYSTEM TO LINK PEOPLE WITH DEMENTIA TO SERVICES**

Although OTA has concluded that case management is an essential component of an effective system to link people with dementia to services, many questions remain to be answered about case management in such a system. Several of these questions are discussed further below:

- . To what extent should a linking system try to maintain at home individuals with dementia who live alone and have no informal caregiver?
- . Should counseling be part of case management in a linking system?
- . In general, should families be regarded by a linking system as "co-case managers" or "co-clients"?
- . How many people with dementia need case management?
- . How much would case management in a linking system increase the use of services?

The answers to these questions have implications for the design and operation of the case management component of a linking system and for the job description and skills of case managers employed by the system.

### ***To What Extent Should a Linking System Try To Maintain at Home Individuals With Dementia Who Live Alone and Have No Informal Caregiver?***

At least 20 percent of people with dementia live alone, and as many as half of them have no informal caregiver to assist them (see ch. 1). In developing a system to link people with dementia to services, it is important to decide how the system should respond to these individuals, who may require a lot of involvement on the part of a case manager if they are to remain in the community.

People with dementia who live alone and have no informal caregiver are at risk for injuries and other problems. Some home health care agencies will not accept them as clients because the agencies do not want to be liable for problems that occur when the

individuals are alone (239). One question in developing a linking system is the degree of risk to an individual that can or should be tolerated, but that risk needs to be weighed against problems people with dementia encounter in institutional settings. A related question is what liability the linking system or its case managers would incur for people with dementia who live alone, have no informal caregiver, and are maintained at home with intermittent services and supervision by a case manager. Both questions require further analysis.

The case managers in the study conducted for OTA in Pennsylvania said that providing services that are not ordinarily considered case management—e.g., taking a client with dementia to a program the first time, being in the person's home when a new aide arrives, or driving the person somewhere if no other source of transportation is available—is sometimes essential in implementing a client's plan of care (934). Such services are especially likely to be needed for people with dementia who live alone and have no informal caregiver. Sometimes, a case manager can arrange to have these services provided by a volunteer or a paid chore worker. But what if that is not possible and the case manager judges that failure to provide the services could cause a major disruption to the client's already precarious functioning? Should case managers employed by a linking system provide the services themselves?

Some private geriatric case managers who are hired by patients or families to provide case management provide services that are peripheral to case management but may be essential to supporting the patient and maintaining the patient's independent functioning. A 1986 survey of private geriatric case managers conducted by Interstudy found that 16 percent of the 117 respondents provided transportation; 16 percent provided homemaker services, and 11 percent provided chore services (357). In some cases, however, the services were provided by case aides or other support staff members who worked with the case manager.

Some case managers also make themselves available to their clients at any time for emergencies. Eighteen percent of the private geriatric case managers who responded to the Interstudy survey just cited said they provided a 24-hour hotline (357). Some public and private case management agencies also provide a 24-hour hotline (746). One private geriatric case manager, speaking to a National Council

on the Aging symposium on case management, told about an instance in which one of her clients, an elderly woman with dementia who was living alone, became very confused in the middle of the night. Ordinarily, a paid homemaker helped the woman get ready for bed before she left for the evening. On this particular night, the usual routine was not followed for some reason. The woman with dementia became agitated and called a friend, who then called the case manager. The case manager went to the woman's house, helped her get into her nightgown, and waited until she fell asleep to leave (136).

OTA does not know whether instances like this occur more often in the case of individuals with dementia than in the case of other individuals receiving case management, but such instances do raise questions about the appropriate role and functions of case managers. If the occasional provision of "non-case-management" services enables case managers to maintain at home clients with dementia (and perhaps other clients) who live alone and have no informal caregiver, should a linking system build into the case managers' job description sufficient flexibility to allow them to provide such services? Alternatively, should case aides of some sort be available in the system to provide the services at the direction of the case manager? These questions remain to be answered.

