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Nursing Home Residents With Dementia: Characteristics and Problems

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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.