

## **Chapter 1**

# **Overview and Policy Implications**

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## Chapter 1

# Overview and Policy Implications

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### INTRODUCTION

At least half of all nursing home residents in the United States have dementia. As awareness of Alzheimer's disease and other diseases that cause dementia has increased in recent years, so have complaints and concerns about the quality and appropriateness of the care provided for individuals with dementia by most nursing homes. In response to these complaints and concerns, some nursing homes have established a special care unit—that is, a physically separate unit in the nursing home that provides, or claims to provide, care that meets the special needs of individuals with dementia. Such units are referred to generically as *special care units*, *dedicated care units*, *Alzheimer's units*, or *dementia units*. OTA uses the term *special care units* in this report.

The number of special care units for individuals with dementia has increased rapidly over the past few years. No comprehensive data are available on the number of special care units before 1987, but information from several studies indicates that the great majority of existing special care units were established after 1983 (181,413,485). The most comprehensive data on special care units in this country were collected in 1987, as part of the National Medical Expenditure Survey. That survey found that 1668 nursing homes—8 percent of all nursing homes—had a special care unit for individuals with dementia in 1987, and that these special care units accounted for more than 53,000 nursing home beds (249). The survey also found that an additional 1444 nursing homes planned to establish a special care unit by 1991, and 535 of the nursing homes that already had a special care unit in 1987 planned to expand the unit by 1991. If all these plans had materialized, more than 3100 nursing homes—14 percent of all nursing homes in the United States—would have had a special care unit in 1991, and almost 100,000 nursing home beds would have been in special care units.

When published in 1990, the figures from the 1987 National Medical Expenditure Survey sur-

prised researchers and others because they were much higher than any previous estimates. Two studies conducted since then indicate that the true number and proportion of nursing homes with a special care unit are probably somewhat lower (194,247). On the basis of these studies, OTA estimates that 10 percent of all U.S. nursing homes had at least one special care unit in 1991.<sup>1</sup> Regardless of the precise figures, however, it is clear that the number and proportion of nursing homes with a special care unit are growing rapidly.

The proliferation of special care units creates both problems and opportunities for individuals with dementia, their families, and many other people and organizations that have an interest in the quality and appropriateness of nursing home care for individuals with dementia. These other interested parties include: nursing home administrators and staff members who provide care for individuals with dementia both in and out of special care units; physicians, nurses, social workers, hospital discharge planners, community agencies, Alzheimer's Association chapters, and other voluntary organizations that refer people with dementia and their families to nursing homes; and nursing home licensing and certification officials, nursing home surveyors, and long-term care ombudsmen who are responsible for regulating and monitoring the quality of nursing home care.

The problems created by the proliferation of special care units are due primarily to the lack of agreement about what a special care unit is or should be and the related lack of standards to evaluate special care units. Existing special care units vary greatly in every respect, including their guiding philosophy, physical design, staff composition, staff-to-resident ratio, activity programs, and patient care practices (64,181,194,199,232,256,275,332,413,485,494). Despite this variation, the operators of virtually all special care units express confidence that they are providing appropriate care for their residents. According to researchers who studied the differences among special care units:

The differences are of such significance that they appear to place special units in direct opposition to

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<sup>1</sup> As discussed later in the chapter, this number includes nursing homes that place some of their residents with dementia in a physically distinct group or cluster in a unit that also serves some nondemented residents.

each other. Nevertheless, without exception, their proponents have hailed the success of the units (332).

Many people have told OTA that some nursing homes that have a special care unit just use the words *special care* as a marketing tool and actually provide no special services for their residents. Most nursing homes charge more for care in their special care unit than in other parts of the facility (413,494). In special care units that provide no special services, individuals with dementia and their families may pay more but receive no better care than they would in another unit in that nursing home or a different nursing home. At worst, they may pay more and receive inferior care in the special care unit.

Many families of individuals with dementia are extremely concerned about the quality and appropriateness of services they may use for these individuals (166,513). As a result, they are likely to respond enthusiastically to claims of "special care." Without standards by which to evaluate special care units, families and individuals and organizations that refer patients and their families to nursing homes cannot know with any certainty whether the units are providing better care than other nursing home units.

Despite these problems, the proliferation of special care units also creates opportunities for individuals with dementia, their families, and others who are concerned about the quality and appropriateness of the nursing home care available to these individuals. Even without standards by which to evaluate the units, it is obvious to all observers that some special care units are providing better care for their residents with dementia than these individuals would receive in most nursing homes. One such unit is described in box 1-A.

The proliferation of special care units means that for the first time in the United States there are numerous nursing homes in which administrators and staff members are concentrating on developing better methods of care for their residents with dementia. This attention to the special needs of nursing home residents with dementia reverses the long-standing reality in many nursing homes in which the special needs of these residents have not been recognized and the residents frequently have not even been identified as individuals with dementia.

This OTA report discusses the complaints and concerns about the care provided for nursing home

residents with dementia that have led to the development of special care units, the theoretical concepts that underlie their design and operation, and the findings of studies that describe and evaluate them. The report analyzes the problems and opportunities created by the proliferation of special care units and discusses the ways in which government has responded or could respond to these problems and opportunities.

### *Congressional Requests*

This report was requested by Senator David Pryor, chairman of the Senate Special Committee on Aging, and Congresswoman Olympia J. Snowe, ranking minority member of the Subcommittee on Human Services of the House Select Committee on Aging. The congressional letters of request for the report stress the need for information about special care units to inform Federal policy with respect to consumer education, research, regulation, and reimbursement for special care units. Congresswoman Snowe noted the lack of information about the cost and effectiveness of special care units and stressed the need for quality standards to help families and others evaluate the units and assess their options for nursing home care for an individual with dementia. Senator Pryor noted the problem of overuse and misuse of physical restraints in nursing homes and asked whether restraints are used less often in special care units and, if so, what alternatives to restraints are being used.

### *Policy Context*

Nursing home care for individuals with dementia is an important public policy issue for three reasons. One reason is that a large number and proportion of nursing home residents have dementia. The 1985 National Nursing Home Survey, a large-scale survey of a nationally representative sample of nursing homes, found that 696,800 nursing home residents—47 percent of all residents—had dementia (469). The 1985 survey also found that 922,500 nursing home residents—62 percent of all residents—were so disoriented or memory-impaired that their performance of the activities of daily living was impaired nearly every day (467). The 1987 National Medical Expenditure Survey, which also included a nationally representative sample of nursing homes, found that 637,600 nursing home residents—42 percent of all nursing home residents—had dementia (237). These figures are based on judgments by nursing

### ***Box 1-A—A Special Care Unit in Lynden, Washington***

*The Christian* Rest Home, a 150-bed nursing home in Lynden, WA has had a special care unit since 1988. The 15-bed special care unit was established because of staff concerns about the safety and well-being of residents with dementia who wander or have other behavioral symptoms that cannot be handled on the facility's regular units.

The special care unit consists of resident bedrooms, an activity/dining area, and an enclosed outdoor courtyard. Three physical changes were made to the building to create the unit: 1) a set of doors was installed in an existing unit to partition off the resident bedrooms and the activity/dining area; 2) a door was made in an exterior wall to give the residents access to the enclosed courtyard; and 3) keypad-operated locks were installed on the exit doors; the doors open when a number code is punched in on the keypad; the doors open automatically if the fire alarm goes off. These physical changes cost less than \$5000.

The special care unit functions as a self-contained entity, but technically it is part of an adjacent unit. Washington State regulations require each nursing home unit to have a separate nurses' station, a separate shower, a separate bathroom for staff, and a separate utility room. To avoid the cost of these separate facilities, the special care unit is considered part of the adjacent unit. Medications, medical treatments, and rehabilitative services for the special care unit residents are delivered from the nurses' station on the adjacent unit.

Some residents of the special care unit have been transferred to the unit from other parts of the nursing home, usually because they wander or have other behavioral symptoms that are more easily handled on the special care unit. Other residents have been admitted directly from home. Although all the special care unit residents have dementia in the opinion of the facility staff, a few have not had a diagnosis of dementia in their medical records,

The objectives of the unit are to assure the residents' safety, to reduce agitation and behavioral symptoms, to maintain independent functioning, and to improve the residents' quality of life. The staff members perceive resident agitation and behavioral symptoms as meaningful expressions of feelings and unmet needs. They attempt to understand and respond to those feelings and needs, in the belief that by doing so, they will reduce agitation and behavioral symptoms and improve the residents' quality of life.

The unit has a relaxed atmosphere. The residents appear calm and contented. They wander freely around the unit and respond to and sometimes initiate verbal interactions with staff members and visitors. Although many of the residents exhibited severe behavioral symptoms before coming to the unit, the unit staff reports that these symptoms are relatively easily managed in the special care unit.

The only type of physical restraint that is used on the unit is a geriatric chair with a tray table that keeps a resident from getting up. These 'geri-chairs' are used only temporarily and only with a doctor's order. Psychotropic medications are used sparingly. They are used in low doses and only after other, behavioral interventions have been tried. On Jan. 13, 1992, 7 of the 15 residents were receiving psychotropic medications, including 4 residents who were receiving antipsychotic medications.

Formal and informal activity programs are conducted on the unit. Each afternoon there is a formal activity program, such as a weekly Bible study and music group, a weekly reminiscence group, a weekly "validation" group, and "high tea"—a Monday afternoon event with real china and lace tablecloths. Other activities, such as food preparation and singing, take place informally on the unit. One resident who likes to fold laundry is encouraged to do so.

Each morning, there is a half-hour hymn sing for all residents of the nursing home. Most of the special care unit residents are taken to this activity. In the afternoons, a few of the special care unit residents are taken to whatever activity program is scheduled for the facility as a whole.

Family members are welcome on the unit at any time. The staff knows the residents' families and involves them in decisions about the residents' care. The staff reports that family members often thank them for the help they give the residents and the emotional support they give the family members. Two formal events—a Thanksgiving potluck supper and a summer barbecue—involve all the unit residents and their families.

During the day, the staff on the special care unit consists of one registered nurse, who functions as the unit coordinator, and two nurse aides. A licensed practical nurse and two other nurse aides take over for the evening shift. Since staff consistency is considered important for the unit, the unit staff members generally are not rotated to other units, although staff rotation is the norm in the rest of the facility. The special care unit staff members work as a team, with little apparent difference in status between the nurses and aides.

*(Continued on next page)*

**Box 1-A—A Special Care Unit in Lynden, Washington-(Continued)**

Until recently, the unit had no separate staff for the night shift (11:00 p.m. to 7:00 a.m.). Before being admitted to the special care unit, many of the residents had been awake, agitated, and difficult to manage at night. Once they came onto the unit, these individuals began to sleep through the night, and the facility found it was possible to leave the unit doors open and have the unit supervised by a staff member on the adjacent unit. Nevertheless, as of December 1991, the facility had decided to assign an aide to the unit for the night shift.

The unit administrator and the facility's staff development coordinator stress the importance of training for the special care unit staff, but they place greater emphasis on staff attitudes. The unit administrator believes there are people who cannot be trained to work effectively on the special care unit because their attitudes and personalities are not suited to the unit. Both the unit administrator and the staff development coordinator stress the need for a flexible, "trial and error," approach to dealing with an individual resident's problems and for staff members who can implement this approach.

Several individuals besides the unit staff members are involved in the care of the residents. The weekly Bible study and reminiscence groups are run by staff of the facility's Therapeutic Recreation Department. The weekly validation group is run by the director of the facility's Social Services Department, who is a psychiatric nurse. She also works with the geriatric mental health team from the local community mental health center to assess and respond to residents' mental health needs. A monthly staff meeting is held to discuss problems and ideas among the special care unit staff and other individuals who are involved in the residents' care.

Special care unit residents are discharged from the unit when the staff considers that the residents can no longer benefit from the unit. The unit discharge policies are explained to family members when a resident is admitted, but many family members are upset when their relative is moved to a different unit. Several spouses of former special care unit residents have created an informal support group that meets almost daily in the facility, presumably to replace the emotional support they previously received from the unit staff.

Discharges are hard on the unit staff members, since they often become attached to the resident and the resident's family. The facility believes, however, that it is important to make space available in the unit for other individuals who will benefit from it. Priority is given to individuals who are at risk because of wandering.

The Christian Rest Home is a private, nonprofit facility. The special care unit serves both Medicaid and private pay residents. Until January 1992, there was no additional charge for care in the unit. Starting in January 1992, private pay residents are charged \$10 more per day in the special care unit than they would be charged in other units in the facility. The special care unit has a waiting list, as does the facility as a whole.

**SOURCE:** Angie Brouwer, Administrator, Christian Rest Home, Lynden, WA, personal communication, Jan. 13, 1992; Linda Jager, RN, Staff Development Coordinator, Christian Rest Home, Lynden, WA, personal communications, Oct. 19, 1990, Dec. 30, 1991, Jan. 13, 1992; Betty Lou Rau, RN, Day Charge Nurse, Special Care Unit, Christian Rest Home, Lynden, WA, personal communications, Oct. 19, 1990, Dec. 30, 1991; Jennifer Johnson, RN, Director of Social Services, Christian Rest Home, Lynden, WA, personal communications, Oct. 19, 1990, Jan. 13, 1992.

home staff members about the residents' mental status. Several small-scale studies based on comprehensive medical and psychiatric evaluations have found that an even higher proportion of residents (67 to 78 percent) have clinically diagnosable dementia (82,389,390).

The second reason nursing home care for individuals with dementia is an important public policy issue is that government expenditures for nursing home care for individuals with dementia are substantial. In 1990, total expenditures for nursing home care from all sources were \$53.1 billion. Federal,

State, and local government expenditures accounted for slightly more than half (52 percent) of that amount (250).<sup>2</sup> Excluding expenditures for the care of individuals in facilities for the mentally retarded, total government expenditures for nursing home care were \$22.8 billion. Individuals with dementia tend to be among those who stay longest in nursing homes and so are most likely to become eligible for government reimbursement through Medicaid (229,258,465). As a result, government probably pays for more than half of all nursing home care for individuals with dementia. Since individuals with dementia constitute at least half of all nursing home

<sup>2</sup>Total government expenditures for nursing home care were \$27.7 billion in 1990. This amount included \$17.2 billion in Federal expenditures (\$2.5 billion from Medicare, \$13.7 billion from Medicaid, and \$1.0 billion from other sources, e.g., the Department of Veterans Affairs) and \$10.5 billion in State and local government expenditures, virtually all of which are Medicaid expenditures (250).

residents, OTA estimates that government expenditures for nursing home care for individuals with dementia amounted to more than \$11 billion in 1990.<sup>3</sup>

The third reason nursing home care for individuals with dementia is an important public policy issue is that government is extensively involved in regulating nursing homes. The Federal Government regulates nursing homes that participate in the Medicare or Medicaid programs. In 1985, 75 percent of all nursing homes participated in one or both programs, and these participating facilities accounted for 89 percent of all nursing home beds (467). All States also regulate nursing homes.

Complaints and concerns about the quality and appropriateness of the nursing home care provided for individuals with dementia are pervasive. Given these complaints and concerns and government's extensive role in regulating nursing homes and paying for nursing home care, the claim of special care unit operators and others that special care units provide better care for individuals with dementia deserves the attention of policymakers.

The existence and proliferation of special care units raise four policy questions. One question pertains to consumer education. The Alzheimer's Association and several other organizations have developed informational brochures and guidelines to assist families and others in evaluating special care units.<sup>4</sup> New Hampshire has also taken this approach (325). The policy question is what, if any, additional steps government should take to inform consumers about special care units.

The second policy question pertains to the adequacy of government funding for research on special care units. Until recently, Federal agencies had funded very little research on special care units. In the fall 1991, the National Institute on Aging funded nine special care unit studies through its "Special Care Units Initiative," and a tenth study was funded through the initiative in 1992. When the results of these studies are available in a few years, they will greatly expand knowledge about special care units. In the meantime, it is important to consider whether

additional government-funded research is needed, and if so, on what topics.

The third policy question pertains to regulation of special care units. As of early 1992, six States—Colorado, Iowa, Kansas, Tennessee, Texas, and Washington—had added requirements for special care units to their general regulations for all nursing homes. Five States—Nebraska, North Carolina, New Jersey, Oklahoma, and Oregon—were developing regulations for special care units, and more States were considering doing so. The policy question is whether the Federal Government or other States should develop special regulations for special care units.

Many special care unit operators and others say it costs more to operate a special care unit than a nonspecialized nursing home unit (12,64,377,477,485). Thus, the fourth policy question is whether government should pay more for the care of eligible individuals in special care units than in other nursing home units.

Until the publication in 1990 of figures on the number of nursing homes that had a special care unit in 1987, most commentators believed there might be several hundred special care units in the United States. It was reasonable then to regard special care units as a relatively small phenomenon and to consider government policies for special care units in that context. Recent data suggesting that 10 percent of all nursing homes had a special care unit in 1991 indicate that special care units are not a small phenomenon. The rapid proliferation of special care units means such units are likely to become a much larger phenomenon. Government policies for special care units should be considered in this new context and in relation to the long-range possibilities and societal objectives for special care units.

Various long-range possibilities for special care units can be imagined. One possibility would be for all nursing home residents with dementia to be cared for in special care units (or in whole nursing homes devoted exclusively to serving individuals with dementia). To OTA's knowledge, no one advocates this alternative, in part because of the huge number of individuals involved—37,600 to 922,500 indi-

<sup>3</sup> Some and perhaps many nursing home residents with dementia are admitted for reasons other than or in addition to their dementia. OTA's estimate refers to the overall cost to government of nursing home care for residents with dementia regardless of the primary reason for their admission.

<sup>4</sup> See, for example, Mace and Gwyther, "Selecting a Nursing Home With a Dedicated Dementia Care Unit," *Alzheimer's Disease and Related Disorders Association* (276).

viduals according to national surveys and the cost and other implications of creating a whole separate nursing home industry to serve them.

A second possibility would be for special care units to serve only certain types of nursing home residents with dementia—for example, residents with behavioral symptoms or residents in a particular stage of their dementing illness. To implement this alternative would require a rationale for determining which types of residents with dementia should be in special care units and criteria for identifying these individuals.

A third possibility would be for special care units to serve: 1) individuals with dementia whose families choose to place them in the unit for any reason, including ability to pay, and 2) individuals the nursing home chooses to place in the unit for any reason, including ability to pay. In this scenario, the total number of special care units and the number and types of individuals with dementia who are cared for in these units would be determined in the future, as they are now, by market demand and the decisions of individual nursing home administrators and staff members.

A fourth possibility would be for special care units to function as research settings to develop and evaluate methods of care for individuals with dementia. Once shown to be effective, the methods of care developed in special care units could be incorporated into the care practices of all nursing homes, thus potentially benefiting all residents with dementia.

Government policies adopted now with respect to consumer education, research, regulation, and reimbursement for special care units will influence which of these long-range possibilities becomes the future reality. Which of the long-range possibilities is desirable depends on several factors, the most important of which are:

- the effectiveness of special care units in general and for particular types of individuals with dementia;
- the relative cost of caring for individuals with dementia in special care units vs. nonspecialized nursing home units; and
- the impact of the different long-range possibilities on nondemented nursing home residents.

By definition, special care units segregate individuals with dementia from other nursing home resi-

dents. Some commentators believe this segregation benefits both demented and nondemented nursing home residents. Other commentators believe that although segregation may benefit nondemented residents, it will result in poorer care for residents with dementia who will, in effect, be warehoused' in segregated units. In the view of these commentators, the anticipated negative effects of segregating nursing home residents with dementia outweigh any possible positive effects of the units. Some of the latter commentators are particularly disturbed by the fact that most special care units are either locked or "secured" in some other way so that residents with dementia cannot get out. The reactions of these commentators to proposed government policies for special care units are likely to reflect their objections to locked units rather than to special care units per se.

Finally, in considering government policies for special care units, it is important to note that the proliferation of special care units is occurring at the same time as numerous other government and nongovernment initiatives that are likely to improve the care of nursing home residents with dementia or provide them with alternatives to nursing home care. These initiatives include the following:

- initiatives intended to improve the care of all nursing home residents, including nursing home residents with dementia, e.g., the regulatory and other changes associated with implementation of the nursing home reform provisions of the Omnibus Budget Reconciliation Act of 1987 (OBRA-87), and separate but related efforts to create 'restraint-free' nursing homes;
- initiatives intended to improve the care of individuals with dementia in any nursing home unit, e.g., training programs for nursing home staff members, special activity and other programs for residents with dementia in nonspecialized units, and the development of effective strategies for resident assessment, care planning, and treatment of behavioral symptoms; and
- initiatives intended to provide appropriate care outside nursing homes for individuals with dementia, e.g., specialized residential care programs inboard and care facilities, group homes, and assisted living facilities; specialized adult day programs; and specialized in-home services.



This OTA report focuses on special care units in nursing homes. A full evaluation of the initiatives listed above is beyond the scope of the report, although the implications of OBRA-87 for nursing home residents with dementia are discussed in this chapter and at greater length in chapter 5, and some of the other initiatives are discussed briefly at the end of this chapter. Ultimately, government policies for special care units should be considered in the context of these other initiatives which may provide alternate or even better ways of accomplishing some of the same objectives as special care units.

