Special Care Units for People With Alzheimer's and Other Dementias: Consumer Education, Research, Regulatory, and Reimbursement Issues

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Foreword

Several million Americans have Alzheimer's disease or another disease or condition that causes dementia. As our population ages, the number of people with these devastating diseases and conditions will increase relentlessly. Families take care of individuals with dementia at home for as long as possible, but most individuals with dementia are likely to spend sometime in a nursing home in the often long course of their illness.

Until recently, little attention has been paid to the special needs of nursing home residents with dementia. In many nursing homes, they have received and continue to receive inappropriate care that exacerbates their cognitive impairments and behavioral symptoms and further reduces their quality of life. There has been a pervasive feeling that nothing positive can be done for nursing home residents with dementia. More often than nondemented residents, they have been overmedicated and physically restrained.

As awareness of Alzheimer's and other dementing diseases has increased, innovative approaches to caring for people with dementia have been developed. Some experts have recommended that nursing homes establish special units for their residents with dementia. OTA estimates that by 1991, 10 percent of all U.S. nursing homes had established at least one such unit.

Special care units promise to provide better care for individuals with dementia than these individuals would receive in nonspecialized nursing home units. On the other hand, existing special care units vary greatly, and many people believe that some special care units are established only for marketing purposes and actually provide nothing special for their residents.

This OTA report analyzes the available information about special care units for people with dementia. It discusses ways in which the Federal Government could encourage and support what is positive about special care units and at the same time protect vulnerable patients and their families from special care units that actually provide nothing special for their residents.

This is OTA's third report on Alzheimer's-related public policy issues. Two previous OTA reports, *Losing a Million Minds: Confronting the Tragedy of Alzheimer's Disease and Other Dementias* and *Confused Minds, Burdened Families: Finding Help for People With Alzheimer's and Other Dementias,* have focused on biomedical and health services research and other components of the care needed by individuals with dementia. OTA hopes that these reports help to define and clarify the problems raised by Alzheimer's and other dementias and identify ways in which the Federal Government can assist in solving them.

OTA was aided in the preparation of this report by members and staff of the Alzheimer's Association, staff of the National Institute on Aging, special care unit researchers, State officials, and others. OTA wishes to thank all these individuals. OTA particularly wishes to thank Nancy Mace for her valuable contributions to this and OTA's two previous reports on Alzheimer's and other dementias. As with all OTA reports, the content of this report is the sole responsibility of the agency and does not necessarily reflect the views of these individuals or the members of the Technology Assessment Board.

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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 frost 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 surprised 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.[1] 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 (64,181,194,199,232,256,275,332,4 13,485, 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

[1] As discussed later in the chapter, tbis 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 (166,5 13). 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 inmost nursing homes. One such unit is described in box l-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 indecisions 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 muse 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 l-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:O0 &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 poilcies 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 specia1 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, Jam 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).[2] 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

zTotalgov ernment 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 1990.3

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.[4] 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-

S 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.

4 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 residents. 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-flee' 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.

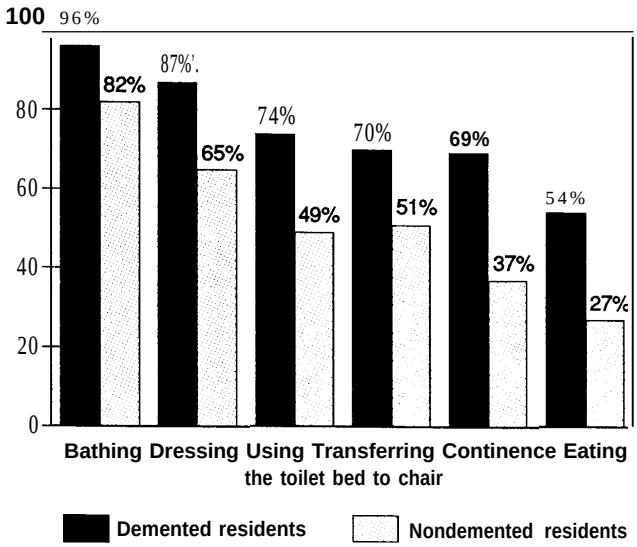
The proportion of individuals with dementia that is in a nursing home at any given time and the proportion that will be in a nursing home at some time in the course of their illness could increase or decrease as a result of several factors. These factors include the availability of appropriate residential 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).

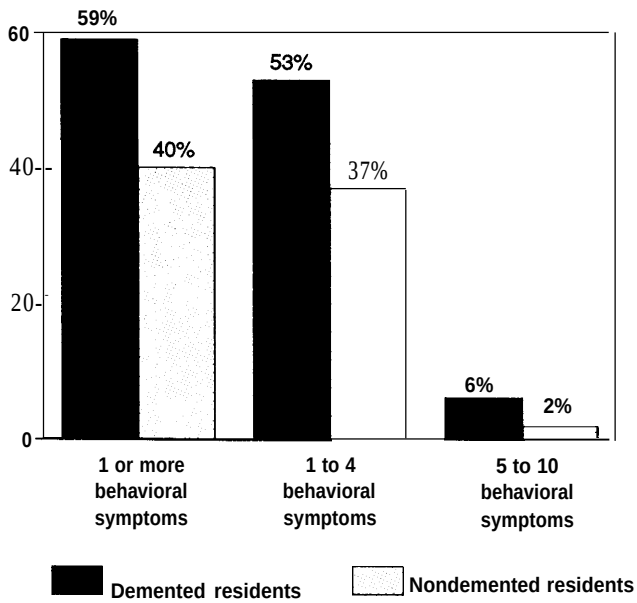
Nursing home residents with dementia are more likely than other nursing home residents to need assistance with activities of daily living (i.e., bathing, dressing, using the toilet, transferring from bed to chair, remaining continent, and eating). The 1985 National Nursing Home Survey found, for example,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

Figure I-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.

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 datafromthe 1987 National Medical Expenditure Survey, Institutional Population Component, Current Residents, Agency for Health Care Policy and Research, Rockville, MD, 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 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? 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 (l8,l9,l80,208,277,285,339,381,389,397,406,414,425). 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).

[5] 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 enouqh 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.
- o 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 l-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 I-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 (107,1 15,125,165,171 241,263,359,385,386).

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.[6] Other nursing homes established special activity programs for their residents with dementia.[7]

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

[6] 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).

[7] See, for example, Hanczaryk and Batzka (173), Johnson and Chapman (21 1), 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 fuctional 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 woodworking 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 disease 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 characteristics 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.

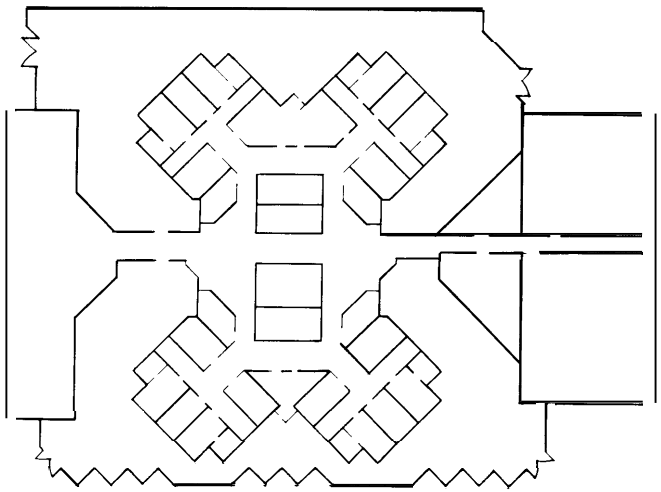
Physical design features are often referred in the special care unit literature as *prosthetic* because they are intended to compensate for, rather than cure, impairments that are believed to be unchangeable. Since the impairments are unchangeable, it is assumed the prosthetic features will be needed 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.

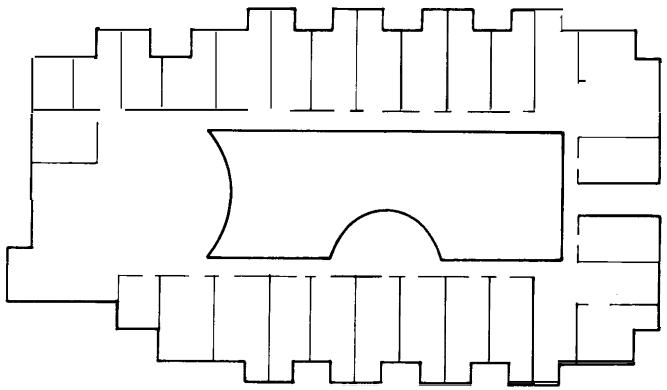
In reality, very little research has been done to test the impact of particular physical design features on individuals with dementia. Moreover, the conclusions of several of the existing studies are contradictory. Some of these studies are described in chapter 4. Unfortunately, some nursing homes incorporate 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



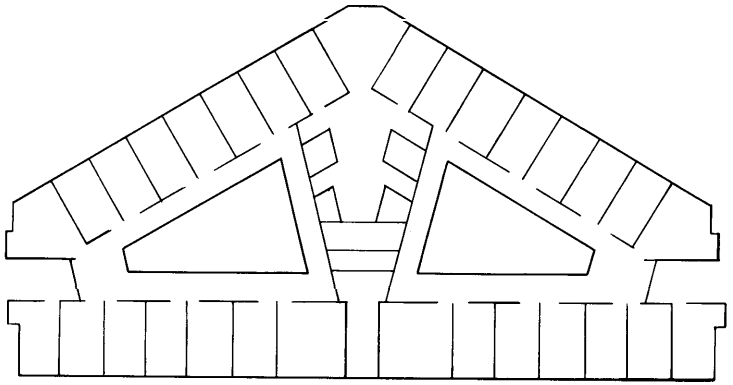
John Douglas French Center, Los Angeles, CA

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.



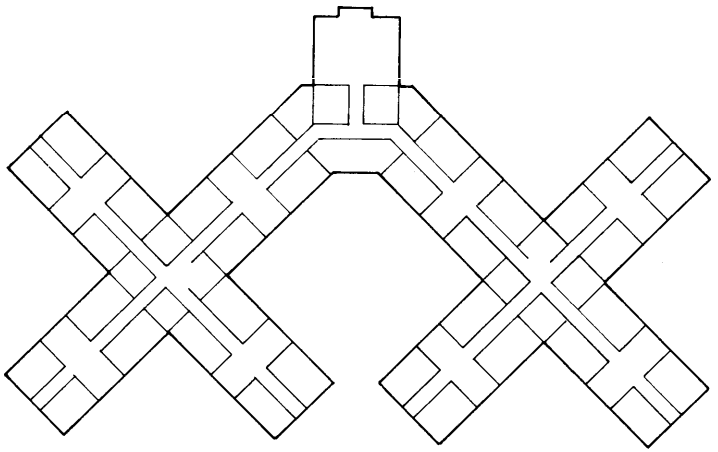
Weiss Institute, Philadelphia Geriatric Center, Philadelphia, PA

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.

SOURCE: M.P. Calkins, *Design for Dementia: Planning Environments for the Elderly and Confused,* 1988; U. Cohen and G.D. Weisman, *Holding On To Home,* 1991; U. Cohen and G.D. Weisman, *Environments for People With Dementia: Case Studies, 1988.*

dementia, when, in fact, no evidence exists that the specifc 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).[8] 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,

[8] 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 (55,128,168,296,358,41 8,5 16).

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 arid 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,[9] 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

[9] 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 areas likely or more likely than other nursing home residents with dementia to receive psychotropic medications.
- Special care unit residents we probably less likely than other nursing home residents with dementia to receive medications of all types.

(Continued on next page)

Table l-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 expectation 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 l-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).

Insummary, 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.[10] 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

10 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 l-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 m 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 maybe 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.
- 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 .11 Inmost 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

11 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 thes 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 .12 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.[13]

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

12 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).

13 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 anew "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 ties 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 administrators 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.[14] 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 waivered 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

14 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.[15]

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

15 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 inmost 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 State 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.[16] 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.[17] 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

16 As described in chapter 5, Colorado's special care unit regulations apply only to locked units.

17 See, 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.[18]

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, but17ofthe55(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.

18 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 (119,340,404,449,45 1, 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 fictions.

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.[19] 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

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

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

homes reduce the use of physical restraints.[20] 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).[21]

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 surwey 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).

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

21 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.[22] 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:[23]

- 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.[24] 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.[25]

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

22 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" (21 1); and Sawyer and Mendelovitz, "A Management Program for Ambulatory Institutionalized Patients With Alzheimer's Disease and Related Disorders" (400).

23 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.

24 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 (SS1) 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).

25 Research Triangle Institute in North Carolina is conducting a study for the us. 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 facilites 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.[26] 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.[27]

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.[28] 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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26 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).

27 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).

28 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.

Chapter 2

Nursing Home Residents With Dementia: Characteristics and Problems

Contents

Tables

Chapter 2

Nursing Home Residents With Dementia: Characteristics and Problems

INTRODUCTION

At least half of all nursing home residents have dementia. Special care units have been developed primarily in response to perceived problems in the care they receive in many nursing homes. The units are intended to offer better care for these individuals.

This chapter provides information about nursing home residents with dementia. It begins with a review of the available data on the number and proportion of nursing home residents who have dementia, the proportion who have a diagnosis of dementia, and the factors that could change the future prevalence of dementia in nursing homes. The second section of the chapter discusses the characteristics of nursing home residents with dementia and compares the characteristics of demented and nondemented residents. This comparison is useful in thinking about what is different about residents with dementia and what should be special about their care.

The third section of the chapter discusses problems in the care provided for residents with dementia in many nursing homes and the impact of the problems on the residents, their families, the nursing home staff members, and nondemented nursing home residents. These problems 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 physical design features and patient care practices recommended for special care units.

Overuse and inappropriate use of psychotropic medications and physical restraints are problems for all nursing home residents, but several studies discussed in this chapter show nursing home residents with dementia are more likely than nondemented nursing home residents to receive psychotropic medications and to be physically restrained. While overuse and inappropriate use of psychotropic medications and physical restraints are major concerns in themselves, they are also perceived by special care unit advocates and others as manifestations of the failure of most nursing homes to use more appropriate methods of care—particularly more appropriate methods of responding to behavioral symptoms. Reduction in the use of psychotropic medications and physical restraints by the substitution of more appropriate methods of responding to residents' behavioral and other symptoms is a primary objective of many special care units.

PREVALENCE OF DEMENTIA IN NURSING HOMES

The 1985 National Nursing Home Survey conducted by the National Center for Health Statistics identified 19,100 nursing homes in the United States (467). The 19,100 nursing homes had 1,491,400 residents and a total bed capacity of 1,624,200.[1]

Estimates of the prevalence of dementia in nursing homes vary, but data from several sources show that at least half of all nursing home residents have dementia. Data from the 1985 National Nursing Home Survey, a large-scale survey of a nationally representative, stratified random sample of all nursing homes, indicate that 696,800 nursing home residents--47 percent of all nursing home residents—had senile dementia or chronic or organic brain syndrome (469). The terms *senile dementia* and *chronic or organic brain syndrome* were used in the past and are sometimes still used for the clinical syndrome referred to in this report and generally as

[1] The term *nursing home* was defined in the 1985 National Nursing Home Survey as a facility that has three or more beds and provides nursing care, personal care (e.g., help with bathing, walking, eating, using the toilet, or dressing) and/or supervision. Another national survey, the 1986 Inventory of Long-Term Care Places, gathered information about *nursing homes* and *residential care facilities*, such as homes for the aged, tbat provide personal care but do not routinely provide nursing care (466). By comparing data from the 1985 National Nursing Home Survey and the 1986 Inventory of Long-Term Care Places, the National Center for Health Statistics concluded that 2200 of the facilities identified as nursing homes in the 1985 National Nursing Home Survey were actually residential care facilities (467); thus, the 19,100 facilities identified by the 1985 National Nursing Home Survey included 16,900 nursing homes with a bed capacity of 1,558,400 and 2200 residential care facilities with a bed capacity of 71,000. Despite this determination, the data on nursing home residents derived from the 1985 National Nursing Home Survey is based on the 1,491,400 residents of the 19,100 facilities, and this OTA report uses those figures.

dementia. These **terms** include dementia caused by Alzheimer's disease.

The figures from the 1985 National Nursing Home Survey on the number and proportion of nursing home residents with senile dementia or chronic or organic brain syndrome were derived from the residents' diagnoses, as recorded in their medical records, and the judgments of members of the nursing staff at each nursing home surveyed. Staff members were shown a list of 10 mental conditions, including senile dementia and chronic or organic brain syndrome, and asked whether the residents in the survey sample had any of the conditions (467). Staff members based their answers on their knowledge of the residents and information in the residents' medical records, including but not limited to the residents' recorded diagnoses.

Other data from the 1985 National Nursing Home Survey indicate that 922,500 nursing home residents—62 percent of all nursing home residents—were so disoriented or memory-impaired that their performance of the activities of daily living, mobility, and other tasks was impaired nearly every day (467). These figures were also derived from interviews with members of the nursing staff at each nursing home and reflect the staff members' judgments based on their knowledge of the residents and information in the residents' medical records.

The 1987 National Medical Expenditure Survey, another large-scale survey conducted by the Agency for Health Care Policy and Research, also included a nationally representative sample of nursing homes. The survey found that 637,600 nursing homeresidents-42 percent of all nursing home residents—had senile dementia or chronic or organic brain syndrome (237). These figures were derived from interviews with nursing home staff members. The staff members were instructed to base their responses on information in the residents' medical records, including but not limited to the residents' recorded diagnoses.

As noted in chapter 1, dementia is a clinical syndrome characterized by decline of cognitive functions, including memory, in an alert individual. To be accurate, a diagnosis of dementia and/or the disease or condition that is causing the dementia must be based on a comprehensive patient evaluation using accepted diagnostic criteria. Estimates of the prevalence of dementia in nursing homes derived from the results of interviews with nursing home staff members may not be accurate because staff members' judgments about residents' mental status are not necessarily based on such an evaluation.

Very few studies have used comprehensive diagnostic evaluations to determine the prevalence of dementia in nursing homes, but the results of three studies that have used such evaluations suggest more than half of all nursing home residents have clinically diagnosable dementia. Based on comprehensive medical and psychiatric evaluations of a random sample of 50 residents of a 180-bed nursing home in Maryland, Rovner et al. concluded that 78 percent of the residents had clinically diagnosable dementia (390). Based on similar evaluations of 65 of the 68 residents of a nursing home in Iowa, Chandler and Chandler concluded that 72 percent of the residents had clinically diagnosable dementia (82). Lastly, based on similar evaluations of 454 individuals admitted to 8 nursing homes in Maryland between February 1987 and March 1988, Rovner et al. concluded that 67 percent of the individuals had clinically diagnosable dementia (389). The results of these three studies cannot be generalized with certainty because of the small number of nursing homes involved, but they suggest the findings of the 1985 National Nursing Home Survey and the 1987 National Medical Expenditure Survey underestimate the true prevalence of dementia in nursing homes.

Dementia-Related Diagnoses of Nursing Home Residents

Although large proportions of nursing home residents were said to have senile dementia or chronic or organic brain syndrome by the nursing home staff members interviewed for the 1985 National Nursing Home Survey and the 1987 National Medical Expenditure Survey and even larger proportions were found to have clinically diagnosable dementia in the three studies just cited, relatively few nursing home residents have a diagnosis of dementia in their medical records. In fact, one of the frequent complaints about the care of nursing home residents with dementia is that their dementia is not carefully or accurately diagnosed and sometimes is not diagnosed at all (17,82,370,389,390,433).

Data from the 1985 National Nursing Home Survey show that at the time of the survey, 16 percent of all residents had a recorded primary diagnosis of dementia or of a disease or condition

that causes dementia. The 16 percent included 3 percent who had a primary diagnosis of Alzheimer's disease or another specified or unspecified degeneration of the brain (ICD-9-CM codes 331.0, 331.2, and 331.9)2; 3 percent who had a primary diagnosis of senile dementia or another organic psychotic condition (ICD-9-CM codes 290-294), 9 percent who had a primary diagnosis of organic brain syndrome (ICD-9-CM code 310); and 1 percent who had a primary diagnosis of senility without psychosis (ICD-9-CM code 797) (467).

Of the nursing home residents who were said by members of the nursing staff at each facility to have either senile dementia or chronic or organic brain syndrome, about one-third had a recorded primary diagnosis of any mental disorder, including 7 percent who had a primary diagnosis of senile dementia or another organic psychotic condition (ICD-9-CM codes 290-294) and 19 percent who had a primary diagnosis of organic brain syndrome (ICD-9-CM code 310) (467). Of the residents who were said by members of the nursing staff to be disoriented or memory-impaired, 4 percent had a primary diagnosis of senile dementia or another organic psychotic condition, and 12 percent had a primary diagnosis of organic brain syndrome.

Nursing home residents generally have several diagnoses in their medical records. Considering all the diagnoses listed in residents' medical records, the 1985 National Nursing Home Survey found 23 percent of the residents had any diagnosis of dementia or of a disease or condition that causes dementia (189). As noted earlier, the 1985 survey found 47 percent of all residents had dementia. Thus fewer than half of the residents with dementia had a recorded diagnosis of dementia or a diagnosis of a disease or condition that causes dementia. Moreover, most of those with a recorded diagnosis of dementia had a general diagnosis, such as chronic or organic brain syndrome. These general diagnoses were widely used in the past but have been largely replaced in most settings by more specific diagnoses that identify the cause of an individual's dementia, e.g., Alzheimer's disease or multi-infarct dementia.

There are many possible reasons why a nursing home resident with dementia may not have a recorded diagnosis of dementia or a diagnosis of a disease or condition that causes dementia. One possible reason is that the physician who determines the person's diagnoses is not aware of the person's dementia. A second possible reason is that although the physician is aware of the person's dementia, the physician does not think the dementia is as important as the person's other medical conditions and therefore does not document it in the person's medical record. A third possible reason is that the physician does not feel competent to diagnose the dementia. A fourth reason is that in some States, Medicaid policies restrict eligibility for Medicaid-funded nursing home care for persons with dementia (83). As a result, physicians who want to help their patients with dementia obtain Medicaid funding for nursing home care may choose not to document the dementia in the patients' medical records. Lastly, many nursing home administrators and staff are reluctant to admit someone they believe will be difficult to manage, and they tend to regard people with dementia as difficult to manage (170,454,520). For this reason, physicians who want to help their patients with dementia to be admitted to a nursing home may not document the dementia in the patients' medical records.

The proportion of nursing home residents with dementia who have a recorded diagnosis of dementia or a diagnosis of a disease or condition that causes dementia is likely to increase in the future and may have already increased since the 1985 National Nursing Home Survey. Findings from the 1987 National Medical Expenditure Survey suggest the proportion of nursing home residents who had such a diagnosis in their medical records was slightly higher in 1987 than it was in 1985 (236).

One reason for the expected increase in the proportion of nursing home residents who have a recorded diagnosis of dementia is the growing awareness among physicians and others of Alzheimer's disease and other diseases that cause dementia. In addition, the resident assessment process mandated by the nursing home reform provisions of the Omnibus Budget Reconciliation Act of 1987 (OBRA-87) requires evaluation of a resident's cognitive status. The Minimum Data Set, the resident assessment instrument developed for the implementation of OBRA-87, includes six questions about cognitive status on its first page (see fig. 5-1 in ch. 5). By calling attention to residents' cognitive

[2] ICD-9-CM codes are diagnostic codes from the *International Classification of Diseases, 9th Revision, Clinical Modification*, published in 1980.

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status, this assessment instrument increases the likelihood dementia will be diagnosed.

Preadmission Screening and Annual Resident Review (PASARR), another mandated component of OBRA-87, also increases the likelihood that dementia will be diagnosed. OBRA-87 requires States to have a PASARR program that 1) screens all nursing home applicants and nursing home residents to determine whether they have mental illness or mental retardation, and 2) evaluates all those found to have mental illness or mental retardation to determine whether they need nursing home care and whether they need "active treatment" 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 "active treatment" must be discharged. (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 "active treatment. ' ')[3]

In the original OBRA-87 language, a nursing home applicant or resident with a primary or secondary diagnosis of a mental disorder as defined in the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders,* 3rd edition (DSM III) **was** considered to have mental illness and therefore to be subject to a PASARR evaluation. According to DSM III, dementia is a mental disorder, but an amendment to the original OBRA-87 language exempted individuals with a primary diagnosis of dementia, including Alzheimer's disease or a related disorder, from the PASARR evaluation process. OBRA-90 extended that exemption to individuals who have any diagnosis of dementia as long as they do not have a primary diagnosis of a serious mental illness (320).

Since a PASARR evaluation can result in a determination that an applicant or resident cannot be admitted to or cannot remain in a nursing home, PASARR creates an incentive for physicians who want to have their patients admitted to or remain in a nursing home to give the patients a diagnosis of dementia in order to exempt them from the evaluation. The current lack of a definitive physical marker for Alzheimer's disease, the most common cause of dementia, means that disproving such a diagnosis would be difficult. OTA is not aware of any data that show an increase in the proportion of nursing home residents who have a diagnosis of dementia since the implementation of PASARR in January 1989, but anecdotal evidence suggests such an increase has occurred, at least in some States.

Factors That Could Change the Future Prevalence of Dementia in Nursing Homes

At least three factors could change the prevalence of dementia in nursing homes in the future. One factor is the availability of alternate residential care settings for people with dementia, e.g. adult foster homes and board and care and assisted living facilities. These types of settings are proliferating in some parts of the country and may substitute for nursing homes for some individuals with dementia.

A second factor that could change the prevalence of dementia in nursing homes is the availability of supportive services for individuals with dementia who live at home, e.g., adult day services and in-home and overnight respite services. Such services may prevent or postpone nursing home placement for some individuals.

A third factor that could affect the future prevalence of dementia in nursing homes is changes in Medicare or Medicaid eligibility, coverage, or reimbursement policies that either encourage or discourage nursing home care for persons with dementia. As noted earlier, Medicaid policies in some States restrict eligibility for Medicaid-funded nursing home care for people with dementia. Any changes in Medicaid policies in those or other States that resulted in more or less restrictive eligibility policies for persons with dementia would affect the number of residents with dementia in nursing homes.

With respect to reimbursement policies, flat rate systems, which reimburse nursing homes at the same rate for all residents, generally create a financial incentive for nursing homes to admit individuals they regard as relatively easy and thus inexpensive to care for and to deny admission to individuals they regard as relatively difficult and thus more expensive to care for (51,416). Since many nursing home administrators and staff members regard individuals

[3] The Omnibus Budget Reconciliation Act of 1990 (OBRA-90) changed the term *active treatment* to *specialized services* for PASARR purposes. OBRA-90 also changed the term *mental illness* to *serious mental illness* for PASARR purposes (320).

with dementia as relatively difficult to care for, they may be reluctant to admit these individuals under a flat rate reimbursement system.

As of 1990, 19 States were using case-mix reimbursement systems for Medicaid-funded nursing home care (51), and Congress has mandated development of a case-mix reimbursement system for Medicare-funded nursing home care. The purpose of case-mix reimbursement systems is to recognize explicitly differences among nursing home residents in the resources required and therefore the cost of their care and to adjust the level of reimbursement to reflect those differences (142,416). To the extent that the level of reimbursement for residents with dementia in a given case-mix system corresponds to nursing home administrators' perception of the relative difficulty and cost of caring for these residents vs. other types of residents, the administrators are likely to be willing to admit individuals with dementia.[4] Anecdotal evidence suggests the level of reimbursement for individuals with dementia vs. other individuals in existing case-mix systems does not correspond to administrators' perceptions of the relative difficulty and cost of their care and in effect discourages admission of individuals with dementia.

Summary

A very large number of nursing home residents have dementia-637,000 to 922,500 individuals according to national surveys. Not all of these individuals have a diagnosis of dementia in their medical records, however. In 1985, at least one-half of all nursing home residents with dementia did not have a diagnosis of dementia in their medical records. Moreover, most of the residents who had a diagnosis of dementia had a general diagnosis, such as organic brain syndrome, rather than a specific diagnosis, such as Alzheimer's disease. These findings support the complaint of many special care unit advocates and others that dementia in nursing home residents frequently is not carefully or accurately diagnosed and sometimes is not diagnosed at all.

The proportion of nursing home residents with dementia that has a diagnosis of dementia in their medical records is probably higher now than it was in 1985. For reasons discussed earlier, that proportion is likely to continue to increase in the future.

The true proportion of nursing home residents with dementia could increase or decrease, depending on several factors, e.g., the availability of appropriate care in alternate settings and Medicare and Medicaid policies that encourage or discourage nursing home care for persons with dementia.

CHARACTERISTICS OF NURSING HOME RESIDENTS WITH DEMENTIA

The 1985 National Nursing Home Survey, the 1987 National Medical Expenditure Survey, and several smaller studies provide information about various characteristics of nursing home residents. OTA has used this information to compare the characteristics of nursing home residents with dementia and nondemented nursing home residents. In this section the two groups of residents are compared with respect to age, gender, race, impairments in activities of daily living, and psychiatric and behavioral symptoms. Two topologies of nursing home residents are discussed.

Information about the characteristics of demented and nondemented nursing home residents is useful in thinking about what should be special about nursing home care for individuals with dementia. The data presented in this section show that residents with dementia generally are older than nondemented residents. They are also more likely to have impairments in activities of daily living and psychiatric and behavioral symptoms. There is considerable overlap, however, between demented and nondemented residents in the distribution of these characteristics.

Information about the characteristics of nursing home residents with dementia is also useful in thinking about whether there are certain types of individuals with dementia who might be more appropriate than other types for special care units. Probably the most important information for this purpose is information about their coexisting medical conditions and physical impairments. To OTA's knowledge, that information is not available from research based on a nationally representative sample of nursing home residents. The 1985 National

[4] Existing case-mix reimbursement systems generally do not use dementia or a resident's cognitive status as variables to define case mix. Other variables, such as disorientation, need for supervision and specific behavioral symptoms, which maybe proxies for dementia, are used to define case mix in some reimbursement systems (142).

Nursing Home Survey provides information about the primary and other diagnoses of all nursing home residents. For residents with dementia, diagnoses related to their mental status have been extracted from the survey data, but their other diagnoses have not been extracted. According to an official of the National Center for Health Statistics, that information would be of questionable validity because of the large number of diagnostic categories and the relatively small number of individuals in many of the categories (189). One of the topologies of nursing home residents discussed later in this section incorporates information about residents' coexisting medical conditions and physical impairments that was derived from data on residents of New York nursing homes.[5]

Age, Gender, and Race

Table 2-1 presents data from the 1985 National Nursing Home Survey on the age, gender, and race of demented and nondemented nursing home residents. For the purpose of the comparisons in this section, demented nursing home residents are residents who had a diagnosis of dementia in their medical records or were said by members of the nursing home staff to have senile dementia or chronic or organic brain syndrome. Nondemented nursing home residents are residents who did not have a diagnosis of dementia in their medical records and were not said by members of the nursing home staff to have senile dementia or chronic or organic brain syndrome.

According to the survey data, demented nursing home residents were, on average, older than nondemented nursing home residents. As shown in table 2-1,48 percent of residents with dementia were over age 85, compared with 33 percent of the nondemented residents.

The proportion of residents with dementia increased with age, from 20 percent of residents under age 65, to 38 percent of those age 65 to 74,49 percent of those age 75 to 84, and 56 percent of those over age 85 (data not shown) (469). Conversely, the proportion of nondemented residents decreased with age.

Three-quarters of nursing home residents with dementia were female (see table 2-l). A preponderance of female residents among all residents with dementia is to be expected since female nursing home residents greatly outnumber male residents. The survey data indicate, however, that female nursing home residents were more likely than male residents to have dementia (48 percent vs. 40 percent, respectively) (data not shown) (469).

The proportion of nursing home residents with dementia did not differ by race. As shown in table 2-1, the proportion of demented nursing home

Table 2-l—Distribution of Demented and Nondemented Nursing Home Residents by Age, Gender, and Race, United States, 1985

	All residents (N=1,491,400)	Demented residents (N =696,800)	Nondemented residents (N= 794,600)
Age			
Under 65.. . .	**1270**	**5%**	**18%**
65-74	14	**12**	**16**
75-84	34	**36**	**33**
85+.	40	**48**	**33**
Gender			
Male.	**28**	**25**	**32**
Female.	**72**	**75**	**68**
Race			
White.	**92**	*92*	*92*
Black.	**7**	*7*	*7*
Other.	**1**	1	1

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.

[5] The 1985 National Nursing Home Survey provides information about the primary reason for residents' admission to a nursing home as reported by their next of kin. According to these next-of-kin reports, the primary reasons for admission for 32 percent of all residents overage 65 who had mental disorders were Alzheimer's disease, confusion, forgetfulness, senility, or other emotional, mental, or nervous conditions. The primary reasons for admission for the remaining residents over age 65 who had mental disorders were stroke (10 percent), atherosclerosis and other heart and circulatory conditions (10 percent), hip or other fractures (7 percent), arthritis or another bone, muscle, or joint condition (4 percent), cancer (1 percent), central nervous system diseases or injuries (2 percent), diseases of the digestive or endocrine systems (3 percent), 1oss of vision or hearing (2 percent), respiratory conditions (2 percent), Parkinson's disease (2 percent), dizziness, fainting, or falls (1 percent), genitourinary diseases (1 percent), old age or general debilitation (3 percent), or other or no main reason (21 percent) (469). Although interesting in itself, this information is of little value in determining the coexisting medical conditions and physical impairments of residents with dementia for two reasons First, the category of *persons with mental disorders* includes residents with schizophrenia, other psychoses, depressive and anxiety disorders, mental retardation, and alcohol and drug abuse, ss well as persons with dementia. In addition, since the residents' next of kin were asked about only one condition-the condition they considered the P-reason for the residents' admission to the nursing home, their responses provide no information about the medical conditions and physical impairments of residents admitted because of mental conditions and no information about secondary medical conditions and physical impairments of residents admitted because of physical conditions.

Table 2-2—Impairments in Activities of Daily Living in Demented and Nondemented Nursing Home Residents, United States, 1985

	All residents (N= 1,491,400)	Demented residents (N =696,800)	Nondemented residents (N= 794,600)
Needs help with:			
Bathing	89%	96%	82%
Dressing	75	87	65
Using the toilet	61	74	49
Transferring	60	70	51
Continence	52	69	37
Eating	39	54	27

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.

Table 2-3—Distribution of Psychiatric Symptoms in Demented and Nondemented Nursing Home Residents, United States, 1987

	All residents (N=1,518,400)	Demented residents (N =643,600)	Nondemented residents (N =856,200)
Depressive symptoms	64%	70%	61%
Psychotic symptoms	30	36	26
Behavioral problems			
0 problems	53	41	63
1+	47	59	40
1-4	43	53	37
5-10	4	6	2

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.

residents who were white, black, or "other" corresponds exactly to the proportion of nondemented nursing home residents in each category.

Impairments in Activities of Daily Living

Table 2-2 presents data from the 1985 National Nursing Home Survey on impairments in activities of daily living among demented and nondemented nursing home residents. The data show nursing home residents with dementia were considerably more likely than nondemented nursing home residents to need assistance with each of the activities of daily living. For example, 96 percent of residents with dementia needed assistance with bathing, compared with 82 percent of nondemented residents. Sixty-nine percent of residents with dementia needed assistance to remain continent, compared with 37 percent of nondemented residents.

Symptoms of Depression and Other Psychiatric Conditions

Data from the 1987 National Medical Expenditure Survey indicate that symptoms of depression and other psychiatric conditions are common among nursing home residents with dementia. The survey data show that 70 percent of nursing home residents with dementia had depressive symptoms, including worry, apprehension, drowsiness, withdrawal, impatience, and suspiciousness (see table 2-3). Sixty-one percent of the nondemented residents had depressive symptoms (464).[6]

The 1987 National Medical Expenditure Survey found 36 percent of nursing home residents with dementia had psychotic symptoms, such as delusions and hallucinations (see table 2-3). Twenty-six percent of nondemented residents had such symptoms.

Although these figures show that many nursing home residents with dementia have depressive and psychotic symptoms, it should be noted that not all nursing home residents with dementia have these symptoms. Seventy percent of the residents with dementia had depressive symptoms according to the survey data, but 30 percent of the residents with dementia did not have such symptoms. Likewise, 36 percent of the residents with dementia had psychotic symptoms, and 64 percent did not.

It is also clear from the survey data that depressive and psychotic symptoms are not unique to residents with dementia. Sixty-one percent of the nondemented residents had depressive symptoms, and 26 percent had psychotic symptoms. In fact, data tabulated for OTA by the Agency for Health Care Policy and Research show that 53 percent of all nursing home residents who had depressive symp-

S The reported prevalence of depression and depressive symptoms among nursing home residents varies greatly depending on the study sample and the procedures by which the condition and its symptoms are identified. Moreover, clinicians disagree about what constitutes depression and depressive symptoms in persons with dementia. A study of 227 residents of one Pennsylvania nursing home found that 87 of the 166 residents with dementia (52 percent) and 69 of the 111 cognitively normal residents (62 percent) had major or minor depression based on self reports and observer ratings (342). Another study of 454 residents of 8 Maryland nursing homes found that 29 of the 306 residents with dementia (9 percent) and 110 of the 148 cognitively normal residents (74 percent) had major depression or depressive symptoms (388,389).

toms and 49 percent of all residents who had psychotic symptoms were not demented (464).

Behavioral Symptoms

Both the 1985 National Nursing Home Survey and the 1987 National Medical Expenditure Survey found behavioral symptoms were more common in nursing home residents with dementia than in other nursing home residents. The 1985 survey collected information about six behavioral symptoms (disrobing/exposing oneself, screaming, being physically abusive to self or others, stealing, getting lost or wandering into unacceptable places, and inability to avoid simple dangers) (468). Fifty-eight percent of residents with dementia exhibited one or more of these symptoms, whereas only 24 percent of nondemented residents exhibited one or more of the symptoms.

The 1987 National Medical Expenditure Survey collected information about 10 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) (237). Fifty-nine percent of nursing home residents with dementia exhibited one or more of these symptoms, compared with 40 percent of nondemented residents (see table 2-3).

Wandering is probably the most frequently cited behavioral symptom of nursing home residents. Data from the 1987 National Medical Expenditure Survey and a previous National Nursing Home Survey conducted in 1977 show 11 percent of all nursing home residents wander (237,465). At least three smaller studies have shown nursing home residents with dementia are more likely than other nursing home residents to wander (98,1 16,417). One study of 402 residents of a 520-bed nursing home in Rockville, MD, found, for example, that 47 percent of the 216 demented residents wandered, compared with 31 percent of the 186 nondemented residents (98).

Sundowning is another frequently cited behavioral symptom of nursing home residents. The term *sundowning* refers to an observed increase in agitated and confused behaviors that occurs in some individuals in the late afternoon. A study of 89 randomly selected residents of one 180-bed nursing home in Washington, DC, found 15 percent of the 59 residents with dementia exhibited this symptom, compared with 7 percent of the 30 nondemented residents (132).

Excessive or disruptive noisemaking, including screaming, moaning, and repetitive verbalizations, is a third frequently cited behavioral symptom of nursing home residents. At least two studies have shown demented residents are more likely than nondemented residents to exhibit this symptom (72,97).

Although these figures indicate nursing home residents with dementia are more likely than other nursing home residents to exhibit behavioral symptoms, it is clear not all nursing home residents with dementia exhibit such symptoms. As shown in table 2-3, the 1987 National Medical Expenditure Survey found 41 percent of nursing home residents with dementia did not exhibit any of the measured symptoms (464). Likewise, the 1985 National Nursing Home Survey found 42 percent of nursing home residents with dementia did not exhibit any of the measured symptoms (468).

It is also clear from the survey data that behavioral symptoms are not unique to residents with dementia. The 1987 National Medical Expenditure Survey found 40 percent of nondemented nursing home residents exhibited one or more behavioral symptoms (see table 2-3). Moreover, data from the two national surveys show 35 to 47 percent of nursing home residents who exhibited one or more behavioral symptoms were not demented (464,468).

The results of a study of a random sample of 1139 residents of 42 New York nursing homes also show behavioral symptoms are not unique to residents with dementia. The study found 23 percent of the residents exhibited serious behavioral symptoms, including dangerous, physically aggressive, and verbally noisy or abusive behaviors (520). Two-thirds of the residents who exhibited serious behavioral symptoms had dementia. By implication, it is clear that one-third of the residents who exhibited serious behavioral symptoms did not have dementia.

Topologies of Nursing Home Residents

Several topologies have been proposed to describe different types of nursing home residents. One typology delineates five general types of residents (339). The five types are based on differences in the primary reason for the individuals' admission to a

nursing home and their expected lengths of stay. The five types are:

1. individuals who are terminally ill and will remain in the facility for 6 months or less;
2. individuals who require short-term rehabilitation or treatment for subacute illness and will remain in the facility for 6 months or less;
3. individuals who are primarily physically impaired and will remain in the facility for longer than 6 months;
4. individuals who are primarily cognitively impaired and will remain in the facility for longer than 6 months; and
5. individuals who have significant cognitive and physical impairments and will remain in the facility for longer than 6 months (339).

In this typology, individuals with dementia are included in two of the groups-long-stay residents who are primarily cognitively impaired and long-stay residents who are both cognitively and physically impaired.

A more complicated typology that was developed with the use of a statistical grouping technique called *grade of membership (GOM)* and data on the characteristics of 3427 residents of New York nursing homes delineates 6 types of nursing home residents (283). The six types are:

1. *limited impaired residents* who usually have a primary diagnosis of heart disease, diabetes, arthritis, or a cognitive or mental disorder but are relatively healthy, have few impairments in activities of daily living or sensory impairments, and require relatively little nursing care;
2. *oldest-old, deteriorating residents* who are over age 85, have multiple medical problems, including cancer, heart disease, arthritis, stroke, diabetes, and digestive, neurological, and pulmonary problems, but no dementia, and require more nursing care than any of the other types except type 6;
3. *acute and rehabilitative residents* who are acutely ill, usually have been admitted from a hospital for rehabilitation following hip fracture, stroke, or another condition, generally do not have dementia, and are usually discharged home after a short stay;
4. *behavioral problem residents* who usually have a primary diagnosis of a mental illness and exhibit psychiatric and behavioral symptoms;
5. *dementia residents* who are relatively old and usually have stroke, dementia, and/or psychiatric symptoms, as well as impairments in activities of daily living; and
6. *severely impaired residents* who are relatively young, often terminally ill, and have medical problems, such as stroke, renal failure, and respiratory and neurological diseases, and severe impairments in activities of daily living; they have the longest stays and usually require nursing services, such as wound care, sterile dressings, and turning and positioning (283).

Table 2-4 presents data on the resident characteristics associated with each of the six types. The figures in table 2-4 represent the probability that an individual who is exactly like that type has the particular characteristic. Individuals with a diagnosis of Alzheimer's disease or senile dementia are included in four types—1,4, 5, and 6 (283). These four types differ greatly in their other diagnoses, physical impairments, and care needs.

