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Mollie Grande
Marquette University Law School

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Special Care Units: History, Regulation, and Criticism

By Mollie Grande

Special care units are nursing home areas dedicated to providing care for patients with dementia. This article describes the characteristics of individuals with dementia who need long-term care, outlines the reasons special care units were created, and discusses issues regarding their regulation. It also addresses common criticisms of special care units, and explains alternatives to nursing home care.

"I never want to be put in a nursing home." This is a comment that many people express, no matter what their age. Individuals who enjoy their freedom express distaste at the idea of confinement to a single building; others fear a situation where they cannot take care of their own personal needs. However, long-term care is something that some people must deal with as they age. In particular, people with cognitive disabilities such as Alzheimer's disease and other related dementias must find an environment in which their needs can be met and they can maintain a high quality of life.

This paper will explore the development of special care units (SCUs), physically separate nursing home units that provide care that "meets the special needs of individuals with dementia." It will describe the characteristics of individuals with dementia that lead them to require long-term care. It will then trace the development of special care units including the reasons that produced them, their characteristics, and regulation. In addition, the criticism of special care units will be discussed. Finally, this paper will explain alternatives to nursing home care, including the ways that technology is allowing people with dementia to remain in the least restrictive environment.

Characteristics of People With Dementia

Before exploring the reasons why special care units were developed, it is necessary to understand the characteristics of individuals with dementia that necessitate some form of long-term care. Dementia is a "clinical syndrome characterized by the decline of cognitive abilities in an alert individual." Dementia has many causes, the most common being Alzheimer's disease. Alzheimer's disease is a "progressive, degenerative disease that damages the brain and causes mental confusion, impaired judgment, and behavioral changes, including aggression in some individuals." Alzheimer's and other dementias are progressive diseases, and as individuals with these conditions "lose cognitive abilities, they become increasingly unable to care for themselves independently."

One major symptom of dementia is the inability to perform basic activities of daily living. Many dementia sufferers require assistance bathing, dressing, getting in and out of bed, using the toilet, remaining continent, and eating. Behavioral symptoms also are common among dementia sufferers. Many exhibit one or more of the following behavioral symptoms:

- Wandering;
- Crying for long periods;
- Getting upset;
- Hoarding;
- Physically hurting themselves or others;
- Dressing inappropriately; or
• Failing to avoid dangerous things\(^9\)

In addition, some dementia sufferers exhibit psychiatric symptoms, for example, delusions and hallucinations or depression.\(^{10}\)

While some people with dementia are relatively healthy except for their dementia, others have coexisting medical conditions and physical impairments as well.\(^{11}\) As a result of these symptoms, long-term care is often needed as these individuals become unable to care for themselves in an appropriate or safe manner.

**Why Were Segregated Dementia Units Developed?**

**Practical Problems with Traditional Nursing Home Care for Dementia Patients**

It is widely acknowledged that the needs of individuals with dementia differ greatly from those of individuals who are physically ill or in a weakened condition due to old age.\(^{12}\) In the 1980s, caregivers began to realize that traditional nursing homes were not providing optimum care for dementia patients.\(^{13}\) "The complaints and concerns regarding the quality and appropriateness of care provided to dementia patients formed the primary reason for the creation of special care units."\(^{14}\)

Understanding the criticisms of care provided in a traditional nursing home is essential to understand the rationale behind the creation of special care units. One criticism is that the physical environment of traditional nursing homes is inappropriate for people with dementia.\(^{15}\) Often there is a high level of noise and stimulation from background music, announcement systems, and televisions. This results in confusion for dementia patients.\(^{16}\) These institutional environments are also not considered to be "home-like" enough for dementia patients.\(^{17}\) In addition, many traditional nursing homes do not provide the cues necessary for dementia patients to find their way and they lack appropriate space for wandering.\(^{18}\)