### ***Should Counseling Be Part of Case Management in a Linking System?***

*In the* context of a linking system, counseling is most likely to be needed for caregivers who do not use services because they feel guilty about accepting help, fearful that others will disapprove of their use of services, ashamed of the patient's behavior, reluctant to make decisions for the patient, or simply too overwhelmed by various feelings to think clearly about solutions to their problems. Counseling also may be needed when family members disagree about the patient's care and what services are appropriate. Lastly, counseling may be needed for some patients who are reluctant to use services, although in many cases the effectiveness of counseling for patients is problematic.

It is unclear whether counseling should be part of case management in a linking system or whether patients and their caregivers who need counseling should be referred by the linking system to other sources of counseling. If counseling is to be pro-

vialled by the linking system, however, the individuals hired as case managers by the system must have the necessary education and training to provide it.

***In General, Should Families Be Regarded as "Co-Case Managers" or "Co-Clients" by a Linking System?***

Families of frail older people frequently perform case management tasks themselves, acting as intermediaries between the older person and formal service providers (85,92,1 10,467,477,753,778). Some commentators have suggested that maximizing a family's performance of case management tasks might increase the family's satisfaction with services, meet patients' needs more appropriately, minimize costs, and eventually decrease the need for a paid case manager (271,753,754,758). Despite this suggestion, few attempts have been made to help families become better case managers (175).

One project did train and assist some families of elderly people (including some families of people with dementia) to perform case management tasks, such as arranging and monitoring services (753,754,758). Together, a social worker and a family member developed a "case management service plan" that allocated case management tasks between them. Family members were given information about community resources, and the social worker contacted them at least every 2 weeks to answer questions, monitor their performance of case management tasks, and provide supportive counseling. The results of the project showed that the families who received the training and assistance accomplished significantly more case management tasks than did a control group of families that did not receive the training and assistance. Additionally, the total duration of services was significantly shorter for the older people whose families received the training and assistance than for older people whose families did not (753).

Interestingly, whether families received this training and assistance was not the largest predictor of their performance of case management tasks. The largest predictor was the cognitive status of the patient. For both the experimental and control groups, families of people with dementia were more likely than families of other individuals to perform case management tasks (753).

A linking system could regard families primarily as "co-case managers" and attempt to maximize families' performance of case management tasks by providing training and assistance to help them perform the tasks successfully. Alternatively, a linking system could regard families primarily as part of the client unit, or "co-clients," whose needs are assessed along with the patient's needs and incorporated into the patient's care plan. Families differ, of course, and whether a specific family is most appropriately regarded as a co-client or a co-case manager depends on the characteristics of the family and the caregiving situation. The presumption of the system--i.e., whether the system generally regards families as co-case managers or as co-clients--is likely to affect how comfortable families are with the system. Certainly, at least some families of people with dementia would prefer to be regarded as co-case managers than as co-clients, because the role of co-case manager would allow them a greater degree of control over services that may be used for their relative with dementia.

Even if a linking system generally regarded families as co-case managers, some families would be more appropriately treated as co-clients. Determining which families could function successfully as co-case managers (with or without training and assistance) and which families should be treated as co-clients would require difficult judgments by case managers in at least some instances. To make these judgments and to help families become better case managers would require special skills on the part of the case managers employed by the linking system.

***How Many People With Dementia Need Case Management?***

Although OTA has concluded that case management is an essential component of an effective system to link people with dementia to services, an important question that remains to be answered is how many people with dementia need case management. Most people would probably agree that people with dementia who live alone and have no informal caregiver to help them all need case management—at least at the point when they become unable to plan for themselves or manage their affairs independently (a point that to some extent rests in the eye of the beholder).

A somewhat more difficult question is how many people with dementia who *have* an informal caregiver need case management. As noted in the previous section, families often perform case management tasks for elderly people, including people with dementia. If accurate information about services and funding for services were readily obtainable, more families and other informal caregivers would be able to arrange services themselves, and fewer people with dementia would need case management. If training and assistance were available to help families and other caregivers perform case management tasks, as suggested above, still more caregivers would be able to arrange services themselves. On the other hand, some family caregivers have intense feelings that still would make it difficult or impossible for them to arrange services themselves, as illustrated in one woman's description of the process of placing her husband in a nursing home:

Finally the dreaded conclusion was reached that he had to go to a nursing home. No one can imagine the devastation I reached at this time. But it had to be done, so I had to find a way to cope. At the time of transition to the nursing home, the most important help I received was from the social service worker. She made phone calls and gathered and gave me information. There was nothing easy about it, but she was a real buffer (670).