The GOM technique is intended to model the complex clinical reality of disease and functional status in elderly people (283). Although the typology just described is derived from data on the characteristics of residents of New York nursing homes, experience in using the GOM technique with data on other nursing home residents indicates ***the*** same six types emerge (282). Thus, the six types probably describe real types of nursing home residents, and the four types that include individuals with dementia probably represent more accurately than the simpler typology described earlier the clinical reality of dementia in nursing homes.

The GOM typology is useful in thinking about which individuals with dementia might be appropriately cared for in special care units vs. nonspecialized units or other settings. For example, in type *6--severely impaired residents*, there is a 20 percent probability that an individual of this type has a primary diagnosis of Alzheimer's disease or senile dementia and therefore might be an appropriate candidate for placement in a special care unit. On the other hand, all individuals of this type have impairments in activities of daily living-100 percent require assistance in transferring, eating, dressing, bathing, toileting, and hygiene, and 100 percent are

Table 2-4—Characteristics of Six Types of Nursing Home Residents, New York State

Variable	Frequency	Type of nursing home residents: Limited impaired (1)	Oldest-old deteriorating (2)	Acute and rehabilitative (3)	Behavioral problem (4)	Dementia (5)	Severely impaired (6)
1. Primary diagnosis							
Cancer	1.43	0.66	1.79	3.01	1.39	0.00	1.32
Heart disease	17.79	35.56	62.83	9.48	0.00	0.00	0.00
Stroke	10.78	0.00	0.00	18.56	0.00	19.46	20.72
Diabetes	4.05	7.77	8.57	1.10	9.47	0.00	0.00
Arthritis	5.94	8.56	14.39	11.10	0.00	0.00	0.00
Renal problems	0.64	0.00	0.00	1.74	0.00	0.06	1.44
Digestive problems	0.70	0.00	1.52	2.27	0.00	0.00	0.00
Hip fracture	1.92	0.00	0.00	9.52	0.00	0.00	0.00
Liver and gall bladder problems	0.12	0.42	0.00	0.00	0.00	0.34	0.00
Alzheimer's disease and senile dementia	15.29	12.07	0.00	0.00	22.68	42.50	20.07
Other neurological problems	10.30	0.00	0.00	24.64	0.00	0.00	27.32
Chronic respiratory problems	1.64	6.79	3.30	0.00	0.00	0.00	0.00
Other respiratory problems	0.61	0.00	1.37	0.81	0.00	0.00	1.17
Infectious disease	0.34	0.00	1.43	0.00	0.00	0.70	0.00
Other endocrine problems	0.18	0.00	0.00	0.00	1.46	0.00	0.00
Metabolic disorder	0.34	0.20	0.00	0.00	0.00	0.00	1.55
Blood disorder	0.49	0.00	3.05	0.00	0.00	0.00	0.00
Mental disorder	18.40	22.20	0.00	0.00	44.54	36.94	17.83
Atherosclerosis	2.56	0.00	0.00	0.00	20.46	0.00	0.00
Other circulatory problems	1.22	0.00	0.00	6.05	0.00	0.00	0.00
Other	5.27	5.78	1.75	11.72	0.00	0.00	8.59
Associated conditions							
2. Cancer	3.33	4.37	14.32	2.36	4.93	0.00	0.00
3. Heart disease	50.60	47.13	100.00	49.95	32.83	62.03	21.23
4. Stroke	16.37	6.07	28.96	17.67	13.49	13.43	22.95
5. Diabetes	12.26	5.96	25.80	17.43	27.91	5.20	7.46
6. Arthritis	22.03	19.36	100.00	12.28	4.25	19.11	0.00
7. Renal problems	6.39	0.00	0.00	0.00	0.00	0.00	29.95
8. Digestive problems	7.56	4.55	55.16	0.00	0.00	0,00	0.00
9. Hip fracture	4.61	2.54	0.00	6.28	0.00	7.21	6.73
10. Liver and gall bladder disease	1.02	1.34	7.00	0.00	0.00	0,00	0.00
11. Alzheimer's disease and senile dementia	8.17	0.00	0.00	0.00	61.62	0.00	10.01
12. Other neurological problems	16.49	0.00	100.00	0.00	0.00	0.00	0.00
13. Chronic respiratory problems	5.16	7.59	23.40	0.00	6.82	2,61	0.00
14, Other respiratory problems	1.93	1.57	0.00	1.38	0.00	3,33	3.10
15, Urological problems	6.39	0.00	0.00	0.00	0.00	0.00	29.95
16, Infectious disease	75.72	100.00	0.00	100.00	100.00	100.00	100.00
17, Other endocrine problems	2.66	2.63	15.70	2.20	0.00	0.00	0.00
18, Metabolic disorder	2.31	3.42	5.00	2.11	6.36	0.00	0.71
19. Blood disorder	6.24	0.00	51.34	0.00	0.00	0.00	0.00
20. Mental disorder	17.54	0.00	0.00	0.00	100.00	0.00	0.00
21. Eye problems	12.28	0.00	100.00	0.00	0.00	0.00	0.00
22. Ear problems	2.83	0.00	31.94	0.00	0.00	0.00	0.00
23. Atherosclerosis	5.46	0.00	27.35	0.00	0.00	7.83	3.82
24. Other circulatory problems	5.25	1.55	29.66	8.49	0.00	0.00	0.00

Table 2-4—Characteristics of Six Types of Nursing Home Residents, New York State--Continued

Variable	Frequency	Type of nursing home residents: Limited impaired (1)	Oldest-old deteriorating (2)	Acute and rehabilitative (3)	Behavioral problem (4)	Dementia (5)	Severely impaired (6)
25. Skin problems.	2.60	0.00	14.27	0.00	2.14	0.00	4.46
26. Fractured extremities.	1.81	0.00	0.00	3.62	0.00	0.00	5.60
27. Comatose.	1.20	0.00	0.00	0.00	0.00	0.00	6.37
28. Terminally ill.	1.32	0.00	0.00	1.79	0.00	0.00	4.95
29. Alcohol abuse.	3.17	4.77	0.00	0.00	26.64	0.00	0.00
30. Drug abuse.	0.26	0.00	0.00	0.00	3.14	0.00	0.00
Limitations							
31. Vision:							
No loss.	74.53	100.00	0.00	100.00	100.00	91.92	54.39
Moderate loss.	19.03	0.00	63.05	0.00	0.00	8.08	45.61
Severe loss.	6.44	0.00	36.95	0.00	0.00	0.00	0.00
32. Hearing:							
No loss.	80.22	100.00	0.00	100.00	100.00	100.00	100.00
Moderate loss.	15.26	0.00	77.15	0.00	0.00	0.00	0.00
Severe loss.	4.52	0.00	22.85	0.00	0.00	0.00	0.00
33. Verbal expression:							
No difficulty.	66.43	100.00	100.00	91.11	83.53	51.13	0.00
With difficulty.	23.72	0.00	0.00	8.89	16.65	48.87	48.31
Totally impaired.	9.85	0.00	0.00	0.00	0.00	0.00	51.69
34. Reception:							
No difficulty	57.50	100.00	47.26	100.00	0.00	40.18	0.00
With difficulty.	34.36	0.00	52.74	0.00	100.00	59.82	38.89
Totally impaired.	8.14	0.00	0.00	0.00	0.00	0.00	61.11
35. Diet:							
Regular.	19.56	*34.80*	0.00	*28.35*	18.81	26.83	0.19
Other.	80.44	*65.20*	100.00	*71.65*	81.19	73.17	99.81
36. Decubiti:							
None.	88.79	100.00	100.00	*93.73*	100.00	100.00	52.33
Single.	9.57	0.00	0.00	*6.27*	0.00	0.00	39,88
Multiple.	1.64	0.00	0.00	0.00	0.00	0.00	7.79
37. Discoloration.	6.02	0.00	59.66	0.00	0.00	0.00	0.00
38. Edema.	15.16	0.00	93.48	*13.38*	21.33	0.00	4.90
39. Weight loss.	13.61	0.00	53.30	*9.86*	42.09	4.39	10.14
40. Severe pain.	8.03	4.19	25.41	*20.44*	9.77	0.00	0.00
41. Contractures.	22.49	0.00	0.00	0.00	0.00	0.00	97.90
42. Dyspnea.	4.71	0.00	46.50	0.00	0.00	0.00	0.00
43. Mobility:							
No impairment.	21.65	100.00	0.00	0.00	100.00	0.00	0.00
With help.	24.37	0.00	0.00	*62.36*	0.00	38.43	0.00
Wheelchairfast.	38.11	0.00	100.00	*37.64*	0.00	61.57	36.15
Chairfast.	14.74	0.00	0.00	0.00	0.00	0.00	59.27
Bedfast.	1.14	0.00	0.00	0.00	0.00	0.00	4.58
44. Transfer:							
No impairment.	29.51	100.00	0.00	0.00	100.00	0.00	0.00
With help.	40.11	0.00	100.00	100.00	0.00	100.00	0.00
Bedfast.	30.39	0.00	0.00	0.00	0.00	0.00	100.00
45. Eating:							
No loss.	22.12	100.00	0.00	0.00	0.00	0.00	0.00
With supervision. . . .	55.85	0.00	100.00	100.00	100.00	100.00	0.00
Totally impaired.	22.03	0.00	0.00	0.00	0.00	0.00	100.00
46. Dressing:							
No impairment.	13.22	62.72	0.00	0.00	100.00	0.00	0.00
With supervision. . . .	36.68	37.28	100.00	100.00	0.00	0.00	0.00
Totally impaired.	50.10	0.00	0.00	0.00	0.00	100.00	100.00

Table 2-4—Characteristics of Six Types of Nursing Home Residents, New York State--Continued

Variable	Frequency	Type of nursing home residents: Limited impaired (1)	Oldest-old deteriorating (2)	Acute and rehabilitative (3)	Behavioral problem (4)	Dementia (5)	Severely impaired (6)
47. Bathing:							
No impairment.	2.25	10.12	0.00	0.00	100.00	0.00	0.00
With assistance.	42.88	89.88	100.00	100.00	0.00	0.00	0.00
Totally impaired.	54.87	0.00	0.00	0.00	0.00	100.00	100.00
48. Toileting:							
No impairment.	27.37	100.00	0.00	0.00	100.00	0.00	0.00
With help.	24.25	0.00	100.00	100.00	0.00	100.00	0.00
Totally impaired.	48.38	0.00	0.00	0.00	0.00	0.00	100.00
49. Bladder control:							
Continent	39.31	100.00	0.00	100.00	0.00	0.00	0.00
Incontinent.	51.59	0.00	100.00	0.00	100.00	100.00	58.92
Indwelling.	7.27	0.00	0.00	0.00	0.00	0.00	32.78
External.	1.84	0.00	0.00	0.00	0.00	0.00	8.29
50. Bowel:							
Continent.	46.57	99.11	0.00	99.17	0.00	0.00	0.00
Incontinent.	53.38	0.00	0.00	0.00	0.00	100.00	100.00
Colostomy.	1.05	0.89	100.00	0.83	100.00	0.00	0.00
51. Personal hygiene:							
No impairment.	12.32	54.55	0.00	0.00	0.00	0.00	0.00
With supervision. . . .	25.84	45.56	100.00	100.00	0.00	0.00	0,00
With assistance.	61.84	0.00	0.00	0.00	100.00	100.00	100.00
52. Learning:							
No impairment.	32.80	91.94	0.00	84.46	0.00	0.00	0.00
With difficulty.	49.09	8.06	100.00	15.54	100.00	93.40	0.00
Totally impaired.	18.11	0.00	0.00	0.00	0.00	6.60	100.00
53. Patient wanders.	9.48	0.00	0.00	0.00	94.33	17.90	0.00
54. Patient verbally abusive.	34.90	0.00	0.00	0.00	100.00	0.00	0.00
55. Patient physically aggressive.	16.95	0.00	0.00	0.00	100.00	0.00	0.00
56. Severe depression. . .	7.36	0.00	0.00	0.00	100.00	0.00	0.00
57. Hallucinations.	6.13	0.00	0.00	0.00	100,00	0.00	0.00
58. Paranoia.	7.65	0.00	0.00	0.00	100.00	0.00	0.00
59. Patient withdrawn. . . .	32.11	0.00	86.14	0.00	100.00	0.00	47.16
60. Delusion.	4.41	0.00	0.00	0.00	82.83	0.00	0.00
61. Hoarding.	5.66	7.25	0.00	7.81	39.77	0.00	0.00
62. Manipulative.	11.97	0.00	0.00	36.44	78.97	0.00	0.00

SOURCE: K.G. Manton, J.C. Vertrees, and M.A. Woodbury, "Functionally and Medically Defined Subgroups of Nursing Home Populations," *Health Care Financing Review* 12(1):50-52, *1990.*

incontinent; they also require extensive nursing services, such as wound care, sterile dressings, and turning and positioning. For these reasons, they might be more appropriately cared for in a nonspecialized nursing home unit. In contrast, in type *4--behavioral problem residents*, there is a 23 percent probability that an individual of this type has a primary diagnosis of Alzheimer's disease or senile dementia and a 62 percent probability that such an individual has any diagnosis of Alzheimer's disease or senile dementia. Individuals in this type have less severe impairments in activities of daily living, generally do not require the kinds of nursing services needed by individuals in type 6, and exhibit behavioral symptoms. Thus they might be appropriate candidates for placement in a special care unit.

Factors That Could Change the Types of Individuals With Dementia in Nursing Homes

The same factors that could change the prevalence of dementia in nursing homes could also change the types of individuals with dementia in nursing homes. These factors include availability of alternate residential care settings for persons with

dementia, availability of supportive services for persons with dementia who live at home, and Medicare and Medicaid eligibility, coverage, and reimbursement policies that encourage or discourage nursing home care for certain types of individuals with dementia. Greater availability of appropriate services for persons with dementia in non-nursing-home settings is likely to reduce the number and proportion of nursing home residents with dementia who are in the middle stages of their illness and are relatively physically healthy except for their dementia and, conversely, increase the number and proportion who are in the late stages of dementia and have numerous medical conditions and physical impairments in addition to dementia. The wider use of case-mix systems to determine the level of Medicare and Medicaid reimbursement for nursing home care is also likely to differentially increase the proportion of nursing home residents with dementia who have numerous medical conditions and physical impairments in addition to dementia.

Another factor that could change the types of individuals with dementia in nursing homes is changes in hospital discharge practices. Following the implementation of the Medicare prospective payment system in 1983, the average length of hospital stays for Medicare beneficiaries decreased, and the average severity of illness increased among individuals who were admitted to nursing homes from hospitals (262,396,430). Future changes in hospital discharge practices that resulted in shorter average length of hospital stays could result in further increases in severity of illness among both demented and nondemented nursing home residents.

Summary

Findings of two national surveys based on representative samples of nursing home residents show residents with dementia are more likely than nondemented residents to have impairments in activities of daily living and depressive, psychotic, and behavioral symptoms. At the same time, survey data show that some nursing home residents with dementia are not impaired in each of the activities of daily living about which information was obtained, that significant proportions of nursing home residents with dementia do not have depressive or psychotic symptoms (30 percent and 64 percent, respectively), and that more than 40 percent of nursing home residents with dementia do not have behavioral symptoms (464). It is also clear from the survey data that although nondemented residents are less likely than demented residents to have impairments in activities of daily living and depressive, psychotic, and behavioral symptoms, significant proportions of nondemented residents have each of these characteristics.

The literature on nursing home care for persons with dementia often implies that virtually all nursing home residents with dementia have behavioral symptoms and that behavioral symptoms in nursing homes are almost always symptoms of demented residents. The survey data contradict both assumptions.

Parenthetically, it is interesting to note that sundowning behavior, which is mentioned often in the literature on nursing home care for persons with dementia, was exhibited by only a small proportion of residents with dementia (15 percent) in the one study OTA is aware of that measured the incidence of this behavior (132). Similar findings for several other behavioral symptoms are noted in chapter 4.

Behavioral symptoms are often difficult for nursing home staff members to manage. As discussed in the following section of this chapter, one of the most frequent complaints about the care provided for residents with dementia by most nursing homes concerns inappropriate staff responses to residents' behavioral symptoms. As a result, one objective of many special care units is to implement more effective methods of responding to these symptoms. Even if all nursing home residents with dementia were in special care units, however, a large proportion of all nursing home residents with behavioral symptoms (35 to 47 percent according to national survey data) would still be in nonspecialized units. Likewise, if special care units were designated to serve only residents with behavioral symptoms-an option that has been suggested—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 exhibit behavioral symptoms.

These findings point out the diversity of nursing home residents with dementia. The typology of nursing home residents based on the GOM technique identifies four distinct types of nursing home residents with dementia-limited impaired residents, behavioral problem residents, dementia residents, and severely impaired residents. Special care units may be more appropriate for some of these

types than others. As discussed in chapter 3, current residents of special care units are somewhat less physically impaired than residents with dementia in nonspecialized nursing home units. Special care units may be shown to be more effective for these less physically impaired residents than for individuals with dementia who have many medical conditions and physical impairments in addition to dementia.

PROBLEMS IN THE CARE PROVIDED FOR NURSING HOME RESIDENTS WITH DEMENTIA

Problems in the care provided for individuals with dementia in many nursing homes are the primary reason for the development and proliferation of special care units. This section discusses these problems and their impact on residents with dementia, their families, nursing home staff members who take care of them, and nondemented nursing home residents.

Complaints and Concerns About the Care Provided for Individuals With Dementia in Many Nursing Homes

The literature on nursing home care for individuals with dementia contains numerous complaints and concerns about the care provided for these individuals in many nursing homes. Table 2-5 lists the most frequently cited complaints and concerns. (An identical list appears in table 1-1 in ch. 1.) This list was derived from OTA's review of 30 articles, reports, and books on nursing home care for persons with dementia (48,55,59,67,107,1 15,125,162,163, 165,170,171,182,191,241,243,263,274,339,346,352, 354,359,364,370,385,386,393,414,446). The inclusion of items in table 2-5 does not imply that data necessarily exist 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 people with dementia in most nursing homes and therefore what should be done differently in special care units.

Some of the complaints and concerns listed in table 2-5 apply primarily to nursing home residents with dementia, e.g., the complaint that dementia often is not carefully or accurately diagnosed and sometimes is not diagnosed at all. Other complaints and concerns listed in table 2-5 would apply equally to nondemented residents if the explicit references to dementia were omitted. To determine which of the frequently cited complaints and concerns about nursing home care for individuals with dementia are the same as the problems in nursing home care for all residents, OTA compared the complaints and concerns listed in table 2-5 with the problems identified by the Institute of Medicine's Committee on Nursing Home Regulation in its landmark 1986 report *Improving the Quality of Care in Nursing Homes (318). The* Institute of Medicine's report identified many problems with the care provided by some nursing homes:

- insufficient attention to residents' rights;
- physical abuse and neglect;
- inadequate medical and nursing care, including failure to identify and treat acute and chronic diseases and conditions;
- lack of well-trained, motivated, and adequately supervised staff;
- insufficient attention to residents' quality of life;
- lack of choices for residents, e.g., choices about when and what they eat, whom they room with, and when they go to bed and get up;
- failure to notify residents about and involve them in decisions about their care and about aspects of the operation of the facility that affect their care and the quality of their lives;
- failure to notify residents' families about and involve them in decisions about the residents' care;
- lack of psychiatric treatment for residents who need it;
- overuse and misuse of psychotropic drugs;
- overuse and misuse of physical restraints;
- failure to create a home-like environment;
- lack of adequate and comfortable lighting, sound levels, and room temperature; and
- lack of interaction between the nursing home and the community (318).

The Institute of Medicine's report emphasized that these problems exist in some but not all nursing homes and that some nursing homes provide high-quality care (318).

Clearly there are similarities between the problems cited in the Institute of Medicine's report and the concerns and complaints listed in table 2-5. There are also some notable differences—particularly in the emphasis placed on certain types of problems. One of these differences is the greater emphasis in the literature on nursing home care for

Table 2-5—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 illesses, 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.

individuals with dementia on aspects of the physical environment of most nursing homes that are perceived to be inappropriate for these individuals. These aspects include the lack of cues to help residents find their way, the lack of appropriate space for residents to wander, and the failure to incorporate other design features that could support independent functioning in cognitively impaired individuals.

A second difference between the problems cited in the Institute of Medicine's report and complaints and concerns listed in table 2-5 is the greater emphasis in the literature on nursing home care for persons with dementia on behavioral symptoms and

staff responses to these symptoms that are perceived to be inappropriate for the residents. As discussed in the previous section, nursing home residents with dementia are more likely than other residents to exhibit behavioral symptoms. Critics of the care provided for individuals with dementia by most nursing homes contend that nursing home staff members often use inappropriate methods—particularly psychotropic medications and physical restraints-to manage residents' behavioral symptoms and that staff members are not aware of other, more effective methods of responding to these symptoms (109,171,191,277,359).

Both the Institute of Medicine's 1986 report and the literature on nursing home care for persons with dementia cite the lack of adequately trained staff in many nursing homes. The Institute of Medicine's report focuses on lack of training in general, whereas the literature on nursing home care for persons with dementia focuses specifically on lack of training about the care of residents with dementia. Training about the care of nursing home residents with dementia is clearly a subset of training about the care of all kinds of nursing home residents, but one rationale for establishing special care units is that it is easier to develop and maintain an adequately trained staff when the focus of training is dementia and the care of residents with dementia than when the focus of training is much broader (263,270,354).

Both the Institute of Medicine's report and the literature on nursing home care for persons with dementia also cite inappropriate use of psychotropic medications and physical restraints. As discussed in the following section, these two problems affect all nursing home residents to some degree, but available data indicate psychotropic medications and physical restraints are used more for nursing home residents with dementia than for other residents.

Use of Psychotropic Medications and Physical Restraints

Psychotropic medications and physical restraints are used extensively in nursing homes and are more likely to be used for nursing home residents with dementia than for nondemented residents. As noted at the beginning of this chapter, overuse and inappropriate use of psychotropic medications and physical restraints are major problems in themselves. They are also perceived by special care unit advocates and others as manifestations of the failure of many nursing homes to use more appropriate methods of responding to residents' behavioral symptoms.

Use of Psychotropic Medications

Various studies have shown that 35 to 65 percent of all nursing home residents are prescribed and/or receive at least one psychotropic medication, including antipsychotic, antidepressant, antianxiety, and sedative/hypnotic medications (18,19,52,366,414, 425, 429,433,461). According to these studies, 9 to 26 percent of residents are prescribed and/or receive more than one such medication.

Nursing home residents with dementia are more likely than other nursing home residents to receive psychotropic medications. A study of medication use by residents of 12 nursing homes in Massachusetts found that during a one-month period, 72 percent of residents with a diagnosis of Alzheimer's disease used at least one psychotropic medication for 5 or more days, compared with 53 percent of all residents (19).

A study of a representative sample of 3352 residents of nursing homes in Rhode Island also found the use of psychotropic medications was significantly correlated with cognitive status (425). Among residents with no cognitive impairment or only mild cognitive impairment, 49 percent received at least one psychotropic medication, compared with 50 percent of those with moderate cognitive impairment and 57 percent of those with severe cognitive impairment. Cognitive impairment was not the only resident characteristic significantly correlated with receipt of psychotropic medications. Sixty-six percent of residents who exhibited behavioral symptoms (e.g., noisiness, abusiveness, wandering, disrobing) received one or more psychotropic medications, compared with 48 percent of those who did not exhibit such symptoms.

Considering only antipsychotic medications, a study of 484 residents admitted to 8 Maryland nursing homes between February 1987 and March 1988 found the use of these medications was significantly higher in residents with dementia than nondemented residents (389). Forty-four percent of the 123 residents with dementia complicated by depression, delusions, or delirium and 34 percent of the 183 residents with dementia uncomplicated by any of these factors received antipsychotic medications. In contrast, 24 percent of the 58 residents with

a mental illness and only 7 percent of the 90 residents with neither dementia nor a mental illness received antipsychotic medications.

Considering antipsychotic and antianxiety medications, a study of 760 residents of 7 Wisconsin nursing homes found the use of these medications was significantly higher in residents with dementia than in nondemented residents (429). Thirty-three percent of the 274 residents with dementia uncomplicated by psychotic symptoms or other mental illness received one or both of these types of medications over a one-month period, compared with 15 percent of residents with neither dementia nor mental illness.

Interestingly, a study of 408 residents of a 508-bed nursing home in Rockville, MD, found that residents who were agitated and demented were significantly more likely than residents who were agitated but not demented to receive antipsychotic medications (28). In contrast, residents who were agitated but not demented were more likely to receive antianxiety medications.

Psychotropic medications are often used to control behavioral symptoms in nursing home residents with dementia, but 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 can cause confusion, disorientation, and oversedation in elderly people, thus tending to exacerbate cognitive deficits in elderly individuals with dementia. Proponents of specialized nursing home care for persons with dementia advocate the use of other approaches to manage behavioral symptoms and argue the staff's first response to these symptoms should not be psychotropic medications. On the other hand, it is clear psychotropic medications are effective in treating certain symptoms in some persons with dementia (121,180,277,347).

One intent of the nursing home reform provisions of OBRA-87 was to limit the use of psychotropic medications in nursing homes. OBRA-87 mandates a bill of rights for nursing home residents, which includes the right "to be free from any physical or chemical restraints imposed for the purposes of discipline or convenience, and not required to treat the resident's medical symptoms." In 1991, the Health Care Financing Administration issued draft interpretative guidelines for surveyors, including specific guidelines on the use of psychotropic medications. The guidelines list specific medications and conditions for which they can and cannot be used. A recent retrospective review of antipsychotic medication use from 1976 to 1985 for more than 8000 residents of 60 nursing homes in 8 States found half of the use of these medications would not have been allowed under the new guidelines (150).

Use of Physical Restraints

Like psychotropic medications, physical restraints are also used extensively in nursing homes. Physical restraints include any externally applied device intended to restrict an individual's free movement (383,446). Examples of physical restraints are Posey vests that are put on the individual and then tied to the individual's bed or chair; geriatric chairs that have a tray table which the individual cannot remove; bed rails; lap belts; chest, waist, leg, and wrist restraints; and mittens that the individual cannot remove. Since physical restraints are defined in large part by the purposes for which they are used, devices such as wheelchair brakes and sheets may also be physical restraints if they are intended to inhibit a person's free movement (182,300).

A 1989 literature review identified four studies that reported on the prevalence of restraint use in U.S. nursing homes (133). The studies show that 25 to 41 percent of residents were restrained at the time the studies were conducted. A recently published study of restraint use in 12 nursing homes in Connecticut found that 1042 of the 1756 residents of these facilities (59 percent) were restrained at the beginning of the study (446). A sample of 397 residents who had not been restrained at the beginning of the study was followed for a year, during which time 122 of the 397 residents were restrained. Thus a total of 1164 of the original 1756 residents (66 percent) were restrained at some time during the year.

Restraint use varies from one nursing home to another. The study of 454 residents of 8 Maryland nursing homes between February 1987 and March 1988 found that in the 3 facilities with the highest use of restraints, an average of 73 percent of the residents were restrained at some time during the year, compared with an average of 55 percent of the residents in the 3 facilities with the lowest use of restraints (61).

Some commentators contend that once restraints are used for a nursing home resident, they generally are used on a regular basis (300), but the study just cited of restraint use in 12 Connecticut nursing homes found use was more varied. Of the 122 residents who were restrained for the first time during the study year, 34 percent were restrained for a single period of time that lasted less than 30 days; 34 percent were restrained during more than one period of time but had long periods when they were not restrained; and 32 percent were restrained on a regular basis, defined as at least 20 days each month (446).

Nursing home residents with dementia are more likely than nondemented nursing home residents to be physically restrained (133,389,446). The study just cited of restraint use in 12 Connecticut nursing homes found that during the study year, 51 percent of the residents who were disoriented were restrained, compared with only 17 percent of those who were not disoriented (446).

The study of 8 Maryland nursing homes conducted between February 1987 and March 1988 also found that the residents with dementia were significantly more likely than nondemented residents to be physically restrained (389). Forty-eight percent of the 123 residents with dementia complicated by depression, delusions, or delirium and 41 percent of the 183 residents with dementia uncomplicated by any of these factors were physically restrained. In contrast, 27 percent of the 58 residents with a mental illness and 13 percent of the 90 residents with neither dementia nor a mental illness were physically restrained. Residents with dementia who also had severe impairments in activities of daily living were much more likely to be physically restrained than residents with dementia who did not have such impairments (61).

A variety of reasons are given for the use of physical restraints for nursing home residents: 1) to protect residents from injury due to falling or wandering; 2) to prevent residents from injuring other residents or staff members; 3) to prevent residents from interfering with their own treatment, for example, by removing feeding tubes or opening wounds; 4) to prevent behavioral problems; 5) to satisfy some residents' families who request that restraints be used, primarily to protect their relative from falling; 6) to protect the nursing home from the risk of being sued for fall-related injuries; and 7) to provide "postural support" or maintain "body alignment,' for example, by keeping a resident from slipping down in his or her chair (133,182,212,300, 311,446). In addition, physical restraints are sometimes used when a nursing home has insufficient staff to adequately supervise residents.

Sometimes physical restraints are also used to punish residents (133,31 1). A telephone survey of a random sample of 577 nurses and nurse aides from 31 nursing homes in New Hampshire found excessive use of restraints was the most frequently mentioned type of resident abuse (348). One-fifth of the nurses and nurse aides said they had observed this type of abuse, and of those who had observed it, two-thirds said they had observed it frequently. Six percent of the nurses and nurse aides reported they had used restraints to punish residents.

Many negative effects of physical restraints have been identified. These negative effects include physiological effects of immobility, such as incontinence, contractures, and loss of bone and muscle mass; increased anxiety and agitation; aggravated behavioral symptoms, such as screaming, hitting, and biting; decreased social behavior and decreased social relationships; demoralization, loss of self--esteem, and emotional withdrawal; and injuries and death due to improper use of the restraints or the residents' attempts to escape from the restraints (3O,l33,l39,l82,2O8,3OO,3O5,383,427,446,49O,498).

A study of 24 agitated nursing home residents with dementia found the use of restraints did not reduce and may have increased their agitation (490). Over the 3-month period of the study, the researchers observed that residents exhibited significantly more agitated behaviors when they were restrained than when they were not. Seven of the 24 residents were restrained more than 50 percent of the day and night. Five of these seven residents exhibited physically aggressive behaviors, such as biting and hitting, while they were restrained. Fifteen of the 24 residents fell at least once during the study period, sometimes while they were restrained. It is not possible to determine from the study data whether they would have fallen more often if they had not been restrained.

As noted earlier, one of the primary objectives of many special care units is to reduce the use of psychotropic medications and physical restraints. Results of studies reviewed in the next chapter suggest that special care units have been successful

in reducing the use of physical restraints but use of psychotropic medications remains high.

Negative Consequences for 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 residents, their families, nursing home staff members who take care of them, and nondemented residents. Inappropriate nursing home care tends to exacerbate the effects of an individual's dementing disease or condition. In many instances, however, it is difficult to distinguish effects of an individual's dementing disease or condition and effects of inappropriate care.

Negative Consequences for Residents With Dementia

Problems in the care provided for nursing home residents with dementia have many negative consequences for the residents. These consequences can be categorized in terms of excess disability, reduced quality of life, reduced physical safety, and reduced access to nursing home care. As noted in chapter 1, excess disability is the discrepancy that exists when a person's fictional impairment is greater than that warranted by the person's disease or condition (47,219). The concept of excess disability implies an individual with dementia has certain impairments in functioning caused directly by his or her dementing disease or condition and other impairments in functioning caused by other factors. One example of excess disability is the increased confusion caused in some persons with dementia by psychotropic medications intended to control their behavior.

Inappropriate nursing home care can cause excess disability in terms of an individual's cognitive functioning, mood, self-care abilities, and behavior. Excess disability in cognitive functioning may be caused, for example, by untreated acute or chronic illness, depression, sensory impairments, or pain, as well as by excessive environmental noise and stimulation and psychotropic medications. Excess disability in behavior maybe caused by inappropriate staff responses to the resident's physical or emotional needs or behavioral symptoms, excessive environmental noise or stimulation, insufficient activities and exercise, use of physical restraints, and other factors. Extreme behavioral responses, referred to as *catastrophic reactions, in* which an individual with dementia becomes acutely agitated, angry, or combative, are often attributed to these factors rather than to an individual's dementing disease or condition (47,274,353,371,385). Although it is difficult in practice to differentiate functional impairments that are or are not warranted by an individual's disease or condition, some of the characteristics of nursing home residents with dementia cited earlier (e.g., the high proportions of residents with impairments in activities of daily living and behavioral symptoms) may be due as much to problems in the care they receive in the nursing home as to their dementing disease or condition (107,1 15,125,165,171,263,353,385,386).

Quality of life is difficult to evaluate in general and particularly difficult to evaluate in individuals with dementia. Poor quality of life is attributed to nursing home residents with dementia when they are observed to be agitated, restless, depressed, crying, screaming, calling out repetitively, and/or extremely withdrawn. In some instances, these reactions are caused by an individual's dementing disease or condition, and in other instances they are caused by inappropriate care (38,107,1 15,125,263).

In addition to excess disability and reduced quality of life, problems in the care provided for nursing home residents with dementia occasionally have drastic consequences in terms of the residents' physical safety. Individuals with dementia sometimes wander away from nursing homes if they are not well supervised and the facility is not locked or otherwise secured. Some of these individuals die before they are found (188).

A final consequence of problems in the care provided for nursing home residents with dementia is reduced access to nursing home care. Nursing home administrators and staff often regard people with dementia as difficult to manage because of their behavioral symptoms and may be reluctant to admit them for this reason. As a result, some individuals with dementia who need nursing home care may not be able to obtain it (109,170,454,520). To the extent that residents' behavioral symptoms are caused or exacerbated by inappropriate care, this access problem is also attributable to inappropriate care.

The reluctance of nursing homes to admit persons with dementia, especially those who are perceived to have behavioral symptoms, was documented in a

1990 report of the General Accounting Office (GAO), *Nursing Homes: Admission Problems for Medicaid Recipients and Attempts To Solve Them (454). The* GAO report was based on interviews with Medicaid and health department officials, long-term care ombudsmen, representatives from nursing home industry associations, advocates for the elderly, hospital discharge planners, and nursing home officials in nine States. The report focuses primarily on the problems Medicaid recipients face when trying to gain admission to nursing homes but also notes the access problems encountered by individuals with dementia. According to the GAO report:

> *Elderly with behavioral problems thought to be caused by Alzheimer's disease or other conditions may have trouble getting into nursing homes whether they are Medicaid recipients or not. Officials in all* nine States indicated that access problems probably exist for these people, but none could estimate the extent of the problems. Residents with Alzheimer's disease often disrupt other nursing home residents. In addition, some Alzheimer's residents have a tendency to wander, making them difficult to manage in nursing homes not specifically designed to allow wandering in a controlled environment. Nursing homes specifically consider behavior during the admissions process, one California advocate explained, and determine how well the individual would fit in with the overall environment of the home. Discharge planners from the Ohio State University Hospital told us that they have trouble placing Alzheimer's patients who are combative or wander. In Mississippi, Alzheimer's residents are considered heavy care residents in a nursing home market oriented toward light care (emphasis added) (454).

It is possible that if residents with dementia received more appropriate nursing home care, they would, in general, be less difficult to care for, and nursing home administrators and staff would be more willing to admit them.

Negative Consequences for the Families of Residents With Dementia

Problems in the nursing home care provided for individuals with dementia also have negative consequences for the residents' families. Many families of individuals with dementia feel intensely guilty and sad about having to place the individuals in nursing homes (45,84,107,128,263,349). Although it might be assumed that family members who have been caring for a person with dementia at home would feel relieved when the person is finally admitted to a nursing home, at least five studies have shown that family members' continue to feel guilty, sad, anxious, and stressed (152,341,349,424,516). These feelings are probably due primarily to the patient's condition and other factors that have made nursing home placement necessary, but the feelings are undoubtedly intensified if the family perceives that the individual is receiving inappropriate or poor-quality care. Families are particularly likely to be anxious if they believe the nursing home staff members are not knowledgeable about dementia (84,162,263).

Other negative consequences for families arise because of the failure of many nursing homes to recognize and respond to families' needs. Nursing homes generally focus their efforts on the residents and may ignore families and fail to involve them sufficiently in the residents' care (349). Families of nursing home residents with dementia generally want to be involved in the individuals' care (46,166,418). Since many of the primary caregiving functions have been assumed by the nursing home, family members may be uncertain about their role. In some instances, a competitive or adversarial relationship develops between the family and the staff, with negative consequences for the family, the resident, and the staff (45,50,55).

Visiting is frequently more difficult for families of nursing home residents with dementia than for families of other nursing home residents (45,125). Although families of residents with dementia generally visit regularly, at least two studies have found their visits are shorter and less enjoyable than the nursing home visits of families of nondemented residents (310,515). If the nursing home fails to recognize and respond to this problem, families may visit less often, again with negative consequences for everyone involved.

Negative Consequences for Nursing Home **Staff** Members

As noted earlier, individuals with dementia are often difficult for nursing home staff members to manage because of their behavioral symptoms (107,167,170,181,191,263,352,359,385). Staff members are most likely to be disturbed by verbally or physically aggressive and demanding behaviors (134,191,506). Other resident behaviors that are disturbing to nursing home staff members are

resistance to care, wandering, repetitive questions, agitation, crying, and withdrawal.

The difficulty of caring for residents with dementia causes stress, lowered morale, and burnout for some, and perhaps many, nursing home staff members (191,263,346,352,398). These staff responses may in turn lead to increased absenteeism and staff turnover. To the extent that residents' behavioral symptoms are caused or exacerbated by inappropriate nursing home care, the job of staff members is unnecessarily difficult. Any resulting absenteeism or staff turnover is unnecessary in the same sense.

Negative Consequences for Nondemented Nursing Home Residents

Nondemented nursing home residents may also experience negative consequences because of problems in the care provided for residents with dementia. Behavioral and psychiatric symptoms of residents with dementia, e.g., agitation, restlessness, screaming repetitive verbalizations, and combativeness, are upsetting for nondemented residents (46,220,263,268,352,373). The cognitive and functional impairments of residents with dementia may also be bothersome to nondemented residents. To the extent that these problems are caused or exacerbated by inappropriate care, they unnecessarily reduce the quality of life of nondemented residents.

There is disagreement about the overall impact on nondemented nursing home residents of living in close proximity with demented residents (270,398). Some commentators argue nondemented residents benefit overall from living in close proximity with demented residents, primarily because of bonding, the potential for mutual assistance, and reduced staff expectations for the nondemented residents (69,486,503). other commentators argue that nondemented residents are harmed overall by living in close proximity with nondemented residents and that it is unfair to nondemented residents to be placed in a 24-hour living situation with someone with dementia (1,148,220,354,373,510).

The two studies OTA is aware of that address this issue indicate nondemented nursing home residents who live in close proximity to residents with dementia have significantly reduced mental and emotional status and reduced social interactions. Wiltzius et al. compared the mental and emotional status of 20 nondemented nursing home residents before and 2 weeks after they were moved into a room with a demented resident (507). Two of the 20 nondemented residents showed signs of cognitive decline after the move; 17 of the 20 residents expressed feelings of depression and loneliness; 12 expressed feelings of anxiety and insecurity over having a roommate who was confused; and 5 were judged by staff members to be less friendly and more irritable after the move. In contrast, 2 of the 20 residents became more friendly and expressed concern for their demented roommate. The control group did not show similar changes over the 2-week period, but it is not clear from the study report whether the control group members were moved at the beginning of the study.

Teresi et al. compared the mental and emotional status and other characteristics of 72 nondemented nursing home residents, one-third of whom shared a room or lived in a room adjacent to a demented resident (438). After 6 months, the nondemented residents who shared a room or lived in a room adjacent to a demented resident were significantly more likely than the other nondemented residents to express dissatisfaction with life in general, the unit, their room, their roommate, and the amount of noise in the room. They were significantly more likely to be perceived as depressed by staff members and significantly less likely to receive visits or phone calls from family or friends.

It is unclear whether the negative outcomes for nondemented residents in these two studies are attributable to characteristics of the demented residents that are caused by their dementing illness or to characteristics that are caused by problems in the nursing home care they receive. In either case, placing the demented and nondemented residents in separate units would eliminate the cause of the problems. As discussed in chapter 1, some commentators believe placing individuals with dementia in special care units may be justifiable solely on the grounds that it benefits nondemented residents, assuming the placements do not harm the demented residents.

Summary

Complaints and concerns about the quality and appropriateness of the care provided for nursing home residents with dementia by most nursing homes are pervasive. In comparison with the prob-

lems identified by the Institute of Medicine in its 1986 report on nursing home care for all types of residents, complaints and concerns about the care provided for residents with dementia focus more on lack of staff knowledge about how to respond to residents' behavioral symptoms and physical aspects of nursing homes that are perceived to be inappropriate for individuals with dementia (e.g., lack of cues to help residents find their way and lack of appropriate space for residents to wander). Both the Institute of Medicine's report and the literature on nursing home care for persons with dementia cite overuse and inappropriate use of psychotropic medications and physical restraints. Although these problems affect all nursing home residents to some degree, they are more likely to affect residents with dementia.

Problems in the care of nursing home residents with dementia have negative consequences for the residents, their families, nursing home staff members, and nondemented nursing home residents. Inappropriate nursing home care tends to exacerbate the effects of an individual's dementing disease or condition. In particular instances, however, it may be difficult to differentiate effects of an individual's dementing disease or condition and effects of inappropriate care.

Inappropriate nursing home care can cause excess disability in terms of a resident's cognitive functioning, mood, self-care abilities, and behavior. To the extent that inappropriate care causes excess disability, it makes the job of nursing home staff members more difficult and may therefore be indirectly responsible for increasing staff stress, absenteeism, and turnover. Likewise, to the extent that inappropriate care causes or exacerbates the cognitive deficits and mood and behavioral symptoms of residents with dementia, it may be indirectly responsible for reducing the quality of life of nondemented residents who live with or near demented residents.

CONCLUSION

A very large number and proportion of nursing home residents have dementia, although many of them do not have a diagnosis of dementia in their medical records. Compared with nondemented nursing home residents, residents with dementia are, on average, older, more functionally impaired, and more likely to have depressive, psychotic, and behavioral symptoms. On the other hand, nursing home residents with dementia are also diverse. According to national surveys, 5 percent of nursing home residents with dementia are under age 65; 4 to 46 percent do not have impairments in activities of daily living, depending on the specific activity; 30 percent do not have depressive symptoms; 64 percent do not have psychotic symptoms; and 40 percent do not have behavioral symptoms. Some are physically healthy except for their dementia, and others have many diseases and physical impairments in addition to their dementia.

For policy purposes, it is important to note that the diversity of nursing home residents with dementia makes it unlikely any particular type of unit will be appropriate for all these individuals. With respect to the long-range possibilities for special care units discussed in chapter 1, it is also important to note that placing all nursing home residents with dementia in special care units would not eliminate residents with behavioral symptoms from nonspecialized units since more than one-third of nursing home residents with behavioral symptoms are not demented.

