

Chapter 7

**Programs and Services
That Specialize in the Care
of Persons With Dementia**

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programs and Services That Specialize in the Care of Persons With Dementia*

The increasing recognition of the needs of those with dementing illnesses has led to the development of programs and services—day care, home care, short-term residential care programs, and nursing home programs—that specialize in caring for those persons. This interest in special services arises in part from recognition of the potential market, in part from the demand of family members and voluntary associations, and in part from the hope that special resources and skills may improve the care of these people.

Although there are now only a handful of these specialized programs, the growing number of them raises important policy questions: What standards should these programs meet? how should they be reimbursed? and is it in the individuals' best interests to be segregated? Some answers depend on understanding whether the care needs of these people are different from those of other chronically ill elderly individuals. Since many of them have been served all along by long-term care programs, particularly nursing homes, what is "new" about special dementia care? Indeed, some of the changes advocated for specialized dementia care are improvements that would benefit many other long-term care recipients.

This is the first generation of such special care programs. Although a few nursing homes have had specialized units for more than a decade, most such programs are less than 5 years old, and the total number of persons receiving special care is small. It cannot be assumed that services that have been found to be beneficial to a few people will be of value to over a million others. Nevertheless, enough information is available to consider some questions:

- Who is served in special units?
- What are the advantages and disadvantages of specialization?

- What kinds of services and programs do patients and families need?
- What kinds of services and programs are appropriate in specialized care?
- What specialized care is currently being provided?

Although an extensive body of literature exists on nursing home care (93) and on respite care for the elderly (91), there is limited information on special dementia care programs; what there is represents the opinions and experiences of clinicians rather than reports of controlled studies. Although there is some research on interventions with the elderly mentally ill and with nursing home residents, much is poorly designed and most does not discriminate between persons with and without dementing disorders (100). Thus this chapter must rely on anecdotal material and "best guesses" of experienced clinicians. Policy makers cannot assume that these represent the best ultimate approaches to care. Additional research is urgently needed.

Seven providers of special services were asked to document their experiences for OTA (18,25,32,42,67,74,84). One contractor had previously surveyed other special care programs (95). Another reviewed in detail the management of incontinence (96). In addition, OTA reviewed reports of specialized nursing home programs, and OTA contractors and staff attended conferences, visited facilities, and consulted with providers in the industry and the nonprofit sector. A few of those providers have worked for many years with chronically mentally ill elderly individuals (a term that includes many persons with dementia). This chapter also draws on the studies of elderly mentally ill persons in State mental hospitals prior to deinstitutionalism (efforts to move people out of such facilities) (20,30,35,36,51,55).

OTA found variations in services and no consensus about what constitutes ideal or cost-efficient care. But OTA did observe a clear move-

* This chapter is a contract report by Nancy Mace, consultant in Gerontology, Towson, MD.

ment toward providing specialty care for persons with dementia and agreement among leading clinicians about the principles of such care.

Specialized care for individuals with dementia can be delivered in any setting and can provide most services noted in chapter 6, including respite for families or long-term residential care. The options for care should be a part of a network of resources for families and those with dementia, who will need different resources as the person's health and the family status change through the course of the illness, and who may need to move back and forth between formal and informal care (100). Ideally, resource clearinghouses, information and referral systems, and case man-

agement services would be available to assist patients in locating specialized care programs and in moving easily from one setting to another. In fact, resources are fragmented, funding is discontinuous, and information is often not available.

Patients and families also need allied resources such as legal advice from attorneys familiar with dementia. Legal issues are described in chapters 5 and 11 and will not be dealt with here. This chapter will be limited to a discussion of special respite and long-term care programs which specialize in care of persons with dementia. However, such services must be thought of as links in a broader spectrum of care needs,

THE RECENT INTEREST IN SPECIAL CARE

What Is New About Special Programs?

Persons with dementia are not entirely new to formal care providers. Until the movement toward deinstitutionalization, persons with dementia whose families could not care for them were housed in State mental hospitals along with individuals suffering from a range of mental disorders. State mental institutions therefore had a history of caring for persons with dementia, and a few institutions developed special care programs for them. Reinstitutionalization resulted in the transfer of public care for those with dementia from State mental hospitals to nursing homes (13). More than half the current residents of nursing homes apparently suffer from dementing illnesses (see ch. 1).

The number of persons with dementia and in need of care is increasing (see ch. 1), and there is a growing concern that the nursing home system—facilities, funding sources, and regulating agencies—does not serve such individuals well. With the increasing public interest in these illnesses has come a parallel interest in both care outside of nursing homes or mental hospitals and in different approaches to care within such facilities.

Who Is Served by Special Units?

The kind of care offered by the few existing special programs is not considered appropriate for everyone with a dementing illness. In nursing homes that have established a special care unit, most individuals with dementia still reside on mixed units. Many nursing home residents are frail and suffer from multiple, severe illnesses. Their mental confusion may result from Alzheimer's disease or from delirium brought about by their illness. These people need more nursing care than the special programs offer. Thus most people with dementia are now cared for in programs designed to serve all frail or ill elderly individuals. Programs that specialize in dementia care address the needs of those who are most difficult to care for or whose care needs have been overlooked.

No generally accepted criteria defining who will be served in special programs have been established. The criteria followed by many programs can be summarized as:

- **Presence of irreversible dementia:** Most programs serve only adults with a clear history of intellectual decline, excluding persons with mental retardation and those with treatable causes of mental impairment.

- **Presence of disruptive behaviors:** In contrast to programs that historically have excluded persons who are incontinent, agitated, combative, prone to wandering, etc., these programs focus on the behaviorally disabled whom they see as most in need of services.
- **Ability to benefit from the program:** This vague criterion is used to describe persons in the midstages of an illness, when behavior problems are most likely to be present, and when the individuals can be observed to respond to social activities. Later in the illness these programs may discharge or transfer persons who need extensive nursing care, who are not ambulatory, who are too ill to show disruptive behaviors, or who are less responsive to group social activities. (Programs that serve people individually in their homes may serve persons who are more seriously impaired than those in group programs.)

Opinions differ on the ideal diagnostic mix of persons who should be served in specialized programs. Some families of individuals with Alzheimer's disease advocate programs that serve only that group. Some programs, notably the Family Survival Project in San Francisco (27), serve all brain-damaged adults, including those suffering from stroke, trauma, Parkinson's disease, Huntington's disease, normal pressure hydrocephalus, and Alzheimer's disease. These programs

strongly advocate a noncategorical program for all brain-injured adults.

The argument centers on whether persons with Alzheimer's disease are more or differently impaired and require different care than other brain-damaged adults. In practice, most programs serve mainly persons with Alzheimer's disease and a sprinkling of persons with various other conditions, reflecting the mix in the community as a whole.

While people with Alzheimer's disease do have characteristic symptoms that distinguish them from those with related disorders, providers report that the behaviors and care needs of most persons with dementia are based as much on the stage of the illness or on individual characteristics as on diagnosis. No service provider reported to OTA that problems were caused by serving individuals with other diagnoses, although a person with any disorder, including Alzheimer's disease, can prove unsuitable for a given program. Several reported that a diagnostic mix was beneficial.

Designing programs for these active and difficult persons who can benefit from such efforts has one major drawback: It could result in choosing only the most responsive individuals, leaving the more difficult or withdrawn to receive less care.

ADVANTAGES AND DISADVANTAGES OF SPECIALIZATION

Table 7-1 summarizes some of the arguments for and against special units for persons with dementia. Few solid data support either side. But care providers seem increasingly convinced that these persons have unique limitations best met by specialized care. The results of the programs discussed in this chapter support that belief. In addition, enthusiasm for special care programs has probably been influenced by a common frustration that long-term care has failed this group.

It should be noted that, although these arguments are most often raised in discussion of nursing home special units, similar concerns confront day care or respite providers. Also, these arguments assume that special care is targeted toward

those with dementia alone. Different issues are raised by the care of persons who are both cognitively impaired and have serious physical illness. Finally, the trend toward specialized care challenges the long-held assumptions of therapeutic nihilism—that there is nothing that can be done for people who are old and “senile” (60).

In weighing the advantages and disadvantages of special care, the effect of widespread adoption of programs must be considered. The few existing programs have enthusiastic staff and are the focus of community interest. Those qualities may not carry over to large-scale programs and may need to be supplemented or enhanced by staffing requirements or formal quality assurance mechanisms.

Table 7-1.—Arguments For and Against Special Programs/Units for Persons With Dementia

Arguments for	Arguments against
The needs of individuals with dementia are not the same. Trained staff in a special environment can produce measurable evidence of benefit in persons with dementia.	People need much the same care. Most nursing home residents suffer multiple illnesses, of which mental impairment is only one. They need regular nursing care.
Quality care should be available to all nursing home residents, but even in the best possible setting the needs of the cognitively impaired are different from those of the cognitively intact.	Provision of special units is unfair to other people who would also benefit from many of the environmental changes that help people with dementia. Instead of segregating people, the quality of all care should be upgraded.
Being around people whose mental functioning is higher can be stressful for persons with dementia, who must constantly struggle to process even simple information. This may be one cause of behavior problems.	Placing persons with dementia with cognitively well persons helps the person with dementia stay alert by providing role models. Isolation in all-dementia units may lead to greater deterioration.
Special units permit special interior design, fire safety equipment, trained staff, and marketing efforts to attract private pay clients. The demand for quality ensures that beds in good facilities will fill quickly.	Special units must hold a bed open until a person with dementia needs it. This is more expensive than quickly filling beds with the next available client.
Cognitively well elderly persons have made it clear in several informal surveys that they do not want to spend their lives with persons who act "crazy" or are disruptive. The lucid client is vulnerable to loss of privacy, loss of personal property, interrupted sleep, and fear of harm by the agitated person. Efforts to protect the lucid client may result in overmedication and restraints, which have negative effects on persons with dementia. There are ethical issues involved in using persons who are paying for their own care as supervisors of other patients.	In mixed units, cognitively well individuals can help "look after" the person with dementia, which allows lower staffing levels and gives the well client something to do.
The current demand for specialized units is such that people will transport family members long distances for residential care.	In areas with a low population density, there will not be enough persons with dementia to support special units, particularly day care.
An all-dementia unit allows staff to develop expertise in care for clients. This benefits residents and is rewarding to staff. Experience has shown that staff do not necessarily "burn out."	Staff will quickly "burn out" on a dementia unit. The issue of burnout and staff satisfaction is not unique to dementia care, but reflects pervasive problems in long-term care.
Patients' rights laws, ombudsmen, and quality assurance regulations assure oversight of persons who are not competent. The new focus on dementia reduces the risk that individuals would be poorly served.	A program serving persons with dementia would create a ghetto in which no one would be able to report abuses or be a legally capable witness. Ombudsmen rarely serve board and care facilities. Persons with dementia often outlive the family members who advocate for them.
Dementia is a medical specialty long overdue for recognition. Specialty programs would attract physicians and nurses interested in this field.	Dementia is not a medical specialty, deserving of separate designation and specialization, because the needs of these individuals are primarily psychological and social.