The woman just quoted probably could have made the phone calls and arranged for her husband's admission to a nursing home herself if she had not been so upset. There are also situations in which the informal caregiver of a person with dementia is almost as impaired as the patient and is totally incapable of arranging services. In both types of situations, most people would probably agree that case management is needed for both the caregiver and the person with dementia.

The advisory panel for this OTA study was unanimous in the view that not *all people with dementia who need services also need case management*. The panel particularly rejected the idea that all family caregivers need a case manager to help them define their service needs. While recognizing that some caregivers need help to define their service needs, panel members pointed out that many family caregivers can define service needs themselves.

In apparent conflict with the advisory panel's view that not all people with dementia who need services also need case management, many of the congressional proposals to provide expanded long-term care services that were introduced in 1988, 1989, and 1990 (100th and 101st Congress) specify that everyone who received the expanded services would also receive case management. Under these proposals, even people who have informal caregivers who are (or believe they are) capable of defining their needs and arranging and monitoring services themselves would receive case management. The case management in the congressional proposals generally includes both "administrative" tasks (e.g., authorizing services in accordance with program regulations) and "clinical" tasks (e.g., helping people define their service needs and select appropriate services in their communities) .14

One way for Congress to address this apparent conflict would be to conclude that case management is, in effect, the price of receiving long-term care services and to assume that caregivers and others will be willing to accept case management to get the services—probably a reasonable assumption in most cases. Case management is an expensive addition to the cost of services, however (105,114). For that reason, Congress might prefer to limit the case management that is required for everyone to those administrative tasks that are essential to allocate services in accordance with program regulations, and to require or allow case management beyond those administrative tasks only for people who are identified as needing them by some specified criteria.

As noted earlier, the term "case management" means different things to different people. Thus, various commentators' views about whether case management is needed in certain contexts or for certain types of people may or may not refer to the same "case management." In addition, although a major purpose of case management is to help people obtain the services they need, ideas about what case management is and who needs it have come almost exclusively from academics, administrators, policy analysts, and case managers—not from people who might need or use it. When people who might need or use case management are asked, their opinions about case management are quite different from the

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<sup>14</sup>The distinction between case management as an administrative process in which the case manager is primarily responsible for allocating services in accordance with program regulations and case management as a clinical process in which the case manager functions more as a professional helper and advocate than as an administrator of services was discussed earlier in this chapter.

ideas of those other individuals, as illustrated by findings from several studies and a fee-for-service case management program discussed below. The discussion below is not comprehensive, nor is it intended to suggest that the ideas of people who have used or may use case management are necessarily correct about what case management is and who needs it and that other people's opinions on these topics are incorrect. Rather the discussion is intended to highlight certain opinions of current and potential users of case management that are relevant to the questions of how many people need case management and how many might use it.

Some insight into people's opinions about case management can be derived from the findings of market research conducted for the Robert Wood Johnson Foundation's Supportive Services Program for Older Persons. The research indicates that many older people and their caregivers do not understand what case management is or why they might need it (318). The Supportive Services Program for Older Persons is intended to demonstrate the feasibility of developing a private market for in-home and community services and to design a package of such services that people will purchase. The first phase of the Supportive Services Program involved market surveys in 13 localities to determine the demand for services of various kinds. The market surveys found that elderly people and their caregivers have three problems with case management:

- . They do not see themselves as "cases" to be managed.
- . They do not understand why they would need a special person or a special set of functions in order to obtain services.
- . They do not understand why they should pay for something that, in the private sector, might be viewed as customer service or public relations (318).

Many people who were contacted for the market surveys expressed confidence in their ability to define their own service needs and did not think they would need a case manager to help (91).