### *Organization of the Report*

The remainder of this chapter summarizes OTA's findings with respect to the characteristics of nursing home residents with dementia and problems in the care they receive in many nursing homes, the characteristics of existing special care units, the available information about their effectiveness, and the regulatory environment for special care units. The implications of these findings for government policies about special care units are discussed. The chapter also discusses several topics not addressed elsewhere in the report, including the theoretical concepts of specialized care for individuals with dementia and legal and ethical issues related to special care units.

Chapter 2 discusses the prevalence of dementia in nursing homes, the characteristics of nursing home residents with dementia, and the most frequently cited complaints and concerns about the nursing home care provided for these individuals. Chapters 3 and 4 analyze the results of the available descriptive and evaluative studies of special care units. Chapter 5 discusses the government regulations that apply to special care units, including the special requirements that are now in effect in six States, and the guidelines for special care units that have been developed by various public and private organizations. Chapter 6 analyzes the problem of government regulations that discourage innovation in the design and operation of special care units.

## **NURSING HOMES AND DEMENTIA**

Because of the aging of the U.S. population, the number of individuals with Alzheimer's disease and other diseases that cause dementia is growing rapidly. The proportion of individuals with dementia

that is in nursing homes now or will ever be in nursing homes is not known, but it is likely that most individuals with dementia will spend some time in a nursing home in the course of their illness. These individuals constitute the pool of potential users of special care units.

This section provides background information about the clinical syndrome of dementia and its causes, the prevalence of dementia, and the use of nursing homes by individuals with dementia. It describes the characteristics of nursing home residents with dementia and discusses the problems in the care they receive in many nursing homes and the impact of those problems on the residents, their families, nursing home staff members, and nondemented nursing home residents.

### *The Clinical Syndrome of Dementia*

Dementia is a clinical syndrome characterized by the decline of cognitive abilities in an alert individual. By definition, dementia involves some degree of memory loss. Other cognitive abilities that are frequently diminished or lost in dementia include judgment, learning capacity, reasoning, comprehension, attention, and orientation to time and place and to oneself. Language functions, including the ability to express oneself meaningfully and to understand what others communicate, are usually also affected.

Dementia can be caused by many diseases and conditions (see app. A). Alzheimer's disease is the most common cause of dementia, accounting for 50 to 80 percent or more of all cases (131,227,448). The second most common cause of dementia is multiple small strokes that lead to multi-infarct dementia.

Alzheimer's disease and most other diseases and conditions that cause dementia are progressive. Over time, as individuals with these diseases and conditions lose cognitive abilities, they become increasingly unable to care for themselves independently. Eventually most individuals with dementia require 24-hour supervision and assistance with every aspect of their daily lives.

### *The Prevalence of Dementia*

OTA estimates that there are now about 1.8 million people with *severe dementia in the United States* and an additional 1 to 5 million people with *mild or moderate dementia* (458). The results of a study conducted in East Boston in the early 1980s suggest that as many as 3.75 million people may

have Alzheimer's disease at all levels of severity (129), but some researchers and clinicians consider this estimate high.

The prevalence of dementia increases dramatically with age. OTA estimates that the prevalence of severe *dementia* increases from less than 1 percent of people under age 65, to about 1 percent of those age 65 to 74, 7 percent of those age 75 to 84, and 25 percent of those over age 85 (458). It has been hypothesized that the incidence of new cases of dementia may level off in individuals over age 85, but followup data from the East Boston study and other sources indicate that the incidence of dementia continues to increase (130,495).

The U.S. population over age 65 is growing faster than younger age groups, and the 85+ age group is growing faster than other segments of the older population. As a result, the number and proportion of individuals with dementia in the population are growing rapidly.

### *Nursing Home Use by Individuals With Dementia*

The proportion of individuals with dementia that is in a nursing home at any one time is not known. Nor is it known what proportion of individuals with dementia will ever be in a nursing home in the course of their illness.

On the basis of figures from the 1985 National Nursing Home Survey--i.e., 696,800 nursing home residents who had senile dementia or chronic or organic brain syndrome and 922,500 nursing home residents who were so disoriented or memory-impaired that their performance of the activities of daily living was impaired nearly every day--and OTA's estimates of the prevalence of dementia nationwide--i.e., 1.8 million Americans who have severe dementia, and 1 to 5 million who have mild or moderate dementia--one could estimate that anywhere from 10 to 33 percent of individuals with dementia of any degree of severity are in a nursing home now. If one surmises that only individuals with severe dementia are likely to be in a nursing home, one could estimate that anywhere from 39 to 51 percent of individuals with severe dementia are in a nursing home now.

A much larger proportion of individuals with dementia are likely to spend some time in a nursing home in the course of their illness, although some

individuals with dementia will never be in a nursing home. Recent projections from data on elderly individuals who died in 1986 suggest that 43 percent of all Americans who reached age 65 in 1990 will spend some time in a nursing home before they die (230). Individuals with dementia are far more likely than elderly individuals in general to be admitted to a nursing home, and it may be that almost all individuals with dementia will spend some time in a nursing home in the course of their illness.

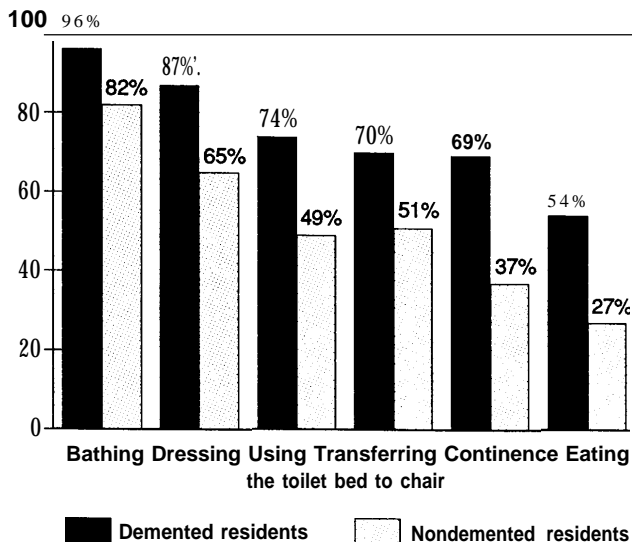
The proportion of individuals with dementia that is in a nursing home at any given time and the proportion that will be in a nursing home at some time in the course of their illness could increase or decrease as a result of several factors. These factors include the availability of appropriate residential care in alternate settings, such as board and care facilities; the availability of appropriate in-home and community services; and Medicaid eligibility, coverage, and reimbursement policies that encourage or discourage nursing home placement for individuals with dementia.

### *Characteristics of Nursing Home Residents With Dementia*

Available information about the characteristics of nursing home residents with dementia is presented in chapter 2. As noted there, nursing home residents with dementia are older on average than other nursing home residents. The 1985 National Nursing Home Survey found that half of the residents with dementia were over age 85, compared with one-third of the other residents (469). The survey also found that three-quarters of the residents with dementia were female. Although a preponderance of female residents with dementia is to be expected since female nursing home residents greatly outnumber male residents, the survey data indicate that female nursing home residents were somewhat more likely than male residents to have dementia (48 percent vs. 40 percent, respectively) (469).

Nursing home residents with dementia are more likely than other nursing home residents to need assistance with activities of daily living (i.e., bathing, dressing, using the toilet, transferring from bed to chair, remaining continent, and eating). The 1985 National Nursing Home Survey found, for example, that 69 percent of residents with dementia needed assistance to remain continent, compared with 37 percent of the other residents (469) (see fig. 1-1).

**Figure 1-1—impairments in Activities of Daily Living in Demented and Nondemented Nursing Home Residents, United States, 1985**



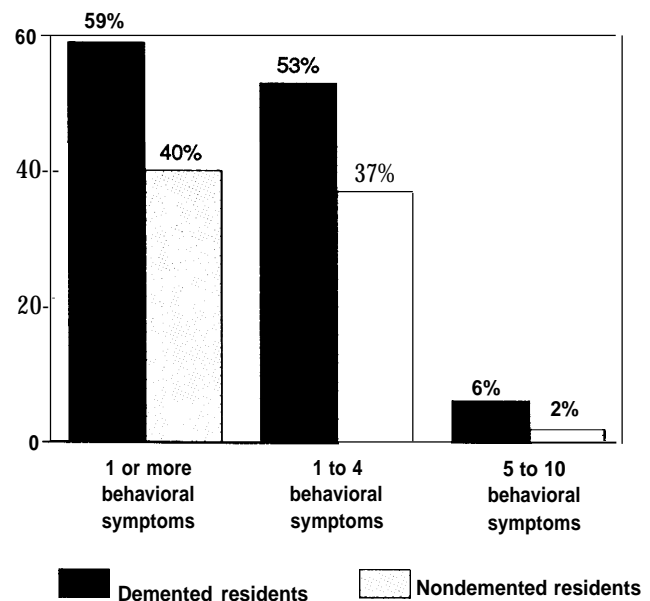
SOURCE: Adapted from U.S. Department of Health and Human Services, "Mental Illness in Nursing Homes: United States, 1985," Public Health Service, National Center for Health Statistics, DHHS Pub. No. (PHS) 89-1758, Hyattsville, MD, February 1991.

Psychiatric symptoms are more common among nursing home residents with dementia than among other nursing home residents. The 1987 National Medical Expenditure Survey found, for example, that 36 percent of residents with dementia had psychiatric symptoms, such as delusions and hallucinations, compared with 26 percent of other residents (464) (see ch. 2).

Behavioral symptoms are also more common among nursing home residents with dementia than among other nursing home residents. The 1987 National Medical Expenditure Survey found that 59 percent of residents with dementia had one or more of ten behavioral symptoms (wandering, physically hurting others, physically hurting oneself, dressing inappropriately, crying for long periods, hoarding, getting upset, not avoiding dangerous things, stealing, and inappropriate sexual behavior) (464). In contrast, 40 percent of other nursing home residents had one or more of these symptoms (see fig. 1-2).

Although these data show that nursing home residents with dementia are more likely than other nursing home residents to have impairments in activities of daily living and psychiatric and behavioral symptoms, not all nursing home residents with dementia have these problems. The survey data

**Figure 1-2—Behavioral Symptoms in Demented and Nondemented Nursing Home Residents, United States, 1987**



SOURCE: Adapted from U.S. Department of Health and Human Services, published and unpublished data from the 1987 National Medical Expenditure Survey, Institutional Population Component, Current Residents, Agency for Health Care Policy and Research, Rockville, MD, 1991.

indicate that 4 to 46 percent of residents with dementia do not have impairments in activities of daily living, depending on the activity, and that more than 40 percent of residents with dementia do not have behavioral symptoms.

Nursing home residents with dementia also differ in their coexisting medical conditions and physical impairments. OTA is not aware of any information from national studies on the proportion of nursing home residents with dementia who have coexisting medical conditions or physical impairments. As discussed in chapter 2, data on the characteristics of 3427 residents of New York nursing homes show that residents with dementia vary greatly in this respect (283). Some are relatively healthy except for their dementia, and others have numerous diseases and physical impairments in addition to their dementia.

The diversity of nursing home residents with dementia has important implications for special care units. First, it is unlikely any particular type of unit will be appropriate for all types of nursing home residents with dementia. Second, with respect to the long-range possibilities discussed earlier, it is clear

that if special care units were designated to serve only individuals with behavioral symptoms, the units would not serve all individuals with dementia who need nursing home care, because more than 40 percent of nursing home residents with dementia do not have behavioral symptoms.

### ***Problems in the Care Provided for Nursing Home Residents With Dementia***

Many complaints and concerns have been expressed about the quality and appropriateness of the care provided for nursing home residents with dementia. These complaints and concerns are the primary reason for the development and proliferation of special care units. They explain to a great degree why there is a market for special care units. They are also the rationale for many of the specific changes in physical design features, patient care practices, and staff training that are recommended for special care units.

Table 1-1 lists the most frequently cited complaints and concerns about the care provided for nursing home residents with dementia. This list is based on OTA's review of numerous articles and books on nursing home care for individuals with dementia (see ch. 2). The inclusion of items in the list does not imply that there is evidence to prove the items are true but rather that the items are aspects of what is believed to be wrong with the care provided for individuals with dementia in many nursing homes.

Some of the complaints and concerns listed in table 1-1 apply particularly to residents with dementia, and others apply equally to nondemented residents. To differentiate these two types of problems, OTA compared the most frequently cited complaints and concerns about the care of nursing home residents with dementia, as listed in table 1-1, with the problems identified by the Institute of Medicine in its 1986 report, *Improving the Quality of Care in Nursing Homes*, which dealt with nursing home care for all types of residents (318). This comparison, which is discussed in greater detail in chapter 2, shows that the complaints and concerns about nursing home care for residents with dementia focus more on the physical aspects of nursing homes that are perceived to be inappropriate for individuals with dementia (e.g., the lack of cues to help residents

find their way and the lack of appropriate space for residents to wander) and the lack of staff knowledge about how to respond to behavioral symptoms. In contrast, the Institute of Medicine report focuses more on the lack of sufficient attention to residents' rights and the lack of choices for residents.

Both the Institute of Medicine's report and the literature on nursing home care for individuals with dementia cite the failure of many nursing homes to create a home-like environment and their failure to identify and treat residents' acute and chronic diseases and conditions. Both sources also cite the lack of adequately trained staff in many nursing homes. The Institute of Medicine's report focuses on the lack of training in general, whereas the literature on nursing home care for individuals with dementia focuses on the lack of training about dementia and the care of residents with dementia.

Both the Institute of Medicine's report and the literature on nursing home care for individuals with dementia cite the overuse and inappropriate use of psychotropic medications and physical restraints. Although these two problems affect all nursing home residents to some degree, they are more likely to affect residents with dementia.

From 35 to 65 percent of all nursing home residents are prescribed and/or receive at least one psychotropic medication<sup>5</sup> and 9 to 26 percent of residents are prescribed and/or receive more than one such medication (18,19,52,366,425,429,433,461). Nursing home residents with dementia are more likely than other nursing home residents to receive these medications (19,389,425,429). Often the medications are used to control behavioral symptoms in residents with dementia, even though many of the frequently used medications have not been demonstrated to be effective for this purpose (18,19,180,208,277,285,339,381,389,397,406,414,425). Moreover, some of the most frequently used medications are known to cause confusion, disorientation, and oversedation in older people and are likely to worsen the fictional impairments of individuals with dementia.

From 25 to 59 percent of all nursing home residents are physically restrained at any one time (133,446,520). Nursing home residents with dementia are far more likely than other nursing home residents to be physically restrained (133,389,446).

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<sup>5</sup> Psychotropic medications include antipsychotic, antidepressant, antianxiety, and sedative/hypnotic agents.

**Table 1-1—Frequently Cited Complaints and Concerns About the Care Provided for Nursing Home Residents With Dementia**

- Dementia in nursing home residents often is not carefully or accurately diagnosed and sometimes is not diagnosed at all.
- Acute and chronic illnesses, depression, and sensory impairments that can exacerbate cognitive impairment in an individual with dementia frequently are not diagnosed or treated.
- There is a pervasive sense of nihilism about nursing home residents with dementia; that is, a general feeling among nursing home administrators and staff that nothing can be done for these residents.
- Nursing home staff members frequently are not knowledgeable about dementia or effective methods of caring for residents with dementia. They generally are not aware of effective methods of responding to behavioral symptoms in residents with dementia.
- Psychotropic medications are used inappropriately for residents with dementia, particularly to control behavioral symptoms.
- Physical restraints are used inappropriately for residents with dementia, particularly to control behavioral symptoms.
- The basic needs of residents with dementia, e.g., hunger, thirst, and pain relief, sometimes are not met because the individuals cannot identify or communicate their needs, and nursing home staff members may not anticipate the needs.
- The level of stimulation and noise in many nursing homes is confusing for residents with dementia
- Nursing homes generally do not provide activities that are appropriate for residents with dementia
- Nursing homes generally do not provide enough exercise and physical movement to meet the needs of residents with dementia.
- Nursing homes do not provide enough continuity in staff and daily routines to meet the needs of residents with dementia.
- Nursing home staff members do not have enough time or flexibility to respond to the individual needs of residents with dementia.
- Nursing home staff members encourage dependency in residents with dementia by performing personal care functions, such as bathing and dressing, for them instead of allowing and assisting the residents to perform these functions themselves.
- The physical environment of most nursing homes is too “institutional” and not “home-like” enough for residents with dementia.
- Most nursing homes do not provide cues to help residents find their way.
- Most nursing homes do not provide appropriate space for residents to wander.
- Most nursing homes do not make use of design features that could support residents’ independent functioning.
- The needs of families of residents with dementia are not met in many nursing homes.

SOURCE: Office of Technology Assessment, 1992.

A study of restraint use in 12 Connecticut nursing homes found, for example, that 51 percent of the disoriented residents were newly restrained over the 1-year course of the study, compared with only 17 percent of the residents who were not disoriented (446). The potential negative effects of physical restraint use for both demented and nondemented residents include the following: incontinence; loss

of bone and muscle mass and other physiological effects of immobility; increased agitation; aggravated behavioral symptoms, such as screaming, hitting, and biting; decreased social behavior; loss of self-esteem; emotional withdrawal; and injuries and death due to improper use of the restraints and residents’ attempts to escape from them (30,133, 139,182,208,300,305,383,427,446,490,498).

**Box 1-B—The Development of Excess Disability in a Nursing Home Resident With Dementia**

One evening an elderly man with dementia who had recently been admitted to a nursing home was picking up his newspaper at the receptionist's desk. Abruptly, he threatened to hit the receptionist with his cane if she did not call him a cab, so he could "go to town." The receptionist contacted the nurses' station and kept the man talking until help arrived. Three staff members responded. They attempted to calm the man verbally, but when these attempts failed, they snatched the cane and forcefully placed him in a "geri-chair." He was wheeled to his room, yelling and kicking. Several visitors and other residents stood by, wide-eyed, watching this scene.

A negative pattern developed with the new resident. He did well during the day with minimal assistance, but every evening he became very confused, agitated, and disruptive. The nursing home staff met with his family, and the family agreed to visit him each evening for a few weeks, until he adjusted to the new environment.

Several weeks passed, the agitation and confusion continued, and the family requested sedation, in part because they were embarrassed about his behavior. An antipsychotic medication was prescribed. Different dosages and administration times were tried to determine a therapeutic level. Several more weeks passed. The resident became less disruptive, but he also began to walk unsteadily, drool, and slur his words. He became incontinent, and he could no longer dress himself.

SOURCE: Adapted from M. Bowsher, "A Unique and Successful Approach to Care for Moderate Stage Alzheimer's Victims," Green Hills Center, West Liberty, OH, unpublished manuscript, no date.

Overuse and inappropriate use of psychotropic medications and physical restraints are problems in themselves. They are also perceived by special care unit advocates and others as manifestations of other problems in the nursing home care provided for individuals with dementia—notably the failure of many nursing homes to use more appropriate methods of responding to the individuals' physical and emotional needs and behavioral symptoms.

Reduction in the use of psychotropic medications and physical restraints is a major objective of many special care units. Evidence cited later in this chapter and discussed at greater length in chapter 3 indicates that in general special care units have been successful in reducing the use of physical restraints but that use of psychotropic medications is as high or higher in special care units than in nonspecialized units.

***Negative Consequences for Nursing Home Residents With Dementia, Their Families, Nursing Home Staff Members, and Nondemented Nursing Home Residents***

Problems in the care provided for nursing home residents with dementia have many negative consequences for the residents. These negative consequences include reduced quality of life, reduced physical safety, and excess disability. The term *excess disability* refers to functional impairment that is greater than is warranted by an individual's disease or condition (47,219). The concept of excess disability implies that an individual has certain

functional impairments that are caused by his or her dementing disease or condition and other functional impairments that are caused by other factors. The latter impairments constitute excess disability.

Inappropriate or poor-quality nursing home care can lead to excess disability in cognitive functioning, mood, activities of daily living, and behavior. Box 1-B illustrates the development of excess disability in a nursing home resident with dementia. The immediate cause of excess disability in this case was a psychotropic medication. Box 1-C later in this chapter describes an alternate set of staff responses in the same situation that solved the problem and avoided the use of psychotropic medications and the excess disability.

In practice, it is often difficult to distinguish fictional impairments caused by an individual's dementing disease or condition and functional impairments caused by inappropriate or poor-quality nursing home care. Many commentators contend, however, that some and perhaps many of the functional impairments of nursing home residents with dementia are due to problems in the care they receive rather than to their dementing disease or condition (107,115,125,165,171,241,263,359,385,386).

Problems in the nursing home care provided for individuals with dementia have negative consequences for the residents' families. Many families of individuals with dementia feel intensely guilty, anxious, and sad about having to place the individual in a nursing home. These feelings may be due

primarily to the patient's condition and other factors that have made nursing home placement necessary, but the feelings are intensified if the family believes the individual is receiving inappropriate or poor-quality care (84,162,263). In addition, the failure of many nursing homes to facilitate and support families' ongoing involvement in their relative's care may result in the development of a competitive or adversarial relationship between the staff and the family which further increases the family members' anxiety (45,50,55,167,349,418).

Problems in the care provided for individuals with dementia also have negative consequences for nursing home staff members. Residents with dementia are often difficult for staff members to care for because of their communication deficits, impairments in activities of daily living, and behavioral symptoms (60,107,167,170,181,191,263,352,359,385). The difficulty of caring for residents with dementia is said to cause stress, lowered morale, and burnout for staff members (191,263,346,352,398). These reactions may in turn lead to increased absenteeism and staff turnover. To the extent that residents' impairments are caused or exacerbated by inappropriate or poor-quality care, the job of staff members is unnecessarily difficult, and any resulting stress, absenteeism, and turnover are also attributable to the inappropriate care.