Special care units have been developed primarily in response to perceived problems in the care provided for residents with dementia in many nursing homes. Some of these problems affect all nursing home residents and others affect primarily residents with dementia. Even if the problems that affect all nursing home residents were solved, some problems that affect primarily residents with dementia would remain. These problems include lack of cues to help residents find their way, lack of appropriate space for residents to wander, and lack of specific staff training about methods of caring for individuals with dementia, including appropriate methods of responding to residents' behavioral symptoms.

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, nursing home staff, and nondemented residents. Better care can only alleviate impairments not directly or inevitably caused by an individual's dementing disease or condition. Likewise, better care for residents can only lessen that portion of family members' feelings of guilt, sadness, and anxiety due to inappropriate care, not the portion of those feelings caused by a resident's impairments or

deteriorating condition. Similar considerations apply to the potential impact of better care on nursing home staff members and nondemented residents. Research findings with respect to the outcomes of special care units should be evaluated with these considerations in mind.

Chapter 3

Special Care Units For People With Dementia: Findings From Descriptive Studies

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Chapter 3

Special Care Units For People With Dementia: Findings From Descriptive Studies

INTRODUCTION

Much of the existing literature on special care units consists of reports about an individual unit. These reports usually describe the physical design features, patient care philosophy, activity programs, and other characteristics of the unit that make it special in the view of the report authors. The reports often present anecdotal evidence of the positive outcomes of the unit and advocate the development of more special care units like the one being described.

Descriptive reports on individual special care units are interesting in that they convey the authors' commitment to providing better care for individuals with dementia and the authors' perceptions about what constitutes appropriate nursing home care for these individuals. On the other hand, the anecdotal evidence presented in these reports about the positive outcomes of individual special care units is not adequate to evaluate their effectiveness. Moreover, many of the descriptive reports on individual special care units do not provide enough detailed information about the characteristics of the units to allow a meaningful comparison of different units.

Research on special care units is in an early stage, but in the past few years, a number of studies of special care units have been conducted. Some of the studies are descriptive, and others are evaluative. The descriptive studies provide information about the number and characteristics of special care units nationally and in certain geographic areas and about the similarities and differences among special care units and between special care units and nonspecialized nursing home units. The evaluative studies attempt to measure the effectiveness of one or more special care units in terms of changes in aspects of their residents' condition and functioning over time.

This chapter discusses what is known about special care units from the available descriptive studies. Chapter 4 discusses the findings of the available evaluative studies. The findings of these studies are discussed in some detail because they provide a basis for informed policy decisions about the development of special regulations and reimbursement for special care units, about the need for and content of consumer education materials on special care units, and about the future direction and level of government support for research on special care units.

Table 3-6 at the end of this chapter lists OTA's conclusions from the descriptive studies discussed in the chapter. (An identical list appears in table 1-2 inch. 1). Probably the most important conclusion for policy purposes is the diversity of existing units. It is also clear from available studies that although most special care units have a method of locking or otherwise securing the unit, many units do not incorporate the other physical design features recommended in the special care unit literature. Moreover, at least one-quarter of existing units report they do not provide special training for their staff members. On the positive side, physical restraints are used far less in special care units than in other nursing home units. On average, special care units also have fewer residents and more staff members per resident than other nursing home units, and special care unit residents are probably more likely than individuals with dementia in nonspecialized units to participate in activity programs.

TYPES OF DESCRIPTIVE STUDIES OF SPECIAL CARE UNITS

Descriptive studies of special care units include studies of three types:

. studies of nursing homes that include questions about special care units,
. studies that compare selected special care units, and
. studies that compare selected special care units and selected nonspecialized nursing home units.

Tables 3-la, 3-lb, and 3-lc list the descriptive studies of each type for which conclusions are currently available at least in draft form. To OTA's knowledge, these tables include all such studies. For each study, the tables identify the citation, the year the study was conducted, the source of funding for the study if given in the study report, and the general method of the study. The following sections review

Table 3-I—Descriptive Studies of Special Care Units

a. Descriptive Studies of Nursing Homes That Include Questions About Special Care Units

Citation	Year of the study	Funding source	Method of the study
Hepburn et. al., 1988	1986	No funding source reported	Mail survey of all 438 licensed nursing homes in Minnesota, with a 76 percent response rate.
Holmes et al., 1992	1990	See note below	Mail and telephone survey of all nursing homes in 5 northeastern States (Connecticut, Massachusetts, New Jersey, New York, and Pennsylvania), with an 81 percent response rate.
Leon et. al., 1990	1987	Agency for Health Care Policy and Research	On-site survey of a nationally representative sample of 759 nursing homes, using questionnaires and face-to-face interviews with facility administrators and staff.
Mayers and Block, 1990	1989	No funding source reported	Mail survey of all 305 nursing homes in Washington State, with a 50 percent response rate.

b. Descriptive Studies That Compare Selected Special Care Units

Cairl et. al., 1991	1990	Administration on Aging	Study comparing 13 nursing home special care units in 10 counties in west central Florida, using an interview schedule for face-to-face interviews with facility staff.
Hyde, 1989	not reported	University of Massachusetts, Gerontology Institute	Study of 7 nursing home special care units in eastern Massachusetts, using a semi-structured interview schedule.
Knoefel, unpublished manuscript	1989	Department of Veterans Affairs	Study of 5 special care units in VA and nonVA facilities, using chart reviews and an interview schedule.
Mace, 1991	1988-1989	No funding source reported	Mail survey of 12 nursing home special care units.
Ohta and Ohta, 1988	not reported	No funding source reported	Study of 16 nursing home special care units, using published and unpublished reports, facility manuals, and site visits.
Weiner and Reingoid, 1989	1985-1986	Partial funding from the Brookdale Foundation	Mail survey of 22 nursing home special care units and several specialized programs in other settings.
White and Kwon, 1991	1987	Oregon State University	Mail survey of 99 nursing home special care units in 34 States.

c. Descriptive Studies That Compare Selected Special Care Units and Selected Nonspecialized Nursing Home Units

Lindman et al., 1991	1990	California Department of Health Services	Study comparing 11 individuals with dementia in 2 nursing home special care units, 11 individuals with dementia in nonspecialized units in 2 nursing homes, and 8 individuals with dementia in 2 residential care facilities, using chart reviews, questionnaires, and patient observation.
Mathew et. al., 1988	Not reported	No funding source reported	Study comparing 13 individuals with dementia in one nursing home special care unit and 34 individuals with dementia in nonspecialized units in 2 nursing homes, using chart reviews and patient observation and examination.
Rovner et. al., no date	Not reported	No funding source reported	Study comparing 19 individuals with dementia in one nursing home special care unit and 20 individuals with dementia in nonspecialized units of the same nursing home, using chart reviews and patient observation and examination.
Sloane et. al., 1990	1987-1989	Alzheimer's Association	Study comparing 10 individuals with dementia in each of 31 nursing home special care units and 32 nonspecialized nursing home units in 5 States, using chart reviews, questionnaires, and patient observation.
Riter and Fries, 1990 1992		Health Care Financing Administration	Study comparing 127 individuals with dementia in 10 nursing home special care units and 103 individuals with dementia in nonspecialized units in the same nursing homes, using chart reviews, questionnaires, and patient observation.

NOTE: Thisstudywasoonducted by researchers atthe Hebrew Home forthe Aged to obtain information about special care units in five States that would allow them to identify a sample of units for their study of the impact of special care units; the latter study is funded by the National Institute on Aging, but no findings are yet available from it.

SOURCE: Office of Technology Assessment, 1992.

the findings of these studies with respect to the number of nursing homes with a special care unit, the characteristics of these nursing homes, the characteristics of the special care units, and the characteristics of their residents.

In 1991, researchers at George Washington University in Washington, DC, mailed a questionnaire about special care units to more than 17,000 nursing homes nationwide (246). Results of this survey with respect to the number of nursing homes that have a special care unit are noted in the following section. As of May 1992, the other findings of the survey were still being analyzed. Once available, these findings will greatly expand existing information about special care units. OTA is aware of two other sources of forthcoming descriptive information about special care units which are described in the last section of the chapter.

NUMBER OF NURSING HOMES THAT HAVE A SPECIAL CARE UNIT

Five studies conducted between 1987 and 1991 provide information about the number and proportion of nursing homes that have a special care unit. The five studies are discussed in this section. Because of differences among the studies and definitional questions, no firm conclusion can be drawn at this time about the number or proportion of nursing homes that have a special care unit. Based on the results of the two most recent studies, OTA estimates that in 1991, 10 percent of all nursing homes in the United States had a special care unit. This proportion varies among States, and at least in some States, it includes nursing homes that group some of their residents with dementia in *clusters in* **units that also serve** nondemented residents, rather than placing the residents in an entirely separate special care unit.

The 1987 National Medical Expenditure Survey conducted by the Agency for Health Care Policy and Research is, thus far, the only study of a nationally representative sample of nursing homes that has included questions about special care units. The sampling frame for the study was 22,064 nursing homes and personal care homes, including all Medicare and Medicaid-certified nursing homes and all State-licensed and otherwise officially recognized nursing and personal care homes that: 1) have three or more beds, 2) provide personal care, and 3) are not primarily facilities for the mentally ill or mentally retarded. Eight percent of the 759 facilities in the survey sample reported having a special care unit (249). Extrapolated to the 22,064 facilities in the sampling frame, this finding indicates that 1668 nursing and personal care homes in the U.S. had a special care unit in 1987. These units were estimated to contain more than 53,000 beds.

The 1987 National Medical Expenditure Survey also found that many nursing and personal care homes had plans to establish a special care unit. The survey data indicate that in 1987, 1444 facilities that did not have a special care unit intended to establish one by 1991. Moreover, 535 of the facilities that already had a special care unit planned to expand their unit by 1991. If all these plans had materialized, more than 3100 nursing and personal care homes (14 percent of the facilities in the survey sampling frame) would have had a special care unit by 1991, and these units would have contained almost 100,000 beds.

When published in 1990, the figures from the 1987 National Medical Expenditure Survey were much higher than any previous estimates, but they were generally accepted as accurate. A few public officials and other individuals in some States told OTA informally that they did not believe as many as 8 percent of the nursing homes in their State had a special care unit in 1987 or that 14 percent would in 1991. Data from the 1987 National Medical Expenditure Survey cannot be broken down by State (246), so the survey data cannot be used to determine the number or proportion of nursing homes in particular States that have a special care unit. The data do show that the proportion of nursing homes with a special care unit varies in different regions of the country, and findings of several studies discussed below indicate the proportion varies by State.

To OTA's knowledge, four studies have attempted to survey all nursing homes in a given geographic area and thus to determine the total number of nursing homes that have a special care unit in that area. One of the four studies, a mail survey conducted from 1989 to 1990 of all 305 nursing homes in Washington State found that only 3 percent of the 154 facilities that responded to the survey (or about 1.5 percent of all nursing homes in the State) reported having a special care unit (294).

A 1986 mail survey of all 438 nursing homes in Minnesota found that 7 percent of the 332 facilities

that responded to the survey reported having a special care unit (18 1). An additional 7 percent of the responding facilities reported they planned to establish a special care unit in the next 2 to 3 years. If these plans had materialized, 14 percent of the responding facilities (or 11 percent of all nursing homes in Minnesota) would have had a special care unit by 1988 or 1989.

In 1990, researchers at the Hebrew Home for the Aged in Riverdale, NY, mailed a questionnaire about special care units to all nursing homes in five northeastern States (194). Seven percent of the 2370 nursing homes in the 5 States reported having at least one special care unit. An additional 5 percent of the nursing homes reported that although they did not have a special care unit, they did place some of their residents with dementia in clusters in units that also served nondemented residents. Thus, a total of 12 percent of the facilities reported using some method to physically group residents with dementia-either in a special care unit or in a cluster in units that also serve nondemented residents. A telephone followup to a random sample of 150 of the nursing homes found that in 15 of the facilities (10 percent), the nursing home administrator and the director of nursing disagreed about whether their facility had a special care unit. The researchers reduced their previous estimate to eliminate these questionable units. Their conservative conclusion is that in 1990, 11 percent of all nursing homes in the 5 States had at least one special care unit or cluster unit.

As noted earlier, in 1991, researchers at George Washington University mailed a questionnaire about special care units to about 17,000 nursing homes nationwide, including all nursing homes thought to have 30 or more beds and to serve primarily elderly people. After the elimination of facilities that had closed or did not meet these criteria, there were 15,490 potential respondents (246). Four thousand questionnaires were completed and returned. The researchers telephoned most of the nursing homes that did not return the questionnaire. As of May 1992, information was available on more than 14,000 nursing homes (90 percent of all nursing homes in the sampling frame). Based on this information, the researchers concluded that in 1991, 1463 nursing homes had a special care unit or a special program for residents with dementia. Ninety percent of the 1463 nursing homes with a special care unit or special program reported the unit or program was in a physically distinct part of the facility. If only these nursing homes are counted as having a special care unit, 1318 nursing homes (9 percent of all nursing homes in the sampling frame) had a special care unit in 1991.

The George Washington University survey found great differences among States in the proportion of nursing homes in the State that had a special care unit or special program for residents with dementia (247). Preliminary analysis of the data shows that in some States a surprisingly high proportion of nursing homes reported having a special care unit or special program for residents with dementia: 36 percent of the nursing homes in Arizona and 27 percent of the nursing homes in Utah reported having such a unit or program.

The George Washington University survey also found that many of the nursing homes that did not have a special care unit in 1991 planned to establish one, and some of the nursing homes that did have a special care unit planned to expand it (247). Preliminary analysis of the survey data shows that 1000 to 1600 of the nursing homes (6 to 10 percent of all nursing homes in the sampling frame) planned to establish a new special care unit or expand their existing unit.

For several reasons, the results of the five studies described in this section are not precisely comparable. First, the studies sampled different types of facilities (i.e., nursing homes and personal care homes, all nursing homes, or nursing homes with more than 30 beds). Second, the studies identified different types of units (i.e., special care units and cluster units), and some of the studies also included special programs. Third, the studies covered different geographic areas. Lastly, the studies were conducted over a 4-year period during which the number and proportion of nursing homes with a special care unit undoubtedly increased.

The preliminary estimate from the 1991 George Washington University survey and the conclusion of the 1990 survey of all nursing homes in 5 northeastern States show that 9 to 11 percent of the nursing homes had a special care unit, a cluster unit, or a special program for residents with dementia. Almost half the units identified in the 1990 survey of all nursing homes in five northeastern States were cluster units (194). It is unclear whether the 1463 special care units and special programs identified in the George Washington University survey include cluster units, and if so, how many.

The biggest discrepancy in the findings of the five studies is between the total number of special care units and special programs identified by the 1987 National Medical Expenditure Survey (1668 units and programs) and the total number identified in the 1991 George Washington University survey (1463 units and programs). These figures suggest there was a decrease in the number of special care units and programs between 1987 and 1991, a highly unlikely conclusion. The figures lend themselves to two other explanations:

1. the 1987 National Medical Expenditure Survey overestimated the number of special care units, and
2. the 1991 George Washington University study underestimated the number of special care units.

One or both of these explanations could be correct.[1]

The 1987 National Medical Expenditure Survey and the 1991 George Washington University survey asked about special care units *and* special programs. The researchers who worked on the special care unit portion of the 1987 National Medical Expenditure Survey concluded on the basis of the survey findings and the results of other studies that virtually all the facilities that reported having a special care unit or a special program in 1987 had at least one special care unit (246). As noted earlier, 90 percent of the 1463 nursing homes identified in the 1991 George Washington University survey as having a special care unit or program reported their unit or program was in a physically distinct part of the facility. If only these nursing homes are counted as having a special care unit, the discrepancy between the findings of the 1987 and 1991 surveys is bigger and more difficult to explain.

An obvious obstacle to developing accurate figures on the number of nursing homes with a special care unit is the lack of a standard definition of the term *special care unit.* All the figures cited in this section are based on self-report, and most reflect the opinions of the nursing home administrators and other survey respondents about what a special care unit is. The 1990 survey of all nursing homes in 5 northeastern States found that only 49 percent of the nursing homes that placed their residents with dementia in a separate unit and only 12 percent of the nursing homes that placed their residents with dementia in clusters in nonspecialized units used the term "special care" for these arrangements (194). Moreover, as noted earlier, in 10 percent of the 150 facilities contacted by telephone, the nursing home administrator and the director of nursing disagreed about whether their facility had a special care unit.

Having a standard definition of the term *special care unit* would facilitate the development of accurate figures on the number of nursing homes with a unit that met that definition. On the other hand, units that did not meet the definition would not be counted. Since research on special care units is in an early stage, it is important not to define away care arrangements that may turn out to be variants of special care units. In this context, it should be noted that the first information about the large number of cluster units in some States was derived from a study that deliberately did not define the term *special care unit* and instead asked a very broad question about the "types of living arrangements available for cognitively impaired (demented) residents' in the facility (177). Although cluster units do not meet some definitions of the term *special care unit,* information on cluster units presented later in this chapter shows that significant proportions of these units incorporate features said to be important in special care units (e.g., physical design features, special staff training, staff support groups, family support groups, and formal admission and discharge criteria).

In summary, findings of the 1987 National Medical Expenditure Survey indicated that 8 percent of all nursing homes had a special care unit in 1987 and that if plans reported in 1987 materialized, 14 percent of all nursing homes would have a special care unit in 1991. Results of several studies conducted since 1987 suggest the figures from the 1987 National Medical Expenditure Survey overestimate the number and proportion of nursing homes that had a special care unit in 1987 and the number and proportion that would have a special care unit by 1991. Based on available data, OTA estimates that in 1991, 10 percent of nursing homes in the United States had a special care unit. This proportion varies in different States, and in at least some States, it

[1] Another theoretically possible but unlikely explanation is that many of the special care units included in the 1987 figure are in personal care homes or nursing homes with fewer than 30 beds which were included in the 1987 National Medical Expenditure Survey but not in the 1991 George Washington University survey.

includes nursing homes that group some of their residents with dementia in clusters in units that also serve nondemented residents.

CHARACTERISTICS OF NURSING HOMES THAT HAVE A SPECIAL CARE UNIT

Nursing homes that have a special care unit differ from other nursing homes in their ownership, certification status, size, and geographic location. Table 3-2 presents information from the 1987 National Medical Expenditure Survey on each of these characteristics for all nursing homes and personal care homes in the survey sample, for the nursing and personal care homes that reported having a special care unit in 1987, and for the nursing and personal care homes that reported they would have a special care unit by 1991 (248). Other sources of information about the characteristics of nursing homes with a special care unit are the 1986 survey of nursing homes in Minnesota (181), the 1990 survey of all nursing homes in 5 northeastern States (194), and a University of North Carolina study conducted from 1987 to 1989 that compared 31 randomly selected special care units and 32 matched nonspecialized units in 5 States (413).

Ownership

As shown in table 3-2, the National Medical Expenditure Survey found that 60 percent of the nursing and personal care homes that reported having a special care unit in 1987 were privately owned, for-profit facilities; 21 percent were privately owned, nonprofit facilities, and 19 percent were publicly owned (249). The proportion of for-profit facilities that reported having a special care unit in 1987 (60 percent) was smaller than might be expected, given that 73 percent of all facilities in the survey sample were for-profit facilities. In contrast, the proportion of publicly owned nursing homes that reported having a special care unit (19 percent) was greater than might be expected, given that only 5 percent of all facilities in the survey sample were publicly owned.

Table 3-2-Characteristics of Nursing Homes That Had a Special Care Unit in 1987 or Planned To Have a Special Care Unit by 1991, United States, 1987

	Number of nursing homes			Number of nursing home beds		
Characteristic of facilities	Total	with a special care unit in 1987	with a special care unit by 1991	Total	In special care units in 1987	In special care units by 1991
Totals	22,064	1,668	3,112	1,645,861	53,798	99,698
	Percent of total			Percent of total		
Ownership						
For profit,	73%	60%	57%[a]	67%	69%	51%
Independent	35	27	28	24	31	21
Multi-facility	38	33	29	44	38	29
Nonprofit	23	2 1[b]	28	24	18	38
Public	5	19b	15	9	13[b]	1 2[b]
SNF Certification						
Yes	40	75[a]	70[a]	64	*76*	81
No	60	25[a]	30[a]	36	*24*	19'
Facility size (number of beds)						
<1oo	69	45	47a	36	34	41
100-149	20	28	26	32	32	24
150+	11	26[a]	27a	32	34	36
Region						
Northeast	19	27	30	22	*22*	20
Mideast	29	16[a]	22	31	18[a]	29[a]
South	30	22	23	30	*23*	21
West	22	37	26	17	37a	29

[a]Statistically significant in comparison to the total column.
[b]Relative standard error X30 percent.

SOURCE: J. Leon, D. Potter, and P. Cunningham, "Availability of Special Nursing Home Programs for Alzheimer's Disease Patients," *American Journal of Alzheimer's Care and Related Disorders and Research 6(1):2-11,* 1991.

In terms of bed capacity, 69 percent of the special care unit beds were in for-profit facilities in 1987; 18 percent were in nonprofit facilities, and 13 percent were in publicly owned facilities (see table 3-2). Thus, the proportion of special care unit bed capacity in for-profit facilities (69 percent) was about the same as would be expected, given that 67 percent of all bed capacity was in for-profit facilities. Special care unit bed capacity in publicly owned facilities (13 percent) was slightly greater than would be expected, given that only 9 percent of all bed capacity was in publicly owned facilities.

The greatest growth in special care units and special care unit bed capacity from 1987 to 1991 was projected to occur in nonprofit facilities. Whereas in 1987,21 percent of special care units and 18 percent of special care unit beds were in nonprofit facilities, by 1991, 28 percent of special care units and 38 percent of special care unit beds were projected to be in nonprofit facilities (see table 3-2).

In 1987, about one-third of all special care units and 38 percent of all special care unit beds were in nursing homes owned by multi-facility corporations (see table 3-2). These proportions were projected to decrease slightly by 1991. The Hillhaven Corp. of Takoma, WA, the Nation's second largest multi-facility nursing home corporation, was probably the first such corporation to establish special care units for persons with dementia. As of late 1990, 56 Hillhaven-owned nursing homes had a special care unit, and these special care units contained 1283 beds (337).

OTA contacted a few other multi-facility nursing home corporations to find out how many of the nursing homes they own have a special care unit. Manor Care Corp. of Silver Spring, MD, reported that as of late 1990, 51 of its nursing homes had a special care unit (157). ARA Living Centers of Houston, TX, reported 35 of its nursing homes had a special care unit (3). Unicare Health Facilities of Milwaukee, WI, reported 15 of its nursing homes had a special care unit (374).

Data from the 1987 National Medical Expenditure Survey indicate that by 1991, multi-facility nursing home corporations planned to have more than 900 nursing homes with a special care unit. If these plans had materialized, the four corporations just mentioned would account for only 17 percent (157 out of 900) of all such nursing homes. These figures indicate that ownership of special care units is not dominated by a small number of multi-facility nursing home corporations.

A 1989 survey by the U.S. Department of Veterans Affairs (VA) found that 31 of the 172 VA medical centers nationwide had one or more special care units (159). The VA has issued no formal department-wide policies on special care units. Thus, the special care units identified in&e survey were established entirely on the initiative of the individual VA medical centers. The 31 units identified by the 1989 survey were in acute care hospital units, intermediate care units, and long-term care units (103).

Certification Status

According to the 1987 National Medical Expenditure Survey, nursing homes that were certified by Medicare or Medicaid as skilled nursing facilities (SNFs) were far more likely than other nursing homes to have a special care unit (248). As shown in table 3-2, this pattern was projected to continue to 1991. A telephone survey of all nursing homes in five States conducted in 1987 and 1988 also found SNFs were more likely than other nursing homes to have a special care unit (413).[2]

Nursing Home Size

As shown in table 3-2, larger nursing and personal care homes are far more likely than smaller facilities to have a special care unit. This finding from the 1987 National Medical Expenditure Survey agrees with the results of the 1986 survey of nursing homes in Minnesota which found that 18 percent of nursing homes with more than 100 beds had a special care unit, compared with only 2 percent of nursing homes with less than 100 beds (181). The University of North Carolina study of 31 randomly selected special care units in 5 States found the nursing homes with a special care unit had an average of 192 beds, compared with an average of 92 beds for all U.S. nursing homes (413). The 1990 study of all nursing homes in 5 northeastern States found that nursing homes with a special care unit had an

2 The SNF category for *Medicaid* certification of nursing homes was eliminated in 1990 due to the implementation Of certain provisions of the Omnibus Budget Reconciliation Act of 1987 (OBRA-87). As a result, the distinction between SNFs and other nursing homes will not be important in future special care unit research.

average of 251 beds, compared with an average of 166 beds for nursing homes with a cluster unit, and 130 beds for nursing homes without either a special care unit or a cluster unit (194).

Nursing Home Location

According to the 1987 National Medical Expenditure Survey, nursing and personal care homes in the West were more likely than nursing and personal care homes in other regions of the country to have a special care unit (248). As shown in table 3-2, 22 percent of all the facilities and 37 percent of the facilities with a special care unit were in the West. In contrast, 29 percent of all the facilities but only 16 percent of the facilities with a special care unit were in the Midwest. Projections for 1991 suggested special care units would be more evenly distributed across the regions.

CHARACTERISTICS OF SPECIAL CARE UNITS

Existing special care units are extremely diverse. Descriptive studies show that special care **units vary in the** number of residents they serve, their patient care philosophies and goals, physical design and other environmental features, staff composition and training, staff-to-resident ratios, provision of staff support groups, activity programs, programs for families, use of psychotropic and other medications, use of physical restraints, admission and discharge policies and practices, and cost. Findings in each of these areas are discussed in the following sections.

Each of the descriptive studies listed in tables 3-la, 3-lb, and 3-lc provides some information about the characteristics of existing special care units. The four nursing home surveys that have included questions about special care units (see table 3-la) provide information about certain characteristics of the units. With the exception of the 1990 survey of all nursing homes in five northeastern States (194), however, these nursing home surveys have included very few questions about special care units, beyond asking whether the facility has such a unit.

The seven studies that compare selected special care units (see table 3-lb) provide much more comprehensive information about the units. The findings of these studies are particularly useful in pointing out the diversity of existing units. On the other hand, none of the studies used a random sample of special care units, so their findings with respect to the proportion of units with certain characteristics are less useful. Even the findings of studies with large sample sizes, e.g., White and Kwon's findings based on a sample of 99 special care units (492), cannot be generalized to all special care units since they are based on nonrandom samples.

The five studies that compare selected special care units and selected nonspecialized nursing home units (see table 3-lc) are useful in identifying characteristics that distinguish the two types of units. Three of these studies have very small samples (1 to 2 special care units and 1 to 4 nonspecialized units) (256,292,391). The other two studies have much larger samples (382,413). The study done by researchers at the University of North Carolina is especially valuable because the special care units were randomly selected from all special care units in the five States studied (413).

Number of Residents

It is often said that nursing home residents with dementia can be better cared for in small rather than large groups, and some commentators have suggested 8 to 20 residents may be ideal (63,93,109). Studies of nonrandom samples of special care units show the number of residents in individual units varies greatly. The 16 special care units studied by Ohta and Ohta had from 10 to 49 residents (332). The 7 special care units studied by Hyde had from 12 to 41 residents (199), and the 12 special care units studied by Mace and Coons had from 8 to 47 residents (275). Although these ranges are wide, some of the units clearly had a very small number of residents (8 to 12 individuals). The 1990 survey of all nursing homes in 5 northeastern States found that special care units had an average of 37 beds (194).

Data from the University of North Carolina study of 31 randomly selected special care units and 32 matched nonspecialized nursing home units show that on average the special care units had fewer residents than the nonspecialized units (36 vs. 59 residents, respectively) (413). The special care units also had fewer rooms and a larger proportion of private rooms—i.e. rooms for only one resident.

Age of the Units

Available data indicate most special care units have been established since 1983, although a few

units have been in operation much longer. The Minnesota nursing homes with a special care unit in 1986 reported that the units had been in operation for an average of 2 years (181). Likewise, the 31 special care units included in the University of North Carolina study conducted from 1987 to 1989 had been in operation an average of 4.6 years: the special care units in nonprofit facilities had been in operation twice as long as the special care units in for-profit facilities (6 years vs. 3 years, respectively) (413). On the other hand, one of the 31 special care units in the University of North Carolina study had been in operation for 25 years. Likewise, the samples of special care units studied by Weiner and Reingold and White and Kwon each included one unit that had been in operation for 20 years (485,494).

Patient Care Philosophies and Goals

None of the descriptive studies that have used a random sample of special care units or attempted to survey all nursing homes in a given geographic area has addressed the question of the units' patient care philosophies or goals.[3] Four studies that used nonrandom samples have addressed this question (64,199,332,485). Based on a nonrandom sample of 22 special care units, Weiner and Reingold identified nine goals of the units (485). The nine goals are:

1. to provide a safe, secure, and supportive environment for residents with dementia;
2. to reduce feelings of anxiety and confusion through environmental and communication support;
3. to help residents reach or maintain optimal levels of physical and cognitive functioning;
4. to provide holistic patient care;
5. to offer staff members understanding, training, education, and freedom from excessive stress;
6. to recognize that individuals with dementia are entitled to experiences and activities that will enhance the quality of their lives;
7. to recognize that individuals with dementia are autonomous and can expect that their special needs and those of their families will be met with sensitivity and appropriateness;
8. to provide patients with opportunities to succeed, which will build their sense of self--esteem, dignity, and hope, and
9. to improve the environment and community of nondemented residents of the facility (485).

The number of units that professed each of these goals and the mix of goals for individual units was not noted in the study report.

Several topologies of special care units have been proposed based on the units' philosophy and goals. These topologies point out one facet of the diversity of existing units. From their study of a nonrandom sample of 16 special care units, Ohta and Ohta identified three types of special care units based on the units' goals: 1) units that have as their primary goal to meet residents' physical care needs; 2) units that have as their primary goals to maintain residents' ability to perform activities of daily living to the greatest extent possible and to minimize memory impairments and behavioral symptoms; and 3) units that have as their primary goal to maintain residents' quality of life, while also maintaining their ability to perform activities of daily living and minimizing their memory impairments and behavioral symptoms (332).

Another typology based on the philosophy and goals of a nonrandom sample of seven special care units posited two types of units: 1) units that adopt a medical model of care and focus primarily on hygiene and physical aspects of care; and 2) units that focus more on psychosocial aspects of care, including continuity with a resident's family and previous life (199). The author of this study also distinguished between special care units that have as a goal to maintain their residents' functioning to the greatest extent possible, with the expectation that some residents' functioning might improve and, in contrast, special care units that emphasize the progressive nature of most diseases that cause dementia and have as a goal to allow the residents to decline over time with as much comfort and dignity as possible.

Lastly, from their study of a nonrandom sample of 13 special care units in Florida, Cairl et al. identified two types of units: 1) units in which the primary goal was behavior management-that is, to reduce resident anxiety, wandering, and behavioral symptoms, and 2) units in which the primary goal was to maximize residents' functioning while preserving their individual dignity (64).

[3] The 1991 George Washington University surve, asked whether the special care units or special programs it identified operated under a different philosophy of care from the rest of the facility. The survey responses with respect to this question have not yet been analyzed (246).

These topologies are useful in thinking about the differences among special care units. It is unclear, however, which of the topologies best represents the differences among existing special care units in their patient care philosophies and goals. It is also unclear whether the topologies encompass the full variation in philosophies and goals among existing special care units since the studies on which the topologies are based used nonrandom samples of special care units.

Physical Design and Other Environmental Features

As discussed in chapter 1, the literature on specialized nursing home care for individuals with dementia emphasizes the importance of physical environment in the care of these individuals. Design features and other physical characteristics of a nursing home are believed to be important for all residents, but especially important for residents with dementia. It is said that the more severe an individual's impairment, the greater the negative effects of an inappropriate environment and, conversely, the greater the positive effects of an appropriate environment (241).

A variety of physical design and other environmental features have been proposed for special care units. Most of these features are intended to compensate directly for residents' cognitive impairments, but some are intended to compensate for physical impairments that may exacerbate an individual's fictional deficits, e.g., reduced visual acuity that can interfere with the individual's perceptions of the environment and thus add to his or her confusion.

Some of the design and other environmental features that have been proposed for special care units are structural, such as arrangement of residents' bedrooms around a common, central area and location of the nurses' station to facilitate resident supervision and staff/resident interaction. Unless a unit is originally constructed with these features, extensive remodeling is required to incorporate them. Other physical design features, e.g., a safe space for wandering, are more easily added to an existing facility, but still require some remodeling. A third type of physical design features can be incorporated in an existing facility without any remodeling. These features include: an alarm or locking system; environmental cues, such as color coding of rooms and corridors to help residents find their way around the unit; and personal markers, such as a picture of the resident placed near the door to his or her room.

Available data indicate that most existing special care units were not originally constructed as special care units and that at least one-fifth were not even remodeled for this purpose. Of the 31 randomly selected special care units in the University of North Carolina study, 21 percent were originally constructed as special care units; 59 percent were remodeled for this purpose; and 21 percent were created without either original construction or remodeling (415). One-fifth of the 99 nonrandomly selected special care units studied by White and Kwon were created without either original construction or remodeling (494). Of the special care units identified by the 1991 George Washington University survey, more than half were created without either original construction or remodeling (247). Clearly, these types of units cannot incorporate physical design features that require either original construction or remodeling.

The most frequently used physical design features in special care units are alarm systems to alert staff when residents try to leave a unit and locking systems to stop residents from leaving the unit. The 1990 survey of all nursing homes in 5 northeastern States found 86 percent of special care units and 78 percent of cluster units had an alarm system or another method for securing exits (194). Likewise, among Minnesota nursing homes that had a special care unit in 1986,73 percent reported the unit had an alarm system, and 41 percent reported the unit was locked (181).

The 1990 survey of all nursing homes in five northeastern States included questions about two other physical design features: environmental cues, such as color coding of rooms and corridors, and modifications to the nurses' station. The survey found that 44 percent of the facilities with a special care unit were using environmental cues, and 35 percent had modified their nurses' station (194). Of the facilities with a cluster unit, 34 percent were using environmental cues, and 13 percent had modified their nurses' stations. Thus, although some facilities had incorporated each of these physical design features, the majority had not.

Findings of descriptive studies based on nonrandom samples of special care units illustrate the diversity of the units in their physical design features

(64,199,332,275,485,494). In their 1985-86 study of a nonrandom sample of 22 special care units, Weiner and Reingold found, for example, that 40 percent of the units were using orientation aids, such as large calendars and daily schedules; by implication, 60 percent were not (485). Twenty-seven percent of the units had increased the communal space on the unit; 23 percent had color-coded corridors and furniture; 15 percent had an outside garden or walkway; and 4 percent had small areas for group activities. By implication, the other units had not incorporated these design features. Only two of the units had eliminated their public address system (485).

White and Kwon found similar diversity in their survey of a nonrandom sample of 99 special care units in 34 States (494). Installation of a security system and creation of a safe outdoor area were the physical changes reported by the largest proportion of the survey respondents. These two changes were also reported to be the most successful of the environmental changes made in creating the units. Still, these changes were made by less than half the units (44 percent and 32 percent, respectively) (493). Likewise, although 70 percent of the units reported using personal markers, such as a resident's picture near the resident's room, smaller proportions of the units (12 to 41 percent, depending on the method) reported using any of the environmental cueing methods listed in the survey questionnaire (492).

White and Kwon included in their survey questionnaire a list of 13 environmental features considered by the researchers to be important for the safety of special care unit residents (494):

1. housekeeping chemicals are secured,
2. breakable items are kept from residents,
3. clutter is minimized,
4. housekeeping carts are secured,
5. patients smoke only with supervision,
6. outdoor exits can be opened but have alarms,
7. patients smoke only in designated areas,
8. exits have automatic fire unlocks,
9. stairs and elevators have alarms or are otherwise secured,
10. wide-angle mirrors or video cameras are used to monitor residents,
11. interior exits are disguised,
12. patients wear sensors that activate an alarm, and
13. half doors or clutch doors are used (493).

The proportion of special care units that reported having these features ranged from 96 percent for *housekeeping chemicals are secured* to **18** percent for *half doors or clutch doors are used* (493).

For their study of 31 randomly selected special care units and 32 matched nonspecialized units, Sloane et al. used a list of 12 environmental features they considered important in the care of nursing home residents with dementia:

1. absence of shiny or slippery floors,
2. absence of loud, distracting noise,
3. absence of odors coming from cleaning solutions,
4. absence of odors coming from bodily excretions,
5. absence of glare from the floors,
6. presence of personal items in residents' rooms,
7. presence of home-like furnishings in public areas,
8. presence of an outdoor area or courtyard accessible to residents,
9. availability of separate rooms or alcoves for small group and family interactions,
10. availability of a kitchen for resident use,
11. absence of routine television use in the main public area, and
12. overall adequacy of the lighting level (413).

The study findings show there were no significant differences between special care units and nonspecialized nursing home units for seven of these environmental features, but five of the features were statistically more likely to be found in special care units than in nonspecialized units (413). These five features are the amount of personal items seen in residents' rooms, the amount of home-like furnishings in public areas, the existence of areas suitable for small group interaction, the availability of a kitchen for residents' use, and the probability of having a television off in public areas. New special care units and units originally constructed as special care units were more likely than other special care units to incorporate the 12 features.

Some people who are knowledgeable about the care of nursing home residents with dementia might question the specific environmental features selected for analysis in these two studies and argue that other environmental features are more important for residents' safety and care. Other people might argue many of the environmental features on the two lists

are important for the safety and care of both demented and nondemented nursing home residents and thus are not specific for special care units. In fact, researchers who have conducted descriptive studies of special care units have commented on the differences of opinion among special care unit operators about which environmental features are important for the safety and care of individuals with dementia (199,275,332).

It is clear from the preceding discussion that use of specific physical design and other environmental features varies in existing special care units. It is also clear that despite the emphasis on environmental features in the special care unit literature, even the most widely used of the features-alarm and locking systems—are present in only three-quarters of all units, and many of the environmental features said to be important in the special care unit literature are being used in only a small proportion of existing special care units. According to the researchers who studied Minnesota nursing homes with a special care unit in 1986, the nursing homes seemed to have paid very little attention to environmental or design considerations for the units (181).

Staff Composition and Training

The literature on specialized nursing home care for people with dementia emphasizes the need for staff members who are knowledgeable about dementia and skilled in caring for individuals with dementia. In fact, one of the frequently cited arguments in favor of establishing special care units is that staff members with the necessary knowledge and skills can be more easily assembled and trained on a special care unit than on a nonspecialized nursing home unit (263,270,354). In theory at least, staff members for a special care unit can be selected specifically to meet the needs of residents with dementia; formal and informal training can be focused on these residents' needs, rather than the more heterogeneous needs of residents of nonspecialized units; and training about the care of residents with dementia can be targeted to the special care unit staff members.

Little information is available about the types of staff on existing special care units. Some nursing homes with a special care unit report having added staff, changed the composition of the staff, and/or changed staffing patterns when the unit was created. The 1990 survey of all nursing homes in 5 northeastern States found 69 percent of the facilities with a special care unit reported providing extra nursing staff for the unit, and 45 percent reported providing additional staff of other, unspecified types (194). Of the facilities with a cluster unit, 40 percent reported providing extra nursing staff for the unit, and 30 percent reported providing additional staff of other, unspecified types. Among the Minnesota nursing homes with a special care unit in 1986, 59 percent reported the staffing pattern on the unit was different than the staffing patterns on their nonspecialized units (18 1), but the differences were not described in the study report.

Several descriptive studies of nonrandom samples of special care units have noted the following staffing changes that have been implemented in one or more of the units studied:

- nurses and aides are not rotated to other units;
- aides are assigned fewer patients but have responsibility for more aspects of their patients' care;
- aides conduct activity programs;
- social workers' and recreation workers' offices are located on the unit;
- part-time assistants are hired for the evening shift to feed patients and help out at bedtime;
- a "clinical coordinator' is designated to develop new programs, educate staff, and market the units (64,275,332,485).

OTA is not aware of any information about the proportion of existing special care units that have implemented any of these staffing changes.

Most—but not all-nursing homes with a special care unit provide some type of specialized training for the unit staff. According to the National Medical Expenditure Survey, 74 percent of nursing homes that reported having a special care unit in 1987 also reported providing special training for the unit staff (248). Nonprofit and public nursing homes and larger nursing homes were more likely than for-profit nursing homes and smaller nursing homes to report providing such training. The 1990 survey of all nursing homes in 5 northeastern States found 70 percent of the facilities with a special care unit and 53 percent of the facilities with a cluster unit reported providing special training for the unit staff (194).

Given the emphasis on the need for staff members who are knowledgeable about dementia and skilled

in caring for individuals with dementia, the proportions of nursing homes in these two studies that reported they do not provide any special training for the staff of their special care units are surprising. Data from the National Medical Expenditure Survey—a survey of a nationally representative sample of nursing homes—indicate 26 percent of the nursing homes that reported having a special care unit in 1987 did not provide any special training for the unit staff (248). Likewise, the 1990 survey of all nursing homes in 5 northeastern States found that 30 percent of the nursing homes with a special care unit and 47 percent of the nursing homes with a cluster unit reported they did not provide special training for the unit staff (194). These figures are particularly surprising since they are based on self-report, and it is unlikely nursing homes would underreport the provision of training for their staff.

Staff-to-Resident Ratios

As noted earlier, the 1990 survey of all nursing homes in 5 northeastern States found that 69 percent of the facilities with a special care unit and 40 percent of the facilities with a cluster unit reported providing extra nursing staff for the unit (194). Likewise, 45 percent of the facilities with a special care unit and 30 percent of the facilities with a cluster unit reported providing additional staff of other, unspecified types. Descriptive studies of nonrandom samples of special care units have also found that some of the units added staff (275,332); nevertheless, staff-to-resident ratios varied greatly from one unit to another.

The University of North Carolina study of 31 randomly selected special care units and 32 matched nonspecialized units found the special care units were staffed at a higher level than the nonspecialized units (291). This difference was statistically significant for nurses, social workers, and activities staff and approached statistical significance for nurse aides. After adjusting for the relative severity of illness of residents of the two types of units, the researchers concluded that the special care units provided about one-third more hours of nursing care per resident than the nonspecialized units (415).

Staff Support Groups

Working with nursing home residents with dementia is often said to be very stressful for the staff (48,107,167,191,263,346,352). To address the perceived problem of staff stress, some special care units provide a support group for the unit staff members. The 1990 survey of all nursing homes in 5 northeastern States found that 44 percent of the nursing homes with a special care unit and 18 percent of the nursing homes with a cluster unit reported having such a support group (194). In contrast, only one of the Minnesota nursing homes with a special care unit in 1986 reported having a support group for the unit staff; two additional facilities reported having stress reduction programs for the special care unit staff (181).

