



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

At least half of all nursing home residents in the United States have dementia. As awareness of Alzheimer's disease and other diseases that cause dementia has increased in recent years, so have complaints and concerns about the care provided for people with dementia in most nursing homes. In response to these complaints and concerns, some nursing homes have established a special care unit—that is, a physically separate unit in the nursing home that provides, or claims to provide appropriate care for residents with dementia.

The number of special care units is increasing rapidly. OTA estimates that in 1991, 10 percent of all U.S. nursing homes had at least one special care unit. This number includes nursing homes that place some of their residents with dementia in physically distinct groups or clusters in nonspecialized units.

The existence and proliferation of special care units creates both problems and opportunities for individuals with dementia, their families, and other people and organizations who have an interest in their care. The problems are due primarily to the lack of agreement about what a special care unit is or should be and the related lack of standards to evaluate special care units. It is said that some nursing homes use the words "special care" as a marketing tool and actually provide nothing special for their residents with dementia.

On the positive side, it is clear that some people with dementia are receiving excellent care in special care units. More importantly perhaps, the proliferation of special care units means that for the first time in the United States, numerous nursing home administrators and staff members are concentrating on developing better methods of care for people with dementia.

OTA's report, *Special Care Units for People With Alzheimer's and Other Dementias: Consumer Education, Research, Regulatory, and Reimbursement Issues*, discusses the complaints and concerns that have led to the development and proliferation of special care units, the characteristics of existing special care units, and the available information about their effectiveness and cost. It analyzes the problems and

opportunities created by the proliferation of special care units and discusses the ways in which the Federal Government has responded and could respond to these problems and opportunities.

Research on special care units is in an early stage, but the available descriptive studies show that existing special care units vary in virtually every respect, including their patient-care philosophies and goals, physical design features, staff-to-resident ratios, activity programs, use of psychotropic medications and physical restraints, admission and discharge practices, and charges. The available evaluative studies provide little evidence for the effectiveness of special care units and suggest that we do not yet know exactly what constitutes effective nursing home care for individuals with dementia.

The findings of these descriptive and evaluative studies have implications for public policies in four areas:

Consumer Education

The diversity of existing special care units substantiates the need for consumer education. Families and others who make decisions about nursing home care for individuals with dementia need to know that special care units vary greatly. They need information about the characteristics of the special care units in their area. If that information is not available, they need to know what questions to ask when they call or visit a special care unit.

The Alzheimer's Association and several other organizations have developed guidelines to help families and others evaluate special care units. Government agencies could help to publicize these guidelines and promote their use.

Research

Until recently, the Federal Government has funded relatively little research on special care units. In 1991-92, the National Institute on Aging funded 10 special care unit studies. These studies represent a significant commitment to this area of research. Given the many unresolved questions about special care units, however, more studies are needed. For public policy purposes, the most important research

questions pertain to the effectiveness of special care units for residents, their families, and nursing home staff members and to the impact of special care units on demented and nondemented residents of nonspecialized nursing home units.

Regulation

Because of the diversity of existing special care units, their rapid proliferation, and the widespread perception that some special care units provide nothing special for their residents, some Alzheimer's advocates, State officials, and others favor the development of special regulations for special care units. As of early 1992, six States—Colorado, Iowa, Kansas, Tennessee, Texas, and Washington—had special regulations for special care units; five States—Nebraska, New Jersey, North Carolina, Oklahoma, and Oregon—were developing such regulations; and other States were considering doing so.

All these regulations are or will be superimposed on the existing regulatory structure for nursing homes—a complex, multifaceted structure that includes Federal Medicare and Medicaid regulations, State licensing regulations, and the survey and certification procedures associated with these regulations. This regulatory structure is changing rapidly now due to implementation of the nursing home reform provisions of the Omnibus Budget Reconciliation Act of 1987 (OBRA-87).

Based on an analysis of the relevant provisions of OBRA-87 and the special care unit regulations now in effect in six States, OTA concludes that OBRA-87 provides a better framework for regulating special care units than any special regulations that have been or could be devised at this time. The advantages of OBRA-87 are its comprehensiveness, its emphasis on individualized care, and its mandated assessment procedures. The objective of developing better methods of care for nursing home residents with dementia is more likely to be served at present by policy initiatives to increase knowledge about the programmatic and design features that are important in their care, to determine how those features fit into the regulatory framework created by OBRA-87, and to support and monitor the implementation of OBRA-87 than by the establishment of new special care unit regulations.

To protect individuals with dementia and their families from nursing homes that claim to provide special care but actually do not, the Federal Government or the States could require nursing homes to disclose certain information about their special care units to potential residents and their families. In particular, nursing homes could be required to disclose:

- what is special about the unit;
- how the unit differs from nonspecialized units in the same facility;
- whether there are behavioral problems that cannot be handled on the unit; and

- whether it is expected that individuals who are admitted to the unit will be discharged before their death and, if so, for what reasons.

Such a disclosure requirement would help families to evaluate units without implying that we already know exactly what constitutes effective care for nursing home residents with dementia.

Reimbursement

At present, no government programs are paying more for the care of an individual in a special care unit than in a regular nursing home unit. Many special care unit operators say that it costs more to provide care in a special care unit, and available data indicate that on average, special care units probably do cost more to operate than nonspecialized units, primarily because of their higher average staffing levels. Given the diversity of existing special care units and the lack of research-based evidence for their effectiveness, however, OTA concludes that government reimbursement should not be increased differentially for care in special care units since to do so would raise government expenditures and create financial incentives for the establishment of more special care units without necessarily improving the care available for individuals with dementia—clearly not a desirable result. This conclusion will have to be reevaluated as research findings about the effectiveness of special care units for nursing home residents with dementia become available.

Alternatives to Special Care Units

The proliferation of special care units is occurring at the same time as numerous other government and nongovernment initiatives that are likely to improve the care of nursing home residents with dementia or provide alternatives to nursing home care for them. In addition to the regulatory changes required by OBRA-87, these initiatives include specialized programs in residential care facilities and adult day centers and specialized in-home services. Government policies for special care units should be considered in the context of these other initiatives, which may provide alternate ways of accomplishing some of the same objectives as special care units.

Copies of the report for congressional use are available by calling 4-9241.

Copies of the report for non-congressional use can be ordered from the Superintendent of Documents, U.S. Government Printing Office, Washington, DC 20402-9325 (202) 783-3238. The GPO stock number for the OTA report, "Special Care Units for People With Alzheimer's and Other Dementias: Consumer Education, Research, Regulatory, and Reimbursement Issues," is 052-003-01296-1. The price is \$11.00. Summaries of reports are available at no charge from the Office of Technology Assessment.

For further information contact OTA's Publications Office. Address: OTA, U.S. Congress, Washington, DC 20510-8025 (202) 224-8996.