In addition to the lack of an appropriate physical environment, traditional nursing homes also are unable to provide an appropriate care environment. Often, the staff of traditional nursing homes do not have adequate knowledge of dementia or how to care for individuals with this disease.\(^{19}\) Often, the needs of dementia patients remain unmet because the patients lack the ability to communicate them, and the staff does not have the requisite training to anticipate their needs.\(^{20}\) Often, nursing home staff inaccurately diagnose dementia patients or fail to diagnose them at all.\(^{21}\) There is often a "pervasive sense of nihilism" about residents with dementia and a presumption or belief that nothing can be done for them.\(^{22}\) Lack of appropriate activities and opportunities for physical movement and exercise for dementia patients is another criticism of traditional nursing homes.\(^{23}\) Further, traditional nursing home staff promotes dependence by performing personal care tasks for the resident with dementia rather than facilitating their independence through assisting them in performing the activities of daily living.\(^{24}\)

Individuals with dementia need individualized care. Often, traditional nursing homes do not have adequate numbers of staff to provide this type of care.\(^{25}\) Another aspect of this individualized care is the need for continuity. Traditional nursing homes do not have adequate staff to provide the continuity in personnel and daily routines required to meet the individual needs of dementia residents.\(^{26}\)

Inappropriate use of physical restraints on dementia patients is another criticism of traditional nursing homes.\(^{27}\) In addition, dementia patients are often "restrained" through use of psychotropic medication.\(^{28}\) In traditional nursing homes, dementia residents are more likely to be physically restrained and prescribed psychotropic drugs than other residents.\(^{29}\)

These problems that traditional nursing homes face in treating patients with dementia have many negative consequences including "excess disability."\(^{30}\) Excess disability is "functional impairment that is greater than is warranted by an individual's disease or condition."\(^{31}\) This excess disability manifests itself in many areas of the individual's life including mental functioning, emotional state, activities of daily living, and behavior.\(^{32}\) In addition, it results in an increase in guilt and anxiety for family members who must place their loved ones in a nursing home.\(^{33}\)

**Philosophical Principles**

Six philosophical principals "constitute the core of what is ... special about special care units."\(^{34}\)
First is the belief that "something can be done for individuals with dementia." This entails understanding that while there is no cure for Alzheimer's disease or other forms of dementia, some of the manifestations and symptoms are treatable, and treatment can increase functioning and quality of life.

Second is the understanding that "many factors cause excess disability in persons with dementia." Such factors include inadequate physical environments and inappropriate use of physical restraints or psychotropic drugs. Through recognizing and altering these factors, excess disability can be eliminated and functioning and quality of life can be enhanced.

Third is knowledge that "individuals with dementia have residual strengths." The quality of life for individuals with dementia can be improved if they are encouraged and assisted in building upon these strengths. In addition, residents gain a sense of competency when they are assisted and encouraged to use their remaining abilities.

Fourth is the understanding that "the behavior of individuals with dementia represents understandable feelings and needs, even if the individuals are unable to express those feelings or needs." The behavioral manifestations of persons with dementia can be improved if caregivers recognize and respond to these feelings or needs. Experts in dementia care believe that if caregivers can determine the meaning of certain behaviors and respond to them, then the use of psychotropic medications and physical restraints could be reduced.

Fifth is the knowledge that "many aspects of the physical and social environment affect the functioning of individuals with dementia." A dementia resident's functioning and quality of life can be positively affected by providing an environment that suits that particular person's characteristics. Physical design features can compensate for impairments in many ways, including:

by assuring safety and security; by supporting functional abilities; by assisting with wayfinding and orientation; by prompting memory; by establishing links with the familiar, healthy past; by conveying expectations and eliciting and reinforcing appropriate behavior; by reducing agitation; by facilitating privacy; by facilitating social interactions; by stimulating interest and curiosity; by supporting independence, autonomy and control; and by facilitating the involvement of families.