Activity Programs

One of the frequently cited complaints about the care provided for individuals with dementia in most nursing homes is the lack of appropriate activities, including adequate physical exercise. Descriptive studies of nonrandom samples of special care units indicate the units provide a great variety of activity programs intended to increase stimulation, reduce idleness and stress, and respond to and maintain residents' interests. These programs include singing, dancing, exercises, painting, crafts, games, parties, pet therapy, field trips, reality orientation, sensory and cognitive stimulation, reminiscence therapy, religious services, housekeeping, cooking, gardening, and sheltered workshop activities (64,275,485, 494). Weiner and Reingold found physical exercise (including walks, dance exercise, and wheelchair exercise) and music therapy were the activity programs provided by the largest proportions of the special care units they studied (84 percent and 58 percent, respectively); 42 percent of the units they studied provided reality orientation, and the same proportion said they provided sensory stimulation. Other types of activity programs were provided by smaller proportions of the special care units (485).

The University of North Carolina study of 31 randomly selected special care units and 32 matched nonspecialized units found virtually no difference in the proportion of units that reported providing activity programs for their residents: 90 percent of the special care units and 91 percent of the nonspecialized units reported providing such programs (290). Information about the particular types of activity programs they provided was not collected, except for reality orientation, which was provided by all the special care units and 97 percent of the nonspecialized units, and reminiscence therapy, which was provided by 90 percent of the special care units and 87 percent of the nonspecialized units. The

1990 survey of all nursing homes in 5 northeastern States found 79 percent of the special care units and 74 percent of the cluster units reported providing reality orientation or cognitive stimulation (194). OTA is not aware of other available data on the proportion of special care units that provide particular types of activity programs. The 1991 George Washington University survey included questions about reality orientation and recreational therapy, but the survey responses for these questions have not yet been analyzed (246).

Programs for Families

Another frequently cited complaint about the care provided for individuals with dementia in most nursing homes is that the needs of the residents' families are not met. Descriptive studies of nonrandom samples of special care units indicate many units have special programs to involve, inform, and support residents' families (64,485,494). Weiner and Reingold found, for example, that 82 percent of the 22 special care units they studied had a family support group (485). Figures from these studies cannot be generalized to all special care units because they are based on nonmndom samples.

The University of North Carolina study of 31 randomly selected special care units and 32 matched nonspecialized units found the special care units were somewhat more likely than the nonspecialized units to provide special programs for families, but this difference was not statistically significant (413). The 1990 survey of all nursing homes in 5 northeastern States found 59 percent of the facilities with a special care unit and 35 percent of the facilities with a cluster unit had a support group for residents' families (194).

Use *of Psychotropic Drugs and Other Medications*

As discussed in chapter 2, nursing home residents with dementia are very likely to receive psychotropic medications, sometimes to control behavioral symptoms which might be more appropriately managed in other ways. One frequently stated objective of special care units is to reduce use of psychotropic medications and substitute other methods for managing residents' behavioral symptoms.

Descriptive studies indicate special care unit residents are as likely or more likely than individuals with dementia in nonspecialized nursing home units to receive psychotropic medications. Two small studies that each compared one or two special care units and two nonspecialized nursing home units found that a larger proportion of the special care unit residents than the demented residents in nonspecialized units received psychotropic medications (256, 298). The University of North Carolina study of 31 randomly selected special care units and 32 matched nonspecialized nursing home units found no significant difference between the 2 types of units in their use of psychotropic medications (413).

In contrast to the use of psychotropic medications, the use of medications of all types appears to be lower in special care units than in nonspecialized nursing home units. The University of North Carolina study of 31 randomly selected special care units and 32 matched, nonspecialized nursing home units found the special care unit residents received significantly fewer medications of all types than residents with dementia in the nonspecialized units (413). Likewise, a pilot study that compared 19 residents with dementia in one special care unit and 20 residents with dementia in nonspecialized units of the same nursing home found the special care unit residents were receiving fewer medications of all types (391).

The lower use of medications of all types on special care units may reflect differences in the characteristics of the residents. As discussed later in this chapter, the findings of several descriptive studies suggest that residents of special care units may have fewer medical conditions than other nursing home residents with dementia (292,382,413); as a result, they may have less need for medications of all types. In addition or instead, the lower use of medications of all types on special care units may reflect deliberate efforts by physicians who treat special care unit residents to reduce medication use, perhaps in recognition of the deleterious effects on cognition of many types of medications. The available data do not allow one to choose between these two explanations or other possible explanations.

Use of Physical Restraints

As discussed in chapter 2, nursing home residents with dementia are often physically restrained, and reduced use of physical restraints is a frequently stated objective of special care units. Descriptive studies show use of physical restraints is much lower in special care units than in nonspecialized nursing

home units (256,292,391,413). The University of North Carolina study found that only 16 percent of the special care unit residents were restrained, compared with 36 percent of the residents with dementia on the nonspecialized units (413).

In theory, lower use of physical restraints in special care units could reflect differences in the characteristics of the residents; that is, if special care unit residents exhibit fewer behavioral symptoms than other nursing home residents with dementia, special care unit residents may be less likely to be physically restrained. This explanation is probably not true, since, as discussed later in this chapter, special care unit residents generally exhibit as many or more behavioral symptoms than other nursing home residents with dementia. A more likely explanation for the lower use of physical restraints in special care units is a deliberate effort by unit operators and staff members to substitute other methods of managing residents' behavioral symptoms. Another possible explanation is that special care unit residents are perceived by staff members as less physically frail and therefore less likely to fall than other nursing home residents with dementia, and as a result, special care unit residents are less likely to be restrained. Available data do not allow one to choose between the latter two explanations or other possible explanations.

Admission and Discharge Policies and Practices

Some existing special care units have formal admission and discharge policies, and others do not. The 1990 survey of all nursing homes in 5 northeastern States found that 43 percent of the facilities with a special care unit and 19 percent of the facilities with a cluster unit reported having formal, written admission criteria for the unit (194). Twenty-eight percent of the facilities with a special care unit and 20 percent of the facilities with a cluster unit reported having formal, written discharge criteria (194). Eight of the 13 special care units in the nonrandom sample of units studied by Cairl et al. reported having formal admission policies, and 3 of the 13 units reported having formal discharge policies (64).

Regardless of whether they have formal admission and discharge policies, special care units vary greatly in their admission and discharge practices. The University of North Carolina study of 31 randomly selected special care units found 40 percent of the units primarily admitted individuals who had been living in other parts of the nursing home; the remaining 60 percent primarily admitted individuals who had been living outside the facility (413). Weiner and Reingold found that two-thirds of the 22 nonrandomly selected special care' units they studied admitted primarily individuals who had been living in other parts of the facility (485).

In response to the 1990 study of all nursing homes in five northeastern States, facilities with a special care unit reported using several criteria to select unit residents. The criteria and the proportion of facilities that reported using them areas follows: 1) the degree of an individual's dementia (85 percent); 2) the individual's need for supervision (73 percent); 3) the individual's behavioral symptoms (79 percent); 4) the individual's limitations in activities of daily living (51 percent); and 5) the individual's ability to ambulate independently (38 percent) (194). For nursing homes with a cluster unit, the corresponding figures are: 1) the degree of an individual's dementia (81 percent); 2) the individual's need for supervision (78 percent); 3) the individual's behavioral symptoms (64 percent); 4) the individual's limitations in activities of daily living (57 percent); and 5) the individual's ability to ambulate independently (44 percent). Most of the nursing homes reported they generally seek individuals with more, rather than less, severe dementia (194). Only 12 percent reported they generally seek individuals with less severe dementia. Likewise, about 40 percent of the nursing homes reported they generally seek individuals with more severe behavioral symptoms, and only 15 to 18 percent reported they generally seek individuals with less severe behavioral symptoms.

Table 3-3 presents data from the University of North Carolina study with respect to the proportion of special care units that encourage or discourage admission of individuals with eight types of symptoms. Most of the units reported that they encourage admission of individuals with confusion, wandering, and agitation (413). Most reported that they discourage admission of individuals who are physically abusive or unable to walk independently.

Reported admission practices may or may not reflect actual admission practices in special care units. Data from the Multi-State Nursing Home Case Mix and Quality Demonstration, a 5-year congressionally mandated study, suggest the major factor

Table 3-3—Proportion of Special Care Units That Encouraged or Discouraged Admission of Residents With Certain Problems

Problem		
Confusion	encouraged	93%
	neither	7
	discouraged	0
Wandering	encouraged	87
	neither	13
	discouraged	0
Agitation	encouraged	53
	neither	40
	discouraged	7
Verbal abusiveness	encouraged	27
	neither	57
	discouraged	17
Physical abusiveness	encouraged	7
	neither	35
	discouraged	59
Urinary incontinence	encouraged	30
	neither	63
	discouraged	7
Unable to walk	encouraged	10
	neither	27
	discouraged	63
Feeding problems	encouraged	17
	neither	67
	discouraged	17

SOURCE: P.D. Sloane, L.J. Mathew, J.R. Desai, et al., "Specialized Dementia Units in Nursing Homes: A Study of Settings in Five States," University of North Carolina, Chapel Hill, NC, March 1990.

distinguishing special care unit residents and residents with dementia in nonspecialized nursing home units is the severity of their physical impairments (382). Among a subsample of 127 residents of 10 special care units and 103 residents with dementia in 10 nonspecialized units in the same nursing homes, the special care unit residents were significantly less likely to have severe limitations in activities of daily living or severe physical impairments. Once other study variables were controlled, the two groups did not differ significantly with respect to behavioral symptoms, including wandering and verbal and physical abusiveness.

Some special care units admit individuals with the expectation that the individuals will remain on the unit until they die, whereas other units admit individuals with the expectation that they will be discharged from the unit at some time prior to death. All but one of the 22 Minnesota nursing homes that had a special care unit in 1986 reported they admitted individuals with the expectation that the individuals would remain on the unit until they died (181). According to the 1990 study of all nursing homes in 5 northeastern States, about half the nursing homes with a special care unit and 60 percent of the nursing homes with a cluster unit reported they seldom discharge residents of the unit or cluster prior to their death (194).

Among special care units that do discharge residents prior to their death, the reasons for discharge vary. In their study of 99 nonrandomly selected special care units, White and Kwon found the two most frequently cited reasons for discharging residents from the units were: 1) that the residents had become nonresponsive (cited by 70 percent of the survey respondents), and 2) that the residents were combative, violent, or harmful to self or others (cited by 63 percent of the units). One-third of the units reported discharging residents who became unable to ambulate, and 14 percent reported discharging residents when the residents' private funds were exhausted (492). Weiner and Reingold cite similar reasons for discharge (485).

The 1990 study of all nursing homes in 5 northeastern States indicate 45 percent of the nursing homes with a special care unit or a cluster unit reported they discharge residents who need intensive medical care (194). Twenty-one percent reported they discharge residents who need tube feeding, and a few of the nursing homes (10 percent or less) reported they discharge residents who have severe decubitus ulcers, contractures, or recurring urinary tract infections.

Costs, Charges, and Payment Methods

Very little information is available about the cost of special care units. The cost obviously varies among units, depending on the cost of any new construction, renovation, or other physical changes to a unit and ongoing operating costs. Respondents to one survey of a nonrandom sample of 12 special care units reported new construction and renovation costs ranging from $4100 to $150,000 (275). Cameron et al. reported initial costs of only $1300, which covered the cost of an alarm system, color coding, and other physical changes made to create a special care unit (70).

Some special care unit operators and others say ongoing operating costs are higher for special care units than for nonspecialized nursing home units. One-third of the respondents in Weiner and Reingold's study of a nonrandom sample of 22 special care units cited higher costs associated with opera-

tion of the unit, whereas the other two-thirds did not (485). Of the 13 special care units in Florida studied by Cairl et al., 7 reported higher operating costs for the special care unit than for nonspecialized units in the same facility; 5 reported no difference in operating costs, and 1 reported lower operating costs (64). Two studies of individual special care units found no difference in operating costs between the special care units they studied and nonspecialized units in the same facilities (70,265).

The Multi-State Nursing Home Case Mix and Quality Demonstration, a 5-year congressionally mandated study that included 20 special care units, 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). As noted earlier, the University of North Carolina study of 31 randomly selected special care units and 32 nonspecialized nursing home units in 5 States had similar findings (413). The greater amount of staff time spent caring for special care unit residents translates into higher average operating costs in the special care units.

Citing higher operating costs, some nursing homes charge more for care in their special care unit than in their nonspecialized units. To OTA's knowledge, no public program currently pays more for care of an individual in a special care unit than in a nonspecialized nursing home unit. Thus, it is only private-pay residents who may be charged more for care in a special care unit than they would be charged in a nonspecialized unit in the same facility.

Compared with nonspecialized units, special care units generally have a higher proportion of private-pay residents (292,413,477). The University of North Carolina study of 31 randomly selected special care units and 32 matched nonspecialized units found, for example, that 60 percent of the special care unit residents were private-pay, compared with 30 percent of the residents of the nonspecialized units (413). Six of the 31 special care units did not accept Medicaid payment at all.

The University of North Carolina study found that 79 percent of the special care units in the study sample charged private-pay residents more for care in the special care unit than the residents would have been charged in a nonspecialized unit in the same facility (415). The excess charge varied from one unit to another and from State to State. The mean excess charge ranged from $3.17 a day in intermediate care facilities (ICFs) in Ohio to $19.75 a day in skilled nursing facilities (SNFs) in California.

Preliminary data from the 1991 George Washington University survey of all special care units nationwide indicate about half of the units charged private-pay residents more in the 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.

Lastly, a small pilot study that compared monthly charges for care in two nursing home special care units and two nonspecialized nursing home units in California found the special care units charged their residents an average of $3196 per month, whereas the nonspecialized units charged their residents an average of $2803 per month (256).

DESCRIPTIVE TOPOLOGIES OF SPECIAL CARE UNITS

Several topologies of special care units have been developed based on information from descriptive studies. Three topologies based on information about unit goals were discussed earlier in this chapter. OTA is aware of three other descriptive topologies based on information about a variety of unit characteristics. One of the topologies is based on information about 13 of the 31 VA special care units identified by the 1989 VA survey discussed earlier in this chapter. This typology reflects differences among the units in their goals and the typical length of stay in the unit (103). On the basis of these differences, three types of units were identified. One type of unit has a relatively short length of stay and focuses primarily on diagnosis, short-term behavioral stabilization, and discharge placement. A second type of unit has an intermediate length of stay and focuses on behavioral management and discharge placement. The third type of unit has a more extended length of stay and focuses primarily on long-term supportive care.

A second typology is based on information about a nonrandom sample of 13 special care units in a 10-county area of west central Florida (64). This typology reflects differences among the units in 13 characteristics: their origin and philosophy, motives for development, level of commitment, target population, policies and procedures, admission and discharge criteria, assessment and followup, physi-

Table 3-4-Ratings on Some Variables for Eight Types of Special Care Units

Type	Cleanliness of public areas	Odors	Staff with specialized training in dementia	Staff/patient interaction	Staff attitudes toward patients	Staff stress level	Administrative philosophy	Administrative attitudes toward patients
Ideal	High	No	Yes	High	Caring	Low	Therapeutic	Caring
Uncultivated	High	No	Yes	High	Caring	High	Maintenance	Apathetic
Heart of gold	Low	No	Yes	High	Caring	High	Therapeutic	Caring
Rotten at the core	High	No	No	Low	Apathetic	Low	Maintenance	Apathetic
Institutional	High	Yes	No	High	Caring	Low	Maintenance	Caring
Limited	Low	Yes	No	Low	Apathetic	Low	Therapeutic	Caring
Conventional	Low	Yes	No	Low	Caring	High	Maintenanca	Apathetic
Execrable	Low	Yes	No	Low	Apathetic	Low	Maintenance	Apathetic

SOURCE: D.T. Gold, P.D. Sloane, L.J. Mathew, et al., "Special Care Units: A Typology of Care Settings for Memory-Impaired Older Adults," *Gerontologist* 31(4):470, 1991,

cal environment, activity programs, staffing patterns, staff training, family involvement, and efforts to evaluate the impact of the unit. Based on differences among the units in these 13 characteristics, the researchers identified three types of units that, in their view, reflect the extent to which the units were tailored for individuals with dementia: "highly specific" units, "moderately specific" units, and "minimally specific' units.

A third descriptive typology is based on the findings of the University of North Carolina study of 31 randomly selected special care units and 32 matched nonspecialized nursing home units in 5 States. This typology was derived from an analysis of narrative accounts dictated by an investigator who visited each of the units (154). These narrative accounts were available for 28 of the 31 special care units and 27 of the 32 nonspecialized units. The unit characteristics used in the development of the typology include: appearance of the units' public area, general maintenance, cleanliness, unit layout, presence of an activity room, decoration of the public areas (institutional or home-like), noise level, odor, ambiance (depressing or cheerful), size of the facility for the population (crowded or uncrowded), resident living arrangements (shared or private), resident appearance (ill-groomed or well-groomed), resident location during the day (in their rooms or in the public areas), resident activity level, resident wandering, use of physical restraints, use of psychotropic medications, presence of an activity director, staff relations with the administration, staff stress level, staff training in dementia, staff attitude toward residents (apathetic or caring), staff/resident interaction (high or low), administrative philosophy (maintenance or therapeutic), admission criteria (lax or strict), the administration's attitude toward the residents (apathetic or caring), and involvement of the administration in resident care. Based on differences among the units in these characteristics, the researchers identified eight types of units: "ideal, uncultivated, heart of gold, rotten at the core, institutional, limited, conventional, and execrable. ' Table 3-4 shows the ratings of each of the types for eight of the characteristics.

The typology based on information from the University of North Carolina study reflects the characteristics of the special care units and the nonspecialized units in the study sample (154). The researchers found a larger proportion of the special care units in the study sample were in the positive types: 43 percent of the special care units were in the "ideal" type; 11 percent were in the 'uncultivated" type, and 4 percent were in the "heart of gold" type. In contrast, none of the nonspecialized units were in the 'ideal' or 'uncultivated' types, and 15 percent were in the 'heart of gold' type. None of the special care units were in two of the negative types, "conventional" and "execrable," and only 7 percent of the special care units were in the "rotten at the core" type. Of the nonspecialized units, 7 percent were in the "conventional" type; 11 percent were in the "execrable" type, and 15 percent were in the 'rotten at the core' type. Thus the special care units seem, in general, to be providing better care than the nonspecialized units for their residents with dementia.

As noted earlier, topologies are useful in thinking about differences among special care units, although it is unclear whether topologies based on nonrandom samples, such as the typology based on information about the 13 special care units in Florida, encompass the full variation among existing special care units. The typology based on information from the University of North Carolina study does not suffer from this potential drawback because that study included a

random sample of special care units. On the other hand, the latter typology is based on an analysis of nonquantitative observations by three individuals, one of whom visited each of the units once. The validity of these individuals' observations cannot be determined. The process by which their observations were combined to create the typology also raises methodological questions.

Both topologies imply that certain types of special care units are more appropriate than other types of special care units for nursing home residents with dementia. Some of the unit characteristics on which the topologies are based are not specific for individuals with dementia, however. With respect to the "execrable' units, for example, the researchers say:

> The administrators of execrable units are apathetic, have weak authority over staff, and are unresponsive either to patient complaints or staff difficulties. Their lax admissions criteria result in the units being filled with patients who are inappropriate for an intermediate care facility. Rather than screen out behavior problems or serious physical comorbidity, directors of execrable units encourage recruitment of any potential patient. Each bed occupied means reimbursement (154).

Clearly, the care provided by these "execrable" units would be inappropriate for nondemented as well as demented nursing home residents.

Although it is obvious poor-quality care is not appropriate for any nursing home resident, there is very little evidence that any specific characteristic of nursing home units is associated with better resident outcomes. The available studies with respect to this issue are discussed in chapter 4. Without some evidence of improved outcomes, it cannot be said with certainty that any particular type of nursing home unit is more appropriate for individuals with dementia, except in the sense that units that provide poor-quality care which would be inappropriate for any resident are, by definition, providing inappropriate care for residents with dementia.

CHARACTERISTICS OF SPECIAL CARE UNIT RESIDENTS

Many reports on individual special care units describe residents of a particular unit, but little research-based information is available about characteristics of special care unit residents or about the ways, if any, in which these residents differ from other nursing home residents. A few descriptive studies provide information about residents of the special care units they studied, and five studies compare the characteristics of special care unit residents and residents with dementia in nonspecialized nursing home units (see table 3-lc). The University of North Carolina study of 31 randomly selected special care units and 32 matched nonspecialized units compared some characteristics of special care unit residents with the characteristics of nursing home residents in general (413). Several of the evaluative studies discussed in chapter 4 also provide comparative information about the baseline characteristics of their subjects (special care unit residents and residents with dementia in the nonspecialized nursing home units). This section summarizes the findings of all of these studies.

Descriptive studies show that on average special care unit residents are younger than other demented and nondemented nursing home residents (256,292, 391,413). Special care units residents are also more likely than other demented and nondemented nursing home residents to be white and male (256,292, 413,492).

Special care units admit individuals with a variety of dementia-related diagnoses, the most common being Alzheimer's disease (275,292,391,413). Residents of special care units are much more likely than residents with dementia in nonspecialized units to have a specific diagnosis, such as Alzheimer's disease, rather than a more general diagnosis, such as senility or organic brain syndrome (99,292,391, 413). Not all special care unit residents have a dementia diagnosis, however. Some special care units admit individuals who have behavioral symptoms but no diagnosis of a dementing illness (64).

The University of North Carolina study of 31 randomly selected special care units and 32 matched nonspecialized nursing home units found that on average the special care unit residents were more severely cognitively impaired than residents of the nonspecialized units, even though all the individuals in the study sample had a dementia diagnosis (413). This difference in the average severity of residents' cognitive impairment was due to the presence on the nonspecialized units of some residents with little or no cognitive impairment despite their dementia diagnosis. Two evaluative studies discussed in chapter 4 also found the special care unit residents in their study samples were significantly more cognitively impaired than residents with dementia in the

Table 3-5—Impairments in Activities of Daily Living Among Special Care Unit Residents, Residents With Dementia in Nonspecialized Nursing Home Units, and All Nursing Home Residents

Functional impairment	Special care unit residents	Residents with dementia in nonspecialized nursing home units	All nursing home residents
Needs help with dressing	81%.	93%	89%
Needs help with getting out of bed	45	78	71
Needs help with ambulating	30	60	54
Incontinent	69	84	71

SOURCE: P.D. Sloane, L.J. Mathew, M. Scarborough, et al., "Physical and Pharmacologic Restraint of Nursing Home Patients With Dementia: Impact of Specialized Units," *Journal of the American Medical Association* 265(10):1280, 1991.

nonspecialized units studied (99,195). On the other hand, two descriptive studies with small samples found no significant difference in the severity of cognitive impairment between individuals with dementia on special care units and on nonspecialized units (256,292).

With respect to coexisting medical conditions, the University of North Carolina study found the special care unit residents were less likely than residents of the nonspecialized nursing home units to have a history of stroke, hip fracture, or other fractures (413). The special care unit residents were significantly more likely to be ambulatory and to be taking fewer medications of all types, thus suggesting they may have fewer medical conditions than the residents with dementia on the nonspecialized units. An earlier study that compared one special care unit with two nonspecialized nursing home units found the special care unit residents had significantly fewer medical diagnoses than the residents of the nonspecialized units (292). Data from the Multi-State Nursing Home Case Mix and Quality Demonstration show that the residents of 10 special care units in the study sample were significantly less likely than the residents with dementia in nonspecialized units in the same nursing homes to have a diagnosis of stroke or diabetes (382). The special care unit residents were somewhat less likely to have a diagnosis of congestive heart failure or chronic obstructive pulmonary disease, but these differences were not statistically significant, and the difference with respect to diabetes was no longer significant when other study variables were controlled. Two other studies found no difference in the presence of specific medical conditions, the average number of medical conditions per resident, or the average number of medications per resident (99,391).

Several studies indicate special care unit residents are less likely than other nursing home residents with dementia to have impairments in activities of daily living (99,256,413). Table 3-5 shows the findings of the University of North Carolina study with respect to the proportion of special care unit residents and individuals with dementia in nonspecialized units who were impaired in dressing, getting out of bed, and continence. These differences were statistically significant. In contrast, two studies with small samples found no significant difference in impairments in activities of daily living between special care unit residents and residents with dementia in nonspecialized nursing home units (292,391). Data from the Multi-State Nursing Home Case Mix and Quality Demonstration show the residents of 10 special care units in the study sample were significantly more likely than the residents with dementia in nonspecialized units in the same nursing homes to have impairments on an index of two activities of daily living described by the researchers as "early loss' activities (grooming and dressing). In contrast, the special care unit residents were significantly less likely to have impairments on an index of four other activities of daily living described by the researchers as "late loss" activities (eating, using the toilet, transferring, and bed mobility) (382).

Special care unit residents may be more likely to exhibit behavioral symptoms than individuals with dementia in nonspecialized nursing home units (256,413). The University of North Carolina study found a trend for a greater prevalence of behavioral symptoms among special care unit residents, but the differences were not statistically significant (413). An earlier study found no difference in the prevalence of behavioral symptoms among the residents of one special care unit and two nonspecialized nursing home units (292). Data from the Multi-State Nursing Home Case Mix and Quality Demonstration show that the residents of 10 special care units in the study sample were significantly more likely

than the residents of nonspecialized units in the same nursing homes to wander and to be verbally and physically abusive (382). These differences were no longer significant, however, when other study variables were controlled. Interestingly, the study data show that the greater likelihood of wandering on the special care unit was due to the greater proportion of residents in the special care units who were physically capable of wandering.

The University of North Carolina study found the special care unit residents were more likely than the individuals with dementia in nonspecialized nursing home units to be out of their rooms and to be participating in activity programs (413). Three studies with small sample sizes also found special care unit residents were more likely than residents of nonspecialized units to participate in activity programs (256,292,391).

Lastly, one study that compared 13 residents of one special care unit and 34 individuals with dementia in 2 nonspecialized nursing home units found the special care unit residents were more likely to fall (292). This difference was not statistically significant. Several studies discussed in chapter 4 also found a higher incidence of falls among special care unit residents than other nursing home residents (99,265,497,521). One of these studies found special care units residents were more likely than the residents of nonspecialized units to be hospitalized for a hip fracture (99).

Since the studies discussed in this chapter are cross-sectional, it is unclear whether some of the findings reflect pre-existing characteristics of the residents and the admission and discharge criteria of the units, or on the other hand, the effect of the unit on residents. With respect to participation in activities, for example it is unclear whether special care units admit individuals who are more likely to participate in activities or whether one effect of the units is to cause greater resident participation in activities.

CONCLUSION

The preceding review of findings from the available descriptive studies of special care units allows some conclusions to be drawn about the number and characteristics of nursing homes with a special care unit, the characteristics of the special care units, and the characteristics of their residents. Table 3-6 lists OTA's conclusions in these four areas. Each **conclusion** is supported by the findings of at least one study that used a representative sample of nursing homes or surveyed all nursing homes in a given geographic area. None of the conclusions is contradicted by the findings of any descriptive study OTA is aware of, including studies with small, nonrandom samples.

The diversity of existing special care units is a common finding in all special care unit research. Because of this diversity, no single descriptive statement is true of all special care units for individuals with dementia, including the statement that they only serve individuals with dementia. With respect to existing units' philosophies and goals, staffing patterns, physical design features, and activity programs, diversity is probably the primary finding from the available studies.

As noted earlier, one of the difficulties in special care unit research is the lack of an accepted definition of the term *special care unit.* Thus far, most descriptive studies of special care units have used self-report—i.e., the statement of a special care unit operator or another nursing home staff member—to determine which nursing home units are special care units. The University of North Carolina study added several additional conditions. For that study, a special care unit was defined as follows:

> a distinct functional area of a nursing home, or the entire home, which identified itself as a dementia unit, served primarily dementia residents, and satisfied at least three of the following conditions: 1) separation from the remainder of the facility by closed doors; 2) over 50 percent of the staff having at least a year's experience with geriatric residents; 3) specific staff training in dementia care; and 4) unit activities being designed with the dementia resident in mind (413).

By defining the term *special care unit in* a particular way, researchers necessarily focus on a subset of all facilities that might be considered or might self-identify as special care units. By doing so, they eliminate some of the diversity that characterizes the full universe of existing special care units. If, for example, the term *special care unit* is defined for a particular study as a physically separate part of the nursing home that has certain physical design features, such as a safe area for wandering, then all special care units in the study sample will, by definition, have a safe area for wandering. As discussed in chapter 4, it is unclear what particular physical design features, if any, are related to

Table 3-6-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 ❋□❋ 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.

(Continued on next page)

positive outcomes for nursing home residents with dementia. Given that uncertainty, it is probably premature to exclude for research purposes special care units that do not have a particular physical design or other feature.

In this context, it is important to note one of the findings of the 1990 study of all nursing homes in five northeastern States, i.e., that 5 percent of the nursing homes reported that although they did not have a special care unit, they did place some residents with dementia in clusters in units that also served nondemented residents (194). The study found that a significant proportion of these cluster units incorporated features said to be important in special care units, although the cluster units were less likely than the special care units in the study States to incorporate the features. It will be important to determine in future special care unit studies whether cluster units are more like special care units than they are like nonspecialized nursing home units

Table 3-6-Conclusions From Descriptive Studies of Special Care Units-(Continued)

- ***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 as 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 in nonspecialized nursing home units to receive medications of all types.
- Special care unit residents are less likely than other nursing home residents with dementia to be physically restrained.
- 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 onnspecialized 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 mom likely than other nursing home residents with dementia to fall.

SOURCE: **Office of Technology Assessment, 1992.**

and to compare the outcomes for residents with dementia of the three types of units.

Four of the conclusions listed in table 3-6 would be regarded by many people as indicators that in general special care units are providing more appropriate care than nonspecialized units for individuals with dementia. These conclusions are that *on average:*

1. special care units probably have fewer residents than nonspecialized nursing home units;
2. special care units probably have more staff per resident than nonspecialized nursing home units;
3. special care unit residents are less likely than individuals with dementia in nonspecialized nursing home units to be physically restrained; and
4. special care unit residents are probably more likely than other nursing home residents with dementia to participate in activity programs.

In contrast, the finding that special care unit residents are as likely or more likely than other nursing home residents with dementia to receive psychotropic medications would be regarded by many people as an indicator that special care units are not providing more appropriate care for individuals with dementia. The issue of criteria for evaluating the quality of special care units is discussed in chapter 1. One question with respect to that issue is whether criteria such as number of residents, staff-to-resident ratios, and use of physical restraints and psychotropic medications are valid criteria for evaluating quality in themselves or whether their validity remains to be demonstrated in terms of their relationship to other resident outcomes.

Lastly, despite these tentative conclusions and observations, the overriding conclusion to be drawn from this review of findings from the available descriptive studies is the need for more research that builds on, clarifies, and expands upon current findings. As noted throughout the preceding discussion, many of the available studies have used very small samples and nonrandom samples. Moreover, since the studies did not use common definitions for the unit and resident characteristics they observed, their findings are not necessarily comparable. These problems are minimized in several sources of forthcoming descriptive information about special care units and special care unit residents which are described in the next section.

FORTHCOMING DESCRIPTIVE INFORMATION ABOUT SPECIAL CARE UNITS AND SPECIAL CARE UNIT RESIDENTS

OTA is aware of several sources of descriptive information about special care units and special care unit residents that will be available in the near future. As noted in the beginning of this chapter, researchers at George Washington University are currently analyzing responses to a questionnaire and telephone interviews with more than 14,000 nursing homes (247). The questionnaire asked for respondents' opinions about the minimum characteristics a nursing home unit should have to be designated as a special care unit. The questionnaire also asked about each of the topics discussed in the preceding sections, including the size and ownership of the nursing home, the size of the special care unit, its physical characteristics, philosophy of care, admission and discharge criteria, staff selection criteria, staff training, staff-to-resident ratio, staff support groups, activity programs, programs for residents' families, use of physical and pharmacological restraints, and reimbursement. Once analyzed, the results of this study will provide valuable information that is not currently available about all of these topics.

Another source of forthcoming information about special care units and special care unit residents is data currently being collected by all nursing homes as a result of the implementation in 1990 of mandatory assessment of nursing home residents in accordance with the nursing home reform provisions of the Omnibus Budget Reconciliation Act of 1987 (OBRA-87). As discussed in chapter 1, all nursing homes are now required to assess each of their residents at the time of the resident's admission to the nursing home and annually thereafter using the Minimum Data Set or a State-designated assessment instrument that includes the same core items. The Minimum Data Set contains questions about each of the resident characteristics discussed in this chapter. Although there will undoubtedly be variation in the way these questions are answered by different nursing home staff members, in different facilities, and in different States, use of the same or similar assessment instruments should increase the availability of comparable information about all nursing home residents, including residents of special care units. Since all nursing home residents must be reassessed annually using the Minimum Data Set, longitudinal data on individual special care unit residents will also become available. Variation in the way the information is collected from one staff member to another and one nursing home to another may, however, compromise its value for research purposes (437).

An early version of the Minimum Data Set has already been used to collect information on about 300 residents of 20 special care units in six States as part of the Multi-State Nursing Home Case Mix and Quality Demonstration-a 5-year study mandated by Congress as part of OBRA-87. The special care units included in the demonstration were designated by the Health Care Financing Administration based on recommendations from the Alzheimer's Association and State officials in the four States in which the demonstration is being conducted (Kansas, Maine, Mississippi, and South Dakota) and in two additional States that are participating in some aspects of

the demonstration (Nebraska and Texas) (137). Information on residents of these special care units was collected in 1990. Data comparing 127 residents of 10 of the special care units and 103 residents with dementia in nonspecialized units in the same nursing homes were reported earlier in this chapter (382). Other findings from the demonstration have not yet been published. Individuals familiar with the demonstration's findings say they show lower use of physical restraints, the same or higher use of psychotropic medications, and a higher incidence of falls in the special care units than in the nonspecialized nursing home units included in the demonstration (15,521). As discussed in chapter 1, the demonstration data also show greater resource use for equally impaired residents with dementia in the special care units than in the nonspecialized units (143).

Because of the current lack of agreed upon criteria for evaluating special care units, there is no way to determine the quality of the care provided by the special care units included in the Multi-State Nursing Home Case Mix and Quality Demonstration. Nor is it possible to determine at this point whether these units are typical of special care units nationally and whether the residents of the units are typical of special care unit residents nationally. Nevertheless, the findings provide valuable information about a relatively large number of special care unit residents and comparable information about residents with dementia in nonspecialized nursing home units.

Chapter 4

Special Care Units For People With Dementia: Findings From Evaluative Studies

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Chapter 4

Special Care Units For People With Dementia: Findings From Evaluative Studies

INTRODUCTION

As noted in chapter 3, much of the literature on special care units consists of descriptive reports about an individual unit. These descriptive reports often present anecdotal evidence of the unit's positive outcomes. Frequently, the reports include case examples that show how the unit benefited one or more of its residents. Many of the reports also describe positive outcomes of the unit for residents' families and unit staff members.

Anecdotal evidence of the positive outcomes of individual special care units is compelling. The case examples are particularly compelling: the individual residents they describe seem typical of nursing home residents with dementia who do not do well in nonspecialized units; these individuals often are admitted to the special care unit in a very agitated or withdrawn condition; they frequently have been overmedicated and physically restrained; characteristics of the unit, including its physical design features, patient care philosophy, and activity programs, seem to match their needs exactly; and they respond positively and dramatically to the unit environment.

Case examples and other anecdotal evidence of the positive outcomes of individual units are not adequate, however, to evaluate the effectiveness of special care units. In the past few years, a number of evaluative studies of special care units have been conducted. These studies attempt to measure objectively the effectiveness of one or more special care units in terms of changes in aspects of their residents' condition and functioning over time. Several of the evaluative studies also measure the effects of special care units on residents' families and unit staff members.

This chapter reviews what is known about special care units from the available evaluative studies. It does not include information from descriptive reports on individual special care units. Findings of the available evaluative studies are discussed in some detail because, like the descriptive studies discussed in chapter 3, they provide a basis for informed policy decisions about the development of special regulations and reimbursement for special care units, about the need for and content of consumer education about special care units, and about the future direction and level of government support for research on special care units.

OTA's conclusions from the evaluative studies discussed in this chapter are summarized in table 4-3 at the end of the chapter. The findings differ, depending on whether the study used a control group. The nine evaluative studies that did not use a control group found positive outcomes for special care unit residents in a variety of areas. If contradictory findings are excluded, the only positive 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 over time 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.

Only two of the six evaluative studies that used a control group found any positive outcomes for special care unit residents. One of these studies found that over a l-year period, 14 residents of one special care unit showed significantly less decline than 14 residents with dementia in nonspecialized units of the same nursing home in their ability to perform activities of daily living (392). The second 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). The 13 special care unit residents also interacted significantly more often with staff members.

Only one of the four evaluative studies that measured the impact of a special care unit on unit staff members found any positive outcomes. The findings with respect to outcomes for residents' families are contradictory, as described later in the chapter.

The limited positive findings in many of these evaluative studies and the complete lack of positive findings in some of the studies are surprising and appear to contradict the conviction of special care

unit operators and others that the units benefit residents, residents' families, and unit staff members. Each of the available studies suffers from one or more methodological problems that could invalidate its findings, e.g., small sample sizes and use of nonrandom samples. Citing these problems, some special care unit advocates discount the lack of positive findings. In contrast, OTA concludes that some of the studies-particularly the six studies that used a control group-constitute credible research in an area in which good research is difficult to design and conduct. Despite methodological problems, the studies' findings are meaningful and deserve careful consideration by policymakers, special care unit advocates, and others.

TYPES OF EVALUATIVE STUDIES OF SPECIAL CARE UNITS

Three types of evaluative studies of special care units have been conducted. In one type, selected characteristics of individuals with dementia, their families, and/or unit staff members are measured at designated intervals before and after the individuals' admission to a special care unit. Changes or lack of changes in the measured characteristics over time are then attributed to the impact of the special care unit. This type of study does not use a separate control group.

The second type of evaluative study does use a separate control group. In this type of study, selected characteristics of the special care unit residents, their families, and/or unit staff members and selected characteristics of other individuals with dementia, their families, and/or staff members in nonspecialized nursing home units or other settings are measured at designated intervals. Changes or lack of changes in the measured characteristics of the two groups of subjects are compared, and any differences between the two groups are attributed to the impact of the special care unit.

A third type of evaluative study measures the effectiveness of particular features and interventions in special care units. One example is research on the effectiveness of various types of devices to deter residents who wander from leaving the unit.

The findings of these three types of evaluative studies are discussed in the following sections. Findings with respect to the effects of special care units on residents, residents' families, and unit staff members are discussed separately.

EVALUATIVE STUDIES WITHOUT A CONTROL GROUP: EFFECTS ON RESIDENTS

OTA is aware of nine evaluative studies of special care units in which a control group was not used (see table 4-l). Seven of the nine studies were conducted in a single special care unit. The other two studies were conducted in two and three special care units, respectively. The samples for 6 of the 9 studies were very small (under 12 individuals each). One of the 3 remaining studies had a sample of 32 subjects, and one had a sample of 53 subjects (24,245). The sample size for the ninth study is not specified in the study report (22).

Table 4-1 lists the physical design and other changes made to create the special care units, as described in the study reports. These changes differed from one special care unit to another. Some changes that were made to create one or more of the units may not have been mentioned in the study reports.

Each of the nine studies found some positive outcomes of the special care units, as summarized below. The study reports emphasize these positive outcomes. Negative outcomes are also reported, but they receive less emphasis in the study reports. The statistical significance of the studies' findings was computed in only four of the nine studies. In the following discussion, OTA uses the terms *statistically significant* and *significant* for research findings with a P value of 0.05 or less.

Bell and Smith found statistically significant improvements in behavior among residents of a newly created 24-bed special care unit (22). Over a 3-month period, the residents became significantly more likely to exhibit three behaviors defined as "positive' by the researchers-having a clean face, having clean clothes, and walking alone. At the end of the 3-month period, the frequency of these behaviors among residents of the newly created unit was similar to their frequency among residents of a 26-bed special care unit that had been operating for over a year. This outcome fit the researchers' hypothesis that behaviors they defined as positive would increase over time in the new unit and behaviors they defined as negative would decrease

Table 4-I—Evaluative Studies Without a Control Group

Citation	Year of the Study	Funding Source	Subjects	Duration of study	Changes Made to Create the Special Care Unit
Bell and Smith, unpublished manuscript	1986	no funding source reported	residents of one 24-bed special care unit and one 28-bed special care unit	6 *months,* from 3 months before to 3 months after the 24-bed unit opened	locked access doors; secure outdoor area; separate lounge, dining area and nurses' station; increased staff-to-resident ratio compared to nonspecialized units in the same two facilities; staff training by the Denver Alzheimer's Association Chapter; efforts to involve families.
Benson et al., 1987 and Cameron et al., 1987	1984-1985	no funding source reported	32 residents of a 46-bed special care unit	one *year*, from just before to one year after the unit opened	unlocked access doors with alarms and double doorknobs; special activity programs; sensory stimulation; reality orientation; personal markers on residents' doors; orientation boards; ongoing staff training; family support groups.
Bullock et al., unpublished manuscript, 1988	1987	no funding source reported	11 residents of a 20 bed special care unit	8 months, from 4 months before to 4 months after the unit opened	"quiet, predictable environment;" increased staff-to-resident ratio compared to the rest of the facility.
Cleary et al., 1988	not reported	no funding source reported	11 residents of a 16-bed special care unit	6 *months,* from 3 months before to 3 months after the unit opened	closed access doors; separate dining and activity areas; efforts to reduce stimulation; consistent dally routine; neutral colors and design; no TV or radio; only one phone; visitor and staff traffic through the unit limited to reduce stimulation; training programs for staff and families.
Greene et al., 1985	not reported	no funding source reported	6 residents of a 26-bed special care unit	4 *months,* from before admission to 4 months after admission for 5 subjects, and one month, from before admission to one month after admission for one subject	locked access doors; separate dining room and day room; calm, reassuring approach; flexible daily routine; familiar background music; residents encouraged to bring in personal Items; 40 hours of staff training; efforts to Involve families.
Hall et al., 1966	not reported	no funding source reported	12 residents of a 24-bed unit that also housed nondemented chairfast residents	*3 months,* from the time the unit opened to 3 months after it opened	unlocked access door; minimal remodeling; efforts to reduce stimulation; no mirrors; no TV; no public address system; home-like atmosphere; textured wall hangings; chairs placed in the corridor to encourage resting; flexible dally routine; residents fed In small groups; visitor and staff traffic through the unit limited to reduce stimulation; no Increase in staff; ongoing staff training; efforts to involve families; family support groups.
Lawton et al., 1984 and Liebowitz et al., 1979	1973-1974	no funding source reported	53 residents of 3 identical 40-bed special care units in a 120-bed nursing home designed for persons with dementia	19 *months,* from one year before to 7 months after the units opened	locked access doors; resident bedrooms situated on three skies of a large central space; designated dining and activity areas; open, centrally located nurses' station; therapeutic kitchen for residents; lounge for residents and their families; staff offices located just outside the unit; movable furniture in central area; washable, vinyl wall coverings in neutral colors; fabric wall hangings; mirrors in residents' rooms; large dock; orientation board; color-coded door jams and bedrooms; residents' name on bedroom door; toilet In each bedroom.
McCracken and Fitzwater, 1988	not reported	no funding source reported	11 residents of a special care unit; unit size not reported	one year, from before to one year after the unit opened	closed unit; no other features of the unit are described in the study report.
Mummah-Castillo, 1987	1983-1984	no funding source reported	10 residents of a 22-bed special care unit	*one year,* from 6 months before to 6 months after admission	doorways painted in contrasting colors; enclosed outdoor area with nonpoisonous plants; furniture with rounded edges; medication carts and housekeeping carts locked; residents encouraged to bring in personal items; home-like atmosphere; visual cues; clocks, calendars, and orientation boards; reminiscence therapy; pet therapy; cooking; encourage resident participation In activities; staff training; staff selected specifically for the unit; efforts to involve families.