SOURCES: M. Ablowitz, "Pairing Rational and Demented Patients in Long-Term Care Facilities," *Journal of the American Geriatrics Society* 31 :627-628, 1983; J. Bergman, "Mentally Ill in Nursing Homes? Yes, if . . .," *Geriatric Nursing* 3:98-100, 1983; R. Cook-Deegan and N. Mace, "Care of Patients With Dementia," Testimony, California Task Force on Alzheimer's Disease, 1986; D. Coons, "A Residential Care Unit for Persons With Dementia," contract report prepared for the Office of Technology Assessment, U.S. Congress, 1986; G. Hall, V. Kirshling, and S. Todd, "Sheltered Freedom: The Creation of an Alzheimer's Unit in an Intermediate Care Facility," unpublished paper, 1985; Hebrew Home for the Aged at Riverdale, "Institutional Approaches to the Care of Individuals With Dementia," contract report prepared for the Office of Technology Assessment, U.S. Congress, 1986; N. L. Mace, "Home and Community Services for Alzheimer's Disease: A National Conference for Families," U.S. Department of Health and Human Services and Alzheimer's Disease and Related Disorders Association, May 2, 1985; J. Pynoos and C.A. Stacey, "Specialized Facilities for Senile Dementia Patients," *The Dementias: Policy and Management* M.L.M. Gilhooly, S. Zarit, and J.E. Birren (eds.) (Englewood Cliffs, NJ: Prentice Hall, 1986).

SERVICES AND PROGRAMS NEEDED BY THOSE WITH DEMENTIA AND THEIR FAMILIES

Chapter 2 describes the characteristics of individuals with dementia, and chapter 4 documents the needs of family caregivers. Ideally, these needs will define the shape of special care programs.

In addition, services should be tailored to surmount the problems of service delivery in rural areas and to meet the needs of varied ethnic groups. For example, since people with dementia

Table 7-2.—OTA Survey: Availability and Use of Services for Persons With Dementia

	Available					Used ^a				
	100 %	-	%	%	Don't know 0/0	No answer %	Yes ^b 0/0	No, never used %	No answer %	
Visiting nurse	51		10		31	7	44	53		4
Paid companion/home health aide	48		16		29	8	59	38		3
Temporary, round the clock respite care.	21		24		47	8	13	61		27
Special dementia unit nursing home care.	21		33		37	9	44	50		7
Adult day care	29		24		39	8	31	66		3
Domiciliary/boarding care.	14		26		51	9	33	61		6

NOTE: Percentages rounded to the nearest whole number
^aBase = those who knew service was available.
^bCurrent and past used combined.

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

have problems in learning, persons from other cultures may have great difficulty adapting to "mainstream" programs.

Needs of Families

Although families report high levels of need for services, an OTA survey of caregivers of individuals with dementia found that services were not available for many (99) (see ch. 4; the study is referred to in this chapter as the OTA survey or study). Table 7-2 shows that many families know services are available, yet families do not always use available services. Of the families surveyed who knew a service was available, 38 percent did not use a home health aide and between 50 and 66 percent did not use other services. Many families are noticeably reluctant to turn any care over to others.

The OTA survey and others (33) have identified several characteristics of care provided by families that could affect the use of specialized services. Care must be affordable. Some resources are available but beyond the reach of families. Although they are concerned that their resources not be exhausted, families prefer to share with the formal system, rather than completely turn over, the costs and tasks of caregiving whenever possible. Current funding sources, notably Medicaid, impoverish the family before providing assistance, and the emphasis on nursing home placement reduces the caregiver's continued participation in care.

Evidence from respite programs (37,74) indicates that families can remain in control of the care

process by paying a portion of respite care costs, by using voucher systems that allow a family to select the provider, by participating in caregiving, and by helping paid providers develop care plans.

Needs of Individuals With Dementia

Arguments for and against specialized care turn, in part, on different views about medical v. social needs, about the potential of these individuals for treatment, and about the benefits of treating the person v. treating the environment.

First, the handicaps of people with dementia, and therefore their needs, differ from those of the physically ill. Since the symptoms are behavioral and the difficulties mental, for much of their illness individuals need physical less care than supervision and support of their remaining mental capacities. That difference makes one of the strongest arguments for specialized care. As these diseases progress, however, the need for physical care increases and the effectiveness of existing special units appears to lessen. More medical and nursing care will be needed. The existence of these shifting needs over time fuels the debate over a social rather than medical model of care. Each model tends to explain the individual behaviors on the basis of its own tenets, despite the fact that the distressing behaviors of dementing illnesses are explained in part by organic illnesses and in part by the social environment (see ch. 2).

Dementia has been described as a "bio-psychosocial phenomenon." Although the biological aspects

are not currently treatable, the psychological and social aspects may be amenable to intervention (52). But the shape of future programs will be heavily influenced by policy and funding, which until now have focused on either a strict medical model (Medicare and Medicaid) or a primarily social one (Older Americans Act). Many persons with dementing illnesses have psychiatric symptoms that may be amenable to treatment (see ch. 2). Services need to include psychiatric skills or access to a psychiatric consultant for help in decreasing such symptoms and maximizing function.

A second unknown is how much can be done for persons with dementia. Current funding policy assumes that people with dementia do not have rehabilitative potential and therefore are eligible only for custodial services at rates that discourage efforts to search for treatable aspects of the individual's illness. Funding does not support the employment of persons skilled in dementia care.

Function may be improved in some individuals by treating "excess disability" (52) (see ch. 2). The term refers to impairments in everyday functioning that are worse than expected considering the underlying biological deficits. Little is known about the prevalence of excess disability among persons with dementia, or about the capacity of persons to respond to treatment. Estimates of the number of those persons in nursing homes and acute care institutions with untreated conditions are high (53). Some but not all will improve significantly if treated. Much of the "improvement" documented among demented nursing home residents (discussed later in this chapter) may actually be elimination of excess disability.

A third disagreement is whether treatment should be directed at the individual or the environment. Federal policy is generally limited to funding interventions that treat the person. Reimbursement of caregiver supports or construction of facilities with special modifications for the purpose of treating someone with dementia would require a change in funding policy. Some techniques, such as reality orientation (29,30,76), behavior modification, remotivation therapy (64), fantasy and validation therapy (28), use of drugs to control behavior, and the potential use of drugs to enhance memory, are intended to effect change

in a person by acting directly on that person. Studies to date have not shown that these techniques consistently improve the functioning of persons with dementia (100). In contrast, some observers (19,60,63) argue that the individual benefits from the creation of a physical and psychosocial environment that supports function and that, conversely, inappropriate environments can result in unnecessary impairment in persons with dementia.

It may be that the environment can be modified (both physically and interpersonally) to support greater function for persons with dementia (48,56,60). The percent of individuals who would respond to an improved physical and psychosocial environment is unknown, but of the special nursing home units reviewed by OTA, all that attended to some type of excess disability or made changes in environment reported improvements in the residents with dementia. One researcher maintains that:

... there is now good evidence that even elderly demented patients are capable of showing a beneficial response to environmental manipulation. However, unlike physical therapy or similar treatments, maintenance of behavior change is dependent on the continuation of the intervention (63).

Evidence that environmental changes may be beneficial if they are continued raises another problem of policy. In general, the intent of Federal programs (such as Medicare) has been to support rehabilitative, short-term care that will enable a person to return to more normal functions, rather than interventions that must remain in place to support improvement.

Many of the people now in nursing homes and included in the estimates of the number of those with dementia, suffer from multiple, severe illnesses. Their cognitive impairment is often due both to delirium and to dementia. They are too ill to benefit from the kinds of programs described in this chapter. Even the best medical care can do little to alter their overall condition. Programs designed to improve the quality of life for people with dementia probably will have little effect on this group. However, there are also an unknown number of people who would respond to interventions but have been consigned to the "hope-

less” category. Questions about the size of the group that could be helped raise another issue of policy: Since not all cognitively impaired people will benefit from special programs, how should

those who would benefit be identified? There is a need for physicians trained in geriatrics to be available for those in nursing homes and similar settings.

SERVICES THAT CAN BE TAILORED TO PERSONS WITH DEMENTIA

In its survey, OTA asked why families did not use a service if it were available (see table 7-3). Only a few reported that the service would not accept a person with a diagnosis of dementia but, depending on the service, 5 to 18 percent reported that staff was not sufficiently knowledgeable about dementia. The most common reasons for not using or no longer using respite services, among those who knew that such services were available, were that the person entered a nursing home, the service was too expensive, the ill person died, or the service was not needed. Thus, some individuals apparently used appropriate respite services until their condition worsened, leading to placement in a nursing home or to death. This conclusion also indicates that respite care is a temporary solution and does not necessarily replace nursing home care (75).

Several different alternative services are being tried by chapters of the Alzheimer’s Disease and Related Disorders Association (ADRDA), individual entrepreneurs, family service organizations, and the health care industry. The search for appropriate care is international (65,81). At this point in the development of dementia care options, the programs are highly individualized. Providers are trying different interventions and exploring innovative ways to reach clients and hold down costs. Special programs apparently are still rare, however. There is no listing of existing services, but the special units in nursing homes and respite programs are estimated to be serving between 1 and 2 percent of persons with dementia. (This figure is based on programs known to American Association of Homes for the Aged (AAHA), American Health Care Association, ADRDA, New York State

Table 7-3.—OTA Survey: Reasons for Not Using Available Support Services^a

Reasons	Base ^b	Paid companion/ health aide	Visiting nurse	Respite care	Adult day care	Domiciliary/ boarding care	Special dementia nursing home care
		36%	42%	17%	240/0	10 %/0	13%/0
The patient entered a nursing home . . .		46	43	40	35	40	24
The service is too expensive.		31	23	24	11	16	19
The patient got worse or died.		21	21	15	17	9	20
The service is not needed		19	27	25	19	26	27
The people available to provide this service are not sufficiently knowledgeable about dementia		16	11	5	5	9	4
The patient refused to accept the service.		15	10	10	25	13	5
Lack of knowledge about how to arrange for this service		9	2	6	4	6	10
The waiting list is too long		4	1	3	2	2	7
The service would not accept the patient because of the patient’s diagnosis		1		4	6	6	5
Other reasons		12	6	13	11	11	14
No answer		6	9	9	8	15	11

^aQuestion was asked of respondents who said respective service was available but was not used.

