Chapter 4

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

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INTRODUCTION

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

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do well in nonspecialized units; these individuals often are admitted to the special care unit in a very agitated or withdrawn condition; they frequently have been overmedicated and physically restrained; characteristics of the unit, including its physical design features, patient care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

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

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

OTA's conclusions from the evaluative studies discussed in this chapter are summarized in table 4-3 at the end of the chapter. The findings differ, depending on whether the study used a control group. The nine evaluative studies that did not use a control group found positive outcomes for special care unit residents in a variety of areas. If contradictory findings are excluded, the only positive outcomes found in more than one of the nine studies are decreased nighttime wakefulness, improved hygiene, and weight gain. A few of the studies found improvements over time in the important areas of residents' ability to perform activities of daily living and residents' behavioral symptoms, but an equal number of studies did not find such improvements.

Only two of the six evaluative studies that used a control group found any positive outcomes for special care unit residents. One of these studies found that over a l-year period, 14 residents of one special care unit showed significantly less decline than 14 residents with dementia in nonspecialized units of the same nursing home in their ability to perform activities of daily living (392). The second study found that 13 residents of one special care unit exhibited significantly fewer catastrophic reactions than 9 residents with dementia in nonspecialized units of the same facility (265). The 13 special care unit residents also interacted significantly more often with staff members.

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

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

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

TYPES OF EVALUATIVE STUDIES OF SPECIAL CARE UNITS

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

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

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

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

EVALUATIVE STUDIES WITHOUT A CONTROL GROUP: EFFECTS ON RESIDENTS

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

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

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

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

Table 4-I—Evaluative Studies Without a Control Group

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

SOURCE: Office of Technology Assessment, 1992.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

All the studies suffer from one or more problems that raise questions about the validity of their findings-both positive and negative. One of these problems is small sample sizes. The second problem is the lack of rigorous research design and implementation. In many of the studies, the outcomes to be measured are not clearly defined, and the measurement process is more impressionistic than objective or standardized. As noted earlier, the statistical significance of the findings was computed in only four of the nine studies. Failure of the studies to include a control group is another problem since without a control group, the impact of the special care unit cannot be separated from the impact of other factors that may affect resident outcomes. Finally, many of the studies were conducted by unit staff members or other individuals who were involved in planning or operating the unit. These individuals have an obvious interest in finding positive outcomes. The potentially powerful effect of their expectations coupled with small sample sizes, lack of a rigorous research design, and lack of control groups means the results of the studies must be suspect.

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

EVALUATIVE STUDIES WITH A CONTROL GROUP: EFFECTS ON RESIDENTS

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

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

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

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

Table 4-2—Evaluative Studies With a Control Group

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

SOURCE: Office of Technology Assessment, 1992.

outcomes that could be attributed to the special care unit.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

The one study that found a significant positive effect of a special care unit on the residents' ability to perform activities of daily living focused on a unit that was created with the addition of an activity room but no other physical design changes (392). Instead, the "special" features of the unit, in the view of the researchers, were staff efforts to identify residents' specific cognitive impairments, to treat depression, delusions, hallucinations, and medication side effects, to maintain residents' physical health, and to increase their involvement in activities. Ongoing involvement of a psychiatrist on the staff seems to be unique to this study. Whether any of these features are different enough from the features of the special care units in the other studies to explain their contradictory findings cannot be determined from the available data.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

of units that might encourage or discourage family visiting.

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

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

CONCLUSION

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

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

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

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

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

SOURCE: Office of Technology Assessment, 1992.

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

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

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

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

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

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