SOURCE: Office of Technology Assessment, 1992.

and eventually reach the same frequency as in the old unit.

Other findings of Bell and Smith's study did not fit their hypothesis. Use of physical restraints, which was significantly higher in the new unit than the old unit at the beginning of the study, increased in both units over the course of the study (22). In addition, at all times during the study, residents of the old unit were significantly more likely than residents of the new unit to exhibit two behaviors defined as negative by the researchers-being incompletely dressed and talking to oneself. One "positive" behavior—talking with others-was significantly more common in the new unit than the old unit, but increased over time in the old unit. Thus some negative behaviors were more common in the old than the new unit, and one positive behavior increased in the old unit over time. "Negative' behaviors, such as shouting, swearing, and hitting, were rare on both units, and their frequency did not change over time.

Benson et al. found statistically significant improvements in mental and emotional status, hygiene, and other physical functions among 32 residents of one 46-bed special care unit (24). Compared with baseline values at the time of the residents' admission to the unit, significant improvements were found at both 4 months and 1 year in the following aspects of the residents' mental and emotional status: the residents made more decisions, comprehended more, were more responsive, exhibited greater interest in themselves and others, and were judged by the researchers to be less lonely, anxious, apathetic, depressed, and self-centered. Improvements in hygiene and other physical functions included increased cleanliness and neatness, better eating habits, normal bowel habits, and normal urinary function. Residents also had less difficulty sleeping, took fewer sedatives, had less diarrhea, and were less malodorous. No statistically significant changes were noted over the l-year course of the study in the proportion of residents who were dependent in activities of daily living (i.e., bathing, dressing, eating, transferring, or walking) or in the proportion of residents who exhibited five behavioral symptoms (i.e., regressive behavior, wandering, nighttime agitation, assaultiveness, and abusiveness) (70).

Bullock et al. found improvements in behavior among 13 female residents of a 20-bed special care unit (56).[1] The researchers compared the frequency of 11 behavioral symptoms over an 8-month period from 4 months before until 4 months after the unit opened. The 11 behavioral symptoms were agitation, anxiety, combativeness, insomnia, resistiveness, uncooperativeness, restlessness, withdrawal, verbal abusiveness, yelling, and taking off one's clothes. In the 4 months after the special care unit opened, the frequency of 9 of the 11 behavioral symptoms was greatly reduced (from 12 to 84 percent, depending on the behavior). The frequency of the other 2 behavioral symptoms—resistiveness and verbal abuse-increased 5 percent and 20 percent, respectively. No other negative outcomes are noted in the study report. On the positive side, the report notes slight reductions in the dosages of psychotropic medications received by some of the residents. The statistical significance of the study's findings was not computed.

As part of the study by Bullock et al., brief interviews were conducted with the unit residents (56). The residents were asked whether they liked the unit; whether they were "very happy," "pretty happy," or "not so happy;' whether they were treated well; and whether they were worried or relaxed. In general, the residents expressed positive attitudes toward the unit. No attempt was made to evaluate the reliability or validity of their responses. Moreover, since the interviews were conducted only once, after the unit opened, it is not clear whether there were changes in the residents' attitudes that could be attributed to the impact of the special care unit.

Cleary et al. found statistically significant improvements in several aspects of the functioning and physical condition of 9 residents of a 16-bed special care unit which is described in the study report as a "reduced stimulation unit" (88). Over a 6-month period from 3 months before to 3 months after their admission to the unit, the residents' average scores improved significantly on the Haycox Dementia Behavior Scale (176), an assessment instrument that

[1] This study differs from the other studies discussed in this section because the special care unit was in a mental hospital rather than a nursing home. OTA has included the study in this analysis of evaluative research on special care units because, like the other special care units included in the analysis, this special care unit is intended to serve only individuals with Alzheimer's disease and related dementias. Other studies that have evaluated specialized units in mental hospitals have focused on units that serve elderly persons with a variety of psychiatric conditions as well as dementia.

includes measurements in 8 areas (language/conversation, social interaction, attention/awareness, spatial orientation, motor coordination, bowel and bladder control, eating and nutrition, and dressing and grooming). The special care unit residents also became significantly less agitated; use of physical restraints was significantly reduced; and the residents' weight increased. No changes were noted in residents' sleep patterns or use of psychotropic medications. The researchers observed more interactions among residents and between residents and staff members, but the study design did not include a measure of these interactions.

As part of the study by Cleary et al. interviews were conducted with the unit residents to assess their feelings of security and well-being (88). The residents were asked the same six questions at four times before and four times after the unit opened. They were asked whether they felt safe; whether they got the help they needed; whether they got enough to eat; whether the unit was "a good place;' whether they had a place to sleep; and whether they were afraid. Nine of the 11 residents in the study sample completed all the interviews. In general, the residents expressed a high level of security. Their responses were also highly consistent, suggesting it is possible to obtain consistent responses from some nursing home residents with dementia. Whether the residents' responses reflect their true feelings is not known.

Greene et al. found improvements in behavior and other aspects of functioning among 6 residents of a 26-bed special care unit (160). The researchers compared the frequency of 10 negative indicators over a 4-month period for 5 of the residents and over a l-month period for one resident. The 10 negative indicators were hostility, agitation, decreased appetite, failure to feed oneself, combativeness, failure to ambulate, incontinence, inability to dress oneself, withdrawal, and hallucinations. The frequency of eight of these indicators decreased to zero over the course of the study, and the frequency of the other two indicators-hostility and failure to ambulate—was greatly reduced. An improvement in cognitive skills was found in two of the three residents in whom cognitive skills were measured. An improvement in mood was found in the three residents in whom mood was measured. The statistical significance of the study's findings was not computed.

Hall et al. found reduced use of psychotropic medications and desirable weight gain in residents of a 24-bed special care unit described in the study report as a "low stimulus unit" (171). In the 3-month period after their admission to the unit, psychotropic medication use was reduced or eliminated in 5 of the 12 individuals in the study sample. Prior to their admission to the special care unit, all 12 individuals had been losing weight. In the 3 months after their admission to the unit, 6 of the residents gained weight; 5 stopped losing weight, and one continued to lose. The statistical significance of the study's findings was not computed.

The study by Hall et al. was intended to evaluate the effectiveness of the special care unit in reducing catastrophic reactions, defined by the researchers to include outbursts of noisiness, agitation, combativeness, sudden withdrawal, increased confusion and fear, intensified pacing, and nighttime wakefulness (171). The study did not include quantitative measurements of these indicators, however. The researchers observed a decreased incidence of two of the indicators-agitation and nighttime wakefulness. Other positive outcomes were also observed, including increased social interaction among the residents, decreased wandering, and reduced incidence of delusions. The researchers point out, however, that these positive findings are based on subjective evaluations and that objective measurements of various outcome indicators are needed.

Lawton et al. found statistically significant increases in friendliness and interest among 53 residents who were moved from a 350-bed nursing home to three 40-bed special care units in a new 120-bed nursing home (245). The researchers compared the residents' cognitive and self-care abilities, behavior, and mood at 4 times in the l-year period before the move and 2 times, one month and 7 months, after the move. Over the 19-month period of the study, the subjects showed a significant decrease in cognitive and self-care abilities. Following the move, the subjects spent less time in their bedrooms and more time in the social spaces, but there were no significant changes in social behavior, involvement in planned or staff-supervised activities, ambulation, behavioral symptoms, use of restraints, or time spent sleeping or doing nothing. There was an increase in solitary activities and a decrease in self-maintenance activities. Although the residents were judged by the staff to be significantly more friendly and interested after the move, they were also judged to be

significantly more depressed. There were no statistically significant changes in any of the other mood states studied (i.e., anxiety, anger, happiness, amusement, agitation, and tranquility).

Lawton et al. also compared the behavior of 80 residents of the 3 special care units and 40 residents of the old 350-bed nursing home (245).[2] The comparison showed the special care unit residents were significantly more likely than the residents of the old nursing home to be involved in planned and staff-supervised activities and significantly less likely to exhibit behavioral symptoms. On the negative side, the special care unit residents were significantly less likely to be involved in self-maintenance activities. There were no significant differences between the special care units residents and the residents of the old nursing home in social behavior, ambulation, involvement in solitary activities, or time spent sleeping or doing nothing.

McCracken and Fitzwater found improvements in special care unit residents' scores on the Haycox Dementia Behavior Scale (297), (as did Cleary et al., discussed earlier). Over the l-year period of the McCracken and Fitzwater study, 8 of the 11 individuals in the study sample showed improvements in their overall scores on the scale. Improvements were noted in all but two of the measured characteristics-motor coordination and dressing and grooming. The three subjects whose overall scores on the scale did not improve showed the **greatest** decline in these two areas, as well as bowel and bladder control, eating and nutrition, and spatial orientation. The statistical significance of these findings was not computed.

Mummah-Castillo found reductions in the dosages of psychotropic medications and desirable weight changes in residents of a 22-bed special care unit (312). Over a l-year period from 6 months before to 6 months after their admission to the unit, 9 of the 10 individuals in the study sample showed a weight gain, and the dosages of psychotropic medications were decreased for 7 of the 10 subjects. The statistical significance of these findings was not computed. The researchers observed that aggressive behaviors and catastrophic reactions **were rare on the unit, but the incidence of these behaviors was** not measured.

In Summary, all nine studies found some **positive** outcomes of the special care units they evaluated. The positive outcomes vary from one study to another, and some of the findings are contradictory. As noted earlier, if the contradictory findings are excluded, the only positive outcomes found in more than one of the nine studies are decreased nighttime wakefulness, improved hygiene, and weight gain.

These studies are frequently cited as evidence that special care units are effective. Often the researchers' general observations, rather than a study's specific findings, are cited. In many instances, findings that are cited from one study are contradicted by findings of another study.

All the studies suffer from one or more problems that raise questions about the validity of their findings-both positive and negative. One of these problems is small sample sizes. The second problem is the lack of rigorous research design and implementation. In many of the studies, the outcomes to be measured are not clearly defined, and the measurement process is more impressionistic than objective or standardized. As noted earlier, the statistical significance of the findings was computed in only four of the nine studies. Failure of the studies to include a control group is another 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 operating 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 means the results of the studies must be suspect.

2 This component of the study had a pre-post design like the other studies discussed in this section and an apparent control group like the studies in the following section of the chapter. The study is included in this section because the status of the control group is unclear. Some, but not all, of the 80 special care unit residents were among the 40 residents of the old nursing home who constituted the control group (245). The study report provides no information about the special care unit residents who were not among the 40 residents of the old nursing home that constituted the control group,

EVALUATIVE STUDIES WITH A CONTROL GROUP: EFFECTS ON RESIDENTS

OTA is aware of six evaluative studies of special care units in which a control group was used (see table 4-2). The samples for these six studies are, on average, larger than the samples for the studies discussed in the previous section. The six studies vary in the outcomes they studied and their duration. The control groups they used also vary: four of the studies used a control group consisting of individuals with dementia in nonspecialized nursing home units that also serve nondemented residents; one study used a control group consisting of individuals with dementia in a segregated but nonspecialized unit; and one study used a control group consisting of individuals on the waiting list for admission to a special care unit. As described below, only two of the six studies found any statistically significant positive outcomes for the special care unit residents.

Chafetz compared changes in cognitive and behavioral characteristics over a 15-month period in 12 residents of a 30-bed special care unit and 18 residents of a 60-bed nursing home unit that served only individuals with dementia but provided no specialized services (80). The study was designed to test the hypothesis that cognitive abilities would decline equally over time in residents of the two units, whereas behavior would decline less in residents of the special care unit. As shown in table 4-2, the staff-to-resident ratios were similar in the two units, but the special care unit staff members were specifically selected and trained to work on the unit. The special care unit provided family meetings and a more extensive activity program than the nonspecialized unit, and a few physical design features distinguished the special care unit from the nonspecialized unit. The study found that both cognitive abilities and behavior worsened over time in residents of the two units. The special care unit had no statistically significant effect on residents' cognitive abilities or their behavior, and there were no positive outcomes that could be attributed to the special care unit.

Coleman et al. compared the rate of hospitalization over a l-year period for 47 residents of 2 special care units and 58 residents of 2 nonspecialized units in the same nursing home (99). The 58 residents of the nonspecialized units included 36 individuals who had a diagnosis of dementia and 22 individuals who did not have a diagnosis of dementia. The study was designed to determine whether special care unit residents are less likely than residents of nonspecialized units to be hospitalized. The staff-to-resident ratios were the same for the special care units and the nonspecialized units. The study report does not describe the differences in physical design or other features of the units. The study found no statistically significant difference in the rate of hospitalization for the special care unit residents and the residents of the nonspecialized units. There was, however, a nonsignificant trend for a larger proportion of the special care unit residents to be hospitalized over the course of the study (21 percent vs. 14 percent, respectively). The higher rate of hospitalization for the special care unit residents was due primarily to a higher incidence of hip fractures: 9 percent of the special care unit residents, compared with only 3 percent of the residents of the nonspecialized units, were hospitalized for hip fractures.

Holmes et al. compared changes in cognitive, functional, and behavioral characteristics over a 6-month period in 49 residents of 4 special care units and 44 individuals with dementia in nonspecialized units in the same 4 nursing homes (195). The study was designed to measure the impact of a special care unit vs. a nonspecialized nursing home unit on individuals with dementia. Table 4-2 lists the many differences between the special care units and the nonspecialized nursing homes in terms of staff, activity programs, and physical design features. Baseline measurements indicated there were statistically significant differences between the special care unit residents and the residents of the nonspecialized units at the start of the study. The special care unit residents were, for example, more likely than residents of the nonspecialized units to be disoriented and to exhibit behavioral symptoms. The special care unit residents were also more likely to be able to ambulate independently. After 6 months, the study found little change in any of the measured resident characteristics, including cognitive abilities, mood, ability to perform activities of daily living, frequency of behavioral symptoms, sleep problems, and ability to ambulate independently. Taking into account differences between the special care unit residents and residents of the nonspecialized units at the beginning of the study, the researchers found no statistically significant positive

Table 4-2—Evaluative Studies With a Control Group

Citation	Year of the Study	Funding Source	subjects	Duration of study	Changes Made to Create the Special Care Unit
Chafetz, 1981	1985-1987	University of Texas southwestern Medical Center and Its affiliated Alzheimer's Disease Research Center	12 residents of a 30-bed special care unit and 8 residents of a 60-bed unit In which individuals with dementia were segregated but no special services were provided	13 to 15 months	in the special care unit: access door secured with special locks; secure outdoor area; 34 hours per week of specialized activities; staff selected specifically for the unit; staff training over a 10-week period and ongoing training; efforts to involve families; family meetings every 6 to 8 weeks. in the comparison unit: no special physical design features; 5 hours per week of nonspecialized activities; no special staff training or special efforts to involve families.
Coleman et al., 1990	1987-1988	University of California, San Francisco, School of Mealicine, and U.S. Health Resources and Services Administration	46 residents of two 28-bed special care units and 58 residents of two 28-bed nonspecialized units in the same facility (of the 58 residents of the nonspecialized units, 36 had dementia, and 22 did not)	one year	no physical design or other special features of the special care units are described in the study report; the report says that the distinguishing features of the special care units "are similar to those found in the literature;" the staff-t-resident ratios were the same on the special care units and the nonspecialized units.
Holmes et al., 1990	not reported	no funding source reported	49 residents of special care units in 4 nursing homes and 44 residents with dementia in nonspecialized units	6 months	in the special care units: dosed access doors with alarms; furniture with rounded edges; special activity rooms; nurses' station located near the exits to facilitate monitoring residents; special activity programs; reality orientation; music programs; Increased staff-to-resident ratios; staff training; multidisciplinary team care. in the comparison units: no special physical design features, activity programs, or staff training.
Maas and Buckwalter, 1990	1986-1988	National Center for Nursing Research	13 residents of a 20-bed special care unit in a State-owned veterans home and 9 residents with dementia in nonspecialized units of the same facility	2 years	in the special care unit: locked access doors; access doors camouflaged with murals; secure outdoor area; separate day room/dining room; dividers in resident rooms to provide privacy; residents' beds dose to the floor; curtains and wall hangings with velcro fasteners to prevent damage if residents pull on them; safety mirrors; safety glass; supplies stored out of view; no highly waxed floors; no stairs In the unit; residents' lockers and all but one drawer are locked to prevent rummaging; flexible daily routine; efforts to reduce stimulation; subdivided dining room to allow residents to eat In small groups; fabric wall decorations; colors that are "functionally stimulating and reassuring;" orientation signs; piped-in music; pet therapy; specialized activity programs; activity barrel filled with pliable plastic items for residents; multidisciplinary team; consistent staff; efforts to involve families. in the comparison units: no special physical design features, activity programs, or staff training.
Rovner et al., 1990	1885-1886	Johns Hopkins University's affiliated Alzheimer'sDisease Research Center	14 residents of a 22-bed special care unit which is part of a 31-bed unit and 14 residents with dementia in nonspecialized units of the same facility	one year	in the special care unit: an activity room; staff training; weekly rounds with a psychiatrist and internist; staff efforts to identify residents' specific cognitive Impairments, to treat depression, delusions, and hallucinations, to recognize medication side effects, to maintain residents' physical health, to reduce use of physical restraints, and to increase participation in activities; 40 hours a week of specialized activities. in the comparison units: no special physical design features, activities, or staff training; less hours of nursing care per resident (2.1 hours/day in the nonspecialized units vs. 2.9 hours/day In the special care unit).
Wells and Jorm, 1987	1986	no funding source reported	12 residents of a special care unit in Australia and 10 individuals with dementia who were on the waiting list for the unit and living at home	3 months, from just before admission to the unit to 3 months after admission	In the special care unit: corridors designed for wandering; secure outdoor area; private rooms; several activity rooms; home-like atmosphere; residents encouraged to bring their own furniture; unit philosophy of "normalization." for the comparison group: respite care, adult day care, and in-home services as needed.

SOURCE: Office of Technology Assessment, 1992.

outcomes that could be attributed to the special care unit.

Maas and Buckwalter compared changes in cognitive, fictional, behavioral, and other characteristics in 13 residents of a 20-bed special care unit and 9 individuals with dementia in nonspecialized units in the same facility (265). The study was designed to measure the effect of a "low stimulus' special care unit vs. nonspecialized nursing home units on residents with dementia, their families, and the unit staff members. As noted in table 4-2, many physical design and other changes were made to create the special care unit. Extensive baseline data were collected in the year before the unit opened (264). After the unit opened, data were collected for one year at 2-month intervals. Due to subject attrition, complete data for the 22 subjects are available for only a 10-month period, from 4 months before to 6 months after the unit opened (265). These data show no statistically significant differences over time in the cognitive or functional abilities of the special care unit residents and the individuals with dementia in the nonspecialized units. The most frequently reported behaviors for both groups of residents were "sleeping/resting, ' ' 'quiet, ' and "pleasant/happy." Catastrophic reactions occurred, but their frequency decreased significantly from baseline levels for both groups of residents.[3] Nevertheless, catastrophic reactions were significantly less frequent in the special care unit residents than in the individuals with dementia in the nonspecialized units. The special care unit residents were also significantly more likely than the individuals with dementia in the nonspecialized units to interact with staff. There were no significant differences between the two groups in the frequency of their interactions with other residents or family members. The researchers noted a general trend for the subjects to become more active after being admitted to the special care unit. This increased activity included both positive and negative behaviors. The researchers point out that:

> Behaviors such as "screaming/yelling," "pacing," "noisy,' and "restless," as well as a decrease in "cooperative' behavior may be seen as nonconstructive. Positive behaviors such as "pleasant/happy, " "talking/visiting," "a wake," and "up and about,' were all reported more frequently among the experimental group. . . Viewed singly, no one behavior (changed) significantly. However, when viewed (together), it seems that important changes in overall level of activity were occurring after introduction of the special care unit (265).

Other results of the study show that for their first four months in the unit, the special care unit residents were significantly less likely to be physically restrained than the individuals with dementia on the nonspecialized units, but for the next 2 months, the special care unit residents were significantly more likely to be physically restrained. Use of antipsychotic medications was significantly higher for the special care unit residents both at baseline and following their admission to the special care unit. There was no significant difference between the two groups in the total number of medications of all kinds that they were taking. Lastly, the special care unit residents were significantly more likely to fall than the individuals with dementia on the nonspecialized units, but the increased incidence of falls was not accompanied by an increase in injuries due to falls.

Rovner et al. compared changes in fictional ability over a l-year period in 14 residents of a 22-bed special care unit and 14 individuals with dementia in nonspecialized units in the same nursing home (392). As shown in table 4-2, the special care unit provided more hours of nursing care and more activity programs than the nonspecialized units. Only one physical design change was made to create the unit. In the view of the researchers, the distinguishing features of the special care unit were the efforts of its multidisciplinary staff to accomplish six objectives: 1) to identify residents' specific cognitive impairments and associated disabilities, 2) to treat depression, delusions, and hallucinations, 3) to identify medication side effects; 4) to maintain residents' physical health; 5) to reduce use of physical restraints, and 6) to increase residents' participation in activities. Baseline measurements indicated that the special care unit residents were significantly younger, on average, than the residents of the nonspecialized units and that the special care unit residents were less likely to be taking medications of all types. The study found that over a l-year

[3] *Catastrophic reaction* was defined in this study as "a reaction (mood change) of the resident in response to what may appear to staff to be minimal stimuli (bathing, dressing, having to go to the bathroom, a question asked of the person) which can be characterized by weeping, blushing, anger, agitation, or stubbornness. The reaction is not necessarily very dramatic or violent, but may appear over-emotional or not appropriate for the stimulus' (265).

period, there was much less decline in the fictional abilities of the special care unit residents than the residents of the nonspecialized units: 14 percent of the special care unit residents and 64 percent of the residents of the nonspecialized units declined in their "level of care" as determinedly the number of activities of daily living with which they needed assistance. This statistically significant positive outcome is attributed by the researchers to the impact of the special care unit.

Wells and Jorm compared changes in cognitive, functional, and behavioral characteristics over a 3-month period in 12 residents of an Australian special care unit and 10 individuals who were on the waiting list for the unit and living in the community (489). The study was designed to compare the effect on individuals with dementia and their families of being in a special care unit vs. being deferred from admission. The study findings with respect to the impact on the subjects' families are discussed later in this chapter. The physical changes made to create the special care unit included an environmental design to allow wandering, a secure outdoor area, and efforts to create a home-like atmosphere. Most of the individuals on the waiting list received respite care, and some received adult day care or in-home services. The study found that over a 3-month period, the cognitive and functional abilities and behavior of all the subjects declined. Except for a temporary worsening of behavioral symptoms among the special care unit residents in the first month of the study, there was little difference in the rate of decline in these characteristics between the special care unit residents and the individuals on the waiting list.

In summary, four of the six evaluative studies that used a control group found no statistically significant positive resident outcomes that could be attributed to the special care unit. One of the studies with a positive resident outcome found that over a l-year period the special care unit residents showed significantly less decline than individuals with dementia in the nonspecialized units in their ability to perform activities of daily living (392). The three other studies that used a control group and measured residents' ability to perform activities of daily living found no significant effect of the special care units in this area. The second study with positive resident outcomes found that special care unit residents exhibited significantly fewer catastrophic reactions than residents with dementia in the nonspecialized units (265). The special care unit residents also interacted significantly more with staff members.

The research design and implementation of these six studies are far more rigorous than the design and implementation of the nine studies discussed earlier that did not use a control group. The outcomes are more precisely defined and measured in these six studies, and their use of a control group increases the presumed validity of their findings.

On the other hand, there are one or more problems with each of the studies that could affect the validity of their findings-both positive and negative. One problem is that several of the studies were conducted by individuals who were involved in planning or working on the special care unit that was the focus of the study. In one of the two studies that found a positive resident outcome (392), the nurses who evaluated the residents' ability to perform activities of daily living were unit staff members whose judgments about the residents could have been biased by their expectations about the effectiveness of the special care unit.[4]

A second problem that could affect the validity of the findings of some of the studies discussed in this section is selection bias. 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 any observed differences in outcomes. To address this problem, all six studies discussed in this section compared the characteristics of the special care unit residents and control group subjects at the beginning of the study, and several of the studies used statistical methods to correct for any observed differences in the two groups.

As discussed in chapter 1, randomization of subjects to the special care unit or the control group would be the ideal way to address the problem of entry point differences among subjects. Two of the studies discussed in this section (265,489) randomly assigned subjects to the special care unit or the

[4] In addition to bias introduced by staff members' expectations, a more subtle form of bias could arise in this and other studies that rely on staff members' evaluations of residents' ability to perform activities of daily living as a result of differences in the way impairments in activities of daily living are perceived on a special care unit vs. a nonspecialized nursing home unit.

control group. Randomization of subjects apparently worked well in the 3-month study by Wells and Jorm (489). Randomization also worked well initially in the longer study by Maas and Buckwalter but eventually broke down, in part because some families were reluctant to move their relative who was doing well in a nonspecialized unit to the special care unit to meet the requirements of the study design (265).

A third methodological problem—and one that could affect the validity of the findings of Rovner et al. (392)—is failure to measure differences in the cognitive abilities of the special care unit residents and control group subjects at the end of a study. As noted earlier, the outcomes measured in the study by Rovner et al. were changes in the subjects' ability to perform activities of daily living (392). In individuals with dementia, ability to perform activities of daily living is related to some degree to cognitive ability (369,508). The special care unit residents and control group subjects in this study did not differ significantly in their cognitive abilities at the beginning of the study, but their cognitive abilities were not measured at the end of the study, and significant differences could have developed. If such differences did develop, they, rather than the impact of the special care unit, could account for the observed differences in the proportion of special care unit residents vs. control group subjects that declined in their ability to perform activities of daily living.

In addition to these methodological problems, there are difficulties in interpreting the findings of the six evaluative studies. In all six studies, the special care units differ in many ways from the control group settings. It is unclear whether particular features of the special care units or their overall milieu account for the studies' findings. A third possibility proposed by Rovner et al. as an explanation for the findings of their study is that increased staff attention to the unit residents could account for the positive outcome, irrespective of any special features of the unit (392). In all these studies, it is also possible that certain aspects of the special care units (i.e., particular features, milieu, or staff attention) have a positive impact and other aspects have a negative impact, and that the two types of impacts cancel each other out. Still another possibility is that certain aspects of the special care units have a positive impact on some residents and a neutral or negative impact on other residents, and that these impacts cancel each other out. Small sample sizes, lack of a common taxonomy for classifying individuals with dementia across studies, and lack of a precise description of the features of each of the special care units make it impossible at present to differentiate among these various explanations.

The one study that found a significant positive effect of a 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). Instead, the "special" features of the unit, in the view of the researchers, were staff efforts to identify residents' specific cognitive impairments, to treat depression, delusions, hallucinations, and medication side effects, to maintain residents' physical health, and to increase their involvement in activities. Ongoing involvement of a psychiatrist on the staff seems to be unique to this study. Whether any of these features are different enough from the features of the special care units in the other studies to explain their contradictory findings cannot be determined from the available data.

STUDIES OF PARTICULAR FEATURES AND INTERVENTIONS IN SPECIAL CARE UNITS: EFFECTS ON RESIDENTS

Unlike studies that evaluate the overall impact of a special care unit, some studies evaluate the effect of particular features and interventions in a special care unit. Such studies do not constitute special care unit research in the same sense as the studies discussed earlier in this chapter because the features and interventions generally can be used in nonspecialized nursing home units and other residential and nonresidential care settings as well as in special care units. The research to evaluate these features and interventions can also be conducted in other settings. For these reasons, studies of particular features and interventions in special care units are not discussed in the same detail in this report as studies that evaluate the overall impact of the units.

The particular features and interventions that have been studied most in special care units are various devices and visual barriers to stop individuals with dementia from escaping or wandering away from the unit. To OTA's knowledge, the frost research on interventions of this kind was a study conducted in the geriatric ward of a psychiatric hospital (198).

That study found that when strips of tape were placed in any of four different grid patterns on the floor in front of the exit doors, the frequency with which demented patients approached and touched the doors decreased significantly. Two other studies have attempted unsuccessfully to replicate these results in special care units (75,77,316). Both studies found that use of strips of tape in front of the exit doors resulted in a temporary increase but no significant long-term change in the number of times per day the special care unit residents opened the exit doors.

Other interventions to stop individuals with dementia from escaping or wandering away have also been tested in special care units. Chafetz found that use of a second spring-loaded latch on the exit doors stopped residents of one special care unit from opening the doors (75,77). Namazi et al. found that concealing the exit doors with either a beige cloth or a green patterned cloth stopped residents of another special care unit from opening the exit doors (316). Two other interventions-painting the door knob the same color as the door and using a door knob cover that allows the knob to turn only when pressure is applied-also decreased the frequency with which special care unit residents opened the exit door (316). The latter two interventions were not as effective as concealing the doorknob with apiece of cloth, however.

Researchers at the Corinne Dolan Alzheimer's Center in Chardon, OH, have conducted studies on many other features and interventions in special care units. The center was designed to facilitate research of this kind. It has 2 separate but essentially identical wings, each housing 12 residents, so alternate interventions that require physical design or other modifications to the unit can be tested in the 2 wings simultaneously and their outcomes compared. Eight interventions studied recently at the center are:

1. use of "significant" vs. "nonsignificant" personal belongings in showcases next to residents' rooms to help them identify their rooms;
2. use of clearly visible toilets in residents' rooms vs. toilets that are concealed behind a curtain to help them locate the bathroom and remain continent;
3. use of certain types, colors, and placements of signs to help residents locate the bathrooms and remain continent;
4. use of partitions of various heights in the dining room and the activity rooms to reduce distractions for residents;
5. use of unlocked vs. locked doors to an enclosed courtyard to enhance residents' sense of autonomy;
6. use of special closet doors that allow residents to see only one set of clothing at a time vs. ordinary closet doors to help residents dress themselves independently;
7. use of refrigerators with glass doors vs. ordinary refrigerators with opaque doors to allow residents to see food and thereby encourage them to eat when they are hungry; and
8. use of familiar tasks (e.g., washing dishes and dusting) vs. unfamiliar tasks (e.g., untangling a box of hangers) to engage residents' attention and sustain their interest (314).

Results of some of these studies were published in late 1991 (317), and results of the other studies will be published in 1992.

The Dementia Study Unit in the Geriatric Research, Education, Clinical Center (GRECC) at the E.N. Rogers Memorial Veterans Hospital in Bedford, MA, has also conducted studies on many particular interventions in special care units. The Dementia Study Unit includes three special care units that serve elderly veterans with dementia. The interventions evaluated in the Dementia Study Unit include:

- use of a hospice-like approach in the care of 40 severely demented special care unit residents (474);
- substitution of normal feeding for tube feeding in six special care unit residents who were being tube fed on admission to the unit (475);
- use of a few beds on one of the special care units to provide respite care for 22 veterans with dementia who were still living in the community (238,405);
- use of antibiotics vs. palliative measures to treat fevers in special care unit residents (135); and
- use of dietary changes and enforced rest periods to maintain normal body weight in six special care unit residents who paced constantly (376).

Studies to evaluate the impact of other features and interventions have been conducted or are underway

in special care units at several other VA medical centers (159).

An analysis of the results of studies of particular features or interventions in VA and nonVA special care units and a comparison of these results with the results of similar studies conducted in nonspecialized nursing home units and other residential and nonresidential care settings is beyond the scope of this report. The important point is that the existence of special care units probably encourages research to evaluate particular features and interventions. It is easier and more efficient to conduct this type of research in a special care unit, in part because all the residents have dementia. In addition, as discussed in chapter 1, the existence of special care units focuses attention on the special needs of nursing home residents with dementia and thereby encourages research to evaluate particular features and interventions to address those needs.

Research on particular features and interventions may help to explain the findings of studies that evaluate the overall impact of special care units. If particular features or interventions are shown to be effective or ineffective in general or for certain types of residents, those findings may explain the contradictory results of studies that evaluate the overall impact of the units. More importantly, however, this research may identify features and interventions that can be used not only in special care units but also in nonspecialized nursing home units and other residential and nonresidential care settings to improve the care of individuals with dementia.

STUDIES THAT EVALUATE THE EFFECTS OF SPECIAL CARE UNITS ON UNIT STAFF MEMBERS

OTA is aware of four studies that evaluate the effect of special care units on unit staff members over time. Two frequently cited reasons for establishing special care units are: 1) a belief that training about dementia can be more easily and effectively provided for the staff of a special care unit than for the staff of nonspecialized nursing home units and therefore that special care unit staff members are likely to be more knowledgeable about dementia, and 2) a belief that it is less stressful for staff members to work with residents with dementia on a special care unit than on nonspecialized units. Three of the available studies measured the effect of a special care unit on staff members' knowledge about dementia; two studies measured the effect of a special care unit on staff stress and burnout, and one study measured the extent to which special care unit and other staff members were disturbed by the behavioral symptoms of residents with dementia.

Chafetz and West compared knowledge about dementia among 1) 11 staff members of one special care unit, 2) 13 staff members of nonspecialized units in the same nursing home, and 3) 30 staff members of nonspecialized units in another nursing home (81). During the 9- to 12-month period of the study, the special care unit staff members participated in 10 weekly training sessions about dementia. The staff of the nonspecialized units did not receive this training. All staff members' knowledge about dementia was measured at the beginning and end of the study using a 20-item true-false quiz. The study found that despite the training received by the special care unit staff members, there were no significant differences among the three groups of staff members in the extent to which their test scores changed over time. The researchers concluded that the training provided for the special care unit staff members did not have a significant or lasting effect on their knowledge about dementia.

Maas and Buckwalter compared knowledge about dementia among 21 special care unit staff members and 55 staff members of nonspecialized units in the same facility (265). During the frost 3 months after the special care unit opened, its staff members and the staff members of the nonspecialized units received 80 hours of training about dementia. The study found that during the baseline period before the unit opened and throughout the course of the study, the special care unit staff members scored slightly higher than the staff members on the nonspecialized units on a 33-item test of knowledge of dementia, but this difference was not statistically significant. There was also no statistically significant change in the scores of the special care unit staff members over the course of the study. Registered nurses (RNs) scored significantly higher than licensed practical nurses (LPNs), nurse aides, and non-nursing staff members, regardless of whether they worked on the special care unit or the nonspecialized units.

Cleary et al. compared knowledge of dementia among the staff of a 16-bed special care unit at one point 3 months before the unit opened and again 3 months after it opened (88). Despite a staff training

program conducted during this time period, the study found no significant change in the staff members' knowledge of dementia. This study did not have a control group.

With respect to job satisfaction, Cleary et al. compared special care unit staff members' scores on a questionnaire administered at one point 3 months before the 16-bed unit opened and again 3 months after it opened (88). The 83-item questionnaire addressed 6 aspects of job satisfaction (working conditions, professional considerations, professional preparation, emotional climate, supervision, and social significance). The study found no significant change in the staff members' scores before and after the unit opened. On the positive side, the researchers point out that the staff members did not seem to react negatively to the isolation of the special care unit, as might have been expected. Moreover, in open-ended interviews, some staff members reported they were spending much less time retrieving patients who wandered away from the unit and were experiencing fewer interruptions when caring for patients. No measurements were made of the latter two outcomes.

Using the same 83-item questionnaire, Maas and Buckwalter compared job satisfaction among 21 special care unit staff members and 55 staff members on nonspecialized units in the same facility (265). The study found job satisfaction was "moderately high" for both groups of staff members during the baseline period before the special care unit opened and throughout the course of the study. There was little difference between the scores of the two groups of staff members on the questionnaire as a whole or any of its six subscales. RNs scored significantly higher than LPNs, nurse aides, and non-nursing staff members on one of the subscales-satisfaction with professional preparation-regardless of whether they worked on the special care unit or the nonspecialized units. After the special care unit opened, LPNs, nurse aides, and other non-nursing staff members who worked on the special care unit scored significantly higher on the same subscale than comparable staff members on the nonspecialized units. There were no significant differences for the staff members on any of the other subscales.

With respect to staff stress, Maas and Buckwalter found a generally low level of stress among 15 special care unit staff members and 49 staff members on nonspecialized units in the same facility both before and after the special care unit opened (265). The special care unit staff members consistently reported less stress than the staff members on the nonspecialized units. Nevertheless, the study found that after the special care unit opened, its staff members experienced a statistically significant reduction in stress, whereas the staff members on the nonspecialized units experienced an increase in stress. The special care unit staff members also had somewhat lower scores than the other staff members on a test of three indicators of burnout-emotional exhaustion, depersonalization, and lack of a feeling of personal accomplishment; this difference in scores was statistically significant for depersonalization but not for the other two indicators. The study's findings with respect to use of sick leave, leave without pay, and overtime are still being analyzed (54).

Finally, in their study of special care units and nonspecialized units in the same four nursing homes, Holmes et al. compared staff members' attitudes toward residents' behavioral symptoms (195). At the beginning of the study, although the special care unit residents had significantly more behavioral symptoms than the demented residents of the nonspecialized units, there was no significant difference between the staff members in the two types of units in the extent to which they reported being disturbed by the residents' behavioral symptoms. After 6 months, there was still no significant difference between the staff members in the two types of units in this regard.

In addition to these four longitudinal studies, two descriptive studies have addressed the issue of staff stress in special care units. One study that compared staff stress on two special care units found that stress was related to the severity of the residents' impairment (506). Staff members on the unit with more impaired residents were more likely to report feeling highly stressed than staff members on the unit with less impaired residents. Interestingly, many of the specific types of stressors identified by staff members on both units were unrelated to resident characteristics and therefore might be expected to occur as frequently in work with nondemented residents and on nonspecialized nursing home units as on special care units. In another study of a nonrandom sample of special care units, the researchers concluded staff stress was related to staff-to-resident ratios: units with less staff per resident were much more likely than units with more

staff per resident to report problems with staff stress (332).

The University of North Carolina study of 31 randomly selected special care units and 32 matched nonspecialized units in 5 States found staff turnover was significantly lower for RNs and LPNs on the special care units (291). Turnover was also lower for nurse aides on the special care units, but this difference was not statistically significant. Accurate interpretation of these findings is difficult because they are based on data collected at one point in time. It is possible that pre-existing differences between the staff members on the two types of units rather than differential effects of the units account for the differences in staff turnover.

In summary, the three longitudinal studies that measured staff knowledge of dementia found no statistically significant effect of the special care units. One of the two studies that measured job satisfaction found a statistically significant improvement in the scores of LPNs, nurse aides, and other non-nursing staff of the special care unit on one of six aspects of job satisfaction. There were no other significant effects of the special care units on job satisfaction. The one longitudinal study that measured staff stress and burnout found a statistically significant reduction in stress among the special care unit staff members and a statistically significant difference between the special care unit staff members and other staff members on one of three indicators of burnout. There were no other significant effects of the special care unit on staff stress or burnout. Lastly, the study that measured the extent to which staff members were disturbed by residents' behavioral symptoms found no significant differences over time for the special care unit staff members and no significant difference between the special care unit staff members and other staff members in this respect.

STUDIES THAT EVALUATE THE EFFECTS OF SPECIAL CARE UNITS ON RESIDENTS' FAMILIES

OTA is aware of four studies that evaluate the effect of a special care unit on residents' families over time. One study conducted in Australia compared the psychological status of 12 family members of individuals with dementia who were admitted to a special care unit and 10 family members of individuals with dementia who were placed on the waiting list and offered in-home services (489). At the beginning of the study, the family members in both groups showed high levels of symptoms on psychological tests of anxiety, depression, guilt, and grief. After 3 months, family members of the special care unit residents showed a statistically significant reduction in symptoms on all the tests. In contrast, family members of the individuals who had been placed on the waiting list showed little change in any of the symptoms, except guilt, which was slightly reduced.

Chafetz measured knowledge about dementia and attitudes toward older people among 12 family members of residents of a 30-bed special care unit (76). Anxiety and depression were measured among 9 of the 12 family members. The study found no statistically significant changes over a l-year period in any of these areas, although there were some nonsignificant improvements in each of the areas except anxiety. This study had no control group.

Cleary et al. measured family satisfaction with care among 11 family members of individuals with dementia who were moved from a nonspecialized unit to a new special care unit in the same nursing home (88). Family satisfaction with the care provided by the nonspecialized unit was quite high, as measured by a 38-item satisfaction questionnaire; nevertheless, family satisfaction increased significantly in the frost 3 months after the special care unit opened. This study had no control group.

In addition to the questionnaire, Cleary et al. conducted open-ended telephone interviews with the family members (88). According to the study report, only 7 of the 11 family members visited their relative with dementia frequently enough in the special care unit to be able to respond in any detail to the open-ended questions. These seven family members reported their relative with dementia was less agitated in the special care unit than he or she had been in the nonspecialized unit. Five of the seven family members also reported they were better able to communicate with their relative in the special care unit. None of the seven family members expressed concern that the special care unit was isolated, and none described difficulties in visiting.

Lastly, Maas and Buckwalter compared family satisfaction with care at 2-month intervals over a l-year period among family members of special care unit residents and residents with dementia in nonspecialized units of the same facility (265). Due to

subject attrition and replacement, the number of family members varied over the course of the study, from 17 to 22 family members of special care unit residents and from 12 to 21 family members of individuals with dementia in nonspecialized units. Both groups of family members reported fairly high levels of satisfaction with the care their relative was receiving. They tended to be most satisfied with their relative's overall care and least satisfied with the nursing care he or she was receiving. Family members of the special care unit residents had somewhat higher satisfaction scores than family members of the individuals with dementia in the nonspecialized units, but these differences were not statistically significant.

In addition to these four longitudinal studies, a number of cross-sectional studies have compared various characteristics of families of special care unit residents and families of individuals with dementia in nonspecialized nursing home units. Since the findings of these studies are based on data collected at one point in time, it is unclear whether they are attributable to the effect of the special care units vs. the nonspecialized units or to preexisting differences between the two groups of families.

The study by Chafetz discussed above had a cross-sectional component that compared knowledge of dementia, attitudes toward older people, anxiety, depression, and guilt among three groups of family members: 1) 18 family members of special care unit residents, 2)7 family members of residents of a nonspecialized nursing home unit that served both demented and nondemented residents, and 3) 8 family members of residents of a unit that served only individuals with dementia but provided no special services (76). The study found no significant differences between family members of the special care unit residents and family members of residents of the two nonspecialized units in any of the measured characteristics. Interestingly, all three groups of family members had low levels of anxiety, depression, and grief. Moreover, in comparison with family members of the individuals in the segregated but nonspecialized unit, family members of the special care unit residents were significantly more depressed and anxious.