^bPercent of total surveyed. Totals more than 100%/0 because of multiple responses

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

Department of Health, Hebrew Home for the Aged at Riverdale, Hillhaven Corp., National Council on Aging, and OTA.)

Companion Care, Home Health Aides, and Visiting Nurses

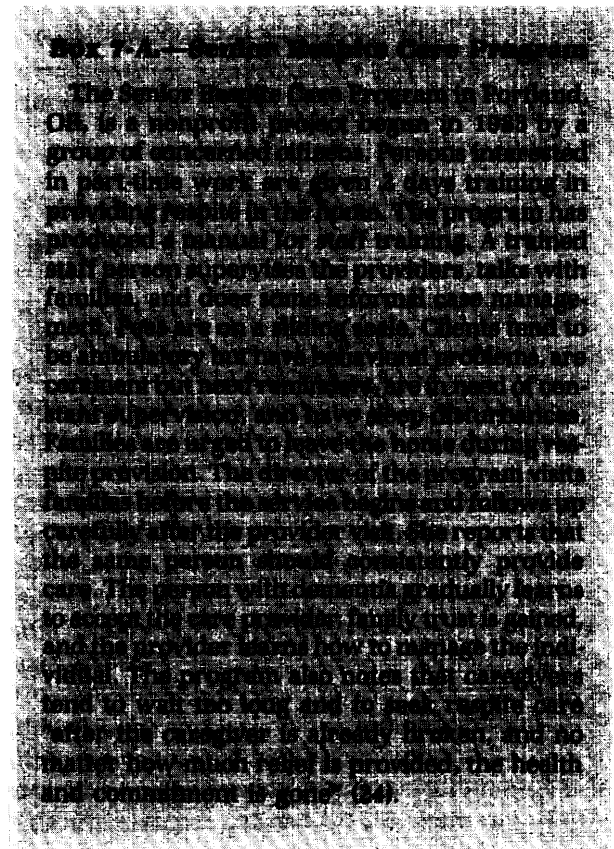
Families report that part-time help at home is the form of respite they need most (37,99). In programs providing such care, a nonprofessional person with special training spends a few hours a week with the individuals with dementia so that the caregiver can leave the home or rest. Fifty-nine percent of the respondents in the OTA study had used an aide in the home and 44 percent had used a visiting nurse. Families often used a home health care agency or made private arrangements, thus the number of these providers who had special training is not known. Some specialized programs use volunteers, others use "paid volunteers," and some pay a salary.

Several ADRDA chapters offer help at home, and others are allied with respite providers. The three programs described in boxes 7-A, 7-B, and 7-C found that a half-day per week, or less than 6 hours weekly, was what families most often needed. Relief was requested most often during regular business hours.

Although programs affiliated with ADRDA or with universities attempt to ensure the quality of in-home providers, there is little or no mandated monitoring of the quality of home care. Home care aides generally are not required to have special training or to be bonded. There is often no requirement for background checks of persons going into the homes of vulnerable persons. Possibilities exist, therefore, that individuals with dementia and their families might be exploited. Some families have refused to use in-home care for these reasons.

Adult Day Care

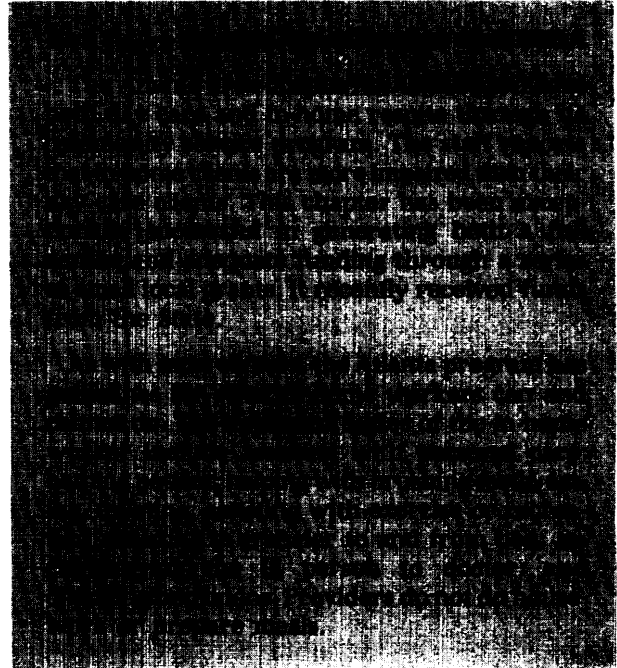
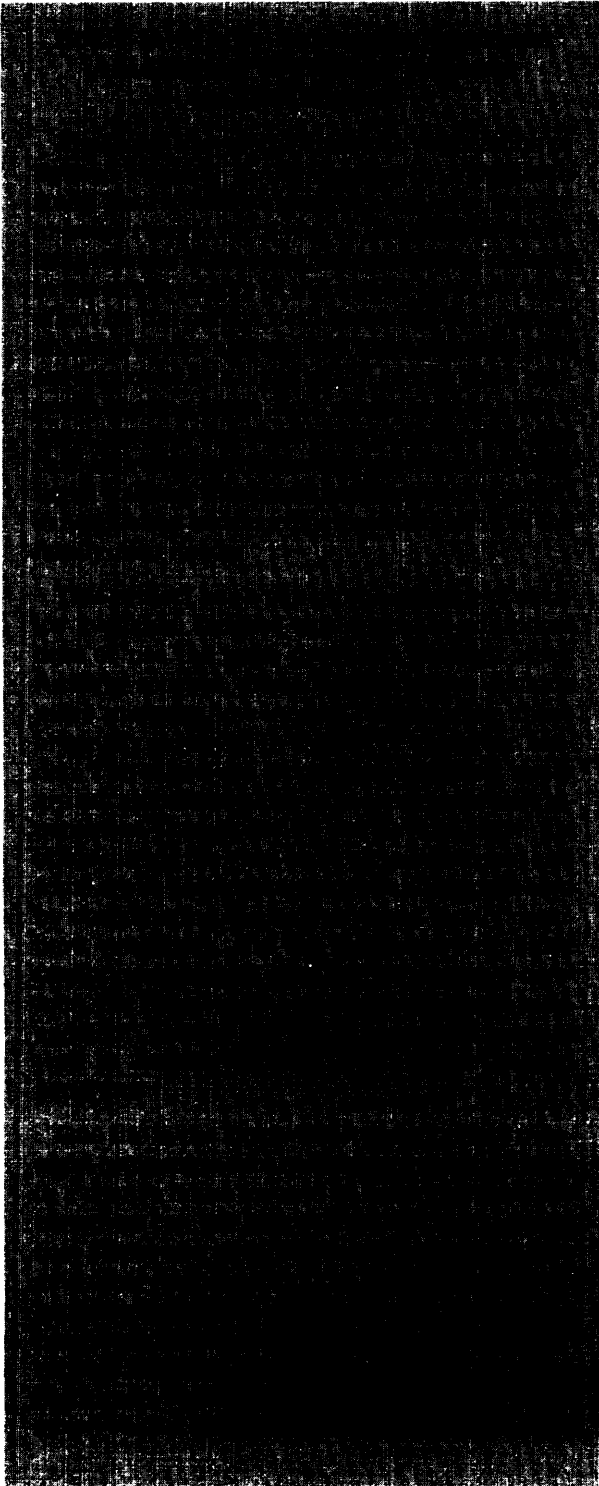
Adult day care has developed as an option of care for frail elderly persons mainly in the past 15 years. It has served primarily individuals who were cognitively intact, but many day care centers have always served a few confused persons. Over the past 5 years, with the increasing interest in



dementia, several day care centers have been established solely for individuals with dementia.

Adult day care contrasts with geriatric day hospitals that have been developed in England. A day hospital offers many of the same services as a regular hospital, except that patients live at home. The emphasis is on medical treatment and rehabilitation (7). Clients have a potential for improvement and the staff includes rehabilitation therapists. There are few day hospitals in the United States, where the focus has been on adult day care.

Day care differs from day hospitals in services offered (less medical, psychiatric, and rehabilitative care), client population (more chronically impaired), the expected outcomes (less client improvement), and staffing pattern (68). Some States (e.g., California) further distinguished between adult day care and adult day health care. Although it offers social programming, day health care places greater emphasis on nursing needs of clients. This distinction is often difficult to make



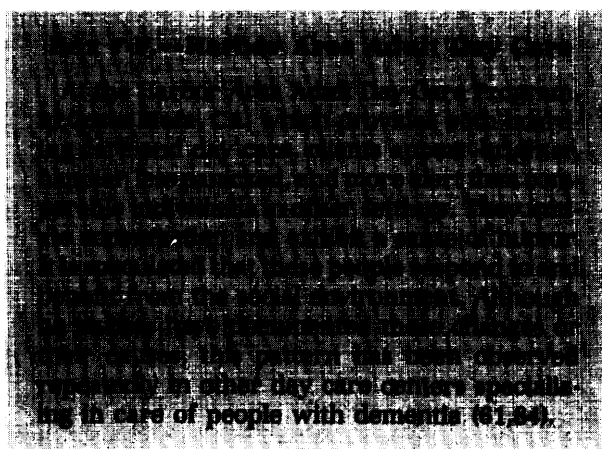
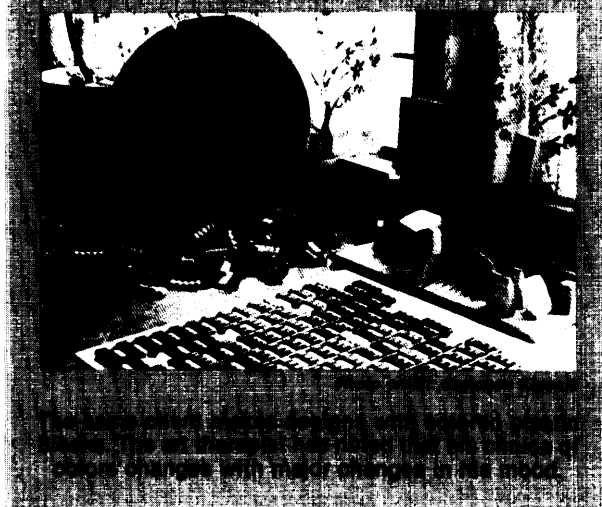
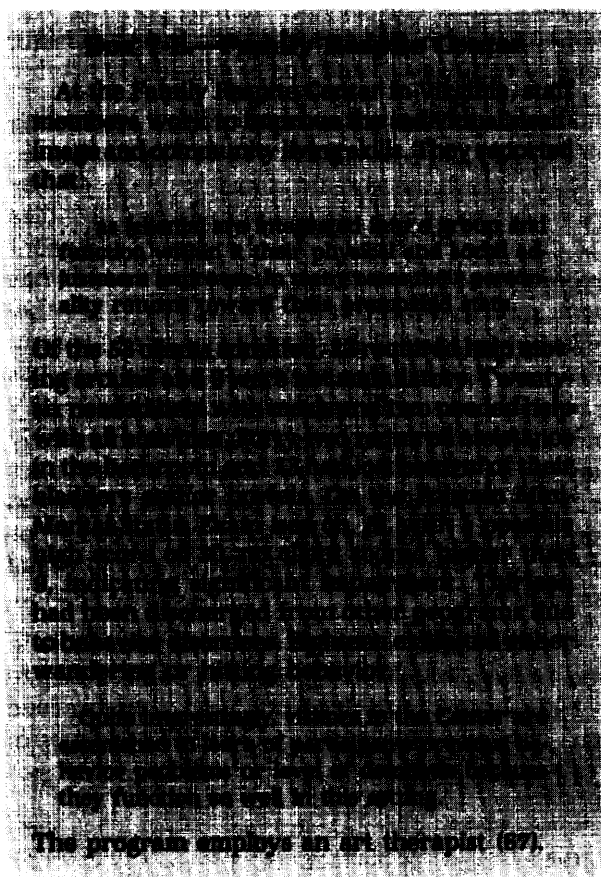
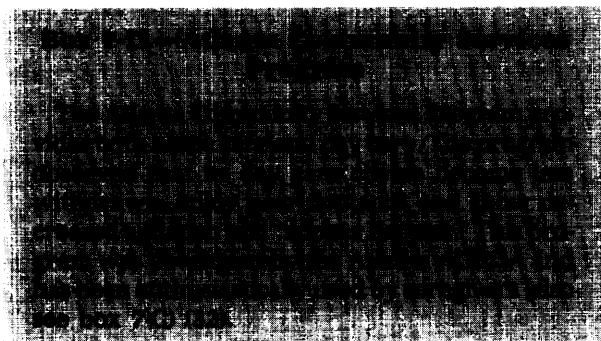
in practice and can serve to exclude persons with dementia, who characteristically need nursing care, socialization, and social services.