Finally, there is the recognition that "individuals with dementia and their families constitute an integral unit." Individuals with dementia can benefit from the involvement of their families. "In addition, the families benefit from their needs being addressed." Families can help nursing homes care for dementia patients by providing physical assistance, emotional support, and advocacy. Residents of nursing home special care units feel more at home when their families are present. Meeting the families' needs benefits everyone involved in the residents' care.

Components of Special Care Units

Special care units have many components that distinguish them from traditional nursing home settings. Special care units are extremely diverse, and vary in many aspects. This section will discuss the elements that many special care units include, although not all special care units provide each of these elements.

First, special care units are segregated. Residents with dementia are separated from other nursing home residents. Segregation allows components to be implemented that would not otherwise be possible if the individual with dementia were in a traditional nursing home. In addition to being segregated, most special care units are locked. This is done either through disguising door handles, requiring electronic passkeys to enter or exit the unit, or installing alarms on the exit doors.

Another characteristic of special care units is the physical or structural design features. The floor plans of special care units often are different from those of a traditional nursing home. Special care units tend to have short or no hallways that serve as an orientation feature for persons with dementia. Often, special care units are designed with an open floor plan to allow staff "easy visual access to
all residents.”60 These open floor plans also aid residents in orienting themselves in the space. Environmental cues also are an integral element of special care units.61 For example, residents are aided in locating certain areas by color-coded halls and personal, identifiable pictures placed next to their room doors.62 Special care unit floor plans also provide for a continuous path to allow residents to wander safely.63 Most special care units also provide direct access to a secure, outdoor courtyard.64 Individuals with dementia have a “reduced ability to receive and process external stimuli.”65 As a result, many special care units limit environmental stimuli such as telephones, radios, televisions, paging systems, high-glare floors, and hurrying staff.66 Limiting these stimuli creates a relaxed atmosphere and reduces residents’ agitation and confusion.67

Special care units have lower staff-to-resident ratios than traditional nursing homes.68 This allows for more individualized care for the residents. Individualization provides the nursing staff with the opportunity to: “(1) identify and change factors that cause excess disability in individual residents, (2) identify and build on the residual strengths of residents and (3) identify and respond to the feelings and needs expressed in the behavior of individual residents.”69 Individualized care is essential because the needs of “residents with dementia are diverse and their characteristics and needs change over time.”70

The staff in a special care unit often has more training and knowledge of dementia than the staff in a non-specialized unit.71 Special care unit staffs often receive more training, especially in dementia care, than the staffs of traditional nursing homes.72 A superior treatment environment is created when staff members are specially selected, trained, and supervised to care for dementia patients.73

As a result of many of these factors, there is lower usage of physical restraints in special care units.74 Although residents receive psychotropic medications to the same or a greater degree than traditional nursing home residents, this may be due to a better understanding of the individual and his/her need for certain medication.75 Some individuals with dementia require prescription drug treatment, including psychotropic medication that reduces mental, emotional, and behavioral symptoms caused by dementia.76

The objectives of special care units differ. “For some units, the primary goal is to maintain residents’ ability to perform activities of daily living. Other units focus on maintaining residents’ quality of life, eliminating behavioral symptoms, or meeting residents’ physical needs.”77

Finally, special care units actively promote involvement of the resident’s family in treatment. Family members and staff get to know one another. Often the staff involves the family in decisions about the resident’s care.78 When family members are involved in the care decisions and life of the resident, the family feels less guilt about placing a loved one in the nursing home and the resident tends to feel less abandoned.79

**Criticism of Special Care Units**

Although many believe there are benefits to special care units, there is no lack of criticism of them. Some critics believe that special care units provide no additional benefits for patients with dementia. Critics fear that a proliferation of special care units will lead to dementia patients being “warehoused” in segregated units where they will receive lower quality care.80 Most of these critics are particularly disturbed by the locked or secure element to segregated dementia units.81