A small pilot study done by researchers at the University of North Carolina found that families of individuals with dementia in one special care unit were, on average, more likely than families of individuals with dementia in two nonspecialized units to be satisfied with the physical aspects of the unit and the care their relative received and to feel their relative with dementia was better off in the unit than at home (292). The findings differed for the two nonspecialized units, however. Compared with families of the special care unit residents, families of individuals with dementia in one of the nonspecialized units were as satisfied with the care their relative received, more satisfied with the physical aspects of the care environment, and more likely to believe their relative was better off in the unit than at home. In contrast, families of the residents in the other nonspecialized unit were less likely than families of the special care unit residents to be satisfied with the physical aspects of the unit and less likely to believe their relative was better off in the unit than at home.

Another small pilot study of two special care units and two nonspecialized nursing home units in California found that families of the special care unit residents were less likely than families of residents of the nonspecialized units to be satisfied with the physical aspects of the unit and less likely to believe their relative was better off in the unit than at home (256). Families of the special care unit residents were also less likely to be satisfied with the number of staff members, the adequacy of the care received by their relative, and the willingness of staff members to discuss the family members' concerns.

Finally, the University of North Carolina study of 31 randomly selected special care units and 32 nonspecialized nursing home units in 5 States found that families of the special care unit residents were significantly more likely than families of individuals with dementia in the nonspecialized units to visit their relative regularly (413).

Accurate interpretation of the findings of these cross-sectional studies is difficult because the findings are based on data collected at one point in time and therefore cannot be attributed with certainty to the differential impact of the special care units vs. the nonspecialized units. It is possible, for example, that the finding of the University of North Carolina study--i.e., that families of special care unit residents were significantly more likely than families of individuals in the nonspecialized units to visit their relative with dementia—reflects pre-existing differences between the two groups of families rather than the impact of programs and policies of the two types

of units that might encourage or discourage family visiting.

Insummary, two of the four longitudinal studies that evaluate the impact of special care units on residents' families had statistically significant positive findings. One of the studies found a significant increase in family members' satisfaction with care, and the other study found a significant reduction in family members' feelings of anxiety, depression, guilt, and grief. The other two longitudinal studies found no significant differences in these areas. The two studies that had statistically significant positive findings were much shorter than the two studies that did not have significant positive findings (3 months vs. 1 year, respectively).

One of the four cross-sectional studies had a statistically significant positive finding with respect to the frequency of visiting by families of the special care unit residents, but it is unclear whether this finding is attributable to the impact of the special care units. The findings with respect to family satisfaction with care are contradictory, perhaps reflecting differences among the particular units in the study samples.

CONCLUSION

Based on the preceding review of findings from the available evaluative studies, some conclusions can be drawn about the effectiveness of special care units. Table 4-3 lists OTA's conclusions from the studies' findings. In general, these studies show few positive outcomes of special care units. With respect to residents' ability to perform activities of daily living, the findings of studies that did not use a control group are contradictory. Three of the studies that used a control group and measured residents' ability to perform activities of daily living found no significant effect of the special care units. In contrast, one study (392) found less decline in ability to perform activities of daily living over a l-year period among the special care unit residents than among residents of the nonspecialized units. Likewise, three of the studies that used a control group and measured residents' behavioral symptoms found no significant effect of the special care units. In contrast, one study (265) found fewer catastrophic reactions among the special care unit residents than among residents of the nonspecialized units. Only one of the four studies that measured the effect of a special care unit on the unit staff members found any significant positive outcomes. The findings with respect to family members' feelings of depression, anxiety, and guilt and their satisfaction with care are contradictory.

As noted at the beginning of this chapter, the fact that many of the available evaluative studies do not show significant positive outcomes of special care units is surprising. The failure of most of the studies to show the expected positive outcomes is attributed by some commentators to methodological problems. The preceding discussion has noted many methodological problems with the available studies. As discussed in chapter 1, there are also numerous difficult conceptual and methodological issues involved in designing special care unit research. These conceptual and methodological issues include uncertainty about which outcomes should be measured; the difficulty of measuring certain outcomes in individuals with dementia; the lack of validated instruments for measuring these outcomes; the difficulty of identifying and correcting for differences between special care unit residents and residents of nonspecialized units that could affect the study outcomes; and attrition in sample sizes over time which means even studies that started with a sample of a respectable size may end up with usable data on so few individuals that only a very strong effect of the special care unit could be detected.

Methodological problems and the difficult conceptual and methodological issues involved in designing special care unit research probably explain part of the failure of many of the available studies to find positive outcomes. Moreover, it must be noted that very few evaluative studies of special care units have been conducted thus far. The preceding sections discuss a total of only 15 studies that have measured impacts on residents and a few additional studies that have measured impacts on residents' families and/or unit staff members. On the other hand, some of the available studies, particularly the studies that used a control group, are well designed and carefully conducted, despite methodological difficulties. The special care units they studied incorporated the patient care philosophies, staff training, programmingg, and physical design features recommended by special care unit advocates, and the researchers used accepted statistical methods to correct for baseline differences among the subjects that could affect the study outcomes. Thus, it is unlikely that the failure of these studies to

Table 4-3-OTA'S Conclusions From the Evaluative Studies of Special Care Units

- Evaluative studies of special care units that did not use a control group have found a variety of positive outcomes in special care unit residents. If contradictory findings are excluded, the positive outcomes found in more than one of these studies are decreased nighttime wakefulness, improved hygiene, and weight gain.
- A few evaluative studies of special care units that did not use a control group have found improvements over time in the important areas of residents' ability to perform activities of daily living and residents' behavioral symptoms, but an equal number of studies of this type have not found such improvements.
- For of the six evaluative studies of special care units that used a control group have found no statistically significant differences between the special care unit residents and the control group subjects in the following areas: cognitive abilities, ability to perform activities of daily living, behavioral symptoms, mood, and rate of hospitalization. Two of the six studies of this type found certain statistically significant positive resident outcomes: one study found that over a l-year period, 14 special care unit residents showed significantly less decline than 14 residents with dementia in nonspecialized nursing home units in their ability to perform activities of daily living; the other study found that 13 special care unit residents had significantly fewer catastrophic reactions than 9 residents with dementia in nonspecialized nursing home units; the 13 special care unit residents also interacted significantly more with the unit staff members. These two studies had no other statistically significant positive resident outcomes.
- Evaluative studies of particular features and interventions in special care units have focused primarily on methods to deter individuals with dementia from escaping or wandering away from the unit. The most successful methods identified thus far are latches and locks the residents cannot open and various methods of concealing the exit doors.
- Three of the four studies that evaluated the impact of special care units on the unit staff members found no statistically significant effects. One of the 4 studies of this type found a statistically significant reduction in staff stress among 15 special care unit staff members and a statistically significant difference between the 15 special care unit staff members and 49 staff members on nonspecialized nursing home units in one of three indicators of burnout. The study also found a statistically significant improvement in the scores of 16 special care unit staff mernbers (licensed practical nurses, nurse aides and other non-nursing staff members) on 1 of 6 indicators of job satisfaction. None of the three studies that measured staff knowledge of dementia found any significant effect of the special care unit.
- Two of the four studies that evaluated the impact of special care units on the residents' families had statistically significant positive findings. One of the studies found a significant increase in the family members' satisfaction with the care provided for their relative with dementia, and the other study found a significant reduction in the family members' feelings of anxiety, depression, guilt, and grief. The other two studies of this type found no significant changes in either of these areas. One cross-sectional study found that families of special care unit residents are more likely than families of individuals with dementia in nonspecialized units to visit their relative regularly, but it is not clear whether this finding is attributable to the effect of the special care unit or to preexisting differences between the two groups of families.

SOURCE: Office of Technology Assessment, 1992.

show positive outcomes is due entirely to methodological problems. Alternate explanations include the possibility that some or many of the features recommended for special care units are not effective and the possibility that some of the recommended features have a positive effect on some or all residents, families, and staff members, that other features have a negative effect, and that these positive and negative effects cancel each other out. Still another possibility is that the primary positive effect of special care units is on residents' quality of life-an outcome that is difficult to define operationally and one that has not been measured directly in any of the studies conducted thus far. Further research is needed to differentiate among these and other possible explanations.

Research on specific interventions in special care units may help to explain the findings of studies that evaluate the overall effect of the units by showing that certain interventions have positive outcomes

and others do not. This type of research is also important because some and perhaps many interventions that are shown to be effective in special care units can also be used in nonspecialized nursing home units, residential care facilities, and other settings to improve the care of individuals with dementia in these settings.

Finally, it is important to note certain findings of several of the studies discussed in this chapter that do not fit with widely held beliefs about nursing home residents with dementia, their families, and nursing home staff members who work with residents with dementia:

- three studies found that the incidence of behavioral symptoms was much lower than expected among residents with dementia (22,265,312);
- one study found that three groups of family members—family members of special care unit residents, family members of residents of a nonspecialized nursing home unit, and family members of residents of a unit in which individuals with dementia were segregated but no special services were provided—had much lower levels of anxiety, depression, and guilt than expected (76);
- two studies found moderately high family satisfaction with the care provided for individuals with dementia in nonspecialized nursing home units (88,265,266); and
- one study found that staff members in four special care units and four nonspecialized nursing home units were not particularly disturbed by the residents' behavioral symptoms (195).

It is unclear whether these findings reflect unique characteristics of particular study samples or are more generally representative. Certainly, if the baseline levels of behavioral symptoms among residents, negative feelings among family members, and distress among staff members are low in general or in particular study samples, it is unrealistic to expect large positive changes in a special care unit.

Chapter 5

Regulations And Guidelines For Special Care Units

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Chapter 5
Regulations And Guidelines For Special Care Units

INTRODUCTION

In response to concerns about the diversity of existing special care units, the lack of standards to assist families, nursing home surveyors, and others in evaluating the units, and widespread allegations that some special care units provide nothing special for their residents, six States have developed regulations for special care units, and other States are in the process of doing so. The Alzheimer's Association has developed legislative principles for special care units to assist States in formulating regulations. In addition, the Alzheimer's Association and many other public and private organizations have developed or are in the process of developing guidelines for special care units.

These regulations and guidelines are or would be superimposed on the existing regulatory structure for nursing homes—a complex, multi-layered structure that includes six major components:

- Federal regulations for Medicare and Medicaid certification of nursing homes,
- State licensing regulations for nursing homes,
- State certificate of need regulations for nursing homes,
- other State and local government regulations that apply to nursing homes,
- the survey and certification procedures associated with each of these types of regulations, and
- the oversight and advocacy 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 Protection Association's Life Safety Codes. Because these standards are incorporated into government regulations, they become part of the regulatory structure. Lastly, about 5 percent of nursing homes in the United States choose to be accredited by a private organization, the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) (214). These nursing homes are surveyed by JCAHO and must meet JCAHO standards, as well as Federal, State, and local government requirements.

The regulatory structure for nursing homes is currently undergoing massive changes due to the implementation of the nursing home reform provisions of the 1987 Omnibus Budget Reconciliation Act (OBRA-87). The provisions of OBRA-87 pertain to the Federal regulations for Medicare and Medicaid certification of nursing homes and the survey and certification procedures associated with those regulations, but the changes mandated by OBRA-87 are so extensive they affect other components of the regulatory structure as well.

This chapter describes the existing regulatory structure for nursing homes, including the changes mandated by OBRA-87. It discusses State regulations and other State policies for special care units. It also describes the guidelines for special care units that have been developed or are being developed by various public and private organizations.

The policy question addressed by the chapter is whether there should be special regulations for special care units. On the one hand, the rapid proliferation of special care units, the lack of standards to help families, nursing home surveyors, and others evaluate the units, and the pervasive allegations that some special care units provide nothing special for their residents argue for the development of regulations. On the other hand, the current lack of agreement about the particular features that are necessary in a special care unit and the lack of research-based evidence of the effectiveness of any particular features make it difficult to determine what the regulations should say beyond general statements about goals and principles and a listing of the issues that require special consideration in the care of nursing home residents with dementia (e.g., physical design, staff training, security, activity programs, family involvement, and resident rights).

As this chapter points out, many of the Federal Medicare and Medicaid regulations mandated by OBRA-87 are directly relevant to the complaints and concerns expressed by families and others about the care provided by most nursing homes for individuals with dementia. The OBRA regulations rarely mention cognitive impairment or dementia, but the resident assessment system developed to implement

OBRA-87 focuses on the assessment of a resident's cognitive status and the identification of problems and care needs that are common among nursing home residents with dementia. OBRA regulations require that residents' needs be assessed, using this or a similar assessment system, and that once their needs are identified, appropriate services be provided to meet those needs.

The regulations for special care units now in effect in six States were not developed in the context of the new OBRA regulations. The six States' regulations address some common areas, but their requirements in each of these areas vary, and each State's regulations include requirements for features not included in the other States' special regulations. Moreover, some of the requirements are very specific. The inclusion of requirements for particular features in special care unit regulations implies that these features are important in the care of nursing home residents with dementia; that other features which are not required by the regulations are not important in the care of these residents; and that the limited resources of nursing homes should be expended for the required features rather than other features. As yet, however, there is no consensus about the particular features that are necessary in a special care unit and no evidence from research to support requirements for any particular features.

OTA concludes from the analysis in this and the preceding chapters that from a Federal perspective, 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, to determine how those features fit into the regulatory framework created by OBRA-87, and to support and monitor the implementation of OBRA-87 than by the establishment of new Federal regulations for special care units. Many of the same considerations that lead to this conclusion would seem to apply equally to the development of State regulations for special care units.

THE EXISTING REGULATORY STRUCTURE FOR NURSING HOMES

Nursing homes are said to be among the most highly regulated entities in this country (201). Federal State, and local government regulations apply to virtually all facets of nursing homes' physical design and operation. Nursing homes are inspected at least annually by surveyors or teams of surveyors who evaluate the facilities' compliance with one or more of these types of regulations. Staff members or volunteers representing the State's Long-Term Care Ombudsman Program also visit nursing homes to investigate and resolve complaints about resident care. This section describes each of the components of the regulatory structure.

Federal Regulations for Medicare and Medicaid Certification of Nursing Homes

The legislation that created the Medicare and Medicaid programs gave the Federal Government the authority to establish requirements for nursing homes that choose to participate in the programs. Nursing homes must be certified as meeting these requirements in order to receive Medicare or Medicaid payment for any of their residents. As of 1985, 75 percent of the nursing homes in this country were certified for Medicare, Medicaid, or both, and these facilities accounted for 89 percent of all nursing home beds (467).

The requirements for Medicare and Medicaid certification of nursing homes have been changed several times in the past two decades, most recently as a result of OBRA-87 and amendments to OBRA-87 enacted since 1987. Prior to the implementation of OBRA-87, there were separate certification requirements for *skilled nursing facilities (SNFs)* participating in the Medicare and Medicaid programs and *intermediate care facilities* (ICFs) participating in the Medicaid program. Effective in 1990, OBRA-87 eliminated the distinction between SNFs and ICFs for Medicaid purposes. A single set of requirements for Medicaid certification of *nursing facilities (NFs)* is now in effect. Separate but very similar requirements for Medicare certification of SNFs are also in effect (456,225).

The current requirements for Medicare and Medicaid certification of nursing homes were first published by the Health Care Financing Administration (HCFA) in February 1989 (462). The final version of these requirements was published by HCFA in September 1991 (463). The requirements address residents' rights, residents' quality of life, resident assessment, care planning, staff credentials, staff training, use of physical restraints, use of psychotropic and other medications, quality of care, nursing, physician, dietary, social work, dental, and

rehabilitative services, activities, handling of residents' funds, record-keeping, physical plant, preadmission screening, and other areas.

Many of the requirements are directly relevant to the complaints and concerns of families and others about the care provided by most nursing homes for individuals with dementia. (See table 1-1 inch. 1 for a list of these complaints and concerns.) The most relevant of the requirements are quoted here from the September 1991 version of the "Requirements for Long-Term Care Facilities" (463).

- "The facility must care for its residents in a manner and in an environment that promotes maintenance or enhancement of each residents 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 aresident's medical, nursing, mental, and psychosocial needs that are identified in the comprehensive assessment. '
- "A comprehensive care plan must be prepared by an interdisciplinary team, that includes the attending physician, a registered nurse with responsibility for the resident, and other appropriate staff in disciplines as determined by the resident's needs, and to the extent practicable, the participation of the resident, the resident's family or the resident's legal representative. '
- "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. '
- "Based on the comprehensive assessment of a resident, the facility must ensure that a resident's abilities in activities of daily living do not diminish unless circumstances of the individual's clinical condition demonstrate that diminution was unavoidable.'
- "Based on the comprehensive assessment of a resident, the facility must ensure that a resident whose assessment did not reveal a mental or psychosocial adjustment difficulty does not display a pattern of decreased social interaction and/or increased withdrawn, angry, or depressive behaviors, unless the resident's clinical condition demonstrates that such a pattern was unavoidable.
- "The facility must provide for an ongoing program of activities designed to meet, in accordance with the comprehensive assessment, the interests and the physical, mental, and psychosocial well-being of each resident."
- "If specialized rehabilitative services, such as but not limited to physical therapy, speech-language pathology, occupational therapy, and health rehabilitative services for mental illness and mental retardation, are required in the resident's comprehensive plan of care, the facility must:

  1. provide the required services, or
  2. obtain the required services from an outside...provider of specialized rehabilitative services. '

- "The resident has the right to be flee from any physical or chemical restraints imposed for purposes of discipline or convenience, and not required to treat the resident's medical symptoms.'
- "Each resident's drug regimen must be free from unnecessary drugs. An unnecessary drug is any drug when used:

  1. in excessive dose (including duplicate drug therapy); or
  2. for excessive duration; or
  3. without adequate monitoring; or
  4. without adequate indications for its use; or
  5. in the presence of adverse consequences which indicate the dose should be reduced or discontinued; or
  6. any combinations of the reasons above. "

. "Based on a comprehensive assessment of a resident, the facility must ensure that:

  1. residents who have not used antipsychotic drugs are not given these drugs unless antipsychotic drug therapy is necessary to treat a specific condition and documented in the clinical record, and

2. residents who use antipsychotic drugs receive gradual dose reductions and behavioral interventions, unless clinically contraindicated in an effort to discontinue these drugs."

- "The facility must provide: a safe, clean, comfortable, and home-like environment, allowing the resident to use his or her personal belongings to the extent possible...(and including) adequate and comfortable lighting levels in all areas; comfortable and safe temperature levels; ..(and) comfortable sound levels. '
- "The resident has the right to retain and use personal possessions, including some furnishings, and appropriate clothing, as space permits, unless to do so would infringe upon the rights or health and safety of other residents. '
- "A facility must not use any individual working in the facility as a nurse aide for more than 4 months, on a full-time, temporary, per diem, or other basis, unless:

  1. that individual has completed a training and competency evaluation program, or a competency evaluation program approved by the State, and
  2. that individual is competent to provide nursing and nursing-related services. '

- "The facility must provide regular performance review and regular in-service education to ensure that individuals used as nurse aides are competent to perform services as nurse aides. *In-service education must include training for individuals providing nursing and nursing-related services to residents with cognitive impairments" (463)* (emphasis added).

With the exception of the last requirement, none of these requirements mentions cognitive impairment or dementia. Many of the requirements refer, however, to residents' needs as identified by the required comprehensive assessment. If the comprehensive assessment identifies the needs of residents with dementia, the regulations require that these needs be met.

OBRA-87 mandated the development of a set of core items to be addressed in the required comprehensive assessment. In 1988, HCFA contracted with a consortium of researchers at Research Triangle Institute, Hebrew Rehabilitation Center for Aged, Brown University, and the University of Michigan to develop a resident assessment system that would include these core items (308). The resulting assessment system consists of two parts: 1) the Minimum Data Set, a 5-page resident assessment instrument, and 2) 18 Resident Assessment Protocols that provide additional information to assist nursing home staff members in assessing and developing care plans for residents with certain problems (309). States may use this assessment system or develop one of their own, provided the system they develop incorporates the core items (308).

The Minimum Data Set emphasizes the assessment of a resident's cognitive status. Six questions about cognitive status appear on the first page of the assessment instrument, immediately after the basic identifying information about the resident (309). (Fig. 5-1 shows the first page of the Minimum Data Set.) Other sections of the assessment instrument include questions about problems and care needs that pertain particularly to residents with dementia. One section asks, for example, whether the resident needs 'supervision, including oversight, encouragement, or cueing" in order to perform activities of daily living (309). Another section asks about mood problems (e.g., agitation and withdrawal) and behavioral symptoms (e.g., wandering, verbal and physical abusiveness, and socially inappropriate or disruptive behavior). That section also asks whether the "behavior problem has been addressed by a clinically developed behavior management program. . .(not including) only physical restraints or psychotropic medications" (309). Other sections ask about the resident's customary routine, the resident's involvement and preferences in activities, the number of medications he or she is taking, the number of days in the preceding week he or she has received antipsychotic, antianxiety, or antidepressant medications, and the frequency of use of physical restraints.

A one-page form to be used for quarterly review of a resident's comprehensive assessment also emphasizes cognitive status and certain problems and care needs that pertain particularly to residents with dementia (309). The form includes questions about memory, cognitive skills for daily decision-making, behavioral symptoms, the number of days in the preceding week the resident has received antipsychotic, antianxiety, or antidepressant medications, and the frequency of use of physical restraints. It also repeats the question about the resident's need for "supervision, including over-

MINIMUM DATA SET FOR NURSING HOME RESIDENT ASSESSMENT AND CARE SCREENING (MDS)

(Status in last **7** days, **unless other time frame indicated)**

SECTION A. IDENTIFICATION AND BACKGROUND INFORMATION

1.	Assessment DATE	Mend'l — Day — Year
2.	RESIDENT NAME	(First) (Middle Initial) (Last)
3.	SOCIAL SECURITY NO.	
4.	MEDICAID NO. (If applicable)	
5.	MEDICAL RECORD NO.	
6.	REASON FOR ASSESSMENT	1. Initial admission assess. 2. Hosp/Medicare reassess. 3. Readmission assessment 4. Annual assessment 5. Significant change in status 6. Other (e.g., UR)
7.	CURRENT PAYMENT SOURCE(S) FOR N H STAY	*(Billing Office to indicate; check all that apply)* Medicaid [a.] Medicare [b.] CHAMPUS [c.] VA [d.] Self pay/Private insurance [e.] Other [f.]
8.	RESPONSIBILITY/ LEGAL GUARDIAN	*(Check all that apply)* Legal guardian [a.] Other legal oversight [b.] Durable power attrny./ health care proxy [c.] Family member responsible [d.] Resident responsible [e.] *NONE OF ABOVE* [f.]
9.	ADVANCED DIRECTIVES	*(For those items with supporting documentation in the medical record, check all that apply)* Living will [a.] Do not resuscitate [b.] Do not hospitalize [c.] Organ donation [d.] Autopsy request [e.] Feeding restrictions [f.] Medication restrictions [g.] Other treatment restrictions [h.] *NONE OF ABOVE* [i.]
10.	DISCHARGE PLANNED WITHIN 3 MOS.	*(Does not include discharge due to death)* 0. No 1. Yes 2. Unknown/uncertain
11.	PARTICIPATE IN ASSESSMENT	a. Resident 0. No 1. Yes [a.] b. Family 0. No 1. Yes 2. No family [b.]
12.	SIGNATURES	Signature of RN Assessment Coordinator Signatures of Others Who Completed Part of the Assessment

SECTION B. COGNITIVE PATTERNS

1.	COMATOSE	*(Persistent vegetative state/no discernible consciousness)* 0. No 1. Yes *(Skip to SECTION E)*
2.	MEMORY	*(Recall of what was learned or known)* a. Short-term memory OK—seems/appears to recall after 5 minutes 0. Memory OK 1. Memory problem [a.] b. Long-term memory OK—seems/appears to recall long past 0. Memory OK 1. Memory problem [b.]
3.	MEMORY/ RECALL ABILITY	*(Check all that resident normally able to recall during last 7 days)* Current season [a.] Location of own room [b.] Staff names/faces [c.] That he/she is in a nursing home [d.] *NONE OF ABOVE* are recalled [e.]

= Code the appropriate response ☐ = Check all the responses that apply

4.	COGNITIVE SKILLS FOR DAILY DECISION-MAKING	*(Made decisions regarding tasks of daily life)* 0. Independent—decisions consistent/reasonable 1. Modified Independence—some difficulty in new situations only 2. Moderately Impaired—decisions poor; cues/supervision required 3. Severely Impaired—never/rarely made decisions
5.	INDICATORS OF DELIRIUM —PERIODIC DISORDERED THINKING/ AWARENESS	*(Check if condition over last 7 days appears different from usual functioning)* Less alert, easily distracted [a.] Changing awareness of environment [b.] Episodes of incoherent speech [c.] Periods of motor restlessness or lethargy [d.] Cognitive ability varies over course of day [e.] *NONE OF ABOVE* [f.]
6.	CHANGE IN COGNITIVE STATUS	Change in resident's cognitive status, skills, or abilities in **last 90 days** 0. No change 1. Improved 2. Deteriorated

SECTION C. COMMUNICATION/HEARING PATTERNS

1.	HEARING	*(With hearing appliance, if used)* 0. Hears adequately—normal talk, TV, phone 1. Minimal difficulty when not in quiet setting 2. Hears in special situations only—speaker has to adjust tonal quality and speak distinctly 3. Highly impaired/absence of useful hearing
2.	COMMUNICATION DEVICES/ TECHNIQUES	*(Check all that apply during last 7 days)* Hearing aid, present and used [a.] Hearing aid, present and not used [b.] Other receptive comm. techniques used (e.g., lip read) [c.] *NONE OF ABOVE* [d.]
3.	MODES OF EXPRESSION	*(Check all used by resident to make needs known)* Speech [a.] Writing messages to express or clarify needs [b.] Signs/gestures/sounds [c.] Communication board [d.] Other [e.] *NONE OF ABOVE* [f.]
4.	MAKING SELF UNDERSTOOD	*(Express information content—however able)* 0. Understood 1. Usually Understood—difficulty finding words or finishing thoughts 2. Sometimes Understood—ability is limited to making concrete requests 3. Rarely/Never Understood
5.	ABILITY TO UNDERSTAND OTHERS	*(Understanding verbal information content—however able)* 0. Understands 1. Usually Understands—may miss some part/intent of message 2. Sometimes Understands—responds adequately to simple, direct communication 3. Rarely/Never Understands
6.	CHANGE IN COMMUNICATION/ HEARING	Resident's ability to express, understand or hear information has changed over **last 90 days** 0. No change 1. Improved 2. Deteriorated

SECTION D. VISION PATTERNS

1.	VISION	*(Ability to see in adequate light and with glasses if used)* 0. Adequate—sees fine detail, including regular print in newspapers/books 1. Impaired—sees large print, but not regular print in newspapers/books 2. Highly Impaired—limited vision; not able to see newspaper headlines; appears to follow objects with eyes 3. Severely Impaired—no vision or appears to see only light, colors, or shapes
2.	VISUAL LIMITATIONS/ DIFFICULTIES	Side vision problems—decreased peripheral vision (e.g., leaves food on one side of tray, difficulty traveling, bumps into people and objects, misjudges placement of chair when seating self) [a.] Experiences any of following: sees halos or rings around lights; sees flashes of light; sees "curtains" over eyes [b.] *NONE OF ABOVE* [c.]
3.	VISUAL APPLIANCES	Glasses; contact lenses; lens implant; magnifying glass 0. No 1. Yes

sight, encouragement, or cueing" in order to perform activities of daily living.

One of the 18 Resident Assessment Protocols is on dementia. The protocol provides additional information about dementia to help nursing home staff members assess the resident accurately and develop an appropriate care plan (309). Several other Resident Assessment Protocols address problems and care needs that are relevant for nursing home residents with dementia, including delirium, psychosocial problems, behavioral symptoms, activities, psychotropic drug use, and physical restraints.

Compared with other assessment instruments used in nursing homes in the past, the resident assessment system developed by the consortium, including the Minimum Data Set and the Resident Assessment Protocols, places much greater emphasis on assessment of residents' cognitive status and the problems and care needs that are common among nursing home residents with dementia. Although the existence of this resident assessment system does not guarantee that a resident's needs will be accurately identified or, once identified, that the needs will be met, the existence of the system certainly makes both outcomes more likely.

As of January 1992, all States were using the resident assessment system developed by the consortium (329). Eleven States had added some items to the Minimum Data Set.

State Licensing Regulations

Each State licenses nursing homes on the basis of State standards. Although nursing homes that choose not to participate in the Medicare and Medicaid programs are not subject to Federal Medicare and Medicaid regulations, all nursing homes are subject to State licensing regulations, including nursing homes that serve only private-pay residents (225,320).

State licensing regulations vary greatly. Some States have very complex, stringent, licensing regulations, whereas other States have simpler, less stringent regulations (94,225,318). In 1984, one-fourth of the States were using the Federal Medicaid regulations for State licensing purposes (318).

Administrative rulings and interpretations of State licensing regulations are common. These administrative rulings and interpretations become part of a State's licensing regulations and generally add to their complexity.

Five States have changed their licensing regulations to add requirements for special care units, and one State has established requirements for special care units as an interpretation of the State's licensing requirements. These State regulations and requirements are discussed later in this chapter.

Federal Medicare and Medicaid regulations require that nursing homes have a State license (463). In effect, therefore, for a given State, the Federal regulations incorporate that State's licensing regulations. In the case of States whose requirements are more stringent or just different than the Federal requirements in some other way, these different and more stringent State requirements effectively become part of the Federal requirements.

State Certificate of Need Regulations

State certificate of need laws require explicit State approval before a nursing home can be built or expanded. As of 1988, 38 States had such laws (333). Certificate of need laws are intended to limit the supply of nursing home beds in a State. It is generally believed that any additional nursing home beds will eventually be filled with Medicaid-eligible residents and ultimately increase State expenditures for nursing home care (318). By controlling the bed supply, certificate of need laws are expected to limit these expenditures.

The process of obtaining a certificate of need is lengthy and complex in many States. Tables 6-2 and 6-3 in chapter 6 list the steps involved in obtaining a certificate of need in Massachusetts and New York. As discussed later in this chapter, at least six States have altered the process for obtaining a certificate of need so that applicants who propose to create special care units receive special consideration.

Other State and Local Government Regulations That Apply to Nursing Homes

Many State and local government regulations apply to nursing homes as well as other buildings, businesses, and health care facilities. These regulations include fire safety codes, zoning codes, building codes, and sanitation codes. Some of these regulations are incorporated into the requirements for obtaining a State license or a certificate of need.

Survey and Certification Procedures

Nursing homes are inspected regularly by individual surveyors or teams of surveyors who monitor the facilities' compliance with each of the types of regulations discussed thus far in this chapter. Although the regulations are clearly important in themselves, their impact depends on how they are interpreted and applied by the surveyors.

Inspection and certification of nursing homes is primarily a State function (149,225). Each State has at least one agency--often referred to as a survey and certification agency—that performs inspections for Medicare and Medicaid certification of nursing homes. This agency usually also performs inspections for State licensing purposes, but other State and local agencies are involved in these inspections as well. heal building inspectors, fire marshals, and sanitarians inspect nursing homes in connection with certification requirements, licensing requirements, and other State and local government regulations that apply to nursing homes. The Department of Veterans Affairs (VA) also inspects all VA and nonVA nursing homes in which it places veterans (289).

The resources allocated by State and local governments to nursing home inspections vary. A 1989 survey of State agencies that perform inspections for Medicaid certification and/or State licensing found that 5 States had fewer than one surveyor for every 10 nursing homes, whereas 5 States had 3 or more surveyors for every 10 nursing homes (149).

OBRA-87 mandated changes in the survey and certification procedures for Medicare and Medicaid certification of nursing homes. Coupled with the new requirements for Medicare and Medicaid certification, the survey procedures mandated by OBRA-87 are intended to focus more on residents and the outcomes of care than on written policies, staff credentials, physical design features, and other factors that may affect a facility's capacity to provide care (309,462,456). The new survey procedures are also intended to allow survey agencies to concentrate their attention on nursing homes that provide substandard care (456). OBRA-87 requires that each nursing home receive an unannounced "standard survey" annually. Facilities that are found in the standard survey to provide substandard care must receive an "extended survey" within 2 weeks. The extended survey is intended to identify the facility's policies and procedures that resulted in the substandard care.

OBRA-87 makes States responsible for the standard and extended surveys (320,456). Annually, the Federal Government is required to conduct validation surveys of at least 5 percent of the nursing homes surveyed by each State in order to determine the adequacy of the State survey. The Federal Government is also required to inspect State-owned nursing homes.

OBRA-87 requires that surveys for Medicare and Medicaid certification of nursing homes be conducted by a multidisciplinary team, including a registered nurse (320). Members of the survey team must meet minimum Federal qualifications, including completion of a federally approved training and testing program. OBRA-87 also requires that State survey and certification agencies employ sufficient staff to investigate complaints and to monitor facilities that do not meet the requirements or are in danger of falling out of compliance (320).

One purpose of the new survey procedures is to reduce the inconsistency of survey procedures in different States and localities (320). OBRA-87 requires that the standard and extended surveys use a survey instrument developed, tested, and validated by the Federal Government. The surveyor training requirements mentioned above are also intended to reduce the inconsistency in survey procedures.

In September 1989, HCFA issued interpretive guidelines to help surveyors apply the new requirements for Medicare and Medicaid certification of nursing homes (320). The guidelines were revised following the release in September 1991 of the final requirements for Medicare and Medicaid certification of nursing homes. In late 1991, HCFA sent the revised guidelines out for review. The guidelines prescribe methods to be used in conducting inspections, including procedures for interviewing residents and reviewing resident assessments and care plans.

State Long-Term Care Ombudsman Programs

The Older Americans Act mandates that every State have a Long-Term Care Ombudsman Program to investigate and resolve complaints of residents of nursing homes and other residential care facilities. The State programs vary, but most States use both paid and volunteer staff and have offices at both the

State and local level. In 1990, State ombudsman programs had an average of one paid staff member at the State or local level for every 3200 nursing home beds; the range in different States was from one paid staff member for every 789 beds to one paid staff member for every 21,500 beds (321). Total spending for State Long-Term Care Ombudsman Programs averaged $11.15 per nursing home bed per year and ranged from $2.09 to $68.05 per bed per year in different States.

Ombudsmen have the authority to enter a nursing home at any time to investigate a complaint or advocate for an individual resident (320). They can also visit nursing homes to become acquainted with the residents, monitor their care generally, and inform them of their rights. A 1990 survey of long-term care ombudsmen found that only 16 percent reported visiting the nursing homes in their jurisdiction more than once a month for any of these purposes (321).

OBRA-87 created a new role for State Long-Term Care Ombudsman Programs in connection with the survey process for Medicare and Medicaid certification of nursing homes. The law requires the survey and certification agency to contact the Long-Term Care Ombudsman Program to inquire about complaints the ombudsman program may have received about a facility that is being surveyed (320). The survey and certification agency is required to invite the ombudsman to attend the exit conference at the end of a facility's survey when the survey findings are discussed. Lastly, the survey and certification agency is required to inform the ombudsman if the facility is not in compliance with any of the certification requirements.

Summary and Implications

The existing regulatory structure for nursing homes is extremely complex, and many aspects of the structure are in flux now because of OBRA-mandated changes in the Federal regulations for Medicare and Medicaid certification of nursing homes and the survey and certification procedures associated with those regulations. The OBRA-mandated changes are likely to improve the care received by nursing home residents with dementia. The resident assessment system developed to implement OBRA-87 focuses much more than assessment instruments used previously in nursing homes on the residents' cognitive status. The assessment system emphasizes the care needs that are common among nursing home residents with dementia, and OBRA regulations require that services be provided to meet those needs.

Two factors could limit the benefits of OBRA-related changes for individuals with dementia. One obvious factor is a failure to implement the changes. Such a failure could occur as the result of a lack of leadership and political will at the Federal, State, or local level. It could also occur as a result of insufficient government funding to implement the changes, including insufficient Medicare and Medicaid reimbursement for nursing home care, insufficient funding for nurse aide training, and insufficient funding for survey and certification staff and surveyor training. Some of this funding comes from the Federal Government, but some comes from States, so finding problems that affect implementation of OBRA are likely to vary from State to State.

The second factor that could limit the benefits of OBRA-related changes for individuals with dementia is lack of knowledge among nursing home administrators and staff members and nursing home surveyors about the implications of the new requirements for residents with dementia. With respect to the OBRA-87 requirements cited earlier in this chapter, these individuals might ask, for example: what constitutes good quality of life for a resident with dementia; what constitutes unavoidable diminution in the resident's ability to perform activities of daily living; what activities meet the interests and needs of nursing home residents with dementia; what rehabilitative services are needed by nursing home residents with dementia; what is a safe, home-like environment, and what are comfortable levels of sound, lighting, and temperature? Research-based answers to these and other similar questions do not exist at present, and certain of the questions are not amenable to research. There is also disagreement among clinicians about the answers. Yet answers are needed for effective implementation of the new requirements.

STATE REGULATIONS AND OTHER STATE POLICIES FOR SPECIAL CARE UNITS

As of early 1992, six States had special regulations for special care units. At least five additional States were developing regulations, and other States were considering doing so. One State had guidelines

for special care units instead of regulations, and one other State was in the process of developing guidelines. Other policies for special care units that have been implemented by a few States include altering the process for obtaining a certificate of need so that applicants who propose to establish special care units receive special consideration, funding individual special care units, and funding research on special care units. This section discusses these State regulations and policies.

Some of the State regulations and policies for special care units have been mandated by State legislatures, and others have been put in place by executive decision. The initiative for the regulations and other policies has usually come from State officials and/or State Alzheimer's disease task forces, but these individuals and groups were often responding to concerns raised originally by family members, special care unit operators, and nursing home surveyors.

The regulations and policies differ in their primary intent. Some are intended primarily to assure that special care units are not established and operated solely for marketing purposes and do, in fact, provide something special for their residents. Other regulations and policies are primarily intended to protect the rights of special care unit residents, particularly those in locked units. Still other regulations and policies are intended to promote the establishment or evaluation of special care units.

Some industry representatives believe that States establish regulations for special care units in part to raise State revenues (337). States generally charge nursing homes fees in connection with new construction or extensive remodeling. Consequently, special care unit regulations that include physical design requirements are likely to generate fee-based income for the State.

Six States' Regulations for Special Care Units

Six States—Iowa, Texas, Colorado, Washington, Tennessee, and Kansas, have special regulations for special care units. Iowa created a new licensing category for special care units, and Texas created a voluntary certification program. Colorado, Washington, and Tennessee added requirements for special care units to their general licensing requirements for all nursing homes, and Kansas added an interpretation on special care units to its licensing requirements for all nursing homes.

The regulations developed by these six States are presented in some detail in this section. OTA's intent in presenting these regulations in detail is to call attention to their diversity and some of the particular features they require.

Iowa's Regulations for Special Care Units

Iowa is the only State that currently requires special care units to have a special license in addition to the license all nursing homes must have. The requirements for the special license were developed in 1988 by a task force appointed by the Iowa Department of Inspections and Appeals. The department's intent in creating a special license was to assure that special care units provide appropriate care for their residents and are not established only for marketing purposes (334). When first implemented in November 1988, the special license was voluntary in the sense that nursing homes had to obtain a license for a special care unit only if they were going to advertise they had such a unit. In the first year, one nursing home applied for a special license.

At the urging of the State's Task Force on Alzheimer's Disease and Related Disorders, the licensing requirements were made mandatory, effective in July 1990. Now, nursing homes must have a special license if they are caring for individuals with dementia in a distinct part of the facility, with a separate staff, and if they care only for individuals with dementia in that part of the facility (334). The license, which was frost referred to as a license for "special units for people with Alzheimer's disease or related disorders," is now referred to as a license for "chronic confusion or dementing illness units or facilities.' This change is intended to preclude facilities from arguing that they do not have to obtain a special license because their residents do not have a diagnosis of Alzheimer's disease. As of July 1991, 17 nursing homes had obtained a special license, and 2 more facilities had applied but not yet been approved for a license.

To obtain a special license, the Iowa regulations require a unit to have:

. a statement of philosophy, with objectives stated in terms of outcomes,

- admission and discharge policies, including a policy requiring a physician's approval for a resident's admission to the unit,
- an interdisciplinary care planning team,
- safety policies that specify a method of locking or otherwise securing the unit and steps to be taken if a resident is missing from the unit,
- policies that explain the programs and services offered in the unit,
- policies that describe the numbers, types, and qualifications of the unit staff,
- policies that assure residents' right to have visitors,
- quality assurance policies,
- preadmission assessment of residents,
- staff training, including at least 6 hours of training for all new staff on nine topics listed in the regulations and 6 hours of inservice training annually for all staff,
- 2 hours of nursing staff time per resident per day, and a staff member on the unit at all times (Iowa Administrative Code, Sections 10A.104(5) and 135c.14).

In October 1990, several physical design specifications were added to the Iowa regulations. They require a special care unit to have:

- a design such that residents, staff, and visitors do not pass through the unit to reach other parts of the facility,
- a locking system that meets the Life Safety Code and is approved by the fire marshal or an alternate system for securing the unit,
- a secure outdoor area with nontoxic plants,
- no steps or slopes,
- a separate dining area used only for unit residents,
- a private area for nurses to prepare resident records,
- a unisex toilet room that is visible from the lounge and activity area, and
- a design that minimizes breakable objects (Iowa Administrative Code, Section 61.13).

Iowa is enforcing the licensing regulations, and several nursing homes have closed their special care unit because the unit did not meet the licensing requirements (169). When officials of the Iowa Department of Inspections and Appeals become aware of a unit that is not licensed, they do not charge the facility with a violation of the regulations, but they do visit the unit to determine whether it is a special care unit within the regulatory definition, and if it is, they notify the facility that a special license is required (334).

The administrator of one nursing home in Iowa that has had a special care unit for 5 years told OTA that although the unit is providing good care for its residents, it does not meet the licensing requirements (452). She believes some of the State's requirements, particularly the physical design specifications added in 1990, are overly rigid and require features that are not necessary for good care of residents with dementia.

Texas' Regulations for Special Care Units

Texas has a voluntary certification program for special care units that was mandated by the State legislature in 1987 and became effective in February 1988. Like the early phase of Iowa's licensing program, nursing homes in Texas only have to obtain a license for a special care unit if they are going to advertise that they have such a unit. The creation of the voluntary certification program was intended to encourage the establishment of special care units. As of September 1991, however, only 8 special care units had been certified, even though the Department of Health is aware of at least 60 nursing homes in the State that have a special care unit (1 12).