Despite enthusiastic reports of the positive effect of day care on persons with dementing illnesses, questions remain about the role of day care and its effect on individuals and families (34,61). One problem is the number of different expectations people have about day care. It has been seen as a treatment, assessment, and rehabilitation program; as a form of support for families; as a means of providing stimulation; and as a vehicle for promoting and maintaining quality of life. Such diverse goals make attempts to study day care's effectiveness difficult. However, care is clearly not appropriate for some individuals and families (e.g., people who have no caregiver or those who are too ill to benefit from the social experience).

A 1984 survey of adult day care programs in the United States estimated that some 2,200 to 2,400 persons with dementia were being served (61). The majority of centers served a mixture of confused and alert clients, but 17 centers (5 per-

cent) specialized in care of persons with dementia. Although still relatively rare, the number of programs focusing on dementia is increasing.

Three special adult day care centers—Atlanta Community Services Program, Family Respite Center in Falls Church, VA, and Harbor Area Adult Day Care in Costa Mesa, CA—reported to OTA on their programs (see boxes 7-D, 7-E, and 7-F). OTA staff visited the latter two programs, as well



as the Alzheimer's Family Center in San Diego (see box 7-G). All were started with the assistance of community groups. All have succeeded in providing care to people who need one-to-one help with meals, who are ambulatory and prone to wander, who need assistance with toileting, and who have behavioral outbursts. All report significant benefits to clients and families. Most programs provide some nursing management to clients and some social services to caregivers.

Day care is consistently reported to be beneficial to clients, in addition to providing respite to families. In the national survey, 84 percent of the centers said their clients with dementia made friends with others, 79 percent thought that clients enjoyed day care, 67 percent reported that pacing and wandering decreased, and 71 percent reported that clients had fewer emotional outbursts (61).

The 1984 survey of day care reported a mean charge per day of \$20 (61). It did not determine costs. The ADRDA estimates a current average daily cost of \$25 to \$30 (5), and the National Institute on Adult Day Care reports an average cost, with subsidies, of \$31 per day (78). The survey reported ratios of one staff person to four or five clients. Some programs are open from early morning to late evening weekdays in order to accommodate working caregivers. These centers were also found to be providing considerable informal support to families through teaching, case coordination, and short-term counseling. Centers supplement staff with volunteers (61).

These findings indicate that, as with other forms of respite, day care probably does not replace nursing homes, but serves instead as a vital sup-

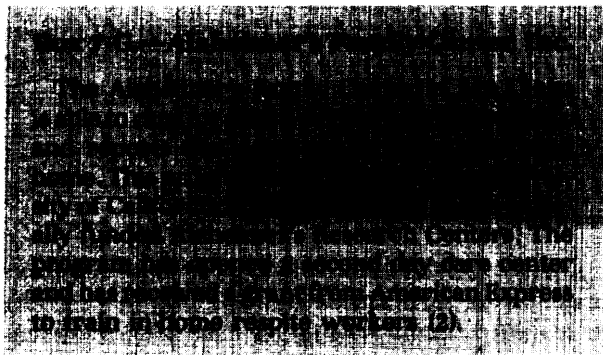
port to families in the period before nursing home placement is needed (see also ch. 4). And they show that not all individuals or families can use day care. Other physical illnesses; a greater need for help with walking, toileting, and eating than the center can manage; and inability to adjust to a new environment prevent some people from using day care. About one client in five dropped out because of inability to adjust to the setting (61). To date there is no way to identify these people in advance. The OTA study found that among families who had access to adult day care, 25 percent reported that the person with dementia rejected the service (i.e., could not adjust to day care or was unable to function in a group).

The most common reasons for discharge from day care, according to the national survey, were (in descending order) client's transfer to a nursing home, client's death, and client's inability to adjust to the program. The OTA study findings were similar. Transportation problems and client moves from one household to another are other reasons for discharge.

Transportation is a serious problem both in the United States (61) and in Great Britain, where day care has been used much longer (3). Elderly caregivers may not be able to drive, and confused, disoriented individuals cannot tolerate a long bus ride—necessary unless the clients live in an area with a high population density. They may be unwilling to board the bus or may wander away when they are dropped off. Some programs have a staff person on the bus to assist clients in and out of the home and the transport vehicle.

Regardless of problems associated with day care, the social responsiveness of those with dementia confirms that it is one way to improve the quality of life for these individuals as well as provide respite for caregivers. Multiple factors of both client and caregiver determine who will successfully use this resource. As with child day care, adult day care may prove to be an excellent employee benefit for adult children caring for a parent.

Unlike some other methods of providing special care, most day care programs are providing substantially the same services and have had enough experience with clients to establish guidelines on what these services should be (54,71,72,



85,101). The National Council on the Aging has published a bibliography of sources (87). Night care has also been proposed for people who could live with family but whose nighttime activities seriously stress the caregiver.

Short-Term Residential Care

Short-term residential care provides stays of days or weeks in a residential setting, usually a nursing home. Only 13 percent of caregivers responding to the OTA survey used short-term residential care, perhaps because it is rarely available. Forty-three percent, however, ranked it as "most important."

These programs have several problems, however. Because the stay is too brief for residents to adjust to the surroundings, they may be more restless and agitated than participants in other programs. Short-term programs may therefore need additional staff. Care may be more difficult if individuals are placed on units with residents who are not confused. And nursing homes report that regulations and paperwork for a short-term admission are so cumbersome that short stays are not cost-effective.

In the past, the urgent need for short-term respite has led to acute hospital admissions for persons whose caregiver must have medical care or rest. Used that way, this is an extraordinarily ex-

pensive resource; it has been proposed, however, that empty hospital beds could be used for respite.

Some programs have found that families are reluctant to take the ill persons with dementia back at the end of the respite period. These are probably families who actually needed to have the person placed in a nursing home but who tried to compromise by using respite. For some caregivers, short-term admission helps them realize how ill the individual is or that the person does not know where he or she is or who is providing care. The presence of nursing staff may confirm for the family that the person really needs more care than they can provide (37,43). These things all make it easier for reluctant caregivers to accept nursing home placement.

Multi-Service Programs

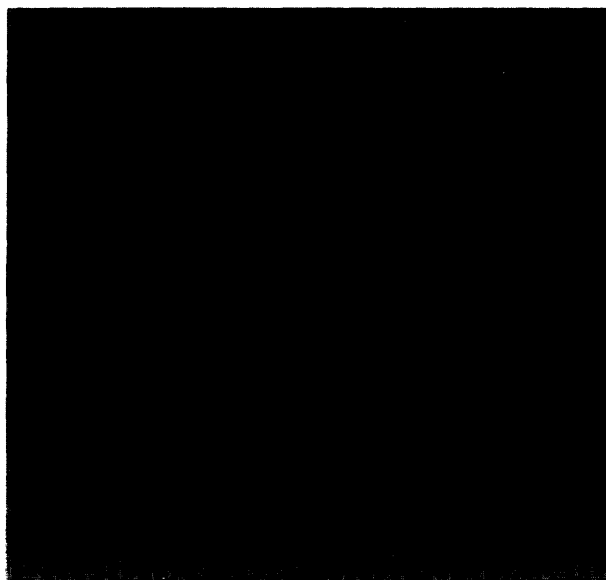
Programs are being developed that offer a wide range of services to the family and the person with dementia. These multi-service programs have the advantage of coordinating care and facilitating referral from one program to another, and allowing staff members to get to know individual clients and families. In addition, the staff at such programs has access to a broad database for research.

California recently authorized a 4-year demonstration project for three Alzheimer's disease institutes that would provide a continuum of traditional and innovative services including diagnosis and assessment, day care, home care, hospice care, and skilled nursing care (Assembly Bill 999).

Other Settings

Other forms of care being considered or tried include vacation programs that serve both the ill person and the caregiver (1), sitter programs in a group site (75), client recreation and therapy while families are being provided group therapy (57), medical teams that do an in-home evaluation, and family-run cooperatives (1,75). Publications on these various programs are slowly becoming available (15,21)38)77,79,101).

Although the family is clearly the most common provider of care, little attention has been given to training family members—the primary caregiver and members of the extended family—in the



Box 7-L—Family Survival Project

The Family Survival Project is a freestanding program in San Francisco that provides information, advice and referral; case coordination; legal counseling; and in-home supportive services to brain-damaged adults. The program attributes its success to its decision to include adults with any form of brain damage: dementia, trauma, vascular accidents, etc. It also sought to form a partnership with the public sector and to identify the family, as well as the patient, as the target population. It did not include income criteria in its model programs and has avoided becoming yet another categorically based service.

The program has been remarkably successful in serving caregivers in a previously unserved segment and in generating government support for its programs, which have been called a "good buy" (74). The Family Survival Project has contracted with the Institute for Health and Aging at the University of California, San Francisco to conduct a study concerning the costs of formal and informal care provided to brain-impaired adults (74).