Case management generally is perceived by academics, administrators, policy analysts, and case managers as a series of interrelated steps that constitute a logical problem-solving process that is directed by a case manager. The results of interviews conducted for OTA with 46 family caregivers of people with dementia in Pennsylvania suggest that

the caregivers had different perceptions about case management. For example, there is no evidence from the interviews that the caregivers perceived case management as a logical problem-solving process or that they regarded the case manager as the central figure directing that process (934). Family caregivers who were looking for services used various sources of information and assistance. Some of them relied less on a case manager for help in negotiating the service system and obtaining needed services than they relied on an in-home aide, a volunteer who delivered meals, or the director of an adult day care program. These caregivers saw themselves, rather than the case manager, as directing the case management process.

The experiences of Connecticut Community Care, a private case management agency, suggest that people often want only certain case management functions. Connecticut Community Care has been providing case management for publicly funded long-term care programs for some time and began offering fee-for-service case management in 1986 (75). The agency markets a comprehensive case management service that includes all the case management functions discussed earlier in this chapter, plus counseling, but people often purchase single case management functions-e. g., client assessment or service coordination. Many of the agency's case managers have been uncomfortable with splitting up what they perceive as interrelated case management functions-separating client assessment from care planning, for example, or care planning from service arrangement.

Connecticut Community Care's fee-for-service case management is controlled by the client, not the case manager, and many of the agency's case managers have been uncomfortable with their loss of control (75). Despite that feeling, the case managers have been pleased with the flexibility they have in responding to these clients' needs and with some of the positive outcomes they have seen. The agency's fee-for-service clients have been happy with the case management services they have purchased.

The results of the Robert Wood Johnson Foundation's market research, the interviews with family caregivers conducted for OTA in Pennsylvania, and Connecticut Community Care's experiences with fee-for-service case management suggest that different people want and need different kinds of help with defining their service needs and selecting, arranging,

and monitoring services. An underlying theme, however, is that people perceive themselves as being in control of the linking process and that they want to retain that control.

The American Nurses' Association, the National Association of Social Workers, the National Council on the Aging, and other commentators state that the primary goals of case management include empowering people, increasing people's sense of control over their own lives, and helping people attain their own objectives (22,483,725,81,893). Achieving these goals is difficult in a complex, fragmented service environment in which resources are limited and the services people want are sometimes unavailable or too expensive--and the difficulty is probably compounded when a person is cognitively impaired and the person's caregiver is unsure of what he or she wants or is ambivalent about using services at all. The difficulty is probably further compounded when the case manager is responsible to an agency for a series of administrative procedures to authorize and account for the use of resources.

If the objectives of a linking system include empowering people, increasing their sense of control, and helping them achieve their own objectives, several requirements must be met. First, there must be a clear recognition that these are objectives of the system. Second, there must be guidelines for implementing them, and third, there must be training for case managers to help them achieve the objectives.

### ***How Much Would Case Management Increase the Use of Services?***

**The** extent to which case management would increase the use of services probably depends in part on whether the case manager has funds and authority to purchase services for clients or just arranges services for them. The National Long-Term Care Channeling Demonstration compared use of services by elderly people in three groups:

1. a "basic case management group," in which a case manager had only limited funds to purchase services and primarily brokered available services for the clients;
2. a "financial control group," in which a case manager had funds and authority to purchase services for the clients; and
3. a control group, in which the clients received no case management or services through the project (although some clients received case man-

agement and/or services from other sources); (147).

Elderly people in the basic case management group, in which the case manager primarily brokered services, were using 11 percent more in-home services than the control group after 6 and 12 months and 6 percent more in-home services after 18 months (147). Elderly people in the financial control group, in which the case manager had funds and authority to purchase services, were using 22 percent more in-home services than the control group after 6 months, 18 percent more in-home services than the control group after 12 months, and 14 percent more after 18 months. Thus, basic case management without funds to purchase services increased service use by 6 to 11 percent over the use which would have otherwise occurred, while case management with funds and authority to purchase services increased service use twice that amount.

