Appendix B

Conceptual and Methodological Issues in Research on Special Care Units

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

Definition of the Term *Special Care Unit*

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

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

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

Individual Variation in Symptom Progression in Dementia

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

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

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

Lack of Validated Measurement Instruments

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

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

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

Accuracy of Proxy Responses

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

Number and Complexity of Variables

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

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

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

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