Critics also are wary of special care units because research findings related to their efficacy are inconclusive.82 The components of special care do not “necessarily translate to better outcomes.”83 Critics also claim that there is little evidence of improved functioning of residents in special care units than in traditional nursing home units.84 Even if care in a special care unit shows better results than a traditional nursing home unit, “there is no research-based evidence to identify the unit characteristics that explain the different outcomes.”85

Another concern is that some facilities are using special care units as marketing tools but do not provide any unique or additional care.86 These nursing homes hope to attract “private-pay residents with Alzheimer’s and other dementias by purporting to offer a range of specialized, more expensive services.”87 They then provide “nothing more than a wing where confused residents are segregated.”88 The concern stems from the fact that under
many state laws, these facilities are not required to justify how or why they are specialized.89

**Regulation of Special Care Units**

Due to the concerns that special care units are being used as a marketing ploy and that not all existing units incorporate the features recommended for special care units, several states have decided to regulate special care units.90 Much controversy exists over whether special care units should be regulated. Proponents of regulation believe it is necessary to protect the residents' quality of care.91 Those who oppose regulation believe that "regulating SCUs now would lock standards into the current level of understanding optimal dementia therapy."92 They feel that it is premature to create regulations when very few studies regarding special care units are available.93 "The fear is that too much regulation could stifle innovation."94

As a result of this controversy, two approaches to regulation have emerged.95 The first approach is aggressive regulation that includes thorough, comprehensive rules concerning the environment, staffing, and content of care. This approach considers specific details that are essential due to the lack of consensus on what appropriate care entails.96 Based on this same lack of consensus, other states have chosen to provide only broad care guidelines.97 States following this model require that nursing homes with special care units "disclose their philosophy or mission statement, admission and discharge policies, emergency procedures, processes used for establishing and changing an individual's plan of care, staffing and staff training, physical environment of the facility (including any security features), frequency and type of resident activities, family support programs, and fee structure."98 This disclosure model of regulation is the most commonly used model.99

The Alzheimer's Association has developed eleven principles that should be included in special care unit legislation or regulation. These legislative principles are:

1. statement of mission;
2. involvement of family members;
3. plan of care;
4. therapeutic programs;
5. residents' rights;
6. environment;
7. safety;
8. staffing patterns and training;
9. cost of care;
10. quality assurance; and
11. enforcement.100

These elements are nearly identical to those of the disclosure model, which shows that there is some agreement about the areas requiring regulation.101

Oregon is one state that has regulated special care units. Oregon's regulations will be used to exemplify the principles of regulations recommended by the Alzheimer's Association. In Oregon, a nursing home must be endorsed by the state in order to offer a special care unit.102 The purpose of the Oregon regulations is to establish standards for Alzheimer's Care Units and criteria for their endorsement.103 The regulations for endorsement ensure that Alzheimer's residents have a positive quality of life as well as "consumer protection, and maximum individualized care that promotes rights, dignity, comfort, and independence in the least restrictive environment."104 Oregon is a disclosure state, therefore it requires nursing homes to provide individuals and their families with a written statement that includes: "(a) the philosophy of how care and services are provided; (b) the admission, discharge and transfer criteria and procedures; (c) the training topics...[and] amount of training spent on each topic...; and (d) the number of direct care staff assigned to the unit during each shift."105

Oregon Administrative Rule 411-057-0040 provides the standards for Alzheimer's care units. The first standard relates to physical design, environment, and safety. It requires a home-like environment that "assist[s] residents in the activities of daily living; enhance[s] their quality of life; reduce[s] tension, agitation, and problem behaviors; and promote[s] their safety."106 The physical design must include a multipurpose room, a secured outdoor space, and walkways that allow residents to wander but prevent them from leaving the premises.107 The regulations also require high
visual contrasts between floors and walls and doorways and walls, adequate and even lighting, and non-reflective surfaces to reduce glare.\textsuperscript{108} The Oregon Regulations further provide that any locking devices used on exit doors must be electronic and release when a key button or key pass located at exits is used.\textsuperscript{109}