To be certified, the Texas regulations require a unit to have:

- safety measures to prevent residents from harming themselves or leaving the unit without supervision,
- policies to prevent residents from abusing the property and rights of other residents,
- staff training, including at least 8 hours of training for all new staff on five topics listed in the regulations and 4 hours of inservice training annually for all staff,
- specified staff-to-resident ratios for each shift,
- staff who are assigned exclusively to the unit,
- a social worker to assess the residents on admission, conduct family support group meetings, and identify and arrange for the use of community resources,
- a specified amount of space per resident in public areas, including the dining area,
- a specified number of showers, bathtubs, toilets, and lavatories per resident,
- a nurses' station with a place to write, a chair, "task illurination, " a telephone or intercom to

the main staff station, and a place to store resident records,

- activity and recreational programs tailored to the individual resident's needs,
- resident access to a secure outdoor area with no toxic plants,
- admission practices that limit admission to individuals with a diagnosis of Alzheimer's disease or a related dementing disorder whose attending physician has documented the reasons for the individual's admission to the unit,
- patient care practices that provide for residents' privacy during treatment and personal care,
- patient care practices that provide for careful, time-limited use of restraints and psychotropic medications,
- at least two exits,
- latches or other fastening devices for the exit doors that are easy to release, even in the dark, and
- if the exit doors are locked, the facility must have a complete sprinkler system or fire alarm system; the locks must release automatically if the sprinkler or alarm system is activated or if there is a power failure; and there may be a keypad or buttons at the door for routine use by the staff (Texas Department of Health, Chapter 145, Subchapter B, 145.301-145.304).

At public hearings in October 1989, witnesses made both positive and negative comments about Texas' voluntary certification program (443). The positive comments focused on the importance of the training requirements and the value of the certification program in providing initial guidelines for facilities and preventing facilities from advertising a special care unit that does not meet minimum standards. The negative comments focused on the difficulty of setting standards in a changing field and the need for revisions to the standards that would require higher staff levels during some periods of the day, documentation of staff training, and programs and policies to address the needs of family members. Officials of two companies that have several nursing homes with special care units in Texas told OTA that the companies consider the State's requirements for voluntary certification difficult to meet and costly; that some of the companies' facilities are certified and others are not; and that the companies do not believe their certified facilities are providing better care than their uncertified facilities (3,141).

Colorado's Regulations for Special Care Units

Colorado has special requirements for "secure units' which apply to locked special care units as well as any other locked nursing home units. The requirements were developed in 1985-1986 by the Colorado Department of Health. Their primary intent is to protect individuals who are placed in locked units (409). The requirements are incorporated in the State's regulations for all nursing homes, and no special license or certification is required for the units.

The Colorado regulations require a' 'secure unit' to have:

- an admissions evaluation team with specified members, including a person with mental health or social work training who is not a member of the nursing home staff,
- admission practices to ensure that individuals are not placed on the unit unless the evaluation team finds that: 1) they are dangerous to themselves or others, or 2) they habitually wander and would not be able to find their way back, or 3) they have significant behavioral problems that seriously disrupt the rights of other residents, and 4) less restrictive alternatives have been unsuccessful in preventing harm to themselves or others, and 5) legal authority for the restrictive placement has been established,
- admission practices to ensure that individuals are not placed on the unit for punishment or the convenience of staff and that the unit is the least restrictive alternative available,
- admission practices to ensure that those placed on the unit because they are dangerous to themselves or wander habitually are protected from residents who are dangerous to others or whose behavior disrupts the rights of others,
- documentation of the reasons for residents' admission to the unit and a physician's approval of the admission,
- written programs to treat the residents it admits,
- practices to allow visitors,
- sufficient staff to provide for the needs of the residents,
- staff who are experienced and trained in the needs and care of the types of residents in the unit,
- additional social work and activities staff to meet the social, emotional, and recreational

needs of residents and the social and emotional needs of residents' families in coping with the residents' illness,
- social services and activities that allow regular interaction with non-confused residents of the facility and the outside community,
- a provision that residents may not be locked into or out of their rooms,
- a specified amount of space per resident in public areas,
- a secure outdoor area, *if the* facility has an outdoor area for residents of other units,
- practices that meet the fire safety standards of the 1985 Life Safety Code, and
- periodic reevaluation of the residents' placement (Colorado regulations for Long-Term Care Facilities, sections 19.1-19.9).

The Colorado regulations specify that residents with Alzheimer's disease whose condition has stabilized may remain on the unit if the evaluation team concludes the "placement is necessary to avoid a likely recurrence of the condition that was the purpose of the initial placement on the unit" (Colorado Regulations for Long-Term Care Facilities, section 19.5.3).

Washington's Regulations for Special Care Units

Washington State has special requirements for "protective units for cognitively impaired residents.' One set of requirements was implemented in 1986 as an interpretation of the State's licensing requirements for all nursing homes (500). In 1989, the interpretation was replaced by a new set of requirements that are incorporated in the State's regulations for all nursing homes. No special license is required for the units.

As of late 1991, Washington State was reviewing all its nursing home regulations, including the requirements for "protective units for cognitively impaired residents' (179). Changes in the requirements are a possibility.

The Washington State regulations require a "protective unit for cognitively impaired residents" to have:

- a dining area that may also serve as a day room for the unit,
- a secure outdoor area with 1) walls or fences of a specified height, 2) an ambulation area with firm stable surfaces that are slip-resistant, 3) exits that release automatically if the fire alarm is activated, 4) outdoor furniture, and 5) non-toxic plants,
- a staff toilet room,
- corridors no less than 10 feet wide in new construction and 8 feet wide in renovated units,
- floors, walls, and ceiling surfaces of contrasting colors; the surfaces may conceal areas the residents should not enter,
- door thresholds that are one-half inch high or less,
- an electrical signaling system in each room for staff use in an emergency,
- no keyed locks on the exit doors or any door between a resident and the exit; exits may be secured by alarms or doors which require cognitive ability to open or by other methods that open automatically if the fire alarm is activated; the releasing devices for the doors must be labeled with directions, accessible by residents, and approved for use by the State fire marshal, and
- no use of a public address system except for emergencies (Washington Administrative Code 248-14-211).

Tennessee's Regulations for Special Care Units

Tennessee has special requirements for "special care units for ambulatory patients with Alzheimer's disease and related disorders.' The regulations were developed on the initiative of the Governor's Task Force on Alzheimer's Disease and went into effect in March 1991. Nursing homes with a special care unit must apply to the State's Board for Licensing Health Care Facilities to have the unit 'designated" as a special care unit. To avoid delays in opening new special care units, nursing homes that are in compliance with the State's general nursing home requirements may open a special care unit without waiting for the Board to designate the unit (36). Eventually, however, all special care units must be designated by the board.

As of June 1992, 12 special care units had been designated by the board, and one additional nursing home had applied for designation of its special care unit (36). Thus far, no nursing home that has applied for designation for a special care unit has been turned down.

The Tennessee regulations require a' 'special care unit for ambulatory patients with Alzheimer's disease and related disorders' to have:

- admission practices such that each resident has a diagnosis made by a physician that identifies the specific cause of the resident's dementia and each resident's need for admission to the unit is determined by an interdisciplinary team that includes a physician who is experienced in managing individuals with dementia, a social worker, a nurse, and a relative or other advocate for the resident,
- access to a protected outdoor area,
- separate dining/activity areas,
- a stated bed capacity that is not exceeded at any time,
- a design such that visitors and staff do not pass through the unit to reach other parts of the nursing home,
- 3.5 hours of direct care per resident per day, including ,75 hours of direct care provided by a licensed nurse,
- resident care plans that are developed, periodically reviewed, and implemented by an interdisciplinary team that includes a physician who is experienced in managing individuals with dementia, a social worker, a nurse, and a relative or other advocate for the resident,
- a 40-hour classroom training program for nurse aides that is in addition to the 40-hour basic training program for all nurse aides and covers the causes, progression, and management of dementia, including methods of responding to residents' behavioral symptoms, alleviating safety risks, assisting residents with activities of daily living, and communicating with residents' families.
- procedures for identifying and alleviating job-related staff stress,
- a family support group that meets at least quarterly, provides family education and support, and allows for family input into the operation of the unit, and
- if the unit is locked, 'extraordinary and acceptable fire safety features and polices' to protect the residents (Tennessee State Rule 1200-8-6-.10)

The original intent of the Governor's Task Force in initiating the special care unit regulations was that Medicaid reimbursement would be increased for special care units that met the specified requirements, but this objective has not been realized. Like all other States, Tennessee provides no higher reimbursement for Medicaid-eligible individuals in special care units than in any other nursing home unit. In the first year after the regulations went into effect, the Board for Licensing Health Care Facilities received many inquiries about the designation of special care units but relatively few applications. The board's director believes this is because the current level of reimbursement for Medicaid-eligible individuals does not cover the additional cost a nursing home would incur to comply with the special care unit requirements.

Kansas' Regulations for Special Care Units

Kansas has requirements for special care units that were issued in 1989 as an interpretation of the State's licensing regulations for all nursing homes. As of September 1991, the Kansas Adult Care Home Program was in the process of revising the licensing regulations and had proposed that the interpretation on special care units be included as a requirement in the revised regulations (267).

The Kansas interpretation requires a special care unit to have:

- admission criteria, including a requirement that the resident have a medical diagnosis and a physician's order to be admitted,
- a staff training program and documentation that staff members have completed the program,
- a staff member on the unit at all times;
- a nurses' sub-station located so that the corridors are visible from the sub-station,
- nurse-call signals that are visible and audible from the corridors and nurses' sub-station,
- living, dining, activity, and recreational areas that are accessible to the residents,
- resident care plans that identify the problems that justify the resident's placement on the unit and identify interventions that could correct or compensate for those problems,
- methods of securing the unit that are the least restrictive possible and comply with all life safety codes (Kansas Administrative Rules, 28-39-78 (a) (6) and (7) and 28-39-87 (c) and (e)).

Kansas is enforcing these requirements. At the beginning of a nursing home inspection, the surveyor asks whether the facility has a special care unit and then evaluates the identified unit, if any, on the basis of the requirements of the interpretation in addition to the general requirements for all nursing homes (267). No information is available about the

number of special care units identified in this way by the surveyors. The director of the State's Adult Care Home Program told OTA that special care units are most likely to have trouble with three of the requirements: 1) the admission criteria, 2) the staff training, and 3) the resident care plan (267).

States That Are Developing or Considering Developing Regulations for Special Care Units

State legislatures in four States have mandated the development of special regulations for special care units. Two State health departments are developing regulations for special care units without a prior legislative mandate, and one State health department is considering doing so. State Alzheimer's disease task forces and other legislatively appointed bodies in several States have recommended the development of regulations for special care units, and in one State, the legislature has mandated the appointment of a committee to determine whether regulations are needed.

In 1989, the Arkansas legislature passed a bill requiring the Department of Human Services to establish a mandatory certification program for special care units. In 1990, after considering the issue of regulations for special care units and with the approval of the bill's legislative sponsor, the department decided not to go ahead with the certification program (147). As of early 1992, however, the State was reconsidering this issue. One possibility being considered was the creation of a new licensing category for special care units.

In 1989, the Nebraska legislature passed a resolution mandating a study of special care unit standards that would result in recommendations for legislation to regulate the units (323). In response, the Governor's Alzheimer's Disease Task Force formed a subcommittee to examine this issue and make recommendations. The subcommittee's report, released in November 1989, specifies principles, goals, and objectives for special care units, a list of recommended policies and procedures that are very similar to Iowa's requirements for a special care unit license, and a proposed training program for special care unit staff members. The subcommittee recommended that the Nebraska Department of Health develop regulations based on the content of this report and the Iowa licensing requirements, The subcommittee concluded that required staffing ratios for special care units should be based on 'acuity ratings of the patients" and that Medicaid reimbursement for residents of special care units should also be based on "acuity ratings" and on the cost to the nursing home of complying with the State requirements for special care units, once developed (323). As of September 1991, the Department of Health was still working on draft regulations (447).

In 1991, the Oregon legislature passed a bill requiring nursing homes and residential care facilities that have a special care unit to register with a State agency, the Senior and Disabled Services Division, by Oct. 1, 1991 (335). Twenty-four facilities registered by that date, including 20 nursing homes and 4 residential care facilities (126). The Oregon legislation also requires that by June 1, 1993, facilities with a special care unit must have a special "endorsement' on their general license. To obtain the endorsement, the special care units will have to meet requirements in three areas: "1) care planning, including physical design, staffing, staff training, safety, egress control, individual care planning, admission policy, family involvement, therapeutic activities, and social services; 2) continuity of basic care requirements; and 3) marketing and advertising of the availability of and services from Alzheimer's care units" (335). As of early 1992, the Senior and Disabled Services Division was developing the requirements for the endorsement. An advisory committee that includes three Alzheimer's advocates, three industry representatives, and one official of an area agency on aging had been appointed to assist the division in developing the requirements(126).

In 1991, the North Carolina legislature passed a bill requiring the State Medical Care Commission to develop standards for special care units in nursing homes and requiring the State Social Services Commission to develop standards for special care units in residential care facilities. Both sets of standards are to address "the type of care provided in a special care unit, the type of resident who can be served on the unit, the ratio of residents to staff members, and the requirements for the training of staff members' (33 1). As of early 1992, both sets of standards had been drafted and were in the approval process (71). As a part of that process, the State legislature asked for a cost impact statement to determine the cost implications of the standards.

The New Jersey Department of Health is developing regulations for special care units (161). The

regulations will require special care units to meet 65 percent of the requirements if they are going to advertise as a special care unit.

The Oklahoma Department of Health is also developing regulations for special care units, primarily in response to recommendations of the State Task Force on Alzheimer's Disease and Related Disorders (326). The regulations will require special care units to have a special license in addition to the license all nursing homes must have.

The New Mexico Department of Health is considering the development of regulations for special care units (499). The department intends to work with the Alzheimer's Association and the School of Nursing at the University of New Mexico on this project.

In the past few years, State Alzheimer's disease task forces in at least two additional States—Arizona, and Indiana-have recommended the development of regulations for special care units (14,65,203). In its 1989 report, the Arizona Advisory Committee on Alzheimer's Disease and Related Disorders cited complaints from many families about 'difficult and stressful encounters with poorly run homes' and about the lack of standards and regulatory guidance in the selection of residential care homes (14). The committee recommended that the Arizona Department of Health Services be authorized "to develop guidelines, set standards, and regulate specific Alzheimer's patient care units in nursing homes that are presented to the public as providing specialized care" (14). Following the release of its 1989 report, the committee developed draft standards. As of early 1992, the State had not yet agreed to enforce the standards, and the committee was seeking ways to obtain voluntary compliance (432).

In Indiana, the State's Family and Social Services Administration contracted with the Alzheimer's Association of Greater Indianapolis to develop standards for special care units and to make a recommendation about whether the State should institute either a voluntary or a mandatory certification program for special care units (428). The contract ran from January 1992 to June 1992. Although the standards proposed by the Alzheimer's Association may eventually be the basis for regulation, the State has not yet committed itself to establishing regulations.

In California, some members of the State's Alzheimer's Advisory Committee drafted guidelines for special care units but concluded that it would take several years to get the guidelines incorporated into the State's nursing home regulations with or without legislation (484). As a result, the committee is working with California's nursing home associations and individual nursing home operators toward eventual voluntary implementation of the guidelines. As of July 1992 the draft guidelines were being reviewed by the associations, consumers, policymakers, and others (255).

In Rhode Island, in early 1992, the Long-Term Care Coordinating Committee, a legislatively appointed body, approved draft legislation to create standards for special care units (284). The draft legislation has been sent to the State legislature.

Lastly, in Virginia, in March 1992, the State legislature passed a resolution requiring the establishment of a committee to determine whether the State should have regulations for special care units. The Virginia Department of Mental Health has appointed the committee.

States That Have Developed or Are Developing Guidelines for Special Care Units or for the Care of People With Dementia in All Nursing Homes

New Hampshire has guidelines for special care units, and Missouri is developing such guidelines. The New Hampshire guidelines are published in an 8-page booklet that has one section for families who are trying to evaluate special care units and another section for nursing home operators who are interested in establishing a special care unit (325). By providing information for families and nursing home operators in the same publication, the New Hampshire booklet directs the attention of the nursing home operators to what families are likely to be looking for in a special care unit.

The New Hampshire State agency that produced the booklet chose to publish guidelines rather than regulations because of an awareness of the diversity of opinions about special care units both inside and outside the State government (216). The agency has not ruled out the possibility of developing regulations in the future.

In 1990, the Missouri Division of Aging appointed a special care unit committee to develop

guidelines (153). One reason Missouri chose to develop guidelines rather than regulations was a belief in the State that nursing homes would expect regulations to be accompanied by increased reimbursement for special care units and that the development of guidelines would not create that expectation.

Massachusetts took a different approach than other States in its "Guidelines for Care of Patients With Alzheimer's Disease and Related Disorders in Massachusetts Long-Term Care Facilities. " These guidelines, published in 1988, pertain to the care of individuals with dementia in any nursing home unit (288). As of late 1991, anew set of guidelines for the care of individuals with dementia in nonspecialized nursing home units was being reviewed (362). At the same time, the Eastern Massachusetts Chapter of the Alzheimer's Association, in cooperation with the Massachusetts Department of Health, was drafting a separate set of guidelines for the care of individuals with dementia in special care units.

In its 1991 report, the Maryland Coordinating Council on Alzheimer's Disease and Related Disorders recommended an approach similar to the 1988 Massachusetts guidelines (286). The Council recommended that the State work with industry and advocacy groups to develop guidelines that would apply to the care of individuals with dementia in any nursing home unit. The Council also recommended that the State collect information about special care units. It recommended against the development of regulations, saying, "States and advocacy groups which have attempted to develop regulations or detailed guidelines for special care units have not been particularly successful" (286).

States That Have Certificate of Need Exceptions for Special Care Units

As noted earlier, certificate of need laws are intended to limit the supply of nursing home beds in a State. At least six States--Georgia, Kentucky, Michigan, Mississippi, New Jersey, and Ohio-have altered the process for obtaining a certificate of need, either on an ongoing or a one-time basis, so that applicants who propose to create special care units or special nursing homes for people with dementia receive special consideration. To OTA's knowledge, only two of these States, Kentucky and Michigan, have special requirements for the units or facilities developed with a certificate of need exception (35,155,161,172). This lack of requirements created consternation in at least one of the other States when State surveyors were preparing for their annual inspection of a facility that had created a special care unit with a certificate of need exception, and the surveyors wanted to know what to look for when they inspected the unit (155).

In Kentucky, the legislature created a time-limited exception to the State's certificate of need law to allow the establishment of "free-standing facilities limited to the care of patients with Alzheimer's or related disorders' (172). The facilities had to be approved by July 1991 and have to meet special licensing requirements. Interestingly, the licensing requirements for free-standing Alzheimer's facilities do not apply to special care units, and free-standing Alzheimer's facilities do not have to meet the State's regulatory requirements for all nursing homes. As of the cutoff time in July 1991, one facility had obtained a license, and another facility was in the process of doing so (343).

Effective in 1989, the Michigan Certificate of Need Commission set aside 200 beds from the total number of allowable new nursing home beds in the State to be used for special care units. The Commission determined that special care units created through this certificate of need exception must:

- admit only patients who require long-term care and have been appropriately classified as having a score below a given level on the Global Deterioration Scale, a widely used assessment instrument,
- participate in the State Alzheimer's registry,
- operate for a minimum of 5 years and conduct and participate in research programs approved by the department to evaluate the effectiveness of special care units and to study the relationship between the needs of Alzheimer's patients and the needs of other nursing home residents,
- be affiliated with a research facility or program,
- be attached or geographically adjacent to a licensed nursing home,
- have no more than 20 beds,
- have direct access to a secure indoor or outdoor area for unsupervised activity,
- have a separate dining room for use only by residents of the unit,
- have a physical environment designed to minimize noise and light reflections, and
- have trained staff (304).

As of March 1991, the first five applicants for certificate of need exceptions had been disapproved because they did not submit a research protocol or were not affiliated with a research program (514).

Other State Policies for Special Care Units

In addition to regulations, guidelines, and certificate of need exceptions, several States have provided finding for individual special care units or for training staff members in special care units. In 1987, Massachusetts initiated its "Alzheimer's Unit Pilot Program" which has provided funding for eight nursing homes to create special care units. Connecticut has provided funding for a 120-bed nursing home and research center devoted to the care of individuals with Alzheimer's disease. Florida has provided funding for a long-term care facility and research center for individuals with Alzheimer's disease. Each of these projects is intended to develop, demonstrate, and evaluate methods of specialized dementia care.[1]

California has funded at least two studies of special care units. One study compared two nursing home special care units, two nonspecialized nursing home units, and two specialized programs for individuals with dementia in board and care facilities (256). The results of this study are discussed in chapter 3. A second study is comparing various methods of preventing individuals with dementia from wandering away from a care setting. The study is evaluating the effectiveness of door alarms and wrist bands vs. a locked perimeter in achieving this purpose (484).

Beginning in 1991, Michigan has provided funding to the Alzheimer's Care and Training Center, a special care unit in Ann Arbor, Michigan, to support research on the care of individuals with dementia and to provide training about dementia for staff of the State's community mental health centers (384). Rhode Island has provided funding for the past six years for a training program that has been instrumental in establishing several special care units and specialized adult day centers (284).

Summary and Implications

Special care units are clearly an area of policy interest in many States. As discussed in the preceding sections, there are now:

- six States with regulations for special care units (IA,TX,CO,WA,TN,KS);
- five States in the process of developing regulations (NC,NE,NJ,OK,OR);
- one additional State that has passed legislation to mandate the development of regulations (AR);
- three additional States in which the State-appointed Alzheimer's task force or long-term care advisory council has recommended the development of regulations (AZ,IN,RI);
- one State that has passed legislation to establish a committee to study the need for regulations (VA);
- one State with guidelines for special care units (NH);
- one State that is developing guidelines for special care units (MO);
- one State with guidelines for the care of individuals with dementia in any nursing home unit (MA);
- one State in which the Alzheimer's task force has recommended the development of guidelines for the care of individuals with dementia that would apply to any nursing home unit (MD);
- six States that have altered the process for obtaining a certificate of need to encourage the establishment of special care units (GA,KY,MI,MS,NJ,OH); and
- six States that have provided funding for individual special care-units, for training in special care units, or for research on special care units (MA,CA,CT,FL,MI,RI).

These figures and the discussion in the preceding sections reflect information available to OTA as of early 1992. The figures indicate that a total of 28 States have, are in the process of developing, or are considering developing policies of some kind for special care units. (Five States are included twice in the list.)

[1] Several other States, e.g., Illinois and New York, have provided funding for nursing homes to develop improved methods of caring for residents with dementia in nonspecialized units. The New York Medicaid program pays an additional $4 a day for residents with Alzheimer's disease in any nursing home (201). Maine and Oregon subsidize the care of some residents with dementia in specialized board and care facilities (303,501).

State policies for special care units are changing rapidly. Interest in the development of regulations for special care units is clearly growing. In some States, this interest is unopposed. In other States, such as Illinois, Michigan, Ohio, and Wisconsin, this issue is controversial, and some groups strongly oppose the development of regulations. Anecdotal evidence suggests that in a few States, regulatory proposals developed by Alzheimer's advocates have been opposed by other Alzheimer's advocates or nursing home industry representatives who have different ideas about whether there should be regulations, and if so, what the regulations should say.

Thus far, State policies for special care units have been developed without regard for the nursing home reform provisions of OBRA-87. Some of the State regulations for special care units were developed before OBRA-87 was passed, and many of the regulations were developed before the publication in February 1989 of the first version of the requirements to implement OBRA-87. It is surprising, however, that current discussion and debate about regulations and guidelines for special care units is proceeding with so little reference to the OBRA requirements. One exception to this observation is the 1991 report of the Maryland Coordinating Council on Alzheimer's Disease and Related Disorders. The report notes the likelihood that OBRA requirements will improve the care of people with dementia in nursing homes and stresses the importance for Alzheimer's advocates of monitoring facilities' compliance with the requirements (286).

Regulations for special care units now in effect in Iowa, Texas, Colorado, Washington, Tennessee, and Kansas have both similarities and differences. Each State's regulations address several common areas, e.g., admission criteria, security, staff training, and some aspects of physical design, but their requirements in each of these areas differ. Moreover, each State's regulations include requirements for features not addressed in other States' special regulations, e.g., Iowa's requirement that the unit and its outdoor area have no steps or slopes, Washington's requirement that floors, walls, and ceilings have surfaces of contrasting colors, and Colorado's requirement that residents may not be locked into or out of their rooms.

What is and is not included in these regulations is significant because of the implication that features required by the regulations are particularly important in the care of nursing home residents with dementia and that other features not addressed by the regulations are not particularly important for these residents. The inclusion of certain features suggests that nursing home resources should be expended for those features and not others.

Many of the requirements for special care units in the six States probably are not more important in the care of nursing home residents with dementia than other nursing home residents, e.g., an interdisciplinary care planning team (IA,TN); policies that explain the programs and services offered in the unit (IA); a social worker to assess residents on admission, conduct family support group meetings, and identify and arrange for the use of community resources (TX); activity and recreational programs tailored to individual residents' needs (TX); a staff member on the unit at all times (KS); and nurse-call signals that are visible and audible from the corridors and the nurses' sub-station (KS).

Some of the requirements in the six States' regulations duplicate provisions of OBRA-87 that apply to all nursing home residents. For example, Iowa and Colorado require that special care units have policies to allow residents to have visitors. The OBRA requirement states, "The resident has the right and the facility must provide immediate access to any resident. . subject to the resident's right to deny or withdraw consent at any time, by immediate family or other relatives of the residents. . and by others who are visiting with the consent of the resident" (463).

In general, the six States' requirements focus more on staff training and physical design features and less on activity programs and programs to involve and support residents' families. Although there is no evidence from research that any one of these features is more likely than the others to produce positive outcomes, some dementia experts would probably favor a greater emphasis on activity programs and family support programs than exists in the six States' requirements.

Notably absent from the requirements of five of the six States is any mention of the role of physicians, except in approving residents' admission to the unit. Likewise, except for the Colorado regulations, mental health expertise and training are not mentioned, and their inclusion in the Colorado regulations may simply reflect the fact that these

regulations pertain to locked units for psychiatric patients as well as locked units for individuals with dementia. Requirements for ongoing physicians' involvement with residents appear in other sections of the States' nursing home regulations and in the Federal regulations for Medicare and Medicaid certification of nursing homes, and there may also be requirements for involving individuals with mental health training in other sections of the States nursing home regulations. Omission of these features in the special care unit requirements suggests, nevertheless, that they are less important in the care of nursing home residents with dementia than the features that are included.

The overall impact of State regulations on the growth of special care units is unclear. Anecdotal evidence suggests that some of the six States' regulatory requirements may discourage the growth of special care units, primarily because of the cost of complying with the requirements. The Hillhaven Corp. estimates that complying with Washington State's requirements increased the remodeling cost for a special care unit that opened in one of their facilities in 1991, from $69,000 to $118,000 (261). As a result, the corporation canceled plans for a special care unit in another facility in the State.

In considering the impact of State regulations on the growth of special care units, it is interesting to note that despite the growing number of special care units in the United States and the growing interest in regulations for special care units in many States, as of early 1992, there were fewer than 60 special care units nationwide that were specially licensed, certified, designated, or registered (17 to 19 units in Iowa, 8 units in Texas, 12 units in Tennessee, and 20 units in Oregon). OTA is not aware of any research that compares these licensed, certified, designated, or registered units to other special care units.

SPECIAL CARE UNIT GUIDELINES DEVELOPED BY OTHER PUBLIC AND PRIVATE ORGANIZATIONS

In addition to States, several other public and private organizations have developed or are in the process of developing guidelines for special care units. Six of these organizations-the Alzheimer's Association, 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 completed guideline documents. The Alzheimer's Association also has legislative principles for special care units. The Alzheimer's Society of Canada, the Alzheimer's Coalition of Connecticut, and the U.S. Department of Veterans Affairs are developing guidelines for special care units. Some multi-facility nursing home corporations have formal guidelines or standards for their special care units. Lastly, the Joint Commission on Accreditation of Healthcare Organizations, a private organization that offers voluntary accreditation for nursing homes, is developing guidelines to assist its surveyors in evaluating special care units in the nursing homes it accredits. This section briefly describes each of these guideline documents and efforts.

Some of the guidelines developed by these organizations are intended as a basis for government regulations, but most are not. None of the six completed guideline documents is intended as a basis for regulations. It is OTA's impression that obtaining agreement among experts in dementia care about the features that should be required in a special care unit is more difficult than some organizations anticipate. As a result, organizations that begin with the intention of developing standards that could be used for regulatory purposes sometimes conclude later on that there is insufficient agreement among experts to support such standards and decide to develop guidelines instead.

The American Association of Homes for the Aging— "Best Practices for Special Care Programs for Persons With Alzheimer's Disease or a Related Disorder"

In 1988, the Task Force on Alzheimer's Disease of the American Association of Homes for the Aging completed its 'Best Practices' document (10).[2] The document is intended to provide guidelines for exemplary special care programs and to help nursing

[2] To OTA's knowledge, the American Association of Homes for the Aging's "Best Practices" document has not been published. It is available from the Association however.

home operators and others distinguish specialized dementia care from standard practice. The document points out that, "although many of the best practices appear at first to be the standards of any quality program, when taken as a whole the best practices define what is special about dementia care' (10). It also emphasizes that little research has been conducted on specialized dementia care, that the "Best Practices" guidelines are based on clinical experience, and that with further experience and research, the guidelines will be validated, improved upon, and expanded. The document is not intended to be used for regulatory purposes.

The 22-page "Best Practices" document addresses seven areas: commitment, philosophy of care, therapeutic program, physical design, specialized staff, communications program, and education and research (10). For each of these areas, a general statement of the best practice is given; the characteristics or components of the best practice are listed; and the desirable outcomes in that area are described.

The Massachusetts Alzheimer's Disease Research Center—"Blueprint for a Specialized Alzheimer's Disease Nursing Home"

In 1989, with funding from the National Institute on Aging and the Administration on Aging, the Massachusetts Alzheimer's Disease Research Center held a 2-day workshop to develop a plan for a specialized Alzheimer's disease nursing home. The workshop participants tried to define what should be special about specialized care for individuals with dementia, what works for these patients, and which patients it works for. The resulting document, released in 1990, provides general conclusions and recommendations but emphasizes the need for rigorous research on specialized dementia care (287). It is not intended to be used for regulatory purposes.

The 20-page "Blueprint" document addresses three areas: policy planning, patient care programs, and architectural design (287). For each of these areas, a series of interrelated recommendations are made based on the workshop discussion and later review and revisions by the workshop participants.

The Alzheimer's Disease Education and Referral Center—"Standards for Care for Dementia Patients in Special Care Units"

In 1991, the Alzheimer's Disease Education and Referral Center completed its guidelines for special care units (6). The center, which is funded by the National Institute on Aging, is a clearinghouse for information about Alzheimer's disease for professionals, patients, families, and the general public. The "Standards" document is available to anyone who requests it. Despite its title, the document does not set standards. It discusses the pros and cons of developing standards for special care units, points out the lack of information about many aspects of specialized care for individuals with dementia, and emphasizes the need for research on the costs and effectiveness of special care units. The document is not intended to be used for regulatory purposes.

The 'Standards' document addresses seven areas: admission, environment, activities, staffing, training, expected impacts, and research issues (6). For each of these areas, a brief summary of current thinking is given.

The University of South Florida's Suncoast Gerontology Center—"Draft Guidelines for Dementia Specific Care Units (DSCUs) for Memory Impaired Older Adults"

In 1991, researchers from the Suncoast Gerontology Center published the findings of a study of 13 special care units in west central Florida (64). As discussed in chapter 3, the researchers used the study findings to create a typology of "minimally specific, moderately specific, and highly specific" units. On the basis of the study findings and the typology, the researchers developed guidelines for special care units (63). The guidelines are not intended to be used for regulatory purposes.

The 19-page "Draft Guidelines" document addresses ten areas: goals and philosophy, target population, admission and discharge criteria, resident assessment, physical environment, activity programs, unit size and staffing, staff training, family involvement, and ongoing evaluation (63). For each of these areas, a theoretical rationale and several specific guidelines are given.

The University of Wisconsin-Milwaukee Center for Architecture and Urban Planning Research— "Environments for People With Dementia: Design Guide"

In 1987, the American Institute of Architects and the Association of Collegiate Schools of Architecture contracted with the Center for Architecture and Urban Planning Research at the University of Wisconsin-Milwaukee for a project to develop environmental design guidelines for special care units and other specialized settings for people with dementia. The project resulted in an annotated bibliography (363), a book of facility case studies (96), a regulatory analysis (94), and a design guide (95). The 97-page design guide discusses particular needs of persons with dementia, related therapeutic goals for the physical environment, and design principles for achieving those goals. It includes facility case examples and illustrations.

The Alzheimer's Association-Legislative Principles and "Guidelines for Dignity"

In 1988, the Alzheimer's Association published a 13-page booklet to help families of individuals with dementia evaluate special care units (276). The booklet provides information about specialized dementia care and advises family members to visit a unit and to observe certain aspects of the physical environment, unit staffing, and resident care before deciding to place their relative with dementia in the unit.

As the number of special care units has increased, the association's national office and many of its more than 200 chapters nationwide have received an increasing number of requests from family members and others for information and advice about special care units. Nursing home operators contact Alzheimer's Association chapters for help in establishing a special care unit, and some chapters are providing formal or informal consultations to such facilities (114,231). State officials also contact the national office and the chapters for assistance in developing State relations for special care units. For these reasons, and because of concerns about special care units that are apparently established only for marketing purposes and provide nothing special for their residents, the association has developed legislative principles for special care units (4).

The association's legislative principles are intended to direct legislators' and regulators' attention to the primary areas a State should include when drafting special care unit legislation or regulations. The 11 areas cited in the association' s principles are: 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). The legislative principles recommend that States involve providers, consumers, ombudsmen, activities and occupational therapists, environmental design specialists, fire and safety officials, and licensure and survey officials in drafting specific standards in each of these areas.

In July 1992, the association released "Guidelines for Dignity: Goals of Specialized Alzheimer/ Dementia Care in Residential Settings." The 41-page "Guidelines" document discusses eight goals and guidelines for achieving the goals. The document is not intended to be used for regulatory purposes.

The Alzheimer's Society of Canada— Forthcoming Guidelines

In 1990, the Alzheimer's Society of Canada, a private voluntary association, received a $500,000 grant from the Canadian Government for a 3-year project to develop guidelines for the care of individuals with Alzheimer's disease in a variety of settings, including special care units (7,313). In the first year of the grant, a literature review was conducted; Alzheimer's Society staff members visited various care settings; and a questionnaire was sent out to 15,000 family caregivers. In 1991, draft guidelines were developed by the society's staff with the assistance of an advisory committee (401). The guidelines, which were circulated for outside review in early 1992, address 11 areas: involvement in decisionmaking, assessment, staffing, programs and activities, training and education for caregivers, support for caregivers, physical and chemical restraints, preventing and responding to abuse, environmental design, and transportation. The society intends to publish two documents based on the guidelines--one document intended primarily for families and one intended primarily for government and provider agencies.

The Alzheimer's Coalition of Connecticut—Forthcoming Guidelines

The Alzheimer's Coalition of Connecticut, a private nonprofit organization that was formed after the expiration of the Governor's Task Force on Alzheimer's Disease, has developed a draft document that describes the important features of a special care unit. Although State officials have been involved in the development of the document, it is not intended as the basis for State regulations (512).

U.S. Department of Veterans Affairs—Forthcoming Guidelines

As discussed in chapter 3, a 1989 survey by the U.S. Department of Veterans Affairs (VA) identified special care units at 31 of the 172 VA medical centers nationwide. In 1991, the VA conducted site visits to 13 of the special care units and telephone interviews with staff of many of the other units. Partly on the basis of these site visits and interviews, the VA is developing guidelines for "Specialized Alzheimer's/Dementia Units" at VA medical centers (103). The guidelines describe three types of units-'diagnostic,' "behavioral management," and "long-term care' units. The guidelines discuss the goals and objectives of the units, the types of residents served, unit size and location, staffing, space and environmental factors, program evaluation, and quality assurance.

Multi-facility Nursing Home Corporations—Special Care Unit Guidelines

Some multi-facility nursing home corporations have guidelines for special care units in the nursing homes they own, Hillhaven Corp., which had 56 nursing homes with special care units in late 1990, has an extensive policy and procedures manual for the units (187). The manual was first developed in 1982 and was updated in 1984 and 1988 (337). It delineates the philosophy and treatment modalities of the units, their admission and discharge criteria and procedures, family services, use of restraints, staff training, and other features. The manual includes resident assessment instruments, guidelines for running a family support group, and a quality assurance checklist.

Unicare Health Facilities, which had 15 nursing homes with special care units in late 1990, also has a manual for its units, called "Lamplighter Units" (281). The manual describes the care needs of nursing home residents with Alzheimer's disease and the philosophy, admission criteria, assessment procedures, staffing, and care methods of the company's special care units. The manual includes a resident assessment instrument. Other multi-facility nursing home corporations that have facilities with special care units may also have guidelines for the units.

The Joint Commission on Accreditation of Healthcare Organizations—Draft Surveyor Guidelines

Since 1989, the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) has been working on guidelines to assist its surveyors in evaluating special care units in the facilities it accredits. As noted earlier, JCAHO is a private organization that currently accredits about 1000 nursing homes in the United States (214). JCAHO's effort to develop guidelines evolved from concerns and questions raised by its surveyors about how to evaluate the increasing number of special care units they were seeing in nursing homes accredited by the commission (434).

JCAHO's surveyor guidelines, currently out for review in a fourth draft, are based on the commission's standards for all nursing homes (213,435). 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 surveyors should follow in evaluating and scoring the special care unit on that standard.

The 152-page fourth draft of the surveyor guidelines is much longer than the other guideline documents discussed in this section. It provides what is, in effect, a detailed answer to the question, "What constitutes appropriate care for nursing home residents with dementia?" Some commentators will undoubtedly disagree with some of its components, and certain of the components probably apply as much to nondemented as demented nursing home residents. There are also instances in which the guidelines tell surveyors to determine whether *appropriate* or *proper care* has been given, leaving open the question of what appropriate or proper care is; the frequency of these instances has decreased, however, in each successive draft of the

document. The guidelines are informative and thought-provoking at the least, and the commission is to be credited with creating comprehensive surveyor guidelines that fit within the broader context of its standards for all nursing homes.

JCAHO intends to pilot test the surveyor guidelines in the summer 1992 in six special care units in the Chicago area (435). Using the guidelines, two JCAHO surveyors will inspect the six units. Within 2 days, two representatives of the Alzheimer's Association will visit the same units. The surveyors' findings and the observations of the Alzheimer's Association representatives will be compared to determine whether the guidelines identify the problems that concern consumers.

Summary and Implications

The completed guideline documents discussed in the preceding sections are intended to educate and inform. They identify areas that require special consideration in the care of nursing home residents with dementia, but unlike the State regulations discussed earlier in the chapter, the guideline documents generally do not prescribe particular features for special care units. The JCAHO draft surveyor guidelines differ from the other guideline documents in that they do prescribe many detailed features for special care units, but the JCAHO guidelines are also intended primarily to educate and inform surveyors and to identify areas of special consideration in the care of residents with dementia.

The areas of special concern identified in the guideline documents are: activity programs, admission and discharge criteria, conditions of participation, cost and reimbursement, enforcement, family involvement, philosophy and goals, physical environment, physical restraints and psychotropic medications, plan of care, policies and procedures, quality assurance, research, resident assessment, resident rights, safety egress control, specialized services (e.g., physician, nursing, social work, and dietary services), and staffing. These areas of concern are not necessarily mutually exclusive, and some are addressed in only one of the guideline documents. Nevertheless, there appears to be some agreement at present about the areas of concern. The State regulations discussed earlier fit conceptually within the same areas of concern.

Having agreement about areas of concern is helpful in organizing a discussion about particular features that might be desirable or required in special care units. On the other hand, agreement about areas of concern is not the same as agreement about particular features. For example, agreement that activity programs and physical environment are areas of concern does not constitute agreement about what the activity programs or physical design features should be. It is OTA's observation that in discussions about guidelines and regulations for special care units, agreement about areas of concern often masks considerable disagreement about particular features of the units and gives a misleading impression that there is consensus about at least some particular features that are desirable and should be required in special care units. Each of the completed guideline documents stresses the current uncertainty about the importance of particular features and the need for research to clarify many unresolved questions in this area.

Finally, it should be noted that like the State regulations for special care units discussed earlier, the completed guideline documents have not been developed in the context of the nursing home reform provisions of OBRA-87. Moreover, some of the specific guidelines in these documents duplicate provisions of OBRA-87 that apply to all nursing homes.

CONCLUSION

As of early 1992, six States had regulations for special care units. Five States were in the process of developing regulations, and other States were considering doing so. These State regulations are intended primarily to assure that special care units are not established and operated solely for marketing purposes and do actually provide something special for their residents. The regulations have been and are being developed in the absence of consensus among experts about the particular features that are necessary in a special care unit and research-based evidence to support requirements for any particular features.

Several public and private organizations have developed or are developing guidelines for special care units. These guidelines identify areas that require special consideration in the care of nursing home residents with dementia but generally do not prescribe particular features for special care units. The six completed guideline documents stress the current uncertainty about the importance of particu-

lar features and the need for research on the effectiveness of various approaches to the care of nursing home residents with dementia. These six guideline documents are not intended to be used for regulatory purposes.

The nursing home reform provisions of OBRA-87 create a broad, comprehensive regulatory structure aimed at assuring high-quality, individualized nursing home care for all residents. As described in this chapter, the provisions of OBRA-87 address many of the complaints and concerns of families and others about the care provided for residents with dementia in many nursing homes. The provisions of OBRA-87 rarely mention cognitive impairment or dementia, but the resident assessment system developed to implement OBRA-87 focuses clearly on the assessment of a resident's cognitive status and the problems and care needs that are common among nursing home residents with dementia. Once a resident's needs are identified, OBRA regulations require that the needs be met.

If fully implemented, the provisions of OBRA-87 would improve the care of nursing home residents with dementia. The problem with OBRA-87 for nursing home residents with dementia is the same problem faced by State officials and others who are trying to develop regulations for special care units: i.e., the lack of agreement among experts about exactly what constitutes appropriate nursing home care for individuals with dementia and the lack of research-based evidence of the effectiveness of various approaches to their care. Solving this problem through Federal support for projects to evaluate different approaches to care may eventually provide a substantive basis for regulations. In the meantime, special care units are ideal settings for the necessary research.

Chapter 6

Regulations And Interpretations of Regulations That Interfere With The Design And Operation of Special Care Units

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Chapter 6

Regulations And Interpretations of Regulations That Interfere With The Design And Operation of Special Care Units

INTRODUCTION

In the course of this study, OTA heard numerous complaints from special care unit operators and others about instances in which Federal, State, and local government regulations or interpretations of regulations interfered with the use of particular physical design features, patient care practices, and staffing arrangements they believed would be appropriate for individuals with dementia. Instances of several different types have been described to OTA:

- instances in which nursing homes could not get approval for particular physical design features, patient care practices, or staffing arrangements for a special care unit;
- instances in which approval for particular physical design features, patient care practices, or staffing arrangements was given by one government agency and later denied by another government agency;
- instances in which approval for particular physical design features was held up for years, thus adding enormously to the cost of building or remodeling the unit; and
- instances in which government officials disallowed particular physical design or other features of special care units on the basis of regulations that were later found not to exist.