Lastly, nondemented nursing home residents may experience negative consequences because of problems in the care provided for residents with dementia. Behavioral symptoms of residents with dementia, e.g., restlessness, screaming, repetitive verbalizations, and combativeness, are upsetting for nondemented residents (46,220,241,263,268,352,373). The cognitive and fictional impairments of residents with dementia may also be upsetting for nondemented residents. Experts disagree about the overall impact on nondemented nursing home residents of living in close proximity to residents with dementia, but the two studies OTA is aware of that address this issue found significant negative effects for the nondemented residents (438,507). In a study of 72 nondemented nursing home residents, Teresi et al. found that the nondemented residents who shared a room or had a room adjacent to a demented resident were significantly more likely than the other nondemented residents to express dissatisfaction with their life and their environment and to be perceived as depressed by staff members (438). They were also

significantly less likely to receive visits or phone calls from family or friends.

It is unclear whether the negative effects on nondemented nursing home residents of living in close proximity to residents with dementia are due primarily to characteristics of the demented residents that are caused by their dementing illness or to characteristics that are caused by inappropriate nursing home care. To the extent that the negative effects are due to characteristics caused by inappropriate care, the inappropriate care is also responsible for the reduced quality of life of the nondemented residents.

Special care units promise to provide better nursing home care than is currently available for individuals with dementia. By providing better care, they expect to benefit residents, residents' families, and nursing home staff members. Better care can only reduce impairments that are not inevitably caused by the residents' dementing disease or condition. Likewise, better care for residents can only alleviate that portion of family members' feelings of guilt, anxiety, and sadness that is due to inappropriate care, not the portion of those feelings that is caused by the residents' impairments or deteriorating condition. Similar considerations apply to the potential impact of better care on nursing home staff members. Research findings with respect to the effect of special care units on residents, families, and nursing home staff members should be considered in the context of these inherent limitations on potential positive outcomes.

The situation is different for nondemented nursing home residents. Placing demented residents in separate units eliminates for nondemented residents the negative effects of living in close proximity with demented residents regardless of the factors that cause the negative effects. Some commentators believe that placing individuals with dementia in physically separate units may be justifiable solely on the grounds that it benefits nondemented residents, assuming the placements do not harm the demented residents (221,356).

## SPECIAL CARE UNITS

The first special care units in this country were established in the mid 1960s and early 1970s (413,485,494). In the mid to late 1970s and the first half of the 1980s, interest in specialized nursing home care for individuals with dementia grew

rapidly because of increasing general awareness of Alzheimer's disease and the special needs of nursing home residents with dementia (273). In this period, some nursing homes established special care units.<sup>6</sup> Other nursing homes established special activity programs for their residents with dementia.<sup>7</sup>

Reports on these early special care units and programs reflect each facility's search for workable approaches in caring for individuals with dementia (273). The reports are primarily descriptive. Many of them include case examples that illustrate the behavioral and other resident problems the unit was designed to address.

Much of the literature on special care units consists of descriptive reports of this kind. These reports generally cite one or more theoretical concepts as the rationale for the physical design features and patient care practices that have been implemented in a particular unit and make that unit special in the view of the report authors. Many of the reports also provide nonquantitative, anecdotal evidence of the beneficial outcomes of the unit.

Reports on early special care units do not suggest marketing interests, but some recent reports do reflect such interests. In the past few years, market demand has clearly become an important factor in the establishment of special care units (273).

This section discusses the theoretical concepts of specialized dementia care that are frequently cited in the special care unit literature. It briefly describes several ideas about special care units from other countries that have influenced the development of special care units in this country. Lastly, it summarizes the findings from the available descriptive and evaluative studies of special care units.

### ***Six Theoretical Concepts of Specialized Dementia Care and Their Implications for Staff Composition and Training and the Individualization of Care***

Six interrelated concepts pervade the literature on special care units. The six concepts are discussed at some length in this report because OTA's review of the literature on special care units and discussions

with experts on dementia care indicate that these concepts constitute the core of what is or should be special about special care units, more so than any particular physical design features or other characteristics of the units. Although experts disagree about particular physical design features and other special care unit characteristics, there appears to be considerable agreement about the concepts.

The six theoretical concepts apply to the care of individuals with dementia generally and are not limited to special care units or even to nursing home care. One or more of the concepts are cited in virtually all articles and books about special care units, although few sources cite them all. The concepts are often used to explain and justify the particular physical design features and patient care practices used in a given special care unit or recommended for special care units generally. The concepts also have important implications for staff composition and training and the individualization of care.

#### **1. Something can be done for individuals with dementia.**

This concept argues against the pervasive nihilism that has characterized the care of individuals with dementia. It posits instead that even though most of the diseases and conditions that cause dementia are incurable at present, some aspects of dementia are treatable, and treatment will improve the individual's functioning and quality of life (91,125,165,268,353,364,371,403). The other five concepts discussed in this section can be thought of as ways of operationalizing the first concept. A corollary to the first concept that is implicit in much of the special care unit literature but explicitly stated by only a few commentators is the value judgment that individuals with dementia have a right to care that improves their functioning and quality of life even if the disease or condition that causes their dementia is irreversible and progressive (33,66,170,399).

#### **2. Many factors cause excess disability in individuals with dementia. Identifying and changing these factors will reduce excess**

<sup>6</sup> For examples of special care units established in this period, see Berger (27), Blumenthal Jewish Home (32), Boling and Boling (34), Bowsher (38), Bnce (44), Clarke (87), Goodman (158), Grossman et al. (163), Kromm and Kromm (234), Liebowitz et al. (253), Peppard (345), Wallace (478), and Wilson and Patterson (505).

<sup>7</sup> See, for example, Hanczaryk and Batzka (173), Johnson and Chapman (211), McGrowder-Lin and Bhatt (299), Sawyer and Mendolovitz (400), and Schwab et al. (403).



disability and improve the individuals' functioning and quality of life.

As discussed earlier, excess disability is functional impairment that is greater than is warranted by an individual's disease or condition (47,219). Excess disability in individuals with dementia can be caused by untreated acute or chronic illnesses, depression, and sensory impairments; overuse or inappropriate use of psychotropic or other medications or physical restraints; excessive environmental noise; lack of stimulation and exercise; inappropriate caregiver responses to individuals' behavioral symptoms, and other factors. The literature on special care units contains numerous examples of situations in which changing a factor that was causing excess disability resulted in dramatic improvement in an individual's functioning and quality of life.

3. Individuals with dementia have residual strengths. Building on these strengths will improve their functioning and quality of life.

Although individuals with dementia are usually described in terms of their impairments, even those with severe impairments have residual strengths and abilities (125,328,353,399,519). It has been noted, for example, that some individuals with dementia who are no longer able to speak coherently can still sing, and some can remember the words to old songs (295,487,491). By building on this strength, music programs and music therapy are intended to improve these individuals' quality of life and allow them to interact on some level with other people.

Another example of the implementation of this concept is the use of familiar activities. Many individuals with dementia remember how to do tasks they did earlier in their lives. Activities such as cooking and laundry-folding for women and wood-working for men are intended to build on these remaining abilities and give the individuals a feeling of competence (108,518).

4. The behavior of individuals with dementia represents understandable feelings and needs, even if the individuals are unable to express the feelings or needs. Identifying and responding to those feelings and needs will reduce the incidence of behavioral symptoms.

The behavior of individuals with dementia is frequently regarded as an inevitable and essentially meaningless consequence of their dementing dis-

ease or condition, and little effort is made to understand or explain it. In contrast, experts in dementia care point out that the behavior of individuals with dementia often expresses meaningful feelings, intentions, and needs (60,125,273,287,353, 361,385,403,408,482,517). They contend that if nursing home staff members and other caregivers can figure out the meaning of the individuals' behavior and respond to that meaning, the caregivers may be able to prevent or resolve behavioral symptoms without resorting to psychotropic medications or physical restraints. Box 1-C describes the same elderly man with dementia who is described in box 1-B and illustrates the way in which interventions based on an understanding of the meaning of an individual's behavior may prevent the development of behavioral symptoms and avoid the use of psychotropic medications and physical restraints. The special care unit literature contains many similar accounts.

The first efforts to explain specific behavioral symptoms in individuals with dementia focused on wandering. Beginning in the 1970s, several researchers have studied wandering behavior and concluded that although the behavior often seems meaningless on the surface, it actually represents a variety of meaningful intentions and needs for different individuals (e.g., a search for someone or something, a search for security, a wish to go home, or a lifelong coping style) (106,306,361,417). Based on this conclusion, a number of innovative and reportedly effective methods of responding to wandering behavior have been developed.

Two books—*Care of Alzheimer's Patients: A Manual for Nursing Home Staff* (165) and *Understanding Difficult Behaviors* (385)—discuss the many possible reasons for behavioral symptoms and suggest ways of responding to the problems based on these reasons. Both books recommend and exemplify a flexible, problem-solving approach to behavioral symptoms. Other commentators have also noted that responding effectively to the behavioral symptoms of individuals with dementia often involves a flexible, trial and error approach (353, 399,516).

Rader refers to wandering and other behaviors of individuals with dementia as *agenda behavior*; that is, behavior by which a person with dementia attempts to meet his or her own agenda (359,361). She urges caregivers of individuals with dementia to

**Box 1-C—The Use of Behavioral Interventions With a Nursing Home Resident With Dementia**

One evening an elderly man with dementia who had recently been admitted to a nursing home was picking up his newspaper at the receptionist's desk. Abruptly, he threatened to hit the receptionist with his cane if she did not call him a cab, so he could "go to town." The receptionist stood up, looked directly at the resident and said in a respectful, matter-of-fact tone, "I see something is bothering you." The resident answered in a low, harsh voice, "I should be working, not being lazy." The receptionist asked him about his work and listened intently as he talked about the work he used to do.

A pattern developed with the new resident. He did well during the day with minimal assistance, but every evening he became very confused and agitated. A nurse aide was assigned to take a walk with him at these times. As they walked together around the facility, they often talked about the past and the resident's busy professional life. Sometimes they just walked. When the resident showed sorrow, the nurse aide shared the sorrow with him by active listening and gently touching him on the arm.

Several weeks passed, The resident became less agitated and more content to wander around the unit, sometimes stopping to take imaginary measurements of a doorway or a piece of furniture. The intervention of the familiar nurse aide prevented the development of a behavioral problem that might have led to the use of psychotropic medications or physical restraints.

SOURCE: Adapted from M. Bowsher, "A Unique and Successful Approach to Care for Moderate Stage Alzheimer's Victims," Green Hills Center, West Liberty, OH, unpublished manuscript, no date.

try to understand the agenda that underlies the individual's behavior and to allow the individual to play out that agenda as much as possible, rather than superimposing the caregiver's own agenda.

On the basis of the concept that the behavior of individuals with dementia represents understandable feelings and needs, Feil and others advocate the use of *validation therapy* (120,136,407). Validation therapy involves understanding and validating the personal meaning of an individual's behavior. It is an alternative to *reality orientation*, a therapy method which requires the caregiver to consistently reorient the confused person to current reality. Many commentators contend that reality orientation is frustrating and usually ineffective for individuals with dementia, except perhaps early in the course of their dementing disease or condition (120,170,273, 359,361, 436,483).

5. Many aspects of the physical and social environment affect the functioning of individuals with dementia. Providing appropriate environments will improve their functioning and quality of life.

The relationship between the environment and the functioning of older people has been the topic of empirical research and theory-building in environmental psychology for 30 years (183,242). It is now generally accepted that the interaction between an older person's environment and the person's charac-

teristics can affect his or her functioning, either positively or negatively. According to Lawton:

The quality of the outcome of a person-environment transaction is a function of the degree of environmental demand or press . . . and the competence of the person. When the degree of demand is matched to the person's competence, a positive outcome in terms of affective response or adaptive behavior is the rule. When press is high in relation to competence, psychological disturbance in the form of strain is likely to occur. When press is low in relation to competence, sensory deprivation and atrophy of skills are likely (243).

In this theory, the terms *environmental demand* and *environmental press* refer to the motivating or activating quality for a particular individual of the physical and other aspects of that individual's environment (242). The term *person-environment fit* denotes the degree of congruence between environmental demand or environmental press and the needs and characteristics of an individual. The theory proposes that person-environment fit can be improved by changing the environment (218,242).

The theory also proposes that the impact of the environment is greater for individuals with low competence, including individuals with dementia, than for other people. According to Lawton:

As individual competence decreases, the environment assumes increasing importance in determining well-being. One corollary of this hypothesis is that

the low-competent are increasingly sensitive to noxious environments. The opposite and more positive corollary is that a small environmental improvement may produce a disproportionate amount of improvement in affect or behavior in the low-competent individual (241).

The concept that appropriate environments will improve the functioning and quality of life of individuals with dementia appears frequently in the special care unit literature. In the context of the theory, the term *environment* includes all aspects of a person's surroundings, but the concept is cited most often in connection with physical aspects of the units. Many articles and books that discuss the design of special care units identify one or more impairments or needs of individuals with dementia and propose physical design features to compensate for or respond to the impairments or needs. Two books exemplify this approach: *Designing for Dementia: Planning Environments for the Elderly and Confused* (67) and *Holding Onto Home: Designing Environments for People With Dementia* (93).

Physical design features are seen as potentially compensating for or responding to the impairments and needs of individuals with dementia in the following general ways:

- . by assuring safety and security;
- . by supporting functional abilities;
- . by assisting with way-finding and orientation;
- . by prompting memory;
- . by establishing links with the familiar, healthy past;
- . by conveying expectations and eliciting and reinforcing appropriate behavior;
- . by reducing agitation;
- by facilitating privacy;
- . by facilitating social interactions;
- . by stimulating interest and curiosity;
- . by supporting independence, autonomy, and control; and
- . by facilitating the involvement of families (62,67,93,184).

Many different physical design features are justified on the basis of the concept that appropriate environments will improve the functioning and quality of life of individuals with dementia. These design features range from the overall shape and floor plan of the unit (see fig. 1-3) to the use of environmental cues, such as color coding of rooms and corridors to help residents find their way, and

personal markers, such as residents' pictures placed near their rooms to help them identify the rooms.

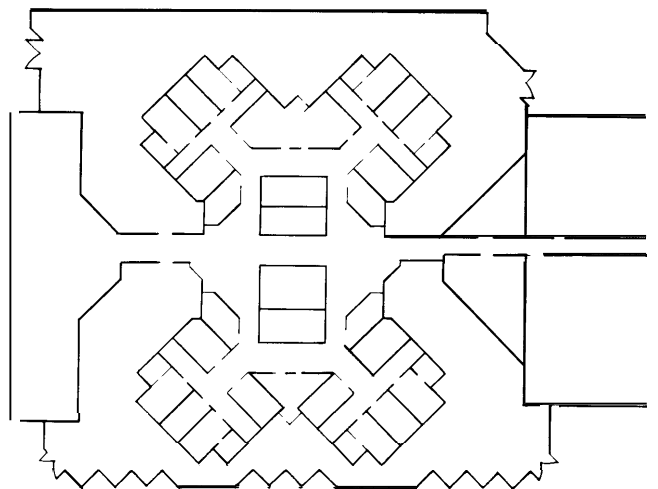
Physical design features are often referred in the special care unit literature as *prosthetic* because they are intended to compensate for, rather than cure, impairments that are believed to be unchangeable. Since the impairments are unchangeable, it is assumed the prosthetic features will be needed permanently. Physical design features that compensate for functional impairments are said to be cost effective because the design features act continuously and may substitute for more costly staff interventions (185,243).

Sometimes very strong claims are made about particular physical design features for special care units, as if there were proof of the effectiveness or lack of effectiveness of the features. Numerous articles state with certainty, for example, that floor patterns with dark areas or dark borders should not be used in special care units because individuals with dementia will perceive the dark areas as holes and be afraid to walk on or over them. Likewise it is often said that certain types of art work, wallpaper, and carpet patterns cause delusions and hallucinations in nursing home residents with dementia. To OTA's knowledge, there is no research-based evidence for these claims.

OTA has heard particular physical design features justified on the basis of claims, such as that individuals with dementia may mistake a light reflected from a shiny floor as a blob that is chasing them, that they feel threatened by the person in the mirror who does not respond to their greeting, that they sometimes mistake their shadows for pools of water and try to jump over, that they try to pick the flowers in floral-print wallpaper, etc. One suspects that these claims arise from anecdotes about individual residents or someone's guess about the response of individuals with dementia to a particular design feature and that the anecdotes and guesses are then generalized to all residents with dementia.

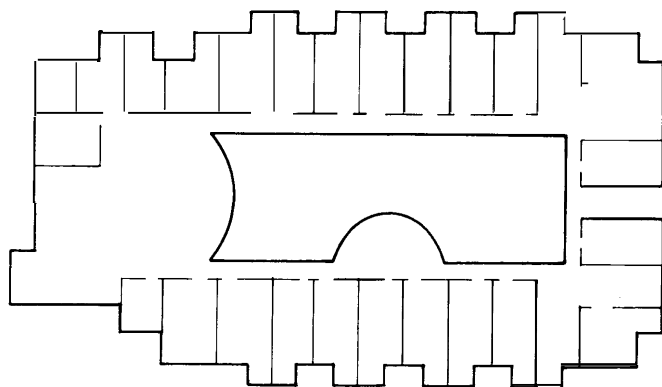
In reality, very little research has been done to test the impact of particular physical design features on individuals with dementia. Moreover, the conclusions of several of the existing studies are contradictory. Some of these studies are described in chapter 4. Unfortunately, some nursing homes incorporate physical design features for which strong claims are made and believe they have thereby created an appropriate environment for their residents with

Figure 1-3—Alternate Shapes and Floor Plans for Special Care Units



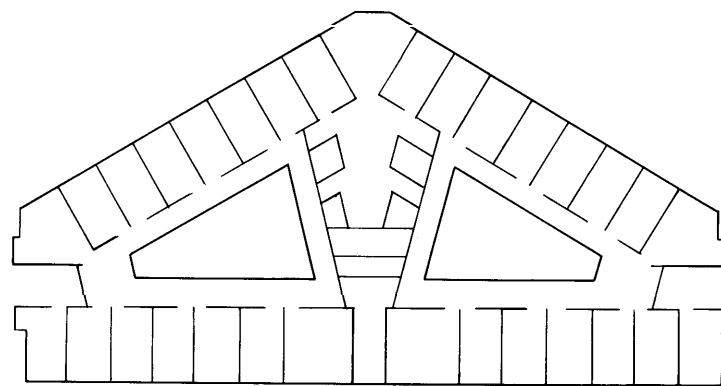
John Douglas French Center, Los Angeles, CA

The building is structured in a "butterfly" shape with 4 units maintaining rooms for "families" of 12-13 residents located around a shared nurses' station. Each family unit includes a mix of private and semi-private rooms. There is direct access to a secure courtyard.



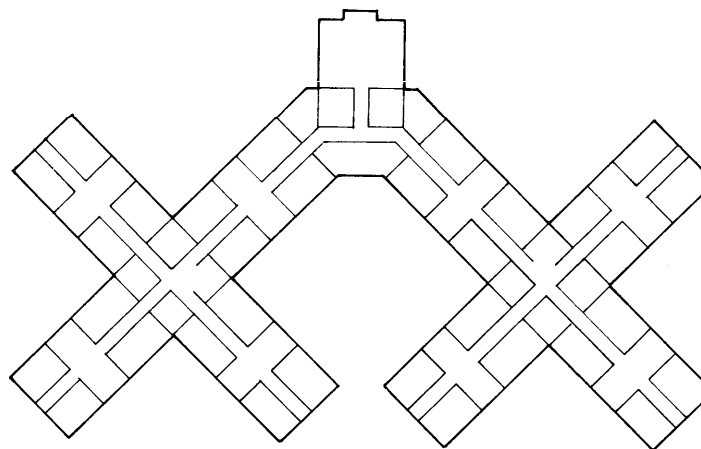
Weiss Institute, Philadelphia Geriatric Center, Philadelphia, PA

The unit is comprised of a large central space, around which residents' rooms are located. The open plan of the 40-bed unit allows staff easy visual access to all residents and provides a continuous path for wanderers. The unit has a therapeutic kitchen for residents.



Corinne Dolan Alzheimer's Center, Heather Hill, Chardon, OH

The building is comprised of 2 triangular units with a shared support and bathing core. The open plan of each 12-bed unit allows staff easy visual access to all residents, and provides a continuous path for wanderers. Each unit has a fully equipped residential-style kitchen. There is direct access to a secure courtyard, as well as to several paved paths beyond the yard for residents and visitors.



Friendship House, West Bend, IN

The building is comprised of 2 units with 4 "households" each. A nurses' station, elevator and services are located at the center of each unit of 4 households. A protected outdoor courtyard is defined by the two units.

dementia, when, in fact, no evidence exists that the specific features are effective. Lawton has noted that:

There is a strong tendency for intuitive, a priori reasoning about what is "good" for Alzheimer patients to become accepted as fact. . . The hunger for information is so great among practitioners that almost any unsupported assertion can be rapidly accepted (244).