Box 7-J.—Comprehensive Services on Aging Institute

The COPSA (Comprehensive Services on Aging) Institute for Alzheimer's Disease and Related Disorders in New Jersey is a statewide program funded by the State for persons with dementia, their families, and the professionals who care for them.

A resource center provides information and referral to families and professionals, ongoing phone consultations, family education and counseling, and liaison with family support groups and professionals. A diagnostic clinic provides diagnostic workups for the memory-impaired and confused, second opinions, and coordination of followup recommendations. A day hospital provides rehabilitation and treatment for persons with dementia, education and support for families, and it is also a training site for health professionals. The consultation and education program provides training and seminars for professionals and technical assistance for the development of dementia programs (22).

techniques of care. Some ADRDA chapters have launched programs that train family members or lay persons in the community to care for persons with dementia. Caregivers might learn to care with less stress to themselves. Other members of the extended family may not provide support or give respite to the caregiver because they feel helpless and do not know what to do. In such situations, a family member can learn to be a respite care provider.

Family training is often done informally by professionals who observe the need. A nurse visiting in the home to treat a person with dementia offers extensive bedside training for the caregiver, for example. Although such services are not covered by Medicare or other sources, they may be of significant value in keeping the individual with dementia in good health and in sustaining the caregiver.

Hospice

Programs and services similar to hospice, which assist individuals and families at the end of the person's life, may be needed. OTA found no such programs except for the excellent care of families and patients provided by major research institutions. The needs of a dying person with dementia and his or her family have needs that differ in some ways from those of other dying individuals. The person may be terminally ill for many months or years, and approaching death can be difficult to predict. Unlike patients dying with cancer, for example, people with dementia are often unable to communicate with family or express their wishes. They may be mute and immobile. Because of the long, slow, deteriorating progress of the illness, the family may have been grieving for a long time, and some families have already begun to emotionally separate from their relative.

A major concern of many families is providing appropriate, but not aggressive, medical care for a person with dementia who is nearing the end of life. Nursing homes may have unwritten policies that are not discussed with families. These policies may include transferring a dying patient to an acute hospital against family wishes, or "not calling the ambulance until morning"—in effect) letting the person die (see ch. 5) (9). Facilities with such unwritten policies do not take into consideration the wishes of the family.

RESIDENTIAL SPECIAL CARE

At some point in a dementing illness, many individuals and families need long-term residential (institutional) care. Such care is most often provided by intermediate and skilled nursing homes. In what ways should these offer persons with dementia special services or specialized care? and in what ways is their care the same as that for other persons with chronic illnesses? Although these facilities have always cared for persons with dementia, some are now developing special units or offering special services.

Foster Homes, Domiciliary Care, and Boarding Homes

Few residential facilities other than nursing homes specialize in the care of persons with dementia (see boxes 7-K and 7-L for descriptions of

Box 7-K.—Suncoast Institute for Applied Gerontology

The Suncoast Institute for Applied Gerontology in Costa Mesa, CA has combined adult day care and boarding home care. It reports that the use of a boarding home exclusively to care for persons with Alzheimer's disease has increased its capacity to tolerate deviant behavior. The program uses a registered nurse who consults at both the day care center and the boarding homes. She helps the staff manage client medications, incontinence, imbalances, sleep disorders, nutrition needs, and behavior problems. She also acts as an intermediary between the facility and the client's physicians.

The philosophy of this program includes supporting clients' dignity, sense of control, and opportunity for choices. Clients have frequent outings, which are cited as important in reducing their agitation. Most of the clients in this program are ambulatory and partially continent. Many have had severe behavior problems. Average monthly room per client are \$1,021 and \$1,050. Room rates in the higher cost unit are more inflated and need a private bath. The facility also carries a mortgage. The reported monthly costs are lower than the \$2,200 average nursing home cost in the area (54).

Box 7-L.—Valenti Alzheimer's Care Center

The Valenti Alzheimer's Care Centers in southeastern Pennsylvania operate under that State's personal care license. Their advertisement accurately describes the program:

Care—In comfortable, home-like settings, we provide round-the-clock care in areas where residents can no longer cope, loss of encouragement, and a positive outlook.

Therapy—A specially oriented staff administers a varied program of daily exercise, music therapy, and participation in simple projects and familiar chores to help clients retain confidence and self-worth (94).

two such programs). Those that do cite limited regulation as one reason they are able to devise creative programs at costs competitive with nursing homes, although as discussed below, that absence of regulation can be exploited by less scrupulous programs.

The Johns Hopkins Hospital in Baltimore operates an adult foster care program that accepts some persons with dementia (69). In Michigan, two foster care homes accept persons with dementia. Illinois reports that a small group home there accepts persons with dementia for short stays (1).

Facilities such as these can offer clients individual attention, a day filled with activities, a sense of safety and security, and a life much closer to normal than that in a larger facility. Although residents in both the Suncoast Institute and the Valenti centers are visibly impaired, the behavioral problems commonly seen in boardinghouses and nursing homes—apathy, drowsiness, pacing, screaming, aggression, absence of initiative, and lack of humor—are not evident (although both report that these occasionally occur).

These programs report that quality boarding home care for persons in the middle stages of their illness is possible. However, such homes are extremely rare. The norm, unfortunately, is substandard facilities that offer no special services and only minimal services that are not appropri-

ate for clients with dementia. Boarding homes rarely employ a nurse (although the two profiled programs do), nor do they provide activities or adequate supervision.

Special facilities can provide a level of supervision and care that is higher than that of most other boarding homes. Although they can provide excellent care for a portion of a person's illness, however, they are neither safe nor appropriate for very ill individuals.

California recently passed legislation addressing quality assurance in board and care (Senate Bill 185). It calls for the development of three levels of care: basic care and supervision, nonmedical personal care, and health-related assistance. The legislation provides for standards and supervision designed to ensure the facility's ability to serve clients at each level of care they intend to offer.

As noted, the same absence of regulation that allows creative programming by dedicated staff can also allow unscrupulous operators to take advantage of individuals with dementia. Although family members are urging the expansion of boarding facilities, many State regulations governing these facilities are lax or absent. If such care is not to be funded by the State, or costs less than nursing home care, some States may overlook the potential for abuse.

Even dedicated providers can make mistakes. One operator is known to have established a "step down" unit for more severely impaired individuals. These residents appeared to be receiving excellent care, and their families were reportedly satisfied. Although the facility had smoke alarms and exterior fire escapes, however, the residents could not assist in their own evacuation in the event of fire and therefore were in an unsafe situation.

Another problem with boarding homes is cost: The profiled facilities are competing successfully with private pay nursing home care and offering excellent programming and professional care, yet no evidence indicates that this kind of care can be provided at rates for boarding homes paid for by Supplemental Security Income (SSI) or the Veterans Administration (VA).

Finally, good quality boarding care is so rare that many families may not be aware of it. Five percent of the respondents in the OTA study had used boarding home care and only 25 percent identified it as "most important." Both the California facility and the one in Pennsylvania were at or near capacity, suggesting that there may be an unmet demand.

Special Units in Nursing Homes

A rapidly growing and controversial program is the development in nursing homes of long-term care units that specialize in the care of persons with dementia. Both the for-profit and the non-profit sectors are hiring experts, establishing planning committees, holding conferences (66), and opening "special" units. Some are drafting "national" guidelines or local standards (14). Some have developed policy and procedures documents (50). Others have not segregated the residents, but offer them special programs in regular units (86).

Special nursing home units are being developed largely in response to the belief that they foster better care and, conversely, that nursing home residents who do not have a dementing illness prefer separate living space. But these reasons do not fully account for the rapid development of special units. Some people in the nursing home industry see separate units as good marketing strategy, and some argue that individuals with dementia are easier to care for in a special setting where they are all together.

There are many persons with dementia in nursing homes (92), but traditional forms of care have failed to successfully treat behavioral problems. One survey of 42 skilled nursing facilities (1,139 patients) found that 64 percent of residents had significant behavioral problems (102). Some specialized programs report successful reduction of these behaviors (16,18).

Major differences have been noted in the amount and type of changes facilities have made for residents with dementia. Some units appear no different from the other units of a facility; others have significant changes in structure or decor, in staffing and staff training, in the amount

and type of services offered, in admission procedures, and in the appearance of residents. Most notable is the variation in what experts perceive these individuals need. For example, some propose that the units be painted in bright primary colors, but others suggest all white, and still others propose pastels. Arguments are buttressed with theories of cognition. Less trivial differences of opinion involve philosophy, staff-to-patient ratios, floor plans, and the number of persons on a unit. Decisions about these factors can represent significant investments for the facilities. Rigorous comparative study is needed to resolve such controversies.

Availability and Costs

The number of special nursing home units open or planned is unknown; OTA found 110 facilities. Specialists in the field report that they frequently hear of new units being developed (5,37)70). Based on this information, and on the opinions of those in the industry, it can be estimated that fewer than 500 special units are developed or close to completion, although more are being planned.

A major for-profit chain, Hillhaven Corp., has a full-time employee to set up special units. The corporation has opened 49 units, and one facility is devoted entirely to persons with dementia. Non-profit organizations are also involved in developing special programs. The Hebrew Home for the Aged at Riverdale (Riverdale, NY) surveyed 38 homes that provide special services or have a special unit (95). AAHA is developing resources for facilities that are opening special units.

Despite the growing movement to create such units, they serve only a small portion of the large number of persons with dementia who live in nursing homes; an estimated 60 to 74 percent of nursing home residents in traditional mixed units have dementia (8,83). Even when a facility has a special unit for some residents, a majority of other residents in the facility also have dementia. Some home health agencies and nursing homes offering special care accept only those who can pay for care privately, excluding those whose care is covered by Medicaid. These programs report that they cannot provide quality care for persons with dementia at Medicaid's low payment rates.

Little information is available on the costs of special care. Because changes in cost are partially tied to changes in the physical plant, extent of programming, and staffing, they can vary according to the facility's perception of what constitutes a special unit. Care approaches vary so widely that costs for individual programs cannot be assumed to be representative, but most units report costs of \$5 to \$10 per day higher than for standard care, although some excellent programs report no difference, and in fact, cost significantly less than other special units. Some programs, both for-profit and not-for-profit, have cost information that is not publicly available.

In a report on the special residential unit, Wesley Hall in Michigan, an OTA contractor wrote:

... residents have consistently scored on the Mental Status Questionnaire by Kehn, et al. (1960), in the range of 0-2, placing them in the category of the severely impaired.

At the time of the completion of the project [12/85], daily costs to residents of the old age home unit were \$29.70; Wesley Hall residents paid \$42.65 a day; and the nursing home section cost \$60.00 per day (18).