Oregon also provides specific rules for staffing and training. In Oregon, "every effort must be made to provide residents with familiar and consistent staff members in order to minimize resident confusion."\textsuperscript{110} The regulations also provide for staff orientation and in-service training.\textsuperscript{111} In addition, the Oregon regulations include an admission, discharge, and disclosure policy.\textsuperscript{112} There also are sections that detail assessment and individual care plan requirements and therapeutic activities.\textsuperscript{113} The Oregon Administrative Rules provide sanctions if a facility fails to comply with the rules. Sanctions include "civil penalties, restriction of admission and/or revocation of the indorsement [sic]."\textsuperscript{114}

The only element of the Alzheimer's Association legislative principles that the Oregon Administrative Rules does not include is a rule regarding cost of care. Although rather brief, the rules contain almost all of the elements for regulation recommended by the Alzheimer's Association. In addition, the Oregon Administrative Rules provide for waiver. This provision allows a facility to receive a three-year waiver of a particular regulation in order allow facilities to try innovative and novel techniques, methods, or procedures—including pilot projects or research.\textsuperscript{115} The use of such waivers allows for innovation and creativity in the development of dementia care while providing regulations.

**Alternative Options to Special Care Units**

Since there are conflicting views on the benefits of special care units, it is also necessary to understand the alternatives to nursing home care.

**Assisted Living Facilities**

Assisted living is "any group residential program not licensed as a nursing home that can respond to unscheduled needs for assistance."\textsuperscript{116} This includes a broad range of care in which services can be tailored to the needs and preferences of the individual with dementia. More specifically, assisted living has been defined as "a service that combines the nursing home's institutional efficiencies of co-locating many clients with a greater emphasis on preserving the homelike qualities of control over one's personal space."\textsuperscript{117}

An assisted living facility is

[a] residential setting that provides or coordinates flexible personal care services, 24-hour supervision and assistance (scheduled and unscheduled), activities, and health related services; has a service program and physical environment designed to minimize the need for tenants to move within or from the setting to accommodate changing needs and preferences; has an organizational mission, services, programs, and a physical environment designed to maximize residents' dignity, autonomy, privacy and independence; and encourages family and community involvement.\textsuperscript{118}

In one specific type of assisted living setting, persons with dementia live in their own apartments, but at the same time can receive some of the services that would be provided at a nursing home, such as help with personal care tasks, taking medication, protective oversight and monitoring, and health care without the need to travel away from home.\textsuperscript{119}

Assisted living sounds like an excellent alternative to nursing home care; however, there are several shortcomings that limit its usefulness. One of these shortcomings is lack of regulation. There are no federal guidelines, and state guidelines vary widely regarding what services are to be provided by assisted living facilities.\textsuperscript{120} These services can range from light housekeeping to assistance with activities of daily living and beyond.\textsuperscript{121} This lack of clear standards allows facilities "a great deal of room in which to maneuver, creating a burden on consumers who must decipher the contract to determine which services to expect."\textsuperscript{122}

Another shortcoming is cost. Assisted living facilities can become very expensive, especially if there is a surcharge for any additional services to the standard package or an entrance deposit in addition to monthly fees.\textsuperscript{123} In addition, the costs of assisted living are "generally paid out-of-pocket by individuals and their families, effectively placing
assisted living beyond the reach of most low and moderate income Americans.”

A third shortcoming is retention policies. If an individual needs more care than the facility can provide he or she may be discharged or evicted. Further, assisted living residents may have limited legal rights when contesting facility decisions regarding their residency. Finally, aggressive marketing techniques are used to sell the assisted living arrangement to “aging, anxious, and often vulnerable individuals.”

**Adult Foster Care Homes**

Adult foster care homes, or “board and care” homes, are small, state-regulated facilities that provide a less expensive means for an individual to gain housing, assistance with personal care, and protective oversight. Adult foster homes are sometimes viewed as a preferable option to nursing homes because they provide twenty-four-hour supervision in a small, home-like environment.