As noted earlier, the concept that appropriate environments will improve the functioning and quality of life of individuals with dementia is cited most often in connection with physical design features for special care units, but it is sometimes also cited in connection with other unit characteristics, such as activity programs and daily routine. Activity programs and the daily routine on the unit are perceived as potentially compensating for the impairments of residents with dementia in many ways, e.g., by supporting functional abilities, prompting memory, conveying expectations, eliciting and reinforcing appropriate behavior, facilitating social interactions, and stimulating interest and curiosity (358,392,519).

Coons has gone farthest in developing a model of specialized dementia care, referred to as a *therapeutic milieu*, in which all aspects of the physical and social environment and the daily routine on the unit are designed to be therapeutic (104,105,109).<sup>8</sup> This model was demonstrated for several years at Wesley Hall, a special care unit in a retirement facility in Chelsea, MI.

A different model of care, referred to as a low stimulus unit, has been developed by Hall and her colleagues (170,171). This model is based on the concept that appropriate environments will improve the functioning and quality of life of individuals with dementia and the perception of these clinicians that individuals with dementia have a "progressively lowered threshold for stress" due to their reduced ability to receive and process external stimuli. Hall and others believe that in traditional nursing home units, residents with dementia are overwhelmed by multiple environmental stimuli, including noise from telephones, televisions, radios, Muzak, and paging systems; high-glare floors; hurrying staff; visitors; other residents; and large group activities. They believe that in response to these stimuli, the

residents become increasingly agitated, confused, and sometimes combative. To compensate for the residents' lowered threshold for stress, Hall and her colleagues propose units in which environmental stimuli are reduced: no telephones ring on the unit; television, radio, Muzak, and paging are eliminated; staff and visitor traffic through the unit is reduced; dining and activities take place in small groups; and resting is encouraged by environmental cues, such as comfortable chairs in the hallways. Many low stimulus units have been established on the basis of this model (169,209,334). While agreeing with some aspects of the low stimulus model, other clinicians and researchers contend that the main problem is not excessive stimuli, but insufficient stimuli of appropriate types. They argue that an increase in selected stimuli will improve the functioning and quality of life of individuals with dementia (107,183,243, 259,272). The ideal level and type of stimuli are unclear, however (96,185,244,287).

Like the other five concepts discussed in this section, the concept that appropriate environments will improve the functioning and quality of life of individuals with dementia is theoretical. It is interpreted differently by different individuals and is used to justify a great variety of physical design features and other unit characteristics. Disagreements among experts about the right characteristics for a special care unit make it difficult for nursing home administrators and others to design a special care unit. These disagreements do not, however, invalidate the underlying concept. Instead, they point out the need for research to test the effectiveness of the recommended characteristics.

6. Individuals with dementia and their families constitute an integral unit. Addressing the needs of the families and involving them in the individuals' care will benefit both the individuals and the families.

Families of individuals with dementia are often said to be the second victim of the dementia. They are generally perceived by experts in dementia care as part of the client unit. As a result, meeting their needs becomes a legitimate objective of specialized dementia care.

Families can also assist in various ways in the care of nursing home residents with dementia. They are a source of valuable information about the residents,

<sup>8</sup> The concept of *therapeutic milieu* was first used in the treatment of mentally ill persons in psychiatric hospitals (215).

who often cannot provide accurate information about themselves. As Hegeman and Tobin have noted, families can “help to preserve the unique identity of residents and help the staff and the resident be **aware** of that identity” (178). Families can also provide physical assistance, emotional support, and advocacy. Their presence helps to make any setting more home-like and familiar for the resident (174,296,358,418).

Meeting the needs of families of nursing home residents with dementia means providing them with information, emotional support, and a structure that facilitates their involvement in the residents' care. Families are perceived to benefit from information about dementia and ways of communicating with a person with dementia, as well as from support groups, counseling, and other forms of emotional support (55,128,168,296,358,418,516).

To facilitate the involvement of families in the residents' care, it is necessary to provide both a welcoming atmosphere and administrative and caregiving practices that recognize the families' legitimate role in the residents' care. Families can be involved, for example, in care planning conferences and other situations in which decisions are being made about the residents' care. They may also be encouraged to act as volunteers on the unit (46,55,125,168,174,418).

By providing information, emotional support, and a structure that facilitates the involvement of families, it may be possible to lessen their feelings of anxiety and guilt and avoid the development of a competitive or adversarial relationship between the staff and the families. Families differ, however, and the best ways of providing information and support and involving families also differ (128,168,358).

#### Implications for Staff Composition and Training

The six concepts discussed above have important implications for staff composition and training. With respect to staff composition, the concepts indicate the need for a multidisciplinary approach to care. To identify and change the factors that cause excess disability requires the involvement of health care professionals capable of diagnosing and treating the causes of excess disability, e.g., acute and chronic illnesses, depression, and sensory impairments. Likewise, to provide activity programs that build on residents' residual strengths, support functional abilities, and facilitate social interactions requires

the involvement of individuals who are skilled in various therapeutic recreation specialties. Although these health care professionals and other therapists do not necessarily have to be part of the unit staff-and to make them part of the staff may be prohibitively expensive-some means of involving them in the residents' ongoing care is essential for effective implementation of the concepts.

With respect to staff training, the concepts require a change for all staff members in widely held nihilistic attitudes about nursing home residents with dementia. In addition, since the concepts do not provide precise formulas for care, staff members must not only understand the concepts but also be able to interpret and apply them in caregiving situations. In most special care units, as in nursing homes generally, nurse aides provide most of the daily care. These aides must be able to interpret and apply the concepts—sometimes in difficult, emotionally-charged situations. To do so requires knowledge, problem-solving skills, and judgment. Special care units that adopt the concept of therapeutic milieu often regard housekeepers and other nonprofessional staff members as part of the care team. These individuals also must understand the concepts and be able to apply them.

#### Implications for the Individualization of Care

Three of the six concepts clearly emphasize the individualization of care. They require the staff members to: 1) identify and change the factors that cause excess disability in individual residents; 2) identify and build on the residual strengths of individual residents; and 3) identify and respond to the feelings and needs expressed in the behavior of individual residents. As noted earlier, nursing home residents with dementia are diverse, and their characteristics and needs change over time. The three concepts that emphasize the individualization of care fit well, at least in theory, with this diversity.

The concept that appropriate environments will improve the functioning and quality of life of individuals with dementia may also fit well in theory with the diverse and changing needs of nursing home residents with dementia. In practice, however, the concept is probably more difficult to apply, since special care units must be designed and built for groups of individuals. The objectives in special care unit design include flexibility and the capacity to adapt to resident change (10,67,287,296,358). Nevertheless, given the extreme diversity of nursing

home residents with dementia, it would seem that the more closely the physical environment of a special care unit matches the needs of one individual or one type of individual with dementia, the less likely the unit would provide the best environment for other types of individuals with dementia. The same concern may apply to other features of special care units, such as activity programs.

This concern has led a few nursing homes to establish several special care units that provide different levels and types of care intended to match the characteristics and needs of residents in different stages of their illness (34,473). A second alternative, adopted by some nursing homes with only one special care unit, is to discharge residents from the unit—usually to a nonspecialized unit in the same facility—when the level and type of care provided in the special care unit no longer matches the residents' characteristics and needs. Both these alternatives require moving residents, which is likely to increase their confusion. Moving residents also may have negative consequences for the residents' families who are often emotionally attached to the unit staff members and for the unit staff members who are often attached to the residents and their families (40,375,473).

A third alternative is to allow special care unit residents to *age in place*, that is, to remain on the unit until they die. Anecdotal evidence suggests that some special care units that adopt this policy become, in effect, terminal care settings as most of the residents progress into the later stages of their illness (40,419). This creates problems for new residents who are admitted to a unit in which most of the other residents are severely cognitively and physically impaired. OTA is not aware of any research that compares these three alternatives, and the special care unit literature contains little discussion of this important issue.

### *Ideas About Special Care Units From Other Countries*

Special care units for people with dementia exist in many other countries. Information about these units reaches the United States primarily through reports from foreign visitors who are knowledgeable about the special care units in their own countries and through reports of Americans who have visited

the units in other countries. There are a few descriptive studies on special care units in particular countries,<sup>9</sup> but most of the available information is anecdotal. OTA is not aware of any formal research comparing special care units in different countries.

Information about special care units in other countries influences thinking about special care units in the United States in several ways. First, special care units in other countries demonstrate alternate models of care. For example, a primary objective of special care units in some countries is to provide a comfortable, home-like environment for their residents. These units have few rules and maintain a flexible daily schedule that is responsive to the habits and preferences of individual residents. In visiting these units, American observers have been impressed with their relaxed atmosphere and the apparent contentment of the residents (273). Reports on special care units of this kind in other countries create an incentive for the establishment of similar units in this country.

Physical restraints are used less frequently or not at all in special care units in some other countries (273,498). The knowledge that restraints are less often used in other countries has been one incentive for reducing their use in the United States.

Special care units in some other countries are more able to innovate than special care units in the United States (273). Awareness of this difference calls attention to the factors that encourage or constrain innovation in different countries. One such factor is nursing home regulations. As discussed in chapter 6, nursing home regulations in the United States sometimes interfere with the implementation of innovative physical design and other features in special care units. Nursing homes are less tightly regulated in most other countries and are therefore more able to innovate. Public programs in many other countries also make a less rigid distinction than public programs in the United States between health care and social services, and the same public programs are more likely to pay for both types of services in other countries. As a result, there are fewer artificial barriers to the development of special care units that provide a mix of medical and social services. Lastly, public funding is more likely to be available for nonmedical residential care in other countries than in the United States. When the same

<sup>9</sup> See, for example, Norman, *Severe Dementia: The Provision of Longstay Care* (330).

public programs pay for both medical and social services and public funding is available for nonmedical residential care, there is a strong financial incentive for government agencies to support the development of nonmedical residential care models that are less costly than nursing homes. Since 1986, for example, the Australian government has provided grants to stimulate the development of special care units in hostels as an alternative to nursing homes for individuals with dementia (101).

Despite these advantages in other countries, no country has the answers with respect to special care units or problems in the care of nursing home residents with dementia (273). Questions about the effectiveness of various models and components of care are pervasive. Clinicians and researchers from other countries frequently come to the United States in search of ideas about physical design features and patient care practices for special care units. Adequately trained staff and sufficient funding are in short supply everywhere.

### *Findings From Research on Special Care Units*

Research on special care units is in an early stage, but some descriptive and evaluative studies have been conducted in the past few years. OTA's conclusions from the available descriptive studies are listed in table 1-2. The findings from these studies are discussed in detail in chapter 3, and some of the most important findings for policy purposes are reviewed in this section. The findings from the available evaluative studies are discussed in detail in chapter 4 and reviewed briefly in this section.

#### Number of Nursing Homes That Have a Special Care Unit

OTA estimates that in 1991, 10 percent of U.S. nursing homes had a special care unit. This number includes nursing homes that group some of their residents with dementia in physically distinct clusters in units that also serve some nondemented residents.

As noted earlier, OTA's estimate is based on the findings of two recent studies. One of the studies—a 1991 survey of all U.S. nursing homes with more than 30 beds—found that 9 percent of the nursing homes reported having either a special care unit or a special program for residents with dementia in a physically distinct part of the facility (246). The

second study—a 1990 survey of all nursing homes in five northeastern States—found that seven percent of the nursing homes reported having a special care unit, and an additional five percent reported that although they did not have a special care unit, they did place some of their residents with dementia in physically distinct groups or clusters in units that also served some nondemented residents (194). Thus, a total of 12 percent of the nursing homes reported using some method to physically group residents with dementia—either in a special care unit or a cluster unit.

The lack of an accepted definition of the term *special care unit* makes it difficult to develop accurate figures on the number and proportion of nursing homes that have a special care unit. The figures cited above are based on self-report. The figures from the 1991 survey generally reflect the opinion of each nursing home administrator or other survey respondent about what a special care unit is. According to the researchers who conducted the 1990 survey, however, some nursing homes that place residents with dementia in a physically separate unit and provide special services in the unit do not use the term “special care” for these arrangements and therefore may not respond affirmatively to a survey question about whether they have a special care unit (436). Surprisingly, the researchers also found that in some nursing homes, the administrator and the director of nursing disagreed about whether the facility had a special care unit (194).

Some people believe the term *special care unit* should mean more than just a physically separate space and the nursing home's claim that it provides “special care. Depending on the additional criteria that are used, some and perhaps many of the nursing homes included in the figures just cited might not be counted as having a special care unit.

To OTA's knowledge, the 1990 survey of all nursing homes in five northeastern States was the first to identify large numbers of nursing homes with cluster units. It is unclear whether cluster units should be counted as special care units. Many of the cluster units identified in the 1990 survey incorporated features that are recommended for special care units (e.g., physical design features, special staff training, and family support groups), although cluster units were less likely than special care units to incorporate these features (194).



**Table 1-2-Conclusions From Descriptive Studies of Special Care Units****Number of Nursing Homes That Have a Special Care Unit**

- **OTA estimates that in 1991, 10 percent** of all nursing homes in the United States had a special care unit. In at least some States, this figure includes nursing homes that place some of their residents with dementia in “clusters” in units that also serve nondemented residents.
- The proportion of nursing homes that have a special care unit varies in different parts of the country and in different States,
- Many nursing homes that do not have a special care unit are planning to establish one, and some nursing homes that have a special care unit are planning to expand the unit.

**Characteristics of Nursing Homes That Have a Special Care Unit**

- Larger nursing homes are more likely than smaller nursing homes to have a special care unit.
- As of late 1987, most nursing homes that had a special care unit were private, for-profit facilities. At that time, multi-facility nursing home corporations owned about one-third of all the facilities that had a special care unit. There is no evidence, however, that ownership of special care units is dominated by a small number of multi-facility nursing home corporations.

**Characteristics of Special Care Units**

- Special care units are extremely diverse.
- Most special care units have been established since 1983, although a few have been in operation for 20 to 25 years.
- The goals of special care units differ. For some units, the primary goal is to maintain residents' ability to perform activities of daily living. Other units focus on maintaining residents' quality of life, eliminating behavioral symptoms, or meeting residents' physical needs,
- Most existing special care units were not originally constructed as special care units, and at least one-fifth were neither originally constructed nor remodeled for this purpose.
- The use of specific physical design and other environmental features varies in existing special care units. Many of the physical design and other environmental features cited as important in the special care unit literature are used in only a small proportion of special care units.
- The most extensively used environmental feature in special care units is an alarm or locking system, found in more than three-fourths of existing units.
- On average, special care units probably have fewer residents than nonspecialized nursing home units.
- On average, special care units probably have more staff per resident than nonspecialized nursing home units.
- Although the majority of existing special care units provide special training for the unit staff, at least one-fourth of existing units do not.
- Less than half of existing special care units provide a support group for unit staff members.
- The types of activity programs provided by special care units vary greatly, but existing special care units are probably no more likely than nonspecialized units to provide activity programs for their residents.
- \* About half of existing special care units provide a support group for residents' families.
- Special care unit residents are likely or more likely than other nursing home residents with dementia to receive psychotropic medications.
- Special care unit residents are probably less likely than other nursing home residents with dementia to receive medications of all types.

*(Continued on next page)*

**Table 1-2-Conclusions From Descriptive Studies of Special Care Units-(Continued)**

- *Special care unit residents are less likely than other* nursing home residents with dementia to be physically restrained.
- o Special care units vary greatly in their admission and discharge policies and practices. About half of all special care units admit residents with the intention that the residents will remain on the unit until they die.
- The cost of special care units varies depending on the cost of new construction or remodeling, if any, and ongoing operating costs. On average, existing special care units probably cost more to operate than nonspecialized nursing home units, primarily because of the higher average staffing levels on special care units.
- Special care units *generally have a higher* proportion of private-pay residents than nonspecialized nursing home units, and the private-pay residents are often charged more for their care in the special care unit than they would be in a nonspecialized unit.

#### **Characteristics of Special Care Unit Residents**

- **Special care unit** residents are younger than other nursing home residents, and they are more likely than other nursing home residents to be male and white.
- Special care unit residents are more likely than other nursing home residents to have a specific diagnosis for their dementing illness.
- Special care unit residents are probably somewhat more cognitively impaired and somewhat less physically and functionally impaired than other nursing home residents with dementia
- Special care unit residents are probably somewhat more likely than other nursing home residents with dementia to participate in activity programs.
- \* Special care unit residents are more likely than other nursing home residents with dementia to fall.

SOURCE: Office of Technology Assessment, 1992.

In this context, it is interesting to note that the special care unit described in box 1-A at the beginning of this chapter is technically not a separate unit, because it does not have a nurses' station and other features the State requires for a nursing home unit. That unit is viewed by the facility's administrators as a separate entity. A similar arrangement in another nursing home might be viewed by its administrators as a clustering of residents with dementia in one section of a larger unit that also serves nondemented residents, and they might report it as such on a survey questionnaire.

#### **Characteristics of Special Care Units and Special Care Unit Residents**

All studies of special care units show that existing units are extremely diverse. They vary in their goals, physical design features, staff-to-resident ratios, staff training programs, provision of staff and family support groups, activity programs, use of psychotropic medications and physical restraints, and admission and discharge policies and practices.

Because of this diversity, no single descriptive statement is true of all special care units.

On average, special care units probably have fewer residents and more staff per resident than nonspecialized nursing home units (291). Staff-to-resident ratios vary greatly among units, however.

Most special care units provide special training for their staff, but at least one-fourth of existing units do not provide special training. In response to the 1987 National Medical Expenditure Survey, 26 percent of the nursing homes with a special care unit reported they did not provide special training for the unit staff (248). Likewise, in response to the 1990 survey of all nursing homes in 5 northeastern States, 30 percent of the facilities with a special care unit and 47 percent of the facilities with a cluster unit reported they did not provide special training for the unit staff (194). Given the emphasis on staff training in the special care unit literature, the finding that more than one-fourth of existing units do not provide special training is surprising. The finding is proba-

bly correct, however, since nursing homes are unlikely to underreport the provision of staff training.

The most widely used physical design feature in special care units is an alarm or locking system, found in more than three-fourths of existing units (181,194,247). Although numerous physical design features have been recommended for special care units, most of the recommended features are used in only a small proportion of existing units (194,485,494).

Some special care units have formal (written) admission and discharge policies, but most probably do not (194). In response to the 1990 study of all nursing homes in five northeastern States, three-fourths of the facilities with a special care unit reported using each of three criteria to select their residents: 1) the degree of the individual's dementia; 2) the individual's need for supervision; and 3) the individual's behavioral symptoms (194). Most of the facilities reported that they seek individuals with more rather than less severe behavioral symptoms, but 15 percent reported that they seek individuals with less severe behavioral symptoms for their unit. One-third reported that the individuals they admit must be able to ambulate independently.

Reported admission practices may or may not reflect actual admission practices in special care units. Findings from the Multi-State Nursing Home Case-Mix and Quality Demonstration—a 5-year congressionally mandated study that includes special care unit residents among the 6800 nursing home residents in the study sample—suggest that the major factor distinguishing special care unit residents from individuals with dementia in nonspecialized nursing home units is the severity of their physical impairments (382). Data from a subsample of 127 special care unit residents and 103 residents with dementia in nonspecialized units in the same facilities indicate that individuals with severe physical impairments and physical care needs are less likely to be admitted to special care units than to nonspecialized units. Once other variables were controlled, there was no significant difference in behavioral symptoms between the special care unit residents and the residents with dementia in the nonspecialized units.

About half of existing special care units admit residents with the expectation that the individuals will remain in the unit until they die (194). Other special care units admit residents with the expecta-

tion that they will be discharged from the unit at some time prior to their death. In the latter units, the reported reasons for discharge are: 1) that a resident has become nonresponsive, physically abusive, or unable to ambulate independently; 2) that the resident needs intensive medical care; and 3) that the resident's private funds are exhausted (194,485,492).

As noted in table 1-2, special care unit residents are as likely or more likely than individuals with dementia in nonspecialized units to receive psychotropic medications (256,292,413). They are much less likely to be physically restrained, however (256,292,391,413). A University of North Carolina study of 31 randomly selected special care units and 32 matched, nonspecialized units in 5 States found that only 16 percent of the special care unit residents were physically restrained at one point in time, compared with 36 percent of the residents with dementia in nonspecialized units (413).

Finally, five studies show that special care unit residents are significantly more likely to fall than other nursing home residents with dementia (99,265,292,497,521). In one study, the special care unit residents were not only more likely to fall but also more likely to be hospitalized for a hip fracture (99). In another study, the increase in falls among special care unit residents did not result in an increase in injuries due to the falls (54). The greater incidence of falls among special care unit residents has received little attention thus far, in part because the relevant data from three of the studies have not yet been published. The reasons for the greater incidence of falls are not known.

### Costs, Charges, and Payment Methods

Very little information is available about the cost of special care units. The cost of creating a special care unit obviously varies, depending on the extent of new construction or remodeling, if any. One study of 12 nonrandomly selected special care units found that the reported costs for new construction and remodeling ranged from \$4100 to \$150,000 (275). Another unit was created for \$1300, which covered the cost of an alarm system, color coding, and a few other physical changes to the unit (70).

Most—but not all—special care units report that their operating costs are higher than the operating costs of nonspecialized units (70,477,485). Of 13 nonrandomly selected special care units in Florida, for example, 7 reported that their operating costs

were higher than the operating costs of nonspecialized units in the same facility; 5 reported no difference in operating costs, and one reported lower operating costs (64).