The consensus is that good care in special units requires more staffing and better-trained staff, and probably more square feet per patient than required by Medicare, Medicaid, or State standards. Some clinicians argue that residents of special units exhibit fewer disturbed behaviors and therefore will use less nursing time than in mixed facilities, and that changes in staffing patterns and task assignment will increase efficiency (26). But it is unlikely that good care can be provided to these difficult individuals with staff-to-resident ratios lower than current minimums. Good studies of cost are urgently needed, but must await a determination of what components are necessary or ideal in a special unit.

Architectural Design

The architectural design of special units is controversial. The most common nursing home design is a long corridor with double rooms opening onto it. There is often a small room for visitors. Meals are eaten in a large communal dining hall

and activities are conducted in a separate area. Each unit has a nurses' station similar to those in hospitals. This design is thought to be detrimental to the functioning of persons with dementia. It discourages social functioning, it is disorienting and noisy, and the communal dining room overstresses people with dementia (17,18).

A "racetrack" design has been proposed for persons with dementia (65). The building's corridor is circular, encouraging the resident with dementia to wander in safety. But the design probably discourages social functioning and orientation. The Philadelphia Geriatric Center has a large central room with residents' rooms opening onto it (55). That arrangement encouraged social interaction and simplified supervision.

Some of the programs observed by OTA were small—from 8 to 15 residents (6,18). Residents had small single rooms. There were one or two small sitting rooms that also served as dining areas and activity spaces. It is easier for residents to orient themselves and to interact with others on small units. Small dining rooms are quieter and less confusing. This type of setting helps people relax so that they can regain old skills or make friends. The industry reports that this design is expensive, although it is not yet clear that variations, such as groups of clusters, would be significantly costlier than traditional units.

Many facilities emphasize the importance of access to a secure outside area where residents may walk, keep a pet, grow flowers, or enjoy the sun. Outside exercise is thought to contribute to the restoration of normal sleep cycles.

Most nursing homes planning a special dementia unit are restricted by the design of the existing building. Some convert a resident room into a sitting room or locate the unit at the end of a corridor where it can be cut off from traffic through the facility. The resulting loss of bed space increases costs.

Interior Decor

Successful programs have encouraged residents and families to furnish rooms extensively with the resident's own possessions. That appears to help them to accept that they live there. Administra-

tors in some facilities argue that personal possessions will be stolen, although small special units report that this has not been a problem. The smaller units and higher staff ratio probably prevent that problem.

Controlling resident egress is a significant concern for institutions caring for wandering individuals. Locked doors may be forbidden by fire codes. While some facilities use buzzers that sound when doors are opened, others report that this system caused staff to check doors constantly. Several electronic sensing devices are now available. Facilities can be secured without locks, however, and successful units have disguised exits or located them so that residents must pass several staff persons before reaching the outside.

There are several schools of thought on decor. (Although many facilities, however, decorate according to their expectation of the family's taste, not the resident's needs.) Low stimulus decorating means reducing visual stimuli—color, decorations, clutter—as much as possible. A pastel decor is a variation of that school of thought. In contrast, Wesley Hall at the University of Michigan uses bright, high-contrast colors (yellow, red, and kelly green with white) to provide visual stimulus and to help those residents who have visual problems (18). The aging eye is better able to see these colors and the contrasts help residents distinguish the boundaries between toilet and floor, or between floor and wall. The lighting level in the unit was increased and glare was reduced, again to assist the aging eye. Wesley Hall has a small kitchen where residents prepare snacks and clean up after meals. The staff uses a desk in the kitchen. There is no nurses' station. These unusual components help to restore normal roles to the residents—for example, getting oneself a glass of milk or helping to dry dishes. The absence of a nurses' station helps to make the relationship of staff to residents more therapeutic.

Furnishings in the most successful units visited by OTA were more "home-like" than in most nursing homes or hospitals. Many of the special units have no paging system, and extraneous, distracting noises such as those of the main kitchen, hallway traffic, or meal carts are reduced or eliminated. Pianos and record players are used often (18).

There is a substantial amount of literature on the characteristics of architecture and environment that benefit the aging person (18,46,47,48, 49,55,88,89). Environmental changes must consider the visual, hearing, and gait impairments of this age group and analyze each aspect of the environment for its tendency to confuse or disorient (101). For the doubly impaired elderly person with a dementia, these factors are even more important but are frequently ignored,

Step Down Units

Special dementia units in nursing homes usually serve residents in the middle stages of their illnesses. As the cognitive abilities of these individuals gradually deteriorates, however, they eventually need a level of care different from that originally established by the unit. Some nursing homes transfer these residents to regular skilled nursing units; others have established "step down units" where these more impaired persons can still be given special sensory stimulation, passive exercise, nutrition support, and be kept as alert and physically active as possible.

Characteristics of Special Programs

Many of the characteristics of special programs in nursing homes and board and care homes are similar to those in day care and respite care.

Characteristics of Residents

The special programs reviewed by OTA were fairly consistent specifying the type of client they serve: those who were ambulatory, exhibited problem behaviors, and, in some cases, were incontinent. In general, these are people in the middle stages of a dementing illness. These individuals are capable of participating in activities and in helping to care for themselves. Some programs report that it is preferable to group residents homogeneously by severity of mental impairment. Others point out that a workable resident mix, staffing, and programming vary with the stage of the illness. Thus existing programs vary in their practices, and most focus on subgroups of these with dementia.

Benefits to Residents

The crucial issue of special services—for family members as well as the government—is whether they are significantly better for people with dementia than other forms of care. Until recently it was assumed that little could be done for persons with dementia beyond providing for their physical needs. The recent interest in dementing disorders has focused clinicians' attention on the quality of life of these persons. Some now assert that people with dementia are capable of considerable improvement in behavior, social function, and life satisfaction or happiness (6,13,16,18,60).

A few programs claim that their clients improve in some respects when given special care. This idea is by no means universally accepted, however, and few practitioners are willing to accept the extent of change claimed by some of these programs. It is agreed that a person's underlying dementia cannot now be reversed, and that individuals with dementia will move toward more severe illness and eventual death. Some programs report an initial improvement in participants, followed by a gradual, but less precipitous decline.

Among the changes reported are:

1. decrease in wandering (18,86);
2. decrease in episodes of agitation (18,39);
3. no screaming or a decrease in screaming (42);
4. few or no drugs needed to control behavior (18,39,90);
5. improved orientation (18,90);
6. decrease in socially unacceptable behaviors (masturbation, rummaging in other patients' rooms, etc.) (18,90);
7. weight gains or improved eating (18,39,90);
8. decrease in depression (18);
9. greater ability to sleep through the night (18,39);
10. a sense of humor (18);
11. a happy, relaxed appearance (18,39);
12. the formation of friendships (18,39,61);
13. reduction or elimination of incontinence (18,96);
14. the initiation of interpersonal exchanges (18); and
15. decrease in hallucinations (39).

It is noteworthy that these changes reflect either decreases in extreme disturbed behavior or increases in socially appropriate behavior. No program reports that residents consistently improved in language skills, motor skills, or memory—problems that are likely evidence of the disease itself, rather than responses to the environment.

The surprising finding that some participants can improve in certain kinds of function may have several explanations. In most experiments, the focus on the intervention and increased staff enthusiasm lead to some improvement. Second, people who are severely impaired may be even more responsive to slight improvements in the environment (55). Third, this finding may also reflect the extent to which inappropriate forms of care add to resident impairment.

All three factors probably contribute to the changes seen. Most clinicians agree that some of the changes listed (often the first seven) can be achieved in some individuals by maintaining them in good health—that is, by eliminating excess disability (see ch. 2). Almost all the residential programs reviewed by OTA that made some environmental changes when they created special units report improvements in their residents. Many day care centers report the same changes in some clients (61), and observation and unpublished reports from other nursing homes suggest similar results. OTA found no appropriately designed and controlled study of participant change. Anecdotal reports of partial improvement are encouraging, however, and fail to support the common position of therapeutic nihilism. OTA found no study seeking to improve psychosocial function in individuals with dementia living at home (and not in day care).

The remaining eight changes were reported by fewer programs, which have served a total of only about 200 individuals. It is not known whether these results can be replicated and, if so, which patients are most likely to respond, and over how much time. The techniques for this special care are only now being developed and have not been tested. Yet the initial reports are encouraging.

It is also important to note, as mentioned, that behavioral gains made by individuals receiving special care will not carry over if the special care

is stopped. In some States, when individuals improve in functioning levels, they are reclassified from skilled to intermediate care and can no longer stay in the special units; they therefore will not maintain any gains. Day care clients in programs that have a rehabilitative mandate may be discharged when clients improve, setting up a “revolving door” pattern, with improvement under special care followed by discharge and worsening symptoms and subsequent readmission.

Overall Approach to Care

Since special programs and reported change vary considerably, it is premature to describe the characteristics of special programs in a final form, or to establish standards or criteria for these programs. Indeed, guidelines or standards could freeze into place approaches that may later prove less than optimal, or could block experimentation with other interventions. Further clinical experience and the replication of the most successful programs are needed.

But that does not mean that nothing can be done. A considerable body of knowledge exists on the nature of dementia (53) that can be applied to techniques of care. And a good deal is known about similar patients—geriatric patients in State hospitals (20,35,36,51) and nursing home residents in general (many of whom are demented). Finally, the overall approach to patient care is widely agreed upon (4, 10, 11,41,62,98). These findings permit some general observations on the approach of special units. The most successful programs (in residential and day care) resemble each other in key factors and strive toward common goals:

- to prevent excess disability due to other health problems or medication;
- to use as few psychoactive medications as possible, and use few if any, physical restraints;
- to maximize an individual's ability to hear and see;
- to enhance remaining function rather than to restore function lost through the disease process;
- to reduce long hours of idleness;
- to use activities and a caregiving style that enhance resident comprehension of appropriate roles as friend, parent, or volunteer,

and that reinforce a sense of personhood and dignity;

- to create a “homey” environment in which residents are dressed and well groomed;
- to use a mixture of flexibility, creativity, and both structured and nonstructured approaches of activities;
- to emphasize the importance of respect for residents and to individualize approaches;
- to recognize the importance of environmental accommodation and the significance of a benign, nonstressful, supportive environment; and
- to support the family in a continuing relationship with the resident.

One observer of special unit residents reports:

... spontaneous interaction between and among residents, staff, and visitors . . . joy or the manifestations of joy—smiling, laughter (13).

The director of Wesley Hall reports residents who appear happy, exhibit spontaneous laughter, and initiate communication with staff and other residents. This unit also has successfully experimented with clowning and focused on the role of humor (17).