In addition, they are a less expensive option than either nursing homes or assisted living facilities. However, there are limitations on their usefulness, such as lack of adequate funding to cover costs. In addition, the care needs of residents in adult foster homes often may exceed what the operator’s training and budget allow.

**Community-Based Long-Term Care**

There is a growing interest in shifting the balance away from institutions to community-based long-term care (LTC). As a result, community-based long-term care has become an increasingly available option for dementia patients. This option allows people to receive care while remaining at home. The services usually are planned and coordinated by an agency that sends staff to care for the individual at home. Community-based long-term care aids individuals with dementia in their activities of daily living, thereby providing relief to their caregivers.

Home and community-based long-term care “covers a broad range of services that extend from skilled-level, medically related services with professional staff to social support services provided by nonprofessionals or informal caregivers (family and friends).” These services are designed to complement the care provided by family caregivers.

However, community-based long-term care often is “piecework and patchwork” and is “characterized by inaccessibility, poor care, unskilled personnel, high out-of-pocket costs, and inadequate linkages to other services, rather than a comprehensive array of services.”

**Adult Day Care Facilities**

Adult day care facilities are centers that provide daytime care and activities for groups of elderly individuals, including those with dementia. They are often used in collaboration with community-based long-term care. In fact, they are sometimes referred to as the “cornerstone of community-based LTC” and are “being touted as the ‘unnursing home’.” These services provide respite for family caregivers, allowing individuals with dementia to remain at home or in the home of a family member, which is a much less expensive alternative than a nursing home.

However, some adult day care facilities will not take incontinent or disruptive clients. In addition, many adult day care centers suffer from financial problems, especially if they rely on charity or private grants. Further, for many middle-income elderly who are not offered a discounted price, the cost of attending five days per week can exceed the amount they are paid in Social Security.

**Technology and Aging in Place**

As technology progresses in the future, remaining at home and aging in place may become a more and more viable option for those with Alzheimer’s disease or other dementias. Technology serves three main functions for a person with dementia: “(1) improving the safety of the individual and others, (2) monitoring and maintaining health, and (3) enhancing quality of life.”

There are two sources of technology for people with dementia. “The first is technology developed by engineers in order to meet the specific needs of people with dementia.” Examples of this type of technology include a stove that automatically turns off if a saucepan is empty and a telephone with pictures of people a dementia patient regularly calls rather than numbers.
Another example is a “smart house” equipped for people with dementia, which links household equipment to a personal computer that alerts someone if a dangerous condition arises.151

A second source is practitioner-developed technology made by those working in the field.152 Examples of technology developed by this means include an electronic sensor placed above the door of a house that alerts a response center if a person with dementia leaves the house at night and a heat sensor installed above the stove to alert someone at a response center who then telephones when a person with dementia has forgotten to turn off the stove.153 The “potential of this approach is greater than that of technology specifically designed for people with dementia, since the technology itself is more generally available and thereby usually cheaper.”154

It is important to note that technology is only one component of support.155 Reliable support services, such as staff of a technology company, volunteers, or family and friends, are a necessary element for effective use of technology.156 Technology is only one part of an entire care plan and cannot replace staff or expertise.157 Technology alone will not allow individuals with dementia to age in place, but it is part of a plan of services that can help make this possible.158

Conclusion

Many older adults would prefer to remain home and age in place. Long-term community-based care, adult day care, adult foster homes, technology, and assisted living are all means to make this possible. However, the needs of some individuals with dementia are greater than these non-institutional settings can fulfill. In such situations, special care units are a viable option for Alzheimer’s and dementia patients.

Although there are critics, special care units do show promise. While further research will lead to more specific knowledge regarding exactly which components of special care units are most effective, at this time special care units are a promising alternative for providing the individualized, home-like care that results in dignity, comfort, and a high quality of life for Alzheimer’s patients.

Endnotes

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76. Id. at 46, 48.
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