The Multi-State Nursing Home Case-Mix and Quality Demonstration found that on average the amount of staff time spent caring for residents with dementia was greater in the special care units than in the nonspecialized units in the study sample (143). The University of North Carolina study had similar findings (413). The greater amount of staff time spent caring for special care unit residents undoubtedly translates into higher average operating costs in the special care units.

Many-but not all-nursing homes charge more for care in their special care unit than in their nonspecialized units (247,256,413,477,494). Most special care units also have a higher proportion of private-pay residents (292,413,477). It is the private-pay residents who are charged more for their care in a special care unit than they would be in a nonspecialized unit. To OTA's knowledge, no public program currently pays more for care in a special care unit than in a nonspecialized nursing home unit.

According to preliminary data from the 1991 survey of all U.S. nursing homes with more than 30 beds, about half the nursing homes with special care units charged their private-pay residents more in a special care unit than the residents would have been charged in a nonspecialized unit in the same facility (246). The excess charge averaged \$9.24 a day and ranged from \$1 to \$83 a day.

#### Effectiveness of Special Care Units

OTA is aware of 15 studies that evaluate the effectiveness of special care units for residents and a few additional studies that evaluate the effectiveness of special care units for residents' families and unit staff members. These studies are discussed in detail in chapter 4.

Nine of the 15 studies did not use a control group (22,24,56,88,160,171,245,297,312). Each of these studies found some positive outcomes. The positive outcomes vary from one study to another, and some of the studies' findings are contradictory. Excluding these contradictory findings, the positive resident outcomes found in more than one of the nine studies are decreased nighttime wakefulness, improved hygiene, and weight gain. A few of the studies found

improvements in the important areas of residents' ability to perform activities of daily living and residents' behavioral symptoms, but an equal number of studies did not find such improvements.

All nine studies suffer from one or more methodological problems that could affect the validity of their findings. One such problem is small sample sizes: 6 of the 9 studies had fewer than 12 subjects. Another methodological problem is inadequate research design and implementation. Some of the studies are more like descriptive reports than rigorous research from which valid conclusions can be drawn; in these studies, the outcomes are not clearly defined, and the measurement process is more impressionistic than objective or standardized. Only four of the nine studies report the statistical significance of their findings. Lack of control groups is another methodological problem, since without a control group, the impact of the special care unit cannot be separated from the impact of other factors that may affect resident outcomes. Finally, many of the studies were conducted by unit staff members or other individuals who were involved in planning or administering the unit. These individuals have an obvious interest in finding positive outcomes. The potentially powerful effect of their expectations, coupled with small sample sizes, lack of a rigorous research design, and lack of control groups mean the studies' results—both positive and negative—are questionable.

Six of the 15 studies evaluating the effectiveness of special care units for their residents used a control group. Four of the six studies with a control group found no statistically significant positive resident outcomes that could be attributed to the special care units (80,99,195,489). The resident outcomes measured in one or more of these four studies were cognitive functioning, ability to perform activities of daily living, mood, behavioral symptoms, and rate of hospitalization.

Two of the six studies with a control group found positive resident outcomes. One study found that over a 1-year period, 14 residents of one special care unit declined significantly less than 14 residents with dementia in nonspecialized units of the same facility in their ability to perform activities of daily living (392). The other study found that 13 residents of one special care unit exhibited significantly fewer catastrophic reactions than 9 residents with dementia in nonspecialized units of the same facility (265).

In the latter study, the special care unit residents also interacted significantly more with staff members, but there was no effect of the unit on the residents' ability to perform activities of daily living.

The samples for the six studies that used a control group are larger than the samples for the nine studies that did not use a control group. Their research design and implementation are more rigorous, and the study outcomes are more precisely defined and measured. Use of a control group also increases the presumed validity of their findings. On the other hand, each of the studies has one or more methodological problems that could affect the validity of its findings. Although the study samples are, on average, larger than the study samples in the nine studies that did not use a control group, some of the samples are still quite small. Selection bias is another problem that could affect the validity of the studies' findings. If the special care unit residents and the control group subjects differed in significant ways at the start of the studies, these differences, rather than the impact of the special care unit, could account for the observed outcomes. Randomization of subjects to the special care unit or control group would be the ideal way to address this problem, but family preferences, subject attrition, and other factors interfered with randomization in one of the two studies in which it was attempted (265,489). Other methodological problems that could affect the validity of the studies' findings are discussed in chapter 4.

Four studies evaluate the effect of special care units on the unit staff over time. Three of these studies found no statistically significant effects (81,88,195). The fourth study found a significant reduction in stress among 15 special care unit staff members and a significant difference on one of three indicators of burnout between the 15 special care unit staff members and 49 staff members on nonspecialized nursing home units (265). This study also found a statistically significant improvement in the scores of the special care unit staff members on one of six indicators of job satisfaction. The study found no other significant effects of the special care unit on staff stress, burnout, or job satisfaction.

Three studies measured staff knowledge about dementia (81,88,265). In each of the studies, the special care unit staff members received training about dementia. None of the studies found any statistically significant effect of the training on the

special care unit staff members' knowledge about dementia (see ch. 4).

Four studies evaluate the effect of special care units on residents' families over time. Two of the four studies found no statistically significant effects (76,265). One of the remaining studies found a significant increase in family members' satisfaction with the care provided for their relative with dementia over the 3-month period after the individual was admitted to a special care unit (88). The other study found a significant reduction in family members' feelings of anxiety, depression, guilt, and grief after their relative with dementia was admitted to a special care unit (489). One descriptive study found that families of special care unit residents were significantly more likely than families of residents with dementia in nonspecialized nursing home units to visit their relative regularly (413). It is not clear whether the latter finding is attributable to the effect of the special care units or to preexisting differences between the two groups of families, however.

A few of the 15 evaluative studies had negative findings. Maas and Buckwalter report a trend for individuals with dementia to become more active after being admitted to a special care unit (265). This increased activity includes both positive behaviors, such as interacting with staff members, and negative behaviors, such as noisiness, restlessness, and screaming. Bullock et al. found an increase in verbal abuse and resistiveness over time among the special care unit residents they studied (56).

In summary, only two of the six evaluative studies that used a control group found any positive resident outcomes. Only one of the four studies that evaluated the effect of special care units on the unit staff found any positive outcomes, and only two of the four studies that evaluated the effect of special care units on residents' families found any positive outcomes. For most outcomes, the positive findings of one study are contradicted by the findings of other studies. Moreover, some of the statistically significant positive findings in these studies are relatively trivial, and a few of the studies had negative findings.

The limited positive findings in some of these evaluative studies and the lack of positive findings in other studies are surprising. After reporting the lack of positive findings in a study of families of

special care unit residents, one researcher commented:

Finally, I am left trying to reconcile these results, showing no special care unit superiority, with the palpable sense of excitement, of mission, and of relief that the special care unit families, but not the other families, show (76).

This comment mirrors the response of many researchers and others to whom OTA has spoken in the course of this study: that is, surprise that the evaluative studies conducted thus far generally do not show the positive outcomes they expected to find and thought they had observed informally.

Methodological problems may account in part for the failure of some of the studies to find positive outcomes. Small sample sizes are a particular problem because studies with very small samples lack the statistical power to detect small, but clinically significant, positive outcomes (279).

In addition to methodological problems, numerous difficult conceptual and methodological issues complicate the process of designing and conducting special care unit research. Table 1-3 lists many of these issues, some of which are discussed in more detail in appendix B.

Citing these methodological problems and conceptual and methodological issues, some commentators discount the findings of the available studies. They imply that no credible research has been done on special care units or that the studies that had no positive findings had no findings at all.

In contrast, OTA concludes that at least the six evaluative studies that used a control group are credible studies in an area in which good research is difficult to design and conduct. These studies were carefully designed and implemented. The special care units they studied incorporated the patient care philosophies, staff training, activity programs, and physical design features recommended in the special care unit literature. Only one of the studies successfully randomized subjects to the special care unit and the control group, but the other studies used accepted statistical methods to correct for pre-existing differences among the subjects that could affect the outcomes. Although each of the studies has methodological problems, it is unlikely the lack of positive findings is due entirely to these problems. Despite

methodological problems, the studies' findings are meaningful and deserve careful consideration by policymakers, special care unit advocates, and others.

It is important to note that none of the available studies directly measured the impact of special care units on residents' quality of life. *Quality of life* is difficult to define operationally and particularly difficult to measure in individuals with dementia. Several of the clinicians who reviewed this report for OTA pointed out, however, that improvements in residents' quality of life maybe the primary positive outcome of special care units.

Finally, for policy purposes, it is important to note that the available evaluative studies provide little or no information about the effectiveness of different types of special care units or particular features in special care units. In each of the six evaluative studies with a control group, the special care units differed in many ways from the control group settings.<sup>10</sup> It is unclear whether the overall milieu of the special care units or their particular features account for the studies' findings. If particular features account for the findings, it is unclear which features.

The only evaluative study with a control group that found a significant effect of the special care unit on the residents' ability to perform activities of daily living focused on a unit that was created with the addition of an activity room but no other physical design changes (392). The distinguishing characteristics of the unit, in the view of the researchers, were the staff's efforts to accomplish the following objectives:

- . to identify residents' specific cognitive impairments,
- . to treat depression, delusions, and hallucinations,
- . to identify medication side effects,
- to maintain residents' physical health,
- . to reduce the use of physical restraints, and
- . to increase residents' participation in activities (392).

The ongoing involvement of a psychiatrist on the staff also seems to be unique to this study. It is unclear which, if any, of these characteristics are different enough from the characteristics of the

<sup>10</sup> Table 4-2 in ch. 4 lists the changes that were made to create the special care units in each of the six studies.

***Table 1-3-Conceptual and Methodological Issues in Designing and Conducting Special Care Unit Research***

- Special care units are extremely diverse. It is difficult to determine which units should be included in a study sample and which of the many possible unit characteristics are important to study. For purposes of evaluative research, it is difficult to determine whether the intervention to be studied should be the unit's overall milieu or its particular features and, if particular features, which features.
- Individuals with dementia are extremely diverse. It is difficult to determine which of their characteristics are important to study.
- The characteristics of individuals with dementia are interrelated and changeover time. In the context of an evaluative study, it is difficult to determine whether these changes reflect the progression of the residents' dementing disease or the effects of the special care units.
- Residents' families and special care unit and other nursing home staff members are diverse. It is difficult to determine which of their characteristics are important to study.
- Many of the potentially important characteristics of the units, the residents, their families, and the staff members are conceptually vague, difficult to define operationally, and difficult to measure.
- The available assessment instruments do not include all the potentially important characteristics of the units, the residents, their families, or the unit staff members. The reliability and validity of some of the available instruments has not been demonstrated, and many of the available instruments exhibit ceiling or floor effects that obscure the full range of responses.
- There is insufficient baseline information about many potentially important resident, family, and staff characteristics.
- It is difficult to identify an appropriate control or comparison group.
- \* Preexisting differences between special care unit residents and individuals with dementia in other settings are likely to bias a study's findings. Because of family preferences and other factors, random assignment of subjects to a special care unit or a control group setting may be impractical.
- Researchers often cannot control the services that subjects in the control group receive.
- There is disagreement about the outcomes to be studied. This disagreement reflects different values in the care of nursing home residents with dementia and different expectations about the areas in which positive outcomes may be found.
- Many potentially important resident outcomes, e.g., quality of life and satisfaction with care, are very difficult to measure in persons with dementia. The outcomes that are easiest to measure are likely to be trivial.
- e There are many conceptual and practical difficulties in obtaining consent for research participation from individuals with dementia and their families.
- Because of their cognitive impairments, nursing home residents with dementia are often unable to participate in conventional research interviews or to provide accurate information about themselves. Sensory impairments and physical illnesses exacerbate this problem.
- Proxy-derived information may not be reliable or valid.
- It is difficult to effectively blind interviewers to the subjects' treatment status.
- \* Sample attrition is very high. Some special care unit studies have lost one-third or more of their subjects in a year. Although longer studies may be more likely to find significant effects, attrition is so great that the final sample may be too small to show the effects.
- The findings of small studies conducted in different special care units often cannot be pooled because of differences in the characteristics of the units.
- It is unclear when measurements should be made. New admissions to a special care unit may exhibit temporary negative effects of the move. Long-time residents may have experienced any positive effects of the unit before the beginning of the study.

SOURCE: Office of Technology Assessment, 1992.

special care units in the other five evaluative studies with a control group to account for their contradictory findings.

## THE REGULATORY ENVIRONMENT FOR SPECIAL CARE UNITS

Because of the diversity of special care units, the fact that existing units frequently do not incorporate recommended physical design and other features, and pervasive claims that some special care units actually provide nothing special for their residents, many Alzheimer's advocates, State officials, and others believe there should be special regulations for special care units. As of early 1992, special regulations were in place or in various stages of development in many States:

- Six States—Colorado, Iowa, Kansas, Tennessee, Texas, and Washington—had special regulations for special care units.
- Five States—Nebraska, New Jersey, North Carolina, Oklahoma, and Oregon—were in the process of drafting or approving special regulations for special care units.
- One additional State—Arkansas—had legislation mandating the development of special regulations for special care units.
- Two States—Kentucky and Michigan—had special requirements for special care units or special Alzheimer's nursing homes established with exemptions from the States' certificate of need process.
- In three additional States—Arizona, Indiana, and Rhode Island, the State-appointed Alzheimer's task force or long-term care advisory council had recommended the development of regulations, and in two of the States—Arizona and Rhode Island—the State-appointed body had developed draft regulations.

At the State level, interest in regulating special care units is growing rapidly. In some States, this interest is unopposed. In other States, the issue of special regulations for special care units is highly controversial.

State regulations for special care units have been or will be superimposed on the existing regulatory structure for nursing homes—a complex, multifaceted structure with six major components:

- 1) the Federal regulations for Medicare and Medicaid certification of nursing homes,
- 2) State licensing regulations for nursing homes,
- 3) State certificate of need regulations for nursing homes,
- 4) other State and local government regulations that affect nursing homes,
- 5) the survey and certification procedures associated with each type of regulations, and
- 6) the oversight procedures of each State's Long-Term Care Ombudsman Program.

In addition to these six components, Federal, State, and local government regulations for nursing homes incorporate standards established by private organizations, such as the National Fire Prevention Association's Life Safety Code standards. Special care units must comply with these standards, as well as the regulations and survey, certification, and oversight procedures listed above and any special regulations that may apply.

Special care unit operators and others often complain that the regulations and survey, certification, and oversight procedures for nursing homes discourage innovation in special care units by interfering with the use of physical design and other features they believe would be effective for residents with dementia. OTA has been told about instances in which special care units could not get approval for the use of innovative features of various kinds; instances in which approval was held up for years, thus adding enormously to the cost of establishing the unit; and instances in which approval was given by one government agency and later denied by another government agency, sometimes after the special care unit opened. Thus, while there is pressure on the one hand for more regulation of special care units, some people advocate less regulation, at least on a selective basis, to allow greater innovation.

The regulatory structure for nursing homes is currently in flux due to implementation of the nursing home reform provisions of OBRA-87 and related legislation. The nursing home reform provisions of OBRA-87 changed the Federal regulations for Medicare and Medicaid certification of nursing homes and the survey and certification procedures associated with those regulations. Many provisions of OBRA-87 are relevant to the frequently cited complaints about the care provided for nursing home residents with dementia. This section summarizes



OTA's findings with respect to the relevant provisions of OBRA-87 and the existing State regulations for special care units. Both of these topics are discussed at greater length in chapter 5.

On the basis of the information presented here and in chapter 5, OTA concludes that OBRA-87 provides a better framework for regulating special care units than any of the existing State special care unit regulations or any special regulations that could be devised at this time. This conclusion and alternatives to address the concerns that lead some people to advocate special regulations for special care units are discussed in a later section of this chapter, as are methods to allow greater innovation in special care units.

### *The Nursing Home Reform Provisions of OBRA-87*

Through OBRA-87, Congress sought to create a comprehensive regulatory structure that would assure high-quality, individualized care for all nursing home residents. Under OBRA-87, a nursing home must now meet the following requirements to be certified for Medicare or Medicaid:

- "The facility must care for its residents in a manner and in an environment that promotes maintenance or enhancement of each resident's quality of life."
- "The facility must promote care for residents in a manner and in an environment that maintains or enhances each resident's dignity and respect in full recognition of his or her individuality."
- "The facility must conduct initially and periodically a comprehensive, accurate, standardized, reproducible assessment of each resident's functional capacity."
- "The facility must develop a comprehensive care plan for each resident that includes measurable objectives and timetables to meet a resident's medical, nursing, mental, and psychosocial needs that are identified in the comprehensive assessment."
- "Each resident must receive and the facility must provide the necessary care and services to attain or maintain the highest practicable physical, mental, and psychosocial well-being, in accordance with the comprehensive assessment and plan of care" (463).

Chapter 5 lists other provisions of OBRA-87 that are relevant to the frequently cited complaints about

the care provided for nursing home residents with dementia. These other provisions deal with maintaining residents' functional abilities, providing activities that meet residents' needs, providing specialized rehabilitative services, minimizing the use of psychotropic medications and physical restraints, allowing residents to use their own belongings, involving residents and their families in care planning, training for nurse aides, and other issues.

The provisions of OBRA-87 rarely mention dementia, but the resident assessment system developed to implement OBRA-87 emphasizes the evaluation of a resident's cognitive status and the problems and care needs that are common among nursing home residents with dementia (see ch. 5). As just noted, the regulations require that residents' needs must be assessed and that once their needs are identified, appropriate services must be provided to meet the needs.

If fully implemented, the provisions of OBRA-87 would greatly improve the care of nursing home residents with dementia. Two factors could limit the benefits of OBRA-87 for individuals with dementia. One obvious factor is a failure to implement the provisions, which could occur for a variety of reasons, including insufficient government funding for nursing home care, for inspections, or for surveyor training. The second factor is lack of knowledge among many nursing home administrators, staff members, and surveyors about what constitutes appropriate care for individuals with dementia—e.g., lack of knowledge about what activities and rehabilitative services would meet the residents' needs.

### *Existing State Regulations for Special Care Units*

As noted above, six States—Colorado, Iowa, Kansas, Tennessee, Texas, and Washington—had regulations for special care units as of early 1992. Each of the States' regulations address several common areas, e.g., admission criteria, safety, staff training, and physical design, but their requirements in these areas differ (see ch. 5). Each State requires some features that are not addressed in the other States' regulations, e.g., Iowa's requirement that a unit and its outdoor area must have no steps or slopes and Washington's requirement that the units' floors, walls, and ceilings must be of contrasting colors. Some of the requirements are very detailed.

Thus far, State regulations for special care units have been developed largely without regard for the provisions of OBRA-87. Some of the six States' requirements for special care units duplicate OBRA requirements that apply to all nursing homes. Some of the special care unit requirements, e.g., those dealing with residents' rights to have visitors, are weaker than the comparable OBRA requirements.

OTA's analysis of the six States' regulations indicates several problems that are likely to arise in any special care unit regulations that could be devised at present. First, by requiring particular features in special care units, the six States' regulations imply that those features are unique to or more important in the care of residents with dementia than in the care of other nursing home residents. Yet some of the required features probably are not more important for residents with dementia than for other residents. Examples are Iowa's and Tennessee's requirements for an interdisciplinary care planning team, Colorado's requirement for sufficient staff to provide for the residents' needs, and Texas' requirement for a social worker to assess the residents on admission, conduct family support group meetings, and identify and arrange for the use of community resources. If these features are important for all nursing home residents, it is misleading and potentially harmful to residents of nonspecialized units to require the features differentially for special care units.

Second, by requiring particular features in special care units, the six States' regulations imply that those features are more important in the care of residents with dementia than other features that are not required by the regulations. Yet experts in dementia care disagree about which features are most important in the care of these residents. The existing special care unit regulations emphasize staff training and physical design features and place far less emphasis on specialized activity programs and programs to involve and support residents' families. Although there is no research-based evidence that any of these features are more likely than the others to produce positive resident outcomes, some experts in dementia care would undoubtedly argue that specialized activity programs and family support programs are as important as staff training and physical design features in the care of these residents.

Third, by requiring particular features in special care units, the six States' regulations imply that the resources available to the unit should be expended for the required features rather than other features. Since most special care units have limited resources, features not required in special care unit regulations are likely to be neglected.

The six States' requirements for physical design features are especially troublesome, in part because they are so detailed. To incorporate some of the required features involves extensive remodeling, with obvious cost implications. In some facilities, the required features cannot be incorporated, even with extensive remodeling. For such facilities, the requirements can lead to costly new construction or a decision by the nursing home not to establish a special care unit (337). If there were evidence of the effectiveness of particular physical design features, it might be reasonable to require the features. To require the features without such evidence is probably inappropriate.

The impact of the six States' special care unit regulations on the growth of special care units in each State is unclear. Anecdotal evidence suggests that the regulations have discouraged some nursing homes from establishing special care units. The States vary in the extent to which they are enforcing their regulations, but several nursing homes in at least two of the States have closed their special care unit because the unit could not meet the State requirements (169,267). It is possible that special care unit regulations could cause the closing of units that provide good care for their residents, even though they do not meet one or more of the State requirements. There is no evidence to determine whether this has occurred.