Staff

The way a facility's staff relates to resident's clearly affects behavior (38). For much of their illness, persons with Alzheimer's disease seem to retain the capacity to read nonverbal communication correctly (26). That has important clinical implications: Staff members who are hurried or irritable, or who belittle a person, may trigger behavioral outbursts. Programs in which staff members “talk down” to participants tend to produce patients who either become stubborn or behaviorally regressed. Staff approaches should be cheerful and calm, allowing patients to make what decisions they are able to.

Changing staff behavior toward residents raises several problems often reported in connection with nursing homes: the need for a motivated, concerned administration; for adequate staff salaries commensurate with the tasks required; and for a stable, adequately trained staff (see ch. 9) (26). The existing special units have attracted

professionals and nurse's aides who wanted a psychological and emotional challenge, who want to be able to give to others (80), and who enjoy the rewards of community interest and the administration's enthusiasm.

Initial training and strong, ongoing support appear to be necessary for staff to work successfully on these units. Several training packages are being prepared or planned (13,17,26,38,45,79,101). The philosophy, techniques, and objectives of these training materials differ, but most emphasize the need for all staff members to be trained—administrators, nurse's aides, therapists, and even housekeeping, dietary, and janitorial personnel. (Housekeeping staff, for example, spend significant amounts of time with residents and therefore affect behavior (44)). A team approach with communication among staff members and across shifts is emphasized (26).

Some programs report that staff members can work on a dementia unit regularly, rather than rotate on and off, if given adequate support. Contrary to the prediction that the staff on all dementia units would “burn out,” some programs have found lower turnover among the staff of special units. Other programs, however, report problems with staff burnout. Consistent staffing seems to be reassuring to the residents. Staff members develop expertise, and they learn the habits of individuals (26).

Persons with dementia usually have a mixture of social and medical needs. The emphasis on social v. medical needs is influenced by the severity of the resident medical problems. Successful programs have staff members with differing expertise who work together as a team. The delivery of a person's care is provided by nonprofessional nurse's aides just as in traditional nursing homes. With training and ongoing support, aides have provided excellent care in special units. One recent book gives instructions and guidance for this group of caregivers (38), and a second addresses nursing staff (26).

The optimal ratio of staff to residents has not been established. Needed levels probably will vary with severity of participant impairment. Wesley Hall reports a day shift staff-to-resident ratio of 1 to 4.4 (18). Green Hills Center reports a day shift

ratio of 1 to 5.8 (90). The ratio in programs examined by OTA varied considerably, but most reported a ratio of no more than 1 to 10, better than the minimum ratio required for licensure in most States. In addition, some programs augment the effective ratio by using trained volunteers to accompany wanderers, or to give one-to-one attention to some individuals during exercises, meals, or activities.

The cognitive difficulties of persons with dementia become a factor when staff members are suspected of robbing or abusing someone. An employee cannot be fired on the basis of a charge by a person who is not mentally competent. Yet retaining such a person may jeopardize residents who cannot complain. At the same time, persons with dementia can erroneously charge that they have been robbed or abused (see ch. 2). In special facilities where all the potential witnesses are cognitively impaired, steps will be needed to ensure the quality of employees and to protect both employees and residents.

Activities

Some believe there is a relationship between the number of hours of completely unstructured idle time and some behavioral problems such as wandering and perservation (59). Because persons with dementia are unable to initiate and plan independently, most new programs reduce the number of hours that the client is idle. Programs are developing varied philosophies about activities, but all agree that activities are a key part of success. Activities cannot be limited to games offered by a non-professional for a few hours a week if they are to benefit individuals with a dementing disorder. Some programs fill a good part of the day with structured tasks. There is also evidence, though, that structured programming should allow flexibility and spontaneity (18,101).

People with dementia live from moment to moment—a truly existential life. Therefore, programming for them should be designed to be enjoyable at the moment, possibly leaving some good feeling retained, rather than being designed to produce a worthwhile product or provide later satisfaction (26). Some programs use projects that allow their clients to work as volunteers or for

pay: stuffing envelopes, assembling garnishes for the main kitchen, etc. One program reports that trips and outings reduce agitation (84).

Activities must be meaningful to the client, must be voluntary, and must offer the client a reasonable chance for success (58). They must address the client's personal and psychosocial needs, and their purpose must be obvious to the person with dementia (101). In Wesley Hall, activities that enable residents to assume old roles—such as homemaker, friend, or volunteer—are emphasized. Exercise, music, personal grooming, housekeeping, preparation of snacks, repetitive, rhythmic activities, visits from children or pets, and simple volunteer tasks have been recommended (18,61,101).

Reality orientation is offered in most programs for persons with dementia, although its usefulness is debated. The term has been applied to several different techniques, some of which are more beneficial than others (26). In general, it is agreed that persons with irreversible dementia will not relearn information but do benefit from a program that gives frequent multiple cues for orientation.

Meals

Persons with dementing illnesses may fail to eat or may eat only one kind of food. They need good nutritional planning, food that enhances sensory information, and a supportive environment. Several programs report that midmorning, midafternoon, and bedtime snacks are helpful.

Behavior Management

Techniques for managing the inappropriate behaviors of special unit residents are as varied as the models of the physical plant (12,18,26,31,40, 42). What is most striking is that many units have successfully reduced problem behaviors, but even the most successful programs report that these behaviors still occur occasionally. At Wesley Hall, in addition to planned activities and changes in the physical environment, several staff techniques are used: first, to divert the individual; when unsuccessful, to withdraw and try later; to use touch and a sympathetic approach; to reinterpret the

behavior as normal (e.g., if a staff member acts in an authoritarian way, it is normal for the client to resist); and to use humor and a lighthearted approach (18).

Others point out that “responses to problematic behaviors cannot be set out in a formula basis. Flexibility and variety are essential qualities which staff must maintain in caring for the [dementia] patient” (13). Problem behaviors are greatly reduced when the environment orients participants and when meaningful activities fill their time. The quality of the interpersonal relationships between staff and participants may be at least as important as techniques of behavior management.

Management of Incontinence

Incontinence is often assumed to be a symptom of dementia. It has been reported as 3.5 times more common in persons with dementia than in persons without dementia; the causes of this dysfunction have not been reported and are rarely evaluated. The problem can lead to further withdrawal and isolation, skin breakdown, and infections (96). Traditional nursing home care has focused on containment, not reversal of the problem.

Many things other than a person's dementia can prevent that person from being continent: medications, too little fluid, diuretics such as coffee in the diet, inability to get to a toilet in time, chair design (causing problems getting up out of it), lack of a well-lighted and visible path to the toilet, loss of eyeglasses, inaccessibility of a walker or cane, insufficient visual contrast to distinguish the toilet, fecal impaction, and urinary tract infections. In addition, cognitively impaired elderly individuals have the same causes of urinary problems as other elderly persons, and may also respond to social cues of appropriate behavior (96). People who still have problems are successfully managed in many day care programs by being taken

to the toilet every 2 hours or on individualized toilet schedules. Many of the unacceptable behaviors that accompany incontinence result from the person's confusion or from inappropriate care that can be easily avoided.

Four of the eleven residents in Wesley Hall had been incontinent before admission, but after several months in the unit this was no longer a problem (18). A best-guess clinical estimate is that at least 50 percent of cognitively impaired elderly individuals with loss of urine control could regain control (96).

Application of Technologies to Care

Little has been done to identify ways in which technologies developed for other uses could be applied to the care of persons with dementia. The application of technologies to care does not necessarily imply that there will be less compassionate or less humane care to these individuals. It may free caregivers from routine tasks and allow them to provide more supportive activities or social experiences. Research Triangle Institute, for example, assessed the feasibility of a wandering notification system, sponsored by the Administration on Aging, National Aeronautics and Space Administration, National Institute on Aging, the National Institute for Handicapped Research, and the Veterans Administration (82). Families would also benefit from more efficient methods for managing human wastes in persons who are incontinent. Devices to prevent a person with dementia from turning on a stove, technologies that would enable a caregiver to locate the person who had wandered away, more efficient equipment to enable a frail caregiver to lift, turn, or bathe a person, and safer bathroom facilities—all would be greatly beneficial to both ill persons and their caregivers (93).

THE EFFECT OF REGULATIONS ON THE DEVELOPMENT OF SPECIAL CARE

Nursing homes are subject to numerous State and Federal quality assurance standards that they say impede quality care of persons with demen-

tia. Other service delivery settings (day care, in-home respite) are subject to so few quality assurance standards that experts express concern over

the lack of protection for persons in these settings who cannot protect themselves. The problems of quality assurance are discussed in chapter 10. This section briefly reviews some of the ways standards may directly interfere with patient care on special units.

Some problems arise from local interpretation of regulations and lack of understanding about the needs of persons with dementia. For example, for sanitary reasons, some facilities are required to use plastic dishes and utensils. Yet people with dementia can be confused because these do not have the familiar color and weight of crockery and silverware. Individuals who are easily distracted do better with one item of food on their plate at a time, but one facility reported that the inspector did not allow this. Food too hot to eat should not be served to confused persons, but one facility reported that serving cooler food violated health standards. Freshly waxed floors create glare, but are required by some inspectors as an indication of a clean facility. Reports of such episodes are scattered and seem to represent a lack of information on the part of State inspection agencies or the need for revision of regulations,

A more general problem is the emphasis of standards on physical evidence of quality—shining floors and sparkling bathrooms, beds perfectly made, and everything put away. Staff members are discouraged from letting residents make their own beds, even if sloppily, or talking with residents instead of tidying up. The pervasive tone of regulations, more than specific incidents, shapes patient care. The focus on the physical plant, combined with financial pressure for efficiency, has resulted in an atmosphere that more resembles a hospital than a home. Long corridors, lack of personal items, glare from waxed floors, and a paging system are disorienting to persons with dementia, who respond to a more homelike environment (18,46,47,49).

Quality assurance regulation depends heavily on paper documentation. Nursing homes report that nurses cannot spend time getting to know their patients or training aides to care for persons with dementia because their time is filled with the required paperwork (97).

The emphasis of regulations on the physical plant and on recordkeeping, in combination with low reimbursement rates for patient care, has resulted in efforts to increase efficiency. For example, an assembly line approach to resident care may be taken: one aide gets the person up, another toilets the person, a third gives out suppositories, and a fourth feeds the residents as a group. This is dehumanizing to all residents and stressful to those who are cognitively impaired (26). There are many examples of such problems. However, facilities have demonstrated that they can improve care within the framework of existing standards. Some have done so without increasing costs. Staffing patterns can be improved without a loss of efficiency (26) and physical plants can be improved (18,70).