The results of a recently completed respite service demonstration project conducted by the Philadelphia Geriatric Center (88,448) also show that case management with funds to purchase services increased service use, but overall use was still lower than one might have expected, given caregivers' expressed need for respite services. The project made respite services available to family caregivers of Alzheimer's patients through a case management process. The caregivers who volunteered for the project received an initial assessment and were randomly assigned to a control or experimental group.

Caregivers in the control group were given a list of local service providers and were reassessed at the end of the study, a year later. Caregivers in the experimental group were offered respite services to be provided in their home, in an adult day center, and/or in a hospital or nursing home (88,448). A case manager was available to help the caregivers identify their needs, to develop a care plan, to assist in arranging respite or other services, and to provide counseling to help caregivers with problems that might interfere with their use of services. Interactions between the case managers and the caregivers in the experimental group varied. The caregivers were contacted at least every 2 months; in some cases, contact was much more frequent.

As noted earlier in this chapter, only about half the caregivers in the experimental group in this study used any respite services over the course of the year

(88,448). Thirty-five percent used in-home respite; 2 percent used adult day care; 7 percent used overnight nursing home care, and 8 percent used more than one kind of respite care. Moreover, most of the caregivers who used respite care used very little of it. Even though the case managers encouraged the use of respite services, therefore, overall use of the services was still low. According to the researchers, some caregivers were so emotionally invested in their role as caregiver that they were unable to accept any services, even with extensive counseling and support. Other caregivers only slowly came to understand the concept of respite care and might have begun to use respite services if the demonstration project had continued beyond the 1-year period.

A comparison of the experimental and control groups at the end of the respite service demonstration project showed that the project intervention—i.e., the case management, the offer of respite care, and the respite services that were used—had no significant effect on caregivers' attitudes, perception of burden, or self-reported physical or mental health (448). The project intervention did have a significant effect on the number of days that patients remained in the community (447). Dementia patients whose caregiver was in the control group were institutionalized or died an average of 22 days sooner than dementia patients whose caregiver was in the experimental group. Interestingly, this difference was not between caregivers who used respite services and those who did not. Rather, it was between caregivers who received the whole intervention—case management, counseling, education, the offer of respite, and any respite services that were used—and caregivers who did not. The researchers suggest that the whole intervention, including the knowledge that respite services would be available if needed, that “constituted a strain-reducing influence that fortified caregivers in the experimental group in their resolve to defer institutionalization as long as possible” (447).

## CONCLUSION

Some people with dementia and some caregivers have characteristics, feelings, or perceptions that make them reluctant to use services or unable to arrange services themselves. These individuals are unlikely to respond to public education programs and may be unwilling or unable to contact an

information and referral source on their own. Some of them do not need services, but many undoubtedly do. These individuals often include some of the most isolated patients and objectively burdened caregivers. Outreach and case management programs are needed to connect these people to services. Although it is unclear how many people with dementia need outreach or case management, it is clear that outreach and case management are essential components of an effective system to link people with dementia to services.

Outreach must be active and individualized to reach isolated people with dementia and isolated caregivers. Some initiatives that often are called outreach, such as lectures to community groups and publicity in various media, are effective in reaching some people with dementia and some caregivers but not those who are most isolated. Individualized approaches are needed for those persons. The gatekeeper model described in this chapter is most likely to be successful in reaching them.

The five core functions of case management identified in table 3-1—assessing a client's needs, developing a plan of care, arranging and coordinating services, monitoring and evaluating the services that are delivered, and reassessing the client's needs—are clearly relevant to many of the characteristics, feelings, and perceptions that keep some people with dementia and their caregivers from using needed services. Clearly, case managers need special knowledge and skills to work effectively with people with dementia. Moreover, some adjustments may be needed in case management procedures to accommodate some—and perhaps many—families' preference and ability to control the process of locating and arranging services themselves.

Finally, it is important to note that neither outreach nor case management can compensate for the insufficient availability of services and funding for services. Outreach Programs can find people who need services, and case managers often can piece together services and funding for a client from the fragmented service system, but the services and funding must exist. Outreach and case management are essential components of a system to link people with dementia to services, but they are not a panacea for all the problems of long-term care.