As noted earlier, Oklahoma is developing regulations for special care units. The regulations are intended by their supporters to set a 'basic standard of care,' rather than to define what would be "ideal or high-quality care" (118). In the development process, the draft regulations have become increasingly detailed, moving away from what some of their supporters first envisioned as broad, general guidelines that would inform families, nursing home administrators, and others about what constitutes basic care. In the spring of 1992, a telephone followup to the 1991 survey of all U.S. nursing homes with more than 30 beds found that some Oklahoma nursing homes that had a special care unit

in 1991 reported they had since closed the unit (246). When asked why they had closed their special care unit, most of the respondents declined to give a reason, but one respondent said the unit in his facility had been closed in anticipation of very detailed regulatory requirements the unit would not be able to meet. OTA has no information about the quality of care provided by this unit or any of the other special care units in Oklahoma that were closed between 1991 and 1992.

## POLICY IMPLICATIONS

Findings from the available research on special care units and the information just presented about the regulatory environment for special care units and problems with the existing State special care unit regulations have implications for each of the policy areas addressed in this report: consumer education, research, regulation, and reimbursement.

### *Implications for Consumer Education About Special Care Units*

*The* diversity of existing special care units substantiates the need for consumer education. Families and others who make decisions about nursing home care for individuals with dementia could reasonably assume that all special care units are alike. They need to know that special care units vary in virtually every respect, including the number of residents they serve, their patient care philosophies and goals, their physical design features, their staff-to-resident ratios, their admission and discharge policies, and their charges. Ideally families and others would have easy access to information about each of these characteristics for the special care units they are considering. If such information is not available, families and others need to know what questions to ask to obtain the information when they call or visit a special care unit.

To compile information about the special care units in a given jurisdiction would be more or less difficult, depending on the number of units in the jurisdiction. In jurisdictions with more than one special care unit, definitional issues would have to be resolved so that information about different units would be comparable. Since the units are likely to change over time, an ongoing effort would be required to update the information.

Compiling and updating information about the special care units in a given jurisdiction could be a project of an Alzheimer's Association chapter, another private agency, or a public agency.<sup>11</sup> In most jurisdictions, a local agency would be the most appropriate organization to perform this task. Because of the amount of detail involved and the necessity for frequent updates, the information could not be effectively compiled and updated at the Federal level. In States with relatively few special care units, it probably could be compiled and updated at the State level.

Descriptive information about the characteristics of particular special care units would be useful to families and others because the characteristics of some units (e.g., the units' patient care philosophies, discharge policies, or design features) would match their individual needs, preferences, and values. It should be recognized, however, that the available research findings do not provide objective standards to help families and others evaluate special care units. Although some unit characteristics may seem right intuitively and match the needs, preferences, and values of some families, the available research findings do not prove that any particular unit characteristics are associated with better resident outcomes.

Based on the available information, the message for consumers is that special care units vary greatly; that there is little research-based evidence of better resident outcomes in special care units than in nonspecialized units; and that although a given special care unit may have better resident outcomes than another special care unit or a nonspecialized unit, there is no research-based evidence to identify the unit characteristics that explain the different outcomes. On the positive side, it can be said that special care units are likely to have fewer residents and more staff members per resident than nonspecialized nursing home units; that in comparison with the residents of nonspecialized units, special care unit residents are less likely to be physically restrained; and that even though there is little research-based evidence of better resident outcomes in special care units than in nonspecialized units, there is much less evidence of worse outcomes in special care units. Consumers need to know, however, that these statements refer to averages that may not apply to a given unit. Although this message

<sup>11</sup>In some jurisdictions, a public or private agency compiles and updates similar types of information about local nursing homes.

does not meet the need for objective standards to evaluate special care units, it does accurately represent what is known about the units.

A few States have or are developing consumer education materials about special care units. New Hampshire has published an 8-page booklet intended for family members who are trying to evaluate special care units and nursing home operators who are interested in establishing a special care unit (325). The booklet describes the characteristics of an individual with Alzheimer's disease, the needs of the individual and the family, and the characteristics of specialized dementia care. It provides questions and a checklist that families can use to evaluate special care units. For nursing home operators, the booklet lists reasons for having a special care unit, questions the nursing home operator and staff should consider in establishing a special care unit, and factors that will influence the success of the unit.

The American Association of Homes for the Aging, the Massachusetts Alzheimer's Disease Research Center, the National Institute on Aging's Alzheimer's Disease Education and Referral Center, the University of South Florida's Suncoast Gerontology Center, and the University of Wisconsin-Milwaukee's Center for Architecture and Urban Planning Research have developed guidelines for special care units, and other organizations are developing such guidelines (see ch. 5). The Alzheimer's Association released its special care unit guidelines in July 1992. Some of these organizations' guidelines are intended primarily to assist families in evaluating special care units and other organizations' guidelines are intended primarily to assist nursing home operators in planning and setting up a special care unit.

OTA's review of the various organizations' special care unit guidelines indicates that the guidelines are quite similar in content, despite some differences in emphasis, format, and wording. Each organization's guidelines cite numerous unit characteristics the organization considers desirable. This information is useful for families and others who are trying to evaluate special care units, but consumers need to know that statements about the desirability of particular unit characteristics are based on expert opinion and that experts disagree about these matters.

Information about the theoretical concepts of specialized dementia care discussed earlier in this chapter may also be useful for families and others

who are trying to evaluate special care units. They need to know, however, that the concepts are not implemented in all special care units and that the same concept may be implemented differently, with different results, in different units.

Given the availability of special care unit guidelines developed by various organizations, there is no need for Federal agencies to develop additional guidelines. Federal agencies that serve elderly people and their families could play a valuable role, however, in disseminating the available guidelines and promoting their use.

As noted earlier, the task of compiling and updating information about the characteristics of special care units in a given jurisdiction is probably most effectively performed by local agencies, including Alzheimer's Association chapters. In some jurisdictions, however, local agencies that receive Federal funding, such as area agencies on aging (AAAs), might be the most appropriate organizations to perform the function.

In the summer of 1992, the Alzheimer's Association contracted for a study to identify and document consumer problems with special care units. The results of this study, which will be available in the spring of 1993, will provide useful information about the extent and types of problems families and others encounter in dealing with special care units and may indicate a need for additional government initiatives in this area.

### *Implications for Research on Special Care Units*

*The* findings of the available special care unit studies confirm the need for research on many unresolved issues. For public policy purposes, the most important research issues are those pertaining to effectiveness. Evaluative research is needed to answer three interrelated questions about the effectiveness of special care units for their residents:

- 1) Do special care units improve resident outcomes?
- 2) If so, is it the overall milieu or particular unit characteristics that are effective, and if it is particular unit characteristics, which characteristics?
- 3) Are special care units effective for all nursing home residents with dementia or only certain

types of residents with dementia, and if only certain types, which types?

Research on the effectiveness of special care units for residents' families, unit staff members, and nondemented nursing home residents is also needed.

Descriptive information is needed to provide a better general understanding of special care units and to develop descriptive topologies. Such typologies, which would be based on unit and perhaps resident characteristics, are important for designing evaluative studies and understanding and generalizing from their findings. To be useful for public policy purposes, descriptive topologies must represent the full range of existing units.

Information is needed about the cost of caring for individuals with dementia in special care units vs. nonspecialized nursing home units. Because of the diversity of special care units, this information will be useful only if it is developed in the context of an inclusive typology of the units.

OTA is aware of several sources of forthcoming descriptive information that will meet some of these needs. One source is the 1991 survey of all nursing homes with more than 30 beds. The survey's findings with respect to the proportion of nursing homes that had a special care unit in 1991 were cited earlier in this chapter. The survey also included questions about the physical features of the units, their admission and discharge criteria, staff training programs, staff support groups, activity programs, family programs, and sources of reimbursement.

A second source of forthcoming descriptive information is the resident assessments mandated by the nursing home reform provisions of OBRA-87. All Medicare and Medicaid-certified nursing homes are now required to assess each of their residents, including special care unit residents, at the time of the residents' admission to the nursing home and annually thereafter. OBRA-87 mandated the development of a set of core items to be addressed in the required assessment, and the core items include each

of the resident characteristics discussed in this chapter.

Lastly, as noted earlier, the Multi-State Nursing Home Case-Mix and Quality Demonstration includes special care unit residents among the 6800 nursing home residents in the study sample. Information has been collected on more than 300 residents of 20 special care units in 6 States (137). To OTA's knowledge, this study is the first to include a time-and-motion analysis of resource use in special care units.

Given the pervasive complaints and concerns about the care provided for nursing home residents with dementia, the extensive involvement of government in regulating nursing homes and paying for nursing home care, and the competing claims of special care unit advocates and critics, one might expect that Federal agencies would have funded many special care unit studies. In 1984, the Task Force on Alzheimer's Disease of the U.S. Department of Health and Human Services noted the need for this research (470). In 1986, Congress mandated special care unit research (P.L. 99-660), but funding for the research was never appropriated. Between 1986 and 1990, seven Federal agencies each provided funding for one special care unit study.<sup>12</sup> Three of the studies were small pilot studies, and two were relatively small components of large-scale nursing home studies. Two of the National Institute on Aging's Alzheimer's Disease Research Centers each provided funding for one special care unit study. The Alzheimer's Association, the Brookdale Foundation, the State of California, and three universities each provided funding for one special care unit study. Most of the other special care unit studies have been small pilot studies with no funding source.<sup>13</sup>

In 1990, the Alzheimer's Disease Research Center at Washington University in St. Louis sponsored a special care unit conference that included workshops for researchers. The intent of the workshops was to identify the problems that were obstructing progress in special care unit research. Many interrelated

<sup>12</sup> The seven agencies and the studies for which they provided full or partial funding are: 1) Administration on Aging: "Special Care Units for Alzheimer's Disease Patients: An Exploratory Study of Dementia Specific Units" (64); 2) Agency for Health Care Policy and Research: 1987 National Medical Expenditure Survey (249); 3) Department of Veterans Affairs: "A Comparison of Alzheimer Care Units: Veterans Administration State, and Private" (232); 4) Health Care Financing Administration: Multi-State Nursing Home Case-Mix and Quality Demonstration (144,382); 5) Health Resources and Services Administration: "Hospitalization Rates in Nursing Home Residents With Dementia: A Pilot Study of the Impact of a Special Care Unit" (99); 6) National Center for Nursing Research: "Nursing Evaluation Research: Alzheimer's Care Unit" (265); and 7) National Institute on Aging: "Five-State Study of Special Care Units in Nursing Homes" (194).

<sup>13</sup> Tables 3-1a, b, and c in ch. 3 and tables 4-1 and 4-2 in ch. 4 list the funding sources for all the special care unit studies discussed in this report.

problems were identified, including the difficulty of obtaining funding for special care unit research, the difficulty of getting special care unit research published, and numerous conceptual and methodological issues in designing and conducting this kind of research (see app. B). Following the conference, the researchers formed an ad hoc group, the Workgroup on Research and Evaluation of Special Care Units, to address the identified problems. By the end of 1991, the workgroup had over 100 members (193). It has no formal sponsor and no funding.

In the fall 1991, the National Institute on Aging funded nine studies under an new "Special Care Units Initiative," and the agency funded a tenth study in early 1992. Two of the studies will develop descriptive topologies of special care units. Two other studies will compare service use and costs for special care unit residents and demented and nondemented residents in nonspecialized units in a total of 24 nursing homes. Another study will compare resident outcomes in the special care units and nonspecialized units in the Multi-State Nursing Home Case-Mix and Quality Demonstration.

The National Institute on Aging's "Special Care Units Initiative" represents a major commitment to special care unit research. The results of the 10 studies will greatly expand knowledge about special care units. Moreover, the studies were funded under an arrangement that requires the 10 research teams to collaborate on the development of common definitions and assessment procedures so that, although the studies focus on different issues, their findings will be comparable.

As noted earlier, the effectiveness of special care units is the most important research issue for public policy purposes. Although several of the National Institute on Aging studies will evaluate the effectiveness of the units they are studying, the complexity of the policy-related questions about effectiveness means more research will be needed on this issue. Some researchers believe that a clinical trial with a randomized case control design will eventually be needed to determine the effectiveness of special care units (143,41 1). Currently funded studies will provide the basis for designing such a clinical trial. The legal and ethical issues discussed later in this chapter also raise important policy-related questions that are not addressed in the National Institute on Aging studies.

To complement special care unit research, studies are needed in two broad areas:

1. physical design features and care methods for people with dementia generally; and
2. alternatives to special care units, including special programs for nursing home residents with dementia in nonspecialized units, special residential care programs inboard and care and assisted living facilities, and special adult day and in-home services.

Studies in the first area can be conducted in special care units or in other residential and nonresidential care settings. It may be easier and more efficient to conduct some of these studies in special care units, however, because all the residents have dementia.

Research on specific design features and patient care methods may help to explain the findings of special care unit research. If certain design features or care methods are shown to be effective or ineffective in general or for certain types of residents, those findings may explain the results of special care unit studies. More importantly perhaps, studies of specific design features and care methods can identify features and methods that will improve the care of residents with dementia in nonspecialized units and other settings as well as in special care units.

The Robert Wood Johnson Foundation and the Cleveland Foundation have funded research on various design features and patient care methods in two special care units at the Corinne Dolan Alzheimer's Center in Chardon, OH. Studies of this kind have also been conducted in some of the special care units at VA medical centers (159). Three special care units that constitute the Dementia Study Unit at the VA medical center in Bedford, MA, have been the site for numerous studies on the care of individuals with dementia in the late stages of their illness. To OTA's knowledge, the Dementia Study Unit is the only research group in the country to focus its efforts on the difficult, emotionally charged, clinical issues in late-stage and terminal care for individuals with dementia. The research group has studied swallowing and feeding difficulties (476), tube feeding (475), use of antibiotics vs. palliative measures to treat fever in late-stage patients (135), and use of a hospice-like approach to care for late-stage patients (474).

### *Implications for Government Regulation of Special Care Units*

*The* diversity of special care units, the fact that existing units often do not incorporate the features recommended for special care units, and pervasive claims that some special care units just use the words *special care* as a marketing tool and actually provide nothing special for their residents lead many Alzheimer's advocates, State officials, and others to support the development of special regulations for special care units. On the other hand, the lack of agreement among experts about what features are most important in the care of residents with dementia and the lack of research-based evidence showing that any particular features are associated with better resident outcomes make it difficult to justify the selection of particular features that should be required in special care units.

The Alzheimer's Association has developed legislative principles that identify 11 areas a State should include when drafting special care unit legislation or regulations: 1) statement of mission, 2) involvement of family members, 3) plan of care, 4) therapeutic programs, 5) residents' rights, 6) environment, 7) safety, 8) staffing patterns and training, 9) cost of care, 10) quality assurance, and 11) enforcement (4). As described in chapter 5, the special care unit guidelines developed by various organizations identify similar areas that require special consideration in the care of nursing home residents with dementia. Thus, there appears to be some agreement about the areas of concern.

Having agreement about areas of concern is helpful in thinking about the particular features that might be desirable or required in special care units, but agreement about areas of concern is not the same as agreement about particular features. For example, agreement that therapeutic programs and physical environment are areas of concern does not constitute agreement about which therapeutic programs or physical design features should be required. OTA has observed that in discussions about special care unit regulations, agreement about areas of concern often masks considerable disagreement about particular features and gives an erroneous impression that there is consensus about the particular features that should be required.

As noted earlier, OTA's analysis of the existing State regulations for special care units indicates

several problems that are likely to arise in any special care unit regulations that could be devised at present. First, regulatory requirements for particular features in special care units imply that those features are unique to or more important for special care unit residents than for other nursing home residents. Yet many of the features that are important for special care unit residents are probably just as important for other residents. This is especially true since most nursing home residents with dementia are not in special care units now and may never be.

Second, regulatory requirements for particular features in special care units imply that those features are more important in the care of special care unit residents than other features that are not required by the regulations and that the resources available to the unit should be expended for the required features. Most special care units have limited resources, so features that are not required in special care unit regulations are likely to be neglected. Yet experts in dementia care disagree about which features are most important in the care of these residents.

The problem of special care unit regulations that omit features regarded as important by some dementia experts could be solved by expanding the regulations to require those features. The more the regulations are expanded, however, the more likely it is that the required features will be important for other nursing home residents as well.

Given these problems, OTA concludes that OBRA-87 provides a better framework for regulating special care units than any special regulations that could be devised at this time. The advantages of OBRA-87 are its comprehensiveness, its emphasis on individualized care, and its mandated assessment and care planning procedures. The primary problem with OBRA-87 for special care units is the same problem faced by anyone who tries to develop regulations for special care units: i.e., the lack of agreement among experts about what features are most important in the care of residents with dementia and thus what should be special about special care units. Solving this problem through support for research to evaluate the effectiveness of particular features may eventually provide a substantive basis for special care unit regulations. In the meantime, it is important to consider alternate ways of addressing the concerns that have led many Alzheimer's

advocates, State officials, and others to favor the development of special care unit regulations.

### Alternatives to Special Care Unit Regulations

Alzheimer's advocates, State officials, and others who favor the development of special care unit regulations often cite the need to protect individuals with dementia from poor-quality care and the need to protect these individuals and their families from nursing homes that claim to provide special care but actually do not. Some people who favor the development of special care unit regulations also cite a need to assist nursing homes in designing their special care units and to assist surveyors in inspecting the units. Each of these objectives can be achieved without special regulations.

In discussions about special care unit regulations, it is sometimes suggested that there are two types of special care units—'good' units and 'bad' units—and that regulations are needed to eliminate the "bad" units. In this context, it is probably more accurate to think about four types of special care units:

1. units that provide the features a given observer considers important for residents with dementia,
2. units that do not provide those features but do provide other features the unit operator, staff, or advisers consider important for residents with dementia,
3. units that claim to provide special care but actually provide nothing special for their residents, and
4. units that provide poor-quality care that would be inappropriate for any nursing home resident.

Anecdotal evidence suggests that there are very few units of the last type, and the one study that has addressed this issue supports that conclusion (154). OBRA-87 provides a sufficient basis for censuring units of that type, without the need for special regulations.

Most special care units are of the first three types. Objective classification of particular units into these types would be difficult, since the classification depends on a given observer's opinion about the features that are important in a special care unit and a judgment about the intentions of each facility's administrators. Although some nursing home administrators may knowingly provide no special services in their special care unit, other administra-

tors probably believe erroneously that they are providing appropriate care. One commentator refers to the latter units and their administrators as "innocent" (21).

An earlier section of this chapter discussed the need for consumer education about special care units. As noted there, families and others who are trying to evaluate special care units need to know that existing units vary greatly. They need comparable information about the characteristics of the special care units in their geographic area and information about characteristics that may be important in a special care unit. Lastly, they need to know that experts disagree about the importance of particular unit characteristics and that their personal preferences and values are relevant in selecting a unit. These types of information will not protect all potential special care unit residents and their families from nursing homes that provide no special services in their special care unit. Neither will these individuals be protected, however, by regulations that require special care units to incorporate features that have not been proven to be effective.

For the purpose of consumer protection, nursing homes could be required to disclose certain information about their special care units to potential residents and their families. In particular, they could be required to disclose what is special about the unit; how the unit differs from nonspecialized units in the same facility; how physical restraints and psychotropic medications are used in the unit; whether there are behavioral problems that cannot be handled on the unit; whether it is expected that individuals who are admitted to the unit will be discharged before their death and, if so, for what reasons. A disclosure requirement could be mandated at the Federal level within the framework of OBRA-87 or at the State level within the framework of State licensing regulations. Such a disclosure requirement would be quite different from regulations that require particular features in a special care unit. It would make useful information available to consumers without suggesting that particular features are known to be effective. A disclosure requirement would not eliminate the need for the other types of consumer information described above.

Guidelines are the best method to assist nursing homes in designing their special care units. Several of the guideline documents mentioned earlier in this chapter and discussed at greater length in chapter 5



are intended primarily for this purpose.<sup>14</sup> More so than regulations, guidelines can convey the objectives of specialized dementia care, the current uncertainty about the most effective methods of care, and the need for innovation and evaluative research in special care units.

Surveyor guidelines developed within the framework of OBRA-87 are the best method to assist nursing home surveyors in inspecting special care units. Since 1989, the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) has been working on guidelines to help its surveyors evaluate special care units. JCAHO is a private organization that accredits hospitals, home health agencies, mental health organizations, and about 1000 nursing homes in the United States (214). The commission's effort to develop guidelines evolved from its surveyors' questions about how to evaluate the increasing number of special care units they were seeing in nursing homes accredited by the commission (434).

JCAHO's draft surveyor guidelines provide what is, in effect, a detailed answer to the question, 'What constitutes appropriate care for nursing home residents with dementia?' The guidelines are based on the commission's standards for all nursing homes (435). No changes have been made to the basic standards. Instead, statements have been added next to many of the standards to explain the implications of the standard for the care of residents with dementia and to describe the process the surveyor should follow in scoring the special care unit on that standard. Although some commentators may disagree with some of the statements, the JCAHO guidelines provide a valuable model which could be adapted to OBRA regulations.

#### Waivers and Other Methods To Allow Innovation in Special Care Units

As noted earlier, special care unit operators and others often complain that the existing regulations and survey and certification procedures for nursing homes discourage innovation by interfering with the use of physical design and other features they believe would be effective for residents with dementia. From a societal perspective, one objective, and

perhaps the most important objective, of special care units is to develop better ways of caring for nursing home residents with dementia. To accomplish this objective, methods must be found to allow and encourage innovation in special care units.