Fire and safety regulations in domiciliary homes and respite settings present more difficult problems. Persons with dementia may not respond to a fire alarm; they move slowly, and when they become frightened they are likely to become stubborn and uncooperative. They may not be able to negotiate stairs and cannot follow instructions. They may wander off as soon as they are evacuated or may try to reenter a building. Fire safety standards in some areas do not address these special problems. For example, some day care centers have been approved by fire marshals under a code that was established to set requirements for a public meeting hall or office; such standards do not consider the special needs of those who use day care centers.

Fire safety regulations can also present obstacles. One design for a specialized unit proposes a large communal room surrounded by residents' rooms (55), but is not acceptable to fire safety experts in some cities. Locked exits, which protect residents from wandering and therefore reduce staff stress, are often not allowed because of safety hazards in case of fire. Some devices that confine an agitated person to his or her room in order for the person to relax (screen doors, half doors, or a bar across the door) are approved by fire marshals in some communities but not in others. Fire safety guidelines that take into consideration the care needs and special limitations of persons with dementia are urgently needed.

Persons with dementing illnesses can be so frail that any intervention may place them at greater risk of injury. For example, if a facility permits a frail person to continue walking, that person is at risk of falling and breaking a hip—a serious injury. If restrained from walking, the individual may lose the ability to walk or may develop pressure sores. When number of falls is used as a criterion of quality, facilities will restrict frail persons from walking. Research is needed to identify ways in which care can be provided while allowing marginal freedom. The risks of various interventions are not well known. A better understanding of which risk is greater—e.g., walking or restraint—would help programs and families make wiser choices.

Standards for domiciliary care and respite care programs (day care, short stay respite, in-home

care) are limited or nonexistent in some States. Even where standards exist they are often poorly enforced or are not designed to protect persons with intellectual impairments. Persons with dementing illnesses are unable to act in their own behalf in unsafe situations. These individuals may not be able to report abuse to their families. Yet severely impaired individuals reside in domiciliary care facilities with minimal standards or in facilities that are consistently out of compliance; OTA found no information on the number of domiciliary care, day care, or in-home respite programs with inadequate safeguards. Recent attention to the problems of dementia and the eagerness of some families to locate special care may attract unscrupulous or incompetent providers to the business.

ISSUES AND OPTIONS

This discussion of services for persons with dementia has identified a number of concerns:

- the fragmented service system;
- inadequate funding of services;
- inadequate staff and poor staff training;
- lack of programs that assist family caregivers; and
- service designs that emphasize acute medical care and cost efficiency at the expense of humane care, quality of life, and patient dignity.

The need for changes that respond to these concerns affect not only persons with dementia but all recipients of long-term care. Given the scope of this assessment, the options discussed here are limited to service that address the needs of persons with dementia.

Would services for persons with dementia replace existing, more costly services? Would establishment of services such as respite reduce the need for nursing home care? These issues are raised repeatedly throughout this report. Although it is tempting for model programs to see themselves as more economical than other programs, it is unlikely that the provision of respite services and specialized dementia care will reduce

costs. These programs are often not direct substitutes for nursing home care and therefore will almost certainly result in greater overall expenditures.

Concern over costs means that planners and taxpayers must ultimately make value judgments about the care of the individuals with dementia. Quality of life for the cognitively impaired person must be balanced against cost, individual safety must be balanced against personal autonomy, the maintenance of those who are chronically ill must be balanced against expenditures to seek a cure, and support of family caregivers must be balanced against the more traditional patient-only treatment.

ISSUE 1: Should the Federal Government support the development of special care for persons with dementia?

Option 1: Implement programs of care for persons with dementia.

Option 2: Offer incentives to develop specialized care.

Option 3: Support health services research into special respite and residential programs for persons with dementia.

Policymakers face a dilemma: Identifying the best kind of care for persons with dementing disorders awaits a better understanding of how much can be done for them. Standards and the establishment of appropriate funding levels must await more information about the kind of care that can be achieved.

The specific changes needed in facilities that serve persons with dementia seem to be controversial. But a body of knowledge already exists about compensating for sensory deficits late in life. Experience was gained in treatment of persons with dementia in some State mental hospitals. Milieu therapy (modifying the social and physical environment to support function) has been generally endorsed as the preferred approach to such individuals. There is also a body of literature on family needs. Finally, there is some generally accepted literature on the style of care and approach to persons with dementia. Thus the general principles that special units need to follow are known. The finding that residents improve somewhat in most special settings is encouraging because it indicates that some benefit can be achieved in the absence of precise knowledge about optimal care.

There is an obvious need for formal care for a large segment of those with dementia, either on a short-term, respite basis or—for some—on a residential basis. Caregivers and voluntary associations are pressing for such care, and it may be that providing it will have significant benefits in caregiver health and employment status.

However, a large Federal investment in special care at this point (option 1) might result in the development of inappropriate services or the replication of existing models that do not serve persons with dementia well. Improving some ‘special services’ on top of existing inappropriate models of care may cost more than developing new care models that better suit the needs of people with dementia.

Use of incentives (option 2) would expedite the development of much-needed services. It would also rely on market forces to determine the nature of quality care. Although this appears to be an excellent option, the generally pervasive belief that little or nothing can be done for persons

with dementia may lead to a situation in which consumers, professionals, and providers have lower than appropriate expectations for care.

Health service research would test underlying principles and the various hypotheses proposed by individual project. It would identify the amount of change possible in people with dementia, the people who are likely to benefit, the points at which they should enter and leave programs, and the impact of specific services on family caregivers. Table 7-4 identifies major questions which such research would answer.

Federal support of research (option 3) helps ensure the quality of research. The Federal Government can provide a focal point or a coordinating task force for health service delivery research that would ensure the coordination of research. A national scope would expedite coordination of State and private sector endeavors as well (also see issue 2, option 3 below).

Federal support of a group of care models with a strong health service research component, although it would leave many people unserved, would be seen by caregivers as a major step forward and would give better information regarding the design and cost of services. In addition, the costs of an experimental program are controlled and predictable. The private sector is moving forward with programs for persons with dementia, holding promise of possible collaboration with the government.

Health service delivery research often establishes model programs that are set up, run, and studied with specific objectives in mind. Such programs would be welcomed by caregivers who are eager to encourage the development of better care. Yet demonstration projects tend to drop their clients after their funding ends. That would be particularly difficult for the frail, confused, elderly person who may take weeks or months to adjust to a new setting. In some areas there may be no other respite programs for families after the model program is completed, thus placing serious stresses on caregivers or precipitate nursing home placement. If such model programs are funded, plans for client care after their completion could be required, or programs could be planned with gradual funding phase-out.

Table 7.4.—issues in Health Service Research**Patient outcomes:**

Which of the patient benefits that have been reported actually occur?
 How can these be measured?
 Which patients benefit?
 How can they be identified?

Family caregiver outcomes

What are the benefits to caregivers of the various services?
 Do they reduce symptoms of stress, enable caregivers to remain employed,
 or extend the time people with dementia can remain at home?
 Which caregivers will benefit from which services?
 Can family members of persons in special residential units continue to provide some of the individualized care the residents need?

Settings:

How much does care cost in each of the settings—residential, day care,
 or home?
 Which setting is right for which patient/family?
 Are stage of illness, family situation, or other factors the critical elements
 in determining which setting is used?

Services:

Which services are essential and which optional for people with dementia? (full-day programming, special activities, special diet or meals, behavior management, continence management, medical care, nursing care, social services, occupational therapy, physical therapy, outdoor recreation, exercise, memory retraining, etc.)
 How can delivery of the various service be evaluated?
 Which elements of the physical plant (e.g., architecture, interior design) are essential and which are optional for people with dementia?
 How much does each of these items of service and physical plant cost?
 What technologies can make patient care easier or more humane?

Staff:

What kind of staff are needed for which patient/settings (geriatricians, neurologists, psychiatrists, nurses, social workers, occupational and physical therapists, nonprofessional staff, etc.)?
 How can professionals best be trained to care for people with dementia?
 Do existing training methods work?
 What staff-patient ratios are necessary for which patients/settings?
 What is the role of volunteers? How should they be selected and trained?

Admission/discharge criteria:

What admission/discharge criteria are used?
 Where do patients come from?
 Where are they discharged to?
 What stage, functional level, or behavioral problems do different programs accept? Why?
 Is special care beneficial to the patient/family? Cost effective?

Cost structures:

Who should pay for which kinds of care (the patient, the family, the government, the private sector)?
 What is the impact of payment adjusted for case mix?
 Does special care cost more per patient?

duality assurance policy:

How can safe and humane care be ensured for people with dementia?
 How can existing standards and regulations be modified to benefit people with dementia?
 Should Federal regulation be extended to adult day care, board and care, and other programs not now regulated by the Federal Government?
 How can quality assurance standards be designed that ensure quality of life?

SOURCE: Office of Technology Assessment, 1987

ISSUE 2: Should the Federal Government set standards for special residential care, respite care, or both, for persons with dementing illnesses?

Option 1: Keep existing Federal standards as they are and leave standards for special units and respite care to the States.

Option 2: Develop guidelines to be met in all federally supported programs and in programs in which care is purchased with Federal funds. Encourage adoption of these standards by the States.

Option 3: Support research that will generate information needed to develop care standards for programs serving people with dementia.

Option 4: Require that persons purchasing care with Federal funds receive care appropriate to their level of impairment.

Option 5: Enforce existing standards.

In the past, the Federal Government has not set standards for facilities and services that do not fall under Medicare or Medicaid. (An entirely separate issue is whether the Federal Government should now become involved on behalf of impaired persons.) The Federal Government could leave standards-setting to the States (option 1). Several States have set or are considering guidelines for care of persons with dementia (14; California Senate Bill 195), but many States are unlikely to do so and the degree of protection varies widely.

Basic standards for protection and fire safety are needed for all settings. The Federal Government could develop guidelines to be met in federally supported programs or when care is purchased with Federal funds (including SSI and VA pensions), and could encourage States to adopt them (option 2). Basic guidelines would provide some protection quickly to individuals who may be in jeopardy and would relieve the States of the expense of separately investigating this issue.

Better enforcement of existing standards (option 5) and requirements that these individuals

be cared for in facilities offering an appropriate level of care (option 4) would provide some protection without developing additional standards.

Should quality assurance standards be developed for special dementia programs—either respite, day care, or nursing homes? Existing standards sometimes get in the way of service provision, some programs have no standards to ensure basic safety, and standards do not always result in the desired outcome-quality care (see ch. 10). In addition, limited knowledge of the characteristics and costs of special programs makes it difficult to set standards. Standards for nursing or social work

time, staff-to-client ratios, or services' provided could freeze certain programs in place and prevent innovation and development of more creative ones. Research into models of care is a necessary preparation for establishing standards of care. The Federal Government could support the research (option 3) needed to identify expected participant outcomes in special programs, to discriminate between severity of dementia and the presence of excess disabilities, and to identify the required inputs that result in optimal recipient function.

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