From a societal perspective, one objective-and perhaps the most important objective of special care units-is to develop better approaches to caring for nursing home residents with dementia. Instances of the types described above discourage innovation. They interfere with the implementation and evaluation of particular physical design or other features. More importantly, repeated instances of these types create an atmosphere in which nursing home operators are reluctant to attempt innovations.

The problem of regulations and interpretations of regulations that interfere with the use of innovative physical design and other features is not limited to special care units. In 1991, the Task Force on Aging of the American Institute of Architects sponsored an invitational conference on the design of facilities for older people (11). Conference participants included architects, gerontologists, health care and social service providers, regulators, and representatives of aging advocacy groups. The conference planners anticipated that a wide range of issues and concerns would arise. To the contrary, the issues and concerns raised by the participants were "remarkably common...and surprisingly concentrated' (1 1). According to the conference report:

> Top on the list of major issues identified by the group was the plethora of regulations which has enveloped the long-term care industry. Even with the admission and recognition of the problem by most Federal, State, and code bodies, the regulatory and code environment continues to become increasingly convoluted instead of coalescing into simpler bases of information. These problems afford little opportunity for design or construction efficiencies to develop. The lack of regulatory consistency drives up the cost of professional services, each project's development timeline, and, in turn, each project's cost. This unnecessary increase in project cost is then passed onto the resident (11).

In 1987, members of the American Association of Homes for the Aging formed a subgroup, the Environmental Code Work Group, to identify, call attention to, and eventually change regulations that interfere with innovative design in all kinds of residential facilities for older people (380). In 1990, the Association received a grant from the Retirement Research Foundation to establish a national clearinghouse on aging and environmental design codes (379). The clearinghouse is a central source of information about research and trends in environmental design for older people and about Federal and State regulations and codes that affect the design of facilities for older people. The primary purpose of the clearinghouse is to assist facilities whose design plans are challenged by government officials or surveyors.

The extent to which regulations and interpretations of regulations interfere with the design and operation of special care units is unclear. Many of the respondents to a 1987 survey of a nonrandom sample of 99 special care units in 34 States reported that regulations had made the creation of their special care unit "difficult, expensive, or impossi-

ble:" 17 percent of the respondents cited local building code regulations; 18 percent cited State nursing home licensing regulations: 26 percent cited local fire code regulations; and 37 percent cited State fire code regulations (494). OTA is not aware of any other data on the proportion of special care units affected by this problem.

To learn more about the problem, OTA contracted for an exploratory study of regulations that might interfere with the design and operation of special care units (201). The study focused on regulations in two States, Massachusetts and New York. OTA's contractor and OTA staff also interviewed Federal and State officials, consumer groups, architects, staff members of two national nursing home associations, and others in the nursing home industry to obtain their opinions about the problem. The results of the study and these interviews are summarized in this chapter. Examples of instances in which regulations or interpretations of regulations have interfered with the design or operation of special care units are described. The last section of the chapter discusses the need for a waiver process that would allow special care units to implement a wide variety of innovative physical design features, patient care practices, and staffing arrangements. Such a process would have to include mechanisms to evaluate the innovations, The process would also have to include mechanisms to protect residents' rights in units in which innovative approaches to care were being tested.

THE IMPACT OF REGULATIONS ON THE DESIGN AND OPERATION OF SPECIAL CARE UNITS

To understand the impact of regulations on the design of special care units, it is useful to understand the way design decisions are made (201). Architects usually **create a list** of all the requirements a building must meet to serve its designated purpose. Each requirement defines a range of possible design solutions. Regulations are among the requirements an architect must include.

As described in chapter 5, nursing home regulations include:

- . Federal regulations for Medicare and Medicaid certification of nursing homes,
- State licensing regulations,
- State **certificate** of need regulations, and
- . other State and local government regulations that apply to nursing homes, such as zoning, building, fire safety, and sanitation code regulations.

In addition, Federal, State, and local government nursing home regulations incorporate standards developed by various nongovernmental organizations. Federal regulations for Medicare and Medicaid certification of nursing homes require nursing homes to comply with the Life Safety Code of the National Fire Protection Association (NPFA) or an equivalent State fire and safety code (463). Other standards incorporated into some nursing home regulations are the "Specifications for Making Buildings and Facilities Accessible to and Usable by Physically Handicapped People" developed by the American National Standards Institute (ANSI), the "Guidelines for Construction and Equipment of Hospital and Medical Facilities" developed by the American Institute of Architects, and building codes developed by the Building Officials and Code Administrators International, Inc. (BOCA).

All these regulations and standards create requirements that restrict design options. Because of the large number and specificity of the regulations and standards, there may be few design solutions left (201). As a result, nursing homes are sometimes said to have been designed "with a cookie cutter. "

OTA's contractor analyzed Federal regulations, State regulations in Massachusetts and New York, and incorporated standards to identify regulations and standards that might preclude use of particular physical design features in special care units. Table 6-1 shows the results of the analysis. Federal and State regulations and standards were identified that might preclude the use of nine design features intended to serve three purposes: 1) coping with resident wandering, 2) reducing agitation and catastrophic reactions, and 3) making the unit more home-like in appearance (201). Some of the design features, e.g., placement of resident rooms off sitting rooms, are specifically prohibited by the regulations and standards. Other design features, e.g., secure exits and use of familiar furniture, are not specifically prohibited in these States, but the regulations and standards limit the ways in which these design features can be implemented.

Another analysis of Federal regulations, Wisconsin State regulations, and incorporated standards had

Table 6-l—Regulations and Standards That Interfere With the Use of Physical Design Features in Special Care Units

Design Features	Federal Regulations	State Regulations	Incorporated Standards
To Cope With Wandering			
1. Create walking loops by building around interior courtyard, atrium, or activity area	Public law 100-203 Section 4201 (181 9)(6)(D)(d) (2)(B) "A Skilled facility must meet such provisions of. . the Life Safety Code of the NFPA as are applicable to nursing homes."	MA105CMR150.017(B) (5) "Activity Areas: All facilities shall provide on every floor and for every unit a comfortable, convenient, well-lighted and ventilated sitting room, day room, or solarium with a direct outside exposure that is separate from patient or resident rooms."	NFPA: 12-2.4.2 "Egress shall not require return through the *zone* of fire origin."
2. Secure exits			NFPA: 12-2.5.5 "Every corridor shall provide access to at least two approved exits." 12-2.2.2.4 "Doors within a required means of egress shall not be equipped with a latch or lock that requires the use of a tool or key from the egress side."
To Reduce Agitation, Control Catastrophic Reactions			
1. Use of interior finishes that reduce noise and glare		MA105CMR1 50.017B (12)(b) "Walls shall have a water-proof, glazed, painted, or similar surface that will withstand washing; floors shall be water-proof, grease-proof and resistant to heavy wear."	NFPA: 12-3.3.1 "Interior finish on walls and ceilings shall be Class A or Class B." 12-3.3.2 "Newly installed interior floor finish in corridors and exits shall be Class L"
2. Use of clutch doors		Massachusetts Department of Public Health, Division of Health Care Quality: "We have strong objections to the use of clutch doors." New York Bureau of Long Term Services: "Dutch doors are frowned on. They can be used as a way of locking people into their rooms. Our fire safety people are not thrilled about them."	NFPA: 12-3.6.3.6 "Dutch doors may be used. . . Both upper and lower leaf shall be equipped with a latching device, and the meeting edges of the upper and lower leaves shall be equipped with an astragal, rabbet, or bevel."
Residential Ambiance			
1. Bedrooms off sitting rooms or residential scale hallways	Reg. 405-1134 "The skilled nursing facility must meet the applicable provisions of the 1985 edition of the Life Safety Code" and "Each room has direct access to a corridor."	New York Public Health Law Sec. 414.4(b) "The facility shall comply with the pertinent provisions of NFPA 101, Life Safety Codes."	NFPA Life Safety Code: 12-2.3.3 "Aisles, corridors, and ramps required for exit access in a hospital or nursing home shall be at least 8 ft (244 cm) in clear and unobstructed width." 12-2.5.1 "Every habitable room shall have an exit access door leading directly to an exit access corridor."
2. Private rooms	Medicaid will reimburse at semi-private rate only.	Rumor among providers in New York that the State will not allow over 1/3 private rooms. State agency denies this, says there are several Medicaid facilities with all single rooms.	
3. Allow residents to control furniture arrangements, Allow residents in semi-private rooms equal access to windows and doors	Uniform Federal Accessibility Standards: 6.3(2) and (3): "Each bed shall have a minimum clear floor space of 42 in (1065 mm), preferably 48 in (1220 mm), between the foot of the bed and the wall; 36 in (91 5 mm). . .on each side of the bed."		ANSI Standards
4. Eliminate formal nurses' station	Reg. 405.1 134(d) "Each nursing unit has at least the following:. . nurses' station. . equipped to register patient calls."		
5. Allow residents to use familiar furniture			NFPA 31-4.5.2 Bedding, furnishings, decorations in health care occupancies. . shall be flame resistant.

SOURCE: J. Hyde, "Federal Policy in the Regulation and Funding of Special Care Alzheimer's Units; The Role of Federal, State, and Municipal Regulation," contract report prepared for the Office of Technology-Assessment, August 1990.

similar findings (94). That analysis also idenitfied regulations and standards that might preclude the use of design features intended to cope with resident wandering, to reduce agitation and catastrophic reactions, and to make the unit more home-like in appearance. In addition to the regulations and standards identified by OTA's contractor, the Wisconsin analysis identified a Wisconsin regulation and a Life Safety Code standard that require frequent testing of alarms on the unit, which the analysts believe might increase resident agitation. They also identified a Wisconsin regulation for resident room size which allows little flexibility in arranging the room for other than sleep purposes.

Although both of these analyses identified regulations and standards that might preclude use of certain design features in special care units, the number of such regulations and standards and the number of design features affected are much smaller than one would expect, given the complaints cited earlier. Moreover, many of the design features are not specifically prohibited. Instead, as noted above, the regulations and standards limit the ways in which the design features can be implemented.

For several reasons, the impact of regulations and standards on the design of special care units is greater than is indicated by the results of the two analyses. First, the analyses do not include local government regulations which may interfere with use of certain design features. Second, the analyses do not address combinations of regulations which together preclude use of design features that are not specifically prohibited by any one regulation. Third, the analyses generally do not address interpretations of regulations that may preclude the use of physical design features not explicitly prohibited by regulations or standards. The case examples later in this chapter illustrate each of these situations.

In addition, cost constraints often increase the impact of regulations and standards on the design of special care units. Due to cost constraints, special care units frequently are designed to meet the minimum allowable standards. Design options may exist that would meet the standards and fulfill other objectives of the special care unit planners, but these options are ruled out because they cost too much (41,201). In such instances, it is the combination of cost constraints and regulations, not the regulations alone, that precludes use of particular design features.

One example of a combination of cost constraints and regulations that interferes with innovative design in special care units pertains to regulations in some States that require a nurses' station on each nursing home unit. The Wisconsin nursing home regulations state, for example:

> A centrally located nursing station having visual access to all resident room corridors must be provided. The station should consist of a desk or work counter, operational telephone, and a nurse call system and should be situated next to a medicine preparation room (351).

Because of the cost of constructing and staffing a nurses' station, regulations that require a nurses' station on each unit, and particularly regulations that require a nurses' station with visual access to all resident room corridors, encourage construction of large units with long, institution-like corridors (94). In contrast, if cost were not a factor, a variety of innovative designs could be used to create small, home-like units with a nurses' station that meets the regulations.

Financing considerations also increase the impact of regulations and standards on the design of special care units. Agencies that provide financing for nursing home construction, such as banks and State bond agencies, are often wary of special use buildings, since the buildings have limited reuse potential (201). The agencies are more likely to provide financing for facilities that meet generic, albeit minimum, standards. Therefore, even if a facility receives approval for a design innovation, the facility may not be able to find financing to build or remodel the unit.

State certificate of need programs may also increase the impact of regulations and standards on the design of special care units. Certificate of need programs sometimes disapprove plans that include features which exceed minimum requirements, e.g., resident room size that exceeds the required minimum square footage. These plans are disapproved because it is assumed that the features will increase the cost of the facility and that these increased costs will eventually be passed on to Medicaid (202,378).

A final factor that increases the impact of regulations and standards and discourages innovation in special care units is the large number of agencies involved in regulating nursing homes in many States. Tables 6-2 and 6-3 show the agencies involved in regulating nursing homes in Massachu-

setts and New York. The agencies listed in these tables are responsible for site control, certificate of need evaluations, licensure, financing, Medicare and Medicaid certification, and/or final inspections (201). The large number of agencies involved in each of these regulatory functions is daunting. It increases the difficulty special care unit operators and others have in obtaining approval for innovative physical design features or even understanding how to seek such approval. The large number of agencies probably also increases the likelihood that even if approval for the use of the innovative features is granted by one agency, it will later be denied by another.

Like physical design features, some patient care practices, staffing arrangements, and other operational aspects of special care units are precluded by regulations and standards. These operational aspects of the units are probably more likely than the physical design features to be affected by interpretations of regulations, as discussed in the following section. Operational aspects of special care units are also affected by cost constraints which require the unit to operate as close to the minimum allowable standards as possible. Although patient care and staffing options exist that would meet the requirements and fulfill other objectives of the unit operators and staff, these options frequently are not implemented because they cost too much.

THE IMPACT OF INTERPRETATIONS OF REGULATIONS ON THE DESIGN AND OPERATION OF SPECIAL CARE UNITS

Interpretations of regulations are unavoidable. When nursing home surveyors, building inspectors, and fire marshals inspect a special care unit, they have to apply their understanding of existing regulations to the particular characteristics of the unit. Likewise, when government officials review design plans for a new special care unit, they have to apply their understanding of the regulations to the particular features of the plan. Unless there is a compelling reason for allowing innovations, these individuals are likely to be conservative in their interpretations.

The format of most regulations is conducive to conservative interpretations (233,378). Existing regulations usually consist of a series of requirements without accompanying statements about the purpose or desired outcomes for the requirements. An explicit statement about the purpose or desired outcome of a requirement would give government officials, surveyors, and others justification for at least considering an innovation that might fulfill the purpose of the requirement, if not its precise stipulation. In the absence of such a statement, government officials, surveyors, and others are unlikely to take the risk of allowing the innovation.

Individual surveyors differ in their interpretations of the same regulations. OTA has heard about instances in which surveyors interpreted regulations that could have been obstacles for a special care unit in a way that made them not obstacles and other instances in which surveyors interpreted regulations that need not have been obstacles in a way that made them obstacles.

Surveyors' attitudes about nursing homes are likely to influence their interpretations of the regulations. A study of nursing home regulation in New York, Virginia, and England identified two different regulatory models (117). In one model, surveyors regard the nursing home operator as an ''amoral calculator who will risk breaking the rules for a profit. " In this model, the surveyor functions as a policeman, and the inspection process is formal, legalistic, and adversarial. In the other model, surveyors regard the nursing home operator as fallible but well-intentioned. The surveyor functions as a consultant, and the inspection process is informal and cooperative. In the United States, most surveyors probably function more in the first model than the second; thus, they are less likely to trust nursing home operators or to be supportive of facility-initiated innovations.

As noted earlier, OTA has been told about instances in which surveyors and other government officials have disallowed the use of innovative physical design or other features of special care units on the basis of regulations that were later found not to exist. In these instances, the officials probably assumed the regulations existed because "that's the way it's always been done. ' Thus, tradition and precedent can preclude innovation in special care units (201,378).

Given the large number and complexity of existing regulations and standards, it can be difficult to determine whether a given regulation exists. For special care unit operators and others who are told

Table 6-2—Massachusetts Agencies Regulating Nursing Homes

Agency	Function	Codes/regulations/standards
1. Site Control		
Local Planning Department	Certifies that the site is zoned for nursing home use or is eligible for zoning variance	Local zoning ordinances
State Executive Office of Environmental Affairs	Reviews environmental impact	Massachusetts Environmental Policy Act, National Environmental Policy Act (especially when the project will receive Federal funding), and other laws, as applicable
II. Determination of Need		
Determination of Need Office, State Department of Public Health	1. Determines that applicant has control of a site which can reasonably be expected to be appropriately zoned and have environmental impact approved	
	2, Determines bed need	Uses a rate of 35 beds per 1000 population over age 65 based on a State census broken down by 6 regions
	3 Determines "reasonableness of capital costs"	Square footage must meet the Federal and State minimum of 318 sq ft per bed but be no more than 400 sq ft per bed; uses Marshall's Evaluation Service to determine allowed construction costs, including architecture, site evaluation, and construction costs; currently about$100 per sq ft
	4. Follows approved projects through licensure to assure compliance	
Rate Setting Commission	Determines if projected operating costs are reasonable	Projected operating costs must be within one standard deviation of the median costs of other facilities in the area
Medicaid Division, State Public Welfare Department	Reviews application to ensure need	
Executive Office of Elder Affairs	Reviews for appropriate affiliation agreements and the management history of proposed operators	
III. Licensure		
Division of Health Care Quality, State Department of Public Health and Architecture Department and Patient Care Surveyors	License the facility, assuring compliance with State and Federal laws concerning the physical plant and patient care	Massachusetts: 105CMI 50-1 59 Federal: Medicare and Medicaid law, HCFA rulings, and related standards (e.g., Life Safety Code and ANSI)
Fire department for the municipality in which the facility is located	Assures fire safety and compliance with codes	Life Safety Code and local ordinances
Building inspector for the municipality in which the facility is located	Ensures compliance with State building codes; decisions maybe appealed to the State inspection Division, Building Section	State Building Code
IV. Obtaining Construction Financing		
State Health Care Finance Agency, HUD, or financial institutions	Ensure financial viability of the project	Review all other approvals, apply own criteria which may include requirements that the facility could be used for other purposes
V. Certification for Medicare and Medicaid		
State Rate Setting Commission	Sets allowed reimbursement rates for Medicare and Medicaid	State policies
Medicaid Division, State Public Welfare Department	Enrolls provider in Medicaid	Must have a Determination of Need certificate, be licensed, have rate set, and be in compliance with Federal Medicaid laws and regulations
VI. Final Inspections		
All agencies	Any agency which has had prior authority may review for compliance before occupancy	
Local Health Departments	Inspect for health code compliance	State and local health codes

SOURCE: J. Hyde, "Federal Policy in the Regulation and Funding of Special Care Alzheimer's Units: The Role of Federal, State, and Municipal Regulation," contract report prepared for the Office of Technology Assessment, August 1990.

Table 6-3-New York Agencies Regulating Nursing Homes

Agency	Function	Codes/regulations/standards
I. Site Control		
Local Planning Department	Site control, zoning requirements, availability of utilities, historical, land, environmental and building issues, soil testing, and financing vehicle	Local and State zoning and land-use codes
II. Certificate of Need		
State Department of Health, Office of Health Systems Management (OHSM), Bureau of Project Management. Copies then submitted to local Health Systems Agency (HSA), internal review bureaus, and OHSM Area Office	Reviews for need, financial feasibility, character and competence	10NYGRR 410-416; 420-422; 730-734
Bureau of Facility Planning	Ensures that the application is in accordance with the current State Medical Facilities Plan (as devised by HSA and OHSM)	Medical Facilities Plan
Bureau of Facility and Service Review	Ensures there is a public need for the facility	State Need Methodology Regulations
Bureau of Long Term Care Services	Ensures that the proposed operator meets the character and competence requirements and that the proposed programs meet regulatory requirements and address the needs of the population to be served	10NYCRR: NY State Public Health Law
Bureau of Architectural and Engineering Facility Planning	Ensures that the proposed facility meets State construction standards, Federal requirements, and ANSI standards	10 NYCRR 710, ANSI
Bureau of Financial Analysis Review	Ensures that the application is financially feasible, i.e., the applicant has sufficient financial resources to build the facility, and when the facility is in operation, sufficient income to remain financially sound	Depending on the financing vehicle, both Federal and State regulations come into play
III. Licensure		
Division of Health Facility Planning, State Department of Health	Reviews and approves construction plans and specifications	10NYCRR 710-711; 713-714
Division of Health Care Standards & Surveillance, State Department of Health	Assures compliance with State operational and patient care requirements	10NYCRR 410-416; 420-422; 730-734
Division of Health Facility Planning, State Department of Health	Issues Operating Certificate, attesting to compliance with State Hospital Code requirements	10 NYCRR 401
IV. Obtaining Construction Financing		
New York Finance Agencies, HUD, or financial institutions	Ensure financial viability of project	Review prior approvals, apply own criteria which may include requirements that facility be used for other purposes
V. Certification for Medicare and Medicaid		
Division of Health Care Standards & Surveillance, State Department of Health	Assures compliance with Medicare/Medicaid operational and patient care standards	42 CRF 442; 483
VI. Final Inspections		
Division of Health Facility Planning and Division of Health Care Standards & Surveillance, State Department of Health	Inspect building for compliance with approved plans	10 NYCRR 710

SOURCE: J. Hyde, "FederalPolicy in the Regulation and Funding of Special Care Units: The Role of Federal, State, and Municipal Regulation, ''contract report prepared for the Office of Technology Assessment, August 1990.

that regulations prohibit a particular physical design or other feature, the prospect of searching the numerous applicable regulations and codes for a given regulation is formidable. Sometimes it is almost impossible to prove a given regulation does not exist (201,378).

Architects, special care unit operators, and others often fear that disputing government officials' or surveyors' interpretations of regulations will have negative consequences beyond the particular design or other feature in question. They fear the officials will delay or deny final approval for the unit. Likewise, they fear that if they annoy the surveyors, the nursing home or special care unit will be cited later for violations of other regulations. Because of the large number and complexity of nursing home regulations, virtually all nursing homes-even very good facilities-are out of compliance with one regulation or another at any one time. Given these fears, some architects, special care unit operators, and others choose not to dispute officials' or surveyors' interpretations of the regulations and to "keep a low profile" instead.

Fire safety regulations and interpretations of these regulations are often cited as limiting the use of innovative physical design features in special care units. Requirements of NFPA's Life Safety Code, which is primarily a fire safety code, are identified as regulatory barriers with respect to six of the nine design features listed in table 6-1. As noted earlier, State and local fire code requirements were the regulations cited most frequently in the 1987 survey of 99 special care units as making the creation of the special care unit "difficult, expensive, or impossible" (494).

Fire safety inspection procedures for nursing homes vary in different States, but most of the inspections are conducted by local fire marshals (522). These local fire marshals have considerable independence in interpreting and enforcing fire safety regulations. It is OTA's impression from discussions with Federal and State officials and nursing home operators that within their own jurisdictions, local fire marshals' interpretations of the regulations carry great weight and are generally accepted as final.

As noted earlier, the Federal Medicare and Medicaid regulations incorporate the NFPA Life Safety Code, but the Federal regulations also allow States to use their own fire and safety codes. Many localities also have fire safety codes. The Health Care Financing Administration, NFPA, and State fire marshals' offices **offer training** for local fire marshals about fire safety regulations and inspection procedures, but fire marshals generally are not required to take the training (217,298,522).

The objectives of fire safety regulations for nursing homes are to minimize the possibility of frees and to limit their effects (217,522). Although there have been few deaths from nursing home frees in the United States in past 15 years (probably less than 30), the prospect of a nursing home fire is horrifying to many people, and the objectives of preventing such a fire or limiting its effects take precedence in their view over other possible objectives. Fire marshals and fire safety inspectors probably are more likely than other people to hold this view. As a result, they are unlikely to approve innovations they believe might increase the risk of a fire, regardless of the potential benefits of the innovations.

CASE EXAMPLES

The following case examples illustrate the impact of regulations and interpretations of regulations on the design and operation of special care units. Some of the examples show how a combination of regulations or a combination of cost constraints and regulations preclude the use of physical design or other features that are not specifically prohibited by any one regulation. Some of the examples also show how regulations that are probably appropriate for nondemented residents interfere with the use of design and other features that may benefit residents with dementia.

Case Examples: Unit Design

One nursing home received a State demonstration grant for a special care unit. An innovative plan was drawn up for a unit composed of several discrete modules in which six to eight residents would share a single sleeping area, living room, and activity areas. The sleeping room would have fewer square feet per resident than the traditional nursing home unit, but that space would be made up in the living room and activity areas. This unit design was considered more appropriate than the traditional design for residents with dementia because the residents would interact with a smaller number of other residents and staff members every day and thus would be less agitated. The unit could not be built

because of regulations that require: 1) no more than four residents per room, 2) a minimum of 110 square feet of space per resident in the sleeping room (as opposed to the 40 square feet per resident in the proposed design), and 3) bedroom doors that open onto a main corridor (202).

A hospital that received a State demonstration grant for a special care unit wanted to build a unit with the residents' rooms arranged in a large loop around a central dining/activity room. This central room would not have windows. The committee of experts assembled to advise the hospital thought the lack of windows in the central room would benefit the residents because it would allow the facility to maintain even light levels and reduce environmental stimulation, thus minimizing sundowning behavior and other manifestations of resident agitation. The lack of windows in the central room violated State regulations, however. After months of meetings and hundreds of hours of architect and staff time, the State granted a waiver for the innovation. The waiver was temporary, however, and the facility had to demonstrate that the dining/activity room could be moved to an outside wall at a later date if the State required such a change (201).

Case Example: Room Arrangement

A nursing home with a special care unit wanted to place the beds in 2-bed resident rooms along opposite walls to increase residents' privacy and allow them equal access to the windows and door. State regulations require that each bed must have 3 feet of space on either side and 4 feet of space at the foot. (The reasons for this requirement are: 1) to assure that beds are accessible to residents in wheelchairs; and 2) to assure that beds are accessible to staff and equipment on all three sides.) Because of these State regulations, the beds could not be placed along the walls and instead had to jut out into the room. To allow for two beds, each jutting out from opposite walls with a 4-foot space between their feet, the rooms would have to be wider and shallower than the typical nursing home room. This was not a problem in itself, but wider rooms, one after another, require longer corridors. The NFPA Life Safety Code requires that nursing home corridors be 8 feet wide. (The reason for this requirement is to assure that in the event of a fire when, it is assumed, residents will be evacuated on stretchers, the corridors will be wide enough to accommodate two stretchers side by side.) Even though the rooms would have the same square footage, each extra foot of room width would require 8 additional square feet of corridor space. Because of the cost of the extra corridor space, the facility had to abandon this innovation (201).

Case Examples: Keypad-Operated Locking Systems

One nursing home remodeled a 41-bed unit to create a special care unit. After considerable research, the staff decided the best locking system would be one with a keypad and a 4-number code which staff members could use to open the exit doors but which the residents probably would not be able to use. The doors would automatically unlock in case of fire. The facility received approval for use of the keypad-operated locking system from the local building inspector, the local fire marshal, and the State official responsible for approving physical plans for all nursing homes. The system had been in place for several months when the unit had its first survey. The survey went well, but the next day, a senior official from the State survey agency arrived to examine the keypad-operated locking system. His assessment, expressed in no uncertain terms, was that the keypad locking system constituted a locked unit and was not allowable. Only when the local Alzheimer's Association chapter intervened did the survey agency agree to allow this locking system (201).

In 1991, the Texas Department of Health began disallowing keypad-operated locking systems in Texas nursing homes and other residential care facilities (78). This decision was based on an interpretation of the Life Safety Code which was apparently endorsed by the Dallas regional office of the Health Care Financing Administration, even though keypad-operated locking systems are approved for use in other parts of the country and were allowed previously in Texas.

Case Example: Dutch Doors

A nursing home decided to install clutch doors in its new special care unit. The certificate of need application for the unit included a description of the clutch doors, and the additional cost of the doors was approved as part of the facility's Medicaid rate. The State project engineer approved the clutch doors after lengthy negotiations, meetings, and correspondence but required additional latches which could be used to attach the top and bottom doors. Nevertheless,

when the State surveyors came for the final inspection before the unit opened, they disallowed the doors on the basis that they constituted 'restraints. ' The doors continued to be disallowed despite facility guidelines that described the rationale for the doors, how they would be used to protect resident privacy, and how they fit with the facility's restraint policy (201).

Case Example: Dietary Practices

The staff of one special care unit wanted to seat small groups of special care unit residents together at meal **times** and feed them family style. The staff also wanted to serve some meals that consisted of only two foods because they believed this approach would reduce resident confusion. They planned to meet the residents' additional nutritional requirements with snacks. These plans were questioned by surveyors who cited State regulations that require "at least three meals a day that are nutritious and suited to special needs of patients and residents' and "trays...large enough to accommodate all of the dishes necessary for a complete meal, arranged and served attractively" (201).

Case Example: Staffing

Several special unit operators interviewed by OTA's contractor complained about State regulations that require specific types and numbers of staff members. One unit operator said, "I am not convinced you need separate people to do recreation and nursing. Each person has a piece of the patient. It is not as holistic as it could be. ' Other unit operators pointed out the value of occupational therapy, recreational therapy, and other therapies in the care of residents with dementia. If cost were not a determining factor, a special care unit could employ the number and types of staff required by the regulations plus additional staff members of these other types. Given cost constraints, this is usually not possible (201).

METHODS TO ALLOW INNOVATION IN THE DESIGN AND OPERATION OF SPECIAL CARE UNITS

As discussed in the preceding sections, some Federal, State, and local government regulations and standards interfere with the use of physical design features, patient care practices, and staffing arrangements that special care unit operators and others consider appropriate for the care of residents with dementia. Interpretations of regulations and combinations of regulations, cost constraints, and other factors also interfere with the use of these features. As a result, potentially effective design features, care practices, and staffing arrangements cannot be implemented and evaluated. Several commentators have pointed out that despite the diversity of existing special care units, all the variation is within the limited framework of existing regulations (200,273).

One possible approach to allow innovation in the design and operation of special care units is to eliminate regulations and standards that are found to restrict innovative physical design and other features. Although this approach may eventually be appropriate, lack of agreement about the particular features that are necessary in a special care unit and lack of research-based evidence for the effectiveness of particular features make decisions to eliminate existing regulations and standards premature at present.

It is possible some existing regulations and standards should be eliminated because they are inappropriate for all nursing homes—for example, regulations that were adopted directly from hospital regulations without regard for the different purposes and clients of hospitals and nursing homes. Some of the regulations and standards discussed in the preceding sections may be in that category, but most probably are not.

As noted earlier, fire safety regulations and interpretations of these regulations are often cited as limiting the use of innovative physical design features in special care units. The preceding sections have noted several innovative design ideas that could not be implemented because of fire safety requirements of the Life Safety Code. Special care unit operators and others whose ideas could not be implemented because of these requirements might argue that the requirements should be eliminated. On the other hand, it is OTA's impression based on informal discussions with many special care unit operators and experts in specialized dementia care that there are few, if any, Life Safety Code requirements that all these individuals would agree to eliminate. In fact, at a recent meeting of the patient care and public policy committees of the National Alzheimer's Association, some Alzheimer's advocates argued that fire safety precautions should be

increased rather than decreased for special care units (21).

Rather than attempting to eliminate regulations and standards that interfere with the design and operation of special care units, an alternate approach to allow innovation is to create a process by which individual special care units could obtain waivers to implement physical design features, patient care practices, and staffing arrangements they believe will benefit residents with dementia. Such a process would have to include mechanisms for protecting residents' rights in units in which innovative features were being implemented. The process should also include mechanisms for evaluating the innovations.

Most existing regulatory codes, including the Life Safety Code, have provisions for granting waivers. In at least some States, however, the waivers that are granted are for relatively trivial changes. A study of waivers granted by the Massachusetts Department of Public Health between 1985 and 1987 found that 98 waivers were granted for physical characteristics of the facilities (200). Almost half of these waivers (43 percent) were to allow the use of mobile medicine carts. The remaining waivers were for exemptions from the paper towel requirement (16 percent), changes in tub design (9 percent), number of baths per resident (9 percent), minor variations in the dimensions of various spaces (7 percent), changes in the number of residents on a unit (6 percent), furniture specifications (4 percent), and other minor modifications (5 percent). No waivers were granted for innovative design features.

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 of health care professionals, Alzheimer's advocates, industry representatives, architects, designers, lawyers, surveyors, fire marshals, and building inspectors. 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 residents of the unit. The panel would also have to monitor the waivered innovations on an ongoing basis to assure the safety and well-being of the residents. Although such panels could be established at any level of government, they probably would be most appropriately set up at the State level since States have the dominant role in regulating nursing homes.

In addition to creating a waiver process for special care units, several other approaches could be used to allow innovation in special care units. One approach would be to encourage government officials, surveyors, fire marshals, and building inspectors to be supportive of innovations. As noted earlier, these individuals tend to be conservative in their interpretations of regulations and standards. Training materials and programs could be created to inform them about nursing home residents with dementia, the need to develop more appropriate methods of care for them, and the role of special care units in developing those methods of care. A training effort of this kind would be essential for the success of a waiver process for special care units because government officials, surveyors, fire marshals, and building inspectors would have to approve the waivered innovations and cooperate with their implementation.

The following approaches could be used to allow and encourage innovation in special care units, as well as other residential facilities for older people:

- The process for obtaining approval for new design or other features could be simplified and streamlined at the State level.
- Relevant regulations and standards could be compiled in a clear and easy to use format.
- Any new regulations could be written in a format that includes an explicit statement of the purpose or desired outcome of each requirement, thus providing government officials, surveyors, and others with a basis for allowing innovations that meet the purpose if not the precise stipulations of the requirement.
- Inconsistencies in the requirements of different agencies, regulations, and codes could be identified and eliminated.

In 1990, the National Institute of Building Sciences initiated a project to compare the NFPA Life Safety Code and the life safety standards in various model building codes in order to identify inconsistencies and conflicts. The objective of the project is to provide recommendations to HCFA about the life safety requirements for nursing homes that participate in the Medicare and Medicaid programs.

CONCLUSION

Probably the most important objective of special care units from a societal perspective is to develop better approaches to care for nursing home residents with dementia. Some Federal, State, and local government regulations and interpretations of regulations interfere with this objective by discouraging innovation. Although special care units are diverse, all the variation is within the limits of existing regulations.

This chapter has discussed the need for a process by which individual special care units could obtain waivers to implement innovations they believe will benefit individuals with dementia. Such a process would have to involve prior review of waiver requests by a panel of health care professionals, consumer advocates, surveyors, architects, designers, and others. It should also involve mechanisms for evaluating the innovations and mechanisms for protecting the rights of residents of units in which new approaches to care are being tested. The panels probably would function most effectively at the State level, but the Federal Government could encourage their development through demonstration grants.

In addition to the creation of a waiver process for special care units, the chapter has discussed several other methods that could be used to allow and encourage innovation in special care units. Some of the methods pertain primarily to special care units, e.g., providing training materials and programs to inform surveyors, fire marshals, 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 and streamlining the process for obtaining approval of new design or other features and eliminating conflicts and inconsistencies in the requirements of different agencies, regulations, and codes.

As described in chapter 5, the current focus of State efforts with respect to special care units is developing regulations to assure that nursing homes that claim to provide special care actually provide something special for their residents. To OTA's knowledge, no State has created a process for waiving regulations that interfere with the design or operation of 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 or impossible for some of the facilities that received the grants to implement the design or other 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 policies to regulate and control the units.

Appendixes

Appendix A

Diseases and Conditions That Cause Dementia

Dementia can be caused by more than 70 diseases and conditions, including the following:

- progressive degenerative diseases, including those in which dementia is inevitable, such as Alzheimer's disease and Pick's disease, and those in which dementia mayor may not occur, such as amyotrophic lateral sclerosis (ALS) and Parkinson's and Huntington's diseases;
- cardiovascular diseases that decrease blood supply to the brain: this can cause loss of brain tissue in the form of many small strokes (multi-infarct dementia) or one or more large strokes; bleeding into the brain, usually related to hypertension, can also cause loss of brain tissue;
- severe depression;
- intoxication caused by prescription and nonprescription drugs and alcohol;
- infections that affect the brain, including Creutzfeldt-Jakob Disease and acquired immune deficiency syndrome {AIDS);
- **metabolic** disorders;
- nutritional disorders;
- normal pressure hydrocephalus; and
- space-occupying lesions, such as brain tumors and subdural hematoma.

SOURCE: U.S. Department of Health and Human Services, Public Health Service, National Institutes of Health, "Differential Diagnosis of Dementing Diseases," NIH Consensus Development Conference Statement 6(1 1):1-6, Oct. 19-21, 1987.

Appendix B

Conceptual and Methodological Issues in Research on Special Care Units

Numerous difficult conceptual and methodological issues complicate the process of designing and conducting special care unit research. Table 1-3 in chapter 1 lists many of these issues. Most of the issues were identified and discussed at a 1990 special care unit conference sponsored by the Alzheimer's Disease Research Center at Washington University in St. Louis, MO (26). Some of the issues are being addressed by subcommittees of the Workgroup on Research and Evaluation of Special Care Units, an ad hoc group of researchers formed following the St. Louis conference, and by the 10 research teams funded through the National Institute on Aging's "Special Care Units Initiative. ' This appendix discusses five of the most difficult issues.

Definition of the Term *Special Care Unit*

One of the most difficult issues in special care unit research at this time is the definition of the term *special care unit.* As noted in chapters 1 and 3, most descriptive studies have used self-report-i. e., the statement of a nursing home administrator or special care unit operator—to identify special care units. This method of identifying special care units misses some units, since some nursing homes that place residents with dementia in a separate unit and provide special services for them-an arrangement that most researchers would regard as a special care unit-do not use the term *special care* for this arrangement. Such nursing homes may not respond affirmatively to a question about whether they have a special care unit (436).

On the other hand, using self-report to identify special care units includes some units and other care arrangements that perhaps should not be included. A few researchers have used additional criteria to determine which units should be included in their samples (see, for example, Sloane et al [413]). By doing so, they necessarily focus on a subset of all facilities that might be considered special care units and thereby eliminate some of the diversity that characterizes the full universe of units.

For some purposes, the use of criteria that limit the definition of *special care unit* is appropriate. For most public policy purposes, however, the definition of *special care unit* should be inclusive rather than exclusive at this early stage in special care unit research. In this context, it is important to note that the first information about the large number of cluster units in some States came from a study that did not use the term *special care unit* at all and instead asked abroad question about 'living arrangements available for cognitively impaired (demented) residents' (177).

Individual Variation in Symptom Progression in Dementia

A second issue that has received considerable attention in the general literature on Alzheimer's disease and dementia but relatively little attention in the special care unit literature is the variation in symptom progression in diseases that cause dementia. Although cognitive abilities decline over time in Alzheimer's disease, the rate of decline varies greatly indifferent individuals (25,37,57,145, 228,338,479). Some individuals with Alzheimer's disease show no decline, and a few show improvement in their cognitive abilities over l-year to 2-year followup periods (145,338). Most studies have found no characteristics of an individual (e.g., age, age of onset, duration of illness, family history of dementia, or entry point test scores) that predict the rate at which the individual's cognitive abilities will decline. Moreover, particular cognitive abilities decline at different rates (37,368).

The rate of decline in ability to perform activities of daily living also varies in different individuals and for different activities (127,145,235,338). A pilot study of 54 nursing home residents with dementia found that 6 months after their admission to the facility, 46 percent of those who survived showed no change in their ability to perform activities of daily living; 29 percent showed a decline in only one activity of daily living; and 24 percent showed a decline in more than one activity of daily living (62). The progression of behavioral symptoms also varies in different individuals and for different symptoms (127,235,394,441).

This variation in symptom progression means that for a given individual, it is difficult to determine whether changes or lack of changes in his or her symptoms over time reflect the course of the individual's disease or the effects of a treatment intervention (e.g., placement in a special care unit). In a study with a long duration and a large sample, individual variation in symptom progression might have a negligible effect on the study's findings. Subject attrition is high in special care unit research, however. Some special care unit studies have lost one-third or more of their subjects in a year (80,265). As a result, it is difficult to maintain a large sample for a long period of time. In a study with a small sample, individual variation in symptom progression could easily obscure the effects of the treatment intervention.

Lack of Validated Measurement Instruments

A third issue in special care unit research is the lack of validated instruments to measure many of the potentially important characteristics of the units, the residents, their families, and the unit staff members. As noted in table 1-3 in chapter 1, many of the available instruments exhibit ceiling or floor effects that obscure the full range of positive or negative changes in resident and family characteristics (57,1 13,145,228,265).

Measuring subjective variables in individuals with dementia is particularly difficult (244,272). Several innovative instruments and methods have been proposed to measure feelings, comfort, and degree of satisfaction (197,271,442), but this remains a formidable problem for special care unit researchers.

Some special care unit studies have used staging instruments to classify their subjects. These instruments define stages of dementia or Alzheimer's disease based on a combination of cognitive impairments, mood, functional impairments, and behavioral symptoms (see, for example, Reisberg et al. [372]). Staging instruments are useful for many purposes, but they tend to mask individual variation in symptom patterns and progression (53,127). Many studies have found only modest correlations between the cognitive impairments caused by an individual's dementing disease and either the individual's ability to perform activities of daily living (43,124,344,369,410,472,508) or the individual's behavioral symptoms (111,394,431,441). Moreover, many dementia experts expect special care units to affect these domains differently: few experts expect the units to reduce residents' cognitive impairments, for example, but many experts expect the units to reduce residents' behavioral symptoms. Staging instruments that combine these domains are likely to obscure any effect of the special care units. For this reason, staging instruments probably should not be used to classify subjects in this research, especially in studies with small samples.

Accuracy of Proxy Responses

A fourth issue in special care unit research is the accuracy of proxy-derived responses. Because of the cognitive impairments of nursing home residents with dementia, researchers sometimes must rely on proxy respondents-usually family members or friends of the resident—to provide information about the residents. Little is known about the accuracy of these responses (278). One study of 53 nursing home residents who were not *severely* cognitively impaired found that proxy responses were more likely to match the residents' responses on questions about readily observable and long-lasting conditions and less likely to match their responses on questions about subjective or temporary conditions (280). Another study of 152 nursing home residents who were not *severely* cognitively impaired found that proxy responses with respect to the residents' satisfaction with specific aspects of their nursing home care were no more likely to match the residents' responses than would be expected by chance (239). The researchers concluded that the ability of family members and friends to represent residents' satisfaction with nursing home services is limited and inconsistent.

Number and Complexity of Variables

A final issue is the sheer number and complexity of the variables in special care unit research. As noted in table 1-3 in chapter 1, it is difficult to determine which of the many characteristics of the units, the residents, their families, and the unit staff members are important to study. The experimental variable, the special care unit, is multidimensional. As Lawton has noted:

> The experimental variable (is) not a redecorated ward or a new building, but an entire system composed of countless physical and staff changes, sometimes a new resident mix, different treatment programs, and not least, changed expectations by staff, residents, and administrators (241).

Some people argue that it is the *milieu* of a special care unit rather than any of its particular characteristics that constitutes the experimental variable. Their contention may be valid, but defining the concept *milieu* has caused difficulties in research on inpatient psychiatric care for 30 years and is unlikely to be any easier in special care unit research (436).

The number and complexity of the variables in special care unit research and the many other conceptual and methodological issues discussed above and listed in table 1-3 contribute to the difficulty of designing and conducting special care unit research. These factors account, at least in part, for the current lack of definitive answers about the effectiveness of special care units.

Appendix C
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