One method to allow greater innovation in special care units is to eliminate regulations that restrict innovative physical design and other features. Although this method may eventually be appropriate, the current lack of agreement about the features that are important in a special care unit and the lack of research-based evidence for the effectiveness of particular features make decisions to eliminate existing regulations premature.

A better method is to create a process by which individual special care units could obtain waivers to implement physical design features, patient care practices, and other innovations they believe will benefit residents with dementia. Most existing regulatory codes have a process for granting waivers, but in some and perhaps many States, the waivers that are granted are for relatively trivial changes (201). The purpose of creating a waiver process for special care units would be to allow the implementation and evaluation of nontrivial innovations. Since such innovations would change the care of individuals with dementia in significant ways, the waivers should only be granted on a facility-by-facility basis after careful prior review by a panel that includes health care professionals, consumer advocates, industry representatives, architects, designers, surveyors, fire marshals, building inspectors, and others. The panel would have to determine whether a proposed innovation was worth evaluating and whether sufficient safeguards had been built into the proposal to protect the residents. The panel would also have to monitor the waived innovations on an ongoing basis to assure the safety and well-being of the residents. A panel of this kind probably would function most effectively at the State level, but the Federal Government could encourage the development of such panels through demonstration grants.

At present, State efforts with respect to special care units are focused primarily on the development

<sup>14</sup> Examples of guideline documents intended to assist nursing homes in designing a special care unit are the American Association Of Homes for the Aging's "Best Practices" document (10); the Massachusetts Alzheimer's Disease Research Center's "Blueprint" document (287); the University of Wisconsin-Milwaukee's Center for Architecture and Urban Planning Research's "Design Guide" (95); and the Alzheimer's Association's "Guidelines for Dignity," released in July 1992. The forthcoming VA guidelines for special care units in VA medical centers will also be useful for nursing homes that are trying to establish a special care unit.

of special regulations. To OTA's knowledge, no State has created a process for waiving regulations that interfere with innovation in special care units. A few States have provided grants to nursing homes and other facilities to create model special care units. In at least one of these States, the State's own regulations made it difficult for some of the facilities that received the grants to implement the features they considered appropriate for individuals with dementia, thus defeating the purpose of the grants. If special care units are to fulfill the societal objective of developing better methods of care for nursing home residents with dementia, policies to allow and encourage innovation must receive at least as much attention as methods to regulate and control the units.

In addition to a waiver process, several other methods to allow and encourage innovation in special care units are discussed in chapter 6. Some of the methods pertain primarily to special care units, e.g., providing training materials and programs to inform surveyors and others about problems in the care of nursing home residents with dementia and the importance of developing alternate approaches to their care. Other methods pertain to all residential facilities for older people, e.g., simplifying the process for obtaining approval of new design or other features, eliminating conflicts and inconsistencies in the requirements of different agencies and regulatory codes, and including in any new regulations an explicit statement of the purpose of each requirement; such a statement would provide government officials with a basis for allowing innovations that meet the purpose, if not the precise stipulations, of the requirement.

Fire safety regulations and interpretations of fire safety regulations are often cited as limiting the use of innovative physical design features in special care units. A conference or invitational meeting jointly sponsored by the Alzheimer's Association, the National Fire Protection Association, and the Federal Government would be a valuable first step in delineating this problem and identifying possible solutions.

### *Implications for Reimbursement for Special Care Units*

Although most special care unit operators report that it costs more to create and operate a special care unit than a nonspecialized nursing home unit, some special care unit operators disagree. As noted earlier, the cost of new construction or remodeling to create a special care unit varies greatly for different units. Ongoing operating costs also vary. This variation in costs provides little justification for an across-the-board increase in government reimbursement for care in special care units.

Ninety percent of government-funded nursing home care is paid for by Medicaid (250). Medicaid reimbursement for nursing home care varies in different States. It is low in many States and very low in some States. High-quality nursing home care for individuals with dementia probably costs more than Medicaid pays in these States, regardless of whether the care is provided in a special care unit or a nonspecialized unit. High-quality nursing home care for individuals with other diseases and conditions probably also costs more than Medicaid pays in these States. To improve quality of care, it may be necessary to increase Medicaid reimbursement for all nursing home care in these States. In the context of this OTA report, however, the question is whether reimbursement should be increased differentially for special care units.<sup>15</sup>

The results of two studies cited earlier indicate that average staff time and therefore the average cost of care is higher for residents with dementia in special care units than in nonspecialized nursing home units (143,413). If future studies confirm this finding, one could argue that government reimbursement should be increased differentially for care in special care units. If the higher average cost of care in special care units is not associated with better resident outcomes, however, increasing government reimbursement will raise government expenditures and create financial incentives for the establishment of more special care units without necessarily improving the care available for individuals with dementia---dearly not a desirable result. On the other hand, if the higher average cost of care in

<sup>15</sup> A related but different question is whether government reimbursement should be increased differentially for nursing home residents with dementia vs. nondemented residents in any nursing home unit. Two studies have found that certain types of residents with dementia (i.e., those who do not have severe impairments in activities of daily living or extensive medical care needs) use more staff time and therefore more of a nursing home's resources than nondemented residents who have the same impairments and medical care needs (16,144). Given these findings, it would be reasonable for government to differentially increase reimbursement for these types of residents with dementia.

special care units is associated with better outcomes for individuals with dementia, policymakers will be faced with a difficult question of values, since increasing government reimbursement for the care of demented and nondemented residents in nonspecialized units would probably produce better outcomes for those individuals as well.

In the past, reimbursement for nursing home care in most State Medicaid programs was based on a flat rate system that paid nursing homes at the same rate for each of their Medicaid-eligible residents, regardless of differences in the resources required for each individual's care. As of 1990, 19 States had switched to case-mix systems to determine the level of Medicaid reimbursement for nursing home care (51). Case-mix systems are intended to match the level of reimbursement for individual residents to the resources used and therefore the cost of their care (142). To implement an increase in government reimbursement for care in special care units probably would involve more complex mechanisms in States with case-mix vs. flat rate reimbursement systems. Such an increase is not indicated, however, unless and until there is better evidence than is currently available that special care units improve resident outcomes.

## LEGAL AND ETHICAL ISSUES IN SPECIAL CARE UNITS

Because of the cognitive impairments of special care unit residents, difficult legal and ethical issues arise in connection with many aspects of their care. These issues are not unique to special care units, but they tend to be magnified in special care units because of the concentration of individuals with dementia and the likelihood that they are in the later stages of their illness and at least moderately cognitively impaired.

Many of the difficult legal and ethical issues in the care of individuals with dementia have been analyzed at length in three previous OTA reports (457,458,459) and in a supplement to *The Milbank Quarterly* based on OTA contract documents (496). These issues are: criteria and procedures for determining an individual's decisionmaking capacity; methods of enhancing decisionmaking capacity; competency determinations; criteria and procedures for designating a surrogate decisionmaker; rights and responsibilities of family members as surrogate decisionmakers; criteria for surrogate decisions;

guardianship and conservatorship; decisions about financial matters, use of services, and medical care in the end of life; advance directives; the role of ethics committees; risk taking and professional and provider liability; and the ethical aspects of resource allocation. Other agencies and individuals have also written extensively about many of these issues.

This section describes some of the particularly troublesome legal and ethical issues that arise with respect to three aspects of the care of individuals with dementia in special care units: locked units, admission and discharge, and informed consent for research participation. These issues and many of the issues noted above require further clarification and analysis as they apply to special care units.

The 1991 report of the Advisory Panel on Alzheimer's Disease includes a section on values (2), and the panel is working on a report on legal issues in the care of individuals with dementia (450). The panel's 1991 report discusses value differences and potential value conflicts among the four main constituencies involved in the care of individuals with dementia: the individuals, their families, formal service providers, and the public. Although not focused on special care units, the panel's analysis of these value differences and potential value conflicts is relevant to some of the most difficult ethical questions that arise in special care units, e.g., questions about whose interests should be given precedence in defining the goals of care, making day-to-day decisions about care, and selecting the outcomes to be studied in special care unit research. In each of these areas, nondemented nursing home residents constitute an important fifth constituency whose interests must be considered.

### *Issues With Respect to Locked Units*

At least three-quarters of existing special care units have an alarm or locking system to keep residents from leaving the unit unescorted or without staff knowledge. Probably at least half of these units are locked, although the exact proportion is not known and undoubtedly varies from State to State.

People's attitudes about locked special care units differ (20,178). Some people regard locked units as a way of providing greater freedom and autonomy for individuals with dementia who otherwise might be physically restrained or medicated to keep them from wandering away from the unit. At the other extreme, some people regard locked units as a form

of involuntary confinement that restricts freedom and autonomy and violates the civil rights of individuals with dementia. Some people consider locked units a necessary placement option, whereas others consider them unnecessary and argue that wandering residents can be managed effectively in an unlocked unit with an alarm system.

People distinguish in various ways between locked units they regard as acceptable and locked units they regard as unacceptable. Some people regard locked units that provide adequate staff and activities as acceptable and locked units that do not provide these features as unacceptable. Likewise, some people regard as acceptable locked units that have direct access to an outdoor area, such as an enclosed courtyard or garden, where residents can wander freely (although they are still confined), whereas they regard as unacceptable locked units that do not have such an outdoor area. It is unclear whether these differences are important from a legal or an ethical point of view.

Some people also distinguish between locked units and units that are not locked but have some other method of keeping residents from leaving the unit, e.g., camouflaging the exit doors or using a type of doorknob that most people with dementia cannot figure out how to open. Again, although some people regard these as distinct alternatives, it is unclear whether the distinction is important from a legal or an ethical point of view.

Units that are not locked but have another method of keeping residents from leaving the unit are often referred to as *secure*, *secured*, *protected*, or *protective* units. These terms are also used—sometimes as euphemisms—for the term *locked*. This semantic problem makes it difficult for people to communicate clearly about the legal and ethical issues raised by various methods of keeping residents from leaving a special care unit.

Some States prohibit locked nursing home units or classify them in a different regulatory category than unlocked units.<sup>16</sup> At least one State official has argued that locked units constitute physical restraints in the context of OBRA regulations and thus

require ongoing efforts to move the residents to a less restrictive environment (85).

Families often worry about the safety of a person with dementia who wanders. Anecdotal evidence suggests that one thing some families are looking for in a special care unit is assurance that the person will be safe. They may prefer a locked unit for this reason. On the other hand, some families may be very reluctant to place their relative with dementia in a locked unit.

The effect of locked units on the residents is unclear. One study compared the behavior of 22 special care unit residents after they encountered a locked vs. an unlocked exit door. The study found that the residents were much less agitated after they encountered the unlocked door (315). Some residents who encountered the unlocked door tested the door several times—apparently to be sure it was unlocked—and then decided not to go out.

### *Issues With Respect to Admission and Discharge*

*Nursing* home admission for a nondemented person raises difficult legal and ethical issues, in part because decisions about nursing home admission are seldom autonomous (8,307). The admission of a person with dementia to a special care unit may raise even more difficult issues if the person is incapable of an autonomous decision, the unit is locked, or both.

Many commentators have debated the similarities and differences between the admission of an elderly person to a nursing home and the admission of a psychiatric patient to a mental hospital.<sup>17</sup> The two situations are generally perceived as different enough so that the legal protections that apply to mental hospital admissions are considered unnecessary or inappropriate for nursing home admissions. In the case of locked units and individuals who lack decisionmaking capacity, however, some people believe additional legal protection is needed. One possibility is a requirement for a legally appointed guardian to give consent when a person who lacks decisionmaking capacity is admitted to a locked

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<sup>16</sup> AS described in chapter 5, Colorado's special care unit regulations apply only to locked units.

<sup>17</sup> S=, for example, Cohen, "Caring for the Mentally Ill Elderly Without DeFacto Commitments to Nursing Homes: The Right to the Least Restrictive Environment" (90); Moody, "Ethical Dilemmas in Nursing Home Placement" (307); and Spring, "Applying Due Process Safeguards" (420).

unit. Another possibility is a requirement for a civil commitment in such cases.

These requirements would provide additional protection for individuals with dementia and at the same time create grave obstacles to special care unit admission. Many families would be unwilling to pursue either guardianship or a civil commitment, and some individuals with dementia have no one to initiate the necessary legal proceedings for them. If better care is available in a special care unit, legal requirements intended to protect potential special care unit residents could be seen instead as denying them access to better care. In fact, if better care is available in a special care unit, any decision not to admit an individual to a special care unit or to discharge an individual from the unit could be seen as denying the individual access to better care. Such decisions could be regarded as discriminatory, depending on the basis for the decision.

Some of the difficult legal and ethical issues with regard to discharge involve a conflict between the presumed right of the unit and its staff to determine who will be cared for in the unit and the presumed right of residents to remain in the unit if they or their families so choose. A recent case in a Washington, DC, nursing home illustrates one such conflict. In this case, the family of a 91-year-old special care unit resident challenged the facility's decision to discharge the resident from the unit (204). The facility, which had a formal discharge policy, wanted to move the resident to another unit because, in the opinion of the unit staff, she could no longer benefit from the special care unit. The family argued that the resident, who had been in the same room for six years, might experience "transfer trauma" as a result of the move. The hearing examiner ruled that the facility could not move the resident even though it was clear that the resident did not meet the facility's criteria for placement on the unit.

A related issue pertains to special care units that admit but later discharge individuals who have behavioral symptoms which, in the opinion of the unit staff, cannot be managed on the unit. Some people believe special care units should be expected to and should be able to care for individuals with severe behavioral symptoms. They suggest that special care units that discharge such individuals may be violating their formal or informal admission

agreement with the residents and the residents' families. On the other hand, the facility is liable for injuries to other residents that may be caused by a physically aggressive resident and responsible to the other residents and their families for the overall atmosphere in the unit, which may be negatively affected by behaviorally disturbed residents.

### *Issues With Respect to Consent for Research Participation*

Special care unit researchers report that obtaining informed consent for research participation by special care unit residents is very difficult (79,411,436). Most of the residents are not capable of giving informed consent, and many residents' families are reluctant to give consent. As a result, studies that require informed consent are likely to end up with small samples that may not be representative of the larger population of residents. To address this problem, some special care unit studies have been designed to avoid the need for informed consent. In such studies, the researchers review the residents' medical records, observe the residents, and talk to the unit staff, but they do not interact directly with the residents because to do so is perceived to require informed consent. In contrast, record reviews, resident observation, and staff interviews are not perceived to require informed consent.

OTA is not aware of any published analyses of the issue of informed consent for research participation by special care unit residents. Much has been written about this issue, however, as it pertains to nursing home residents in general and individuals with dementia in any setting. In addition, several researchers who are part of the Workgroup on Research and Evaluation of Special Care Units are preparing a paper on ethical issues in special care unit research that includes a discussion of informed consent for research participation (495).

In the late 1970s and early 1980s, the National Commission for the Protection of Human Subjects in Biomedical and Behavioral Research and the Presidents' Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research studied and made recommendations about informed consent for research participation by nursing home residents (322,350). Other commenta-

tors have also made recommendations on this issue.<sup>18</sup>

All of these recommendations arise from serious concerns about the potential exploitation of nursing home residents as research subjects. They would strictly limit the types of research that could be conducted in nursing homes and the participation of residents who are not capable of informed consent. The National Commission for the Protection of Human Subjects in Biomedical and Behavioral Research recommended, for example, that research involving nursing home residents should only be allowed if it is relevant to a condition the subjects suffer from, i.e., therapeutic research, and only if appropriate subjects cannot be obtained in any other setting. Cassel recommended that surrogates should be formally designated to make decisions about research participation on behalf of residents who are not capable of informed consent (74).

None of these recommendations has been incorporated into law, and no special regulations on informed consent for research participation by nursing home residents are now in effect. OBRA-87 gives residents the right to refuse to participate in research (463) but does not address the issue of informed consent for research participation. Thus, research in nursing homes is governed by the general Federal law which allows consent for research participation by a *legally authorized representative* on behalf of an incompetent person. The term *legally authorized representative* is not defined in the Federal law.

In 1981, the National Institute on Aging sponsored a conference to explore the legal and ethical issues with respect to informed consent for research participation by individuals with dementia in any setting (301). After the conference, a task force drew up guidelines that recommend the use of noninstitutionalized subjects whenever possible (302). Federal law requires institutions that receive Federal research funds to have an institutional review board (IRB) to review research proposals involving human subjects, and the task force's guidelines cite several criteria IRBs could use to evaluate the informed consent procedures to be used in a given study. The guidelines point out that the greater the risks posed by a study and the less likely an individual subject

will benefit directly, the more stringent the informed consent procedures should be. These guidelines are not part of any official regulations, however.

Researchers generally turn to a nursing home resident's family to obtain consent for research participation. It is assumed the family's decision will reflect the wishes and best interests of the resident. The one published study OTA is aware of that has addressed families' decisions about research participation by an elderly relative casts doubt on that assumption. The researchers asked the families of 168 nursing home residents with dementia to consent to the residents' participation in a low-risk study of urinary catheters (480). About half the families consented. Fifty-five of the families said they believed their relative would not consent to participate in the study, but 17 of the 55 (31 percent) consented anyway. Twenty-eight of the families said they would not choose to participate in the study themselves, but 6 of the 28 (20 percent) consented for their relative with dementia to participate.

The preliminary findings of a similar study being conducted by researchers at the University of Chicago are more positive. As of the spring 1992, the researchers had interviewed 100 noninstitutionalized individuals with mild to moderate dementia and their family caregivers (395). The individuals with dementia were asked whether they would participate in several hypothetical, high- and low-risk medical studies. The family caregivers were asked three questions: whether they would consent for their relative with dementia to participate in the studies, whether they thought their relative would consent to participate, and whether they would be willing to participate themselves. Preliminary findings from the study show discrepancies between the responses of the individuals with dementia and their family caregivers, but the family caregivers generally have not volunteered their relative with dementia for high-risk studies (395). In fact, the caregivers have been less willing than the individuals with dementia to consent to the individuals' participation in high-risk studies. On the other hand, the family caregivers have been more willing than the individuals with dementia to consent to the individuals' participation in the low-risk studies.

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<sup>18</sup> See, for example, Annas and Glanz, "Rules for Research in Nursing Homes" (13); Cassel, "Research in Nursing Homes: Ethical Issues" (73); Cassel, "Ethical Issues in the Conduct of Research in Long Term Care" (74); and Dubler, "Legal Issues in Research on Institutionalized Demented Patients" (122).

Numerous studies that have used hypothetical scenarios to compare treatment decisions by elderly individuals and their families have found discrepancies between their responses (119,340,404,449,451,523). It has been suggested that family members would be more likely to make a treatment decision the way their elderly relative would make it if they were specifically instructed to do so, and the findings of one study support that suggestion (449). Even when families are asked specifically to make a decision the way their elderly relative would make it, however, the decisions are not always the same (404,449).

If the necessary descriptive and evaluative research is to be conducted in special care units, informed consent procedures must be devised that will protect the residents from exploitation and at the same time allow the use of research methods that require informed consent, e.g., methods that involve direct interaction with the residents. Some commentators have suggested the use of a durable power of attorney for this purpose (13,302). With a durable power of attorney, a person who is still capable of making decisions for himself or herself can designate someone to make decisions in the future when he or she is no longer capable. The problem with this approach is that most special care unit residents probably are not capable of executing a valid durable power of attorney, and many will not have executed a durable power of attorney for research participation at an earlier time when they were capable of doing so.

Some special care units now require individuals with dementia to have a durable power of attorney for health care decisions prior to their admission to the unit. Anecdotal evidence indicates that in some cases, these documents are being executed by individuals who are not capable of making decisions for themselves (156). The same problem could arise with a durable power of attorney for research participation.

Other approaches that have been proposed are the use of a nursing home council (13), a multidisciplinary nursing home committee (23,74), or an independent advocacy group (29) to approve and oversee nursing home research, including the procedures that would be used to obtain informed consent. Certainly if a panel were established to allow waivers for special care unit research, as suggested

earlier in this chapter, that panel could perform these functions.

Lastly, it must be noted that although most special care unit residents probably are not capable of giving valid informed consent, some are, and they should be asked. Preliminary findings of the ongoing University of Chicago study of informed consent for research participation by noninstitutionalized individuals with dementia show that many of these individuals are able to provide helpful information about their values and preferences, even though they are not capable of giving valid informed consent (395). Some and perhaps many special care unit residents may also be capable of providing such information.

## OTHER ISSUES OF IMPORTANCE TO NURSING HOME RESIDENTS WITH DEMENTIA

Three additional issues are important for all nursing home residents with dementia, including special care unit residents. These three issues are discussed briefly below.

### *The Availability of Physicians' Services*

Physicians' services are essential for all nursing home residents with dementia. Yet the special care unit literature contains little discussion of the role of physicians in special care units. With the exception of the Tennessee regulations, the existing State regulations for special care units do not mention physicians except to require that a physician approve a resident's admission to the unit and document the reason for the admission. Requirements for ongoing physician care appear in other sections of these States' nursing home regulations and in the Federal regulations for Medicare and Medicaid certification of nursing homes. The lack of such requirements in the special care unit regulations implies, however, that physicians' role is limited to admission-related functions.

Clearly, the appropriate role of physicians in the care of nursing home residents with dementia goes far beyond admission-related functions. One of the most frequent complaints about the care of these residents is that acute and chronic illnesses that exacerbate their cognitive impairments and reduce their functioning often are not diagnosed or treated. Diagnosis and treatment of these illnesses will

reduce excess disability and improve the residents' quality of life, even if the conditions that cause their dementia are incurable and progressive. Ongoing physician involvement is essential to identify and treat residents' acute and chronic illnesses.

One stated objective of some special care units is to get away from the "medical model" of care and adopt a "social model" instead. Semantics aside, this objective is unrelated to the role of physicians, who are as essential in a social as a medical model of care (146). In special care units, as in nursing homes generally, the physician may be a team member rather than the team leader (226), but there is no question about the need for initial and ongoing physician involvement in the care of residents with dementia in special care units and other nursing home units.

### *The Availability of Mental Health Services*

Many commentators have noted the lack of adequate mental health services in nursing homes (58,175,339,393). Although Alzheimer's disease and most of the other diseases that cause dementia generally are not considered mental illnesses, their manifestations include mental, emotional, and behavioral symptoms that may respond to behavior management techniques, psychotropic medications, and other mental health treatments. Psychiatrists, psychologists, psychiatric nurses, psychiatric social workers, and other mental health professionals with expertise in the evaluation and treatment of these symptoms seldom work in nursing homes.

The lack of adequate mental health services in most nursing homes is attributable to several factors. One factor is a lack of reimbursement. A second factor is the *IMD exclusion*. As an optional Medicaid benefit, States may choose to provide Medicaid reimbursement for the care of individuals under age 22 or over age 65—but not individuals age 22 to 65—in an *institution for mental diseases (IMD)*. Medicaid regulations define an IMD as "an institution that is primarily engaged in providing diagnosis, treatment, or care of persons with mental diseases, including medical attention, nursing care, and related services" (460). If a nursing home is classified as an IMD, it loses Medicaid funding for all its residents age 22 to 65. If the nursing home is in a State that does not provide Medicaid reimbursement for care in IMDs, it loses Medicaid funding for all its residents. Because of a fear of being classified

as an IMD, some nursing homes choose not to employ mental health professionals, not to provide mental health services, or both (192,205).

Medicaid regulations cite 10 criteria to be used in determining whether a facility is an IMD. No single criterion is definitive; rather, the criteria are to be used together to determine whether a facility's "overall character is that of a facility established and maintained primarily for the care and treatment of individuals with mental diseases" (460). Two of the criteria are troublesome to nursing homes that care for individuals with dementia:

- 1) "The facility specializes in providing psychiatric/psychological care and treatment. This may be ascertained through review of patients' records. It may also be indicated by the fact that an unusually large proportion of the staff has specialized psychiatric/psychological training or by the fact that a large proportion of the patients are receiving psychopharmacological drugs" (460).
- 2) "More than 50 percent of all the patients in the facility have mental diseases which require inpatient treatment according to the patients' medical records" (460).

The second criterion, often referred to as the "50 percent rule," excludes residents with senility or organic brain syndrome "if the facility is appropriately treating the patients by providing only general nursing care." According to the regulations, residents with senility or organic brain syndrome are excluded because these conditions "are essentially untreatable from a mental health point of view" (460). Residents with senility or organic brain syndrome are not excluded from the 50 percent rule "if the facility is treating these patients for the effects of a mental disorder, as opposed to providing general nursing and other medical and remedial care" (460).

A third factor that may discourage the provision of mental health services in nursing homes is Preadmission Screening and Annual Resident Review (PASARR), a program mandated by OBRA-87 that requires States to: 1) screen all nursing home applicants and nursing home residents to determine whether they have mental illness or mental retardation, and 2) evaluate all those who are found to have mental illness or mental retardation to determine whether they need nursing home care and whether they need "specialized services" for their mental



illness or mental retardation. Mentally ill and mentally retarded nursing home applicants and residents who are found in a PASARR evaluation not to need nursing home care or to need “specialized services” must be placed elsewhere. Mentally ill and mentally retarded nursing home residents who have been in a nursing home for 30 months or more can choose to remain in the nursing home even if they are found not to need nursing home care or to need “specialized services” (320).

The impact of PASARR on the availability of mental health services in nursing homes is unclear and probably differs from State to State. Anecdotal evidence suggests that at least in some States, PASAAR has had the same effect as the IMD exclusion—that is, to cause some nursing homes not to employ mental health professionals, not to provide mental health services, or both, because of a fear that if the facility employs mental health professionals or provides mental health services, it will be perceived as caring for mentally ill people and therefore lose Medicaid funding.

The Federal regulations for Medicare and Medicaid certification of nursing homes include provisions that would seem to require the involvement of mental health professionals in assessing residents’ care needs and the provision of some mental health services.<sup>19</sup> It is unclear how these provisions will be interpreted and implemented.

The American Association of Retired Persons (AARP) is currently funding a study of barriers to mental health care in nursing homes (260). The study, which will be completed in 1993, will provide information about regulations, reimbursement, and other factors that interfere with access to mental health services by all nursing home residents, including residents with dementia.

### *The Use of Psychotropic Medications*

As noted earlier, a large proportion of nursing home residents receive psychotropic medications, and residents with dementia are more likely than other residents to receive these medications. Psychotropic medications are frequently referred to in the special care unit literature and elsewhere as *chemical restraints* or *pharmacological restraints*. The use of the word *restraints* in this context implies

that psychotropic medications are an undesirable treatment option. This implication fits well conceptually with the growing concern about the overuse and inappropriate use of physical restraints and psychotropic medications in nursing homes. On the other hand, many commentators have noted that psychotropic medications are a valuable treatment option for some individuals with dementia (19,28,121,180,277,347,353,367,381,402,412). For individuals with depressive or psychotic symptoms or extreme agitation, psychotropic medications may be the best treatment option. The important consideration in these instances is the selection of the right medication, in the right dose, for the right indication.

Clearly, psychotropic medications should not be used as a substitute for behavioral or environmental interventions that may be as effective or more effective and do not have the negative side effects often associated with psychotropic medications. Research is needed to determine the indications, dosages, and long-term effects of various psychotropic medications. Referring to psychotropic medications as *restraints* may create an atmosphere in which individuals with dementia will not receive medications that could significantly improve their quality of life.

## ALTERNATIVES TO SPECIAL CARE UNITS

As noted at the beginning of this chapter, the proliferation of special care units is occurring at the same time as numerous other government and nongovernment initiatives that are likely to improve the care of nursing home residents with dementia or provide alternatives to nursing home care for them. This section briefly describes a few of these initiatives. Each of the initiatives offers an alternate way of accomplishing one or more of the same objectives as special care units.

### *Initiatives To Reduce The Use of Physical Restraints for All Nursing Home Residents*

**OBRA-87** and related legislation require nursing homes to reduce their use of physical restraints. Prior to and since the implementation of the OBRA regulations, many organizations have developed training programs and materials to help nursing

<sup>19</sup>See sections 483.20(b)(2)(111) and (vii), 483.20(f), and 483.45(a), Federal Register, Sept. 9, 1991 (463).

<sup>20</sup>See, for example, Rader, “The Joyful Road to Restraint-Free Care” (360).

homes reduce the use of physical restraints.<sup>20</sup> The National Institute on Aging has funded a 3-year clinical trial on reducing the use of physical restraints in nursing homes, and the Food and Drug Administration (FDA) has increased its surveillance of restraining devices (327).<sup>21</sup>

In 1989, the Kendal Corp. in Pennsylvania initiated "Untie the Elderly," a national program to create 'restraint-free' nursing homes. In December 1989, the corporation and the Senate Special Committee on Aging cosponsored a policy-oriented symposium on reducing the use of physical restraints in nursing homes. The corporation also sponsors workshops to help nursing homes reduce their use of physical restraints and publishes a newsletter that describes the successful efforts of some nursing homes to decrease restraint use.

In 1991, the Jewish Home and Hospital for Aged in New York City initiated a three and a half year "Restraint Minimization Project," with funding from the Commonwealth Fund. The project is intended to demonstrate ways of reducing restraint use in nursing homes. It is being implemented in 14 nursing homes in 4 States.

Nursing homes often use physical restraints because they are afraid of being sued for fall-related injuries to residents who are not restrained. Yet historically, there has been a greater risk of facilities being sued for overuse or misuse of restraints (196,224). By establishing a clear standard of care, OBRA requirements for reduced use of physical restraints will increase the legal risks associated with their overuse or misuse.

As noted earlier, several studies have found that on average physical restraints are used far less in special care units than in other nursing home units. It is unclear whether this difference will be sustained as the implementation of OBRA-87 creates pressure on all nursing homes to reduce their use of physical restraints. The 481 nursing homes that responded to a 1991 survey conducted by the American Association of Homes for the Aging reported that the proportion of their residents who were physically restrained had decreased from an average of 43 percent in 1989 to an average of 23 percent in 1991 (9). Only 13 percent of the nursing homes reported

having instituted a restraint reduction program before 1989, the year the pertinent OBRA regulations went into effect.

### *Dementia Training Programs for Nursing Home Staff Members*

One of the most frequently cited problems in the care of nursing home residents with dementia is lack of staff knowledge about dementia. Many organizations and individuals have developed training programs and materials to address this problem. One video training program, "Managing and Understanding Behavior Problems in Alzheimer's Disease and Related Disorders," was funded by the National Institute on Aging and has 10 training modules, each focused on a different behavioral symptom (439). Other programs and materials include the following:

- a training manual developed by the St. Louis Chapter of the Alzheimer's Association (39);
- a training manual and tape series developed by the Wisconsin Alzheimer's Information and Training Center (509);
- a video training program developed by Community Services Institute, Inc. (102);
- a training guide and resource manual developed for the New Jersey Department of Health (471);
- a video training program developed by Church Home and distributed by the American Association of Homes for the Aging (86); and
- a training manual written by Lisa Gwyther and distributed by the Alzheimer's Association and the American Health Care Association (165).

These training programs and materials are likely to improve the care of nursing home residents with dementia generally.

In 1987, the Alzheimer's Family Center, Inc. of San Diego, CA, established a School of Dementia Care which trains and certifies health care professionals to work with individuals with dementia (422). In 1991, the Federal Government provided funding to the center through the Job Training and Partnership Act to train "Certified Nursing Assistant Alzheimer Care Specialists" to work with individuals with dementia in nursing homes, adult day centers, and other settings (324).

<sup>20</sup> See, for example, Rader, "The Joyful Road to Restraint-Free Care" (360).

<sup>21</sup> In June 1992, the FDA proposed a new rule that would require labeling of physical restraints. The required label would include directions for use of the restraints, a warning of potential hazards, and the phrase *prescription only*.

### *Specialized Programs for Residents With Dementia in Nonspecialized Nursing Home Units*

Instead of or in addition to a special care unit, some nursing homes have specialized programs for residents with dementia in nonspecialized units. It is unclear how many nursing homes have such programs. In response to a 1991 survey of all U.S. nursing homes with more than 30 beds, 13 percent of the 1463 nursing homes that said they had a special care unit or program for their residents with dementia reported that the program was *not in* a physically separate part of the facility (247). Thus, it is likely that at least several hundred nursing homes have specialized programs.

Some nursing homes have specialized day care or activity programs.<sup>22</sup> One facility established a “wanderer’s lounge” where specialized activities are provided several hours a day for 15 to 20 demented residents of the facility’s nonspecialized units (299).

Rovner established an experimental special care program for demented residents of nonspecialized units in one Maryland nursing home (387). The program was intended to duplicate the essential components of an apparently effective special care unit described earlier in this chapter and in chapter 4 (392). The special care program consisted of weekly visits to each resident by a psychiatrist and a nurse with the purpose of identifying residents’ cognitive impairments, treating psychiatric symptoms, reducing medication side effects, maintaining residents’ physical health, reducing the use of physical restraints, and increasing the residents’ participation in activities (387). Five hours of specialized activities were provided daily. The special care program is being evaluated. Its impact will be compared with the impact of the special care unit described earlier to determine their relative cost and effectiveness.

### *Specialized Living Arrangements Outside Nursing Homes*

Outside nursing homes, special care units and other specialized living arrangements for people with dementia have been established in residential care facilities, assisted living facilities, mental hospitals, and other settings. Three of the best known special care units in the United States are in residential care facilities:<sup>23</sup>

- the Alzheimer’s Care Center in Gardiner, ME (303);
- the Corinne Dolan Alzheimer’s Center at Heather Hill in Chardon, OH (317), and
- Wesley Hall in the Chelsea United Methodist Retirement Home in Chelsea, MI (105).

In many discussions about special care units, no distinction is made between these three units and other model special care units in nursing homes. From a public policy perspective, however, there are important differences between special care units in residential care facilities and special care units in nursing homes. Residential care facilities are much less regulated than nursing homes. The Federal Government does not regulate residential care facilities.<sup>24</sup> States license various types of residential care facilities (251), but some types of residential care facilities are not licensed in each State, and the licensing requirements, where they exist, are less comprehensive and far less stringent than the licensing requirements for nursing homes.<sup>25</sup>

Since special care units in residential care facilities are not subject to the same kinds of regulatory requirements as special care units in nursing homes, they are able to implement innovative physical design features, staffing arrangements, and patient care practices that may be difficult or impossible to implement in a nursing home. Because of the minimal regulatory requirements, special care units

<sup>22</sup> See for example, Clendaniel and Fleishell, “An Alzheimer Day Care Center for Nursing Home Patients” (89); Hanczaryk and Batzka, “Adventure Program” (173); Johnson and Chapman, “Quest for Life” (211); and Sawyer and Mendelovitz, “A Management Program for Ambulatory Institutionalized Patients With Alzheimer’s Disease and Related Disorders” (400).

<sup>23</sup> The term *residential care facilities* refers to a variety of living arrangements that provide room and board and some degree of protective supervision. Examples are retirement homes, homes for the aged, group homes, and adult foster homes.

<sup>24</sup> The only Federal role in the regulation of residential care facilities is through the Keys Amendment to the Social Security Act. The Keys Amendment requires States to certify to the U.S. Department of Health and Human Services that all residential care facilities in which a significant number of Supplemental Security Income (SSI) recipients reside meet appropriate standards. A 1989 GAO report found that the department does little more than record the receipt of the certifications and that only four States were submitting the required certifications (453).

<sup>25</sup> Research Triangle Institute in North Carolina is conducting a study for the U.S. Department of Health and Human Services of State licensing requirements and other State regulations for residential care facilities. In addition to a 50-State review of existing regulations, the study will compare the quality of care provided in licensed and unlicensed residential care facilities in 10 States.

in residential care facilities usually cost less to construct and operate than special care units in nursing homes. As a result, they usually charge less than nursing homes.

Despite these advantages, there are serious potential problems with special care units in residential care facilities. Anecdotal evidence suggests that most of these units are established outside a nursing home in order to avoid nursing home regulations (273). This may be entirely appropriate if the intent is to avoid regulatory requirements that restrict the use of physical design or other features the unit operator believes will benefit individuals with dementia; it is clearly inappropriate if the intent is to avoid regulatory requirements that are important for the safety or well-being of individuals with dementia. Many government reports have documented widespread abuse, exploitation, and neglect of elderly and other individuals in residential care facilities.<sup>26</sup> Given the vulnerability of individuals with dementia, the proliferation of special care units in minimally regulated residential care facilities raises the prospect of severely deficient care.

Specialized living arrangements for people with dementia are also being developed in assisted living facilities. The term *assisted living facilities* refers to living arrangements in which a variety of supportive services are available to residents who each have a separate apartment that is lockable and has its own kitchen (501). Some people consider assisted living facilities a type of residential care facility, and other people consider them a separate category of living arrangements. They are less likely to be regulated than other residential care facilities and therefore probably present greater potential for deficient care.<sup>27</sup>

Psychogeriatric units in public and private mental hospitals often serve elderly individuals with dementia as well as elderly individuals with acute and chronic mental illnesses, but some mental hospitals have units that serve only individuals with dementia. Such units exist, for example, in two Virginia state hospitals (56,252).

Lastly, some organizations have developed or are developing campus-like settings that provide a variety of living arrangements and other specialized services for individuals with dementia.<sup>28</sup> The living arrangements available in such settings may include apartments for an individual with dementia and his or her spouse, residential care or assisted living units, and nursing home units.

In addition to programs intended to improve the care of nursing home residents with dementia or provide alternate residential care options for them, many services have been developed to assist individuals with dementia who are living at home and their caregivers. These services include adult day care, respite care, specialized hospice programs, and a variety of other in-home and community-based services. All these programs and services provide alternatives to special care units for some people with dementia. Government policies for special care units should be considered in relation to the full range of care options for these individuals.

## CONCLUSION

A large number of nursing home residents in the United States have dementia—637,600 to 922,500 according to national surveys—and almost all people with dementia will probably spend some time in a nursing home in the course of their illness. These individuals may receive inappropriate care that will result in excess disability and severely reduced quality of life.

Special care units of various types have been developed and are proliferating in response to this problem. Special care units promise to provide better care for individuals with dementia than these individuals would receive in other nursing home units. It is unlikely all nursing home residents with dementia will ever be cared for in special care units, but methods of care developed in special care units could eventually be implemented in other nursing home units as well.

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<sup>26</sup> See, for example, "Board and Care Homes in America: A National Tragedy" (455), and "Board and Care: Insufficient Assurances That Residents' Needs are Identified and Met" (453).

<sup>27</sup> Oregon has developed special regulations for assisted living facilities. In 1987, the State Medicaid program began paying for care in designated assisted living facilities for individuals who are eligible for Medicaid-funded nursing home care (501). One of these facilities serves individuals with dementia (504).

<sup>28</sup> See, for example, Stein Gerontological Center, "Pathways: Program Development Plan" (423).

Better methods of care for nursing home residents with dementia are likely to benefit not only those residents, but also their families, the nursing home staff members who **take care of them, and other** nursing home residents who are not demented. Families will benefit because they will be more satisfied with the care provided for their relative with dementia and therefore may feel less guilty about having placed the individual in a nursing home and less anxious about his or her well-being. Nursing home staff members will benefit because the residents are likely to be easier to manage. Nondemented nursing home residents will benefit because the behavioral and other symptoms of residents with dementia are often disturbing to them; better methods of care are likely to reduce the incidence of these symptoms and thus improve the quality of the nondemented residents' lives.

The number of nursing homes that have a special care unit is increasing rapidly. OTA estimates that 10 percent of all U.S. nursing homes had a special care unit in 1991.

Existing special care units vary greatly in virtually all respects. Although experts agree about the theoretical principles of specialized dementia care, the theoretical principles are implemented differently in different special care units and are not implemented at all in some special care units, and there is considerable disagreement about the particular features that are necessary in a special care unit.

Proponents of special care units make strong claims about their effectiveness, but the available research provides little support for the claims. Only two of the six special care unit studies that used a control group found any positive outcomes for special care unit residents. Only one of the four studies that measured the impact of a special care unit on the unit staff members and only two of the four studies that evaluated the effect of special care units on the residents' families found any positive outcomes. None of these studies is definitive by itself, but their combined findings are impressive and suggest that we do not yet know exactly what constitutes effective nursing home care for individuals with dementia.

Because of the diversity of existing special care units, their rapid proliferation, and the widespread perception that some special care units use the words *special care* as a marketing tool and actually provide no special services for their residents, there is strong

pressure to regulate special care units. On the other hand, given the lack of agreement among experts about the particular features that are necessary in a special care unit and the lack of research-based evidence of the effectiveness of special care units, it is difficult to determine what regulations should say beyond general statements about goals and principles and a listing of issues that require special consideration in the care of residents with dementia, e.g., staff training, environmental design, security, activity programs, family involvement, and resident rights.

Special care unit regulations are likely to discourage innovation by suggesting that we already know what constitutes effective care for nursing home residents with dementia. Regulations are also likely to lock in for the future current beliefs about the features that are important in special care units.

OTA concludes that the objective of improving nursing home care for individuals with dementia will be better served at present by initiatives to develop greater knowledge and agreement about the particular features that are important in the care of nursing home residents with dementia than by the establishment of regulations for special care units. Some people argue that we cannot wait for the results of such initiatives to develop special care unit regulations. It is said that regulations are needed now to protect individuals with dementia from poor-quality care. In contrast, OTA concludes that OBRA-87 provides a sufficient basis for censuring units that provide poor-quality care, without any special regulations. It is also said that regulations are needed to protect individuals with dementia and their families from nursing homes that fraudulently claim to provide special care but actually provide nothing special for their residents. OTA concludes that individuals with dementia and their families can be better protected from these nursing homes by initiatives that would: 1) make available guidelines that describe the theoretical concepts and design and other features that are believed to be important in special care units, 2) make available information about the characteristics of special care units in local jurisdictions, and 3) require nursing homes to disclose to families and others what is special about their special care unit. As noted earlier, these initiatives will not protect all potential special care unit residents and their families from nursing homes that provide no special services in their special care unit. Neither will these individuals be protected by

regulations that require special care units to incorporate features that have not been shown to be effective.

The potential of special care units to develop better methods of care for nursing home residents with dementia is exciting. That potential cannot be realized without a greater commitment than currently exists to evaluation of the units and their

impact on residents, residents' families, unit staff members, and nondemented nursing home residents. Such evaluation must be pursued with the recognition that some of the features that are currently believed to be essential in special care units may not be effective and that once effective methods of care are identified, they may not be unique to individuals with dementia.